Lived experience of Māori diagnosed with Obstructive Sleep Apnoea and using Continuous Positive Airway Pressure

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Abstract

Māori have the highest rates of obstructive sleep apnoea in New Zealand, yet there is limited literature that focuses exclusively on the Māori experience. This research aimed to explore and understand Māori experiences of being diagnosed with obstructive sleep apnoea and using a continuous positive airway pressure machine in a historical, cultural, political, and social context. Key principles of Kaupapa Māori research and narrative inquiry were adopted to explore participants distinct experiences.

Five Māori diagnosed with obstructive sleep apnoea and using continuous positive airway pressure devices to treat this condition were interviewed. Findings were themed: around before diagnosis, during diagnosis and post-diagnosis. The findings presented supported earlier studies with regards to delays in diagnosis of OSA through emphasising the importance of patient-clinician relationships on patient outcomes. What came through strongly was the influence that social determinants of health had on the participants experience, with stories being shared around financial burden, housing, employment, transport, and social inclusion issues. What motivated participants to use their CPAP more regularly was the feeling of increased energy levels and being around (alive) longer for their whānau.

The findings have implications at a societal level and for sleep service specialists or services engaged in supporting Māori living with obstructive sleep apnoea. This study has highlighted the demonstrated lived experiences of Māori who are diagnosed with OSA and using CPAP, so further research in this area would be advantageous in helping to promote OSA as a commonly undiagnosed medical condition.

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Chapter One: Introduction

Introduction

We spend around a third of our lives sleeping, and sleep is deemed to help us achieve optimal health and wellbeing (Jenson & Herr, 1993; Ramar et al., 2021; World Health Organisation, 2004). Healthy sleep allows us to maintain good cognitive function, which is linked to mood and mental performance along with vascular and metabolic health (Watson et al., 2015). Our duration of sleep is just as important as the quality of the sleep we experience and the routines we have to maintain good sleep practice (Ramar et al., 2021). Sleep is characterised as being in a state of unconsciousness but still having the ability to be awakened by normal sensory stimuli (Martini & Ober, 2001). There are two levels of sleep: ‘deep sleep’ and ‘rapid eye movement’ (REM) sleep. During deep sleep the entire body is relaxed, and cerebral cortex activity is at a minimum. Our heart rate slows down along with our breathing, and energy utilisation and blood pressure lowers. Throughout REM, dreaming occurs and our breathing and blood pressure can vary. The body is less receptive to external stimuli during this sleep phase, and there are noted decreases in muscle tone. The eyes move rapidly during this phase, hence why it is referred to as the ‘rapid eye movement’ phase. We cycle through the deep sleep and REM phases while sleeping, with the initial phase of deep sleep lasting for 90 minutes followed by 5-20min periods of REM which gradually increases again.

Martini and Ober (2001) emphasise the impact sleep has on the central nervous system (CNS) and how extended periods of sleep disturbance can have various negative impacts on our mental functioning. People may experience problems with conscious activities which lead to slowed reaction times, irritability, and behavioural changes. Not only is this a risk for the individual’s own safety but also for others around them. Research has found there is a greater risk of workplace accidents which occur secondary to sleep deprivation, and individuals are also at greater risk of accidents while commuting to and from work (Vargas-Garrido et al., 2021). Sleep deprivation can trigger irritability and behavioural changes, which can cause stress within relationships and families and, thus, lead to increased aggressive behaviour (Kamphuis et al., 2012). This may be linked to the negative effects sleep deprivation has on the prefrontal cortical functioning; these include loss of control of emotions and loss of regulation of impulses and behaviour.

Long-term sleep deprivation has also been associated with increased risk of morality due to the development of cardiovascular disease, obesity, diabetes, and cancer, which in turn increases the societal burden (Luyster et al., 2012). Global studies have shown that the total economic burden of sleep disorders is significant. In 2004, the economic cost of OSA in Australia was $US7.5 billion (Streatfeild et al., 2021). In the United States during 2000, OSA was linked with more than 800,000 motor vehicle accidents, leading to a total cost of more than $15.9 billion while claiming 14,000 lives (Sassani et al., 2004). A New Zealand study estimated that the total annual societal cost of OSA was at $40 million, or $419 per case, with accidents being the main contributor (Gander et al., 2010). In short, sleep deprivation and untreated sleep disorders can have a significant negative impact on people’s mental and physical health and mood regulation, and can be detrimental to others’ safety (Ramar et al., 2021). Each of our sleep needs vary, but the American Academy of Sleep Medicine and Sleep Research Society (SRS) recommend that an average adult should have seven or more hours of sleep each day in order to achieve and maintain wellbeing (Ramar et al., 2021).

There are a broad range of reasons why people experience inadequate sleep, from disturbances which range from physical or mental health problems and intrinsic problems with sleep regulation, to social pressures and demands such as shift work (Paine et al., 2011). The American Academy of Sleep Medicine states that there are approximately 80 different types of sleep disorders (Ito & Inoue, 2015) and that common sleep disorders include insomnia, snoring, sleep deprivation and restless legs syndrome (Health Navigator, 2022a). In New Zealand and internationally, the most common sleep disorder is obstructive sleep apnoea (OSA) (Gander, 2003).

Obstructive sleep apnoea is characterised by repetitive episodes of hypopnoea (airflow reduction) and apnoea (cessation) as a result of the upper respiratory airway being obstructed (American Academy of Sleep Medicine, 2001). Typical symptoms include snoring (loud), and breathing pauses, along with fragmented sleep due to recurrent arousals and brief awakenings (Gibson et al., 2018; Lyons et al., 2020; Paine et al., 2011; Woods et al., 2015). The cause of OSA is still not clear, however, it is known that the pharyngeal collapses because of insufficient neuromuscular response and a reduction in the airway passage due to factors such as obesity and/or anatomical structural changes (Lévy et al., 2015).

Like the effects of sleep deprivation, OSA can lead to excessive daytime sleepiness and changes in blood pressure from the frequent episodes of reduced oxygenation. This can increase the risk of cardiovascular disease such as stroke, myocardial infarction, hypertension, diabetes, and motor vehicle accidents (Bakker et al., 2014; Marin et al., 2005; Young et al., 2002). There is a scarcity of data on the prevalence of OSA, but a recent study based on reliable data available from studies across 16 countries estimated almost one billion people were affected, with some countries having a prevalence of over 50% (Benjafield et al., 2019). It was estimated that 936 million adults aged between 30-69 years (men and women) have mild to severe OSA and 425 million adults aged between

30-69 years have moderate to severe OSA globally. Prevalence rates were higher in China, USA, Brazil, and India. Furthermore, it is estimated that approximately 70-80% of patients with OSA have not been diagnosed or are not being treated (Altevogt & Colten, 2006).

The topic of OSA became of interest to me while working at Northland District Health Board (DHB) as a Clinical Procurement Coordinator during the period of 2016-2018. My role involved procuring clinical products for all areas of the DHB, which included everything from bandages to surgical power tools. One project I worked on required procurement of a large volume of continuous positive airway pressure (CPAP) devices for the Respiratory Outpatients Sleep Service based at Whangārei Hospital. I was tasked to build a business case based on need, suitability, cost, and volumes of CPAP devices purchased over the previous five years. It was here that I discovered that the volume of patients accessing the Sleep Service and number of CPAP devices had significantly grown and I started to ask questions such as why had demand grown so quickly and had any analysis been undertaken? The short answer was no earlier analysis had been completed and after some research of my own, I found it difficult to find data or general information about OSA in New Zealand. That is when I decided to adopt this issue as the key focus of my thesis research. It was evident from the data I obtained from the DHB that Māori were more severely impacted by OSA, so this then became a critical area of research that needed to be done based on the inequities that already exist for Māori overall but are particularly pronounced in Northland.

In New Zealand, data is scarce on the prevalence of OSA with the most recent study being over a decade ago. In 2009, Mihaere et al. conducted a national study sent to 5,500 Māori and 4,500 non-Māori participants with a 71.4% response rate. They estimated that 12.5%

of males and 3.4% of females aged between 30-59 years in New Zealand had OSA (Mihaere et al., 2009). Evidence from this study found that Māori men and women presented with higher prevalence rates of OSA symptoms compared to non-Māori. Māori participants were also found to have a larger mean neck size than non-Māori, and neck size is an indicator of central obesity which is correlated with OSA. In a parallel New Zealand study, 364 participants (Māori=169, non-Māori=195) were monitored overnight in their homes for breathing disturbances. Similar inequities were found with Māori experiencing more severe respiratory disturbances and higher prevalence OSA estimates compared to non-Māori (Mihaere et al., 2009). These results support clinical observations which are linked to higher prevalence of OSA for Māori (Baldwin et al., 1998; Frith & Cant, 1985). Another national survey focusing on insomnia symptoms showed that Māori (28.6%) had a greater prevalence of reported chronic sleep problems lasting more than six months compared to non-Māori (24.6%) (Paine et al., 2007). This study found that people reporting sleeping problems had poor general health, quality of life, concentration, and memory. Their ability to manage minor problems was diminished and they experienced interpersonal relationship difficulties. Furthermore, there were greater rates of socio-economic deprivation, unemployment and working night shifts associated with those experiencing sleep problems, all factors which are disproportionately higher for Māori and may be a major contributor to inequalities in OSA.

Treatment is available for OSA and the first-line therapy for OSA is CPAP (Bakker et al., 2014; Sullivan et al., 1981). CPAP delivers air to the upper airway through a full face or nasal mask at a prescribed level to keep the upper airway open. CPAP is a highly effective treatment which can help reduce daytime sleepiness and risk of cardiovascular diseases (Barbé et al., 2010; Martínez-García et al., 2009; Montserrat et al., 2001; Young et al., 2002). However, like most clinical treatments, CPAP is only effective if used regularly and, in some populations, there is evidence of high refusal rates or infrequent use (Engleman & Wild, 2003; Wearn et al., 2021). New Zealand studies have shown that Māori (Bakker et al., 2011; Campbell et al., 2012) and Pacific (Campbell et al., 2012) populations have significantly lower use of CPAP compared to non-Māori/non-Pacific. Additional evidence indicates that lower CPAP use is associated with lower education attainment levels and high socio-economic deprivation after adjusting for ethnicity.

It is evident through existing research that the severity and prevalence of OSA and infrequent use of CPAP is greater for Māori. Inequities of health status between Māori and non-Māori exist for most diseases and illnesses, and this is shown through Māori having higher hospital admission rates and dying younger than non-Māori (Ajwani et al., 2003; Ministry of Health, 2006; Reid & Robson, 2006). When inquiring about these inequities, we must consider the wider determinants of health at play such as social, political, environmental and economic factors (Durie, 2019). Durie recognises that inequities occur across all these areas for Māori even before they engage with health services; therefore, they are on the backfoot from the outset. Quantitative data can provide us with a view of these inequities, but we must also take into consideration qualitative data allowing us to understand how Māori experience wellbeing and illness alongside engagement with health services which are designed from a westernised medical view of the world. The approach adopted for this research was Kaupapa Māori (Māori approach) combined with narrative inquiry which enabled a qualitative framework for Māori to share their experiences. This research aims to hear these stories from Māori about how they viewed their life before diagnosis of OSA, followed by their experiences of the health system during the period of diagnosis and life after diagnosis when they returned home to their whānau with a CPAP device.

Summary of chapters

Chapter One herein offered an overview of the background of this study. I outlined the aims and rationale for undertaking this research on Māori experience of living with OSA and CPAP. Chapter Two provides an overview of OSA in the global and local context and explains the CPAP device. I then turn to the local context of the New Zealand health system and sleep services. Finally, I explore the socio-historical context of hauora (health) Māori and discuss the effects of colonisation on Māori, which are evident in the over-representation of Māori in health and social statistics, and the drive for change for iwi (tribe), hapū (sub-tribe), hapori (community) and whānau to be empowered to focus more on wellbeing instead of the deficit lens focus on treating illness.

Chapter Three describes the methodology and methods applied in this research. During the data collection phase, a Kaupapa Māori research methodology was applied, and a narrative inquiry approach was applied to the findings. Chapters Four, Five and Six present the findings and analysis of the participants' experiences pre-, during and post-diagnosis of OSA.

Chapter Seven provides a summary of the socio-historical context for Māori, the social determinants of health and sleep health inequities. I offer concluding thoughts with recommendations on additional research areas which can be focused on to further explore Māori experience of OSA and CPAP.

Chapter Two: Background

Basic sleep physiology

A third of our lives are spent sleeping, and lack of sleep can lead to various health and social wellbeing consequences (Bakker et al., 2011; Jenson & Herr, 1993; Ramar et al., 2021; World Health Organisation, 2004). When we sleep well, we can cognitively perform well, and it makes us feel good while ensuring the metabolic and vascular functions in our bodies are optimal (Watson et al., 2015). Sleep also serves other purposes in that it regulates somatic growth (growth hormone release), neural growth and processing, memory consolidation, thermoregulation and energy conservation (Lee-Chiong, 2008). There is great variation between individuals in the total duration of sleep required daily, with most adults sleeping six to nine hours. Sleep duration of less than five to six hours is linked with sleepiness and other symptoms of sleep deprivation. Ramar et al. (2021) note that length of sleep is equally as important as the quality of sleep we get.

For many, falling asleep can be easy, but you may awake later in the night and find it difficult getting back to sleep tossing and turning and disturbing our partners. Alternatively, falling sleep may be the difficult part. Therefore, it is important what we do to prepare ourselves before going to sleep at night, or during the day if a shift worker. Common practices towards supporting high-quality sleep can include setting your body clock through keeping a routine, doing physical activity during the day while avoiding naps, refraining from the use of stimulants in the evening, such as cigarettes, alcohol or caffeine, and reducing blue light exposure, such as through mobile phones or laptops (Health Navigator, 2022b).

Sleep is defined as a naturally recurrent and alterable biobehavioural state shown by immobility, perceptual disengagement, and subdued consciousness (Tubbs et al., 2019) or being unconscious without being awakened by normal sensory stimuli (Martini & Ober, 2001). It involves interaction between voluntary decisions and involuntary biological activities, where making the room dark and lying down are voluntary actions and the release of melatonin and brain activity are involuntary biological events.

There are two stages of sleep which include ‘non-rapid eye movement’ (NREM) and ‘rapid eye movement’ (REM) sleep (Martini & Ober, 2001). During deep sleep the entire body relaxes, and cerebral cortex activity is at its lowest. A 30% decrease is observed in the body’s heart rate, respiratory rate, energy utilisation and blood pressure. During REM, dreaming occurs and the body’s respiratory rate and blood pressure can fluctuate. The body is less amenable to external stimuli during this sleep phase, and there are distinguishable decreases in muscle tone. The eyes move rapidly during this phase, and therefore it is referred to as the ‘rapid eye movement’ phase. A person alternates through both the deep sleep and REM phases while sleeping, with the early phase of deep sleep lasting for an hour and a half followed by 5-20min periods of REM which progressively increases. Sleep is seen as a health behaviour by an individual which impacts on their health (Tubbs et al., 2019). Characterising sleep as a health behaviour emphasises how behaviours and neurobiology interrelate, and how individuals can amend health outcomes through sleep.

Obstructive sleep apnoea

There are approximately 80 sleep disorders classified by the American Academy of Sleep Medicine (Ito & Inoue, 2015). Obstructive sleep apnoea is the most common sleep breathing disorder diagnosed in New Zealand and overseas (Gander, 2003). International research has found that OSA is common in adults, affecting 2% of females and 4% of males (Bearpark et al., 1993; Partinen & Hublin, 2005; Young et al., 2002). In New Zealand, as in other counties, OSA is underdiagnosed; therefore, these rates could be much higher (Epton et al., 2017).

Obstructive sleep apnoea occurs while people are sleeping, leading to frequent episodes of partial or complete obstruction of the upper airway (Park et al., 2011; Pretto et al., 2010; Punjabi et al., 2009; Zhang et al., 2022). The body’s response to these apnoea episodes is the brain’s arousal, leading to activation of the sympathetic nervous system and desaturation of oxygen levels in the blood (Heinzer et al., 2015). Typical symptoms present in the form of loud snoring and long breathing pauses. This leads to patients waking feeling very sleepy, experiencing morning headaches and still being tired due to the poor quality of sleep they experience (Arnardottir et al., 2016; Bassiri & Guilleminault, 2000; Campbell et al., 2012; Mihaere et al., 2009; Mirrakhimov et al., 2013; Young et al., 1993).

The primary way OSA is diagnosed is using the apnoea hypopnoea index (AHI), which records the average number of significant breathing disturbances per hour (Dassanayake et al., 2021). This is carried out during a sleep study using a form of polysomnography (PSG) and is deemed a gold standard approach to diagnosis (Paine et al., 2011). PSG monitors the patient’s brain activity, eye movements, muscle tone, heart rate, respiratory rate, blood oxygen levels and leg movements.

Gold standard delivery of a PSG is with the patient staying overnight at a hospital and being fully attended to by medical staff.

New Zealand research shows significant inequities between Māori and non-Māori adults regarding quality of sleep, based on either self-reported episodes or diagnosed OSA. Risk factors include age, gender, obesity, smoking and alcohol consumption (Young et al., 2002). Being obese is one of the strongest risk factors for OSA, and Māori are more likely to be overweight compared to non-Māori. This is linked to Māori being overrepresented in lower skilled employment, lesser paid occupations, resulting in reduced access to healthy foods which cost more. Additionally, OSA is associated with morbidity and mortality from high blood pressure, heart disease, diabetes, and stroke (Blakey, 2006; Marin et al., 2005; Paine et al., 2011; Young et al., 2002). For example, approximately 70-80% of New Zealanders diagnosed with OSA also experience Resistant Hypertension (RHT), which is a blood pressure reading which remains above a goal blood pressure despite the use of three or more antihypertensive agents (Dassanayake et al., 2021).

Ethnic inequities exist with Māori experiencing higher rates of insufficient sleep, partly explained by increased rates of socio-economic deprivation, poorer health status and differing lifestyle behaviour, such as more Māori working night shifts than day shifts (Paine & Gander, 2016). Excessive daytime sleepiness leads to increased motor vehicle accidents (Young et al., 2002), disproportionally impacting Māori (Robson & Harris, 2007). Evidence from New Zealand sleep clinics has shown that when Māori patients do access health services, they tend to present with severe OSA (Baldwin et al., 1998; Frith & Cant, 1985). Research also indicates that undiagnosed adults with OSA are high users of healthcare services, and early recognition can reduce morbidity and demand for healthcare services (Wittmann & Rodenstein, 2004). Previous research has focused on low socio-economic status populations, among which certain ethnic groups are overrepresented, and thus provides inadequate details of ethnic disparities (Partinen & Hublin, 2005).

