UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Psychology

FACTORS INFLUENCING ADJUSTMENT TO CHRONIC ILLNESS AND THE ROLE OF THE SELF-HELP GROUP IN THIS PROCESS.

by

Bridget Dibb

Thesis submitted for the degree of Doctor of Philosophy

April 2004

ABSTRACT

UNIVERSITY OF SOUTHAMPTON
ABSTRACT
FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
SCHOOL OF PSYCHOLOGY
Doctor of Philosophy
FACTORS INFLUENCING ADJUSTMENT TO CHRONIC ILLNESS AND THE ROLE OF THE SELF-HELP GROUP IN THIS PROCESS
By Bridget Dibb

The primary aim of this study was two-fold: to determine what influences changes in quality of life (QoL) over time and to determine what aspects of QoL changed over time. There was a particular focus on what role social comparison may play in changes in QoL during the process of adjustment to chronic disease.

A longitudinal design was used where QoL was measured at baseline and ten months later at follow-up.

To determine these relationships a qualitative study and a pilot study were carried out to develop and validate two new questionnaires. The main study then consisted of a survey where 550 people with Ménière's disease completed questionnaires at baseline and 301 completed measures of QoL again at follow-up, ten months later. Three different aspects of QoL were measured (functional, goal-oriented, and perceived positive change since the onset of the illness), and baseline predictor variables were classified as the catalyst (disease severity measures), the antecedents (demographic factors and the psychological factors self-esteem, optimism, and perceived control), and the mechanisms (the social comparison variables). Response shift was also measured using the ThenTest approach.

A cross-sectional analysis at baseline showed that social comparison was indeed associated with adjustment after controlling for the antecedents and the catalyst. Longitudinally, support for the main prediction was found where negative social comparison emerged as a primary predictor of worse functional QoL, providing evidence for the influence of social comparison within a self-help group on adjustment. However, those who had been members of the society for longer showed better functional QoL which indicates that the self-help group was having a positive effect on QoL over time. Self-esteem and the perception of movement towards goals emerged as important predictors of functional QoL over time. In addition, an overt change occurred in the perception of goal-directed movement where at Time 1 there was the perception of moving away from goals and by Time 2, there was the perception of moving towards goals. Predictors of change in this perception were self-esteem, perceived control and social support. The implications of these results for adjustment and self-help groups are discussed.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF DIAGRAMS

DECLARATION OF AUTHORSHIP

I, Bridget Dibb, declare that the thesis entitled,
'Factors influencing adjustment to chronic illness and the role of the self-help group in this process'
and the work presented in it are my own. I confirm that:

- this work was done wholly while in candidature for a research degree at this University;
- no part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission.

ACKNOWLEDGEMENTS

The first person I must thank is my excellent supervisor, Lucy Yardley, for her continuing support and sound advice. I consider myself very lucky to have had the benefit of her knowledge and guidance. The concept of this study lay with Lucy and so, quite literally, this study would not have come about without her. Thank you.

I would also like to thank Constantine Sedikides, my second supervisor, for his valuable input over the years.

This study was an ESRC Case award, part-funded by the Ménière's Society. The Ménière's Society were interested in assessing the effectiveness of the self-help group in meeting the needs of their members, this was achieved in tandem with the PhD project which resulted. I would like to thank both the ESRC and the Ménière's Society for making this project possible. Glenys Osborne was a great help and source of knowledge about Ménière's disease and the Ménière's Society. A special thank you goes to Brenda Shield and Elaine Fenner for being so helpful and accommodating, especially when sending out all those questionnaires!

I would also like to acknowledge and thank my husband Graham and my children, Craig and Morgan, for their endless patience and encouragement to accomplish this study. Without their support this project would have been much harder to complete. Thank you also to my parents, Margaret and David Johnson, for their support and help.

Thanks also go to Maggie Donovan-Hall and Diana Jackson. Thank you both for being there as my sounding board and for being so encouraging at all those lunches and coffee breaks.

Finally, I would like to thank the participants of the study, without whom there would be no study at all. Many members gave up their time to participate despite having to contend with their illness, to which I am very grateful.

GLOSSARY OF ABBREVIATIONS

Dneg = downward information interpreted negatively

Dpos = downward information interpreted positively

GOQoL = Goal-oriented QoL scale

GOQoL-T1 = goal-oriented QoL measured at Time 1

GOQoL-T2 = goal oriented QoL measured at Time 2

Info = comparison for information purposes

IPQ-R = Illness perception questionnaire, revised

LOT = Life Orientation Test, measures dispositional optimism

QoL = Quality of Life

PTGI = posttraumatic growth inventory, measures perceived positive change

PTGI-T1 = perceived positive change measured at Time 1

PTGI-T2 = perceived positive change measured at Time 2

SE = self-esteem

SF-36 = Short Form 36, functional QoL questionnaire

SF-36-T1 = functional QoL measured at Time 1

SF-36-T2 = functional QoL measured at Time 2

T1 = Time 1

T2 = Time 2

ThenTest = approach where questionnaire items are reworded so as to be retrospective

TT = ThenTest

Upos = upward comparison interpreted positively

Uneg = upward comparison interpreted negatively

CHAPTER ONE: INTRODUCTION

1.0. Introduction

The percentage of people diagnosed with a chronic illness is on the increase. In 2001 32% of the population were reporting a long-standing illness within the UK, which is a third more than those reporting a long-standing illness in 1972 (Office of National Statistics, 2003). As chronic illnesses are long-term and have no cure, this leaves the individual to manage and adjust to their illness themselves. As part of this self-management process many people join self-help groups. Self-help groups provide medical information and advice on coping and managing the illness. Unfortunately, there are no official statistics on the number of self-help groups in operation within the UK, nor are there any statistics on the number of people who join these groups. However, there are websites available which give access to over 2000 UK patient support groups (Kenny & Kenny, 2003) and a directory of British self-help groups with over 820 national self-help groups covering 750 different illnesses and needs (Garrill & Garrill, 2003), although there may be some overlap between these two sources there are presumably more groups which are not listed on these websites. The USA have published statistics on self-help groups; in 1989 it was estimated that over 10 million people would be members of a self-help group (health or other) in the USA by the year 2000 (Jacobs & Goodman, 1989). These figures are not difficult to accept as with at least 2000 illness self-help groups in the UK, if all groups have the same membership as the Ménière's Society (The Ménière's Society has over 5500 members) that makes around 11 million people who belong to an illness self-help group in the UK. Even allowing for smaller membership numbers amongst some of these groups these figures still indicate a large percentage of the population who join illness self-help groups.

Despite the increase in numbers of people with chronic illness and the large number of people who rely on self-help groups to help manage their illness, currently we have limited knowledge about the benefits of self-help groups (Jacobs et al., 1989). This highlights a need to understand the role of the self-help group in the process of adjustment to chronic illness. Self-help groups have blossomed since the 1970's, however various studies on their operational mechanisms have not been overly informative due to the problems associated with researching self-help groups (Jacobs et al., 1989). Self-help group members have been shown to be proactive in changing their lives and to make active use of help from others. This has led to a positive bias in the samples available for self-help group research which can only be removed by the random selection of people who are not self-help members to artificially created self-help groups. However, this is not a solution as "self-help groups do not exist as interventions apart from their members who are both instruments and the objects of the intervention: change the characteristic of their membership and the intervention is changed as well" (Levy, unpublished, as cited in Jacobs et al., 1989, p. 539). Details of these mechanisms, what is helpful and, indeed, unhelpful could benefit both self-help groups and the medical profession. Such knowledge would ensure the self-help group would provide its members with the best forms of support delivered in the most beneficial way. Knowledge that membership of the self-help group is helpful would also encourage medical professionals to recommend them to their patients, and the self-help groups could then provide an additional legitimate service which would ease the burden of the health services. Knowledge about what helps healthy psychological adjustment to a chronic illness within a self-help group could also be useful to those who do not adjust well and to those who rely heavily on their medical professional for assistance.

Sponsored by the Ménière's Society, a national self-help group, this project focused on factors that influence adjustment to chronic illness and aspects of quality of life (QoL) that change over time. This involved assessing adjustment by measuring change in QoL from baseline to follow-up and determining the predictors (including social comparison) of this adjustment. Social comparison, where we compare ourselves with others, is a likely process at work within a self-help group (Gibbons & Gerrard, 1989; Medvene, 1992) as members can compare with each other to find out how they cope with the symptoms and how the illness progresses. While social comparison has been looked at as a dependent variable within a self-help group (Helgeson, Cohen, Schulz, & Yasko, 1999), no studies have looked at the effects of social comparison on adjustment within a self-help group. Only a few studies have attempted to link social comparison theory to adjustment and the results are as yet inconclusive. This study attempted to clarify this issue by measuring the effects of social comparison within the self-help group over time.

This study was unique, as no such study had been carried out using a sample of people with Ménière's disease, no such study had been conducted on adjustment within large, national self-help groups, and there is no conclusive evidence that shows a relationship between social comparison and adjustment. In addition, this study involved the development of two new scales (a social comparison scale and a goal-oriented QoL scale). Most Ménière's disease studies to date have focussed on the biology or the handicap; a large number of studies have looked at possible links between Ménière's disease and psychopathology. This research stems from the disputed proposition that Ménière's disease is a psychosomatic illness and linked to neuroticism, anxiety and hypochondria (Yardley, 1994). However, this question does not enter the remit of this study; this study does not attempt to confirm or refute these claims and so this aspect of Ménière's disease is not reviewed in detail here.

To provide the context for this project, this chapter firstly describes in detail what Ménière's disease is. In addition, self-help groups and their role within chronic illness are explored, and the Ménière's Society, a national self-help group is described.

1.1. Ménière's disease

The population used in this study were all people with Ménière's disease. First identified by Prosper Ménière's in 1861, Ménière's disease is a chronic disorder of the inner ear. Diagnosis is made based on a history of four main symptoms, tinnitus, hearing loss, vertigo, and a feeling of fullness in the ear (Saeed, 1998; Yardley, 1994). The incidence of Ménière's disease is about 1 to 2 per 1000 and tends to occur equally in both men and women (Ménière's Society, 2003).

1.1.1. Biology

Ménière's disease is described as a chronic, progressive illness of the vestibular system. The symptoms are intermittent punctuated with periods of remission; this makes it an unpredictable illness, as the person is not aware when they will next experience an attack of vertigo. The aetiology is unknown, however there are several proposed causes which include anatomical abnormalities, viral infections, defective genes, a psychosomatic disorder, and auto-immune dysfunction (Saeed, 1998). There is also no cure at present; there are various treatments which attempt to reduce the symptoms, but their effectiveness is very variable.

As mentioned above, there are four classic symptoms which point to a diagnosis of Ménière's disease, namely, tinnitus, spells of vertigo, a feeling of fullness in the ear, and low frequency hearing loss. Tinnitus is a ringing or buzzing in the ear; it can be constant or intermittent and usually worsens during a vertiginous attack. Vertigo, spinning and dizziness are experienced to the degree that the individual cannot move, often accompanied by nausea and vomiting. These attacks can last several hours. This is accompanied by a feeling of fullness in the ear which is very uncomfortable and is worse during the active stages of the illness, and fluctuating hearing loss which gradually worsens over time. The progressive hearing loss eventually results in deafness once the disease has 'burnt out' (the late stage where the vertigo has ceased). The illness is usually unilateral (affects only one ear) initially, however in many cases (50%) it may become bilateral, where both ears are affected.

Symptoms and experiences of the illness range widely from person to person with the only commonality being hydrops. Hydrops is either due to the overproduction or under reabsorption of the fluid present in the inner ear (called endolymph). The membrane which lines the inner ear (the endolymphatic membrane) can become damaged in this situation as the pressure of the excess endolymph distorts the membrane. This is thought to be the root of the cause of the four symptoms (Yardley, 1994; Zeitoun & Irving, 1999). Hydrops can only be determined after autopsy (Yardley, 1994; Zeitoun et al., 1999). This explains why a person can be given the diagnosis of 'certain Ménière's disease' only after death. The diagnosis one can receive until then is 'definite Ménière's disease.'

There are two main classifications of treatments for Ménière's disease; medicinal and surgical. The medicinal treatments range from diuretics which are aimed at reducing the severity of the vertigo to drugs (for example, antihistamines, phenothiazines, and tranquilizers) which partially suppress the vestibular system. However, these drugs do not stop the vertigo completely and the side effects which accompany these drugs mean that they are usually unsuitable for long-term use (Yardley, 1994). The surgical procedures available tend to be either destructive or non-destructive. There are two main destructive procedures. Labyrinthectomy destroys the vestibular organ so removing the source of the vertigo. However, as it also destroys all hearing this procedure is usually only performed on those who have already lost all hearing. The second destructive surgical procedure severs the vestibular nerve so preventing balance information from reaching the brain. This procedure is 90% successful in preventing vertigo, however it carries the risk of other complications. Should the operation not be performed correctly other side effects like facial paralysis and hearing loss may result.

Non-destructive procedures like endolymphatic sac surgery aim to reduce the vertigo. For example, the endolymphatic shunt allows the release of excess endolymph and so relieves the pressure caused by the build up of excess endolymph. This procedure can alleviate the vertigo and does not interfere with hearing, however it is only 70% successful (which is the same success rate as a placebo operation) and often needs to be refitted (Yardley, 1994).

1.1.2. Psychosocial factors

The symptoms of this illness can be incapacitating, rendering the individual unable to move for fear of making the vertigo worse, since head movement stimulates the inner ear and provokes symptoms (Gant & Kampfe, 1997). The intermittent and unpredictable nature of the illness can have a negative effect on well-being (Honrubia, Bell, Harris, Baloh, & Fisher, 1996). The vertigo, frightening in itself, is often accompanied by nausea and vomiting (Yardley, 1994). This illness leads to a reliance on others to help and assist, resulting in a loss of independence. There also tends to be a reduction in social functioning brought on by feelings of helplessness which, in turn, leads to isolation (Yardley, Todd, Lacoudraye-Hater,

& Ingham, 1992). In a study with Ménière's disease patients over half found difficulties in completing activities when experiencing vertigo (Hagnebo et al., 1997) indicating that this illness interferes with normal living. There is the additional stress of having an attack in public as the person with Ménière's Disease is assumed either to be drunk and therefore ignored or to be suffering from a heart attack in which case they are rushed to hospital unnecessarily (Yardley, 1994). Intermittent tinnitus, too, has a negative effect, often interfering with sleep and distracting the person from their every-day activities (Hiller & Goebel, 1992). Problems with communication with others occur due to the hearing loss and tinnitus which compounds the problems faced in social situations and also causes problems at work (Yardley, 1994).

1.2. The Ménière's Society

The Ménière's Society is a charity run as a large self-help group. The founder, Marie Nobbs, started the group in 1984 and it now has over 5500 members. The average length of membership is about five years although there are some who have been members since the beginning. Although most of its members do not meet each other, there are a small number of local groups which do meet. For most of the members the only contact is by means of a quarterly magazine which they call 'Spin.' Members also make indirect contact with each other through the magazine by means of the 'letters to the editor' section, which consists of letters from the members telling their stories of their life with Ménière's disease. These stories are of great importance to others who are in a similar situation as they give advice on what does and does not help the writer of the story in the management of their illness. In this way, the letters may offer solutions to the reader's problems. However, the letters section is not all that Spin contains; other sections provide detailed medical information about Ménière's disease.

1.3. Self-help groups

The self-help group has been defined as "a supportive, educational, usually change-oriented mutual aid group that addresses a single life problem or condition shared by all members" (Kurtz, 1997, p. 4). The aim is to; empower, give support, impart information (Borkman, 1997; Kurtz, 1997), transform identities, achieve insight, reframe, convey a sense of belonging, communicate experiential knowledge, and teach coping methods (Kurtz, 1997).

Kurtz (1997) has described self-help groups as existing on one end of a continuum with psychotherapy groups at the other end and support groups in the middle . All these groups focus on information giving and change in the individual. At the self-help group end of the continuum there is a stronger focus on information and support than there is on change, although this differs from group to group. Both psychotherapy groups and support groups are professionally led, whereas self-help groups are patient-led and contact with professionals is occasional or exists only if they are members too. Yalom (1975) proposed twelve therapeutic factors at play within a psychotherapeutic group. These factors have been extended to self-help groups (Butler & Fuhriman, 1980; Citron, Solomon, & Draine, 1999; Llewelyn & Haslett, 1986). These factors include recapitulation of the primary family group, identification, universality, instillation of hope, guidance, interpersonal (two factors: learning how to get along with others and how others view them), catharsis, cohesiveness, self-understanding, altruism, existential factor. These factors are deemed important in instigating change in the therapeutic situation and have been applied to self-help groups. However, these self-help groups have tended to be psychiatric groups which may differ from illness self-help groups

Self-help groups usually begin with a group of people who have a shared problem (Kurtz, 1997) and they differ in size and focus. Rules and norms, too, differ from one group to another. Some, like Alcoholics Anonymous, follow a structured programme to facilitate change, whereas others provide more of an information and support service to their members (Kurtz, 1997). The Ménière's Society is patient-led and may be classified as an unaffiliated group (Schubert & Borkman, 1991) in that it is independent from medical professionals.

Professionals view professionally-led self-help groups as more effective than those not led by a professional (Rappaport, 1994; Salzer, Rappaport, & Serge, 1999), and there is a tendency for health professionals to underestimate the importance of self-help groups (Lieberman &

Snowden, 1994). This is probably due to the fact that in the professional's eyes only a professional can instigate the change a self-help group hopes to effect.

There are many different types of self-help groups which differ from each other in structure and organisation. Although these groups also differ in their approach, most have the common goal of helping the individual to cope and adjust to life with their illness. The role of a self-help group in adjustment to a disease, overcoming a problem, or coping with an illness or a problem has so far been unclear. Research on self-help groups, mostly atheoretical (Kurtz, 1997; Stewart, 1990), has largely focused on what self-help groups provide and the sort of person likely to join a self-help group. Although some studies have shown benefits, these have largely been cross-sectional studies (Kurtz, 1997). In addition, most of the previous research has been conducted on the type of self-help group which meets at regular times and follows a structured format. There are, however, a large number of groups which do not fit this pattern, such as the Ménière's Society. This type of group is large and the members do not necessarily meet each other. Their method of contact is through circulars and magazines which contain both information on how to cope, what the latest medications are, and usually letters from members who tell their stories of life with their illness.

Some studies have found self-help groups to be beneficial. They have been found effective in reducing hospital stays, reducing the rate of re-hospitalisation (Salzer et al., 1999) and reducing the use of professional services (Kurtz, 1997). Self-help groups have the benefit of giving on-going support, unlike the more financially conscious organisations (Salzer et al., 1999). Lieberman and colleagues describe the process of belonging to a group as important in the process of change, as other people's stories and perspectives can be heard (or as in the case of the Ménière's Society, read) and this can have the effect of changing one's own perspective (Lieberman, Solow, Bond, & Reilbstein, 1979). This new perspective can influence self-identity; "mutual help organisations can be understood as contexts for identity transformation" (Rappaport, 1994, p.128).

In an open-ended questionnaire study with undergraduates Medvene found the biggest reason for undergraduates joining a group was for information, however, attendance was also linked to affiliation (Medvene, 1992). This implies that those who need only information will attend until they have received information while those who have joined to affiliate would remain members for longer. The information gained in this study was reported to assist in problem solving. This information was considered valid when coming from someone who had similar experiences with regard to their problems. A self-help group is an obvious place to find the source of this 'valid' information.

Research into the effects of belonging to a self-help group for people with cancer found that those who were members of a self-help group perceived less satisfaction with their own social support than those who were not members of a self-help group. The main reasons given for joining the group were that they were looking for others who could understand what they had been through because they had the same experiences (Steffen, 1997).

Not all research shows self-help groups to have a positive effect. In their longitudinal study with women with breast cancer Helgeson and colleagues (1999) found education to be a significant factor in promoting adjustment in groups receiving education about their illness relative to those who participated in a peer-discussion group only. It led to an increase in self-esteem, positive affect and less uncertainty about their illness. However, the effect of belonging to a peer discussion group was negative, as it led to more negative downward comparisons and more intrusive and anxious thoughts about the illness. This could be due to the fact that eight weeks of peer discussion may have been too short to have an effect. They conducted a follow-up study one and two years later to determine the long-term effects of both education and peer discussion groups and found that the benefits of the education were still evident whereas the peer discussion group continued to show a negative effect. The findings of the preceding two studies are similar to those of Jacobs, Ross, Walker and Stockdale (1983) whose study with Hodgkin's disease patients found an education group to have a significant positive effect on problem solving, hostility, and reassurance while a peer support group did not show these positive relationships and had a negative effect on activity, a subscale of the Cancer Patient Behaviour Scale. They reasoned that the eight weeks of peer support may not have been long enough to effect a change.

Surprisingly few studies have looked at the role of social comparison within a self-help group (social comparison is reviewed in detail in Chapter 3). Some investigators have included social comparison as an outcome measure, measuring what type of social comparison occurs after intervention (participation in a control, education, peer-discussion, or peer-discussion and education group (Helgeson et al., 1999). Others have looked at it as an independent variable, however, none of the studies have determined the effects of the social comparison occurring within a self-help group on adjustment to the illness. In addition, the studies which exist created their self-help groups for the purpose of the study, in other words the groups were artificially created and this has been considered to invalidate the data as the self-help groups and the members should not be considered as separate from each other, the members make the group. This brings into question the validity of assigning participants to self-help groups (Jacobs et al., 1989). This thesis was interested in the social comparison occurring within a naturally occurring self-help group.

1.4. Conclusion

This chapter has set the scene for this thesis, which has a principal focus on the social comparison within a self-help group and its relationship to adjustment. This chapter has highlighted the growing tendency for people with a chronic illness to join a self-help group. As social comparison is a likely process at play within the self-help group, an understanding of its influence on adjustment would be of benefit to all concerned with adjustment to chronic illness. The next two chapters provide a more detailed exploration of the quality of life (QoL) and social comparison literature. These chapters also define these constructs as they are used within this thesis. Chapter 4 provides a recapitulation of the conclusions from the first three chapters and a model of adjustment is proposed. The research questions and methods are then described. Chapters 5, 6, and 7 are the three empirical chapters of the thesis. All three give a detailed account of what was done and why, and the results they yielded. Chapter 8 is the final chapter of the thesis. It brings together all the empirical results of this study and relates them back to the literature. The results are also considered in terms of the model proposed in Chapter 4. Finally, the strengths and weaknesses of the study and future directions for research are discussed.

CHAPTER TWO: QUALITY OF LIFE (QOL) AND ADJUSTMENT

2.1. Introduction

Having introduced this study as research into what influences adjustment to chronic illness this next chapter shows how QoL can be disrupted by a crisis and how it recovers, referred to here as the process of adjustment. Although the aim of this research is to explore what influence social comparison may have on the adjustment process this chapter is confined to just the construct QoL and the process of adjustment.

The first section of this chapter discusses the meaning of the construct QoL, the importance of goals to QoL, the effects of an illness on perceived QoL, and what adjustment is. QoL and adjustment are defined and an explanation is given of the theoretical background which determines how to measure QoL and adjustment. The third section discusses the influence on QoL of 'other factors' such as demographic characteristics, disease severity, self-esteem, perceived control and optimism. Finally, conclusions drawn from the review are summarized highlighting those aspects important to QoL and adjustment.

2.2. Quality of life

There is a vast array of differing opinions about the meaning of QoL and adjustment and this makes for confusing reading. The plethora of QoL studies that exists also differ in the methods used to measure QoL, which highlights the diversity of the concept. For example, some studies use the absence of physical symptoms to gage QoL while others use the absence of psychopathology, and others measure the extent to which daily living is interfered with. While it is not the place of this review to resolve this argument it does highlight the importance of defining the concept to ensure clear understanding of what QoL means in this study.

QoL has been linked to happiness and goals and this is not a recent phenomenon. Around 430 BC Aristotle was one of the first to describe the goal of life as the pursuit of goodness, and the end result, happiness. In more recent times Parducci (1995) also links happiness to goal attainment. He defines happiness as "a theoretical average across all pleasures and pains" (p. 1). This definition emphasises the idea that the perception of QoL is relativistic in nature, as both pleasure and pain need to be experienced in order for a person to have an awareness of what pleasure or pain mean. Researchers have also linked QoL to goal achievement (O'Boyle, McGee, & Joyce, 1994), where a person feels they have achieved a good QoL if they have achieved their goals. Various other studies have linked goal setting (Recker, Peacock, & Wong, 1987), goal attainment (Kuijer & de Ridder, 2003), and movement towards goals (Carver & Scheier, 1990) to perceived QoL. This thesis also argues that subjective goals play an important part in the perception of QoL, it uses Carver and Scheier's model (discussed in section 2.5.1) to link the perception of movement towards goals to QoL.

QoL has also been viewed as both an objective and a subjective state by health professionals and researchers. This is another reason why many QoL studies differ in their definitions. The objective view, which was once dominant, followed the medical model approach which assessed QoL based on physical health and functioning only. For example, objective QoL refers to those aspects of life which can be determined by objective measures, such as how far you can walk. This can lead to the QoL of an individual with a chronic illness automatically receiving a low rating due to the physical handicap associated with their illness. Subjective QoL usually refers to those aspects of QoL which cannot be determined by external measures, such as perceptions and values. Two distinct facets of subjective QoL have been distinguished (Keyes, Shmotkin, & Ryff, 2002). The first is subjective well being, which refers to a general happiness and satisfaction with life. The second is psychological well being, which refers to goal achievement and personal growth. The subjective aspects of QoL are more holistic, recognizing QoL as a subjective experience involving happiness, values and goals as well as physical health. This approach takes into consideration the psychological perspective of the individual so that their level of adaptation to the situation can be considered. When this approach is taken, QoL is not just based on physical handicap but also the individual's perception of their situation. Taking the above example, the QoL of a person with a chronic illness is not assessed only on how far they can walk but also on their satisfaction with their life. Functional QoL is referred to in this study as health-related QoL on a day-to-day basis, which may include both objective and subjective aspects of QoL.

The general definition of QoL taken in this study is that it is a subjective judgement of the standard of our lives. However, this study takes the stance that both goals and functionality are important. QoL is associated with happiness and goals, and also with health and physical functioning, and so incorporates both the subjective and objective aspects of QoL.

2.3. Effects of Illness on QoL

Today the number of people living with a chronic illness has increased due to advances in medicine which have resulted in the treating of illnesses which would once have been fatal so extending the normal life span. A chronic illness is, by definition, an illness that is long-term and for which there is no cure (Sidell, 1997). As our physical health has a direct effect on QoL, the effects of a chronic illness too are long-term and direct. The effects of physical health on QoL are shown in a study by Brazier (1992), where physical problems were found to lower QoL on the domains, physical functioning, pain, and social functioning. Garratt (1993) also found for the impact of health on QoL in a study of people with chronic lower back pain which showed that people with pain experienced lower QoL when compared to a healthy population. These findings show that deterioration in physical health leads to a drop in QoL after the onset of an illness, at least initially.

The disruption to the physical dimension of life has a ripple effect on other aspects of life. This often means that normal activities can no longer take place and important goals may now be out of reach. This indicates that subjective, or goal-oriented QoL, too, can be affected by an illness and the norms and values so central to QoL may become meaningless (Sidell, 1997). The consequence is that goals which were once within reach may become unattainable and most of what the individual knew about the world and how to live in it may become redundant. The feeling of having to start again and learn a new way of life is unsettling. The individual experience of this will depend on the degree of value attached to the goals which have been disrupted. Those goals which were of utmost importance and which become unattainable will have a greater impact on QoL than those which are of lesser importance. This disruption to normal functioning can also lead to a loss of independence (Sidell, 1997). In addition, the uncertainty and loss of direction can be frightening and may lead to feelings of powerlessness (Sidell, 1997). This situation can result in feelings of loss of control over life. More will be said about control and disease severity under 'Other factors influencing QoL and adjustment' (section 2.6.).

An example of this impact can be seen in the effects of Ménière's disease on normal living. As mentioned in Chapter 1, Ménière's disease is an intermittent illness interspersed with periods of remission. While in remission, there is little advanced warning of the next active stage of the illness, which leads to uncertainty and worry. The active stages of the illness can be so severe that the person often has to leave their job, which has both social and financial ramifications. The loss of independence is worsened by a reluctance to go out without a chaperone for fear of an attack of vertigo while out of the home. This again affects the social aspects of life, as does the tinnitus and fluctuating hearing loss which hinders communication. Managing the vertigo, too, can be frightening in itself as the person feels unsteady and as if they are going to fall at any minute. These feelings are compounded by the embarrassment of being unsteady in public, as others often interpret it as drunkenness.

The extent of the effects of an illness on the physical aspects of life may be observed or determined by objective measures which assess disruption of QoL based on the level of functioning. The subjective aspects are more difficult to assess. Subjective quality of life is best determined by measures which do not link quality of life to disease and functioning, but instead to happiness, goals and goal attainment. This is best done by subjective self-report measures to access the individual's perspective.

The above section explains the effects of illness on QoL. However, studies which have assessed more subjective domains have found these effects to be temporary. As noted above, initially the onset of an illness leads to a drop in perceived QoL due to the disruption to goals. However, over time the subjective QoL appears to recover to the point where once again a satisfactory QoL is reached. This means that most people do make some sort of cognitive recovery from the crisis, enabling a changed but contented perspective on life (Schwartz & Sprangers, 2000). This process is referred to as adjustment. In this study, the processes which may influence these factors within a self-help group are studied.

2.4. Adjustment

Adjustment to chronic illness is the main focus of this study and generally refers to a cognitive change in the way we view ourselves and the world (Sprangers & Schwartz, 1999a). The disruption brought on by the crisis leads to a complete re-evaluation of who we are. This leads to a shift in our frame-of-reference to accommodate this new situation which allows a re-interpretation of what is 'normal.' The altered perception experienced after adjustment leads to new priorities and enables the setting of new goals. In this way, adjustment is intrinsically linked to QoL, as adjustment is what allows the perception of quality of life to adapt to changed circumstances and enables a better perceived QoL. For example, different goals may now be viewed as important. This may result in the overall QoL rating not showing any change before and after the onset of illness, although closer inspection would show that the construct does not have the same meaning that it had before the onset of the illness. Detailed study of what the QoL concept means to that individual may show changes in goals or values or both. Adjustment accounts for these alterations in quality of life so that the overall level of quality of life may be the same or better than before the onset of the illness (Carver & Scheier, 2000).

This process is what people with chronic illnesses experience and so is relevant to a person with Ménière's disease. Knowledge of this process and factors which influence it are of importance as this knowledge may highlight both factors which facilitate it and factors which hinder it, information which the individual, management programs, and self-help groups may benefit from.

The theoretical processes of adjustment will be discussed in detail in the next section.

2.5. Theoretical aspects of QoL and Adjustment

Most QoL theories give clear explanations for achieving happiness, but few accommodate adjustment. Some theories emphasize need satisfaction (Maslow, 1954), and some goal satisfaction (Allport, 1937), but these theories do not explain the process of adjustment. Three major theories of QoL and adjustment are reviewed below that do account for how adjustment occurs. These theories provide the basis for the view of QoL and adjustment taken in this study. The proposed mechanisms of adjustment outlined in these theories also determined the way in which the construct was measured in this study.

2.5.1. Control Process Model

The Control Process Model (Carver et al., 1990) is a self-regulation model which states that behaviour is goal directed. A series of hierarchically organised feedback loops allows goals to lead to goal-directed behaviour using comparisons between the actual status and a referent (ideal). QoL is associated with this goal-directed behaviour by means of our assessment of the success or failure of the goal-directed behaviour. This is determined by means of feedback loops which compare the perceived rate of progression towards the goal with the ideal rate of progression towards the goal. The feedback loop consists of the input (the reality or actual goal-directed movement), the reference value (the preferred goal-directed movement), the comparator (the actual comparison between the input and the referent), and the output (goal attainment expectancy). There is a continual attempt to reduce the perceived difference between input and referent by means of a "discrepancy reducing feedback loop" (Carver et al., 2000, p. 22), which leads to goal directed behaviour. Emotion is experienced as a direct result of the comparison between the ideal rate of progression and the actual rate of progression towards goals, by means of a meta-monitoring feedback loop. Positive affect is experienced if progressing faster than expected, in which case QoL is perceived as good and negative affect is experienced when progressing slower than expected towards goals, in which case QoL is perceived as bad. This concept is not completely new; Allport's (1937) theory, too, introduced emotion but as a result of goal (dis) satisfaction rather than the rate of progression towards the goals.

This model is relevant to this study as it explains how adjustment to chronic illness may occur. Goals which become unattainable due to chronic illness can be adjusted. By means of feedback loops, different routes to the same overall goal can be selected by means of choosing other sub-goals. In addition, the same feedback process can adjust the main goal itself. This can happen when main goals cannot be reached by other routes and takes the form of disengagement, which is a healthy response to an unattainable goal. Other goals which are more attainable can then be chosen. The referent goal, the ideal against which reality is compared with, too can adjust. External influences such as life experience or the social and cultural environment can lead to changes in the referent which in turn bring about changes to goal attainment (Carver et al., 1990). Discrepancies in the rate of progression towards goals can be adjusted by altering changes in the progression towards goals (actual) or in the expected rate of progression towards goals (ideal).

According to this theory, adjustment does not occur immediately, rather there is initially persistence at attempting goal achievement. It is only after time and through the lack of achievement that adjustment occurs. Previous experience of similar situations, too, affects behaviour, as favourable past experience leads to an optimistic attitude regarding the current goal and the person may try harder. Conversely, previous bad experience may lead to general doubt regarding the outcome of this behaviour and the behaviour may stop (Carver et al., 1990). This highlights the importance of optimism in maintaining goal-oriented behaviour.

A person with Ménière's disease may initially not be able to pursue their goals or move towards them at the same speed as they were used to and this could lead to the experience of negative affect. This dissatisfaction may wane as over time adjustment to both perceived speed of movement towards the goal (actual and expected) and the goal (referent) itself change, and positive affect may again be experienced.

This theory forms the basis of the definition of quality of life used in this study.

2.5.2. Cognitive Adaptation Theory

The Cognitive Adaptation Theory (Taylor, 1983) offers an explanation as to what occurs cognitively after a crisis such as the onset of an illness. Three reactions to a crisis are proposed. These three reactions are important to this study as they describe the process which people with Ménière's Disease may have gone through or are still going through, after the onset of their illness.

The first reaction is the search for meaning. This may take the form of searching for reasons to explain the occurrence of the illness. Many people need to know why the illness has occurred to them. These reasons help them come to terms with their illness. This process includes both causal attributions and a re-evaluation of one's situation.

Taylor (1983) found in her study with breast cancer patients that positive re-evaluation led to positive adjustment (as measured by interviewer and physician ratings, mood, and well-being). When asked what changes had occurred as a result of their illness over half of her sample claimed to have experienced positive changes. Thirty percent thought they had experienced no changes at all and only seventeen percent claimed they had experienced negative changes. Also, the participant's views of her own adjustment were typically very positive, seeing themselves as not only better adjusted in the present than during the treatment but also better adjusted than before the onset of the cancer (Taylor, 1983; Taylor, Lichtman, & Wood, 1984). This shows a positive re-evaluation of their situation.

Another questionnaire study, which supports this element of Taylor's (1983) theory, compared the positive effects that occur after an illness with the positive effects which may have occurred naturally anyway in a normal population (Andrykowski, Brady, & Hunt, 1993). Cancer patients were matched and compared with healthy participants. Both groups reported similar positive changes, with the cancer group showing a better outlook on two domains. 'Love of spouse' was better for the cancer group with 66% of those with cancer indicating it was better than before the cancer diagnosis and 45% of the control group saying it was better than before a given period of time. 'Satisfaction with religion', too, was higher for the cancer group, with 52% of the cancer group reporting that it was better than before the cancer diagnosis, and 27% of the control group reporting it to be better than before the same point in time. In addition, a review by Affleck and Tennen (1996) showed common positive effects to be 'strengthening relationships, a perception of positive personal change, and a valued change in life's priorities, and personal goals' (p.902). These studies give examples of what sort of positive change may be perceived.

In another study, which aimed to assess the extent to which people perceive positive experiences, two patient groups were compared, a Myocardial Infarction (MI) group and a breast cancer group (Petrie, Buick, Weinman, & Booth, 1999). Those with MI were more likely to report the experience of positive effects than the breast cancer group. For the MI patients the most reported positive effect was 'a health lifestyle change' (68%), the next two most common changes were 'a greater appreciation of life' (28%), and 'improved close relationships' (23%). For the breast cancer group, the most often reported change was 'an improved close relationship' (33%), followed by 'a greater appreciation of life' (27%), and 'a change in personal priorities' (20%). This study indicates that the type of illness may determine the type of positive change experienced by the person. Furthermore, disease severity was not associated with the tendency to report positive change, as no difference in disease severity was found between those who reported positive change and those who did not (Petrie et al., 1999).

Although there may well be disease specific responses when it comes to perceiving positive change, the conclusion drawn from these studies is that positive change is experienced for different illnesses but to varying degrees. This suggests that a population of people with Ménière's disease may well experience positive change as well, although the degree of positive change may differ from other illness populations.

The search for meaning may be a reason why people join self-help groups, as this is a place where they can hear or read about many other people's causal attributions and this may help them to achieve some sort of answer to their own question.

The second response to a crisis, according to the Cognitive Adaptation Theory, is the attempt to regain 'a sense of mastery' (Taylor, 1983). This occurs in response to the loss of control often associated with an illness. As has been mentioned in 'Effects of an Illness' (Section 2.3) the experience of the illness may leave the person with a sense of lack of control over both their life and their illness. This can result in a need to regain control which may be achieved by proactive changes, for example, to diet and/or exercise. Regaining a sense of mastery is important with respect to both the management of the illness and as a preventative measure against anticipated recurrence. Taylor (1983) also shows the close link between the sense of mastery and the search for meaning. In her study of cancer patients, the reasons given for the illness (sense of meaning), although consisting of differing reasons, were all controllable reasons.

Once again, joining a self-help group may well be a way of regaining this sense of control as members gain information about the illness and how to manage it from the group. The members of the Ménière's Society may have joined the group to try to regain control over what may seem to them an uncontrollable situation.

More will be said about control under 'Other factors which influence QoL and adjustment' (section 2.6.).

The third response to a crisis is the need to self-enhance (Taylor, 1983). This need results from the drop in self-esteem experienced with the loss of control after the onset of an illness. Self-enhancement consists of cognitions and behaviours that will help to increase self-esteem. Taylor (1983) proposes downward social comparison as a means of countering the drop in self-esteem, as most of the women in her study said that they were better off than someone else. No study has explicitly looked at self-esteem before and after joining a self-help group and this would be a difficult thing to measure as it would have to take place in a naturally occurring situation rather than a contrived group situation. No one has suggested that only people low in self-esteem join self-help groups or that by the time they leave the group they have high self-esteem. However, it has been suggested that self-help groups would only benefit those low in self-esteem and this group would benefit more from downward comparison than those high in self-esteem, in addition, no negative effects of upward comparison have been found for this group (Gibbons et al., 1989). This, and the need to increase self-esteem, with the addition Taylor's study where downward comparison was used to increase self-esteem it is possible to see how a self-help group may assist in increasing self-esteem. More will be said about the effects of self-esteem under 'Other factors which influence QoL and adjustment' (section 2.6.).

This theory highlights three important aspects of the adjustment process; the search for meaning, perceived control, and self-esteem.

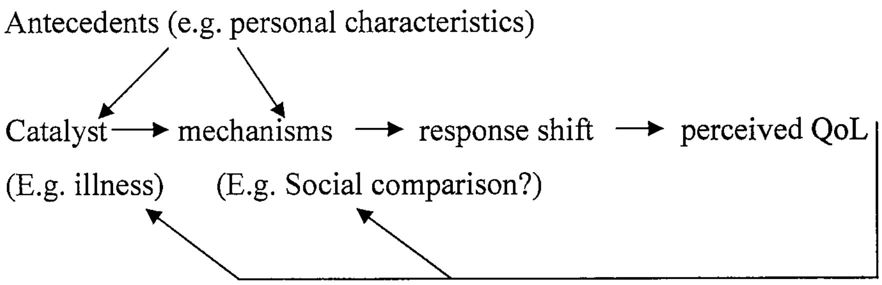
2.5.3. Response shift

Response shift is the name given to the internal process of adjustment by Sprangers and Schwartz (1999). It refers to change that occurs to a person over time, after a crisis, after the onset of an illness, or a shocking experience (Schwartz et al., 2000). This approach is important to this study due to its explanation of the mechanics of cognitive adjustment which can occur over time or as a result of experience. This is applicable to this study as the participants are not engaged in therapy or any other activity which may cause change. Rather their adjustment occurs naturally over time while belonging to a non-directive self-help group.

Based on the assumption that people want to feel good about themselves, response shift offers an explanation for how we recover from a crisis (Sprangers et al., 1999b). Their proposed model gives a clear explanation for how adjustment occurs. As with the Control Process model, adjustments occur, both consciously and unconsciously (Gibbons, 1999), by means of feedback loops. The model consists of five elements (see Diagram 1). Initially the *catalyst* occurs; this is an event or action which initiates the process of the response shift. It is the occurrence/phenomenon which alters the status quo, for example, the onset of Ménière's disease. It could take the form of a treatment, an event, a car crash, or the onset of an illness (Schwartz et al., 2000). What effect the *catalyst* has on the person is dependent to a large extent on the *antecedents.* These constitute individual characteristics such as demographic factors, personality traits, personal circumstances, and expectations. The meaning the person gives to their new situation is determined partly by their personal characteristics. After the *catalyst* has occurred the *mechanisms* will be employed, the mechanisms help bring about the response shift. Examples of the *mechanisms* are proposed as: coping styles, social support, adjustments to goals, changes in emotion, expectations, and, in this study, social comparisons are proposed. Which *mechanisms* are used will again be dependent on the *antecedents*. Different *mechanisms* can have different effects on the outcome. The effects of the *mechanisms* produce a *response shift* (a cognitive change) which results in an altered view (Sidell, 1997; Sprangers et al., 1999a). Once this dynamic process has stabilised the altered view of the situation allows a new or different *perceived quality of life*. This process is iterative, with the new *perceived quality of life* feeding back to the interpretation of the *catalyst* where other *mechanisms* may be employed (Schwartz et al., 2000). Optimism, control and self-esteem, already highlighted as important to adjustment by Carver and Scheier (1990) and Taylor (1983), are proposed as precursors to the response shift, although no further explanation is given (Sprangers et al., 1999b).

The theory is based on the assumption that we try to view ourselves and the world positively, with the consequence that response shift is usually adaptive, although it is possible that it could be maladaptive (Schwartz et al., 2000). This is proposed as occurring, for example, when downward social comparison may lead to an over-identification with the worse-off other and a negative response shift could result (Sprangers et al., 2000).

Diagram 1: The process of response shift



(Sprangers et al., 1999b)

Response shift results in a new perceived QoL

Although one may argue that response shift may occur in any number of ways it is one of those enigmatic concepts which is difficult to assess in its entirety. Sprangers et al. (1999) propose that it can occur in any one of three ways (Sprangers et al., 1999b; Sprangers et al., 1999a). The first way is the re-evaluation or 're-conceptualization' of one's goals. For adjustment to occur in this way goals that were viewed as important before are re-evaluated and now become unimportant. The change brought about by the mechanisms may mean that old goals are no longer seen in the same way and different goals are seen in a new light and become important. For example, the more negative aspects of the goal are focused on, so that instead of seeing running as a pleasurable exercise it is now seen as inducing vertigo, and unpleasant, as an attack out of the home would be frightening.

A change in values is the second way that Sprangers et al. have proposed that response shift may occur. Implicit in change in goals, it has nonetheless been singled out as a way for adjustment to occur in its own right (Sprangers et al., 1999a). For adjustment to occur this way it is what the person feels is important to them that has changed. The goal may still be seen as the same goal but it is no longer a valued goal. For example, while long distance running may still be seen as pleasurable it may cease to be seen as important, while spending time with family may become very important.

The third method, by which response shift may occur, as proposed by Sprangers et al. (1999), is a change in internal standards of measurement. This means that the standards by which we judge something to be good/bad or important/unimportant have changed. This can be likened to using a different strength lens on a camera, or using a different projection on a map, in this way the same object or goal appears different due to the change in the way it is measured. Under the new scale of measurement, something we valued less before appears more valuable. For example, how a person with Ménière's disease judges their situation as satisfactory may alter so that after a change in the internal standards of measurement the calibration of their rating gives a better score than before the change.

This theory provides the basis on which to ground the understanding of the adjustment process to Ménière's disease.

2.6. Other Factors which influence QoL and Adjustment

Some factors have an additional influence on the way quality of life is perceived. The effects of these factors are therefore important to consider when measuring quality of life, and may prove relevant to the members of the Ménière's Society. There are many of these factors, however, only those found to be relevant to adjustment to chronic illness in the literature are reviewed here.

2.6.1. Demographic Characteristics

Demographic characteristics, such as age and sex, influence the way in which QoL is perceived (Sidell, 1997). Different goals are valued at different stages of life, and socially, other people's reactions to you differ at different stages. In addition, certain age groups and sexes are more prone to develop certain illnesses and so will have different experiences to other age groups. As Ménière's disease tends to emerge later in life there may be age-related factors which will influence adjustment.

Age affects different aspects of QoL differently; deterioration in physical health and functioning is not necessarily accompanied by a reduced subjective QoL. For example, two studies using the SF-36, a measure of QoL that assesses day-to-day functioning, have found a decrease in QoL with age. The first study used a non-clinical sample and found older age to predict poorer QoL, especially on the physical functioning, role limitation, and general health perception domains (Brazier et al., 1992). In the second study of people with hypertension, older age again led to lower QoL ratings, except on the mental health domain which showed an increase with age (Ware et al., 1995). However, amongst the findings in a longitudinal study on women with breast cancer, age was found to negatively predict mood; those of older age reported better mood (McCaul et al., 1999). In another study of the subjective aspects of QoL (life satisfaction), it was again the older adults who showed better well being (Keyes et al., 2002). Finally, another study of subjective QoL using the SEIQoL (The Subjective Evaluation of Individual QoL is a subjective, interview-based measurement tool) also found the elderly recorded higher QoL levels than the younger adults (O'Boyle et al., 1994). This, once again, shows the importance of measuring both objective and subjective aspects of QoL when determining QoL.

Many QoL studies show that sex can predict QoL (Sidell, 1997). Women tend to experience a lower QoL than men. Evidence for this is provided by a study which found that women in the general population experienced lower QoL than men (Brazier et al., 1992). In another study, also in the general population, women had lower QoL ratings on all domains except for general health perceptions (Jenkinson, Wright, & Coulter, 1993). These studies show sex differences in a normal population, however, whether this pattern emerges for an ill population or people with Ménière's Disease has yet to be determined.

Factors such as marital status and socio-economic status, too, affect QoL. In a study with women with breast cancer it was the married women who had lower QoL (McCaul et al., 1999). In addition, those with a lower socio-economic status give lower QoL ratings (Brazier et al., 1992).

