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WORKING-AGE ADULTS' PERSPECTIVES ON LIVING WITH PERSISTENT POSTURAL-PERCEPTUAL DIZZINESS: A QUALITATIVE EXPLORATORY STUDY

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3 **WORKING-AGE ADULTS' PERSPECTIVES ON LIVING WITH PERSISTENT POSTURAL-**
4 **PERCEPTUAL DIZZINESS: A QUALITATIVE EXPLORATORY STUDY**
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ABSTRACT

Objectives

To a) explore the experiences of Persistent Postural-Perceptual Dizziness (PPPD), formerly chronic subjective dizziness, on the personal, work and social lives of working-age adults; b) enhance current understandings of the condition and its impacts on the lives of working-age adults; and c) highlight points for consideration and importance to clinical practice.

Methods

This qualitative exploratory study drew on Interpretive Descriptive methodology. Working-age adults (n=8) diagnosed with PPPD were recruited from a single New Zealand community based specialist clinic. Data from interviews (n=8) and post-interview reflections (n=2) were analysed using Thematic Analysis.

Results

Three themes were constructed: 1) It sounds like I'm crazy – referring to the lack of medical, social and self-validation associated with PPPD; 2) I'm a shadow of my former self – representing the impact of the condition on sense of self and life trajectory; and 3) How will I survive? – highlighting individual coping processes.

Conclusion: This study contributed to the existing body of knowledge by highlighting the complexity and fluidity of experiencing PPPD. It also drew attention to the tension between the acute illness framework that forms the basis of many therapeutic interactions and the enduring psychosocial support needs of the person experiencing PPPD. The findings highlighted that contextual factors need to be taken into account and that a person-centred and bio-psychosocial approach, rather than a condition-specific biomedical approach, is needed for care to be perceived as meaningful and satisfactory.

Strengths and limitations of this study

- This study is novel in that it exclusively explores the experience of PPPD a) as a condition in its own right; and b) from a working-age adult's perspective.
- In contrast to the existing literature, which predominantly approaches the impact of dizziness from a service utilisation or socio-economic perspective, this study focusses exclusively on the perceived impact in three life domains: personal, social and work life.
- The emerging PPPD literature is primarily situated in the biomedical paradigm highlighting complexities in diagnosis and treatment. This study takes a biopsychosocial approach to the enquiry.
- Strict inclusion criteria and restricted access to potential participants meant that diversity in age, gender and ethnicity could not be achieved in the sample. It is possible that a larger, more heterogeneous sample could have generated broader perspectives.
- Five participants had a therapeutic relationship with the primary investigator (AS), who had been employed as a clinician at the recruiting facility prior to the start of this study. The impact of this relationship on data collection is unknown.

INTRODUCTION

Dizziness, encapsulating a range of ill-defined, non-specific, inconsistent and often transitory sensations,[1-3] is estimated to affect approximately 30% of the general population at least once in their lifetime.[1-6] As an acute transitory or secondary problem, dizziness has received a fair amount of investigative attention, particularly in the elderly population.[7-14] However, very few studies have explored chronic dizziness as a primary standalone condition and at the time this study was conceptualised none had focussed exclusively on the experience of dizziness from the perspective of working-age adults.[5,7-14]

Persistent Postural-Perceptual Dizziness (PPPD) is a common form of chronic dizziness with an incidence peak between 30 and 50 years of age, and with a higher reporting rate in females.[3,11,15] In the literature, PPPD is described as a non-vertiginous, idiopathic form of dizziness characterised by inconsistent sensations of imbalance, hypersensitivity to self-motion or movement within the environment, exacerbated or intensified by being in an upright position or in settings with complex visual stimuli.[16-19] Although its aetiology is largely unknown, the onset of PPPD commonly follows an event affecting the vestibular organs and/or central pathways, hypothesised as triggering a maladaptation to oculo-vestibulo-sensory stimuli.[16-26]

Research demonstrates that chronic conditions interfere with daily life and influence the way individuals experience their personal, social, and work life,[10,12,22,27,28] consequently affecting long-term health outcomes.[13,29-36] It is widely acknowledged that attention to personal and contextual factors are fundamental to effective and satisfactory healthcare delivery and better outcomes.[37,38] However, current predominantly quantitative inquiries into PPPD do not adequately explore the experience and impact of PPPD from the perspective of those who have the condition. This observation and the absence of explicit exploration in to dizziness in the working-age population, the group predominantly affected by this condition, served as key drivers for this study. By filling these identified gaps, this study aims to contribute to the existing body of knowledge, while having the express intent of developing insights for health professionals supporting this population.

METHOD

Design

This qualitative exploratory study drew on Interpretive Descriptive methodology, an inductive approach suited to the exploration of clinically relevant phenomena for the purpose of informing clinical practice.[39-40]

Patient and public involvement

The narratives of people living with PPPD and their reports of receiving insufficient support, captured by the primary investigator (AS) in her role as a clinician prior to this study, generated interest in this research and informed the research question. Patients provided the data for this research and a summary of the findings was shared with those who wished to be informed.

Participants and setting

Participants were purposefully sampled from one community based specialist clinic in New Zealand. Adults who self-identified as working-age, predominantly between 18 and 65 years of age, and who experienced all four of the main characteristics typical for PPPD,[20, 23-26] (see Table 1) were invited to take part in the study. These inclusion criteria helped to distinguish PPPD from other conditions, which may overlap symptomatically, and ensured that the age group of interest was represented in the sample. Self-identification as being of working-age was deemed important considering that an increasing number of people remain in the workforce beyond the age of 65.[41] Eligibility was further dependent on the person's ability to give informed consent and engage in interviews conducted in English. Diversity was sought in age, gender and ethnicity.

Table 1: Four of the main characteristics of PPPD that formed part of the inclusion criteria.

-
- Persistent (≥ 3 months) sensations of non-vertiginous dizziness, light-headedness, heavy-headedness or subjective imbalance present on most days;
 - Chronic (≥ 3 months) hypersensitivity to self-motion or to movements of objects in the environment regardless of direction or position;
 - Exacerbation of symptoms in the upright position and/or settings with complex visual stimuli (e.g., grocery stores) or when performing precision visual tasks (e.g. reading, using a computer);
 - Absence of active physical neuro-otologic illnesses, medical conditions, or medications that may cause dizziness (normal ENT and audiometric testing, and normal or near normal balance function).
 - Significant functional impairment or distress
-

Taken from the consensus document of the committee for the classification of Vestibular Disorders of the Bárány Society,[30]

An administrator employed by the participating locality contacted all regional clients on the clinic database diagnosed with PPPD and informed them of the study by forwarding the participant information sheet. Contact details of those interested in the study were shared with the primary investigator (AS) who contacted each potential participant and screened for eligibility.

Data collection

Participants took part in a one-off, semi-structured, individual interview with AS at a location and time convenient to them. Participants were also invited to submit a written reflection up to 24 hours after the interview to elaborate on their response to interview questions or share additional information they perceived relevant. Interviews lasted between 60 to 90 minutes and were audio-recorded and transcribed verbatim by AS. Interviews concentrated on the experience of PPPD and its impact on the participant's personal, social and work life, and took an iterative approach, starting with some questions as prompts (see Table 2), which were expanded upon depending on participant responses.

Table 2: Sample of prompt questions

1	What can you tell me about your dizziness? What do you experience?
2	
3	What aspects of your dizziness have the greatest impact on your life and in what way?
4	
5	What makes living with your dizziness easier/harder?
6	
7	What strategies do you use to manage your condition?
8	
9	
10	

Data analysis

Analysis started after the first interview and took place in parallel with data collection, so that questions could be further developed throughout the data collection process, with the aim of gaining deeper insights into participants' personal experiences of PPPD.[43] Data from the interviews and post-interview reflections were analysed using Thematic Analysis.[43-45] This process included familiarisation with collected data, coding at a semantic level, identifying key ideas of interest, identifying candidate themes, refining candidate themes, naming and defining final themes.[44,45] After familiarisation with the data, AS took a primarily semantic approach and critical realist view to coding, then met with the co-authors to discuss coding and initial impressions. Coding was returned to and improved upon in a recursive manner. Theme construction was consultative and iterative, with all authors meeting regularly to discuss findings and to test interpretations, ensuring a rigorous process was applied to analysis.[43-45]

RESULTS

Study population

Thirty-three patients (n=33) were invited to take part, of which nine responded and were eligible. One person declined for personal reasons and eight (n=8) agreed to take part (see Table 3 for an overview of participant characteristics).

Table 3: Participant characteristics

Participant	Gender	Age	Ethnicity	Approx. time post onset in years	Employment
Ethan	Male	51	NZ European	1-3	Full-time
Lyna	Female	54	NZ European	3-10	Part-time
Ava	Female	37	NZ European	1-3	Part-time
Thea	Female	66	NZ European	>10	Part-time
Elvy	Female	30	NZ European	< 1	Extended sick leave
Naeve	Female	43	NZ European	3-10	Part-time
Sofie	Female	53	NZ European	3-10	Full-time
Molly	Female	36	NZ European	>10	Full-time

Average age = 46

Pseudonyms were used as identifiers to preserve participant anonymity.

