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# “I will try anything” the experience of working age stroke survivors 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 (46–64 years) UK-based stroke survivors who experience chronic post-stroke pain (≥3 months). The interviews were analysed using interpretative phenomenological analysis.

**Results:** The analysis led to three Group Experiential Themes: “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.

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## KEYWORDS

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

## > IMPLICATIONS FOR REHABILITATION



- Post-stroke pain is an invisible disability, difficult to describe to others and therefore often overlooked and misunderstood by others.
- Differential pain diagnoses should be given to patients with clear explanations of the underlying mechanism, characteristics and prognosis.
- 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.
- Healthcare professionals, particularly in primary healthcare services would benefit from training on post-stroke pain.

## Introduction

Post-stroke pain has been described as an underreported, under-recognised, and undertreated consequence of stroke, which is complex and multifaceted in nature [1]. Reported prevalence varies considerably, from 19 to 74% [2]. Differences in criteria and methodologies [3] as well as variations in post-stroke pain variables (e.g., time of onset, pain location) may account for this variation. Some evidence suggests a greater prevalence of post-stroke pain in younger stroke survivors [3]. Post-stroke pain can arise from stroke-related tissue damage (nociceptive pain) or nerve damage in the central or peripheral nervous system (neuropathic pain) [4]. It is regarded as chronic when lasting or reoccurring for three months or more [5]. Various post-stroke pain subtypes exist; the most common being hemiplegic shoulder/arm pain, musculoskeletal pain, headache, and central post-stroke pain (CPSP) [3,4]. Commonly stroke survivors experience more than one pain subtype [4].

Post-stroke pain affects daily functioning and wellbeing. It is associated with reduced activities of daily living and quality of life [3,6], relationship difficulties [3], loneliness [7], fatigue [6,8], depression [3,6] and suicidality [9]. It can also negatively influence rehabilitation, leading to delayed or limited recovery [10,11]. 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. Compared to adults with chronic pain aged over 60, younger adults with chronic pain have been found to experience a lower quality of life, less satisfaction with their economic and social situation and more mood difficulties [12].

Variations in clinical presentation, severity, and duration of post-stroke pain [13] can hinder accurate and timely diagnosis. In particular, variations in pain onset, which can be at the time of stroke or months later [14], can create a barrier to diagnosis. Individuals experiencing delayed pain onset may no longer be

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under the care of specialist stroke services when pain develops. Further diagnostic barriers are stroke-related cognitive or language difficulties [15], limited knowledge of post-stroke pain in healthcare professionals [10] and lack of specific post-stroke pain measures [16]. Pain descriptors underlying pain measures are reported unreliable [17] in the classification of post-stroke pain [18].

Post-stroke pain care has been described as lacking accessibility, expertise, and continuity [19]. Participants in Scandinavian post-stroke pain studies described feeling unacknowledged, misunderstood, and side-lined by healthcare professionals [19,20]. Additionally, current treatment options for post-stroke pain are limited and not always effective [21]. There is an overreliance on pharmacological treatments [18], which for certain cases and pain subtypes (e.g., CPSP) show limited effectiveness [22]. Alternative treatment options (e.g., acupuncture and massages) tend to lack an evidence-base for chronic pain following stroke [14]. In the face of limited effective treatment options, individuals engage in problem-focused (e.g., seeking alternative treatment and planning activities) and emotion-focused coping (e.g., distraction, making downward counterfactual comparisons and acceptance) [23–25].

The complexity of chronic post-stroke pain, its debilitating nature and the difficulties in its identification and treatment warrant further research. Current knowledge, mainly from quantitative research, has focused on defining clinical characteristics, describing pathophysiology, and quantifying consequences and treatment outcomes. Though useful, the range of possible findings is limited by the predetermined nature of the variables measured and the broader narratives of people suffering persistent post-stroke pain are barely captured by research. Furthermore, given the prevalence of post-stroke pain in younger adults [3] and their unique stroke [26] and pain experience [12,27], research on the experience of younger adults with chronic post-stroke pain would be beneficial. 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?”

## Methods

### Design

#### *Theoretical framework*

A qualitative idiographic approach was chosen, which aimed to generate 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’ lived experience of major life events [28,29] and is particularly useful in research on healthcare [28] and pain [30]. IPA adopts the epistemological stance of the researcher [31], which was critical realism in this research. Critical realism holds that there are phenomena that exist that can be studied but that the interpretation can only be partial [32]. It suggests that the existence of a social world independent of the subjective experience of the individuals, is only made accessible through interpretation and in this case, through the lens of the participants and researchers.