The cultural and social context, too, affect QoL. Environmental effects such as culture influence our self-concept as it develops, which in turn influences our personal QoL construct (Carver et al., 1990; Good, 1994). Our social context also affects QoL to the extent that the referent (our ideal goals) with which we compare our situation may be influenced by what goes on around us (Carver et al., 1990; Good, 1994; Kleinman, 1995; Mombers, De Vries, & Van Heck, 1997).

The above factors, other demographic factors not mentioned here, and personal characteristics influence the way QoL is perceived, however, it would be impossible to control for all of these factors. Only those deemed to be the most important for inclusion in this study were selected.

2.6.2. Disease Severity

Although adjustment may allow a higher personal rating of perceived QoL than medical professionals and family members, illness none-the-less affects QoL. Those who have adjusted may give a high rating as their focus has moved beyond the negative effects of the illness to the subjective which have shown a perceived improvement. These people, along with those not yet adjusted are still very much aware of the impact of the illness on their lives and how their life has changed. In addition, those illnesses with more severe symptoms may result in worse perceived QoL than those with less severe symptoms or prognoses.

Disease severity is closely related to the perceived threat brought on by the illness. As mentioned in 'Effects of an illness' (section 2.3), disease severity leads to a drop in QoL before adjustment occurs. This was shown in a study which assessed QoL and physical health, where those with chronic physical problems had lower perceived QoL than did those with less serious problems (Brazier et al., 1992). In addition, comparisons between four chronic illnesses showed perceived QoL to drop as the seriousness of the illness increased (Garratt, Ruta, Abdalla, Buckingham, & Russell, 1993). This study showed that those with lower back pain experience a lower QoL than those with varicose veins, which is usually not considered a serious illness (Garratt et al., 1993). Prognoses differ with the type of chronic illness and from person to person. The perception of the severity of the prognosis may, again, affect outlook on QoL. Evidence was found for conditions with more severe prognoses leading to lower QoL in a study which compared two healthy populations with three different disease populations (Spitzer et al., 1981). No published study has yet assessed the QoL of people with Ménière's disease using standardized QoL measures and so to date no immediate comparison can be made between people with Ménière's disease and people with other illnesses.

The phase of the illness can be important too. Some illnesses, like Ménière's disease, are intermittent, and most chronic illnesses are progressive. The bad stages of an intermittent illness are associated with greater physical interference with goal attainment, as well as greater psychological stress and anxiety. The phase of the illness is important to Ménière's disease, which is intermittent. However, as this illness is punctuated with periods of remission and some people eventually experience a 'burn out' of the symptoms, the duration of the illness may not be associated with perceived QoL but rather the phase of the illness. The progressive nature of the illness means that those who have had the illness for longer are more likely to experience a worse QoL. In addition, the lack of a cure or the uncertainty of the success of the treatment, too, affects QoL (Sidell, 1997). Knowing your illness will get worse and that your QoL may be worse than it is now can be stressful in itself and affect your outlook on life.

2.6.3. Self-esteem

Self-esteem can be described as “a judgement about one’s own worth” (Fitzgerald Miller, 1992, p. 397). It influences our perception of life, and in turn, our perception of life may influence our level of self-esteem. Taylor (1983) introduced this concept in relation to reactions to a crisis, as there is a tendency to attempt to increase self-esteem after the onset of a crisis. Schwartz and Sprangers (2000), proposed self-esteem as a precursor to response shift.

The level of self-esteem held by a person influences their perception of QoL as it influences the interpretation of events. People with high self-esteem experience more positive affect, interpret events positively, and expect more positive outcomes, whereas people with low self-esteem tend to interpret events more negatively (Aspinwall & Taylor, 1993). People with low self-esteem, also, do not have the same confidence as a person with high self-esteem and may experience a sense of self-doubt (Fitzgerald Miller, 1992). High self-esteem correlates with adjustment to illness, with those high in self-esteem experiencing less uncertainty and better adjustment. People with high self-esteem are also more likely to be proactive in the management of their illness (Taylor, 1983). In this way, self-esteem is intricately linked to QoL and adjustment.

We have a tendency to feel positive about ourselves and to try to raise our self-esteem (Beach & Tesser, 2000), consistent with Taylor’s claim that self-enhancement results after a crisis. Wills (1981) proposed downward social comparison as a method by which the level of self-esteem may be raised. It is the comparison with worse-off others that makes us feel good about ourselves and raises self-esteem (this was also proposed by Taylor in her Cognitive Adaptation Theory). More will be said about this in the chapter on social comparison (Chapter 3).

Self-esteem can be affected by differences between the ideal state and reality. As an illness brings about uncertainty and the reduction in physical disability this can bring about a drop in self-esteem (Fitzgerald Miller, 1992; Wills, 1981). Evidence for this comes from a longitudinal study of women with breast cancer, where self-esteem was found to negatively correlate with uncertainty (Bogart & Helgeson, 2000). The drop in self-esteem then results in a need to increase it (Fitzgerald Miller, 1992; Wills, 1981).

2.6.4. Perceived control over illness

Control over illness refers to the extent to which a person feels they have control over their illness and its treatment or management. Control is "a belief that one has at one's disposal a response that can influence the aversiveness of an event" (Thompson, 1981, p. 89). Control was introduced by the Cognitive Adaptation Theory as a reaction to a crisis and proposed by the Response Shift model as a precursor to response shift. The disruption caused by the onset of an illness can result in a lowered perceived control over life and the illness and this brings with it a sense of uncertainty and vulnerability brought on by the loss of control. A person with Ménière's disease may experience a loss of control, due to not only the vertigo, tinnitus and hearing loss themselves, but also because of the unpredictable nature of the attacks. However, we have a tendency to try to regain control (Taylor, 1983).

High control has been associated with better adjustment. There are two broad types of control, personal (internal) control and vicarious (external) control. Personal control is where we feel we are in control and what we do determines the outcomes of certain situations. Vicarious control is where we feel that others have control over our situation. In a study of people with epilepsy, mastery (control) and QoL (as measured by the WHOQoL on six domains; physical, psychological independent, social relationships, environment, and spirituality) were significantly related (Amir, Roziner, Knoll, & Neufeld, 1999). In this study, it was internal (personal) control which was associated with better QoL scores. This indicates that perceived control is significantly and positively associated with QoL. Both personal and vicarious control were found to be significantly associated with adjustment (as measured by the Global adjustment to illness scale, two locus of control over illness scales, a mood scale, self-esteem, an index of well-being, and a scale of marital adjustment) in a women's cancer study which tested the effects of control and attributions on coping and adjustment (Taylor et al., 1984). In another, longitudinal, study with coronary heart patients (Helgeson, 1992), participants were interviewed to assess the relationship between perceived control and adjustment (as measured by the psychosocial adjustment to illness scale which measures adjustment on seven domains, health care, vocational environment, domestic environment, sexual relationship, extended family relationship, social environment, and psychological distress). In this sample nearly half the participants felt they had a lot of control and most of the remainder felt they were 'somewhat' in control, the remainder feeling they had 'a little control' or 'none.' Results again showed that personal feelings of control were better associated with adjustment than vicarious control, showing agreement with the study by Amir et al. (1999) described above. However, perceived control was found not to be associated with prognosis. Those with a poor prognosis but with a greater sense of personal control showed better adjustment, the crucial point being that the prognosis is not important to adjustment but rather whether the situation is viewed as controllable or not.

In her review, Thompson (1981) further divides control into four types of control, one of which is behavioural control. This is where we can carry out an action to maintain control. This may take the form of exercise or altered diet etc. In this vein, it is possible that joining a self-help group may be considered to be behavioural control. Cognitive control involves the processing of information or reinterpretation to help maintain control. Information control refers to having the information necessary to maintain control, and retrospective control refers to causal attributions. Self-help groups may provide informational control through the information they provide to their members. Knowing we have behavioural control has a positive effect on QoL as it leads to a higher tolerance threshold, enabling us to deal with situations that are more difficult. This in turn lessens the anxiety associated with the unpredictable nature of some illnesses. In the study by Taylor et al. (1984) mentioned above, retrospective and information control were not significantly related to adjustment. However, cognitive and elements of behavioural control were significantly related to adjustment. With regard to behavioural control, control over exercise and leisure time were significantly related to adjustment, whereas control over diet and management of treatment were not related to adjustment. This suggests further distinctions within the perception of control. Some people feel they have control over the illness but not the treatment and for others it is the reverse (Helgeson, 1992).

There are no reported statistics for control over illness for people with Ménière's disease; however, feelings of lack of control may be the motivation for a person with Ménière's disease to join the Ménière's Society. This may be a form of behavioural control, where they may feel it can help them to regain some control over their situation.

2.6.5. Optimism

Optimism is the tendency to have hopeful expectations about future events and the tendency to expect successful goal attainment. It has already been introduced in the Control Process model as having an influence on goal-directed behaviour, and is proposed by the Response Shift model as a precursor to response shift. In support of this, optimism was found to lead to successful goal attainment in a study with undergraduate students (Scheier & Carver, 1985). In this study, optimism was found to correlate positively with 'a positive reinterpretation' and negatively with the number of reported physical symptoms, indicating that optimism is associated with better perceived health.

The relationship between QoL and optimism may be stronger in situations where chronic illness is present, as the persistence and motivation associated with optimism is all the more important in overcoming problems associated with chronic illness (de Ridder, Schreurs, & Bensing, 2000). In an interview study where women with breast cancer were interviewed prior to surgery and then again at ten days, three months, six months, and one year post surgery (Carver et al., 1993), optimism was associated with active coping before surgery, acceptance of the situation, and use of humour to assist coping up to six months after surgery. It was inversely associated with denial, which indicates that the optimistic person is more likely to face up to the reality of the illness (Carver et al., 1993). This study also showed that optimism was inversely associated with distress, and less likely to lead to helplessness. In another study with undergraduates, optimism was again indirectly associated with QoL, as it was associated with problem focused and approach coping, which can lead to better QoL

(Scheier & Carver, 1987). An optimistic person is more likely to get actively involved in the management and treatment of his/her illness, and to expect the treatment and other coping methods to be a success. Perhaps the act of joining the Ménière's Society can be interpreted as an indication of optimism as it shows an interest in self-management.

In a study of people with Parkinson's Disease and Multiple Sclerosis (de Ridder et al., 2000), although both groups showed similar levels of adjustment (as measured by the Sickness Impact Profile) they differed in the relationship between optimism and QoL. Optimism was more important for those with Multiple Sclerosis. These patients showed an inverse relationship between optimism and depression, and optimism was also related to better adjustment physically, socially and psychologically. The Parkinson's disease patient group showed optimism to be associated with avoidant coping and better adjustment on only the psychological dimension. These findings show that the importance of optimism may be illness dependent, as optimism had a different effect in people with Multiple Sclerosis than those with Parkinson's disease. However, this study shows that, irrespective of degree of importance, optimism is still associated with QoL. In a previous study with people with Ménière's disease (Andersson, Hagnebo, & Yardley, 1997) optimism was measured and found to have a mean score of 20.7, using the LOT (Scheier et al., 1985) which when compared to a sample of women with breast cancer is low (Carver et al., 1993).

There is evidence that the above three factors, namely, self-esteem, control and optimism, are all inter-linked. In a study of optimism in undergraduate students, Scheier et al., (1994) found optimism, self-esteem and mastery (control) to be significantly correlated, with those high in optimism being more likely to be high in self-esteem and control. The perception of positive change has also been linked to optimism, where the tendency to expect positive outcomes also leads to a tendency to interpret events positively (see Affleck & Tennen, 1996, for a review). This shows that these three psychological factors are likely to be important for people with Ménière's disease.

2.7. Summary

The understanding of QoL and adjustment taken in this study is based on the Control Process Model, the Cognitive Adaptation Theory, and the Response Shift Model. Perceived QoL is seen as incorporating both functional (the influence of health and illness on day-to-day functioning) and goal-oriented (the difference between the ideal and actual rate of progression towards goals, and happiness) elements. Adjustment is described as a process by which perceived QoL adapts to the changes associated with chronic illness. It occurs in relation to the ideal goals, ideal goal progression and perceived goal progression by the methods described above; a change in goals, values, standards of measurement, and perceiving positive change. This process involves the use of mechanisms that involve the regaining of perceived control, self-enhancement, and the perception of positive change. This approach to QoL means that the adjustment level must be determined by both objective and subjective QoL measures, and the extent of perceived positive change. The importance of other factors which influence QoL and adjustment have also been highlighted, these factors include self-esteem, optimism, and perceived control over illness.

2.8. Conclusions

To conclude, the diverse nature of QoL has been highlighted, indicating the need to measure its different aspects in order to tap into the complex whole. Other important, influencing factors and the part they play have been reviewed. The conclusions drawn from the review of the literature have led to the definition of QoL and measurement strategies.

The level of QoL at any given time can be used to determine the level of adjustment achieved as the adjustment occurs to the perceived QoL. Measurement of adjustment should include more than one type of measure in order to ensure all important aspects of QoL and adjustment are covered. Measures should include an objective measure to measure the impact of physical health on the ability to function on a day-to-day basis (functional QoL). A second definition of QoL can be derived from the Control Process Model, i.e. QoL results from the difference between the actual rate of progression towards goals and the ideal rate of progression. Hence, a subjective measure of QoL can be used to measure the extent of the interruption of moving towards goals. Thirdly, a measure to determine the degree of perceived positive change experienced since the onset of the illness should be included. According to the Cognitive Adaptation Theory this occurs after the onset of a crisis and is therefore an indication of adjustment. These three areas of QoL will give an indication of the level of adjustment achieved. To determine predictors of adjustment over time it is necessary to measure QoL at two points in time to examine change in QoL relative to the possible predictors. By measuring QoL over time, it is also possible to measure response shift. Using retrospective tests at Time 2 as to how respondents now feel they were at Time 1 a comparison between how they were then (at Time 1), and how they now feel they were then (Time 2) can be made (i.e. the ThenTest approach which is described in detail in Chapter 4 and 7). This allows a comparison of the measurement of QoL recorded with two potentially different standards of measurement as they were made at different times; this is a measure of response shift (Sprangers et al., 1999a).

One of the main aims of this study was to assess the role social comparison may play in adjustment. However, due to the important part self-esteem, control, optimism, and demographic information play in QoL and adjustment, it will also be necessary to measure and control for these factors. In this way, it can be determined whether social comparison does have a significant effect even after they have been controlled for.

This chapter has laid the foundation for the method used to go about measuring adjustment. The next chapter takes a look at social comparison theory and reviews the literature on social comparison and its effect on the way individual situations are perceived.

CHAPTER THREE: SOCIAL COMPARISON THEORY

3.1. Introduction

The question this study addresses is whether social comparison influences adjustment to chronic illness and so, having reviewed QoL and adjustment in the previous chapter, there now follows a review of the social comparison theory and literature. This chapter explains what social comparison is and why it is considered to be a good theory for explaining some of the processes that occur within a self-help group. Most importantly this chapter explains how social comparison may come to influence adjustment.

Research to date shows that social comparison can have a strong influence on the perception of various aspects of life. The situation, abilities, behaviour, and/or opinions of other people (the targets) are used as a yardstick to determine whether our own situation, abilities, behaviour and/or opinions are extreme, better, or worse than others'(Festinger, 1954; Tennen, McKee, & Affleck, 2000). The knowledge gained from this comparison enables a person to moderate their emotions, maintain their self-esteem, and judge their abilities (Aspinwall et al., 1993). The important implication here is that perhaps social comparison may also influence adjustment to chronic illness.

While the literature on social comparison is vast, the main focus of this chapter will be on previous studies which have assessed the effects of social comparison as an independent variable. Studies which have manipulated aspects of social comparison as a dependent variable will not be reviewed in detail, but will be mentioned only where it is relevant to this study. This is because the focus of this study is on the effects of social comparison on adjustment, where social comparison is a possible predictor variable.

The review begins with a description of the theory, and then relates the theory to the context of self-help groups. Finally, a review of the studies which have looked at the influence of social comparison on health, psychological factors, and response shift will be discussed.

3.2. The Theory

In 1954, Festinger published a paper in which he proposed that we have a *need* to self-evaluate in order to determine what behaviour is appropriate, performed well, or not performed well. Ideally, this self-evaluation requires an objective standard against which to judge our own behaviour. However, as objective standards are not always available to provide information, comparing ourselves with others is a way of obtaining that information. This paper was notable as it initiated a ripple of subsequent studies by other researchers who have since developed the theory further. As people who join self-help groups are likely to compare with one another this theory may offer an explanation for what occurs within a self-help group.

Social comparison, as is implied in the name, involves the process of comparing oneself with another person; this other person is referred to as the 'target.' The most helpful comparison comes from similar targets or those with similar problems (Buunk & Gibbons, 1997; Festinger, 1954; Mollerman, Pruyn, & van Knippenberg, 1986; Schachter, 1959). The similarity of the target is important as if the target is too different there is no basis on which to make the comparison in the first place (Gibbons & Gerrard, 1991). However, too much similarity, too, can be a problem if the comparison is interpreted negatively as this could be threatening to the 'comparer,' i.e. the person doing the comparing (more will be said about this later).

When we socially compare, the comparison may take place in different directions: upward (with someone better off), lateral (with someone about the same), or downward (with someone worse-off). When we compare ourselves with those who perform better than ourselves we are engaging in upward comparison. Both Festinger (1954) and Schachter (1959) proposed that we mostly compare in a lateral (those similar to ourselves) and upward (those better off than ourselves) direction although there have been further studies which have contested this, as will be discussed below.

The 'dimension' is that aspect about the target which is being compared - for example, how a person copes with their Ménière's disease as opposed to how well they can swim or how stressful their job is. The dimension selected for comparison may change if the comparer is trying to increase the distance between themselves and the target. This can occur when the original dimension is perceived as threatening – when, for example, the comparer may feel that they will get worse and become like the worse-off other or they may feel dejected that they are not as well off as the better off other. If there is the potential for becoming like the threatening target, differences may be sought on other dimensions in order to reduce the perception of becoming more like the target. So, for example, should a target's experience of Ménière's disease sound too unpleasant the comparer may seek differences in other dimensions such as age, sex or physical fitness in order to refute the negative similarity on the illness severity dimension. Similarly, targets with a different problem can enhance that problem dimension for a comparer for whom the dimension is not a problem (Gibbons, 1999). In Gibbon's study female college students who were experiencing academic problems reported fewer physical problems after being interviewed by a disabled person than those participants who were interviewed by a non-disabled person. This study shows that social comparison can have the effect of reducing the importance of one's own problems. Since the target's problem, which is a different problem, is worse for the target, the comparer feels healthier than the target on this aspect. In this way the illnesses (or the problems) of other people will enhance dimensions in the comparer that until then may have been taken for granted. For example, should a person with Ménière's disease find themselves in the presence of a cancer patient, the person with Ménière's disease may feel that their problems are not so bad relative to cancer.

Schachter (1959) introduced the element of threat to the theory. He proposed a threat/affiliation theory where we feel the need to be with and compare ourselves to others (the same or better) more when we are under some sort of threat than when we are not under threat. Under threat we experience uncertainty, which in turn drives us to try to solve the issue at hand and moderate our emotional reaction (Wood & Van der Zee, 1997). An illness can be interpreted as a threat, and as expected, social comparison does occur amongst those with illnesses (Tennen et al., 2000). Mollerman (1986) found evidence for this in a study with cancer patients, whose need for social comparison increased as contact with medical professionals waned and, in this situation, the social comparison resulted in reduced feelings of uncertainty. This, in turn, explains the need to hear from others with the same illness. In a situation where one feels uncertain, social comparison can provide information on how to cope (Gibbons et al., 1991) and provides reassurance that the comparer is not the only person experiencing these problems (Helgeson & Mickelson, 1995). This makes social comparison an appropriate theory to apply to the self-help group as self-help group studies (reviewed in Chapter 1) have found that self-help groups give 'support and information' (Borkman, 1997; Kurtz, 1990; Kurtz, 1997), and 'universality' (Helgeson et al., 1995), that is, knowledge that you are not the only person with the illness. Indeed, knowledge that you are not the only person is one of Yalom's (1970) twelve curative factors for therapeutic groups (reviewed in Chapter one). This idea, that social comparison may occur within self-help groups, is not new, as it has been suggested by both Gibbons and Gerrard (1991) and Medvene (1992), however, there are no studies which have studied the social comparison processes within an existing self-help group.

There have been further developments in social comparison theory regarding the motives for the comparison. Wood et al. (1985) proposed two functions of social comparison. The first, self-evaluation, is consistent with Festinger, where we evaluate our standing on a given aspect. The second function is self-enhancement, to increase positive affect by inflating self-esteem (Wood, Taylor, & Lichtman, 1985); we can experience positive affect from the social comparison.

Festinger's original theory was a purely social one. However, Wood et al. (1985) claimed that social comparison is not solely a social process as Festinger originally proposed, but is also cognitive. When we encounter threat, we attempt to mitigate the threat and accompanying misfortune with cognitions. Firstly, hypothetical worse-off worlds may be imagined, or positive aspects of the misfortune may be sought. In addition, the person's standards may be adjusted so that their current condition/situation no longer seems so bad. Finally, the person may only concentrate on dimensions on which he/she is not disadvantaged (for example, job satisfaction instead of illness progression) thereby appearing advantaged (Wood et al., 1985). All the above reactions are cognitive rather than social as they occur within the individual and do not involve another person. Social comparison is also not seen by Wills (1997) as a coping mechanism but rather as part of the cognitive adjustment process. This is because it does not involve effort, and by Lazarus and Folkman's (1984) definition coping involves effort (Tennen et al., 2000).

In 1981 Wills developed his downward comparison theory. He argued that the function of social comparison was to increase subjective well-being. In this paper he concluded that social comparison does indeed increase after the onset of a threat, as proposed by Schachter (1959), but he determined that the comparison direction was downward and not upward as previously claimed. Downward comparison was preferred as it results in positive feelings (increased subjective well-being), and this positive affect repairs the negative affect induced by the threat itself and the uncertainty that accompanies it. Wills proposed that we can actively choose downward comparison to improve subjective well-being and, if necessary, derogate the target in order to increase the perceived social distance to prevent the comparison becoming too threatening (again emphasising the cognitive aspect of social comparison). Downward comparison shifts the focus from the self and one's own problems (Wills, 1997) and may lead to positive adjustment to the illness (Tennen et al., 2000). So far, this link to adjustment is theoretical and has not yet been empirically demonstrated. On the other hand, should downward comparison become too much of a focus the person could over-identify with the worse–off target and believe that they too could deteriorate. People who belong to a self-help group would be in contact with both those who are better-off and those who are worse-off. Downward comparison theory would hold that these members would selectively compare with only those who were worse-off and try to avoid those who are better-off.

Wills (1997) suggested that downward comparison may only be beneficial when the situation will not deteriorate. This is because downward comparison includes two interpretations about similarity. Firstly, it compares 'fate' similarity, which refers to the current similarity. If the comparer and the target are not currently similar there will be an increase in subjective well-being as the comparer is better off at that moment. Secondly, downward comparison may induce 'future' similarity, where there is a chance that the person will become more like the downward target in the future. In this case negative affect is experienced if the target is worse off. If there is little or no chance of this happening then the person will experience an increase in subjective well-being and positive affect. Of course, there are many illness self-help groups in which the illness is progressive. This development of the theory would suggest that people with progressive illnesses who also belong to a self-help group would not enjoy or benefit from downward comparison and therefore might avoid downward comparison. However, Wills also warned that downward comparison leads to conflicting emotions, as people feel lucky and uncomfortable at the same time (Wills, 1981); lucky that they are not as badly off as the target but also uncomfortable for having these feelings about another person. This also has implications for illness self-help groups where downward comparison and its possible negative effects in this situation may be unavoidable.

Gibbons and Gerrard (1991) agree that downward comparison leads to an increase in subjective well-being which results in positive affect. The person realises that he/she is not as badly off as the target and this boosts self-esteem. By comparing with those worse-off not only does one realise that in actual fact you are not so badly off after all, but also one does not feel quite so alienated by the illness, as there are others who have it too, others who are worse off. The person feels that they are not so unique and strange. Once again, this can be easily applied to a self-help group where one of the benefits is the realisation that you are not alone in the difficulties you have.

In their cancer research, Taylor, Aspinwall, Guiliano, Dakof and Reerdon (1993) found downward comparison to be prevalent as most participants felt they were better off than others were, which implies a downward comparison. Other studies, too, have found positive effects for downward social comparison. Schulz and Decker found support for downward comparison in their study with disabled patients (Schulz & Decker, 1985). These participants found themselves better off even when the target was not disabled. This led the researchers to conclude that it is not just the target which is important but selective characteristics which make the comparer look good. In another study with cancer patients, Wood et al. (1985) found that downward comparison was the most common type of comparison and also the preferred type, as downward comparison was made even when upward targets were available. These studies show that downward comparison can be beneficial even when the dimension is illness oriented, contrary to what Wills (1997) suggested.

A notable paper by Taylor and Lobel (1989) suggested that social comparison may not be as simple as 'either upward or downward,' but that the same individual engages in both, but for different reasons. They proposed that upward social comparison results in social contacts and the gaining of information about their situation. This is because those doing better are considered better qualified to give information than those who are not doing as well. However, they proposed that downward comparison is not used for gathering information but for self-enhancement as it results in positive affect. Bogart and Helgeson (2000) found support for this in their breast cancer study, which showed that upward comparison led to information whereas downward comparison led to self-enhancement. Helgeson and Taylor (1993) also found that downward comparison served an evaluative function while upward affiliation provided information in a study with patients partaking of a cardiac rehabilitation program. Again, they found that patients rated themselves as better off than most despite the fact that a substantial percentage of the sample (40%) said that they did not compare with others at all. The upward affiliation is inspiring and informative which means that it fulfils both the emotional and problem solving needs. Wills (1991), too, believes that information can only be learnt from upward comparison as is evident in his paradox which is apparent in each comparison direction. This states that for upward comparison although the self-concept can change due to the information available the information is also unfavourable emotionally to the self. Similarly, for downward comparison while it produces positive affect it may not change the self-concept as the information is not as useful.

Social comparison theory developed further with the work of Buunk, Collins, Taylor, Van Yperen and Dakof (1990) who proposed that there is a lot more to upward and downward comparison than previously thought. They maintained that it is not the direction which leads to a change in affect but the *interpretation* of the comparison information. They proposed that both upward and downward comparison can be interpreted either positively or negatively. Upward comparison can be interpreted positively when feelings of hope are expressed in comments such as, 'perhaps I too could be like that'. Alternatively, upward comparison could be interpreted negatively when the person feels like giving up as they feel they could never be like the comparison target. Feelings of helplessness may then be experienced. Downward comparison can be interpreted positively when the person feels 'I'm doing OK' or 'I am lucky' after a comparison with a worse-off other. The person may experience positive feelings such as gratefulness and a sense of luck. Alternatively, downward comparison may be interpreted negatively, 'Oh, that is how I'm going to be in the future.' The person may then experience negative feelings like depression. Buunk et al. found that, for their cancer patients, a comparison which produced a positive affect was the most common type of comparison whether it was in an upward direction, where 78% felt good, or a downward direction, where 82% felt good. In their second study, with married people, positive downward comparison was most common (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990). Buunk and colleagues therefore proposed the Identification/Contrast model (Buunk & Ybema, 1997) which states that what determines the way in which the comparison information is interpreted is whether the person identifies with or contrasts themselves with the target. Identification with the target leads to feeling there is the potential to be more like the target in the future. Identification with an upward target will produce hope and comfort and this will lead to positive affect as the person concentrates on the similarities between themselves and the better-off target. Downward identification, on the other hand, will lead to negative affect as the person is focusing on the similarities between themselves and the worse-off target and the person realises that it is possible to decline. Identifying with a downward target may lead to avoidance and not bothering to cope (Van der Zee, Buunk, Sanderman, Botke, & Van den Bergh, 2000). Contrasting with the target is where the person identifies differences between themselves and the target. A person who contrasts himself or herself with a better-off other is looking at the differences and will experience negative affect. Contrasting with an upward target can be interpreted as a threat while contrasting with a downward target will be comforting as the person then sees himself or herself as different from the worse-off target. Contrasting with a downward target means the person has found differences between themselves and the worse-off other and this will lead to positive affect.

The Identification/Contrast theory implies that the most healthy and helpful combination is upward identification and downward contrast. However, whether one contrasts or identifies may be related to dispositional characteristics (Buunk et al., 1990). The next step would be to see if one could influence whether one contrasts or identifies with the target. Collins (1996) proposed that, although people may evaluate themselves as not doing so well relative to the target (upward contrast), they can still experience positive affect as they now have important information . Gibbons and Buunk (1999) later added a third function of social comparison. Although they agreed that the aim is to gather information about the self (like Festinger and Schachter), and to self-enhance, or to feel better (Wood et al., 1985) they propose a third function, self-improvement, to become better.

Brickman and Bulman (1977) claimed that people will actually avoid a social comparison which makes them look worse, i.e. upward comparison. They propose that people may choose to avoid social comparison as this is seen as a public announcement of their status on a certain domain and this may expose their inferiority which would result in negative feelings and lower self-esteem. For example, when upward comparison is negative attempts are made to avoid the comparison or render it meaningless. In a series of four studies with high school and university students, those who felt they were worse off tried to find ways in which they were different to the better-off target and thus render the social comparison meaningless due to the lack of similarity between the self and the target. They, in fact, found positive affect to be experienced when the upward target was dissimilar. The better-off person may also not want to engage with a downward target due to the negative affect they may create in the downward target. They proposed that if everyone were equal then no one would feel any negative effects from comparing, however, this situation would also produce the least positive affect, as one is never superior. Of course, this contradicts the other theories which have proposed that upward comparison leads to positive affect as it instils hope (Buunk et al., 1990; Taylor & Lobel, 1989).

There is also either a reluctance to admit to social comparison or a lack of awareness of its occurrence as we are all socially comparing at some time (Gibbons & Buunk, 1999) and yet in some cases people will not admit that they are socially comparing. In their study, Helgeson and Taylor (1993) found that 40% of their cardiac participants said they had made no social comparison at all. This they found strange as social comparison should be greatest after the onset of an illness (Helgeson & Taylor, 1993; Wills, 1991) and one would have thought that these newly diagnosed patients would socially compare a great deal. The reasons for the low percentage were posited as; a) social comparison is not important for coping; b) social comparison is unconscious; c) people avoid it due to negative feedback; d) people avoid it because it is inappropriate (Helgeson et al., 1993). This highlights a problem with social comparison studies, where some people do not feel comfortable openly comparing themselves with others, as they do not feel it is right to view others in a bad light. This may also be why gossip, which is just another form of social comparison, is viewed so negatively by most people.

3.3. Social comparison and self-help groups

Social comparison theory may explain the mechanics of what role the self-help group may play in a person's adjustment to an illness. This has been suggested by both Medvene (1992) who said that self-help groups provide information, and Gibbons and Gerrard (1991) who suggested that self-help groups reduce anxiety as the person knows they are not the only one with the illness. People who join self-help groups are people with a common problem (Kurtz, 1990) and, as said above, according to Festinger (1957) we socially compare with similar others. Also, Schachter (1959) claimed that threat increased the need to be with similar others and an illness is classified as a threat, in addition social comparison has been found to be active amongst those with illnesses (Tennen et al., 2000). In a similar vein, a review of social comparison by Kulik and Mahler (1997) concluded that the threat associated with the onset of an illness encourages verbal affiliation with those with a similar problem as opposed to those with other problems. People are interested in talking to the person who has the most and best information about the threat. Taken together these findings suggest a reason for the emergence and proliferation of self-help groups.

Bauman and colleagues have shown in their cancer self-help group study that people belonged to the group so that they could compare themselves with similar others within their group (Bauman, Gervey, & Siegel, 1992). Alcoholics Anonymous actively use social comparison to facilitate their self-help program (Medvene, 1992). They use upward and downward targets in their 12-step program to help with the change they are attempting to induce in the individual. Initially the new participant has a mentor, an upward companion on whom to model their behaviour, this is what would be called upward identification in the Identification/Contrast model. The last step of the program involves taking on a newcomer, a downward companion, who they can help. The use of downward comparison here signifies reaching a new stage as the person is asked to help someone who is still struggling with alcohol. In this way, social comparison is used to assist adjustment to life without alcohol.

Stories too can hold social comparison information (Taylor, Aspinwall, Guiliano, Dakof, & Reerdon, 1993). In their study with undergraduates, Taylor et al. (1993) found that the source of the story was important. Stories from the original source were given higher preference than those that came from a third person. More meaning is attributed to the first person story as there is more of an understanding between the storyteller and the listener. This, again, suggests a motive for belonging to a self-help group where it is easy to hear about or read about first person experiences. In Taylor et al.'s study it was the positive stories that were preferred to negative ones, the reason for this was that the information content is higher in the positive stories.

This section has shown that social comparison is likely to be an active process within self-help groups and that people join them so that they can compare themselves with a person in a similar situation. However, no studies have been identified which have looked specifically at the role that social comparison within a self-help group may play in the adjustment process.

3.4. Effects of social comparison

So far, this review has looked at the mechanisms of social comparison, how it operates, and how it is likely to be active amongst self-help group members. Below follows a brief discussion of selected studies which have explicitly shown how social comparison can affect our perceptions, leading to the conclusion that social comparison can influence adjustment as well. This sections hints at the possible effects that social comparison may have on the adjustment process.

The psychological effects of social comparison have been demonstrated in several studies. For instance, upward comparison has been found to induce hope (Gibbons, Blanton, Gerrard, Buunk, & Eggleston, 2000). This longitudinal study used students to assess the effects of comparison level on later academic performance. Comparison level was found to be positively related to subsequent exam results. In a cross-sectional study with elderly women (Heidrich & Ryff, 1993), social comparison was found to be higher in those with more problems with activities of daily living and lower levels of well-being. Those who experienced positive affect as a result of these comparisons had lower levels of distress; this was more true for those who engaged in downward comparison, also, those who experienced negative social comparison showed higher depression levels (Heidrich et al., 1993). Although this study shows an association between positive social comparison and aspects of psychological health (positive relations with others and personal growth) and between negative social comparison and depression these results are based on cross-sectional data which means that no relations of causality can be claimed. However, these findings are encouraging and indicate that a longitudinal study would be worthwhile.

Social comparison has also been associated with increasing self-esteem after the onset of a crisis like a chronic illness. In a study with cancer patients, although social comparison was not actually measured, comments made about what positive change had occurred since the onset of their cancer included downward comparison statements (Taylor, 1983). These comparisons increased self-esteem as the comparer always appeared better than the downward target.

In a cross-sectional study using a sample selected from the general population in Holland (Van der Zee, Buunk, & Sanderman, 1995) physical health was not strongly related to comparisons. However, those who were stressed (as measured by the GHQ) were more likely to view life negatively and make negative social comparisons. Downward comparison was associated with better perceptions of health. In addition, what the authors call 'relative evaluations' – evaluations of health relative to others – were significantly associated with general health evaluations. This once again hints at an association between social comparison and the way QoL is perceived.

The above studies show examples of the effects of social comparison. These studies all measured social comparison in completely different ways. In addition, in each case the outcome measures, although important to psychological health, were different. Consequently, they provide converging evidence for the influence that social comparison can have. However, the above studies assessed the effects of social comparison in areas which are not health related. The element of an illness may induce a different result.

3.5. Aspects of health and social comparison

Social comparison may be different for people with health problems and also may be different depending on the health problem. This is because factors such as prognosis and course of illness (in which case stage of illness is important) differ from one illness to the next, which means that different types of social comparison may be important.

3.5.1. Prognosis

The specific prognosis of each individual illness can have a particular effect on the interpretation of the social comparison. Here social comparison is the dependent variable as it is dependent on the stage and possible outcome of the illness. The interpretation of both upward and downward comparisons is affected by whether or not the person will decline on the dimension in question. This will determine whether the comparison is interpreted positively or negatively (Wood et al., 1997). When the person will not deteriorate then upward comparison will lead to hope and inspiration (Wood et al., 1997). When the illness is progressive, downward comparison will be avoided. This is because the interpretation of the comparison is with one's future self (Gibbons et al., 1991). How the target is doing on the dimension influences our own future expectations on the same dimension (Van der Zee et al., 2000). However, the prognosis is not related to the frequency of comparison (Buunk et al., 1990). Accordingly, someone with Ménière's disease may avoid downward comparison when their illness is active as the comparison may be interpreted as their future.

3.5.2. Stage of illness

Wills (1991) proposes that the frequency of social comparison changes over the time-course of the illness (Tennen et al., 2000). We socially compare more after the onset of an illness and then gradually less over time. In addition, the type of social comparison changes over time. In the early stages of an illness, there is more downward comparison to increase self-esteem. Later there is a switch to upward comparison for information useful for active coping. One would then expect that members of a self-help group would all be engaged in differing amounts and types of comparisons, as they would most likely be at different stages of their illness.

The target can also change; as the situation changes a target that is even more similar may be chosen and should the problem improve so the target level changes. If the problem worsens then the target level may be lowered (Gibbons, 1999). The target could be interpersonal (comparison with others) or intrapersonal (where the person compares his/her present state to how it was in the earlier stages of the illness). Tennen et al. (2000) propose that over time one makes less comparisons with others and more downward comparisons with one's previous self, something that was not possible at the onset of the illness as there was no past history of life with the illness with which to compare. Strictly speaking, this is not a social comparison but an introspective one. No mention is made of any comparison to past situations prior to when the illness started. Perhaps this is because the healthy self, as a target before the illness began, is not a similar enough target any more.

3.6. Social comparison and adjustment

This section looks at a model proposed by Vanderzee, Buunk and Sanderman (1995) and at evidence that social comparison can in fact influence adjustment to chronic illness. The studies below all look at the positive and negative effects of social comparison on some aspect of subjective well-being. Collectively, these studies provide the grounding on which the argument made in this thesis, that social comparison influences adjustment, is based.

VanderZee, Buunk, and Sanderman (1995) proposed a model which explained the link between social comparison and general health evaluations. The study on which the model was based recruited residents of a Dutch town to participate in a questionnaire study. They measured and assessed the relationship between general health evaluations (perceptions), social comparison (their need for comparison and 'relative evaluations', i.e. whether they perceived themselves as doing better or worse relative to similar others), psychological distress, and health problems. This was a cross-sectional questionnaire study which showed that the health problems, general health evaluations and distress were inter-correlated. Distress was associated with both the relative evaluations and the need to socially compare. This need to socially compare was positively associated with downward comparison, relative evaluations, and general health evaluation. Their model proposed that the link between social comparison and general health perceptions is mediated by psychological distress. However, it should be remembered that the data was cross-sectional and, as noted in the paper, their social comparison scales were not validated indicating that their results can only be classified as indicative of the effects they propose. However, this model is important to the current study as it has similarities, as it proposes that social comparison influences perceptions of health. The present study differs from the above model as the model proposed for this study (detailed in Chapter 4) is an adjustment model, where it is proposed that social comparison influences adjustment to the illness and it does so by a direct influence of social comparison on health perceptions. In addition, where the VanderZee et al. model proposed that it is mainly positive downward comparison which is the important process the current study proposes that it can be upward or downward comparison which is active, but that the important factor is that it is positive comparison which instigates positive adjustment to the situation allowing a different perception of QoL to that of before the onset of the illness.

In another study VanderZee, Buunk, Sanderman, Botke, and Van den Bergh (2000) proposed that to facilitate adjustment one uses support from individuals and this support helps with the adjustment necessary following the disruption of values, norms and standards which occurs after the onset of an illness. This is because we feel the need to affiliate with those who, too, have this illness or are having a similar crisis. We socially compare with these others to determine how we are doing or coping with our illness. There is no objective standard for how to cope with Ménière's disease and the person's access to the specialists who may know is infrequent, and so their best source of information may be from other people with Ménière's disease.

Several studies on Rheumatoid Arthritis (RA) patients and social comparison contribute to this point. Blalock et al (1989) conducted a cross-sectional interview study with 75 patients. Their conclusions were that the target played an important part in determining the direction and the dimension of the comparison. Comparisons to another RA patient were made only on the dimension of desired performance and comparisons to non-RA patients were made only with respect to performance difficulty. Most participants selected non-RA targets when setting standards, which was significantly associated with 'satisfaction with ability,' and after removing those who compared with both targets equally from the calculation, they found that the majority of participants selected RA patients if they wanted to compare their physical situation. Social comparison ceased to be a significant predictor for adjustment (as measured by self-esteem, depression, life satisfaction, and positive affect) once satisfaction with ability was controlled for. However, this still indicates that social comparison was having some effect on adjustment. Blalock et al. suggested that comparison with non-RA persons may facilitate a feeling of normality which they do not get from the comparison with another RA patient. The above study highlights an important element which may be central for self-help groups. As their sample preferred to make comparisons with non-ill people on certain dimensions, a similar effect may be found in self-help groups, in which case the self-help group could have a negative effect since the comparison targets available are other ill people.

In another RA study, DeVellis et al. (1990) also found more negative affect to be associated with downward comparison and they postulated that this was due to the fact that RA is progressive and these participants experienced no hope or positive feelings from observing what may be their future. This echoes what Wills has said about downward comparison and progressive illnesses. Also, in another study Blalock et al., (1990) interviewed RA patients and found that more upward comparison and lateral comparison occurred than did downward comparison and nearly half of all comparisons were with people who do not have RA. This sample also tended to emphasize the dissimilarity between themselves and the target regardless of whether they were engaged in an upward or downward comparison. Adjustment level (as measured by depression and anxiety) was not associated with social comparison, nor with the direction of the comparison. However, they found evidence of better adjustment in those who identified with the non-RA target, which can be classified as positive upward identification according to the Identification/Contrast model (Buunk et al., 1997). A final RA study (DeVellis, et al., 1991) used questionnaires with women RA patients. This was also an experimental study which manipulated the dimension of the comparison, to be either coping or symptoms. They found that where a downward comparison was possible the dimension was changed to a more favourable one, in other words, downward comparison was avoided in order to avoid being seen as worse-off.

In another study Ybema and Buunk (1995) found upward comparison to be more beneficial than downward comparison for disabled individuals. This was an experimental study which manipulated the level of the target in a transcript of an interview which the participant read. Upward comparison was found to lead to positive affect especially for those high in perceived control. The authors concluded that this was due to the identification process associated with upward comparison. Another cross-sectional study with disabled people showed that one's own situation influences the comparison level (Buunk, 1995). Those who reported being in a worse situation (either severe problems or unsuccessful coping) preferred upward targets, while those in a better situation preferred downward comparison (Buunk, 1995). This means that those who perceived their problems as worse did not like to compare with those whose problems were also bad. Once again, this raises questions about the self-help group. As people who belong to an illness self-help group will be at varying stages of the illness a situation may arise where social comparison with those worse-off is unavoidable and this may not be helpful for those who are experiencing setbacks. In another cross-sectional questionnaire study with cardiac patients (Helgeson et al., 1993), engaging in social comparison was not associated with physical status. Those who came into contact with upward targets admitted to making more comparisons than those in contact with downward targets. Of those who socially compared, most preferred upward comparison, which led to feeling lucky.

In another cancer study, patients were interviewed and results showed high self-esteem to be associated with an ability to avoid negative comparison (Buunk et al., 1990). However, Gibbons and Gerrard (1989) warn that the positive effects of downward comparison are short-lived as there is no useful information from downward comparison and, in addition, people experience guilt from downward comparison. In addition, comparison with downward targets may encourage feelings of invulnerability by the comparer, affecting subsequent inappropriate behaviour.

In a longitudinal trial with women with cancer, the effectiveness of types of interventions were tested. Patients were randomly assigned to one of four conditions; a peer discussion group, an education group, a peer discussion plus education group, and a no intervention group (Bogart et al., 2000). Only 29.8% of the sample admitted to making social comparisons and so the statistics are based on this subgroup. On the whole the group made more positive downward comparisons than negative. However, the interesting finding in this study is that those in the peer discussion group did not fare so well in the results as those who belonged to the education group or the peer discussion-and-education group (Helgeson et al., 1999). Adjustment (as measured by the SF-36) was better for those in the education group as opposed to the peer discussion group. In fact, no positive effects of the peer discussion group were found, with this group showing more negative interactions, more negative downward comparisons, and more intrusive thoughts regarding the illness. They postulate that this is because the education arms the individual with information which is useful for coping and helps to provide meaning to the situation. However, one would then expect the peer-discussion plus education group to show the most positive results but this was not the case. This study is of interest for three reasons. Firstly, although the aim was to assess the effectiveness of the different intervention methods it looked at social comparison within a support group. Secondly, the outcome measure was adjustment as measured by a QoL scale as opposed to the absence of depression seen in other studies (for example, Blalock, Afifi, De

Vellis, Holt, & De Vellis, 1990). Finally, it found social comparison to be unhelpful for those in the peer discussion group. Not only does this show how social comparison (downward in this case) can be unhelpful, but it also shows how support groups may be unhelpful if they do not include education as part of their process. This study has some parallels with the one presented in this thesis in that it indirectly looked at the effects of social comparison on adjustment for those who belong to an illness group. However, there is an important difference. The study which Helgeson and colleagues carried out, randomly assigned cancer patients to one of four groups. It could be argued that this renders the results invalid as the members make the group and cannot be separate from it (Jacobs et al., 1989). The study presented in this thesis used an ecologically valid setting - a self-help group which was already in existence and which was not professionally led. This means that the members of the Ménière's Society have all volunteered to join the group themselves; no one has asked or encouraged them to do this. The argument here is that those who join voluntarily are probably different to those who are participating in a study by joining a group and this may have an effect on how they socially compare and perceive their own QoL.

The above two sections (3.5 and 3.4) have shown how social comparison can affect our perceptions. More specifically this last section (3.6) has shown how it may affect adjustment as they hint strongly at the possible effects of social comparison within self-help groups.

3.7. Factors that may mediate or moderate the effect of social comparison

Below are three psychological variables previously shown to be associated with social comparison, namely, perceived control over illness (Bennebroek, Buunk, Van der Zee, & Grol, 2002; Tennen et al., 2000; Ybema & Buunk, 1995), self-esteem (Bennebroek et al., 2002; Tennen et al., 2000; Wills, 1981), and optimism (Tennen et al., 2000). These factors can influence the way in which social comparison information is interpreted.

3.7.1. Perceived control over illness

Perceived control over the illness encompasses perceptions of how stable the illness is and whether it is possible to modify the illness in question. The last issue relates to how easily the person will be able to stop an illness getting worse and how easily he/she can make things better. The impact of chronic illness has been shown to lead to feelings of loss of control over life (Helgeson, 1992) and these feelings influence and are influenced by social comparison. The degree of perceived control depends on whether the focus is on the illness/symptom severity or the coping success/failure (Helgeson, 1992; Ybema et al., 1995), since in the case where the illness is progressive the individual often focuses on control over the way they cope and manage the illness. Major, Testa and Bylsma (1991) proposed that one of the important factors which influences the effect of upward and downward comparison is the perceived control of the dimension, in this case, the illness. Low perceived control leads to a negative mood for those with a more severe illness. This is because if the perceived control is low over a severe illness then he/she may be left with feelings of helplessness. High perceived control over a severe illness will lead to positive affect (Helgeson, 1992). Similarly, upward identification made with high perceived control results in positive affect (Van der Zee et al., 2000). Ybema and Buunk (1995) also agree that if the person experiences low perceived control then they will experience negative affect after downward comparison, since it will be interpreted as threatening. However, those high in control are able to avoid negative downward comparison and the consequent negative affect (Buunk et al., 1990). In support of the above, Bogart and Helgeson (2000) found that after upward comparison those breast cancer patients with a low internal locus of control felt helpless, and after downward comparison these same participants felt threatened and experienced negative affect.