Six interviews took place in person, one via Skype, and one over the phone as preferred by the participants. Two participants submitted post-interview reflections.

Seven participants stated their employment status would be different if it were not for their dizziness; two had parenting responsibilities for children younger than 12, and one for teenagers. Two participants said they had no social support, two had a supportive partner, and four had an extensive support network of partner, friends, and family. Level of education was not formally collected however, from the information participants shared in the interview all had or have held roles that required a professional education.

Themes

Three themes were constructed from the data: 1) *It sounds like I'm crazy*; 2) *I'm a shadow of my former self*; and 3) *How will I survive?* Each theme will be discussed below, supported by data illustrating key aspects of each construct. Pauses in speech are identified by (.), text that has been removed or added with [...].

It sounds like I'm crazy

This theme referred to the participants' perception of PPPD not being medically and socially confirmed as credible and valid, therefore lacking legitimacy. Having a diagnosis, even if only

1
2
3 speculative, was perceived as highly important for validation. Most participants perceived validation
4 to be withheld due to the invisibility of PPPD, absence of clear diagnostic markers, and widespread
5 unfamiliarity with the condition among health professionals and the public:
6
7

8
9 *“To start with, I was very frustrated, about (.) I had this issue (.) and they really were just, (.)*
10 *really did not know what to do (.) yeah that was bit frustrating. Dizziness is a really, sort of (.)*
11 *I don't know, an area that people don't know much about.” (Ethan)*
12
13
14

15 Although disappointing, most participants believed this lack of understanding was only natural
16 considering the difficulty they had themselves articulating the experience of dizziness. In particular,
17 when trying to explain it to those who had not shared their experience:
18
19

20
21 *“People don't really understand um (.) it sounds like an excuse if you think you're feeling like*
22 *that (.) people don't understand what they haven't experienced themselves.” (Molly)*
23
24

25 When asked to describe their dizziness, participants would often resort to imprecise, vague or
26 incohesive language. Failing to find the vocabulary that encapsulated their experience was perceived
27 by most participants as embarrassing and frustrating, with some becoming visibly agitated when
28 trying to do so:
29
30
31

32
33 *“The main symptoms is you don't feel yourself. Summing it up (.) what does that mean?*
34 *[Participant taps fingers] That means, I think, the (.) like I said [sigh], so (.) OK, if you take the*
35 *big picture (.) you don't feel as much as yourself (.) you don't feel yourself.” (Ethan)*
36
37
38
39

40 From their accounts, it was clear that participants engaged in a perpetual process of sense making;
41 looking for patterns and triggers, in an attempt to understand the variability and inconsistencies in
42 which PPPD presents itself and to establish a degree of credibility for themselves as well as others.
43 Despite this, they were unable to give meaning to the complexity of the condition, which appeared
44 detrimental to participants' own illness beliefs and self-validation with many discrediting their own
45 experiences. For example, Thea reported saying to her husband:
46
47
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51

52 *‘I have no idea what is wrong with me; probably it's all in my head!’” (Thea)*
53
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1
2
3 Invisibility and contestability of PPPD featured in all participant interviews, and was mostly perceived
4
5 as a problematic:

6
7 *“The hardest thing with this particular thing is that it is not a visible thing (.) yeah, that can*
8
9 *make it difficult.” (Lyna)*

10
11 Yet, participants appeared to have a dichotomous relationship with invisibility. Some counted
12
13 invisibility as a blessing, especially when they needed to maintain a façade of normality. Others saw
14
15 it as a hindrance and felt under pressure to convince others, including health professionals, that
16
17 their dizziness was real. A few even wished that they could exchange their dizziness for something
18
19 far more obvious and ‘acceptable’:

20
21 *“I don’t know how many times I wished I had lost an arm or something instead of, which*
22
23 *sounds horrible and sounds really selfish because I don’t know how difficult it would be to*
24
25 *have lost a limb or something but just it is more visual so you feel like people will*
26
27 *understand.” (Elvy)*

28
29
30 The relationship with invisibility varied depending on the participants’ context and it was not
31
32 unusual for them to fluctuate between the two sentiments. For example, keeping up appearances
33
34 seemed particularly important in the context of employment, especially for those who perceived
35
36 themselves to have little job security. Participants spoke of their fear of having their competence
37
38 judged by their manager or colleagues, being overlooked for promotions, or losing their professional
39
40 identity, for example:

41
42 *“Based on past experience it hindered and not helped (.) so it’s better to say nothing and*
43
44 *seeming as normal as possible cause the more flawed you seem, the more they sort of go ‘oh*
45
46 *she’s got this and this wrong’, it’s sort of like a black mark against you, the more normal you*
47
48 *can seem and the less maintenance the better I think [...] I never draw attention to it or*
49
50 *make a big deal of it, cause they look at you as a hypochondriac, so it’s better to just say*
51
52 *nothing.” (Molly)*

1
2
3 While, at times, maintaining an appearance of normality was perceived as necessary, it was also
4 experienced as counterproductive to legitimisation and unhelpful in situations where participants
5 wanted their dizziness to be recognised or taken into account. For example, when they had to cancel
6 a social activity or decline invitations. Although most seemed to manage this tension well, this
7 constant navigation was described as exhausting.

8
9
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11
12
13 Having to convince health professionals that the dizziness was real appeared to be an uphill battle
14 for all participants, each of them recounting multiple stories where they had felt disappointed or
15 angry about health professionals' lack of understanding and knowledge:
16
17

18
19
20 *"To start with, I was very frustrated, about (.) I had this issue (.) and they really were just, (.)*
21 *really did not know what to do (.) yeah that was frustrating."* (Ethan)

22
23
24 Lack of validation impinged on therapeutic relationships with many participants claiming to have lost
25 confidence or trust in their health professionals. Participants experienced health professionals as
26 being aloof, which they ascribed to the health professionals' inability to provide them with answers
27 or a cure, perhaps making them feel obsolete and therefore quickly losing interest:
28
29

30
31
32
33 *"My GP is not, not very good, well she seemed OK to start with but it is not sort of something*
34 *that you, I don't know can excise or give antibiotics for or hand pills or [...]."* (Elvy)

35
36
37 From the participants' stories, it was clear they did not necessarily expect health professionals to
38 have all the answers. Although diagnostic certainty was important, there were other aspects such as
39 attitudes and behaviours from health professionals that contributed to validation and perhaps even
40 carried more weight:
41
42

43
44
45 *"[...] and even if you had found nothing, I still felt that probably you could have*
46 *helped me with the problems I was having anyway, because that is what your*
47 *interest was and that is what you are all about."* (Thea)

48
49
50
51
52 All participants indicated being listened to and being understood was crucial to validation, and
53 health professionals who showed an interest in participants and their situation were perceived as
54 trustworthy. Thea stated that an open discussion with an interested and understanding health
55
56
57

1
2
3 professional gave her a sense of direction and made her feel empowered. As well as being important
4
5 for validation, this example highlights that health professional behaviours and attitudes may have
6
7 broader impact on perceived control for people with PPPD.

8
9
10 Regardless of validation, participants still framed the condition as draining them of resources and
11
12 wellbeing, which we will discuss in relation to the next theme.

13 14 **I'm a shadow of my former self**

15
16 This theme captured the perceived shift in self-identity, in response to the challenges created by the
17
18 condition. Participants spoke about *feeling different* from a physical point of view and about *being*
19
20 *different*, which referred to a changed sense of self. Although they appeared to be related, *feeling*
21
22 *different* was more fluid and variable compared to *being different*.

23
24
25 *Feeling different* was often explained as 'feeling off', 'not feeling your usual self', or 'not feeling
26
27 normal'. For example, Thea said she did 'not feel sick or unwell', she just did 'not feel right'.

28
29
30 *Feeling different* appeared to be sensory in nature and was often referred to as 'feeling
31
32 overwhelmed', 'disoriented', or 'muddled' and appeared closely related to other symptoms
33
34 participants experienced such as nausea or visual disturbances:

35
36 *"I often have the feeling of being (.), feeling muddled in my thinking and disorientated (.)*

37
38 *yeah, just sort of a feeling of (.) not being quite aware of where I am in space."* (Lyna)

39
40 *Feeling different* appeared to be fluid, with many participants commenting they had transient
41
42 episodes of normality, which gave them a sense of relief and hope mixed with slight unease as
43
44 occasions like these were only short-lived:

45
46 *"When I wake up and I have a good day then I just think that I am cured [laughs] I sort of*

47
48 *forget (.) because I get back into what feels normal to me."* (Lyna)

49
50
51 Occasional normality appeared to complicate the participants' ability to make sense of their
52
53 condition, as described in theme one, with some seeing it as an indicator that their dizziness was
54
55 imaginary.

