

The Experience of Chronic Subjective Dizziness:  
A Qualitative Exploratory Study

Ann Sezier

MPhil

2016

The Experience of Chronic Subjective Dizziness:  
A Qualitative Exploratory Study

Ann Sezier

A thesis submitted to Auckland University of Technology in fulfilment of  
the requirements for the degree of Master of Philosophy (MPhil)

2016

School of Clinical Sciences  
Auckland University of Technology

## Table of Contents

List of Figures .....	iv
List of Tables .....	v
Interview Transcription Guide.....	vi
Attestation of Authorship .....	vii
Acknowledgements.....	viii
Ethics Approval .....	ix
Abstract .....	x
<b>Chapter 1 Introduction .....</b>	<b>1</b>
1.1 Context for the Study .....	1
1.2 Personal Reflections .....	3
1.2.1 <i>Researcher's interest</i> .....	3
1.2.2 <i>Researcher's assumptions</i> .....	5
1.3 Focus of Inquiry .....	6
1.4 Structure of the Thesis .....	6
<b>Chapter 2 Literature Review .....</b>	<b>8</b>
2.1 Defining Chronic Subjective Dizziness .....	8
2.1.1 <i>Diagnostic complexities and epidemiology</i> .....	10
2.1.2 <i>Symptomology of Chronic Subjective Dizziness</i> .....	11
2.2 Literature Search .....	11
2.2.1 <i>Method</i> .....	11
2.2.2 <i>Summary of studies</i> .....	13
2.2.3 <i>Quality assessment</i> .....	13
2.2.4 <i>Search process and results</i> .....	13
2.3 Findings.....	15
2.3.1 <i>Background information</i> .....	15
2.3.2 <i>The personal experience of dizziness.</i> .....	21
2.3.3 <i>Reflection on current knowledge and knowledge gaps.</i> .....	24
2.4 Summary.....	25
<b>Chapter 3 Research Design .....</b>	<b>26</b>
3.1 Methodology .....	26
3.1.1 <i>Interpretive description</i> .....	26

3.1.2	<i>Methodological suitability</i> .....	27
3.2	Research Methods .....	28
3.2.1	<i>Sampling</i> .....	29
3.2.2	<i>Recruitment strategy</i> .....	30
3.2.3	<i>Sample size</i> .....	30
3.2.4	<i>Data collection</i> .....	30
3.2.5	<i>Data analysis</i> .....	32
3.3	Rigour .....	34
3.4	Ethical Considerations .....	35
3.5	Summary .....	38
<b>Chapter 4</b>	<b>Findings</b> .....	<b>39</b>
4.1	Participants .....	39
4.2	Results .....	40
4.2.1	<i>Theme one: 'It sounds like I'm crazy'</i> .....	41
4.2.2	<i>Theme two: 'I'm a shadow of my former self'</i> .....	48
4.2.3	<i>Theme three: 'How will I survive?'</i> .....	57
4.2.4	<i>The bigger picture</i> .....	64
4.3	Summary .....	65
<b>Chapter 5</b>	<b>Discussion</b> .....	<b>66</b>
5.1	Legitimacy .....	66
5.1.1	<i>Clinical relevance and implications for practice</i> .....	68
5.2	Biographical Disruption and Self-identity .....	70
5.2.2	<i>Clinical relevance and implications for practice</i> .....	72
5.3	Direction for an Uncertain and Unpredictable Future .....	74
5.3.1	<i>Implications for clinical practice</i> .....	75
5.4	Study Strengths and Limitations .....	77
5.5	Directions for Future Research .....	78
5.6	Summary of Findings .....	81
5.7	Conclusion. ....	82
<b>References</b>	.....	<b>83</b>
<b>Appendix A: Interview Guide</b>	.....	<b>94</b>
<b>Appendix B: Example Memo and Diagram</b>	.....	<b>95</b>

<b>Appendix C: Example of Coding.....</b>	<b>98</b>
<b>Appendix D: Information Sheet.....</b>	<b>100</b>
<b>Appendix E: Consent Form .....</b>	<b>105</b>
<b>Appendix F: Demographics Form .....</b>	<b>106</b>
<b>Appendix G: Counselling Agreement.....</b>	<b>108</b>
<b>Appendix H: Māori Committee Consultation and Feedback .....</b>	<b>109</b>

## List of Figures

<i>Figure 1.</i> Literature search process and results.....	14
<i>Figure 2.</i> Thematic map. ....	42

## **List of Tables**

Table 1. Definitions of Chronic Subjective Dizziness and associated constructs .....	10
Table 2. Key search terms .....	12
Table 3. Summary of included studies.....	18
Table 4. Participant characteristics .....	40

## Interview Transcription Guide

The following symbols and formatting are used when quotes from participant interviews are provided:

<i>“Italics”</i>	Indicates a direct participant quote taken from a transcript
#	Indicates data extract taken from researcher account (where recording failed)
*	Indicates data extract taken from post-interview written reflection
[Text]	Information added by the researcher to provide context or clarification
[....]	Indicates text removed from the original transcript
CAPITALS	Indicates emphasis on words as spoken by participants
(.)	Indicates a short pause in speech
(...)	Indicates a long pause in speech



## Attestation of Authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning."

Signature:

A handwritten signature in cursive script that reads "Ann Sezier". The signature is written in dark ink and is positioned above a horizontal line.

Date: June, 2016.

Ann Sezier

## Acknowledgements

I could not have completed this study without the support, wisdom, generosity, knowledge and encouragement of so many people:

To the participants in this study, thank you all very much for sharing your personal experiences and expert knowledge so openly. Many of you said that taking part in this study was worthwhile if it meant others would benefit from your experience. I hope I have done your stories justice.

To my supervisors Denise Taylor, Nicola Kayes, and Nicola Saywell, thank you for your wisdom, direction and support. My Ann-isms (words only existing in my mind) and superfluous writing must have driven you to despair at times? Without your enquiring minds and guidance this work would not nearly be what it is today.

I also wish to acknowledge the recruitment locality for giving me access to participants, and for supporting me in the recruitment process.

To my husband David, thank you for being my champion, for giving me the much needed moral, as well as intellectual, support. I would have gone stir crazy had you not taken me out on those little 'coffee and cinnamon brioche-trips' to break up my days in front of the computer. I am ready for that long awaited holiday, and this time Sally Thorne, and Braun and Clarke will not be joining us! Let's go!

To my colleagues and fellow researchers at the Centre for Person Centred Research, thank you for the numerous little snippets of wisdom, encouragement and ad hoc philosophical discussions. To my colleague and Thematic Analysis mentor Gareth Terry, thank you for your analytical knowledge and practical guidance. Without your help I would still be coding (round 10!). I have no way of acknowledging your extensive input, other than by citing your publications as much as possible!

To Sally Thorne, thank you for the workshops and my 'private audience', which was truly inspiring and pushed my thinking in a direction it would have never gone. I feel privileged to have met you.

Thanks to Helen Doherty for proof reading my work and last but not least, a big thank you to AUT University and the School of Clinical Sciences who not only supported me financially but also gave me access to all the resources I needed, including those valuable writing retreats.

## **Ethics Approval**

Ethical approval for this study was granted on November 19th, 2014 from the Auckland University of Technology Ethics Committee (AUTEC). AUTEC Reference number 14/256.

## **Abstract**

This study explored the experience of Chronic Subjective Dizziness (Persistent Postural-Perceptual Dizziness). Chronic Subjective Dizziness stands out from many forms of dizziness because of its relative invisibility and diagnostic uncertainty. Although it is a common condition seen in healthcare practice, knowledge and understanding of Chronic Subjective Dizziness remains limited.

Research specific to Chronic Subjective Dizziness is in its infancy and initial scoping of the literature revealed that none specifically focused on the personal experience of the condition. This qualitative study drew on the methodology of Interpretive Description to explore the experience of working-age adults affected by Chronic Subjective Dizziness recruited from a specialist clinic in New Zealand. Inductive thematic analysis was used to analyse data generated from eight individual semi-structured interviews.

Three themes were constructed: 'It sounds like I'm crazy', 'I'm a shadow of my former self' and 'How will I survive?' This study identified that the experience of Chronic Subjective Dizziness was shaped by perceived illegitimacy of the condition, biographical disruption and a changed self-identity as well as the uncertainty and unpredictability of the condition. These appeared to be influenced by the individual's stage of life, priorities and personal needs, and availability of support systems and resources.

This study contributes to the current knowledge base in many ways. To the best of my knowledge, this is the first study to explore the personal experience of Chronic Subjective Dizziness as a condition in its own right, and to focus solely on a working-age adult population. The approach taken to this research, including methodology and methods for data collection and analysis, produced insights and points for consideration immediately applicable to health care practice.

This study highlighted that health professionals could do more to support those affected by Chronic Subjective Dizziness. Key points for health professionals to consider include: support needs are unique to the person, their priorities, and circumstances and support should as such be individually matched; legitimisation and unobstructed access to specialist services are key to successful management of the condition; and health professionals may benefit from re-evaluating current practice including their approach to assessment and treatment.

## **Chapter 1 Introduction**

This qualitative study explores the experience of working age adults affected by Chronic Subjective Dizziness (Persistent Postural-Perceptual Dizziness). It is widely acknowledged in the literature that chronic conditions interfere with daily life and have an impact on personal, social and work life (Lonardi, 2007). Research also suggests that the personal experience of a chronic condition not only shapes the way those affected manage their condition, but also has an impact on long-term health outcomes (Turner & Kelly, 2000).

A few studies have explored the experience of dizziness, but most made no distinction between acute and chronic, or whether dizziness was a primary or secondary problem (Kruschinski, Theile, Dreier, & Hummers-Pradier, 2010; Mendel, Lutzen, Bergenius, & Bjorvell, 1997; Mueller, Shuster, Strobl, & Grill, 2012; Olsson Möller et al., 2014; Yardley & Beech, 1998). Furthermore, no studies have isolated working-age adults from the elderly population, nor have they isolated the findings from those who have a confirmed diagnosis from those who do not. This study intends to advance current knowledge of the experience of dizziness by focusing solely on those who are of working age and for whom no structural pathology could be identified, two distinct characteristics of Chronic Subjective Dizziness (Bronstein, Lempert, & Seemungal, 2010; Herdman, 2007; Holle et al., 2015; Staab & Ruckenstein, 2005). New insights in the experience of Chronic Subjective Dizziness, and its impact on people's personal, social and work life may help health professionals better understand and support clients, and as such help them better manage their condition. The findings of this study also suggest greater reflection on assessment and treatment approaches currently recommended in the literature. Therefore, health professionals may use the findings of this study as a basis for evaluating current clinical practice.

This chapter presents the context for this study, followed by my personal reflections on the motivation for this study, and an outline of my assumptions as a clinician and researcher that formed the basis for this study. It concludes with a structure of the study.

### **1.1 Context for the Study**

Dizziness is a blanket term used to cover an array of sensations ranging from giddiness and light-headedness, to vertigo, pre-syncope and unsteadiness (Baloh, 1995; Barraclough & Bronstein, 2009; Bronstein et al., 2010; Herdman, 2007; Holmes & Padgham, 2011; Mendel et al., 1997; Ruckenstein & Staab, 2009). Scientifically, dizziness is defined as "a perceived disturbance of the spatial relationship between the self and the external world" (Matheson,

Darlington, & Smith, 1999, p.17), often secondary to a range of conditions (Baloh, 1997; Barraclough & Bronstein, 2009; Furman & Cass, 1996; Herdman, 2007).

Incidence and prevalence of dizziness is unclear (Sloane, Coeytaux, Beck, & Dalara, 2001; Yardley, Owen, Nazareth, & Luxon, 1998). Ambiguous use of the term 'dizziness', as described above, is often raised as a limitation in epidemiological studies (Hain, 2013; Herdman, 2014; Maarsingh et al., 2010; Matheson et al., 1999; Sloane et al., 2001). Data collection is also largely dependent on self-reporting, which is often hindered by the transitory, inconsistent and non-specific nature of dizziness (Duracinsky et al., 2007; Hannaford et al., 2005; Holmes & Padgham, 2011; Maarsingh et al., 2010). Despite these issues, dizziness is considered among the most common problems experienced by the general population and incidence is known to increase with age, especially in the female population (Nanda & Tinetti, 2003; Neuhauser et al., 2008; Sloane et al., 2001). Recent studies suggest that the lifetime prevalence of dizziness in the general population is approximately 30% (Bronstein et al., 2010; Hannaford et al., 2005; Neuhauser et al., 2008; Ten Voorde, van der Zaag-Loonen, & van Leeuwen, 2012). Dizziness is considered a major problem in the elderly and has been investigated in this population (Lasisi & Gureje, 2010; Matheson et al., 1999; Mueller et al., 2013; Olsson Möller et al., 2014). However, little is known about prevalence of dizziness in the working-age population (Yardley et al., 1998). Drawing on the findings from a variety of international studies, Hain (2014) estimated that roughly 15% of the middle-aged population is affected by dizziness.

Chronic dizziness is not only hard to define, it is also considered hard to diagnose and difficult to treat, which according to Bronstein et al. (2010) means that health professionals feel "a slight decline in spirit" (p.129) when they are presented with clients experiencing persistent dizziness. This is understandable in view of the extreme importance given in the literature to precise symptom description as the basis for differential diagnosis and effective treatment (Barraclough & Bronstein, 2009; Bronstein et al., 2010; Ruckenstein & Staab, 2009). Despite its challenges, chronic dizziness should not be ignored, as studies have shown it to be a disabling condition with a high negative impact on quality of life (Holmes & Padgham, 2011; Mueller et al., 2013; Neuheuser et al., 2008). There is a growing number of specialist services worldwide for people affected by dizziness, vertigo and imbalance. However, people affected by dizziness are rarely referred to specialist services (Lasisi & Gureje, 2010; Neuheuser et al., 2008). In New Zealand, multidisciplinary or one-stop specialist services remain scarce. This not only means that few people affected by dizziness are referred to specialist services, but when they are, they are often referred from service to service. Based on conversations with my

clients, access to specialist services in New Zealand appears to be hindered by distance, finances, and poor referral processes. This may be related to specialist services being predominantly located in metropolitan areas and requiring private funding or insurance for all or part of its services, if the cause of the condition is not due to trauma. Consequently, the first port of call for people with dizziness is often their general practitioner or perhaps emergency services if dizziness is acute and significant. Discussions with fellow health professionals highlighted that not many were aware of specialist services, nor did they know how best to refer clients to such services. From a physiotherapy perspective, treating people affected by dizziness is often perceived as a specialist area requiring specific diagnostic and therapeutic skill sets (Herdman, 2007, 2014). Although there is a growing number of vestibular trained physiotherapists in New Zealand, they are often dispersed and not easily identifiable, or accessible to the general public. Participants in this study were recruited from one of the few multidisciplinary specialist services in New Zealand, where I was employed as a vestibular-trained physiotherapist.

## **1.2 Personal Reflections**

Researchers engaging in qualitative research are advised to be reflexive about their personal experiences and professional beliefs that inspire them to conduct a study, not only because it informs the processes and the findings of the research, but also supports the strategies that ensure the quality of the work (Berger, 2015; Caelli, Ray, & Mill, 2003). The researcher's interest discussed below will highlight the professional motivation for this study, while researcher assumptions will disclose the personal beliefs and values I bring to this study.

### **1.2.1 Researcher's interest**

My interest in exploring the experience of Chronic Subjective Dizziness originated from my work as a vestibular physiotherapist. At the start of this study, I was working in a specialist multi-disciplinary service for people with dizziness and balance disorders in New Zealand. In my role as a clinician, I frequently encountered clients affected by Chronic Subjective Dizziness or persisting dizziness for which no pathology could be found. Although each client presented differently, there were some distinct commonalities. For example, clients would often describe feelings of being 'disconnected from the world', 'being foggy headed or spaced out', or feeling as if their head was 'stuffed with cotton wool'. These nebulous symptoms would often be associated with more tangible symptoms, such as perceived postural imbalance, difficulty with visual precision tasks, or hypersensitivity to motion. Although the latter were well referenced in the literature, the ill-defined symptoms were not. If they were discussed it was usually in

association with co-morbidities such as anxiety. I observed that for most of my clients those ill-defined symptoms were more troublesome, appeared to interfere with life in an important way, and appeared to be refractory to treatment. Colleagues made similar observations and from informal discussions and participation in professional chat forums, it appeared not uncommon for health professionals to feel they had little to offer this client group. From a biomedical perspective, the framework that underpins my profession and current knowledge of Chronic Subjective Dizziness, there are two recommended treatment approaches: vestibular rehabilitation and pharmacological treatment (Bittar & von Sösten-Lins, 2015). Reports on the success rate of these approaches are ambiguous, and their strength is claimed to lie in their combination with psychotherapy, in particular Cognitive Behavioural Therapy (Edelman, Mahoney, & Cremer, 2012; Martin & Staab, 2012; Ruckenstein & Staab, 2009). The majority of my clients had not been offered pharmacological treatment or psychotherapy. The very few that had were reluctant to accept this, as the suggestion signalled to the client that health professionals perceived their condition to be psychogenic, a notion most of my clients rejected. As a physiotherapist, the only 'treatment' I had to offer was vestibular rehabilitation, which aims to improve dizziness through gradual introduction of exercises that draw on principles of desensitisation/habituation (Herdman, 2007; Martin & Staab, 2012). Evidence from one small-scale study suggests vestibular rehabilitation is effective for Chronic Subjective Dizziness ([www.vestibular.org](http://www.vestibular.org), n.d). However, if and how it reduces the nebulous symptoms described above, is unclear.

In practice, clients would tell me that they had difficulty managing essential activities of daily life, without adding exercises to their daily routine. Further, I observed that clients who could tolerate their exercises better over time, did not necessarily function better. It became apparent to me that improved outcomes in the clinical setting were meaningless if they did not translate into real life and that I needed to re-evaluate my approach. This insight led me to question the biomedical model I was predominantly working from, and contemplate applying a bio-psychosocial lens to try to achieve better treatment outcomes for this client group. It was not my intention to contest vestibular rehabilitation as a treatment approach, but rather to explore ways of making it more relevant and applicable. To do so, I felt the need to better understand the personal experience of Chronic Subjective Dizziness, including the most troublesome features of this condition and gain insight on how these influenced people's lives. I was also interested in exploring with people what would constitute a good outcome for them in the context of their condition and how that might differ from my perspective as a clinician. The current literature on Chronic Subjective Dizziness did not provide me with the answers to those questions. In fact, I was unable to identify papers that explored the personal experience



of Chronic Subjective Dizziness, or what was important for clinicians to consider when working with people affected by this condition. Furthermore, as a clinician I wondered if adults of working-age, the population group most affected by Chronic Subjective Dizziness, had priorities or needs that differed from other population groups. For example, the few studies that did focus on the experience of chronic dizziness were predominantly concerned with the impact on the elderly (Holmes & Padgham, 2011; Kruschinski et al., 2010; Olsson Möller, 2014). Were there circumstances unique to working-age adults that should be taken into account in the therapeutic interactions? As there were so many unknowns and little evidence on this topic, there was a need for an explorative approach to investigate the experience of Chronic Subjective Dizziness, as well as a focus on working-age adults. This study grew from a clinical dilemma and the desire to provide insights that were directly applicable to my practice as a physiotherapist. This is consistent with my chosen methodology, interpretive description (Thorne, 2008), described in detail in Chapter 3.

### **1.2.2 Researcher's assumptions**

It is unavoidable for clinicians to engage in a naturalistic enquiry without having prior knowledge or assumptions about a topic of interest. In fact, Thorne (2004) sees it as inherent to the interpretive descriptive methodology, scaffolding this present study, that researchers bring empirical as well as experiential knowledge to the research. Furthermore, assumptions may influence data analysis and researchers are therefore encouraged to be explicit about them (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). As a physiotherapist working in the field, I had my own assumptions derived from my clinical practice. At the onset of this study, I identified these through discussion with fellow researchers and through written reflections. These assumptions include:

- a) Ill-defined symptoms associated with Chronic Subjective Dizziness are part of the condition itself, not the result of an anxiety disorder or other psychological co-morbidity.
- b) Working-age adults have more responsibilities such as family, work, social and financial obligations that influence their experience of Chronic Subjective Dizziness compared to the more researched elderly population.
- c) Better description of the symptoms will lead to better understanding of the condition and is necessary for improving health care interactions.

### **1.3 Focus of Inquiry**

This study sought to answer the following research question: How do working-age adults experience Chronic Subjective Dizziness?

Chronic dizziness, including Chronic Subjective Dizziness, has a considerable impact on the individual's functioning, wellbeing and quality of life (Lonardi, 2007; Mueller, Shuster, Strobl, & Grill, 2012; Ten Voorde et al., 2012; Yardley et al., 1998). This will be further discussed in Chapter 2.

Understanding the dynamics of a chronic condition, including how people experience it, what aspects have the greatest impact on their lives, and what strategies people apply to manage their condition, is believed to be fundamental to effective and satisfactory health care delivery (Greenstreet, 2006). It is also considered that personal experience influences health related behaviours, participation and health outcomes (Yardley & Beech, 1998), as discussed in Chapter 2.

This study aims to highlight points for clinicians to consider when supporting those affected by Chronic Subjective Dizziness, and provide clinicians with insights that may help them reflect on, and perhaps modify, current health care practices.

### **1.4 Structure of the Thesis**

Chapter 2: Literature Review, provides a more detailed context to this study and provides a summary of the extant literature relevant to the topic, first from a quantitative perspective, and then through a qualitative or subjective lens. It provides a summary of key findings, derived from existing literature, as a reference point and rationale for this study.

Chapter 3: Research Design, provides an overview of interpretive description, the research methodology adopted in this study, and offers a rationale for why this methodology was considered appropriate. It will outline the methods used for data collection, and describe how thematic analysis was applied for data analysis, followed by ethical considerations and steps taken to ensure rigour.

Chapter 4: Findings, presents the experience of Chronic Subjective Dizziness in a narrative format incorporating extracts from participant interviews. Findings will be presented as three themes followed by a significant observation that supports the importance of interpreting findings in the context of the individual experience.

Chapter 5: Discussion, will further analyse and discuss the findings in the context of existing literature. Consistent with interpretive descriptive methodology, it will highlight the key findings relevant for clinical practice. It will conclude with study limitations, suggestions for future research and a brief conclusion.

## Chapter 2 Literature Review

### 2.1 Defining Chronic Subjective Dizziness

This study focused on Chronic Subjective Dizziness, a particular subtype of dizziness that has had many appellations and definitions since it was first described by Brandt and Dieterich (1986) as Phobic Postural Vertigo or PPV. Phobic Postural Vertigo was defined as a somatoform disorder characterised by a persistent sense of disequilibrium and recurrent spells of dizziness associated with phobic avoidance behaviours (Brandt & Dieterich 1986; Brandt, 1996; Brandt, Huppert, & Dieterich, 1994; Huppert et al., 2005). Its classification as a somatoform disorder was based on the observation that the majority of patients with Phobic Postural Vertigo presented with psychiatric disorders such as anxiety, depression, conversion or obsessive-compulsive disorders. This belief was reinforced by the frequent absence of organic or neuro-otological disorders that could explain its associated symptoms (Brandt, 1996; Brandt et al., 1994; Huppert et al., 2005; Kapfhammer et al., 1997; Pollak et al., 2003; Staab, 2012). Brandt and Dietrich's aetiological theorisation was heavily criticised by leading researchers in the field which led to a series of studies conducted by Ruckenstein and Staab in the early to mid-90's. Their research generated new understandings that resulted in an alternative formulation (Staab, 2012). Ruckenstein and Staab (2009), among others, acknowledged that behavioural factors may play a role in the onset and trajectory of the condition yet identified these as co-morbidities rather than diagnostic markers. The focus of this new formula, Chronic Subjective Dizziness or CSD, is as such more directed towards the syndrome's physical symptoms (Bronstein et al., 2010; Honaker et.al; 2010; Ödman & Maire, 2008; Ruckenstein & Staab, 2009; Staab, 2012).

Staab & Ruckenstein (2005, p.677) defined Chronic Subjective Dizziness as:

- a) Persistent ( $\geq 3$  months) sensations of non-vertiginous dizziness, light-headedness, heavy-headedness or subjective imbalance present on most days;
- b) Chronic ( $\geq 3$  months) hypersensitivity to one's own motion or to movements of objects in the environment;
- c) Exacerbation of symptoms in settings with complex visual stimuli (e.g., grocery stores) or when performing precision visual tasks (e.g. reading, using a computer);
- d) Absence of active physical neuro-otologic illnesses, medical conditions, or medications that may cause dizziness;

- e) Normal radiographic images of the brain; and
- f) Normal or non-diagnostic findings on balance function tests.

In scientific literature, the term Phobic Postural Vertigo is however still occasionally used, predominantly in non-English literature (Ruckenstein & Staab, 2008; Staab, 2012). The term Chronic Subjective Dizziness remained current until early 2014, when for undisclosed reasons and after an international consensus process, members of the Barany Society submitted a proposal to the World Health Organisation to add Chronic Subjective Dizziness to the International Classification of Diseases (ICD) under its new name: Persistent Postural-Perceptual Dizziness, also referred to as PPPD (Vestibular Disorders Association, n.d). Persistent Postural-Perceptual Dizziness has since been added to the World Health Organisation's draft list, due to be published as the ICD-11, in 2017 (Holle et al., 2015). To date, empirical literature on Persistent Postural-Perceptual Dizziness is underdeveloped which means that the difference between Chronic Subjective Dizziness and Persistent Postural-Perceptual Dizziness remains largely unexplained. In a recent podcast, Shepard (2015) claimed that the two entities are in essence the same, a notion also supported by Holle et al. (2015). Compared to Chronic Subjective Dizziness, the description of Persistent Postural-Perceptual Dizziness, as published on the Vestibular Disorders Association's website, offers more details on symptoms and triggers, and appears to further distance itself from the somatoform aetiology of Phobic Postural Vertigo.

This historical journey not only showed that causal beliefs have changed, but the re-classification and removal of the term 'subjective' from its name also indicated attempts were made to translate new understandings about causality into practice. For clarification, a comparison and overview of the descriptions that define all three constructs are shown in Table 1.

This study was conceptualised as international consensus was reached to re-name the condition Chronic Subjective Dizziness as Persistent Postural-Perceptual Dizziness, but before it was published. Consequentially, inclusion and exclusion criteria for participant selection were based on the definition of Chronic Subjective Dizziness, as described by Staab and Ruckenstein (2005) and not on the recently published diagnostic criteria for Persistent Postural-Perceptual Dizziness. A fundamental difference between the two definitions was that in Persistent Postural-Perceptual Dizziness participants should be symptomatic for a minimum of 50% of the time (Holle et al., 2015). This time-based criterion was not used in participant selection for this current study. Furthermore, the term Chronic Subjective Dizziness is still in use by experts in

the field, as evidenced by a recent publication by Indovina et al. (2015), co-authored by Staab, a member of the Barany Society responsible for the recent name change.

**Table 1. Definitions of Chronic Subjective Dizziness and associated constructs**

<b>Phobic Postural Vertigo (PPV)</b>	<b>Chronic Subjective Dizziness (CSD)</b>	<b>Persistent Postural-Perceptual Dizziness</b>
Persistent sense of unsteadiness or postural imbalance and recurrent dizziness attacks associated with phobic avoidance behaviours (Huppert et al., 2005)	Persisting sensation of dizziness with subjective imbalance lasting longer than 3 months, hypersensitivity to movement, exacerbation of symptoms in setting with complex visual stimuli without any physical neuro-otological illness, medical condition or medication causing dizziness, normal brain radiology and non-diagnostic findings on function tests (Staab & Ruckenstein, 2005).	Persisting subjective non-rotational vertigo or dizziness lasting longer than 3 months, present for at least 50 % of the time, hypersensitivity to motion stimuli, including self-motion or motion of objects in the visual surround, difficulties with precision visual tasks. Normal values on clinical balance tests. No objective testing for diagnosis of PPPD (Holle et al., 2015).

### **2.1.1 Diagnostic complexities and epidemiology**

Much has been published about the complexity of diagnosing dizziness, and the variable meaning ascribed to the term ‘dizziness’ was identified as one of the contributing factors (Barracough & Bronstein, 2009; Bronstein et al., 2010; Hain, 2013; Maarsingh et al., 2010; Matheson et al., 1999; Sloane et al., 2001). This current study focused on Chronic Subjective Dizziness, a specific subtype of chronic dizziness, often diagnosed by exclusion because of its relative invisibility and absence of bio-physiological markers that may identify a structural pathology (Barracough & Bronstein, 2009; Bronstein et al., 2010; Holle et al., 2015; Staab & Ruckenstein, 2005).

