

BMJ Open Working-age adults' perspectives on living with persistent postural-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 postinterview 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 biopsychosocial approach, rather than a condition-specific biomedical approach, is needed for care to be perceived as meaningful and satisfactory.

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 stand-alone condition and, at the time this study

Strengths and limitations of this study

- This study is novel in that it exclusively explores the experience of persistent postural-perceptual dizziness (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 socioeconomic 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.

was conceptualised none had focused 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 women.^{3 11 15} Drawing on the International Classification of Disorders-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. 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 and were patients referred to the clinic by a general practitioner (GP) or specialist consultant. All had been comprehensively assessed by a team of experienced and vestibular trained otorhinolaryngologists, audiologists and physiotherapists and were diagnosed with PPPD. Adults who self-identified as working-age, predominantly between 18 and 65 years of age, and who experienced all five of the main characteristics typical for PPPD,^{20 24–27} (see [box 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

Box 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 (eg, grocery stores) or when performing precision visual tasks (eg, 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}

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.

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, semistructured, 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 and 90 min 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 [box 2](#)), which were expanded on depending on participant responses.

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.^{42 43} Data from the interviews and postinterview reflections were treated as a single data set and analysed using thematic analysis following Braun and Clarke's six phase approach.^{43–45} This process included familiarisation with collected data, coding, identifying key ideas of interest, identifying candidate themes,

Box 2 Sample of prompt questions

- ▶ What can you tell me about your dizziness? What do you experience?
- ▶ What aspects of your dizziness have the greatest impact on your life and in what way?
- ▶ What makes living with your dizziness easier/harder?
- ▶ What strategies do you use to manage your condition?

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, who had read and coded a selection of transcripts at random, to discuss coding and initial impressions. Coding was returned to and improved on in a recursive manner primarily by AS and GT (coauthor experienced in thematic analysis). 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 1](#) for an overview of participant characteristics).

Six interviews took place in person, one via Skype and one over the phone as preferred by the participants. Two participants submitted postinterview 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 speculative, was perceived as highly important for validation. Most participants perceived validation to be withheld due to the invisibility of PPPD, absence of clear diagnostic markers and widespread unfamiliarity with the condition among health professionals and the public:

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

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

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

When asked to describe their dizziness, participants would often resort to imprecise, vague or incohesive language. Failing to find the vocabulary that encapsulated

Table 1 Participant characteristics

Participant	Gender	Age	Ethnicity	Approx. time postonset 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.

their experience was perceived by most participants as embarrassing and frustrating, with some becoming visibly agitated when trying to do so:

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

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

I have no idea what is wrong with me; probably it's all in my head!' (Thea)

Invisibility and contestability of PPPD featured in all participant interviews and was mostly perceived as a problematic:

The hardest thing with this particular thing is that it is not a visible thing (.) yeah, that can make it difficult. (Lyna)

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

I don't know how many times I wished I had lost an arm or something instead of, which sounds horrible and sounds really selfish because I don't know how difficult it would be to have lost a limb or something but just it is more visual so you feel like people will understand. (Elvy)

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

Based on past experience it hindered and not helped (.) so it's better to say nothing and seeming as normal as possible cause the more flawed you seem, the more they sort of go 'oh she's got this and this wrong', it's sort of like a black mark against you, the more normal you can seem and the less maintenance the better I think [...] I never draw attention to it or make a big deal of it, cause they look at you as a hypochondriac, so it's better to just say nothing. (Molly)

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

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

[...] the other thing I would say is 'that it's real' you know, 'it's real, and I think it's (.)

You feel embarrassed to say what it is because you can't really describe (.) it's kind of something and nothing, if you know what I mean? (Thea)

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

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

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

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

All participants indicated being listened to and being understood was crucial to validation, and health professionals who showed an interest in participants and their situation were perceived as trustworthy. Thea stated that an open discussion with an interested and understanding

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

Regardless of validation, participants still framed the condition as draining them of resources and well-being, which we will discuss in relation to the next theme.

I'm a shadow of my former self

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

Feeling different appeared to be sensory in nature and was often explained as 'feeling off', 'not feeling your usual self' or 'not feeling normal'. For example, Thea said she did 'not feel sick or unwell', she just did 'not feel right'.

