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Predictors of Adjustment to Ménière's Disease

by

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ABSTRACT

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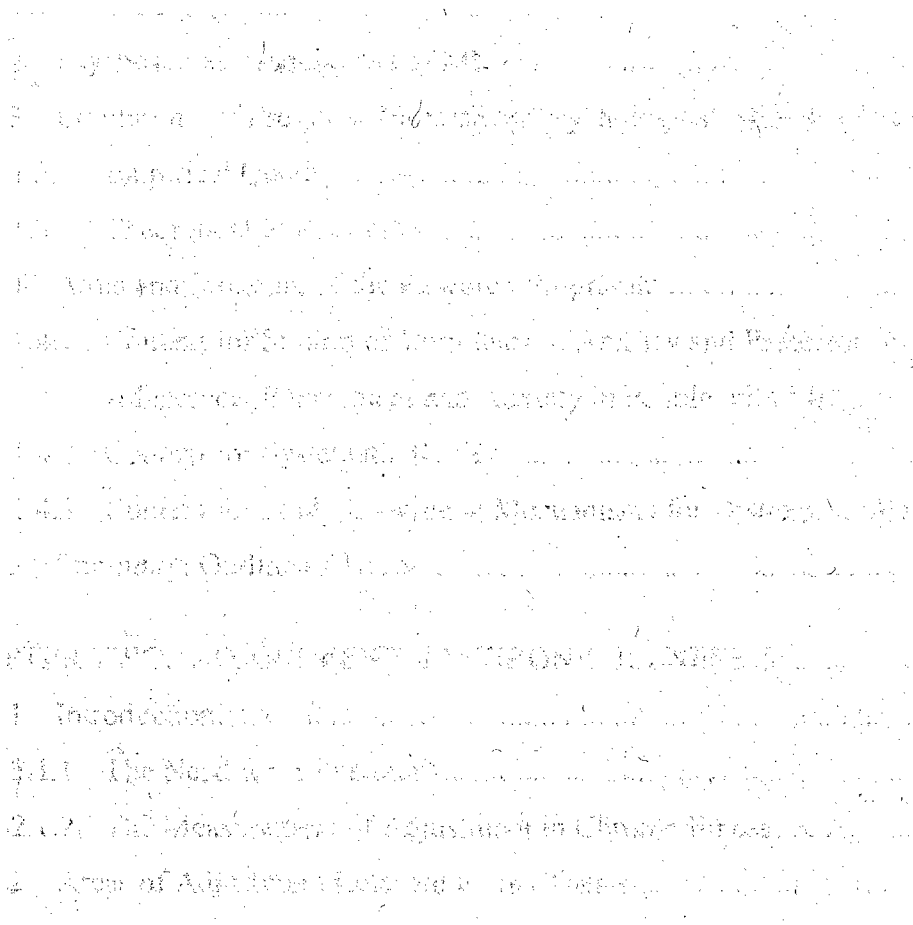
High levels of distress are often reported among people with Ménière's disease (MD). The aim of the research programme was to identify modifiable psychological factors that influence adjustment, to inform future support for people with MD.

Part of the research programme was nested within a randomised controlled trial (RCT; n=360) assessing the effectiveness of physical or psychological based self-treatment. A cross-sectional questionnaire study aimed to identify psychological correlates of anxiety at baseline of the RCT. This data was also used longitudinally to assess whether they predicted adjustment three months post-treatment. Correlates of baseline anxiety included illness perceptions, negative beliefs about dizziness, intolerance of uncertainty and somatic anxiety. Independent predictors of anxiety at follow-up comprised somatic anxiety, intolerance of uncertainty, illness coherence, and emotional representations. Enablement was predicted by shorter illness duration and illness coherence. No predictors of adherence were found.

To identify psychological mechanisms that might explain MD related distress, a systematic review on the role of psychological factors in MD was carried out. It examined the literature for the possible presence of components of four mechanisms of distress (post-traumatic stress disorder (PTSD), worry, health anxiety and anxiety sensitivity). The most evidence was found for the possible presence of PTSD and health anxiety. To see whether these mechanisms were actually present and influenced distress, they were measured explicitly in a cross-sectional study of 800 people with MD and 484 healthy controls. Additional aims of the study were to assess what proportion of participants met clinical levels for anxiety, depression and PTSD, and to compare people with MD with healthy controls. PTSD and health anxiety were both present and associated with distress. People with MD had higher

levels of anxiety, depression and health anxiety than healthy controls, and levels of PTSD were higher than the general population.

Adjustment to MD appears to be a multifactorial construct, with different factors affecting different types of adjustment. With further development of empirically sound research including more longitudinal and qualitative research, a greater understanding of the mechanisms linking MD with adjustment may enable psychological treatment and support to be more effectively tailored to the particular problems of people with MD.



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ABBREVIATIONS

BPPV	Benign Paroxysmal Positional Vertigo
DIPS	Diagnostic Inventory of Personality and Symptoms
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
FABQ	Fear-Avoidance Beliefs Questionnaire
HADS	Hospital Anxiety and Depression Scale
IUS	Intolerance of Uncertainty Scale
MD	Ménière's Disease
MMPI	Minnesota Multiphasic Personality Inventory
PEI	Patient Enablement Instrument
PTSD	Post-Traumatic Stress Disorder
RCT	Randomised Controlled Trial
IPQ-R	Revised Illness Perception Questionnaire
SR	Stress Reduction
VSS	Vertigo Symptom Scale
VR	Vestibular Rehabilitation

Chapter One: Researching Predictors of Adjustment to Ménière's Disease

1.1 Medical Aspects of Ménière's Disease

1.1.1 What is Ménière's Disease?

Ménière's disease (MD) is a chronic disease of the inner ear that is characterised by recurrent, spontaneous, episodic vertigo, tinnitus (a ringing, buzzing or roaring noise in the ears), a sense of aural fullness or pressure in the ear, and hearing loss (Committee on Hearing and Equilibrium, 1995). Although it is not life threatening, MD is an incurable disease with disabling consequences. The disease is usually described in the context of three stages (Saeed, 1998). In the first stage, vertigo attacks (sensations of spinning resulting in unsteadiness, sweating, nausea and vomiting) are the main symptom. Some hearing loss, fullness and tinnitus are also experienced in one ear immediately before and during attacks, but between attacks these symptoms generally return to normal. Attacks are unpredictable, can occur at any time (day or night), and can last from anything between a few minutes to 24 hours, resulting in disequilibrium that may last for days. The length of time between attacks can range from a few days to several years. As the disease progresses to the second stage, the vertigo diminishes, but the tinnitus and hearing loss fluctuate and become progressively worse. In the last stage of the disease, spontaneous vertigo attacks may disappear altogether, but hearing loss and tinnitus become severe. The disease may also affect the second ear.

The symptoms are attributed to a condition called endolymphatic hydrops in which fluctuations in endolymphatic fluid levels rupture the membranes in the inner ear that separate it from perilymphatic fluid, causing the fluids to mix. This disturbs the balance and hearing organs which produces the resulting symptoms. Despite much investigation, it is not known why endolymphatic hydrops occurs, although genetic, anatomical, traumatic, viral, allergy, autoimmunity, and psychosomatic causes have all been suggested (Moffat & Ballagh, 1997).

1.1.2 Epidemiology

The prevalence and incidence of MD in the UK is unclear and outdated (Watanabe, 1983; Wilmot, 1979). A recent prospective general population based study carried out in Finland found the prevalence of MD was 513 per 100,000 (0.5%), with a peak prevalence of 1709 per 100,000 (1.7%) in the 61-70 age group (Havia et al., 2005). Although MD can affect people of all ages, onset has been reported to usually occur between the ages of 38 and 50 (Friberg & Stahle, 1999), although initial onset of the disease can occur in people who are younger and may be more common than previously thought among people aged over 65 (Ballester et al., 2002). Males and females are generally found to be equally affected by the disease (Friberg & Stahle, 1999).

1.1.3 Treatment

Although MD cannot be cured, several forms of aids and drug, surgical and physiotherapy-based treatments are available to try to manage the disease. During an acute attack, the only treatment available is medication (vestibular suppressants and anti-sickness drugs) to control the vertigo and sickness. On a more long-term management basis, a greater choice of methods are available. A white noise generator can be used to mask tinnitus, and hearing aids can be used to help with hearing loss. Diuretics and a diet limited in salt, caffeine and alcohol can be used to try to reduce the severity and frequency of vertigo attacks, however, the effectiveness of this is anecdotal, with no quality studies existing to provide support for their use (Ruckenstein et al., 1991; Thai-Van et al., 2001). Drugs (betahistine) can also be taken to increase blood flow to the inner ear, reducing the frequency of vertigo. The rationale for the use of the drug is based on an unproven medical theory, but some studies have found the drug to be effective in reducing vertigo (Ruckenstein et al., 1991). The use of stress management techniques can reduce symptoms that are aggravated by anxiety and autonomic arousal associated with anxiety (Furman et al., 1998; Yardley & Redfern, 2001). Physiotherapy-based balance retraining exercises (called vestibular rehabilitation) can be used to try to reduce dizziness and improve balance between attacks. These exercises, however, are not suitable until symptoms

have stabilised (Clendaniel & Tucci, 1997), which can take up to six weeks after a severe attack.

If these maintenance treatments are not successful, several surgical procedures can then be performed on the inner ear in an attempt to reduce vertigo attacks. A medication (gentamicin) can be injected to damage sensory hair cells in the inner ear, reducing vestibular sensitivity and therefore reducing vertigo attacks. There are high levels of risk associated with this treatment, as the dosage needs to be high enough to damage the sensory hair cells, but if it is too high it can damage hearing. A surgical operation (endolymphatic sac decompression) reduces the pressure of fluid in the inner ear. This is a popular treatment choice as it is not destructive to hearing, but there is a great deal of controversy surrounding the procedure regarding whether it is anything more than a placebo treatment. A neurosurgical operation (vestibular nerve section) involves cutting a nerve in the inner ear so that neural input from the inner ear that causes vertigo is not sent to the brain. Hearing is not affected by this procedure, but because of the location of the nerve, there is a high risk of complications if anything besides the intended nerve is damaged. The most severe surgical operation (labyrinthectomy) destroys the inner ear, preventing vertigo, but also destroys hearing in that ear. This last method is generally only considered when hearing has already deteriorated considerably due to the disease (Saeed, 1998). A new development in non destructive treatment is the prevention or reduction of vertigo by the application of pressure pulses from a device (known as Meniett) to the middle ear through a surgically inserted ventilation tube (Densert & Sass, 2001).

1.2 Psychosocial Associations of MD

A distinctive level of psychological distress has been noted in association with MD since it was first identified by Prosper Ménière in 1861. Like other chronic illnesses, the psychosocial sequelae resulting from MD can be more debilitating than the disease itself (Kinney et al., 1997). Severe psychosocial consequences have been recognised and well researched for each of the key symptoms separately, however, a person with MD has to cope with the combined effect of all the symptoms together (Gant & Kampfe, 1997).

Vertigo is frequently identified as being the most distressing aspect of MD, and is the symptom that has the greatest impact on quality of life (Yardley et al., 2003). Vertigo affects almost every aspect of life. Studies have reported effects on physical, occupational, social, familial, emotional, cognitive, and behavioural aspects of life (Cohen et al., 1995; Erlandsson et al., 1996; Yardley, 1994c; Yardley, 2000; Yardley et al., 1992b). Vertigo attacks carry a risk of injury from falling, and may result in some people becoming unable to drive or travel. It may affect their job through regular time off, poor performance, or having to change jobs or give up work altogether. It may lead people to give up certain social or leisure activities, and may cause tension within the family. If an attack happens when a person is in a public place and without friends or family, witnesses sometimes needlessly call an ambulance or mistakenly stigmatise the person as being drunk and criticise or avoid them, offering no help at all. Emotionally, vertigo is unpleasant and frightening, and results in a sense of loss of control and helplessness as the vertigo attacks experienced in MD are incurable and unpredictable.

High levels of anxiety are often reported among those who experience vertigo (Eagger et al., 1992; Soderman et al., 2002), particularly when it is experienced for the first time (Pollak et al., 2003). Qualitative accounts suggest that in addition to the unpleasant and frightening nature of vertigo, this initial anxiety is associated with not knowing what is happening to them, the fear that they might be dying or that they have a serious illness such as a tumour or heart attack (Erlandsson et al., 1996; Gant & Kampfe, 1997; Yardley, 1994c). Depression has also been reported among people who experience vertigo (Coker et al., 1989; Monzani et al., 2001). It has been proposed that emotional stress might contribute to triggering attacks in those who have MD (Soderman et al., 2004). Personality variables may also play a role in how people cope with MD once they have it (Clark & Swartz, 2001; Savastano et al., 1996).

Some people who experience recurrent vertigo are disappointed by the lack of information and support that they are given by their doctors (Yardley, 1994c; Yardley et al., 2003), and feel obliged to find strategies to help themselves cope using trial and error (Gant & Kampfe, 1997). People with vertigo often develop their own rules and coping strategies to deal with when an attack occurs or to try to avoid

future attacks. After a severe attack of vertigo the balance system can be left not working properly until it settles down and stabilises again. In the meantime, a person can be left with residual symptoms of dizziness and imbalance. This is because the balance system works by coordinating information from the vestibular organs in the inner ear, the eyes, and the internal sense of awareness of the positioning and status of the body (called proprioception). When any of this information changes or is incomplete, the balance system has to adjust to the different information it is receiving and coordinate it differently to maintain balance. This process is called central adaptation or compensation (Yardley, 2001). Therefore people with vestibular disorders tend to be more reliant on their sense of vision and proprioception to maintain their balance. If these senses are not fully developed, people with vestibular disorders can be prone to becoming dizzy when they make quick or pronounced movements such as getting up or turning around too quickly, or reaching up or bending down. Movement in particular environments can also cause dizziness, such as travelling in a car, lift, or escalator, walking down the aisle of a supermarket, or being in an open or busy place (Yardley, 1994c). People with vertigo can sometimes have difficulty distinguishing between dizziness associated with an attack, residual dizziness, and movement-provoked dizziness. This can result in an alertness to symptoms of minor dizziness and the development of negative beliefs and fear that these symptoms are the start of a severe vertigo attack, or will result in physical danger, serious illness, or social incompetence through letting people down or embarrassing themselves (Yardley, 1994a). These beliefs often lead to self-imposed handicap, resulting in an avoidance of situations and activities that can cause provoked dizziness and an increased dependence on friends or family members (Yardley & Beech, 1998; Yardley & Putman, 1992; Yardley et al., 1992b). This tendency to interpret residual or general symptoms as disease related, and its association with catastrophic thoughts and poor adjustment is also reported in other chronic illnesses, including multiple sclerosis and asthma (Main et al., 2003; Skerrett & Moss-Morris, 2006).

Vertigo is associated with several anxiety disorders. In DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision), under the diagnosis 'anxiety disorder due to a general medical condition', vestibular disorders are listed as an example of a medical condition that can cause panic attacks

(American Psychiatric Association, 2000). Many people who experience panic or agoraphobia associated with dizziness have been found to have undetected balance problems (Yardley et al., 1994a), and many people who experience severe dizziness also report panic attacks (Yardley et al., 2001b). Chronic tinnitus is also associated with a number of psychosocial difficulties. It has been linked with anxiety, depression, handicap, sleep problems, concentration difficulties, stress and personality factors (Andersson, 2002; Budd & Pugh, 1996; Langenback et al., 2005; Reynolds et al., 2004). The tinnitus experienced by people with MD is severe and has been found to cause more annoyance, depression, and interference with sleep and speech than tinnitus due to other aetiologies (Stouffer & Tyler, 1990). Hearing loss is also associated with anxiety, depression, reduced quality of life, a sense of isolation, and feelings of being a burden (Gant & Kampfe, 1997; Mo et al., 2005).

1.3 Limitations of Previous Research on Psychological Aspects of MD

1.3.1 Empirical Quality

In the past, conclusions concerning psychological aspects of MD have often been based on research of poor empirical quality, case studies, or the unresearched opinions of the author (Watson et al., 1967; Crary & Wexler, 1977). Crary and Wexler (1977) carried out a review of the psychiatric and psychological literature on Ménière's disease. They identified two main types of research: clinical studies and empirical studies. The clinical studies were not replicable from the information given, did not all specify that they had used only Ménière's patients, and were based on a sample size of one, or did not specify their sample size. Crary and Wexler concluded that the findings reported in the clinical studies lacked scientific objectivity and were based only on clinical anecdotes and opinion.

The empirical studies were evaluated against Crary and Wexler's recommended methodological criteria. They found that 6 of the 21 (28.6%) studies were not replicable, 2 (9.5%) studies did not exclusively or clearly use participants with MD, 15 (71.4%) studies did not control for experimenter bias, 12 (57.1%) did not use statistical methods to an appropriate standard, 12 (57.1%) did not present their statistical results adequately, 13 (61.9%) did not use a control group, and of the 8

(38.1%) that did, only 5 (23.8%) controlled for age and sex, and only 2 (9.5%) had control groups that were vertiginous. No studies matched the control group on levels of vertigo with the Ménière's group. Crary and Wexler concluded by stating that almost all of the previous research is scientifically flawed, particularly because vertigo was not controlled for. Better-designed empirical studies have failed to replicate the findings of the earlier studies that Crary and Wexler criticise in their review. Despite this, such research continues to be referred to, giving a misguided view of people with MD. This lack of empirical quality is not unique to the psychological research on MD, but has also been found in a review of the medical treatment of MD (Thorp et al., 2000).

1.3.2 Theoretical Frameworks

In addition to being characterised by poor empirical quality, research on psychological factors in MD has only been considered within a limited theoretical framework. Most of the research to date has been approached from within the boundaries of the opposing perspectives of psychosomatic vs. somatopsychic explanations. Those supporting the psychosomatic argument suggest that the disease and distress are a result of personality characteristics and/or a response to stressful events, and those who support the somatopsychic argument propose that the distress arises in response to the nature of the disease.

It is interesting to note that Crary and Wexler's (1977) review concluded that whilst they did not rule out the plausibility of the psychosomatic argument, once they had discounted all empirically poor research, they found no support for the psychosomatic view. The only methodologically sound way of resolving this debate would be to carry out a prospective study. However, due to the low incidence of MD, a prospective study would be almost impossible to carry out, making this debate one that is not ever likely to be resolved. This lack of resolution appears to have hampered other approaches from being considered.

Researchers have frequently treated people with MD as a homogeneous group with regards to their mental health, but subgroups have been identified with high and normal psychometric and distress scores (Savastano et al., 1996), suggesting that

some people respond differently to the disease than others. This can be interpreted in different ways. It is possible that (as with all illnesses) some people with MD have some form of psychological predisposition to distress, which is then fostered by the nature and severity of the disease. Alternatively, different experiences of the disease and its treatment may lead people to form different expectations and beliefs about their illness and treatment, which then influence their distress and behaviour.

Despite the well-documented psychological distress in MD, the focus of research to date has not resulted in findings that can be applied to reduce psychological distress. To date, only two studies have endeavoured to provide psychological treatment, and these were both single subject case studies (Elwood et al., 1982; Hagnebo et al., 1998b). There is a need for research to move on to consider theories and models that have been applied to other chronic illnesses that may also be relevant to MD, in order to discover what factors and processes are involved in forming and contributing to distress, so that support and therapy can be better tailored to the particular problems of people with MD.

1.4 Aims and Structure of the Research Programme

The aim of the research programme was to identify modifiable psychological factors that affect adjustment, to inform future help for people with MD. The structure of the research programme followed in this thesis is described in Figure 1 and comprises four studies. The first study assessed psychological correlates of anxiety in Ménière's disease. It was a cross-sectional questionnaire based study looking at the correlations between anxiety, and demographic and illness characteristics, expectations and beliefs about illness and intolerance of uncertainty (chapter 3). The second study looked at predictors of adherence, enablement and anxiety in people with Ménière's disease. It was a longitudinal questionnaire based study to assess whether demographic and illness characteristics, expectations and beliefs about illness and intolerance of uncertainty could predict adjustment outcomes (adherence, enablement and anxiety) in people with MD undertaking self-treatment (chapter 4). The third was a systematic review on the role of psychological factors in MD, looking for the possible presence of components of four mechanisms of distress (post-traumatic stress disorder (PTSD), worry, health anxiety and anxiety sensitivity;

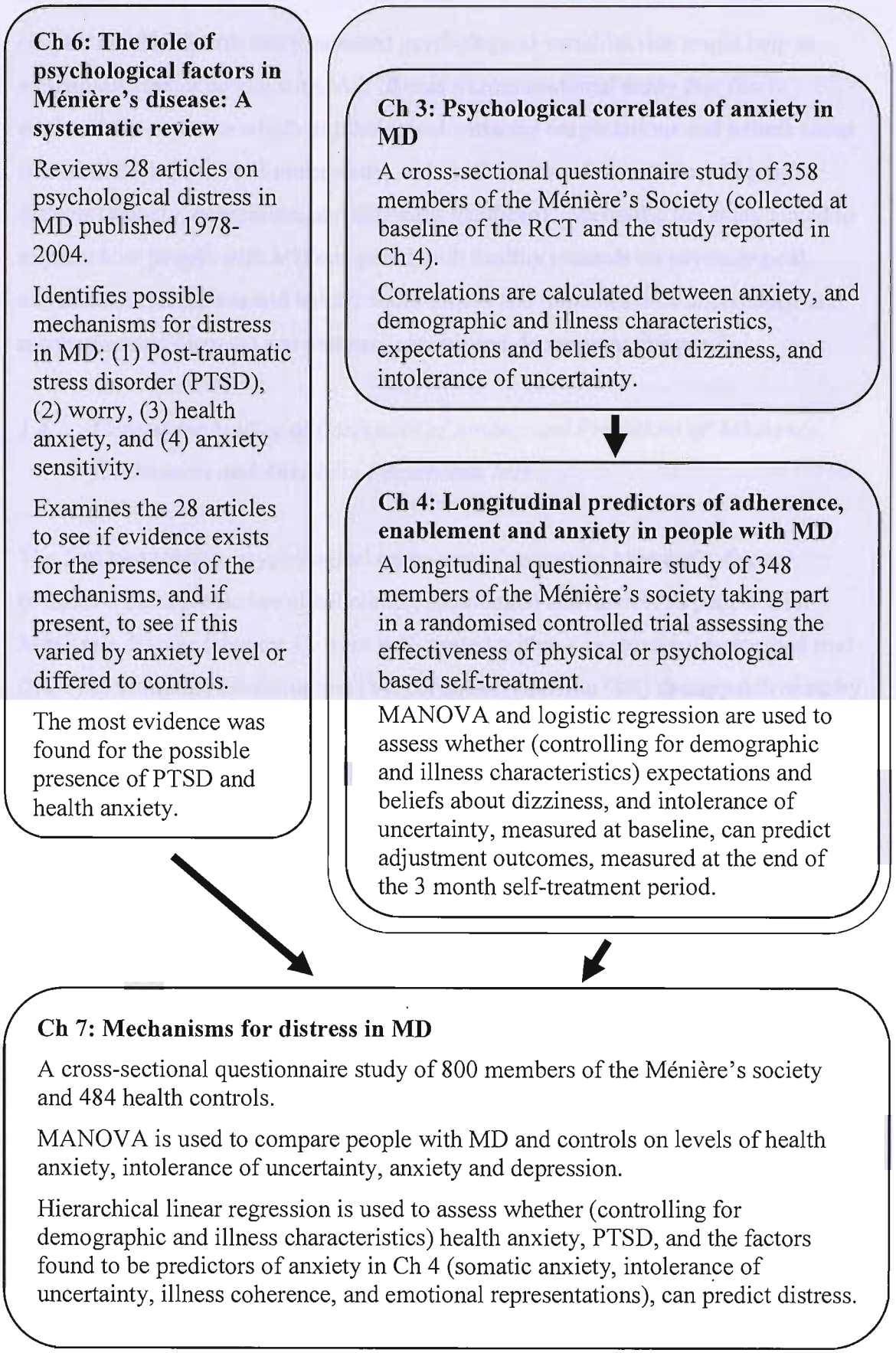


Figure 1

Overview of research programme

chapter 6). The fourth study assessed psychological variables that might help to explain distress in people with MD. It was a cross-sectional study that firstly explored the extent to which psychological variables (expectations and beliefs about illness and intolerance of uncertainty, and mechanisms of distress) could predict distress (anxiety, depression, and dizziness handicap). Secondly, the study aimed to explore how people with MD compared with healthy controls on psychological variables (expectations and beliefs about illness and intolerance of uncertainty, and mechanisms of distress) and distress (anxiety and depression; chapter 7).

1.4.1 Context for Studies of Correlates of Anxiety and Predictors of Adherence, Enablement and Anxiety in People with MD

The first two studies, psychological correlates of anxiety in Ménière's disease (chapter 3), and predictors of adherence, enablement and anxiety in people with Ménière's disease (chapter 4), were both nested within a randomised controlled trial (RCT) of vestibular rehabilitation (VR) or stress reduction (SR) therapy delivered by bibliotherapy for people with MD (results not reported here). I was the research associate employed by the Ménière's Society for this trial, responsible for managing the day to day running of the trial under the supervision of a Professor of Health psychology at the University of Southampton (who was also my supervisor for this thesis).

Measures of demographic and illness characteristics, expectations and beliefs about dizziness, and intolerance of uncertainty were taken at baseline of the RCT. These measures were not part of the RCT but were selected by me to be added to the data being collected at this time point. These data were used to assess their correlation with baseline anxiety for the study on psychological correlates of anxiety in Ménière's disease, and the same data was used as baseline data to predict adjustment outcomes at the end of the 3 month self-treatment period for the study on predictors of adherence, enablement and anxiety in people with Ménière's disease.

For the purpose of the RCT, it was calculated that a sample size of 100 per group was required to detect a treatment effect size of 0.33 with two tailed $\alpha = 0.05$ and

90% power. Allowing for 20% dropout, 360 participants therefore needed to be recruited. Participants were recruited from the Ménière's Society, a self help group for people with MD. To be eligible to participate, members had to have been given a diagnosis of Ménière's disease. This was so that we could exclude people who may have joined the Ménière's Society because they have a condition similar to but not the same as MD. Members also had to have experienced symptoms of dizziness or imbalance over the past 12 months. This was so that only members who would benefit from treatment would be recruited. However, as VR is only suitable for people whose symptoms have stabilised, members were excluded from participating if they had experienced any severe vertigo attacks within the last 6 weeks. Members also had to be contactable by post for the key stages of the trial. As medical conditions such as cervical or cardiovascular disorder could be aggravated by the VR treatment, eligible members willing to take part in the trial were then required to consult their GP to check there were no medical reasons why they should not take part in the trial.

The VR self-treatment involved carrying out a programme of graded eye, head and body movements that are used to improve balance and reduce dizziness. These movements stimulate the balance system, causing movement-provoked dizziness. Over time, the balance system gradually habituates to the movement-provoked dizziness, so the movements result in less dizziness. Compensation is achieved when the movements no longer result in any dizziness. As the VR exercises provoke dizziness in order to promote compensation, participants may find this aversive. The VR exercises were begun in a sitting position, progressing to standing and walking as the exercises became easier. VR also involved carrying out general activities (such as ball games, walking, sport, dance or exercise classes, and travelling), and special exercises for poor balance (such as turning over in bed, reaching and coping with striped surfaces, moving objects and lights).

The SR self-treatment involved choosing as many as preferred from four stress reduction methods, which were controlled breathing, physical relaxation, stress management, and thought control. The rationale for the SR treatment is that as arousal and stress may aggravate symptoms of dizziness, reducing stress can improve adjustment and relieve symptoms (Yardley & Redfern, 2001). Controlled breathing

works by slowing down breathing to reduce nausea. Physical relaxation reduces symptoms by relaxing muscles and slowing heart rate. Stress management involves making lifestyle changes to make life less stressful. Thought control involves distraction or changing thoughts to help take participants' minds off their symptoms. Unlike the VR self-treatment, the stress reduction methods cannot provoke symptoms.

The protocol for the RCT was approved by the Ethical Committee of the School of Psychology, University of Southampton. Information packs were sent to 4,800 members of the Ménière's Society, inviting them to participate. After completing baseline questionnaires, 360 participants were allocated to one of three conditions (VR, SR, or Control) using a computer randomisation programme. Those in the VR and SR groups were sent the corresponding self-treatment booklet to use for 3 months. At the end of the 3 month self-treatment period, a post-treatment questionnaire pack was sent to all three groups.

1.4.2 Context for Systematic Review

There has been no systematic review of articles on psychological distress in MD since 1977, so it is useful to systematically identify all articles published since then. This will help to see how our understanding of the area has developed. A systematic review is a better quality review than a literature review for several reasons. Systematic reviews are research question driven, and comprehensive, obtaining all relevant research. Systematic reviews also take into account the scientific quality of the research, limiting bias and chance effects that may be found, whereas literature reviews do not normally do this. This then provides reliable, replicable results for conclusions and decisions, based on all the empirically sound evidence available. This approach is particularly helpful and preferable to a literature review given the opposing approaches reported in the history of research on MD, as it can help to resolve conflicting evidence and answer questions to which the answer may seem uncertain without considering methodological issues.

The systematic review is included in the research programme rather than the literature section because it synthesises the results of the studies according to a

retrospective examination of mechanisms for distress, rather than just summarising reported findings. This was done because much of the research on the role of psychological factors in MD had only considered psychosomatic vs. somatopsychic explanations, and the goal of this systematic review was to consider the relevance of other theories and models of distress. The purpose of the systematic review was to systematically identify and classify by quality all studies of psychological factors associated with MD between 1978 and 2004, and then review them in a way that moves beyond the question of psychosomatic or somatopsychic causation, and addresses empirical quality and other theoretical frameworks. The findings from each of the studies identified and included in the review were tabulated to match them to the components of PTSD, worry, health anxiety, and anxiety sensitivity. If the components were present, the review sought to identify whether they varied by anxiety level and if there was a difference between people with MD and controls on these factors.

1.4.3 Context for Study Looking at Mechanisms for Distress in MD

This final study drew together the strands of the systematic review and the longitudinal study. A major limitation of the systematic review was that the components of the theories were examined retrospectively in studies that did not set out to actually measure these mechanisms. This study therefore took the two theories that the most evidence was found for the possible presence of in the systematic review (PTSD and health anxiety), and investigated whether there was any evidence for them when they were measured explicitly. This study also included the factors which significantly predicted anxiety in the study on predictors of adherence, enablement and anxiety in people with Ménière's disease (somatic anxiety, illness coherence, emotional representations, and intolerance of uncertainty) as additional expected predictors of MD related distress (measured by anxiety, depression and handicap). Hierarchical linear regression was chosen to analyse the data, as it was important to control for the effects of demographic and illness characteristics on MD related distress. As many of the independent variables were correlated, the use of hierarchical regression also enabled the assessment of the variables' effects on distress after partialing out any shared variance between the

variables. This allowed the identification of the most prominent variables in MD related distress.

As some levels of distress can also be found in the general population, it was useful in this study to include a healthy control group to compare whether they were different to people with MD on levels of distress. It was not relevant to ask healthy people about MD or illness specific variables (illness characteristics, illness coherence, emotional representations, dizziness handicap, and PTSD), but they were compared on all other relevant measures (intolerance of uncertainty, health anxiety, anxiety and depression). Crary and Wexler (1977) recommended the use of vertiginous controls. This was attempted, but due to delays in the study this data was being collected with, it was not possible to obtain the data in time for the completion of this thesis.

1.5 Summary: Outline of Thesis

The assumption on which this research programme was founded is that the distressing nature and severity of MD, personality, and the experience of the disease and its treatment, may lead people to form particular expectations and beliefs about illness and treatment which may influence adjustment to the disease. As there is a paucity of theoretically framed research on psychological factors in relation to MD, chapters 2 and 5 review psychological concepts studied in relation to distress and behaviour in other chronic illnesses, and explore whether they could be relevant to MD. Chapter 2 explores expectations and beliefs about illness and treatment and personality factors that have been shown to influence adjustment. In chapter 3, some of the expectations and beliefs about illness and treatment and personality factors described in chapter 2 are assessed in a cross-sectional questionnaire study of MD to see whether they are relevant to MD related distress or not. This is extended in chapter 4, where the expectations and beliefs about illness and personality factors measured in chapter 3 comprise the baseline data of a longitudinal study to predict adjustment in people with MD three months after undertaking physical or psychological self-treatment.

Chapter 5 considers psychological mechanisms that explain the processes by which distress might develop. The mechanisms most relevant to MD include worry, post-traumatic stress disorder, anxiety sensitivity, and health anxiety. The chapter then considers how each model could be applied to MD to explain how distress develops in relation to MD. Chapter 6 then systematically reviews all articles published between 1978 and 2004. It addresses empirical quality and theoretical frameworks, moving beyond the question of psychosomatic or somatopsychic causation by retrospectively examining the mechanisms discussed in chapter 5 to see whether any evidence exists that might explain MD related distress. Chapter 7 builds on the literature reviewed and suggestions made in chapters 5 and 6, as well as the findings from chapter 4. A cross-sectional questionnaire based study is reported that measures PTSD and health anxiety to assess whether these mechanisms are actually present or not in a sample of people with MD. The study examines these mechanisms, together with factors found to be predictors of anxiety in chapter 4, to identify key predictors of MD related distress.

Chapter 8 summarises the main findings of the empirical studies and considers the issues and implications that they have for understanding the psychological determinants of adjustment in people with MD. The success of the application to MD of psychological concepts studied in relation to distress and behaviour in other chronic illnesses is discussed, along with the limitations of the thesis. The chapter raises questions for future research to consider, relating to both the theoretical literature and clinical implications for consideration in relation to future treatment of people with MD.

Chapter Two: Adjustment to Chronic Illness

2.1 Introduction

The nature and severity of Ménière's disease (MD), as well as the experience of the disease and its treatment, may lead people to form particular cognitions about their illness and treatment, which influence their distress and behaviour. The mental health of people with MD has been reported to be similar to patients with other types of chronic illness (Yardley et al., 2003). Therefore, this chapter will examine some of the psychological factors that have been found to influence adjustment in MD and other chronic illnesses. This chapter will begin by outlining why adjustment is needed, and how it has been measured in the literature on chronic illness. Then the aspects of adjustment that are relevant to this thesis will be discussed. These will be grouped under three main headings: expectations and beliefs about illness, personality, and adjustment outcomes.

2.1.1 The Need for Adjustment

In acute illness, although changes are made, people are not expected to adjust to illness per se; it is acceptable to temporarily withdraw from everyday life until recovery occurs. Parsons (1951) defined this as the 'sick role'. The four main principles of the sick role are that (1) a sick person is exempt from their normal roles and responsibilities (relative to the nature and severity of the illness); (2) a sick person cannot choose to get better and therefore needs to be looked after; (3) a sick person should view sickness as undesirable and should want to get well; and (4) a sick person should seek out a health professional and cooperate to get well.

Chronic illness by contrast, is a disease that is long-lasting, limits function in some way, often gets progressively worse, and cannot be cured (De Ridder, 2004). As recovery is not achievable in chronic illness, the sick role is no longer appropriate to be retained (Segal, 1976). The chronically ill person is expected to move away from this role and incorporate the illness into their lives, returning to roles and responsibilities, achieving as much independence as is possible. Therefore a person

with chronic illness has to find and adjust to a new way of living with their illness and the requirements of daily life (Crumbie, 2002).

Adjustment to chronic illness has been discussed in relation to a process called response shift (Sharpe & Curran, 2006). Sprangers and Schwartz (1999) define response shift as 'a change in the meaning of one's self-evaluation of quality of life as a result of changes in internal standards, values and the conceptualization of quality of life'. A response shift is attained through behavioural, cognitive, and affective mechanisms in response to a catalyst such as a change in health, and can also be influenced by antecedents of stable or dispositional characteristics. If a person does not make these changes, they are not likely to adjust well to their illness, resulting in poor perceived quality of life. The concept of response shift was originally introduced as the effect of current knowledge and experience superceding perceptions measured previously, with previous perceptions being seen retrospectively as inaccurate in the light of new knowledge (Howard & Dailey, 1979). However, in discussing the clinical implications of response shift Wilson (1999) argues that there are three determinants of response shift. The first of these is "a change in the respondent's internal standards of measurement or scale recalibration", the second is "a redefinition of the target construct or concept redefinition", and the third is "change in the respondent's values or the importance of component domains constituting the target construct" (1999; pg 1578). The first two determinants are related to the traditional concept of response shift, but in the third determinant, previous perceptions do not have to be considered to be inaccurate, but based on different values and importance levels at the time points when the constructs were measured. It has been proposed that a person's ability to adjust to chronic illness is mediated by response shift (Sprangers & Schwartz, 1999; Wilson, 1999). Wilson (1999) suggests that somatisation and hypochondriasis occur when a response shift has not been made in adapting to their changed health status, and also describes the placebo effect in terms of the occurrence of a response shift in response to education and reassurance from a health care professional.

The third determinant of response shift (change in values) is similar to a process called acceptance, which can be seen as a specific type of response shift. Acceptance is the recognition that change in symptoms is not realistic or achievable, and is only

an appropriate technique where control or avoidance is not possible or beneficial (Hayes et al., 1999). Acceptance has been investigated in relation to chronic illness, and McCracken (1998) defined acceptance as comprising several steps. The first is the recognition that the illness is present. The second is to give up ineffective attempts at avoiding or controlling the illness. The third is behaving in a way that does not have to equate the illness with disability, and the fourth is to focus on having a good quality of life in the face of illness. Risdon and colleagues (2003) added that acceptance also includes the recognition that a cure may not be found, and that accepting illness should not be viewed as personal failure. Research on acceptance in chronic pain and chronic fatigue syndrome has shown that higher levels of acceptance are associated with better adjustment to chronic illness (McCracken & Eccleston, 2005; Van Damme et al., 2006). Acceptance also appears to be a more important indicator of adjustment than coping (McCracken & Eccleston, 2003).

Due to the characteristics and course of the disease, a person with MD can unpredictably fluctuate between acute phases, chronic phases and symptom free phases. In acute phases, a person may be bedridden with a vertigo attack, having to fully occupy the sick-role until the attack subsides. In chronic phases, a person is able to function, but may have to deal with other symptoms of dizziness and imbalance, tinnitus, a sense of pressure in the ear and hearing loss. There may also be phases (usually earlier on in the disease course) where a person with MD may experience remission with no symptoms at all. Therefore, people with MD have to continually readjust according to the phase of illness they are in. This may make the achievement of response shift difficult, as people with MD have to change their internal standards, values and quality of life not just according to the individual stage of illness that they are experiencing, but also to the fact that their illness will fluctuate.

2.1.2 The Measurement of Adjustment in Chronic Illness

It is important to consider how people adjust in addition to what they are adjusting to (Radley, 1989), especially as it has been well noted that people with the same chronic illness can have very different psychological responses to their illness

(White, 2001). This variation in response has led to many attempts by researchers to try to understand what factors are involved in successful adjustment to chronic illness. In their crisis theory, Moos and Schaefer (1984) propose that coping and adjustment to illness is comprised of several adaptive tasks. Some of these which are particularly relevant to MD include: coping with the symptoms and resulting disability, controlling negative feelings and retaining a positive outlook for the future, maintaining a satisfactory self image and sense of competence, and preparing for an uncertain future. These adaptive tasks can all be influenced by three main areas: illness related factors, background and personal factors, and physical and social environmental factors.

There has been a lack of parity in the literature in defining and measuring what is meant by adjustment. Sharpe and Curran (2006) reviewed several approaches to adjustment, and proposed a composite model of adjustment to chronic illness. They summarise the definition of successful adjustment to illness as the ability to "maintain a positive view of the self and the world in the face of a health problem" (pg1161). Their model describes the outcome of positive adjustment as the presence of active coping strategies and the facilitation of helpful health behaviours. Negative outcomes are associated with a focus on feared consequences, which leads to anxiety, and the inability to separate self-schema from illness representations, which leads to depression.

Adjustment to chronic illness has been operationalised in previous research in many ways, and has been assessed by measures of quality of life, wellbeing, coping style, depression, anxiety, disability, global distress, illness specific measures, behaviour problems, post traumatic stress disorder symptoms, self-esteem, life satisfaction, social support, social activities and adjustment, subjective health, acceptance of illness, and marital satisfaction (De Ridder, 2004; Felton et al., 1984; Meijer et al., 2002; Oxlad & Wade, 2006; Pakenham, 1999; Rodrigue et al., 2000; Schroevers et al., 2006). These variables can generally be divided into two categories: process variables that can influence and contribute to good or poor adjustment (e.g. social support and coping style), and outcome variables that can be specific or global markers of whether adjustment has been achieved (e.g. quality of life, wellbeing, and behaviour). Studies have been criticised for using some variables such as depression

interchangeably between the two categories (Sharpe & Curran, 2006). One reason why some factors are used as process variables in some studies and outcome variables in others may be accounted for by the reciprocal nature of adaptation described by Bandura. Bandura's social cognitive theory (2002) describes outcomes as being the result of the reciprocal influence between internal personal factors (including cognitive, affective and biological factors), behaviour, and environmental factors. Therefore, some factors such as depression may be reciprocal in their influence on and by other factors such as quality of life.

The outcome variables that are commonly used by studies to assess adjustment to chronic illness can also be further grouped into affective or behavioural outcomes, although there is often some degree of overlap between them. A number of clinical models of affective outcomes in the form of psychological disorders are described in the DSM-IV-TR (American Psychiatric Association, 2000), some of which will be discussed in chapter 5 (Mechanisms of distress associated with chronic illness). A great deal of health psychology research, however, has focused on proposing and testing a number of theories and models to try to explain and predict behavioural outcomes. These are often grouped together under the umbrella of 'social cognition models' and include the health belief model, protection motivation theory, the theory of planned behaviour, and the health action process approach (see Conner & Norman, 1995). It is important to note that as all chronic illnesses are not the same, and different issues are relevant to different illnesses, the measurement of both process and outcome variables of adjustment should be based on relevant research (Schroevers et al., 2006).

2.2 Areas of Adjustment Relevant to this Thesis

In a discussion of adjustment to MD, Nobbs (1987), who has MD herself, states that many fears and anxieties result from the distressing symptoms, and argues that "it is possible that the whole lifestyle of an individual can change and **must** change in order to try and live something of a normal life" (Nobbs, 1987, pg 3).

The process variables that will be discussed in this chapter will be considered in two sections: the first relates to expectations and beliefs about illness, while the second

considers personality factors. Both of these sections will first outline general psychological factors that may be relevant, followed by illness specific factors that may be relevant, and then factors that may be specifically relevant to MD. Adjustment outcomes will then be discussed in a further section, which will consider affective adjustment and treatment-specific adjustment. Although the above factors have been grouped into these categories for the purpose of this overview, it is important to note that as adjustment to MD is a complex process, it likely that there may be a reciprocal relationship between the 'process' and 'adjustment' factors (Bandura, 2002).

2.2.1 Expectations and Beliefs About Illness

This section will begin by discussing self-efficacy and outcome expectations as described in Bandura's social cognitive theory. These are variables that are believed to be relevant to adaptation in almost all circumstances. This will be followed by a consideration of the role of illness perceptions, which include concepts analogous with self-efficacy and outcome expectations, but are specific to the context of illness. As fear and avoidance of symptoms are commonly reported in some chronic illnesses, these will be discussed next, followed by a discussion of beliefs about the consequences of dizziness, as a specific example of fear and avoidance relevant to MD.

2.2.1.1 Self-efficacy and outcome expectations.

Key concepts of social cognitive theory are the roles of perceived self efficacy and outcome expectations in influencing behaviour and outcome. Bandura defines perceived self-efficacy as people's "beliefs in one's capabilities to organise and execute the courses of action required to produce given attainments" (Bandura, 1997, page 3). Self efficacy is based on four main sources of information: enactive mastery experience (previous experience of the prospective task); vicarious experience (modelling based on the observed successes or failures of comparable others); verbal persuasion (expressed belief in abilities by significant others); and physiological and affective states (the influence of symptoms and mood). In addition to these areas, self efficacy can also be mediated by cognitive, motivational, affective and selective

processes. Outcome expectations are assessments of the consequences that a behaviour is expected to produce (Bandura, 2002). Bandura describes three types of outcome expectations: physical effects (such as pleasure or pain); social effects (such as approval or rejection); and self-evaluative effects (such as self-satisfaction or self-criticism). Levels of self efficacy and outcome expectations interact to produce either positive or negative cognitions, behaviours and emotions. Positive outcomes can only be achieved if self efficacy and outcome expectations are both high. Within the chronic illness literature, however, self efficacy tends to receive much more attention than outcome expectations. This is likely to be due to the fact that, given the nature of many chronic illnesses, management, treatment and prognosis can be variable or unknown, limiting the scope to design interventions targeting outcome expectations. Self efficacy, however, is more likely to vary between individuals, and can be measured with disease specific self efficacy measurement tools (e.g. Riazi et al., 2004), and targeted through interventions.

Clark and Dodge (1999) reviewed longitudinal studies of self efficacy and concludes that self efficacy is not a trait, but is specific to particular behaviours. They found that while self efficacy was useful in predicting exercise and sun safety behaviours, it was not useful in predicting reduction in addictive behaviours such as smoking, or sexual risk taking behaviours. Self efficacy and outcome expectations have not been investigated in relation to MD, but have been researched in relation to several chronic illnesses, with particular reference to how they influence self-management behaviours, and disability.

Self efficacy has been found to be relevant to adjustment to chronic pain. Arnstein (2000) measured self efficacy and disability in 479 chronic pain patients. Using path analysis, Arnstein found that self efficacy mediated the relationship between pain intensity and disability. In a study of primary care chronic pain patients, Denison and colleagues (2004) found that self efficacy beliefs were even stronger predictors of disability than fear avoidance beliefs and behaviours. Similar findings have been noted in non-clinically recruited participants. Turner and colleagues (2005) assessed older adults with chronic pain, and found that increased self efficacy was related to lower levels of disability and depression, and greater use of positive pain coping strategies. Self efficacy has also been found to be relevant to outcomes in other

chronic illnesses, including diabetes (Johnston-Brooks et al., 2002), chronic obstructive pulmonary disease (Kohler et al., 2002) , heart disease (Sulivan et al., 1998), cancer (Graves, 2003) and multiple sclerosis (Riazi et al., 2004).

As self efficacy beliefs have been found to be modifiable, several studies have used interventions to improve self efficacy for self management behaviours. Graves (2003) carried out a meta-analysis of intervention studies to improve quality of life using components of social cognitive theory (including self efficacy and outcome expectations) with cancer patients. The meta-analysis reviewed 38 studies, and found that using social cognitive theory based interventions improved quality of life in people with cancer. Specific improvements were found in relation to global affect, depression, social, and objective physical outcomes, but using social cognitive theory based interventions did not improve anxiety, coping or overall physical outcomes. Interventions were also found to be more effective in a group setting rather than individual.

2.2.1.2 Illness perceptions.

People's personal expectations and beliefs specifically relating to their illness and treatment have been found to be a major influence on how they cope and respond to their illness and treatment (Lau & Hartman, 1983; Leventhal et al., 1980; Leventhal et al., 1984; Weinman & Petrie, 1997). A common sense self regulation model of illness perceptions has been proposed in which responses to illness are influenced by beliefs about identity, cause, consequences, time line (Leventhal et al., 1980; Leventhal et al., 1984), and control or cure (Lau & Hartman, 1983). Leventhal and colleagues (Leventhal et al., 1980; 1984) defined identity as the label and symptoms associated with an illness, and cause as what a person believes to have caused or contributed to their illness. A person may have a different number of causes for each of the illness identities, and these could be related to personal or external factors. Consequences are the expected outcomes and effects of the illness, and time line is whether the person believes their illness to be acute, episodic, or chronic in duration. Lau and colleagues (1983; 1989) added to this, proposing that beliefs about the controllability and cure of the illness are also relevant. These can be either through personal control or treatment effectiveness. In addition to these components, Moss-

Morris and colleagues (2002) have suggested that illness coherence, and emotional representations are also important illness perceptions. Illness coherence is the extent to which patients understand their illness, and emotional representations are the presence of emotional responses to the illness.

Illness perceptions are most commonly measured using the Illness Perceptions Questionnaire (Moss-Morris et al., 2002; Weinman et al., 1996). Illness representations have not been studied in people with MD, vertigo or dizziness, but have been used to predict adaptation to and recovery from a number of other chronic illnesses. Lawson and colleagues (2004) measured illness perceptions in people with type I diabetes and found that care-seeking behaviour was associated with belief in treatment effectiveness and personal control. Consequences were also associated, but in different ways. Those who worried about the short term consequences of diabetes but did not perceive diabetes as a serious health threat were more likely to undertake care-seeking behaviour. Horne and Weinman (2002) found that a strong illness identity was also associated with health care utilisation in people with asthma. Helder and colleagues (2002) found that having a strong illness identity was associated with poorer well being in people with Huntington's disease. Reynolds and colleagues (2004) found that illness perceptions are also important predictors of anxiety and depression in people with tinnitus (one of the symptoms of MD). They found that a strong illness identity and the perception that tinnitus has severe consequences were associated with both anxiety and depression, with only perceived severe consequences independently predicting anxiety and depression, accounting for 13.6% of the variance in anxiety scores, and 34.6% of the variance in depression scores. Beliefs about the consequences of illness have also been found to be relevant to adherence to treatment. Llewellyn and colleagues (2003) studied people with haemophilia to assess their adherence to their self treatment. They found that those who perceived their illness to have more severe consequences, as well as having a stronger illness identity, were more likely to adhere to their treatment programme. Contrary to this, however, Horne and Weinman (2002) found that less severe beliefs about consequences of asthma predicted 30% of the variance in adherence to asthma prevention medication. They suggest that as this was a cross sectional study, the unexpected direction of results might be a result of better asthma control resulting in fewer perceived consequences, rather than the other way around. Hobro and

colleagues (2004) have suggested that illness representations could be used to cluster groups of people to provide treatment that is tailored to their needs.

Hagger and Orbell (2003) carried out a meta-analysis of studies investigating the relationship of illness representations with coping behaviours and illness outcomes. They identified 103 studies on illness representations, of which 45 met their inclusion criteria for the meta-analysis. Across the studies, poor illness outcomes were defined as categories of disease state, physical functioning, psychological distress, psychological well-being, role functioning, social functioning, and vitality. Poor illness outcomes were related to having a strong illness identity, belief that the illness has serious consequences, belief in a chronic timeline, and low perceived control. Of studies that also considered the additional dimensions of illness coherence and emotional representations, having a poorer understanding of illness and a greater emotional response to illness were also associated with poorer outcomes (Hobro et al., 2004; Jopson & Moss-Morris, 2003).

2.2.1.3 Fear and avoidance.

A great deal of research has been carried out on cognitions about illness in the form of fear of symptoms and how these fears lead to avoidance of activities and situations that might trigger symptoms. This then results in greater levels of disability and handicap. Although much of this research stems from work with chronic pain populations, there are also similarities with research on panic and agoraphobia, and anxiety sensitivity; the latter is discussed in chapter 5 (Mechanisms of distress associated with chronic illness) rather than here.

Fears have been identified as a key variable affecting adjustment to chronic pain and the avoidance of activity that is believed to cause or worsen pain (Asmundson et al., 1997). Fears have also been found to be significant in predicting the progression of symptoms from acute to chronic in people with chronic pain. Klenerman and colleagues (1995) conducted a prospective study of 300 people with acute back pain who had only presented with their acute symptoms one week previously. Measures of fear avoidance beliefs were found to predict chronicity both two and twelve

months later. Fears have also been found to lead to increased disability and handicap in relation to imbalance and falling among older adults (Yardley, 1998).

Several cognitive-behavioural models have been proposed to suggest which fears result in avoidance and why. Lethem and colleagues (Lethem et al., 1983) defined symptom perception as comprising components of both sensation and emotional reaction. If a person responds adaptively to the sensation and confronts their fear then synchrony remains between these components. When there is desynchrony between them, an 'exaggerated pain perception' occurs which leads to cognitive and behavioural avoidance. This outcome is proposed to be influenced by four factors: stressful life events at and prior to the time of injury; previous experience of pain; personal coping strategies; and the personality factors of hypochondriasis, hysteria and depression. Philips (1987) proposed that in addition to current pain levels and environmental rewards for avoidance, avoidance is influenced by three main cognitions which can be either strengthened or weakened by subsequent behaviour. The cognitions are: expectations that symptoms will increase with exposure and decrease with avoidance, self-efficacy regarding the effects of actions and the capacity to control the pain, and negative memories of past exposure to symptoms. Waddell and colleagues (Waddell et al., 1993) suggested that beliefs that physical activity and work can make symptoms worse are related to disability. They created the 'Fear-Avoidance Beliefs Questionnaire' (FABQ), and found that beliefs about physical activity predicted 9%, and beliefs about work predicted 23% of the variance in disability.

Vlaeyen and colleagues (1995) propose that people with chronic pain are caught in a vicious cycle in which painful experiences are interpreted in a catastrophising manner. This leads to the fear of movement or (re)injury, which results in avoidance, and subsequent disability, disuse, and depression, which maintains the pain. Vlaeyen and colleagues' model is not dissimilar to the cognitive model of panic attacks proposed by Clark (1986), in which if a trigger is perceived as a threat, the sense of apprehension that follows leads to physical sensations of somatic anxiety. If these sensations are interpreted in a catastrophic manner, then the cycle may escalate and result in a panic attack. Agoraphobia occurs when a person avoids situations where panic might occur or situations where escape might be difficult.

