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"IT'S BEEN A HELLUVA YEAR": THE EXPERIENCE OF VESTIBULAR DISORDERS ON THE SIGNIFICANT OTHER'S QUALITY OF LIFE

A dissertation on a study presented to

The Discipline of Speech Pathology and Audiology

School of Human and Community Development

Faculty of Humanities

University of the Witwatersrand

In fulfilment of the requirements

for the degree M.A. Audiology

by

NATANYA LEE BERRY

March 2017

DECLARATION

I, Natanya Lee Berry, hereby declare that this dissertation is my own work and effort. It has never been submitted to another university or institution. All materials and sources of information that have been used in this dissertation have been appropriately indicated and acknowledged by a complete reference list.

_____

Natanya Lee Berry

March 2017

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ABSTRACT

In health care, there appears to be greater consideration for the biopsychosocial model of disability and viewing disability in terms of functional health. Recently, the effect of impairment on the significant other's (SO's) quality of life (QOL) has been explored. In audiology, there appear to be very few published studies in this area, particularly related to vestibular disorders. The purpose of this study was to investigate the experiences of vestibular disorders on the SO's QOL.

A qualitative research design was employed, including 11 interviews and two focus groups. Participants were SO's of individuals with chronic vestibular disorders, and were recruited from a private audiology practice in Gauteng through purposive sampling strategies. Data were analysed using thematic analysis.

Eight primary themes emerged in the data analysis: social implications, financial implications, searching for a diagnosis, emotional effects, changes in family dynamics, support systems, comparison-oriented coping mechanisms, and referrals for psychological services. Findings suggested that SO's experienced third-party vestibular disability; however, having the appropriate support systems, including family and friends, was pertinent. It was also indicated that the relationship with the audiologist was essential in providing better understanding of the condition and prognosis thereof, resulting in less frustration and improved adaptation to the reported changes. A key finding was the lack of referral for psychological or counselling services.

These findings suggest the need to account for third-party vestibular disability in clinical, theoretical, and academic settings, and they call for the inclusion of third-party disability in policy-making.

Keywords: vestibular disorders, quality of life, significant others, third-party disability

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LIST OF ABBREVIATIONS

AAA	American Association of Audiology
AICA	Anterior inferior cerebellar artery
CDVAT	Computerised Dynamic Visual Acuity Testing
CDP	Computerised Dynamic Posturography
DALY	Disability Adjusted Life Years
DFI	Dizziness Factor Inventory
DHI	Dizziness Handicap Inventory
ENT	Ear, Nose and Throat Specialist
GST	Gaze Stabilisation Testing
HADS	Hospital Anxiety and Depression Scale
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
HRQOL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability, and Health
LSM	Living Standards Measure
MdDS	Mal de Débarquement Syndrome
MRI	Magnetic Resonance Imaging
NIDCD	National Institute on Deafness and other Communication Disorders
PICA	Posterior inferior cerebellar artery
QALY	Quality Adjusted Life Years
QOL	Quality of Life
SO	Significant other
SOS-HEAR	Significant Other Scale for Hearing Disability

UCLA-DQ	University of California, Los Angeles: Dizziness Questionnaire
VADL	Vestibular Disorders Activities of Daily Living
VAP	Vestibular Activities and Participation
VEDA	Vestibular Disorders Association
VEMP	Vestibular Evoked Myogenic Potential
vHIT	Video Head Impulse Testing
VHQ	Vertigo Handicap Questionnaire
VNG	Videonystagmography
VRBQ	Vestibular Rehabilitation Benefit Questionnaire
WHO	World Health Organisation

GLOSSARY OF TERMINOLOGY

Activity limitation	Difficulty experienced by an individual in executing a task or action (WHO, 2017).
Africanism	A feature of language or culture regarded as characteristically African.
Chronic	The definition of chronic varies according to the specific condition or diagnosis; however, it is generally accepted that a chronic condition requires medical management or rehabilitation for a period of three months of longer (Larsen, 2009).
Disability	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range, Considered to be normal for a human being. The term disability reflects the consequences of impairment in terms of functional performance and activity by the individual. Disabilities thus represent disturbances at the level of the person (WHO, 2004).
Impairment	Any loss or abnormality of psychological, physiological or anatomical structure or function. It is concerned with abnormalities of body structure and appearance, organ or system resulting from any cause. In principle, impairments represent disturbances at the organ level (WHO, 2004).
Participation restriction	A difficulty experienced by an individual to meet personal, social, or occupational demands (WHO, 2017).
Significant other	Umbrella term referring to a partner in a marriage, union, or domestic relationship.

CHAPTER 1: INTRODUCTION

1.1. Introduction to Chapter

Chronic disorders can considerably affect a person's quality of life. In the field of audiology, the development of a long-lasting vestibular impairment may yield a range of psycho-emotional, socio-economic, and other responses which may directly or indirectly extend to significant others (SOs). This study extends the exploration of the impact of vestibular impairment and describes the experiences of vestibular disorders on the SO's quality of life.

In order to fully appreciate the findings and discussion of this dissertation it is important that the concepts of the topic are thoroughly explored as this provides the basis for the understanding of the results. This chapter, therefore, provides an insight into the human balance system as well as the relevant disorders, as well as an introduction into the concept of quality of life. Furthermore, the chapter concludes with an outline of the structure and presentation of this dissertation.

1.2. An Orientation to the Human Balance System

The human balance system comprises of a complex set of three sensory inputs, namely the vestibular system, the visual system and the somatosensory system. In order for the human body to maintain physical balance, precise functioning and coordination of all three systems is required (VEDA, 2017). Within the area of balance disorders, the vestibular system is of particular interest to audiologists as it is housed within close proximity to the auditory end organs within the bony labyrinth of the temporal bone (Stach, 2010). In order to fully understand the intricacies of the balance system and the associated disorders, it is

necessary to have a complete overview of the three sensory inputs. However, the field of audiology encompasses the vestibular system within its scope of practice (American Association of Audiology, 2004) and, therefore, for the purpose of this study, the primary focus will be on the vestibular system, including both the peripheral and central components.

The three sensory inputs are processed centrally in order to allow for execution of motor abilities by the musculoskeletal system (Konrad & Nakayama, 2006). Each of the three sensory inputs has individual functions in maintaining balance; however, they are unable to work independently and rely on integration with each other for homeostasis (Allison & Fuller, 2013). The somatosensory system consists of the joints, ligaments, muscles, and skin, which contain receptors that provide the necessary tactile information, such as temperature and pressure, as well as positional input, such as joint position and muscle contraction (Allison & Jeka, 2004). The visual system is responsible for environmental orientation and detecting of motion of the body in relation to space and objects. This includes head movement and postural sway (Allison & Jeka, 2004; Babu, Rubin & Isaacson, 2008).

The vestibular system interacts with the visual and somatosensory inputs in order to allow for postural stability and homeostasis. This system can be classified into the peripheral and central systems. The peripheral vestibular system is located in the membranous labyrinth of the inner ear chamber, and contains five significant vestibular organs, namely the three semicircular canals and two otolith organs (Herdman & Clendaniel, 2014). The otoliths, namely the utricle and saccule, allow for the detection of linear acceleration and deceleration (both vertical and horizontal) whereas the three semicircular canals are responsible for detecting rotary changes in head movement through the presence of endolymph and otoconia (Allison & Fuller, 2013; Gulya, Minor, & Poe, 2010). Bilaterally, the horizontal semicircular canals are situated within the same plane, thereby allowing for differentiation between left

and right movements of the head (Seikel, King & Drumright, 2010). The anterior and posterior semicircular canals are coplanar, meaning that the left anterior canal is parallel to the right posterior canal. This results in a push-pull arrangement, thereby allowing the brain to detect head movement through comparing the sensory input (Schubert, 2014).The function of the anterior semicircular canals is to sense head rolls whereas the posterior semicircular canals are able to detect vertical movements of the head (Seikel et al., 2010). The ability of the semicircular canals to detect specific movements is achieved through the presence of sterocilia and kinocilia which are embedded within the endolymphatic fluids. As the fluid moves, the cilia become stimulated which activates the sensory response (Seikel et al., 2010).

In addition to the five vestibular structures, blood supply to the vestibular system is provided via the basilar artery which branches into the posterior-inferior cerebellar artery (PICA), the anterior-inferior cerebellar artery (AICA) and the internal auditory artery (Furman, Cass & Whitney, 2010). The PICA is a vital artery which supplies blood to the central vestibular system, specifically the inferior portion of the cerebellar hemispheres and the inferior parts of the vestibular nuclear complex. The AICA is the only form of blood supply for the peripheral vestibular system. In addition it also provides blood supply to the anterior-lateral part cerebellum as well as a portion of the pons (Herdman & Clendaniel, 2014).

1.3. Spinning in Circles: Types of Vestibular Disorders

A balance disorder may occur due to a peripheral dysfunction in any one of the three sensory systems, their blood supply, injury to the musculoskeletal system, or due to a central pathology (Herdman & Clendaniel, 2014). A hypofunction may result in feelings of dizziness or vertigo which may be further exacerbated by secondary side effects of nausea, vomiting,

tinnitus or hearing impairment. Many individuals presenting with vestibular impairments report feelings of dizziness or vertigo however there are often incongruences in the definition of the symptom (Kelly, Tellan, Arriaga & Stein, 2003). A study by Newman-Toker et al. (2007) indicated that more than half of patients were unable to accurately report on the presenting symptoms. For these reasons, a detailed case history is considered to be one of the most pivotal parts of the test battery in order to allow for differential diagnosis (Buki & Tarnutzer, 2014).

In general, non-vestibular causes of dizziness can be categorised into four main causes – presyncope, psychosomatic, metabolic, neurologic, and intoxication. Individuals presenting with types of disorders often describe symptoms that correspond with the term 'dizziness'; i.e. feelings of light-headedness with no motion components. The following table (Table 1.1.) depicts a brief summary of non-vestibular related causes, associated signs and symptoms as well as examples of dizziness.

Table 1.1.

Non-Vestibular Types of Dizziness

Cause	Associated signs and symptoms	Example of disorder
Presyncope	Blurred vision, subdued hearing, pallor, weakness	Orthostatic hypotension
Psychosomatic	None	Phobic postural vertigo
Metabolic	Decreased concentration, tremor, perspiration, pallor, palpitations	Diabetes mellitus
Neurologic	Dysarthria, diplopia, impaired consciousness	Brainstem ischemia
Intoxication	Cloudiness, drowsiness, ataxia, gaze-evoked nystagmus, saccadic pursuit	Substance abuse

Note: Adapted from *Vertigo: Its multisensory syndromes* (2nd edition, p. 24), by T. Brandt, 2003, Munich, Germany: Springer; adapted from *Basic otorhinolaryngology: A step-by-step learning guide* (Chapter 13), by R. Probst, G. Grevers and H. Iro (Eds.), 2006, Germany: Georg Thieme Verlag.

When one experiences a rotary sensation, this is classified as 'true' vertigo; however, a to-and-fro vertigo may also be experienced as a result of otolith organ hypofunction (Brandt, 2003; Bronstein & Lempert, 2013). Probst (2006) describes vertigo as being "a disturbance of integrity caused by contradictory sensory information processing" (p. 280).

According to this definition, vertigo may occur due to a functional peripheral hypofunction or impaired central processing. In older adults, vertigo may result from multisensory disturbances (Probst, 2006). Vertigo typically co-occurs with accompanying symptoms of nausea, vomiting and gait disturbances (Bronstein & Lempert, 2013).

Vertigo may present as episodic attacks or may be persistent. Recurrent episodic vertigo may result from disorders of the eighth cranial nerve, peripheral vestibular system or central vestibular system. Persistent vertigo, on the other hand, may stem from a variety of causes including infections, tumours, autoimmune ear disease, trauma or vascular or iatrogenic causes (Brandt, 2003). The following table (Table 1.2.) differentiates the various causes of episodic and persistent vertigo.

Table 1.2.

Causes of Episodic vs. Persistent Vertigo

Types of vertigo	Causes of vertigo
Episodic	1. CNVIII involvement (e.g. acoustic neuroma, cerebello-pontine angle cyst, vestibular neuritis) 2. Peripheral vestibular disorder (e.g. Ménière's disease, BPPV, perilymph fistula) 3. Central vestibular disorder (e.g. vertebrobasilar ischemia, AICA ischemia)
Persistent	1. Bacterial infection (e.g. tuberculosis labyrinthitis, syphilitic labyrinthitis, bacterial meningitis, cholesteotoma)

2. Viral infection (e.g. vestibular neuritis, HIV)
3. Tumour (e.g. acoustic neuroma, meningioma, metastatic carcinoma)
4. Vascular (e.g. labyrinth infarction, hyperviscocity syndrome)
5. Autoimmune inner ear disease
6. Trauma (e.g. temporal bone fracture, labyrinthine concussion, perilymph fistula)
7. Iatrogenic (e.g. post-ear surgery, transtympanic gentamycin treatment)

Abbreviations: CNVIII – 8th cranial nerve; BPPV – Benign Paroxysmal Positional Vertigo; AICA – Anterior Inferior Cerebellar Artery; HIV – Human Immunodeficiency Virus

Note: Adapted from *Vertigo: Its multisensory syndromes* (2nd edition, pp. 25 – 26), by T. Brandt, 2003, Munich, Germany: Springer.

As noted in the above table, there may be overlap between certain disorders and their presentation which may be due to various factors, such as the developmental course of certain disorders or the severity of the disorder.

1.4. Epidemiological Studies in Vestibular Disorders

At present there does not appear to be any published data in South Africa recording the statistics of vestibular disorders. However, global statistics report that dizziness and vertigo are two of the most common symptoms for which medical attention is sought amongst working-age adults (Davis & Moorjani, 2003; Grill, Müller, Brandt & Jahn, 2013;

Kroenke & Price, 1993; Neuhauser et al., 2005; Yardley et al., 1998). Due to discrepancies in the use of the terminology, as discussed previously, it is important to consider that the symptoms described are not unique to vestibular impairment and therefore this must be interpreted with caution.

There are also challenges arising in epidemiological studies related to vestibular impairment due to variance and inaccuracies in diagnosing and reporting (Grill et al., 2013). Data from studies, particularly in the United States, estimate the prevalence of dizziness and vertigo to range between 20-35% (Davis & Moorjani, 2003; Kroenke & Price, 1993; Neuhauser et al., 2005; Yardley et al., 1998). However, these figures may include non-vestibular causes, such as hypoglycaemia and orthostatic hypotension. In a large-scale in-depth study, Neuhauser et al. (2005) found that 7.4% of the general population in Germany experience vertigo as a result of a central or peripheral vestibular disorder. Agrawal, Carey, Della Santina, Schubert and Minor (2009), on the other hand, also performed a large-scale study in the United States and found that 35.4% of the population was estimated to present with a vestibular impairment. These two studies clearly illustrate the variation in prevalence studies.

However, it has been widely agreed that, when analysing the specifics of the data, the prevalence is significantly higher in the female population and in the elderly population (Agrawal et al., 2009; Gopinath, McMahon, Rochtchina & Mitchell, 2009; Jonsson, Sixt, Landahl & Rosenhall, 2004; Neuhauser et al., 2005).

Agrawal, Ward and Minor (2013) reported that, in comparison to males, females are three times more likely to present with vestibular disorders. Another investigation conducted by Schmidt, Flores, Rossi and da Silveira (2010) found that 67.2% of individuals presenting with vestibular impairment were females. This may be due to a greater tendency to develop

vestibular disorders as a result of female hormonal variations and metabolic disorders. Complications may arise from changes in the metabolism of oestrogen and progesterone, which are hormones responsible for ovarian cycles. Central and peripheral vestibular impairments are frequently listed as potential complications. These metabolic changes occur during menstruation, gestation and menopause (Silva, 2000). One study determined that, during pregnancy, the osmotic fluid action appears to affect the inner ear and, therefore, may be strongly linked to the increased incidence of Ménière's disease in pregnant women (Uchide, Susuki, Takiguchi, Terada & Inoue, 1997). In 2010, the National Institute on Deafness and Other Communication Disorders (NIDCD) found that there were approximately 615 000 Americans living with Ménière's disease, with 45 500 newly diagnosed patients being identified each year (NIDCD, 2007).

Prevalence studies in the elderly population have reported a significant increase in dizziness and vertigo. In one such study, 80% of Americans over the age of 80 years reported to have experienced dizziness (Ator, 2010). However, these symptoms may be due to non-vestibular causes such as blood pressure or medication side-effects (Goldberg, Wilson & Cullen, 2012). It has been found that elderly individuals presenting with vestibular-related dizziness and vertigo typically suffer from disorders such as Parkinson's disease and multisystem atrophies. In addition, elderly individuals may present with degenerative cerebellar diseases, such as those associated with malignancy (i.e. paraneoplastic syndrome), phenytoin intoxication, hereditary ataxias, alcoholism, and myxoedema. Paget's disease has also been identified as a common cause of vestibular disorders in the elderly (Sinclair, Morley & Vellas, 2012).

1.5. Quality of Life

The World Health Organisation (WHO) defines quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997, p. 1). Quality of life is further shaped by physical and psychological health, independence, social relationships, belief systems and environmental influences (WHO, 1997).

In terms of audiology, the majority of research related to quality of life has focused on hearing impairment, with many studies dating to 1980. These studies have documented the adverse effects of hearing impairment on emotional, behavioural and social health (Bess, Lichtenstein, Logan & Burger, 1989; Smith & Kampfe, 1997; Stephens, 1980; Stephens & Hetu, 1991). In comparison to hearing impairment, there appears to be a lack of research in the area of vestibular disorders. In terms of vestibular disorders, studies document the psychological distress of the disorder on the patient, such as fears related to an unexpected vertiginous attack, falling, and stigmatisation (Hallam & Stephens, 1985; Yardley, 1994a; Yardley, 1994b; Yardley, Verschuur, Clifford, Luxon, & Haacke, 1992). There are also high levels of anxiety surrounding the vestibular disorder (Hallam & Stephens, 1985; Yardley, 1994a; Yardley, 1994b; Yardley et al., 1992).

The majority of existing research appears to explore the experiences and quality of life of individuals presenting with vestibular impairment. As such, there appears to be a considerable need to further investigate the impact of vestibular disability on SOs. In 2001, the WHO recommended the area of third-party disability for further research. The WHO has defined third-party disability as "the study of disability and functioning of family members due to the health condition of significant others" (WHO, 2001, p. 251). Again, there is a noticeable lack of data published in vestibular disorders in comparison to that of hearing

impairment. Piker, Jacobson, Tran, McCaslin and Hale (2012) have published a study regarding spousal perceptions of vertigo, highlighting the significance of spousal congruence in the perception of the disability. This study required 50 patients with vestibular impairment and their partners to individually complete various dizziness questionnaires and psychological outcome measures which reported on perceived vertigo and dizziness handicaps. Through statistical analysis, the patients' responses were compared to their respective partners' responses, and definitive consistencies were identified amongst the responses, thereby confirming congruency of patient and spousal perceptions of vertigo and dizziness (Piker et al., 2012).

Stephens, Pyykkö, Kentala, Levo and Rasku (2012) have also discussed third-party disability in vestibular disorders; however, their study was limited to Ménière's disease and utilised a quantitative approach. In this study SO's listed a wide range of effects of Ménière's disease on their lives and lifestyle, which were subsequently categorised according to the International Classification of Functioning, Disability, and Health (ICF) framework. This study suggested significant emotional consequences related to the presenting Meniere's disease, which ultimately affected SO's ability to engage in various activities and limited their participation, both vocationally and leisurely.

1.6. Rationale for Study

With a move towards a biopsychosocial model in health and health-related conditions, it is important for clinicians to consider the impact of the disability on the family, and, for adults, this is most commonly relevant for spouses. Literature in psychology has shown that living with an individual with a disability has detrimental effects on the spouse's or family member's overall well-being, and in medical treatment, the spouse is often overlooked

(Keefe, Buffington, Studts, & Rumble, 2002). However, spousal support has proven to be imperative in rehabilitation, as researchers have found that it is oftentimes the spouses who encourage therapy attendance and carryover in the home environment (Stark & Hickson, 2004; Tye-Murray & Schum, 1994). In addition, from a psychological standpoint, family members have a significant effect on the patient's adjustment to the health condition (Martire, Lustig, Schulz, Helgeson & Miller, 2004).

In light of the background offered by this introductory chapter, it is vital that the effects of the health condition on the spouse are addressed within any rehabilitation or therapeutic session. The following chapter will provide literature which suggests the presence of a health condition results in wide-ranging consequences on the quality of life of SOs and this impact may promote third-party disability.

In the development of this research topic and throughout the analysis of available published data, research in the area of quality of life related to vestibular disorders appears to be limited to the patient's experiences, with a seemingly lack of research into the concept of third-party disability, despite there being a 16 year period since the WHO's call for action in this area (WHO, 2001). Research in the field of vestibular disorders spanning over the past three decades – such as Herdman and Clendaniel (2014), Jacob & Furman (2001), Marks (1981), Mira (2007), and Rudge and Chambers (1982) – indicates that individuals with vestibular dysfunction experience increased negative psychosocial and emotional consequences. Research in other healthcare fields, such as hearing impairment in audiology, which also suggests adverse patient experiences, have published data documenting a substantial amount of third-party disability experienced by SOs (Scarinci, Worrall & Hickson, 2008, 2009; Scarinci, Hickson & Worrall 2012a). In light of the existing literature, one may, consequently, surmise that third-party vestibular disability is commonplace.

However, further investigations into this assumption is warranted. Therefore, the primary purpose of this study was to investigate the quality of life experiences of SOs specifically related to the effects of vestibular disorders.

1.7. Outline of Chapters

This dissertation has been structured in various chapters in order to fully investigate the relevant aspects of the research.

- Chapter 1 has provided an orientation to the research topic by providing important theoretic knowledge regarding the underlying concepts of the research topic.

- Chapter 2 explores a theoretical framework to the study by exploring relevant constructs and previous research findings which are necessary in the interpretation and discussion of the results of the current research.

- Chapter 3 discusses specific detail with regard to the methods used to collect and analyse the data from the research. This also includes ethical considerations related to the study as well as the measures taken to ensure that the data collected and presented is reliable and trustworthy.

- Chapter 4 presents the results of this study through using a thematic analysis approach. The results of the study are presented as themes with relevant excerpts in verbatim from the participants' interviews and focus groups.

- Chapter 5 offers a comprehensive discussion of the results of the study through providing a further in-depth expansion of the findings with reference to previous research and literature in the field.

- Chapter 6 forms the conclusion of the dissertation and discusses the implications thereof as well as recommendations for future research.