Research into the incidence and prevalence of Chronic Subjective Dizziness is scarce. In fact, epidemiologic data for dizziness associated with any single condition is limited (Neuhauser et al., 2008). A retrospective study by Ödman and Maire (2008) reported approximately 10% of the patients visiting a neurological clinic were diagnosed with Chronic Subjective Dizziness, which they considered significant. Staab (2012) claims it to be the second most common disorder in patients suffering from dizziness, with an incidence peak between 30 to 50 years of age. Staab (2012) also identified that females are twice as likely as men to

present with Chronic Subjective Dizziness, an observation made about dizziness in general by other authors in the field (Benecke, Agus, Kuessner, Goodall, & Strupp, 2013; Neuhauser et al., 2008; Ten Voorde et al., 2012). The prevalence of Chronic Subjective Dizziness in a New Zealand context is unknown.

### **2.1.2 Symptomology of Chronic Subjective Dizziness**

Characteristics of Chronic Subjective Dizziness are complex and wide ranging and therefore difficult to capture, yet may include:

- a) Light- or heavy- headedness
- b) Feelings of disequilibrium or imbalance
- c) Sensations of movement 'inside the head'
- d) Sensations of surface movement such as the floor moving towards or away from an individual
- e) Feeling dissociated from the environment
- f) Sensitivity to self-motion, movement from others or objects in the visual surround
- g) Exacerbation of symptoms in visually complex environments such as shopping centres, stores etc.
- h) Difficulties with precision visual tasks such as reading or working on a computer

(Staab & Ruckenstein, 2005).

## **2.2 Literature Search**

Preliminary scoping of the literature highlighted that the working-age adult's experience of Chronic Subjective Dizziness as a stand-alone construct, has yet to be explored despite the consensus that dizziness has a significant impact on the person's functioning and their support needs (Mendel et al., 1997; Mueller et al., 2012; Olsson Möller et al., 2014; Yardley & Beech, 1998). The scope of this narrative review was therefore broadened to explore the current state of knowledge about the personal experience of dizziness in the adult population in general.

### **2.2.1 Method**

Drawing on the principles of systematic review, a comprehensive search was conducted using the following three databases: EBSCO Health Databases (incorporating CINAHL, MEDLINE and SPORTDiscuss), OVID (including Cochrane, AMED and Evidence Based Medicine Reviews) and SCOPUS. Text-word searches using the following key search terms

‘dizziness’ and ‘vertigo’ combined with ‘experience’, ‘living’, ‘life’, ‘coping’, ‘adjusting’ ‘adapting’, and ‘perception’, using truncation and Boolean operators ‘OR’ and ‘AND’, were conducted (see Table 2 for a full search strategy). The key subject terms ‘vertigo’ and ‘dizziness’ were chosen based on the findings that although they are separate constructs, they are interchangeably used in the literature (Holmes, 2010; Holmes & Padgham, 2011). Vertigo was also part of the term ‘Phobic Postural Vertigo’, used to describe Chronic Subjective Dizziness prior to the mid-90’s and still in use with publications as recent as 2010. Relationship terms were chosen based on key terms commonly used in the chronic conditions literature. This was followed by a manual search of citations in retrieved papers.

**Table 2. Key search terms**

<b>Population (OR)</b>	<b>(AND)</b>	<b>Relationship term (OR)</b>
Dizz*		Experienc*
Vertig*		Liv*
		Life
		Cop*
		Adjust*
		Adapt*
		Percept*

***Selection criteria for inclusion***

- Peer reviewed publications between 1986, when Chronic Subjective Dizziness was first described as Phobic Postural Vertigo, by Brandt and Dieterich (1986), and December 2015.
- Publications with a focus on the adult population.
- Qualitative studies exploring the experience of dizziness from the individual’s perspective.

***Selection criteria for exclusion***

- Publications not in English, to avoid translation and interpretation errors.
- Quantitative studies with a focus on measuring dizziness impact, participation restriction or burden. Note: while these papers were not deemed to meet eligibility criteria for inclusion, some provided additional contextual information where appropriate and relevant.



- Qualitative studies that did not primarily focus on the personal experience of dizziness, for example, papers with a focus on the experience of a therapeutic intervention for dizziness.
- Qualitative studies where the experience of dizziness was secondary to a complex condition, and could not be separated from the experience of other associated symptoms, for example, studies reflecting on the experience of dizziness, fatigue, headaches, and imbalance following traumatic brain injury.

### ***Screening for relevance***

Identified papers were imported to a reference management system (Endnote) and screened for relevance based on title, or title and abstract if required. Full texts of potentially relevant papers were retrieved, and their reference lists manually searched for additional relevant papers. All papers of potential interest were added to the full text library and were read in full. Those that met the inclusion criteria were reviewed and summarised.

#### **2.2.2 Summary of studies**

Included papers are presented in alphabetical order in Table 3. Data were extracted from each paper including authors, year of publication, study design, purpose, participant characteristics, setting and key findings relevant to the topic of interest.

#### **2.2.3 Quality assessment**

Papers fitting the inclusion criteria were assessed for methodological quality using a Critical Appraisal Skills Programme (CASP) Checklist appropriate to their study design. The aim of this quality assessment was to systematically determine each study's clinical relevance ([www.casp-uk.net](http://www.casp-uk.net)). Key methodological weaknesses, if any, were highlighted (see Table 3). Studies were not excluded on the basis of quality, to allow for a full overview of the current state of evidence, but key strengths and limitations are reported so the findings can be considered within that context

#### **2.2.4 Search process and results**

The literature search process and results are presented in Figure 1. The literature search retrieved 3093 articles of which twenty-two papers appeared relevant to the topic of interest. A further two papers were identified through manual reference list searches. Twenty-four papers were read in full, of which nineteen papers were excluded based on the exclusion criteria detailed above. While these papers were not deemed to meet eligibility criteria for

inclusion, some provided additional contextual information. The five remaining papers included in this study were summarised, and are presented in Table 3, (see pp. 18-20).

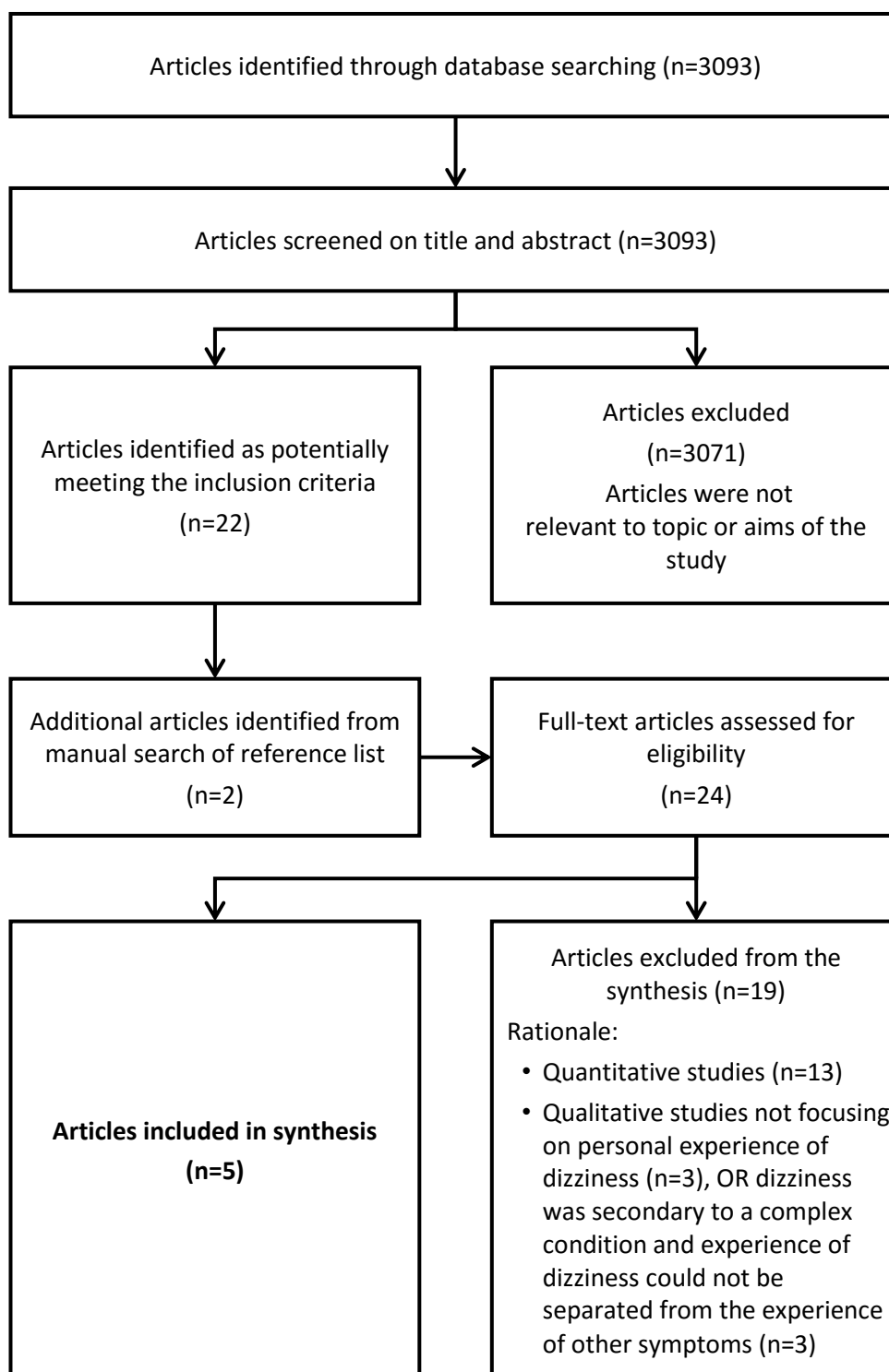


Figure 1. Literature search process and results. Adapted from Moher, Liberati, Tetzlaff, & Altman. The PRISMA Group (2009).

## **2.3 Findings**

This literature review aimed to explore existing knowledge on the personal experience of dizziness, the individuals' perception of how it affects their lives, and what factors influence their experience. As such, quantitative studies exploring dizziness impact, participation restriction and burden of dizziness based on data derived from standardised outcome measures or questionnaires developed by health professionals, were excluded. Such studies are unlikely to reflect the whole range of issues people with dizziness experience, or highlight personal factors that shape the experience (Bronstein et al., 2010; Mueller et al., 2012; Yardley et al., 1998). These studies do however provide important background information. As a result, findings are presented in two sections: section 2.3.1 discusses key findings from excluded studies and provides a context for Section 2.3.2, which synthesises and critically evaluates the findings from the five included studies.

### **2.3.1 Background information**

A broad range of quantitative studies has shown that of the majority of individuals experiencing dizziness, between 50 to 80%, were moderately to severely impaired because of their dizziness (e.g. Bronstein et al., 2010; Dros et al., 2011; Neuhauser et al., 2008; Ten Voorde et al., 2012; Yardley et al., 1998). Dizziness has also been found to affect the individual's physical and emotional wellbeing, and self-reported quality of life. One common threat to quality of life was the interruption to activities of daily life, predominantly due to avoidance behaviours such as not wanting to leave the house or take part in activities that require a lot of movement (Neuhauser et al. 2008; Yardley et al., 1998). There were different estimations of how common such behaviours were. Neuhauser et al. (2008) stated that between 10 and 19% of their study cohort displayed avoidance behaviours, while Yardley et al. (1998) reported this to be as high as 50%. Furthermore, dizziness was associated with increased utilisation of health care resources and being a socio-economic burden (Bronstein et al., 2010; Dros et al., 2011; Neuhauser et al., 2008; Ten Voorde et al., 2012; Yardley et al., 1998).

#### ***Impact on quality of life***

Quality of life was considered to be heavily dependent on the individual's personal factors and circumstances, and correlated with participation restriction, which was reported to be significant after 36 years of age and subject to rise incrementally with age, especially in elderly females (Yardley et al., 1998; Takano et al., 2010). Physical and functional impairment was reported to affect health related quality of life more than emotional impairment (Ten

Voorde et al., 2013). The impact and burden of dizziness appeared to be strongly influenced by dizziness-associated symptoms such as nausea, vomiting, headache, concentration, memory and tiredness (Mendel et al., 1999). Perceived unsteadiness, visual-perceptual problems, and autonomic symptoms not only affected individuals' confidence in their ability to move around quickly and freely, but also made them feel unable to go out alone, out of fear of falling and related consequences, such as harming themselves or others. As a result, many preferred to stay at home where they felt safe and comfortable (Holmes & Padgham, 2011; Lasisi & Gureje, 2010; Mendel et al., 1999; Mueller et al., 2014; Takano et al.; 2010).

Geographical, environmental and situational factors also appeared to influence the impact of dizziness on people's lives. For example, people living in major cities such as London, appeared to be more affected by their dizziness than those living in smaller cities (Bronstein et al., 2010). Bronstein et al. (2010) theorised that use of public transport, longer commutes, employment status, employment demands, priorities, living arrangements or social support systems may be different for people living in metropolitan areas. Takano et al. (2010) also claimed that education and wealth influenced the experience and quality of life, based on their observation that well educated and wealthier people seek more opportunities to socially interact and take part in more pleasurable activities.

### ***Impact on social life***

The majority of studies showed that a large proportion of people experienced a disrupted social life because of their dizziness, with some claiming to be selective when it came to participating in social activities (Takano et al., 2010; Tinetti et al., 2000), for example, not being able to go out with the family or pursue outdoor activities. Many individuals reported feeling socially isolated and feared stigmatisation. Dizziness also affected travelling, with 50% claiming they had difficulties using public transport or travelling by car (Bronstein et al., 2010; Mendel et al., 1999). High dependency on others for outdoor mobility and restricted social networking were two factors associated with reduced quality of life (Holmes & Padgham, 2011; Lasisi & Gureje, 2010; Mendel et al., 1999; Mueller et al., 2014; Takano et al.; 2010).

### ***Impact on work-life***

Despite the fact that the impact of dizziness on work-life has yet to be comprehensively explored, there is some evidence to suggest it has the potential to negatively impact vocational outcomes. For example, research reports that 21% of people affected by dizziness, stopped working and 27% had to change their job because of their dizziness (Bronstein et al., 2010). Impact on work-life also seemed to be influenced by a person's

profession and socio-economic status, with non-manual skilled workers appearing less affected by dizziness, compared to their manually skilled or unskilled counterparts (Yardley et al., 1998). From a socio-economic perspective, a significant proportion of employed individuals, approximately 40%, claimed to have difficulties at work with 15 to 40% claiming to have taken sick leave because of their dizziness (Holmes & Padgham, 2011; Möller et al., 2014; Neuhauser et al., 2008). Loss of working days and reduction of workload was perceived to have had a considerable impact on work productivity; however, for individuals who had been forced by dizziness to give up their job, there was also a humanistic impact such as loss of sense of belonging and self-worth (Benecke et al., 2013; Rogers, 1995).

### ***Impact on health care resources***

Dizziness was associated with a high demand on General Practitioners (GPs) and specialist services such as neurological and Ear Nose and Throat (ENT) specialists, and accident and emergency services (Benecke et al., 2013; Bronstein et al., 2010; Neuhauser et al., 2008).

This background information highlighted that the impact of dizziness is complex and far-reaching, and is influenced by multiple personal and socio-economic factors. While it is important to understand the relationship between dizziness and certain key outcomes, it does not help health professionals to understand what it is about the personal experience that contributes to these outcomes, nor how the experience could be improved through people's engagement with health services (Mueller et al., 2012). A pre-requisite for quality of care and better health outcomes is tailoring care to the individual's needs, which relies on knowing and understanding what the individual's priorities are in terms of their dizziness (Attree, 2000; Clark, Moorland, Greaves, Greaves, & Jolley, 2013; Greene et al., 2014; Kruschinski et al., 2010; Mendel et al., 1997). As such, a summary of included studies, exploring the personal experience of dizziness and a synthesis of the findings, follows next.

**Table 3. Summary of included studies**

<b>Author and publication date</b>	<b>Study purpose</b>	<b>Study design</b>	<b>Participant characteristics</b>	<b>Core findings relevant to topic of interest</b>	<b>Strengths and weaknesses of the study</b>
Kruschinski, Theile, Dreier, & Hummers-Pradier, 2010	To explore the priorities of primary care patients regarding their dizziness complaints with an aim to improve quality of care	Qualitative explorative study, Content analysis of semi structured face to face interviews	N=20 with dizziness of any cause or duration Recruited from 9 GP practices N=12 females, N=8 males > 65 yrs. Mean age = 79 yrs. Setting: Germany	Participants focused on aetiology of dizziness and believed their dizziness could be cured, improved or stabilized. Participants engaged in self-help strategies, identified the importance of family, peer and professional support to cope with dizziness. Some accepted, came to terms with dizziness; others trivialised, ignored dizziness but most wanted to regain control over dizziness. Main fear was loss of mobility and independence.	Strengths: good methodological audit trail. Weaknesses: broad inclusion criteria, no diagnostic homogeneity, data collection - mean interview duration 19 min.
Mendel, Lutzen, Bergenius, & Bjorvell, 1997	To explore the experience of living with vertigo and dizziness.	Qualitative explorative study applying grounded theory to analyse semi-structured face to face interviews	N=10 with history of chronic dizziness, diagnosed with a peripheral vestibular disorder from an audiology out -patient clinic in University setting. N=6 female, N=4 male between 24 and 62 yrs. Setting: Sweden	Participants felt insecure, rebuffed, a loss of dignity, and exhausted. Reactions from health professionals and others perceived as affirming or dismissive. Planning and adapting as a way of functioning. Recommendations: on-going support from healthcare professionals is needed (including information and better teamwork).	Strengths: well documented research process, good audit trail, sound methodological choice for study. No major weaknesses were identified

Author and publication date	Study purpose	Study design	Participant characteristics	Core findings relevant to topic of interest	Strengths and weaknesses of the study
Mueller, Shuster, Strobl, & Grill, 2012.	To investigate the perspectives of individuals with vertigo and dizziness on the experience of functioning and health using the International Classification of Functioning (ICF)	Qualitative descriptive design, using the meaning condensation procedure to analyse semi-structured face – to- face interviews	N=12 with chronic dizziness, recruited from an out-patient clinic, mixed diagnosis. N=5 females, N=7 males, age between 29 and 75 years of age Setting: Germany	Many different aspects of functioning and health are relevant. Activity and participation was most affected (daily routines, handling stress and demands, maintain standing positions, walking, moving around, outdoor mobility, driving motorised vehicles and using public transport, shopping, housework, paid employment, sports and socialising) followed by aspects of body functions (conscious functioning, temperament and personality functions, emotional functions, nausea and vomiting, gait and movement). Various environmental and personal factors contribute to complexity of functioning (medication, attitudes of strangers and health professionals).	Weaknesses: Query inappropriate research methods used: some data (personal factors and coping strategies) did not fit within the ICF framework. Aims of study not congruent with claims.

Author and publication date	Study purpose	Study design	Participant characteristics	Core findings relevant to topic of interest	Strengths and weaknesses of the study
Olsson Möller et al., 2014	To explore the older person's experience of living with chronic dizziness	Qualitative explorative design. Content Analysis of semi-structured face-to-face interviews	N=13 with history of chronic dizziness Recruited from a primary healthcare N=7 females, age between 74-84 N=6 males, age between 73 and 87 yrs Setting: Sweden	Overarching theme: Fighting for control in an unpredictable life. Main themes: striving towards normality and having a precarious existence. Conclusions: taking safety precautions, physical and psychological support are needed, need for continuum of care, consider impact on life in process of supporting.	Strengths: Robust research process and methodology. Good audit trail Weaknesses: Exclusion criteria not disclosed
Yardley & Beech, 1998	To examine coping beliefs and mechanisms of people with vertigo	Post-structuralism deconstruction using content analysis of semi-structured face to face interviews	N=25 recruited from RCT exploring benefits of vestibular rehab for peripheral vestibular disorders (community based) N=25 females, N=10 male age between 26 and 78 yrs. Average 60 yrs Setting: United Kingdom	Participants identified themselves as powerless, dependent on health professionals for diagnosis and support and on others for physical assistance. Participants make commendable efforts to cope, despite predominantly applying avoidance behaviours. Identification of dizziness as an illness is important.	Strengths: Strong analysis and discussion. Weaknesses: Incomplete audit trail (ethical considerations and participant - researcher relationship missing).



### **2.3.2 The personal experience of dizziness.**

From the five qualitative studies included in this review (see pp18-20), three specifically focused on exploring the experience of chronic dizziness (Mendel et al., 1997; Mueller et al., 2012; Olsson Möller et al., 2014). One study was not explicit about dizziness duration (Yardley & Beech, 1998), while the others included participants with acute and chronic dizziness (Kruschinski et al., 2010; Mendel et al., 1997; Mueller et al., 2012; Olsson Möller et al., 2014). Two focused solely on dizziness from an elderly population's perspective (Kruschinski et al., 2010; Olsson Möller et al., 2014), while the other three included adults of all ages (Mendel et al., 1997; Mueller et al., 2012; Yardley & Beech, 1998). Two studies specifically focused on participants with dizziness of vestibular origin (Mendel et al., 1997; Yardley & Beech, 1998), while the other three included dizziness of any cause including idiopathic dizziness (Kruschinski et al., 2010; Mueller et al., 2012; Olsson Möller et al., 2014).

Mueller et al. (2012) used the International Classification of Functioning or ICF as a framework for qualitative data analysis and they identified that 471 aspects of life and functioning, linked to 142 ICF categories, were affected by dizziness. These findings not only demonstrated the complexity of dizziness, but also highlighted a broad range of influencing factors relevant to the personal experience, a spectrum hard to explore through quantitative measurements alone (Mueller et al., 2012; Olsson Möller et al., 2014). All five studies showed that dizziness itself, and its associated symptoms such as unsteadiness, nausea, etc. significantly interfered with daily life, even with the most basic activities such as listening and reading, let alone the more complex tasks such as managing a daily routine, work and travel. Community participation, forming personal and formal relationships, employment, and sports and recreation were also severely affected (Mendel et al., 1997; Mueller et al., 2012; Olsson Möller et al., 2014; Yardley & Beech, 1998). The findings from all five studies could be categorised into three themes: impact on the individual's life, support needs and coping strategies.

#### ***Impact on the individual's life***

In contrast to the quantitative studies that provided background information, qualitative studies captured more of the emotional impact of dizziness. For example, individuals claimed to feel vulnerable and insecure, especially those who experienced sudden unpredictable spells of dizziness or vertigo (Mendel et al., 1997; Mueller et al., 2012; Yardley & Beech, 1998). Leading an unpredictable life and having to carefully plan all activities meant that dizziness was always on the individual's mind and that they were on constant alert, which

meant they often felt physically and mentally exhausted (Mendel et al., 1997; Olsson Möller et al., 2014). Physical and emotional exhaustion interfered with social engagements, with many claiming that avoiding social interactions or reduced participation in social activities had led to losing friends (Mendel et al., 1997; Mueller et al., 2012).

Findings also showed that individuals only disclosed their dizziness to a very select few, out of fear of critical scrutiny or stigmatisation (Mendel et al., 1997; Yardley & Beech, 1998). Supportive people such as close family and friends were often described as not really understanding the condition, which participants found isolating (Mendel et al., 1997). However, social support was described as immensely important and appeared to help individuals to cope with their dizziness (Yardley & Beech, 1998). Depending on their attitudes and responses, social connections including family, friends and colleagues were either a help or a hindrance in the coping process (Kruschinski et al., 2010).

The literature suggested that fear of loss of mobility and consequently loss of functional independence was a great concern for those experiencing chronic dizziness (Kruschinski et al., 2010). The prospect of needing to live in a care home, as a result of loss of mobility caused by falls or consequences thereof, appeared to generate high levels of anxiety (Kruschinski et al., 2010). This anxiety was even more pronounced in people who had a caring role (Kruschinski et al., 2010), indicating that having responsibilities for others is also an important consideration in the experience of dizziness. Individuals not only perceived dizziness as a physical threat, for example the danger of loss of balance and risk of falls, they also felt they had become dependent on others, which was severely restricting their lives (Mendel et al., 1997; Olsson Möller et al., 2014; Yardley & Beech, 1998). Being dependent on others was described as frustrating and embarrassing (Olsson Möller et al., 2014).

In relation to work-life, findings showed that for those who were employed, having flexibility was key (Kruschinski et al., 2010). Flexible working hours, and having the ability to alter work tasks and duties, were named as the main strategies for holding down a full time job. Without flexibility, sick listing was the only option (Mendel et al., 1997).

### ***Healthcare and support needs***

Most of all, individuals expressed their need for affirmation, and showed that lack of affirmation has a range of consequences (Mendel et al., 1997; Olsson Möller et al., 2014; Yardley & Beech, 1998). For example, individuals questioned their own sanity (Mendel et al., 1997) and felt unsupported (Olsson Möller et al., 2014). Lack of affirmation from health professionals led to negative associations, with the professionals commonly being labelled un-

empathetic and incompetent (Mendel et al., 1997; Olsson Möller et al., 2014). There was a remarkable consistency in the perceived lack of support from the medical and allied health professionals, across all studies. Despite regular contact with healthcare providers individuals argued there was a lack of support. Support was not measured by the amount of contact individuals had with health professionals, but by the quality of those interactions (Kruschinski et al., 2010; Mendel et al., 1997; Olsson Möller et al., 2014; Yardley & Beech, 1998). Quality of support was described as receiving information, especially around aetiology, and advice on how to live with dizziness (Kruschinski et al., 2010; Mendel et al., 1997; Yardley & Beech, 1998). How best to manage the dizziness depended on the individual's beliefs about illness, for example those who believed that their dizziness could be cured wanted medication or welcomed a specialist referral. Those who did not believe in a cure wanted to know about strategies that could help them attain a reasonable quality of life (Kruschinski et al., 2010).

### ***Coping strategies***

Coping is a complex process with a broad spectrum of strategies ranging from accepting, coming to terms, regaining control, trivializing, to ignoring (Kruschinski et al., 2010). Regaining control stood out as a coping strategy, with most individuals commenting they had to fight to live their life in a way they were used to, or in a way they were happy with (Olsson Möller et al., 2014; Yardley & Beech, 1998). Regaining control was achieved by either not giving in to the dizziness and keeping on doing what was normal despite its consequences, through adaptation, or by avoiding activities (Kruschinski et al., 2010; Olsson Möller et al., 2014; Yardley & Beech, 1998). Keeping active and refusing to accept help from others, or refusing to use mobility aids were often used as examples of not giving in. Holding on to objects or people when walking, planning activities in advance, and preparing for the worst, were examples of adapting. Giving up activities like reading or watching TV, use of alcohol and participation in sports and recreational activities were examples of avoidance behaviours (Kruschinski et al., 2010; Mendel et al., 1997; Olsson Möller et al., 2014; Yardley & Beech, 1998). Adaptive or avoidance behaviours were seen as a way of controlling the condition, yet engaging in such behaviours was perceived as restrictive and was claimed to make individuals feel sad and defeated (Kruschinski et al., 2010; Mendel et al., 1997). This was particularly the case for people who claimed to have no choice but to adapt or avoid, and who felt that these strategies were forced upon them (Olsson Möller et al., 2014). Yardley & Beech claimed that seeing 'the self' as a victim versus "courageous copers" strongly influenced how individuals experienced their dizziness and how they perceived its impact on their lives (1998, p. 318).

Coping was therefore seen as a fluid process where individuals moved perpetually between determination to cope and inability to cope (Yardley & Beech, 1998).

Other coping strategies were: (1) risk management, by changing physical environments to eliminate hazards risk (Kruschinski et al., 2010; Olsson Möller et al., 2014); (2) trialling alternative or complimentary therapies such as acupuncture, herbal medicine or massage; and (3) engaging in self-help strategies such as applying relaxation techniques (Kruschinski et al., 2010).

### **2.3.3 Reflection on current knowledge and knowledge gaps.**

The literature search brought to light the paucity of studies exploring the personal experience of chronic dizziness, despite the recognition of its importance (Bronstein et al., 2010; Yardley & Beech, 1998). It also appeared that none of the studies found in the search, particularly focused on Chronic Subjective Dizziness, which makes this current study, to the best of my knowledge, the first study to do so.

Most papers did not differentiate between the experience of acute dizziness and chronic dizziness, nor did they appear to consider it important to differentiate between idiopathic dizziness and dizziness secondary to an underlying condition. By focussing on Chronic Subjective Dizziness, I am making this distinction, and by comparing the findings from this current study with those from existing literature (see discussion in chapter 5), I hope to find nuances in experiences that warrant making that distinction.

Further, most studies solely focused on the elderly, or were age non-specific but weighted more towards the elderly population. Dizziness in the elderly is considered complex, as it is often the result of an age-related multisensory disorder or medical condition (Tinetti et al., 2000). These conditions affect postural control and muscular-skeletal or sensory systems, rendering individuals more vulnerable to situational challenges (Holmes & Padgham, 2011; Möller et al., 2014; Mueller et al., 2014; Kruschinski et al., 2010). Decline in balance, associated falls, loss of mobility, and reduced independence or participation may then result in loss of confidence, emotional distress, anxiety and/or depression (Takano et al., 2010; Tinetti et al., 2000). As highlighted in this narrative review, the elderly have concerns about death, hospitalisation and forced transitioning into care facilities, which in turn increased their levels of anxiety and depression (Dros et al., 2011; Lasisi & Gureje, 2010; Möller et al., 2014; Mueller et al., 2013; Tinetti et al., 2000). Individuals with multiple physical and psychological symptoms reported higher levels of participation restriction (Mendel, Bergenius, & Langius, 1999; Yardley

et al., 1998) and lower health related quality of life (Ten Voorde et al, 2012). Isolating the impact of dizziness from the impact of aging, in relation to quality of life, is a difficult and complex process, which may confound research findings (Neff et al., 2002). Although, some authors touched upon the impact of dizziness on work-life, their focus on the elderly may suggest that researchers consider dizziness to be more problematic for the elderly,

The key aim of this present study is to bring nuances to light that the existing literature has not done to date, and hereby gain new insights into the experience of dizziness as perceived by people of working age and the factors that shape the experience; with an expectation that this will deepen current knowledge and bring forth understandings essential to the advancement of clinical practice.

