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Bargaining and balancing life with CPAP.
A grounded theory.

Kim Ward

A thesis submitted in complete fulfilment of the requirements for the degree of Doctorate of Philosophy in Nursing.

Faculty of Medical Health Sciences, The University of Auckland, 2016.
Abstract

Aim: To explore experiences of using continuous positive airway pressure (CPAP). CPAP is recognised as a cost-effective treatment for obstructive sleep apnoea, which left untreated increases morbidity and mortality. CPAP can be challenging for users, with adherence perceived as poor. This thesis adds to limited evidence regarding CPAP from users’ perspectives, and contributes original knowledge about how users successfully manage therapy.

Methods: Adults prescribed CPAP for sleep apnoea (n=12) and their partners (n=4), recruited through a main-centre respiratory service in New Zealand, participated in semi-structured interviews. Using constructionist grounded theory, data were analysed until theoretical saturation was reached.

Findings: This study identifies that living with CPAP involves a process of individual change management underpinned by the substantive theory bargaining and balancing life with CPAP. The process comprises three main categories: becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP. Partners and/or family members form a collaborative support team with CPAP-users, positively influencing therapy management through joint problem-solving and decision-making. By making choices, participants balance reactions to needing CPAP with the factors that motivate its use and the consequences of their choices. Using or not using CPAP is contingent upon participants determining which choice helps them to feel most well. Indeed, this study highlights participants as active, reasoned decision-makers in their healthcare who identify personal motivations for CPAP use based on personal experience and knowledge about CPAP and sleep apnoea. Furthermore, propensity to persevere acts as a condition under which users make choices about CPAP. The process concludes once mastery is achieved.

Conclusions: By using grounded theory, this study reveals how people live with CPAP. Theoretical models of change management and decision-making underpin the theory bargaining and balancing. True to the principles of patient- and family-centred care, partners should be incorporated in the process from diagnosis to successful CPAP management. Further research should explore the role of partners in the successful management of CPAP and develop this study’s findings regarding elements that hallmark success with CPAP. Interventions should address factors that leverage inclination to persevere with CPAP, and identify those for whom managing CPAP is counterproductive.
Acknowledgements

If I have seen further, it is by standing on the shoulders of giants.

Sir Isaac Newton (1642-1727)

Over the last four years, as I wrote this thesis it struck me many times that completing a project like this is not an individual endeavour, but relies on the support and goodwill of many people. The phrase, ‘standing on the shoulders of giants,’ has often echoed in my thoughts. These acknowledgements express my heartfelt thanks to the following giants all of whom contributed in some way to the completion of this work.

I acknowledge the generosity of Judy Kilpatrick, Head of the School of Nursing and the Faculty of Medicine and Health Sciences at the University of Auckland without whose support this thesis would have been much harder to complete. In particular, I am grateful for the Senior Health Research Scholarship awarded by the faculty that allowed me to complete this thesis full time. The support and advice of my supervisors and of Robyn Dixon, Barbara McKenzie-Green and Jane Mills were instrumental in attaining this sought after scholarship. Thank you all.

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I also acknowledge others who have inspired me. The writings of noted grounded theory scholars and particularly other nurse grounded theorists have provided a legacy on which to build. It feels humbling to be part of their tradition and through this tradition be able to raise awareness of ordinary people and their extraordinary lives. Thank you for having gone before me. Scholars Bridie Kent and Nicola North were first to suggest that I could complete a doctorate and encouraged me during early postgraduate study. Bridie’s support and friendship during that time was invaluable, and the words of both Bridie and Nicola gave me the courage to ‘give it a go.’ Appreciation also goes to my academic advisor Stephen Buetow, who supported the provisional year doctoral process.

More recently appreciated sanity savers include the expertise of learning advisor Julie Bartlett-Trafford, the Auckland University of Technology (AUT) grounded theory group and my friends. This year, when I most despaired of being able to write well and pull the thesis together, Julie came to my rescue with tissues and professional, practical assistance. Equally, appreciation goes to our
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of fun.

Finally, I acknowledge with gratitude the participants in this study who willingly gave their time and
shared their lives with me. I acknowledge their readiness to support this research process in the
hope of improving the lives of other CPAP-users and others with long-term conditions. I truly hope I
have honoured your contribution with this project.

My thesis is all the richer for the contributions of these people. Thank you all for being giants.
Publications and Presentations

Publications


Ward K, Hoare K, Gott M. Becoming a team for good-sleep: Findings from a grounded theory study about living with CPAP. Under review.


Presentations

Universitas: Doctoral school, Sept 2012; The University of Auckland. A doctoral grounded theory study about living with CPAP for OSA. Verbal presentation.


5th World Congress on Sleep Medicine 2013; Valencia, Spain. World Association of Sleep Medicine; 2013. A preliminary review of what is known about the experience of CPAP for OSA from the users’ perspective. Poster presentation.

Faculty of Medical and Health Sciences, The University of Auckland 2013, Faculty seminar. August 2013. Living with CPAP for OSA: A grounded theory study. Verbal presentation.

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<tbody>
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<td>AHI</td>
<td>apnoea-hypopnoea index</td>
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<td>BMI</td>
<td>body mass index</td>
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<td>CPAP</td>
<td>continuous positive airway pressure</td>
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<tr>
<td>CASP</td>
<td>critical appraisal skills programme</td>
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<tr>
<td>DMQ</td>
<td>decision-making questionnaire</td>
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<td>GT</td>
<td>grounded theory</td>
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<tr>
<td>IPDAS</td>
<td>international patient decision aid standards</td>
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<tr>
<td>HBM</td>
<td>health beliefs model</td>
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<tr>
<td>OSA</td>
<td>obstructive sleep apnoea</td>
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<tr>
<td>P&amp;FCC</td>
<td>patient- and family-centred care</td>
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<tr>
<td>QOL</td>
<td>quality of life</td>
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<tr>
<td>RCT</td>
<td>randomised-controlled trials</td>
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<tr>
<td>RDI</td>
<td>respiratory disturbance index</td>
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<td>SECI</td>
<td>side effects of CPAP inventory</td>
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<tr>
<td>SCT</td>
<td>social cognitive theory</td>
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<tr>
<td>TRB</td>
<td>theory of planned behaviour</td>
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<td>TTM</td>
<td>trans-theoretical model</td>
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Co-authorship forms

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Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work.

Chapter 2, section 2.1.

What is known about the experiences of using CPAP for OSA from the users' perspective? A systematic integrative literature review.

Nature of contribution by PhD candidate: Kim Ward was responsible for review design; data collection, data analysis and synthesis; manuscript preparation and submission; managed the review of the manuscript and response to reviewers.

Extent of contribution by PhD candidate (%): 80

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Evolving from a positivist to constructionist epistemology while using grounded theory.

Nature of contribution by PhD candidate

Kim Ward was responsible for the article concept; manuscript preparation and submission; managed the review of the manuscript and response to reviewers.

Extent of contribution by PhD candidate (%)

85

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**Chapter 4, section 4.3.**

Participants’ views of telephone interviews within a grounded theory study.

**Nature of contribution by PhD candidate**

Kim Ward was responsible for study concept and design; obtaining ethical and local institution approval; participant recruitment; data collection and data analysis; manuscript preparation and submission; managed the review of the manuscript and response to reviewers.

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| Nature of contribution by PhD candidate | Kim Ward was responsible for study concept and design; obtaining ethical and local institution approval; participant recruitment; data collection and data analysis; manuscript preparation and submission; managed the review of the manuscript and response to reviewers. |

| Extent of contribution by PhD candidate (%) | 90 |

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Chapter 5, section 5.5.
Making choices about CPAP: Findings from a grounded theory study. Currently under review.

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BARGAINING AND BALANCING LIFE WITH CPAP

CHAPTER ONE

The Beginning
Chapter 1. Introduction

Sleep, rest of things, O pleasing Deity,

Peace of the soul, which cares dost crucify,

Weary bodies refresh and mollify.

Ovid attributed (43 BC-AD 18)$^2$

Humans spend approximately one-third of their lives sleeping. Popular literature spanning centuries records the nature of sleep, highlighting human preoccupation with sleep and its link to good health. The English dramatist Thomas Dekker$^3$ commented, “what an excellent thing sleep is... that golden chain that ties health and our bodies together.”$^{(p.9)}$ The famed orator E. H. Chapin described a good sleep as a “blessing” and alluded to the torment caused by disrupted sleep.$^4$ ($p.80$) A good sleep is restorative while a disrupted sleep lowers mood, reduces ability to function and increases the possibility of accidents.$^5-^8$ The importance of restorative sleep is a key concern for the participants in this thesis.

This introductory chapter introduces the thesis topic, my reasons for choosing this project and the research aim and objectives to set the scene for the rest of the thesis. The following section provides background information to situate the study and give local and international context. Chapter one concludes by outlining the structure of the chapters that follow.

The consequences of non-restorative sleep are numerous, and typically associated with excessive daytime sleepiness, slowed neurocognitive function and snoring. Medical literature is extensive regarding the issue of non-restorative sleep and highlights obstructive sleep apnoea (OSA) as a common cause.$^9-^{11}$ Records of sleep apnoea appear early in popular literature. Shakespeare, an astute observer of human behaviour, described many clinical disorders, including sleep apnoea. In Henry IV$^12$ Pointz describes Falstaff as,

Fast asleep behind the arras, and snorting like a horse … Hark, how hard he fetches breath.$^{(Part I, Act 11, Scene IV)}$

Similarly, Charles Dickens$^{13}$ character Joe in The Posthumous Papers of the Pickwick Club was described as “a wonderfully fat boy,” who exhibited symptoms of sleep apnoea: “...he’s always asleep. Goes on errands fast asleep, and snores as he waits at table.”$^{14}$ ($p.812$) First described clinically during the 1950s, the symptoms of sleep apnoea have been recognised for over a century, and OSA is now associated with a significant number of co-morbidities.$^{11, 14, 15}$

The condition OSA is classified under ‘sleep disordered breathing’ which describes a range of conditions characterised by compromised breathing during sleep.$^{10}$ Globally, sleep disordered breathing represents an increasingly significant component of clinical respiratory care management, exceeded only by asthma and chronic obstructive pulmonary disease.$^9,^{16}$ Indeed, OSA is the most
common sleep-related breathing disorder, affecting millions of people worldwide. OSA describes the presence of intermittent partial or complete obstruction of the pharynx that is associated with snoring, sleep fragmentation, daytime sleepiness and related consequences. Typically, people with OSA are obese, older men. However, sufferers also include women, younger men, and lean people with altered maxillofacial architecture. With the advent of improved diagnostics, the prevalence of OSA has become evident, as has the impact on health and the socioeconomic burden of untreated OSA.

Treatment for OSA varies depending on the severity and the likely cause of the condition. Options for mild OSA include mandibular advancement devices. Nasal septoplasty and maxillofacial surgeries may correct OSA resulting from altered maxillofacial architecture. However, for moderate to severe OSA the most commonly considered treatment is overnight positive-pressure ventilation because of its proven clinical and cost effectiveness. Positive-pressure ventilation has been a recognised therapy for respiratory disturbances, including obstructive lung conditions, since the 1950s. The variant used in sleep apnoea is continuous positive airway pressure (CPAP) via either a full face or a nasal mask. The face mask encloses both the nose and mouth and is firmly secured with straps that fit around the head and chin. The nasal mask is smaller and fits over just the nose, but with similar straps to the face mask. A hose, attached to the mask, connects to the CPAP machine that is usually positioned beside the bed. The device delivers air under pressure that pneumatically splints the upper airway during sleep. Considered the gold standard for treatment of sleep apnoea, CPAP has been recognised as an effective treatment for OSA since the early 1980s. A significant body of research conducted since the 1980s has improved the function of the CPAP device and mask and has increased understanding of the consequences of untreated sleep apnoea. Nevertheless, concern exists that CPAP is under-utilised by sleep apnoea sufferers and that poor compliance jeopardises clinical outcomes. Consequently, information available about using CPAP derives from experimental research preoccupied with interventions to improve compliance.

Although non-compliance with CPAP is a concern, there appears only partial clarity around issues that may influence peoples’ use of CPAP and how people successfully manage their CPAP. Studies allude to the problem of non-compliance. These studies stimulated my interest in investigating how users successfully integrate CPAP into daily life. My view is that describing the management of CPAP from the users’ perspective might be critical to the successful administration of therapy. My background as a nurse with experience in intensive care and respiratory care nursing led to curiosity about how people experienced care and then translated treatment into a home environment. This curiosity stimulated the following questions: What did using CPAP feel like? What was it like to live with? How was CPAP experienced at home? Furthermore, it appeared that while consideration of the difficulties experienced by patients was evident in the literature, interest in the patients’ views about their experience was limited. Consequently, I developed the following question to guide this study: ‘What is it like to live with night-time CPAP for sleep apnoea?’
Objectively quantifying answers to this question seemed incongruous with the idea of exploring personal experiences. CPAP-users responses would be about their experience and reflect personal points of view. Experiencing CPAP as the users viewed it would be determined by different worldviews and give rise to multiple subjective realities, rather than an objective generalisable version of what living with CPAP was like. Therefore, I chose a qualitative research paradigm.

Increasingly, the value of qualitative research in providing an evidence base for treatment is being recognised. Unlike quantitative research, qualitative study acknowledges that the world is experienced subjectively by participants and that meaning is personal and/or shared and can change. Qualitative methodologies illuminate human behaviour and process by interpreting the meaning of shared experiences. Using the qualitative paradigm to determine the meaning of situations, objects, or in this thesis treatment regimens, to the people using them provides a wider range of evidence to draw upon when planning care.

When choosing the most pertinent methodology to guide this research the question *What is it like to live with night-time CPAP for sleep apnoea?* was pivotal. I decided that those who used CPAP were the most appropriate people to explain the processes involved in learning to use, manage and maintain its use. During this study, I listened to participants’ stories that described the process of living with CPAP. The *participant perspective* was the focus of interviews that formed the source of data for analysis: the participants’ words. For these reasons, and with the support of my supervisors, I chose a grounded theory approach for this project guided by the seminal work of Glaser and Strauss, Corbin and Strauss, and more specifically by Charmaz.

Grounded theory research is characterised by the study of phenomena in natural settings. Grounded theory explicates social process and imbues research outcomes with explanatory power through the construction of a substantive theory explaining behaviour. By answering questions about the ‘how’, ‘why’ or ‘what’ of a phenomenon, grounded theory makes it possible to describe the meaning of treatment to patients. Moreover, social contexts can be explored in relation to patients’ healthcare needs. A grounded theory approach is interpretive and inductively generates new theory, rather than originating from theory. Using a constructionist version of grounded theory also enabled my role as an integral part of the research process to be acknowledged.

Consequently, this thesis presents a grounded theory, constructed using participant accounts, that provides an explanatory conceptual framework of experiences using night-time CPAP for obstructive sleep apnoea. To provide context for this work the following sections of this chapter elaborate on OSA syndrome, why it warrants treatment and how it is typically treated. Thereafter, the structure of the thesis is outlined.

### 1.1. Research aim and purpose

The primary aim of this study was to explore experiences of CPAP from users’ perspectives. The intent was to determine insights into behaviours associated with using CPAP. Information sought
related to the meaning of CPAP to users and decision-making processes around CPAP use. Therefore, this study focused specifically on users’ personal views to determine the various behaviours involved in living with and using CPAP. It was anticipated that the new knowledge produced might include strategies that people employ and conditions under which participants choose to use CPAP, along with how users make decisions and the consequences of those decisions.44, 48

Therefore, study objectives included:

- Interview people who use CPAP as a therapy for obstructive sleep apnoea.
- Gather and analyse data concurrently to form a theory about living with CPAP.
- Incorporate the perspectives of CPAP-users’ partners (added following early analysis).
- Produce academic publications to disseminate the new knowledge generated from this project.
- Provide recommendations based on information produced by this project to inform clinical knowledge, care delivery, health policy and future research.

1.2. Background context

This section provides context for the thesis by defining OSA and its prevalence. I outline the consequences and costs of untreated sleep apnoea, elaborating on CPAP as the preferred treatment and providing local context for the study.

1.2.1. Aetiology, consequences and diagnosis of obstructive sleep apnoea

The sleeping disorder OSA results from intermittent narrowing or complete obstruction of the upper airway during sleep.49, 50 While the partial collapse of the pharynx results in flow limitation or hypopnoea, complete obstruction briefly halts breathing and is termed apnoea.51 Collapsibility of the upper airway can occur anywhere between five to over 100 times per hour, resulting in repeatedly disturbed gas exchange that in turn leads to hypoxaemia and hypercapnia (blood de-oxygenation and elevated carbon dioxide levels). These changes trigger repeated micro-arousals from sleep to return breathing to normal.52 Associated symptoms include snoring, witnessed apnoeas and fragmented, non-restorative sleep leading to excessive daytime sleepiness, or hypersomnia.50, 52, 53

Attributed to the insufficiency of pharyngeal musculature, airway collapsibility in OSA is exacerbated by weight gain, age and excess alcohol use.50 The Wisconsin Sleep Study and the Sleep Heart Health Study identified menopausal status and additional co-morbidities such as stroke and cardiovascular disease as further contributory factors.54-56 Anomalies of maxillofacial architecture may also cause or worsen airway collapse during sleep.9

OSA is implicated as an independent risk factor for hypertension and cardiac sequelae up to and including death.55, 57-60 Population-based epidemiologic studies suggest that even mild sleep apnoea is associated with significant morbidity.61, 62 The underlying mechanism for cardiac
sequelae is triggered by the increase in respiratory effort required to overcome pharyngeal collapse and sympathetic nervous system activation due to hypoxaemia and hypercapnia. Hoyos et al. hypothesise that the resulting endothelial dysfunction results in pro-inflammatory and pro-thrombotic states that are also independent risk factors for cardiovascular impairment. Additionally, there is a strong association between OSA and obesity, indicating an increased likelihood of OSA in the presence of obesity. Indeed, studies indicate approximately 70% of OSA sufferers are obese, making obesity one of the most important risk factors for OSA. Recent studies also show that the presence of obesity and unmanaged OSA has implications for the development of metabolic syndrome and diabetes.

Further consequences of sleep apnoea include a reduction in quality of life, with negative impacts on relationships, home and social life. Symptoms of depression are increased in the presence of OSA, affecting social and family encounters. The adverse effects of sleep fragmentation and hypoxaemia on neurocognitive function are also a concern. People with untreated OSA are likely to experience reduced work productivity and more frequent occupational and vehicular accidents than people without sleep apnoea.

The diagnosis and severity of sleep apnoea are determined via overnight polysomnography sleep studies, plus the presence of daytime symptoms such as observer reports of snoring and apnoea or an elevated Epworth Sleepiness Score (between 9 and 24). Criteria used to diagnose OSA vary internationally. However, an apnoea-hypopnea index (AHI*) ≥ 5 plus daytime symptoms, or AHI ≥ 15 without other symptoms is typically accepted as indicative of OSA. Other criteria for diagnosing OSA include elevated respiratory disturbance index (RDI), where RDI ≥ 30 indicates severe apnoea, attendant oxygen desaturation, electroencephalogram to monitor sleep-wake state and measurements of neck circumference.

1.2.2. Prevalence of obstructive sleep apnoea

Typically, evidence regarding the prevalence of obstructive sleep apnoea is derived from United States (US) and European data as currently scant Australasian data exists. In the US, two seminal prospective studies, the 1993 Wisconsin Sleep Cohort study and 1997 Sleep Heart Health study, identified the prevalence of sleep-disordered breathing. Both studies indicated that around 15% of the population (around 5.3 million people) were affected by sleep-disordered breathing, including OSA. Recent data from the Wisconsin Sleep study and a European study indicate prevalence of sleep-disordered breathing is likely to be nearer 10% to 17% of men and 3% to 9% of women.

Recent international studies indicate that the prevalence of OSA is between 3% and 7%. As of 2015, the United Nations estimates that 3% to 7% of the global population represents 219 million to 511 million people. It is estimated that one in five overweight US adults have at least mild sleep apnoea (AHI ≥ 5). In Australia, sleep disorders affect 9% of the population, with 4.7% of the Australians receiving a diagnosis of OSA. The higher incidence of OSA in men than

*AHI: number of apnoeas and hypopnoeas per hour of sleep.
women is reflected globally. Furthermore, there is growing concern about under-diagnosis in the general population, particularly in women. In New Zealand, OSA affects up to 4% of men and 2% of women, with an increased 0.3% prevalence within the Māori and Pacific Island communities. As of 2011, New Zealand ranked third in the league of obesity in developed nations. In 2013, 66.7% of New Zealand’s Pacific Island population and 45.5% of Māori were classified as obese, compared with 27.8% of New Zealand Europeans. Therefore, the slightly higher prevalence of OSA in Māori and Pacific peoples can be associated with the increased incidence of obesity in these groups. Mihaere et al. noted that the prevalence of OSA in New Zealand reflected international evidence and aligned with findings that prevalence increases as BMI and age increases.

1.2.3. Costs of untreated obstructive sleep apnoea

The estimated economic, social and personal costs of OSA are high. Studies indicate that sleep apnoea incurs increased healthcare costs, that costs increase with severity and over time, and that cost saving is possible with successful treatment. Canadian and US medical costs for OSA patients prior to diagnosis were roughly double the cost for people without OSA, with an estimated US$15.9 billion spent in 2006. Overnight hospital stays of patients with untreated OSA were also twice that of patients without OSA. In 2004, the economic cost of sleep disorders in Australia was estimated at Aus$7.133 billion per year (US$7.5 billion), rising to an estimated Aus$36.4 billion per year in 2010. In New Zealand, the estimated annual societal cost of untreated OSA in 2010 was approximately NZ$40 million. Health costs significantly decrease for those with successful treatment. Studies predict that reduced accidental road trauma due to successful treatment of sleep apnoea will yield estimated savings of US$7.9 billion. Although Patel et al. reported reduced sleepiness as a result of CPAP use, the cost of reduced work productivity as a result of hypersomnia currently remains hidden.

As previously outlined, OSA has a strong association with obesity. Healthcare expenditure ascribed to obesity-related disease in developed countries is estimated at 2-7% of national health care costs. In the UK annual health care costs of obesity are estimated at £3.2 billion. Although the proportion of these costs attributed to OSA is unknown, the probability of having sleep apnoea increases in the presence of obesity. The World Health Organisation (WHO) estimate that 65-75% of people with OSA are obese (BMI ≥30.0). In light of the association between sleep apnoea and obesity, the predicted global increase in obesity is likely to lead to an increase in the prevalence of OSA.

1.2.4. Treatment with CPAP

While a range of treatment options exists for OSA, the gold standard is overnight CPAP. Applied via a face or nasal mask, CPAP acts as a pneumatic splint holding the pharynx open during sleep. The primary purpose is relief from respiratory dysfunction that reduces the workload on the heart, along with secondary relief of daytime sleepiness and attendant sequelae.
Numerous international studies have established that CPAP improves quality of life and relieves the symptoms and consequences of OSA including hypersomnia and hypertension. Doing so also empowers sufferers to lead a more active lifestyle, increasing the likelihood of successful weight loss. Internationally CPAP treatment is considered cost-effective and after 13 years of use becomes cost saving due to improved physiological function and reduction in accidental trauma. Although treatment costs vary from country to country, evidence regarding treatment costs and cost saving is derived from US and European data as currently no Australasian data exists. The total yearly cost of using a CPAP device, including equipment and follow-up visits (excluding electricity, which is estimated at US$75 per year), is approximately US$350 or €358. Therefore, successful treatment with CPAP mitigates the economic, social and personal costs of untreated OSA.

Medical industry standards or guidelines have not yet addressed optimum hours of CPAP use. Nonetheless, usage of anywhere between four and a half to six or more hours every night on a routine basis is advocated. Interventional studies leading to improvements in the device and the mask have made CPAP easier to use. Improvements include the introduction of heated humidification, modification to the various masks and to air pressure delivery. However, CPAP can be painful on the face, may wake the user during sleep and has associated side effects. Studies suggest compliance with this therapy is poor, despite empirical evidence generated over the last three decades that OSA is a significant health problem for which CPAP is an effective and recommended treatment.

1.2.5. Local context

Globally, a variety of organisations determine eligibility criteria for treatment with CPAP, ranging from government ministries, public health systems and health insurance, to private funding agencies. The study presented in this thesis was conducted through a district health board respiratory service in a central region of New Zealand where a government-funded public health system operates. People diagnosed with OSA who meet criteria detailed in Table 1 are eligible for a CPAP device free of charge. For those with health insurance, it is possible to receive care privately. Spare tubing and masks are available for purchase for any CPAP-user, as are spare machines.
Table 1: Local health authority criteria for CPAP

<table>
<thead>
<tr>
<th>Obstructive apnoea dominant (&gt;75% of all events)</th>
<th>Mixed apnoea and hypopnoea (50%:50% mix)</th>
<th>Hypopnea dominant (&gt;75% of all events)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHI* with one or more symptoms**</td>
<td>10-30</td>
<td>25-40</td>
</tr>
<tr>
<td>AHI minimal symptoms</td>
<td>&gt;30</td>
<td>&gt;40</td>
</tr>
<tr>
<td>AHI when observed in conjunction with profound desaturations and/or respiratory failure and/or grossly fragmented sleep</td>
<td>-</td>
<td>&gt;25</td>
</tr>
</tbody>
</table>

** Symptoms:
- Epworth Sleepiness Scale >10 (out of 24)
- High-risk occupation including all commercial drivers
- History of motor vehicle accidents / near misses
- Under 70 years of age with confirmed heart failure

*AHI: apnoea-hypopnoea index, as demonstrated by overnight polysomnography, is the number of apnoea and/or hypopnea events per hour of sleep. If the AHI is apnoea dominant the threshold to meet criteria is lower than if the AHI is hypopnea dominant.

1.3. Thesis structure

This thesis follows the traditional presentation of a Ph.D., however, a number of chapters contain manuscripts that are published, in press or under review. Effort has been made to limit the repetition inherent in a thesis with publication, but it is acknowledged that occasional repetition of content is possible. The next chapter in this thesis presents an article published in *Sleep Medicine Reviews*. During an early stage of this research, I conducted a substantial integrative literature review to synthesise international evidence regarding users’ experiences of CPAP for sleep apnoea. The paper identifies current evidence about experiencing CPAP that supports the importance of exploring this topic. The review also draws attention to the focus of sleep medicine literature on improving compliance with CPAP therapy. Chapter two concludes by considering the discourse of compliance.

Chapter three outlines theoretical concepts underpinning this work and introduces the methodology of constructionist grounded theory. Conducting this study through a social constructionist lens comes with the understanding that “knowledge is a compilation of human-made constructions," and that ontologically, truth is not absolute but is conditional on context and interaction. The epistemology underpinning grounded theory differs depending on the grounded theorist’s chosen to follow. As such, I consider two epistemologies that influenced how this method was chosen to obtain, analyse and interpret the research data. I discuss these and my theoretical influences in a paper published in the *Journal of Research in Nursing* and presented in chapter three. In subscribing to Charmaz’s constructionist version of grounded theory, the investigator is
Chapter 1

acknowledged as an integral part of the research process. In chapter three, I consider the implications that being part of the research process has for the researcher.

Chapter four expands upon the tenets of a grounded theory study and provides examples of their application in this research project. In this chapter, I also discuss my decision to use telephone interviews with participants by presenting a paper reporting on semi-structured interviews over the telephone, published in the Journal of Advanced Nursing. Following the methods chapter, I present the outcome of the project as findings in chapter five. Two papers in this chapter, outlining components of the theory constructed from this research, are currently under review for publication.

Chapter six presents a discussion based on the findings presented in chapter five and incorporates extant theories to strengthen the substantive theory from this study. The thesis concludes in chapter seven by outlining strengths and limitations of the study and provides recommendations for policy and practice.

1.4. Chapter 1 Summary

This chapter has introduced the consequences of non-restorative sleep and identified the major contributing condition of OSA. The chapter provides an overview of OSA, how it affects people, the importance of CPAP treatment and the value of research on this topic. This introduction has also outlined reasons for exploring the use of CPAP from the users' perspective and for the methodology chosen. The next chapter sets the scene for the rest of the thesis by identifying pre-existing evidence about experiencing CPAP from the users' perspective.
CHAPTER TWO
Setting the Scene
Chapter 2. Literature Review

This chapter provides a review of literature relating to the thesis topic in order to set the scene and support the need for this study. Placement of the literature review in a grounded theory study is contested. Therefore, I begin by discussing the role and timing of a literature review when using grounded theory. The main body of the chapter that follows is a published systematic, integrative literature review regarding the user’s perspective of CPAP.

In the seminal text, *The Discovery of Grounded Theory*, Glaser and Strauss\textsuperscript{42} recommended delaying a literature review in the substantive area of research until the core variable of a grounded theory had emerged. Glaser and Strauss’ focus on developing new theory led them to recommend this strategy to mitigate contamination from existing theories and to free their students from the influence of received knowledge; scholars would then be less likely to force data into pre-existing theories, safeguarding originality. However, given that other strategies exist to protect theory integrity, prevention of forcing the data appears inadequate grounds for delaying the literature review. Moreover, as Corbin and Strauss\textsuperscript{43,137} recognise, most professionals are already familiar with knowledge in their field, and in today’s environment of university, ethics and grant applications, this purist approach is accepted as unfeasible.\textsuperscript{138}

Indeed, I agree with Charmaz\textsuperscript{45} that in reality conducting a literature review in the area of study appears pragmatic. Reviewing substantive literature can provide sensitising concepts for analysis and sampling, along with a sound rationale for the topic and research approach.\textsuperscript{48,139} Equally, appraisal of existing knowledge helps contextualise and situate the study by revealing previous approaches to research in the area.\textsuperscript{139} Understanding the representation of a phenomenon in the literature exposes dominant discourses and subliminal preconceptions. I consider that exposing subliminal or received knowledge is important in terms of researcher reflexivity, something I consider more in chapter three. Moreover, Charmaz,\textsuperscript{45} Birks and Mills\textsuperscript{48} and other grounded theory scholars argue that engaging with literature is helpful and enhances insight during data analysis, as represented by the discussion sections of the papers included in this thesis.\textsuperscript{138-140} Additionally, Chapter 6 demonstrates that further literature review of extant theories relevant to the topic is necessary to add explanatory power to the constructed theory.\textsuperscript{48}

2.1. Setting the scene

The review that follows synthesises international evidence regarding personal experiences using CPAP for OSA with the specific objective of determining what, if anything, was already known. In so doing I established that this was an underexplored topic.
The following integrative review is published and cited as,


This paper is reproduced here in its entirety with permission from the journal Sleep Medicine Reviews (impact factor 9.258; H index: 87; SJR indicator 2.71).

ARTICLE: What is known about the experiences of using CPAP for OSA from the users’ perspective? A systematic integrative literature review.

2.1.1. Abstract

Background: Economic, social and personal costs of untreated obstructive sleep apnoea (OSA) are high. Continuous positive airway pressure (CPAP) is recommended and cost effective. Increasing OSA prevalence may accompany predicted globally increasing obesity.

Objective: To synthesise international evidence regarding personal experiences using CPAP for OSA.

Methods: A systematic integrative literature review was conducted and quality assessment criteria applied.

Results: 22, of 538, identified papers met inclusion criteria. Thematic analysis identified three themes: 1) users’ beliefs about CPAP influence users’ experiences of CPAP; 2) CPAP users are primed to reflect negatively on experiences of CPAP; and 3) spouse and family influence users’ experiences of CPAP. Personality and attitude impact expectations about CPAP prior to use, whilst engagement of spouse and family also influence experiences. Analysis highlighted that users’ reporting of CPAP experiences is constrained by investigator defined assessment methods. Overall, research relating to experiences using CPAP is limited.

Conclusion: Users’ perspectives of CPAP are constrained by researchers’ concern with non-compliance. Typically experiences are not defined by the user, but from an ‘expert’ healthcare perspective using words which frame CPAP as problematic. Family and social support is a significant, but neglected area of experiencing CPAP warranting further investigation. More information from users is required to determine how CPAP can be managed successfully.

Keywords: Continuous positive airway pressure; nasal CPAP; obstructive sleep apnoea; hypopnoea; patient experiences; integrative review
2.1.2. Introduction

Obstructive sleep apnoea (OSA) is a chronic syndrome that carries both personal and societal costs. In OSA collapsibility of the upper airway during sleep leads to repeated momentary cessation of breathing of anywhere between five to over 100 times per hour resulting in decreased blood oxygen saturation. This leads to repeated arousals and associated symptoms such as snoring and hypersomnolence. The resultant reduction in quality of life has negative impacts on relationships, home and social life.

The estimated economic and social cost of OSA is high. OSA has a strong association with obesity, and is implicated as an independent risk factor for hypertension and cardiac sequelae. People with untreated OSA are also likely to experience occupational and vehicular accidents more frequently than the general population. Canadian and United States (US) medical costs for OSA patients prior to diagnosis were roughly two-fold the cost for people without OSA, with an estimated US$15.9 billion spent in 2006.

In population-based epidemiologic studies, even mild sleep apnoea has been associated with significant morbidity. Global studies indicate the prevalence of OSA syndrome (apnoea-hypopnoea index [AHI] ≥ 5 plus daytime sleepiness) is between 3% and 7%. Additional evidence indicates that one in five overweight US adults have at least mild sleep apnoea (AHI ≥ 5 events/hour). Under-diagnosis in the general population is also of growing concern.

Night-time continuous positive airway pressure (CPAP) via nasal or face mask is a recommended, effective and popular treatment option for OSA. CPAP applied via a face or nasal mask acts as a pneumatic splint holding the pharynx open during sleep. The primary purpose is relief of respiratory dysfunction so decreasing workload on the heart plus secondary relief of daytime sleepiness and attendant sequelae. However, CPAP can be painful on the face, may wake the user during sleep and has associated side effects. Despite empirical evidence generated over the last three decades, that OSA is a health risk and CPAP is an effective and recommended treatment, studies suggest that poor compliance with this therapy remains a concern.

Internationally, CPAP as a treatment for OSA is considered cost-effective and after 13 years of use becomes cost saving. The World Health Organisation suggests that 65-75% of people with OSA are obese (body mass index [BMI] ≥ 30.0 kg/m²). The predicted global increase in obesity will therefore lead to an increase in prevalence of OSA. Exploring management of CPAP from the user perspective is crucial to successful administration of therapy. This manuscript identifies and synthesises international evidence regarding users’ personal experiences of using CPAP. For the purposes of this review ‘experience of CPAP’ is defined as personal perceptions, opinions or knowledge gained from personal use of CPAP for OSA.

2.1.3. Methods

An integrative review was conducted and all studies that examined the experience of night-time CPAP for OSA were included. An integrative review provides a systematic approach to examining
studies that have adopted diverse methodologies. This approach provides a comprehensive exploration of a particular phenomenon or healthcare problem by drawing on a wide range of evidence rather than maintaining a focus on the clinical trial.

**Search strategy**

The following search strategy was used in the online databases Medline, PsycINFO, the cumulative index to nursing and allied health literature (CINAHL Plus), Cochrane and Web of Science (including social sciences citation index plus expanded). Predetermined inclusion and exclusion criteria were applied (see Table 2).

**Table 2: Review inclusion and exclusion criteria**

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Papers focusing on any element of adult patients’ personal experiences of using CPAP for OSA</td>
<td>Papers not including any element of the patients’ personal experiences of using CPAP for OSA</td>
</tr>
<tr>
<td>English language</td>
<td>Papers focusing on CPAP for reasons other than OSA</td>
</tr>
<tr>
<td>Participants aged 18 + inclusive</td>
<td>Not English language</td>
</tr>
<tr>
<td>Empirical studies</td>
<td>Papers focusing on children (up to age 18)</td>
</tr>
<tr>
<td>Papers from Jan 1990 to Sept 2012</td>
<td>Non-empirical studies, theoretical, discussion papers or dissertations</td>
</tr>
<tr>
<td></td>
<td>Papers prior to 1990</td>
</tr>
</tbody>
</table>

**Key:** CPAP: Continuous positive airway pressure; OSA: obstructive sleep apnoea

*Report of patients’ personal experiences included their own words or their response to a choice of predetermined constructs.

Searches were carried out via title, subject and keyword. Search terms were designed to capture variants of the terms ‘continuous positive airway pressure’, ‘obstructive sleep apnoea’, and ‘patients’ experience’ with appropriate wildcards inserted to search for word truncations (see Table 3).

**Table 3: Review search terms**

<table>
<thead>
<tr>
<th>‘continuous positive airway pressure’</th>
<th>‘obstructive sleep apnoea’</th>
<th>‘patients’ experience’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous positive airway pressure (CPAP)</td>
<td>Sleep apn?ea*</td>
<td>Experience*</td>
</tr>
<tr>
<td>Nasal continuous positive airway pressure (NCPAP)</td>
<td>Obstructive sleep apn* (OSA)</td>
<td>Perception*</td>
</tr>
<tr>
<td></td>
<td>Sleep apn?ea syndrome (OSAS)</td>
<td>Adapt*</td>
</tr>
<tr>
<td></td>
<td>Hypopn?ea</td>
<td>Coping behaviour</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coping</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Living</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Point of view*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom distress</td>
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<td></td>
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</tbody>
</table>

**Key:** * Alternate endings applied during search; ? Alternate spelling applied during search
Search Outcome

538 studies were identified during the initial search. The study selection and inclusion process included tiered screening for eligibility via title, abstract and then full text (see Figure 1).

Figure 1: Flowchart showing literature selection

Crosschecking of rejected articles was carried out independently by KW and MG with consensus reached where ambiguity existed. Reference tracking yielded an additional 19 articles for screening, five of which contributed to the total 22 papers included in this review (see Table 4).
Table 4: Evidence on experiences of using CPAP for OSA

<table>
<thead>
<tr>
<th>Author/year, country/quality</th>
<th>Study design</th>
<th>Setting and sample †</th>
<th>Focus and outcomes of each study ‡</th>
<th>Data related to personal experiences of using CPAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aloia et al., 200728 USA Quality Good</td>
<td>Quantitative Prospective observational replication study - participants blinded</td>
<td>Teaching hospital, purposive sample of 140 (93 men)</td>
<td>Focus was on predicting 6-month adherence to CPAP within the first days of CPAP use. Patterns of adherence were reported as highly variable night-to-night and established within the first week of treatment. Statistically significant side effects reported included discomfort (p&lt; 0.02), congestion (p&lt; 0.05), and feeling closed in (p&lt; 0.03). Mask type was not controlled for, or measured so may have influenced adherence.</td>
<td>Participants that identified physical and social side effects of CPAP via a checklist of ‘most common’ were limited to those experiencing problems. Checklist side effects were predetermined and derived using literature and expert opinion alone.</td>
</tr>
<tr>
<td>Ayow et al., 2009148 Canada Quality Fair</td>
<td>Qualitative Prospective descriptive comparative case study - semi-structured interviews</td>
<td>Urban multisite sleep clinic, purposive sample of 8 (4 men)</td>
<td>Facilitators and barriers to CPAP use were identified by comparing CPAP users’ perspectives with non-users. Factors influencing use/non-use were physical, psychological, financial, and social comparison and stigma as seen from opposing perspectives depending on case. Social and family structures were not explored∞ and theoretical saturation did not occur.</td>
<td>Exploration of experiences using CPAP was restricted to the influence of their experiences on adherence. Factors observed included physical benefits versus frustration with device versus social factors, such as feeling ugly using CPAP and guilty for not using CPAP.</td>
</tr>
<tr>
<td>Broström et al., 2007149 Sweden Quality Good</td>
<td>Quantitative Retrospective cross-sectional descriptive - survey</td>
<td>Urban hospital CPAP clinic, purposive sample of 247 (203 men)</td>
<td>Described prevalence of Type D personality in OSA patients treated with CPAP for ≥ six months and the association with self-reported side effects and adherence. Side effects were assessed using side effect of CPAP inventory (SECI). The 30% of participants categorised as type D personality reported more side effects from CPAP, with higher frequency (p&lt; 0.05-0.01) and lower adherence, than patients without type-D personality.</td>
<td>The experience of using CPAP was examined in relation to frequency, magnitude and impact of predetermined side effects and their influence on adherence in the Type D personality. SECI∞ was based on personal accounts of using CPAP, the literature and expert opinion.</td>
</tr>
</tbody>
</table>

† Apnoea Hypopnea Index (AHI/hr) reported as range of events/hour; CPAP use reported since titration (unless otherwise stated) in range of mean hours/night (hrs/n) and period of use in days or months (mths). ‘Non-user’ refers to those who had been commenced on CPAP but abandoned treatment, data provided for non-users is pre abandonment.

‡ As determined by authors of original study, and not the authors of this review, unless denoted by ∞
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Methodology</th>
<th>Setting</th>
<th>Sample Size</th>
<th>AHI Range</th>
<th>CPAP Use Duration</th>
<th>Results/Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broström et al., 2009</td>
<td>151</td>
<td>Sweden</td>
<td>Quantitative Retrospective cross-sectional descriptive - survey</td>
<td>Urban hospital CPAP clinic, purposive sample of Professionals 105 (20 men) Patients 350 (230 men)</td>
<td>Age 36-54 yrs AHI 10-98/hr CPAP use 0-182 mths, 79% &gt;4hrs/n</td>
<td>Compared the perceptions among CPAP users against perceptions of healthcare professionals regarding users’ informational needs, CPAP side-effects (using SECI) and effect on adherence. Possibilities to learn were perceived as greater by CPAP users than by professionals. Patients perceived less frequent side effects with a lower impact on adherence than did healthcare professionals.</td>
<td>The experience of using CPAP was examined in the context of side effects impacting adherence. Most common side effects were reported as blocked nose, mask leaks, dry throat, and uncomfortable mask pressure.</td>
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<tr>
<td>Broström, Nilsen et al., 2010</td>
<td>152</td>
<td>Sweden</td>
<td>Qualitative Exploratory Retrospective inductive approach - semi-structured interviews</td>
<td>Rural pulmonary clinic, purposive sample 23 (13 men)</td>
<td>Age 33-74 yrs AHI 30-94/hr CPAP use 0.5-148 mths, 79% &gt;4hrs/n</td>
<td>CPAP users’ experiences of adherence to CPAP were explored by analysing and describing patients’ in-depth accounts of using CPAP. Two themes emerged: ‘putative facilitators’ and ‘putative barriers’. Facilitators included symptom avoidance, knowledge of health risk, and negative social consequences. Barriers included side effects, practical problems and poor personal or professional support.</td>
<td>Exploration of experiencing CPAP was focused on factors impacting adherence. Self-belief and self-efficacy led to a positive attitude towards CPAP, as well as the reverse. Fear of negative social consequences led to guilt. SECI was developed from this study.</td>
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<tr>
<td>Broström, Årestedt et al., 2010</td>
<td>153</td>
<td>Sweden</td>
<td>Quantitative Retrospective instrument development &amp; validation - survey</td>
<td>Urban hospital CPAP clinics, purposive sample 329 (263 men)</td>
<td>Age 21-82 yrs AHI 10-92/hr CPAP use 0.5-182 mths, hrs/n unreported</td>
<td>The side-effects to CPAP inventory (SECI) was developed to measure magnitude and frequency of side-effects and impact on use. Variables of difficulty were sought to assist those unlikely to adhere to CPAP. SECI measurement properties were reported as satisfactory, promising and able to discriminate between adherent and non-adherent CPAP users.</td>
<td>Expression of experiences using CPAP was restricted to a list of 15 pre-determined side-effects. The 15 side-effects were assembled on the basis of in-depth interviews with 23 CPAP users, review of the scientific literature and consensus of a multi-professional expert panel.</td>
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<tr>
<td>Researcher(s)</td>
<td>Quality</td>
<td>Country</td>
<td>Study Design</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Characteristics</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Dickerson &amp; Kennedy 2006</td>
<td>Fair</td>
<td>USA</td>
<td>Qualitative Retrospective Heideggerian phenomenology - semi-structured interviews</td>
<td>Urban medical centre &amp; rural hospital, purposive convenience sample of 17 (12 men)</td>
<td>Age 40-73 yrs</td>
<td>Help-seeking experiences in support group attendees were explored to understand patients' experiences and difficulties using CPAP.</td>
<td>Four themes emerged: (1) becoming motivated to persist with help from the group, (2) accommodating to the device, (3) listening and telling stories to gain practical knowledge, and (4) implementing a support group as a caring community.</td>
<td>Exploration of experiences using CPAP was restricted to the influence of user support group participation on motivation to use CPAP. Experiences of using CPAP were described within theme (2): these were struggling to persist accommodating to an uncomfortable therapy and trading exhaustion for the discomfort of CPAP.</td>
</tr>
<tr>
<td>Dickerson &amp; Akhu-Zaheya 2007</td>
<td>Good</td>
<td>USA</td>
<td>Quantitative</td>
<td>urban sleep centre, purposive sample of 20 (9 men)</td>
<td>Age 31-72 yrs</td>
<td>Accommodation to nasal CPAP and motivation to use was explored during three months post CPAP initiation.</td>
<td>Five themes emerged: (1) trouble using CPAP, (2) persisting through initial and recurring frustration, (3) difficulty recognising subtle improvements, (4) accessing help and problem-solving, (5) becoming part of the routine or abandoning CPAP. Perseverance through tribulations by developing a positive mindset was the constitutive pattern.</td>
<td>The meaning CPAP users made of their experiences were explored to understand the motivation to comply with treatment. Difficulties encountered using CPAP as time passed by both users and non-users were described. The experience of using CPAP became routine or was otherwise abandoned.</td>
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<tr>
<td>Engleman et al., 1996</td>
<td>Poor</td>
<td>Scotland</td>
<td>Quantitative</td>
<td>Scottish National Sleep Laboratory, purposive sample of 204 (187 men)</td>
<td>Age 43-63 yrs</td>
<td>Daytime function, nocturnal symptoms and road traffic incident (RTI) rate were assessed before and after CPAP initiation to examine perceived benefit of CPAP and identify determinants of CPAP use. Excessive sleepiness and RTIs reduced by CPAP.</td>
<td>Greater self-reported CPAP use was associated with better resolution of sleepiness (p &lt; 0.0001) and greater improvement in daytime function and nocturnal symptoms.</td>
<td>A minor part of the survey examined experiences using CPAP via a 12 item problem list, assessed on a four-point scale, and limited to those experiencing problems. Focus was on function, in-particular driving competence. Source of the 12 items not reported.</td>
</tr>
<tr>
<td>Galetke et al., 2011</td>
<td>Good</td>
<td>Germany</td>
<td>Quantitative</td>
<td>Sleep laboratory, purposive sample of 303 (234 men)</td>
<td>Age 46.5-70.5 yrs</td>
<td>CPAP adherence was analysed focusing on reasons for abandonment. ‘Most’ patients (27%) who stopped treatment reported mask side effects and discomfort from the device and 17% became non-users due to lack of symptoms pre-initiation. Non-users were likely to be moderately obese women with mild OSA. Findings emphasised that the pattern of adherence became established in first 3-6 months of use.</td>
<td>CPAP adherence was restricted to the comfort of treatment and predetermined side effects of treatment using an analogue scale. Side effects and source not reported.</td>
<td>Assessment of patient experiences using CPAP was restricted to the comfort of treatment and predetermined side effects of treatment using an analogue scale.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>AHI Range</td>
<td>CPAP Use</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Hoffstein et al., 1992&lt;sup&gt;158&lt;/sup&gt;</td>
<td>Quantitative Cross-sectional descriptive - survey</td>
<td>Sleep clinic, purposive sample of 96 (gender not given)</td>
<td>Age 37 – 62 yrs</td>
<td>AHI 11-153/hr</td>
<td>CPAP use 0-28 mths, 1-8 hrs/n</td>
<td>Factors influencing acceptance of nasal CPAP were analysed including perceived beneficial effects, equipment problems, side effects and suggestions for improvement. Ontario patient cohort was compared with other populations. 81% of respondents believed CPAP was effective for subjective complaints. Non-compliant respondents (those who stopped CPAP - 18%) perceived no beneficial effects, made more adverse comments about CPAP and their families noticed no improvement.</td>
<td>Assessment of patient experiences using CPAP was restricted to two of eight yes/no questions. A choice of answers to questions was offered, but not reported: predetermined side effects were reported as based on common complaints and comments voiced by other clinic patients.</td>
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<tr>
<td>Holmåhl et al., 2009&lt;sup&gt;159&lt;/sup&gt;</td>
<td>Quantitative Prospective - RCT</td>
<td>University hospital, purposive sample of 200 (189 men)</td>
<td>Age 29-79 yrs</td>
<td>AHI &gt;15/hr (no range)</td>
<td>CPAP use 1-144 mths, 4-6+ hrs/n</td>
<td>Nurse specialist-led follow-up visits (intervention) were compared with physician-led visits (control) for stable CPAP patients. Patient satisfaction, quality of life, medical events and health resource utilisation were assessed. Nurse specialist follow-up optimised the use of health resources while retaining patient satisfaction with follow-up without increasing medical risks. Women were absent from the intervention group.</td>
<td>Assessment of patient experiences using CPAP was restricted to two open questions about the most positive aspect of CPAP (reduced tiredness) and the most negative aspect of CPAP (dependence on the CPAP device and mask problems - 50% response rate). 99% of participants rated the overall experience of CPAP as good or excellent</td>
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<tr>
<td>Meslier et al., 1998&lt;sup&gt;160&lt;/sup&gt;</td>
<td>Quantitative Retrospective cross-sectional descriptive - survey</td>
<td>French Respiratory Homecare Network, purposive sample of 3225 (2796 men)</td>
<td>Age 48-70 yrs</td>
<td>AHI unreported</td>
<td>CPAP use 6-48+ mths, 1-9 hrs/n</td>
<td>CPAP users’ perceptions of benefits from CPAP, quality of life, CPAP tolerance and compliance were investigated. 80% of sample had improved symptoms despite discomfort from CPAP device: 52.2% reported dry mouth and throat, 47% blower noise disturbing bed partner. 57% of sample rated nasal mask tolerance as good/very good. Overall satisfaction with CPAP was good /very good (90%) which correlated with self-reported compliance (p&lt;0.01).</td>
<td>Assessment of patient experiences using CPAP was restricted to the pre-determined side effects list to examine CPAP tolerance and their influence on compliance. Source of side effects not reported. Participants appeared satisfied with therapy despite side effects.</td>
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<tr>
<td>Moroni et al., 2011</td>
<td>Italy</td>
<td>Quality Good</td>
<td><strong>Quantitative</strong></td>
<td>Prospective - tool validation</td>
<td>Setting not specified, purposive sample of 96 (78 men) Participants who stopped CPAP (n=29) were not re-surveyed. Reason unreported.</td>
<td>Maugeri OSA syndrome questionnaire (MOSAS) was developed and validated to assess psychological and physical impact of OSA and to determine risk for non-adherence to CPAP. Good statistical quality of MOSAS reported. CPAP use of &lt;4 hrs/n led to higher median scores for the psychological impact of OSA, whilst greater CPAP discomfort and nuisance led to reduced CPAP use (p&lt;0.01).</td>
<td>Assessment of patient experiences using CPAP was restricted to the seven-item assessment of “discomfort and nuisance of CPAP”, section B of MOSAS, which focused on ability to use CPAP and difficulties with the CPAP device.</td>
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<td>Pépin et al., 1995</td>
<td>France</td>
<td>Quality Fair</td>
<td><strong>Quantitative</strong></td>
<td>Prospective cross-sectional comparative - survey</td>
<td>Setting not specified, purposive sample 193 (165 men)</td>
<td>Subjective benefits and side effects of nasal CPAP were examined including compliance at six-month intervals. Side effects reported were mainly local to the nose, with 50% of patients reporting at least one side effect. Greater OSA severity led to greater perceived benefit from CPAP. Compliance was high at mean 6.5 hrs/n use with 88% of respondents using CPAP every night. Study participation may have been a confounding bias.</td>
<td>Assessment of patient experiences using CPAP was restricted to side effects and measurement of compliance. Source of side effects and response options were not reported.</td>
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<tr>
<td>Sage et al., 2001</td>
<td>Australia</td>
<td>Quality Fair</td>
<td><strong>Quantitative</strong></td>
<td>Exploratory Retrospective cross-sectional descriptive - survey</td>
<td>Setting not specified, purposive sample 40 (30 men)</td>
<td>Predicted 1-month compliance with CPAP in recently diagnosed OSA patients using variables derived from the Health Beliefs Model (HBM”) Perceived barriers and benefits of CPAP were shown to predict compliance. Perceived benefits of CPAP was inversely associated with % of days that CPAP not used. Participants’ confidence to use CPAP showed univariate, but not multivariate, relationships with both variables.</td>
<td>Assessment of patient experiences using CPAP was via the ‘barriers to CPAP’ portion of the questionnaire which related to expected future CPAP experience based on experiences of the first night of use. Initial perceptions were shown to impact continued CPAP use.</td>
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</table>

\* Respiratory disturbance index (RDI) measured as events per hour.

