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Living with Ménière's Disease: Understanding Patient Experiences of Mental Health and Well-Being in Everyday Life

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Additional information is available at the end of the chapter

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Abstract

This chapter will discuss the current knowledge of the mental health and wellbeing impact of Ménière's. To date, our understanding is limited, with small sample sizes, no controls, and the inability to account for confounding factors. Our work in the UK Biobank aimed to further our understanding of the impacts of Ménière's at the population level.

Secondly we will consider the patient perspective of what it means to live with Ménière's. This is essential to develop appropriate healthcare pathways and ensure patients are able to lead fulfilling lives. There is very limited information about how the patient experiences and makes sense of the disease (or not) - including its triggers and physical sensations - in everyday life.

Our findings suggest that Ménière's adversely impacts on mental health, an individual's emotional state and their life satisfaction. We demonstrate the complex processes of adjustment (physical, social and emotional) following a diagnosis of Ménière's. Although a cure is not currently available, our study illustrates that much can be learnt from the adaptation strategies developed by long-term sufferers in order to help individuals with new diagnoses; an experience that is both daunting and disruptive to patients' everyday lives.

Keywords: Ménière's disease, UK Biobank, Qualitative, mental health, well-being, interdisciplinary

1. Introduction

Ménière's disease is a complex multifactorial disorder of the inner ear, consisting of several concurrent symptoms (e.g. aural pressure, hearing loss, tinnitus and vertigo). Patients with Ménière's range from minimally symptomatic highly functional individuals to severely affected disabled patients. Each of the main triad of Ménière's symptoms can impact on quality of life. Tinnitus may be associated with sleep disturbance, depression, irritability, reduced concentration and auditory difficulties [1]. Hearing loss can result in communication difficulties, which can cause problems in work and social life. Vertigo is known to cause anxiety and restrict physical and social activities, therefore significantly impacting on patients' health and well-being [1]. Vertigo is often considered to be the most detrimental and debilitating symptom of Ménière's [2].

Research on the mental health and well-being impact of Ménière's disease is limited. Moreover, quantitative studies in this area are negatively influenced by small sample sizes (often with fewer than 500 participants), a lack of groups to compare the mental health impacts with (i.e. no control groups), and an inability to account for confounding factors. Furthermore, our understanding of how the mental health impact of Ménière's may shift over time is partial at best.

The patient perspective of what it is like to live with this disease within the context of their day-to-day life is critically important for developing appropriate healthcare pathways and ensuring that patients are able to lead as fulfilling lives as possible [3]. While some studies have considered the adverse impact of Ménière's on quality of life, along with patients' perspectives regarding triggers and symptoms of the disease [4], there is very limited information about how patients experience and manage the disease (or not), including its triggers and symptoms in everyday life. In addition, we are currently unaware of the role that other people may play in this process [5–7] or how these issues impact on the sense of mental health and well-being amongst people with Ménière's.

This chapter will build upon existing research in this area, describing a comprehensive, multi-layered two-phase analysis of the impact of Ménière's on patients' mental health and well-being. First, epidemiological analysis from the most powerful Ménière's resource currently available (the UK Biobank, www.biobank.ac.uk) will provide insights on the mental health and well-being impacts of Ménière's at a population level (Phase I). Secondly, qualitative research (Phase II) will provide deeper insights into patients' experiences of living with and negotiating the triggers and symptoms of Ménière's disease on a day-to-day basis, including the role of significant others in this process.

2. Ménière's and mental health at the population level

In Phase I, the UK Biobank dataset was utilised to understand how Ménière's influences mental health and well-being at the population level. This study contained 1376 individuals with self-reported Ménière's and included comprehensive phenotypic data (e.g. anthropometric

measures, early life, lifestyle, family history, medical history, general health and well-being and diet). The aim of this population-level research was to investigate whether people with Ménière's have different mental health and subjective well-being than individuals without the condition. The impact of disease duration on mental health and level of subjective well-being was also investigated within cases.

2.1. Phase I methods

2.1.1. *The UK Biobank, Ménière's diagnosis and mental health*

The UK Biobank is a phenotypically rich study of over 500,000 individuals aged between 37 and 73 years in 2006–2010 [8]. All participants were interviewed by a nurse, who collated a list of health conditions for each participant. There were several options for ear/vestibular disorders, including tinnitus, vertigo, labyrinthitis, Ménière's disease, otosclerosis or a generic ear/vestibular disorder. The 1376 individuals who reported symptoms of Ménière's disease were selected. An investigation of prescribed medications and key symptom data (e.g. tinnitus and hearing loss) was utilised to validate the variable. For each individual reporting Ménière's, an age of diagnosis was also available and this was utilised to determine disease duration.

The UK Biobank incorporated extensive questions on mental health and subjective well-being. A subsection of questions asked participants to record the frequency of depressed mood, unenthusiasm, tiredness and tenseness within the 2 weeks prior to recruitment. Further questions focused on the number and duration of depression episodes over each participant's life. Participants rated their overall happiness and their satisfaction with health, work, friends and family and finances to provide a range of measures of subjective well-being. Participants were also asked to complete the Eysenck Personality Inventory (EPI) [9].