1
2
3 *Being different*, on the other hand, appeared to refer to participants' personal identity. Some talked
4 about *being a different person* compared to the person they were before the onset of their dizziness:

5
6
7 "I think (.) there was the [Ethan] before the dizziness and the [Ethan] afterwards. So, I'm (.) I
8
9 look at myself as a slightly different [Ethan]." (Ethan)

10
11 Participants stated they were *no longer capable of doing normal things in a normal way*, and seemed
12 to distance themselves from 'normal people':

13
14
15 "Mmm (.) yeah, I think a normal person is I guess someone that doesn't have this. That
16
17 would without thinking (.) as they drop something just pick it up without thinking or if they
18
19 stand and have to talk to someone for a long time, that just stand and they wouldn't have to
20
21 think 'right, so I need to stand near a wall, so I can touch it and don't fall over' or I ideally sit
22
23 down [...] you have to think about alternatives (.) it's all going through my head, whereas a
24
25 normal person would just do it without thinking." (Molly)

26
27
28 All participants talked about 'no longer recognising themselves', for example, Naeve spoke about
29 'no longer being the strong, confident and independent person' she used to be. She was certain 'she
30 never used to be like this', referring to being emotional and feeling like crying all the time. Ava
31 described herself as 'so needy' while Lyna spoke about being 'anxious and cautious all the time' and
32 having lost 'the ability to be spontaneous'. *Being different* appeared to be a slow, involuntary
33 transformational process, an alteration in their sense of self and social identity.

34
35
36
37
38
39
40 *Feeling* and *being different* meant that participants had to compensate and make significant lifestyle
41 changes, often with significant impact on their perceived quality of life. *Being different* had a
42 substantial impact on personal, social and work relationships with participants avoiding activities
43 they would normally have enjoyed and participated in, such as family outings, social gatherings, or
44 attending work-related events and professional development opportunities. For many it was the
45 lack of enjoyment and the exacerbation of symptoms afterwards that influenced participation. From
46 their accounts, it was clear that participants resented making those lifestyle changes but felt that
47 they had no choice.

1
2
3 *“It has had a huge impact on me really (.) I sort of feel like I lost quite a bit of freedom of*
4 *movement in what I might do with my life, and being able to take on (.) you know, sort of*
5 *going for a new job or anything like that (.) I feel like I can’t do (.) or travelling overseas, I feel*
6 *I couldn’t do that myself, I need to have my partner with me (.) yeah, that sort of thing (.) it’s*
7 *been quite limiting.” (Lyna)*

13 The majority of participants expressed concerns for the effect their dizziness had on personal
14 relationships and alluded to having changed life-roles. Elvy and Naeve feared for a relationship
15 breakdown with their partner; Elvy, Ava, Sofie and Ethan talked about the breakdown of friendships
16 while Molly and Ava were reluctant to form any new relationships.

21 *“mmm, just feeling really (.), helpless and hopeless just that I can’t be there for my family*
22 *how I normally would be and same with friends [...] I’m not able to just pop round how I*
23 *normally would [...] Associated guilt that I am ruining my husband’s life and dreams of also*
24 *having children, travel, socialising, as he is stuck with me being dependent on him driving me*
25 *and earning our living.” (Elvy)*

32 Naeve and Ava also described themselves as ‘terrible mothers’ for ‘not being able to do things
33 normal mothers would do’, while Ethan indicated to feel remorse for removing himself from family
34 activities such as watching TV with his family since the onset of his dizziness. Lyna talked about times
35 her children would be concerned for her wellbeing and how frustrating it was for her to be ‘a burden
36 on them’ and her husband.

42 Participants experienced *a sense of loss and* appeared to be grieving for their *old self*. Yet, some
43 tried to reach a level of acceptance and in the process were able to identify positive aspects to their
44 *new self or new lifestyle*. A sense of loss was often associated with a concern about the future and
45 maintaining hope, which the next theme addresses.

51 **How will I survive?**

52 This theme showed the complexity of coping with PPPD and adjusting to life disruptions, described
53 as a dynamic, complex process. Participants fluctuated between three dominant states: 1) *wanting it*

1
2
3 *fixed*; 2) *having a sense of hope*; and 3) *getting on with it*, all of which were interlaced with a sense
4
5 of survival.

6
7 Participants' narratives suggested they move fluidly between states, often subconsciously,
8
9 sometimes with states co-existing. The move between states did not seem to follow a pattern, but it
10
11 appeared more common for participants relatively new to the condition to fluctuate between the
12
13 closely related, *wanting it fixed* and *having a sense of hope*.
14

15
16 Those who had the condition for a longer period of time seemed to spend more time and effort
17
18 trying to adapt, yet, this was more in an attempt to establish a better quality of life and re-establish
19
20 *a new sense of self* as described in theme two. Adapting was not necessarily a sign that participants
21
22 had accepted their condition. Regardless of how long they had been living with PPPD, all participants
23
24 would have preferred to have their dizziness resolved.
25

26
27 *Wanting it fixed* took on two meanings. First, wanting someone do the fixing:

28
29 *"I just wanted to fix it, so like, come on let's fix it someone give me a pill, what do we do*
30
31 *here, what is the deal, go surgery? Major surgery? Brain tumour removed? (.) yeah, good*
32
33 *let's go, let's do it! I just wanted it resolved."* (Ava)
34

35
36 Second, having the tools to fix it themselves:

37
38 *"Yeah, realising that it was me that had to do it, that nobody else could give me a pill and fix*
39
40 *me, I had to do it (.) yeah, that was quite a big, a big step."* (Lyna)
41

42
43 *Having a sense of hope*, was talked about in myriad ways, yet often covertly. Participants spoke
44
45 about their future in a way that showed they were *hoping to get better*, referring to improvements
46
47 that enabled them to lead a satisfying and meaningful life, within the limitations of their condition.

48
49 The data also carried undercurrents of hope for recovery and a *return to normality*:

50
51 *"I have got better but we don't know why or how (.) and it's just not at that level yet where I*
52
53 *can go back to functioning normally [...] I have to believe that I get back to what I was."*
54
55 (Ava)
56
57
58
59
60

1
2
3 Participants appeared to actively keep hope alive, regardless of how long PPPD had been part of
4
5 their lives. To keep hope alive, they appeared to use the following strategies:

- 6
7 a) Positive thinking or self-talk. For example, by telling herself 'today will be a good day', Elvy
8
9 used positive thinking as a way to keep hope alive.
10
11 b) Goal setting. Although most participants stated they inherently knew their goals were
12
13 unattainable and as such rarely achieved, the process of goal setting appeared to sustain hope.
14
15 c) Participation in activities that promote health and wellbeing. For example, Lyna talked about
16
17 how doing a low intensity cardio-program on good days gave her some hope.
18
19 d) Drawing strength from incremental improvements or by the sudden realisation an
20
21 improvement had occurred. In Sofie's case it was the sudden realisation that the incidences of
22
23 unsteadiness she experienced when walking into a crowd had become less frequent and
24
25 severe.
26
27

28 Hope also appeared to be kept alive passively, by the occasional moments where the person had felt
29
30 *episodes of normality*, described in theme two. Yet, these moments of hope were not always
31
32 experienced as positive. For example, Elvy described these short-lived episodes, as 'hideous',
33
34 referring to the disappointment she felt when episodes of normality had passed and she realised her
35
36 hope was unsubstantiated. This dual relationship with hope was one of the factors that made PPPD
37
38 so troubling for those experiencing it.
39

40 Participants further talked about *hope being lost or taken from them*, which they described as times
41
42 when they had felt despair, sadness or grief for what they had lost. For example, Naeve spoke about
43
44 the anger she felt when health professionals told her that she *just needed to learn to live with it*.

45
46 It was also apparent that hope was endangered or lost by the lack of knowledge and prognostic
47
48 uncertainty.
49

50
51 *"I think it's just the frustration of not knowing (.) if I am actually ever going to get better as*
52
53 *well, cause nobody, it's like how long is a piece of string, it sort of (.) if I had like a clear 'yes*
54
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3 *you definitely going to get better' then I go ok, eventually I don't know how long it's gonna*
4
5 *take but I will (.) hopefully, I will get there, but I just don't believe it myself." (Elvy)*
6

7 Hope was described as an important component in the coping process and participants expressed
8
9 that without hope, life with PPPD would become unbearable:

10
11 *"I could not live with this, if it was forever (.)I would get really depressed." (Ava)*
12

13 Losing hope appeared to be a painful process and having hope taken away was described as cruel.

14
15 Losing hope seemed to go hand in hand with a range of emotions such as sadness, disappointment,
16
17 betrayal, anger, grief, self-reproach and regret:

18
19 *"Feelings of wondering how I will go on living like this. Is this how it is going to be from now*
20
21 *on? Just huge amounts of disappointment, regret for not doing more before I got sick, and I*
22
23 *guess grieving for my old life where although because of my job I tried to never take things*
24
25 *for granted and was grateful for the life I had, but now realise I had so much more than what*
26
27 *I realised." (Elvy)*
28

29
30 Similarly, Ava commented:

31
32 *"I think depression would have been very easy to fall into to, (.) as I said right at the start I*
33
34 *definitely did feel (.) I like to think I didn't feel overwhelmingly sorry for myself (.) I felt a bit*
35
36 *cheated (.) um, yeah (.) that a yeah (.) sort of (.) yeah, definitely (.) [Participant's mood*
37
38 *changed to more thoughtful] [I] never fell into the 'oh, I am cursed and stay in bed and cry',*
39
40 *but yeah, I definitely felt, (.) I felt angry sad." (Ava)*
41

