

# Using interpretative phenomenological analysis to probe the lived experiences of persistent postural-perceptual dizziness (PPPD)

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## Abstract.

**BACKGROUND:** Persistent Postural-Perceptual Dizziness (PPPD) is a chronic neuro-vestibular condition characterised by subjective dizziness, non-spinning vertigo, and postural imbalance. Symptoms are typically induced by situations of visuo-vestibular conflict and intense visual-motion.

**OBJECTIVE:** Little research has focused on the lived experiences of people with PPPD. Therefore, our objective was to present an in-depth exploration of patient experiences and sense-making, and the effect of PPPD on psycho-social functioning.

**METHODS:** We conducted semi-structured interviews with 6 people with PPPD, who were recruited from an Audiovestibular department in Wales. We present a case-by-case Interpretive Phenomenological Analysis (IPA) for each participant and present common themes.

**RESULTS:** Our analysis revealed a range of superordinate and subordinate themes, individualised to each participant, but broadly described under the following headings: dismissal and non-belief, identity loss, dissociative experiences, poor psychological well-being and processes of sense-making.

**CONCLUSIONS:** The qualitative experiences documented in this study will help clinicians and researchers to better understand the lived experiences of PPPD, how PPPD patients make sense of their symptoms, and the psycho-social impacts of the condition.

Keywords: Persistent Postural-Perceptual Dizziness (PPPD), visual vertigo, qualitative, psycho-social functioning

## 1. Introduction

Persistent Postural-Perceptual Dizziness (PPPD) is a functional debilitating neuro-vestibular condition characterised by chronic episodes of dizziness,

disequilibrium, non-spinning vertigo and postural imbalance [45]. In 2017, the definition of PPPD was established after several previous and overlapping conditions and symptoms were combined under one unifying diagnosis [45]. These included space and motion discomfort [21], phobic postural vertigo [5], visual vertigo [6], and chronic subjective dizziness [32]. Symptoms associated with PPPD are triggered by situations of visuo-vestibular conflict,

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intense visual-environments, and active or passive motion [7, 34]. Commonly reported triggers include cluttered supermarket aisles, repeated patterns, and busy moving traffic [29, 44, 45]; such scenes are also associated with visual stress more generally [38]. Such visually triggered dizziness is more prevalent in females and during middle age [12, 35, 50], and is also associated with migraine (including vestibular migraine) and brain injury [14, 20, 28, 35].

PPPD can develop following recovery from an acute vestibular compromising illness such as vestibular neuronitis or labyrinthitis [45, 52] and may result from an interaction between such events and a pre-existing predisposition to visual stress or dizziness that exists on a spectrum in the healthy population [36]. Leading theories suggest that those with visually-triggered dizziness have become ‘visually dependant’ – relying more on visual cues over vestibular cues for balance and stability [6, 8, 41, 45]. It is common for patients to develop anxiety [17, 46, 59], though anxiety may also be a predisposing risk factor for PPPD associated symptoms [21, 46, 47], and is correlated with heightened experience of sensory sensitivity across multiple senses [37]. Regardless of origin, symptoms associated with PPPD are complex, heterogeneous, and often co-occur with other illnesses or conditions that together markedly diminish quality of life [4, 59].

### 1.1. Impact of PPPD on daily life

Chronic dizziness can be a disabling experience resulting in functional impairments such as difficulties in walking, navigating three-dimensional space, maintaining postural control, or controlling active and passive motion [11, 33]. These functional impairments are often so physically restricting that they satisfy the diagnostic criteria for a medically recognised disability [31]. These individuals do however fight to gain control of the condition and the disabling status it produces [33]. Chronic dizziness can then result in behavioural adaptations in order to avoid triggering symptoms, such as abnormal [stiffened] gait or posture and becoming hypervigilant to self-motion and other potential triggers [22, 31].

### 1.2. Making sense of dizziness

Chronic dizziness can produce a confused state where individuals are unable to make sense of their symptoms or illness [3, 51]. Patients also show misconceptions surrounding the aetiology of their

dizziness and have a poor understanding of potential treatment avenues, but develop their own ‘work arounds’ to avoid a loss of mobility and independence [25]. In the case of PPPD, the diagnostic label itself may have negative psycho-social implications as the name and acronym of the condition may be considered conceptually confusing, without medical merit, or even a label given to psychosomatic experience [18, 40]. On the other hand, being able to make sense of symptoms through diagnostic labels can allow for patients to better articulate health compromising illnesses which, in turn, can result in more positive health outcomes [2, 48].

### 1.3. Lived experiences of PPPD

Despite being one of the most common causes of chronic dizziness, very little is known about the lived experience of people with PPPD. It is important to understand the diverse range of experiences of this condition and how it affects individuals across the different domains of their lives. This is useful for researchers as it could potentially spark new avenues for investigation, and useful for clinicians who often have to identify PPPD within a complex set of symptom presentation. Previous research has found patients typically become less confident in themselves and in conducting daily activities, and this ultimately results in a subjective loss of self where they struggle to navigate living with PPPD [see 40]. Living with chronic dizziness has also been shown to encourage feelings of insecurity, exhaustion and a loss of dignity, which can be reinforced if interactions with healthcare professionals are perceived as dismissive [30].

No qualitative studies on the lived experiences of PPPD have adopted the hermeneutic approach of Interpretative Phenomenological Analysis (IPA). IPA is an experiential qualitative research method that generates rich contextual data based on lived experiences. The method has been successful in capturing the lived experiences of numerous health compromising illnesses that are hard to articulate such as anorexia, multiple sclerosis, fibromyalgia, and HIV [1, 15, 16, 49]. Applying this tool allows patients to share their unique experiences and project their voices to the health sciences and clinical community.

