



KEY FINDINGS:

Living with Ménière's disease:

Understanding patient
experiences of mental health
and well-being in everyday life

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AIMS OF THE PROJECT

In this project we explored how Ménière's disease impacts upon people's mental health and well-being in the context of their everyday lives and routines.

Ménière's disease is a long-term progressive inner ear disorder, defined by episodes of severe vertigo, aural fullness (pressure within the ear), tinnitus and fluctuating hearing loss. Approximately 120,000 people within the UK are diagnosed with Ménière's, each living with varying severities of these combined symptoms.

Previous research has identified associations between Ménière's disease and reduced quality of life amongst diagnosed individuals. During the early stages of the illness, unpredictable recurrent attacks of vertigo can be the most distressing symptom. As vertigo attacks settle down during the later stages, experiences of tinnitus and hearing loss (in one or both ears) may become increasingly debilitating.

Within this earlier research, we identified important knowledge gaps regarding the ways in which different

people experience and adapt to the condition, and how this varies through their life-times.

First, there was little understanding of how people make sense of the condition and what it means for their daily activities, personal hobbies and ambitions. What psychological, physical and social resources do people use to adjust their activities and goals in the face of Ménière's?

Second, limited information was available about how the timing of illness onset and progression influences the ways in which people with Ménière's experience and feel able to manage their symptoms over time.

Finally, there were few in-depth insights into the role of significant others (be they partners, close family members or friends) in shaping the day-to-day experiences of Ménière's disease for those with the condition, and vice-versa.

These are some of the knowledge gaps explored by this study.

HOW WE COLLECTED THE DATA

Two complementary methods were used at different phases of this study to explore how people experience and adapt to the progressive nature of Ménière's disease.

Population-level insights were gained in Phase 1 using data from the UK Biobank. The UK Biobank is a study of 500,000 individuals. It has a wealth of information regarding each participant's health and lifestyle (e.g. health conditions, diet, exercise etc.). The UK Biobank also has data on mental health and well-being.

In the UK Biobank 1,376 individuals reported Ménière's disease. A comparison of the mental health and well-being of individuals reporting Ménière's ('cases') was made with individuals not reporting Ménière's (described as 'controls').

A range of analyses investigated: a) the frequency and duration of depression; b) life satisfaction; c) the role of family support in cases and controls. Amongst the 1,376 participants with Ménière's, the role of disease duration on mental health and well-being was investigated.

In Phase 2, in-depth qualitative interviews were conducted to gain detailed understandings of everyday life with Ménière's disease from the perspective of those living with the condition on a day-to-day basis. These focused on 20 people at different stages of the condition.

The interview discussions extended beyond the identification of beliefs about common triggers and symptoms in order to understand how people attempt to deal with – both practically and psychologically – the unpredictable nature of the condition, how this has changed over time, and the importance of social support in this process.

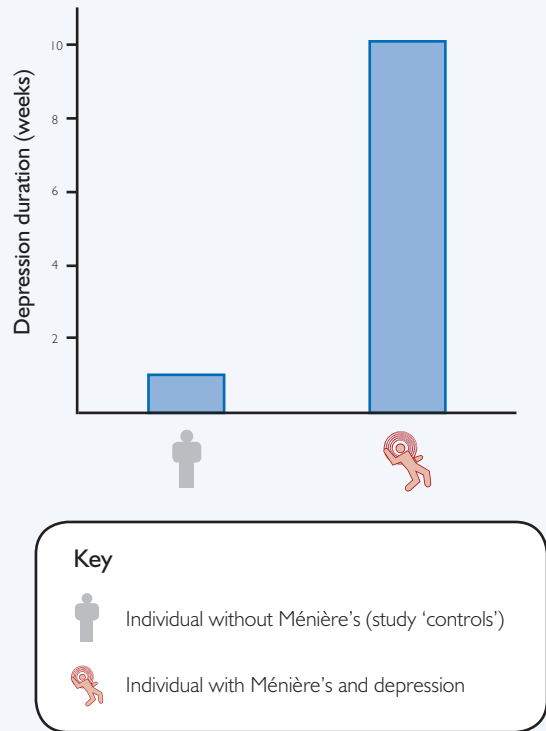
A further eight in-depth interviews were carried out with 'supportive others'; partners and family members identified by participants as central to their efforts to manage and adapt to the condition.