A national survey undertaken by Mihaere et al. (2009) indicated that Māori have a greater prevalence of OSA than non-Māori. Results from 5,500 Māori participants and 4,500 non-Māori participants aged between 3-50 years found that OSA symptoms were more significant in Māori compared to non-Māori (all $p<0.001$). Māori men were also found to have a larger neck size and circumference than non-Māori men. This was similar for Māori women in comparison to non-Māori women. The obesity rate among Māori is a concern because additional weight around the neck adds further pressure to the already restricted air passages in the upper airway (Blakely et al., 2006). Therefore, OSA should be considered an essential public health issue globally (Baumel et al., 1997) and a health issue of significance for Māori. Similarly, a community study of 364 adults in Wellington (Māori=169, non-Māori=195), where patients were monitored overnight in their homes, found a higher respiratory disturbance index (RDI) at all thresholds for Māori than non-Māori (Mihaere et al., 2009). Māori also had more significant prevalence estimates of OSA.

Continuous positive airway pressure devices

A recommended treatment prescribed for OSA is continuous positive airway pressure (CPAP) device (Bakker et al., 2014; Kushida et al., 2006). CPAP is provided by a small unit that supplies airflow via a face or nasal mask while the patient sleeps. The continuous flow of air allows the patient’s airway to remain open while sleeping, preventing episodes of hypopnea or apnoea. Hypopnoea is a period of shallow breathing and apnoea is a complete pause in breathing (Summer & Singh, 2022). The continuous airflow from a CPAP allows patients to experience improved quality of sleep, daytime functioning, and a reduced risk of cardiovascular-related conditions (Bakker et al., 2014). The concept of CPAP was first discovered in the 1970s when used for treating an injured lung, and in 1980, Colin Sullivan, an Australian doctor, suggested using nasal CPAP to treat OSA (Sullivan et al., 1981). Up until the discovery of CPAP, tracheostomy was the treatment used to treat OSA (Guilleminault et al., 1981). The first available CPAP to purchase were manufactured in 1985 in North America, and the technology has evolved significantly for these devices.

A form of automatically adjusting CPAP is known as an APAP. The difference between the two is that CPAP delivers a continuous positive airway pressure during both inspiration and expiration. Alternatively, the APAP automatically titrates pressure in response to the upper airway closing or narrowing during apnoea or hypopnea. Furthermore, there is a bi-level PAP otherwise known as BPAP, and this machine works by delivering high pressure air during inspiration and low-pressure during expiration.

Irregular use of CPAP to treat OSA is a barrier to effective treatment (Brown et al., 2021). International literature has found significant variances in the usage of CPAP, with 29-83% of patients wearing their masks for less than four hours per night (Weaver & Grunstein, 2008). Evidence shows that the optimal use of CPAP should be six or more hours, which should provide a more significant improvement in sleep quality. A systematic review of 22 studies on users' experience of CPAP for OSA found that users preconceived attitudes and expectations about CPAP prior to use influenced the experience, as did participants attitudes to therapy. This was both in a positive and negative sense (Ward et al., 2014). Additionally, many researchers were found to prime CPAP users to reflect negatively on the therapy, and the spouse and families were found to have a great influence on users' experience of CPAP. In other qualitative studies, researchers found that participants reported feeling benefits early on in treatment, which encouraged them to continue using it (Luyster et al., 2016).

Despite the treatment sounding relatively easy to use, many patients find it difficult for several reasons: machine noise, mask leakage, mask discomfort, and dry mouth and nasal passages (Bakker et al., 2014; Gibson et al., 2018; Kalan et al., 1999). I have personally experienced the challenges of using CPAP when admitted to intensive care units following acute exacerbation of asthma symptoms leading to respiratory arrest. CPAP is a form of non-invasive pre-hospital treatment for acute respiratory failure or for alleviating respiratory distress, instead of an invasive endotracheal tube being placed into the patient's airway (Finn et al., 2022). From what I recall of receiving CPAP, the mask felt extremely claustrophobic, and the nurses had to keep readjusting the straps and mask position on my face. It was also extremely noisy, like a constant flow of wind being blown into your face at high speed, and I found it difficult to hear anything else around me. Despite the discomfort, each time I was given CPAP, I did feel it was much easier to breathe and it allowed my body to rest while the machine did the breathing for me. It is also worth noting that my experience was short term and not required every night when I slept.

Most patients access a CPAP in a less traumatic way than my experience and are referred for a sleep study at a sleep service, which is either publicly or privately funded and usually based at a hospital or private clinic provider. Following the sleep study, patients will be advised how many times they stopped breathing and what effect this had on their oxygen saturations, heart rate and blood pressure. It will then be determined if the patient is eligible for CPAP or not. These clinics are limited to patients with the greatest need (Gibson et al., 2018), but work has been done to extend the assessment service to the primary care setting, with general practitioners conducting these assessments under the guidance and advice from a sleep specialist (Epton et al., 2017). Further exploration of the available sleep services in New Zealand will be discussed in the following section.

As mentioned earlier, CPAP is not the only line of treatment for OSA. Alongside APAP and BIPAP devices is oral appliance (OA) therapy or surgery (Kirby, 2011; Sutherland et al., 2014). The selection of treatment options is guided by the severity of symptoms and patient preference, with results differing from all lines of therapy (Okuno et al., 2016). Identifying where the site of obstruction is occurring is also useful when determining the best line of treatment, and this can be done via endoscopy or use of a pressure catheter while the patient is sedated (Vena et al., 2021). Globally, the gold standard and most commonly prescribed treatment for OSA is CPAP (Gupta et al., 2022).

Structure of New Zealand public health system

As mentioned in the previous section, OSA and CPAP are accessed via sleep services both publicly and privately funded. Like many advanced countries, New Zealand has experienced many changes in health status and the health system over the last 100 years (Organisation for Economic Co-operation and Development, 1994). There have been significant changes in the causes of death, from diseases such as smallpox to long-term chronic conditions, such as cardiovascular disease and cancers (Blank, 1994). This increase in long-term chronic conditions coupled with an ageing population, who mostly experience such diseases, means there is an increase in demand for health services. The 1938 Social Security Act aimed to provide free universal health services to all New Zealanders (Hyslop et al., 1983), but this was never truly realised due to differences in views between the government and medical professionals (Gauld, 2001). In 1941, the General Medical Services (GMS) benefits were introduced, which saw a subsidised dual public and private health system develop. Medical professionals disagreed with the subsidy approach, and general practitioners were given the mandate to have the government subsidy paid on a fee-for-service basis with the ability for GPs to charge a co-payment (Goodyear-Smith & Ashton, 2019). This led to public hospitals that were fully funded existing alongside privately owned general practices receiving partial government funding. More and more health services became government funded over time (Goodyear-Smith & Ashton, 2019) and health expenditure increased significantly, with widening inequities in health provision causing concerns among the government and health sector leaders (New Zealand Parliamentary Library, 2009).

Major structural reform began during the 1980s to address these concerns, and this was repeated several times with the most recent reform occurring in July 2022. Up until that date, the New Zealand public health system consisted of 20 DHBs. District health boards were established as crown entities through the New Zealand Public Health and Disability Act 2000 and were responsible to the Minister of Health (New Zealand Parliamentary Library, 2009). Health reforms during the 1990s saw primary health care and hospital services evolve in silos, and the expected gains of the reforms have not been achieved. Goodyear-Smith and Ashton (2019) noted that future reforms need to focus on improving equity of outcomes through growing cultural competency and the size of the workforce, increasing kaupapa Māori services and the integration of services and structures, while taking a stronger population health approach.

Many of these factors were considered by government and health sector leaders, and, in April 2021, the Minister of Health announced a health and disability system review which aimed to future-proof the health and disability system (Ministry of Health, 2022a). The system needed to be better balanced towards wellness, equity, and access as well as being sustainable. It also needed to remove duplication.

On 1 July 2022, the health system underwent a large transformation with the establishment of the new Pae Ora (Healthy Futures) Act and four new entities. The Ministry of Health (MoH) continued to play the chief steward role in the health system, but its focus moved to solely setting the direction and policy, providing advice to the government on funding and system settings, regulating the system, and monitoring outcomes (Ministry of Health, 2022b). The Public Health Agency was established within the Ministry and has the role of leading and strengthening public health. Te Whatu Ora (Heath New Zealand) was established as a new national organisation responsible for leading and coordinating the delivery of health services for Aotearoa. Te Aka Whai Ora (Māori Health Authority) was tasked as an independent statutory authority responsible for leading hauora Māori. Finally, Whaikaha – Ministry of Disabled People was created to provide a strong lens on disability across government. The Pae Ora Act also called for Iwi Māori Partnership Boards to be used as leaders of tino rangatiratanga (absolute sovereignty) and mana motuhake (self-determination) for local health services planning and decision making.

To remove duplication, the 20 DHBs were disestablished, with Te Whatu Ora taking on the role of operating hospital and health services. Te Whatu Ora, would however, be divided into four regions. Public health units across the country, along with Te Hiringa Hauora, became part of the National Public Health Service which sits within Te Whatu Ora. The new concept of localities or place-based care was introduced as a way for communities to plan and organise health and other services around community members' needs and priorities. For many employees within DHBs, day one didn't present any immediate changes other than having a new employer's name. Due to the large scale of the current health system transformation, the estimate is that it will be three to five years before we note significant improvement in patient services after years' of workforce and funding constraints.

Sleep services in New Zealand

When the data for this current study was collected in 2021, DHBs were still in existence and worked in partnership with private providers to offer sleep services to the New Zealand population. All the participants in this study had accessed a DHB publicly funded sleep service. Sleep services are not always known as a sleep service and are commonly associated with respiratory clinics or services within a DHB. A survey conducted in 2019, which was a repeat of a survey conducted in 2018, was responded to by 18 of the 20 DHBs and showed significant variation between DHBs in the provision of respiratory, including sleep services (Meyer et al., 2022). The survey focused on staffing levels and the respiratory services offered in different DHBs, assessing the changes since the survey was originally completed in 2006. It was observed in the 2006 survey that there was substantial variation of services and lack of monitoring of both DHB performance and health outcomes.

Since 2006, there has been improvement in the number of respiratory clinicians providing respiratory and sleep services to New Zealand patients. Per 100,000 population, the number of respiratory staff has increased from 0.67/100,000 in 2006 to 1.18/100,000 in 2019 (Meyer et al., 2022). When compared to our global counterparts, we are still lagging behind the United Kingdom which has 2.1/100,000 respiratory staff and Australia 1.9/100,000. There is also marked variation, more than five-fold, between each DHB on the available Respiratory Nurse Specialists and Nurse Practitioners. Variation in local models of care could be a contributing factor to the level of qualified and number of nurses employed in each DHB. Some DHBs offer acute respiratory services of generalist or respiratory specialist roles and others have a mixed model. Only six of the 18 DHBs have dedicated specialist teams, and this has a major impact on the patient outcomes for certain acute respiratory conditions. Smaller DHBs, including rural DHBS, who were more reliant on specialist teams are disadvantaged through the reduced access to this level of care.

Meyer et al. (2022) go on to note that workforce constraints have worsened over the last two years with the COVID pandemic reducing the number of international staff being able to enter New Zealand on work visas. This has been especially difficult for small remote communities. In such communities, there is usually only one or two general practitioners who work at the local medical centre, which can be miles away from the nearest town centre or hospital. These doctors also work after-hours, so not being able to access locum doctors, who commonly come from overseas, has led to increased job burnout rates for doctors and nurses. Despite international borders opening, these pressures still exist for not just general practitioners but all doctors and nurses in New Zealand who are experiencing job burnout.

More specifically, Meyer et al. (2022) review of sleep services found that there was a four-fold variation in the number of sleep studies carried out and availability of CPAP devices for patients with OSA. DHBs that had higher levels of CPAP studies were also found to not meet the demand of their population. The researchers' survey showed that despite improvements in some respiratory interventions, there has been little reduction in the variation across DHBs over the last 14 years since the last survey was conducted. With one in six people in New Zealand experiencing respiratory disease, which is responsible for one in eight hospital admissions, and respiratory diseases being the third leading cause of New Zealand deaths, respiratory services need to be prioritised through the current health system reforms. District, primary and secondary care services need to be more closely integrated, with greater access required for rural centres. Important services such as respiratory care must be involved with the transformation from the early stages, and learnings from previous research taken into consideration.

Socio-historical context

At this point, I have primarily explored OSA and use of CPAP in terms of how it is understood within a bio-medical perspective and the public health structures that are in place to support treatment. To deepen our understanding of the broader factors that contribute to a higher prevalence of OSA among Māori, it is important that we go beyond the bio-medical and consider the socio-historical background of Māori that has led us to this point in time today.

The profound negative effects of colonisation of indigenous cultures and their wellbeing are well known and documented (Durie, 2003; Kauanui, 2008; Laenui, 2000; Marrone, 2007; Moreton-Robinson, 2016; Petersen et al., 2010; Simpson, 2014; Simpson & Smith, 2014; Tobias et al., 2009). Māori are the indigenous people of Aotearoa and arrived in New Zealand around 1000 CE from Polynesia (Durie, 2009). This is approximately 800 years before the British settlers arrived. Prior to the arrival of European settlers, Māori lived a healthy lifestyle with very little illness and disease (Buck, 1966). There was no evidence of endemic or epidemic diseases, and children had low mortality rates. With the arrival of European settlers, firstly Abel Tasman in the mid-1600s and Captain James Cook in the mid-1700s, various diseases were introduced to Māori, such as measles, typhoid, tuberculosis and venereal disease (Buck, 1966; Moewaka Barnes & McCreanor, 2019). Cook noted on his arrival in New Zealand that the natives were active, strong looking and well made, with the men having very good features, and overall, the Māori appeared in a good state of health, living to a good old age (Cook, 1770).

It may be argued that with the arrival of European settlers, advanced western economic, scientific and educational knowledge, was introduced to New Zealand, supporting Māori to continue their good state of health and wellbeing, yet this was not the case. Life changed quickly for Māori as new diseases were introduced, and other effects of colonisation started to show, including oppression, loss of land and culture, and the direct harm from killings and kidnapping (Cook, 1770; Monkhouse, 1769; Salmond, 1991). Māori were assimilated into the western culture, which had a long-lasting impact on this indigenous population (Fernandez, 2015). Colonisation was a process of establishing and maintaining a power imbalance favouring colonisers at the expense of Māori. The power imbalance came about from the introduction of colonial systems which controlled resources and privileges in the construct of the western world (Reid & Robson, 2006). As a result, a new culture was created with a new history and ways of being. For many Māori, this meant a loss of cultural identity and deculturation, both of which have been widely associated with poor health for Māori (Durie, 2001; Marie et al., 2008). It is difficult to comprehend that everything that you have ever known to live by is no longer relevant, from what shelter you live in and how you care for your whānau, through to foods and traditional medicines. This was the beginning of a destructive and health demoting journey for tangata whenua (people of the land). Māori commonly refer to themselves as ‘tangata whenua’, and this shows the direct link through whakapapa (genealogy) to the land and their need to live in harmony with it (Ngata et al., 1986). It also emphasises that all living things have a reciprocal relationship with tangata whenua (Mikaere, 1994). This worldview of the land or natural world displays the importance that Māori place on the interconnectedness and interdependence of all things. Whakapapa shows us the connections of tangata whenua with the land and the entire universe and helps inform relationships. Therefore, loss of land for Māori was not just about loss of materials but also disruption of their whakapapa with the land, which in turn resulted in disruption of their overall wellbeing.

In the mid-1800s, Lord Normanby, the Colonial Secretary, provided instructions stating that the acquisition of all Māori land should not lead to Māori being marginalised by the British (Durie, 1999). The signing of Te Tiriti o Waitangi (Treaty of Waitangi) in 1840 supposedly progressed this thinking by signalling there was agreement between Māori chiefs and the British Crown to work in partnership and share the land. Te Tiriti o Waitangi has three articles and was first drafted in English before then being translated into te reo Māori (Māori language) by missionaries. This resulted in two different versions or understanding of Te Tiriti. In Article One, the English version states that Māori gave the Queen ‘’all rights and powers of sovereignty” over their land (Orange, 2013); however, in the Māori version, the Queen was to have “te kāwanatanga katoa”, the complete governance of their land (Orange, 2013). The difference in translation of the term “sovereignty” caused tension. For the English, it meant full and exclusive transfer of power to the Crown, but for Māori, sovereignty as it was known to them was “te kāwanatanga”, which meant Māori would have governance with an “administrative authority” (Durie, 1999).

Article Two also contained different versions of understanding, with the English version stating that Māori leaders and people were assured “exclusive and undisturbed possession of their lands and estates, forest, fisheries, and other properties” (Orange, 2013). However, the Māori version guaranteed Māori “te tino rangatiratanga” (self-determination, sovereignty), meaning they would have complete authority of their chieftainship over “taonga katoa” (their treasures). Tino rangatiratanga recognises the mana (authority) of the chiefs, and “taonga katoa” refers to protection of the cultural, economic and social resources along with material properties (Durie, 1999). Article Three stated in both the English and Māori versions, that Māori were to have “all the Rights and Privileges of British Subjects” (Orange, 2013). What this meant to Māori was that they were agreeing to the government of the Crown in exchange for protection, while keeping mana over their own affairs, so emphasises equality (Waitangi Tribunal, 2019). Not long after Te Tiriti was signed, the Crown commenced a long journey of breaches of the agreement and legislative rulings which caused direct rejection of Māori culture and te ao Māori (Māori worldview) alongside widespread and devastating land confiscation (Tuffin, 2008).

As a result of Māori slowly losing their tribal lands, many migrated to urban centres to explore other employment and living arrangements. The 1950s saw many Māori migrate from their small well-connected communities to major urban centres to seek employment opportunities and also explore the other opportunities these urban settings provided (Poata-Smith, 1997; Walker, 1990). The move was of benefit for

Māori while employment was in abundance; however, it led to disconnection from te ao Māori and reduced mātauranga Māori (Māori knowledge) within family units. Some Māori attempted to uphold their connections to whānau, marae (meeting house), iwi and hapū back home in the smaller settlements, but this has proven to be difficult with many losing their cultural identity. Kingi et al. (2017) support this notion, saying that urbanisation of Māori from small rural communities has been linked to disruption of social and cultural settings, which enables us to understand why some Māori living in cities have no knowledge or their whakapapa or tikanga Māori (Māori custom).

New Zealand is not alone when analysing the impacts of colonisation. For many indigenous populations, colonisation has had a similar impact (Axelsson et al., 2016; Paradies, 2016). One such impact for New Zealand was the dramatic decline in the Māori population from an estimated 200,000 in the year 1800 to approximately 45,000 in 1901 (Durie, 2011) as a result of increased mortality and decreased fertility secondary to infectious diseases, malnutrition, loss of land and the influx of European settlers (Moewaka Barnes & McCreanor, 2019). European settler numbers had grown to 770,000 by 1901, outnumbering Māori. This contributed to the diminishment of the Māori language and overall deculturalisation resulting in socio-economic inequities. By the 1880s, Māori life expectancy was 30 years less than the settlers, with many Māori dying in their mid-20s and settlers dying in their mid-50s. Significant trauma occurred for Māori in the form of material, cultural and psychological consequences following on from the effects of war and colonisation.

