The Experience of Adults Living with Chronic Pain in the Context of a Neurological Condition

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Thesis Portfolio Abstract

Background: Sudden onset neurological conditions, such as spinal cord injury and stroke, are unexpected, life-changing events. Research suggests that survivors grieve the life they knew, while commonly trying to cope with significant impairments impacting their everyday life. Some impairments are condition specific while others are shared across conditions, such as chronic pain.

Aim: This research portfolio aimed to increase understanding of the experience of chronic pain following two sudden onset neurological conditions, namely spinal cord injury and stroke, in adults.

Design: The portfolio consists of two main research papers, a systematic review which thematically synthesises qualitative findings on adults' experience of chronic neuropathic pain following spinal cord injury and an interpretative phenomenological analysis (IPA) study which investigates the experience of working age adults living with chronic post-stroke pain. These are presented alongside an introduction, bridging section, extended methodology, and overall discussion.

Findings: The systematic review identified six themes; 'The pain as an unusual, intense, unpredictable and uncontrollable sensation', 'The pain's influence on life', 'Trying to understand the pain', 'The challenge of describing the pain to others', 'The search for pain relief' and 'Learning pain acceptance over time'. The IPA study identified three master themes: 'The solitude of the pain experience', 'Unsatisfactory healthcare and the need for self-care' and 'The development of pain acceptance'.

Conclusions: The findings suggest that spinal cord injury and stroke patients have similar experiences of living with chronic pain. The pain is described as an invisible impairment, which is difficult to relate to others and can easily be overlooked in the context of other visible, more prototypical impairments. Primary healthcare settings are described as lacking specialist knowledge, leading to unsatisfactory identification, diagnosis and treatment. Recommendations for clinical applications and future research are provided.

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List of Abbreviations

ABI	Acquired Brain Injury
BPS	British Psychology Society
CASP	Critical Appraisal Skills Programme
CBD	Cannabidiol
CBT	Cognitive Behaviour Therapy
CNP	Chronic Neuropathic Pain
CPSP	Central Post-Stroke Pain
GDPR	General Data Protection Regulation
GP	General Practitioner
HCPC	Health and Care Professions Council
IPA	Interpretative Phenomenological Analysis
MASCIP	Multidisciplinary Association of Spinal Cord Injury
MeSH	Medical Subject Headings
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	Prospective Register of Systematic Reviews
RCP	Royal College of Physician
SCI	Spinal Cord Injury
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research Type
UEA	University of East Anglia
UK	United Kingdom
WHO	World Health Organisation

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Chapter 1. Introduction

This research portfolio aims to develop an understanding of the experience of adults living with chronic pain in the context of a neurological condition. Neurological conditions are caused by disease-, infection- or injury-related damage to the central or peripheral nervous system (World Health Organisation (WHO), 2016). The National Health Service (NHS, 2020) estimates the existence of over 600 types of neurological conditions, which can broadly be categorised into sudden onset conditions (e.g. stroke and spinal cord injury), intermittent and unpredictable conditions (e.g. epilepsy), progressive conditions (e.g. Parkinson's disease) and stable conditions (e.g. cerebral palsy in adults).

Many neurological conditions severely impact individuals' quality of life; compared to other long-term conditions, neurological disorders cause the lowest health-related quality of life for individuals (Berrigan et al., 2016). Furthermore, certain neurological conditions are life limiting; deaths associated with neurological disorders are 35% more likely to be premature (Public Health England, 2018). Neurological conditions place a high burden on patients, carers and the NHS; in 2013-2014, 14% of the UK's social care budget was spent on neurological conditions (NHS, 2020).

Neurological conditions can cause a variety of impairments for individuals, of which many are disorder specific, but some are shared across conditions. An example of a commonly experienced impairment across neurological conditions is chronic pain, which affects around 20-40% of patients with neurological conditions (Borsook, 2012). Pain is the response of the sensory nervous system to harmful or potentially harmful stimuli (International Association for the Study of Pain (IASP), 2017). It is a multidimensional phenomenon, including central, peripheral, autonomic and psychological factors, which are experienced differently by each person (Harrison & Field, 2015; Widar & Ahlström, 2002). Pain is described as chronic when it persists past the normal healing time of three months and therefore does not fulfil the function of physiological nociception (Treede et al., 2015).

Chronic pain interferes with all aspects of a person's daily life; it demands attention, decreases concentration on non-pain stimuli, drains energy and causes mood disturbances (Katz et al., 1996). Chronic pain has been associated with a reduction in activities of daily living, social activities and quality of life and an increase in occupational and family difficulties as well as the occurrence of depression and anxiety (Dueñas, Ojeda, Salazar, Mico, & Failde, 2016; Lerman, Rudich, Brill, Shalev, & Shahar, 2015). However, while some individuals experience significant dysfunction, others adjust relatively well to the ongoing experience of pain in the context of neurological conditions

(Widar & Ahlström, 2002). Various studies have highlighted the role of resilience and coping styles in relation to individual differences in psychological adjustment to chronic pain (Jensen, Turner, Romano, & Karoly, 1991; Newton-John, Mason, & Hunter, 2014; Sturgeon & Zautra, 2010). In particular, the acceptance of pain, which is described as individuals' willingness to experience pain and engage in activity regardless of pain, has been shown to reduce disability and enhance mood in individuals with chronic pain (McCracken & Eccleston, 2005; McCracken & Zhao-O'Brien, 2010).

Pain in the context of a neurological condition can occur as a direct or indirect effect of the disease. Pain caused directly by the disease, through damage to nerves within the somatosensory system, is known as neuropathic pain (Borsook, 2012; Costigan, Scholz, & Woolf, 2009). Pain caused indirectly by the disease is associated with disease-related changes in body control (e.g. spasms), posture (e.g. frozen shoulder) and movement (e.g. pain due to overuse of muscles in operating a wheelchair). This pain tends to be nociceptive in nature, relating to tissue damage.

Chronic pain in the context of neurological conditions is under-researched, reflecting a lack of understanding of the underlying mechanisms of chronic pain and a lack of objective pain measures in these conditions (Borsook, 2012). As a consequence treatment options are limited (Borsook, 2012). Given the debilitating effects of neurological conditions and chronic pain, together with the reported lack of research and treatment options, it appears important to broaden our understanding of chronic pain in the context of neurological conditions. This can be achieved by taking a qualitative approach to research; rather than predefining variables, qualitative research permits individuals living with chronic pain in the context of a neurological condition to freely describe their experience.

This thesis portfolio focuses on adults' experience of chronic pain in the context of sudden onset neurological conditions, namely, spinal cord injury and stroke. Spinal cord injury is caused by a traumatic (e.g. road traffic accident) or non-traumatic (e.g. disease or degeneration) event, which results in damage to the spinal cord (WHO, 2013). Stroke is defined as a lesion in the brain caused by either lack of blood flow (ischemic stroke) or bleeding (hemorrhagic stroke) (Grysiewicz, Thomas, & Pandey, 2008). The focus of this portfolio is exclusively on adults' pain experience, as children's experience is unique and would need to be investigated separately (Walco, Dworkin, Krane, LeBel, & Treede, 2010). As part of this portfolio a systematic review of qualitative research will be presented, which synthesises adults' experience of chronic neuropathic pain following spinal cord injury. This is followed by a bridging section leading to the presentation of a research study, which uncovers working age adults’ experience of living with chronic pain following stroke. An extended methodology of the paper is presented afterwards. The portfolio concludes with an overall discussion and critical evaluation.

Chapter 2

Adults' Experience of Chronic Neuropathic Pain following Spinal Cord Injury - A Systematic Review of Qualitative Research

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REVIEW ARTICLE

Adults' experience of chronic neuropathic pain following spinal cord injury - A systematic review of qualitative research

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Abstract

Purpose: The aim of this review was to identify and synthesise qualitative research on adults' (≥18) experience of chronic (≥3 months) neuropathic pain following spinal cord injury. *Methods:* Four electronic databases were searched. Eligible papers used a qualitative or mixed-methodology, presented primary data and were written in English. Six papers were identified; their quality was assessed, data extracted and findings synthesised using thematic analysis. *Results:* Six overarching themes were identified; 'The pain as an unusual, intense, unpredictable and uncontrollable sensation', 'The pain's influence on life', 'Trying to understand the pain', 'The challenge of describing the pain to others', 'The search for pain relief' and 'Learning pain acceptance over time'. *Conclusions:* Chronic neuropathic pain can be perceived as one of the most debilitating consequences of spinal cord injury and can overtake individuals' lives. This review found that it is often experienced as an uncontrollable and unusual sensation, which individuals find difficult to describe and quantify. Frustration can be experienced with regards to others' lack of understanding and empathy, absence of a clear diagnosis and suitable information, and overreliance on pharmacological treatment. Recommendations for clinical applications and future research are provided. *(Word Count Abstract: 189)*

➢ **Implications for Rehabilitation**

- Individuals with spinal cord injury can perceive chronic neuropathic pain as the most debilitating consequence of their condition. The pain can negatively impact individuals' everyday functioning, social relationships and emotional wellbeing.
- Chronic neuropathic pain following spinal cord injury can present as a variety of unusual sensations, which can be difficult to describe and which are not easily captured by pain measures. Therefore, a jointly created, individualised formulation of the pain experience might be beneficial.
- Individuals suffering from chronic neuropathic pain following spinal cord injury benefit from receiving a clear diagnosis and suitable information. Having an understanding of the nature of the pain can prevent the formation of inaccurate, unhelpful illness beliefs.
- Healthcare professionals should consider recommending adjunctive or alternative therapies to pharmacological interventions, such as pain management programmes and peer support.

Keywords: Spinal cord injury; chronic pain; neuropathic pain; neuralgia; qualitative systematic review

Introduction

Spinal cord injury (SCI) is an unexpected, traumatic and life-changing event [1], characterized by total or partial autonomic, motor and sensory dysfunction below the level of the lesion [2]. Even though SCIs are rare, with reported worldwide incidence varying between 10.4 and 83 per million inhabitants per year [3], improved survival rates and enhanced life expectancy of individuals with SCI mean that the number of people living with SCI is increasing [1].

Currently, no treatment enables restoration of autonomic, motor or sensory functioning after SCI [4] and even though neuroplasticity can cause spontaneous recovery, other difficulties can emerge, such as the experience of neuropathic pain in affected areas [5]. The emphasis is therefore on the development of preventative strategies and treatments which focus on reducing the negative psychosocial and secondary health consequences of SCI, which can be significant [4, 6]. Individuals with SCI commonly experience difficulties with activities of daily living, socialising and working, which reduces their quality of life [1, 4, 7] and places them at greater risk for depression, anxiety [8], addiction [9] and suicide [10]. Individuals with SCI are also more at risk of developing acute [11] and chronic health problems [12], such as respiratory and cardiovascular difficulties, urinary and bowel problems, osteoporosis and pain syndromes [12].

Pain following SCI is described as the most distressing and debilitating secondary health complication of SCI [13, 14]. SCI-related pain contributes directly to disability; it impedes rehabilitation and further reduces individuals' physical and psychosocial functioning, wellbeing and quality of life [5, 15]. A recent systematic review by Van Gorp et al. [16] reported that between half and two-thirds of the SCI population experience SCI-related pain. One third describes their pain as severe. Historically, prevalence rates of SCI-related pain varied greatly due to a lack of universal descriptions, terminology and classification systems; however, in 2012 Bryce et al. [17] agreed the International Spinal Cord Injury Pain Classification. Typically, individuals experience various forms of SCI-related pain simultaneously.

Neuropathic pain is defined as pain caused by damage to the somatosensory nervous system [15]. It is commonly described as the most intense type of SCI-related pain. A systematic review by Burke et al. [18] found that 53% of individuals with SCI suffered from neuropathic pain; rates were higher in individuals who were older or diagnosed with quadriplegia. Neuropathic pain can be localised to the area of the body supplied by the nerves damaged by the injury or can be diffuse [5]. It tends to be chronic

(≥3 months) [19] and can worsen over time [15, 18]. Neuropathic pain can be difficult to identify, as it does not necessarily present with visible signs of damage or injury and may not occur immediately after the injury but develop over time [18]. Individuals may report spontaneous and/or stimulus-evoked pain [5] and may use unusual terms to describe the pain (e.g. burning, numbness, pins and needles and electric shock) [5]. Allodynia, hyperaesthesia, paraesthesia or dysesthesia, which relate to an uncomfortable, altered sense of touch or pain perception, as well as aftersensations and referred pain, are also commonly present in individuals with SCI-related neuropathic pain [5, 20]. In contrast to nociceptive pain, which is related to tissue damage, the mechanisms underlying neuropathic pain are more complex and less well understood [15, 21]. Based on its unusual presentation, variability in occurrence and complex underlying mechanisms, neuropathic pain can be difficult to diagnose.

Chronic neuropathic pain (CNP) has been found to be associated with reduced quality of life [22, 23], enhanced functional impairment, sleep difficulties, and reduced physical and mental health [24-28]. However, differences in the level of pain-related distress and disablement between individuals exist. Pain theories such as Sharp’s cognitive behaviour therapy reformulation model [29] and Vlaeyen and Linton’s fear-avoidance model [30] suggest individual differences in pain experience are related to individuals’ appraisal and interpretation of the pain, rather than the sensation itself.

Treatment guidelines for neuropathic pain following SCI recommend a holistic, multidisciplinary pain management approach. This is in line with the biopsychosocial model of pain, which acknowledges that biological, psychological, cognitive, behavioural, social and environmental factors affect the experience of pain [31, 32]. Nevertheless, despite limited effectiveness, risk of side effects and negative long-term consequences, the prescription of nonopioid analgesics and nonsteroidal anti-inflammatory medication is routine clinical practice in the treatment of SCI-related pain [14]. Research evaluating the effectiveness of non-pharmacological treatments for SCI-related pain is limited; yet some studies have demonstrated treatment effectiveness. For example, a survey of 575 people with SCI-related pain, of whom 69% had neuropathic pain, found non-pharmacological treatments (e.g. relaxation, physical activity) more effective than pharmacological treatments [33]. Additionally, randomized controlled studies have shown the positive effect of multidisciplinary cognitive behaviour programmes on patients’ wellbeing and functioning [33, 34].

Given the high prevalence, unique presentation, unpleasant and debilitating nature of CNP following SCI and the lack of effective treatment options, it seems important to understand the lived experience of CNP following SCI from the patient's perspective. An increasing number of qualitative studies across the world investigate the experience of living with CNP following SCI. Studies have commented on physical, psychological and social functioning and pain management [35, 36]; however, to date there has been no synthesis of the findings [37]. The aim of this systematic review therefore was to synthesise qualitative research on the subjective experience of individuals living with CNP following SCI to answer the question: What is the experience of adults living with CNP following SCI? We focussed on the experience of adults, as the experience of neuropathic pain in children has been found to be unique [38].

Methods

A systematic review of qualitative research was conducted using Khan et al.'s [39] framework for conducting systematic reviews and the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) statement by Moher et al. [40]. The review was registered with the International Prospective Register of Systematic Reviews (PROSPERO); the full study protocol is available on their database [41].

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research type) search strategy tool for qualitative and mixed-method studies [42] was used to define key elements of the review question as potential search terms:

- **S**ample - Adults with spinal cord injury
- **P**henomenon of **I**nterest - Chronic neuropathic pain
- **D**esign - Free-form textual information from interviews, focus groups and case studies
- **E**valuation - Experience, perception, attitude, view, feeling, opinion, reflection, belief and thought
- **R**esearch type - Qualitative or mixed-method design

The review adopted the IASP definition of chronic pain; pain that persists for three months or longer [43]. Adults are defined as individuals over the age of 18.

Eligibility criteria

The criteria for inclusion of papers in the review were:

- Studies exploring adults' (≥18) experience of CNP following SCI, from their perspective.

- Studies with a qualitative or mix-method design, which provide narrative data (i.e. first person quotations) regarding the experience of adults with CNP following SCI from their perspective.

The criteria for exclusion of papers in the review were:

- Studies that describe the experience of multiple pain syndromes, where it is not possible to extract information relevant solely to the experience of CNP following SCI.
- Studies focusing on acute neuropathic pain after SCI (<3 months).
- Studies presenting insufficient data relating to adults' experience of CNP following SCI.
- Studies exploring the experience of CNP following SCI in children (<18).
- Studies focusing primarily on adults' experience of SCI-related pain management, treatment and interventions.
- Studies focusing on adults' experience of SCI in general, without having a clear focus on pain after SCI.
- Studies exploring the experience of CNP following SCI from the perspective of anyone other than the person living with the condition, unless the perspective of the person living with SCI-related CNP can be clearly separated from other people's accounts.
- Studies not published in English.
- Papers presenting a review or summary of studies.

Search strategy

The search strategy, developed in consultation with a medical librarian, was designed to identify a broad range of relevant papers. Four electronic databases EMBASE (Ovid), CINAHL Complete (EBSCOhost), PsycINFO (EBSCOhost) and MEDLINE Complete (EBSCO host) were searched on the 17 January 2020. Search terms were identified using the SPIDER search strategy tool [42] and consultation of relevant literature. The search terms derived under the 'Evaluation' part of the SPIDER search strategy tool were not included in order to prevent the unnecessary limitation of search results. In line with recommendations of Jenuwine and Floyd [44], text-word searching was combined with the use of Medical Subject Headings (MeSH) in MEDLINE Complete, Thesaurus in PsycINFO, and Subject Headings in CINAHL Complete and EMBASE. The following search strategy was used with MEDLINE Complete (EBSCO) but is representative of the search strategies used for the remaining databases:

> "MH Spinal Cord Injuries" or “spin* N4 injur*” or “spin* cord”
> AND
> "MH "Neuralgia" or "MH "Chronic Pain" or “nerv* N3 pain*” or “neuro* N3 pain*” or neuropathy or neuralg* or neurodynia* or “chronic N3 pain*”
> AND
> "MH "Qualitative Research" or qualitative or "case stud*" or “mixed method*” or ethno* or phenomeno* or IPA or "grounded theor*" or “conversation analys*” or "thematic analys*" or “content analys*” or “discourse analys*” or interview* or "focus group*" or narrative

Advanced search techniques (i.e. truncation, proximity search, phrase searching) were used to broaden the search results, while remaining sensitive and specific. Databases were searched using their default search setting, which includes author, title, abstract and key words, as well as other categories such as ‘floating subject word’ in OVID.

Paper selection

The initial search without limits applied identified 1,668 papers. This was followed by a search that limited results to papers published in English language and given that MEDLINE Complete was searched separately, a limit was set to exclude MEDLINE articles when searching CINAHL Complete and EMBASE. The application of these limits resulted in a reduction of papers to 461.

Forty-one duplicates were removed, and the titles and abstracts of the remaining 420 papers were screened against pre-set inclusion and exclusion criteria, eliminating a further 401 papers. For the remaining 19 papers, the full text was screened for relevance and eligibility based on the pre-set criteria. This process eliminated 14 additional papers; six provided no first-person accounts of individuals living with the condition (i.e. quotations) [13, 45-49], four did not enable the extraction of pain experience particularly relevant to neuropathic pain [50-53], two focused on pain management [54, 55], one was a review [56] and one did not define the pain experience as chronic [57]. Five papers were found to be eligible for inclusion [15, 35, 36, 58, 59]. To identify studies potentially missed by the search, forward and backward citation searching of those five papers was employed [60]. This process resulted in the identification of another paper eligible for inclusion [61]. Six papers were therefore included in this review. Figure 1 summarises the search process within a PRISMA flowchart [40]. One of the papers included in this review [58] re-analysed data collected for two other studies included in this review [35, 61]. It was decided to include the paper, as the analysis was substantially different from the original two papers and findings provided unique insights [62]. This review therefore synthesises the results of six papers, based on five studies. The papers' eligibility for inclusion was confirmed by a second reviewer.

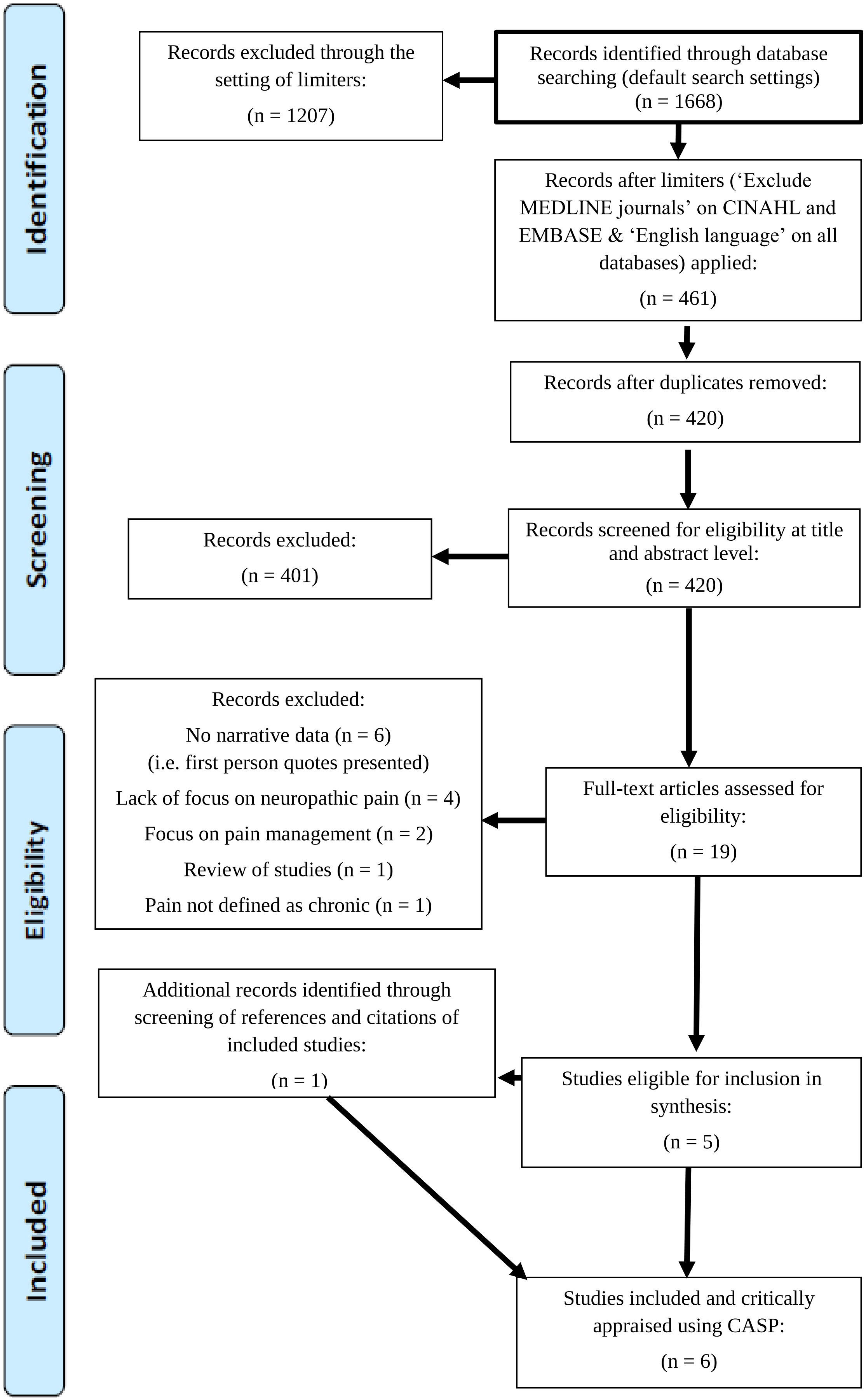

Figure 1. PRISMA Flowchart [40] summarising the selection process for the identification of relevant and eligible papers for the review.

Quality appraisal

Study quality was assessed using the Critical Appraisal Skills Programme (CASP) systematic review checklist for qualitative research [63]. Study quality was rated as low (0-3), medium (3.5-7.5) or high (8-10) [64]. All papers were assigned quality ratings by the first author (JB) and 50% were independently rated by a second reviewer (KC) to highlight potential bias (Appendix B). A strong agreement [65] in quality ratings between the two raters was found; $\kappa = .81$ (95% CI, .61 to 1), $p<.001$. All six papers were judged to be of high quality.

Data extraction

Descriptive characteristics and findings were extracted and recorded systematically by the first author (table 1). The process of data extraction aimed to enhance theoretical and interpretative validity, by detailing the key aspects of the original papers and their findings prior to the authors' synthesis [66].

Synthesis method

A range of methods for synthesising qualitative research are available; however, Barnett-Page and Thomas [67] noted that most are not distinctly different from one another. For this review, it was decided that findings within papers would be synthesised following Braun and Clark's [68] guidance on inductive thematic analysis, in which identified themes are strongly linked to the data analysed [68]. The chosen method of synthesis enables aggregation of findings as well as their interpretation [69]; new insights and recommendations can be created, while staying close to the original data.

The synthesis comprised of multiple stages. Firstly, the final set of papers to be included in the review was read repeatedly to create a deep level of familiarity and understanding. Secondly, themes, participants' quotations and authors' interpretation were extracted from the 'results'/'findings' section of papers. One of the papers had a mixed-methodology. In line with our eligibility criteria, only the qualitative part of the paper's analysis was therefore considered. Thirdly, the extracts were coded by the first author and emergent themes were noted and grouped into over-arching themes as appropriate (Appendix C). Finally, a narrative summary together with participants' quotations was developed.

First author's background

It is important to consider the first author's background to judge her personal influence on the synthesis process. The first author is a final year Trainee Clinical Psychologist who has worked in various mental and physical healthcare settings but has not worked in a spinal cord injury or pain service. Potential biases of the first author in the interpretation of findings were addressed through discussions with the wider research team.

Findings

Firstly, study characteristics alongside quality considerations were examined, followed by a synthesis of findings summarised as overarching themes. Study characteristics are summarised in table 1.

Table 1. Descriptive characteristics of papers included in the review.

Author (Year); Country; Setting	Sample	Method	Analysis	Findings
Buscemi et al. [15], Italy, SCI unit	9 participants of whom 7 were male. Age: 32-75 years; average age 52. Time since injury: 2-32 years; average 4 years. Time since pain onset: 3-35 years; average 10 years.	Qualitative. Participants split across two focus groups (90 minutes). Additional, one-to-one interviews; one held virtually by email.	Thematic analysis [68]. First coding phase in Italian; second coding phase & thematic analysis in English.	Theme 1: “The continuous influence of pain in life” Theme 2: “Constructing knowledge about living with CNP” -Sub-theme 1: “Understanding CNP” -Sub-theme 2: “Finding out what works” Theme 3: “Developing specialist practice”
Hearn et al. [35]; UK, SCI outpatient clinic	8 participants of whom 5 were male. Age: 26-77 years; average age 47. Time since injury: 1-32 years; average 11 years. Time since pain onset: >3 months.	Qualitative. Semi-structured interviews (40-120 minutes).	Interpretative Phenomenological Analysis (IPA) [70].	Theme 1: “The chasm between biomedical perspectives and patient beliefs and needs” -Sub-theme 1: “Excessive reliance on insufficient medication” -Sub-theme 2: “Losing faith in healthcare professionals” -Sub-theme 3: ”Lack of input into own care” Theme 2: “The battle for ultimate agency in life” -Sub-theme 1: “I am winning” -Sub-theme 2: “Pain is winning” Theme 3: “The coexistence of social cohesion and social alienation” -Sub-theme 1: “SCI population are united but alone in their experience” -Sub-theme 2: “Painful self as an affliction on social relationships”
Hearn et al. [58]; UK, SCI outpatient clinic	16 participants of whom 10 were male. Age: 23-82 years; average age 53. Time since injury: 4 months - 32 years; average 6 years. Time since pain onset: >3 months.	Mixed-method. Data from Hearn et al [35, 61]; gained through semi-structured interviews (40-120 minutes).	IPA [70] for the interpretation of metaphors.	Theme 1: “Pain as personal attack” Theme 2: “The desire to be understood” Theme 3: “Conveying distress without adequate terminology”

Table 1. Descriptive characteristics of papers included in the review (continued).

Author (Year); Country; Setting	Sample	Method	Analysis	Findings
Hearn et al. [61]; UK; SCI inpatient clinic	8 participants of whom 5 were male. Age: 23-82 years; average age 60. Time since injury: 4-14 months; average 8 months. Time since pain onset: >3 months.	Qualitative. Semi-structured interviews (40-60 minutes).	IPA [70].	Theme 1: “The dichotomy of safety perceptions” -Sub-theme 1: “Confinement in ‘prison’ vs. shelter in a ‘safe haven’ ” -Sub-theme 2: ”Positive perceptions of staff” Theme 2: “Adherence despite Adversity” -Sub-theme 1: “Desperation and hopelessness” -Sub-theme 2: “Resigned and indifferent” Theme 3: “Fighting the future” -Sub-theme 1: “Pain is impermanent” -Sub-theme 2: “Pain is persistent, and I accept it”.
Henwood and Ellis [36]; Canada; Neurospinal rehabilitation centre	24 participants of whom 17 were male. Age: 31-69 years. Time since injury: 1-30 years. Time since pain onset: >6 months.	Qualitative. Participants split across three focus groups.	Constant comparative method of analysis [71].	Theme 1: “The nature of pain” - Sub-themes: “Type”, “Pain onset”, “Distribution”, “Descriptors”, “Severity”, “Patterns” and “Augmenters” Theme 2: “Coping” Theme 3: “Medication failure” Theme 4: “Pain impact”
Henwood et al. [59]; Canada; Rehabilitation centre	7 participants of whom 5 were male. Age: 30-67 years. Time since injury: 2-36 years. Time since pain onset: >1 year. All participants were judged to have an acceptance approach to living with CNP.	Qualitative Semi-structured interview (60-90 minutes).	Grounded theory [72].	Theory description: “Moving forward with the pain”, describes the process of acceptance through the process of “increasing independence” and “evolving pain view”. Individuals move sequentially through these phases: - “Comprehending the perplexity of CNP” - “Seeking pain resolution” - “Acknowledging pain permanence” - “Redefining core values” - “Learning to live with the pain” - “Integrating pain”.

Study Characteristics

Context

All papers aimed to explore the experience of adults living with CNP following SCI. Two papers let participants freely decide which areas of their experience they wanted to focus on [35, 61], two set the areas to be explored as the pain experience itself, life with pain, and healthcare provision and management [15, 36], one focused on the use of metaphors in describing the experience of CNP following SCI [58] and one focused on the experience of individuals who are accepting of the pain [59].