Feeling different was also often referred to as 'feeling overwhelmed', 'disoriented' or 'muddled' and appeared closely related to other symptoms participants experienced such as nausea or visual disturbances:

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

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

When I wake up and I have a good day then I just think that I am cured [laughs] I sort of forget (.) because I get back into what feels normal to me. (Lyna)

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

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

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

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

Mmm (.) yeah, I think a normal person is I guess someone that doesn't have this. That would without thinking (.) as they drop something just pick it up

without thinking or if they stand and have to talk to someone for a long time, that just stand and they wouldn't have to think 'right, so I need to stand near a wall, so I can touch it and don't fall over' or I ideally sit down [...] you have to think about alternatives (.) it's all going through my head, whereas a normal person would just do it without thinking. (Molly)

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

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

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

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

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

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

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

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 coexisting. 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:

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

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

- Positive thinking or self-talk. For example, by telling herself ‘today will be a good day’, Elvy used positive thinking as a way to keep hope alive.
- Goal setting. Although most participants stated they inherently knew their goals were unattainable and as such rarely achieved, the process of goal setting appeared to sustain hope.
- Participation in activities that promote health and well-being. For example, Lyna talked about how doing a low intensity cardioprogram on good days gave her some hope.
- Drawing strength from incremental improvements or sudden realisation an improvement had occurred. In Sofie’s case, it was the sudden realisation that the incidences of unsteadiness she experienced when walking into a crowd had become less frequent and severe.

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

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

It was also apparent that hope was endangered or lost by the lack of knowledge and prognostic uncertainty.

I think it’s just the frustration of not knowing (.) if I am actually ever going to get better as well, cause nobody, it’s like how long is a piece of string, it sort of (.) if I had like a clear ‘yes you definitely going to get better’ then I go ok, eventually I don’t know how long it’s gonna take but I will (.) hopefully, I will get there, but I just don’t believe it myself. (Elvy)

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

I could not live with this, if it was forever (.) I would get really depressed. (Ava)

Losing hope appeared to be a painful process and having hope taken away was described as cruel. Losing hope seemed to go hand in hand with a range of emotions such as sadness, disappointment, betrayal, anger, grief, self-reproach and regret:

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

Similarly, Ava commented:

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

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

Yeah you have to (.) kind of have to suck it up I guess and move on. (Molly)

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

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

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

I think it was just gradually getting used to it (.) yeah, is almost like become accepting that I have these symptoms or whatever it is (.) I think it is like anything isn't it, when you kind of accepting that you have something and it is always going to be with you (.) you just get on with things. (Sofie)

Getting on with it appeared to involve changing hopes for the future, and making conscious lifestyle changes as a strategy for coping. Strategies included managing

situations and adapting activities (eg, pacing and planning), all of which were aimed at keeping the participant feeling safe and comfortable. The fluctuating nature of PPPD and the associated experience of having hope 1 min and losing hope the next meant that getting on with it was not an easy process. Some participants seemed to actively resist the getting on with it process, as this was seen as giving in, while others seemed to come to 'some sort of acceptance' fairly quickly, and had resigned themselves to the idea that adaptation was needed for survival.

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

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 well-being 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 focused 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 ageing person, effective treatment and support translated predominantly to prevention of falls and falls-related sequelae, having access to social services, and provision of home care and mobility aids.¹² These were not relevant to participants in the present study where, in absence of a cure, helpful and desirable support was associated with having opportunities for open and supportive discussions with health professionals that helped them make sense of their condition, its disruption to self-identity and life trajectory. Although the experience of altered sense of self and biographical disruption was also not a new finding and has been extensively explored in the chronic conditions literature,^{59–62} it has never been thoroughly explored in the context of vestibular disorders.

Another interesting finding in this study was the participants' inability to articulate and make sense of their symptoms, which they perceived as frustrating and embarrassing, jeopardised self-validation. When self-validation is threatened, individuals engage in self-stigmatisation.^{29 33 34} These mental models are known to influence personal experiences of a health condition, attitudes towards it, ways individuals adapt to their situation and what coping strategies they apply to live a meaningful life, all of which ultimately impact health outcomes.^{63 64} Current clinical guidelines emphasise the increasing importance of detailed symptom description and pattern recognition as the basis for accurate diagnosis and effective treatment.^{1–3 7} When clinicians focus on accurate symptom description and sense making it may signal to clients experiencing PPPD that their credibility is in question, exacerbating self-stigmatisation and potentially damaging therapeutic relationships. Participants highlighted the importance of having a diagnosis; however, health professionals may benefit from reflecting on current diagnostic practices and processes, and be cognisant of how these are perceived by clients. Alternate approaches that provide reassurance and focus on the experience of dizziness in the context of the client's personal situation, may counter self-stigmatisation, demonstrate medical validation and lead to more satisfactory care experiences and better outcomes.