### 1.4. The current study

The aim of this study was to explore how individuals with PPPD make sense of their symptoms

and condition and to better understand the lived experiences of PPPD, including the psycho-social impacts of the condition. We recruited six participants with an active diagnosis of PPPD. We probed lived experiences using a semi-structured interview with questions based around experience. In line with the idiographic approach, we present and analyse superordinate and subordinate themes that reflect how each of the six participants interpret their world and experiences. The researcher's role is to be a conduit of the hermeneutic process by interpreting their descriptions of their world and help understand and express the participants' sense-making processes around life with PPPD. Inherent in an idiographic approach with small numbers of participants is the risk that the world views and experiences described may not reflect the wider PPPD population. We hope, however, that the data generated reflect some portion of patients' experiences and, as such, both deepen our conceptual understanding of the condition, improve sensitivity to context [56], and stimulate further qualitative research.

## 2. Method

### 2.1. Participants

Six participants (four females and two males), with an active diagnosis of PPPD, between the ages of 29 and 54, were recruited. Five participants were recruited through clinics (i.e., following an assessment with a clinical scientist who diagnosed PPPD, the patients were given a web link to access if they would like to be contacted to take part in research in this area). The remaining participant contacted the lead researcher stating they had recently been given a diagnosis of PPPD and would like to be involved in patient-focused research projects. All participants currently live in the United Kingdom. One participant also had an active diagnosis of fibromyalgia and another had endometriosis. All participants are given a pseudo-name for anonymity.

This study was approved by the Cardiff University School of Psychology Ethics committee and the Cardiff and Vale University NHS Health Board.

### 2.2. Procedure

Data were collected using semi-structured interviews. Interviews lasted between 1 and 2 hours. Two interviews were conducted online (with video) whilst

the remaining four were conducted using the telephone, depending on the participant's preference. Due to the constraints of Covid-19 no physical face-to-face interviews took place. All interviews were audio-recorded and transcribed verbatim by the lead researcher. Participants were asked questions when the topics naturally arose; questions related to lived experiences of PPPD.

### 2.3. Ensuring rigour

The lead researcher (RG) consulted the third researcher (KWS), an experienced IPA researcher [54, 55], for mentorship and training in the IPA method. The interview schedule was co-produced by these researchers and piloted before data collection and iteratively updated and refined. The transcripts, notes and themes were analysed separately by both researchers, who then met to discuss their interpretations. The transcripts were also analysed by third author HDS for clinical interpretation (e.g. quotes that could be accounted for by other co-morbid conditions) to ensure coherent triangulation of themes.

### 2.4. Analytic strategy

All six transcripts were analysed using Interpretative Phenomenological Analysis [IPA, 42]. IPA is a qualitative research method which offers a systematic approach to analysing qualitative data by exploring an individual's personal journey [39, 43, 58]. The method aims to establish how the participant makes sense of their world and its events and obtain information regarding their cognitions, emotions and how they understand events in their internal and external worlds [39]. IPA is epistemologically congruent with the intent of exploring the lived experience of those living with complicated health conditions and is used often in the field of health psychology. In addition, its idiographic nature was deemed ideal for use with patients who report being dismissed or not listened to, as the method fully invests in their unique story in a supportive non-judgemental manner [40].

A case-by-case analysis was conducted that followed Smith, Flower and Larkins [26] guidelines and involved iterative reading of transcripts and listening to the audio files. Transcripts were annotated to highlight thoughts, ideas and key phases, and these annotations were built into notes and codes for each transcript. Initial codes were created based on each individuals' account of their lived experiences of

PPPD. These codes were then refined and condensed to represent superordinate and subordinate themes [39]. Themes were developed based on thematically similar concepts identified during the coding process. Subordinate themes were categorised based on the clustering of codes that indicated a concept or theme was prevalent to a given participants’ narrative. The superordinate theme is a label applied to give an overarching description of conceptually related subordinate themes. Thus, each case-by-case analysis presented in this paper is a combination of superordinate and subordinate themes that best reflect that individual participants’ lived experience of PPPD.

The transcripts, notes and themes were also all read by a clinical scientist (HDS) familiar with co-occurring conditions, to check whether experiences and symptoms ascribed to PPPD were not more clearly associated with one of the co-occurring conditions.

### 3. Results: A case-by-case interpretative phenomenological analysis

The themes and quotes extracted below relate to lived experiences of the participants that go beyond the direct and common symptoms of PPPD, as this was not the aim of the study to reiterate these. We also present a summary table of cross-participant themes – thoughts and experiences that were shared across multiple participants (Table 1) and individual themes specific to each participant (Table 2). Note, each quote presented in the analysis is referenced by indicating the pseudo-name of participant and the line number of the quote in the transcript.

#### 3.1. Participant 1: Lara

Lara is a 29-year-old woman who has completed an undergraduate degree, a master’s degree and three years of PhD study and now works in agriculture.

Table 1  
Summary of cross-participant themes

CROSS-PARTICIPANT THEMES		
<b>Dismissal and Non-belief</b> Poor recognition by healthcare professionals (and questioning own sanity) Dismissal perceived as being related to gender stereotypes around women and health concerns	<b>Identity loss</b> Related to ability to function and carry out roles in everyday life Mixed views on whether people with PPPD identify as disabled	<b>Dissociative Experiences</b> Possible connection to dizziness and anxiety Disorientation when waking from sleep
<b>Poor psychological wellbeing</b> Anxiety and helplessness Social withdrawal and isolation Greater disclosure of poor wellbeing by women	<b>Processes of sense-making</b> Individual differences in personal reflections on living with PPPD Shared need to make sense of symptoms to promote a sense of ownership over the condition	

