Living with Ménière’s disease: an interpretative phenomenological analysis

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ABSTRACT

Purpose: To explore the meanings of Ménière’s disease from the perspective of people living with this condition and to understand what was considered significant and important in participants’ everyday lives.

Materials and methods: Four women with Ménière’s disease participated in face-to-face semi-structured interviews. Accounts were recorded, transcribed, and analysed using an iterative process integral to Interpretative Phenomenological Analysis.

Results: Three interconnected themes were identified. “You have no control whatsoever” conveys participants’ perceptions of vertigo as having a disruptive and ongoing impact on physical and psychosocial function in everyday life. “Ménière’s takes away your life completely” describes Ménière’s as impinging on participants’ most meaningful activities and relationships, and as restricting their ability to live their lives on their own terms. “You get on with life” recounts participants’ efforts to refashion their lives whilst living with this condition and manage its most harmful effects. The psychosocial impact of living with Ménière’s disease and its relevance to rehabilitation is discussed.

Conclusions: Ménière’s disease has an enduring physical and psychosocial impact. Clinicians who acknowledge and respond to an individual’s subjective experience of their condition may be key to their engagement in therapy. Service users should have a voice in health service design and delivery.

IMPLICATIONS FOR REHABILITATION

- Ménière’s disease is a long-term disabling condition that not only impacts on physical and psychosocial functioning but also restricts quality of life through stigmatisation.
- Fear of triggering an attack of vertigo may prevent people with Ménière’s disease from engaging with rehabilitation.
- Therapists who adopt a biopsychosocial approach and who recognise patients’ symptoms as a positive form of resistance may be better equipped to empathetically support patients to engage in new activities that may be vital to improving their lives.

Introduction

Ménière’s disease is an idiopathic vestibular disorder of the inner ear, characterised by spontaneous vertigo, tinnitus, hearing loss, and aural fullness [1]. Symptoms may be experienced during sudden, usually unilateral, episodic attacks which generally last from 20 min to several hours, and are often accompanied by imbalance, sweating, nausea, and vomiting [1–3]. Symptom severity and the frequency of attacks may fluctuate considerably from person to person [2]. As the condition progresses, symptoms, such as disequilibrium, hearing loss, and tinnitus persist between acute attacks [1]. After 5–15 years, severe acute attacks of vertigo are thought to diminish or “burn out,” but unsteadiness, tinnitus, and moderate hearing loss may continue in the long-term [1].

Ménière’s disease is typically diagnosed between the ages of 30 and 60 years [1], with a female to male ratio of 1.89:1 [4]. Diagnosis is often delayed because the four symptoms that characterise this condition may not emerge simultaneously [1], and other peripheral and central vestibular disorders must be ruled out before a diagnosis is made [3]. Estimates of prevalence vary considerably, ranging from 21 to 37 per 100,000 in Japan [5] to 513 per 100,000 in Finland [6]. Prevalence may also increase with age [4].

Activity limitations and participation restrictions are a significant feature of Ménière’s disease [7]. Many people living with Ménière’s disease may restrict everyday activities in an effort to reduce possible triggers [8] and to avoid embarrassment or discomfort when coping with symptoms in social situations [2]. These behaviours, initially adopted as a management strategy, may also turn into lifestyle adaptations that diminish participation in meaningful and enjoyable activities in the long-term [2]. Such actions are thought to delay psychological and neurophysiological recovery, prolong symptoms, and add to distress [9]. The physical consequences and psychological effects of long-term, and distressing symptoms may further disrupt participation in valued activities and interests in daily life [2,10,11]. The unpredictability
of attacks and worries about managing vertiginous episodes are thought to make Ménière’s disease particularly difficult to deal with [11].

Ménière’s disease has been reported as having a significant negative impact on emotional and psychological well-being [11–17] and quality of life [10,16,18,19]. Post-traumatic stress disorder, health anxiety, intolerance of uncertainty [14,15], and fear of acute attacks [20] are also thought to contribute to the distress reported by people living with this condition. Support from family, significant others, and healthcare professionals may mitigate some of the negative consequences of Ménière’s disease on psychological well-being [10]. Individuals have also reported that Ménière’s disease may have a positive effect on relationships with significant others, personal development, appreciation of life, personal strength, and spirituality [21].

Treatment options are limited, but vestibular suppressants and antiemetics may minimise symptoms during attacks [3], and Betahistine may reduce the frequency and severity of vertiginous episodes [22]. Medical ablation with Gentamicin resolves vertigo in most cases but further hearing loss may be experienced, and the effects on long-term balance impairment are not known [1]. Vestibular rehabilitation usually delivered by physiotherapists is not curative but uses exercises to deliberately and repetitively provoke symptoms to habituate, compensate, or reduce responsiveness to stimuli, or to substitute lost vestibular function using other balance pathways [23]. Vestibular rehabilitation may improve the perception of dizziness symptoms [24], dizziness handicap, postural control, and quality of life in people with Ménière’s disease [25,26], as well as the ability to cope with and understand symptoms, reduce anxiety and symptom severity, and diminish negative beliefs about symptoms [27]. Implicit psychotherapeutic elements within physical rehabilitation programmes are also thought to contribute to success [9]. For example, vestibular rehabilitation programmes may teach participants that symptoms are tolerable and manageable, as well as promoting positive ways of coping, and becoming more active [15].

Many authors have argued that people living with Ménière’s disease should be offered psychological support to help mitigate the negative psychological, emotional, and social consequences of living with this condition [2,1,14–16,18,21,28,29]. Psychological therapies and peer support groups that aim to improve the understanding of Ménière’s disease, increase participation in everyday life, and diminish the negative impact on quality of life and psychosocial functioning have been advocated [2,13,30,31]. Multiple self-help and self-care strategies, such as developing and adopting positive approaches, and/or avoiding of precipitating factors, as well as complementary and alternative medicine, have been identified and positively appraised by people living with Ménière’s disease [32]. Common elements of these strategies include; pursuing self-health agency and searching for a sense of self, regaining control over health and life in general, and receiving support from significant others and healthcare practitioners [32]. However, despite evidence that healthcare professionals appreciate the relevance of adopting a collaborative, patient-focussed approach, a comparison of current practice for people with Ménière’s disease against best practice models for chronic illness revealed that current care practices may not meet patients’ needs or facilitate high-quality outcomes due to a lack of coordinated care and limited support for patients to actively participate in their own care [33].

To date, only a limited number of qualitative studies have been undertaken about the experience of living with Ménière’s disease. In two of these studies [8,34], participants’ voices and the meaning of this condition in individual’s lives were largely absent from the final account because of the way in which data were aggregated to meet the main aims of these studies. Long and Bennett [35] explored participants’ experiences of complementary and alternative medicine using 20 researcher-guided written narratives, and 23 letters of correspondence to a support group magazine. The narratives varied in length and detail, and although clarifications were sought from one participant, the method did not allow further probing or questioning of participants’ accounts. A wide range of beneficial interventions was reported from participants who were likely to be in favour of these approaches. Erlandsson et al. [12] explored illness adjustment and interpretation of symptoms associated with Ménière’s disease via a focus group (n = 4) and four semi-structured interviews with participants in Sweden. Discussion topics centred on beliefs and expectations of Ménière’s disease, psychosocial consequences, adjustment processes, and experiences of Swedish healthcare. Participants recounted strong negative emotions particularly in relation to their first attack which they linked to future social withdrawal. Healthcare services were also criticised for providing limited information about Ménière’s disease, and a lack of opportunity to discuss worries and fears. Participants also suggested that meeting someone else with Ménière’s disease soon after diagnosis would be beneficial. In a more recent qualitative study, Bell et al. [36] explored the impact of Ménière’s disease on mundane as well as more meaningful social practices with twenty people with this condition and eight partners/spouses in the United Kingdom (UK). Findings suggested that after foregoing social practices that had become unsustainable in light of the daily disruptions caused by Ménière’s disease, time and social support were needed to find meaning from newly taken on social practices.