Further thought should be given to what constitutes effective treatment of PPPD. Existing literature suggests three dominant treatment approaches: vestibular rehabilitation, pharmaceutical management and cognitive-behavioural therapy.^{2 16 18 22 24 64–69} What is often missing from the predominantly biomedical PPPD literature is a focus on the need for psychosocial support and how

failing to provide this may diminish the effectiveness of those recommended treatments. In the literature, unsatisfactory outcomes are frequently ascribed to poor patient motivation or non-adherence to prescribed therapeutic interventions.⁶⁹ In the present study, supported by the findings of Corbin and Strauss,⁷⁰ the emotional and cognitive load resulting from (self)stigmatisation, disruption to self-identity and life-trajectory and fear for the future detracted from other rehabilitation efforts. Identifying and acknowledging these factors as well as gaining insight in the patient's priorities and support needs should form a fundamental part of treatment. In fact, paying attention to individual and context-specific psychosocial support needs may be the gateway to effective treatment and better outcomes.

Guidance on how to establishing relationships, where an open and more meaningful dialogue can take place, as well as the benefits of taking a more person-centred approach to clinical practice is present in the existing literature.^{52 54 71 72}

CONCLUSION

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

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REFERENCES

- Hain. Epidemiology of Dizziness. http://dizziness-and-balance.com/practice/approach/dizzy_epi.html (accessed Dec 2014).
- Herdman SJ, Rehabilitation V. *Vestibular rehabilitation*. 3rd edn. Philadelphia, USA: F. F. A. Davis Company, 2007.
- Sloane PD, Coeytaux RR, Beck RS, et al. Dizziness: state of the science. *Ann Intern Med* 2001;134:823–32.
- Hannaford PC, Simpson JA, Bisset AF, et al. The prevalence of ear, nose and throat problems in the community: results from a national cross-sectional postal survey in Scotland. *Fam Pract* 2005;22:227–33.
- Matheson AJ, Darlington CL, Smith PF. Incidence of dizziness in the elderly: correlation with oculomotor, optokinetic and postural function. *NZ J Psychol* 1999;28:17–22.
- Jönsson R, Sixt E, Landahl S, et al. Prevalence of dizziness and vertigo in an urban elderly population. *J Vestib Res* 2004;14:47–52.
- Duracinsky M, Mosnier I, Bouccara D, et al. Literature review of questionnaires assessing vertigo and dizziness, and their impact on patients' quality of life. *Value Health* 2007;10:273–84.
- Lasisi AO, Gureje O. Disability and quality of life among community elderly with dizziness: report from the Ibadan study of ageing. *J Laryngol Otol* 2010;124:957–62.
- Maarsingh OR, Dros J, Schellevis FG, et al. Causes of persistent dizziness in elderly patients in primary care. *Ann Fam Med* 2010;8:196–205.
- Mueller M, Strobl R, Jahn K, et al. Burden of disability attributable to vertigo and dizziness in the aged: results from the KORA-Age study. *Eur J Public Health* 2014;24:802–7.
- Nanda A, Tinetti ME. Chronic Dizziness and Vertigo. *Geriatric Medicine: An Evidence-Based Approach*. New York, NY: Springer, 2003.
- Olsson Möller U, Hansson EE, Ekdahl C, et al. Fighting for control in an unpredictable life - a qualitative study of older persons' experiences of living with chronic dizziness. *BMC Geriatr* 2014;14:97.
- Tinetti ME, Williams CS, Gill TM. Health, functional, and psychological outcomes among older persons with chronic dizziness. *J Am Geriatr Soc* 2000;48:417–21.
- Uneri A, Polat S. Vertigo, dizziness and imbalance in the elderly. *J Laryngol Otol* 2008;122:466–9.
- Neuhauser HK, Radtke A, von Brevener M, et al. Burden of dizziness and vertigo in the community. *Arch Intern Med* 2008;168:2118–24.
- Bronstein AM, Lempert T, Seemungal BM. Chronic dizziness: a practical approach. *Pract Neurol* 2010;10:129–39.
- Staab JP. Chronic subjective dizziness. *Continuum* 2012;18:1118–41.
- Staab JP. Chronic dizziness: the interface between psychiatry and neuro-otology. *Curr Opin Neurol* 2006;19:41–8.
- Ruckenstein MJ, Staab JP. Chronic subjective dizziness. *Otolaryngol Clin North Am* 2009;42:71–7.
- Bittar RS, Lins EM. Clinical characteristics of patients with persistent postural-perceptual dizziness. *Braz J Otorhinolaryngol* 2015;81:276–82.
- Holle D, Schulte-Steinberg B, Wurthmann S, et al. Persistent Postural-Perceptual Dizziness: A Matter of Higher, Central Dysfunction? *PLoS One* 2015;10:e0142468.