#### *Research team*

The lead researcher, who conducted recruitment, and collected and analysed the data was a female Clinical Psychology Trainee with work experience in various mental and physical healthcare settings. She had experience in conducting clinical interviews and quantitative research and had training in and supervision for

conducting qualitative research. This study was her first experience of conducting qualitative research. She held no clinical or personal experience of stroke but had a special interest in neuropsychology. The research team consisted of a female Clinical Neuropsychologist (C. F.) with experience in stroke psychology and a female Academic Health Psychologist (J. S.) who had researched individuals’ experience of various health conditions including neurological conditions.

#### *Study design*

Semi-structured, audio-recorded interviews following an open and flexible interview schedule (Appendix) were conducted in October 2019 with a small, purposive sample and analysed using IPA. All participant-facing study materials, as well as the interview schedule, were reviewed by a Patient and Public Involvement (PPI) volunteer, who acquired a brain injury (ABI) in adulthood. No pilot interviews were conducted, as in order to capture each participants’ idiographic account, participants were encouraged to guide and structure the interview.

#### *Ethics*

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, Approval reference: 2018/19 – 148). Local organisational approvals were sought. Health and Care Professions Council [33], British Psychology Society [34] and the UEA codes of conduct were followed [35].

#### *Participants*

Participants were UK-based, community-dwelling, English-speaking, working age adults, who experienced stroke-related pain for three months or more. Individuals would have been excluded from the study if they were aged under 18 or 65 years or above, 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 the support of three voluntary sector organisations, who were emailed regarding the research. One organisation invited the lead researcher to attend meetings of local support groups to introduce the study to potential participants. Social media advertisements were also utilised for recruitment. Participants made aware of the research through advertisements contacted the researcher directly. Participants recruited through participating organisations gave written consent to be contacted by the researcher.

The researcher was in contact with eight stroke survivors; all were found to meet eligibility criteria, and all agreed to participate. The majority requested to be interviewed at home ( $n=6$ ) rather than their recruitment organisation ( $n=2$ ). Interview duration ranged from 44 to 72 minutes, with an average of 55 minutes. Four participants were female and four male, aged between 46 and 64, (mean age = 56.5 years). They were between one- and twenty-one-years post stroke, with an average of 7.1 years. None reported having received a differential post-stroke diagnosis, but their pain descriptions were consistent with musculoskeletal pain, shoulder pain, CPSP and headache. Three participants reported two forms of post-stroke pain. Seven received pharmacological treatment for their pain; four sought private treatment options, such as physiotherapy, instructed exercise and Cannabidiol (CBD) oil. Participants were assigned pseudonyms. A summary of participant characteristics is presented in Table 1.

### Data collection

Participants were interviewed by the lead researcher in person. 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 [29].

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 they found difficult to express. Interviews were audio-recorded. At the end of each interview, participants were provided with a debriefing form containing summary details of the study, contact details of the lead researcher (J. B.) and support systems (e.g., GP, stroke-related voluntary organisations) to contact if issues related to the study arose.

### Data analysis

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

Data were analysed following Smith et al.'s [29] 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 on the first interview then guided conceptualisation of Personal Experiential Themes, grounded in details of the participant's narrative. Subsequent interviews were examined against those previously analysed, thereby analysing frequency, convergence, and divergence of themes. Themes with conceptual similarities were grouped together, theme names re-considered, and themes with weak evidence or which did not fit the emerging structure were dropped and newly discovered themes were compared against previously analysed interviews. Master and Subordinate Group Experiential 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 [29] framework for IPA and considering Yardley's [36] 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 [31,37]. 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 Personal and Group Experiential Themes.