The participants also reported regular prescription medications, and use of the major antidepressant class—the selective serotonin reuptake inhibitors (SSRIs)—was monitored.

2.1.2. *Statistical analysis*

The mental health impact of individuals with Ménière's was compared to the whole control population of non-Ménière's sufferers. Linear regression models were utilised to investigate whether a diagnosis of Ménière's influenced the frequency of depression, tiredness, tenseness or unenthusiasm experienced in the 2 weeks prior to recruitment. Similar models were utilised to: (a) investigate how Ménière's influenced subjective well-being; (b) compare the frequency of family contact for cases and controls; and (c) examine the longest duration of depression in cases and controls.

Logistic regression models were used to investigate the odds of: (a) reporting depression; (b) reporting an episode of depression lasting over a week; and (c) utilising SSRIs in Ménière's cases compared to controls.

The role of disease duration on mental health and well-being was investigated. Individuals diagnosed for 5 or more years were compared to those diagnosed within the past 5 years.

Models were adjusted for potential confounders, including participants' age, sex, socioeconomic status, waist circumference, home location (urban versus rural as defined by the UK Biobank using the participant's postcodes and the 2001 census data) and ethnicity as covariates. Further adjustment for tinnitus severity was carried out to determine whether this symptom significantly contributed to any mental health associations. Personality is one of the biggest predictors of happiness [10] and therefore the EPI was included as a covariate in the statistical models. All analyses were conducted using STATA/SE Version 12.1 (College Station, USA). Statistical significance was denoted by $P < 0.05$ unless otherwise stated; Bonferroni correction methodology was utilised where appropriate.

2.2. Phase I results

The demographics of the 1376 Ménière's cases and controls are summarised in **Table 1**. As noted in previous studies, there was a preponderance of females (62% versus 54%). The data suggested that individuals with Ménière's had higher proportions of disability benefit than controls (5.3% versus 2.2%, $P < 0.001$) and were more likely to hold disabled badges than controls (8.7% versus 3.6%, $P < 0.001$). Ménière's cases were more likely to be unable to work

Demographics	All MD sufferers	All controls
N	1376	501,306
Sex		
Male (%)	517 (37.6)	228,677 (45.6)
Female (%)	859 (62.4)	272,629 (54.4)
Mean age at recruitment in years (95% CI)	63.4 (63.0–63.8)	60.4 (60.4–60.5)
Ethnicity (%)		
White	1333 (96.9)	471,525 (94.1)
Mixed	7 (0.5)	2951 (0.6)
Asian	14 (1.0)	9869 (2.0)
Black	2 (0.1)	8065 (1.6)
Chinese	2 (0.1)	1572 (0.3)
Other	7 (0.5)	4554 (0.9)
Missing/unknown	11 (0.8)	2770 (0.5)
Household income		
Less than £18,000	351 (25.5)	96,874 (19.3)
£18,000–£30,999	319 (23.2)	107,891 (21.5)
£31,000–£51,999	250 (18.2)	110,546 (22.0)
£52,000–£100,000	171 (12.4)	86,124 (17.2)
More than £100,000	34 (2.5)	22,900 (4.6)
Missing/unknown	251 (18.2)	76,971 (15.4)

Demographics	All MD sufferers	All controls
Home location		
Urban	1154 (83.9)	427,775 (85.3)
Rural	222 (16.1)	73,513 (14.7)
Disability benefit		
None	1155 (85.5)	465,963 (94.0)
Attendance	6 (0.5)	1150 (0.2)
Disability benefit	72 (5.3)	10,810 (2.2)
Blue badge holder	118 (8.7)	17,871 (3.6)
Employment		
None	8 (0.6)	2795 (0.6)
Employed or self-employed	534 (39.0)	265,185 (53.2)
Retired	588 (43.0)	160,550 (32.2)
Look after home	50 (3.7)	20,032 (4.0)
Don't work because of illness	101 (7.4)	18,940 (3.8)
Unemployed	16 (1.2)	8817 (1.8)
Voluntary	62 (4.5)	17,481 (3.5)
Student	9 (0.7)	4553 (0.9)

Table 1. Demographics of the 1376 Ménière's sufferers and the 501,306 controls in the UK Biobank.

because of illness (7.4% versus 3.8%, $\chi^2 P < 0.001$), although it should be noted that the large majority of individuals did work.

2.2.1. Depression

Participants with Ménière's were at higher odds of reporting:

Doctor diagnosed depression odds ratio (OR): 1.53 (95% confidence intervals (CI) 1.32, 1.70, $P < 0.001$, **Figure 1**).

A week long period of depression (OR: 1.33; 95% CI: 1.07, 1.65; $P = 0.011$).

The use of SSRIs (OR: 1.32; 95% CI: 1.01, 1.71; $P = 0.041$).

Ménière's was associated with longer durations of depression—on average this was 10 weeks longer than controls (95% CI: 5.2, 15.2, $P < 0.001$, **Figure 1**).