Bell et al. [36] added to the understanding of Ménière’s disease from the perspective of social practice theory, and Erlandsson et al. [12] offered as yet the only study to explore how people living with Ménière’s disease experienced and interpreted their symptoms during the course of the condition. However, relatively little is known about how individuals make sense of and manage Ménière’s disease in their own terms, in the contexts of their everyday lives, and in the context of healthcare provision. This type of knowledge is valuable because it can bring to light unanticipated views and perspectives that may challenge unexamined assumptions about rehabilitation practices, and what people living with long-term health conditions identify as critical to their well-being. This study, therefore, aimed to explore the meanings of Ménière’s disease from the perspective of individuals living with this condition, and to deepen the understanding of what is important in their lives and in their experiences of rehabilitation, focussing on participants’ concerns and priorities.

Materials and methods

Theoretical perspective

This study offers an Interpretative Phenomenological Analysis [37,38] of participants’ accounts of living with Ménière’s disease. This research approach involves detailed examination of participants’ lifeworlds, how people make sense of a lived-through concrete experience, and the meanings they derive from their experiences [38]. Interpretative Phenomenological Analysis has an idiographic focus; first, in the sense that researchers undertake a detailed and in-depth analysis, and second in the sense of their commitment to understanding an experiential phenomenon from the perspectives of particular people in particular contexts [38].
Table 1. Participant characteristics.

| Name (pseudonym) | Age (years) | Marital status | Occupation | Interview location (duration) | Time since onset (years) |
|------------------|-------------|----------------|------------|-------------------------------|-------------------------|
| Angela           | 71          | Married        | Retired health care support worker | Local community (63 min) | 35                      |
| Yvonne           | 61          | Married        | Retired early on health grounds previously a senior infant school teacher | Home (89 min) | 12                      |
| Esther           | 80          | Married        | Retired civil servant | Home (89 min) | 48                      |
| Joanne           | 49          | Married        | Medically retired, former financial consultant | Local community (102 min) | 6                       |

Angela lived with Ménière’s disease for twenty years before being diagnosed. She experienced severe attacks of vertigo for over 25 years before undergoing successful surgery. She previously took prescribed medication to control vomiting during an attack but reported only one severe attack of vertigo since her surgery eight years prior to taking part in the study. At the time of the interview, Angela had difficulty with her balance and occasionally used a walking stick. She also had permanent tinnitus, and hearing loss. She used hearing aids but struggled with sound distortion.

Yvonne was diagnosed with Ménière’s disease after living with symptoms for six years. She reported frequent (approximately monthly) and severe episodes of vertigo, constant tinnitus and variable degrees of hearing loss. Yvonne took prescribed medication to control symptoms during an attack. She sometimes required a walking stick.

Esther was diagnosed with Ménière’s disease relatively quickly while she was in her early 30’s. She described frequent vertigo attacks (approximately weekly) and took prescribed medication 2-3 times a day to help control symptoms. She also had constant tinnitus and reported distorted and impaired hearing. Esther described herself as feeling unbalanced most of the time. She did not report using walking aids.

Joanne reported a relatively quick diagnosis which happened within a few weeks of the onset of symptoms. She described moderate to severe attacks at least once a week and symptoms of vertigo and tinnitus, as well as hearing loss for which she used hearing aids. Joanne used a walking stick and occasionally a motorised wheelchair due to impaired balance.

The research coordinator of the Ménière Society UK (a national charity for people with dizziness and balance disorders) gave the principal researcher (KKT) permission to contact society members who had previously agreed within the local group that the contact details of interested participants were shared. The recruitment was conducted through the leader of a London branch of the organisation. It was advertised in the local group and via social media. Interested participants were contacted by KKT and were given the opportunity to ask further questions. Interview dates were arranged with those who subsequently volunteered to participate.

Participants were all members of the Ménière Society, UK, over the age of 18 years, able to converse fluently in English. All participants had a self-reported medical diagnosis of Ménière’s disease, and experienced hearing loss, vertigo, tinnitus, and unsteadiness which would support the diagnosis. In order to offer an insightful account of their lived experience with Ménière’s disease, all participants had experienced their initial symptoms for at least three years, and were willing to discuss their experiences in detail.

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years. Individuals with other vestibular disorders were excluded. Five individuals requested information about the study. Four agreed to participate. The other potential participant did not meet the inclusion criteria as she was newly-diagnosed. Participants’ ages ranged from 49 to 80 years (median 66 years), and they had lived with Ménière’s disease from 6 to 48 years (median 23 years). All participants were white British women, married, retired or medically retired, and lived in Greater London, UK. See Table 1 for details. Pseudonyms have been used to preserve anonymity and confidentiality.

### Data collection

Data were collected through face-to-face semi-structured interviews. This method gives the researcher some control of the overall topic whilst at the same time allowing participants to talk freely [43]. Giving participants latitude to talk about what is important to them is central to Interpretative Phenomenological Analysis [38]. As research participants may find it distressing to talk about personally meaningful and possibly unanticipated topics, they were advised of this possibility before volunteering to participate and were offered the opportunity to pause or stop the interview if necessary. Telephone support from the Ménière’s Society was also available.

A semi-structured interview schedule (Supplementary material) focusing on participants’ lived experience was prepared using guidance from Smith et al. [38]. Questions were kept as open as possible to privilege participants’ perspectives and priorities, and to encourage them to talk at length. Questions explored everyday life with Ménière’s disease, the impact of this condition on the self and others, difficulties and positive experiences, management of Ménière’s disease, experiences of healthcare, including physiotherapy, and future outlook. According to participants’ stated preference, two interviews were conducted in participants’ own homes, and two in quiet meeting rooms in the local community. Interviews lasted between 63 and 103 min (median 89 min) and were conducted using a conversational style. All interviews were carried out by KKT, digitally recorded and fully transcribed. The first interview was used as a pilot, but as no significant changes were made to the interview guide, the data were used in the final analysis.

### Data analysis

Following Smith et al. [38], data analysis started with a period of immersion in the transcripts and proceeded idiographically by listening and re-listening to each recording and reading the transcripts. An exploratory free text analysis was undertaken. Analysis centred on understanding what mattered to participants in their lives, and how they made sense of their experiences. During re-reading, exploratory and indicative notes from the first stage of the analysis were re-documented, patterns inferred from the analysis were verified, and then mapped and connected. These connections were collated and labelled as candidate themes. Recurring themes from the entire data set were then identified, and clustered into convergent superordinate themes that encapsulated the meaning of Ménière’s disease for the participants in this study. Three superordinate themes and seven subthemes were inferred from the analysis (Table 2).