Table 2  
Summary of individual participant themes

INDIVIDUAL PARTICIPANT THEMES		
<b>Participant 1</b> <i>Theme 1.</i> Identity Crisis <i>Theme 2.</i> Sexism	<b>Participant 2</b> <i>Theme 1.</i> Fear & Anxiety <i>1a.</i> Unknown nature of PPPD symptoms <i>1b.</i> Potential consequences of an episode <i>1c.</i> Failure to function adequately <i>Theme 2.</i> Social Withdrawal and Isolation <i>Theme 3.</i> Time spent with healthcare professionals	<b>Participant 3</b> <i>Theme 1.</i> Making Sense of Symptoms through Metaphor <i>Theme 2:</i> Out of Body Experiences <i>2a:</i> Hallucinations <i>2b:</i> Disassociation
<b>Participant 4</b> <i>Theme 1.</i> Embodied Understanding of Health <i>1a.</i> Understanding through physical familiarity <i>1b.</i> Accepting the limits of the human body <i>1c.</i> Health is analogous to war and conflict	<b>Participant 5</b> <i>Theme 1.</i> An Anxious Predisposition <i>Theme 2.</i> The Disabling Nature of PPPD <i>2a.</i> PPPD is Physically Disabling <i>2b.</i> Feeling Drained: Sup-Optimal Functioning <i>2c:</i> <i>The Cognitive Dissonance between a Disability and the Disabled Identity</i>	<b>Participant 6</b> <i>Theme 1.</i> The Identity Loss of the Matriarch <i>Theme 2.</i> PPPD as the Cause of Anxiety and Panic <i>Theme 3.</i> Ownership Through Language <i>Theme 4.</i> Disassociation and Depersonalisation

Lara has been experiencing PPPD for 2 years. Prior to this she would describe herself as a ‘Jolly. Energetic. And not in a conceited way but like Superwoman’ (Lara: 597 – 598). Lara was originally diagnosed with anxiety and this was thought to explain her vertiginous symptoms. After persevering with health care professionals, anxiety was found to be a misdiagnosis when she was later diagnosed with PPPD. Lara was not recruited through our clinic and therefore we do not have full vestibular history and test results available.

#### *Superordinate Theme 1.1: Identity Crisis*

Lara stated that living with PPPD has impaired her life so much so that she no longer recognises who she is:

‘I felt like I lost my identity. Completely. I was known as the person that who did stuff all the time, I was so active, I was really jolly all the time and like really energetic and I lost all of those things. And I had a massive identity crisis. I was like “I don’t even know who I am if I can’t do all this stuff and if I’m just really sad all the time and I don’t adventure”’. (Lara: 585-588) ‘I was so fun! I could do all these things and now I’m not. And I’m sad. And I’m crap. And I can’t do my job. And my self-confidence and ability, as like, to do my job and be a friend and cool person like plummeted’ (Lara: 666-668)

The condition made her unable to take part in many activities that she considered crucial to her identity and ultimately left her feeling like her identity was stolen from her by the condition and replaced with vestibular and [negative] psychological symptoms.

#### *Superordinate Theme 1.2: Sexism: Men’s microaggressions in clinical assessments*

Lara believes that these negative, unempowering and ‘dismissive’ interactions are, in part, due to her perceived gender and sex; that she is prejudged based on outdated and offensive associations of the female. She alludes to this stigma and how it resonates with negative connotations of the neuroticism, attention-seeking and medical malingering which she believes affected her clinical treatment.

‘Like the doctors were [emphasised] so rude like some of them it was so bad it was because I’d been in a couple of times about something before and I think it was just like ‘oh she’s, it’s just this anxious woman just keeps coming in’. (Lara: 246-249)

She also states that this is not a ‘one off’ event but one that has prevailed, insidiously, throughout her journey to a diagnosis:

‘So, it was a doctor and even before I’d gone in (and I was upset) he’d already decided there was nothing wrong with me. You could tell. Like, you could tell. Middle-aged, middle-class man. Crying lady. I’ve seen it, because it happened at the doctors before’ (Lara: 379-382)

Lara interprets the behaviour she has witnessed and experienced, from male medical professionals as ‘so [emphasis] dismissive and rude’ (Lara: 401) and that these interactions are microaggressions evident of covert sexist attitudes that affect clinical interactions.

### *3.2. Participant 2: Zaynab*

Zaynab is a 43-year-old female Optometrist. Zaynab was diagnosed with endometriosis 14 years prior to the study and has undergone numerous operations in relation to the health compromising illness ‘about 10 operations in the last 10 years’ (Zaynab: 19-20). PPPD symptoms developed approximately three-four years ago and after recovery from acute Benign Paroxysmal Positional Vertigo (BPPV). In addition, she also has Migraines and is vitamin B12 deficient. Clinical examination revealed no significant neurological red flags. Caloric testing showed evidence of significant peripheral vestibular asymmetry with the left side being less reactive than the right. Video head impulse test (vHIT) results, however, suggested good physiological compensation for this. Videonystagmography (VNG) did not show any significant abnormalities.

#### *Superordinate Theme 2.1: Fear & Anxiety*

This superordinate theme captures Zaynab’s fear. Subordinate themes are the composites of fear she faces: (a) the fear of when *symptoms* will present (b) the fear of the potential *consequences* of symptoms and (c) the fear that, because of PPPD, she will *fail to function* adequately.

#### *Subordinate Theme 2.1a: Unknown nature of PPPD symptoms*

Zaynab discloses that she fears the unknown nature of PPPD and when the next episode will present.

‘I’d say dizziness made me anxious (...) The anxiety of is it going to happen? When is it going to happen? I’ve got no way of determin-

ing whether it's going to happen or not. It just randomly comes out of nowhere (. . .) If I knew the trigger factors at the time, then maybe I'd be a little bit more confident but because I didn't know why it was happening, I had no control over it' (Zaynab: 444-446)

Zaynab articulates her anxiety that surrounds not knowing where or when the episodes would strike. Interestingly, her account does not indicate that she fears the symptoms themselves but rather the unexpected nature of them. Her use of the past tense also suggests that once she was informed by healthcare professionals how and why her symptoms persist that control is established, and fear diminishes.