\** Health Beliefs Model emphasises subjective health experience and patients’ beliefs about treatment.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Methods</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Age Range</th>
<th>AHI Range</th>
<th>CPAP Use</th>
<th>Study Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sawyer et al., 2010[12]</td>
<td>Mixed methods</td>
<td>Exploratory prosaic thematic analysis - semi-</td>
<td>Urban veterans sleep clinic,</td>
<td>15 (13 men)</td>
<td>42-66 yrs</td>
<td>23.5-79.5/hr</td>
<td>1-7 weeks, 4.5-5.5 hrs/n</td>
<td>The influence on CPAP adherence of patients’ beliefs and perceptions of OSA diagnosis and CPAP treatment was examined preceding and during seven weeks post treatment initiation. Quantitatively underpowered. Differing beliefs and perceptions between adherers (≥6 hrs/n) and non-adherers (&lt;6 hrs/n) included OSA risk perception, self-efficacy, outcome expectations, treatment goals, treatment facilitators and barriers. Participants’ second interview alone explored perceived effects of CPAP therapy. The experience of positive social influences motivated CPAP use, whilst those socially unsupported needed to be self-driven. Participants described using CPAP as a “botheration” and experienced difficulty reconciling pre-CPAP symptoms with treatment.</td>
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<tr>
<td>USA Quality Good</td>
<td></td>
<td>structured interviews</td>
<td>purposive sample</td>
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<tr>
<td>Smith et al., 1998[16]</td>
<td>Quantitative</td>
<td>Exploratory descriptive correlational - semi-</td>
<td>Setting not specified,</td>
<td>21 (13 men)</td>
<td>34-78 yrs</td>
<td>“severe”</td>
<td>3-39 mths, 5-8.5 hrs/n</td>
<td>Barriers to CPAP use were explored, including learning needs of patients and family and the knowledge and skills needed to manage CPAP post-discharge. There was a minor focus on the patient/caregiver relationship. Learning needs related to troubleshooting equipment, maintaining mask comfort, managing headgear and machine settings along with understanding OSA pathology. Assessment of patient experiences using CPAP was via semi-structured family interview in the context of experiencing difficulty with CPAP. Family members involved themselves with overcoming barriers to nightly CPAP use.</td>
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<tr>
<td>USA Quality Good</td>
<td></td>
<td>structured interviews &amp; QOL tools</td>
<td>purposive sample &amp; 20 caregivers</td>
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<tr>
<td>Tyrrell et al., 2006[162]</td>
<td>Qualitative</td>
<td>Exploratory retrospective - semi-structured</td>
<td>French Respiratory Homecare</td>
<td>9 (8 men)</td>
<td>32-70 yrs</td>
<td>&gt;30/hr</td>
<td>&gt;6 mths pre abandoning CPAP, 4.5 hrs/n</td>
<td>The usefulness of HBM was explored to determine psychological issues leading patients to abandon CPAP. Health beliefs influenced abandonment though respondents were not preoccupied with OSA. CPAP was stopped due to mask problems, machine noise, difficulties or fatigue, and unmet expectations of a cure by CPAP. One participant understood the life-threatening nature of OSA and two reported feeling better on CPAP. Assessment of patient experiences using CPAP was restricted to perceptions of illness, treatment problems and reasons for abandoning CPAP. Participants experienced difficulty reconciling symptoms and diagnosis with goals and expectations of treatment.</td>
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<tr>
<td>France Quality Fair</td>
<td></td>
<td>interviews &amp; survey</td>
<td>Network, purposive sample</td>
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<tr>
<td>Veale et al., 2002[163]</td>
<td>Qualitative</td>
<td>Retrospective discourse analysis - semi-directive interviews around themes of sleep, health &amp; treatment</td>
<td>Pulmonary rehabilitation unit,</td>
<td>30 (gender not given) of which 15 were commencing CPAP</td>
<td>39-74 yrs</td>
<td>11-169/hr</td>
<td>initial stages of treatment, not quantified.</td>
<td>How patients live with OSA was analysed in-depth. The CPAP machine was a major preoccupation in the initial level of analysis and was perceived as a medical prosthesis identifying participants as ill. Treatment was a focus for 15 participants, but not for the investigator. The theme of health was central to the discourse in the final level of analysis. Daytime sleepiness was overwhelmingly important to the participants. Users of CPAP for chronic obstructive pulmonary disease undetermined.* Assessment of patient experiences focused on concerns living with OSA rather than CPAP. Although two questions explored the difficulties with and long term expectations of CPAP. CPAP was described as a problem or nuisance with noise and nasal mask problems raised 21 times. CPAP users claimed better sleep on CPAP but expressed general dissatisfaction. 17.7% hoped for a ‘miracle cure’.</td>
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<tr>
<td>France Quality Fair</td>
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<td>purposive sample</td>
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*Note: CPAP use was limited in this study due to the difficulty of adhering to the treatment.
| Wang et al., 2012<sup>164</sup> | **Quantitative**  
Retrospective cross-sectional - phone survey | Setting not specified, purposive sample  
193 (162 men)  
**Age** 42-62 yrs  
**AHI** 40-80/hr  
**CPAP use** 27-96 mths, hrs/n unreported | The prevalence of non-adherence to CPAP in Tianjin OSA patients was assessed. CPAP adherence was shown to be low in Tianjin, China as half the cohort abandoned or failed to commence CPAP treatment. Initial perceptions impacted continued use. Adherence appeared to be defined as continuing treatment. | Patient experience of adhering to CPAP was examined via the question: how many hours/night and number of nights was CPAP used? Those deemed non-adherent were then asked to ‘explain their lack of adherence’.

**Key:**  
AHI apnoea-hypopnoea index; BMI basal metabolic rate; CPAP continuous positive airway pressure; HBM health beliefs model; OSA obstructive sleep apnoea; QOL quality of life; RCT randomised controlled trial RDI respiratory disturbance index; SECI side effects of CPAP inventory; ∞ Denotes limitation observed by review authors, not original authors.
Data Extraction

Data extraction was performed using a standard pro forma, capturing relevance of each paper to the review, focus of the study design and study limitations. Both quantitative and qualitative data relating to patient experience, along with demographic details of the patient sample were extracted from each included study (see Table 4).

Data Evaluation

Study quality was assessed. No gold standard for quality scoring in integrative reviews currently exists. Quality assessment of studies is simpler within single methodologies or where research design is similar; integrative reviews include studies adopting a wide variety of methods creating challenges to quality assessment. Qualitative studies were systematically assessed via the critical appraisal skills programme (CASP) quality assessment tool. It was noted that CASP tools had not been developed for the quantitative research designs in this review. Therefore, the Hawker et al. quality assessment tool was sourced for quantitative studies as it is flexible across all quantitative designs. Papers were assessed for methodological rigour and relevance to the research question. Assessment criteria included provision of a clear statement of research aim; appropriateness of the methodology to the research question; appropriate recruitment strategy, data collection and analysis; evidence of ethics and attention to bias. Studies evaluated via these criteria were assessed as good, fair, poor or very poor. Quality cross checking was carried out independently by KW and MG and consensus reached. The evaluation yielded two ‘poor’ studies, nine ‘fair’ studies, and eleven ‘good’ studies (see Table 4).

Data Synthesis

Data synthesis occurred in phases. Data were extracted and tabulated to allow for identification of common themes by KW using Word Excel as a sorting tool. This enabled data about patient experience of CPAP from studies of differing methodologies to be grouped into common themes. The themes were then refined (see Table 5).

Table 5: Phases of synthesis

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
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<tbody>
<tr>
<td>Immersion in the data</td>
<td>Re-reading included papers in detail and noting initial ideas</td>
</tr>
<tr>
<td>Initial coding</td>
<td>Coding systematically across all included papers for common topics and features of patient experiences of continuous positive airway pressure.</td>
</tr>
<tr>
<td>Identifying themes</td>
<td>Sorting codes into themes</td>
</tr>
<tr>
<td>Refining themes</td>
<td>Double checking that data fits themes and with the research question.</td>
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<td></td>
<td>Report writing to refine final themes.</td>
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</table>

(Adapted from Braun & Clarke, 2006)
2.1.4. Results

Of the 22 papers included in the review, seven used qualitative methods,148, 150, 152, 154, 155, 162, 163 one mixed methods32 and the remainder quantitative methods.28, 31, 76, 143, 149, 151, 153, 156-161, 164 Five studies were exploratory and had small sample sizes.31, 32, 152, 162, 171 Sample populations were recruited from urban and/or rural sleep or pulmonary clinics. Three studies sampled from national networks.156, 160, 162 Studies were conducted in America,28, 32, 154, 155, 161 Canada,148, 158 Sweden,149-153, Scotland,156 Germany,157 France,143, 160, 162, 163 Italy,76 China164 and Australia.31 Participant age ranged between 30 and 75 years with five studies including both younger and older participants.28, 76, 153, 159, 161 OSA was reported as moderate to severe except in three studies that did not report severity.154, 155, 160 CPAP use varied from just one night,28, 31 to the first six months of use,32, 76, 150, 155, 163 to six months or more.149, 157, 159, 160, 162, 164 Six studies included participants who had abandoned treatment.143, 148, 155, 157, 161, 162

The studies identified by this review of the literature regarding personal experiences of CPAP use all investigated factors that helped or hindered CPAP use. Experiences were positively influenced by factors such as a good therapeutic response to CPAP, or negatively by factors such as side effects. Thematic analysis identified three themes relating to experiences using CPAP: 1) users’ beliefs about CPAP influence users’ experiences of CPAP; 2) experiencing CPAP is investigated and reported as synonymous with experiencing difficulty; and 3) spouse and family influence users’ experiences of CPAP. The process of thematic analysis also highlighted that users’ reporting of CPAP experiences was constrained by investigator-defined assessment methods, as outlined in the following section.

Overview of the state of the evidence

The study design of the included papers was identified as a key determinant of what the data captured about experiencing CPAP. Nine of the 22 studies investigated CPAP as part of a larger study,31, 32, 76, 143, 156-160, 164 and none of the included studies captured all aspects of experiencing CPAP. Commonly studies only investigated discrete aspects of experience and focused in particular upon difficulties or problems using the CPAP device.76, 148, 154-156, 162 A number of studies examined only one discrete aspect of patients’ experience, such as side effects.28, 143, 151-153, 158, 160, 163

Although the majority of studies investigated aspects of users’ experiences of CPAP, these were based on predetermined response categories that had not been derived from user accounts of CPAP use. For example, where side effects were listed as response options28, 31, 143, 149, 151, 153, 156-158, 160 these were derived from the CPAP literature and expert or investigator opinion rather than from data derived from CPAP users themselves. Responses were also limited to a Likert31, 76, 153, 157 or categorical scale.28, 158 The exception to this was the SECI,153 which was developed on the basis of in-depth interviews with 23 CPAP patients, plus professional expert review.152 Though in-depth interviews allowed full expression of CPAP users’ views in the development of SECI, subsequent
administration focused on only the perceived frequency, magnitude and impact of side effects of CPAP.\textsuperscript{149, 151}

The qualitative\textsuperscript{148, 150, 152, 154, 155, 162, 163} and mixed methods studies\textsuperscript{32} identified in the review captured aspects of experiencing CPAP from the users’ perspectives through semi-structured interview and open-ended questionnaire items. Attempts were made to avoid leading the participant by using broader terms, i.e. ‘CPAP use’ rather than ‘adherence’, to promote freer expression of participants’ perspectives.\textsuperscript{152} However, questions, and therefore findings, were limited to factors influencing volition to use CPAP,\textsuperscript{148, 152, 154} difficulties with CPAP in the initial stages of treatment\textsuperscript{150, 155, 163} or the expectations of long-term treatment.\textsuperscript{32, 162} Two quantitative studies,\textsuperscript{159, 164} although soliciting the participant viewpoint via open-ended questions, were less comprehensive in their exploration. Wang et al.\textsuperscript{164} asked just two simple questions: were the respondents’ adherent to their treatment and if not why not? Holmdahl et al.\textsuperscript{159} asked participants to describe only the most positive and most negative aspect of their treatment; these were reported respectively as reduced tiredness and dependence on CPAP and mask problems.

Duration of CPAP use differed across the studies from just one night\textsuperscript{28, 31} to many years.\textsuperscript{149, 151-153, 159} Duration of use was reported to influence the experiences participants had with their CPAP. For example, the closer participants were to CPAP initiation the more dissatisfied they were with CPAP.\textsuperscript{159, 160, 163} However 90\%\textsuperscript{160} and 99\%\textsuperscript{159} of participants surveyed after six months or more of CPAP use rated their satisfaction with the experience of CPAP as good or excellent. The exception to this was participant samples where treatment had been abandoned due to dissatisfaction, irrespective of CPAP duration.\textsuperscript{148, 155, 157, 162}

**Theme 1. Users’ beliefs about CPAP influence users’ experiences of CPAP**

Users’ preconceived attitudes and expectations about CPAP prior to use influenced experiences, as did participant attitudes towards the therapy.\textsuperscript{31, 149, 152} Perceptions that CPAP would improve symptoms and reduce health risk\textsuperscript{148, 150, 152} were reinforced by reduced hypersomnia and improved function.\textsuperscript{31, 32, 148, 152, 154, 159} Conversely mild OSA symptoms or poor symptom improvement increased the likelihood of poorer experiences with CPAP.\textsuperscript{31, 32, 148, 152, 154, 159} Unmet expectations such as continued hypersomnia, perceived as a failed ‘miracle cure’,\textsuperscript{162, 163} led to negative perceptions of treatment.\textsuperscript{148, 150, 154, 163, 164} Patients rated their ability to learn about CPAP, and the subsequent positive effect on CPAP use, as greater than healthcare personnel rated patients’ ability.\textsuperscript{151} Similarly, a formal support group\textsuperscript{154} and engaged caregivers in the family home\textsuperscript{67} facilitated CPAP use by mitigating users’ experiences of potential barriers.\textsuperscript{32, 148} However, initial and on-going practical difficulty using CPAP apparatus,\textsuperscript{31, 152, 154, 159} including frustration and physical discomfort\textsuperscript{31, 150, 162} negatively influenced the experience of using CPAP.

Fear of health and social consequences associated with CPAP use was an identified sub-theme in six studies.\textsuperscript{31, 32, 148, 150, 152, 163} Not using CPAP was perceived to risk relationships, productivity, participation in society, and driving licences and manifested as fear that motivated use.\textsuperscript{32, 148} Consequently, not using CPAP triggered guilt.\textsuperscript{148, 152} Participants felt ugly and embarrassed wearing
the CPAP mask. Others feared the stigma of being seen as odd and were deterred by the perception that needing a medical prosthesis identified them as ill.

However, hindrances such as side effects and negative perceptions of others were not always of consequence, especially if the user had high self-efficacy. Positive mind-set and confidence using equipment aided perseverance with therapy. Conversely, those with negative mindset experienced higher magnitude and frequency of side effects and were more likely to allow problems to hinder use.

**Theme 2. CPAP users are primed to reflect negatively on experiences of CPAP**

Most studies were conducted from the standpoint that CPAP is a difficult therapy. The terms researchers used referred to problems, difficulties or trouble using CPAP, describing it as a nuisance and torment that caused discomfort and imposition during sleep. CPAP use resulted in adverse side effects to tolerate or struggle with. In particular, 17 of the included studies investigated or reported side effects of CPAP to some degree. Nasal and mask related problems predominated, with 50% of participants in one study experiencing at least one side effect.

Needing to persevere with therapy to master use of the device, particularly at the outset of treatment, was evident in the findings. Participants expressed frustration and ‘botheration’ using the device and needing to get used to or ‘flunk’ their treatment. Problem-solving and adaptation over time were reported as essential to master the device otherwise treatment was abandoned. Three studies investigated reasons for abandoning treatment, side effects being a commonly cited cause. Trade-off was made between the exhaustion of OSA and the discomfort of CPAP, whilst greater perceived discomfort and nuisance of CPAP resulted in reduced use. Only one study focused specifically on the benefits of CPAP, although two other studies also reported better sleep, improved daytime function and reduced hypersomnia.

**Theme 3: Spouse and family influence users’ experiences of CPAP**

Few papers addressed CPAP use in daily life, although six studies examined elements associated with those living and working with the CPAP user. Partners experienced personal and social distress prior to CPAP initiation and were motivated to support the patient during the adaptation phase. For example, married users problem-solved and incorporated CPAP into their lives quicker than unmarried users. Committed partners involved themselves with overcoming barriers hindering CPAP use, as did others in the family home. Equally negative or absent family support led to poorer experiences with treatment, with male spouses less involved with their partners CPAP treatment than female spouses.
Chapter 2

2.1.5. Discussion

Overall, analysis of the 22 papers in this review identified limited information about experiences CPAP users’ have from their own perspective. The literature reports phenomena that help or hinder CPAP use, with a focus on enhancing compliance. The choice of research design, such as survey, pre-determined problem checklists or interview questions, influenced what was reported about and limited capture of all aspects of experiences of using CPAP. Understanding about users’ experiences using CPAP is therefore incomplete.

With the exception of SECI153, checklist content was derived from investigator knowledge and expert opinion rather than opinions of individuals using CPAP. Dempsey and Dempsey172 identify that some of the limitations of checklists include assuming all potential conditions of a phenomenon are identified along with the risk of autosuggestion.172 Reliability or validity173 of checklists was also unclear in a number of studies as the source of side effects,143, 156, 160 or side effects used were unreported.157 Both consistent and non-consistent CPAP users reported similar side effects with similar frequency when checklists were administered,28 suggesting that mechanisms other than side effects alone impact volition to maintain therapy. In contrast to checklists and survey questions, data from semi-structured interviews allowed open responses from the participant. However, by giving attention to influencing factors,148, 152, 162 such as being motivated to adhere154 or identifying reasons for abandoning CPAP150, 155 studies using semi-structured interviews were constrained by a predefined topic of adherence to CPAP. Dissatisfied users may have stopped treatment and been unavailable to the longer range studies that demonstrated satisfaction with therapy. Additionally, sampling participants in the initial stages of CPAP treatment may have focused research on initial problems versus long-term adaptation.

While CPAP use can be challenging, the problem-oriented terminology adopted by most studies76, 143, 150, 154-156, 158, 160 32, 162, 163 may set up the expectation that all users will find CPAP problematic. However, few studies employed positive descriptors relating to CPAP use. Equally, anticipating side effects by documenting them in the research instrument limits exploration to only problems users have with CPAP. Limiting the research instrument in this way may exclude information from CPAP users who have no difficulty. Rather than considering CPAP as inherently problematic for all users the focus of future research might be how patients successfully manage their CPAP.

With the exception of the SECI development152, 153 most studies focusing on difficulties using CPAP did not consult CPAP users when developing surveys. Given the now accepted concept of patients as experts in their conditions and treatment, this is contrary to current thinking.174-177 Underestimating patients’ capacity to maximise facilitators such as education and support from health professionals, along with the capacity to adjust to CPAP mitigates collaborative partnership.174 For example, one study in the review showed CPAP users perceived that side effects had a less adverse effect on adherence and that they were more able to learn about OSA and CPAP than health professionals believed.151 In the same way, under-utilising end-users’ in the research setting increases potential for missed avenues of exploration.
The importance of an engaged spouse and family was significant to the CPAP user, although limited research was found by this review.\textsuperscript{150, 161} This topic is underexplored and current studies are limited by a focus on adherence. Equally, the fear of social stigma was underexplored within the studies of this review. Recognising that using CPAP is a social experience is important. Further investigation into the significance of spouse and family engagement with the CPAP user is warranted.

### 2.1.6. Conclusion to the review

This is the first systematic review of patient experiences of CPAP and has identified limited evidence about CPAP experiences from the users’ perspective. Untreated OSA is associated with high personal and economic cost and maintaining adherence to CPAP is acknowledged as a complex issue.\textsuperscript{178} However, current research is constrained by researchers’ concern with non-compliance, which limits understanding and risks imposing unsuitable treatment regimens on CPAP users. Typically, experiences of CPAP are not defined by the user, but from an ‘expert’ healthcare perspective, using language that defines CPAP as inherently problematic. Addressing CPAP users’ concerns through a problem-oriented paradigm may miss important clues about how people experience using and successfully managing CPAP. Research that more comprehensively involves CPAP users’ opinions using their own words is required to determine how patients manage this therapy successfully.

**Practice points:** There is already evidence suggesting adherence rates to CPAP treatment are low. This integrative review identifies that when treating patients with CPAP for sleep apnoea it may be useful to:

- Be aware that existing attitudes of patients and their partners towards CPAP treatment may influence experiences with CPAP therapy.
- Acknowledge to the patient that using CPAP can be challenging, but that persevering can yield positive results.
- Engage the partner in the planned treatment regimen.
- Use the SECI tool in practice to determine the extent to which side effects impact the patient.

**Research agenda:** Research to date has focused on the problematic nature of CPAP. However, there is a dearth of research with those who do not have problems with CPAP. Future research should include:

- Engaging end-users in the development of assessment and research tools, for example, using cognitive interviewing techniques.
- Exploring the extent and significance of partner and family engagement with CPAP to the users’ experience of CPAP.
- Interviews with patients who have used CPAP for an extended period (for example longer than 6 months) to identify which strategies support prolonged use.
2.2. Postscript to integrative review

As identified by the preceding review, sleep medicine literature expresses a concern that CPAP is under-utilised by users.25, 28-37, 179 Indeed, a large body of research regarding CPAP for sleep apnoea has a strong focus on improving compliance with this therapy.23-26, 180-185 The importance of and need to improve compliance and the problem of non-compliance have been an area of interest in the medical and research literature for decades.186-188 The term compliance continues to describe patient behaviour and pervades the vernacular of medical and nursing literature. While conducting the review in the previous section, it became clear that improving compliance with CPAP was a principal focus in the sleep medicine literature. How sleep medicine defines non-compliance and the influence this could have upon the participants warrants consideration. Since the compliance narrative is so dominant in the literature, it was reasonable to assume that it also influenced my thinking. This project explores user’s experiences with prescribed CPAP, and I wanted focus to remain upon success with treatment. Consequently, I chose to scrutinise the concept of compliance within healthcare to guard against the influence of received knowledge and to draw upon the topic as a potential source for theoretical sensitivity.189, 190 Using Michel Foucault’s191-193 perspectives regarding surveillance, governmentality and the responsibilised self, the following sections consider how compliance is enacted within healthcare and potentially with the participants in this study.

2.3. Considering the discourse of compliance in healthcare

Given the potential to spend health dollars on a treatment that might go unused, the expectation of compliance with a healthcare directive appears reasonable. The concept of compliance is associated with a healthcare provider-centred exchange in which power in the healthcare relationship resides with the provider.194 In the context of this study, the nursing, medical and allied health staff at the respiratory clinic from which I recruited participants represented the healthcare provider. I anticipated I might encounter data that would reflect the power dynamic between clinic staff and the participants. Therefore, I used Michel Foucault’s191-193 focus on the interplay of power in society as a useful construct through which to consider the discourse of compliance in healthcare.

2.3.1. How did compliance become a healthcare discourse?

In Discipline and Punish, Foucault196 referred to how people are made knowable via discourses. Discourses reflect the ways that people know and talk about knowledge by bringing or speaking realities into being, such as the medical discourse.192, 196 Therefore, a discourse asserts a preferred version of the world. For example, a hospitalised person inhabits the role of ‘the patient,’ rather than being the version of themselves at work. In terms of the medical discourse, clinicians and scientists are presumed to know the ‘truth’ about ill-health and have the authority to label it a disease, provide medical advice and prescribe treatment.197-199 Compliance, or the more contemporary term
adherence, describes the ideal that a person’s behaviour coincides with medical advice. For example, a person with sleep apnoea might comply with prescribed nightly use of CPAP to avoid the consequences of untreated sleep apnoea outlined in the introductory chapter. Non-compliance is the action of not heeding medical advice and behaving contrary to directions, commonly viewed as deviant behaviour with negative connotations. Therefore, non-compliance for the CPAP-user would be using the device for less than the prescribed hours each night. This view is predicated on the passive role of the patient as a receiver of expert medical service, rather than as a person active in their own healthcare.

Scholars argue that compliance is a loaded term overlooking the inherent complexities and constraints of complying with treatment. The binary nature of the concept means that if there is compliance, there must be non-compliance; the patient is either compliant or non-compliant and by inference a good or bad patient. Foucault described such a dichotomy as a “regime of truth” determined by the values and customs of the medical discourse. Non-compliance suggests a refusal to comply, attended by deviant behaviour and negative depiction of the ‘difficult patient.’ Indeed, non-compliance has been an accepted nursing diagnosis since the 1970s. In 2003, the World Health Organisation suggested the alternative term ‘adherence,’ evocative of a mutually acceptable course of action. However, in reality adherence, much like compliance, refers to following a recommended course of action.

Playle and Keeley suggested that the discourse around patient compliance is framed to place blame on the individual to reduce the culpability of health providers and policy makers. Labelling an individual non-compliant enables clinicians to lay blame upon a person adequately educated but who chooses not to comply. For example, in New Zealand, people who use CPAP less than the required hours per night and are employed as drivers risk losing their driving license. Those who do not drive for a living risk losing the device. Consequently, the conceptualisation of the problem of non-compliance locates the problem within the individual and frames the implementation of interventions and research. Patient education becomes a medico-centred model of control, rather than a patient-centred model of care. Similarly, the production of health literacy research, health promotion behaviours and health behaviour models all seek to identify persons prone to non-compliance and consequently to intervene. These views position compliance as an issue of self-discipline, or governmentality.

2.3.2. Compliance as governmentality and the responsibilised self

Foucault described the process of governmentality (or biopower) as one of regulating and disciplining populations, and claimed that discourse informs the power to discipline. Foucault suggested that modern day discourses focus upon control of the individual through observation and documentation to maintain social order and promote health and productivity. The clinical examination is a manifestation of this. Similarly, most CPAP devices incorporate an hours-of-use counter to allow clinicians to monitor and document usage.
Foucault\textsuperscript{192, 196} repositioned the concept of power from a top-down hierarchical power to a dispersal of state power into new social sites of control such as the self, manifesting as ‘self-control.’\textsuperscript{210} Concepts of self-efficacy, self-care and self-management are apparent within Foucault’s\textsuperscript{192} technologies of the self. Recent studies concerned with promoting adherence to CPAP reflect this view.\textsuperscript{211-216} Individuals are ‘responsibilised’ by causing them to understand the social risk of illness and, in particular, to understand that such a risk is not the responsibility of the state, but a responsibility of the person to exercise self-care.\textsuperscript{196} Most of the studies already cited in this thesis regarding patient uptake of CPAP typically begin by outlining the health risks and social costs of untreated sleep apnoea. Indeed, recent studies, including a Cochrane review, concluded that educational and behavioural interventions that improve understanding of CPAP and enhance self-efficacy with CPAP serve to increase CPAP use.\textsuperscript{180, 182, 184, 217, 218}

Not complying with CPAP risks increased daytime somnolence and the possibility of road trauma, as described in chapter one (see section 1.2). The responsibilised actor mitigates this risk by complying with therapy. Consequently, risk reduction through compliance with medical therapies such as CPAP characterises the responsibilised self.\textsuperscript{210} Moreover, the identification of risk gives clinicians a point of intervention in the non-sick patient. Risk is to be reduced or controlled, and the reduction of risk can only be achieved by patients disciplining their lifestyles and complying with advice.\textsuperscript{219} Consequently, the ‘free’ are not so free, being obligated to mitigate risk to behave for the greater good rather than please themselves.\textsuperscript{196}

### 2.3.3. Compliance as surveillance or reciprocity

Foucault’s\textsuperscript{195} earlier work adopted Bentham’s ideal of the prison panopticon to illustrate the power of surveillance. The panopticon was a rotunda of cells around a central guard tower from which guards could see prisoners without the prisoners’ knowledge. The prison metaphor symbolises surveillance, the perception of being watched without knowing when, and self-regulating action accordingly, such as observing the speed limit. Similarly, the hours-of-use counter on a CPAP machine, monitored by both clinicians and researchers, illustrates healthcare surveillance. The act of monitoring implies an assumption the patient is likely to deviate and cannot be trusted, so conveying power to the watcher rather than the monitored patient. Therefore, power by surveillance becomes central to the issue of compliance, as the clinician ‘watcher’ has the power to label the CPAP-user as non-compliant.\textsuperscript{196} This concept raised the possibility of comment from participants in the current study regarding their CPAP use.

Playle and Keeley\textsuperscript{186} argue that at a covert level compliance is an issue of professional power and control and that non-compliance is a label denying the legitimacy of actions that differ from clinician directive. Regulation of patients by medical expertise seductively promises restoration and maintenance of good health. This regulation works in society beyond the clinic walls as people self-police to adhere to expert advice and remain well. The power of reciprocity is at play here. The view of the clinician as an expert in diagnosis, prescribing and treatment invites reciprocation from the patient to comply with the expert service provided.\textsuperscript{220} To not comply challenges professionally
held beliefs and is viewed as deviant. By judging the appropriateness of patient behaviour, the clinician undermines patient autonomy.

### 2.3.4. Considering compliance in the context of this study

Foucault’s ideas of surveillance and governmentality implicate the patient as a victim, having treatment imposed upon them, in contrast to sharing in the social transactions of healthcare. Foucault promotes the idea of the top-down creation of the person, scripted by discourse rather than as agent in the creation of discourse. However, the discourse of diseases, such as sleep apnoea, might be construed as a mutual construction through the patient’s experience of a disease and the doctor’s view of disease. In this scenario, the eager patient would readily submit to the discourse of medicine to stop the disease and feel better.

Similarly, unlike prisoners, patients are not physically confined by medical surveillance. A person who constantly falls asleep during the day may engage in a medical transaction to constructively attempt to reduce sleepiness, or they may mobilise other strategies to resolve discomfort. Indeed, application of the medical discourse is not conclusive, as individuals may opt to exercise free choice. The panopticon metaphor has potential when applied to custodial institutions or even intensive care environments. However, the option to choose calls into question the extent of surveillance within healthcare. Equally, it may be naïve to imagine that the state and only the state is the source of governmentality and surveillance. As Miller and Rose observe, the emergence of systems of rule may be sporadic, ad hoc and local. Peer pressure springs to mind.

Considering the discourse of compliance in healthcare draws attention to the assumptions within healthcare and by association, me. Additionally, considering the influence of compliance raises the possibility for the clinician-patient relationship and/or the experience of surveillance to be a source of comment by participants in this study. Complying with therapies to remain well is reasonable, and questioning the need for compliance a right in itself. While the locus of the non-compliance ‘problem’ might reside with the CPAP-user, the literature provides notably scant evidence regarding CPAP-user views on complying with therapy. What does exist describes patients’ notions of non-compliance as constructive, conscious decision-making. Rarely does it seem that authors focus on how patients manage therapies successfully. In chapter three, I discuss the importance of reflecting on the discourse of compliance to this grounded theory study and illustrate the contribution of this critique of compliance in healthcare to theoretical sensitivity in chapter four (see 3.5.2, p.53 and 4.4.1, p.81 respectively).
2.4. Chapter 2 Summary

In summary, untreated OSA is associated with high personal and economic cost, and maintaining the use of CPAP is acknowledged as a complex issue.\textsuperscript{178} The integrative review presented in this chapter indicates that current research is constrained by researchers’ concern with non-compliance, which limits understanding and risks imposing unsuitable treatment regimens on CPAP users. Typically, experiences of CPAP are defined from an ‘expert’ healthcare perspective, using language that defines CPAP as problematic. Addressing CPAP users’ concerns through a problem-oriented paradigm may miss important clues about how people experience and successfully manage CPAP. Furthermore, family and social support is a significant but neglected area of experiencing CPAP and warrants further investigation. Research that more comprehensively involves CPAP users is required to determine how patients manage this therapy successfully.

A systematic, integrative literature review is useful for synthesising qualitative and quantitative evidence. Findings of this integrative review indicate that when recommending CPAP it may be useful to consider patient views and beliefs about the treatment before use, including attitudinal disposition, and not approach treatment as likely to be problematic in the first instance. Although CPAP may be a difficult therapy to use, this review has identified limited evidence regarding users’ perspectives on using CPAP.\textsuperscript{27} Currently, the literature examines the topic from a problem-oriented paradigm and with a focus on optimising compliance. Therefore, I explored how the tacit and explicit assumptions underlying the discourse of compliance in health serve to position patients, clinicians and researchers. By focusing on improving compliance it is possible that research to date has missed important clues about how people experience using and successfully managing CPAP. Consequently, the grounded theory study reported in this thesis emphasises the patients’ perspective and, rather than considering CPAP as a problem to overcome, focuses on exploring how users live with this therapy. The following chapter outlines my theoretical viewpoint. Additionally, I discuss the nature of theory and the philosophical underpinning of grounded theory methodology.
CHAPTER THREE

Methodology
Chapter 3. Methodology

“But epistemology is always and inevitably personal. The point of the probe is always in the heart of the explorer: What is my answer to the question of the nature of knowing?”

Bateson, 1979 (p. 87)

Grounded theory is a commonly used research methodology/method that is useful for constructing theory directly from the data when there is little evidence to support a hypothesis. Given the limited evidence available, I chose a grounded theory methodology to explore how users of CPAP managed to live with their therapy. The purpose of this chapter is to describe this research approach, and the associated theoretical position of both grounded theory and myself as a researcher.

This chapter begins by discussing the nature of theory and how theoretical paradigms change over time. What follows is a published article that describes grounded theory and gives justification for choosing this methodology. In this article I outline the theoretical position of both grounded theory and the evolution of my philosophies as a nurse and researcher, culminating in my current position of social constructionism. Establishing a theoretical position prior to starting a study supports the credibility of the analysis and the claims generated from the data, along with meeting criteria for judging the quality of a grounded theory project. Therefore, attention is given to the theoretical principles of grounded theory. The chapter concludes by presenting how the principle of reflexivity manifests in grounded theory.

3.1. The nature of theory

Birks and Mills state that in a grounded theory project the researcher must be able to demonstrate methodological congruence with the research design. This entails demonstration of agreement between the stated aims of the research, the methodological approach used and the researchers’ personal philosophical position. Philosophical viewpoints underpin methodology and method. Accordingly, this section examines the nature of theory and presents the philosophical positions of social constructionism and pragmatism.

Van Lange, Kruglanski, and Higgins describe theories as ideas that “pull the strands of seemingly disparate occurrences and tie them into coherent systems guided by common principles.” Theories have explanatory power and provide a conceptual framework for exploring a phenomenon, situation or behaviour. Buetow describes theories as operating within a hierarchy of levels, from least abstract level to most abstract. On the least abstract level is micro theory, offering explanations about narrowly defined phenomenon that are practice-based and easy to test empirically. Mid-range theories focus on the more abstract social and organisational phenomena;
they can predict behaviour and are testable. An example would be the health beliefs model.\textsuperscript{215, 228} The aim of a grounded theory study is to generate theory at this substantive mid-range level. More wide-ranging grand theories provide fresh perspectives on phenomena, but the level of abstraction makes empirical testing difficult. Parse's\textsuperscript{229, 230} theory of human becoming is an example of grand theory. The most abstract level of theory is meta-theory, or theory about theory. According to Buetow,\textsuperscript{38} pragmatism, and social constructionism fall under the rubric of meta-theory.

The theoretical frameworks of pragmatism and social constructionism influenced the evolution of grounded theory. The article in this chapter explores the influence of social constructionism on Charmaz's variant of grounded theory, along with my methodological choices. Pragmatism influenced earlier variants of grounded theory, particularly Anselm Strauss' work. Strauss studied as a student of early pragmatist thinker George Herbert Mead, who himself was influenced by the work of his friend and philosopher John Dewey. Dewey was a proponent of pragmatism, a philosophy assuming that the construction of society, reality and self occurs through interaction and relies on language and communication within social groups. In the third edition of \textit{Basics of Qualitative Research}, Corbin\textsuperscript{231} writes that pragmatism is "easily recognisable as the framework for our own methodology."\textsuperscript{222} The ideas of Mead\textsuperscript{232, 233} formed the foundation for symbolic interactionism, but it was Blumer\textsuperscript{234} who later clarified Mead's ideas and coined the term 'symbolic interactionism.'

Symbolic interactionism refers to people interpreting and creating meaning from their experiences with other people. Blumer\textsuperscript{234} identified three underlying premises of symbolic interactionism that are clarified and extended by Charmaz.\textsuperscript{235} The premises are as follows. Firstly, people act towards things based on the meaning things have for them. The meaning of things, people or situations arises from individual interpretive processes and via social interactions that include shared language and communication. Secondly, meaning is interpreted, modified and re-created over time in response to internal processes of perception and logic as well as interaction with others and with external factors.\textsuperscript{234, 235} Thirdly, the meaning attributed to things, particularly problematic things and situations, subsequently impacts human action and processes.\textsuperscript{45, 233, 236, 237}

Strauss chose to study human action and interaction and, as Corbin\textsuperscript{238} describes, the above methodological principles were visible in his work, although not overtly stated. Barney Glaser, who developed grounded theory with Strauss, differed from Strauss in terms of theoretical perspective, which will be discussed later in this chapter. The differing philosophical perspectives of noted grounded theorists speak to the evolving nature of the methodology. Corbin\textsuperscript{239} notes that her thinking about methodology has been influenced and changed over time, and describes herself as a "mixture of many things."\textsuperscript{2}(p.9) Indeed, her recent writing reflects a social constructionist influence.\textsuperscript{239} The next section considers the evolving nature of theories in science and grounded theory.
3.2. Evolving theories in science

In *The Structure of Scientific Revolution*, Kuhn\(^{240}\) theorises that scientific progress is characterised by periods of universally accepted scientific paradigms, or “normal science,” punctuated by moments of intellectual revolution.\(^{241}\) The presence of enough significant irregularities that cannot be explained by a current theoretical perspective prompts new ways of thinking. As a result, new ideas are trialled, leading to a shift in paradigm. For example, until the early 1900s Descartes’ ‘luminiferous ether’ was believed to be the medium by which light travelled.\(^{242}\) The 1887 Michelson-Morley experiment disproved the existence of ether by showing light travelled at the same speed in all directions and conditions, and so caused a revolutionary paradigm change that preceded Einstein’s Theory of Relativity.\(^{243}\) This is one example supporting Kuhn’s\(^{244}\) idea that a scientific paradigm is rendered “invalid only if an alternative candidate is available.”\(^{247}\)

A scientific paradigm shift appears most dramatic within scientific worldviews that have become stable and familiar. For example, late 19th-century physicists believed their discipline required only refinement, as nothing remained to discover. Enter Albert Einstein’s Theory of Relativity, which challenged the then reputable paradigm of Newtonian mechanics.\(^{242}\) However, the assumption that paradigm changes are dramatic and sudden overlooks the possibility of paradigm change being more subtle or more frequent than Kuhn suggested.\(^{245, 246}\) Following a profound paradigm shift there is clearly no going back; the proof that light travels without ether made rejection of the old paradigm absolute. However, the truth that luminiferous ether did not exist was rejected for some time after being proven.\(^{242}\) Change was therefore slow to eventuate, and a critical mass of believers in the new paradigm was required before change occurred.

A shift in paradigm may be more subtle and, with historical hindsight, it may result not from world-shaking epiphanies but rather a series of smaller turning points.\(^{245}\) Irregularities present within a paradigm may merely reflect incompatibilities with the methods of solving a puzzle; finding the answer may require a different question. For example, the growing popularity of the qualitative paradigm of scientific enquiry over the last twenty years has challenged the primacy of quantitative enquiry.\(^{38, 39, 41}\) Qualitative research is recognised for its ability to capture meaning or interpret peoples’ experiences.\(^{247}\) Understanding the meaning of phenomena, such as healthcare, to the people experiencing them provides a wider evidence base to consult when planning care. Therefore, progress in science is marked by the evolution of scientific thinking as much as by intellectual revolution.\(^{241, 245, 246}\)

The variants of grounded theory that now exist, including Charmaz’s constructionist grounded theory, are an example of the evolution of scientific thinking. Charmaz\(^{44}\) suggests that two main epistemologies inform contemporary grounded theory: objectivism and constructionism. Objectivism describes the conviction that reality is mind-independent, upholding the validity of objective phenomena over subjective experience. Constructionism speaks to socially constructed realities and is more congruent with exploring patient experiences than an objectivist approach (see Table 6).\(^{44, 47, 226}\)
<table>
<thead>
<tr>
<th><strong>Epistemology:</strong></th>
<th><strong>Objectivism</strong></th>
<th><strong>Constructionism</strong></th>
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<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Reality is objective and external to the mind.(^{47, 248}) Knowledge derived from observation of objects and events.(^{38})</td>
<td>Reality is individually constructed through the interpretation of the natural world.(^{44, 47}) The researcher’s own worldview becomes a valid influence on the theories offered.</td>
</tr>
<tr>
<td><strong>Assumptions</strong></td>
<td>The researcher takes an objective and neutral stance and discovers social and physical reality by observing and measuring the external conditions of the phenomena studied.(^{44, 47})</td>
<td>Multiple realities exist.(^{226}) The researcher must consider many possible explanations when constructing meaning associated with the phenomena studied.(^{48, 248})</td>
</tr>
<tr>
<td><strong>Applications in research</strong></td>
<td>Used to develop a reductionist theory with the intention of explanation and prediction of phenomena, as with quantitative research paradigm.(^{44, 47}) Emphasis on replicable, generalisable and quantifiable prediction while controlling for contextual factors as seen with interventional studies to improve CPAP compliance.(^{23, 24, 34, 142, 214, 249-252})</td>
<td>Underpins study of how and why participants construct meaning and actions in particular situations.(^ {44}) Emphasis on analysis of individuals’ experiences and perceptions of phenomena with respect to the context within which they exist, plus emphasis on researcher as integral to the development of findings.</td>
</tr>
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Similar to historical changes in scientific thinking, my thinking has evolved since I first became a nurse. Table 7 reflects the parallel changes in both grounded theory and my theoretical perspective, both of which I discuss in the following article.
Table 7: Three epistemological stages of grounded theory and of KW

<table>
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<tr>
<th>Stage of metamorphosis</th>
<th>Grounded Theory (GT)</th>
<th>Author KW</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st generation GT: post-positivism dominant school of thought at the time Glaser and Strauss developed and wrote about GT. Researcher as detached and objective. Research approached with a ‘tabula rasa’* Scope for broader application.</td>
<td>Post-positivism dominant school of thought as evidence-based practice (EBP) pervaded nursing and KW embarked on her training as a nurse - 1987. Evidence based on objectively researched data. Representation and generalisability possible.</td>
<td></td>
</tr>
<tr>
<td>2nd generation GT: Symbolic interactionism is becoming a clearer influence on Strauss and Corbin's GT work. Researcher as less detached but not yet considered fully integral to the research process. ‘Tabula rasa’ in contention. Scope for practical application to similar cohorts.</td>
<td>Questioning the hegemony of EBP as compared to real life experiences of subjective and relative patient experiences. Mismatch observed between evidence based on objectively researched data and real-life experiences. Need for representation and generalisability questioned.</td>
<td></td>
</tr>
<tr>
<td>3rd generation GT: Kathy Charmaz developed principles of constructionist GT. Researcher as an integral part of the research process. ‘Tabula rasa’ as an impossibility. Scope for application to this group of people in this context.</td>
<td>KW developed understanding about her social constructionist views of the world as constructed together in community. Socially constructed real-life experiences provide legitimate practice-based evidence. Representation and generalisability incompatible.</td>
<td></td>
</tr>
</tbody>
</table>

Key: *Tabular rasa: blank slate.