1.8. Chapter Summary

The purpose of this study is to focus on the experiences of SOs in relation to their spouses' vestibular disorders. Through analysing the need for research in this particular field, this chapter has offered an introduction into the concepts surrounding the dissertation topic and has set out to provide insight into the development of the research aims and question. In doing so, the necessary foundations have been explored leading onto a structured rationale for the study.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction to Chapter

The term 'disability' has traditionally been "conceptualised as being a multidimensional experience for the *person* [emphasis added] involved" (World Health Assembly, 2001, as cited in MacKinlay, 2008, p.146). The findings of this study have challenged this view of disability to include the experiences of significant others (SOs) in the definition. An important basis for this dissertation is to explore the different models of disability, as well as the frameworks and guidelines proposed by the literature. This chapter, therefore, endeavours to provide a foundation for the development of the current research topic through offering an in-depth analysis of the relevant concepts and themes related to this study.

2.2. Defining Disability

In the 18th and 19th centuries and the development of 'modern medicine' a biomedical approach was adopted by the healthcare practitioners which viewed illness as an objectively identifiable health condition requiring the necessary diagnosis and medical treatment thereof (Peterson, 2011). This paradigm appears to still be a dominant model which is widely used in Western healthcare systems (Walsh, 2004).

However, towards the end of the 19th century, there was a shift in the view of the management of health-related conditions, which may be best described by Nothnagel (1882) as cited in Shorter (2005): "I will repeat once again, medicine is about treating sick people and not diseases" (p. 3). This perspective introduced the social model of disability, which recognises that there are factors beyond the health condition which may facilitate or hinder

the individual's well-being. This model provides a strong emphasis on facilitators and barriers such as relationships, psychological traits, and social participation (Peterson, 2011).

This concept of a 'patient-as-a-person' reminisces with Hippocratic holistic thinking and, in the 1970's, the medical community identified the need to further expand on the models of disability and, thus, the biopsychosocial model was proposed (Shorter, 2005). The biopsychosocial model may be seen as a hybrid of the medical and social models of disability and amalgamates the positive attributes of each paradigm. Essentially, this model of health considers the impact of the health condition, individual characteristics as well as societal perspectives in diagnostic processes as well as intervention. This model acknowledges the concept of quality of life and is, therefore, considered to be interactive model of health. As will be discussed in the following section, the development of International Classification of Functioning, Disability, and Health (ICF) by the WHO is founded on the basis of the biopsychosocial model of disability (Peterson, 2011).

2.3. World Health Organisation

2.3.1. International Classification of Functioning, Disability, and Health

With the realisation of the interrelatedness between health conditions and quality of life, the WHO initiated the development of the ICF framework. In 2001, this framework was introduced to healthcare systems, and has created opportunities for individuals, including healthcare workers, patients and their families, to gain a holistic idea of the impact of health conditions, and "functional health" (WHO, 2001, p.3). The ICF can be defined as a health-related classification system which describes body functions and structures, activities and

participation. Included in this system are individual and societal perspectives as well as the environmental factors which may influence one's functioning (WHO, 2004).

Research has suggested that the ICF may be useful for healthcare workers, particularly for treatment planning, as it provides insight into the physical disability, as well as individual and societal perspectives (Peterson, 2011). The following diagram (Figure 2.1.) illustrates the ICF framework:

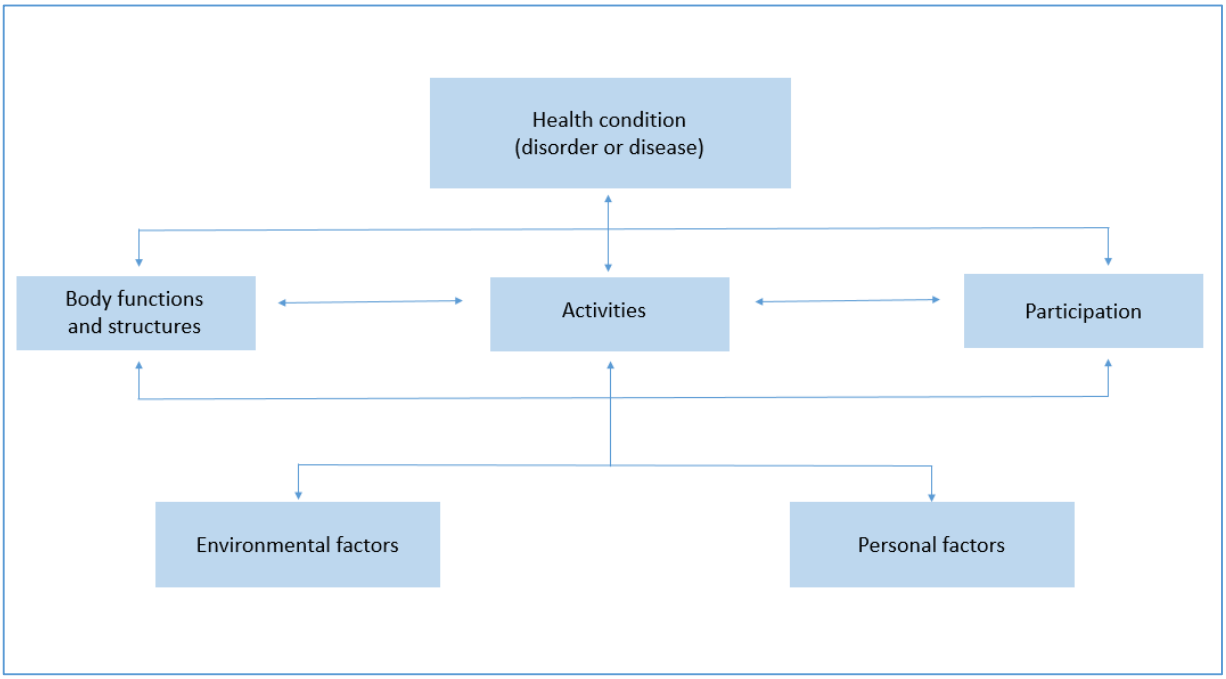


Figure 2.1. The ICF framework. Adapted from *International Classification of Functioning, Disability and Health: ICF* (p. 18), by World Health Organisation, 2001, Geneva: World Health Organisation.

At present, the ICF is used to describe the individual's abilities in terms of function; however, the framework is constantly being revised, and suggestions have been put forth to expand the ICF to explicitly include quality of life too (McDougall, Wright & Rosenbaum, 2010). The WHO describes quality of life as being the individual's subjective perception of the effect of his/her health condition in relation to their personal and cultural context (WHO Quality of Life Group, 1998). Currently, it is possible for clinicians to make use of the 'activity limitations' and 'participation restrictions' domains of the ICF to infer quality of life indicators; however, McDougall et al. (2010) argue that by excluding quality of life, these domains do not provide accurate nor sufficient information. McDougall et al. (2010) suggest that by explicitly including quality of life, clinicians are able to gain more in-depth information into the individual's overall well-being as well as attain a complete picture of human life.

2.3.2. Recommendation for third-party disability research

In the development of the ICF framework, the WHO recommended an area of research described as the "study of disability and functioning of family members due to the health condition of significant others" (WHO, 2001, p. 251). It was labelled "third-party disability" (WHO, 2001, p. 251). In the 16 years since the proposal of this area of future research, there is limited published research documenting third-party disability. In a review of the available literature, Peterson (2011) reiterates the WHO's recommendation; however, does not provide any theoretical or practical application thereof. It appears that studies in the area of third-party disability are currently concentrated in the fields of speech-language pathology and audiology, specifically with reference to research in aphasia (e.g. Grawburg, Howe, Worrall & Scarinci, 2013) and hearing loss (e.g. Scarinci et al., 2008, 2009; 2012a).

2.4. Third-Party Disability Research in Audiology

At the forefront of research in third-party disability in audiology are Nerina Scarinci, Linda Worrall and Louise Hickson of the University of Queensland, Australia. Their research has been centred on third-party hearing disability, specifically with regard to older adults (Hickson & Scarinci, 2007; Scarinci et al., 2008, 2009).

These studies have demonstrated the extensive third-party hearing disability experienced in almost every aspect of the spouses lives. Furthermore, in accordance with the ICF framework, Scarinci et al. (2008) identified that the activity limitations and participation restrictions domains were very applicable to the spouses of adults with hearing impairment, specifically with regard to communication, domestic life, interpersonal interactions, community life and social life. In terms of the contextual domains of the ICF it was found that the environment presented an array of factors which directly influenced the third-party hearing disability, including products and technology, natural environment and human-made changes to the environment. Personal factors, such as gender and coping style, were also associated with the third-party disability (Scarinci et al., 2008). Through this study, Scarinci et al. (2008) were able to provide a strong motivation for the inclusion of third-party hearing disability in practice, theory, policy and research.

These findings further encouraged Scarinci et al. (2012b) to develop the Significant Other Scale for Hearing Disability (SOS-HEAR), which utilised concepts acquired from their previous qualitative studies to formulate a tool to measure the third-party hearing disability. Through implementing this tool clinically, Scarinci et al. (2012b) reported that 98% of spouses indicated that they experienced at least one area of third-party hearing disability.

Scarinci et al. (2012a) have emphatically emphasised that the rehabilitation process is significantly important for the spouse as well as the person with the hearing impairment.

Recommendations are made for inclusion of spouses in the assessment and intervention phases as, based on the findings from previous research, important holistic information can be gained from both the patient and the spouse (Scarinci et al., 2012a).

Within the South African context, de Andrade (2015) completed a thesis which provides insight into caregivers' embodiment of third-party disability in rural settings. This study focused on the experiences of caregivers of deaf children and suggested that third-party disability may be influenced by the available structures within the communities and, in the absence of the necessary support, may result in psychological, emotional and physical consequences for the caregiver (de Andrade, 2015).

The following figure (Figure 2.2.) illustrates the application of the ICF to third-party disability, as proposed by Scarinci et al. (2012a).

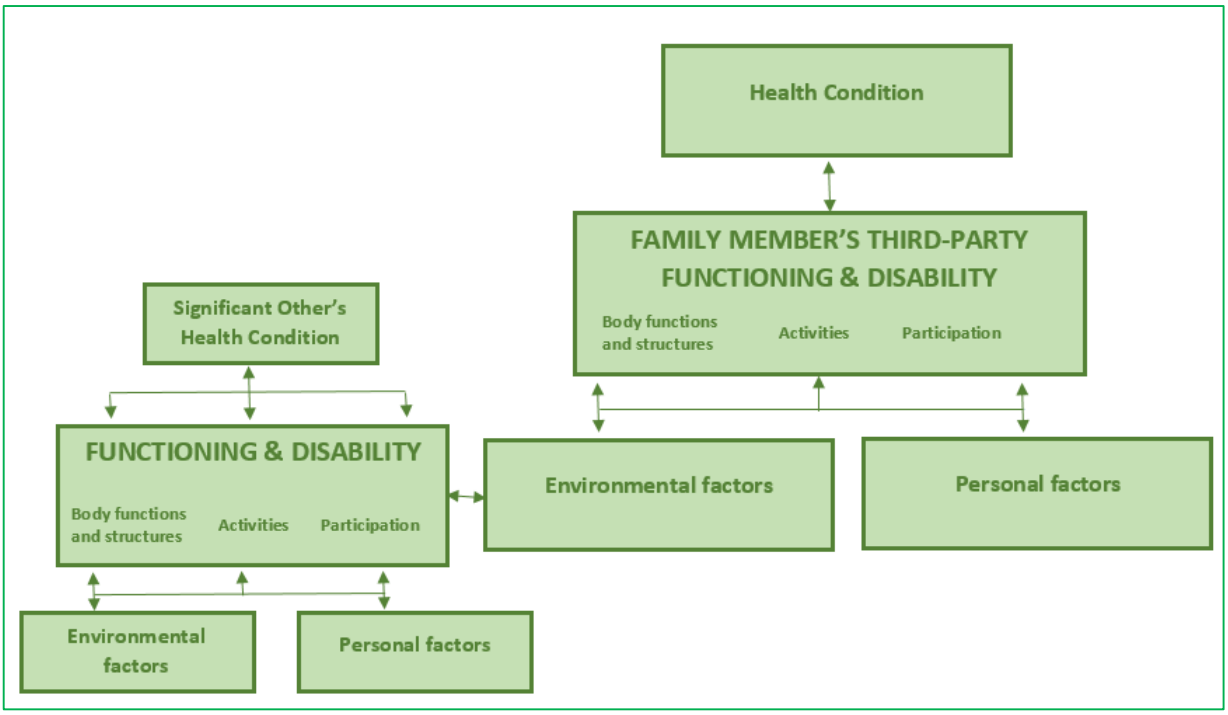


Figure 2.2. The ICF and its application to third-party disability. Adapted from *Third-party disability in spouses of older people with hearing impairment* (p. 4), by N. A. Scarinci L. M. Hickson, & L. E. Worrall, 2012a, USA: American Speech-Language-Hearing Association.

2.4.1. Vestibular-related quality of life studies

In audiology the majority of research related to quality of life has focused on hearing impairment, with studies dating to the 1980s. These studies have documented the adverse effects of hearing impairment on emotional, behavioural and social health (Bess et al., 1989; Smith & Kampfe, 1997; Stephens, 1980; Stephens & Hetu, 1991).

More recently, there have been a large number of studies documenting the psychological distress of vestibular disorders on the individual, particularly the presence of anxiety disorders. According to Goldberg et al. (2012), the impact of vestibular disorders on quality of life has mostly been researched in the area of Ménière's disease. Studies have found that as a result of the fear of an unexpected vertiginous attack, the fear of falling, and the fear of stigmatisation, individuals often engage in safety-seeking behaviours and avoidance (Hallam & Stephens, 1985; Yardley, 1994a; Yardley, 1994b; Yardley et al., 1992). As a result, a sense of anxiety is created for the individual, thereby creating self-imposed restrictions in daily activities (Green, Verrall, & Gates, 2007; Kinney, Sandridge & Newman, 1997).

During the early 1980's, terminology such as 'street neurosis', 'supermarket syndrome' and 'space phobia' were proposed to describe the anxious tendencies of individuals presenting with vestibular disorders (Marks, 1981; Rudge & Chambers, 1982). More recently, authors have described how the presence of dizziness symptoms significantly affect the quality of life of individuals with pre-existing psychogenic disorders and result in marked functional impairment (Jacob, Furman, Durrant & Turner, 1996; Ten Voorde, van der Zaag Loonen & van Leeuwen, 2012). Jacob and Furman (2001) reported that the relationship between vestibular disorders and psychological distress is bidirectional. This means that the presence of a vestibular impairment may result in anxiety; however, the converse may also be

true, whereby the presence of an anxiety disorder may result in dizziness, i.e. psychogenic dizziness. This notion illustrates the complex interaction between vestibular disorders and psychological disorders.

A retrospective study on individuals presenting with both dizziness and psychogenic problems found that in 33% of cases anxiety was the sole cause of the dizziness. It was also determined that presence of a neurotological disorder exacerbated a pre-existing psychogenic disorder in 34% of the individuals and triggered a new psychogenic disorder in the remaining 33% of the individuals (Jacob & Furman, 2001). Further studies cite that at least 25% of individuals complaining of dizziness present with agoraphobia and panic attacks (Mira, 2007). Eagger, Luxon, Davies, Coelho and Ron (1992) confirmed the high incidence of panic disorder in individuals suffering from vestibular impairments, as their study found that 50% of individuals presenting with a peripheral vestibular hypofunction experience panic disorders, with or without agoraphobia as well as major depression. In addition, Schmidt et al. (2010) reported that the associated auditory symptoms may further aggravate the physical and psychological distress brought about by the vestibular disorder.

Mendel, Bergenius and Langius (1999) found that individuals reported the psychosocial aspects related to the vestibular impairment to be "the worst functional impairment" (p. 292) resulting in restrictive activities and avoidance of situations. Simple tasks such as driving a car have been reported by individuals with vestibular impairment as a difficult and dangerous activity (Cohen, Ewall & Jenkins, 1995). According to Herdman and Clendaniel (2014), the majority of individuals with vestibular disorders avoid or reduce their participation in leisure activities, particularly those that may require head movement. Activities of daily living, such as showering, may also trigger symptoms. The mere anticipation of triggering a vertiginous attack may result in severe anxiety, which further

limits the individual's participation in various activities, thereby creating possible social isolation and depression (Herdman & Clendaniel, 2014).

In addition to the psychological effects of vestibular disorders, few studies have documented the relationship between vestibular impairment and cognitive impairment, particularly within the elderly population. Magnetic resonance imagery (MRI) studies have shown that the hippocampus atrophies as a result of bilateral vestibular dysfunction, thus correlating with the decline in spatial memory tasks (Smith, Zheng, Horii & Darlington, 2005). The resultant cognitive impairment in individuals presenting with vestibular hypofunction may be another contributing factor to reduced quality of life in this population as Fillit and Butler (1997) report that even a mild cognitive decline may result in avoidance of social activities and a loss of functional independence.

Due to the significant impact of vestibular disorders on quality of life, it may be useful for audiologists and other health professionals involved in the treatment process to consider the use of the Disability Adjusted Life Years (DALY) and the Quality Adjusted Life Years (QALY). These two tools are used inversely. The DALY measures the number of years lost due to a poor quality of life following illness or disability, i.e. health loss, mortality and morbidity. The QALY, on the other hand, measures health gain and the burden of the disorder in order to provide information for treatment planning. It allows clinicians to estimate the number of years added to life given a specific course of treatment (Airoldi, 2007).

As a result of the complex interaction between vestibular disorders and psychological distress, there have been a variety of vestibular-specific scales and measures developed in order to assist clinicians in better understanding the implications on quality of life. These measurement tools include: Dizziness Handicap Inventory (DHI), Vertigo Handicap

Questionnaire (VHQ), Dizziness Factor Inventory (DFI), University of California, Los Angeles: Dizziness Questionnaire (UCLA-DQ), Vestibular Disorders Activities of Daily Living (VADL), Vestibular Rehabilitation Benefit Questionnaire (VRBQ) and Vestibular Activities and Participation (VAP) (Herdman & Clendaniel, 2014). For the purpose of this research study, it is necessary to analyse the uses as well as advantages and disadvantages of each of these assessment tools, as illustrated in the following table:

Table 2.1.

Analysis of Quality of Life Scales for Vestibular Disorders

Name	Purpose	Consistency and reliability	Advantages	Disadvantages
DHI	Analyses physical factors, emotional and functional consequences of vestibular disorder	High consistency and reliability scores	Quick and easy to use Useful for analysing symptoms	Meaning of "sometimes" rating may be unclear Fails to provide holistic view of patient Unable to detect small changes Not useful for treatment planning Does not include self-care skills
VHQ	Describes common social, psychological and behavioural consequences of vestibular disorder	High internal consistency Good test-retest reliability	Provides good analysis of anxieties Analyses behavioural restrictions	Does not consider performance of ADLs
DFI	Considers the symptoms, responses of SOs and activity levels related to vestibular disorder	Further testing required	Includes domain of "responses of significant other"	Does not include self-care skills Lengthy to complete
UCLA-DQ	Qualitative scale to characterise vertigo based on frequency, intensity, impact on	Original paper does not provide this information	Useful as quick screening	Generic items therefore limited utility

	activities, impact on quality of life and fear of dizziness			
VADL	Evaluates subjective impact of vestibular disorder on ADLs	High internal consistency Good test-retest reliability	Focus of ADLs Detailed list of self-care skills Detailed scale to rate level of performance Useful basis for structured assessment interview	Does not address symptoms Does not address emotions 10-point scale may be too difficult to select level
VRBQ	Analyses the subjective sensation of vertigo, its symptoms, and quality of life	Good internal consistency Strong reliability Moderate responsiveness	Attempts to quantify difference between patient's current and normal states	Does not provide new insights as derived from previous scales Does not include self-care skills
VAP	Assesses the activities and participation of individuals with vestibular disorder	Excellent test-retest reliability Poor to excellent agreement per item	Relationship to ICF Provides a variety of activities	Does not include personal self-care tasks

Abbreviations: DHI – Dizziness Handicap Inventory; VHQ – Vertigo Handicap Questionnaire; DFI – Dizziness Factor Inventory; UCLA-DQ – University of California Los Angeles: Dizziness Questionnaire; VADL – Vestibular Disorders Activities of Daily Living; VRBQ – Vestibular Rehabilitation Benefit Questionnaire; VAP – Vestibular Activities and Participation; ADL – Activity of Daily Living; ICF – International Classification of Functioning, Disability, and Health.

Note: Adapted from *Vestibular Rehabilitation* (pp. 113 – 115), by S. J. Herdman & R. A. Clendaniel, 2014, Philadelphia PA: FA Davis Company

2.4.2. Vestibular-related third-party disability studies

In the previous sections of this chapter, the psychosocial aspects related to vestibular impairment were explored. As a result of these factors researchers have superficially investigated the effects of vestibular disorders on the SO's quality of life. However, there are very minimal published data in this field. Schulz, Visintainer and Williamson (1990) have reported on the emotional, financial, physical and familial effects of disability on the spouse, and findings from Piker et al.'s (2012) study have also highlighted the significance of spousal congruence in the perception of the disability. Research has illustrated that findings from studies in hearing impairment, headache, pain, and even cancer have been extrapolated for use in clinical practice, all of which have reinforced that spousal perception of the disability must be in congruence with that of the patient (Piker et al., 2012).

With reference to the current research study, the most comparable study in this area appears to be Stephens et al.'s (2012) article documenting the effects of Ménière's disease on the patient's SO. Although this research may be seen as similar to the current research topic, one must be cognisant of the fact that Stephens et al.'s (2012) study focused solely on Meniere's disease, which is only one of many types of vestibular disorders with which individuals may present. This research, in contrast, has included any chronic vestibular disorder, in an endeavour to document a broader (yet, simultaneously detailed) overview of the SOs' experiences.

Stephens et al.'s (2012) study required participants, who were SOs, to produce a list of the effects of the Ménière's disease on their lives (both positive and negative). This study further analysed the responses in relation to age, gender, relationship to patient, and the duration of the Ménière's disease. Responses were then classified according to the ICF framework.

The results of Stephens et al.'s (2012) study indicated that overall Ménière's disease has a negative influence on the SOs, both physically and psychologically. All of the domains of the ICF framework were affected by the Ménière's disease. In the impairments domain, emotional problems (e.g. fear, stress, worry) were the dominant responses listed by the patients. The majority of the participants' reflections of the Ménière's disease appear to be clustered in the domains of activity limitations and participation restrictions, especially related to communication difficulties (as a result of the hearing impairment) mobility concerns around transportation (as a result of balance problems) (Stephens et al., 2012).