2.2.2. Mental health impact

Ménière's was associated with increased frequency of depression, tiredness, tenseness and unenthusiasm in the 2 weeks prior to recruitment, although adjustment for the participant's

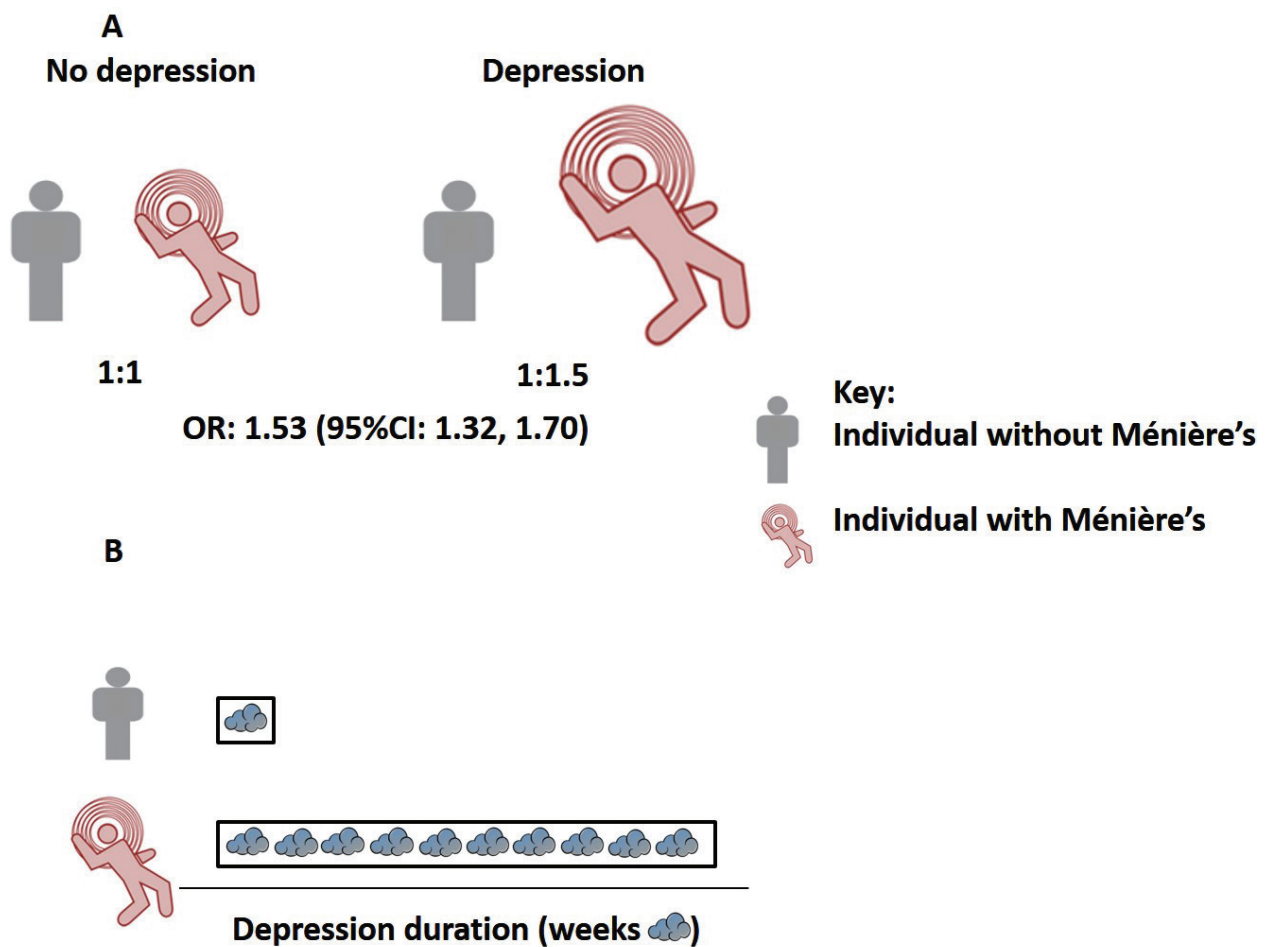


Figure 1. Graphic demonstrating the association between Ménière's and (A) depression and (B) the duration of depression.

neuroticism subscale of the EPI attenuated the regression coefficients with only tiredness remaining significant (**Figure 2**).

Tinnitus, a major symptom of Meniere's, is linked to mental health. Adjustment for tinnitus severity in a subset of the population ($n = 168,341$), with a similar prevalence of Ménière's (0.25% versus 0.27%), attenuated all the mental health associations.

2.2.3. Subjective well-being

Individuals with Ménière's had lower health satisfaction scores than controls and were on average less happy overall. However, there was no difference between cases and controls in terms of satisfaction with their family relationships, friendships and financial situation (**Figure 3**). Higher odds of having social interaction with family and friends on a daily basis (odds ratio 1.5; 95% CI: 1.3, 1.8, $P < 0.001$) or 2–4 times per week (1.2; 1.0, 1.4, $P < 0.01$) was noted for Ménière's cases when compared to controls. The frequency of social interaction predicted individual satisfaction with friends and family.