Adapted from Birks and Mills48

At the outset, Kuhn244 theorised that paradigm change results from dramatic crises of unresolved irregularities during periods of ‘normal science’ prompting a move to a new and incommensurate paradigm of enquiry. However, Kuhn agreed that paradigm change is science’s version of “picking up the other end of the stick.”244 (p.85) Essentially, paradigm change represents on-going revisions leading to the evolution of different scientific frameworks through which to solve problems. The following article reflects a more modest and personal paradigm change that altered my philosophical position from a positivistic view to a constructionist view. Reference to evidence-based practice within the article is time bound, that is, as it was understood in the 1980’s, not as it might be understood now.

The following article is cited as,


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ARTICLE: Evolving from a positivist to constructionist epistemology while using grounded theory.

3.2.1. Abstract

Specifying epistemology guiding health research provides evidence of a researcher’s worldview and thus the rationale for methodological choices. A challenging quagmire of epistemological options exists for the novice nurse researcher, often difficult to navigate, particularly in the absence of a philosophical grounding.

During her doctoral journey, the first author (KW) explored living with overnight mask ventilation for sleep apnoea using a social constructionist grounded theory. Choosing this methodology required that KW reconcile her background in evidence-based nursing practice with the various theoretical legacies underpinning grounded theory.

In this article, the philosophical roots of both evidence-based nursing and grounded theory are explored. The influence that both context and the researcher’s relationship with their participants and data have upon knowledge construction is also considered. Parallels are drawn between a developing awareness of epistemology and the evolution of grounded theory research from positivism to social constructionism. This paper will assist novice researchers to consider assumptions about the origins of knowledge and subsequently be of help when choosing a research methodology.

Keywords: epistemology, evidence-based practice, grounded theory, nursing research, positivism, social constructionism

What this paper contributes: This paper fills a gap by documenting considerations given to epistemological and methodological choices. Specifying and reconciling the tensions between an evidence-based nursing background and qualitative research contributes to wider epistemological debates. Moreover, this paper contributes to qualitative research literature by offering clarity to some of the ambiguities that exist between constructivist and constructionist grounded theory. This paper will be of particular interest to researchers seeking to understand the links between epistemology and methodology and those interested in reconciling tensions between evidence-based nursing and qualitative research.
3.2.2. Introduction

Epistemology, identified as best ‘fit’ with a researcher’s study methodology, acts as a ‘lens’ through which a research topic is approached.\textsuperscript{254, 255} Denzin and Lincoln\textsuperscript{40} identify ‘ontology’ as what is known to be real, and ‘epistemology’ as concerning the “relationship between the inquirer and the known.”\textsuperscript{(p.16)} Documenting the ontology and epistemology underpinning health research is a way of evidencing a researcher’s worldview.\textsuperscript{256, 257} However, few papers examine the considerations that researchers give to their epistemological and methodological choices. Typically, documented accounts of the tensions that exist between a positivist evidence-based clinical nursing background and the epistemologies underpinning qualitative methodologies, including grounded theory, are limited to theses. For the novice researcher, the varieties of epistemological options that exist are difficult to navigate particularly where philosophical grounding is absent from academic training. This paper documents the tensions experienced between a nursing career founded upon the evidence-based movement and a current social constructionist epistemology recognised while conducting a grounded theory research project.

Grounded theory (GT), a popular choice for nurse researchers, is useful to explore how people experience and act within their everyday worlds.\textsuperscript{231, 258} We chose this methodology to explore people’s experiences of overnight mask ventilation (CPAP) for sleep apnoea. Nurses have influenced the development of grounded theory including Jeanne Quint Benoliel, who worked with the founders of grounded theory on the seminal \textit{Awareness of Dying} study.\textsuperscript{259, 260} Other nurses include Juliet Corbin, who collaborated with Anselm Strauss,\textsuperscript{231} Phyllis Noerager Stern\textsuperscript{258} and contemporary authors Mills and Birks.\textsuperscript{48} Traditionally, the medical model and more recently the evidence-based practice (EBP) movement have influenced nursing. Both influences rely upon objectively quantifying evidence and a positivist epistemology.\textsuperscript{261, 262} The positivist epistemology underpinning nursing might be considered at odds with the epistemologically ‘other’ world of GT. Nurse, and grounded theorist, Juliet Corbin\textsuperscript{263} alluded to an epistemological discord when she reflected that:

\begin{quote}
I found the quantitative part of the class pretty dry. … However, when the class presentation turned to a discussion of qualitative research methods, I said, “What is this? Tell me more.” There was something about qualitative research that I found very appealing, though at the time I couldn’t have told you what that was.\textsuperscript{(p.36)}
\end{quote}

The following reflective account reconciles an unquestioning positivist upbringing in healthcare as a nurse trained in the hospital system with a growing awareness of KW’s epistemology as a grounded theorist, and addresses theoretical issues and contradictions in academic nurse-researcher development. The different philosophical underpinnings of prominent grounded theorists Glaser, Strauss and Charmaz reflect an evolution similar to that of KW as a nurse and researcher: from positivism to constructionism. In this paper, the evolution of grounded theory methodology/methods is used to parallel the changing beliefs about epistemology that emerged during research and offers clarity to the ambiguities between constructivist and constructionist GT.
3.2.3. KW's experience of evidence-based nursing

I (KW) learned my craft as a nurse during the late 1980s as publications, such as the Briggs Report,264 catalysed a move towards evidence-based practice (EBP). The confidence in EBP demonstrated by healthcare providers and policymakers contributed to the dominance of positivist scientific reasoning within health and supported the authority of EBP to claims of objective truth and knowledge.262, 265, 266 The scholarship of key nursing figures like Alison Kitson and Brendan McCormack, and organisations such as the Joanna Briggs Institute argued for the salience of EBP as a framework for nursing.267 EBP was given a ‘gold standard’ status and was based upon the positivist assumptions that experience and fact are separate. Moreover, the concept of EBP supported the notion of truth as ‘out there’ awaiting discovery.256, 262, 268, 269 Therefore, evidence-based nursing required assumptions be made about reality and what constitutes knowledge: namely, that human responses to healthcare can be objectively measured, causation can be identified, responses can be predicted and that such predictions can be generalised.270 Questioning the tenets of evidence-based nursing practice did not occur to me, nor that ‘evidence’ was anything other than proven by objective, quantitative enquiry. Practice as an intensive care nurse further reinforced the tenets of a hegemonic positivist enquiry due to increased exposure to evidence-based medicine in this setting.

In the decades since, I have come to believe that truth and reality are ‘slippery’ concepts reliant upon personal experiences and beliefs: the patient’s physical body is not nursed in isolation from their mental self, their beliefs, their experiences or their social worlds. To do so would take the patient as a person out of context. For example, if experiencing pain is “what the [patient] says it is,” and therefore subjective, then so are other experiences of healthcare.271 (p.95) Consider the asthma patient who, counter to current knowledge on best practice, insisted on nebulised medication and became agitated at any attempt to persuade her to use an inhaler with a spacer.272 At this moment, I used practice-based evidence by administering nebulised medicine instead of an inhaler, which would have been evidence-based practice.273 Stern et al.274 said that as a patient “a positivistic approach to patient care leaves one pleading, ‘Nurse, listen to me!’”274 (p.371) I listened. Thinking about this change in my practice prompted other questions about my patient’s experiences and my practice. In particular, I wondered what people who used CPAP as a treatment for sleep apnoea thought of this therapy.22 How did they go about living with CPAP, what was it like living with CPAP, and how was the experience for them? Objectively quantifying answers to these questions seemed incongruous – answers from the patients themselves would be relative to their experience and their versions of truth. Employing a positivist paradigm would, therefore, be problematic.

Problems with ‘belief in a knowable world’

The dualist epistemology and realist ontology of positivism - reality as objectively observable, fixed, predictable and generalisable - is based on a “belief in a knowable world.”226, 275 Judging knowledge by meeting criteria for level one on the hierarchy of evidence, reifies the objectively knowable, such as the systematic review of homogenous randomised-controlled trials (RCTs).276-278 Accordingly,
the positivist (realist) focus on absolute truth, where one version is legitimate, *transcends* context. The risk is that EBP is too rigidly applied. For example, a realist based nursing concept such as reducing obesity reduces ill health, taken out of context means a healthy Polynesian athlete with a body mass index >30 is deemed a health risk. Equally, dualism views the mind as separate from the body: the mind operates independently of the physical world, and the knower (subject) is separate from the known (object). This idea appears to suggest the mind works independently of the brain, but does not account for the change or compromise to mental-self observed following head trauma.

Nursing scholars of the 1980s and 90s grappled with and cautioned against defining EBP as a panacea to improve practice and patient outcomes. Should practice be based upon a hierarchy of best evidence, headed by RCTs and systematic review, or based upon discerning use of all forms of available evidence? Later nurse scholars questioned what constituted ‘evidence’, and the dominance of the EBP discourses of ‘normal science’. Other scholars applied energetic postmodern critique to attempts by the EBP movement to define nursing practice.

The emergence of post-positivist and postmodern epistemologies signified attempts to acknowledge the difficulty in defining truth as solely objective. During the 1960s and 1970s, the realisation that ‘hard’ science had diminished meaning to people caused a rejection of realist ontology. This rejection led to new interpretive modes of research, like grounded theory, and the development of epistemologies like social constructionism.

### 3.2.4. Grounded Theory as an evolving method

GT is a strategy for systematically collecting, analysing and constantly comparing qualitative data to develop mid-range theories regarding the hows and whys of social life. Findings are presented and grounded in the participants’ words about their experience. Glaser and Strauss sought truth in the everyday, ordinary and marginalised. They elevated the status of those studied by drawing attention to the complexity of everyday experiences as illustrated in *Awareness of Dying*. By explaining action, GT is useful for exploring peoples’ responses to health problems. Examples include Quint Benoliel’s work about nursing the dying, Charmaz’s exploration of self-identity in chronic illness and more recently Bowers’s collaborations exploring peoples’ experiences of residential and aged care.

Glaser and Strauss’ seminal text *The Discovery of Grounded Theory* was a response to concern that sociologists were preoccupied with verifying theory, rather than generating theory. The original (Glaserian) GT was located towards the end of the modernist second moment of qualitative research (post-WWII to the 1970s), characterised by a belief in human progress achieved through a search for truth and knowledge. As Charmaz stated, Glaser and Strauss challenged the thinking of the time by showing that positivist quantitative research was not the only legitimate form of inquiry. In ‘Discovery,’ Glaser and Strauss incisively argued that GT research should be informed by both objectivist and constructivist methods. Glaser and Strauss advocated the
researcher remain impartial and detached. Nonetheless, they departed from positivism by rejecting the notion of theory deduced from a-priori assumption, instead believing in a blank theoretical slate (‘tabula rasa’) when embarking upon research.

Consequently, the theoretical context of original GT was influenced by Barney Glaser, a statistician loyal to the virtues of post-positivist critical realism, and Anselm Strauss, who operated in the contrasting pragmatist and interpretivist paradigm of symbolic interactionism.47, 298 At a time when realist positivist research dominated, the fusion of Glaser and Strauss’ analytical research skills and philosophical views imbued qualitative research with a newfound credibility and respectability.44, 300, 301 At the same time, the search for positivist evidence-based truth and knowledge was happening within nursing.264, 267 For Glaser and Strauss, as for nursing, truth and knowledge were underpinned by a realism and objectivism that emphasised the real world, if looked for, is out there.291

A new way of knowing in GT

While Glaser remained steadfast to the concepts of objectivist GT (researcher as impartial blank slate), Strauss asserted that symbolic interactionism should guide GT research, developing his approach in collaboration with nurse academic Juliet Corbin.137, 298 For Strauss, symbolic interaction enabled interpretation of both the personal and social impact of, for example, a pain management regimen. In contrast, a Glaserian objectivist framework would overstress environmental factors and their influence upon individuals under treatment. Such differences in perspective created tensions that led to Strauss’ departure from ‘classic’ Glaserian GT and beginnings of a move from post-positivist to constructionist GT.137, 231, 302-304

The movement of GT away from positivist associations reflected a growing awareness of the dominance of institutions like EBP and discord between evidence based on objectively researched data and real-life experiences. The developing focus of GT on contextual human action and interaction aligned with the concept of constructed and re-constructed meaning.236, 239 Subsequently, Glaser and Strauss’ student Kathy Charmaz, evolved GT via a constructionist epistemology that resonated with me (KW).44, 45, 47, 290

‘Constructionist’ or ‘constructivist’

The terms constructionism and constructivism are used interchangeably by various authors, including Charmaz, making any differences unclear.47, 290, 305-308 Sismondo308 argues that depending on the author and context in which the terms are employed, constructions may be knowledge, facts or things. For example, in grounded theory research, theories and accounts are constructions based upon data and observation.

Constructivism in part refers to learning theory, developed by Piaget and Vygotsky, relating to childhood developmental stages during which knowledge is individually constructed through experience.306, 309, 310 Though constructivist learning theory is commensurate with knowledge-as-constructed, it emphasises an individually constructed version of reality.223, 306 Sismondo308 and Andrews311 argue that constructivism also refers to the construction of realities that, over time,
become perceived as objective realities, such as the taken-for-granted institution of ‘hospital.’ Therefore, a constructivist GT would emphasise the participant’s reality in the outcome without accounting for the influence the researcher has in the construction of the research process. For these reasons, constructivism does not fully align with socially constructed knowledge.

Social constructionism advances the premise that reality is constructed and re-constructed both individually from the sum of experience, and in relationship and conversation with others. Knowledge and meaning are also acknowledged as culturally and historically situated and contextually bound. Constructionism, therefore, emphasises the socially interactive basis through which common knowledge is constructed and re-constructed via discourse. Consequently, the co-construction of a grounded theory, by researcher and participants, remains inconsistent with positivist notions of truth and knowledge as objective.

Furthermore, and despite calling her version of GT constructivist, Charmaz argues for acknowledgement of both the researcher as co-constructer of the research outcome and the research process. In referring to “my constructionist approach,” Charmaz, indicates her choice of the term (constructivist or constructionist) is dependent on the context of the discussion: in a book about constructionist research for example. Charmaz states her initial descriptor of constructivist was to distance her version of GT from both the objectivism of Glaserian GT and the absolute relativist stance of radical constructionism (see Table 8).

### Table 8: Knowledge and reality from objectivist to radical constructionist.

<table>
<thead>
<tr>
<th>Epistemology:</th>
<th>Objectivism</th>
<th>Constructivism - individual</th>
<th>Constructionism - contextual</th>
<th>Radical (relativist) constructionism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emphasis is on:</td>
<td>Knowledge exists, awaiting discovery.</td>
<td>Individual construction of knowledge.</td>
<td>Social construction of knowledge (including individual constructions).</td>
<td>Multiple versions of constructed knowledge.</td>
</tr>
<tr>
<td>Reality is:</td>
<td>Objective and external to our perception of it.</td>
<td>Individually constructed and reconstructed through interpretation of personal experiences.</td>
<td>Constructed and reconstructed following personal experiences in concert with social, cultural and political contexts.</td>
<td>Subjectively perceived in multiple differing ways, arising from multiple, and differing, worldviews.</td>
</tr>
</tbody>
</table>

Note Glaser and Strauss’ student, Phyllis Noerager Stern, refuted that they advocated grounded theorists assume an objectivist stance. However, she does infer that Glaser believed a researcher’s epistemological viewpoint should not impact upon a “good grounded theory.”

Prefixing constructionism or constructivism with the word ‘social’ situates the epistemology in a social context. As an alternative to positivism, constructionism enables negotiated (constructed) knowledge, reality and meaning as part of human experience in union with others. So the emphasis of a social constructionist GT is on the truth as understood by an individual or group, sharing a particular healthcare experience with those around them, to illuminate the mundane and everyday moments where living really happens. Within this dictum, Charmaz offered new ways to
approach GT research that included contextually bound meaning, rejected the concept of tabula rasa, and required a repositioning of the researcher within the participant/researcher relationship.

**Contextually bound meaning in constructionism**

As already described, knowledge and meaning are acknowledged as culturally and historically situated and contextually bound. Unlike the positivist view that real truth is out there, constructionism aligns with truth and reality that are not discovered, but are re/constructed by people in the course of their everyday contexts. Constructionism, as opposed to positivism, is rooted in context and meaning is contextually bound where different versions of truth are valid. A difficulty with this idea for positivists may lie in interpreting constructions as ‘made up’. Applying context to constructions may negate this difficulty by situating them in the real world of personal and social experience. Reconsider the example of the patient who knew she needed nebulised asthma medication. Someone with long-standing respiratory disease, always ‘successfully’ treated with a nebuliser, may refuse an inhaler and spacer out of anxiety and mistrust. Insistence on inhaler and spacer may increase anxiety with negative health consequences. So the context of this patient’s constructed beliefs became a significant contributor to this instance of practice-based evidence. Consequently, a constructionist nursing concept, with emphasis on understanding shared meaning, shifts its meaning dependent on context.

**Repositioning the researcher and ‘tabula rasa’**

Since constructionist GT emphasises collaboration, co-construction and dialogue the position of the researcher relative to the participant is changed. Early objectivist Glaserian GT, much like evidence-based research, placed the researcher apart from the participant; an impartial elsewhere objectively observing the data and not part of the process. The outcome was obtained through methods unbiased by researchers’ values or ideals. However, a constructionist approach to research incorporates the researcher. Not only is the participant’s socially constructed view of reality valued, but also the investigator’s prior knowledge is recognised, and their influence upon the research process scrutinised. By interpreting the data, Charmaz asserts that researchers contribute to – co-construct – theory development rather than remotely observing and reporting. As mentioned, a constructivist GT would emphasise the participants’ reality in the outcome, without accounting for the influence of the researcher upon the construction of the research process. Therefore, Charmaz maintains, the researcher must scrutinise their own research experience, decisions and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher’s interests, positions and assumptions influenced inquiry.

Consequently, from a dualist EBP viewpoint, co-construction means that an unbiased stance is no longer possible. Starting with an unbiased and atheoretical blank slate means not presupposing what the results will be while being open to coming across a-priori theories in the data. However, researchers do have their theoretical perspectives and a-priori assumptions when commencing research. For example, Glaser counselled against a literature review before collecting data to
mitigate bias. However, no research proposal or ethics application is complete without a review of the topic and context of the research.\textsuperscript{224} Once the review is done knowledge gained cannot be unknown so the slate cannot be blank.\textsuperscript{140}

Accordingly, in constructionist GT, researchers’ tacit knowledge and the existing literature are valued as ‘sensitising concepts’ within the research process.\textsuperscript{189,302} Specifying and critiquing tacit and existing knowledge during the research process also maintains transparency and situates the study.\textsuperscript{140,319,320} Prior experience and knowledge would influence research decisions, which in turn would influence the outcome; it made sense that I was not remote from the research process. As Charmaz\textsuperscript{45} and Thornberg\textsuperscript{140} caution, not detailing a-priori assumptions, as may happen with positivist based methodologies, leaves the research outcome “prone to all manner of prejudices and preconceptions, which are no less powerful for remaining subliminal.”\textsuperscript{140 (p.246)}

3.2.5. Reconciling a positivist ‘upbringing’ with constructionist grounded theory

Burr\textsuperscript{321} considers social constructionism an overarching theoretical position under which various types of research can be conducted. Mallon\textsuperscript{305} further suggests a social constructionist standpoint may not be as anti-realist as it appears to be. The increase of mixed methodology studies reflects this idea.\textsuperscript{147,257} Even positivist methodologies can be viewed through a social constructionist lens.\textsuperscript{322} Kitson\textsuperscript{323} (p.536) supports the notion of such “methodological pluralism” as a means to inform evidence-based practice and cautions that positivist definitions of evidence do not provide all the evidence for nursing practice. This point is illustrated by Traynor et al.’s\textsuperscript{324} study showing that nurses’ personal clinical experiences strongly influence decision-making. Indeed, constructionist GT may permit methodological pluralism during the analysis process, since exploring the properties of the way that something is requires consideration from different angles.\textsuperscript{44,140,236,290} A positivist stance towards GT might limit the depth of the exploration by asking why questions, instead of how and what questions.\textsuperscript{290}

Following my positivist nursing upbringing, it would be reasonable to expect a choice of Glaserian GT. Such an ‘upbringing’ certainly validates realist precision and control of methods that verify and predict hypotheses and causal relationships. Without positivist research, penicillin, principles of contemporary clinical examination and advances in wound care would not exist.\textsuperscript{325,326} However, I struggle with the notion of a blank slate and the researcher as an impartial observer. The logic of not discounting the influence of the researcher upon the research process and outcome remains compelling. Additionally, the absolute relativist stance of radical constructionism, where differing realities remain valid, renders a viable research outcome with application to practice unlikely.\textsuperscript{226,315} For this reason, and perhaps because of a foundation in EBP, I rejected radical constructionism and settled upon social constructionism.
3.2.6. Concluding reflections on an evolving epistemology

Kuhn\textsuperscript{244} depicted paradigm change as science’s version of “picking up the other end of the stick” to question the meta-narrative of EBP as ‘normal science.’\textsuperscript{244 (p.85), 327} In scrutinising assumptions as Kuhn depicted, this paper has documented how a foundation in evidence-based nursing, underpinned by a positivist epistemology, has been reconciled with a social constructionist worldview developed whilst conducting a grounded theory research project. Documenting this journey will be of help to other novice researchers.

The growing popularity of qualitative scientific enquiry, particularly grounded theory, over the last twenty years has challenged the sovereignty of quantitative enquiry.\textsuperscript{39, 40} However, the popularity of either methodology does not infer one scientific paradigm is better than the other, only that questions each can answer are different.\textsuperscript{38, 328} Acknowledging this prevents one paradigm from being the privileged arbiter of what stands as valid knowledge, and permits dialogue between scientists to explore multiple ways of knowing. Equally, exploring a problem from conflicting perspectives maintains an open dialogue between scientists in order to sustain conversations and find practical clinical solutions.\textsuperscript{273}

Like my nursing career, the development of grounded theory represents an evolution from positivism to constructionism.\textsuperscript{301, 304} In terms of my evolving epistemology, the belief that the knower constructs reality in concert with others and within context is congruent with a choice of constructionist grounded theory and research topic. Having reached this point, it is also important to acknowledge what my professional upbringing in EBP contributes to what is now a social constructionist epistemology. I now understand that not only are other methodologies valid options, it is also possible to employ them via a social constructionist lens.

Consequently, a background in EBP provides an appreciation for the value of differing paradigms, allowing the researcher to align with whichever paradigm a research problem requires, whilst also understanding their own epistemological influences. This knowledge enables the researcher to be consciously versatile in their methodological choices: even though GT has evolved, constructionist grounded theorist researchers may still choose to undertake Glaserian GT. In the same way, I can appreciate quantitative research underpinning evidence-based nursing practice and also move forward with a constructionist epistemology. This versatility is, perhaps, a reason for the popularity of grounded theory, and why I can reconcile a positivist upbringing with a social constructionist epistemology.
Key points for policy, practice and/or research

This paper documents how a personal epistemology has evolved during a grounded theory research project.

- Future papers should provide additional commentary documenting similar journeys in the context of novice researchers’ experiences with differing epistemologies.
- Further methodological and epistemological debate should develop discussions regarding social constructionism in the context of grounded theory.
- Incorporating philosophical grounding into doctoral education where this has been absent is an important consideration for education practice.

The final, definitive version of this paper has been published in the Journal of Research in Nursing, 20(6), 2015 by SAGE Publications Ltd. All rights reserved. ©Kim Ward
3.3. Postscript to the preceding article

Writing the previous article reinforced my conviction that a positivist, and therefore dualist, approach to research runs the risk of excluding contextual and practical knowledge. This includes knowledge contributed by patients and families as consumers of healthcare.\(^{270}\) It is important to acknowledge the difficulty in defining truth as wholly objective. Even Karl Popper, a consummate positivist, called for conclusions reached by reasoning and experience to be critically and socially appraised.\(^{329}\) I agree with Collingridge and Gantt\(^ {247}\) who argue that dualist views within science inadequately address issues of meaning and human experience: the why and the how. Medical research has a strong focus on physiological factors and interventions to improve health, as reflected by the literature review of chapter two.\(^ {24, 26}\) However, the healthcare consumers’ ‘voice’ within medical literature can be constrained and their potential contribution to healthcare knowledge hidden.\(^ {27}\)

Conducting a grounded theory project through a social constructionist lens enables interpretation of both the personal impact of a treatment regimen and the effect this has in an individual’s social world, producing findings that are relevant to patients’ lives and healthcare practice.\(^ {175, 225}\) However, subscribing to a social constructionist stance required me to consider what construction in this context meant.

3.4. Considering the nature of construction vs. co-construction

Charmaz\(^ {330}\) wrote, “we [the researchers] construct” because the terms that we choose to describe data segments show how “we define what we see as significant in the data.”\(^ {p.115}\) Therefore, the data corpus incorporates constructions I created using the participants’ words, such as codes, conceptual ideas and analytic memos. The spirit of social constructionism determined that I consider the nature of the ‘social’ in the construction of this research and theory. Accordingly, I had to decide if as constructor of this research I was also co-constructor with my participants.

Scholars have argued that participants are co-constructors because they each contribute data and, when asked, conceptual feedback. Nagy Hesse-Biber and Leavy\(^ {331}\) agree with Charmaz\(^ {290}\) that data and meaning are co-constructed with participants through the interactive process of interviewing. Thornberg and Charmaz\(^ {332}\) argue that “according to constructivist grounded theory, you and your participants construct data through your interpretive acts.”\(^ {p.44}\) Charmaz\(^ {45}\) says something similar: a constructionist approach “sees both data and analysis as created from shared experiences and relationships with participants.”\(^ {p.238}\) Mills, Bonner, & Francis\(^ {333}\) also talk about co-construction saying, “in the act of reflective memo writing, we are writing the ‘worded world’ of theory, as an adjunct to the simultaneous processes of the co-construction of data and the analysis.”\(^ {p.11}\) If I co-construct the data and the analysis with my participants, does it follow that by interacting with participants during the interviews we co-construct meaning and by association conceptual ideas? From the first moment of theoretical sampling participants become involved in checking out conceptual ideas.\(^ {231}\) Asking participants about what they thought of constructed concepts contributes to the theory because I adjust theoretical concepts in response to their
feedback. Reichertz calls this “an intersubjectively constructed and shared ‘truth.’” Accordingly, receiving participant feedback helped refine the theory and helped me decide on further theoretical sampling.

Corbin contributes to the debate on co-construction by conceding that,

…in a way [the findings are] a co-construction because it does present their words along with mine.

One might even say, due to this reciprocal influence, that researcher and participants co-construct the research together...

However, when talking about the interpretive nature of the research process Charmaz comments on the researcher’s “relationships with respondents, and the interactional construction and rendering of the data” (emphasis added). Charmaz goes on to say,

From the beginning, the researcher actively constructs the data in concert with his or her participants. … Rather, the categories reflect the interaction between the observer and observed.

I argue that the effort that goes into constructing the outcome of the research is shared with the participants, and I acknowledge participants’ input into the theoretical construction. I drove the construction, but the participants were in the car and had a say about where we went. However, I was the only one present during all of the interviews, analysis, memo writing, and reading, making me the main driver of the research and theory development. I made decisions about theoretical sampling, about categories and about relationships between categories. The participants informed those decisions and commented on the constructed concepts as we went along, but eventually interviews ceased and I handled the on-going analysis. At this point, the participants left the car. Therefore, I agree with Charmaz, that the researcher and participants co-construct data, but that the eventual construction of the theory rests with the researcher.

3.5. Reflexivity

The article included in this chapter describes the underpinning philosophical stance of this grounded theory study. The remainder of chapter three describes further methodological tenets of grounded theory that were not included in the article but are pertinent to understanding the research decisions made during the study. Within a grounded theory project, researcher reflexivity is important. I will now discuss how reflexivity contributes to strategies that demonstrate trustworthiness of qualitative knowledge and the implications that reflexivity has for the researcher’s position within the research.

3.5.1. Trustworthiness of knowledge and reflexivity

The quality of a grounded theory project relies on the demonstration of trustworthiness and authenticity of the knowledge produced. Demonstrating the trustworthiness of qualitative research
gives surety to the researcher and the reader that assumptions made by the researcher are clear. \cite{336, 337} Strategies for demonstrating trustworthiness of knowledge include reflexivity and methodological congruence. \cite{44, 327, 338} Reflexivity includes acknowledging and accounting for the preconceived notions of the researcher. Or as Charmaz\cite{44} put it, the researcher scrutinises and accounts for the influence of “interests, positions and assumptions” prior to and throughout the research process. (p.188) In this chapter, I clarify my epistemology and demonstrate reflexivity by explicating personal theoretical perspectives. The second part of chapter two provided a reflexive critique of the discourse of compliance in healthcare and what this discourse might mean for me as a researcher. Methodological congruence allows the components of each methodology to be assessed in their own right rather than compared with disparate methods: does the question match the method and is the method executed competently? \cite{166, 247, 319, 339} Furthermore, methodological congruence is contingent on reflexivity, since not clarifying an underpinning epistemology means methodological congruence cannot be adequately assessed. \cite{166, 327}

Further tactics for trustworthiness include demonstrating both the authenticity and resonance of constructions with personal or participant experiences, and the usefulness of the research. \cite{44, 327, 338} For example, sharing constructions with colleagues, participants and other experts in the field determines resonance of the findings. Similarly, reflexive memoing of thought processes during grounded theory analysis contributes to transparency and reliability, not because this enables replicability, but because it enables the reader to ‘see’ how a conclusion was reached. \cite{140, 319, 338} Memoing and diagramming during analysis also demonstrates transparency in the research process and provides an audit trail. Therefore, I provide examples of memos throughout the remainder of this thesis. Chapter four further illustrates methods that demonstrate trustworthiness of the constructed theory, such as how I shared constructions and the process of theoretical sampling and constant comparison. \cite{302, 319} The usefulness of this grounded theory project is evidenced by the recommendations for policy and practice given in chapter seven and in the publications.

### 3.5.2. Positioning the researcher through reflexivity

As discussed, I chose a constructionist grounded theory to enable interpretation of social processes regarding CPAP use. \cite{44, 47} Additionally, a constructionist approach acknowledges the role of the researcher as both integral to and having an influence on the research process. \cite{44, 290} This became readily apparent during a grounded theory study group meeting during which we coded a section of troublesome anonymised data from this study. The group coded data from a participant who referred to losing weight so many times that eventually I asked if she had managed to lose weight since starting CPAP. The group drew attention to my motivation for asking this question. They coded it as you as authority and asked whether I was thinking as a researcher or a nurse when I asked that question. I realised that no amount of naval gazing could mitigate deep-seated received knowledge. As a nurse and teacher, I am compelled to promote wellness through healthy living, but as a researcher, I need to let go of my compunction to teach. Thereafter, I monitored what I was thinking as I continued interviewing, both during the interview and by recording and reviewing my
questions. Sharing the research process in this way operated as a check and balance against subliminal assumptions.

Gergen urges researchers to practise reflexivity - to “consider all propositional realities and dictates” in the context of time, place and person. (p.414) In this respect, reflexivity is also demonstrated by the clear explication of assumptions underpinning researchers’ existing theoretical knowledge in their field. For example, I embarked on research into experiencing CPAP as not only a nurse, but as a respiratory nurse with prior knowledge regarding the proven efficacy of CPAP use. Wondering what it was like to live with CPAP was pre-empted by assumptions like ‘this looks so uncomfortable, it must be hard to keep using it’.

Leading grounded theorists state that the role of received knowledge and literature are welcome in the research process as ‘sensitising concepts’, so long as they are laid out and critiqued during the process to maintain transparency and to situate the study. Awareness of received knowledge requires reflexivity to notice discourse operating in any circumstance, such as the discourse of compliance that I discussed in chapter two. Reflexivity provides the clinician and/or researcher with a broader understanding of their power, and reveals their potential influence upon other individuals. With this in mind, I felt it important to attend to a point raised during the review in chapter two in which I noted a focus on compliance in the CPAP literature that troubled me. The narrative of compliance merited scrutiny since I was exploring users’ experiences with prescribed CPAP treatment. Considering a concept like compliance from a Foucauldian perspective permitted a challenge to the hegemony of taken-for-granted realities and positions of patient and clinician within the healthcare discourse. I was conscious that the discourse of compliance, deeply rooted in the literature, might also influence how I interacted with my participants during the project. Accordingly, in the second part of chapter two I gave consideration to the discourse of compliance in health. As a consequence, I took care to review the wording of interview questions to ensure a focus on the experience of using CPAP, rather than failing to use CPAP. An example of how my reflexivity enhanced theoretical sensitivity is given in chapter four (see 4.4.1. p.81).

3.6. Chapter 3 Summary

Glaser and Strauss created grounded theory during the late 1960s. During the 2000s, Glaser and Strauss’ student Kathy Charmaz developed grounded theory using a constructionist standpoint that corresponds to my worldview. The article in this chapter described how my thinking changed since I began nursing, to align with a current social constructionist epistemology. This chapter outlined the theoretical foundations leading to my choice of grounded theory for this study, supporting the congruence of constructionist grounded theory with the exploration of how people live with CPAP. I have described some concepts that hallmark a grounded theory study including the positionality of the researcher and the topic of reflexivity. The next chapter introduces the methods of this grounded theory project.
CHAPTER FOUR

Grounded Theory Research Methods
Chapter 4. Grounded theory research methods

The previous chapter considered the theoretical basis of grounded theory and discussed how social constructionism has influenced the research design of this study. I outlined the creation of grounded theory by Glaser and Strauss and discussed Charmaz’s variant of grounded theory. Chapter 3 described concepts that characterise a grounded theory study including the philosophical position of the researcher and the topic of reflexivity. Chapter 4 explains the methods used in grounded theory and shows how they were utilised during the study.

The first section of this chapter provides detail about the attention given to ethical considerations for this study. The following section gives an overview of the tenets of grounded theory including the coding framework used and the principle of constant comparison. The next section on data collection outlines sampling techniques and introduces the participants. Embedded in the data collection section is a publication that reports on participants’ experiences of the semi-structured qualitative interview via the telephone. A section explaining the methods of analysis used follows, showing how I conducted different phases of coding and how theoretical sampling and constant comparison were integrated throughout the project. I also demonstrate the importance of memoing and diagramming for achieving theoretical saturation. The chapter concludes by describing tactics for evaluation used in this grounded theory study. Throughout the chapter, I draw on examples from this study, such as memos and diagrams, to illustrate the various techniques used.

4.1. Ethical considerations

Ethics approval safeguards the interests of the participant. The approval process also encourages the researcher to scrutinise their role within the research as outlined by the article in section 3.2. Both the New Zealand Health and Disciplinary Ethics Committee (NTX/11/06/048) and the local district health board’s (DHB) Research Review Committees (A+5120) approved this study in July 2011. Following initial analyses, I sought an amendment to ethics approval to accommodate the inclusion of partners of CPAP-users and to extend approval until November 2014 (NTX/11/06/048/AM02). In New Zealand, ethics approval also ensures that Treaty of Waitangi principles of partnership, protection and participation are upheld. The Treaty of Waitangi (Te Tiriti o Waitangi) is New Zealand’s founding document signed on 6th February 1840 by representatives of the Māori tribes and the Crown. The treaty details an agreement between signatories that states principles on which to found the governance of New Zealand and informs contemporary bi-cultural policy. Accordingly, the local health board committees included a Māori research review committee. Appendix 1 details the various ethics forms, which outline the underpinning institutional ethical requirements.
To meet obligations under the Treaty principles I consulted with Māori cultural advisors during the approval process. The local DHB’s associate director of nursing for Māori health (of Ngāti Kahu, Ngātioerangi, Te Arawa descent) provided advice on relevance to Māori, engagement with Māori stakeholders, processes to inform Māori health development and appropriate dissemination pathways. This region of New Zealand also has a significant Pasifika population. Therefore, I consulted with the DHB’s manager for Pacific health. She offered advice on relevance to Pasifika and engagement with stakeholders, along with processes to inform Pacific health development and appropriate dissemination pathways. Offering interviews in person accommodated cultural preference, with cultural support offered to Māori and Pacific Island people via He Kamaka Oranga for Māori or the Pacific Family Support Unit in order to foster culturally safe communication. Many health service consumers are competently bilingual, and since I do not speak Te Reo or Pacific Island languages, all interviews were in English. Further consultation with the Māori Health Service Advisor yielded an offer of her personal, cultural support if requested by Māori participants or to discuss any issues that arose during data collection (see Appendix 1.4 for letters of support.)

Clinic staff identified appropriate participants prior to clinic appointments with the guidance of the respiratory service sleep physiologist. To minimise the potential for coercion I did not participate in the selection process. Consequently, I had no knowledge of the participants until after they had agreed to participate. Each CPAP-user participant received an information pack from clinic staff. Partner participants received an information pack by post. The pack outlined reasons for and details of the study, and included a consent form to complete if they chose to participate (see Appendix 1.3). The pack informed participants about the confidential nature of information collected and its secure storage. All data (audio-recordings, interview transcripts and research notes) were stored on a password-protected computer or in a locked filing cabinet in a locked office; I was responsible for safekeeping, and only supervisors Professor Gott and Dr. Hoare had additional access to this information.

All participants provided written consent and agreed to a telephone interview. Consideration of ethics does not cease once ethics approval is given. Therefore, it was important to continue seeking verbal consent throughout the process. Contact with participants was solely via telephone, so I re-confirmed consent at each contact point to protect participant confidentiality and the right to re-consider participating. Respect for participants was prioritised throughout the process by arranging interviews at the participants’ convenience. Choosing individual rather than dyadic interviews with CPAP-users and partners also protected confidentiality. Moreover, during individual interviews I did not disclose any information shared by a participant’s partner in a prior interview. At no time did I attempt to end an interview without first assuring that the participant had shared as much as they needed. Allowing Māori participants to speak until finished is culturally important. Additionally, I recognised that it was important for all participants not to truncate the interview. Indeed, doing so would have defeated my purpose. Bowers and Charmaz assert that ending an interview without returning the interviewee back to a “normal state of conversation” is unethical. While I considered disclosure of deeply personal information unlikely, the possibility existed. I agree with Bowers that “you cannot leave a person who has fallen apart without putting them back
together.” With this in mind, I prepared closing questions asking what participants had learned about themselves from their experience with CPAP; what advice they would offer to someone newly diagnosed with sleep apnoea about to use CPAP; and if there was anything I should know they had not already shared. I concluded by offering the opportunity to ask questions and thanking them for their time (see Appendix 2).

I was also conscious of possible tension between my role as a registered nurse and as a researcher. The Health Practitioners Competency Assurance Act and the Nursing Council Code of Conduct require my attention to obligations as a registered nurse to cause no harm, or through inaction cause harm. I anticipated no specific risk to participants (psychological or physical) associated with taking part in this study. However, there was potential for disclosed information to be sensitive in nature, and a respiratory service psychologist referral was available for debriefing should psychological distress occur and if desired by the participant. Had I any concerns about clinical safety of a participant I was also able, with their consent, to refer to clinic staff.

On conclusion of this work, obligations to participants continue and each will receive a lay summary of the findings and a copy of pertinent published work from this study. Additionally, ethics committees, the DHB and interested parties within the respiratory service from which the participants were recruited will receive a summary report. Findings from this study have been, and will continue to be, disseminated in peer reviewed medical, nursing and social sciences journals and will be circulated locally within DHBs, regionally via the Respiratory NZNO section and through other appropriate national publications and national and international conference presentations.

4.2. Overview of the tenets of grounded theory

Execution of a grounded theory study requires that certain tenets of the method be employed. The tenets may vary depending on the grounded theory author followed. For example, Glaser argued for a ‘tabular rasa’ approach to initial coding and therefore a delayed literature review. By contrast, I agree with Thornberg and Charmaz who are clear that an open mind is more important than an “empty head.” However, there are some hallmarks of the method that identify a grounded theory study as authentically GT. These include concurrent data collection and analysis, constant comparative method, theoretical sampling, theoretical saturation, and theory generation along with memo-writing and abstraction. Implementation of grounded theory methods are outlined in the following sections: 4.3 Data collection in grounded theory, and 4.4 Data analysis in grounded theory.

The data collection section introduces the study setting, the participants and data collection techniques. This section also shows how sampling, including theoretical sampling, facilitated recruitment of participants. I explain the rationale for choosing semi-structured individual interview and discuss the use of telephone interviewing. The following data analysis section outlines the coding conventions used and describes how I elevated raw data from low-level codes to high-level categories. However, the sections on collection and analysis require preliminary context, which I
provide in the following brief sections on the practice of coding interview transcripts and the constant comparative method.

4.2.1. Coding

Coding is an analytic tool used to foster interpretation of data with the purpose of constructing a theory to explain what is happening in the data. In GT, the focus of coding is to identify action and process. I adopted Charmaz’s variant of coding and used an inductive coding paradigm since theoretical ideas constructed from the data formed the basis for subsequent coding.

Initial coding, sometimes called open coding, is the first step in analysis and allows identification of important words or phrases that are labelled accordingly. Occasionally, participants’ words that are expressive or succinctly capture what the data describe become *in vivo* codes. An example is the phrase “getting used to it.” Each participant used this phrase, which later became a category and then a sub-category of the theory. Subsequent grouping of initial codes into categories formed the basis of preliminary theoretical ideas. Thereafter, I used focused coding to saturate categories and to pinpoint action. Charmaz promotes the use of gerunds during coding to draw focus away from individuals and onto “what is happening in the data.” Gerunds are nouns formed from verbs by adding ‘ing’ and are useful to pinpoint action and sequence. For example, *be* (as in *be quiet*) becomes *being*. Similar codes are grouped together under sub-categories that are subsumed by higher-level abstract categories. Figure 2 illustrates this process.

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**Theory:** the woven together theoretical explanation of how people live with CPAP for sleep apnoea.

**Main categories:** sub-categories are connected and through abstraction form conceptual ideas that explain parts of the theory. Achieved through advanced coding. Also called selective or theoretical coding.

**Sub-categories:** mid-level categories that represent groups of codes that are re-grouped or clustered together. Properties and dimensions of sub-categories are developed. Achieved through intermediate coding. Also called, focused, axial or selective coding.

**Codes:** words or phrases used to anchor key points in the data that facilitate categorisation of ideas. Achieved by initial coding. Also called open coding.

---

*Figure 2: Process of data analysis in constructing a Grounded Theory.*
Leading grounded theorists have labelled phases of coding using various terms and meanings, as Figure 2 details. Consequently, understanding coding was a challenge. For example, the coding phase that follows initial coding for Glaser is selective coding; for Strauss and Corbin it is axial coding, and Charmaz uses focused coding. More recently, Birks and Mills described the stages of coding according to when they occur, using the terms initial, intermediate and advanced. Although I adopted Charmaz’s variant of grounded theory, the simplicity of Birks and Mills’ coding terminology appealed and became the terms used to define the stages of coding in this project. Figure 2 represents the coding process as sequential steps. However, the iterative nature of concurrent data collection and analysis along with constant comparison meant that coding phases alternated and overlapped. Indeed, conceptualisations occurred early in data analysis albeit open to later modification. Equally, it was necessary to return to initial coding activities during advanced analysis to be sure that theory integration remained grounded in the data. Section 4.3 elaborates on the coding strategies employed in this study.

### 4.2.2. Constant comparison

Central to analysis in grounded theory is the practice of constant comparison. Comparison is made between codes, categories, concepts and incidents in an on-going process using results from previous stages. Constantly comparing interpretations from initial analysis allows corroboration through successive investigation. Constant comparison also strengthens the substantive theory by ensuring identification of all possible properties and dimensions of phenomena. For example, on encountering the phrase ‘good sleep’ I returned to earlier data to explore the properties and meaning that ‘good sleep' had to participants. Each participant described a concern with getting a ‘good sleep.’ Throughout subsequent analysis whenever I encountered a reference to good sleep I compared what was said to what participants had already said. Doing this enabled construction of the properties of poor and good sleep, illustrated by Figure 3.
A good sleep meant that participants achieved some or all of the conditions in the inner ring in Figure 3. For example, sleeping through the night uninterrupted was good for some participants irrespective of duration, while for others ‘good’ was being asleep for a set number of hours despite disturbance. Experiencing one or more properties of poor sleep meant good sleep was not achieved.

The iterative nature of constant comparison facilitates the formation of conceptual categories that create a theoretical framework to ease the coding of subsequent data into theory. To enable constant comparison, both data collection and analysis occurred concurrently. Concurrent data collection and analysis allowed the revision and adaptation of interview questions. Consequently, I was able to refute or corroborate findings and check logically derived assumptions through theoretical sampling.

4.3. Data collection in grounded theory

Glaser determined “all is data,” meaning that the term ‘data’ describes all the dimensions and context of what is being “told.” Scholars have debated the issue of what constitutes data in GT. However, in this study, data refers specifically to what participants said about their experiences of using CPAP. In this regard, data was whatever they felt important to impart, be it about feelings, situations, people or inner thoughts about using CPAP. The following section details the considerations I gave to techniques for data collection, including sampling technique, participant recruitment and data generation.