Of the selected papers, three described research which took place in the United Kingdom [35, 58, 61], two in Canada [36, 59] and one in Italy [15]. The studies took place in specific neurospinal centres; four were conducted in outpatient settings [15, 35, 36, 59], one in an inpatient setting [61] and one across inpatient and outpatient departments [58].

Samples

All papers had used purposive sampling, with the exception of Henwood et al. [59] who collected a theoretical sample for which all participants had to have reached a level of pain acceptance. The number of participants ranged from 7 to 24. The total number of participants in this review is 56. All samples had more male than female participants in line with incidence rates of SCI, which are higher for men [73]. The reported average age of participants across studies ranged from 47 to 60. Two studies did not provide a detailed breakdown of age but described the age range of participants as 31-69 [36] and 30-67 [59]. With the exception of Buscemi et al.'s [15] participants, who were Italian-speaking, all participants were English-speaking. Marital status and occupation were reported in four [15, 35, 36, 61] of the six studies. There were no studies which reported details of participants' ethnicity or caring responsibility (e.g. childcare).

All but one paper [15] reported their sample to consist of people with traumatic and non-traumatic (i.e. disease or degeneration) SCI. The average time since injury ranged from 4 months (inpatient study) to 36 years [15, 35, 36, 58, 59, 61].

All papers stated that participants had been diagnosed with CNP; however, none provided details of measures confirming the diagnosis, reported on how the diagnosis was reached or the degree of confidence with which the diagnosis was given. All participants had experienced pain for more than three months [21]. The average time since pain onset ranged from 4 months (inpatient study) to 11 years; two studies did not provide this information, but reported pain to have been present for at least six months [36] or one year [59]. Papers varied greatly with regards to describing participants' pain experience; for example, papers reported subjective characteristics of the pain and its location, frequency of occurrences (per day/week), use of analgesic medication and use of various measures for pain intensity (i.e. visual analogue scale and individualised numerical rating scales).

Significant cognitive impairment was an exclusion criterion in all, but one [36], studies. Some papers further excluded people with medical and psychological difficulties which could affect valid engagement in research [15, 59, 61] and four excluded non-English speaking participants [35, 58, 59, 61].

Method for data collection and analysis

Five papers described a qualitative design [15, 35, 36, 59, 61] and one described a mixed-method design [58]. Four papers reported the use of semi-structured interviews [35, 58, 59, 61], one the use of focus groups [36] and one focus groups followed by face-to-face or virtual interviews [15]. Variability was also present across papers with regards to data analysis procedure; three adopted interpretative phenomenological analysis [35, 58, 61], one thematic analysis [15], one grounded theory [59] and one a constant comparative method of analysis [36]. Even though Buscemi et al. [15] conducted the first coding in Italian, the second coding and analysis were conducted in English, as were all other studies. All studies audio-recorded their data collection process and transcribed the derived data.

Methodological and ethical rigor

All papers reported a self-selected sample; four papers [15, 35, 58, 61] noted this as a limitation. With regards to eligibility criteria, inclusion criteria were stated by all papers, but were less clear in two of the papers [15, 36]. With the exception of Henwood and Ellis [36] all papers provided exclusion criteria. Four papers reported that some individuals who were approached declined participation [15, 35, 36, 61]; only two provided reasons given for this [15, 36]. Having unclear eligibility criteria and no details regarding rate and reason for non-participation can result in a biased sample.

All papers received ethical approval by an independent body. The majority of studies clearly stated approval, consent and confidentiality processes; however, none describe details regarding data storage during and after the research. The importance of securely processing and storing personal data is summarised in the General Data Protection Regulation [74]. Henwood et al. [36, 59] studies both do not provide details regarding the anonymization of participants' details. However, in contrast to the other studies, they provided few details of participants. Despite the fact that discussing the experience of CNP following SCI is likely to be an emotive topic, only two studies offered debriefing to participants [36, 61].

With the exception of Buscemi et al. [15], none of the studies described the epistemological stance taken by researchers or provided greater detail of the researcher's role and background, so that readers could judge their subjective impact on the data collection and analysis process.

Chosen data gathering procedures appeared appropriate across studies; however, the reason for the use of focus groups by Buscemi et al. [15] in addition to face-to-face / virtual interviews was unclear. To aid consistency in data collection, all papers described the use of interview / focus group questioning schedules, which were provided within papers; an exception was Henwood et al. [59].

Study findings

All papers provided clear descriptions of their findings, describing them as themes. Across papers, themes were supported with first person quotations and the authors' interpretation. First person quotations were fewer and less rich in details in Hearn et al.'s [58] mixed-method paper and Henwood et al.'s [59] paper aimed to build theory. The Henwood and Ellis [36] paper was the only paper not providing at least one quotation per theme. Variability in findings was discussed and different views of individuals highlighted across all but two papers [58, 59]. Triangulation with regards to data analysis was reported across all papers.

All findings resulted in clearly formulated and practical recommendations to enhance the care and treatment of adults experiencing CNP following SCI. Recommendations around further research were limited across studies.

Synthesis of findings

All qualitative data relating to adults' experience of CNP following SCI were used in the synthesis of results. Given the scarcity of papers, even themes within papers which were not supported by a direct quotation from a participant were included in the analysis. However, the findings of the quantitative analysis of the mixed-methods paper were not considered.

Given that all papers focused solely on CNP, their use of the word 'pain' referred particularly to CNP. In line with this, the following synthesis will also use the word 'pain' to represent CNP. A table illustrating the strength of overarching themes based on their prevalence across papers can be found in the appendices (Appendix D).

The pain as an unusual, intense, unpredictable and uncontrollable sensation

The Henwood and Ellis' [36] paper gave the most detailed description of the experience of the pain itself; however, four further papers [15, 35, 58, 59] also provided some details. Henwood and Ellis [36] found that participants experienced other types of pain in addition to CNP and that different types of pain interacted with each other. CNP created the "background on which other pains superimposed" [36, p. 41]. Their description highlighted the variability of pain presentation across individuals; wide variation was described in pain onset, description, distribution, patterns of occurrence and triggers.

Henwood and Ellis [36] found that participants used unusual descriptions for their pain, such as "a sharp hot dagger", "burning", "frozen", and "hit by a hammer" [36, p. 41]. Similarly they found that participants used words, rather than numbers, to communicate the severity of their pain; for example, "very, very, very bad" and "terrible" [36, p. 41]. This is in line with findings of other papers; for example a participant in Hearn et al. [58, p. 980] described their pain in a way others can relate to but then mentions that their pain is more severe:

> Well it's like pins needles but like a more, harder, do you know what I mean? A bit more intense, more intensive pins and needles. And then you get like an odd thunder strike, as if lightning's taken your leg.

The pain was also described as unpredictable and uncontrollable across studies. Participants described that the pain held all the power and that they could not predict when and how they will be impacted, which resulted in a constant feeling of unease. A participant in Hearn et al. [58, p. 980] study said:

> It seems to be, it quietens down for a bit, and then it sort of rears its ugly head, and then gets, can be severe, really bad, not so bad, whatever.

Hearn et al. [35] speculated that the sense of the pain being uncontrollable might be particularly distressing for individuals with SCI as they already have lost control of parts of their body due to their injury. Henwood et al. [59] more generally suggested that the experience of CNP following a traumatic injury can be particularly difficult for individuals as they have a variety of other disablements. This is highlighted in the following comment of one of their participants:

> I couldn't deal with the pain. I found it too hard to take. I was disabled plus I had to suffer through this pain. [59, p. 218].

The pain's influence on life

Four papers [15, 35, 36, 58] directly commented on the significant impact of the pain on activities of daily living, social life and emotional wellbeing. For some participants the impact of their CNP exceeded the impact of SCI on their life, highlighted in the following comment by a participant in the study by Buscemi et al.' [15, p. 581]:

> It should be taken into account that one of the biggest disabilities is not losing the movement of the legs but having constant pain, having pain that does not allow you to move, does not give you the serenity to stay with others quietly or to do your job or other activities.

Participants reported their pain to be all consuming and described it as a powerful force that controls their lives and activities. This is highlighted by another one of Buscemi et al.'s [15, p.581] participants:

> At a certain point, pain holds the power, it becomes so important that you cannot manage to think of anything else, it attracts all attention to itself.

Across studies participants reported that the pain affected their relationships. Participants chose to remain silent about their pain experience as they did not want to burden others and generally felt others lacked understanding and empathy. Participants also reported social isolation due to the functional limitations of their pain experience in the context of their SCI; for example, one of the participants in Henwood and Ellis' [36, p. 43] study describes how their pain limits their social activities by reducing energy levels and mobility:

> What limits me with friends, I don't want to talk to them so much. I don't have that much energy so they come around, I should say, less and less. I'm going to a church, so I was very active there before and I find that it's difficult to get out to my church.

Trying to understand the pain

Many participants described feeling uninformed about their pain by healthcare services; this is highlighted in a comment made by a participant in the study by Buscemi et al. [15, p. 583]:

> What is missed is firstly the lack of information because nobody knows or explains what neuropathic pain really is.

Participants therefore actively sought understanding of their pain. Variations with regards to the understanding of the pain and its characteristics across participants were noted. Henwood and Ellis [36, p. 41] reported that for some of their participants, "pain was associated with the first recognition of sensation following the SCI". One individual perceived the presence of pain as a positive indicator of improvement in his neurological status. Another remarked that he was told that the pain was temporary and would go away, but it never did. It appears that time since injury is related to participants understanding of the chronicity of pain, as in Hearn et al. [61] paper, which interviewed adults shortly after their accident, five of the eight participants viewed their pain as temporary. For example one participant said:

> The pain won't be there when I get home. I'm certain that it won't … I think that by the time I leave, I'm getting better and better, and the pain will go away … It's not an unknown thing, it will go away. [61, p. 1783].

It appears that at first participants were hopeful about the meaning and duration of their pain but that over time and through experience they learn to understand the pain's chronicity.

Pain characteristics, such as felt sensation, onset, distribution, intensity, pattern, trigger and relief strategies vary greatly between participants. Given this diversity, participants reported having to learn to understand their pain over time. For example one participant noted "Thousands of experiments…I'm continuously searching, I experiment on myself" [15, p. 581], which suggests the adoption of a 'trial and error' approach to learning about the pain.

Overall, there appears to be a lack of information provided to individuals suffering from CNP following SCI, which leaves them to create individual illness beliefs and possibly hopeful expectations that are adapted through gained experience over time.

The challenge of describing the pain to others

Three papers [35, 36, 58], described that people with CNP following SCI experience difficulties describing their pain experience to others. Participants felt that their own understanding of the pain was limited, which affected their ability to make others understand their pain. Furthermore, they felt there were no universal terms to describe their pain sensation and the magnitude of it and that only direct experience can lead to true understanding. This is highlighted in a comment of a participant in Hearn et al. [35, p. 2208]:

> No matter how much family and friends, partners etc., they can believe that they understand, they will never ever truly be able to grasp how painful things are, because you can't physically describe it [...] unless you experience it, you can't.

Participants were found to use metaphors to describe their pain experience to others. Hearn et al. [58, p. 981-982] explained that participants adapted well known metaphors in a way that highlights the severity of their pain; for example, "... it's all like pins and needles and, uh, a bit stronger than pins and needles, it almost feels like nails.". Similarly, participants used metaphors when describing the impact their pain has on them; for example one of Hearn et al.'s [35, p. 2207] participants said:

> It [pain] hasn't held me back so far [...] just like carrying around another bag I suppose. Don't think about it. It's just another weight... .

This highlights how creative participants were in conveying their experience, which might be due to the lack of universal terminology or the individual nature of CNP.

Given the difficulties communicating their pain experience, it is perhaps not surprising that participants also reported not feeling understood and believed by others. Henwood and Ellis [36, p. 41] summarised this by stating:

> Participants commonly expressed frustration in their efforts to describe their pain, and generally believe that others, including health practitioners, are incapable of appreciating the true sense of their pain.

Participants were particularly critical of healthcare professionals ability to emphasise with the pain; an exception were participants in Hearn et al.'s [61] study who describe health practitioners as knowledgeable, understanding and empathetic. This might reflect a response specific to inpatient/specialist health practitioners.

Participants in the studies by Buscemi et al. [15] and Hearn et al. [35] commented on the value of peer support, as they felt others who share their pain experience can offer support and understanding.

The search for pain relief

This theme was one of the most prominent across papers, described by five of the six papers [15, 35, 36, 59, 61]. Participants were described as investing effort, time and money in actively pursuing ways to eliminate or reduce their pain. Participants in early stages of the condition often believed total pain relief was achievable [61]. However, in later stages of the condition, participants sought the most effective ways to reduce their pain experience to enhance their activities of daily living and wellbeing.

Participants reportedly sought pain relief through visiting various healthcare settings including general physician and emergency departments [36]. A common and strongly supported theme was that participants felt their pain was mainly attended to through pharmacotherapy. The majority of participants across papers reported their dislike for medication; they felt medication resulted in inadequate pain relief, the presence of undesirable side effects and the risk of addiction. The following quotation highlights the perception of the ineffectiveness of medication and association with negative side effects:

> Increase, increase… I felt stunned, not in a confusion state but very sleepy, and I said 'I hold my pain', I prefer to hold the pain with me rather than be stunned. [15, p. 583].

Henwood and Ellis [36] found that participants described a cyclical pattern in which medication was prescribed, the dose increased to a maximum, followed by discontinuation and the introduction of a new medication. Despite shared negative views on pharmacotherapy, participants adhered to medication due to a perceived lack of alternatives. However, many participants wished for pain management programmes to be broadened beyond pharmacotherapy; this is highlighted in a comment of one of the participants in Buscemi et al.'s [15, p. 583] study:

> In my opinion, alternative therapies should be proposed, at least suggested, when there is not a therapy that works well, therapies, such as acupuncture, maybe noninvasive color therapy, or music therapy. They are all palliatives, but put altogether, sometimes offer the possibility of living better with your pain.

Participants across papers described various ways in which they had to learn about ways to manage their pain. Examples were, soaking in warm water, stretching, physical activity, acupuncture, massages, hypnotherapy, marijuana, cognitive restructuring and distraction [15, 36]. Even though many strategies were described, not all participants perceived them as beneficial [15]. Also, even when gaining some pain reduction, some participants described that the cost in terms of energy, time and money was too great, leading to the abandonment of strategies over time [59].

Alongside the frustration with overreliance on medication and lack of alternatives from healthcare services, participants in three of the papers [15, 35, 61] described a general state of dissatisfaction with their healthcare and treatment by professionals. Participants commented on the lack of information provided, multidisciplinary work, and knowledge and empathy in health practitioners [15].

Learning pain acceptance over time

Four papers [35, 36, 59, 61] described participants' ability to develop pain acceptance over time. Henwood et al.'s [59] paper developed a theory that describes the journey to pain acceptance; findings in other papers support the stages described by them. Reaching a level of pain acceptance was described as developing slowly over time; "you take it step by step and accept it step by step" [59, p. 219]. However, a minority of people appear able to develop pain acceptance relatively soon after their injury. A participant in Hearn et al. [61, p. 6] inpatient study showed pain acceptance just four months after his injury;

> Yeah, I've come to terms with it [pain], and I've come to terms that I'm going to go home, this same way, with pain.

Henwood et al. [59] described that participants that gained pain acceptance reached a point at which they acknowledged the chronicity of their pain and the limited means to relief it. This was followed by recognition of the necessity to live with the pain. The following quotation highlights this:

> And then I finally said to myself, nothing's going to work. I might as well try to live with it, and learn to live with it, and since then I haven't tried pursuing any type of pain relief. [59, p. 219].

This realisation was followed by participants realigning themselves with their core values; they stopped actively fighting the pain and engaged in valuable activities despite the presence of pain. Through this they were able to see their life with pain more positively, feel better within themselves and find renewed pleasure in life. The following quotation highlights these findings:

> Then I decided for myself, no, I'm going to change my attitude and then go on, do my studying, do my learning, and then forget about the pain. [59, p. 219].

Henwood et al. [59] described that through the experienced attitudinal shift the pain started to merge with participants' self-identity. For example, a participant from Hearn et al. [35, p. 2207] described:

> 100%, it's me. It's my identity. It's who I am. It's what happens to me.

Discussion

To our knowledge this is the first review to assess and synthesise qualitative research on the subjective experience of adults living with CNP following SCI. It highlights a striking lack of focus on individuals' experience of CNP following SCI within qualitative research; only six papers were identified, drawing on five studies, conducted by three different research teams across three western countries. Healthcare research has been dominated by quantitative studies exploring mechanisms, occurrences and outcomes; however, within recent years the importance of determining people's understanding, experiences and views of health conditions has been increasingly recognised [75]. Four of the six identified papers were published within the last five years, which might indicate an increased focus on the exploration of lived experience within the area. Qualitative research is unique in broadening our understanding of a health condition; without relating to predefined criteria, individuals living with the condition can freely describe their experience. This can aid the development of new, and the adaption of current, measures and interventions and guide clinical recommendations by including patients' view [76]. Furthermore, findings are context-specific, meaning that social and cultural variations can be considered in derived recommendations; based on this, further research on the experience of CNP following SCI in different, particularly non-western countries, is advised.

All the papers identified were rated to be of high quality; their data gathering and analysing processes were rigorous and transparent. They presented clear study and analysis procedures, stated the use of interview / focus group question guides, reflective strategies and triangulation and described the representativeness of their samples. However, papers could have provided more details regarding the researchers' background, as this would have added to transparency [77]. Furthermore, given the difficulty in assessing and diagnosing neuropathic pain and differentiating it from other types of pain, it would have been beneficial if studies commented on their confidence in the accuracy of participants' neuropathic pain diagnosis and on the diagnostic process that was undertaken. All papers clearly described their ethical considerations; however, none reported on data storage during and after completion of the study and only two papers commented on debriefing their participants. It would have been beneficial if papers commented on ethnicity and marital status as these are found to have an association with pain and/or spinal cord injury [78, 79]. Participants across papers were self-selecting and even though self-selection is commonly the only practical way to recruitment, transparency can be enhanced by stating frequency and reason for declining participation; however, only two papers commented on this [15, 36].

The synthesis of findings across papers resulted in the emerging of the overarching themes 'The pain as an unusual, intense, unpredictable and uncontrollable sensation', 'The pain's influence on life', 'The challenge of describing the pain to others', 'Trying to understand the pain', 'The search for pain relief' and 'Learning pain acceptance over time'.

The first theme described the idiosyncratic nature of CNP following SCI, as great variations with regards to pain characteristics were described. The pain was commonly described as unpredictable, uncontrollable, unusual and intense and for some people it is more distressing than any other SCI-related consequences. The unique sensation of neuropathic pain and its heterogeneous presentation are widely reported [5, 80]. Reviews have highlighted that the varied and unusual presentation of neuropathic pain contributes to suboptimal management, since diagnosis is difficult [81]. Additionally, the presence of comorbid conditions, such as depression and sleep difficulties, is associated with suboptimal treatment of the pain, as their treatment is commonly prioritised over pain [81]. This might be particularly problematic for individuals with CNP following SCI, as SCI is associated with sleep disturbance [82], depression and anxiety [83]. Similarly, healthcare professionals might prioritise other SCI-related consequences that might be more immediately apparent (e.g. spasms) despite individuals perceiving their CNP to be their main difficulty. Perceiving pain as more troublesome than other SCI-related consequences is a shared experience with neuropathic pain following other major health events, such as organ transplant [84] and stroke [85].

The second theme summarised the experience of pain-related limitations on activities of daily living and social and emotional consequences. The findings are in line with the wider research on neuropathic pain, which highlights the negative consequence it commonly has on quality of life (i.e. loss of function, anxiety, depression, disturbed sleep and cognition) [86]. For some individuals, the impact of their pain on their ability to engage in activities was greater than other SCI-related impairments (e.g. paralysis); pain is therefore an important factor to consider in rehabilitation [87] and adaption to injury. With regards to the social impact of the pain, many individuals reported limiting their social contact. This is consistent with a review of chronic pain that found impaired social integration and reduced relationship quality associated with increased stress and negative emotions [88]. The review also highlighted that some individuals did not disclose their suffering to others, which is in line with current findings. This might reflect the perception of others lacking understanding and empathy, which is commonly reported by individuals suffering with neuropathic pain [89]. Additionally, individuals might want to spare their loved ones the burden of sharing their pain experience; potentially because they feel they are already burden enough. A study by Smith and Osborn [90] found that individuals with chronic benign lower back pain perceived themselves as burden with no social value.

The third theme described that a lack of information provision results in the formation of idiosyncratic illness beliefs and expectations, which are adjusted over time as individuals learn to understand their pain and its characteristics. This lack of information, particularly regarding the origin and chronicity of CNP suggests there may be difficulties with providing clear diagnoses. Difficulties diagnosing neuropathic pain are recognised in the wider literature [81]. Holding incorrect appraisals regarding the origin and consequences of the pain can be problematic; for example, the fear-avoidance model [30] suggests that holding negative appraisals of pain can lead to worsening of the pain experience [91]. Based on this, the identification and understanding of illness beliefs should be considered by healthcare professionals, particularly in cases where provision of accurate information is limited. Participants' accounts suggest that over time and with experience individuals develop an understanding of their unique pain experience, which might even be more accurate than generic information provided. Nevertheless, it appears that healthcare professionals fall short on supporting individuals in their sense making process.

The fourth theme described participants' perceived difficulty in conveying their pain experience to others. This appeared to reflect the idiosyncratic, unusual presentation of CNP and lack of universal terminology. Hearn et al. [58] suggest that pain expressions tend to become more restricted and universal with the development of pain measurement tools, which suggests that the current ones for neuropathic pain [92] are either not widely used or not adequate for capturing individuals' experience of CNP following SCI. Participants reported feeling frustrated about others' inability to understand and emphasise with their pain, which is a commonly found theme across sufferers of neuropathic pain [89]. However, even though not reported by many of the papers, some participants felt understood by peers who have similar experiences. The value of peer support groups for individuals with SCI is widely documented [93, 94]; however, no research or clinical guidance around peer support specifically for individuals with CNP following SCI appears to be available.

The fifth theme described participants' experience of seeking pain relief. With the exception of individuals in inpatient settings, participants reported negative experiences of care, with an overemphasis on pharmacotherapy and lack of alternative options. This is consistent with the findings of Lofgren and Norrbrink [54]. It suggests that treatment guidelines for neuropathic pain following SCI, which recommend a holistic, multidisciplinary pain management approach [31, 32], are not consistently followed. Particularly in primary care, professionals might be more familiar with general treatment guidelines for neuropathic pain, which tend to focus on medical/pharmacological interventions [95-97]. Non-medical/pharmacological therapies for neuropathic pain are less well researched, which is likely to affect their inclusion in national treatment guidelines. It appears that challenges with the definition and measurement of neuropathic pain make it difficult for studies to investigate effectiveness of alternative interventions. For example, a systematic review by Van de Wetering et al. [98] which investigated the effectiveness of Cognitive Behaviour Therapy (CBT)-based interventions for chronic neuropathic pain could not draw conclusive findings due to limited methodological quality. Based on the lack of alternative treatments offered, individuals are left to their own resources to find alternative ways to relieve pain, which can add additional strain. Participants within this review voiced frustrations regarding the perceived lack of knowledge and empathy of healthcare professionals. A study by Upshur, Luckmann and Savageau [99] investigating primary care providers' concerns about managing chronic pain, highlighted that care providers acknowledge not being adequately trained in supporting patients with chronic pain. However, it was also highlighted that primary care providers perceived patients’ lack of compliance and their behaviour around self-management as problematic. This suggests mutual misunderstanding and frustration, which is likely to impact practitioner and patient interactions and care management. Importantly, this appears less of a concern in specialist settings; participants in this review perceived inpatient staff as available, knowledgeable and compassionate. Therefore, reduced specialist knowledge around neuropathic/chronic pain in primary care settings could be a key factor contributing to patients’ dissatisfaction.

The final theme described participants’ journey towards acceptance of the pain. Pain acceptance was derived slowly over time; after an initial focus on seeking pain relief, participants started to realise the limits of pain relief and the chronicity of their pain, which prompted the recognition of having to live with the pain. Finally, pain was incorporated in participants self-view. Studies investigating the role of acceptance in neuropathic pain are rare; however, much research has developed the understanding of acceptance in chronic pain. McCracken’s [100, p. 93] definition of pain acceptance, namely “willingness to experience continuing pain without needing to reduce, avoid, or otherwise change it”, fits the experience described by participants in this review. The review findings were also in line with findings by LaChapelle, Lavoie and Boudrea [101, p. 201]; they found that in their sample of women with arthritis and fibromyalgia “acceptance was a process of realizations and acknowledgements, including realizing that the pain was not normal and help was needed, receiving a diagnosis, acknowledging that there was no cure and realizing that they needed to redefine normal”. LaChapelle et al. [101] suggest that factors that enhance pain acceptance are having a diagnosis, social support, receiving information and acknowledging chronicity. These are all factors that participants of this review perceived to be less present for them, which could be a potential barrier to them finding pain acceptance. This highlights the need for individuals with CNP following SCI to be provided with a diagnosis and information and for healthcare professionals to consider patients’ social support structures.

Strengths and limitations

Strengths

The review is the first to focus on highlighting the lived experience of individual with CNP following SCI by synthesising qualitative research findings; thereby strengthening the inclusion of the patient voice in this area of research. The review had a broad search strategy, provided clear eligibility criteria, and used independent reviewer to assess eligibility and quality of papers. All the papers identified were rated to be of high quality; their synthesis followed a rigorous and transparent process. To avoid bias in the synthesis process, identified themes were reviewed by two members of the research team independently.

Limitations

Despite using text-word search and MeSH terms, the initial pool of papers identified was relatively small. This reflects the limited research available, but means that review findings may not be widely applicable. Studies from non-Western countries may have been missed by the exclusion of non-English papers. Additionally, even though holding a clear, universal definition of what constitutes chronic pain (≥3 months), we wonder if this definition is indeed held universally or is another reason for non-western studies to be excluded. Given the importance of social and cultural context in the experience of pain, it is possible the findings of this review might be less applicable to non-western countries.

Clinical implications

This review highlighted that despite the multitude of SCI-related consequences, the presence of CNP should not be overlooked as it may be perceived as the most distressing and disabling consequence of SCI.

Given the lack of a framework, the idiosyncratic nature of the pain and individuals difficulties in rating or describing the pain, healthcare professionals might find it difficult to understand the pain characteristics, intensity and impact. This in turn could affect their ability to assign a diagnosis, and provide suitable information and intervention. Disorder-specific pain screening measures, such as the Spinal Cord Injury Pain Instrument (SCIPI) [102], can aid the diagnostic process. Furthermore, a jointly created formulation of the pain experience, using the patients’ words, might aid joint understanding, the development of rapport and future treatment planning. This process might also aid identification of patient held illness beliefs, which should be considered, given that negative pain appraisals can enhance the pain experience.

This review highlighted the lack of non-intrusive and non-pharmacological treatment options offered to individuals with CNP following SCI. Healthcare professionals should consider offering non-intrusive, non-pharmacological alternative treatments to patients, as even though these might not be described in national guidelines on the treatment of general neuropathic pain, they are described in specialist guidelines on CNP following SCI. Furthermore, even though limited, there is evidence regarding the effectiveness of alternative treatment options. For example, Norrbrink et al. [34] showed the effectiveness of a CBT-based pain management programme for individuals with CNP following SCI. Similarly, Heutink et al. [33] highlighted that individuals experiencing chronic spinal cord injury pain perceived massages, physiotherapy, physical activity and relaxation techniques as beneficial. Furthermore, offering Acceptance and Commitment therapy might aid the development of pain acceptance, as it has been found effective for other chronic pain conditions [103. 104].

Additionally, given the widely recorded benefits of peer support in providing information, empathy and a sense of belong and the lack of specific groups for individuals with CNP following SCI, healthcare professionals should consider suggesting SCI or chronic pain support groups to their patients. Given the potential lack of local groups and patients' mobility difficulties, online support platforms could be suggested.

Implications for research

Participants presented in papers covered a broad range of ages, time since injury and time since pain onset. However, given the different views voiced by inpatient participants included in this review [58] it might be valuable for future research to explore nuances in lived experience by individuals earlier on in their pain experience. Furthermore, exploring differences in lived experience between working age and older adults might highlight unique challenges at different life stages. It would also be useful to explore children’s experience of living with CNP following SCI; they are likely to have a unique view that might not be captured. Additionally, given the context-sensitive nature of qualitative studies, researchers might want to consider exploring the lived experience of CNP following SCI in non-western countries.

Across studies it was noted that various ways to capture pain description and severity were used; there appears to be a lack of universal measures that capture the subjective experience of participants. Furthermore, participants' accounts suggest that numerical measures might not be suitable. Efforts should be made to design a measure that sufficiently captures individuals' experience of CNP following SCI.

Further research is needed to test the effectiveness of alternative interventions for CNP following SCI, such as education programmes, pain management groups and psychological intervention. Furthermore, given the widely recognised benefits of peer support, it appears important to explore its effect on individuals with CNP following SCI. Future research should seek to answer questions such as do people have peer support available to them, what are the benefits, are their perceived differences in face-to-face and online support and do they feel supported even in more generic SCI or chronic pain groups.

Conclusions

Findings of this novel systematic review of qualitative research on the experience of adults living with CNP following SCI suggest that individuals with SCI experience their CNP as an uncontrollable, unpredictable, unusual and intense sensation, which is difficult to describe and quantify. It is described to be all consuming, affecting all aspects of individuals' lives; for some, the CNP is more debilitating than any other SCI-related consequence. There appears to be a lack of information provided to individuals with CNP following SCI, which might reflect difficulties with assessment and diagnostic. Individuals therefore form illness beliefs, which may not always be accurate or helpful. There also appears to be a lack of support and care for individuals' with CNP following SCI; felt frustration was reported with regards to lack of understanding by others, primary healthcare professionals' perceived lack of knowledge and compassion and over emphasis on pharmacotherapy without the provision of alternative treatments. In the perceived absence of adequate information provision and long-term care, individuals have to form their own understanding and acceptance of their pain over time.

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Data availability

The search history and list of derived papers are available on request.

Disclaimer

The views expressed in this research article are of the authors and are not an official position of the University of East Anglia.