Well-known Māori leaders such as Sir Apirana Ngata, Te Puea Herangi, Maui Pomare and Te Rangihiroa were influential in advocating that Māori developing their lands would help create economic growth and improve nutrition and fertility, resulting in Māori population growth (Pool & Kukutai, 2018; Walker, 2001). Land development and other schemes from the 1890s aimed to improve sanitation of water and reduce mortality and morbidity for Māori. This had a positive effect in raising the Māori population to 100,870 (Statistics New Zealand, 1945), but with their land ownership being less than 10%, the disparity between Māori and European life expectancy of 15 years continued (Pool & Kukutai, 2018). The Māori population continued to slowly increase, and as at 30 June 2021, Stats NZ estimated the Māori ethnic population at 17% (875,300) of the national population (Statistics New Zealand, 2021). However, inequities of health status continued between Māori and non-Māori for most diseases and illnesses, and this is shown through Māori having higher hospital admission rates and dying younger than non-Māori (Ajwani et al., 2003; Ministry of Health, 2006; Reid & Robson, 2006).

Positive changes in the way the government operates started to occur in the 1970s. In 1975, the Treaty of Waitangi Act established the Waitangi Tribunal in recognition of the multiple breaches of Te Tiriti (Waitangi Tribunal, 2019), despite concerns that the Tribunal was only able to make non-binding recommendations (Durie, 1999). Durie went on to note that in response to Te Tiriti, the 1988 Royal Commission on Social Policy made recommendations based on three principles which needed to be included when developing social policy. These were participation, partnership, and protection. Participation meant that Māori should be involved at all levels in the development of policy and provision of services. Partnership meant that Māori would have a working relationship with government agencies. Finally, protection implied that Māori had the same rights and privileges as other New Zealanders, particularly regarding the promotion of health and prevention of illness.

We are starting to see a shift in the younger generation decolonising colonial processes through greater application of the principles of socio-cultural processes to strengthen and reaffirm Māori culture and ways of being (Hutchings & Lee-Morgan, 2016; Kingi et al., 2017; Rua et al., 2017). Decolonisation can be known as indigenisation, that is, a way forward for Māori towards recovery of cultural frameworks and reaffirming traditional indigenous ways of being (Rua et al., 2021). This is important in helping strengthen cultural identity and overall wellbeing for Māori. But this is not just a journey of growth and change for Māori. Pākehā (European people) also need to develop their own understanding of Te Tiriti as this will help to reduce discrimination and racism, which are some of the important social determinants affecting health, wellbeing and quality of life.

Social determinants of health

When we consider why some groups of people experience more illness than others, it is important to not just focus on individuals' genetics or behaviours alone. We must take into consideration the broader societal context in which the individual is situated. If we do not consider these broader settings, then we risk considering an individual's behaviour in isolation—which can lead to victim blaming (Krieger, 1994; Pearce, 1996; Susser, 1973, 1985; Susser, 1989). Social determinants of health are the social (non-medical) conditions in which individuals are born, grow, live in and work. How these conditions impact the health of particular groups, given their positioning within wider society, are all key influencers of wellbeing (Hill et al., 2013). Some examples of the social determinants of health include: income and social protection; education; unemployment and job insecurity; working life conditions; food insecurity; housing, basic amenities and the environment; early childhood development; social inclusion and non-discrimination; structural conflict, and access to affordable health services of decent quality (World Health Organisation, 2021).

Socio-economic status (SES) is a key determinant of health and measures an individual’s position relative to others taking into consideration income, employment and education (Campbell et al., 2012). In New Zealand, SES is measured by the New Zealand Deprivation Scale (NZDep18), which is a small area measure based on variables from the five-yearly census data. Variables include internet access; people receiving means-tested benefits; household incomes; employment; qualifications; home ownership; single parenting; household size and dwelling conditions (Environmental Health Intelligence New Zealand, 2022). NZDep is displayed as deciles, with decile 1 representing areas with the least deprivation scores and decile 10 representing areas with the most deprivation scores. The NZDep2013 reported that Māori live in areas with high deprivation scores (Atkinson et al., 2014). In 2013, 23.5% of Māori lived in decile 10 areas, compared with 6.8% of non-Māori, and only 3.8% Māori lived in decile 1 areas, compared to 11.6% non-Māori. Furthermore, non-Māori were shown to be more advantaged than Māori across all socio-economic indicators. Māori experienced lower rates of school completion and much higher rates of unemployment. More Māori received income support and more Māori received personal income less than $10,000 annually. Māori are more likely to live in houses without any telephone or internet access and without transport. Rented accommodation and a crowded household were also experienced more by Māori.

When we consider health statistics alone, we observe higher rates of illness and disease for Māori compared to non-Māori.

I. Ischemic heart disease was the leading cause of death for Māori in 2010-12, with the exception of Māori females, for whom lung cancer was the most common cause of death.
II. Māori experienced a disproportionate burden of cancer.
III. Māori had lower breast and cervical screening rates to 31 March 2015.
IV. Cardiovascular disease mortality rates among Māori were more than twice as high as those for non-Māori in 2010-12.
V. Rheumatic heart disease mortality was more than five times higher than non-Māori, and similarly with related hospitalisation rates in 2010-12.
VI. COPD mortality rates were more than three times higher for Māori aged 45 than for non-Māori in 2012-14.
VII. SUDI (sudden unexplained death of infants) was five times higher for Māori than among non-Māori in 2010-12.
VIII. Amenable mortality rates for Māori aged between 0-74 years were almost two and a half times higher than for non-Māori in 2010-12.
IX. Māori were more likely than non-Māori to access health services later and experience severe disorders or existing conditions.
X. Māori were less likely to report they had seen a general practitioner in the last 12 months compared to non-Māori in 2013/14, with many Māori whānau reporting that cost was a barrier to seeing their general practitioner and lack of transport.
XI. Māori were more likely than non-Māori to have reported not collecting their prescription from a pharmacy due to cost in 2013/14.

Reid and Robson (2006) emphasise that increased socio-economic deprivation and poorer health outcomes lead to higher rates of admission to hospital, which is clearly demonstrated in the above statistics. While socio-economic factors play a role in the overall poor health status of Māori, they should not be considered alone (Durie, 2001; Dyall, 1997; Howden-Chapman & Cram, 1998; Ministry of Health, 1999; Pelkowitz & Crengle, 2004). Addressing socio-economic inequalities can reduce disparities in risk-factor profiles among ethnic groups. Any approach to managing risk factors and interventions must consider the social, political, economic, and physical environment in which people live.

Sleep health inequities

As mentioned earlier, there is a clear pattern of inequities in Aotearoa between Māori and non-Māori across health status, mortality, and morbidity rates, including self-reporting of sleep problems (Robson & Harris, 2007). Māori are also impacted more than non-Māori by various risk factors and negative health effects from sleep problems. These have a flow-on effect, thus increasing the inequities between Māori and non-Māori in terms of cardiovascular disease, motor vehicle accidents and general quality of life (Bakker et al., 2011). We know that risk factors of OSA include obesity, which is linked with cardiovascular disease. Māori have higher rates of alcohol consumption, which is linked to motor vehicle accidents. We know that Māori have lower education attainment and work in lower-skilled employment such as shift work, which is linked with OSA. We also know that Māori earn less income than other New Zealanders, therefore reducing their ability to buy nutritious food, live in warm and dry houses and access health care.

When we consider the social determinants of health for Māori, we know that they experience higher rates of these indicators; therefore, we can start to understand why Māori have higher rates of OSA. With the context of the socio-historical experiences of Māori in Aotearoa (New Zealand) and social determinants of health discussed, we can start to understand that these inequities are a result of differential access to goods, services, and opportunities of society. Even when Māori do have access to CPAP, adherence rates are lower compared to non-Māori (Bakker et al., 2011). Evidence shows that this relates to the lower education levels and socio-economic status of Māori. Education increases an individual's understanding of the importance of maintaining one's health status, and how to navigate the health system. Additionally, individuals with lower socio-economic status experience greater levels of stress and depression, which leads to lower prioritisation of their own wellbeing. Furthermore, there is a lack of lived experience research in this area in New Zealand, so this study will help fill these gaps.

This thesis aims to:

a.) Develop a deeper understanding of the experiences of Māori who are diagnosed with OSA and use CPAP.

b.) Identify enablers and barriers for Māori diagnosed with OSA and using CPAP.

Chapter Three: Methodology

Aim & Rationale

The objectives of this research were to understand the Māori experience of how life was pre-, during and post-diagnosis of OSA and their use of CPAP. This chapter discusses the steps taken to investigate the research topic and outline each participant's experience.

Methodology

Kaupapa Māori research approach

Adopting a methodology like Kaupapa Māori was important for this research as it allowed knowledge to be developed and theory grounded in traditional Māori culture as well as current and past realities in a culturally appropriate way. Cram (2001) highlights that Māori experience challenges with research as realities are often misinterpreted and the research is 'done to them' rather than 'with them', diminishing tino rangatiratanga over the process. Kaupapa Māori research allows us as Māori to reclaim the research space and offset the commonly displayed negative and deficit-focused perceptions. This approach allows for a 'by Māori, for Māori, with Māori' orientation which places the interests of Māori at the centre. Through applying this methodology, the Māori way of being is viewed in a more positive lens (Smith et al., 2017). Whānau Māori (Māori family) already experience daily challenges and Smith et al. (2017) note that this approach allows for them to be empowered and uplifted. Cram (2017) reinforced this by stating that a Kaupapa Māori approach ensures research is informed by "an agenda of Māori being Māori, being fully human, and living in health and prosperity" (p.1).

The true benefit of Kaupapa Māori research is that it normalises what it means to be Māori and ensures researchers privilege te ao Māori worldviews and knowledge (Wilson et al., 2022).

Smith et al. (2017) speaks of how Kaupapa Māori research is a Māori way of thinking and doing things. Furthermore, it has a dual purpose of allowing Māori to work towards decolonisation and tino rangatiratanga (self-determination). It is not only a way of sharing Māori knowledge, but also an intervention strategy to deconstruct colonial paradigms (Cram, 2017) as it challenges the Pākeha (English) hegemony and reclaims Māori realties (L. Smith, 2012). Kaupapa Māori research empowers tino rangatiratanga for Māori by ensuring Māori can guide the direction of the research and knowledge shared. No hard and fast definition is held for Kaupapa Māori research, but it is linked to being Māori and is also connected to Māori principles and philosophies. L. Smith (2012) states that it therefore ensures that the assumptions of Māori culture, language and beliefs are deemed to be valid and legitimate, which can serve as a starting point of research and action. This allows the opportunity to shift the discourse from victim blaming to more fully understanding the lives of Māori and social determinants of Māori health inequities.

Te ao Māori is the Māori worldview and whakapapa of how we have genealogical connections to people, the environment, and the universe. Māori understand this process of connecting and relationships as whakawhanaungatanga (Barlow, 1991). Whakapapa is a way of how we as Māori organise knowledge in relation to creation and the development of being, with a strong focus on spirituality and whānau connections. It will be demonstrated through this current research that whakapapa was acknowledged during each interview by commencing the process with whakawhanaungatanga (process of establishing relationships). This allowed me to connect with all the participants by knowing their tupuna (ancestors), whānau, iwi and/or hapū. It also allowed for a genuine connection to be made and participants to feel relaxed and trusting of me. Further, I adhered to ‘titiro, whakarongo…. korero – look, listen, speak’, which means allowing time for the participants to adapt to the interview setting in order to share their story. I was also able to view the participants as part of a collective rather than as an individual, which is in line with tikanga Māori.

Kaupapa Māori research asserts that being Māori is valid and legitimate; therefore, respect must be paid to the language, knowledge and treasures shared during the process, as these have been passed down through generations (G. Smith, 2012). Mātauranga Māori is the epistemology of Māori, and it supports the purpose and meaning of Māori knowledge (Tau, 1999). Mātauranga Māori is sacred, hence why there are certain tikanga linked to the knowledge and learning gained when applying a Kaupapa Māori research methodology. Knowledge is seen to uphold the mana of Māori, so this may be seen in some Māori being entrusted with knowledge of certain subjects to protect the sacredness.

Kerr et al. (2010) speak of three fundamental principles in Kaupapa Māori research:

I. Research that is by Māori for Māori.
II. Māori views are the normative construct.
III. The research benefits Māori.

In addition, L. Smith (2012) developed a series of questions that a researcher and the Māori communities being researched can ask during the decision-making process. The questions are focused on identifying who defined the research question, who will it benefit or potentially negatively affect, and lastly who will gain knowledge of the study. There is a shift with the researcher no longer having sole control over the research but ensuring that Māori research responds to Māori needs and aspirations (Cram, 2015). Furthermore, principles to be adopted should include whakapapa, whakawhanaungatanga, whakawātea (a cleansing approach), whakaae (agreement) and whakamana (enhancement of authority) (Paipa et al., 2015). This ensures the research is informed by Māori values and makes sense to Māori.

Throughout my research process, I upheld all of these principles, which was demonstrated by ensuring the participants defined the space and terms in which to meet; meeting all participants face-to-face, looking, listening and then speaking; bringing kai (food) to share at the interview; offering a koha (gift) in the form of a kai voucher, and ensuring I remained respectful of the participant, upheld their mana, and deemed it an honour to be able to listen to their story, which was a taonga (treasure) being passed over to me.

In summary, a Kaupapa Māori research epistemology is mātauranga Māori, and we have a role as researchers to make space for mātauranga Māori. Within the context of this current research, my role was to explore knowledge of wellness and not just illness.

Narrative inquiry analysis

The chosen analytical method for this study was narrative inquiry. Qualitative research, such as narrative inquiry, integrates well with Kaupapa Māori research (Walker et al., 2006). Sharing knowledge through telling stories is a traditional method for Māori; therefore, adopting a narrative approach to analyse the data is deemed to be a valuable approach (Bishop & Glynn, 1999). Whakawhanaungatanga, a key principle of Kaupapa Māori research, enables the narrative process by allowing the participant and researcher to build a relationship where the participant comes first (Clandinin & Connelly, 2000). Narrative also allows for the cultural and historical context to be considered when the stories are being told (Creswell, 2018). Semi-structured interviews are commonly used for narrative inquiry; the interview appears to be more like a conversation, which allows it to remain participant-centred (Riessman, 2013). Narrative allows for the development of self-concept and personal identity (Riessman, 2008), which permits sense-making for the individual (Polkinghorne, 1988) and creates meaning and order in our lives (Wertz, 2011). The researcher and the participant are given an opportunity to develop a synergy, leading to a deeper understanding of the experiences that are being shared (Caine et al., 2013).

Gaining a deeper understanding of each participant's experience, otherwise known as an experience-centred approach, was central to this study. Narrative inquiry also allowed me to concentrate on the meaning of words during the conversations and how important the experiences were for participants. This enabled me to identify themes for the analysis process. Based on how participants commonly defined their experience, their responses were grouped into three overarching themes: pre-diagnosis, during diagnosis and post-diagnosis. Participants were able to describe the same phenomena in their narrative, but the experience of the phenomena can never be told the same way twice when taking into consideration the social circumstances or context in which the participant is positioned in.

Methods

Participant recruitment

I facilitated the recruitment of participants through working at a primary health organisation (PHO) based in Whangārei in Tai Tokerau (Northland) and having strong relationships with primary care providers. Participants were recruited by advertising the research project at local general practice and Māori health provider clinics. Patients who were known to these clinics were offered the opportunity to participate. Eligible participants met the following criteria:

1. Māori male or female aged >30 years.
2. Residing in Northland District Health Board catchment.
3. Currently using Continuous Positive Airway Pressure for treatment of OSA for >3 months.
4. Willing to talk about their experiences.

It took two to three months to recruit the participants for this study. The sample size was relatively small with five participants in total, however this number of participants was considered suitable as the aim was exploring rich and detailed insights rather than generalised findings (Creswell, 2018). The sample size was also determined by the length of time given to complete this thesis project, including interviewing, transcribing and the whakawhanaungatanga process.

Information sheets were offered to all interested participants. The information sheets contained comprehensive information about the research and the patient’s rights. An email address or phone number to contact the researcher was provided on these sheets so that any interested patients could contact me before agreeing or declining to participate.

Participant demographics

The table below (Table 1) outlines the participants pseudonyms and demographics.

Table 1: Summary of participants and demographics

Pseudonym	**Age**	**Gender**	**Rural/Urban**	**Comments**
Mark	70	Male	Rural	
Anthony	57	Male	Urban	Brother of Anthea
Anthea	65	Female	Urban	Sister of Anthony
Paula	62	Female	Rural	
Miriam	65	Female	Rural	

Interview structure

Central to any kōrero in Māori culture is whakawhanaungatanga, which is explained as kinships, relationships and connectivity (Bishop, 2011). To create whakawhanaungatanga, the interviews began with a karakia (prayer) to formally open the hui (meeting) before introductions allowing us to get to know each other and our whakapapa. I bought kai to share, and we either ate the kai during the interview or at the completion of the interview. I allowed the participants to guide this process.

Semi-structured interviews, along with a narrative approach, were utilised to gain participant accounts. Interviews were audio recorded and transcribed. Semi-structured interviews are a helpful way to collect qualitative data as they allow for the researcher to obtain open-ended data, to discover the participants thoughts, feelings and beliefs about a specific topic (DeJonckheere & Vaughn, 2019). This approach is directed by covering topics or questions with follow-up questions to delve deeper into the participants personal and sensitive issues. Whakawhanaungatanga (the building of substantial relationships) are built throughout this interview process, primarily if more than one interview is undertaken. Establishing and maintaining a relationship is important and is an ongoing part of the research approach. Furthermore, establishing these relationships in a te ao Māori context allows for power and control constraints to be addressed, as this research uses a participatory research practice and is driven by the participant. The benefit of whakawhanaungatanga is that it allows for more open space in which sensitive discussions can take place (Bishop, 2011).

The interviews were conducted and recorded over 1-2 hours in a kanohi ki te kanohi (face-to-face) setting. The days and times of the interview discussions centred on what suited the participants and the venue at which they wished to be interviewed. In line with aroha ki te tāngata (a respect for people), I allowed the participants to define their own space and meet on their terms (Cram, 2017). I met three participants in their homes, one online via Zoom, and one at her workplace. Two participants met with me during the week as they didn't work, or only worked part-time. The other three participants met with me during the weekend, as they worked during the week. Participants were also invited to have whānau attend the interview with them.