3.7.2. Self-esteem

Self-esteem can influence the interpretation of the comparison, which in turn feeds back to influence self-esteem. Self-esteem and the relevance of the social comparison to self-esteem are factors which influence the way in which upward and downward social comparison are interpreted. Here, other characteristics of the target and their similarity to the comparer are important, that is, how similar they are on dimensions other than the one in question (Major, Testa, & Bylsma, 1991). Downward comparison occurs where self-esteem has been threatened as it increases subjective well-being and self-esteem (Wills, 1991). Downward comparison leads to positive affect only for those with low self-esteem; this is due to relief obtained from the feeling of threat (Gibbons et al., 1991). Upward comparison only leads to positive affect in those with high self-esteem as the comparison does not damage self-esteem but provides more hopeful information (Gibbons et al., 1991). Buunk et al. (1990) found that those with high self-esteem tended to avoid negative comparison (upward or downward); those with high self-esteem who engaged in downward (positive) comparison experienced self-enhancement which helped to preserve their positive self-concept.

Contrary to Gibbons and Gerrard (1991), Aspinwall and Taylor (1993) found that both those with low self-esteem and those with high self-esteem showed the same improvement in mood after upward comparison. Both also showed a decrease in positive mood after downward comparison, with low self-esteem showing the smaller decrease of the two. These two studies agree that for people with low self-esteem downward comparison improves mood and those with high self-esteem showed improved mood after upward comparison. However, where these two studies differ is that Aspinwall and Taylor found that those low in self-esteem in the upward condition experienced an improvement in mood (the same improvement as those high in self-esteem) while Gibbons and Gerrard found their low self-esteem group (in the upward comparison condition) to show less of a mood improvement than the high self-esteem group in the same condition. These differences may be explained by how the two studies carried out their research as they used different instruments to measure self-esteem. Gibbons and Gerrard used the Janis-Field Feelings of Inadequacy Scale and Aspinwall and Taylor used Rosenberg's self-esteem scale. The Janis-Field Feelings of Inadequacy Scale has been found to measure different aspects of self-perception rather than a measure of self-esteem (Church, Truss, & Velicer, 1980), this may explain why these studies reached different conclusions about the effects of self-esteem and social comparison.

Perceived control and self-esteem are interrelated; if the situation is not alterable then upward comparison will lead to negative affect and lowered self-esteem. This is because the person can never be like the target and so the comparison is interpreted negatively.

3.7.3. Optimism

Optimism is closely associated with self-esteem. As stated above, downward comparison tends to lead to positive affect only for those low in self-esteem. Gibbons and Gerrard (1991) postulate that this effect occurs due to the optimistic and hopeful feelings those with low self-esteem experience as a result of knowing that there are others who are worse off but who are managing to cope. In another study, again with undergraduates (Gibbons, 1999), the preferred comparison level was found to be lower after an academic setback. However, optimistic people (as measured by the life satisfaction scale) did not lower their comparison level even after a set back. In fact, Gibbons (1999) goes as far to say that optimism may help prevent the occurrence of a negative response shift due to this lack of a downward shift in level.

3.8. Response Shift as a Consequence of Social Comparison

The process of response shift was reviewed in Chapter 2. Social comparison has been proposed to act as a catalyst for response shift (Gibbons, 1999; Sprangers et al., 1999a). The facilitating role of social comparison is proposed to occur due to the change in perspective and information that is learnt from the comparison. This thesis argues that social comparison can and does act as a mechanism in the process of response shift.

After the onset of an illness the frequency of social comparison increases and this can facilitate the response shift, i.e. the cognitive adjustment to life with an illness (Gibbons, 1999). The response shift is mediated by social comparison as social comparison changes the perception of one's situation. This change in perception occurs due to the change in perspective that is experienced from the comparison of a person's own situation relative to that of another. Through socially comparing we see a new/different perspective of ourselves which can change how we feel and how we perceive ourselves and our situation. We socially compare all the time but, as said above, after the onset of an illness the amount and type of social comparison changes. There is a switch to downward comparison and the frequency increases (Wills, 1991). The response shift may induce a changed, more positive perspective where the loss of perceived control over health is not seen as so negative or so important, as one's standards and goals have changed. This change in perspective brought about by the different view which social comparison may facilitate is proposed as causing either a change in the way that goals are viewed, a change in what the person values or a change in the way the person determines their QoL (change in the internal standards of measurement), otherwise know as response shift. This may be what is occurring amongst people with chronic illness who belong to self-help groups. Membership of a self-help group places the person in a situation where they can readily socially compare in either direction. Their interpretation of this comparison may lead to a change in the way they view their own illness, leading to a response shift (a cognitive change). However, the response shift can be maladaptive if downward comparison focuses on negative aspects of the target and possible deterioration. This would lead to a negative response shift.

3.9. Conclusion

This chapter has explained how social comparison works and in so doing has shown how social comparison may influence perception and lead to adjustment. This review has explained how social comparison operates and how it may work within a self-help group. The Identification/Contrast model proposes that we experience affect as a direct result of social comparison. The affect experienced along with the knowledge learnt after socially comparing may lead to a change in perspective thereby allowing a change (response shift) which allows a new perceived QoL. However, this review has also shown the importance of other factors to social comparison, factors such as the dimension (symptoms or coping), direction (up, down, and lateral), and information. The Identification/Contrast model confines the direction to either upward or downward, confines the dimension to disease severity, and does not include information as a reason for socially comparing. However, other studies have shown the importance of lateral comparison and have distinguished between dimensions (coping and symptoms).

The review also emphasized the lack of research into the social comparison processes which occur within self-help groups, and Chapter 1 revealed that self-help groups can be both helpful and unhelpful, although the reasons for this are not always clear. This chapter has not only shown the importance of social comparison in illness populations but has proposed that social comparison is probably one of the main processes occurring within self-help groups. The above studies also hint at a relationship between social comparison and adjustment but there is as yet no conclusive evidence.

Having reviewed the literature on self-help groups, QoL, and social comparison and identified a lack of conclusive evidence regarding the relationship between social comparison and adjustment the next chapter describes how the empirical chapters go about determining whether a relationship between these constructs exists.

CHAPTER FOUR: THIS STUDY

4.1. Introduction

The preceding chapters identified a gap in the literature with regard to the role that social comparison plays in the adjustment process. These chapters also highlighted the importance of determining this relationship in light of the number of people with chronic illnesses who join self-help groups. Following on from these reviews, this chapter brings the conclusions together and proposes a model which explains the relationship between social comparison and adjustment. This chapter also lays out the procedure necessary to answer the research questions and describes which statistical analyses would be used in the data analysis.

4.2. Conclusions drawn from the literature review

Chapter 1 described the tendency for those with a chronic illness to become involved in the management of their own disease. This often involves joining a self-help group. With large numbers relying on these groups it is surprising that so little is known about the advantages and disadvantages of these groups and, indeed, the adjustment process itself. As the sample used in the study were people with Ménière's disease this too was described in Chapter 1, as was the self-help group to which they belonged. While Chapter 1 showed how important self-help groups can be to people with a chronic illness, Chapters 2 and 3 gave a detailed account of factors in the literature important to QoL and social comparison. The chapter on QoL was important as in this study adjustment was measured by changes in QoL over time and this required a detailed review of QoL. This review not only defined QoL for this study but also described how it should be measured.

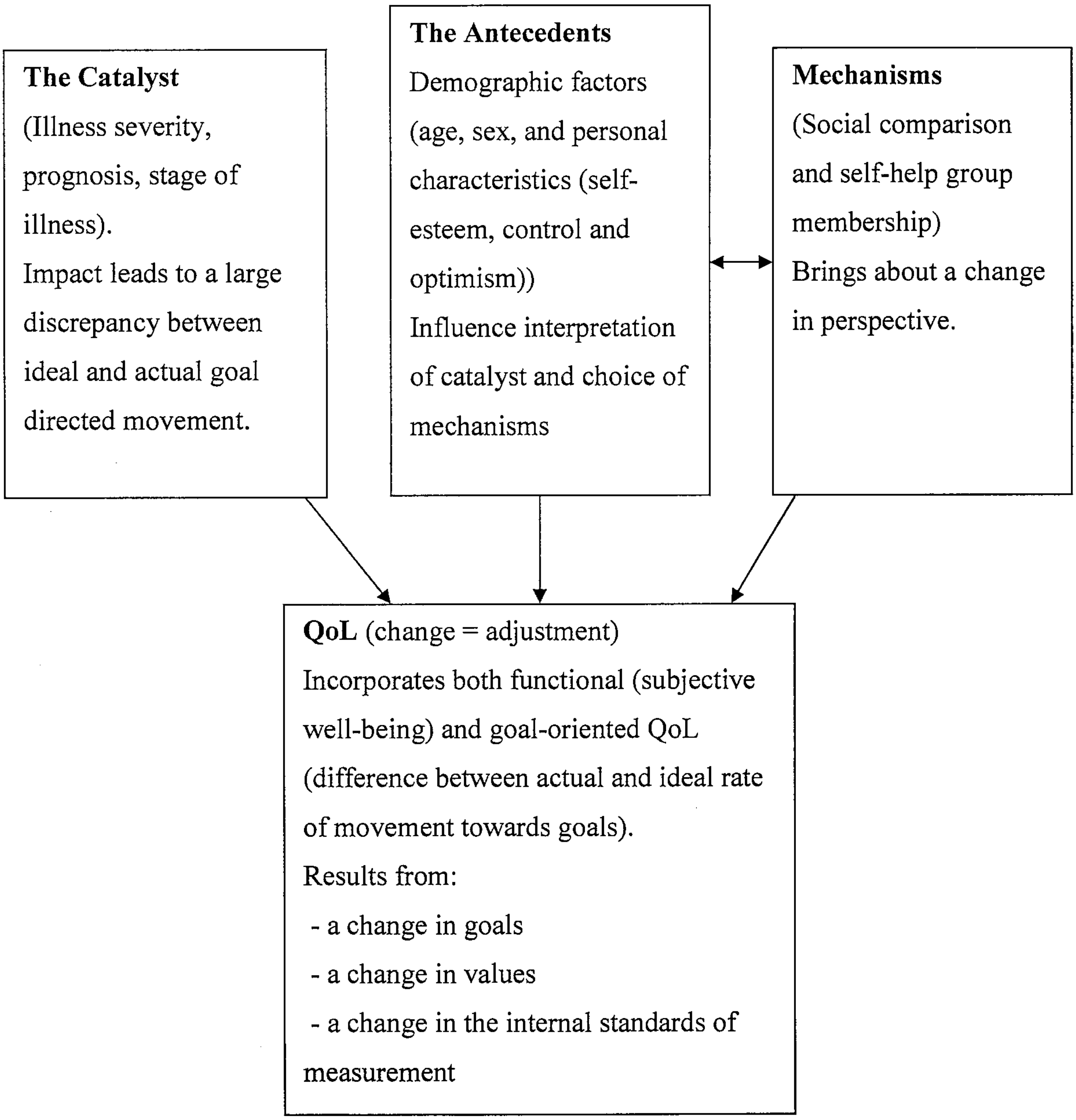
Chapter 3 reviewed social comparison, what it is and how it operates, as social comparison is a process likely to occur within self-help groups. Of course, the main question this study aimed to answer was what effects social comparison had on the adjustment process. This chapter was important in highlighting what factors were necessary to measure when investigating social comparison. In particular, the chapter showed the dimension and the direction to be important in measuring social comparison. The review of social comparison theory and literature found the Identification/Contrast model to emerge as important (Buunk et al., 1990). This model proposes that whether we interpret social comparison information as positive or negative depends on whether we identify or contrast ourselves with the target (whether better-off or worse-off). This model was used in this study to help to determine how to measure social comparison. This chapter also highlighted the gap in the knowledge about the role social comparison may play in adjustment. Evidence from the literature led to the model proposed in this study, a description of which follows below.

4.3. The model

Diagram two, below, shows a model for the relationship between adjustment and social comparison as proposed by this study. The conclusions drawn from Chapter two indicate that QoL is experienced as the result of the perceived difference between the ideal and actual pace of goal-directed movement. This is based on Carver and Scheier's Control Process Model (1990) which states that affect is experienced based on the rate of acceleration towards goals and not on goal satisfaction itself. Borrowing response shift terminology, the sudden and direct impact of an illness on the actual goal progression, the *catalyst*, initially leads to a larger discrepancy between ideal progression and actual (perceived) goal progression and consequently movement towards goals is either stopped or extremely slow, and this results in a lowered perceived QoL. The perceived meaning of the *catalyst* is influenced by the *antecedents* or personal characteristics of the individual. For example, an optimistic outlook (*antecedent*) may lead to positive outcome expectancies and a positive interpretation of the illness (*catalyst*). As a way of dealing with the *catalyst, mechanisms* are used to help regain some form of 'normality.' The *antecedents* also influence the choice of these *mechanisms* and how they are used. This occurs when individual characteristics influence the interpretation of the social comparison information and/or the coping strategy chosen. The process of adjustment, by means of the *mechanisms*, allows the ideal goal progression and actual goal progression to acclimatise to the new situation (response shift), which means the discrepancy between the ideal progression and the actual goal progression reduces and perceived movement towards goals begins again, increasing the level of perceived QoL. Adjustment, in this study, is proposed as occurring according to feedback loops as Carver and Scheier, and Schwartz and Sprangers suggest, i.e. these feedback loops can result in; a change in the internal standards of measurement, a reconceptualization of one's goals, and a change in one's values. These changes can occur to the ideal goal and the ideal goal-directed movement. This in turn occurs due to the effects of coping, behaviour change, perceived positive change and, as proposed in this study, social comparison.

Diagram 2: A Model of Adjustment

This model of adjustment shows the effects of the many factors on QoL which bring about adjustment to QoL.



The Catalyst
(Illness severity, prognosis, stage of illness).
Impact leads to a large discrepancy between ideal and actual goal directed movement.

The Antecedents
Demographic factors (age, sex, and personal characteristics (self-esteem, control and optimism))
Influence interpretation of catalyst and choice of mechanisms

Mechanisms
(Social comparison and self-help group membership)
Brings about a change in perspective.

QoL (change = adjustment)
Incorporates both functional (subjective well-being) and goal-oriented QoL (difference between actual and ideal rate of movement towards goals).
Results from:
- a change in goals
- a change in values
- a change in the internal standards of measurement

As an example, a person who is experiencing a standard of QoL which they feel to be 'normal' will experience a setback due to the interruption that Ménière's disease brings. The onset of the Ménière's disease is the *catalyst.* Unable to carry on a normal life as before, they may feel their situation to have worsened as day-to-day living evolves around the treatment of the illness and not the normal routine the person has been used to (a large discrepancy between actual and ideal goal progression). This person does not feel as if they are moving towards their goals and so feels that their QoL is worse than before. Life now consists of managing their Ménière's disease and perhaps avoiding situations or activities which may induce an attack of vertigo. This person may feel unable to continue to be active and independent due to uncertainty about when the next attack of vertigo may occur. Hobbies and sports may have ceased due to the exaggerated unsteadiness and spinning which accompany the vertigo. The psychological effects of this situation can also be a burden, as the person feels uncertain and sometimes frightened. They tend to be more housebound due to the fear of an attack out of the home. They find the tinnitus interferes with concentration and the hearing loss leads to isolation due to the reduced communication. The net result is that normal activities are curtailed leaving the person unable to do what they usually enjoy doing.

The impact of Ménière's disease on a person means they experience a lower QoL than before the onset due to the altered lifestyle. In order to help manage the illness this person may decide to join a self-help group run by people with Ménière's disease. This enables them to access information about the illness, to not feel so alone, and to hear other people's accounts of their experience of the illness. In reading about other people's experiences, this person begins to feel that their situation is not as bad as they first thought (positive downward comparison). They may feel lucky that they are not as badly off as some and/or they may feel hopeful that one day they might be able to cope as well as others. This change in perspective on their situation allows them to set new, realistic goals which are within reach and this leads to a better perceived QoL (reduced discrepancy between ideal and actual goal-directed movement).

4.4. This study

The questions posed by this study are the following:

4.4.1. Research Questions

What aspects of QoL change over time?
What factors predict change in QoL and in particular does social comparison influence adjustment?

A longitudinal questionnaire study was planned to determine which aspects of QoL changed over time and to determine the predictors of QoL, as a cross-sectional study would not have provided evidence of a predictive relationship between social comparison and adjustment. A questionnaire study was the obvious choice as a larger number of participants can be reached in this way.

However, initial searches for measures suitable for use in the study were not productive. No goal-oriented QoL measure was found that was suitable for postal surveys, leading to the necessity to develop one. In addition, although a social comparison scale was found it omitted many aspects highlighted as important in the literature. For example, it omitted distinguishing between dimensions, did not include the lateral direction, and omitted socially comparing for information purposes only. It was therefore necessary to design two new questionnaires. This, in turn, demanded a qualitative study to assist in the development of the social comparison scale, as it was necessary to determine if the group was in fact socially comparing and, if so, in what way (Chapter 5). Following on from the qualitative study was a preliminary study to develop the new scales and validate them with existing, previously validated scales.

4.5. Procedure

This section describes each stage of the study, each empirical study to be undertaken. The description covers how these studies were carried out and why. The following sections describe the project plan designed to test the hypotheses.

4.5.1. Preliminaries

Ethical approval was applied for with and received by the Department of Psychology, University of Southampton.

4.5.2. The development and validation of the new questionnaires

This study consisted of a preliminary qualitative study and a questionnaire study which validated two new questionnaires.

To assist in the development of an appropriate social comparison scale a qualitative interview study was carried out with a small number of people to determine whether this group were in fact socially comparing and if so in what way. A semi-structured schedule (Appendix B) was used, as this would best allow the participant to express their own thoughts and opinions about the people they read about in their self-help group magazine, Spin (described in Chapter 1). Exploratory thematic analysis was then used to analyse the transcripts as this too would allow dominant themes to emerge. Themes which arose often across participants would indicate important social comparison issues. The analysis of the interviews, assisted by the literature, allowed the development of the Social Comparison in Illness Scale (SCI).

A goal-oriented QoL scale was designed and developed based on the Control Process model (Carver et al., 1990) and the Schedule for the Evaluation of Individual QoL (SEIQoL) (McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991). Both scales were then validated in a preliminary questionnaire study (Chapter 5).

This study used pre-existing, previously validated questionnaires to validate the newly developed ones. The Social Comparison in Illness scale (SCI) was completed alongside the Identification/Contrast scale (Van der Zee et al., 2000) and the Goal-oriented QoL scale (GOQoL) was completed alongside the SF-36 (Ware, Snow, Kosinski, & Gandek, 1993), a generic QoL scale.

The statistics used in this study were mainly correlations, to determine the relationship between the newly developed scales and the previously validated ones in order to validate the new scales, and factor analysis, to determine the underlying structure of the scales.

4.5.3. Answering the Research Questions

Once validation of the two new scales was complete, the questionnaire pack to be used in the main survey was designed (Appendix E). The procedure for answering each research question is briefly described below (detailed in Chapters 6 and 7).

-QoL and self-esteem, perceived control, and optimism

Those high in optimism, self-esteem and control would experience better QoL. This hypothesis was tested with the cross-sectional data, presented in Chapter 6. Bivariate correlations between variables showing a positive relationship would indicate that the hypothesis was correct.

-Aspects of QoL which change during the process of adjustment

To determine which aspects of QoL changed over time, response shift was measured (Sprangers et al., 1999a). As detailed in Chapter 2, response shift is a cognitive change which results in a new perceived QoL. This can occur in three ways (change in values, change in goals, and change in the internal standards of measurement). In order to measure the change in the internal standards of measurement the ThenTest approach was used. Here a Time 1 QoL measurement and a retrospective test at Time 2 of QoL at Time 1 allows two measures of QoL at Time 1. Taken at two different points in time, these ratings are indications of perceived QoL at the same point in time (Time 1). The Time 2 measurement is a retrospective test, it is a repetition of the same QoL scales already completed but reworded so as to be retrospective. Five subscales of the SF-36 (four subjective and one objective) and the GOQoL were measured at Time 1, at Time 2, and retrospectively at Time 2. Aspects of QoL which have changed were revealed by differences between Time 1 (Time 1 rating of QoL at Time 1) and Time 2 (Time 2 rating of QoL at Time 1) means. In this way it was possible to determine which aspects of QoL underwent the change. It was predicted that only the subjective domains would show a change, while the objective domain would show no change. This is because a cognitive change is more likely to influence those aspects of QoL using a cognitive (subjective) measurement than those using an objective one. A change in goals and values was measured by determining changes in the ranking of goals over time. Any differences between these scores indicates a change in the way that QoL is internally measured (as assessed by paired t-tests) (Sprangers et al., 1999a).

-Predictors of QoL over time

This study also aimed to measure predictors of change in QoL over time, in particular, social comparison. A longitudinal study was necessary, where QoL and predictors were measured at Time 1 and QoL was measured again at Time 2. The aim was to assess the effects of social comparison on adjustment after controlling for other important variables. Hierarchical regression analysis was used for this analysis as it was the most suitable procedure given that the aim was to find predictors of adjustment. This meant entering all other variables showing a relationship with QoL over time before entering the social comparison variables. In this way, the variance explained by social comparison, after controlling for the variance explained by other significant correlates, could be determined. To allow for the large number of possible variables a large sample size was necessary. Regression analysis is also suitable for testing models and the relationship between the variables. Relationships between predictor variables and outcome variables would reveal the accuracy of the model proposed in this chapter. (Although structural equation modelling is another statistical method of achieving this it was not an option for this study, as the number of variables and relationships was too large relative to sample size, and could not be reliably represented in terms of latent variables).

4.6. Summary

Chapters 5, 6, and 7 are the three main empirical chapters of the study. The qualitative study has been included as a preliminary part of the questionnaire development and validation study in Chapter 5. Chapter 6 presents the start of the main study, the cross-sectional study, and Chapter 7 presents the longitudinal study. Chapter 8 contains the discussion and conclusions of the whole study.

CHAPTER FIVE: DEVELOPMENT AND VALIDATION OF NEW SCALES ASSESSING GOAL-ORIENTED QOL (GOQOL) AND SOCIAL COMPARISON IN ILLNESS (SCI)

5.1. Introduction

An extensive search of the literature in Chapters 2 and 3 showed there to be no suitable social comparison scale or goal-oriented scale for use in the main survey; this meant that there was a need to develop two new scales: a social comparison in illness scale (SCI) and a goal-oriented QoL scale (GOQoL). This chapter details two studies. The first empirical study of this chapter was an exploratory qualitative study used in the development of the SCI, while the second study comprised the development and quantitative validation of the two new scales.

5.2. Development of the SCI

5.2.1. The need for a social comparison measure

The conclusions reached in Chapter 3 described those issues found to be important in the literature for the measurement of social comparison according to the definition taken in this study. The Identification/Contrast Model (Buunk et al., 1990) formed the basis of the understanding of social comparison which proposes that we experience affect after comparing, the type of affect experienced depending on whether we have identified or contrasted ourselves with an upward or downward target. While these issues are important to this study other aspects of social comparison also emerged as important in the literature, for example, distinguishing between the symptoms of the target and the coping success/failure of the target (Helgeson, 1992). The lateral direction too may be important, as social comparison theory assumes that we socially compare with those who are similar , and it seems likely that this may be a major function of a self-help group (Festinger, 1954). It was therefore necessary to include lateral comparison as a comparison level in addition to upward and downward comparison.

Other social comparison scales available were not suitable for inclusion in this study. The Iowa-Netherlands Comparison Orientation Measure (INCOM) (Gibbons et al., 1999) measures individual differences in comparison orientation and so is not appropriate for use in this study. The Identification/Contrast Scale (Van der Zee et al., 2000) is based on the Identification/Contrast model. This scale is compatible with the objectives of this study as it measures the degree of emotion experienced after either upward or downward comparison. This information tells us whether the person is experiencing positive affect due to upward identification (where we see the target as similar to ourselves), downward contrast (where we see the target as different to ourselves) or both. Similarly, should they experience negative affect it can be determined whether this is due to upward contrast, downward identification, or both. However, the Identification/Contrast scale covers only the upward and downward direction which results in either a positive or negative affect, and the lateral direction is not included. The Identification/Contrast scale also does not allow for different dimensions of the target. For example, the Identification/Contrast scale focuses only on the emotion the comparer experiences from comparisons with the target rather than on the dimension on which the comparison is made, for example, disease severity or coping success. It also does not include a subscale to measure comparison for information purposes, an aspect which emerged as important in the literature.

The lack of an ideal scale to accommodate these important factors motivated the development of a new scale. However, the development of the social comparison scale required a preliminary qualitative study in order to determine whether members of this self-help group were using Spin (the self-help group magazine) to socially compare with other members and if so how they were using social comparison. This would allow the design of the items of the scale to be relevant to the participants.

5.2.2. Introduction to the Qualitative study

Fifteen semi-structured interviews were carried out to assist in the development of a social comparison scale. This scale would then be administered as part of a bigger self-completed questionnaire to 1000 members of the Ménière's Society.

5.2.3. Participants

A sample of 15 was sought in order to determine whether or not this group were socially comparing and if so in which way. As the number of members resident in the two local postal codes consisted of forty-one, nearly three times what was aimed for, screening questionnaires were sent out to these Ménière's Society members (Appendix A). The screening questionnaire gathered demographic information such as age and sex; in addition, an item asked whether they had been diagnosed with Ménière's disease by an ENT specialist. The reason for this last item was that not all members of the Ménière's Society have Ménière's disease and only those with a diagnosis from an ENT specialist would be able to take part in the qualitative study. The Ménière's Society not only consists of members who have Ménière's disease but also those with Ménière's Syndrome (similar symptoms) and health professionals who were interested in Ménière's disease. The questionnaire also asked the member if they would like to take part in an interview. Those who agreed were asked to return their questionnaire in the prepaid envelope. Out of the 25 replies, 15 people were interviewed. The number was restricted due to the richness of the information received from the qualitative interviews and due to the fact that no new themes or categories were arising by the 15th interview. Nine of the participants were women and six were men. The age ranged from 29 to 79 years and fourteen of the participants were married. The interviews were conducted at the participants' home or place of work at a time which suited them. The letter of invitation had informed the participant that the interview would be recorded; this was to make sure that only those who did not object were interviewed. The interviews lasted between forty five minutes and an hour and a half. The tapes were transcribed by a typist and then analysed, which is described below.

5.2.4. Procedure and analysis

The interview followed a semi-structured schedule (Appendix B) covering aspects of the magazine, Spin, they found helpful. The participant was first asked casually to comment on what they found helpful in Spin. The structure was inductive, as the participant was not asked directly if they either read the letters to the editor section or compared themselves with the people they read about. The structure of the interview was such that should they have read the letters section or have an opinion about these this would emerge naturally without prompting. As all participants spontaneously admitted to not only reading the letters to the editor but finding this section to be one of their favourite, the questions then focused on why they liked (or disliked) the letters, what type of letters were found helpful and what type were found unhelpful.

Interview transcripts were then analysed using thematic analysis to determine the important themes which were apparent (for examples of the transcripts see Appendix C). The code categories were broad. Anything that referred to socially comparing was highlighted to be further coded. These sections were then categorized according to the dominant message of the statement.

5.2.5. Results

As mentioned above, all participants read the letters to the editor section. In fact, for all participants the letters to the editor and the medical section were their favourite sections. The dominant themes which arose from the analysis were: Downward Comparison (subcategories: Information, Positive, Negative, and Future), Upward Comparison (subcategories: Information, Positive), Lateral Comparison (subcategories: Similar, and Others), Acceptance, and Trajectory. Examples of these categories and subcategories are given according to category below.

Category: Downward: Negative

This category included any negative comments regarding reading about a person who is worse off than they are. Six participants made downward negative comments.

[the letter] Could depress people (participant 3, line 27)

[She describes a letter she has read about a woman having a tough time coping] I found that very, very upsetting because she described that she had the symptoms 24 hours a day, seven days a week, 52 weeks a year (participant 3, lines 127 - 130)

[I find the letters] depressing because they are much worse [than I am] and have no hope (participant 6, lines 23 - 25)

It does make you feel down that there will never be an end to it (participant 25, line 159)

The above comments show how reading about someone else's experiences of Ménière's disease can leave the reader feeling down or depressed. According to the Identification/Contrast Model (Buunk et al., 1990) a person who feels these emotions after seeing or hearing about others who are worse-off is identifying with them. This means that they look for similarities with themselves and the worse-off other which leads to the perception that they are just like the worse-off other and therefore their problems might get to be as bad one day.

Category: Downward: Positive

Any comments made by the participant which indicated that they felt positive after reading about those worse-off than themselves were classified as downward positive statements. Thirteen participants made downward positive comments.

...I've been lucky (participant 1, line 142)
There's always somebody worse than you, it picks me up (participant 2, line 33)
There's a lot of people out there a lot worse than me – it makes me count my blessings (participant 3, line 50)
Puts your own problems into perspective (participant 3, line 113)
I'm afraid it's rather gladdening to read that other people have it much worse, [I] take some comfort in that (participant 8, line 21)
Whatever it is it could be worse, a hell of a lot worse (participant 12, line 237)

In the case of the above comments, the person is not identifying with the worse-off other but is instead contrasting. This means that they have identified differences and do not feel similar to this person. As the target is worse-off and the comparer did not feel any similarity with him/her, the comparer tends to feel positive affect, for example, feeling lucky or grateful that they do not have the illness as badly as the target.

Category: Downward: Information

Comments which referred to gaining information from those worse-off without indicating that they experienced positive or negative emotion were classified as downward information. Seven participants made comments about gaining information from those who were worse off.

...A bit depressing but, yes, I'd say on the whole they're helpful (participant 6, line 69)
If you were to have a drop attack you'd recognise it for what it is (participant 8, line 142)
People that have had these experiences have always got something interesting to offer (participant 24, line 166 - 167)
A lot of people have different things,[it helps to know] (participant 25, lines 77 - 78)

In the above comments, despite the fact that the target is worse-off, the comparer has found the comparison useful from an information point of view.

Category: Downward: Future

Any reference to his or her future selves when comparing with someone worse-off were classified as downward future. Nine participants made comments regarding a negative future after reading about those worse off. Four of those who made downward negative comments also made comments classified in this category as well.

It makes me wonder whether that is what is in store for me, (participant 6, line 27)
There's no guarantee that that will happen to me, (participant 6, lines 62 - 63)
Am I ever going to be that bad?,(participant 7, line 27)
Have I got that to come, (participant 7, line 49)
It makes me feel negative towards the future, (participant 12, line 212)
'Oh golly, could I deteriorate and go into this sort of situation?', (participant 24, lines 189 - 190)

This category is an extension of downward negative. The person has identified with the worse-off other to the extent that they feel that their future will be the same as the target. This induces negative affect: as the target is worse-off, the comparer, too, will be worse-off in the future.

Category: Upward: positive

This classification was made where a comparison had been made with a person who was better off than they were at the time of the comparison and this was interpreted positively. As with downward positive, this category also consisted of thirteen participants.

Its worked for somebody, you automatically think perhaps it would work for me, (participant 4, lines 134 - 135)

If they can do it, I can still do it, (participant 6, lines 52 - 53)

[I] feel reassured – there's hope for me, (participant 9, lines 52 - 54)

Read about..., I've learnt its good, that's helpful, (participant 9, lines 118 - 119)

It makes me feel good that there are some strong people because you want to be strong as well, (participant 25, lines 152 - 153)

Here, upward identification has occurred, inducing positive affect where the comparer experiences hope that they, too, will improve.

Category: Upward: information

As with the downward equivalent, this category refers to information gained from an upward target where there is no reference to affect. Seven participants made comments regarding gaining information from those who were better off.

Other people have had better contact with the medical profession, (participant 1, line 87)
Look at what they've done and try it, (participant 2, line 41)
It is nice to read stories of how they get over the fear of going out (participant 22, lines 204 - 205)
It has helped as well with medicines they take and when they help them, (participant 25, lines 22 - 23)

These comments show that the target has received better information than they have and this has helped the comparer.

Category: Lateral: similar

The lateral category refers to comparisons where the target is on the same 'level,' with regard to the illness, as the comparer. The subcategory Similar refers to where the person has commented on the fact that there are others like him/herself. Twelve participants made lateral similar comments.

That's me! He described the symptoms better than I ever could, (participant 3, line 303)
Its nice to know that other people are going through the same thing as you, (participant 7, lines 27 - 28)
I'm ...probably in exactly the same boat as that person, (participant 22, line 177)
Someone's having exactly the same experience as yourself – valuable, (participant 24, lines 10 - 12)

This category shows how the person finds comfort in finding others who have experienced what they have and can understand what it is that they go through.

Category: Lateral: Others

This subcategory refers to comments where the person refers to other people with Ménière's disease, for example, where he/she does not feel alone when he/she reads the letters. Nine participants made lateral other comments, examples of which are presented below.

Its nice to know other people suffer from it, (participant 1, line 75)

Its nice to know someone's there, (participant 2, line 92)

Feel better once you've read...because I usually feel very isolated, (participant 4, lines 32 - 33)

I think it's the reassurance that you're not the only one with it, (participant 4, line 164)

..and you feel there is support, (participant 4, line 168)

A group of people who actually understood, (participant 6, lines 93 - 94)

This category shows how knowing that others who have experienced the same thing are there gives comfort, they feel supported.

Category: Acceptance

This category includes comments where the person shows signs of accepting their illness due to reading the letters.

One did stand out, which made you accept it, you just live with it, (participant 2, line 59)

I would read it as you can't turn your back on the truth, (participant 25, lines 378 - 379)

I used to skip at the beginning, the awful ones, the awful stories......now I read them,(participant 19, lines 35 - 36)

There were only three comments which were classified into this category. They show how the reading of the letters helped them come to terms with their own illness.

Category: Trajectory

This section consists of comments concerning letters about a person's situation changing, for better or for worse. Five participants made comments which were categorised as trajectory comments.

You find some have recovered from bad attacks, (participant 1, lines 67 - 68)

[She feels that after reading stories of where the person can now lead a normal life that she too might be able to live a normal life again] – 'well maybe if I get it in both ears then life is not over for me….' (participant 6, line 42]

[She was worse], but she's overcome, its given me encouragement that I can carry on and do things, (participant 4, line 52)

Comments which included both a downward or an upward trajectory could have been included in this category. However, all the trajectories were actually positive; they all were about a person who was very ill or struggling to cope and managed to get better or cope better. None of the statements were about someone who was doing well but then deteriorated.

5.2.6. Summary

The most popular categories, i.e. those mentioned by most participants, were downward positive (thirteen participants), upward positive (thirteen participants), and lateral similar (twelve participants). This shows a tendency to interpret stories positively (whether they describe people in a better or a worse situation) and an appreciation of finding someone whose experiences are similar to the participant. Participants took great comfort from finding others with the same illness, knowing they were there and knowing that someone else knows what they are going through. However, the participants did not just feel better or worse after reading about other people's stories they also gained information, and they did this from both upward and downward stories.

What is interesting from these results is that there were no upward negative comments. In other words, none of the participants felt dejected and negative after reading about others who were better off than they were. The acceptance category was only mentioned by three participants and so would appear to be of less importance than the other categories. The trajectory category was a little more popular with a third of the sample making a trajectory comment.

5.2.7. Conclusion

The purpose of the study was to determine how members of the Ménière's Society were using the self-help group, and more specifically Spin, to socially compare. All the members interviewed spontaneously admitted to socially comparing, with the Letters section being the most popular section, and the medical (factual) section coming a close second. The participants were gaining information from all their social comparisons, upward and downward. The dominant themes to emerge from this study were that members of this group were identifying with those better off and contrasting with those worse off, which, according to the Identification/contrast model, is healthy as it prevents depressive thoughts and anxiety about the future. Although lateral comparison was important to this particular group, the authors of the Identification/Contrast model do not include lateral comparison in their model. Comparison with others who have similar experiences was mentioned by 12 of the 15 participants. Downward comparison could lead to identification with the worse off other, to the extent that the comparer could experience negative affect and worry about their own future – nine people made comments about a possible negative future.

The trajectory category identified in this study consisted of comments made by a third of the sample and so was included as an important category. The trajectory category is interesting and could be classified as upward positive, as although the person was worse they are now better and it is this fact that gives them encouragement. It has not been classified as upward positive as the comments refer to the history, of being worse and then getting better, as important. The last category to discuss is the acceptance category. This category reflects one of Yalom's 12 curative factors. However, as less than a third of the sample made comments classified as acceptance of their illness it is unlikely that this is a function of social comparison for this group. Only three people talked about accepting their situation due to the letters, indicating that this category is probably not of great importance.

This study has shown that for the development of a social comparison scale the following aspects should be considered: upward (positive and information); lateral (others and similar), downward (negative, future, positive, and information); and trajectory.

5.3. Development of the SCI and GOQoL

5.3.1. The Social Comparison in Illness scale (SCI)

The design of the SCI was based on the Identification/Contrast model (Buunk et al., 1990). The authors of this model also developed a social comparison scale, the Identification/Contrast scale (Van der Zee et al., 2000), briefly discussed in the introduction to this chapter. However, their scale omitted several aspects of social comparison considered to be important in this study. The SCI scale was designed based on the Identification/Contrast scale; the items are worded in a similar way. It measures comparison direction (upward, downward, and lateral comparisons) resulting in either positive or negative mood experiences (four items each). With respect to the concept of people moving towards goals important to QoL it was thought that it might be the trajectory which is important to the comparer rather than simply either up or down direction. Only positive trajectories (four items) were included as only positive trajectories were mentioned in the interview study. However, both positive and negative affective responses to the positive trajectory were included. For example, *'When I read the letters from someone who was coping badly but now is coping well, I feel hope,'* is a positive response to a positive trajectory. *'When I read about someone who was coping badly and is now coping well, I feel helpless that I am not coping well too'* is a negative response to a positive trajectory. In addition, this scale was designed to be illness oriented and so a distinction was made between the domains, level of coping and symptom severity. Finally, the SCI included a section which measured the extent of comparing for information purposes only (four items).

The wording was oriented throughout towards a person who would be socially comparing through reading about other people with the same illness. The scale consisted of 20 items coded on a 5-point scale from strongly disagree = 1 to strongly agree = 5. A total score was obtained by summing all items together.

5.3.2. The Goal-Oriented QoL scale (GOQoL)

Chapter 2 detailed the need to measure three different aspects of QoL in order to capture the diverse nature of the construct. Having found suitable measures to cover 'functional' QoL and the 'perception of positive change,' only the 'goal-oriented' element needed to be accounted for. Having based the definition of goal-oriented QoL on the Control Process Model (Carver et al., 1990), a scale which assesses QoL with respect to progression towards goals and life satisfaction was needed. The subjective scales considered were the Patient Generated Index (PGI) (Ruta, Garratt, Leng, Russell, & MacDonald, 1994), and the Subjective Evaluation of Individual QoL (SEIQoL) (McGee et al., 1991). However, neither of these scales were suitable. The PGI is a subjective measure but it does not include questions concerning the perception of moving towards one's goals, a point which is the essence of the subjective QoL construct in this study. The SEIQoL is an interview–based questionnaire which, in a similar way to the PGI, asks the participant to nominate five domains of importance in their lives. This questionnaire makes use of both a vertical and a horizontal visual analogue scale (VAS) to measure the current status of that domain and the overall QoL. The complicated nature of this scale means that it can only be used in the presence of an interviewer and is not suitable for postal surveys. The second drawback, as with the PGI, is that it does not include items which assess the perception of moving towards goals. Instead, it measures current status with respect to that domain (goal) and overall QoL.

This gap in QoL measures led to the development of a new goal-oriented QoL measure, one which measures the perception of moving towards one's goals and life satisfaction.

The GOQoL scale was designed to measure goal-oriented QoL on two dimensions. First, it assessed current status with respect to overall QoL on five nominated domains (family, health, social, financial/work, and spirituality). This would indicate level of satisfaction with the current situation. This is based on the SEIQoL (O'Boyle et al., 1994). Secondly, an assessment of the perception of moving towards or away from goals was necessary. This subscale was based on the Control Process Model (Carver et al., 1990).

In the GOQoL the participant was first asked to rate their overall quality of life on a seven point Likert scale, ranging from 'the worst it could be' to 'my ideal situation' (this was coded –3 to +3). In the SEIQoL the participant was asked to nominate five domains of importance to him or her and rate their importance on another VAS. However, for the GOQoL the participants were provided with five domains which they were asked to rank in order of importance. The reasons for this decision were based on two points. Firstly, as this was a quantitative study there was a need to contain the vast selection of possible options which may be nominated by the participants. Secondly, studies using measures which ask the participant to nominate the domains have found the same domains to be nominated time and time again. The nominated domains were chosen from a review of five studies, three of which used the SEIQoL (McGee et al., 1991; O'Boyle et al., 1994), one which used the PGI (Ruta et al., 1994) and the fifth used the Repertory Grid method (Thunedborg, Allerup, & Joyce, 1993). The most common domains were health, family, relationships, social life, work, finances and religion. Five broad domains were then devised, (1) family and relationships, (2) work and/or finances, (3) social life and activities, (4) health (physical and emotional), (5) spirituality (religion or beliefs). There was no assumption that the nominated domains were important to the participant, the participant simply ranked them in the order of importance to him or her.

The next items in the scale were set in pairs and related to the above domains. The first question in each pair was based on the SEIQoL, the participant was asked to rate how close they felt they were to their ideal situation with regard to the above domains (five items – one for each domain). This used a seven point Likert scale, ranging from 'extremely far away (the furthest I could be)' (this was coded –3), to 'the closest I could be,' (coded +3). The second question for each domain was based on the Control Process Model and asked the person whether they felt they were moving towards or away from their ideal situation with respect to each domain (five items – one for each domain). This was also scored on a 7-point Likert scale ranging from 'moving very quickly away' (-3) to 'moving very quickly towards' my ideal situation (+3).

A score for current status on domains was obtained by summing the first item from each pair. Similarly, a score for perceived progression towards one's goals (called trajectory) was obtained by summing the second item from each pair. It was also possible to use the ranked domains to achieve a weighted version of both the status and trajectory items. This was done by multiplying the ranked domain with the relevant status or trajectory question. This allowed the importance of that domain to influence the overall score so that the domains more important to that person received a higher positive or negative score than those of lower importance

5.4. The validation of the SCI and the GOQoL

This section describes how the two newly developed scales were validated. Postal questionnaires were administered to a sample of members of the Ménière's society (this sample did not take place in the main study, in Chapters 6 and 7, as they were removed from the group before the main sample was selected). Both the two new scales were completed alongside previously validated scales. Significant correlations between the new scales and the previously validated ones would indicate that the new scale was measuring the same construct as the old one, so showing that it is valid.

5.4.1. Method

Participants:

The participants for this study consisted of 196 members of the Ménière's Society, described in Chapter 1. All the participants had received a diagnosis of Ménière's disease from an ENT specialist.

Design

This was a postal survey study which aimed to validate the two new questionnaires. The SF-36 was used to validate the GOQoL and the Identification/Contrast scale was used to validate the SCI. The disease severity scales assisted in the validation of the GOQoL. Validation of the two new scales was shown by significant correlations with the previously validated scales.

For the GOQoL, the correlations with the SF-36 were expected to be significant but moderate, as this would indicate that the two scales were measuring different aspects of QoL. The GOQoL and the SF-36 were also expected to show a similar pattern of correlations with the disease severity scales. Validation of the SCI was shown by significant correlations with the factor components of the Identification/Contrast scale.

Also included in this questionnaire pack was a self-help group scale. This scale, reviewed in section 5.5.1.3. was adapted from a self-help group scale which was used to assess the usefulness of groups which met on a regular basis (Citron et al., 1999). It was adapted by changing the wording so as to make sense to a member of a self-help group which does not meet at all but maintains contact through their specialist magazine. It was included in this pilot study to check that the adaptation of the wording employed for this study did not affect the reliability of the scale.

Questionnaire design

The questionnaire pack consisted of nine scales (see Appendix D): the newly developed Social Comparison in Illness Scale (SCI); the Identification/Contrast scale (Van der Zee et al., 2000); the newly developed goal-oriented quality of life scale (GOQoL); the SF-36 (Ware et al., 1993); a self-help group scale (Citron et al., 1999); items assessing demographic information; and three disease severity scales: tinnitus (Halford & Anderson, 1991), hearing (Lutman, Brown, & Coles, 1987) and dizziness (Yardley, Masson, Verschuur, Haacke, & Luxon, 1992). As the two new scales have already been described the following section consists of the other scales used in the questionnaire.

Identification/contrast scale

This scale was discussed in the introduction and in the preceding section and was included in this study to validate the SCI. It is a scale which measures the type of emotion (positive or negative) experienced after either upward or downward comparison. It consists of 12 items and is scored on a five-point Likert scale from strongly disagree = 1 to strongly agree = 5. A total score can be obtained by summing the items. Principal component analysis showed the factors, upward identification (positive), downward contrast (positive), upward contrast (negative), and downward identification (negative), to emerge when a four factor structure was requested (Van der Zee et al., 2000). Both positive factors correlate with each other and both negative factors correlate with each other. Upward identification and downward contrast are positive affect scenarios where identification with someone better off and contrasting with someone worse off lead to positive affect. Conversely, identifying with someone worse off and contrasting with someone better off leads to negative affect. The wording was modified to read *'when I read about others...'* as opposed to *'when I see others....'*

SF-36

The SF-36 (Jenkinson et al., 1993; Ware et al., 1993) questionnaire was included to validate the GOQoL scale. It is a subjective questionnaire in that it is completed by the individual and is a measure of their own physical and psychological health and functioning on a day-to-day basis. It consists of thirty six items which includes items which measure the participant's subjective perception of their situation (for example, How would you rate your health in general?), and items which measure aspects which use an objective rating (for example, Does you health limit you in walking half a mile?). It concerns functional aspects of QoL, as opposed to goals and so what it measures is referred to as functional QoL throughout this thesis.

Prior to the decision to use the SF-36 other questionnaires were considered. The questionnaire used for the validation of the GOQoL needed to be suitable for postal questionnaires and therefore simple to complete. It was important, too, that the chosen measure should not be too lengthy as it was to be administered alongside the other questionnaires. A questionnaire of excessive length is off putting and may reduce the response rate. The other questionnaires considered were, WHOQOL (The WHOQOL Group, 1998), the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP), the McMaster Health Index Questionnaire (MHIQ).