Participants were recruited from across the south west of England, with the assistance of the Ménière's Society.

WHAT DID WE LEARN AT THE POPULATION LEVEL?

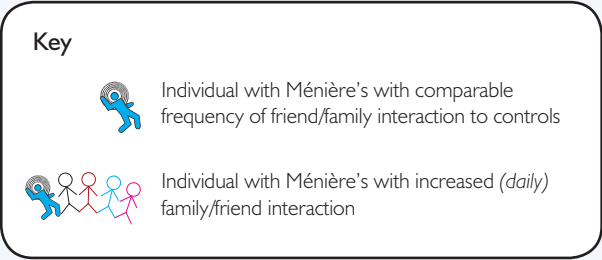
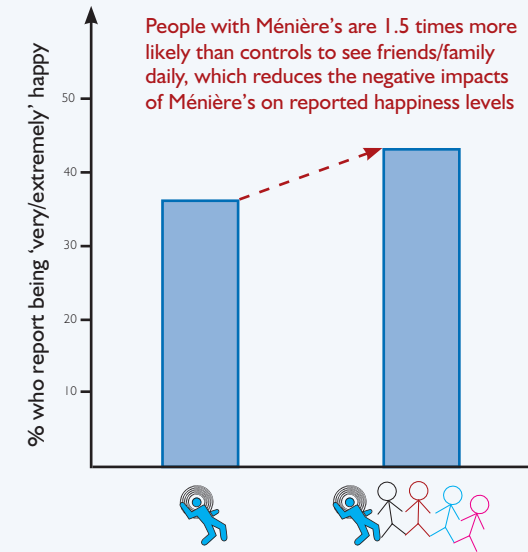
Individuals with Ménière's were 1.5 times more likely to report depression than those without (i.e. the 'controls').

The duration of depression was up to 10 weeks longer in people with Ménière's compared to controls.



Disease duration was important in mental health – individuals diagnosed for at least five years had lower levels of depression than recently diagnosed individuals. This perhaps suggests greater levels of adaptation to (and/or understanding of) the condition over time.

Support from friends and family was particularly important for maintaining well-being. Individuals with Ménière's tended to see family and friends more regularly than controls.



We now look to the Phase 2 findings to unpick what might be contributing to these trends.

THE CHALLENGES OF UNCERTAINTY

Central to many of the adverse mental health impacts discussed by participants were the challenges of coming to live a 'routinely unpredictable' life.

Participants expressed deep-seated anxieties about when symptoms may occur, in what forms, how severely, and whether they would advance to the other ear.

These anxieties were linked to feelings of *vulnerability* (as one participant said, it's like 'driving with a dodgy brake'), *social embarrassment* (particularly when observed having a severe vertigo attack in public), and *frustration* due to their loss of independence during active phases of the condition.

Many relied on close family and friends to get them home during an attack. One participant had even trained her spouse to give her the anti-sickness injection during severe episodes. Another spouse noted the benefit of using a baby monitor at home to give their partner peace and privacy during an attack, whilst remaining on hand to help as needed.

The symptoms – and fear of symptoms – permeated many aspects of participants' daily routines.

Everyday challenges ranged from waiting for the bedroom coving to stop 'dancing' before getting up in the morning, to negotiating the unsettling sensations of personal and public transport, navigating the 'sensory overload' of routine places, socialising with distorted hearing, adjusting to shifting emotional and physical relationship dynamics with loved ones, and adapting to the intense exhaustion experienced at the end of what used to be viewed as just an 'average' day.

These experiences varied with the severity of symptoms, between active and remission phases of the condition and with shifting life circumstances.

IMPLICATIONS:

Adjusting to life with Ménière's was experienced by participants as a steep learning curve with three parts: understanding variability in symptom severity; searching for personal triggers; and adjusting to the life-changing nature of the condition. This booklet aims to share some of the steps taken to adjust.