4.3.1. Sampling in Grounded Theory

Sampling for this study sought representation of a particular cohort and not a population. Therefore, the study began with purposive sampling. Purposive sampling, sometimes called initial or selective sampling, involves selecting participants most relevant to the topic of study. For this study, I focused on recruiting people with a personal knowledge of using CPAP. Respiratory service clinic staff facilitated this process on my behalf (see 4.1 Ethical considerations). I had no prior knowledge of participants or what they might say, and having selected participants based on their use of CPAP I needed to begin somewhere. Therefore, data collection commenced with the first person who agreed to participate. Once I had constructed some codes from initial interviews, I theoretically sampled to explore the codes. Early codes included being constantly tired, realising and getting sick of it. These codes prompted me to explore how participants determined the need for medical help and contributed to an early sub-category reaching a limit.

Theoretical sampling is a part of the constant process of analysing data and comparing it with freshly collected data. Theoretical sampling is central to all forms of grounded theory as it enables construction of first the codes, then the categories and then, via the process of abstraction, the constructed theory. During theoretical sampling, I made decisions about who next to
interview based upon what my first, and then successive participants were able to tell me about their experiences. I made decisions to include questions or people to provide richer information for saturating codes and categories constructed from on-going data analysis. Birks & Mills state that theoretical sampling ought to begin as early as the first data collection event. The following memo, written after the first interview, illustrates why I decided to include questions to explore the concept of getting a good sleep.

Memo: 20 08 2011: Thoughts on “getting a good sleep.”

I am curious about the concept of good sleep. Arthur referred several times to getting a good sleep:

Sometimes, …around 2:30, 3[am], when I feel ‘OK I have had enough of it now’ and take it off and probably have another two hours of good sleep. … I would like to have a good night’s sleep. I would like to have no disturbances. … There is always the feeling - if I could get to sleep without the mask. It’s just like you can fall off to sleep with a shirt and trousers on, but if you get into your nightclothes, your pyjamas you are more comfortable to sleep. Otherwise, I do get good sleep when I sleep with it [CPAP]…

Maybe disturbance has a lot more to do with removing the mask. Can good sleep mean many things? Like the perception that ‘I have this mask on, so it must be good’ versus the idea that ‘without the mask I am more comfortable, so I feel the sleep is better / deeper’. Is it to do with the level of arousal during sleep maybe, versus deep sleep where no external interference causes wakening? Or maybe pulling the mask off is the simple, practical motivator of needing to be comfortable, rather than any deeper motivation for self-determination or brooking authority. A balancing of the physiological need to use CPAP for well-being, versus a visceral need to sleep unencumbered without causing detriment to one’s physiological self?

Perception of self as having organic needs – the working of the body versus having mental well-being needs, as in the perception of the effect of ‘good sleep’ on one’s state of mind during the day. Is it like, ‘what is good for my body may not be good or feel good for my mind?’ I think I need to explore how other people define good sleep.

The above memo prompted me to include the questions ‘how do you feel you sleep with the mask/without the mask’ and ‘what do you feel about the sleep you have with the mask on/without the mask?’ However, the responses that these questions yielded were limited to descriptions of discomfort using CPAP. To develop the concept of good sleep I probed further by adding the prefix question ‘tell me what goes through your mind when you think about good sleep?’ Appendix 2.2 provides a schematic showing the development of interview questions.

†† While I have corrected spelling and punctuation in the included memos, they are reproduced as written to reflect my thought processes at the time of writing.
Additionally, prior to conversion of this project from masters to a doctoral thesis I determined that partners and close family and friends were integral to the process of using CPAP. Although I had not initially considered those around the CPAP user as part of the process, data from the first three interviews proved otherwise. Extending the scope of the study enabled exploration of the significance of partner and family engagement. Partner participants were theoretically sampled using a snowball, or chain referral technique, by asking enrolled study subjects to extend the invitation to participate. If verbal agreement was given a participant information pack, including the consent form, was mailed out.

In a grounded theory study, the sampling of participants is interwoven with data analysis. Both sampling and analysis continue until codes and categories are theoretically saturated. Charmaz states that theoretical saturation describes the point at which “gathering more data about a category reveals no new properties nor yields any further theoretical insights about … data.” Put simply, saturation is the point at which to stop sampling for data relevant to a category. Saturation of categories occurred by the seventeenth interview, which concluded sampling for this study. The data analysis section of this chapter provides further detail regarding theoretical saturation.

4.3.2. Participant Recruitment

Recruitment of participants was facilitated in collaboration and with permission from the respiratory service of the local District Health Board. The study was conducted in Auckland, one of New Zealand’s major cities with a population of approximately 1.4 million people in 2013. Participants were recruited during a sleep clinic visit, being previously prescribed and started on CPAP therapy via a face or nasal mask for OSA. People were eligible to participate in the study if they were aged eighteen years and over, were able to give informed consent, used CPAP for OSA, and were partners of those who used CPAP for OSA. Participants included people who had become regular CPAP-users, where regular use included not all night and not every night. Recruiting participants after at least six weeks of use meant there would have been time to develop views of what it was like to live with CPAP. OSA affects all cultures, social groups and genders. However, the demographic mix of the final sample group was unknown prior to recruitment. Nevertheless, I was successful in recruiting one person identifying as Mäori and one person identifying as Pasifika, reflective of the current population in New Zealand.

The final number of participants required for this study was determined through theoretical sampling and saturation. In total, sixteen adult participants were recruited (men n=9, women n=7) who were CPAP users (n=12), or partners of CPAP-users recruited to the study (n=4). Table 9 introduces participants in the order of interview, to reflect how the coding and category construction informed theoretical sampling. The section that follows presents the choice of interview method and outlines the question progression throughout the study.
### Table 9: Participant demographics at the time of the interview

<table>
<thead>
<tr>
<th>Participants#</th>
<th>Age (years)</th>
<th>Ethnicity</th>
<th>Occupation</th>
<th>Time since CPAP initiation**</th>
<th>CPAP use at time of interview**</th>
<th>Interview (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>48</td>
<td>Indian</td>
<td>Sales</td>
<td>2-3 months</td>
<td>Each night, all night</td>
<td>38</td>
</tr>
<tr>
<td>2</td>
<td>57</td>
<td>NZ Eur</td>
<td>Self employed</td>
<td>3-4 months</td>
<td>Each night, not always all night</td>
<td>57</td>
</tr>
<tr>
<td>3</td>
<td>76</td>
<td>Indian</td>
<td>Retired</td>
<td>7-8 months</td>
<td>Each night, 8 hours</td>
<td>37</td>
</tr>
<tr>
<td>4</td>
<td>34</td>
<td>NZ Eur</td>
<td>Storeman</td>
<td>For “a while”</td>
<td>“Not all the time”</td>
<td>45</td>
</tr>
<tr>
<td>5</td>
<td>49</td>
<td>NZ Eur</td>
<td>Admin</td>
<td>3 years</td>
<td>Each night, 5-7 hours</td>
<td>59</td>
</tr>
<tr>
<td>6</td>
<td>43</td>
<td>NZ Eur</td>
<td>Admin</td>
<td>12 months</td>
<td>Each night, 6 hours</td>
<td>70</td>
</tr>
<tr>
<td>7</td>
<td>35</td>
<td>Samoan</td>
<td>Homemaker</td>
<td>6 years</td>
<td>Not every night</td>
<td>72</td>
</tr>
<tr>
<td>8</td>
<td>56</td>
<td>NZ Eur</td>
<td>Manager</td>
<td>11 months</td>
<td>Each night for last 3-4 months</td>
<td>70</td>
</tr>
<tr>
<td>9</td>
<td>44</td>
<td>NZ Eur</td>
<td>Trainer</td>
<td>Ed’s partner</td>
<td></td>
<td>59</td>
</tr>
<tr>
<td>10</td>
<td>70</td>
<td>Indian</td>
<td>Retired</td>
<td>Curzon’s partner</td>
<td></td>
<td>24</td>
</tr>
<tr>
<td>11</td>
<td>63</td>
<td>NZ Eur</td>
<td>Retired</td>
<td>Partner of CPAP-user not interviewed</td>
<td></td>
<td>42</td>
</tr>
<tr>
<td>12</td>
<td>44</td>
<td>NZ Eur</td>
<td>Teacher</td>
<td>6 ½ years</td>
<td>Each night, all night</td>
<td>82</td>
</tr>
<tr>
<td>13</td>
<td>62</td>
<td>Māori</td>
<td>Retired</td>
<td>5 years</td>
<td>Each night, 7 hours initially, now 3-4 hours (since becoming her husband’s carer)</td>
<td>53</td>
</tr>
<tr>
<td>14</td>
<td>28</td>
<td>NZ Eur /Afro-Caribbean</td>
<td>Student</td>
<td>2 years</td>
<td>Not every night, 3-4 hours</td>
<td>60</td>
</tr>
<tr>
<td>15</td>
<td>56</td>
<td>NZ Eur</td>
<td>Manager</td>
<td>2 years, 11 months</td>
<td>Each night, all night (Second interview)</td>
<td>30</td>
</tr>
<tr>
<td>16</td>
<td>56</td>
<td>NZ Eur</td>
<td>Nurse</td>
<td>Hal’s partner</td>
<td></td>
<td>39</td>
</tr>
<tr>
<td>17</td>
<td>56</td>
<td>NZ Eur /MiddleEastern</td>
<td>Self employed</td>
<td>“About 2 years ago.” Abandoned CPAP after “about a year.”</td>
<td></td>
<td>7</td>
</tr>
</tbody>
</table>

**Key:** #Names are pseudonyms to protect the identity of participants; *Partner participants are suffixed ‘P’; NZ Eur - New Zealand European; **Self-report
4.3.3. Data generation in grounded theory – the interview

Seeking information in dialogue with participants is a powerful way of exploring peoples’ experiences. Consequently, the interview has become a popular method of collecting data in qualitative research. Kvale and Brinkmann propose that the qualitative interview is a conversation in which both parties inter-change views about a shared interest. With this in mind, I viewed the interviews I conducted as shared dialogues that I guided, but which focused on the use of CPAP from users’ perspectives. Indeed, participants reflected on the interview as being “just like a conversation” (Arthur, Lily, IanP).

Individual interviews are commonly used in grounded theory and can provide rich data. Despite the likelihood of overlap in each participant’s experience, I chose individual interview as I sought multiple perspectives of the experience of CPAP for sleep apnoea and little data already existed. Semi-structured interview is a method of data generation that allows comprehensive exploration of a topic from an individual’s perspective. Focus groups may be useful in grounded theory for generating initial concepts on which to base later interviews. However, focus groups have been criticised for the potential of allowing a dominant voice to be heard to the detriment of quieter voices in a group. Semi-structured interview is congruent with a social constructionist paradigm as it allows participants to share socially and personally constructed understanding regarding a topic of interest. Nevertheless, the individual interview is not without pitfalls. I was conscious that interviewees might have agreed to an interview out of politeness or because of a perceived power imbalance. Had this been the case, rapport might have been jeopardised. I took steps to mitigate this by scripting introductory dialogue with participants prior to the interview, ensuring their questions were answered, and that the purpose of the study was clear (see Appendix 2.1).

Interviews began using a few common questions and prompts. These included:

- Tell me in your own words about your experience with CPAP
- Tell me about the things that preoccupy you during your night-time routine
- What does your CPAP mean to you?
- How do you explain your sleep apnoea or CPAP to others? and
- What kind of things have you done to help yourself manage with this therapy?

I developed these questions and prompts with the intent of providing a starting point for participants to tell their stories about using CPAP. The questions had a broad focus making initial interviews largely unstructured. Corbin and Strauss suggest that unstructured interviews provide dense data and a solid platform from which to proceed with further interviews. Starting interviews as an unstructured dialogue also allowed issues relevant to the participants to surface. Broad open questions revealed information important to the participant and avoided leading while keeping the participant on topics related to CPAP use. Additionally, incorporating the above questions into each interview facilitated comparative analysis between participants.
Thereafter, I adapted lines of inquiry based on the information disclosed. As interviews progressed, I added and adapted questions to explore new concepts and develop category construction. The questions for partner-participants followed the same pattern as for CPAP-user participants with wording amended to reflect that they were the partners and not users (see Appendix 2.3). Later interviews became semi-structured, rather than unstructured, as I focused on developing conceptual ideas. I also had to hand a selection of prompts should the flow of dialogue slow, including:

- That is interesting… Could you explain that a little more…
- Let’s see, you said…
- Just how do you mean that…?
- How do you feel about…?
- On the basis of the way things look to you now what do you think about…?

The above probes were used to encourage participants to elaborate on what they were saying and to clarify information I did not fully understand. Following initial interviews, participants expressed opinions about their definitions of health including ideas around body image, ideas about “getting used” to the CPAP machine, changes to intimacy with their bed-partner and particularly how partners were involved in the process of CPAP use. Accordingly, these ideas led to the inclusion of extra questions exploring these concepts (see Appendix 2.2 and 2.3). I also chose to interview by telephone. The following article explains this choice and reports the data gathered from study participants about their experience of taking part in a semi-structured telephone interview.

The following article is cited as,


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ARTICLE: Participants’ views of telephone interviews within a grounded theory study.

4.3.4. Abstract

Aim: To offer a unique contribution to the evolving debate around the use of the telephone during semi-structured interview by drawing on interviewees’ reflections on telephone interview during a grounded theory study.

Background: The accepted norm for qualitative interviews is to conduct them face-to-face. It is typical to consider collecting qualitative data via telephone only when face-to-face interview is not possible. During a grounded theory study, exploring users’ experiences with overnight mask ventilation for sleep apnoea, the authors selected the telephone to conduct interviews. This article reports participants’ views on semi-structured interview by telephone.

Design: An inductive thematic analysis was conducted on data pertaining to the use of the telephone interview in a grounded theory study.

Methods: The data were collected during four months of 2011 and six months in 2014. The article presents an inductive thematic analysis of sixteen participants’ opinions regarding telephone interviewing and discusses these in relation to existing literature reporting the use of telephone interviews within grounded theory studies.

Findings: Overall, participants reported a positive experience of telephone interviewing. From participants’ reports we identified four themes from the data: being ‘phone savvy; concentrating on voice instead of your face; easy rapport; and not being judged or feeling inhibited.

Conclusion: By drawing on these data, we argue that the telephone as a data collection tool in grounded theory research and other qualitative methodologies need not be relegated to second best status. Rather, researchers can consider telephone interview a valuable first choice option.

Keywords: data collection, grounded theory, nursing research, participant views, qualitative research, telephone interviewing
Summary statement

• Why is this research or review needed?
  • A tacit assumption exists that face-to-face is best for semi-structured interview.
  • Available literature on the telephone as a qualitative data collection tool in its own right is sparse.
  • There is scant literature on the telephone as a data collection tool in grounded theory.

• What are the key findings?
  • Offering valuable participant reflections around the use of the telephone during semi-structured interview addresses an underexplored area in the grounded theory literature and contributes to wider debate.
  • The value of nonvisual paralinguistic cues amplified via the telephone should not be overlooked and can be considered as useful as facial expression and body language during qualitative interview.
  • Interviewees reported a positive experience of semi-structured interview via the telephone, including confident telephone use and freedom to disclose personal or sensitive information via the telephone without feeling judged or inhibited.

• How should the findings be used to influence research?
  • This article provides insight into an untapped avenue of data collection that might provide ideas for future research practice and methodological debate.
  • Telephone interview need not be relegated to a second best option during qualitative and grounded theory research.
  • Further research is recommended to comprehensively compare qualitative face-to-face and telephone interview.
4.3.5. Introduction

The interview, in its various forms, is an internationally recognised method of data collection in several of research methodologies.\textsuperscript{38, 41, 45, 48, 257, 371, 379, 380} It is typical to use face-to-face interviews in qualitative research, whereas historically, telephone interviewing has been confined to quantitative research in the form of the telephone-administered survey.\textsuperscript{381, 382} In the main, the international literature available relating to telephone interviewing is focused upon the validity and reliability of the telephone as a medium for data collection within quantitative methodologies.\textsuperscript{383-385} However, telephone interviewing is rarely considered as a means to apprehend another’s social world within qualitative studies.\textsuperscript{386} During our grounded theory study, exploring users’ experiences with overnight mask ventilation (CPAP) for sleep apnoea, we selected telephone interview as a method to conduct semi-structured interviews. To explore this method of interviewing we nested an exploratory study within the larger grounded theory study. In this article, we report participants’ views on this method of interviewing and discuss these within the context of the existing international literature.

Background

In grounded theory, there is an emphasis on observation in the field as data: being able to see participants act within their social settings.\textsuperscript{45, 48, 231} However, the social setting of our grounded theory study exploring users’ experiences with CPAP was participants’ bedrooms as they went to sleep using CPAP. Consequently being present in someone’s bedroom was incongruous with ethical requirements for the study. Observation was therefore ruled out as a method of data collection and we offered participants semi-structured interview. Participants agreed on interview via telephone and we subsequently chose to explore their experience by inviting views regarding this mode of interviewing.

Birks and Mills\textsuperscript{364} suggest that, while telephone interview can be used to mitigate logistical issues during a grounded theory study, it should not be a first choice method because the absence of visual cues might disadvantage the researcher.\textsuperscript{380} While Charmaz\textsuperscript{45, 387} and Corbin and Strauss\textsuperscript{231} make no comment on using the telephone to conduct a grounded theory interview, they implicitly assume that an interview be conducted face-to-face. Kvale and Brinkman\textsuperscript{388} express the same view, as do Holloway and Wheeler,\textsuperscript{389} despite commenting on the growing popularity of the telephone interview. Equally Denzin and Lincoln\textsuperscript{379} and Green and Thorogood\textsuperscript{41} offer in-depth chapters regarding methodological and ethical debate around interviewing but make no comment about the use of the telephone.

Overall, few studies have comprehensively compared qualitative face-to-face and telephone interview and those that do typically focus on the interviewer.\textsuperscript{364} King and Horrocks\textsuperscript{390} confirm that the available literature on the telephone as a data collection tool in its own right is sparse, although they do offer practical advice when considering this approach. For us, as for Holt,\textsuperscript{391} the tacit assumption that face-to-face is the best option for the qualitative interview was evident from the lack of comment in technical texts. However, recent literature comments on the growing popularity of the
telephone for semi-structured interview and prompts the question: to what degree is the telephone interview useful for data collection in a grounded theory study?\textsuperscript{382, 391-395}

**Telephone interview in grounded theory**

We conducted a literature search via science direct, Google scholar and web of science to determine the extent of telephone interviewing as a method in grounded theory studies. The search terms ‘telephone interview’ and ‘grounded theory’ and limiting between 1990 and 2014 yielded nineteen grounded theory studies that had used the telephone to interview their participants. Ten of these studies employed grounded theory methods to develop a descriptive or thematic analysis only and were discarded. Table 10 below outlines the remaining nine studies.

**Table 10: Grounded theory studies using telephone interview**

<table>
<thead>
<tr>
<th>Author(s) &amp; Date</th>
<th>Methodology as described</th>
<th>Number and duration of interviews</th>
<th>Rationale for using telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arment Trout 2007\textsuperscript{396}</td>
<td>Grounded theory (GT) study. *Tenets of GT described, saturation not mentioned.</td>
<td>8 7</td>
<td>Participants choice.</td>
</tr>
<tr>
<td>Chetpakdeechit, Hallberg et al. 2009\textsuperscript{397}</td>
<td>GT approach. Tenets of GT described.</td>
<td>0 12</td>
<td>Participants geographically dispersed and time constrained.</td>
</tr>
<tr>
<td>Duggleby, Penz et al. 2010\textsuperscript{398}</td>
<td>GT approach. Tenets of GT described.</td>
<td>7 20, plus 4 focus groups 50-70 minutes.</td>
<td>Access to geographically dispersed participants.</td>
</tr>
<tr>
<td>Highet, Stevenson et al. 2014\textsuperscript{399}</td>
<td>GT model. Tenets of GT described.</td>
<td>24 4</td>
<td>Not stated.</td>
</tr>
<tr>
<td>Kylmä, Vehviläinen-Julkunen et al. 2004\textsuperscript{400}</td>
<td>GT design. Tenets of GT described, saturation not mentioned.</td>
<td>32 Number and duration not stated.</td>
<td>Telephone used for follow-up.</td>
</tr>
<tr>
<td>Mottram 2011\textsuperscript{401}</td>
<td>GT study. Tenets of GT described, unclear if saturation achieved.</td>
<td>245 Number and duration not stated.</td>
<td>Telephone used for follow-up.</td>
</tr>
<tr>
<td>Penz &amp; Duggleby 2011\textsuperscript{402}</td>
<td>GT study. Tenets of GT described.</td>
<td>0 27</td>
<td>Access to geographically dispersed participants.</td>
</tr>
<tr>
<td>Schreiber &amp; MacDonald 2010\textsuperscript{403}</td>
<td>GT study. Tenets of GT described.</td>
<td>22 11</td>
<td>Telephone used for follow-up.</td>
</tr>
<tr>
<td>Simms 1981\textsuperscript{404}</td>
<td>GT study. Tenets of GT described, saturation not mentioned.</td>
<td>0 23</td>
<td>Not stated.</td>
</tr>
</tbody>
</table>

*Tenets of GT described include: constant comparison, concurrent data collection and analysis, theoretical sampling, theoretical saturation, and theory generation.\textsuperscript{32, 45, 48, 231}
Of these nine studies, only Simms⁴⁰⁴ and Chetpakdeechit et al.⁴⁰⁷ used telephone interview as a first line choice, with only the latter giving a rationale for this choice of geographically dispersed participants. We identified an additional six studies that examined the effect of telephone interview on qualitative data or survey data finding results comparable with face-to-face interview (Refer to ⁴⁰⁵, ⁴⁰⁶-⁴⁰⁸). Holt⁴⁰¹ also used telephone to conduct narrative interviews and reported that participants viewed the experience positively, although data pertaining to telephone interview was not thematically analysed. The lack of literature about telephone interviewing in grounded theory is incongruent with the rise of telephone use globally. Accordingly, previous research has highlighted the pertinence of exploring interviewees’ experiences of the telephone interview.³⁸⁴, ³⁹¹, ⁴⁰⁶

### 4.3.6. The study

**Aim**

The aim of the study was to draw upon interviewees’ reflections on semi-structured interviewing via telephone. In so doing, we offer a unique contribution to the evolving debate around the use of the telephone during qualitative interview.

**Design**

A grounded theory study was the design of choice for a main study in which this study was nested.⁴⁵, ⁴⁸, ²³¹ Telephone interviews were conducted. Data pertaining to the use of the telephone were drawn from the larger grounded theory study and analysed thematically.¹⁶⁹ We used the consolidated criteria framework for reporting qualitative studies (COREQ).⁴⁰⁹

**Participants**

Seventeen in-depth, semi-structured interviews were conducted with sixteen participants (nine men and seven women) recruited through a respiratory outpatients’ clinic in the Auckland region of New Zealand. Criteria for inclusion were adults, aged eighteen years and over that were either prescribed night-time CPAP via face or nasal mask for obstructive sleep apnoea, or were the spouse of someone prescribed night-time CPAP for sleep apnoea. Participants prescribed CPAP were regular users, where regular included not all night or not every night. People under the age of eighteen years or who used CPAP for other conditions were excluded from the study. Purposive sampling of participants occurred at the outset of the study, with subsequent theoretical sampling adopted until theoretical saturation of the main body of data occurred.⁴⁵

**Ethical considerations**

Ethical approval to conduct the study was obtained from a national ethics committee, and the host organisation (reference NTX/11/06/048/AMO2) and each participant was sent an information sheet and consent to complete prior to their interview. The participant information sheet outlined that each interview would be conducted by telephone and take approximately one hour. Cultural protocol required that interviews be offered in person to Māori and Pacific Island participants if preferred, to
foster culturally safe communication. However, no participants chose this option. Once a signed consent was received, each participant was contacted via telephone to arrange a mutually suitable time for an interview. At no point did the interviewer and participants meet face-to-face.

Data collection

At the close of each semi-structured interview, KW invited participants to comment about the experience of interview over the telephone. Prompts included, what was it like not seeing the interviewer’s face and did they believe they had disclosed more or less than if the interviewer had been physically present? The data were collected during four consecutive months in 2011 and six consecutive months in 2014. The average interview duration was 52 minutes, the shortest being 24 minutes and the longest 82 minutes. All interviews were conducted by KW and were audio recorded and transcribed verbatim.

Data analysis

Data pertaining to this article were drawn from a grounded theory study, but analysed thematically. KW used an inductive approach where the content of the data directed coding and theme development. Transcripts of participants’ comments about telephone interview were coded to identify initial themes. Coding enabled grouping of data and tabulation, using Microsoft Word, for further sorting and identification of common themes around experiences of telephone interview. Themes were refined and are presented below supported by participant quotations.

Rigour

Tactics to assure rigour occurred throughout data collection and analysis. KW transcribed all interviews verbatim and rechecked transcription for accuracy. MG and KH reviewed tabulated data and reached consensus regarding relevant extracts for each theme. Memoing and discussion with co-authors allowed KW to clarify and refine themes as analysis progressed, and provided an audit trail of thematic development. KW described themes to participants during later interviews. Participants comments helped refine themes with resonance, eliminate incongruous themes and confirmed that analysis agreed with their experience.

4.3.7. Findings

The sixteen participants in this study were aged between twenty-eight and seventy years. Three female participants and one male were spouses of CPAP users. At the time of interview, participants had used CPAP for sleep apnoea for between two months to seven years. Overall, participants reported a positive experience of telephone interviewing. Only one participant stated a preference for face-to-face conversation, but concluded that the telephone interview had been “pretty good.” From each participants reports we identified four themes from the data: being ‘phone savvy; concentrating on voice instead of your face; easy rapport; and not being judged or feeling inhibited. A pseudonym identifies each participant.
Theme: Being ‘phone savvy

The participants in this study identified themselves as habitual telephone users, claiming to “do a lot of ‘phone stuff” in their work. Molly described previous telephone interviews and that being interviewed this way was “good because I don’t have to go out, and sit in [an] office.” Felicity concurred:

I’m quite relaxed sitting out here on my porch outside with my feet up. In my own environment, ... it hasn’t made me less relaxed than it would be. It’s quite easy just being at home and waiting for the ‘phone to ring.

Participants described doing “a lot of talking on the ‘phone,” and being able to “talk easily for an hour.” Similarly, Ian felt being interviewed on the telephone had “been fine; as you can tell I don’t have problems talking!”

Although interviews were offered in person to Māori and Pacific Island participants, they declined, indicating a willingness and comfort with the medium of telephone interview and lack of concern about not being face-to-face. Molly said:

You will have some [Māori] people that will be concerned about this kind of thing, culture and all this, but no, not me. I was brought up in the Māori environment, yeh, but that wasn’t thrown in our faces all the time. We mix with all cultures, my parents, you know, they wanted us to mix with all cultures, it didn’t really bother us.

Theme: Concentrating on voice instead of your face.

Participants in the study were asked how they found being unable to read the interviewer’s facial expression or body language. Not being physically present was described as useful “[because] you can concentrate on the person’s voice and what their emphases are.” Lily added that, “I think it just seems more like a conversation, more than an interview, when it’s on the ‘phone,” claiming that the advantage to telephone for her was “it actually makes you think [more] carefully about the answers than if you were face-to-face.” Ed considered that if he were able to see KW, the interviewer, he would have judged by her facial expression that he was talking too much. He added:

Sometimes judgments come across on the face, and no one likes to be judged. It doesn’t matter what kind of judgment it is. If someone thinks they’ve been judged on something they’ve said, then they’ll clamp up. And that doesn’t very often come across verbally but it will come across facially, so I think the telephone interviews are just as good.

Others echoed this sentiment: Felicity said, “[be]cause of the way you are speaking you don’t sound like you’re pulling faces.” Ian agreed, and elaborated by saying that if KW were “it [would not] matter ‘cause I don’t know and I’ll just rabbit on.” Only one participant expressed concern that not being able to see each other during the interview might cause misunderstanding. However, he concluded we “understood each other quite well.”
**Theme: Easy rapport**

Being unable to see KW, the interviewer, appeared to have no negative impact on establishing rapport. Gina stated that because she received written information about the study it did not “matter that I didn’t see your face: I know who I’m talking to.” Arthur identified with KW’s role as a professional and his belief that he was “talking to a person who’s really … working on why people are using a CPAP machine.” Ian believed he might be intimidated face-to-face from knowing KW was a professional but that this was mitigated by using the telephone: “there [are worries] you might be more qualified than me, or I might be more intimidated or something like that, but over the ‘phone it’s just a conversation.” No participant reported holding back information because of discomfort during the telephone interview.

**Theme: Not being judged or feeling inhibited**

On commencing each telephone interview participants were assured there were no right or wrong answers to any of the questions asked and were invited to talk freely about their experiences with CPAP. On closing, six participants made comments specific to not being judged: that not seeing KW’s face meant they were unable to assume KW was judging their comments and therefore did not feel judged in any way about what they were saying. Barry said:

> Looking at a person’s face, like, you might be thinking of something, and I can [mis]interpret it. ... you might look away, and I might think “oh she’s not interested,” as an example. Whereas this way, you’re just asking questions and I’m talking, so I don’t have any preconceptions.

Being unable to see KW meant that participants reported feeling more relaxed and able to be open and honest in their disclosures. Lily commented:

> I am in a familiar space that I feel comfortable in. So, I’m being quite real about it, rather than putting on an act that might happen in an interview situation. ... I think it’s quite good because I think you can be really honest because you can’t see me and I can’t see you. ... There’s not that judgment of face-to-face.

Ian agreed, “I think I will probably be more reserved if I was in front of you ... it’s easier for me to talk on the ‘phone.” Both Gina and Molly reported they had disclosed as much information, if not more, than they would have in a face-to-face interview. Despite divulgence of deeply personal information being unanticipated, topics such as sexual activity and orientation were brought up by the participants. While Hal and Olive said being face-to-face would have made little difference to what they disclosed others believed the relative anonymity of the telephone reduced inhibitions. Ed stated:

> People will say things over the telephone that they won’t say face-to-face definitely. It would have been more difficult face-to-face I think. Yeh, I think so, especially talking about relationship stuff. I’m a man, we don’t talk about that sort of stuff ... even if it is with a gay man. I think I would have had more issues talking to you face-to-face about it, than I would have on the telephone.
4.3.8. Discussion

This article is the first to report participant opinions about telephone interview in the context of a grounded theory study. Overall, participants were very positive about their experience of being interviewed over the telephone, supporting the findings of the only other study in this field.391 Offering valuable reflections on this approach addresses an underexplored area in the grounded theory literature and contributes to wider debate.

The theme “being ‘phone savvy” illustrates the confidence participants had communicating by telephone. Shuy384 suggests that face-to-face interviews deliver more accurate responses because of the “contextual naturalness” of being mutually present.\(^9\) We contend that the prominence of telephone and the confidence of users in contemporary society might well render it contextually natural. The International Telecommunications Union\(^{414}\) estimates that 95.5% of the global population subscribe to a mobile cellular network indicative of a contemporary ‘phone savvy social landscape. Nonetheless, Holloway and Wheeler\(^{389}\) recommend that telephone interview be shorter and more structured than face-to-face interview. However, this is at odds with our findings and the studies in Table 10.

People are accustomed to using the telephone not just to talk, but also to email, text message and find information. For our participants being ‘phone savvy meant they were comfortable using the telephone in daily life and reported that participating in an interview by telephone was convenient. Not only were they saving time, but being in a familiar environment also meant they were able to feel comfortable in their interaction. Moreover, participants identifying as Māori or Pacific Island agreed. Offering face-to-face interview to Māori and Pacific Island participants is culturally appropriate and ensures inclusion of potential participants.415 However, it is important to acknowledge the willingness of cultural populations to embrace modern day communication modes. We argue, therefore, that the popularity and contextual naturalness of the telephone make it a user-friendly tool for semi-structured interview.

There are also practical reasons why telephone interviewing might be preferred. For example, conducting fieldwork and interviewing in person is considered one of the more time-consuming and resource intense activities during qualitative research.384 Interviewing face-to-face impacts on the participant’s time, and can incur travel costs or limit access to geographically dispersed participants. Circumventing time-related costs by interviewing via telephone might be a pragmatic alternative as reflected by the rationales of three studies in Table 10.391,416 As Kira et al.\(^{417}\) found, being able to control their own spaces was also an advantage for our participants. For example, Ned was able to double up activities and prepare for an outing during his telephone interview. Negotiating a time to talk when other family members were not around has also been described as a practical advantage.391,408

The inability to ‘read’ visual cues has rendered telephone interview a less traditional method of qualitative data collection. During qualitative research and grounded theory research in particular, visual cues provided by facial expression and body language are considered important.380 The theme ‘concentrating on voice instead of your face’ offers an alternate view. Consider the intimate
nature of having another person’s voice close against one’s ear; each breath, sigh, hesitation and intonation or emotion easily heard. Such nonvisual paralinguistic cues can be as useful as facial expression and body language. Both Novick and Opdenakker argue that the absence of supporting hand gestures and visual cues provide an opportunity to clarify the meaning of a sigh or pause, rather than misinterpreting the meaning of a gesture. Participant responses reported under the theme ‘concentrating on voice’ aligned with this view and supported Musselwhite et al.’s suggestion that telephone interview moderates response bias. Therefore, the addition of a variety of paralinguistic prompts mitigates the absence of visual cues during telephone interview.

Not being face-to-face with the interviewee is also linked to poorer rapport with interviewees. Participants in our study refuted this as illustrated by the theme ‘easy rapport.’ What the participants said suggested that good rapport was not reliant specifically on being physically present, but on the social context and identification with the interviewer/ee. Knowing KW as a nurse might also have supported rapport although this was implied. Holt considers that not intruding into the participant’s physical space frees the participant from another’s surveillance. Such freedom from surveillance seemed congruent with mitigating our participants’ experiences of CPAP use monitoring by respiratory clinic nurses. We agree with Mealer and Jones that the relative anonymity of telephone interview might have allowed respondents to feel more relaxed leading to an enhanced interviewer/ee relationship.

Owing to the perceived difficulty building rapport during telephone interview concerns exist regarding the honesty and depth of disclosure by interviewees. Participants’ reflections, themed ‘not being judged or feeling inhibited,’ supports the view that the anonymity afforded by telephone interview might reduce transference, prejudice or misjudgement on the part of the participant, or interviewer. Sturges and Hanrahan suggest personal disclosure is easier face-to-face. Polit and Beck agree, suggesting that although telephone interview might have advantages, it might be less effective when the interviewer is unknown to the participant or when a participant is asked to share deeply sensitive information. However, others contend that it is easier to disclose personal information from a stance of relative anonymity. Also argued, is that such anonymity further frees the participant to disclose sensitive information. The findings of this study support freer, more relaxed disclosures. Participant responses did not reflect a reluctance to share personal information and contradict Shuy’s contention that face-to-face provides a better forum for sensitive questions. Moreover, our participants’ responses resonate with Trier-Bieniek’s findings that exploring sensitive topics via telephone might produce more honest data.

We recognise that using the telephone for research is increasing internationally due to the resource intense nature of in person interviews. Researchers experienced in qualitative methodologies may hold to the view that face-to-face is the best method for qualitative interviewing. However, the rising use of social media indicates a need within research to engage with changing technologies, such as blogs, telephone, and web-based conferencing to optimise inclusion of participants. Accordingly, we offer points for consideration for researchers contemplating using the telephone to conduct semi-structured interviews (see Table 11). Considerations are additional to that provided on qualitative interviewing in the many available texts on the topic.
Table 11: Practical considerations for qualitative interviewing by telephone

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prior to the interview</strong></td>
<td></td>
</tr>
<tr>
<td>Signal anticipated interview duration and the depth of discussion expected.</td>
<td>To prevent misperceptions that the interview is an informal chat.</td>
</tr>
<tr>
<td>On obtaining written consent make an initial phone call to introduce the researcher and gain verbal consent.</td>
<td>To promote rapport.</td>
</tr>
<tr>
<td>Agree upon a time of day suitable for the interview and re-confirm consent verbally at each step.</td>
<td>To protect the right to have time to consider participating and protect confidentiality.</td>
</tr>
<tr>
<td>Encourage participants to take the call in a private location and plan to make the call in a private location.</td>
<td>To reduce risk of interruption.</td>
</tr>
<tr>
<td>Ensure the recording device is compatible with the phone used and test the set-up.</td>
<td>To ensure no data is inadvertently lost.</td>
</tr>
<tr>
<td>Be alert to hearing impairments, mobility issues or language difficulties.</td>
<td>To mitigate for these prior to commencing interviews.</td>
</tr>
<tr>
<td>Use a head-set if available.</td>
<td>For researcher comfort and to free hands for note taking.</td>
</tr>
<tr>
<td>Attend to the pace of speech, practice if it needs to change.</td>
<td>To enable clarity for the participant, e.g. swift speech is harder to follow in the absence of lip reading.</td>
</tr>
<tr>
<td><strong>During the interview</strong></td>
<td></td>
</tr>
<tr>
<td>Confirm you are talking to the correct person.</td>
<td>To protect confidentiality and the integrity of the data.</td>
</tr>
<tr>
<td>Re-introduce yourself and remind your participant who you are. Review the aims of the interview. Briefly describe the researcher’s setting, invite the participant to do the same.</td>
<td>To situate the researcher in the mind of the participant and promote rapport.</td>
</tr>
<tr>
<td>Confirm that your scheduled interview time remains convenient.</td>
<td>To ensure a reschedule is unnecessary.</td>
</tr>
<tr>
<td>Remind your participant the interview will be recorded and that the call is confidential.</td>
<td>The visual cue to audio-recording will be absent.</td>
</tr>
<tr>
<td>Signal depth of discussion expected and likely duration at the start of the interview.</td>
<td>To mitigate expectations that the interview will be task focused or a chat.</td>
</tr>
<tr>
<td>Be prepared to probe ambiguities, pauses, sighs or assumptions, e.g. you know.</td>
<td>To resolve ambiguities in the absence of visual cues.</td>
</tr>
<tr>
<td>Master the pregnant pause.</td>
<td>To reduce the risk of inappropriate interjection when the participant needs time to think.</td>
</tr>
<tr>
<td>Use vocal acknowledgements such as mmm, aha, OK.</td>
<td>To ensure your participant can hear that you are still listening.</td>
</tr>
</tbody>
</table>

Adapted from our experiences during this study, and King & Horrocks, Burke & Miller, Carr & Worth, Holt, Mealer & Jones, Musselwhite et al. and Stephens.
**Strengths and Limitations**

This study was nested within a larger grounded theory study within which established principles of grounded theory were followed. However, sampling specific to the larger study’s requirements meant informants were restricted to CPAP-users and their partners. We were also unable to sample based on previous experience with face-to-face interviewing, although four participants described previous involvement in face-to-face interviews and focus groups. Recruitment for this study was via a clinic and, according to ethical requirements, participants were able to self-select independent of the researcher. Although the participant information sheet outlined the provision of a face-to-face interview to those that preferred, it is not possible to know whether those that chose not to participate did so because of the telephone interview. Participants came from one region of New Zealand. Therefore, future research should include qualitative studies using different informant populations and a larger dataset.

**4.3.9. Conclusion to the article: Participants’ views of telephone interviews within a grounded theory study.**

As part of our grounded theory study, we chose to conduct semi-structured interviews by telephone. Participants were able to reflect on their experiences of the semi-structured interview via telephone and contribute to currently scant information on the approach. Counter to the tacit assumption that face-to-face is the best method for semi-structured interview, our participants viewed interview via telephone as a favourable experience. Exploring participants’ experiences of qualitative telephone interview within our grounded theory study provides insight into an untapped avenue of data collection along with ideas for future research practice and methodological debate. Accordingly, further research needs to address comparisons made between experiences of face-to-face and telephone interview in the same study. Additionally, to engage with changing technologies in grounded theory research, studies incorporating telephone, blogs and other social media should be considered.

That the above research participants viewed the medium of telephone for interview positively supports the view that the telephone is a user-friendly interview tool. Given the global popularity of the telephone as a means to communicate, interviewing via this medium in contemporary society appears pragmatic. We argue that the value of intonation, hesitation and other paralinguistic cues amplified via the telephone should not be overlooked. Equally, the freedom of the relative anonymity of the telephone is useful when exploring potentially sensitive topics. The value of face-to-face interview is not disputed. However, for research participants accustomed to using the telephone, we contend that the tool need not be relegated to a second best option on the basis of geographical or resource constraint during qualitative and grounded theory research.

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4.4. Data Analysis in Grounded Theory

The previous section, including the article reporting on the use of telephone as an interview tool, addressed the practical issues of data collection and generation along with introducing the participants. The remainder of this chapter focuses on the handling of data once collected.

I began analysis by transcribing each interview verbatim into MSWord along with details such as respondent behaviours, questions that provoked the strongest responses and my reactions.\(^{424}\) Doing my own transcribing meant spending a lot of time listening to the sound of my participants’ voices and words and involved thorough immersion in what was said. Although a slow process, transcribing led to early immersion in the data that became an advantage during analysis. I heard participant stories many times while I rechecked and corrected transcripts, leading to an easy recall of who said what and when with a clear memory of intonation and tone of voice. ‘Hearing’ previous participants in my mind while coding subsequent transcripts made constant comparison easier to do as I could quickly locate a related comment. ‘Hearing’ also made it easier for me to maintain the integrity of the participants’ stories throughout analysis by remaining grounded in their words, which was fundamental to constructing the substantive theory explaining what it is like to live with CPAP. Had someone else transcribed for me I would have missed the advantage afforded by such intimacy with the data. Following transcription, I began coding.

Coding during different phases of analysis (as depicted in Figure 2, p.59) involves various forms of logical reasoning. Research texts describe quantitative research as using a hypothetico-deductive approach since it involves the testing of a-priori ideas.\(^{38, 421, 425}\) Therefore, the term deductive is typically associated with quantitative methodologies. Conversely, qualitative research is considered inductive since ideas are generated from the data.\(^{425}\) Scholars argue that grounded theory uses inductive reasoning, while others contend that grounded theory is both inductive and deductive in nature.\(^{43, 334, 425-428}\)

Grounded theory as an inductive approach is predicated on the researcher not making assumptions about what will be ‘found’ in the data, since little evidence exists at the outset of a grounded theory project from which to derive a hypothesis. Therefore, results of initial analyses originate from the data through inductive inference. However, as soon as information about a topic is gathered, construction of ideas begins. Charmaz\(^ {429}\) states that induction involves raising analysis up from a range of individual cases into higher-level categories, and that “making deductions about them” involves going back into the data looking for individual cases that corroborate and saturate categories.\(^ {p.243}\) Once initial codes are induced from data, the next step is to deduce where next to seek information to develop codes through theoretical sampling and constant comparison.

Both Charmaz\(^ {412}\) and Corbin and Strauss\(^ {43}\) state that deducing where to look next refines categories by validating them against further data, leading to more definitive higher-level categories. Therefore, more than one type of logical reasoning determines the outcome of a grounded theory. Consequently, a simultaneous process of both induction and deduction occurs. Moreover, Haig\(^ {428}\) and Reichertz\(^ {334}\) propose that to generate theory, grounded theory takes logical reasoning a step
further by introducing abductive thought, which allows abstraction of data to the conceptual level, as shown in Figure 4.

Abduction, first described by Charles Sanders Peirce, involves entertaining all possible explanations of data to reach the most plausible interpretation, or “fit.” Since the grounded theorist is exploring new territory, any given portion of data might generate more than one tentative mini-theory. For example, I initially coded data that described sharing information about using CPAP with non-family members using a number of different codes, including mitigating stigma, working with fear, overcoming barriers and fearing stigma and rejection. Figure 5 illustrates the application of the forms of reasoning, depicted in Figure 4, to an excerpt of data about sharing information.

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**Chapter 4**

**Initial coding**

**Interrogate data:** theoretical sampling, constant comparison

**Codes, & conceptual categories**

**Abduction**

**Tentative mini-theories**

**Deducing**

**Inducing**

Figure 4: Reasoning in grounded theory research

Adapted from 430

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**Figure 5: Application of reasoning**
Eventually, the code *joking around* in the above figure led to the intermediate code *disclosing*, that contributed to strategies for *mitigating stigma*. Participants joked around as a strategy to pre-empt another's rejection because of imagined stigma, and not because they had experienced negative comments from another person, as I originally thought. Haig\(^{428}\) described the abductive research process as one of theory generation, theory development and theory appraisal. The process is not sequential, but iterative and continual, following early generation of ideas after which the researcher asks more questions of the data. Consequently, abstracting the concepts in Figure 5 led to the construction of the sub-category *imagining and managing stigma*.

Using data to iteratively induce and test ideas and concepts throughout the grounded theory process develops theory by "inference to the best explanation."\(^{432, 433}\) Abductively unravelling any confusion during analysis is achieved through theoretical sampling and constant comparison.\(^{355, 412}\) Additionally, theoretical sensitivity enhances the process of abduction by allowing the researcher to be open to many possible explanations with which to interrogate the data.\(^{434}\)

The next section illustrates the development of theoretical sensitivity using reflexivity. Sections that follow associate the methods used for analysis with each type of reasoning described above to show how they function together to generate theory. Using examples from this study, I show how inductive reasoning generated early codes and initial categories that led to the inclusion of additional questions and participants through deductive reasoning. Illustration of abductive reasoning follows, enhanced by memoing and diagramming. I conclude by describing how I determined that theoretical saturation and trustworthiness of the theory were achieved.

### 4.4.1. Raising theoretical sensitivity using reflexivity: Considering the discourse of compliance

Theoretical sensitivity is an essential component of the grounded theory research process that describes the ability to recognise elements pertinent to the construction of theory in the data.\(^{231, 434}\) Glaser and Strauss\(^{42}\) described a grounded theorist’s level of sensitivity as an aggregate of insight into personal assumptions about themselves and the area of research along with prior intellectual knowledge. Researchers use a variety of strategies and sources to raise theoretical sensitivity, including literature on related topics, professional and/or personal experience and data analysis itself.\(^{189, 190}\) Scholars state that received knowledge is welcome in the grounded theory research process as a ‘sensitising concept’, so long as it is laid out and critiqued during the process to maintain transparency.\(^{140, 302, 319}\) Using reflexivity to critique received knowledge enables awareness of dominant discourses and subliminal preconceptions that might have implicitly influenced the research process. Moreover, the process of critique enhances theoretical sensitivity by increasing analytical possibilities. An example of this is the consideration I gave to the concept of compliance in healthcare in chapter two (see p.30).

Conducting the integrative review in chapter two raised my sensitivity to the possibility that the discourse of compliance might have an influence upon the participants in this study. Being alert to the discourse of compliance during this project served two purposes. Firstly, I was able to scrutinise
thinking while interviewing to ensure I did not unintentionally influence dialogue and consequently
derail analysis. Secondly, reviewing received knowledge around compliance was useful as a
sensitising concept, aptly demonstrated by the in vivo code *being a good client* that I had
constructed from data already gathered.\(^{140, 302, 319}\) The following excerpts from a memo illustrate
how the discourse of compliance played out within participant accounts.

**Memo: Being “a good client” - “I should be using it.”**

**13 01 2013:** Barry said he had “been a good client in the sense that I’ve used it a lot.” I notice
that some others make similar comments. Barry spoke of having a “good six hours” with the
mask on, and taking it off in the early hours having done “enough.” Almost as a reward for
wearing the mask for long enough. There is a sense of balancing comfort against the
consequences of not using the machine and the impression that it is possible to be a ‘bad’
client. Is this a dichotomy of good versus bad user - what does this mean to CPAP-users?