The participants in Stephens et al.'s (2012) study listed 75 participation restrictions, which resonate with those described by Scarinci et al. (2008), including domestic life interpersonal interactions and relationships, as well as community, social, and civic life. Shopping and household chores were also identified as two activities which had been negatively affected by the Ménière's disease. Within those domain, recreational and leisure activities were also mentioned by the participants, who stated that "exercising and jogging must always be done together" and "previously, we went to a lot of concerts, but nowadays we have to carefully consider…" (Stephens et al., 2012, p. 860).

Environmental factors listed in Stephens et al.'s (2012) article strongly highlights the change in dietary requirements as a concern of the SO. In addition, participants in the study suggested that their role in the relationship had changed to that of a carer rather than a partner.

Only 5% of the participants in Stephens et al.'s (2012) study alluded to positive experiences that were derived from the patient's Ménière's disease, however, the published article does not provide detail regarding these experiences.

2.5. Third-Party Disability Rehabilitation

With an increasing number of studies describing SOs' experiences of their partner's health condition, studies in the area of intervention for the third-party appear very scarce, with many sources mentioning the need for the inclusion of SOs in treatment or rehabilitation in passing. As studies in vestibular disorders are only at the 'tip of the iceberg' in terms of research, this section will offer a more general overview on the rehabilitation process regarding the third-party disability.

As has been previously described in this chapter, Scarinci and colleagues have produced a number of articles relating to third-party disability in audiology. In their article Scarinci et al. (2012a) provide an indication of the process in which to include SOs in the rehabilitation phases. It is emphasised in their research that family relationships can either help or hinder the patient's response to rehabilitation, and that complete support from the SO is imperative in encouraging the patient's successful rehabilitation. Stephens (1996) further mentions that SOs should be integrated into the treatment programme from the assessment stages and detailed accounts about the effects of the impairment for both the patient and the SO, as well as discussions on goal setting should be included (Stephens, 1996).

This view of family-centred care reflects current trends in rehabilitation, supporting a model of open and honest communication among all entities involved (i.e. patient, family and clinician) (Scarinci et al., 2012a). Traditionally, family-centred care has been the benchmark in paediatric healthcare (Hughes, Bamford & May, 2008). However, with the acknowledgement of third-party disability, Scarinci et al. (2012a) emphasise this approach should be considered in all facets of healthcare, and particularly in older couples who "may be more likely to be co-dependent and to operate as a unit" (p. 8).

Paramount to the rehabilitation process, according to Scarinci et al. (2012a) is the development of a structured, time-framed programme focusing on various aspects of the disability as well as the third-party disability, with a specific focus on those who have been identified as high-risk (Scarinci et al., 2012a).

2.6. Chapter Summary

Through offering an analysis of the literature which is relevant to this research study, this chapter has endeavoured to present the necessary background information to orientate the reader to the topic. It has further provided a context for the results of this study, which will be discussed in Chapters 4 and 5 of the dissertation. This chapter has illustrated the gross need for research in the area of third-party disability in a broader spectrum, and, more specifically, in vestibular disorders, in order to provide a theoretical basis to improve healthcare systems globally. Despite a small number of available literature in vestibular disorders alluding to third-party disability, in the form of Stephens et al.'s (2012) and Piker et al.'s (2012) articles, there does not appear to be adequate available literature explicitly documenting the third-party vestibular in a range of vestibular disorders.

CHAPTER 3: METHODOLOGY

3.1. Introduction to Chapter

Following the review of the current literature, there is an apparent need for research into the SOs' experiences of vestibular disorders. In light of this need, the methodology for this study was designed to allow for further qualitative investigation into these experiences. This chapter provides an explanation of the particular research design and methods used to gather and interpret the data for this study. It begins with an outline of the aims of the research, followed by a description of the qualitative research design employed for this study. Thereafter, the chapter examines the sample selection and the approaches of data collection and analysis, concluding with a reflection of the ethical aspects and reliability considerations for this study.

3.2. Aims of the Study

The primary aim of this study was to investigate significant other's (SO's) experiences of living with an individual who has a vestibular disorder.

The sub-aims were as follows:

- To explore the effects of vestibular disorders on the SO's social, emotional, familial, vocational, and financial wellbeing.
- To describe the social, emotional, familial, vocational, and financial effects of living with a SO who has a vestibular disorder.
- To identify which strategies SOs employ to overcome potential challenges of living with an individual who has a vestibular disorder.

3.3. Research Design

The study incorporated a qualitative research design in order to provide the researcher with an in-depth understanding of the patterns of behaviours, attitudes and beliefs of SOs, while further allowing for investigation into how individuals make sense of the situation (Hakim, 2000; Ohnmacht, 2015). Qualitative research can be considered as an umbrella term which covers various techniques of analysing data in order to interpret the meaning of social phenomena (Hai-Jew, 2015).

In accordance with the biomedical model of disability, many healthcare professionals have traditionally employed a quantitative approach towards healthcare, thereby translating into quantitative-based research (Holloway & Galvin, 2017). However, qualitative data have been shown to offer the opportunity to provide important information regarding the experiences of individuals with the healthcare setting and is, therefore, becoming more frequently utilised in health-related studies (Pope & Mays, 2006). As stated by Patton (2002), healthcare professionals "who only look at test results and don't also listen to their patients are making judgments with inadequate knowledge" (p. 14). In addition, as the implications of this study may be beneficial in informing policy-makers, a qualitative design was deemed to be the most applicable to thoroughly convey the SOs' experiences and attitudes (Block, 2006).

3.4. Sample and Sampling

Prior to discussing the participants and sampling strategies in this study, it is important to clarify the use of the following terminology:

- Patient: the individual who presents with the vestibular impairment; not included as a participant in the study
- SO: the participant of the study; the partner of the individual with a vestibular disorder

Prior to commencing recruitment, the researcher aimed to achieve a sample size of a minimum of 10 participants. In qualitative research studies, there are no rigid guidelines regarding sample size (Lichtman, 2013). Lichtman (2013) suggests that the required number of participants is determined by individual judgement. For the purposes of this study, the researcher deemed a sample size of 10 participants to be appropriate as it would allow for a vast array of experiences to be described in detail. Further, it would allow for correlation among responses in order to allow for thematic analysis techniques to be used in the data analysis.

This research included 11 SOs of individuals presenting with chronic vestibular disorders. The participants were recruited from a Johannesburg-based audiological private practice which has a special interest in vestibular impairment. The participants for this study were recruited through the use of purposive sampling, which is a non-probability sampling strategy allowing for variables to be controlled through specified data, thereby collecting data from a predetermined group (Engel & Schutt, 2010; Sharma, 2008). The use of this sampling strategy is beneficial for the purposes of this study as it is considered to be most relevant method for collecting data in qualitative research (Guest & Macqueen, 2008). Due to the nature of this research, specific inclusionary criteria were developed by the researcher and, therefore, this sampling strategy was justified for this research topic. The inclusion criteria were as follows:

- Participants were required to be SOs of individuals with vestibular disorders. The diagnoses of the vestibular disorders were made by the audiologist at the private practice or relevant Ear, Nose and Throat (ENT) specialist, through the use of a battery of tests, including both subjective and objective measures. As a standard, the test battery required for diagnosis included a complete diagnostic audiological evaluation, a subjective bedside dizziness assessment, Videonystagmography (VNG) testing, Video Head Impulse Testing (vHIT), and Vestibular Evoked Myogenic Potential (VEMP) testing. Depending on specific case history factors, findings from previous test results and requests from the referring medical practitioner, additional tests conducted by the audiologist may have included Computerised Dynamic Posturography (CDP) testing, Computerised Dynamic Visual Acuity Testing (CDVAT) and Gaze Stabilisation Testing (GST).
- For the purposes of this study, the patient was required to present with a chronic vestibular disorder, i.e. the symptoms of which persist for 3 months or more. These symptoms may be episodic or persistent. This was an important criterion as the experiences of acute or temporary vestibular disorders may yield very different responses.
- The individual with the vestibular disorder was required to be a current patient at the chosen research site (i.e. the vestibular disorder was still under management). This was an important aspect for the participation of the SO in the study as it allowed the researcher to gain current insights of the SO.
- Participation was required to be in English. The majority of the patients at the research site communicate in English. There was a concern that the use of an interpreter for non-English speakers during the data collection may disrupt the flow of conversation. Furthermore, as South Africa presents with 11 official national

languages plus countless foreign languages (Orman, 2008), multiple interpreters may have been required. When using an interpreter for research purposes specific skills and training is required (Tribe & Sanders, 2014), and it may not have been possible to acquire the appropriate interpreter for various languages.

Participants were recruited through the use of information sheets (Appendix A) which were provided via email and/or in person at the time of the patient's consultation. These information sheets contained information which allowed potential participants to be informed of the various aspects of the study, such as the nature and purpose thereof, the participants' obligations and responsibilities, the right to refuse or withdraw from the study at any point without any negative consequences, and, finally, the anonymity and confidentiality considerations of the study. Willing participants were then requested to sign an informed consent sheet which acknowledged that they were informed of the above, and that permission was provided to the researcher to audio and/or video record the interviews and/or focus groups respectively.

The response rate was calculated as 26.2%. The response rate refers to the percentage of individuals in the sample who participate in the research. According to Lodico, Spaulding and Voegtle (2010), response rates of 30% to 50% are considered to be typical, even after numerous reminders, and vary based on various factors, such as the purpose of the study and the relationship between the participants and the researcher. In the case of this research study, the researcher did not have a direct relationship with any of the participants, which may have contributed to the low response rate. However, upon analysis of the data, it was deemed that a larger sample size may not have been necessary as, based on the qualitative nature of the study, it may have resulted in redundancy (Bloom & Trice, 2011). Additionally, as

emphasized by Sim and Wright (2000), it was important to obtain data that revealed "depth rather than breadth" (p. 50), as this would provide greater insight into the investigated topic. The final sample size was considered to be acceptable as it ensured that responses were reliable and representative of particular trends and patterns. The following table (Table 3.1.) provides a detailed illustration of the participant demographics:

Table 3.1.

Participant Demographic Information (n=11)

Participant Number	Participant's Age (years)	Participant's Gender	Relationship to Patient	Patient's Gender	Patient's Diagnosis
1	64	Male	Husband	Female	Ménière's disease
2	57	Female	Life partner	Male	Vestibular neuritis
3	37	Female	Wife	Male	Acoustic neuroma
4	53	Female	Wife	Male	Vestibular neuritis
5	76	Female	Wife	Male	Ménière's disease
6	49	Male	Husband	Female	Ménière's disease
7	72	Male	Husband	Female	Mal de Débarquement
8	58	Male	Husband	Female	Vestibular migraine
9	62	Female	Wife	Male	Ménière's disease
10	71	Male	Husband	Female	Ménière's disease
11	46	Female	Life partner	Male	Acoustic neuroma

As evident in the above table, the genders were similarly-matched with five of the participants being male, and six of whom were female (n=11). The mean age of participants was 58.7 years, with a range of 37 to 76 years. Nine out of 11 participants were married to their partners, with the remaining two being considered as partners. Of the 11 participants, five of the patients presented with a confirmed diagnosis of Ménière's disease, two of presented with vestibular neuritis, two with vestibular migraine, two with acoustic neuromas, and finally one with Mal de Débarquement (MdDS). In order to orientate the reader to the various pathologies described by the participants, the following table (Table 3.2.) provides a summary of the relevant descriptions thereof.

Table 3.2.

Descriptions of the Relevant Vestibular Disorders

Disorder	Description
Ménière's disease	Ménière's disease is a chronic, untreatable vestibular disorder. It occurs in unpredictable attacks, most likely due to increased pressure of endolymph in the inner ear and/or the presence of potassium in the inner ear. Currently there is no known cause, although there are many theories. Ménière's disease is characterised by a progression of symptoms, including fluctuating hearing loss, tinnitus, aural fullness, hyperacusis, spontaneous vertigo, nausea and vomiting. The average age of onset is 40 to 60 years (Haybach, 2013).
Vestibular neuritis	Vestibular neuritis is a disorder of the vestibular nerve, usually as a result of a viral infection. Symptoms generally include an abrupt onset of severe dizziness, with a gradual recovery

	lasting several weeks. No changes in hearing are reported; however, a sense of disorientation, haziness and fatigue may persist (Schubert, 2013).
Vestibular migraine	According to Kramer and Buskirk (2014), approximately 40% of migraine sufferers present with some form of vestibular dysfunction. This disorder is characterised by unilateral onset of severe, throbbing headaches, together with photophobia, phonophobia, nausea, vomiting and vertigo. The trigger for migraines varies between individuals, which may result in it being difficult to treat (Kramer & Buskirk, 2014)
Acoustic neuroma	An acoustic neuroma is a benign, slow-growing tumour that develops on the auditory and vestibular nerves of the inner ear. The tumour compresses the nerves usually resulting in a unilateral hearing loss, tinnitus and dizziness. It may also interfere with the trigeminal nerve, resulting in facial paralysis or paresis, and may be life-threatening if it causes pressure on the brainstem and cerebellum. The age of onset is generally between 30-60 years (VEDA, 2008).
MdDS	MdDS is a movement illusion, which generally occurs as an after-effect of travelling on water. Although the sensation generally disappears within 24 hours of cessation of the precipitating event, for some it may be persistent. The most common explanation is that the brain is unable to re-adapt once the movement has stopped. This results in symptoms of

	disequilibrium and occasionally vertigo (Haybach & Kinne, 2014).

Abbreviation: MdDS – Mal de Débarquement Syndrome

3.5. Data Collection

3.5.1. Data collection methods

This study was conducted through use of two sequential data collection methods, namely individual semi-structured face-to-face interviews and small focus groups, each of which will be discussed in-depth. According to Morgan (1997), there are many benefits of using a combined approach of individual interviews and focus groups. Generally, the individual interviews provide data that is rich in depth, whereas groups yield a wide range of responses. Through incorporating both methods in a qualitative study, a plethora of information may be collected, analysed and interpreted by the researcher.

3.5.1.1. Phase one: the individual interviews

The initial phase of the data collection involved semi-structured individual interviews. For the purpose of this research, it was deemed appropriate to conduct the individual interviews prior to the focus groups, as this provided the researcher with background considerations for each participant. This was beneficial as it allowed the researcher to facilitate the interaction in focus groups, as will be discussed in the following section. In addition, it was advantageous to conduct the focus groups after the individual discussions, as it prevented the participants' responses from being influenced by other participants' experiences.

As will be comprehensively discussed later in this chapter (see 'Ethical Considerations'), informed consent was obtained prior to each phase of the data collection process. Thereafter, the researcher made contact with the relevant participant, either telephonically or via email, and a mutually agreeable time, date and place was arranged for the interview.

3.5.1.2. Phase two: the focus groups

The second method included the use of focus groups. Focus groups are considered to be a useful means of data collection as they allow for in-depth analyses of social phenomena (Hennink, 2014). Additionally, focus groups allow the researcher to validate and further explore topics from the initial interviews which require clarification and expansion (Parahoo, 2014). The participants from the interview stages were invited to partake in a small focus group via information sheets and consent forms (see 'Ethical Considerations'). Although focus groups may be critiqued due to potentially skewed data (for example, due to personality traits, certain participants may feel discouraged from sharing their thoughts), the researcher attempted to control this by moderating the discussion and allowing for fair turn-taking between participants (Hollander, 2004; Krueger & Casey, 2009). In addition, the focus groups included a small number of participants. This was deemed beneficial as it allowed for a more personal, informal environment – this allowed the participants to express themselves more freely with detailed accounts. In addition, smaller groups were considered to be more appropriate due to the sensitivity of the topic (Litosselliti, 2003).

For the purpose of this study, it was not compulsory for all participants to contribute towards the focus groups. However, it was deemed necessary by the researcher to have at least two groups as this would enhance the reliability of the results. The participants for the focus groups were selected based on availability for specified time slots. Discussions were

moderated through the use of a predetermined guide based on the results from the individual interviews. In doing so, this ensured that all topics and sub-topics were covered, and that there was consistency amongst the two focus groups (Hennink, 2014).

The focus groups consisted of the following participants:

- Focus group 1 (n=3): participants 2, 5 and 8
- Focus group 2 (n=2): participants 4 and 9

The seating arrangements for each focus group are illustrated in the following figures (Figure 3.1. and Figure 3.2.):

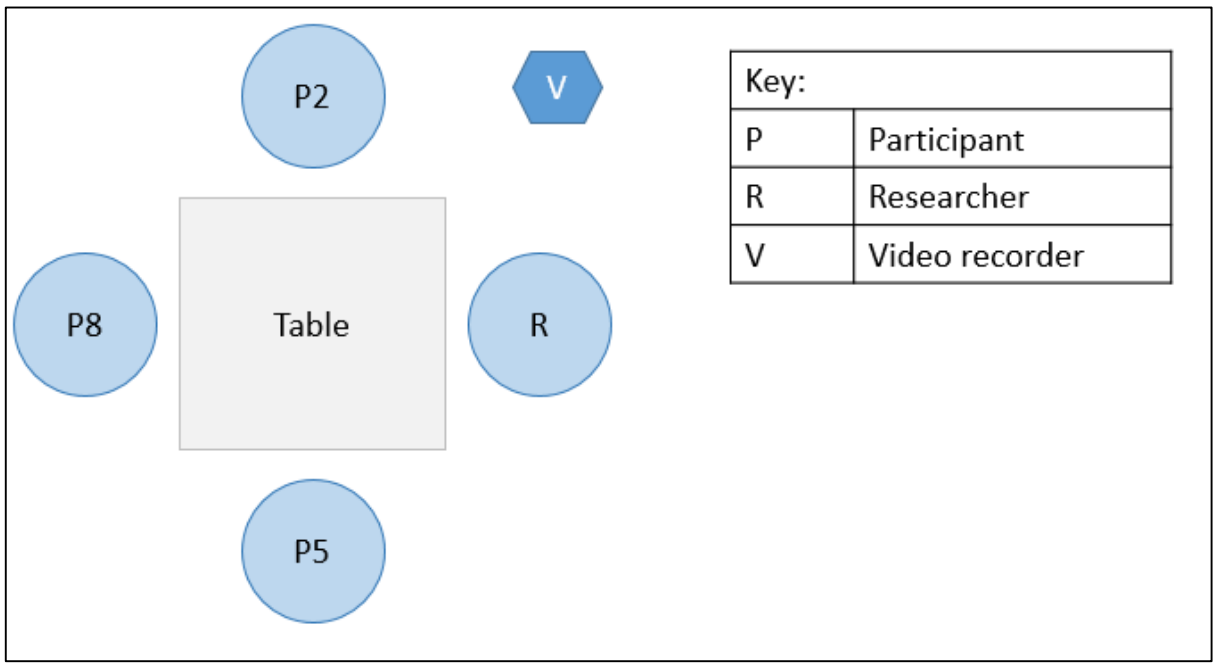


Figure 3.1. Seating arrangement for focus group 1 (n=3).

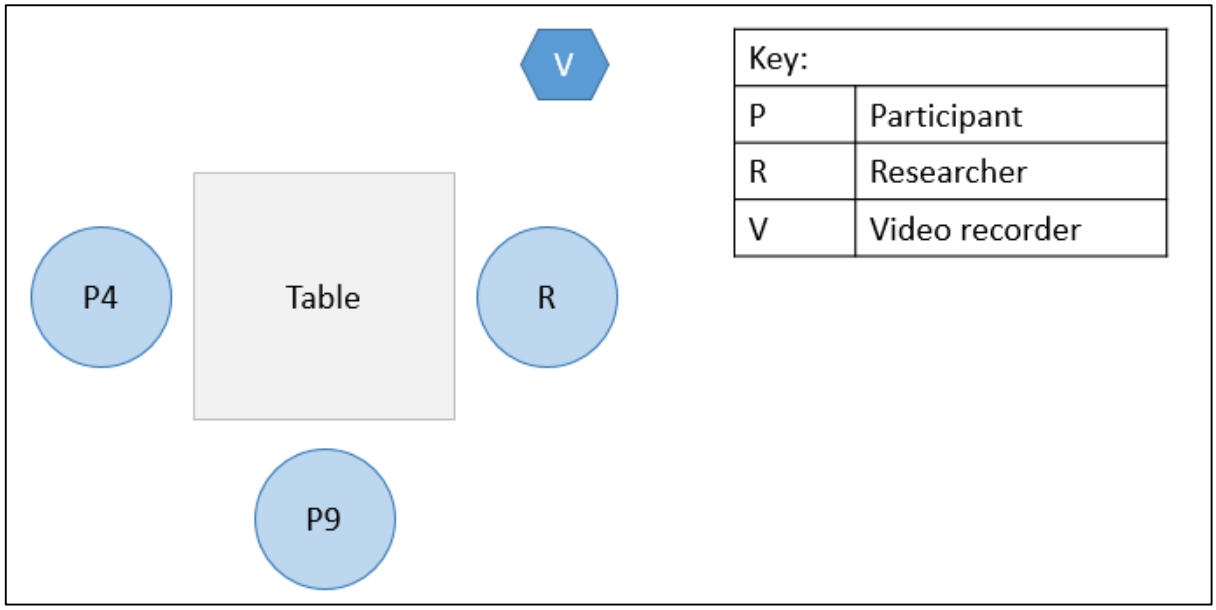


Figure 3.2. Seating arrangement for focus group 2 (n=2).

3.5.2. Research instruments

3.5.2.1. The individual interview guide

An interview guide (Appendix B) was utilised during the interviews in order to ensure a degree of consistency. This interview guide was developed in a semi-structured format which allowed for a natural flow of conversation between the researcher and the participant, thereby providing the participant latitude to freely express his/her thoughts (Hesse-Biber & Leavy, 2011). This was seen to be beneficial for the purpose of this study as it encouraged the participants to express their thoughts more freely and provide more detail on the topic. By having a pre-determined guide, it also allowed the researcher to direct the discussion towards the point of interest.

In order to develop a reliable, somewhat standardised interview guide, it was necessary to analyse previous research and available tools. For example, the study conducted

by Schulz et al. (1990) illustrated the effects of vestibular disorders on the SO and were described in terms of emotional, financial, physical and familial consequences. This provided a basis of the categories on which the guide was structured. The results from Stephens et al.'s (2012) study also proved pertinent in the formulation of the interview guide as it provided a plethora of sentiments expressed by SO of patients with Ménière's disease, as discussed in the literature review. As literature in the area of third-party vestibular disability appears to be scarce, findings from research in third-party hearing disability by Scarinci et al. (2008) were also extrapolated. The development of the interview guide was also grounded on the analysis of the available vestibular quality of life scales that were presented in the previous chapter.

3.5.2.2. The focus group guide

In order to allow for a natural flow of conversation there was no formal structure to the focus group. Rather, the researcher acted as facilitator and observer during the session in order to document the discussion held between participants and initiate or maintain topics where necessary. The topics presented during the focus groups were based on the responses that were previously recorded in the individual interview phase of the study.

