

## The role of fluctuating soundscapes in shaping the emotional geographies of individuals living with Ménière's disease

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The potential for everyday soundscapes to evoke diverse emotions amongst different cultural and acoustic communities is increasingly recognised within the literature. However, few studies have examined how these soundscapes can shift with the onset and progression of specific hearing impairments. This paper explores such shifts, drawing on a series of in-depth narrative interviews conducted in the south west of England with individuals diagnosed with Ménière's disease; a long-term progressive vestibular disorder characterised by episodes of vertigo, tinnitus, sensorineural hearing loss and, for some people, hyperacusis (high sensitivity to sudden irregular sounds). Located in the subfield of 'emotional geographies', the paper discusses how participants were forced to connect with and attune to previously unremarkable aspects of their everyday soundscapes in ways that were both emotionally and socially challenging. Four aspects of participants' embodied, emotional soundscapes are critically explored: hearing life in '2D'; corporeal and environmental 'sonic intruders'; corporeal sound 'symbols'; and seeking to regain a semblance of control through soundscape (re)-negotiations. Such insights are important to inform conscious acoustic design efforts that respect the 'ears and voice' of people living with varying levels of auditory sensitivity, rather than urban and community planning policies that continue to prioritise vision and transit.

**Keywords:** soundscapes; emotional geographies; wellbeing; hearing impairment; Ménière's disease; narrative interviews

### Introduction

A burgeoning corpus of research has identified the highly subjective and often emotional ways in which humans relate to diverse acoustic environments (Cain, Jennings, & Poxon, 2013; Davies et al., 2013; Hill, 2015; Medvedev, Shepherd, & Hautus, 2015). Although traditionally dominated by studies documenting the detrimental effects of noise exposure (Dumyahn & Pijanowski, 2011), efforts to understand how people attend to the *totality* of sound phenomena in their living environments have been promoted via Schafer's (1977) concept of the 'soundscape'. Whilst Schafer (1977) defines this somewhat simply as 'the sonic environment', Rodaway (1994) suggests it represents a 'state of being with respect to sound in the environment' (p. 86). Recent studies have emphasised this subjective soundscape quality, noting that 'environmental sounds are meaningful events that affect people' in myriad ways (Cain et al., 2013, p. 232), with the same sounds often eliciting varied responses depending on the perceptions, preferences and past experiences of the listener (Jennings & Cain, 2013).

Soundscapes are thought to consist of: (a) *sound signals*, referring to foreground sounds that directly and consciously capture attention; (b) *soundmarks*, including sounds that are particularly characteristic of a community (sometimes called *sound symbols*, generating specific

subjective responses due to collective associations); and (c) *keynote sounds*, constituting the sonic 'ambience' of a place, including sounds that are heard frequently or continuously enough to form a sonic background that is rarely consciously noticed or reflected upon (Schafer, 1977). *Acoustic communities* arise when a particular soundscape plays a pervasive role in the lives of those within the community, be it a community of geography or interest (Ray, 2006).

Although Schafer's work catalysed a valuable attentiveness to sound and the social life of sound, it has since been critiqued for: (a) conflating sound with listening; (b) imposing biased judgements about which sounds 'matter' (demonstrating what Arkette, 2004, describes as 'urban prejudice'); and (c) focusing primarily on the orchestration of 'idealised' soundscapes rather than engaging with the complexities and contradictions of diverse sonic environments as they are encountered within specific social and cultural contexts (Kelman, 2010). A number of studies have therefore broadened the concept (explicitly or implicitly) to better engage with the varied ways in which diverse sounds within different settings are experienced, interpreted and valued (or otherwise). Much of this work has been conducted with residents of, or visitors to, geographical localities with culturally and/or personally significant sonic characteristics, such as the 'tranquillity' of the countryside, the 'conviviality' of street music, and the 'comfort' of home (Duffy & Waitt, 2013; Jennings & Cain, 2013; Marry & Defrance, 2013; Rehan, 2015; Simpson, 2014). These studies highlight the potential for specific sounds and sonic rhythms to stimulate place attachments (Pistrick & Isnart, 2013), emphasising how different forms of routine 'sonic connection' shape processes of place-making and therefore people's sense of place (Duffy & Waitt, 2013).

As we habituate to local soundscapes, we can develop 'deaf spots' (Duffy, 2010, p. 43), often becoming subconsciously selective in what we hear. At the same time, cultural norms shape expectations of what we 'should' and 'should not' hear or be exposed to within different settings. As such, Matless (2005) describes the auditory geographies of hearing and listening as 'already cultural acts' (p. 747), explaining how sounds can be caught up within relations of power that shape 'judgements of sonic intrusion or harmony' (p. 748). Such judgements can, in turn, influence people's individual sense of belonging or alienation within different settings, with sounds 'pressing' upon different bodies in varied ways (Duffy & Waitt, 2013). There is a need, then, to engage with and understand the complexity of cultural, social and emotional interactions with soundscapes amongst diverse acoustic communities.

To date, studies have focused primarily on *hearing* acoustic communities, rather than those negotiating distorted soundscapes as a result of temporary or permanent hearing impairments. With over 5% of the global population estimated to live with disabling hearing loss (World Health Organisation, 2015), the need to understand the soundscapes of these alternative acoustic communities has been underestimated to date. As noted by Skagerstrand, Stenfelt, Arlinger, and Wikström (2014, p. 261), 'investigation of the soundscape that is valid for the hearing impaired population cannot be solely based on a general population. It is desirable to increase the knowledge of hearing impaired persons and hearing aid users' experience of various soundscapes'. This paper responds to this call in what follows, exploring how everyday soundscapes can contribute to micro-geographies of embodied disability (Imrie & Edwards, 2007) amongst people living with Ménière's disease; a chronic, progressive, distressing vestibular disorder (Tyrrell et al., 2015). In so doing, it moves beyond polarised biomedical or social models of disability, building instead on social relational models (Thomas, 2004) that recognise disability as the product of dynamic, embodied interactions occurring within specific sensory, material, social and cultural assemblages at particular times and for certain individuals/groups (Chouinard, Hall, & Wilton, 2010; Crooks, Dorn, & Wilton, 2008).