Topics that were explored during the interview included:

1. Life prior to diagnosis of OSA.
2. Experience of diagnosis process.
3. Enablers and challenges of living with OSA and using CPAP.
4. Experience of navigating the public health system.
5. Impact on cultural self-identity.

I opened up the formal part of the interview by providing an overview of the research and asked participants to share their experience of obstructive sleep apnoea (OSA) and using CPAP. I used the five topics to guide the kōrero but allowed participants to speak freely and follow their natural direction of kōrero.

Once the interview process was completed, the participants were offered a koha (gift) to acknowledge their time and contribution. This was in the form of a $100.00 Pak ‘n Sav food voucher. If kai had not been consumed during the interview, I would then stay on after the interview to have kai with the participant.

Analysis

After the interviews were completed, I manually transcribed the interview audio recordings. I initially attempted to use NVIVO but found it difficult to develop themes as the participants each had five different ways of describing their experience. There was significant benefit in manually transcribing the interviews as it allowed me to reconnect with each participant’s narrative and discover elements of the discussion that I didn’t initially recall after the interview finished. It did take several hours to carry out this task, but I felt it provided me with the opportunity to really listen and hear their stories. It took several attempts to find consistent subordinate themes, but after repeating the process of analysing the data for each participant and comparing the findings, I was able to draw some commonalities among their stories.

After reading and re-reading the data, it became apparent that participants described their experiences within three main themes: ‘before diagnosis’, ‘during diagnosis’ and ‘post-diagnosis’ However, I did note that with most of the participants being diagnosed with OSA several years ago, varying between 12-30 years prior, their recollection of their experiences in the 'before diagnosis' and 'during diagnosis' phases were not as extensive as their ability to describe their experience 'post-diagnosis'.

Within these three themes, there were a number of subordinate themes identified. These are catalogued in Table 2.

Table 2: Summary Table of Research Results

Main Themes	**Subordinate Themes**
Before Diagnosis of OSA	Early signs and symptoms of OSA Whānau observation and experience
During Diagnosis of OSA	Referral process Experience of overnight sleep study
Post-Diagnosis of OSA	Benefits of using CPAP CPAP adherence and general use Maintenance of CPAP Attending sleep service appointments Engagement with and impact on whānau Educating others on benefits of CPAP Use of CPAP away from home

Ethics

Researching Māori knowledge

For Māori, ethical obligations in the context of research are about maintaining and strengthening connections/relationships, and this is enabled through the use of tikanga Māori (Cram, 2017). Through Kaupapa Māori research, the researcher is accountable to the Māori community, iwi and hapū (Te Awekotuku, 1991). The original intent was to form a Māori Advisory Group of kaumātua (elders), with initial discussions about my research being held with two kuia and one koroua and seeking their guidance on how to ensure I upheld the principles of a Kaupapa Māori approach. This was stalled due to the COVID-19 lockdowns and restrictions, which meant I had to restrict face-to-face contact with this group. I therefore opted for a Māori cultural supervisor, Pita King, alongside my main supervisor, who was able to provide the support I was seeking. Being able to engage frequently and openly with Pita ensured my research stayed tika and pono to its purpose and delivery.

Confidentiality and safety of participants

The confidentiality and safety of the participants was paramount in this research. To ensure the participants' identities were protected, pseudonyms were used. All data collected – audio recordings and transcriptions – were password protected, with only me and my supervisors having access.

Dissemination

The kōrero shared in this thesis ultimately belongs to the participants, their whānau, hapū and iwi. Therefore, a copy of this research will be offered to each participant. Results with health significance and recommendations for patients will be made available to Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority, by sharing a finalised copy of the summary research findings.

Now I move from the methodology section to the key findings and analysis section which is presented in three sections: before diagnosis, during diagnosis and post diagnosis.

Chapter Four: Key Findings and Analysis – Before Diagnosis

Introduction to key findings and analysis

Understanding the journey of a patient with OSA from diagnosis through to the use of CPAP as a long-term form of treatment is vital to inform sleep services and future related research. This understanding is enriched by the narrative approach used in this research, as it enabled participants to share how their journey began, developed, and continues over time. Therefore, the findings and analysis chapters have been structured to reflect these journeys as an ongoing process, themed into 'before diagnosis,' 'during diagnosis,' and 'post diagnosis.'

Before diagnosis

The before diagnosis section was centred around participants describing early signs of OSA in the form of snoring and waking feeling tired still. Commonly reported symptoms of OSA occur during sleep include snoring, witnessed apnoea, disturbed sleep, drooling, reflux, shortness of breath and choking. Symptoms reporting during the day include fatigue, depression, and headaches upon waking. The nocturnal symptoms are more specific to OSA compared to the daytime symptoms (Bassiri & Guilleminault, 2000). Loud snoring and daytime fatigue are the most reported OSA symptoms in adults (Neill et al., 1997).

Early signs and symptoms of OSA

When participants were asked when they first became aware of something not being quite right, they had noticed signs and symptoms themselves which included snoring, and waking up tired the next day. For example:

> *Well, I honestly believe that I must have been suffering from sleep or sleep apnoea, years ago, years ago, probably. I think that's why I started when I was about 30 or something. Yeah, very young…Because I used to snore quite a bit. I was snoring, and I still. I don't know whether I snore now, and I was snoring quite a bit. I didn't realise I had a problem with sleeping, you know… "you know you're snoring, and then you stopped" so I was told.* (Mark)

> *Because you don't feel it do you? Like that you stopped breathing and things. I was just getting up. I was so tired, and I couldn't understand that I was sleeping for eight hours, and I was tired. And that's what I said, I can sleep all day and I still wake up tired. What's with that? And so that's how I came to that… they used to say I'm grinding my teeth.* (Miriam)

> *I didn't realise I had a problem sleeping…you know you were snoring and then you stopped (breathing)… so I was told.* (Anthea)

Anthea described her brother Anthony's symptoms as being similar to hers:

> *When he (Anthony) snored, there was a pause. He was holding his breath. His problem was he was holding, he was snoring, holding his breath and we would be watching him. One-time last year we had to wake him up so he can start breathing again.* (Anthea)

Anthony said he would get a fright when one of his whānau woke him up because he was snoring.

> *Even if someone touched me. What the…? Yeah. They said I was snoring. I said no I'm not… Awkward. Really awkward.* (Anthony)

Paula described how her friend, who is a registered nurse, stayed overnight and noticed her snoring and holding her breath. This was followed by her mokopuna watching her do the same thing and it had frightened him.

> *So, it happened where we are living now, down at my dad's old homestead. And I had my friend stay over, and she's a registered nurse, and she was sleeping on the floor. And the next day she told me…I need to go see a doctor. And I said what for? And she told me that I had this, and I thought oh nah. Just ignored it a couple of weeks later. And I believe what she says - she tells me. But I thought no - I can't be...And anyway, a couple weeks later, [daughters name] and her husband came down, and with all the kids, and we only got a little bach (small home) – the same size of that one that I described. And all the kids were spread out on the floor, and I was on the couch. And the next day [daughters name] looked really scared, and I said, "What's wrong with me?" and she said "It's [grandsons name]". I said "What's the matter with him? She said, "Mum, you frightened him" and I said "How did I do that? I was asleep". She said he'd been up watching my sleeping all night. And um he said that I stopped breathing. And I didn't know*

> *any of that. But anyway, when I heard that again, I thought of my friend who had told me about it and I thought, okay, just for you guys, I'll go get this checked out.* (Paula)

The participants account of their experiences was consistent with earlier studies which support that OSA symptoms tend to be first noticed by family members as the individual with OSA is asleep at the time they occur (Gibson et al., 2018; Ho & Brass, 2011). With the nocturnal symptoms of snoring and apnoea being reliant on a sleeping partner and whānau observing, this means individuals that live alone may not be aware of their symptoms, therefore, going undiagnosed. This is one of the reasons why a vast majority of individuals remain undiagnosed (Ho & Brass, 2011). In fact, it is estimated that approximately 70-80% of patients globally with OSA have not being diagnosed or are not being treated (Altevogt & Colten, 2006). Undiagnosed and untreated OSA can lead to abnormal physiology which can have significant implications which include cardiovascular disease, stroke, metabolic disease, diabetes, excessive daytime fatigue, occupational errors or accidents, motor vehicle accidents and worst-case scenario – death. All of these concerns result in serious economic burden (Knauert et al., 2015) .

Impact of daytime fatigue on driving

The flow-on effects of daytime sleepiness can have a significant negative impact on people, such as poor general health, quality of life, concentration and memory (Paine et al., 2007). As mentioned earlier, evidence from other studies support an increased risk of motor vehicle accidents resulting from OSA related daytime sleepiness

(Knauert et al., 2015). In this study, three participants talked about feeling extremely tired while driving and falling asleep at the steering wheel.

> *Oh, then there was that incident too. And I thought it was because I was so busy, and I just was on the move all the time. I thought it was just tired – I was studying too that mātauranga Māori. And I had to travel from here, down to Otaki at least once a month for the whole weekend. And my youngest daughter, she was also studying, so her and I normally go down. Anyway, I finished work up here at half past three, pick my daughter up, we headed straight down to Otaki. And I thought um – I thought I was alright I was just tired. But we got to Whangārei and at the lights at the hospital at the intersection there and the lights stopped, and I stopped. And next minute my daughter is going like this (pulling on clothes) "Mum wake up!" I'm going "What?" And I didn't think anything of it. And I said "Holy shit, I'm tired" so I made her swap over. And then that other incident with my son in law happened.* (Paula)

> *Mine was I was travelling. You know, during my home visits and things then on the weekends and stuff I used to come back home. But I found that I was falling asleep driving. And then that became quite noticeable to me anyway and I thought, to do the sleep apnoea test.* (Miriam)

> *When I use to come home here, and I'd bloody sit down, maybe watch TV or something and be bloody asleep bang straightaway. Wake up when, when it's like 10 or 11 o clock, something like that. It's just constant man and I don't know how many times, well my daughter, well she still doesn't trust me, but I don't do it anymore, but I use to have the boys and I can remember coming home from Waipoua. And, you know, we've been up to Tane Mahuta and I was coming back. And I woke up on the other side of the bloody road, with my boys…. And that wasn't once, it was many times then I'd wake up and think fucking hell. Terrible so.* (Mark)

Research has shown that excessive sleepiness is one of the main causes of increased motor vehicle crash risk among those who have OSA (George & Smiley, 1999; Young et al., 1997). Similarly, it is also associated with occupational accidents (Hlavac, 2012). Sleep deprivation from OSA has been shown to manifest in the form of difficulty concentrating, delayed psychomotor reaction times, impaired automatic behaviour and poor memory recall (Yee et al., 2002). With regard to occupational accidents, various studies have linked OSA with an increase in rates of injuries (Heaton et al., 2010; Sanna, 2013), reduced productivity at work (Mulgrew et al., 2007), and an overall negative impact on the economy (AlGhanim et al., 2008; Hillman et al., 2006). A small New Zealand study carried out on 40 injured drivers (mean age 44 years) by Yee et al. (2002) at Wellington Hospital, who were admitted to the emergency department, found that over one-third had OSA. These researchers do go on to state that although sleep apnoea has been linked with motor vehicle accidents, evidence does show that most individuals with OSA can drive their vehicles safely.

Although everyday tasks, such as driving, can still be maintained while living with OSA, researchers have explored the role of OSA in how interpersonal relationships become strained while dealing with this health issue, particularly when undiagnosed. For example, Paine et al. (2007) note that people’s ability to manage minor problems was diminished and they experienced relationship issues. One participant felt that his snoring resulted in him sleeping in a separate bedroom as it was negatively impacting his wife, and, subsequently, his relationship ended with this wife.

> *I'm not blaming me for my broken marriage breakups.... Yeah, honestly, bloody, I never with my marriage. That breakup, and then I had a partner and in the end, I was sleeping in my room. But I used to go to work, even when I would go to work, I was buggered. Just tired. Just go to meetings and bloody fall asleep in seconds.*
> (Mark)

Earlier studies have shown that sleeping with a snoring partner can lead to increased daytime fatigue (Ulfberg et al., 2000), depression and stress (Doherty et al., 2003), frustration and interference at work for both the patient and partner (Luyster et al., 2016). Reports from partners about their poor sleep quality highlighted not only the snoring but also witnessing apnoea episodes (Doherty et al., 2003; Luyster et al., 2016). Furthermore, patients and partners report decreased intimacy as a result of not sharing a bed which can cause a further strain on relationships (Luyster et al., 2016).

Overall, most of the participants in this study found that early signs and symptoms, particularly snoring and apnoea, were present for some time without them necessarily thinking or knowing anything was wrong. Even though the participants would notice waking up suddenly or feeling tired the following day, most of the time it was their sleeping partner or whānau that witnessed the snoring and apnoea attacks. For some whānau, it was traumatic to witness, and in some cases and for others, it caused a strain on relationships.

Some of the participants described daytime sleepiness, which resulted in them falling asleep at the wheel while operating a motor vehicle. What is clear is that OSA for Māori is not simply an individualised health issue, but something that involves the wider whānau unit. Whānau play an important role in seeking medical help for issues that can affect a member of whānau, and that the supports that come with whānau can sometime become strained in the process. Much of this stems from a lack of awareness of the symptoms of OSA and how best to seek help. We now shift to the participants' experiences of visiting the sleep clinic and discovering their diagnosis of OSA.

Chapter Five: Key Findings and Analysis – During Diagnosis

This chapter focuses on participants' experience of being diagnosed with OSA and follows their journey from the referral process to the overnight sleep study and being sent home with a CPAP device. Of particular focus in this section was the participants experience of the initial sleep study. Some participants found the experience positive and were surprised at how many times they stopped breathing. Alternatively, one participant felt embarrassed when the sleep service discovered she had no electricity at home, and he said there was no point in her having CPAP. We start this section exploring participants recollection of how they were referred by their doctor for a sleep study.

Referral process

When describing his referral experience, Mark spoke about how it was not his regular general practitioner who picked up on his symptoms, suspecting OSA and referring him for sleep study, but a trainee doctor who was working at his general practice.

> *Well, I didn't know, honestly. And the thing is, yeah, wasn't until I met this young doctor, she was training. And she sent me to get tested… yeah. And then the young doctor sort of thought we get this checked out…she sent me for a test, and I think what happened was I went in there with what I thought was asthma, and I said to her I'm just having trouble with my breathing. And she said, I'll get it tested. So, initially it was an asthma test, you know where you get tested for asthma. And then she said maybe we should send you into SleepWell because I always feel buggered*

> *when I wake up. So, she said we'll send you over to the clinic in Whangārei.* (Mark)

It was interesting to note that a new doctor identified Mark's symptoms as needing more investigation and not the general practitioner he visits regularly and who has more knowledge of his medical history. Participants in a New Zealand study experienced similar with their own general practitioners having varying knowledge of OSA and CPAP. One participant in the Gibson et al. (2018) study stated his general practitioner told him “He is just getting older”, despite the family saying his symptoms were abnormal. Moreover, participants in another New Zealand study expressed confusion about local referral pathways and not realising that their local DHBs could sort this for them (Bakker et al., 2014) (Gibson et al., 2018). This resulted in the participants experiencing a slow referral process or limited access to information on OSA. However, the same was not found in this research. No participants reported a slow or confusing referral process. Even though no participants in this study commented on this issue, another reason why referrals may be either delayed or non-existent for Māori is that they only tend to present to their doctor or accident and emergency when symptoms are severe (Garrett et al., 1989). Even if they are referred, very few Māori and Pacific peoples attend sleep clinics (Frith & Cant, 1985) (Baldwin et al., 1998),

Paula recounted how her regular general practitioner promptly identified the symptoms and made a referral to the sleep clinic.

> *Okay, so I went to see my doctor at that time…. Told him about it, and then he must have referred on to some other guy… I had to go to Whangārei.* (Paula)

The referral process can also be considered in the context of how important the patient-general practitioner relationship is. Even though most doctors have positive intent when engaging with patients, evidence does demonstrate that lack of connection and miscommunication between the patient from a non-dominant ethnicity and medical staff is not uncommon (Cram et al., 2003). Often poor engagement between the patient and doctor leads to negative outcomes for both parties (Beck et al., 2002). In this study, participants didn't go into detail on the types of relationship they had with their doctor or other health professionals during the referral process, or if the doctors were Māori or non-Māori. Why this is relevant is that racism is an important determinant of health and cause of ethnic health inequities in Aotearoa (Harris et al., 2018; Paradies et al., 2015; Priest & Williams, 2018). There is a long history of qualitative research which examines peoples experience of racism and possible impacts on health by ethnicity (Barnes, 2013; Huria et al., 2014; Mayeda & Dutton, 2014; Reid et al., 2019). Previous research also shows a consistent link between racism and negative health which is predominantly experienced by Māori, Asian and Pacific populations compared to European measures (Harris et al., 2012; Harris et al., 2018). In the next section, participants do comment further on the types of relationships they had with staff during the overnight sleep study.

Experience of overnight sleep study

For most patients, a sleep study is required to diagnose OSA (Hlavac, 2012). Level I sleep studies are known as polysomnography and are carried out in a sleep clinic with a sleep technician observing. A polysomnography monitors a patient's brainwave activity, heart rate, oxygen saturations, nasal flow, thoracic/abdomen/limb movements, and body positioning. Level II studies are unattended but record the same vital statistics as a Level I. Level III records airflow, breathing effort, oxygen saturation and heart rate, whereas Level IV studies only measure two parameters—oxygen saturation and heart rate (Hlavac, 2012). All participants had differing experiences of the sleep study. Paula said that the doctor at the sleep service decided not to help her because she told him she had no electricity at their house to use the CPAP. She felt he dismissed her due to her poor living standards and said to her "it's not worth it". Paula ended up getting a mortgage on her house to get electricity cables put in so she could use the CPAP device.

> *Yeah, and I remember the doctor getting the one in Auckland – Whangārei – might of been embarrassed because I didn't, we didn't have power where we live. There's no running water, no power, where we live and he goes "oh, well". And it was like he cut off right there. And I thought this fella didn't give us a choice at all. And then – but it made me go and put some power cables down here. I think he was a surgeon or something… Carrying this on… I felt like I was cut off right then and there. And then I went back [and] talked to old Hoffer down here and he said oh well you have a choice – you can go do that thing with the power on. Oh, I had to*

> *mortgage my house…I didn't know about mortgages then. Honestly as old as I am nobody would [have] told me that when I bought my house you should put any extra money on it the paid off quickly. Nobody. So, I was just cruising around all these years with the same old yeah and then… another cousin said to me "Oh go to the bank". Cause, I had no idea usually, we used what he called them finance companies to get our stuff. Nobody ever told me to go to the bank for a loan… I was ignorant of it all. But when they told me that I thought oh my gosh… So, we mortgaged um our house – costs about… might have been about 15,000 [dollars] to put the cables in… It had no power no running water. The outdoors… there was a long drop out there... So, the reason we ended up down there is because one of my children – their house burnt down in Moerewa, and they've got six kids. So, it was just us two. So, it was only common sense that we let them have that place up there and we go down.* (Paula)

This discussion highlights the dominant role the medical professional plays when providing health care services to patients. Despite good intentions of medical professionals wishing to share decision-making with patients, doctors often take for granted their role of power via their own cultural and capital symbolism which is justified through the institution of medicine (Nimmon & Stenfors-Hayes, 2016). Goodyear-Smith and Buetow (2001) argue that power is unavoidable in social relationships, and doctors need power to meet their obligations to multiple parties, which include patients, communities, and themselves. However, at the same time, patients need the ability of essential services such as electricity to meet their health needs and meet their own responsibilities. Lack of harmony between doctor and patient attracts paternalism, and resolution can be reached through negotiated care.