3.5.3. Data recording

For both methods of data collection data were recorded and transcribed, as indicated by the following table (Table 3.3.).

Table 3.3.

Recording Type According to Method of Data Collection

Method	Recording
Face-to-face interviews	Audio recording was used in order to accurately record and describe the discussion.
Focus groups	Video recording was used in order to accurately record and transcribe the discussion. This recording method was beneficial for transcribing purposes in order to clearly identify the speaker during each interaction. In addition, the video recording provided additional information in terms of body language, facial expressions, participants' actions and group interactions (Hennink, 2007).

3.6. Data Analysis

3.6.1. Anonymisation of participants

One of the ethical aspects of this study included a confirmation to the participants that their identities would remain anonymous throughout the report writing (as further explained under 'Ethical Considerations'). As illustrated in the 'Participants' Demographics' section, each participant was allocated a unique number (1 – 11) which assisted in both the analysis and presentation of the collected data.

3.6.2. Preparation for analysis

Prior to the analysis of the data the recordings from the individual interviews as well as focus groups required transcription. This was initially done by the researcher and the transcriptions were typed on the researcher's personal laptop on Microsoft Word. Each document included the unique participant number as the title and were saved as such. Pauses and intonation were not included in the transcription process as the data would undergo thematic analysis (Gale, Heath, Cameron, Rashid & Redwood, 2013; Hammersley, 2010). A coding system was developed to identify the speakers during the interview (i.e. the letter 'R' preceded the researcher's responses, whereas the letter 'P' followed by the relevant number preceded the participant's responses, such as P1 for Participant 1). In addition, each line of the transcription was numbered for ease of reference.

Throughout the process of data analysis, there was a crucial focus on quality checks in order to ensure that the results of the study were trustworthy, reliable and valid (King & Horrocks, 2010). In accordance with this element, once the transcriptions had been prepared by the researcher, a peer was recruited to review the transcripts in order to corroborate the data. The peer did not have any direct relationship with the research site or the participants of the study and was not granted access to the participants' personal details. The peer was provided with a copy of the recordings and an electronic copy of the typed transcriptions, and was requested to provide edits (through using the track changes feature in Microsoft Word) of any variations found. Once the peer had completed this, the researcher reviewed the changes and it was noted that researcher had omitted five function words (such as 'of' or 'in') during the initial transcriptions. No further differences in the transcriptions were identified.

3.6.3. Thematic analysis

Data were analysed through the use of thematic analysis. Thematic analysis was considered to be a useful analysis method for this study as it is appropriate for large data sets, allowing for the analysis of the topic as a whole (Guest et al., 2012). This approach allowed the researcher to draw inferences from the data, through analysis the data in terms of its context (Hennink, 2014; Winston, 2012). This section will provide a detailed account of the data analysis process.

3.6.3.1. Familiarisation with the data

The initial stage of data analysis process involved a preparatory phase in order to become familiar with the entire data set, as suggested by Spencer, Ritchie, O'Connor, Morrell and Ormston (2013). This is important foundation to the interpretation of the data (Ritchie, Spencer & O'Connor, 2003). As the researcher was present and conducted all of the individual as well as group interviews, there was already a degree familiarisation with the data. However, further preparation involved reading all of the transcripts and any field notes and comments which had been included post-interview.

3.6.3.2. Constructing an initial thematic framework

A thematic framework was then developed through identifying recurring themes in the data sets. This was achieved through systematically detecting patterns which appropriately related to the topic under investigation. In doing so, codes were provided to each passage which was considered to be relevant and/or important (Gale et al., 2013).

3.6.3.3. Indexing and sorting the data

Once the initial themes were identified and accordingly labelled, a numbered index was developed which included a list of the relevant themes. This index was constantly revised throughout the research process in order to account for possible omissions during the initial coding phase (Gale et al., 2013). In order to relate the index to the relevant phrases, the index number was written next to the corresponding item in the transcriptions (Gale et al., 2013).

3.6.3.4. Reviewing the data extracts

This final step is included in the analysis of the data in an attempt to refine the thematic framework. Various processes were included in this step in order to ensure that the data was wholly reviewed and the necessary themes were identified (Spencer et al., 2013). During this stage, themes that may have been overlooked during the initial indexing were detected and included in the framework. In addition, the existing themes were revised to determine if any themes may require segmenting or merging.

3.6.4. Presentation of the data

As this research employed a qualitative approach, specific attention was given to the implicit and explicit meaning of the participants' responses, rather than a tally of responses (Ritchie et al., 2003). Therefore, the results of the study have been presented in themes with supporting excerpts from the relevant interviews. The quotations in the results section have been italicised in order to distinguish it from the researcher's text. In addition, the relevant line numbers in accordance with the transcriptions have been provided in parentheses for

reference purposes. In the participants' interviews, certain Africanisms were used, such as "ja" or "lekker". Although there are literal translations for these words, the researcher decided to include the words verbatim with translations provided in parenthesis, as it augments the context of this research study.

3.7. Ethical Considerations

In conducting this research, the researcher adhered to the ethical considerations outlines in the Declaration of Helsinki (World Medical Association, 2013). These principles are necessary for all research involving human subjects. In addition, ethical clearance was obtained from the University of the Witwatersrand Human Research Ethics Committee (HREC) – Medical prior to the commencement of the data collection (Protocol number: M150644) (Appendix C).

Throughout the study, the researcher ensured that the principles of maleficence, autonomy, justice, truth-telling and promise-keeping were adhered to (South African Speech, Language, Hearing Association, 2010). A letter of permission from the research site was obtained, and is included in the appendices (Appendix D). In addition, informed consent was obtained from each participant, thereby allowing the participants to be independent in their decision to participate in the research (Johnson & Christensen, 2012). The information sheets were distributed to each potential participant containing the following information:

- Nature and purpose of the study
- Participants' obligations and responsibilities
- Right to refuse or withdraw from the study at any point
- Anonymity and confidentiality aspects of the study

Willing participants were required to sign the consent forms which were attached to the information sheets. The procedure for obtaining consent was as follows:

- Information sheets together with the consent forms were distributed to each potential participant. For patients who were new to the practice (research site), these were distributed via email. This was deemed to be the most convenient method as all patients at the particular practice were required to complete e-mailed forms prior to the initial consultation. For those who did not have e-mail addresses, did not have access to printing facilities or where existing patients at the practice, printed copies were provided to the SOs at the consultations.
- Due to the varying methods of data collection, the following separate consent forms were necessary (see Appendix A):
    - Face-to-face interview consent form
    - Focus group consent form
    - Audio recording consent form
    - Video recording consent form
- Willing participants were requested to return the completed consent forms via e-mail or hand-delivery to the practice.

Although anonymity and confidentiality of participants could not be ensured due to the need for consent forms as well as the participation in the focus groups, the researcher ensured anonymity and confidentiality in the report writing. No identifying information has been included in the dissertation or appendices thereof, and each participant has been referred to through allocated numbers. Only the researcher has access to the identifying information of the participants.

Additionally, as the topic under investigation may be sensitive or emotional for participants, it was necessary to consider the need for appropriate counselling services. Firstly, this is important as, in order to account for reliability and validity during the study, the individuals presenting with the vestibular disorders have been excluded from the data collection process. The topic itself may have also resulted in emotional reactions by the participants. In addition to overcome these factors, research supervisors and lecturers from both the Speech Therapy and Audiology as well as Psychology departments at the University of the Witwatersrand were consulted, whereby it was advised that participants be made aware of the nature of the study in order to provide informed consent, as well as to provide relevant contact details for psychologists, counsellors and/or social workers if necessary. As previously discussed, informed consent has been obtained from each participant prior to the commencement of the study. In addition, written details of an appropriate referral were provided to each participant (with permission from the psychologist).

Following the completion of the study, debriefing has been provided to the participants in the form of e-mail and/or printed summaries.

3.8. Trustworthiness of the Findings

Qualitative research relies heavily on the skill, competence and rigour of the researcher in terms of both collecting and analysing the data. Therefore, potential bias may occur as well as possible misinterpretation (Patton, 2015). A necessary factor in the research process was to ensure that the data collection and analysis were conducted in such a manner that the results of the study were seen to be trustworthy, reliable and valid. Within qualitative research studies, the literature is inconsistent in advocating the use of pilot studies (Offredy & Vickers, 2010). As the aim of this research study was to have a sample size of 10 participants,

the inclusion of a pilot study was not considered to be necessary. However, in order to assess whether any changes were required, a pilot study was included for the face-to-face interviews only, as this was the most structured aspect of the study. Pilot studies are beneficial as they allow the researcher to determine what, if any, amendments need to occur in order for the research to be reliable and valid (Gitlin & Lyons, 2008). Although typically the data from pilot study participants are not included in the final study, Offredy and Vickers (2010) explain that it may be acceptable to include the pilot study participants, should there be no (or very minimal) changes to the final data collection process.

The pilot study participant was randomly selected from the initial three participants who expressed interest in the research. The pilot study participant was provided with the appropriate information sheet and consent forms (Appendix E). Thereafter, the researcher met with the participant at a convenient time and location in order to conduct the face-to-face interview. Upon completion of the interview, the researcher discussed issues related to the overall interview. Furthermore, it was requested that the participant e-mail any additional comments to the researcher that he/she may have deemed necessary. Overall, the pilot study participant reported no changes were necessary and commented that the questions posed as well as the manner in which they were presented were appropriate.

As a result of the feedback provided by the pilot study participant, the researcher included the data collected during the face-to-face interview.

In order to enhance the validity of the research study, triangulation of the data was ensured through the inclusion of both the individual interview as well as the focus groups in the data collection process, thereby overseeing all aspects of the research concepts. Triangulation is a useful method of maximising the validity as it makes use of a variety of methods to draw conclusions, thereby improving the confidence in such conclusions (Hall, 2008).

Furthermore, Lincoln and Guba's (1985) framework for enhancing the trustworthiness of the study was employed. This includes the concepts of credibility, dependability, confirmability and transferability. These concepts have been applied throughout the study in order to ensure that the data collected and analysed in the research is valid and reliable, thereby strengthening the results of the study so that it may potentially be applied for theoretical, practical and policy-making purposes.

Credibility refers to the internal validity of the research, and suggests that the reported data is truthful and accurately represents the participant's perspectives. In order to account for this concept, it was important to consider the plausibility of the findings and review whether the results were truly representative of the partners' experiences. Therefore, triangulation and debriefing have been utilised by the researcher (Pitney & Parker, 2009). As mentioned previously, the researcher specifically made use of data triangulation, whereby different methods (i.e. individual interviews as well as focus groups) were included in the data collection process. The second method of assessing the credibility involved the reviewing of the data by a peer of the researcher (Pitney & Parker, 2009). To accomplish this research tactic, the researcher adhered to the steps set out by Pitney and Parker (2009). The researcher informed the peer of the background to the study and ensured that the peer was familiar with the aims of the study, as well as with the methods of data collection and analysis. Thereafter, the reviewer audited the data by analysing whether any bias in data interpretation was evident.

Dependability refers to the reliability of the data over time (Pitney & Parker, 2009). This can be indirectly assessed through relating the data and the interpretations thereof to previous studies, as described in both the 'Literature Review' and 'Discussion' sections of this dissertation. In doing so, it is possible to deduce that although the data from this

particular study is novel, it correlates with findings from previous researchers in similar topics.

Confirmability refers to the congruency between the data and the interpretations thereof (Pitney & Parker, 2009).

Finally, transferability refers to the external validity of the research, i.e. the generalisability of the data to other settings (Lichtman, 2013). Although this research was conducted at a single research site, the disorders with which the patients present are not unique to this setting. As reported in the literature review, dizziness and vertigo are two of the most common symptoms for which medical attention is sought amongst working-age adults, with the prevalence ranging from 20-35% (Davis & Moorjani, 2003; Kroenke & Price, 1993; Neuhauser et al., 2005; Yardley et al., 1998). These statistics are correlated from studies conducted worldwide. In addition, international literature indicates that the results can be transferred across multiple settings, with studies from Schulz et al. (1990) as well as Piker et al. (2012) indicating similar overarching themes. However, in order to confirm this, it is suggested that this study be repeated in various other settings (both private and public), as will be further discussed under 'Implications and Recommendations'.

3.9. Chapter Summary

This chapter has provided an outline of the various phases involved in undertaking this study, which required multiple different methods of data collection within a qualitative framework to give deeper insight into the SOs' experiences of vestibular disorder. The methodology has been presented in relation to published research literature which provides justification for the methods, processes and techniques involved in each stage. It has further taken into account the ethical elements which were considered in the formulation of the

research topic as well as in the approaches which were assumed to collect and analyse the data.

CHAPTER 4: RESULTS

4.1. Introduction to Chapter

The application of thematic analysis to the data analysis, eight overarching themes related to the experiences of the partners were identified in the study, namely social, financial, hunting for a diagnosis, emotional, family dynamics and household chores, support systems, comparison-oriented coping mechanisms, and referral for psychology and/or counselling services. In this section, these themes will be explored further and supported through the use of quotations from the 11 face-to-face interviews as well as the from the two focus groups.

4.2. Theme 1: Social Implications of Vestibular Disorders on Significant Others (SOs)

Within the social theme, participants described three main areas in which changes to their lifestyle had been identified. These areas included (a) eating out, (b) hobbies and (c) social isolation.

4.2.1. Eating out

Participants reported that eating out at restaurants can be particularly challenging, especially for those partners who have to avoid certain foods and triggers. Participant 1, in his description, exemplified this challenge when he said *"... eating out is no longer – it's more of a gamble than a pleasure which is not nice"* (Lines 20 – 21). He further explained that in order to control the dizziness, he felt that certain triggers need to be avoided – *"but it has now been controlled reasonably well, using just diuretics, low salt diet and no caffeine, no alcohol, no tobacco. And there are the migraine triggers as well which we have to avoid.*

Now the effect of this is that it's not easy to eat out" (Lines 14 – 17*).* Participant 8 corroborated this by stating that her SO *"was too nervous to go out and eat in case it something would cause the migraines"* (Lines 754 – 755). Patient 11 also reported that her partner *"doesn't like to go out to restaurants so much. So there have been quite a few dinners and things that we've had to miss out on. He'll go if it's like a big one – like a birthday or something"* (Lines 1034 – 1037).

Participant 10 reported that going out to restaurants was not the only environment which presented as a challenge. Although they *"basically had to stop [eating out] at the moment"* (Line 664), eating at family and friends can also be a stressful event. This idea was presented when he stated, *"but I think eating out has definitely been a big one [adjustment]. We used to go out fairly often during the week – and not just to restaurants – to friends and family too. It's actually easier to eat at restaurants because you can be a bit fussy and specific about how you want something made. When you go to someone's house, it feels quite awkward having to ask them what ingredients are in the food. And then when [wife's name] can't eat something, everyone starts feeling… embarrassed I guess is the word. So it can be very stressful"* (Lines 917 – 923).

Participant 10 also explained how his eating habits have had to change as a result of the food restrictions - *"we've had to cut out a lot of salt from our cooking. When we go out to eat we also have to be very careful and be sure to emphasise to the waiter or waitress not to add any salt to either meal. In the beginning, we used to say to leave the salt out for only her meal but so often they would get it wrong so now I don't eat salt at all either"* (Lines 912 – 915). Participant 6 further alluded to changes in his personal dietary habits as a result of his wife's Ménière's disease when he said, *"it definitely has had quite a toll. I think because we have to be so mindful of what we eat…"* (Lines 564 – 565).

4.2.2. Hobbies

Another social activity that participants reported to be affected by their SOs' vestibular disorder was their hobbies. According to Participant 1, *"we used to belong to a gourmet cookery club and we would go out and have good food and fine wines. We can't do that anymore because she can't drink and the limitations with food is just far too much [sic]… We can't do it, so it's just not part of our lives anymore"* (Lines 85 – 87). Participant 8 also explained that they cannot engage in hobbies that they once enjoyed together as a result of the vestibular disorder. This was described when she said, *"um, concerts, definitely. We both enjoy going to see musicians, especially when the big ones come out like U2. We were actually booked to go see Seal in Cape Town in June, but we're probably not going to be able to go"* (Lines 760 – 762). Participant 11 also explained how she and her partner previously enjoyed going to the shops together but this has since changed: "*I guess what I have noticed is we've actually spent a lot less time together recently because he isn't always so keen on going out. We usually do things like grocery shopping or buying things for the house or whatever together but I tend to do it a lot more on my own now… The dizziness comes more into play when we go to busy places like shopping centres. I think there is just so much going on and he already feels so unsteady that it just completely overwhelms him… Anything that gets too busy we have to avoid"* (Lines 1022 – 1025 and Lines 1044 – 1049).

Participant 4 explained that she had noticed a decrease in her personal hobbies when she said, *"I haven't really been to my art classes in the evenings this week"* and that *"usually I read before bed but this week I've been too exhausted"* (Lines 336 – 337).

According to Participant 7, he felt guilty when engaging in hobbies such as golf, as this is something he and his wife would previously do together. This was exemplified when he said, *"oh, golf… I guess to a degree it has [affected me], yes. I still go every now and then*

but I do feel a tad guilty. Even though she says I must go" (Lines 669 – 675). These feelings of guilt were reiterated by other participants in different circumstances, which will be described further under the 'Emotions' theme.

Participant 9 further acknowledged changes to her hobbies and, in fact, noted that some changes had been positive. During her discussion, she stated *"would you believe that I've actually taken up golf! [Husband's name] loves it, but he got too scared to go to the driving range alone. So I said once that I would go with and turns out it was actually quite enjoyable! Um, but there are things that I don't really like doing but have to anyway. Like, when he goes to buy new speakers and DVDs. He loves music. I enjoy it too, but it doesn't really interest me as much as it does him. It's not major changes, but you know, it's different"* (Lines 842 – 847).

4.2.3. Social isolation

The final sub-theme which emerged was that of social isolation. This was reiterated numerous times throughout the discussions with the participants, as illustrated by the following table (Table 4.1.).

Table 4.1.

Feelings of Social Isolation as Experienced by SOs

Participant No.	Excerpt from participants' interviews
2	*"We can't go out at all… we can't go for dinners or shopping or anything like that."* (Lines 181 – 185) *"We tend to just stay at home and relax…"* (Lines 185 – 186)
3	*"… We have friends and family come to us."* (Lines 263 – 264) *"We used to go to our friends… but [husband's name] doesn't really like to at the moment because he just hasn't been himself."* (Lines 264 – 265)
4	*"Believe it or not, we used to be a very social family…"* (Line 305) *"…we don't socialise all that much anymore."* (Line 356)
5	*"I don't see friends that often."* (Line 434)
6	*"Yes, I would say that has definitely been the biggest change! We're still relatively young, so we enjoy going out to eat or to the movies, or just, you know, walking around the shops on the weekend. We've cut down on that a lot."* (Lines 528 – 530) *"Well, our friends tend to come to us more than we go to them… we definitely see people more in than out these days."* (Lines 578 – 580)

8	*"We've definitely had to change things socially, especially in the beginning when we still trying to identify the triggers. He was too nervous to go out and eat in case it something would cause the migraines. But even now, we've had to miss out on some things or change plans with friends because he was having a bad day. Even when he has good days now, it's not the same. He still doesn't like bright lights and loud noises."* (Lines 753 – 757) *"Well, really anywhere that there may be flashing lights. We had to miss a play at Montecasino last month because he wasn't feeling up to. You know, it's been a change. You can never make proper plans in case they have to change. In the beginning I'm sure our friends thought that we were being evasive and trying to avoid seeing them."* (Lines 765 – 768)

4.3. Theme 2: The Financial Implications of Vestibular Disorders on SOs

4.3.1. An increase in medical expenses strain the monthly budgets

Participants described the significant financial effects of having a partner with a vestibular disorder. According to many of the participants, medical expenses incurred appear to be a very costly factor. This was exemplified by Participant 2 who reported *"I think financially it definitely had a huge toll on us! Both of us work, because we have to. And even then we just make ends meet. He actually ended up having to borrow money from his sister, which isn't so 'lekker' [translation: nice]. But we were so desperate for him to get better!"* (Lines 166 – 169). Participant 4 confirmed the financial impact on their budget with the statement, *"financially, yes. It has put a bit more pressure on us"* (Lines 314 – 315). This was also reported by Participant 11 who stated, *"I think that's also another reason that we don't go out so much"* (Line 1051).

Participant 1 was straightforward in his response to the financial implications, when he said, *"it's cost a lot of money"* (Line 48), and *"… it's not cheap"* (Lines 49 – 50).

Participants further explained how the assessment can be expensive. Participant 4 stated that they *"booked an appointment [at the audiologist], which cost a small fortune!"* (Lines 322 – 323). This was further asserted by Participants 6 and 10 respectively who said, *"Well, it wasn't cheap [going for all the assessments]! I would say between all the assessments we probably spent close onto R8000.00"* (Lines 501 – 502), and *"… that was quite an expensive time [going to see all the doctors for the assessments]"* (Line 962).

The numerous assessments and various healthcare referrals, which participants reported to have resulted in an unnecessary spend of medical and personal savings, have been highlighted in Theme 3 below.

Participant 5 provided a clear example of how the increase in medical expenses personally affected her wellbeing when she reported that although she would like to seek psychological services for herself, she is unable to because of the costs that they have already incurred related to her husband's diagnosis. This was depicted in her statement *"'Ja' [translation: yes], but it's more money then [to see a psychologist]. You know, we're both old now. There isn't much in our savings after these last two years... Quite honestly, I can't afford to pay someone to listen to me talk about my problems"* (Lines 429 – 432).

4.3.2. Comorbid hearing losses adds another dynamic to the financial implications

For those individuals who present with a comorbid hearing loss, the cost of hearing aids was a further consideration for their budget. This was emphasised by Participant 1 who said, **"***It's expensive. It's R60 000 and it's a bit of a strain on the budget. It's certainly a significant portion"* (Lines 115 – 116). Participant 9 also stated, *"Well, we're both retired… So we've had to take a bit from our savings for the assessments and for the hearing aids… Hearing aids definitely don't come cheap!"* (Lines 853 – 856).

Participants 5 and 10 also indicated that the initial cost of the hearing aid is not the only expense involved, and that follow-up appointments are also required in order to ensure that the hearing aids are working optimally. This was highlighted in the following statements by Participant 5: *"That's another expense – hearing aids are not cheap and medical aid barely covers them! He is always moaning that they're not working, but then when we take them to the audiologist they are. So I don't know"* (Lines 455 – 457) and Participant 10: *"The most expensive part has been the hearing aids, especially because her hearing fluctuates so aside from the actual cost of purchasing the devices, there have also been all the*

follow-up appointments to try and get them fitted and working well for her" (Lines 962 – 965).