I describe it like waves on a sea shore; either you get little waves, little ripples or a fairly still sea and you're, you're okay. But every so often, for reasons which I think are difficult to understand... the waves get bigger and bigger, and you go through quite severe vertigo, tinnitus and disorientation. And then it, over a period of time – which can take some days or weeks – it starts to settle down again. The thing that's worrying about once you're in the condition is when it's going to impact again.

Richard

You're so desperate to find what starts it, you're so desperate to find what finishes it, and you think you're onto something, and then something happens and you think 'Well, that's that theory out the window!' You try and diarise, you try and find triggers. If it's happening every day, it's like, you know, well maybe it's when I wear my brown socks! Maybe it's the red jumper!

Louisa

I limit myself in that I do drive on my own but I limit it to 10/15 minutes so I can do the shopping, I can go to the dentist, the doctor, the vet, my pilates class, that's the furthest point. But I always have cover as well. Various friends are set up for various things... So I've got some super friends, and if I do that, then I feel safer.

Susan

I guess it's also a feeling of powerlessness... because when she does have an attack, I can't do anything anyway. Well I can help, I can be there but in a way, she's better just sitting still. So then you just have to deal with it.

David, husband of Susan

Just give them plenty of love and back up, and sympathy and understanding. No 'Pull yourself together', none of that. That doesn't help. So just say 'There's light at the end of the tunnel. People do recover, so you've just got to go through it.'

Matt, husband of Maggie, had also suffered with a long-term vestibular disorder

STRATEGIES FOR NEGOTIATING UNCERTAINTY

Participants described efforts to maintain a steady equilibrium, avoiding conditions that might 'upset their gyros'. One participant suggested 'you are quite like a metronome', becoming reluctant to create unnecessary vulnerabilities for the body. Over time, participants talked about pushing themselves to gently 'nudge' the pulse of the metronome in an effort to reduce their restrictions and rebuild their confidence.

Whilst the effectiveness of the medication for Ménière's varies from person-to-person, most participants indicated using at least one form of medication on a regular basis. Although taken for precautionary reasons, this cocktail of daily medication was seen as a short-term solution, making some participants feel uneasy. Surgical options were often viewed as a 'last resort', with concerns raised about risks and longer-term repercussions.

Many participants sought out others with the condition (online or in person), to reduce feelings of isolation and share self-management tips. Others preferred to find their own way through it and avoid the risk of exposure to traumatic or distressing stories, particularly those often found online.

Participants adopted a range of contingency strategies to manage vertigo-related anxieties. These included carrying sick bags, tissues, and anti-sickness medication, using ear defenders and sunglasses (to avoid noise/light triggers), wearing a medical bracelet with emergency contact details when out, and having family/friends at the other end of the phone.

In order to prepare for future hearing loss, participants noted the benefits of taking part in lip reading classes, becoming more attuned to people's body language, re-positioning themselves and trying to be more assertive in raising awareness of their hearing loss in order to create better conditions for communication.

Participants tried various lifestyle shifts (with varying degrees of success), be they diet-related (low salt, caffeine, alcohol), complementary (vitamin B12 supplements, acupuncture, Bowen technique, chiropractic jaw adjustments), finding appropriate forms of physical activity to build core strength, and minimising stress, whilst maximising sleep/relaxation.

IMPLICATIONS:

These findings emphasise the need to provide constructive information to patients, and their families, about what they may experience and why, with a particular focus on both physical and psychological self-management options.

I describe it as something that gets you... It's like a little alien within. And if it's really little and you feel it's there, you can stop it. If it gets too big, you have no control over it, and then actually, if you get into a full blown attack and you're sick, you can't take Stemetil because it comes straight back up, even under your tongue. I've taken one of those and thought 'I'll be fine in ten minutes, I'll be fine' and actually it's taken me an hour because the attack is so deep that you can't, you can't get control of it quickly enough.

Louisa

You're very conscious of the horizon... supermarkets used to be a problem; the bright lights, the intensity of it... I go into small ones because you can see the exit, you can visualise it. But big ones, you could get lost in and then your horizons start to go again. So there's lots of places that you subconsciously and consciously avoid. Noise, bright lights, dark lights with no horizon.