Table 1. 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 pain syndrome	Current pain treatment	Interview location
Jack	46	White British	School; Medically retired	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	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	Family; Friends; Online support group	None	2017	Word finding; Balance; Somatosensory (Pain)	CPSP	Medication	Home
Kiara	56	Black British	Not disclosed; Medically retired	Family; Support group; Church	Epilepsy; Depression	1998	Aphasia; Memory; Pain	Musculo-skeletal pain & Headache	Medication	Charity Centre
Judith	63	White British	University; Medically retired	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	Family; Friends	None	2018	Motor functioning; Balance; Processing speed; Emotion-regulation; Pain	Shoulder pain; CPSP	Medication	Home

**Table 2.** Summary of group experiential themes and group-level sub-themes.

Group experiential themes	Group-level sub-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

To facilitate assessment of reliability and validity of the research, Group Experiential Themes are presented together with participants' comments, and discussed in relation to the wider literature on stroke and chronic pain.

## Results

Three Group Experiential Themes, present for all participants, were derived, illuminating the experience of working age adults living with chronic post-stroke pain (Table 2).

### *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 group-level sub-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 was 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. She felt her lack of visible impairment and younger age, meant she was not perceived as a stroke survivor and did 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 cause emotional upset. This is highlighted in a comment by Harry, in which he described occasionally feeling frustrated with his partner as he felt 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 voiced his frustration with his pain-related inability to relax and his partner's difficulty empathising with it. All participants reported that even people close to them had difficulties understanding their suffering. They reported that even if they received understanding, support and empathy from people close to them initially, this subsided over time, as others forgot about their pain, due to lack of visual reminders, or assumed participants would get better over time.

#### *"I'm not going to tell you unless you're going to help me"*

This group-level sub-theme summarises the process of weighing up the usefulness of sharing the pain experience with others. It was described by all but one participant. A common reason for not sharing the pain experience was that participants felt others would not relate to their accounts. 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].

Participants also described that even if they told others about their pain in the beginning, when they first noticed it, they became less likely to do so as time passed. They felt that given the chronicity of their pain, continuous sharing of their experience and associated feelings could be considered nagging or moaning and without additional benefits as highlighted 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].

Other reasons for not sharing the pain experience were, not wanting to pay attention to the pain and be reminded of it, or the stroke. For some, talking about pain increased their pain sensation; others wanted to experience times the pain was not the centre of their lives, or when they were not reminded of the traumatic experience of the stroke itself.

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

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].

### *Unsatisfactory healthcare and the need for self-care*

All participants reported negative experiences with 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). Participants felt misunderstood and alone in their pain experience.

*“I don't think I received care”*

This group-level sub-theme summarises participants' experience of not receiving adequate care for their post-stroke pain by the healthcare service, as shown 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 perceived specialist hospital acute care and rehabilitation as helpful but felt disappointed with primary care; a view shared by other participants. She hoped for a proactive, nurturing approach in which she was followed-up and assessed. Her comment also suggests that describing the pain experience to healthcare professionals is difficult; a view also voiced by Judith:

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

Judith highlighted that her pain experience does not fit standard categories of pain, which she felt prevents healthcare professionals 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 she felt her post-stroke pain description did not fit existing pain categories, causing her to miss out on treatment. Her pain appears to be CPSP, which tends to be particularly unusual in its presentation and experience. None of the participants had received a differential post-stroke pain diagnosis. Some 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.

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 voiced his frustration over healthcare professionals not being able to give him clarity and insight with regards to the pain he feels. His comment implies he felt his care was not evidence-based but based on guesswork. Peter also voiced that his treatment has been based on trial and error:

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 highlighted the difficulties experienced in treating post-stroke pain, particularly when multiple types of pain occur simultaneously. This quotation also suggests an overemphasis on pharmacotherapy in the treatment of chronic post-stroke pain. Except for one participant who decided against pain medication due to it “masking” rather than solving pain, all participants took regular pain medication and voiced dissatisfaction with it being

the only treatment offered. Pain medications were described as ineffective, having negative side effects and risking addiction.

*“I'm not really a doctor but I presume it's something ...”*

This group-level sub-theme highlights that participants were spending time and effort developing their own theories of the causes, triggers, underlying mechanisms, and consequences of their pain. These illness beliefs, regardless of accuracy, affected participant's emotions and behaviours, as highlighted by a comment by Peter, for whom the belief that pain signified another stroke, appeared to cause anxiety, whereas the belief that it was a consequence of stress, did not:

[...] 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].

In contrast to most participants Judith, a retired doctor, reported not being overly worried 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 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 pain was a sign of stroke recovery or stroke disability:

[...] 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. Holding the belief that pain is a sign of recovery could support mood and rehabilitation but could also delay help seeking. Judith's statement also implies her beliefs might change over time (“I keep watching”); something found for most participants.