Similarities exist between people with balance disorders and those with chronic pain, panic and agoraphobia, in that they both appear to have a high level of avoidance of movements, activities, and situations that are perceived to provoke symptoms (Cohen et al., 1995; Yardley & Beech, 1998; Yardley et al., 1995; Yardley & Redfern, 2001). Fears and negative beliefs can be more disabling than the symptoms themselves, leading to high levels of disability and handicap (Crombez et al., 1999; Kinney et al., 1997; Waddell et al., 1993). The particular types of cognitions that have been investigated in relation to balance disorders will be discussed in more detail in the next section.

2.2.1.4 Dizziness beliefs.

In order to try to understand the processes involved in responses to vertigo, Yardley and colleagues (1992b) carried out a qualitative study. They interviewed 23 people who experienced vertigo about their reactions to vertigo and how it had affected their lives. They report four main themes relevant to how participants' lives are affected by vertigo: practical restrictions on lifestyle; effects of recurrent vertigo on social relations; self-generated rules; and emotional responses to vertigo.

Within these themes the results could be broken down further into subcategories. Within the practical restrictions on lifestyle theme, participants reported being limited in general routine activities such as travelling and normal daily activities, participants were limited with regard to their work, either finding it difficult, having to take time off or having to leave altogether. Participants were also unable to pursue social and leisure activities. The theme on effects of recurrent vertigo on social relations included effects within the immediate family, where the participant became dependent on family members for support which could cause anxiety and tension. Social relations with others were affected by vertigo in two ways. Participants either encountered and anticipated unpleasant responses, believing that others could not understand the illness and believing that others thought they were drunk, or found people to be understanding, sympathetic and helpful. The third theme of self-generated rules included rules concerned with restriction and avoidance of movements, activities, travel, and social or occupational situations that they believed might provoke vertigo. Participants also had rules about living with vertigo, in that

they would not tell others about having vertigo, they would avoid going out alone, and they would suppress awareness of the dizziness, choosing to carry on as normal. The fourth reported theme of emotional responses to vertigo included one of fear of the vertigo itself, that it may have serious implications, and feeling helpless. There were also emotional responses in relation to its effects on lifestyle. Participants reported a loss of self-confidence, a personality change with increased levels of introversion, anxiety and introspection, depression, and frustration and distress resulting from the restriction of activities.

The findings of this qualitative study were then used to create the dizziness beliefs scale (Yardley, 1994a), in which catastrophic negative beliefs about dizziness comprised four factors of belief. Two factors related to fears that dizziness would lead to physical danger (as a result of imbalance, falling or loss of consciousness) or social incompetence (as a result of embarrassment or inability to fulfil roles). These two factors can also both be grouped together under a composite factor loss of control. The third factor involved the belief that dizziness is a sign of a serious illness, and the fourth factor was the belief that dizziness will develop into an attack of severe vertigo.

When used in a longitudinal study, Yardley (1994a) found that the composite factor loss of control was significantly associated with handicap, even after controlling for handicap measures taken six to seven months previously. A later study used a shorter single scale version of the dizziness beliefs scale, measuring beliefs about dizziness at baseline and found that negative beliefs about dizziness predicted handicap (Yardley et al., 2001a). Yardley and colleagues (2001a) also found in this study that fewer negative beliefs were reported by those who had received treatment than those who had not received treatment, suggesting that treatment has an important role to play not just in reducing symptoms, but also in reducing the anticipated consequences of future dizziness.

2.2.2 Personality

This section will begin by discussing the relationship between differences in general personality traits and adjustment to illness and MD. This will be followed by a

discussion of the different methods of coping with illness and negative events. As uncertainty is common to many chronic illnesses, including MD, intolerance of uncertainty will then be discussed as a personality characteristic that is specifically relevant to MD.

2.2.2.1 Personality traits.

A great deal of research has been carried out on the relationship between personality and health, with theories even dating back to ancient Grecian times. Several models of how personality might be related to health have been proposed, including a stress moderation model, health behaviour model, constitutional predisposition model, and illness behaviour model (for a description of each see Wiebe & Smith, 1997). Numerous traits and taxonomies have also been proposed, which are also too many to list in detail here, but can be found in most basic psychology textbooks.

The earliest work on personality factors in MD was carried out by Fowler and Zeckel (1953), who carried out a series of psychiatric interviews and a battery of personality tests (comprising the Bernreuter personality inventory, the picture frustration test, the Jenkins trait study, Rorschach tests, and thematic apperception). Although much of their results described patterns of childhood paternal threat and sexual inadequacy characteristic of the psychoanalytic approach, they also concluded that of the 23 patients they studied, nine had compulsive personalities, two were schizoid, five were hysterical, four were obsessive-compulsive, two had depressed-hypochondriasis, and one had subclinical schizophrenia. Using a measure that is more commonly recognised in current personality research, Hinchcliffe (1967b) used the Minnesota Multiphasic Personality Inventory (MMPI) to compare the personalities of 44 people with MD and 20 people with otosclerosis (a middle ear disorder causing hearing loss). They found that people with MD had a higher incidence of hypochondriasis, depression and hysteria (also referred to as the psychosomatic-V profile), than people with otosclerosis. Stephens (1975) also carried out personality assessments in 104 people with MD, comparing them with 62 patients with idiopathic peripheral vertigo and 170 ENT outpatients. Using the Middlesex Hospital Questionnaire and the Eysenck Personality Inventory , Stephens found that people with MD had higher levels of obsessionality, anxiety and phobic

anxiety, but lower hysteria and lie scores than ENT outpatients, and higher levels of obsessionality and depression than those with idiopathic peripheral vertigo. In contrast, people with MD have also been found to showed significantly lower scores on the Middlesex Hospital Questionnaire for obsession, and significantly higher scores for somatization when compared with other vertigo sufferers (Rigatelli et al., 1984)

A study that does consider personality in relation to outcomes within a group of people with MD was carried out by Savastano and colleagues (1996). They found that number of ENT hospital stays was correlated with depression, trait anxiety, disease conviction and somatic perceptions of the disease, and that the length of time since their last attack was negatively correlated with dysphoria, depression and neuroticism. Using cluster analysis, they identified two subgroups of Meniere's patients. One group had normal illness behaviour scores, were less than 3 years since diagnosis but over 6 years since onset, and had a stronger tendency to interpret the disease in psychological terms. The second group were older patients with a longer history of MD and more hospital stays. These patients had high levels of depression, anxiety, neuroticism, psychoticism, hypochondriasis, dysphoria and irritability, with a strong disease conviction and a tendency to interpret their disease in somatic terms with greater affective inhibition. Optimism has also been assessed in people with MD, but has been found not to be associated with symptom severity (Andersson & Hagnebo, 1996). A qualitative study (Erlandsson et al., 1996) that carried out interviews and focus groups with people with MD reported that participants were 'highly responsible persons' who made 'extremely high demands on themselves' (page 49). This suggests the possibility that people with MD may also have high levels of conscientiousness, although this would need to be assessed more rigorously.

A great deal of the early research on MD focused on the involvement of personality factors, with limited consideration of other factors. In this respect, the history of research on MD shares a great deal with that of multiple sclerosis in early (and few remaining current) attempts to classify it as a psychosomatic illness (Antonak & Livneh, 1995). One of the key limitations in much of the work on the associations between personality and chronic illness is the inability to take pre-illness measures of

personality. Research has shown that retrospective measures are unreliable as they can be affected by current symptoms (Philips, 1987). Therefore, although research can demonstrate an association between personality and chronic illness, it is not able to determine the causality of this relationship (Wiebe & Smith, 1997). Much of the personality research done with people with MD has focused on comparing people with MD with other vestibular, medical, or healthy groups, the practice of which has been criticised on a number of levels (Crary & Wexler, 1977), which have already been described in chapter 1 of this thesis. Almost no research has been carried out that assesses how personality might be related to outcomes within a group of people with MD, although it has been theorised that personality factors might moderate or mediate response to vestibular symptoms (Clark & Swartz, 2001). Research has also been heavily focused on clinical and psychiatric aspects of personality.

2.2.2.2 Coping.

Choice of coping strategy has been reported to mediate the effect that stressful events have on adjustment, with some ways of coping aiding positive adjustment and some hindering it (Folkman & Lazarus, 1988a). Although many definitions of coping exist, it is most frequently defined as "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Folkman & Lazarus, 1988b, pg 310). How people cope could therefore influence how well they adjust to chronic illness.

Folkman and colleagues (1986) reviewed early research on coping and identified four ways that coping has been previously studied in relation to health issues. Coping had been studied in the context that (1) coping is the result of personality factors, (2) a person will cope with all stressful events in the same way, (3) how people cope depends on the controllability they have over the situation, and (4) personality factors are more influential when controllability of the stressful situation is low, and the way a person copes is more influential when controllability of the stressful situation is high. Folkman and colleagues (1986) integrated these approaches into their proposed cognitive theory of psychological stress, which is a process based framework for coping that is widely accepted and followed. In this framework, they propose that through primary and secondary cognitive appraisal a

person firstly appraises if their well being is at risk, and secondly, if they are at risk what can they do about it. They describe two types and functions of coping: problem focused coping, and emotion focused coping. Many measures have been created based on this framework and types of coping, the most common including the Ways of Coping Checklist (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985), and the COPE (Carver et al., 1989).

In a review of studies on coping since the cognitive theory of psychological stress was developed, Lazarus (1993) makes several generalizations about how people cope with stressful events. Lazarus surmises that people often use most types of coping in every event, and although some types are more stable than others, the type of coping used can change within the same event. Emotion-focused coping is more commonly used when events are uncontrollable, with problem-focused coping being used more when events are controllable. Lazarus also confirms that coping appears to mediate emotional state, and finally concludes that research is generally focused on the antecedents of coping, or the consequences of different types of coping.

Research that looks at coping specifically in relation to chronic illness, paints a complex picture. In relation to chronic illness, coping has been reported to be unrelated to symptom severity in people who have hypertension, diabetes, cancer and rheumatoid arthritis (Felton et al., 1984). Newman (1990) warns that in addition to individual differences between people, different illnesses have different symptoms, timelines, consequences, and prognoses, and so should not be expected to be comparable. Newman offers a broad definition of coping which includes "any action/cognition which takes place in relation to the disease or illness" (1990, pg 161). Choice of coping strategy in people with a chronic illness may also be related to previous experience, imitation and modelling of others with the same condition, and the views of significant others, such as family members or doctors (Lethem et al., 1983).

The capacity to cope with stressful life situations has been found to be an important predictor of adjustment to MD. A greater capacity to cope is associated with better general quality of life, less frequent vertigo severity and somatic anxiety, and less severe tinnitus and hearing disability (Soderman et al., 2001). Greater capacity to

cope with stressful situations has also been found to predict lower levels of anxiety and depression, psychosocial and sleep dysfunction, and better mental health (Soderman et al., 2002). Therefore distress may be improved by helping people formulate strategies to cope with the perceived consequences of their illness and everyday stressors.

Hagnebo, Melin and Andersson (1999b) used the Ways of Coping Questionnaire with a small sample of 50 people with MD. They found that those who used an escape/avoidance or distancing coping strategy had higher levels of perceived functional handicap, and those who used a self-controlling coping strategy had lower levels of perceived functional handicap. Anxiety sensitivity was also measured, with high levels of anxiety sensitivity being found to be associated with the coping strategies of accepting responsibility and escape/avoidance. Hagnebo and colleagues also found that although coping strategies were not related to symptom severity, the use of a positive reappraisal coping strategy was associated with being older and having MD for longer. This suggests that better adjustment may develop over time. This last finding is very different to research carried out with tinnitus sufferers, which found that maladaptive coping strategies are related to symptom severity, anxiety and depression, and more likely to be used by those who were older and had tinnitus for longer (Budd & Pugh, 1996). Coping has also been measured in people with hearing loss, however, in their review of coping with a hearing impairment, Andersson and Willebrand (2003) argue that although coping has been studied in relation to hearing disorders, with approach and avoidant coping strategies being used, a great deal of work remains to be done.

Yardley (1994b) created an illness specific coping questionnaire to assess constructive and maladaptive types of approach and avoidance coping behaviours in people with vertigo. The questionnaire identified four types of coping: problem focused information seeking, distraction, denial and relinquishing responsibility. Like Hagnebo and colleagues (1999b), Yardley also found that choice of coping strategies were not associated with symptoms. The coping strategies of distraction and relinquishing responsibility had the greatest impact, being associated with both greater handicap and distress. Relinquishing responsibility was also able to predict

handicap after controlling for symptom severity, distress, and locus of control beliefs.

2.2.2.3 Intolerance of uncertainty.

Increased levels of uncertainty are common to many chronic illnesses. Uncertainty may be experienced with regard to the presence or severity of symptoms, prognosis, or the effectiveness of treatment. Individual differences may occur, however, in how people tolerate these uncertainties and adapt their lives to accept and incorporate their presence and resulting outcomes. The presence and dislike of uncertainty has been well noted anecdotally within MD (Crary & Wexler, 1977; Dowdal, 2002), but no research has been conducted that investigates the concept of uncertainty in further depth among people who have MD.

The construct of intolerance of uncertainty has been defined as "a cognitive bias that affects how a person perceives, interprets, and responds to uncertain situations on a cognitive, emotional, and behavioural level" (Dugas et al., 2005a, p. 58). A person who is intolerant of uncertainty has "an excessive tendency to find uncertain situations stressful and upsetting, to believe that unexpected events are negative and should be avoided, and to think that being uncertain about the future is unfair" (Dugas et al., 2005a, p. 58). Intolerance of uncertainty is most commonly measured using the intolerance of uncertainty scale (Freeston et al., 1994; Buhr & Dugas, 2002), although other scales do exist (e.g. Mishel, 1981). High levels of intolerance of uncertainty can lead to inaccurate appraisals of threat (Dugas et al., 2005a; Freeston et al., 1994) and result in a greater use of vigilance and avoidance behaviours (Mishel, 1981). Although gender differences are commonly found in research on worry, with females being more likely to worry more than males, no gender differences have been found in intolerance of uncertainty (Robichaud et al., 2003).

In the literature, intolerance of uncertainty has mainly been associated with worry in the context of generalised anxiety disorder (Dugas et al., 2004a), but has also been investigated in relation to obsessive compulsive disorder (Starcevic & Berle, 2006), and hypochondriasis (Langlois & Ladouceur, 2004). Through the use of

discriminant function analyses, intolerance of uncertainty has been found to be the main process involved in discriminating people with generalised anxiety disorder from normal controls (Dugas et al., 1998). Intolerance of uncertainty has been found to be a strong predictor of worry even after controlling for other factors such as anxiety and depression (Buhr & Dugas, 2002), dysfunctional beliefs (Dugas et al., 2004b), obsessions and compulsions, and panic sensations (Dugas et al., 2001), perfectionism and perceived control (Buhr & Dugas, 2006). Tolin and colleagues (2003) report that intolerance of uncertainty was higher in those who demonstrated obsessive-compulsive checking behaviours than those without checking behaviours, and normal controls.

The association of intolerance of uncertainty with generalised anxiety disorder, obsessive compulsive disorder and hypochondriasis has led to the suggestion that intolerance of uncertainty may be an underpinning feature of anxiety disorders more generally (Holaway et al., 2006). Although this remains to be tested using other specific anxiety disorder groups, Ladouceur and colleagues (1999) found that a mixed anxiety disorder group did have higher levels of intolerance of uncertainty than non-clinical controls. However, when different anxiety disorders are compared, intolerance of uncertainty has been found to be significantly more strongly associated with generalised anxiety disorder than a mixed anxiety disorder group comprising primarily people with obsessive-compulsive disorder (Ladouceur et al., 1999), or those with panic disorder and agoraphobia (Dugas et al., 2005b).

Although intolerance of uncertainty is described as a stable trait (Dugas et al., 1997), it can be manipulated to increase or reduce subsequent levels of worry. Ladouceur and colleagues (2000) used an experimental task-based manipulation to induce increased and decreased levels of intolerance of uncertainty. After checking the success of the manipulation, they measured worry related to the task. They found that those in the increased intolerance of uncertainty group reported more task related worries than those in the decreased intolerance of uncertainty group. Although the study would have been strengthened by measuring worry and intolerance of uncertainty at baseline before the task, it does suggest that intolerance of uncertainty may be improved through interventions.

Attempts to treat intolerance of uncertainty have indeed been successful. Dugas and Ladouceur (2000) went on to demonstrate this by carrying out a small scale study delivering an individual cognitive-behavioural intervention over seventeen sessions with four people with generalised anxiety disorder. The intervention was targeted at reducing intolerance of uncertainty, and was successful, with no evidence of generalised anxiety symptoms at six and twelve month follow-up. Through the use of time series analysis, they also report that the relationship between intolerance of uncertainty and worry is unidirectional, with changes in intolerance of uncertainty always preceding changes in worry. Cognitive-behavioural interventions targeting intolerance of uncertainty have also been found to be effective in a group treatment setting (Dugas et al., 2003), and the individually delivered intervention has been successfully adapted to treat patients with hypochondriasis (Langlois & Ladouceur, 2004).

2.2.3 Adjustment Outcomes

This section will discuss two main types of adjustment outcomes, affective adjustment and treatment-specific adjustment. Affective adjustment will be discussed in the section on psychological distress. As a large part of this thesis was nested within a clinical trial assessing treatment effectiveness, it was also relevant to consider the treatment-specific outcomes of adherence and enablement in relation to treatment, which will be discussed separately.

2.2.3.1 Psychological distress.

Psychological distress is a particularly relevant outcome variable to adjustment to MD, as the presence of anxiety and depression among people with MD has been prominently reported in the literature since the disease was first documented. Given that MD cannot be cured and there is no guarantee that symptoms can be easily controlled, it is appropriate that the reduction of distress should be an outcome of good adjustment to MD. The nature of the relationship between distress and MD has been a source of great debate over the years, but the prevalence of distress in people with MD has never been questioned, with it even being suggested that the emotional disability associated with MD is greater than the physical disability (Kinney et al.,

1997). Other researchers have also suggested that the consideration of distress should be incorporated into routine care (Monzani et al., 2001). Hagnebo and colleagues (1999a) carried out an experimental study, manipulating cognitive stress, and found that in participants who had MD, state anxiety and depression were correlated with subjective measures of instability, and depression was correlated with discomfort. In a different study in which Hagnebo and colleagues (1997) investigated the impact of Ménière's disease on daily life, they also found that anxiety and depression were related to present discomfort from symptoms. Honrubia and colleagues (1996) also assessed the impact of symptoms on quality of life. They found that anxiety and depression was associated with an impairment in daily activities, a lower quality of life, and an increased fear of becoming dizzy.

Although distress is well documented in the literature, few studies report the proportion of scores reaching clinical levels. One study that does was carried out by Soderman and colleagues (2002), who report that in a Swedish sample of people with MD, 17% of participants who completed the Hospital Anxiety and Depression Scale (HADS) scored 11 or more on the anxiety subscale, reaching the recommended cut-off for clinical anxiety, with a further 34% of participants scoring 8 or more, meeting the criteria for possible clinical anxiety. For the depression subscale, they found that only 3% could be classified as having clinical depression, but 13% could be classified as having possible clinical depression. Coker and colleagues (1989) also assessed levels of depression in people with MD, but used the Minnesota Multiphasic Personality Inventory, and the Diagnostic Inventory of Personality and Symptoms (DIPS). They found that among those who had experienced vestibular symptoms within the last three months, depression was found in 80% according to the MMPI, and 70% according to the DIPS. The rate was much lower among those who had not experienced symptoms within the previous three months, with 32% being classified with depression according to the MMPI, and 39% according to the DIPS.

It has been suggested that stress and emotional distress can cause MD (Hinchcliffe, 1967a; Rigatelli et al., 1984). However, the most reasonable explanation is that once a person has MD, psychological distress can contribute to the presence of residual and provoked dizziness (Yardley & Redfern, 2001). Symptom severity has been found to be associated with distress in several studies. However, most studies have

assessed this cross-sectionally, making causality impossible to ascertain. Holgers and Finizia (2001) found that emotional distress accounted for 40% of the variance in tinnitus severity in 116 people with MD. Andersson and Hagnebo (1996) found that depression was also associated with vertigo symptom severity as well as reduced confidence in balance and reduced levels of optimism. Kentala and colleagues (2001) compared levels of anxiety in those who experienced a drop attack, a type of vertigo that occurs suddenly and unexpectedly. They found that 60% of those who experienced drop attacks had high levels of anxiety, compared with 33% in those who did not experience drop attacks. Savastano and colleagues (1996) also found that psychological distress was associated with greater healthcare utilisation, however this finding should be interpreted cautiously as they did not control for symptom severity.

The one study that has assessed distress (in the form of stress) longitudinally and prospectively, was carried out by Andersson and colleagues (1997). They used time series analysis to assess the temporal relationship between daily stress and symptoms in Ménière's disease. They asked 20 participants to complete a daily diary comprising assessments of each of their symptoms and their stress levels using a visual analogue scale. They found that stress was associated with symptoms, but they occurred on the same day rather than one preceding another. As it was unknown whether the stress occurred before or after on the same day, Soderman and colleagues (2004) investigated this further. Using a case-crossover design, they asked participants with MD to complete questionnaires immediately after attacks, and during control periods when they had not had attacks. Participants recorded events of physical, emotional and mental stress that had taken place in the previous 48 hours. They found that exposure to emotional stress preceded attacks by approximately three hours. However, the findings of this study are limited. The retrospective design of the study means that participants may have been influenced by their post attack feelings of stress (Philips, 1987). The researchers also did not obtain and control for the participant's views on whether they thought stress might trigger their symptoms. If participants had beliefs that stress triggers their symptoms, they may have retrospectively attributed a greater meaning to events than if they had been measured prospectively. Although empirical evidence is limited, many people with MD believe that stress and distress precede symptoms. In a

qualitative study investigating the role of psychological factors in MD, Erlandsson and colleagues (1996) found that several of their participants reported that their symptoms were triggered by stress, worry, and negative expectations, and therefore felt that they always had to be in control of their emotions to avoid attacks.

2.2.3.2 Enablement.

Enablement is a concept that combines elements of satisfaction with health care and health related quality of life. Two approaches to enablement have been developed concurrently but independently, one from a general practice background (Howie et al., 1998), and one from a nursing background (Stamler, 1996). The former is the development of a measure called the Patient Enablement Instrument (PEI), derived from the literature on satisfaction as a specific form of satisfaction, designed to assess subjective benefit relating to specific health issues following primary care consultations. The latter is theory based, derived from the use of the word 'enable' in psychological, sociological, educational, and nursing and health literature. Howie and colleagues (1998) define enablement as a person's perception, as a result of health care, of their ability to cope with their illness and life in general, their confidence in maintaining their health, and the extent to which they feel able to understand their illness. Stamler defines enablement as something which can "assist the patient to acquire or expand the means, abilities, and/or opportunities to complete a task, or fulfil a role to the patient's perceived satisfaction" (Stamler, 1996, pg 339). In both these approaches, enablement is an outcome variable focused on the benefit and outcome of health care, whereas health related quality of life is not necessarily related solely to health care. In contrast, satisfaction also assesses a range of factors associated with how people feel about the processes and interactions involved in and associated with the quality of treatment delivery, but has been criticised as being poorly defined, poorly measured, and too broad in concept (Sitzia & Wood, 1997).

The PEI has been found to be marginally correlated with other satisfaction scales, validating its existence as a separate construct (Howie et al., 1998). Howie and colleagues (1999) attempted to identify correlates of enablement by gathering data from 25,994 general practice consultations conducted by 50 doctors in 10 practices. They found that higher levels of enablement were associated with being over 65

years old, being male, knowing the doctor well, and receiving a prescription when one was wanted. Greater enablement was also found among those who had social and psychological problems concomitant with their medical problems, and among those who wanted to discuss more than one problem during the consultation. Price and colleagues (2006) used the PEI to assess enablement resulting from acupuncture consultations, and found that assessment of practitioner empathy was the key predictor of enablement, with age and gender not influencing enablement. In a qualitative study using the Stamler framework of enablement to evaluate patient education classes for people with diabetes, Stamler and colleagues (2001) found that participants felt more enabled and had increased levels of mastery, and lower reported anxiety. However, the lack of operationalisation of the framework in this study makes the classification of enablement difficult to identify, since all positive comments that were made by participants were classified as enablement. The PEI, however, is defined as being specifically related to coping, confidence and understanding.

The purpose of assessing satisfaction has been to assess patients' response to and quality of health care (Fitzpatrick, 1997). Enablement has been used for the same purpose, mainly to assess interactions with health care professionals. However, the definitions of enablement given above could also be used to measure the outcome of other aspects of care, such as an assessment of the effectiveness of treatment programmes from the patient's perspective. The concept of enablement as defined by Howie and colleagues (1998) could be particularly relevant to treatment of MD. This is because as MD cannot be cured, nor control guaranteed, the treatment of MD is rarely solely concerned with the reduction of symptoms, but also values improvements in educational and psychological aspects experienced by the person with MD as a successful outcome of treatment (Kato et al., 2004; Paparella, 1991). As it is natural for the course of MD symptoms to fluctuate, the measurement of enablement would allow for a broader assessment of benefit from treatment aside from symptoms.

2.2.3.3 Adherence.

Adherence occurs when patients are "working together with their clinician in planning and implementing the treatment regimen" (Myers & Midence, 1998, pg 2). Adherence is an important issue in treatment, as the effectiveness and outcome of treatment can be compromised by poor adherence, leading to undesirable treatment outcomes as well as increased financial costs and time spent with health care professionals (Myers & Midence, 1998). Adherence is particularly relevant to chronic illness, as patients are expected to partner with their health practitioner, taking on responsibility for self-management of their health and illness (Holman & Lorig, 2000). Although self-management based treatments for MD (described in chapter 1) generally do not have direct implications for risk to health or mortality in the same way that they might for people with diabetes or heart disease, they do have implications for ability to manage and cope with symptoms and subsequent quality of living. As such, it is important to acknowledge that non-adherence to treatment could be due to the fact that the person undergoing treatment may assess quality of life using different outcomes to their health care practitioner, with side effects and consequences of treatment impinging on factors the person undertaking the treatment values as quality of life (Crossley, 2000). Given the importance of adherence to treatment effectiveness, many researchers have sought to identify what influences adherence and whether it can be predicted before treatment begins. Unfortunately much of the research reviewed to date suggests that the factors associated with adherence are numerous and inconsistent (Sluijs et al., 1993; Turk & Rudy, 1991). In a meta-analysis of research on adherence carried out over the previous 50 years, DiMatteo (2004) concludes that adherence may not be a unified construct, and that the lowest levels of adherence were found for treatments that required keeping an appointment or maintaining a health behaviour. In relation to chronic illness that requires these kinds of behaviours, cognitive factors such as self efficacy, illness perceptions, treatment beliefs, and social support appear to be important associates of adherence (Horne & Weinman, 2002; Llewellyn et al., 2003; Oman & King, 1998; Turk & Rudy, 1991).

Sluijs and colleagues (1993) assessed whether adherence to physiotherapy was associated with patient characteristics, illness characteristics, patient attitude or

therapist behaviour in a study of 222 physiotherapists and 1,681 of their patients. They found that adherence was associated with the patient characteristic of age, with adherence increasing with age, but decreasing with level of education. The illness characteristics associated with adherence comprised believing that their illness was more serious, caused more disability and hindrance, and would eventually disappear. With regards to patient attitude, a greater sense of helplessness (that exercising will not help much), and more perceived barriers (e.g. difficulties in finding time and incorporating exercise into daily routine, poor motivation, and forgetting) were related to non-adherence. Of factors related to the therapist behaviour, only receiving positive feedback from the therapist was associated with adherence. When all the factors measured were entered into a discriminant analysis, the main factors distinguishing adherers from non-adherers were perceived barriers, positive feedback, and degree of helplessness. A qualitative study carried out by Yardley and colleagues (2001c) investigated beliefs associated with adherence to treatment in people with either low back pain or dizziness. They found that non adherence was partially associated with beliefs about the cause of illness that were inconsistent with the treatment, but that these beliefs and behaviours could also be affected by interactions with therapists.

One of the main self-management treatments for MD is vestibular rehabilitation (a physiotherapy based programme of graded eye, head and body movements), which has been found to be effective in reducing residual symptoms of dizziness, anxiety and depression, and improving balance, handicap, independence, and active coping strategies (Gurr & Moffat, 2001; Johansson et al., 2001; Yardley et al., 2004b). Stress reduction is also encouraged, as the physiological arousal that results from anxiety can also aggravate symptoms (Yardley et al., 1992a; Yardley & Redfern, 2001).

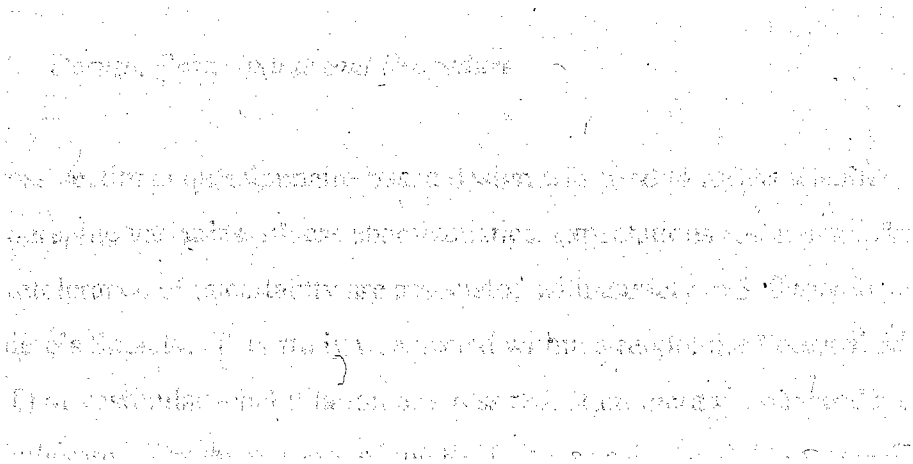
Despite the benefits of vestibular rehabilitation, it is only effective if it is adhered to. Vestibular rehabilitation can be unpleasant to carry out as it involves provoking dizziness. Yardley and colleagues (1998) carried out a primary care based randomised control trial of vestibular rehabilitation delivered by a nurse during two 30-40 minute sessions at participant's homes. Participants were asked to carry out the exercises by themselves twice a day. They report in the discussion of their study

that one in four of the participants assigned to the treatment group did not complete their treatment, and of those that did continue the treatment, the nurse noted that many of the participants did not carry out the exercises in a correct way to provoke enough dizziness. A subsequent study (Yardley et al., 2004a) also reported poor adherence rates. In this study, nurses only had one session with participants, but gave additional telephone support one and three weeks later. They reported that although 71% of participants carried out exercises most days of the week, only 55% carried out the exercises for at least 9 weeks or until they no longer had symptoms. These two studies, however, comprised participants with chronic dizziness resulting from a variety of aetiologies, and both included social support from a nurse. The randomised controlled trial that chapters 3 and 4 are nested within (Yardley & Kirby, 2006), assessed adherence levels in participants with MD to vestibular rehabilitation or stress reduction booklet-based self-management programmes. The trial showed that although adherence rates were low for both groups, significantly more participants adhered to the instructions in the stress reduction booklet than the vestibular rehabilitation booklet (50% and 37.5% respectively). At the end of the trial we also measured reported reasons for non-adherence using the Problematic Experiences of Therapy Scale. We found that non-adherers scored more highly on all subscales, reporting that the booklets aggravated or caused severe symptoms, were uncertain how to follow the instructions, had doubts about the effectiveness of the booklets, and encountered more practical obstacles. When the booklet groups were compared, the two groups had different reasons for non-adherence. For those who were allocated to the vestibular rehabilitation booklet group, symptom aggravation or severity was the main reason for non-adherence, and for the stress reduction group it was practical problems such as being too busy or not remembering. The trial did not examine any baseline predictors of adherence, therefore little is known as to what other individual, affective, cognitive or behavioural factors may be involved in adherence to vestibular rehabilitation in people with MD.

2.3 Conclusions

Chapter 1 explored how distress seems to be a major feature in MD. This current chapter has considered some of the process and outcome variables that may be

relevant to adjustment to MD. The next two chapters will report studies in which some of these variables were assessed to investigate whether they are associated with MD related distress. The expectations and beliefs about illness that were assessed were illness perceptions, fear and avoidance, and dizziness beliefs. These are the variables described in this chapter at the illness specific level and MD specific level. The variables described at the general level (self efficacy and outcome expectations) are already assessed to some extent within illness perceptions and dizziness beliefs and so therefore will not be assessed separately. Similarly, the most illness-specific personality characteristic, intolerance of uncertainty, was chosen to be assessed. As the aim of this thesis is to identify psychological factors that are modifiable, intolerance of uncertainty was the only personality characteristic to be assessed, as research has shown it can be manipulated and treated successfully. The primary adjustment outcome throughout this thesis was distress, with a particular focus on anxiety, as this has been given the most attention within the literature and is particularly prominent in vestibular disorder. However, as part of the research for this thesis was nested within a clinical trial assessing treatment effectiveness, it was also relevant to consider the outcome variables of adherence and enablement.



Chapter Three: Psychological Correlates of Anxiety in Ménière's Disease

3.1 Rationale and Aims

High levels of anxiety are often reported among those who experience vertigo (Eagger et al., 1992; Gant & Kampfe, 1997; Yardley et al., 1994b), and the psychological sequelae resulting from Ménière's disease (MD) can be more debilitating than the disease itself (Kinney et al., 1997). Despite high levels of anxiety being recognised in the literature, most studies have only investigated the presence of anxiety in relation to personality factors. Although personality factors may be a contributing factor in some cases, anxiety could also be associated with other factors, such as expectations and beliefs about illness.

Chapter 2 described how expectations and beliefs about illness and intolerance of uncertainty might be relevant to adjustment to MD. This study therefore tested the hypothesis that anxiety would be associated with expectations and beliefs about illness and intolerance of uncertainty. These factors could all be addressed through psychological interventions if found to be relevant. In addition, this study also assessed what percentage of participants had clinical or possible clinical levels of anxiety.

3.2 Method

3.2.1 Design, Participants and Procedure

A cross-sectional questionnaire-based design was used to assess whether demographic variables, illness characteristics, expectations and beliefs about illness and intolerance of uncertainty are associated with anxiety in 360 members of the Ménière's Society. This study was nested within a randomised controlled trial (RCT) of vestibular rehabilitation or stress reduction therapy delivered by bibliotherapy. For the purpose of the RCT, it was calculated that a sample size of 100 per group was required to detect a treatment effect size of 0.33 with two tailed $\alpha = 0.05$ and 90% power. Allowing for 20% dropout, 360 participants therefore needed to be recruited. Participants were recruited from the Ménière's Society, a self

help group for people with MD. To be eligible to participate, members had to have been given a diagnosis of Ménière's disease. This was so that we could exclude people who may have joined the Ménière's Society because they have a condition similar to but not the same as MD. Members also had to have experienced symptoms of dizziness or imbalance over the past 12 months. This was so that only members who would benefit from treatment would be recruited. However, as VR is only suitable for people whose symptoms have stabilised, members were excluded from participating if they had experienced any severe vertigo attacks within the last 6 weeks. Members also had to be contactable by post for the key stages of the trial. As medical conditions such as cervical or cardiovascular disorder could be aggravated by the VR treatment, eligible members willing to take part in the trial were then required to consult their GP to check there were no medical reasons why they should not take part in the trial.

These stringent inclusion criteria for the RCT did not appear to influence the representativeness of the sample as a group of members of the Ménière's Society. The study detailed in chapter 7 (understanding distress in Ménière's disease) also recruited participants who were members of the Ménière's Society, but did not include any inclusion criteria other than having been diagnosed with MD. The mean ages and age ranges, gender, illness duration and reported vertigo symptoms between the two studies appeared to be similar, suggesting that the participants who took part in the RCT could be considered to be representative as members of the Ménière's Society.

Participants taking part in the RCT were posted questionnaire measures (see Appendices A - E) for this study together with their baseline questionnaire measures for the RCT. Data for this study also forms the baseline data for chapter 4 (Predictors of adherence, enablement and anxiety on people with Ménière's disease). Although the data is used in both studies, it is analysed differently for the purposes of each study.

3.2.2 Measures

3.2.2.1 Demographic and illness characteristics.

As no scales exist that measure all the symptoms of MD together, the symptoms of MD (vertigo, hearing loss, tinnitus and fullness in the ear) were measured separately. Length of time (in months) since symptoms began, gender, and age were assessed using single items.

Vertigo was assessed using the long version of the Vertigo Symptom Scale (VSS; Yardley et al., 1992a). As there is a great deal of overlap between vertigo and somatic anxiety symptoms, the scale was designed to measure the concepts separately in two distinct subscales. The 'vertigo severity' subscale (19 items) measures the frequency and severity of vertigo, dizziness, and imbalance symptoms, and is unrelated to measures of somatic anxiety. The 'somatic anxiety' subscale (15 items) measures somatic anxiety and autonomic symptoms that are secondary to pure vertigo symptoms. Symptoms are assessed using a 5-point scale, ranging from never to very often. Both subscales had good internal consistency, both achieving a Cronbach's alpha of .90.

As it was beyond the scope of the study to measure hearing impairment objectively using audiometric tests, the symptom of hearing loss was assessed using five questions from the nine item Hearing Disability Questionnaire (Lutman et al., 1987). This is a subjective scale that measures disability/handicap resulting from hearing impairment. The five questions that were selected were chosen because they related to subjective severity of hearing impairment rather than impact on social life, isolation or embarrassment. One question was excluded because its response could be affected by vertigo as well as hearing impairment. Questions were assessed using either a 3 or 4-point scale. The internal consistency of the scale was acceptable (α = .83).

Tinnitus and fullness in the ear were assessed using the Tinnitus Severity Index and Aural Pressure Index (Stahle et al., 1981; Cass, 1999). These are single item measures that assess severity and frequency using a seven-point scale. The Tinnitus

Severity Index responses ranged from 'none' to 'severe; primary problem', and the Aural Pressure Index responses ranged from 'none' to 'almost constant and incapacitating'.

3.2.2.2 Psychological variables.

Expectations and beliefs about illness that were measured comprised illness perceptions, fear and avoidance and dizziness beliefs. Intolerance of uncertainty was the only personality factor measured.

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). The IPQ-R is based on the components of illness representations identified in Leventhal's Self-Regulatory Model. The scale is made up of nine dimensions. The first dimension is the 'identity' subscale (14 items), which is concerned with the symptoms the patient is experiencing and whether they believe each symptom is related to their illness. This subscale was not used in the current study, as symptoms were measured using different scales more specific to MD (these are detailed in section 3.2.2.1). The second and third dimensions are related to the timing of the illness. The 'timeline acute/chronic' subscale is concerned with how long the patient expects the illness to last, and the 'timeline cyclical' subscale asks patients if the illness fluctuates or is unpredictable. The fourth dimension is the 'consequences' subscale, which looks at patients' expectations of the effects of the illness and its outcomes. The fifth and sixth dimensions are related to the control of and recovery from the illness. The 'personal control' subscale measures patients' belief in personal control and their self efficacy in controlling their illness, whereas the 'treatment control' subscale measures patients' belief in the effectiveness of treatments. The seventh dimension, the 'illness coherence' subscale represents the extent to which patients understand their illness. The eighth dimension is the 'emotional representations' subscale, which measures the presence of emotional responses to the illness (depression, anger, worry, anxiety, and fear) that may have an impact on health related behaviours. The 'timeline acute/chronic', 'timeline cyclical', 'personal control', 'treatment control', 'illness coherence' and 'emotional representations' subscales are displayed together in the questionnaire, and comprise 38 items. The internal consistency of the

dimensions used in this study were acceptable (timeline acute/chronic $\alpha = .81$, timeline cyclical $\alpha = .78$, consequences $\alpha = .82$, personal control $\alpha = .84$, treatment control $\alpha = .77$, illness coherence $\alpha = .92$, emotional representations $\alpha = .86$). The last dimension is a 'causal' dimension (18 items) which explores patients' ideas about what may have caused their illness. All subscales are scored using a 5-point scale ranging from strongly disagree to strongly agree (with the exception of the 'identity' subscale which is scored using a yes/no response format).

The Dizziness Beliefs Scale (Yardley, 1994a), measures the extent to which participants believe that dizziness will result in negative consequences. Responses are assessed using a 5 point scale ranging from strongly disagree to strongly agree. Principal component analysis found that the scale could be broken down into either a three or four factor model. The first factor is 'loss of control' comprises items related to practical and social consequences of dizziness. In the four factor model this is further separated into two factors, 'physical danger' (four items) which assesses the belief that their dizziness will result in them being physically harmed, and 'social incompetence' (six items), which looks at beliefs about not being able to fulfil normal roles and the social embarrassment of becoming dizzy in public. The next factor is 'serious illness' (three items) which measures the belief that the dizziness is a sign of an underlying disease. The last factor, 'severe attack' (four items) comprises items that measure concerns that dizziness will develop into a severe attack of vertigo. The subscales used in this study were the 'physical danger', 'social incompetence' and 'severe attack' subscales, which demonstrated acceptable internal consistency (physical danger $\alpha = .76$, social incompetence $\alpha = .82$, severe attack $\alpha = .82$). The 'serious illness' subscale was not used in this study because participants know that they have Ménière's disease, and that this is the cause of their dizziness.

The Fear Avoidance Beliefs Questionnaire (FABQ; Waddell et al., 1993) was derived from theories of fear and avoidance behaviour, and measures the extent to which participants believe that their symptoms can be made worse by physical activity and work. Principal component analysis indicates the scale is made up of two factors, one measuring beliefs relating to 'work' (four items) and the second measuring beliefs relating to 'physical activity' in general (seven items). The work

subscale was not used in this study. The 'physical activity' subscale is scored using a 7-point scale ranging from completely disagree to completely agree. The FABQ was originally designed for people with low back pain, and so the 'physical activity' subscale was adapted for the purposes of this study by replacing references to the word 'pain' with the word 'vertigo', and removing references to participants' backs. The internal reliability for the adapted scale ($\alpha = .79$) was similar to the reliability reported for the original scale ($\alpha = .77$).

Intolerance of uncertainty was measured using the Intolerance of Uncertainty Scale (IUS). The IUS (Freeston et al., 1994) contains 27 statements describing how people might respond to uncertain situations. The aspects of responses that are measured comprise emotional and behavioural consequences of uncertainty and how respondents believe they reflect on their character, expectations that future events should be predictable and attempts to control future events, and all-or-nothing responses in uncertain situations. The IUS is scored using a 5-point scale ranging from 'not at all characteristic of me' to 'entirely characteristic of me'. The scale demonstrated good internal consistency, with a Cronbach's alpha of .95.

3.2.2.3 Anxiety.

Anxiety was assessed using the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS was chosen because it does not include somatic symptoms of anxiety that are analogous with secondary symptoms of dizziness. The anxiety subscale and the depression subscale both comprise seven items each and are scored using a 4-point scale of individual statements rating how often or not they experience the feelings referred to in each statement. The internal consistency of the anxiety subscale was acceptable ($\alpha = .85$).

3.2.3 Data Treatment

All questionnaire packs were checked through on return, and if a page or more of data was missing from the packs when they were returned, participants were contacted by phone or post to see if they were willing to fill in the missing page(s). Range, minimum and maximum scores were checked on all variables, and 20% of

the data entry was checked revealing an accuracy rate of 99.94%. When two answers were given for the same question, they were treated as missing. Missing data for the VSS, Hearing Disability Scale, IPQ-R (excluding causes), HADS, IUS, FABQ, and the Dizziness Beliefs Scale were replaced with the participant's personal average for that subscale if at least half of the items in that subscale had been answered (Ware et al. 1993, 2000). No substitutions were made for the IPQ-R illness causes, or single item scale data.

3.3 Results

Of the 360 participants, 247 were female (68.6%) and 113 were male (31.4%). The age range was 28-90 years. The length of time since their symptoms began ranged from 18 to 660 months. Two participants dropped out before completing all the measures. The means and standard deviations of the demographic and illness characteristics, illness perceptions and negative beliefs about dizziness and intolerance of uncertainty are given in Table 1. Following the clinical cut off points recommended for the HADS (Zigmond & Snaith, 1983), 56.2 % of participants met the criteria for possible clinical levels of anxiety (≥8 points), and 27.4 % met the criteria for clinical levels of anxiety (≥11 points).

3.3.1 IPQ-R Causal Items

Moss-Morris and colleagues (2002) specified that the causal items of the IPQ-R should not be treated as a whole scale. They recommend that factor analysis should be used to identify groups of items that can then be used as causal belief subscales. To identify whether participants' beliefs about what may have caused their illness formed meaningful clusters, the causal items were entered into a principal component analysis. Varimax rotation was used and the selection criterion was eigenvalues over 1. Principal component analysis identified five factors that accounted for 57.23% of the variance (see Table 2). Factors were best interpreted by items with loadings of 0.5 or more. The first factor corresponded to the psychological attributions factor identified by Moss-Morris and colleagues (2002), but also included the psychological item 'my own behaviour', which unexpectedly did not load onto the factor in the original paper. The second factor consisted of two

Table 1

Mean scores, standard deviations (SD), number of participants (N) in each analysis, and correlation coefficients (r) with anxiety for all variables

	Mean	SD	Correlation with anxiety	
			N	*r*
Anxiety	8.31	4.36	-	-
Demographic and Illness characteristics				
Gender	-	-	358	.12 *
Age	59.22	12.32	358	-.06
Illness duration (months)	165.66	119.01	358	-.01
VSS: Vertigo	20.95	14.14	358	.12 *
VSS: Somatic anxiety	21.48	12.52	358	.39 ***
Tinnitus	3.79	1.52	357	.08
Fullness in the ear	3.25	1.48	358	.21 ***
Hearing disability	13.51	7.63	358	.12 *
Psychological variables				
IPQR: Timeline acute/chronic	24.17	3.68	358	.09
IPQR: Timeline cyclical	14.89	3.07	358	.03
IPQR: Consequences	20.50	4.69	358	.34 ***
IPQR: Personal control	19.54	4.56	358	-.16 **
IPQR: Treatment control	15.44	3.35	358	-.20 ***
IPQR: Illness coherence	16.62	4.92	358	-.27 ***
IPQR: Emotional representations	19.72	5.03	358	.61 ***
IPQR: Psychological attributions	17.10	5.30	355	.33 ***
Intolerance of uncertainty	59.68	21.05	358	.62 ***
FABQ: Physical	14.46	6.16	358	.24 ***
Dizziness Beliefs: Physical danger	12.83	3.50	358	.38 ***
Dizziness Beliefs: Social incompetence	21.94	4.57	358	.38 ***
Dizziness Beliefs: Severe attack	14.95	3.37	357	.26 ***

* $p<0.05$, ** $p<0.01$, *** $p<0.001$

Table 2

Principal component analysis of the IPQ-R causal items

	Factor Loadings				
Causal Items	1	2	3	4	5
Stress or worry	**.774**	-.103	.007	-.084	.139
My own behaviour	**.545**	.246	.149	.419	.250
My mental attitude	**.637**	.188	.101	.453	.040
Family problems or worries	**.735**	.015	.121	.025	-.094
Overwork	**.646**	.135	.245	-.217	.103
My emotional state	**.811**	.152	.058	.059	-.018
My personality	**.556**	.316	.109	.465	.066
Alcohol	.196	**.800**	.099	.036	.126
Smoking	.121	**.798**	.023	-.110	.093
Accident or injury	-.050	**.576**	.289	.135	-.150
A germ or virus	-.008	-.174	**.711**	.181	-.083
Poor medical care in my past	.073	.262	**.551**	-.105	.166
Pollution in the environment	.188	.199	**.658**	-.106	.259
Altered Immunity	.194	.161	**.659**	.211	-.003
Chance or bad luck	.068	.089	-.026	**-.678**	-.044
Hereditary	-.030	-.009	.051	.044	**.901**
Ageing	.293	.213	.307	-.097	-.079
Diet or eating habits	.365	.218	.207	.211	.427
% of variance for rotated factors	19.92	11.79	11.30	7.24	6.99

risk factor items, 'alcohol' and 'smoking', and the accident or chance item 'accident or injury'. The third factor included the immunity items 'a germ or virus', 'pollution in the environment', 'altered immunity', and the risk factor item 'poor medical care in my past'. The fourth and fifth factors contained only single items, 'chance or bad luck', and 'hereditary' respectively. The items 'ageing' and 'diet or eating habits' did not load onto any of the factors. The scree test showed only one clear factor that could be extracted from the analysis. This first factor was also the only one that corresponded to the original factors, as items loading on factors II-V were either single items, or included an unclear mix of original factors. On this basis of the scree test and the theoretical interpretation of factors, only factor I was retained to be entered into the main analyses. This 'psychological attributions' factor had good internal reliability, with a Cronbach's alpha of 0.84.

3.3.2 Correlates of Baseline Variables and Anxiety

Pearson's correlation coefficients were used to assess the relationship between anxiety and all demographic and illness characteristics, expectations and beliefs about illness and intolerance of uncertainty. The results, along with the number of participants in each analysis, are reported in Table 1. Inter-correlations between demographic and illness characteristics, expectations and beliefs about illness and intolerance of uncertainty are reported in Tables 3 – 4. Sixteen of the 21 correlations with baseline anxiety were significant, with significant correlation coefficients ranging from 0.115 to 0.622. As so many analyses were carried out there was an inflated probability of type 1 error. Therefore the following discussion only focuses on correlation coefficients of at least a medium effect size ($r > .3$). Only five of the significant correlations with baseline anxiety had a medium effect size ($r > .3$), and two had a large effect size ($r > .5$).

Of the demographic and illness characteristics, anxiety was moderately correlated only with reporting worse symptoms of somatic anxiety. Three of the eight subscales of the IPQ-R were correlated with anxiety with at least a medium effect size. Medium effects were found for greater levels of anxiety being associated with believing that MD and its outcomes would have greater consequences and believing that MD is caused by psychological factors. A large effect was found for the association between greater levels of anxiety and having a greater emotional response to having MD, and being more intolerant of uncertainty. Two of the subscales of the dizziness beliefs scale were moderately associated with anxiety, with higher levels of anxiety being associated with the belief that becoming dizzy will result in being physically harmed, and will result in not being able to fulfil normal roles and embarrassment if dizziness occurs in public.

Table 3

Inter-correlations (Pearson's r) among demographic and illness characteristics, and correlations between demographic and illness characteristics and psychological variables

	1	2	3	4	5	6	7	8
Demographic and Illness characteristics								
1 Gender	-							
2 Age	-.08	-						
3 Illness duration	.00	.24***	-					
4 VSS: Vertigo	.10	-.15**	.09	-				
5 VSS: Somatic anxiety	.12*	-.15**	.05	.47***	-			
6 Tinnitus	-.11*	-.10	.02	.00	.06	-		
7 Fullness in the ear	.03	-.08	-.03	.21***	.45***	.23***	-	
8 Hearing disability	-.13*	.29***	.14**	.09	.20***	.17***	.14**	-
Psychological variables								
9 IPQR: Timeline acute/chronic	-.12*	-.11*	.14**	.09	.13*	.14**	.05	.13*
10 IPQR: Timeline cyclical	-.01	-.24***	-.07	.12*	.11*	-.05	.14**	-.03
11 IPQR: Consequences	-.11*	-.13*	.07	.34***	.40***	.08	.27***	.34***
12 IPQR: Personal control	-.05	-.12*	-.07	-.06	-.08	-.06	-.10	-.17**
13 IPQR: Treatment control	-.02	.05	-.05	-.14**	-.15**	-.09	-.08	-.14**
14 IPQR: Illness coherence	-.04	-.19***	.02	-.07	-.08	.01	-.04	-.13*
15 IPQR: Emotional representations	.10	-.17***	-.08	.19***	.30***	-.02	.16**	.08
16 IPQR: Psychological attributions	.05	.04	.02	-.02	.04	.01	-.03	.04
17 Intolerance of uncertainty	.05	-.05	-.05	.08	.29***	.03	.11*	.07
18 FABQ: Physical	.05	.05	.04	.18***	.27***	-.05	.13*	.13*
19 Dizziness Beliefs: Physical danger	.13*	.10	.03	.13*	.32***	-.08	.12*	.10
20 Dizziness Beliefs: Social incompetence	.13*	-.09	.02	.22***	.25***	-.02	.10	.09
21 Dizziness Beliefs: Severe attack	.14**	-.24***	.02	.17***	.21***	.07	.14**	.02

* p≤.05, ** p≤.01, *** p≤.001

Table 4

Inter-correlations (Pearson's r) among all psychological variables

	1	2	3	4	5	6	7	8	9	10	11	12
Psychological variables												
1 IPQR: Timeline acute/chronic	-											
2 IPQR: Timeline cyclical	.05	-										
3 IPQR: Consequences	.31***	.16**	-									
4 IPQR: Personal control	-.20***	.04	-.19***	-								
5 IPQR: Treatment control	-.35***	.01	-.31***	.66***	-							
6 IPQR: Illness coherence	.05	.09	-.15**	.20***	.20***	-						
7 IPQR: Emotional representations	.14**	.20***	.54***	-.19***	-.25***	-.32***	-					
8 IPQR: Psychological attributions	-.10	.06	.20***	.13*	.10	-.18***	.26***	-				
9 Intolerance of uncertainty	.13*	.13*	.30***	-.14**	-.17***	-.29***	.54***	.25***	-			
10 FABQ: Physical	.08	.07	.29***	-.24***	-.25***	-.24***	.30***	.13*	.31***	-		
11 Dizziness Beliefs: Physical danger	.07	.02	.25***	-.18***	-.13*	-.22***	.36***	.18***	.34***	.38***	-	
12 Dizziness Beliefs: Social incompetence	.15**	.22***	.42***	-.26**	-.22***	-.23***	.48***	.19***	.37***	.36***	.56***	-
13 Dizziness Beliefs: Severe attack	.15**	.25***	.27***	-.20**	-.20***	-.08	.37***	13*	.34***	.25***	.43***	.61***

* p<.05, ** p<.01, *** p<.001

3.4 Discussion

The purpose of this study was to explore whether anxiety was associated with expectations and beliefs about illness and intolerance of uncertainty, and to ascertain the percentage of participants who met the criteria for clinical or possible clinical anxiety. The theoretical implications of the findings will now be explored, followed by a discussion of the clinical implications and suggestions for future research. The limitations of the study will then be discussed.