The researchers are women, with a therapy background. KKT, the principal investigator, who led the analysis, is a physiotherapist with a special interest in vestibular rehabilitation. AMc (occupational therapist) and EC (physiotherapist), are qualitative researchers with a particular interest in Interpretative Phenomenological Analysis. Their role in the analysis was not to verify the themes, but to open up the analysis by exploring the principal investigator’s understandings and interpretations of the provisional themes, through a process of critical dialogue [44]. This process involved the discussion of the meaning of metaphors and some of the more psychologically complex data.

### Findings

#### Theme 1: Vertigo in the driving seat: “you have no control whatsoever”

In recounting their lives with Ménière’s disease, all participants described vertigo (violent spinning) as the symptom that posed the most significant challenge to themselves, and their everyday lives. Vertigo precipitated not only a disturbing loss of bodily control and a sense of acute social embarrassment but also a deep sense of fear about the next attack. These three concerns are described in the following three subthemes.

#### Subtheme 1: Loss of bodily control

Participants experienced an unwelcome and radical transformation of their embodied selves, and a disturbing foregrounding of the body and bodily functions, during attacks. All participants emphasised how unwell and powerless they felt during these episodes:

> You just get so dizzy and, um, it’s very ... You can’t walk or stand. Um. It’s very, very hard to explain. You just feel so ill, really […] Spinning, feeling sick, very sick. […] You’ve just got, you know no control, really. (Esther)

> It’s like being drunk, feeling light-headed and dizzy and sick all in the same go but at the same time having a hangover where you feel foul. […] It’s drunk in the sense that you don’t have control. (Joanne)

Angela not only emphasised the physical impact of the attack but also situated her attacks within a deeply unpleasant and fearful psychological space (“the most awful place”), as well as a public place where, without warning, her body let her down in the most mortifying way:

> … I was fearful of having a spin in public. And when you have a spin or a drop attack and you get violent vomiting within a few minutes; and you can’t get up and go anywhere; which is followed by evacuation of the bladder, and in a very, very horrible case once, the bowel. It is very, very frightening … just the fear that it’s going to happen again, and you have got no control, sometimes, no warning.
Sometimes, you can feel poorly before it happens. And you get a slight warning but I’ve had it happen when it’s just kind of like a bolt out of the blue. Like … a drop attack, like someone shot me in the back. And I’ve clapped to the ground … Then, you are totally, utterly, totally out of control in the most awful place that you would never want to return to. (Angela)

Yvonne described an attack that strongly conveyed her sense not only of bodily dysfunction, but also of profound separation of herself from the world:

It’s like a goldfish bowl on my head. And it’s all pounding trying to get in but I can’t take that information in. And I don’t absorb information if there’s a lot going on … I don’t know, I seem to get rooted to the ground. I lose my balance but I can’t actually physically walk […] I can’t think to walk. […] I say it’s a goldfish bowl because I feel that I’m sitting in part of the world but I’m not actually in the world. It’s all going on around me and I … my head is spinning. Nobody really knows it’s spinning. I can’t do anything about it. Um, and I just feel in another world. I’m not part of it. I can’t reach out to the other world. (Yvonne)

The image of the goldfish bowl captured a disorientating sense of separation, of being simultaneously in and out of the world. Yvonne also described an awareness that to other people there appeared to be nothing intrinsically wrong, alluding to what she perceived as the invisibility of Ménière’s disease. She may have anticipated their gaze, and this unpleasant feeling may have rooted her to the ground.

All participants offered an understanding that some of the distress associated with living with vertigo may derive not only from a loss of bodily control but also participants’ experiences of, and perceptions about, having attacks in places where others could see them, and where they thought they might be harshly judged. This sense of loss of control is explored in the following subtheme.

Subtheme 2: Loss of control of the self in the social world

During an attack, participants perceived themselves as acting in a socially improper manner and expected that others thought similarly. Esther and Yvonne, in particular, felt diminished through what they assumed was the harsh appraisal of others, specifically with respect to false assumptions about intoxication. This type of negative appraisal may have been felt especially keenly because rather than being “generinely” ill, Yvonne and Esther suspected that others judged them as being in some way to blame for their behaviour. Esther dwelt on these experiences and recalled them with a sense of social horror. For example, she described having an attack of vertigo at a funeral and recalled staggering about and falling as she tried to give her condolences to the family. She thought about this episode a great deal, it distressed her, and it troubled her to think of herself as others may have seen her:

I hadn’t, definitely, had anything alcoholic that day [at a friend’s funeral]. And it’s so, so embarrassing, you know, to stagger about like that. That’s really, you know, I kept thinking about it when I got home. And uh, I just had to let it drop really, you know. It might seem as if, um, you keep on saying to them, oh, you know, ‘sorry’, they might think you’re covering up for drinking at that time, you know. I don’t know really. But that was awful, really awful. (Esther)

For Yvonne, this sense of embarrassment also seemed particularly acute when an attack happened in public, in front of colleagues and acquaintances:

…embarrassed by the vertigo as well, embarrassed. Um, embarrassed if I went out or if any other parents saw me because people do label you as being drunk and I’ve never drank at all … I just couldn’t carry on working, … and I stopped socialising completely. I withdrew from everybody … I was indoors and all I can say is the front door was just like black and I could not get past the front door. I just became agoraphobic and I can still … now, it was a tunnel that I’ve always said I was in and I couldn’t get out of that tunnel … It was impossible … so my life consisted of staying indoors all day … Um … yeah, just takes away your life completely […] I would try all day to get the door open […] On the odd day that I would manage a little walk, the anxiety and the pounding heart, and the panic didn’t seem worth doing. It was horrendous. Um … and I didn’t think I’d ever get past it at all. (Yvonne)

Yvonne assumed that she was the focus of critical appraisal which she recalled as having a significantly negative impact on her sense of self, and her everyday life. Her subsequent withdrawal from the world, from what she understood as the unsympathetic gaze and assessment of others (particularly the parents of the children at the school where she held a senior position), was described in psychologically troubling terms. Yvonne recalled the steps she took to shield herself from others, and of trying to contain the most distressing parts of living with Ménière’s disease, away from the public gaze. Although Yvonne’s actions could be interpreted as taking back control through managing the worst parts of her attacks (the public “display”), they also unfortunately rendered her unable to access or participate in the world outside, a world where she previously had status and found meaning. None of the other participants described the same degree of self-exclusion or the same degree of fear and panic about being outside as Yvonne.

Angela described losing her composure in front of others as particularly problematic for her. She admonished herself for losing control in this way and particularly for what she saw as a childish “silly” reaction to having an attack in public:

You get out of control. The anxiety controls you. And that is, no one wants that. You’ve got a fast heart rate, which is something you get when you’re having a spin. It sort of mirrors it and you don’t … if you’re having a spin or you’ve got anxiety. And then, you’d get anxious. I mean, it’s horrid. You lose control. And then, you do silly things. […] Well you could say, start crying in front of other people (mimics crying). (Angela)

Joanne also alluded to feelings of social discomfort in her account. However, she explained that over time she had grown in confidence in coping with an attack in public, and she felt it important not to let her feelings of embarrassment in front of strangers weigh heavily on her:

Oh, stuff it. I’m only here this once and I’m not putting up with this for that long. I’m just going to … It does make you more confident. You have to speak up to tell people how they can help you. You have to learn to get over embarrassment because things get embarrassing like when you need the toilet or when you’re falling over or when you’ve knocked something over. You have to learn how to cope with embarrassment. (Joanne)

It may be possible to infer from these accounts that the older participants (Esther, Angela, and Yvonne) who grew up in the 1930s–1960s may have been more concerned about meeting what they judged to be conventional standards of acceptable behaviour than the youngest participant (Joanne) who grew up in the 1970s–1980s. Status may also have been relevant. For example, Yvonne held a respected position in society as school teacher and, similarly, the older participants may have felt that they were expected to maintain what they understood as acceptable standards of adult behaviour by acting as role models for younger generations.