Richard

I think fitness is the key – if you're not physically fit, I think that makes a massive difference. I would sort of advocate people to walk, walk, walk, every day. Get out walking or something... It's finding what suits you.

Dawn

I go online and I buy my own sick bags. I can't find them locally... And I take it everywhere with me, a sick bag, because that makes me feel a lot better... and for a while, I wore – well I do now if I go out – I've got a bracelet with it written on so that I can point to it.

Debbie

On Facebook there's Ménière's UK. That always helps because there's lots of things, lots of tips. And it's just nice to say: 'Oh I feel really rough' and they say, you know 'Get well soon' and everything. That's made a lot of difference to me. I get a lot of support there.

Debbie



TARGETED PSYCHOLOGICAL SUPPORT

In addition to practical strategies for managing uncertainty, several participants described efforts made to manage the psychological anxiety linked to the attacks and the future progression of the condition.

Whilst some participants had used anti-depressants during the worst phases of the condition, they expressed a preference for counselling options.

Participants distinguished between different forms of counselling depending on their personal situations; whether they were dealing with a separate traumatic event that was adding to their emotional distress at the time (e.g. bereavement, familial caring duties), or whether they were primarily trying to manage the anxieties of life with Ménière's (cognitive behavioural therapy, CBT, was valued in this regard by some participants).

Given the tangible physical basis to participants' anxiety levels, many felt that psychological support would be most effective from someone who understands the condition. Being able to learn about and practise anxiety management techniques during remission phases was also considered important, rather than waiting for the anxiety to take full hold.

Several participants felt that, with the passing of time, they stopped fighting the attacks so much, instead managing them to the best of their ability whilst learning to 'ride the storm'.

Some participants talked about the value of mindfulness in this context, whilst others relied on thoughts of the 'before and after' to cope. However, the latter was recognised as a risky strategy should attacks last longer or follow a different pattern to those experienced on previous occasions.

Participants also described strategies used to distract themselves during attacks, be it watching the clouds through the bedroom window, listening to the radio, or appreciating the companionship of a pet.

Set against the recognition of the life changing nature of the condition, participants felt there are worse illnesses to live with and sought to make the most of remission phases. Many tried to find meaning in the condition, and several used hope to maintain a sense of morale during the most challenging phases.

IMPLICATIONS:

There is a need to move beyond the prescription of anti-depressants to adequately address the mental health impacts of Ménière's. The value of tailored psychological support was noted, particularly during stressful life transitions, be they condition-related or otherwise (e.g. early parenthood, retirement, bereavement, familial caring/illness).

I had a bit of CBT training a while back and I think I use some of those strategies. Just to sort of get me in the zone and get me in a good frame of mind. I haven't done counselling or anything like that, I don't think that would help. I mean, I think counselling is good if there's something for you to get over, but this isn't going to go away. I think maybe counselling is a bit sort of retrospective – when it's an ongoing issue, I don't think it would help me.

Maggie

I would be home with my mum. I used to manage to cook her something and then I had to put it on the floor, and kneel, and push it to her room. That's how I fed my mum. I felt that ill I couldn't stand up... it was awful. It was wearing me out.

Caroline

The Ménière's, I've had to accept that it isn't mind over matter at all. Rather than thinking, 'Right, change the way you think' and all that kind of stuff, I've had to just think 'Ride the storm'. That's had to be my kind of mantra. I am actually quite critical of CBT. I suppose if you'd got to a situation where you literally felt you couldn't walk out the front door to put the bins out, then it might work.

Emma

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.

Becky



THE CHALLENGES OF A LARGELY INVISIBLE CONDITION

Coupled with the challenges of unpredictability, is the relative invisibility to the outside world of many of the symptoms of Ménière's, except the socially embarrassing experience of a vertigo attack (which can be misinterpreted as drunkenness).

There was a sense that few people understand the full extent of the condition and its implications for the everyday lives of participants, leading many to describe feelings of isolation, as if living on 'Planet Ménière's'.

This lack of awareness or understanding sparked feelings of frustration for many participants, particularly when exposed to people who trivialise the condition.