With a prevalence of approximately 0.25% in the United Kingdom (Tyrrell et al., 2015), Ménière's is characterised by episodes of vertigo, aural fullness (pressure), tinnitus and sensorineural hearing loss, and is experienced as a debilitating condition, associated with high levels of psychosocial morbidity and reduced quality of life (Kirby & Yardley, 2008). During early stages of the illness, unpredictable and recurrent attacks of vertigo have been reported as the most distressing symptom (Dibb & Yardley, 2006). As the vertigo attacks settle down during the later stages, experiences of tinnitus and hearing loss (in one or both ears) become increasingly debilitating (Yardley, Dibb, & Osborne, 2003). Whilst studies have examined the detrimental impacts of the condition on communication efforts and verbal spousal interactions (e.g. Stephens, Pyykko, Kentala, Levo, & Rasku, 2012a), very little consideration has been given to the social and emotional repercussions of the wider soundscape shifts experienced with the onset and progression of Ménière's disease.

Contrary to common misperceptions, the world of the hearing impaired is seldom a quiet one (Rodaway, 1994). For people living with Ménière's, experiencing fluctuating sensations of hearing loss, tinnitus and hyperacusis (high sensitivity to sudden irregular sounds), corporeal sounds can become so dominant as to move to the foreground of the soundscape, acting as a *sound signal*. In so doing, they effectively mask and prevent the processing of many external environmental sounds (e.g. soundmarks and keynote sounds), forcing affected individuals to connect with and attune to previously unremarkable aspects of their everyday soundscapes in ways that can be both emotionally and socially challenging. As noted by Rodaway (1994), people's experience of sound (particularly sound sources over which they have little control) is often highly emotional; 'because we cannot close our ears as we can our eyes, we are more vulnerable to sound' (p. 95).

To explore the emotional implications of these soundscape shifts, I locate the study within the subfield of 'emotional geographies', which has evolved to encourage more critical engagement with, and geographic scholarship regarding, the complex temporality, spatiality and sociality of human emotions (Bondi, Davidson, & Smith, 2005). As detailed by Bondi (2005), an increasing concern with emotions has emerged primarily from earlier traditions of humanistic, feminist and non-representational geography. Criticising humanistic scholarship for its preoccupation with individual emotional experiences, feminist theorists have emphasised the relationality and fluidity of emotion, illustrating how emotions extend beyond the individual to permeate both social and physical environments (Bondi, 2005). Meanwhile, non-representational geographers have called for greater attention to be paid to the transient, pre-reflective precursors to emotion, focusing on the dynamic performative interplay between emotion and 'affect' (the so-called 'how' of emotion) (Andrews, 2011). Grounded in an understanding of emotions as relational, embodied and fluid (Bondi, 2005), this paper recognises emotions as integral to our 'knowing', 'being' and 'doing' (Andrews, 2011). It examines how and why emotions evolve around and within everyday soundscapes for individuals with Ménière's, explores the emotional transitions experienced as soundscapes change with the progression of the condition, and elucidates dynamic, socio-spatially mediated relationships between impaired listening, emotions and belonging (Duffy, 2010).

To unpick the emotional geographies permeating the soundscapes of people living with Ménière's, I draw on: (a) the notion of 'emotional amplification' (Kingsbury, Crooks, Snyder, Johnston, & Adams, 2012), examining shifts in the intensity of emotions experienced as a result of the condition in relation to specific people, settings and sensory encounters; and (b) ideas of 'emotional safekeeping', described by Davidson (2010) as an on-going practice of self-care and heightened bodily vigilance in the context of 'complex and relational, socio-spatial practices' (p.

368). Appreciating that emotions may be personal or shared, the paper considers the emotional transitions experienced by both those with the condition and partners/family members deemed integral to its day-to-day management.

### **A narrative approach**

This paper forms part of a wider study that aimed to understand how Ménière's disease impacts upon people's mental health and wellbeing (Phoenix, Tyrrell, & Bell, 2015). The study drew on qualitative narrative methods, providing in-depth insights into the complexities of life following the onset of impairment (O'Day & Killeen, 2002) and allowing the illness experience to be situated within the context of each participant's everyday and whole lives (Phoenix, Smith, & Sparkes, 2010). Ethical approval for the study was secured from the University of Exeter Medical School Research Ethics Committee (Approval Reference 13/09/029).

With the assistance of the Ménière's Society UK, a purposive sample of 20 Ménière's patients was recruited from across the south west of England, focusing on individuals over the age of 18 who had experienced Ménière's symptoms within the previous 12 months and who had been diagnosed by an Ear Nose and Throat consultant (see Table 1 for sample composition). Purposive sampling allowed diverse 'information-rich' views to be captured from individuals at different stages of the condition, thereby enabling insights into its complexity and variability rather than focusing solely on the 'typical' or average case (Flyvbjerg, 2006). Based on participant preferences, partners were present for four of these interviews, providing useful insights into the shared nature of illness adjustment (Polak & Green, 2015). An additional eight semi-structured interviews were carried out with the partners of other participants to explore further the shared impact of Ménière's on close relationships.

*Table 1: Sample composition [Insert here]*

Data collection took place between January and June 2015. All interviews were undertaken at a time and place of participants' choosing (mostly in their homes due to the challenges of travel as a result of the condition), each lasting between 1 and 3.5 hours. Although an interview guide was developed to inform the interview process, questions were employed flexibly to encourage participant-led, open-ended responses. Each interview started by asking participants to reflect upon what was going on in their lives when they first started experiencing symptoms and how things had progressed from there. Discussed in participants' own ways, these interviews provided rich descriptions of: how participants experienced the unpredictable nature of the condition in their everyday lives and over time; the perceived impacts of the condition on their mental health, social roles, identities, friendships and relationships; the mechanisms (practical, emotional, psychological and social) used to self-manage the condition; and efforts to understand and make sense of its impacts. All interviews were digitally recorded and transcribed verbatim, taking care to capture any non-verbal expressions of emotion that permeated participants' accounts, including sighs, laughter, crying, pauses and hesitations.