The WHOQOL is a QoL measure which assesses QoL over six domains (Skevington, 1999) and has cross-cultural validity, being used in 15 countries. However, it consists of 100 items and was therefore too large for inclusion in this study. The WHOQOL-BREF is a 25-item questionnaire, a simplified version of the WHOQOL, which is best used where a brief assessment of QoL is needed. However, the WHOQOL-BREF is not sensitive to change in the social domain (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000). In addition, both the WHOQOL and WHOQOL-BREF are not yet widely used (Carr & Higginson, 2001). The NHP is a well-used QoL questionnaire which assesses QoL using 38 items. However, it is a scale which assesses the more severe end of the illness continuum. In addition, due to its dichotomous coding (yes/no) it is not sensitive to small changes in health status. The SIP and its UK adaptation, the Functional Limitation Profile (FLP) is a long questionnaire containing 136 items which make up 12 categories. It is time consuming to complete and questions have been raised about how sensitive to change it is. The McMaster Health Index Questionnaire (MHIQ) consists of 59 items and measures health on three domains, physical, social and emotional functioning. However, its value for use in an elderly population has not yet been determined (Bowling, 1992).

The most suitable questionnaire found was the SF-36 (Jenkinson et al., 1993) which is a widely used generic quality of life questionnaire that has been validated in the UK. In support of this, a review of 3921 QoL reports shows the SF-36 accounting for 10% of the total (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). There are many versions of the SF-36, the one to be used in this study is the one which is the most widely used in the UK and was developed in 1993. It consists of 36 items and covers eight domains and an additional item on perceptions of change in health. The eight domains are, physical health, mental health, pain, vitality, role emotional (where health has interfered with one's role emotionally), role functional (where one's health has interfered with one's role functionally), social functioning, and general health (Jenkinson et al., 1993). It also measures both positive and negative health states (Brazier et al., 1992). As it is a generic questionnaire it is recommended that it be used alongside other questionnaires, for example, an illness specific QoL questionnaire (Garratt et al., 1993; Jenkinson et al., 1993). The benefits of using this scale are that it has been widely used in the UK, which allows comparisons to be drawn between illnesses, and it is sensitive to small variations in health status due to its Likert-style questions. Many of the SF-36 publications are of working age people only, however, in a study with those aged over 65 it was found to be both valid and reliable (Sharples, Todd, Caine, & Tait, 2000).

Summary scores are calculated for the eight domains according to the SF-36 manual (Ware et al., 1993). Initially the relevant items are summed; these totals are then transformed. This occurs where the lowest possible score for each group of items making up that summary score is subtracted from the total. The result of this subtraction is then divided by the possible range for that domain. The result of this is then multiplied by 100 to achieve a score out of 100. High scores on the SF-36 show better health. Two summary scores for physical and mental health can be calculated following the manual (Ware et al., 1995).

Self-Help Group scale

This scale measures the extent of helpfulness of the self-help group (the extent to which they experienced change on 12 of Yalom's dimensions of change), and is an adaptation of Lieberman's (1973) Mechanisms of Change scale. This in turn was developed from Yalom's (1970) list of twelve therapeutic factors which instigate change in a therapeutic situation. These factors are: recapitulation of the primary family group; identification; universality; instillation of hope; guidance; interpersonal learning (output); catharsis; cohesiveness; self-understanding; altruism; interpersonal learning (input); existential factors. There is one item per factor leading to 12 items. This scale has been used with self-help groups which meet regularly and which have a direct involvement in instigating change in their members. It has since been adapted for use in other self-help group studies (Butler et al., 1980; Citron et al., 1999; Llewelyn et al., 1986). The questionnaire attempts to determine in what way the group is helpful and in what way it instigates change. With this in mind, it seemed that with a little adaptation the Mechanisms of Change questionnaire would be useful for this particular study.

Both Llewelyn and Haslett (1986) and Citron et al. (1999) omitted two of Yalom's factors in their questionnaire. In a pilot study with self-help group members, these factors (recapitulation of the primary family group and existential factors) appeared not to be important. This is probably due to the fact that these two curative factors are more important to those in a therapeutic setting, such as individual therapy (Yalom, 1970). Self-help group members were unlikely to find these factors as reasons why the self-help group was helpful (Llewelyn et al., 1986). As so few of the Ménière's Society members actually meet, it seemed unlikely that they will see the group as their family and so the item measuring 'recapitulation of the family group,' was omitted from this study. However, existential factors may be relevant as three (20%) participants in the interview study (above) commented on coming to terms with their illness due to the stories they had read. For example, one participant said that it was through reading the letters that she realized that she had lost her independence and that she felt she should try a little harder. This comment could be classified as taking responsibility and, based on this, the item measuring this factor was included in the scale. There is also some question as to whether the two factors on interpersonal learning would be relevant to a self-help group such as the Ménière's Society. Learning how to get along with others surely involves some face-to-face contact and negotiation. The Ménière's Society members, of course, mostly do not have this contact. Can they learn about interpersonal relations from reading letters? Kurtz (1997), too, questions the importance of this factor in a self-help group. This is more relevant to psychotherapeutic groups where confrontational meetings do take place, and so the items relating to these factors (one item for each of the two factors) were also be omitted from the scale in this study. The other nine items (nine factors) were reworded to be more appropriate for a self- help group like the Ménière's Society, which relies on its quarterly magazine to help its members.

Participants in this study were asked to indicate the degree of usefulness of the Ménière's Society on each dimension of change by circling the relevant answer (similar to Citron et al., 1999) for nine items on a three-point Likert scale, not helpful (1) to very helpful (3). A total score was calculated by summing all the items together.

Items assessing demographic information

A demographic section was also included to assess demographic and health-related factors thought to influence QoL and adjustment. These were: age, sex, an item on whether the person suffers from any other illnesses, an item asking if they are on any medication other than medication for their Ménière's disease, type of diagnosis (have you been diagnosed with Ménière's disease by a hospital doctor?), and length of membership of the Ménière's Society.

Disease severity scales

The effect of physical functioning on QoL is direct and can be extensive. Effects of this type can cloud the other issues which concern this study, such as social comparison. For the purposes of the main study it was necessary to control for these effects. This was done with disease severity scales which assesses the physical incapacity experienced. It was also necessary to assess the relationship of the disease severity scales to the GOQoL. A comparison of this relationship and the relationship to the SF-36 to the disease severity scales was also necessary as part of the validation process. One would expect a similar relationship between the disease severity scales and the two QoL scales. Currently there is no single disease severity scale for Ménière's disease and so three separate scales covering the main symptoms were included, namely, tinnitus, hearing loss, and dizziness. All three disease severity scales were chosen based on their ability to measure the severity of the symptom, or the degree of impairment they experienced.

-Tinnitus

Several tinnitus questionnaires were considered for inclusion. The Tinnitus Severity Index (Folmer, Griest, Meikle, & Martin, 1999) seeks to assess the negative aspects of tinnitus. However, its validity and reliability have not been reported and the items do not appear to be very sensitive. For example, for people with Ménière's disease tinnitus can be intermittent and there is no item which refers to periods of quiet (without tinnitus) in this scale. The Tinnitus Handicap Questionnaire (THQ) measures tinnitus by the degree of handicap which the person experiences (Kuk, Tyler, Russell, & Jordan, 1990) and so is not a simple measure of severity. Similarly, the Tinnitus Reaction Questionnaire (TRQ) measures tinnitus by the degree of psychological distress which the person experiences (Wilson, Henry, Bowen, & Haralambous, 1991) rather than severity of tinnitus itself.

The above scales were not suitable for this study as they tended to measure handicap as opposed to disability. The scale chosen for inclusion in this study was the Subjective Tinnitus Severity Scale (STSS),which was designed to measure the patient's perception of the experience of tinnitus (Halford et al., 1991). It consists of 16 items which cover both severity and handicap. It is a scale which allows for the fact that tinnitus is something which is difficult to measure due to the fact that it is so subjective. It has shown a high reliability and validity. It also asks questions relating to periods of quiet (without tinnitus) which makes it more suitable for a population of people with Ménière's Disease. It has a dichotomous scoring, yes = 1 and no = 0 (ten items score 1 with yes and six items score 1 with no), and a total score is obtained by summing all the items. Due to the intermittent nature of Ménière's disease participants were asked to complete the questionnaire as if it was a day when their tinnitus was bad.

-Hearing Loss

The hearing disability scale to be used here is a subscale of the hearing disability and handicap scale used in the Medical Research Council National Study of Hearing (Lutman et al., 1987). It is a short scale which is both reliable and valid. This scale shows a factor structure which loaded onto four principal components (Lutman et al., 1987). These factors were, 'everyday speech,' 'speech-in-quiet,' 'localisation,' and 'handicap.' In this study , as only the severity of the hearing loss was necessary only those items which loaded on the severity factors (everyday speech, speech-in-quiet, and localisation) were included, five items in total. An example of the type of an item is, *'Can you follow what is being said on the radio news when the volume is turned up only enough to suit other people?'* The scale is scored so that zero indicates no hearing difficulty. Three of the items are scored on a three-point Likert scale with not at all = 2 to easily = 0. Two of the items are scored on a four-point Likert scale from not at all = 3 to no difficulty (or usually) = 0. Before a total score can be calculated, recoding needs to take place so that the highest score for each item is six. A total score can then be obtained by summing all the items together. Participants were asked to tick the answer most appropriate to them without the use of a hearing aid, should they use one.

-Dizziness

The dizziness scale chosen for this study was the vertigo subscale from the Vertigo Severity Scale (Yardley et al., 1992). Of the vertigo scales which exist this scale is the only severity scale, others like the Dizziness Handicap Inventory (Jacobson & Newman, 1990) are handicap scales. It is a reliable and previously validated scale which assesses the severity of the vertiginous episodes based on the frequency of the attack, the length of the attack, and the frequency of other related symptoms such as nausea and vomiting. It consists of 19 items which are scored on a five-point Likert-type scale with 0 indicating 'never' and 4 indicating 'very often' (more than once a week). An overall score for vertigo can be obtained by summing all the items. A high score shows severe vertigo.

5.4.2. Procedure

Two hundred Ménière's Society members were randomly selected using a computer programme. This involved using the RAND command in Microsoft EXCEL to randomly generate numbers which were assigned to all the members of the society, so ensuring a random selection of participants. Although the membership numbers had been made available, the names and addresses were withheld by the Ménière's Society in order to maintain confidentiality. Participant numbers were then assigned to the membership numbers and it was only the participant number which appeared on the questionnaire; again, this was done for confidentiality purposes. The questionnaire pack contained a letter of introduction from the Ménière's Society, and an introduction letter from the researcher which also assured confidentiality, anonymity and freedom to withdraw (Appendix D). Also included in the pack were a copy of the questionnaire (Appendix D), and a prepaid return addressed envelope.

After only a 30% response rate, a further 400 questionnaire packs were sent out to another 400 members, once again randomly selected. This resulted in a 34% response rate (206 questionnaires returned in total). Four participants were excluded as they did not have Ménière's disease. A further six were excluded due to the high percentage of missing data. This left a data set of 196 participants.

5.4.3. Analysis

The SF-36 scores were recoded in accordance with the scoring manual (Ware et al., 1993). The Hearing scale was recoded as two of the items have a three-point scale and two have a four-point scale. The recoding meant that each item was coded out of six so that 0, 1, and 2 were recoded 0, 3, and 6 for the three-point items and for the four-point scale 0, 1, 2, and 3 were recoded 0, 2, 4, and 6 respectively.

For all scales (except question 1 and 2(i-v) of the GOQoL scale) missing data was dealt with by imputing the summary score mean for that subscale (Ware et al., 1993). For question 1 and 2 (i-v) of the GOQoL scale missing data was dealt with by imputing group means, this is because summary score means do not exist for these items. Where more than 50% of the summary items were missing the participant was removed from the data set (Ware et al., 1993).

Reliability analysis was then calculated using Cronbach's alpha. Exploratory principal component analysis with Varimax rotation was performed on the two social comparison scales (SCI and Identification/Contrast scale). Sub-scales were calculated by adding those items with high loadings on each factor (three items per factor), and bivariate correlations calculated with all the sub-scales.

5.4.4. Results

-Items assessing demographic information

The sample consisted of only those who had been diagnosed with MD, as those with different diagnoses had been excluded from the study. The age range was 26 to 82 with a mean and median of 58 years. There was a predominance of women in the study with 131 (67%) women and 65 men. The duration of the illness ranged from those just diagnosed to those who had had Ménière's disease for 36 years, with a mean of 9.24 years and a median of 7 years. Reported length of membership showed a range of just joined (0 years) to 20 years. The mean for length of membership was 4.89 years with a median of 3 years. Most of the participants had another illness, and the majority were on medication (n=117 and n=125 respectively).

-Reliability

Cronbach's alpha was calculated for all scales, results of which are shown in Tables 1 to 5. All scales showed an alpha of over the acceptable level of .7.

Tables 1 - 5: Reliability Coefficients for all the sub-scales and scales used in the study:

Table 1: Social comparison in Illness scale

Subscale	N	Items	M	SD	α
Information	196	4	15.2	2.60	.76
Upward information interpreted positively	196	6	22.9	3.54	.86
Downward information interpreted positively	196	2	7.39	1.89	.88
Upward information interpreted negatively	196	6	14.3	4.19	.86
Downward information interpreted negatively	196	2	6.11	2.02	.81

Table 2: Identification/Contrast scale

Subscale	N	Items	M	SD	α
Upward information interpreted positively	196	3	11.2	2.32	.90
Downward information interpreted positively	196	3	11.12	2.49	.89
Upward information interpreted negatively	196	3	7.81	2.55	.84
Downward information interpreted negatively	196	3	8.56	3.19	.95

Table 3: Goal-oriented QoL scale

Subscale	N	Items	M	SD	α
-State	196	6	1.71	5.67	.82
-State (weighted)	196	6	7.19	18.0	.74
-Trajectory	196	6	.86	4.41	.81
-Trajectory (weighted)	196	6	3.01	13.8	.73

Table 4: SF-36

Subscale	N	Items	M	SD	α
-Physical health	196	10	22.9	5.54	.81
-Role-physical	196	4	5.57	1.72	.91
-Body pain	196	2	8.60	2.79	.94
-General health	196	5	14.4	5.10	.87
-Vitality/energy	196	4	12.9	4.71	.87
-Social functioning	196	2	6.63	2.56	.83
-Role emotional	196	3	4.69	1.34	.86
-Mental health	196	5	20.8	5.52	.86

Table 5: Disease severity and self-help group scales

Scale	N	Items	M	SD	α
Tinnitus	196	16	7.29	4.25	.87
Hearing	196	5	13.8	8.02	.85
Dizziness	196	19	21.5	17.0	.91
Self-help	196	9	24.5	3.03	.84

-Validation of the Social Comparison Scale

To determine what factor components were inherent in the SCI scale, exploratory factor analysis was conducted on the scale. Potentially, analysis of these items could produce different factors corresponding to information, coping, symptoms, upward, lateral, trajectory, and/or downward principal components. However, five principal component factors were found to be present, together they accounted for 67.7% of the variance (Table 6). Four of these factors correspond to the Identification/Contrast scale (upward positive, upward negative, downward positive, and downward negative), with the addition of a fifth factor, information. The first four are made up of the following items: (a) all negative upward, lateral and trajectory comparisons (both dimensions; coping and symptoms); (b) all positive upward, lateral and trajectory comparisons (both dimensions); (c) all downward negative comparisons (both targets); (d) and all downward positive comparisons (both dimensions).

Table 6: Factor Analysis of Social Comparison Scale, Factor Matrix Loadings after Varimax rotation

Subscale/Item	ucpos	ucneg	Info	dcpos	dcneg
Information					
I read the letters to see…					
-…have any advice…	.282	-.151	**.803**	.	.
-…if I am coping better or worse….	.227	.152	**.679**	.374	.130
-…if I am more or less ill…	.306	.451	**.490**	.355	.105
-…medical advice in the letter…	.345	.	**.738**	-.110	.
Upward positive comparison					
When I read the letters from people...					
-…coping better, I feel inspired	**.676**	-.116	.232	.137	.150
-…with milder symptoms, I feel hopeful…	**.707**	.	.180	.129	.
Lateral positive comparison					
-…who are coping the same, I don't feel so alone…	**.704**	.	.314	.197	.
-… who have MD in a similar way to me, I don't feel so alone…	**.643**	.	.284	.102	.
Trajectory positive					
-…who had MD badly but now is in remission, I feel hopeful…	**.771**	-.286	.	.136	.
-who was coping badly but now is coping well, I feel hope…	**.853**	.	.	.	.125

Table 6 continued

Subscale/Item	ucpos	ucneg	Info	dcpos	dcneg
Downward positive comparison					
-... who are not coping as well, I feel lucky...	.270	.	.109	**.869**	.
-...with worse symptoms, I feel lucky...	.229	-.153	.	**.874**	.
Upward negative comparison					
...-coping better I feel depressed...	-.192	**.734**	.	.	.111
-...with milder symptoms I feel sorry for myself...	.	**.821**	.	.	.
Lateral negative comparison					
-...who are coping the same, I feel depressed...	.	**.880**	.	-.106	.105
-...who have MD the same as I do, I feel depressed ...	.	**.802**	.	-.158	.149
Trajectory negative					
-...whose symptoms were bad but now are better, I feel, 'I am never going to be like that.'...	-.101	**.451**	.123	.	.420
-...who was coping badly and now is coping well, I feel helpless...	.	**.62**	.	.	.424
downward negative comparison					
-...who are not coping as well as I am, I feel scared...	.	.250	.	.	**.829**
-...with worse symptoms than I, I feel 'have I got this to come?...	.	.172	.	.	**.875**
Eigen values	3.7	3.7	2.2	1.96	1.94
Percentage of variance explained	18.65	18.51	11.03	9.78	9.72

(Factor loadings >.5 are highlighted in bold; correlations < 0 are represented by a full-stop)

info = social comparison for information purposes

ucneg = upward information interpreted negatively

ucpos = upward information interpreted positively

dcneg = downward information interpreted negatively

dcpos = downward information interpreted positively

Factor analysis on the Identification/Contrast scale using Eigen-values greater than one to extract factors produced three factor components. The first two factors consisted of upward identification (positive) and downward contrast (positive) respectively. The third factor consisted of both the negative comparisons, that is, upward contrast and downward identification. Thereafter, a four-factor structure was imposed as suggested by Van der Zee et al. (2000), the results of which are show in Table 7. These four factors are, downward identification (downward negative), upward identification (upward positive), downward contrast (downward positive), and upward contrast (upward negative). Together these factors account for 83.46% of the variance.

Table 7: Factor Analysis of Identification/Contrast scale Factor Matrix Loadings

Item	Downward Identification	Upward identification	Downward contrast	Upward contrast
When I read about others...				
...doing worse, I experience fear I will decline	**.904**	.	.	.294
..are doing worse, I fear for my future	**.902**	.	.	.317
...doing worse, I fear I will go the same way	**.915**	.	.	.239
...who experience more difficulties, I feel relieved	.	.243	**.870**	-.106
...who experience more difficulties, I feel relieved	.	.219	**.880**	.
...who experience more difficulties, I realise how well I am doing...	.	.276	**.822**	-.154
...who experience fewer problems, I than I realise it is possible to improve...	.	**.875**	.268	.
...who experience fewer problems than I, I am pleased that things can get better...	.	**.901**	.204	.
...who are experiencing fewer, problems than I it gives me hope...	.	**.871**	.256	.
...who are doing better than I, I find it threatening...	.304	.	.	**.780**
...who are doing better than I, I feel frustrated...	.241	.	-.107	**.856**
...who are doing better than I, I feel depressed...	.280	.	-.140	**.830**
Eigen value	2.71	2.55	2.44	2.32
Percentage of variance explained	22.57	21.23	20.36	19.30

(Factor loadings >.5 are highlighted in bold; correlations near zero are represented by a full-stop)

Table 8 shows the correlations between the Identification/Contrast subscales and the SCI subscales. These correlations show the expected relationship. The Identification/Contrast downward comparison interpreted negatively (downward identification), where one identifies with someone worse-off, correlates the most highly with downward comparison interpreted negatively of the SCI scale (downward negative). Upward identification (I/C), where one identifies with someone better-off, is most highly correlated with upward comparison interpreted positively (SCI) (upward positive). Downward contrast (I/C), where one sees themselves as different to someone worse-off, correlates principally with downward positive comparison (SCI) (downward positive). Finally, for upward contrast (I/C), where one sees a person who is better-off as different to oneself, upward negative comparison (SCI) (upward negative) correlates most strongly. Interestingly, information (SCI) correlates moderately with all four of the Identification/Contrast subscales.

Table 8: Correlations between subscales of the Identification/Contrast scale and the Social Comparison in Illness scale.

	I/C Downward	Upward	Downward	Upward
Social Comparison Scale	Identification	Identification	Contrast	Contrast
Upward negative comparisons	.394**	-.341**	-.382**	.611**
Upward positive comparisons	.111	.536**	.371**	.098
Comparisons for information	.214**	.206**	.234**	.177**
Downward positive comparisons	-.011	.279**	.570**	.005
Downward negative comparisons	.773**	-.033	-.160*	.533**

(** correlation is significant at the 0.01 level (2-tailed))

Table 9 shows correlations between the SCI and I/C subscales and both the SF-36 total score and the GOQoL summary scores. The factor components from the SCI scale are paired with the relevant factor components of the I/C scale. So for example, Upward contrast (I/C) was paired with upward comparisons interpreted negatively (upward negative). These correlations were carried out to determine whether QoL was associated with social comparison. Results show upward negative (I/C and SCI) and information (SCI) to correlate with all the GOQoL subscales and the SF-36 total score. For upward positive (I/C) correlations with state (weighted), trajectory and trajectory (weighted) are significant. Downward positive (SCI) correlates significantly with only the state and state (w) summary score and downward contrast (I/C) correlates significantly with all the QoL scores. Downward negative (SCI and I/C) correlates significantly with all the QoL scores, with the I/C showing slightly higher correlations than the SCI.

Table 9: Correlations between SF36, GOQoL, Mechanisms of change scale, the Identification/Contrast Scale and Social comparison scale

	State	State(w)	Trajectory	Trajectory (w)	SF36
Upward negative (SCI)	-.375**	-.352**	-.393**	-.386**	-.422**
Upward contrast (I/C)	-.397**	-.385**	-.346**	-.334**	-.492**
Upward positive (SCI)	-.052	-.061	-.013	-.015	-.073
Upward identification (I/C)	.135	.121*	.174*	.172*	.040
Information (SCI)	-.181	-.204*	-.143*	-.153*	-.184*
Downward positive (SCI)	.141	.146*	.020	.016	.092
Downward contrast (I/C)	.286**	.266**	.227**	.218**	.234**
Downward negative (SCI)	-.166*	-.145*	-.160*	-.151*	-.184*
Downward identification (I/C)	-.214*	-.200**	-.225**	-.222**	-.240**

(** correlation is significant at the 0.01 level (2-tailed), * correlation is significant at the 0.05 level (2-tailed)). (w) = weighted version of the subscale

Finally, the self-help group scale was correlated with the SCI, I/C, and QoL (GOQoL summary scores and SF-36 total score). Correlations between the self-help group scale and all the QoL scales were close to zero and have not been presented here. Of the correlations with the social comparison factor components only upward positive (SCI and I/C), downward positive (SCI and I/C) and information (SCI) were significant at the .01 level.

-Validation of the Goal-Oriented Quality of Life Scale (GOQoL)

The GOQoL produced four summary scores. The state summary score measures how close one feels one is to one's ideal state with regard to one of the five domains. The weighted state variable refers to the state summary score which is weighted according to how important each domain was relative to the other domains. The trajectory score refers to the summary score of those items which measure the perception of moving towards or away from those goals. Again, the weighted version consists of the multiplication of the items and their relative importance. Correlations between the different versions of the GOQoL are shown in Table 10. All correlations are high and are significant at the .01 level.

Table 10: Correlations between the State, State (weighted), trajectory and trajectory (weighted) scales.

Variable:	State	State (w)	Trajectory
State (w)	.974**		
Trajectory	.733**	.707**	
Trajectory (w)	.709**	.708**	.983**

(** correlation is significant at the 0.01 level (2-tailed)). (w) = weighted version of the subscale

To validate the GOQoL scale bivariate correlations were conducted with the SF-36. In order for validation to be achieved the two scales should correlate significantly. These correlations are shown in Table 11, and show moderately significant positive correlation. The highest correlation is with the social functioning domain of the SF-36 and the four versions of the

GOQoL. Although not identical, the difference between the SF-36 correlations with the GOQoL state and weighted subscales is negligible.

Table 11: Correlations between the SF36 subscales and Goal-oriented Quality of Life

Scale: GOQoL:	State	State, weighted	Trajectory	Trajectory, weighted
SF-36:	.698**	.691**	.490**	.469**
Physical function	.486**	.487**	.337**	.322**
Role limit (physical)	.520**	.501**	.355**	.335**
Role limit (mental)	.571**	.545**	.450**	.429**
Social function	.711**	.705**	.494**	.472**
Mental	.536**	.527**	.383**	.367**
Energy	.581**	.573**	.363**	.323**
Pain	.302**	.336**	.210**	.221**
Health perception	.553**	.559**	.385**	.376**
Change	.391**	.382**	.505**	.504**

(** correlation is significant at the 0.01 level (2-tailed))

Table 12 shows the bivariate correlations between the QoL summary scores (SF-36 and GOQoL) and the disease severity scores. All these correlations are negatively significant and the strength of the correlations between the SF-36 summary scores and the GOQoL scores is similar. This means that the greater the disease severity, the lower the perceived QoL for both functional and goal-oriented QoL.

Table 12: Correlations between the SF-36, the Subjective QoL Scale and the Disease Severity Scales.

	Tinnitus	Hearing	Dizziness
GOQoL:			
State	-.388**	-.239**	-.333**
State, weighted	-.375**	-.229**	-.327**
Trajectory	-.225**	-.154*	-.165*
Trajectory, weighted	-.216**	-.133*	-.158*
SF-36:			
Physical	-.347**	-.236**	-.271**
Role limit (physical)	-.242**	-.264**	-.440**
Role limit (mental)	-.282**	-.163*	-.319**
Social functioning	-.353**	-.237**	-.458**
Mental health	-.442**	-.206**	-.349**
Energy	-.351**	-.223**	-.381**
Pain	-.352**	-.269**	-.245**
Health perception	-.417**	-.282**	-.331**
Change	-.144*	-.126	-.162*

(** correlation is significant at the 0.01 level (2-tailed),
* correlation is significant at the 0.05 level (2-tailed)).

5.5. Discussion

The aim of this study was to validate two new scales (a social comparison scale and a goal-oriented QoL scale) for use in a QoL survey. Based on the literature the two new scales were designed and administered along side previously validated scales for validation. Also included were three disease severity scales, a modified self-help scale, and a section assessing demographic information.

The new SCI scale was based on theory and the results of the interview study. It was developed to measure the effects of social comparison on adjustment in the main survey to determine what sort of social comparison is helpful to this population, It included the concept of a trajectory of illness as opposed to a static 'better than' or 'worse than' comparison. Lateral comparison was also seen as an important level along with upward and downward comparison. Information was also included as a reason for socially comparing and it distinguishes between dimension (coping and symptoms)

However, factor analysis revealed that both lateral and trajectory comparisons were assimilated with the upward comparisons, with those interpreted negatively grouped with the upward negative items, and those interpreted positively grouped with the upward positive items. In addition, target level, too, was not important as symptom and coping were grouped together according to direction and affect. The only distinguishing characteristics of the grouping were broad direction (either upward or downward) and the affect experienced, the interpretation of the comparison information. This factor structure matches that of the I/C scale with the exception of an additional information factor which is not present in the I/C scale.

Both the SCI and I/C subscales were reliable, with the I/C showing slightly higher alpha scores for most of the subscales. For validation, correlations between the matching SCI and I/C subscales were significant indicating that for each subscale, the more one engaged in, for example, positive upward comparison (SCI) the more one engaged in upward identification (I/C). These results support the I/C model (Buunk et al., 1997) showing the four factors important to the model to be important in this study. However, these results also highlight the importance of including the 'information' items in a separate scale.

The SCI and I/C were also correlated with the QoL scales (SF-36 and GOQoL); results show that on the whole positive comparison correlates positively with QoL and negative social comparison correlates negatively with QoL. This indicates that positive social comparison is associated with better adjustment while negative social comparison is associated with worse adjustment. Although the results were very similar, the I/C showed mostly higher correlations than did the SCI. Curiously, information showed a moderately negative correlation with all the QoL variables. Further research would be needed to confirm whether or not too much information about one's illness leads to a worse adjustment or whether it simply reflects a desire for more information when one is most ill.

The design of the new QoL scale, based on the SEIQoL and the Control Process model, measures life satisfaction, and the perception of moving towards one's goals. Four subscales of goal-oriented QoL can be calculated from the GOQoL scale. Firstly, the 'status' subscale is a measure of where the individual perceives themselves to be with respect to five ranked domains. Secondly, the 'trajectory' subscale measures the perception of moving towards one's goals with respect to the same five domains. The third and fourth versions are weighted versions of the status and trajectory measures.

All four versions proved to be reliable when Cronbach's alpha tests were administered and all four show high correlations with each other. This shows that respondents did not seem to make a great distinction between distance from the ideal goals and rate of progression towards goals. For validation of this scale, the four subscales were correlated with the SF-36 domains. Significant correlations would indicate the GOQoL's validity. All correlations were significant; where the higher the perceived current functioning the more one perceived oneself to be moving towards one's goals. The social function domain of the SF-36 showed the highest correlation, as might be expected as the GOQoL chiefly measures aspects of QoL on social domains. Although all four subscales correlated significantly, the state subscale showed higher correlations with the SF-36 domains. This is not totally unexpected as the state version is measuring current standing with respect to domains as does the SF-36 (but the latter with respect to functionality within the domains). On the other hand, the trajectory version is measuring a perception of movement towards goals. The weighted and unweighted versions show similar correlations with the SF-36 domains. However, in most cases it is the unweighted version which has the higher correlation.

As a final test all four of the GOQoL subscales and the SF-36 domains were correlated with the disease severity scales. One would expect disease severity to have a negative effect on both goal-oriented and functional QoL. The expected pattern of correlations emerged, with high QoL scores (SF-36 and GOQoL) associated with low disease severity scores. The correlations were negatively and moderately significant, with the GOQoL subscales showing slightly lower correlations than the SF-36 domains. The fact that the GOQoL subscales show a similar pattern to the SF-36 domains is another confirmation of its validity.

These results support the Control Process model (Carver et al., 1990) by indicating that perception of proximity to goals and rate of moving towards goals is, indeed, associated with QoL.

The self-help scale was a modified version of one designed for therapeutic groups. It was found not to correlate with QoL but it did correlate with positive social comparison, that is, upward identification, downward contrast, and also with information. This indicates that positive social comparisons (upward and downward) were more important than negative social comparisons within the self-help group. Stories, which were interpreted positively, are associated with what the members find helpful about the Ménière's Society, but stories which were interpreted negatively were not associated with what the members find helpful about the Ménière's Society. This finding is consistent with results of research with cancer patients on the benefits of positive stories where 72% of the participants found positive stories helpful (Taylor et al., 1993).

5.6. Conclusion

In conclusion, both new scales have successfully been shown to be reliable and valid with subscales that have alpha scores similar to the previously validated scales. SCI factor components correlate significantly with the I/C components, confirming its validity. However, the I/C model was correct in that comparison level and target were the most important factors of social comparison. In view of these results, in the main study the I/C scale is probably the better scale to use than the SCI as the I/C scale has shown slightly higher reliability and higher correlations with the QoL scales and is well validated and widely used.

However, it excludes the information items which have emerged as important reasons for socially comparing in this study, and so it may be valuable to supplement the I/C scale with a scale measuring social comparison for the purpose of gaining information rather than regulating affect.

The GOQoL, too, showed good reliability and was validated by correlating with the SF-36. The unweighted trajectory subscale was chosen to be used in the main survey as the unweighted versions of the GOQoL scale was both more reliable and showed slightly better bivariate correlations with the other scales than the weighted versions. In addition, the SF-36 already measures current status of QoL, and the trajectory category, which had emerged as important in the qualitative study, coincided with the QoL definition used in this study.

The SHG scale proved to be reliable, however, it did not correlate significantly with QoL. It would appear that the therapeutic factors it measures are not relevant to QoL. Although it correlates with positive social comparison this scale is measuring something different to the objective of this study, and as the aim is to find predictors of QoL it did not seem valuable and so it was not included in the main study.

Having validated the two new scales, the next step was to design and conduct the first part of the main survey to measure adjustment, social comparison, and other predictors of adjustment, which follows in Chapter 6.

CHAPTER SIX: THE CROSS-SECTIONAL SURVEY

6.1. Introduction

The aim of this study was two-fold. While the overall aim of the main study was to measure change in QoL over time with the intention of determining what predicts this change over time, the cross-sectional hypotheses were more specific. The cross-sectional study served the purpose of collecting the baseline data for the longitudinal analysis while also testing the principal cross-sectional hypotheses. The first hypothesis was that those high in optimism, perceived control over illness, and self-esteem would have better adjustment as suggested by previous research (Carver et al., 2000; Citron et al., 1999; Moss-Morris et al., 2001; Taylor, 1983). The second hypothesis was that social comparison would be associated with adjustment after controlling for factors previously shown to be significant in the literature. These factors comprised the variables described above, as well as demographic characteristics and measures of disease severity (Jenkinson et al., 1993).

The review of QoL and adjustment in chapter 2 showed this to be a broad and complex concept and this highlighted the need to measure QoL in more than one way to capture its diverse nature. In light of this, three different measures were used in this study to capture three different aspects of the concept. These aspects included the impact of health on functional QoL, the perception of progressing towards goals, and the perception of positive change since the onset of the illness. That health and illness have an impact on QoL is well-known (Brazier et al., 1992; Jenkinson et al., 1993) so a measure of the perceived impact was considered important. The perception of movement towards goals is also highlighted as important to QoL in Carver and Scheier's (1990) self-regulation model, which emphasises the importance of goal achievement in the perception of QoL. The perception of positive change since the onset of the illness is important as a measure of adjustment after a crisis (Tedeschi & Calhoun, 1996). This follows Taylor's (1982) Cognitive Adaptation Theory which states that giving meaning to an event is something which occurs as part of the adjustment process after the onset of a crisis.

6.2. Methods

This was a longitudinal study with the dependent variable, change in QoL, measured with three different scales, functional QoL as measured by the SF-36, goal-oriented QoL as measured by the Goal-Oriented QoL scale, and perceived positive change as measured by the Posttraumatic Growth Inventory. The independent variables were categorized as *catalysts* (illness severity), *antecedents* (demographics and personal characteristics like self-esteem, optimism, and perceived control), and *mechanisms* (social comparison and use of the self-help group).

The questionnaire to be used in this survey was designed after the validation of two newly developed questionnaires (Chapter 5). Due to the length of the questionnaire the decision was taken to split the questionnaire into two thereby hoping to increase the response rate. Questionnaire 1b would only be sent to those who agreed to receive it.

6.2.1. Participants

The sample consisted of one thousand Ménière's Society members who were randomly selected and sent questionnaire 1a (Appendix E). The participants all suffered from Ménière's disease or a related illness. Five hundred and fifty participants responded giving a 55% response rate. Of these respondents 499 agreed to be sent questionnaire 1b (Appendix F), 390 completed and returned their questionnaires giving a 78% response rate for questionnaire 1b.

6.2.2. Procedure

One thousand members of the Ménière's Society were randomly selected using Microsoft Excel's random number generator. These numbers were then checked by the Ménière's Society staff to see if all were still current members and were people suffering from Ménière's disease or a related illness. This was necessary as not all members of the Ménière's Society have Ménière's disease, some are professionals or relatives of those who have Ménière's disease. All were then sent a copy of Questionnaire 1a, and a covering letter explaining the aims of the research (Appendix E), which also assured confidentiality and anonymity. Also included was a letter of introduction from the Ménière's Society explaining what the research was all about. A prepaid return envelope was also included to encourage a response. Those not wishing to take part in the study were asked to return their questionnaire, uncompleted, in the prepaid envelope provided.

All the questionnaires were numbered with a participant number which was linked to their Ménière's Society membership number. This was to maintain confidentiality as only the Ménière's Society could link the participant number to the membership number. In this way those who wanted to receive questionnaire 1b could also be traced. This was also important as the follow-up questionnaire (questionnaire 2) was to be sent out ten months later to those who consented and it was, of course, necessary to be able to link responses to questionnaires 1a, 1b and 2.

The procedure followed the same pattern as that of the validation study (Chapter 5) except that this time there were two questionnaires. Questionnaire 1b was only sent to those who indicated on questionnaire 1a that they were happy to receive it. Questionnaire 1b was sent off immediately that questionnaire 1a was returned.

To further encourage a higher response rate than that of the validation study a short article was published in the Ménière's Society's quarterly magazine, Spin, explaining how the results of the research might benefit the members. Although this article was designed to encourage participation the wording still conformed to the Departmental Ethical guidelines.

6.2.3. Measures

The scales used in the survey are listed below. The scales used to measure the dependent variable, change in QoL, are described first. They are listed according to the aspect of QoL which they measure. Following this are the scales used to measure the independent variables, also listed according to that aspect which they measure.

Dependent variable

-Functional QoL - SF-36

Reviewed in Chapter 5 (section 5.5.), the SF-36 (Ware et al., 1993) is a generic quality of life measure and was used to measure the perceived impact of health on functional QoL. The questionnaire consists of 36 items which sum to the eight domain scores, which when entered into a formula, derive two summary scores, the physical and the mental summary scores (Ware et al., 1993). The eight domains were: role physical, role mental, general health, mental health, vitality, pain, social functioning, and physical health. All eight domains have a reported alpha of .76 and above (Jenkinson et al., 1993). Scoring of the scale took place according to the scoring manual (Ware et al., 1993).

-Goal-Oriented QoL - GOQoL

The trajectory subscale of the GOQoL measured the second aspect of QoL, the perception of movement towards or away from goals. It was designed and validated for use in this study, the development of which was described in Chapter 5 (section 5.4.2.). It consists of 5 items scored on a 7-point Likert scale ranging from -3 (very quickly away) to +3 (very quickly towards). All 5 items are summed to reach a summary score. A positive score indicates a perception of movement towards one's goals while a negative score indicates a perception of movement away from one's goals. Chapter 5 reported an alpha of .81 for the unweighted version of the trajectory scale. This scale also included the ranking of 5 domains in order of importance to the individual. These ranked domains can be multiplied by the above items to reach a weighted version of the scale. In this way the relative importance of each domain can be included in the summary score.

-Perceived positive change – The Posttraumatic Growth Inventory (PTGI)

This is a measure of perceived positive change since a crisis such as the onset of an illness (the third aspect of QoL). It is based on the philosophy that after a traumatic event we tend to look for some good which may have come about as a result of the trauma. In this respect, it can be both an outcome and a predictor of QoL. As an outcome it measures the degree of adjustment reached by assessing the degree of positive change perceived. As a predictor it is a coping strategy which may in turn have an effect on QoL. It has a high reported Cronbach's alpha of .94 indicating it has a high internal consistency. Its design is based on categories within which perceiving positive change falls, 'changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life' (Tedeschi et al., 1996). It consists of 21 items which are rated on a 6-point Likert scale ranging from 0 (no change at all) to 5 (to a very great degree). All 21 items are summed to reach an overall summary score. Five reported factors emerge from factor analysis, namely, relating to others, new possibilities, personal strength, spiritual change, and appreciation of life.

Independent variables

The catalyst – Disease Severity Scales

As there was no disease severity scale for Ménière's disease four separate scales were included to cover the four core symptoms, namely, vertigo, hearing, tinnitus and a 'feeling of fullness in the ear.'

-Vertigo

Vertigo was measured with the vertigo subscale of the Vertigo Symptom Scale (Yardley et al., 1992) which was reviewed in Chapter 5 (section 5.4.2.). This consists of 19 items which are scored on a 5-point Likert scale ranging from 0 (never) to 4 (very often, more than once a week). A summary score is calculated by summing all the items together. A high score indicates severe vertigo. It has a high reported reliability of .80 and also includes items which measure the accompanying symptoms of vertigo, namely, nausea and vomiting.

-Hearing scale

The hearing scale used in this study was a subscale of the questionnaire used in the MRC National Study of Hearing (Lutman et al., 1987) which was reviewed in Chapter 5 (section 5.4.2.). It consists of 5 items, two scored on a 3-point scale and three scored on a 4-point scale. All items were recoded before they were summed to reach a single summary hearing score. A higher score indicates severe hearing difficulties.

-Tinnitus and Fullness of the ear

Both tinnitus and 'fullness of the ear' were measured with single items taken from Stahle's staging procedure for Ménière's disease (Cass, 1999; Stahle, 1978), which uses a seven-point scale to assess the severity of the symptoms. The tinnitus scale ranges from 0 = none (no symptoms) to 6 = severe, primary problem. The 'fullness' scale ranged from 0 = none (no symptoms) to 6 = almost constant and incapacitating.

The Antecedents – Demographic factors and personal characteristics

-Items measuring demographic information

This section consisted of single items which measured age, sex, occupation (or last occupation if retired, or spouse's occupation if a homemaker), social support (live-in and external), and whether they had a dependent whom they had to look after. Two items also assessed professional support, the perceived degree of helpfulness of both their GP and ENT specialist (1 item each rated on a 5-point Likert scale).

-Perceived control over illness

This was measured by the control over illness subscale of the IPQ-R (Moss-Morris et al., 2001). It consists of six items rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), where a high score indicates agreement with the statement about control and a low score indicates disagreement. It has a reported alpha of .81 and good test-retest reliability.

-Self-Esteem

Rosenberg's (1965) self-esteem scale was used to measure self-esteem. This scale consists of ten items rated on a 4-point Likert scale, scored so that a low score indicates high self-esteem, 5 items are reverse coded. A summary score is reached with the addition of all 10 items. It is a widely used scale, especially within the field of QoL (Helgeson, 1992; Helgeson et al., 1993; Taylor, 1983). It is easy to complete and is fairly short, both factors which make it favourable for a questionnaire study.

-Optimism

The Revised Life Orientation Test (Scheier, Carver, & Bridges, 1994) measures dispositional optimism and consists of 6 items (plus four filler items) rated on a 5-point Likert scale. Three items are reverse scored before a summary score is calculated, which is reached by adding all 6 items. A high score indicates high optimism. It has a reported alpha of .78.

The mechanisms - social comparison and use of the self-help group

-Social comparison

The Identification/Contrast Scale (Van der Zee et al., 2000), which was reviewed in Chapter 5 (section 5.4.2.), measured the type and degree of affect experienced after both upward and downward social comparison. It consists of 12 items rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Four subscales can be derived, each with three items, namely, upward information interpreted positively, upward information interpreted negatively, downward information interpreted positively, and downward information interpreted negatively. All four subscales have a reported alpha of .87 and above (Van der Zee et al., 2000).

Included with this scale was the 4-item information subscale of the Social Comparison in Illness Scale (SCI) which was also reviewed in Chapter 5 (section5.4.1.). This subscale measured the degree of comparing for information purposes only. It, too, is rated on a 5-point Likert scale ranging from 1 to 5. In Chapter 5 it showed an alpha of .76.

Both the above social comparison scales were scored so that a high score indicates that the individual agrees with the social comparison statement and a low score indicates that they disagree.

-Use of the Self-Help Group

Five items measured the extent to which the participant made use of the self-help group. This included reading the fact sheets, writing a letter to the editor, contacting another member, contacting the helpline, and joining a local group. Although these items may contain some social comparison information through contact with others they are considered a measure of the use of the self-help group. These items had a binary coding and were added together to reach one '*use of SHG*' score (range 0 to 5) so that a high score indicated having engaged in more of the self-help group activities. A single item, '*extent of reading SHG magazine*', measured the extent to which the magazine was read. It was rated on a 5-point Likert scale ranging from 1 (*not at all)* to 5 (*I read everything, from cover to cover).* Seven items measured which sections of the magazine were read. These seven items covered the seven core sections of the magazine: medical section, questions and answers, special features and news, Pen Pals, Fundraising news, Local Group news, the Letters to the Editor. These were binary items which were summed to reach a '*sections read*' summary score (range 0 to 7). There followed three items about the Letters to the editor section. The first, '*read all letters,*' asked if the participant reads all the letters (binary item) the next two items asked if the participant preferred letters about someone better-off, '*letter-up,*' or it they preferred letters about someone worse-off, '*letter-down.*' The last two items were rated on a three-point scale (yes, neutral, no). The variables '*extent of reading SHG magazine*,' '*sections read*,' '*read all letters*,' '*letter-up*' and '*letter-down*' are considered to be social comparison variables as the magazine contains social comparison information in the form of descriptions of patients' disease and treatment in the medical section, letters to the editor which contains stories of life with Ménière's disease, and details of how other members of the society are managing their illness.

6.2.4. Initial Data Preparation

The questionnaires were all coded and entered into SPSS. Every fifth questionnaire was later double checked for accuracy and the number of mistakes was insignificant. Summary scores for the scales were calculated following the individual scale instructions.

6.2.5. Missing data

Individual summary score means were imputed for the scales for which at least 50% of the scale had been answered. This was done following the recommendations of Ware et al. 1993. As the hearing scale consisted of only five items any missing items meant that the participant was removed.

6.3. Results

This section describes the sample characteristics before presenting the scale characteristics, and finally the regression statistics.

6.3.1. Sample characteristics

The characteristics of the sample used for the cross-sectional analysis are presented in the tables below. Descriptive statistics are given for the sample n = 370 and not n = 509 as the former was the sample size for questionnaire 1b and so was the sample used in the regression statistics. Some variables presented below have smaller numbers due to missing data.

Variables measuring demographic factors

Table 13 below shows the average age of the sample along with the mean time since diagnosis, mean time since first symptom, and the average length of membership of the society. The large age range indicates the diversity of the sample. Of note is the large discrepancy between time since diagnosis and time since first symptom. This highlights a characteristic of this illness; the Ménière's disease diagnosis is based on a history of symptoms leading to a long time-gap between first symptom and the actual diagnosis.

Table 13: Means and standard deviations for age, time since diagnosis, time since first symptom, and length of membership, all in years.

	Mean	Std deviation	Median	Range
Age (n = 367)	57.7	12.6	59	21 – 86
Time since diagnosis (yrs) (n = 348)	9.28	7.81	7	0 – 41
Time since first symptom (yrs) (n = 354)	13.3	10.10	10	1 – 53
Length of membership (yrs) (3 outliers have been removed from this calculation) (n = 354)	4.87	3.50	4	1 – 17

Table 14 shows that a high percentage of the sample had been diagnosed with Ménière's disease by an ENT specialist. There was only a slight predominance of women in the sample. Most of the sample lived with someone who can help to look after them and only a small percentage lived with a dependent whom they had to look after.

Table 14: Percentages of sample for type of diagnosis, sex, and social support.

	N	%
Percentage diagnosed with MD (n = 369)	334	90.5%
Sex (369): - women	220	59.6%
- men	149	40.4%
Social support (n=370):-live with someone who can help	301	81.4%
- live near someone them who can help	107	28.9%
- have a dependent who they look after	65	17.6%

Table 15 shows how this sample felt about their GP and ENT specialist. Most of the sample found both to be helpful or very helpful with only a small percentage finding them either unhelpful or very unhelpful.