Subtheme 3: Living with fear and fighting for control. Despite living with vertigo for many years all participants portrayed each new attack as a very frightening experience:
You're not able to do anything umm, because of the fear factor that's inside you. You'll be ... the fright of it happening, you know. (Angela)

I was frightened of being dizzy on my own indoors but I could cope with it a bit. I was terrified of being out like it. (Yvonne)

... when the peak of the spin happens, I usually shout out in fear. (Joanne)

Even Esther, who had lived with vertigo for nearly 50 years, described herself as feeling increasingly fearful in the middle of a severe attack, as if she was unable to trust her previous experience that it would come to an end and that she could manage:

When you got these bad attacks, you know I still get them, you think 'Oh, gosh. Will it go?' If it hangs on a long time, you think, 'If I'm permanently like this', um you know, 'How would I ever cope?' [...] And um, you know, you really ... you don't know. You get really frightened, and you don't know anything. (Esther)

Participants’ accounts suggested that the most disturbing symptoms settled between attacks, and yet the psychological impact of each attack was long-lasting. A distrust of their Ménière’s endured, but perhaps more significantly, despite three participants living with this condition for over ten years, all participants described a deep-rooted fear of the next attack suggesting that time spent living with Ménière’s disease did not have a significant moderating effect. This fear about how the body may reveal itself during an attack, and how that might be experienced, and with whom, cast a shadow over their day to day activities, even when they felt free of the symptoms themselves. All participants anticipated episodes of vertigo, not in the sense of being able to predict when it would happen, but because the fear of the next attack occupied their thoughts as they carefully constructed their day to day lives to avoid triggering an attack:

I'm prone to panic attacks if I drive on the motorway. And I used to pooh-pooh panic attacks. Yes, that was me! Cirkey, never again. I do not take any risks driving anywhere where there is not a hard shoulder [...] I don’t ever drive fast because just in case when a lorry goes by me, it gives me a feeling that I might be going to have a spin. I know I'm not, I don’t think I am. But I get this panic attack feeling. (Angela)

It's sad but I just couldn’t do it (attend her son’s wedding reception). And if I had done have it and I've gone dizzy and gone down on the floor, I would have spoiled it for absolutely everybody, you know. So, it’s just not something that I can do. (Yvonne)

It's something ... I tend to watch, um, all movements. Um. Because if I sort of did something silly, I would definitely, um, have an attack. (Esther)

I just feel like there’s a cut-off before Ménière’s, after Ménière’s. There’s a definite before and after. Now, there are so many things that I can’t do and you feel like you have to replace them with things you can. But actually, it’s not possible to do one for one. It’s not possible. (Joanne)

Activities such as running a bath, bending down to pick something up, cleaning, driving, and visits to the dentist or the hairdressers, were carefully planned, or avoided. Participants recounted a running inventory of possible triggers which included noisy environments; watching television, listening to the radio, shopping, going to concerts, or cafes and restaurants, conversations with more than one person at a time; visual effects and visually conflicting environments such as strobe and fluorescent lighting, and objects passing across the sight line in cars or trains. This concern about everyday activities and environments and the ongoing fear of triggering the next attack negatively impacted on participants’ spontaneity and enjoyment:

Just not doing anything and enjoying anything ... like you know, cooking. Just popping outdoors. Everything, Everything indoors. (Angela)

In summary, all participants in this study described vertigo as the most frightening and disruptive part of their lives with Ménière’s disease. Each acute attack of vertigo was prefigured through participants’ fear of having an attack, or of triggering an attack. Participants stressed how unwell they felt during an attack and for a significant period of time afterward. The peak of an attack was experienced as a loss of bodily control and bodily integrity, and as an exposure of a vulnerable and diminished sense of self. Not all participants described such profound bodily disorientation as Yvonne which may reflect the severity of her attacks, but all participants talked about their more severe attacks as intense and frightening experiences. After an attack, participants described dwelling on the horror of what had happened, and the fear of it happening again. For the most part, they avoided, as far as possible, routine activities and actions that might trigger another attack. Each attack might, therefore, be understood as both the culmination of what had been most feared, as well as the portend of an attack yet to come. In this sense, the lived experience of vertigo could be understood as continuous through time, rather than occurring in discrete episodes which otherwise left participants free to live their lives as they chose.

Theme 2: A world turned upside down: “Ménière’s takes your life away completely”

All participants talked about the ways in which Ménière’s disease disrupted their projects, activities, and relationships. They all described the impact Ménière’s disease had on their family life and more generally described lives that had been held in check or constrained by this condition. These two ways in which their lives had been irrevocably changed by Ménière’s disease are explored in the following subthemes.

Subtheme 1: Ménière’s spoiling and disrupting family life

In describing the way an attack unpredictably intruded on an important occasion in family life, Joanne captured the sense of disruption echoed in other accounts:

... your Ménière’s doesn’t know it’s Christmas ... ‘Oh, by the way, I’m having a spin.’ ‘Oh, but it’s Christmas.’ ‘Sorry.’ (Joanne)

All participants described occasions such as weddings, funerals, and other planned events with friends or family, that had to be avoided or cancelled at the last minute, or where their involvement was prematurely curtailed due to an attack, or to avoid risking an attack:

It’s a handicap because I can’t do everything that everyone else can do. I can’t drive in the motorway. I would love to go to a gallery or to see my grandson who’s working in (another part of the country). But I feel if I was just thinking of getting car keys and go, I can’t. (Angela)

... if there’s things that I think that will upset me (provoke an attack), um, uh, if it’s to do with the family, I try to get on with it. And then, know that probably I will be quite ill the next day or that evening. (Esther)

Esther described herself as losing out on what she considered to be normal family life and the impact Ménière’s disease had on her children particularly:

I get, I get quite upset, you know. Especially when I was younger, um, I used to see people sort of twice my age doing things that I wanted to do and I couldn’t do. And um ... you know and ... if it affected the children, you know, when we ... We didn’t really have many holidays when they were younger. (Esther)
Like Esther, Yvonne and Joanne also believed the lives of close family members were constrained in some way by Ménière’s disease:

Retirement is very different from what you probably planned in your 40s... Um... so, we [sighs] so it affects both of us as to what your plans were, what you do on a daily basis. If he [husband] goes far afield... I know he's worried and he will phone me. And even if I am dizzy... I need to sound okay because I know then it will ruin what he's doing because he'll want to come back home to make sure I'm okay. (Yvonne)

Yvonne believed that Ménière’s disease impinged on both her and her husband’s visions for the future. She perhaps saw herself as a burden, and, even at her most vulnerable during an attack, she described trying to protect him from worrying about her. Her actions may have lessened feelings of guilt, but also demonstrated that Yvonne and her husband were both burdened by living with Ménière’s disease.