*Subordinate Theme 2.1b: Potential consequences of an episode*

Symptoms may trigger at any place and/or time. This is the cause of great anxiety and fear for Zaynab resulting in behavioural adaptations to avoid potentially calamitous scenarios.

'I came home and said to my husband I don't feel safe driving. I don't want to have a dizzy spell and, you know, have an accident or something (. . .) I'm worried that I might be causing danger to myself or to anyone' (Zaynab: 277-278, 464)

Here, we see Zaynab reflect on her experiences of PPPD and integrate a conscious awareness of how symptoms may, in potentially dangerous scenarios such as driving, put herself and others in danger. This fear of causing harm results in behavioural adaptations that avoid behaviours that may be dangerous if an unexpected bout of dizziness or disequilibrium was triggered.

*Subordinate Theme 2.1c: Failure to function adequately*

The final manifestation of fear Zaynab shows is the fear that she will be unable to function adequately as both a person and optometrist.

'If I feel like I'm not 100% (. . .) I would say to my husband; I don't know if I, you know, want to work full time anymore. So, I started to like work half a day' (Zaynab: 457, 216)

*Superordinate Theme 2.2: Social Withdrawal and Isolation*

Living with PPPD and dealing with chronic symptoms results in social withdrawal and isolation for Zaynab.

'What I'd do is just, you know, isolate myself (. . .) I'll just go off, you know, make an excuse and just go alone. Just to be able to concentrate on it and deal with rather than having all the other things around me' (Zaynab: 244, 258-259)

The experiences of dizziness are shown to be overpowering and to cloud mental focus to the detriment of social interactions. Note, this account resonates with other themes such as sensory sensitivity and visual-overload described below.

*Superordinate Theme 2.3: Time spent with healthcare professionals*

Adequate clinical time with a patient is crucial for Zaynab to feel like effective assessment and rehabilitation of health problems has occurred – both as a practitioner of optometry and as a PPPD patient.

'Time is very important. Even in our job, you know, if we're given more time with our patients, I think we can do more for them and patients feel that as well (. . .) to be honest the most informative experience and the most helpful experience was seeing Maria [the clinical scientist]. Because she erm took probably an hour to go through all my case history, do everything, try to (she did!) loads of tests, trying to figure out what was going on' (Zaynab: 336-337, 304-306)

In contrast to the quote above, Zaynab discloses that interactions with general practitioners and specialists who are pressed for time have led to dismissive interactions and misdiagnosis—an experience that is, unfortunately, shared among the participants of the study and can lead to patients feeling like an annoyance or a burden.

'When I saw the specialist, I literally saw him for like 5 minutes. He was quite dismissive to be honest he was like "oh are you dizzy now?" and I said "no" because I wasn't at the time and I hadn't had an episode for a while and he just said, "oh it's just a migraine" and said "it's probably just a vestibular migraine" and that's it and "I'm discharging you". And I was like OK . . . ' (Zaynab: 85-86, 100)

'If you feel like somebody's running late or somebody's actually very late you don't want to take up much of their time' (Zaynab: 338-339).

### 3.3. Participant 3: Owen

Owen is a 33-year-old male computer games designer who is an avid gamer and enjoys spending time playing online virtual video games (including head-mounted virtual reality games) and building computers. Owen was also diagnosed with ADHD in childhood. When asked how long he has experienced PPPD symptoms he stated ‘supposedly, I’ve had it all my life’ (Owen: 88), however he has only recently been given the diagnosis of PPPD by a clinical scientist. Owen presented at clinic with a complex history of balance problems accompanied by vomiting, anxiety and gastrointestinal symptoms. He reported that a number of factors can exacerbate his symptoms including: stress, motion, breathing exercises and busy visual and auditory environments. VHIT showed reduced vestibular ocular reflex (VOR) gain on stimulation of the right anterior canal, suggesting dysfunction in that canal. No hearing problems were reported. Owen has also been diagnosed with non-epileptic seizures, which could relate to some of his reported experiences.

#### *Superordinate Theme 3.1: Making Sense of Symptoms through Meaningful Metaphor*

Articulating experiences of PPPD is reported to be qualitatively difficult with Owen stating:

‘It’s just unless you’ve experienced it yourself, it’s hard to put into words’ (Owen: 662)

Owen uses a meaningful metaphor (the computer metaphor) to make sense of his condition and to articulate his lived experiences:

‘The best way I can describe it, is like a driver conflict where you got a driver for your mouse but then suddenly your mouse stops working but it’s interfering with the keyboard and you start trying to type out erm trying to use the keyboard to get to the restart option, but things keep getting inverted or relocated and they’re constantly shifting. They’re not making sense even on the keyboard even though the letters are printed their actual functions have changed and the more, when you try fighting it, the more you complicate the actual issue on the PC itself’ (Owen: 950-956)

The computer metaphor is used to articulate complicated vestibular and sensory experiences. The idea that he uses this metaphor to make sense of his condition is further reinforced by his use of language that supports the motif throughout the narrative such as:

‘rebooting (...) programmed myself to (...) process (...) reset (...) restart’ (Owen: 936, 497, 940, 782, 937).

#### *Superordinate Theme 3.2: Out of Body Experiences*

This superordinate theme captures two types of experience Owen reports, (a) hallucinations and (b) dissociative experiences.

##### *Subordinate Theme 3.2a: Hallucinations*

Owen openly discusses hallucinogenic experiences. It is unclear whether the experiences he is referring to originate from PPPD, seizures, ADHD or a combination of these comorbidities. Although the symptoms are present and valid, they may or may not be the consequence of PPPD alone.