Societies with western values assume that people who live in a house should have electricity and water. If they don't have these bare necessities, then that is their fault, constituting a form of victim blaming (Krieger, 1994; Pearce, 1996; Susser, 1973, 1985; Susser, 1989). This victim blaming plays out in bolstering already existing barriers that Māori experience in accessing health services compared to non-Māori (Davis et al., 2006; Ministry of Health, 2018). Health professionals spend less time with Māori and are less likely to properly explain health information to them (Durie, 2019). A Kaupapa Māori approach to health care services moves the narrative from victim blaming and personal weaknesses to a more social determinant focus on health and wellbeing (Cram, 2019). This means taking the broader context of the patient's lived reality into account when delivering medical care.

There were occasions in this study that showed more positive experiences with health care experiences during diagnosis. Miriam reported feeling immediate improvement in her energy levels and described her experience at the Auckland-based sleep clinic as "awesome". She spoke of her friend who used to work in the clinic, and how she helped Miriam navigate the process.

> *And then that became quite noticeable to me anyway and I thought, to do the sleep apnoea test. I fitted the criteria so. When I was down in Auckland, see this is the trouble about knowing*

> *people. One of my friends use to work in the unit and I was talking to her. And she said, oh, are you in Auckland? And I said yes, I am, and she said oh come over tomorrow. And we'll do the things. I went over. And then the next day, they sent me to Auckland. And I did the sleep over and then that night you know by the end of the night. It was actually an awesome experience when I went. I thought it was only for obese people, you know, when I went into the ward in Auckland, they had, I think there was two of us that were big. And there was three Māori, which surprised me. And they explained, you know, about putting the stuff on your head and you go to sleep and then they work out who, you know you're hooked up, and stuff like that. Like I said it was a new experience. I went to bed early anyway. And then they woke me up about 11 o'clock… and then they put the machine on me and then they had to physically wake me up the next day because I was just, I would have just carried on sleeping. And when I got up, I was bouncing. I was feeling so great. I didn't want to get up except you know, you have to vacate the ward and all the rest of it. And then I came home. I drove home and I talked a lot, and I talked fast.* (Miriam)

Likewise, Paula recalled that the sleep clinic staff were great; however, they did send her home with lots of paper, which she had to figure out by herself. Being provided with lots of information can be overwhelming for the individual at the time of the sleep study or diagnosis. Bakker et al. (2014) found this a common experience for New Zealand-based participants when asked what their knowledge of OSA and CPAP was prior to or during the treatment period. A large amount of information provided prior to, and during, their first sleep study led to reports of feeling overwhelmed, as exemplified by the following excerpt:

> *Oh, they were great – they gave a lot of paper. Yeah, but the paper doesn't impact on me it was what they'd seen… And I didn't… mean that in a negative sense, it kind of gave me a fright… I have to go home and think about what they said… Yeah, just had to figure it out.* (Paula)

One of the most common experiences reported was how the participants were so surprised at how many times they stopped breathing.

> *And you have to go up to Auckland and do some test to see if you qualify. If you get that machine. So, this little townie girl went up the Auckland, to a big city and do the test up there and we had a comparison I think those days [I was] in hospital for two days. And stayed like at night two nights. And just to compare results or the findings from how I sleep with all these gauges on me, so they can monitor the machine and then it was true that they see that I had stopped breathing a couple of times and that's why I needed that machine. And yet, for myself I thought, yeah, there were times when you know you gasp. And I said 'I wouldn't of called that stopped breathing', but then they were the experts at it. And from then on, I think I got the machine. I don't think I was a very good*

> *machine user to start off with you know it's not, it's not bloody easy to hook up a machine on you when you're not used to having a machine. It's alright when you're up at the Auckland hospital because they take it off like I think five or six hours. They let you sleep five hours, take it off. And tell you the results of it and then they plug it back on you… They said I had stopped breathing I think two or three times I held my breath too long, going, oh you mean I've been doing this for years. Don't know, I just expected it as being normal.* (Anthea)

Similarly, Mark was surprised that he had stopped breathing for about an hour during the night.

> *So, they did the test, and the outcome was that I stopped breathing at least 58 minutes overnight… and I was like what. Oh, bullshit. Because I couldn't figure it out that 58 minutes. Oh really, and then they put me on this machine. Man, it's just made a big difference to my life.* (Mark)

Participants indicated a range in terms of how many times they stopped breathing with Paula told by the staff at the sleep clinic that she was the worst case they had seen.

> *I went do the test in Auckland. Went to the sleep lab. And they said to me, um, if I wake up and there's this machine is at your*

> *doorway, then that's for you to take home – you have sleep apnoea. Oh, anyway they did do that, there was one there for me, but they were also waiting for me to wake up to talk to me. They said I was the worst patient they ever had, never seen anything like it. And I'm going what? And because in my view I thought it was because the bed was uncomfortable, and it was a strange place. I thought that was why I couldn't sleep, but they said I stopped – must have been breathing 500 and something times. I got up probably five or six times to go to the toilet during the night. Yeah, I see it straight out I was the worst. I don't know if they still have those documents but you're welcome to go and find them.*
> (Paula)

I was unable to find research that supported Paula's comments about being told she was the worst case that they had ever seen after her overnight sleep study, and specifically for a Māori patient. However, research does support that the experience of the public health system for Māori is often hostile and alienating (Graham & Masters-Awatere, 2020). The public health system needs to find avenues to ensure Māori have a positive experience when engaging with their services.

Overall, participants' general practitioners had varying knowledge of OSA. One participant commented that it was a trainee doctor who identified his symptoms as a concern and referred him for further investigation, whereas other participants stated that their regular general practitioner was very responsive to their symptoms and made an immediate referral. This analysis underlined the importance of relationships between the patient and doctor, and how a positive relationship can result in a positive outcome and vice versa The findings in relation to participant reflections on the overnight sleep study revealed mixed experiences.

One participant was completely disregarded by the sleep doctor when she told him she had no electricity at her house to use the CPAP. He said, “Oh well” and left the patient to find a solution. This resulted in the participant mortgaging her house to put electricity cables down so she could get electricity to use the CPAP. Other participants had good experiences, stating that they felt immediate relief from the CPAP when they woke up the next morning. They also stated they were surprised about how many times they had stopped breathing. These comments highlight how experiences of the public health system for Māori is often hostile and alienating and that the public health system needs to find avenues to ensure Māori have a positive experience when engaging with their services.

We now move to the next chapter which looks at how participants experienced post-diagnosis and using their CPAP at home.

Chapter Six: Key Findings and Analysis – Post Diagnosis

This chapter focuses on how participants learned to live with their new diagnosis of OSA and using CPAP. Of the three main themes before, during and post-diagnosis, the latter was the main area which participants reflected on when describing their overall experience. This could be related to post-diagnosis being easier to recall with it being more recent.

Benefits of using CPAP

All the participants shared stories of positive experiences from using their CPAP device at home. The most common benefits reported were increased levels of energy which improved their mood, and for some, productivity at work which was viewed as a motivator or enabler to continue the treatment. There were barriers expressed with use of the CPAP from issues with the mask, to being too noisy and general operation of the device. The participants talked about how they managed to navigate the health system to get repairs made to their CPAP or buy replacement parts. The patient-clinical relationship was highlighted as important and sharing educating whānau members about CPAP helped the participants and whānau feel more comfortable with its use. Several of the participants shared experiences of being embarrassed about sleeping away from home with their CPAP, sometimes choosing not to travel or sleeping in their car. We begin this section with participants describing what positive effects they noticed from using CPAP.

> *And then I came home. I drive home and I talk a lot, and I talk fast. I came back home, and I went to sleep again that night and same thing woke up two days and then I went to work the following day,*

and everybody said what the hell happened to you? You're like an energiser bunny. You know, and I said, I have this blimming CPAP machine I'm telling you it's, it's wonderful…And yeah, it's been wonderful… you know, like the energiser bunny thing… The benefit is because it makes me feel good. Makes me feel rested… I've tried to sleep without it, but I wake up, gasping for breath. And I think, what you call it… I'm hooked on it now. If I don't have it on, I panic… Cause there's a link there and at least I will get a decent sleep. I said because the other thing besides all that internal stuff with your organs, is that if you have a decent sleep, it gives you more energy, you go out you're more motivated you're more positive, you know, and then you will eat better and all of those things, your mood is better. (Miriam)

Oh, I feel good… I can run a mile. I can run four miles if I want to. (Anthony)

I called it my boyfriend… I have lots of energy. Just get out in the garden. (Paula)

And then they put me on this machine. Man, it's just made a big difference to my life. I mean I got to have it all the time. I use it all the time. And it's just made me more active. It even changed my work ethics. And, you know, I'd get a job, and that's all I'd do. I wasn't looking for any other work that needed to be done in that area. I'll just do the job that I was set out to do. Whereas now, I go

> *to a job I think oh shit that's falling to bits, I'll fix that while I'm here. I never used to do those sorts of things…. Yeah, and I'm here more alert. I don't know if this is good or bad, but more outspoken. Yeah cause, they can't bloody pull the wool over my eyes anymore. Whereas now I'm like what, oh whatever you're not bloody doing that. And so, yeah, I'm more alert and I go to sleep at 10, get up at five, every morning. You know, getting back to work, whereas now I don't see that as a problem. If I need to be there to finish the job, I'll do it. Whereas before if I run out of time, say I've got a job, say if I think it's going to take me an hour to get back, so if it's three o'clock, that's me. Whereas now I will call them to say hey I'm going to be late, can you put me down for late log out at 1800hrs.* (Mark)

Several studies internationally, and a limited number of New Zealand studies, have reported similar benefits from patients using CPAP for OSA (Bakker et al., 2011, 2014; Brown, 2020; Brown et al., 2021; Gibson et al., 2018; Luyster et al., 2016; Shoukry et al., 2011; van de Mortel et al., 2000; Ward et al., 2014). Gibson et al. (2018) found that participants stated that their overall experience was positive. Similarly, participants in the Bakker et al. (2014) study reported an increase in alertness and overall improvement in their OSA symptoms. One participant from the Bakker study reported that his increased energy levels gave him the ability to go to the gym, lose weight and improve his diet.

Other studies about user experiences of CPAP and OSA have been angled more from an expert healthcare perspective (Ward et al., 2014). One of these studies was a systematic review of 22 studies on users' experience of CPAP for OSA. This study found that users preconceived attitudes and expectations about CPAP influenced the experience, as did participants attitudes to therapy. This was both in a positive and negative sense (Ward et al., 2014). Furthermore, CPAP users were found to be primed to perceive the treatment in a negative way by healthcare workers. This behaviour can be related to the Health Belief Model, which suggests that patients' readiness to act is based on how susceptible they are to the consequences of the illness if not treated, known as risk perception, compared to their perception of how serious the illness can get on their current functioning. The patients' perception that a course of action is advantageous or not is based on having weighed benefits gained from the action against the costs of inaction (Quine et al., 2000).

When participants were asked what motivates participants to use CPAP, most said that it made them feel better, more energised, and how it was important for their whānau. This can be linked to whakapapa and the yearning to want to stay around (alive) as a kaumatua for the younger people in their whānau. One participant explained that her motivation to use her CPAP was because she had a fear of not waking up if she didn't.

> *The energy, getting my energy back. Cos some days it's really draining like my days are long… Yep. I just tell myself I want to go to sleep so that machine goes on…. I'm thinking of the reasons why I should – the fear of not kind of waking up. That's one of*

> *them… Well, all that matters to me, because I really believe that the machine, I have is essential to me. I know. It can actually help people.* (Paula)

> *Oh, I don't know, I just think it's just part of my life and if I don't use it then, I'm the one that's gonna suffer from it, and I like to be around for my kids too. My grandkids. Live a bit longer anyway and enjoy them. You need to enjoy them when they're younger cause when they grow up, they don't want to see their grandfather.* (Mark)

One participant described how when she talks to other whānau who have OSA, she tries to motivate them by thinking about the future of her mokopuna (grandchildren).

> *Well, you want to see your moko's (grandchild) 21st? You're not going to do that if the sleep apnoea thing is not working for you to motivate them and stuff. Some of them do it for a little while and then they get hoha (annoyed).* (Miriam)

CPAP adherence and general use

Participants discussed what motivated them to use the CPAP, but it was also apparent that there were varied reasons as to non-adherence as well. Previous studies have found that many patients experience issues with CPAP adherence due to multiple reasons (Campbell et al., 2012) such as discomfort when wearing the nasal or face mask, mask leakage, noise of the machine, dry mouth and nasal symptoms (Gibson et al., 2018; Scott et al., 2007). Throughout this study, many of the participants described similar issues with wearing the mask and not knowing how to operate the CPAP machine. Paula recounted the issues with wearing the mask, the positioning of the straps, being unsure how to operate the machine and not wanting to go other places to stay because she was embarrassed about people seeing her wear the mask.

> *It was horrible for a long time, a long-time… the air kept blowing out. Far out … I was just wearing it on your face… It was horrible… It took quite a few years to actually learn about the machine… Even today I don't quite understand the heat on it. The numbers on it. Yeah, it does confuse me… Yeah, and it's been this long time…. like my nephew and this lady, are the only ones that I know they don't like it over their face…. From the mask. From the strap… Um, sometimes when it gets too tight, yeah that's a real pain.* (Paula)

Anthea described how the noise of the machine would wake her up. She said the machine would ‘knock’ and ‘vibrate’. She also experienced issues with wearing the mask, but gradually adapted to it. Despite experiencing these issues, she wasn’t deterred from using the CPAP machine. She stated that she wouldn’t leave home without it and makes sure to take good care of it.

> *When you come back to reality it's like how the heck [do] you sleep with these hooked up?... The noise of the thing of the machine, the vibration used to put me to sleep. But then I used to wake up. And then it [was] like a bit of a shock to find you got a machine on your*

> *face… I've adapted now. And um I think about two years ago, I couldn't go anywhere without it. I had sort of got into a routine… But no, it's for me that I set up my machine. But I always look after it properly. But yeah, I set it up, making sure that there's water in it, and handy to a plug – now and again in the bedroom I move the bed around and realise oh hell I need an extension I've gone too far away from the cord. So, things like that now I just leave the bed in one place. Those are the things that I have to look at. I find I need the machine and I must have the machine. But lately, because I know they say don't rely on your machine if you can get off it… I realise I've fallen asleep for up to like four hours without the machine. Going oh I didn't even have it on, and I had a deep sleep. So, there are times where I can fall asleep, without thinking about plugging it in. Yeah. I find it a good thing.* (Anthea)

Miriam described being 'hooked on' her CPAP. Despite experiencing issues with the device leaking, she is still determined to wear it and finds it hard to fall asleep if she doesn't wear it.

> *It lasted for a long time but then something happened. And I think I had a leak in the machine, so I get it tested quite regularly. I know the guy in Whangarei… I have a full mask. Because I said I wasn't sure sometimes to breathe through my mouth and sometimes to breathe through my nose. But yeah, my machine. And I look after it diligently… I'm hooked on it now. If I don't have it on, I panic… And*

> *because when I put it on…I can't feel anything, but it actually, it's making a difference because when I pull it off. It's just 'whoof'. They said how can you sleep with all of that air going like that and I said I don't even feel it. But if I don't have it on, I can't sleep. To this day I don't think I can sleep without it because I'm so dependent on it. But the [sleep specialist name] says to me that you must be the only one in the whole of New Zealand that's used it since day one. You know I use it diligently every day. I have cousins and they put it on in the garage and leave it on, so the doctor won't know that they're not using it. I said oh that's ridiculous. What's that doing? You're wasting your power, you know, things like that.* (Miriam)

Miriam’s comments were interesting about how other whānau turn on their CPAP at night so the doctor can see the machine is being operated, but they don’t wear the mask. The CPAP machines have an ability to report usage and event data back to the individual’s local sleep service. Built-in connectivity options allow for both clinicians and patients to monitor progress and if there are any significant changes in their condition, then they are quickly picked up by the sleep service. The data can either be collected through a built-in smart card, and downloaded when they next visit the sleep service, or live monitoring through WIFI capability to a secure Positive Airway Pressure website (Shapiro & Shapiro, 2010; Swieca et al., 2017). Patients turning on their CPAP at night but not wearing the mask demonstrates how the individual is concerned about getting in trouble with their doctor if caught not adhering to the treatment and possibly being subject to victim blaming.

Anthea talked about some of the barriers her brother Anthony experienced while using his CPAP prior to and after his above-shoulder amputation. At first it was easy to put the mask on with two arms, but this became a challenge post-amputation.

> *And because the straps you know, you tighten them to fit your head. And make sure the mask is in place. So that was fine with him, but because he had such a big head, [the] bands use to stretch, and they didn't always go back so he was getting a new [one]. Where you put the head piece on, and the strap will just ah... automatic[ally] attach… Because he had no coordination you know when you've got one arm you're not quite all there, you forget where all the pieces are, and you're playing around here and there, so they got a magnetic one and it worked good for him. But during the COVID they sent one of those other ones you know because of the no communication and touching. So, he's back to the band, but I haven't taken him in for us to get those done up again.* (Anthea)

> *When I had two arms, it was good. Now I have one arm, can't put it over my head. It’s hard.* (Anthony)

> *It's easier now you've got the magnetic. No, you still struggle. When he puts it over his head it keeps flipping back and forth. So, he's got to keep doing it a couple of times to push it right at the back for it to hold… The back of his head holds it in place and then*

> *he can use his hand to pull down the nozzle part. And I've seen him struggling. As long as nobody adjusts the straps, he can just slide it over his head… There were times when he goes to bed with the machine on and the nozzles come off. And I go in the room because now and then I check on him. And it's come off to the side and he's still fast asleep dead to the world. A couple of times I've woken you up, aye. Straighten your machine or your mask, or as I just leave him because to wake him up in a deep sleep might be not a good idea.* (Anthea)

Again, this situation can be related to the Health Belief Model which suggests that patients' readiness to act is based on how susceptible they are to the consequences of the illness if not treated, known as risk perception, compared to their perception of how serious the illness can get on their current functioning. The patients' perception that a course of action is advantageous or not is based on having weighed benefits gained from the action against the costs of inaction (Quine et al., 2000) in which the patient must weigh the benefits of the treatment compared to the barriers of using the treatment. It would be easy to understand why Anthony would feel deterred from using CPAP considering the barriers he experiences when using the CPAP from his physical disability.