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Chapter 3. Bridging Section

Spinal cord injury and stroke are considered sudden-onset neurological conditions and are related to the experience of an unexpected, often traumatic and life-changing event. Chronic pain in the context of these sudden-onset neurological conditions is an under-researched area, despite pain following these events being a relative common experience (Burke, Fullen, Stokes, & Lennon, 2017; Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2006). In particular, research around patients' experience of pain in the context of these sudden-onset neurological conditions has been scarce. Nevertheless, the systematic review enabled some insights into what it is like to live with chronic neuropathic pain in the context of a spinal cord injury. The review highlighted that adults with spinal cord injury tend to experience the pain as an uncontrollable, unpredictable, unusual and intense sensation, which can be immensely debilitating. The pain appears to be not well understood and is difficult to describe, quantify and diagnose. A lack of understanding, knowledge and compassion by healthcare professionals was described together with an overreliance on pharmacotherapy. Understanding and acceptance of the pain was found to develop over time.

Similar findings have been noted by some Swedish studies which explored stroke survivors' experience of post-stroke pain. The pain was described as debilitating; impacting activities of daily living, relationships and mood (Lindgren, Gard, & Brogårdh, 2018). Stroke survivors had difficulties comprehending their pain and felt their pain was misunderstood by others around them (Lindgren, Gard, & Brogårdh, 2018; Widar, Ek, & Ahlström, 2004). Long-term care provision was described as unsatisfactory; lacking accessibility, continuity and expertise of healthcare professionals (Widar, Ek, & Ahlström, 2007). None of the studies exploring post-stroke pain focused on the experience of neuropathic pain and none were conducted in the UK. Therefore further research was warranted and a study exploring individuals' experience of post-stroke pain in the UK was designed as part of this thesis portfolio.

Since neuropathic pain is integral to neurological conditions in many cases and distinct to other types of pain, the initial plan was to focus on chronic neuropathic pain within both research papers. The research study was initially planned to focus on central post-stroke pain (CPSP), which is defined as neuropathic pain caused by stroke-related damage to the central nervous system (Henry, Lalloo, & Yashpal, 2008). However, significant recruitment difficulties, possibly related to difficulties with the identification and diagnosis of CPSP, necessitated re-design of the research study to focus on all types of chronic post-stroke pain (i.e. neuropathic and nociceptive pain). Within the research study the population was restricted to working age adults, aged 16 to 64. This was based on research suggesting their experience might differ from that of older adults. Working age adults are suggested to have increased occupational duties, enhanced family responsibilities and greater financial needs (Black-Schaffer & Winston, 2004; Morris, 2011; Snögren & Sunnerhagen, 2009). The focus on working age adults’ could not be adapted in the systematic review as papers were too scarce to include an age limitation.

Chapter 4

The Experience of Working Age Adults Living with Chronic Post-Stroke Pain: An Interpretative Phenomenological Analysis

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Doctoral Programme in Clinical Psychology
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The experience of working age adults living with chronic post-stroke pain: An interpretative phenomenological analysis

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Abstract

Purpose: To investigate the experience of working age adults living with chronic post-stroke pain in the United Kingdom (UK). *Methods:* Semi-structured interviews were conducted with eight working age (18-64 years) UK-based stroke survivors who experience chronic post-stroke pain (≥3 months). The interviews were analysed using interpretative phenomenological analysis. *Results:* Three themes emerged from the analysis, namely 'The Solitude of the Pain Experience', 'Unsatisfactory Healthcare and the Need for Self-Care' and 'The Development of Pain Acceptance'. Findings suggest that individuals see their post-stroke pain as an invisible disability, which is overlooked and misunderstood by others. Furthermore, in the absence of a differential post-stroke pain diagnosis, clear, accurate information and alternatives to pharmacological treatments, individuals with post-stroke pain invest their own resources in finding answers and a way to live with the pain. *Conclusions:* The findings suggest the need for further education on post-stroke pain for healthcare professionals, the consideration of pain in post-stroke assessments, the need for clear differential pain diagnoses and the provision of accurate information to patients. Research is needed to establish non-pharmacological evidence-based treatment approaches, such as pain management programmes, peer support and psychological interventions. *(Word Count Abstract: 187)*

- **Implications for Rehabilitation**
- Individuals experiencing post-stroke pain consider it an invisible disability, which is difficult to describe to others and therefore often overlooked and misunderstood by people around them.
- Particularly in the context of other stroke-related impairments, invisible pain might not get the attention and care it requires.
- Improvements need to be made in the assessment and diagnosis of post-stroke pain. Differential pain diagnoses need to be made and communicated to patients; clear explanations of underlying mechanism, characteristics and prognosis of the pain should be provided.
- Treatments other than pharmacology, such as a pain management programmes, peer support, family therapy and psychological interventions, should be considered and patients should be supported in finding a way to live a meaningful life despite the pain.
- It should be considered that younger stroke survivors might be particularly affected as chronic pain can impact on employment and parenting.
- Healthcare professionals, particularly in primary healthcare services would benefit from training on post-stroke pain.

Keywords: Stroke; chronic pain; post-stroke pain; working age; lived experience; interpretative phenomenological analysis

Introduction

In the United Kingdom (UK) more than 110,000 people each year experience a stroke [1]. Stroke is the fourth leading cause of death in the UK [2]; however, the number of people surviving stroke is increasing [3]. Currently there are over 1.2 million stroke survivors in the UK [2]. Although stroke typically occurs in older adults, with the average age of stroke in the UK (excluding Scotland) being 74 for men and 80 for women [4], the number of younger people experiencing a stroke (defined as <65 within this research) is increasing [5]. Currently, around one quarter of strokes occur in adults of working age [1], defined as 16-64 years by the Office for National Statistics [6].

Two thirds of stroke survivors experience a significant impairment of functioning as a result of stroke [2]. Difficulties with motor functioning, perception, language, cognition, somatosensory processing and mood are frequently reported [1, 7]. Young stroke survivors have been argued to experience better functional outcomes in cases of severe impairments [8]; however, they may live longer with these impairments [9]. Functional impairments can greatly affect stroke survivors’ lives; reduced social participation, relationship breakdown, enhanced dependency and financial difficulties are common [10, 11]. For younger stroke survivors these functional, social and economic consequences can be particularly challenging as working age adults often have increased occupational duties, enhanced family responsibilities and greater financial needs [8, 12, 13]. Furthermore, they may experience more profound changes in their anticipated future and a shift in their self-; concept towards premature aging [12]. These factors can leave younger stroke survivors particularly vulnerable to post-stroke depression and anxiety [14, 15].

Early, specialist and intensive intervention has been shown to greatly improve functional outcomes of stroke survivors [16]. Based on this stroke services within the UK National Health Service (NHS) provide intensive multidisciplinary support immediately following stroke; hospitals offer hyperacute and acute stroke care, which can be followed by early supported discharge or stroke specialist community rehabilitation for up to six months post stroke [17]. After six months, care is often transferred back to General Practitioners (GPs). Despite the recognised effectiveness of this stroke care model [18] condensing support to the first six months post stroke may result in reduced support thereafter. A survey of 1251 UK stroke survivors highlighted that around half experienced unmet needs one to five years following their stroke [19]. A frontloaded stroke care model may be particularly problematic for stroke-related impairments that are less visible or have a delayed onset; an example is post-stroke pain.

Post-stroke pain has been described as an underreported, underrecognised and undertreated consequence of stroke, which is complex and multifaceted in nature [20]. Reported prevalence rates vary considerably across studies, ranging from 19% to 74% [21]. Differences in criteria and methodologies [22] as well as variations in post-stroke pain variables (e.g. time of onset, pain location) are likely to account for the discrepancy. Some evidence suggests a greater prevalence of post-stroke pain in younger stroke survivors [22]. Post-stroke pain can arise from stroke-related tissue damage (nociceptive pain) or nerve damage in the central or peripheral nervous system (neuropathic pain) [23]**.** It is regarded as chronic when lasting or reoccurring for three months or more [24]. Various post-stroke pain subtypes exist; the most common ones being hemiplegic shoulder / arm pain, musculoskeletal pain, headache and central post-stroke pain (CPSP) [22, 23]. Commonly stroke survivors experience more than one pain subtype [23].

Variations in clinical presentation, severity and duration of post-stroke pain [25] can hinder accurate and timely diagnosis. In particular, variations in pain onset, which can be at the time of stroke or months later [26], can create a barrier to diagnosis. Given the frontloaded intervention model of UK stroke services, individuals experiencing delayed pain onset may no longer be under the care of specialist stroke services when the pain develops. Further diagnostic barriers are stroke-related cognitive or language difficulties [27], limited knowledge of post-stroke pain in healthcare professionals [28] and lack of specific post-stroke pain measures [29]. Pain descriptors underlying pain measures are reported unreliable [30] in the classification of post-stroke pain [31].

To date there has been no research on the views of UK stroke survivors with post-stroke pain. However, a handful of studies in Sweden highlighted that patients experienced their post-stroke pain as difficult to comprehend, due to the presence of multiple pain characteristics (i.e. varied sensation and pain location) [32, 33]. They also commented on the pain's negative impact on their everyday life, their relationship and their mental wellbeing [32, 33]. Additionally, post-stroke pain care was described as lacking accessibility, expertise and continuity [32]. Participants described feeling unacknowledged, misunderstood and side-lined by healthcare professionals [32, 34]. These experiences are in line with ones described by patients experiencing chronic pain in the context of other health conditions [35].

Reviews have highlighted that current treatment options for post-stroke pain are limited and not always effective [36]. There is an overreliance on pharmacological treatments [31], which for certain cases and pain subtypes (e.g. CPSP) show limited effectiveness [37]. Alternative treatment options (e.g. acupuncture and massages) tend to lack an evidence-base for chronic pain following stroke [26]. In the face of limited effective treatment options, individuals appear to engage in both problem-focused (e.g. seeking alternative treatment and planning activities) and emotion-focused coping (e.g. distraction, making downward counterfactual comparisons and acceptance) [38-40].

The way in which individuals cope with their pain is important, as post-stroke pain has been shown to negatively impact daily functioning and wellbeing. Post-stroke pain has been associated with reduced activities of daily living and quality of life [22, 41], relationship difficulties [22], loneliness [42], fatigue [41, 43], depression [22, 41] and suicidality [44]. Furthermore, research indicates that post-stroke pain can negatively influence rehabilitation, leading to delayed or limited recovery [28, 45]. Given the unique life stage of working age adults, it is possible that the socioeconomic and psychosocial impact of post-stroke pain is enhanced in that age group. Research in chronic pain has shown that compared to older adults (aged over 60 within the study) younger adults experienced a lower quality of life, less satisfaction with their economic and social situation and more mood difficulties [46].

The complexity of chronic post-stroke pain, its debilitating nature and the difficulties in its identification and treatment warrant further research. Current knowledge, mainly gained from quantitative research, has focused on defining clinical characteristics, describing pathophysiology, and quantifying consequences and treatment outcomes. Though useful, the range of possible findings was limited as researchers predetermined the variables to be measured. The broader narratives of people suffering from persistent post-stroke pain are barely captured by research. A handful of qualitative studies, conducted in Scandinavia, have started to develop a broader understanding of individuals' experience of the condition, such as their challenges and ways to manage the pain through coping strategies and healthcare treatments [32, 33, 34, 38, 47]. However, given that culture impacts pain perception [48], it appears important that research exploring individuals' experience of chronic post-stroke pain is conducted in the UK. Additionally, given the suggested higher prevalence of post-stroke pain in younger adults [22] together with the fact that younger adults' have a unique stroke [49] and pain experience [46, 50], research that particularly focuses on younger adults with chronic post-stroke pain is desirable.

The current study therefore aimed to answer the question; ”What is the experience of working age adults living with chronic post-stroke pain in the UK?”. A qualitative idiographic approach was chosen, which aimed at generating rich, detailed accounts of the experience of chronic post-stroke pain in working age stroke survivors (defined as age 18-

64 within this study) in the UK. Interpretative phenomenological analysis (IPA) was adopted as it is committed to providing a rich understanding of individuals' experience of major life events [51, 52] and is proposed to be particularly useful in healthcare research [51] and research on pain [53]. Compared to other qualitative approaches, IPA is distinct in its focus on the in-depth analysis of participants' individual perspectives, thereby considering their unique contexts [53]. Each participant's narrative is analysed in great depth, focussing on the individual's perception and experience of an event, without the consideration of other participants' narratives and pre-existing theoretical preconceptions or aiming to produce an objective statement of the event itself [53].

In capturing UK-based working age adults' narratives of living with chronic post-stroke pain, we aimed to support the development of a new context-specific understanding of post-stroke pain, which might aid the development of new, or adaption of current, measures and interventions and guide local clinical recommendations [54].

Methods

Design

Semi-structured, audio-recorded interviews following an open and flexible interview schedule (Appendix E) were conducted with a small, purposive sample and analysed using IPA. IPA adopts the epistemological stance of the researcher [55]; critical realism was the stance assumed in this research.

All participant-facing study materials were reviewed by a Patient and Public Involvement (PPI) volunteer who sustained an acquired brain injury (ABI) in adulthood and who advises researchers on suitability of materials for people with ABI.

Ethical, governance and legal approval was granted by the Faculty of Medical and Health Sciences Research Ethics Committee of the University of East Anglia (UEA) (Appendix F). Local organisational approvals were sought. Health and Care Professions Council [56], British Psychology Society [57] and the UEA codes of conduct were followed [58].

Participants

Participants were UK-based, community-dwelling, English-speaking adults (age 18-64), who experienced stroke-related pain for three months or more. Individuals were excluded from the study if they lacked capacity to consent to participation, had a chronic pain condition prior to their stroke or had significant cognitive, language, mental health or substance misuse difficulties that would prevent valid engagement in the research.

Participants were recruited through voluntary sector organisations and social media advertisements (Appendix G). Participants made aware of the research through advertisements contacted the researcher directly; whereas, participants recruited through participating organisations gave written consent to be contacted by the researcher.

Eight stroke survivors participated, four female and four male, aged between 46 and 64, (mean age = 56.5 years). Participants were between one and twenty-one years post stroke, with an average of 7.1 years. None of the participants had received a differential post-stroke diagnosis by a healthcare professional; however, their pain descriptions were suggestive of musculoskeletal pain, shoulder pain, CPSP and headache. Three participants experienced two forms of post-stroke pain simultaneously. Seven of the participants received pharmacological treatment for their pain; four sought various alternative treatment options, such as physiotherapy, instructed exercise and Cannabidiol (CBD) oil, privately. Participants of this study were assigned pseudonyms. A summary of participant characteristics is presented in table 2.

Table 2 Characteristics of participants.

Name (Pseudonym)	Age	Ethnicity	Education & Occupation	Social Network	Self-Reported Health Difficulties in Addition to Stroke	Year of Stroke(s)	Self-Reported Stroke-related Impairments	Suggested Diagnostic Label	Current Pain Treatment	Interview Location
Jack	46	White British	School; Medically retired police officer	Family; Support group	Antiphospholipid syndrome; Hypertension; Epilepsy	2015; 2018; 2018	Word finding; Visuospatial; Executive functioning; Pain	Headache	Medication	Home
Peter	60	White British	College; Medically retired IT engineer	Family; Online support group	Hypertension; Diabetes; Anxiety; Depression	2009	Memory; Balance; Pain	Shoulder pain & CPSP	Medication; CBD oil	Home
Linda	64	White British	Not disclosed; Part-time work in a school	Family; Friends; Online support group	None	2017	Word finding; Balance; Somatosensory (Pain)	CPSP	Medication	Home
Kiara	56	Black British	Not disclosed; Medically retired nurse	Family; Support group; Church	Epilepsy; Depression	1998	Aphasia; Memory; Pain	Musculo-skeletal pain & Headache	Medication	Charity Centre
Judith	63	White British	University; Medically retired doctor	Family; Friends; Support group	None	2017	Motor functioning; Visuospatial; Somatosensory (Pain); Dysarthria	CPSP	Medication; Private physiotherapy and exercise groups	Home
Harry	48	White British	University; Full-time carer	Family; Friends	Epilepsy	2017	Motor functioning; Balance; Pain	Musculo-skeletal pain	Physiotherapy	Home
Tiwa	52	Black British	College; Homemaker	Family; Church; Support group	None	2004	Motor functioning; Memory; Aphasia; Balance; Pain	Musculo-skeletal pain	Medication; Gym	Charity Centre
Brian	63	White British	School; Medically retired project manager	Family; Friends	None	2018	Motor functioning; Balance; Processing speed; Emotion-regulation; Pain	Shoulder pain; CPSP	Medication	Home

Data collection

Participants were interviewed at either the recruitment organisation (n = 2) or their home (n = 6), according to their preference. Written consent for participation was obtained prior to the interview. Demographic information was collected to understand the homogeneity of the sample and provide context to the personal narratives of participants.

To avoid constraining participants’ narratives and imposing an external view, the interview schedule used a series of open-ended questions to elicit narratives, beginning with a broad, general question (“Can you tell me about your experience of living with chronic post-stroke pain?”), which allowed participants to set the agenda [52].

The interview process was flexible to allow for cognitive and communication difficulties to be addressed; participants were given additional time to express themselves and could act out, draw and write down concepts that they found difficult to express. Interviews were audio-recorded. Interviews ranged from 44 to 72 minutes, with an average of 55 minutes. At the end of the interview participants were provided with a debriefing form containing summary details of the study, contact details of the lead researcher (J. B.) and other available support systems (e.g. GP, stroke-related voluntary organisations), which could be contacted if issues related to the study arose (Appendix H).

Data analysis

Audio recordings were transcribed by the researcher and a professional transcriber. To ensure confidentiality, personally identifiable information in transcripts was anonymised.

Data were analysed following Smith et al.’s [52] guidelines. Each transcript was read independently of the others multiple times and analysed in the context of the participant’s individual experience. Observations and reflections regarding content, language and context were noted alongside statements of personal reflexivity. Initial notes made on the first interview then guided the conceptualisation of higher level themes, which were grounded in details of the participant’s narrative. The following interviews were examined against those previously analysed ones; thereby analysing frequency, convergence and divergence of themes. Themes with conceptual similarities were grouped together, theme names were re-considered, themes that had weak evidence or did not fit the emerging structure were dropped and newly discovered themes were compared against previously analysed interviews. Master and subordinate themes were identified that reflected the lived experience of chronic post-stroke pain for the group as a whole.

Quality, rigour and trustworthiness within this study were addressed by adapting Smith et al.’s [52] framework for IPA and considering Yardley’s [59] guidelines for methodological rigour. To aid rigour, transparency and trustworthiness, decision processes were tracked. To increase study quality and validity, personal reflexivity was captured using a reflective diary [55, 60]. In order to prevent analytic bias, the analysis, conducted by the lead researcher, was discussed with the wider research team to allow for agreement to be reached regarding derived themes. The lead researcher, who collected and analysed the data is a female Clinical Psychology Trainee with work experience in various mental and physical healthcare settings. She holds no clinical or personal experience of stroke but has a special interest in neuropsychology. The research team consisted of a female Clinical Neuropsychologist (C. F.) with experience in stroke psychology and a female Health Psychologist (J. S.) who has researched individuals' experience of various health conditions including neurological conditions.

In order to enable assessment of reliability and validity of the research, themes are presented together with participants' comments and findings are discussed in relation to the wider literature in stroke and chronic pain.

Findings

Three master themes, present for all participants (Appendix I), were derived, which illuminate the experience of working age adults living with chronic post-stroke pain (table 3).

Table 3. Summary of master and subordinate themes.

Master Themes	Subordinate Themes
1. The Solitude of the Pain Experience	(a) "No one really understands" (b) "I'm not going to tell you unless you're going to help me"
2. Unsatisfactory Healthcare and the Need for Self-Care	(a) "I don't think I received care" (b) "I'm not really a doctor but I presume it's something …" (c) "It's like self-management - I just do what I can myself"
3. The Development of Pain Acceptance	(a) Mourning the 'old' self and life (b) Accepting the 'new' self and life

The solitude of the pain experience

All participants described feeling alone with their pain. They felt others do not understand, forget or downplay what they are going through and find it difficult to empathise. Based on this, participants reported weighing up the benefits and costs of sharing their pain experience with others.

"No one really understands"

This subordinate theme summarises the feeling, described by all participants, that others around them find it difficult to understand and relate to their pain. Some participants believed that others' lack of understanding is related to their pain being an invisible or hidden disability.

> […] people's reaction is 'You, what, when, how?', 'You've had a stroke?'. You know you have this idea of [a] 80 / 90 year old person um in a wheelchair, who can't take … can't use their whatever. That's the vision of it and I'm not, I don't think I'm a vision of a person who's had a stroke and so perhaps to other people it's hard for them to sort of grasp. If you're sitting in a wheelchair, if you can't talk or walk, you can actually see that, [but] this pain is just permanent and invisible. [Linda].

Linda described perceiving her pain as an "invisible" stroke impairment which, compared to visible signs of impairment and suffering (e.g. "sitting in a wheelchair"), might not receive attention and empathy. In line with this, she feels that her lack of visible impairment and younger age, mean she is not perceived as a stroke survivor and does not receive the understanding and empathy afforded to other stroke survivors.

Participants described that lack of understanding by others can create difficulties in their everyday life, social interactions and can cause emotional upset. This is highlighted in a comment by Harry, in which he describes occasionally feeling frustrated with his partner as he feels she cannot relate to the burden he faces with regards to his pain.

> […] when I stop moving then I get pain. It's like when I'm lying in bed and I wake up in the morning, cos I haven't been [moving] and my partner says like 'Well, maybe you should move round more', I say 'I've got to relax. I can't spend my whole night moving around' .It's like give me a chance, you know. At some point I've got to be able to relax. [Harry].

Harry voices his frustration with his pain-related inability to relax, as well as his partner's difficulty empathising with it. All participants reported that even people close to them had difficulties understand their suffering. Participants also reported that even if they received understanding, support and empathy from people close to them initially, this would subside over time, as either others forgot about their pain, due to the lack of a visual reminder, or assume participants would get better over time.

“I’m not going to tell you unless you’re going to help me”

This subordinate theme summarises the process of weighing up the usefulness of sharing the pain experience with others. It was described by all but one participant. One of the common reasons for not sharing one's pain experience was that participants felt others won’t relate to their accounts. However, another commonly named reason was that participants did not want to burden others.

> […] I think there’s nothing worse than inflicting your pain you’re suffering on anybody else. They’ve… everybody has got their problems. Um mine is specific to me and theirs is to them […]. [Linda].

Linda’s comment suggests she feels that sharing her pain experience inflicts pain on others. Also she acknowledges that others have their own difficulties to which she does not want to add; therefore, she keeps her suffering to herself. Participants also described that even if they told others about their pain in the beginning, when they first noticed it, they would be less likely to do so as time passes. They felt that given the chronicity of their pain, their continuous sharing of their experience and associated feelings could be considered nagging or moaning and does not hold any additional benefits. This is highlighted in a statement by Peter:

> […] I won’t bring it up in conversation; say to somebody ‘Oh I had this so and so pain blah blah…’, like two old biddies meeting in the bleeding grocers. One’s moaning about her kidneys the other one is talking about her gout. Um, I can’t be dealing with that. I’ve got a problem, I live with it […]. [Peter].

Peter states that he does not tend to tell others about his pain, as he considers it as “moaning” and does not see the benefit. Rather he implies that “moaning” to others could mean that he gets to hear about other people’s problems, which he feels he “can’t be dealing with”. Taking on other people’s problems and negative emotions might be too overwhelming given that he already struggles with his own difficulties.

Another reason for not sharing the pain experience with others was reported to be not wanting to pay attention to the pain and be reminded of it. For some participants talking about pain increased their sensation; whereas others wanted to experience times where pain was not the centre of their lives. Additionally for Harry, talking about the pain also meant talking about the stroke, which was a traumatic experience he does not want to be reminded about.

> […] I'll be honest, the one I go to there's a different GP every time and I don't want to keep repeating my story, you know. For my shoulder [pain] I saw two different GP's for that and I each time I have to keep repeating the same story and it's like… at the time I wanted to forget what had happened. [Harry].

Harry avoids talking to GPs about his stroke and the associated impairment, as for him having to retell his story evokes negative emotions. However, this would imply that by not opening up to his GP he might not get the care and support he needs with regards to his pain.

All seven participants would share their pain experience with others if they perceived it as useful to them. Participants mentioned sharing their pain experience with immediate family members and friends to elicit practical support (e.g. help cooking) or understanding with regards to their behaviour (e.g. walking more slowly), and with healthcare professionals to initiate treatment. Harry summarised his weighing up of sharing his pain experiences in the following way:

> I'm not going to tell you [about the pain] unless you're going to help me. […] I've got to talk to my partner cos I live with her. You know, I've got no choice. But I'm not going to tell the guy next door. […] He's not interested. Why would he be interested and why he .. and why would I be interested in telling him, cos he's not going to help me. You've got to tell someone and then they'll go… […] 'oh it's a shame'. [Harry].

Harry's comment suggests that he does not want to share his experience unless he receives practical support as a result of it. He shares his pain experience with his partner to raise her awareness, implying that it is essential to them living and raising children together. However, he does not tell others to receive empathy, which for him does not have any worth.

Unsatisfactory healthcare and the need for self-care

All participants reported negative experiences with the long-term care of their pain, leaving them to find their own answers with regards to diagnosis (e.g. illness beliefs) and management (e.g. alternative treatments). Again, participants felt misunderstood and alone in their pain experience. This is summarised in a comment by Linda:

> I feel sort of maybe a bit abandoned now, which I shouldn't, but I do. That nobody, when I say nobody I mean medically nobody not friends, um thinks it's [the pain] any big deal, because to them it isn't but to me it is quite a big deal actually [Linda].

Linda mentioned that she feels “abandoned”, implying that she feels alone in her suffering and that in addition to her social network, healthcare professionals don’t understand and empathise with her suffering.

“I don't think I received care”

This subordinate theme summarises participants’ experience of not receiving adequate care for their post-stroke pain by the healthcare service. This is summarised in a comment by Linda:

> […] I feel let down by my GP. Not the hospital, the hospital was great and they discharged me […] to the care of the GP, [which] should be care and it wasn’t. I don't think I received care. All the contact with the GP has been me phoning them and asking either to see somebody or ‘What do you advise?’. […] It’s all been just verbally and it is quite hard I think to describe pain […] [Linda].

Linda highlights that she perceived the specialist care by the hospital, during her acute and rehabilitation phases as helpful but that she feels disappointed with the “care” of her GP; a view shared by other participants. It appears that Linda hoped for a more proactive, nurturing approach in which she was followed-up and assessed. Linda’s comment also suggests that describing the pain experience is difficult. This view was also voiced by Judith:

> […] unless it fits into previously described categories they don’t really understand what you’re thinking […] [Judith].

Judith highlights that she feels her pain experience does not fit into the known categories of pain, which she feels prevents healthcare professional from understanding, relating and diagnosing the pain accurately.

> […] there’s lots of arguments about… ‘is it that or not’. People, yes language is so important in classifying things, pinning it down. So if you’re a slight variance of that, language isn’t quite the same, you are not in … not counted in that category. So you, you know that treatment is not for you. [Judith].

Judith’s comment suggests that she feels her post-stroke pain description does not fit into existing pain categories, which causes her to miss out on treatment. Judith’s pain appears to be CPSP, which tends to be particularly unusual in its presentation and experience. Importantly, none of the participants were given a differential post-stroke pain diagnosis and some clearly voiced that it would be helpful to have had a diagnosis.

Participants described that underlying their dissatisfaction with the care received from primary healthcare service was a lack of specialist knowledge. This might also explain why some participants clearly voiced satisfaction with secondary / specialist stroke services.

> It's the not knowing when you, you know, when you're feeling things and then nobody can give you any answers to what it is. I mean there's a lot of guess work involved um and I think that's all down to lack of knowledge. [Brian].

Brian voices his frustration over healthcare professionals not being able to give him clarity and insight with regards to the pain he feels. His comment implies that he feels that his care is not evidence-based, but rather based on guesses. In line with Brian's comment, Peter voiced that he feels his treatment has been based on a trial and error approach:

> I would have said it was very much uh a trial, because it was trying to find something that worked. I'm not too sure… I think I'm on gabapentin which is for pain of some sort. I've got a whole list all right […] [Peter].

Peter's comment highlights the difficulties experienced in treating post-stroke pain, particularly when multiple types of pain are experienced simultaneously. This quotation also suggests an overemphasis on pharmacotherapy in the treatment of chronic post-stroke pain. With the exception of one participant, who decided against pain medication as treatment due to it "masking" the pain rather than solving it, all participants took regular pain medication and all voiced dissatisfaction with regards to it being the only treatment offered. Pain medications were described as ineffective, having negative side effects and being risky with regards to addiction.

"I'm not really a doctor but I presume it's something …"

This subordinate theme highlights that given the complex and multifaceted nature of chronic post-stroke pain and in the absence of clear, accurate information regarding the pain, participants were spending time and effort on developing their own beliefs around the causes, triggers, underlying mechanisms and consequences of their pain.

A comment by Peter highlights the importance of illness beliefs, regardless of their accuracy.

> […] where I get pains at the side of my head and they worry me, cos I've had strokes. They automatically they … you start thinking 'oh god is it something coming on'. Um I've heard that if it's at the side of your head its stress related, which is all well and good cos I live 24 hours a day with stress. [Peter].

For Peter one belief, namely the pain being a sign of another stroke, appears to cause anxiety, while another belief, namely the pain being a consequence of stress, does not.

In contrast to most participants Judith, a retired doctor, reported not being overly concerned about her pain experience. Her beliefs about her post-stroke pain were influenced by information she sought on the biological underpinnings of her pain and its association to her stroke.

> […] there have been lots of things that I have been exploring about how you perceive um touch and pressure and pain sensations. And I started thinking, well, maybe it's a different kind of receptor that's being stimulated because the sensory nerves are a bit knocked off by the stroke or the pathway is knocked off by the stroke. [Judith].

Judith's comment suggests that she spent time and effort "exploring" and forming her belief about the pain. She sees her pain as a consequence of the neurological damage caused by stroke; an explanation that does not create feelings of anxiety. However, despite having a medical understanding of the cause of the pain, she was uncertain if the pain was a sign of stroke recovery or stroke disability. This is highlighted in the following comment:

> […] I keep watching it to see what it's going to do, cos you know, to me it might be … it might be a sign of hopeful recovery and if it wasn't there maybe I'd forget about recovery or think that I'm better. So, I'm not sure if it is reminding me of disability and therefore is a negative thing or is it is a hopeful thing. [Judith].

Judith's stroke had significantly reduced her motor ability, creating a high level of dependency. Having some kind of sensation in her limbs could therefore either represent an internal recovery process, which makes her feel hopeful, or remind her of her inability to control and feel her body the way she did before stroke. Even though holding the belief that the pain is a sign of recovery can be protective in terms of mood and rehabilitation efforts, it might have the effect that individuals postpone help seeking. Judith's statement also implies that her beliefs might change over time ("I keep watching"), which is something that was found for the majority of participants.