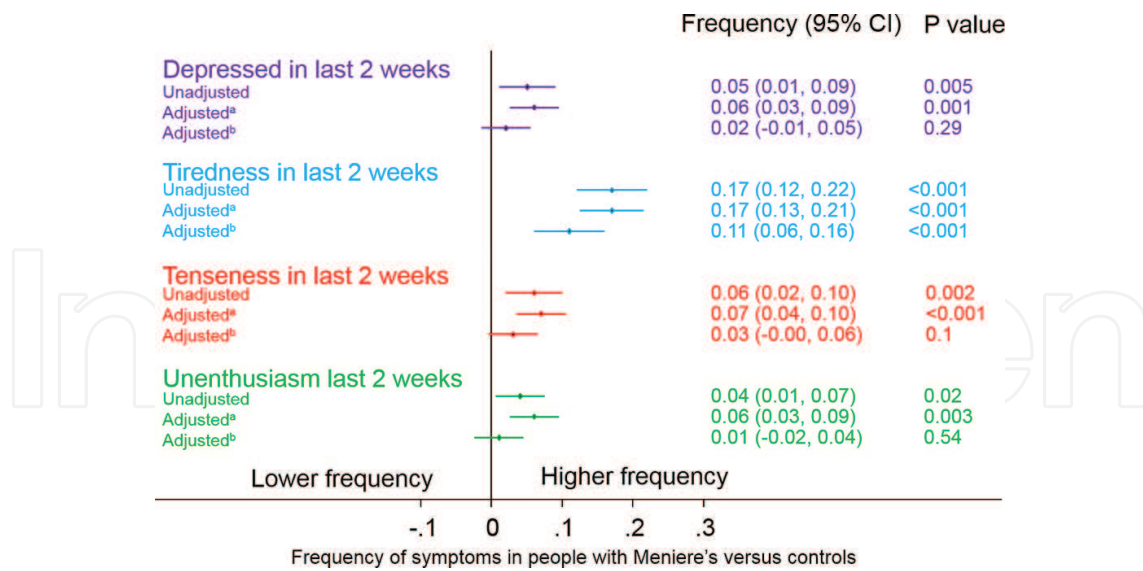


Figure 2. Change in frequency of depression, tiredness, tenseness and unenthusiasm in cases compared to controls. Adjusted^a accounts for common covariates and Adjusted^b includes the EPI.

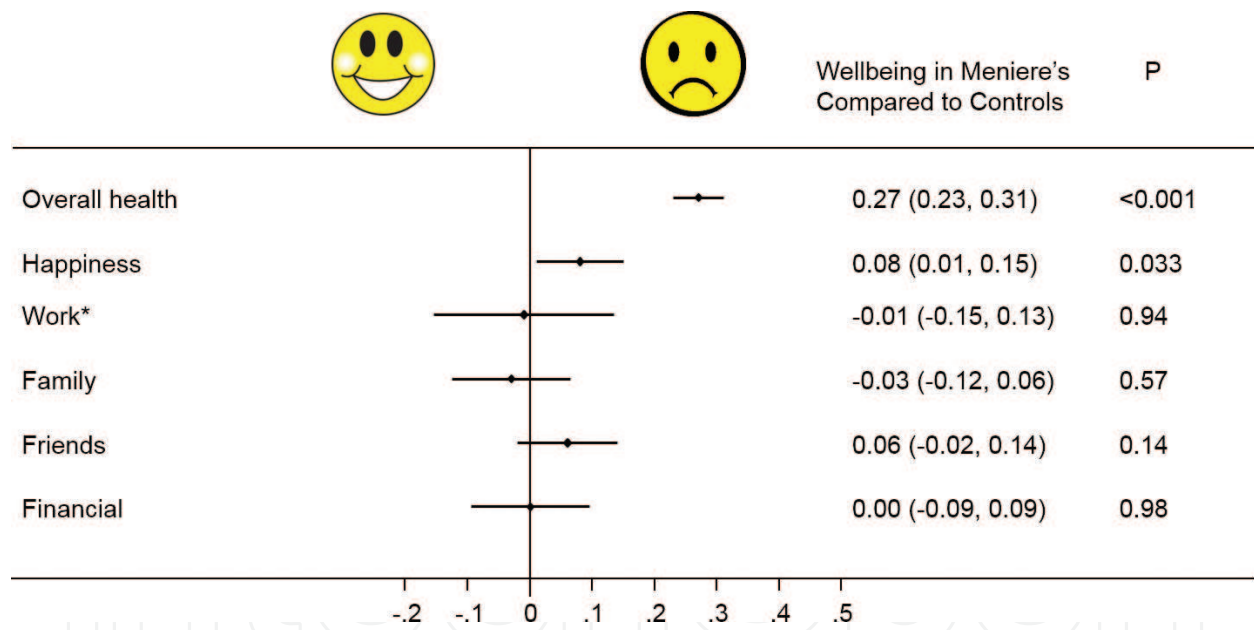


Figure 3. Differences in well-being in cases and controls. *Work satisfaction only asked in individuals with a job.