- Staab JP, Eckhardt-Henn A, Horii A, et al. Diagnostic criteria for persistent postural-perceptual dizziness (PPPD): Consensus document of the committee for the Classification of Vestibular Disorders of the Bárány Society. *J Vestib Res* 2017;27:191–208.
- Odman M, Maire R. Chronic subjective dizziness. *Acta Otolaryngol* 2008;128:1085–8.
- Popkirov S, Staab JP, Stone J, et al. Persistent postural-perceptual dizziness (PPPD): a common, characteristic and treatable cause of chronic dizziness. *Pract Neurol* 2018;18:5–13.
- Shepard NT. Persistent Postural-Perceptual Dizziness [audio podcast No.27; April 2015]. www.neuropt.org/special-interest-groups/vestibular-rehabilitation/podcasts (accessed on 09 Oct 2015).
- Seemungal BM, Passamonti L. Persistent postural-perceptual dizziness: a useful new syndrome. *Pract Neurol* 2018;18:3–4.
- Staab JP, Ruckenstein MJ. Chronic subjective dizziness: effect of course of illness on treatment outcome. *Arch Otolaryngol Head Neck Surg* 2005;131:675–9.
- Mendel B, Lützen K, Bergenius J, et al. Living with dizziness: an explorative study. *J Adv Nurs* 1997;26:1134–41.
- Armentor JL. Living with a contested, stigmatized illness: experiences of managing relationships among women with fibromyalgia. *Qual Health Res* 2017;27:1–11.
- Holmes S, Padgham ND. A review of the burden of vertigo. *J Clin Nurs* 2011;20:2690–701.
- Larun L, Malterud K. Identity and coping experiences in Chronic Fatigue Syndrome: a synthesis of qualitative studies. *Patient Educ Couns* 2007;69:20–8.
- Lonardi C. The passing dilemma in socially invisible diseases: narratives on chronic headache. *Soc Sci Med* 2007;65:1619–29.
- Petrie KJ, Weinman J. Why illness perceptions matter. *Clin Med* 2006;6:536–9.
- Rebman AW, Aucott JN, Weinstein ER, et al. Living in limbo: contested narratives of patients with chronic symptoms following Lyme disease. *Qual Health Res* 2017;27:1–13.
- Ten Voorde M, van der Zaag-Loonen HJ, van Leeuwen RB, et al. Dizziness impairs health-related quality of life. *Qual Life Res* 2012;21:961–6.
- Turner J, Kelly B. Emotional dimensions of chronic disease. *West J Med* 2000;172:124–8.
- Reuben DB, Tinetti ME. Goal-oriented patient care — an alternative health outcomes paradigm. *N Engl J Med Overseas Ed* 2012;366:777–9.
- Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. *Med Care Res Rev* 2013;70:351–79.
- Thorne SE. *Interpretive description (Vol. 2)*. Walnut Creek, CA: Left Coast Press, 2008.
- Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 1997;20:169–77.
- Khawaja M, Boddington B. Too early to retire? Growing Participation of Older New Zealanders in the Labour Force. *NZ Pop Rev* 2009;35:75–93.
- Braun V, Clarke V. *Successful Qualitative Research: a practical guide for beginners*. London, England: Sage, 2013.
- Clarke V, Braun V, Hayfield N. Thematic analysis. Smith J, ed. *Qualitative psychology: a practical guide to research methods*. 3rd ed. London, England: Sage, 2015.
- Terry G. Doing thematic analysis. In: Lyons IE, Coyle A, eds. *Analysing qualitative data in psychology*. 2nd edn: London, England Sage, 2016.
- Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn* 1983;5:168–95.
- Hale ED, Treharne GJ, Kitas GD. The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology* 2007;46:904–6.
- Furze G, Roebuck A, Bull P, et al. A comparison of the illness beliefs of people with angina and their peers: a questionnaire study. *BMC Cardiovasc Disord* 2002;2.
- Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In: Cameron LD, Leventhal H, eds. *The Self-Regulation of Health and Illness Behaviour*. London, England: Routledge, 2003.
- Nettleton S. 'I just want permission to be ill': towards a sociology of medically unexplained symptoms. *Soc Sci Med* 2006;62:1167–78.
- Roger K, Wetzel M, Hutchinson S, et al. "How can I still be me?": Strategies to maintain a sense of self in the context of a neurological condition. *Int J Qual Stud Health Well-being* 2014;9:23534.
- Yardley L, Beech S. 'I'm not a doctor': deconstructing accounts of coping, causes and control of dizziness. *J Health Psychol* 1998;3:313–27.
- Bright FA, Kayes NM, Cummins C, et al. Co-constructing engagement in stroke rehabilitation: a qualitative study exploring how practitioner engagement can influence patient engagement. *Clin Rehabil* 2017;31:1396–405.
- Cole MB, McLean V. Therapeutic relationships re-defined. *Occupational Therapy in Mental Health* 2003;19:33–56.
- Kayes N, Mudge S, Bright F, et al. Whose behaviour matters? Rethinking practitioner behaviour and its influence on rehabilitation outcomes. In: McPherson K, Gibson B, LePlege A, eds. *Rethinking rehabilitation*. London: CRC Press, 2015.