Table 15: Descriptive data for Professional support

Percentage who find their GP:	N	%
- helpful and very helpful	213	58.1%
- neutral	97	26.4%
- unhelpful and very unhelpful	57	15.5%
Percentage who find their ENT specialist:		
- helpful and very helpful	197	58.4%
- neutral	71	21.1%
- unhelpful and very unhelpful	69	20.5%

The spread of occupational status within the sample is presented in Table 16. The top two categories (1 and 2) made up 45.2% of the whole sample. It should be remembered that this calculation was based on present occupation, previous occupation if retired, or spouse's occupation if the person was a homemaker.

Table 16: Socio-economic status frequencies using the NS-SEC to classify occupation.

NS-SEC (simplified method)	N	%
1. Higher managerial professions		
1.1 Higher managerial occupations	11	3%
1.2 Higher professional occupations	37	10.1%
2. Lower professional occupations	117	32.1%
3. Intermediate occupations	85	23.3%
4. Small employers	26	7.1%
5. Lower supervisory and technical occupations	21	5.8%
6. Semi-routine occupations	36	9.9%
7. Routine occupations	15	4.1%
8. Never worked	17	4.7%

Disease severity characteristics

The descriptive data for the four Ménière's symptoms, vertigo, hearing, tinnitus, and fullness of the ear, are presented separately below.

Vertigo (Table 17) shows a mean higher than the median indicating that it is positively skewed, since most participants rated their vertigo as not very severe and a small number rated it extremely severe. Data from another study of people with Ménière's disease, using the same scale (Yardley et al., 1999) are presented as a comparison. The mean has been transformed as the scale was scored 1 to 5 (Yardley et al., 1999) whereas in this study it was scored 0 to 4. The comparison shows this sample to have more severe vertigo than both the comparison sample with Ménière's disease (n = 8) and, as is expected, the healthy control group (n = 40). Of the three symptoms which usually accompany vertigo, nausea was the most commonly experienced in this study, while falling and vomiting were experienced to a lesser extent (Table 18).

Table 17: Vertigo (Vertigo Symptom Severity) descriptive data

Vertigo (n = 370)	Mean	Median	Range	Std dev
Scale mean	21.53	17	0 – 76	17.84
Item mean	1.13	.89	0 – 4	.94
MD sample (Yardley et al., 1999)	.99	-	0 – 4	.45
Control (healthy) (Yardley et al., 1999)	.32	-	0 – 4	.31

Table 18: Vertigo characteristics

4.1% (15) experience no vertigo					
Symptoms experienced with vertigo (percentages with n in brackets)					
	Never	1-3 times/year	4-12 times/year	More than once a month	More than once a week
Fall	60.5% (224)	20.5% (76)	8.1% (30)	2.2% (8)	8.6% (32)
Nausea	20.8% (77)	23.2% (86)	20% (74)	13% (48)	23% (85)
Vomit	57.3% (212)	18.1% (67)	11.4% (42)	6.8% (25)	6.5% (24)

The hearing data (Table 19) show that the mean is slightly higher than the median, indicating that most of the sample rated their hearing difficulties as not severe while a small number rated their hearing difficulties as more severe.

Table 19: Hearing descriptive data

	Mean	Median	Range	Std dev
Hear (n = 370)	13.32	13	0 – 30	7.55
68.9% (255) had no difficulties hearing in a quiet environment				
26.2% (97) had no difficulties localizing the source of the sound				
6.5% (24) had no difficulties hearing in a noisy environment				

For tinnitus and fullness (Tables 20 and 21), the mean is almost the same as the median indicating a normal distribution curve.

Table 20: Tinnitus descriptive data

	Mean	Median	Range	Std dev
Tinnitus (n = 370)	3.84	4	0 – 6	1.45
3% (11) no tinnitus 3% (11) had rarely noted tinnitus 15.9% (59) had occasional tinnitus 14.6% (54) had frequent tinnitus 17.0% (63) had almost constant tinnitus 42.2% (156) had constant tinnitus 4.3% (16) had severe tinnitus				

Table 21: Fullness descriptive data

<table>
<tr><th></th><th>Mean</th><th>Median</th><th>Range</th><th>Std dev</th></tr>
<tr><td>Fullness (n = 370)</td><td>3.16</td><td>3</td><td>0 – 6</td><td>1.61</td></tr>
<tr><td colspan="5">8.9% (33) no feeling of fullness
7.3% (27) had infrequent fullness
17.6% (65) had occasional fullness
17.0% (63) had frequent but mild fullness
27.6% (102) had frequent but moderate fullness
17.3% (64) had a frequent and severe but not incapacitating feeling of fullness
4.3% (16) had an almost constant and incapacitating feeling of fullness</td></tr>
</table>

Self-esteem, optimism, control, and social comparison descriptive data

Perceived control over illness (IPQ-R subscale) and self-esteem (Rosenberg, 1965) show an almost normal distribution where the mean and median are very nearly the same (Table 22). Comparison with the two populations supplied by Moss-Morris et al. (2001) show the Ménière's disease patients to be more similar to the chronic pain patients than to the acute pain patients with respect to perceived control over illness, i.e. to have lower perceived control than acute pain patients. The self-esteem means show the Ménière's disease sample had higher self-esteem than the population data. Optimism (Revised Life Orientation Scale) shows a mean which is lower than both the heart patients and, as is expected, the college students (Scheier et al., 1994) indicating that the Ménière's disease sample had lower optimism than both the healthy population and a heart-disease population.

The social comparison variables, upward information interpreted positively, downward information interpreted positively, downward information interpreted negatively, upward information interpreted negatively, and social comparison for information, show all the means to be close to the median. This indicates a normal distribution. Since a high score indicates more of the aspect being measured these statistics show the participants agreed more with the positive social comparison items and disagreed more with the negative items. Comparison with a study of cancer patients (Van der Zee et al., 2000) shows the Ménière's sample were more inclined to engage in positive social comparison, both upward and downward, than the cancer group.

Table 22: Percentages, means and standard deviations for perceived control, self-esteem, optimism, and social comparison.

	Mean (SD)	Median
Perceived Control (range 6 – 30, n = 365)	18.7 (4.69)	18
Chronic pain (Moss-Morris et al., 2001)	18.4 (4.01)	-
Acute pain (Moss-Morris et al., 2001)	22.9 (3.52)	-
Self-esteem (range 10 – 40, n = 365)	29.5 (5.04)	30
Population (Rosenberg, 1965)	34.7 (4.86)	-
Optimism (range 0 – 24, n = 369)	13.8 (4.31)	14
LOT scores for heart patients (Scheier et al., 1994)	15.2 (4.05)	-
LOT scores for college students (Scheier et al., 1994)	14.3 (4.28)	-
Social comparison item means, standard deviations, and medians for the sample (n = 368)		
Downward positive comparison (range 1 – 5)	3.82 (.74)	4
Cancer study, n=118(Van der Zee et al., 2000)	2.81 (1.24)	
Upward positive comparison (range 1 – 5)	3.68 (.71)	4
Cancer study, n=118(Van der Zee et al., 2000)	3.14 (1.32)	
Downward negative comparison (range 1 – 5)	2.91 (.94)	3
Cancer study, n=118(Van der Zee et al., 2000)	3.01 (1.22)	
Upward negative comparison (range 1 – 5)	2.70 (.85)	2.67
Cancer study, n=118(Van der Zee et al., 2000)	2.79 (1.26)	
Information (range 1 – 5)	3.80 (.60)	4

Use of Self-help group

Table 23 shows the percentage of participants who engaged in the various self-help group activities or made use of the self-help group facilities. Of the 'Use of self-help group' variables a large percentage had read the fact sheets provided by the society. However, the other facilities (contact a group member, contact the Ménière's Society, join a local group, and write a letter to the magazine) were not taken up by many. The '*extent of reading the SHG magazine*' variable shows that a high percentage read most or all of Spin (the Ménière's Society magazine). The break down of this shows that the medical section, the question and answer section (also medical), the news section, the fundraising section, the local group news section, and the letters to the editor section (all social comparison variables) were read by the majority of the sample. The letters to the editor section was read by 96.3% of the sample. However, not all those who read the letters read all the letters. The frequencies regarding what type of letter they preferred show most reported a neutral preference for both the upward and the downward letters.

Table 23: Use of Self-help group frequencies.

Variable	Percentage yes (n)	Percentage no (n)	
Use of Ménière's Society			
-contacted the help line	12.2 (45)	87.8 (325)	
-read the fact sheets	94.6 (350)	5.40 (20)	
-made use of contact list	11.9 (44)	88.1 (326)	
-joined a local group	5.40 (20)	94.6 (349)	
-written a letter to Spin	15.7 (58)	84.3 (311)	
Extent of reading Self-help group magazine	Percentage (n in brackets)		
-cover to cover	42.8 (157)		
-most of articles/sections	44.7 (164)		
-a few articles/sections	10.4 (38)		
-flip through	1.60 (6)		
-not at all	.50(2)		
Sections read	Percentage yes (n)	Percentage no (n)	
-medical articles	98.1 (363)	1.90 (7)	
-Questions and Answers	97.8 (362)	2.20 (8)	
-news	93.2 (345)	6.80 (25)	
-Penpals	43.5 (161)	56.5 (209)	
-Fundraising	60.3 (223)	39.7 (147)	
-Local group news	57.2 (211)	42.8 (158)	
-Letters to the editor	95.7 (354)	4.30 (16)	
-tread all letters	72.1 (266)	27.9 (103)	
-letter-up	Yes – 8.60 (32)	Neutral – 79.7 (295)	No – 11.6 (43)
-letter-down	Yes – 6.50 (24)	Neutral – 76.5 (283)	No – 17.0 (63)

The impact of illness on QoL data

The descriptive data for the eight SF-36 domains and the two summary scores are presented in Table 24 along with the population norms from another SF-36, UK-based study. Role physical, where one's health interferes with one's role in a physical way, has a lower rating than the other domains. As is expected all the domains show lower ratings than the population norms of both the comparison studies.

Table 24: Means and standard deviations for the SF-36 domains for Time 1.

A higher score indicates better functional health for the eight domains (range 0 – 100)

Variable	Time 1 means (n = 370)	Population norm mean
-Role Physical	46.0 (44.75)	86.4*
-Role mental	59.2 (44.93)	83.4*
-Vitality	47.1 (22.98)	61.5*
-Mental health	66.2 (20.22)	74.1*
-Physical functioning	68.8 (27.40)	88.9*
-General Health	51.5 (24.05)	74.1*
-Social functioning	64.7 (30.03)	88.6*
-Pain	66.5 (27.50)	82.1*
Physical score	44.1 (10.87)	
Mental score	43.7 (12.32)	
SF-36	87.6 (18.30)	

*(Jenkinson, Layte, & Lawrence, 1997).

Goal oriented quality of life

Table 25 shows the means and standard deviations for the GOQoL, which measures perceived goal-directed movement.

Since the range is –3 (very quickly away) to +3 (very quickly towards), the GOQoL mean shows that this group felt they were moving slowly away from their goals (the median was .0). The five domain means (family, work/finances, health, social activities, and spirituality) show the average rank assigned to that domain, where 5 indicates the highest rank and 1 the lowest. The ranking of the five domains show 'family' to be rated the highest with 'health' coming a close second (Table 25). 'Work/finances' and 'social activities' rate third and fourth respectively with 'spirituality' being rated the least important of the five domains.

Table 25: GOQOL means and standard deviations.

Variable	Time 1 means used in Time 2 analysis (n = 369)
GOQOL	-.20 (4.27)
- family	4.55 (.71)
-health	4.14 (.74)
-work/finances	2.45 (.88)
-social	2.22 (.79)
-spirituality	1.65 (1.06)

Perception of positive change since the onset of the illness

The 'perception of positive change since the onset of the illness' (as measured by the Post-traumatic Growth Inventory) means and standard deviations are presented in Table 26. The data is slightly skewed with the mean higher than the median. This means that more of the sample perceives a small positive change after the onset of their illness but a small number perceive a great deal of positive change. The Ménière's disease sample appeared to perceive considerably less positive change after the onset of their illness than both the undergraduate population who had experienced no trauma and the undergraduate population who had experienced a traumatic event in the last year (Tedeschi et al., 1996).

Table 26: PTGI means, standard deviations and medians for Time 1 and Time 2

Ménière's sample at baseline (n = 365) (range 21 – 105)		Tedeschi and Calhoun (1996) sample	
		With trauma (n = 63)	Without trauma (n = 54)
Mean (std dev)	Median	Mean	Mean
35.0 (22.13)	32.0	69.8	81.9

6.3.2. Further Data Preparation

Two skewed variables, the Vertigo Symptom Scale and the Post-traumatic Growth Inventory (PTGI) were subjected to a squared root transformation before any further analysis took place. However, optimism became reverse skewed and more severely so after the transformation. In this case the original, untransformed variable was used.

The self-esteem variable was recoded so that a high score indicated high self-esteem. This was done so as to be similar to the other predictor variables which are all scored so that a high score indicates more of the aspect being measured.

6.3.3 Scale Characteristics

Table 27 shows the internal reliability for all the scales used in the survey. The analysis shows that all scales have an alpha level of .74 or above. For the GOQoL scale the weighted version did not show such a high reliability as the unweighted version and so only the unweighted summary score was used in the regression analysis.

Table 27: Reliability

Scale	α
Posttraumatic Growth Inventory	.93
Vertigo subscale (VSS)	.93
Hear	.83
GOQoL	.80
GOQoLw	.75
Identification/Contrast scale:	
-Upward information interpreted negatively	.84
-Upward information interpreted positively	.89
-Downward information interpreted negatively	.95
-Downward information interpreted positively	.87
-Information subscale (SCI)	.74
Control over illness subscale (IPQ-R)	.87
Life Orientation Test (optimism)	.86
Self-esteem (Rosenberg)	.90
SF-36	
-pain	.95
-role physical	.92
-role emotional	.90
-vitality	.88
-mental health	.86
-physical functioning	.93
-general health	.85
-social functioning	.85

Factor analysis (FA) on the Identification/Contrast and the information subscale of the SCI items showed that the predicted four principal components emerged with information making up a fifth factor (Table 28).

Table 28: Factor Analysis of Identification/Contrast Scale

Item	info	ucneg	ucpos	dcneg	dcpos
I/C1	**.798**	.	-.160	.	.137
I/C2	**.723**	-.194	.355	.	.
I/C3	**.604**	-.283	.390	.	-.118
I/C4	**.761**	.	.	.	.141
I/C5	.	.207	.	**.904**	.
I/C6	.	.250	.	**.924**	.
I/C7	-.101	.227	.	**.918**	.
I/C8	.	.120	**.800**	.	.296
I/C9	.	.	**.828**	.	.223
I/C10	.	.211	**.775**	.	.325
I/C11	.	.	.302	.	**.799**
I/C12	.	.	.208	.	.885
I/C13	.	.	.205	.	**.876**
I/C14	.	**.789**	.	.282	.
I/C15	.	**.858**	.134	.162	.
I/C16	.	**.816**	.175	.239	.
Eigen values	1.20	1.28	1.62	4.56	3.56
% variance explained	13.58	14.93	15.41	17.02	15.65

(Factor loadings > .5 are highlighted in bold; correlations near zero are represented by a full-stop.)

info = social comparison for information purposes
ucneg = upward information interpreted negatively
ucpos = upward information interpreted positively
dcneg = downward information interpreted negatively
dcpos = downward information interpreted positively

The factor components of the PTGI were found to be unstable as factor analysis did not result in five reported underlying factors, but instead four factors emerged. When forced into a 5 factor structure not all the correct items loaded onto the correct factor (these results have not been presented here).

Factor analysis on the Physical component score and the Mental component score of the SF-36 showed they loaded onto one factor. These two variables were therefore summed before further analysis took place.

Table 29, below, shows the bivariate correlations between all the predictor variables and the three outcome variables. Significant correlations are shown in bold.

Table 29: Correlations for SF-36, the GOQoL, and the PTGI with Time 1 predictor variables (correlation coefficient, p values in brackets for significant variables).

Variable	SF-36	GOQoL	PTGI
Age	.099	.018	-.014
Sex	**-.192 (.000)**	.062	.027
Feeling of fullness in the ear	**-.426 (.000)**	**-.213 (.000)**	**.108 (.039)**
Tinnitus	**-.101 (.022)**	**-.141 (.007)**	-.036
Hear	**-.140 (.002)**	**-.149 (.004)**	.057
Vertigo	**-.586 (.000)**	**.342 (.000)**	**.174 (.001)**
Control over illness	**.218 (.000)**	**.292 (.000)**	**.200 (.000)**
Self-esteem	**.509 (.000)**	**.430 (.000)**	.042
Optimism	**.434 (.000)**	**.411 (.000)**	**.108 (.040)**
Social comparison for information	-.037	.001	**.145 (.006)**
Positive Upward comparison interpreted	**.162 (.002)**	**.339 (.000)**	**.303 (.000)**
Negative Upward comparison interpreted	**-.347 (.000)**	**-.227 (.000)**	**.116 (.028)**
Positive Downward comparison interpreted	**.365 (.000)**	**.380 (.000)**	**.142 (.007)**
Negative Downward comparison interpreted	**-.157 (.002)**	**-.120 (.022)**	.005
Time since diagnosis	.015	-.032	.056
Time since first symptom	-.028	.001	.056
Length of membership with the Society	.051	.056	.068
Live-in Social support	**.129 (.003)**	.047	-.018
External Social support	-.084	.010	.048
Live-in dependents	-.053	-.029	.000
Use of self-help group	**-.147 (.005)**	-.029	**.176 (.001)**
Sections read (of magazine)	**-.137 (.008)**	-.032	**.184 (.000)**
Extent of reading self-help magazine –	**-.135 (.010)**	-.069	**.178 (.001)**
Reading all the 'Letters to the editor'	-.080	-.063	**.117 (.023)**
Preference for letters about people better-off	.040	-.020	.026
Preference for letters about people worse-off	.064	-.018	-.050
GOQoL-T1	**.511 (.000)**	-	.092
PTGI-T1	**-.160 (.002)**	.092	-
Occupation	**.115 (.010)**	-.024	.002
Perceived helpfulness of ENT specialist	**.238 (.000)**	**.202 (.000)**	.057
Perceived helpfulness of GP	.099	**.165 (.002)**	**.192 (.000)**

(significant correlations are shown in bold)

6.3.4. Hypothesis testing

The aims of the study were to (1) determine whether those high in self-esteem, perceived control, and optimism had better adjustment (hypothesis 1), and (2), to determine whether, after controlling for demographic characteristics, disease severity, optimism, control, and self-esteem, social comparison would still be significantly associated with adjustment (hypothesis 2).

Hypothesis 1

Table 29 shows the results of the bivariate correlations which show all the correlations that are significant. Optimism and control are positively and significantly correlated with the three QoL measures. Self-esteem positively correlates with all three measures, however this correlation is only significant for the SF-36 and the GOQoL. This largely supports the hypothesis that those high in optimism, self-esteem, and control experience better adjustment.

Hypothesis 2

Using hierarchical regression the effects of social comparison on QoL were assessed after entering demographic variables (*antecedents*: personal characteristics) at step1, disease severity variables (*the catalyst*) at step 2, and self-esteem, optimism, and control over illness (*antecedents*: psychological variables) at step 3. These variables have all been shown to influence QoL in previous studies and so in order to determine the true effects of social comparison while controlling for the shared variance these variables were entered first in the equation. Finally, at step 4, the social comparison variables (the *mechanisms*), six in all, namely, the four factor components, downward positive, downward negative, upward positive and upward negative, also, Information, and 'sections read.' The variable 'extent of reading the self-help group magazine' was not included in the regression equation as it measures a very similar aspect of the self-help group as 'sections read.' As these two variables also showed a high correlation of .7 only 'sections read' was included in the regression equation as it showed a slightly higher correlation with the QoL variables. The results of the three regression equations (three outcome measures) are presented separately below.

-Dependent variable: Functional QoL (SF-36)

Table 30 shows the individual beta statistics and summary of the regression statistics for the SF-36. Each step was significant, with 50.7% of the variance being accounted for at step four. Sex was negatively associated with QoL indicating that males reported higher QoL than females. Fullness and vertigo, too, negatively predicted QoL. This is as expected as the more severe the symptoms the worse the perception of QoL. Optimism and self-esteem both positively predicted QoL. This means that those high in optimism and self-esteem perceived a better QoL than those with low scores on those variables. Of the social comparison variables there are two which were significant. Downward information interpreted positively, positively predicted QoL. This means that the more that participants felt lucky that they were not as badly off as the downward target the better their QoL was perceived to be. Upward information interpreted negatively, negatively predicted QoL. This means that the more the participants felt despair in response to someone better-off the worse they perceived their own QoL to be.

Table 30: Summary of hierarchical regression analysis for variables predicting functional QoL (SF-36), N = 352.

Variable	Beta	SE	β
Step 1			
Age	.101	.077	.069
Sex	-6.77	1.97	-.181*
Step 2			
Age	.	.07	-.030
Sex	-2.70	1.66	-.072
fullness	-2.08	.566	-.184*
Tinnitus	.702	.573	.056
Vertigo	-4.628	.452	-.500*
Hearing	.	.110	-.014
Step 3			
Age	.	.059	-.063
Sex	-2.4	1.528	-.064
Fullness	-2.195	.511	-.194*
Tinnitus	.823	.521	.065
Vertigo	-3.536	.426	-.382*
Hearing	.	1.00	-.017
Self-esteem	.827	.196	.229*
Perceived control	.	.165	-.021
Optimism	.796	.227	.186*
Step 4			
Age	-.119	.060	-.081*
Sex	-3.904	1.551	-.104*
Fullness	-1.986	.503	-.176*
Tinnitus	.795	.514	.063
Vertigo	-3.299	.426	-.357
Hearing	.	.099	.001
Self-esteem	.701	.194	.194*
Perceived control	-.238	.168	-.061
Optimism	.584	.226	.137*
Downward positive	1.429	.410	.170*
Upward positive	-.159	.394	-.018
Downward negative	.102	.295	.016
Upward negative	-.916	.342	-.127*
Sections read	.	.007	.022
Information	.	.313	-.013

Note. $R^2 = .040$ for Step 1; $\Delta R^2 = .330$ for Step 2 ($p < .000$); $\Delta R^2 = .123$ for Step 3 ($p < .000$); $\Delta R^2 = .035$ for Step 4 ($p < .001$), (values close to zero are represented by a full-stop).

Mediation and moderation analyses were performed, but did not add substantially to either the explanation of variance or to the interpretation of the findings.

-Dependent variable: Goal-oriented QoL (GOQoL)

For the GOQoL, which measures the perceived extent of moving towards one's goals, the same variables were added to the hierarchical regression. The last three steps were significant accounting for a total of 35.6% of the variance. Looking at the variables individually (Table 31) one can see that the disease severity variables and the psychological variables (self-esteem, perceived control, and optimism) behaved in an opposite way with fullness and vertigo negatively predicting perceiving the movement towards one's goals and optimism, control, and self-esteem positively predicting the movement towards one's goals. This means that the worse the symptoms the less the participant perceived moving towards their goals and the higher self-esteem and optimism the greater the perception of moving towards their goals. As for the social comparison variables, both upward and downward positively interpreted information were significant, positively predicting the perception of moving towards one's goals.

Table 31: Summary of hierarchical regression analysis for variables predicting goal-oriented QoL (GOQoL), N = 351.

Variable		Beta	SE	β
Step 1				
	Age	.	.018	.014
	Sex	.677	.457	.080
Step 2				
	Age	.	.017	-.039
	Sex	1.197	.437	.141*
	fullness	-.342	.150	-.132*
	Tinnitus	-.113	.151	-.039
	Vertigo	-.630	.120	-.297*
	Hearing	.	.029	-.063
Step 3	Age	.	.015	-.076
	Sex	1.477	.398	.174*
	Fullness	-.353	.134	-.137*
	Tinnitus	.	.135	-.015
	Vertigo	-.338	.112	-.160*
	Hearing	.	.026	-.042
	Self-esteem	.204	.051	.248*
	Perceived control	.118	.043	.131*
	Optimism	.179	.059	.184*
Step 4				
	Age	.	.016	-.102*
	Sex	1.085	.405	-.127*
	Fullness	-.352	.132	-.136*
	Tinnitus	.	.134	-.003
	Vertigo	-.289	.112	-.136*
	Hearing	.	.026	-.026
	Self-esteem	.190	.051	.231*
	Perceived control	.	.044	.099*
	Optimism	.142	.059	.145*
	Downward positive	.319	.107	.167*
	Upward positive	.223	.103	.114*
	Downward negative	.	.077	.037
	Upward negative	.	.090	.044
	Sections read	.	.002	.023
	Information	-.122	.062	-.071

Note. $R^2 = .006$ for Step 1; $\Delta R^2 = .156$ for Step 2 ($p < .000$); $\Delta R^2 = .179$ for Step 3 ($p < .000$); $\Delta R^2 = .042$ for Step 4 ($p < .001$), (values close to zero are represented by a full-stop).

As with functional QoL, mediation and moderation analyses were performed, but did not add substantially to either the explanation of variance or to the interpretation of the findings.

-Dependent variable: Perceived positive change (PTGI)

For the PTGI the same variables were entered in the same way as before using hierarchical regression (Table 32). The last three steps were significant with 18% of the variance accounted for at step four. Looking at the individual variables, of the disease severity scales only vertigo was significant, positively predicting the perception of change. This means that the more severe the participant's vertigo the more they were likely to perceive positive change. Perceived control was significant and it positively predicted perceiving positive change, meaning that the more control perceived the more positive change that was perceived. Of the social comparison variables 'sections read' was significant and it positively predicted perceiving positive change. This means that the more sections read in Spin the more the respondent perceived positive change. For the other social comparison variables, upward comparisons interpreted positively and negatively were significant with both positively predict perceiving positive change.

In summary, the person who experienced high perceived control experienced both positive and negative affect after upward comparison, and who read all or most of the sections in Spin was likely to experience greater positive change after the onset of their illness.

Table 32: Summary of hierarchical regression analysis for variables predicting perceived positive change (PTGI), N = 350.

Variable	Beta	SE	β
Step 1			
Age	.	.009	-.02
Sex	.	.224	.017
Step 2			
Age	.	.009	.010
Sex	.	.228	-.019
fullness	.	.078	.058
Tinnitus	-.126	.079	-.090
Vertigo	.189	.062	.184*
Hearing	.	.015	.023
Step 3			
Age	.	.009	-.003
Sex	.	.227	.007
Fullness	.	.076	.073
Tinnitus	.	.077	-.063
Vertigo	.227	-.063	.221*
Hearing	.	.015	.052
Self-esteem	.	.029	-.002
Perceived control	.	.025	.210*
Optimism	.	.034	.102
Step 4			
Age	.	.009	-.040
Sex	-.158	.224	.038
Fullness	.	.073	.040
Tinnitus	.	.074	-.003
Vertigo	.202	.061	.196*
Hearing	.	.014	.075
Self-esteem	.	.028	.022
Perceived control	.	.024	.195*
Optimism	.	.033	.079
Downward positive	.	.059	.015
Upward positive	.246	.057	.258*
Downward negative	.	.042	-.027
Upward negative	.169	.049	.210*
Sections read	.	.001	.116*
Information	.	.045	.001

Note. $R^2 = .001$ for Step 1; $\Delta R^2 = .044$ for Step 2 ($p < .005$); $\Delta R^2 = .060$ for Step 3 ($p < .000$); $\Delta R^2 = .109$ for Step 4 ($p < .000$), (values close to zero are represented by a full-stop).

6.4. Discussion

The first hypothesis was supported, confirming the findings from research in other samples suggesting that those high in self-esteem, perceived control and optimism experience better adjustment. Quality of life and the perception of movement towards goals was positively associated with optimism and self-esteem. Perceived control was positively associated with the perception of movement towards goals and the perception of positive change.

The second hypothesis was also supported: social comparison was associated with adjustment after the above variables plus the demographic variables and the disease severity variables had been controlled for. Positive social comparison was associated with positive adjustment and negative social comparison was associated with negative adjustment showing that social comparison can have both a positive and a negative effect on perceived QoL.

This supports the Identification/Contrast model which proposes that positive social comparison is associated with positive adjustment and negative social comparison is associated with negative adjustment (Buunk et al., 1990). In addition, Taylor's (1983) Cognitive Adaptation Theory proposes that downward social comparison assists adjustment as it increases self-esteem, as does Wills' (1981) downward comparison theory.

These results also support Gibbon's proposition that social comparison assists in the altered perception associated with response shift (Gibbons, 1999). The association found between negative social comparison and negative adjustment is also consistent with the response shift literature, which states that negatively interpreted information may lead to identification with the worse-off other, resulting in negative affect and a negative interpretation of one's own subjective well-being (Van der Zee et al., 2000).

Vertigo positively predicted perceived positive change. This could mean that when the vertigo is very bad we seek positive meaning in order to cope. This supports the literature on perceived positive change where it has previously been found to be associated with the worst stage of a crisis (Tedeschi et al., 1996). Only perceiving positive change was positively associated with negative upward comparison. However, this is also consistent with the perceived positive change literature. We tend to perceive more positive change when the situation is at its worst (Tedeschi et al., 1996). This is why severe vertigo was positively associated with perceiving more positive change. A negative interpretation of upward comparison information, which may be linked to an accurate perception of having worse vertigo than others, may be associated with a worse perception of the present situation which may in turn lead to greater efforts to perceive positive change.

The reading of Spin was also associated with the perception of positive change. This has practical implications for the SHG, which can edit the social comparison information which the members read. Since negative upward comparison was also associated with perception of positive change, the implication here might be that positive stories are more effective in inducing positive change than negative ones, perhaps because they inspire revaluation of the situation. However, as these results are based on cross-sectional data the causal direction of the relationships between these variables can not be determined. A longitudinal design is necessary in order to evaluate prediction of adjustment outcome. The next chapter describes the results of the longitudinal follow-up to this survey.

CHAPTER SEVEN: THE LONGITUDINAL SURVEY

7.1 Introduction

The results in Chapter six supported the cross-sectional hypothesis by showing positive social comparison, both upward and downward, to be associated with positive adjustment (functional QoL, goal-oriented QoL, and perceived positive change) and negative (upward) social comparison to be associated with negative adjustment. However, cross-sectional statistics are based on correlations between variables across participants, derived from questionnaires collected simultaneously. In this situation predictor variables are not antecedents of the outcome variables. Causality can be inferred but no more. To determine better predictors of change in QoL over time a longitudinal design is necessary where change within each participant over time is determined by measuring QoL at two points in time.

For this purpose a longitudinal follow-up was carried out ten months after the cross-sectional study. This was considered a sufficiently long period for allowing adjustment to occur naturally over time. In addition, change was measured over ten months in a study by Helgeson (2001), who used the SF-36 to assess change in breast cancer patients to intervention. Variables from the cross-sectional data, in Chapter six, were used to predict change in QoL (adjustment) ten months later, where adjustment was measured with the same three measures as at baseline.

The review of the literature in Chapters two and three showed there to be an absence of conclusive research which has looked at the effects of social comparison on adjustment especially for the social comparison occurring within a self-help group. Studies to date have been cross-sectional or have not been based on self-help group samples. This study hoped to determine the effects of social comparison within self-help groups on adjustment in order to answer this question.

The primary research question was: What predicts change over time? The hypothesis was that positive social comparison would predict positive adjustment while negative social comparison would predict negative adjustment. To answer this question the relationship of each baseline predictor variable to QoL at follow-up was examined while controlling for QoL at baseline.

A second element of this longitudinal study was designed to measure the contribution of response shift to change in QoL over time. This was achieved by means of the 'ThenTest approach,' utilising some of the QoL items employed at both baseline and follow-up. The items selected consisted of the GOQoL, and five domains of the SF-36: mental health, general health, role physical, role emotional, and physical functioning. These items were rephrased as retrospective questions, asking the participant at follow-up to indicate how they felt their QoL was at baseline. The prediction for the response shift data was that the physical functioning scale would show no change while the remaining SF-36 scales and GOQoL would show a change. This is because a cognitive change (response shift) is more likely to effect the cognitive aspects of QoL than the physical ones. Consequently, items measuring cognitive aspects of QoL, such as the subjective and emotional domains of the SF-36 and the GOQoL, are more likely to show a change than items measuring physical aspects, such as the SF-36 physical domain. The SF-36 physical functioning domain was therefore predicted to be the least susceptible to response shift.

7.2. Method

7.2.1. Participants

Participants for this study consisted of the 362 people with Ménière's Disease, all members of the Ménière's Society, who agreed at baseline (Time 1) to receive the longitudinal questionnaire.

7.2.2. Procedure

Ten months after questionnaire 1a was administered questionnaire 2 (Appendix G) was sent out to only those who had agreed to receive it at Time 1. As with the two earlier questionnaires this questionnaire was accompanied by a letter of introduction which contained informed consent statements. The letter informed the participant that the completion and return of the questionnaire was taken to mean that the participant had given informed consent to take part in the study. The letter reminded the participant that they could withdraw at any time and that participation was confidential and anonymous. The letter also contained information about the questionnaire. This consisted of an explanation of the purposes of the questionnaire along with guidelines on how to complete it. Also included in the questionnaire pack was a prepaid envelope for the return of the questionnaire to increase the response rate. Of the 362 questionnaires sent out, 301 were returned, giving an 83% response rate.

7.2.3. Measures

This was a longitudinal design where the follow-up study was carried out ten months after the baseline data was collected (written up in Chapter 6). At baseline the outcome measures and the predictor measures were administered. At follow-up the three outcome measures were once again administered in addition to the ThenTest. This meant that the follow-up questionnaire was divided into two sections. The scales included in the first part of this questionnaire were the GOQoL, the PTGI, and the SF-36 (the GOQoL (section 5.4.1.) and SF-36 (section 5.4.2.) were reviewed in Chapter 5 and the PTGI was reviewed in Chapter 6, section 6.2.3.). The SF-36 is a generic QoL measure which assesses the impact of health on eight domains of QoL. The GOQoL was developed for the purposes of this study (Chapter 5, section 5.4.1.) and measures perceived movement towards or away from one's goals with regard to five life domains. The PTGI (Posttraumatic Growth Inventory) assesses the extent of perceived positive change since the onset of the illness or crisis. The second part of the questionnaire was designed to measure response shift using the 'ThenTest' approach. This section consisted of the GOQoL and five domains of the SF-36 (role-emotional, role-functional, physical functioning, mental health, and general health) which were reworded to be retrospective questions. Careful instructions were given both in the covering letter and on the questionnaire as to how to answer the items (Appendix G). For example, the instructions and a reworded item for the GOQoL were '*please circle the answer which comes closest to how you think you felt when you first filled out the questionnaire, ten months ago*' and '*How quickly did you feel you were moving towards or away from your ideal situation with your family and friends?*' An item of the SF-36 general health domain was reworded '*In general, would you say your health, when you first filled out the questionnaire, was...*' (five options).

7.2.4. Analysis

Within-subjects T-tests were used to determine the significance of the differences between means at Time 1 (T1), ThenTest (TT), and Time 2 (T2). Partial correlations were used to determine which variables were significantly associated with the T2 outcome variable after controlling for the T1 outcome variable. Multiple regression was then used to determine the unique impact of each predictor variable on the dependent variable while controlling for any shared variance that the other predictor variables may contribute. Hierarchical regression was selected since the order of entry of the predictor variables was predetermined by the research question. The research question asked whether social comparison was significantly affecting QoL after all other variables shown to be significant had been controlled for. Therefore, in order to determine the unique contribution of the social comparison variables they were entered into the equation last so that all common variance with the other predictor variables was controlled for.

7.2.5. Data Preparation

As with the baseline data, summary score means were imputed for all sub-scales with missing data of 50% or less (Ware et al., 1993). Subscales with more than 50% missing were designated as missing data (left blank). These scales were automatically excluded from the statistics; this accounts for why some scales have different sample sizes than others.

Initial checks on the Time 2 data showed the PTGI-T2 to be skewed (as it was at Time 1) and so it was subjected to a square root transformation before conducting any further analysis.

Prior to running the regression equations further data preparation was necessary. Firstly, in each regression equation the Time 1 dependent variable was centered before entering it at step 1 of the regression (Tabachnick & Fidell, 2001). This was due to the high correlation each Time 1 variable has with its Time 2 counterpart. Also, all the other variables except sex, hearing, 'sections read,' and 'read all the letters' were centered to reduce multicollinearity brought about by the moderately high bivariate correlation between these variables.

Each regression was run first to assess the presence of outliers, and the results below show the final regression statistics which were run without the outliers (3 cases).

7.3. Results

First, the sample characteristics at T1 of the non-respondents (i.e. those participants who completed questionnaire 1a and 1b but did not complete questionnaire 2) are compared with the characteristics of the respondents included in these analyses. Second, the results of the test for response shift are presented. Finally, the results of the testing of the main hypotheses are presented, using predictor variable data collected at T1 to predict the dependent variable data collected at T2.

7.3.1. Sample Characteristics of the non-respondents of questionnaire 2

The characteristics of the whole sample were presented in Chapter 6 (section 6.3.1.). The non-respondents at T 2 (consisting of both those who did not agree to receive the T2 questionnaire and those who agreed but then did not participate) differed significantly from those who continued to participate on six variables. Of the SF-36 domains, role physical ($t = 2.199$, $p < .05$) and social functioning ($t = 2.398$, $p <.05$) were rated lower by the non-respondents. The total summary score, too, was lower for the non-respondents ($t = 2.044$, $p < .05$). The non-respondents also considered their GP to be less helpful than did the respondents ($t = 2.095$, $p < .05$). The non-respondents also did not agree with both the upward comparison ($t = 2.226$, $p < .05$) and downward comparison ($t = 3.017$, $p < .01$) statements interpreted positively to the same degree as the respondents. There were no significant differences for any of the other variables.

7.3.2. Change in QoL from baseline to follow-up

-SF-36

The eight SF-36 domains, the two summary scores, and the total summary score for Time 1 (T1), Time 2 (T2), and the ThenTest (TT) are presented in Table 33. The Table shows the mean SF-36 score on each domain for T1, T2 and ThenTest. The range is 0 to 100 and a higher score indicates better health. Full details of the tests for significance between the differences between these means are shown in Table 36. Participants felt their physical functioning to be better at T1 than at T2 and to be better than their energy levels (vitality) at both times. Role physical, where one's health interferes with one's role in a physical way, had a lower rating than many of the other domains at both times. The ThenTest ratings were lower than the T1 and T2 ratings. This retrospective test indicates that the person now (at T2) feels that they had worse QoL at Time 1 than they actually thought at Time 1.

Table 33: Means and standard deviations for the SF-36 domains for participants who responded at both Time 1 and Time 2.

A higher score indicates better functional health for the eight domains (range 0 – 100)

Variable	Time 1 means and standard deviations (n = 301)	Time 2 means and standard deviations (n= 301)	ThenTest means and standard deviations (n = 298)
SF-36	88.69 (18.49)	88.90 (17.35)	-
-Role Phys	48.17 (45.10)	46.17 (43.83)	40.51 (43.58)**
-Role mental	60.69 (44.73)	65.11 (41.50)	54.84 (43.75)*
-Vitality	47.94 (23.44)	47.71 (22.05)	-
-Mental health	67.07 (20.36)	67.31 (19.60)	62.73 (22.39)**
-Physical functioning	69.72 (27.44)	68.54 (26.21)	69.68 (26.89)
-General Health	51.82 (24.27)	51.68 (24.00)	49.06 (23.95)**
-Social functioning	66.40 (29.72)	67.96 (28.80)	-
-Pain	67.12 (27.05)	66.17 (26.67)	-
Phys score	44.44 (10.09)	43.64 (11.02)	-
Mental score	44.24 (12.22)	45.26 (11.84)	-

(* = $p < .05$ and ** = $p < .005$ where the difference with the T1 means is significant)

-Goal Oriented Quality of Life (GOQoL)

Table 34 shows the means and standard deviations for the GOQoL (T1, T2, and TT), which measures perceived goal-directed movement, with a range of –3 (moving away from goals) to +3 (moving towards goals). The Time 1 GOQoL (GOQoL-T1) means show a negative rating indicating that these participants felt they were moving slowly away from their goals at Time

1 (overall mean -.16). At Time 2 they rated movement towards goals as positive (overall mean .67) indicating that they felt they were moving slightly towards their goals. The ThenTest mean shows the lowest rating of -.26 indicating that at T2 they saw their movement away from their goals at T1 as worse than they thought at the time.

The five domain means (family, work/finances, health, social activities, and spirituality) show the average rank assigned to that domain. Changes in the ranks from baseline to follow-up show changes in domain priorities over time. Once again, the statistics measuring the significance of the difference between these measures are discussed below and shown in Table 36 and 37.

Table 34: GOQoL means and standard deviations

Variable	Time 1 means and standard deviations (n = 301)	Time 2 means (n = 301)
GOQOL	-.16 (4.45)	.67 (4.06)
- family	4.55 (.71)	4.58 (.63)
-work/finances	2.38 (.88)	2.36 (.86)
-social	2.20 (.79)	2.25 (.82)
-health	4.16 (.72)	4.17 (.71)
-spirituality	1.71 (1.08)	1.67 (1.04)

-Perception of Positive Change since the onset of the illness

The 'perception of positive change since the onset of the illness' (as measured by the Post-traumatic Growth Inventory) means and standard deviations are presented in Table 35. The range was 21 to 105. Paired t-tests showed a significant difference between Time 1 and Time 2 ($t = -2.059$, $p < .05$) indicating that the group perceived significantly more positive change at Time 2. It was slightly skewed at both Time 1 and Time 2 with the mean higher than the median. This shows that more people felt they had experienced only a slight change while a small number felt they had experienced change to a greater degree.

Table 35: PTGI means, standard deviations and medians for Time 1 and Time 2.

Time 1 mean (n = 298)		Time 2 mean (n = 300)	
Mean (s.d.)	Median	Mean (s.d.)	Median
35.77 (22.19)	33.00	38.03 (22.55)	35.50

Response Shift

One of the aims of this study was to measure response shift. Showing that a response shift occurred provides evidence that adjustment has occurred in this sample, and the design also permitted the determination of aspect(s) of QoL which underwent change and how that change occurred. Response shift can occur by changes in goals, changes in values, or changes in internal standards of measurement. If a response shift occurred according to the ThenTest then one can infer that this implies a change in the internal standards of measurement within this sample (Sprangers et al., 1999a). To this end the differences in QoL between T1, T2, and TT were assessed. Evidence of changes in the internal standards of measurement would arise from differences between T1 and TT, since these two variables, although based on data collected at different times, are a measure of the perception of QoL as it was at the beginning of the study, and/or significant differences between T2 and TT where there is no change between T1 and T2. With this in mind, paired T-tests were used to determine whether there was a difference between the QoL scales at T2 and TT, T1 and T2, and T1 and TT.

Table 36: Paired T-test statistics (2-tailed) for Time 2 and ThenTest differences

		M	SD	T	Sig
GOQoL					
	T2	.73	4.05		
	TT	-.26	4.05	4.803	**.000**
	T1	-.16	4.45		
	T2	.68	4.06	-3.60	**.000**
	T1	-.1186	4.45		
	TT	-.261	4.05	.711	.478
SF-36: Physical functioning					
	T2	69.44	26.27		
	TT	68.68	26.89	-1.303	.194
	T1	69.72	27.44		
	T2	68.54	26.21	1.31	.190
	T1	69.63	27.51		
	TT	69.68	26.89	-.053	.957
SF-36: Role Physical					
	T2	46.26	43.80		
	TT	40.65	43.59	2.299	**.003**
	T1	48.33	45.10		
	T2	46.17	43.83	.908	.365
	T1	48.47	45.01		
	TT	40.51	43.58	3.51	**.001**
SF-36: Role emotional					
	T2	64.27	41.70		
	TT	55.02	43.71	3.579	**.000**
	T1	60.89	44.67		
	T2	65.11	41.50	-1.631	.104
	T1	60.64	44.63		
	TT	54.84	43.75	2.29	**.023**
SF-36: Mental health					
	T2	67.04	19.57		
	TT	62.73	22.39	4.726	**.022**
	T1	67.07	20.36		
	T2	67.31	19.60	-.275	.783
	T1	66.88	20.43		
	TT	62.73	22.39	4.51	**.000**
SF-36: General health					
	T2	51.45	23.94		
	TT	49.06	23.95	2.977	**.000**
	T1	51.82	24.27		
	T2	51.68	24.00	.166	.868
	T1	51.62	24.26		
	TT	49.06	23.95	2.99	**.003**

Table 36 shows there to be no significant difference between T1 and T2 for any of the five SF-36 domains, however, the GOQoL does show a significant difference between Time 1 and Time 2. This means that the participant felt that their goal-directed movement had changed but felt there had not been change in the functional QoL factors.

The differences between T2 and TT (Table 36) show there to be a significant difference on the GOQOL means and all the SF-36 subjective domains, but no significant difference in the physical domain. The direction of the change can be determined from the means and they show TT to have lower means than T2. This indicates that at T2 this group felt they had improved from T1 to T2 on the subjective domains. These two sections of the questionnaire were completed at the same point in time (Time 2). Relative to how they felt then, their retrospective baseline ratings were lower, as they felt they had improved despite the fact that they felt their physical state had not changed.

There was also a significant difference between T1 and TT for the subjective domains of the SF-36 but not for the physical domain or the GOQOL. This implies there was a shift in the interpretation of the standard of QoL in the subjective domains (mental health, general health, role physical and role emotional) from T1 to T2, as the level of QoL at T1 was rated differently at the two different points in time. Time 1 was given a more severe rating at T2 (TT) than it was when rated at T1. This shows there to be a positive response shift, where by participants felt they had improved when no change had taken place (as shown by the lack of a significant difference between SF-36 subjective domain scores T1 and T2).

An explanation for this apparent contradiction could be that a response shift had occurred. Possible reasons for this response shift might be found in the GOQoL statistics. These results show a significant change from T1 to T2 and a significant difference between T2 to TT (Table 36). This indicates an accurate assessment of perceived goal-directed movement by the individual. The change in the GOQoL is overt; participants were aware of feeling that their movement towards their goals was greater at T2 than at T1. This change from moving slowly away to moving slowly towards one's goals may explain why the T1 SF-36 subjective domains were rated so severely at T2, more so than at T1. The awareness of having been further from one's goals at T1 led to a perception of having had worse subjective QoL at T1 than at T2 and this was extended to the other subjective domains which received a more negative rating at T2, although there had been no actual change in physical functioning.

This result is probably best explained with the help of an example. A person diagnosed with Ménière's disease may feel that they are moving slightly away from their goals at T1 due to the impact of the illness on their lives, and they may rate the GOQoL-T1 as -1, the subjective SF-36 domains as 3, and the physical SF-36 domain as 3. When they complete the SF-36 again at T2 their illness and its effects on their lives are unchanged, and so they accurately report their status on all the SF-36 domains as still 3. However during the intervening ten months they may have learned to accept and live with their illness so that at T2 they have adjusted and now feel they are moving towards their goals. Consequently they may rate the GOQoL as +1 as they feel they have improved. When they come to the retrospective ThenTest section they accurately rate their GOQoL-T1 as -1 as they feel they were making less progress towards their goals at T1. However, as a consequence of their awareness of subjective improvement at T2 relative to T1, they also deduce that other aspects of their QoL at T1 must have been worse than at T2, and so they give the subjective SF-36 domains lower ratings of 1 or 2. The physical scale of the SF-36 is stable because it is based on objective functioning (e.g. ability to climb stairs), which can be accurately recalled and reported at all times, and these have not changed.