2.2.4. Disease duration

Within the Ménière's cohort, disease duration was associated with lower levels of depression in the 2 weeks prior to recruitment ($P < 0.05$). Furthermore, individuals diagnosed for more than 5 years were at lower odds of visiting a doctor about depression 0.60 (0.41, 0.90) than recently diagnosed individuals. Longer disease duration was also associated with improved health satisfaction ($P < 0.01$, **Figure 4**).

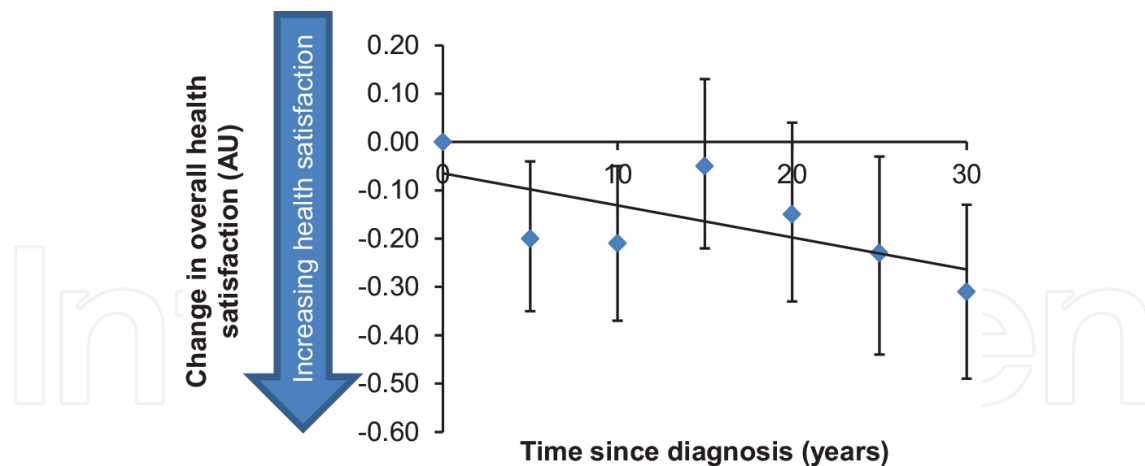


Figure 4. Scatter plot representing how health satisfaction within the Ménière's sufferers changes with time since diagnosis. Regression analysis indicated a significant relationship between overall health satisfaction and disease duration ($P < 0.01$).

3. Ménière's and mental health at the individual level

Complementing the population-level analyses, Phase II adopted an in-depth qualitative approach to understand and contextualise people's experiences of Ménière's in their everyday lives. Ethical approval for this phase of the study was secured from the University of Exeter Medical School Research Ethics Committee (Approval Reference 13/09/029).

3.1. Phase II method

With the assistance of the Ménière's Society UK, a purposive sample of 20 Ménière's patients was recruited from across south west England, focusing on individuals diagnosed by an Ear Nose and Throat consultant, reporting symptoms within the previous 12 months (see **Table 2** for sample composition). Purposive sampling allowed information-rich views to be shared by individuals at different stages of the condition, offering insights into the variability of the condition rather than focusing only on the 'typical' or average case [11]. Four participants requested that their partners be present during their interviews, offering emotional support and also providing valuable perspectives on the shared effort of managing and adapting to the onset and progression of Ménière's [12]. A further eight semi-structured interviews were undertaken with partners of other participants to examine these shared and relational impacts in more detail.

Data collection commenced in June 2015, with interviews lasting between 1 and 3.5 hours, all conducted at a time and place of participants' choosing. A flexible interview guide was developed to inform the interview process, using open questions and active listening techniques to facilitate participant-led, open-ended responses. All of the interviews began by giving participants an opportunity to reflect (in their own words) on what was happening in their lives when they first started experiencing symptoms and how things had progressed from there. Follow-up questions focused on: participant interpretations, perceptions of their everyday experiences of the condition; the perceived impacts of the condition on their mental health,