55. Dwamena F, Holmes-Rovner M, Gaulden CM, *et al.* Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2012;12:CD003267.
56. Little P, Everitt H, Williamson I, *et al.* Observational study of effect of patient centeredness and positive approach on outcomes of general practice consultations. *BMJ*;20013:908–11.
57. Bronstein AM, Golding JF, Gresty MA, *et al.* The social impact of dizziness in London and Siena. *J Neurol* 2010;257:183–90.
58. Neff BA, Staab JP, Eggers SD, *et al.* Auditory and vestibular symptoms and chronic subjective dizziness in patients with Ménière's disease, vestibular migraine, and Ménière's disease with concomitant vestibular migraine. *Otol Neurotol* 2012;33:1235–44.
59. Asbring P. Chronic illness -- a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *J Adv Nurs* 2001;34:312–9.
60. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982;4:167–82.
61. Delbene R. Patients' narratives of chronic illnesses and the notion of biographical disruption. *Commun Med* 2011;8:17–27.
62. Greenstreet W. From spirituality to coping strategy: making sense of chronic illness. *Br J Nurs* 2006;15:938–42.
63. Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease. *BMJ* 2007;335:968–70.
64. Crisan H, Courtis Ndes, des Courtis A, *et al.* Persistent Postural-Perceptual Dizziness (PPPD): A systematic review of 10 Years' progress in diagnosis and treatment. *J Otol Rhinol* 2016;5:5.
65. Edelman S, Mahoney AE, Cremer PD. Cognitive behavior therapy for chronic subjective dizziness: a randomized, controlled trial. *Am J Otolaryngol* 2012;33:395–401.
66. Holmberg J, Karlberg M, Harlacher U, *et al.* One-year follow-up of cognitive behavioral therapy for phobic postural vertigo. *J Neurol* 2007;254:1189–92.
67. Holmberg J, Karlberg M, Harlacher U, *et al.* Treatment of phobic postural vertigo. A controlled study of cognitive-behavioral therapy and self-controlled desensitization. *J Neurol* 2006;253:500–6.
68. Thompson KJ, Goetting JC, Staab JP, *et al.* Retrospective review and telephone follow-up to evaluate a physical therapy protocol for treating persistent postural-perceptual dizziness: A pilot study. *J Vestib Res* 2015;25:97–104.
69. Yardley L, Donovan-Hall M, Smith HE, *et al.* Effectiveness of primary care-based vestibular rehabilitation for chronic dizziness. *Ann Intern Med* 2004;141:598–605.
70. Corbin J, Strauss A. Managing chronic illness at home: three lines of work. *Qual Sociol* 1985;8:224–47.
71. McCormack B, Karlsson B, Dewing J, *et al.* Exploring person-centredness: a qualitative m r studies. *Scand J Caring Sci* 2010;24:620–34.
72. Street RL, Makoul G, Arora NK, *et al.* How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74:295–301.