Participants also touched on the challenges posed by the combination of fluctuating hearing loss, tinnitus and hyperacusis (high sensitivity to sudden, loud sounds). Again, this is largely invisible and the public rarely seemed to respond appropriately. It therefore served to complicate communications at work (e.g. in meetings) and in social scenarios (e.g. when trying to chat in cafés with clattering cutlery and coffee machine noises in the background).

In addition to these invisible symptoms, participants described a range of other physical manifestations that they had experienced since the onset of Ménière's (e.g. stiff neck, tremors, a metallic taste). These sensations were always on the same side as their Ménière's-affected ear and yet were rarely attributed to Ménière's when discussed during GP appointments.

Participants were unclear whether these were symptoms of Ménière's, side-effects of medication, or symptoms of separate conditions altogether. Awareness of these different sensations often triggered a sense that the mind was playing tricks on participants, adding to anxiety levels but also to feelings of boredom as they found themselves to be monitoring their health all the time.

IMPLICATIONS:

Dedicated medical support (e.g. via the introduction of vestibular nurses) could support patients to understand why they are feeling different physical sensations, which of those are likely to be linked to Ménière's or otherwise, what can be done about them, and how to explain symptoms to raise awareness amongst others.



I have a fear of falling over or making a fool of myself. That's why I panic I think. I think it's the panic that I just want to get home. Then of course you end up with your home as your prison, isn't it, because you don't get out.

Caroline

When you say what you've got, nobody understands it. I think they just don't get quite how difficult it is when you suddenly get an attack, you suddenly go. Actually the fact there are so many components also contributes to the lack of understanding. You know, how can you not hear me and yet be sensitive to sound?

Susan

The NHS doesn't tell you these things: 'Okay you've got Ménière's, we'll see you in six months', but they don't explain to you all these little things that can happen, and so you go through a long period of time - and all these strange little bits and pieces happen - and you think 'Well, do I need to go and see the doctor about that? Is that something else?'

Angus

When people first spoke to me, they said 'Oh you feel a bit dizzy', but I would never use the word dizzy... Mine is more - everything gets distorted? I can't get my balance. I fainted when I was younger and that's dizzy to me. I don't really get that, I get something a bit more severe than that. For a few months, when I first had the condition, I used to get quite angry. I needed to deal with that because I can't change how other people perceive it.

Nicola



RAISING AWARENESS OF “PLANET MÉNIÈRE’S”

Many steps are needed to raise awareness of Ménière’s amongst diverse social groups in order to ease the social and emotional challenges faced by individuals living with the condition. This requires some degree of assertiveness on the part of patients, but more importantly, it would benefit from national-level action to educate the public, employers, leisure, medical and commercial institutions.

The public: suggestions made to address the lack of public awareness of Ménière’s included the identification of a high profile celebrity ambassador for Ménière’s, the production of a documentary (e.g. a Horizons episode) on the implications of life with a vestibular disorder, or the inclusion of a credible Ménière’s-related storyline in one of the popular television soaps. Such efforts could help friends and employers to better understand and make appropriate adjustments for the condition.

Employers: employer responses to Ménière’s had a major impact on whether participants felt able to stay in paid employment or not. Continued employment was more likely when employers and HR staff had researched

and made relevant allowances for the condition (restructuring job roles, allowing flexible working arrangements, and improving the physical and social working environment).

Public, medical and commercial institutions: several participants described the challenges of navigating and communicating within public settings (e.g. shops, leisure spaces, medical settings) due to the noise levels, crowding, and the lack of public seating, toilets, and functional hearing loops (even in some GP surgeries).

Given the increasing efforts made to ensure public settings are physically accessible (e.g. wheelchair friendly), there was a sense that staff working in these settings should be trained in the use of hearing loop technology; it is not enough to advertise the presence of a hearing loop if it is not in operation.

Frustrations were also raised regarding the tendency for audiology and ENT departments to call out patients’ names at the time of their appointment rather than using a visual system that people with hearing impairments can better engage with.



I would tell everybody, or as many people who will listen, because I think you need to have people around you that understand that it’s out of your control. It’s very unpredictable. It can be a very little thing. It can be a very big thing... the more understanding that people have around you, just the easier it is for you to deal with.