**24 01 2013:** I’ve just coded Dave’s comment “I should be using it more” under ‘Not using
though I know it’s good for me.’ However, his comment is bugging me. What is going on in
his head when he says that – from who does the expectation of should originate: clinicians,
family or himself? Is this linked to the concept of compliance – or is he just irritated that the
septoplasty did not give the results he was hoping for? Is there a degree of guilt in there?
And what stops him using it though he knows he “should”?

Dave continued, “I’ve just got to get a bit more motivated because it will make me feel better
‘cause that’s what the nurse said.” Is getting used to it an intrinsic process rather than
imposed from external sources like clinicians?

**08 02 2014:** I wonder if users associate using their machine enough with being a “worthy
candidate,” meaning being allowed to keep the device (Barry). It seems the case whether
they report using CPAP every night or believe they need to use CPAP more often than they
do. Participants talk about the “threat” of having the machine taken away, “which isn’t kind of
nice to have looming over you really” (Felicity). Gina reported being told specifically that not
using CPAP and not coming to her appointments would result in having the machine taken
away.

Participants know their hours of use are counted and describe being “told.” Along with the
practical consequences of not using CPAP (the expectation of being a ‘good client’ for friends
and family: not falling asleep during dinner, not waking them with snoring), are participants
describing fear based upon the expectation of use imposed by their health professionals?

**07 10 2014:** I think ‘being told’ links with the code ‘being a good client’ in that both refer to the
perception that healthcare staff expected the CPAP machine be used exactly as prescribed.
Participants related both ‘being told’ and ‘feeling told’ to use it. Ned described the “threat” of
having his driving license taken away if he did not use his CPAP. Gina, Pete and Dave were
also “told” they could lose their machines if they were not used enough. Peter referred
specifically to being told off stating, “I should actually just take it back to them and say I’m
trying to manage without it, but they’ll probably tell me off, as they did last time.” Apart from Pete, it seems that being a good client is a fear that motivates the choice to use CPAP.

The above memo excerpts illustrate how Foucault’s ideas of governmentality and surveillance, enacted in society in this healthcare setting, took the form of self-regulation rather than direct coercion. Awareness of monitoring motivated CPAP-use out of fear, as not complying defined the user as non-compliant and sanctioned the return of the CPAP device. Considering the discourse of compliance enhanced my sensitivity to how participants described the meaning of being monitored. The category becoming motivated eventually subsumed the code being a good client.

4.4.2. Initial to intermediate coding using inductive reasoning

As outlined in section 4.2.1, p.59, coding begins with raw data. Induction describes the logic of working something out based on the evidence available, in this case participant accounts. Inductive reasoning aligns with Glaser’s inference that a ‘blank slate’ is an important platform from which to commence coding, although I agree with Charmaz and Corbin that prior assumptions are always present in this process. While I had no idea what I would be told, I did have some understanding that CPAP was uncomfortable for some, and that perhaps the consequences of sleep apnoea might act to motivate CPAP use. To limit the potential for forcing the data, I coded at the beginning of the study using a line-by-line approach.

Line-by-line coding involves describing what is happening in the data in a way that anchors key points in the data. Such meticulous coding meant remaining close to the data and immersed in what participants were saying, so preventing early leaps of logic away from the data and participants’ words. Corbin and Strauss believe that such detailed work provides a strong foundation that facilitates later stages of analysis. The following example from the second interview illustrates how I managed initial coding at the beginning of the study (see Figure 6). The raw transcript is centre; the right-hand column shows line-by-line coding and the left-hand column shows higher-level, more focused coding using gerunds.
Figure 6: Initial and focused coding, second interview.

Note that each line of transcript above is not always a full sentence. Glaser\textsuperscript{352} referred to this as fracturing the data in order to re-view events from varied viewpoints.

I underlined data that seemed significant and memoed as thoughts arose, using comments boxes. The above memo, dated 28 08 2011, denotes early ideas about data that later contributed to the code \textit{reaching a limit}. Similarly, I coded Barry's reflections regarding his daughter \textit{bearing witness} to his breathing cessation early in the study. Both of these codes were eventually elevated to a sub-category and later became part of the first main category. Other initial conceptual ideas from early analysis included ‘getting a good sleep’, ‘communicating for good sleep’ and ‘establishing the need for CPAP’, before finally settling on a category that encompassed these ideas, one that had also
been constructed from the very beginning: *becoming aware*. This process of moving back and forth between data reflected the dance of double back steps that occurs to conceptualise data into theory.189

After line-by-line coding, I returned to the transcript to focus the coding. As confidence grew, coding became more fluid with simultaneous line-by-line and focused coding, especially where a salient thought needed capturing. The excerpt in Figure 7 is an example of intermediate coding from a later transcript.

![Figure 7: Initial and focused coding, ninth interview](image)

N-Vivo became a useful data management tool, but only for later phase coding and categorising. I continued to code and memo using comments boxes as I went through transcripts, as memoing separately felt counterintuitive. The call out boxes above show the focused codes and the categories after inserting the data into NVivo nodes. Initial coding within the transcript document meant I remained immersed in participants’ stories. Subsequent coding into NVivo enabled comparison with other data, codes and categories as analysis progressed.

Initial coding enabled the construction of categories based upon groups of similar ideas. Thereafter, I began following leads in the data with focused coding. As theoretical sensitivity increased, and
theoretical coding began, the need for such scrutiny of the data diminished. Elevating intermediate codes using gerunds became a prominent part of the process (see Table 12).

Table 12: Elevating data to categories

KW: Tell me anything about the way you feel about yourself physically with CPAP …

<table>
<thead>
<tr>
<th>Data</th>
<th>Initial coding</th>
<th>Intermediate codes</th>
<th>Sub-category</th>
<th>Main category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Umm, yeah well I think it is pretty grotesque. There's no doubt about that. There's no way you can make it nice; it is hideous looking, it's very clinical, it's a little bit scary. (Lily)</td>
<td>CPAP is not pretty</td>
<td>Changing / unchanging body image</td>
<td>IMAGINING STIGMA</td>
<td></td>
</tr>
<tr>
<td>…and not having anybody else to worry about made it easy to use, as I said it looks like - I’m sure of you woke up to somebody with one of those on you’d feel like you were in the movie set of silence of the lambs! [laughs]. (Barry)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you weren’t a sympathetic person … you’d probably struggle … seeing your partner in one of those. …And the stigma of the thing with it is the hating it, …I’m lucky I’m single …you could imagine a couple of disparaging comments when you first start and if you are a sensitive soul like I tend to be, all of a sudden it’s like ‘I don’t want to do that…’ (Barry)</td>
<td>Expecting stigma</td>
<td>Self-stigmatising</td>
<td>IMAGINING STIGMA</td>
<td></td>
</tr>
<tr>
<td>Oh, just make a bit of a joke I suppose, and err, deal with it from there… (Dave) We’ve kind of laughed about it; that’s the way we’ve handled it. Joked about it and laughed about it. (Lily)</td>
<td>Joking around</td>
<td>Finding a way to make it acceptable - managing own expectations</td>
<td>OVER-COMING BARRIERS</td>
<td></td>
</tr>
<tr>
<td>I learnt to make a kind of joke about it. (Felicity)</td>
<td>Not hiding</td>
<td>Not fearing stigma - Disclosing</td>
<td>MAKING CHOICES ABOUT CPAP</td>
<td></td>
</tr>
<tr>
<td>I think most people now know that I have sleep apnoea, that I either work with or … all of our friends do, so I’m not hiding it. (Ed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The examples in Table 12 illustrate how portions of data contributed to initial codes, which were later subsumed by higher-level codes and categories. I found using gerunds instead of nouns particularly useful as it drew attention to action and process. Indeed, Saldaña argues descriptive coding of interviews using nouns is inappropriate since people are more than nouns. Therefore, using gerunds to code for process emphasised action, interaction and how the dynamics of
Chapter 4

consequences, time and change influenced participants’ decisions.\textsuperscript{349} Charmaz\textsuperscript{330} believes using gerunds in this way focuses analysis on enacted processes rather than individuals and aids theory construction. Following initial coding, the next section describes how I began following leads in the data.

4.4.3. Evolution of questions and development of categories using deductive reasoning

Starting to follow leads in the data as I coded required deductive reasoning. I looked at information from the participants and thought about what it meant. The following memo expands on the short memo depicted in Figure 6 (p.84), which outlines the sub-category reaching a limit that initially became part of the first main category.

\textbf{Memo: Reaching a limit}

\textbf{18 03 2013:} I initially inferred that the impact of symptoms that led to ‘reaching the limit’ for action would wax and wane. That sometimes participants would have ‘had enough’ but at other times they might feel their problem didn’t warrant action (see drawing right). However, this was not borne out by the data. Though it may have taken time for them to act, the pathway towards action was straightforward and once the point of ‘had enough’ was reached participants sought medical advice:

I could just not figure out what was the problem. (Arthur)
I went to the Dr, and I asked her about … ‘cause I just got sick of it… (Barry)

I think that impetus to seek help is either self-driven and/or others driven or a mixture of both. With Barry’s description of his daughter’s ‘witnessing,’ I think [deduced] that others might have similar experiences. Ed described that close family members expressed concern for his life, and he became unhappy about constant daytime fatigue. Others recognised that they had felt unwell for some time and reached a point at which this was no longer acceptable, and they needed to do something about it. Felicity confessed, “it was the driving thing that took me to the Dr, more than anything else.” So, is it one thing, or a series of things that precipitate action? I will add some questions about that.

The above memo outlines why I chose to ask about conditions under which people reached the decision to visit a doctor. After conducting further interviews and analysis, I revisited the memo:

\textbf{15 08 2014:} For some [participants] it seems to take a series of events to catalyse action. Molly’s friend had been “offended” that she had fallen asleep during a conversation. All the
same, participants still reach a tipping point of “had enough.” A tipping point or threshold from which they do not look back. Even if they go round the houses to get there:

…it wasn’t a waste of time in the sense that I’ve found out what was wrong with me. (Dave)

Molly’s grandchildren had also said they could hear her snoring from outside the house. However, for Molly the tipping point was falling “asleep at the lights …the car at the back of me was tooting [and] I realised there must be something wrong with me.” Reaching the tipping point results in a decision to make a change – or at the very least to explore options for change to find out what might be wrong and what can be done about it. Do participants establish priorities for wellness because of catalysts to action?

I hypothesised that reaching a limit was a threshold that participants passed, denoted by a decision to seek medical advice, rather than being part of the first main category. I was able to ask subsequent participants, including spouses by this stage, who agreed that this concept resonated with them.

A second example of making deductions about categories relates to the importance of partners to the process of living with CPAP. A series of memos provided material for the first article in the findings chapter regarding the role of partners in CPAP use. The short excerpt below illustrates my deductions about including partners of CPAP-users in the study to corroborate what CPAP-user participants said about the importance of their partners and close family and friends.

Memo: Spousal engagement

16 01 2012: Barry said that not having a spouse to be horrified at the machine was a good thing. Whereas, Ed felt that not having a partner would be worse because then he would have to disclose to someone about the CPAP without the certainty of a favourable response. Ed described a strong relationship and a deep emotional investment in spousal well-being that was reciprocal. This couple did everything together and, as a result, mastered the use of and integration of CPAP into their life. Curzon’s words suggest that marital harmony eases accepting, adjusting and integrating CPAP. Curzon acquiesced to his wife’s wishes that he use CPAP because he “chose not to quarrel.” There is more than one person (CPAP-user) involved in the decision-making process around CPAP. I wonder what having a partner means for the CPAP-user then, and why those with partners and those without have different perceptions – how do partners influence the process?

Subsequently, four people were included whose partners had used CPAP for between eleven months (OliveP) and over ten years (KayeP). Partner participants described congruent experiences to that of the CPAP-users in their lives. Therefore, both inductive and deductive reasoning helped construct new avenues of inquiry that led to confirmation of participants reaching a threshold to action and that partners were an integral part of living with CPAP. However, deeper abstraction required abductive reasoning to facilitate theoretical saturation and theory integration.
4.4.4. Achieving theoretical saturation with memos and diagrams using abductive reasoning

Charmaz\textsuperscript{412} determines that theoretical saturation is reached when the properties of categories are fully saturated with data. Thereafter, additional data yields no further properties and those properties that exist explain variation and relationship between categories. Charmaz\textsuperscript{412} emphasises the abductive process of theoretical sampling as the main driver of theoretical saturation, supported by continued comparisons and memo writing.\textsuperscript{436} Comparing incident to incident throughout the data facilitates the subsuming of codes into categories and on into higher-level categories, and enables theoretical saturation. However, knowing when saturation is reached is a different matter and one I struggled with.

Reichertz\textsuperscript{334} claims that abductive reasoning is both logical and innovative, meeting criteria for being ‘scientific’ while allowing new knowledge to be constructed by reaching into “the sphere of deep insight.”\textsuperscript{(p.1210)} Such conceptual insights owe genesis to memoing and diagramming. Noted grounded theorists emphasise the value of memo writing to enhance the process of theory integration and saturation.\textsuperscript{42, 43, 45, 48} Clarke\textsuperscript{437} captured the importance of memos, recognising them as “intellectual capital in the bank.”\textsuperscript{(p.85)} Indeed, by comparing early memos to late memos during memo sorting, I rediscovered forgotten ideas constructed early during this project. A clear example is the memo in which I had pondered the properties of good sleep without realising I had written a message to myself about the concept of ‘balancing’ (see section 4.3, p.62).

Glaser\textsuperscript{438} argued that memoing is so important that all activities should cease in favour of recording a memo. Consequently, I scribbled memos on receipts or surreptitiously wrote during church. Had I not recorded those ideas they would now be lost, along with the audit trail of thinking and the evolution of the constructed theory. For instance, sections 4.3.1 on sampling and 4.4.3 on deduction would have been much harder to write without the memos included.

However, I had trouble with the free-writing process until I developed a way to memo into comment boxes while coding manuscripts in Microsoft Word. Writing about a complex, multifaceted set of ideas during analysis using only the flat and linear medium of language yielded tangled prose.\textsuperscript{439} Fortunately, free drawing, diagramming and constructing conceptual models offered a more intuitive way to think in the abstract, untangle ideas and establish connections within the data. Drawing and diagramming has been a component of grounded theory analysis since its inception. Strauss and Corbin\textsuperscript{353} advocated the use of memos and diagrams to assist abstraction of data to conceptualisation, and continue to do so in their latest edition.\textsuperscript{43} Birks and Mills\textsuperscript{355} differentiate between diagramming as an analytical tool and the abstract representation of a model. Clarke\textsuperscript{440} further elaborates on the usefulness of diagrams, to map out relationships and “axes of difference, concern and controversy” during situational data analysis.\textsuperscript{(p.210)} Charmaz\textsuperscript{45} also offers the technique of clustering as a visual technique to catalyse memo writing. The following memo succinctly illustrates this process.
Memo: Clustering codes

07 06 2014: I am ignoring the epistemology paper just now, in favour of re-clustering codes/categories and preparing to interview the next spouse. I am in the zone – I do not want to lose grip. I had coded the first spouse interview away from the NVivo nodes to allow production of new stuff and to prevent inadvertently trying to fit that interview’s data into what I already had. I expected different stuff so did not want to taint it with what I had in NVivo. Next, I printed out all the nodes, cut them up and reassembled them (see photos...).

After that, I mapped them into a PowerPoint slide and applied statements and arrows that connect the different categories together (see PowerPoint slide [reproduced on p.92]). Now I’m going to copy the NVivo project and re-construct the categories to reflect where I am at. I want to leave the original NVivo project where it is so I do not lose initial decisions amongst the changes I have made. That way I can see where I have come from if that makes sense. I’m unconvinced I have all the codes/categories in the right places, especially as there are a couple that stand alone, and a couple that fit everywhere. I need to go back to the data I already coded to cross check what I have where, but it feels like it is becoming more coherent. I felt like I needed to do this clustering before doing the next interview so that I could be surer of the gaps.

Establishing the interplay between categories and validating connections by diagramming signified that coding had reached an abstract and advanced level of analysis. I was beginning theoretical integration as I was starting to integrate the categories into the theory. Glaser and Charmaz name this phase of analysis theoretical coding, while Strauss and Corbin refer to axial and selective coding. Nevertheless, I ascribe to Birks and Mills view that making connections and seeing relationships between incidents within the data begins with the first piece of data and the process of theoretical sampling (see Figure 4, p.80). In reality, the first data collection point generates conceptual leaps. The process of constant comparison and theoretical sampling – checking out ideas – keeps such conceptual leaps anchored to the data, eventually leading to theoretical saturation and integration.

Drawing ideas and creating graphics of conceptualisations freed me to write. Buckley and Waring refer to diagramming as an under-utilised tool for both depicting analytical steps and for generating analytical ideas. As a kinaesthetic and visual learner, diagramming and drawing became an important part of the analytic process, allowing me to ‘see’ what I was thinking, discern gaps and
refine ideas. If the drawing was unclear, so were concepts. For example, the memo about reaching a limit owed its genesis to a drawing on a receipt while waiting at traffic lights (see Figure 8, transcribed for clarity).

![Figure 8: Motivators to action drawn 20 08 2011](image)

Similarly, Figure 9 shows that refining the conceptual model of the theory in this project (see Figure 12 in Chapter 5, p.98) began on the back of an envelope.

![Figure 9: Modelling in the moment](image)

Notice the circular nature of the pencil marks in the above figure. This depiction often featured in my drawings, finally directing me to the circular nature of the decision-making process that informs the overall theory. After collecting larger amounts of data, the diagrams became complex and were challenging for others to decipher, while I worked to discern patterns and connections throughout the data (see Figure 10).
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Key:

[Diagram: Constructing the main category making choices about CPAP]

Accepting CPAP & Being Motivated

- Being relieved - Getting OSA under control
- Pursuing CPAP
  - Affirming CPAP
    - Having a happy spouse / others
    - Feeling the difference
- Understanding OSA physiology & consequences
  - Strategy: Comparing before & after
- Choosing CPAP: choosing life
  - Prioritising 30/07/2014
- Being Pragmatic
  - Being realistic: Not expecting a cure
  - Accepting - being happy with CPAP
  - Maintaining perspective

Making choices

- Needing CPAP
  - Being serious and taking responsibility
  - Having the security
  - Exhausting possibilities - no alternative

Questioning CPAP

- Checking there isn't another way
  - Rationalising cause - obesity, jaw shape
- Dealing with disappointment
  - Being emotional - how could that be me?
  - Being despondent
  - Doubling CPAP - change slow to happen

Making CPAP normal? transitioning

- Just getting on with CPAP

Seeking another way

- Getting away without it
- Recalculating family goal with medical goal - COLLECTIVE GOOD
- Conflict - battling with self and others - COST COLLECTIVE GOOD
- Spousal non-engagement - convincing spouse - different priorities
- Excluding spouse

10/07/2014: Memo I think maintaining perspective may go here, as it's about being clear there are worse things to worry about than how you might look with a mask on. This is the best option for OSA so best get on with it. This is the way they rationalise their decision to treatment, having gone through wishing they didn't have to have it, but realising that CPAP is the best it's going to get. It's under persevering currently and being pragmatic - body image unaffected.

06/06/2014: Memo This is about finding a boundary - e.g. how much is just enough. When being convinced is accepted, but not enough to motivate continued use, or all night every night.

13/02/2014: Memo This is all Gina - all my other participants may have questioned CPAP or considered other possibilities, even to the point of pulling the mask off in the night, but only Gina has avoided it for weeks at a time.

The only other poor user would be Dave, who didn't offer any excuse - he was quite clear that he was being lazy and only used CPAP so his mates weren't disturbed by his snoring on trips away. So is this a relevant category? Talk to other poor users?
Figure 10 shows part of a larger diagram constructed between the ninth and twelfth interviews. Diagramming and drawing, as illustrated by Figures 9 and 10, enabled sorting of theoretical codes to discern properties, conditions or strategies, and where next to seek information. Depicting thought processes taps into the creative and innovative thinking required to integrate theoretical categories through abduction. Diagramming electronically also offered the advantage of recording memoed thoughts during diagram construction and changes in my thinking. The complexity of Figure 10 illustrates Buckley and Waring’s assertion that diagramming performs a number of purposes that include visually representing conceptualisations, stimulating analysis and the abductive thinking process.

4.5. Evaluative tactics in grounded theory

Memos and diagrams enabled sharing of constructions with those familiar with the study and topic to give surety to the research process. However, other tactics were required to give surety to the complete grounded theory. Along with memoing and diagramming, ‘testing’ the theory with colleagues and other experts in the field offers a further evaluative tactic for determining theoretical saturation. Accordingly, abductive reasoning provides for both the generation and the evaluation of theories constructed from data.

A story that resonates with others provides conviction that interpretations reflect what participants are trying to convey and that the theory is believable, applicable and “feels right.” Glaser suggests that evaluative criteria for fit, work, relevance and modifiability are met, while Charmaz asserts that a grounded theory should demonstrate credibility, originality, resonance and usefulness. As a result of theoretical sampling, constructing the theory implicitly involves participants checking conceptual ideas. During interview, participants willingly commented on my developing concepts, enabling the process of refining where concepts made sense and discarding when they did not. Colleagues were able to relate the theoretical concepts in the story to personal experiences of long-term treatment. Scholars in a grounded theory group that I attended judged my rendering of the data as sufficient to agree with the constructed storyline and theory. The following memo excerpt, written following a conversation with a colleague, encapsulates abductive reasoning using writing, diagramming and the evaluative process of discussion.

Memo: Assessing resonance

11 11 2014: George understands grounded theory and has a spouse using CPAP for OSA. During an informal conversation, we chatted about my grounded theory study and the theory of ‘choosing a good sleep and getting used to CPAP.’ Overall, the model as I described it (using my categories) resonated with George. He described his partner as understanding about OSA but having difficulty with mask discomfort, particularly dry eyes. George had experienced frustration and anger towards his spouse when CPAP was not used, as he then

*** Pseudonym
experienced the consequences of the snoring and resultant poor sleep. He reflected what partner-participants had said. George managed now by reminding his spouse to use the CPAP either before bed or during the night if the snoring woke him.

George described reconciling his sense of guilt at waking his spouse with his need for a good sleep. He talked about their negotiations as a balancing act between meeting his needs and accommodating the feelings of his partner. He recounted his partner’s difficulties with the mask and described how she balanced the impact of what she knew about the health consequences of untreated sleep apnoea with the side effects of the CPAP and her lifestyle choices. As we talked, we drew the below diagram together (Figure 11).

![Diagram](Figure 11: The inner battle: gaining equilibrium between treating the condition, managing side effects and lifestyle.)

What George described illustrated how the interface between overcoming and yielding to barriers was circular. George’s spouse balanced the consequences of each corner of the above figure on a nightly basis. Her feelings, on any given night, either amplified or diminished the annoyance she felt towards CPAP side effects. For example, if her eyes were not sore that night using CPAP was easier; if they were sore abandoning CPAP was more likely. Not using her CPAP, however, positioned George as the antagonist. He then had to balance his needs for a good sleep with those of his partner by negotiating for a reciprocal sleep.

The above makes me think that the code ‘negotiating reciprocal sleep’ has a better fit with the sub-category ‘navigating communication,’ as George described the frustration and irritation he experienced balancing the expression of his needs against those of his spouse. Getting his communication right was a constant balancing act.
The conversation with George determined my conceptualisations as resonant, credible and original. Additionally, this memo formed the turning point in the theory construction of this project. I had constructed both codes *bargaining* and *balancing* as early as the second interview, but had woven and subsumed both into other codes and categories. However, this conversation not only brought both codes together, but it also brought them into stark relief and made the relevance of *bargaining and balancing* to all categories obvious. Consequently, the next chapter presents findings from this study to show how participants enacted bargaining and balancing.

### 4.6. Chapter 4 Summary

Chapter 4 has presented the research methods employed in this study, underpinned by the principles that characterise a constructionist grounded theory. Examples from the study incorporated in this chapter articulate decisions that guided data collection and analysis and advanced development of credibility and trustworthiness of the work. Chapter 5 presents the theory constructed from this study.
CHAPTER FIVE

Findings
Chapter 5. Findings

The aim of this project was to construct an explanatory theory about how CPAP-users live with CPAP for obstructive sleep apnoea. The previous chapters have described the grounded theory research process used to generate the theory. Chapter 3 discussed the philosophies underpinning grounded theory and described how social constructionism influenced the research approach. Chapter 4 detailed the hallmark methods that comprise a grounded theory along with how these methods for sampling, data generation and data analysis were used. This chapter uses the findings of the research process described to present the constructed grounded theory: 

*bargaining and balancing life with CPAP*. 

The first section of this chapter outlines the theory of *bargaining and balancing life with CPAP*. The following sections present the three main categories that explain how participants enacted *bargaining and balancing*. These sections incorporate two articles under review for publication. The first article reports key components of the preliminary category *becoming a team for good-sleep* that includes subcategories *bearing witness, being a team* and *becoming aware*. The second article reports the second main category, *making choices about CPAP*. The following section reports the final main category *becoming used to CPAP*, to conclude the process of *bargaining and balancing life with CPAP*. 

Details of the main categories are presented as a storyline, a recognised way of presenting constructions from the data to the reader. Writing storyline was a technique presented by Strauss and Corbin to aid theory integration during advanced analysis. Glaser criticised storyline, arguing it was a framework imposed on data that constrained ‘emergence.’ Following Glaser’s criticism, Birks and Mills contended that the potential of storyline was left untapped, and they subsequently extended its application as an aid for analysis and for presenting a grounded theory to readers. Using storyline to unify categories into a theoretical explanation requires the storyteller to write and re-write the story until the links between categories are clear and any variation accounted for. Gaps in the story signify gaps in analysis that direct the researcher back to the data or on to further theoretical sampling. Consequently, writing storyline is a creative way to discern gaps during theory integration. The storyline in the next section outlines the theory constructed from this study. The storylines presented in the articles that follow reflect the stage of theory construction at the time of writing. 

Participants’ comments support the storyline and evidence category construction. Where possible I have maintained the verbatim nature of participants’ words to preserve the integrity of what they reported and to demonstrate analytical rigour. Insertions to assist clarity are denoted by [...]. Un-bracketed ellipses, … denote omitted text. When describing both CPAP-users and partners of CPAP-users, the word ‘participant’ is used. ‘Partner’ describes bed- and/or life-partner.
5.1. The Theory: Bargaining and balancing life with CPAP

The theory constructed from this study is *bargaining and balancing life with CPAP*. Figure 12 depicts the theory’s main categories and sub-categories.

The top arrow in Figure 12, pointing left to right, illustrates a pathway with a beginning, middle and end. Participants progressed in one direction through the three phases of the pathway starting with *becoming a team for good-sleep*.

I identified *bargaining and balancing* as the main social process explaining how people manage to live with CPAP. During analysis a category *making choices* appeared to describe the social process that connected the main categories, and was titled *choosing CPAP*. Participants made choices throughout the pathway about why and how to use CPAP. For example, participants chose to seek help, decided what would motivate them or chose to yield to barriers. However, while comparing my thoughts with earlier analysis, I noticed that I had already used the gerund ‘balancing’ (see memo, p.62). Thereafter, talking with George revealed that before making any choices participants *bargained and balanced* to evaluate the evidence they had about how CPAP could help them (see memo, p.93). The following excerpt from a memo written during advanced analysis depicts how my thinking subsequently coalesced.
Memo: Bargaining and balancing instead of choosing?

09 04 2015: The more I think about it, the more I think ‘choosing’ is not right. Participants do make choices, but I think it is more complex than that. Bargaining and balancing seem a better fit. At the beginning of the process, witnesses had to bargain with their partners to seek help. Then snorers bargained and balanced the pros and cons of using CPAP. They reasoned that, ‘it is better for my wife, it is better for my health, but it is uncomfortable to use.’ While troubleshooting and deciding whether to persevere with CPAP (which was a choice predicated on assessing the benefit against the difficulties of using CPAP) participants balanced experiencing wellness, having the propensity to persevere and being pragmatic about the need for CPAP against disliking how it felt and abandoning it altogether. It was all an act of bargaining and balancing.

The account that follows outlines bargaining and balancing life with CPAP. The theory comprises three main categories described as follows; becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP. The subcategories for each of the main categories are italicised in the following summarised storyline.

Becoming a team for good-sleep

Becoming a team for good-sleep begins with partners bearing witness to the symptoms of sleep apnoea. Typically a partner, and occasionally family or friends, witnessed apnoic episodes and endured the associated snoring. Consequently, both witnesses and snorers experienced poor sleep. By sharing their experiences, witnesses enabled snorers to start becoming aware (the second sub-category) of sleep apnoea symptoms, such as constant daytime fatigue. Witnesses drew snorers’ attention to how often they fell asleep during social occasions or at other inappropriate times. The impact of any given symptom differed for each participant. However, it required bargaining by witnesses, together with an awareness of symptoms, to prompt the snorer to seek treatment. Negotiations between partner (and/or family and friends) and snorer illustrated the establishment of a team who shared the same goal of good sleep and demonstrated the third subcategory of being a team. Indeed, any person close to the snorer became part of their team for good sleep. Team members subsequently collaborated with initiating and integrating CPAP. Joint decision-making facilitated successful therapy management and consequently good sleep. Conversely, a dysfunctional team hindered this process. The importance of being a team focused on good-sleep is emphasised in the first article in this chapter.

By becoming aware, snorers reached a limit. Reaching a limit illustrates the point at which snorers chose to act in favour of improving sleep by seeking medical help. Choosing to act and subsequently receive a sleep apnoea diagnosis signified a threshold through which participants passed and did not return: once snorers became aware of having sleep apnoea, they remained aware. On receiving a CPAP device snorers began making choices about CPAP, which is the second main category of the theory.
Making choices about CPAP

CPAP-users reacted to the new treatment, the first subcategory of making choices about CPAP. Participants were either relieved at finally having a solution to the snoring and fatigue or disappointed about needing the device. Consequently, they devised various strategies to become motivated to use the device. Comparing how unwell they felt before using CPAP with enhanced well-being upon using treatment supported making CPAP a priority. Feeling well was a tangible experience and made the balance of reasons to use CPAP fall in favour of continued use. Therefore, affirming the positive consequences of CPAP supported the motivation to prioritise CPAP.

Participants who did not immediately feel well needed different motivations to convince themselves that using CPAP was a good idea. These participants balanced the promised but intangible returns of using CPAP against the challenges they encountered. Each participant identified the gravity of his or her diagnosis. Participants explained the physiological consequences of untreated sleep apnoea and recognised the risk posed to cardiovascular health. Moreover, participants feared the life-limiting nature of untreated sleep apnoea. All participants described how maintaining an open airway during sleep would improve oxygenation to improve physical and psychological well-being. Consequently, being afraid of poor health also became motivating.

Participants reported varying degrees of struggling with CPAP and becoming motivated facilitated overcoming barriers, the third subcategory to CPAP use. CPAP-users also recognised that using CPAP could be stigmatising, and so persevered with strategies to mitigate stigma and to troubleshoot challenges with CPAP. Struggling with the mask was common and users engaged in a process of trial and error to deal with discomfort. Joint problem-solving as part of a good-sleep team supported troubleshooting. Conversely, some participants acted by yielding to barriers, the fourth subcategory. Typically, participants yielded to barriers intermittently, reasoning that they could get away without CPAP at any given moment. Moreover, bargaining and balancing could lead to choosing another way to manage sleep apnoea rather than use CPAP. The second article in this chapter elaborates how participants balanced the positives and negatives of CPAP use to make a definitive decision about using CPAP and pass the second threshold.

Becoming used to CPAP

All participants in this study had passed the first threshold and were using CPAP. Not all participants passed the second threshold, but those who did ceased making choices about using CPAP. If participants were able to maintain motivation and definitively choose to use CPAP, the final category of becoming used to CPAP began. Participants made adaptations to established routines and rituals to subsume CPAP into daily life and consequently chose new routines, which is the first subcategory of this final main category. Once the challenges of using CPAP were overcome, making CPAP a normal part of life was relatively straightforward and with time became routine. Participants had finished getting used to CPAP, the second subcategory, and were now mastering CPAP. Using CPAP no longer required conscious effort, and other matters occupied
participants’ thoughts. Nevertheless, CPAP remained undiminished in its importance in maintaining good sleep for users, their partners and other family members.

In summary, bargaining and balancing life with CPAP revolves around the wish for a good sleep and explains how participants grew accustomed to using CPAP to improve sleep. The circular arrows in Figure 12 represent periods in which participants bargained and balanced the advantages and disadvantages of using CPAP prior to making a choice. Moreover, participants bargained and balanced both in relationships with those around them and with themselves. Participants continued to bargain and balance in a small way until mastering CPAP. The following sections elaborate on the details of the above storyline.

5.2. Main Category 1: Becoming a team for good-sleep

The first main category describes how snorers realised they had a sleep apnoea problem and is comprised of three sub-categories (see Figure 12). The article that follows focuses on the sub-categories bearing witness, becoming aware and being a team. By bearing witness partners, along with other family members, were integral to becoming aware and being able to cross the first threshold in Figure 12. Therefore, the following article illustrates the importance of partners throughout the process of living with CPAP.

The following manuscript is under review for publication.
ARTICLE: Becoming a team for good-sleep: Findings from a grounded theory study about living with CPAP.

5.2.1. Abstract

Untreated sleep apnoea increases morbidity and mortality. Continuous positive airway pressure is a recognised, cost-effective treatment. However, treatment can be challenging for users, and limited evidence exists about this therapy from the users’ perspective. Therefore, we explored users’ experiences of living with continuous positive airway pressure for obstructive sleep apnoea, using constructionist grounded theory.

Adult participants prescribed positive airway pressure for sleep apnoea (n=12) were recruited through a main-centre respiratory service in New Zealand. Theoretical sampling led to the addition of partners’ views (n=4). Data were collected during four months of 2011 and six months of 2014 using semi-structured interviews and analysed according to grounded theory convention; theoretical saturation was reached.

This study resulted in a grounded theory, bargaining and balancing life with CPAP comprised of three main categories: becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP. This paper focuses on the first main category regarding the importance of significant others to the process of living with this therapy. This category highlights that people in close relationship with positive airway pressure-users are integral to managing therapy successfully. Indeed, it was apparent that users and partners formed a team with the mutual goal of achieving a good sleep. Partners experienced and bore witness to consequences of untreated sleep apnoea, prompting the snorer to seek treatment. Joint problem-solving and decision-making facilitated successful therapy management. Conversely, un-collaborative partners hindered this process.

Partners and significant others are not simply bystanders, but are integral to using positive airway pressure, and should be incorporated in the process from diagnosis to management of treatment. In the spirit of patient- and family-centred care, formally inviting therapy-users’ designated partners along to sleep-clinic visits increases the probability of successful therapy management at home. Further research, including intervention studies, should explore the role of partners in successful positive airway pressure management and other long-term therapies.

Keywords: continuous positive airway pressure; family-centred care; grounded theory; obstructive sleep apnoea; partners; patients’ experience.
What is known about this topic?

- Continuous positive airway pressure can be challenging for users, and sleep medicine interventional literature focuses on improving CPAP use.
- There is limited evidence about this therapy from users’ perspectives or regarding the importance of partners to this process of living with CPAP.

What this paper adds

- Experiences of participants reported in this paper reveal that the teamwork of a close relationship optimises CPAP use.
- Supporting the inclusion of designated partners during the healthcare process aligns with patient- and family-centred care and should become the norm in order to improve clinical outcomes for sleep apnoea sufferers.
- Findings reported in this paper support further research to explore the transferability of recommendations to other long-term conditions.

Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPAP</td>
<td>continuous positive airway pressure</td>
</tr>
<tr>
<td>OSA</td>
<td>obstructive sleep apnoea</td>
</tr>
<tr>
<td>P&amp;FCC</td>
<td>patient- and family-centred care</td>
</tr>
</tbody>
</table>
5.2.2. Introduction

The causes and consequences of the chronic condition obstructive sleep apnoea (OSA) are internationally recognised and well documented in the literature, as are the high personal and societal costs of untreated OSA. Continuous positive pressure (CPAP) via face or nasal mask is an internationally established gold standard therapy for OSA. However, the device can be challenging for users and studies have shown that adherence is often poor. The association between OSA and obesity suggests that the global increase in obesity may herald a worldwide health and economic matter if treatment for OSA is unsuccessful. Therefore, exploring factors that support CPAP use at home is important.

Untreated sleep apnoea causes the quality of relationships, home life and social life to suffer. Heart and vascular health are also at risk from untreated OSA. Successful treatment with CPAP is known to be both clinically effective and cost-effective. To address concerns about poor adherence to CPAP, studies have extensively explored supportive interventions that may aid the CPAP-user. However, a recent review identified limited evidence from the users’ perspective regarding experiencing CPAP for OSA, determining that current literature addresses concerns about adherence through a problem-oriented paradigm. Exploring management of CPAP from users’ perspectives is an important step to understanding success with CPAP. Moreover, the recent review identified that partners and other family members influenced CPAP-users’ experiences. This view is supported by two subsequent studies. Hu et al.’s study focused upon the process of seeking medical help for OSA and identified family as a source of information regarding sleep apnoea symptoms. However, the role of partners in the process of using CPAP was not explored. Rodgers focused on the process of being diagnosed with OSA and identified partners as an important source of support for sleep apnoea sufferers as they pursued treatment. The current study extends these findings by identifying processes that explain how partner support occurs. Evidence regarding how couples cope with chronic illness underscores the role of supportive partners in long-term therapy care. Indeed the inclusion of family members is credited with improved long-term condition management. A small number of studies highlight the problems that untreated sleep apnoea causes for typically female partners of sleep apnoea sufferers. However, the influence of partners in CPAP management at home is underexplored.

Evidence about how users successfully live with CPAP is limited, as is evidence regarding the role of partner involvement, and other family members, in the management of CPAP. It is within this context that the present study explored CPAP-users’ experiences to determine how people manage this therapy successfully. This paper presents an important component of the findings that focus on the first main category of this grounded theory study to illustrate the role of CPAP-users’ partners and family.
5.2.3. Method

Given the limited previous research in this area, we considered a qualitative method most appropriate to address the study aim. We used semi-structured individual interviews and a constructionist grounded theory approach, as described by Charmaz and Birks and Mills. Grounded theory provides a way to address gaps in knowledge by constructing a theory explaining participants’ actions from the ground up. Accordingly, the coding framework was inductively derived from the data. This report uses the consolidated criteria framework for reporting qualitative studies (COREQ).

Local context

This study is situated in a main centre of New Zealand where the public health system is government funded. People with sleep apnoea who meet nationally established diagnostic criteria are eligible for a CPAP device free of charge. Mihaere et al. identified that the prevalence of sleep apnoea in New Zealand aligns with international evidence, with prevalence increasing as body mass index increases.

Ethics

The host organisation and the relevant national ethics committee provided ethical approval for the study (reference NTX/11/06/048/AMO2). The respiratory service lead physiologist identified participants prior to clinic. On arrival, participants received an information pack from clinic staff that outlined reasons for and details of the study, including written consent to complete if they chose to participate. At each contact point, KW verbally re-confirmed consent to protect participants’ confidentiality and the right to re-consider participation.

Recruitment

Participant sampling was purposive at the beginning of the study with a focus on recruiting adults with a personal knowledge of using CPAP. Participants were adults prescribed CPAP via nasal or face mask for OSA (n=12). As data analysis progressed, new participants were theoretically sampled, based on information they might provide. This included partner-participants to corroborate data provided by CPAP-user participants regarding the support of close others. Theoretical sampling also led to a second interview with one of the participants, to compare experiences of CPAP over time, and to the inclusion of partners (n=4) of CPAP-users recruited to the study. Partner participants received an invitation to the study by post. According to ethical requirements participants self-selected independent of the researcher. It is unknown how many participants declined to participate during purposive sampling. One partner-participant declined during theoretical sampling. ‘Partner’ describes bed- and/or life-partner. People aged seventeen years and under or those prescribed CPAP for other illnesses were excluded.
**Data collection and analysis**

Grounded theory methods favour observation in the field for data generation: seeing participants act within their social settings.\(^{45, 48, 231}\) As the setting for this study was participants' sleeping places, ethical requirements rendered observation in the field inappropriate. Although interviews were offered in person if preferred, all participants chose to be interviewed by telephone. A recent study discussing the use of telephone for qualitative interview identified that telephone is an acceptable method of qualitative data collection.\(^{469}\) In total, KW conducted, audio-recorded, transcribed and coded seventeen individual in-depth, semi-structured interviews during four consecutive months in 2011 and six consecutive months in 2014. Interview notes, including respondent behaviours and interviewer reactions, and anonymised data were managed and stored using QSR NVivo10.\(^{172, 347}\)

Interviews began with open-ended questions, or prompts, to elicit information relevant to the participant about CPAP. These included: tell me about your CPAP, and about your night-time routine, what does CPAP mean to you, and how do you explain sleep apnoea or CPAP to others? Semi-structured dialogue enabled KW to follow new lines of inquiry as new categories were constructed from the data.\(^{48, 231, 371}\) Subsequent questions focused on exploring and developing main categories.

Data collection and analysis occur concurrently in grounded theory.\(^{45, 48, 258}\) Therefore, analysis commenced with coding of the first transcript to identify initial constructs.\(^{45, 48}\) Comparing coding of previous interview data with each subsequent interview generated increasingly focused questions that enhanced category construction. Coding enabled grouping of data into categories that were later subsumed by major conceptual categories and then abstracted into the final theory.\(^{470}\) Constantly comparing data to data and codes to codes, along with concurrent data collection and analysis, facilitated evaluation of each code, category and abstract concept against participants' words. Continually returning to gathered data enabled construction of the findings as an authentic reflection of the participants' accounts. Data collection concluded by the seventeenth interview once saturation of codes and categories had occurred.\(^{45}\)

**Rigour**

A grounded theory is judged sound when it fits data that has strong logical links with the analysis, resonates with participants and others familiar with the topic and offers new insights into practical implications.\(^{45, 352}\) KW regularly shared constructions with colleagues and a grounded theory peer group who challenged interpretations, giving surety that they were grounded in the data. Memoing, diagramming and discussion with MG and KH allowed KW to clarify and refine constructions as analysis progressed, along with providing an audit trail of the theory development.\(^{45, 48, 231}\) Colleagues related theoretical concepts in the story to personal experiences of long-term treatment. Moreover, theoretical sampling implicitly involved participants checking conceptual ideas during theory construction.\(^{412}\) Participants comments helped refine concepts that made sense, eliminated those that did not and confirmed that rendering of the data agreed with their experience and understanding.
5.2.4. Findings

Sixteen participants (men n=9, women n=7) were recruited. CPAP-users reported receiving a moderate to severe OSA diagnosis and were regular users, where regular included all night, every night to not all night, and/or not every night (see Table 13).

Table 13: Participant demographics at the time of interview

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age (Years)</th>
<th>Ethnicity</th>
<th>Time since CPAP initiation**</th>
<th>CPAP use at time of interview**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthur*</td>
<td>45-54</td>
<td>Indian</td>
<td>2-3 months</td>
<td>Each night, all night</td>
</tr>
<tr>
<td>Barry</td>
<td>55-64</td>
<td>NZ Eur##</td>
<td>3-4 months</td>
<td>Each night, not always all night</td>
</tr>
<tr>
<td>Curzon</td>
<td>75-84</td>
<td>Indian</td>
<td>7-8 months</td>
<td>Each night, 8 hours</td>
</tr>
<tr>
<td>Dave</td>
<td>25-34</td>
<td>NZ Eur</td>
<td>For “a while”</td>
<td>“Not all the time”</td>
</tr>
<tr>
<td>Ed</td>
<td>45-54</td>
<td>NZ Eur</td>
<td>3 years</td>
<td>Each night, 5-7 hours</td>
</tr>
<tr>
<td>Felicity</td>
<td>35-44</td>
<td>NZ Eur</td>
<td>2 year</td>
<td>Each night, 6 hours</td>
</tr>
<tr>
<td>Gina</td>
<td>35-44</td>
<td>Samoan</td>
<td>6 years</td>
<td>Not every night</td>
</tr>
<tr>
<td>Hal</td>
<td>55-64</td>
<td>NZ Eur</td>
<td>11 months</td>
<td>Each night for last 3-4 months</td>
</tr>
<tr>
<td>IanP*</td>
<td>35-44</td>
<td>NZ Eur</td>
<td>Ed’s partner</td>
<td></td>
</tr>
<tr>
<td>JarotP</td>
<td>65-74</td>
<td>Indian</td>
<td>Curzon’s partner</td>
<td></td>
</tr>
<tr>
<td>KayeP</td>
<td>55-64</td>
<td>NZ Eur</td>
<td>Partner of CPAP-user recruited but not interviewed</td>
<td></td>
</tr>
<tr>
<td>Lily</td>
<td>35-44</td>
<td>NZ Eur</td>
<td>6½ years</td>
<td>Each night, all night</td>
</tr>
<tr>
<td>Molly</td>
<td>55-64</td>
<td>Maori</td>
<td>5 years</td>
<td>Each night, 7 hours initially, now 3-4 hours as husband’s carer.</td>
</tr>
<tr>
<td>Ned</td>
<td>25-34</td>
<td>NZ Eur plus other</td>
<td>2 years</td>
<td>Not every night, 3-4 hours</td>
</tr>
<tr>
<td>Hal</td>
<td>Second interview</td>
<td>2 years, 11 months</td>
<td>Each night, all night</td>
<td></td>
</tr>
<tr>
<td>OliveP</td>
<td>55-64</td>
<td>NZ Eur</td>
<td>Hal’s partner</td>
<td></td>
</tr>
<tr>
<td>Pete</td>
<td>55-64</td>
<td>NZ Eur plus other</td>
<td>“About 2 years ago.”</td>
<td>Abandoned CPAP after “about a year.”</td>
</tr>
</tbody>
</table>

Key: * Participants listed in order of interview; * Partner-participants suffixed ‘P’; ## New Zealand European; **Self-report

Overall, this study resulted in the construction of a grounded theory, *bargaining and balancing life with CPAP*, and comprised three main categories, *becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP*.

The focus of this paper is the first main category, *becoming a team for good-sleep* that explains how partners, close others and CPAP-users functioned together. (‘Partner’ describes life and/or bed-partner of the CPAP-user.) CPAP-user participants also reported on the contributions made by others, including close family and friends. To provide context, the following account summarises *bargaining and balancing life with CPAP* using storyline, a recognised technique for extending analyses and for presenting grounded theory findings. In the following, sub-categories for each of the main categories are italicised.
Storyline

The first main category, becoming a team for good-sleep, with its sub-categories of bearing witness, becoming aware and being a team, is the focus of this article and is described in detail below. Through being a team and becoming aware, snorers reached a limit signified by the point at which they chose to act in favour of improving sleep by seeking medical help. Reaching a limit represents a threshold through which participants passed and did not return as once snorers became aware of having sleep apnoea, they remained aware.