4.3.3. Poor reimbursement and support from medical aids

Those participants whose SOs have medical aid added that the available medical savings are not sufficient to cover the cost of the assessments, rehabilitation sessions and/or hearing aids. Participant 1 emphasised that *"medical aid doesn't pay for everything"* (Line 50), with Participant 4 explaining that they "*finish[ed] our medical savings quite early in the year. So we've had to pay for doctor's appointments and medication ourselves. So we aren't able to save as much at the end of the month"* (Lines 316 – 318). This was reiterated by Participant 5 who said; *"medical aid covers miniscule amounts, and most of the doctors that we see don't charge medical aid rates so there's always a shortfall"* (Lines 430 – 431). Participant 11 also shared her view on medical aids when she reported*, "Even though we're on medical aid, the funds get used up quite quickly so there's been a lot that we've had to pay for ourselves. And I think with the tumour, because it needs constant monitoring, it's been back and forth between the ENT and the audiologist with all the assessments and scans. So there's definitely been a huge increase in our medical expenses"* (Lines 1051 – 1055). Participant 7 referred to the issue with poor referral systems and described how it affected his medical savings – *"our medical savings were wiped out a lot quicker than normal, having to see so many specialists"* (Lines 683 – 684).

4.3.4. The vestibular disorder is not the only medical expense in the household

Participants 3 and 6 also indicated that their SO was not the only member of the household who required medical attention, and that having young children increases their medical expenditure too. Participant 3 stated *"our medical aid is completely depleted though! You can imagine, having three kids and now this… So there have been quite a few out-of-pocket expenses, especially in the beginning, when we were going from one doctor to the next, and having all these assessments done"* (Lines 255 – 258), whereas Participant 6 said, *"I support the household on my own – which is fine. But you know, medical aid runs out very quickly, even on one of the top plans! And having two young kids, who also get the flu and what-not, doesn't help either. We got through our self-payment gap a lot quicker than previous years!"* (Lines 514 – 517).

4.4. Theme 3: The Hunt for a Diagnosis

A third theme that was strongly identified by the participants in this study was the 'hunt for a diagnosis'. Participants expressed that their SOs underwent a variety of assessments and sought numerous healthcare professionals before receiving a diagnosis. Within their descriptions of this process, the participants reinforced elements of other domains in this chapter, such as the financial implications associated with the consultations as well as the emotional effect of not having received a formal or definitive diagnosis (i.e. anxiety-related symptoms). The following table (Table 4.2.) provides a depiction of these factors.

Table 4.2.

From Pillar to Post: Excerpts on the Referral Process

Participant No.	Participants' descriptions of the referral process
7	**"***So many of the doctors we saw came highly recommended but you go there and they actually don't know what's wrong. I mean, its blood tests, scans, MRIs… and they can't give you a straight answer. Then you go to the next one and it's the same story all over again… we finally got referred to a great ENT in Pretoria who recommended [audiologist's name]. Finally, it seems like we're on the right track."* (Lines 686 – 692)
8	*"We started off at the neurologist first and he did a full work-up with blood tests, MRIs and all that. Then when he found nothing, he sent us to the ENT because he thought maybe it was some sort of infection in the ear. The first ENT said he couldn't find anything but gave us some medication – think it was Stugeron. When that didn't help, we went back and he prescribed cortisone. By then I was a bit sceptical – surely you can't prescribe such hectic medication if you don't know the cause? So my youngest daughter actually went on to Google to see what possible causes could be, and she came across [practice name's website]. So that's how we landed up here."* (Lines 737 – 744)

10	*"At the time we went to a whole lot of doctors who couldn't diagnose it. It was only after about three or four weeks of this, that we were eventually referred to an ENT specialist who ran a whole lot of tests and said it seems like you have* Ménière's *disease."* (Lines 896 – 899)

4.5. Theme 4: Emotional Effects of Vestibular Disorders on SOs

From the interviews, each of the participants described various aspects related to the emotional aspects of having a partner with a vestibular disorder. During the interviews, participants were asked to indicate whether there were any ripple effects of the vestibular disorder which emotionally affecting them. The following table (Table 4.3.) provides excerpts which capture the essence of the emotional consequences of third-party disability:

Table 4.3.

The Emotional Consequences of Third-Party Disability

Participant No.	Excerpts from the data
2	*"It's awful."* (Line 143)
5	*"So all-in-all, it's been a 'helluva' last year or two."* (Lines 387 – 388) *"It's not easy, I can tell you that much."* (Line 390) *"They say G-d won't give you more than you can handle – He must think I'm very strong because I'm really being tested here!"* (Lines 437 – 439)

6 *"It's been a long road."* (Line 511)

4.5.1. Feelings of frustration emerge in relation to the SOs' vestibular disorders

Frustration appeared to be one of the key emotions expressed by six of the participants during the interviews. Some participants were vague in their descriptions and described the entire situation as being difficult. For example, Participant 10 said, *"I do get quite frustrated. Not at [wife's name] but just with the whole situation…"* (Lines 946 – 947). Participant 7 also highlighted this idea with the following sentence – *"I guess it has been a bit frustrating"* (Lines 629 – 630). This was also described by Participant 11 in her statement: *"I would say it has been quite frustrating"* (Line 1028). Participant 3 indirectly hinted towards the frustration during a particular conversation and described it as *"quite a trying time over the last few months"* (Line 218).

During the interview, Participant 4 explained that her husband's emotional state caused widespread frustration among family members, including those who were no longer residing with them: *"When someone in your household has a negative aura it affects everyone. Me, the children, even my son who has moved out of home gets frustrated when he calls because everyone here is in a bad mood"* (Lines 296 – 298).

Other participants were more specific with the frustration. The social aspect, in particular, appeared to strongly drive this emotion, with Participant 2 stating that *"the social aspect is quite frustrating"* (Line 189) and Participant 8 saying, *"I think the social aspect is where we both feel it [the frustration] the most"* (Line 773). Participant 1 further reported that the limitations resulted in frustrations – **"***it's the frustration of the limited lifestyle"* (Line 56).

As a result of the frustration, two of the participants also noted that they had begun arguing. This was stated by Participant 7 who said, "*We have been arguing a bit more than normal. I guess I've just been getting annoyed by the fact that she's constantly moaning about not feeling well. Like it's been months you know? I get it"* (Lines 637 – 639) as well as by Participant 8 in her interview, where she said, *"it's been a trying time I think, for both of us. There have been situations where I've wanted to do something, or go somewhere, and we haven't been able to… We've had a few arguments over the last few months about it. We never really used to argue about anything so it has been a change"* (Lines 779 – 781).

Participant 10 further expressed that *"there are so many 'unknowns' that come with it, and definitely a lot of frustration involved.* (Lines 984 – 985). This concept of the 'unknown' was also mentioned by Participant 6 who reported *"there's always that fear of the unknown"* (Lines 610 – 611). In Participant 6's discussion, however, he suggested that this fear was related to anxiety rather than frustration.

4.5.2. SOs experience a loss of independence

A recurring theme within this study was an apparent loss of independence experienced by the participants of this study as a results of their SOs' vestibular disorders. This was described by three of the participants at great length who provided the following reports, as illustrated by Table 4.4.

Table 4.4.

SOs Experience a Loss of Independence as a Result of their Partners' Vestibular Disorders

Participant No.	Excerpt from the data
3	*"Well it's definitely not easy… I think in the beginning it was a bit worse because we didn't know what was going on. And he was too scared to drive or go anywhere by himself. So it took up a lot of my time too. Not that I mind, you know. But with three young children it can be very difficult to juggle things around."* (Lines 231 – 235)
5	*"Well, because it comes in attacks he is very anxious. He won't drive the car anymore, and won't go out to the shops by himself. He actually won't go to the shops at all at the moment. Whether that's the depression or the anxiety around the attacks, I don't know."* (Lines 449 – 451) *"He was very independent! It's like he's a different man now."* (Line 473) *"[He relies on me for] Just everything. The driving, the shopping, taking him for appointments. He literally is too scared to do anything alone in case he either has a seizure or a dizzy attack."* (Lines 475 – 476)

9	*"I think the biggest change that we've experienced is going out just in general. [Husband's name] doesn't like to drive anymore in case he has an attack, so I have to go with him everywhere. And if I'm not available, our daughter comes to help. Also, he doesn't like being left alone. So even if I go for my nail appointment, he tends to come with! It's definitely made us inseparable [laughter]."* (Lines 830 – 834) *"I think in the beginning it was a bit of an adjustment. I was used to being relatively independent and just making my own plans. Now we have to coordinate plans a lot more, and I have to do things that I wouldn't normally do beforehand."* (Lines 837 – 840)

The above excerpts indicate that the participants' SOs have become increasingly reliant on them to manage everyday tasks. Driving appeared to be a recurring theme in all three participants' accounts. Two of the participants appeared to have accepted the changes and seem to be coping with the increased dependency, with Participant 9 being light-hearted about the situation in the excerpt *"it's definitely made us inseparable [laughter]"* (Line 834). However, it was mentioned that it can be a challenging situation having to *"juggle things around"* (Participant 3, Line 235). Participant 9 further elaborated that her husband is like *"a different man now"* (Line 473) which significantly reinforces the overarching theme, and the need for third-party counselling.

4.5.3. Psychological manifestations of the emotional consequences

The emotional effects of the vestibular disorders on SOs appeared to have a direct psychological impact on the SOs. In particular, participants in this study made reference to the development of symptoms of anxiety disorders, as well as feelings of guilt, desperation, and loneliness. Various participants also described interpersonal influences of the symptoms of mood, anxiety and other psychological disorders, as will be discussed further.

4.5.3.1. Symptoms of anxiety disorders

When analysing the data, the participants specifically described anxiety related to their partners' vestibular disorders. This was exemplified in four of the participants' responses. Participant 6 stated "*Of course [I feel anxious about my wife's dizziness]!"* (Line 533). "*Even though we try our best to change the foods and avoid triggers, there's always that fear of the unknown. Like, what if this take-out triggers an attack? Or what if she falls and hits her head and no one is there to help. It makes me anxious"* (Lines 609 – 612). Participant 8 further elaborated *"It's definitely unsettling to see him like this. And it does make me feel quite anxious"* (Lines 729 – 730) and *"It was quite frightening in the beginning. You know, the worst things come to mind, like, what if it's a brain tumour or something sinister like that?"* (Lines 733 – 734). Participant 9 referred to a *"fear of the unknown"* (Line 877) when she said, *"In the beginning I was very anxious because I didn't know what it was or what to expect"* (Lines 861 – 862). This was reiterated by Participant 10 who stated, *"When something is unfamiliar it's, um, it's very difficult to understand what is happening which can be very frightening"* (Lines 903 – 904).

These quotations provide direct examples of the anxiety experienced by the participants. In three of the cases, the participants suggested that they felt more anxious

initially, either before or soon after their partner was diagnosed with a vestibular disorder, as they did not understand the disorder, its symptoms and/or the implications thereof.

In relation to the anxiety, increased stress levels were also reported by four of the participants. Participant 5, in particular, elaborated on this when she said, *"I'm very stressed and on edge. So I've been a bit snappy with everyone. I'm not usually like that. I mean obviously everyone is now and then, but I've definitely been more so than usual. And I know I am. My kids keep telling me to relax and that I'm being mean to them or to [husband's name]. But I feel like I have the weight of the world on my shoulders. And it's just piling up more and more"* (Lines 406 – 410).This statement was supported by quotations from Participant 2 who stated *"it is emotionally strenuous"* (Line 200), Participant 9 who reinforced *"it was very stressful"* (Line 815), as well as Participant 10 who added *"it can be very stressful"* (Line 922).

4.5.3.2. Interpersonal influences of mood, anxiety and other psychological disorders

In the study, three of the participants reported that their emotions were directly influenced by the emotions experienced by their SOs. In their descriptions, the participants reported how their emotions were in synchrony with that of their partners. This was exemplified by Participant 4 who reported *"When someone in your household has a negative aura it affects everyone. Me, the children, even my son who has moved out of home gets frustrated when he calls because everyone here is in a bad mood"* (Lines 296 – 298). Participant 10 also shared this perspective when he said, *"I think what affected me emotionally was seeing [wife's name] so frustrated, and, somewhat depressed about this whole disease, especially in the first year or so when the attacks were more regular"* (Lines

928 – 930). Participant 11 also elaborated in her statement, *"he sits there all grumpy and depressed, which obviously puts me in a bad mood!"* (Line 1037).

4.5.3.3. SOs experience guilty consciences

Two of the participants in this study indicated that they experienced feelings of guilt in relation to their SOs vestibular disorders. These feelings were shared by Participants 6 and 7. This was demonstrated in Participant 6's interview when he said, *"Sometimes I feel like I need a break, which sounds terrible. I mean, imagine what she feels if I think I need a break!"* (Lines 566 – 567), and in Participant 7's description, when he said, *"I still go every now [to golf] and then but I do feel a tad guilty. Even though she says I must go"* (Lines 674 – 675).

4.5.3.4. Non-recurring themes related to the psychological impact of vestibular disorders

Within this study there were certain sentiments which were expressed by participants, which did not recur, but were deemed as noteworthy elements of this study. This included feelings of desperation, as explicitly stated by Participant 2 when she said, *"... we were actually both so desperate"* (Line 156), feelings of social isolation, as described by Participant 5's statement, *"Sometimes you really feel like you're the only one going through all this"* (Lines 437 – 438), as well as a sense of loneliness, as indicated by Participant 11 who stated, *"I think that I was just so used to doing things together that now it's different. It was nice to have that companionship when you go to the shops. So I guess you could say it's been a bit lonely recently"* (Lines 1030 – 1032).

4.5.4. Emotional burnout

Four of the participants in the study made reference to exhaustion during the discussions. The exhaustion appears to be primarily as a result of increased responsibilities which the participant has had to assume since the onset of the vestibular disorders. Although the majority of the patients refer to exhaustion in general terms in their discussions, the excerpts appear to allude to emotional exhaustion and, consequently, emotional burnout.

Emotional burnout was directly referred to in Participant 6's interview when he stated *"it's also been very draining. Sometimes I feel like I need a break…"* (Lines 566 – 567). Exhaustion was also highlighted in Participant 2's statement, where she said, *"It's exhausting. He's exhausted from being sick. I'm exhausted from having to do so much around the house. It's really… It's not fun, let's put it that way!"* (Lines 200 – 202). Participant 5 asserted this notion with her statement, *"it's very exhausting to have to do everything for both of us, plus our children and grandchildren also need me from time to time"* (Lines 476 – 478). Participant 5 went on further to explain how the exhaustion is affecting her in her daily life: *"I'm sure they've seen me fall asleep in the chair a few times from being so exhausted, but they probably assume it's because I'm an old woman!"* (Lines 415 – 417).

Participant 4 specifically described physical exhaustion in her interview, where reported that she has been *"exhausted"* (Line 337) as her partner was presenting with poor sleep quality as a result of the vestibular disorder, thereby affecting her sleep quality: *"He can't sleep, and he's constantly tossing and turning so that keeps me up as well. So I've been really struggling to keep my eyes open during the day"* (Lines 282 – 284). As a result she has had difficulty concentrating during the day, which was demonstrated when she said *"sure, I mean it's definitely going to be difficult [to concentrate] if you're tired. No one can really function well in that state"* (Lines 332 – 333). This has further affected her hobbies,

specifically reading before bedtime, as described previously: *"usually I read before bed but this week I've been too exhausted"* (Line 337).

4.5.5. Changes in SOs' personalities

Two of the participants in the study reported that they have noted a change in their personalities where they indicated that they were *"not myself"* (Participant 5, Line 426; Participant 10, Line 937). These perceived changes in personality were further explained by the Participant 5, who reported that it *"would just be nice if my family understood what was happening instead of them telling me I'm not myself"* (Lines 425 – 426), as well as by Participant 10 who suggested that he *"definitely didn't feel like myself"* (Lines 936 – 937). Upon further review of these participants' thoughts, it was noteworthy that neither of the two participants had sought any form of counselling services.

4.5.6. Effect of comorbidities

As this study explored the effects of vestibular disorders, hearing loss was a common comorbidity. Therefore, during the discussions, many of the patients made reference to their partners' hearing loss. Participant 10 reported the following: *"The worst part, I think for both of us, was when the hearing started to really get affected, and when it spread to the other ear that was very challenging too. [Wife's name] has always been quite healthy and young and vibrant, so I think when she started wearing the hearing aids it was a bit of a shock for both of us. It did make us feel our age!"* (Lines 930 – 934). Participant 1 also described the effects of his wife's hearing loss when he said, *"Well she has two hearing aids and a thing that links to her phone. So when her hearing aids are in, she's fine. When they're not, you have to shout. But she has had hearing problems for many years already… The problems come in*

when the hearing aids need to be repaired or service. But luckily enough we usually get a loan pair when that happens. If she's left without them she's virtually… She feels completed isolated from society" (Lines 108 – 120).

Participant 3 also reiterated the effects of hearing loss when she stated *"It's definitely been quite a trying time over the last few months – especially with the hearing loss. He's constantly asking me to repeat myself. And even when we go out, like to a restaurant – he may as well not even be there because he can't hear the conversations"* (Lines 218 – 221). She elaborated further in the statement *"[The dizziness hasn't affected me] as much as the hearing loss"* (Line 226). Participant 5 further reported that the comorbid hearing loss was affecting her. She stated *"… his hearing has been such a problem. I can't even communicate with him some days, because he just doesn't hear me"* (Lines 458 – 459).

According to Participant 11, *"the hearing loss has been the most difficult adjustment. He went from having completely normal hearing to suddenly this major hearing loss. So it's been such a struggle doing things that we would have in the past. Like, even going to a restaurant is very challenging"* (Lines 1006 – 1009).

Participant 6, on the other hand, had a different perspective and he reported *"I just feel like the hearing can be managed easier than the dizziness… [with the dizziness] there's always that fear of the unknown… It makes me anxious"* (Lines 609 – 612).

4.6. Theme 5: Family Dynamics and Household Chores

Within the domain of family dynamics, four of the participants reported changes to their lifestyles.

Participant 5, in particular, reported how she has her usual responsibilities of assisting her children and grandchildren as well as an additional responsibility of managing her

husband's business – *"I've had to take on a lot of the business admin myself, because it's really been taking a huge toll…"* (Lines 390 – 391). In the discussion, she described this to be a stressful situation with the statement, *"Well, I have 7 grandchildren who I would spend a lot of time with [sic]. I've now had to cut back on that to help out with the business. But sometimes my kids need me to help with fetching from school, or looking after them in the afternoons. So now that's affecting the business. It's really such a constant challenge trying to juggle everything. It's very stressful"* (Lines 400 – 404). Participant 5 further elaborated on this when she said, *"It's very exhausting to have to do everything for both of us, plus our children and grandchildren also need me from time to time"* (Lines 476 – 478), as well as *"I've had to take on a lot. I already mentioned the business, but I also have to run a household and do the groceries, cook, clean"* (Lines 452 – 453).

Participant 2 also discussed her struggles with having to absorb additional household responsibilities, when she said *"Ja [translate: yes], that can be quite a pain too. We don't have a maid. I usually do most of the stuff around the house anyway. Like cooking and cleaning and making the beds. But he does normally help with things. When he's having these attacks though? Uh-uh, he can't. He actually physically just can't. Either he's dizzy, or nauseas or just so tired that it's too much for him. I really don't like cleaning, and if we could afford someone to help around the house I would love it! So it's hard for those few weeks. And our house definitely doesn't stay as clean as I would like… But I try"* (Lines 192 – 198).

According to Participant 3, the increased responsibilities of having to assist her husband with driving *["… he was too scared to drive or go anywhere by himself. So it took up a lot of my time too"* (Lines 233 – 234)] resulted in having to rely on others to assist with her usual responsibilities, such as fetching the children from school, or making dinner. This was indicated when she said, *"We've even had people drop off groceries or make us a dinner when they know we've had to go to the appointments"* (Lines 245 – 246), as well as *"I think*

having to juggle my time around, and also rely a lot more on others to help fetch my kids from crèche [has been the most challenging aspect of the last few months]" (Lines 238 – 239).

Participant 4 also described that her responsibilities included her children and that, since the onset of the vestibular disorder, she has been experiencing exhaustion as a result of the increase in her daily errands. This was exemplified in her statement, *"Well two of my kids are still in high school so, as tired as I am, I still need to fetch them, take them to sports or extra lessons, help with homework. I still have my responsibilities so I just get on with it. I'm sure by the weekend I'll be finished though"* (Lines 291 – 293).

4.7. Theme 6: Support Systems

A common theme described by many of the participants in this study was importance of support systems. These support structures included community support, support from family and friends, support from each other, as well as support from the audiologist.

4.7.1. Support from the community

Two of the participants in the study referred to community support as being paramount to helping them mediate the various aspects of vestibular disorders. For example, Participant 3 reported difficulties in managing time and explained, *"Luckily our community is amazing. We can really rely on everyone at our [place of worship] to assist. Yes. [Husband's name] is usually there once or twice a day so everyone knows us and our family. It's been quite amazing to see how, in times of need, people are willing to help so much. We've even had people drop off groceries or make us a dinner when they know we've had to go to the appointments. Especially the ones in Pretoria – with the traffic, we get home quite late in the*

evenings and then to start preparing dinner is a bit of a 'schlep'… I can't thank them enough" (Lines 238 – 249).

Participant 6 also described how he relies on support from the school community to assist with lifts: *"So the kids are actually in a lift-scheme at the moment. Which has been a huge help… The kids have had to cut down a bit on their activities. If they have a friend who goes as well, like [daughter's name] has a friend at ballet, they will help with lifts"* (Lines 589 – 595).

4.7.2. Support from friends and family

One of the commonly recurring themes during the interviews was that of support from family and friends. This was exemplified by excerpts in the following table (Table 4.5.).

Table 4.5.