"It's like self-management - I just do what I can myself"

This subordinate theme highlights that given participants' perception of primary care services being detached and reactive, participants felt they had to be proactive in their pain management. The lack of treatment options offered by GPs and the dissatisfaction around pharmacotherapy appeared to drive participants to use their own resources to find alternative treatment options. This is highlighted in a comment by Harry:

> […] I suppose it's just coping with it and just, you know, trying to kind of still look for kind of solutions that aren't just masking the pain… they're actually curing it or you know easing it. And I mean I take I took cod liver oil and magnesium or all sorts of, you know, sprays and different things. And it's like, you know, I will try anything […]. [Harry].

Harry describes that he tried various methods to cure or at least reduce his pain, but implies that none have been successful. This is consistent with the experience of other participants, of spending their resources on alternative treatment options (e.g. CBD oil, osteopathy, physiotherapy and acupuncture), which commonly are perceived as ineffective. His statement, "I will try anything", highlights how desperate he feels to find something other than pharmacotherapy, which was the only treatment offered to him and which he feels is masking rather than solving his pain problem.

The majority of participants reported wishing that they could share their experience and treatment approaches with others who are also suffering from post-stroke pain. For example, Linda stated:

> Oh I'd want to talk to them [other individuals with post-stroke pain]. […] I wouldn't have to explain why I'm not having the pizza, why I don't want the tomato sauce, why I… they'd know. Um and it would be interesting to see how they've coped with it and maybe they have an answer. Maybe they say 'If you take um two paracetamol in the morning and two at night you'll be fine all day'. [Linda].

Linda's statement highlights that she would like to find others who share her experience of post-stroke pain. She implies that she would feel understood and accepted, which is something she feels others, who do not experience post-stroke pain, lack. She would also like to share treatment approaches, implying she views other people with post-stroke pain as more expert than healthcare professionals.

The development of pain acceptance

This theme describes the journey to reaching a point of acceptance. Participants appeared to move from mourning their 'old' self and life to accepting their 'new' self and life. The process of acknowledging the chronicity of the pain together with the lack of control over the pain appeared to aid the process. Furthermore, making downward counterfactual comparisons to times and situations which were or would be worse and people who are worse off, appeared to help the process of pain acceptance.

Mourning the 'old' self and life

This subordinate theme summarises the loss all participants experienced with regards to their way of life before chronic pain. Participants reported everyday struggles that occasionally lead to feelings of sadness, frustration and anger as they are reminded of their life without the pain. In particular participants reported having difficulties cooking, sleeping, and sitting still. For example, Harry reported the following:

> I got to keep constantly wandering the house, you know, cos the moment I sit down I'm going to go 'Oh my [the pain]!'. You know… I don't want to live like that. […] when I was working previously, I'd be sitting down … I'd be sitting down for, you know, hours. [Harry]

Harry reported on the loss of his ability to be relaxed and carefree, not having to think about how often he has stretched and moved his body. He also reported on the loss of his ability to fulfil his previous employment duties. Another participant, Jack, who faced being medically retired due to experiencing frequent, debilitating headaches, reported that losing his employment felt like losing part of his identity, namely being the "provider" of the family.

> […]I've always been the provider, because of my illness [headaches] now and all that the only thing I can give to my children is advice […]. [Jack].

Jack's comment implies that by losing his role as "provider" for his family he cannot support his children financially the way he had planned. He had to adapt his father role and offer his children non-financial support (i.e. advice), which he perceives as less valuable. Only two participants had younger children, but both mentioned their role as a parent had changed as a result of their chronic pain experience.

Even though all participants described parts of their lives and selves they had lost due to the post-stroke pain, the majority did not allow themselves to dwell on it. This is highlighted in a comment by Linda:

> I think in a way it's made me sad that I've lost the person I was, um but on the other hand I think it's made me / has made me in some ways a better person. And I don't think you can mourn for what you are, because you can't go back, you can only ever go forward in life. So you can't look back and say 'If only…'. It happened now, so look on the positive 'I'm alive'. [Linda].

Linda, similarly to the majority of participants in this study appeared to have reached a level of acceptance of her pain and her 'new' life and self with the pain. She reported that she went through a period of feeling sad; mourning the person she lost. It appears that the stroke and the life with the pain have made her grow as a person seemingly making her more appreciative of what she has (being “alive”), which leads over to the next subordinate theme.

Accepting the ‘new’ self and life

Five participants appeared to have found a way to live with their pain; the pain is part of who they are and how they live their lives with the pain. This is highlighted in a response by Peter:

> Uh for the first couple of years you think ‘I’m going to get better, I’m going to get better’ and then it slowly dawns on you that you’re not. You’re going to / have to sort of settle with how you are and make the most of how you are… pain disabilities whatever. Um and I went through a whole situation of denial almost denial I suppose of the pain and all the rest of it but then I accepted it. It was part of me it was a part of the new me […]. [Peter]

Peter’s statement highlights a journey towards acceptance of the pain in which he firstly went through a period of believing the pain would recede, implying that the pain was something external that needed to be fixed, to then accepting the pain as part of “the new me”. Across all five participants who appeared to have reached a level of acceptance towards their pain, the acknowledgement that the pain is chronic and uncontrollable, with regards to lack of effective treatments, appeared to have been important. This is highlighted in a comment by Kiara:

> Cos as I said my brain, there’s nothing I can do about my pain so I’m coping. So I'm going to church, so I completely forget about my pain and the same going to the shops and um appointment. Yes, I always go. I’ve got pain every day every night, as I said. [Kiara].

Over the years Kiara has learned that there is no remedy for her pain, which she suffers from every day, based on this she learned to “cope” and live her life despite the pain.

Something else that appeared to enhance participants’ ability to accept their life with the pain and feel more positive was engaging in a process of downward counterfactual comparisons to times and situations which were / would be worse and to other people who they view as worse off. In particular participants felt they were “lucky” as they survived the stroke and got away “fairly lightly” in comparison to other stroke survivors. Linda for example reported that she is appreciative of her life with the pain, as she is aware of the mortality associated with strokes:

> […] every day is precious. Oh my god, you know. So, I could be so much worse; I could be dead. That's the alternative and that's how you… I think you should look at life you know. [Linda].

Similarly, Peter mentioned being more appreciative of his current situation as he feels his post-stroke pain is not as bad as other stroke-related impairments;

> […] there are a lot of people out there worse off than me, stroke survivors that are worse off, a lot worse off. I am relatively lucky. I got away fairly light. [Peter].

All participants who found acceptance referred to the pain as part of their new self and life; a few even stated that the pain made them a better version of themselves. In addition to personal growths, the experience of post-stroke pain also provided a source of strength and identity for participants. For example Peter mentioned:

> […] I won't give in to the pain. I won't give in to the stroke. I'm a survivor I'm not a um uh a victim. [Peter].

Peter sees himself as a survivor of the stroke; the pain might be seen as a reminder of that won battle and therefore has a positive connotation.

Participants who were not accepting of their pain differentiated themselves from other participants through their enhanced focus on finding ways to cure the pain.

Discussion

This study is the first to explore working age adults' experience of living with chronic post-stroke pain in the UK using IPA. Three master themes were identified which illuminate the experience as stated by participants of this study; namely, (1) The Solitude of the Pain Experience, (2) Unsatisfactory Healthcare and the Need for Self-Care and (3) The Development of Pain Acceptance.

The solitude of the pain experience

All participants described feeling alone in their pain experience. They described others as unable to understand, relate and empathise with their pain. They only shared their pain experience with others, if they had to elicit practical support or explain their behaviour. Factors preventing participants from sharing their experience were, expecting others not to relate, not wanting to burden others or appear to be "moaning", not hearing about other people's problems in return and not wanting to be reminded of the pain.

A study by Widar et al. [32], conducted in Sweden, found participants also felt others lacked understanding and compassion regarding their post-stroke pain. However, participants described feeling cared for by people around them, which was associated with receiving attention, advice and practical help. Even though this was not clearly mentioned in the current study, receiving practical support was reported as the main reason for participants to open up to others, implying that they received some care as a result of sharing their pain. Feeling misunderstood by others is a theme commonly reported in the wider literature of chronic pain; studies have highlighted that individuals with chronic pain often feel others do not belief them and think they exaggerate or imagine their pain [61]. This may reflect pain being an invisible disability, as suggested not only by participants of this study, but also by people with other chronic pain conditions [62, 63]. Pain in the context of stroke may be particularly invisible and easy to overlook, as attention and care may focus on other, more visible, stroke impairments [32]. In line with this, a study by Dale Stone [64] found that young female stroke survivors felt only visible disabilities are taken seriously by others. Additionally, being younger and therefore not fitting the public image of a stroke survivor, they felt their stroke impairments were considered less than those of older stroke survivors. This view was shared by some participants within the current study.

As suggested by participants within this study, research by Cano et al [65] found that frequent and ongoing disclosure of pain to others is not beneficial and can result in negative consequences, such as invalidation by others and erosion of support. Based on this, it is understandable that participants engaged in a process of weighing up the costs and benefits before disclosing their pain experience to others.

In contrast to a study that found individuals with chronic pain withdraw socially [66], participants of this study did not report withdrawing from others; however, they reported emotionally withdrawing as they felt others lack understanding and empathy of their suffering.

Unsatisfactory healthcare and the need for self-care

All participants reported a negative experience with the long-term care of their pain. Perceived lack of knowledge of post-stroke pain in primary care was associated with a lack of diagnoses and accurate, clear information provided. Dissatisfaction with the overreliance on medication and the lack of alternative treatments were voiced. Feeling abandoned by healthcare services, participants reported using their own resources to manage their pain.

Consistent with two studies exploring post-stroke pain in Sweden [32, 38], the current study found that participants reported not receiving accurate and clear information from healthcare providers regarding post-stroke pain, leaving them to form their own beliefs. Within the current study we highlighted that certain illness beliefs might be helpful or unhelpful with regards to participants' mood, recovery-focus and help-seeking behaviour. This is in line with research conducted on other chronic pain conditions, which shows that illness beliefs can impact rehabilitation outcomes [67, 68]. Furthermore, the finding is in line with the ‘common sense model of illness’, which proposes that patients’ illness perceptions impact their coping ability and outcome [69].

Participants within the current study associated the lack of information and effective treatment with a lack of knowledge of post-stroke pain in primary healthcare services. This was also a theme in Widar et al.’s [32] study of post-stroke pain patients in Sweden. However, in their study participants’ opinions on care provision and professional knowledge were more balanced. Within the current study, positive healthcare experiences were exclusively related to hospital care.

None of the current study’s participants had been diagnosed with a differential post-stroke pain type; this observed lack of differential diagnosis is in line with findings of Swedish studies [32, 33, 38]. Given that post-stroke pain can have a delayed onset and other stroke impairments might take priority, post-stroke pain might not be detected during the time of specialist stroke input, which in the UK, is often limited to hospital admission and early supported discharge. Furthermore, post-stroke pain sensations might not fit current measures and diagnostic labels, which is something suggested by participants of the current study as well as a Swedish study [31].

Participants of the current study reported being exclusively offered pharmacotherapy, which let them to use their own resources to find alternative treatments. This is in contrast to the experience of post-stroke pain patients in a Swedish study, who reported being offered different treatment options for their pain by their healthcare providers [33].

The development of pain acceptance

All participants reflected on the person they were before the stroke, the person without chronic pain, and the person they were with post-stroke pain. All participants described a period in which they mourned the life and self they lost; within this they described everyday struggles they face, the negative impact their pain has on their mood and their search for pain relief. However, the majority of participants also described their newly gained life with the pain, in which they accept the pain as part of them and live their life regardless of the pain experience. This finding is in line with Acceptance and Commitment model, which has been used to understand and treat chronic pain [70]. It suggests that controlling and avoiding suffering (i.e. from pain) can lead to exacerbation of the negative experience and that engaging in value-directed behaviour (i.e. engaging in meaningful activities despite the pain) can reduce the suffering [70]. For participants, acknowledging the chronicity of the pain and lack of control over it (i.e. the absence of effective remedy), as well as making downward counterfactual comparisons to times and situations which were, or would be worse and people who are worse off, appeared to help the process of finding pain acceptance.

Within this study participants did not focus on pain-related limitations they face and adaptions they have to make, in contrast to findings by Lindgren et al. [33, 47] in which pain-related losses were more prominent. Some practical adaptions such as using a cooking glove or stretching were mentioned; however participants did not dwell on these adaptations, possibly reflecting a level of acceptance of their life with pain. None of the previously conducted studies reported on post-stroke pain patients' role as parents; this might be due to the lack of focus on working age adults. However, the current study suggests individuals with post-stroke pain experience a change in their parenting role. This finding appears important as a study which investigated the mother-child relationship for mothers with chronic pain found that the experience of chronic pain can lead to an increased use of dysfunctional parenting strategies and reduced relationship quality [71].

The finding that reaching a level of pain acceptance was associated with accepting chronicity and lack of control is consistent with findings by Widar et al. [38]; a few of whose participants found pain acceptance once they acknowledged improvement and pain relief were unlikely. None of the participants within this study reported receiving support in reaching a level of pain acceptance; the passage of time taught them their prognosis and ways to endure and live with the pain. The same was found in a Swedish study exploring post-stroke shoulder pain [47]. Their study also found that personal traits, such as stubbornness, optimism and perceived high level of pain tolerance aided the process of pain acceptance. In contrast, the current study found that making downward counterfactual comparisons appeared to aid the development of pain acceptance; that such comparisons are commonly used in chronic illness to maintain a positive view of the situation has been documented [72].

Acceptance is considered an emotion-focused strategy of coping, whereas finding alternative treatment is considered a problem-focused strategy of coping [73]. Within this sample, it appeared that participants used both emotion-focused and problem-focused coping. However, for participants that appeared less accepting of their pain problem-focused coping (i.e. searching for a remedy) was used predominately.

Strengths and limitations

This study is the first to investigate UK working age adults' experience of chronic post-stroke pain. It adds to the general understanding of living with post-stroke pain by providing a non-restrictive, in-depth and interpretative account of individuals' narratives through the adoption of IPA. In order to include stroke survivors whose voice might not necessarily be heard, this study was flexible and adaptive in its inclusion of individuals with cognitive difficulties, aphasia and mobility difficulties. The study held high ethical standards and was committed to uphold principles of rigour, transparency and trustworthiness.

With regards to limitations of this study, ideally the sample would have been more homogenous, particularly with regards to time since stroke / onset of pain, pain type and participants' age. Additionally, although the current sample fits the description of a working age, it appears that given that the average age was 56.5, certain challenges of younger stroke survivor (i.e. in their 30s and 40s) with post-stroke pain were not captured adequately (e.g. adapted parent role and income difficulties). The sample was self-selected; therefore, individuals who were either greatly troubled by their pain or those not / less affected by their pain might have been less likely to participate. It is to note that findings are a co-construction of the participants' accounts and the lead researcher's interpretation, in line with the double hermeneutic process. Based on this other interpretations may be possible. Although the lead research had no prior clinical experience in stroke, which could have impacted the interpretation of findings, significant stroke experience was held by members of the wider research team.

Generalisation of findings is limited, as findings are contextualised. However, given that our results are broadly consistent with those of studies in Sweden, that interviewed older stroke survivors, the conclusions drawn may resonate with a wider group of individuals with post-stroke pain, their social network and healthcare professionals.

Clinical implications

Insights from our participants can inform the care and treatment offered to individuals with chronic post-stroke pain in the UK. Post-stroke pain can be difficult to diagnose as its onset can be delayed, its characteristics vary, it can be overshadowed by more severe and visible post-stroke impairments and individuals might have difficulties describing it, potentially using descriptions of unusual sensations rather than pain. Nevertheless, it is crucial that healthcare professionals in primary and secondary care directly assess for post-stroke pain and make patients aware that such sensations can appear at a later stage when patients may no longer be in specialist stroke services. Chronic post-stroke pain patients might avoid discussing their pain, minimise or misunderstand it, which makes it important for healthcare professionals to ensure that pain is part of their post-stroke assessment.

It is important that individuals with chronic post-stroke pain are given a differential diagnosis clearly stating the type of post-stroke pain experienced alongside accurate information about the characteristics of the pain, such as its cause, presentation and prognosis. Having a differential diagnosis of the pain (i.e. CPSP, musculoskeletal pain, shoulder pain and subluxation) is important as treatment recommendations vary [74]. The Royal College of Physician (RCP) guidelines [74] covering post-stroke pain suggest that non-pharmacological treatment should be offered in addition to pharmacological treatment, regular reviews of patients should be provided, especially for those with CPSP, and collaboration with pain management services should be considered. Based on participants' accounts, healthcare professionals' adherence to these guidelines appears variable, if not limited. Education on post-stroke pain and its management appears needed for healthcare professionals, particularly in primary care services. Additionally, it would be beneficial to include detailed pain assessment and treatment recommendations in the general NICE guidelines on stroke and spinal injury care. Currently they only cover shoulder pain for stroke [75] and pain in the acute phase for spinal cord injuries [76].

Setting up specific support groups for stroke survivors experiencing pain should be considered. Individuals might not experience a sense of belonging in more general stroke groups given that their pain is an invisible impairment; they might not feel understood by other group members. Alternatively, clinicians might want to suggest social media as a way to connect to other individuals with post-stroke pain.

Research implications

This study highlighted a current unmet need in the care of individuals with chronic post-stroke pain. Therefore, research is warranted to explore various treatment options; in particular, it would be valuable to investigate the effectiveness of Cognitive Behaviour Therapy-, or Acceptance and Commitment Therapy-based pain management programmes, as these have been shown to be effective in treating other chronic pain conditions [77-79]. Research into the effectiveness of systemic approaches to treatment, such as family therapy, might also be useful given that participants voiced feeling that others lack understanding and empathy for their suffering. Research could also explore the usefulness of peer support. Research efforts should also focus on developing measures that capture the experience of post-stroke pain patients, as currently their experience appears not to fit the existing categories. Additionally, a future study might want to explore the nature of beliefs held by individuals with chronic post-stroke pain and their associated consequences / associations in more detail, as the current findings suggest that holding certain pain beliefs can be either helpful or unhelpful with regards to mood, support seeking behaviour and rehabilitation.

This research focussed on working age adults' experience of post-stroke pain, but only the youngest two participants described the impact of pain on family life and occupation. Future research may want to consider investigating the impact of post-stroke pain on the life of an even younger sample.

Conclusions

The current study highlighted unmet needs in the care of individuals with chronic post-stroke pain in the UK. The lack of differential post-stroke pain diagnoses, clear and accurate information and non-pharmacological intervention options, leave individuals with post-stroke pain on a lonely quest to find their own answers about the cause, prognosis and treatment of their pain; a quest in which they feel misunderstood and abandoned by healthcare.

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Data availability

The research data can be made available on request; please contact the corresponding author.

Disclaimer

The views expressed in this research article are of the authors and are not an official position of the University of East Anglia.

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Chapter 5. Extended Methodology

Chapter Overview

This chapter is an extension of the methodology of the research study. It provides a more detailed account of the epistemological position of interpretative phenomenological analysis (IPA) and situates it within the context and position of the lead researcher. Alongside this, the concepts which underpin IPA and rationale for adopting IPA are discussed. A summary of the first author's reflexivity throughout this process is provided. Ethical and risk considerations of the research are detailed and additional information regarding the research process, sampling, data transcription and analysis are provided.

Methodological Rationale

Ontology, epistemology and methodology.

Three philosophical assumptions, namely ontology, epistemology and methodology, underpin the overall design of a study (Creswell, 1998).

Ontology refers to the nature of reality (Pietkiewicz & Smith, 2014); it is concerned with the extent to which reality is distinct from human experience and understanding (Braun & Clark, 2013). Researchers hold different ontological positions depending on their belief around the existence of "a single, stable reality 'out there' [that is] waiting to be discovered" (Swift & Tischler, 2010; p. 561). Researchers who believe in the existence of a single, stable reality, which can be objectively understood through rigorous research, hold a realist ontological position (Swift & Tischler, 2010). This position aligns itself with a quantitative methodology. In contrast, researchers who believe in the existence of multiple socially constructed realities, which can only be understood through the lens of the participant and researcher, hold a relativist ontological position (Swift & Tischler, 2010). This position aligns itself well with a qualitative methodology.

Epistemology refers to the nature of knowledge (Pietkiewicz & Smith, 2014); how knowledge is created and acquired (Scotland, 2012). Researchers subscribe to an epistemological position based on their belief on how knowledge can be produced (Swift & Tischler, 2010). A researcher, who believes that the truth can be known, holds a positivist epistemological position (Brown & Clark, 2013). This position aligns itself with a quantitative methodology, which believes empirical methods can control biases and find the truth (Slevitch, 2011). In contrast, a researcher, who believes that there are multiple truths, which are mediated through social and cultural influences, holds a constructionist epistemological position (Brown & Clark, 2013). This position aligns itself with a qualitative methodology, which believes human experience needs to be understood in the context of a person's cultural and social environment and acknowledges the researcher's influence on the research process (Slevitch, 2011).

A researcher's ontological and epistemological position determines the most appropriate methodology with which to answer a research question. Qualitative research is based on the ontological position that reality is a result of the mental constructs of people and that therefore multiple realities exist (Guba & Lincoln, 1994). Therefore, the epistemological position held is that reality can only be accessed through people's understanding of it (Sale, Lohfeld, & Brazil, 2002). Qualitative research takes an inductive reasoning approach, which is defined by open-ended research questions that direct the study, but do not predict findings (Swift & Tischer, 2010).

The lead researcher of the study presented in the previous chapter adopted a critical realist position, which suggests the existence of a social world independent of the subjective experience of the individuals, but only made accessible through interpretation (Levers, 2013). It is based on the search for a general understanding of the experience of living with chronic post-stroke pain, while holding in mind the limitation of only being able to access this understanding through the participants' and researcher's lens (Fletcher, 2017). In line with this a qualitative methodology was adopted.

Interpretative phenomenological analysis.

IPA is unique in its aim to provide a rich account of how people make sense of major personal life experiences (Smith, Flowers, & Larkin, 2009). Rather than understanding phenomena in the context of pre-defined categories, IPA enables these to be explored in their full nature (Smith, et al., 2009).

IPA is based on the principles of phenomenology, hermeneutics and idiography. Phenomenology is a philosophical approach to the study of human understanding of experiences (Smith et al., 2009). It focuses on peoples' perceptions of their world and their meaning-making. It particularly focuses on phenomena that hold idiographic meaning and make up a person's world (Smith, 2011). It acknowledges that the understanding of an experience is embedded in a particular social and cultural context (Smith et al., 2009).

Hermeneutics is defined as the theory of interpretation (Smith et al., 2009). It refers to the need to understand an individual's mind-set and language in order to interpret their interpretation of their experience; thus creating a double hermeneutic. The researcher therefore co-constructs the understanding of an experience.

Idiography describes a focus on the particular, not only in terms of an individual case or event but also the detail of the account, and therefore the depth of analysis (Smith et al., 2009). It refers to an in-depth analysis of an individual's perspective in the context of their environment (Pietkiewicz & Smith, 2012). The commitment to a single case is the basis of idiography; however, generalisation of findings is possible, although sampling and context need to be considered (Harre, 1979).

IPA balances all three principles. It retains an idiographic focus by selecting a small, purposive and homogenous sample in which each person's account is reviewed in great detail and in light of the person's socio-cultural background. It is phenomenological as it focuses on a person's sense-making of a particular experience and it is hermeneutic because it embraces the process of the researcher interpreting the participant's interpretation of the experience, through a detailed and systematic analysis.

The research study presented in the previous chapter aligned itself well with IPA, as it focuses on the unrestricted, in-depth analysis of working age adults' understanding of living with chronic post-stroke pain. The aim of the research was to be open to the experience of chronic post-stroke pain as understood and described by participants without imposing personal presuppositions and predetermined hierarchies of meaning. Other qualitative approaches would appear less suitable for providing such a rich understanding of individuals' experiences. For example, the main focus of grounded theory is the development of theoretical conceptualisations underlying phenomena and that of content analysis is quantifying data by creating frequency based categories. Thematic analysis, in contrast to IPA, focuses less on individuals' subjective sense-making of experience and has a less transparent process around the subjectivity of the researcher's interpretation of data.

The philosophical base of IPA lies somewhere between Social Constructionism and Critical Realism (Larkin, Watts, & Clifton 2006). Given the principle of double hermeneutic, which acknowledges the researcher's influence on the collection and analysis of data, IPA does not identify an epistemological position but rather adopts the researcher's position. The lead researcher of the research study adopted a critical realist stance.

To the best of the author's knowledge, the presented research study was the first to explore chronic post-stroke pain using IPA.

Reflexivity

In line with double hermeneutic, qualitative research acknowledges the unique impact of the researcher on the research process and findings (Berger, 2015). According to Horsburgh (2003), “Given that the researcher is intimately involved in both the process and product of the research enterprise, it is necessary for the reader to evaluate the extent to which an author identifies and explicates their involvement and its potential or actual effect upon the findings” (p. 309). The researcher’s characteristics and underlying positions can affect the research in various ways. Firstly, they can affect access to knowledge, as participants’ willingness to share their experiences may vary depending on the researcher’s characteristics and positions (Berger, 2015). Secondly, the researcher’s underlying positions can affect the design of the study, such as the research question, sampling and interviewing procedure, and the way in which information is processed and analysed; therefore affecting findings and conclusions (Berger, 2015).

Reflexivity describes a researcher’s conscious and deliberate effort to be self-aware (Berger, 2015). Through reflexivity the researcher increases their awareness of their role in the creation of knowledge (Dodgson, 2019). Careful self-monitoring facilitates an understanding of how personal biases, beliefs and experiences affect the research (Dodgson, 2019). According to Berger (2015) qualities that are relevant to a researcher’s position are “personal characteristics, such as gender, race, affiliation, age, sexual orientation, immigration status, personal experiences, linguistic tradition, beliefs, biases, preferences, theoretical, political and ideological stances, and emotional responses to participant[s]” (p.220). Reflexivity aids the establishment of quality, rigor and trustworthiness and is therefore important in knowledge creation in qualitative research (Berger, 2015; Dodgson, 2019).

The lead researcher used a reflective journal to record reflections on the influence of personal characteristics and beliefs, to log reasons underlying decisions made and describe thoughts and feelings that arose throughout the research process. This process enabled the lead researcher’s subjectivity to be acknowledged and considered during data collection and analysis. The following example entry was written after the first research interview was conducted:

> “I feel like a sponge filled with sadness. For years I worked in clinical setting and heard many sad stories about trauma and hardship, but I think I never felt as sad as now. Is it because working with people with brain damage in younger years reminds me of how my family’s life was shaken up by my brother’s and mother’s brain injury? Or is it due to a feeling of absolute helplessness? This was the first

> time I talked to someone in great detail about their life, covering things that might be difficult, without offering further support. It is a strange feeling to know that the only thing I can give back to this individual is to make their voice be heard.”.

This excerpt highlights how personal experiences and being new to the research role affected the interview process (i.e. rapport with the participant, interview direction and information filtering). Bracketing, which is the process of consciously putting aside one’s own belief about and prior knowledge of the studied phenomenon (Chan, Fung, & Chien, 2013), was not fully possible; however, by being aware of these influences they can be considered when making sense of the data.

Lead researcher’s background, position and context.

I am a 31-year-old female clinical psychology trainee. I am White-German and have been living in the UK for 10 years. I recently got married and have no children. I grew up in the Christian faith. I have never experienced any significant illnesses or health impairments.

My main clinical experience prior to clinical psychology training was in the field of neuropsychology. I worked as part of a neuropsychology team in a dementia service, which was closely linked to the stroke psychology team. With regards to personal experience, my mother was diagnosed with multiple sclerosis 20 years ago and my younger brother was born with significant brain damage after experiencing asphyxiation. My professional and personal experiences have shown me the impact brain damage can have on a person’s life and the systems around them.

I am fascinated by the workings of the brain and am keen to enhance my understanding of neuropsychology further after completion of my clinical psychology degree. Being able to provide patients with a biopsychosocial understanding of their difficulties, strategies for improvement and a space for mourning and finding acceptance is a privileged position, which I experience as immensely fulfilling. My interest in neuropsychology and brain injury was the determining factor for my choice of research topic. I had no previous experience in stroke, but was keen to enhance my knowledge in the area. The topic choice and research question were developed through a long process of immersing myself in the stroke literature. I chose the topic of post-stroke pain, as it was described as a significant and greatly debilitating consequence of stroke, yet I had never previously considered it.

I felt the area of post-stroke pain was generally under-researched and lacking the voice of stroke survivors living with post-stroke pain. Based on this, I chose a qualitative research design. Completing a qualitative project on the scale of a clinical psychology doctorate thesis was daunting. All my previous research projects had a quantitative design. Being a novice to qualitative research meant I felt particularly insecure about my ability to complete a ‘good’ piece of work. I often noticed myself having thoughts questioning my ability. For example, I noted the following in my reflective journal after completing my first interview.

> “Overall, I managed to build good rapport. I gave him space to express his views and feel as though I did not overly guide his accounts through my questioning. However, I was thinking throughout the interview ‘Am I asking all my questions?’, ‘Is it important that I covered the areas I thought about as prompts in my interview schedule - but then again they are just prompts’, ‘Is this good data?”

It was important for me to notice my felt insecurity and discuss it in supervision. I wanted to prevent my worries about doing it ‘right’ affecting the next interviews. My thoughts could have made me become more restrictive in future interviews; thereby narrowing the participants’ accounts. I also noticed the influence of my insecurities on the data analysis process. During the analysis of my second interview I noted the following:

> “He spoke a lot about different types of pain; which ones are even stroke-related? Should I have been more focused in the interview, but then again discussions prior to the interview and questions during the interview highlighted the focus on pain that resulted from stroke.”

At this point during the analysis I felt worried that my data is a mixture of discussions of different pain syndromes. I was concerned that this would impact my ability to answer my research question. However, after analysing all interviews and taking time to reflect, I noticed that worries around my interview ability almost masked the fact that the participants' inability to clearly differentiate their post-stroke pain from other pains and stroke-related impairments appeared to be an emerging theme.