3.4.1 Theoretical Implications

Anxiety was significantly correlated with most of the variables measured, but only seven of these variables had a medium or large effect size. The only demographic or illness characteristic that had at least a medium sized association with anxiety was reporting worse symptoms of somatic anxiety. Symptoms of vertigo, fullness in the ear, and hearing disability symptoms only demonstrated small or small to medium effect sizes in their relationship with anxiety. Age, illness duration and tinnitus were not significantly correlated with anxiety. It is surprising that tinnitus was not associated with anxiety at all, as it is often identified as a symptom that is associated with distress (Andersson, 2002; Budd & Pugh, 1996; Langenback et al., 2005; Reynolds et al., 2004; Stouffer & Tyler, 1990). This lack of association could be due to the fact that the RCT that this study was nested within involved undertaking treatment for vertigo, so therefore it is possible that people who found their tinnitus more distressing chose not to take part. It was also surprising that there was only a small effect size for the relationship between symptoms of vertigo and anxiety. Vertigo is frequently associated with anxiety in the literature (see chapter 1 for a summary). However, as this study was nested within a RCT that involved a treatment that required the deliberate initiation of dizziness, it is possible that people who found their vertigo symptoms to be anxiety provoking chose not to take part.

The finding that anxiety is related to expectations and beliefs about illness should not be surprising, as MD has been reported to negatively affect many dimensions of life (Cohen et al., 1995). It is interesting to note that two variables, emotional representations and the personality factor intolerance of uncertainty, had correlation

coefficients that were over 0.6. This is a large effect size, especially when considered in the context that somatic anxiety, which might be expected to have the strongest correlation with anxiety, only had a medium to large effect size of 0.39. The high correlation of intolerance of uncertainty with anxiety is also of interest because the illness perception subscale 'timeline cyclical', which measures the degree to which the illness is perceived as fluctuating (and is therefore unpredictable), was not significantly related to anxiety. This suggests that anxiety is not related to the perceived level of fluctuation and unpredictability, but to the extent to which a person believes they can tolerate and cope with this uncertainty.

In addition to somatic anxiety, medium effect sizes were also found for four other variables. These were belief that MD and its outcomes has greater consequences, belief that MD is caused by psychological factors, belief that becoming dizzy will result in being physically harmed, and belief that becoming dizzy will result in social difficulties (e.g. not being able to fulfil normal roles and embarrassment if they become dizzy in public). The lack of a correlation between vertigo and anxiety in the light of the high levels of correlation of anxiety with expectations and beliefs and intolerance of uncertainty suggests that the meaning and interpretation of symptoms may be more important in relation to anxiety than the presence of symptoms themselves.

Among the inter-correlations, four main patterns of relationships were shown by the medium and large effect sizes. They suggest that the IPQ-R consequences subscale and somatic anxiety may be important variables, as the IPQ-R consequences subscale was associated with eight variables, and somatic anxiety was associated with five variables. Consistent moderate inter-correlations also existed between some of the more emotional and catastrophic variables (IPQ-R emotional representations subscale, intolerance of uncertainty, the FABQ-physical subscale and the three dizziness beliefs subscales). The belief that MD and its outcomes will have greater consequences was associated with having a greater emotional response to having MD, intolerance of uncertainty, and the belief that dizziness will result in not being able to fulfil normal roles and embarrassment if dizziness occurs in public. Greater consequences were also associated with reporting worse symptoms of vertigo, somatic anxiety and hearing disability, and the belief in a chronic timeline of

symptoms. Higher levels of somatic anxiety were associated with symptoms of vertigo and fullness in the ear, as well as having a greater emotional response to having MD, the belief that MD and its outcomes will have greater consequences, and the belief that becoming dizzy will result in being physically harmed. A greater belief in treatment effectiveness was associated with a greater belief that personal actions could also effectively control their illness, and also with the belief in an acute timeline of symptoms. This last pattern could be interpreted to suggest that people who have fewer residual or provoked symptoms between attacks (and so perhaps view their illness as a series of acute attacks rather than a chronic condition), believe that this is due to treatment or personal efforts to manage the symptoms.

3.4.2 Clinical Implications and Future Research

Taken in combination, these findings have positive implications for the treatment of MD related distress. This study suggests that anxiety levels appear to be most strongly associated with the expectations and beliefs about illness that people have about MD, in terms of what the symptoms mean to them and how they respond emotionally to this, as well as how they cope with and integrate the symptoms into their lives. It is possible that these factors could be addressed through psychological interventions such as Cognitive Behavioural Therapy that can be specifically designed to help with these cognitions.

The current study also found that 56.2% of participants had possible clinical levels of anxiety, and 27.4% had clinical levels of anxiety. Such high proportions of possible and definite clinical levels of anxiety in this group of members of the Ménière's Society combined with the identification that specific types of cognitions are associated with anxiety should certainly warrant the design, implementation and assessment of psychological interventions to help people who experience MD related distress.

3.4.3 Limitations

This study was limited by its cross-sectional design. Therefore, no inference can be made as to the direction of relationship between anxiety and the other variables. It is

also important to recognise that as participants were recruited from the Ménière's Society, results cannot be generalised to all people with MD, as there may be differences between people who decide to join the Ménière's Society and those who do not.

3.4.4 Conclusions

This study has shown that anxiety is associated with demographic and illness characteristics and psychological variables. The next chapter describes a longitudinal study that examined whether the variables measured in this study predicted adjustment outcomes following treatment.

Chapter Four: Predictors of Adherence, Enablement and Anxiety in People with Ménière's Disease

4.1 Rationale and Aims

The aim of this study is to assess whether expectations and beliefs about dizziness, and intolerance of uncertainty measured at baseline, can predict adjustment outcomes following vestibular rehabilitation (VR) or stress reduction (SR) self-treatment. People who experience severe vertigo often have high levels of anxiety and self-imposed disability to avoid provoking dizziness and its consequences (Yardley & Putman, 1992). As no medical treatment exists that can cure Ménière's disease (MD), it is necessary to consider therapies that may alleviate symptoms and distress. As arousal and stress may aggravate symptoms of dizziness, SR can improve adjustment and relieve symptoms (Yardley & Redfern, 2001). VR has been found to improve anxiety and depression (Gurr & Moffat, 2001), and encourages active coping strategies, improving handicap and independence (Yardley et al., 2004b). For this reason anxiety was included as an adjustment outcome. However, as VR involves provoking dizziness in order to habituate to it, high dropout rates and poor adherence to the treatment instructions have been reported (Yardley et al., 1998). This study therefore sought to also identify factors that predicted adherence to the treatments. In addition, as MD cannot be cured, nor control of symptoms guaranteed, it was also useful to assess the effectiveness of treatment programmes from the patient's perspective by including enablement as an adjustment outcome.

Expectations and beliefs about illness have been found to have a major influence on how people adjust to their illness and treatment (Lau & Hartman, 1983; Leventhal et al., 1980; Leventhal et al., 1984; Weinman & Petrie, 1997). The aim of this study was to identify whether illness perceptions, fear and avoidance, dizziness beliefs, and intolerance of uncertainty can influence adjustment outcomes following treatment. If relevant, future research could then address these factors in order for the maximum benefit to be derived from VR and SR. It was hypothesised that in line with previous research on illness perceptions, poor adjustment outcomes would be associated with the belief that the illness has serious consequences, belief in a chronic timeline, low perceived control, poorer illness coherence and greater emotional response. Poorer

adjustment outcomes were also hypothesised to be associated with negative dizziness beliefs, greater fear and avoidance, and a greater intolerance of uncertainty. The relationship between adherence and dizziness beliefs, fear and avoidance, and intolerance of uncertainty, was hypothesised to be moderated by treatment experience because of the aversive effects of VR relative to SR. Dizziness beliefs, fear and avoidance, and intolerance of uncertainty were hypothesised to have a stronger influence on adherence in the VR self-treatment group than the SR self-treatment group. Demographic and illness characteristics were also controlled for to take account of their effects on expectations and beliefs about illness and intolerance of uncertainty.

4.2 Method

4.2.1 Design, Participants and Procedure

A longitudinal questionnaire design was used to assess the effect of baseline measures of expectations and beliefs about illness and intolerance of uncertainty (controlling for demographic and illness characteristics) on adherence, enablement and anxiety measured 3 months later. This study was nested within a randomised controlled trial (RCT) of vestibular rehabilitation or stress reduction therapy delivered by bibliotherapy (for details on how participants were recruited to the RCT, see chapter 1, section 1.4.1). The flow of participants through the RCT is shown in Figure 2. The 360 members of the Ménière's Society that were taking part in the RCT were sent, by post, questionnaire baseline measures for this study (see Appendices A - E) with their baseline questionnaire measures for the RCT. Measures of adherence, enablement and anxiety were included with the 3 month post treatment questionnaires for the RCT (see Appendix F). The baseline data for this study is also used for chapter 3 (Psychological correlates of anxiety in Ménière's disease). Although the data is used in both studies, it is analysed differently for the purposes of each study.

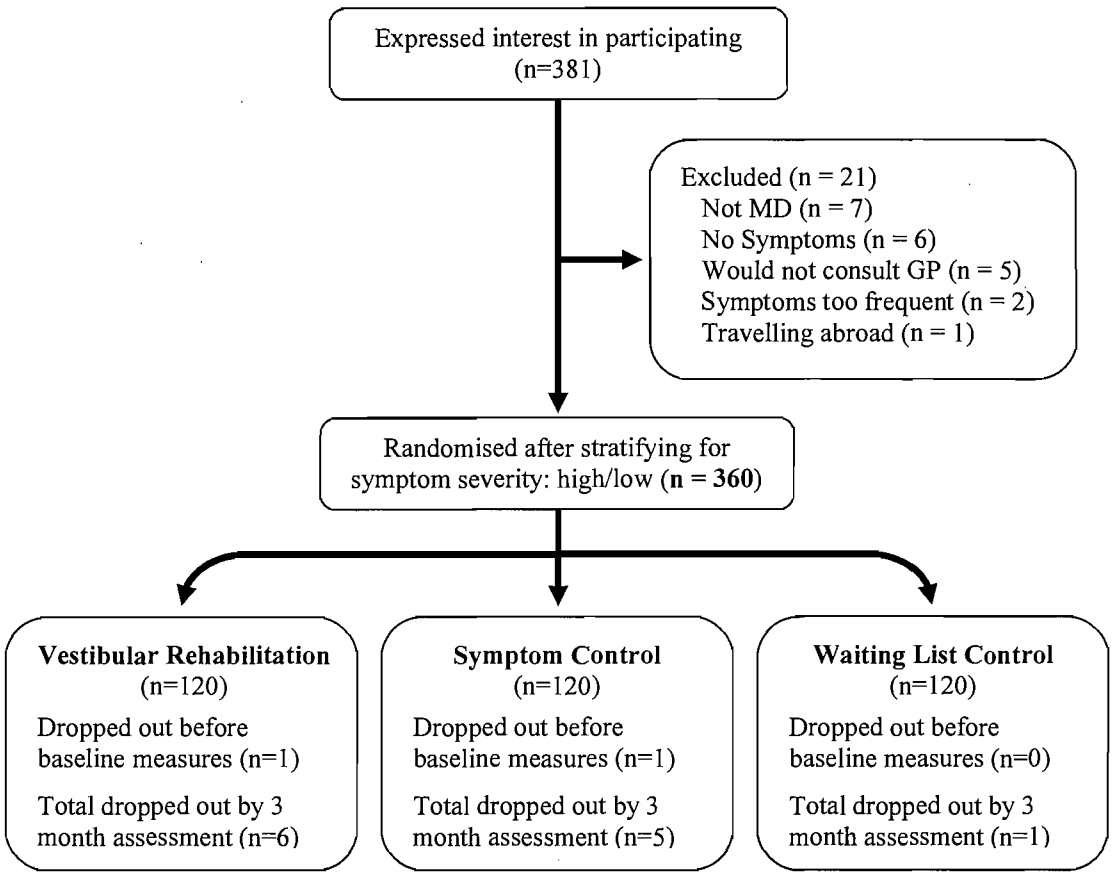


Figure 2

Flow of participants through the RCT

4.2.2 Measures

Independent variables measured at baseline comprised demographic and illness characteristics, expectations and beliefs about illness and intolerance of uncertainty. Expectations and beliefs about illness that were measured comprised illness perceptions, fear and avoidance and dizziness beliefs. Intolerance of uncertainty was the only personality factor measured. Adjustment outcomes (the dependent variables) were measured at the end of the 3 month treatment period and comprised adherence, anxiety, and enablement.

Several of the scales were used in the previous study, and so are only described briefly here. See chapter 3 for more details about measures of illness characteristics, expectations and beliefs about dizziness, intolerance of uncertainty, and anxiety.

4.2.2.1 Demographic and illness characteristics.

As no scales exist that measure all the symptoms of MD together, the symptoms of MD (vertigo, hearing loss, tinnitus and fullness in the ear) were measured separately. Length of time (in months) since symptoms began, gender, and age were assessed using single items.

Vertigo was assessed using the 'vertigo severity' and 'somatic anxiety' subscales of the long version of the Vertigo Symptom Scale (VSS; Yardley et al., 1992a).

As it was beyond the scope of the study to measure hearing impairment objectively using audiometric tests, the symptom of hearing disability was assessed using five questions from the nine item Hearing Disability Questionnaire (Lutman et al., 1987).

Tinnitus and fullness in the ear were assessed using the Tinnitus Severity Index and Aural Pressure Index (Stahle et al., 1981; Cass, 1999).

4.2.2.2 Expectations and beliefs about illness and intolerance of uncertainty.

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). The subscales used were the 'timeline acute/chronic', 'timeline cyclical', 'consequences', 'personal control', 'treatment control', 'illness coherence', 'emotional representations', and 'causal' subscales.

Dizziness beliefs were measured using the 'physical danger', 'social incompetence' and 'severe attack' subscales from the Dizziness Beliefs Scale (Yardley, 1994a).

Fear and avoidance was measured using an adapted version of the 'physical' subscale from the Fear-Avoidance Beliefs Questionnaire (FABQ; Waddell et al., 1993).

The personality trait intolerance of uncertainty was measured using the Intolerance of Uncertainty Scale (IUS; Freeston et al., 1994).

4.2.2.3 Adherence.

Adherence to treatment was assessed using five items from which a single dichotomous item was created. Adherence or non adherence was not derived from a total summed score, but from a particular set of conditional responses to the questions. Participants were asked how many out of the 12 weeks they carried out the therapy for (item 1; six possible responses: 'never started', 'one week', '1-2 weeks', '3-5 weeks', '6-8 weeks', or '9-12 weeks'), and if they stopped because they no longer had symptoms of dizziness or unsteadiness (item 2: yes / no). If they had stopped due to no longer having symptoms, participants were asked after how many weeks of therapy their symptoms ceased (item 3: five possible responses: 'one week', '1-2 weeks', '3-5 weeks', '6-8 weeks', or '9-12 weeks'). Participants were also asked how many days a week (item 4: five possible responses 'never started', 'one day', '2-3 days', '4-5 days', or 'every day'), and how many times a day they carried out the therapy (item 5: three possible responses: 'never started', 'once a day', or 'twice a day'). Participants were classified as adhering if they had completed 9-12 weeks of treatment (irrespective of how many days a week or times a day they had carried out the therapy), or had only stopped earlier because they no longer had symptoms of dizziness or unsteadiness. Participants who completed less than 9 weeks of treatment and still had symptoms were classified as not adhering.

4.2.2.4 Enablement.

Enablement was assessed using the Patient Enablement Instrument (PEI; Howie et al., 1998) which was designed to assess subjective benefit relating to specific health issues following primary care consultations. It measures patients' perceptions of their ability to cope with their illness and life in general, their confidence in maintaining their health, and the extent to which they feel able to understand their illness. The PEI comprises six items, and is scored using a 3-point scale with responses of much better/more, better/more, and same or less. The internal consistency of the scale was good ($\alpha = .93$).

4.2.2.5 Anxiety.

Anxiety was assessed using the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The scale had good internal consistency ($\alpha = .87$). Participants were classified as having low levels of anxiety if they scored 7 or less, and high levels of anxiety if they scored 8 or more (the lowest value recommended by the authors of the scale to detect borderline clinical levels).

4.2.3 Data Treatment

All questionnaire packs were checked through on return, and if a page or more of data was missing from the packs when they were returned, participants were contacted by phone or post to see if they were willing to fill in the missing page(s). Range, minimum and maximum scores were checked on all variables, and 20% of the data entry was checked revealing an accuracy rate of 99.94%. When two answers were given for the same question, they were treated as missing. Missing data for the PEI, VSS, Hearing Disability Scale, IPQ-R (excluding causes), HADS, IUS, FABQ, and the Dizziness Beliefs Scale were replaced with the participant's personal average for that subscale if at least half of the items in that subscale had been answered (Ware et al. 1993, 2000). No substitutions were made for the IPQ-R illness causes, or single item scale data.

On examining the distributions of the variables, enablement was not normally distributed. A large mode occurred at zero, with the remaining scores appearing more equally distributed. Therefore enablement was recoded as a dichotomous variable, with participants being classified as making no improvement if they responded 'the same or less' to all questions, or as some improvement if they responded 'much better/more' or 'better/more' for any of the questions. Consequently, all three dependent variables used were dichotomous variables.

4.2.4 Statistical Analysis

Preliminary analyses were carried out to identify whether any interactions were present between treatment group and adjustment outcomes, and to identify

significant variables to be entered into a logistic regression. The baseline variables were divided into two groups. The first comprised demographic and illness characteristics (which were to be controlled for in the logistic regressions) and the second comprised the psychological variables (expectations and beliefs about illness and intolerance of uncertainty). As the power of multivariate analyses of variance (MANOVA) is reduced when dependent variables are not correlated with each other, MANOVA was only used for dependent variables that were moderately correlated with each other. Dependent variables that were not inter-correlated were analysed using analyses of variance (ANOVA). Because of the way SPSS is set up for MANOVA and ANOVA, in order to carry out the analyses the independent (demographic and illness characteristics, and psychological variables) variables of the study (demographic and illness characteristics, and psychological variables) were entered into the dependent variables box in SPSS, and the dependent variables for the study (adjustment outcomes and treatment group) were entered into the independent variable fixed factor box in SPSS. This reversal of variables did not compromise the analyses as MANOVA and ANOVA are tests of difference between variables, and do not imply causal association between them. Therefore it does not matter which way round the variables are entered into the analyses.

Among the demographic and illness characteristics, only the vertigo and somatic anxiety scales were moderately correlated and so were entered together as dependent variables in a MANOVA. All other demographic and illness characteristics (age, gender, illness duration, tinnitus, fullness in the ear, and hearing disability) were entered as single dependent variables using ANOVA. Among the psychological variables, IPQ-R: consequences, IPQ-R: emotional representations, FABQ-physical, Intolerance of uncertainty, and the three dizziness beliefs subscales were all moderately correlated and so were entered as dependent variables in a MANOVA. IPQ-R: personal control and IPQ-R: treatment control were also moderately correlated and therefore grouped together. The remaining psychological variables (IPQ-R: psychological attributions, IPQ-R: timeline acute/chronic, IPQ-R: timeline cyclical, and IPQ-R: illness coherence) were entered as single dependent variables using ANOVA. Each single or correlated group of dependent variables were entered into three sets of analyses (one 2x2 and two 2x3 reversed ANOVA or MANOVA). The fixed factors for the 2x2 analyses were adherence (adherers vs. non adherers)

and treatment group (VR vs. SC; as the control group were not given a treatment, adherence could not be measured in the control group). For the 2 x 3 analyses second analyses the fixed factors were enablement (some improvement vs. no improvement), and treatment group (VR vs. SC vs. Control). For the second set of 2 x 3 analyses the fixed factors were anxiety (high vs. low) and treatment group (VR vs. SC vs. Control). SPSS automatically calculates the interaction between multiple fixed factors, so this did not need to be calculated and inserted as a third dependent variable, the output was automatically generated. To control for type 1 error within each group (demographic and illness characteristics vs. psychological variables) for each set of adjustment outcomes (adherence vs. enablement vs. anxiety), sequentially rejective Bonferroni corrections were used (Holm, 1979). This method was chosen above the standard Bonferroni method because when the number of tests being carried out is five or more, the standard test is underpowered and therefore inappropriate to use (Bender & Lange, 2001).

Where no interaction was found between adjustment outcomes and treatment groups, data for all treatment groups were pooled for further analyses. Significant baseline variables identified in the MANOVAs and ANOVAs were entered into binary logistic regressions to determine their combined influence on the adjustment outcomes. Two binary logistic regressions were carried out. The first was to predict enablement, and the second to predict anxiety. For each regression, demographic and illness characteristics found to be significant in the MANOVA and ANOVAs were entered together as covariates on the first block using the enter method, and the psychological variables found to be significant in the MANOVAs and ANOVAs were then entered together as covariates on the second block using the forward conditional method.

For the first logistic regression, enablement was included as the dependent variable, illness duration was entered as a covariate in the first block, and illness coherence was entered as a covariate in the second block. For the second logistic regression, anxiety was included as the dependent variable. Somatic anxiety, vertigo and fullness in the ear were the covariates in the first block. Covariates in the second block comprised intolerance of uncertainty, all three dizziness beliefs subscales,

FABQ-physical, and IPQ-R subscales consequences, emotional representations, illness coherence, psychological attributions, and treatment control.

4.3 Results

Of the 360 participants that were initially recruited, 247 were female (68.6%) and 113 were male (31.4%). The age range was 28-90 years (mean = 59.22, S.D. = 12.32). The length of time since their symptoms began ranged from 18 to 660 months (mean = 165.66, S.D. = 119.01). (For other baseline participant characteristics see chapter 3, section 3.3)

Two participants dropped out before baseline measures were returned, with a further 10 dropping out by the end of the 3 months (four from the SR group, one from the control group, and five from the VR group). Consequently, of the 348 participants completing the study, 114 participants were in the VR group, 115 were in the SR group, and 119 were in the control group.

4.3.1 Predictors of Adherence

The means and standard deviations of adherers and non-adherers on all baseline variables are presented in Table 5. After adjusting for type 1 error, the preliminary MANOVAs and ANOVAs showed no significant main or interaction effects for adherence and treatment group on the psychological variables or the demographic and illness characteristics. The demographic and illness characteristics and the psychological variables were not found to be directly associated with whether participants adhered or not, or with the treatment group participants had been allocated to. The demographic and illness characteristics and the psychological variables were also not found to be associated with whether participants who adhered to treatment were more or less likely to be in a particular treatment group.

Table 5

Descriptive statistics for all baseline variables as a function of adherence (means with standard deviation in brackets are displayed unless specified otherwise)

	Adherence	
	Adherers (n=105)	Non-adherers (n=122)
Demographic characteristics		
Gender: Males (n and % of group)	35 (31.1%)	38 (33.3%)
Gender: Females (n and % of group)	70 (66.7%)	84 (68.9%)
Age	58.40 (12.31)	59.00 (12.57)
Illness characteristics		
Illness duration	154.11 (117.42)	157.85 (101.32)
VSS: Vertigo	22.50 (15.49)	20.93 (12.78)
VSS: Somatic anxiety	20.82 (12.23)	22.41 (12.97)
Tinnitus	3.73 (1.44)	3.84 (1.58)
Fullness in the ear	3.20 (1.43)	3.23 (1.47)
Hearing disability	12.17 (7.04)	14.33 (7.47)
Psychological variables		
IPQR: Timeline acute/chronic	23.37 (3.74)	24.51 (3.73)
IPQR: Timeline cyclical	14.71 (3.00)	15.25 (2.80)
IPQR: Consequences	20.41 (4.48)	20.83 (4.59)
IPQR: Personal control	19.94 (4.28)	19.34 (4.52)
IPQR: Treatment control	15.83 (3.03)	15.31 (3.23)
IPQR: Illness coherence	16.82 (5.49)	16.36 (4.86)
IPQR: Emotional representations	19.21 (4.94)	20.07 (4.56)
IPQR: Psychological attributions	16.86 (5.82)	17.33 (4.92)
Intolerance of uncertainty	57.10 (21.01)	62.77 (21.52)
FABQ: Physical	13.91 (6.51)	15.27 (5.87)
Dizziness Beliefs: Physical danger	12.71 (3.38)	12.95 (3.65)
Dizziness Beliefs: Social incompetence	21.87 (4.64)	22.39 (4.37)
Dizziness Beliefs: Severe attack	14.86 (3.40)	15.26 (3.19)

4.3.2 Predictors of Enablement

The means and standard deviations of all baseline variables for those who felt some vs. no improvement in enablement are presented in Table 6. The preliminary analyses identified only one psychological variable that was associated with

Table 6

Descriptive statistics for all baseline variables as a function of enablement (means with standard deviation in brackets are displayed unless specified otherwise)

	Enablement	
	Some improvement (n=173)	No Improvement (n=175)
Demographic characteristics		
Gender: Males (n and % of group)	48 (27.7%)	61 (34.9%)
Gender: Females (n and % of group)	125 (72.3%)	114 (65.1%)
Age	59.12 (12.64)	58.70 (11.65)
Illness characteristics		
Illness duration	144.94 (107.22)	185.51 (121.44)
VSS: Vertigo	21.9 (14.29)	20.26 (14.16)
VSS: Somatic anxiety	20.87 (11.82)	21.97 (12.95)
Tinnitus	3.75 (1.46)	3.84 (1.53)
Fullness in the ear	3.26 (1.46)	3.26 (1.46)
Hearing disability	12.77 (7.52)	14.06 (7.65)
Psychological variables		
IPQR: Timeline acute/chronic	23.63 (3.50)	24.68 (3.85)
IPQR: Timeline cyclical	15.04 (3.00)	14.72 (3.15)
IPQR: Consequences	20.29 (4.49)	20.61 (4.90)
IPQR: Personal control	20.04 (4.14)	19.11 (4.92)
IPQR: Treatment control	15.94 (2.98)	14.99 (3.53)
IPQR: Illness coherence	15.98 (5.01)	17.44 (4.65)
IPQR: Emotional representations	20.05 (4.32)	19.21 (5.65)
IPQR: Psychological attributions	17.33 (5.20)	16.80 (5.46)
Intolerance of uncertainty	61.57 (21.42)	57.99 (21.00)
FABQ: Physical	14.98 (6.25)	13.85 (6.07)
Dizziness Beliefs: Physical danger	13.03 (3.47)	12.57 (3.55)
Dizziness Beliefs: Social incompetence	22.27 (4.4)	21.59 (4.73)
Dizziness Beliefs: Severe attack	15.13 (3.28)	14.80 (3.47)

significant differences in enablement. Participants were more likely to report some improvement in enablement if they felt they had a poorer understanding of their illness at baseline than those who reported no improvement in enablement (IPQ-R illness coherence: $\underline{F}$ (1,342) = 7.39, $\underline{p}$ = .007, η_p^2 = .021).

Illness duration was the only demographic and illness characteristics found to be significantly related to enablement. Those who have had MD for less time were more likely to report improvement in enablement (illness duration: $\underline{F}$ (1, 341) = 8.34, $\underline{p}$ = .004, η_p^2 = .024).

An interaction effect was also found. Tinnitus was found to influence enablement in different ways for those in the VR treatment group compared to those in the SR treatment group ($\underline{F}$ (2,341) = 5.49, $\underline{p}$ = .004, η_p^2 = .031), however, none of the follow up comparisons were significant.

The logistic regression results are displayed in Table 7, and show that both illness duration and illness coherence were independent predictors of enablement. Improvement in enablement was predicted by having had MD for less time (Wald $\chi 2$ (1, N = 348) = 10.37, p = .001), and having a poorer understanding of illness at baseline (Wald $\chi 2$ (1, N = 348) = 7.00, p = .008). The regression model for enablement was significant (model $\chi 2$ = 18.40, p <.001; Nagelkerke R square = .069).

Table 7

Logistic regression results for predictors of enablement (N=348)

Predictors	B	SE	Wald	Odds Ratio
Illness duration	-.003	.001	10.37 ***	.997
IPQR: illness coherence	-.061	.023	7.00 **	.941

** = p<.01, *** = p<.001

4.3.3 Predictors of Anxiety

The means and standard deviations of those with low vs. high levels of anxiety are presented in Table 8. The preliminary MANOVAs and ANOVAs identified that 10 of the 13 psychological variables were significantly associated with differences in anxiety levels. The two MANOVAs including psychological variables (the first with seven dependent variables, and the second with two dependent variables) were both significant. Follow up ANOVAs found that all seven variables in the first MANOVA (Wilks' Λ = .79, F [7, 336] = 12.59, p < .001, $\eta p2$ = .208) were

Table 8

Descriptive statistics for all baseline variables as a function of anxiety (means with standard deviation in brackets are displayed unless specified otherwise)

	Anxiety	
	Low (n=176)	High (n=172)
Demographic characteristics		
Gender: Males (n and % of group)	65 (36.9%)	44 (25.6%)
Gender: Females (n and % of group)	111 (63.1%)	128 (74.4%)
Age	59.65 (11.60)	58.14 (12.66)
Illness characteristics		
Illness duration	157.82 (107.60)	173.19 (124.34)
VSS: Vertigo	19.48 (14.94)	22.71 (13.29)
VSS: Somatic anxiety	17.28 (9.70)	25.69 (13.41)
Tinnitus	3.79 (1.47)	3.80 (1.52)
Fullness in the ear	3.02 (1.35)	3.50 (1.52)
Hearing disability	12.63 (6.98)	14.24 (8.13)
Psychological variables		
IPQR: Timeline acute/chronic	23.90 (3.72)	24.42 (3.69)
IPQR: Timeline cyclical	14.75 (3.00)	15.01 (3.15)
IPQR: Consequences	19.50 (4.50)	21.43 (4.70)
IPQR: Personal control	19.94 (4.42)	19.19 (4.70)
IPQR: Treatment control	15.95 (2.95)	14.96 (3.56)
IPQR: Illness coherence	17.85 (4.75)	15.55 (4.75)
IPQR: Emotional representations	17.83 (4.59)	21.48 (4.84)
IPQR: Psychological attributions	16.21 (4.97)	17.94 (5.50)
Intolerance of uncertainty	51.25 (15.68)	68.49 (22.67)
FABQ: Physical	13.46 (5.72)	15.38 (6.49)
Dizziness Beliefs: Physical danger	11.97 (3.24)	13.66 (3.58)
Dizziness Beliefs: Social incompetence	20.61 (4.57)	23.28 (4.17)
Dizziness Beliefs: Severe attack	14.15 (3.3)	15.79 (3.27)

significantly associated with anxiety at follow up. Participants were more likely to be anxious if they believed that dizziness would result in them being physically harmed, would result in them being socially incompetent as a result of embarrassment or inability to fulfil roles, and that dizziness would develop into a severe attack of vertigo (dizziness beliefs - physical danger: $F [1, 342] = 21.27$, $p <$

.001, ηp^2 = .059; dizziness beliefs - social incompetence: F [1, 342] = 32.99, p < .001, ηp^2 = .088; dizziness beliefs - severe attack: F [1, 342] = 21.54, p < .001, ηp^2 = .059). Anxiety was also higher among participants who at baseline had a greater intolerance of uncertainty (F [1, 342] = 69.89, p < .001, ηp^2 = .170), and believed that physical activity could make their symptoms worse (FABQ physical: F [1, 342] = 8.76, p = .003, ηp^2 = .025). Anxiety was higher among participants who at baseline had a greater emotional response to their illness, and believed that their illness and its effects had greater consequences (IPQ-R emotional representations: F [1, 342] = 51.76, p < .001, ηp^2 = .131; IPQ-R consequences: F [1, 342] = 16.70, p < .001, ηp^2 = .047). Follow up ANOVAs were also carried out for the second MANOVA (Wilks' Λ = .98, F [2, 341] = 4.11, p = .017, ηp^2 =.024) comprising the IPQ-R subscales personal control and treatment control as dependent variables. Lower levels of anxiety were found only among those who at baseline had a greater belief that treatment would be effective in controlling their illness (IPQ-R treatment control: F [1, 342] = 8.13, p = .005, ηp^2 = .023). The individual ANOVAs found that anxiety was higher among participants who at baseline believed that their illness was caused by psychological attributes (IPQ-R psychological attributions: F [1, 339] = 8.98, p = .003, ηp^2 =.026) and felt they had a better understanding of their illness (IPQ-R illness coherence: F [1, 342] = 21.29, p < .001, ηp^2 = .059). Beliefs about whether MD was acute, chronic or cyclical and beliefs about personal ability to control MD did not significantly differ between those with high and low levels of anxiety.

Three of the eight demographic and illness characteristics were identified as being related to anxiety at three months post-treatment. A MANOVA comprising vertigo and somatic anxiety as dependent variables was significant (Wilks' Λ = .87, F [2, 341] = 24.01, p < .001, ηp^2 = .123). Follow up ANOVAs identified greater reported levels of both vertigo and somatic anxiety as being associated with anxiety (VSS vertigo: F [1, 342] = 5.06, p = .025, ηp^2 = .015; VSS somatic anxiety: F [1, 342] = 47.24, p < .001, ηp^2 = .120) Individual ANOVAs found that anxiety was also higher among those who reported worse symptoms of fullness in the ear (F [1, 342] = 9.44, p = .002, ηp^2 = .027).

Demographic and illness characteristics and psychological variables were not significantly associated with differences in treatment group, and none of the variables were associated with anxiety in different ways in the three treatment groups.

The logistic regression results are presented in Table 9 and indicate that only 4 of the 13 predictor variables were independent predictors of anxiety. Higher levels of anxiety were predicted by greater baseline scores in somatic anxiety, intolerance of uncertainty and having a greater emotional response to illness, and having a poorer understanding of illness at baseline (VSS somatic anxiety: Wald χ^2 (1, N = 345) = 15.67, $p < .001$; intolerance of uncertainty: Wald χ^2 (1, N = 345) = 15.45, $p < .001$; IPQ-R emotional representations: Wald χ^2 (1, N = 345) = 4.53, $p = .033$; IPQ-R illness coherence: Wald χ^2 (1, N = 345) = 5.01, $p = .025$). The regression model for anxiety was significant (model $\chi^2 = 99.828$, $p < .001$; Nagelkerke R square = .335).

Table 9

Logistic regression results for predictors of anxiety (N=345)

Predictors	B	SE	Wald	Odds Ratio
VSS: somatic anxiety	.056	.014	15.67 ***	1.058
IPQR: illness coherence	-.062	.028	5.01 *	0.940
Intolerance of uncertainty	.032	.008	15.45 ***	1.032
IPQR: emotional representations	.066	.031	4.53 *	1.069

* = p<.05, *** = p<.001

4.3.4 Post Hoc Analysis

Independent predictors of enablement comprised having had MD for less time and a poorer understanding of their illness before treatment began. Education was a feature of both of the treatment interventions, so it is not surprising that those who felt they had a poorer understanding of their illness before treatment felt enabled by being given more information about their illness, and that those who felt they already understood all there was to understand about the illness were not enabled by more information. However, participants who have had MD for less time may not have had enough time or opportunity to build up a good understanding of their illness,

whereas participants who have had the disease for longer may have already learnt to cope as well as they possibly can, allowing less room for improvement. From a theoretical viewpoint, an interaction could be hypothesised between these variables, that illness duration may be moderating the relationship between illness coherence and enablement.

To test this prediction, an interaction term was calculated between length of time since symptoms began and illness coherence. This was entered into a binary logistic regression with length of time since symptoms began and illness coherence being entered on the first block, and the interaction term on the second block. Although the overall model was significant (model $\chi^2 = 19.06$, $p < .001$; Nagelkerke R square = .071), the interaction term was not significant (Wald χ^2 (1, N = 348) = 0.66, p = .418).

4.4 Discussion

The purpose of this study was to identify variables that might affect adjustment outcomes in this group of members of the Ménière's Society who were taking part in a RCT of treatment effectiveness. The study grouped the baseline independent variables into two blocks, demographic and illness characteristics, and the psychological variables of expectations and beliefs about illness and intolerance of uncertainty, to examine their effects on the adjustment outcomes of adherence, enablement, and anxiety following treatment. For the adjustment outcomes of enablement and anxiety, the data for each treatment group could be pooled because no differences were found in the baseline variables between the treatment groups or between the effects of the treatment groups on enablement or anxiety. The theoretical implications of the findings for each of the adjustment outcomes will now be discussed separately in turn. The clinical implications will then be discussed, followed by the limitations of the study and recommendations for future research.

4.4.1 Theoretical Implications

4.4.1.1 Adherence.

None of the psychological variables or demographic or illness characteristics were found to influence adherence. It is surprising that dizziness beliefs and fear and avoidance in particular did not predict adherence. Dizziness beliefs and fear and avoidance were expected to be stronger in those who did not adhere in the VR group, because VR involves invoking dizziness. As fear of vertigo is well documented (Nobbs, 1987; Yardley & Beech, 1998; Yardley & Putman, 1992; Yardley et al., 1992b) it is possible that those who were more fearful chose not to participate in the trial.

One possible explanation for the lack of significant findings could be that the measure of adherence used was not sensitive enough to detect an effect, resulting in a type 2 error. However, it was unfeasible to assess adherence using observational methods, as participants in the RCT were located around the country and were required to carry out the exercises once (ideally twice) a day for up to twelve weeks. As part of the purpose of the RCT was to assess whether participants could carry out the self-treatment with no additional support, the presence of an observer (even via webcam) would have been likely to be perceived as a form of social support, therefore the study would not have been assessing unsupported self management. The self management booklets did include a page at the back where participants could log their progress week by week if they wanted to, but these were not required to be returned for the purposes of this study or the RCT in order to maintain only minimal levels of support.

It is possible that a multi item scale would have been more effective than the derived single item assessing adherence. However, the exact same single item measure of adherence to VR self treatment has been used in two published studies (Yardley & Kirby, 2006; Yardley & Donovan-Hall, 2007). We found in the RCT that this study was nested within (Yardley & Kirby, 2006) that adherence was significantly different between the two treatment groups. More participants adhered to treatment in the SC group (50%) than the VR group (37%). We also found greater reduction in

symptoms, anxiety and depression at 6 month follow up for those who adhered to the VR treatment, and a greater reduction in symptoms at 6 month follow up for those who adhered to the SR treatment. Yardley and Donovan-Hall (2007) also used the same measure of adherence to VR treatment in a study specifically looking at predicting adherence. Like the RCT, they found that those who adhered to treatment had better outcomes (lower levels of symptoms and handicap at 3 month follow up). They also found that adherence could be predicted by intention to adhere, and was also related to change in symptoms during the treatment. Early improvement in symptoms was predictive of continued adherence. Given these findings using the same adherence measure, it is less likely that the null findings in this study are due to the adherence measure used.

4.4.1.2 Enablement.

Only one illness characteristic and one psychological variable were related to enablement. Improvement in enablement was associated with and could be independently predicted by self reported shorter illness duration and poorer understanding of their illness at baseline. As enablement did not differ by treatment group (including the control group who received no treatment), participants who reported feeling more enabled at the end of the study may have been more optimistic. It was interesting that a poorer understanding of MD at baseline predicted enablement regardless of which treatment group participants were in. Although education was a component of the VR and SR treatment groups, the control group did not receive any intervention and therefore no additional information about MD. Therefore this finding could have been influenced by a response shift, as enablement was measured by asking participants how enabled they felt at the end of the study compared retrospectively with how they felt at the beginning of the study. Belief in the effectiveness of personal actions and treatment in controlling symptoms can be compared to Bandura's (2002) concepts of self-efficacy and outcome expectations (described in chapter 2), indicating that they may be relevant in adjustment to MD, and could be explored in future work.

It is interesting that the post hoc analyses investigating how illness duration might affect enablement were not significant. This indicates that those who had had the

disease for longer did not feel they had a greater understanding of their illness than those who had had the disease for a shorter duration. Although illness duration and illness coherence were both independent predictors of enablement, it appears that they were not interlinked in any way in how they affected enablement.

4.4.1.3 Anxiety.

Anxiety was associated with the highest number of variables. Demographic and illness characteristics associated with higher levels of anxiety were having worse symptoms of vertigo, somatic anxiety, and fullness in the ear. Psychological variables associated with higher levels of anxiety were having a greater emotional response to the illness, believing that the illness has negative consequences, believing that the illness was caused by psychological attributes, not believing that treatment would be effective in controlling the illness, and having poorer understanding of the illness. People with higher levels of anxiety also had a greater intolerance of uncertainty, believed that dizziness would result in physical danger, social incompetence, and a severe attack, and believed that their symptoms could be made worse by physical activity. Of all these variables, having a high level of anxiety was independently predicted by greater baseline scores in somatic anxiety, intolerance of uncertainty, emotional response to illness, and having a poorer understanding of their illness.

It is not surprising that higher levels of anxiety would be related to higher levels of somatic anxiety or symptoms of MD. It is, however, notable that illness duration did not influence anxiety, which suggests that people at all stages of the disease may need help in addressing anxiety; the causes of anxiety are not something that members of the Ménière's Society get used to over time. A large number of psychological variables were found to contribute to anxiety. This suggests that those with high levels of anxiety do not seem to be particularly well adjusted to having MD, as they are more intolerant of the uncertainty that is characteristic of MD, and perceive MD to have negative consequences to which they respond in an emotional and fearful way. This is reflected in the finding that people with high levels of anxiety also felt they had a poorer understanding of the illness; it is plausible that people would need to feel that they had reached some level of understanding of their

illness before they could adjust to it. These findings with regard to illness perceptions are similar to results found in people with chronic pain (Hobro et al., 2004) and multiple sclerosis (Jopson & Moss-Morris, 2003). The finding that intolerance of uncertainty is a strong predictor of anxiety supports previous research that identifies intolerance of uncertainty as a key construct of worry (Buhr & Dugas, 2002). The finding that negative beliefs about dizziness were associated with poor adjustment outcomes is consistent with other studies on beliefs about dizziness. Yardley (1994a) found the belief that dizziness would result in social incompetence to be the belief most closely related to handicap in a sample of people with vestibular disorder, and Yardley and Beech (1998) reported that attempting to conceal dizziness was a commonly used social coping strategy in people with dizziness.

4.4.2 Clinical Implications

Whitney and Metzinger Rossi (2000) recommended that people with MD need to be educated about the disorder and falls prevention. The findings of the current study suggest that more needs to be done in addition to this, and makes a start in indicating the issues where psychological treatment may need to be specifically focused. Enablement appears to be more related to practical factors which should be helped by education, particularly in the earlier stages of the illness. It is through addressing the variables related to anxiety that psychological treatments may be the most helpful. Illness coherence is likely to be improved through education, and relaxation techniques could be incorporated to help reduce somatic anxiety. In order to reduce intolerance of uncertainty, support should be focused on helping the person with MD to resolve their inability to fulfil normal roles, by helping them adjust to the fact that they will not be able at times to do certain things. If anxiety is due more to the importance of the role (e.g. if children need to be collected from school) they could be encouraged to make contingency plans for other people to follow if an attack was to occur. Emotions, bodily symptoms, beliefs and reactions seem to have become linked in a strong and unhelpful way. Those who report worse symptoms are more anxious, and the belief that MD is caused by psychological factors also increases anxiety. When people do experience dizziness, they believe it will result in negative consequences, physical danger, social incompetence and a severe attack, which all increase anxiety. Understandably, based on these beliefs they then respond to

dizziness in an emotional and fearful way. Cognitive and behavioural treatment could be used to help people with MD to work through these beliefs and reactions and formulate strategies to cope with the perceived consequences of their illness. This should be with the aim of improving how people cope with the disease, and reducing the amount of distress they experience.

4.4.3 Limitations

It is important to note that the predictors and adjustment outcomes related to treatment found in this study should not be generalised to all people with MD, as the study was limited to participants from the Ménière's Society. Members of the Ménière's society may not be representative of the general medical population of people with MD. It is possible that members of the self help group may be significantly different from those who do not feel the need to join, for example members may have wanted to join as a result of higher levels of anxiety than non members. Therefore, the findings of this study should also be replicated using a non-self help group population. The study was also limited by only using self-report measures. This may have particularly influenced the analysis of adherence, as the single item measure used could only indicate self report of frequency, and not whether participants were actually carrying out the VR or SC treatments correctly. In an RCT assessing the effectiveness of VR treatment (delivered via a therapist), Yardley and colleagues (1998) note that the therapist delivering the treatment observed that although participants were carrying out the VR exercises, they were not performing them at the correct intensity to maximise benefit. Unfortunately intensity could not be measured via self report, although the VR booklet instructed that the exercises in the VR treatment should be carried out at an intensity that provoked dizziness, and if it did not, then participants should progress to a more complex exercise.

4.4.4 Future Research

Although this study was longitudinal, causal relationships cannot be implied between the predictor variables and the adjustment outcomes. Future research should attempt to incorporate psychological treatments to test if they are effective in reducing

anxiety in people with MD, and if so, monitor how long effects last for. Some of the psychological variables found to predict anxiety in this study were addressed in the VR and SR treatments used in the RCT that this study was nested within (Yardley & Kirby, 2006). We found that in people who adhered to the treatments, although anxiety was not significantly reduced by the VR booklet at the end of the three month treatment period, it was significantly reduced at the six month follow up. However, anxiety was not significantly reduced by the SR booklet. McCracken and Eccleston (2003) suggest that treatment interventions that focus on acceptance rather than coping with chronic illness may be more beneficial in improving adjustment. Future intervention work in MD could explore this further, as it may be particularly helpful in improving intolerance of uncertainty, which was the largest predictor of anxiety in this study.

The RCT (Yardley & Kirby, 2006) also found that positive outcomes were strongly related to adherence. However, only approximately half of participants adhered to treatment, with the main reasons for non adherence being given as symptom aggravation in the VR group, and practical obstacles in the SR group. The current study did not find any variables that predicted adherence. This suggests that the issues surrounding adherence to psychological and physical treatment in people with MD are either more complex than anticipated, or solely related to symptoms and practical issues. As part of the purpose of the RCT was to assess whether participants could carry out the self-treatment with no additional support, it could be possible that this lack of support contributed to the low levels of adherence. Carrying out VR is complex for people with MD because when symptoms occur, they have to discern on their own whether they are provoked or naturally occurring. Given the poor adherence rates reported in the RCT, it is essential that future research continues to attempt to identify factors that may influence adherence so that they can be addressed in future treatment.

4.4.5 Conclusions

This study has shown that expectations and beliefs about illness and intolerance of uncertainty can affect adjustment outcomes in this group of members of the Ménière's Society. The next chapter reviews psychological mechanisms that explain

the processes by which distress can develop, and considers how each mechanism could be applied to MD to explain how distress might develop in relation to MD.

Chapter Five: Mechanisms of Distress Associated with Chronic Illness

High levels of psychological distress have been widely noted among people with Ménière's disease (MD), and a large body of research has been carried out investigating the psychological factors associated with MD. The theoretical frameworks within which psychological factors of MD have been considered have been quite limited; much research has been carried out measuring psychological symptoms, but few studies have actually considered mechanisms or models that might explain the psychological symptoms.

This chapter reviews some of the mechanisms of distress that are associated with chronic illness. The chapter begins by describing how the four mechanisms (worry, post-traumatic stress disorder, anxiety sensitivity, and health anxiety) that are discussed in this chapter were selected. The previous research using each of these mechanisms is then described in relation to chronic illnesses and their findings discussed. The chapter also considers how each mechanism can be applied to MD as a mechanism for distress.

5.1 Introduction

Dizziness is associated with several psychological disorders. These are grouped under the DSM-IV-TR (American Psychiatric Association, 2000) headings of anxiety disorders (acute stress disorder, agoraphobia and/or panic disorder, anxiety disorder due to a general medical condition, generalized anxiety disorder, and posttraumatic stress disorder), somatoform disorders (conversion disorder, hypochondriasis, and somatization disorder), dissociative disorders (depersonalisation disorder), mood disorder (depression) personality disorders (obsessive-compulsive disorder) or adjustment disorder (Jacob et al., 2002; Sloane et al., 1994; Yardley, 2000). It is important to recognise that these disorders are discussed in relation to dizziness in general, so obviously not all of these disorders would necessarily apply to MD, but they do serve as a good starting point for consideration.

In considering which of these disorders to investigate for this review, the diagnostic criteria in DSM-IV-TR were consulted, as it lists specific criteria for each disorder, and suggests conditions where symptoms may be better explained by a different disorder. Adjustment disorder, acute stress disorder, and posttraumatic stress disorder (PTSD) are quite similar, in that if a stressor is not deemed to be traumatic then adjustment disorder is diagnosed. If the stressor is deemed to be traumatic then acute stress disorder is diagnosed if symptoms last for less that 1 month and posttraumatic stress disorder if the symptoms last longer (Mylle & Maes, 2004; Ozer et al., 2003). In the case of MD, attacks have been described as traumatic (Erlandsson et al., 1996), with psychological symptoms lasting a long time, so therefore PTSD would be the most appropriate of these to investigate in relation to MD. As MD is a specific and diagnosed illness, then this rules out the applicability of generalised anxiety disorder (which should not be diagnosed if the focus of the anxiety and worry is confined to complaints related to medical illness), obsessive-compulsive disorder (which should not be diagnosed if excessive worries are about real-life problems) and somatoform disorders (which are only diagnosed if medical illness has been ruled out). Included in the disorders that might be better explained by other disorders are agoraphobia and/or panic disorder (which should not be diagnosed if better explained by PTSD), depersonalisation disorder (which should not be diagnosed if better explained by acute stress disorder), anxiety disorder due to a general medical condition (adjustment disorder in which the stressor is a serious general medical condition), and depression (adjustment disorder with depressed mood in response to the stress of having a general medical condition).

Although many of the disorders do not appear to be appropriate as they are better explained by other disorders, they do contain psychological symptoms that relate to models and mechanisms that could be applied to MD that are not listed in DSM-IV-TR. The first of these is worry, which is a key symptom of generalised anxiety disorder, but is not ruled out in the context of medical illness. The second mechanism is health anxiety, which is similar to the somatoform disorders, but again is not ruled out by the presence of medical illness. The third mechanism is anxiety sensitivity, which can include symptoms of panic attacks and agoraphobia, and is also one of the few models to have already been used specifically with people with MD (Hagnebo et al., 1999b).

Therefore, the theoretical frameworks that have been selected for consideration in this review are worry, PTSD, health anxiety, and anxiety sensitivity. These theories have all already been used in research on other chronic illnesses, and as the mental health of people with MD has been found to be similar to patients with other types of chronic illness (Yardley et al., 2003) these theories are appropriate to be considered as mechanisms for distress in MD. Each mechanism will be discussed in turn below, firstly outlining the research in relation to other chronic illnesses, and then secondly considering the relevance to MD.

5.2 Theoretical Frameworks

5.2.1 Worry

Worry is a topic that has historically received little attention beyond its contribution to anxiety disorders, and research on the mechanisms and functions of worry is still a new and developing area. Surprisingly, it is only over the past few years that researchers have begun to investigate the concept of worrying in relation to chronic medical conditions, such as psoriasis (Fortune et al., 2000) and chronic pain (Aldrich et al., 2000; Eccleston et al., 2001). In the acute phase of any illness, worrying is considered to be normal and serves the necessary function of prompting problem solving behaviour. However, as an illness becomes chronic, the combination of heightened vigilance to threat and continued failed attempts to solve an unsolvable problem encourage the development of chronic worrying (Aldrich et al., 2000).

Worrying in chronic illness is not related to clinical anxiety or a tendency to worry in general (De Vlieger et al., 2006; Eccleston et al., 2001). However, the belief that worrying has positive benefits has been found to be directly correlated with high levels of trait anxiety, negative automatic thoughts and emotion focused coping (Davey et al., 1996b) and encourages the continuation of worrying. Research has shown that worry is not necessarily a trait characteristic, but the product of a number of factors and their interactions, which can be induced and manipulated. Factors traditionally found in worriers have been experimentally manipulated in both worriers and non worriers in a series of studies, and have been shown not to be a

result of worrying, but conditions that produce worrying (Startup & Davey, 2001; Startup & Davey, 2003; Davey et al., 1996a; Davey et al., 1996b). These factors include stop rules, negative mood, high sense of responsibility, low problem solving confidence, and increased risk perception.

Stop rules refer to the approach that people use when deciding when to end a task (Martin & Davies, 1998). People either use an 'as many as can' stop rule (where people persevere with a task until they have thought of everything), or a 'feel like continuing' stop rule (where people can stop the task when they have had enough and feel like stopping). Startup and Davey (2001) propose that worriers bring an implicit as many as can stop rule to tasks. They found that when they instructed worriers to use an as many as can stop rule, they spent more time and gave more reasons on an item generation task than non-worriers. However, when worriers were instructed to stop when they felt like it, they gave less reasons and spent less time on the task than non-worriers.