## **2.4 Summary**

This chapter collated and evaluated the current body of evidence regarding the experience of dizziness. It highlighted that, despite the consensus that the individual's experience is important, research focusing on the experience of Chronic Subjective Dizziness from a working adult's perspective, has been scarce, thus strengthening the rationale for this current study. My approach to the generation of new knowledge will be discussed in Chapter 3.

## **Chapter 3 Research Design**

This chapter outlines the qualitative research approach taken to this study. In the context of the underpinning ontological and epistemological assumptions, it describes interpretive description as the research methodology, and explains why this was found best suited to answer the research question and meet the aims of the study. Methods used for participant sampling, data collection and analysis are then elaborated upon, followed by relevant ethical considerations and steps taken to ensure methodological trustworthiness.

### **3.1 Methodology**

As discussed in the literature review, research relevant to Chronic Subjective Dizziness has predominantly focused on categorisation and etiological theorisation. Although important, such studies offer health professionals little insight into the experience of people living with the condition or the meanings they ascribe to that experience. As such, they are limited in their ability to inform health professionals how they might better support people with Chronic Subjective Dizziness in clinical practice. A key driver for this study was to produce new knowledge that would help health professionals better understand Chronic Subjective Dizziness, as a precursor to better practice. As such, a qualitative study design was deemed the most appropriate approach to use (Öhman, 2005; Thorne, 2008).

Interpretive description is the methodological approach used in this research. This choice was guided by this study's research question: What is the personal experience of Chronic Subjective Dizziness for adults of working age?

#### **3.1.1 Interpretive description**

Interpretive description is a disciplinary qualitative research approach philosophically aligned with naturalistic enquiry (Thorne, 2008; Thorne et al., 2004) and located within the interpretivism paradigm (Grant & Giddings, 2002). As an inductive approach, it seeks to explore clinically relevant phenomena, for the purpose of informing clinical practice (Thorne, 2008). Interpretive description draws on aspects of traditional qualitative methodologies such as grounded theory and phenomenology, but inherently it is a more applied approach and therefore does not bind the researcher to the strict philosophical alignment of these methodologies. Instead, interpretive description encourages researchers to draw on their disciplinary philosophical traditions and give primacy to the more pragmatic application to real world clinical practice. This gives health researchers more flexibility to explore applied topics

which are of interest to their profession, while preserving research quality and integrity (Thorne, 2008).

Interpretive descriptive studies are underpinned by the following epistemological and ontological assumptions:

- a) New insights into a topic of interest draws on pre-existing empirical and experiential knowledge;
- b) Generated new knowledge is the result of the researcher and participant's individual and co-constructed situational interpretations of experiences influenced by the research process;
- c) Multiple, often contradictory, realities shape new knowledge;
- d) Research findings should be interpreted in context of the reality in which knowledge was constructed;
- e) Similarities or patterns and individual differences found within subjective experiences are of interest (Thorne, 2008).

### **3.1.2 Methodological suitability**

Interpretive description was considered an appropriate methodology for this study for a variety of reasons:

As discussed in Chapter 2, the experience of Chronic Subjective Dizziness has yet to be fully investigated, making this an explorative study. Studies of an explorative nature are generally more suited to an approach that draws on naturalistic enquiry (Grant & Giddings, 2002; Thorne, 2008; Thorne et al., 2004). This study also fits with the key assumption of interpretive description, which argues for subjective and experiential knowledge as a key source of data to inform clinical practice (Hunt, 2009; Thorne, 2008; Thorne et al., 2004).

This study's research question originated from my experience as a physiotherapist supporting individuals experiencing Chronic Subjective Dizziness. This study aims to provide health professionals with new insights, meaningful and directly applicable to practice. This study's findings will help shape professional interactions and meet the individual needs of clients. Interpretive description was developed for this exact purpose and draws on an inductive approach to inform and advance health care practice, by exploring phenomena that are clinically relevant (Hunt, 2009; Thorne, 2008; Thorne et al., 2004). Thorne considers it fundamental to the methodology that research starts with a practice-informed question,

where the aim of the research is to generate new knowledge and insights capable of shaping or advancing clinical practice (Thorne, 2008; Thorne et al., 2004).

This study approached knowledge, and new knowledge generation, from a contextualist perspective, which means that data interpretation needs to take full account of the context, is provisional rather than generalisable, and that knowledge is true in the context of how it was generated (Braun & Clarke, 2009; Clarke, Braun, & Hayfield, 2015; Madill et al., 2000; Terry, 2016). Researchers and participants co-construct knowledge through the research process (Thorne, 2008). In this study knowledge was constructed through the interview process, the setting in which it was conducted, and by the presence or absence of a prior therapeutic relationship between participants and myself, the researcher. Interpretive description is aligned with this philosophical stance, in that it requires findings to be present in the data but interpreted in context of the time and situation in which the individual's experience was captured (Thorne, 2008; Thorne et al., 2004). Thorne (2008) claims that ranges of sources of knowledge are relevant as scaffolding for research. In this context, both pre-existing empirical and experiential knowledge, as illustrated in the previous chapters, formed the basis for this research (Thorne, 2008). Both knowledge streams will therefore influence new knowledge generated by this study.

This study took a realist view, which meant that reality was viewed as socially constructed and that it acknowledged the notion that there are multiple, perhaps contradictory, realities (Braun & Clarke, 2013). Interpretive description supports these philosophical views and aims to highlight commonalities, but also variations, across the individual experiences of a phenomenon (Thorne, 2008). Gaining new insights into the experience of Chronic Subjective Dizziness depends on recognising patterns in the experiences, individually or across, and in the factors that shaped them.

## **3.2 Research Methods**

Research methods for sampling, data collection and analysis were chosen for their agreement with interpretive descriptive methodology (Hunt, 2009; Thorne, 2008). As such, the chosen methods support the inductive approach taken to this study and lend themselves to producing clinically relevant findings. These are discussed below.



### **3.2.1 Sampling**

This study applied a purposive sampling strategy, an approach consistent with interpretive description (Thorne, 2004). Purposive sampling ensured the phenomenon of interest was represented in the research through the use of strict inclusion criteria, and informed the recruitment strategy (Braun & Clarke, 2013; Thorne, 2004, 2008).

#### ***Inclusion criteria***

- a) Adults of working age, between 18 and 65 years. However, some flexibility in the upper age limit was allowed in the context of an aging population and the increasing older workforce (Khawaja & Boddington, 2009). Participants over 65 years of age, who were in paid employment, were still considered if they met all other inclusion criteria.
- b) Experiencing symptoms matching the definition of Chronic Subjective Dizziness as described by Ruckenstein and Staab (2009) (see p. 8).
- c) Able to participate in interviews conducted in English.

#### ***Rationale***

- a) As discussed in the literature review, the occurrence of Chronic Subjective Dizziness spans adolescence to adulthood with the majority of people being between 40 and 50 years of age (Ruckenstein & Staab, 2009). This study therefore particularly aimed to include people of working age. In the literature, working age is a fluid concept, with a lower age limit typically set between 15 and 20 years, and an upper age limit between 60 and 65 years. In this study, only adults over 18 years of age were considered to ensure that participants were able to give informed consent, while the upper age limit ensured that the experience of Chronic Subjective Dizziness on work-life could be captured.
- b) Participants had to have experienced dizziness that matched the definition of Chronic Subjective Dizziness as described by Staab and Ruckenstein (2005) to ensure that the phenomenon could be explored (Braun et al., 2015).
- c) Participants were required to have the ability to express themselves in interviews conducted in English for various reasons, including:
  - Incorporating interpreters into qualitative research adds another level of complexity. Insufficient control over the accuracy of translation, and researcher-interpreter or interpreter-participant relationship are known to influence the research process (Temple & Edwards, 2002, Temple & Young, 2004).

- Engaging interpreters may jeopardise the rich description interpretive description seeks to obtain.
- Interpreter remuneration was not budgeted for in this study.

### **3.2.2 Recruitment strategy**

Strict inclusion criteria meant that the sample pool was limited. Only one recruitment locality, in the North Island of New Zealand, could guarantee that all necessary medical investigations had been completed, to rule out any otological, medical, or psychiatric pathology. This locality was a recently established specialist service, providing diagnostic tests and assessments for people with suspected vestibular dysfunction and dizziness or balance disorders, where I was employed as a physiotherapist at the time of study commencement.

The recruitment locality's electronic client database was used to identify potential participants. Recent establishment of the recruitment locality meant that the sample pool was restricted to clients who had registered with the locality from December 2013 onwards.

Parameters were set to identify people who had previously given written consent to be approached for research purposes and their medical notes screened for eligibility.

To minimise the risk of coercion that could arise from my role conflict (i.e. physiotherapist and researcher), no one for whom I still had therapeutic responsibility or who had been my client within the last three months was invited to participate. With that exception, all those identified as potentially meeting the inclusion criteria were invited to take part. Those that showed an interest were further screened to confirm that they had not been diagnosed with a condition other than Chronic Subjective Dizziness that could explain their symptoms.

### **3.2.3 Sample size**

This study aimed to recruit between eight and ten participants. This sample size was considered to be sufficient for examining the experience of Chronic Subjective Dizziness, allowing for adequate diversity, while ensuring that the study was feasible as a Masters project, restricted by time and finances (Terry, Hayfield, Clarke, & Braun, in press).

### **3.2.4 Data collection**

Individual face-to-face interviews were the primary method of data collection; however, phone or Skype interviews were offered if preferred or more practically viable for

the participant. Participants were invited to submit written reflections via post or email, up to 48 hours post-interview. In my clinical role as a physiotherapist I observed that people often struggled to communicate their experience of dizziness, and would frequently contact me following a consultation, to share additional information or “things I forgot to mention, but feel are important for you to know”. Polkinghorne (2005) regards this as one of the limitations of spoken data collection; that it is dependent on the person’s ability to access their thoughts about their experience and translate this into spoken language that effectively communicates their experience in that moment. Allowing submission of post-interview reflections not only gave participants an alternative way to articulate their experiences, but also gave them the opportunity to share sensitive information they may not have felt comfortable sharing in a face-to-face interview. Interpretive description considers these “collateral data sources” to be a good adjunct as they often enrich the data and help to construct a deeper understanding of the experience under investigation (Thorne, Reimer Kirkham, & MacDonald –Emes, 1996, p. 174).

The interviews were semi-structured, which meant that they aimed to explore the meaning or experiences of life events yet were adequately focused so that they shed light on shared experiences (DiCicco-Bloom & Crabtree, 2006). In keeping with the nature of semi-structured interviews, predetermined open-ended questions that stimulate initial dialogue were chosen as a guide (see Appendix A). Follow-up questions and probes were used in response to participant responses with the purpose of gaining deeper insights into the individual’s personal experience of Chronic Subjective Dizziness.

An iterative approach to data collection was taken. Questions were further developed throughout the process of data collection, from interview to interview, with the aim of gaining a greater understanding in the experience of Chronic Subjective Dizziness. Evolving interview questions allow researchers to access more depth and richness in the data, which helps to answer the research question more efficiently (Braun & Clarke, 2013; DiCicco-Bloom & Crabtree, 2006). In the context of the current study, while in earlier interviews a lot of attention was given to the symptomatic experience, later interviews focused more on how these symptoms interfered with participants’ lives.

Participants were able to choose the time and venue for the interview; however, it was suggested that this should take place either in their home or on AUT premises for privacy reasons.

Approximately 60 minutes were allocated for face-to-face interviews and up to 45 minutes for phone interviews. Interviews were digitally recorded and transcribed verbatim. I transcribed the interviews within 24 to 72 hours of data collection to ensure the transcription maximally reflected the spoken word and captured the meaning of the conversation without losing important details (Braun & Clark, 2013).

Field notes captured the interaction with participants, including particulars about the setting or environmental factors that may have influenced the interview. These were then used as a way of describing key features of the participant's context for the interpretation of findings.

### **3.2.5 Data analysis**

Thematic analysis, as described by Braun and Clarke (2006) was used to analyse the transcripts and adjunct data. Thematic analysis is a theoretically flexible technique for qualitative data analysis, not linked to any particular methodology or method of data collection. As it is not dependent on any specific theoretical or philosophical assumptions, and due to its well-described technical processes, it is accessible to researchers new to the field of qualitative research (Clarke et al., 2015; Terry et al., in press; Braun & Clarke, 2006, 2013). Thematic analysis can be inductive, deductive or a combination of both; however, to remain consistent with the interpretive descriptive methodology and the exploratory nature of this study, an inductive approach to data analysis was selected (Thorne, 2008).

A key principle of inductive thematic analysis is that the analysis occurs "at the intersection of the data and the researcher's theoretical assumptions, disciplinary knowledge, and research skills and experience" (Clarke et al., 2015, p. 230). This principle of inductive thematic analysis echoes the philosophical foundations of interpretive description, as discussed above, and is therefore considered a suitable match for this study's chosen methodology.

Thematic analysis as described by Braun and Clarke (2006) follows a six-phase process. However, this does not always follow a linear progression, and tends to be used recursively. The six phases not only provided a framework for analysis, aiming to ensure findings were present in the data, but also were key to interpretive description (Clarke et al., 2015). These six steps are described in more detail below.

### ***Step one: Familiarisation***

Familiarisation refers to becoming well acquainted with the data while informally starting to search for deeper meanings within individual data units and starting to recognise patterns or commonalities within a data set (Braun & Clarke, 2006). In the context of interpretive description this process is referred to as active engagement with the data, which is an important part of the rigour strategies described below (see p 34). In this study, familiarisation involved conducting and transcribing the interviews myself, checking transcriptions against the recordings for accuracy, reading and re-reading transcripts, writing analytical memos and diagrams to help me construct a deeper understanding of the data (Braun & Clarke, 2006, 2013; Thorne, 2008) (see Appendix B).

### ***Step two: Coding***

Familiarisation provided a solid basis for coding (Braun & Clarke, 2013; Clarke et al., 2015). A complete coding approach was taken to this study, as this was in line with the explorative nature of the study and ensured that the entire data set was coded for everything relevant to the research question (Braun & Clarke, 2013). Semantic codes were used to capture what was explicit while latent codes represented the underlying ideas or deeper meanings within the data, which may rely on theoretically informed researcher's knowledge to identify (Braun & Clarke, 2013; Saldaña, 2013). A coding extract with examples of both semantic and latent codes is presented in Appendix C. A thorough thematic analysis involves multiple rounds of coding to ensure the coding is relevant and comprehensive (Clarke et al., 2015). Four rounds of coding were applied to this study, with constant refinement of the coding framework as the main goal.

### ***Step three: Theme identification***

With the topic of interest and the research question in mind, similar patterns within and between all data sources were constructed, highlighting commonalities and inconsistencies of meaning (Braun & Clarke, 2006; Thorne, 2008). Codes with similar meanings were clustered together to form candidate themes, with repeated checks that the meanings between raw and coded data were preserved, and that theme development was data driven (Thorne, 2008).

### ***Step four: Theme revision***

Candidate themes were reviewed to check if they represented the meaning of the coded data and then again in the context of the entire data set. Developing themes were

repeatedly assessed and challenged through discussions with supervisors and fellow researchers to ensure interpretation of the data was robust (Clarke et al., 2015). Candidate themes were adjusted until I was sure that the analysis addressed the research question, reflected the content of the data, and captured key participant meanings.

#### ***Step five: Defining and naming themes***

Themes were named by using participants' own words, which represented the central organising principle or 'essence' of each theme. Theme definitions were created and examined to ensure they were internally consistent and coherent, and their boundaries and relationships were established (Clarke et al., 2015).

#### ***Step six: Thematic analysis report***

Thematic analysis report refers to the write up of the results, which drew on a mixture of data extracts, researcher notes from the entire research process, and researcher interpretation. Data were analysed both illustratively (as examples), and analytically (as objects of wider interpretation). These are presented in Chapter 4.

### **3.3 Rigour**

Rigour refers to the strategies put in place that raise the quality of the research and ensure credibility (Noble & Smith, 2015). Interpretive description recommends that these strategies be embedded throughout the research process (Thorne, 2008; Thorne, et al., 2004). In addition to generic standards that ensure quality in all qualitative studies, Thorne (2008) identifies four key criteria for judging credibility in interpretive descriptive studies. Each of these is discussed below in the context of the current study.

#### ***Epistemological integrity***

Thorne (2008) described epistemological integrity as the consistency between the research question and the philosophical assumptions of the chosen methodology. In this project this was demonstrated by ensuring that the questions and the aims of the study were compatible with the chosen research methodology and methods, including sampling, data collection and analysis.

### ***Representative credibility***

A study is considered to have representative credibility if the claims made about a phenomenon are congruent with the sampling method (Thorne, 2008). The purposive sampling strategy used in this study ensured credibility in multiple ways:

- a) Purposive sampling made certain that the phenomenon under investigation was present in the sample.
- b) The sample size allowed for commonalities to be found between individual experiences.
- c) Homogeneity of the samples (i.e. targeting people with Chronic Subjective Dizziness) reduced the risk that the experience under investigation was related to other conditions other than Chronic Subjective Dizziness, while diversity within the sample allowed for the breadth of experience within the category of Chronic Subjective Dizziness.

Active and prolonged engagement with the data before proceeding with analysis also added credibility by ensuring that findings captured the deeper meanings of the experience (Braun & Clarke, 2013; Thorne, 2008).

### ***Analytical logic***

A study's credibility also depends on the analytical reasoning and thought processes that shaped the analysis, and show others on what basis claims are made (Thorne, 2008). My analytical reasoning processes were made explicit by providing analytical examples, my interpretation of these, and by using the six-phase approach to thematic analysis, as recommended by Braun and Clarke (2013).

### ***Interpretive authority***

Keeping the interpretations grounded in the data and providing the reader adequate detail about the data so that this can be verified is one of the ways interpretive authority was demonstrated in this study. Engaging in analytical discussions and peer review, where coding and thematic decisions were discussed and challenged, further ensured interpretive authority (Thorne, 2008).

## **3.4 Ethical Considerations**

Ethical guidelines and procedures as outlined by the Auckland University of Technology Ethics Committee (AUTEC, 2014) were followed and particular consideration was given to the following five key principles:

### ***Informed and voluntary consent***

Participation was voluntary. Initial contact with potential participants was made via the recruitment locality administrator, independent from this study. They were informed of the study by a written invitation and participant information sheet (see Appendix D). Potential participants were given two to three weeks to consider the invitation and were encouraged to ask for further information or contact the research team to discuss the study before making a decision. Those agreeing to take part were sent a consent (see Appendix E) and demographics form (see Appendix F) which they returned in person at the time of their interview, or via email if they preferred, to take part in a phone or internet based interview. Prior to commencement of the interviews, participants were reminded of the purpose of the study, and the research process including the right to withdraw from the study any time prior to data analysis. During the interview process, participants had control over the information they wished to share and were not pressured to answer questions if they did not wish to do so.

### ***Respect for rights of privacy and confidentiality***

Privacy and confidentiality were considered to be most important. Participant privacy was protected at all times and identities were obscured by allocating an ID number to each participant. Participants were informed that no information that could identify them would be used in report writing and they were offered a choice about how they would like to be represented in the study, either by a pseudonym or by an allocated ID number. Consent and demographic forms were stored in two separate locked filing cabinets situated in a code-protected research office, on university premises. Interview recordings and transcripts were stored under the participant's ID number in password protected closed access files on the university's secure server and on my own personal password protected home computer. Participants were not informed about other participants and interviews were scheduled so that participants never met.

### ***Minimisation of risk***

Although this study was considered low risk, consideration was given to the possibility that participants might feel obliged to participate in this research. To alleviate this risk, only participants who expressed a prior interest in being contacted about research and who were no longer receiving active treatment, were invited to participate. Participants were also informed that their participation in this research would not advantage or disadvantage them in any way.



Consideration was also given to the possibility of emotional distress. Although it was not anticipated that participation in this study would have a negative physical effect, it was possible that exploring the participant's experience of Chronic Subjective Dizziness and how this affects their life, could potentially cause strong emotional responses. As a precaution, I discussed with the participants that if this became apparent through the interview, the interview would be paused or discontinued, and they would be offered support either from myself, one of the research supervisors or a professional counselling service free of charge. The agreement with the counselling service of the university was that if participants were distressed as a result of taking part in this study, they could access up to three professional counselling sessions (see Appendix G).

#### ***Truthfulness, including limitation of deception***

Potential participants were informed of all aspects of the research process and no deception, concealment or covert observation took place in this study.

I considered that participants may have felt uncomfortable with my dual role as clinician and researcher. It was explained to participants that the research was conducted independently from the recruitment locality and that this research was part of my master's project. Participants were informed that although they may have known me as their physiotherapist when they were under active treatment, I would be interviewing them as a researcher and not as a clinician.

#### ***Social and cultural sensitivity, including commitment to the principles of the Treaty of Waitangi***

Although this study did not specifically target Māori, ethnic diversity was considered important as it was anticipated this would add different perspectives and more richness to the data. However, not only are Māori underrepresented in the recruiting locality's electronic client database, but of those that were in the database none were registered as presenting with symptoms associated with Chronic Subjective Dizziness. Consultation was sought with five otolaryngologists in the greater Auckland area who confirmed a similar pattern in their localities i.e. none of the people referred to their service with symptoms of Chronic Subjective Dizziness, were Māori. This issue was discussed with the AUT School of Rehabilitation and

Occupation studies Mātauranga Māori committee<sup>1</sup> (see Appendix H). It was felt that I had taken all possible steps to ensure Māori were not deliberately excluded from this study and that inclusivity had been considered. Although it is possible that Māori experience Chronic Subjective Dizziness differently and that the findings do not resonate with Māori, this study may still have implications for Māori and all effort will be made to ensure that the findings are accessible to Māori.

### **3.5 Summary**

This chapter provided an overview of interpretive description as the chosen methodology for exploring the experience of Chronic Subjective Dizziness and why it was considered appropriate for answering the research question. Thematic analysis and how it was applied to this study was discussed, while ethical considerations and strategies for rigour provide the reader with the necessary background with which to interpret the findings of this study. These are detailed below (Chapter 4).

---

<sup>1</sup> Māori advisory group that ensures principles of the Treaty of Waitangi, integral to NZ culture, are honoured; and that research respects and meets commitments of relevance and inclusivity of the indigenous people of New Zealand.

## Chapter 4 Findings

This chapter introduces the participants, followed by a discussion of the findings resulting from the thematic analysis as discussed in Chapter 3 (pp. 32-34). In this analysis, I constructed three key themes that represent the participant's experience of Chronic Subjective Dizziness and the impact on their lives: 'It sounds like I'm crazy', 'I'm a shadow of my former self' and 'How will I survive?'

This chapter then concludes with a final discussion point highlighting that the perceived impact of Chronic Subjective Dizziness cannot be seen in isolation.

### 4.1 Participants

A preliminary client-database search at the recruiting locality showed that 33 people matched the diagnostic criteria of Chronic Subjective Dizziness, and were of working age. All were invited to take part in this study. Five potential participants responded, all of whom fulfilled the inclusion criteria and passed the additional screening as specified in Chapter 3 (see p. 30). A second recruitment drive, six months later, brought forward five more potential participants. All fulfilled the inclusion criteria; however only three agreed to take part and passed further screening. This brought the participants in this study to a total of eight.

Key participant characteristics, taken from the demographics form (see Appendix F), such as gender, age, ethnicity, chronicity of dizziness, and employment status are presented in no particular order, in Table 4. Six participants lived in a metropolitan area; two lived in a medium to large town. Participants who were currently on sick leave or who were employed part-time claimed that their employment status would be different if it were not for their dizziness. Two participants had parenting responsibilities for children younger than 12 years of age; one had parenting responsibilities for teenagers. Two participants claimed to have no social support, two had a supportive partner, four had an extensive support network of partner, friends, and family and whānau. Although no information on level of education or financial status was collected it was apparent from the information participants shared in the interviews, about their work or profession, that they had high levels of education.

Six of the eight participants were former clients of mine, with whom I had built a therapeutic relationship in my capacity of physiotherapist, and two were unknown to me. Five participants were interviewed face-to-face (two in their home, three preferred to be interviewed at AUT), one via Skype, and two by phone. All interviews were audio recorded

except for one where the recording failed due to operator error. A detailed account of this interview was made post-interview, drawing on field notes taken during the interview and on immediate recall. The participant this applies to and any data extracts taken from the written record, have been identified with a hash tag (#) in Table 4 and throughout this chapter. Two participants, one of whom was the participant whose recording failed, submitted written reflections via email within 24 hours of their interview. These were also included in the data analysis, and extracts taken from these reflections marked with an asterisk (\*).

**Table 4. Participant characteristics**

<b>Participant (Pseudonym)</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Approx. time post onset (years)</b>	<b>Employment status</b>
Ethan	Male	51	NZ European	>1 - <3	Full time self- employed
Lyna	Female	54	NZ European	>3 - <10	Part-time employed
Ava	Female	37	NZ European	>1 - <3	Part time employed
Thea	Female	66	NZ European	>10	Part time employed
Elvy	Female	30	NZ European	< 1	Extended sick leave
Naeve #	Female	43	NZ European	>3 - <10	Part-time employed
Sofie	Female	53	NZ European	>3 - <10	Full time employed
Molly	Female	36	NZ European	>10	Full time employed

## 4.2 Results

Three interrelated themes were constructed from the data: 'It sounds like I'm crazy', 'I'm a shadow of my former self' and 'How will I survive?' The first theme, 'It sounds like I'm crazy', represents the participants' reference to validation of the condition. It encapsulated three sub-themes: 'What is this?', 'Nobody knows' and 'Looking normal'. Theme two, 'I'm a shadow of my former self', reflects the participants' perceived change of self and the associated sense of loss. It encapsulated two sub-themes: 'A different person' and 'A different lifestyle'. Theme three, 'How will I survive?' shows the complexity of adjusting to life

disruption and encapsulated three sub-themes: ‘Sense of hope’, ‘Fix me’ and ‘Getting on with it’. These three themes and their sub-themes are depicted in Figure 2. Each theme and their corresponding sub-themes will be discussed, supported by participant quotes and data extracts that illustrate key aspects of each construct. More detailed interpretation and implications for practice will be discussed in Chapter 5.

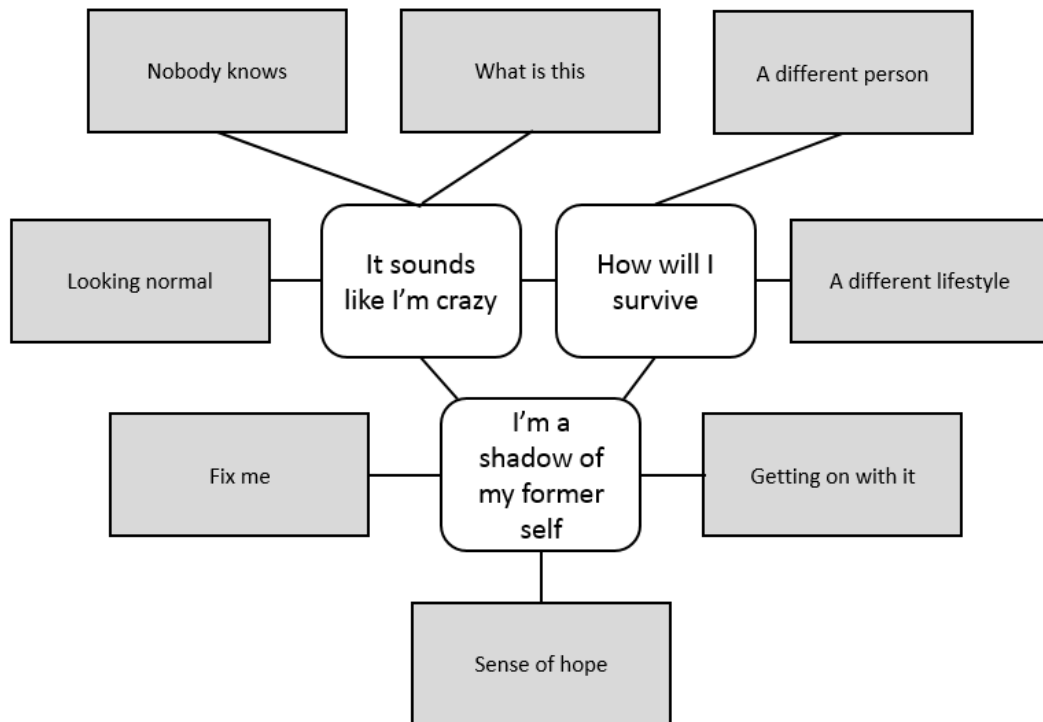


Figure 2. Thematic map.