Interview transcripts were checked for accuracy against the original interview recordings. Following a period of data immersion, listening back to recordings and annotating transcripts with initial codes and themes, each transcript and a working coding framework were uploaded to Nvivo 10 (qualitative data management software). All uploaded data were subject to thematic narrative analysis (Riessman, 2008), situating themes within each participant's life story and

identifying nuanced, intersecting themes within the data. Emerging findings were shared and discussed with peers ('critical friends') and a local Ménière's support group as part of a member checking process (Sparkes & Smith, 2014). The latter provided a valuable opportunity to ensure the emerging analysis and interpretations resonated with their personal understandings, experiences and perceptions.

Through this analytical process, the intense emotions permeating participants' complex sonic experiences of life with Ménière's became increasingly apparent. In what follows, I examine four facets of participants' emotional soundscapes: (a) hearing life in '2D'; (b) corporeal and environmental 'sonic intruders'; (c) corporeal sound symbols; and (d) regaining a semblance of control through soundscape (re)negotiations. The emotions evoked by the first three facets primarily reflect Kingsbury et al.'s (2012) notion of 'emotional amplification', particularly concerning the increasing centrality of anxiety in participants' lives and relationships, whilst the last facet illustrates Davidson's (2010) practices of 'emotional safekeeping'.

### Hearing life in '2D'

Sensorineural hearing loss is characterised by the inability to detect certain sound frequencies (in the case of Ménière's, the lower frequencies) and is often accompanied by a loss of directionality of sound and difficulties distinguishing foreground sounds against background noise (Skagerstrand et al., 2014). This selective loss of frequencies had significant impacts on how participants attended to their everyday soundscapes, with one participant (Louisa) explaining how she feels she hears in '2D' rather than 3D with Ménière's.

**Louisa:** I do say that most of the time without a hearing aid, I hear in 2D and not 3D and it's quite bizarre. So you can hear noise, but you don't know where it's from because you're only getting it one side... It must be like looking through one eye the whole time, which actually if you look round the room with one eye, it's a completely different view to two... I mean I don't think it's [2D hearing] actually a proper scientific thing, it's just the way I can describe it [Unilateral]

This '2D' hearing was experienced as disorientating in everyday scenarios characterised by unexpected sound signals. For example, one participant described a sense of panic in response to bicycle bells when out walking, leaving her unsure how to avoid oncoming bikes:

**Becky:** With being single sided deaf, sometimes when I'm out walking the dog, someone will ring the bell on a bike and I don't know which side they're on. So I will go to one side, always the side they're coming along, and they're like "Why did you do that you crazy lady?" [Bilateral]

Becky's account reflects Rodaway's (1994) assertion that hearing impairments can create an 'upside down' auditory geography, confusing the geographical orientation of affected individuals whilst moving through their daily lives. This auditory inversion compounds the general sense of disorientation already experienced by people with Ménière's as a result of life with varying degrees of vertigo. Moreover, it hinders opportunities for appropriate 'intercorporeal attunement' in certain scenarios (Brown, 2012). In the type of encounter described by Becky above, for example, sensorineural hearing loss compromised her ability to detect the precise location of the cyclist approaching from behind. As such, she felt unable to respond, physically or verbally, as socially expected, and lacked the time within such a momentary encounter to explain or justify her discordant embodied response to the passing cyclist. This contributed to a moment of 'dissonance' and unwelcome conflict with

the cyclist, thereby undermining Becky's self-confidence in her ability to choreograph bodily encounters appropriately in everyday local settings (Brown, 2012).

The soundscape distortion arising from this so-called 2D hearing was particularly distressing amongst participants with a passion for music, be it singing, playing an instrument, or listening/engaging in popular music cultures. Previous studies have highlighted the use of portable music players and headphones as one of limited means for reasserting some degree of control over our personal soundscapes (Ray, 2006), acting as metaphorical 'ear-lids' (Schafer, 1977). With the selective distortion experienced following the onset of sensorineural hearing loss, however, people with Ménière's can lose the capacity to 're-aestheticise' their auditory place experiences in this way, particularly when both ears are affected (the bilateral form of the condition). As such, personal musical soundscapes – characterised by sounds that were previously valued (i.e. sounds that 'mattered' to the individual) – had come to sound like the 'worst karaoke singer imaginable'.

**Angus:** I can't listen to the radio, I can't listen to music. I, I used to love music, absolutely you know, I, I would have music on twenty four hours a day. But it sounds like the worst karaoke singer imaginable now, I just can't listen to it, there's no point. My favourite tune in all the world, I cannot recognise when it's played now, so I really miss that. And because I've got the time to do it now, you know, I'm not doing anything because I can't hear (laughs), now I could but I can't hear so I can't listen to the things I'd like to [Bilateral].

Angus' narrative highlights a sense of loss, which was shared by other participants with bilateral Ménière's who could no longer perceive accurately and enjoy meaningful songs and artists. Previous studies have emphasised the affective power (Evans, 2014), expressive capacity (Bartel & Clements-Cortés, 2014) and intensity of emotional feeling often evoked by music (Andrews, Kingsbury, & Kearns, 2014; Wood & Smith, 2004), reducing feelings of isolation and stress (Laukka, 2007), particularly with the time available during retirement to proactively engage with valued music genres (Hays & Minichello, 2005). Since Angus was forced to take early retirement when the Ménière's shifted to a bilateral state, he had come to spend much time alone at home, which he felt unable to fill meaningfully with previous passions, including his love of music. This auditory distortion was particularly distressing for those who had previously participated in the *making* of music, whose social lives and aspects of their identities coalesced around local musical groups and choirs.