Worriers have higher levels of negative mood than non worriers, and negative mood has been found to cause people to produce more steps in a catastrophising task (Startup & Davey, 2001). Negative mood has also been found to interact with other factors to influence worry. Martin and Davies (1998) propose a mood-as-input model, in which negative or positive mood have different effects depending on the contexts they are experienced in. Martin and colleagues (1993) found that although more responses were produced in an item generation task when participants were given an 'as many as can' stop rule if they were in a negative mood (as the negative mood influences them to believe they have not done enough), participants also produced more responses when they were given a 'stop when feel like it' stop rule if they were in a positive mood (as their positive mood leads them to enjoy the task more and so continue). Mood has also been found to interact with level of responsibility. Startup and Davey (2003) found that worriers approached a catastrophising task with an implicit higher level of responsibility than non-worriers, but when mood was experimentally manipulated to be negative and responsibility to be high, all participants produced more steps in a catastrophising task.

Worriers do not have poor problem solving ability, but have poor problem solving confidence and poor perceived control (Davey, 1994). Davey and colleagues (1996a) found that when they experimentally manipulated problem solving confidence to be low or high, all participants in the low condition reported higher levels of anxiety and produced more steps in a catastrophising task than the high condition.

MacLeod et al. (1991) found that although worriers had higher levels of risk perception, the probability judgements of worriers could be reduced to the same levels as controls by getting them to generate reasons why a negative event would not happen. They proposed that risk perception is increased by (1) a greater accessibility of reasons supporting the occurrence of an event, in combination with a decreased accessibility of reasons why a negative event would not occur, and (2) by whether a person can recall the occurrence of an event, and mental rehearsals of scenarios in which negative events occur (and an inhibition of scenarios with positive outcomes; MacLeod et al., 1991).

5.2.1.1 Worry in Ménière's disease.

Many features of MD are potentially conducive to chronic worrying. The aversive nature of MD attacks (both physical and emotional) naturally results in negative mood. Given the limited medical understanding of the disease and the absence of a cure, little can be done to help sufferers and they are expected to cope and take on the responsibility of self-management (Yardley & Beech, 1998; Yardley, 1994c), which involves an element of trial and error regarding the success of management strategies (Gant & Kampfe, 1997). This may promote belief in the benefit of worrying, and encourage people with MD to have a high sense of personal responsibility, and follow an 'as many as can' stop rule. MD also promotes an increased risk perception, as many sufferers can recall the occurrence of attacks in different situations (which would be expected to be rehearsed in order to try to avoid these possible triggers), and the unpredictability of attacks does not lend itself well to generating reasons why the event would not happen again. Combined with the incurability of the disease, these factors may lower problem solving confidence.

5.2.2 PTSD

PTSD is defined in DSM-IV-TR (American Psychiatric Association, 2000) as:

> The development of characteristic symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity (criterion A1). The person's response to the event must involve intense fear, helplessness, or horror (criterion A2). The characteristic symptoms resulting from the exposure to the extreme trauma include persistent re-experiencing of the traumatic event (criterion B) through recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions (criterion B1), recurrent distressing dreams of the event. (criterion B2), acting or feeling as if the traumatic event were recurring (criterion B3), intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event (criterion B4), or physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event (criterion B5). There must be persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (criterion C) through at least three from: efforts to avoid thoughts, feelings, or conversations associated with the trauma (criterion C1), efforts to avoid activities, places, or people that arouse recollections of the trauma (criterion C2), inability to recall an important aspect of the trauma (criterion C3), markedly diminished interest or participation in significant activities (criterion C4), feeling of detachment or estrangement from others (criterion C5), restricted range of affect (e.g., unable to have loving feelings) (criterion C6), sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span) (criterion C7). There should be persistent symptoms of increased arousal (criterion D) through two of the following: difficulty falling or staying asleep (criterion D1), irritability or outbursts of anger (criterion D2), difficulty concentrating (criterion D3), hypervigilance (criterion D4), or exaggerated startle response (criterion D5). The full symptom picture must be present for more than 1 month (criterion E), and the disturbance must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (criterion F).

Research on PTSD has traditionally focused on traumatic experiences relating to combat, accidents, personal assault, and man-made or natural disasters. However, research has recently suggested that the symptoms of PTSD can also be caused by a number of medical events such as childbirth (Ballard et al., 1995), myocardial infarction (Shemesh et al., 2001), stroke (Sembi et al., 1998), HIV diagnosis (Kelly et al., 1998), and cancer (Cordova et al., 1995); in fact enough research has now been carried out to warrant review articles of PTSD following cancer (Kangas et al., 2002) and other medical illnesses and their treatment (Tedstone & Tarrier, 2003).

Although not currently recognised by the DSM-IV-TR criteria, a growing number of authors are researching subcategories of PTSD, or PTSD-like symptoms, which may be common in medical illness and treatment, resulting in distress, disability, avoidance, and poor adherence to treatment (Mayou & Smith, 1997). Suggested subcategories include 'partial PTSD' which is where symptoms for criterion B, C and/or D are absent - but criterion F must be fulfilled (Mylle & Maes, 2004); 'subthreshold PTSD', where threshold for criterion C and/or D are not reached, but at least one symptom exists - and criterion F must be fulfilled (Mylle & Maes, 2004); and 'lifetime PTSD', which is classified if a person is not currently experiencing symptoms, but has done at some time since the trauma (Brewin et al., 2000).

The requirement and/or definition of a trauma experience required for a PTSD diagnosis has also been questioned, with several authors proposing that PTSD symptoms can also be caused by the cumulative effect of a number of constantly stressful (but not necessarily traumatic) situations. For example, Scott and Stradling (1994) present evidence for what they call 'prolonged duress stress disorder' (PDSD), and Lloyd and Turner (2003) found that 'cumulative adversity' predicted PTSD. Alonzo (2000) suggests that the response to traumatic life events and chronic illness related events may be more like a continuum, with each event moving them along the continuum, reducing their effectiveness at coping with subsequent events. This is reflected in the findings of Asmundson et al. (2000a), who found that dysfunctional chronic pain patients were more likely to experience PTSD symptoms, which they suggest could be an indication of a collapsed 'psychological immune system'.

Meta-analyses have found that the strongest predictors of PTSD are the factors that take place during or just after the trauma (e.g. severity, dissociation, emotionality), with pre-trauma factors being less predictive (Brewin et al., 2000; Ozer et al., 2003). Other behaviours may also be relevant in the development of PTSD symptoms in people with chronic illness, as Miller and colleagues (1996) found that people with chronic illness who were high monitors of illness information (which could perhaps be described as a feature of increased arousal – criterion D) had greater levels of intrusive and avoidant ideations (symptoms featured in criterion B and C) than those who were low monitors.

5.2.2.1 PTSD in Ménière's disease.

Criterion A: MD attacks are sudden, unexpected and although they are not actually life threatening, they may be perceived as being life threatening and traumatic, particularly during the first attack when the person does not know what is happening to them. Vertigo attacks also carry a real risk of injury from abruptly losing control or falling during an attack (Yardley, 1994c). The vertigo experienced in MD is severe. Qualitative analysis of the experience of severe vertigo has revealed that attacks can be sudden and violent enough for witnesses to call an ambulance or doctor, and that it is a extremely unpleasant, terrifying, bewildering, and stigmatising experience resulting in anxiety that something is seriously wrong, a sense of loss of control over the body, and feelings of helplessness and powerlessness (Yardley et al., 1992b; Yardley, 1994c). After a number of medical investigations (some of which provoke symptoms), on diagnosis, people then learn that these attacks cannot be cured or avoided, and could occur unexpectedly at any time or place, at an unknown frequency for the rest of their life. In addition to this, their intermittent tinnitus and loss of hearing is likely to become constant and get progressively worse, and may or may not eventually spread the other ear. It would be quite reasonable for this kind of attack and diagnosis to be perceived as traumatic, and the disease progression, investigation, and treatment are likely to be a constant and cumulative source of stress.

Criterion B: Due to the nature of MD, sufferers will physically re-experience attacks, and the high level of psychological distress noted in MD sufferers might suggest the possible presence of recurrent and intrusive recollections of attacks which may be triggered by places, more minor physical symptoms, or emotions associated with previous attacks.

Criterion C: If a person with MD views their first or all vertigo attacks as traumatic experiences, it is likely that they will take measures to try to prevent the attack from occurring again (which will be unsuccessful due to the nature of the disease). The avoidance of activities and situations, and reduced interest in previous activities could be reflected in high levels of disability and handicap (which could be expected to increase as the person experiences further attacks and associated stimuli grow in number).

Criterion D: In addition to the symptoms of MD itself, the limited amount of information known about the disease, and lack of cure, may also encourage people with MD to have persistent anxiety, irritability, and increased arousal, thus contributing further to feelings of fear, helplessness, and intrusive and avoidant ideations. When exposed to stimuli associated with a vertigo attack, people with MD may experience a physiological reaction, such as a panic attack.

Criterion E: As MD is a recurrent chronic illness, if the above criteria are fulfilled, it would be likely that they would continue for more than 1 month, and would be likely to be chronic (lasting more than 3 months).

Criterion F: High levels of psychological distress and handicap are widely noted in people with MD, so it is possible that social or occupational areas of functioning are also affected as a result of this.

5.2.3 Anxiety Sensitivity

Anxiety sensitivity is the fear of anxiety symptoms, which is often based on the belief that they will result in negative or harmful consequences (Reiss & McNally, 1985). It creates a vicious circle in which, for example, palpitations are

misinterpreted as a sign that the sufferer might have a heart attack, which then increases their anxiety, which in turn increases the sensations of anxiety arousal. High levels of anxiety sensitivity increase alertness, worry and avoidance of anxiety symptoms (Reiss et al., 1986).

Anxiety sensitivity was proposed as a trait personality characteristic (Reiss & McNally, 1985), and although it is a relatively stable trait, it has been found to be partially dependent on stress and mood states. High anxiety sensitivity levels have been found to drop following treatment among those with major depression (Otto et al., 1995), and anxiety sensitivity levels varied over 5 weeks according to the stressfulness of each assessment period during Air Force cadet basic training (Zinbarg & Schmidt, 2002).

Anxiety sensitivity has mainly been linked with panic and agoraphobia (Clark, 1986; Taylor, 1995). Although high anxiety sensitivity levels are prevalent among those who have panic attacks, high levels of anxiety sensitivity do not necessarily always lead to panic attacks. Donnell and McNally (1990) found that two thirds of their participants with high anxiety sensitivity had never had an unpredictable panic attack, and Cox et al. (2001) found that only 55% of high anxiety sensitivity participants had panic attacks, and only 30% met criteria for an anxiety disorder. Following research investigating the factor structure of anxiety sensitivity, it is now considered that anxiety sensitivity may have different outcomes besides panic, depending on the dominating factor. Although there has been much debate over the factor structure of anxiety sensitivity, it is now generally accepted that anxiety sensitivity is made up of three lower order factors: fear of somatic sensations; fear of cognitive dyscontrol; and fear of publicly observable anxiety symptoms; and a single higher overall factor (Zinbarg & Schmidt, 2002). These factors have been found to relate to different conditions, for example, panic patients score highly on all factors (Taylor & Cox, 1998), chronic pain patients score highly on the fear of somatic sensations (Zvolensky et al., 2001), and depression is most related to fear of cognitive dyscontrol (Taylor et al., 1996).

Schmidt, Lerew and Joiner (2000) propose a 'scar' model of anxiety sensitivity, in which an anxiety-relevant stressor increases anxiety sensitivity levels, which leads to

a higher risk of maladaptive reactions to that stressor. This vicious cycle is strengthened by exposure to relevant stressors over time. They suggest that sensitivity is likely to increase following the experience of spontaneous panic, and that scarring is most likely to occur during a period of low arousal, when panic is least expected.

In a review of anxiety sensitivity in chronic medical conditions, Asmundson, Wright, and Hadjistavropoulos (2000b) state that anxiety sensitivity consistently predicts general and condition-specific distress and fears. Anxiety sensitivity has been found to be associated with increased fear and avoidance behaviour, negative affect, and use of analgesic medication independent of pain severity in chronic pain patients (Asmundson & Norton, 1995; Asmundson & Taylor, 1996). Anxiety sensitivity is a predictor of PTSD symptoms following childbirth (Keogh et al., 2002), and is correlated with tinnitus distress (Andersson & Vretblad, 2000). However, Bravo and Silverman (2001) found a negative association between anxiety sensitivity and history of medical illnesses in older adults. They suggest that this is due to an increase in self-confidence resulting from overcoming illness.

5.2.3.1 Anxiety sensitivity in Ménière's disease.

If a person with MD had high anxiety sensitivity levels then, as among chronic pain patients with high anxiety sensitivity, they would be more likely to have a greater alertness to sensations, and an avoidance of illness related symptoms. The avoidance of dizziness symptoms often results in the balance system not being used to coping with the movements that trigger dizziness, and so dizziness is ironically more easily provoked by such triggers, further increasing avoidance and anxiety. Dizziness is also a physical symptom of anxiety, so it is possible that in response to any anxiety provoking situation (unrelated to MD), a person with MD may experience dizziness and misinterpret this as the beginning of an MD attack, which will increase the anxiety and the dizziness.

Although prospective studies of MD are not feasible, it is likely that the anxiety sensitivity levels of MD sufferers are increased by the negative mood and stress that result from having such an aversive chronic disease. The 'scar' model may be

particularly relevant to MD, as MD causes a constant distress from tinnitus and hearing loss, and as vertigo attacks are unpredictable and can occur during periods of low arousal, this increases the likelihood of scarring.

5.2.4 Health Anxiety

Health anxiety is usually discussed within the context of hypochondriasis, as a milder form of the disorder. DSM-IV-TR defines hypochondriasis as a "preoccupation with fears of having, or the idea that one has, a serious disease based on the person's misinterpretation of bodily symptoms", and causes "clinically significant distress or impairment in social, occupational, or other important areas of functioning" (American Psychiatric Association, 2000, page 507). However, DSM-IV-TR currently has no separate or differentiating criteria for health anxiety. Diagnostic criteria for psychosomatic syndromes have been proposed by a group of psychologists (Fava et al., 1995), who define health anxiety as "(A) Generic worry about illness, concern about pain and bodily preoccupations (tendency to amplify somatic sensations) of less than 6 months duration; (B) Worries and fears readily respond to appropriate medical reassurance, even though new worries may ensue after some time; (C) Worries and fears are not secondary to mood or anxiety disorders" (page 4).

The dominant theory of how health anxiety develops and is maintained is a cognitive-behavioural theory (Salkovskis & Warwick, 1986; Warwick & Salkovskis, 1990; Salkovskis & Bass, 1997). Development is a result of knowledge and previous experience of illness (in self or others), and previous experience of unsatisfactory medical management, leading to the formation of specific assumptions about symptoms, disease and health behaviours. These can result in a confirmatory bias in the patient's thinking if a critical incident results in the misinterpretation of bodily symptoms and signs as an indication of serious illness (Salkovskis & Bass, 1997). Once present, health anxiety is then maintained by three factors. These are selective attention to illness-related information, which reinforces the confirmatory bias of illness assumptions; physiological arousal resulting from anxiety, causing an increased perception of threat; and avoidance behaviour, which increases preoccupation with the threat. These developmental and maintenance factors all

impact on four main cognitive factors that influence the severity of health anxiety. These are: perceived likelihood of illness (probability); perceived cost, awfulness, and burden of the illness (cost); perceived ability to cope with the illness (coping); and perception of the extent to which external factors will help (rescue). People with health anxiety are often resistant to the idea that psychological problems may be related to their condition, generally focusing only on physical explanations or solutions, and are often mislabelled as having a personality disorder (Warwick & Salkovskis, 1990).

Health anxiety is a concept that is only beginning to be applied to chronic illness, due to the recent recognition that people can become preoccupied with fear of the symptoms of a medical illness that they do actually have (differentiating it from hypochondriasis). Although it has been stated that health anxiety can occur in those who are physically ill, (Warwick & Salkovskis, 1990; Salkovskis & Bass, 1997; Furer et al., 2001), the literature in this area has not really moved beyond theory, with actual research in this area being quite limited. Part of the reason for this could be due to the same concept being recognised and researched under different names. Williams (1997) draws comparisons with the principles underlying health anxiety in his model of 'dysfunctional illness behaviour', and hypochondriasis is also a variable that contributes to 'abnormal illness behaviour' (Clark & Smith, 1998; Trigwell et al., 1995). The relevance of health anxiety to chronic pain has been discussed by Hadjistavropoulos and Hadjistavropoulos (2003). They describe a vicious circle in which the experience of chronic pain can increase health anxiety, with high levels of health anxiety predicting poor prognosis. Furer, Walker and Freeston (2001) propose that people with 'chronic, intermittent, or degenerative conditions' might be at a greater risk of developing health anxiety. They suggest that uncertainty in such conditions, having a condition with no clearly recognised cause, and having a condition that is life threatening, all may increase anxiety and impact on quality of life.

5.2.4.1 Health anxiety in Ménière's disease.

As MD is a chronic, intermittent condition with great levels of uncertainty and no clear cause, sufferers may be at a greater risk of developing health anxiety. The

probability of an attack occurring is unknown, and so the anxiety created by this may lead sufferers to default to a high level of perceived likelihood, as it cannot be ruled out. In addition, the balance system's sensitivity to provoked dizziness (increased by the avoidance of symptoms), may also be misinterpreted as the beginning of an attack, reinforcing anxiety and attention to illness-related information. MD attacks are severe, and so a high level of perceived cost, awfulness and burden would be expected. External (rescue) factors are quite limited, as there is little that can be done to control or treat the disease, although some people with MD avoid going out alone (Erlandsson et al., 1996; Yardley et al., 1992b), so they have someone to 'rescue' them if an attack occurs whilst they are out. Perceived ability to cope is the factor that has the most variability and scope for improvement, although currently there is no specific help given on how to cope and live with MD, with sufferers having to find their own ways of coping, through self help groups or other ways.

5.3 Conclusions

This chapter has provided a rationale for why worry, PTSD, anxiety sensitivity, and health anxiety might be relevant to the development of distress in relation to MD. The next chapter will systematically review articles on the role of distress in MD and retrospectively examine the mechanisms discussed here to see whether any evidence exists that might explain MD related distress.

Chapter Six: The Role of Psychological Factors in Ménière's Disease: A Systematic Review

There has been no systematic review of articles on the role of psychological distress in Ménière's disease (MD) since 1977, and the theoretical frameworks in which psychological factors of MD have been considered have been quite limited. This chapter systematically reviews all articles published between 1978 and 2004. It addresses empirical quality and theoretical frameworks, moving beyond the question of psychosomatic or somatopsychic causation by retrospectively examining the four mechanisms discussed in chapter 5 (worry, post-traumatic stress disorder (PTSD), health anxiety and anxiety sensitivity) to see whether any evidence exists that might explain MD related distress. Where evidence was present, it was examined to see whether it varies by anxiety level and/or if there was a difference between people with MD and controls.

6.1 Aims and Objectives

The purposes of this review were:

- To obtain and examine all the relevant literature in the English language on psychological factors in MD since 1977.
- To assess the quality of studies and classify them into good, medium or poor categories.
- To evaluate and interpret studies to assess whether the components of each of the four mechanisms had been measured.
- To assess studies to see if the components were present to a greater extent in people with MD than control groups.
- To assess studies to see if the presence of components was greater in people with MD who have higher levels of psychological distress (as measured by anxiety and negative affect) than those with lower levels of distress.

6.2 Method

6.2.1 Search Strategy

Database searches were carried out in PsychInfo, Medline, Embase and Web of Science (WoS) to identify relevant studies of psychological factors in MD. The time period of the search ranged from Jan 1978- May 2004 (although Embase begins at 1980, and WoS begins at 1981). The searches were limited to published studies in the English language. The search terms used were "meniere$" ($ = truncation symbol) for PsychInfo which retrieved 80 articles. For Medline, Embase and WoS, the following search terms were entered together in a single search: "meniere$ and (psych$ or stress$ or anxiety or depression or handicap$ or emotion$ or distress$ or fear$ or avoid$ or 'quality of life' or social$ or somat$ or cognition$ or cognitive or behavio?r$ or cope or coping or personality or panic$ or worry$ or neurotic$ or neuros?s or self-efficacy or helpless$)". This retrieved 244 article from Medline, 251 articles from Embase, and 138 articles from WoS. "Disability" and "trauma$" were originally included in the search terms, but were removed due to the number of irrelevant medical articles they identified (AAO-HNS Committee on Hearing and Equilibrium Guidelines for Reporting Treatment Results in Ménière's disease, have specified that disability should be reported in all treatment studies).

6.2.2 Study Selection

The titles and abstracts of the retrieved 713 articles that fulfilled the database search terms were reviewed according to the following inclusion and exclusion criteria:

- Exclude articles that are not empirical studies of psychological factors involved in MD. (e.g. summaries about diagnosis, management or treatment of MD, reviews, comments, experiences, case studies, or opinions)
- Exclude articles when the purpose of the article is to evaluate a medical treatment (drug, surgery, physiotherapy), unless the main focus of the article is psychological.
- Exclude articles when search terms are implied in a medical, not psychological sense (i.e. stress, depression).

- Exclude articles when the only measure of psychological factors is a biological measure (e.g. stress hormones or proteins).
- Include articles of psychological treatment (counselling / psychotherapy / cognitive and/or behavioural therapy) if they also use psychological outcome measures.
- Exclude articles that do not have any statistical or qualitative analysis of psychological factors stated.
- Exclude articles if people with MD are a subgroup of a sample and their results are not presented separately from other participants.

If it was unclear from the title and abstract whether or not an article should be included, the full text of the article was obtained and read. The full texts of 79 articles were obtained (see Appendix G for table listing articles and why articles were excluded), of which after reading 24 fulfilled the inclusion criteria (listed in Appendix H, 1-24). Three of the journals with the highest frequency of articles that fulfilled the inclusion criteria (Otology and Neurology, Journal of Psychosomatic Research, and Acta Oto-Laryngologica) and two other journals that are relatively new (Journal of Vestibular Research and Noise & Health) were then handsearched to check for articles that may have not been included in the databases. Handsearching identified a further three articles that fulfilled the inclusion criteria (listed in Appendix H, 25-27). The references of all included articles were then checked through, identifying one further article (see Appendix H, 28) that had been missed due to excluding disability from the search strategy, resulting in a total of 28 articles being included in the review. Each of these articles was given a unique reference number between 1 and 28 (each study and corresponding reference number are listed in Table 10). All studies will be referred to by their reference number for the rest of this chapter.

6.2.3 Study Quality

Before reviewing the research in the context of each mechanism, articles were ranked according to three methodological criteria: adequate sample size; appropriateness of measures used; appropriateness of the method of analysis.

6.2.3.1 Adequate sample size.

It is important to have enough participants in a study to detect an effect size of interest at a power of 0.8. If sample size is too low, the power of the study may be reduced, increasing the chances of a type I or II error being made. The confidence intervals for a small sample size are also likely to be wide and have poor precision, reducing the validity of findings. Studies were evaluated to see if they had an adequate sample size by comparing the sample size used in each analysis with the minimum sample size to detect a medium or large effect size recommended by Cohen (1992) when alpha = .05 and power = .08. Only six of the twenty-seven quantitative studies had enough participants to detect a medium effect size for all their analyses (8, 9, 15, 16, 24, 27), with a further two studies having enough participants to detect a medium effect size for more than half of their analyses (22, 23). A large effect size could be detected for all analyses for six studies (6, 11, 13, 14, 18, 25), for more than half analyses for three studies (2, 4, 20), and less than half for one study (5). Eight studies had sample sizes insufficient to detect a large effect size for any of their analyses (1, 10, 12, 17, 19, 21, 26, 28). One study was unclassified as no information was available regarding recommended sample size for the type of analysis used (3). Evidence that used a sample size big enough to detect a medium effect size was classified as good quality, evidence that could detect a large effect size was classified as medium quality, and evidence that could not detect a large effect size was classified as poor quality.

6.2.3.2 Appropriateness of measures used.

Single-item measures are an unreliable measure of complex constructs like attitudes and beliefs, so as far as possible multiple-item measures should be used. Measures should be validated, and particularly in the case of MD (as some symptoms of MD are analogous to psychological variables) scales used should have good content validity (i.e. psychological measures should be independent of MD symptoms). The appropriateness of the measures used in each study were assessed by obtaining and checking the measures to see if they were validated multiple-item measures, and if they were independent of MD symptoms. It was not possible to obtain the Guilford-Martin Personality Inventory used in study 21. Eighteen of the studies used at least

one validated scale that was independent of MD symptoms (although they may have also used other inappropriate measures in addition; 1, 2, 4, 9, 10, 11, 12, 13, 14, 17, 18, 19, 20, 22, 23, 26, 27, 28). Eight of the studies only used measures that were either unvalidated scales, single item questions only, or validated scales that contained questions that overlapped with MD symptoms (3, 5, 6, 8, 15, 16, 24, 25). Evidence was classified as either good or medium quality (depending on adequateness of sample size) if appropriate measures were used, and as poor quality if inappropriate measures were used.

6.2.3.3 Appropriate method of analysis.

Statistical tests (particularly parametric tests) have a number of assumptions that must be met in order for the test to produce accurate results. Violation of these assumptions can reduce the reliability of the test result. Studies were checked to see if appropriate methods of analysis were used for their data. Twenty-one of the studies used appropriate methods for all their analyses (3, 4, 5, 6, 8, 9, 10, 11, 13, 14, 16, 17, 18, 20, 21, 22, 23, 25, 26, 27, 28), with a further six studies (1, 2, 12, 15, 19, 24) using some inappropriate methods of analyses such as using the wrong test for the type of data or study design, or inappropriately combining groups to boost numbers (although quality of reporting was sometimes poor, so it is possible that correct methods were used, but not clearly explained). Evidence was classified as either good or medium quality (depending on adequateness of sample size) if appropriate analysis was used, and poor quality if inappropriate analysis was used or inferential statistics were not used for the analysis of a particular piece of evidence.

6.2.3.4 Qualitative study.

The criteria ranking for the qualitative study was given based on the characteristics of good qualitative research (sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance) described by Yardley (1999). The qualitative study was of a good standard for two of the four characteristics of good qualitative research, however it fell down on 'commitment and rigour' and 'transparency and coherence' due to its mixing of methods (interview and focus group) without providing any rationale for this, not specifying

which type of qualitative analysis was used, and using a sample size that may not have been sufficient to explore the full range of experience of MD. Therefore it was classified as a medium quality study.

6.2.4 Presence of Mechanisms

Key components that contributed to each of the four mechanisms were identified from their descriptions in the literature. Components that overlapped different mechanisms were identified and grouped in an additional section to the four mechanisms (the features of the mechanisms and the shared features are described in the Results section). Studies were then assessed to see if they contained concepts that were the same or similar to the components of the mechanisms and their shared components. If components were present in the studies, the studies were then further assessed to see if they compared people with MD with control groups, or measured the feature as a function of high or low psychological distress. If they did, then the direction of results was noted.

6.3 Results

6.3.1 Data Extraction

Data extracted from the articles are shown in Table 10, comprising the sample size of MD patients (also by gender if given); the age of participants; the aims of the study; the measures used; the design; details of the control group (if used); whether means and standard deviations are presented; whether statistical analyses are presented in full; and the findings of the study.

Table 10

Summary of studies of psychological factors in Ménière's disease

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
1	Anderson & Harris (2001)	19 (12f, 7m)	Range 32-83	To describe health-related quality of life among patients with MD in whom conventional therapy failed and who requested further medical intervention.	Well-being (QWB) Depression (CES-D) SF-12	Cross sectional questionnaire study (QWB previous 6 days) recruited from a treatment centre	Data from other studies - several other disease groups	Means given for all S's together. No S.D's given.	Y for correlations. t-values not presented, only mean weight and significance.	1. QWB symptoms consistent with acute episodes of MD were trouble learning, remembering or thinking clearly; physical symptoms; spells of feeling upset, depressed or crying; trouble sleeping; excessive worry or anxiety. 2. MD patients had a loss of 43.9% in QWB when compared with people with no symptoms and full functional status. 3. QWB scores were lower on days with acute episodes of MD symptoms. 4. SF-12 Physical = greater than 1 SD below general mean. 5. SF-12 Mental = 0.5 SD below general mean. 6. CES-D mean = 23 (over 16 is clinically significant) 7. CES-D was significantly correlated with the QWB and the SF-12 physical and mental; and the QWB was correlated with the SF-12 physical.
2	Andersson & Hagnebo (1996)	26 (17f, 9m)	Mean=50 (SD=9.4) Range 33-68	To investigate the relationships among measures of dysphoria, optimism, confidence in balance and daily monitored symptoms of MD.	Dysphoria (BDI) Optimism (LOT) Confidence in everyday activities (CEA) Symptoms (VAS)	Cross sectional questionnaire study - recruited from two hospitals.	Data from other studies – MD/dizziness, hearing loss, tinnitus.	Y	Y for correlations. t-values not presented, only significance.	1. Dysphoria was related to less confidence in balance, less optimism and with more vertigo symptoms. 2. Confidence in balance was related to less vertigo symptoms. 3. Optimism was not significantly related to MD symptoms. 4. No substantial difference in scores when compared with other studies, except for a higher CEA score in this study.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
3	Andersson et al. (1997)	20 (13f, 7m)	Mean=50.6 (SD=9.7) Range 32-68	To investigate the temporal relationship between daily stress and symptoms in Meniere's disease.	Stress (VAS) Symptoms (VAS) Presence of attack Beck Depression Inventory Psychiatric Problems	Longitudinal diary study (7 months). Time series analysis.	None	Y	Y	1. Same day associations between stress and symptoms. 2. No evidence that symptoms were caused by stress on previous days. 3. Individual differences occurred, with stress being less important for some participants.
4	Berrios et al. (1988)	30 (13f, 17m) (of 207 inner ear disorder patients)	Mean=50 (SD=31)	To investigate psychiatric morbidity associated with inner ear disorders.	General Health Questionnaire (GHQ) Symptom severity (VAS1- at first ENT visit, VAS2- at time of completing GHQ) Past psychiatric history Audiological tests	Cross sectional questionnaire study - recruited from a ENT clinic	Noise injury (17), Other deafness (32), Presbyacusis (90), Tinnitus (38).	Y	Y	1. Meniere's disease patients rated their initial symptom severity as significantly higher. 2. Of the 207 participants, 122 met GHQ 'caseness', 20 (32%) of these had MD. 3. No correlation was found between 'agoraphobic' items of the GHQ and Meniere's disease.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
5	Cohen et al. (1995)	50 (36f, 14m)	Mean=50.6 (SD=11.5)	To determine the level of disability among patients with Meniere's disease, and to see if unpredictability of attacks and the lack of a safe place to rest during attacks are the most disabling problems.	Employment Ability to perform their job since having MD Tasks required in job Independence in activities of daily living when (1) during a Meniere's attack, and (2) when symptom free Audiological and vestibular function tests. Most bothersome symptoms.	Cross sectional study - recruited from an Otolaryn-gology Clinic	None	N	Yes for findings 1 Only significance given for findings 2 and 3.	1. Primary complaints were vertigo, hearing loss, both vertigo and hearing loss, fatigue, and the unpredictability of attacks. Vertigo affected job performance significantly more than other symptoms. 2. Independence is significantly reduced during Ménière's attacks. 3. No significant relationship was found between the objective audiological / vestibular tests, and the subjective self-reports of functional status – the same symptoms bothered different participants to different extents.
6	Coker et al. (1989)	48 (21 active symptoms - 9f, 12m, 27 inactive symptoms - 6f, 11m)	Active Mean=42 Range 24-70 Inactive Mean=48 Range 31-66	To examine the psychological profile of patients with Ménière's disease.	Minnesota Multiphasic Personality Inventory (MMPI) Diagnostic Inventory of Personality and Symptoms (DIPS) Questionnaires on the type, frequency and severity of dizziness.	Cross sectional questionnaire study - Patients recruited from the files of the college of medicine.	US population of adults with mental illness Mayo Clinic medical patients.	N	Only significance given.	1. Meniere's active cases were significantly different to the control groups on the MMPI and DIPS. 2. Meniere's inactive cases were significantly different to the control groups on the DIPS, but only different to the US population on the MMPI. 3. Depression was diagnosed in 80% (MMPI), and 70% (DIPS) of the active group, and in 32% (MMPI), and 39% (DIPS) of the inactive group. 4. The DIPS diagnosed 1 active and three inactive patients as having adjustment disorder, three active and three inactive patients as having psychological factors affecting physical condition, and one inactive patient as having substance abuse. The MMPI diagnosed 1 inactive patient as having adjustment disorder, and 2 inactive patients as having substance abuse.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
7	Erlandsson et al. (1996)	8 (3f, 1m-interview) (1f, 3m-focus group)	Interviews: Mean=61.3 Range 50-69 Focus group: Mean=56 Range 27-74	To enhance understanding of the psychological mechanisms present in a traumatic event such as the sudden onset of MD, and to explore how the patients experience and interpret their symptoms during the course of the disease.	Qualitative investigation of: Good or bad adjustment to the illness. What patients have found intolerable (or tolerable) Whether or not they have been able to live a normal life How they relate to their doctors and utilize hospital care.	Qualitative approach – focus groups (4 x 2.5 hr sessions) and interviews	-	-	-	1. Vertigo attacks were often provoked by stress, worry, negative thoughts / expectations, and sensory sensations. 2. Vertigo attacks led to fear and phobic reactions, depressed mood, social withdrawal, professional problems, and occasional social isolation, as attacks are beyond patient's control and stigmatising. 3. The first traumatic Ménière's attack was significant, and clear in participant's memories, causing anxiety and phobia. 4. Psychological and psychophysiological signs built up prior to and following attacks. 5. Uncertainty and fear on diagnosis. 6. Security and support from contact with doctors, but dissatisfied with medical care. 7. Avoidance of situations and places where an attack has taken place. 8. Depressed mood resulting from lack of control and mental preparation for catastrophe. 9. Coping strategies included emotional, cognitive, acceptance and acceptance / reorientation strategies. 10. Some secondary gains (support and consideration), and reduced level of ambition. 11. There is more than one illness profile for MD, and psychological stress reactions (possibly influenced by earlier experiences in life) are crucial to adaptation to having MD.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
8	Hagnebo et al. (1997)	514 (53% f, 47% m)	Mean=55.5 (SD=10.2) Range 21-70	To investigate the impact of Ménière's disease on the patient's daily life and to analyse the relationships between discomfort from the cardinal symptoms and environmental, emotional and activity factors.	VAS, Likert type, or open ended questions on: Onset and development of MD symptoms. Present discomfort Premonitory symptoms The vertigo attack Awareness of connection between discomfort and environmental conditions, emotional and bodily states. Coping with attacks. Quality of life (stress, avoidance, discomfort free situations, general wellbeing and life satisfaction). Other symptoms.	Cross sectional questionnaire study. 304 were recruited from an ENT clinic register, and 210 were recruited from the Swedish Association of Patients with MD.	None	Y (Only for total discomfort scale)	Y	1. Significantly more discomfort from hearing impairment was found in men than women. 2. Those who had their illness for 3-5 years had significantly more discomfort from vertigo than those who had had their illness for over 11 years. 3. Discomfort from hearing impairment was significantly correlated with age. 4. Total present discomfort was significantly correlated with a negative influence on leisure time, work, social life, mood and family life, as well as with reports of unsteadiness, insomnia, anxiety, dysphoria, lack of concentration, ache in neck and shoulders, palpitations and gastrointestinal complaints. 5. A majority of subjects avoided activities or situations because of their symptoms, and most reported premonitory symptoms and experienced relations between environmental, emotional and activity factors and vertigo attacks.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
9	Hagnebo et al. (1998a)	514 (47% f)	Mean=55.5 (SD=10.2) Range 21-70	To investigate the premonitory sensations of attacks as reported by a group of people with MD. Three scales were developed and principal component analyses were used to investigate the possibility that sensations would cluster into categories.	Somatic sensations (SOM) Psychological state before/during an attack (PSYCHOL) Situational characteristics surrounding an attack (SIT) Rating of disease progression since diagnosis.	Cross sectional questionnaire study. 304 were recruited from an ENT clinic register, and 210 were recruited from the Swedish Association of Patients with MD.	None	Y	Y	1. 94% reported at least some premonitory symptoms of an attack. 2. Situational characteristics are significantly higher premonitory symptoms of attacks for females than for males. 3. Somatic symptoms were significantly higher for those who reported worse symptoms since diagnosis than those who had improved or remained unchanged. 4. Situational characteristics were significantly higher for those who reported worse symptoms since diagnosis than those who had improved.
10	Hagnebo, Johnsson et al. (1999a)	10 (4f, 6m)	Mean=55 Range 29-69	To investigate the effects of cognitive stress on balance.	Balance (BSV) The Beck Anxiety Inventory (BAI) The Beck Depression Inventory (BDI) The Fear Questionnaire (FQ) The State Trait Anxiety Inventory (STAI -S / -T) Discomfort and instability (VAS)	Experimental and questionnaire design - 2 counter-balanced sessions (resting and stress (via the stroop colour-word conflict task).	10 Non-Meniere's patients with dizziness 10 Participants free from dizziness	Y	Y	1. Balance was unexpectedly significantly worse after the resting session than the stress session, and was worse with eyes closed than eyes open. 2. No significant differences were found in the ratings of discomfort and instability after the stress or resting sessions. Subjective ratings were not correlated with postural measurements. 3. All three groups did not reach clinical anxiety (BAI) or depression (BDI), and had low phobic avoidance, but did all have above norm state and trait anxiety. No significant differences were found between the MD patients and the controls. 4. No correlations were found between balance and emotional factors. 5. In MD patients, state anxiety and depression correlated with instability, and depression correlated with discomfort. In the Non-MD dizziness group anxiety (BAI) was correlated with instability. In the dizzy free group phobic fear was correlated with both instability and discomfort.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
11	Hagnebo, Melin et al. (1999b)	50 (32f, 18m)	Mean=56 (SD=13) Range 30-84	To investigate whether stress-related coping strategies would predict the perceived handicap from dizziness, reported discomfort from illness, and anxiety sensitivity. Also to investigate the relations of anxiety sensitivity to perceived handicap from dizziness and reported discomfort from illness.	Ways Of Coping Questionnaire (WOCQ) Anxiety Sensitivity Index (ASI) Dizziness Handicap Inventory (DHI) Background data on duration, frequency, medical care, most disabling symptom, vertigo in specific situations and states, present discomfort from illness (VAS).	Cross sectional questionnaire study	None	Y	Y	1. The coping strategies of distancing, and escape/avoidance positively, and self-controlling negatively, predicted only functional handicap, accounting for 33% of the variance. 2. Coping strategies did not predict discomfort from illness. 3. The coping strategies of accepting responsibility and escape/avoidance, predicted anxiety sensitivity, accounting for 34% of the variance. 4. Anxiety sensitivity was correlated with emotional handicap and reported discomfort. 5. No gender differences were found. 6. The coping strategy of positive reappraisal was correlated with age and duration of illness. Duration of illness was also correlated with reported discomfort.
12	Hiller & Goebel (1999)	18 (Of 166 tinnitus sufferers)	Not given specifically for MD	To investigate whether specific patterns of tinnitus history or aetiology are related systematically to the level of psychological distress.	The Structured Tinnitus Interview	Cross sectional study.	10 other groups of tinnitus sufferers.	Y	Y	1. Psychological distress (hearing problems; intrusiveness; problems with relaxation & sleep; emotional distress; dysfunctional cognition; psychosocial impairment; occupational impairment) was not significantly increased in patients whose tinnitus was associated with Ménière's disease compared with other etiologies.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
13	Holgers & Finizia (2001)	116 (53f, 63m)	Mean=62 Range 24-85	To analyse the quality of life and tinnitus suffering in patients with Ménière's disease and compare them with patients suffering from tinnitus.	The Nottingham Health Profile (NHP) The Tinnitus Severity Questionnaire (TSQ) Hearing test (Pure Tone Average; PTA)	Cross sectional study – recruited from an audiological clinic	182 patients suffering from tinnitus.	Means and S.D's given only for the NHP	Only significance and correlations given	1. Emotional disturbances could explain 40.3% of the variance in tinnitus severity in MD, compared with 20.6% in patients with tinnitus. Sleep disturbances accounted for 6.4%, and domestic work accounted for 6.1% of the variance in tinnitus severity in MD. Social isolation, energy, mobility and pain did not contribute significantly to the variance. 2. Working age patients with Ménière's disease suffered from significantly more sleep disturbances and social isolation than those of working age with tinnitus.
14	Honrubia et al. (1996)	47 (29.8% m) (of 343 neurotologic patients)	Mean=58.3	To evaluate dizziness characteristics and their impact on quality of life.	UCLA-Dizziness Questionnaire (frequency, severity, daily activities, QoL, fear) Generalized Contentment Scale Clinical Anxiety Scale	Cross sectional questionnaire study	83 patients with BPV; 27 with Peripheral disorders; 98 with Migraine; 53 with Central diseases; and 35 with Psychogenic disorders	Y	Only significance given	1. More women than men had MD. 2. Frequency of dizziness was not significantly associated with quality of life or fear of becoming dizzy in MD. 3. The impact of dizziness severity on ability to carry out daily activities was significant for all groups.
15	Kato et al. (2004)	159 (85f, 74m)	Mean=52.4 Range 20-83	To develop a disease-specific instrument to measure the quality of life in patients with Ménière's disease and to assess quality of life outcomes after endolymphatic sac decompression.	Ménière's Disease Outcomes Questionnaire (MDOQ)	Cross sectional questionnaire (Retrospective survey)	None	Means and range given (but no SD's)	Only significance given	1. Significant improvement in quality of life was reported by 87% of patients after endolymphatic sac decompression.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
16	Kentala et al. (2001)	243 (174f, 69m)	Mean=44 Range 17-79	To characterize the occurrence of drop attacks (DA) in a group of persons consecutively diagnosed as MD patients as they entered at tertiary reference unit and to search for an association between DA and other symptoms of MD to characterize the patients categorized as having DA.	Symptoms, earlier diseases, accidents, use of drugs tobacco and alcohol. Audiological and vestibular function tests. Occurrence, description and severity of DA. Daily life disturbance caused by DA.	Cross sectional study	None	Means given (no S.D's given, but can be calculated from given variance), but not for all variables measured.	Y for correlations, and factor analyses, but only significance given for ANOVA's and Regression analyses.	1. DA was experienced by 72% of the MD patients. 2. Patients with DA had more intense tinnitus, and their vertigo was more likely to be provoked by visual factors, pressure changes, head positioning, or physical strain. They also had more lightheadedness, and movement difficulties. 3. No significant difference was found between DA and non DA MD patients in age at onset, duration of disease, gender, or intensity of vertigo. 4. Patients with DA also had more anxiety, facial sensitivity disturbances, visual blurring, and dysarthria. These cranial nerve symptoms appeared more often if the vertigo attacks were frequent, if the tinnitus was intense, if the patient had a headache, lightheadedness, or movement difficulties outside the vertigo attack. 5. Hearing and vestibular tests significantly deteriorated as MD progressed, and loss of hearing was significantly correlated with anxiety. 6. 75% of the variance in drop attacks could be explained by occurrence of DA, cranial nerve symptoms, visual blurring, physical-strain induced vertigo, visually induced vertigo, movement difficulties outside vertigo attacks, and functional symptoms. 7. Classifying DA from non DA was predicted by lack of migraine, spontaneous nystagmus in ENG examination, functional symptoms, tinnitus, short duration of hearing loss, and cranial nerve symptoms.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
17	Kinney et al. (1997)	51 (31 medically treated - 15f, 16m) (20 surgically treated - 11f, 9m)	medically treated Mean=51 (SD=11.4) Range 19-64 surgically treated Mean=48 (SD=10.3) Range 30-64	To evaluate a group of medically and surgically treated MD patients to see (1) if there is a significant long-term change in hearing, (2) if there is a difference in hearing between medically and surgically treated patients, and (3) is there a specific long-term disability / handicap in MD, and what is it's character.	Audiometric tests Hearing Handicap Inventory for Adults (HHI) Dizziness Handicap Inventory (DHI) Tinnitus Handicap Inventory (THI) SF-36 Health Survey	1 year post-treatment study	SF-36 validation scores for 'minor medical' and 'serious medical' groups.	Y	Y for correlations, but only significance stated for t-tests and ANOVA's.	1. No statistically significant differences in long-term hearing results were detected from natural history of medically or surgically treated patients with Meniere's disease. 2. Variability of handicap suggests reaction to hearing loss, dizziness and tinnitus vary among individuals. More than three quarters of patients reported that hearing loss, dizziness and tinnitus affected their quality of life to some degree. No difference was found between treatment groups. 3. No difference was found between treatment groups on the SF-36. When compared with minor and major medical controls for the SF-36, MD patients functioned like minor medical controls for physical scales and general health perceptions, and like major medical controls for emotional scales. MD scores for mental health were lower than both control groups.
18	Monzani et al. (2001)	39 (32f, 7m) (of 206 neurotologic patients)	Not given specifically for MD	To establish whether anxiety and depressive symptoms are different for different vestibular diseases.	Neurotological tests UCLA-Dizziness Questionnaire (frequency, severity, daily activities, QoL, fear) The Hospital Anxiety and Depression Scale (HADS)	Cross sectional study	86 health control volunteers (not compared with MD) 87 patients with peripheral disorders, 38 with central disorders, 42 with BPPV.	Y	Only significance given.	1. Patients with Meniere's disease did not have significantly higher anxiety and depression when compared with other vestibular disorders (The group with Central disorder had significantly higher levels of depression than all other groups).

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
19	Rigatelli et al. (1984)	8 (of 60 consecutive patients with vertigo)	Not given specifically for MD	To carry out a psychosomatic study of patients with vertigo.	An anamnestic-biographic interview Self-depression scale (SDS) Self-anxiety scale (SAS) Middlesex Hospital Questionnaire (MHQ; anxiety, depression, phobic anxiety, obsessional traits and symptoms, somatization and hysterical traits) Diagnostic evaluation	Cross sectional study	60 non vertiginous and non surgical pathology patients. (not compared with MD) 8 patients with neuro-sensorial deafness, 16 with vertebro-basilar insufficiency, 14 with neuronitis, and 12 with nucleoreticular syndrome of Ararslan	Y for overall group, but only means given for MD group.	Y	1. Three of the four patients who remembered one or more significant life-event stresses preceding the appearance of vertigo had MD. 2. Patients with MD showed no significant differences compared with other vertigo sufferers, on depressive symptomatology and anxiety. 3. Patients with MD showed significantly lower scores on the MHQ for obsession, and significantly higher scores for somatization when compared with other vertigo sufferers.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
20	Savastano et al. (1996)	50 (46% m)	Mean=49 Range 25-72	To evaluate illness behaviour, personality traits, anxiety and depression in patients with Meniere's disease.	Illness Behaviour Questionnaire (IBQ) Eysenck Personality Inventory (EPI) State Trait Anxiety Inventory (STAI) Zung Self –Rating Depression Scale (Zung SDS)	Cross sectional study	Established norms for each questionnaire.	Y	Only significance given.	1. Mean scores were higher than normal for neuroticism, with a stronger psychological perception of disease and a lower level of affective inhibition. 2. Anxiety and depression scores were not higher than normal. 3. Cluster analysis of the IBQ scores identified two subgroups of Meniere's patients, one with normal scores who had less than 3 years since diagnosis, but over 6 years since onset, and a stronger tendency to interpret the disease in psychological terms. The second group with high levels of depression, anxiety, neuroticism, psychoticism, hypochondriacal, dysphoric and irritable, with a strong disease conviction and a tendency to interpret their disease in somatic terms with greater affective inhibition. These were older patients with a longer history of MD and more hospital stays. 4. Time since onset was correlated with disease conviction. 5. In patients under 50, age was correlated with somatic perception of the disease, and had higher scores of psychological perception of the disease and lower denial scores than older patients. 6. ENT hospital stays was correlated with depression, trait anxiety, disease conviction and somatic perceptions of the disease. 7. Time since last attack was negatively correlated with dysphoria, depression and neuroticism.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
21	Sawada et al. (1997)	CMI & Y-G test: 34 (20f, 14m) Stress Q: 46 (33f, 13m)	CMI & Y-G test: Mean=55.9 Range 23-77 Stress Q: Mean=54.2 Range 28-74	To examine the relation between the psychosomatic profiles of patients with MD and antidiuretic hormone (ADH)	Cornell Medical Index (CMI) Guilford-Martin Personality Inventory (Y-G test) Stress Questionnaire Plasma ADH levels	Cross sectional study	Normal controls for the CMI only, taken from another study	Means & S.D's only given for the ADH levels for stress aware or not aware (on the stress Q) groups.	Only significance given.	1. MD results for the CMI test were 38% type I (normal), 37% type II (subnormal), 22% type III (subneurosis), and 3% type IV (neurosis). 2. In the CMI test, types III and IV were significantly more often observed in Meniere's disease than normal controls. 3. No relationship was found between ADH groups and Y-G types or CMI types. 4. In the Y-G test, patients with Meniere's disease were classified as normal (average and calm types). 5. 78% were conscious of their stress before an attack, due to work problems, social conflicts, and physical conditions. 6. ADH was significantly higher in those who reported stress before vertigo on the stress Q.
22	Soderman et al. (2001)	112 (58f, 54m) (Gentamicin: 26 - 12f, 14m), (Endolymph -atic sac surgery [ELS]: 59 - 35f, 24m), (Untreated: 27 - 11f, 16m)	Genamicin: Mean=63 Range 46-88 ELS: Mean=53 Range 28-75 Untreated: Mean=53 Range 30-74	To evaluate self-rated quality of life associated with vertigo, hearing loss, and tinnitus. To evaluate potential relationships between these findings and treatment regimens and SOC in three different treatment groups of MD (gentamicin, endolymphatic sac surgery, untreated).	Demographic data Disease symptom-specific items. Vertigo Symptom Scale (VSS) The Hearing Disability Handicap Scale (HDHS) The Tinnitus Severity Questionnaire (TSQ) The American Academy of Otology-Head and Neck Surgery (AAO-HNS) questionnaire for evaluating the results of treatment of MD. The Sense of Coherence Scale (SOC)	Cross sectional study – recruited from 2 hospitals.	Data from other studies (268 randomly selected from the population, and a sample of patients with peripheral vestibular disorders)	Y	Y	1. Gentamicin-treated patients had less vertigo, but no difference was found between groups in general quality of life. 2. No difference was found between the vertigo, tinnitus or hearing loss on impacting general or symptom related quality of life. 3. No significant differences were found between the three treatment groups on VSS, HDHS, TSQ, or SOC. 4. Males had significantly higher somatic anxiety (VSS), and females had significantly higher scores on the non speech sound scale (HDHS). 5. A strong Sense of Coherence seems to be an important predictor in quality of life – stronger SOC was related to better general quality of life, less frequent vertigo severity symptoms and somatic anxiety, and less severe tinnitus and hearing disability. 6. SOC means did not differ significantly from the health reference group or patients with peripheral vestibular disorders.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
23	Soderman et al. (2002)	112 (58f, 54m)	Mean=55 Range 28-88	To evaluate self-reported quality of life in a group of patients with Meniere's Disease by a multidimensional approach and to identify predictors of the results.	Short form -12 (SF-12) Sickness Impact Profile (SIP) Hospital Anxiety and Depression Scale (HADS) Sense of Coherence Scale (SOC) Function Level Scale (FLS) Vertigo Symptom Scale - short (VSS) The Hearing Disability Handicap Scale (HDHS) Tinnitus Severity Questionnaire (TSQ)	Cross sectional study – recruited from 2 hospitals.	Reference groups from other studies – sample of population of Stockholm county for SIP; healthy individuals for SOC; people with peripheral vestibular disorders for SOC, SIP, and HADS; Swedish reference material for SF-12	Means & S.D's were given for the SF-12, HAD, SOC, but not for the others. The SF-12, HAD and SIP means were given when divided by FLS groups.	Correlation coefficients and their significance were given for the multiple regression. For all other tests, only significance given.	1. MD patient scores were significantly lower for mental and physical dimensions of the SF-12 than reference group. 2. MD patient scores were significantly lower that Stockholm county reference group for all dimensions of SIP except eating, but significantly higher than peripheral vestibular disorder patients for psychosocial, sleep, home management, and recreation dimensions. 3. HADS scores did not differ significantly from patients with peripheral vestibular disorders. 17% had definite clinical anxiety, and a further 34% had possible clinical anxiety. 3% had definite clinical depression, and a further 13% had possible clinical depression. 4. SOC scores did not differ significantly from healthy individuals or patients with peripheral vestibular disorders. 5. Those whose activities of daily living (FLS) were not affected by vertigo had a significantly higher quality of life in all areas of SIP (except eating), HADS and SF-12 (except mental component) 6. Older age predicted poorer physical health (SF-12). 7. Higher SOC predicted better scores in anxiety and depression (HADS), psychosocial dimension and sleep subscale (SIP), and mental component (SF-12). 8. The VSS predicted the recreation subscale and physical and psychosocial dimensions (SIP), FLS, and physical component (SF-12). 9. Tinnitus predicted anxiety (HADS). 10. The speech perception subscale (HDHS) predicted the mental component (SF-12). 11. Demographic variables, SOC, vertigo, tinnitus and hearing variables accounted for 38% of the variance in the SIP, 44% of the mental component of the SF-12, 43 % of the physical component of the SF-12, 60% of the anxiety subscale of the HADS, 50% of the depression subscale of the HADS, and 40% of the FLS.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
24	Stouffer & Tyler (1990)	63 (31 f, 32 m), (of 528 audiology – otology patients)	Mean=50 (S.D=16)	To obtain data on reactions to tinnitus – comparing aetiological categories by: pitch, loudness, annoyance, depression, and interference with: sleep, concentration and speech.	Questionnaire Part A: (by patient) description of tinnitus, problems associated with tinnitus, and other aspects of tinnitus. Part B (by audiologist) : primary diagnosis, primary complaint, air-conduction threshold)	Cross sectional study – recruited from audiology-otology departments of 4 hospitals	95 patients with noise induced hearing loss (NIHL), 64 with presbycusis, and 62 with middle ear disease.	Y	Only significance given for MD results.	1. Subjective loudness, annoyance, depression and interference with sleep and speech were significantly greater for MD than NIHL patients. 2. Annoyance, depression, and interference with concentration and speech were significantly greater for MD than presbycusis patients. 3. Loudness was significantly greater for MD than middle ear disease patients.
25	Takahashi et al. (2001)	60 (41f, 19m)	Mean=44.6 (SD=14.9)	To understand the influence of behavioural characteristics and lifestyle on the onset of Meniere's disease.	Questionnaire on: The behavioural characteristics of Type A, self restraint and escape The causes of anxiety. Means of relaxation. Symptoms incidental to anxiety that seem to be caused by autonomic nervous disorders including stuffed ear or tinnitus, a churning stomach or diarrhea, giddiness or fainting, dry eye and palpitations or perspiration.	Cross sectional study – recruited from outpatient clinics	936 people who worked in the same industry as the MD patients	Y	Y for some of the correlations, Only significance given for Mann-Whitney U test.	1. Patients with Meniere's disease had significantly larger scores than controls on all subcategories of behavioural characteristics (type A, self-restraint, and escape), anxiety, and symptoms of anxiety. 2. No difference was found on means of relaxation. 3. Subcategories of behavioural characteristics were all correlated for both MD and control groups. 4. Strength of anxiety was not correlated with behavioural characteristics or severity of symptoms for MD patients, but was for the control group. 5. In the MD patients, severity of symptoms was significantly correlated with the behavioural characteristic - escape, and was weakly correlated with all behavioural characteristics for the control group.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
26	Willatt & Yung (1988)	20 (12f, 8m)	Actual ages given Range 25-70	To identify, by a complete patient assessment, those factors important in recovery following labyrinthectomy	The Health Locus of Control Scale Eysenck Personality Inventory (EPI) The Leeds scale (anxiety / depression) Demographic data and medical history. Neuro-otologial, opthalmological and cardiovascular examination. Postural, audiological and caloric tests.	Cross sectional study	None	Actual scores given	Only significance given.	1. Those who made a poor recovery were significantly more likely to have an external health locus of control, be extraverted, anxious and/or depressed. 2. No correlation was found between recovery of the patient and the patient's ability to perform tests of maintenance of postural equilibrium (good recovery was defined by being able to resume a normal occupation and social life).
27	Yardley et al. (2003)	509: Main Q (296f, 211m) 370: Second Q (perceived attitudes of health professionals and usage of Ménière's society resources of main sample.	Mean=58.9 (SD=13.03) Range 21-86	To determine the factors associated with better or worse quality of life in a sample of people with Ménière's disease.	SF-36 Disease severity The Vertigo Symptom Scale (VSS) Demographic data, medical history, length of Ménière's society membership, living with someone who could provide help, living with a dependent, usage of Ménière's society resources, perceived helpfulness of attitude of GP and ENT consultant.	Cross sectional study – recruited from the Ménière's Society	Normative means (from another study) for the SF-36 for people with and without a long-term health problem.	Y	Y	1. People with MD had similar levels of physical and social functioning, energy and vitality, mental health and pain as people with a long term health problem, but had greater physical and emotional role limitations. 2. Variables associated with a less good quality of life were more severe vertigo, fullness in the ear, tinnitus, hearing loss, being younger, being female, living alone, having a lower occupational status and believing that the attitude of health professionals is unhelpful. 3. Use of the Ménière's society resources was higher among those with worse scores. 4. No relationship was found between SF-36 scores and duration of illness or membership of the Ménière's society. 5. The majority of respondents use the Ménière's society as source of medical information, rather than for social purposes such as contacting other members. 6. Usage of Ménière's society resources were significantly correlated with more severe vertigo and fullness in the ear, longer duration of illness and longer duration of membership.