#### 4.2.1 Theme one: ‘It sounds like I’m crazy’

This theme refers to perceived legitimacy of the condition and captures participants’ expressed need to be taken seriously and to be believed. There were many nuances in the way participants talked about legitimacy but validation from a health professional was most commonly referred to. Next, participants talked about validation from ‘others’ such as family, friends, acquaintances or work colleagues, as well as their own illness beliefs and self-validation. The emphasis varied between participants, often with one carrying more weight than the other. For example, although most participants felt a need to convince health professionals their condition was ‘real’; some were more concerned with how their condition was perceived by friends or colleagues, while for others it was both. Being disbelieved, or not

being taken seriously, appeared to shape the participants' own beliefs about their condition or experience, indicating the importance of legitimacy from others for self-validation. Depending on this external validation, participants seemed to fluctuate between a strong belief that what they experienced was 'real', and therefore worthy of understanding and support, and self-doubt. From the data, prerequisites of validation appeared to be 'knowledge' and 'understanding'. Deeper insights and data extracts that support these findings are presented below through the three sub-themes: 'What is this?', 'Nobody knows' and 'Looking normal'.

### ***'What is this?'***

When participants were asked to describe their dizziness, it was evident that 'dizziness' was a fluid and multi-layered concept. Each participant had their own set of symptoms, uniquely experienced by each individual, yet for all participants, symptoms that got in the way of life seemed the most salient. Simply listing these symptoms as if they were a concrete experience would miss the point of the participants' stories. The following extracts illustrate the variability between individual descriptions and their lack of clarity.

*"So sometimes, it sounds like I am crazy [participant laughs], it feels like the whole inside of my head is kind of just turning and, but (.) I know I am not moving cause it's not (.) you know [participant laughs] clearly not (.) but I feel like my whole head is just like trying to turn in a different direction and I then I might try to turn back the other way." (Elvy)*

*"It's almost like you have a little smudge on your brain, something that makes things a little blurry (...) but I think mainly I am sharp, but I would be like (...) it is weird, that I am talking to you and I am experiencing this at the moment, I have to, I'm really concentrating on what you are saying, so I can get it right, cause I do find that I probably wander a little bit." (Sofie)*

*"[...] a feeling that the floor was coming towards me and then moved away again [...] like there was too much movement in my head, like nothing was contained." (Naeve<sup>#</sup>)*

As these extracts show, it was common for participants to use imprecise and vague language (e.g. 'smudge on your brain') within the dataset. This indicated that participants found it difficult to articulate their dizziness in a way that represented all aspects of their experience and made sense for those who had not shared the experience.

Participants expressed embarrassment or frustration with their inability to clarify what 'being dizzy' meant, for themselves and for others, or for failing to find the vocabulary that encapsulated all aspects of that experience. Hearing themselves during the interview, trying to convey the experience of their dizziness, participants often apologised for their confusing and

unclear descriptions. Some became visibly agitated as demonstrated by gestures, postural changes, or changes in their tone of voice.

*"[...] the main symptoms is you don't feel yourself. Summing it up. What does that mean? [Participant taps fingers] That means, I think, the (.) like I said [sigh], so (.) OK, if you take the big picture (.) you don't feel as much as yourself (.) you don't feel yourself, but it is (.) it does (.) it is slowly getting better." (Ethan)*

Most participants portrayed their inability to succinctly describe their dizziness as a seed of doubt, for themselves and others. It was assumed that this was one of the reasons why they were not believed or taken seriously and they could hardly blame people for disbelieving them as 'it sounds crazy'.

*"[...] the other thing I would say is 'that it's real' you know, 'it's real, and I think it's (.) You feel embarrassed to say what it is because you can't really describe (.) it's kind of something and nothing, if you know what I mean?'" (Thea)*

Participants also engaged in a perpetual process of sense making. It was clear they were looking for patterns, cause and effect, or triggers, in an attempt to understand the variability in presentation, including onset, intensity and duration of their symptoms, yet were unable to give meaning to the complexity of the condition. For instance, Ethan noted:

*"Hmm, (...) the dizziness is (.) you don't feel yourself, and it comes and goes or the extent can change throughout the day. I find it is not totally constant (.)" (Ethan)*

Failing to describe and make sense seemed to further instil self-doubt, with some participants referring to themselves in negative terms, such as 'loopy', 'cuckoo', 'idiot', 'Muppet', 'hypochondriac', or 'drama queen'. Self-doubt was apparent throughout the data, yet it appeared to co-exist with a strong belief that the experiences were real. This appeared to create an internal turmoil that made participants question their mental health.

*"[Participant names husband] will say 'what is wrong with you?' well, 'I don't know' (laughs). 'I have no idea what is wrong with me, probably it's all in my head!'" (Thea)*

Self-doubt also appeared to have unfortunate consequences; for example, Thea refrained from seeking support out of fear of looking foolish:

*"In fairness, I must, to [names consultant], I never really talked to him about my visual vertigo, I didn't know that's really what it was (...) that's what I was calling it, and I just felt that that's how I am, after all these years, that is just how it is (...) I'm, umm (...) so I never really been to anyone and said look this is what is happening to me, because I just thought well (.) just pardon me, that is just how (...) how can you go and really talk to someone about these things, they just, probably just say 'oh yeah'." (Thea)*

In Thea's case, not being able to describe or make sense of her experiences left her feeling embarrassed to discuss these with her consultant. Lack of guidance and support resulted in Thea adopting various avoidance behaviours that, combined with a loss of confidence in herself and her capabilities, adversely affected her quality of life. These described behaviours were often reinforced by health professionals not being able to categorise their experiences into a nameable condition. This issue will be further discussed in the next sub-theme.

### ***'Nobody knows'***

Most participants spoke about the health professionals' lack of knowledge about the condition, which often meant that they were faced with diagnostic and prognostic uncertainty.

*"To start with, I was very frustrated, about (.) I had this issue (.) and they really were just, (...) really did not know what to do (...) yeah that was bit frustrating [...] what is interesting is (.) a lot of people say you get over this quickly (.) uhm, but what I've read and googled is that some people do get over it quickly, some people take years or never get over it. So there is a real difference of uhm (...) and you know (.) dizziness is a really, sort of (.) I don't know, an area that people don't know much about." (Ethan)*

It was apparent from Ethan's account that prognostic uncertainty was frustrating for him. It was common for participants to speak of using alternative sources to health professionals for information (e.g. Google) as they felt their health professional was not providing enough information and advice. In Sofie's case, lack of knowledge aroused anger and disappointment that ultimately lead to loss of confidence in health professionals.

*"It's made me a little untrustworthy on the medical side of it, cause I, not only from this, but I actually had another symptom that was all happening at the same time, hmm (.) and I went for two years, trusting this person I was talking to, and got it all wrong [...] I've perhaps become a little untrusting of the medical side." (Sofie)*

Participants also described being 'let down' by health professionals, undermining a sense of trust they had prior to the advent of their new condition. This was evident in Ethan's story:

*"It made me feel certainly that (.) that the GP knows very little about that and they tend to refer you to a specialist (.) where I always thought the GP knows the answer." (Ethan)*

For other participants, it was not the lack of knowledge, diagnostic uncertainty or unclear prognosis that was identified as a significant problem; it was their health professionals' lack of interest and support that caused them the most concern.

*"[...] the other physio I saw really got to me as well, she was sort of saying I was hyperventilating and how it was all in my head and need to see a psychologist and gave me a sheet of paper of things to avoid like (.) human environment, administration, talking, laughing, fluorescent light bulbs, lights (...) incredibly unhelpful and (...) yeah, I*



*was sort of in, in tears and she said that she didn't know what was wrong with me but I should go and do this, so I was like, it's a (...) I think I took that on board more than (...) yeah, I think I do care a lot about what people say and how people feel." (Elvy)*

Elvy's story showed that a professional opinion carries a substantial weight, as demonstrated by the strong emotional response it generated ("I was ...in tears"). Lack of knowledge in this case not only resulted in an unsubstantiated diagnosis but also led to unfounded and potentially counterproductive advice, perceived as unsupportive and therefore unhelpful. Providing Elvy with a list of possible triggers of hyperventilation, without ways to navigate what are often long lists, left her feeling more isolated than she had previously.

Naeve <sup>#</sup> said she was angry when her GP told her 'she needed to live with it' and that it was 'her burden to carry' and felt that it was only when she met with 'someone who knows what it is like' or 'someone with an understanding', that she felt listened to.

One participant linked the lack of interest or support back to health professionals' inability to resolve the problem, while others linked it back to lack of knowledge and awareness, and therefore competence

*"My GP is not, not very good, well she seemed OK to start with but it is not sort of something that you, I don't know can excise or give antibiotics for or hand pills or (...) it's yeah, so just feel like (...) yeah." (Elvy)*

Elvy's example showed that there is a perception that if a problem cannot be fixed, health professionals perhaps regard themselves as obsolete and lose interest in the person. Health professionals who showed a genuine interest in the person and their experiences were often perceived as trustworthy and helpful, regardless of whether they were able to contribute towards a diagnosis or were able to do anything that would improve the participant's experience. It was clear that participants felt that these characteristics were often missing from non-specialist services.

*"...and even if you had found nothing, I still felt that probably you could have helped me with the problems I was having anyway, because that is what your interest was and that is where (...) that is what you were all about ... and I felt I would believe what you told me (...) and I think that is another thing, to believe in the people that are trying to help you." (Thea)*

Participants talked about 'being fortunate' to have been referred to a specialist service. Feeling supported by such a service was often seen as a turning point as participants argued that being understood and feeling supported gave them a 'sense of direction'. One participant talked about how an open discussion with an 'interested and understanding health professional' was 'empowering' and how she felt better equipped to deal with her dizziness. Many therefore

advocated for early referral to such services, and showed disappointment with the time it took before they were referred.

*"When [...] I said, you know, that I had (.) testing and that there was a vestibular imbalance. He [the neurologist] said 'we already knew that'. (...) But 'what is that?' I mean, it's not (.) it's not, I mean, 'what is it?' 'How does it affect me?' 'What happens with it?' (.) and no, they don't have an understanding, and I think it is a very individual thing I believe, cause when I said about the exercises, things that I will be doing to try and help myself, he said 'well oh, our physio's could have done this and this and that, 'and they are all good physio's' and I do feel, I and I do feel there is not any understanding (...) you know." (Thea)*

These discourses show the importance of 'feeling listened to' and 'being understood', not only in the context of receiving validation from health professionals but also in the context of self-validation. Showing an interest in the person and their experience appeared to remove any self-doubt a person may have had. In the example below, the interest shown by a health professional helped Ethan to validate for himself that his problem was real that he was worthy of medical attention.

*"Initially the family doctor, it's like (.) you know (.) yeah, (.) there was not a lot of knowledge about that, so that was a little frustrating (.) that as I got to see the people who'd had (...) (looking for word) an interest in that (...) and that they could see, I was not just dreaming, (.) you know, people DO have these problems (.)" (Ethan)*

Participants did not only talk about the role of health professionals, but also referred to the understanding of others as important.

*"uhm (...) I think it's more the, you have to kinda suck it up and (...) cause people don't really understand, uhm (...) it sounds like an excuse if you think you're feeling like that (...) people don't understand what they haven't experienced themselves (...)." (Molly)*

Participants therefore actively sought peer support, people who have had similar experiences and were therefore able to understand and validate the experience; yet this was seldom found.

*"I've sort of tried to find (.), there have been a few other people that I have come across that I have met that have similar conditions (.) not the same, but similar (...) and I sort of felt very (.) when I was at my worst, I felt I really needed some sort of support group." (Lyna)*

Peer support appeared to be as important to the person as receiving support from health professionals. The absence of recognition of their condition within the wider society meant that participants often recounted finding any such support extremely helpful. The invisibility of the condition to the wider community will be discussed in the next sub-theme.

### ***‘Looking normal’***

Participants talked about the invisibility of the condition and referred to the frustration associated with not having any visible markers that explained their experience or justified their behaviours. For some, finding quantifiable or measurable proof was therefore extremely important as evidenced by their determination to have their dizziness endlessly investigated.

*[Participant talks about pursuing diagnostic testing] “it also meant that I was able to uhm (.) say to people ‘oh look, here is a graph, this is what I am like’ kind of thing and people are sort of ‘oh’ rather than ‘she’s making it up’, cause you sort of a (.) general (.) uh, the general feeling before (.) sort of (.) they would have said (... ) ‘see I am not just making it up (.) that’s what I am like’ umm, well I always knew that something was not right (.) it was more for other people ‘see, I’m sort of full of shit’. ‘This is why I can’t do this, and can’t do that’ sort of thing.” (Molly)*

Others had resigned themselves to their condition and its invisibility and talked about ‘giving up’ on trying to find objective proof of their condition. However, none appeared to have come to a complete acceptance of their condition. Despite talking about ‘moving on’ and ‘getting on with it’, they appeared to continue to engage in the perpetual sense-making process, and expressed a willingness to participate in further investigations, should that be presented to them.

*“I was pretty obsessed, I mean I spent a lot of time going, and a lot of money, going to doctors and tests and (...) things like that became more and more frustrated and I think in the end it was so easy just to (.) kind of ‘oh, I just switch that off and just live with it’ and it is not so severe enough that it is gonna invade my life anymore, uhm, it’s annoying, but it is not going make me live my life differently.” (Sofie)*

Invisibility did not only represent the absence of diagnostic certainty or the lack of proof that an organic condition was the source of the participants’ experiences; it also represented the physical invisibility of the condition.

*“It’s not visible, it’s not a visible thing (.) sort of thing, like an excuse when you say ‘I can’t do that cause because I feel like this.’” (Molly)*

*“I find that, I guess the hardest thing with this particular thing is that it is not a visible thing (...) yeah, that can make it difficult.” (Lyna)*

Participants talked in a dichotomous way about physical invisibility. For some the invisibility of the condition was beneficial so that they could maintain a façade of normality. Keeping up appearances seemed particularly important in the work environment, especially for participants who were employed and had little job security. They feared being judged by colleagues, or being deemed incompetent. For example, Naeve<sup>#</sup> said she needed to keep going, so she tried not let anyone see, but when it came to lunch time she wondered how she

would survive till three, when her workday ended. Participants spoke about trying to be 'discreet', or 'faking it' and stated that they were very careful about whom they confided in.

*"I just have to not mention it, cause as soon as you mention it they [talking about acquaintances and friends] look at you, 'oh my god, I cannot believe that you are making this lame, poor not real excuse' kind of thing, so you have to sort of not say anything (...) No, never (.) You just keep that to yourself and deal with that yourself, yeah. Definitely, cause based on past experience it hindered and not helped (.) so it's better to say nothing and seeming as normal as possible cause the more flawed you seem, the more they sort of go 'oh she's got this and this wrong', it's sort of like a black mark against you, the more normal you can seem and the less maintenance the better I think [...] I NEVER draw attention to it or make a big deal of it, cause they look at you as a hypochondriac, so it's better to just say nothing." (Molly)*

Simultaneously, invisibility was also a hindrance. Invisibility was extremely unhelpful in their quest to be taken serious, or to be understood. To improve understanding some wished the condition was visible, as illustrated in Lyna's quote below:

*[Participant talks about being open about her dizziness] "Uhm, with my family I am, uhm (.) a lot of people (.) yes, a couple of friends (.) well no (.) but (...) it is very hard for people who don't have it, to understand it, so it is quite an isolating experience (...) and because I look normal, they think I am normal (...) yeah, (...) yes, so (...) people know but they don't really know (.) the extent to what I am affected." (Lyna)*

Some even expressed that they wished they could trade their condition for a more visible one, such as amputation or cancer, as this was perceived to be more acceptable and better understood.

*"I don't know how many times I wished I had lost an arm or something instead of, which sounds horrible and sounds really selfish because I don't know how difficult it would be to have lost a limb or something but just it is more visual so you feel like people will understand and I have always been told 'don't worry about what other people think' that sort of thing, or just, you know it's about you and you need to concentrate on you and that is really difficult though when you (...) yeah." (Elvy)*

Most participants, however, appeared to fluctuate between wanting their dizziness to be visible and wanting to appear as normal as possible, and would manage this tension depending on the context they were in. It was apparent from their stories that navigating this tension was exhausting and detrimental to their sense of self. This issue will be further discussed in theme two.

#### **4.2.2 Theme two: 'I'm a shadow of my former self'**

This theme captures participants' perceived change of identity and refers to a shift in self-identity, in response to the challenges imposed on them by their condition. This encapsulates not only how participants felt different from a physical point of view ('feeling

different'), but also refers to a changed 'sense of self' ('being different'). 'Feeling different' and 'being different' appeared to be reciprocally related, yet 'feeling different' was more fluid and variable compared to 'being different'. 'Being different' appeared to be a slow involuntary transformational process, an alteration in their sense of who they are as a person and their social identity. This theme also represents the lifestyle changes participants felt they had to make and the impact of those changes on their quality of life. Participants often stressed that they had no choice, and it was clear that participants resented these undesired identity and lifestyle changes. The changes were often talked about with a 'sense of loss' and participants appeared to be grieving for the 'old me'. On the other hand, some seemed to have reached a level of acceptance and identified positive aspects to 'the new me' or their new lifestyle.

This theme is supported by two sub-themes: 'I'm a different person' and 'Having a different lifestyle', as presented in Figure 2. These sub-themes will serve as a structure for presenting further insights in these findings, supported by data extracts.

#### ***'A different person'***

Being 'a different person' was discussed in a variety of ways, but two distinct nuances were identified: 'feeling different' and 'being different'. Feeling different was often explained as 'feeling off', 'not feeling your usual self', 'feeling uncomfortable' or 'not feeling normal'.

*"I don't feel sick, I don't feel unwell (...) I just don't feel right." (Thea)*

Feeling different appeared to be sensory in nature and was often referred to as 'feeling overwhelmed', 'disoriented', or 'muddled' and appeared closely related to the symptoms participants experienced such as nausea or visual disturbances.

*"I think certainly with the dizziness comes and goes, it makes you feel not yourself and you don't quite feel as clear headed as you used to be." (Ethan)*

*"I often have the feeling of being (.), feeling muddled in my thinking and disorientated, [...] uhm, (.) Yeah, just sort of a feeling of (...) not being quite aware of where I am in space." (Lyna)*

The language used was often tentative, relying on hedging (e.g. 'sort of ') to explain the sense of feeling different. 'Feeling different' also appeared to be fluid or in flux, with many participants commenting that they had transient episodes of 'feeling normal'.

*"When I, when I managed to have chat with some of the girls at the gym it was just like 'oh my gosh, it feels like normal, like wow this is so cool' and then the world was not good all [...] some days I will be 'ok' in the general continuum of hideousness." (Elvy)*

However, this fluidity often complicated the participants' ability to make sense of their condition, which reinforced their self-doubt as discussed in theme one.

Participants also referred to these episodes of normality as 'cruel' as they gave them some hope for improvement or remission, only for this to be taken away when the episode of normality came to an end.

*"I sort of would feel for a while, would feel I kind of actually starting to get somewhere and I get that hideous word 'hope' and then I feel like 'oh gosh, this getting somewhere, what if I am getting there' (.) and then just for whatever reason I just be back and 'oh, I am not getting there (...) I am not getting any better'." (Elvy)*

The description of hope becoming negative was common in the interviews, with participants arguing it was the lack of ability to control their 'remission periods' that made it so troubling. 'Being different' appeared to refer to participants' 'sense of self' or personal identity. Participants talked about being a different person compared to the person they were before the onset of their dizziness.

*"I think (...) there was the [Ethan] before the dizziness and the [Ethan] afterwards. So, I'm (.) I look at myself as a slightly different [Ethan]". (Ethan)*

*"Oh, I guess everybody has a little spark that makes a person, then whether it be (.) I don't know, like baking (.) I used to love baking for people and that sort of thing, or like watching tennis, or playing tennis and that sort of thing, or going round to (...) or planning overseas trips, we used to do quite a bit of travelling, is having a large effect on my life since this ordeal started." (Elvy)*

Participants no longer saw themselves as 'normal' or no longer capable of doing 'normal things' in a 'normal way', and seemed to distance themselves from 'normal people'.

*"Mmm (...) yeah, I think a normal person is I guess someone that doesn't have this. That would without thinking, that just as they drop something just pick it up without thinking or if they stand and have to talk about someone for a long time, that just stand and they wouldn't have to think 'right, so I need to stand near a wall, so I can touch it and don't fall over' or I ideally sit down, so trying to find somewhere where I can sit down and if not (.) you have to think about alternatives (.) that kind of thing (.) if I keep looking at that pole, don't look down, too far, get your head this, put your hands here, put your feet here (.) it's all going through my head, whereas a normal person would just do it without thinking." (Molly)*

The majority of participants also expressed how they 'no longer recognised themselves'; for example, they spoke about no longer being the strong, confident or independent person they used to be. Naeve <sup>#</sup> said she never used to 'be like this', referring to being emotional and feeling like crying all the time'. Or as Ava stated:

*"I feel so needy. "(Ava)*

Some spoke about having become anxious or cautious, and having lost their ability to be spontaneous.

*"It has made me more anxious (.) yeah, yeah (.) so less (.) let's go with the flow, I guess, mmm [...] it has had a huge impact on me really (...) in that I can't be spontaneous (...) I sort of feel like I lost quite a bit of freedom of movement in what I might do with my life, and being able to take on (.) you know, sort of going for a new job or anything like that (.) I feel like I can't do (.) or travelling overseas, I feel I couldn't do that myself, I need to have my partner with me (...) yeah that sort of thing (...) it's been quite limiting." (Lyna)*

Most participants appeared to no longer feel good about themselves with some referring to themselves as pathetic, no longer 'fun to be with' or 'high maintenance'. For example, Naeve <sup>#</sup> said she was 'no longer a pleasure to be around'. Others commented on the potential for these changes to impact on their relationships:

*"Oh yeah, like I don't want to go out as much (.) So, uhm (.) they (.) if my wife was a party girl, she would want to divorce me." (Ethan)*

However, one participant spoke about having discovered that the 'new self' was 'actually a pretty strong person'

It was however clear that most participants preferred and missed 'the old self' and hoped that someday, the old self would return.

*"Initially I wanted to be the old [Ethan], and that was very frustrating and that I would say was anxiety (.), trying to be get back (.) I needed to be back to the old [Ethan], you know (.) but I don't have to be back to the old (Ethan). The (.) I have accepted that the new [Ethan] is (.) will have some limitations (...)." (Ethan)*

'Being different' was also talked about in a social context. Participants disclosed that their 'new me' no longer enjoyed social engagements, which led to social withdrawal and isolation. Some appeared to have come to an acceptance that this was simply something they had to do to 'keep themselves comfortable and safe', as demonstrated in the extract below; yet it was always talked about with regret.

*"It feels like I am a ninety-year-old person (...) yeah, very uhm so quite into (...) sorry [participant starts crying] quite, mmm, (...) antisocial, sort of thing because seeing people makes me feel so much worse." (Elvy)*

Participants talked, often with disappointment, about no longer being able to fulfil the role they had occupied in life prior to the onset of Chronic Subjective Dizziness and how their social identity had changed. Naeve <sup>#</sup> talked about wanting to be a good mum and a good wife and became distraught during the interview when she talked about how her symptoms are made

worse by being touched and how her reluctance to be touched was detrimental to her relationship with her son, and husband. Experiencing a change or a loss of social identity, for example seeing oneself as a bad partner, parent, friend, or employee, was often talked about in the context of feeling guilty, useless or being a burden.

*“mmm, just feeling really (...), helpless and hopeless just that I can’t be there for my family how I normally would be and same with friends [....] I’m not able to just pop round how I normally would or had a new baby, my best friend like, can’t just go and chuck the washing on or (...) just little things but that make yeah (.) make you YOU kinda [....], and feel just really bad cause(.) yeah, not so able to participate yeah (.) like you normally would. Associated guilt that I am ruining [names husband]’s life and dreams of also having children, travel, socialising, as he is stuck with me being dependent on him driving me and earning our living.” (Elvy)*

For others it was the fear of how their dizziness strongly affected other people’s lives. For example, Ava talked about the impact her dizziness had on her son, how he had become accustomed to staying at home and was reluctant to leave the house at times or how he had missed school because of her inability to get him there:

*“So it was debilitating at that point, I was too scared to get behind the wheel, I couldn’t do anything, couldn’t drop [names son] off to school, couldn’t do anything (...) if I keep myself wrapped in cotton wool to a certain degree then I can get [names son] to school and pick him up and I can do the basics that I need to do, so (.)” (Ava)*

Changes in ‘sense of self’ appeared to be connected with validation. Participants who received validation from health professionals and social supports seemed to be less aware of changes in their ‘sense of self’ or appeared to be less affected by those changes.

It was common for participants to connect their changed ‘sense of self’ with an enforced ‘change of lifestyle’, which will be further discussed in the next sub-theme.

### ***‘A different lifestyle’***

It was clear from all participants’ narratives that Chronic Subjective Dizziness has had a substantial impact on their lives, with many indicating that they had to think carefully about how they go about activities of daily life.

*“Well (...) that then stops me from a lot of things because I can’t work, I can’t definitely can’t walk, I used to love going out for big walks and stuff (.) and I can’t do that because I can’t judge where things are.” (Ava)*

Some participants were quite open about the limiting or disabling effect it had on their life and how much thought and effort went into ‘normalising’ life.



*"I found that they [they symptoms] have quite a limiting effect on my life, and I had to work quite hard to try get back to some sort of normality (.) normal life, but I still (.) what would be quite normal activities for some people (...) for me. I had to take a deep breath, I had to plan so that I know that I can keep myself safe and comfortable."*  
(Lyna)

Participants even talked about how they now had a completely different lifestyle compared to their lives before the dizziness.

*"I am adapting to a slightly different (...) I'm adapting to (...) hmmm, I'm (.) I find myself adapting to having a different lifestyle, to what I used to have."* (Ethan)

Others were resistant to letting it take over their lives entirely. For example, when asked how Chronic Subjective Dizziness had affected their lives, Molly and Sofie answered:

*"uhm no, not at all (.) No, I just (...) I don't think you can (.) make it (...) I don't think it is something that is so bad that you can let it rule your life (.)"* (Molly)

*"It is not so severe enough that it is gonna invade my life anymore, uhm, it's annoying, but it is not going make me live my life differently [...] no, no (.) No no, still travel, still live my life normally."* (Sofie)

Although such responses gave the impression that for some participants the impact of Chronic Subjective Dizziness was low, they did seem to have made some significant adaptations:

*"I would never consider doing something like abseiling or cleaning windows or anything like that [laughs] obviously I would not be able to do that, but I wouldn't be interested in doing that anyway (...) yeah, so it doesn't affect me like that in that respect (...) and if I have to drive somewhere with someone, I just have to be mindful looking out a window and that, and (...) uhm, avoid driving long distances if I can."*  
(Molly)

When participants were alerted to such contrasts in their statements, Ava responded:

*"Actually all of those can be broken down to one thing and I never thought about it like this before, but it's having some form of control over what is happening in my life (.) that's actually it (.) I can't just sit back and have some strange thing that nobody can put a label on and nobody can tell me how to fix it can come in and dictate the terms of my days (.) I can't have it so those little lies come in under that (.) taking back a bit of control."* (Ava)

By masking the impact dizziness had on their lives, and by acknowledging the lifestyle changes they had to make, participants seemed to retain 'a sense of control' over their lives. Of those who acknowledged that they had made some significant lifestyle changes, none appeared to feel that they had a choice or control over those changes. Changing lifestyles was therefore often referred to as a negative consequence of experiencing Chronic Subjective Dizziness and therefore undesirable.

*"I find myself go read a book or lie down a lot more as I used to (.) so, you know (.) and I probably go upstairs or in to (.) uhm, go into different room from my wife and daughter(.) they watch tv and have all sorts of video's going on and stuff(.) last night I watched it with them (.) but I go more upstairs and read a book you know [...] yeah (...) I wish it was not the case, and hopefully it will get better, mmm (...)." (Ethan)*

However, some like Ethan tried to offset the negative effects with some positive ones:

*"I find myself adapting to having a different lifestyle, to what I used to have. So, hmm (...) I don't drink a lot of alcohol of any kind. I (...) uhm, I do quite a bit more exercises (.) which is a good thing, than I used to. Go for a walk in the evening (.) uhm I avoid noisy places, uhm, you know (.) [...] yeah, I used to work all the time (...) uhm so I enjoy my work, but (.) when I look at it (.) this, you know, uhm (...) I didn't need to (.) uhm, so (...)." (Ethan)*

The effect of lifestyle changes was predominantly felt in two areas, participants' professional and social lives. Chronic Subjective Dizziness affected participants' professional life in a variety of ways. In order to maintain their job or cope with the demands of their job, some participants talked about having to manage their job around their symptoms. For example, participants talked about having to put strategies in place such as planning, pacing, taking breaks and not getting overly tired, therefore, spreading the workload, or delegating tasks to others:

*"I used to operate always at a reasonably high level, so (.) board meetings, as many meetings, I go and notice that I am not (.) I still do it, no one will notice, but I notice that (.) Ok (.) I haven't got the stamina that I had before, to go from meeting to meeting to meeting to meeting, to do that, to jump to a client, I haven't got the stamina (.) [...] so now I have to put strategies in place. (...) you don't have that sort of stamina you used to be, and (...) yeah, that's (...) yeah. So you have to pace yourself. I think you have (...) like my ability to come to a decision or come up with an answer is still the same, but (.) I don't have the capacity to knock them out as quickly as I can." (Ethan)*

Not everyone was in the fortunate position of being able to manage their work around their symptoms and instead they began working from home, so that they could work at times when their dizziness affected them the least, or they reduced their work hours by taking on a part-time position.