**Maggie:** I was a really keen singer in a local choir - I've had to give that up because my hearing is so distorted that it makes me feel queasy. I'll go to practices occasionally and I get about halfway through and say "It's no good. I'm just beginning to feel sick. I've got to go" [Unilateral].

Another participant, Debbie, had given up playing the saxophone after nearly 20 years as she found the sonic experience too disorientating with Ménière's. However, she laughed as she explained how her working life and musical background had to some extent equipped her to cope with the intrusion of tinnitus in her affected ear, rendering it far easier to adapt to than her near daily vertigo episodes.

**Debbie:** Because I've worked for twenty odd years in a bar, with a band in front of me, I could turn that [the tinnitus] off... I mean I do notice it, and it roars and the different tones and everything, but even at night it doesn't bother me... and sometimes I can sort of wiggle my head a bit to the [tinnitus], and make a rhythm of it [Unilateral].

For most participants, however, the experience of fluctuating hearing loss coupled with tinnitus and hyperacusis was particularly challenging. As noted by Becky, 'I think deafness would be one thing to handle, but deafness with tinnitus, it's just something else. It's really bad, it's really mean'. Participants' narratives suggested that the tinnitus and hyperacusis acted as 'sonic intruders' within everyday geographies that had previously been experienced as calm or, at least, relatively unremarkable.

### **Corporeal and environmental 'sonic intruders'**

As noted in the introduction, Schafer (1977) identified a series of elements that can combine to shape people's soundscapes. Focusing primarily on idealised orchestrated soundscapes (Kelman, 2010), Schafer (1977) explained how foreground elements (sound signals) that capture people's primary attention are typically hard to ignore. Faced with the auditory complexities of life with Ménière's, many participants conveyed the challenges of adapting to overbearing corporeal sounds of tinnitus. This often compromised their ability to detect or enjoy preferred sounds in their external environments. Whilst many felt able to acclimatise to the tinnitus over time, some (particularly those with bilateral symptoms) explained how the sheer volume, variation and unpredictability of tinnitus tones compromised their efforts to do so, and described the intense frustration arising from a lack of sonic respite.

**Becky:** I couldn't cope at all with it [tinnitus] initially, it was just awful. There was no respite from it, you know, I could hear it over everything. Every sort of area of my life where I would have found a respite from something, like walking the dogs, I could hear it over that [Bilateral].

Mirroring the experiences of other participants, Becky highlighted how places she would previously have visited for peace, for example visiting the nearby Dartmoor national park to engage in positive emotional work at the end of day, had become distressing because the tranquillity of such settings sensitised her to the sound of her internal tinnitus. Many participants expressed a deep appreciation for the rare moments of peace experienced with brief pauses in their tinnitus; moments they had previously taken for granted prior to the onset of the condition.

**Emma:** I remember once describing to someone what it feels like and I said "It feels a bit like you're in the middle of a cross-channel ferry and an aeroplane at the same time" and that's how it feels. There's this constant sort of blueblueah, kind of weird noises... I think the thing about Ménière's is you notice when things are normal, rather than taking it for granted, you notice silence, when there's no tinnitus I'll think "Oh my goodness, there's no tinnitus" [Unilateral].

The challenge came when these pauses became increasingly infrequent, and efforts to mask the tinnitus with alternative environmental sounds felt futile (e.g. with white noise generators, radio, sound boxes). At these points, sensations of hyperacusis, tinnitus, imbalance and vertigo were experienced as relentless and a sense of despondency seemed to take hold. As conveyed by Jennie's account below, the buffeting of corporeal noise (aggravated in many cases by external environmental sounds, as discussed below) drove some participants to intense and highly debilitated emotional and affective states, which many struggled to fully articulate in the context of the interview.

**Jennie:** Now it's on both sides, it's been horrendous really with this bloody - one's screaming, one's humming, next it'll be whooshing. I've got this pure tone [sound box], have you seen those? It's brilliant, a sound effects box, and you can have like running water, all these birds, you know, trees and all this, the sea. So, you put that

on because it, my tinnitus changes all the time, every day it's different, different volume. So you put it on and then you pitch it when you go to bed (pause). Do you know what though? My tinnitus has been so loud that there's not a volume on there that it'll go up to. That's how bad it got this year. There isn't a volume on the machine that will drown it out (long pause). Sometimes, I mean I tell you this now, and it is upsetting but (pause) you know (chokes up), you do just sometimes (crying and long pause)... you do, I, I have, I have thought at times, you know (whispers), I could just die really, I'd be quite happy (crying) [Bilateral].

High levels of tinnitus-related depression amongst sufferers (including those with and without the added symptoms of Ménière's) have been indicated in previous literature (Stephens et al., 2012b; Yoshida et al., 2011) but there is little in-depth understanding of how and why it influences people's everyday geographies. As a result, many people underestimate the widespread nature of the distress it can cause within people's daily lives (Murphy, 2012).

Tinnitus and hearing loss can be particularly difficult for individuals living with the added burden of hyperacusis; loud or sudden sounds in the external soundscape create a wall of sound, aggravating the tinnitus and often bringing it back into focus during occasions when sufferers had otherwise habituated to it. This was particularly common in participants' accounts of previously taken-for-granted social settings, such as time spent in cafes, bars and restaurants. The discordant sounds of clattering cutlery and glasses, chairs scraping and the laughter of other café-goers combined in these settings to form disabling sensory assemblages that aggravated their corporeal soundscapes and thereby hindered opportunities for conversation or conviviality. As indicated in the extract from Angus' interview below, when living with Ménière's symptoms in both ears, it does not take that much external sound for verbal acoustic information to be lost.

**Angus:** It's nigh on impossible to get away from noise in society in general, and I find that almost any noise distracts from me being able to hear what someone's saying. And that's another aspect I find particularly difficult with it is, I, I don't seem able to, you know, blank out other noises at all, they take over everything... You go into a cafe for a drink, the espresso machine, Gordon Bennett! It, it's horrendous [Bilateral].