All participants alluded to feeling guilty about the impact of Ménière’s disease on close family members such as children, parents, and husbands, and questioned the extent to which they could meet their own expectations of being a good parent, wife or daughter:

I always felt like I wanted to say sorry or overcompensate in other ways, you know, because I wasn't like her [Joanne’s daughter] friends’ mums, you know. (Joanne)

Joanne talked in terms of disappointment as well as self-reproach. She explained later in the interview that these feelings stemmed from not having the same amount of energy or the same physical capacities as other mothers.

The importance of close family came across strongly in all accounts, however, some offers of help and support were also perceived as somewhat diminishing, and perhaps unwittingly reinforced participants’ perceptions of themselves as frail and vulnerable:

That annoys me if they [family members] take away what I might be able to try and do by saying, ‘Oh, well we thought you couldn’t, so we didn’t ask you.’ As much as they are being kind and thoughtful I would prefer to make my own choices. (Yvonne)

... if we’re having an honest and frank conversation, I feel it’s almost like being prostituted because you have everything bought for you because it’s not my money... But you do feel guilty and it makes you feel quite sick... but it makes you feel sort of claustrophobic. (Joanne)

Following medical retirement, the responsibility for providing financially for the household fell solely to Joanne’s husband. He also put money into an account for Joanne. However, she struggled to reconcile this arrangement with what she perceived as a cheapening of her status and her sense of self-worth. She also described herself as burdened by guilt, perhaps because she had previously measured her value to her family (and possibly her own self-worth), at least in part, in terms of the financial contributions she had made through her business career. Joanne’s sense of nausea, and claustrophobia might, therefore, be understood in an existential sense. These financial arrangements encroached upon and disrupted the possibility of defining herself on her own terms and limited her freedom to set the parameters of her existence in ways that were personally meaningful. Under the burden of these constraints she felt nauseous, suffocated, and oppressed; a sign perhaps of her realisation of the contingencies of her life with Ménière’s disease. None of the other participants talked in similar terms, although they all experienced similar restrictions on their opportunities and freedoms. Joanne, as the youngest participant and still of working age, may have felt more acutely burdened by these thoughts, and they may have been prominent in her thoughts at the time of the interview.

Subtheme 2: Living life bounded by Ménière’s. All participants described Ménière’s disease as placing limits on multiple aspects of their lives. Social, relational, intellectual, and cultural involvements were felt to be constrained by Ménière's disease, and the long-term nature of this condition meant that these constraints were experienced in all life stages following the onset of symptoms. Esther, who had lived with this condition for nearly 50 years, captured this sense of loss and disruption well:

It's all minuses, I think really. It, uh, upsets, uh, every sort of phase of your life, really, isn't it? You know, there are things you can't do. [...] You just have to cope. But it does take a lot of your life away. (Esther)

Joanne described herself as having lost her appetite for life, and perceived herself as inward-looking and lacking in confidence:

I don't have the zest for life I had before. I'm not as curious. I tend to play safe and insular because I know what's familiar and what doesn't make me unwell. I am less physical because I don't do the sport I used to do. Used to. That's the other one, 'Used to'. I am less confident in situations because I spend seven days a week, certainly five working days a week in the home. So, I'm very self-conscious making conversation about something political. (Joanne)

I feel tiny, I feel small, and I feel behind. Not below, but behind. I feel 'wait for me.' I could do that. Perhaps I'll find another way, 'wait for me.' But people want to do it for you. (Joanne)

Joanne portrayed a world that seemed to have shrunk around her, and which centred not only on reducing the risk of provoking symptoms, and of having another attack but also on avoiding other activities that might on the surface seem to have nothing to do with Ménière’s disease, such as her involvement in her intellectual life (“conversation about something political”). She seemed to regret what she had lost of her previous life, the activities and involvements that she had formerly found satisfying and rewarding, a list of things that she “used to do.”

Angela spoke similarly about living a restricted life, and the limitations she perceived her fear of attacks placed on her ability to live her life on her terms:

It doesn't kill you but it takes your life away... When it's very bad, you can't live your life, but you want to live. It doesn't, you know, you're not going to die from it. But it literally takes your life away. (Angela)

Yvonne described her work as a senior school teacher as very satisfying. It formed an important part of her identity and her conception of living a full and rewarding life, and yet her experiences of having an attack away from home, and in front of (in her view) judgemental others, led to her decision to stop work. She described giving up work as painfully hard. It was a decision she still described as difficult to talk about:

Still makes me feel sad now. So, I try not to actually think about it, ... because I loved it, absolutely loved it. But I try not to – even now – dwell on those. You know, you can't have it back and there's no point in dwelling on it because that's it. But at that time, extremely sad. And you're envious because everybody – not everybody – but it seems that everybody you know has got a life. You're the only one at that time that hasn't. (Yvonne)

Joanne also described work as an important part of her identity, a fundamental construct of her life that held both moral and personal significance. Giving up a fulfilling job on medical grounds was described as particularly distressing:
So I was brought up that you worked. I've never not been in work since college. [...] And I loved ..., I loved that job. It was people. It was all communication-based. And I loved it. I loved my job. I loved ... I was very blessed with the job that I loved. Very blessed. I miss that. Hmm. [...] I miss going to work desperately, desperately miss it. (Joanne)

In summary, participants described living with Ménière’s disease as disrupting not only their day to day lives but also important family occasions and close family relationships. Ménière’s disease was portrayed as intrusive, and as having an enduring effect on participants’ personal, social, cultural, and working lives. Overall, it seemed that this condition lowered participants’ expectations about their capacity to live their lives and to participate in family life in ways they had hoped and anticipated. Planned contingencies to avoid events that may trigger an attack or mitigate an attack, may have conferred some sense of control over their Ménière’s disease, but the psychosocial costs for these participants seemed significant. However, as the next theme suggests, over time, participants found ways to move forward with their changed circumstances by, for the most part, reluctantly incorporating Ménière’s disease and the management of this condition into their refashioned lives.

Theme 3: Moving forward with Ménière’s Disease: “you get on with life”

Participants did not describe Ménière’s disease as a welcome, enlightening, or positive force in their lives but rather as a bothersome, unalterable fact that they had to deal with on an ongoing basis. On the whole, and overtime, participants acknowledged that Ménière’s disease had salience in their lives but that it was possible to live with it, and, with differing degrees of success, to limit its most deleterious effects on their sense of self. In getting on with life, all participants talked about trying to push the impact of their condition away from their centre of attention to reduce its day to day prominence. At the same time, by seeking help from healthcare professionals, participants also took a more direct approach to reducing the worst of its effects. These two ways of moving forward with Ménière’s disease are described in the following two subthemes.