*[Talking about a new part-time job] "not only is it something I can do from home but when I'm having a bad day, I can wait till 8 o'clock at night to do it (...) I can pick the times where I am feeling good (.) and get things done so it's keeping the woes at bay. There is no debt collectors knocking at the door, but it's not ideal." (Ava)*

Reducing work hours was a good solution for some, yet for Ava this meant a significant reduction in income and greater financial strain, which forced her into making further lifestyle changes for herself and her son.

*"I'm dying to get back to work (.) so broke it's not funny, living on a diet of Weetbix and toast for the most part now, because we just can't afford to (...) yeah, mind you I am starting to get paid for one of the jobs in fruit and veg (.) which is awesome." (Ava)*

Participants also experienced times, especially at the onset of their condition, when their symptoms were so severe that they could not get to their place of work or could not perform their duties, and therefore had to give up work altogether.

*"I had to stop work (.) when it really got bad I had to stop work completely for a few months and then I went back for mornings only, so that I would come home and have a rest and then I just tried a few different combinations until I had a combination that worked for me, and I was very lucky in that my boss was really understanding and willing to go with that." (Lyna)*

For some participants, giving up work, even for a short period of time, was not a decision to be taken lightly; although some participants felt it was a necessity, it was often an option they could not financially afford. For example, Naeve <sup>#</sup> said she needed the money, so she couldn't let go of her job. She said she would have loved to stop working for a while and take the time to 'get better' yet said that in her line of work good part-time jobs were not easy to come by, so she had to 'keep it together and keep going'. Others talked about a fear of significant consequences such as loss of job, loss of confidence in their capabilities, or loss of competence.

*"I had a meeting with Occ Health and HR and so sort of they were saying they don't know how much longer they can hold my contract for [...] if I leave sort of thing then I have the difficult to try to prove to my employer and myself as well that I am competent and able to do you know, do a job, and there is the whole (...) you are out of practice, you need to maintain your professional development hours, your licence [...] so that's part of it as well, and I am trying not sort of to worry (.) but when my email pings like 'oh is this gonna be the email that says you're gone or (.)' I just want to keep like a hook in the door." (Elvy)*

Some jobs or situations made it easier for the person to manage their condition; for example, office jobs appeared to be easier to manage compared to customer-facing or manual jobs. Also people who were self-employed could structure their day better and could spread their workload. Those in a senior position felt they could delegate tasks more or were able to better plan their workday around their symptoms.

*"Fortunately I organise my own day or I have a PA [...] I plan (.) so that I am not overworking or over yeah (.) over doing it. With my (.) lucky I have an office job, I think if I have a manual job I would really struggle I would have to change jobs. [...] man, if I had a manual job, before I could probably have had a manual job, but I wouldn't want to, I am not that sort of person, but someone who got this who is in a manual job, say a lawn mowing contractual or a gardener or a (...) landscaper (.) you know, I think you find it really difficult to hold that job." (Ethan)*

Participants also talked about 'a sense of loss' and in the professional context this meant participants felt they had lost the freedom to maintain, or progress in, their chosen career path, for example by continuing professional development, seeking promotion or taking on more duties.

*"I think being very upset that I had to give away what I had only just got, in the sense of career wise, I worked really long and hard to get to that level [...] I was actually gonna start getting us somewhere so there was that forward motion that I been waiting to achieve" (Ava)*

It was evident that the lack of flexibility to make professional changes was extremely stressful for some participants, which in turn was not helpful in their efforts to manage the condition.

Lifestyle changes also had an important impact on relationships and social life. No longer participating in social events or activities appeared to have a significant impact on the person, with many talking about feeling isolated. For example, Naeve # said that she no longer exercised. She used to swim competitively and all her friends are still in that milieu, but not being able to take part in competitions meant that she did not socialise with them as much. Many participants talked about having lost friends, or feared they would lose friends as a result of not being able to participate in the social activities they previously engaged in.

*"The only thing I feel bothered by is, if people say let's go to that pub or something and let's go now (...) then I feel myself back out as fast as I can." (Lyna)*

Some participants reflected upon how embarrassing it was to have to pull out of social commitments at the last minute, and believed it better not to commit to, or engage in, social activities at all.

*"It was actually when I was still pretending I was ok and I was still working but I was really struggling and I wasn't achieving what I needed to achieve, and so I had to make that decision of I don't want to ruin my reputation, I'm gonna have to be honest about what is happening and pull back instead (.) So all (.) everything over that couple of months (.) I was using every ounce of energy and focus and stuff to get my work stuff done and I was cancelling all the social stuff so I was trying to still live (.) both (.) but yeah, I was just in a bit of denial (...) so I was still making plans even though deep down I probably knew I wasn't gonna be able to make it (...) and that annoys people after a while." (Ava)*

Participants recognised that this was one of the reasons living with Chronic Subjective Dizziness was so isolating.

*"Feelings of complete isolation and as though my life is over [...] Isolation because not being able to handle going out for dinner/lunch/coffee on a social side of things, and when I have managed to go out feeling as though I'm not contributing to*

*conversation/being the friend I used to be because my brain just feels 'fried' heavy.”  
(Elvy)*

Participants claimed that withdrawing from social engagements was not always their own choice; sometimes family or friends would make that decision for them by simply not inviting them anymore.

*“I think my partner is a bit more wary of inviting me to things that he knows I will find hard and my daughter is probably a little more worried about me, a little bit more than she would (...), yeah.” (Lyna)*

While some reluctantly accepted that isolation was an inevitable result of changing their lifestyle, others appeared to fight isolation and therefore continued to participate in activities they did not enjoy.

*“Yes, just generally kind of acting like a normal person and not let it affect anything else (.) cause like I said no one (.) would never understand what it’s like to have it [...] I would not avoid, (.) I would go, but I just wouldn’t.” (Molly)*

*“I’m just conscious that if am out with friends, that (..) and I feel a bit weird like that, I don’t mention it (.) because they don’t need to know if we are having a nice night out.”  
(Sofie)*

It was clear from the way participants talked about their lifestyle changes, that these were perceived as imposed and were as such undesirable and met with resentment. Many participants indicated that these lifestyle changes greatly affected their quality of life.

*“I am not (.) uhm, and a (.) I’m back to having a reasonable quality of life. The quality of life I had before was superior, if I like to say that word (.) so, my quality of life has been compromised by it (.) so, but I can live, (.) you need to (.) I need to live with that.”  
(Ethan)*

Being a different person and having a changed lifestyle are significant consequences of Chronic Subjective Dizziness. The next theme will explain how participants coped with these enforced changes.

#### **4.2.3 Theme three: ‘How will I survive?’**

This theme encapsulates the complexity of coping with Chronic Subjective Dizziness and shows a dynamic process where participants fluctuated between three dominant states presented as sub-themes, ‘Fix me’, ‘Sense of hope’ and ‘Getting on with it’, with an interim state of survival. Participants appeared to fluidly move between states, often subconsciously, or found themselves in more than one state at the same time. The move between states did not seem to follow a pattern but it appeared more common for participants fairly new to the

condition to fluctuate between ‘wanting it fixed’ and ‘having a sense of hope’. Those who had had the condition for a longer period of time seemed to spend more time adapting. Length of time living with the condition was, however not the only element of importance. The nature of the participants’ symptoms also played a role. For example, it was harder for people who experienced nausea and vomiting to adapt than it was for people who felt unsteady. Fluctuating between the three states was often perceived as exhausting and even if participants indicated they had adapted to having Chronic Subjective Dizziness, it was clear that they had learned to tolerate this condition that had invaded their lives, but never to accept it. Learning to live with it was therefore a gradual, fluid, complex and never-ending process. The three sub-themes are discussed below.

### **‘Fix me’**

All participants expressed the desire to have the problem resolved. However, some spoke about ‘fix me’ in a way that indicated that ‘being fixed’ was the only way forward. It was clear they wanted someone or something ‘to fix’ them, so they could return to living a normal life, regardless of what was required, as demonstrated in Ava’s extract below.

*“So [I] was more frustrated sad (.) and I just wanted to fix it, so like, come on let’s fix it someone give me a pill, what do we do here, what is the deal, go surgery? Major surgery? Brain tumour removed? (...) Yeah, good let’s go, let’s do it! I just wanted it resolved [....].” (Ava)*

For other participants, ‘fix me’ was more of a dormant wish. Although they would prefer to ‘be fixed’, they inherently seemed to know that their dizziness was not something anyone or anything could fix, and that if any ‘fixing’ could be done, they would have to do it themselves. Fixing was therefore not in the forefront of their minds so instead they talked more about ‘improvements’ or ‘getting better’ so they could have a better quality of life, as demonstrated in the extract below:

*“Yeah, and realising that it was me that had to do it, that nobody else could give me a pill and fix me, I had to do it (...) yeah, that was quite a big, a big step (...) and that people don’t necessarily have all the answers (.) that it is still one of these funny things [laughs].” (Lyna)*

Although ‘Fix me’ appears to be a less substantial sub-theme compared to the others that follow, it was in fact present in all other sub-themes as a strong undercurrent, and very closely related to hope.

### ***‘Sense of hope’***

Hope was talked about in a myriad of ways, yet often covertly. Participants spoke about their future in a way that showed they were hoping ‘to get better’ referring to ‘improvements’ that enabled them to lead a satisfying and meaningful life within the limitations of their condition. The data also carried undercurrents of hope for recovery and return to normality:

*“I have got better but we don’t know why or how (.) and it’s just not at that level yet where I can go back to functioning normally [....] I have to believe that I get back to what I was.” (Ava)*

A dichotomy was observed in the way participants experienced hope: they either had glimmers of hope for recovery overshadowed by solid reasoning, for example:

*“Generally people do get better, however there is this word that they used (...) there is no absolute about it (...) so it might not (.) I keep the exercises up and it’s (.) and I’ve read about it and some people take two to three years, some got it for the rest of their lives, some people FIVE years [....] and actually I feel (.) yeah, a lot better than I was, I feel 10 times better than I was a year ago, I do the exercises and stay positive.” (Ethan)*

or, they had a profound sense of hope bordering on conviction, which was overshadowed by glimmers of doubt:

*“I think, I’ll (.) to the end of this journey (.) my gut feeling is that I will get back to where I was (.) that’s my gut feeling, and I don’t think I am lying about that (.) I think it is potentially logical (...) might not happen (.)[but] it’s, [I] think it’s logical.” (Ava)*

Regardless of these nuances, hope appeared to be an important part of coping:

*“If somebody had said to me right at the start (.) come January you feel a little bit better but still not completely able to get back out there (.) I don’t know what I would have done, I don’t know how I would have coped (...) I mean (.) not like physical take much pills or anything (...) but I think it would have really, really damaged (.) damaged me.” (Ava)*

Participants appeared to actively keep hope alive, regardless of how long Chronic Subjective Dizziness had been part of their lives. To keep hope alive, they appeared to use the following strategies:

a) Positive thinking or ‘self-talk’. Most participants claimed to use positive thinking as a way to keep hope alive. For example:

*“I sort of tried like ‘right today is going to be the turning day, it’s gonna be a better day, it’s not going to be as bad or (...) that sort of thing [....].” (Elvy)*

b) Goal setting. Most participants who engaged in goal setting admitted that goals were rarely achieved or they knew that their goals were unachievable; yet the process of goal setting appeared to sustain hope. For example, Ava set herself milestones she inherently knew were unattainable:

*"I kept setting myself deadlines (.) I was like (.) look, worst case scenario (.) by my birthday (.) so this is April when I had to give up work, my birthday is in June, by my birthday we're good to go (...) so just suck it up just deal with it (.) so I kept setting these little goals, just get through to your birthday (.) but by the same token I actually convinced myself (.) I'll be ok by my birthday [laughs] and then my birthday would roll around and I would be like 'shit'! So I think, I think lying to myself a little bit and making myself those promises (...) yeah, if I sat down and deeply picked at it (...) and didn't know when it was getting fixed (...) if I hadn't set myself those goals (.) if I had accepted this is where you are now (.) make some lifestyle changes because it might never get better, it is so defeatist (.) and I can't live like that (...) I have to believe that I get back to what I was." (Ava)*

c) Participation in activities that promote health and wellbeing:

*"Exercising has been good, so keeping moving just trying to do a bit of cardio quite often (.) has just kept me from feeling too depressed about things, and gradually I guess (.) through the balance exercises that I've (.) you gave me, it's taught me to if I just (...) do things gradually and build up gradually then I eventually get to a point where I want to be (.) but I just had to accept that is a very gradual (.) for me that is a very gradual process (...) yeah." (Lyna)*

d) Drawing strength from improvements, either incremental improvements or by the sudden realisation that these had occurred. For example:

*"All of a sudden going one day 'gosh, I haven't had one of those incidences for a while' and just realising that they actually got further apart and not as severe so for me I have just gone 'well, it has got better'." (Sofie)*

Hope also appeared to be kept alive passively, by the occasional but short-lived moments where the person had felt 'their usual self' or had felt 'normal again', as referred to on p. 49.

For example:

*"When I wake up and I have a good day then I just think that I am cured [laughs] I sort of forget (...) because I get back into what feels normal to me" (Lyna)*

However, this type of hope was often referred to as 'cruel' or 'false hope' as it turned out to be unfounded.

Participants reflected on 'false hope', or on the times when hope was lost or taken from them, resulting in a sense of despair, sadness or grief for what they had lost. For example, in her post-interview reflections, looking back on her journey of recovery so far, Elvy \* wrote:



*"Feelings of wondering how I will go on living like this. Is this how it is going to be from now on? Just huge amounts of disappointment, regret for not doing more before I got sick, and I guess grieving for my old life where although because of my job I tried to never take things for granted and was grateful for the life I had, but now realise I had so much more than what I realised."*

It was apparent that hope was endangered or lost by the lack of knowledge and prognostic uncertainty.

*"I think it's just the frustration of not knowing, and not knowing if I am actually ever going to get better as well, cause nobody, it's like how long is a piece of string, it sort of (.) if I had like a clear 'yes you definitely going to get better' then I go ok, eventually I don't know how long it's gonna take but I will (.) hopefully, I will get there, but I just don't believe it myself (...) there's been some weeks it's just (.) well not weeks, days and it's like keep going, keep trying (...) cause I am pig headed I think." (Elvy)*

Hope was an important component in the coping with Chronic Subjective Dizziness process and losing hope, appeared to be a contributing factor in the development of low mood. For example, in her interview Naeve # talked about 'wanting a cure, wanting it to go away' and went on to say, "I could not live with this, if it was forever ... I would get really depressed".

*"I think depression would have been very easy (...) to fall into to, as I said right at the start I definitely did feel (.) I like to think I didn't feel overwhelmingly sorry for myself (.) I felt a bit cheated (...) uhmm, yeah (...) that a yeah (...) sort of (...) yeah, definitely (...) [Participant's mood changed to more thoughtful] [I] never fell into the 'oh, I am cursed and stay in bed and cry', but yeah, I definitely felt, (...) I felt angry sad." (Ava)*

### ***"Getting on with it"***

It was apparent that in addition to 'wanting it fixed' and 'hoping for recovery', there was a third component in the coping with Chronic Subjective Dizziness process. 'Getting on with it' represents participants' intent to get the best out of life despite having this 'debilitating condition':

*"Yeah you have to (...) kind of have to suck it up I guess, and move on." (Molly)*

*"I think (.) when it was at its worst, I couldn't have lived with it like that (.) I had to get it to a point where I could do things." (Lyna)*

'Getting on with it' did however appear to have a double meaning. For some 'getting on with it' stood for 'forgetting' about recovery, the 'old self', and the 'old life', and adapting to a 'new me' and a new lifestyle:

*"So, there is the, the new [Ethan] [who] cannot do what the old [Ethan] did. But it's not [...] but there is, there is a group of things that I (.) [I'm] not gonna put myself in that*

*situation, you know it's going to be too difficult, you know. And then the rest of my life, which is here now (.) Yeah, sometimes I feel 'off' during that day, you know have an 'off day' or an 'off few hours' (...) things go [participant makes a sound] you know, a little bit dizzy, (...) you just have to live, just got to suck it up!" (Ethan)*

For others 'getting on with it' appeared to be an interim step, a way of surviving the condition while awaiting recovery:

*"I have said to my GP on my last visit to her before Christmas (...) I said to her 'you know what', you can edit this bit out, 'fuck the dizziness' cause the dizziness feels like it's gonna take a long time to sort out." (Ava)*

Participants talked about 'Getting on with it' as the result of coming to the sudden realisation that they had to find 'a way get on with life'. For example:

*"I thought 'well, (.) You just got to get on with life cause if you sit home, there is no point doing that' ." (Ethan)*

Others talked about 'getting on with it' as a gradual process:

*"I think it was just gradually getting used to it [...] yeah, is almost like become accepting that I have these symptoms or whatever it is [...] I think it is like anything isn't it, when you kind of accepting that you have something and it is always going to be with you (...) you just get on with things." (Sofie)*

'Getting on with it' appeared to involve changing dreams and hopes for the future, and making conscious lifestyle changes, as a strategy for coping, including avoiding activities or situations or adapting (e.g. pacing and planning), all of which were aimed at keeping the participant feeling safe and comfortable. 'Getting on with it' was not an easy process; some participants seemed to adapt reluctantly, while others seemed to have come to 'some sort of acceptance' and had resigned themselves to the idea that adaptation was needed for survival:

*"I just have to work within the parameters I have been given. So I'm looking at it from an engineering point of view [...] so I think Ok, I got some parameters, new parameters now (.) and if I work within those and then I will have a reasonable quality of life (.) so I won't be doing trips to Disneyland, I am not going on a cruise boat, and (.) uhm, you know (.) I will not be getting up to my house to wash the roof, getting up any high ladders, and gardening is alright (.) when I get up and feel dizzy, well it's alright after a couple of minutes (.) and I move on. So and the fact that I can't concentrate for a longer period of time (.) as before (.) I just took a break, have a coffee, get back to it (.) yeah, and, and that gets better." (Ethan)*

*"It's been quite difficult because [names her type of profession] is an awful lot of (.) different types of things you have to do. Uhm, so it's a lot of multi-tasking (...) so I guess it is, at work I cope with that by being quite well planned, so that I can do, I know things are organised and I don't have to do much of (.) on the spot thinking or planning." (Lyna)*

Making those changes did not come without its challenges. A myriad of internal and external factors appeared to play in role in adaptation. Internal factors referred to personal strengths, for example their ability to put things into perspective, to think positively and be resilient, for example, Molly thought about situations that could be worse than the one she found herself in:

*“Well you have to just suck it up, you are not an invalid, you are alive (...) you just need to get on with life. There is nothing bad wrong with you, you have to harden up (...) so I quickly had to harden up and get on with it [...] I was not dead, and not in a wheelchair (.) You should be able to just get on with life.” (Molly)*

Ethan on the other hand, saw a silver lining of positives he could appreciate:

*“Fortunately I can still go to work, I can still have a decent quality of life, I can still drive, I can still go for a walk with my wife [...] uhm, so (.) uhm, (.) I do quite a bit more exercises (.), which is a good thing, than I used to. Go for a walk in the evening [...] do more things around the home (.) do more gardening at home, I have fun, do a lot more things at home [...] yeah, I used to work all the time [...] If I look at it at the positive side, I can still have a reasonable quality of life and uhm, (...), and that is pretty similar to what I used to have [...] that is a positive thing (.) so not, I am not actually focusing on all the negative things.” (Ethan)*

Sofie ‘normalised’ her condition by referring to it as one of the many ‘life experiences’ a person can have; this one just happened to be hers:

*“I just of think well it’s (.) Yes, it is (.) it has been not much fun but (.) it is just one of those life experiences, that happen and that people have to deal with in lots of different ways (.) I got this and other people have got other things. [...] Because it is not as often or as powerful as it used to be, I kind of talked, told myself it is actually gonna get better but you may have to live with this, and this is just gonna happen to you from time to time (...) so like when you had, like you get a sore back, oh well, that’s just how my back is and that is gonna get me now and then, that’s how I kind of come to it!” (Sofie)*

Ava’s personal strategy was to use ‘fight talk’ and ‘challenge’ her dizziness:

*“I am trying [to] find little [way] outs (.) I’m going’ HAHA, (.) you didn’t think of THIS dizziness! I can do THIS!” (Ava)*

Other factors that helped participants to ‘get on with it’ were external factors. External factors referred to environmental factors such as support and understanding, or receiving validation from others; however, there were also circumstantial or situational factors such as the time of onset of the condition, demands on the person, or the position they were in.

*“There are ways and means around everything but you’ve got to (.) You have to be in a position that you can give yourself those things, those opportunities, those chances.” (Ava)*

Most participants seemed to appreciate advice from professional services specialising in balance and dizziness, but most of all they talked about ‘feeling listened to’ and ‘feeling supported’ as a real turning point in the way they were able to adapt to the challenges imposed on them by their condition.

*“I feel so empowered (.) from having been up to see you, to have a little bit of understanding (...) uhm, if I never get any better than this. I’d feel, I just progressed so much, I am just so thrilled from what, what I’ve had [...].” (Thea)*

*“Yeah, now there is more of an acceptance (.) and that I have seen the right people, the neurologist, [names ENT specialist] and then you, you know (.).” (Ethan).*

An important observation I made in this research was that experience of Chronic Subjective Dizziness could not be taken out of context, which I called ‘the bigger picture’. With the exception of one participant, who did not disclose any other conditions, all participants had other health conditions that played a role in how they experienced, and coped with, their dizziness. This context is explored in the next section.

#### **4.2.4 The bigger picture**

Participants talked about how having other conditions complicated matters in two ways. For some, having Chronic Dizziness affected how they managed the other condition. For example, Elvy and Naeve # both talked about how the dizziness stopped them from doing the exercises that helped them manage their back pain.

*“I hurt my back quite badly, it must have been 6 years ago and I slipped a disc, or they think I have slipped a disc, long story as well (...) so my back hasn’t been good, so I haven’t really sort of slept well, I need to be up and moving a lot which initially was really difficult because I was not able to do any of my normal exercises to try and kind of help it but that was really difficult with the moving, like any movement at all (...) so it is much better from when it first but yeah, still no (...) not very good.” (Elvy)*

For others, it was more about how the dizziness was ‘just one more thing to cope with on top of previous injuries’. For example, Ava talked about how managing multiple conditions was exhausting. She also disclosed that her dizziness and the falls she experienced as a result of tripping over or misjudging distances had serious consequences, making her other conditions worse. Serious musculoskeletal problems, sustained years ago in two separate car crashes, have as a result of her many falls deteriorated.

*“The osteo was very specific, because when I do get dizzy, I will miss steps, I will (...) I have fractured my hand, I re-damaged my neck a couple of times because of falls, falls are not recommended for me (...) so yeah, she is not happy with me going out for walks.” (Ava)*

Despite making living with Chronic Subjective Dizziness more complicated, having other conditions meant also for some participants that they could draw on pre-existing coping strategies. For example, Molly and Lyna claimed to draw on self-management strategies from other health management programs, such as pain management and relaxation programs.

*“I have been going to meditation classes which I have found hugely helpful for the dizziness and for my irritable bowel condition, to deal with pain as well (.) That has allowed to keep me much calmer about things [...] The other thing is that the physio there [talks about the pain clinic] just put me on a gradual exercise [program], build it up gradually (.) so it is the same sort process of gradually, gradually just build yourself back up again, don’t overdo it, and (.) back off a bit, and you know you’ve done too much and (.)” (Lyna)*

Both participants had been able to draw parallels between the two chronic conditions and had transferred skills they had to better manage their dizziness. Looking at the bigger picture and drawing on pre-existing skills is clinically relevant and important for the overall management of Chronic Subjective Dizziness. This point will reappear in the discussion.

### **4.3 Summary**

This chapter presented the findings supported by extracts from participant interviews. These will be further discussed within the context of the research question, existing knowledge and relevance to clinical practice in Chapter 5.

## Chapter 5 Discussion

This current study sought to explore the experience of Chronic Subjective Dizziness from a working-age adult's perspective. This study's findings were remarkably similar to findings from a broad range of studies around other chronic conditions, especially those that are unverifiable or invisible, such as chronic pain and chronic fatigue. In this chapter, I will discuss the findings of the present study in the context of pre-existing knowledge and highlight key points of interest applicable to clinical practice. To do so, I will draw on the chronic conditions literature as well as the current knowledge presented in the literature review (Chapter 2). Key discussion points and their implications for practice will be presented below. This chapter will close with the study's strengths and limitations, followed by suggestions for further research and conclusion.

### 5.1 Legitimacy

Legitimacy and validation, or lack thereof, were key discussion points in the current study. In the context of this study, legitimacy refers to the perception that the condition is medically and socially confirmed as credible and valid; and that the patient's experience and behaviours are as such acceptable (Ware, 1992). Issues with legitimisation and the consequences of invalidation are also extensively discussed in existing literature on the experience of dizziness (Mendel et al., 1997; Olsson Möller et al., 2014) and chronic conditions in general (e.g. Furze et al., 2002; Hale, Treharne, & Kitas, 2007; Leventhal, Brissette, & Leventhal, 2003; Mendel et al, 1997; Nettleton, 2006; Yardley & Beech, 1989). This highlights the importance of legitimisation and validation to the way in which Chronic Subjective Dizziness is experienced and managed.

Participants in the present study identified three types of validation: medical, social, and self-validation. These, together with illness beliefs, have been identified in existing chronic conditions literature as key components of legitimisation (Furze et al., 2002; Leventhal et al., 2003). Although illness beliefs was not a topic of discussion in the current study, it is plausible that they may have contributed to the perceived invalidation, particularly in relation to causal beliefs. As previously discussed, aetiology of Chronic Subjective Dizziness among experts in the field have long been disputed (see p. 8). The condition's recent name change may reflect a more open-minded view of causality, but participant narratives in this present study implied that attitudes and behaviours of health professionals are lagging behind. The description of Chronic Subjective Dizziness as a somatoform disorder in publications as recent as 2014 (e.g.

Bittar, 2014) may offer a partial explanation as to why the understanding of Chronic Subjective Dizziness as a somatoform disorder remains deeply embedded within researchers' and practitioners' causal beliefs. These beliefs are unlikely to be helpful in the legitimisation process.

In resonance with the existing chronic conditions literature, participants in this study raised two characteristics of Chronic Subjective Dizziness as threats to validation: the unverifiable nature and the invisibility of the condition. Perhaps unique to this study, participants also identified lack of knowledge and understanding, as explanations for why health professionals displayed what they perceived as unsupportive and disinterested attitudes and behaviours. This suggests that it is not only the nature of the condition that plays a role in why people, with Chronic Subjective Dizziness, feel discredited; but that health professionals should also be factored in. In turn, validation affects the individual's attitude towards health professionals (Mendel et al., 1997; Möller, et al., 2014). For example, in this study, health professionals that failed to give validation were mistrusted and deemed incompetent by participants. Like the findings from the chronic conditions literature, the main threats to social validation were invisibility of the condition and social discourses around such conditions. As demonstrated by the account of one participant in this study, having proof that there is 'something wrong' changes social perceptions, giving social validation (see extract from Molly's interview, p. 47). When medical and/or social validation were threatened, for example when participants were unable to describe and make sense of the condition themselves, their own illness beliefs became tainted with self-doubt, which appeared detrimental to self-validation. When self-validation is threatened, individuals may engage in self-stigmatisation (Mendel et al., 1997), as illustrated by the participants in this study (see extract from Thea's interview, p. 43).