Maintenance of CPAP

Most participants had experienced issues with getting replacement parts and maintenance done on their CPAP. They also described issues with having to cover costs to purchase consumables, travel to get maintenance done or access a replacement device while their own device was being repaired or serviced.

I had to go into Whangārei…Travel in there and they test that machine out... The only hoha [annoying] *part was the expense, to be honest. The fittings for the machine. They were expensive. Yeah, like the hoses… I can remember the last hose I bought it was about sixty bucks or something… Last year so they gave me a new machine... So, I must have had it 12 years, 11 years. And it was because I woke up one night, I could smell wire burning. And I know it was coming from my mask, but I couldn't tell because I'm a smoker, though I had it for a while and then I thought, nah, something's wrong with this picture. And I rang them up and I said, can you guys just check the machine? The lady just opened the bag up and smelt it and that was it and chucked it straight in the rubbish… Oh yeah, I was buying them and that's an expense – that's big too…That money cost about $80 for that mask... Oh, I'm just grateful for what they give anyway… I guess I can say that if I didn't have the money to make sure, like, if something, like, if I need something, really need it, especially if it's got to do with that, I'll make sure I get it… But if I didn't have that option, yeah, that would be a problem.* (Paula)

There was a time when I had to pay for, when I first got it on, I had to pay for, the strap was loosened too much. You have to go buy it or if you drop your machine and break it, you have to replace it. And yeah, it was expensive. I mean, a loan was about $90, and if *he broke it one night you know, you need it the next night. Sometimes I was caught out – you know – not enough money. Or no money – let's put it that way, because of the cost. And then, I used to jump on his machine just to compensate you know… I would jump on his. Or he'll have his at night and during the day I would get on his and sleep it off. Just, just to put me right. Cost was an issue. Going to get it. Going to the check-ups and the machines. You with your bags up in the hospital. Now we go up to Whangārei and we used to go to Auckland, that's because they never had a sleep place here. Yeah, but um, we had to pay our way back then. Didn't know about the travel service that the hospital offers. How often? Every 3 months? You get the new straps. They wanted us to pay for it. I said not his fault you know. It's just wear and tear. It made it a bit harder on him.* (Anthea)

Well, I can't afford it, but I will because I think it's beneficial for me... For a lot of patients, that's not their priority, and because it's mainly men, they're not going to do that, they rather give it for their kids to put food on the table and all those sorts of things… Especially for up here. And you know when they go to get them checked, they have to take them to the hospital. They go on the hospital truck to Whangārei, but they don't give them a spare... Yeah. That was one of the things I complained about. I did that one time, and I actually went to Whangārei to get it. Because I said I couldn't sleep for two days. And so, I tracked it to see where it was.

> *But like you say, because I knew the system, I could do that... I was going spare because I couldn't go two days without it. I thought I could see it in two days. But I was really, really tired, so I hunt for it after that… I know my patients they put it on the truck and it goes away for a weekend, and it's sitting there, and I pick it up and take it down to them because they forget about it.* (Miriam)

Having to decide between money for food and money to replace their medical equipment was difficult for participants. Their experiences also highlighted the issues of those living in rural communities for whom the main hospital is some distance away, meaning it takes longer to get repairs or loan equipment. Bakker et al. (2014) reported similar findings, with Māori participants stating that despite their CPAP being government funded, financial barriers existed with long-term treatment due to having to replace a device if broken or stolen. When situating the financial cost of replacing broken equipment in a social context, it is more likely for Māori to shoulder a greater burden compared to non-Māori. We know that Māori have lower education attainment and work in lower skilled employment, such as shift work, which is linked with OSA. We also know that Māori earn less income than other New Zealanders, thus reducing their ability to buy nutritious food, live in warm and dry houses and access health care. Informed by the context of the socio-historical experiences of Māori in Aotearoa and social determinants of health (see Chapter 2), we can start to understand that these inequities are a result of differential access to society’s goods, services and opportunities. Even when Māori do have access to CPAP, adherence rates are lower compared to non-Māori (Bakker et al., 2011).

Anthea described Anthony’s issues with the machine, which included the machine not turning off and issues with the length of the cord from the device to the power plug.

> *He is always having a problem with his, something down – it doesn't shutdown when you take it off. You're supposed to take the mask off, and the machine will stop. But his won't stop, it keeps going, you've got to go to the wall and turn the plug off. So, we've had quite a few problems with that. And they had to make the cord a bit longer for [Anthony name]. Longer than mine anyway. But not about the hose part, it’s the extension part, the cord. It can go from that end of the room to out there.* (Anthea)

Paula described how expensive it was to buy filters, so she improvised by soaking the filters in bleach.

> *So there really are, I can't understand why they would even, like for something that's going to save a life why they would, the expense on it would be so hard because the filters, these little wee filters the size of my thumb…They’re $11 just for one. And I'm going holy heck... Yeah. And then later down the track, I realised that the filters were getting dirty or too dirty, and I was oh my gosh, is that what I'm soaking in during it? And that encouraged me a lot to wear it, because I thought oh even if I'm not sick, I'm going to still wear this. Yeah, yeah. I thought what’s in the air – holy*

> *heck...Yeah. Well look, the filters and that was a struggle. So, oh it's not a struggle, it's just it's annoying that it's that much. And I try and improvise so even they go black. I'm still sitting there trying to soak them in Janola so I can reuse them again... I said I'm trying to look for things that look similar to – that I can use for a filter… Yeah. When I haven't been able because we're gonna go all the way to Whangārei to pick the stuff up. So, try anything basically... They are ridiculous. I can't get over the price… I do that to this day, I still try. Yeah. It's not because I don't have the money. I think it's just a ridiculous cost for something. Is it really needed?... I haven't bought them for. Oh gosh, when was the last time? Sometime this year I've been… Probably twice or so a year twice. But I get, I get a few even if there's a little filter in the middle and there's a hole, I try and make do with it, the air out the edges. Just fill in the holes… Maybe I should take the one of my filters and show them – this is what you suck in every night.* (Paula)

Numerous educational materials on CPAP machine-related websites warn against the dangers of using bleach to clean any parts of the CPAP (American Thoracic Society, n.d.; CleanCPAP, 2020; Pritchard, 2022). One website noted that cleaning your CPAP with bleach, chlorine, alcohol-based solutions, scented oils, or moisturising soaps could lead to the degrading of CPAP equipment and, thus, cause discomfort for the patient during use. The financial barriers described by Paula are firmly located within a social determinants landscape and the colonial impacts on Māori socio-economic status within contemporary society. These continue to be play out in relation to both health inequities, and the tactics Māori use to maintain their health within unhealthy environments/situations. Paula’s response to controlling the (filter) situation is like the tactics that homeless people employ to control their adverse living conditions in the streets. Tactics are used by homeless people to transform unhealthy public places into more health-enhancing settings. This demonstrates that people living in deprivation are able to develop strategies to survive and look after themselves, despite public perception that they don’t look after themselves (Stolte & Hodgetts, 2015).

Miriam, who works as a nurse, described her observations of patients she knew who had OSA and experienced issues with maintaining their CPAP. Again, the issue of cost being a barrier was raised.

> *And then some of my patients – oh, one of the other biggest things besides getting them to use it when they do use it, if it breaks down. Do you know how costly those things are? So, they won't buy another one. They can't afford it. Most of my patients can't afford it. And you see them they've taped it up. They've done this. You know they've tried to repair it. I said you know you can have it replaced once a year. The whole unit in its entirety, you know, because I do. I wait until then, and I ask for a new one. He just gives it to me, doesn't ask to look at it, thank God. They're piling them up and I said just in case it breaks you know. And I said you can do that. I said ask them. They're tell you how to do it without costing you anything. You know, like for the strapping and things.*

> *It's like $96. It's like, what the hell… And I tell them about the transport that they said they have to go to Whangārei to get their bits and I said no you don't. You just ring up because there's a chemist in Whangārei that has all of this stuff, and they're happy for you know to set up an account where they send it to you, and you pay them. You got to pay for it before you get it. But I mean, I was doing it and I said it was costing me 1000s, not 1000s, 500 or so, and you know I wasn't even going, and I said, well just take it out of my account. And then when I totalled it up, I've spent over $500. Nah – there's got to be a better way. So yeah, I worked it out. But you see, I would go looking for that.* (Miriam)

However, there were also accounts of support within the health care system towards maintenance of the CPAP equipment. Anthea talked about the support she got with her CPAP, which was making unusual noises, after being admitted to Whangārei hospital. The sleep service staff were very responsive and came to look at it while she was there and provided replacement equipment. There was no mention of any cost being incurred.

> *But a couple of times I've landed in hospital, and my machines played up. So, I just said, Oh I need my machine. Oh, we'll call them to come into the ward and check your machine out. So, a couple of times they've come into the ward and done my machine. You know just make sure it's all good. I said it's getting noisy. This doesn't sound like a car [laughter]. Normally it's a humming noise*

> *but one time up at the hospital mine was sounding like it you start up the car [laughter]. They replace a lot of our stuff you know. I think your bands are getting worn out. And yeah, they replace them… Well, now when I see that humming noise, that was fine, they just replaced the box.* (Anthea)

It is not known why Anthea received such a fast response from the sleep service staff while she was on the ward in hospital. This could be related to the sleep service staff being situated locally and having an existing relationship with her. Again, this supports the argument that established relationships between patient and clinician do lead to favourable outcomes. If services were to be more centralised, and moved away from Whangārei, then patients may not receive this personalised service.

Despite Mark living over 80 kilometres away from his nearest sleep service, Mark reported a more positive experience and stated he was given replacement parts free of charge.

> *Initially I was seeing them every, oh monthly, now it's three-monthly emails and now its six monthly. And they usually give me parts, you know, just replace the facemask last year. No, they're pretty good.* (Mark)

Attending sleep service appointments

Some participants talked about the fatigue of engaging with the health care system after their diagnosis. This fatigue was often centred around the frequency of follow-up appointments with their sleep service/clinic and how they were asked the same questions year after year. Sometimes the Auckland specialist travelled to Whangārei, which was closer to where the participants lived.

> *Once a year. I actually have one next week with them… They just asked me the same old question. Gosh, it's been such a long time. I can't even picture in my head. It's about really how long can I sit in the car without falling asleep or reading a book. Stuff like that um. Yeah.* (Paula)

> *They had a specialist [who] would come to Whangārei and all the Whangārei patients were booked on to him. He had three or four days here in Whangārei and then disappeared for months and then come back. Yeah, so we were booked in with him while he was doing patients in Auckland and here… Yeah. He was awesome. The people we've got up here were very um – how can I put it? Homely. They were, you know, sociable. They were better than Auckland… Yeah, they were down to earth up here… Yeah, they had, they give you their time up here and have a laugh with you. But Auckland you could never… Well for me, there have been some Māori ones and they do, you know, they build a bond, I think.* (Anthea)

> *Nicer up here than down in Auckland – more personable.* (Anthony)

As sleep services evolved in Tai Tokerau, specialist doctors were based at Whangārei hospital allowing patients to deal with local clinicians. Anthea and Anthony both described having a good experience with the doctors that were based locally in Whangārei compared to the Auckland doctors. Several studies have demonstrated that when patients experience a good relationship with their doctor or nurse, then this leads to better outcomes (Hall et al., 1988; Ong et al., 1995; Stewart, 1995). The link between patient-clinician relationship and patient adherence to treatment is supported by a wealth of literature, in fact a meta-analysis of 127 studies supported the prediction that patient adherence is significantly influenced by the communication of clinicians (Zolnierek & Dimatteo, 2009).

Furthermore, from a cultural appropriateness lens, for Māori, whanaungatanga (relationships) are highly valued; therefore, whakawhanaungatanga is important. The benefit of whakawhanaungatanga is that it allows for more open space in which sensitive discussions can take place (Bishop, 2011). Therefore, it is important that clinicians take time to build whanaungatanga with patients to help improve outcomes.

Engagement with and impact on whānau

All the participants described the impact of using CPAP on their whānau, and at times the negative impacts it had on relationships. Some were embarrassed for their whānau to see them wearing the CPAP mask, others didn’t mind having their mokopuna learn about the device and why they had to wear it.

Paula commented that she doesn’t like her husband or mokopuna seeing her wear the CPAP. As previously mentioned, participants in the Gibson et al. (2018) study expressed similar concerns about the embarassment, otherwise known as whakama by Māori, of being seen wearing the CPAP and long-term problems with mask fit. Whakama is an important construct to understand when observing interaction of Māori between each other and in cross-cultural settings (Sachdev, 1990). Whakama is often used in the contemporary Māori setting when referring to the sense of shame, feeling inferior or uneasy in social situations. This is most evident when Māori are expected to operate in a Pākeha context. The most common cause of whakama is when Māori feel disadvantaged compared to their own – Māori, or to Pākeha. Withdrawal from friends and families is a common action when the person feels whakama, so drawing themselves inwards and socially excluding themselves. Sachdev goes on to say that sometimes this behaviour is seen to be psychiatric related but is not quite the case here and withdrawal gives the individual an opportunity to their group, renewed and accepted, leaving the past behind.

> *So, so what happens down home, and I get really annoyed because it doesn't affect my husband, even my grandkids, I don't like them seeing anybody. Oh, she's still asleep, don't want to wake her up. And I get really annoyed with that, because I don't want them to see me with it on. But yeah, that kind of stuff. And so, my grandkids asked me what was wrong with me, and I explain to them that if I didn't use it, I might die. I actually put it on their face so they can see what it's like. And they leave me alone.* (Paula)

Miriam talked about how many of her whānau also had OSA, and she described their experience with using CPAP. Of particular focus was how the men in her whānau didn’t like to be seen wearing it in front of their partners, demonstrating the behaviour of whakama.

> *My cousins, they're all males and they're macho and they're, you know, big booty things, and everyone laughs at them when they put their machine on. I said don't be stupid, I said, aren't you glad that they actually can sleep? I said, look, he’s just getting bigger and bigger. And, you know, it's all – well he's big. My other cousin they've had it. He wasn't big, but he would fall he couldn't lie down and sleep. He would drink and sleep at the table. I said, he's the one that had it on in the garage. I said I'll show you how to use it and things. Put it on at night and he says oh no – Queenie won’t like it if I hop into bed and have this. And I said oh for goodness' sake, you know. But he never ever got around to using it. That's what he did, he'd rather drink drunk, sleep at the table than put that on. And that was a stigma thing you know everybody laughs at me. Everyone knows he sleeps at the table. But I said you know, just if you tried it, when she goes away you know like I said tell her to go away for a thing, or you go somewhere for by yourself, and try it, come, and stay with me for a couple of days and then you know, I'll show you how to use it. And then we can both go to sleep with the machines on, you know. But he was always too busy, you know, things like that. Men are just… you have to drag them, aye…*

> *Yeah, my brother and his, his partner says that she loves it more than she loves him. Because it's so quiet because he's not snoring. He always packs it with them when they go somewhere, but she's not sleeping with him when he hasn't got his machine on. She's so funny and she said 'oh, I'm in love with that machine'. She said it's so quiet.* (Miriam)

Anthea said that one of her whānau called her an 'alien' when she wore the facemask.

> *My nephew used to go "Oh, you look like an alien"… Space invader… Yeah, and you go [sound effects of space invader] and you know they pull jokes all the bloody… Oh, it's alright – you can handle your own giving it to you but it's when he's telling all those other people… And like – I think it's in the kitchen Kobi. My moko's they get freaked out when they come in – especially the little ones. And like the ones now are alright but one of my moko's from Auckland comes back and she use to look at me like this. And then I think "oh, it's the bloody mask". So yeah, I've found it was quite scary. But she now, she's just adjusted. She just goes over there and plays with it. It's tutu (annoying). And I say, "now you fellas can't play with nana's things". And they go [*breathing in and out loudly pretending to be wearing the mask]. *It gives them something – they don't realise what it is. So, it's a bit of a learning.* (Anthea)

Conversely, one participant talked about how the CPAP mask was constructed as an object of fun. Black humour is a common behaviour used by patients when faced with serious illness and it is deemed as a coping mechanism. One study which focused on the social support of women diagnosed with breast cancer, found that black humour was frequently used to help alleviate the seriousness of the illness crisis (Lugton, 1997)

> *All the kids and the mokos in the house and around, you know, were saying they call it my Darth Vader mask. “Oh, Aunty you've got a Darth Vader mask.” They call me Aunty. They come in the room, and they all pull on it and playing with it while I'm sleeping.* (Miriam)

While Miriam was able to use black humour about her condition, Anthea described the difficulties she experienced managing her own declining health while being the main caregiver for her younger brother who had an above-shoulder amputation post-cancer. While this was not specific to CPAP, it was important to capture the important role that Anthea plays in providing care for her brother Anthony because she spoke of it frequently during this study, both in general and specifically in relation to him using CPAP.

> *My medical history is not – well over the last. Ever since I finished smoking, I just accumulated all these illnesses. And I would of finished smoking about 15 years ago now. And ever since then I've been going sick and getting sicker and getting ill and getting all sorts of illnesses. So, I've got everything from*

> *heart problems to diabetes. Yeah, not breathing correctly – asthma. I even caught asthma in my late 50s. And I had never had asthma in my whole life and you're telling me I've got asthma now? I've got arthritis I suppose that comes with age. I have a nanny nap now – it's getting to be a daily ritual and I'm going, oh my gosh… And I'm the caregiver for Anthony too – that's another thing I have to look at the moment. As you can see, he's amputee. He had cancer. Three, four years ago… It was a cyst that started off like a boil, a hard boil under the skin. And for about six months he kept saying my arm is sore and I can't lift it I can't leave it. And, and the doctor said it's alright, take some painkillers, it's only a cyst. But then, eventually they gave us the big news it's gone cancerous. And it's starting to spread because he couldn't move his arm for a few months. Yeah. But it took us a while. We gave up on the doctor we actually went to a specialist, and it was through that they moved us along the line and see it's like a cancer. So, we went to the Cancer Society and yep.* (Anthea)

As a carer for her brother, Anthea can be referred to as an informal caregiver, which is a valued role for Māori. It is a role that helps maintain relationships and integrity. From a te ao Māori perspective, whānau is the core unit from which caregiving comes (Collins & Wilson, 2008). Whānau members are the most common caregivers for care recipients from within the same household due to the close relationships they hold. Most roles of a caregiver are similar for Māori and non-Māori; however, some are more unique to Māori. This is due to the differing definitions of whānau as well as values and qualities Māori have. When non-Māori are asked what whānau means, they define this as ‘extended family’. However, for Māori, who pre-colonial times organised themselves around whānau, hapū and iwi kinship groups, whānau goes beyond the definition of ‘nuclear’ and ‘extended family’.