These barriers to conversational engagement led to feelings of isolation, with previously unremarkable settings increasingly experienced as an 'invasive kind of sociality' (Davidson, 2010, p. 381) where the presence of even small numbers of people can feel oppressive or confusing. Participants therefore experienced a loss of place as they were no longer able to engage with these social settings in a meaningful way; whilst some chose to physically withdraw themselves from these situations as a form of self-protection, others explained the negative sense of being physically present but mentally elsewhere (a form of what Smith, 2012, terms 'socio-emotional distancing'). As commented by Angus, 'so then you're just sitting there, and basically you might as well be a statue sat in the corner... it's not pleasant'. This withdrawal had significant repercussions for participants' sense of identity; their heightened awareness of personal bodily (in this case, auditory) limits prevented them from relating to friends and family in ways that were previously both socially and personally valued.

**John:** It's very hard to take part because I can't follow easily what's going on. And, as one of my friends said, words were my thing, playing with words. And I think now it's much harder to do it because I can't hear the words (pause). They may like that because there's no excruciating puns coming in their direction. But, you know, there we are. So, that side affects it really. It's disappointing when (sighs) - we're going to



the theatre tomorrow and we're meeting up in the theatre bar and having something to eat beforehand, but in that sort of environment, I won't be able to follow really at all. So that's just the way it is [Unilateral but with no functional hearing in non-Ménière's ear due to an accident as a teenager].

This withdrawal also had implications for the close family, friends and partners of participants because it compromised their ability to engage in mutually enjoyable experiences and conversation, often undermining the spontaneity and intimacy between them. In the context of these entwined emotional geographies, the auditory sensations of Ménière's contributed to perceptions of inhabiting divergent sonic worlds, with tendencies towards social detachment creating 'strained' atmospheres, impacting on both their social and intimate relations.

**Karen** (wife of Angus): It is difficult sometimes because it does affect us such a lot. And I think it's just the, the conversation because I like to chat but we spend a lot of time in silence because background noise is obviously, just too much for him. And it, it makes him so tired and disorientates him. So in the car, he can't really hear me so, you know, if we're going on journeys, we don't talk very much and don't have the radio on. I sometimes put it on quite low and he'll turn his hearing aids off... so, you know, we do spend quite a lot of time in silence, which is quite sad really.

Participants with young children highlighted the negative emotional impacts of feeling unable to withdraw from certain noisy environments due to their parental responsibilities and their desire to build and 'practise' family in culturally expected ways (Hallman & Penbow, 2007). For example, one participant (Becky) explained the challenges of meeting her child's desire to play with other children whilst managing personal anxieties about the repercussions of these loud environments for her Ménière's and a sense of guilt for wishing to be elsewhere. These situations resulted in contrasting emotional geographies for parent and child, with flows of joy and playfulness between the children countered by sensations of anxiety and guilt for Becky.

**Becky:** At birthday parties, or things where they've got loud music for kids, I've got my ear defender things which I use but (pause) it still doesn't really prevent the noise from travelling through the bone... so it's stressful and worrying. You're kind of torn between staying or going, and balloons are really awful... I feel really stupid about the balloons, because I'm sure it looks daft but I, they do make me feel very anxious, the anxiety that they might pop is quite (laughs), when kids have got them in their mouths I'm like "Ohhh no!" [Bilateral]

Becky describes the sensation of noise 'travelling through the bone', indicating a painful physicality to the penetration of sounds through the body. Other participants explained how loud sounds in the external soundscape were not only uncomfortable and disorientating, but had also catalysed sensations of imbalance and vertigo. For example, Maggie recalled how the sound of a train pulling into the platform at London Paddington had been 'so acute that it triggered an attack... so life is quite terrifying a lot of the time'. As a result of these experiences, loud sounds were linked to high levels of anxiety, producing a deeply embodied response for some participants. For example, in the account below, Jennie recalls a period of panic attacks at work, where she was exposed to a range of sounds that she felt unable to control, such as the hand dryer in the toilets, the shared printers, the weekly fire alarm drill and so forth. She describes an 'electric' sensation in her hands as her lips went blue with dread upon exposure to these types of noises, suggesting an intensely visceral experience that exacerbated feelings of discomfort and alienation at work (Duffy & Waitt, 2013). This anxiety was manifest within the body but also came to permeate the increasingly disabling places that Jennie was forced to frequent on a regular basis.

**Jennie:** I'm pretty much non-stop living with, you know, this hyperacusis... I'd say in the last three years (pause), if we were going to go to a cafe we'd have to sit outside, because there'd be cutlery smashing, coffee machines going, banging, people grinding chairs along the wooden floor - absolutely getting, making me in tears. And I'll tell you what was happening around this 3, 4 year point, I started having these panic attacks. It's funny, it's coming back to me now I'm talking to you. I started having these panic attacks where (pause) I, I'd be at work and I'd suddenly get this - now this sounds really weird right - but I'd get this aura come over me where I'd know, "Hang on, I'm going to have a, the Ménière's is coming" ... and then I'd start having a panic attack and (pause), my hands would go completely electric... and my lips would be blue, where I am so scared there's a spin coming [Bilateral].

Later in Jennie's interview, she emphasised how such anxieties were intensified by a lack of perceived control over potentially problematic sound sources; 'if I go and turn the tap on now or pull the flush, then I can cope with it because I'm in control - now, if you go out and turn the tap on into that metal sink, I will freak out'. This issue of control, or lack thereof, emerged as a central theme throughout participants' accounts. Many sought to develop new sensory knowledges (Maslen, 2015) over time in their efforts to regain control, be it through learning to read their body for signs of change in the condition or trying to alter their everyday environments to minimise their exposure to disorientating sonic encounters.

### **Corporeal sound symbols**

Perhaps the most pertinent emotion linked to corporeal sound signals was an intense sense of anxiety as participants came to associate corporeal changes, including irregular shifts in tinnitus tone or volume or sudden drops in hearing capacity, with more active phases of the condition and indications of condition progression (for example, to their second ear). Tinnitus was therefore experienced as emotional, not only through lack of respite but also through acting as a corporeal warning signal for additional and in many ways more imminently debilitating symptoms of Ménière's.