I decided to focus my research on working age adults, as I felt their voice was rarely heard throughout the literature. Furthermore, I expected their experience to be distinct from that of older adults given their life stage. I noticed holding certain beliefs around what it must be like to live with chronic post-stroke pain as a younger stroke survivor. I expected that living with chronic post-stroke pain must have a negative impact on relationships, occupation and leisure activities. I also expected participants to describe a negative experience of care and treatment, which was based on the limited treatment options described in the literature as well as my own experience of receiving treatment in the National Health Service (NHS). I noted my beliefs and presumptions in my reflective journal with the aim of bracketing them off. Making myself consciously aware of my beliefs and presumptions about the research topic meant I was more able to control confirmation bias.

During the interview process I was aware of how the relationship with participants could be influenced by differences in ‘Social GGRRAAACCEEESSS’, an acronym developed by Burnham and colleagues (2013) to describe difference in inherent characteristics of people, which can impact relationships. I was particularly aware that during a time where Brexit splits the nation, participants would be interviewed by someone not British. I wondered if this could impact participants’ willingness to open up. Also I was conscious that male participants might feel less comfortable talking about certain topics, such as their relationships, to a female researcher. Furthermore, I wondered if the fact that I look younger and do not have a significant health impairment would cause participants to feel I cannot relate to their accounts. In an effort to address these concerns I decided to plan in slightly more time prior to starting the interview. The time was used for small talk about topics such as plans for the day and weather, and preparing a drink. Having this extra time prior to starting the interview helped develop a positive, open and collaborative relationship.

In line with IPA, I acknowledge that absolute ‘bracketing’ is not possible and that as a researcher I will have influenced the research process and therefore the findings and conclusions. However, through the process of self-reflection and regular research supervision, I made myself aware of my impact in order to account for it.

Ethical Considerations

Ethical approval.

The research study described in this paper received ethical approval through the University of East Anglia’s Faculty of Medicine and Health Research Ethics Committee (Appendix F). No additional approvals were required by participating organisations. The study adhered to the ethical and practice codes of the University of East Anglia (UEA), Health and Care Professionals Council (HCPC) and British Psychological Society (BPS) and followed the standards for institutional committees on human experimentation stated within the Helsinki declaration (BPS, 2018; HCPC, 2016; UEA, 2016; World Medical Association, 2013).

Capacity and informed consent.

As stroke causes brain damage, stroke survivors' capacity to consent participation was carefully considered (Mamo, 2014). Gatekeepers were asked to consider individuals' capacity to consent to participation; lack of capacity to consent to participation was outlined as an exclusion criterion. Additionally, prior to the interview the lead researcher carefully evaluated if participants understood, retained and weighed-up the information presented about the study and could communicate their decision to participate. If a participant's capacity to consent would have been in question, this would have been discussed with the participant and the interview would have not been conducted. All participants were judged to have capacity to consent and were therefore provided with a 'Consent to Participate Form' (Appendix J)

Participants were provided with a detailed information sheet (Appendix K) and encouraged by the lead researcher and gatekeeper to ask questions about the research, so that their consent was fully informed. Participants were informed that their participation is voluntary, they can decide not to share information, they can withdraw from the study by contacting the lead researcher at any time until one week after the interview and their decision to participate/withdraw would not impact their level of care provided by the participating service/organisation (BPS, 2014).

Written consent to be contacted, in cases where participants were referred to the study by a gatekeeper (Appendix L), to participate and to hold personal information was gathered.

Confidentiality.

The management of research data for the research study adhered to the General Data Protection Regulation (GDPR; United Kingdom Government, 2018). The 'Participant Information Sheet' informed participants about information that would be collected. Each participant was assigned a number and pseudonym (made-up name) and an excel table matching participants' personal details to their assigned number was stored in encrypted form on secure UEA servers. All written information, with the exception of the consent forms ('Consent to Contact' and 'Consent to Participate'), was anonymised through the use of participants' assigned numbers. Paper documents were held in locked cabinets, within locked offices, at UEA. An exception was the 'Consent to Contact Form', which was stored securely at the respective recruitment sites, in line with local policies regarding the storage of personal information (e.g. patient file), or securely destroyed (e.g. shredded), after a copy had been sent to the lead researcher through post or email. One gatekeeper, who was a stroke survivor and volunteered at one of the recruitment organisations, provided the lead researcher with contact details of potential participants, stating participants gave their verbal consent for their details to be passed on to the researcher. When prompted to complete the form he stated that he perceived the ‘Consent to Contact Form’ to be impractical, as he did not tend to have it with him when talking about the study to group members. The lead researcher consequently contacted the ethics committee, who suggested that the wording of the form could be changed to “If consent was discussed and the gatekeeper and participant are unable to sign the form during the conversation, it would be sufficient that the gatekeeper initials the appropriate boxes and signs the form” for future recruitment (Appendix M). However, the study had since been closed; therefore, the form remained unchanged.

Participants were verbally advised prior to the interview to avoid using personally identifiable information during the audio recorded interview. Audio recordings of interviews were stored on dictaphones and transferred to encrypted memory sticks at the earliest opportunity; participants’ assigned numbers were used to store the recordings. Dictaphone recordings were subsequently deleted. Audio recordings were transcribed by the lead researcher and a clinical trial assistant employed by UEA, as part of her private work. A confidentiality agreement (Appendix N) was signed and secure data transfer procedures, through the UEA One Drive system, were used (Appendix O). All personally identifiable information, such as names and places, were anonymised and participants’ pseudonyms were used throughout the transcripts and research write-up. Pseudonyms will also be used in all future publications. Direct quotations are used in this thesis and will be used in future publications of the findings; these were considered carefully to ensure no personally identifiable information was included.

The data were accessed only by the lead researcher, research supervisors and the professional transcriber. In the future UEA auditors may access the data. Research data will be stored on secure/encrypted UEA servers and in locked cabinets, within locked offices, for 10 years after study completion (in line with UEA guidelines). All data will be securely destroyed after the stated period. The primary research supervisor will take responsibility as data custodian.

Participants were informed about the limits of confidentiality verbally prior to the interview and in writing in the ‘Participant Information Sheet’. The research plan and accompanying ethical approval set out that confidentiality would be breached if a significant risk to the participant or someone else were to be identified as a result of the participant’s accounts. In the event of serious concerns about participants’ or others’ safety, contact would have been made with participants' GPs (contact details provided on the 'Demographic Information Form'). In the case of severe and immediate risk, emergency services would have been contacted and guidance might have been sought from the local safeguarding team. Relevant third parties would have been made aware of the situation; for example, research supervisors, research sponsor and/or recruitment site manager. If a breach in confidentiality was required, the lead researcher would have, as far as possible, informed the participant about the steps taken. In the unlikely event of criminal disclosures during the interviewing process, the same procedure for breaching confidentiality would have been followed.

Risk.

Participants were informed about all potential risks of the study in the 'Participant Information Sheet'. A risk management plan was designed and adhered to (Appendix P).

During one of the interviews a participant reported low mood and multiple suicidal risk factors. A risk assessment during the interview concluded the presence of low risk, as the participant reported not having current or recent suicidal thoughts or ideations and reported various protected factors. However, the presence of low mood, a disclosed previous suicide attempt in addition to the presence of various current life stressors meant that the lead researcher sought guidance from the primary research supervisor. A joint decision was made to contact the participant to discuss the lead researcher's concerns and suggest that the participant discusses their current situation with their General Practitioner (GP) in order to be provided with additional support. The participant decided that prior to seeking further support from their GP they would like to make certain life changes. However, the participant agreed for the lead researcher to write a letter to their GP making them aware of the participant's current situation so that support could be offered in the future. The letter to the GP was approved by the primary supervisor.

Insurance and indemnity arrangements.

The research study presented in this paper was covered by the University of East Anglia's indemnity arrangements.

Additional Methodological Information

Sampling.

IPA does not prescribe a fixed sample size and in contrast to most positivist research using probabilistic sampling paradigms, larger samples are not more desirable than smaller samples (Pietkiewicz & Smith, 2014). The aim of IPA is an in-depth analysis of a phenomenon rather than generalisation. According to Pietkiewicz and Smith (2014) the chosen sample size depends on the depth of the analysis, the richness of the derived data, the chosen procedure to compare across cases and pragmatic restrictions, such as time constraints. The presented research study aimed to recruit a reasonably homogenous sample of up to 12 participants, as research studies using IPA in the exploration of related topics were found to have similar participant numbers (Hunt & Smith, 2004; Leahy, Desmond, Coughlan, O'Neill, & Collins, 2016; Murray & Harrison, 2004; Osborn & Smith, 1998). The current study concluded with a sample of eight individuals, which appeared appropriate given the richness of data and the planned analysis procedure.

Procedure.

In line with 'Patient and public involvement (PPI) in research' guidelines, all documents handed out to participants were reviewed by a PPI representative, who sustained an acquired brain injury in adulthood. Amendments to spelling, grammar, use of language and content were subsequently made (National Institute for Health Research, 2010). For example the reference to the type of analysis used within the study (i.e. IPA) was removed from the title of the Participant Information Sheet, as it was deemed unnecessary use of technical language.

Participants were recruited from stroke-associated third sector organisations and social media advertisements. The lead researcher introduced the study to organisations through phone and email conversation and by attending service meetings. Gatekeepers, who were responsible for advertising the study to colleagues and suitable participants, were identified in each organisation. Gatekeepers were provided with a detailed information sheet regarding their responsibilities and the research procedures (Appendix Q).

Gatekeepers identified suitable participants, based on predefined inclusion and exclusion criteria. Once a suitable participant was identified the gatekeeper informed them about the study and provided them with the 'Participant Information Sheet'. Gatekeepers were encouraged to address any concerns and/or questions of the person and inform them that they can get in contact with the lead researcher directly if concerns and/or questions remain. Suitable participants who were interested in the study were provided with a ‘Consent to Contact Form’ and were supported in completing it by the gatekeeper. Completed 'Consent to Contact Forms' were held securely at the recruitment sites, after a copy was sent to the lead researcher by email or post. Gatekeepers contacted the lead researcher by phone or email to inform her about the identified participant. During this interaction gatekeepers had the opportunity to raise any concerns regarding the location of interviews. The lead researcher contacted interested participants by telephone or email (depending on their preference and details provided) to answer questions, re-assess inclusion and exclusion criteria and agree a suitable time and location for the interview.

Gatekeepers were provided with posters (Appendix R), which could be hung in buildings of the recruitment organisations. The study was also advertised through social media sites relating to stroke and pain. Advertisements made potential participants aware of the research opportunity so that they could contact the lead researcher directly. Interested participants, who contacted the lead researcher directly, were informed about the study, encouraged to ask questions and given a 'Participant Information Sheet'. The inclusion and exclusion criteria of the study were discussed and for suitable and interested participants a date, time and location for the interview was agreed.

Six of the eight participants contacted the lead researcher directly; three became aware of the study through recruitment organisations and three through social media advertisements. For two individuals the ‘Consent to Contact Form’ was completed and the lead researcher got in contact with them via phone.

The lead researcher was in contact with 16 additional individuals who showed initial interest in the study but did not participate. Seven did not contact the lead researcher after receiving information about the study, two decided not to participate without providing a reason, three lived too far away for the lead research to offer a home visit (over two hour driving radius), two did not fit the study criteria and two were referred to the study after it was closed. Given that the lead researcher was already in conversation with participants at the time of declining the research, the initially proposed ‘Declined Study Letter’ (Appendix S) was not sent, rather more personal conversations were held around non-participation. For the two individuals referred by a gatekeeper after the study was closed, the gatekeeper decided that they, rather than the lead researcher, would contact participants to inform them about the closure of the study.

All participants that were interested in the study but unable to participate and all recruitment organisations were offered the option of being sent a lay summary of the research findings once the study concluded. Preferred contact details (email or postal address) were collected for people interested; these are stored in an excel table on a secure UEA server.

Participants were offered the option of being seen either at their home or at the recruitment site, if applicable. For participants that chose to be interviewed at the recruitment site, the lead researcher agreed this with the recruitment organisations; gatekeepers were asked to book suitable rooms. Six participants were seen at their home and two at a recruitment organisation.

Participants were seen for interviews at one time point. Interviews were planned to last between 60-90 minutes depending on the participant’s cognitive and language ability, as well as the richness of their narratives. The average length of interviews was 55 minutes; ranging from 44 to 72 minutes. Participants had the option to have breaks, a shorter interview and a loved one present, but none of the participants chose these. Interviews were audio-recorded through the use of a dictaphone.

Prior to interviews, participants were reminded of the purpose of the study, their role in the study and their right to decline answering questions and withdraw from the study without providing a reason. Within this conversation the researcher evaluated participants’ ability to understand, retain and weigh-up information in order to consent to participate. All participants were judged to have capacity to consent. Participants were provided with a ‘Consent to Participate Form’ and together with the lead researcher completed a ‘Demographic Information Form’ (Appendix T). For participants who experienced difficulties providing information in the ‘Demographic Information Form’, the lead researcher contacted the participant within one week of the interview to gather the missing demographic information. The 'Demographic Information Form' required participants to provide contact details of their GP. Participants were informed that the disclosure of risk to self and others will lead to information being shared with their GP.

The interview schedule (Appendix E) used a series of open-ended questions to elicit narratives, beginning with a broad, general question (“Can you tell me about your experience of living with chronic post-stroke pain?”), which allowed participants to set the agenda (Smith et al., 2009). Further interview questions served as prompts for the interviewer, but were not strictly adhered to. The interview questions were chosen in light of the research question.

The interview process was flexible to allow for cognitive and communication difficulties to be addressed; participants were given additional time to express themselves and could act out, draw and write down concepts that they found difficult to express.

At the end of the interview, participants were provided with a ‘Debrief Sheet’ (Appendix H) and given the opportunity to ask questions. They were reminded of their right to withdraw their participation prior to information being anonymised. Data were anonymised one week from the date of the interview. Participants were informed that they could withdraw from the study, without providing a reason for their withdrawal, by informing the lead researcher by phone or email.

The ‘Consent to Participate Form’ offered participants the option of being sent a lay summary of the research findings; postal address and/or email address were collected. When being send the lay summary of findings participants can contact the lead researcher in order to discuss findings further.

Transcription.

A UEA clinical trial assistant was hired to support the transcription process. Conducting one’s own transcriptions can aid data immersion; however, other means of data immersion are possible as outlined in Smith and colleagues’ (2009) step one of the data analysis procedure. The lead researcher immersed herself in the data by repeatedly listening to interview audio recordings and re-reading interview transcripts. In addition professionally transcribed transcripts were carefully reviewed.

Analysis.

The following six steps by Smith and colleagues (2009) were followed:

- Step 1: The researcher immerses themselves in the data by listening to the audio recording of the interview and re-reading the interview transcripts. The reflective diary is used to capture the researcher’s reflexivity.
- Step 2: Initial notes on description, language and concepts represented in the transcripts are made in the right margin of the page (Appendix U).
- Step 3: Initial notes are used to identify emerging themes, which are noted in the left margin. In line with ‘double hermeneutics’, the researcher interprets the participant’s interpretation of the phenomenon. The emergent themes are therefore reflective of the participant’s words and the researcher’s interpretation (Appendix U & V).
- Step 4: Connections across emergent themes are made and super-ordinate themes developed. As part of this process, themes with conceptual similarities are grouped together, theme names re-considered, and themes with weak evidence or ones that do not fit the emerging structure are dropped (Appendix W).

- Step 5: After completing step one to four for one participant, the researcher then moves to the next participant's account of the phenomenon. Each case is dealt with in isolation; understandings from previous cases are put aside to not influence the analysis of the new case.
- Step 6: Patterns across cases are identified. Themes and super-ordinate themes shared across cases are used to build master themes (Appendix X).

To analyse the research data, the lead researcher followed the steps outlined by Smith and colleagues (2009). The lead researcher consciously tried to block biases and assumptions in line with bracketing (Chan et al., 2013). The lead researcher's interpretation of data was discussed with supervisors in an effort to assure credibility and validity of the analysis.

Data were presented in a way that highlights the shared experience of living with chronic post-stroke pain, as understood through the master themes. However, the uniqueness of individuals was preserved through discussions of the meaning of each theme for a particular participant. This was supported through the selection of quotations that represented themes, but highlighted participants' individuality.

Previous Study Proposal.

The research study conducted was based on a previously proposed study that aimed to investigate working age adults' experience of central post-stroke pain (CPSP). CPSP is a certain type of post-stroke pain, which is defined as neuropathic pain caused by stroke-related damage to the central nervous system (Henry, Lalloo, & Yashpal, 2008). It was formally known as thalamic pain syndrome and Déjerine and Roussy syndrome. It is estimated that CPSP accounts for one-third of post-stroke pain cases (Widar, Samuelsson, Karlsson-Tivenius, & Ahlstrom, 2002); 8% of stroke survivors develop CPSP (Henry et al., 2008).

Compared to other post-stroke pain syndromes CPSP is commonly described as particularly unpleasant and debilitating (Kim, 2009). It is chronic, constant and perceived as severe in intensity (Harrison & Field, 2015; Klit, Hansen, Marcussen, Finnerup, & Jensen, 2014). It also presents, similar to neuropathic pain in other conditions, as unusual sensations; words such as burning, shooting, aching, throbbing and/or stinging are often used by individuals to describe the pain (Kim, 2009). Diagnosing CPSP is particularly difficult as it has a varied timescale of onset (Kim, 2009), can be masked by the presence of other post-stroke impairments (e.g. aphasia) and co-morbid conditions (e.g. depression) (Henry et al., 2008) and lacks universal diagnostic criteria (Klit, Finerup, & Jensen, 2009). The treatment of CPSP has been found to be particularly challenging in comparison to other post-stroke pain conditions; pharmacological treatments and physiotherapy have been found to be less effective (Harvey, 2010).

Given the particular presentation and unpleasant experience of CPSP together with its treatment resistant nature, it appeared useful to investigate working age adults' experience of CPSP in the UK. Focusing on this age group and country appeared appropriate as studies found that both impact pain perception (Peacock & Patel, 2008; Rustøen et al., 2005). No previous studies had been conducted on this topic.

A study was therefore designed to investigate working age adults' experience of CPSP in the UK. Ethical and clinical governance approval was sought through the Health and Research Authority. The study received full approval on 12 March 2019 (Research Ethics Committee; REC Number: 19/LO/0326; Appendix Y). Local approval was granted by three NHS trusts and two stroke / brain injury charities. Multiple large organisations were identified as recruitment services to counteract the challenge of the low prevalence rate of CPSP in stroke survivors. Recruitment started in May 2019; the lead research held various phone conversations with gatekeepers and attended team meetings to inform them about the study, answer questions and aid recruitment. Over the period of two months however, no participants were identified. Feedback from gatekeepers was that services rarely see stroke survivors in working age and that CPSP is a rare occurrence. Pain services were contacted to gauge if they treat individuals with CPSP. This resulted in the understanding that UK pain services rarely see individuals with pain associated with a stroke. Furthermore, conversations with stroke survivors themselves highlighted that none had a clear diagnosis of their post-stroke pain and found it difficult to assess if they would fit the criteria of the study. Given the significant recruitment difficulties in the context of the tight timeline of the Doctorate of Clinical Psychology, an alternative study was proposed.

Discussions held within the research team and with other members of the Clinical Psychology Doctorate Programme resulted in the design of the research study presented within this thesis portfolio. Even though the presented study is closely linked to the previously designed study in terms of methodology, it was felt that the focus on chronic post-stroke pain, rather than CPSP, represented a change in topic rather than an adaption in eligibility criteria of the previous study. Based on this the study on CPSP was closed on the 18 August 2019 (Appendix Z).

Recruitment difficulties of the initially proposed study seem to have been related to a lack of understanding and diagnosis of CPSP. Even though half of the participants of the research study presented in this portfolio described pain experiences consistent with CPSP, none were diagnosed with it. This was also true for the other half of participants; none were given differential pain diagnoses. Furthermore, given that CPSP is more difficult to diagnose than other post-stroke pain types, as it can present as an unusual sensation rather than pain, it might be overlooked when presenting simultaneously with other pain types. In the presented research study two of the four individuals with pain sensations in line with CPSP experienced different types of post-stroke pain simultaneously.

In conclusion, the process of having to adapt the previously proposed study to include multiple post-stroke pain syndromes enhanced the lead researcher’s understanding of research and various ethical approval processes and highlighted an apparent lack of awareness of CPSP among healthcare professionals and stroke survivors.

Chapter 6. Overall Discussion and Critical Evaluation

Chapter Overview

This chapter summarises the findings of the systematic review and research study, placing them in relation to one another and discusses their novel contributions to research on pain in the context of neurological conditions. It provides a critical review of the two papers, summarises their clinical implications and identifies further research needed.

Summary of Findings

Chronic pain in the context of neurological conditions is a common, debilitating and treatment resistant impairment (Borsook, 2012), but research in this area remains limited. The aim of this portfolio was to develop an understanding of the experience of adults living with chronic pain in the context of a neurological condition, in order to inform the care of patients and identify further research needs. In particular, this portfolio focused on adults' experience of chronic pain in the context of sudden onset neurological conditions, namely, spinal cord injury and stroke. It was hoped that focussing on these two conditions would allow communalities in the lived experience to emerge.

The systematic review explored adults' experience of living with chronic neuropathic pain following spinal cord injury. The research study explored working age adults' experience of chronic pain following stroke using interpretative phenomenological analysis (IPA). The initial plan was to research the experience of living with neuropathic pain, which can be a direct effect of both spinal cord injury and stroke. However, there were significant recruitment difficulties, possibly reflecting difficulties in the detection and diagnosis of neuropathic pain following stroke (i.e. central post-stroke pain). This led to a re-design of the research study, to focus on all types of chronic post-stroke pain. The focus on working age adults, which was based on research suggesting this population has a unique experience of post-stroke impairments given their enhanced duties and responsibilities (Black-Schaffer & Winston, 2004; Morris, 2011; Snögren & Sunnerhagen, 2009), could only be implemented in the research study, as derived papers for the systematic review were too few to include an age restriction.

The systematic review, which synthesised existing qualitative research on the subjective experience of adults living with chronic neuropathic pain following spinal cord injury, identified six themes. The first theme 'The pain as an unusual, intense, unpredictable and uncontrollable sensation' described the varied and unique characteristics of the pain. The second theme 'The pain's influence on life' described pain-related limitations to activities of daily living and social and emotional consequences. The third theme ‘Trying to understand the pain’ described how individuals make sense of their experience in the face of limited information provided by healthcare services. The fourth theme ‘The challenge of describing the pain to others’ described participants’ difficulty conveying their pain experience to others. The fifth theme ‘The search for pain relief’ described participants’ self-driven quest for pain relief. The sixth theme ‘Learning pain acceptance over time’ described how participants accepted the pain as part of themselves and their life over time.

The research study on working age adults’ experience of living with chronic post-stroke pain derived three master themes. The first theme ‘The Solitude of the Pain Experience’ described how all participants felt alone in their pain experience; others were seen as unable to understand, relate and empathise. Participants were found to weigh up the benefits (i.e. practical support) and costs (i.e. burdening others) of sharing their experience. The second theme ‘Unsatisfactory Healthcare and the Need for Self-Care’ described an unmet care need experienced by participants. A lack of knowledge by primary healthcare professionals was described, leading to lack of formal diagnosis, accurate information and comprehensive treatment plan. In the absence of medical information, participants developed their own beliefs about the pain and its treatment. The third theme ‘The Development of Pain Acceptance’ described the journey from mourning the old self and life to accepting the new self and life with the pain. Acknowledgement of chronicity and lack of control, as well as engagement in downward counterfactual thinking, appeared to aid the process of finding pain acceptance.

Taking the findings described by the two papers together, there appears to be multiple commonalities described by individuals with pain in the context of spinal cord injury and stroke. Firstly, pain in the context of both neurological conditions, was described as persistent, uncontrollable and unpredictable. Patients with spinal cord injury and stroke both described their pain as 'unusual', consistent with the wider research on neuropathic pain (Finnerup, 2013; Marchettini, Lacerenza Mauri, & Marangoni, 2006). The systematic review highlighted that spinal cord patients occasionally regarded pain as the most distressing consequence of their neurological condition; however, although reported in the post-stroke pain literature (Kim, 2009), this was not found by the current study. This might be due to the fact that most participants in the current study are living with or had to overcome other significant stroke impairments, such as mobility limitations and aphasia. Therefore, rather than quantifying the associated distress of impairments they appeared to focus on overcoming one after the other.

Pain in the context of both neurological conditions appeared to be underrecognised by healthcare professionals leading to a lack of diagnosis and provision of clear and accurate information regarding the origin, characteristics, prognosis and consequences of the pain. Diagnosing pain in the context of neurological conditions might be particularly difficult as neuropathic pain, which can be a direct consequence of the condition, is heterogeneous and unusual in its presentation and might not be captured by current pain measures (Cruccu & Truini, 2009). Additionally, it appears that disorder-specific (i.e. spinal cord injury or stroke) pain measures or generic pain measures validated for stroke and spinal cord injury are not commonly used in clinical practice. Particularly in the context of a sudden onset neurological condition, following a potentially critical event, the focus of healthcare professionals might be on life threatening and visible impairments, rather than pain, which is seen as an invisible impairment. Furthermore, certain impairments associated with the neurological condition, such as mobility difficulties and aphasia, can result in patients being less likely to attend services and express their pain (Nesbitt, Moxham & Williams, 2015). Given that pain in the context of a neurological condition can have a delayed onset (Henry, Lalloo, & Yashpal, 2008) patients might not be under the care of specialist teams that can offer support in the identification and diagnostic process.

Patients with spinal cord injury or stroke were found to form their own understanding of their pain experience in the context of missing information. They formed their own beliefs and expectations, which adjusted over time as they learned to understand the pain’s characteristics. Beliefs about pain appeared to influence mood, recovery-focus and help seeking behaviour. For example, holding the belief that pain signals another stroke can cause stress, whereas holding the belief that it is a normal part of recovery can provide additional rehabilitation motivation, but also might reduce help seeking behaviour. That illness beliefs held by individuals with widespread pain can lead to positive and negative consequences is also highlighted by other research (Buitenhuis & de Jong, 2011; Järemo, Arman, Gerdle, Larsson, & Gottberg, 2017).

In line with difficulties of understanding their own pain, spinal cord injury, as well as stroke, patients appeared to have difficulties explaining their pain to others. A common experience was feeling others lack understanding and empathy, which seems to be related to the pain being an invisible impairment; this is a theme also found in the wider pain research (Cooper, 2013). Unique to working age stroke survivors was their feeling of receiving even less understanding and sympathy; this was associated with them not fitting the commonly held image of a stroke survivor due to their young age and potential lack of visual stroke impairments. People with spinal cord injury or stroke were found to not always disclose their suffering to others, not only because they expected others not to be able to relate, but also because they did not want to burden others. The topic of peer support for pain was mentioned for spinal cord injury and stroke patients; the benefit of sharing experiences and feeling understood was described, but no peer support groups appear to exist that focus on pain in the context of these neurological conditions. Spinal cord injury patients might be able to attend general spinal cord injury support groups. However, working age adult stroke survivors described not feeling part of, or benefitting from, attending general stroke survivor support groups due to their younger age and lack of visible impairments.

Both spinal cord injury and stroke patients reported dissatisfaction with the long-term care of their pain. Healthcare professionals in primary, or non-specialist, care were reported to lack knowledge, understanding and empathy. In contrast, both studies found that secondary, or specialist care professionals were perceived to be knowledgeable, understanding and compassionate. This suggests that pain in the context of a neurological condition is well understood in specialist care settings, but knowledge may be limited in primary care, where individuals' pain is managed long-term. That primary care providers perceive themselves as not being adequately trained in supporting patients with chronic pain was found by Upshur, Luckmann and Savageau (2006); therefore, supporting patients with chronic pain in the context of a neurological condition might require even more specialist training. Treatment approaches for pain in the context of spinal cord injury and stroke were found to be dominated by pharmacotherapy. Alternative treatment options, although desired by patients, appear to be rarely offered, despite recommendations in treatment guidelines for neuropathic pain following spinal cord injury and stroke suggesting broad, multidisciplinary, collaborative approaches to treatment (MASCIP, 2008; Royal College of Physician (RCP), 2016). There might be a lack of awareness of these specific guidelines in healthcare professionals. Given the lack of alternative treatments offered by healthcare providers, individuals across both studies were found to use their own resources to find alternative ways to relieve pain.

The pain was described as limiting individuals' social activities and activities of daily living, as well as negatively impacting their mood. However, participants of the post-stroke study did not dwell on these struggles and reported them to have been more present when the pain was first experienced. Participants of the stroke study were less impaired with regards to their general physical ability compared to participants of the spinal cord injury review, which might explain their reduced focus on everyday struggles.

Spinal cord injury and stroke patients were both found to develop acceptance of their pain over time. Participants started to realise the limits of pain relief and chronicity of their pain, which prompted the recognition of having to live with it. Unique to the post-stroke pain population, in this thesis research, was the use of downward counterfactual thinking, such as viewing oneself as lucky for surviving the stroke or being less impaired compared to other stroke survivors. It is possible that this was not a focus of the research conducted on pain following spinal cord injury, but it might also reflect that spinal cord injury patients did not feel less impaired compared to their peers, as the main impairment associated with spinal cord injury, paraplegia, is experienced by all.

Given the findings of the two research papers it appears there is a large overlap in the way spinal cord injury and stroke patients experience living with chronic pain. Furthermore, their experience appears similar to that of other chronic pain patients with regards to being an invisible impairment, others lack of understanding, negative impact on daily and social activities, dominance of pharmacological interventions and deriving pain acceptance over time (McCracken & Eccleston, 2005; Snelgove & Liossi, 2009). However, the additional impairments commonly associated with spinal cord injury and stroke, are likely to make diagnosis and treatment of pain even more difficult.

Methodological Strengths and Limitations

The adoption of a qualitative approach enabled a rich, detailed understanding of the way patients experience chronic pain in the context of a neurological condition. By allowing participants to freely express themselves, rather than limit their reported experience to prescribed variables, new insights were gained. An inductive thematic analysis was chosen to synthesise finding in the systematic review, as this method allows for new insights and recommendations to be generated, while staying close to the original data (Braun & Clark, 2006). For the research study IPA was adopted, which is unique in its aim to create a rich understanding of individuals’ experience of major life events (Brocki & Wearden, 2006, Smith, Flowers, & Larkin, 2009) and has been proposed to be particularly useful in healthcare research (Brocki & Wearden, 2006) and in the research of pain (Smith & Osborn, 2015).

The systematic review was rigorously conducted; search terms and eligibility criteria were clearly identified, MeSH and free-text search were combined, various databases were utilised, mixed-method papers and unpublished work were included, a standard checklist for quality assessment was used, a systematic and transparent synthesis process was applied and a second individual confirmed eligibility of papers, quality ratings and derived themes. A limitation of the review was that it was based on a limited number of papers, which related to even fewer studies and were conducted by only three research teams; based on this, findings might not be widely applicable.