Validation in the chronic conditions literature was described as important for various reasons. The mental models individuals build around their condition not only influence the person's experience of their condition and their attitude towards the condition, but also how they manage their condition. This then shapes how individuals adapt to their situation and what coping strategies they apply to live a meaningful and satisfactory life, all of which are considered to determine health outcomes (Armentor, 2015; Larun & Malterud, 2007; Lonardi, 2007; Madden & Sim, 2006; Petrie & Weinman, 2006; Rebman et al., 2015). Societal behaviours and social validation may also influence the social role individuals adopt and shape social engagement and participation (Mendel et al., 1997; Mueller et al., 2012). As an example, participants in the present study, who felt discredited by friends or colleagues or who

perceived no support, appeared to withdraw from social engagements (see p 46). In response, those affected by chronic conditions, including those in the present study, assumed one of two personas. Either they adopted 'a sick or victim role', which meant they were open and honest about their dizziness and limitations; or they concealed their condition and tried to act 'normal' and appear as capable as possible (Jowsey, Ward, & Gardner, 2013; Mendel et al., 1997; Yardley & Beech, 1998). According to the chronic conditions literature, taking on either persona has its drawbacks. Seeking sympathy or support without having any compelling evidence of 'a real illness' opens individuals to critical scrutiny, while those who conceal their condition open themselves up to social stigmatisation, by failing to adopt normal social or public behaviours (Jowsey et al., 2013; Lonardi, 2007; Mendel et al., 1997; Yardley & Beech, 1998). Participants talked about not 'being sick', yet would sometimes use the sick-role as an excuse for not having to participate in social events or fulfil societal expectations. However, most participants felt fraudulent as they did not look ill and could not fulfil the obligation that goes with the privilege of being ill, which is to get better. This is also clearly described in Parson's sick-role theory (Parson, 1951).

Finally, in resonance with the contested chronic conditions literature, when medical validation is not given and individuals are unable to make sense of their condition, they tend to actively seek validation by consulting various healthcare services (Bury, 1982; Hale, Treharne, & Kitas, 2007; Yardley & Beech, 1998). This was an interesting notion, clearly demonstrated in the current study. For example, some participants had visited multiple health professionals and disclosed that they were only able to cease this behaviour once they had seen someone who validated their experience. Although participants welcomed diagnostic and prognostic certainty, they also indicated that receiving a diagnosis was not necessarily their main priority. In this present study and that of Olsson Möller et al. (2014), participants indicated that they felt validated when health professionals took the time to listen, showed an interest in the condition and demonstrated understanding, something they felt was achieved by being referred to a specialist service. This may suggest that validation is more important than receiving a definite diagnosis.

#### **5.1.1 Clinical relevance and implications for practice**

There is a growing body of evidence that legitimisation is fundamental to successful management of chronic conditions (Bury, 1982; Leventhal et al., 2003). This study has shown that the experience of Chronic Subjective Dizziness is complex and unique to each individual, and is more than physical discomfort and impairment. By acknowledging its complexity and by



validating the experience, empowering therapeutic relationships can be built (Anderson & Funnell, 2002). One would hope that by renaming and reclassifying the condition as a vestibular disorder, the importance of validation and legitimacy is acknowledged by leaders in the field. However, this knowledge needs to be translated into practice. The importance of validation is not strongly emphasised in the Chronic Subjective Dizziness literature, which concentrates predominantly on diagnostics and identification of comorbidities, such as anxiety and depression, nor does it strongly feature in the vestibular rehabilitation literature.

The few qualitative studies that explored the experience of dizziness claimed that validation was demonstrated by offering individualised support, which in turn was identified as providing effective treatment, giving access to social services, aids and home care (Olsson Möller et al., 2014). The present study differed from these studies, in that participants were working-age adults and their narratives around support and care showed that they had other priorities and support needs, compared to those of the predominantly elderly population. Participants in the present study viewed effective support as having unobstructed access to specialist services, including timely referrals, and engaging in a therapeutic relationship that focused on personal support needs. They associated specialist services with health professionals who had knowledge of Chronic Subjective Dizziness, who showed interest, and demonstrated an understanding of their situation.

One way to meet these support needs is to provide more dedicated specialist services and clearer referral pathways. This would allow unobstructed access to appropriate resources and services. Alongside this, there could be a re-evaluation of current clinical practice where primacy is given to legitimisation and individually matched support.

In the context of physiotherapy, the importance of validation and the clinician's role in legitimisation is not made explicit. In the literature, symptomology and pattern recognition as the basis of accurate diagnosis and effective treatment is considered highly important (Bronstein et al., 2010; Herdman, 2007, 2014; Staab, 2012). It is however not made clear that persistent focus on symptoms can be problematic as it detracts from the complexity of this condition, as highlighted in the findings of this study (Chapter 4). As previously discussed, the frustration and embarrassment associated with not being able to describe their dizziness or make sense of it, was detrimental to the individual's illness beliefs, self-validation and mental wellbeing. Further, it did very little for the all-important therapeutic relationship as it signalled to the participants that they were not believed, and unworthy of their health professional's time (see pp.42-43). It may therefore be beneficial for health professionals to re-evaluate their

assessment processes and reflect on what is important to know, at what time and why, and be cognisant of how the assessment process and therapeutic interactions, including attitude and behaviour are perceived by the client. For example, it may be beneficial for health professionals to reassure their client that failing to make sense does not invalidate their experience.

Further thought should also be given to 'treatment' of Chronic Subjective Dizziness. The current literature recommends three dominant treatment approaches: vestibular rehabilitation, pharmaceutical management, and psychotherapy (Edelman, Mahoney, & Cremer; 2012; Holmberg, Karlberg, Harlacher, & Magnusson, 2007; Holmberg, Karlberg, Harlacher, Rivano-Fischer, & Magnusson, 2006; Ruckenstein & Staab, 2009; Staab, 2012). Pre-defined treatment plans may endanger validation in two ways: prescribing anti-depressants and psychotherapy carries the risk that if the prescription is not well considered or explained, the perception of the condition as a somatoform disorder could be reinforced. Furthermore, findings of this study suggest that satisfactory care and support is based on health professional's understanding of what is important to the individual and matching the support they offer to the person's needs. The core components of individually matched support in this study were described as: a) knowledge and information sharing, b) showing insight and understanding of what affects the person the most and c) exploring practical coping and management strategies that match the individual's situation. This does not dismiss the current proposed treatment guidelines for Chronic Subjective Dizziness. It merely highlights that internal and external factors play a role in how people manage their condition, and that health professionals may benefit from exploring what management strategies are used and evaluating whether these are the most appropriate, or exploring what self-management skills people already possess that are transferable. As demonstrated in the findings of this study, most if not all participants had other health conditions that should be considered. Taking a more client-centred and holistic approach is recommended, as this may increase the client's confidence to modify unhelpful behaviours, adopt successful coping strategies and manage their condition optimally (Roger, Wetzell, Hutchinson, Packer, & Versnel; 2014). This in turn may lead to a more satisfactory outcome for the client.

## **5.2 Biographical Disruption and Self-identity**

Multiple studies in the chronic conditions literature have described Bury's notion of biographical disruption, where injury or illness was recognised as a critical event that changes

the trajectory of a person's life, interrupts plans and expectations for the future, and disrupts personal and social identity (Bury, 1982; Greenstreet, 2006; Jowsey et al., 2001; Soklaridis, Cartmil, & Cassidy, 2011; Wilson, 2007). Some individuals are more susceptible to experiencing biographical disruption than others (Soklaridis et al., 2011), and age has been reported to influence the meaning given to such an event (Thorne, 1999; Thorne et al., 2002; Wilson, 2007). While this study did not seek to explore biographical disruption, participants' narratives indicated that this was a common experience that impacted how they perceived and managed the condition. Individuals with Chronic Subjective Dizziness seemed to experience multiple disruptions, at various points in their journey; the first disruption did not necessarily coincide with the onset of the condition, an observation also made in the chronic conditions literature (e.g. Delbene, 2011; Wilson, 2007). In this present study, many participants felt a sense of disruption when faced with a lack of prognostic certainty and in the context of fluctuating symptoms. Disruption was also felt when participants experienced episodes of feeling 'normal' again and tentatively hoped that natural recovery had occurred, only to realise that these periods were short lived. These disruptions were described as cruel and appeared to strip the individuals of their sense of hope. Data from this study supported Delbene's findings (2011) that individuals felt they had fallen victim, or were being held hostage, by Chronic Subjective Dizziness, an entity that no one knows much about but that had taken over their lives and removed their sense of control. Biographical disruption, and loss of control are frequently associated with loss of identity and changes in sense of self (Bury, 1982; Charmaz, 1983; Delbene, 2011; Greenstreet, 2006; Wilson, 2007). These were reflected in the current study where participants claimed they were no longer themselves; their self-image or perception of who they were in relation to others had changed, and they felt uncomfortable within themselves. In the chronic conditions literature, changes in sense of self were claimed to shape the individual's level of participation and engagement (Charmaz, 1983; Roger et al., 2014).

Participants in this study indicated that they could handle the dizziness, but not the disruption it caused to their lives and to their sense of self. They found the disturbance of dreams and plans for the future and trying to regain continuity in their lives, especially hard to deal with. It has been suggested that Chronic conditions involuntarily 'fast-forward' individuals to a later stage of life (Bury, 1982; Delbene, 2011). This was also observed in the current study; symptoms such as giddiness, imbalance, inability to read, disorientation and poor memory are symptoms commonly associated with conditions affecting the elderly and not necessarily young healthy adults. This apparent 'premature aging process' has been argued to result in an

identity shift that is even more disturbing than the disruption caused by the condition itself (Bury, 1982; Charmaz, 1983; Delbene, 2011). These notions were clearly illustrated in the current study, with participants describing how they had lost freedom, independence and social connection as the result of these symptoms, and one participant claimed she felt like a 90-year-old person because of it (see p.51). It is claimed that such disruptions also affect how others perceive individuals, in a social context (Bury, 1982; Charmaz, 1983).

In line with the existing literature, many participants in this study felt that in order to cope with the condition, they had to transform their identity and re-define themselves (Asbring, 2000; Bury, 1982; Roger et al., 2014). However, the prospect of doing so was perceived as upsetting and tiring. Interestingly, participants who appeared to have successfully managed 'the changing self' appeared to manage their condition better than those who had not. Delbene (2011) suggested that perhaps this was due to timing of the disruption, and posits that if the onset of the condition comes at a time where the individual "subjectively selects the meaning of one's life story", the effect of the biographical disruption is more pronounced (p.25). This was an interesting idea that seemed to apply to some of the participants in this study who appeared to be extremely affected by this forced change of self, compared to others who seemed to have 'come to terms' with it. For example, the participant in this study for whom the biographical disruption happened in her early teens, perhaps where the sense of self was not entirely formed, appeared to be less affected, and in fact claimed that the condition did not rule her life or who she was as a person (see extract from Molly's interview, p.52). This was in contrast to participants, who experienced the 'change of self' a little later in life, and were perhaps in the process of establishing a meaningful life story in the context of growing a family, a career, and a social life. This observation would benefit from further exploration and may be important for those aiming to support working-age adults affected by Chronic Subjective Dizziness, especially those in the early to mid-stages of adulthood.

### **5.2.2 Clinical relevance and implications for practice**

The existing literature and findings of this study have shown that change of self is a fluid process and that biographical disruption may happen more than once, and to various degrees. It is important for health professionals to consider the onset of the condition in relation to stage of life and age of the person and to identify what support needs they may have. Key to a positive outcome may be for health professionals, to get to know the person,

identify what is most disruptive to their lives, what strengths they possess to respond to disruptions, and what skills or strengths they need to cope.

Participants in this study expressed that having access to health professionals with experience and understanding of Chronic Subjective Dizziness is not only re-assuring but also extremely helpful. Knowing that support is available was often enough for individuals to feel empowered and to persevere in their quest to manage this long-term unpredictable condition. Their need for unobstructed and unlimited access is however difficult to operationalise as health services are limited by financial constraints. For example, in New Zealand, there are not enough specialist services or resources that individuals can draw upon on an on-going basis or when needs change. Participants in this study also highlighted that they have difficulties performing activities of daily life. For example, one participant claimed that when the dizziness was severe, she could not drive her son to school (see extract from Ava's interview, p 52). Providing childcare or home support that could step in as required, or collaboratively negotiating a 'plan B' would have alleviated stress for that person and limited the impact of Chronic Subjective Dizziness on others. Health professionals may not consider and therefore be sensitive to the notion of biographical disruption and changing sense of self. Failing to acknowledge these is likely to have an impact on the therapeutic interventions clinicians propose. Understanding and acknowledging them may support validation and legitimisation as previously described.

The current study has demonstrated that there is an expectation for individuals affected by Chronic Subjective Dizziness to accept the condition as part of their life. However, there are no clear guidelines that help individuals to manage the condition and its integration into daily life. Simply telling clients 'to live with it' or advising them to use strategies that would prevent them from performing the most essential activities of daily life were not perceived as helpful. Although participants appeared to be resourceful and seemed to have adopted multiple management strategies, not all of these were successful or appropriate. As an example, some adopted avoidance behaviours, yet were unhappy with the isolating effect that had. Participants often claimed that they did not know if what they did was helpful. Many had put restrictions on their life as a result of not knowing if certain activities would negatively affect their condition, for example, participants talked about avoiding travel, sport or exercise despite claiming that previous to their dizziness these activities were a big part of their life. None were unaware that activities could be adapted so they were still manageable and enjoyable without the risk of adversely affecting their condition. Offering individuals options

and a variety of management strategies could therefore be a key component of specialist care and support.

### **5.3 Direction for an Uncertain and Unpredictable Future**

The onset of Chronic Subjective Dizziness is unlike many acute illnesses. This goes against social expectations and the acute illness framework from which health professionals predominantly work (Bury, 1982; Charmaz, 1983; Greenstreet, 2006). For health professionals who work in an acute illness framework, it is not uncommon to consider their role as providing a diagnosis, effective treatment and a cure (Bury, 1982; Charmaz, 1983; Delbene, 2011). One participant made a valuable observation that with Chronic Subjective Dizziness none of these could be accomplished, potentially giving health professionals the impression that their role had become futile and that they had nothing to offer.

The acute illness framework also influences societal perceptions and expectations (Charmaz, 1983). In fact, participants in this study appeared to operate from the acute illness framework themselves, at various points. Yet many seemed to have transitioned to a chronic illness model as described by Patterson (2001). In fact, many participants in this study appeared to oscillate between two frameworks, and sought on the one hand a diagnosis and cure while on the other hand seeking direction and support to live a better life despite their dizziness. As a by-product individuals not only appeared to lose their 'sense of belonging' (Lian and Lorem, 2016), but standing with one foot in the acute illness framework and the other in a chronic framework, may also be why participants in this study felt as if they were in limbo, and claimed to be so exhausted.

In the present study, participants talked about having to adjust to the unpredictability of the condition itself but also to an uncertain future while longing for a 'normal' life. Participants not only had no idea why this condition occurred, but also did not know if it would get any better or if they would be able to resume a normal life. Living with uncertainty is difficult, and the need to balance disruption with the need for continuity requires constant effort (Bury, 1982; Nilsen & Anderssen, 2014; Roger et al., 2014). According to the chronic conditions literature, individuals alternate between living in hope and living in despair (Nilsen & Anderssen, 2014; Roger et al., 2014). Although this study did not intend to explore hope, it appeared to be an important resource most participants drew on in order to cope with dizziness. Humans persistently navigate between hope and reality, having hopes and dreams is what gives life meaning (Eaves, Nichter, & Ritenbaugh, 2016; Greenstreet, 2006; Milne, Moyle,

& Cooke, 2009). Hope is also important for illness adjustment and outcome after disruptive life events (Bright, Kayes, McCann, & McPherson, 2011; Veres, Tin, Thorne, & Ginsburg, 2014).

The literature discusses many variations of hope (Bright et al., 2011; Eaves et al., 2016; Van Lit & Kayes, 2014). In this study, individuals talked about 'having hope' and 'losing hope'.

Participants who had hope, hoped for something such as a full recovery or a significant improvement that would allow them to regain their previous sense of belonging and stability. They also talked about having hope for the future, for example hoping that one day they would enjoy life again or get a reasonable quality of life back. Having hope seemed to make people feel empowered. Losing hope, on the other hand, was often met with despair, for example, one participant said that if someone had told her she would not get any better, it would have seriously damaged her (see extract from Ava's interview, p 59). Sometimes hope was not lost but taken away, for example, when health professionals were unsupportive. Hope is also believed to be related to stage of life. For example, Nair (2003) posits that working-age adults have hopes concerning careers, work, family and social relationships. These are different from an elderly population where hope was found to be more related to a good 'end of life experience', which referred to remaining as independent as possible and keep living in their own home. The effect of age and stage of life on hope was also reflected in the present study; for example, younger participants hoped to be a good spouse, mother, employee whereas the participant who was entering retirement hoped to spend a meaningful time with her husband travelling and 'simply enjoying life'. Hope was described as a fluid but often paradoxical resource that comes and goes, that is given and taken away, that was simultaneously unsettling yet necessary for living an ever-changing reality. Roger et al. (2014) argued that individuals who hoped to regain a sense of normality were looking for a sense of belonging (Roger et al., 2014). For participants in this study, one of the main ingredients for having or creating a sense of belonging appeared to be 'having a sense direction'. Establishing a collaborative support program comprising strategies that suited the participants' circumstances was discussed as supplying that sense of direction. It was clear from participants' narratives that they needed direction to navigate an unpredictable life and regain a sense of normality.

### **5.3.1 Implications for clinical practice**

Health professionals tend to operate from an acute illness framework (Charmaz, 1983). Yardley and Beech (1998) suggest clinicians adjust their framework and 'match' it to that of the individual. To do so clinicians first need to establish which framework the individual

mentally occupies at the time of consultation. For example, individuals who have experienced dizziness for some time and who want to explore how best to manage the condition may not necessarily appreciate being offered a battery of diagnostic tests and assessments. Instead, exploring how best to live with the condition, taking into account the personal situation of the individual such as available support systems, professional demands, and socio-economic status may be more useful for that person at that time. Paterson (2001) recommends that health professionals are flexible and that they have skills that allows them to move fluidly between the two illness- frameworks, depending on their client's position. Paterson (2001) also pointed out that changing frameworks is not a linear process and that people move frequently from one to the other depending on context. From this viewpoint, it may be beneficial for health professionals to have skills that allow them to work in an agile way so that they can adjust attitudes and behaviours to match the person and their needs. Being cognisant of those frameworks and understanding which is dominant for the person is crucial for health professionals supporting individuals with Chronic Subjective Dizziness (Delbene, 2011; Paterson, 2001). An example of health professionals operating in a different medical framework was clearly demonstrated when one participant in the current study claimed to be misunderstood by her neurologist. The participant wanted her neurologist to understand the effect the condition had on her life, and engage in a supportive discussion, while the neurologist focused on diagnosis and treatment (see extract from Thea's interview, p. 46).

In the context of hope, it is essential that health professionals recognise hope as critical to successful management of a long-term condition. Although it may be difficult to preserve hope without instilling false hope, health professionals should take care not to dash hope (Eaves et al., 2016; Greenstreet, 2006; Pergert & Lützén, 2012). Hope should not only be respected, but clinicians should try to gain a better understanding of hope and consider that it is a fluid construct, variably present depending on context and personal circumstances.

To find a sense of direction and regain some stability participants identified that they needed an exchange of knowledge and sharing of information. Their definition of knowledge was broad, and did not necessarily reflect health professionals' notions of knowledge. For example, participants in this study accepted that health professionals did not have all the answers yet were keen for clinicians to share what knowledge they had, evidence-based and experiential knowledge. The participants also valued access to peer knowledge or someone they could identify with.



In summary, there are some key points health professionals may find beneficial to reflect on. First, the experience of Chronic Subjective Dizziness needs to be seen in the context of general health and wellbeing. This means that other co-existing conditions, external and internal factors as well as environmental and situational circumstances should be taken into account. Second, an individually matched approach to care and support is likely to demonstrate to the individual that their experience is legitimate and this validation may in turn lead to empowering therapeutic relationships. Health professionals may also find it beneficial to reflect on their current practice, gain insight into which illness framework they work from, and evaluate if their assessment and treatment plans are sensitive to the client's illness perceptions and expectations. Discussing individual coping strategies and exploring strategies that match the person in the context of their illness beliefs, status of hope, environmental factors and available social supports may be crucial to satisfactory health care and successful outcomes.

#### **5.4 Study Strengths and Limitations**

The chosen methodology has brought to light aspects of Chronic Subjective Dizziness that existing literatures, have not done before. Prior to the current study, the personal experience of this condition had not been comprehensively explored, nor had there been a focus on working-age adults, the population considered to be most affected by this condition. Exploring the personal experience of Chronic Subjective Dizziness exclusively from a working-age adult's perspective, allowed me to cast a light on information, important to health care practice, currently missing from the literature. The findings of this study should however be read in the context of its limitations, which are acknowledged and discussed below.

Because of a relatively small sample pool of people that met the inclusion criteria (p. 29), participants could not be purposefully selected for diversity. Rather, convenience sampling was adopted. Both approaches are consistent with interpretive description (Thorne, 2004), but it did mean that some populations, whose perspectives may have added additional breadth and depth to the findings were not included in this study. In particular, no Māori (indigenous population of New Zealand) or Asian (growing immigrant population of New Zealand) took part in this study. Cultural differences may influence the individual experience of dizziness, as priorities and socio-cultural roles may be different and may have also highlighted different support needs. My attempts to include Māori in this study may have highlighted issues that warrant further investigation, as discussed on pp. 37-38.

There was also a gender imbalance in the study sample, with a female-male ratio of seven to one. Having more male participants in this study may have identified different priorities or issues, and may have offered a more comprehensive perspective. However, given Chronic Dizziness is more prevalent in female populations, with a ratio of three to one, it is likely this gender imbalance is more representative for the population under investigation.

As a researcher, I had the advantage of having had a therapeutic relationship with six of the eight participants through my work as a clinician at the recruitment locality prior to commencement of the study. This meant I had prior knowledge of some of the issues most participants were facing. I see this as positive as most participants felt comfortable to share their experiences with me, which may have produced richer data. However, I also acknowledge it may have influenced data collection and analysis, by giving direction to some of the questions and findings.

Further, in the process of data collection two participants preferred phone interviews to face-to-face interviews, and chose the interview to be conducted during their lunch breaks. Coincidentally these participants were also those with whom I did not have a prior therapeutic relationship. These circumstances may have brought a different dynamic than the face-to-face interviews, as there was no way I could 'read' body language or pick up on non-verbal cues. Being interviewed in a work environment may have also meant that these participants were more guarded, or were unable to reveal the essence of their experience due to time constraints. Yet, it may have also enriched the data in that the interviews took on slightly different angles. Perhaps due to the interview setting, discussion was more directed towards work and work-related social experiences, bringing slightly different and interesting perspectives to light.

Irrespective of these limitations, findings of this study have shed light on the experience of Chronic Subjective Dizziness and its perceived impact on working-age adult's lives. The study has also underlined a number of points for consideration relevant to clinical practice and highlighted areas for future research.

## **5.5 Directions for Future Research**

Research exploring Chronic Subjective Dizziness has to date been limited to quantitative studies and the experiential perspective has been largely uncharted territory. As such, a wide range of questions around this topic remain unanswered.

As highlighted in the literature review, a small number of studies examined the personal experience of dizziness; these were either completed with participants affected by acute dizziness such as Benign Positional Paroxysmal Vertigo or as part of a more complex diagnosis such as traumatic brain injury or Meniere's disease. Most studies also approached dizziness from the perspective of an elderly population. This study is to my knowledge the first of its kind in this topic area. Given the limitations of my sample described above, further exploration with more diverse samples is warranted.

Chronic Subjective Dizziness affects people of all ages, including adolescents and young adults. For example, one participant's onset of Chronic Subjective Dizziness was during adolescence and the experience of her dizziness was different at that time compared to the time of her interview. It would therefore be beneficial to explore the personal experience from adolescents' perspectives as this might highlight different issues or priorities specific to their stage of their lives, for example, exploring how Chronic Subjective Dizziness shapes the formation of a sense of self, hope or social relationships.

Dizziness in the New Zealand context, from all perspectives, has yet to be fully explored. However, the absence of Māori affected or diagnosed with Chronic Subjective Dizziness raises questions. These include: Is Chronic Subjective Dizziness prevalent in Māori? If Māori do suffer from Chronic Subjective Dizziness, then additional questions arise. Do Māori seek advice or support for their condition? What are the socio-economic or cultural issues that affect Māori seeking help? Are there cultural aspects that influence Māori experience of dizziness, perhaps in the context of illness beliefs? Does the Māori model of health provide Māori with the strengths and skills to manage this condition better than other populations? Do Māori seek expert advice for their Chronic Subjective Dizziness and if so what are the barriers for them to follow up with referrals? Do Māori have different support needs?

A longitudinal study could also explore how the experience of Chronic Subjective Dizziness changes over the lifespan, as social, personal and environmental factors influencing the experience and personal priorities change. This study has shown that Chronic Subjective Dizziness affects social relationships and the lives of those within the family unit. Exploring Chronic Subjective Dizziness from a child's or partner's perspective may also highlight the fact that support needs stretch to the extended family. It would also be beneficial from the perspective of satisfactory care delivery, to explore the effect of 're-branding Chronic Subjective Dizziness as Persistent Postural Perceptual Dizziness'. For example, does the

nomenclature change affect the health professional's causal beliefs of the condition, or does it change health professionals' attitudes and behaviours towards legitimisation?

This study suggests that understanding the experience of Chronic Subjective Dizziness is important for supporting those affected by the condition and for long-term outcomes. From a physiotherapist's perspective it would be worthwhile exploring how clinicians reflect on their current assessments of individuals affected by Chronic Subjective Dizziness. For example, do clinicians use different assessment approaches based on chronicity, or are clinicians conscious of the framework they operate from i.e. acute illness framework versus chronic conditions framework and how easy or difficult is it for them to move between the two depending on the client they are presented with at the time.

While a number of studies have investigated the impact of dizziness and participation restrictions, most of these have used existing standardised outcome measures, which do not always capture the full extent of issues experienced by those affected by the condition. It may be beneficial to develop a more inclusive measure to map the influencing factors and priorities of individuals with an aim to identify support needs. This could form the basis for developing collaborative individualized support/ treatment plans that go beyond current recommended management approaches.

It may also be beneficial to explore what strengths and skills clinicians need to 'map the factors that influence the person's life' or to recognise what their client's needs are', and in a similar way to explore the clinician's self-assessed aptitude to 'match' their skills to the individual's needs. It would be worth exploring whether physiotherapists or other related allied health professionals that may be involved with supporting this population, have the required consultancy skills. Is it part of undergraduate or expert clinician education? For example, are health professionals taught how to identify the person's needs, to map a support plan responsive to individual needs? Could an agile approach to care delivery be useful; i.e. where a variety of management strategies are proposed as potentially most successful to least favourable, where support plans are incrementally implemented and adjusted in response to problems encountered on the way? Further exploration of core components of satisfactory support plans, including components of a collaborative partnership formation in the context of chronic conditions framework, are required.

## 5.6 Summary of Findings

This study explored the experience of Chronic Subjective Dizziness from a working-age adult's perspective with the aim of generating new knowledge that may help health professionals better understand and support those affected by this condition. Findings from eight participant interviews suggest that the experience of Chronic Subjective Dizziness is marked by three complex factors: a) 'illness beliefs and legitimisation' underpinned by theme one: 'It sounds like I'm crazy'; b) 'biographical disruption and changed self-identify', underpinned by theme two: 'I'm a shadow of my former self'; and c) 'finding direction in an uncertain and unpredictable life' underpinned by theme three: 'How will I survive?'.

These findings are unique in the context of the existing literature on Chronic Subjective Dizziness, which has been predominantly quantitative in nature. To the best of my knowledge, there are no qualitative studies that explore this topic from an experiential perspective. These findings are, however, not unique in the context of the broader chronic conditions literature, and resonate with the findings from a range of studies that explore invisible and contested conditions, such as chronic pain or chronic fatigue.

This study also refuted the assumptions I made prior to commencing this study (see p. 5). First, I assumed that in clinical practice not enough attention was given to the more nebulous symptoms associated with Chronic Subjective Dizziness and that poor understanding of these symptoms got in the way of successful treatment. This study highlighted that receiving a diagnosis is important for the coping process, however in order to help people manage their condition health professionals need to go beyond symptoms and diagnosis and acknowledge the complexity of the condition. Continued focus on symptomology can not only be perceived as unhelpful but may also, in some cases, be counterproductive for the legitimisation process. As demonstrated in the participants' narratives, there is a mismatch between what health services currently have to offer people affected by Chronic Subjective Dizziness, and what the individuals need. The findings of this study suggest that health professionals predominantly approach Chronic Subjective Dizziness from an acute illness perspective, with a focus on pattern recognition, symptomatic treatment and cure, and that service delivery falters or comes to a halt when the characteristics of this acute illness model are not applicable. From a biomedical perspective symptoms are ill defined and often nebulous; there are no specific patterns in its presentation, and there is no prognostic certainty. Second, I assumed that working-age adults have more responsibilities compared to the elderly and that these shape the experience. While this study and the findings of the

literature review indicate that age and stage of life are important to the experience of a chronic condition, there is no indication that these are related to the level of responsibility. Age and stage of life do appear to shape individual priorities and the support needs of a person, so they should be taken into consideration in clinical practice.

This study is clinically relevant in that it urges health professionals to rethink the conceptual framework they routinely work from. It also encourages health professionals to re-evaluate what they have to offer people affected by Chronic Subjective Dizziness, and focus on the individual needs of the person, their priorities and internal and external influences on their coping behaviours. It is also recommended that health professionals discuss support expectations, and collaborate with the person on how that is best delivered.