Participants described their emotional responses to these shifts as a complex mix of anxiety and empowerment. Whilst recognition of these patterns empowered them to understand when their symptoms may be about to worsen (and thereby protect themselves from particularly vulnerable situations, such as driving), they knew of limited means to prevent symptom deterioration (leading to frustration and anxiety).

**Tom:** When the tinnitus starts, I tend to get a bit paranoid because the tinnitus, for me, tends to be a forerunner to the attacks. So as the tinnitus builds over days, usually at the end of that week, something's going to happen [Unilateral].

The severity of the 'something' mentioned by Tom constituted the main source of anxiety; people who had experienced many attacks explained that they had learned to 'ride the storm' but also provided examples of particularly debilitating attacks that had taken them by surprise. Angus explained how in his worst attack, he was effectively impaired across three of his core senses; with bilateral Ménière's, his hearing and balance capabilities were already compromised, and the severe visual disturbance encountered as a result of the vertigo rendered him functionally 'blind' in that moment. Given the close relationship between visual and auditory perception (Rodaway, 1994), Angus' soundscape was dramatically altered, creating a highly disconcerting emotional geography that he later referred to as 'an absolute humdinger of an attack'.

**Angus:** I was on my own [during the vertigo attack] and had to Dial 999 - I have now registered for their text service - but I've just thought that were the same circumstances to apply, i.e. being in the middle of an attack when I contacted them, I would not have been able to text. It was difficult enough trying to locate the 999 buttons let alone try and actually write something as nothing focussed and the slightest movement caused further vertigo and sickness [Bilateral].

Participants also explained how distinctive shifts in tinnitus patterns had come to symbolise (unwanted) milestones in their Ménière's trajectory. A gradual awareness of tinnitus sensations featured in participant narratives of initial Ménière's onset. At the time, these were largely dismissed as external environmental sounds (e.g. a car murmur or the 'hum' of an air conditioner) but were retrospectively interpreted as early corporeal signs of the condition. This, in turn, catalysed severe anxieties amongst participants who felt they were starting to experience tinnitus in their previously unaffected ears, which they interpreted as a sign of potential progression to a bilateral state.

**Dawn:** At that stage, so like way back [before first major attack], I used to lie down on my pillow and I used to think it was like hearing my pulse in my head, which obviously was pulsatile tinnitus. So it did start quite a few years before I was diagnosed, thinking about it, but you kind of just dismiss it, that's why I'd forgotten about it. But it was like 'bang bang bang bang', just in that ear. So it was, early signs were definitely that pulsatile tinnitus... On Boxing Day this year, what I now know was tinnitus was so loud that I thought I was going deaf in that ear [the non-Ménière's ear] because I, I was in the shower and there's a fan in the shower. I said to my husband "Can you put the fan on?" He said "It's on already" and I, I didn't hear it... and I couldn't hear anything he was saying, he just had to come right up to me to speak. And so I, I was in a tailspin really, but the next day it got a bit better and the next day it got better again [Unilateral].

The 'tailspin' described by Dawn in response to a perceived risk of going bilateral was alluded to by nearly all participants. This reflected a fear of undergoing frequent episodic vertigo attacks again, but also deep-seated concerns about the everyday soundscapes that would result from distorted hearing, tinnitus and hyperacusis in both ears. Another participant, Becky, who was already living with bilateral tinnitus, explained her tendency to engage in a constant analysis of the sounds within her soundscape, drawing on and refining her sensory knowledge over time to distinguish between the corporeal and the environmental. She used this approach as a means to manage her anxieties about the risk of further hearing loss with the progression of her bilateral state.

**Becky:** I did also use a fish tank at first to help when the tinnitus became bilateral - I used it at night in my bedroom so as to not listen to the silence of the bedroom when I was up doing night feeds [breastfeeding her baby]. It was helpful because it told me I hadn't gone deaf and I could quickly confirm my hearing was still intact. But after a while it was irritating and my tinnitus was always louder than it so we got rid of it and I am more robust at handling the tinnitus now. I still do panic now even, when a background hum stops, say the fridge motor has a rest or someone outside turns off their lawnmower, I panic and wonder if I have lost my hearing and I brush my ear and check I can hear [Bilateral].

Both Dawn and Becky allude to shifts in their affective and embodied reactions to the tinnitus over time, conveying an emotional transition from a state of panic to a more measured response; although underpinned by ongoing concerns about the risks of experiencing complete bilateral hearing loss, both participants felt better able to cope by interpreting such changes as

part of the wider tendency towards symptom fluctuation with Ménière's rather than a sign of impending and permanent loss. These extracts illustrate how participants became highly attuned to the minutiae of their soundscapes in ways that they never had been prior to the onset of Ménière's, in an effort to both understand and monitor the condition as it evolved.

### **Regaining a semblance of control through soundscape (re)-negotiations**

In the face of an unpredictable condition, surrounded by dynamic and sometimes 'threatening' sonic environments, participants described a range of strategies used to regain a semblance of control over their distorted soundscapes. In so doing, they were pro-actively engaging in practices of emotional safekeeping to keep their emotional lives on an 'even keel' (Longhurst, 2016) whilst negotiating an often uncomfortable and unpredictable balance between 'socio-spatial safety and anxiety' (Davidson, 2010, p. 383).

The most commonly discussed approach involved the use of sensory prostheses, including hearing aids (of varying acoustic sophistication), directional microphones and other personal hearing solutions (e.g. contego loop systems). Although only really effective in quiet acoustic settings, many participants explained how hearing aids had helped them to focus on 'useful' sounds rather than internal corporeal noises, whilst also acting as a visible reminder to other people of their hearing needs. Amongst participants whose vertigo had stabilised for a period of time, however, concerns were noted about the risk of such prostheses 'tipping their equilibrium again', which acted as a barrier to uptake.