Ref No.	Article Reference	MD Sample Size	Age	Aim	Measures used	Design	Control Group	Means & S.D's presented	Statistical Analysis Presented	Findings
28	Yardley et al. (1999)	8 (of 172 vertigo patients)	Not given specifically for MD	To validate the Vertigo Symptom Scale for a non-European, Spanish speaking population	The Vertigo Symptom Scale (VSS) The Vertigo Handicap Scale (VHQ) Beck Anxiety Inventory (BAI) Beck Depression Inventory (BDI)	Cross sectional study – recruited from hospital	40 people free from known physical and psychological disorder.	Y	Y	1. Patients with Meniere's disease were significantly higher than the control group on vertigo (VSS) and vertigo handicap (VHQ), but not on somatic anxiety (VSS).

6.3.2 Presence of Mechanisms

Studies were reviewed for evidence for the components of each mechanism. Several components were a feature of more than one mechanism. In order to clearly distinguish between mechanisms, the results for these shared components and the components unique to each mechanism are given separately.

6.3.2.1 Shared components.

Four of the six components shared by more than one mechanism had been investigated (see Table 11). No studies examined the components of worrying or uncertainty causing distress. In addition to this, high risk/threat perception and high perceived likelihood of occurrence and avoidance behaviour were not studied by any good or medium quality studies. The good and medium studies only investigated the components of anxiety and negative affect. For anxiety, the studies found no significant difference between people with MD and people with peripheral vestibular disorder (23), people with peripheral vestibular disorders, people with central vestibular disorders, and people with benign paroxysmal positional vertigo (BPPV; 18), and healthy reference values (20). The same findings were observed for depression, with the exception of people with central vestibular disorders, who had higher levels of depression than people with MD (18).

In the qualitative study (7) participants nevertheless described the presence of all the shared components, which they reported were related to the lack of control during attacks, worry about and avoidance of the occurrence and/or possible triggering of future attacks, shame at appearing drunk, and uncertainty and fear of disease progression.

Table 11

Studies investigating shared components grouped by quality and direction of findings

	Good quality studies			Medium quality studies			Poor quality studies		
	+	NS	-	+	NS	-	+	NS	-
Anxiety (present in Worry, HA and AS)		23			18, 20		25	10, 19, 28	
Negative affect (present in Worry and AS)		23			18, 20	18	1, 24	2, 10, 19, 24	2
Worrying (present in Worry, HA and AS)									
Uncertainty causing distress (present in HA and AS)									
High risk/threat perception & high perceived likelihood of occurrence (present in Worry and HA)							2	2	
Avoidance behaviour (present in PTSD, HA and AS)								10	

+ = Presence of component is higher in people with MD than control groups or is higher in those with greater psychological distress; NS = Presence of component is not significantly different between people with MD and control groups / is not related to psychological distress; - = Presence of component is lower in people with MD than control groups or is lower in those with greater psychological distress.

6.3.2.2 Worry.

The components of worry are: poor perceived control; frequent mental rehearsal of negative outcomes and lack of mental rehearsal of positive outcomes; perseverative approach to tasks; low problem solving confidence; high sense of responsibility; and emotion focused coping. Only the component of low problem solving confidence was studied, and this was by one poor quality study (2). The study found that the problem solving confidence of people with MD was higher than people with dizziness in another study, but that problem solving confidence was significantly lower in those with greater levels of psychological distress.

Four of the components (poor perceived control; frequent mental rehearsal of negative outcomes & lack of mental rehearsal of positive outcomes; high sense of responsibility; emotion focused coping) were described in the qualitative study (7). This reported that participants disliked the loss of control over their body and their

situation during attacks, and frequently rehearsed negative thoughts about their symptoms resulting in anxiety and depression. Participants also reported being highly responsible persons before disease onset, and said they used emotional strategies to cope with their disease.

6.3.2.3 PTSD.

Six of the 12 components of PTSD were investigated in one good quality study, three medium quality studies, and five poor quality studies. These are presented in Table 12. No studies measured the components of re-experiencing; intense fear, helplessness, horror; arousal causing hypervigilance; arousal causing an exaggerated startle response; feeling detached from others; or sense of foreshortened future.

Table 12

Studies investigating components of PTSD grouped by quality and direction of findings

	Good quality studies			Medium quality studies			Poor quality studies		
	+	NS	-	+	NS	-	+	NS	-
Re-experiencing									
Distress / Impairment in social, occupational or other areas of functioning	23		23	1, 13		13	1, 17, 27	12, 17, 27	1, 17
Intense fear, helplessness, horror									
Arousal causing sleeping problems	23		23	13			24	24	
Arousal causing irritability					20		24	24	
Arousal causing concentration difficulties							24	24	
Arousal causing hypervigilance									
Arousal causing an exaggerated startle response									
Reduced interest / participation in activities	23		23						
Feeling detached from others									
Restricted range of affect						20			
Sense of foreshortened future									

+ = Presence of component is higher in people with MD than control groups or is higher in those with greater psychological distress; NS = Presence of component is not significantly different between people with MD and control groups / is not related to psychological distress; - = Presence of component is lower in people with MD than control groups or is lower in those with greater psychological distress.

The good and medium quality studies found that for the component distress / impairment in social, occupational or other areas of functioning, people with MD had significantly worse scores when compared to healthy reference values (23) and people with tinnitus (for social impairment only; 13), and impairment in functioning was worse in people with greater levels of psychological distress (1). People with MD had better scores when compared to people with peripheral vestibular disease (23), and people with tinnitus (for occupation only; 13). For the component 'arousal causing sleeping problems', people with MD had worse scores than healthy reference values (23), and people with tinnitus (13), but better scores than people with peripheral vestibular disorders (23). Similar results were found for reduced interest / participation in activities, with people with MD having worse scores than healthy reference values (23) but better scores than people with peripheral vestibular disorders (23). People with MD were not significantly different to healthy reference values in levels of irritability (20), but did have significantly less restricted range of affect.

The qualitative study (7) also discussed 6 of the 12 components (Re-experiencing; distress / impairment in social, occupational or other areas of functioning; intense fear, helplessness, horror; arousal causing hypervigilance; feeling detached from others; sense of foreshortened future). The authors described how participants kept thinking about the possibility of a new attack occurring, and that their social, family, and professional lives were impaired, in some cases to the point of giving up work and social activities. Participants reported traumatic memories attached to their first experience of vertigo, which they had interpreted as a sign of serious illness, and on diagnosis were frightened to learn that the disease was incurable. Participants also said they were vigilant to symptoms, withdrawn after onset, and some reported feeling suicidal at times.

6.3.2.4 Anxiety sensitivity.

The components of anxiety sensitivity are: fear (of anxiety symptoms, somatic sensations, loss of control, publicly observable symptoms, or MD specific fears); belief that anxiety symptoms will result in negative consequences; panic attacks;

avoidance of anxiety symptoms; alertness; stress; and increased maladaptive reactions to stressors over time.

Only the component of fear was measured by one (poor quality) study, which found no significant difference between people with MD, people with non MD dizziness, or dizziness free patients. Another poor quality study did however, measure general anxiety sensitivity (using the anxiety sensitivity index). This study suggested that people with MD were comparable to female college students and females suffering from anxiety disorders, but had lower levels than agoraphobic females (11), but this was not confirmed using statistical testing.

The qualitative study (7) discussed five of the components (fear; belief that anxiety symptoms will result in negative consequences; avoidance of anxiety symptoms; alertness; and stress). The authors identified the role of fear among participants in relation to attacks, disease progression and loss of control. Participants also reported a belief in and avoidance of getting upset in case it triggered an attack. They also reported vigilance to signs prior to attacks, and believed that attacks could be triggered by stress.

6.3.2.5 Health anxiety.

Seven of the 13 components of health anxiety were measured by two good quality studies, three medium quality studies, and five poor quality studies. These are presented in Table 13. The only component measured by the two good quality studies was low perceived ability to cope. People with MD were not significantly different in coping ability to a healthy reference group or patients with peripheral vestibular disorder (23), but ability to cope was worse in those with high levels of psychological distress (22). No significant difference was found between people with MD and people with tinnitus for the component of high perceived cost, awfulness, or burden (13). Similarly, no difference was found between people with MD and people with noise injury, other deafness, presbyacusis, or tinnitus on the component 'mislabelled as a personality disorder' (4). For the component 'specific illness assumptions and behaviours', results of the one medium quality study were mixed, depending on which subscale of the Illness Behaviour Questionnaire was

Table 13

Studies investigating components of Health Anxiety grouped by quality and direction of findings

	Good quality studies			Medium quality studies			Poor quality studies		
	+	NS	-	+	NS	-	+	NS	-
High perceived cost, awfulness, or burden					13				
Specific illness assumptions and behaviours				20	20	20			
Amplification/misinterpretation of somatic sensation							19		
Reassured by staff, but other worries emerge									
Low perception that external factors can help									
Resistant to psychological considerations, focus on physical solutions					20	20			
Physiological arousal from anxiety							25	28	
Selective attention to illness information									
Preoccupation with threat									
Low perceived ability to cope	22	23							
Previous experience of illness in self or others									
Experience of unsatisfactory medical management									
Mislabelled as a personality disorder					4		6, 19, 20, 25	19, 20	19

+ = Presence of component is higher in people with MD than control groups or is higher in those with greater psychological distress; NS = Presence of component is not significantly different between people with MD and control groups / is not related to psychological distress; - = Presence of component is lower in people with MD than control groups or is lower in those with greater psychological distress.

being considered. People with MD were significantly higher than healthy reference values for the subscale psychosomatic perception; not significantly different for general hypochondriasis, disease conviction, dysphoria, denial, and irritability; and significantly lower for affective inhibition (20). As support for the component of being resistant to psychological consideration and focusing on physical solutions would require low psychosomatic perception, and high disease conviction, these findings do not support this component.

The qualitative study (7) discussed seven of the components (high perceived cost, awfulness or burden; amplification / misinterpretation of somatic sensation; reassured by staff but other worries emerge; physiological arousal from anxiety; selective attention to illness information; preoccupation with threat; and experience of unsatisfactory medical management). Participants said they felt that symptoms were a great burden and distressing; associated strong emotions and somatic sensations with attack onset; described being vigilant towards symptoms and factors associated with attacks (to avoid them); thought constantly about the possibility of a new attack; and were reassured by medical staff, but were dissatisfied with information and healthcare provided.

6.4 Discussion

The purpose of this systematic review was to identify and assess research on psychological factors in MD since 1977 in relation to four mechanisms of distress in order to evaluate evidence for different explanations for how MD might be related to psychological distress. The aims were to see if components of the four mechanisms had been measured at all and if so, whether the presence of components were greater in participants with MD than controls, and whether levels of the components were greater in participants with MD who had higher levels of psychological distress. This discussion will firstly discuss findings relating to the presence of the mechanisms. Secondly, the findings comparing people with MD and control groups will be discussed. The limitations and implications of the control groups used in the reviewed studies will then be considered. Finally, the limitations of this systematic review will be discussed.

6.4.1 Presence of Mechanisms

The 28 studies identified in this systematic review had measured some aspects of all of the four different mechanisms, although not all of the individual components had been measured. The mechanisms share some of the same components, with anxiety and depression being the only shared components that were measured by good or medium quality studies. Excluding the shared components, the highest frequency of studies measuring components was found for the mechanisms of PTSD and health

anxiety. PTSD components measured by good or medium quality studies comprised distress or impairment in functioning, sleeping problems, irritability, reduced interest or participation in activities, and a reduced range of affect. The health anxiety components of high perceived cost, awfulness or burden, specific illness assumptions and behaviours, and being resistant to psychological considerations and focusing on physical solutions were measured by good or medium quality studies. Much less research was found on the components of anxiety sensitivity, with general anxiety sensitivity and the component of fear being measured by only poor quality studies. The least amount of research had been carried out using the components of worry, with only the component of low problem solving confidence being measured by one poor quality study. It is also important to note that the low frequency of studies measuring the mechanisms is not an indication that the mechanisms are not applicable, but rather that their presence has not been considered by many studies.

6.4.2 Comparison Between MD and Control Groups

When the studies were assessed to see whether the components were present to a greater extent in people with MD than control groups, results among the good and medium quality studies varied depending on the type of control group that was used. Therefore healthy control groups and patient control groups will be discussed separately.

6.4.2.1 Healthy control groups.

When compared with healthy control groups, people with MD had higher scores than healthy controls on measures of distress or impairment in functioning, sleeping problems, a reduced interest or participation in activities, and the illness behaviour category of psychosomatic perception. People with MD showed no significant difference to healthy controls on measures of anxiety, depression, perceived ability to cope, and the specific illness behaviour categories of general hypochondriasis, disease conviction, dysphoria, denial, and irritability. People with MD only had lower scores than healthy controls for the illness behaviour category affective inhibition.

6.4.2.2 Patient control groups.

When people with MD were compared with patient groups, people with MD had significantly higher social impairment scores and sleeping problems when compared with people with tinnitus. People with MD did not differ from patient controls on anxiety measures when compared with people with peripheral vestibular disorders, central vestibular disorders, or benign positional vertigo. Depression measures were no different in people with MD when compared to people with peripheral vestibular disorders or benign positional vertigo. No difference was found between people with MD and people with peripheral vestibular disorders for perceived ability to cope. High perceived cost, awfulness or burden was no different in people with MD when compared to people with tinnitus. No difference was also found in the measurement of personality disorders between people with MD and those with noise injury, presbyacusis, other deafness, or tinnitus. People with MD had significantly lower levels of depression only when compared with people with central vestibular disorders, and less impairment in occupational functioning when compared with people with tinnitus. They also had better scores for sleeping problems, and reduced interest or participation in activities when compared to people with peripheral vestibular disorders.

6.4.2.3 Limitations and implications of control groups used in studies.

As a wide variety of control groups has been used it makes the results difficult to compare directly. It may be useful for future work to use a more standardised approach when choosing control groups, to provide a clearer picture of how people with MD compare to controls. Crary and Wexler (1977) argued that all differences between groups are negated when vertigo is controlled for, and emphasised the importance of controlling for vertigo symptoms when designing studies. They drew attention to the differences in research findings up to 1977 depending on whether people with MD were compared with people who had vertigo or not. These differences are still evident in the research identified within the current review. Although many of the studies included in the current review did use control groups, they did not all use vertiginous control groups. Some studies used healthy controls or healthy or patient based norm scores for standardised measures, whereas others

used different patient groups that can roughly be divided into those with conditions that include vertigo as a symptom, and those that had hearing disorders. In some studies, authors did not collect their own control data, but used results from other studies as their control data. Such comparisons are not ideal as they cannot minimise differences due to extraneous variables. In total, only four studies collected their own control data which included people with dizziness or vertiginous conditions (studies 10, 14, 18, and 19), but none of these studies mentioned matching controls with participants on severity of vertigo. Because of the absence of matched vertiginous controls in study design, research still cannot confirm nor disprove Crary and Wexler's (1977) premise that differences between groups are negated when vertigo is controlled for.

Nevertheless, it is striking that the majority of studies found anxiety and depression not to be significantly different in people with MD compared to healthy or patient control groups. The focus of the literature has historically been on debating the cause and context of distress, but has never questioned the presence of distress (Hinchcliffe, 1967a; Hinchcliffe, 1967b; House et al., 1980; Nobbs, 1987; Stephens, 1975). Although this lack of significant difference appears to be a contradiction of what is commonly observed and reported of people with MD, it is important to note that even among the good and medium quality studies, the quality of the control group data was limited. The good quality study by Soderman and colleagues (2002) included 22% of people with MD in their control group of people with peripheral vestibular disorder. The medium quality study carried out by Savastano and colleagues (1996) did not collect control data, but appeared to statistically compare their MD group against clinical cut-off values without the use of standard deviations. Although the lack of significant difference should therefore not be given too much weight, it should also be noted that the evidence for elevated anxiety and depression in MD originated largely from poorer quality studies in psychiatric populations, which appear not to be representative of MD patients in general.

6.4.3 Variation by Distress Level

The third aim of this review was to determine whether the presence of components was greater in people with MD who have higher levels of psychological distress than

those with lower levels of distress. This question was not considered by many studies included in this review, and should certainly be considered in future studies. In the studies that did consider the differences between those with high and low levels of distress, people who had higher levels of distress were likely to have poorer problem solving confidence, a greater impairment in functioning, and a lower perceived ability to cope.

6.4.4 Empirical Quality and Implications for Future Research

It is disappointing that in over 25 years, and after the key paper by Crary and Wexler (1977) concluded that most of the research up to that date was of poor empirical quality, that so few studies of basic empirical quality have been conducted on psychological factors in MD. The majority of the full texts of published articles obtained and considered for the review were not suitable because they were either not empirical studies (personal accounts, review articles or articles on diagnosis, management or treatment, clinical case studies, or opinions), or had included a percentage of people with MD but did not distinguish their results from participants with other illnesses by presenting their data separately. Other studies collected data, but carried out no inferential statistics, reporting only descriptive data. A great deal of the information cited about people with MD is based on findings from such studies, and yet they have a poor empirical basis. Researchers should be more aware of the quality of the research when drawing conclusions from research about people with MD.

Of the studies that were selected for the review, the overall quality was also disappointing. A number of studies were substantially underpowered, so it is possible that non-significant results may be type two errors, and significant results may not necessarily be representative or generalisable beyond the observed sample. Studies would benefit from a more rigorous planning procedure, planning the design and methodology of future studies at an a-priori stage, particularly sample size calculations, quality and appropriateness of measures, and type of analysis. Despite there being so many poor quality studies, there were a handful of studies that were clearly of a much better overall quality than others, so it is encouraging to know that some good research is being carried out.

All studies apart from one were cross sectional, and the one longitudinal study did not use multidimensional measures. Future studies of psychological factors in people with MD should definitely consider the use of longitudinal designs in order to determine whether the psychological factors develop and/or change over time within individuals as the disease progresses, or if different individuals respond in different ways.

Although limited in its quality, the qualitative study was the only one to be carried out in this area since 1977, and it described many of the components for all the mechanisms. Although the qualitative study results cannot be regarded as measurement of the components, it does suggest a possible presence that warrants further investigation. A good starting point for future research would be to explore and represent the experiences and views of people with MD further though sound qualitative studies. Future research should also include empirically sound research that specifically investigates and compares the presence of these mechanisms in people with MD.

6.4.5 Limitations of the Systematic Review

This systematic review had several limitations, which will be discussed in turn. Firstly, in the search strategy, search terms for the databases Medline, Embase, and WoS were entered together as one search term. This limited the sensitivity to see which terms were most predictive compared with the results that might have been returned if the search terms had been entered and combined separately.

The second limitation is that I was the only person involved in the study selection and data extraction process. Ideally, two or more people should be involved in this process for three main reasons. The first reason is to reduce the possibility that relevant studies could be missed, the second is to check the clarity of the inclusion and exclusion criteria, and the third is to reduce individual bias in the selection and data extraction process. The rate of agreement between reviewers can be calculated, and any differences in opinion between the reviewers can be resolved through

discussion. However, given the time and effort involved in these processes, it was beyond the scope of this thesis to have a second reviewer.

Although the purpose of this systematic review was to introduce the consideration of alternative mechanisms of distress, this unique approach to data extraction and synthesis can also be viewed as a limitation. This is because the components of the mechanisms were examined retrospectively in studies that did not set out to actually measure these mechanisms, with the concepts and findings from the actual studies being reinterpreted in ways that were not intended by the authors. Therefore, if viewed as a piece of empirical work, this methodology is fundamentally flawed. However, if this methodology is viewed as an evaluation of the literature, it could be considered to provide a stronger base on which to base hypotheses for future empirical work than just a straightforward literature or systematic review. This is because in addition to the quality evaluations that are made of the studies (which is an advantage of systematic reviews in general), qualitative comparisons are drawn between the actual findings of the studies and the components hypothesised in the systematic review. These comparisons are then grouped so that any possible patterns can be identified. Future work can then be carried out to assess whether or not these patterns can be confirmed when the hypothesised components are explicitly measured empirically. If this systematic review had simply summarised the main findings from the studies included, it would have been a very different review, and less helpful in moving the field forward from the psychosomatic vs. somatopsychic debate into considering models of distress that have methods of psychological treatment associated with them.

It is important to note however, that the findings of any systematic review, including this one, are only as reliable as the quality of the studies allow, and due to the lack of quantity and quality of research, the findings of this review can only be taken as a preliminary indication of the possible presence of each mechanism.

6.4.6 Conclusions

Evidence was found for each of the four mechanisms. In suggesting PTSD as a mechanism for distress in MD, elevated levels were found for the components of

distress or impairment in functioning, sleeping problems, and reduced interest or participation in activities. For health anxiety, people with MD had elevated scores on the component of specific illness assumptions and behaviours. The presence of anxiety sensitivity was suggested by high scores on a general anxiety sensitivity questionnaire. Beyond the elements that were reported in the qualitative study, no elevated levels were found for the components of worry. This review has therefore provided sufficient support for each of the four mechanisms to suggest that these areas are worthy of further and more specific investigation, whilst also prompting researchers in the area of MD to pay more careful attention to methodological issues.

As this review was limited by its retrospective approach, the study reported in the next chapter investigated whether there is any evidence for the mechanisms when they are measured explicitly and whether they can help us to understand how distress develops in MD. It would be beyond the scope of this thesis to measure all four mechanisms, as the final study was also intended to measure the relative influence of significant predictors of anxiety found in chapter 4. Therefore, as the most evidence was found in this review for the possible presence of the mechanisms of PTSD and health anxiety, only these two mechanisms were measured in the final study.

Chapter Seven: Understanding Distress in Ménière's Disease

7.1 Rationale and Aims

Although high levels of psychological distress have been widely noted among people with Ménière's disease (MD), few studies have actually considered psychological mechanisms that might explain the psychological symptoms. Understanding the mechanisms linking MD with distress would enable psychological treatment and support to be more effectively targeted.

There were three main aims to this final study. The first aim was to build on and draw together the observations from the systematic review (chapter 6) and the study on predictors of adjustment outcomes in people with MD (chapter 4) to further explore which of these factors contribute most to distress (measured by anxiety, depression and handicap). A major limitation of the systematic review was that the components of the mechanisms were examined retrospectively in studies that did not set out to actually measure these mechanisms. This study therefore took the two mechanisms for which the most suggestive evidence was found in the systematic review (post-traumatic stress disorder (PTSD) and health anxiety), and investigated whether there was any evidence for their contribution to distress when they are measured explicitly. This study also sought to investigate whether the four independent predictors of anxiety following self treatment identified in chapter 4 would firstly, also predict anxiety under non-treatment conditions (in conjunction with different covariates), and secondly, be relevant predictors of other measures of adjustment. Although it would have been interesting to see how all the independent variables measured in chapter 4 performed in relation to the other measures of adjustment included in this study, this would have resulted in a large number of variables being included, reducing the power of the study as well as potentially reducing the response rate. Therefore only the variables that had independently predicted anxiety were included. Consequently, in addition to PTSD and health anxiety, intolerance of uncertainty, the two IPQ-R subscales illness coherence and emotional representations, and somatic anxiety were included as additional expected predictors of MD related distress in this study. Demographic and illness characteristics were also measured, to take account of their effects on distress.

It was originally intended to model and test the relationships between these variables using structural equation modelling, however, preliminary analysis revealed that this method of analysis was not the most appropriate. One of the assumptions of path analysis requires that the indicator variables should only be correlated with the latent variables they contribute to. This assumption was tested in two ways. The first was to examine the correlations between all the variables. The second was to carry out factor analyses to see whether the individual questionnaire items loaded only onto their respective variables, and whether the variables loaded together onto the constructs being proposed in the hypothesised models. Observation of the correlations (in Tables 15 and 16) between variables revealed that almost all variables were correlated with each other. The results of the factor analysis (not reported here), showed that the factors were not distinct, and a great deal of cross-loading existed between factors in factor analyses using both varimax and oblique rotation. Therefore, it was decided that rather than try to model the relationship between the variables, it would be more appropriate to try to identify the variables that best predicted distress. Once clearly defined, these could then be modelled in future research. It was expected that demographic and illness characteristics and psychological variables would all be related to distress to some extent. The hypothesis was that after controlling for demographic characteristics, illness characteristics would predict distress, and that after controlling for demographic and illness characteristics, psychological variables would predict distress.

The second and third aims relate to comparing participants in the MD group with the control group. Recommended clinical cut-off levels exist for the measures of anxiety, depression and PTSD used in this study. Therefore, the second aim of this study was to assess what proportion of participants met clinical levels for these variables. Studies of people with vertigo often report they have higher levels of distress than controls (e.g. Monzani et al., 2001). However, the systematic review in chapter 6 found that among the good and medium quality studies reviewed, no significant difference existed in levels of distress between people with MD and control groups. Therefore the third aim of this study was to compare whether people in the MD group differed from healthy controls. It was not relevant to ask healthy people about illness specific variables, but they were compared with the MD group

on all other relevant measures. Crary and Wexler (1977) also recommended the use of vertiginous controls. This was attempted, but due to delays in the study this data was being collected with, it was not possible to obtain the data in time for the completion of this thesis. It was hypothesised that a proportion of participants would meet clinical levels, and that where comparisons could be made between the MD and control groups, that levels of distress would be higher in the MD group.

7.2 Method

7.2.1 Design

The study used a cross-sectional questionnaire-based design. The protocol was approved by the Ethical Committee of the School of Psychology, University of Southampton. Consent was assumed to be given if the participant completed and returned the questionnaire (this was stated in the information sheet).

As it was originally intended to analyse the data collected for the study using structural equation modelling, the sample size calculations were based on this intention. Using the rule of thumb that a study should have eight times the number of independent variables plus 50 per regression path (Tabachnick & Fidell, 2007), 686 participants were required. Allowing for 10% unusable returns, and an expected 55% response rate (Yardley et al., 2003), it was calculated that a minimum of 1373 people needed to be contacted. In order to boost response rates, two reminders were used. The use of two reminders has been reported to boost response rate by 15% after the first reminder, and a further 11% after the second reminder (Barclay et al., 2002).

7.2.2 Participants and Procedure

Participants were recruited by sending packs to 1,400 randomly selected members of the Ménière's Society, inviting them to participate. The packs (see Appendices I - K) contained a covering letter from the Ménière's Society, an information sheet, the questionnaire booklet, and a return freepost envelope. In addition to this, we enclosed a control information sheet, control questionnaire booklet and a second

return freepost envelope and requested that the person pass these on to a friend or relative without Ménière's disease who might be willing to complete them (see Appendices L & M). The information sheet and questionnaire for the control group was printed on yellow paper so they would not be mixed up with the information sheet and questionnaire for the MD group. There were no inclusion or exclusion criteria for the study other than the requirement that participants completing the questionnaire for people with MD had a diagnosis of MD, and that participants completing the control questionnaire for people without MD did not have MD or severe dizziness.

The MD group were asked to return the pack if they did not want to take part in the study, and it was stated in the information sheet that if they did not return the pack either completed or uncompleted they would receive up to two reminders. The initial packs for the MD group were labelled with a unique identification number so that non-responders could be identified. To maintain the confidentiality of participants, the identification number could only be matched to participants by the Ménière's Society. One month after the initial packs were sent, non-responders were sent a reminder pack containing the covering letter from the Ménière's Society, an amended information sheet that did not refer to the control questionnaire, the questionnaire booklet and a return freepost envelope (see appendix N). One month after the reminder packs were sent, the documents were sent again in a second reminder pack (see appendix O). Control questionnaires were not included in either of the reminder packs.

7.2.3 Measures

Several of the scales were used in the previous two studies (chapters 3 and 4), and so are only described briefly here. See chapter 3 for more details about the Vertigo Symptom Scale, the Hearing Disability Questionnaire, Tinnitus Severity Index and Aural Pressure Index, the Revised Illness Perception Questionnaire, the Intolerance of Uncertainty Scale, and the Hospital Anxiety and Depression Scale.

7.2.3.1 Demographic and illness characteristics.

As no scales exist that measure all the symptoms of MD together, the symptoms of MD (vertigo, hearing loss, tinnitus and fullness in the ear) were measured separately. Length of time since symptoms began (illness duration), length of time since last attack (illness recency), gender, and age were assessed using single items. Single items were also used to confirm whether participants completing the questionnaire for people with MD had a diagnosis of MD, and whether participants completing the questionnaire for people without MD (the control group) did not have MD or suffered from severe dizziness. Vertigo was assessed using the 'vertigo severity' subscale of the long version of the Vertigo Symptom Scale (VSS; Yardley et al., 1992a). Hearing disability was assessed using five questions from the nine item Hearing Disability Questionnaire (Lutman et al., 1987). Tinnitus and fullness in the ear were assessed using the Tinnitus Severity Index and Aural Pressure Index (Stahle et al., 1981; Cass, 1999).

7.2.3.2 Psychological variables.

Illness perceptions were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). Only the 'illness coherence' and 'emotional representations' subscales were included in this study.

Somatic anxiety was assessed using the 'somatic anxiety' subscale of the long version of the Vertigo Symptom Scale (VSS; Yardley et al., 1992a).

The personality trait intolerance of uncertainty was measured using the validated English version of the Intolerance of Uncertainty Scale (IUS; Buhr & Dugas, 2002). The original version of the IUS (Freeston et al., 1994) which was used in the studies reported in chapters 3 and 4, was validated in French and then later translated into English. Only minor differences exist between the two versions in how the questions are worded.

Health anxiety was measured using the short form Health Anxiety Inventory (SHAI) and subscales from the Health Anxiety Inventory (HAI; Salkovskis et al., 2003). The

HAI and SHAI are suitable for use with people who have a physical illness, as they do not include items measuring the belief that a person has an illness. The scales can distinguish between people who have health anxiety and anxiety disorders, and those who have physical illness. The SHAI comprises 14 items and measures whether people are excessively concerned about their health. The 4 item short version of the negative consequences scale was used. This measures the extent to which a person perceives that having a serious illness results in negative consequences such as poor quality of life, loss of dignity, or that they cannot be cured. Items on these two scales are scored on a 4-point scale ranging from 0 to 3, and if people select more than one answer, the score for the highest answer is used. Two subscales from the long version of the HAI were also used: the reassurance seeking and avoidance behaviour subscales. The reassurance seeking subscale comprises 9 items measuring to what extent people seek reassurance from different sources such as friends, family, books, and health professionals. Each item in this subscale is rated on a scale of 0 to 8, with anchors every two points of 'never', 'rarely', 'sometimes', 'often', and 'daily'. The avoidance behaviour subscale includes 10 items and measures the extent to which people would avoid situations because of fear or unpleasant feelings. These situations include talking, reading or thinking about illness, watching TV programmes about illness, or going to hospital or the doctors. This subscale is also rated on a scale of 0 to 8, with anchors every two points of 'would not avoid it', 'slightly avoid it', 'definitely avoid it', 'markedly avoid it', and 'always avoid it'. Minor amendments were made to the items that referred to having a serious disease, to specify a serious disease other than MD. This was done so that the scores in the MD group were not artificially elevated by MD being a serious disease. These amendments did not compromise the internal consistency of the scales (SHAI α = .88, SHAI: negative consequences α = .74).

PTSD was measured using the PTSD Checklist (PCL; Weathers et al., 1993), a 17 item scale that follows the DSM-IV criteria for PTSD. Items 1-5 relate to criterion B (re-experiencing), items 6-12 relate to criterion C (avoidance / numbing), and items 13-17 relate to criterion D (arousal). Participants rate on a 5 point scale the extent to which they had been bothered by symptoms over the last month. Response options comprise 'not at all' (1), 'a little bit' (2), 'moderately' (3), 'quite a bit' (4), and 'extremely' (5). Blanchard and colleagues report that the PCL has the best

diagnostic efficiency when a total score of 44 or more is used as a cut-off for PTSD diagnosis (Blanchard et al., 1996). The authors allow the introductory text and questions to be worded to refer generally to stressful experiences in the past, or to be changed to refer to a specific event. For the purposes of this study, the introductory text and questions were worded to specifically refer to severe Ménière's attacks. This specific version of the scale maintained good internal consistency in this study, with Cronbach's alphas of 0.90 for the whole scale, 0.83 for the re-experiencing subscale, 0.82 for the avoidance / numbing subscale, and 0.81 for the arousal subscale.

7.2.3.3 Distress.

Depression and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Dizziness handicap was measured using the total score of the Dizziness Handicap Inventory (DHI; Jacobson & Newman, 1990). The DHI comprises 25 items that evaluate the extent to which dizziness is perceived to impact on functional, emotional and physical aspects of everyday life. The scale is scored on a three point scale, with 0 points for answering 'no', 2 points for answering 'sometimes', and 4 points for answering 'yes'.

7.2.4 Data Treatment

Range, minimum and maximum scores were checked on all variables, and 10% of the data entry was checked revealing an accuracy rate of 98.57% for the MD group, and 99.93% for the control group. When two answers were given for the same question, they were treated as missing. Data were excluded if less than half of the questionnaire had been completed. Missing data were replaced with the participant's personal average for that subscale if at least half of the items in that subscale had been answered (Ware et al., 2000). If less than half of the items in a subscale had been answered, the variable mean was imputed.

7.3 Results

Figure 3 presents the return and exclusion rates for the study. Of the 1400 members of the Ménière's Society that were invited to take part in the study, 1241 (88.6 %) people returned the questionnaire (860 [61%] at the initial administration, 280 [20%] at reminder 1, and 101 [7.2%] at reminder 2). Of these, 847 (60.5 %) had completed the questionnaire (604 [43.1%] at the initial administration, 182 [13%] at reminder 1, and 61 [4.4%] at reminder 2). Of the 394 (28.1%) questionnaires that were returned uncompleted, 21 questionnaires were undelivered, 4 recipients were recently deceased, 14 were too unwell, 21 said they did not have MD, 37 said they did not have any symptoms at the moment, 4 had too many other diseases to be able to answer the questions in relation to MD only, 29 said they were not able to complete the questionnaire at this time, 2 said they were no longer members of the Ménière's Society, 1 said they were not distressed by MD, 4 said they were too distressed, and 257 did not give a reason. A total of 47 questionnaires were excluded from the MD group. Six participants were excluded as less than half of the questionnaire had been answered, 34 had not been diagnosed with MD, and 7 did not answer the question confirming whether or not they had been diagnosed with MD. The final number of MD group responses that were included in the analyses was 800 (57.1%), comprising 295 (36.9%) males and 505 (63.1%) females. The age range was 25 - 90 years.

Of the 1400 questionnaires requested to be passed to someone without MD, 494 (35.3 %) were returned completed. A total of 10 questionnaires were excluded from the control group. Eight were excluded as they had MD or severe dizziness, and 2 did not answer the question confirming whether or not they had MD or severe dizziness. The final number of control group responses that were included in the analyses was 484 (34.6%), comprising 216 (44.6%) males and 268 (55.4%) females. The age range was 18 - 93 years. The means and standard deviations for all variables measured in the MD and control groups are presented in Table 14.

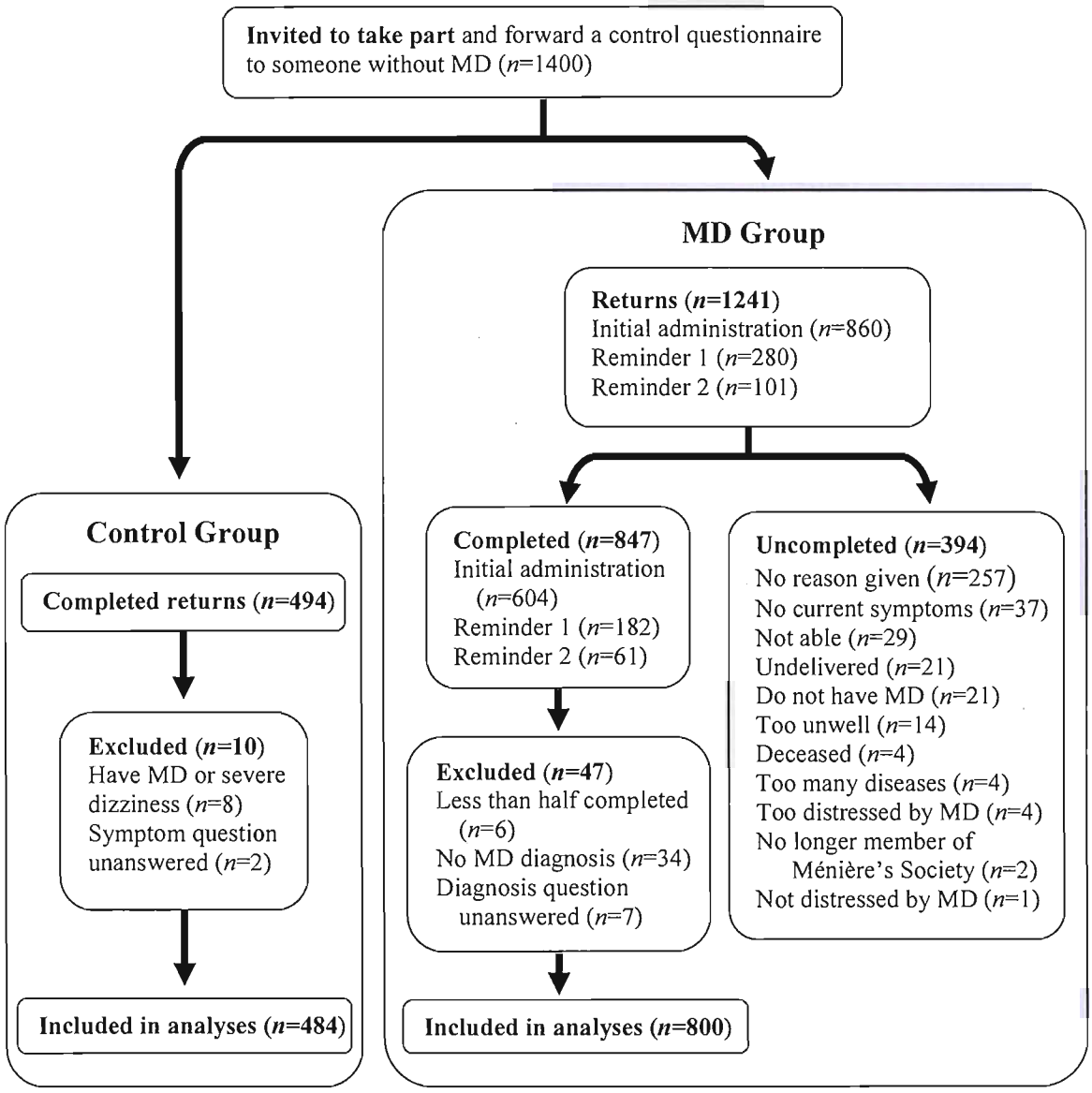


Figure 3

Return and exclusion rates for study

Table 14

Means, standard deviations (SD) and effect size (Cohen's d) comparing the MD and control groups (unless specified otherwise)

	MD group (*n*=800)		Control group (*n*=484)		Effect size
	Mean	SD	Mean	SD	*d*
Demographic characteristics					
Gender (females *n* presented)	505	-	268	-	.16
Age	60.54	12.54	55.57	14.44	.37
Illness characteristics					
Illness duration (months)	168.86	122.78	-	-	-
Illness recency (days)	512.94	1037.40	-	-	-
Tinnitus	3.80	1.54	-	-	-
Fullness in the ear	3.24	1.55	-	-	-
Hearing disability	13.87	7.46	-	-	-
VSS: Vertigo	19.39	15.53	-	-	-
Psychological variables					
VSS: Somatic anxiety	18.91	12.75	-	-	-
IPQR: Illness coherence	16.77	4.86	-	-	-
IPQR: Emotional representations	18.12	5.62	-	-	-
Intolerance of uncertainty	51.33	20.28	50.29	16.62	.06
SHAI	11.01	6.14	8.56	5.10	.43
SHAI: Negative consequences	2.79	2.17	2.56	1.94	.11
HAI: Avoidance behaviour	10.58	10.41	10.15	10.20	.04
HAI: Reassurance seeking	17.35	8.66	16.13	9.09	.14
PTSD	31.62	11.40	-	-	-
Distress					
Anxiety	7.68	4.68	5.88	3.73	.43
Depression	5.49	4.02	3.12	2.72	.69
Handicap	47.20	24.44	-	-	-

7.3.1 Predictors of Anxiety, Depression and Handicap

The bivariate correlations between each predictor variable and the dependent variable are shown in Table 15. With the exception of illness duration and age (for depression and handicap), all variables were significantly correlated with anxiety, depression and handicap. Large effect sizes were observed for the presence of PTSD symptoms, having an emotional response to MD, being intolerant of uncertainty, and reporting more health anxiety, somatic anxiety, and vertigo. The bivariate correlations between all the predictor variables are presented in Table 16. Many of the predictor variables were significantly correlated, with the largest effect sizes being observed amongst the psychological variables.

Three hierarchical regressions were carried out to assess the effects of illness characteristics on distress, controlling for demographic characteristics, and the effects of the psychological variables on distress, controlling for demographic and illness characteristics. In each hierarchical regression, age and gender were entered into the first step. Illness characteristics (illness duration, illness recency, vertigo, tinnitus, hearing disability and fullness in the ear) were entered into the second step. Psychological variables (PTSD, intolerance of uncertainty, somatic anxiety, the illness coherence and emotional representations subscales of the IPQ-R, health anxiety, health anxiety related beliefs about negative consequences of illness, and health anxiety related avoidance behaviour and reassurance seeking) were entered on the final step. Anxiety, depression, or handicap total score was the dependent variable for each of the three regressions. As many of the variables were significantly correlated, the collinearity diagnostics were checked. Tolerance levels below 0.2, and variance inflation factors above 10 are considered to be indicative of multicollinearity (Field, 2005). The tolerance and variance inflation factors were within acceptable limits for all the predictor variables.

Table 15

Bivariate correlations (Pearson's r) between anxiety, depression and handicap, and demographic and illness characteristics and psychological variables

	Anxiety (*r*)	Depression (*r*)	Handicap (*r*)
Demographic characteristics			
Age	- .15 ***	- .02	- .04
Gender	.20 ***	.07 *	.22 ***
Illness characteristics			
Illness duration	.01	- .00	.05
Illness recency	- .16 ***	- .19 ***	- .28 ***
Tinnitus	.17 ***	.17 ***	.17 ***
Fullness in the ear	.36 ***	.36 ***	.43 ***
Hearing disability	.17 ***	.27 ***	.32 ***
VSS: Vertigo	.40 ***	.46 ***	.58 ***
Psychological variables			
VSS: Somatic anxiety	.59 ***	.56 ***	.65 ***
IPQR: Illness coherence	- .22 ***	- .22 ***	- .21 ***
IPQR: Emotional representations	.66 ***	.57 ***	.52 ***
Intolerance of uncertainty	.66 ***	.54 ***	.47 ***
SHAI	.61 ***	.53 ***	.45 ***
SHAI: Negative consequences	.40 ***	.44 ***	.28 ***
HAI: Avoidance behaviour	.14 ***	.20 ***	.16 ***
HAI: Reassurance seeking	.27 ***	.22 ***	.26 ***
PTSD	.73 ***	.73 ***	.65 ***

* $p<.05$, *** $p<.001$

Table 16

Bivariate correlations (Pearson's r) between all demographic and illness characteristics and psychological variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Demographic characteristics																
1 Gender																
2 Age	-.06															
Illness characteristics																
3 Illness duration	-.01	.27***														
4 Illness recency	-.08*	.12***	.21***													
5 Tinnitus	.04	-.10**	.02	-.02												
6 Fullness	.10**	-.15***	-.10**	-.21***	.36***											
7 Hearing disability	-.03	.18***	.20***	.01	.18***	.16***										
8 Vertigo	.13***	-.23***	-.07	-.32***	.14***	.37***	.14***									
Psychological variables																
9 Somatic anxiety	.20***	-.13***	.01	-.23***	.19***	.48***	.21***	.62***								
10 IPQ-R: Illness coherence	.01	-.03	.09**	.11**	-.02	-.13***	-.02	-.07*	-.11**							
11 IPQ-R: Emotional representations	.17***	-.20***	-.05	-.15***	.10**	.30***	.10**	.28***	.38***	-.43***						
12 Intolerance of uncertainty	.12***	-.11**	.00	-.14***	.12***	.24***	.11**	.24***	.39***	-.26***	.62***					
13 SHAI: Health anxiety	.08*	-.16***	.05	-.10**	.17***	.25***	.11**	.26***	.46***	-.23***	.55***	.56***				
14 SHAI: Negative consequences	.00	-.07*	.01	-.07	.05	.13***	.10**	.11**	.21***	-.25***	.50***	.48***	.56***			
15 HAI: Avoidance behaviour	-.03	.09*	.02	-.04	-.01	.03	.04	.02	.09**	-.12***	.13***	.19***	.06	.17***		
16 HAI: Reassurance seeking	.13***	-.06	.00	-.08*	.02	.18***	.05	.13***	.20***	-.12***	.29***	.28***	.41***	.22***	-.01	
17 PTSD	.07	-.10**	-.02	-.20***	.20***	.41***	.26***	.44***	.58***	-.25***	.63***	.68***	.58***	.45***	.25***	.29***

* p<.05, ** p<.01, *** p<.001

The results of the regressions are presented in Table 17 and show large overall effects of the predictors on distress. Psychological variables were more important in predicting anxiety, psychological variables and illness characteristics were almost equal in importance in predicting depression, and illness characteristics were more important in predicting handicap. It is interesting to note that different variables contributed to different types of distress. Three variables significantly contributed to all three types of distress. The biggest contribution was made by PTSD, followed by having an emotional response to MD, and somatic anxiety. By contrast, four variables did not predict any of the types of distress. These were the length of time since symptoms first began (illness duration), reported tinnitus severity, the extent to which people understood their MD (illness coherence), and health anxiety related reassurance seeking behaviour.

For anxiety, 68% of the variance was accounted for by the final model. Psychological variables accounted for 43% of this variance, and illness characteristics accounted for 19%. In the final model many of the psychological variables were significant predictors. The variables that made the biggest contribution to anxiety included the presence of PTSD symptoms, followed by having an emotional response to MD. After these, experiencing symptoms of somatic anxiety, being intolerant of uncertainty, and reporting more health anxiety made the next largest contributions to anxiety. Believing that having a serious illness (other than MD) would result in negative consequences had a much smaller, but still significant effect on anxiety. Although vertigo and fullness in the ear were strong predictors of anxiety in the second model, when the psychological variables were added, they lost their significance in the final model. The only demographic or illness characteristic that contributed to anxiety in the final model was being female, and this only made a small contribution.

A total of 62% of the variance in depression was accounted for by the final model. Psychological variables accounted for 33% of the variance, and illness characteristics accounted for 28%. Like anxiety, the psychological variables that contributed most to the final model of depression were the presence of PTSD symptoms and having an emotional response to MD. This was followed by somatic anxiety, with smaller

Table 17

Multiple regressions of psychological factors on anxiety, depression and handicap controlling for demographic variables and symptom severity

	Anxiety (β)	Depression (β)	Handicap (β)
Step 1			
Demographic characteristics			
Age	-.14***	-.02	-.03
Gender	.19***	.07	.22***
R^2	.06	.00	.05
F	25.11***	2.05	20.04***
Step 2			
Demographic characteristics			
Age	-.08*	.07*	.06*
Gender	.14***	.01	.14***
Illness characteristics			
Illness duration	.06	-.01	.06*
Illness recency	-.02	-.04	-.11***
VSS: Vertigo	.26***	.36***	.44***
Tinnitus	.02	.03	-.01
Fullness in the ear	.21***	.19***	.21***
Hearing loss	.10**	.17***	.21***
R^2 change	.19	.28	.42
F	32.47***	39.94***	88.26***
Step 3			
Demographic characteristics			
Age	-.01	.12***	.09***
Gender	.07**	-.03	.09***
Illness characteristics			
Illness duration	.02	-.03	.04
Illness recency	.02	-.00	-.08***
VSS: Vertigo	.01	.15***	.24***
Tinnitus	-.00	.01	-.01
Fullness in the ear	.01	.01	.05*
Hearing loss	.00	.07**	.14***
Psychological variables			
VSS: Somatic anxiety	.19***	.13***	.21***
IPQR: Illness coherence	.04	.03	-.01
IPQR: Emotional representations	.24***	.17***	.17***
Intolerance of uncertainty	.19***	.00	.02
SHAI	.16***	.10**	.04
SHAI: Negative consequences	-.05*	.09**	-.04
HAI: Avoidance behaviour	-.00	.04	.04*
HAI: Reassurance seeking	-.03	-.04	.04
PTSD	.28***	.38***	.21***
R^2 change	.43	.33	.17
F	97.30***	74.13***	83.25***
Total R^2	.68	.62	.64

* p<.05, ** p<.01, *** p<.001

effects contributed by reporting more health anxiety, and believing that having a serious illness (other than MD) would result in negative consequences. The illness characteristics that were significant in the second model comprised reporting worse vertigo, a sense of fullness in the ear, and hearing disability. In the final step reporting worse vertigo still made a moderate contribution to depression, with hearing disability making a smaller but still significant contribution. Being older also made a moderate contribution to depression in the final model.

The final model accounted for 64% of the variance for handicap. Only 17% of the variance was accounted for by the psychological variables. Illness characteristics accounted for a much larger 42% of the variance. The psychological variables that were most important in predicting handicap were PTSD symptoms, followed by symptoms of somatic anxiety and having an emotional response to MD. A small effect on handicap was also made by health anxiety related avoidance behaviour. In the second model, vertigo was the largest predictor of handicap, and remained so in the final model even after the psychological variables had been taken into account. A sense of fullness in the ear, hearing disability, and having more recent symptoms were also significant predictors of handicap in the second model. In the final model these illness characteristics also remained significant, but had a much smaller effect on handicap. Moderate contributions to handicap were made in the final model by being older and being female.