A second way in which response shift can occur is due to a reconceptualization of goals (Sprangers et al., 1999a). To determine if there was a change in goals the ranking of the importance of the GOQOL domains at Time 1 was compared with the order of the rank at Time 2 by means of paired t-tests (2-tailed). Any change in the order would show a change in the conceptualisation of goals. Table 37 shows there to be no significant difference in the order of the importance of the goals, therefore, one can conclude that response shift was not mediated by a change in the importance of the goals.

Table 37: Paired t-test (2-tailed) results showing the differences between Time 1 and Time 2 ranked domains of the GOQoL.

Variable		mean	std dev	t	sig
Family	-T1	1.46	.71	.249	.804
	-T2	1.44	.64		
Health	-T1	1.84	.73	.821	.412
	-T2	1.81	.69		
Work/Finances	-T1	3.63	.89	-.345	.730
	-T2	3.65	.85		
Social life	-T1	3.80	.79	.800	.424
	-T2	3.75	.82		
Spirituality	-T1	4.26	1.10	-1.46	.147
	-T2	4.33	1.06		

In conclusion, this change in the perception of movement towards and away from goals was in a positive direction, indicating that there was a change from moving slowly away to moving slowly towards goals. This change led to a change in the internal standards of measurement. These results provide evidence of a response shift within this sample as there was no change on the physical domain of the SF-36. A response shift may be taken as an indication of psychological adjustment, and as this response shift is positive the adjustment, too, is positive. The next step is to discover what has contributed to this shift in perception, and this will be conducted in the next section using multiple regression analysis.

7.4. Predictors of QoL over time

The longitudinal hypothesis stated that socially comparing at Time 1 would predict QoL (as measured by the three outcome measures) at Time 2, and in particular that positive social comparison would predict positive adjustment and negative social comparison would predict negative adjustment. The testing of the hypothesis involved three separate hierarchical regression equations. This is a consequence of measuring QoL with three different scales. The results are presented separately below.

7.4.1. Dependent variable: SF-36 (functional QoL)

To test the hypothesis that social comparison influences adjustment over time, partial correlations were calculated initially to determine which Time 1 variables were significantly associated with T2 QoL (SF-36-T2) while controlling for T1 QoL (SF-36-T1).

All the predictor variables were included in the partial correlations as well as both the other outcome variables (GOQoL and PTGI). This is because the PTGI can be interpreted as both an outcome and a predictor (Tedeschi et al., 1996). As an outcome, a crisis leads to seeking meaning and self-enhancement (Taylor, 1983) and perceiving positive change (Tedeschi et al., 1996). Perceiving positive change in turn can be a coping process, and thereby act as a predictor of QoL (Tedeschi et al., 1996). The GOQoL, too, can be a dependent or an independent variable. Striving for and attaining goals are integral to self-regulation theory (Carver et al., 2000; Scheier & Carver, 2001) and goals are likened to values which have a close association with life satisfaction and QoL (Carver et al., 1990; Keyes et al., 2002). As an independent variable, the success or failure of goal striving or attainment can have a direct effect on QoL. As a dependent variable, health and illness can interfere with goal-directed movement and so a measure of this can give an indication of an important aspect of QoL.

Table 38 below shows that seven variables were significantly associated with change in SF-36 scores. Self-esteem and optimism both had a positive correlation with increased QoL. The 'length of membership with the society' variable was positive and significant, indicating that greater length of membership was associated with an increase in QoL. Perceiving oneself as moving towards one's goals (as measured by the GOQoL) was also positively associated with change in QoL. This indicates that the more participants perceived themselves as moving towards their goals at T1, the greater their perceived improvement in QoL at T2.

The self-help variable 'use of self-help group,' and the social comparison variables: upward comparison interpreted negatively, 'extent of reading the self-help magazine,' 'sections read,' and 'reading all the letters in the letters to the editor section,' were all significant and negative. This means that participants experienced deterioration in QoL if at baseline when they socially compared with someone who was perceived as better off than themselves they interpreted this negatively ('I can never be like that person'). Deterioration in perceived QoL was also more likely the more the individual participated in the self-help group (e.g. Writing a letter of contacting a local group), the more the individual read the self-help group magazine, and read the various sections of the magazine, and read all the letters in the 'letters to the editor section.'

Table 38: Partial correlations for SF-36-T2 with Time 1 predictor variables where SF-36-T1 has been controlled for (missing data excluded pair wise).

Variable	Coefficient	Significance
Age	-.0217	.709
Sex	.0077	.895
Feeling of fullness in the ear	.0284	.625
Tinnitus	.1109	.055
Hear	.0336	.563
Vertigo	-.0109	.851
Control over illness	.0635	.277
Self-esteem	.2570	**.000**
Optimism	.1704	**.003**
Social comparison for information	-.0595	.307
Upward comparison interpreted positively	-.0101	.863
Upward comparison interpreted negatively	-.1446	**.013**
Downward comparison interpreted positively	.0344	.555
Downward comparison interpreted negatively	-.0424	.424
Time since diagnosis	-.0320	.893
Time since first symptom	-.0233	.695
Length of membership with the Society	.1372	**.019**
Live-in Social support	.0850	.142
External Social support	-.0252	.665
Live-in dependents	-.0306	.598
Use of self-help group	-.1865	**.001**
Sections read	-.2522	**.000**
Extent of reading self-help magazine	-.1280	**.028**
Reading all the letters in ‘Letters to the editor’	-.1286	**.027**
Preference for letters about people better-off	-.0674	.246
Preference for letters about people worse-off	-.0676	.245
GOQoL-T1	.1214	**.036**
PTGI-T1	-.0206	.724
Occupation	.0047	.936
Perceived helpfulness of ENT specialist	.0869	.151
Perceived helpfulness of GP	.1081	.063

To assess the unique variance of the dependent variable accounted for by each of these significant variables while controlling for the others they were entered into a regression equation. SF-36 at T2 was entered as the dependent variable and SF-36 at T1 was entered at step 1 (first centered). Of the significant predictor variables, optimism, self-esteem and GOQoL-T1 were entered at step 2. In this way these variables were controlled for when determining if social comparison influences adjustment. Finally, at step 3 the social comparison and self-help variables significant at the partial correlation stage were introduced. The '*extent of reading the SHG magazine*' variable was omitted as it is very similar to the '*sections read*' variable already included in the regression, with which it was correlated .7. All three steps of the regression were significant, accounting for a total of 68.2% of the variance (Table 39). Individual beta statistics of the step 3 variables show that goal-oriented QoL at T1, and self-esteem to be significant. Self-esteem and goal-oriented QoL have a positive beta indicating that they had a positive effect on QoL over time. However, '*sections read*' had a negative beta indicating that it had a negative effect on QoL over time. After controlling for these variables, the '*sections read*' variable, *upward information interpreted negatively*, and '*reading all the letters*' (all social comparison variables) were no longer significant.

Table 39: Summary of Hierarchical Regression Analysis for variables predicting functional QoL (N = 301)

Variables	Beta	SE B	Std. Beta
Step 1			
SF-36 – T1	.748	.034	.801*
Step 2			
SF-36-T1	.630	.040	.675*
GOQoL	.373	.164	.093*
Self-esteem	.491	.168	.145*
Optimism	.	.190	.020
Step 3			
SF-36-T1	.585	.041	.672*
GOQoL	.400	.161	.100*
SE	.446	.166	.132*
Optimism	.	188	.021
Upward negative comparison	-.317	.254	-.046
Use of self-help group	.	.007	-.051
Length of membership	.	.004	.007
Sections read	.	.006	-.111*
Reading all the Letters	.	.008	-.010

Note. $R^2 = .642$ for Step 1; $\Delta R^2 = .031$ for Step 2 ($p < .000$); $\Delta R^2 = .019$ for Step 3 ($p < .01$)

A check for mediators was performed using the approach recommended by Baron and Kenny (1986). Each possible mediator was entered into a regression equation alone, after which they are entered at the same step in another regression equation. Mediators are indicated by those variables which were significant when entered alone but which cease to be significant when entered at the same time as another variable (a mediator). These results are not presented here as no mediation was apparent.

A check for moderating variables was conducted using further regression analyses. Self-esteem, control and optimism had been shown to moderate the effects of social comparison in previous studies and so were multiplied by the five social comparison variables (upward and downward comparison interpreted both negatively and positively and 'sections read'). Length of membership of the society was also included as a moderator as social comparison changes over time and therefore may have different effects at different times during a person's membership. The interaction variables were entered at step 3. These results have not been presented in tables as there were no significant partial correlations between these interaction terms and change in SF-36 scores over time. For this reason no further regression analyses were needed.

7.4.2. Dependent variable: Goal-oriented QoL

To test the hypothesis, does social comparison influence a second aspect of QoL, the perception of movement towards/away from goals, partial correlations were run with the GOQOL-T2 and the Time 1 predictor variables, controlling for GOQOL-T1.

None of the social comparison variables significantly correlated with change in GOQOL-T2 (Table 40). However, perceived control, higher self-esteem, and living with someone who can help were positively correlated with perceiving increased goal-directed movement at Time 2.

Table 40: Partial correlations for GOQOL- T2 with the predictor variables (missing variables omitted pair wise).

Variable	Coefficient	Significance
Age	-.0093	.873
Sex	.0212	.715
Feeling of fullness in the ear	.0223	.700
Tinnitus	.0262	.652
Hear	-.0093	.873
Vertigo	-.0204	.726
Perceived control over illness	.1260	**.030**
Self-esteem	.1789	**.002**
Optimism	.0594	.306
Social comparison for Information	.0602	.300
Upward comparison interpreted positively	.0951	.101
Upward comparison interpreted negatively	-.0736	.205
Downward comparison interpreted positively	.1059	.068
Downward comparison interpreted negatively	-.0582	.317
Time since diagnosis	.0108	.857
Time since first symptom	.0071	.904
Length of membership with the society	.0598	.309
Live-in Social support	.1317	**.023**
External Social support	-.0273	.638
Dependents	-.0919	.113
Use of self-help group	-.1010	.082
Extent of reading the self-help group magazine	-.0460	.430
Sections read	-.0938	.105
Reading all the 'letters to the editor'	-.0452	.437
Preference for letters from those better-off	-.1120	.053
Preference for letters from those worse-off	-.0179	.757
PTGI-T1	-.0896	.123
Occupation	.0260	.656
Perceived helpfulness of ENT specialist	.0995	.100
Perceived helpfulness of GP	.0861	.139

To determine the impact each of the above significant variables had on the outcome variable while controlling for the impact of the other variables a hierarchical regression was conducted. The results are presented below (Table 41). GOQOL-T2 was entered as the dependent variable and GOQOL-T1 was entered into the first step of the equation (first centered). Control over illness and self-esteem were entered at step 2. Live-in social support was entered into the third step. In this way social support would only show significance if it was not mediated by the two psychological variables, self-esteem and perceived control over illness. The results show that step 2 was significant, accounting for 2% of the variance, while step 3 was non-significant, only accounting for a further .2% of the variance. The beta statistics at step 3 show only self-esteem to have a significant long-term positive effect on goal-oriented QoL. While perceived control over illness and live-in social support also have a positive effect on perceived goal-directed movement, they are not the primary predictors, their effects are mediated by self-esteem.

Table 41: Summary of Hierarchical Regression Analysis for variables predicting goal-oriented QoL at Time 2 (N = 301)

Variables	Beta	SE B	β
Step 1			
GOQoL – T1	.564	.043	.614*
Step 2			
GOQoL-T1	.494	.047	.538*
Self-esteem	.	.040	.123*
Perceived control	.	.042	.089
Step 3			
GOQoL-T1	.491	.047	.535*
Self-esteem	.	.040	.123*
Perceived control	.	.042	.083
Live-in social support	.667	.492	.063

Note. $R^2 = .378$ for Step 1; $\Delta R^2 = .024$ for Step 2 ($p < .005$); $\Delta R^2 = .004$ for Step 3 (ns)

7.4.3. Dependent variable: Perceived positive change

To test the hypothesis that social comparison promotes greater perceived positive change after the onset of the illness partial correlations were calculated to assess which variables were significantly associated with PTGI-T2 (Table 42) while controlling for PTGI-T1.

Fullness of the ear showed a positive correlation, indicating that the more severe the fullness was the greater the perception of positive change. Time since diagnosis and time since first symptom, too, were significant. These variables were negatively correlated with perceived positive change, indicating that those members only recently diagnosed, when the symptoms were at their worst, experienced more increase in positive change than those who were diagnosed a while ago. As with the GOQOL, no social comparison variables were significant and in this case none of the psychological variables, self-esteem, control, or optimism, were significant either.

Table 42: Partial correlations for PTGI-T2 with the Time 1 predictor variables where PTGI-T1 has been controlled for (missing data excluded pair wise).

Variable	Coefficient	Significance
Age	-.0536	.358
Sex	-.0578	.321
Feeling of fullness in the ear	.1653	**.004**
Tinnitus	.0687	.238
Hear	.0242	.678
Vertigo	.1027	.077
Control over illness	.0842	.149
Self-esteem	-.0192	.743
Optimism	-.0175	.764
Social comparison for Information	.1117	.054
Upward comparison interpreted positively	.0319	.584
Upward comparison interpreted negatively	.0217	.709
Downward comparison interpreted positively	-.0800	.169
Downward comparison interpreted negatively	-.0029	.960
Time since diagnosis	-.1574	**.008**
Time since first symptom	-.1862	**.002**
Length of membership with the society	-.0691	.240
Live-in social support	.0133	.820
External social support	-.0417	.475
Dependents	.0083	.887
Use of the self-help group	-.0400	.493
Extent of reading self-help magazine	-.0216	.830
Sections read	.0230	.693
Reading all the letters in 'letters to the editor'	.0107	.854
Preference for letters from those better-off	.0242	.678
Preference for letters from those worse-off	.0346	.552
Occupation	-.0107	.855
Perceived helpfulness of ENT specialist	-.0251	.679
Perceived helpfulness of GP	.0334	.567
GOQoL – T1	.0414	.478

In the regression equation, PTGI-T2 was entered as the dependent variable. PTGI-T1 was (first centered) entered at step 1, 'feeling of fullness in the ear' was entered at step 2, and time since diagnosis and time since first symptom were entered into the third step to determine whether or not these variables were still significant after accounting for disease severity. Only step 1 was significant, accounting for 51% of the variance, while step 2 and 3 together only accounted for a further .9% of the variance (Table 43), indicating that there was no significant predictor for PTGI at Time 2. However, a feeling of fullness in the ear, time since diagnosis and time since onset of the illness all showed positive, significant partial correlations indicating that, while not the primary predictors, all positively predicted perceiving positive change since the onset of the illness. A feeling of fullness in the ear is a sign of active disease and mediates the effects of time since diagnosis and time since onset. Again, as with the GOQOL, no interactions were added to the regression equation as no social comparison or psychological variables were significant.

Table 43: Summary of Hierarchical Regression Analysis for variables predicting perceived positive change at Time 2 (N = 301)

Variables	Beta	SE B	Std. Beta
Step 1			
PTGI – T1	.705	.042	.702*
Step 2			
PTGI-T1	.692	.042	.702*
Fullness	.102	.052	.084
Step 3			
PTGI-T1	.693	.042	.703*
Fullness	.	.052	.079
Time since diagnosis	.	.001	.015
Time since first symptom	.	.001	-.094

Note. $R^2 = .512$ for Step 1; $\Delta R^2 = .007$ for Step 2 (ns); $\Delta R^2 = .007$ for Step 3 (ns)

7.5. Discussion

The aims of this study were to measure change in QoL over time and to assess what factors influenced this change. Assessing this change involved looking at the ThenTest data. The results of the longitudinal analysis showed that a positive response shift did indeed occur in this sample. Participants felt at follow-up that their QoL was better than at baseline, even though no significant change had occurred with regard to the impact of the illness on physical QoL. This indicates that a response shift occurred by a change in the internal standards of measurement. A change in perception of movement towards goals was probably responsible for this change, as an overt improvement was observed in this aspect of QoL. They felt at Time 2 that they were moving towards their goals, whereas at baseline they felt they were moving away from them. The fact that a change in the perception of movement towards goals changed the perception of the other domains (for example, the subjective domains: mental health, general health, role physical, and role emotional) when no actual change had occurred indicates the importance of perceived goal-directed movement to the overall perception of QoL, as it influences perception of other subjective domains.

Adjustment (both functional and goal-oriented) was positively and significantly predicted by self-esteem and perception of movement towards goals. This finding supports both the self-esteem literature and previous research where striving for and attaining valuable goals has been shown to be associated with life satisfaction (Carver et al., 1990). The significance of this variable in predicting change in QoL provides further support for the idea that perception of change in movement towards goals was responsible for the response shift, again providing evidence of the importance of goals in QoL (Carver et al., 1990). Since perceiving oneself as moving towards goals is a possible cause of response shift it is interesting to note the predictors of this variable. The main longitudinal predictor was self-esteem, with perceived control over illness and living with someone who can help as secondary predictors. This shows the importance of self-esteem, control and social support in goal-oriented QoL.

With regard to the hypothesis that social comparison would be associated with adjustment, social comparison was found to predict change in functional QoL over time. Partial correlations that were significant were; upward comparison interpreted negatively, the extent of reading the magazine, and reading all the letters in the letters to the editor section. These variables were all significantly and negatively associated with functional QoL. Reading about someone who is either coping better or has less severe symptoms and interpreting this negatively (that is, in a dejected way because they feel they can never by like that person) appears to have a negative effect on the way the individual's own QoL is perceived. This indicates that the social comparison occurring within the self-help group can have a negative effect on functional QoL over time, as those who reported reading all the sections of the self-help group magazine at baseline reported a deterioration in QoL. This shows that reading the self-help group magazine can have a negative effect.

There are a number of possible interpretations of this result. This variable is a measure of the quantity of social comparison engaged in by means of reading the magazine, including both upward and downward positively and negatively interpreted comparisons. Both cross-sectionally and longitudinally, upward comparison information interpreted negatively predicted worse functional QoL. It is possible that the upward comparisons which may exist in various areas of the magazine (eg. Letters to the editor, Penpals, the medical section and fundraising) may contribute to the negative effect on QoL in those who interpret this information negatively. According to the Identification/Contrast model, instead of identifying with the positive targets, these participants have contrasted with the better-off other which leads to negative affect. In addition, in a situation where it is difficult to avoid any of the stories (since interpreting them as positive or negative involves reading them first to determine their category), it is possible that reading all or most of the letters has a negative effect. This would explain why reading all the letters was also associated with a decrease in QoL.

The negative effect of upward information interpreted negatively on functional QoL was mediated by self-esteem. This indicates that the positive effect of high self-esteem helps counteract the negative affect experienced after contrasting with someone better off. No significant moderators emerged.

The length of membership with the Ménière's Society also showed a significant and positive partial correlation, while '*the extent of using the self-help group*' was negatively associated with functional QoL. This could suggest that the total length of membership had a positive effect on adjustment, despite the finding that the more the members engage with the society the worse their QoL. However, as it appears to be unhelpful to read all of the magazine, and making use of the self-help group by participating in the services it provides also has a negative effect, perhaps it is the other therapeutic factors that the self-help group provides which are generating this benefit. These factors were discussed in Chapter one, and the next Chapter, Chapter eight, will expand on this discussion by proposing which factors are likely to be the most important.

These findings add support to the research which has shown that self-help groups do not always have a positive effect (Ablon, 1981; Helgeson, Cohen, Schulz, & Yasko, 2001; Sprangers et al., 1999a; Vachon, Lyall, Rogers, Freedman-Letofsky, & Freeman, 1980); ; (Van der Zee et al., 1995; Van der Zee, Oldersma, Buunk, & Bos, 1998). It is possible that social comparison in self-help groups has unclear benefits, as it could be similar to meeting in person (Van der Zee et al., 1998) which has been found to lead to identification due to the fact that the source of the information is so credible. Comparison over time will also lead to identification (Buunk et al., 1997), and in the case of a self-help group the identification is with an ill person. Blalock et al. (1989) have shown that those Rheumatoid Arthritis (RA) patients who identified with a non-RA patient showed better satisfaction with ability than those who identified with another RA patient. However, in their study social comparison was not a primary predictor of adjustment (as measured by self-esteem, depression, life satisfaction and positive affect) as it ceased to be significant after controlling for satisfaction with ability. In a self-help group comparison will occur with only the other members who have the same condition as oneself; the stories are all of other people with Ménière's disease, whether they are upward or downward. Perhaps, as in Blalock's (1989) Rheumatoid Arthritis study, upward comparison would be more helpful if made with a person who does not have Ménière's disease. Helgeson et al. (2001), in their comparison of interventions with cancer patients, found peer discussion to increase the number of downward comparisons interpreted negatively. This was a local self-help group where people met and where the membership was finite. The Ménière's society is a national group, where people do not meet, and the membership is much longer than that of a local group. It is possible that excessive social comparison information read in the self-help group magazine over years of membership leads to identification, and can also have a negative effect on QoL. However, it is important to note that length of membership was positively associated with functional QoL, suggesting that membership can have benefits if identification is not excessive.

Perceived positive change was associated with the more acute symptoms associated with the early stages of the illness, consistent with previous research (Tedeschi et al., 1996)). No social comparison variables predicted either perceived positive change after onset or perception of movement towards/away from goals. In addition, no positive social comparison variables were found to predict positive adjustment for any of the three outcome measures. These results differ from the cross-sectional analyses, which showed positive social comparison (downward) to predict better functional QoL and the perception of movement towards goals, and positive upward comparison to predict increased perception of positive change and an increased perception of movement towards goals. However, downward positive comparison nearly reached significance longitudinally for the perception of movement towards goals. These results, showing that social comparison may have a mainly negative effect over time, provide some support for those theories which propose that in illness downward comparison is not helpful due to its interpretation as one's future self (Buunk et al., 1990). It is interesting in this context to note that downward information interpreted positively and a preference for reading letters from those better-off were nearly significant longitudinally in the partial correlations, predicting change in perceived movement towards goals with the former having a positive effect while the latter had a negative effect. Increase in perceiving positive change over time was positively associated with a feeling of fullness in the ear and negatively associated with the length of time since diagnosis and the length of time since the first symptom.

The second hypothesis, that self-esteem, control, and optimism would predict adjustment over time, was also supported. Self-esteem had a positive effect on functional and goal-oriented QoL. Perceived control over illness and optimism did emerge as predictors in the partial correlations but not in the regression equation and so are not primary predictors and may be mediated by self-esteem. Control and having someone who lives with you who can help also had a positive effect on perceiving movement towards goals.

In sum, this study has shown response shift to have occurred in this sample by means of a change in the internal standards of measurement. This has probably occurred due to the change the sample has experienced in the perceived movement towards their goals. While at the beginning of the study they felt they were moving away from their goals, they felt they were moving towards them at the end of the study.

High self-esteem was found to be important longitudinally for both functional QoL and the perception of movement towards goals. Regarding the primary hypothesis, that social comparison influences adjustment, at time 1, the social comparison information from reading the self-help group magazine, reading all the letters in the letters to the editor section, reading all the sections in the magazine, and making use of, or participating in the self-help group facilities all have a negative effect on functional QoL at time 2.

Social comparison does not appear to be important for perceiving one's own movement towards goals, probably because they are internal goals and not subject to social influences to the same extent as functional QoL. Functional QoL may be more susceptible to social comparison as the domains which make up this aspect of QoL may be of a more social nature, that is, functional QoL may consist of aspects which are more readily talked about and therefore available as social comparison material. For example, daily activities (physical functioning), and worries (mental health) may be more readily communicated than personal feelings about goals regarding one's family or finances. The perception of positive change also does not appear to be influenced by social comparison. This may be because the perception of positive change occurs mainly when the situation is at its worst and so the social comparison engaged in at time 1 is unlikely to have a big effect on the perception of positive change ten months later.

The next chapter, Chapter 8, will summarize the empirical studies and discuss all the findings together in relation to the literature. The conclusions of these studies will also be discussed in light of the model proposed in Chapter 4 leading to overall conclusions regarding social comparison within a self-help group and the validity of the model.

CHAPTER EIGHT: THE DISCUSSION

8.1. Introduction

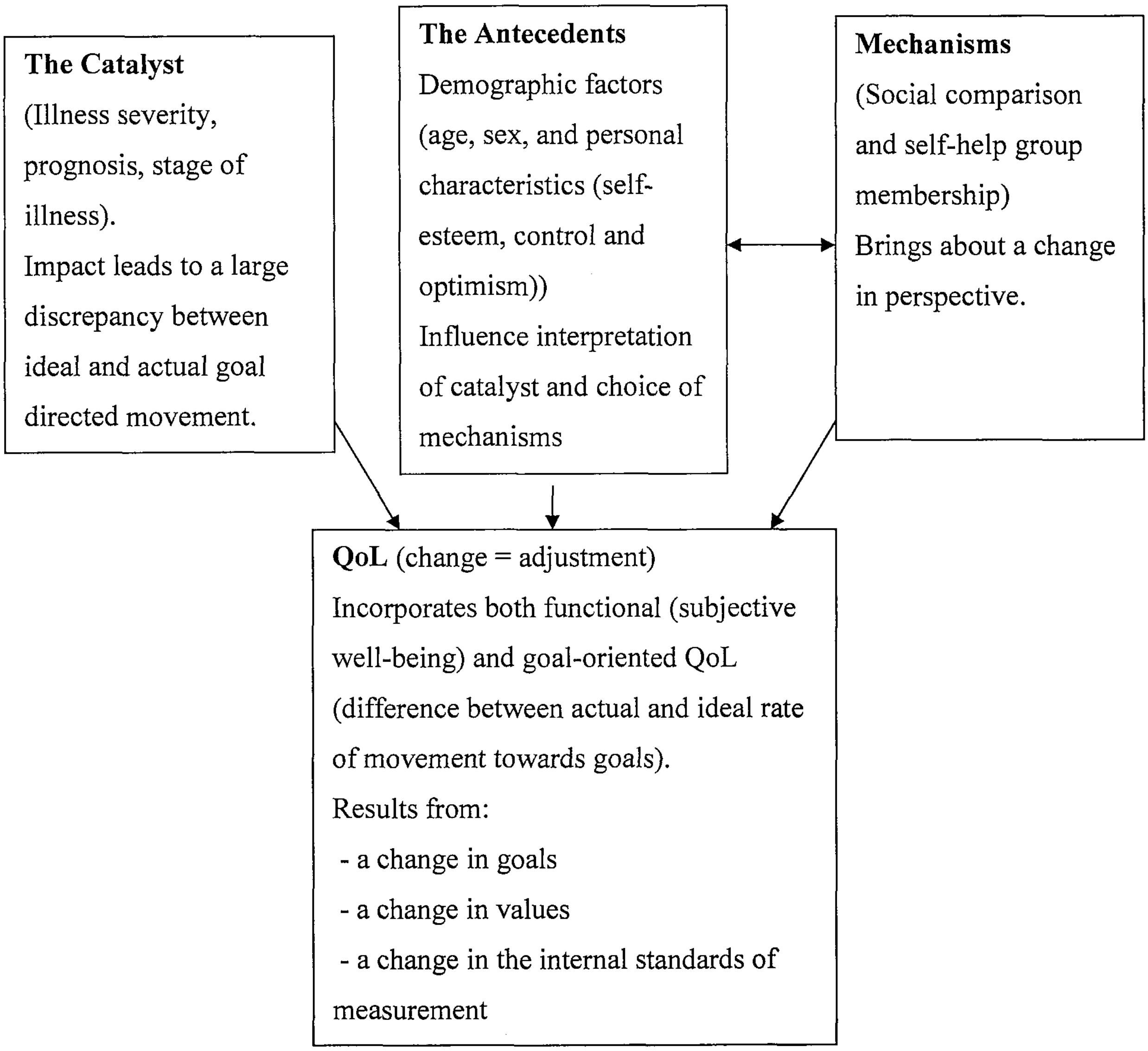
This final chapter assesses whether the hypotheses of the empirical chapters were supported or not and describes these results in relation to the model proposed in Chapter 4. In order to do this the first section of this chapter reviews the proposed adjustment model. The main messages from this study are also reviewed relative to previous research, and the implications of the results for self-help groups are discussed. Lastly, the limitations of the study are assessed and, the conclusions and future directions for research suggested.

8.2. Summary of the model

The adjustment model, proposed in Chapter 4, described the process of a *catalyst* (chronic illness) bringing about a large discrepancy between ideal movement towards goals and perceived movement towards goals. Interpretation of the *catalyst* and choice of *mechanisms* (ways of dealing with the *catalyst*) are dependent on the *antecedents* (personal characteristics). While the *antecedents* and the *mechanisms* both influence QoL, this model proposes that social comparison processes (*mechanisms*) influence QoL over and above the influences of the *antecedents* and this brings about a change in the perception of QoL.

Diagram 3: A Model of Adjustment

This model of adjustment shows the effects of the many factors on QoL which bring about adjustment.



The Catalyst
(Illness severity, prognosis, stage of illness).
Impact leads to a large discrepancy between ideal and actual goal directed movement.

The Antecedents
Demographic factors (age, sex, and personal characteristics (self-esteem, control and optimism))
Influence interpretation of catalyst and choice of mechanisms

Mechanisms
(Social comparison and self-help group membership)
Brings about a change in perspective.

QoL (change = adjustment)
Incorporates both functional (subjective well-being) and goal-oriented QoL (difference between actual and ideal rate of movement towards goals).
Results from:
- a change in goals
- a change in values
- a change in the internal standards of measurement

8.3. Summary of the empirical chapters

8.3.1. Chapter 5

This chapter described a qualitative study and the development and validation of two new scales. While the qualitative study was designed to assist in the development of a social comparison scale, it yielded some interesting comments from the participants which described how they felt about reading about other people with Ménière's disease (see section 8.3.3.). The qualitative study also successfully assisted in the development of the Social Comparison in Illness scale which was then validated against a pre-existing scale in the validation study. This new scale, a subscale of which was used in the main survey of this thesis, measured upward, downward and lateral comparison, distinguished between the coping and illness dimension, and included information as a reason for socially comparing. It also included a fourth direction called trajectory. This last direction was included based on the results of the interview study where participants indicated that they found those stories in which the person had not been coping well but overcame their situation and now copes well (also on the illness dimension) to be helpful. No other social comparison scale includes these distinctions.

This chapter also reported the development of a goal-oriented QoL scale (GOQoL), comprising two subscales. The first subscale was designed based on the SEIQoL, an interview based measure of current status of QoL on five domains, which is unsuitable for postal survey use. The second subscale was based on Carver and Scheier's Control Process Theory (1990). It measured the perception of movement towards or away from one's goals on the same five QoL domains as the first subscale described above. This scale is unique as no other such scale is available.

The results of this preliminary research showed that this group were indeed socially comparing with other members of the self-help group by means of the magazine. Results also showed that both the new scales, the Social Comparison in Illness scale and Goal-Oriented QoL scale, had good internal reliability. Both scales were also successfully validated against the existing scales. Despite this the decision was taken to use the Identification/Contrast scale in the main study as the Social Comparison in Illness scale items loaded onto the same factors that the Identification/Contrast scale measures showing the two scales to measure the same factors. However, the Identification/Contrast scale is well known as it has been tested and used in other social comparison studies and this meant that results from this study may be viewed as more reliable than if depending on a new measure despite the fact that it was found to be both reliable and valid. The Identification/Contrast scale was used in the main study with the inclusion of the information subscale of the Social Comparison in Illness scale as this emerged as important in the interview study and in the literature and yet is omitted from the Identification/Contrast scale.

8.3.2. Chapter 6

Chapter 6 presented the results of the cross-sectional study where the baseline data was collected. This study predicted that variables classified as *mechanisms* (social comparison variables) would influence QoL after variables classified as a *catalyst* or as *antecedents* were controlled for. There was the additional expectation that the *antecedents* (self-esteem, perceived control and optimism) would be related to QoL after controlling for levels of the *catalyst* (illness severity).

To examine these predictions other *antecedents* (age and sex) found previously to influence QoL were entered into a regression equation predicting QoL at step 1, *catalyst* variables were entered at step 2, the *antecedents* (self-esteem, perceived control, and optimism) were entered at step 3, and the social comparison variables (the *mechanisms*) were entered at step 4 for each of the three outcome measures. In this way the effects of social comparison on QoL were determined after controlling for the other variables in the equation. The results are discussed separately below.

- Cross-sectional predictors of functional QoL

Social comparison was found to predict functional QoL after the *catalyst* and the *antecedents* had been controlled for. The social comparison variables which emerged as primary predictors were downward information interpreted positively, which positively predicted functional QoL, and upward information interpreted negatively, which negatively predicted QoL. This showed that comparing with someone worse off and feeling oneself to be in a better situation was associated with better functional QoL, although the causal direction of this relationship cannot be established as these results were based on cross-sectional data. Likewise, comparing with someone better off and feeling dejected was associated with worse QoL; again the direction of the causal relationship between these variables cannot be determined. The results showed that positive social comparison was associated with positive adjustment and negative social comparison was associated with negative adjustment. This not only supported the Identification/Contrast model (Buunk et al., 1990) but also confirmed the hypothesis and the model proposed in this study.

Variables which had a positive effect on QoL were optimism and self-esteem, both *antecedents*, this was the case even after controlling for other *antecedents* such as age and sex, and the *catalyst* variables. This supports one of the predictions of this study and the literature, however, perceived control did not emerge as significant for functional QoL and so this aspect of the prediction was not supported. Other variables which had an effect were gender (an *antecedent*), where males reported better functional QoL, and two *catalyst* variables (a feeling of fullness in the ear and vertigo) which were negatively related to QoL, supporting the literature which shows physical illness to have a negative impact on QoL.

- Cross-sectional predictors of goal-oriented QoL

All the social comparison variables were having a positive effect on goal-oriented QoL with both upward and downward comparison information interpreted positively emerging as primary predictors. As with functional QoL, the direction of the relationship cannot be confirmed. It is possible that perceiving oneself as moving towards goals leads to the positive interpretation of the social comparison information instead of the other way around. Other positive primary predictors were gender (where females reported perceiving themselves as moving towards their goals), optimism, perceived control, and self-esteem (all *antecedents*), the latter three variables supporting one of the hypotheses of this study. Primary predictors which had a negative effect were age (an *antecedent*) and a feeling of fullness in the ear (a *catalyst* variable). This shows that those with worse symptoms and who were older did not perceive themselves as moving towards their goals.

- Cross-sectional predictors of perceived positive change

All the primary predictors showed a positive relationship meaning that they were associated with more perceived positive change. Only one *antecedent* emerged as a primary predictor, perceived control, with those who perceived more control perceiving more positive change. Vertigo, too, showed a positive relationship with perceived positive change. This means that when the vertigo was at its worst more positive change was perceived. This is consistent with the literature which shows that we tend to perceive more positive change when the situation (or the illness) is at its worst. The positive relationship indicates that those who score high on the vertigo scale do indeed perceive more positive change. Three social comparison variables emerged as primary predictors. Reading many of the sections of Spin, the self-help group magazine, and interpreting upward comparison information both positively and negatively were all associated with perceiving more positive change. This could indicate that when individuals endure the worse phases of the illness they engage in more upward comparison and read the self-help group magazine which then leads to a greater perception of positive change.

8.3.3. Chapter 7

This chapter presented the longitudinal results where baseline data (Time 1) and follow-up data (Time 2) were used to determine the long-term predictors of QoL. The analysis at this stage was designed to answer the following two research questions: what aspects of QoL changed over time? And what predicts change in QoL over time?

- (1) What aspects of QoL changed over time?

This aspect of the study was investigated using five of the SF-36 subscales (one objective subscale (physical functioning), and four subjective subscales (mental health, role emotional, role physical, and general health)), and the GOQoL. Changes in goals were measured from T1 to T2 using the ranked goals of the GOQoL and changes in the internal standards of measurement were measured by means of the ThenTest approach using both the SF-36 subscales and the GOQoL.

There were no changes in the order of ranked domains of QoL, indicating that participants had not altered their priorities regarding what domains of QoL they considered most important. However, the ThenTest results showed a response shift to have occurred on the subjective QoL subscales of the SF-36 but not the objective subscale. Although no actual change took place (Time 1 to Time 2 change was non-significant on the SF-36 subscales) there was a perception of change in the subjective subscales (Time 1 and ThenTest, and Time 2 and ThenTest differences were significantly different). This indicates that a change in the internal standards of measurement had occurred. This probably occurred due to an overt change in the perception of movement towards goals (where Time 1 to Time 2 changes were significantly different). This aspect of QoL, measured by the GOQoL, had shown an actual change; at Time 1 this group had felt that they were moving away from their goals, but by Time 2, they felt they were moving towards their goals. This change affected the perception of other subjective aspects of QoL giving the impression that they too had undergone a change when actually no change had occurred. These results are interesting as changes in goal-directed movement have not been measured in this way before and these results show clearly that goal-directed movement is important to QoL, so much so that it overshadows other subjective aspects of QoL.

- (2) What predicts change in QoL over time?

This research question was answered using partial correlations, where Time 2 QoL was correlated with all predictor variables while controlling for QoL at Time 1. As all significant partial correlations were influencing QoL over time they are discussed separately below according to each of the three aspects of QoL measured.

-Predictors of change in functional QoL

For functional QoL the positive partial correlations were self-esteem, optimism, length of membership of the society, and perceived goal-directed movement. This indicates that those high in self-esteem and optimism at Time 1 had an increase in functional QoL at Time 2. Length of membership also predicted functional QoL over time; the longer the length of membership of the society at Time 1 the greater the increase in functional QoL at Time 2. This suggests that the self-help group was having a positive effect on adjustment over time, which means that the membership of this self-help group was beneficial; this self-help group was assisting its members in positive change (with regard to adjustment in functional QoL) over time.

The qualitative interview study (chapter 5) may be able to shed light on possible reasons for the beneficial effects of belonging to the self-help group. Interviewees described many of the therapeutic processes that Yalom (1970) has suggested occur in therapeutic groups, showing that these processes are at play within the self-help group as well. Firstly, comments made by participants which were classified as lateral comparison reveal what Yalom has called *universality,* the feeling that you are not the only one experiencing these problems. This may have been beneficial to the members, leading to enhanced perceived QoL over time. Comments made about receiving advice also show that the person was receiving *guidance* by belonging to the self-help group. Both *cohesiveness* and *identification* were apparent in comments which stated that the person felt better knowing that others were going through the same thing and that others understand what they are going through. Finally, comments about reading about members with what was classified as an upward positive trajectory in the interview study suggest an *installation of hope*, another of Yalom's therapeutic factors. These factors, although not tested longitudinally, reveal possible answers as to why membership of the self-help group had a positive effect over time.

The perception of movement towards goals also positively predicted functional QoL over time. This, once again, shows the importance of goals to the perception of QoL and supports work by Carver and Scheier (Carver et al., 1990) which describes perceived QoL as hinging on perceived goal-directed movement.

Those variables which influenced functional QoL negatively over time were all classified as social comparison variables in this study. They included upward comparison interpreted negatively, making much use of the self-help group, reading many sections of the magazine, Spin, reading the magazine from cover to cover, and reading all the letters in the 'letters to the editor' section. That upward comparison information interpreted negatively emerged as a secondary predictor shows that this group were contrasting with the better off other and feeling dejected and hopeless about their own situation in response to the information.

Making much use of the self-help group, at first glance, appears to contradict the positive effect that length of membership of the society has on QoL. However, these two variables were measuring very different things. Use of the self-help group measured the extent to which the participant engaged with and made use of the self-help group resources. These included writing a letter to the editor for inclusion in Spin, contacting the helpline for advice, contacting another member, reading all the fact sheets, and joining a local group. With the exception of reading the fact sheets, the other resources were not used by a large percentage of the group, which means that only a relatively small number of participants were experiencing the negative effect brought on by this degree of involvement with the society. Possible reasons for this negative effect could be due to other factors particular to this subgroup. This use of the society's resources may indicate an overdependence on the society and a lack of healthy coping strategies. This suggestion is supported by the positive influence of the society over time (length of membership) where the role of the society is more one of support and information provider. The typical member, who read mostly the medical information section and the letters to the editor section and did not interpret these negatively, nor read all sections of Spin obsessively, experienced improved QoL at Time 2.

The other three social comparison variables which negatively influenced functional QoL over time all involved reading Spin. This indicates that those who read Spin cover to cover, perceived a worse functional QoL at Time 2, while those who read only selected sections and relevant articles perceived an improved QoL at Time 2. As reviewed in Chapter 3, comparing oneself with someone who is in a better situation than yourself can be interpreted both positively and negatively depending on whether one identifies or contrasts oneself with the target (Buunk et al., 1990). Contrasting with someone who is better off leads to feelings of dejection and negative affect. This occurs when the person finds differences between themselves and the target and these differences, along with an absence of feeling similar to the target, lead to feeling as if they could never be like the target. These feelings influence behaviour too, as no attempt is then made (for example, behaviour change) to try to be like the target. These negative feelings and the lack of trying to improve then have a negative effect on QoL over time. That excessive reading of Spin had a negative effect may again be due to negative interpretation of any reference to other people with Ménière's disease who may be managing their illness better, or whose illness is not as severe as the person reading Spin as supported by the influence of upward comparison information interpreted negatively.

-Predictors of change in goal-oriented QoL

Three significant partial correlations emerged predicting goal-oriented QoL. Self-esteem and perceived control were positively correlated with the GOQoL, showing that those high in self-esteem and perceived control at Time 1 perceived better movement towards goals at Time 2. The positive effects of high self-esteem and perceiving more control over illness had a long-term (at least ten months) positive effect on perceiving oneself as moving towards goals. This, again, supports previous QoL research which has shown these variables to be important to QoL and adjustment (Taylor, 1983). Both these variables are listed in Cognitive Adaptation Theory as being central to QoL, and an important part of the adaptation process after a crisis where there is a need to recover damaged self-esteem and to regain control over life.

Social support, too, positively predicted perception of movement towards goals. This means that having someone who lives with you who can also help you at Time 1 led to the perception of movement towards goals at Time 2. This is consistent with the social support literature which has shown that social support can have positive effects such as improving well-being (see Leppin & Schwarzer, 1990, for a review).

Social comparison did not emerge as a predictor of goal-oriented QoL over time. However, it was significantly correlated with the GOQoL at baseline, showing positive social comparison to predict positive adjustment and negative social comparison to predict negative adjustment. It is not possible to determine the causal direction of this association; it is possible that social comparison has an immediate effect on perceived movement towards goals, but it is equally possible that perceived movement towards goals has an effect on whether social comparisons are interpreted positively or negatively. Longitudinally, positive social comparison still had a positive effect however, it did not quite reach significance.

-Predictors of change in perceived positive change

The perception of positive change showed a positive correlation with a disease severity variable (*catalyst*); a feeling of fullness in the ear. According to the literature we tend to experience more positive change immediately after the onset of the crisis and when the situation is at its worst (Tedeschi et al., 1996) which explains why there is a positive correlation here. More positive change would be experienced when the symptoms are at their worst. Perceiving positive change was also negatively correlated with the time since the first symptom and the time since the first diagnosis. Once again this is consistent with the literature where the longer the time since the first symptom and the diagnosis the less positive change that is perceived as this tends to happen immediately after the crisis has occurred, when the situation is at its worst. Perceived positive change was not predicted by social comparison longitudinally. At baseline upward comparison (both positive and negative) was important, however, at follow up no social comparison variables were significant; although comparison for information was having a positive effect it did not reach significance. As with the GOQoL, this shows an immediate relationship, however, the direction of this relationship cannot be determined as it is based on correlational data.

8.4. How these results relate to the proposed model of adjustment

Evidence that this model has been supported could be found in significant relationships between QoL and the *catalyst,* the *antecedents* and the *mechanisms.* In this study, support for the model would consist of evidence that the *catalyst* has an initial dramatic effect on QoL, that there is a significant influence of *antecedent* personal characteristics (self-esteem, perceived control, and optimism) on QoL, and a significant relationship between social comparison and QoL.

Evidence to support the model can be found in the cross-sectional data where the disease severity variables (the *catalyst*) had a significant influence on QoL. Self-esteem, optimism and perceived control influenced both functional and goal-oriented QoL and perceived control also influenced perceiving positive change at baseline. These relationships show that personal characteristics (*antecedents*) do influence QoL.

The personal characteristics also show a significant relationship with QoL longitudinally, showing the *antecedents* to be important to change in QoL. Longitudinally gender was significant and self-esteem influenced change in both functional and goal-oriented QoL, while perceived control influenced change in goal-oriented QoL

Social comparison (a *mechanism*), too, influenced change in QoL, as shown by the significant relationship between upward social comparison variables and the self-help social comparison variables and functional QoL at follow-up. This relationship showed a negative relationship at follow-up.

Finally, support for the definition of QoL in this model, as dependent on the perception of movement towards or away from goals was supported by the permeating effects that changes in this perception had on other subjective aspects of QoL.

8.5. Is the literature supported?

Aspects of this study have supported previous research. In QoL research QoL has been linked to self-esteem (Aspinwall et al., 1993; Bogart et al., 2000; Wills, 1981), optimism (Carver et al., 1993; de Ridder et al., 2000; Scheier et al., 1987; Scheier et al., 1985) and perceived control (Amir et al., 1999; Carver et al., 1990; Helgeson, 1992; Taylor, 1983; Taylor et al., 1984; Thompson, 1981) and the results of this study show these three constructs to be associated with better QoL. Optimism has been linked to QoL in the respect that it can facilitate striving for goals, especially where previous experience has proved the behaviour to be successful (Carver et al., 1990). This leads to optimistic expectations of the outcome of subsequent behaviour meaning that the behaviour is more likely to occur than if the behaviour/action had been previously unsuccessful (Carver et al., 1990). In addition, self-esteem and perceived control have been highlighted as important to QoL and adjustment in the

Cognitive Adaptation Theory (Taylor, 1983). In this theory three responses to a crisis are proposed. Two of them are a need to regain control over one's life and the need to self-enhance, or increase self-esteem. Both are helpful in the recovery period where there is a tendency to regain control and increase self-esteem which was lowered by the onset of the illness. This study has shown support for these responses to a crisis, both self-esteem and perceived control at Time 1 were positively predicting QoL at Time 2

The response shift model (Sprangers et al., 1999a) proposes that as part of the adaptation process after a crisis we experience a cognitive change which allows a new, better perceived QoL. The logic of this model states that a person with any chronic illness may experience this cognitive shift over time and so adjust to their new life of living with their illness. Evidence for a cognitive shift would support Sprangers and Schwartz's model. In this study response shift was measured over ten months using the ThenTest. The results of this test confirmed that this group were adjusting positively to their illness. Despite the fact that no change was evident in objective QoL they perceived their subjective Time 1 QoL to have been worse than at Time 2. This indicates that they felt that they had improved although no such improvement had occurred. The most likely reason for this shift in perception is the overt change in perception of movement towards goals. While at Time 1 this group felt they were moving away from their goals, by Time 2 they felt that they were moving towards their goals. This again highlights the importance of goals to QoL (discussed above) first proposed by Carver and Scheier (1990); not only did the change in goals parallel the response shift but the perception of movement towards goals was a primary predictor of change in functional QoL over time.