Pseudonym	Age bracket (yrs)	Ménière's duration	Unilateral/bilateral symptoms?	Employment status	Presence of others during interview?
Participants with Ménière's					
Maggie	51–60	<5 yrs	Unilateral	Full time	–
Nicola	31–40	<5 yrs	Unilateral	Full time	–
Jane	61–70	<5 yrs	Unilateral	Retired	–
Louisa	51–60	<5 yrs	Unilateral	Full time	–
Susan	61–70	<5 yrs	Unilateral	Retired	–
Melissa	31–40	<5 yrs	Unilateral	Full time	–
Tom	41–50	<5 yrs	Unilateral	Full time	–
Debbie	61–70	>5 yrs	Unilateral	Non-working	Husband (Mick)
Becky	31–40	>5 yrs	Bilateral	Non-working	Daughter (toddler)
Dawn	51–60	>5 yrs	Unilateral	Early retirement	–
Angus	61–70	>5 yrs	Bilateral	Early retirement	–
Chloe	51–60	>5 yrs	Unilateral	Part time	–
Yvonne	61–70	>5 yrs	Unilateral	Early retirement	–
Caroline	51–60	>5 yrs	Shifting to bilateral	Nonworking	Husband for last half hour
Jennie	41–50	>5 yrs	Bilateral	Part time	Teenage daughter for last half hour
Emily	51–60	>5 yrs	Unilateral	Nonworking	Husband, teenage daughter
Richard	61–70	>5 yrs	Unilateral	Retired	–
Elaine	71–80	>5 yrs	Unilateral	Retired	Husband
John	71–80	>5 yrs	Unilateral	Early retirement	Grandson (periodically through interview)
Emma	51–60	>5 yrs	Unilateral	Self-employed	–
Participants supporting someone with Ménière's					
Karen	62–70	N/A	N/A	Full time	–
David	61–70	N/A	N/A	Self-employed	–
Magda	61–70	N/A	N/A	Part time	–
Matt	61–70	N/A	N/A	Self-employed	–
Sandy	61–70	N/A	N/A	Retired	Wife (Dawn) for last half hour
Mick	71–80	N/A	N/A	Retired	Wife (Debbie)
Toby	51–60	N/A	N/A	Full time	–
Tessa	41–50	N/A	N/A	Part time	Daughter (toddler)

Table 2. Sample composition for the qualitative study.

social roles and identities, friendships and relationships; interactions with the medical profession; the mechanisms by which they tried to self-manage and adapt to the condition over time; and the role of social support in this process.

Interview transcripts were anonymised, checked against the original interview recordings and copies sent back to participants for member-checking purposes [13]. After a period of data immersion, listening back to recordings and annotating transcripts with initial codes and themes, a copy of each transcript and an initial thematic coding framework were uploaded to NVivo 10 (qualitative data management software). Each transcript was then subject to further thematic narrative analysis [14], with the aim of situating emerging themes within each participant's life story, and identifying more subtle, intersecting themes within the data [15]. In order to ensure the analysis and interpretations resonated with individuals living with Ménière's, the early findings were shared and discussed with members of a Ménière's support group in August 2015.

3.2. Phase II results

A key aim of Phase II was to understand more about the adverse mental health impacts observed with the onset and progression of Ménière's, and how participants experienced and negotiated these impacts during their everyday lives. We explore this further in what follows, focusing particularly on the strategies used to adapt to a life of uncertainty in the face of Ménière's, and the roles of supportive partners, family and friends in this process.

Recurring throughout participants' narratives were anxieties linked to the sudden onset of symptoms (vertigo in particular), their varying severity and the unpredictable progression of the condition [16–18]. The accumulation of these anxieties over time resulted in a significant loss of confidence, independence and a deep sense of frustration amongst participants, who likened it to 'driving a car with a dodgy break' and serving a 'prison sentence' with no clear release date. Given the limited efficacy of medication or surgery in treating the condition, participants (and their families) felt powerless in many respects, with even long-term sufferers describing it as 'an alien being' sitting in the body. Throughout participants' interviews, it was apparent that the process of adjusting to life with Ménière's was experienced as a steep and emotionally challenging learning curve, often requiring significant compromises to everyday practices and pleasures.

Participants described lifestyle shifts made in an effort to regain some semblance of control over Ménière's, be they diet-related, or focused more on physical activity, rest and relaxation. Some of these were in response to recommendations from their Ear Nose and Throat consultants (e.g. reducing salt, caffeine and alcohol), whereas others were strategies they had identified through trial and error in the process of learning to 'read' their body as the condition progressed. These included, for example, the use of specific vitamin supplements, postural adjustments, finding activities that would build their core strength without aggravating symptoms (e.g. modified versions of yoga, pilates, tai chi) and maximising sleep and rest where possible. However, participants warned against being overly simplistic in drawing links between stress, relaxation and vertigo severity. Many identified occasions when they had been under significant stress and not had a vertigo attack, or at their most relaxed and

still had an attack. As such, although participants engaged in efforts to minimise stress and maximise opportunities for rest and relaxation, they indicated these stress pathways to be complex, inconsistent and intertwined with other factors going on in their lives at the time.

Managing anxiety was highlighted as particularly challenging, even amongst those who had lived with the condition for over 10 years, with many describing a 'shrinking world', loss of spontaneity and sense of isolation. While participants perceived varied potential in counselling, cognitive behavioural therapy and mindfulness interventions, many called for improved access to tailored psychological support from therapists able to appreciate and work with the tangible physical underpinnings of their anxieties. Some conveyed a 'ride the storm' mentality, combining determination with careful contingency strategies in order to cope with the unpredictability of the condition. These participants often described strategies used to distract themselves during less acute, but nonetheless destabilising, stages of an attack, be it watching the clouds through the bedroom window, listening to the radio or taking comfort from the companionship of a quiet cat or dog (reflecting wider literature on the value of companion animals in coping with long-term chronic illness [19, 20]).