7.3.1.1 Post hoc mediation analyses.

Despite high bivariate correlations with all three measures of distress, intolerance of uncertainty was only significant in independently predicting anxiety, and did not appear to have a role in handicap or depression once other factors were taken into account. This suggests that the effect of intolerance of uncertainty may have been mediated by other variables in the analyses. A potential mediator variable should be correlated with the independent variable (Baron & Kenny, 1986). The bivariate correlations presented in Table 16 show that five variables had moderate to large correlations with intolerance of uncertainty and therefore could be considered to be potential mediators. These were PTSD (r = .68), emotional representations (r = .62), health anxiety (r = .56), health anxiety related beliefs about negative consequences of

illness (r = .48), and somatic anxiety (r = .39). Baron and Kenny (1986) state that a mediational relationship requires the fulfilment of three conditions which can be tested through a series of regressions. In the first, the independent variable must predict the mediating variable. In the second, the independent variable must predict the dependent variable. For the third condition, the mediator must predict the dependent variable whilst controlling for the independent variable. For mediation to occur, the effect of the independent variable in the third condition should be either not significant or smaller than in the second condition. If present, this change in effect can be tested for significance. To test whether PTSD, emotional representations, health anxiety, health anxiety related beliefs about negative consequences of illness, or somatic anxiety were mediating the relationship between intolerance of uncertainty on depression and handicap, the regressions recommended by Baron and Kenny (1986) were conducted.

PTSD almost fully mediated the effect of intolerance of uncertainty on handicap and depression. PTSD reduced the effect of intolerance of uncertainty from a standardised Beta coefficient of .54 to .08 for depression, which was only just still significant (p = .022). For handicap, the inclusion of PTSD as a mediator reduced the effect of intolerance of uncertainty from a standardised Beta coefficient of .47 to .05. This resulted in intolerance of uncertainty no longer remaining significant in its effect on handicap (p = .138).

The other four potential mediators also reduced the effect of intolerance of uncertainty on depression and handicap, however the effects were much smaller (Depression: IPQ-R emotional representations: IUS Beta = .29, SHAI: IUS Beta = .35, SHAI negative consequences: IUS Beta = .42, Somatic anxiety: IUS Beta = .41; Handicap: IPQ-R emotional representations: IUS Beta = .24, SHAI: IUS Beta = .32, SHAI negative consequences: IUS Beta = .44, Somatic anxiety: IUS Beta = .26).

To test whether the mediational paths were significant, the Aroian version of the Sobel test (as described in Baron & Kenny, 1986) was used (Preacher & Leonardelli, 2006). The results show that PTSD, emotional representations, health anxiety, health anxiety related beliefs about negative consequences, and somatic anxiety were all significant mediators of intolerance of uncertainty on depression and handicap

(Depression: PTSD: Aroian = 15.61, p<.001; IPQ-R emotional representations: Aroian = 9.84, p<.001; SHAI: Aroian = 8.88, p<.001; SHAI negative consequences: Aroian = 6.58, p<.001, Somatic anxiety: Aroian = 9.36, p<.001; Handicap: PTSD: Aroian = 14.12, p<.001; IPQ-R emotional representations: Aroian = 8.97, p<.001, SHAI: Aroian = 6.96, p<.001, SHAI negative consequences: Aroian = 1.96, p<.05, Somatic anxiety: Aroian = 10.43, p<.001).

7.3.2 Clinical Levels of Anxiety, Depression and PTSD

Scores for anxiety, depression, and PTSD were used to create categorical variables to assess how many participants met possible or clinical levels of these variables. Anxiety and depression were coded as non clinical if scores were in the 0-7 range, possibly clinical if scores were in the 8-10 range, and clinical if scores were 11 or more (Zigmond & Snaith, 1983). The frequency and percentage of the MD and control groups at each level are presented in Table 18 which shows that nearly half of the MD group compared to a quarter of the control group report at least possible clinical levels of anxiety. A total of 27.9% of the MD group compared to 11.4% of the control group had clinical levels of anxiety. The odds ratio for the MD group compared with the control group was 2.54 for possible clinical levels of anxiety, and 3.45 for clinical levels of anxiety. Just over a quarter of the MD group reported at least possible clinical levels of depression, compared with 8.2% of the control group. A total of 11.8% of the MD group and 1.2% of the control group had clinical depression. The odds ratio for the MD group compared with the control group was 4.45 for possible clinical levels of depression, and 12.18 for clinical depression.

A one sample chi-square test was carried out to see whether the distribution of the MD group across clinical categories differed significantly from the control group. The expected frequencies were calculated from the proportions of the control group for each clinical category. The analysis showed that the distribution of the MD group across clinical categories was significantly different from the control group for both anxiety ($\chi 2$ (2, N = 800) = 252.56, p < .001) and depression ($\chi 2$ (2, N = 800) = 853.24, p < .001). For both anxiety and depression, there was a greater frequency of participants in the MD group than expected for the possible clinical and clinical categories, and a lower frequency than expected for the non-clinical category.

Table 18

Clinical groupings of MD and control groups for anxiety, depression and PTSD

	MD group		Control group	
	N	% (of MD group)	N	% (of control group)
Anxiety (HADS)				
Non-clinical (< 7 points)	418	52.3	356	73.6
Possible clinical (8-10 points)	159	19.9	73	15.1
Clinical (≥11 points)	223	27.9	55	11.4
Depression (HADS)				
Non-clinical (< 7 points)	571	71.4	444	91.7
Possible clinical (8-10 points)	135	16.9	34	7.0
Clinical (≥11 points)	94	11.8	6	1.2
PTSD (PCL)				
Re-experiencing	244	30.0		
Avoidance / numbing	231	28.9		
Arousal	351	43.9		
0/3 clusters met	347	43.4		
1/3 clusters met	197	24.6		
2/3 clusters met	139	17.4		
3 clusters met	117	14.6		
Score ≥ 44	131	16.4		
3 clusters met & score ≥ 44	97	12.1		

PTSD was scored as recommended by the National Center for PTSD using a combination of both total score and symptomatic clusters (Weathers et al., 1993). The requirements for clinical levels of criterion B (re-experiencing) were that at least one item on that subscale had to score a 3 or above. The requirements for clinical levels of criterion C (avoidance / numbing) was that at least 3 items on that subscale had to score a 3 or above. To meet the requirement for clinical levels of criterion D

(arousal), at least 2 items on that subscale had to score a 3 or above. The frequency and percentage of people with MD who met the combined requirement, as well as each requirement separately, are presented in Table 18, which shows that 12.1% of participants met the criteria of the National Center for PTSD. Blanchard and colleagues (1996) published the psychometric properties of the scale and recommended that just the score of 44 or more is used. Using this method of classification, 16.4% of participants were classified as being likely to have PTSD. Mylle & Maes (2004) state that many people may suffer from some PTSD symptoms which need treatment, whilst not fulfilling the full DSM diagnostic criteria. They discuss the concept of partial PTSD, one form of which includes the presence of only one of the B, C, or D symptomatic clusters, in response to a traumatic event that is causing distress. Using this criterion, 42% of participants reached the threshold for one or two of the three symptomatic clusters. In each symptomatic cluster, 43.9% reached the threshold for increased arousal, 30% reported re-experiencing, and 28.9% reported avoidance or numbing.

7.3.3 Comparison Between MD and Control Groups

Preliminary t-tests were carried out comparing the MD group and the control group on age and gender, intolerance of uncertainty, all health anxiety subscales, and anxiety and depression. As significant differences were identified for age ($t(910) = 6.27$, $p < .001$) and gender ($t(995) = 2.74$, $p = .006$), the between group comparisons were carried out controlling for age and gender. Using age and gender as covariates in a MANCOVA violated the homogeneity of regression assumption, since the differences between the MD and control groups on the psychological variables varied as a function of age and gender. Therefore, the use of MANCOVA was inappropriate (Tabachnick & Fidell, 2007). As suggested by Tabachnick & Fidel (2007), blocking was used as an alternative, with age (recoded using median split as being under or over 60 years) and gender being entered into the MANOVA as additional fixed factors. The fixed factors compared in the MANOVA were group (MD vs. control), age (< 60 years vs. ≥ 60 years), and gender (male vs. female). The interactions between these variables were also tested. The dependent variables were anxiety, depression, intolerance of uncertainty, health anxiety, health anxiety related

beliefs about negative consequences of illness, and health anxiety related avoidance behaviour and reassurance seeking.

Significant differences were found between the MD and control group (Wilks'Λ = .88, $\underline{F}$ (7, 1266) = 24.31, $\underline{p}$ < .001, η_p^2 = .12). Follow up ANOVAs were carried out to identify which dependent variables the MD and control group differed on. Participants in the MD group were significantly more anxious and depressed than controls (anxiety: $\underline{F}$ (1, 1272) = 33.82, $\underline{p}$ < .001, η_p^2 = .04, depression: $\underline{F}$ (1, 1272) = 111.98, $\underline{p}$ < .001, η_p^2 = .08). The MD group also reported more health anxiety, and were more likely to believe that having a serious illness (other than MD) would result in negative consequences (health anxiety: $\underline{F}$ (1, 1272) = 52.86, $\underline{p}$ < .001, η_p^2 = .04, health anxiety related beliefs about negative consequences of illness: $\underline{F}$ (1, 1272) = 4.63, $\underline{p}$ = .032, η_p^2 < .01). No difference was found between the MD and control group for intolerance of uncertainty, avoidance behaviour or reassurance seeking.

Significant differences were also found between males and females which differed in the MD and control groups (group x gender interaction: Wilks'Λ = .99, $\underline{F}$ (7, 1266) = 2.22, $\underline{p}$ = .03, η_p^2 = .01). However, when follow up ANOVAs were carried out to identify the dependent variables that the difference related to, no significant ANOVA results were found, although intolerance of uncertainty reached a near significant effect ($\underline{F}$ (1, 1272) = 3.62, $\underline{p}$ = .057, η_p^2 < .01).

The MANOVA multivariate tests also indicated a significant effect for gender (Wilks'Λ = .95, $\underline{F}$ (7, 1266) = 9.71, $\underline{p}$ < .001, η_p^2 = .05), age (Wilks'Λ = .97, $\underline{F}$ (14, 2532) = 2.93, $\underline{p}$ < .001, η_p^2 = .02), and gender x age (Wilks'Λ = .98, $\underline{F}$ (14, 2532) = 2.11, $\underline{p}$ = .009, η_p^2 = .01). As the purpose of this analysis was to assess group changes, follow up ANOVAs were not carried out to further investigate these effects.

7.4 Discussion

This study sought to assess psychological variables that might help to explain the psychological distress widely noted in people with MD, and whether there was any evidence for the contribution of PTSD and health anxiety to distress when they were measured explicitly. The results of this study were consistent with the hypotheses.

The first hypothesis was that after controlling for demographic characteristics, illness characteristics would predict distress, and that after controlling for demographic and illness characteristics, psychological variables would predict distress. It is important to note that as this was a cross-sectional study, the use of the term predictors in this study relates only to cross sectional predictors and should not be misinterpreted as implying causation between variables. The second hypothesis was that a proportion of participants would meet clinical levels, and that where comparisons could be made between the MD and control groups, that levels of distress would be higher in the MD group.

The theoretical and clinical implications of each of these two sets of findings will be discussed in turn. The limitations of this study and recommendations for future research will then be discussed.

7.4.1 Implications of Findings on Predictors of Distress

The psychological mechanisms of PTSD and health anxiety were both found to be independently relevant to understanding distress in this group of members of the Ménière's Society. Three types of MD related distress were studied: anxiety, depression and handicap.

The psychological variables that were associated with all three types of distress were PTSD, having an emotional response to MD, and symptoms of somatic anxiety. As these variables were related to all three types of distress they will be discussed first, and then the remaining predictors of anxiety, depression and handicap will be discussed separately. The implications of the post hoc tests and non-significant variables will then be considered.

7.4.2 Implications Relating to PTSD, Emotional Response to MD, and Somatic Anxiety

The finding that PTSD is associated with distress is consistent with the suggestions made by Scott and Stradling (1994), Lloyd and Turner (2003), and Alonzo (2000), who all proposed that cumulative stressful events may lead to an increased risk of

PTSD like symptoms. The findings of this study are similar to those of Asmundson and collegues (2000a), who found that dysfunctional chronic pain patients were more likely to experience PTSD symptoms. The strong association of distress with having an emotional response to MD suggests that distressed participants may benefit from additional support in dealing with how they feel about their illness. It is important to note, however, that although an increased emotional response may lead to increased symptoms of somatic anxiety, their associations with distress were independent of one another. The high association of somatic anxiety with distress suggests that the participants with MD in this study may benefit from vestibular rehabilitation interventions that have been found to reduce symptoms typical of somatic anxiety (Yardley et al., 2004a; Yardley & Kirby, 2006).

7.4.2.1 Implications relating to anxiety.

The finding that anxiety was mainly influenced by psychological variables suggests that this aspect of adjustment to MD is relatively independent of how severe symptoms may be. The finding that women were more likely to be anxious than men is in line with other research on anxiety in people with vertigo (Monzani et al., 2001). Participants who had high levels of anxiety appear to be excessively concerned about their health. Health anxiety can be reduced, however, with cognitive behavioural therapy (Jones, 2002).

7.4.2.2 Implications relating to depression.

Depression was influenced by both psychological variables and illness characteristics. Although reporting worse vertigo and hearing disability were predictors of depression, the finding that illness recency did not predict depression suggests that it is the severity and not the recency of these symptoms that are important in depression. This could be associated with the finding that PTSD was the strongest predictor of depression, as more severe symptoms may be perceived as traumatic. Although severity was more important than recency for predicting depression, in predicting handicap, both severity and illness recency were significant predictors.

7.4.2.3 Implications relating to handicap.

The findings that vertigo and hearing disability were the most handicapping symptoms support the findings of Cohen and colleagues (1995), who also reported these two to be the most disabling symptoms. Handicap was also influenced by both psychological variables and illness characteristics, with illness characteristics being more strongly associated with handicap than with depression. Health anxiety was much less closely associated with handicap than with anxiety or depression. Avoidance behaviour was the only aspect of health anxiety to predict handicap, and even then only making a small contribution.

Given that avoidance is a factor in PTSD, and PTSD was one of the strongest predictors of handicap, it is useful to compare the differences between the measures in terms of what aspects of avoidance they are measuring. Health anxiety related avoidance behaviour refers to avoidance of doctors, hospitals, and information and exchanges about illness. This is avoidance at a more general level, whereas the handicap measure refers to specific activities and situations that are avoided because they do or might cause dizziness and unsteadiness and result in physical, functional and emotional implications. Avoidance in PTSD refers to the avoidance of any thoughts, conversations, activities or situations that might even remind a person of their MD attacks or how the attacks make them feel. The findings of this study suggest that handicap is more associated with traumatic avoidance as a result of the participants' MD attacks than it is to avoidance and anxiety about illness in general. This is consistent with other studies which have reported dizziness related handicap to be exacerbated by self-imposed avoidance (Yardley & Beech, 1998; Yardley et al., 2001a; Yardley & Putman, 1992).

7.4.2.4 Implications relating to post hoc tests and non-significant variables

Intolerance of uncertainty was associated with all three types of distress, but in different ways. A high level of intolerance of uncertainty was directly and quite strongly associated with anxiety, but was almost fully mediated by PTSD symptoms in its effect on depression and handicap. This suggests that the uncertain nature of MD has a complex effect on distress, directly influencing anxiety, and indirectly

influencing depression and handicap via the perception of the uncertainty associated with MD as traumatic and stressful.

It is interesting to note that four variables did not predict any of the three types of distress. Two of these were psychological variables: the extent to which people understood their MD (illness coherence) and health anxiety related reassurance seeking behaviour. The lack of significance of illness coherence was particularly unexpected, as education is an important factor in self management and adjustment to vestibular disorders (Dowdal, 2002; Yardley, 2000). It is possible that illness coherence may be an 'active' variable, relevant to adjustment outcomes when it is manipulated via an intervention and not so relevant when it is not being manipulated via an intervention. Another possible explanation is that as participants were recruited from a self help group, participants were well informed about MD and so this was not a source of distress for them. It was also unexpected that reassurance seeking was unrelated to distress, as greater use of the Ménière's Society services has been reported to be associated with poorer adjustment in a previous study (Dibb & Yardley, 2006). Also of note is the unusual behaviour of age in the multiple regressions. Age became more significant in each step of the depression and handicap analyses. Given that age was not correlated with depression or handicap, it is possible that its effects on depression and handicap are indirect, via an interaction with other variables in the analyses.

7.4.3 Implications of Findings on Clinical Levels of Distress and Comparisons Between MD and Control Groups

Findings will be discussed firstly in relation to anxiety and depression, and secondly, in relation to PTSD.

7.4.3.1 Anxiety and depression.

A proportion of participants had clinical levels of distress, and comparisons between the MD and control groups indicated that levels of distress were higher in the MD group than the control group. The results showed that in this sample of people with MD who are members of the Ménière's Society, 47.8% of participants met the

requirement for possible clinical anxiety, and 27.9% had scores above the cut-off for clinical anxiety. For depression, 28.5% of participants met the requirement for possible clinical depression, and 11.8% for clinical depression. These proportions are greater than those reported by Soderman and colleagues (2002). They reported that 51% of participants scored 8 or more, meeting the criteria for possible clinical anxiety, with 17% scoring 11 or more reaching the recommended cut-off for clinical anxiety. For the depression subscale, Soderman and colleagues found that 16% of participants could be classified as having possible clinical depression, with only 3% being classified as having clinical depression. These proportions were still higher than the proportions reported by the control group in the current study, but much lower than the MD group. The larger proportions found in the MD group of the current study may be due to participants being recruited from a self-help group. Soderman and colleagues (2002) recruited their participants from hospital otolaryngology and audiology departments. It is possible that higher levels of distress were a motivating factor in joining the self-help group.

7.4.3.2 PTSD.

PTSD was classified using several methods. The method recommended by the National Center for PTSD (Weathers et al., 1993) who distribute the PCL scale, is a combination of both a total score of 44 or more, and threshold fulfilment of all the B, C, and D symptomatic criteria. This most stringent of methods was used in this analysis, and classified 12.1% of participants as being likely to have PTSD. Blanchard and colleagues (1996) published the psychometric properties of the scale and recommended that just the score of 44 or more is used. Using this method of classification, 16.4% of participants were classified as being likely to have PTSD.

The National Institute for Clinical Excellence guidelines (2005) report that the population prevalence of PTSD is 1.5% to1.8 %. Tedstone and Tarrier (2003) carried out a review of studies that measured PTSD in medical illness and its treatment. They report the prevalence rates for PTSD following a range of medical conditions and treatments. For myocardial infarction, the PTSD prevalence rates ranged from 0% to 16%. Following cardiac surgery, prevalence rates ranged from 10.8% to 18%. The prevalence rate following stroke was 9.8%, and following

treatment in hospital intensive care ranged from between 14% to 59%. The prevalence of PTSD among patients who were aware during general anaesthesia was 6.6%. The findings of the current study suggest that the proportion of people in this study who are likely to have PTSD are much higher than the general population, slightly higher than those who have had a stroke, and are comparable to people who have had a myocardial infarction or cardiac surgery. It is possible that the elevated proportions found among participants may be the result of cumulative adversity in the form of recurring attacks. As participants were recruited from a self help group, these rates cannot be generalised to all people with MD, as they may be higher than if participants had been recruited via hospital departments.

Mylle & Maes (2004) state that many people may suffer from some PTSD symptoms which need treatment, whilst not fulfilling the full DSM diagnostic criteria. They discuss the concept of partial PTSD, one form of which includes the presence of only one of the B, C, or D symptomatic clusters, in response to a traumatic event that is causing distress. Using this criterion, 42% of participants reached the threshold for one or two of the three symptomatic clusters. Therefore, as many as 42% of participants in this study may have partial PTSD. To identify key areas that treatment could focus on, it is helpful to look at the percentages of participants who reached the threshold in each symptomatic cluster. The highest proportion of participants at 43.9% experienced increased arousal, 30% reported re-experiencing, and 28.9% reported avoidance or numbing. This tells us that although all areas need addressing, particular focus should be given to symptoms of arousal. This also supports the findings in the first analysis that somatic anxiety and PTSD both independently contributed to all three types of distress measured.

7.4.4 Limitations and Future Research

This study had several limitations, which are discussed in turn. The main limitation of this study was that it had a cross sectional design. Therefore it is important to recognise that causality cannot be implied between the predictor and outcome variables, only that they are associated.

The measure used to assess PTSD in this study (the PCL) has been reported to have good diagnostic efficiency (Blanchard et al., 1996). However, PTSD has not previously been studied in people with MD. Therefore, given the strong association of PTSD with distress found in this study, future research should seek to replicate the current findings using clinical interviews. If these findings are replicated, it may be beneficial to assess PTSD in people with MD who are distressed in order to determine the best form of treatment for distress. The current study only measured PTSD symptoms experienced over the past month. Given the fluctuating nature of MD symptoms, it would be interesting if future studies could assess the lifetime prevalence of PTSD symptoms in people with MD.

It is important to note that some of the strongest predictors may be confounded with (i.e. they have components that measure the same concept as) the dependent variable that they are predicting. The IPQ-R emotional representations subscale includes feeling depressed, upset, angry, worried, anxious, and afraid as a result of thinking about their illness. Therefore it is not surprising that the subscale is a strong predictor of depression and anxiety. There are also many similarities between some of the question items of the Hospital Anxiety and Depression Scale, and the PTSD checklist. Anxiety, depression and PTSD are often reported as occurring comorbidly in the literature; however, it is important to note that PTSD also requires the presence of other symptoms beyond anxiety and depression, and the treatment of PTSD has also been shown to effectively reduce anxiety and depression at the same time without being a focus of treatment (National Institute for Clinical Excellence, 2005). Anxiety is also conceptually related to somatic anxiety, health anxiety, and intolerance of uncertainty, which were all significantly associated with anxiety. Nevertheless, it is also important to recognize that each predictor variable remained associated with anxiety after any shared variance had been removed. Each variable can therefore be described as tapping into a different aspect of overall anxiety, and is therefore helpful in identifying the specific aspects of anxiety that could be focused on in treatment to help reduce overall levels of anxiety.

A great deal of conceptual overlap also exists between the dependent variable handicap, and the two predictor variables PTSD and the avoidance subscale of the Health Anxiety Inventory, in that they all measure aspects of avoidance. The

avoidance in the handicap measure refers to specific activities and situations that are avoided because they may or do cause dizziness and unsteadiness and result in physical, functional and emotional consequences. Avoidance in PTSD refers to the avoidance of any thoughts, conversations, activities or situations that may remind a person of their MD attack or how the attacks made them feel. Health anxiety related avoidance behaviour refers to avoidance of doctors, hospitals, and information and exchanges about illness in general. The handicap and PTSD measures appear to have a greater conceptual overlap as they both focus on illness specific related avoidance, whereas the health anxiety related avoidance appears to refer to avoidance of illness at a more general level. This is reflected in their inter-correlations. PTSD and handicap were highly correlated, whereas the correlations of health anxiety related avoidance with handicap and PTSD were small. However, although there is a great deal of similarity between PTSD related avoidance and handicap, there is also an important distinction. The questions in the handicap inventory relate to how dizziness impacts on functional, emotional, and physical aspects of everyday life, i.e. particular problems that result directly from symptoms of dizziness. Many of the questions are worded 'Because of your problem...'. The avoidance questions in the PTSD checklist however, ask about avoidance relating not to symptoms themselves, but to anything that may remind them of symptoms that have occurred in the past. This difference is important in distinguishing between avoidance for the purpose of reducing future symptoms or consequences of symptoms (handicap), and avoidance that is not related to actual symptoms per se, but the avoidance of traumatic memories (PTSD). Given the conceptual overlap between these predictor variables and outcome variables, it is important to recognise that the association found between them is not particularly informative. Future work should consider, where theoretically feasible, assessing the associations between these predictor and outcome variables when shared components have been removed (for example, by excluding conceptually similar subscales or by using factor analysis to identify and exclude items with high cross loadings between scales), to see whether the associations found here still remain.

The finding that participants in the MD group were significantly more distressed than the control group supports the research and generally accepted consensus that elevated levels of anxiety are often found among people with vestibular disorders

(Jacob et al., 2002; Sloane et al., 1994; Yardley, 2000). However, elevated levels of distress may have been a motivating factor in participants' decision to join the self help group, and so these results cannot be generalised to all people with MD without replication in a non self help group sample. This is especially salient in the context that the three good or medium quality studies included in the systematic review (chapter 6) that found no significant difference between people with MD and controls on anxiety and depression all recruited their participants from hospitals and not self help groups. However, it is important to take into account that the current study had a very large sample size, and therefore effect size should be compared rather than significance levels. In the current study, effect sizes were almost medium for anxiety (d = .43), and medium to large for depression (d = .69). Soderman and colleagues (2002) reported very small effect sizes (HADS: anxiety d = .07, HADS: depression d = .09). However, their control group of people with peripheral vestibular disorder was limited in its validity as a control group, as 22% of the group had MD. Therefore it is not surprising that the effect size was so small. Savastano and colleagues (1996) compared people with MD against normal reference values for anxiety and depression and reported only a small effect size for anxiety (STAI: state d = .30, STAI: trait d = .12), and a medium effect size for depression (Zung SDS d = .46). Monzani and colleagues (2001) also used the HADS to compared people with MD with people who had diagnoses of peripheral vestibular disorder, central vestibular disorder, and benign paroxysmal positional vertigo (BPPV). They report small effects between MD and peripheral vestibular disorder (anxiety d = .16, depression d = .27), central vestibular disorder (anxiety d = .25, depression d = .35), and BPPV (anxiety d = .27, depression d = .03). Monzani and colleagues also included a healthy control group in their study, but did not compare them with the MD group. They only reported comparisons between the control group and all the other groups combined. As they included the means and standard deviations for all groups separately, effect size could still be calculated, and revealed very large effect sizes (anxiety d = 1.25, depression d = 1.23) between the MD group and the healthy control group. Despite finding no overall difference and small effects between people with MD and controls on levels of distress, Savastano and colleagues (1996) did identify that two clusters existed within their sample of people with MD. One cluster of people was well adjusted to MD, and the second cluster was severely distressed. Although high levels of clinical distress were reported in the current

study, a high proportion of participants did not reach clinical levels (52.3% for anxiety, 71.4% for depression, and at least 43.4% for PTSD).

The findings of Savastano and colleagues (1996) and the current study suggest that people with MD should not be treated homogeneously regarding distress. Whether a person with MD is a member of a self help group or not, some people with MD do not find the disease distressing and others find the disease highly distressing. It is this latter group of people that would benefit from additional psychological support and treatment to enable them to achieve better adjustment to MD.

7.4.5 Conclusions

This chapter has described the final study in the research programme of this thesis. Few previous studies have explored the relevance of psychological mechanisms in MD or drawn on psychological theory when studying distress in MD. The current study found that the psychological mechanisms of PTSD and health anxiety are helpful in understanding distress in people with MD who took part in the study. The MD group were also significantly more distressed than the control group in terms of anxiety, depression, health anxiety, and health anxiety related beliefs about the negative consequences of illness. When classified using clinical cut offs, a moderate proportion of the MD group reached clinical levels of distress on measures of anxiety, depression and PTSD. The next chapter will review these findings in relation to the findings of the other studies in this research programme, and discuss how this thesis could inform future help for people in adjusting to MD.

Chapter Eight: Researching Predictors of Adjustment to Ménière's Disease

8.1 Rationale and Aims

The assumption on which this research programme was founded is that the distressing nature and severity of Ménière's disease (MD), combined with an intolerance of uncertainty and expectations and beliefs about illness and treatment, may influence adjustment to the disease. The aim of the research programme was to identify modifiable psychological factors that influence adjustment, to inform future support for people with MD.

This chapter will begin by summarising the main findings of the research programme. The chapter will then consider the issues and implications that the findings have for understanding the psychological predictors of adjustment in people with MD. This will be done firstly in relation to the previous literature, and secondly in relation to clinical practice. The limitations of the research programme will then be discussed. Finally, the chapter will suggest questions for future research to consider in relation to adjustment to MD.

8.2 Main Findings of the Research Programme

The aims and main findings of the empirical studies and systematic review will be summarised in turn below.

8.2.1 Chapter 3: Psychological Correlates of Anxiety in MD

Chapter 3 reported a cross-sectional questionnaire-based study of members of the Ménière's Society. The purpose of this study was to explore to what extent anxiety was associated with expectations and beliefs about illness and intolerance of uncertainty, and to ascertain the percentage of participants who met the criteria for clinical or possible clinical levels of anxiety.

The study found that 56.2% of participants had possible clinical levels of anxiety, and 27.4% had clinical levels of anxiety. Anxiety was most highly correlated with being intolerant of uncertainty and responding in an emotional way to having MD.

The next largest effects were found for symptoms of somatic anxiety and the beliefs that becoming dizzy has serious consequences and results in physical danger, an inability to fulfil normal roles and embarrassment. Those who were more anxious also believed that MD and its outcomes are caused by psychological factors.

8.2.2 Chapter 4: Predictors of Adherence, Enablement and Anxiety in People with MD

Chapter 4 presented a longitudinal questionnaire-based study of members of the Ménière's Society who were also taking part in a randomised controlled trial assessing the effectiveness of physical (vestibular rehabilitation) or psychological (stress reduction) based self-treatment. The purpose of this study was to identify whether expectations and beliefs about illness and intolerance of uncertainty measured at baseline could predict the adjustment outcomes of adherence, enablement and anxiety following treatment (controlling for demographic and illness characteristics).

8.2.2.1 Predictors of adherence.

After adjusting for type 1 error, no predictors were found for adherence.

8.2.2.2 Predictors of enablement.

Improvement in enablement was associated with having had MD for a shorter duration, and believing that they had a poor understanding of their illness at baseline. Both these variables were independent predictors of enablement.

8.2.2.3 Predictors of anxiety.

High levels of anxiety were associated with negative beliefs at baseline about the consequences of dizziness: that dizziness will result in physical danger, embarrassment and an inability to fulfil normal roles, and will develop into a severe attack of vertigo. Anxiety was also higher among participants who at baseline had a greater intolerance of uncertainty, and believed that physical activity could make

their symptoms worse. Illness perceptions were also associated with anxiety. Anxiety was higher among those who believed that MD and its effects were caused by psychological factors and had serious consequences, and who responded in an emotional way to MD. Lower levels of anxiety were found among those who felt they had a good understanding of MD and expected that treatment would be effective. Several of the demographic and illness characteristics were also associated with anxiety. Anxiety was higher among those with worse symptoms of vertigo, somatic anxiety, and fullness in the ear.

High levels of anxiety were independently predicted by greater symptoms of somatic anxiety, intolerance of uncertainty, an emotional response to MD, and having a poorer understanding of MD at baseline.

8.2.3 Chapter 6: The Role of Psychological Factors in MD: A Systematic Review

Chapter 6 was a systematic review of the role of psychological factors in MD. The purpose of the systematic review was to identify and assess research on psychological factors in MD since 1977, and examine them in relation to four possible mechanisms of distress: worry, post-traumatic stress disorder (PTSD), health anxiety and anxiety sensitivity. In order to identify possible evidence for different explanations of MD related distress, studies included in the review were examined to see whether any retrospective evidence existed for the components of each mechanism. Where evidence was present, it was examined to see whether it varied by distress level and/or if there was a difference between people with MD and controls.

8.2.3.1 Presence of components.

The 28 studies identified in the systematic review measured some aspects of all of the four different mechanisms, although evidence was not found for all of the individual components. The highest frequency of studies measuring relevant components was found for the mechanisms of PTSD and health anxiety. The PTSD components measured comprised distress or impairment in functioning, sleeping problems, irritability, reduced interest or participation in activities, and a reduced

range of affect. For health anxiety, measured components included high perceived cost, awfulness or burden, specific illness assumptions and behaviours, and being resistant to psychological considerations and focusing on physical solutions.

Much less research was found on the components of anxiety sensitivity, with general anxiety sensitivity and the component of fear being measured by only poor quality studies. The least amount of research could be identified for the components of worry, with only the component of low problem solving confidence being measured by one poor quality study.

8.2.3.2 Variation by distress level.

Few studies investigated whether psychological factors varied by distress levels. The studies that did reported people who had higher levels of distress were more likely to have poorer problem solving confidence, a greater impairment in functioning, and a lower perceived ability to cope.

8.2.3.3 Comparison between MD and control groups.

Control groups were separated into healthy and patient control groups. When compared with healthy control groups, people with MD had greater levels of distress or impairment in functioning, sleeping problems, reduced interest or participation in activities, and were more likely to view their illness as being caused by psychological factors. People with MD showed no significant difference to healthy controls on measures of anxiety, depression, perceived ability to cope, and the specific illness behaviour categories of general hypochondriasis, disease conviction, dysphoria, denial, and irritability. People with MD had lower scores than healthy controls for the illness behaviour category affective inhibition. Although this lack of significant difference in anxiety and depression appears to be a contradiction of what is commonly observed and reported of people with MD, it is important to note that even among the good and medium quality studies, the quality of the control group data was limited. The good quality study by Soderman and colleagues (2002) included 22% of people with MD in their control group of people with peripheral vestibular disorder. The medium quality study carried out by Savastano and

colleagues (1996) did not collect control data, but appeared to statistically compare their MD group against clinical cut-off values without the use of standard deviations. Although the lack of significant difference should therefore not be given too much weight, it should also be noted that the evidence for elevated anxiety and depression in MD originated largely from poorer quality studies in psychiatric populations, which appear not to be representative of MD patients in general.

When people with MD were compared with patient groups, people with MD had significantly more social impairment and sleeping problems when compared with people with tinnitus. People with MD did not differ from patient controls on levels of anxiety when compared with people with peripheral vestibular disorders, central vestibular disorders, or benign positional vertigo. Depression was also no different in people with MD when compared to people with peripheral vestibular disorders or benign positional vertigo. No difference was found between people with MD and people with peripheral vestibular disorders for perceived ability to cope. High perceived cost, awfulness or burden was no different in people with MD when compared to people with tinnitus. No difference was also found in the measurement of personality disorders between people with MD and those with noise injury, presbyacusis, other deafness, or tinnitus. People with MD had significantly lower levels of depression only when compared with people with central vestibular disorders, and less impairment in occupational functioning when compared with people with tinnitus. They also had less sleeping problems, and more interest or participation in activities when compared to people with peripheral vestibular disorders.

8.2.4 Chapter 7: Understanding Distress in MD

Chapter 7 reported the final empirical study: a cross-sectional questionnaire survey of members of the Ménière's Society. The study had three main purposes. The first aim of this study was to explicitly measure PTSD and health anxiety, investigating the extent to which these and the psychological variables found to be most relevant to anxiety in chapter 4 were related to distress (controlling for demographic and illness characteristics). Three types of MD related distress were studied: anxiety, depression and handicap. The second aim was to assess what proportion of

participants met clinical levels for anxiety, depression and PTSD. The third aim of this study was to compare whether people in the MD group differed on psychological variables to healthy controls.

8.2.4.1 Predictors of anxiety.

Anxiety was primarily influenced by psychological variables. The best predictors of anxiety were the presence of PTSD symptoms, followed by having an emotional response to MD. After these, experiencing symptoms of somatic anxiety, being intolerant of uncertainty, and reporting more health anxiety made the next largest contributions to anxiety. Believing that having a serious illness (other than MD) would result in negative consequences had a much smaller, but still significant effect on anxiety. Being female was the only variable from the demographic and illness characteristics that contributed to anxiety after psychological variables were included, and this only had a small effect.

8.2.4.2 Predictors of depression.

Like anxiety, the psychological variables that contributed most to the final model of depression were the presence of PTSD symptoms and having an emotional response to MD. This was followed by somatic anxiety, with smaller effects contributed by reporting more health anxiety, and believing that having a serious illness (other than MD) would result in negative consequences. After psychological variables were included, reporting worse vertigo still made a moderate contribution to depression, with greater hearing disability and being older making smaller but still significant contributions to depression.

Post hoc analyses showed that PTSD almost fully mediated the effect of intolerance of uncertainty on depression. Emotional representations, health anxiety, health anxiety related beliefs about negative consequences, and somatic anxiety were also found to significantly mediate the effects of intolerance of uncertainty on depression.

8.2.4.3 Predictors of handicap.

Illness characteristics were more relevant to predicting handicap than anxiety or depression. The psychological variables that were most important in predicting handicap were PTSD symptoms, followed by symptoms of somatic anxiety and having an emotional response to MD. A small effect on handicap was also made by health anxiety related avoidance behaviour. Vertigo symptoms also had a large effect on handicap, even after the psychological variables had been taken into account. A sense of fullness in the ear, hearing disability, and having more recent symptoms had smaller but significant effects on handicap. Moderate contributions to handicap were also made by being older and being female.

Post hoc analyses showed that PTSD fully mediated the effect of intolerance of uncertainty on handicap. Emotional representations, health anxiety, health anxiety related beliefs about negative consequences, and somatic anxiety were also found to significantly mediate the effects of intolerance of uncertainty on handicap.

8.2.4.4 Clinical levels of anxiety, depression and PTSD.

The study found that 47.8% of participants with MD had possible clinical levels of anxiety ($\geq$8), with 27.9% of these meeting the criteria for clinical levels of anxiety ($\geq$11). This was significantly different to the control group, for which 26.5% participants had possible clinical levels of anxiety, with 11.4% of these meeting the criteria for clinical levels of anxiety. The odds ratio for the MD group compared with the control group was 2.54 for possible clinical levels of anxiety, and 3.45 for clinical levels of anxiety.

For depression, 28.7% of participants with MD met the criteria for possible clinical levels, and 11.8% for clinical levels. Again, this was significantly different to the control group, for which 8.2% met possible clinical levels, but only 1.2% of these reached clinical levels. The odds ratio for the MD group compared with the control group was 4.45 for possible clinical levels of depression, and 12.18 for clinical depression.

For PTSD, using the classification method of combining both a total score of 44 or more and threshold fulfilment of all the arousal, re-experiencing and avoidance / numbing symptomatic criteria, 12.1% of participants with MD were classified as being likely to have PTSD. When just the score of 44 or more was used, 16.4% were likely to have PTSD. As many as 42% of participants with MD may have had partial PTSD, reaching the threshold for one or two (but not all three) of the arousal, re-experiencing and avoidance/numbing symptomatic clusters. A total of 43.9% of participants reached the threshold for increased arousal, 30% reported re-experiencing, and 28.9% reported avoidance or numbing.

8.2.4.5 Comparison between MD and control groups.

Although effect sizes were very small, participants in the MD group were significantly more anxious and depressed than the control group. They also reported more health anxiety, and were more likely to believe that having a serious illness (other than MD) would result in negative consequences. No difference was found between the MD and control group for intolerance of uncertainty, avoidance behaviour or reassurance seeking.

8.3 Theoretical Implications

The theoretical implications and contributions of this research programme will now be considered. Firstly, the implications of the findings on predictors of distress will be discussed and a model of predictors of adjustment outcomes will be proposed based on the findings of this research programme. Secondly the implications of the systematic review will be examined, and thirdly, the implications of the findings on clinical levels of distress in people with MD will be explored.

8.3.1 Theoretical Implications of the Findings on Predictors of Distress

This research programme has found that PTSD like symptoms and responding to MD in an emotional way are key independent predictors of distress. These findings are consistent with the findings of meta-analyses on predictors of PTSD (Brewin et al., 2000; Ozer et al., 2003), which report that factors that take place during or just after a

trauma are the most predictive, and include emotionality as an example of these factors.

Furer, Walker and Freeston (2001) suggested that people have a greater risk of developing health anxiety if they have a 'chronic, intermittent, or degenerative' illness where uncertainty and no clearly recognised cause are present. The findings of this research programme are consistent with this. Health anxiety and intolerance of uncertainty were both important variables in predicting poor adjustment outcomes. The levels of health anxiety reported by participants with MD were significantly higher than those of the control group in this research programme. Although not compared statistically, the levels of health anxiety found in people with MD in this research programme appear to be similar to those of medical patients who were attending a general practice clinic, gastroenterology clinic, or an MRI scan (Salkovskis et al., 2002). However, these levels appear lower than those reported by people with panic disorder, and much lower than people with hypochondriasis (Salkovskis et al., 2002).

Although the presence and dislike of uncertainty has been well noted anecdotally within MD (Crary & Wexler, 1977; Dowdal, 2002), this research programme is the first to investigate the empirical presence and effects of it. The finding that intolerance of uncertainty was an independent predictor of anxiety findings is consistent with the literature. Anxiety and worry are similar constructs, and previous research has found intolerance of uncertainty to be a central component of worry in the context of generalised anxiety disorder (Dugas et al., 2004a; Dugas et al., 1998). The finding that intolerance of uncertainty was almost fully mediated by PTSD in predicting depression and handicap was unexpected, but can be explained by the literature, as Holaway and colleagues (2006) have suggested that intolerance of uncertainty may be an underpinning feature of anxiety disorders more generally. As PTSD is an anxiety disorder, it makes sense that intolerance of uncertainty influences adjustment outcomes via its effect on PTSD.

People with anxiety disorders have been reported in the literature to have higher levels of intolerance of uncertainty than normal controls (Ladouceur et al., 1999; Tolin et al., 2003). It was therefore interesting that despite intolerance of uncertainty

being a predictor of distress, levels were not significantly higher in the MD group than the control group. On comparison with the findings of previous research, it would appear that the lack of difference between the groups was not due to scores being elevated in the control group, but that the MD group did not have elevated scores. Although not tested statistically, the scores of the MD group appeared to be comparable to those of non anxious people in other research (Buhr & Dugas, 2002; Buhr & Dugas, 2006; Tolin et al., 2003), and lower than people with anxiety disorders (Holaway et al., 2006; Tolin et al., 2003). This suggests that only the most distressed subgroup of the MD group was influencing the predictive effect, but that the distribution of the whole MD group was comparable to normal populations. Again, future research should test these comparisons statistically.

Previous research has found that poor illness outcomes are related to the belief that the illness has serious consequences, belief in a chronic timeline, low perceived control, having a poorer understanding of illness and a greater emotional response to illness (Hagger & Orbell, 2003; Hobro et al., 2004; Jopson & Moss-Morris, 2003). The findings in this research programme were consistent with this and suggest that there is a pattern in how people perceive illness that is related to poor adjustment outcomes. It is also important to note that, in addition to the length of time for which a participant had had MD, illness perceptions were the only variables to predict the positive adjustment outcome of enablement. In particular, the strongest effect was found to be for the expectation that treatment would be effective. This construct is akin to Bandura's (2002) description of outcome expectations. Further exploration of these findings would be useful, and has implications for how treatment options are presented to people with MD, especially in the context that successful management of MD is not guaranteed.

Fears have been reported to be important in adjustment to chronic illness and fear-related avoidance of activity is believed to cause or worsen conditions (Asmundson et al., 1997; Klenerman et al., 1995; Yardley, 1998). Waddell and colleagues (1993) suggested that disability is related to beliefs that physical activity can make symptoms worse. In this research programme, beliefs that physical activity can make symptoms worse were found to be associated with anxiety, but this effect did not remain once somatic anxiety, illness coherence, intolerance of uncertainty, and

emotional representations were taken into account. A similar concept, health anxiety related avoidance, only had a small effect on anxiety, depression and handicap. This effect did, however, just hold for handicap after other factors were taken into account, supporting previous findings. Avoidance, however, is also a component of PTSD, which was a very strong predictor of all three adjustment outcomes. It is possible that fear avoidance beliefs are manifesting in a particular way via PTSD symptoms. However, as PTSD is a multifactorial variable, it is possible that it was a strong predictor due to the greater combined variance from the re-experiencing, avoidance/numbing and arousal subscales.

Negative beliefs about dizziness were found to be associated with anxiety, but did not independently predict anxiety once somatic anxiety, illness coherence, intolerance of uncertainty, and emotional representations were taken into account. Yardley and colleagues (1994a; Yardley et al., 2001a) found that negative beliefs about dizziness were predictors of handicap. Although the effects of negative beliefs about dizziness on handicap were not tested in this research programme, negative beliefs about dizziness appear similar to health anxiety related negative consequences of illness in that both are forms of catastrophic thinking. Health anxiety related negative consequences of illness were significantly correlated with all adjustment outcomes. This variable was also a small but significant independent predictor of anxiety and depression, but did not predict handicap once other factors were taken into account. Although not tested, this suggests that negative beliefs about the consequences of illness could be mediated by one of the other variables, such as PTSD for the reasons given above.

Although the purpose of this research programme was not to measure change as a result of treatment, it was hypothesised in this research programme that there would be differences in predictors of adjustment outcomes between the treatment groups that participants were in for the randomised controlled trial that the research was nested within. This interaction effect was expected due to the unpleasantness of the vestibular rehabilitation treatment, the intended anxiety reducing aspects of the stress reduction treatment, and the inclusion of a control group that received no intervention. Therefore, it was surprising that no meaningful differences were found in predictors of adjustment outcomes between the treatment groups. As there is a

great deal of uncertainty in how MD symptoms fluctuate, and given that people with MD in this research programme appeared to have normal levels of intolerance of uncertainty, it is possible that these participants have become resilient to the emotional effects of different physical states that were induced by the three treatment groups (unpleasant, relaxing, no different to normal). This possibility is also supported by the finding that illness characteristics did not independently predict anxiety. It is also possible that illness characteristics were not important in predicting anxiety, enablement and adherence. In combination with the finding that only a subgroup of participants reached clinical levels of distress, the lack of difference between treatment groups suggests that poor adjustment to MD is not common in everyone with MD, but seems to be associated with individual differences in response to symptoms and their consequences rather than the symptoms themselves. It is important to note, however, that although predictors did not interact with treatment group to influence adjustment outcomes in this research programme, the randomised controlled trial (RCT) that part of this research programme was nested within (Yardley & Kirby, 2006) did report a treatment effect on outcome.

Bandura (2002) suggested that a reciprocal influence may exist between cognitive, affective and biological factors, behaviour, and environmental factors. Although regression models were used in this research programme to regress outcome adjustment measures onto predictors, it is quite likely that relationships might be reciprocal between predictors and outcome adjustment measures. Future research should explore this.

Based on the findings of this research programme, Figure 4 proposes a model of predictors of adjustment outcomes. Demographic and illness characteristics were found to influence adjustment outcomes, and although it was not the purpose of this research programme to test this formally with mediation, many of these effects disappeared once the psychological variables were added into the analyses. This effect was particularly noticeable for intolerance of uncertainty, and post hoc tests suggested that intolerance of uncertainty was mediated by the other psychological variables for the outcome variables of depression and handicap. Psychological variables were found to be key predictors of adjustment outcomes. Adherence was

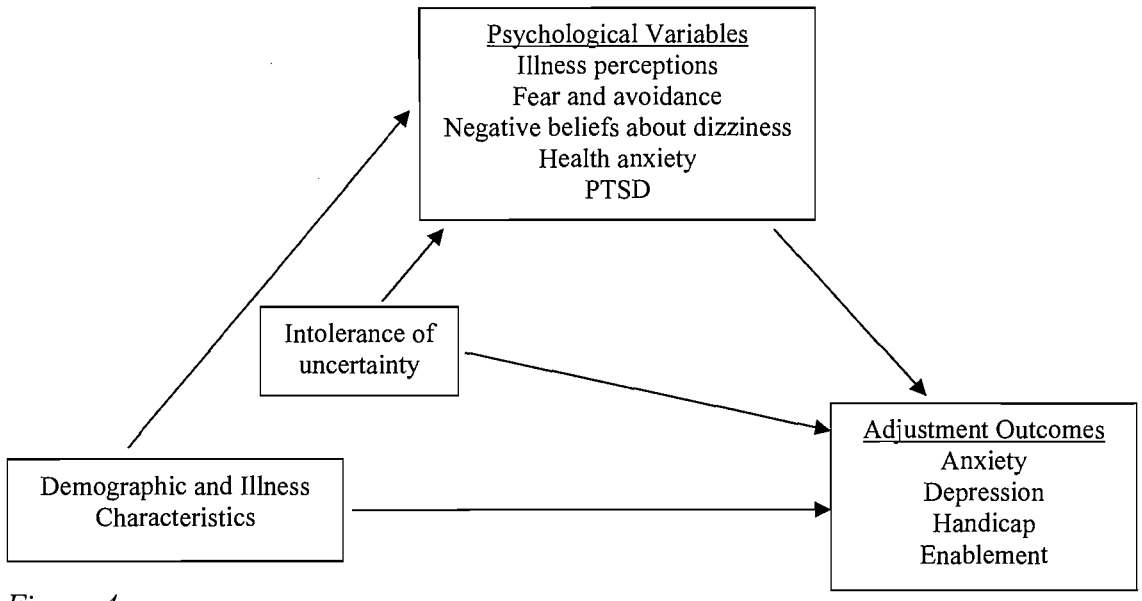


Figure 4

Proposed model of the predictors of adjustment

excluded from the model, as none of the variables appeared to predict adherence in a meaningful way.

8.3.2 Theoretical Implications of the of the Findings of the Systematic Review

The systematic review in this thesis makes a significant contribution in identifying and understanding the existing research on the role of psychological factors in MD. Although van Cruijsen and colleagues (2003) identified and reviewed a large amount of research in the area, they did not extensively investigate the validity of the claims made by each set of authors by assessing the empirical quality of the research, as was done in the systematic review. They did, however, recognise that a proportion of the research was "based upon clinicians' opinions and subjective reports from the patients", and that "many researchers have used psychological tests without standardized psychometric properties" (page 341). By explicitly assessing the empirical quality of research, the systematic review offers discernment as to which studies make the most valid and reliable contributions to the understanding of psychological factors in MD. Unfortunately, the findings of the systematic review suggest that only a limited amount of good quality research has been carried out since Crary and Wexler (1977) concluded in their review that the quality of work in

the area needed to be improved. Although only limited progress has been made since then, the systematic review does identify the key pieces of research to which greater attention should be given. This is particularly important, as some of the most cited studies in the area did not even meet the basic inclusion criteria for the systematic review.

Another advantage of the systematic review over the review by van Cruijsen and colleagues was the introduction of alternative explanations of MD related distress. The theoretical focus of van Cruijsen and colleagues' review was on the psychosomatic vs. somatopsychic argument (discussed in chapter 1), the debate of which offers little in the way of meaningful findings that can be translated into support for people with MD who are distressed. By introducing the consideration of mechanisms that can be modified through specific psychological interventions such as cognitive behavioural therapy, it is hoped that future research will investigate the role of these and other mechanisms, so understanding and subsequent treatment provision in this area can move forward.

8.3.3 Theoretical Implications of the of the Findings on Clinical Levels of Distress

The findings of this research programme that only a proportion of participants experience clinical levels of distress (anxiety, depression and PTSD), supports the observation by van Cruijsen (2003) that emotional factors are only relevant to a subgroup of people with MD. These findings are also similar to those of Savastano and colleagues (1996), who also identified clusters of participants who were well adjusted or severely distressed. However, they identified only small effects for anxiety and medium effects for depression when compared against norm scores. This research programme identified medium effects for anxiety and medium to large effects for depression. Although larger effects, these may be comparable with the findings of Savastano and colleagues in the sense that participants for this research programme were recruited from a self help-group, and therefore may have joined the group as a result of higher levels of distress. There appears to be a greater difference between people with MD and controls for depression than anxiety in both studies.

The proportions of participants meeting clinical levels of anxiety were also comparable between the studies described in chapters 3 and 7. Clinical levels of anxiety were found in 27.4% of participants in the study in chapter 3, and 27.9% in chapter 7. Levels of possible clinical anxiety were, however, significantly higher in chapter 3 (56.2%) than in chapter 7 (47.8%). An explanation for this could be due to the study in chapter 3 being nested within a randomised control trial that offered a new format of treatment. As existing treatment availability and effectiveness is limited, it is possible that people who took part in the trial were more anxious about their MD, which prompted them to volunteer. It could also be suggested that more anxious people were recruited due to the trial requiring participants to have current symptoms severe enough (but not too severe) to require intervention. However, this argument is not supported by the findings, as illness characteristics did not independently predict anxiety, and the vertigo scores for two studies are not significantly different from each other.

The levels of PTSD (12.1%) found in this programme of research were much higher than the 1.5 to1.8 % reported in the general population ((National Institute for Clinical Excellence, 2005). These levels were also slightly higher than those who have had a stroke (9.8%), and are comparable to people who have had a myocardial infarction (0-16%) or cardiac surgery (10.8% - 18%; Tedstone & Tarrier, 2003). These high levels of PTSD and distress are in line with the findings of Asmundson and colleagues (2000a), who found that dysfunctional chronic pain patients had high levels of PTSD and suggested they showed evidence of a collapsed 'psychological immune system'. Vertigo attacks in MD are unpredictable and are often reported as frightening (Pollak et al., 2003; Yardley et al., 1992b; Yardley, 1994c), so these results are consistent with the proposals of Lloyd and Turner (2003) and Alonzo (2000), both of whom suggest that PTSD can develop as the result of a gradual continued exposure to aversive events.

Following the concept of partial PTSD proposed by Mylle and Maes (2004), 43.9% of participants reached the threshold for increased arousal, 30% for re-experiencing, and 28.9% for avoidance or numbing. This is particularly interesting when interpreted in the context of the findings of Miller and colleagues (1996), who found that people with chronic illness who were high monitors of illness information had

greater levels of intrusive and avoidant ideations than those who were low monitors. It could be hypothesised that people with MD who are high monitors of information are prompted by this to join the Ménière's Society as it provides an external source of information about MD. As high monitoring of illness information in itself could be interpreted as being a form of alertness, or arousal, this hypothesis also offers an explanation for why PTSD arousal might have been so high in the members of the Ménière's Society in this research programme.