‘About two years ago I was helping the neighbour carry basic white chairs up the stairs. I was talking to her and the I just, to me was like someone grabbed the back of my head and just pulled me back but I ended up swimming in the ocean. So, I was in the middle of the ocean it was night and I was confused like wait, wasn’t I just on the stairs? And umm ended up having to swim for a bit. To me it felt like 20 minutes. Got to that beach. As soon as I got to that beach I was waking up and I was like what the hell?’ (Owen: 490-496)

##### *Subordinate Theme 3.2b: Disassociation*

He also recalls episodes that appear more like a dissociative state, where he isn’t aware of his embodied state.

‘Like this one time in a dizziness episode my Dad challenged me; said okay, if you could do 50 laps of the pool (which was an Olympic size swimming pool) I’ll give you £30. And I ended up going into this absolute trance I can’t remember doing it... until my mum slapped me out of it!’ (Owen: 704-708)

These experiences are interesting as, to date, no formal documentation of PPPD patients reporting such symptoms is published. As this type of experience is socially stigmatised, patients may not often disclose such experience. It should, however, be noted that the hallucinations and trance-like state Owen reports could be associated with his seizures or other comorbidities. Owen is the only participant to disclose hallucinations, but he is not the only PPPD participant to disclose dissociative experiences (see Sian – participant 6).

### 3.4. Participant 4: Regina

Regina is a 40-year-old woman with active diagnoses of PPPD and Fibromyalgia.

She presented at clinic with dizziness symptoms that could last for a few minutes at a time, or for longer periods, and could also coincide with migraine headaches. Quick head movements and busy visual environments exacerbated her symptoms. There was no change in her hearing, but she had long standing left sided tinnitus. VHIT showed reduced VOR gain in 2 out of 6 semi-circular canals, suggesting dysfunction in those canals. Both bedside testing and VNG identified slight smooth pursuit abnormalities but clinically they were normal.

Regina was a health care worker before ultimately giving up work due to the demands of her health problems.

#### *Superordinate Theme 4.1: Embodied Understanding of Health*

This superordinate theme captures Regina's sense making techniques through her understanding of embodiment. Subordinate themes reflect her (a) sense making of illness through the physical familiarity of symptoms (b) acceptance of the limits of the human body and (c) understanding of health compromising illness as analogous to war and conflict.

#### *Subordinate Theme 4.1a: Understanding through physical familiarity*

Regina explains that she simultaneously experiences multiple health compromising illness and that she understands the conditions with the more predictable symptoms best.

'I think fibro I probably understand best. And then migraines, because I know the warning signs. And then vertigo because its unpredictable. Erm, yeah it's a little more difficult to understand' (**Regina: 330-332**)

#### *Subordinate Theme 4.1b: Accepting the limits of the human body*

Regina's daily interactions with health compromising illnesses have forced her to accept the limits of her body.

'Yeah, just learning to cope and make the most of any good days erm yeah just learning to listen to what your body says and rest when you need to (...) I know there's a certain way I'm feeling before a flare up and in that case, I try and take it

easy... I don't ask why me I just think well it's a part of me and just wait for it to eventually go away' (**Regina: 185-187, 224-225, 371-372**)

The persistence and the demands of her health compromising illnesses are shown to have given Regina an embodied awareness of her state and how she has learned to listen to and accept the limits of her body. She also expresses gratitude for symptom free days. This understanding of herself within her physical body may also be the reason as to why she does not centralise PPPD and its experiences.

#### *Subordinate Theme 4.1c: Health is analogous to war and conflict*

Linguistic imagery devices that denote conflict and war are present throughout Regina's narrative when discussing her health issues.

'It's just a matter of battling my way home (...) it can be a bit of a mind battle (...) just keep going (...) manage what's happening and move forward' (**Regina: 163-164, 372, 534-535**)

These indicators that Regina interprets living with her conditions as conflict are interesting given that she also explains that she has come to accept the limits of chronic illness. This implies there is acceptance of the tension between herself and her chronically ill identity, rather than acceptance replacing all conflict and tension.

### 3.5. Participant 5: James

James is a 40-year-old man. James had previously presented at clinic with a history of probable labyrinthitis followed by BPPV, which were successfully treated. On further testing however, he was found to have underlying right sided peripheral vestibular dysfunction for which he was given vestibular rehabilitation. This was successful initially, but he continued to experience symptoms of generalised foggy and dizziness on moving around. In addition, James experiences headaches, and reports unilateral tinnitus on the right side for the past year. James is an engineer.

James describes himself as 'a normal guy, quite like sports and being active (...) just a regular guy' (**James: 5-7**). James states that he is 'pretty much over it now' (**James: 225**) and feels 'pretty normal again' (**James: 226**) but slight symptoms do persist.



*Superordinate Theme 5.1: An Anxious Predisposition*

James is the only participant within the study to disclose that he believes that he was, to some degree, an anxious person before vestibular insult and the manifestation of PPPD.

‘I am a bit of a worrier- I think. I never used to think I was, but I’ve realised I am a bit in comparison to others’ (James: 369-370).

*Superordinate Theme 5.2: The Disabling Nature of PPPD*

This superordinate theme captures James’ thoughts, feelings and perceptions of PPPD as a disability. Three subordinate themes reflect the physical, psychological and social dimensions of this theme: (a) the physical disability, (b) feeling drained and sub-optimal functioning and (c) cognitive dissonance between living with a disability and accepting the label of disabled.

*Subordinate Theme 5.2a: PPPD is Physically Disabling*

This subordinate theme captures the physically disabling nature of the condition that incapacitated James.

‘Initially I was incapacitated for months ( . . . ) I was like handicapped weren’t I, so I just felt, everything just felt more difficult ( . . . ) well when I was peak ill, I wasn’t anything! I was just lying on my left side doing nothing. I was yeah, I was just erm; miserable, frustrated erm crippled’ (James: 300-303, 391-393)

The idea that James could not, or would not, view himself as anything could reflect the effect of this incapacitation on his identity, which we know can be affected by life with PPPD (see Lara – participant 1, theme 1).