Regarding social comparison, firstly, social comparison was occurring within this self-help group supporting Gibbons and Gerrard (1989), and Medvene (1992). Secondly, positive social comparison was associated with better QoL and negative social comparison was associated with worse QoL at the cross-sectional analysis. This supports the Identification/Contrast model (Buunk et al., 1990) and the role of downward comparison as proposed by Taylor (1983) and Wills (1981), and further support was found for this longitudinally when negative social comparison was found to predict worsening QoL. This supports the Identification/Contrast Model (Buunk et al., 1990) which proposed that negative social comparison will result in negative affect. Positive social comparison had a positive effect on goal-oriented QoL and social comparison for information had a positive effect on perceived positive change, although these did not reach significance over time. It is possible that as positive social comparison was significant at the cross-sectional stage it has an immediate effect and so the effect is not evident over time, however the design of this study did not allow for this to be confirmed.

As discussed in Chapter Seven, the negative effects of social comparison may be due to the target. Buunk and Ybema (1997) propose that comparison over time leads to identification. The average length of membership with the Ménière's society was just under five years, with a large range. It is possible that comparison for this length of time can lead to identification with the person(s) described in the letters to the editor section. This may be compounded by the fact that the letters are published in a magazine which may be referred to repeatedly, this indefinite availability of the social comparison information may facilitate the identification process. In addition, as the identification occurs with other people with Ménière's disease this could have a negative effect on QoL over time. In support of this supposition is the research on patients with rheumatoid arthritis by Blalock and colleagues (1989) where they found that comparison with people who did not have rheumatoid arthritis to result in better satisfaction with ability when compared to comparisons made with fellow rheumatoid arthritis patients. This implies that those with Ménière's disease might show a positive relationship between social comparison and QoL if they compared themselves with those who do not have Ménière's disease.

Another study which showed negative effects of self-help groups, probably due to social comparison, was a study with cancer patients (Helgeson et al., 1999). In this study, patients who engaged in a peer discussion group showed negative effects on QoL, probably due to negative downward comparisons. Interestingly, an education only group showed positive effects, and a peer-discussion plus education group still showed poorer results as compared to the education only, showing that the peer discussion was having a negative impact on the positive effect of the education.

However, in this study the self-help group was having a positive effect over time, and this suggests that other processes involved in the self-help group (such as gaining information, knowing of people who understand what you have gone through, and support) were important for this. This supports other studies which show the positive effects of self-help groups. For example, Medvene's (1992) study of undergraduates showed they joined groups primarily for information from those with similar experiences and problems, another study found self-help groups to provide peer support (Molinari, Nelson, Shekelle, & Crothers, 1994), and a third study found self-help groups to provide a group of people who understand the person's own experiences (Steffen, 1997).

8.6. What do these results mean for people with Ménière's disease?

The results showed that those who had high self-esteem, optimism and perceived control over illness at Time 1 experienced a better QoL at Time 2. Therefore, those who are low in self-esteem, perceived control and not dispositionally optimistic may need additional assistance. This could take the form of increased social support, as this was found to be a significant positive predictor of goal-oriented QoL. However, excessive use of the society for support was associated with a worse outcome at Time 2. Those that became over involved with the society may be doing so because they spend too much time dwelling on their illness. This is supported by research into worrying (Aldrich, Eccleston, & Crombez, 2000) in the context of chronic pain. Worrying is an over-involvement on the part of the person with their illness. They experience 'heightened vigilance, worry, and ineffective problem solving' (p. 464). It also interferes with other cognitions compounding the focus on the illness, and is associated with repetitive and negative self-evaluations. Applying this to Ménière's disease, it may mean that the person becomes so involved with their Ménière's disease that they think of nothing else (interfering with other cognitions). In addition they may engage in negative self-evaluation which may in turn negatively influence goal setting, and goal-directed behaviour, which over time is associated with a drop in perceived QoL. In addition, excessive interest in the self-help group may have a detrimental effect over time on one's identity as long-term social comparison leads to identification (Gibbons, 1999, as described above) , and identification with an ill person, regardless of whether the ill person is an upward or downward target, may still lead to maintaining an illness-centered identity. This may lead to the adoption of illness behaviours in situations where they are not appropriate. In addition, the constant reminder of a possible negative future through downward comparison information may have a negative effect. The results suggest that it is important to not be so illness focused, and to not rely too much on the society. This means focusing on other things and finding other ways of coping rather than depending too much on the society.

8.7. Implications for the Ménière's Society and other self-help groups

These results offer some guidance to the Ménière's society. Firstly, these results show that nearly 100% of the members read Spin and two of the most popular sections are the medical section and the letters to the editor section. This indicates that these two forms of information provision are probably having the most influence on the members. As information is a prime reason for reading the magazine (and indeed joining the group in the first place) the quality and accuracy of this information is of the utmost importance. As it is the negative interpretation of this information which can have a negative effect tactics which promote a positive interpretation would be helpful. One possibility would be for the self-help group to restrict what they publish in their magazine to only confidence building material or perhaps reduce the percentage of unsettling descriptions which may induce anxiety. Another possibility would be to warn all new members of the contents of the typical magazine when they join, so forewarning them and giving them the option of omitting certain sections of the magazine. Regarding the letters section, stories which are written in such a way as to be encouraging and not threatening may be of assistance, in this way negative interpretations of comparisons might be avoided. Although length of membership of the self-help group had shown a positive effect, there was a negative effect for those who engaged in negative social comparison. This information is important to those involved with self-help groups, as knowing how to avoid negative comparison would be beneficial to the members. This could be taken further by avoiding all disturbing descriptions of illness episodes or stories that could be interpreted negatively as these may encourage a negative interpretation of the information which has a negative effect. In this study, making excessive use of the self-help group had a negative effect on QoL over time. This action can be linked to one of Yalom's (1970) therapeutic factors. Catharsis is the term given to the action of engaging in a group to share one's experiences. The action of writing a letter to the editor and joining a local group had a negative effect and this means that the cathartic process which usually occurs in self-help groups could actually have a negative effect on the individual's adjustment. In support of this, a study looking at three self-help groups found that those who received support only (without interacting and providing support as well) experienced feelings of inferiority and psychological indebtedness (Maton, 1988). Possibly membership of an illness group may encourage dwelling on negative aspects of the illness, as shown by this negative effect of making greater use of the self-help group, and extensive reading of the magazine. Finally, as making more use of the society's resources had a negative effect over time and this was probably due to an over dependence on the society, articles which encourage independence and advice on healthy coping methods, too, would be beneficial for the members.

The importance of perceived goal-directed movement emerged from the predictor and response shift results, this emphasizes the importance of setting realistic goals, no matter how small; having something to aim for in life is pertinent to experiencing a 'good' or 'bad' QoL and the results of this study show that the effects are long-term (ten months at least).

8.8. Limitations

This study has some limitations which must be taken into consideration. Firstly, there was no comparison group included in the study and so the results are not generalisable to everyone with Ménière's disease, nor to all self-help groups. People with Ménière's disease who do not belong to the Ménière's society may make comparisons with people who do not have Ménière's disease and this may have a positive effect on QoL, as shown by the rheumatoid arthritis study described above. However, these people would also not benefit from the support and information provided by the society which this study has shown to have a positive effect on perceived functional QoL over time. Other self-help groups may differ in that the comparison engaged in within the group may be particular to this group. People with other illnesses may socially compare (Gibbons et al., 1989; Medvene, 1992; Tennen & Affleck,

1997) but other non-illness self-help groups may show a different pattern of comparisons. The unpredictable nature of the illness and the fact that it is a progressive illness may mean that negative interpretations occur more easily than for illnesses with different characteristics. However, these results are indicative of a relationship that may well occur for other illness self-help groups.

Another limitation is the method of data collection used. Postal questionnaires were used which means that the data collected was subject to all the usual biases that accompany self-report studies. For example, the social desirability bias may occur where participants may not answer items truthfully but rather score the answer they think would most please the researcher, thereby looking good themselves. Also, responses may be influenced by a perception of threat by the participant, which is relevant should he/she worry about confidentiality and anonymity surrounding giving answers and information to strangers.

The data may also be positively biased as in comparison to those who completed questionnaires at T2, those who only completed the T1 questionnaire perceived their illness to impact more on their social life and physically interfered with the carrying out of their roles. This group also did not perceive the same support from their GP. Finally, this group did not make as many positive social comparisons as the group who continued to T2. This perception of greater interference by the illness and less social contact and professional support may have lead to more severe ratings at T2, the absence of which may mean a slight positive bias of the results.

In addition, only two time points were used to collect data and this means that there is a limitation in the ability to draw causal conclusions. This is because it is not possible to detect causal effects operating with different time-frames from the ten month follow-up, and this means that evidence for causal effects is more limited than experimental studies allow.

In addition, this study was not able to use Structural Equation Modelling due to insufficient sample size relative to number of variables, so was only able to examine a sub-set of relationships between variables rather than all mediators simultaneously

8.9. Conclusions

This study set out to determine the long term effects of social comparison on adjustment. It was a longitudinal study which assessed the QoL of members of an illness self-help group in order to determine factors which influence adjustment to their illness. This study was unique in a number of ways. Firstly, it was a longitudinal study of an illness self-help group. The self-help group was already in existence, an important point necessary for gathering valid data from self-help groups. Secondly, it is the only known longitudinal study of social comparison in an illness group. Thirdly, this is the only study to measure aspects of QoL which have changed over time in this way using a scale which measured perception of movement towards goals and using the ThenTest approach. This study also included the development and validation of two new questionnaires, a social comparison in illness scale which distinguishes between comparison directions, between comparison dimensions, and a goal-oriented QoL scale which is unique as it measures the perception of movement towards/away from goals.

Of the variables which predicted change in QoL over time, perceived movement towards goals surfaced as important. In the analysis of what aspects of QoL changed over time it was apparent that the perception of movement away from goals changed to the perception of movement towards goals and this change permeated to other subjective aspects of QoL, giving the impression that a positive change had occurred there as well when, in fact, no change in objective and subjective functioning had occurred. Other predictors which emerged as important were self-esteem, social support, length of membership of the society, optimism, and perceived control. Social comparison, too, influenced QoL over time. On the whole, the group made more positive comparisons (upward and downward) than negative comparisons. However, negative social comparison had a negative effect over time due to contrast with those members who were in a better situation. These results support the hypothesis proposed in this study, that social comparison influences adjustment over time. However, despite this negative effect in some participants, a positive, subjective adjustment did occur in this group as a whole, as while they showed no actual change in functional QoL they perceived a change, and there was an actual change in the perception of goal-directed movement.

There are implications for other illness self-help groups, although the extent to which these effects can be generalised has yet to be determined. There is consensus in the literature that social comparison is probably at work within self-help groups and this study has supported that. This means that the positive and negative effects of upward and downward comparison might be similar in other illness groups. An acknowledgement of the possible positive and negative effects would be important in ensuring positive outcomes of membership of self-help groups. This means an awareness that the type of interpretation (positive or negative) of social comparison and the degree of involvement in the group can determine whether the self-help group has a positive or negative effect on the individual's adjustment to their illness.

As with all research, the answers of one study lead to more questions. Further studies into this topic should determine how to distinguish those who are likely to over-depend on a self-help group and perhaps provide them with different support to those who use the self-help group for information and continue to cope on their own. In addition, it would be of interest to determine whether those people with Ménière's disease who do not belong to a self-help group socially compare in the same way. Further studies would also be necessary to determine if the pattern of relationships found in this study are found amongst all self-help groups or are particular to the Ménière's society. Since making great use of the society had a negative effect on QoL it would be of benefit to determine what aspects about this sub-group or their situation lead to them to make more use of the society. This would not only be beneficial to their own adjustment but perhaps also to members of other illness self-help groups. Finally, as positively interpreted social comparison information predicted positive QoL further research into how to influence the interpretation of the information would be beneficial to all who socially compare and in particular self-help groups, where social comparison is active.

To conclude, this study has shown conclusive evidence for the effects of social comparison on adjustment and highlights the importance of this knowledge in terms of both the potential positive and negative effects it can have within a self-help group. Knowledge of this kind will hopefully assist those involved with self-help groups to avoid a negative outcome.

9.0. APPENDICES

Appendix A: The screening questionnaire

University
of Southampton

Dear Member of the Ménière's Society,

My name is Bridget Dibb. You may have read in the December Spin about the study I am doing for the Ménière's Society. I am a Health Psychologist in Training from the University of Southampton and I am looking at what the Ménière's Society does for you, and what you would like it to do.

I would like to talk to some of the members to get an idea of how they feel about being a member of the society. If you are happy to talk to me, I would like to came and see you at your home at a time that suits you. The visit will be an informal chat that should take about forty minutes. I am interested in finding out what you read in Spin and how you feel about Spin.

To protect your privacy everything you say will be held in confidence. I will be writing up the results of the study so that others can benefit from it but no real names will be used. I will record our talk so that I can write up a record of what you say, but no-one else will hear the tapes of our conversation; they will then be kept in a locked cabinet until the end of the study when they will be erased.

If you agree to let me visit you then please could you fill out the form over the page and return it in the prepaid envelope. Even if you agree now that I can visit, you can still change your mind later if you like. Please don't feel that you have to take part, and if at any stage you have any questions or worries then please feel free to contact me at the above address or at telephone number: 023 8059 5785.

Thank you for your time,

Bridget Dibb
Health Psychologist in Training

University
of Southampton

If you do agree to take part in this study by allowing me to visit you then please could you answer the questions below.

Please could you tell me your:

Age..........

Sex..........

Have you bee diagnosed with Ménière's disease by a hospital doctor?.............

When were you given this diagnosis?.................

Do you have any other illnesses?...

Please could you sign your name and date it to show that you have read this letter, understand it and are completing it of your own free will. The results of the study will be written up but no names will be used to ensure confidentiality. Please be aware that you can change your mind and not take part at any time.

Signed:

Date:

Please print your name...

For contact so that I can arrange a visit please fill in the following:

Address:..

....

....

Telephone number:..

Please could you return this in the prepaid envelope. Please not that not everyone will be contacted for an interview.

Thank you for your time and help.

Bridget Dibb

Health Psychologist

Appendix B: The interview schedule

GENERAL INTERVIEW SCHEDULE

I am interested in what you like to read in Spin, can you tell me about it?

Can you tell me what you like to read about?

So how do you feel when you read it?

Can you tell me more, are there any other parts that you like to read?

I'd like to know more about what it is you like to read? How do you feel when you read it?

What about the letter section, can you tell me what you read in that?

Can you tell me what it is that you like to read in this letter?

Can you give me an example of a helpful letter that you have read?

So how do you feel when you read these letters?

Can you me any more about what it is that you like about them?

Can you think of any letters that you don't want to read?

Can you give me an example of a letter that you don't like reading?

How do you feel when you read these letters?

Can you tell me any more about what it is that will stop you from wanting to read them?

Is there anything else that the society does which you like? What? Why do you like that?

Is there anything about the society that you feel could be changed or improved? What? Why is that?

Presentation section

How do you feel about the way the magazine looks?

What about the size of the letters and the way the columns are laid out?

Do you find the list of contents useful?

Would a picture/diagram encourage you to read an article?

Do you find that you read some things because they seem easier to read?

Prompts

Can you tell me more

That is interesting I'd like to here more.

In what way

Could you explain/describe that for me

Appendix C: Examples of the transcripts

Participant 3

SC3 That is the difficulty. I'm afraid I'm, as I say I'm lucky, the way the disease affects me, it enables me to have a full-time job without any great problems. And I'm afraid having a full-time job and a full-time home life as well means that time is scarce. I do always try and make the time to read it – don't always succeed.

BD And which parts do you read?

SC3 If I'm reading anything, I'm particularly interested in research and treatments for the disease, but I think – sorry, I beg your pardon if I'm going off at a tangent, but I think the Ménière's Society has got a real narrow path to tread with *Spin*, because it's… Ménière's is such a disease that affects so many people in so many different ways, and I think they've got to be very careful what they present, and how they present, because on the one hand it could trivialise it, which would be terrible, and on the other hand, it could, if they went too deeply into it, it could depress people who have recently been diagnosed with it, so I think they've got to keep a fairly delicate balance, and I think they actually manage to achieve that quite well.

BD So you read the research and medical sections? Why do you find those interesting?

SC3 I suppose 1) because I'm interested in it, secondly because I have been very badly served by the medical profession myself. I've had very little advice, practically no treatment, I've not been able to talk to my doctor about this for the last 8 years, because he's not interested. I've not been referred to any specialist for at least 10 years. Therefore I get no advice from my GP or from the health service on what might be happening with Ménière's Disease, so it's almost a matter of reading that myself and then trying to work out if there's anything in there that could help me, because certainly my doctor isn't going to.

BD So you're reading it for information? And do you find it helpful?

SC3 Yes, I do, I do.

BD And how do you feel when you read what's going on?

SC3 Mainly extremely lucky, because for me it makes me realise that there's a lot of people out there a lot worse off than I am, and therefore it makes me count my blessings. It also frustrates me a little bit, in that, I mean for all the research that's going on into Ménière's, it is, in the great scheme of things, very little. And I really do feel for people who have the affliction far worse than I have. I'm very lucky – 90% of my time I can lead a normal life, but I can read in there that there are people who can't, and that really gets at me, because I can empathise with the situation that they're in. For the short time that I have it, I get extremely frustrated.

BD How do you feel when you read those stories, about people not doing as well as yourself?

SC3 As I say, I feel a great sympathy for them, but also a great frustration, because there's not a lot that I can do to help them, if you know what I mean. And I know that medical science can't do an awful lot to help many of them either, so it's always nice to read in there… as I say I read all the medical bits, but I also read the letters very much, because it's nice to hear from people who are taking very positive stands towards it.

BD Do you find that helpful?

SC3 Oh yes, yes.

BD In what way is that helpful?

SC3 It's always nice to… I mean, everybody's got to have their own way of dealing with this. My way of dealing with it is basically to convince myself that I haven't really got it, and I can do that in the periods of remission that I'm in, but I know it's always lurking in the background, and there's always that knowledge, always that fear that the thing is going to leap out and grab you when you're least expecting it. As it did a few weeks ago here, I mean, as I said to you, I'd be interested in contributing to your further research because [we had?] a very important meeting here a few weeks ago, about 30 people there, ranging from very senior military officers to very senior representative managers from a defence contractor, plus my own staff and many of my colleagues, and I had to be laid under the table because I had an attack half way through the meeting, and everybody thinks you're drunk, which is very embarrassing, particularly if it's in the afternoon. So, reading how people who are worse off than I am, cope with their symptoms, and really being able to laugh at that sort of situation, because if you took it too seriously, you'd finish up in the depths of depression. You have to really laugh at it, and many of the letters in there are very, very positive, from people who are obviously suffering a lot worse than me, but taking a very positive attitude, and I find that reassuring.

Participant 24

SC24 Well, I actually read all of it, and I'm interested in the research findings certainly, and I'm always sort of scanning it to see whether they're coming up with some wonderful cure. And sometimes I read about certain things that are done, and thought "Oh, I certainly couldn't stand that" – being spun round, and then…I also like the letters that people send, because you often find that someone's having exactly the same experience as yourself, and in fact, that's quite a valuable part of it, you think "Oh yes…" For instance, someone mentioned that every time they drank down tonic water, they got dizzy, and I thought "Well, that's happened to me", so I immediately cut out tonic water. And in the more recent one, someone was mentioning that they always have pains in the ears preceding an attack. I thought "Well, yes, that's just like me", so I do scan the letters. Sometimes I'm appalled because people are suffering so much more than I am suffering, it's quite depressing sometimes, but I think it's valuable that people have got that way of expressing themselves, so yes, I find that good. Dietary tips I've certainly been interested, and I've had back numbers where you know, it's gone through certain foods that have got so much salt in: that's our biggest enemy actually, the salt, especially in any prepared foods, or anything you buy in these convenience foods, it's quite frightening, especially when you learn that you've got to multiply by 2 ½, the sodium content. So you're not just getting you know, what seems to be a minimal amount, you're getting a huge amount, but I found that…I think that happened just after Christmas, I'd had some friends, and thought "It would be nice if we had curry", so "I can't be bothered to do it, I'll get it from Marks & Spencers". We had these curries, and they were quite delicious, very nice, but 2 or 3 days afterwards I went down with a really massive attack, which lasted about 5 days, so I sort of checked back, and I found that they'd had the equivalent of about 10 grams of salt in each of them, which was a huge amount. So most of the convenience foods, and the vegetarian foods, I think have got a lot of salt because it disguises the fact they're not very tasty! So that interests me, and in the beginning when I was first diagnosed and feeling really bad, cos it was much more severe then, I in desperation rang 1 or 2 of the sort of contact numbers in the area – there are not many people living in Hampshire I think who actually are on the listing…telephone people, but the couple I phoned were very, very kind, but they were in a worse state than I was, so I tended not to do that very often. And I don't think I feel that I could offer anything myself… perhaps I could, I'm not volunteering at the moment.

BD About the letters that you like to read, what is it about the letters do you think?

SC24 Well people really…as I say, coming up with these odd little points about things that they think might have triggered the attack, I'm always searching to find out what it is that does it, because it seems to come out of the blue, you see, you're perfectly well one day…at the most recent one, someone is mentioning aspartame, I think that was the ingredient, and someone had discovered it in Ovaltine. So I suppose everyone is so different, it wouldn't affect everyone, but I treat my diet as….I used to have migraine, and I think in my case migraine very gradually turned into Ménière's Disease…I don't know at what point it changed over, so anything that would bring on migraine I leave alone severely, which means a very restricted diet.

BD You mentioned that there were some letters that you read where the person wasn't doing so well as yourself…

SC24 That's right, yes.

BD How do you feel when you read those?

SC24 Sometimes I wonder whether you can almost induce an attack, when they're describing their symptoms, so I have to read that with caution. I wouldn't say that every time I read *Spin* it…in fact, not very keen on the name actually.

BD Of the magazine?

SC24 Yes, yes. I know it's a wonderful sort of pun, and a joke, and it's clever to have thought of it, but it's not something I really like to think about.

BD Can you elaborate on that?

SC24 Well, the last thing you want to think about is spinning, yes, and it brings back memories of what's just happened to you, so I don't know whether that's a small point, but…and when my friends say "Oh what's this?" And I say "It's the magazine for Ménière's Disease", they say "*Spin*?!" So everyone sees it…I suppose you've just got to accept it, but there we are. But I do admire the way the magazine's put together, and you know, the people who are supporting it, and the fact that it is well-founded, and there's nothing frivolous – I wouldn't want it to go to be a frivolous magazine. And there's a little section at the back for people who want penfriends again, perhaps some people find people they want to correspond with through that, yes.

BD Can you tell me anything more about the letters that you like to read?

SC24 I read them all, yes. I suppose I'm just interested in people relating their symptoms, and you know, when they can be a bit optimistic, that's nice as well. Some people you know, they've had remissions for years, or it only comes on occasionally. Because not many people understand the illness: even amongst one's friends they think "Oh well, just a bit dizzy", unless they've actually seen you in the process of having one of these terrible attacks. That did happen a couple of years ago, and I was driving to see someone, pick them up – we were going to an art exhibition, and suddenly – this is the one and only time it's ever happened to me while I've been driving - but I thought the steering had given out on the car actually, and I just managed to make it to the parking place, and staggered to the friend's door, and I was violently ill as soon as I got there, so it was an absolute revelation to her: she had no idea. Have you ever seen people when they've been having these attacks?

Participant 25

SC25 Well, I like reading the letters, and also any new development on research, and the medicine that they advise to take. It is a help, because at first no-one, when I developed this Ménière's, no-one seemed to know much about it, but with the magazine you know that others are suffering like you are, so in a way it helps to know that other people know what it is like. Yes, it is a good magazine, although I've never written any letters yet, but it has helped. I have telephoned some contacts, because there again it gives you a few contacts to get in touch with, and this has helped me, yes.

BD And the letters that you like to read, can you tell me more about that?

SC25 Yes, at first you think it's happening only for people of...you know, older people, but then you read some young women, some young men, are suffering with it, and of course, you think that is a good thing that you were fine when you were young - it's only happened for me in later years. But it helps as well with medicines they take, and when they help them, because I was on Cinnarizine, and then someone told me that...one of the contacts from the magazine told me they were on Serc. Now the doctor has gradually put me on Serc, and I find it is helping me in the way I'm not so sleepy, and so I haven't had a vertigo yet this far, this year, I haven't had one yet this year, but I had one last year. I usually keep a record of what I have. But it is you know, worth the... I mean, it is very little, we give £10...you know, I give something else when I renew my subscription, but it's very good value for money. Also they give you... about the conferences, and you try to follow what the specialists have to say about it. But every time you get the magazine you are hoping they will have found...discover a cure, because the medicine helps, but it doesn't cure. And of course on the appearance people seem fine and healthy, but it is a very disabling....nightmare, I would call it, it is a nightmare. But it helps to have the magazine.

BD In what way does it help?

SC25 Well, reading that they are doing research, also helping knowing that...I thought of having the operation, but then in the magazine they say it's not always successful, and of course it can make you deaf. So it makes you think that you have a choice that either you carry on as you are and put up with the occasional vertigo, or rather than to go for the operation, until they absolutely find something that is a cure. I wouldn't mind having an operation if it made me deaf, but I know of a lady who had the operation, and it left her permanently dizzy, not with vertigo, but permanently dizzy, and no-one would want that, because in between attacks we recover, and we are normal. But it gives you the contact...but I haven't been in contact with my Hampshire group because it's in Eastleigh, and it's bad enough now with these problems that I have to rely on my husband such a lot, but it is...to go to the group meeting it's in Eastleigh, and I don't drive, so it is a problem. It's also good the magazine for my husband, because he reads it, and it makes him understand better what it is, what it is like. But it isn't a very big magazine, but it is enough, they have penpals for...you know, I keep busy enough, I don't need...but some people say their experience when they travel, such as this lady who travelled to Australia. Some say that it helps...I was concerned, I had a big journey by plane at Christmas, and I was concerned I would have a vertigo in the plane, but then they say that sometimes it helps. And it is true, by the time I arrived, the noise in my ears that I have constantly had cleared, and for the 6 weeks I was away, I never had any problem. I came back, the noise was still clear, my ear was completely clear, and slowly it came back, a little by little 'til now it is...you know I have this noise in my ear, which is always a sign that you will be getting a vertigo. It gets really bad at times, and this is when you have to be prepared. But I have a good doctor, so she understands. But this is a... a lot of people have different things: some people have tinnitus, it is not just for Ménière's, it is as well...some are deaf and have tinnitus you see. You can have that – my sister has tinnitus but she never had vertigo. As I said, you can have Ménière's and not really have problem...noise in your ear.

Appendix D: The validation questionnaire pack

(Due to the restrictions on page layout for the thesis the reproduction of the questionnaire in this document has meant that the layout of the questionnaire differs slightly from how it was presented to the participants)

University
of Southampton

Department of

Psychology

University of Southampton

Highfield

Southampton

SO17 1BJ

United Kingdom

Dear Member of the Ménière's Society,

My name is Bridget Dibb and I am a Health Psychologist in Training at the University of Southampton. In partnership with the Ménière's Society I am carrying out some research into what life is like for a person with Ménière's Disease, what may be helpful and/or unhelpful.

You may have read something about what I am going to be doing in Spin. I have already carried out some interviews to which I had an overwhelming response. I am now at the point where I need to send out some questionnaires. You have been selected and I would be very grateful if you would complete it and return it in the prepaid envelope provided. The questionnaire should take about 40 minutes to complete. I realise that this involves your time and help, but your input is very valuable. You will be asked to answer some questions about your health, your Ménière's Disease, Spin, and the Ménière's Society. Personal information will not be released to or viewed by anyone other than the researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

When you complete and return of this questionnaire I will take it as evidence of you giving informed consent to be included as a participant in this study, for your data to be used for the research, and that you understand that published results of this research project will maintain your confidentially. Your participation is voluntary and if you do not wish to complete the questionnaire then I would be grateful if you could return it, uncompleted, in the prepaid envelope.

Should you have any queries about this study then please contact me Bridget Dibb at 023 80 595785.

Thank you for your help,

Bridget Dibb

Health Psychologist in Training

LIFE WITH MENIERE'S STUDY

SECTION A: LIFE SATISFACTION Questionnaire number......

The following questions refer to how you see the quality of your life.
Please tick the box which most closely reflects how you feel.

1) How would you rate the overall quality of your life now?

☐ the worst it could be	☐quite bad	☐ slightly bad	☐neither good nor bad	☐slightly good	☐quite good	☐my ideal situation

2) If you were to rate the following areas of life according to importance, what order would you put them in? Please could you place number 1 next to the one you feel is the most important, and number two next to the one which is the next most important, and so on. Please answer all the questions.

i) Family and relationships..........
ii) Work and finances............
iii) Social life and activities.......
iv) Health (physical and emotional)...........
v) Spirituality (Religion or beliefs).........

With regard to the 5 areas of life listed above, please could you try to imagine your ideal situation in each area. Please tick the box which is the most accurate for you. Please answer all the questions.

3) How close do you feel you are to your ideal situation with your family and friends?

☐the furthest I could be	☐quite far away	☐somewhat far away	☐neutral (half way)	☐somewhat close	☐quite close	☐the closest I could be

4) How quickly do you feel that you are moving towards or away from your ideal situation with your family and friends?

☐very quickly away	☐ quite quickly away	☐slowly away	☐not moving at all	☐ slowly toward my ideal	☐quite quickly towards	☐very quickly towards

5) How close do you feel you are to your ideal situation with your work and finances?

☐the furthest I could be	☐quite far away	☐somewhat far away	☐neutral (half way)	☐somewhat close	☐quite close	☐the closest I could be

6) How quickly do you feel that you are moving towards or away from your ideal situation with your work and finances?

☐very quickly away	☐ quite quickly away	☐slowly away	☐not moving at all	☐ slowly toward my ideal	☐quite quickly towards	☐very quickly towards

7) How close do you feel you are to your ideal situation with your social life and activities?

☐the furthest I could be	☐quite far away	☐somewhat far away	☐neutral (half way)	☐somewhat close	☐quite close	☐the closest I could be

8) How quickly do you feel that you are moving towards or away from your ideal situation with your social life and activities?

☐very quickly away	☐ quite quickly away	☐slowly away	☐not moving at all	☐ slowly toward my ideal	☐quite quickly towards	☐very quickly towards

9) How close do you feel you are to your ideal situation with your health (physical and emotional)?

☐the furthest I could be	☐quite far away	☐somewhat far away	☐neutral (half way)	☐somewhat close	☐quite close	☐the closest I could be

10) How quickly do you feel that you are moving towards or away from your ideal situation with your health (physical and emotional)?

☐very quickly away	☐ quite quickly away	☐slowly away	☐not moving at all	☐ slowly toward my ideal	☐quite quickly towards	☐very quickly towards

11) How close do you feel you are to your ideal situation with your spirituality (religion and beliefs)?

☐the furthest I could be	☐quite far away	☐somewhat far away	☐neutral (half way)	☐somewhat close	☐quite close	☐the closest I could be

12) How quickly do you feel that you are moving towards or away from your ideal situation with your spirituality (religion and beliefs)?

☐very quickly away	☐ quite quickly away	☐slowly away	☐not moving at all	☐ slowly toward my ideal	☐quite quickly towards	☐very quickly towards

SECTION B: HEALTH

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions, please give the best answer you can and make any of your own comments if you like. Please answer all the questions. (Please tick one)

1) In general, would you say your health is: Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐

2) Compared to one year ago, how would you rate your health in general now?

a)Much better now than one year ago ☐
b)Somewhat better now than one year ago ☐
c)About the same ☐
d)Somewhat worse now than one year ago ☐
e)Much worse now than one year ago ☐

The following questions are about activities you might do during a typical day.

3) Does your health limit you in these activities? If so, how much?

(Please tick one box on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b) **Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
c) Lifting or carrying groceries	☐	☐	☐
d) Climbing **several** flights of stairs	☐	☐	☐
e) Climbing **one** flight of stairs	☐	☐	☐
f) Bending, kneeling, or stooping	☐	☐	☐
g) Walking **more than a mile**	☐	☐	☐
h) Walking **half a mile**	☐	☐	☐
i) Walking **100 yards**	☐	☐	☐
j) Bathing and dressing yourself	☐	☐	☐

4) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Answer Yes or No to each question)

	Yes	No
a) Cut down on the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished less** than you would like	☐	☐
c) Were limited in the **kind** of work or other activities	☐	☐
d) Had **difficulty** performing the work or other activities (eg. It took extra effort)	☐	☐

5) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Answer Yes or No to each question)

	Yes	No
a) Cut down on the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished** less than you would like	☐	☐
c) Didn't do work or other activities as **carefully** as usual	☐	☐

(Please tick one)

6) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

Not at all ☐
Slightly ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

7) How much bodily pain have you had during the past 4 weeks?

None ☐
Very mild ☐
Mild ☐
Moderate ☐
Severe ☐
Very Severe ☐

8) During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)?

Not at all ☐
Slightly ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

The next questions are about how you feel and how things have been with you during the past month. (For each question, please indicate the one answer that comes closest to the way you have been feeling).

(Please tick one box on each line)

9) **How much time during the past month**:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life	☐	☐	☐	☐	☐	☐
b) Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c) Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d) Have you felt calm and Peaceful?	☐	☐	☐	☐	☐	☐
e) Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f) Have you felt downhearted and low?	☐	☐	☐	☐	☐	☐
g) Did you feel worn out?	☐	☐	☐	☐	☐	☐
h) Have you been a happy person?	☐	☐	☐	☐	☐	☐
i) Did you feel tired?	☐	☐	☐	☐	☐	☐
j) Has your **health limited** your social activities (like visiting your friends or close relatives)?	☐	☐	☐	☐	☐	☐

10) Please choose the answer that best describes how true or false each of the following statements is for you.

(Please tick one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seem to get ill more easily than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

SECTION C: MENIERE'S SOCIETY MEMBERSHIP

The following statements concern how you may feel about being a member of the Ménière's Society. Please circle the appropriate number. Please answer all the questions.

Being a member of the Ménière's Society is helpful as I can learn how to be like other members that are coping well.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful as I learned that others have problems too, and I realise I am not alone in experiencing the problems I have.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society has given me hope as I now know of others coping well and I hope that I, too, can cope that well.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful because I get a lot of advice and suggestions on how to cope with problems.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful because I can write a letter or phone another member and express how I feel without being criticised for it.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful because it is good to belong to a group of people who care about other people with MD.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful because it helps me to work out why I feel the way I do about my illness.
(1) Not helpful (2) Not sure (3) very helpful

Being a member of the Ménière's Society is helpful because if I can be of any help to others with MD then I, too, feel better.
(1) Not helpful (2) Not sure (3) very helpful

9) Being a member of the Ménière's Society is helpful because it helps me realise that I must be responsible for myself and make my own decisions.

(1) Not helpful (2) Not sure (3) very helpful

SECTION D: ABOUT YOURSELF

Please could you answer all the following questions:
Age:………………………..
Sex: Male/Female.
In addition to your Ménière's Disease, have you got any other medical illnesses or conditions? (Please be specific)……………………………………………………………………………………..
Are you taking any medication or treatments other than your Ménière's medication? (Please specify)………………………………………………………………………………………………
Have you been diagnosed with Ménière's Disease by a hospital doctor? Yes/No
When were you diagnosed with Ménière's Disease (how long ago)?(Years and months)…………………..
How long have you been a member of the Ménière's Society for?
(Years)………………………………….

SECTION E: LETTERS

The following questions refer to the Letters' section in SPIN. Please state whether you agree or disagree with the following by ticking the appropriate box. Please answer all the questions

1) I read the letters in Spin to see if they have any advice for me.
☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

2) I read the letters to see if I am coping better or worse with my illness than the person writing the letter.
☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

3) I read the letters to see if I am more or less ill than the person in the letter.
☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

4) I read the letters to find out about the medical advice given to the person in the letter.
☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

5) When I read the letters from people coping better than I am, I feel inspired.
☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

6) When I read the letters from people coping better than I am, I feel depressed, ‘I can never be like that.’

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

7) When I read the letters from people with milder symptoms than I have, I feel hopeful and encouraged.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

8) When I read the letters from people with milder symptoms than I have, I feel sorry for myself.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

9) When I read the letters from people who are coping the same as I am, I feel depressed.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

10) When I read the letters from people who are coping the same as I am, I don’t feel so alone.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

11) When I read the letters from people who have MD the same way that I have it, I feel depressed.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

12) When I read the letters from someone who has MD in a similar way to me, I feel not so alone.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

13) When I read the letters from people who are not coping as well as I am, I feel lucky and grateful.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

14) When I read the letters from people who are not coping as well as I am, I feel scared that my life may become like that.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

15) When I read the letters from people with worse symptoms than I have, I feel lucky and grateful.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

16) When I read the letters from people with worse symptoms than I have, I feel ‘have I got this to come?’

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

17) When I read the letters from someone who had MD badly but is now in remission, I feel hopeful and encouraged.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

18) When I read the letters from someone who was coping badly but now is coping well, I feel hope.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

19) When I read about someone whose symptoms were bad but have now got better, I feel that I am never going to be like that.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

20) When I read about someone who was coping badly and is now coping well, I feel helpless that I am not coping well too.

☐strongly disagree ☐disagree ☐ neither agree or disagree ☐ agree ☐ strongly agree

SECTION F: READING ABOUT OTHERS

Please tick the answer which is correct for you. Please answer all the questions.

1) When I read about others who are doing worse than I am, I experience fear that I will decline.

☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

2) When I read about others who are doing worse than I am, I fear that my future will be similar.

☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

3) When I read about others who are doing worse than I am, I fear that I will go the same way.

☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

4) When I read about others who experience more difficulties than I do, I am happy that I am doing so well myself.

☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

5) When I read about others who experience more difficulties than I do, I feel relieved about my own situation.

☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

6) When I read about others who experience more difficulties than I do, I realise how well I am doing.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

7) When I read about others who are experiencing less problems than I am, I realise that it is possible to improve.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

8) When I read about others who are experiencing less problems than I am, I am pleased that things can get better.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

9) When I read about others who are experiencing less problems than I am, it gives me hope that my situation will improve.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

10) When I read about others who are doing better than I am, I find it threatening to notice that I am not doing so well.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

11) When I read about others who are doing better than I am, I sometimes feel frustrated about my own situation.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

12) When I read about others who are doing better than I am, I sometimes feel depressed realising that I am not so well off.
☐Strongly disagree ☐Disagree ☐Not sure ☐Agree ☐Strongly agree

SECTION G: TINNITUS

The next section refers to your tinnitus, please circle either Yes or No, for each question.
Does your tinnitus sometimes make it difficult for you to concentrate? Yes No
Are you almost always aware of your tinnitus? Yes No
Do you find that your tinnitus bothers you, when you are doing something physical, like dressing or gardening? Yes No
Does you tinnitus cause you problems in getting off to sleep? Yes No
Would you say that generally your tinnitus does not bother you? Yes No
Do you sometimes go for hours without noticing your tinnitus? Yes No
Is you tinnitus very noisy? Yes No
Does your tinnitus frequently upset you? Yes No
Do you often have a day or more completely free from tinnitus? Yes No
When you are busy, do you quite often forget about your tinnitus? Yes No
Is your tinnitus present for at least part of every day? Yes No
Does your tinnitus often interfere with your ability to relax? Yes No

Would you say, that although your tinnitus can be irritating, it does not get you down? Yes No

Do you often talk about the problems your tinnitus causes to others? Yes No

Is it unusual for your tinnitus to annoy you, when you are trying to read or watch television? Yes No

16) Would you say that, you would have a much more enjoyable life, if you did not have tinnitus? Yes No

SECTION H: HEARING

The questions in this section cover your hearing. Please tick the box which 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 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

SECTION I: DIZZINESS

The following section refers to the vertigo and dizziness you experience.

Please circle the appropriate number to indicate about how may 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). Please answer all the questions.

	0	1	2	3	4
	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:

1) A feeling that things are spinning **or moving around, lasting:** (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4
2) **Unsteadiness so severe that** you actually fall.	0	1	2	3	4
3) **Nausea (feeling sick),** stomach churning	0	1	2	3	4
4) A feeling of being light-headed, **‘swimmy’ or giddy, lasting:** (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4
5) **Vomiting**	0	1	2	3	4
6) **Unable to stand or walk** properly without support	0	1	2	3	4
7) Feeling unsteady, about to lose **balance, lasting:** (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4

Appendix E: Questionnaire pack 1a

(Due to the restrictions on page layout for the thesis the reproduction of the questionnaire in this document has meant that the layout of the questionnaire differs slightly from how it was presented to the participants)

University
of Southampton

Hello,

My name is Bridget Dibb; you may have read in Spin about the study I am carrying out for the Ménière's Society, together with Dr Glenys Osborne from the Ménière's Society and Dr Lucy Yardley at Southampton University. I am looking at what life is like for a person with Ménière's Disease, and what may be helpful for them.

You can help with this research by filling in this questionnaire, which asks what you feel the quality of your life is at the moment. This questionnaire will be used to show doctors and the government what the problems faced by people with Ménière's Disease are and what can help them. It is important that we find out how ALL the members of the society that we write to feel, so we would like you to fill in the questionnaire even if you do not currently have any symptoms or problems. The more people who complete the questionnaire the more convincing the results will be to the health professionals.

If you wish to take part, just complete the questionnaire and return it in the prepaid envelope provided. Returning the completed questionnaire will be taken as your consent to take part in the study. If you consent now but change your mind, you can withdraw at any time without giving a reason. Your questionnaire will not be seen by anyone other than myself and no names will be used in the write-up of this study. Of course, you do not have to take part and if you do not wish to complete the questionnaire then I would be grateful if you could return it, uncompleted, in the prepaid envelope.

If you have any questions about this study then please feel free to contact me, Bridget Dibb, at 023 80 595785.

Thank you for your help,

Bridget Dibb
Researcher

LIFE WITH MENIERE'S STUDY

Please complete this questionnaire even if you have not experienced any symptoms recently.

SECTION A: HEALTH

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions, please give the best answer you can and make any of your own comments if you like. Please answer all the questions.

(Please tick one)

1) **In general, would you say your health is:**

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐

2) **Compared to one year ago, how would you rate your health in general now?**

a)Much better now than one year ago ☐
b)Somewhat better now than one year ago ☐
c)About the same ☐
d)Somewhat worse now than one year ago ☐
e)Much worse now than one year ago ☐

The following questions are about activities you might do during a typical day.

3) **Does your health limit you in these activities? If so, how much?**

(Please tick one box on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b) **Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
c) Lifting or carrying groceries	☐	☐	☐
d) Climbing **several** flights of stairs	☐	☐	☐
e) Climbing **one** flight of stairs	☐	☐	☐
f) Bending, kneeling, or stooping	☐	☐	☐
g) Walking **more than a mile**	☐	☐	☐
h) Walking **half a mile**	☐	☐	☐
i) Walking **100 yards**	☐	☐	☐
j) Bathing and dressing yourself	☐	☐	☐

4) **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

(Answer Yes or No to each question)

	Yes	No
a) Cut down on the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished less** than you would like	☐	☐
c) Were limited in the **kind** of work or other activities	☐	☐
d) Had **difficulty** performing the work or other activities (eg. It took extra effort)	☐	☐

5) **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

(Answer Yes or No to each question)

		Yes	No
a)	Cut down on the **amount of time** you spent on work or other activities	☐	☐
b)	**Accomplished** less than you would like	☐	☐
c)	Didn't do work or other activities as **carefully** as usual	☐	☐

(Please tick one)

6) **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?**

Not at all ☐
Slightly ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

7) **How much bodily pain have you had during the past 4 weeks?**

None ☐
Very mild ☐
Mild ☐
Moderate ☐
Severe ☐
Very Severe ☐

8) **During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)?**

Not at all ☐
A little bit ☐
Moderately ☐
Quite a bit ☐
Extremely ☐

The next questions are about how you feel and how things have been with you during the past month. (For each question, please indicate the one answer that comes closest to the way you have been feeling).

(Please tick one box on each line)

9) **How much time during the past month:**	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life	☐	☐	☐	☐	☐	☐
b) Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c) Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d) Have you felt calm and Peaceful?	☐	☐	☐	☐	☐	☐
e) Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f) Have you felt downhearted and low?	☐	☐	☐	☐	☐	☐
g) Did you feel worn out?	☐	☐	☐	☐	☐	☐
h) Have you been a happy person?	☐	☐	☐	☐	☐	☐
i) Did you feel tired?	☐	☐	☐	☐	☐	☐
j) Has your **health limited your social activities** (like visiting your friends or close relatives)?	☐	☐	☐	☐	☐	☐

10) Please choose the answer that best describes how true or false each of the following statements is for you.

(Please tick one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seem to get ill more easily than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

SECTION B: TINNITUS

Please tick the answer which most accurately describes the tinnitus you experience:

0	**None**
I	**Rarely noted**
II	**Occasional**
III	**Frequent**
IV	**Almost constant**
V	**Constant**
VI	**Severe; primary problem**

SECTION F: DIZZINESS

The following section refers to the vertigo and dizziness you experience. Please circle the appropriate number to indicate about how may 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). Please answer all the questions.

	0Never	**1**A few times (1 –3 times a year)	**2**Several times (4-12 times a year)	**3**Quite often (on average, more than once a month)	**4**Very often (on average more than once a week)
How often in the past 12 months have you had the following symptoms:					
1) A feeling that things are spinning or moving around, lasting: (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4
2) **Unsteadiness so severe that** you actually fall.	0	1	2	3	4
3) **Nausea (feeling sick), stomach churning**	0	1	2	3	4
4) **A feeling of being light-headed, 'swimmy' or giddy, lasting:** (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4
5) **Vomiting**	0	1	2	3	4
6) **Unable to stand or walk properly without support**	0	1	2	3	4
7) **Feeling unsteady, about to lose balance, lasting:** (PLEASE ANSWER ALL THE CATEGORIES)					
a) less than 2 minutes	0	1	2	3	4
b) up to 20 minutes	0	1	2	3	4
c) 20 minutes to 1 hour	0	1	2	3	4
d) several hours	0	1	2	3	4
e) more than 12 hours	0	1	2	3	4

SECTION C: A FEELING OF FULLNESS OF THE EAR

Please could you indicate which of the following most accurately describes the feeling of fullness you experience in your ear(s):

0 - None

I - Infrequent

II - Occasional

III - Frequent but mild

IV - Frequent but moderate

V - Frequent and severe but not incapacitating (unbearable)

VI - Almost constant and incapacitating (unbearable)

SECTION D: HEARING

The questions in this section cover your hearing. Please tick the box which 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 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

SECTION E: ABOUT YOURSELF

Age:............................Sex: Male/Female.

What is your occupation?...............................

If you are retired, what was your occupation?.....................................

If you a homemaker what is your spouse's occupation?..

Have you been diagnosed with Ménière's Disease by a hospital doctor? Yes/No

When were you diagnosed with Ménière's Disease (how long ago)?.......................

When do you think you experienced your first symptom of Ménière's Disease?.......................

How long have you been a member of the Ménière's Society for?.....................................

Do you: a) live with someone who looks after you?..... Yes No

b) live with someone who you have to look after?....... Yes No

c) Have someone to help you who lives nearby?........ Yes No

Would like to take part in the next study o Life with Ménière's? Yes No

Thank you for completing the questionnaire.