Tukukino (1984) describes the Māori concept of whānau as represented by three components: tipuna (ancestors), whanui (tribal families) and whānau te rito (closer family). These components are closely connected and allow for balance, identity, and cohesiveness. Tipuna acknowledges our ancestors and whānau who have passed on, so carries a spiritual and emotional element to whānau wellbeing. Our ancestors are what define our identity; therefore, knowledge of our whakapapa is important for whānau. The concept of whanui relates to tribal families and most Māori acknowledge their iwi when linking ties. Whanui allows us to develop personal connections with wider groups of people, and again whakapapa plays an important role here. Lastly, whānau te rito refers to the closer family, such as parents, brothers, sisters, cousins, aunties, uncles, and grandparents. This component of whānau provides immediate physical and emotional support. The role and responsibilities of information caregiving can be seen to be similar to those practised as whanaungatanga for Māori, which encapsulates aroha and tiaki (care for/look after) (Ashwell et al., 2004). In her caregiving role, Anthea can be seen as whānau te rito exercising aroha or tiaki for her brother, but it could just as easily have been a cousin, auntie or uncle who took on the role as caregiver.

Educating others on benefits of CPAP

The close relationships within whānau te rito also played out in opportunities to educate others who were also experiencing OSA about the benefits of using their CPAP. Paula noted:

> *So, I've got a nephew, he's 34-35 years – he's quite big. And he told me he had a machine. I told him because he always looked tired. So, I asked him, and he told me the machine and I said to him, why aren't you using it? And he said, oh, because I don't like the feel of it when I'm asleep. And there's a lady that I work with, she's a social worker that visits me every week. She's in her 60s, early 60s. She said the same thing. I said are you stupid? But you know how important this is. Because I knew when I got them, try that machine at the change that was happening for me. Like, they were right. I was getting up quite a lot, maybe four or five times a night in the night-time to go to the toilet. Like the moment I had that machine. The thing on my face, I had more energy. I can remember that really? Yeah.* (Paula)

Likewise, Miriam said:

> *It was really good because I was able to explain it why they should have that and how they should have it and make sure it fits and all the rest of it… I have another cousin who has one of the things that saved him he was supposed to die like six years ago, and we were always talking… he says, oh you know after you told me*

> *about the thing… because it might help me, and it's helped him. He's still alive today and he diligently uses this mask. Same as if I didn't have it, I would have probably died… I think that it's only just raising the awareness. I said give us the machines the different types of machines so that we can go out, when we do our, you know like, promotion on something we could do that, have the machines then show them and they can have a tutu with them, just to see what it's like. Like I said, you want to look at my Darth Vader machine because I do that with our whānau, and I show them, and the kids know more about it than the bloody adults.* (Miriam)

Miriam was very proactive with sharing her knowledge and experience of using CPAP with friends and whānau. While wearing CPAP at home seemed relatively easy, challenges presented when participants wanted to travel and sleep overnight elsewhere.

Use of CPAP away from home

Use of CPAP away from home was challenging for most participants. Three participants commented about using their CPAP away from home. They had experiences of using it at a marae and described how they felt about others at the marae seeing them use it as well as observing others using their CPAP. One participant said she would never use it at a marae and preferred to sleep in her car instead. Using CPAP limited their ability to stay away from home.

> *It's my excuse, so now I don't have to go and stay at anybody's place. Nah, I don't [want] anybody to see me wear that and I'll just say – tell them that…. Can't imagine them even wearing one in a*

marae…I would never… I've actually gone and slept in my car without the machine, like when we're at the marae. (Paula)

And I couldn't sleep at maraes, tangis or go to my sibling's place without taking the machine. And I was too embarrassed to take the machine to the marae, but I'd seen some kaumatuas go there and their biggest problem was finding a plug because everybody's got their phones plugged in. And you know I said I'm not going to go sleep at the marae anymore. But even going back dad's house, he had no power. So that was out of the question. My brother was – so I used to do daily visits or just a one nighter come back to town, because I did struggle with the machine, not having it available for me. Now I travel with it. Specially now I'm going away for a week or so like visit my kids up in Auckland or go out for the day. Or visit anybody on that day. And so, I just pack up the bag and take my goodies and night-time I'm up to here… And when I go to other people's houses, and I look for the power point – I said, "Where's your power point?" Behind the bed. I'm not sleeping in there now I'm going into the sitting room. So, it's finding a power point to be handy to me. It used to be embarrassing, but I'm over that… But our two kaumatua come on the marae and they go well I'm going to sleep with it if I have to sleep here. And no sweat, he just plugged it in. And he was quite happy to just knock out you know and here's me going, 'My God' and here was me getting embarrassed to take it to the marae. Even the bag it comes with,

> *you know you get to recognise the bag and you fellas on the sleep pap. And I never realised, you know I never realised that all the bags were the same. I thought oh mine just looks like a makeup bag. And I'll pass it over and then I realised hell everybody on the machine knows I've got a machine… So, it was a bit of an embarrassment back then and but now I've got no problem of, especially between my whānau, I can go between them carrying my machine. Why do you have every time you get in the car, and you have to take this? Because I need to have a good sleep tonight, not terrible night with you, er. When it comes to Māori stuff like you're either gonna stay away from home for a tangi or celebration of some sort, wedding, birthday. So, it's overnighter. Māoris don't just go and come home, go and come home – they stay with the whānau.* (Anthea)

> *Yeah, I have. Up at the marae…Pretty good. Yeah, but sometimes it keeps you away from the marae… Nah, I don't even worry about it. I'll just say I don't care. That's your problem.* (Mark)

Anthea described how challenging it was for her brother, Anthony, to go away overnight.

> *I know for him it's not easy to go somewhere else or overnight stays and stuff, like he has his course, he goes camping and stuff – he goes without the machine.* (Anthea)

> *So, if there's no power, it's a barrier to use because you can't take your machine.* (Anthony)

> *Some camping grounds, you know like now, for the disabled they go to camping grounds, and they have power points available for them.* (Anthea)

> *Sometimes I'm too shy to put it out. Too embarrassed, too shy. Yeah. When I'm home, I'm out.* (Anthony)

Miriam described how she observed people at the marae snoring and thinking they most likely have sleep apnoea and don't know it, or they may have a machine somewhere and aren't wearing it.

> *And I've seen some people nodding off and up in the marae. Big people and I'll hear them snoring and, in my head, is going 'This guy has sleep apnoea.' He's got a machine somewhere. And he could probably do it right now… They don't know. I'd say they don't know.* (Paula)

The stigma of patients being self-conscious and reluctant to wear CPAP was a common phenomenon reported by participants in this study. Wearing a visually unattractive CPAP mask makes OSA a visible condition or disability (Zarhin, 2018). This shifts OSA from a discreditable stigmatised medical condition that could be hidden into a discredited one that becomes more obvious (Goffman, 1963). In a study where in-depth interviews with OSA patients were carried out, Zarhin (2018) found participants were driven by their desire to maintain an ideal body image, and all were deeply worried about how CPAP makes them look unappealing. Some of the participants described feeling like a ‘monster’, or only wore it in the dark to avoid people seeing them. In the context of ableism, wearing CPAP means being seen by others as disabled, and being disabled is perceived as negative. Therefore, there is a need to destigmatise disability.

Similarly to earlier comments on whakama, the avoidance of engaging with whānau and friends, or staying on a marae could be viewed as impacts on cultural identity (cf., Durie, 1999). When westernised medical equipment negatively impacts indigenous peoples from practising cultural traditions, this can be seen as a continuation of broader processes of colonisation that works to deculturalise and further assimilate Māori into settler society. If CPAP users choose not to engage with tikanga Māori due to the embarrassment associated with the use of CPAP machines, then this can have an impact on CPAP adherence rates.

Overall, participants shared the benefits they received from using CPAP, which included increased energy levels leading to greater productivity during the day. Experiences about adherence were also shared on the general use of the device, with many participants describing issues with face mask seal or leaks, straps being uncomfortable and general issues with operating the machine. Disabilities were also highlighted as a barrier to using the CPAP which has a relatively complex setup.

Concerns about digital surveillance and turning on the CPAP but not wearing the mask was also noted as mode of non-adherence.

The phenomenon of treatment burden came through strongly: with participants describing financial burden; problems with equipment; impact on whānau; and experiences of attending healthcare appointments. Costs associated with replacing equipment and being rurally located were a significant burden for participants. The importance of the patient-clinician relationship was noted, and it was clear that having a doctor who was local to the area proved to be a good experience in the provision of healthcare. Lastly, many participants identified challenges with using their CPAP away from home, and the impacts on social participation and ability to engage with important cultural practices.

Chapter Seven: Conclusion and Discussion

Conclusion

Understanding the journey from pre-diagnosis through to post-diagnosis of OSA and CPAP therapy is an important step for informing sleep services across Aotearoa. The aim of this study was to develop a deeper understanding of the experiences of Māori, including enablers and barriers, who are diagnosed with OSA and use CPAP. The key findings found in the '*before diagnosis'* phase were centred around early signs of OSA and whānau observation and experience. '*During diagnosis,'* participants centred their experience on how they were referred to a sleep specialist and the overnight sleep study. The final chapter was focused on participants experiences '*post-diagnosis.'* This was the larger chapter with participants finding it easier to describe how they live life once diagnosed and return home with their CPAP device. They shared experiences on benefits from treatment, adherence to treatment, maintaining their equipment, attending health appointments, through to engaging with and the impact on whānau, and sleeping away from home.

International research has found that OSA is common in adults, affecting 2% of females and 4% of males (Bearpark et al., 1993; Partinen & Hublin, 2005; Young et al., 2002). OSA is the most common sleep breathing disorder diagnosed in New Zealand and overseas (Gander, 2003). In New Zealand, as in other countries, OSA is underdiagnosed; therefore, these rates could be much higher (Epton et al., 2017). Typical symptoms present in the form of loud snoring and long breathing pauses which leads to patients waking feeling very sleepy, experiencing morning headaches and still being tired due to the poor quality of sleep they experienced.

Long-term sleep deprivation has been associated with increased risk of morality due to the development of cardiovascular disease, obesity, diabetes, and cancer, which in turn increases the societal burden (Luyster et al., 2012). Global studies have shown that the total economic burden of sleep disorders is significant. In 2004, the economic cost of OSA in Australia was $US7.5 billion (Streatfeild et al., 2021). In the United States during 2000, OSA was linked with more than 800,000 motor vehicle accidents, leading to a total cost of more than $15.9 billion while claiming 14,000 lives (Sassani et al., 2004). A New Zealand study estimated that the total annual societal cost of OSA was at $40 million, or $419 per case, with accidents being the main contributor (Gander et al., 2010).

Continuous positive airway pressure is a gold standard treatment for OSA, and when used regularly, it has shown to provide benefits of improved quality of sleep and daytime functioning (Bakker et al., 2014). However, irregular use of CPAP to treat OSA is a barrier to effective treatment (Brown et al., 2021) and many patients find using CPAP difficult for several reasons: machine noise, mask leakage, mask discomfort, and dry mouth and nasal passages (Bakker et al., 2014; Gibson et al., 2018; Kalan et al., 1999).

Findings of the current study supported previous research which suggests inequities exist in Aotearoa between Māori and non-Māori across health status, morbidity rates and self-reporting of sleep problems (Robson & Harris, 2007). This flows on to negative health effects from sleep problems in terms of motor vehicle accidents and general quality of life (Bakker et al., 2011). Being obese is one of the strongest risk factors for OSA, and Māori are more likely to be overweight compared to non-Māori. Obesity is a common risk factor for OSA, not only because it is a predecessor for medical conditions such as cardiovascular diseases, but also because it causes anatomical changes in the airway causing increased narrowing or obstruction (Levy & Waitoki, 2015). The WHO estimate that obesity has tripled since 1975, with 1.9 billion adults being overweight and 650 million obese (World Health Organisation, 2021). Body mass index (BMI) is the index of weight-for-height to commonly determine if someone is overweight or obese. A BMI of 25-29.9 indicates that one is overweight, while 30 and above is deemed as obese; however, there have been criticisms about the BMI calculation, as Humphreys (2010) notes. For example, it does not consider the presence of lean muscle (common among many athletes), which weighs heavier than fat. High BMI does not always indicate obesity, and clinicians are strongly encouraged to take other factors into consideration, in particular neck circumference for OSA patients.

Neck size is a risk factor that has been shown to be more closely associated with OSA than BMI (Baldwin et al., 1998; Bassiri & Guilleminault, 2000). Increasing neck circumference is an independent predictor for observed apnoea. From a New Zealand context, Mihaere et al. (2009) found that Māori present with higher prevalence rates of OSA symptoms and tend to have larger mean neck size than non-Māori, and neck size is an indicator of central obesity, which is correlated with OSA.

In a way, the situation is a vicious cycle in which individuals become obese due to social, economic, and environmental factors. This leads to the development of other diseases and illness, including OSA, resulting in sleep deprivation, low energy levels and reduced exercise, which further worsens their obesity and quality of life. This vicious cycle is one in which Māori are disproportionately represented compared to non-Māori (Reid & Robson, 2006). From a psychological perspective, obesity is associated with feelings of whakamā (embarassment), social embarassment or being seen as a fault of the individual in that they are lazy or stupid (Russell & Carryer, 2013). Other examples of obesity stigma include verbal insults, negative body language and inappropriate comments from physicians (Doolan-Noble et al., 2019; Russell & Carryer, 2013).

When considering the context of the socio-historical experiences of Māori in Aotearoa and social determinants of health, we can start to understand that these inequities are a result of differential access to goods, services, and opportunities of society, and why Māori have higher rates of OSA. When we take a broader look at the context of Māori health status, it is important that we consider the socio-historical background of Māori which has led us to this point in time. Colonisation of Māori in Aotearoa has had profound negative effects on their indigenous culture and overall wellbeing. (Durie, 2003; Kauanui, 2008; Laenui, 2000; Marrone, 2007; Moreton-Robinson, 2016; Petersen et al., 2010; Simpson, 2014; Simpson & Smith, 2014; Tobias et al., 2009). Life changed quickly for Māori as new diseases were introduced, and other effects of colonisation started to show including oppression, loss of land and culture and direct harm from killings and kidnapping (Cook, 1770; Monkhouse, 1769; Salmond, 1991).

Māori were assimilated into western culture, which had a long-lasting impact on this indigenous population (Fernandez, 2015). For many Māori, this meant a loss of cultural identity and deculturation, both of which have been widely associated with poor health for Māori (Durie, 2001; Marie et al., 2008). As a result of Māori slowly losing their tribal lands, many migrated to urban centres to explore other employment and living arrangements. The 1950s saw many Māori migrate from their small well-connected communities to major urban centres to seek employment opportunities and also explore the other opportunities these urban settings provided (Poata-Smith, 1997; Walker, 1990). The move was of benefit for Māori while employment was in abundance; however, it led to disconnection from te ao Māori and reduced mātauranga Māori within family units. Some Māori attempted to uphold their connections to whānau, marae, iwi and hapū back home in the smaller settlements, but this has proven to be difficult with many losing their cultural identities.

Urbanisation of Māori from small rural communities has been linked to disruption of social and cultural settings (Kingi et al, 2017), which enables us to understand why some Māori living in cities have no knowledge of their whakapapa or tikanga Māori. When reviewing the existing sleep services in Aotearoa, studies recognised a lack of national oversight which has led to local variation having negative impacts on some of the poorer areas in Aotearoa. This results in less access to specialist respiratory staff and extensive waiting lists. In 2019 it was found that only six of the 18 DHBs had dedicated specialist teams, and this had a major impact on patient outcomes (Meyer et al., 2022). It is with hope that the current health reforms which have seen a Māori Health Authority – Te Aka Whai Ora, established alongside Health NZ – Te Whatu Ora, will help address some of these issues through developing a stronger locally led and centrally enabled health system; one that is designed by whānau, iwi, hapū and hapori.

All participants were Māori and shared their experiences within the broader context of their lives. Health was just one part of their world, and it was important for them to share their experiences within their whānau and whakapapa context because this is how Māori view the world – interconnected and interdependent of all living things. What is clear is that OSA for Māori is not simply an individualised health issue, but something that involves the wider whānau unit, All the participants described the impact of using CPAP on their whānau, and at times the negative impacts it had on relationships. Some were embarrassed for their whānau to see them wearing the CPAP mask, others didn’t mind having their mokopuna learn about the device and why they had to wear it. Some participants reflected on why it was important to remember to use their CPAP because it was important for them to be around for their whānau. So whānau was seen as a motivator to look after themselves and use the CPAP regularly. Whānau play an important role in seeking medical help for issues that can affect a member of whānau, and that the supports that come with whānau can sometime become impacted in the process.

What became apparent is that all participants were unaware of their snoring and apnoea events. This led to fragmented sleep and was predominantly witnessed by whānau or friends. This is supported by findings from other studies which found that symptoms are usually recognised by a family member (Gibson et al., 2018; Ho & Brass, 2011). This leaves the question of how many people live alone and do not have whānau to observe them experiencing these symptoms. Furthermore, participants did not link their daytime sleepiness to the fragmented sleep and were not aware of the negative effects this was causing. Several participants described feeling tired, falling asleep and even driving their vehicle off the road down a bank with the grandchildren in it. Excessive sleepiness is one of the main causes of increased motor vehicle crash risk among those who have OSA (George & Smiley, 1999; Young et al., 1997). The flow-on effects of daytime sleepiness can have a significant negative impact on people, such as poor general health, quality of life, concentration and memory (Paine et al., 2007).

Many of the participants described that they were unaware they had OSA. It was estimated that 936 million adults aged between 30-69 years (men and women) have mild to severe OSA and 425 million adults aged between 30-69 years have moderate to severe OSA globally. It is further estimated that approximately 70 – 80% of patients with OSA have not being diagnosed or are not being treated (Altevogt & Colten, 2006). Undiagnosed adults with OSA are high users of healthcare services, and early recognition can reduce morbidity and demand overall for healthcare services (Wittmann & Rodenstein, 2004). Evidence from New Zealand sleep clinics has shown that when Māori patients do access health services, they tend to present with severe OSA (Baldwin et al., 1998; Frith & Cant, 1985). Māori experience more barriers to accessing health services compared to non-Māori (Davis et al., 2006; Ministry of Health, 2018). Health professionals spend less time with Māori and are less likely to properly explain health information to them (Durie, 2019). The patient-clinician relationship was highlighted as important. Two participants described having a good experience with the doctors that were based locally in Whangārei, compared to the Auckland doctors that visit Whangārei. This was viewed as being an enabler for using CPAP. Several studies support that when patients experience a good relationship with their doctor or nurse, then this leads to better outcomes (Hall et al., 1988; Ong et al., 1995; Stewart, 1995). Furthermore, from a cultural appropriateness lens, for Māori, whanaungatanga (relationships) are highly valued; therefore, whakawhanaungatanga (the building of substantial relationships) is important. The benefit of whakawhanaungatanga is that it allows for more open space in which sensitive discussions can take place (Bishop, 2011). Therefore, it is important that clinicians take time to build whanaungatanga with patients to help improve outcomes. Adopting a Kaupapa Māori approach to health care services not only builds positive therapeutic alliances but also opens up ways to move the health narrative from victim blaming and personal weakness to a more social determinant focus on health and wellbeing (Cram, 2019).