The research study upheld high ethical standards and the principles of rigor, transparency and trustworthiness by adopting a patient and public involvement approach, being inclusive for individuals with aphasia and mobility difficulties, using a reflective diary as well as supervision, having an audit trail of the analysis process and using the wider research team to confirm derived themes. The current study's findings are in line with findings derived by studies conducted in other countries; therefore, conclusions drawn should be meaningful to the wider population of individuals with post-stroke pain. A limitation of the current research study was that the sample was not as homogenous with regards to pain type and onset, and participants' age. Given that these variables appeared to influence participants view on certain themes, such as gaining pain acceptance and role as parents, more focused insights might have been gained from a more homogenous sample. Even though in line with IPA, the employment of a self-selected sample can create biased findings and should be considered; participants of the study might have been the ones less impacted by their pain.

Overall, both research papers followed a rigorous and transparent process in which multiple steps were taken to account for possible bias and subjectivity. Limitations were named and their impact on the findings discussed.

Clinical Implications

Findings of both studies suggest that healthcare professionals need to increase their awareness of the potential occurrence of pain as a result of sudden onset neurological conditions, such as spinal cord injury and stroke. It should be considered that patients might find it hard to describe their pain or even avoid voicing it to others, which can impact accurate and timely diagnosis. Similarly, the use of some pain measures might not identify patients' pain experiences, as symptoms may not fit prescribed pain categories. An in-depth assessment and patient-centred formulation of the pain would be beneficial in capturing not only individual pain symptoms, but also other aspects of the pain experience, such as the pain's impact on daily life, relationships and sense of self. In line with guidelines from the National Institute of Health and Care Excellence (NICE, 2013; 2016) the assessment of pain should be part of the comprehensive assessment during the acute phase; however, given that pain onset can be delayed, patients should be made aware that pain could occur at a later stage and should be given information as to where to seek help and support at that time. Furthermore, primary healthcare professionals would benefit from additional education on pain in the context of neurological conditions, so they can offer effective long-term support. It is important that pain in neurological patients is identified and accurately diagnosed and if possible, differential pain diagnoses should be given, as treatment approaches can vary (RCP, 2016). It is also important that patients are given clear and accurate information about the cause of the pain, its characteristics and prognosis in order to prevent distress associated with inaccurate illness beliefs, and potential reduction of rehabilitation efforts and support seeking behaviour. The current research highlighted that patients prefer non-pharmacological treatments; therefore, treatment other than pharmacotherapy should be considered. Also healthcare providers should follow the special treatment guidelines for pain in the context of spinal cord injury (MASCIP, 2008) and stroke (RCP, 2016). Encouraging attendance of peer support groups might be beneficial as these can help patients feel understood; however, it should be considered whether support would be best provided by groups for people with the same neurological condition or for people with chronic pain syndromes. Patients might feel alone and misunderstood with regards to their pain diagnosis even when being with family and friends. Based on this information and support should also be offered to patients' close social networks.

Further Research

Further research on chronic pain following neurological conditions is required. In particular, research should explore the experience of primary healthcare providers in caring for patients with chronic pain in the context of a neurological condition in order to highlight their perceived challenges. These can then be addressed with the development of specific education and training programmes.

Much more research is needed to identify evidence-based, non-pharmacological treatment approaches to pain in the context of neurological conditions; the effectiveness of pain management programmes, systemic and psychological therapy should be explored. This understanding is needed to improve treatment guidelines and pave the way to the introduction of pain assessment and treatment recommendations in the general NICE guidelines on stroke and spinal injury care. Given that patients felt even their close family and friends lacked understanding and empathy, it might be beneficial to investigate the experience of family members and friends of patients with pain in the context of a neurological condition. This might identify ways to better support the system around the person. Furthermore, patients' experiences of attending condition-specific, and chronic pain, support groups should be compared to identify which might be better suited for individuals with chronic pain in the context of a neurological condition. Research effort should be focused on exploring the barriers clinicians face with regards to using validated, disorder-specific (i.e. spinal cord injury and stroke) pain measures. Furthermore, it should be explored if these measures are broad enough to capture neuropathic, as well as nociceptive pain and enable a diagnosis of different, potentially co-occurring pain types within the conditions of spinal cord injury and stroke.

The research highlights that there might be differences in how younger adults experience their pain in the context of a neurological condition compared to older adults due to their different life stage and commitments. Future research should investigate the impact of age on the experience of chronic pain in the context of other neurological conditions, to ensure that the needs of younger and older adults are met appropriately.

Conclusions

The two papers presented within this portfolio provide novel insights into the experience of living with chronic pain in the context of a neurological condition. The findings suggest that spinal cord injury and stroke patients have a similar experience of living with chronic pain. The pain is described as an invisible impairment, which is difficult to relate to others and can easily be overlooked in the context of other more visible, condition-related impairments. Overall, there appears to be an unmet healthcare need for patients with chronic pain in the context of neurological conditions. Healthcare professionals, particularly in primary care services, appear to lack knowledge potentially affecting the timeliness of diagnosis and treatment. Interventions are often limited to pharmacotherapy with no alternatives provided. In the perceived absence of adequate information provision and care, individuals feel alone in their search for knowledge, pain relief and a new way of living alongside the pain.

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Appendix A

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

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

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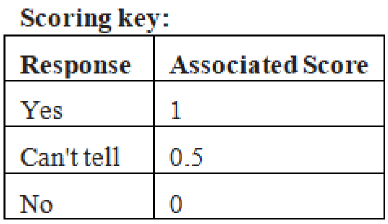
Appendix B

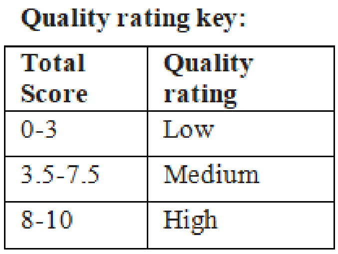
Quality Appraisal of Selected Papers (CASP Ratings)

CASP criteria	**Henwood & Ellis (2004)**	**Henwood et al. (2012)**	**Hearn et al. (2015)**	**Hearn et al. (2016)**	**Hearn et al. (2017)**	**Buscemi et al. (2018)**
1. Was there a clear statement of the aims of the research?	1	1	1	1	1	1
2. Is a qualitative methodology appropriate?	1	1	1	1	1	1
3. Was the research design appropriate to address the aims of the research?	1	1	1	1	1	1
4. Was the recruitment strategy appropriate to the aims of the research?	1	0.5 (1)	1	1	1	1
5. Was the data collected in a way that addressed the research issue?	1	1	1	0.5	1	0.5
6. Has the relationship between researcher and participants been adequately considered?	0.5	0.5	0.5	0.5	0.5	1
7. Have ethical issues been taken into consideration?	1	1	1	0.5	1	1
8. Was the data analysis sufficiently rigorous?	1	1	1	1	1	1
9. Is there a clear statement of findings?	1	0.5 (1)	1	1	1	1
10. How valuable is the research?	1	1 (0.5)	1	1	1	1
Total CASP rating 1st rater:	*9.5*	*8.5*	*9.5*	*8.5*	*9.5*	*9.5*
Total CASP rating 2nd rater:	*9.5*	*9*	*9.5*	-	-	-



Scoring key:

Response	Associated Score
Yes	1
Can't tell	0.5
No	0



Quality rating key:

Total Score	Quality rating
0-3	Low
3.5-7.5	Medium
8-10	High

Appendix C

Example of the Synthesis Process; Excerpt from Buscemi et al. (2018)

Overarching Themes	Identified Themes	Transcript	Initial Notes
The pain as an unusual, intense, un-predictable and un-controllable sensation	Relationship with SCI	Theme 1. The continuous influence of pain in life: "The biggest problem at the moment is suffering pain" (Marco)	*CPN is worse than SCI*
The pain's influence on life	Impact on daily life	CNP was reported to have a negative impact on all aspects of life such as relationships, work and leisure, physical and psychological well-being. It was regarded as the most significant issue in participants' lives.	*Impact on activity of daily living, occupation, relationships and physical and psychological wellbeing*
The pain as an unusual, intense, un-predictable and un-controllable sensation	Relationship with SCI	Indeed, for one participant, it exceeded the impact of the SCI itself.	*Greater impact than SCI*
The pain's influence on life	Impact on daily life	Participants described their pain, whether it was constant or not, as having the capacity to exert an almost total dominion over their thoughts and actions:	*Pain is overpowering thoughts and behaviour*
The pain's influence on life	Q: Relationship with SCI / Impact on daily life	"It should be taken into account that one of the biggest disabilities is not losing the movement of the legs but having constant pain, having pain that does not allow you to move, does not give you the serenity to stay with others quietly or to do your job or other activities" (Bruno, constant pain all day, every day, FG1).	*Q: Pain is worse than other SCI consequences; impact on daily living, occupation and relationships*
The pain's influence on life	Impact on daily life	This quotation lays open the meaning of the physical, psychological and social disruption that underpinned the experience of CNP. Bruno described his pain experience as worse than the impact of his SCI. The pain constantly nags away at him, demanding attention. It is prohibitive and all powerful. He is uncomfortable at rest and finds	*Pain takes control over life*

		no relief from movement. Whatever he does he cannot escape the pain or the impact of it in his life. Silvio, Davide, Laura and Sara below, also spoke of their pain as an intrusive and disturbing force in their everyday lives:	*No pain relief*
The challenge of describing the pain to others / The pain's influence on life	Q: Inability to describe the experience / Impact on relationships	"I try to bear it [the pain], at a family level, with friends, I don't show it, and I keep my pain and I bear it. It's very hard, especially some days and during the evening". (Silvio, pain 6 days a week, FG1)	*Q: Participants suffer in silence; not share their experience*
The pain's influence on life	Q: Impact on daily life	"The pain makes me tired. I arrive home [from work] and I'm really tired, so tired that during the week I go to bed at 8.30–9. I can't cope any longer". (Davide, constant pain, every day, interview)	*Q: The pain reduces participation in life*
The pain's influence on life	Q: Impact on daily life	"During the night, I only think of it [the pain], if I have pain it becomes a nightmare. I don't sleep anymore". (Laura, pain one day a week, FG1)	*Q: Impact of pain on sleep*
The pain's influence on life	Q: Impact on daily life	"[In the morning when I wake up] I already feel tired, and in a bad mood towards the coming day". (Sara, pain every day, e-mail exchange) For these participants, pain enshrouded their daily lives. They described certain parts of the day as particularly distressing. Exhaustion from work, lack of sleep, disturbed sleep and the effort of shielding others from the impact of pain all took their toll. Marco spoke similarly:	*Q: Impact of pain on sleep, which impacts the day*
The pain's influence on life	Q: Impact on relationships	"I don't wake up happy and therefore I know already that I'll be slower, that I'll be more nervous with relationships. During the day, I have, in my	*Q: The pain's control over participants' lives; it stops them from engaging (takes away joy)*

		mind, focused on only that my day finishes as soon as possible. With my job, it is the day, I try to go back (home) as soon as possible, I try to avoid going out with friends" (Marco, constant pain, 5 days a week, FG2).	
The pain's influence on life	Impact on relationships	Pain affected Marco's attunement to the world. He not only spoke of the impact of pain on his physical self but also offered insight into how his response to pain was embodied through his tentative relations with others. Pain not only placed limits on his life as he struggled through work at high cost to his friendships and social relationships ("with my job it is the day"), but also placed limits on his capacity for joy and pleasure, hoping only that his day finished as soon as possible. A similar view was articulated by Sara:	*Great impact on relationships*
The pain as an unusual, intense, unpredictable and uncontrollable sensation	Q: Lack of control	"Slowly pain has removed the power to do things that I used to like and that distract me [from the pain] such as reading or painting" (Sara, pain every day, e-mail exchange)	*Q: People see themselves as victims of the pain, being powerless of its influence*
The search for pain relief	Ways to cope	It was not uncommon for participants to use absorbing activities such as reading or painting as a way of coping with pain nor was it unusual for participants to understand pain in adversarial terms such as those described by Sara and by Marco above. Sara places pain in the context of an adversary that in the past she could control through her participation in enjoyable activities. However, over time, she lost this sense of mastery. For Sara the pain "removed the power". She wants it understood that despite her best	*Distraction through engaging in all-consuming activities was reported as coping strategy.*

The pain's influence on life	Impact on daily life	efforts the pain exerted its own agency and took away her control. Bruno spoke in similar terms. For him pain was an "itself", with the capacity to draw down his world, to close it off until the pain became the sole focus of his being:	*Pain's capacity to determine peoples' lives; it reduces peoples' activities until nothing is left other than the pain itself*
The pain's influence on life	Q: Impact on daily life	"At a certain point, pain holds the power, it becomes so important that you cannot manage to think of anything else, it attracts all attention to itself" (Bruno, constant pain all day, every day, FG1).	*Q: The pain can be the only thing left for people*
The pain's influence on life	Impact on daily life	In summary, the first overarching theme illustrated the enduring and intrusive effect of pain on everyday life. Participants described the ways in which CNP manifested itself, how CNP was perceived to disrupt daily actions and activities, and the times during which pain had the potential to overwhelm or hold sway over their sense of self and the things that mattered in their lives. For these participants, pain did not simply reside inside the body. It spilled out into the world, disturbing relationships with colleagues, friends and partners, constraining expectations and future possibilities. In this theme, participants described their pain and pain experience, and typically constructed pain as an independent agent or adversarial entity. Participants' sense of control over their pain was often in flux, but the threat of pain was a constant source of unease. The consequences on everyday life were significant and the potential impact on the sense of self profound. The possibility of being lost in pain, as described by Bruno, called attention to his vulnerability, and sense of helplessness, and	*Pain's impact on everyday life*
The pain's influence on life	Impact on daily life / Impact on relationships		*Pain impacts everyday life, relationships and future plans.*
			Pain perceived as external force.
The pain as an unusual,	Lack of control		*Self as helpless and out of control*

intense, unpredictable and uncontrollable sensation		uncovered the deeply psychologically troubling experience of living with chronic neuropathic pain.	

Note: Direct quotations of participants used within the paper are underlined.

Appendix D

Prevalence of Overarching Themes across Papers

First Author (Year)	The pain as an unusual, intense, unpredictable and uncontrollable sensation	The pain's influence on life	Trying to understand the pain	The challenge of describing the pain to others	The search for pain relief	Learning pain acceptance over time
Buscemi et al. (2018)	✓	✓	✓	✗	✓	✗
Hearn et al. (2015)	✓	✓	✗	✓	✓	✓
Hearn et al. (2016)	✓	✓	✗	✓	✗	✗
Hearn et al. (2017)	✗	✗	✓	✗	✓	✓
Henwood & Ellis (2004)	✓	✓	✓	✓	✓	✓
Henwood et al. (2012)	✓	✗	✓	✗	✓	✓

Appendix E

Interview Schedule

Interview Schedule

Research Question:

What is the experience of working age adults living with chronic post-stroke pain?

Interview Schedule:

1. Can you tell me about your experience of living with chronic post-stroke pain?
    a. How do you experience the pain?
    b. What does the pain mean to you?
    c. How do you make sense of the pain?
    d. What is your experience of everyday life with the pain (e.g. family life, occupation)?
        i. Can you think of specific examples to highlight this?
    e. How do you view yourself with the pain?
    f. What is your experience of being diagnosed (or not) with a stroke-related pain condition?
    g. How do you / did you experience the care you receive / received for the pain?
    h. What is your experience of managing the pain?
2. Is there anything else that you wish to share about your experience of living with chronic post-stroke pain?

General prompts:

- Can you tell me more about that?
- What does that mean to you?
- How do you make sense of that?

Appendix F

Faculty of Medicine and Health Research Ethics Committee Approval Letter

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Johanna Bruger
MED

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

03 September 2019

Dear Johanna

Title: The Experience of Working Age Adults Living with Chronic Post-Stroke Pain: An interpretative Phenomenological Analysis

Reference: 2018/19 - 148

Thank you for your response to the recommendations of the FMH Ethics Committee to your proposal. I have considered your amendments and I can now confirm that your proposal has been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely

Prof Alastair Forbes
Chair
FMH Research Ethics Committee

CC Catherine Ford (MED)

Appendix G

Social Media Advertisement

Do you have long-term pain following stroke?

A new research study aims to explore how working age adults (18 - 64) experience long-term pain following stroke, by finding out about their experience of post-stroke pain, the impact it has on their life and identity, their experience of receiving treatment for it and their experience of managing the pain.

We hope to raise awareness of the importance of considering post-stroke pain in the care and rehabilitation of young stroke survivors. Insights from the study might also help others who live with long-term post-stroke pain by showing them they are not alone.

Taking part in the study involves an interview which is approximately 60-90 minutes long; shorter interviews are possible too and breaks can be taken.

We would like to invite you to take part in this study if you:

- Are aged 18-64
- Live in the UK and are not hospitalised or living in a care home
- Speak fluent English
- Have had pain over 3 months, due to a stroke

Unfortunately you are not able to participate if you experience:

- Severe thinking, memory or communication difficulties
- Severe mental health difficulties or substance misuse problems
- A long-term pain condition that was present before your stroke
- Difficulties that hinder you in making your own decision about taking part in this research

If you are interested in taking part, have more questions or are unsure if you fit the criteria, please get in contact by emailing j.bruger@uea.ac.uk or by calling 07926310961.

Twitter Advertisement

Are you a UK Stroke Survivor aged 18-64 with long-term (>3 months) post-stroke pain who would like to participate in research? We are researching experiences of living with long-term post-stroke pain. If you are interested please contact: j.bruger@uea.ac.uk.

Appendix H

Debrief Sheet

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

DEBRIEF SHEET

Dear Sir / Madam,

RE: "*The experience of working age adults living with chronic post-stroke pain"*

Thank you very much for taking the time today to talk to me about your experience of post-stroke pain.

Study Overview

After a stroke, people often feel their life has changed. There can be changes in memory, thinking, mobility, language and mood. Additionally, people also commonly experience pain as a result of their stroke. In most cases post-stroke pain can be managed well through treatments like medication and physiotherapy. However, for some people the pain persists and impacts their life.

As stroke typically occurs in older adults, most research is conducted with people over the age of 65. Studies that specifically focus on stroke survivors in their working age (18-64) tend to focus on exploring causes and frequencies of stroke, rehabilitation outcomes and return to work rates. However, studies rarely explore younger stroke survivors' experience of the stroke and its consequences for their life.

This study will explore working age adults' experience of living with chronic post-stroke pain. People of working age have different responsibilities (e.g. work, family and finance) to people of retirement age; based on this they are likely to have a unique experience of living with chronic post-stroke pain.

The aim of this study is to raise awareness of the importance of considering post-stroke pain in the care and rehabilitation of young stroke survivors. Insights from the study might also help others who live with chronic post-stroke pain by making them aware that they are not alone in facing the condition.

What will happen next?

Our interview was recorded on a dictaphone in order for me to listen back to what we discussed. The recording will be transferred onto a password protected memory stick at the earliest opportunity; it will be saved using your participant number rather than your name. The recording will then be typed into a document in order to be analysed; all personally identifiable information will be removed. I will compare your experience to that of other people who chose to participate in this study. I will see if there are common themes in the way you and others experience chronic post-stroke pain.

You can decide to withdraw from this study within the next week. After that point your answers will have been anonymised and therefore it will no longer be possible to withdraw. If you decide that you no longer wish your answers to be included in this study please get in contact with me (details above). You do not have to provide a reason to withdraw from this study and your withdrawal will not affect the care you receive from the service / organisation that recruited you.

When consenting to participate in this study, you have been given the option to receive a written summary of the findings from this study. If you decided that you would like to receive a summary, I will send it to you once the final report has been written. It is likely that this will be after May 2020. If you wish, I can also discuss study findings with you over the phone. Findings of this study will also be fed back to the participating services / organisations and will be published in a research paper and/or conference.

What if the interview has caused me distress?

It is possible that our conversation may have covered personal and potentially distressing experiences. It is normal that talking about difficult experiences can be distressing. However, if you find yourself significantly upset or distressed following our conversation today, then you might want to consider the following suggestions:

- You may find it helpful to discuss how you are feeling with family or friends.
- You may find it helpful to discuss your feelings with the professional who referred you to this study. You could discuss with them if additional support is available to you.
- It may be helpful to talk to your General Practitioner (GP). They will be able to tell you about services in your area that can support you (e.g. your local wellbeing service, counselling or support groups).
- It may help to contact the Stroke Association (0303 3033 100 or helpline@stroke.org.uk), Different Strokes (0345 130 7172, 01908 317 618 or info@differentstrokes.co.uk) or Headway (0808 800 2244 or helpline@headway.org.uk) for support and advice about stroke.
- If you are worried about your mental wellbeing outside of working hours, you could contact your local GP Out Of Hours Service or seek free, confidential help and support from The Samaritans by calling 116 123 (or emailing jo@samaritans.org).

Everyone has different ways of coping with difficult situations and feelings and some people do not find talking about their feelings helpful or therapeutic. However, if you notice that your ways of coping are not making you feel better, please let your GP know or get in touch with one of the organisations listed above, so they can help you.

Thank you very much for sharing your story with me today.

Yours sincerely,

Johanna Bruger
Trainee Clinical Psychologist, University of East Anglia.

Supervised by Dr Catherine Ford and Dr Joanna Semlyen

Appendix I

Table of Master and Subordinate Theme Prevalence across Participants

Master Themes:	**The Solitude of the Pain Experience**		**Unsatisfactory Healthcare and the Need for Self-Care**			**The Development of Pain Acceptance**	
Subordinate Themes:	*“No one really understands”*	*“I’m not going to tell you unless you’re going to help me”*	*“I don't think I received care”*	*"I’m not really a doctor but I presume it’s something …”*	*“It’s like self-management - I just do what I can myself”*	*Mourning the ‘old’ self and life*	*Accepting the ‘new’ self and life*
Jack	✓	✓	✓	✓	✓	✓	X
Peter	✓	✓	✓	✓	✓	✓	✓
Linda	✓	✓	✓	X	✓	✓	✓
Kiara	✓	✓	O	✓	✓	✓	✓
Judith	✓	✓	✓	✓	✓	O	✓
Harry	✓	✓	✓	✓	✓	✓	O
Tiwa	✓	X	✓	X	✓	✓	✓
Brian	✓	✓	✓	✓	✓	✓	X

Note: Participants’ names are pseudonyms. ✓ = Commented on theme; X = Not commented on theme; O = Partially commented on theme.

Appendix J

Consent to Participate Form

University of East Anglia

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

CONSENT TO PARTICIPATE FORM

Title of Study: The experience of working age adults living with chronic post-stroke pain

Name of Primary Researcher: Johanna Bruger

Name of Research Supervisors: Dr Catherine Ford and Dr Joanna Semlyen

Please place your initials in the following boxes as appropriate.

1. I confirm that I have read the 'Participant Information Sheet' (Version 1; 11th July 2019) for the above mentioned study. I have had time to consider the information, ask questions and receive satisfactory answers. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, up until one week after the interview has taken place, by contacting the researcher. I understand that I do not need to give any reason for withdrawing from the study and that my withdrawal will not affect the care I receive from the service / organisation from which I was recruited. ☐

3. I understand that the interview will be audio recorded and that direct quotes might be used in the publication of this research. I understand that my responses will be anonymised; no personally identifying information will be used in any publications. ☐

4. I understand that I will be asked to provide demographic information that will inform the research, but that I do not have to provide any information that I do not feel comfortable sharing. Furthermore, I understand that demographic information used in this research will be carefully considered so that I remain anonymous. ☐

5. I understand that my personally identifiable information will be held securely in locked cabinets, within locked offices, at the University of East Anglia (UEA) and that all data will be destroyed after 10 years. I understand that in addition to the research team, relevant sections of my medical notes and data collected during the study may be looked at by individuals from UEA. This will only be the case if this is relevant / necessary for the research (e.g. audit purposes). I give permission for these individuals to have access to my records. ☐

6. I agree to take part in the above research study. ☐

If you wish to receive a written summary of the findings from the above mentioned study please provide your contact details (postal address or email address) below:

____

____

____

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Participant Number: __________________ Recruitment Site: ______________________

Appendix K

Participant Information Sheet

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

INFORMATION ABOUT THE STUDY

(Participant Information Sheet)

Dear Sir / Madam,

RE: "*The experience of working age adults living with chronic post-stroke pain"*

I would like to invite you to take part in this research study. This information sheet summarises the key points of the study to help you decide if you would like to take part.

What is the purpose of this study?

This study aims to explore how working age people experience chronic post-stroke pain, e.g. their experience of the pain, the impact the pain has on their life and identity and their experience of receiving care / managing the pain. It is hoped that the knowledge gained from this research will inform healthcare professionals, as well as family members / friends, so that they can provide the best support and care possible. Insights gained from this study may also help to show stroke survivors with long-term pain following stroke that they are not alone.

Do I have to take part?

No, participation is voluntary. Declining this study or withdrawing from it at a later stage does not affect your involvement with the service / organisation and does not impact your level of care. You can withdraw from this study up to one week after the interview has taken place. At that point, what you have shared with us will be made anonymous so your details remain confidential.

What will happen to me if I take part?

If you would like to take part you will be asked to sign the 'Consent to Contact Form'. The professional that recruited you for this study will then share your contact details with me and I will be in contact as soon as possible. At this point you can ask me any questions you might have. We will then agree a suitable date, time and location to meet for the interview. This could be at the recruitment service / organisation or at your home.

When we meet, you can ask any further questions you might have about the study. If you would like to take part, I will ask you to sign the ‘Consent to Participate Form’. I will then ask you to provide some information about yourself (e.g. age, occupation and details about the stroke and pain). After this we will start the interview. If you wish you can have someone you trust present at the interview.

The interview will last for approximately 60-90 minutes; it is possible to take breaks and end interviews earlier. During the interview I will ask questions about your experience of the pain and the impact the pain has on you and your life. The interview is flexible and allows you to talk about things you feel are important. You do not have to share anything with me that makes you feel uncomfortable.

Talking about the stroke and the pain could be upsetting; we can take time during or after the interview to attend to the way you are feeling. If you feel you would like further support, I can help you in making contact with different support services and/or your General Practitioner (GP). If I am concerned about your own or others safety, I might have to discuss my concerns with others involved in your care (i.e. your GP). However, I will always try to discuss everything with you first.

The interview will be recorded on a dictaphone in order for me to listen back to what we discussed. The recording will be transferred onto a password protected memory stick at the earliest opportunity. It will be saved using your participant number rather than your name. The recording will then be typed into a document in order to be analysed. All personally identifiable information will be removed.

Will my taking part be kept confidential?
The University of East Anglia, which is based in the United Kingdom, is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of East Anglia will keep identifiable information about you for 10 years after the study has finished. After this they will be securely destroyed.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the Data Protection Team; dataprotection@uea.ac.uk.

In the rare event of serious concerns about safety, I might need to share information about you to ensure your safety or the safety of someone else. If this occurred, I would inform your General Practitioner so they could help you manage the situation. In the case of severe and immediate risk to you or others, I would contact emergency services and might need to seek guidance might need to be sought from a local specialist team (safeguarding team). In such situations it might be necessary for me to make relevant third parties aware of the situation; e.g. my primary supervisor, the research sponsor and/or site manager. If a breach in confidentiality was required you would be informed about the steps taken.

What are the possible benefits of taking part?
By sharing your experience you can help raise awareness of the impact chronic post-stroke pain has on the life of people in their working age. It is hoped that this will help inform healthcare professionals, as well as family members / friends about chronic post-stroke pain. This might lead to improved support and care and might help others realise that they are not alone. You might also find talking about your experiences helpful.

What are the possible disadvantages of taking part?
Talking about your life with chronic post-stroke pain is personal and potentially emotional. Please remember you do not have to share anything that makes you feel uncomfortable. If you feel upset during / after the interview, we can address this in the session, take breaks and if needed, discontinue. If you feel you would like further support, I can help you make contact with different support services and/or your GP.

What happens when the interview is over?
After the interview, the interview recording will be typed so that it can be analysed and used for the final report. The final report will contain anonymised direct quotes from you and other participants. We hope that this research will be published in an academic journal and/or presented at a conference. You can request a summary of the findings and I am happy to talk these through with you over the telephone.

Can I claim for travel expenses?
You cannot claim for travel or parking expenses; however, it is possible to conduct the interview at your home.

Is it possible that I might be declined the opportunity to take part in the research?
Individuals participating in this research project need to fit certain criteria; for example, people who experienced a chronic pain condition prior to their stroke cannot participate in this research. The professional who approached you about this research will have assessed your suitability for the research; however, I will also assess if you fit the study’s criteria at the first point of contact. People might also be declined the opportunity to take part in the research if enough people have been interviewed. If you are declined the opportunity to take part in the research, you will be sent a letter telling you this. However, you will have the opportunity to contact me to request an easy-read summary of the research findings.

What if there is a problem?
If you have any worries or concerns about any part of this study, you can contact me and I will do my best to support you. You can also contact my primary

supervisor, Dr Catherine Ford (Clinical Psychology Doctorate Programme, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich NR4 7TJ; catherine.ford@uea.ac.uk; 01603 591240).

To make an independent complaint about this research, please contact:
Dr Niall Broomfield, Head of Clinical Psychology Department
Clinical Psychology Doctorate Programme, Faculty of Medicine and Health Sciences University of East Anglia, Norwich, Norfolk, NR4 7TJ;
n.broomfield@uea.ac.uk

Who organises and funds this research?
This research is being conducted as part of a Doctorate in Clinical Psychology at the University of East Anglia. A small research budget has been made available by the University.

Who has reviewed the study?
This study has been reviewed by the Clinical Psychology Department and the Faculty of Medical and Health Sciences Research Ethics Committee of the University of East Anglia.

Thank you for taking the time to read this information sheet. If you have any questions please feel free to contact me.

Many thanks,

Johanna Bruger, Trainee Clinical Psychologist

Supervised by: Dr Catherine Ford and Dr Joanna Semlyen

Appendix L

Consent to Contact Form

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

CONSENT TO CONTACT FORM

Title of Study:
The experience of working age adults living with chronic post-stroke pain

Name of Primary Researcher: Johanna Bruger

Name of Research Supervisors: Dr Catherine Ford and Dr Joanna Semlyen

Please place your initials in the following boxes as appropriate.
(If consent was discussed in a telephone conversation the professional working in the recruitment service / organisation, should initial the appropriate boxes)

1. I confirm that I have been informed about the above-mentioned study by a professional of the service / organisation and I have been provided with a 'Participant Information Sheet' (Version 1; 11th July 2019).