Please would you now return the questionnaire in the prepaid envelope.

Appendix F: Questionnaire pack 1b

(Due to the restrictions on page layout for the thesis the reproduction of the questionnaire in this document has meant that the layout of the questionnaire differs slightly from how it was presented to the participants)

University
of Southampton

Department of

Psychology

University of Southampton

Highfield

Southampton

SO17 1BJ

United Kingdom

Hello,

This letter accompanies the next study of Life with Ménière's Disease.

First of all, thank you so much for returning the first questionnaire. There has been a very positive response which is good, as this will make the results of the research more meaningful.

Thank you also for agreeing to take part in the next stage of the study. This part also involves completing a questionnaire. It is linked to the first questionnaire but differs from it in that it focuses on different aspects of life. This is important, as it will broaden the available knowledge of what life is like for someone with Ménière's Disease. This may help with increasing the understanding of Doctors and Health Professionals of the sort of experiences and feelings a person with Ménière's Disease has.

I would like to assure you that the information you give me is confidential and no names are linked to the research or the write-up of the research. Returning the completed questionnaire indicates your consent to take part in the study. However, if you have changed your mind and do not wish to take part then please return the uncompleted questionnaire to me.

If you have any questions about this study then please feel free to contact me, Bridget Dibb, at 023 80 595785.

Thank you for your help,

Bridget Dibb

Researcher

LIFE WITH MENIERE'S DISEASE: QUESTIONNAIRE TWO

This questionnaire should take about 20 minutes to complete, please answer the questions according to how you feel now.

SECTION A: LIFE SATISFACTION

1) If you were to rate the following areas of life according to importance, what order would you put them in? Please could you place number 1 next to the one you feel is the most important, and number two next to the one which is the next most important, and so on. Please answer all the questions.

i) Family and relationships..........

ii) Work and/or finances...........

iii) Social life and activities.......

iv) Health (physical and emotional)...........

v) Spirituality (Religion or beliefs).........

Please circle the answer which most comes closest to how you feel.

2) **How quickly do you feel that you are moving towards or away from your ideal situation with your family and friends?**

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

3) **How quickly do you feel that you are moving towards or away from your ideal situation with your work and/or finances?**

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

4) **How quickly do you feel that you are moving towards or away from your ideal situation with your social life and activities?**

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

5) How quickly do you feel that you are moving towards or away from your ideal situation with your health (physical and emotional)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

6) How quickly do you feel that you are moving towards or away from your ideal situation with your spirituality (religion and beliefs)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

SECTION B: LETTERS

Please circle the answer which comes closest to how you feel. Please answer all the questions

1) I read the letters in Spin to see if they have any advice for me.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

2) I read the letters to see if I am coping better or worse with my illness than the person writing the letter.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

3) I read the letters to see if I am more or less ill than the person writing the letter.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

4) I read the letters to find out about the medical advice given to the person in the letter.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

5) When I read about others who are doing worse than I am, I experience fear that my health will decline.

Strongly disagree	Disagree	Not sure	Agree	Strongly agree

6) **When I read about others who are doing worse than I am, I fear that my future will be similar.**

Strongly disagree Disagree Not sure Agree Strongly agree

7) **When I read about others who are doing worse than I am, I fear that I will go the same way.**

Strongly disagree Disagree Not sure Agree Strongly agree

8) **When I read about others who experience more difficulties than I do, I am happy that I am doing so well myself.**

Strongly disagree Disagree Not sure Agree Strongly agree

9) **When I read about others who experience more difficulties than I do, I feel relieved about my own situation.**

Strongly disagree Disagree Not sure Agree Strongly agree

10) **When I read about others who experience more difficulties than I do, I realise how well I am doing.**

Strongly disagree Disagree Not sure Agree Strongly agree

11) **When I read about others who are experiencing fewer problems than I am, it makes me happy to realise that it is possible for me to improve.**

Strongly disagree Disagree Not sure Agree Strongly agree

12) **When I read about others who are experiencing fewer problems than I am, I am pleased that things can get better.**

Strongly disagree Disagree Not sure Agree Strongly agree

13) **When I read about others who are experiencing fewer problems than I am, it gives me hope that my situation will improve.**

Strongly disagree Disagree Not sure Agree Strongly agree

14) **When I read about others who are doing better than I am, I find it threatening to notice that I am not doing so well.**

Strongly disagree Disagree Not sure Agree Strongly agree

15) **When I read about others who are doing better than I am, I sometimes feel frustrated about my own situation.**

Strongly disagree Disagree Not sure Agree Strongly agree

16) **When I read about others who are doing better than I am, I sometimes feel depressed realising that I am not so well off.**

Strongly disagree Disagree Not sure Agree Strongly agree

SECTION C: MANAGEMENT OF MENIERE'S DISEASE

Please indicate how much you agree or disagree with the following statements about your Meniere's Disease by circling the correct number.

1) **There is a lot which I can do to control my symptoms**

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

2) **What I do can determine whether my illness gets better or worse**

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

3) The course of my illness depends on me

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

4) Nothing I do will affect my illness

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

5) I have the power to influence my illness

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

6) **My actions will have no affect on the outcome of my illness**

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

SECTION D: LIFE CHANGES

For each statement please show the degree of change you have experienced since your MD began.

0	1	2	3	4	5
I did not experience this change as a result of my MD	I experienced this change to a very small degree as a result of my MD	I experienced this change to a small degree as a result of my MD	I experienced this change to a moderate degree as a result of MD	I experienced this change to a great degree as a result of my MD	I experienced this change to a very great degree as a result of my MD

I changed my priorities about what is important in life.	**0 1 2 3 4 5**
I have a greater appreciation for the value of my own life.	**0 1 2 3 4 5**
I developed new interests.	**0 1 2 3 4 5**
I have a greater feeling of self-reliance.	**0 1 2 3 4 5**
I have a better understanding of spiritual matters.	**0 1 2 3 4 5**
I more clearly see that I can count on people in times of trouble.	**0 1 2 3 4 5**
I established a new path for my life.	**0 1 2 3 4 5**
I have a greater sense of closeness with others.	**0 1 2 3 4 5**
I am more willing to express my emotions.	**0 1 2 3 4 5**
I know better that I can handle difficulties.	**0 1 2 3 4 5**
I am able to do better things with my life.	**0 1 2 3 4 5**
I am better able to accept the way things work out.	**0 1 2 3 4 5**
I can better appreciate each day.	**0 1 2 3 4 5**
New opportunities are available which wouldn't have been otherwise.	**0 1 2 3 4 5**
I have more compassion for others.	**0 1 2 3 4 5**
I put more effort into my relationships.	**0 1 2 3 4 5**
I am more likely to try to change things which need changing.	**0 1 2 3 4 5**
I have a stronger religious faith.	**0 1 2 3 4 5**
I discovered that I'm stronger than I thought I was.	**0 1 2 3 4 5**
I learned a great deal about how wonderful people are.	**0 1 2 3 4 5**
I better accept needing others.	**0 1 2 3 4 5**

SECTION E: LIFE FROM YOUR POINT OF VIEW

Please circle the answer which comes closest to how you see yourself:

I feel that I'm a person of worth, at least on an equal plane with others.

Strongly agree Agree Disagree Strongly disagree

I feel that I have a number of good qualities.

Strongly agree Agree Disagree Strongly disagree

All in all, I am inclined to feel that I am a failure.

Strongly agree Agree Disagree Strongly disagree

I am able to do things as well as most other people.

Strongly agree Agree Disagree Strongly disagree

I feel I do not have much to be proud of.

Strongly agree Agree Disagree Strongly disagree

I take a positive attitude toward myself.

Strongly agree Agree Disagree Strongly disagree

On the whole, I am satisfied with myself.

Strongly agree Agree Disagree Strongly disagree

I wish I could have more respect for myself.

Strongly agree Agree Disagree Strongly disagree

I certainly feel useless at times.

Strongly agree Agree Disagree Strongly disagree

At times I think I am no good at all.

Strongly agree Agree Disagree Strongly disagree

SECTION F: OUTLOOK

Please circle the correct answer

In uncertain times, I usually expect the best.

Strongly disagree Disagree Neutral Agree Strongly agree

It's easy for me to relax.

Strongly disagree Disagree Neutral Agree Strongly agree

If something can go wrong for me, it will.

Strongly disagree Disagree Neutral Agree Strongly agree

I'm always optimistic about my future

Strongly disagree Disagree Neutral Agree Strongly agree

I enjoy my friends a lot.

Strongly disagree Disagree Neutral Agree Strongly agree

It's important for me to keep busy.

Strongly disagree Disagree Neutral Agree Strongly agree

I hardly ever expect things to go my way.

Strongly disagree Disagree Neutral Agree Strongly agree

I don't get upset too easily.

Strongly disagree Disagree Neutral Agree Strongly agree

I rarely count on good things happening to me.

Strongly disagree Disagree Neutral Agree Strongly agree

Overall, I expect more good things to happen to me than bad.

Strongly disagree Disagree Neutral Agree Strongly agree

SECTION G: THE MENIERE'S SOCIETY

Please answer the following questions about the Meniere's Society.

To what extent do you use the Meniere's Society?

I contact the help line	Yes	No
I read the fact sheets	Yes	No
I contact other members on the Contact List	Yes	No
I have joined a local group	Yes	No
I have written letter(s) to Spin	Yes	No

To what extent do you read Spin? (please circle)

1 – **Not at all**

2 – **I flip through reading a few headlines but nothing more**

3 – **I read a few selected articles/sections**

4 – **I read most of the articles/sections**

5 – **I read everything, from cover to cover**

If you do read Spin, which parts do you read?

The medical articles	Yes	No	
Questions and Answers	Yes	No	
Special Features and news	Yes	No	
Pen Pals	Yes	No	
Fund-raising news	Yes	No	
Local Group news	Yes	No	
The Letters	Yes	No	
If 'Yes', do you read all the letters?	Yes	No	
Do you prefer the letters about someone who is better-off than yourself?	Yes	Neutral	No
Do you prefer the letters about someone who is worse-off than yourself?	Yes	Neutral	No

How do you find your present GP's attitude to your illness?

Very unhelpful Slightly unhelpful Neutral Slightly helpful Very helpful

How do you find your present ENT specialist's (Hospital Doctor's) attitude to your illness?

Very unhelpful Slightly unhelpful Neutral Slightly helpful Very helpful

Thank you for completing this questionnaire. Please could you now return it in the prepaid envelope.

Appendix G: Questionnaire pack 2

(Due to the restrictions on page layout for the thesis the reproduction of the questionnaire in this document has meant that the layout of the questionnaire differs slightly from how it was presented to the participants)

University
of Southampton

Department of

Psychology

University of Southampton

Highfield

Southampton

SO17 1BJ

United Kingdom

Hello,

I would like to thank you once again for your participation so far. You will be pleased to know that this is the last time I will be bothering you. The study is nearing completion with only one more questionnaire left which is included here with this letter.

This questionnaire is divided into two sections with the first section consisting of some of the questions you have already answered in the first questionnaire, about ten months ago. Please could you answer them again as to how you feel now. The second section again consists of some questions which you may find familiar. These questions may be confusing as they are worded slightly differently. They ask you how you think you were ten months ago, when you first filled out the questionnaire. I would like you to answer the questions as you remember yourself to have been then. I realise you might find this strange but your answers will be important in the overall analysis of the questionnaires.

All the information you give me is treated in the strictest confidence and no names are used in the write-up of the study. Returning the completed questionnaire indicates your consent to take part in the study. Your participation is very valuable to us but should you have changed your mind about taking part then please return the questionnaire to me uncompleted.

If you have any questions about this study then please feel free to contact me, Bridget Dibb, at 023 80 595785.

Thank you for your help, I look forward to hearing from you,

Bridget Dibb
Researcher

LIFE WITH MENIERE'S STUDY: Final questionnaire

The first section of this questionnaire contains questions which are the same as you answered before in the questionnaire sent out about ten moths ago. Please could you follow the instructions and answer the questions again as to how you feel now.

SECTION ONE

Please complete this questionnaire even if you have not experienced any symptoms recently.

HEALTH

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions, please give the best answer you can and make any of your own comments if you like. Please answer all the questions.

(Please tick one)

1) In general, would you say your health is:

	Excellent	☐
	Very good	☐
	Good	☐
	Fair	☐
	Poor	☐

2) Compared to one year ago, how would you rate your health in general now?

a)Much better now than one year ago	☐
b)Somewhat better now than one year ago	☐
c)About the same	☐
d)Somewhat worse now than one year ago	☐
e)Much worse now than one year ago	☐

The following questions are about activities you might do during a typical day.

3) Does your health limit you in these activities? If so, how much?

(Please tick one box on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b) **Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
c) Lifting or carrying groceries	☐	☐	☐
d) Climbing **several** flights of stairs	☐	☐	☐
e) Climbing **one** flight of stairs	☐	☐	☐
f) Bending, kneeling, or stooping	☐	☐	☐
g) Walking **more than a mile**	☐	☐	☐
h) Walking **half a mile**	☐	☐	☐
i) Walking **100 yards**	☐	☐	☐
j) Bathing and dressing yourself	☐	☐	☐

4) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Answer Yes or No to each question)

	Yes	No
a) Cut down on the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished less** than you would like	☐	☐
c) Were limited in the **kind** of work or other activities	☐	☐
d) Had **difficulty** performing the work or other activities (eg. It took extra effort)	☐	☐

5) During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Answer Yes or No to each question)

		Yes	No
a)	Cut down on the **amount of time** you spent on work or other activities	☐	☐
b)	**Accomplished** less than you would like	☐	☐
c)	Didn't do work or other activities as **carefully** as usual	☐	☐

(Please tick one)

6) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?	Not at all	☐
	Slightly	☐
	Moderately	☐
	Quite a bit	☐
	Extremely	☐

7) How much bodily pain have you had during the past 4 weeks?	None	☐
	Very mild	☐
	Mild	☐
	Moderate	☐
	Severe	☐
	Very Severe	☐

8) During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)?	Not at all	☐
	A little bit	☐
	Moderately	☐
	Quite a bit	☐
	Extremely	☐

The next questions are about how you feel and how things have been with you during the past month. (For each question, please indicate the one answer that comes closest to the way you have been feeling). (Please tick one box on each line)

9) **How much time during the past month**:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life	☐	☐	☐	☐	☐	☐
b) Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c) Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d) Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e) Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f) Have you felt downhearted and low?	☐	☐	☐	☐	☐	☐
g) Did you feel worn out?	☐	☐	☐	☐	☐	☐
h) Have you been a happy person?	☐	☐	☐	☐	☐	☐
i) Did you feel tired?	☐	☐	☐	☐	☐	☐
j) Has your **health limited** your social activities (like visiting your friends or close relatives)?	☐	☐	☐	☐	☐	☐

10) Please choose the answer that best describes how true or false each of the following statements is for you.

(Please tick one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seem to get ill more easily than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

LIFE SATISFACTION

1) If you were to rate the following areas of life according to importance, what order would you put them in? Please could you place number 1 next to the one you feel is the most important, and number two next to the one which is the next most important, and so on. Please answer all the questions.

i) Family and relationships..........
ii) Work and/or finances...........
iii) Social life and activities.......
iv) Health (physical and emotional)...........
v) Spirituality (Religion or beliefs).........

Please circle the answer which most comes closest to how you feel.

2) How quickly do you feel that you are moving towards or away from your ideal situation with your family and friends?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

3) How quickly do you feel that you are moving towards or away from your ideal situation with your work and/or finances?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

4) How quickly do you feel that you are moving towards or away from your ideal situation with your social life and activities?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

5) How quickly do you feel that you are moving towards or away from your ideal situation with your health (physical and emotional)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

6) How quickly do you feel that you are moving towards or away from your ideal situation with your spirituality (religion and beliefs)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

SECTION D: LIFE CHANGES

For each statement please show the degree of change you have experienced since your MD began.

0	1	2	3	4	5
I did not experience this change as a result of my MD	I experienced this change to a very small degree as a result of my MD	I experienced this change to a small degree as a result of my MD	I experienced this change to a moderate degree as a result of MD	I experienced this change to a great degree as a result of my MD	I experienced this change to a very great degree as a result of my MD

I changed my priorities about what is important in life.	**0**	**1**	**2**	**3**	**4**	**5**
I have a greater appreciation for the value of my own life.	**0**	**1**	**2**	**3**	**4**	**5**
I developed new interests.	**0**	**1**	**2**	**3**	**4**	**5**
I have a greater feeling of self-reliance.	**0**	**1**	**2**	**3**	**4**	**5**
I have a better understanding of spiritual matters.	**0**	**1**	**2**	**3**	**4**	**5**
I more clearly see that I can count on people in times of trouble.	**0**	**1**	**2**	**3**	**4**	**5**
I established a new path for my life.	**0**	**1**	**2**	**3**	**4**	**5**
I have a greater sense of closeness with others.	**0**	**1**	**2**	**3**	**4**	**5**
I am more willing to express my emotions.	**0**	**1**	**2**	**3**	**4**	**5**
I know better that I can handle difficulties.	**0**	**1**	**2**	**3**	**4**	**5**
I am able to do better things with my life.	**0**	**1**	**2**	**3**	**4**	**5**
I am better able to accept the way things work out.	**0**	**1**	**2**	**3**	**4**	**5**
I can better appreciate each day.	**0**	**1**	**2**	**3**	**4**	**5**
New opportunities are available which wouldn't have been otherwise.	**0**	**1**	**2**	**3**	**4**	**5**
I have more compassion for others.	**0**	**1**	**2**	**3**	**4**	**5**
I put more effort into my relationships.	**0**	**1**	**2**	**3**	**4**	**5**
I am more likely to try to change things which need changing.	**0**	**1**	**2**	**3**	**4**	**5**
I have a stronger religious faith.	**0**	**1**	**2**	**3**	**4**	**5**
I discovered that I'm stronger than I thought I was.	**0**	**1**	**2**	**3**	**4**	**5**
I learned a great deal about how wonderful people are.	**0**	**1**	**2**	**3**	**4**	**5**
I better accept needing others.	**0**	**1**	**2**	**3**	**4**	**5**

SECTION TWO

This second section asks you to answer the questions as to how you think you were when you filled out the first questionnaire ten months ago. In other words, could you think back to the time you first filled in the questionnaire and answer the questions as to how you were then.

Please answer this section as to how you feel you were at the time you FIRST FILLED IN THE QUESTIONNARIE, about ten months ago.

	(Please tick one)	
1) In general, would you say your health, when you first filled in the questionnaire, was:	Excellent	☐
	Very good	☐
	Good	☐
	Fair	☐
	Poor	☐

	(Please tick one)	
2) When you first filled in the questionnaire to what extent did your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?	Not at all	☐
	Slightly	☐
	Moderately	☐
	Quite a bit	☐
	Extremely	☐

For each question, please indicate the one answer that comes closest to the way you were feeling when you first filled out the questionnaire about ten months ago.

(Please tick one box on each line)

3) **How much time:**	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life	☐	☐	☐	☐	☐	☐
b) Were you a very nervous person?	☐	☐	☐	☐	☐	☐
c) Did you feel so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d) Did you feel calm and Peaceful?	☐	☐	☐	☐	☐	☐
e) Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f) Did you feel downhearted and low?	☐	☐	☐	☐	☐	☐
g) Did you feel worn out?	☐	☐	☐	☐	☐	☐
h) Were you a happy person?	☐	☐	☐	☐	☐	☐
i) Did you feel tired?	☐	☐	☐	☐	☐	☐
j) Did your **health limited** your social activities (like visiting your friends or close relatives)?	☐	☐	☐	☐	☐	☐

4) Please choose the answer that best describes how true or false each of the following statements was for you when you first filled out the questionnaire ten months ago.

(Please tick one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seemed to get ill more easily than other people	☐	☐	☐	☐	☐
I was as healthy as anybody I know	☐	☐	☐	☐	☐
I expected my health to get worse	☐	☐	☐	☐	☐
My health was excellent	☐	☐	☐	☐	☐

5) If you were to rate the following areas of life according to how important they were to you when you first filled out the questionnaire, what order would you put them in? Please could you place number 1 next to the one you feel was the most important, and number two next to the one which was the next most important, and so on. Please answer all the questions.

i) Family and relationships……….
ii) Work and/or finances…………
iii) Social life and activities…….
iv) Health (physical and emotional)………..
v) Spirituality (Religion or beliefs)………

Please circle the answer which comes closest to how think you felt when you first filled out the questionnaire, ten months ago.

1) How quickly did you feel that you were moving towards or away from your ideal situation with your family and friends?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

2) How quickly did you feel that you were moving towards or away from your ideal situation with your work and/or finances?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

3) How quickly did you feel that you were moving towards or away from your ideal situation with your social life and activities?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

4) How quickly did you feel that you were moving towards or away from your ideal situation with your health (physical and emotional)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

5) How quickly did you feel that you were moving towards or away from your ideal situation with your spirituality (religion and beliefs)?

Very quickly away	Quite quickly away	Slowly away	Not moving at all	Slowly toward my ideal	Quite quickly towards	Very quickly towards

Thank you for completing this questionnaire. Please could you now return it in the prepaid envelope.

This is the last questionnaire of this study and so I would like to thank you for your participation in the whole study. Your input from the beginning has been most valuable, as only those who have completed all the questionnaires will be used in the final analysis.

Many thanks and best wishes,

Bridget Dibb.

10.0. REFERENCES

Reference List

Ablon, L. (1981). Dwarfism and social identity: self-help group participation. *Social Science and Medicine, 15,* 25-30.

Affleck, G. & Tennen, H. (1996). Construing benefits from adversity: adaptational significance and dispositional underpinnings. *Journal of Personality, 64,* 899-922.

Aldrich, S., Eccleston, C., & Crombez, G. (2000). Worrying about chronic pain: vigilance to threat and misdirected problem solving. *Behaviour Research and Therapy, 38,* 457-470.

Allport, G. W. (1937). *Pattern and Growth in Personality.* London: Holt, Rhinehart & Winton.

Amir, M., Roziner, I., Knoll, A., & Neufeld, M. Y. (1999). Self-efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. *Epilepsia, 40,* 216-224.

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.

Andrykowski, M. A., Brady, M. J., & Hunt, J. W. (1993). Positive psychosocial adjustment in potential bone marrow transplant recipients: cancer as a psychosocial transition. *Psycho-oncology, 2,* 261-276.

Aspinwall, L. G. & Taylor, S. E. (1993). Effects of social comparison direction, threat, and self-esteem on affect, self-evaluation, and expected success. *Journal of Personality and Social Psychology, 64,* 708-722.

Baron, R. M. & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51,* 1173-1182.

Bauman, L. J., Gervey, R., & Siegel, K. (1992). Factors associated with cancer patients' participation in support groups. *Journal of Psychosocial Oncology, 10,* 1-20.

Beach, S. R. H. & Tesser, A. (2000). Self-Evaluation Maintenance and Evolution. In J.Suls & L. Wheeler (Eds.), *Handbook of Social Comparison: Theory and Research* (pp. 123-140). New York: Kluwer Academic/Plenum Publishers.

Bennebroek, F. T. C., Buunk, B., Van der Zee, K., & Grol, B. (2002). Social comparison and patient information: what do cancer patients want? *Patient Education and Counseling, 47,* 5-12.

Blalock, S. J., Afifi, R. A., De Vellis, B. M., Holt, K., & De Vellis, R. F. (1990). Adjustment to rheumatoid arthritis: the role of social comparison processes. *Health Education Research, 5,* 361-370.

Blalock, S. J., De Vellis, B. M., & De Vellis, R. F. (1989). Social comparison among individuals with rheumatoid arthritis. *Journal of Applied Social Psychology, 19,* 665-680.

Bogart, L. M. & Helgeson, V. S. (2000). Social comparison among women with breast cancer: A longitudinal investigation. *Journal of Applied Social Psychology, 30,* 547-575.

Borkman, T. (1997). A selective look at self-help groups in the United States. *Health and social care in the community, 5,* 357-364.

Bowling, A. (1992). *Measuring Health: a review of QoL measurement scales.* Bristol: Open University Press.

Brazier, J. E., Harper, R., Jones, N. M. B., O'Cathain, A., Thomas, K. J., Usherwood, T. et al. (1992). Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *British Medical Journal, 305,* 160-164.

Brickman, P. & Bulman, R. J. (1977). Pleasure and pain in social comparison. In J.Suls & T. A. Wills (Eds.), *Social Comparison processes: theoretical and empirical perspectives* (pp. 149-186). Washington: Hemisphere Publishing Corporation.

Butler, T. & Fuhriman, A. (1980). Patient perspective on the Curative Process: A Comparison of Day Treatment and Outpatient Psychotherapy Groups. *Small Group Behaviour, 11,* 371-388.

Buunk, B. P., Collins, R. L., Taylor, S. E., VanYperen, N. W., & Dakof, G. A. (1990). The affective consequences of social comparison: either direction has its ups and downs. *Journal of Personality and Social Psychology, 59,* 1238-1249.

Buunk, B. P. & Gibbons, F. X. (1997). Social comparison in health and illness: a historical overview. In B.P.Buunk & F. X. Gibbons (Eds.), *Health, Coping and Well-being:*

Perspectives from Social Comparison Theory (pp. 1-23). New Jersey: Lawrence Erlbaum Associates Inc.

Buunk, B. P. & Ybema, J. F. (1997). Social comparison and occupational stress: the identification-contrast model. In B.P.Buunk & F. X. Gibbons (Eds.), *Health, Coping and Well-Being* (pp. 359-388). New Jersey: Lawrence Erlbaum Associates Inc.

Carr, A. J. & Higginson, I. J. (2001). Measuring quality of life: are quality of life measures patient centred? *British Medical Journal, 322,* 1357-1360.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S. et al. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65,* 375-390.

Carver, C. S. & Scheier, M. F. (1990). Origins and functions of positive and negative affect: a control-process view. *Psychological Review, 97,* 19-35.

Carver, C. S. & Scheier, M. F. (2000). Scaling back the goals and recalibration of the affect system are processes in normal adaptive self-regulation: understanding 'response shift' phenomena. *Social Science and Medicine, 50,* 1715-1722.

Cass, S. P. (1999). Staging and Outcomes for Meniere's Disease. In J.P.Harris (Ed.), *Meniere's Disease* (pp. 311-325). The Hague: Kugler Publications.

Church, M. A., Truss, C. V., & Velicer, W. F. (1980). Structure of the Janis-Field feelings of inadequacy scale. *Perceptual and Motor Skills, 50,* 935-939.

Citron, M., Solomon, P., & Draine, J. (1999). Self-help groups for families of persons with mental illness: perceived benefits of helpfulness. *Community Mental Health Journal, 35,* 15-30.

Collins, R. L. (1996). For better or worse: the impact of upward social comparison on self-evaluations. *Psychological Bulletin, 119,* 51-69.

de Ridder, D., Schreurs, K., & Bensing, J. (2000). The relative benefits of being optimistic: optimism as a coping resource in multiple sclerosis and Parkinson's disease. *British Journal of Health Psychology, 5,* 141-155.

De Vellis, R. F., Holt, K., Renner, B. R., Blalock, S. J., Blanchard, L. W., Cook, H. L. et al. (1990). The relationship of social comparison to rheumatoid arthritis symptoms and affect. *Basic and Applied Social Psychology, 11,* 1-18.

Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7,* 117-140.

Fitzgerald Miller, J. F. (1992). Enhancing self-esteem. In J.Fitzgerald Miller (Ed.), *Coping with chronic illness: overcoming powerlessness* (pp. 397-412). Philadelphia: F.A. Davis Company.

Folmer, R. L., Griest, S. E., Meikle, M. B., & Martin, W. H. (1999). Tinnitus severity, loudness, and depression. *Otolaryngology - Head and Neck Surgery, 121,* 48-51.

Gant, N. D. & Kampfe, C. M. (1997). Psychosocial challenges faced by persons with Ménière's' Disease. *Journal of Applied Rehabilitation Counseling, 28,* 40-49.

Garratt, A. M., Ruta, D. A., Abdalla, M. I., Buckingham, K., & Russell, I. T. (1993). The SF-36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? *British Medical Journal, 306,* 1440-1444.

Garratt, A. M., Schmidt, L., Mackintosh, A., & Fitzpatrick, r. (2002). Quality of life measurement: bibliographic study of patient assessed health outcome measures. *British Medical Journal, 324,* 1417-1425.

Garrill, S. & Garrill, J. (2003). Directory of British self-help groups. Directory of British Self-help groups [On-line]. Available: www.doctor.gp/help/

Gibbons, F. X. (1999). Social comparison as a mediator of response shift. *Social Science and Medicine, 48,* 1517-1530.

Gibbons, F. X., Blanton, H., Gerrard, M., Buunk, B., & Eggleston, T. (2000). Does social comparison make a difference? Optimism as a moderator of the relation between comparison level and academic performance. *Personality and Social Psychology Bulletin, 26,* 637-648.

Gibbons, F. X. & Buunk, B. P. (1999). Individual differences in social comparison: development of a scale of social comparison orientation. *Journal of Personality and Social Psychology, 76,* 129-142.

Gibbons, F. X. & Gerrard, M. (1989). Effects of upward and downward social comparison on mood states. *Journal of Social and Clinical Psychology, 8,* 14-31.

Gibbons, F. X. & Gerrard, M. (1991). Downward comparison and coping with threat. In J.Suls & T. A. Wills (Eds.), *Social Comparison: Contemporary Theory and Research* (pp. 317-345). New Jersey: Lawrence Erlbaum Associates Inc.

Good, B. J. (1994). *Medicine, rationality, and experience: an anthropological perspective*. Tyne & Wear: Cambridge University Press.

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's Patients. *Scandinavian Audiology, 26,* 69-76.

Halford, J. B. & Anderson, S. D. (1991). Tinnitus severity measured by a subjective scale, audiometry and clinical judgement. *The Journal of Laryngology and Otology, 105,* 89-93.

Heidrich, S. M. & Ryff, C. D. (1993). The role of social comparisons processes in the psychological adaptation of elderly adults. *Journal of Gerontology, 48,* p127-p136.

Helgeson, V. S. (1992). Moderators of the relation between perceived control and adjustment to chronic illness. *Journal of Personality and Social Psychology, 63,* 656-666.

Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry, 56,* 340-347.

Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (2001). Long-term effects of educational and peer discussion group interventions on adjustment to breast cancer. *Health Psychology, 20,* 387-392.

Helgeson, V. S. & Mickelson, K. D. (1995). Motives for social comparison. *Personality and Social Psychology Bulletin, 21,* 1200-1209.

Helgeson, V. S. & Taylor, S. E. (1993). Social comparison and adjustment among cardiac patients. *Journal of Applied Social Psychology, 23,* 1171-1195.

Hiller, W. & Goebel, G. (1992). A psychometric study of complaints in chronic tinnitus. *Journal of Psychosomatic Research, 36,* 337-348.

Honrubia, V., Bell, T. S., Harris, M. R., Baloh, R. W., & Fisher, L. M. (1996). Quantitative evaluation of dizziness characteristics and impact on quality of life. *The American Journal of Otology, 17,* 595-602.

Jacobs, C., Ross, R. D., Walker, I. M., & Stockdale, F. E. (1983). Behaviour of cancer patients: a randomized study of the effects of education and peer support groups. *American Journal of Clinical Oncology, 6,* 347-350.

Jacobs, M. K. & Goodman, G. (1989). Psychology and self-help groups: predictions on a partnership. *American Psychologist, 44,* 536-545.

Jacobson, G. P. & Newman, C. W. (1990). The development of the dizziness handicap inventory. *Archives of Otolaryngology Head Neck Surgery, 116,* 424-427.

Jenkinson, C., Layte, R., & Lawrence, K. (1997). Development and testing of the Medical Outcomes Study 36-Item Short Form health survey summary scale scores in the United Kingdom. *Medical Care, 35,* 410-416.

Jenkinson, C., Wright, L., & Coulter, A. (1993). Quality of life measurement in health care: a review of measures and population norms for the UK SF-36. Oxford, Health Services Research Unit.

Ref Type: Pamphlet

Kenny, T. & Kenny, B. (2003). Self-help and patient support groups. Patient UK [On-line]. Available: www.patient.org.uk/

Keyes, C. L. M., Shmotkin, D., & Ryff, C. D. (2002). Optimizing well-being: the empirical encounter of two traditions. *Journal of Personality and Social Psychology, 82,* 1007-1022.

Kleinman, A. (1995). *Writing at the margin.* California: University of California Press.

Kuijer, R. G. & de Ridder, D. (2003). Discrepancy in illness-related goal and quality of life in chronically ill patients: the role of self-efficacy. *Psychology and Health, 18,* 313-330.

Kuk, F. K., Tyler, R. S., Russell, D., & Jordan, H. (1990). The psychometric peoperties of a tinnitus handicap questionnaire. *Ear and Hearing, 11,* 434-445.

Kurtz, L. F. (1990). The self-help movement: review of the past decade of research. *Social work with groups, 13,* 101-115.

Kurtz, L. F. (1997). *Self-help and support groups: A handbook for practitioners.* (vols. 34) California: Sage Publications.

Lazarus, R. A. & Folkman, S. (1984). *Stress, appraisal and coping.* New York: Springer.

Leppin, A. & Schwarzer, R. (1990). Social support and physical health: an updated meta-analysis. In L.Schmidt & P. Schwenkmezger (Eds.), *Theoretical and applied aspects of health psychology* (pp. 185-202). Amsterdam, Netherlands: Harwood Academic Publishers.

Lieberman, M. A. & Snowden, L. R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In T.J.Powell (Ed.), *Understanding the Self-help Organization: Frameworks and Findings* (pp. 32-49). California: Sage Publications.

Lieberman, M. A., Solow, N., Bond, G. R., & Reilbstein, J. (1979). The Psychothyerapeutic impact of women's consciousness-raising groups. *Archives of General Psychiatry, 36,* 161-168.

Lieberman, M. A., Yalom, I. D., & Miles, M. B. (1973). *Encounter groups: first facts.* New York: Basic Books Inc.

Llewelyn, S. P. & Haslett, A. V. J. (1986). Facotrs perceived as helpful by the members of self-help groups: an exploratory study. *British Journal of Guidance and Counselling, 14,* 252-262.

Lutman, M. E., Brown, E. J., & Coles, R. R. A. (1987). Self-reported disability and handicap in the population in relation to pure-tone threshold, age, sex and type of hearing loss. *British Journal of Audiology, 21,* 45-58.

Major, B., Testa, M., & Bylsma, W. H. (1991). Responses to upward and downward social comparisons: The impact of esteem-relevance and perceived control. In J.Suls & T. A. Wills (Eds.), *Social Comparison: Contemporary Theory and Research* (pp. 237-260). New Jersey: Lawrence Erlbaum Associates.

Maslow, A. H. (1954). *Motivation and personality.* New York: HarpernCollins Publishers Inc.

Maton, K. I. (1988). Social support, organizational characteristics, psychological well-being, and group appraisal in three self-help group populations. *American Journal of community psychology, 16,* 53-77.

McCaul, K. D., Sandgren, A. K., King, B., O'Donnell, S., Branstetter, A., & Foreman, G. (1999). Coping and adjustment to breast cancer. *Psycho-oncology, 8,* 230-236.

McGee, H., O'Boyle, C. A., Hickey, A., O'Malley, K., & Joyce, C. R. B. (1991). Assessing the quality of life of the individual: The SEIQoL with a healthy and a gastroenterology unit population. *Psychological Medicine, 21,* 749-759.

Medvene, L. (1992). Self-help groups, peer helping, and social comparison. In S.Spacapan & S. Oskamp (Eds.), *Helping and being helped* (pp. 49-81). California: Sage Publications, Inc.

Ménière's Society (2003). Ménière's Society. Ménière's Society [On-line]. Available: www.meniere's.co.uk

Molinari, V., Nelson, N., Shekelle, S., & Crothers, M. K. (1994). Family support groups of the Alzheimer's Association: An analysis of attendees and nonattendees. *The journal of applied gerontology, 13,* 86-98.

Mollerman, E., Pruyn, J., & van Knippenberg, A. (1986). Social comparison processes among cancer patients. *British Journal of Social Psychology, 25,* 1-13.

Mombers, F. M. C., De Vries, J., & Van Heck, G. L. (1997). Quality of life of healthy persons and patients with a chronic disease: A study with the Dutch, WHOQOL-100. *Quality of Life, March/August.*

Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, r., Cameron, L. D., & Buick, D. (2001). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health.*

O'Boyle, C. A., McGee, H., & Joyce, C. R. B. (1994). Quality of life: Assessing the individual. *Advances in Medical Sociology, 5,* 159-180.

O'Carroll, R. E., Smith, K., Couston, M., Cossar, J. A., & Hayes, P. C. (2000). A comparison of the WHOQOL-100 and the WHOQOL-BREF in detecting change in quality of life following liver transplantation. *Quality of Life Research, 9,* 121-124.

Office of National Statistics (2003). Trends in self-reported sickness by sex and age, 1972 to 2001. Office of National Statistics [On-line]. Available: www.statistics.gov.uk/StatBase/ssdataset.asp?vlnk=6637&Pos=ColRank=1&Rank=544

Parducci, A. (1995). *Happiness, pleasure, and judgment: The contextual theory and its applications.* New Jersey: Lawrence Erlbaum Associates, Publishers.

Petrie, K. J., Buick, D. L., Weinman, J., & Booth, R. J. (1999). Positive effects of illness reported by myocardial infarction and breast cancer. *Journal of Psychosomatic Research, 47,* 537-543.

Rappaport, J. (1994). Narrative studies, personal stories, and identity transformation in the mutual-help context. In T.J.Powell (Ed.), *Understanding the self-help organization* (pp. 115-135). California: Sage Publications.

Recker, G. T., Peacock, E. J., & Wong, P. T. P. (1987). Meaning and purpose in life and well-being: a life-span perspective. *Journal of Gerontology, 42,* 44-49.

Rosenberg, M. (1965). *Society and the adolescent self-image.* Princeton: Princeton University Press.

Ruta, D. A., Garratt, A. M., Leng, M., Russell, I. T., & MacDonald, L. M. (1994). A new approach to the measurement of quality of life: The patient-generated index. *Medical Care, 32,* 1109-1126.

Saeed, S. R. (1998). Diagnosis and treatment of Ménière's' Disease. *British Medical Journal, 316,* 368-372.

Salzer, M. S., Rappaport, J., & Serge, L. (1999). Professional appraisal of professionally led and self-help groups. *American Journal of Orthopsychiatry, 69,* 536-540.

Schachter, S. (1959). *The psychology of affiliation.* Palo Alto, C.A.: Stanford University Press.

Scheier, M. F. & Carver, C. S. (1987). Dispositional optimism and physical well-being: the influence of generalized outcome expectancies on health. *Journal of Personality, 55,* 169-210.

Scheier, M. F. & Carver, C. S. (2001). Adapting to cancer: the importance of hope and purpose. In A.Baum & B. L. Andersen (Eds.), *Psychosocial Interventions for Cancer* (pp. 15-36). Washington, DC: American Psychological Association.

Scheier, M. F. & Carver, C. S. (1985). Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health Psychology, 4,* 219-247.

Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a re-evaluation of the Life Orientation Test. *Journal of Personality and Social Psychology, 67,* 1063-1078.

Schubert, M. A. & Borkman, T. J. (1991). An organizational typology for self-help groups. *American Journal of community psychology, 19,* 769-787.

Schulz, R. & Decker, S. (1985). Long term adjustment to physical disability: The role of social support, percieved control, and self blame. *Journal of Personality and Social Psychology, 48,* 1162-1172.

Schwartz, C. E. & Sprangers, M. A. G. (2000). *Adaptation to changing health: Response shift in quality of life research.* Washington: American Psychological Association.

Sharples, L. D., Todd, C. J., Caine, N., & Tait, S. (2000). Measurement properties of the Nottingham Health Profile and Short Form 36 Health Status Measures in a population sample of elderly people living at homes: Results from ELPHS. *British Journal of Health Psychology, 5,* 217-233.

Sidell, N. L. (1997). Adult adjustment to chronic illness: a review of the literature. *Health and social work, 22,* 5-11.

Skevington, S. M. (1999). Measuring quality of life in Britain: introducing the WHOQOL-100. *Journal of Psychosomatic Research, 47,* 449-459.

Spitzer, W. O., Dobson, A. J., Hall, J., Chesterman, E., Levi, J., Shepherd, R. et al. (1981). Measuring the quality of life of cancer patients. *Journal of Chronic Disease, 34,* 585-597.

Sprangers, M. A. G. & Schwartz, C. E. (1999a). Integrating response shift in health-related quality of life research: a theoretical model. *Social Science and Medicine, 48,* 1507-1515.

Sprangers, M. A. G., Van Dam, F. S. A. M., Broersen, J., Lodder, L., Wever, L., Viser, M. R. M. et al. (1999b). Revealing response shift in longitudinal research on fatigue. *Acta Oncologica, 38,* 709-718.

Sprangers, M. A. G., Van Dam, F. S. A. M., Broersen, J., Lodder, L., Wever, L., Visser, M. R. M. et al. (2000). Response shift and fatigue: the use of the Thentest approach. In C.E.Schwartz & M. A. G. Sprangers (Eds.), *Adaptation to changing health: response shift in quality of life research* (pp. 137-152). Washington,DC: American Psychological Association.

Stahle, J. (1978). Incidence of Meniere's disease. *Archives of Otolaryngology Head Neck Surgery, 104,* 99-102.

Steffen, V. (1997). Life stories and shared experience. *Social Science and Medicine, 45,* 99-111.

Stewart, M. J. (1990). Expanding theoretical conceptualizations of self-help groups. *Social Science and Medicine, 31,* 1057-1066.

Tabachnick, B. G. & Fidell, L. S. (2001). *Using multivariate statistics.* (4th ed.) Allyn & Bacon.

Taylor, S. E. (1983). Adjustment to threatening events. *American Psychologist, November,* 1161-1173.

Taylor, S. E., Aspinwall, L. G., Guiliano, T. A., Dakof, G. A., & Reerdon, K. K. (1993). Storytelling and coping with stressful events. *Journal of Applied Social Psychology, 23,* 703-733.

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology, 46,* 489-502.

Taylor, S. E. & Lobel, M. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. *Psychological Review, 96,* 569-575.

Tedeschi, R. G. & Calhoun, L. G. (1996). The Posttaumatic Growth Inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9,* 455-471.

Tennen, H. & Affleck, G. (1997). Social comparison as a coping process: a critical review and application to chronic pain disorders. In B.P.Buunk & F. X. Gibbons (Eds.), *Health, Coping and Well-being: Perspectives form Social Comparison Theory* (pp. 263-298). New Jersey: Lawrence Erlbaum Associates.

Tennen, H., McKee, T. E., & Affleck, G. (2000). Social comparison processes in health and illness. In J.Suls & L. Wheeler (Eds.), *Handbook of Social Comparison: Theory and Research* (pp. 443-483). New York: Kluwer Academic/Plenum Publishers.

The WHOQOL Group (1998). Development of the World Health OrganizationWHOQOL-BREF quality of life assessment. *Psychological Medicine, 28,* 551-558.

Thompson, S. C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. *Psychological Bulletin, 90,* 89-101.

Thunedborg, K. P., Allerup, P. B., & Joyce, C. R. B. (1993). Development of the repertory grid for measurement of individual quality of life in clinical trials. *Journal of Methods in Psychiatric Research, 3,* 56.

Vachon, M. L. S., Lyall, W. A. L., Rogers, J., Freedman-Letofsky, K., & Freeman, S. J. J. (1980). A controlled study of self-help intervention for widows. *American Journal of Psychiatry, 137,* 1380-1384.

Van der Zee, K., Buunk, B. P., & Sanderman, R. (1995). Social comparison as a mediator between health problems and subjective health evaluations. *British Journal of Social Psychology, 34,* 53-65.

Van der Zee, K., Buunk, B. P., Sanderman, R., Botke, G., & Van den Bergh, F. (2000). Social comparison and coping with cancer treatment. *Personality and Individual Differences, 28,* 17-34.

Van der Zee, K., Oldersma, F., Buunk, B., & Bos, D. (1998). Social comparison preferences among cancer patients as related to neuroticism and social comparison orientation. *Journal of Personality and Social Psychology, 75,* 801-810.

Ware, J. E., Kosinsko, M., Bayliss, M. S., McHorney, C. A., Rogers, W. H., & Raczek, A. (1995). Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. *Medical Care, 33,* AS264-AS279.

Ware, J. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *SF-36 Health Survey: Manual and interpretation guide.* Lincoln, Rhode Island: QualityMetric, Inc.

Wills, T. A. (1991). Similarity and self-esteem in downward comparison. In *Social Comparison: Contemporary theory and research* (pp. 51-78). New Jersey: Lawrence Erlbaum Ass.

Wills, T. A. (1997). Modes and families of coing: An analysis of downward comparison in the structure of other cognitive and behavioural mechanisms. In B.Buunk & F. X. Gibbons (Eds.), *Health, coping and well-being: perspectives from social comparison theory* (pp. 167-193). Mahwah, New Jersey: Lawrence Erlbaum Ass. Inc.

Wills, T. A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin, 90,* 245-271.

Wilson, P. H., Henry, J., Bowen, M., & Haralambous, G. (1991). Tinnitus Reaction Questionnaire: Psychometric properties of a measure of distress associated with tinnitus. *Journal of Speech and Hearing Research, 34,* 197-201.

Wood, J. V., Taylor, S. E., & Lichtman, R. R. (1985). Social comparison in adjustment to breast cancer. *Journal of Personality and Social Psychology, 49,* 1169-1183.

Wood, J. V. & Van der Zee, K. (1997). Social comparisons among cancer patients: under what conditions are comparisons upward and downward. In B.P.Buunk & F. X. Gibbons (Eds.), *Health, coping and well-being: Perspectives from social comparison theory* (pp. 299-328). New Jersey: Lawrence Erlbaum Associates Inc.

Yalom, I. D. (1970). *The theory and practice of group psychotherapy.* (3rd ed.) New York: Basic Books.

Yardley, L. (1994). *Vertigo and dizziness.* London: Routledge.

Yardley, L., Medina, S. M. G., Jurado, C. S., Morales, T. P., Martinez, R. A., & Villegas, H. E. (1999). Relationship between physical and psychosocial dysfunction in Mexican patients with vertigo: a cross-cultural validation of the Vertigo Symptom scale. *Journal of Psychosomatic Research, 46,* 63-74.

Yardley, L., Masson, E., Verschuur, C., Haacke, N., & Luxon, L. (1992). Symptoms, anxiety and handicap in dizzy patients: Development of the Vertigo Symptom Scale. *Journal of Psychosomatic Research, 36,* 731-741.

Yardley, L., Todd, A. M., Lacoudraye-Hater, M. M., & Ingham, R. (1992). Psychosocial consequences of recurrent vertigo. *Psychology and Health, 6,* 85-96.

Ybema, J. F. & Buunk, B. P. (1995). Affective responses to social comparison: a study among disabled individuals. *British Journal of Social Psychology, 34,* 279-292.

Zeitoun, H. & Irving, R. M. (1999). Ménière's' disease: Aspects of management. *The Ear, 1,* 24-27.