Support from Friends and Family

Participant No.	Excerpts from data collection
6	*"Well our friends tend to come to us more than we go to them… we definitely see people more in than out these days."* (Lines 578 – 580) *"No [we don't see them less]. Not really. Just instead of going out for dinner, they'll come to us for take-outs."* (Lines 582 – 583)
7	*"Luckily we have some really great friends though, so they're happy to come to us now instead of going out."* (Lines 664 – 665)
8	*"In the beginning I'm sure our friends thought that we were being evasive and trying to avoid seeing them. But I think because it's been*

	going on for so long now, they've become used to it and know that we'll join whenever we can." (Lines 767 – 770)
9	*"We're lucky to have such a strong marriage, and a close knit family and group of friends."* (Line 867 – 868)
10	*"Luckily over the years, our close friends and family have learned what is ok and what may be a trigger, but it took quite a long time for everyone to get on board."* (Lines 919 – 920)
	"Yes, well, we're lucky to have supportive friends, and a quite a close-knit family so we all help each other through the hard times. I think it was very difficult for (wife's name) to acknowledge that she had something wrong initially, so she tried to keep it away from everyone. But now everyone accepts it, and understands that there are limitations that come with it. Everyone has been really great." (Lines 987 – 991)
11	*"They've been very understanding of when we've had to cancel plans or change venues to accommodate for [husband's name]."* (Lines 1073 – 1074)

4.7.3. Support from each other

Four of the participants also explained that they support each other in their marriage or partnership. Participant 1 stated, *"We're very fortunate to have each other to lean on"* (Line 91), and Participant 9 reinforced this statement when she said, *"We're lucky to have such a strong marriage…"* (Lines 867 – 868). Participant 6 suggested that the presence of the vestibular disorder has added meaning to *"the saying 'through thick and thin'… Through sickness and health'"* (Lines 571 – 572). Participant 11 further illustrated the importance of

supporting each other with her beliefs, *"Well I think the fact that we've always had such a good relationship and that we've been together for 20 years helps. We understand each other, we've been through other hurdles together. So I feel like this is just another challenge that we need to get through"* (Lines 1067 – 1069).

4.7.4. Support from the audiologist

Participant 9 commented that support from the audiologist was paramount in helping her cope with the diagnosis and the associated changes: *"Oh, yes. She's great. I know that I can call her, or one of the other staff members at any time and they're always available to help. She also gave us so many resources on Ménière's which really helped us to understand it better. I think, right from the start, that's what helped tremendously. Otherwise, you get this fear of the unknown… Think of it like… cancer. G-d forbid. If you were diagnosed with it, or your husband, you would want to know everything – where is it, has it spread, what stage, what's the prognosis, what's the treatment. I think just knowing all that gives you peace of mind…"* (Lines 874 – 881).

4.8. Theme 7: Comparison-Oriented Coping Mechanisms

Two of the participants made use of comparisons during their interviews in order to explain their coping mechanism. This was exemplified by Participant 1 in his statement, *"The fact that there is a much worse case also in the family has made it far easier. So they're like 'Oh, well you have it as well'".* (Lines 41 – 42). He further elaborated, "*Yes, well he is 37 and he has had it very badly. In such a way that during a meeting he would lie down or start vomiting. So it has really affected his lifestyle and that's why he went for the operation.*

Which is, so far as I can tell, has not been entirely successful. And since then, he has gone into a depression. And that hasn't happened with us thankfully" (Lines 65 – 68).

Participant 9 also described that the idea that others are worse off has helped her accept the changes more easily when she said, *"I think a lot of it has to do with personality. I'm quite an easy-going person, and things don't really affect me in general. I always think that, you know, others are probably far more worse [sic] off than what we are, from every aspect"* (Lines 865 – 868).

4.9. Theme 8: Referrals for Psychology and/or Counselling Services

During the interviews, patients elaborated on their thoughts regarding the psychological aspects of third-party disability. Two of the patients in the study reported that they had been seeing a psychologist prior to the diagnosis, and felt that it also assisted them to cope better with the vestibular disorder. This was exemplified by Participant 6 who reported, *"Well, truthfully we actually have been seeing a therapist for quite some time now – not related to the Ménière's. We have touched base on it during the sessions. We were seeing someone for marriage counselling, couple's therapy, and then when the Ménière's was diagnosed our audiologist suggested that we see a psychologist because it can change your lifestyle and it's quite a major disease so can cause a lot of extra stress on a relationship. Our psychologist actually didn't know much about Ménière's beforehand, so she had to call the audiologist to find out more. But she's been really helpful"* (Lines 552 – 561). Participant 9 further elaborated when she said, *"Well, I've actually been going to see a psychologist for the last 10-11 years, so I think just that in general helps"* (Lines 871 – 872).

The potential benefits of psychology were also reiterated by Participant 10, despite not having consulted with a psychologist. He stated the following: *"Psychology? No, she hasn't*

seen anyone about the Ménière's … me neither. I don't recall it ever being suggested… Possibly in the beginning [it would have been helpful to see a psychologist], when we were both still trying to get used to it and understand it all. It probably would have been a good idea to have consulted someone. It was a very stressful time. Over the years we've managed to deal with it ourselves, so I personally don't think it would be necessary at this point… I think that would be a very wise decision [to see a psychologist from the beginning]. There are so many 'unknowns' that come with it, and definitely a lot of frustration involved" (Lines 965 – 981). This was also shared by Participant 11 when she said, *"Possibly. I've never been to a psychologist before so it didn't even cross my mind. Maybe it would have been helpful"* (Lines 1063 – 1064).

Three of the participants felt that they did not require psychological services. For example, Participant 1 stated, *"We're coping quite well so we don't feel it's necessary at this point"* (Line 72) and Participant 8 supported this notion when he said, *"It actually was mentioned at one of the sessions at the audiologist, but neither of us have [sic] really felt the need to right now"* (Lines 787 – 788). Participant 5 did not feel that it was necessary to consult a psychologist or counsellor, despite expressing that *"I wouldn't say that I really need to see anyone. Would just be nice if my family understood what was happening instead of them telling me I'm not myself"* (Line 425 – 426).

In Participant 7's discussion, he implied that psychology was not something that would benefit him and therefore had not sought any counselling services. He said, *"No. I wouldn't do that [talk to a psychologist]. I don't know. I'm not really into that kinda [sic] stuff"* (Line 647).

4.10. Chapter Summary

This chapter has provided an insight into the results of this study through presenting the eight themes which epitomise the SOs' experiences of vestibular disorders. The following figure (Figure 4.1.) illustrates the themes discussed in this chapter.

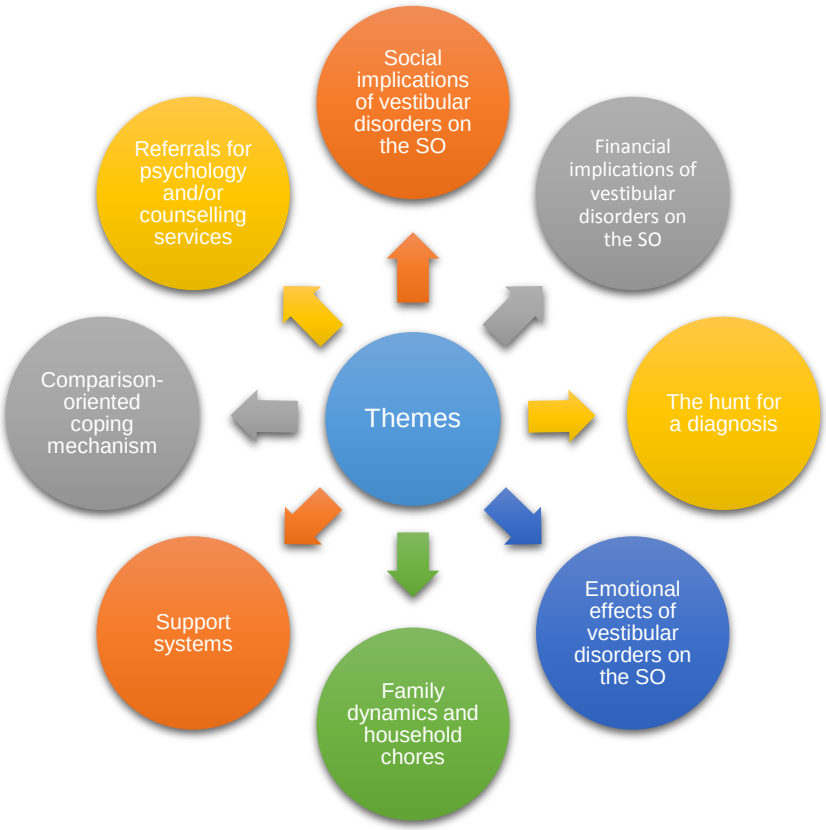


Figure 4.1. Summary of the themes.

Although themes were described individually, there is overlap amongst the responses and experiences, which can be seen through the repetition of certain excerpts in different domains. The results of this study confirm that SOs encounter a variety of experiences through their partners' vestibular disorders.

CHAPTER 5: DISCUSSION

5.1. Introduction to Chapter

Through a qualitative paradigm, this study has provided reflections of the experiences of 11 significant others (SOs) of individuals with vestibular disorders, which have indicated that the effects of vestibular disorders extend to the SOs. The introductory chapters to this dissertation have presented the relevant existing literature surrounding the concepts which have been explored in this study.

In this discussion chapter, the findings of this study are considered and expanded through conceptualising the results and providing a contextualisation of results in relation to existing literature. The purpose of this chapter is to provide an in-depth analysis of the themes described in the preceding chapter in order to fully understand the lived experiences of partners of individuals with vestibular disorders within the research context. This chapter will provide significant information to yield the implications of the study, which will be discussed in the following chapter.

5.2. Third-Party Disability

An overarching finding of this study was that the participants experienced a concept known as third-party vestibular disability. Third-party disability has been described by the WHO (2001) as "the study of disability and functioning of family members due to the health condition of significant others" (p. 251). The third-party disability to which the SOs refer appears to have manifested in terms of social, psycho-emotional as well as financial implications, all of which will be further explored in the subsequent sections.

5.2.1. Third-party disability within a context of resources and privilege

As described in the methodology section, this research was conducted in the private sector. The private healthcare sector in South Africa is considered to be well-resourced with high quality systems of care in place (Giaimo, 2016). In South Africa access to the private healthcare facilities tends to be limited to the higher LSM (Living Standards Measure) socioeconomic groups, which is estimated to be between 15 to 33% of the South African population (Giaimo, 2016; Swanepoel, Storbeck & Friedland, 2009). Even within this context of privilege, it was described that financial difficulties were experienced as a direct result of the vestibular disorder. These financial implications were further seen to affect the SOs thereby resulting in third-party disability.

5.2.1.1. Third-party disability as a result of medical expenses

Despite being part of what is termed as the "affluent" sector (Giaimo, 2016, p. 188), the participants made reference to the financial aspects related to illness and described the increasing costs of medical care, with emphasis on what they perceive to be an unnecessary spend of financial resources. Although the medical costs are associated with the ill spouse's health condition, this domain was strongly reiterated throughout numerous interviews. This aspect of third-party disability experienced by the participants in the study may be as a result of the shared financial costs incurred in a relationship. The participants further alluded to the negative implications of the increased medical costs, such as decreased savings, reduced participation in hobbies and the psychological impact of financial stress. These concepts have been supported in the literature by various authors who have further elaborated on the so-called 'domino effect' which may result (Piazza & Charles, 2012). The following figure (Figure 5.1.) provides an illustration of this chain reaction:

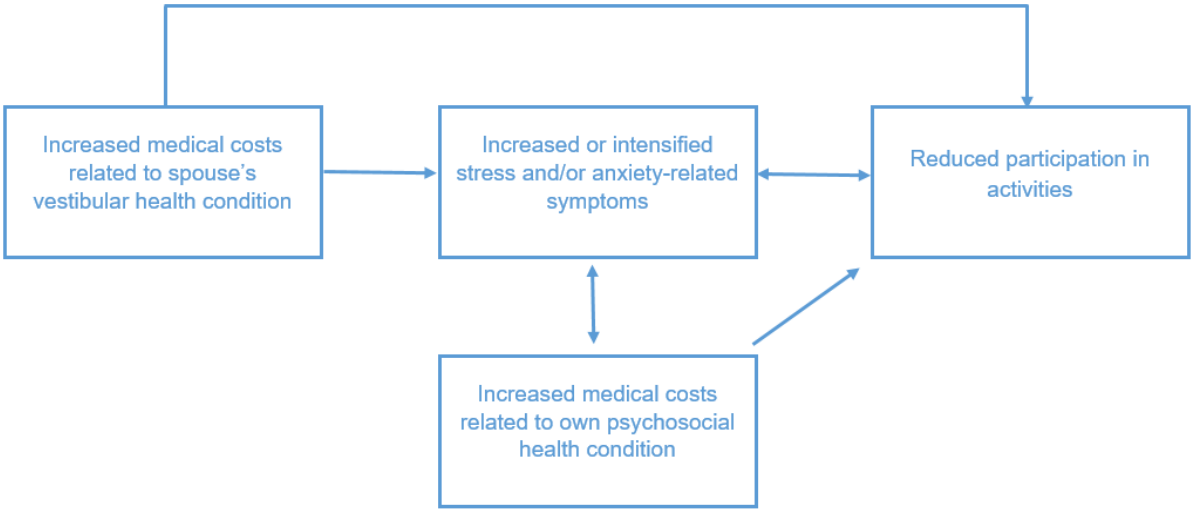


Figure 5.1. Flow chart of the financial aspect of third-party disability in vestibular disorders.

The above flow chart depicts how increased medical costs which occur as a result of the SO's health condition may give rise to psychological symptoms in the non-disabled partner which may, in turn, result in reduced participation in activities (e.g. hobbies). Consequently, this may further negatively impact on one's own psychological well-being which may require an increase in one's own spend of medical expenses (e.g. due to the need for psychological services). The increase in medical expenses (whether due to the SO's vestibular disorder or one's own psychosocial distress) may further exacerbate the participation restriction domain and, thus, cause a cycle of events to occur.

The reason for the increased medical spend may be partly attributed to the inappropriate diagnostic procedures and referral processes (Mathur, 2011). Difficulties in diagnosing vestibular disorders have been documented by various authors who report that poor understanding of the pathophysiology for the balance organs remains key in the improper choice of diagnostic procedures undertaken by healthcare professionals (Luxon & Bamiou, 2007; Mathur, 2011). In addition, many patients with vestibular disorders are

misdiagnosed due to the complexity of the case and/or the lack of the correct diagnostic equipment (Mathur, 2011).

Furthermore, the cost of private healthcare worldwide appears to be escalating. In reference to this phenomenon, it has been reported that the global medical costs increased at an average of 9.7% per annum between the years 2010 to 2012, with South African medical costs increasing at an average rate of 8.6% per annum during the same years (Rising Costs in the Healthcare Sector, 2013). A more recent article notes that private healthcare has increased by 300% in the last decade (Ngoepe, 2016). Referring to these escalating costs, the South African healthcare system, in particular, has been described as "wasteful" with "overtreatment" and "excessive pricing" (Thomas, Karodia, Soni & Inderpal, 2013, p. 32).

Stemming from this concern by the participants was that of the poor reimbursement by medical schemes. Thomas et al. (2013) noted that the major medical funders reportedly believe that the tariffs levied by private healthcare professionals were unjustified. In South Africa, healthcare providers function on a fee-for-service basis, which may result in the provision of unnecessary, costly services. As a result of this, medical schemes have reportedly attempted to contain the medical costs in an effort to curb over-use by the public and over-servicing by the healthcare providers (Awosika, 2007).

Another expense reported by the participants which further compounds the third-party disability experienced was that of hearing aid expenses. This did not only relate to the cost of the actual device, but also to follow-up visits required for retests and adjustments. This was particularly reiterated by participants whose SOs were diagnosed with Ménière's disease. The expense of hearing aids reportedly added another financial burden to the household, with participants reporting the cost of hearing aids ranging up to R60 000 with poor reimbursement from the medical schemes.

5.2.1.2. Third-party disability within an anthropological context

Within the domain of resources and privilege, the participants in the current study further described various situations from an anthropological perspective, including leisure activities involving food, hobbies and self-care. Recurrent references to various social situations which had been affected by their SOs' vestibular disorders were identified by participants in this study.

One of the most frequently mentioned circumstance was that of food and practices surrounding meals. Scott (2009) stated that "eating is often a social activity, performed in the company of friends and family for the purpose of pleasure as much as biological necessity" (p. 93). This quotation provides an anthropological perspective that eating meals can be seen as a social event which defines social relationships, thereby forming a significant part of the social circumstances of life (Crowther, 2013). Scott (2009) further elaborated on the practices involving meals, such as dinner parties, family get-togethers, and religious holidays.

Due to the challenges that dizzy individuals experience with regard to eating out, and the necessary avoidance of the triggers, the participants reported that their partners had developed social isolation behaviours. As a result, these social isolation behaviours appeared to have translated into the participants daily lives, which can be identified through the use of the word "*we*" when describing the context surrounding meals.

Other anthropological considerations which have been derived from this current study include situations such as shopping, engaging in self-care rituals (such as going for manicures), or enjoying leisure activities (such as reading or playing golf).

5.2.2. Psycho-emotional third-party disability

One of the domains which echoed throughout all of the participants' responses was the psycho-emotional effects of the vestibular disorder. According to Glover-Graf (2012), the impact of being a partner of an individual with a disorder, whether it be psychological or physical, can be overwhelming. Previous research in the field of spinal cord injury has noted that the caregiving partner presents with equal (if not more) amounts of stress, fatigue, resentment, and anger, when compared to the partner with the injury. This appears to be due to the psychological and social effects of caring for the partner (Glover-Graf, 2012). Figure 5.2 below depicts the five domains within the concept of psycho-emotional third-party disability, as described by the participants in the study. These domains are spousal burden, survivor guilt, emotional dependency, emotional contagion and courtesy stigma.

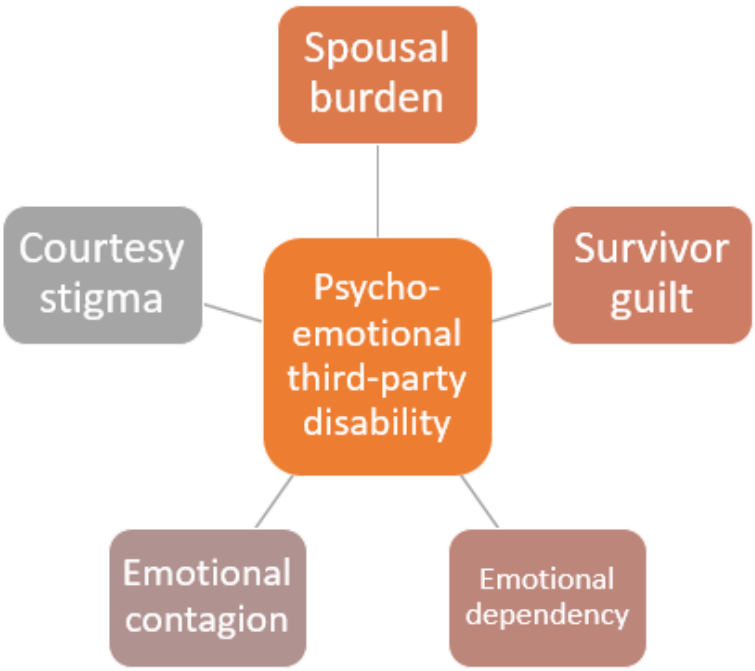


Figure 5.2. The domains of psycho-emotional third-party disability as described by the participants in the study.

5.2.2.1. Spousal burden

Spousal burden refers to the emotional responses experienced by partners of individuals with chronic medical conditions. Emotional reactions may include feelings of anxiety, frustration, stress and fatigue. There is a substantial amount of research and academic sources which indicate that having a close relative with a chronic condition has a definitive link to increased psychological distress. A study conducted by Ohman & Söderberg (2004) found that the healthy family members experienced a reduced sense of freedom, with increased feelings of responsibility toward the unhealthy individual. Pinquard and Sorenson (2005) report that research suggests that spouses are four times more likely to experience significant emotional burden than non-spousal caregivers, as they tend to lack roles and social activities outside of the home (Pinquart & Sorensen, 2005). The following figure (Figure 5.2.1) depicts the four aspects related to spousal burden described by the participants in the study, namely frustration, anxiety, stress and emotional burnout:

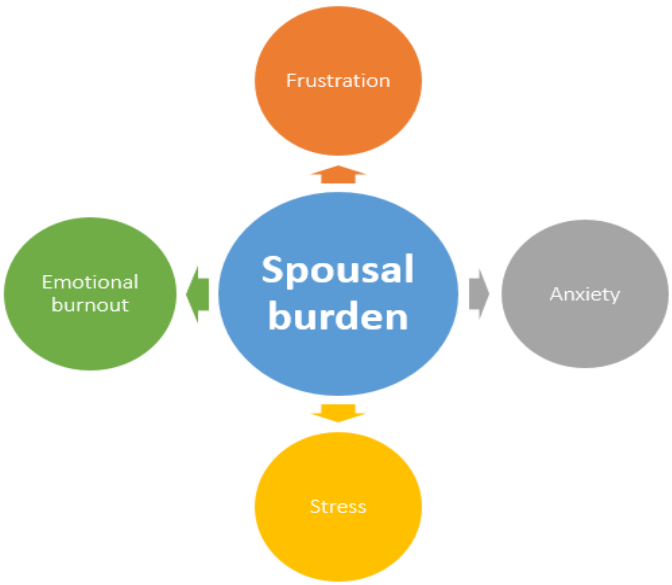


Figure 5.2.1. The aspects of spousal burden as described by the participants of the study.

Participants in the study made reference to the word "*frustration*", alluding to this emotion being directed at their partner but, more so, concerning the situation and disorder itself. The literature notes that, oftentimes, the frustration may appear to be directed at the person when it is related to the disorder, which may result in arguments and problems in the relationship (Fremes & Carteron, 2003). According to Fremes and Carteron (2003), both the patients and their family members may go through the various stages of grief, as proposed by Elisabeth Kübler-Ross – denial, anger, bargaining, depression and acceptance. Therefore, frustration is seen to be a common theme in chronic disorders.

Anxiety in relation to the partner's health condition was also described by participants, with phrases such as "*fear of the unknown*" being commonly mentioned. The literature correlates with the emotions expressed by participants and suggests that anxiety related to family disability is often experienced and is a normal part of the process of adapting to a changed or changing lifestyle (Bryan, 2006). Atwood and Gallo (2010) reported that studies have indicated that anxiety related to a spouse's health condition can continue for up to a year post-onset before dissipating, and may significantly affect daily routines (Atwood & Gallo, 2010).

Research suggests that this spousal anxiety needs to be addressed therapeutically in order to promote better outcomes in coping with the diagnosis and symptoms experienced by their loved ones. Many of the psychosocial aspects which the SOs describe may be attributed to underlying chronic anxiety, and therefore, research has demonstrated that therapy is an effective tool to decrease anxiety, worries and emotional distress (Kabat-Zinn, 2005; Neacsiu, Bohus & Linehan, 2014).