2. I confirm that I have been asked to take part in the above-mentioned study and that I have agreed to be contacted by the researcher.

3. I give consent for the professional who informed me about the above mentioned study to share my contact details and any potential risks identified with conducting the interview at my home with the researcher.

Contact details (either telephone number or email address):

____

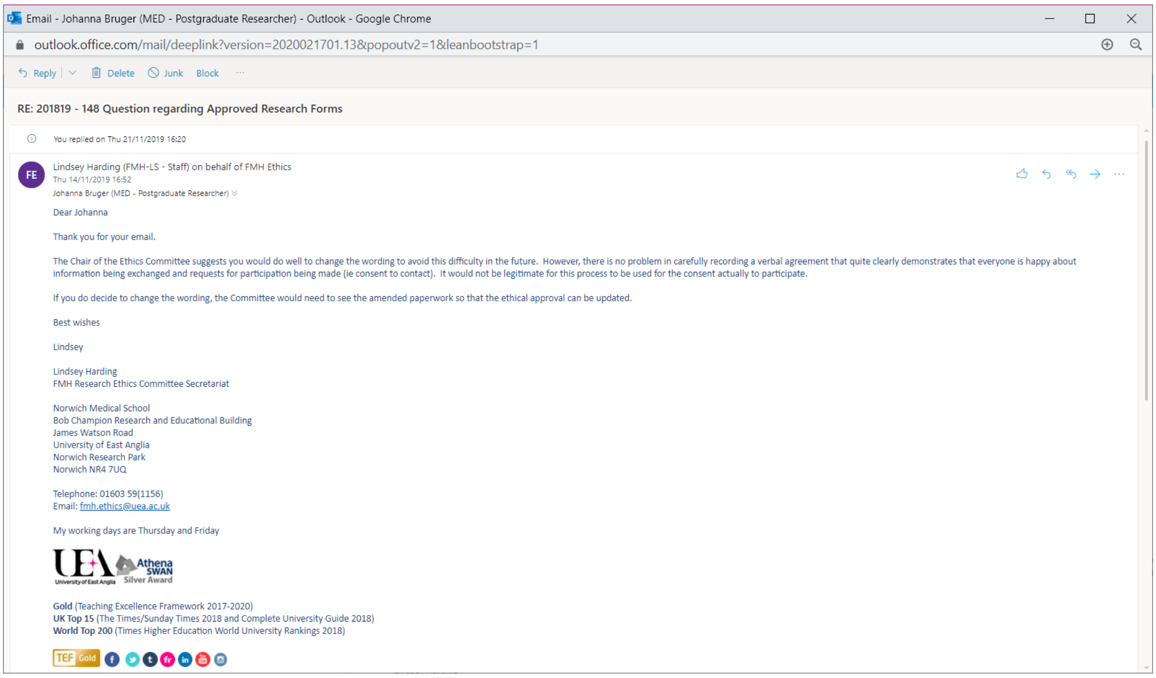
Name of Participant	Date	Signature

____________________	____________________	____________________
Name of Gatekeeper	Date	Signature

Recruitment Site: ________________________

Appendix M

Confirmation from the Faculty of Medicine and Health Research Ethics Committee that Verbal Consent to Contact is Acceptable



RE: 201819 - 148 Question regarding Approved Research Forms

You replied on Thu 21/11/2019 16:20

Lindsey Harding (FMH-LS - Staff) on behalf of FMH Ethics
Thu 14/11/2019 16:52
Johanna Bruger (MED - Postgraduate Researcher)

Dear Johanna

Thank you for your email.

The Chair of the Ethics Committee suggests you would do well to change the wording to avoid this difficulty in the future. However, there is no problem in carefully recording a verbal agreement that quite clearly demonstrates that everyone is happy about information being exchanged and requests for participation being made (ie consent to contact). It would not be legitimate for this process to be used for the consent actually to participate.

If you do decide to change the wording, the Committee would need to see the amended paperwork so that the ethical approval can be updated.

Best wishes

Lindsey

Lindsey Harding
FMH Research Ethics Committee Secretariat

Norwich Medical School
Bob Champion Research and Educational Building
James Watson Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Telephone: 01603 59(1156)
Email: fmh.ethics@uea.ac.uk

My working days are Thursday and Friday

Gold (Teaching Excellence Framework 2017-2020)
UK Top 15 (The Times/Sunday Times 2018 and Complete University Guide 2018)
World Top 200 (Times Higher Education World University Rankings 2018)

Appendix N

Transcription Confidentiality Agreement

1

University of East Anglia

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

TRANSCRIPTION CONFIDENTIALITY AGREEMENT

Title of Study:
The experience of working age adults living with chronic post-stroke pain

Name of Primary Researcher: Johanna Bruger

Name of Research Supervisors: Dr Catherine Ford and Dr Joanna Semlyen

I confirm that I will treat audio recordings and transcriptions of these recordings from 'The experience of working age adults living with chronic post-stroke pain' study as confidential. I agree that:

- I will not copy data (audio recordings and transcriptions of recordings) from 'The experience of working age adults living with chronic post-stroke pain' study.
- I will not share or discuss data (audio recordings and transcriptions of recordings) from 'The experience of working age adults living with chronic post-stroke pain' study with anyone outside of the research team involved, through any means.
- I will only access data through secure means (a personal UEA OneDrive folder) and only for the purposes of transcription.
- I will return all data to the Primary Researcher after the transcriptions are completed.

Veronica Bian
Name of Transcriber

N/A (UEA Employee)
Transcribing Organisation

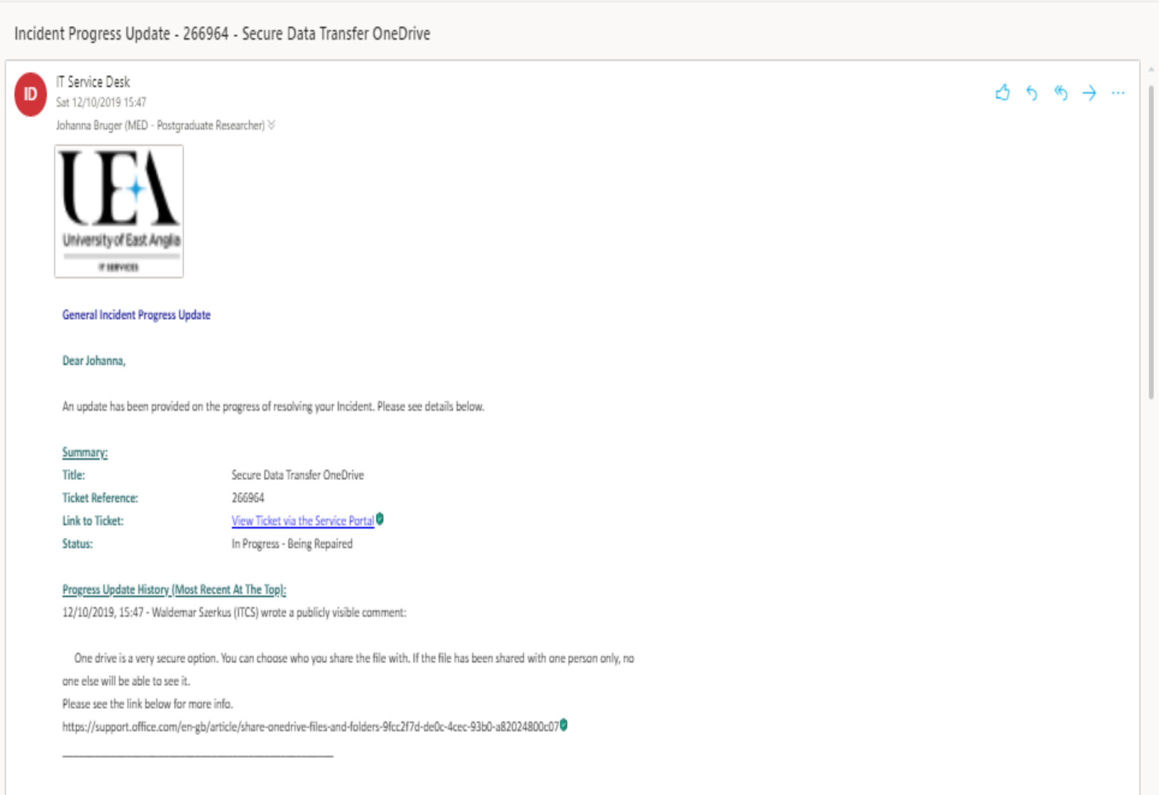
18/10/19
Date

VBian
Signature

Version 1 (29/06/2019)

Appendix O

Confirmation of Security of the UEA OneDrive System for Data Transfer



Incident Progress Update - 266964 - Secure Data Transfer OneDrive

IT Service Desk
Sat 12/10/2019 15:47
Johanna Bruger (MED - Postgraduate Researcher)

General Incident Progress Update

Dear Johanna,

An update has been provided on the progress of resolving your Incident. Please see details below.

Summary:

Title:	Secure Data Transfer OneDrive
Ticket Reference:	266964
Link to Ticket:	View Ticket via the Service Portal
Status:	In Progress - Being Repaired

Progress Update History (Most Recent At The Top):

12/10/2019, 15:47 - Waldemar Szerkus (ITCS) wrote a publicly visible comment:

One drive is a very secure option. You can choose who you share the file with. If the file has been shared with one person only, no one else will be able to see it.
Please see the link below for more info.
https://support.office.com/en-gb/article/share-onedrive-files-and-folders-9fcc2f7d-de0c-4cec-93b0-a82024800c07

Appendix P

Risk Management Plan

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

RISK MANAGEMENT PLAN

Home Visits / Lone Working

If participants are referred to the study by a gatekeeper, the gatekeepers will provide information on risks associated with a home visit at the time of referring a participant to the study.

The risk associated with home visits will be addressed through the researcher adhering to the lone worker policy of the University of East Anglia (UEA) and the Cambridge and Peterborough NHS Foundation Trust 'Working Alone in Safety' policy.

Research visits will be conducted within standard working hours (9am to 5pm). The researcher will make a call to one of their research supervisors prior to commencing the appointment, providing details of who they are with, where they are and when they are to be finished. The research supervisor will be called after the appointment to be informed of the researcher's safety. If for any reason this does not occur the research supervisor will call the researcher twice (10 minute interval) and will then escalate the situation to a member of the UEA Clinical Psychology Doctorate Programme executive team.

If during the appointment the researcher feels unsafe they will abort the interview and leave the participant's house. If this is not possible they will call the research supervisor using an agreed code ("Please cancel all of my appointments for the rest of the day") and answer "No" to the question "Are you safe?". The research supervisor will call 999 and inform a member of the UEA Clinical Psychology Doctorate Programme executive team.

Risk to Participants / Others

Prior to commencing interviews the researcher will explain clearly under what circumstances a breach in confidentiality may occur; for example, if there was a serious concern about the safety of the participant or others. If breaching confidentiality was warranted due to serious safety concerns, the individual's General Practitioner would be informed and asked to manage the situation. In the case of severe and immediate risk to the participant or another individual, emergency services would be contacted; guidance would be sought from the local safeguarding team as appropriate. The actions taken would be documented and the primary supervisor and research sponsor made aware of the incident as soon as possible. If possible the participant would be informed about the steps taken. The process of breaching confidentiality is explained in the 'Participant Information Sheet' and participants will be reminded verbally about this process prior to commencing the interview

Managing Distress during the Interview

The researcher will utilise her clinical skills to manage any distress participants may experience during the interview. Participants will be offered breaks and the option to end interviews early should they feel distressed during the interview. Interviews can be rescheduled. If necessary, participants will be signposted to services offering further support (e.g. GPs) or the researcher will make contact with supporting services on behalf of participants. Participants using harmful ways of coping (e.g. drugs and alcohol) will be provided with information of local supporting services. A 'Debrief Sheet' will be handed to participants at the end of the interview; it entails various contact details of support organisations.

Support Available for the Primary Researcher

The Primary Researcher has access to multiple forms of support to manage the demands of doctoral-level research (e.g. university advisor, supervisor, personal support tutor, year tutor and buddy systems) and will have regular research supervision meetings and keep a reflective journal throughout the study.

Appendix Q

Gatekeeper Information Sheet

University of East Anglia

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

GATEKEEPER INFORMATION SHEET

Dear Professionals,

RE: "*The experience of working age adults living with chronic post-stroke pain: An Interpretative Phenomenological Analysis.*"

Thank you for taking the time to consider whether this research is suitable for your service user. The aim of this study is to explore UK working age adults' experience of chronic post-stroke pain.

This guide aims at directing you through the process of identifying suitable participants. There is also a 'Participant Information Sheet', which provides detailed information about the study in an easy-read format.

Identifying potential participants:

Inclusion Criteria - Individuals can take part if they meet these criteria:

- Aged 18-64
- Confirmed diagnosis of stroke(s)
- Living in the UK and in the community
- Fluent in English
- Experience chronic post-stroke pain:
  - Pain resulting from stroke-related injury
  - Onset of pain at the time of the stroke or afterwards
  - The most common types of post-stroke pain are spasticity-related pain, musculoskeletal pain (subluxation and contractures), post-stroke headache and central post-stroke pain (neuropathic pain resulting from brain's inability to process 'normal' sensations (e.g. warmth, cold and touch))
  - Duration of the pain for more than three months

Exclusion Criteria – Individuals cannot take part if they meet these criteria:

- Significant difficulties with cognition (thinking skills) and/or communication that are likely to prevent engagement in the research even after reasonable adaptions have been made
- Significant mental health difficulties and/or substance misuse that are likely to prevent engagement in the research
- A chronic pain condition prior to stroke
- Family members, friends or professionals from health or social care have either expressed concerns about the person's capacity to make decisions such as whether

to take part in research, or there has been a recent assessment that has indicated that the person lacks capacity to consent to research

Information you may wish to share with potential participants

- This study is conducted by Johanna Bruger, a Trainee Clinical Psychologist at the University of East Anglia, under supervision of Dr Catherine Ford (Clinical Psychologist) and Dr Joanna Semlyen (Health Psychologist).
- The study aims to explore working age adults' experience of living with chronic post-stroke pain.
- If participants decide to take part in the study they will meet with me for an approximately 60-90 minute interview (either at their home or the recruitment service / organisation) that will be recorded. Interviews can be shorter and breaks can be included if necessary. The interview is flexible and allows people to decide what aspects of living with chronic post-stroke pain they would like to discuss.
- Participants can have someone they trust present at the interview; however, his person will not be able to participate in the interview.
- The study is not connected to participants' involvement with services / organisations and will not affect their care.
- Participation is voluntary. People can participate if they feel comfortable to do so and fit the inclusion criteria.
- The aim of this study is to raise awareness around the importance of considering post-stroke pain in the care and rehabilitation of young stroke survivors. Insights from the study might also help others who live with chronic post-stroke pain by making them aware that they are not alone in facing the condition.
- If you have a service user who may be eligible and interested in taking part, please give him / her the 'Participant Information Sheet', which provides detailed information about the study in an easy-read format. If he / she has any questions that are not covered by the information sheet and that you cannot answer, please assure them that these questions will be addressed when I contact them.
    - Please reassure potential participants that even if they have consented to be contacted (i.e. they have completed the 'Consent to Contact Form'), there is no obligation to continue with the study. Participants can withdraw at any time until one week after the interview was conducted without having to provide any reason. Participants can withdraw from this study by getting in touch with me by phone or email.

Next steps

- If you have a service user who would like to take part in this research, please complete the 'Consent to Contact Form' with him / her and inform me by phone. Please send me a copy of the 'Consent to Contact Form' by email. Please keep the 'Consent to Contact Form' safe within your service (e.g. patient file, electronic patient records), in line with local guidance of storage of personally identifiable information.
- Please inform the service user that I will be in contact with them shortly to discuss their participation in this study.

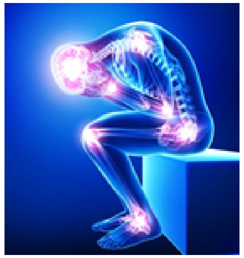
Thank you very much for taking the time to support this research project. If you have any questions please feel free to contact me.

Many thanks,
Johanna Bruger, Trainee Clinical Psychologist

Supervised by Dr Catherine Ford and Dr Joanna Semlyen

Appendix R

Study Poster



Do you experience long-term pain following a stroke?

A new research study aims to explore how working age adults (18 - 64) experience long-term pain following a stroke, by finding out about their experience of post-stroke pain, the impact it has on their life and identity, their experience of receiving treatment for it and their experience of managing the pain.

We hope to raise awareness of the importance of considering post-stroke pain in the care and rehabilitation of young stroke survivors. Insights from the study might also help others who live with long-term post-stroke pain by showing them they are not alone.

Taking part in the study involves an interview which is approximately 60-90 minutes long; shorter interviews are possible too and breaks can be taken.

We would like to invite you to take part in this study if you:

- Are aged 18-64
- Live in the UK and are not hospitalised or living in a care home
- Speak fluent English
- Have had pain for over 3 months, due to a stroke.

Unfortunately you are not able to participate if you experience:

- Severe thinking, memory or communication difficulties
- Severe mental health difficulties or substance misuse problems
- A long-term pain condition that was present before your stroke
- Difficulties that hinder you in making your own decision about taking part in this research

If you are interested in taking part, have more questions or are unsure if you fit the criteria, please get in contact by emailing j.bruger@uea.ac.uk or by calling 07926310961.

Appendix S

Decline Study Letter

Norwich Medical School,
Postgraduate Research Service,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
Email: j.bruger@uea.ac.uk
Tel.: 07926310961

Dear ___________________________,

RE: "*The experience of working age adults living with chronic post-stroke pain"*

Thank you very much for your interest in this research study. I am looking for stroke survivors of working age (18-64) who experience chronic post-stroke pain (>3 months) and who would like to talk about their experience of living with the pain.

The criteria for taking part or the large interest in this study mean that unfortunately you cannot take part. However, I very much appreciate your interest in this study and would therefore like to offer you a summary of the research findings, once the study has finished. If you would like me to send you a summary of the findings, please let me know, either by telephone or email.

Many thanks for your interest in this research.

Kind regards,

Johanna Bruger
Trainee Clinical Psychologist, University of East Anglia

Supervised by Dr Catherine Ford and Dr Joanna Semlyen

Appendix T

Demographic Questionnaire

Demographic Information

Demographic information will be used to understand the homogeneity of the sample and to provide context to the personal narratives of participants. Details of the participants' General Practitioner will be collected in order to enable contact in the case of risk / safeguarding concerns.

This form will be completed by the researcher through discussion with the participant.

Participant Number:	
Gender (F/M):	
Age:	
Ethnicity:	
Occupation (pre- & post-stroke): - Currently working (Y/N)	
Years of education: - Highest level	
Support network: - Family (e.g. married, children (age)) - Friends - Community - Living situation (e.g. alone)	
Current physical health (excluding stroke) (conditions & medications):	

Current mental health (conditions & medications):	
Nature of stroke: - Date of stroke & their age at the time - Type of stoke - Location of stroke - Type & length of treatment (acute & rehabilitation settings; currently in treatment) - Previous stroke(s) (date & type)	
Stroke-related impairments: - Memory - Language - Mobility - Falls - Etc.	

Nature of post-stroke pain: - Details of pain diagnosis (e.g. type, when & by whom) - Duration of pain (e.g. date of pain onset, months since pain onset) - Frequency of pain (e.g. persistent, intermitted) - Location of pain - Intensity of pain (scale 0-10) - Details of past pain treatments - Details of current pain treatment	
Contact details of General Practitioner (e.g. name, address and phone number of care service):	

Recruitment Site: ________________________

Appendix U

Example of the Analysis Process; Excerpt from Linda’s Transcript

Page / Line	Master Theme	Emergent Theme	Transcript	Initial Coding
1 / 1-26	“No one really understands” “No one really understands” “No one really understands” “No one really understands” “No one really understands” “Accepting the new self and life”	Pain as invisible Difficulty describing Not seen as stroke survivor Different type of stroke survivor Feeling alone Accepting of it	R: Okay, so Linda can you tell me about your experience of living with chronic post stroke pain? Linda: I *think* because it’s something other people can’t see it’s *really difficult*. I can say to someone I’ve got a pain in my face or a pain in my hand, people don’t see it it’s a hidden thing. I know some people it’s obvious with me it’s not. If I say to people I’ve had a stroke they all go ‘What a stroke, how, where?’. Um and I think it’s hard for me to associate perhaps with some other people who have had a stroke, because it *looks very different*. Um pain is something that I guess you just live with. Um as I said, if I don’t talk, I don’t move its fine.	*Shows reflection.* *Very difficult* to describe to others due to the pain’s invisible nature. Can’t show her suffering to others, can only describe it. Feeling different to other stroke survivors (feeling alone); post-stroke pain is a different kind of stroke impairments – it’s invisible. Not fitting the image of a stroke survivor – being younger and not physically impaired. Difficulty in connecting and feeling part of the stroke survivor community *Looks in the sense of not being visual.* Can’t complain, can’t treat, and can’t hope for recovery – “just live with” it. Is this a sign of pain acceptance? The pain holds her back in participating in ‘normal’ everyday life – it has the tendency to stop her from

	"Mourning the old self and life"	Everyday impairment	The minute I want to say something, *which people do all the time*, or pick up something I'm *totally aware* that the pain is there again. R: And you mentioned that for you it's like hidden… Linda: Yeah. R: How do you think that it is different to if it wouldn't be?	talking and moving. Feeling impaired, burdened and almost silenced by the pain. *Feeling of unfairness 'others can do it'.* *Highlights severity of pain.*
	"No one really understands"	Others lack empathy and understanding	Linda: I think people are just more considerate if they can see something and it's a constant reminder. So if I broke my arm	Implying that people are not considered to her pain, which is invisible. Others can forget about her pain / impairment / burden, as they are not reminded of it.
	"No one really understands"	Invisible impairment; Others don't understand	and had it in *plaster* and couldn't, I don't know, pick up something with my hand or eat properly it would be obvious why. And I think people, my	She does not want to remind people about her suffering but would like sympathy. Having a *visual reminder of suffering / impairment ("plaster")* would make her life easier. Feeling misunderstood by others – others don't understand why she behaves a certain way.
	"No one really understands"	Family unaware of pain effect	friend and family, obviously know about the stroke. And the effect it's something I	People close to her are aware of her stroke but might not consider the effect it had on her – as they won't see it and she does not want to continuously remind them about it.
	"I'm not going to tell you unless you're	Not burden others	don't make a point of and I *hope I don't nag*	Given that there is no visual reminder *("plaster")* for her post-stroke impairment she has to to let others know and keep reminding them (they

	going to help me” “No one really understands” “No one really understands” “No one really understands”	Others forget No visual sign of suffering Chronic nature Feeling alone	to them about. But because they can’t see it after a while you forget it’s there. I guess it’s not a visible… I haven’t got a *plaster* across my mouth that say’s ‘Take care when talking’ or on my hand to say ‘I might drop things’. I know it’s there and I *always know it’s there*, but it’s invisible. It’s an invisible disability.	will “forget”) but she worries that her behaviour is considered *nagging, which she sees as a negative quality*. There is a wish for others to be aware of her difficulties without her having to tell them / remind them. She suffers in silence – her pain is constant and forever *(chronic pain)* and she will have to carry it alone as others are unaware. Pain as disability, even if not visible for others.

Note: Linda is a pseudonym. Descriptive comments: Normal text; Linguistic comments: *Italic text*; Conceptual comments: Underlined text. This part of the analysis was conducted by hand on printouts of transcripts for each of the participants.

Appendix V

Example of the Analysis Process; Linda's Table of Themes

All Themes	**Line No.**	**Key Words / Exemplary quotes / Short summary**
Pain as invisible	3	Difficult to describe as other cannot see
Difficulty describing	4	Difficult to describe as other cannot see
Not seen as stroke survivor	6	Not fitting the image of a stroke survivor – being younger and not physically impaired
Different type of stroke survivor	7	Difficulty in associating with other stroke survivors who are more impaired
Feeling alone	7	Difficulty in connecting and feeling part of the stroke survivor community
Accepting of it	9	Just having to live with it but it is always there and she is aware
Everyday impairment	10	The pain holds her back in participating in 'normal' everyday life – it has the tendency to stop her from talking and moving.
Others lack empathy and understanding	16	Others are more considerate if they can see impairments
Invisible impairment; Others don't understand	17	She does not want to remind people about her suffering but would like sympathy
Family unaware of pain effect	19	People close to her are aware of her stroke but might not consider the effect it had on her
Not burden others	21	Don't make a point of it, don't nag
Others forget	22	As others cannot see impact it had on her they forget; she does not have a plaster or sign to notify others that she can't always talk or sometimes drops things
No visual sign of suffering	23	There are no visual signs to make others aware of her suffering and explain her behaviour to them
Chronic nature	25	The pain is constant and forever (chronic pain)
Feeling alone	25	She knows it's there but others do not
Constant reminder	31	As it is a hidden disability she has to keep reminding people of her stroke and the pain
Solitude of suffering	49	Don't want to burden others with her constant pain but she is always aware of it

Impaired activities of daily living	50, 63	She avoids using the oven, is slower in packing at the till and seeks practical support from others
Feeling disbelieved	56, 59	She feel like she need to explain herself and thinks others might see her stroke as an ‘excuse’
Downward counter-factual thinking	61	Being a survivor – feeling proud
Wanting awareness	77	Yellow lanyard to make people aware that she has a disability
Feeling disbelieved	80	If she asks for support she feels judged (due to others not being able to see her disability)
Others awareness	90	It would be great if others could identify her as having a disability as she would receive practical support without having to ask for it
Feeling disbelieved	104	Feeling judged by cashier: ‘why on earth should I’ slow down
Judgemental others	102, 103, 115	Not embarrassed about speaking up – why should she be embarrassed if she does not believe others are judgemental
Incomprehensibility of pain	114	Using stroke to explain disability rather than pain
Other’s lack understanding	118	If others are abrupt she thinks ‘try live in my shoes’
Other’s unaware	121	They see a normally functioning human being
Suffering in solitude	124	Even if she would open up to others about her difficulties she would still be the one living with it – What is the point?
Downward counterfactual thinking	128	I am not a stroke I am a survivor
Self as empathetic	132, 140	More tolerant after stroke
Social comparison	145, 149	Everyone has some problems as get older, different things for different people
Other’s judge	150, 153	She would be aware if others might have a problem and not judge them – implies others are not
Post-stroke self	156	Grown to be more empathetic
Impaired activity of daily functioning	160	Plan ahead and avoid things
Development of pain acceptance	164	Learn to live with it but have occasional low days
Downward counter-factual thinking	169	Self as survivor, had other difficult life experiences
Threat to self	171	Pain can define her but she won’t let it
Not burden others	172	She lives with it and nobody else has to hear it all the time
Remaining active	175	Don’t want it to stop her – just work through it

Self as determined	180	Stubborn
Threat to self	181	Don’t want to be defeated – find another way (adapt)
Having to adapt	182	Did water aerobics – did another way to do exercises
Remaining active	186	Don’t say cannot do something – still cooks
Overcoming challenges	189	Even if things go wrong it won’t stop her – dropped pizza
Emotional adjustment	190	Some days it is hard buts she comes out the other side
Grieving old self	198, 203	Feeling sad and having self-pity
Control appraisal	200	Nothing she can do to reduce it
Limited relief	201	Medication does not work
Constant awareness	204	Only unaware of pain when she sleep
Pain description	209	Not pain but discomfort
Downward counterfactual thinking	211, 212	Count blessings every day, it is minor in comparison with other things
Choosing new self	213	Don’t want to be woman who is sad and moans
Downward counterfactual thinking	217	Life is short
Regain control	220	She can control activities, not let pain rule over her
Impaired activities of everyday functioning	223	Get to a point where she needs to rest
Defining new self	224	Can’t be who she is because she is so much more
Self as positive	229	Was and has been positive person
Downward counterfactual thinking	231	Sometimes has to remind herself how lucky she is
Developing pain acceptance	233	Has to accept it as she cannot change it
Seeking alternative treatment	233	Explored acupuncture (self-initiative)
Seeking alternative treatment	241	CBD oil
Pain as vague concept	242	Difficulty distinguishing between pains
Medication	247	Amitriptyline best
Lack of treatment options	247	No one came up with anything else – just meds
Required self-management	251	Help not accessible have to find it yourself
GP as non-expert	253	Felt let down by GP
Poor care	258	Should be care but was not
Lack of care	262	Was not assessed in person, dealt with over phone
Difficulty describing pain	265	Hard to describe pain – individualised, subjective pain experience

Chronic nature	267-271	Wearing and constant cannot imagine life without it
Impact activities of daily living	272	Triggers are cleaning teeth and eating
Unpredictability	276	Don’t know triggers
Impact activity of daily living	279	Drink more – pee more
Poor care	286	No follow-up care
Loss	291	Had to stop working
Lack of care	293	Would have liked to have check-ups
Lack of care	298	Did not receive anything in terms of care
Required self-management	298	She had to find resources e.g. stroke association
Lack of care	303	Staff had nothing else to offer
Different type of stroke survivor	303	Joint a group of stroke survivors but did feel she connect as she is ‘too well’
Downward counterfactual thinking	311	It helps to feel more positive to see others who are more unwell - feeling lucky
Grieving old self	314	There are days she feels low
Need for adaption	320-330	Stopped eating pizza; use other hand as support
Constant awareness	330	Aware of possible triggers and anticipate problems in everyday life
Unusual sensation	335	Feel cold as more intense
Adapted living	336-342	Wear gloves & had new jacket - adaptions
Grieving old self	349-351	Aware of what could do before and cannot do now
Accept & adapt	351	Adaptions in life
Impact activities of daily living	366	Struggle to undo zip
Unusual sensations	368-372	Fingertip more sensitive
Varied pain intensity	383	Almost forgot pain but as day goes on becomes more intense
Acceptance	387	It is life and she finds her way
Defining new self	388	Survivor – it won’t define who she is
Grief	390	Feeling low
Remaining active	397	Never put off doing something but might have less joy
Uncontrollable	400-402	Cannot reduce pain
Continue living	405	Won’t spend life not eating and drinking
Control appraisal	407	Nothing she can do to make it go away
Difficulties accepting	409	Would take pills to make life more pleasant, try not to self-pity as does not

		help her
Emotional solitude	417	Feeling low and keeping to self
Not burden others	420	Nothing worse than inflicting pain on others
Impact activities of daily living	423	Manage energy, avoid doing something the next day if she feels she did too much the day before
Developing acceptance	431	Learn to adapt and accept, like she would if she had only one arm
Threat to self	432	Pain not going to beat her
Seeking peer support	433	Would like to talk to someone in a similar position
Lack of professional awareness	435	Seeking a medical professional who understands
Unusual sensation	437	Like an electric shock
Seeking expert advice	444	Would like to see a neurologist
GP as non-expert	445	GP does not understand her pain description
Feeling disbelieved	447-450	Like phantom limb, does not want people to think that her explanations are ‘rubbish’
Difficulties describing	451, 452	Can’t define it clearly, need to live in her body to feel it
Other’s disbelieve	451	Maybe she looks ‘too well’ for others to understand
Others’ lack of empathy	453	Need to be her to see how she struggles
Self as empathetic	457	Stroke made her more aware and understanding of others
Threat to self	459	Don’t want to be miserable, don’t want to be affected, don’t want it to be who she is
Other’s lack of understanding	463	Feels other’s don’t understand unless they experienced it
Different type of stroke survivor	474	Idea of a 80 90 year old in wheelchair, not a vision of a person who had a stroke
Others’ lack of understanding	477	Others cannot grasp
Pain description	479	Pain as permanent and invisible
Seeking empathy and understanding	486-189	Other can become aware of her suffering if spend time with her; her family is aware
Feeling understood not judged	495	Rather than saying ‘silly cow’, her friend helped her pick something up
Others’ awareness	498	Others need to have a general awareness of other people in order to be sympathetic