42
43 Interlaced with hope, participants talked about *a need to get on with it*, moments of realisation that
44
45 they had to come to terms with their situation and find a way to live a meaningful and satisfactory
46
47 life despite of the situation they were in; or, as Molly described it:

48
49 *"Yeah you have to (.) kind of have to suck it up I guess and move on." (Molly)*
50

51 *Getting on with it* often stood for forgetting about recovery, the 'old self', and the 'old life', and
52
53 adapting to a 'new me' and 'a new lifestyle':
54

1
2
3 *“So, there is the, the new [Ethan] [who] cannot do what the old [Ethan] did (.) and then the*
4
5 *rest of my life, which is here now (.) yeah, sometimes I feel ‘off’ during that day, you know*
6
7 *have an ‘off day’ or an ‘off few hours’ [...] you just have to live, just got to suck it up.” (Ethan)*
8

9 *Getting on with it* was described as a gradual process that required time as well as cognitive
10
11 processing:

12
13 *“I think it was just gradually getting used to it (.) yeah, is almost like become accepting that I*
14
15 *have these symptoms or whatever it is (.) I think it is like anything isn’t it, when you kind of*
16
17 *accepting that you have something and it is always going to be with you (.) you just get on*
18
19 *with things.” (Sofie)*
20

21
22 *Getting on with it* appeared to involve changing hopes for the future, and making conscious lifestyle
23
24 changes as a strategy for coping. Strategies included managing situations and adapting activities (e.g.
25
26 pacing and planning), all of which were aimed at keeping the participant feeling safe and
27
28 comfortable. The fluctuating nature of PPPD and the associated experience of having hope one
29
30 minute and losing hope the other meant that *getting on with it* was not an easy process. Some
31
32 participants seemed to actively resist the getting on with it process, as this was seen as giving in,
33
34 while others seemed to come to ‘some sort of acceptance’ fairly quickly, and had resigned
35
36 themselves to the idea that adaptation was needed for survival.

37
38 Participants’ non- linear progression from *wanting it fixed*, to *having a sense of hope*, and *getting on*
39
40 *with it* appeared to be highly influenced by the extent to which they experienced changes to their
41
42 identity and loss of control over their life trajectory, as well as the support they received from
43
44 significant others and health professionals. Contextual factors, such as having responsibilities for
45
46 others or having the freedom to adjust workloads or commitments also strongly influenced the way
47
48 participants managed PPPD and coped with the challenges imposed by the condition.
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DISCUSSION

This study highlighted that the experience of PPPD and its impact on everyday lives of working age adults is highly dependent on perception of legitimacy. Key discussion points in this current study were: a) the importance of medical and social validation for self-validation and wellbeing; and b) the influence of experiential and contextual factors on coping mechanisms and management of PPPD. The detrimental effect of delegitimisation on self-identity and coping has been thoroughly discussed in the existing chronic conditions literature,[45-51] which established verifiability and visibility as main determinants of legitimacy.[45,47,50,51] Yet, participants in the current study brought another dimension to the validation discourse, namely the impact of what was perceived as health professionals' lack of knowledge and understanding. Participant narratives indicated that this instilled feelings of distrust and professional incompetence, undermining the relationship between patients and health professionals. Furthermore, participants questioned whether this lack of understanding fuelled a perceived disinterest in the patient and commitment to support them, which then cascaded into a lack of respect for health professionals. There is a growing body of evidence that genuine therapeutic relationships, encompassing trust and mutual respect, can act as a therapeutic agent and influence treatment outcomes.[52-56] This present study highlighted that attitudes and behaviours of health professionals contribute to the way people with PPPD experience and manage their condition. These findings also indicated that irrespective of diagnostic uncertainty and invisibility, validation and legitimisation can be achieved through health professionals' capability to build effective therapeutic relationships.

The few existing studies addressing the experience of dizziness predominantly took an elderly person's perspective and found validation could be demonstrated by offering individualised support, which translated into provision of effective treatment, access to social services, aids and home care.[12] The present study's focus on working-age adults brought to light that although participants sought effective treatment, social services, aids and home care were not relevant to them. Instead, participants associated personalised support with opportunities for open and supportive discussions

1
2
3 with health professionals that helped them make sense of their condition and its disruption to self-
4
5 identity and life trajectory. Although recognition for altered sense of self and biographical disruption
6
7 was not a new finding in the chronic conditions literature,[57-59] it has never been thoroughly
8
9 explored in the context of chronic dizziness.

10
11 Another important finding in this study was the participants' inability to articulate and make sense of
12
13 their symptoms, which they perceived as frustrating and embarrassing, jeopardising self-validation.
14
15 When self-validation is threatened, individuals may engage in self-stigmatisation.[29,33,34] These
16
17 mental models are known to influence personal experiences of a health condition, attitudes towards
18
19 it, ways individuals adapt to their situation and what coping strategies they apply to live a
20
21 meaningful life, all of which ultimately impact health outcomes.[61-62] Current clinical guidelines
22
23 emphasise the increasing importance of detailed symptom description and pattern recognition as
24
25 the basis for accurate diagnosis and effective treatment.[1-3, 7] When clinicians focus on accurate
26
27 symptom description and sense making it may signal to clients experiencing PPPD that their
28
29 credibility is in question, exacerbating self-stigmatisation, and potentially damaging therapeutic
30
31 relationships. Participants highlighted the importance of having a diagnosis; however, health
32
33 professionals may benefit from reflecting on current diagnostic practices and processes, and be
34
35 cognisant of how these are perceived by clients. Alternate approaches that provide reassurance and
36
37 focus on the experience of dizziness in the context of the client's personal situation, may counter
38
39 self-stigmatisation, demonstrate medical validation and lead to more satisfactory care experiences
40
41 and better outcomes.

42
43
44 Further thought should be given to what constitutes effective treatment of PPPD. Existing literature
45
46 suggests three dominant treatment approaches: vestibular rehabilitation, pharmaceutical
47
48 management, and cognitive-behavioural therapy.[2,16,18,23,27,62-67] What is often missing from
49
50 the predominantly biomedical PPPD literature is a focus on the need for psycho-social support and
51
52 how failing to provide this may diminish the effectiveness of those recommended treatments. In
53
54 the literature, unsatisfactory outcomes are frequently ascribed to poor patient motivation or non-
55
56

1
2
3 adherence to prescribed therapeutic interventions.[67] In the present study, supported by the
4
5 findings of Corbin and Strauss,[68] the emotional and cognitive load that resulted from the
6
7 disruption to self-identity and life-trajectory, and fear for the future detracted from other
8
9 rehabilitation efforts. Identifying and acknowledging these contextual factors as well as gaining
10
11 insight in the patient's priorities and support needs should form a fundamental part of treatment. In
12
13 fact, paying attention to psychosocial support needs may be the gateway to effective treatment.
14

15 **CONCLUSION**

16
17 This current study sought to explore the experience of PPPD, a chronic but non-specific form of
18
19 dizziness typically affecting working-age adults. Findings supported those found in existing chronic
20
21 conditions literature; in particular those concerned with self-identity for people with invisible or
22
23 unidentifiable conditions. Yet, the focus on PPPD and working-age adults brought to light some
24
25 nuances not previously described in the literature, resulting in deeper understandings. This study
26
27 highlighted points for consideration by health professionals to enhance clinical practice. These
28
29 include: a) the importance of building a therapeutic relationship and how this can be achieved; b)
30
31 the role health professionals play in the validation process; and c) the need to tailor support and
32
33 management of the condition to the person's needs, priorities and context.
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FOOTNOTES

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A reporting checklist for qualitative studies based on the SRQR guidelines were used for reporting.[69]

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

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	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1,2,5
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	2,3
Purpose or research question	#4 Purpose of the study and specific objectives or questions	2,4
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	1,2,5

guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

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14	Researcher	#6	2, 5, 23
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57	Units of study	#12	2,6,7,8
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		participation (could be reported in results)	
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2	Data processing	#13 Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6,7
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9	Data analysis	#14 Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	2,7,8
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16	Techniques to enhance trustworthiness	#15 Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	7
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21	Syntheses and interpretation	#16 Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8-19
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27	Links to empirical data	#17 Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8-19
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31	Integration with prior work, implications, transferability and contribution(s) to the field	#18 Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	4,19-21
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40	Limitations	#19 Trustworthiness and limitations of findings	3
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43	Conflicts of interest	#20 Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	23
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48	Funding	#21 Sources of funding and other support; role of funders in data collection, interpretation and reporting	23
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BMJ Open

WORKING-AGE ADULTS' PERSPECTIVES ON LIVING WITH PERSISTENT POSTURAL-PERCEPTUAL DIZZINESS: A QUALITATIVE EXPLORATORY STUDY

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3 **WORKING-AGE ADULTS' PERSPECTIVES ON LIVING WITH PERSISTENT POSTURAL-**
4 **PERCEPTUAL DIZZINESS: A QUALITATIVE EXPLORATORY STUDY**
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ABSTRACT

Objectives

To a) explore the experiences of Persistent Postural-Perceptual Dizziness (PPPD), formerly chronic subjective dizziness on the personal, work and social lives of working-age adults; b) enhance current understandings of the condition and its impact on the lives of working-age adults; and c) highlight points for consideration and importance to clinical practice.