8.4 Clinical Implications

Although the predictors of anxiety identified in this research programme suggest that anxiety may be reduced by treatment of psychological factors alone, for the effective treatment of handicap and depression, a combination of psychological and physical treatment may be required. This is partially supported by three RCT's of psychological and physical treatment for people with vertigo or MD (Johansson et al., 2001; Yardley et al., 2004a; Yardley & Kirby, 2006). All three RCT's added cognitive behavioural elements to physical (vestibular rehabilitation) treatment to improve anxiety, avoidance and relaxation.

Johansson and colleagues' (2001) RCT was a small scale (treatment group n = 9; control group n = 10), individualised programme delivered in five sessions over seven weeks. Participants had a range of dizziness related diagnoses, including MD. The RCT by Yardley and colleagues (2004a) was larger in scale (treatment group n = 83; control group n = 87), with participants having a range of dizziness related diagnoses, including MD. Treatment exercises were taught to participants in one 30 to 40 minute session by a nurse, which participants then carried out for 12 weeks with the support of a treatment booklet and two follow-up telephone calls from the nurse. The RCT by Yardley and Kirby (2006) was also large in scale (physical treatment group n = 120, psychological treatment group n = 120, control group n = 120). Participants in this RCT were only recruited if they had been diagnosed with MD. This RCT used the same physical (vestibular rehabilitation) treatment booklet as Yardley and colleagues (2004a), but without any additional support. An alternative psychological treatment (stress reduction) booklet was also tested. All three RCT's reported significant improvement in handicap.

Johansson and colleagues (2001) and Yardley and colleagues (2004a) both reported that participants who had received treatment had reduced levels of handicap, but showed no significant reduction in anxiety or depression. However it should be noted that Johansson and colleagues (2001) assessed change in trait anxiety not state anxiety. Yardley and Kirby (2006) also found reduced levels of handicap in both treatment groups at the end of the 12 week treatment period and 24 week follow up. A slight reduction in anxiety was also reported in the physical treatment group at 12 weeks. However this was not sustained at the 24 week follow up. No improvement was reported for depression. Adherence rates were low, and we found that in people who did adhere to the treatments, for those undertaking physical treatment, anxiety was significantly reduced at the 24 week follow up, and depression was reduced at 12 weeks, and 24 weeks. Improvements in handicap in both treatment groups at both time points were maintained. However, neither anxiety nor depression were reduced by the stress reduction booklet. The findings of the last RCT (Yardley & Kirby, 2006) are the most interesting, as they suggest that physical but not psychological treatment was effective in reducing anxiety and depression, although it should be noted that the psychological treatment used was only a minimal one. Therefore, although the findings of this research programme suggest that pre-treatment illness characteristics do not appear to be important in predicting adjustment outcomes, the findings of the RCT suggest that changes in illness characteristics may be relevant. It is important to note that vestibular rehabilitation is not suitable for people with MD who have current, severe symptoms. Therefore it is still important to develop psychological treatments to help these people with their adjustment to MD.

The findings of this research programme suggest that the psychological aspects of the treatment of MD may benefit from being supplemented with treatment that specifically addresses PTSD, health anxiety, intolerance of uncertainty and emotional responses to MD. Research has shown that these problems can be successfully modified through treatment. The use of CBT has been effective in reducing health anxiety. Jones (2002) found that use of a cognitive behavioural self-help booklet reduced health anxiety and anxiety after four weeks. CBT has also been effective in reducing intolerance of uncertainty (Dugas & Ladouceur, 2000; Dugas et al., 2003). Dugas and Ladouceur (2000) encouraged participants to recognise the difference

between worrying about situations that would or would not benefit from problem solving strategies, and taught participants appropriate strategies to deal with both situations. Dugas and colleagues (2003) also taught participants problem-solving strategies, and encouraged participants to re-evaluate any positive beliefs they had about the benefits of worrying, and also used cognitive exposure. Trauma focused CBT is an established and recommended treatment for PTSD (National Institute for Clinical Excellence, 2005). As was found in this research programme, the occurrence of PTSD with anxiety and/or depression is common (National Institute for Clinical Excellence, 2005). However, it has been suggested that PTSD often remains unrecognized when the primary presenting problem is depression or an anxiety disorder (Zimmerman & Mattia, 1999). This may explain why PTSD has not been explored as a possible mechanism for distress in people with MD before. The comorbidity of PTSD with anxiety and/or depression should not complicate treatment, as the effective treatment of PTSD has been found to improve untreated symptoms of anxiety and depression (National Institute for Clinical Excellence, 2005). Therefore, it may be beneficial for clinicians to screen patients who seem particularly distressed and poorly adjusted to having MD for the possible presence of PTSD.

8.5 Limitations

The limitations of this research programme include five main areas, which will be discussed in turn. The first limitation comprises the retrospective methodology used in the systematic review. The second relates to the cross sectional design of much of the research programme. The third limitation discusses the sole use of self report measures. The fourth limitation is concerned with the recruitment of participants from a self help group, and the fifth with the lack of recruitment of vertiginous controls.

8.5.1 Methodology of the Systematic Review

Although making a significant contribution to the field by introducing the consideration of alternative mechanisms of distress, the unique methodology of the systematic review could also be seen as a limitation. The systematic review did not

just summarise and report the findings of the included studies, but synthesised the results of the included studies according to a retrospective examination of components of four mechanisms of distress. In other words, the systematic review identified and reinterpreted findings that were the same or similar to the components of the mechanisms in studies that did not specifically intend to measure these components or mechanisms. Therefore the possible evidence found in the systematic review can only be interpreted as a preliminary indication that the mechanisms could be present. Despite this limitation, and the fact that this method has not been used by other reviewers, it was a worthwhile approach to follow. This is because much of the research in the field of psychological factors in MD had become focused on the debate between psychosomatic vs. somatopsychic explanations of distress. Although this debate cannot be resolved due to the low incidence of MD making prospective studies impossible to carry out, other mechanisms had not been considered. The approach and findings of the systematic review therefore provide a base on which future work can be developed.

8.5.2 Cross Sectional Design

The studies reported in chapters 3 and 7 both only used data collected at a single time point, and were therefore cross sectional in design. It is therefore important to recognise that the findings of association from these studies cannot be interpreted as showing causality between the predictor and outcome variables, only that they may be associated. Even though the study reported in chapter 4 used data collected at one time point to statistically predict data collected at a later time point, the findings of this study can also not be interpreted as an indication of directional causality, as all variables were not experimentally controlled or manipulated, nor were any changes in variables measured from one time point to the next.

8.5.3 Self Report Measures

This research programme was limited by the sole use of self report measures. How participants perceive their symptoms, beliefs, and behaviours may not be the same as more objective measures might reveal. Poor correlations between subjective and objective measures have been reported in studies testing the effectiveness of

vestibular rehabilitation (Meli et al., 2006). The use of objective measures may have enabled a more reliable comparison between participants as two people can interpret the same severity of symptoms differently. However, the objective measures used to assess vestibular dysfunction are not necessarily accurate either, as they measure processes that can receive input from a number of different biological and psychological mechanisms. As MD is a relatively rare disease, to obtain the numbers of participants required for this research programme using objective measures would have required participants or researchers to travel across the country. This was beyond the scope of this research programme.

8.5.4 Recruitment from a Self Help Group

Participants were recruited from the Ménière's Society, a self help group. Consequently, the results of this research programme may not be representative of the general medical population of people with MD, and so should not be generalised to all people with MD. Dibb & Yardley (2006) found greater use of the Ménière's Society services to be associated with poorer adjustment. Therefore, it is possible that members of the self help group may be significantly different from those who do not feel the need to join, for example members may have wanted to join as a result of higher levels of anxiety than non members.

8.5.5 Vertiginous Controls

Crary and Wexler (1977) recommended the use of vertiginous controls, as they argued that as vertigo is a particularly distressing symptom, differences between people with MD and healthy controls could be just be due to the presence of vertigo, rather than MD. The current research programme did attempt to obtain a vertiginous control group, but due to delays in the study this data was being collected with, it was not possible to obtain the data in time for the completion of this thesis.

8.6 Further Research

The findings of this research programme identified a number of questions that future research could address in relation to psychological adjustment to MD.

This research programme achieved the preliminary identification of theoretically viable mechanisms of distress. Future research should seek to replicate and explore these findings in more detail than has been possible in this research programme, preferably including a non self help group population. The presence of other mechanisms should also be explored and tested. The strong effect of PTSD on distress found in this research programme should be confirmed using clinical interviews. Given the fluctuating nature of MD symptoms, it would also be interesting if future studies could assess the lifetime prevalence of PTSD symptoms in people with MD.

The aim of the research programme was to identify modifiable psychological factors that influence adjustment, to inform future help for people with MD. As modifiable psychological factors that affect adjustment have been identified, future research should aim to address and incorporate these factors into interventions and assess whether they are effective in improving adjustment.

Given the poor adherence rates reported in the RCT that this research was nested within (Yardley & Kirby, 2006), and the lack of significant predictors of adherence found in this research programme, it is essential that future research continues to attempt to identify factors that may influence adherence so that they can be addressed in future treatment. It should be considered that the decision to adhere or not to treatment may not be identified by beliefs and expectations prior to treatment, but by peri-treatment experiences, and how participants view and respond to those experiences. Such differences were identified by Yardley and Kirby (2006). We found that adherence was associated with whether participants experienced problems during treatment in relation to making symptoms worse, being uncertain if they were carrying out the treatment correctly, being doubtful if the treatment was effective, or for practical reasons such as remembering or being too busy. These factors should be explored further in relation to adherence. It is possible that although individual differences, beliefs and expectations do not appear to influence adherence itself, they may influence how people interpret peri-treatment experiences. As participants were given the self treatment booklets with no additional support, it is also possible that

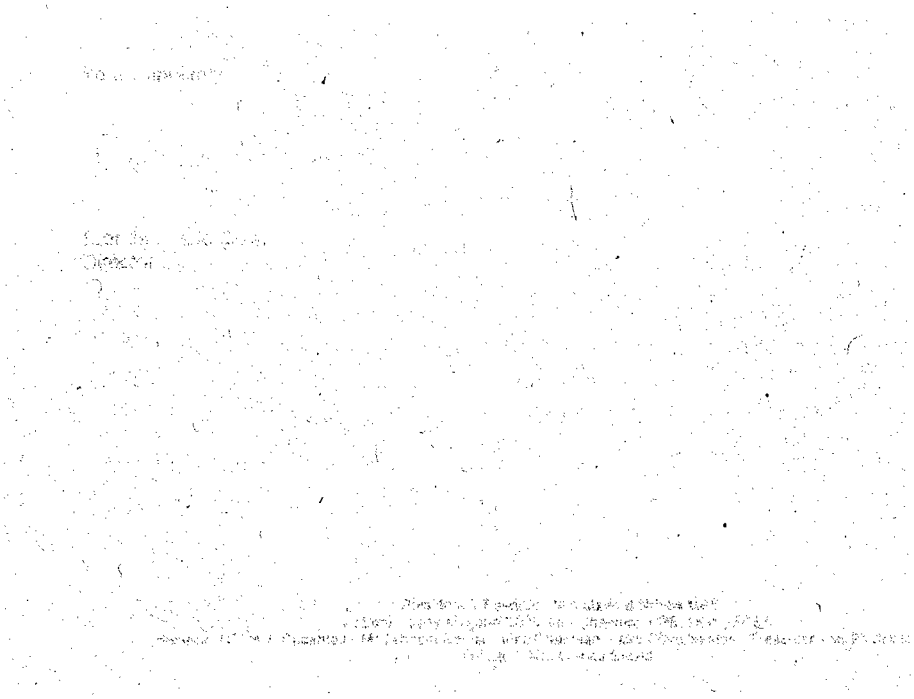
adherence could have been improved if more support was given, for example through a telephone call to see how the participant was getting on with the treatment.

It was not possible to use structural equation modelling to model the relationship between variables in this research programme. The variables used in this study had a great deal of overlap between the constructs. For example, the measures of PTSD included subscales on avoidance, re-experiencing and arousal. Avoidance was also a factor involved in handicap and health anxiety, and arousal was also measured by somatic anxiety. In order to use structural equation modelling, measures need to be selected that measure different aspects of distress separately. Future work should attempt to identify whether other measures with less overlap between constructs can be modelled to provide further understanding on the process of adjustment to MD.

A number of areas for future work were identified by the systematic review. Only 28 studies were identified to have been conducted on psychological factors in MD between 1978 and 2004 that met the basic inclusion criteria of the systematic review. Although a handful of studies have been carried out since the systematic review was completed that meet the inclusion criteria, (for example: Dibb & Yardley, 2006; Soderman et al., 2004; Van Cruijsen et al., 2006; Yardley & Kirby, 2006) the rate of empirically sound research on psychological factors in MD remains slow. The systematic review also identified that only one longitudinal and only one qualitative study had been carried out. As the symptoms of MD fluctuate and change as the disease progresses, future longitudinal research is needed to assess whether different psychological variables are more relevant than others at different stages of the disease, and if psychological variables also fluctuate. Qualitative research is particularly helpful in generating models and hypotheses which can later be developed into new measures or methods. As very little is known about the role of psychological factors and adjustment in MD, a good starting point for future research would be to carry out qualitative studies to explore the beliefs and experiences of people with MD and use these to generate models and hypotheses relating to adjustment to MD.

8.7 Conclusions

This research programme has identified that only a proportion of members of the Ménière's society experience clinically high levels of distress. Overall, the participants with MD in this research programme did show greater levels of distress than healthy controls for some variables but not for others. Adjustment to MD appears to be a multifactorial construct, with different factors affecting different types of adjustment. The mechanisms of PTSD and health anxiety were proposed and found to be relevant to MD related distress. With further development of empirically sound research including more longitudinal and qualitative research, it is hoped that a greater understanding of the mechanisms linking MD with adjustment will enable psychological treatment and support to be more effectively tailored to the particular problems of people with MD.



Appendices

Appendix A: Covering letter used for studies in chapters 3 and 4

Ménière's Society

helping people with vertigo, tinnitus and deafness

98 Maybury Road, Woking, Surrey GU21 5HX
Voice (01483) 740597 Textphone (01483) 771207 Fax (01483) 755441
Email info@menieres.org.uk
www.menieres.org.uk

Dear Member

As you will see in the latest edition of SPIN, No. 45, Sarah Kirby of Southampton University is carrying out a research trial that will be testing the benefit of balance retraining exercises (called vestibular rehabilitation), and stress reduction methods. This work is funded by the Ménière's Society Research Fund.

Sarah has asked us to send out the enclosed questionnaire to members. We do appreciate that you may not wish to participate, or that your illness may prevent you from doing so, in which case please return it uncompleted in the enclosed stamped addressed envelope.

Your details have not been given to Sarah and you will only receive further correspondence from her should you agree to take part.

If you do to take part, Sarah will be your point of contact on any aspect of your participation.

Yours sincerely

Brenda Shield

Brenda Shield (Mrs)
Director

Appendix B: Information sheet used for studies in chapters 3 and 4

University of Southampton

Department of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone: 023 8059 2581
Fax: 023 8059 4597
Email: sarah.kirby@soton.ac.uk

Hello,

My name is Sarah Kirby; I am a researcher working for the Ménière's Society under the supervision of Professor Lucy Yardley at Southampton University.

I am writing to offer you the opportunity to take part in a research trial that will be testing the benefit of balance retraining exercises (also called vestibular rehabilitation) and stress reduction methods (to help you to control your symptoms). They are not a cure for Ménière's disease, but they may help your balance and increase your confidence in being able to cope with your symptoms. At the moment these therapies are only available from a few specialist centres that people have to travel to. This means that not everyone who needs treatment is getting it. This research trial will be testing the therapies in the form of self-treatment booklets that have been specially designed for people with Ménière's disease. We are aiming to find out three things:

(1) To see if people can treat themselves using the booklets, without the help of a specialist.

(2) To find out how many people find the booklets helpful.

(3) To see if there is anything that might predict who is most likely to benefit from using the booklets.

More details about the therapies and the trial are given over the page.

If you would like to take part in the trial, please take the enclosed letter to your GP. Your GP will tell you if there are any medical reasons why you should not take part. You will not be able to take part in the trial unless you have consulted your GP. If you have a history of heart problems or arthritis in their neck, you will need to check that the therapies will not make your condition worse. The therapies are not suitable for people who have had a severe attack of vertigo within the last six weeks.

After you have seen your GP, please complete the enclosed questionnaires and return in the pre-paid envelope provided. You will then be contacted over the following few weeks.

You are under no obligation to take part in this trial. If you choose to take part in the trial, you can leave at any time, without having to give a reason, and without it affecting your future medical care. Personal information will not be released to or viewed by anyone other than researchers involved in the trial. Results of the trial will not include your name or any other identifying characteristics.

If you have any questions about the trial, or any concerns during the trial, then please feel free to contact me, Sarah Kirby, on 023 8059 2581. Please keep this letter, as it contains information about the trial and how to contact me if you want to.

Thank you for your help,

Sarah Kirby

A randomised controlled trial of the effectiveness of self-treatment booklets for people with Meniere's disease

How do the therapies work?

The balance retraining exercises work by carefully practicing movements that make you dizzy. Your brain slowly learns to cope with the movements, and in time they will not make you dizzy anymore. This will improve your dizziness and imbalance between attacks of vertigo, and boost your confidence in being able to cope with your vertigo.

The exercises cannot cause any damage to your balance system, but they will not help you if you have sudden attacks of vertigo twice a month or more. This is why these exercises are not recommended for people who have had an acute vertigo attack in the last six weeks.

Stress is known to make the symptoms of Ménière's disease worse, so reducing your stress levels should help to control some of your symptoms. The stress reduction methods in the 'controlling your symptoms' booklet will not provoke your symptoms.

If I choose to take part, what will I have to do?

If you would like to take part in the trial, and have not had a severe attack of vertigo within the last six weeks, please take the enclosed letter to your GP. Your GP will tell you if there are any medical reasons why you should not take part. You will not be able to take part in the trial unless you have consulted your GP. If you have a history of heart problems or arthritis in their neck, you will need to check that the therapies will not make your condition worse. After you have seen your GP, please fill in the enclosed questionnaires and return in the pre-paid envelope provided. You will then be put into a group and contacted over the following few weeks.

There will be three groups in the trial – the first group will receive the 'balance retraining' booklet; the second will receive the 'controlling your symptoms' booklet; and the third group (a control group) will not receive either booklet until after 24 weeks.

You will be sent a pre-treatment questionnaire pack to fill in and return. You will then receive one of the self-treatment booklets to use for 12 weeks (unless you are in the control group that receives no booklets until after 24 weeks).

You will be contacted by telephone after 3 weeks to see if your symptoms have changed since the start of the trial. After 12 weeks, you will be sent a post-treatment questionnaire pack to fill in and return.

After 24 weeks, you will be sent a follow-up questionnaire pack, to see if any long-term changes have taken place.

At the end of the trial, everybody in all groups will receive a copy of the booklet(s) they have not had.

How much time will the therapies and trial take?

Both of the therapies take 10 minutes, and should ideally be carried out twice a day, every day for 12 weeks per therapy. The whole trial will last for 24 weeks.

If you have any questions or concerns about the trial, please contact Sarah Kirby, on 023 8059 2581

Appendix C: Consent form used for studies in chapters 3 and 4

University of Southampton

Department of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone: 023 8059 2581
Fax: 023 80 595 785
Email: sarah.kirby@soton.ac.uk

Consent Form

A randomised controlled trial of the effectiveness of self-treatment booklets for people with Meniere's disease

Please circle YES or NO to each of the questions:

Have you read the information sheet?..... YES / NO

Do you feel you have an understanding of what the study is about?..... YES / NO

Do you understand that you are free to withdraw from the study at any time, without having to give a reason, and without it affecting your future medical care?..... YES / NO

Do you confirm that you have consulted your GP to ensure that there are no medical reasons why you should not take part in this trial?..... YES

Do you agree to participate in this study?..... YES / NO

Signed_____ Date_____

Please give your name and contact details (BLOCK CAPITALS PLEASE)

Name _____

Address _____

_____

_____ Postcode_____

Telephone Number: Daytime: _____ Evening: _____

When is the best time of day to contact you?.....Morning / Afternoon / Evening

Appendix D: Recruitment questionnaires used for studies in chapters 3 and 4

General Information

1.	How long has it been since your first experienced your symptoms? (please write number of years/months in the box)	

2.	What is your Gender? (please circle)	Male	Female

3.	What is your Age? (please write in the box)	

Therapy Expectations

These questions are about what you are expecting to happen as a result of using the self-treatment 'balance retraining' and 'controlling your symptoms' booklets. Please indicate your response by ticking the appropriate boxes.

Do you expect that as a result of using the **Balance Retraining booklet**, you will be:

		Much Better	Better	Same or Less
1.	Able to cope with life?			
2.	Able to understand your illness?			
3.	Able to cope with your illness?			
4.	Able to keep yourself healthy?			

		Much More	More	Same or Less
5.	Confident about your health?			
6.	Able to help yourself?			

Do you expect that as a result of using the **Controlling Your Symptoms booklet,** you will be:

		Much Better	Better	Same or Less
7.	Able to cope with life?			
8.	Able to understand your illness?			
9.	Able to cope with your illness?			
10.	Able to keep yourself healthy?			

		Much More	More	Same or Less
11.	Confident about your health?			
12.	Able to help yourself?			

Vertigo Symptom Scale (Past 12 months)

Please tick the appropriate box to indicate about how many times you have experienced each of the symptoms listed below during the past 12 months (or since the vertigo started, if you have had vertigo for less than one year). The range of responses are:

Never	A few times (1-3 times a year)	Several times (4-12 times a year)	Quite often (on average, more than once a month)	Very often (on average, more than once a week)

How often **in the past 12 months** have you had the following symptoms:

		Never	A few times	Several times	Quite Often	Very Often
1.	A feeling that things are spinning or moving around, lasting: (PLEASE ANSWER ALL THE CATEGORIES)					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hour					
d)	several hours					
e)	more than 12 hours					
2.	Pains in the heart or chest region					
3.	Hot or cold spells					
4.	Unsteadiness so severe that you actually fall					
5.	Nausea (feeling sick), stomach churning					
6.	Tension/soreness in your muscles					
7.	A feeling of being light-headed, "swimmy" or giddy, lasting: (PLEASE ANSWER ALL THE CATEGORIES)					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hour					
d)	several hours					
e)	more than 12 hours					
8.	Trembling, shivering					
9.	Feeling of pressure in the ear(s)					
10.	Heart pounding or fluttering					
11.	Vomiting					
12.	Heavy feeling in arms or legs					

		Never	A few times	Several times	Quite Often	Very Often
13.	Visual disturbances (e.g. blurring, flickering, spots before the eyes)					
14.	Headache or feeling of pressure in the head					
15.	Unable to stand or walk properly without support					
16.	Difficulty breathing, short of breath					
17.	Loss of concentration or memory					
18.	Feeling unsteady, about to lose balance, lasting: (PLEASE ANSWER ALL THE CATEGORIES)					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hours					
d)	several hours					
e)	more than 12 hours					
19.	Tingling, prickling or numbness in parts of the body					
20.	Pains in the lower part of your back					
21.	Excessive sweating					
22.	Feeling faint, about to black out					

Thank you for completing this questionnaire. Please make sure you have answered all the questions, and then return it with the completed consent form in the envelope provided as soon as possible to: Mrs Sarah Kirby, Psychology Department, University of Southampton, Highfield, Southampton, SO17 1BJ.

If you have any questions or concerns about the trial, then please contact Sarah Kirby on Tel: 023 8059 2581.

Appendix E: Baseline questionnaires used for studies in chapters 3 and 4

Participant ID no_____

University of Southampton

Department of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone: 023 8059 2581
Fax: 023 8059 4597
Email: sarah.kirby@soton.ac.uk

A randomised controlled trial of the effectiveness of self-treatment booklets for people with Meniere's disease

Questionnaire Pack One

This questionnaire pack contains questions about your Ménière's symptoms; your opinions about your illness; how you are feeling; how your illness affects your life; and how you cope with the uncertainty caused by your illness.

Please answer all the questions in each section as accurately as possible, making sure you do not miss out any of the questions. Your answers will remain confidential at all times.

Once you have filled in this questionnaire, please return it in the pre-paid envelope provided. You will then be sent a self-treatment booklet (unless you are in the group who receives the booklets after 24 weeks).

If you have any questions or concerns, then please contact me on 023 8059 2581

Thank you for taking part in this trial.

Sarah Kirby

Tinnitus

Please circle the box that most accurately describes the tinnitus you experience:

None	Rarely Noted	Occasional	Frequent	Almost Constant	Constant	Severe; Primary problem

Feeling of fullness in the ear

Please circle the box that most accurately describes the feeling of fullness you experience in your ear(s):

None	Infrequent	Occasional	Frequent but mild	Frequent but moderate	Frequent and severe but not incapacitating	Almost constant and incapacitating

Hearing

The questions in this section cover your hearing. Please circle the answer that applies to you without the use of your hearing aid, should you use one. Please answer all the questions.

1.	Can you follow the television news when the volume is turned up only enough to suit other people?			
	Easily	**With some difficulty**	**With great difficulty**	**Not at all**
2.	Can you follow what is being said on the radio news when the volume is turned up only enough to suit other people?			
	Not at all	**With great difficulty**	**With some difficulty**	**Easily**
3.	If you are sitting with a group of people and someone you can't see starts to speak, are you able to tell where the person is sitting?			
	Usually	**Sometimes**	**Not Usually**	
4.	How difficult do you usually find it to follow somebody's conversation when other people are talking close by?			
	Great difficulty	**Some difficulty**	**No difficulty**	
5.	When talking in a quiet room with someone who is a clear speaker, how much difficulty do you have in understanding what they are saying?			
	No difficulty	**Some difficulty**	**Great difficulty**	

Vertigo Symptom Scale (Past month)

We would like to know what dizziness-related symptoms you have had just recently. Please tick the appropriate box to indicate about how many times you have experienced each of the symptoms listed below during the past month. The range of responses are:

Never	A few times	Several times	Quite often (every week)	Very often (most days)

How often **in the past month** have you had the following symptoms:

		Never	A few times	Several times	Quite Often	Very Often
1.	A feeling that either you, or things around you are spinning or moving, lasting less than 20 minutes.					
2.	Hot or cold spells.					
3.	Nausea (feeling sick), vomiting.					
4.	A feeling that either you, or things around you are spinning or moving, lasting more than 20 minutes.					
5.	Heart pounding or fluttering.					
6.	A feeling of being dizzy, disorientated or "swimmy", lasting all day.					
7.	Headache, or feeling of pressure in the head.					
8.	Unable to stand or walk properly without support, veering or staggering to one side.					
9.	Difficulty breathing, short of breath.					
10.	Feeling unsteady, about to lose balance, lasting more than 20 minutes.					
11.	Excessive sweating.					
12.	Feeling faint, about to black out.					
13.	Feeling unsteady, about to lose balance lasting less than 20 minutes.					
14.	Pains in the heart or chest region.					
15.	A feeling of being dizzy, disorientated or "swimmy", lasting less than 20 minutes.					

Your Views about Your Illness

We are interested in you own personal views of how you now see your current illness. Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	Views About Your Illness	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	My illness will last a short time					
2	My illness is likely to be permanent rather than temporary					
3	My illness will last for a long time					
4	This illness will pass quickly					
5	I expect to have this illness for the rest of my life					
6	My illness is a serious condition					
7	My illness has major consequences on my life					
8	My illness does not have much effect on my life					
9	My illness strongly affects the way others see me					
10	My illness has serious financial consequences					
11	My illness causes difficulties for those who are close to me					
12	There is a lot which I can do to control my symptoms					
13	What I do can determine whether my illness gets better or worse					
14	The course of my illness depends on me					
15	Nothing I do will affect my illness					
16	I have the power to influence my illness					
17	My actions will have no affect on the outcome of my illness					
18	My illness will improve in time					
19	There is very little that can be done to improve my illness					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
20	My treatment will be effective in curing my illness					
21	The negative effects of my illness can be prevented (avoided) by my treatment					
22	My treatment can control my illness					
23	There is nothing which can help my condition					
24	The symptoms of my condition are puzzling to me					
25	My illness is a mystery to me					
26	I don't understand my illness					
27	My illness doesn't make any sense to me					
28	I have a clear picture or understanding of my condition					
29	The symptoms of my illness change a great deal from day to day					
30	My symptoms come and go in cycles					
31	My illness is very unpredictable					
32	I go through cycles in which my illness gets better and worse					
33	I get depressed when I think about my illness					
34	When I think about my illness I get upset					
35	My illness makes me feel angry					
36	My illness does not worry me					
37	Having this illness makes me feel anxious					
38	My illness makes me feel afraid					

Causes of My Illness

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what other people (including doctors or family) may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Possible Causes	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	Stress or Worry					
2	Hereditary – It runs in my family					
3	A Germ or virus					
4	Diet or eating habits					
5	Chance or bad luck					
6	Poor medical care in my past					
7	Pollution in the environment					
8	My own behaviour					
9	My mental attitude e.g. thinking about life negatively					
10	Family problems or worries caused my illness					
11	Overwork					
12	My emotional state e.g. feeling down, lonely, anxious, empty					
13	Ageing					
14	Alcohol					
15	Smoking					
16	Accident or injury					
17	My personality					
18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me: -

1. _____
2. _____
3. _____

Your Feelings

Please read each item below and place a tick in the box opposite the reply which comes close to how you have been feeling in the last week. Don't take too long over your replies: your immediate reaction will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- Time to time, Occasionally
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I have lost interest in my appearance:

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I look forward with enjoyment to things:

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Dizziness Handicap Inventory

The purpose of this scale is to identify difficulties that you may be experiencing because of your dizziness or unsteadiness. Please answer "yes", "no", or "sometimes" to each question. *Answer each question as it pertains to your dizziness or unsteadiness problems only.*

1	Does looking up increase your problem?	Yes	Sometimes	No
2	Because of your problem, do you feel frustrated?	Yes	Sometimes	No
3	Because of your problem, do you restrict your travel for business or recreation?	Yes	Sometimes	No
4	Does walking down the aisle of a supermarket increase your problem?	Yes	Sometimes	No
5	Because of your problem, do you have difficulty getting into or out of bed?	Yes	Sometimes	No
6	Does your problem significantly restrict your participation in social activities such as going out to dinner, going to movies, dancing, or to parties?	Yes	Sometimes	No
7	Because of your problem, do you have difficulty reading?	Yes	Sometimes	No
8	Does performing more ambitious activities like sports, dancing, household chores such as sweeping or putting dishes away increase your problem?	Yes	Sometimes	No
9	Because of your problem, are you afraid to leave your home without having some-one accompany you?	Yes	Sometimes	No
10	Because of your problem, have you been embarrassed in front of others?	Yes	Sometimes	No
11	Do quick movements of your head increase your problem?	Yes	Sometimes	No
12	Because of your problem, do you avoid heights?	Yes	Sometimes	No
13	Does turning over in bed increase your problem?	Yes	Sometimes	No
14	Because of your problem, is it difficult for you to do strenuous housework or gardening?	Yes	Sometimes	No
15	Because of your problem, are you afraid people may think you are intoxicated?	Yes	Sometimes	No
16	Because of your problem, is it difficult for you to go for a walk by yourself?	Yes	Sometimes	No
17	Does walking down the street increase your problem?	Yes	Sometimes	No
18	Because of your problem, is it difficult for you to concentrate?	Yes	Sometimes	No
19	Because of your problem, is it difficult for you to walk around your house in the dark?	Yes	Sometimes	No

20	Because of your problem, are you afraid to stay home alone?	Yes	Sometimes	No
21	Because of your problem, do you feel handicapped?	Yes	Sometimes	No
22	Has your problem placed stress on your relationships with members of your family or friends?	Yes	Sometimes	No
23	Because of your problem, are you depressed?	Yes	Sometimes	No
24	Does your problem interfere with your job or household responsibilities?	Yes	Sometimes	No
25	Does bending over increase your problem?	Yes	Sometimes	No

Positive Well-Being

Please circle a number on each of the following scales to indicate how often you feel each phrase has applied to you in the past few weeks.

		All the time			Not at all
1	I have been happy, satisfied or pleased with my personal life.	3	2	1	0
2	I have felt well adjusted to my life situation.	3	2	1	0
3	I have lived the kind of life I wanted to.	3	2	1	0
4	I have felt eager to tackle my daily tasks or make new decisions.	3	2	1	0
5	I have felt I could easily handle or cope with any serious problem or major change in my life.	3	2	1	0
6	My daily life has been full of things that were interesting to me.	3	2	1	0

Views about Uncertainty

Many people have said that one of the most troublesome aspects of Ménière's disease is the uncertainty about how ill or well you will be in the future. You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you (circle the number that describes you best for each item). Please answer all the questions.

The range of responses are:

1 Not at all characteristic of me	2 A little characteristic of me	3 Somewhat characteristic of me	4 Very characteristic of me	5 Entirely characteristic of me

How characteristic of you are each of the following statements:

1	Uncertainty stops me from having a firm opinion.	1	2	3	4	5
2	Being uncertain means that a person is disorganized.	1	2	3	4	5
3	Uncertainty makes life intolerable.	1	2	3	4	5
4	It's not fair that there are no guarantees in life.	1	2	3	4	5
5	My mind can't be relaxed if I don't know what will happen tomorrow.	1	2	3	4	5
6	Uncertainty makes me uneasy, anxious, or stressed.	1	2	3	4	5
7	Unforeseen events upset me greatly.	1	2	3	4	5
8	It frustrates me not having all the information I need.	1	2	3	4	5
9	Being uncertain allows me to foresee the consequences beforehand and to prepare for them.	1	2	3	4	5
10	One should always look ahead so as to avoid surprises.	1	2	3	4	5
11	A small unforeseen event can spoil everything, even with the best of planning.	1	2	3	4	5
12	When it's time to act uncertainly paralyses me.	1	2	3	4	5
13	Being uncertain means that I am not first rate.	1	2	3	4	5
14	When I am uncertain I can't go forward.	1	2	3	4	5
15	When I am uncertain I can't function very well.	1	2	3	4	5
16	Unlike me, others always seem to know where they are going with their lives.	1	2	3	4	5
17	Uncertainty makes me vulnerable, unhappy, or sad.	1	2	3	4	5

1 Not at all characteristic of me	2 A little characteristic of me	3 Somewhat characteristic of me	4 Very characteristic of me	5 Entirely characteristic of me

18	I always want to know what the future has in store for me.	1	2	3	4	5
19	I hate being taken by surprise.	1	2	3	4	5
20	The smallest doubt stops me from acting.	1	2	3	4	5
21	I should be able to organize everything in advance.	1	2	3	4	5
22	Being uncertain means that I lack confidence.	1	2	3	4	5
23	I think it's unfair that other people seem sure about their future.	1	2	3	4	5
24	Uncertainty stops me from sleeping well.	1	2	3	4	5
25	I must get away from uncertain situations.	1	2	3	4	5
26	The ambiguities in life stress me.	1	2	3	4	5
27	I can't stand being undecided about my future.	1	2	3	4	5

Physical Activities

These questions relate to how physical activities affect your vertigo (including symptoms which you may call dizziness, giddiness or unsteadiness). For each statement please tick the box to say how much physical activities such as bending, lifting, walking, or driving affect or would affect your vertigo.

		Completely Disagree	Mostly Disagree	Slightly Disagree	Unsure	Slightly Agree	Mostly Agree	Completely Agree
1	My vertigo is caused by physical activity							
2	Physical activity makes my vertigo worse							
3	Physical activity might harm me							
4	I should not do physical activities which might make my vertigo worse							
5	I cannot do physical activities which might make my vertigo worse							

Dizziness Beliefs

These questions are about your beliefs and concerns when you experience dizziness or vertigo. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.

'When I get dizzy, I sometimes think that…'

	Possible Beliefs	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	I will lose control.					
2	I will cause embarrassment by staggering in public.					
3	I will be unable to manage potentially dangerous activities (e.g. crossing the road, walking downstairs, driving, handling machinery).					
4	I will faint or pass out.					
5	I will hurt myself by stumbling or falling over.					
6	I will be unable to behave normally in public.					
7	I will lose consciousness.					
8	I will do something embarrassing.					
9	I will fall over.					
10	I will let people down.					
11	I will feel sick.					
12	The dizziness will get worse and worse.					
13	I will vomit in front of people.					
14	The dizziness will go on for a long time.					

Thank you for filling in this questionnaire. Please make sure you have answered all the questions, and then return it in the envelope provided as soon as possible to: Mrs Sarah Kirby, Psychology Department, University of Southampton, Highfield, Southampton, SO17 1BJ.

If you have any questions or concerns about the trial, then please contact Sarah Kirby on Tel: 023 8059 2581.

Appendix F: Follow up questionnaire used for study in chapter 4

Participant ID no_____

University of Southampton

Department of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

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A randomised controlled trial of the effectiveness of self-treatment booklets for people with Meniere's disease

Questionnaire Pack Two

This questionnaire pack contains questions asking about your Ménière's symptoms, how you are feeling, and how your illness affects your life.

Please answer all the questions in each section as accurately as possible, making sure you do not miss out any of the questions. Your answers will remain confidential at all times.

Once you have filled in this questionnaire, please return it in the pre-paid envelope provided.

If you have any questions or concerns, then please contact me on 023 8059 2581

Thank you for taking part in this trial.

Sarah Kirby

Tinnitus

Please circle the box that most accurately describes the tinnitus you experience:

None	Rarely Noted	Occasional	Frequent	Almost Constant	Constant	Severe; Primary problem

Feeling of fullness in the ear

Please circle the box that most accurately describes the feeling of fullness you experience in your ear(s):

None	Infrequent	Occasional	Frequent but mild	Frequent but moderate	Frequent and severe but not incapacitating	Almost constant and incapacitating

Vertigo Symptom Scale (Past month)

We would like to know what dizziness-related symptoms you have had just recently. Please tick the appropriate box to indicate about how many times you have experienced each of the symptoms listed below during the past month. The range of responses are:

Never	**A few times**	**Several times**	**Quite often** (every week)	**Very often** (most days)

How often **in the past month** have you had the following symptoms:

		Never	**A few times**	**Several times**	**Quite Often**	**Very Often**
1.	A feeling that either you, or things around you are spinning or moving, lasting less than 20 minutes.					
2.	Hot or cold spells.					
3.	Nausea (feeling sick), vomiting.					
4.	A feeling that either you, or things around you are spinning or moving, lasting more than 20 minutes.					
5.	Heart pounding or fluttering.					
6.	A feeling of being dizzy, disorientated or "swimmy", lasting all day.					
7.	Headache, or feeling of pressure in the head.					

		Never	A few times	Several times	Quite Often	Very Often
8.	Unable to stand or walk properly without support, veering or staggering to one side.					
9.	Difficulty breathing, short of breath.					
10.	Feeling unsteady, about to lose balance, lasting more than 20 minutes.					
11.	Excessive sweating.					
12.	Feeling faint, about to black out.					
13.	Feeling unsteady, about to lose balance lasting less than 20 minutes.					
14.	Pains in the heart or chest region.					
15.	A feeling of being dizzy, disorientated or "swimmy", lasting less than 20 minutes.					

Positive Well-Being

Please circle a number on each of the following scales to indicate how often you feel each phrase has applied to you in the past few weeks.

		All the time			Not at all
1	I have been happy, satisfied or pleased with my personal life.	3	2	1	0
2	I have felt well adjusted to my life situation.	3	2	1	0
3	I have lived the kind of life I wanted to.	3	2	1	0
4	I have felt eager to tackle my daily tasks or make new decisions.	3	2	1	0
5	I have felt I could easily handle or cope with any serious problem or major change in my life.	3	2	1	0
6	My daily life has been full of things that were interesting to me.	3	2	1	0

Your Feelings

Please read each item below and place a tick in the box opposite the reply which comes close to how you have been feeling in the last week. Don't take too long over your replies: your immediate reaction will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- Time to time, Occasionally
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I have lost interest in my appearance:

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I look forward with enjoyment to things:

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Dizziness Handicap Inventory

The purpose of this scale is to identify difficulties that you may be experiencing because of your dizziness or unsteadiness. Please answer "yes", "no", or "sometimes" to each question. *Answer each question as it pertains to your dizziness or unsteadiness problems only.*

1	Does looking up increase your problem?	Yes	Sometimes	No
2	Because of your problem, do you feel frustrated?	Yes	Sometimes	No
3	Because of your problem, do you restrict your travel for business or recreation?	Yes	Sometimes	No
4	Does walking down the aisle of a supermarket increase your problem?	Yes	Sometimes	No
5	Because of your problem, do you have difficulty getting into or out of bed?	Yes	Sometimes	No
6	Does your problem significantly restrict your participation in social activities such as going out to dinner, going to movies, dancing, or to parties?	Yes	Sometimes	No
7	Because of your problem, do you have difficulty reading?	Yes	Sometimes	No
8	Does performing more ambitious activities like sports, dancing, household chores such as sweeping or putting dishes away increase your problem?	Yes	Sometimes	No
9	Because of your problem, are you afraid to leave your home without having some-one accompany you?	Yes	Sometimes	No
10	Because of your problem, have you been embarrassed in front of others?	Yes	Sometimes	No
11	Do quick movements of your head increase your problem?	Yes	Sometimes	No
12	Because of your problem, do you avoid heights?	Yes	Sometimes	No
13	Does turning over in bed increase your problem?	Yes	Sometimes	No
14	Because of your problem, is it difficult for you to do strenuous housework or gardening?	Yes	Sometimes	No
15	Because of your problem, are you afraid people may think you are intoxicated?	Yes	Sometimes	No
16	Because of your problem, is it difficult for you to go for a walk by yourself?	Yes	Sometimes	No
17	Does walking down the street increase your problem?	Yes	Sometimes	No
18	Because of your problem, is it difficult for you to concentrate?	Yes	Sometimes	No
19	Because of your problem, is it difficult for you to walk around your house in the dark?	Yes	Sometimes	No

20	Because of your problem, are you afraid to stay home alone?	Yes	Sometimes	No
21	Because of your problem, do you feel handicapped?	Yes	Sometimes	No
22	Has your problem placed stress on your relationships with members of your family or friends?	Yes	Sometimes	No
23	Because of your problem, are you depressed?	Yes	Sometimes	No
24	Does your problem interfere with your job or household responsibilities?	Yes	Sometimes	No
25	Does bending over increase your problem?	Yes	Sometimes	No

Dizziness Beliefs

These questions are about your beliefs and concerns when you experience dizziness or vertigo. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.

'When I get dizzy, I sometimes think that…'

	Possible Beliefs	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	I will lose control.					
2	I will cause embarrassment by staggering in public.					
3	I will be unable to manage potentially dangerous activities (e.g. crossing the road, walking downstairs, driving, handling machinery).					
4	I will faint or pass out.					
5	I will hurt myself by stumbling or falling over.					
6	I will be unable to behave normally in public.					
7	I will lose consciousness.					
8	I will do something embarrassing.					
9	I will fall over.					
10	I will let people down.					
11	I will feel sick.					
12	The dizziness will get worse and worse.					
13	I will vomit in front of people.					
14	The dizziness will go on for a long time.					

Physical Activities

These questions relate to how physical activities affect your vertigo (including symptoms which you may call dizziness, giddiness or unsteadiness). For each statement please tick the box to say how much physical activities such as bending, lifting, walking, or driving affect or would affect your vertigo.

		Completely Disagree	Mostly Disagree	Slightly Disagree	Unsure	Slightly Agree	Mostly Agree	Completely Agree
1	My vertigo is caused by physical activity							
2	Physical activity makes my vertigo worse							
3	Physical activity might harm me							
4	I should not do physical activities which might make my vertigo worse							
5	I cannot do physical activities which might make my vertigo worse							

Your dizziness or unsteadiness now

This question relates to your dizziness or unsteadiness now. Please circle the most appropriate response.

Overall would you say that during the past week or two you have been feeling better, worse, or much the same as when you first completed these questionnaires?					
Much worse	A little worse	Much the same	A little better	Much better	Completely well

Therapy Empowerment

Please tick the appropriate box for each question.

Compared with when you first filled out the questionnaires, do you feel you are:

		Much Better	Better	Same or Less
1.	Able to cope with life?			
2.	Able to understand your illness?			
3.	Able to cope with your illness?			
4.	Able to keep yourself healthy?			

		Much More	More	Same or Less
5.	Confident about your health?			
6.	Able to help yourself?			

EXTRA SECTION

The following pages only need to be filled in by people who received a self-treatment booklet 12 weeks ago.

If you are in the group that does not receive the self-treatment booklets until after 24 weeks, you do not need to fill in this section. Please make sure you have answered all the questions in the previous sections, and then return the questionnaire pack in the envelope provided.

Please contact me (Sarah Kirby) if you have any questions or concerns about the trial.

Carrying out the therapy

These questions relate to how often you were able to carry out the therapy and reasons why you decided to stop doing the therapy.

Please circle the most appropriate responses.

1.	For how many weeks did you carry out the therapy?					
	Never Started	One Week	1-2 Weeks	3-5 Weeks	6-8 Weeks	9-12 Weeks

2.	Did you stop doing the therapy because you no longer had symptoms of dizziness or unsteadiness?	Yes	No
2a.	If you answered **YES**, after how many weeks did you stop doing the therapy because you no longer had symptoms of dizziness or unsteadiness?		
	One Week	1-2 Weeks	3-5 Weeks	6-8 Weeks	9-12 Weeks

3.	How many times a week on average did you carry out the therapy?				
	Never Started	One Day	2-3 Days	4-5 Days	Every Day

4.	How many times a day on average did you carry out the therapy?		
	Never Started	Once a day	Twice a day

Taking part in the Therapy

We would like to know how easy or difficult it was for you to carry out the therapy. We want to find out if it was difficult in any way for you to carry out at home, and if so, what difficulties were and how often they prevented you from practicing the techniques you have learnt. Please circle the most appropriate response.

Problems due to symptoms						
1	I had to skip the therapy because it made my symptoms worse.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
2	I was prevented from carrying out the therapy by severe symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
3	I could not carry out the therapy because it caused more symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
Problems due to uncertainty or doubts about the therapy						
4	I could not carry out the therapy because I was unsure how to do it properly.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
5	I was unable to carry out the therapy because it was difficult to know what to do.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
6	I skipped the therapy because I was not sure if it was helping.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
7	I skipped the therapy because it did not seem relevant to my symptoms and problems.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
8	I did not carry out the therapy because I was not convinced it was right for me.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
Practical Problems						
9	Lack of time prevented me from carrying out the therapy.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
10	It was not possible to find suitable opportunities to carry out the therapy.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
11	I was too busy or tired to carry out the therapy.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
12	I found it difficult to remember to carry out the therapy.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly

Total time spent on each type of exercise / method

Please only complete the section about the self-treatment booklet you have been using.

If you received the 'Balance Retraining' self- therapy booklet:

The booklet asked you to carry out the basic exercises in a sitting position to begin with, changing to standing and then walking if the exercises became easier to do. The booklet also asked you to choose some special exercises and general activities to practice.

We would like to know how many weeks (if at all) you were able to spend doing each type of exercise. Please tick the most appropriate box for each type of exercise. Please answer all the questions.

		Did not use	One week	1-2 weeks	3-5 weeks	6-8 weeks	9-12 weeks
a.	Sitting						
b.	Standing						
c.	Walking						
d.	Special exercises						
e.	General activities						

If you received the 'Controlling Your Symptoms' self-therapy booklet:

The booklet asked you to choose which method(s) of stress reduction you wanted to try each week. We would like to know how many weeks (if at all) you spent doing each of the stress reduction methods listed below.

Please tick the most appropriate box for each method. Please answer all the questions.

		Did not use	One week	1-2 weeks	3-5 weeks	6-8 weeks	9-12 weeks
a.	Controlled breathing						
b.	Relaxation						
c.	Thought control						
d.	Stress management						

Thank you for filling in this questionnaire. Please make sure you have answered all the questions, and then return it in the envelope provided as soon as possible to: Mrs Sarah Kirby, Psychology Department, University of Southampton, Highfield, Southampton, SO17 1BJ.

If you have any questions or concerns about the trial, then please contact Sarah Kirby on Tel: 023 8059 2581.