On receiving a CPAP device, snorers began making choices about CPAP, the second main category of the theory. In the first sub-category reacting, participants described relief at finally having a solution to snoring and sleepiness, or disappointment about receiving the device. Consequently, they devised various strategies to become motivated to use the device, the second sub-category. Comparing how unwell they felt before CPAP with subsequently enhanced well-being affirmed the positive consequences of CPAP and supported prioritising CPAP. Participants who did not immediately feel an improvement had to balance the promised but intangible returns of using CPAP against the challenges they encountered. Participants feared the life-limiting nature of untreated sleep apnoea and described expectations of how CPAP would improve physical and psychological health. Consequently, being afraid of poor health became motivating. Additionally, participants reported various struggles with CPAP, and becoming motivated facilitated overcoming barriers, the third sub-category. CPAP-users persevered with a process of trial and error to troubleshoot challenges, and developed strategies to mitigate stigma. Conversely, some participants described yielding to barriers, the fourth sub-category. Typically, participants yielded intermittently, reasoning that they could get away without CPAP at any given moment. However, through bargaining and balancing some participants chose alternatives to continued use of CPAP.

If participants maintained motivation and definitively chose to use CPAP, they passed the second threshold and began becoming used to CPAP, the final main category. Participants made adaptations to subsume CPAP into daily life and consequently chose new routines, the first sub-category of the final category. Once the challenges of using CPAP were overcome, getting used to CPAP became relatively straightforward. With time, using CPAP became routine and a normal part of daily life. Participants were now mastering CPAP, the final sub-category. CPAP use no longer required conscious effort but retained importance in maintaining good sleep for users and partners.

5.2.5. Becoming a team for good-sleep

The following presents the subcategories of becoming a team for good-sleep in detail, using participants’ words to evidence constructions.

Bearing witness

Without testimony from loved ones, most CPAP-user participants claimed they would have remained ignorant of sleep apnoea symptoms:
He encouraged me to try and see someone about it. For years and years. But I never would, I didn’t see it as a big issue, ’cause I never really counted [the apnoeas], obviously. (Ed)

I was unaware of having sleep apnoea, my wife said I had it. (Hal)

Lily made explicit comment about her husband having “witnessed” her night-time breathing cessation, as did other participants:

Even the grandchildren used to say they can hear me. “Nana, we can hear you from up the road!” (Molly)

She said, “Oh, Dad, you stopped breathing in the middle of the night.” (Barry)

JarotP described being scared when hearing her husband stop breathing while asleep. Fear that the sleep apnoeic might die compelled bed-partners to remain awake:

In the beginning, my lack of sleep was [from] making sure I didn’t fall asleep until I had heard him breathe again. (IanP)

Close friends bore witness for some participants. Friends ejected Ned from a shared camper van, sending him to “the other side of the parking lot.” Falling asleep during social gatherings was common, and Molly recalled offending her friend who suggested she “get looked at.” Partners mitigated snoring by going to sleep before snoring began, sleeping with earplugs or in different rooms. Others were more direct:

If we both went to bed at the same time, it wasn’t okay. I would listen and wait. Every third or fourth breath he would snore, so I used to sleep with my elbows above my head and bring my elbow down and hit him. (KayeP)

The experience of frustration with, and fear for, the snorer motivated witnesses’ to act in recognition of symptoms and shared poor sleep. Witness’ testimony initiated a collaborative team process with the aim of improved sleep for both parties.

**Becoming aware**

The actions of witnesses enabled snorers to become aware of sleep apnoea symptoms such as snoring and fatigue. Each CPAP-user described the time before CPAP and realised they had been feeling unwell. Participants were conscious of persistent fatigue and of how easily they could fall asleep:

I used to go round to [my sister’s] place sometimes and fall asleep in the middle of the day with toddlers jumping all over me. Really, I was just too tired to get out of my own way. (Lily)

Barry described his lethargy as a “dragging ball and chain,” and an apathetic “can’t be bothered” approach to life, while others woke “feeling a bit like I’ve got a hangover every day” (Felicity, Lily). It took several events for some participants to understand they needed to take action:

I had fallen asleep at the traffic lights and the cars at the back were waiting for me. I didn’t realise I had fallen asleep. (Molly)
Participants described how “embarrassing” falling asleep during dinner or with friends was (Felicity). Moreover, maintaining a career meant being able to “keep up with the young fellas at work” (Hal). Participants were aware of the risk they posed to their families and other road users and needed to understand why they were so sleepy, for the safety of others:

I’ve got this big problem where I could cause an accident at any time, not just for my own safety or my children’s safety, but for anybody else on the road too. (Felicity)

The fear of losing a driving license or their job spurred them to action as they began to realise the consequences of not seeking help for their sleep problems.

**Being a team**

If it were not for their witnesses, most CPAP-users confessed to remaining ignorant of their sleep apnoea. Hal acknowledged being “unaware of having sleep apnoea” until his wife alerted him, and although he believed her immediately, most partners described some difficulty convincing the snorer to take action. Similarly, CPAP-users described the difficulty family and friends had convincing them there was a problem. While most CPAP-users affirmed a supportive partner, partners recalled behaving differently, especially prior to CPAP initiation. Bed-partners expressed tension between “selfishly” meeting their sleep needs by “being quite bullying” about the snoring versus allowing the snorer to maintain their autonomy (IanP). Partners and friends urged their loved ones to seek help:

In the end, I kinda harassed him enough that he went to the doctors. He’d obviously get quite annoyed about it, ‘cause he wasn’t really aware how bad it was. (IanP)

CPAP-users’ attributed their success using CPAP to the collaborative nature of close relationships. Despite trouble using CPAP, Ed claimed “the strength in the relationship” had significantly enhanced his eventual success; his partner had attended all outpatient appointments and had “lived through my sleep apnoea with me” (Ed). Lily agreed:

[OSA] is a hard thing to explain, or get totally right. I think it was good [my husband] came to the appointment. It’s probably quite important that you’re both hearing the same information at the same time. I think some people think they’ve heard of sleep apnoea, and they know about CPAP machines, but they don’t actually understand how serious it is. (Lily)

Lily believed her husband’s understanding of her CPAP enhanced their ability to function together and share the “adventure,” helping her “figure it out.” Participants described how families assisted with CPAP during travel and reminded them to wear the mask if they forgot:

But my children, they just take the machine as part of their Nana, part of me. And when we go away on holidays they make sure to find a space where my machine won’t be touched or banged around. They know how to pack up the machine and put it where nothing will harm it. (Molly)

Although two participants were single, and imagined withholding CPAP use until they could trust a new bed-partner, both remained able to identify other family members who supported their CPAP use and who became part of their *team for good-sleep.*
The expression of empathy and concern for what partners endured before CPAP further characterised motivation to function as a team. Hal imagined that sleep apnoea would be "pretty frightening" to observe, and along with others affirmed the importance of witnesses. CPAP-users illustrated commitment to the team aim of a good sleep and reciprocity toward bed-partners by relating adapted sleep habits, changed sleeping positions to prevent cold air blowing on bed-partners and the importance of maintaining night-time rituals and intimacy. For the snorer, using CPAP for the benefit of loved ones was clear since frightening or inconveniencing the people around them was upsetting. The desire to protect loved ones or the wider community was a stronger motivation than clinicians’ advice. Dave stated the “best thing” about his CPAP was travelling companions no longer heard his “terrible snoring.” Similarly, Ned used CPAP, not for his benefit, but “because it helps my wife get a better night's sleep” (Ned). Therefore, teamwork between witnesses and CPAP-user optimised the likelihood of a good sleep and success with CPAP.

Three participants provided negative cases for being a team by describing a conflicted team. Pete abandoned CPAP, and despite having an engaged team member in his wife, chose to ignore her concerns about his health, opting to “control” OSA by himself. Although persevering with CPAP, Felicity hid under the bed sheets to conceal the CPAP mask from her husband. She was hesitant about his support, describing his annoyance at both her snoring and the noise that the device made and confided:

I suppose he tries to make light by cracking jokes, but it doesn’t necessarily make me feel any better. (Felicity)

Gina confessed that her husband knew little about the purpose of her CPAP, except that her snoring stopped. I asked if he reminded her to put the mask on at night:

Erm… Nah, no he doesn’t. Because he knows, it’s something it’s my responsibility. So, he doesn’t really; doesn’t really understand about it and why I have to wear it and why I don’t. (Gina)

Gina reported her husband’s concern that they not use “too much power,” and when she did describe his support, she revealed his focus, “…he really encourage me, because he want me to lose weight, to have a baby.” Gina remained focused on the issue of weight loss throughout her interview. Using CPAP was important to Gina, but not to the other members of her family. Indeed, she described her in-laws perception of her as a “sick person” and unworthy of her husband. Despite describing her sleep apnoea as a “risk to her life” and being clear she wanted to “live long,” Gina’s potential team for good-sleep had conflicting priorities to her own and she reported not using her CPAP.

5.2.6. Discussion

This paper is the first to describe the considerable impact of partners, and other family members, on success using CPAP by establishing and maintaining a team for good-sleep. By exploring CPAP-users reports regarding the role of the partners in the management of CPAP, this study adds to
limited evidence and knowledge on this topic. Data drawn from the study support the concept of a collaborative relationship between the CPAP-user and others in close relationship who share the goal of restorative sleep. This paper advances knowledge by identifying the CPAP-user and partner as a pre-existing collaboration and, therefore, a source of support throughout the care process. Katzenbach and Smith\textsuperscript{471} define team as a small group of people “committed to a common purpose, set of performance goals, and approach for which they hold themselves mutually accountable.”\textsuperscript{[165]} Although used in the context of organisations, this definition is congruent with participant accounts in this study. \textit{Bearing witness} and \textit{being a team} illustrates the presence of an established team that was a precondition to seeking treatment for OSA and that continued to function throughout the use of CPAP. When those in close relationship with the CPAP-user were a collaborative team, integrating CPAP into daily life went well. A compromised team was associated with compromised integration of CPAP.

The sleep medicine and healthcare literature has explored the significance of the partner/patient relationship, but from a problem-oriented paradigm and focusing on adherence to CPAP.\textsuperscript{452, 453, 468, 472-474} Furthermore, attention has been on the impact of the female bed-partner and has until now not explored the experiences of male bed-partners. In contrast, this study focused on successful management of CPAP and the pivotal role of partners, incorporating various gender and cultural perspectives and the perspectives of partners themselves. Partners have a stake in the use of CPAP, and our data indicate that they are key to supporting the CPAP user. This study also highlights the impact of OSA on other people closely associated with the sleep apnoeic and supports previous literature.\textsuperscript{474}

Learning to use CPAP can be a challenge for some and doing so in a close and meaningful relationship as part of a good-sleep team facilitated problem-solving. Wagner and Lang’s\textsuperscript{475} work on interpersonal competence and motivation reflects Bandura’s\textsuperscript{476} social cognitive theory and argued that interpersonal reciprocity in close relationships characterises successful learning situations. Moreover, Weaver et al.\textsuperscript{214} found that perceived high self-efficacy correlated with increased likelihood of adherence with CPAP. Sage et al.\textsuperscript{31} highlighted that with perceived low self-efficacy target behaviours for the CPAP-user, such as problem-solving, became harder. Bandura\textsuperscript{477} argued that self-efficacy is bolstered by fostering collective efficacy. Accordingly, the presence of a collaborative team would enhance confidence and ability to problem-solve. Additionally, Deutsch’s\textsuperscript{479} theory of cooperation and competition outlines the positive outcomes engendered by a collaborative relationship with aligned goals. Extrapolating these theories to learning to manage CPAP implies that capitalising on a close reciprocal relationship for a CPAP-user would promote mastery of CPAP management at home. Our findings support this idea, and we argue this could be achieved by formally including a designated partner in clinic visits as part of the healthcare process. Rodgers\textsuperscript{453} and Hu et al.\textsuperscript{452} identify the importance of partners in CPAP use. Elfstrom et al.\textsuperscript{480} acknowledge the possibility of partner as collaborator with the CPAP-user, as do other authors who suggest engaging partners and family in educational situations.\textsuperscript{31, 152, 217, 473} However, none extend this concept further by recommending interventions to optimise this pre-existing and ready-made collaborative relationship.
Paediatric nursing and healthcare literature provide well-documented evidence for families as partners in care. A growing body of international evidence in adult healthcare literature supports the inclusion of family members in care, to enhance experiences of care and improve long-term condition management. International health policy promotes patient- and family-centred care (P&FCC) as a hallmark of contemporary care in the community. P&FCC redefines relationships in healthcare to include those in close relationship with the patient, rather than caring for individuals in isolation from social support networks. Accordingly, guiding principles of P&FCC include participation and collaboration. P&FCC is not a new concept. Cacioppo and Hawkley established that encouraging collaborative relationships promotes health, and studies involving in-hospital patients confirm that including family in care is preferred by and beneficial to patients. The Institute for P&FCC stress the importance of offering patients the opportunity to define ‘partners in care’ and their contribution to the care process. The Institute argues that by involving the ‘partner’ (as nominated by the patient) in the consultation process, healthcare providers acknowledge the collaborative role of partners and enable allies for quality and safety.

Given the commonly dyadic nature of sleep, it is important to understand how collaboration between bed-partners contributes to ‘good-sleep’ practices. Understanding is growing in the fields of aged care and chronic conditions regarding one partner’s illness being a shared stressor; as is increasing recognition of the couple-as-collaborators in problem-solving and disease management. Foster et al. found collaboration with a designated ‘medicine companion’ proved useful during the initial six months of antiretroviral therapy. Similarly, studies show how collaborative relationships can arrest the decline in cognitive functioning and improve problem-solving and support with challenging life transitions. Findings from our study reflect findings in chronic condition literature that demonstrate social support is significant in managing long-term therapy.

Data from this study indicate that inviting CPAP-users to include a ‘designated other’ during clinician and/or nurse-led clinic consults could optimise collaborative relationships and enhance problem-solving for successful CPAP use. We recommend formally inviting the prospective CPAP-user and partner to post-polysomnography appointments, if not all clinic visits, as sleep study results and education about CPAP are typically provided during these visits. Spitz and Ward found help from male spouses was less available, aligning with our and other findings that male spouses were commonly less involved with their partner’s CPAP use. Therefore, it is of particular importance to invite bed-partners of female CPAP-users to clinic. The focus of having a partner present should optimise the collaborative relationship between the partner and CPAP-user with the aim of supporting the integration of CPAP into daily life. Leveraging the strength of the couple allows joint problem-solving and decision-making from a position of shared knowledge. We caution against co-opting partners as enforcers of CPAP compliance as this is inconsistent with the concept of ‘team’. Not every relationship is functional; however, formally inviting a partner might increase the likelihood of a successful collaboration, so increasing the probability of successful CPAP management at home.
Strengths and limitations

Grounded theory is a well-recognised qualitative research method with established principles adhered to in this study. Findings are grounded in the data and resonate with other aged and chronic care studies. Consequently, our recommendations may be transferable across other areas of long-term condition care. Since limited evidence exists on the role of the partners, of any gender and across cultures, further research is required. Gallant et al. noted that a person’s social interactions can help or hinder illness management. Focusing on the individual in sleep healthcare research precludes the exploration of characteristics that constitute a collaborative patient/partner dyad. This study was conducted in only one region of New Zealand. Therefore, future qualitative or quantitative multi-centre studies with larger sample sizes could further explore factors necessary for success with CPAP as identified in this study. The focus of this study was on experiences of CPAP from the users’ perspective. Partner participants were recruited to this study to corroborate CPAP-user experiences on integrating CPAP. CPAP-users also referred to the contribution of other close family and friends. Therefore, exploring the role of partners and others in close relationship with the CPAP users should be a focus of further research.

5.2.7. Conclusion to the article: Becoming a team for good-sleep.

This paper reports the contributions of partners and close family to forming a team focused on good-sleep and their importance to success with CPAP. A functional good-sleep team is associated with sustained and accelerated progress integrating CPAP, whereas a conflicted team is associated with stalled or hindered progress. Given that witnessing by partners often functions as a precondition to seeking treatment for OSA, inviting their continued involvement during post-polysomnography clinic visits seems logical. We argue that partners are not merely bystanders, but are integral to the process of using CPAP and should be incorporated in the journey from diagnosis to successful management of CPAP in the home. Formally inviting a designated partner to sleep clinic visits would provide an opportunity for optimising success with CPAP and should become the norm. Indeed, this might be the case with any long-term condition management. Furthermore, inviting, welcoming and encouraging partner participation formalises the commitment to a patient- and family-centred approach to care delivery, and imbues the role of a person’s social support with importance. Partner participation may leverage collaboration by enhancing shared knowledge about the condition of OSA, and the purpose and technical aspects of CPAP. In this context, we argue for including the partner of a person using CPAP to enhance successful management of the therapy, and for further research to explore the role of partners in the successful management of CPAP at home.
5.3. Bargaining and balancing in relationship

The previous article has shown how partners catalysed the process of becoming aware by bearing witness to the effect of sleep apnoea on loved ones. Snorers and partners became a team focused on working together for a good-sleep who collaborated with initiating and integrating CPAP into daily life. This section illustrates bargaining and balancing in relationship followed by an account of crossing the first threshold in Figure 12 (see p.98).

The first half of the memo, assessing resonance, clarified how participants bargained and balanced in relationship (see p.93). George claimed that using CPAP would be good for his wife and good for his own sleep. Similarly, participants with a partner spoke of balancing their need for a good sleep against allowing their loved one to retain personal responsibility for CPAP use. The challenging nature of balancing needs and negotiating reciprocal sleep captured the difficulties of bargaining in relationship during the preliminary category:

It’s quite hard, ‘cause I don’t wanna come across as like the, “did you remember, did you remember!” … I guess I do make sure [when travelling] that he [has everything] and I ask … “have you made sure you’ve got x, y or z”. But I try not to because it’s not really my equipment and my responsibility. (IanP)

IanP’s comment illustrated the on-going negotiation required during interactions between spouses and CPAP-users. The size of the circular arrows in Figure 12 represents the iterative nature and intensity of negotiation. For example, by the third category participants, who had become a team for good-sleep, were now maintaining reciprocal sleep. Partners continued to encourage the snorer to use CPAP so all concerned could sleep well, but bargaining and negotiation was far less intense:

… if I go up to bed first, and I fall asleep before I’ve put my mask on … I’ll be aware of Baby standing there going “mum, mum, put your mask on you’re making terrible noises.” It’s just a normal thing in our family now. (Lily)

CPAP-users and partners now had the same goal, “which is that he sleeps properly, and therefore, I sleep properly” (IanP). Subsequently, negotiation between partners during the final category became less intense, shown by the smaller circular arrows under becoming used to CPAP in Figure 12. Bargaining and balancing in relationship became a less intense maintenance process of gentle reminders to use CPAP, rather than the more intense bargaining in the first category that brought snorers to awareness of sleep apnoea.

5.4. Crossing a threshold by reaching a limit

The participants’ experiences of both becoming aware and witnessing initiated and contributed to the point of reaching a limit. The impetus to seek help was either self-driven and/or ‘others’-driven or a mixture of both. Barry and Ed both described becoming unhappy about constant daytime fatigue and situations where a close family member expressed concern for their lives. Others
recognised that they had felt unwell for some time and reached a point at which this was no longer acceptable and they needed to do something about it. Felicity, Curzon and Molly reported falling asleep during social gatherings, and Felicity, Ned and Ed's tipping point was the risk of falling asleep while driving:

It was the driving thing that took me to the Dr, more than anything else - I was scared that they would take my license away. (Felicity)

For Hal, it was as simple as his wife saying that he had sleep apnoea that caused him to take action. He “believed her” straightaway and sought help. For others, it took a series of events to catalyse action. Molly had a friend and her grandchildren give her information about her symptoms. However, it was falling asleep at the lights while driving that caused her to realise she needed help. Gina described her fear of dying and wanting to have the sleep apnoea under control:

I don’t wanna live like this in my life forever; I wanna change because I want to live long, and that’s why I said to you it’s such a scary thing to have. (Gina)

Others echoed the fear of limited longevity.

My partner [would] wake me up regular times during the night thinking I might die because I’d stopped breathing. (Ed)

Therefore, participants needed to reach a tipping point before taking action; there was a limit to the amount of sleep disruption or partner disturbance they could tolerate before becoming “sick of it” (Barry). Once participants reached this limit, they remained aware of having sleep apnoea and moved on with the next phase of the process.

The first main category has shown how partners catalysed the process of becoming aware by bearing witness to the effect of sleep apnoea on loved ones. The included article illustrates how partners enacted bargaining with loved ones to seek help so that both parties could sleep well. Subsequently, participants balanced maintaining the status quo against acknowledging they had reached a limit and seeking help. On receiving CPAP, snorers began making choices about CPAP, the second main category of the theory bargaining and balancing life with CPAP.
5.5. Main Category 2: Making Choices about using CPAP

Making choices about CPAP continues to illustrate participants’ bargaining and balancing to get used to living with CPAP. The manuscript that follows presents this category, which is comprised of the sub-categories reacting to CPAP, becoming motivated, overcoming barriers and yielding to barriers. For the purposes of this article, the heading acting groups the third and fourth subcategories.

The article also shows that the conditions time and perseverance influenced participants’ progress along the pathway. Corbin and Strauss describe contextual conditions as those which “shape the nature” of problems or situations by generating actions, interactions or emotional responses. Such responses yield consequences that may further shape conditions and actions:

For example, partners acted by letting loved ones know they had ceased breathing while asleep. For some participants, this warning generated fear of poor health and signified reaching a limit after which snorers consequently sought medical help. Strauss and Corbin developed the conditional/consequential matrix to identify levels of conditions. Micro levels on the matrix signified conditions close to the individual, while more removed macro conditions captured political or social levels. In later years, Corbin and Strauss, who developed the matrix as an analytic tool, and Charmaz cautioned against imposing the matrix upon data. Nevertheless, data from participants illustrated that the process of living with CPAP operated under the lower level conditions of time and perseverance.

The following manuscript is under review for publication.
ARTICLE: Making choices about CPAP: Findings from a grounded theory study about living with CPAP.

5.5.1. Abstract

Aim: To explore experiences of living with continuous positive airway pressure for sleep apnoea, from participants' perspectives.

Background: Untreated sleep apnoea incurs high societal and personal health costs. Although positive airway pressure is a recognised, cost-effective treatment, concern exists that patients underuse this therapy. However, there is limited evidence regarding users' views of this treatment.

Methods: Sixteen participants, recruited through a main-centre respiratory service in New Zealand, participated in semi-structured interviews during four months of 2011 and six months of 2014. Adults prescribed positive airway pressure for sleep apnoea (n=12) and their partners (n=4) participated. Using grounded theory methods, data were analysed until theoretical saturation was reached.

Findings: This paper reports the second of three main categories from the grounded theory: bargaining and balancing life with CPAP, titled making choices about CPAP. The category emphasises participants' ability to self-motivate and develop supportive strategies via a dynamic choice-making process based on clinical information and personal opinions about treatment. Participants chose whether to and how to integrate therapy into daily life by overcoming barriers, such as the perception of stigma, and allowing enough time to persevere with decision-making and therapy management.

Conclusion: This study highlights participants as active, reasoned decision-makers in their healthcare who can identify choices that motivate positive airway pressure use. Focusing supportive interventions on motivations identified by participants may optimise choices for positive airway pressure use. Future studies should examine the efficacy of targeted and tailored interventions that support patient decision-making when choosing this therapy.

Keywords: continuous positive airway pressure, grounded theory, obstructive sleep apnoea, patient decision-making, patients' perspective
SUMMARY STATEMENT

• Why is this research needed?
  • There is limited evidence from the users’ perspective regarding continuous positive airway pressure, which can be a challenging therapy for users.
  • Supportive interventions may aid the positive airway pressure-user; however, how this relates to the individual user is underexplored.

• What are the key findings?
  • This paper recognises that participants were able to self-identify supportive strategies for the management of positive airway pressure at home.
  • Findings suggest that giving patients opportunities to collaborate fully in decision-making about treatment is an important clinical consideration.
  • Our findings add to mounting evidence that supports the need to customise decision-support interventions as part of care in chronic conditions like OSA.

• How should the findings be used to influence research?
  • Future studies should examine the efficacy of targeted and tailored interventions that support patient decision-making when choosing CPAP.
  • Future qualitative and quantitative, multi-centre studies with larger sample sizes could further explore factors influencing success with CPAP identified in this study, including the influence of stigma.
  • Future nursing research could explore the use of gain-framed information and interventions aimed at increasing self-efficacy and active problem-solving regarding CPAP use.

Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CPAP</td>
<td>continuous positive airway pressure</td>
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<tr>
<td>HBM</td>
<td>health beliefs model</td>
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<td>OSA</td>
<td>obstructive sleep apnoea</td>
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<tr>
<td>SCT</td>
<td>social cognitive theory</td>
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<tr>
<td>TTM</td>
<td>trans-theoretical model</td>
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Chapter 5

5.5.2. Introduction

People spend around one third of life sleeping. Good sleep is restorative while sleep deprivation is distressing. In *Macbeth*, Shakespeare described sleep as “chief nourisher in life’s feast.” Yet many things can disrupt sleep and lead to lowered mood and daytime functioning, reduced productivity and increased risk of errors. Sleep medicine literature is extensive regarding the issue of non-restorative sleep, and highlights obstructive sleep apnoea (OSA) as a common cause of disrupted sleep. Evidence regarding treatment options for OSA demonstrates that continuous positive airway pressure (CPAP) is the gold standard intervention. However, ongoing concern with CPAP compliance highlights a gap in understanding about how to minimise non-compliance. Addressing this gap by exploring how CPAP-users successfully manage therapy adds to the literature and may provide new strategies to optimise support for CPAP users.

Background

A long-term condition, OSA is prevalent in 3-7% of the general population worldwide. OSA is caused by the partial or complete collapse of the pharynx during sleep, which obstructs breathing. These obstructions, or apnoeas, may occur from five to over 100 times an hour causing hallmark symptoms that include snoring and excessive daytime fatigue. Untreated OSA is physically, socially and economically costly. Consequences include increased risk of hypertension, neurocognitive dysfunction, cardiovascular disease and mortality, and reduction in the quality of relationships and social life. Additionally, rates of medical intervention and risk of accidental trauma increase while OSA remains untreated.

CPAP, via nasal or face mask, pneumatically splints the pharynx open during sleep. There is strong evidence supporting the efficacy and cost-effectiveness of CPAP when used as prescribed. Yet CPAP can be challenging to use, with evidence suggesting patients underuse CPAP. Intervenotional literature concerned with improving the use of CPAP is plentiful. To determine barriers to using CPAP, investigators have addressed issues such as self-efficacy in CPAP use, and used health beliefs models to predict CPAP compliance. Studies based on health beliefs and other psychological models have also examined inclination to adhere to CPAP therapy. However, a recent review identified that current literature addresses problems with CPAP adherence from primarily an ‘expert’ standpoint and through a problem-oriented paradigm. Furthermore, it appeared that while concern with the difficulties experienced by patients was evident in the literature, research into the patient experience was limited.

Not all CPAP-users are non-compliant, and do manage to use CPAP successfully. We argue that focusing research efforts on adherence, without accounting for experiences of CPAP from the users’ perspective, constrains understanding. It is within this context that the present study explored participants’ experiences of CPAP using grounded theory to provide insight into factors sustaining CPAP use at home. This paper presents an important component of the findings focusing on the second main category from this grounded theory study, and incorporates the processes employed by participants that comprise *making choices about CPAP*. 
5.5.3. Methods

Given the limited research on this topic, we employed a qualitative design using constructionist grounded theory (GT), and semi-structured individual interviews. GT addresses gaps in knowledge by using participants’ accounts of their experiences to construct an explanatory theory about their actions. Therefore, the coding framework was inductively derived from the data. This paper uses the consolidated criteria for reporting qualitative studies (COREQ) checklist.

Setting and participants

A respiratory clinic in a main centre of New Zealand provided the recruitment setting. People who meet nationally established diagnostic criteria for OSA, are eligible for a CPAP device free of charge, which includes participants in this study. The prevalence of OSA in New Zealand reflects international evidence and aligns with findings that prevalence increases as body mass index increases. Initial purposive sampling focused on recruiting adults aged eighteen years or older with personal knowledge of using CPAP for OSA. In total sixteen participants were recruited (women n=7, men n=9; see Table 14).
Table 14: Participant demographics at the time of interview

<table>
<thead>
<tr>
<th>Demographics at time of interview</th>
<th>Number of participants</th>
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<tbody>
<tr>
<td>Age band</td>
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<td>25-35</td>
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<td>NZ European plus other</td>
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<tr>
<td>Time since CPAP initiation**</td>
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<tr>
<td>(CPAP-users n=12*)</td>
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<tr>
<td>“a while”</td>
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<tr>
<td>1 year or less</td>
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<tr>
<td>2 years or less</td>
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<tr>
<td>3 years or less</td>
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<tr>
<td>5 years or more</td>
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<tr>
<td>Pete * abandoned CPAP after “about a year.”</td>
<td></td>
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<tr>
<td>Hal interviewed twice, at 11 months and at 2 years, 11 months</td>
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<tr>
<td>CPAP use **</td>
<td></td>
</tr>
<tr>
<td>(CPAP-users n=12)</td>
<td></td>
</tr>
<tr>
<td>Each night, all night †</td>
<td>6</td>
</tr>
<tr>
<td>Each night, not all night ‡</td>
<td>2</td>
</tr>
<tr>
<td>Not every night §, but all night</td>
<td>1</td>
</tr>
<tr>
<td>Not every night, not all night</td>
<td>3</td>
</tr>
</tbody>
</table>

**Key:** * Pseudonyms identify participants; ** self-report at interview; † between 5 to 8 hours depending on usual duration of sleep; ‡ CPAP removed before the end of usual duration of sleep; § less than 6 nights per week; ± Only one CPAP-user reported an apnoea-hypopnoea index <15

As data analysis progressed, participants were sampled theoretically. Theoretical sampling is a characteristic of GT whereby participants are selected based upon knowledge they might provide to aid theory construction.45, 48, 231 Participants included adults who used CPAP for OSA via face or nasal mask (n=12). Theoretical sampling led to both a second interview with one of the participants, to compare experiences of CPAP over time, and to the inclusion of partners (n=4) of CPAP-users recruited to the study who were invited to participate by mail. ‘Partner’ describes bed- and/or life-partner. Ethical requirements determined that participants self-selected independent of the researcher and it is unknown how many declined to participate during initial sampling. One partner-participant declined during theoretical sampling. People using CPAP for other conditions or aged seventeen years and under were excluded.
Ethical considerations

Local and national ethics committees provided ethical approval for this study (reference NTX/11/06/048/AMO2). Prior to a respiratory clinic appointment the clinic lead physiologist identified potential participants. On arrival, each potential participant received an information pack from clinic staff, outlining rationale and details of the study, and written consent to complete if they chose to participate. All participants provided written consent and agreed to telephone interview. KW re-confirmed consent at each contact point to protect confidentiality and the right to re-consider participating.

Data collection and analysis

We chose semi-structured interviews to generate data and since no participants opted for an in person interview they took place via telephone. A recent study suggests that qualitative interview via telephone is an acceptable method of data collection. During four consecutive months in late 2011 and six consecutive months in early 2014, KW audio recorded, transcribed, anonymised and coded seventeen individual, in-depth interviews. Interview data and interview notes were stored and managed using QSR NVivo10.

We developed questions or prompts to elicit data relevant to the participant regarding CPAP that were loosely structured during early interviews. These included: tell me about your night-time routine, and about your CPAP; how do you explain sleep apnoea or CPAP to others; and what does CPAP mean to you? Semi-structured dialogue allowed the exploration of information as new categories were constructed from the data. Thereafter, questions focused on developing the main categories.

In GT data collection and analysis are concurrent, and analysis commences with the first transcript. Analysis began with line-by-line coding to immerse KW in the participants’ stories and to identify initial constructs. Coding enabled clustering of data into categories using gerunds to identify action. Lower-level codes and categories were subsumed by main categories and then integrated into the final theory. Constant comparison is a hallmark of a GT project. Constantly comparing on-going coding with earlier data, facilitated the evaluation of each code and category against the participants’ words. Constant comparison also generated increasingly focused questions, which were adapted and developed as analysis progressed to explore new ideas and facilitate category development. Theoretical saturation of categories was achieved by the seventeenth interview.

Rigour

A sound grounded theory fits data that have strong logical links with the analysis, offers new insights with practical implications and resonates with participants and others familiar with the topic. Memoing, diagramming and discussion with MG and KH and a GT peer group refined constructions during analysis and provided an audit trail of the research and gave surety that findings were grounded in the data. Colleagues were able to relate theoretical concepts in the story to
personal experiences of long-term treatment. Moreover, due to theoretical sampling participants were implicitly involved in the checking of conceptual ideas during theory construction and confirmed that rendering of the data agreed with their experience and understanding. The following includes participant quotations to provide context and evidence for the constructed categories.

### Findings

Overall, the study resulted in the construction of the theory, *bargaining and balancing life with CPAP*, using three main categories: **becoming a team for good-sleep**, **making choices about CPAP** and **becoming used to CPAP**. The significance of the first category is reported elsewhere. This paper focuses on the second main category **making choices about CPAP**, and includes the importance of the conditions *time* and *perseverance*. The following storyline summarises *bargaining and balancing life with CPAP* to provide context. Storyline is a recognised technique for presenting GT findings and extending analysis. In the following, sub-categories for each of the main categories are italicised.

**Storyline**

**Becoming a team for good-sleep** began with partners, and occasionally family or friends, *bearing witness* to the symptoms of OSA, leading to poor sleep for both witnesses and snorers. By bargaining and sharing their experiences, witnesses enabled snorers to start *becoming aware* of OSA symptoms, such as constant daytime fatigue. Through negotiating and joint decision-making, snorer and partner became a team who shared the goal of good sleep, illustrating the third subcategory of *being a team*. By *being a team* and *becoming aware*, snorers reached a limit signified by the choice to act, and improve sleep by seeking medical help.

On receiving a CPAP device, participants began **making choices about CPAP**, the second category reported in this paper and comprising the subcategories *reacting*, *become motivated*, *acting by overcoming barriers* or *by yielding to barriers*. Once diagnosed with OSA, participants made decisions based on personal beliefs about treatment alongside clinical information about using CPAP. Through bargaining and balancing personally and with their partner, participants processed reactions to needing CPAP and developed motivations regarding CPAP use.

Participants who remained motivated and persevered with the decision to use CPAP started **becoming used to CPAP**, the final category. Participants made adaptations to integrate CPAP into daily life by *choosing new routines*. Once the challenges of using CPAP had receded, *getting used to CPAP* became relatively straightforward. In the presence of *time* and *perseverance*, *mastering CPAP* became possible. CPAP became a normal and routine part of life that no longer required conscious effort but retained importance in maintaining good sleep for users and partners.
5.5.5. Making choices about CPAP

The category, making choices about CPAP, proposes that participants made decisions at a micro level (personal and nightly) and macro level (social and long-term) to achieve a good sleep and captures factors influencing participants’ choices as shown by Figure 13.

![Figure 13: Making choices about CPAP: Subcategories and associated codes]

The interplay between the subcategories and codes in Figure 13 highlights behavioural processes that lead to making choices about CPAP and that the presence of conditions time and perseverance supported decision-making.

Reacting to CPAP

All participants described their reactions to the news they needed CPAP. Participants reported feeling relieved that a reason existed for their symptoms and that a solution could be offered, which generated optimism for future wellness. Arthur††† spoke of having sleep apnoea “under control” by using CPAP and Felicity described reassurance that her symptoms were not “just imagin[ed].” OliveP was “very pleased” and reflected other partners’ comments that no snoring meant a good night’s sleep for everyone.

Despite feeling relieved, participants also described feeling disappointed and being mistrustful of CPAP as a solution. Participants questioned the accuracy of overnight polysomnography and how a diagnosis could be reached based on “just one very disturbed night’s sleep” (Felicity).

Participants rationalised reasons for having sleep apnoea and sought alternative solutions before

††† Participant names are pseudonyms and partner-participants are suffixed ‘P.’
accepting CPAP as the best option. Dave and Ed hoped surgery would mitigate the need for CPAP and every participant theorised that weight loss would do the same. Therefore, unsuccessful weight loss or ineffective surgery disappointed participants. IanP reflected the resignation described by others saying, “the only opportunity now is the machine.” Expectations that mastering CPAP would be “a piece of cake” led to further disappointment when it was not (Ed, Lily and Hal).

Additionally, participants reported imagining stigma associated with using CPAP. Participants described being embarrassed or ashamed while wearing the mask or fearing what others would think of them needing CPAP. Dave likened sleeping with someone using CPAP to “sleeping with Darth Vader” and Lily revealed that the “mask doesn’t make me feel like I look nice [for my husband].” Barry referred directly to the “stigma of the thing” and felt being single protected him from “disparaging comments” by a bed-partner. Similarly, others described expectations of a “horrified reaction” on seeing the CPAP device and feared that non-users would find “the latex face part… a bit creepy looking,” or “freaky” (Ed, IanP, Felicity). Moreover, participants described a perception that mainly older, overweight men suffered OSA. This perception dismayed the CPAP-users who described themselves as young, fit or female. Lily remarked, “how could that be me?”

**Becoming motivated**

All participants described strategies to motivate CPAP use. Participants emphasised affirming CPAP as effective and some did this by testing or trialling the therapy. At CPAP initiation, Felicity decided to “give it a test period” of a month to see if it worked. Participants who tested sleeping without CPAP reported feeling worse the next day. All participants acknowledged that CPAP made a positive difference and referred in some way to “seeing a benefit” compared to before CPAP initiation (Hal). Lily was “almost light-headed with energy,” and Barry described having “a new lease on life.” Felicity commented:

> I wish I didn’t have to put it on … but the pay off, feeling OK when you wake up … it doesn’t really make it too questionable. I actually look forward to getting in bed and sticking it on, despite my embarrassment, because of my renewed energy levels. (Felicity)

Partners also reported an “instant change” and “sleeping better” (JarotP, IanP, Lily). Accordingly, each participant reasoned that “seeing the benefit” and having an undisturbed bed-partner made CPAP use worthwhile.

**Being afraid** of the consequences of not using CPAP also motivated participants. All understood that not using CPAP jeopardised their health and increased the risk of road accidents, poor daytime functioning and reduced life expectancy. KayeP was firm in her view that without CPAP her husband “would be dead.”

Participants who accepted CPAP as a treatment option affirmed CPAP, and those who feared the consequences of non-use spoke of prioritising CPAP despite having difficulties. Lily said the mask was “hideous, but you feel more hideous if you don’t use it.” Gina declared, “I just ignore all other things, but I just think of my life. So that is the only way I [am] just committing on this machine.” Arthur, Curzon, and OliveP said CPAP was “good for” them and was “a solution” that worked as
promised because snoring stopped, they felt well and their partners were “really happy.” Participants described CPAP as life-giving, allowing them to “live long” (Gina). Framing CPAP as a positive choice rendered any negative experience as minor and unworthy of attention. Consequently, participants experienced “needing” CPAP, being “dependent” or having “reliance” on CPAP and feeling “panic” if unable to use CPAP. Hal captured the intensity of needing and prioritising CPAP by equating CPAP use to “a religious experience.” The third and the fourth subcategories illustrate that motivations supported the actions chosen regarding CPAP use.

**Acting, by overcoming barriers**

Participants reported strategies for mitigating stigma in response to feelings of shame, embarrassment or fear of rejection because of CPAP use. When participants anticipated feelings of embarrassment, they concealed the device by hiding it away, not taking it travelling or not disclosing it to a new partner. Gina chose not to use CPAP around her in-laws because of “shame” and Felicity hid from her husband by “pulling the sheet right up” over her mask. Others chose the opposite of hiding, instead joking and talking openly about using CPAP. Despite hiding from her husband, Felicity made her CPAP “a party joke” to reduce others’ discomfort with her mask and to mitigate potential ridicule. Similarly, Hal, Ed and Lily raised their sleep apnoea treatment in conversation to counter any assumptions made by others.

Finding information about OSA and CPAP was important to participants and navigating communication with health professionals occurred with varying degrees of ease. CPAP-users talked about how useful it was to have OSA explained to them, and how the CPAP worked. Nevertheless, each CPAP-user reported struggling with CPAP, which ranged from profound issues, such as claustrophobia, facial sores or severe dry mouth, to minor skin irritations:

> …I [had] this freaking thing on my face and it was really tight, like a Hoover turned on! I just didn’t want to use it. … First the face mask didn’t fit properly. I had a chubbier face and … when [I] moved the fat on my face would landslide [causing] problems with the mask fitting and air leaks. (Ed)

Most made similar comments about problems with mask-fitting, and all participants described troubleshooting to “figure it out” (Lily). Participants reported trialling different masks and figuring out the best position for the tubing or the machine, such as drilling a hole in the bedroom wall so the machine, which sounded “like a vacuum cleaner,” could go into the next room. Dave described troubleshooting saying:

> Once I got it sort of mastered, and I duct taped it up [so] it didn’t fall apart, and I’d sussed out the strap I definitely felt like I had a lot more energy. (Dave)

Hal agreed that getting used to CPAP was a process of “trial and error” and “practice makes perfect.”
Acting, by yielding to barriers

Most participants yielded to barriers intermittently, reasoning that they could get away without CPAP at any given moment. Barry, Ed and Arthur referred to a “certain point” in the night at which they had used “enough” CPAP and chose to “pull it off,” while Dave and Ned confessed to occasionally not using CPAP “more out of laziness.” Gina hid her CPAP to appear a “well” wife for her in-laws’ “strong boy.” She described wanting to use CPAP, but that doing so conflicted with her husband’s goals of saving electricity and conceiving a child. Her husband focused on Gina’s weight loss to become pregnant, and not her use of CPAP. Pete found CPAP “very annoying” and preferred to attempt weight loss to manage his sleep apnoea, despite his wife’s concern and reporting little success. Pete and Gina placed other priorities ahead of using CPAP, choosing another way to manage their symptoms.

Time and perseverance

Figure 12 illustrates that the conditions of time and perseverance operated throughout the theory and are relevant to all categories, including making choices about CPAP. While feelings of relief and symptom improvement motivated most participants, some acknowledged that disappointment or struggles with CPAP and troubleshooting needed time and perseverance to overcome. OliveP captured the relationship between persevering, the passage of time and becoming used to CPAP:

Persevere for a while, and then you’ll get used to it and then you won’t ever want to be without it. (OliveP)

Lily reported it was “perseverance” and her husband’s help that improved her confidence using CPAP. Most participants agreed that it “took a while to get used to” CPAP (Felicity). Hal reflected:

The first six months or so was challenging… and to be quite honest it was all to do with the masks. … So, I’m really only at the point at eleven months that I’m actually starting to master it. (Hal)

The wish to be well, to be present with their family and friends or not fall asleep while driving overpowered the wish not to use CPAP. Therefore, participants convinced themselves that it was worth persevering with CPAP despite initial tribulations. Overall, with time and perseverance, participants overcame barriers and became “used to” using CPAP, passing the threshold to the final main category in the process of living with CPAP.

5.5.6. Discussion

This paper is the first to describe the strategies that users employ to live with CPAP, from their perspective and without focusing on adherence. Sleep medicine literature argues that patients underuse CPAP. Therefore, attention has been on resolving difficulties with the treatment. In contrast, this study focused on the experience of living with CPAP. Beliefs about what using the device signified for their identity, and/or difficulties with the practicalities of its use, hampered participants until they overcame these difficulties. Motivated decision-making by participants
sustained those who had challenges getting used to CPAP and supported others’ pragmatic decision to “just get on with” using CPAP. Participants made reasoned decisions based on reactions to CPAP, their beliefs about pertinent motivating factors and the information available. Our findings have resonance with similar studies in chronic kidney disease and cancer management that illustrate how the choice-making process corresponds with personal views about treatment and personal life.\(^{501-503}\)

Studies exploring barriers to CPAP use have identified that high levels of self-efficacy (optimistic self-belief when facing challenges) positively influence the ability to use CPAP.\(^{184, 214}\) Conversely, certain behaviours, such as problem-solving, become harder with perceived low self-efficacy.\(^{31}\) These studies reflect our finding that being prepared to persevere is a factor in using CPAP, particularly when troubleshooting difficulties getting used to the device. Our findings highlight the importance of taking the time to persevere with using CPAP, particularly where time is needed to troubleshoot challenges.\(^{180, 504}\) We argue that decision-management interventions aimed at enhancing self-efficacy might support perseverance and promote mastery of CPAP management at home.\(^{459}\) For example, Baldwin et al.\(^{505}\) advocate self-generated health arguments, defined as personal arguments for engaging in a specific health behaviour, and facilitated through interventions such as motivational interviewing. Self-generated health arguments have proven effective in smoking cessation and reflect the self-persuasion processes participants adopted in this study.\(^{505}\) Studies using gain-framed information focusing on the positives of treatment (versus loss-framed information) were effective when advocating illness prevention behaviours and also reflected processes participants adopted.\(^{506}\) Similarly, self-management interventions aimed at increasing self-efficacy and active problem-solving while accommodating to CPAP have shown promise.\(^{184, 507}\)

During the reacting phase of making choices, participants in this study reported a perception that CPAP use is stigmatising. However, there is little evidence regarding stigma specifically associated with using CPAP.\(^{508}\) We identified one study that touched on the experience of stigma in relation to CPAP use, but did not focus on or explore this concept.\(^{148}\) Five other studies were identified that only alluded to the presence of stigma but did not elaborate.\(^{31, 150, 152, 163, 509}\) Evidence regarding the process of stigma in the broader context of health is wide-ranging, and stigma has been linked to the reproduction of social difference and the diminished power of the stigmatised.\(^{510-512}\) Deacon\(^{513}\) defines stigma as a social process of “othering, blaming, and shaming” causing status loss and reinforcing inequality.\(^{p.418}\) Consequently, literature on stigma has typically examined public stigma towards people.\(^{514}\) However, participants in this study did not report stigma because of another’s comments, but because of personal beliefs about what others would think.

Our findings reflect Vauth et al.’s\(^{514}\) that self-stigmatising may promote positive coping strategies when self-efficacy is strong, but that self-stigmatising with low self-efficacy contributes to treatment avoidance. To pre-empt negative comments and attest to the value of using CPAP, participants chose to disclose CPAP use to others, rather than allow perceived stigma to deter use. These findings have implications for practice that include supporting people’s confidence to disclose CPAP by providing targeted information about its importance. Additionally, the perception that only overweight, older men experience OSA was significant to participants. While the prevalence of
OSA is higher in this demographic, it is important for clinicians to acknowledge to patients that slight, young and female persons also suffer OSA, to forestall assumptions.

Key studies have established that improvements in the mechanics of CPAP devices lessen side effects of CPAP with improvements to quality of life, but not to adherence.\textsuperscript{24, 131, 515} These studies highlight the complexity of factors that support CPAP use and the importance of addressing issues such as stigma. Moran et al.\textsuperscript{509} claim there is little evidence supporting long-term effects of stigma. However, we contend the literature underexplores the influence of stigma on CPAP use and warrants further research.