**Richard:** I'm a bit naughty because I don't wear a hearing aid, although I'm starting to go through the process of more hearing tests. The problem with that is that I'm told that everything sort of, you know, your brain compensates and all your systems compensate. And if I start wearing a hearing aid, it's [the vestibular system] going to say, "Oh, you've done something different now." And I'm going to have to re-compensate. And my worry is, in the re-compensating process it'll start to upset me again. I don't know, I don't know whether that's rational or irrational but I'm, I'm just concerned that it could happen [Unilateral].

Richard's comment about being 'naughty' suggests he feels this decision is somehow transgressive; that his anxiety and reluctance to 'tip' his equilibrium counters the medical advice he has been given. However, this response was not uncommon and even those who had successfully adapted to the hearing aid admitted that the initial few weeks after the fitting were somewhat disorientating. One participant (Louisa) explained that the brain has to 'learn to work with this false ear, your hearing aid... to attune to what you need to hear and not every sound that is coming at you'. This supports the notion that auditory perception is partially learnt (Rodaway, 1994), and therefore needs to be re-learnt when the reliance shifts to sensory prostheses. Some participants noted the value of having physical volume controls for their hearing aids in certain social scenarios. For example, Angus laughed about his 'grandchild setting', explaining that he will often turn them down/off during more 'precariously noisy' social events. As noted by Hull (1990), whilst you can 'look away' from something you do not wish to see, you cannot 'listen away'; turning off the hearing aids was the closest participants could get to this, though this did not protect them from their sensitivity to irregular loud sounds or the internal tinnitus.

Other participants described how they had learned to deliberately shift their spatial-temporal routines in order to minimise feelings of auditory and therefore emotional disturbance, highlighting how illness-related coping strategies are often embedded in diverse places and social

relations (Smith, 2012). Shifts involved reducing the risk of encountering crowds in their preferred social settings by going at different times, and maximising opportunities to find non-intrusive 'acoustic corners', for example in cafes and restaurants. This was thought to be easier during the summer months when they could eat outside and enjoy outdoor pursuits rather than relying solely on indoor settings with hard surfaces and 'hostile' acoustics. In so doing, they were reconstructing the socio-emotional map of their lives (Cristoforetti, Gennai & Rodeschini, 2011) to maintain a sense of pleasure in previously valued settings, but without forcing themselves to cope with overly intrusive auditory experiences in the process.

**Susan:** The tinnitus doesn't bother me as much and the noise doesn't bother me as much now. I think, some of that, I've learnt is kind of attitude and not, not fighting it... so to not resist it and try a bit of exposure, rather than running away from it and going "Oh this is awful, this is awful"... So, I mean I have to be careful where I go. There are some places that are still quite uncomfortable. But, you know, so we'll tend to go to a restaurant and find a quiet corner. I always ask for a quiet table. I go earlier, you know, you get all these tricks that kind of work, so I can do that now at least, but I couldn't for a long time [Unilateral].

Participants also noted the importance of learning to be more confident in managing their hearing loss and minimising the anticipated stigma of not hearing or responding to people as might be socially expected. As indicated by Angus, few people understand that one can be hard of hearing and yet highly sensitive to sound and therefore they do not necessarily react appropriately; 'people's perception is you can't hear, you need to shout, right, which obviously doesn't help!' Participants talked about trying to be more assertive in raising awareness of their hearing loss in order to help others to appreciate the sounds that 'matter' to them (positively and negatively) and thereby create the best possible conditions for communication in social situations. They also explained how they had become more attuned to people's body language, re-positioning themselves, and often channelling sound to their ear with their hand.

**Louisa:** When I'm speaking to people now I'm far more aware of how they're speaking. I'm interpreting their body language much more, because maybe I'm not hearing absolutely everything, every word they're saying. So, you know, you do adjust, you do adjust everything. Whenever I'm in a room full of a lot of people and a lot of noise, if I want to talk to someone I will always, always have them on my left because that's where my hearing is better. Although I have a hearing aid, I still almost hear too much noise here so, you know, at meetings I always sit on the same chair. The little things that you learn... and I, if it's really loud, you cup your hand over your good ear and that again brings the sound right in to here [Unilateral].

Nonetheless, another participant, Becky, did highlight the challenges of finding the confidence to be emotionally genuine and honest about one's sensory capacities in such situations, especially if shy or not particularly outgoing or when engaging with people who lack empathy or patience. Taken together, these narratives emphasise the significant emotional transitions negotiated by participants in the process of understanding and adapting to the changing soundscapes experienced with the onset and progression of Ménière's, and the interpersonal nature of emotions (Bondi, 2005) as they flow between those experiencing and those witnessing such unpredictable sensory shifts.

## Conclusions

In this paper, I have enhanced existing understanding of the everyday soundscapes of people living with Ménière's disease; a debilitating long-term vestibular condition characterised by

fluctuating episodes of vertigo, sensorineural hearing loss, tinnitus and, for many, hyperacusis. In so doing, I have: (a) responded to recent calls for knowledge concerning the soundscape experiences of people living with hearing impairments (Skagerstrand et al., 2014), moving beyond Schafer's 'idealised' or 'orchestrated' soundscapes (Kelman, 2010) to examine the complex relationships between fluctuating corporeal and environmental sounds, dynamic socio-cultural contexts, inter-corporeal emotional flows, and shifting sensory knowledges in the context of life with Ménière's; and (b) extended the focus in the current Ménière's literature on verbal communication limitations (e.g. Stephens et al., 2012a), providing a richer understanding of the condition's emotional and social repercussions by examining the totality of patients' everyday soundscapes.

Recognising the emotional amplification (Kingsbury et al., 2012) and need for emotional safekeeping (Davidson, 2010) encountered as a result of the condition, I have examined four dimensions of participants' emotional soundscapes, including: a shift to 'hearing life in 2D' with the onset of sensorineural hearing loss and associated challenges of intercorporeal attunement; the distress caused by corporeal and previously unremarkable environmental 'sonic intruders', particularly in the face of hyperacusis; the role of tinnitus as an embodied warning signal of impending condition deterioration; and the process of trying to regain a semblance of control and emotional balance through soundscape (re)-negotiations.