In this study, stress was described to be a major factor in the psychosocial adjustment to having a SO with a vestibular disorder. This is supported in the literature by various

researchers who report that family members who act as caregivers tend to experience higher stress levels than non-caregivers (Pinquart & Sorenson, 2005). Research indicates that the level of stress is strongly influenced by the care recipient (i.e. the dizzy patient). Family members of individuals who require increased support appear to demonstrate more stress than those who are more self-sufficient (Pinquart & Sorensen, 2005). This relates to the concept of increased dependency, which is discussed further (see 5.2.3 'Emotional dependency').

Another significant finding from the current study was that of emotional burnout which was experienced by the participants. Burnout can be described as physical, emotional, and mental exhaustion as a result of involvement in an emotionally-demanding situation. In spouses, burnout usually occurs as a stress response (Pierce & Lutz, 2013). It may result in apathy, whereby the individual experiences a disinterest in work, relationships and hobbies, which therefore affects the overall quality of life (Capezuti, Malone, Katz & Mezey, 2014). Furthermore, burnout may result in feelings of depersonalisation and, at times, a lack of self-care (Jackson & O'Brien, 2009). Both of these symptoms were described by participants in the current study. In addition, words such as "*exhausted*" and "*draining*" were frequently used in the interviews. Participants in the study also described a decreased interest in usual hobbies as a result of the exhaustion, which gives further evidence as to the extent of the burnout which the participants were experiencing.

5.2.2.2. Survivor guilt

Survivor guilt is a term that is commonly used to refer to survivors of a traumatic incident (Sherman, 2011). However, certain psychologists and authors have used this in reference to illness (both physical and mental). Such is the case in the current study whereby participants expressed their feelings of guilt in relation to their partners' vestibular disorders.

Although the concept of survivor guilt in chronic illness or disorders is not fully explored in the literature, Lasada, Marquez-Gonzalez, Penacoba and Romero-Moreno's (2010) research, suggests that guilt is often related to psychological distress and may be a contributing factor to the development of spousal depression related to chronic medical conditions. Feelings of guilt may also give rise to adverse behaviours such as verbal aggression, which may ultimately further exacerbate the guilt experienced, as well as add to the stress experienced by the spouse (Lasada et al., 2010), thereby intensifying the spousal burden.

The results of the study reported various circumstances which yielded guilty feelings in the participants. References to guilt in this study were related to being able to enjoy hobbies which the dizzy spouse could not participate in, as well as participants' feelings of guilt about the emotional burnout experience. The former concept is known anecdotally, however, does not appear to be well-documented in the literature. Various blogs and online forums for spouses have discussions related to this aspect of guilt, such as Greenway (2015) who described "I feel guilty if I go eat by myself or leave him to do something I want to do", Dee (2014) who wrote "I feel guilty when I take time away from home" or Cindy (2015)'s comment "I would feel guilty to have fun without my husband".

Likewise, the latter notion of guilt does not appear to be explored in the literature. The participants' descriptions of this aspect of survivor guilt suggests insight into the third-party disability experienced, and highlights the idea that third-party disability is multifaceted in that it may be manifested in various psycho-emotional domains.

5.2.2.3. Emotional dependency

When analysing the responses of the participants across the various categories, it also seemed as though their partners had become extremely reliant on them since the onset of the

vestibular disorder. Mueller et al. (2014) found that dizzy individuals present with decreased autonomy, particularly older adults. This may be due to an increased risk of falling resulting in increased anxiety and fear-induced activity restriction (Agrawal et al., 2009; Hauer et al., 2011).

Under this domain of emotional dependency, the participants in the study also made reference to possible personality changes in the dizzy spouse. The literature strongly supports this concept of personality change as a result of a loss of independence as it effects a significant change in one's quality of life, and may also provoke feelings of being a burden unto others (Houk, 2002). The current study analysed this idea from the SO's perspective and suggested that the same applies to the non-disabled partner who reports on changes in quality of life, as well as the increased burden as a result of dizzy partner's increased dependency traits.

Contrariwise, ensuing from this domain of emotional dependency was the positive bonding experience which was described in the results where reference was made to the increased dependency. It was stated that the increased dependency role with which the participant had been afforded had encouraged her to pursue a new hobby with her partner. According to Atwood and Gallo (2010), various studies have indicated that certain relationships may be strengthened when one of the partner's develops a health-related condition. The authors explain that individuals who are in a stable and supportive relationship pre-morbidly, tend to be better prepared to withstand such changes in the dynamics. Long-term studies have suggested that 25% of couples experience increased satisfaction within their marriage following a chronic disorder. This may be due to adjustment periods, as well as a re-evaluation of priorities within the partnership (Atwood & Gallo, 2010).

5.2.2.4. Emotional contagion

Emotional contagion is well-described by Sullins (1991), as cited in Roy (2016), as "the process by which individuals seem to catch the 'mood' of those around them" (p. 1252). This concept was reported by various participants in the current research study who described symptoms of depression and anxiety as a direct result of their significant other's emotional reaction towards the vestibular disorder. This concept is strongly reinforced in the literature, particularly amongst couples who are interdependent (Vangelisti, 2013). According to Vangelisti (2013), when one partner is ill or disabled, the spouse's emotional state tends to correlate with that of the partner with the health problem. Most often this results in negative affect, specifically depression occurring amongst both entities. Longitudinal studies by Joiner (1994), and Segrin, Badger, Meek, Lopez, Bonham and Sieger (2005) confirm the notion that depression is a very common phenomenon in married couples, and that a deterioration in one's emotional state inadvertently affects that of the other's. Anxiety as a result of emotional contagion has also been widely documented in various studies (unrelated to vestibular disorders) (Gump & Kulik, 1997; Segrin, Badger, Dorros, Meek & Lopez, 2007).

There are many studies which demonstrate high correlations between vestibular disorders and psychiatric distress. These studies have spanned over at least three decades (Marks, 1981; Rudge & Chambers, 1982). More recent studies include those conducted by Jacob and Furman (2001), which describes the bidirectional relationship between dizziness and anxiety, while simultaneously reporting that at least 33% of dizziness is caused exclusively by anxiety disorder, as well as Mira (2007), who further supports this statement with reports of agoraphobia and panic attacks in 25% of dizzy individuals. In accordance with Staab and Ruckenstein's (2009) study, a proposed model of the relationship between dizziness and anxiety can be illustrated in the following figure (Figure 5.2.2.):



Figure 5.2.2. Overlapping concepts of anxiety disorders and neurotologic disorders.

The above model is an important consideration in the development of the notion of emotional contagion in vestibular disorders as it demonstrates the overlap of anxiety disorders and neurotologic disorders, in this case vestibular disorders. Due to the interconnectedness of the different concepts related to anxiety and dizziness, the current study has not overtly differentiated between the three patterns. Previous literature alluding to emotional contagion in vestibular disorders, such as Piker et al. (2012), similarly do not distinguish this pattern, but instead indicate that a definitive 1:1 relationship exists whereby anxious patients had anxious spouses and, conversely, non-anxious patients had non-anxious spouses.

5.2.2.5. Courtesy stigma

The theory of courtesy stigma was indirectly implied during the participants' interviews through their accounts of social withdrawal. Courtesy stigma is a term which is used to describe stigma by association due to the psychological aspects surrounding the stigma of disability (MacRae, 1999). According to various sources, stigma is commonly

experienced in patients with vestibular disorders (Balaban & Thayer, 2001; Best, Eckhardt-Henn, Tschan, & Dietrich, 2009; Eckhardt-Henn et al., 2008; Staab & Ruckenstein, 2003; Yardley, 2000). As described previously, stigma may be perceived, experienced or internalised (Brohan, Slade, Clement & Thornicroft, 2010). Based on the three categories of stigma defined by Brohan et al. (2010) as well as the results of this current study, the following figure (Figure 5.2.3.) provides a proposal of the development of stigma in third-party disability:

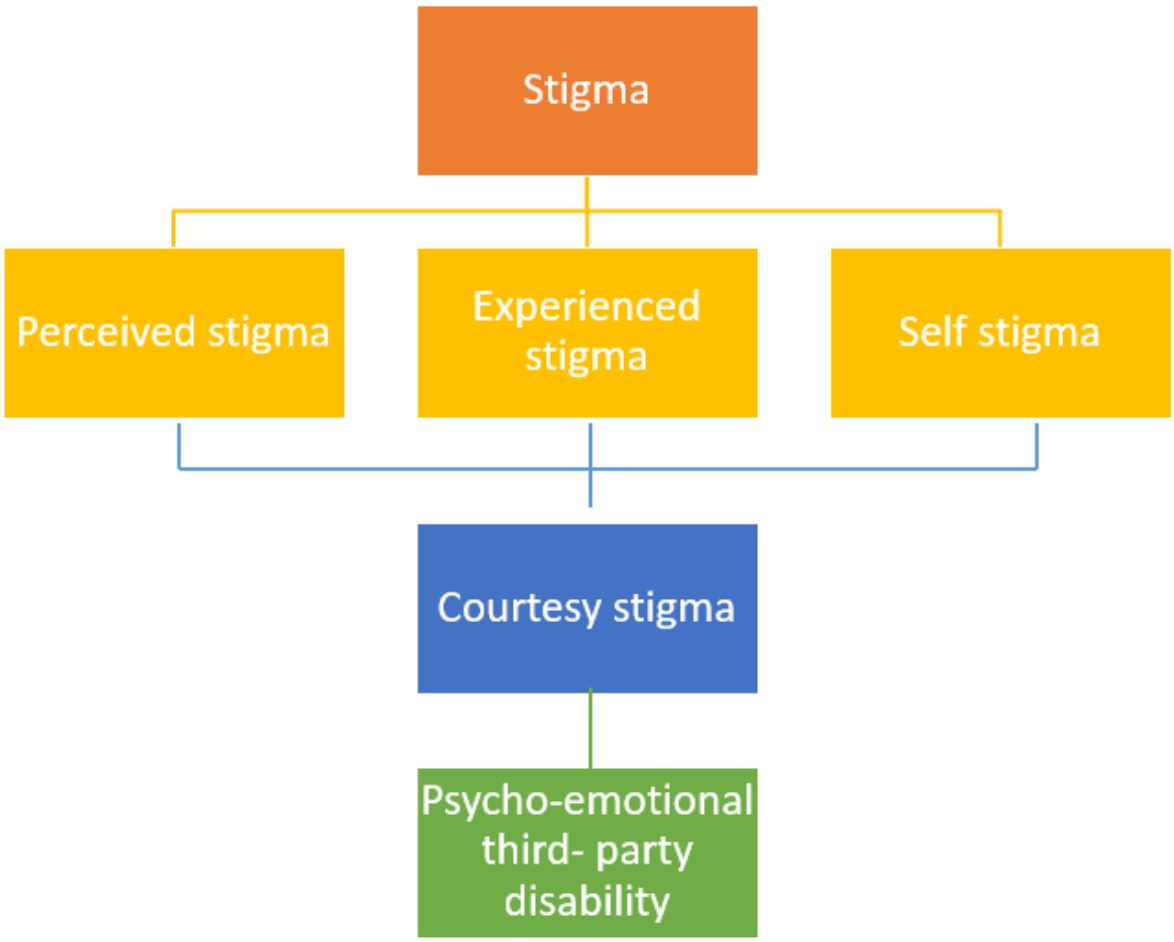


Figure 5.2.3. Proposed model of the development of stigma in psycho-emotional third-party disability.

As illustrated in the above figure, there are three manners in which stigma may develop. Perceived stigma refers to how the individual thinks that others view him or her; experienced stigma refers to actual discrimination; and self-stigma refers to an internalisation of public stigma (Brohan et al., 2010). Resulting from these three manifestations of stigma, the concept of courtesy stigma may develop. In the case of vestibular disorders, the non-dizzy partner may develop one or more of the three domains of stigma thereby resulting in what has become known as courtesy stigma. This, consequently, may result in the development of psycho-emotional third-party disability.

5.3. Role Shifting

Glover-Graf (2012) has reported that when a partner presents with a chronic disorder, the other partner may assume the role of the parent. This results in changes in the family roles (Glover-Graf, 2012). In this study, the concept of role shifting was noted in various interviews with the participants. The participants explained that they were required to assume more responsibility since the onset of their SOs' vestibular disorders, such as shopping, cooking and driving. The emotional dependence, which was described in the 'psycho-emotional third-party disability' domain also appears to result in role shifting as the dizzy spouse becomes significantly reliant on their partner.

This is an important concept to consider in vestibular disorders, as the literature notes that the changes in family dynamics, together with the social, financial and emotional effects of caring for one's spouse may result in maladaptive responses to changes in the household as well as possible resentment over time (Marini, 2012). Zarit and Edwards (2008) further note that the frustration experienced by the family members, particularly spouses, is a normal reaction to assuming the role of a caregiver, and that these feelings can be relieved through

support from other family members, friends and healthcare professionals. With specific reference to vestibular disorders, Friedland and Minor (2009) suggest that counselling is necessary due to the changes in family dynamics which often occur in the presence of chronic conditions. Studies have also demonstrated that social support significantly decreases the subjective psychological burden among immediate family members and that they are less likely to develop health-related issues of their own (Zarit & Edwards, 2008).

5.4. Community of Practice

There is a large body of research which explores the relationship between social support and health status. Social support refers to (a) emotional support, (b) appraisal support, (c) informational support, and (d) instrumental support (Bomer, 2004). During this research process the four types of support were not explicitly differentiated; however, through analysing the results two primary systems were identified, namely emotional support, and informational support.

According to Bomer (2004) in terms of hierarchy, family tends to be at the forefront of support systems, followed by friends, neighbours, and lastly formal support services (such as support groups or counselling). The support systems in this study are illustrated in the following figure (Figure 5.3.):



Figure 5.3. The types of support systems as described by the participants in this study.

In audiological research Piker et al. (2012) substantiate the concept of family being a crucial element of the support team, when they suggested that the family members hear the patient's cries of despair and are in the best position to place vertigo or dizziness into perspective when the patient feels consumed by sensations. In this study, friends and family as support systems appeared to be on par with each other, with six participants mentioning friends as key support systems and five participants describing family (including spouses) as important support systems.

Support from friends and family can be essential in improving outcomes related to overall health and well-being. Bassavanthappa (2011) differentiates between two systems, namely social networks and social support. Social networks are defined as groups of people with whom a connection is formed. Social networks have been described in the literature as

being crucial in reducing stress and illness, as well as encouraging coping strategies and adaptability. Social support refers to "emotional sustenance that comes from friends, family members and even health care providers to help a person when a problem arises" (Bassavanthappa, 2011, p. 49). The results of this study indicate that both of these terms are applicable, as the participants made reference to both forms of support systems during the interviews.

Community-based support systems, such as schools and places of worship, are also seen to be integral in assisting families in various situations (Krippner, 2005). Participants in the current research reported that the community-based external support systems have been of great value to them during their partner's rehabilitative process, particularly providing assistance when time is needed for consultations with the healthcare professionals. It is important, however, to differentiate this type of support from social support (i.e. emotional sustenance, as described previously). From the excerpts provided by the participants, it was apparent that the individuals from whom the participants received support, provided the support in physical terms rather than emotional. However, Krippner (2005) reports that community-based institutes may also serve as valuable resources to many individuals, whereby social support, psychosocial support, and a sense of belonging can indeed be received (Krippner, 2005).

The results of the study also provided accounts of couples supporting each other, and describing "*strong marriage*(s)" (Participant 9, Line 868) and "*good relationships*" (Participant 11, Line 1067) as being paramount to being able to deal with the consequences of the vestibular disorders. Although in some cases, the concept of spousal support was not explicitly discussed by the participants, through analysing the responses various circumstances of spousal support can be identified, for example participants reported that they had reduced their participation in social events, most notably eating at restaurants, and

further explained that their personal dietary habits had changed in order to assist and support their partners in avoiding the triggers. Other examples of spousal support in this study include assisting the dizzy partner with transport and shopping.

Roy (2011) reports that positive intimate relationships are essential when there are health-related stressors from one or both individuals. The role of spousal support in the field of health studies is a major focus area and there is an overwhelmingly large amount of evidence that suggests spousal support has a "powerful buffering effect" in reducing the morbidity of disease (Martire et al., 2004; Roy, 2011, p. 46; Stark & Hickson, 2004; Tye-Murray & Schum, 2994). According to Roy (2011), this is applicable to both the individual with the illness as well as the partner. It is further emphasised that relationships have to be reciprocal when confronted with stressful events as it affects both entities in the partnership. This statement suggests that spousal support is essential in mitigating both the ill spouse's disability, as well as the healthy spouse's third-party disability (Roy, 2011).

Conversely, it is also important to consider the emotional status thereof as negative partnerships may have an adverse effect on morbidity and general well-being (Roy, 2011). Therefore, it is possible that for some participants in the current study, this may not be seen as an effective coping mechanism. This is an important consideration for healthcare professionals to consider when providing and/or referring for counselling for vestibular disorders.

Although the literature in this area with specific reference to vestibular disorders is sparse, spousal reinforcement and support has been highlighted in other chronic health conditions. Block, Kremer and Callewart (1999) reported on a study whereby spousal response to pain was compared between two groups. It was found that the pain reduced significantly in the group whereby spouses were encouraging and supportive of the

rehabilitation and associated psychological aspects surrounding the health condition (Block et al., 1999). Another study by Manne, Ostroff, Winkel, Grana and Fox (2005) in the field of breast cancer found unambiguous results whereby a significant negative consequence on quality of life was identified in relation to unsupportive partners.

With regard to vestibular disorders, Piker et al.'s (2012) study appears to be most prominent in discussing spousal congruence. This study emphasised the need for the spouse to be in agreement with the symptoms experienced by the dizzy individual, as well as the subsequent treatment plan in order to promote recovery (Piker et al., 2012).

The final form of support described by the participants in this study was that formal support systems (including audiology and psychology) were crucial parts of the support system. This was highlighted by participants in the current research, and will be further elaborated in the subsequent section 5.4.1. (The need for a biopsychosocial approach).

5.4.1. The need for a biopsychosocial approach

The inclusion of counselling services in general healthcare has been viewed by many as a positive addition in order to promote holistic treatment approaches. It is well-documented that many medical conditions present with comorbid psychological distress (Papadopoulos & Bor, 1995). This study has further explored the comorbid psychological distress from a third-party disability perspective, as previously conveyed.

Traditionally, medical practice focused primarily on the medical model of disability, whereby a patient is simply diagnosed and treated for the disorder (Papadopoulos & Bor, 1995). However, with the development of the biopsychosocial model, the patient's interaction has become more collaborative which encourages more active participation in the treatment process (Papadopoulos & Bor, 1995). McDaniel, Campbell and Seaburn (2013) further

reiterate that, within this model, the inclusion of family members is vital as it promotes effective and efficient management and care of the patient.

As can be seen in the current study, third-party disability in vestibular disorders is rife. Families are considered to be a primary source of caregiving (Craft-Rosenberg & Pehler, 2011), and this study demonstrated the significant impact which vestibular disorders has on the spouse within a variety of domains. Therefore, the results of this study strongly support the need for audiologists and other healthcare professionals working in the field of vestibular disorders to adopt a biopsychosocial approach to disability. In doing so, the literature emphasises that vestibular specialists should have a degree of counselling knowledge and skills in order to allow for appropriate management of the individual (Bronstein & Lempert, 2007). According to Roy (2011) thorough counselling from the diagnostic healthcare professional is the most essential part of overall treatment.

Despite the growing literature advocating for the inclusion of counselling services in managing health conditions, few of the participants in the current study reported that they (or their dizzy spouse) had been referred for psychological intervention. Papadopoulos and Bor (1995) note that healthcare professions who have been exposed to counselling services tend to encourage referrals for psychology, as well as make use of psychological approaches when counselling on the diagnosis. Papadopoulos and Bor (1995) also report that studies have indicated that practitioners who are well-informed on psychological approaches and referrals tend to have improved communication skills with their patients. Roy (2011) further suggests that time constraints may be cause for poor referral rates for counselling services. However, through using questionnaires such as the Hospital Anxiety and Depression Scale (HADS) a quick screening can be performed which will provide the healthcare practitioner with a guideline as to which patients require formal psychological evaluations. This can be provided to the patient to complete at home and reviewed at the follow-up session, or returned via

email (Nicassio, Greenberg & Motivala, 2010). In doing so, this further encourages holistic management of the patient and may greatly improve prognosis and compliance with recommendations, treatment and rehabilitation (Papadopoulos & Bor, 1995).

In this study, none of the participants referred to any form of support group in assisting them to navigate through their experiences of third-party disability. As the concept of third-party disability in vestibular disorders is fairly novel, with previous studies in this field being scarce, the literature does not appear to make reference to the concept of support groups in this regard. However, references are made toward the inclusion of parent support groups for paediatric hearing loss, as well as patient support groups for audiologic (re)habilitation (Beauchaine, Hoffman & Sabo, 2017; Maltby & Knight, 2000; Snow, 2004). The results of this study advocate for the development of vestibular support groups for both the patient as well as his/her spouse. Participants in the study made reference to loneliness and isolation, particularly with Participant 5's account, when it was stated "*sometimes you really feel like you're the only one going through all this*" (Lines 437 – 438). Furthermore, the participants in the focus groups responded well towards the situation and it was informally observed that the participants exchanged contact details following the sessions. This provides compelling preliminary evidence for the establishment of support groups for vestibular disorders.

5.5. Comparison-Oriented Coping Mechanisms

The use of comparisons as a coping mechanism for dealing with their partners' diagnoses were described by participants in this study. The literature refers to various types of comparisons; however, both of the participants appear to make use of 'downward comparisons', i.e. viewing their situations in a positive light relative to others. Downward

comparisons are reportedly quite common in coping with chronic illness, and psychologists postulate that this is linked to efforts to restore subjective well-being (Wills & Sandy, 2001). However, through using downward comparisons, a concern within the field of psychology, is that it affects one's capacity for honest self-evaluations in order to preserve self-esteem, and therefore, may actually be a more harmful than a beneficial coping strategy (Wood, Taylor & Lichtman, 2003).

In analysing the participants' responses, a clear distinction in the difference in the way in which the participants described the comparisons was noted, with Participant 1 referring to a specific individual, and Participant 9 referring to more of a general, passive downward comparison. Passive comparisons occur through observations in daily life, and through exposure to examples in the media, without actively seeking out the information (Wills & Sandy, 2001).

The literature also adds a noteworthy perception to the idea of using downward comparisons as a coping mechanism, and suggests that as one's situation worsens, less opportunity for downward comparison arises due to less targets being available (Wood et al., 2003). Therefore, although the participants in this current study found the use of downward comparisons as a seemingly effective coping strategy, health psychology advises that this is not applicable or appropriate for everyone.