Subtheme 1: Pushing Ménière’s to the fringes

Getting on with life and keeping busy were described by all participants as a means of keeping Ménière’s in abeyance, of pushing it, as far as it was possible, to the margins of their consciousness:

I’ve learned to live with it. I keep busy. (Angela)

You get on with life and just hope it won’t come back again, you know. But with this, it’s always around, you know, in some form or the other with me [...] It never goes. (Esther)

I think you just can’t think too far ahead. You’ve just got to enjoy the now, really, and not dwell on it. (Yvonne)

The effort of holding Ménière’s back, as if trying to keep it in parentheses, was described by all participants as an ongoing process, that was not always completely successful. Joanne captured this best in the following quotation where she described managing to diminish but not eradicate her fear of vertigo whilst also acknowledging that at times, it still had the capacity to overwhelm her:

Um, so, I know I carry it with me. It’s like having to have a permanent handbag, the same handbag. Tough. You can’t change it. That’s the handbag you have to carry with you. But you somehow think it’s gone ... you realise after you have your next spin that you thought it had gone. And as soon as you have your next one, you think, ‘Oh.’ So, you get a bit sad. Not so frustrated, just sad and tired. Yeah. And cheated. [...] And I carry it with me rather than let it consume me. I get days when it consumes me. (Joanne)

The image of a handbag conveyed the threat of vertigo as an enduring burden in Joanne’s life. Re-imagining this threat as a familiar object, situated in the everyday world, rather than as an unknowable dread that hung over her, may have allowed her to get on with life without her fear of the next attack dominating her thoughts. However, each subsequent attack of vertigo reminded her that it had never really gone away, and that she had no real control over it. In addition to feeling dejected about this, she explained that with each new attack, she felt cheated out of the life she could have had without Ménière’s disease. She described her life as a series of recurring assaults where each attack repeatedly robbed her of the freedom to live a life of her choosing.

As presented in theme 2, all participants described living with Ménière’s disease as irrevocably changing their lives, what they could achieve, their sense of identity and their relationships with others. However, Yvonne was the only participant to speak of embracing a new identity that encompassed Ménière’s in a positive way after many years of struggling to reconcile her new self with her previous, possibly preferred self:

I am the Yvonne I am now. Whereas where I lived before, I was Yvonne that ran the [school] and everything else. [...] Um, yeah, moving here, telling people from day one, this is what I’ve got, I think it’s just accepting who I am now. I suppose accepting and liking, because I was Yvonne that ran the [school] where I worked. I did the youth clubs, I did the Scouts ... I did everything. So, that was ... I had these titles. And I suppose it’s just accepting and liking the Yvonne that I am now. (Yvonne)

Unlike the other participants, following retirement on medical grounds, Yvonne moved to a new area. She described herself as starting afresh, of leaving behind her previously successful and independent self and presenting her new self to new neighbours and friends. She did not find adjusting to a new self particularly straightforward but having changed location, and taken on new roles, she may have felt that she no longer needed to preserve her old sense of self and this perhaps left room for her to “enjoy the now.” In her new circumstances she perceived herself as accepted and as valued:

And I never feel a burden. I never feel that it’s a problem. It’s just, ‘Yeah, that’s okay. She’s got Ménière’s.’ ‘Okay.’ So yeah, I don’t feel any pressure from any of them [new friends], and they are really kind and understanding. (Yvonne)

All participants described trying to live a life that was not entirely overwhelmed by the impact of Ménière’s disease. For the most part, participants described staying in the moment and taking each day on its merit. Yvonne’s change in circumstances was unique to this group of participants and this perhaps offered her the space she needed to move on from her old life in which she had invested so much. In contrast, the other participants had to reconcile their changed selves to the patterns and fabric of their existing lives and this may have made it more difficult to consistently keep Ménière’s to the fringes of their day to day lives.

Subtheme 2: Tackling Ménière’s head on

All participants sought out professional support to help them live their lives with Ménière’s. All participants except Esther were offered physiotherapy. Yvonne and Angela had most experience of physiotherapy. Both talked about facing up to what they
perceived as the challenge of physiotherapy, but ultimately described it as a helpful means of living positively with this condition. The challenge of physiotherapy was concerned with overcoming the fear of provoking dizziness, and other symptoms such as nausea, whilst doing physiotherapist-prescribed exercises that intentionally elicited these symptoms:

I was frightened to do the exercises because they make you go dizzy. (Yvonne)

The more you challenged it [by doing the exercises], the better it is. It’s good to challenge it if you’ve got the guts to do so. Which I do. […] And you shouldn’t be … you shouldn’t play everything safe. You should have a go. Yeah? And that’s good for you on the achievement level. And also, it’s good for your balance as well, the more you challenge it, although it’s hard, and it’s not particularly nice. (Angela)

Both Yvonne and Angela perceived physiotherapy-prescribed exercises as helpful, but both stressed the emotional effort involved in facing and overcoming fear, and in summoning up the courage required to undertake these exercises. Joanne similarly worried about risking a feeling of good health to attend a physiotherapy appointment:

The horror of getting there [the physiotherapy department]. Because by the time I get there, halfway, I’ve probably got some of the symptoms. I’m probably woolly-headed. I’m probably feeling a bit sick. I’m probably feeling anxious because I’m like, ‘Well, is a spin coming or not?’ […] Why am I wasting my good feeling on going to a hospital appointment? (Joanne)

In the above quotation, Joanne implied that she believed that she only had a finite amount of “good feeling,” and this represented a precious resource that she risked losing by doing something like physiotherapy that could make her feel ill. These quotations lend support to the idea that living with an unpredictable condition, where the symptoms are incapacitating and difficult to manage in a public setting, people may put off seeking help, particularly when the treatment offered, or even just travelling to a treatment centre, is likely in itself to trigger the symptoms of an attack.

Physiotherapists were perceived as helpful if they offered hope about the possibility of living with Ménière’s disease in a positive way, as well as providing face-to-face support through the most frightening phases of vestibular rehabilitation. In addition to expertise, personal qualities such as confidence, empathy, concern, and sensitivity were also described as helping to allay anxiety and fear:

I think you’ve got to feel that you’re not a burden to them [physiotherapists], really, that they will listen to you and they will cope with you because you’re afraid. You’re frightened to do it. Um, it’s not like a leg massage or something […] I got a brilliant physio that did the exercises with me every week […] … she sounded happy in her job. She wanted to get me better. I think, um, I think a sense of achievement at the end that she [therapist] had succeeded in her bit … and it was a two-way thing, I had to do what she tells me … And I had a lifeline then. That’s what it turned into. (Yvonne)

In describing physiotherapy as a “lifeline,” Yvonne emphasised that physiotherapy offered a means of escape from a difficult and distressing situation, and perhaps more literally, a chance to get back to her former life, and her former self. Yvonne also felt that she could share her troubles with her therapist. Once Yvonne understood the rationale of treatment, she believed she was going to get better, so she persevered with the exercises. This was a significant hurdle that Yvonne had to overcome, and a turning point in her life. Yvonne also explained that what might be considered as “little things” were also important to her as she tried to overcome her fear of physiotherapy. Thoughtful acts such as pulling up a chair and being guided in and out of the physiotherapy department when she felt disorientated, were described as helpful and instilled confidence.

Careful attention to these often-overlooked components of good practice and physiotherapists who seemed to intuitively understand her fears and anxiety, registered with Yvonne, and counted in her overall positive evaluation of physiotherapy. However, not all physiotherapists were seen to offer the same degree of dependability, or to exercise the same level of expertise or empathy. Yvonne described herself as having little confidence in her first physiotherapist:

I don’t know if this right or wrong because you’re the physio [the interviewer is a physiotherapist] – but if she’s having a bit of paper and telling me what to do, that didn’t fill my confidence to start with when she said, uh, ‘We can try this but they’re not going to be any good for you.’ Um, I needed it all to be in her head. (Yvonne)

Having a high degree of confidence in an individual physiotherapist may be particularly important in a situation where the treatment might be as unpleasant as the symptoms of the condition itself.