*Subordinate Theme 5.2b: Feeling Drained: Sub-Optimal Functioning*

James’ narrative emphasises the secondary fatigue that arises from living with PPPD and having to manage the demands of the condition through general daily life.

‘It was so draining. It was just, like I said I felt like I was functioning at 70–80 percent ( . . . ) everything was more difficult. More draining ( . . . ) Gradually started getting better but I just felt horrendous . . . . But for months (like months!) after I felt like I was functioning at sort of 80 per-

cent ( . . . ) You just feel drained. Everything was draining. It was mentally draining. Cause things were harder than they should be . . . it was tough’ (James: 301-303, 235, 268, 329-331)

Note that James highlights both physical and mental fatigue which may reflect the physical and psychological demands of the condition.

*Subordinate Theme 5.2c: The Cognitive Dissonance between a Disability and the Disabled Identity*

The use of language that denotes disability is prevalent throughout James’ narrative which builds and reinforces the motif of PPPD as a disability.

‘Debilitating ( . . . ) crippled ( . . . ) handicapped’ (James: 562, 393, 302)

Despite the linguistic technique building a theme of disability, James articulates that he would be uncomfortable identifying as disabled and labelling PPPD as a disability:

‘If it was a permanent thing then its 100 percent a disability. But I mean the fact that it passed; disability is a bit strong but at the time it was disabling yeah . . . but I dunno if I’d want to be classed as disabled. But yeah, it is disabling so it is yeah’ (James: 313-315).

This extract raises two interesting points; the first, that James believes PPPD is a disability whilst it persists and would be classifiable as a disability if it were permanent. Since some patients do not ever fully recover from PPPD, this raises the question of whether they would consider themselves disabled. Secondly, the extract alludes to the stigma of being associated or classified as disabled; functionally he described himself as disabled, but he would not feel comfortable being labelled so.

*3.6. Participant 6: Sian*

Sian is a 49 year-old woman who presented at clinic with a complex history of balance problems and visually evoked dizziness. Sian’s VHIT showed reduced VOR gain on simulation of the left posterior canal, suggesting dysfunction in that canal. VNG did not show any abnormalities, and positional testing did not show evidence of BPPV. Sian experiences anxiety (linked to her dizziness symptoms), for which she has received CBT, and migraines, for which she has taken amitriptyline. Sian is a wife and mother and describes herself as a family oriented ‘home-bird’

(**Sian: 10**). She has two adult children with her husband and identifies strongly with the role of caregiver, mother and wife. Sian has developed severe agoraphobia due to her PPPD and feels this has ‘in some ways, completely ruined my life’ (**Sian: 735**).

*Superordinate Theme 6.1. The Identity Loss of the Matriarch*

Sian heavily identifies with the role of the Matriarch and explains that living with PPPD has challenged her ability to function as a matriarch within her family unit.

The identity of the mother is central to Sian’s understanding of herself and her identity. The experiences of PPPD have inhibited her ability to function as the mother she always has been.

‘Then you know I say when it’s all passed and I’m feeling and I’ve got a grip on this is my mind playing tricks on me I’ll say right to my daughter tomorrow when you know in between my work calls or whatever let’s go to the park, stick our trainers on and just walk around the park and enjoy the flowers then come home. And she’s like “yeah we’ll do that” - by the following day I’m finding an excuse not to do it because I’m convinced something bad will happen when I get there’ (**Sian: 385-390**).

Sian’s account shows us that anxiety is inhibiting her from conducting typical behaviours and actions of being a mother. Interestingly, Sian’s general narrative shows that she interprets her anxiety as the by-product of PPPD. This is explored further in Sian’s subordinate theme 6.3. Sian discloses that she maintains the motivations to undertake motherly tasks but her experiences and symptoms, in particular the fear and anxiety around symptoms stop her from executing these behaviours. This places Sian in a state of additional psychological distress as she then must deal with the psychological guilt her identity crisis as a mother brings.

As part of her identity as the matriarch, Sian identifies with the role of wife. Living with PPPD, she explains, has resulted in her avoiding typical activities that a partner may do with their significant other.

‘Now my husband will say “do you want to go for a walk on the beach?” and I’ll be like, “you can drive to the beach and I’ll sit in the car “and and I try to . . . I try to dress something else up as nice like I’ll . . . I’ll make us a picnic and flask and we’ll have a car picnic. Almost like I’ll go but

I . . . But I have to stay in my safe place. And I try to make it attractive to stay in the car rather than going out. And I’ve also done things like said okay then no problem knowing that its perhaps really windy then purposefully not taken a coat or a jumper. And when we’ve got there, I’ve said ‘Oh no. I haven’t got a coat or a jumper- you go for a quick walk I’ll be alright [laughs]’ (Sian: 374-381)

Sian also shows how deep rooted this issue is and how she can no longer execute general behaviours that, to her, are crucial to successfully functioning, and thus identifying, as the archetype of the wife.

‘My husband has said I really fancy a chicken salad for tea, you know, when I get home and he’s got home, and I’ve said “you’ll have to take me- you’ll have to go with me to the supermarket” cause we haven’t got the chicken and I have not been able to leave the house to go and get the chicken. You know to, to... that’s not right. That’s not right.’ (**Sian: 462-466**)

These extracts show that living with PPPD has rendered Sian unable to conduct everyday behaviours and tasks that she believes are crucial to her identity as a wife. They also show the cumulative effects of PPPD on previously taken-for-granted activities, and the potential consequences of these insidious impacts on self-esteem and relationships.