Methods

This qualitative exploratory study drew on Interpretive Descriptive methodology. Working-age adults (n=8) diagnosed with PPPD were recruited from a single New Zealand community based specialist clinic. Data from interviews (n=8) and post-interview reflections (n=2) were analysed using Thematic Analysis.

Results

Three themes were constructed: 1) It sounds like I'm crazy – referring to the lack of medical, social and self-validation associated with PPPD; 2) I'm a shadow of my former self – representing the impact of the condition on sense of self and life trajectory; and 3) How will I survive? – highlighting individual coping processes.

Conclusion: This study contributed to the existing body of knowledge by highlighting the complexity and fluidity of experiencing PPPD. It also drew attention to the tension between the acute illness framework that forms the basis of many therapeutic interactions and the enduring psychosocial support needs of the person experiencing PPPD. The findings highlighted that contextual factors need to be taken into account and that a person-centred and bio-psychosocial approach, rather than a condition-specific biomedical approach, is needed for care to be perceived as meaningful and satisfactory.

Strengths and limitations of this study

- This study is novel in that it exclusively explores the experience of PPPD a) as a condition in its own right; and b) from a working-age adult's perspective.
- In contrast to the existing literature, which predominantly approaches the impact of dizziness from a service utilisation or socio-economic perspective, this study focusses exclusively on the perceived impact in three life domains: personal, social and work life.
- The emerging PPPD literature is primarily situated in the biomedical paradigm highlighting complexities in diagnosis and treatment. This study takes a biopsychosocial approach to the enquiry.
- Strict inclusion criteria and restricted access to potential participants meant that diversity in age, gender and ethnicity could not be achieved in the sample. It is possible that a larger, more heterogeneous sample could have generated broader perspectives.
- Five participants had a therapeutic relationship with the primary investigator (AS), who had been employed as a clinician at the recruiting facility prior to the start of this study. The impact of this relationship on data collection is unknown.

INTRODUCTION

Dizziness, encapsulating a range of ill-defined, non-specific, inconsistent and often transitory sensations,[1-3] is estimated to affect approximately 30% of the general population at least once in their lifetime.[1-6] As an acute transitory or secondary problem, dizziness has received a fair amount of investigative attention, particularly in the elderly population.[7-14] However, very few studies have explored chronic dizziness as a primary standalone condition and at the time this study was conceptualised none had focussed exclusively on the experience of dizziness from the perspective of working-age adults.[5,7-14]

Persistent Postural- Perceptual Dizziness (PPPD) is a common form of chronic dizziness with an incidence peak between 30 and 50 years of age, and a higher reporting rate in females.[3,11,15] Drawing on the International Classification of Disorders (ICD-11) and the Bárány Society's diagnostic criteria , PPPD is best summarised as an idiopathic, non-vertiginous form of dizziness characterised by persistent but often inconsistent sensations of imbalance, hypersensitivity to self-motion or movement within the environment, exacerbated or intensified by being in an upright position or in settings with complex visual stimuli, [16-22]. Although its aetiology is largely unknown, the onset of PPPD commonly follows an event affecting the vestibular organs and/or central pathways, hypothesised as triggering a maladaptation to oculo-vestibulo-sensory stimuli.[16-27]

Research demonstrates that chronic conditions interfere with daily life and influence the way individuals experience their personal, social, and work life,[10,12,22,23,28] consequently affecting long-term health outcomes.[13,29-36] It is widely acknowledged that attention to personal and contextual factors are fundamental to effective and satisfactory healthcare delivery and better outcomes.[37,38] However, current predominantly quantitative inquiries into PPPD do not adequately explore the experience and impact of PPPD from the perspective of those affected by the condition. This observation and the absence of explicit exploration in to dizziness in the working-age population, the group predominantly troubled by this condition, served as key drivers for this study.

1
2
3 By filing these identified gaps, this study aims to contribute to the existing body of knowledge, while
4
5 having the express intent of developing insights for health professionals supporting this population.
6

7 **METHOD**

8 **Design**

9
10 This qualitative exploratory study drew on Interpretive Descriptive methodology, an inductive
11
12 approach suited to the exploration of clinically relevant phenomena for the purpose of informing
13
14 clinical practice.[39,40]
15
16

17 **Patient and public involvement**

18
19 The narratives of people living with PPPD and their reports of receiving insufficient support,
20
21 captured by the primary investigator (AS) in her role as a clinician prior to this study, generated
22
23 interest in this research and informed the research question. Patients provided the data for this
24
25 research and a summary of the findings was shared with those who wished to be informed.
26
27

28 **Participants and setting**

29
30 Participants were purposefully sampled from one community-based specialist clinic in New Zealand
31
32 and were patients referred to the clinic by a general practitioner (GP) or specialist consultant. All had
33
34 been comprehensively assessed by a team of experienced and vestibular trained
35
36 otorhinolaryngologists, audiologists, and physiotherapists and were diagnosed with PPPD. Adults
37
38 who self-identified as working-age, predominantly between 18 and 65 years of age, and who
39
40 experienced all five of the main characteristics typical for PPPD,[20,24-27] (see Table 1) were invited
41
42 to take part in the study. These inclusion criteria helped to distinguish PPPD from other conditions,
43
44 which may overlap symptomatically, and ensured that the age group of interest was represented in
45
46 the sample. Self-identification as being of working-age was deemed important considering that an
47
48 increasing number of people remain in the workforce beyond the age of 65.[41] Eligibility was
49
50 further dependent on the person's ability to give informed consent and engage in interviews
51
52 conducted in English. Diversity was sought in age, gender and ethnicity.
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Table 1: Five of the main characteristics of PPPD that formed part of the inclusion criteria.

-
- Persistent (≥ 3 months) sensations of non-vertiginous dizziness, light-headedness, heavy-headedness or subjective imbalance present on most days;
 - Chronic (≥ 3 months) hypersensitivity to self-motion or to movements of objects in the environment regardless of direction or position;
 - Exacerbation of symptoms in the upright position and/or settings with complex visual stimuli (e.g., grocery stores) or when performing precision visual tasks (e.g. reading, using a computer);
 - Absence of active physical neuro-otologic illnesses, medical conditions, or medications that may cause dizziness (normal ENT and audiometric testing, and normal or near normal balance function).
 - Significant functional impairment or distress
-

Taken from the consensus document of the committee for the classification of Vestibular Disorders of the Bárány Society.[21,22]

An administrator employed by the participating locality contacted all regional clients on the clinic database diagnosed with PPPD and informed them of the study by forwarding the participant information sheet. Contact details of those interested in the study were shared with the primary investigator (AS) who contacted each potential participant and screened for eligibility.

Data collection

Participants took part in a one-off, semi-structured, individual interview with AS at a location and time convenient to them. Participants were also invited to submit a written reflection up to 24 hours after the interview to elaborate on their response to interview questions or share additional information they perceived relevant. Interviews lasted between 60 to 90 minutes and were audio-recorded and transcribed verbatim by AS. Interviews concentrated on the experience of PPPD and its impact on the participant's personal, social and work life, and took an iterative approach, starting with some questions as prompts (see Table 2), which were expanded upon depending on participant responses.

1
2
3 *Table 2: Sample of prompt questions*
4

5 What can you tell me about your dizziness? What do you experience?
6

7 What aspects of your dizziness have the greatest impact on your life and in what way?
8

9 What makes living with your dizziness easier/harder?
10

11 What strategies do you use to manage your condition?
12

13 14 **Data analysis**

15
16 Analysis started after the first interview and took place in parallel with data collection, so that
17 questions could be further developed throughout the data collection process, with the aim of
18 gaining deeper insights into participants' personal experiences of PPPD.[42,43] Data from the
19 interviews and post-interview reflections were treated as a single data set and analysed using
20 Thematic Analysis following Braun and Clarke's six phase approach.[43-45] This process included
21 familiarisation with collected data, coding, identifying key ideas of interest, identifying candidate
22 themes, refining candidate themes, naming and defining final themes.[44,45] After familiarisation
23 with the data, AS took a primarily semantic approach and critical realist view to coding, then met
24 with the co-authors, who had read and coded a selection of transcripts at random, to discuss coding
25 and initial impressions. Coding was returned to and improved upon in a recursive manner primarily
26 by AS and GT (co-author experienced in Thematic Analysis). Theme construction was consultative
27 and iterative, with all authors meeting regularly to discuss findings and to test interpretations,
28 ensuring a rigorous process was applied to analysis.[43,45]
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46 **RESULTS**

47 **Study population**

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49 Thirty-three patients (n=33) were invited to take part, of which nine responded and were eligible.
50
51 One person declined for personal reasons and eight (n=8) agreed to take part (see Table 3 for an
52 overview of participant characteristics).
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Table 3: Participant characteristics

Participant	Gender	Age	Ethnicity	Approx. time post onset in years	Employment
Ethan	Male	51	NZ European	1-3	Full-time
Lyna	Female	54	NZ European	3-10	Part-time
Ava	Female	37	NZ European	1-3	Part-time
Thea	Female	66	NZ European	>10	Part-time
Elvy	Female	30	NZ European	< 1	Extended sick leave
Naeve	Female	43	NZ European	3-10	Part-time
Sofie	Female	53	NZ European	3-10	Full-time
Molly	Female	36	NZ European	>10	Full-time

Average age = 46

Pseudonyms were used as identifiers to preserve participant anonymity.