Debbie: *'I find having a dog helps, especially this one... I find that touching her does make me feel better... it makes me feel like life's worth living really... She lays still – if she was jumping about I wouldn't be able to stand it, but she seems to sense when I'm not very well and she stays so close to me and still that it does make a difference'.*

Contingency strategies ranged from keeping anti-sickness medication in every pocket/bag, carrying sick bags, tissues, a torch (in winter with shorter hours of daylight), using ear defenders (in noisy settings), wearing sunglasses (to avoid bright light triggers, particularly those living with Ménière's and migraine) and wearing a medical bracelet to convey their emergency contact details if out alone. Perhaps the most important contingency strategy discussed by participants was the role of a reliable support network, be it partners, family or friends, as illustrated in the extract from Dawn's interview below.

Dawn: *'You don't ever feel like "Oh I'm better now, I'll move on." Not completely. There's a little, small percentage of you that's thinking, "Am I going to be okay doing this?"... I have to have a back-up plan. Like, my back-up plan now is that I've trained my husband to actually have his mobile phone with him all the time, which is a massive breakthrough, trust me!'*

Once 'rescued' and brought back to the familiarity of home (described by one participant as their 'cave'), participants explained that they preferred to be left alone to ride out the attack, knowing that someone would be there if needed. In part, this links to feelings of social embarrassment about one's physical state during an attack, but also to the sense that others cannot do much to help at that stage anyway. The increased reliance on partners, family and friends to fulfil this support role was upsetting for some participants, particularly when they felt their condition was compromising the independence of others as well as their own. As one partner commented (the husband of a participant with long-term Ménière's), 'it's not a disease one person gets – if it's a couple, it's a disease that two people get'. Participants, including those with Ménière's and the partners interviewed, explained the need to find a balance between being stoic whilst also recognising limitations. This is illustrated in the extract from Toby's interview below (husband of a participant trying to adapt to bilateral Ménière's).

Toby: *'I mean she probably thinks it's bothered me more than it actually has. The bit that bothers me is to see her suffering. I don't care that I can't go to a pub or cinema... I really don't care about that. She's very stoic, I say this to people – she wouldn't have any gas and air when she had the children. She's a right little tough nut... I mean she won't let it beat her. She'll just, you know, she'll do different-, we'll just do different things.'*

In this extract, Toby draws on an earlier biographical experience (childbirth) to emphasise and show respect for his wife's strength and determination, noting the shared process of finding alternative activities to do together that better accommodate the needs of the condition. Although this was recognised as difficult in particularly active phases of vertigo, several participants described positive examples, including going on outdoor walks, finding quiet pubs/restaurants for lunch or dinner (sitting outside weather-permitting or eating early indoors to avoid crowds and noise), people watching by the coast and visiting nature-based/heritage attractions at quiet times of the day/year. Although this process of finding compensations—be it alone or with a partner, family or friends—often took time, it was deemed particularly important amongst longer-term sufferers:

Emma: *'With the gap that's created by perhaps not being able to do what you would normally do, try and fill it with something else that brings you happiness and pleasure... I've done loads of sewing... and I make these little bags – this is my therapy – I like to have something to show for my day... I've chosen fabrics which are nice and tactile, and in fact I've got a delivery coming today of really amazing bright coloured velvets with velvet silk!'*

Finding these personal 'havens' [21] sometimes required significant (and ongoing) shifts in aspirations and outlook over time, with participants coming to value pleasures and activities they had previously taken for granted. This is indicated in the interview extract below from a participant who had lived with severe symptoms for over 12 years:

Emily: *'I was sort of going along, going along, going along, going along, and then somewhere along this path, I thought "Hang on, we don't do anything. I haven't got a life". I, I, I existed, but I hadn't got a life... But now we have found little places where we can go, so we have got a bit of a life now.'*

The importance of 'counting blessings' came through as particularly important in the interviews of longer-term sufferers. Participants talked about trying to focus on the 'good' things in their lives, making the most of remission phases and cherishing the support networks they have in place to co-navigate the condition. This is conveyed in the extract from Becky's interview below; Becky had lived with Ménière's since she was 17 years old. In her early thirties at the time of the interview, and having recently become a parent, she described the changes in her attitude to the condition since starting to experience bilateral symptoms of tinnitus and imbalance:

Becky: *'I've changed so much in how I've dealt with it. Because before I would have been like, "Oh just get on with it!" to other Ménière's people, you know, "I did". But now I completely understand how devastating an illness it can be... So I just, I'm grateful for each day of normality... I still appreciate living in the now, and living when like my balance is good, and my hearing is good, and the tinnitus isn't so bad... just very much, counting my blessings... focusing on what's good rather than what might happen.'*

Several participants used hope to maintain a sense of morale during the most challenging phases of the condition, particularly with regards to the potential for future medical and

technological advances (e.g. stem cells, refined hearing aid and directional microphone technology, etc.) to bring greater understanding of, and predictability to, their condition. Indeed, two participants expressed a reluctance to undergo any of the (albeit limited) surgical procedures currently available for fear of compromising their eligibility for any better, more appealing options emerging further down the line. This touches on the recognition in the wider long-term illness literature that 'absolute faith in medicine may be problematic, prohibit change and be constraining to live by' [22]. As such, it seems important for participants to find a balance between taking comfort from those hopes while also allowing themselves to use all the resources available in the present to fully accept and adapt to their current situation.