Others’ sympathy	507	Some are sympathetic others are not
Others’ judgement	510	What are you making a fuss about?
Self as empathetic	513-519	Post-stroke awareness of other’s needs makes her a better person
Grieving old self	522	Sad that she lost person she was
Accepting new self	524	Being a better, new person; can’t go back to old self so having to accept
Downward counterfactual thinking	527	Look at positive she is alive
Adapted engagement	530	Not stop her but do things differently, different pace etc.
Grieving old self	533	Think where she could be and where she is
Accepting new self	535	Don’t mourn old self as she is a better person now
Grieving old self	537	Feeling sad for where she is
Chronic nature	542	Pain is always there
Threat to self	543	If you let it, it will bring you down
Development of acceptance	543-546	Took time; need to push it in the background
Threat to self	546	Don’t want to be the woman with pain in her face
Wanting old self	554	Pain is 24/7 – would give a lot to be without it
Grieving old self	563	Missing life before, wanting to go back
Who is the old self	564	Can’t remember life without pain
Disbelieve	572	Initially was in disbelief
Different type of stroke survivor	578	Was on a ward with visually impaired stroke survivors – felt like a fraud
Impact of chronicity	584, 588	Knowing that it won’t go is upsetting; it is there and it is taff
Threat to self	591	Don’t want it to define her and stop her
Downward counterfactual thinking	593	Every day is precious, could be much worse
New self	600	It’s a different me
Threat to self	602	Don’t want it to be who she is, just part of her
Threat to self	604	Can’t be who you are unless you want it to overtake you
Subjective pain description	609-615	Cos you can’t – pain is pain, can’t score it – it’s chronic
Lack of sympathy and care	615-618	Feeling abandoned and nobody thinks it’s a big deal but it is
Acceptance	620	Nobody got promised a charmed life – need to make the best out of it
Subjective pain description	626-628	Don’t think can grade pain
Threat to self	628	Either accept it or let it take over

Seeking empathy	633-640	Wanting others to see her suffering
Others unaware	641-643	It is invisible and private; others don’t get it
Difficult to describe	641	Hard to share
Hidden disability	649	Need to observe her to know
Seeking others understanding	650-654	Others should know her suffering without her having to tell them
Seeking empathy	659	Other would have more empathy if they could see
Feeling judged	661	Don’t want to feel like she makes a fuss
Others lack empathy	666-669	Would be good if others could walk in her shoes
Pain acceptance	672	Living with the pain and not letting it determine who she is
Seeking empathy	675	Would like people to be more aware; if she were in a wheelchair others would have sympathy
Others lack awareness	682	People don’t get it and she does not want to complaint
Seeking empathy	692	She wants support and awareness of her suffering
GP as non-expert	699	Lack awareness, need to listen
Difficult to describe	700	Difficult to describe
Developing pain acceptance	701-707	At first feels more intense then goes into background
Seeking peer support	708-712	Wanting to talk to others with only pain
Different type of stroke survivor	712-716	Feel others are different
Control appraisal	718-725	Cannot do anything about the pain, its chronic, which is what others don’t understand
Grieving old self	727-730	Would be nice to have some remedy that makes it go away even if just temporarily
Seeking peer support	734-745	Wanting to find others who understand how she feels
Seeking peer support	747-755	She would not have to explain herself - receiving understanding and treatment ideas
Different type of stroke survivor	755	Others more visibility disabled
Seeking peer support	757-761	Wanting to be united with others and share her experience

Note: Linda is a pseudonym. Table of themes were created for each of the participants.

Appendix W

Example of the Analysis Process; Superordinate Themes derived from Linda's Interview

1. **Making sense of the pain experience**
    a. Pain descriptions *(unusual sensations, difficulties in describing, chronicity)*
2. **Lack of care**
    a. GP as non-expert
    b. Lack of treatment options
    c. Required self-management
3. **Suffering in solitude**
    a. Others lack of empathy *(awareness, understanding, hidden disability, forgetting, judgement)*
    b. Not sharing *(wanting to forget, wanting to not burden others, difficulties explaining)*
    c. Lack of peer support *(different type of stroke survivor)*
4. **Development of pain acceptance**
    a. Negative control appraisal *(chronicity and lack of treatment)*
    b. Downward counterfactual thinking *(being lucky, others are worse off)*
    c. Mourning 'old' self *(feeling low on occasion, remembering what was and what could have been)*
    d. Developing a 'new' self *(post-stroke growth, part of her, having to adapt, regaining control/not being stopped, under threat of pain taking over)*

Note: Linda is a pseudonym. Superordinate themes were noted for each of the participants prior to comparing across participants.

Appendix X

Example of the Analysis Process; Example Extract of Master Theme Table

Solitude of pain experience			
Subordinate Themes	Line No.	Participant	
"No one really understands"	11-17	Jack	"..once been told, I managed to tell a train ticket man that um I've got a brain injury. Cos it was easier to say that than to say I had a stroke or any of that sort of stuff, cos no one really understands. But then I realised that a lot of people don't even understand brain injury. In fact his replace, his reply was um 'If I had a pound for every time someone said they had a brain injury I'd be a millionaire'".
	545-551		"…cos it doesn't make any sense. 'So you've got a headache?'… Not really… this I…'You're just tired, then just go to sleep' and no it's more to it than that. Having to explain what my brain does, so I don't anymore. There's no point um because my brother and my sister and my wife will just think 'Do you know what, just give it, give it a week, a couple of weeks, he's getting better. Sometimes I see him getting better '. That's what they'll say."
	714-726		Researcher: "…what would happen if you were saying 'have a brain injury'…? " Jack: "Understanding I suppose. There's a… I read a book where um James Cracknell was talking about it and he said he struggled, really really struggled with even his family and his wife. Um because when you say the words about brain injury what they expect is you to be dribbling wheelchair, cos that would be easier you know. And they'd probably dab the … you know … dab your eye and bath you and all that, but when you're walking around and you can talk and you can do this and you have a brain injury that lets you down quite often. Um it's, it then it's not an excuse for my wife. She won't accept, you know… 'you were good yesterday', well today cos you're brain injury that we should just accept that um well no you shouldn't expect anything."
	264-268	Peter	"I carry my stick. One of the reasons is obviously so I don't fall over, but also it's an indicator. It lets people know I have a hidden disability, cos that's what it is you see. And if you've got a stick they tend to realise."
	703-713		"I get increasingly annoyed when I go to uh Sainsbury's, there's a disabled spot and I got too put it in there and there's some taxi driver decided to pull in there. I don't say what's wrong with me I just say I'm disabled, because it's none of their damn business, you see. I'm not a moaner I get on with life. And I get frustrated when people who have got hardly anything wrong with them… um anybody would think it was the end of the world. I

			know somebody who lost a leg, ok, from there um after a police dog bit him when he was committing a crime. He’s in a wheelchair, he can walk, he can have a false leg, but no he’s in a wheelchair and that annoys me. I would love to work I can’t.”
	3-7	Linda	“I think because it’s something other people can’t see it’s really difficult. I can say to someone ‘I’ve got a pain in my face or a pain in my hand’, people don’t see it. It’s a hidden thing. I know some people it’s obvious, with me it’s not. If I say to people ‘I’ve had a stroke’ they all go ‘What a stroke, how, where?”
	16-26		“I think people are just more considerate if they can see something and it’s a constant reminder. So if I broke my arm and had it in plaster and couldn’t, I don’t know, pick up something with my hand or eat properly it would be obvious why. And I think people, my friend and family, obviously know about the stroke and the effect it’s something I don’t make a point of and I hope I don’t nag to them about. But because they can’t see it after a while you forget it’s there. I guess it’s not a visible… I haven’t got a plaster across my mouth that say’s ‘Take care when talking’ or on my hand I say I might drop things. I know it’s there and I always know it’s there but it’s invisible. It’s an invisible disability.”
	118-121		“I mean if people are polite, no I mean if somebody’s a bit sort of curt and abrupt and I think to myself try living a day in my shoes, you know. What you see on the outside… that’s the bit that is harsh, because you see a normal functioning human being.”
	445-454		“My GP does… the woman I saw, I don’t think she understands when I say about the pain. And again because it’s not visible … you know. People talk about when they have a leg or arm amputated that they have this phantom pain where their leg isn’t and I guess unless you've had that you think that’s rubbish. And because you can’t see this and I can’t define it any clearer um perhaps, perhaps I look too well if that makes sense.Uh because uh you have to live in someone’s body to feel it, it’s difficult. I don’t know how else to … you see, I’m back to my water.”
	463-465		“I don't think people have got any idea at all (laughs). Seriously, I don’t. Um perhaps if you’re in the medical profession you do, I don’t know. I don’t think unless you’ve been there you have any idea.”
	472-480		“Peoples reaction is ‘You what, when, how? You’ve had a stroke?’. You know you have this idea of 80 / 90 year old person um in a wheelchair, who can’t take can’t use their whatever. That’s the vision of it and I’m not, I don’t

			think I'm a vision of a person who's had a stroke. And so perhaps to other people it's hard for them to sort of grasp. If you're sitting in a wheelchair, if you can't talk or walk, you can actually see that… This pain is just permanent and invisible. It's the same words I know I keep saying, but that's what it feels like."
	633-644		"I do wish in some ways that other people could see it, you know. If you like draw a picture of somebody. You colour one side red um or whatever black… cos that's what… you can't do that to yourself. Um walk a day in my shoes, good quote, then you'd know. Even you as a researcher um have no idea and thank god you don't. I'm not wishing it on anybody. But I don't want sympathy, I don't want people to apologise for things or anything else, but it would be nice if they sometimes could feel more what I feel. Um and as I said it's not wishing that on them but just… it's very invisible, it's very private, it's hard to share because people don't always get it and that's not just medical people, just people, both medical and otherwise, that don't get it."
	675-678		"... and I'd like people to perhaps be more aware. But it's hard, because you can't see. As I said if I was in a wheelchair people would be a lot more sympathetic. Um if I had my arm in a plaster people would say can I help you."
	81-85	Kiara	"… because um I know I had a stroke. So let's think, cos most people had a stroke got… most got a stick or anything but I haven't got anything. So because of that people don't know that my two foot, no hand is um … Nobody knows cos I've got no sticker or anything, yes. But um people know most people know that I have pain yes that I had the pain."
	155-158		R: "Yes so you had hope after the stroke that the pain would go; is that what you were saying?" Kiara: "Well maybe that's what… at church they always say… I said mine is chronic pain, so they pray but it doesn't work."
	150-151	Judith	"Well I think that I haven't discussed in much in depth because I think people don't know what you're talking about."
	173-178		"Well I've told my husband that I had it because I'd say to him … he is a doctor so I thought he would understand what I was talking about. And I said 'I've got this really weird sensation in my arm and leg like pins and needles but it feels like a scolding sensation'. He just says 'Have you had it before?'. 'Yes'. 'Well, it's probably no different from what you had before. Does it go away?'. 'Yes'. 'Ok then no work exploration'."

	504-510		Judith: “Um I think that not all, not all post stroke abnormalities are visible and just cos it’s there a long time it doesn’t mean it’s gone. It isn’t easy to stop talking about it.” Researcher “Mm.” Judith: “But it might still be there, so you know other people should still be aware that there might be something there that’s bugging other bugging somebody.”
	438-451 287-297 696-700	Harry	Researcher: “What do you think generally people’s ideas are around chronic post stroke pain … what that means? Harry: “Well, I don’t think they know.” Researcher: “You don’t think they know?” Harry: “No, they haven’t got a clue. I didn’t know.” Researcher: “Mm.” Harry: “No one… the physios didn’t know.” Researcher: “What was their reaction then?” Harry: “Well they didn’t associate it with the stroke. It wasn’t it. As just when I spoke to them about the leg it was just ‘Oh you’ve…’, it was almost as if, ‘Well you’ve got a pain’.” Researcher: “Mm.” Harry: “So it was me saying to them do you think it’s the stroke? Do you think it’s that? And them saying ‘I don’t know’.” “I’m like always moving, so that I don’t stop moving, because when I stop moving then I get pain. It’s like when I’m lying in bed and I wake up in the morning, cos I haven’t been… and my partner say like ‘Well maybe you should move round more’. I say ‘I’ve got to relax. I can’t spend my whole night moving around’. It’s like give me a chance, you know, at some point I’ve got to be able to relax. And it’s like she says… oh I’m not blaming her… but she says …it sounds like I am but… ‘You know, maybe it’s because you sit in that chair too long so…?’. I’ve only been in there like 10 minutes, you know. It’s like I’m allowed to sit down for ten minutes or have I got to keep constantly wandering the house.” “ […] it will actually make someone go ‘Oh we need to look into that because it happens. It’s a proper thing. It’s not just someone going ‘My back hurts’, you know, it’s quite a few people with the same condition saying ‘Actually this hurts, you know, and it didn’t hurt before so…’.”
	226-259	Tiwa	Researcher: “Okay, okay what do you think would happen if you do tell other people?” Tiwa: “Oh god (laughs).”

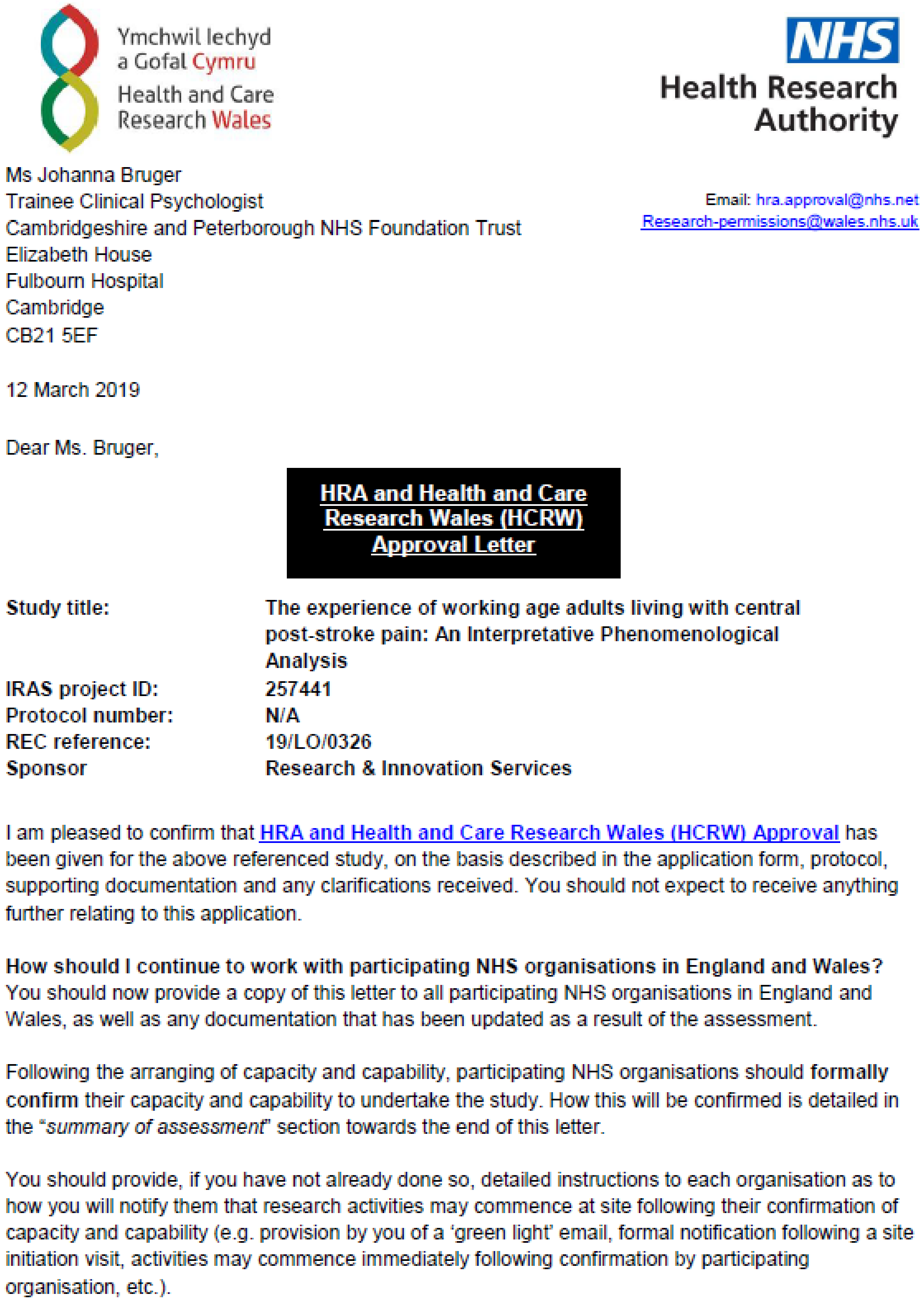
			Researcher: “What do you think would happen? Do you think others would understand your pain?” Tiwa: “No.” Researcher: “You feel they don't understand?” Tiwa: “No.” Researcher: “What do you think they don't understand about it?” Tiwa: “Um um Jessica, daughter, yes um understands.” Researcher: “She understands?” Tiwa: “Yes tt slower slower not good.” Researcher: “Say that again.” Tiwa: (laughs) “Jessica um slower understands ddd ddd, yes.” Researcher: “So she understands but then over time…” Tiwa: “Yes.” Researcher: “She understands more or less?” Tiwa: “No.” Researcher: “She does not understand?” Tiwa: “Yes.” Researcher: “Okay so let me just check… is that that she understands a little bit ‘I understand mum, you can't do that, I do that’ but then eventually is like ‘You still need to do it’?” Tiwa: “Yes.” Researcher: “So she doesn't have that patience that over time it won't get better?” Tiwa: “Yes.” Researcher: “Okay, okay. How is that for you?” Tiwa: “Angry.” Researcher: “You feel angry?” Tiwa: “Yes, yes.” Researcher: “Yes and is she the only person you try to tell how the pain impacts you?” Tiwa: “Yes.”
	428-435		Researcher: “[…] do you think the fact that you now have a lot of pain on your right side impacts any of the relationships you have, with your friends, your daughter or your mum?” Does that impact the relationships at all?”

			Tiwa: “Yes um um Jessica um understands difficult um um daugh um mum understand little bit (laughs), yes.” Researcher: “So it is difficult for them to understand.” Tiwa: “Yes.”
	123-125 333-336	Brian	“No, I haven’t really talked to anybody, um other than healthcare professionals, because I just assumed that they wouldn’t have enough knowledge to comprehend what I was trying to say.” “I haven’t even spoken to her [wife] about this, in any detail. This would be um… because I just feel in my heart that it’s a waste of time and it will be detrimental to talk about it because of her lack of knowledge.”

Note: Participants’ names are pseudonyms.

Appendix Y

Health Research Authority Ethics and Clinical Governance Approval Letter for the Study ‘The Experience of Working Age Adults Living with Central Post-Stroke Pain: An Interpretative Phenomenological Analysis’



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

Ms Johanna Bruger
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
Elizabeth House
Fulbourn Hospital
Cambridge
CB21 5EF

12 March 2019

Dear Ms. Bruger,

HRA and Health and Care Research Wales (HCRW) Approval Letter

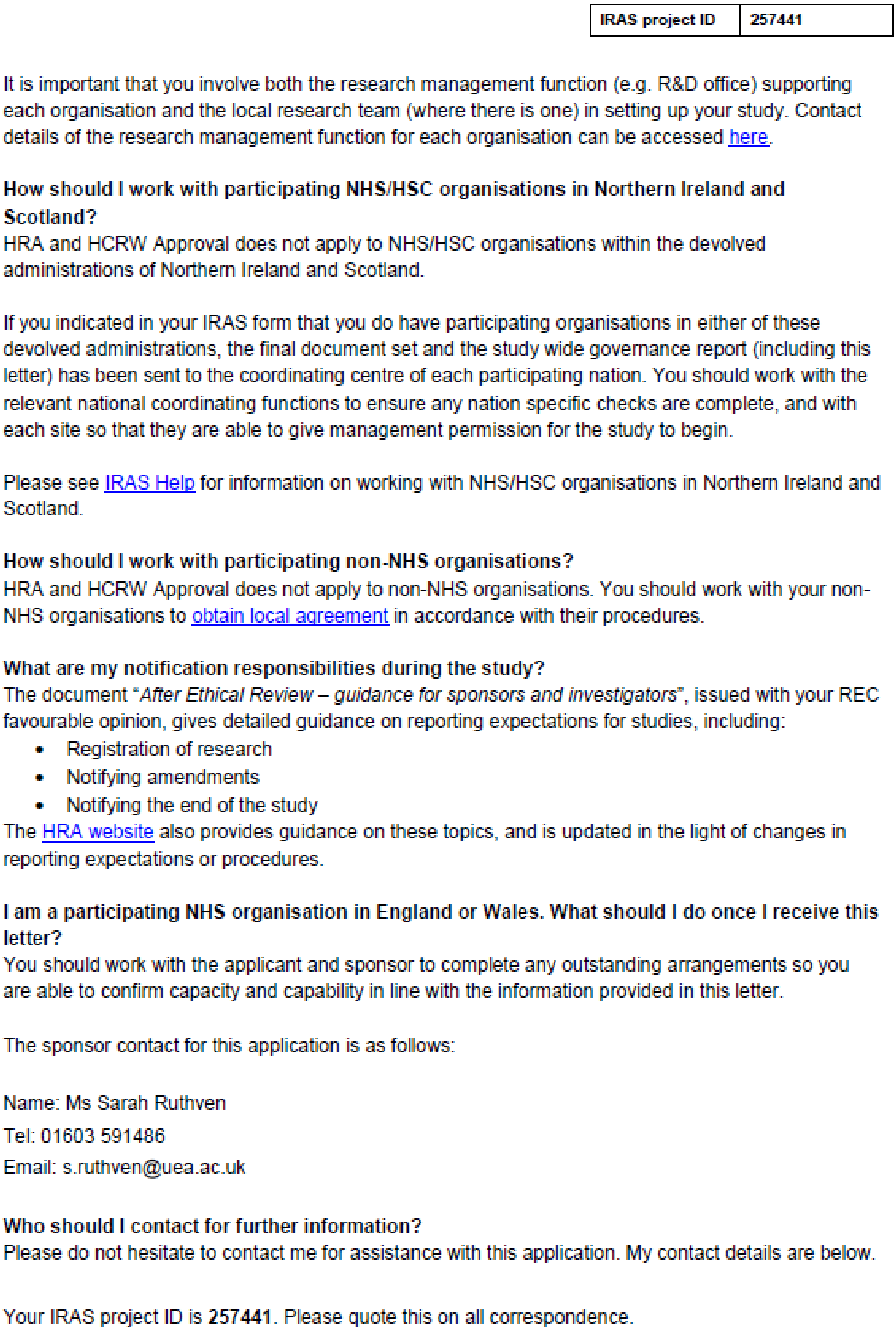
Study title:	**The experience of working age adults living with central post-stroke pain: An Interpretative Phenomenological Analysis**
IRAS project ID:	**257441**
Protocol number:	**N/A**
REC reference:	**19/LO/0326**
Sponsor	**Research & Innovation Services**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the “*summary of assessment*” section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a ‘green light’ email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).



IRAS project ID	**257441**

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

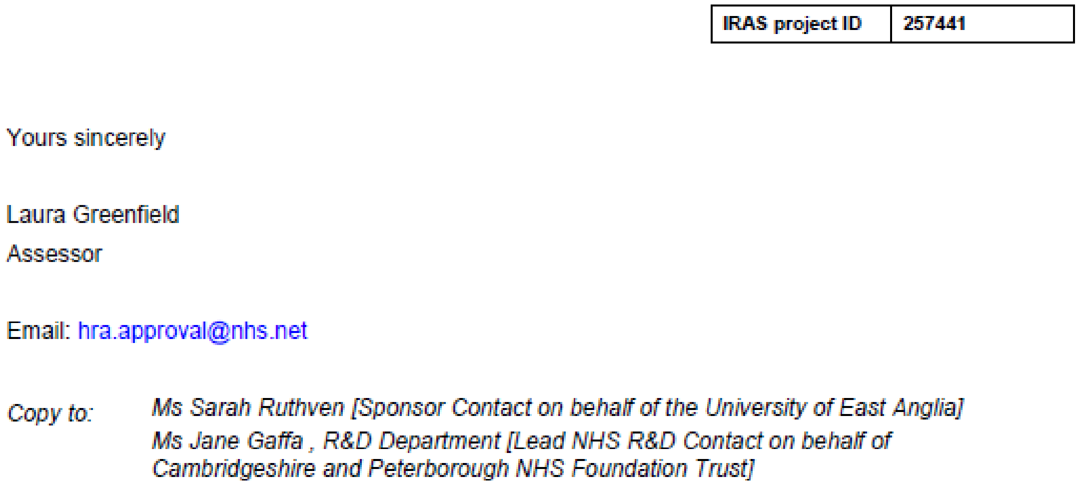
I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Sarah Ruthven
Tel: 01603 591486
Email: s.ruthven@uea.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **257441**. Please quote this on all correspondence.



IRAS project ID	**257441**

Yours sincerely

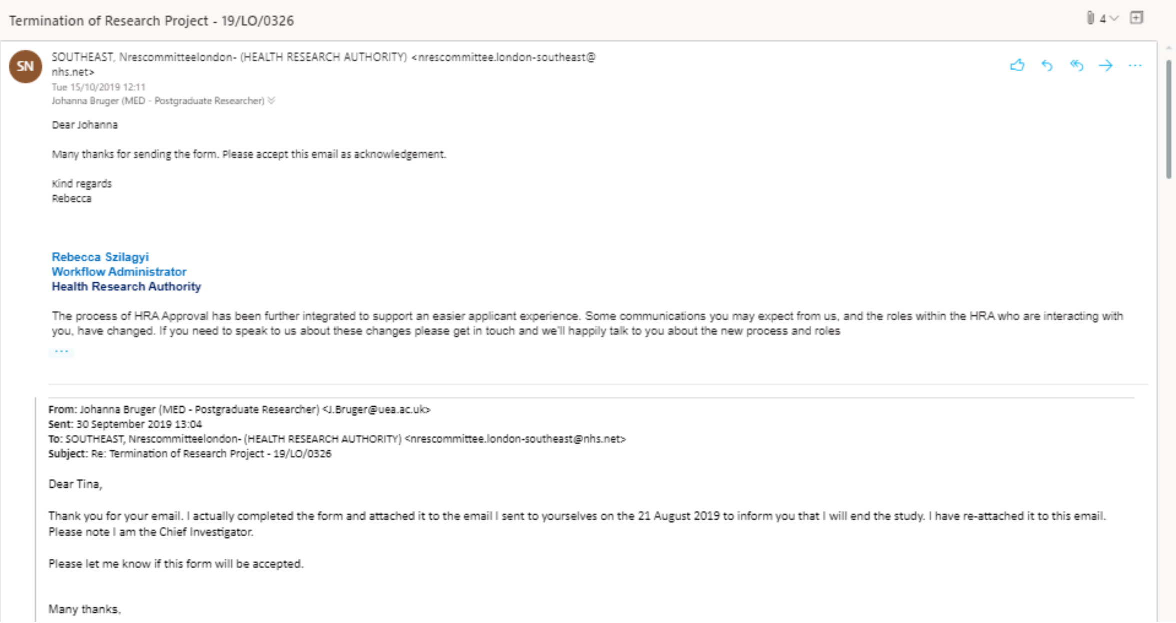
Laura Greenfield
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Sarah Ruthven [Sponsor Contact on behalf of the University of East Anglia]*
Ms Jane Gaffa , R&D Department [Lead NHS R&D Contact on behalf of Cambridgeshire and Peterborough NHS Foundation Trust]

Appendix Z

Confirmation of Termination for the Study ‘The Experience of Working Age Adults Living with Central Post-Stroke Pain: An Interpretative Phenomenological Analysis’



Termination of Research Project - 19/LO/0326

SOUTHEAST, Nrescommitteelondon- (HEALTH RESEARCH AUTHORITY) <nrescommittee.london-southeast@nhs.net>
Tue 15/10/2019 12:11
Johanna Bruger (MED - Postgraduate Researcher)

Dear Johanna

Many thanks for sending the form. Please accept this email as acknowledgement.

Kind regards
Rebecca

Rebecca Szilagyi
Workflow Administrator
Health Research Authority

The process of HRA Approval has been further integrated to support an easier applicant experience. Some communications you may expect from us, and the roles within the HRA who are interacting with you, have changed. If you need to speak to us about these changes please get in touch and we'll happily talk to you about the new process and roles

...

From: Johanna Bruger (MED - Postgraduate Researcher) <J.Bruger@uea.ac.uk>
Sent: 30 September 2019 13:04
To: SOUTHEAST, Nrescommitteelondon- (HEALTH RESEARCH AUTHORITY) <nrescommittee.london-southeast@nhs.net>
Subject: Re: Termination of Research Project - 19/LO/0326

Dear Tina,

Thank you for your email. I actually completed the form and attached it to the email I sent to yourselves on the 21 August 2019 to inform you that I will end the study. I have re-attached it to this email. Please note I am the Chief Investigator.

Please let me know if this form will be accepted.

Many thanks,