## **5.7 Conclusion.**

This study contributed to the existing body of knowledge about Chronic Subjective Dizziness by highlighting the importance of understanding the personal experience and the perceived impact on affected individuals. It has demonstrated that Chronic Subjective Dizziness is complex and dynamic, and affects people in different ways depending on the context and personal priorities. It also exposed that the current acute illness framework that forms the basis of many therapeutic interactions does not satisfactorily respond to the needs of the individual living with the condition, and in fact may be counterproductive. This study has generated some points for health professionals to consider when designing service delivery and enhancing clinical practice, and has shown areas where further research is needed.

## References

- Anderson, R. M., & Funnell, M. M. (2010). Patient empowerment: Myths and misconceptions. *Patient Education and Counseling*, 79(3), 277-282. doi:10.1016/j.pec.2009.07.025
- Armentor, J. L. (2015). "Living with a contested, stigmatized illness: Experiences of managing relationships among women with fibromyalgia." *Qualitative Health Research*, 12(1), 1-11. doi:10.1177/1049732315620160
- Asbring, P. (2001). "Chronic illness - A disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia." *Journal of Advanced Nursing*, 34(3), 312-319. doi:10.1046/j.1365-2648.2001.01767.x
- Attree, M. (2001). Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality care. *Journal of Advanced Nursing*, 33(4), 456-466. doi:10.1046/j.1365-2648.2001.01689.x
- Baloh, R. W. (1995). Approach to the dizzy patient. *Otolaryngology Head Neck Surgery*, 112 (1), 3-7. doi: 10.1016/S0194-5998(95) 70299-7
- Baloh, R. W. (1997). When your patient complains of dizziness: an overview. *Family Practice Recertification*, 19(11), 14-24. Retrieved from <http://www.ascendmedia.com>
- Barracough, K., & Bronstein, A. M. (2009). Vertigo. *BMJ*, 339, 747-752. doi:10.1136/bmj.b3493
- Benecke, H., Agus, S., Kuessner, D., Goodall, G., & Strupp, M. (2013). The burden and impact of vertigo: Findings from the REVERT patient registry. *Frontiers in Neurology*, 4(136), 1-7. doi:10.3389/fneur.2013.00136
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. doi:10.1177/1468794112468475
- Bittar, R. S., Sohsten Lins, E.M, (2015). Clinical characteristics of patients with persistent postural-perceptual dizziness. *Braz J Otorhinolaryngol*, 81(3), 276-822. doi:10.1016/j.bjorl.2014.08.012
- Brandt, T. (1996). Phobic postural vertigo. *Neurology*, 46(6), 1515-1519. doi:10.1212/WNL.46.61515
- Brandt, T. H., & Dieterich, M. (1986). Phobischer Attacken Schwankschwindel: Ein neues Syndrom. *Munchener Medizinische Wochenschrift*, 128, 247-250. Retrieved from <https://www.thieme-connect.com>
- Brandt, T., Huppert, D., & Dieterich, M. (1994). Phobic postural vertigo: a first follow-up. *Journal of Neurology*, 241(4), 191-195. doi:10.1007/BF00863767

- Bright, F. A. S., Kayes, N. M., McCann, C. M., & McPherson, K. M. (2011). Understanding hope after stroke: a systematic review of the literature using concept analysis. *Topics in Stroke Rehabilitation, 18*(5), 490-508. doi:10.1310/tsr1805-490
- Bronstein, A. M., Golding, J. F., Gresty, M. A., Mandalà, M., Nuti, D., Shetye, A., & Silove, Y. (2010). The social impact of dizziness in London and Siena. *Journal of Neurology, 257*(2), 183-190. doi:10.1007/s00415-009-5287-z
- Bronstein, A. M., Gresty, M. A., Luxon, L. M., Ron, M. A., Rudge, P., & Yardley, L. (1997). Phobic postural vertigo. *Neurology, 49*(5), 1480-1481. doi:10.1212/WNL.49.5.1480
- Bronstein, A. M., Lempert, T., & Seemungal, B.M. (2010). "Chronic dizziness: a practical approach." *Practical Neurology 10*(3): 129-139. doi:10.1136/jnnp.2010.211607.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: a practical guide for beginners*. London, England: Sage.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*(2), 167-182. doi:10.1111/1467-9566.ep11339939
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward Greater Clarity in Generic Qualitative Research. *International Journal of Qualitative Methods, 2*(2), 1-24. Retrieved from [http://www.ualberta.ca/~iiqm/backissues/2\\_2/pdf/caellietal.pdf](http://www.ualberta.ca/~iiqm/backissues/2_2/pdf/caellietal.pdf)
- CASP checklist. Critical Appraisal Skills Programme (2014). Retrieved from [www.media.wix.com/ugd/dded87\\_29c5b002d99342f788c6ac670e49f274.pdf](http://www.media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf)
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195. doi:10.1111/1467-9566.ep10491512
- Clark, M., Moreland, N., Greaves, I., Greaves, N., & Jolley, D. (2013). Putting personalisation and integration into practice in primary care. *Journal of Integrated Care, 21*(2), 105-120. doi:10.1108/14769011311316033
- Clarke, V., Braun, V. & Hayfield, N. (2015). *Thematic analysis*. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (3rd ed). London, England: Sage.
- Delbene, R. (2011). "Patients' narratives of chronic illnesses and the notion of biographical disruption." *Communication & Medicine, 8*(1): 17-27. doi:10.1558/CAM.V811.17
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321. doi:10.1111/j.1365-2929.2006.02418.x



- Dros, J., Maarsingh, O. R., Beem, L., van der Horst, H. E., ter Riet, G., Schellevis, F. G., & van Weert, H. C. P. M. (2011). Impact of dizziness on everyday life in older primary care patients: A cross-sectional study. *Health and Quality of Life Outcomes*, 9, 44. doi:10.1186/1477-7525-9-44
- Duracinsky, M., Mosnier, I., Bouccara, D., Sterkers, O., Chassany, O., Attal, N.,.....Toupet, M. (2007). Literature review of questionnaires assessing vertigo and dizziness, and their impact on patients' quality of life. *Value in Health*, 10(4), 273-284. doi:10.1111/j.1524-4733.2007.00182.x
- Eaves, E., Nichter, M., & Ritenbaugh, C., (2016). Ways of Hoping: Navigating the Paradox of Hope and Despair in Chronic Pain. *Culture, Medicine & Psychiatry*, 40(1), 35-58 24. doi:10.1007/s11013-015-9465-4
- Edelman, S. (n.d), *Psycho-Physiological Dizziness Syndrome*. Retrieved from [http://www.notsa.org.au/PPDS\\_Information%20flyer.pdf](http://www.notsa.org.au/PPDS_Information%20flyer.pdf)
- Edelman, S., Mahoney, A. E., & Cremer, P. D. (2012). Cognitive behavior therapy for chronic subjective dizziness: a randomized, controlled trial. *American Journal of Otolaryngology*, 33(4), 395-401. doi:10.1016/j.amjoto.2011.10.009
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80-92. doi:10.1177/160940690600500107
- Ferreira, L. S. D. S., Pereira, C. B., Rossini, S., Kanashiro, A. M. K., Adda, C. C., & Scaff, M. (2010). Psychological assessment in patients with phobic postural vertigo. *Arquivos De Neuro-Psiquiatria*, 68(2), 224-227. doi:10.1590/S0004-282X2010000200013
- Furze, G., Roebuck, A., Bull, P., Lewin, R.J.P., & Thompson, D.R. (2002). A comparison of the illness beliefs of people with angina and their peers: a questionnaire study. *BMC Cardiovascular Disorders*, 2(4). doi:10.1186/1471-2261-2-4
- Grant, B. M., & Giddings, L. S. (2002). Making sense of methodologies: A paradigm framework for the novice researcher. *Contemporary Nurse*, 13, 10-28. doi:10.5172/conu.13.1.10
- Greene, R. A., Dasso, E., Ho, S., & Genaidy, A. M. (2014). A Person-Focused Model of Care for the Twenty-First Century: A System-of-Systems Perspective. *Population Health Management*, 17(3), 166-171. doi:10.1089/pop.2013.0040
- Greenstreet, W. (2006). Spiritual care. From spirituality to coping strategy: making sense of chronic illness. *British Journal of Nursing*, 15(17), 938-942. Retrieved from <https://create.canterbury.ac.uk/id/eprint/8141>
- Hain (2013). *Epidemiology of Dizziness*. Retrieved December 08, 2014, from [http://dizziness-and-balance.com/practice/approach/dizzy\\_epi.html](http://dizziness-and-balance.com/practice/approach/dizzy_epi.html)

- Hale, E. D., Treharne, G. J., & Kitas, G. D. (2007). The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology*, 46(6), 904-906. doi:10.1093/rheumatology/kem060
- Hannaford, P. C., Simpson, J. A., Bisset, A. F., Davis, A., McKerrow, W., & Mills, R. (2005). The prevalence of ear, nose and throat problems in the community: results from a national cross-sectional postal survey in Scotland. *Family Practice*, 22(3), 227-233. doi:10.1093/fampra/cmi004
- Herdman, S. J. (2007). *Vestibular Rehabilitation* (3rd ed.). Philadelphia, USA: F. A. Davis Company.
- Herdman, S.J., Clendaniel, R., & Steele, R. (2014). *Vestibular Rehabilitation* (4th ed.). Retrieved from <http://AUT.ebib.com>
- Holle, D., Schulte-Steinberg, B., Wurthmann, S., Naegel, S., Ayzenberg, I., Diener, H.-C., & Obermann, M. (2015). Persistent Postural-Perceptual Dizziness: A Matter of Higher, Central Dysfunction. *PLoS ONE*, 10(11), e0142468. doi:10.1371/journal.pone.0142468
- Holmberg, J., Karlberg, M., Harlacher, U., & Magnusson, M. (2007). One-year follow-up of cognitive behavioral therapy for phobic postural vertigo. *Journal of Neurology*, 254(9), 1189-1192. doi:10.1007/s00415-007-0499-6
- Holmberg, J., Karlberg, M., Harlacher, U., Rivano-Fischer, M., & Magnusson, M. (2006). Treatment of phobic postural vertigo. A controlled study of cognitive-behavioral therapy and self-controlled desensitization. *Journal of Neurology*, 253(4), 500-506. doi: 10.1007/s00415-005-0050-6
- Holmes, S., & Padgham, N. D. (2011). A review of the burden of vertigo. *Journal of Clinical Nursing*, 20(19/20), 2690-2701. doi:10.1111/j.1365-2702.2010.03585.x
- Honaker, J. A., Gilbert, J. M., & Staab, J. P. (2010). Chronic subjective dizziness versus conversion disorder: discussion of clinical findings and rehabilitation. *American Journal of Audiology*, 19(1), 3-8. doi:10.1044/1059-0889(2009/09-0013)
- Hunt, M. R. (2009). "Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work." *Qualitative Health Research*, 19(9), 1284-1292. doi:10.1177/1049732309344612
- Huppert, D., Strupp, M., Rettinger, N., Hecht, J., & Brandt, T. (2005). Phobic postural vertigo--a long-term follow-up (5 to 15 years) of 106 patients. *Journal of Neurology*, 252(5), 564-569. doi:10.1007/s00415-005-0699-x

- Indovina, I., Riccelli, R., Chiarella, G., Petrolo, C., Augimeri, A., Giofrè, L., ... Passamonti, L. (2015). Role of the Insula and Vestibular System in Patients with Chronic Subjective Dizziness: An fMRI Study Using Sound-Evoked Vestibular Stimulation. *Frontiers in Behavioral Neuroscience*, 9, 334. doi:10.3389/fnbeh.2015.00334
- Joachim, G., & Acorn, S. (2000). Living with chronic illness: the interface of stigma and normalization. *Canadian Journal of Nursing Research*, 32(3), 37-48. doi:10.1046/j.1365-2648.2000.01466.x
- Jowsey, T., John Ward, N., & Gardner, K. (2013). Agents in time: Representations of chronic illness. *Health Sociology Review*, 22(3), 243-254. doi:10.5172/hesr.2013.22.3.243
- Kapfhammer, H. P., Mayer, C., Hock, U., Huppert, D., Dieterich, M., & Brandt, T. (1997). Course of illness in phobic postural vertigo. *Acta Neurologica Scandinavica*, 95(1), 23-28. doi: 10.1111/j.1600-0404.1997.tb00063.x
- Katsarkas, A. (2008). "Dizziness in aging: the clinical experience." *Geriatrics*, 63(11), 18-20. Retrieved from <http://ubmadvanstar.com>
- Kruschinski, C., Theile, G., Dreier, S. D., & Hummers-Pradier, E. (2010). The priorities of elderly patients suffering from dizziness: A qualitative study. *European Journal of General Practice*, 16(1), 6-11. doi:10.3109/13814780903479914
- Khawaja, M., & Boddington, B. (2009). Too early to retire? Growing Participation of Older New Zealanders in the Labour Force. *New Zealand Population Review*, 35:75-93. Retrieved from [http://www.population.org.nz/wp-content/uploads/2011/02/nzpr-vol-35\\_khawaja-and-boddington.pdf](http://www.population.org.nz/wp-content/uploads/2011/02/nzpr-vol-35_khawaja-and-boddington.pdf)
- Larsson, A. T., & Grassman, E. J. (2012). Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness? *Sociology of Health & Illness*, 34(8), 1156-1169. doi:10.1111/j.1467-9566.2012.01460.x
- Larun, L., & Malterud, K. (2007). "Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies." *Patient Education and Counseling*, 69(1-3): 20-28. doi:10.1016/j.pec.2007.06.008
- Lasisi, A. O., & Gureje, O. (2010). Disability and quality of life among community elderly with dizziness: Report from the Ibadan Study of Ageing. *Journal of Laryngology and Otology*, 124(9), 957-962. doi: 10.1017/S0022215110000538
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In: Cameron LD, Leventhal H, editors. *The Self-Regulation of Health and Illness Behaviour*. London, England: Routledge

- Lian, O.S., & Lorem G.F. (2016). "I do not really belong out here anymore": Sense of being and belonging among people with medically unexplained long-term fatigue. *Qualitative Health Research*. Retrieved from <http://qhr.sagepub.com>
- Lonardi, C. (2007). The passing dilemma in socially invisible diseases: Narratives on chronic headache. *Social Science & Medicine*, 65(8), 1619-1629.  
doi:10.1016/j.socscimed.2007.07.007
- Maarsingh, O. R., Dros, J., Schellevis, F. G., van Weert, H. C., van der Windt, D. A., ter Riet, G., & van der Horst, H. E. (2010). Causes of persistent dizziness in elderly patients in primary care. *Annals of Family Medicine*, 8(3), 196-205. doi:10.1370/afm.1116
- Madden, S., & Sim, J. (2006). Creating meaning in fibromyalgia syndrome. *Social Science & Medicine*, 63(11), 2962-2973. doi:10.1016/j.socscimed.2006.06.020
- Matheson, A.J., Darlington, C.L., & Smith, P.F. (1999). Incidence of dizziness in the elderly. Correlation with oculomotor, optokinetic and postural function. *New Zealand Journal of Psychology*, 28(1), 17-22. Retrieved from <http://www.psychology.org.nz/wp-content/uploads/NZJP-Vol281-1999-3-Matheson2.pdf>
- Mendel, B., Bergenius, J., & Langius, A. (1999). Dizziness symptom severity and impact on daily living as perceived by patients suffering from peripheral vestibular disorder. *Clinical Otolaryngology and Allied Sciences*, 24(4), 286-293. doi:10.1046/j.1365-2273.1999.00261.x
- Mendel, B., Lutzen, K., Bergenius, J., & Bjorvell, H. (1997). Living with dizziness: an explorative study. *Journal of Advanced Nursing*, 26(6), 1134-1141. doi:j.1365-2648.1997.tb00805.x10.1046/j.1365-2648.1997.00447.x
- Milne, L., Moyle, W., & Cooke, M. (2009). Hope: a construct central to living with chronic obstructive pulmonary disease. *International Journal of Older People Nursing*, 4(4), 299-306. doi:10.1111/j.1748-3743.2009.00185.x
- Ministry of Health NZ. *Dizziness*. Retrieved on May 25, 2016, from <http://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/dizziness>
- Mueller, M., Schuster, E., Strobl, R., & Grill, E. (2012). Identification of aspects of functioning, disability and health relevant to patients experiencing vertigo: a qualitative study using the international classification of functioning, disability and health. *Health & Quality of Life Outcomes*, 10(1), 75-75. doi:10.1186/1477-7525-10-75
- Mueller, M., Strobl, R., Jahn, K., Linkohr, B., Peters, A., & Grill, E. (2014). "Burden of disability attributable to vertigo and dizziness in the aged: results from the KORA-Age study." *European Journal of Public Health* 24(5): 802-807. doi:10.1093/eurpub/ckt171

- Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(7), e1000097. doi:10.1371/journal.pmed1000097
- Nanda, A., & Tinetti, M. E. (2003). *Chronic Dizziness and Vertigo*. In Geriatric Medicine: An Evidence-Based Approach. New York, NY: Springer.
- Neff, B. A., Staab, J. P., Eggers, S. D., Carlson, M. L., Schmitt, W. R., Van Abel, K. M., . . . Shepard, N. T. (2012). Auditory and Vestibular Symptoms and Chronic Subjective Dizziness in Patients with Ménière's Disease, Vestibular Migraine, and Ménière's Disease with Concomitant Vestibular Migraine. *Otology & Neurotology*, 33(7), 1235-1244. doi:10.1097/MAO.0b013e31825d644a
- Nettleton, S. (2006). "I just want permission to be ill': towards a sociology of medically unexplained symptoms." *Social Science & Medicine*, 62(5), 1167-1178. doi:10.1016/j.socscimed.2005.07.030
- Neuhauser, H. K., Radtke, A., von Brevern, M., Lezius, F., Feldmann, M., & Lempert, T. (2008). Burden of dizziness and vertigo in the community. *Archives of Internal Medicine*, 168(19), 2118-2124. doi:10.1001/archinte.168.19.2118
- Nilsen, G., & Anderssen, N. (2014). Struggling for a normal life: Work as an individual self-care management strategy among persons living with non-malignant chronic pain. *Work*, 49(1), 123-132. doi:10.3233/WOR-131642
- Noble, H., & Smith, J. (2015) Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18(2), 34-35. doi:10.1136/eb-2015-102054
- Ödman, M., & Maire, R. (2008). Chronic subjective dizziness. *Acta Oto-Laryngologica*, 128(10), 1085-1088. doi:10.1080/16501970510040056
- Öhman, A. (2005). "Qualitative methodology for rehabilitation research." *Journal of Rehabilitation Medicine*, 37(5), 273-280. doi:10.1080/16501970510040056
- Olsson Möller, U., Hansson, E. E., Ekdahl, C., Midlöv, P., Jakobsson, U., & Kristensson, J. (2014). Fighting for control in an unpredictable life - a qualitative study of older persons' experiences of living with chronic dizziness. *BMC Geriatrics*, 14(1), 97-97. doi:10.1186/1471-2318-14-97
- Parsons, T. (1951). Illness and the role of the physician: A sociological perspective. *American Journal of Orthopsychiatry*, 21(3), 452-460. doi:10.1111/j.1939-0025.1951.tb00003.x
- Paterson, B. L. (2001). The Shifting Perspectives Model of Chronic Illness. *Journal of Nursing Scholarship*, 33(1), 21-26. doi:10.1111/j.1547-5069.2001.00021.x
- Pergert, P., & Lützn, K. (2012). Balancing truth-telling in the preservation of hope: A relational ethics approach. *Nursing Ethics*, 19(1), 21-29. doi:10.1177/0969733011418551

- Petrie, K. J. and J. Weinman (2006). "Why illness perceptions matter." *Clinical Medicine* 6(6): 536-539. Retrieved from [https://www.fmhs.auckland.ac.nz/assets/fmhs/som/psychmed/petrie/docs/2006\\_why\\_IPS\\_matter.pdf](https://www.fmhs.auckland.ac.nz/assets/fmhs/som/psychmed/petrie/docs/2006_why_IPS_matter.pdf)
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, 52(2), 137-145. doi:10.1037/0022-0167.52.2.137
- Pollak, L., Klein, C., Stryker, R., Kushnir, M., Teitler, J., & Flechter, S. (2003). Phobic postural vertigo: a new proposed entity. *The Israel Medical Association Journal*, 5(10), 720-723. Retrieved from <https://www.ima.org.il/FilesUpload/IMAJ/0/54/27309.pdf>
- Radcliffe, M. (2010). Modern life makes me dizzy, but I'm certain about this. *Nursing times*, 106(4), 27. Retrieved from <http://www.nursingtimes.net.exproxy.aut.ac.nz/>
- Rebman, A. W., Aucott, J.N., Weinstein, E.R., Bechtold, K.T., Smith, K.C., Leonard, L. (2015). "Living in limbo: contested narratives of patients with chronic symptoms following Lyme Disease." *Qualitative Health Research*, 13(1), 1-13. doi:10.1177/1049732315619380
- Roger, K., Wetzel, M., Hutchinson, S., Packer, T., Versnell, J. (2014). "How can I still be me?" Strategies to maintain a sense of self in the context of a neurological condition. *International Journal on Health and Well-being*, 9, 23534. doi.org/10.3402/qhw.v9.23534
- Rogers, J. A. (1995). Work is key to recovery. *Psychosocial Rehabilitation Journal*, 18(4), 5-10. Retrieved from <http://www.psycnet.apa.org/journals/prj/18/4/5.pdf>
- Ruckenstein, M. J., & Staab, J. P. (2009). Chronic subjective dizziness. *Otolaryngologic Clinics of North America*, 42(1), 71-77. doi:10.1016/j.otc.2008.09.011
- Saldaña, J. (2013). *The coding Manual for Qualitative Researchers* (2nd ed.) London, England: Sage.
- Shepard, N. T. (2015, April). No. 27: Persistent Postural-Perceptual Dizziness [audio podcast]. Retrieved October 09, 2015, from <http://www.neuropt.org/special-interest-groups/vestibular-rehabilitation/podcasts>
- Sloane, P. D., Coeytaux, R. R., Beck, R. S., & Dallara, J. (2001). Dizziness: state of the science. *Annals of Internal Medicine*, 134(9), 823-832. doi:10.7326/0003-4819-134-9\_Part\_2-200105011-00005
- Soklaridis, S., Cartmill, C., & Cassidy, D. (2011). Biographical disruption of injured workers in chronic pain. *Disability & Rehabilitation*, 33(23/24), 2372-2380. doi:10.3109/09638288.2011.573056

- Staab, J. P. (2006). Chronic dizziness: the interface between psychiatry and neuro-otology. *Current Opinion in Neurology*, 19(1), 41-48. Retrieved from <http://journals.lww.com>
- Staab, J. P. (2012). Chronic subjective dizziness. *Continuum*, 18(5), 1118-1141. doi:10.1212/01.CON.0000421622.56525.58
- Staab, J. P. (2014). The influence of anxiety on ocular motor control and gaze. *Current Opinion in Neurology*, 27(1), 118-124. doi:10.1097/WCO.0000000000000055
- Staab, J. P., Rohe, D. E., Eggers, S. D. Z., & Shepard, N. T. (2014). Anxious, introverted personality traits in patients with chronic subjective dizziness. *Journal of Psychosomatic Research*, 76(1), 80-83. doi:10.1016/j.jpsychores.2013.11.008
- Staab, J. P., Ruckenstein, M. J., & Amsterdam, J. D. (2004). A prospective trial of sertraline for chronic subjective dizziness. *Laryngoscope*, 114(9), 1637-1641. doi:10.1097/00005537-200409000-00025
- Staab, J.P., & Ruckenstein, M.J. (2005). Chronic Subjective Dizziness: Effect of course of illness on Treatment outcome. *Archives of Otolaryngology Head and Neck Surgery*, 131(8), 675-679. doi:10.1001/archotol.131.8.675
- Takano, N. A., Cavalli, S. S., Ganança, M. M., Caovilla, H. H., De Oliveira Santos, M. A., De Toledo Piza Peluso, E., & Ganança, F. F. (2010). Quality of life in elderly with dizziness. *Brazilian Journal of Otorhinolaryngology*, 76(6), 769-775. doi:10.1590/S1808-86942010000600016
- Temple B, Edwards R. (2002). Interpreters/translators and cross language research: reflexivity and border crossings. *International Journal on Qualitative Methods*, 1(2), 1-22. Retrieved from [https://www.ualberta.ca/~iiqm/backissues/1\\_2Final/pdf/temple.pdf](https://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/temple.pdf)
- Temple B, Young A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, 4(2), 161-78. doi: 10.1177/1468794104044430
- Ten Voorde, M., van der Zaag-Loonen, H. J., & van Leeuwen, R. B. (2012). Dizziness impairs health-related quality of life. *Quality of Life Research*, 21(6), 961-966. doi:10.1007/s11136-011-0001-x
- Terry, G. (2016). Doing thematic analysis. In E. Lyons & A. Coyle (eds.) *Analysing Qualitative Data in Psychology* (2nd ed.). London, England: Sage.
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (in press). Thematic analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (2nd ed.). London, England: Sage.
- Thorne, S. E. (1999). The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36(5), 397-404. doi:10.1016/S0020-7489(99)00031-0
- Thorne, S. E. (2008). *Interpretive description* (Vol. 2). Walnut Creek, CA: Left Coast Press.

- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: insights from a metastudy. *Qualitative Health Research*, 12(4), 437-452. doi:10.1177/104973202129120007
- Thorne, S., Reimer Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20(2), 169-177. Retrieved from <https://jaff6.files.wordpress.com/2012/04/sici1098-240x19970420-2-169-aid-nur9-3-01.pdf>
- Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). "The Analytic Challenge in interpretive description." *International Journal of Qualitative Methods*, 3(1): 1-11. Retrieved from [http://www.ualberta.ca/~iiqm/backissues/3\\_1/pdf/thorneetal.pdf](http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf)
- Tinetti, M. E., Williams, C.S., & Gill, T.M. (2000). "Health, functional, and psychological outcomes among older persons with chronic dizziness." *Journal of the American Geriatrics Society* 48(4): 417-421. doi:10.1111/j.1532-5415.2000.tb04700.x
- Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine*, 172(2), 124-128. doi: 10.1136/ewjm.172.2.124
- Van Lit, A., & Kayes, N. (2014). A narrative review of hope after spinal cord injury: Implications for physiotherapy. *New Zealand Journal of Physiotherapy*, 42(1), 33-41. Retrieved from <http://physiotherapy.org.nz/assets/Professional-dev/Journal/2014-March/Van-Lit.pdf>
- Veres, A., Bain, L., Tin, D., Thorne, C., & Ginsburg, L. (2014). The neglected importance of hope in self-management programs – a call for action. *Chronic Illness*, 10(2), 77-80. doi:10.1177/1742395313496827
- Vestibular Disorders Association. (n.d.). *Persistent Postural-Perceptual Dizziness*. Retrieved from [https://vestibular.org/sites/default/files/page\\_files/Documents/PPPD\\_CSD.pdf](https://vestibular.org/sites/default/files/page_files/Documents/PPPD_CSD.pdf)
- Ware, N.C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, 6 (4), 347-361. doi: 10.1525/maq.1992.6.4.02a00030
- Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness*, 29(4): 610-626. doi:10.1111/J.1467-9566.2007.01008.x
- World Health Organization. (2015). *International Classification of Diseases, ICD-11 beta draft*. Retrieved September 15, 2015, from <http://apps.who.int/classifications/icd11>
- Yardley, L. (1994). "Prediction of handicap and emotional distress in patients with recurrent vertigo: symptoms, coping strategies, control beliefs and reciprocal causation." *Social Science & Medicine*, 39(4): 573-581. doi:10.1016/0277-9536(94)90100-7



Yardley, L., & Beech, S. (1998). 'I'm not a doctor'. Deconstructing accounts of coping, causes and control of dizziness. *Journal of Health Psychology*, 3(3), 313-327.  
doi:10.1177/135910539800300303

Yardley, L., Owen, N., Nazareth, I., & Luxon, L. (1998). Prevalence and presentation of dizziness in a general practice community sample of working age people. *British Journal of General Practice*, 48(429), 1131-1135. Retrieved from  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1410052/pdf/brjgenprac00087>

# Interview Guide



*Project title:* **Experiencing Chronic Subjective dizziness**

*Project Supervisors:* **Prof Denise Taylor, Dr Nicola Kayes, Nicola Saywell**

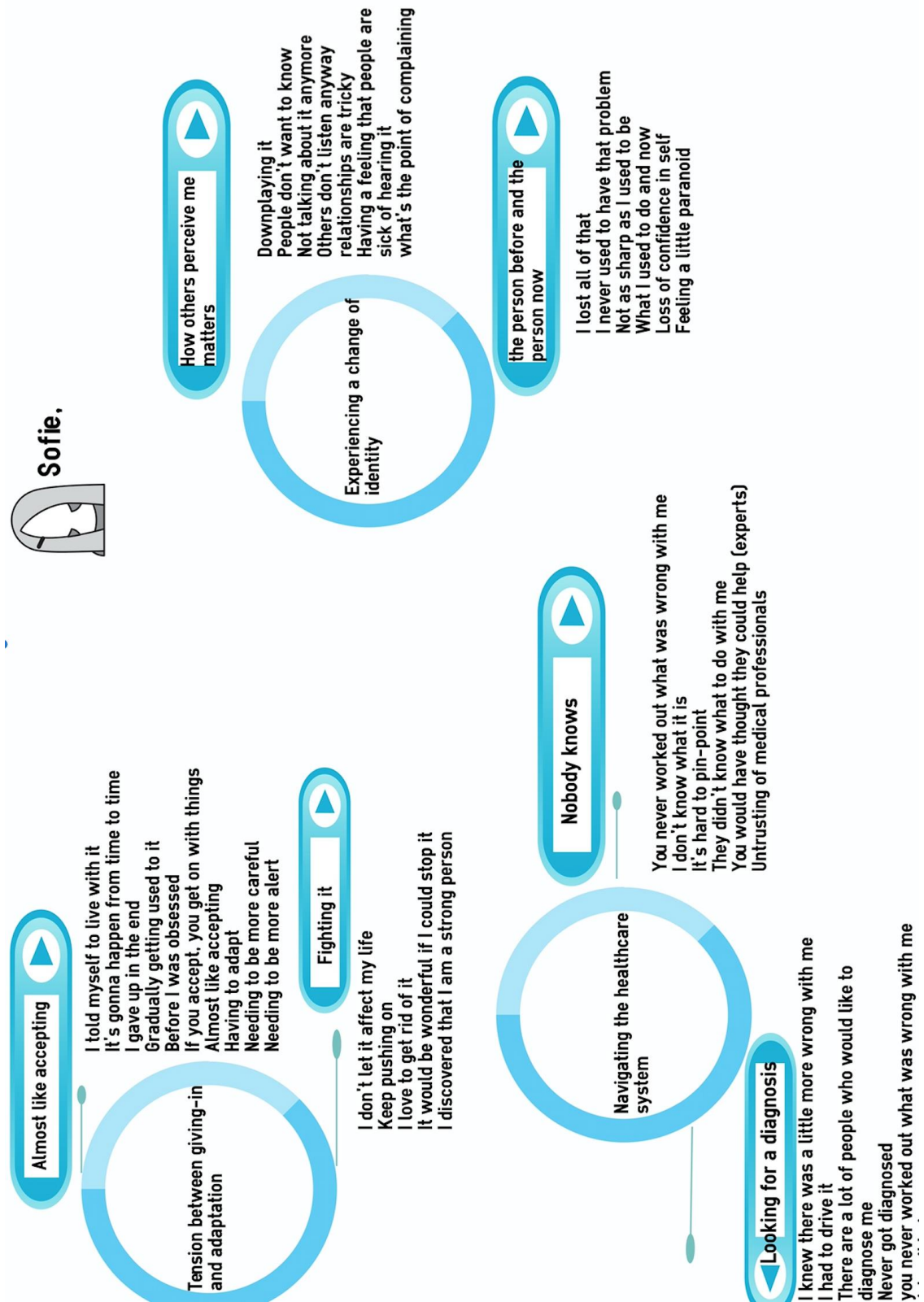
*Researcher:* **Ann Sezier**

## Prior to interview (10 minutes)

1. Refreshments and introduction of participant/researcher
2. Consent form and demographic form
3. Outline plan for interview (setting expectations such as establishing if break will be needed, time limitations, remind them about the study being recorded etc.)