Six interviews took place in person, one via Skype, and one over the phone as preferred by the participants. Two participants submitted post-interview reflections.

Seven participants stated their employment status would be different if it were not for their dizziness; two had parenting responsibilities for children younger than 12, and one for teenagers.

Two participants said they had no social support, two had a supportive partner, and four had an extensive support network of partner, friends, and family. Level of education was not formally collected however, from the information participants shared in the interview all had or have held roles that required a professional education.

Themes

Three themes were constructed from the data: 1) *It sounds like I'm crazy*; 2) *I'm a shadow of my former self*; and 3) *How will I survive?* Each theme will be discussed below, supported by data illustrating key aspects of each construct. Natural pauses in participants' speech are identified by (.), text that has been removed or added with [...].

It sounds like I'm crazy

This theme referred to the participants' perception of PPPD not being medically and socially confirmed as credible and valid, therefore lacking legitimacy. Having a diagnosis, even if only

1
2
3 speculative, was perceived as highly important for validation. Most participants perceived validation
4
5 to be withheld due to the invisibility of PPPD, absence of clear diagnostic markers, and widespread
6
7 unfamiliarity with the condition among health professionals and the public:
8
9

10 *"To start with, I was very frustrated, about (.) I had this issue (.) and they really were just, (.)*
11 *really did not know what to do (.) yeah that was bit frustrating. Dizziness is a really, sort of (.)*
12 *I don't know, an area that people don't know much about."* (Ethan)
13
14
15

16 Although disappointing, most participants believed this lack of understanding was only natural
17
18 considering the difficulty they had themselves articulating the experience of dizziness. In particular,
19
20 when trying to explain it to those who had not shared their experience:
21
22

23 *"People don't really understand um (.) it sounds like an excuse if you think you're feeling like*
24 *that (.) people don't understand what they haven't experienced themselves."* (Molly)
25
26
27

28 When asked to describe their dizziness, participants would often resort to imprecise, vague or
29
30 incohesive language. Failing to find the vocabulary that encapsulated their experience was perceived
31
32 by most participants as embarrassing and frustrating, with some becoming visibly agitated when
33
34 trying to do so:
35
36

37 *"The main symptoms is you don't feel yourself. Summing it up (.) what does that mean?*
38 *[Participant taps fingers] That means, I think, the (.) like I said [sigh], so (.) OK, if you take the*
39 *big picture (.) you don't feel as much as yourself (.) you don't feel yourself."* (Ethan)
40
41
42

43 From their accounts, it was clear that participants engaged in a perpetual process of sense making;
44
45 looking for patterns and triggers, in an attempt to understand the variability and inconsistencies in
46
47 which PPPD presents itself and to establish a degree of credibility for themselves as well as others.
48
49 Despite this, they were unable to give meaning to the complexity of the condition, which appeared
50
51 detrimental to participants' own illness beliefs and self-validation with many discrediting their own
52
53 experiences. For example, Thea reported saying to her husband:
54
55
56

57 *'I have no idea what is wrong with me; probably it's all in my head!'"* (Thea)
58
59
60

1
2
3 Invisibility and contestability of PPPD featured in all participant interviews, and was mostly perceived
4 as a problematic:
5
6

7
8 *“The hardest thing with this particular thing is that it is not a visible thing (.) yeah, that can*
9 *make it difficult.” (Lyna)*
10
11

12 Yet, participants appeared to have a dichotomous relationship with invisibility. Some counted
13 invisibility as a blessing, especially when they needed to maintain a façade of normality. Others saw
14 it as a hindrance and felt under pressure to convince others, including health professionals, that
15 their dizziness was real. A few even wished that they could exchange their dizziness for something
16 far more obvious and ‘acceptable’:
17
18
19
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23
24 *“I don’t know how many times I wished I had lost an arm or something instead of, which*
25 *sounds horrible and sounds really selfish because I don’t know how difficult it would be to*
26 *have lost a limb or something but just it is more visual so you feel like people will*
27 *understand.” (Elvy)*
28
29
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33 The relationship with invisibility varied depending on the participants’ context and it was not
34 unusual for them to fluctuate between the two sentiments. For example, keeping up appearances
35 seemed particularly important in the context of employment, especially for those who perceived
36 themselves to have little job security. Participants spoke of their fear of having their competence
37 judged by their manager or colleagues, being overlooked for promotions, or losing their professional
38 identity, for example:
39
40
41
42
43
44
45

46 *“Based on past experience it hindered and not helped (.) so it’s better to say nothing and*
47 *seeming as normal as possible cause the more flawed you seem, the more they sort of go ‘oh*
48 *she’s got this and this wrong’, it’s sort of like a black mark against you, the more normal you*
49 *can seem and the less maintenance the better I think [...] I never draw attention to it or*
50 *make a big deal of it, cause they look at you as a hypochondriac, so it’s better to just say*
51 *nothing.” (Molly)*
52
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1
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3 While, at times, maintaining an appearance of normality was perceived as necessary, it was also
4
5 experienced as counterproductive to legitimisation and unhelpful in situations where participants
6
7 wanted their dizziness to be recognised or taken into account. For example, when they had to cancel
8
9 a social activity or decline invitations. Although most seemed to manage this tension well, this
10
11 constant navigation was described as exhausting.
12

13
14 Having to convince health professionals that the dizziness was real appeared to be an uphill battle
15
16 for all participants, each of them recounting multiple stories where they had felt disappointed or
17
18 angry about health professionals' lack of understanding and knowledge:
19

20
21 *"[...] the other thing I would say is 'that it's real' you know, 'it's real, and I think it's (.)*
22
23 *You feel embarrassed to say what it is because you can't really describe (.) it's kind of*
24
25 *something and nothing, if you know what I mean?" (Thea)*
26
27

28 Lack of validation impinged on therapeutic relationships with many participants claiming to have lost
29
30 confidence or trust in their health professionals. Participants experienced health professionals as
31
32 being aloof, which they ascribed to the health professionals' inability to provide them with answers
33
34 or a cure, perhaps making them feel obsolete and therefore quickly losing interest:
35
36

37
38 *"My GP is not, not very good, well she seemed OK to start with but it is not sort of something*
39
40 *that you, I don't know can excise or give antibiotics for or hand pills or [...]." (Elvy)*
41

42 From the participants' stories, it was clear they did not necessarily expect health professionals to
43
44 have all the answers. Although diagnostic certainty was important, there were other aspects such as
45
46 attitudes and behaviours from health professionals that contributed to validation and perhaps even
47
48 carried more weight:
49

50
51 *"[...] and even if you had found nothing, I still felt that probably you could have*
52
53 *helped me with the problems I was having anyway, because that is what your*
54
55 *interest was and that is what you are all about."* (Thea)
56
57

58 All participants indicated being listened to and being understood was crucial to validation, and
59
60 health professionals who showed an interest in participants and their situation were perceived as

1
2
3 trustworthy. Thea stated that an open discussion with an interested and understanding health
4 professional gave her a sense of direction and made her feel empowered. As well as being important
5 for validation, this example highlights that health professional behaviours and attitudes may have
6 broader impact on perceived control for people with PPPD.
7
8
9
10

11
12 Regardless of validation, participants still framed the condition as draining them of resources and
13 wellbeing, which we will discuss in relation to the next theme.
14
15
16

17 **I'm a shadow of my former self**

18
19 This theme captured the perceived shift in self-identity, in response to the challenges created by the
20 condition. Participants spoke about *feeling different* from a physical point of view and about *being*
21 *different*, which referred to a changed sense of self. Although they appeared to be related, *feeling*
22 *different* was more fluid and variable compared to *being different*.
23
24
25
26
27
28

29 *Feeling different* was often explained as 'feeling off', 'not feeling your usual self', or 'not feeling
30 normal'. For example, Thea said she did 'not feel sick or unwell', she just did 'not feel right'.
31
32
33

34 *Feeling different* appeared to be sensory in nature and was often referred to as 'feeling
35 overwhelmed', 'disoriented', or 'muddled' and appeared closely related to other symptoms
36 participants experienced such as nausea or visual disturbances:
37
38
39

40
41 *"I often have the feeling of being (.), feeling muddled in my thinking and disorientated (.)*
42 *yeah, just sort of a feeling of (.) not being quite aware of where I am in space."* (Lyna)
43
44

45 *Feeling different* appeared to be fluid, with many participants commenting they had transient
46 episodes of normality, which gave them a sense of relief and hope mixed with slight unease as
47 occasions like these were only short-lived:
48
49
50

51
52 *"When I wake up and I have a good day then I just think that I am cured [laughs] I sort of*
53 *forget (.) because I get back into what feels normal to me."* (Lyna)
54
55
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1
2
3 Occasional normality appeared to complicate the participants' ability to make sense of their
4
5 condition, as described in theme one, with some seeing it as an indicator that their dizziness was
6
7 imaginary.