Healthcare appointments with doctors and physiotherapists were seen by participants as offering an opportunity to talk about how they were feeling about their lives with Ménière’s, to air their concerns and to be listened to. However, participants reported quite varied experiences in their encounters with healthcare practitioners and were offered limited opportunities to talk about the impact of Ménière’s disease on their lives. Joanne, for example, stressed the value she placed on working with a healthcare professional who would make a genuine attempt to understand her as an individual and not just as a person with a particular condition. In her experience, physiotherapists and other healthcare professionals did not offer her the opportunity to talk about the impact of Ménière’s disease on their lives. Joanne, for example, stressed the value she placed on working with a healthcare professional who would make a genuine attempt to understand her as an individual and not just as a person with a particular condition. In her experience, physiotherapists and other healthcare professionals did not offer her the opportunity to talk about herself, and were perceived as unable to understand or respond to the enormity of what she felt was at stake in her life with Ménière’s:

I’ve been taken away from myself. […] I can’t emphasise enough just how at risk I personally feel. And I’ve heard other people say the same which you don’t get the opportunity to talk about when you’re at your appointments. (In physiotherapy) I felt like a monkey being put through the hoops […] And I really didn’t have it explained to me why it was helpful […] ‘Why don’t you ask me how I am? Why don’t you ask me how I’m feeling? […]’ I don’t ask my condition or want me to display my condition. Ask me how I am, […] For all the 100 things that go badly wrong and that are crap, it only takes one nugget of nice be it somebody’s time, be it somebody’s patience, that can actually reset. (Joanne)

Ménière’s disease is considered to be a psychologically troubling condition and yet Yvonne was the only participant who had received counselling. Yvonne described her General Practitioner as someone she could talk to, who seemed from her perspective to understand the value she placed on being able to unburden herself:

I do think it really does depend on when you’re at the height of the problem and you’re first diagnosed, meeting the right people. I really … Because they’re the ones that can boost your confidence and help you with your anxiety and really good counselling as well. She was really a good counsellor. Um, and I had at that time a brilliant GP [General Practitioner] that I don’t think I’d get today that offered appointments. And his sentence was, ‘If you need to talk, come and talk.’ And I could go and talk to him. Didn’t need anything else but I needed somebody professional to talk to. So, I think I was lucky at that time that he did just talk. He listened. He boosted my confidence. (Yvonne)

It may have been important for Yvonne to feel that she had permission to talk to a healthcare professional without feeling guilty about troubling someone else such as a family member. Yvonne also suggested that timing was crucial. She highlighted
the importance of having someone available to talk to at the height of a crisis, and immediately following diagnosis when the earliest stages of grief or shock may be experienced. Esther similarly emphasised the importance of getting support in the early stages:

[The General Practitioner] seemed to know and want to help. He was really nice. Um, but, as I say, when they don’t, you come away and you think, ‘Nobody can help me.’ Especially when you first start. […] It’s a terrible feeling. Yeah, ‘If I’m stuck like this and nobody can help me’ and a feeling of despair. (Esther)

Yvonne and Angela also acknowledged that self-help group meetings were a place where they could talk to other people who had experienced similar problems and could empathise:

I’ve probably over the years have tried explaining it but I don’t think anybody can understand fully what somebody else feels unless you’ve got it. That’s why you need the support group because explaining it is just not the same as experiencing it. (Yvonne)

Being a member of a self-help group was described as overwhelmingly positive by all participants. Living with Ménière’s disease gave members of this group an insider status, with this came what was understood as the privilege of joking about Ménière’s which was not extended to outsiders. Making light of this condition and its effects may have helped to diminish its relative importance in their lives at that moment, and the camaraderie perhaps gave them some relief to laugh at it, and perhaps indirectly at themselves:

The groups help because you’re with like-minded people … And only us, when we meet up, can take the Mickey out of it. Other people can’t … (Joanne)

The group also offered its members the chance to not only get some support, but also to share their expertise with others. For Esther, giving as well as receiving support not only demonstrated that she had the capacity to help others living through similar situations but also perhaps that she had not suffered in vain:

But [the support group] it’s having … I suppose really, it’s in a way like, um, the Samaritan thing, isn’t it? There’s somebody there that would speak to you on the end of the line. Because, um, all right, as I say, friends understand to an extent. […] But, um, sometimes, with Ménière’s if it’s something you’ve experienced you can help the other person, you know. And, um, people say, “I’ve helped them.” I don’t know, I’ve tried, when I’ve gone there, you know. (Esther)

All participants sought out help to manage their Ménière’s and to reduce its influence in their lives. Although all participants claimed some success from their continued efforts, these successes took time to develop, were hard won, and required ongoing work. Professionals and voluntary groups were described as an important source of support, but professionals were not always regarded as able, aware of, or equipped with the appropriate resources, skills, and expertise to care for these participants in ways that they described as helpful. Although some aspects of physiotherapy were positively appraised, participants also described themselves as fearful of and resistant to attending physiotherapy appointments.

Discussion

This study aimed to explore the meaning of Ménière’s disease from the perspective of individuals living with this condition, and to deepen the understanding of how participants made sense of this condition in the context of their everyday lives. Three interconnected themes were inferred from the analysis. The first theme described the pervasive and disruptive influence that vertigo held in the lives of participants, and the impact this had on the sense of themselves in the public world. The second theme recounted the sense of intrusion that Ménière’s wrought on participants’ everyday activities and personal relationships. The final theme described participants’ ongoing efforts to minimise the impact of Ménière’s in their lives, and the potential value of physiotherapy, but also the possibility that physiotherapy might be avoided for fear of triggering symptoms. These findings are discussed with reference to their relevance for physiotherapists and for other therapists and rehabilitation professionals.

Participants described vertigo as the most problematic feature of their lives with Ménière’s disease. The reasons for this were at least in part attributed to the unpredictable nature of the attacks, participants’ perceptions of attacks as intense and frightening experiences, and, in addition to feeling acutely unwell, the experience of vertigo as an embarrassing loss of bodily control, and bodily competence. These findings lend weight to the view that attacks of vertigo should be understood, in themselves, as emotionally charged, traumatic events that may carry an enduring psychological impact [45]. Our findings emphasise that attacks occurring in the presence of other people were portrayed as particularly diminishing, distressing, and humiliating. A form of “felt stigma” [46, p.1054] was described by our participants where negative appraisals from familiar, as well as unknown others, were anticipated during attacks.

Yang et al. [47, p.1530] characterised stigma as rooted in intersubjective space and as threatening the “lived value” of what matters most in a person’s local world. It is this view of stigma that best captures the stigma experiences recounted by participants in this study, and which resonates with findings about the impact of Ménière’s disease on everyday social practices [36]. In our study, participants’ narratives also revealed feelings of vulnerability stemming from their stigma experiences which had a negative and long-lasting effect on their sense of self. Consistent with previous studies [9,11,12], this key finding supports the view that participants did not experience vertigo as an isolated physical symptom with transitory effects, but rather as an enduring concern that manifested other forms of psychological and psychosocial suffering which, in turn, formed a significant part of the lived experience of this long-term condition.

It is not our intention to portray participants’ stigma experiences as residing solely within the individual, as a self-generated problem. The stigma experiences that participants recounted in this study operate and come into being through broad social structures, and through hegemonic views about the meaning of disordered bodies. Our findings should, therefore, be understood within the broader context of the social oppression paradigm [48]. However, until recently, physiotherapy research has paid little attention to issues such as stigma [49,50]. We argue that physiotherapists who recognise Ménière’s disease not only as an ongoing rather than episodic physical and psychological condition, but also as a socially-situated condition, would be well placed to work with people living with Ménière’s within the biopsychosocial conceptualisation of health and disability. This approach would enable physiotherapists to more fully understand the concerns of people living with this condition and to support patients to manage their cognitions about the public experience of living with an unpredictably ailing and disordered body.