Time (minutes)	Topics for discussion
10	<b>Start up</b> <ol style="list-style-type: none"> <li>1) Briefly outline the study and explain its purpose</li> <li>2) Introduce the participant to the topic of discussion and what is of particular interest</li> <li>3) Let the participant briefly explain about their dizziness (onset, duration etc.)</li> </ol>
40	<b>Consultation questions</b> Questions asked should help to identify the symptoms the participant experiences, and gain information about their significance in relation to their lives
	<ul style="list-style-type: none"> <li>• Can you tell me a bit about your dizziness? What do you experience?</li> <li>• What are these symptoms like to live with? Is it easier to live with one symptom compared to the other?</li> <li>• Can you describe some of the ways you deal with those symptoms? Is there anything that makes those symptoms better or worse?</li> <li>• In what way does your dizziness affect you?</li> <li>• Which symptoms affect you or your life the most? And in what way?</li> </ul>
5	<ul style="list-style-type: none"> <li>• Exit question: Is there anything else you would like to share or discuss?</li> </ul>
5	Close of the interview, thank participant, and remind them that if they would like to receive a copy of the findings that this will not be available for the next 18 months or so and establish with participant what the best way is for them to receive the information (email findings or face to face meeting?)

## Appendix B: Example Memo and Diagram



**Memo [name of participant] (impressions of interview immediately post interview Sept. 2015)**

This interview was different from previous interviews, as I had never met the person before so there was no preceding therapeutic relationship. Although it was easier not to switch to therapy mode instead of researcher mode, I also felt that the person was more guarded and less forthcoming with 'rich information'. The interview took place during her work lunch break and on the phone (at her request) and she only had limited time (1/2 hr.).

Overall impressions:

Not 'giving in' to the dizziness came through strongly in this interview. Participant took great care to portray herself as a strong person, and was eager to demonstrate that despite dizziness she had been able to 'get on with life'. Participant appeared to have 'come to terms' with the dizziness and seems to have stopped noticing or standing still by the things she is no longer able to do. Felt she had not made any adaptations to her life or lifestyle. She was keen to show that the dizziness did not beat her.

Mid interview this strength made space for a brief moment of vulnerability, where she admitted to have 'missed out' on things. At that time she also talked about her frustration with medical professionals for not finding what is wrong with her but also for their lack of interest, for not being pro-active to find out what was wrong with her. She talked about being less trusting of medical professionals as part of the experience.

From a social perspective, P. did not want to talk about dizziness with friends 'because they don't want to hear about it' - she tries not to let on how her dizziness affects her as this is not something she wants to bother her friends and family with. She reflects on her own life where she has heard others complain and superimposes this on herself - not wanting to frustrate others with her problems.

Talked about coping strategies and the effect on personal, social and work life.

**Re-reading of [participant] interview transcript Oct. 2015**

I read contradiction – between not wanting dizziness to rule her life yet realising that she can't do things she used to, yet insisting she leads a normal life.

Need for support but not wanting to burden people with her problems so not talking about it downplaying it for others

Slowly getting to a stage of accepting vs sudden realisation

"First I was obsessed about it.... Now I'm giving up" changing states of mind about condition

Uses self-talk a lot as a coping mechanism: I am telling myself,

Having hope = 'it would be wonderful if it was gone', seeing improvement = hope 'I would like it gone, it is slowly getting better'

The expert knowledge – I know something is a little more wrong with me - you don't know what is wrong with me- people that should know didn't – the frustration and anger coming from that discrepancy. Frustrated by lack of recognition by health professionals of expert knowledge as a person that lives with the condition.

Finding it hard to put into words - pinpoint what it is and what causes or exacerbates it. Who knows? Knowing something is wrong with my body, you should know what is wrong but you don't, you can't figure it out – causes anger and frustration

Who knows: knowing something is wrong with my body, you should know what is wrong but you don't, you can't figure it out – causes anger and frustration – those who should be in the know, don't... there is an expectation health professionals should know. Feeling let down by doctors.

Relationships can be tricky – has a supportive partner who understands but keeps it hidden from family and friends or acquaintances.

## Appendix C: Example of Coding

Interview with Thea (transcript extract)

Quote	Code (S= semantic and L=latent)
AS: Can you tell me a little bit about your dizziness? If you could describe what your dizziness is like for you (.) that would be a good starting point	
Thea: ok (...) umm it is not a not a clearly defined [clears throat] really but over the years it's (.) I had to change, to change my lifestyle a little bit. Like when I was young, I used to be able to go on, you know, go on rollercoasters, go (.) umm, well do anything pretty much but over the years and particularly after I had my children, I found that I couldn't go on swings and take my daughter on swings. I couldn't (.) umm, (.) go (.) I had to be careful on anything that moved really and having said that I always, even as a child got car sick, so (.) I had certainly, gradually progressed (.) umm, so that where I have been over the last few years, I (.) umm, just had felt, apart from the times when I actually had little setbacks, where I was in bed and vomiting during the daytime and just about every day, as at part of days I would, I kind of felt unsteady. Some days I can't really read properly, I couldn't read properly. Quite clearly I kept reading, kept reading (.) umm, and I found that anything that I had to move my eyes quickly, then I, I (.) over the years, I really had to avoid those (.) that sort of thing. Like I couldn't go (.) (Clears throat) excuse me (.) go on a jetty or anywhere that has got the slightest movement and (.) for some of those things if, if I kind of pushed the boundaries (.) they wouldn't (.) It would make me feel unwell while it lasted but it could last for quite some time after that. and that is not necessarily dizzy (.) it's not actually dizzy, it's just more uh (...) maybe the	<p>Not clearly defined (S)</p> <p>Progressive condition (S)</p> <p>Having to adapt to a different lifestyle (S)</p> <p>Feeling restricted in life (L)</p> <p>Feelings of missing out (L)</p> <p>Unable to do what mothers normally would do. Bad mum? (L)</p> <p>Having to be careful (S)</p> <p>Trying to make sense of it (L)</p> <p>Progressive condition (S)</p> <p>Little set-backs -Variability of the condition (S)</p> <p>Not being able to do the daily things of life (L)</p> <p>Avoidance behaviours (S)</p> <p>Sensitivity to motion (S)</p> <p>Not giving in –pushing the boundaries (S)</p> <p>Leading a restricted life (L)</p>

<p>nausea was always quite strong and I always kind of felt (.) if it is just all in the mind, it is more of visual thing (...) my vision was not quite balanced (...) rather than (...) but having said that if I move my eyes too quickly I would, could spin round (...) literally round and round spin.</p>	<p>Having no control (L)</p> <p>Trying to make sense (L)</p> <p>Is it all in my mind? (S)</p> <p>Perpetual sense making process (L)</p>
---	---

## Appendix D: Information Sheet

30<sup>th</sup> May, 2014

# Participant Information Sheet



### Project Title: Experiencing Chronic Subjective Dizziness

Hello, Kia Ora,

My name is Ann Sezier, you might know me as the physiotherapist at the New Zealand Dizziness and Balance Centre (NZDBC) and this is an invitation to take part in a research study about Chronic Subjective Dizziness (CSD). This study is part of my Master's degree thesis and is supervised by Associate Professor Denise Taylor, Dr Nicola Kayes and Lecturer Nicola Saywell from AUT University.

This information sheet will explain the research study and will help you decide if you would like to take part. Before you make that decision, you may want to talk about this study with your whānau/family, a friend or support person, so you do not have to make a decision today.

Your decision to participate is your choice and will not advantage or disadvantage you in any way; you will also not need to give a reason or explanation if you decide against taking part. If you decide to take part but change your mind later, you can pull out of the study up until the completion of data collection without having to give a reason your contribution to the study will then not be used and your details or recordings will be destroyed.

If, after reading this information sheet, you have further questions please feel free to contact me or any of my supervisors. You will find our contact details at the end of this sheet.



**What is the purpose of this research?**

At the New Zealand Dizziness and Balance Clinic (NZDBC), I frequently see people who are affected by CSD or who experience on-going dizziness for which no clear medical reason or pathology can be found.

It is my experience, and that of my colleagues, that people affected by CSD have symptoms that are not easy to describe, yet they appear to be really bothersome, and people often seek advice on how to deal with them. Unfortunately, literature tells us little about these symptoms, or in what way they affect people's lives. The purpose of this study is to get a better description and understanding of these symptoms and explore how these symptoms affect people's personal, social and work life.

**How was I identified and why am I being invited to participate in this research?**

As a former client of the NZDBC you have given permission to be contacted and to be invited to participate in research if the study is related to your condition. The NZDBC records show that at the time of your assessment, you presented with dizziness and symptoms that fit the description of CSD. This makes you a potential participant for this study.

**Who can participate?**

You can take part in this study if:

You have had dizziness for a minimum of 3 months

You are of working age (between 18 and 65 years old)

You have no firm diagnosis explaining your dizziness, for example a known medical or neurological illness

If you think you might like to take part but you are not sure if you have any of the symptoms of interest, please give me, or one of my supervisors, a call.

**What will happen in this research?**

If you decide to take part, you will be invited to participate in a one-off face-to-face interview. You can choose a suitable date, time and place for this interview; it can be in your own home if this is convenient. If you prefer not to meet face to face or if this is

not practical, for example due to travel distances, we can arrange a phone or Skype (internet) interview. If you are happy to be interviewed but would rather not do this at your own home, then we can arrange to meet at one of the AUT University campuses.

The interview will take approximately 60 to 90 minutes of your time. At the interview, I will briefly explain the study and give you the opportunity to ask further questions after which you will be asked to sign a consent form. I will ask your permission to audio record the interview, which will later be transcribed word for word. I may also take some notes of what was said during the interview.

I will ask you questions about the symptoms you are experiencing and how these affect you. You are also welcome to bring whānau/family, friend or support person to the interview.

After the interview, you may have some further thoughts on a topic we discussed or you may have wished that you had mentioned something that did not spring to mind at the time of the interview. I welcome any further thoughts or reflections you are willing to share with me via email or letter.

#### **What are the discomforts and risks?**

There are no foreseeable risks associated with taking part in this study. You will be asked to share your experience of living with chronic dizziness and how the symptoms you experience affect you. You may find talking about your condition in this way upsetting but you will not be pressured to answer a question, and it is entirely up to you how much information you wish to share.

#### **How will these discomforts and risks be alleviated?**

If taking part in this study has caused you distress and you would like to discuss this with someone after the interview, please let me know so I can connect you with some support.

#### **What are the benefits?**

There is no guarantee you will benefit directly from being involved in this study. However, some people find that being able to talk about their experiences is helpful.

Your contribution to this study will help me in obtaining my master's degree qualification and will help health professionals to learn more about the symptoms associated with CSD. This may inform further research on how best to help people with the same or a similar condition.

**How will my privacy be protected?**

Your participation will be kept confidential, which means that only the research team will know that you are taking part in this study. The information you share as part of the research study will be used under a pseudonym of your choice. This will ensure that you cannot be identified as a participant in this study.

Your personal details and medical information will not be used in this study. The interviews will be transcribed by the researcher, or by a transcriptionist who is bound by a confidentiality agreement. The voice recordings, transcripts and other materials such as notes will be separately and securely stored in locked filing cabinets on AUT premises.

**What are the costs of participating in this research?**

Your participation in this research study will be at no cost to you other than your time. If you prefer to be interviewed at AUT University, your travel costs will be reimbursed by means of a petrol voucher or taxi voucher. If the interview takes place by phone, then the researcher will cover the costs by calling you at a convenient time. You will be provided with a return stamped envelope if correspondence is required.

**What time do I have to consider this invitation?**

You will have 2 to 3 weeks to consider if you wish to accept the invitation to participate. This will start from the day the letter was sent to you.

**Will I receive feedback on the results of this research?**

If, you wish to receive a copy of your interview or transcription then you can indicate this on the consent form. This will be released after the study is completed.

Also, if you would like to receive a summary of the findings you can say so on the consent form. The findings should be available after the thesis has been published which is approximately 18 to 24 months after you take part. If you would like to have these findings explained in person, a face-to-face meeting can be organised.

**What will happen to the results of this study?**

Findings of the study will be published in the form of a Master's thesis. A summary of the study findings may also be presented to health care professionals and academics at conferences or through publications in peer-reviewed journals. It is hoped the findings will help us to better understand CSD so that the study may inform clinical practice. The findings may also be used for undergraduate and post-graduate teaching and may inform further research on how best to support or guide people living with CSD.

**How do I agree to participate in this research?**

If you choose to take part, please contact me, or any member of the research team, directly. If you would like to discuss this study with a member of the research team that is not involved with the NZDBC, then please contact Nicola Kayes or Nicola Saywell. All contact details are provided at the end of this information sheet.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisors: Associate Prof Denise Taylor, Dr Nicola Kayes or Nicola Saywell (See below for contact details).

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, *ethics@aut.ac.nz*, 921 9999 ext. 6038

**Whom do I contact for further information about this research?**

[Pictures of researcher and supervisors and contact details removed from participant information sheet for confidentiality reasons]

*Approved by the Auckland University of Technology Ethics Committee on 19<sup>th</sup> November 2014 AUTC Reference number 14/356*

## Appendix E: Consent Form

# Consent Form



*Project title:* **Living with Chronic Subjective Dizziness**

*Project Supervisors:* **Prof Denise Taylor, Dr Nicola Kayes, Nicola Saywell**

*Researcher:* **Ann Sezier**

---

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 30<sup>th</sup> May, 2014.
- ☐ I have had an opportunity to ask questions and to have them answered
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature: .....

Participant's name: .....

Participant's contact details:

.....  
.....  
.....  
.....

Date:

*Approved by the Auckland University of Technology Ethics Committee on 19<sup>th</sup>  
November 2014 AUTECH Reference number 14/356*

## Appendix F: Demographics Form

# Demographics



**Project title:** *Experiencing Chronic Subjective Dizziness*

**Project Supervisors:** *Prof Denise Taylor, Dr Nicola Kayes, Nicola Saywell*

**Researcher:** *Ann Sezier*

**Participant ID:**

1. Date of birth: ..... Age ..... Initials:

2. Gender Male ☐ Female ☐

3. Which ethnic group, or groups, do you identify with (choose as many as apply)

New Zealand European	<input type="checkbox"/>	Niuean	<input type="checkbox"/>
Māori	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Samoan	<input type="checkbox"/>	Indian	<input type="checkbox"/>
Cook Island Māori	<input type="checkbox"/>	Other (such as Dutch, Japanese, Tokelauan)	<input type="checkbox"/>
Tongan	<input type="checkbox"/>	Please specify:	

4. How long have you had your dizziness?

Between 3 months and 1 year	<input type="checkbox"/>	Between 3 to 10 years	<input type="checkbox"/>
Between 1 to 3 years	<input type="checkbox"/>	Longer than 10 years	<input type="checkbox"/>

6. What symptoms have you had in the past month (please tick as many that apply)

Vertigo (the feeling the room spins)	<input type="checkbox"/>	Sensitivity to movement of others (for example if they wave their hands when they speak)	<input type="checkbox"/>
Dizziness (the feeling you spin)	<input type="checkbox"/>	Sensitivity to crowded spaces (shopping malls, supermarkets, cinema)	<input type="checkbox"/>
Sensitivity to movement (for example when you	<input type="checkbox"/>	Other (please specify):	<input type="checkbox"/>

look up or down, or roll  
over in bed)

---

7. What is your employment status?

I am unemployed	<input type="checkbox"/>	I am retired	<input type="checkbox"/>
I work part-time	<input type="checkbox"/>	I am a stay at home parent	<input type="checkbox"/>
I work full-time	<input type="checkbox"/>	I work free-lance (hours and days that suit me)	<input type="checkbox"/>
I'm a student	<input type="checkbox"/>	Other Please specify: .....	<input type="checkbox"/>

---

If it wasn't for your dizziness, would your employment status be different?

YES <input type="checkbox"/>	NO <input type="checkbox"/>
------------------------------	-----------------------------

---

8. Who is supporting you?

I am alone (no support)	<input type="checkbox"/>	I have a supportive partner	<input type="checkbox"/>
I am alone but have plenty of support (friends, family/whanau)	<input type="checkbox"/>	I have my extended family/ whanau	<input type="checkbox"/>
		Other Please specify: .....	<input type="checkbox"/>

---

9. Do you have responsibilities for others? (Tick as many that apply)

No, I am not responsible for anyone other than myself	<input type="checkbox"/>
Yes, I have small children (less than 12 yrs.)	<input type="checkbox"/>
Yes, I have teenagers (older than 12 but younger than 18 yrs.)	<input type="checkbox"/>
Yes, I am responsible for my partner/spouse	<input type="checkbox"/>
Yes, I am looking after an elderly, disabled or person with special needs.	<input type="checkbox"/>

Approved by the Auckland University of Technology Ethics Committee on 19<sup>th</sup> November 2014

AUTEC Reference number 14/256

*Note: The Participant should retain a copy of this form*

## Appendix G: Counselling Agreement



# MEMORANDUM

**TO** Ann Sezier

**FROM** Kevin Baker

**SUBJECT** Psychological support for research participants

**DATE** 25<sup>th</sup> September 2014

Dear Ann

I would like to confirm that Health, Counselling and Wellbeing are able to offer confidential counselling support for the participants in your AUT research project entitled:

“Experiencing chronic subjective dizziness”

The free counselling will be provided by our professional counsellors for a maximum of **three** sessions and must be in relation to issues arising from their participation in your research project.

Please inform your participants:

- They will need to contact our centres in person, or by phone **09 921 9992 for City campus (WB219) and South Campus (MB reception)** or **09 921 9998 North Shore Campus (AS104)** to make an appointment.
- They will need to let the receptionist know that they are a research participant.
- They will need to provide your contact details to confirm this.
- They can find out more information about our counsellors on our website: [http://www.aut.ac.nz/students/student\\_services/health\\_counselling\\_and\\_wellbeing](http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing)

Yours sincerely

Kevin Baker  
Head of Counselling  
Health, Counselling and Wellbeing

**Health, Counselling & Wellbeing**  
**Auckland 1020**

**Tel: 09 921 9992**  
**55 Wellesley Street, Auckland.**

**Private Bag 92006,**



## Appendix H: Māori Committee Consultation and Feedback

### SCHOOL OF REHABILITATION AND OCCUPATION STUDIES

#### MATAURANGA MĀORI COMMITTEE

##### Project Outline for Discussion

<b>Title of project: “ Experiencing Chronic Subjective Dizziness: a thematic analysis”</b>
<b>Research team members and affiliations</b> Researcher: Ann Sezier physiotherapists at the New Zealand Dizziness and Balance Clinic (NZDBC)/Research officer PCRC, School of Occupation and Rehabilitation Studies, AUT Primary Supervisor: Assoc. Prof. Denise Taylor, HRRI, School of Occupation and Rehabilitation Studies, AUT Co-supervisors: Dr. Nicola Kayes, PCRC, School of Occupation and Rehabilitation Studies, AUT Nicola Saywell ,HRRI School of Occupation and Rehabilitation Studies, AUT
<b>Research question or hypothesis + benefits/relevance for Māori</b> <u>Aims:</u> This study is part of a Master’s thesis exploring the experience of Chronic Subjective Dizziness (CSD), and how it affects the lives of working-age adults. The aim is to gain insight from people affected by CSD to improve our understanding of this condition. <u>Background:</u> Dizziness is considered a common disorder, despite a gap in the knowledge of incidence and prevalence, with an estimated 25 to 50% of the people who experience dizziness remaining undiagnosed (Oberman, 2013; Hain, 2013; Honaker, Gilbert, Shephard, Blum & Staab, 2012; Maarsingh et al., 2010; Ruckenstein & Staab, 2009). This study will focus on Chronic Subjective Dizziness (CSD), which according to Staab (2012) is the second most common disorder in patients suffering from dizziness. In the literature, CSD as a syndrome is well described but those affected by this condition frequently voice non-specific symptoms, which are not referenced, or poorly explored, in research. Drawing on my own experience as a clinician and from discussions with other health professionals, this dearth of information is frustrating, as patients often seek reassurance or an explanation for these symptoms. There is also anecdotal evidence, from patients and web based discussion boards, that people affected by CSD are frustrated by what they perceive as a lack of interest or understanding from health professionals for their symptoms and how these disrupt their lives. The deleterious personal and socio-economic consequences of living with chronic conditions have been widely investigated in populations with diseases such as arthritis or stroke, but not in those living with chronic dizziness (Neuhauser et al., 2009). Emerging evidence does suggest that living with chronic dizziness has a significant impact on quality of life with socio-economic consequences (Ten Voorde, Zaag-Loonen & Leeuwen, 2012; Yardley et al., 1998) but is predominantly focussed on the elderly population (Lin & Bhattacharyya, 2012; Dros et al., 2011; Neuheuser et al., 2008; Yardley, Owen, Nazareth & Luxon, 1998; Mendel, Lutzen, Bergenius & Bjorvell, 1997). Demographic data of people affected by CSD, collected by Ruckenstein & Staab (2009), revealed that the incidence of CSD spans from adolescence to adulthood, with a mean age of 46.7 years (Odman & Maire, 2008). Personal aspirations, social demands, and employment expectations change across the lifespan. The impact of chronic dizziness on the elderly may not translate to a younger population. This study will therefore specifically focus on the working- age adults. <u>Relevance to Māori:</u> The prevalence of CSD in the Māori population is unknown as literature searches reveal that this area of interest has yet to be explored. A client database search showed that from the approximately 500 people referred to the clinic since its establishment 18 months ago, only 30 clients fit the inclusion criteria of CSD and

<p>none identified as Māori. Consultation with the senior physiotherapist at the Counties Manukau District Health Board's balance clinic and with private ENT consultants indicate that while a number of Maori present with balance issues, they do not commonly present with CSD.</p> <p>From this, it is extremely unlikely we will have Maori participants taking part. However, the explorative nature of this study will lead to a better understanding of the symptoms commonly experienced, which will in turn help us to gain a better understanding of this condition. This may increase the general awareness of the condition, which will benefit all patients including Maori.</p>
<p><b>Research participants:</b> For this study, a maximum of 10 participants will be chosen for this study. This is determined by the purpose of the project and a limited sampling pool. Potential participants need to fit the strict inclusion criteria for the diagnosis of CSD, which means that they need to present with non-vertiginous dizziness which has been extensively investigated but for which no medical, oto-neurological or psychiatric pathology can be found. Their dizziness will be exacerbated by balance changes commonly referred to as motion sensitivity, and/or sensitivity on exposure to complex visual stimuli, and will be present for at least 3 months (Ruckenstein &amp; Staab, 2009; Odman &amp; Maire, 2008; Staab, 2007). Furthermore they will be working age adults (between 18 to 65 years of age).</p>
<p><b>What stage is the research project at? (e.g. proposed or implemented)</b></p> <p>This research is being carried out as part of a MPhil. The PGR1 has been approved. This study will be presented to AUTC for ethical approval this month.</p>
<p><b>Methodology</b> This study draws on qualitative descriptive methodology and suits an explorative approach, considering how little is known about the experience of CSD.</p>
<p><b>Data collection</b> Semi-structured individual interviews will be conducted, recorded and transcribed verbatim. Data may also be collected through participant's diaries or written stories, if they wish to share this. Phone interviews will be offered if preferred by the participant or when the participant does not reside within the greater Auckland area. Participants are welcome to have a support person (friend or whanau) present at the interview if they wish.</p>
<p><b>Recruitment processes</b> Recruitment will be iterative and will cease at 10 participants, based on Braun and Clarke's (2013) view that data analysis obtained from more than 10 to 12 single interviews becomes unmanageable for the purpose of a Master's thesis. However, the sample size may be smaller as a result of the strict inclusion criteria, which will undoubtedly limit the pool size of potential participants. Participants will be recruited from the NZDBC client database. Only those who have previously consented to be invited to participate in research related to their condition will be informed of this study. Within the pool of potential participants, diversity in age (within the working age adult range of 18 to 65 years), gender and employment status will be sought. Once participants express their interest to participate, they will be screened for eligibility.</p>
<p><b>Data analysis</b> Data will be analysed using a hybrid of inductive and deductive thematic analysis as described by Clarke and Braun (2012). Transcriptions will be coded and sub-themes will be grouped into meaningful overarching themes.</p>
<p><b>Dissemination of results</b> The results of this study will be presented in form of a thesis as part of my Masters in Philosophy degree. A summary of findings will also be provided to participants in the most appropriate form (e.g. face to face or in writing). At a later date, the results may also be made available to rehabilitation service providers to inform their service developments; presented at conferences; published in peer-reviewed journals; and integrated into undergraduate and postgraduate teaching.</p>
<p><b>Consultation with Māori to date:</b> No other Maori consultation has happened to date.</p>
<p><b>Cultural / ethical issues and how managed</b> As identified above, Maori participation cannot be assured in this study. We do however hope the findings of this study will be of benefit for</p>

Maori (and other ethnicities) as it will heighten the general understanding of this condition and increase knowledge. This may result in the symptoms experienced by people with this condition being seen as more legitimate, enhancing understanding of health practitioners, but also potentially resulting in increased access to services. If Maori participants can be recruited then the researcher will be respectful and sensitive to their needs by asking them about their view on sharing their experience with the researcher, about ways we can make this information exchange culturally appropriate. For example, where best to meet for the interview, if they would like to bring a whanau member to the interview, or if they would like to have the results disseminated in form of a hui or at the local Marae. Unless preferred by the participant, interviews will be conducted face to face. There will be an opportunity for a karakia at the start of the interview and Kai will be shared.

**Any specific areas for discussion?** I would welcome the committee's views on how to best manage our cultural responsibilities as researchers in cases like this where there is limited understanding of the prevalence of CSD in Maori.