5.6. Chapter Summary

Through the discussion of the results of this study, it is evident that the effects of vestibular disorders are more than medical in nature and extend beyond the dizzy individual. Chronic vestibular disorders are multi-faceted in their manifestations and result in an array of experiences. The concept of third-party disability has been strongly reinforced throughout the

study. The participants in this study described the far-reaching effects of their SOs' vestibular disorders within a privileged context of access to resources. The need for a biopsychosocial approach towards vestibular disorders has been clearly illustrated in this research and provides a definite recommendation for the inclusion of SOs in assessment and management of vestibular disorders.

CHAPTER 6: CONCLUSION

6.1. Summary of the Dissertation

This research, via its qualitative nature, has offered an awareness into the daily life experiences of vestibular disorders, through the perspective of the significant others (SOs). To summarise the overall findings of this study, one may deduce that third-party vestibular disability is rife. With reference to the specific sub-aims of this study, the experiences of vestibular disorders on the SOs' quality of life have been explored and identified in accordance to eight primary themes, namely social implications, financial implications, searching for a diagnosis, emotional effects, changes in family dynamics, support systems, comparison-oriented coping mechanisms, and referrals for psychological services. By means of individual open-ended interviews and small focus groups, the SOs described these domains through providing vivid illustrations of their day-to-day experiences. Key outcomes of the data analysis indicated that SOs felt a sense of social isolation and a deprivation of leisure activities as a direct result of the vestibular disorders' physical and psycho-emotional manifestations. The psycho-emotional consequences were described in abundance, and included accounts of spousal burden, survivor guilt, emotional dependency, emotional contagion, and, finally, the development courtesy stigma. Further, significant financial affliction was experienced by the SOs as a result of a multiplicity of factors, including shared medical expenses, the reduced vocational abilities of the 'unhealthy' spouse, poor reimbursement from medical schemes, and the adverse, yet perhaps expected, psycho-emotional reactions of the SOs which required further therapeutic support.

In order to cope with the undesirable experiences, SOs reported that having the appropriate support systems, including family and friends, was pertinent. It was also indicated that the relationship with the audiologist was essential in providing better

understanding of the condition and prognosis thereof, resulting in less frustration and improved adaptation to the reported changes. However, in contrast to these seemingly beneficial coping mechanisms, a key finding from this study indicated that the required referrals for psychological or counselling services were, in fact, neglected in the rehabilitation process.

With the influence of a biopsychosocial approach to disability, the information yielded in this study provides important insight into the overall well-being and therapeutic requirements of SOs, and provides recommendations in various areas, including recommendations for clinicians in the practice of vestibular assessment and rehabilitation, suggestions for the inclusion of third-party vestibular disability in an academic and theoretical paradigm, as well as proposals for the inclusion of third-party vestibular disability in policy-making.

6.2. Implications of the Study

6.2.1. Implications for practice

A major area of consideration that this study revealed was that of counselling for vestibular disorders. Through the participants responses it was evident that they were strongly reliant on the audiologist for information on the diagnosis, prognosis and intervention plan. Audiologists are often the practitioners who manage the vestibular disability on a long-term basis. Therefore, it is important that there is open and honest communication between the therapist and the patient and his/her partner. It is important to establish this relationship from the initial encounter and provide the necessary counselling within the audiological scope of practice. As such, patients should be encouraged to bring their partners to the initial

assessment and rehabilitation sessions as it assists the partner in understanding all the implications surrounding the vestibular disorder, and better prepares them for the rehabilitation process and expectations in terms of quality of life changes that they may expect. In addition, more than one counselling session may be necessary as the results of the study suggested that information provided at the time of diagnosis may have been missed by either the audiologist or the patient's partner. Therefore, by scheduling additional counselling appointments, one can ensure that all the relevant information is provided in an appropriate manner, with sufficient time for the patient and the partner to process the information and ask questions. Furthermore, audiologists should consider providing information in a multimodal manner, making use of verbal and written communication, as well as images and videos where applicable.

In order for audiologists to become better communicators in terms of counselling, audiologists may wish to consider enrolling in courses or workshops. Effective communication and counselling is essential to improve outcomes. Although undergraduate courses in audiology provide lectures in psychology, further training should be encouraged, and should specifically focus on the various audiological and vestibular disorders.

Another implication from this study was the importance of multidisciplinary collaboration. Participants in the study mentioned that psychological intervention was not always recommended at the time of diagnosis. Participants who had sought counselling services reported this to be beneficial to the adjustments experienced; however, further explained that the psychologists were not necessarily experienced in working with certain vestibular disorders, and required contact from the audiologists to guide them further. Particularly during the initial stages of diagnosis, audiologists should take into account the need for holistic referrals, in order to allow for the best outcomes for the patient. Audiologists

should therefore consider working more collaboratively with psychologists and encourage greater awareness of vestibular disorders amongst professionals.

This suggestion further translates into another implication of this study, which is increased awareness of vestibular disorders amongst professionals as well as the public. The results of the study indicated that healthcare professionals did not appear to be aware of the signs and symptoms of vestibular disorders, which resulted in misdiagnosis. In addition, the participants in the study also stated that they were not always referred to audiologists for further investigations, suggesting that role of audiologists in the assessment and management of vestibular disorders was not well-known amongst healthcare professionals and the general public. Audiologists should therefore be encouraged to educate others on the various aspects related to vestibular disorders, including the audiologist's role, in order to enhance patient care and provide more holistic services.

Relatedly, the results of this study provided documented evidence of the benefit of establishing educational and support groups amongst patients as well as relatives. Through the inclusion of focus groups in this study, it was evident that the participants responded well to meeting with other spouses and discussing their experiences. Participants in the study explained that, at times, they felt "… like you're the only one going through all this." (Participant 5, lines 437 – 438). Although this may be known anecdotally, at present there are no known formal support groups for spouses in South Africa. Therefore, this study documented the importance of establishing support groups for the patient's spouse.

This research study further highlighted the need for regular therapy in order to alleviate the effects of the vestibular disability on both the patient and the partner. As the presence of a vestibular impairment may be severely debilitating in the physical sense, it is usually necessary for the patient to attend regular sessions with the audiologist in order to

promote the best possible therapy outcomes. In addition, the audiologist can assist with addressing disabling issues that may be unfavourable towards rehabilitation, either directly or through the use of appropriate referrals.

Finally, in terms of implications for practice, this study also suggested increased financial burden for the patients and their SOs, as a result of various factors, including inappropriate referrals to healthcare professionals, a lack of awareness of the role of audiologists in assessing and managing vestibular disorders, the cost of assessments and rehabilitation sessions, as well as the reported poor reimbursement from medical schemes. In order to overcome this burden, it is important that audiologists, other healthcare professionals, and the general public are aware of the available services in the public sector which may be appropriate for referrals. This can be achieved through the establishment of vestibular assessment and management clinics within these public sector, the development of existing services within these environments, as well as through marketing of these services.

6.2.2. Implications for theory

This research study provided valuable insight into the biopsychosocial model of disability, specifically with regards to the assessment and management of vestibular disorders. The biopsychosocial model of disability has been explored in detail in the literature review; however, in the analysis of the literature it was evident that the theory with regard to vestibular disorders was lacking. Although the results of the study suggested that audiologists do incorporate the principles of the biopsychosocial model, an elaboration on this in the literature with specific reference to vestibular disorders could potentially enhance audiologists' knowledge and, subsequent, application of this model in their interactions with

the patients and their families, as well as improve referral rates and procedures to other healthcare professionals.

Correlating to the biopsychosocial model, the results of the study also strongly advocate for the literature to increase the focus on counselling for vestibular disorders. Much of the available literature related to vestibular disorders adopts information on counselling for chronic disorders in general, as well as research that has been conducted in other fields (such as cancer or chronic pain). In order for audiologists (and other healthcare professionals) to expand and improve on their service delivery, it is imperative that the literature supports the biopsychosocial model and includes an emphasis on the need for counselling in vestibular disorders.

Furthermore, in order to encourage audiologists to employ this model when assessing and managing vestibular disorders, it is recommended that institutions expand their coursework to include a focus on the psychosocial aspects of vestibular disorders. Ideally, this should be provided at an undergraduate level so that students who complete their studies can implement these skills once they enter the workforce. However, if this is not viable, postgraduate courses and/or additional CPD workshops should be offered specifically concentrating on vestibular disorders.

6.2.3. Implications for policy

In terms of implications of this study for policy, this research pertains most prominently to the ICF framework. Currently the ICF does not explicitly discuss quality of life as a domain and, even less so, is the inclusion of third-party disability in the framework. As discussed in the literature review, clinicians often make use of the activities and

participation domains of the ICF to infer quality of life; however this does not provide sufficient information. In South Africa, there has been a huge shift to work within the ICF model when assessing and managing patients. The exclusion of quality of life from this framework may significantly affect therapy outcomes, and result in an escalation of co-occurring psychosocial disorders, such as the themes mentioned in this current study.

Another concept that has been discussed in the literature review is the HRQOL. This is primarily a measurement used to report on the burden of disease, rather than a policy per se. However, it is a valuable tool in the healthcare industry. The results of this study also suggest that the HRQOL measurement be expanded to include third-party disability in its design. Through incorporating the HRQOL concept into various policies, healthcare practitioners can use the data longitudinally, to inform of changes in quality of life over a period of time. In addition, it can provide valuable information in comparing different disorders as well as different treatment plans. In summary, the results of this research (in conjunction with previous research conducted in various other healthcare fields) suggest that healthcare policies shift towards viewing chronic disorders more holistically and provide clear definitions on quality of life, as well as third-party disability.

Specifically within the South African context, this study also advocates for the government as well private medical schemes to consider the burden of disease and the effects of chronic disorders with reference to third-party disability. Policymakers ought to consider the implications of this study, and move towards an inclusion of the concept of third-party disability when developing guidelines and policies, such as government grants, health insurance, and life insurance. As this study has indicated, it is not only the dizzy patient who is affected by the disorder. The effects of vestibular disorders extend into the spouse's general well-being and, as mentioned by various participants in the study, continue to affect

other members of the family. As will be described in the section below, future studies should also investigate third-party disability experienced by children and other family members.

6.3. Limitations of the Study

It is important that the limitations of this study are explored in order to fully reflect on the research process and provide recommendations for future research (as will be described in the following section). The limitations that have been identified include the following:

- The sample for this study included participants whose partners all attended the same private practice. It is important to note, however, that the patients did not necessarily consult with the same audiologist. At the time of the data collection, there were two audiologists who had a special interest in vestibular disorders and the patient-load was equally divided between them. Therefore, although inclusion of only one site for this study may present a limitation, the researcher attempted to control for this through including both audiologists' caseloads, with no preference given to either database.

- The second limitation was that the focus of this study was on private sector only. Although, the socio-economic status in South Africa is significantly polarised, with an estimated 67% to 85% of the population reliant on the public healthcare sector (Giaimo, 2016; Swanepoel et al., 2009), this study identified that, within a context of resources, there are many challenges that are experienced by the SOs.

- Another limitation which was identified was the small sizes of the two focus groups (n=3 and n=2). In this study, participation in the focus groups was not a requisite to participation in the study. Data collection was worked around the participants' availability and schedules, especially in light of their spouses' needs and when

considering third-party disability, and, therefore, arranging a mutually agreeable time amongst all participants proved challenging. However, the focus groups expanded on the information gained in individual interviews regardless of their sizes.

6.4. Recommendations for Future Research

As discussed previously in this dissertation, there appear to be minimal studies in the area of third party disability in vestibular disorders. Therefore, this study may be seen as a preliminary study in this area. Therefore, in terms of recommendations for future research, the following has been suggested:

- Future research should aim to include other family members in the sample, e.g. children, as different perspectives and experiences are likely to be presented.

- It would be interesting for future research to compare the experiences of each spouse (i.e. the dizzy patient as well as the partner)

- An ethnographic element to the research may be valuable to include, as this would enhance the study and provide additional information into the experiences which the participants may have omitted in their interviews. It would also add to the triangulation of the data.

- The inclusion of a severity index may be interesting to incorporate in future studies. This may provide a basis for the researcher to compare the experiences in terms of the actual or perceived severity of the disorder.

- Future research may also consider an evaluation of the effect of counselling with regards to the way in which the spouse (and other household members) adjust to the vestibular disorder.

- A detailed comparison of the way in which individuals experience different vestibular disorders may be a worthwhile study to pursue, for example Ménière's disease vs. vestibular neuritis.

- A longitudinal study to evaluate changes in partners' reflections after a set amount of years may also yield essential data which can inform management protocols for both audiologists and psychologists working in the area of vestibular disorders.

- This study focused solely on the private healthcare sector. Within South Africa there is a need for future studies to explore the public sector as individuals who rely on public healthcare may present with different experiences.

- An area of vestibular disorders where there is significant opportunity for research is that of paediatric vestibular disorders. This should be considered for all future studies in vestibular disorders as there is a definite need for this to be further explored in all contexts.

6.5. Conclusion

This study has provided valuable information regarding the experiences of SOs in relation to chronic vestibular disorders. Currently there are few studies in the field of vestibular disorders which explore quality of life, and in particular, third-party disability. Existing research indicates that family members have a significant impact on the progression

of chronic disorders. Furthermore, previous research has illustrated detrimental psychosocial effects of living with an individual who has a chronic disorder. The results of this study provide an entry-point into future research in the area of vestibular disorders. With a move towards a biopsychosocial model in health and health-related conditions, these findings may be valuable in inferring guidelines for practitioners to consider when managing vestibular disorders, as well as provides data that may be pertinent to policymakers both internationally and nationally. In summary, the findings from this research have indicated that it is vital that the effects of the vestibular disorder on the spouse are addressed within any assessment or rehabilitative encounter in order to promote positive outcomes for both the patient and the relatives.

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Appendix A: Research Study Consent Form for Participants

SPEECH PATHOLOGY AND AUDIOLOGY
SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT
FACULTY OF HUMANITIES
UNIVERSITY OF THE WITWATERSRAND
Private Bag 3, WITS, 2050
Tel: (011) 717 4577 Fax: (011) 717 4572

Hello,

My name is Natanya Berry and I am currently a Masters student in the field of Audiology at the University of the Witwatersrand. In order to complete the requirements of the post-graduate degree, I am required to conduct a research study. My research is entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*".

I would like to invite you to participate in this research study. Participants for this study have been recruited through means of a purposive sampling strategy, meaning that you have been invited to participate based on a number of criteria, including your partner presenting with a chronic vestibular disorder (i.e. longer than 3 months).

This research will explore the experiences of partners' of individuals with vestibular (balance/dizziness) disorders, as well as the potential social, emotional, occupational and financial effects of the disorder on the partner. This purpose of the research is to provide a resource to professionals working in the field of vestibular disorder in order to potentially improve patient management through highlighting the need for appropriate counselling and referrals for the partners. It may also provide the necessary documentation for the World Health Organisation to explicitly include the area of Quality of Life within the relevant frameworks and policies.

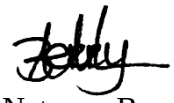
The study will comprise of an initial audio-recorded interview, at a location of your choice, as well as a follow-up focus group (which will be video-recorded). It is not compulsory to participate in the focus group following completion of the interview. Participation throughout the study is voluntary and your personal information as well as responses will remain confidential throughout the research study. Should you refuse to participate or withdraw from

the study at any point, there will be no penalties or loss of benefit. Following the completion of the study, written feedback will be provided to all participants.

Kindly complete the relevant attached consent forms should you wish to participate. For any further queries, please do not hesitate to contact me on 0834460060 or natanyaberry@gmail.com.

Your participation is greatly appreciated.

Kind regards,



Natanya Berry
(MA) Audiology Student

RESEARCH STUDY: CONSENT FOR INTERVIEW

I, _____, hereby agree to participate in the interview portion of the study for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*". I understand that my participation in the study is voluntary and confidential, and that refusal to participate or withdrawal from the study will not incur any penalty or loss of benefit.

Signature: _____ Witness: _____
Date: _____ Place: _____

……..

RESEARCH STUDY: CONSENT FOR INTERVIEW (AUDIO RECORDING)

I, _____, hereby provide consent for Natanya Berry to make use of audio recording during the interview portion of the study interview for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*".

Signature: _____ Witness: _____
Date: _____ Place: _____

……..

RESEARCH STUDY: CONSENT FOR FOCUS GROUP

I, _____, hereby agree to participate in the focus group portion of the study for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*". I understand that my participation in the study is voluntary and confidential, and that refusal to participate or withdrawal from the study will not incur any penalty or loss of benefit.

Signature: _____ Witness: _____
Date: _____ Place: _____

……..

RESEARCH STUDY: CONSENT FOR FOCUS GROUP (VIDEO RECORDING)

I, _____, hereby provide consent for Natanya Berry to make use of audio recording during the interview portion of the study interview for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*".

Signature: _____ Witness: _____
Date: _____ Place: _____

Appendix B: Interview Guide

As the nature of the interviews were semi-structured, the following questions served as a guideline.

- Describe your partner's diagnosis.
- What do you understand by the diagnosis?
- What do you think is the cause of the disorder?
- How do you feel about the disorder?
- How has the disorder affected you socially?
- How has the disorder affected you occupationally?
- How has the disorder affected you financially?
- How has the disorder affected the family roles and dynamics?
- Prior to the disorder, did you rely on your partner for household chores? How has this been affected?
- Has the disorder affected simple activities for your partner, e.g. dressing, bathing, eating? How does this affect you?
- How would you describe your partner's level of independence before the diagnosis vs. after the diagnosis?
- If your partner has a vertiginous episode / presenting with difficulty walking when you go out, how do you feel?
- How do you think the disorder has affected your partner emotionally?
- How have the emotional consequences of the disorder affected you?

- Do you think your partner is aware of the effects the disorder is having on you / on the relationship?
- What strategies have you employed to overcome the challenges associated with the disorder (e.g. caregiver, psychology)?

Appendix C: Ethical Approval from HREC (Medical)

R14/49 Miss Natanya Lee Berry

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150644

NAME: (Principal Investigator)	Miss Natanya Lee Berry
DEPARTMENT:	Speech Pathology and Audiology Better Balance and Hearing
PROJECT TITLE:	The Impact of Vestibular Disorders on the Quality of Life of Significant Others
DATE CONSIDERED:	26/06/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Victor de Andrade
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	27/07/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix D: Permission from Research Site

SPEECH PATHOLOGY AND AUDIOLOGY
SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT
FACULTY OF HUMANITIES
UNIVERSITY OF THE WITWATERSRAND
Private Bag 3, WITS, 2050
Tel: (011) 717 4577 Fax: (011) 717 4572

Dear Ms Benigson and Mrs Henen,

My name is Natanya Berry and I am currently a Masters student in the field of Audiology at the University of the Witwatersrand. In order to complete the requirements of the post-graduate degree, I am required to conduct a research study. My research is entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*".

As a result of a global shift towards viewing disability in terms of functional health, the World Health Organisation has recommended research in the area of Quality of Life (QOL) for both the patient as well as significant others. In the field of audiology, there have been few studies in this area, particularly related to vestibular disabilities. Therefore, the purpose of this study is to investigate the experiences of vestibular disabilities on the partner's quality of life in order to explore the potential social, emotional, familial, vocational and financial effects, as well as describe the strategies employed by the partners to overcome such challenges.

I would like to request permission from your practice to conduct the research with partners of individuals presenting with vestibular disabilities who attend your practice. The data will be collected through means of a semi-structured interview as well as focus groups (including audio and video recording) in which partners of individuals presenting with vestibular disorders will be invited to participate. Participation in the study is voluntary and identifying details of the practice as well as the participants will be omitted during report writing. Refusal to participate or withdrawal of participation will not incur any negative consequences. Following the completion of the study, debriefing will be provided to the practice and participants in the form of written summaries. In addition, the contact details for relevant psychologists, social workers and counsellors will be made available to the participants prior to participation in the study.

The potential implications of the study may serve to be beneficial to professionals working in the field of vestibular disabilities through describing the importance of the social model of disability as well as the need for appropriate counselling and referrals for the individuals' partners. It may also provide the necessary documentation to explicitly include quality of life within the WHO's ICF framework and expand on third-party disability, within various research fields as well as the ICF framework.

Should you have any further queries, please do not hesitate to contact me on 0834460060 or natanyaberry@gmail.com.

Kind regards,



Natanya Berry
(MA) Audiology Student

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RESEARCH SITE: CONSENT

I, Lara Benigson, hereby grant Natanya Berry consent to obtain patient information from my practice, Better Balance and Hearing, in order recruit potential participants for the study entitled "*The Impact of Vestibular Disorders on the Quality of Life of Significant Others*".

Signature:  Witness: 

Date: 05/06/2015 Place: Bedfordview

Appendix E: Pilot Study Consent Form

SPEECH PATHOLOGY AND AUDIOLOGY
SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT
FACULTY OF HUMANITIES
UNIVERSITY OF THE WITWATERSRAND
Private Bag 3, WITS, 2050
Tel: (011) 717 4577 Fax: (011) 717 4572

Hello,

My name is Natanya Berry and I am currently a Masters student in the field of Audiology at the University of the Witwatersrand. In order to complete the requirements of the post-graduate degree, I am required to conduct a research study. My research is entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*". I would like to invite you to participate in the pilot study for this research.

This research will explore the experiences of partners' of individuals with vestibular (balance/dizziness) impairments, as well as the potential social, emotional, occupational and financial effects of the disorder on the partner. This purpose of the research is to provide a resource to professionals working in the field of vestibular disorders in order to potentially improve patient management through highlighting the need for appropriate counselling and referrals for the partners. It may also provide the necessary documentation for the World Health Organisation to explicitly include the area of Quality of Life within the relevant frameworks and policies.

The purpose of the pilot study is to pre-test the data collection methods in order to determine the need for any changes. The pilot study will comprise of an audio-recorded interview, at a location of your choice. Participation in the study is voluntary and your personal information as well as responses will remain confidential throughout the research study. Should you refuse to participate or withdraw from the study at any point, there will be no penalties or loss of benefit. Following the completion of the study, written feedback will be provided to all participants.

Kindly complete the two attached consent forms should you wish to participate. For any further queries, please do not hesitate to contact me on 0834460060 or natanyaberry@gmail.com.

Your participation is greatly appreciated.

Kind regards,



Natanya Berry
(MA) Audiology Student

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PILOT STUDY: CONSENT

I, _____, hereby agree to participate in the pilot study for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*". I understand that my participation in the study is voluntary and confidential, and that refusal to participate or withdrawal from the study will not incur any penalty or loss of benefit.

Signature: _____ Witness: _____
Date: _____ Place: _____

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PILOT STUDY: CONSENT (AUDIO RECORDING)

I, _____, hereby provide consent for Natanya Berry to make use of audio recording during the pilot study interview for the research entitled "*The Impact of Vestibular Disability on the Quality of Life of Significant Others*".

Signature: _____ Witness: _____
Date: _____ Place: _____