4. Discussion

Our research demonstrates that the unpredictable and disabling symptoms of Ménière's result in sufferers experiencing prolonged periods of depression. In addition, it provides insight into how this is experienced in the context of everyday life. We strengthen and extend the evidence from a number of studies suggesting the adverse mental health impact of Ménière's [1, 2, 23], while also supporting previous evidence regarding the impact of Ménière's on fatigue, tenseness and unenthusiasm [23]. The importance of tinnitus severity and mental health outcomes was also highlighted.

Ménière's was strongly associated with lower health status satisfaction. This was unsurprising given the unpredictable nature of the condition and the known association with depression. Indeed, many of our participants lived with an ongoing sense of anxiety as symptoms caused their body to 'dys-appear', or emerge problematically into direct consciousness [24]. Moreover, this occurred in ways that were not only unpredictable but also uncontrollable. Losing control over a body that, prior to the onset of symptoms (severe or otherwise), had become disciplined and predictable through acts of routinised self-regimentation (working, exercising, eating, socialising and so forth—without the need for careful and strategic planning) further contributed to mental distress [25].

The similarity in other life domains between people with Ménière's and controls, including satisfaction with family, friends and financial status, is particularly noteworthy. It might be anticipated that because of their condition people with Ménière's would be less satisfied with all aspects of their life. However, previous work on other chronic health conditions has suggested that people do not always rate their quality of life as badly as healthy people might anticipate [26]. Further some studies have demonstrated small differences in reported life satisfaction or happiness between people with serious physical disabilities and 'normal' control subjects [27]. One explanation for this might be found in our participants' accounts of learning to find joy and happiness in activities that formed the fabric of their daily life, but had previously been taken for granted. Included here was the realisation of unwavering support and in some instances, new found closeness with the people around them. Indeed, the data suggested that individuals with Ménière's had more contact and satisfactory relationships with family and friends.

In day-to-day life, people with Ménière's can feel isolated, afraid, dependent and on some occasions embarrassed. Yet, reflecting previous literature on chronic illness [21], our research highlights the value of support networks and suggests they may enable people with Ménière's to live satisfying lives. We would, therefore, emphasise the importance of not just informing friends and family about the condition, but educating them on how they might best assist during its various manifestations. This might range from being mindful of inclusive forms of communication for those with impaired hearing, to supporting from afar during an attack. Aasbo et al.'s [28] concept of 'biographical we' is useful here in helping to understand the great effort partners of chronically ill put in to re-establish normality and continuity in everyday life; effort, that as our research signalled, can come at a cost of their own needs being overlooked. 'Ménière's is a disease that two people get' and this aspect warrants greater consideration as part of the broader patient treatment pathway.

Improvements in the frequency of depression episodes and health satisfaction were noted as disease duration increased. This may reflect the disease progression pathway, which usually involves a reduction in the number of vertigo attacks experienced by individuals as the disease progresses [29]. Our participants' improved ability to read their bodies and recognise signs of an impending attack suggests the development of *Ménière's literacy*. Borrowing from the concept of *interactive health literacy*, whereby individuals develop an improved capacity to act independently on knowledge with motivation and confidence in an empowered way [30], *Ménière's literacy supports* adaptation by individuals to their condition and/or medical interventions and lifestyle changes reducing the frequency of vertigo attacks. Given that vertigo is considered to be the most detrimental symptom in Ménière's [2], reductions in vertigo severity should, therefore, improve mental health and well-being. All of this is not to suggest that adaptation diminishes the ongoing sensory, emotional and social challenges that people with Ménière's face in their everyday life [16]. Indeed, our research showed that at a population level, disease duration did not alter the frequency of tiredness, tenseness or a lack of enthusiasm experienced by Ménière's sufferers. While some aspects of Ménière's may improve over time and an individual may adapt to some extent, overall it continues to impact negatively on everyday life.

5. Conclusions

Our research findings emerged from cross-sectional data. It cannot and does not seek to determine the causal pathway of Ménière's disease. Our interpretations of the qualitative data are shaped as much by the absence of certain voices as they are by the presence of others. To that end, it is noteworthy that our sample for Phase II consisted primarily of women (16 female patients, 3 female supportive partners), with just four participants experiencing bilateral symptoms of tinnitus, imbalance and hearing loss (i.e. symptoms in both ears).

Those limitations noted, the research provides the most comprehensive study of the mental health and well-being impacts of Ménière's to date and highlights the adverse mental health effects of Ménière's. By utilising the UK Biobank, the inclusion of key confounders and sufficient numbers to investigate the role of disease duration in Phase I has enabled us to offer a

unique contribution to the field. Likewise, a combined focus on the individual everyday realities of living with Ménière's disease provides original insight into how it intersects with mental health and well-being in a number of different ways and across a variety of contexts. While offering a holistic and detailed analysis of this subject, the research also provides a working example of interdisciplinary, integrated research and the value it can bring to our attempts to understand complex health conditions like Ménière's disease in a way that respects the importance of the big picture, without ignoring the individual 'expert' voices of patient experience.

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