Louisa

Like, at work, the hand dryer... it’s so loud, I just asked ‘Can I have some paper towels in the toilet because I can’t put the hand drier on?’ They were funny about that. Then, we have a fire alarm on a Wednesday, which was freaking me out. So I said, ‘Can you just let me know?’ Because we could have one anytime between 9 and 11.30 am, ‘Can you just let me know?’ No, too much effort... Anyway, they were awful... it was so stressful, in the end I joined the Union.

Jennie

I changed my working weeks, I cut my hours down... my boss is really good... because she experienced me in a really bad attack so that was really good, her seeing it. I’ve found with this condition, people can’t see it? So they think you’re fine, and there’s so many times when you’re not fine but you’re trying to be fine.

Nicola

We do lots of [heritage-type] properties now, so we enjoy doing that, but we have the ongoing problem there that a lot of them, the audio loops don’t work... Last summer, we asked about a hearing loop, and after much searching they couldn’t find one. Eventually they decided that they’d got a print out of the audio tour... We get outside, open it up, and it’s in Chinese!

Angus



FINDING PERSONAL 'HAVENS'

Recognising the limitations encountered with the onset of Ménière's, some participants emphasised the importance of finding compensations; activities or 'personal havens' that bring a sense of well-being without imposing undue stress.

For some participants, these havens existed in the home, such as time spent with companion animals, or whilst immersed in a pleasurable activity, such as sewing, painting and reading (hard-copy books rather than screens).

Participants also talked about valued outdoor pursuits, be they in the garden close to home or further afield (when conditions were not too windy). Through such pursuits, participants were gently pushing themselves beyond their comfort zone but in spaces with pleasurable and less imposing sensory characteristics than those encountered in more crowded built up areas.

The need for this personal 'haven' extended to some of the family members interviewed, although they tended to organise their activities around being 'on call' for their partner during more active phases of the condition.

Importantly, several participants explained the value of shared havens with partners and/or close family and friends. These included walking together, going out in the camper van, and visiting National Trust-type properties. They also described looking (with varying levels of success) for compromises, such as subtitled cinema, captioned theatre, and quieter restaurants, often visiting earlier to avoid the risk of crowding.

With holiday travel and planning noted as particularly difficult by many participants, the value of having a 'home-from-home' was noted. This included, for example, mobile homes and camper vans, allowing for a degree of spontaneity to go away when feeling well enough. These flexible leisure strategies provided the comfort and security of feeling 'at home' even whilst away.

IMPLICATIONS:

These personal havens illustrate the perceived importance of 'pushing back', and not letting the world close in with the onset of Ménière's. Central to this was the search for new pleasurable ways of being in the world, even if different to the hobbies and activities enjoyed prior to illness onset.



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!

Emma

I just love it out in the garden. I lose myself doing something out there for 2/3 hours. If Dawn was poorly for a day or whatever, I could be out there for a short while, trot in and see if everything's alright, trot out again, carry on. I'm lucky on that side of it.

Sandy, husband of Dawn

You make compensations to your lifestyle. I started doing serious long distance walking, and I completed the South West Coast Path. I was getting exercise, good visual cues, good clean air... satisfaction that I was actually achieving something. It took years, you know, which, I was happy with. You have to find an outlet that overcomes this, this desperate concern that you're in some sort of downward spiral.

Richard

We really like going away in our camper. We can go and just sit in it, somewhere, and watch the world go by. It's nice and quiet. We went out for the day the other weekend, it was really sunny, so we went down to the seafront. As we started off, I don't know, there was a calming feeling.

Karen, wife of Angus

FURTHER INFORMATION

Project:

www.ecehh.org/research-projects/understanding-menières

Ménière's Society:

www.menières.org.uk

Blogs/blog entries:

- themighty.com/what-its-like-to-walk-in-my-shoes-as-a-person-with-menières-disease
- www.racheldavieswriter.com/category/level-up-series
- www.mindovermenieres.com
- <http://dennisstelling.blogspot.co.uk>
- www.healingthedizzies.com
- www.hear4u.co.uk/blog

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