Sian goes on to express guilt associated with her limitations:

‘I feel extreme guilt as a mother and as a wife. Because I know that they would perhaps like to go to the park and you know, don’t get me wrong, they’re old enough to go and do it themselves but as a family to go to the park ( . . . ) go the cinema, go for a picnic ( . . . ), go have an hour on the beach, go to the cinema, whatever. You know when you can, and all that sort of stuff and and I’ll do anything to get out of it. I’ll say “oh go on your own you’re 23 I don’t want to watch those sorts of films’ or ‘go with your father’ or you know, and I feel . . . guilty for not sharing in those things with them or not helping them experience those things’ but I don’t feel sad that I’m missing out cause I don’t feel as though I’m missing out because the fear is so extreme. I don’t want to feel that fear – I’m happier not feeling the fear and being safe in my own home. (..) But I also feel that it’s a shame.’ (**Sian: 401 – 408**)

Sian also shows the inner struggle that she feels where she must deal with both the guilt of her avoidant behaviours and the relief that she does not have to engage in activities that may trigger her symptoms. This results in a cognitive dissonance between the two opposing states and a complicated cycle between guilt and relief and guilt for feeling relief.

*Superordinate Theme 6.2: Persistent Postural-Perceptual Dizziness as the Cause of Anxiety and Panic*

Throughout Sian's narrative she makes it clear that she believes that her anxiety and panic conditions are the by-product of living with PPPD.

'So, so this [PPPD] has created an awful situation with anxiety and panic and agoraphobia (...) which then has created an agoraphobia situation (...) So I know I'm in this I know I'm on a hamster wheel of visual things can trigger this off balance feeling and that then triggers the anxiety and panic which just exacerbates the whole thing. So, I feel like I'm in a bit of a mess with it actually [laughs] (...) There's a vestibular problem you know there's a mental health problem now really, I think has been created as a result of it and has compounded as a result of it' (Sian: 150, 172, 193-196, 740-742)

Sian's secondary psychological conditions are understood in relation to PPPD, and she shows that she believes that the PPPD has caused the psychological conditions. She also notes that she is stuck in a cycle between the vestibular and psychological symptoms but again documents that it is the symptoms associated with PPPD that triggers her anxiety and panic.

*Superordinate Theme 6.3: Ownership Through Language*

Sian uses language that captures her lived experiences to form psychological ownership over her symptoms. She articulates and re-labels her symptoms in ways she finds accessible for herself.

'I say to my husband oh I'm really *boaty* at the minute (...) I get that a lot with just people passing me or I might be moving that way and somebody else is moving that way and that creates the *boaty*. That creates the *boaty* feeling. So the vision causes the kind of *whoozy* in the head and mine and other peoples motion causes the *boaty*.' (Sian: 122, 294-297)

By labelling her symptoms in relation to how she understands and experiences them, this allows her to gain psychological ownership over them and make the symptoms her own and more predictable.

*Superordinate Theme 6.4: Disassociation and Depersonalisation*

Experiences of disassociation and depersonalisation are disclosed by Sian. She states that during episodes she commonly feels experiences of disassociation or disconnected from the body she inhabits.

'I feel sometimes like I... I... I can't really put into words... the, you know, the disassociation that they refer to? That I'm not... there. I'm not there. I'm sort of there but I'm not there (...) it was very bright and I hadn't taken sunglasses and I just (...) You know I wasn't blind, I could hear noises, but it was like I can remember standing there talking to my parents, by my car (by my safe place!) so I can get in anytime I want to and just chatting away and it was very bright and I hadn't taken my sunglasses and I just.. I could hear them talking but it was like... I don't know what you're on about it was like blah bah blah blah blah blah... it was like... as if I was zoned out, I was there but I wasn't there. I could see. You know I wasn't blind. I could hear noises, but it was like as if I was just not really there. And I get that a lot and I then straight away and the panic hits in and I think straightway what's going on?! What's going on?! Is there something wrong with my brain cause I'm not really here? What's going on? What's going on? (...) It's almost as if I'm having a night terror but awake'. (Sain: 480-495)

Sian captures the confusion these dissociative experiences give her by recounting the numerous rhetorical questions she would ask herself during an episode. Furthermore, by comparing the experience to a night-terror she captures the pure essence of fear that the experience brings. Finally, she states that:

'I've never actually said: "you know what, I feel totally dissociated at the moment and that's part of my panic". So, I let it, let it... I've never actually said that...'. (Sian: 504-506)

This captures the fear that some symptoms may carry negative social connotations or worry loved ones. Sian openly admits she has never disclosed this symptom before.

## 4. Discussion

Currently, there is no objective diagnostic test for PPPD. Diagnosis relies on the patient's presentation and previous history [45], and therefore self-reported patient experiences are highly relevant to the evolving understanding of the condition, how to recognise it and what impacts it may have on an individual's life. The findings presented in this paper reflect the world view of six unique individuals with an active diagnosis of PPPD. The themes reflect their understanding and sense making of their own experiences of PPPD. We used a novel experiential method (Interpretative Phenomenological Analysis, IPA), to produce personal idiographic representations of what it is like to live with PPPD, each bound by their personal context, bio-psycho-social state, and individual relationships with the condition.

Our analysis revealed superordinate and subordinate themes that were personalised to each participant. Themes that emerged across more than one patient included dismissal and non-belief, identity loss, dissociative experiences, poor psychological well-being and processes of sense-making. Dismissal and non-belief refer to negative clinical interactions where participants did not feel heard or validated that their symptoms were real. Note, this theme was particularly prevalent in narratives of female participants possibly suggesting a gender inequality in clinical interactions around PPPD. Participants who disclosed an identity loss showed this either psychologically or physically when PPPD has disabled them. Dissociative experiences refer to trance like feelings, or feelings of not being present. Poor psychological well-being reflects the subordinate themes of anxiety, fear, and a failure to function adequately. Finally, processes of sense-making captures the diverse ways that the participants understand and make sense of their symptoms and condition which include an embodied (or mind/body based) understanding, meaningful metaphor, and physical familiarity.