8
9
10 *Being different*, on the other hand, appeared to refer to participants' personal identity. Some talked
11
12 about *being a different person* compared to the person they were before the onset of their dizziness:

13
14 "I think (.) there was the [Ethan] before the dizziness and the [Ethan] afterwards. So, I'm (.) I
15
16 look at myself as a slightly different [Ethan]." (Ethan)

17
18
19 Participants stated they were *no longer capable of doing normal things in a normal way*, and seemed
20
21 to distance themselves from 'normal people':

22
23 "Mmm (.) yeah, I think a normal person is I guess someone that doesn't have this. That
24
25 would without thinking (.) as they drop something just pick it up without thinking or if they
26
27 stand and have to talk to someone for a long time, that just stand and they wouldn't have to
28
29 think 'right, so I need to stand near a wall, so I can touch it and don't fall over' or I ideally sit
30
31 down [...] you have to think about alternatives (.) it's all going through my head, whereas a
32
33 normal person would just do it without thinking." (Molly)

34
35
36 All participants talked about 'no longer recognising themselves', for example, Naeve spoke about 'no
37
38 longer being the strong, confident and independent person' she used to be. She was certain 'she
39
40 never used to be like this', referring to being emotional and feeling like crying all the time. Ava
41
42 described herself as 'so needy' while Lyna spoke about being 'anxious and cautious all the time' and
43
44 having lost 'the ability to be spontaneous'. *Being different* appeared to be a slow, involuntary
45
46 transformational process, an alteration in their sense of self and social identity.

47
48
49 *Feeling* and *being different* meant that participants had to compensate and make significant lifestyle
50
51 changes, often with significant impact on their perceived quality of life. *Being different* had a
52
53 substantial impact on personal, social and work relationships with participants avoiding activities
54
55 they would normally have enjoyed and participated in, such as family outings, social gatherings, or
56
57 attending work-related events and professional development opportunities. For many it was the
58
59
60

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2
3 lack of enjoyment and the exacerbation of symptoms afterwards that influenced participation. From
4
5 their accounts, it was clear that participants resented making those lifestyle changes but felt that
6
7 they had no choice.
8
9

10 *“It has had a huge impact on me really (.) I sort of feel like I lost quite a bit of freedom of*
11 *movement in what I might do with my life, and being able to take on (.) you know, sort of*
12 *going for a new job or anything like that (.) I feel like I can’t do (.) or travelling overseas, I feel*
13 *I couldn’t do that myself, I need to have my partner with me (.) yeah, that sort of thing (.) it’s*
14 *been quite limiting.” (Lyna)*
15
16
17
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19

20
21 The majority of participants expressed concerns for the effect their dizziness had on personal
22
23 relationships and alluded to having changed life-roles. Elvy and Naeve feared for a relationship
24
25 breakdown with their partner; Elvy, Ava, Sofie and Ethan talked about the breakdown of friendships
26
27 while Molly and Ava were reluctant to form any new relationships.
28
29

30 *“mmm, just feeling really (.), helpless and hopeless just that I can’t be there for my family*
31 *how I normally would be and same with friends [...] I’m not able to just pop round how I*
32 *normally would [...] Associated guilt that I am ruining my husband’s life and dreams of also*
33 *having children, travel, socialising, as he is stuck with me being dependent on him driving me*
34 *and earning our living.” (Elvy)*
35
36
37
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39

40
41 Naeve and Ava also described themselves as ‘terrible mothers’ for ‘not being able to do things
42
43 normal mothers would do’, while Ethan indicated to feel remorse for removing himself from family
44
45 activities such as watching TV with his family since the onset of his dizziness. Lyna talked about times
46
47 her children would be concerned for her wellbeing and how frustrating it was for her to be ‘a burden
48
49 on them’ and her husband.
50
51

52 Participants experienced *a sense of loss and* appeared to be grieving for their *old self*. Yet, some
53
54 tried to reach a level of acceptance and in the process were able to identify positive aspects to their
55
56 *new self or new lifestyle*. A sense of loss was often associated with a concern about the future and
57
58 maintaining hope, which the next theme addresses.
59
60

How will I survive?

This theme showed the complexity of coping with PPPD and adjusting to life disruptions, described as a dynamic, complex process. Participants fluctuated between three dominant states: 1) *wanting it fixed*; 2) *having a sense of hope*; and 3) *getting on with it*, all of which were interlaced with a sense of survival.

Participants' narratives suggested they move fluidly between states, often subconsciously, sometimes with states co-existing. The move between states did not seem to follow a pattern, but it appeared more common for participants relatively new to the condition to fluctuate between the closely related, wanting it fixed and having a sense of hope.

Those who had the condition for a longer period of time seemed to spend more time and effort trying to adapt, yet, this was more in an attempt to establish a better quality of life and re-establish *a new sense of self* as described in theme two. Adapting was not necessarily a sign that participants had accepted their condition. Regardless of how long they had been living with PPPD, all participants would have preferred to have their dizziness resolved.

Wanting it fixed took on two meanings. First, wanting someone do the fixing:

"I just wanted to fix it, so like, come on let's fix it someone give me a pill, what do we do here, what is the deal, go surgery? Major surgery? Brain tumour removed? (.) yeah, good let's go, let's do it! I just wanted it resolved." (Ava)

Second, having the tools to fix it themselves:

"Yeah, realising that it was me that had to do it, that nobody else could give me a pill and fix me, I had to do it (.) yeah, that was quite a big, a big step." (Lyna)

Having a sense of hope, was talked about in myriad ways, yet often covertly. Participants spoke about their future in a way that showed they were *hoping to get better*, referring to improvements that enabled them to lead a satisfying and meaningful life, within the limitations of their condition.

The data also carried undercurrents of hope for recovery and a *return to normality*:

1
2
3 “I have got better but we don’t know why or how (.) and it’s just not at that level yet where I
4
5 can go back to functioning normally [...] I have to believe that I get back to what I was.”
6

7
8 (Ava)
9

10 Participants appeared to actively keep hope alive, regardless of how long PPPD had been part of
11
12 their lives. To keep hope alive, they appeared to use the following strategies:
13

14 a) Positive thinking or self-talk. For example, by telling herself ‘today will be a good day’, Elvy
15
16 used positive thinking as a way to keep hope alive.
17

18 b) Goal setting. Although most participants stated they inherently knew their goals were
19
20 unattainable and as such rarely achieved, the process of goal setting appeared to sustain hope.
21
22

23 c) Participation in activities that promote health and wellbeing. For example, Lyna talked about
24
25 how doing a low intensity cardio-program on good days gave her some hope.
26
27

28 d) Drawing strength from incremental improvements or by the sudden realisation an
29
30 improvement had occurred. In Sofie’s case it was the sudden realisation that the incidences of
31
32 unsteadiness she experienced when walking into a crowd had become less frequent and
33
34 severe.
35

36 Hope also appeared to be kept alive passively, by the occasional moments where the person had felt
37
38 *episodes of normality*, described in theme two. Yet, these moments of hope were not always
39
40 experienced as positive. For example, Elvy described these short-lived episodes, as ‘hideous’,
41
42 referring to the disappointment she felt when episodes of normality had passed and she realised her
43
44 hope was unsubstantiated. This dual relationship with hope was one of the factors that made PPPD
45
46 so troubling for those experiencing it.
47
48

49 Participants further talked about *hope being lost or taken from them*, which they described as times
50
51 when they had felt despair, sadness or grief for what they had lost. For example, Naeve spoke about
52
53 the anger she felt when health professionals told her that she *just needed to learn to live with it*.
54
55

56 It was also apparent that hope was endangered or lost by the lack of knowledge and prognostic
57
58 uncertainty.
59
60

1
2
3 *"I think it's just the frustration of not knowing (.) if I am actually ever going to get better as*
4 *well, cause nobody, it's like how long is a piece of string, it sort of (.) if I had like a clear 'yes*
5 *you definitely going to get better' then I go ok, eventually I don't know how long it's gonna*
6 *take but I will (.) hopefully, I will get there, but I just don't believe it myself."* (Elvy)
7
8
9
10
11

12 Hope was described as an important component in the coping process and participants expressed
13 that without hope, life with PPPD would become unbearable:
14

15
16 *"I could not live with this, if it was forever (.)I would get really depressed."* (Ava)
17

18 Losing hope appeared to be a painful process and having hope taken away was described as cruel.

19 Losing hope seemed to go hand in hand with a range of emotions such as sadness, disappointment,
20
21 betrayal, anger, grief, self-reproach and regret:
22

23
24
25 *"Feelings of wondering how I will go on living like this. Is this how it is going to be from now*
26 *on? Just huge amounts of disappointment, regret for not doing more before I got sick, and I*
27 *guess grieving for my old life where although because of my job I tried to never take things*
28 *for granted and was grateful for the life I had, but now realise I had so much more than what*
29 *I realised."* (Elvy)
30
31
32
33
34
35

36 Similarly, Ava commented:
37

38
39 *"I think depression would have been very easy to fall into to, (.) as I said right at the start I*
40 *definitely did feel (.) I like to think I didn't feel overwhelmingly sorry for myself (.) I felt a bit*
41 *cheated (.) um, yeah (.) that a yeah (.) sort of (.) yeah, definitely (.) [Participant's mood*
42 *changed to more thoughtful] [I] never fell into the 'oh, I am cursed and stay in bed and cry',*
43 *but yeah, I definitely felt, (.) I felt angry sad."* (Ava)
44
45
46
47
48
49