Bell et al. [36] reminded clinicians of the importance of understanding the embodied experience of chronic illness and disability, and of paying attention to the psychosocial meaning of not only public but also clinical spaces. Our study further suggests
that people with Ménière’s disease may, for example, place high value on rehabilitation professionals who offer reassuring information about the location and available facilities in the clinic, who meet and orientate patients, provide safe and private areas for rest and recovery, and offer alternatives to travelling to appointments, such as providing domiciliary visits, telephone support or using webcams via tablets or laptops for home-based video consultations. Muller et al. [24] reported that provision of expert telephone support for people with chronic dizziness undergoing VR was an important element in exercise adherence. Giving people with Ménière’s disease a stronger voice in the design and delivery of services and clinical environments may also help break down barriers to accessing physiotherapy, reduce the fear of attending appointments, and encourage patients to invest in rehabilitation efforts that have the capacity to help them live richer and more fulfilling lives. These involvements may help to address concerns about the long-term provision of health services for people living with this condition [33].

Through their narratives, participants suggested that parts of their lives had been irrevocably caught up with and claimed by Ménière’s disease. These feelings were described as particularly prominent when participants first experienced the symptoms of vertigo, but also persisted over the longer-term. We inferred from our analysis that whilst participants may have reluctantly given over important and valued life experiences to Ménière’s as suggested in other studies [2,7], at the same time, they preserved and refashioned other parts of their lives. We argue that what could be understood as a negative strategy, may have helped participants to manage the impact of vertigo in their everyday lives by avoiding activities that were thought likely to trigger attacks of vertigo, and by prioritising participation in personally meaningful events and valued forms of self-expression.

When faced with a disruptive and unpredictable illness like Ménière’s disease, a sense of mastery might be difficult to achieve. Letting go of some forms of participation, whilst holding onto others, could be understood as a way of engaging in a kind of active resistance that prevents this condition from having a wholly uncontrolled effect on everyday life. Physiotherapists might recognise these efforts in light of what they enable people living with Ménière’s to continue to achieve, rather than as an entirely negative means of coping, or as an intolerance of uncertainty [9]. However, timely advice and support may be needed for those who struggle to let go of hard won but perhaps self-limiting strategies that prevent engagement in the kinds of challenging activities that may be vital to extending and improving their lives in the longer-term.

Although participants described trying to push the impact of Ménière’s to the margins of their lives, physiotherapy assessment processes and the prescription of treatment that intentionally provoked vertigo symptoms, were described as having the unintentional consequence of bringing Ménière’s back into the forefront of participants’ worlds. It is not perhaps surprising that under these circumstances, participants described being fearful of physiotherapy, and of having to summon up courage to carry out prescribed exercises, or even to attend an appointment. Our findings suggest that physiotherapists may gain much from understanding what patients feel they are placing at risk when they attend appointments. Participants’ accounts suggested that when living with a condition that placed limits on everyday life, it was important that physiotherapy was seen as part of the effort to liberate them from their everyday constraints, through building trust and confidence, and by offering hope. Without a sound understanding of these complex issues, the potential benefits of vestibular rehabilitation (see McDonnell and Hillier [23]) in their fullest sense may not be realised.

We found that work roles were identified as particularly vulnerable to disruption, and family relationships were described as difficult to manage. Our participants regretted the impact of Ménière’s disease on their family life and made sense of practical and emotional support in ways that family members and healthcare professionals may find surprising. Offers of support, for example, may have paradoxically added to the psychological burden of living with this condition by working to undermine the sense of self within the family over time. Consistent with the views of Long and Brette [32], our findings suggest that it would be useful for physiotherapists and other rehabilitation professionals to understand the ongoing narrative of an individual’s life with Ménière’s, how they configure their lives, and the cognitive, physical, and emotional work that accompanies living with this condition. Our findings underline the need for physiotherapists in the UK to continue to use a biopsychosocial approach [29] and to draw on the expertise of other healthcare professionals such as psychologists who may be best placed to offer further insights and advice.

Contrary to the findings of Manchaiah et al. [21], our participants did not report any tangible benefits from living with Ménière’s disease, despite being asked about this in the interview. We cannot offer a clear explanation of this finding, but it may simply reflect that our participants were occupied by the more negative impacts of the condition (possibly explaining their membership of the support group), which perhaps required the most serious and therefore deeply felt forms of reflection and adjustment, and this is what was attended to in the interviews.

In acknowledging the limitations of this study, the following points should be considered. All participants had been given a diagnosis of Ménière’s disease, however, we did not seek medical confirmation and further audiology testing was not undertaken to diagnose Ménière’s disease or to exclude other vestibular dysfunction. Age and time spent living with this condition may have contributed to differences in the lived experience of this condition. These differences have been discussed where this was felt to be the case. Participants recruited from support groups may feel comfortable talking about their health, have better connections to sources of support, or be particularly knowledgeable about their condition, and have something to say [51]. Individuals from social and ethnic minority groups as well as people from low income backgrounds are also less likely to be members of these groups [51]. Also, vertigo is thought to have the greatest impact on quality of life and is thought to motivate individuals to join self-help groups [10] which may account for the significance of vertigo in participants’ accounts. It is also possible that individuals who suffer significantly with vertigo are those who seek and need the support offered by physiotherapists. Furthermore, although it was not our intention, all participants and all researchers are women. All the women were happy to talk at length to the researcher, which may reflect easy rapport building amongst women or simply the skill of the researcher. We are unable to make any specific claims, but unconscious gendered sociocultural perspectives may have had an impact on data collection and analysis. We did not consider the data through a particular lens or look for topics that may be particularly relevant to women nonetheless; men and individuals who are not members of a support group may offer perspectives that differ from those we report here.

The impact of participants being interviewed by a physiotherapist is also not known. Participants may have felt obliged to report positive experiences of physiotherapy. Alternatively, the
study may have been seen as an opportunity to express concerns about physiotherapy. It is impossible to say if these issues had any bearing on the study but both positive and negative experiences of physiotherapy were reported.

Overall, the value of this study lies in its in-depth focus on the perspectives of the participants, and the potential implications of the interpreted account for physiotherapists and other rehabilitation professionals working with people with Ménière’s disease. As with all Interpretative Phenomenological Analysis, we are not claiming that the findings are representative, or directly generalisable. However, by providing a rich, in-depth and contextualised exploration and analysis of the data, this study offers insights that physiotherapists can interrogate and, through a process of analytical generalisation [52], consider in relation to their own professional and experiential knowledge.

Conclusion
The physical and psychosocial impact of living with Ménière’s disease is far reaching and ongoing. A biopsychosocial approach is needed to fully understand the issues faced by people living with this condition and to appropriately respond to their individual needs. People living with Ménière’s may be reluctant to or fearful of attending physiotherapy appointments and may find clinical environments challenging and unwelcoming. These feelings and perceptions are highly context-dependent and may be difficult to meaningfully address without using a multidisciplinary approach and involving people with Ménière’s disease in the design and delivery of physiotherapy and vestibular rehabilitation services.

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