The process of choosing CPAP reported in this paper reflects stages of behaviour change, and similar observations have led investigators to examine the inclination to adhere to CPAP via various theoretical models.\textsuperscript{179, 213, 251, 500} Stepnowsky et al.\textsuperscript{516} found that variables drawn from both the sequential trans-theoretical model (TTM) of behaviour change and Bandura's social cognitive theory (SCT) correlated with variance in nasal-CPAP adherence after one month of use. Testing the health beliefs model (HBM) as a predictor of CPAP use has shown that prior expectations of CPAP influenced compliance.\textsuperscript{31, 215} Identifying stages of behaviour change has generated a variety of stage-based interventions such as interactive web-based tools and group cognitive behavioural therapy based on SCT.\textsuperscript{182, 504, 517} Olsen et al.\textsuperscript{30} note that results from theory-driven stage-based interventions are promising despite being resource intense. However, other studies suggest stage-based interventions have been unsuccessful at providing a perfect fit to support CPAP use.\textsuperscript{509, 518-521} This study emphasises that decision-making processes about using CPAP are not sequential, unlike behavioural models such as TTM.\textsuperscript{522, 523} Indeed, participants engaged in a circular process: reactions underpinned the choice of motivations, which in turn supported actions chosen that affirmed or modified reactions (see Figure 13). The dynamic nature of this process might account for the difficulties inherent in designing interventions that fit all circumstances.\textsuperscript{509}

A recent Cochrane review of educational and behavioural interventions concluded some evidence exists that supportive interventions to encourage CPAP use are better than no interventions, with cognitive behavioural therapy as the most promising.\textsuperscript{217, 218} Based on our findings, we advocate matching supportive interventions to what the patient says suits their circumstance.\textsuperscript{509, 524} For example, a person who has grasped the physiological consequences of OSA may need only targeted support to manage mask issues. Other users may wish for more detailed information about the physiology of CPAP use to support affirming CPAP. We argue that providing targeted and tailored decision aid interventions might better support patient-centred integration of CPAP.

There is a significant body of literature on the utility of patient decision aids that support decision-making for health.\textsuperscript{524, 525} The International Patient Decision Aid Standards (IPDAS) collaboration advocates the use of and quality standards for decision aids.\textsuperscript{526} Typically, patient decision aids are used to support complex decisions about life-limiting and long-term conditions. However, sleep medicine literature has given little attention to the use of such aids.

Consideration of CPAP-users as active, reasoned choice-makers in their healthcare is important.\textsuperscript{188} Studies have highlighted that patients rate their ability to learn about long-term therapies as greater
than clinicians rated patients’ ability.\textsuperscript{151, 527} These findings suggest that giving patients opportunities to collaborate fully in decision-making about treatment is reasonable, whereas discounting patients’ ability to participate in decision-making risks limiting the resources necessary to support informed choices. It is important to establish concordance between patient preferences and the treatment offered. Concordance may be achieved by providing targeted information to support decision-making, which in turn might support therapy use.\textsuperscript{524, 528} Our findings add to mounting evidence that supports the need for customised decision support interventions in chronic conditions like sleep apnoea.

\textit{Strengths and limitations}

GT is an established research method with recognised principles, which have been followed in this study. Findings constructed from the data resonate with other chronic care and patient decision-making studies. This study has established a platform for future research, and recommendations in this paper may be transferable to other long-term conditions.\textsuperscript{332, 363} Ethical requirements determined that participants self-selected independent of the researcher. Therefore, the number of participants during initial recruitment who declined to participate is unknown. One participant declined to participate during subsequent theoretical sampling, stating time constraints. Recruitment of study participants came from one region of New Zealand. Future qualitative or quantitative multi-centre studies with larger sample sizes could further explore factors necessary for success with CPAP identified in this study.

\textbf{5.5.7. Conclusion to article: Making choices about CPAP}

In conclusion, this study has explored the role of making choices about living with and using CPAP. Data from this study demonstrate participants’ ability to self-motivate by choosing strategies that support CPAP use by means of a circular and dynamic process of making choices. Positive feelings about using CPAP reinforced beliefs about its health benefits. Furthermore, participants were prepared to engage in troubleshooting and trial and error to achieve mastery of the CPAP mask and device. This study demonstrates that CPAP-users can articulate which personal motivations are most likely to help in each circumstance. Choosing to place health, longevity or daily functioning over any negative feelings about CPAP meant participants prioritised commitment to therapy. With each individual, priorities and motivations differed. Since CPAP-users make personal choices about what will motivate CPAP use, it is important to offer tailored decision aids that target and support motivations identified by the users themselves. Future studies should examine the efficacy of targeted and tailored interventions that support patient decision-making about CPAP.
5.6. Bargaining and balancing with self

The preceding article has elaborated how participants balanced the positives and negatives of CPAP use to make a definitive decision about using CPAP. This section illustrates how participants bargained and balanced with themselves to make choices about CPAP and pass the second threshold in Figure 12 (see p.98). Thereafter, chapter five concludes by presenting the third and final main category, becoming used to CPAP.

Section 5.3 described how participants bargained and balanced in relationship. Additionally, CPAP-users engaged in a significant amount of bargaining with themselves as represented by the large circular arrow in Figure 12. Throughout making choices about CPAP, participants balanced the consequences of CPAP use against non-use until they arrived at a decision about using CPAP. Figure 14 in the following memo depicts the effect of the inner battle on deciding to use CPAP. This memo, first presented in chapter 4, continues below and elaborates how participants bargained and balanced with themselves:

Memo: Assessing resonance continued

11 11 2014: George described how the difference the days’ events made to the likelihood of his wife using her CPAP. If it had been a good day, then CPAP was more likely to be experienced positively. If it had been a bad day or the rash from the mask was troublesome, then using CPAP was more likely to be a poor experience. George explained the associated decision-making as being on a continuum relating to bargaining and balancing to gain equilibrium between the pros and cons of CPAP use. Therefore, George acknowledged the experience of overcoming and yielding to barriers was cyclical; that his wife moved back and forth between dealing well with the challenges she faced with CPAP and becoming adversely affected by those challenges. Being discouraged by challenges resulted in bargaining that ‘getting away without CPAP’ was OK. We depicted this as a seesaw (see Figure 14).

![Figure 14: Effect of the inner battle on choosing CPAP](image-url)
Moreover, bargaining and balancing usually happened at 2 am, not during ‘rational’ daylight hours, adding complexity to the decision-making process. The pathway would then not be a straight line so much as a line with a spiral in the middle.

CPAP-users described varying components of bargaining with self on a daily basis. For example, some recounted occasionally reaching a point during the night of having worn CPAP for “long enough” and removing the mask to have a “proper sleep” (Arthur). Arthur stated that using CPAP protected his health, meant he slept well and woke “refreshed.” However, it was only sleeping without the mask that was “proper.” The contradiction in his comments spoke to how participants swung between fully endorsing CPAP use and “getting away” without it.

5.7. Crossing the second threshold by making a decision

All participants in this study passed the first threshold, but not all participants passed the second. Those who did were able to maintain motivation and definitively choose to use CPAP, and so started becoming used to CPAP, the final category.

Evidence drawn from the data illustrated how participants who passed the second threshold expressed a preparedness to persevere. Participants enacted perseverance through time spent troubleshooting and not giving up until they had mastered CPAP. Persevering also meant being prepared to commit time to the process of becoming used to CPAP. For example, rather than make a full commitment to CPAP Felicity had bargained with herself, deciding to “give it a go” for a month before evaluating how she felt. On balance, Felicity experienced greater wellness using CPAP and decided to continue use. The subcategory, being motivated, presented in the second article illustrates how experiencing wellness was integrated into the bargaining and balancing process.

Additionally, a pragmatic mind-set meant that benefits of CPAP easily outweighed the disadvantages, making the transition to using CPAP simple:

We just got on with it really, to be honest with you. … I don’t understand what problems [others would] have. You got a machine; you have to have it, and that’s all there is to it. I don’t understand what the big deal is [incredulous tone]! (KayeP)

I just got in with it - [chuckles]. … [My family] just got to get used to it, you know, because I really didn’t have to. I just adjusted myself to it, because I had to. (Molly)

Conversely, prevaricating about using CPAP extended the time required to become accustomed to it. Indeed, Pete abandoned CPAP altogether. He had bargained that he would not need to use it if he could find another way to control his sleep apnoea:

Yeh, well I didn’t like it, it’s very annoying when I’m trying to sleep. … Well, I think it does [make a difference], but I’ve been doing other things to try, like keeping the weight down and trying to do other things, so I don’t have to use. It’s just like, the machine is a bit of a pain in
the arse [laughs]. … I get tangled up in it, and it just keeps on waking me up and it’s just the sort of thing I can do without. (Pete)

Despite his wife’s concern for his health and reporting little success with weight loss, Pete made a definitive decision not to use CPAP.

In summary, the preceding articles in this chapter reported and explained the first two main categories that comprise the grounded theory *bargaining and balancing life with CPAP*. While *becoming a team for good-sleep*, CPAP-users realised that sleep apnoea was a problem about which they needed to act. CPAP-users’ partners and/or other family members formed a collaborative support team with CPAP-users, which positively influenced therapy management. By *making choices*, participants balanced their reactions to needing CPAP with the factors that motivated them to use CPAP and the consequences of their choices. Using or not using CPAP was contingent upon participants determining which choice helped them to feel most well. CPAP-users established personal motivations to use CPAP that were influenced by how they felt using it, knowing how CPAP supported good health and understanding how using it helped those around them. Nonetheless, bargaining and balancing did not always lead to becoming used to CPAP, as *yielding to barriers* describes, since some participants chose to manage sleep apnoea through weight loss rather than CPAP use. Although *overcoming barriers* reinforced CPAP-users’ motivations, *yielding to barriers* meant participants either stalled within, or left, the process of “getting use to” CPAP. However, most participants persevered with troubleshooting and allowed enough time for *becoming used to CPAP*, the final main category presented in the next section.
5.8. Main Category 3: Becoming used to CPAP

Upon making a decision about using CPAP and passing the second threshold, participants continued along the pathway by becoming used to CPAP. After choosing to use CPAP on a regular basis, participants moved on to creating a “business as usual” scenario. The final sections of this chapter explain how participants completed the integration of CPAP into their lives. The end of the pathway begins with choosing new routines, which together with the second subcategory getting used to it, results in mastering CPAP.

5.8.1. Choosing new routines

By choosing new routines, participants made adaptations to established routines and rituals in order to integrate CPAP into daily life. Choosing new routines was not simply choosing a new way to sleep, but choosing to make good sleep important and therefore making the requisite effort to use CPAP. Although becoming used to CPAP began while overcoming barriers, CPAP-users cemented the intention to become used to CPAP by taking action to subsume CPAP into normal everyday life. Consequently, participants re-oriented and adapted rituals and routines. Adapting “just the little things” enabled “re-learning” of night-time routines to accommodate CPAP (Felicity). Hal compared his present day to before he used CPAP:

… now [I] put chapstick on before I go to bed and zinc and castor oil around my nose, only takes a few seconds, so that’s usually when my wife’s putting on her face cream and hand cream and all that, so it’s a bit of a ritual really… (Hal)

CPAP-users and partners collaborated to negotiate new routines, such as when to turn out the light, or fit sex around using CPAP:

When you wake up at night, and you’re thinking, oh - romantic thoughts! That’s never going to happen when you’re wearing the mask. Ever! … So, I take the mask off about an hour before we get up so we can still do [sex]. It’s all those little things that I try to make sure we still do … it’s important for us to maintain whatever rituals we had from before. (Ed)

Some participants chose to relinquish spontaneous sex, or sex altogether, to accommodate CPAP use:

I suppose, in the bedroom sexual wise… you can’t be quite so spontaneous, but that’s fine too, we’re not as young as we used to be. (OliveP)

New routines also involved ensuring that bedroom furniture could house the CPAP machine, both at home and while travelling. Again “just the little things” mattered when organising the sleeping environment. Participants ensured there was ample space beside the bed and that tubing would reach:

…if we ever stay anywhere like a hotel I’m always checking which side the plug’s on. …

When I went on my daughter’s year seven camp, and there were no power points in the room, I was a bit freaked out about that. (Lily)
In the same way that a traveller ensures they have their passport, CPAP-users and partners double-
checked they had spare equipment and all necessary items prior to leaving on a trip. IanP said
CPAP was a vital piece of “medical equipment” that “kept Ed alive,” and insisted it remain with them,
as did Lily. In becoming accustomed to CPAP, participants described finding normality in their
night-time routines by making CPAP a familiar part of getting ready for bed.

To become used to CPAP, participants took action described in the sub-categories choosing
motivations, overcoming barriers and choosing new routines. Once the challenges of using CPAP
had receded, making CPAP a normal part of life was relatively straightforward and over time “just
became the routine” (Lily). While establishing routines, participants described “getting used to”
using CPAP. Each participant used the phrase “getting used to it” in varying contexts. Since every
participant used these words, the phrase became a fitting in-vivo code that was elevated to a
subcategory. The following section outlines the concept of “getting used to” CPAP.

5.8.2. “Getting used to it”

Participants reported that being able to sleep regularly wearing CPAP was contingent on getting
used to it. For some, becoming accustomed to CPAP was quick and unproblematic, while others
required time and effort troubleshooting the device and mask. Participants used the phrase in
different tenses depending on their stage of CPAP use. Those in the first months of treatment
expressed an expectation they would get used to it and made a conscious decision to do so.
Others spoke of having trouble, but expecting that eventually, they would be accustomed to it.
Participants also described needing to get used to it, being in the process of or already being used
to it. The following excerpts illustrate the different stages of getting used to CPAP:

I was just wondering [at the start] whether I would get used to it … but then, I’m used to it
now. (Curzon)

…and I had lots of issues at the beginning with sores on my nose. Yeh, so, it took a bit to get
used to. (Felicity)

So, it’s just a matter of getting used to it now. (Hal’s first interview)

I hated it when I first had it. The first few nights I ripped it off and threw it across the room. I
said to my partner it’s like having a Hoover on backwards and someone’s shoved the hose in
your mouth. But, you know, I’m used to it now. (Ed)

Having a good result from CPAP made getting used to it all the easier. However, CPAP-users who
struggled with CPAP described a feeling of having to get used to it. For those who had tried
everything else, from surgery to dental appliances, CPAP was the only alternative. Dave expressed
a sense of having no choice, saying “I’ve got to get used to it” (original emphasis). Participants who
struggled described having to get used to CPAP as a commitment to something unpleasant. They
“should” use CPAP because it was “good” for them and they understood the physical consequences
of not using CPAP despite being disappointed there was no alternative.
As with any new habit, participants found ways to make CPAP a normal part of life. Those who
described being used to CPAP compared wearing a CPAP mask to using other everyday items.
Users found the familiar and normal in something that was initially unfamiliar, difficult to use and not
normal, as the following excerpts illustrate:

It’s a bit strange to start with - it’s quite awkward, but you know once you get a bit used to it,
it’s just like your toothbrush really isn’t it.  (Dave)

For him, it’s like putting on a pair of pyjamas and going to bed, and it’s nothing more. Like an
uncomfortable pair of pyjamas that you put on every night.  (KayeP)

I will become used to it because I look at it just like the way you would wear spectacles. The
person who is not used to wearing spectacles always feels like there is something on their
face. [But] I wear spectacles and it doesn’t really bother me at all, and the times I probably
sleep and “oh my glasses are still on”.  (Arthur)

Participants framed using CPAP as “a normal thing” (Hal, OliveP, Lily). Becoming used to CPAP by
transforming new routines into everyday activities rendered CPAP mundane as it receded into the
minutiae of daily life:

Now it is almost a routine thing, I just slip it on and go to sleep, and when I get up, I just
remove it. That’s it.  (Curzon)

Much like cleaning teeth or putting on face cream, using CPAP now required little thought.
Reaching this point signified that participants had mastered CPAP.

5.8.3. Mastering CPAP

In Hal’s first interview, he described the struggle he had experienced getting used to CPAP; he
found it a challenge and had given up in the early months. However, two years later, Hal had
forgotten his struggle, speaking in an almost evangelical manner of a therapy that was very much
“part of the furniture” and posed no challenge at all. Hal's initial struggle had faded in his memory.
He had mastered CPAP and was now an expert user. Indeed, he had participated in other CPAP
research and, similar to other participants, enjoyed giving advice to new CPAP-users he
encountered.

Hal’s comments resonated with others. Participants who reported mastering CPAP described it as
“just there,” and not really thought about (IanP). Having receded into the background of everyday
life, participants were “just getting on with using it” (Ed, emphasis added). Using CPAP did not
warrant discussion and had become of little consequence in the grand scheme of things:

It’s just become a part of just going to bed. It’s just a part of it now.  (Barry)

[CPAP] is part of the furniture, it’s part of everyday life. I guess it’s like [taking] your false
teeth out… we don’t think about it…  (KayeP)

By embedding new routines, participants described a point where using CPAP had become
“business as usual,” and most used the words “part of” to represent the full integration of CPAP into
their lives. Participants frequently used the word *just* to signify that using CPAP no longer needed attention. Lily concluded, “of course, you just put it on each night and you hardly even notice.”

Having mastered CPAP, other matters now occupied participants’ minds, rather than thoughts about using CPAP.

Although participants had moved beyond having to think about CPAP in any actively conscious way, the importance of CPAP was undiminished in terms of its role in their lives. For example, CPAP travelled as hand luggage because users would rather lose their baggage than their CPAP. The code *CPAP in my handbag* captured participants’ need for CPAP:

> I keep [CPAP] with me at all times, … So, if anything else happens like if our bags got lost at least I have that machine (laughs). It’s a bit like I always check that I’ve got my puffer in my handbag and double check. ‘Cause I think, well, as long as I’ve got the Ventolin [then] that’s fine. And the CPAP machine has become a little bit like that. (Lily)

CPAP also retained its importance in maintaining a good sleep for close family, who reminded CPAP-users to put on CPAP and to check equipment:

> … like your husband [says] ‘you’ve been really shitty the last couple of days, is your machine not working properly?’ And you think ‘yes!’ And then you look, and you realise it’s got a rip in the mask or the little rubber nose thing had come out, and I didn’t realise. (Felicity)

CPAP only became a feature again if there was a risk of not having it to hand. Consequently, participants planned to have spare equipment while travelling:

> It goes everywhere with me. For example, I’ve got tubes and electric cord, and mask and seal down at the beach, so when I go down I just have to grab my machine. … it’s all part of the routine. (Hal)

> I knew I needed the machine; I did explain to them if I go on the marae I have to take the machine. (Molly)

Achieving mastery of CPAP represented the end of a process that had begun with *becoming aware* of the need for CPAP and *becoming a team for good-sleep*. Each participant had passed the threshold between category one and category two as they had all initiated CPAP therapy. Not all participants passed the threshold between category two and three. However, those who did concluded by *becoming used to CPAP*. For participants who reached this point, CPAP had become “just part of who we are” (IanP).
5.9. Chapter 5 Summary

In conclusion, participants in this study bargained and balanced the perceived advantages and disadvantages of using CPAP. CPAP-users made choices based on the outcome of bargaining and balancing that led to becoming used to CPAP, or abandoning CPAP. Participants established motivations to use CPAP and navigated difficulties with its use. When motivations failed, or when difficulties became insurmountable, CPAP-users left the process of getting used to CPAP, temporarily or permanently. Partners played an integral role in making the person with sleep apnoea aware that they had a problem, catalysing action and providing support to the CPAP-user. Eventually those with good personal support, who were prepared to persevere and give time to getting used to CPAP, arrived at a point where CPAP use became a normal part of everyday life.
LIVING WITH CPAP

CHAPTER SIX

Discussion
Chapter 6. Discussion

This thesis began by introducing the topic and the reasons for choosing this project along with the research aim and objectives. I developed the rationale for conducting the study in chapter two, and in chapter three discussed the philosophies underpinning grounded theory, describing how social constructionism influenced my research approach. Chapter four explicated the hallmark methods that comprise a grounded theory and their use. In keeping with the aims of this research, chapter five used findings to present the constructed theory: *bargaining and balancing life with CPAP*, that illustrates how CPAP-users became accustomed to CPAP. This substantive theory encompasses the categories, *becoming a team for good-sleep*, *making choices about CPAP* and *becoming used to CPAP*. To provide a platform for a discussion about the significance of my findings within the context of existing knowledge, this chapter discusses existing theories relevant to *bargaining and balancing life with CPAP*. Since no single extant theory supports the complete bargaining and balancing process engaged in by participants, I introduce a variety of theories that support separate elements of the process.

The first two sections of this chapter develop concepts drawn upon in the storyline and the accompanying articles in chapter five. The theory of *bargaining and balancing* operated within the minds of the participants as they debated with themselves about using CPAP. Additionally, *bargaining and balancing* operated within personal relationships as participants solved problems and reached decisions together. Therefore, section 6.1 addresses the concept of team, which corresponds with behaviours reported by participants in the first main category. Section 6.2 describes models of change management that correspond to *bargaining and balancing*, incorporating ideas from Kübler-Ross’ stage theory of grief, the theory of planned behaviour and the trans-theoretical model of change. Participants reaching a definitive decision to persevere with using CPAP marked the third main category. Accordingly, section 6.3 introduces and discusses the decision theories of rational choice and decisional conflict in the context of *bargaining and balancing life with CPAP*. The chapter concludes with a discussion about the integration of medical technologies into everyday life as an extension of the participants’ sense of physical self.

Rather than use extant theories as a preconceived framework, I remained true to the grounded theory principle of allowing the data to guide the theoretical framework for the study. However, once I had constructed a theory I was able to explore relevant extant theories to situate and support my grounded theory. For example, theories of change management and personal decision-making underpin the process of *bargaining and balancing* that participants engaged in while becoming a team and making choices about CPAP. Therefore, relevant extant theories provide explanatory power and increase the potential for applicability beyond the substantive area of research. Moreover, by using supporting extant theories the discussion that follows draws this grounded theory into wider debate.
6.1. Being a team and living with CPAP

The first article presented in the findings chapter introduced the concept of the couple as a team, describing them as a team focused on working together for good-sleep. I used Katzenbach and Smith’s\textsuperscript{471} definition of team as two or more people “committed to a common purpose.”\textsuperscript{p.165} The term ‘team’ describes members of a cooperative unit who discuss, problem-solve and work together to achieve a common goal.\textsuperscript{471, 529} In the context of this study, the team members were typically the CPAP-user and partner. Bed-partners’ experiences of their partner’s sleep apnoea symptoms precipitated the formation of the ‘team’. A small number of studies highlight the problems that untreated sleep apnoea causes for typically female partners of sleep apnoea sufferers.\textsuperscript{449, 460-467} Problems include disturbed sleep with associated symptoms of daytime fatigue and consequent marital conflict.\textsuperscript{530} Findings from the current study are consistent with other studies that identified the partner as a factor in the decision to seek treatment.\textsuperscript{531, 532} Two recent grounded theory studies, based in Taiwan\textsuperscript{452} and in America,\textsuperscript{453} have explored experiences of treatment for OSA. Hu et al.’s\textsuperscript{452} study focused upon the process of seeking medical help with findings emphasising the difficulties with and side effects of CPAP. Similar to this study, Hu et al. identified family as a source of information regarding sleep apnoea symptoms. However, the role of partners in the process of using CPAP was not explored. Rodgers\textsuperscript{453} focused on the process of being diagnosed with OSA. Rodgers’ findings support those of this study that partners were an important source of support for sleep apnoea sufferers as they pursued treatment. The current study has extended these findings by incorporating the views of partners and by identifying the social processes explaining how partner support occurs. A common purpose shared by participants was achieving a good sleep, which progressed to becoming used to CPAP. I identified that a collaborative team led to the successful integration of CPAP into daily life, while an un-collaborative team jeopardised the integration of CPAP.

The concept of team and teamwork is not new and has become a feature of healthcare policy and the corporate landscape.\textsuperscript{533-537} Using concept analysis, Xyrichis and Ream\textsuperscript{535} defined teamwork among healthcare professionals as a dynamic process of interdependent collaboration, open communication and shared decision-making to achieve common goals for patient care. Similarly, Procter and Currie\textsuperscript{536} argued for an element of interdependence in effective teamwork in a civil service setting. Katzenbach and Smith\textsuperscript{471} state that certain factors characterise teams who demonstrate good performance. These factors include the presence of a meaningful rationale for a team goal; for example, participants described the mutual goal of achieving a good sleep. JarotP described supporting her husband because:

He’s much better; he doesn’t snore, and I also get good sleep. (JarotP)

Other performance characteristics of an effective team include relevant skills and information about the goal, a willingness to engage with the work required, spending ample time together and celebrating achievement.\textsuperscript{471} This supports Lily’s description of how she and her husband were a team:
He helped me to figure it out, 'cause there were a few nights where I just couldn't work it out. I bumped it or something, and the dial went off and I'd freak out, and he would be: hang on a minute it can't be this hard. And he'd be sitting there trying to do it. (Lily)

Typically, behavioural and social psychology literature uses the term social support to describe teamwork in interpersonal relationships. Social support refers to the level of support or conflict present within interpersonal relationships. A characteristic of effective interpersonal relationships is the availability of social support.

Berkman et al. explored the construct of social support in health and developed a model of social networks, using Durkheim’s social integration theory and Bowlby's attachment theory. Using this model, they demonstrated that effective psychosocial support is important for good health. Berkman et al. acknowledged that not all social ties are supportive, but those that are exhibit emotional, instrumental, appraisal and informational support. Emotional support described the presence of love, caring and of being valued; instrumental support described tangible and practical assistance such as the above example with Lily; and appraisal support related to available help with decision-making and giving appropriate feedback, which corresponds to the following example:

I thought, my goodness [Hal’s] taking an awful long time to take the next breath and first thing in the morning I said to him, I think you’ve got sleep apnoea, and he said, I think you might be right. And he did something about it immediately, which was good. (OliveP)

Similarly, Thoits argued that social support is comprised of two broad support categories of emotional sustenance and active coping assistance.

Berkman et al.’s and Thoits models of social support resonate with findings from studies with middle-aged and older adults showing that marital collaboration supports problem-solving. The reciprocity between social support and coping is particularly evident in older people’s health and cancer care. Manne and Badr, present a model of couples’ psychosocial adaptation to cancer that emphasises intimate relationship as a resource drawn upon by individuals. Similarly, I identified that collaboration between CPAP-users and their partners enhanced problem-solving. Where the good-sleep team was effective in this study, the above-described qualities of both organisational teams and interpersonal social support were evident. Specifically, collaboration between IanP and Ed epitomised the above definitions of effective teamwork. Conversely, Gina, who had not openly communicated with her husband or shared her goal of using CPAP, did not optimise the team potential in her relationship. Williams et al. argued that an individual’s success in managing change depends in part on a functional relationship with important others. Birditt et al. found that high-quality relationships enact higher levels of support than low-quality relationships. Moreover, a recent meta-analysis of 148 studies concluded that the likelihood of mortality decreases in the presence of strong social relationships. Additionally, there is evidence that negative interpersonal processes are predictive of increased incidence of cardiovascular disease. Evidence indicates that social support, as per Berkman et al.’s definitions, reinforces adaptive coping styles and affirms that the relationship between support and coping is interdependant.
The studies referred to above indicate that it is important to assess the support available to prospective CPAP-users. The above authors urge clinicians to take social relationships as seriously as other risk factors for disease. Indeed, a further meta-analysis and systematic review identified that couple-oriented interventions in chronic illness, including elements of disease education and building relationships in illness management, reduced physical and psychological symptoms and enhanced relationship function. Optimising the couple as a team when designing interventions, which in the context of this thesis could involve inviting a partner to sleep clinic consults, is clearly important.

The article *Becoming a team for good-sleep* identified that the concept of family members as partners in care is gaining importance, particularly in paediatric care, long-term condition management and in-hospital patient care. Baron et al. concluded that pressure from a bed-partner to use CPAP did not increase use, and may even have interfered with its use. Nevertheless, I found seven studies in the sleep medicine literature that supported the concept of a good-sleep team. Elfstrom et al. identified that partners either collaborated with the CPAP-user, took over the handling of treatment or let the CPAP-user handle treatment alone. Elfstrom et al. acknowledged the possibility of partner as collaborator with the CPAP-user and, along with other authors, recommended engaging partners in educational situations. A United States research team explored the influence of female partners on male CPAP use. Baron et al. reported that participants with low relationship conflict reported a greater increase in next-day collaboration with the CPAP device, and that the presence of a quality relationship increased adherence to CPAP. Broström et al. also identified that a partner’s engagement facilitated CPAP adherence. Their findings suggest that a supportive relationship enhances motivation to use CPAP, which corresponds with the findings of this study reported in chapter five (see section 5.2, p.101).

### 6.2. Making a change and living with CPAP

This section discusses relevant change theories in the context of *bargaining and balancing life with CPAP*. It is reasonable to assume that if people are unwilling to comply with evidence-based health therapies, time, effort, money and lives are wasted. Consequently, behavioural scientists have extensively explored health-related change management and decision-making processes, resulting in the development of various behaviour change theories. This end-point of *bargaining and balancing* reflects self-management principles as once users had achieved mastery they were able to manage CPAP themselves. However, the concept of self-management does not reflect data from participants or the decision-making process they engaged in throughout *bargaining and balancing*. Nor does self-management account for the social nature of using CPAP. Thus, the following sections focus on change management theories and decision theories to lend explanatory power to the process of making choices about CPAP. By building on work as a team, participants in this study were able to make choices about using CPAP and subsequently make changes to integrate CPAP into everyday life. Incorporating CPAP into daily life involved making changes to
daily routines. In the article *Making choices about CPAP* we describe the participants as reasoned decision-makers in their healthcare and more than capable of making a change.\textsuperscript{559} Therefore, the process of implementing CPAP use corresponds to various models of change theory. I consider Kurt Lewin’s\textsuperscript{560} three stage change process, Kübler-Ross\textsuperscript{561} description of bargaining during grief, and the more contemporary theories of reasoned action and the trans-theoretical model of change.

The work of noted social scientist Kurt Lewin (b.1890-1947) regarding theoretical approaches to change contributed significantly to the development of social change theory.\textsuperscript{560, 562-564} Lewin\textsuperscript{560} described a three stage change process of *unfreezing*, *moving* and *freezing*. While *unfreezing*, the need and motivation for change is established, which in turn challenges comfort levels. Change occurs during the second stage of *moving*: a period of transition during which comfort levels are in upheaval. Reinforcing and embedding the change into everyday life results in the final stage of *freezing* when comfort levels return to baseline. Lewin used his theory to illuminate social and group dynamics during change.\textsuperscript{560} However, the model also corresponds with the processes that individual participants described in this thesis. Becoming a team for good-sleep and establishing the need for CPAP led participants to choose motivations for implementing a change that corresponds to the disruption of *unfreezing*. *Moving* corresponds to the middle main category, *making choices about CPAP*, during which participants transitioned from treatment initiation to making a definitive decision to continue using CPAP. Finally, participants mastered CPAP, describing it as part of everyday life, which resembles Lewin’s *freezing* stage. However, Lewin’s model does not consider the personal and internal negotiations that participants described as part of *bargaining and balancing* the pros and cons of CPAP within each of the three categories in the current study. In the following sections, I address this point by discussing Kübler-Ross’ stage theory and the transtheoretical model of change, which correspond to elements of the *bargaining and balancing* process engaged in by participants in this study.

### 6.2.1. Bargaining in Kübler-Ross’ stages of grief and dying

Kübler-Ross\textsuperscript{561} drew attention to the emotional processes involved in managing the changes associated with dying and grieving. She identified five stages in the process, labelling these as denial, anger, bargaining, depression and acceptance.\textsuperscript{561, 565} Kübler-Ross’ bargaining stage corresponds to the act of bargaining exhibited throughout the process of *becoming used to CPAP*. She described bargaining as trading or negotiating a compromise or an ‘out’ from a situation in the hope of postponing the inevitable.\textsuperscript{566} Kübler-Ross’ model has been broadly embraced and applied to other personal change events, such as disability, serious illness, marital separation and work performance reporting.\textsuperscript{567-571} In the current study, witnesses who bargained with the snorer prompted them to seek treatment. Partners drew attention to how often snorers’ fell asleep at inappropriate times and reported that snoring disturbed partners’ sleep. Following the diagnosis of OSA, further bargaining encouraged OSA sufferers to persevere with and maintain use of CPAP. Partners encouraged snorers to use their CPAP, bargaining that doing so would keep them well and alive for longer:
He preferred me to have it; he thinks it’s going to extend my life. … He expects me to stay well until after he passes on. (Molly)

He didn’t care [about the mask]. He just wanted to get back the person that he married that didn’t fall asleep. (Lily)

IanP bargained with himself that despite the risk of appearing the bully, “harassing” Ed about his snoring would protect both Ed’s health and IanP’s sleep:

Obviously, things would have escalated because he wouldn’t have sought help, his breathing would have gotten worse, I probably wouldn’t have been able to sleep, we probably would have ended up in separate bedrooms. … But I also knew that, quite selfishly, I couldn’t cope anymore with the lack of sleep. (IanP)

Similarly, CPAP-users individually reasoned that by using CPAP for a certain number of hours a night they could abandon the mask for the remainder of the night. In an attempt to postpone the inevitable, participants also reasoned that if they lost weight they might not need CPAP.  

Kübler-Ross’ stage theory has long been criticised because the apparent linear approach to the stages of grief and dying do not correspond with the chaotic, circular nature of the grieving process. Kübler-Ross clarified her stance, making clear that the five stages were tools for understanding loss and not prescriptively linear. Just as the stages of grieving are not linear, it was also possible for participants to achieve acceptance of CPAP without progressing through protracted choice-making. Equally, it was possible for participants to become stuck within the choice-making cycle and not become used to CPAP. While Kübler-Ross’ bargaining stage is a useful reflection of the participants’ experience, it focuses on dealing with a difficult change. However, most participants in this study experienced CPAP as a positive change and were able to rationalise their choices to integrate CPAP. The following section discusses additional models of change that correspond to and support the bargaining and balancing process. The models discussed include the theory of reasoned action and the trans-theoretical model of change.

### 6.2.2. Living with CPAP and theoretical models of change

In the main, participants in this study gave careful consideration to seeking medical help for their sleep problem, and subsequently to the decisions surrounding CPAP use. What participants reported about managing the change required to integrate CPAP supports various theoretical models of change management, such as the cognitive theory of planned behaviour. The wish to promote CPAP-user compliance has generated an abundance of related sleep medicine literature, as described in the integrative review in chapter two. Accordingly, sleep medicine researchers have also used the trans-theoretical model of change to explain CPAP adherence, also discussed in this section.

Many studies have used the theory of planned behaviour to predict varied health behaviours, as illustrated by the few examples cited. The theory of planned behaviour was developed from the theory of reasoned action, proposed by Fishbein and Ajzen, which argues that intention is...
the precursor of behaviour. Ajzen subsequently incorporated the concept of perceived behavioural control into the reasoned action model, renaming it the theory of planned behaviour (TPB). Perceived behavioural control describes how factors that help or hinder engagement with behaviour influence the extent of self-belief in the ability to perform that behaviour. Both theories propose that a person’s attitude towards a behaviour predicts their intention to engage in the behaviour, and that the level of intention is the best predictor of engaging in that behaviour. TPB corresponds with the bargaining and balancing that participants engaged with during deliberations around using CPAP. For example, participants who viewed using CPAP as a positive step, and perceived using CPAP as important to their partner, reported the intention to get used to CPAP. Moreover, those who spoke of a determination to persevere expressed the belief that they would eventually become accustomed to CPAP. However, just one study was identified that applied the TPB in the area of CPAP use; the study reported that intention to purchase CPAP predicted the actual purchase of a device. The TPB supports the intention component of making changes to use CPAP. Additionally, findings from this study add weight to the use of TPB in future research regarding CPAP use.

While the TPB is useful for explaining behavioural intention, the theory does not account for the decision processes that lead to a change. A more comprehensive cognitive theory of behaviour change used in sleep medicine research is the trans-theoretical model of change (TTM). Indeed, Aloia et al. and Stepnowsky et al. used elements of the TTM to clarify inconsistencies in determining reasons for poor adherence to CPAP. The TTM proposes that people who identify more pros than cons to using it will become accustomed to CPAP. To explore how people change behaviour, the model offers an integrative framework incorporating three central constructs: stages of change, self-efficacy beliefs as described by Bandura, and decisional balance. The remainder of this section addresses the stages of change and self-efficacy constructs, and the following section discusses the decisional balance construct.

The stages of change construct in the TTM corresponds to varying phases of readiness experienced by persons preparing to engage in a new behaviour. Prochaska and DiClemente identified five distinct phases of change: pre-contemplation or not intending to change; contemplation of a change; preparing to change; acting by engaging in the new behaviour; and maintaining the change over time. Of course, contemplating, preparing, acting and maintaining resemble the phases in Figure 12 (see p.98). Contemplating and preparing correspond to initial phases in the model where participants contemplated taking action to seek medical advice regarding the symptoms of sleep apnoea. Upon reaching a decision and receiving a diagnosis, participants prepared to use CPAP by making choices about motivating factors. CPAP users took action that led to overcoming barriers to CPAP use, and those that passed the second threshold of making a definitive decision were able to maintain the change over time.

While the stages of change construct in the TTM focuses on both behavioural intention and actual behaviour, the self-efficacy construct corresponds to a person’s belief in their ability to manage a change. The notion of self-efficacy has informed extensive sleep medicine literature regarding CPAP adherence. Both articles in the findings chapter draw attention...
to the relevance of self-efficacy to the participant experiences reported in this thesis, so this discussion is not repeated here.

As with Kübler-Ross’ model, the TTM has been criticised for being overly linear nature. Moreover, application of the model to compliance with CPAP has proven inconclusive, with only Aloia et al. finding elements of the TTM predictive of adherence to CPAP at six months after treatment initiation. Applying the stages of change to this study overlooks how participants internally debated and oscillated between decisions before settling on one. Based on my data, I argue that progress through phases is more dynamic than linear and occurs at varying rates. For example, some participants remained caught in contemplation and preparation, expecting that eventually they would get used to CPAP, while others moved quickly to the maintenance and mastery stages of CPAP use. Studies using the TTM, such as Marcus et al.’s study on promoting exercise, also propose that individuals relapse to earlier stages of change. However, I identified that once beyond the thresholds of reaching a limit and making a definitive decision shown in Figure 12, participants did not go back. The third central construct of the TTM is decisional balance based on decision theory, discussed in the next section.

6.3. Decision theory and living with CPAP

By choosing to seek medical help and subsequently become used to CPAP, participants in this study made a number of decisions. Reaching a decision by making choices among given alternatives requires a series of continuous cognitive processes. Decision theory attempts to describe and predict these cognitive processes. Decision theories assume that a decision has consequences and that actors prefer a particular consequence. Decision theories elaborate on the process of acting and reasoning to optimise achievement of goals through the concept of rational choice.

Decision theory in its broadest sense describes societal processes that bring about group decisions, known as game theory or social process theory. Normative decision theory focuses on predicting decisions by ‘perfectly rational’ actors to identify how individuals or groups would or ought to behave in a given choice situation. However, decision theories also deal with aspects of selecting a choice from a range of possibilities by an individual. Descriptive decision theories are primarily inductive and emphasise that an individual’s decision is optimal from specifically his or her point of view. Therefore, descriptive decision theories focus on making sense of how people make decisions, which aligns with the focus of this study on how people live with CPAP.

The following sections discuss two descriptive decision theories that correspond to elements of bargaining and balancing life with CPAP, namely rational choice theory and Janis and Mann’s conflict theory model of decision-making.
6.3.1. Rational choice theory and making choices

Findings from this thesis illustrate a decision-making process that corresponds to assumptions of rational choice theory. Rational choice theory assumes that striving to optimise goals or preferences in the presence of restrictions results in choices that determine behaviour. Rational choice theory operates on three core assumptions:

- Behaviour can be explained as a selection from a range of choices.
- Beliefs, consistently held preferences and constraints are key determinants of a person’s behaviour, and
- People select a choice that is optimal in relation to their preferences and beliefs, and to any constraints encountered.

These three assumptions correspond with the findings reported in the second article of chapter five, which identified that participants chose outcomes that were optimal for them, given the constraints they encountered. For example, CPAP-users framed choices as an optimal balance between the pros and cons of using CPAP. Participants assessed the available evidence about using or not using CPAP and balanced these against the actual or anticipated benefits of using CPAP. Therefore, participants expressed a preference to sleep well, and within the constraints of their beliefs towards using CPAP and the practicalities of using CPAP, they made choices that determined CPAP use.

Kroneberg and Kalter argue that inadequacies in the various versions of rational choice theory have led to the development of the theory from a ‘narrow’ to ‘wide’ version. Although based on exchange theory, rational choice theory was subsequently developed as a theory of decision-making in economics, which is associated with the narrow version of rational choice theory. However, rational choice theory also has a sociological focus that treats social life as the product of rational choices made by individuals. Scholars apply sociological rational choice theory to a variety of social interactions and group decision-making. Sociological rational choice theory developed as studies produced evidence to support the relevance of the theory in areas such as family, religion and gender. However, this theory is not without controversy and the core assumptions have been adapted and modified according to the area of research in which it is applied. Accordingly, the sociological or ‘wide’ version of rational choice theory departed from its economic basis and incorporated the following assumptions:

- Personal beliefs can be subjective, incomplete, imperfect and biased.
- Consistently held preferences can encompass a diversity of motivations such as altruism or fairness.
- Constraints are both objective and subjectively perceived by the individual, and
- The desire to act aligns with personal identity, values and internalised norms.

The debate continues regarding the status of a wide version of rational choice theory as a legitimate meta-theory, with scholars arguing both for and against. Nevertheless, the additional premises correspond closely with participants’ experiences. In terms of personal beliefs,
participants’ knowledge about sleep apnoea and CPAP did not always correspond with empirical evidence. For example, Pete was determined that losing weight was the answer to treating his sleep apnoea, and Felicity had believed sleep apnoea was limited to overweight older men. Ned was motivated to use his CPAP not for his health, but because of a desire to facilitate his wife’s sleep. Being fair to his wife underpinned his motivation to use CPAP, rather than his own welfare.

Objective constraints included problems with mask-fitting, whereas the sub-category imagining stigma illustrates subjectively perceived constraints (see section 5.5.5, p.125). Indeed, a variety of factors described by participants aligns with the assumptions of rational choice theory and underpins participants’ decision-making about living with CPAP.

Boudon argues for the versatility of rational choice theory and applies it to a variety of collective social events such as the fall of an empire or the advent of war. In hindsight, such events can appear irrational, although ‘rational’ to the decision-makers of the time. This point highlights that rational choice theory describes choices that are subjectively rational from the decider’s point of view. The subjective nature of such decisions aligns with the hypothesis that “any action is caused by reasons in the mind of the individual.” This hypothesis accounts for why someone might choose to abandon CPAP despite understanding the risks and consequences of untreated OSA, or might choose to persevere with CPAP despite significant mask-fitting difficulty. Either decision needs to be rational in the mind of only the person faced with the choice.

Critics of rational choice theory claim the theory ignores the impact of impulsive, emotional, altruistic or habitual action. Indeed, Goldthorpe argued that rational choice assumes people make decisions in full knowledge and without being conflicted. Data from the current study reported in chapter five, supports Goldthorpe’s argument (see section 5.5, p.117). Therefore, while rational choice theory corresponds to the process of bargaining and balancing during the second main category of this study, it does not explain how all participants made choices. For example, Gina bargained and balanced her choice of CPAP non-use based on feelings of conflict between meeting her husband’s wishes and her own. Equally, participants made impulsive decisions during the night based on how they felt in the moment. In these situations, participants balanced the experience of mask discomfort, for example, against knowledge that using CPAP would improve their health. Therefore, components of bargaining and balancing also correspond to a cognitive dissonance model, or more specifically Janis and Mann’s decisional conflict model, discussed in the following section.

6.3.2. Conflict theory model of decision-making

Participants in this study modelled components of Janis and Mann’s decisional conflict theory. Janis and Mann’s model provides an added dimension to cognitive dissonance theory that states people avoid information that conflicts with their beliefs. Janis and Mann proposed that individuals behave according to five coping patterns when faced with a choice regarding a course of action. Typically, a threat-based stress, such as an emergency warning or a message that urges protective action, precipitates the need to make a choice about a course of action. In this context,
a sleep apnoea diagnosis represents a threat-based message with implications for heart health and longevity. The decision to use CPAP is, therefore, a protective action.

The coping patterns that comprise decisional conflict theory are: un-conflicted inertia, un-conflicted change, defensive avoidance, hyper-vigilance and vigilance. The vigilance coping pattern describes an adaptive process that leads to high quality decisions that, in this case, would mean using CPAP. The other four coping patterns can be adaptive, but more often result in poor decision-making with poor consequences. Table 15 outlines the five coping patterns.

Table 15: Coping patterns of Janis and Mann’s decisional conflict theory

<table>
<thead>
<tr>
<th>Coping pattern</th>
<th>Description of pattern</th>
<th>Loss from not changing</th>
<th>Loss from changing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Un-conflicted inertia</td>
<td>Decision ignored, status quo maintained. Interest in information about the issue is low.</td>
<td>Low</td>
<td>High or low</td>
</tr>
<tr>
<td>Un-conflicted change</td>
<td>Decision to change made without question. Interest in information about the issue is low.</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Defensive avoidance</td>
<td>When there is no hope of finding a better solution procrastinating, shifting responsibility or wishful thinking occur. Exposure to information is selective and affirms the decision-maker's choice.</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Hyper-vigilance (or 'panic')</td>
<td>When there is not time or hope of finding a better solution information gathering is hurried and poorly evaluated leading to hasty decisions that seem to promise immediate relief but overlooks the full range of consequences.</td>
<td>High</td>
<td>Low or high</td>
</tr>
<tr>
<td>Vigilance</td>
<td>When there is time and hope of finding a better solution information gathering, assessment and evaluation of options are considered and balanced prior to making a decision.</td>
<td>High</td>
<td>Low or high</td>
</tr>
</tbody>
</table>

Data drawn from this study corresponds to the above coping patterns, except for hyper-vigilance and un-conflicted inertia. A criterion for hyper-vigilance is lack of time. However, all participants had time to think about using CPAP. In terms of un-conflicted inertia, interest in information about symptoms had led participants to seek medical help. Therefore, they had made a decision to start using CPAP, rather than ignore the need for treatment completely. Figure 15 provides a graphic representation based on Janis and Mann’s model to illustrate participants’ coping styles during the decision-making process.
Figure 15: Living with CPAP using Janis & Mann’s decisional conflict model

Yes, no and maybe responses in the above model are based on the decision-maker’s subjective judgement, not on what is considered best clinical practice. Information about losses from OSA describes what the participants perceived as a loss. This corresponds with the sub-category becoming motivated presented in the findings chapter that outlines what the participants understood to be the consequences of untreated sleep apnoea (see section 5.5.5, p.126). Similarly, information about losses from using CPAP corresponds to the side effects and stigma addressed in overcoming and yielding to barriers in the same findings section.