*“It's like self-management - I just do what I can myself”*

This group-level sub-theme highlights that given participants' perception of primary care services as detached and reactive, they felt a need 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:

[...] 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 described trying various methods to cure or reduce pain but implied that none were 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) and finding them ineffective. His statement, “I will try anything,” highlights how desperate he felt to find something other than pharmacotherapy, the only treatment offered to him, which he felt masked rather than solved his pain.

Most participants reported wishing they could learn from the experience of other stroke survivors living with chronic post-stroke pain and share their experience of different treatment approaches with others:

Oh, I'd want to talk to them [other individuals with post-stroke pain]. [...] 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].

### ***The development of pain acceptance***

This Group Experiential 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. 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 group-level sub-theme summarises the loss all participants experienced with regards to their way of life before experiencing chronic post-stroke pain. Participants reported everyday struggles that occasionally lead to sadness, frustration, and anger as they were reminded of their life without the pain. They reported having difficulties cooking, sleeping, and sitting still, as mentioned for example by Harry:

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]

Jack, who faced being medically retired due to experiencing frequent, debilitating post-stroke headaches, reported that losing his employment felt like losing part of his identity as “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].

For Jack, the loss of role as “provider” for his family meant he could not support his children financially the way he had planned. 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 lost to the post-stroke pain, most did not allow themselves to dwell on it.

### ***Accepting the “new” self and life***

Five participants appeared to have found a way to live with their pain; accepting the pain as part of who they are and how they live their lives:

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, from a period of believing the pain would recede, as if something external needed to be fixed, to 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, appeared important:

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 had learned that there is no remedy for her pain, which she suffers daily, based on this she learned to “cope” and live her life despite the pain.

Something that appeared to enhance participants' ability to accept life with the pain and feel more positive, was engaging in downward counterfactual comparisons to times, situations, and people they viewed as worse off. They felt they were “lucky” to survive the stroke and get away “fairly lightly” in comparison to other stroke survivors. Linda for example reported being appreciative of her life with the pain, as she was 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 felt his post-stroke pain was 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 growth, the experience of post-stroke pain provided a source of strength and identity for some participants:

[...] 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 stroke survivor; the pain is a reminder of a battle won.

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 Group Experiential 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 felt alone in their pain experience, finding others unable to understand, relate and empathise with their pain; only sharing pain experience to elicit practical support or explain their behaviour. Widar et al. [19], also found participants felt others lacked understanding of their post-stroke pain. Feeling misunderstood by others is a theme commonly reported in the literature on chronic pain; studies highlight that individuals with chronic pain often feel others do not believe them and think they exaggerate or imagine their pain [38]. This may reflect the invisibility of pain, as suggested by study participants and people with other chronic pain syndromes [39,40]. Post-stroke pain may be particularly overlooked, as attention and care may focus on more visible, stroke impairments [19]. Consistent with this, Dale Stone [41] found young female stroke survivors felt only visible disabilities were taken seriously by others. Being younger and 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. [42] found that frequent and ongoing disclosure of pain to others is not beneficial and can have negative consequences, such as invalidation by others and erosion of support. Based on this, it is understandable that participants of the current study engaged in a process of weighing up the costs and benefits before disclosing their pain experience to others.

### ***Unsatisfactory healthcare and the need for self-care***

Consistent with Swedish studies of post-stroke pain [19,23], participants reported not receiving accurate or clear information regarding post-stroke pain, leaving them to form their own beliefs. In the current study, certain illness beliefs seemed helpful or unhelpful in relation to mood, recovery-focus, and help-seeking behaviour. This is consistent with research on other chronic pain syndromes suggesting illness beliefs affect rehabilitation outcomes [43,44] and the "common sense model of illness," which proposes that illness perceptions affect coping and outcome [45]. Our participants linked lack of information and effective treatment with lack of knowledge of post-stroke pain in primary healthcare. This was also a theme in Widar et al.'s [19] study of post-stroke pain patients in Sweden. However, in their study, participants' opinions on care provision and professional knowledge were balanced, whereas within our study, positive healthcare experiences were exclusively related to hospital care. None of our participants had received a differential diagnosis of post-stroke pain, consistent with findings of Swedish studies [19,23,46]. As post-stroke pain can have delayed onset and other stroke impairments might take priority, it may not be detected during specialist stroke input, which is often limited to hospital admission and early supported discharge. Furthermore, post-stroke pain might not fit current measures and diagnostic labels, as suggested by participants of the current study and a Swedish study [18]. Our participants reported only being offered pharmacotherapy and using their own resources to find alternative treatments. In contrast, in a Swedish study, different treatment options for pain were offered by healthcare providers [46].