The emotions conveyed by participants regarding their sonic experiences were enmeshed, highly embodied, and ranged from fear, anxiety and isolation, to frustration and, at times, guilt with regards to the impact on partners and family. These experiences altered feelings of both belonging and alienation within settings that had largely been taken for granted prior to the onset of Ménière's, often resulting in socio-emotional or even physical distancing from once unremarkable, but increasingly disabling sensory assemblages. Over time, participants indicated emotional transitions as they began to resign themselves, and in many ways adapt, to a life characterised by fluctuating and distorted soundscapes. Within these transitions, they came to cherish rare moments of peace (both corporeal and environmental), and to reconfigure the spatial-temporal fabric of their everyday lives to maximise opportunities for sonic respite where possible.

Central to many of the emotions experienced by participants was a lack of perceived control over their everyday soundscapes, both in terms of the occurrence and intrusiveness of corporeal sounds and the 'acoustic horizons' of sounds emanating from their external environments. With technological advancement and amplification, the power and reach of commonplace sounds have significantly extended (Pistrick & Isnart, 2013). Whilst individuals without hearing impairments can mask unwanted sounds to some extent through the use of portable music systems and headphones (technological 'earlids'), the corporeal auditory experiences of participants in this study often limited the benefits or efficacy of such personal solutions. This, coupled with a lack of public understanding of hearing and wider vestibular impairments, renders people with severe Ménière's symptoms particularly vulnerable, often feeling 'out of place' when negotiating their everyday geographies.

These findings ask us to consider what a more harmonic sonic geography might sound like for people living with Ménière's, or indeed people faced with any one of its individual auditory symptoms (tinnitus, hyperacusis, sensorineural hearing loss). How can we nurture a sense of belonging and enable affected individuals to perform practices of emotional safekeeping within the socio-spatial contexts of their everyday routines? Schafer (1977) calls for more conscious acoustic design that respects the 'ear and voice' (p. 238), rather than urban and

community planning that continues to prioritise vision and transit. For people with Ménière's, this might encompass the inclusion of sheltered spaces (indoor and out) that maximise acoustic comfort; perhaps replacing hard surfaces indoors with soft furnishings, and equipping open wind-swept outdoor spaces with vegetated protected 'acoustic corners'. Design responses alone, however, are unlikely to be sufficient here.

Campaigns could be initiated to promote the installation and appropriate use of hearing loops in public places (including institutional staff training such that they can help people to connect to these loops as required). Other campaigns could be directed at, for example, cycling groups, encouraging them to call out which side of the road/path they are approaching from, rather than ringing a bell and responding angrily when pedestrians move to the 'wrong' side. School curricula could touch on the realities of life with a sensory impairment, such that people grow up understanding that people with a hearing impairment can be sensitive to sound and may not react well when shouted at. As noted by Brown (2012, p. 817), 'the challenge is then surely to cultivate socio-material spaces and times that engender more attunement' (or inter-corporeal sensory and emotional empathy), be it between differently mobile subjects, or between those living within varied sensory worlds. Whilst people with sensory impairments are expected to adapt to their own condition, this need not be a one-sided process; society should better appreciate the invisible nature of such impairments and learn how to act appropriately when affected individuals do not respond as anticipated.

Given the substantial variability in the severity and expression of Ménière's symptoms amongst the diagnosed population, future studies could combine the in-depth qualitative methods used here with more wide-ranging survey based approaches to explore the reach of these experiences amongst the wider population. As noted by Friedner and Helmreich (2015, p. 94), 'attending to different degrees, kinds, genres, and articulations of hearing and perceiving sound... can open up new ways of 'hearing with' and 'being with' varied others'. In-depth longitudinal qualitative studies could also usefully explore changes in experiences, perceptions and emotional responses to everyday soundscapes as conditions such as Ménière's progress, exploring processes of adaptation and the existence of 'turning points' in how people cope with (or otherwise) more distressing soundscape shifts. Participant-produced sound diaries could be used to capture more intuitive, pre-reflective social and emotional soundscape interactions (Duffy & Waitt, 2013). Finding ways to meaningfully engage affected individuals in collaborative community design and planning initiatives could ensure greater consideration is given to acoustic comfort; initiatives that may also benefit the hearing community, providing windows of relative tranquillity in an otherwise amplified world.

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**Table 1. Sample composition**

Pseudonym	Age bracket (yrs)	Ménière's duration	Employment status
<b>Participants with Ménière's</b>			
Maggie	51-60	<5yrs	Full time
Nicola	31-40	<5yrs	Full time
Jane	61-70	<5yrs	Retired
Louisa	51-60	<5yrs	Full time
Susan	61-70	<5yrs	Retired
Melissa	31-40	<5yrs	Full time
Tom	41-50	<5yrs	Full time
Debbie	61-70	>5yrs	Non-working
Becky	31-40	>5yrs	Non-working
Dawn	51-60	>5yrs	Early retirement
Angus	61-70	>5yrs	Early retirement
Chloe	51-60	>5yrs	Part time
Yvonne	61-70	>5yrs	Early retirement
Caroline	51-60	>5yrs	Non-working
Jennie	41-50	>5yrs	Part time
Emily	51-60	>5yrs	Non-working
Richard	61-70	>5yrs	Retired
Elaine	71-80	>5yrs	Retired
John	71-80	>5yrs	Early retirement
Emma	51-60	>5yrs	Self employed
<b>Partners of participants with Ménière's</b>			
Karen	62-70	N/A	Full time
David	61-70	N/A	Self employed
Magda	61-70	N/A	Part time
Matt	61-70	N/A	Self employed
Sandy	61-70	N/A	Retired
Mick	71-80	N/A	Retired
Toby	51-60	N/A	Full time
Tessa	41-50	N/A	Part time