50 Interlaced with hope, participants talked about *a need to get on with it*, moments of realisation that
51 they had to come to terms with their situation and find a way to live a meaningful and satisfactory
52 life despite of the situation they were in; or, as Molly described it:
53
54

55
56
57 *"Yeah you have to (.) kind of have to suck it up I guess and move on."* (Molly)
58
59
60

1
2
3 *Getting on with it* often stood for forgetting about recovery, the ‘old self’, and the ‘old life’, and
4
5 adapting to a ‘new me’ and ‘a new lifestyle’:
6

7
8 “So, there is the, the new [Ethan] [who] cannot do what the old [Ethan] did (.) and then the
9
10 rest of my life, which is here now (.) yeah, sometimes I feel ‘off’ during that day, you know
11
12 have an ‘off day’ or an ‘off few hours’ [...] you just have to live, just got to suck it up.” (Ethan)
13

14 *Getting on with it* was described as a gradual process that required time as well as cognitive
15
16 processing:
17

18
19 “I think it was just gradually getting used to it (.) yeah, is almost like become accepting that I
20
21 have these symptoms or whatever it is (.) I think it is like anything isn’t it, when you kind of
22
23 accepting that you have something and it is always going to be with you (.) you just get on
24
25 with things.” (Sofie)
26

27
28 *Getting on with it* appeared to involve changing hopes for the future, and making conscious lifestyle
29
30 changes as a strategy for coping. Strategies included managing situations and adapting activities (e.g.
31
32 pacing and planning), all of which were aimed at keeping the participant feeling safe and
33
34 comfortable. The fluctuating nature of PPPD and the associated experience of having hope one
35
36 minute and losing hope the next meant that *getting on with it* was not an easy process. Some
37
38 participants seemed to actively resist the getting on with it process, as this was seen as giving in,
39
40 while others seemed to come to ‘some sort of acceptance’ fairly quickly, and had resigned
41
42 themselves to the idea that adaptation was needed for survival.
43
44

45
46 Participants’ non- linear progression from *wanting it fixed*, to *having a sense of hope*, and *getting on*
47
48 *with it* appeared to be highly influenced by the extent to which they experienced changes to their
49
50 identity and loss of control over their life trajectory, as well as the support they received from
51
52 significant others and health professionals. Contextual factors, such as having responsibilities for
53
54 others or having the freedom to adjust workloads or commitments also strongly influenced the way
55
56 participants managed PPPD and coped with the challenges imposed by the condition.
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DISCUSSION

This study highlighted that the experience of PPPD and its impact on everyday lives of working age adults is highly dependent on perception of legitimacy. Key discussion points in the current study were: a) the importance of medical and social validation for self-validation and wellbeing; and b) the influence of experiential and contextual factors on coping mechanisms and management of PPPD.

The detrimental effect of delegitimisation on self-identity and coping has been thoroughly discussed in the existing chronic conditions literature,[45-51] which established verifiability and visibility as main determinants of legitimacy.[45,47,50,51] Yet, participants in the current study brought another dimension to the validation discourse, namely the impact of what was perceived as health professionals' lack of knowledge and understanding. Participant narratives indicated that this instilled feelings of distrust and professional incompetence, undermining the relationship between patients and health professionals. Furthermore, participants questioned whether this lack of understanding fuelled a perceived disinterest in the patient and commitment to support them, which then cascaded into a lack of respect for health professionals. There is a growing body of evidence that genuine therapeutic relationships, encompassing trust and mutual respect, can act as a therapeutic agent and influence treatment outcomes.[52-56] The present study highlighted that attitudes and behaviours of health professionals contribute to the way people with PPPD experience and manage their condition. These findings also indicated that irrespective of diagnostic uncertainty and invisibility, validation and legitimisation can be achieved through health professionals' capability to build effective therapeutic relationships.

Our findings showed some similarities with those from existing studies concentrating on the experience of dizziness, especially studies where the underlying condition shared some of its symptoms and relative invisibility with PPPD.[57,58] However, prior studies seldom focussed on the working-age adults' experience of dizziness and if they did, not in association with an esoteric condition such as PPPD. Differences in age-related contextual factors and priorities highlighted different support needs. For example, for an aging person, effective treatment and support

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2
3 translated predominantly into prevention of falls and falls-related sequelae, having access to social
4 services, and provision of home care and mobility aids.[12] These were not relevant to participants
5
6 in the present study where, in absence of a cure, helpful and desirable support was associated with
7
8 having opportunities for open and supportive discussions with health professionals that helped them
9
10 make sense of their condition, its disruption to self-identity and life trajectory. Although the
11
12 experience of *altered sense of self* and *biographical disruption* was also not a new finding and has
13
14 been extensively explored in the chronic conditions literature,[59-62] it has never been thoroughly
15
16 explored in the context of vestibular disorders.

17
18
19 Another interesting finding in this study was the participants' inability to articulate and make sense
20
21 of their symptoms, which they perceived as frustrating and embarrassing, jeopardised self-
22
23 validation. When self-validation is threatened, individuals engage in self-stigmatisation.[29,33,34]
24
25 These mental models are known to influence personal experiences of a health condition, attitudes
26
27 towards it, ways individuals adapt to their situation and what coping strategies they apply to live a
28
29 meaningful life, all of which ultimately impact health outcomes.[63,64] Current clinical guidelines
30
31 emphasise the increasing importance of detailed symptom description and pattern recognition as
32
33 the basis for accurate diagnosis and effective treatment.[1-3,7] When clinicians focus on accurate
34
35 symptom description and sense making it may signal to clients experiencing PPPD that their
36
37 credibility is in question, exacerbating self-stigmatisation, and potentially damaging therapeutic
38
39 relationships. Participants highlighted the importance of having a diagnosis; however, health
40
41 professionals may benefit from reflecting on current diagnostic practices and processes, and be
42
43 cognisant of how these are perceived by clients. Alternate approaches that provide reassurance and
44
45 focus on the experience of dizziness in the context of the client's personal situation, may counter
46
47 self-stigmatisation, demonstrate medical validation and lead to more satisfactory care experiences
48
49 and better outcomes.

50
51
52 Further thought should be given to what constitutes effective treatment of PPPD. Existing literature
53
54 suggests three dominant treatment approaches: vestibular rehabilitation, pharmaceutical
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1
2
3 management, and cognitive-behavioural therapy.[2,16,18, 22,24,64-69] What is often missing from
4
5 the predominantly biomedical PPPD literature is a focus on the need for psycho-social support and
6
7 how failing to provide this may diminish the effectiveness of those recommended treatments. In
8
9 the literature, unsatisfactory outcomes are frequently ascribed to poor patient motivation or non-
10
11 adherence to prescribed therapeutic interventions.[69] In the present study, supported by the
12
13 findings of Corbin and Strauss,[70] the emotional and cognitive load resulting from
14
15 (self)stigmatisation, disruption to self-identity and life-trajectory, and fear for the future detracted
16
17 from other rehabilitation efforts. Identifying and acknowledging these factors as well as gaining
18
19 insight in the patient's priorities and support needs should form a fundamental part of treatment. In
20
21 fact, paying attention to individual and context specific psychosocial support needs may be the
22
23 gateway to effective treatment and better outcomes.
24
25
26
27 Guidance on how to establishing relationships, where an open and more meaningful dialogue can
28
29 take place, as well as the benefits of taking a more person-centred approach to clinical practice is
30
31 present in the existing literature,[52,54, 71,72].

32 33 34 **CONCLUSION**

35
36 The current study sought to explore the experience of PPPD, a chronic but non-specific form of
37
38 dizziness typically affecting working-age adults. Findings supported those found in existing chronic
39
40 conditions literature; in particular those concerned with self-identity for people with invisible or
41
42 unidentifiable conditions. Yet, the focus on PPPD and working-age adults brought to light some
43
44 nuances not previously described in the literature, resulting in deeper understandings. This study
45
46 highlighted points for consideration by health professionals to enhance clinical practice. These
47
48 include: a) the importance of building a therapeutic relationship and how this can be achieved; b)
49
50 the role health professionals play in the validation process; and c) the need to tailor support and
51
52 management of the condition to the person's needs, priorities and context.
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FOOTNOTES

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1,2,5
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	2,3
Purpose or research question	#4 Purpose of the study and specific objectives or questions	2,4
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	1,2,5

guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

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		participation (could be reported in results)	
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2	Data processing	#13 Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6,7
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9	Data analysis	#14 Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	2,7,8
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16	Techniques to enhance trustworthiness	#15 Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	7
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21	Syntheses and interpretation	#16 Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8-19
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27	Links to empirical data	#17 Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8-19
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31	Integration with prior work, implications, transferability and contribution(s) to the field	#18 Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	4,19-21
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40	Limitations	#19 Trustworthiness and limitations of findings	3
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43	Conflicts of interest	#20 Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	23
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48	Funding	#21 Sources of funding and other support; role of funders in data collection, interpretation and reporting	23
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