From a social determinant perspective, many of the participants described barriers with accessing health services: transport to health services, housing, employment, income, social inclusion, and basic amenities. Some of the participants described barriers of access to sleep services for repairs and replacement parts of their CPAP. Living rurally presented challenges for them in that they couldn’t get their CPAP repaired quickly and were sometimes left without a replacement device while waiting for the repair. Financial issues were also central to adherence to CPAP regimes. Having to decide between money for food or money to replace broken medical equipment was difficult for participants. Lacking the money to pay the necessary replacement equipment, such as filters, meant that at least for one participant, there was exposure to dangerous bleach fumes daily. Participants’ experiences also highlighted the issues of living in rural communities in which the main hospital is some distance away, meaning it takes longer to get repairs or loan equipment. Bakker et al. (2014) reported similar findings, with Māori participants stating that despite their CPAP being government funded, financial barriers existed with long-term treatment due to replacing a device if broken or stolen.

When situating the financial cost of replacing broken equipment in a social context, it is more likely for Māori to experience a greater burden compared to non-Māori. We know that Māori have lower education attainment and tend to work in lower skilled employment, such as shift work, which is linked with OSA (Bakker et al., 2011). We also know that Māori earn less income than other New Zealanders, therefore reducing their ability to buy nutritious food, live in warm and dry houses and access health care. With the context of the socio-historical experiences of Māori in Aotearoa we can start to understand that these inequities are a result of differential access to goods, services, and opportunities of society. Even when Māori do have access to CPAP, adherence rates are lower compared to non-Māori (Bakker et al., 2011).

But how can we address these inequities? To make a difference, we need to revisit deeply rooted historical, cultural, and systemic issues. Inequity is a by-product and embedded in the colonisation process, and the negative impact of colonisation is now being seen in the Māori population. The Māori population has been undermined in all aspects of economics, social determinants, and politics. Initiatives designed to improve hauora for Māori are starting to show; one significant one being the establishment of Te Aka Whai Ora – Māori Health Authority and the Whānau Ora initiative. Greater focus and funding is being provided to Māori health providers, cultural competence training is developing, and the shifting of power back to whānau, iwi and hapū is becoming more common across government agencies (Hobbs et al., 2019). Government departments are being held more accountable to their responsibilities under Te Tiriti o Waitangi, so it is no longer an after-thought during decision-making processes, but more of a priority. Equity focused policies and practices both internationally and nationally are now strongly encouraged.

Additionally, education increases an individual’s understanding of the importance of maintaining health status, and how to navigate the health system. While this puts the onus of the problem on the patient, many participants talked about the value of educating others, especially whānau, about the importance of CPAP. Taking a Māori-led approach to education pathways would be undoubtedly useful.

It may well be that understanding and knowledge about OSA and CPAP needs to be discussed more widely in everyday Māori settings. Some participants talked about the whakama of using CPAP on the marae and as a result excluded themselves from important cultural connections and rituals. One participant said she would never use it at a marae and preferred to sleep in her car instead. The stigma of patients being self-conscious and reluctant to wear CPAP was a common phenomenon reported by participants in this study. Additionally, if the participant chooses not to engage with tikanga Māori due to embarrassment of CPAP, then this can create a cultural/health dilemma for Māori, where cultural needs are put to the side to address one’s immediate health needs privately. Whakama as a cultural concept is often used in a contemporary Māori setting when referring to the sense of shame, feeling inferior or uneasy in social situations (Sachdev, 1990). This is most evident when Māori are expected to operate in accordance with Pākehā social norms, as can be seen with the use of CPAP machines while trying to engage with traditional Māori cultural practices, like tangi. One way in which whakama can manifest is when Māori feel disadvantaged compared to their own, either to Māori or to Pākehā. Withdrawal from friends and families is a common action when the person feels whakama, so drawing themselves inward and socially excluding themselves is a key feature. The broader medical field needs to understand these kinds of cultural dilemmas that Māori have had to deal with for generations so that public health initiatives can provide more positive outcomes for Māori. Previous research also supports the assumption that socio-economic factors, such as cultural background, economic and education affect CPAP adherence (Bakker et al., 2011; Palm et al., 2021). This, along with the broader points discussed in this section, are issues that need to be considered when designing medical treatment for indigenous populations, particularly if such interventions are expected to be successful.

Limitations

It would have been worthwhile to have access to a broader range of participants across different regions in Aotearoa. Being able to understand the experiences of participants with OSA and using CPAP in other regions outside Northland would have provided a broader understanding. It would have been beneficial to interview participants younger than 50 years as they are in a different stage of their life which may involve more social gatherings, studying and focus on careers and younger families. This study focused on the primary participant who had OSA, but it would have been worthwhile to interview their partners and family members about their experiences of living with someone that has OSA and uses CPAP.

Future research

This study has highlighted and demonstrated the lived experiences of Māori who are diagnosed with OSA and using CPAP in an effort that further research in this area would be advantageous in helping to promote awareness about OSA as a commonly undiagnosed medical condition. Alongside research, it is recommended that there is greater coordination between primary, secondary, and tertiary sleep service providers so that Māori no longer slip through the cracks of a public health system that often does not reflect the cultural realities in which their lives are situated. Data collected from this study can be used to enhance educational resources for patients diagnosed with OSA and needing to use CPAP, with a strong equity focus on the Māori population. Lastly, the current treatment approach of using CPAP needs to be reconsidered to meet the needs of indigenous populations, such as Māori, more culturally and socio-economically appropriate ways.

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Appendix A: Massey University ethics approval

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 14 August 2020

Dear Nikki Canter-Burgoyne

Re: Ethics Notification - **NOR 20/21 - Exploring lived experience of Maori diagnosed with Obstructive Sleep Apnoea (OSA) using Continuous Positive Airway Pressure (CPAP).**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Northern Committee** at their meeting held on **Friday, 14 August, 2020**.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 350 5573; 06 350 5575 F 06 355 7973
E humanethics@massey.ac.nz W http://humanethics.massey.ac.nz

Appendix B: Information Sheet

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Exploring lived experience of Māori diagnosed with Obstructive Sleep Apnoea and using Continuous Positive Airway Pressure (CPAP) treatment.

PARTICIPANT INFORMATION SHEET

Ko Maungataniwha te maunga
Ko Tokerau te moana
Ko Aurere to awa
Ko Māmaru te waka
Ko Parapara te marae
Ko Ngati Tara te hapu
Ko Ngāti Kahu te iwi
Ko Nikki Canter-Burgoyne toku ingoa

Tēnā koe,

I am a Massey University student completing a Master's Degree in Psychology and I am interested in finding out from you your experience of being diagnosed with Obstructive Sleep Apnoea and using CPAP as a form of treatment. I would like to explore how this has impacted you. Hearing your stories and your understanding will help me better understand what works well for Māori and what are some of the challenges, which could help improve services for Māori. There will be around 5 Māori individuals sharing their stories for this project.

Because your perspective is important to this project, I invite you to participate in it.

If you agree to participate, I will come to interview you at an agreed location such as your home or at your local primary care provider. Or if you prefer, I could meet you elsewhere where you would feel more comfortable or that is more convenient for you. The interview will take between 1-2 hours. The interview will be confidential and can be held in private, however if you wish to have a friend or whānau member there to support you, that will be fine. The interview will be audio recorded with your permission.

Please note that I will be using some of your stories in the writing of my thesis. Your personal details will be kept anonymous and pseudonyms used the research document.

After the interview, the audio recording will be written up by me. I will provide a written summary of the interview via email or post. I will also provide a summary of the completed thesis at the completion of this research.

In appreciation of your time, a small koha ($100.00) of a petrol or food voucher will be given to you at each meeting.

When my thesis has been finished and marked, you be provided with the option to receive a summary of the document or full version.

Your Rights:
You are under no obligation to accept this invitation. If you decide to participate you have the right to

- Withdraw from the study within 6 weeks of the interview;
- Decline to answer any particular question;
- Ask for the audio recording to be turned off at any time during the interview;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used;

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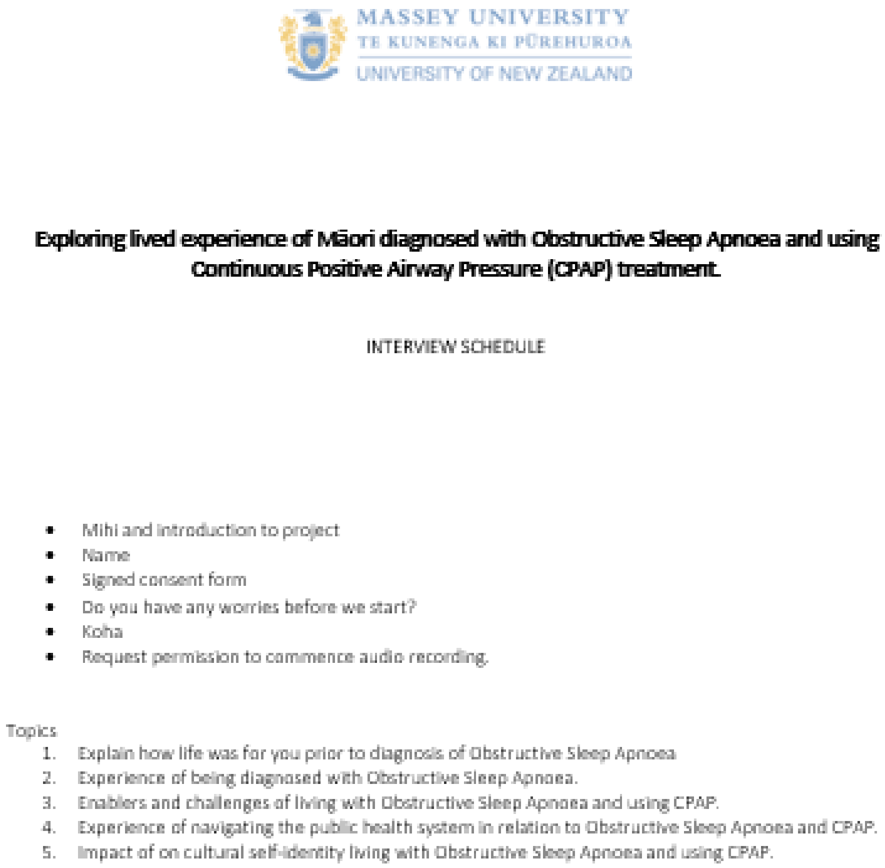
- Be given access to a summary of the project findings when it is concluded.

Project Contacts
Please do not hesitate to contact myself or my supervisors if you have any questions about this project.

- Nikki Canter-Burgoyne can be contacted on 027 444 6124 and via email at nikki.canter-burgoyne.1@uni.massey.ac.nz
- Dr Veronica Hopner can be contacted on 09 414 0800 ext. 43101 and via email v.hopner@massey.ac.nz
- Pita King can be contacted on 09 414 0800 ext. 43439 and via email p.r.w.king@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 20/21. If you have any concerns about the conduct of this research, please contact Dr Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43347, email humanethicsnorth@massey.ac.nz.

Appendix C: Interview Schedule



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Exploring lived experience of Māori diagnosed with Obstructive Sleep Apnoea and using Continuous Positive Airway Pressure (CPAP) treatment.

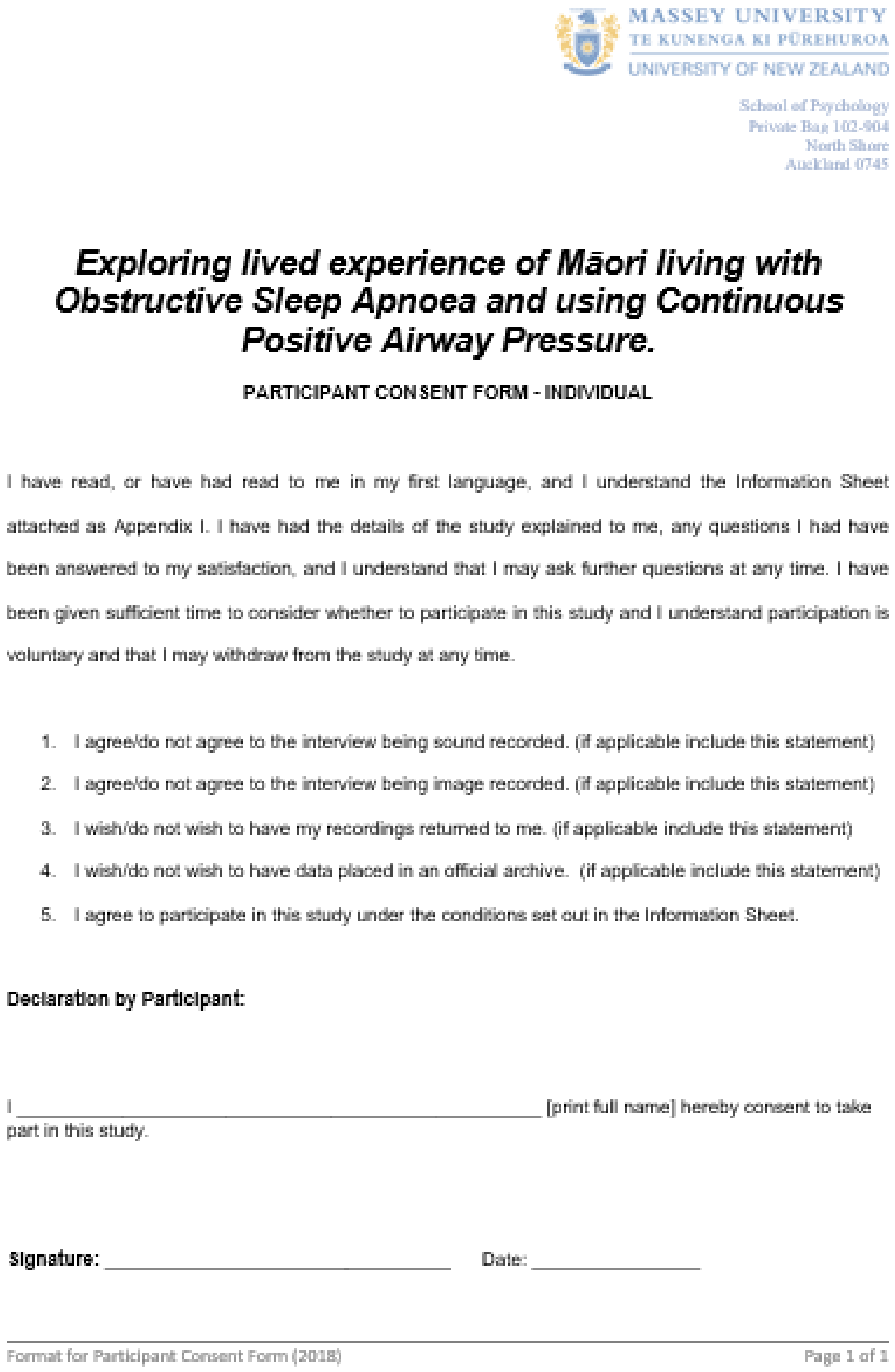
INTERVIEW SCHEDULE

- Mihi and introduction to project
- Name
- Signed consent form
- Do you have any worries before we start?
- Koha
- Request permission to commence audio recording.

Topics

1. Explain how life was for you prior to diagnosis of Obstructive Sleep Apnoea
2. Experience of being diagnosed with Obstructive Sleep Apnoea.
3. Enablers and challenges of living with Obstructive Sleep Apnoea and using CPAP.
4. Experience of navigating the public health system in relation to Obstructive Sleep Apnoea and CPAP.
5. Impact of on cultural self-identity living with Obstructive Sleep Apnoea and using CPAP.

Appendix D: Participant Consent Form



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School of Psychology
Private Bag 102-904
North Shore
Auckland 0745

Exploring lived experience of Māori living with Obstructive Sleep Apnoea and using Continuous Positive Airway Pressure.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read, or have had read to me in my first language, and I understand the Information Sheet attached as Appendix I. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded. (if applicable include this statement)
2. I agree/do not agree to the interview being image recorded. (if applicable include this statement)
3. I wish/do not wish to have my recordings returned to me. (if applicable include this statement)
4. I wish/do not wish to have data placed in an official archive. (if applicable include this statement)
5. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I ____ [print full name] hereby consent to take part in this study.

Signature: ___________________________________ Date: ________________

Format for Participant Consent Form (2018) Page 1 of 1

Appendix E: Glossary

Māori Term	**English Term**
Aotearoa	New Zealand
Aroha	Love
Aroha ki te tangata	Respect for people
Hapori	Community
Hapū	Sub-tribe
Hauora	Health
Hoha	Annoying
Hui	Meeting
Iwi	Tribe
Kai	Food
Kanohi ki te kanohi	Face-to-face
Karakia	Prayer
Kaumatua	Elders
Kaupapa Māori	Māori approach
Koha	Gift/Donation
Kōrero	Talk/Speak
Koroua	Elderly man
Kuia	Elderly woman
Mana	Status/authority
Manaaki	To support
Māori	Indigenous people of New Zealand

Marae	Meeting house
Mātauranga Māori	Māori knowledge
Moko	Grandchild
Mokopuna	Grandchild/children
Pākeha	English
Tai Tokerau	Northland Region
Tangata whenua	Indigenous People
Taonga	Treasure/prized possession
Taonga katoa	All treasured things
Te ao Māori	Māori world view
Te kawanatanga katoa	All rights and powers of sovereignty
Te reo Māori	Māori language
Tiaki	Care for
Tikanga Māori	Māori custom
Tino rangatiratanga	Self-determination
Tipuna	Ancestors
Titiro	Look
Tupuna	Ancestors
Wāhine	Woman/Women
Whakaae	Agreement
Whakama	Embarassment
Whakamana	Enhancement of authority
Whakapapa	Genealogy
Whakarongo	Listen

Whakawātea	Cleansing
Whakawhanaungatanga	Process of building relationships
Whānau	Family, to be born, give birth
Whānau Māori	Māori family
Whānau te rito	Closer family
Whanaungatanga	Relationship
Whanui	Tribal family
Whare	House