### 4.1. Dismissal and non-belief

The majority of participants in this study disclosed that they did not feel listened to or validated when trying to seek a diagnosis for their PPPD symptoms. It is commonly documented by the PPPD patient group that they do not always feel listened to, taken seriously, or supported by healthcare professionals in ascertaining the correct diagnosis and rehabilitation programmes [40]. This actually led some partici-

pants to question their own sanity. PPPD symptoms can sometimes trigger 'gas-lighting' effects, where patients believe they have 'lost their minds', especially when medical professionals misdiagnose their symptomatic presentation or do not make the patient feel that their experiences are valid or 'real' [40]. Our data echo these findings.

It is important to note that some of the female participants interviewed in our study believe that sexist attitudes towards women and PPPD symptoms negatively impacted their clinical interactions, journey to a diagnosis and sense of self-worth and validation. This is consistent with reports from women perceiving that healthcare professionals did not take their symptoms seriously in other conditions, for example chronic pain and endometriosis [9, 10, 19, 53].

### 4.2. Identity loss

In our sample, living with PPPD was reported to result in a loss of the psychological self, consistent with previous research [40]. Impediments to day-to-day activities such as shopping or driving were seen to seriously diminish self-worth when they interact with an individual's self-identity, for example as a mother, wife or worker.

While participants describe how PPPD and chronic dizziness are both physically and psychologically disabling, clearly reducing quality of life [31], it does not follow that our participants felt comfortable identifying with the label of disability. We believe that this is due to the complex invisible nature of the condition and the fact that recovery is possible. Future research should investigate whether establishing PPPD as a disability during active symptoms could be helpful to some patients, providing validity to the condition and allowing patients to access a range of support tools to manage their life.

### 4.3. Dissociative experiences

Two of our participants reported dissociative or trance-like experiences. It is not entirely clear whether these were similar in nature, or whether the trance-like experiences reported by participant 3 are better explained by his comorbid seizures (or indeed whether dizziness can be a trigger for his seizures). Participant 3 also reported hallucinogenic experiences of a rather different nature from participant 6's dissociative experiences, and the connection between PPPD and the hallucinations is unclear, since participant 3 had a complex pattern of PPPD, seizures

and a previous ADHD diagnosis. For participant 6, there appears to be a connection between anxiety and dissociative experiences.

Research has associated out-of-body or dissociative experiences with vestibular compromise due to the system's role in spatial mapping and the perception of the self within space [13, 24, 27]. It is believed that dissociated symptoms occur when distorted vestibular signals mismatch with alternative sources of sensory input, creating an incoherent spatial reference frame resulting in experiences of detachment [23]. Interestingly, no prior research has explored out-of-body experiences, hallucinations or dissociative symptoms in PPPD. Our data are thus intriguing, but we cannot generalise beyond the two (rather different) reports in our study at present. The reason why these types of symptom have not been previously associated with PPPD may be due to the social inhibitions of disclosing such symptoms. Thus, it is difficult to speculate on whether they are rare, and how they interact with, or derive from, co-morbid conditions.

#### 4.4. Psychological well-being

The participants reported that living with PPPD negatively impacts their general psychological well-being. This is evident through a number of superordinate and subordinate themes such as; social withdrawal and isolation, the manifestation of anxiety, dissociation and fear of symptoms and consequences. These findings are broadly consistent with previous literature on symptoms now associated with PPPD [40, 57], but allowed a more in-depth and individual analysis of factors contributing to well-being. Future research should look to establish if these idiosyncratic themes are emergent across a larger cohort of patients.

#### 4.5. Processes of sense-making

Each individual in this study expressed a need to make sense of their symptoms and condition in a way that allows them to better understand and articulate their experiences. This may potentially promote a sense of ownership over the symptoms and wider condition. The individual nature of these narratives may suggest that the way people make sense of PPPD is as heterogenous as the people who experience condition. Those who are acutely aware of their bodily sensations may make sense of symptoms in relation to the body and other bodily experiences. Whilst some-

one with an interest in computers may understand the condition using the computer as a metaphor for experience. Thus, the data presented in this paper suggest that making sense of PPPD is a heterogenous process, while the drive to do so is shared.

It is worth noting that a fundamental goal of IPA is to establish how a given sample make sense of a phenomenon. Given that the process of sense making in PPPD has emerged across participants, this would suggest that the IPA methodology has been implemented appropriately and has usefully served this goal.

#### 4.6. Limitations and strengths

A key limitation of the approach taken here is uncertainty about how generalisable themes arising in a small sample are to a wider population. There is always a trade-off between breadth and depth in any research. Relatedly, since this study focusses on narratives from individual participants, it is difficult to disentangle the influences of comorbid conditions – as highlighted above for the reports of hallucinations, trance-like or dissociative states.

A key strength of the study is the commitment to the ideographic approach – where we fully invest in the participant's story and support them through the process of disclosure, reflection, and sense-making. We have given PPPD patients a platform to share their lived experiences with a trained qualitative research psychologist in an informal semi-structured interview. Although our sample was small, we believe that our patients felt empowered by actively contributing to the scientific understanding of the condition. The IPA method has been a highly effective tool for encouraging discourse and disclosure of highly sensitive health-related information [1, 15, 16, 49]. By using the experiential tool, we were able to effectively illicit deeply personal qualitative accounts of PPPD, shaped around experiences and stories. We confirmed some themes already associated with PPPD, and other themes that have not previously been associated with PPPD (out of body experience).

#### 4.7. Conclusions

This qualitative research study used the experiential IPA method to explore the lived experiences of people with PPPD. In particular, we probed how individuals with a diagnosis of PPPD make sense of their symptoms and the psycho-social impacts of the condition. Our analysis revealed a range of superordinate

and subordinate themes. These included dismissal and non-belief, identity loss, out of body experiences, poor psychological well-being and processes of sense-making. Our findings cannot necessarily be generalised to the wider PPPD community, however this was not our intention. Rather, the identified themes can help magnify underrepresented PPPD voices in the scientific literature and stimulate future research.

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