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Appendix G: Inclusion / exclusion decision table for full text articles obtained for the systematic review

	Article	Include / Exclude	(State why)
1.	Anderson, J. P. & Harris, J. P. (2001). Impact of meniere's disease on quality of life. Otology & Neurotology, 22, 888-894.	Included	
2.	Andersson, G. & Hagnebo, C. (1996). Dysphoria, optimism, confidence in activities and daily symptoms of meniere's disease. Journal of Audiological Medicine, 5, 83-91.	Included	
3.	Andersson, G., Hagnebo, C., & Yardley, L. (1997). Stress and symptoms of meniere's disease: A time-series analysis. Journal of Psychosomatic Research, 43, 595-603.	Included	
4.	Anon (1997). How to cope with meniere's disease. American Family Physician, 55, 1193-1194.	Excluded	Not a study DMT summary*
5.	Bech, P., Allerup, P., & Rosenberg, R. (1978). The Marke-Nyman Temperament Scale: Evaluation of transferability using the Rasch item analysis. Acta Psychiatrica Scandinavica, 57, 49-58.	Excluded	Results not separate N=175: MD (22)
6.	Berrios, G. E., Ryley, J. P., Garvey, T. P. N., & Moffat, D. A. (1988). Psychiatric morbidity in subjects with inner ear disease. Clinical Otolaryngology and Allied Sciences, 13, 259-266.	Included	
7.	Blomgren, J. (1989). Vestibular disorders. Causes and effects of a hidden problem. Children Today, 18, 14-17.	Excluded	Not a study Personal account / DMT summary
8.	Brandt, T. H. (1998). Neuro-otological and psychiatric abnormalities. Journal of Neurology and Neurosurgery and Psychiatry, 65, 619.	Excluded	Not a study Letter
9.	Briner, W., Risey, J., Guth, P., & Norris, C. (1990). Use of the million clinical multiaxial inventory in evaluating patients with severe tinnitus. American Journal of Otology, 11, 334-337.	Excluded	Results not separate N=41: MD (6)
10.	Bronheim, H., Strain, J. J., & Biller, H. F. (1991). Psychiatric aspects of head and neck surgery 1. New surgical techniques and psychiatric consequences. General Hospital Psychiatry, 13, 165-176.	Excluded	Not a study Otolaryngology Review

11.	Bush, F. M., Harkins, S. W., & Harrington, W. G. (1999). Otalgia and aversive symptoms in temporomandibular disorders. Annals of Otology Rhinology and Laryngology, 108, 884-892.	Excluded	MD not specified as participants
12.	Clark, M. R., Sullivan, M. D., Fischl, M., Katon, W. J., Russo, J. E., Dobie, R. A. et al. (1994). Symptoms as a clue to otologic and psychiatric diagnosis in patients with dizziness. Journal of Psychosomatic Research, 38, 461-470.	Excluded	Results not separate N=65: MD (?)
13.	Cleveland, P. & Morris, J. (1990). Meniere's disease: The inner ear out of balance. RN, 53, 28-32.	Excluded	Not a study DMT summary*
14.	Coker, N. J., Coker, R. R., Jenkins, H. A., & Vincent, K. R. (1989). Psychological profile of patients with meniere disease. Archives of Otolaryngology Head & Neck Surgery, 115, 1355-1357.	Included	
15.	Dowdal, O. M. (2002). Early vestibular rehabilitation in patients with Meniere's disease. Otolaryngologic Clinics of North America, 35, 683-690.	Excluded	Not a study DMT summary*
16.	Eagger, S., Luxon, L. M., Davies, R. A., Coelho, A., & Ron, M. A. (1992). Psychiatric morbidity in patients with peripheral vestibular disorder: A clinical and neuro-otological study. Journal of Neurology and Neurosurgery and Psychiatry, 55, 383-387.	Excluded	MD excluded from study
17.	Elwood, S., Carlton, J. H., & Cliffe, M. J. (1982). A psychological contribution to the management of meniere's disease. Practitioner, 226, 1149-1152.	Excluded	Not a study Clinical case study (1 case)
18.	Erlandsson, S. I., Eriksson, M. M., & Wiberg, A. (1996). Meniere's disease: Trauma, distress and adaptation studied through focus interview analyses. Scandinavian Audiology Supplement, 25, 45-56.	Included	
19.	Erlandsson, S. I. (1998). Psychological counselling in the medical setting - some clinical examples given by patients with tinnitus and meniere's disease. International Journal for the Advancement of Counselling, 20, 265-276.	Excluded	Not a study Theoretical article
20.	Farber, S. D. (1989). Living with meniere's disease: an occupational therapist's perspective. American Journal of Occupational Therapy, 43, 341-343.	Excluded	Not a study Personal account

21.	Feenstra, L. (1997). The management of tinnitus with or without meniere's disease. Acta-Oto-Laryngologica, Suppl 526, 47-49.	Excluded	Not a study DMT summary*
22.	Filipo, R., Lazzari, R., Barbara, M., Franzese, A., & Petruzzellis, M. C. (1988). Psychologic evolution of patients with meniere's disease in relation to therapy. American Journal of Otology, 9, 306-309.	Excluded	No statistical analysis
23.	Furman, J. M., Balaban, C. D., & Jacob, R. C. (2001). Interface between vestibular dysfunction and anxiety: more than just psychogenicity. Otology & Neurotology, 22, 426.	Excluded	Not a study Letter
24.	Furman, J. M. & Jacob, R. G. (2001). A clinical taxonomy of dizziness and anxiety in the otoneurological setting. Journal of Anxiety Disorders, 15, 9-26	Excluded	Not a study Theoretical review
25.	Gant, N. D. & Kampfe, C. M. (1997). Psychosocial challenges faced by persons with meniere's disease. Journal of Applied Rehabilitation Counselling, 28, 40-49.	Excluded	Not a study DMT summary*
26.	Gordon, A. G. (1997). Insight into auditory hallucinations and psychosis [1]. International Journal of Geriatric Psychiatry, 12, 410-411.	Excluded	Not a study Letter
27.	Grigsby, J. P. & Johnston, C. L. (1989). Depersonalization, vertigo and meniere's disease. Psychological Reports, 64, 527-534.	Excluded	Not a study Clinical case study (2 cases)
28.	Groen, J. J. (1983). Psychosomatic aspects of meniere's disease. Acta-Oto-Laryngologica, 95, 407-416.	Excluded	Not a study Clinical impressions (21 cases)
29.	Hadj-Djilani, A. & Gerster, J. C. (1984). Meniere's disease and fibrositis syndrome (psychogenic rheumatism): Relationship in audiometric and nystagmorgraphic results. Acta-Oto-Laryngologica, Suppl 406, 67-71.	Excluded	Psychological factors not measured.
30.	Hagnebo, C., Melin, L., Larsen, H. C., Lindberg, P., Lyttkens, L., & Scott, B. (1997). The influence of vertigo, hearing impairment and tinnitus on the daily life of meniere patients. Scandinavian Audiology, 26, 69-76.	Included	
31.	Hagnebo, C., Andersson, G., & Melin, L. (1998). Correlates of vertigo attacks in meniere's disease. Psychotherapy and Psychosomatics, 67, 311-316.	Included	
32.	Hagnebo, C., Melin, L., & Larsen, H. C. (1998). Cognitive behavioural treatment of a patient suffering from meniere's disease. Scandinavian Journal of Behaviour Therapy, 27, 42-48.	Excluded	Not a study Case study (1 case)

33.	Hagnebo, C., Johnsson, A., Melin, L., & Larsen, H. C. (1999). Cognitive stress, emotional factors and balance in meniere's disease: An experimental study. Scandinavian Journal of Behaviour Therapy, 28, 37-46.	Included	
34.	Hagnebo, C., Melin, L., & Andersson, G. (1999). Coping stragegies and anxiety sensitivity in meniere's disease. Psychology, Health and Medicine, 4, 17-26.	Included	
35.	Halama, A. R. (1987). The etiopathogenesis of Meniere's disease. Ear, Nose, and Throat Journal, 66, 107-111.	Excluded	Not a study DMT summary*
36.	Hallam, R. S. & Stephens, S. D. (1985). Vestibular disorders and emotional distress. Journal of Psychosomatic Research, 29, 407-413.	Excluded	MD not specified as participants Unsure of triad-mentions dizziness (not severe) but not vertigo
37.	Hallam, R. S. & Hinchcliffe, R. (1991). Emotional stabilty; Its relationship to confidence in maintaining balance. Journal of Psychosomatic Research, 35, 421-430.	Excluded	MD not specified as participants
38.	Hiller, W. & Goebel, G. (1999). Assessing audiological, pathophysiological, and psychological variables in chronic tinnitus: A study of the reliability and search for prognostic factors. International Journal of Behavioural Medicine, 6, 312-330.	Included	
39.	Homer, J. J., Sheard, C. E., & Jones, N. S. (2000). Cognitive dissonance, the placebo effect and the evaluation of surgical results. Clinical Otolaryngology, 25, 195-199.	Excluded	Not a study Theoretical review
40.	Hooter, L. J. (2000). Living with meniere's disease. Seminars in perioperative nursing, 9, 185-187.	Excluded	Not a study Personal account
41.	House, J. W., Crary, W. G., & Wexler, M. (1980). The inter-relationship of vertigo and stress. Otolaryngologic Clinics of North America, 13, 625-629.	Excluded	Not a study Theoretical article
42.	Kato, B.M., LaRouere, M.J.,Bojrab, D.I., Michaelides, E.M. (2004) Evaluating Quality of Life after Endolymphatic Sac Surgery: The Ménière's Disease Outcomes Questionnaire. Otology and Neurotology, 25, 339 - 344	Included	
43.	Kentala, E., Havia, M., & Pyykko, I. (2001). Short-lasting drop attacks in meniere's disease. Otolaryngology Head and Neck Surgery, 124, 526-530.	Included	

44.	Kinney, S. E., Sandridge, S. A., & Newman, C. W. (1997). Long-term effects of meniere's disease on hearing and quality of life. American Journal of Otology, 18, 67-73.	Included	
45.	Kitahara, M., Matsubara, H., Takeda, T., & Yazawa, Y. (1979). Bilateral meniere's disease. Advances in Oto Rhino Laryngology, 25, 117-121.	Excluded	No statistical analysis No means, sd's or statistical analysis (only % given.)
46.	Kodama, A., Kitahara, M., & Kitanishi, T. (1993). Patients' anxieties and doctors' impressions in cases of meniere's disease with bilateral fluctuant hearing loss Equilibrium Research Supplement, 9, 5-8.	Excluded	Not in English
47.	Kodama, A., Kitahara, M., & Komada, K. (1994). Tinnitus evaluation using the tinnitus grading system. Acta-Oto-Laryngologica, Suppl 510, 62-66.	Excluded	Results not separate N=87: MD (32)
48.	Mizukoshi, K., Ino, H., Ishikawa, K., Watanabe, Y., Yamazaki, H., Kato, I. et al. (1979). Epidemiological survey of definite cases of meniere's disease collected by the seventeen members of the Meniere's Disease Research Committee of Japan in 1975-1976. Advances in Oto Rhino Laryngology, 25, 106-111.	Excluded	No statistical analysis No means, sd's or statistical analysis (only % given.)
49.	Monzani, D., Casolari, L., Guidetti, G., & Rigatelli, M. (2001). Psychological distress and disability in patients with vertigo. Journal of Psychosomatic Research, 50, 319-323.	Included	
50.	Moody-Antonio, S., & House, J. W. (2003). Hearing outcome after concurrent endolymphatic shunt and vestibular nerve section	Excluded	Evaluation of medical treatment, and focus of article is not psychological
51.	Morrison, A. W. (1981). Meniere's disease. Journal of the Royal Society of Medicine, 74, 183-189.	Excluded	Not a study DMT summary*
52.	Murphy, M. P. & Gates, G. A. (1999). Measuring the effects of meniere's disease: Results of the Patient Oriented Severity Index (MD POSI) version 1. Annals of Otology Rhinology and Laryngology, 108, 331-337.	Excluded	No statistical analysis only validation of Index. Conclusions based on higher mean scores (untested for significance)

53.	Nozawa, I., Imamura, S. I., Hashimoto, K., & Murakami, Y. (1998). Psychosomatic aspects of patients complaining of dizziness or vertigo with orthostatic dysregulation. Auris Nasus Larynx, 25, 33-38.	Excluded	Results not separate N=85: MD (14)
54.	O'Connor, K., Chambers, C., & Hinchcliffe, R. (1989). Dizziness and perceptual style. Psychotherapy and Psychosomatics, 51, 169-174.	Excluded	MD not specified as participants
55.	Perez, N., Garmendia, I., Granero, M., & etc (2001). Factor analysis and correlation between DHI and dizziness characteristics and impact on quality of life scales. Acta-Oto-Laryngologica, Suppl 545, 145-154.	Excluded	Results not separate N=337: MD (125)
56.	Persoons, P., Luyckx, K., Desloovere, C., Vandenberghe, J., & Fischler, B. (2003). Anxiety and mood disorders in otorhinolaryngology outpatients presenting with dizziness: Validation of the self-administered PRIME-MD Patient Health Questionnaire and epidemiology. General Hospital Psychiatry, 25, 316-323.	Excluded	Results not separate Group n =143: MD (28)
57.	Rigatelli, M., Casolari, L., Bergamini, G., & Guidetti, G. (1984). Psychosomatic study of 60 patients with vertigo. Psychotherapy and Psychosomatics, 41, 91-99.	Included	
58.	Savastano, M., Maron, M. B., Mangialaio, M., Longhi, P., & Rizzardo, R. (1996). Illness behaviour, personality traits, anxiety, and depression in patients with meniere's disease. Journal of Otolaryngology, 25, 329-333.	Included	
59.	Sawada, S., Takeda, T., & Saito, H. (1997). Antidiuretic hormone and psychosomatic aspects in meniere's disease. Acta-Oto-Laryngologica, Suppl 528, 109-112.	Included	
60.	Soderman, A. C. H., Bergenius, J., Bagger-Sjoback, D., Tjell, C., & Langius, A. (2001). Patient's subjective evaluations of quality of life related to disease specific symptoms, sense of coherence, and treatment in meniere's disease. Otology & Neurotology, 22, 526-533.	Included	
61.	Soderman, A. C. H., Bagger-Sjoback, D., Bergenius, J., & Langius, A. (2002). Factors influencing quality of life in patients with meniere's disease, identified by a multidimensional approach. Otology & Neurotology, 23, 941-948.	Included	

62.	Stouffer, J. L. & Tyler, R. S. (1990). Characterization of tinnitus by tinnitus patients. Journal of Speech and Hearing Disorders, 55, 439-453.	Included	
63.	Stouffer, J. L., Tyler, R. S., Kileny, P. R., & Dalzell, L. E. (1991). Tinnitus as a function of duration and etiology - counselling implications. American Journal of Otology, 12, 188-194.	Excluded	No statistical analysis (only %)
64.	Swinson, R. P., Cox, B. J., Rutka, J., Mai, M., Kerr, S., & Kuch, K. (1993). Otoneurological functioning in panic disorder patients with prominent dizziness. Comprehensive Psychiatry, 34, 127-129.	Excluded	MD not specified as participants
65.	Takashashi, M., Ishida, K., Iida, M., Yamashita, H., & Sugawara, K. (2001). Analysis of lifestyle and behavioural characteristics in meniere's disease patients and a control population. Acta-Oto-Laryngologica, 121, 254-256.	Included	
66.	Theilgaard, A., Laursen, P., Kjaerby, O., Paludan, B., Hoffmann, G., Zilstorff, K. et al. (1978). Meniere's disease. II. A neuropsychological study. ORL Journal for Oto Rhino Laryngology and its Related Specialities, 40, 139-146.	Excluded	No statistical analysis. Data not given (only graphs where precise scores are not clear).
67.	Torok, N. (1982). "How I do it" - otology and neurotology. A specific issue and its solution. Etiology as a guide to the management of meniere's disease. Laryngoscope, 92, 337-338.	Excluded	Not a study DMT summary*
68.	Tupper, S. Z. (1999). When the inner ear is out of balance. RN, 62, 36-39.	Excluded	Not a study Personal account / DMT summary *
69.	Van Cruijsen, N., Wit, H., & Albers, F (2003). Psychological aspects of Ménière's disease. Acta Oto-Laryngologica, 123, 340–347.	Excluded	Not a study Review article
70.	Wexler, M. & Crary, W. G. (1986). Meniere's disease: The psychosomatic hypothesis. American Journal of Otology, 7, 93-96.	Excluded	Not a study Review article
71.	Willatt, D. J. & Yung, M. W. (1988). Prognostic factors in labyrinthectomy. Journal of Laryngology and Otology, 102, 785-787.	Included	
72.	Wilmot, T. J. (1979). Meniere's disorder. Clinical Otolaryngology and Allied Sciences, 4, 131-143.	Excluded	Not a study DMT review*
73.	Yardley, L., Dibb, B., & Osborne, G. (2003). Factors associated with quality of life in Ménière's disease. Clinical Otolaryngology. 28, 436-441.	Included	

74.	Yardley, L., Masson, E., Verschuur, C., Haacke, N., & Luxon, L. (1992). Symptoms, anxiety and handicap in dizzy patients: Development of the vetigo symptom scale. Journal of Psychosomatic Research, 36, 731-741.	Excluded	Results not separate N=127: MD (11) (MD was combined with V+T (13) and V+HL(9)
75.	Yardley, L., Luxon, L. M., & Haacke, N. P. (1994). A longitudinal study of symptoms, anxiety and subjective well-being in patients with vertigo. Clinical Otolaryngology and Allied Sciences, 19, 109-116.	Excluded	MD Results not given N=101: MD (6)
76.	Yardley, L. (1994). Prediction of handicap and emotional distress in patients with recurrent vertigo: Symptoms, coping stragegies, control beliefs and reciprocal causation. Social Science and Medicine, 39, 573-581.	Excluded	MD not specified as participants
77.	Yardley, L., Britton, J., Lear, S., Bird, J., & Luxon, L. M. (1995). Relationship between balance system function and agoraphobic avoidance. Behaviour Research and Therapy, 33, 435-439.	Excluded	MD not specified as participants
78.	Yardley, L., Gresty, M., Bronstein, A., & Beyts, J. (1998). Changes in heart rate and respiration rate in patients with vestibular dysfunction following head movements which provoke dizziness. Biological Psychology, 49, 95-108.	Excluded	MD not specified as participants
79.	Zilstorff, K., Thomsen, J., Laursen, P., Hoffmann, G., Kjoerby, O., Paludan, B. et al. (1979). Meniere's disease: A neuropsychological study II. Advances in Oto Rhino Laryngology, 25, 100-105.	Excluded	No statistical analysis. Data not given (only graphs where precise scores are not clear).

* DMT summary = article about the Diagnosis, and/or Management, and/or Treatment of Meniere's disease.

Appendix H: Sources where articles included in the systematic review were found

Included Articles	Source where article was identified
1. Anderson & Harris (2001)	WoS; Medline; Embase
2. Andersson & Hagnebo (1996)	Embase
3. Andersson, Hagnebo, & Yardley (1997)	WoS; Medline; Embase; Psychinfo
4. Berrios, Ryley, Garvey, & Moffat (1988)	Embase
5. Coker, Coker, Jenkins, & Vincent (1989)	WoS; Medline; Embase
6. Erlandsson, Eriksson-Mangold, & Wiberg (1996)	WoS; Medline; Embase; Psychinfo
7. Hagnebo, Melin, Larsen, Lindberg, Lyttkens, & Scott (1997)	WoS; Medline; Embase
8. Hagnebo, Andersson, & Melin (1998a)	WoS; Medline; Embase; Psychinfo
9. Hagnebo, Johnsson, Melin, & Larsen (1999a)	Psychinfo
10. Hagnebo, Melin, & Andersson (1999b)	Embase; Psychinfo
11. Hiller & Goebel (1999)	WoS; Embase; Psychinfo
12. Kato, LaRouere, Bojrab, & Michaelides (2004)	WoS
13. Kentala, Havia, & Pyykko (2001)	WoS; Medline
14. Kinney, Sandridge, & Newman (1997)	WoS; Medline; Embase
15. Monzani, Casolari, Guidetti, & Rigatelli (2001)	WoS
16. Rigatelli, Casolari, Bergamini, & Guidetti (1984)	Medline; Embase; Psychinfo
17. Savastano, Maron, Mangialaio, Longhi, & Rizzardo (1996)	WoS; Medline; Embase
18. Sawada, Takeda, & Saito (1997)	WoS; Medline; Embase
19. Soderman, Bergenius, Bagger-Sjoback, Tjell & Langius (2001)	WoS; Medline; Embase
20. Soderman, Bagger-Sjoback, Bergenius, & Langius (2002)	WoS; Medline; Embase
21. Stouffer & Tyler (1990)	Psychinfo
22. Takahashi, Ishida, Iida, Yamashita, & Sugawara (2001)	WoS; Medline; Embase; Psychinfo
23. Willatt & Yung (1988)	Medline; Embase
24. Yardley, Dibb, & Osborne (2003)	WoS; Medline; Embase
25. Holgers & Finizia (2001)	Handsearch
26. Honrubia, Bell, Harris, Baloh, & Fisher (1996)	Handsearch
27. Yardley, Medina, Jurado, Morales, Martinez, & Villegas (1999)	Handsearch
28. Cohen, Ewell, & Jenkins (1995)	In references of article no: 1,2,3,7,8,9,10,14,19,20,24

Appendix I: Covering letter used for study in chapter 7

Ménière's Society

helping people with vertigo, tinnitus and deafness

The Rookery, Surrey Hills Business Park, Wotton, Dorking, Surrey RH5 6QT
Helpline 0845 120 2975 or 01306 876883 Admin & minicom 01306 876 057
www.menieres.org.uk Email info@menieres.org.uk

5 December 2005

Dear Member

Southampton University Psychology Department has worked in the past with the Society carrying out research which has resulted in some concrete proposals on how people with Ménière's disease can improve their life (Spin 47 and the two booklets, Balance Retraining, and Controlling your symptoms). Sarah Kirby, a PhD student in the Psychology Department, who has previously worked with the society, is now carrying out work to see whether any extra useful support is needed in helping people with Ménière's disease with the distress that a number experience at various stages of the disease. (This work is partially funded by the society).

To carry out this work Sarah needs responses to the enclosed questionnaires. It is fully understood that for a number of reasons you may be unable to respond. In this case it would be greatly appreciated if you would still return the uncompleted questionnaire so that we know that it at least reached you.

I would like to assure you that no details about you have been given to Sarah or the University. You will only receive correspondence from her if you agree to take part in the study, and if this is the case you should correspond directly with her on any further matters concerning details of the study.

Yours sincerely

Humphrey Bowen

Humphrey Bowen (D Phil, C Eng)
Trustee of the Meniere's Society

Appendix J: Information sheet used for MD group for study in chapter 7

University of Southampton

School of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone: 023 8059 2581
Fax: 023 8059 4597
Email: sek@soton.ac.uk

How distress develops in Ménière's disease

Information & consent form

My name is Sarah Kirby, and I am a PhD student at the University of Southampton. I am writing to invite you to take part in a research study investigating distress in Ménière's disease. This study is being partially funded by the Ménière's Society.

It is well known that some people with Ménière's disease experience distress and disability. However, very little is known about the beliefs, concerns, feelings and behaviours that may contribute to distress. If we understood more about these, doctors and the Ménière's Society could improve the support they provide.

If you would like to take part in the study, all you need to do is fill in questionnaire number 1 (for people **with** Meniere's disease). This should take no more than 30 minutes to complete. If you are not distressed by your Ménière's disease, your answers are still important as we can compare your scores with those of people who are distressed.

It is up to you to decide whether or not to take part, and you may change your mind at any time without giving a reason. If you do **not** want to take part then please send back the uncompleted questionnaire so I know your decision. If I do not hear from you, I will send you up to two reminders. However, this will not happen if you return the questionnaire (completed or uncompleted).

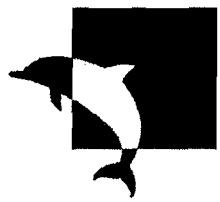
I need to compare your answers with those of people without Meniere's disease. To help me do this, please could you ask a friend or relative if they would be happy to complete questionnaire number 2 (for people **without** Meniere's disease) and return it to us in the extra envelope provided. But if you do not know someone who can fill in questionnaire number 2, please still send back your answers to questionnaire 1.

If you complete and return the questionnaire, I will assume that you give your consent to take part in the study. Personal information will not be given to or seen by anyone other than the researchers involved in this project. Published results of the study will not include your name. A summary of this research project will be sent to you upon request. If you have any questions, please contact me Sarah Kirby, on (023) 8059 2581 or sek@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Version 1 – for people with Ménière's disease

Appendix K: Questionnaire use for MD group for study in chapter 7



University
of Southampton

How distress develops in Ménière's disease

Questionnaire No.1

(for people **with** Ménière's Disease)

1.	What is your Gender? (please circle)	Male	Female
2.	What is your Age? (please write in the box)		
3.	Have you been diagnosed with Ménière's disease by a doctor? (please circle)	Yes	No
4.	How long has it been since your first experienced your symptoms? (please write number of years/months in the box)		
5.	How long has it been since your last attack? (please write number of months / weeks / days in the box)		

6. Please circle the box that most accurately describes the tinnitus you experience:

None	Rarely Noted	Occasional	Frequent	Almost Constant	Constant	Severe; Primary problem

7. Please circle the box that most accurately describes the feeling of fullness you experience in your ear(s):

None	Infrequent	Occasional	Frequent but mild	Frequent but moderate	Frequent and severe but not incapacitating	Almost constant and incapacitating

The questions in this section cover your hearing. Please circle the answer that applies to you without the use of your hearing aid, should you use one. Please answer all the questions.

8.	Can you follow the television news when the volume is turned up only enough to suit other people?			
	Easily	With some difficulty	With great difficulty	Not at all
9.	Can you follow what is being said on the radio news when the volume is turned up only enough to suit other people?			
	Not at all	With great difficulty	With some difficulty	Easily
10.	If you are sitting with a group of people and someone you can't see starts to speak, are you able to tell where the person is sitting?			
	Usually	Sometimes	Not Usually	
11.	How difficult do you usually find it to follow somebody's conversation when other people are talking close by?			
	Great difficulty	Some difficulty	No difficulty	
12.	When talking in a quiet room with someone who is a clear speaker, how much difficulty do you have in understanding what they are saying?			
	No difficulty	Some difficulty	Great difficulty	

Please tick the appropriate box to indicate about how many times you have experienced each of the symptoms listed below during the past 12 months (or since the vertigo started, if you have had vertigo for less than one year). The range of responses are:

Never	A few times (1-3 times a year)	Several times (4-12 times a year)	Quite often (on average, more than once a month)	Very often (on average, more than once a week)

How often **in the past 12 months** have you had the following symptoms:

		Never	A few times	Several times	Quite Often	Very Often
13.	A feeling that things are spinning or moving around, lasting: **(PLEASE ANSWER ALL THE CATEGORIES)**					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hour					
d)	several hours					
e)	more than 12 hours					
14.	Pains in the heart or chest region					
15.	Hot or cold spells					
16.	Unsteadiness so severe that you actually fall					
17.	Nausea (feeling sick), stomach churning					
18.	Tension/soreness in your muscles					
19.	A feeling of being light-headed, "swimmy" or giddy, lasting: **(PLEASE ANSWER ALL THE CATEGORIES)**					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hour					
d)	several hours					
e)	more than 12 hours					
20.	Trembling, shivering					
21.	Feeling of pressure in the ear(s)					
22.	Heart pounding or fluttering					
23.	Vomiting					
24.	Heavy feeling in arms or legs					

		Never	A few times	Several times	Quite Often	Very Often
25.	Visual disturbances (e.g. blurring, flickering, spots before the eyes)					
26.	Headache or feeling of pressure in the head					
27.	Unable to stand or walk properly without support					
28.	Difficulty breathing, short of breath					
29.	Loss of concentration or memory					
30.	Feeling unsteady, about to lose balance, lasting: **(PLEASE ANSWER ALL THE CATEGORIES)**					
a)	less than 2 minutes					
b)	up to 20 minutes					
c)	20 minutes to 1 hours					
d)	several hours					
e)	more than 12 hours					
31.	Tingling, prickling or numbness in parts of the body					
32.	Pains in the lower part of your back					
33.	Excessive sweating					
34.	Feeling faint, about to black out					

The purpose of this scale is to identify difficulties that you may be experiencing because of your dizziness or unsteadiness. Please answer "yes", "no", or "sometimes" to each question.

Answer each question as it pertains to your dizziness or unsteadiness problems only.

35	Does looking up increase your problem?	Yes	Sometimes	No
36	Because of your problem, do you feel frustrated?	Yes	Sometimes	No
37	Because of your problem, do you restrict your travel for business or recreation?	Yes	Sometimes	No
38	Does walking down the aisle of a supermarket increase your problem?	Yes	Sometimes	No
39	Because of your problem, do you have difficulty getting into or out of bed?	Yes	Sometimes	No
40	Does your problem significantly restrict your participation in social activities such as going out to dinner, going to movies, dancing, or to parties?	Yes	Sometimes	No
41	Because of your problem, do you have difficulty reading?	Yes	Sometimes	No
42	Does performing more ambitious activities like sports, dancing, household chores such as sweeping or putting dishes away increase your problem?	Yes	Sometimes	No

43	Because of your problem, are you afraid to leave your home without having someone accompany you?	Yes	Sometimes	No
44	Because of your problem, have you been embarrassed in front of others?	Yes	Sometimes	No
45	Do quick movements of your head increase your problem?	Yes	Sometimes	No
46	Because of your problem, do you avoid heights?	Yes	Sometimes	No
47	Does turning over in bed increase your problem?	Yes	Sometimes	No
48	Because of your problem, is it difficult for you to do strenuous housework or gardening?	Yes	Sometimes	No
49	Because of your problem, are you afraid people may think you are intoxicated?	Yes	Sometimes	No
50	Because of your problem, is it difficult for you to go for a walk by yourself?	Yes	Sometimes	No
51	Does walking down the street increase your problem?	Yes	Sometimes	No
52	Because of your problem, is it difficult for you to concentrate?	Yes	Sometimes	No
53	Because of your problem, is it difficult for you to walk around your house in the dark?	Yes	Sometimes	No
54	Because of your problem, are you afraid to stay home alone?	Yes	Sometimes	No
55	Because of your problem, do you feel handicapped?	Yes	Sometimes	No
56	Has your problem placed stress on your relationships with members of your family or friends?	Yes	Sometimes	No
57	Because of your problem, are you depressed?	Yes	Sometimes	No
58	Does your problem interfere with your job or household responsibilities?	Yes	Sometimes	No
59	Does bending over increase your problem?	Yes	Sometimes	No

Please read each item below and place a tick in the box opposite the reply which comes close to how you have been feeling in the last week. Don't take too long over your replies: your immediate reaction will probably be more accurate than a long thought-out response.

60. I feel tense or 'wound up':

Most of the time.....
A lot of the time .....
Time to time, Occasionally .....
Not at all.....

61. I feel as if I am slowed down:

Nearly all the time.....
Very often.....
Sometimes.....
Not at all.....

62. I still enjoy the things I used to enjoy:

Definitely as much.....
Not quite so much.....
Only a little.....
Hardly at all.....

63. I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all.....
Occasionally.....
Quite often.....
Very often.....

64. I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly.....
Yes, but not too badly.....
A little, but it doesn't worry me.....
Not at all.....

65. I have lost interest in my appearance:

Definitely.....
I don't take so much care as I should..
I may not take quite as much care.....
I take just as much care as ever.....

66. I can laugh and see the funny side of things:

As much as I always could.....
Not quite so much now.....
Definitely not so much now.....
Not at all.....

67. I feel restless as if I have to be on the move:

Very much indeed.....
Quite a lot.....
Not very much.....
Not at all.....

68. Worrying thoughts go through my mind:

A great deal of the time.....
A lot of the time.....
From time to time but not too often..
Only occasionally.....

69. I look forward with enjoyment to things:

As much as I ever did.....
Rather less than I used to.....
Definitely less than I used to.....
Hardly at all.....

70. I feel cheerful:

Not at all.....
Not often.....
Sometimes.....
Most of the time.....

71. I get sudden feelings of panic:

Very often indeed.....
Quite often.....
Not very often.....
Not at all.....

72. I can sit at ease and feel relaxed:

Definitely.....
Usually.....
Not often.....
Not at all.....

73. I can enjoy a good book or radio or TV programme:

Often.....
Sometimes.....
Not often.....
Very seldom.....

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, over the past six months. Identify the statement by ringing the letter next to it i.e. if you think that the statement (a) is correct, ring statement (a); it may be that more than one statement applies, in which case, please ring any that are applicable.

74.	**a.**	I do not worry about my health.
	b.	I occasionally worry about my health.
	c.	I spend much of my time worrying about my health.
	d.	I spend most of my time worrying about my health.
75.	**a.**	I notice aches / pains less than most other people (of my age).
	b.	I notice aches / pains as much as most other people (of my age).
	c.	I notice aches / pains more than most other people (of my age).
	d.	I am aware of aches / pains in my body all the time.
76.	**a.**	As a rule I am not aware of bodily sensations or changes.
	b.	Sometimes I am aware of bodily sensations or changes.
	c.	I am often aware of bodily sensations or changes.
	d.	I am constantly aware of bodily sensations or changes.
77.	**a.**	Resisting thoughts of illness is never a problem.
	b.	Most of the time I can resist thoughts of illness.
	c.	I try to resist thoughts of illness but am often unable to do so.
	d.	Thoughts of illness are so strong that I no longer even try to resist them.
78.	**a.**	As a rule I am not afraid that I have a serious illness (other than Meniere's disease).
	b.	I am sometimes afraid that I have a serious illness (other than Meniere's disease).
	c.	I am often afraid that I have a serious illness (other than Meniere's disease).
	d.	I am always afraid that I have a serious illness (other than Meniere's disease).
79.	**a.**	I do not have images (mental pictures) of myself being ill.
	b.	I occasionally have images of myself being ill.
	c.	I frequently have images of myself being ill.
	d.	I constantly have images of myself being ill.
80.	**a.**	I do not have any difficulty taking my mind off thoughts about my health.
	b.	I sometimes have difficulty taking my mind off thoughts about my health.
	c.	I often have difficulty in taking my mind off thoughts about my health.
	d.	Nothing can take my mind off thoughts about my health.
81.	**a.**	I am lastingly relieved if my doctor tells me there is nothing wrong.
	b.	I am initially relieved but the worries sometimes return later.
	c.	I am initially relieved but the worries always return later.
	d.	I am not relieved if my doctor tells me there is nothing wrong.
82.	**a.**	If I hear about an illness I never think I have it myself.
	b.	If I hear about an illness I sometimes think I have it myself.
	c.	If I hear about an illness I often think I have it myself.
	d.	If I hear about an illness I always think I have it myself.

83.	**a.** If I have a bodily sensation or change I rarely wonder what it means. **b.** If I have a bodily sensation or change I often wonder what it means. **c.** If I have a bodily sensation or change I always wonder what it means. **d.** If I have a bodily sensation or change I must know what it means.
84.	**a.** I usually feel at very low risk for developing a serious illness (other than Meniere's disease). **b.** I usually feel at fairly low risk for developing a serious illness (other than Meniere's disease). **c.** I usually feel at moderate risk for developing a serious illness (other than Meniere's disease). **d.** I usually feel at high risk for developing a serious illness (other than Meniere's disease).
85.	**a.** I never think I have a serious illness (other than Meniere's disease). **b.** I sometimes think I have a serious illness (other than Meniere's disease). **c.** I often think I have a serious illness (other than Meniere's disease). **d.** I usually think that I am seriously ill (other than Meniere's disease).
86.	**a.** If I notice an unexplained bodily sensation I don't find it difficult to think about other things. **b.** If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things. **c.** If I notice an unexplained bodily sensation I often find it difficult to think about other things. **d.** If I notice an unexplained bodily sensation I always find it difficult to think about other things.
87.	**a.** My family / friends would say I do not worry enough about my health. **b.** My family / friends would say I have a normal attitude to my health. **c.** My family / friends would say I worry too much about my health. **d.** My family / friends would say I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness (other than Meniere's disease) of a type which particularly concerns you (such as heart disease, cancer, multiple sclerosis and so on). Obviously you cannot know for definite what it would be like; please give your best estimate of what you think might happen, basing your estimate on what you know about yourself and serious illness in general.

88.	**a.** If I had a serious illness I would still be able to enjoy things in my life quite a lot. **b.** If I had a serious illness I would still be able to enjoy things in my life a little. **c.** If I had a serious illness I would be almost completely unable to enjoy things in my life. **d.** If I had a serious illness I would be completely unable to enjoy life at all.
89.	**a.** If I developed a serious illness there is a good chance that modern medicine would be able to cure me. **b.** If I developed a serious illness there is a moderate chance that modern medicine would be able to cure me. **c.** If I developed a serious illness there is a very small chance that modern medicine would be able to cure me. **d.** If I developed a serious illness there is no chance that modern medicine would be able to cure me.
90.	**a.** A serious illness would ruin some aspects of my life. **b.** A serious illness would ruin many aspects of my life. **c.** A serious illness would ruin almost every aspect of my life. **d.** A serious illness would ruin every aspect of my life.
91.	**a.** If I had a serious illness I would not feel that I had lost my dignity. **b.** If I had a serious illness I would feel that I had lost a little of my dignity. **c.** If I had a serious illness I would feel that I had lost quite a lot of my dignity. **d.** If I had a serious illness I would feel that I had totally lost my dignity.

Choose a number from the scale below to show how much you would avoid each of the situations listed below because of fear or other unpleasant feelings. Then write the number you chose in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8

Would not avoid it	Slightly avoid it	Definitely avoid it	Markedly avoid it	Always avoid it

92. Consulting your family doctor..... ____.
93. Visiting a friend in hospital..... ____.
94. Visiting a relative in hospital..... ____.
95. Going to a hospital for treatment..... ____.
96. Talking about illness..... ____.
97. Reading about illness..... ____.
98. Visiting a hospital for other reasons (e.g. delivering a message) ..... ____.
99. Watching TV programmes about illness..... ____.
100. Listening to radio programmes about illness..... ____.
101. Thinking about illness..... ____.

Choose a number from the scale below which best describes how often you seek reassurance about your health, from each of the sources described below. Then write the number you have chosen in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8

Never	Rarely	Sometimes	Often	Daily

102. Friends..... ____.
103. Family..... ____.
104. Reading books..... ____.
105. Checking body for changes..... ____.
106. Family doctor..... ____.
107. Nurses..... ____.
108. Hospital outpatient clinic..... ____.
109. Hospital casualty..... ____.
110. Other (specify) ..... ____.

Below is a list of problems and complaints that people sometimes have in response to severe Ménière's attacks. Please read each one carefully, then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

		Not at all	A little bit	Moderately	Quite a bit	Extremely
111.	Repeated, disturbing *memories, thoughts,* or *images* of a severe Ménière's attack from the past?	1	2	3	4	5
112.	Repeated, disturbing *dreams* of a severe Ménière's attack from the past?	1	2	3	4	5
113.	Suddenly *acting* or *feeling* as if a severe Ménière's attack *were happening again* (as if you were reliving it)?	1	2	3	4	5
114.	Feeling *very upset* when *something reminded you* of a severe Ménière's attack from the past?	1	2	3	4	5
115.	Having *physical reactions* (e.g., heart pounding, trouble breathing, sweating) when *something reminded you* of a severe Ménière's attack from the past?	1	2	3	4	5
116.	Avoiding *thinking about* or *talking about* severe Ménière's attacks or avoiding *having feelings* related to it?	1	2	3	4	5
117.	Avoiding *activities* or *situations* because *they reminded you* of a severe Ménière's attack from the past?	1	2	3	4	5
118.	Trouble *remembering important parts* of a severe Ménière's attack from the past?	1	2	3	4	5
119.	*Loss of interest* in activities that you used to enjoy?	1	2	3	4	5
120.	Feeling *distant* or *cut off* from other people?	1	2	3	4	5
121.	Feeling *emotionally numb* or being unable to have loving feelings for those close to you?	1	2	3	4	5
122.	Feeling as if your *future* will somehow be *cut short*?	1	2	3	4	5
123.	Trouble *falling* or *staying asleep*?	1	2	3	4	5
124.	Feeling *irritable* or having *angry outbursts*?	1	2	3	4	5
125.	Having *difficulty concentrating*?	1	2	3	4	5
126.	Being *"super-alert"* or watchful or on guard?	1	2	3	4	5
127.	Feeling *jumpy* or easily startled?	1	2	3	4	5

Many people have said that one of the most troublesome aspects of Ménière's disease is the uncertainty about how ill or well you will be in the future. You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you (circle the number that describes you best for each item). Please answer all the questions.

The range of responses are:

1	2	3	4	5
Not at all characteristic of me	**A little characteristic of me**	**Somewhat characteristic of me**	**Very characteristic of me**	**Entirely characteristic of me**

How characteristic of you are each of the following statements:

128	Uncertainty stops me from having a strong opinion.	1	2	3	4	5
129	Being uncertain means that a person is disorganized.	1	2	3	4	5
130	Uncertainty makes life intolerable.	1	2	3	4	5
131	It's unfair having no guarantees in life.	1	2	3	4	5
132	My mind can't be relaxed if I don't know what will happen tomorrow.	1	2	3	4	5
133	Uncertainty makes me uneasy, anxious, or stressed.	1	2	3	4	5
134	Unforeseen events upset me greatly.	1	2	3	4	5
135	It frustrates me not having all the information I need.	1	2	3	4	5
136	Uncertainty keeps me from living a full life.	1	2	3	4	5
137	One should always look ahead so as to avoid surprises.	1	2	3	4	5
138	A small unforeseen event can spoil everything, even with the best planning.	1	2	3	4	5
139	When it's time to act uncertainly paralyses me.	1	2	3	4	5
140	Being uncertain means that I am not first rate.	1	2	3	4	5
141	When I am uncertain I can't go forward.	1	2	3	4	5
142	When I am uncertain I can't function very well.	1	2	3	4	5
143	Unlike me, others seem to know where they are going with their lives.	1	2	3	4	5
144	Uncertainty makes me vulnerable, unhappy, or sad.	1	2	3	4	5
145	I always want to know what the future has in store for me.	1	2	3	4	5
146	I can't stand being taken by surprise.	1	2	3	4	5
147	The smallest doubt can stop me from acting.	1	2	3	4	5
148	I should be able to organize everything in advance.	1	2	3	4	5
149	Being uncertain means that I lack confidence.	1	2	3	4	5

1 Not at all characteristic of me	2 A little characteristic of me	3 Somewhat characteristic of me	4 Very characteristic of me	5 Entirely characteristic of me

150	I think it's unfair that other people seem to be sure about their future.	1	2	3	4	5
151	Uncertainty keeps me from sleeping soundly.	1	2	3	4	5
152	I must get away from all uncertain situations.	1	2	3	4	5
153	The ambiguities in life stress me.	1	2	3	4	5
154	I can't stand being undecided about my future.	1	2	3	4	5

We are interested in you own personal views of how you now see your current illness. Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	Views About Your Illness	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
155	The symptoms of my condition are puzzling to me					
156	My illness is a mystery to me					
157	I don't understand my illness					
158	My illness doesn't make any sense to me					
159	I have a clear picture or understanding of my condition					
160	I get depressed when I think about my illness					
161	When I think about my illness I get upset					
162	My illness makes me feel angry					
163	My illness does not worry me					
164	Having this illness makes me feel anxious					
165	My illness makes me feel afraid					

Thank you for filling in this questionnaire. Please make sure you have answered all the questions, and then return it in the pre-paid envelope provided as soon as possible to: Mrs Sarah Kirby, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ.

If you are concerned by your responses to any of the issues raised in this questionnaire, please contact the Ménière's Society, or discuss them with your doctor

Appendix L: Information sheet used for control group for study in chapter 7

University of Southampton

School of Psychology

University of Southampton
Highfield
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United Kingdom

Telephone: 023 8059 2581
Fax: 023 8059 4597
Email: sek@soton.ac.uk

How distress develops in Ménière's disease

Information & consent form

My name is Sarah Kirby, and I am a PhD student at the University of Southampton. I am carrying out a research study investigating distress in Ménière's disease, which your friend or relative is taking part in. This study is being partially funded by the Ménière's Society.

It is well known that some people with Ménière's disease experience distress and disability. However, very little is known about the beliefs, concerns, feelings and behaviours that may contribute to distress. If we understood more about these, doctors and the Ménière's Society could improve the support they provide.

I need to compare the answers of people with Ménière's disease with those of people without Meniere's disease. This is so I can see if people with Ménière's disease respond differently or in the same way to people without Ménière's disease. This is why your friend or relative has asked if you would be happy to fill in a questionnaire.

If you would like to take part in the study, all you need to do is fill in questionnaire number 2 (for people **without** Meniere's disease), and return it to us in the extra envelope provided. This should take no more than 20 minutes to complete.

It is up to you to decide whether or not to take part, and you may change your mind at any time without giving a reason. If you do **not** want to take part then please send back the uncompleted questionnaire so I know your decision. If you choose not to take part, it will not negatively affect the friend or partner who gave you this questionnaire.

If you complete and return the questionnaire, I will assume that you give your consent to take part in the study. Personal information will not be given to or seen by anyone other than the researchers involved in this project. Published results of the study will not include your name. A summary of this research project will be sent to you upon request. If you have any questions, please contact me Sarah Kirby, on (023) 8059 2581 or sek@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Version 2 - for people without Ménière's disease

Appendix M: Questionnaire use for control group for study in chapter 7

University
of Southampton

How distress develops in Ménière's disease

Questionnaire No.2

(for people **without** Ménière's Disease)

1.	What is your Gender? (please circle)	Male	Female
2.	What is your Age? (please write in the box)		
3.	Do you have Ménière's disease or suffer from severe dizziness? (please circle)	Yes	No

You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you (circle the number that describes you best for each item). Please answer all the questions.

The range of responses are:

1 **Not at all characteristic of me**	2 **A little characteristic of me**	3 **Somewhat characteristic of me**	4 **Very characteristic of me**	5 **Entirely characteristic of me**

How characteristic of you are each of the following statements:

4	Uncertainty stops me from having a strong opinion.	1	2	3	4	5
5	Being uncertain means that a person is disorganized.	1	2	3	4	5
6	Uncertainty makes life intolerable.	1	2	3	4	5
7	It's unfair having no guarantees in life.	1	2	3	4	5
8	My mind can't be relaxed if I don't know what will happen tomorrow.	1	2	3	4	5
9	Uncertainty makes me uneasy, anxious, or stressed.	1	2	3	4	5
10	Unforeseen events upset me greatly.	1	2	3	4	5
11	It frustrates me not having all the information I need.	1	2	3	4	5
12	Uncertainty keeps me from living a full life.	1	2	3	4	5
13	One should always look ahead so as to avoid surprises.	1	2	3	4	5
14	A small unforeseen event can spoil everything, even with the best planning.	1	2	3	4	5
15	When it's time to act uncertainty paralyses me.	1	2	3	4	5
16	Being uncertain means that I am not first rate.	1	2	3	4	5
17	When I am uncertain I can't go forward.	1	2	3	4	5

1 Not at all characteristic of me	2 A little characteristic of me	3 Somewhat characteristic of me	4 Very characteristic of me	5 Entirely characteristic of me

18	When I am uncertain I can't function very well.	1	2	3	4	5
19	Unlike me, others seem to know where they are going with their lives.	1	2	3	4	5
20	Uncertainly makes me vulnerable, unhappy, or sad.	1	2	3	4	5
21	I always want to know what the future has in store for me.	1	2	3	4	5
22	I can't stand being taken by surprise.	1	2	3	4	5
23	The smallest doubt can stop me from acting.	1	2	3	4	5
24	I should be able to organize everything in advance.	1	2	3	4	5
25	Being uncertain means that I lack confidence.	1	2	3	4	5
26	I think it's unfair that other people seem to be sure about their future.	1	2	3	4	5
27	Uncertainty keeps me from sleeping soundly.	1	2	3	4	5
28	I must get away from all uncertain situations.	1	2	3	4	5
29	The ambiguities in life stress me.	1	2	3	4	5
30	I can't stand being undecided about my future.	1	2	3	4	5

Please read each item below and place a tick in the box opposite the reply which comes close to how you have been feeling in the last week. Don't take too long over your replies: your immediate reaction will probably be more accurate than a long thought-out response.

31. I feel tense or 'wound up':

Most of the time.....
A lot of the time .....
Time to time, Occasionally .....
Not at all.....

32. I feel as if I am slowed down:

Nearly all the time.....
Very often.....
Sometimes.....
Not at all.....

33. I still enjoy the things I used to enjoy:

Definitely as much.....
Not quite so much.....
Only a little.....
Hardly at all.....

34. I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all.....
Occasionally.....
Quite often.....
Very often.....

35. I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly.....
Yes, but not too badly.....
A little, but it doesn't worry me.....
Not at all.....

36. I have lost interest in my appearance:

Definitely.....
I don't take so much care as I should.
I may not take quite as much care....
I take just as much care as ever.....

37. I can laugh and see the funny side of things:

As much as I always could.....
Not quite so much now.....
Definitely not so much now.....
Not at all.....

38. I feel restless as if I have to be on the move:

Very much indeed.....
Quite a lot.....
Not very much.....
Not at all.....

39. Worrying thoughts go through my mind:

A great deal of the time.....
A lot of the time.....
From time to time but not too often..
Only occasionally.....

40. I look forward with enjoyment to things:

As much as I ever did.....
Rather less than I used to.....
Definitely less than I used to.....
Hardly at all.....

41. I feel cheerful:

Not at all.....
Not often.....
Sometimes.....
Most of the time.....

42. I get sudden feelings of panic:

Very often indeed.....
Quite often.....
Not very often.....
Not at all.....

43. I can sit at ease and feel relaxed:

Definitely.....
Usually.....
Not often.....
Not at all.....

44. I can enjoy a good book or radio or TV programme:

Often.....
Sometimes.....
Not often.....
Very seldom.....

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, over the past six months. Identify the statement by ringing the letter next to it i.e. if you think that the statement (a) is correct, ring statement (a); it may be that more than one statement applies, in which case, please ring any that are applicable.

45.	**a.**	I do not worry about my health.
	b.	I occasionally worry about my health.
	c.	I spend much of my time worrying about my health.
	d.	I spend most of my time worrying about my health.
46.	**a.**	I notice aches / pains less than most other people (of my age).
	b.	I notice aches / pains as much as most other people (of my age).
	c.	I notice aches / pains more than most other people (of my age).
	d.	I am aware of aches / pains in my body all the time.
47.	**a.**	As a rule I am not aware of bodily sensations or changes.
	b.	Sometimes I am aware of bodily sensations or changes.
	c.	I am often aware of bodily sensations or changes.
	d.	I am constantly aware of bodily sensations or changes.
48.	**a.**	Resisting thoughts of illness is never a problem.
	b.	Most of the time I can resist thoughts of illness.
	c.	I try to resist thoughts of illness but am often unable to do so.
	d.	Thoughts of illness are so strong that I no longer even try to resist them.
49.	**a.**	As a rule I am not afraid that I have a serious illness.
	b.	I am sometimes afraid that I have a serious illness.
	c.	I am often afraid that I have a serious illness.
	d.	I am always afraid that I have a serious illness.
50.	**a.**	I do not have images (mental pictures) of myself being ill.
	b.	I occasionally have images of myself being ill.
	c.	I frequently have images of myself being ill.
	d.	I constantly have images of myself being ill.
51.	**a.**	I do not have any difficulty taking my mind off thoughts about my health.
	b.	I sometimes have difficulty taking my mind off thoughts about my health.
	c.	I often have difficulty in taking my mind off thoughts about my health.
	d.	Nothing can take my mind off thoughts about my health.
52.	**a.**	I am lastingly relieved if my doctor tells me there is nothing wrong.
	b.	I am initially relieved but the worries sometimes return later.
	c.	I am initially relieved but the worries always return later.
	d.	I am not relieved if my doctor tells me there is nothing wrong.
53.	**a.**	If I hear about an illness I never think I have it myself.
	b.	If I hear about an illness I sometimes think I have it myself.
	c.	If I hear about an illness I often think I have it myself.
	d.	If I hear about an illness I always think I have it myself.

54.	**a.** If I have a bodily sensation or change I rarely wonder what it means. **b.** If I have a bodily sensation or change I often wonder what it means. **c.** If I have a bodily sensation or change I always wonder what it means. **d.** If I have a bodily sensation or change I must know what it means.
55.	**a.** I usually feel at very low risk for developing a serious illness. **b.** I usually feel at fairly low risk for developing a serious illness. **c.** I usually feel at moderate risk for developing a serious illness. **d.** I usually feel at high risk for developing a serious illness.
56.	**a.** I never think I have a serious illness. **b.** I sometimes think I have a serious illness. **c.** I often think I have a serious illness. **d.** I usually think that I am seriously ill.
57.	**a.** If I notice an unexplained bodily sensation I don't find it difficult to think about other things. **b.** If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things. **c.** If I notice an unexplained bodily sensation I often find it difficult to think about other things. **d.** If I notice an unexplained bodily sensation I always find it difficult to think about other things.
58.	**a.** My family / friends would say I do not worry enough about my health. **b.** My family / friends would say I have a normal attitude to my health. **c.** My family / friends would say I worry too much about my health. **d.** My family / friends would say I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness of a type which particularly concerns you (such as heart disease, cancer, multiple selerosis and so on). Obviously you cannot know for definite what it would be like; please give your best estimate of what you think might happen, basing your estimate on what you know about yourself and serious illness in general.

59.	**a.** If I had a serious illness I would still be able to enjoy things in my life quite a lot. **b.** If I had a serious illness I would still be able to enjoy things in my life a little. **c.** If I had a serious illness I would be almost completely unable to enjoy things in my life. **d.** If I had a serious illness I would be completely unable to enjoy life at all.
60.	**a.** If I developed a serious illness there is a good chance that modern medicine would be able to cure me. **b.** If I developed a serious illness there is a moderate chance that modern medicine would be able to cure me. **c.** If I developed a serious illness there is a very small chance that modern medicine would be able to cure me. **d.** If I developed a serious illness there is no chance that modern medicine would be able to cure me.
61.	**a.** A serious illness would ruin some aspects of my life. **b.** A serious illness would ruin many aspects of my life. **c.** A serious illness would ruin almost every aspect of my life. **d.** A serious illness would ruin every aspect of my life.
62.	**a.** If I had a serious illness I would not feel that I had lost my dignity. **b.** If I had a serious illness I would feel that I had lost a little of my dignity. **c.** If I had a serious illness I would feel that I had lost quite a lot of my dignity. **d.** If I had a serious illness I would feel that I had totally lost my dignity.

Choose a number from the scale below to show how much you would avoid each of the situations listed below because of fear or other unpleasant feelings. Then write the number you chose in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8

Would not avoid it	Slightly avoid it	Definitely avoid it	Markedly avoid it	Always avoid it

63. Consulting your family doctor..... ____.
64. Visiting a friend in hospital..... ____.
65. Visiting a relative in hospital..... ____.
66. Going to a hospital for treatment..... ____.
67. Talking about illness..... ____.
68. Reading about illness..... ____.
69. Visiting a hospital for other reasons (e.g. delivering a message)..... ____.
70. Watching TV programmes about illness..... ____.
71. Listening to radio programmes about illness..... ____.
72. Thinking about illness..... ____.

Choose a number from the scale below which best describes how often you seek reassurance about your health, from each of the sources described below. Then write the number you have chosen in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8

Never	Rarely	Sometimes	Often	Daily

73. Friends..... ____.
74. Family..... ____.
75. Reading books..... ____.
76. Checking body for changes..... ____.
77. Family doctor..... ____.
78. Nurses..... ____.
79. Hospital outpatient clinic..... ____.
80. Hospital casualty..... ____.
81. Other (specify)..... ____.

Thank you for filling in this questionnaire. Please make sure you have answered all the questions, and then return it in the pre-paid envelope provided as soon as possible to: Mrs Sarah Kirby, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ.

Appendix N: Reminder 1 information sheet used for MD group for study in chapter 7

University of Southampton

School of Psychology

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United Kingdom

Telephone: 023 8059 2581
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Email: sek@soton.ac.uk

How distress develops in Ménière's disease

Information & consent form

My name is Sarah Kirby, and I am a PhD student at the University of Southampton. You should have received a letter from me a month ago asking whether you would consider taking part in a research study investigating distress in Ménière's disease. This study is being partially funded by the Ménière's Society.

If you have already sent back the questionnaire, either completed or unanswered, then please accept my apologies for writing to you again. If you do **not** want to take part then please send back the uncompleted questionnaire so I know your decision. If I do not hear from you, I will send you a final reminder. However, this will not happen if you return the questionnaire (completed or uncompleted).

It is well known that some people with Ménière's disease experience distress and disability. However, very little is known about the beliefs, concerns, feelings and behaviours that may contribute to distress. If we understood more about these, doctors and the Ménière's Society could improve the support they provide.

If you would like to take part in the study, all you need to do is fill in questionnaire number 1 (for people **with** Meniere's disease). This should take no more than 30 minutes to complete. If you are not distressed by your Ménière's disease, your answers are still important as we can compare your scores with those of people who are distressed.

It is up to you to decide whether or not to take part, and you may change your mind at any time without giving a reason. If you complete and return the questionnaire, I will assume that you give your consent to take part in the study. Personal information will not be given to or seen by anyone other than the researchers involved in this project. Published results of the study will not include your name. A summary of this research project will be sent to you upon request. If you have any questions, please contact me Sarah Kirby, on (023) 8059 2581 or sek@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Appendix O: Reminder 2 information sheet used for MD group for study in chapter 7

University of Southampton

School of Psychology

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Telephone: 023 8059 2581
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How distress develops in Ménière's disease

Information & consent form

My name is Sarah Kirby, and I am a PhD student at the University of Southampton. You should have received a reminder letter from me a month ago asking whether you would consider taking part in a research study investigating distress in Ménière's disease. This study is being partially funded by the Ménière's Society.

If you have already sent back the questionnaire, either completed or unanswered, then please accept my apologies for writing to you again. If you do **not** want to take part then please send back the uncompleted questionnaire so I know your decision. If you have not sent back the questionnaire, then this is the final opportunity to do so and I will not write to you again.

It is well known that some people with Ménière's disease experience distress and disability. However, very little is known about the beliefs, concerns, feelings and behaviours that may contribute to distress. If we understood more about these, doctors and the Ménière's Society could improve the support they provide.

If you would like to take part in the study, all you need to do is fill in questionnaire number 1 (for people **with** Meniere's disease). This should take no more than 30 minutes to complete. If you are not distressed by your Ménière's disease, your answers are still important as we can compare your scores with those of people who are distressed.

It is up to you to decide whether or not to take part, and you may change your mind at any time without giving a reason. If you complete and return the questionnaire, I will assume that you give your consent to take part in the study. Personal information will not be given to or seen by anyone other than the researchers involved in this project. Published results of the study will not include your name. A summary of this research project will be sent to you upon request. If you have any questions, please contact me Sarah Kirby, on (023) 8059 2581 or sek@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Reminder 2

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