### ***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. Participants did not significantly

focus on pain-related limitations they face and adaptations they had to make, in contrast to findings by Lindgren et al. [46,47] in which pain-related losses were more prominent. Some practical adaptations 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; possibly reflecting lack of focus on working age adults. Our study suggests individuals with post-stroke pain experience change in their parenting role. This is important as a study of mother-child relationships for mothers with chronic pain found that chronic pain led to increased use of dysfunctional parenting strategies and reduced relationship quality [48].

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. [23]; 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. A Swedish study exploring post-stroke shoulder pain [47] found personal traits, such as stubbornness, optimism, and perceived high level of pain tolerance, aided the process of pain acceptance. In our study, making downward counterfactual comparisons also appeared to aid the development of pain acceptance. This has also been documented by studies of other conditions, which found that such comparisons are used in chronic illness to maintain a positive view of the situation [49]. Acceptance is considered an emotion-focused strategy of coping, whereas finding alternative treatment is considered problem-focused coping [50]. Within this sample, it appeared that participants used both emotion-focused and problem-focused coping. However, for participants less accepting of their pain, the problem-focused search for a remedy dominated.

### ***Strengths and limitations***

This is the first study to investigate UK working age adults' experience of chronic post-stroke pain, adding to the 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. To include stroke survivors whose voices might not normally 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.

Ideally the sample would have been more homogenous, particularly with regards to time since stroke and pain onset, pain type and age. Though participants were of working age, the average age was 56.5, so certain challenges of younger stroke survivors with post-stroke pain may not be captured adequately (e.g., adapted parent role and income difficulties). The sample was self-selected; therefore, individuals either greatly troubled, or less affected, by pain might have been less likely to participate.

Generalisation of findings is limited, as findings are contextualised. However, given that our results are broadly consistent with those of studies in Sweden with 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 struggle 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, working across the chain of care, to ensure that pain is part of their post-stroke assessment. Having streamlined, evidence-based, guided national stroke care across the whole chain of post-stroke care (secondary to primary), which considers long-term conditions such as post-stroke pain, as suggested by the “Action Plan for Stroke in Europe 2018–2030” [51], would be beneficial.

Our results highlight the importance of providing differential diagnosis of the type of post-stroke pain and accurate information about the characteristics of the pain, such as cause, presentation, and prognosis. Receiving a differential diagnosis of the pain (i.e., CPSP, musculoskeletal pain, shoulder pain and subluxation) is important as treatment recommendations vary [52]. The Royal College of Physician (RCP) guidelines [52] 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, 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. It would be beneficial to include detailed pain assessment and treatment recommendations in the general NICE guidelines on stroke care, which currently only cover shoulder pain for stroke [53].

Setting up specific support groups for stroke survivors experiencing pain could 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. Specific post-stroke pain support groups could counteract social isolation and consequently improve physical and emotional functioning, as found in a study of individuals experiencing chronic pain and who engaged in a 10-week mind-body physical activity program [54]. 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 unmet needs in the care of individuals with chronic post-stroke pain. 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, shown to be effective for other chronic pain conditions [55–57]. Research on the effectiveness of systemic approaches to treatment, such as family therapy or peer support,

might also be useful given that participants voiced feeling that others lack understanding and empathy for their suffering. 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, future research might usefully explore the nature of beliefs held by individuals with chronic post-stroke pain and associated consequences in more detail, since the current findings suggest that holding certain pain beliefs may be helpful or unhelpful with regards to mood, support seeking behaviour, and rehabilitation.

### Conclusions

The current study highlights unmet needs in the care of working age adults with chronic post-stroke pain in the UK. The lack of differential post-stroke pain diagnosis, clear and accurate information, and non-pharmacological intervention options, currently appear to 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 on which they feel misunderstood and abandoned by healthcare.

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## Appendix

### 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)?
  - 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?
  - i. Can you think of specific examples to highlight this?
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?