Un-conflicted change in the above model is congruent with data from participants, such as Curzon, Molly and KayeP, who reported no hesitation in using CPAP. Each described CPAP as a solution to a problem that worked, that required little thought and that they “just got on with” (Molly):

Nothing goes in my mind, just when I go to sleep I know that I have to take the machine on, I just take it on and that’s it. (Curzon)
Chapter 6

You got a machine; you have to have it, and that’s all there is to it. I don’t understand what the big deal is! (KayeP)

Pete provided data most consistent with defensive avoidance. Pete rationalised he did not need CPAP as he would lose weight instead, despite reporting little actual weight loss. He spoke of gathering information that supported his decision to abandon CPAP:

I’ve been doing other things to try and - like keeping the weight down and trying to do other things, so I don’t have to use [CPAP]. It’s just the machine is a bit of a pain in the arse [laughter]. But I’ve been that busy I haven’t actually been fatigued because I just have to concentrate on what I’m doing. It’s like I sort of can try and do without it. … They [clinic staff] said you should be using it. Otherwise you’ll die, but I don’t think I’ve been stopping breathing so much as I used to. … Sleep apnoea is a thing that - I’ve spoken to quite a few people - that you can try and control it yourself. As I say I’ve dropped a bit of weight - about 4-5 kilos, which they’ve said would be a good thing for it. … I would like to try and be tested again and see what the outcome was for that. (Pete)

Pete avoided information that conflicted with his belief that losing weight would work as a solution to his sleep apnoea, instead focusing on information that supported his belief. His strategy was consistent with bolstering of preferred alternatives to diminish cognitive dissonance. Moreover, he hypothesised that a repeat sleep study would show he no longer had sleep apnoea.

However, the majority of participants exhibited a vigilant coping strategy. Participants weighed the pros and cons of not using CPAP against the pros and cons of using it to determine an optimum course of action. Arthur sought further information to determine if it was realistic to hope for an alternative to CPAP:

So, it is trying to work two things at one time: knock off weight and use the machine and seeing where we go from there. … I did try to find out whether [OSA] is genetic, but then the answers I got were ‘no,’ it could be that it is just overweight. (Arthur).

Despite difficulty at the outset, Hal described a thorough search for information about sleep apnoea and CPAP and was determined to persevere with CPAP use. Similarly, Ian and Ed took a measured approach to information gathering and the assessment and evaluation of options prior to making a firm decision to commit to living with CPAP:

I suspect that if Ed’s gone to all this trouble of having three surgeries and each one of those has been successful in their own right, they just haven’t helped in the bigger picture. And so, if he is prepared to go down that road, and it’s still not right and he still needs the machine then absolutely it just says to me that the only opportunity now is the machine. (Ian)

Indeed, CPAP-users with an un-conflicted change coping style or a vigilant coping style were more likely to persevere and succeed with CPAP than those who favoured defensive avoidance.

What the decisional conflict model in Figure 15 does not illustrate is how bargaining and balancing throughout the process of getting used to CPAP led to movement back and forth between defensive
avoidance and vigilance. A unique feature of the decisional conflict model is the influence of situational factors that can cause the same person to make a rational decision in one circumstance, but a poor decision in another.\textsuperscript{616} This is consistent with the night-to-night variability of CPAP use observed by Weaver et al.\textsuperscript{250} and others,\textsuperscript{28, 36, 37, 617} along with findings from this study as reported in chapter five (see section 5.5, from p.117).\textsuperscript{559} Despite describing consistent CPAP use, participants made a choice to use or not to use CPAP based on the circumstances of that moment, for example, taking the mask off part way through the night, or choosing not to take CPAP on school camp (see memo, p.132).

The conflict theory model of decision-making has been applied in areas such as education,\textsuperscript{615} mental health,\textsuperscript{618} human resource management\textsuperscript{614} and chronic disease management.\textsuperscript{619} Grytten et al.'s\textsuperscript{619} survey investigating reasons for non-starting and stopping disease-modifying therapy in multiple sclerosis identified that an avoidance coping style predicted not starting therapy. However, examples of sleep medicine studies using the conflicted decision model are scant. Stepnowsky et al.\textsuperscript{34} identified that an active coping style increased use of CPAP, while Moran et al.\textsuperscript{509} noted an active coping style made little difference to use. Additional studies by Stepnowsky et al.\textsuperscript{179, 516} explored social cognitive correlates of CPAP use in experienced users and the determinants of nasal CPAP compliance. They concluded that when pros outweighed cons CPAP use increased. Additionally Crawford et al.\textsuperscript{181} promoted the encouragement of adaptive coping styles.

Further exploration of the behaviours of people who correspond to the vigilance coping pattern might determine users most likely to succeed with CPAP. Aligning data from this study with the vigilance coping pattern provides evidence that assessing coping styles in prospective CPAP-users might have predictive value. Education and behavioural medicine research have used coping style assessments.\textsuperscript{615, 620} For example, de Heredia et al.\textsuperscript{615} used an adapted Melbourne Decision Making Questionnaire (DMQ), based on Janis and Mann's model, to analyse the decision patterns and decision-making self-esteem of university students. Using assessment tools like the DMQ provides the opportunity to target supportive interventions at those who relate more closely to less effective coping patterns. Thereafter, interventions that address particular coping styles can be tested to determine the possibility of transitioning CPAP-users from sub-optimal CPAP use to successful CPAP use.

The theories of change management and decision-making that support the process of bargaining and balancing, both individually and as a marital team, underpin the process of integrating CPAP into everyday life. The last section of this chapter uses the notion of embodiment to illustrate how CPAP as a health technology can become an integral part of life and of self.

### 6.4. Integration of health technology and becoming used to CPAP

In the final category of bargaining and balancing life with CPAP, participants described becoming used to and successfully living with CPAP. Participants expressed the wish never to be without
their device, as CPAP had become so important in maintaining good health that it became part of who they were. Participants were keen to keep the device close, even if it meant travelling with CPAP as hand luggage. By this stage, CPAP was successfully incorporated into daily life, bargaining was minimal and balance was achieved. Lily stated, “I can't imagine life without it really.” Indeed, participants described CPAP as “part of the furniture,” as though their CPAP had become embodied as part of who they were and what they did in daily life. However, accommodation of medical devices in the home and lives of CPAP-users as an extension of self is underexplored in the sleep medicine literature. Typically, literature focuses on the use of medical technology to facilitate independent living at home, such as tele-health innovations, health information systems and assisted living technology in child health and aged care. For example, a Taiwanese study explored factors underlying usage of assistive devices in cerebral palsy from children's perspectives. They identified that children only accepted devices easily to join in with school activities. Similarly, Tong et al.’s review of qualitative evidence regarding adult life with peritoneal dialysis identified seven themes, none of which related to the integration of peritoneal dialysis as a normal part of life. Rather, peritoneal dialysis equipment, although necessary, was a disruptive intrusion that enabled maintenance of normal life including the freedom to work and travel.

Studies that have explored accommodation of medical devices in the home and lives of users have done so using Maurice Merleau-Ponty’s concept of embodiment. Merleau-Ponty countered mind-body dualism by stating that the mind and body are fused and not separate and argued that people experience the world through their bodies. In total, I identified six studies that used his ideas to explore how people extend the construct of body to medical prostheses and medical devices. Wilde’s study, regarding the lived experience of indwelling urinary catheter, identified themes that resonated with participant reports in the current study. Participants adjusted to the change of having an indwelling catheter through embodiment of the catheter as part of self. Similar to reports in section 5.8.3, participants gave little active thought to the catheter that was now such a part of their lives (see p.137). Three of the six studies, identified through a recent meta-synthesis, explored amputation and prosthetic use and included an analysis of the embodied sense of the prosthesis as part of the body and of self. Wilde’s study, regarding the lived experience of indwelling urinary catheter, identified themes that resonated with participant reports in the current study. Participants adjusted to the change of having an indwelling catheter through embodiment of the catheter as part of self. Similar to reports in section 5.8.3, participants gave little active thought to the catheter that was now such a part of their lives (see p.137). Three of the six studies, identified through a recent meta-synthesis, explored amputation and prosthetic use and included an analysis of the embodied sense of the prosthesis as part of the body and of self. A more recent phenomenological study by Mills also explored the integration of prosthetic limbs into daily life. Mills identified that viewing the prosthesis as part of the body occurred when wearers focused beyond the prosthetic itself and onto the achievement of goals through wearing the prosthetic. More specifically, a Scandinavian study explored the experiences of ten people using medical technology at home, including long-term oxygen or renal therapy. Fex et al. identified that participants transitioned to a “new state of living in which the individual and technology were in tune.” This is similar to the way participants in the current study described CPAP as “just part of everyday life” and “part of who we are.”

Domestication of health technology, a variant of the embodiment concept, is used to explore the incorporation of medical technology in the home. Storni discusses technologically mediated self-care in long-term conditions in terms of appropriation and domestication, which is defined as incorporating technology into daily life by making a device one’s own. Similarly, Carter et al. described a process of domestication whereby new devices, such as an electric toothbrush, are
incorporated into everyday life. Carter et al. describe how participants learned about a new item and altered daily routines to subsume it into everyday life. Indeed, participants in the current study described how CPAP became much like wearing a pair of pyjamas or using a toothbrush every night (see section 5.8.2., p.136). The use of these everyday metaphors illustrates Merleau-Ponty’s belief that language can reveal the taken-for-granted nature of an object, and revealed how CPAP became implicitly normal for these participants. Therefore, findings from the current study, and the studies discussed above, illustrate that being able to describe a therapy as an integral part of the self represents a hallmark of success with CPAP and with other long-term therapy integration.

### 6.5. Chapter 6 Summary

This discussion aimed to situate the findings of this grounded theory research in the context of relevant extant theories and existing knowledge, and to show the relevance of these findings in relation to sleep medicine literature. As described in chapter two, sleep medicine literature has focused on the importance of CPAP and the problem of the non-compliant CPAP-user. In particular, research has applied various theoretical models to develop interventions to support CPAP use and to identify the non-compliant. In contrast, I identified how most CPAP-users in this study were successful with the integration of CPAP through a process of bargaining and balancing. Identifying how CPAP-users are successful provides important and targeted information to optimise uptake of this therapy. This discussion raises important questions about the relevance of optimising close personal relationships. Findings showed that enhanced social support via close relationships optimised integration of CPAP into daily life, and add to scant evidence regarding the role of partners as collaborators for good sleep. Additionally, developing the concept of effective social support in long-term conditions may provide a useful foundation for effective teamwork within personal relationships in the broader context of health.

To support the substantive grounded theory *bargaining and balancing life with CPAP*, I discussed a variety of extant theories related to change management and decision-making. These included Kübler-Ross’ stage model; the theory of planned behaviour; a trans-theoretical model of change; and rational choice and decisional conflict models. Each of these theoretical models has a degree of congruence with a separate part of the bargaining and balancing process described by participants and so strengthens understanding of long-term therapy use.

The absence of a single existing theory that comprehensively accounts for the entirety of *bargaining and balancing* indicates that the current research contributes to theory regarding change and decision-making in relation to the use of CPAP. Although sleep medicine literature has used theoretical models to explain non-compliance, scant evidence exists to explain the successful use of CPAP. The theory of *bargaining and balancing* is the first to identify the components of successful CPAP use. Further research is now warranted to explore these components in more detail. Additionally, little is understood about the process of embodiment experienced by participants successfully using CPAP. To date, sleep medicine literature has also not explored integrating
CPAP into everyday life in terms of domestication and embodiment of technology. Therefore, the concept of medical devices embodied as part of daily life provides a new avenue of inquiry for sleep medicine researchers to examine the levels of success patients have with CPAP therapy. Moreover, identifying people who have successfully become used to CPAP provides a source of information for the development of clinical and patient education resources.

Findings from this study and the points discussed in this chapter provide a platform for recommendations that contribute to health policy, research and education. I address these recommendations and make concluding comments to this project in the following final chapter of the thesis.
Chapter 7. Conclusion

This final chapter concludes the thesis by re-visiting the research question, the choice of methodology and the outcomes of the study. I outline the contributions of this research to knowledge, and discuss limitations of the study, followed by recommendations for practice, policy and education. I conclude by reflecting upon my learning throughout this project.

7.1. Revisiting the study aim

Evidence regarding the experience of using overnight continuous positive airway pressure (CPAP) for sleep apnoea is limited. The aim of this project was to explore the experiences of CPAP from users’ perspectives using grounded theory. The intent was to explain how people live with CPAP by asking them what CPAP was like to live with.

By attending to the requirements of a sound grounded theory, as agreed by a consensus of authors, I have given a reasoned interpretation of the data provided by participants.42, 43, 45, 46, 640 This thesis has described and illustrated the steps taken to maintain a transparent research process and to evidence the credibility of the knowledge constructed. Constructing the theory of bargaining and balancing life with CPAP, through becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP, achieves the study aim and provides new knowledge on this topic. The following section summarises how this research contributes to knowledge.

7.2. Thesis Overview: Generating new knowledge

The first chapter in this thesis introduced sleep apnoea and outlined the large body of literature showing that sleep apnoea is detrimental to good health and that CPAP is an effective treatment. I provided reasons for choosing this project by describing my professional background, theoretical position and the experience I brought to the study, along with the aim and objectives. Chapter two developed the rationale for the study by providing evidence that supported the need for this project. In chapter three, I discussed the philosophies underpinning grounded theory and described how social constructionism influenced my research approach. Chapter four illustrated how I applied the principle methods of a grounded theory approach to construct the substantive theory presented in chapter five. Bargaining and balancing life with CPAP is comprised of three main categories: becoming a team for good-sleep, making choices about CPAP and becoming used to CPAP, that illustrate the process of getting used to living with CPAP. In chapter six, I situated the findings in the context of existing knowledge to strengthen the constructed theory. I discussed the concept of team as it related to the first main category, and introduced various theoretical models of change management and decision-making as they related to the second main category. I concluded
Chapter 7

chapter six by applying the concept of embodiment to the process of integrating medical technology into both daily life and to self as described by the third category. Finally, in this chapter I summarise the thesis and highlight contributions made to knowledge within each chapter of this thesis. To evidence the generation of new knowledge, I also draw upon each of the manuscripts included in this thesis, which are either published or under review.

The experience of using CPAP for sleep apnoea is not widely described in the literature. Chapter two presents a systematic integrative review on this topic, titled What is known about the experiences of using CPAP for OSA from the users’ perspective, published in Sleep Medicine Reviews. Conducting this review drew my attention to the discourse of compliance and prompted an exploration of the concept using Foucault’s ideas of surveillance and governmentality. Considering compliance in healthcare exposed received knowledge that might influence my position as a researcher and raised theoretical sensitivity to data regarding being told and being a good client. However, this data proved a small part of the overall theory, as participants were concerned with becoming used to CPAP more than with being compliant with clinician directives.

Early findings of the review in chapter two were presented in poster format at the 5th World Congress on Sleep Medicine in Valencia, Spain in 2013 organised by the World Association of Sleep Medicine. The completed review showed that sleep medicine research has focused on ways to improve compliance with CPAP rather than on how people manage therapy successfully, and confirmed that current knowledge about experiencing CPAP from the users’ perspective is limited. Consequently, discerning clues about ways to support new or struggling CPAP-users from those who already successfully managed the therapy is a novel way of approaching the topic of CPAP use. During the article revision process both reviewers commented on a need for a review in this field and that along with summarising current knowledge about using CPAP, the article defined a clear research agenda for the future. The reviewers also agreed that research should not be limited to understanding only the barriers to CPAP use, but should also focus on identifying what motivates people to use CPAP. Therefore, the review added to current knowledge by synthesising the scant evidence available, and has been cited to support subsequent sleep medicine literature. Moreover, by conducting the review I was able to confirm that users’ experiences of using CPAP had not been previously explored using a grounded theory approach. As described in the manuscript, the systematic integrative review method draws on a wide range of evidence from studies that use diverse methodologies. This review has also been cited in support of subsequent integrative review methods in other areas of research.

As part of a methodological discussion in chapter three, I entered the debate regarding the evolution of grounded theory through a social constructionist lens by reflecting on my personal theoretical evolution. The paper, Evolving from a positivist to constructionist epistemology while using grounded theory published in the Journal of Research in Nursing, provides unique documentation of my transition from nurse to researcher. I agree with Kathy Charmaz and Annie Topping that most researchers, including grounded theorists, grapple with personal standpoints privately and out of public view. To a beginner researcher, the lack of readily available information specific to my development as a researcher was frustrating. Therefore, I documented the resolution of tensions
between received notions of science and the development of epistemology during my doctoral study in this paper. Although other doctoral students share such deliberations, I brought the debate into the open in a more accessible way than via thesis repositories. In her published review of this paper Topping\textsuperscript{645} says that at an individual level this personal account brings into view the challenge and bricolage of:

\begin{quote}
...achieving the right balance between locating the researcher and how they see the world in the pursuit of transparency and data-driven constructions of grounded theory… (p.464)
\end{quote}

Rather than remain purely introspective, this paper also explored the philosophical roots of evidence-based nursing practice and grounded theory. I believed it important to clarify the ambiguity that existed between the terms constructivist and constructionist grounded theory. By doing so, I made a further contribution to the qualitative research literature.

In chapter four the manuscript, \textit{Participants’ views of telephone interviews within a grounded theory study} published in the Journal of Advanced Nursing, focused upon the method I chose for generating data. While the use of semi-structured interviews is typical in a grounded theory project, using the telephone to conduct them is not. I had identified limited evidence regarding qualitative interview by telephone and chose to challenge the assumption that face-to-face is the most appropriate method for semi-structured interviewing. Using data from participants in the CPAP study, I demonstrated that it is unnecessary to relegate the telephone to second best status as a data collection tool in grounded theory and other qualitative research. The reviewers agreed that the manuscript provided “insight into an untapped avenue of data collection that might provide ideas for future research practice and methodological debate in qualitative research, especially as applied in health sciences.” Reviewer comments included “this paper raises a useful point in relation to assumptions made in designing research involving interviews.” Reviewer one added that the tabulated guideline for telephone interviews provided in the article made the article important for qualitative research methodology.

Chapter five addressed the primary focus of this thesis, namely to understand how users experience using CPAP and to construct a theory explaining how CPAP-users live with the therapy. I argued that understanding how users successfully manage CPAP is necessary in order to understand how to help those who are less successful with therapy. In my view, people who succeed with the integration of CPAP in daily life have significant expertise in the use of this therapy. Chapter five drew upon sixteen participants’ expertise with CPAP to contribute new knowledge to the medical literature and from which the health community can learn.

Incorporated into the findings chapter are two manuscripts currently under review for publication. The first manuscript, \textit{Becoming a team for good-sleep}, clearly identifies the partner of a CPAP-user as integral to the process of managing CPAP well. Sleep medicine research has not engaged with the role of the partner in the use of CPAP, and this paper reveals that the teamwork of a close relationship optimises CPAP use. The second paper, \textit{Making choices about CPAP}, describes the second main category and endorses the process of individual choice-making in CPAP use. I argue that individuals have the capacity to make choices and be active, reasoned decision-makers in their
healthcare. Therefore, findings from this study provide new evidence to support opportunities for patients to collaborate fully in decision-making about using CPAP, and in the broader context of healthcare. Additionally, the final main category becoming used to CPAP, presented in chapter five, provides evidence to support the concept of embodiment of CPAP as part of self. Accordingly, this thesis provides a unique explanation of how users achieved mastery of CPAP, which represents the end of the process explained by bargaining and balancing life with CPAP.

The discussion chapter highlighted that although non-compliance with CPAP has been explored using cognitive behavioural models, successful use of CPAP has not. I applied a variety of theories in the absence of one comprehensive, overarching theory to account for the entirety of bargaining and balancing life with CPAP, demonstrating that the current research provides a unique contribution to theory and sleep medicine literature. Once constructed, the substantive theory of bargaining and balancing had resonance with participants and colleagues who heard it described or provided critique on the theory model in Figure 12 (see p.98). Using various extant theories further strengthens elements of my findings and the theory of bargaining and balancing, and corroborate the components of successful CPAP use identified in this study. This corroboration supports the recommendations for further research outlined in the following sections. Supporting the use of CPAP, and of other long-term therapies, is important for the health and well-being of individuals and communities. Acknowledging the bargaining and balancing process can facilitate the development of interventions and targeted support models, to support successful living with CPAP. Moreover, there is scope for transferability of the theory and findings reported in this thesis to other long-term conditions.

7.3. Strengths and limitations

The previous section details the new knowledge contributed by this study. However, it is important to acknowledge the limitations inherent in any research project. Throughout this study, I have adhered to the recognised principles of grounded theory, as outlined and illustrated by chapters three, four and five. Accordingly, findings from the study are grounded in the data and resonate with other studies in the fields of aging and chronic conditions, and with experts in the field and colleagues from outside healthcare. Nevertheless, as with any study a variety of factors influenced the research process and had the potential to influence the outcome. For example, ethical requirements determined that participants self-select, and those who declined might have offered data leading to an alternate interpretation. Similarly, my interpretation of the data in this project is unique to me. Another grounded theorist may have constructed an alternative theory. Other influencing factors include my position as an emerging researcher, the recruitment process, the use of grounded theory and the context of this study. I will discuss each of these factors in turn.

As an emerging grounded theorist, I refined my interview and research skills as the project progressed. Being research naïve proved an advantage at times, as I was unaware of extant theoretical concepts that may have forced the data. However, returning to early transcripts through constant comparison drew attention to participant cues missed during initial interviews. During later
interviews, I was able to improve the depth of data generated. Early analysis felt slow until I gradually learned to conceptualise the data, to work out how to memo effectively and to grapple with concepts such as theoretical sensitivity and theoretical sampling. Consequently, I have developed skills that will serve me as I continue with future research.

I obtained ethical approval to recruit for the study through a local respiratory clinic, and early recruitment was unproblematic. However, obtaining approval to recruit from a single site limited my options during theoretical sampling and slowed the research process. The clinic I had permission to recruit from facilitated a number of other studies during the later stages of my research, and after my inclusion criteria became more specific. For example, I wished to interview a CPAP-user under the age of 30 years to gain a younger person’s perspective, in contrast to those already interviewed. Charmaz advises that when seeking study approval, avenues for recruitment should be as flexible as possible to account for the needs of theoretical sampling. Eventually, I achieved my recruitment goal. However, due consideration of the need to recruit more broadly, for example from non-healthcare settings such as local churches or community groups, would have provided greater flexibility during theoretical sampling.

Grounded theory is a well-recognised qualitative research method with established principles; the primary focus is to construct theory relevant to the studied topic. Therefore, findings were limited to what participants reported about their specific set of circumstances, which was using CPAP for sleep apnoea in New Zealand. This study was conducted in one region of New Zealand with participants recruited via one respiratory clinic. CPAP treatment is government-funded in New Zealand, unlike the United States for example, which may influence how it is experienced in other user-pays locations. Therefore, extending this study to other geographical areas within New Zealand and internationally is warranted. I detail this and other recommendations in the next section.

7.4. Recommendations for practice, policy, research and education

In addition to the recommendations detailed in the five articles included in this thesis, recommendations for the application of study findings to practice and policy, education and future research are as follows.

7.4.1. Practice and Policy

In my view, the foremost finding of this study is how necessary partners are to the process of becoming used to CPAP. Although partners and close family members are not excluded from treatment planning, currently they are not formally invited as part of the process. Therefore, recommendations for practice and policy are:
Engage designated partners during the healthcare process and planned treatment regimen by formally inviting participation.

Mandate through policy related to the treatment of sleep apnoea that designated partners of patients be formally invited to sleep clinic appointments.

I have argued for the support of CPAP-users as active decision-makers in their care and for aligning treatment regimens with the principles of patient- and family-centred care. Therefore, further recommendations include:

- Establish concordance between patient preferences and treatment offered.
- Provide information targeted to the individual regarding sleep apnoea and CPAP to support decision-making.
- Match supportive interventions to what the patient says suits their circumstance.
- Consider the use of patient decision-aids to support personal motivating factors, identified by CPAP-users, to optimise choices regarding therapy use.

7.4.2. Education

The article in chapter three provided recommendations related to education practice during doctoral study. Additional recommendations for patient education regarding use of CPAP are:

- Acknowledge to the patient that using CPAP can be challenging, but that persevering can yield positive results.
- Consider use of patient education resources that draw upon the experiences and advice of other CPAP-users.
- Consider the use of patient support groups or a buddy system where an experienced CPAP-user is available to provide advice to a novice CPAP-user.

In terms of clinician education regarding CPAP:

- Incorporate evidence drawn from the users’ perspective in training programmes related to CPAP treatment for sleep apnoea, where this does not already occur.

7.4.3. Research

Recommendations on the use of the telephone for qualitative interview are provided by the article in chapter four. Additional recommendations for future research regarding use of CPAP for sleep apnoea are to:

- Shift the emphasis of research from the assumption that CPAP is inherently problematic for all users by broadening the focus of studies to include successfully managing CPAP rather than solely improving adherence.
- Further explore and confirm factors necessary for success with CPAP identified in this study using multi-centre international qualitative studies.
• Conduct quantitative multi-centre studies with larger sample sizes to further explore factors necessary for success with CPAP identified in this study.
• Explore the significance of partner and family engagement with the CPAP-user, and the role of partners in the successful management of CPAP at home.
• Build on this study with qualitative studies using informant populations different to this study, including young and /or single participants.
• As data drawn from this study shows, it is important to more comprehensively involve CPAP-users and their families in the development of assessment and research tools, such as cognitive interviewing techniques and decision aids.
• Develop the sparse evidence regarding the use of decision aids in sleep medicine.
• Examine the efficacy of targeted and tailored interventions that support patient decision-making when choosing CPAP.
• Further explore the influence of stigma on CPAP use.
• Corroborate the transferability of the bargaining and balancing process to other areas of long-term conditions.
• Explore the transferability of recommendations from this study to other long-term conditions.

7.5. Reflections on learning

Undertaking a Ph.D. is to train as a researcher and I feel that I have developed the skills necessary to conduct subsequent projects as an emerging researcher. However, my learning has been far more than that.

A popular competency based learning model describes learning a new skill in four stages of competence: unconsciously incompetent, consciously incompetent, consciously competent and unconsciously competent. The purpose of a Ph.D. is to complete a research apprenticeship, and this thesis represents a four-year transition from having little knowledge of being a researcher, and being unconsciously incompetent, to being a consciously competent grounded theorist. I found the grounded theory process creative, dynamic and exciting, but also wondered if I would ever fully ‘get it.’ Would I ever grasp coding or theoretical saturation, or know if I had a theory? Technical texts along with grounded theorist colleagues gave assurance that I would know once I had a central social process because I would suddenly see it “appear frequently in the data.” Although a number of such epiphanies occurred throughout the research process, I feared I would never be able to integrate the data into a coherent whole. However, once identified, the idea of bargaining and balancing was “hard to resist” and I saw the process everywhere. At this point I began to believe I could be a consciously competent grounded theorist. A colleague advised that completing a Ph.D. was an endurance event, that learning the skills to finish required tenacity, determination and perseverance not unlike getting used to CPAP. Despite despairing at times that I would ever grasp the concepts necessary to complete this project, I have learned how to do grounded theory and that I have tenacity, determination and perseverance. I now aspire to the stage of being ‘unconsciously competent’ as a grounded theorist.
Similarly, I aspire to becoming unconsciously competent as a writer. Learning to do grounded theory has been a delight, and being immersed in the process and philosophies stimulating. However, learning to write competently both academically and for publication has been a significant challenge. Learning how to write coherently has been frustrating. Over time, fewer amendments have been required on work reviewed by my supervisors. While there remains room for improvement, I believe I have finally managed to develop the skills of an emerging writer.

Joining a grounded theory discussion group at the start of this project has also taught me the importance of peer support with a group of like-minded scholars. Joining the group four years ago revealed the inadequacy of my grounded theory knowledge, and I said little. However as I grew in confidence I was able to offer my work for critique and benefit from the group’s collective knowledge. This year I realised, as the more ‘senior’ members of the group completed their studies and left, that I am now one of the ‘senior’ members and have contributions to make. Indeed, I have been startled to hear my own voice answer questions for newer members of the group. Given the importance of this group to my learning, I intend to continue to contribute to the group once this thesis is complete.

Finally, I have learned about the generosity and willingness of participants to support research and to trust me with the intimate details of their lives. Without them, this thesis would not have happened, and I hope I always remember the lesson never to take their participation for granted.

7.6. Chapter 7 Summary

By re-visiting the research aim, this concluding chapter has reminded the reader why I chose the project and demonstrated how I achieved the aim. Drawing upon the content of each chapter has demonstrated the contributions of this thesis to new knowledge. Reviewers’ comments on published, under review and in press articles provide additional evidence to support the construction of new knowledge from this study. I acknowledged the limitations of the study and provided recommendations for practice, policy, education and research. The thesis has highlighted the importance of viewing people as reasoned decision-makers in their healthcare and capable of succeeding with CPAP for sleep apnoea. Findings demonstrate the importance of viewing the individual as part of a family and raises important considerations for the inclusion of people in healthcare decisions regarding CPAP use. Therefore, the thesis has the potential to make an important contribution to improving the quality of care in sleep medicine and for the increased uptake of CPAP. Indeed, this project has supported the argument that if providing healthcare and conducting healthcare research is about the patient, then it should also involve the patient and include their family.

“Nothing about me, without me.”

649-652
References


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401. Mottram A. "They are marvellous with you whilst you are in but the aftercare is rubbish": a grounded theory study of patients’ and their carers’ experiences after discharge following day surgery. J Clin Nurs [Internet]. 2011 [cited 2014 Aug 28]; 20(21-22):3143-51. Available from: http://dx.doi.org/10.1111/j.1365-2702.2011.03763.x


556. Ward K, Hoare K, Gott M. Becoming a good-sleep team: findings from a grounded theory study about living with CPAP. Under review.


Appendix 1. Ethics application and approval forms

Appendix 1.1. National application form for the ethical approval of a research project

NATIONAL APPLICATION FORM FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

Part 1: Basic Information

1. Full project title (include protocol number if applicable)
   Non-invasive ventilation: the patients’ perspective. A study to explore the patients’ experiences of Continuous Positive Airway Pressure (CPAP) therapy.
   Ethics Number: NT/11/06/46  
   ADHB RRC number: 5120

2. Short project title (lay title)
   Night time CPAP: the patient’s experience.

3. Principal investigator’s name and position
   Kim Ward  
   Nurse Educator NETP Coordination & Workforce Development ADHB  
   & University of Auckland Masters Nursing student.

4. Contact address of principal investigator
   Nursing Development Unit,  
   Level 15, Support Building,  
   Auckland Hospital  
   Private Bag 92 021 Grafton
   Work phone no. 09 630 9943 ext. 23378  
   Emergency no.* 021 405 081  
   Fax +64 9 375 4374  
   Email kward@adhb.govt.nz

5. Principal investigator’s qualifications and experience in the past five years (relevant to proposed research)
   The Principal investigator is Kim Ward, RGN with Post Graduate Diploma in Health Sciences: Advanced Nursing, conferred June 2005, by the University of Auckland. This proposal is being conducted for a Thesis to complete a Nursing Masters Degree with the University of Auckland.
   Aug 2006 – Present: Nurse Educator: Graduate Nurse Coordination & Workforce Development ADHB  
   Mar 2006 – Sept 06: Facilitator for PG paper NRSNG 710 (Respiratory Specialty paper) University of Auckland
Appendices

6. Co-investigator's name(s), qualifications and position(s) and, if more than one locality, principal investigator at each locality

A
None

B

C

D

E

F

G

7.1 Address of A above

Work phone no.

Emergency no.*

Fax

Email

8. Where this is supervised work

8.1 Supervisor's name

Position

Daytime phone number

Professor Meryn Gott

Professor of Health Sciences & Director of Research
- The University of Auckland

(09) 923 1655

m.gott@auckland.ac.nz

8.2 Signature of supervisor (where relevant)

Declaration: I take responsibility for all ethical aspects of the project

9. List locality organisations involved, including contact address, and complete the locality assessment in Part 4: Declarations (refer to the Guidelines (NAFG-2009-v1))

Auckland Hospital,
Park Road
Private Bag 92.024 Grafton, Auckland

10. I wish the protocol to be heard in a closed meeting.

Yes  No

If the answer is yes, please provide a reason why you wish the protocol to be heard in a closed meeting in accordance with the Official Information Act 1982.

- 

11. If the study is based, in part or in full, overseas, which countries are involved?

- 

12. Has this application been reviewed by another ethics committee in New Zealand or overseas?

Yes  No

(if yes, advise which country, the name of the committee(s) and the decision(s) of the committee(s))

Please note a copy of the report(s) may be requested.

- 

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13. Human tissue – Does the project involve collection or use of human tissue? If yes, complete Part 5.
   - Yes □ No □

   - Yes □ No □

15. Xenotransplantation – Does this research involve the transplantation of living biological material from one species to another? If yes, complete Part 7.
   - Yes □ No □

10. Consent – Are all participants able to provide consent for themselves? If no, complete Part 8.
   - Yes □ No □

17. Lay summary – give a brief lay (non-technical) summary of the study (not more than 200 words) such as you would give as an explanation to participants.

   This study aims to explore patient perspectives about the experience of using non-invasive ventilation (NIV) therapy in the form of continuous positive airway pressure (CPAP) via nasal or face mask for obstructive sleep apnoea.

   A large body of research has explored the reasons for a patient’s use or refusal to use their CPAP therapy and looked at interventions to aid the person in their use of this therapy (Sawyer, 2007; Smith, Lasserson, & Haniffa, 2004). In these studies however, people were not asked directly about their experience of CPAP or for their thoughts on how delivery could be improved. Equally, how this therapy affects home and social life and whether these factors influence compliance were not explored.

   To develop a deeper understanding of a patient’s experience of non-invasive ventilation CPAP therapy participants will be interviewed via the phone to allow them to describe their own experience of CPAP therapy in obstructive sleep apnoea. The participants will be between 6 weeks and 6 months into their therapy. Themes will be developed from patient accounts to provide a picture of their collective experiences of this therapy.

18. Proposed starting date (dd/mm/yyyy)
   - 01 August 2011

19. Proposed finishing date (dd/mm/yyyy)
   - 06 March 2012

20. Duration of project in New Zealand (mm/yyyy)
   - 8 months

21. Proposed final report date (mm/yyyy)
   - 26 November 2012

22. Has the clinical trial been registered?
   - Yes □ No □
   If yes, name the register.
   
   If no, has registration been applied for?
   - Yes □ No □
   Comment:
   Not Applicable
Appendices

Part 2: Ethical Principles

A. Validity of research

Operational standard paragraphs 53–59

Scientific basis

A1. Aims of the project

A1.1 What is the hypothesis/research question(s) and/or the specific aims of the project? (State briefly.)

Comment:
The aim of the project is to explore patient perspectives about the experience of using non-invasive ventilation (NIV) therapy in the form of continuous positive airway pressure (CPAP) via nasal or face mask for obstructive sleep apnoea.

A2. Scientific background of the research

A2.1 Has this project been scientifically assessed by independent review?

☐ Yes ☐ No

If yes, describe the process, for example, HRC funding assessment process. A copy of the report should also be attached. The researcher’s response may also be included.

This project has been reviewed by my supervisor Professor Merryn Scott and via the ethics advisor during the University of Auckland School of Nursing review process.

If no, do you intend to have the project scientifically assessed and by whom?

This project is under locality review via the ADHB research review committee.

A2.2 Describe the scientific basis of the project (300 words maximum). Where this space is inadequate, continue on a separate sheet of paper. Do not delete page breaks or renumber pages.

Non-invasive ventilation (NIV), a recognised therapy for respiratory disturbances since the 1950s, is now used successfully as a therapy for breathing difficulties during respiratory insufficiency and obstructive lung diseases including obstructive sleep apnoea (OSA) (W. Ward Flemons, 2004; Girault et al., 1997; Liesching, Kwok, & Hill, 2003; Mohsenin, 2001; Peppard, Young, Patla, & Skatrud, 2000; Ram, Picot, Lightowler, & Wedzicha, 2004; Riha, Engleman, Douglas, & Naughton, 2009; Shahar et al., 2001; Stradling, Pepperell, & Davies, 2000; Sullivan, Berthon-Jones, Issa, & Eves, 1981). OSA affects up to 4% of men and 2% of women in New Zealand and results from repetitive narrowing or complete obstruction of the upper airway (Partinen, 1995; Young et al., 1993). This leads to oxygen desaturation, brief arousal from sleep with associated surges in blood pressure resulting in daytime sleepiness and associated negative effects on health and quality of life (W. Ward Flemons, 2004; W. W. Flemons & Reimer, 2002). OSA is associated with obesity, the cardiac sequelae of cerebrovascular disease, and has been implicated as an independent risk factor for hypertension and accidental trauma (W. Ward Flemons, 2004; P. Gander, Scott, Mihaere, & Scott, 2010; Mohsenin, 2001; Smeltzer & Bare, 2003; Stradling et al., 2000). The purpose of CPAP therapy in OSA is relief of respiratory dysfunction so decreasing the workload on the heart. Relief of symptoms such as hypertension, sleepiness, and improved quality of life also empower the person to a more productive lifestyle and increase the likelihood of successful weight loss.
Despite this, there is evidence that compliance with this therapy is often poor (Smith et al., 2004). Past research has explored the reasons for a patient's use or refusal to use their NIV therapy and looked at interventions to aid the person in their use of the therapy (Beecroft, Zanon, Lukic, & Hanly, 2003; W. Ward Flemons, 2004; W. W. Flemons & Reimer, 2002; Sawyer, 2007; Stepnowsky, Bardwell, Moore, Ancoli-Israel, &Dimsdale, 2002; Terri E Weaver et al., 1997; Terri E. Weaver et al., 2003; Wild, Engleman, Douglas, & Espie, 2004). In these studies however, patients were not asked directly about their experience of CPAP or for their thoughts on how delivery could be improved. Equally, how this therapy affects home and social life and whether these factors influence compliance were not explored (Sawyer, 2007). In considering specific interventions to study past researchers have needed to make assumptions on what the patient would think and feel about having obstructive sleep apnoea and using the night time CPAP mask in its various forms. In this study no assumptions are made, rather it is an opportunity to uncover what the patient really thinks and feels and what their motivations are in the use of this therapy. Since the patient's experience is key in this study Glaser & Strauss' (1967)(1967) qualitative method of grounded theory is most obvious as a means to explore, discover and develop a deeper understanding of patients' experiences with CPAP and so develop an explanatory framework for their experience. (Charmaz, 2000; Corbin & Strauss, 2008; Glaser & Strauss, 1967; A. L. Strauss & Corbin, 1997).

A3. Study design

A3.1 Describe the study design. Where this space is inadequate, continue on a separate sheet of paper. Do not delete page breaks or renumber pages.

Semi-structured telephone-administered interviews will be used during the sixth week to sixth month of prescribed CPAP therapy to explore and gain understanding of each patient's view. Studies have shown that patients begin non-adherence to therapy as early as the fourth day (Terri E Weaver et al., 1997). Therefore this timeframe will allow for patient experiences of starting this therapy to be fresh, yet still have had time to develop a clear understanding of perspectives around their use of CPAP with any difficulties already identified by the patient along with possible coping strategies. Each interview will be of 30 to 60 minutes duration. Via the constant comparative methodolgy of grounded theory transcribed text from interviews will be coded by the investigator into categories leading to summary themes to develop an explanatory framework (Charmaz, 2006; Pope, van Royen, & Baker, 2002; Pope, Ziebland, & Mays, 2000; Thomas, 2002).

Patients will be sourced from the Respiratory Service Sleep Clinic at Auckland District Health Board. With the assistance of the Respiratory Service Sleep Service Physiologist patients meeting the inclusion criteria will be identified prior to their Sleep Clinic appointment. At the time of their clinic appointment they will be given information about the study and invited to participate. (Please refer to attached Letter of Invitation, Participant Information sheet and Consent From / Rely Slip.)

It is anticipated that 10 to 15 individuals may be included in the study.

A4. Participants

A4.1 How many participants do you intend to recruit? (Include details for each locality organisation.)

The sample size in this grounded theory study is that required to obtain theoretical data saturation where no new information is being uncovered in each of the derived categories (Charmaz, 2006; Patten, 2002). It is anticipated that up to but not limited to 15 individuals may be included in the study. This is a typical sized sample for a qualitative study (Charmaz, 2006; Stake, 1990; Thomas, 2002). Note that this number may increase if the data gathered has not fully saturated the categories.
A4.2 Give a justification for the number of research participants proposed, giving the details of power calculations when appropriate.

As for A4.1.

As all cultures, social groups and each gender is affected by obstructive sleep apnoea the cultural, social and gender mix of the sample group remains unknown as no patient will be excluded based on these factors. Anecdotal evidence provided by the Respiratory Service team suggests that there will likely be an over representation of Māori and Pacific Island peoples, though their patient demographic has changed significantly since Counties Manukau DHB regained access to their region’s sleep patients (Whyte, 2011). Prior to this it is estimated that approximately 40% of the patients seen were Māori or Pacific Island people. This is now estimated to be around 25 - 30% (Whyte, 2011). A 1998 New Zealand study outlined the presentation of the Māori and PI groups at sleep clinic were roughly one third Māori and PI to two thirds New Zealand European (Baldwin et al., 1998). Demographic data suggest that the gender mix will be predominantly male (Ministry of Health, 2008b, 2010; Ministry of Health Clinical Trials Research Unit, 2009).

A4.3 If randomisation is used, explain how this will be done.

Not Applicable

A5. Statistical method

A5.1 Is the method of analysis quantitative?

☐ Yes ☐ No

Or qualitative?

☐ Yes ☐ No

If the method of analysis is wholly qualitative, go to question A5.4. If the method of analysis is wholly or partly quantitative, complete the following:

A5.2 Describe the statistical method that will be used to analyse the data.

-

A5.3 Has specialist statistical advice been obtained about this study?

☐ Yes ☐ No

If yes, from whom? (A brief statistical report should be included if appropriate.)

A5.4 If the method of analysis is wholly or partly qualitative, specify the method. Why is this method appropriate? If interviews are to be used, include the general areas around which they will be based and a copy of the interview guide, if one is to be used. Copies of any questionnaires that will be used must be included.

A lot of information is available in the literature around the use of interventions to improve the patient experience of CPAP (Beecroft et al., 2003; W. Ward Fiimens, 2004; W. W. Fiemons & Reimer, 2002; Sawyer, 2007, Smith et al., 2004; Stepnowsky et al., 2002; Terri E. Weaver et al., 1997, Terri E. Weaver et al., 2003; Wild et al., 2004). However little information exists on the topic of a patient’s experience using CPAP. As a result very little material is available on which to base a questionnaire. In considering specific interventions to study past researchers have needed to make assumptions on what the patient would think and feel about having obstructive sleep apnoea and using the night time CPAP mask in its various forms. In this study no assumptions are made; rather it is an opportunity to uncover what the patient really thinks and feels and what their motivations are in the use of this therapy. Since the patient’s experience is key in this study the qualitative method of grounded theory is most obvious as a means to explore and develop a deeper understanding of patients’ experiences with NIV and an explanatory framework for their experience (Charmaz, 2006). Grounded theory allows the investigator to remain “grounded” in the data – the patients’ story. The intent is to retain the integrity of their story without the addition of the investigator’s preconceived ideas of what their story includes. For example, where a brief literature review on health beliefs occurred prior to undertaking this study a full in depth review would be undertaken only after the data analysis to prevent confounding bias which may cause the investigator to inadvertently lead patient responses during the interviews (Charmaz, 2006; Glaser & Strauss, 1967; McCann & Clark, 2003). The point is to skillfully persuade the patient to talk about their own lives with CPAP and obstructive sleep apnoea with as little partiality from the investigator as possible.
An open-ended approach using semi-structured telephone interviews will be used starting with a general request of the participant to tell their story of what it is like needing and using NIV for obstructive sleep apnoea. The point is to skilfully persuade the patient to talk about their own lives with CPAP and obstructive sleep apnoea with as little partially from the investigator as possible. Each interview will be a guided dialogue using a few common questions to facilitate across-case analysis.

The following questions will be used to maintain direction of the interview:

- Tell me what needing CPAP means to you?
- Tell me what having obstructive sleep apnoea means to you?
- How do you explain having obstructive sleep apnoea and needing CPAP to your family?
- Tell me about your sleep time routine / what pre-occupies you during this time?
- What kind of things have you done to help yourself cope with this therapy?

Data analysis will be concurrent with the data collection. The transcribed text of each guided dialogue will be coded by the investigator. Here the constant comparative methodology of grounded theory using Charmaz’s (2003) constructivist paradigm will be used by the investigator whereby codes from each interview will be compared with codes and text from preceding interviews and sorted into categories. These categories will lead to formation of summary themes which will form a background theoretical framework to ease coding subsequent data into themes (Charmaz, 2006; Pope et al., 2000). This process will continue after data-collection finishes until no further themes emerge (Charmaz, 2005; Dempsey & Dempsey, 2000; Williams & Irrita, 1998). The summary themes will then lead to the development of an explanatory framework for the patients’ experiences (Pope et al., 2002; Pope et al., 2000; Thomas, 2002). Categories and themes derived from codes will remain grounded in the words of the patient about how this therapy affects their lives (Adams, 2010; Charmaz, 2006; Pope et al., 2002; Pope et al., 2000; Thomas, 2002).

Concurrent data collection and analysis will also allow revision and adaptation of interview questions (Dempsey & Dempsey, 2000; Glaser & Strauss, 1967; A. Strauss & Corbin, 1990). In this way grounded theory allows the investigator to elicit a wide range of information around the subject that could then be further investigated in a later study using a survey questionnaire (Dallas, Norr, Dancy, Kavanaugh, & Cassata, 2005). Once data saturation is reached no new cases will be added (Dempsey & Dempsey, 2000).

### A6. Expected outcomes or impacts of research

#### A6.1 What is the potential significance of this project for improved health outcomes?

More than 3500 New Zealanders die each year from obesity related disease, approximately ten times the annual road toll (Ministry of Health, 2003, 2004, 2010; Ministry of Health and University of Auckland, 2003; Ministry of Health Clinical Trials Research Unit, 2009; Ministry of Transport, 2011). The estimated cost of obesity is between 2-7% of a nation’s annual health budget equating to approximately $460 million for New Zealand (Ministry of Health, 2008a; WHO, 2000). These figures incorporate health care costs from obesity associated conditions including obstructive sleep apnoea (Chowdhury, Adams, & Whellan, 2010; Ministry of Health 2004). The estimated total annual societal costs of obstructive sleep apnoea for New Zealanders aged 30–60 years in 2010 were $40 million (range $33–$90 million) or $419 per case, with accidents being the major contributor (P. Gander et al., 2010). A 1998 study outlined the presentation of the Māori and Pāi groups at sleep clinic were roughly one third Māori and Pāi to two thirds New Zealand European (Baldwin et al., 1998). A national survey carried out by Mhaere et al (2009) revealed a higher prevalence of obstructive sleep apnoea among Māori and among men (Mhaere et al., 2009). It was found that Māori between the ages of 30 – 59 years were 4.3 times more likely to have respiratory disturbance index ≥ 15 (95% CI = 1.3–13.9 (2006)). Though ethnicity was not found to be an independent risk factor the prevalence of obstructive sleep apnoea syndrome (OSAS) was conservatively estimated to be 4.4% for Māori men, 4.1% for non-Māori men, 2.6% for Māori women, and 0.7% for non-Māori women. Māori were also more likely than non-Māori to report OSAS risk factors and symptoms (Baldwin et al., 1998; P. H. Gander, Marshall, Harris, & Reid., 2005, Māori Medical Practitioners Association, 2000; 2009).
Appendices

Māori and Pacific Island people make up 14% and 5.6% respectively of our New Zealand population (Ministry of Health, 2007). As Māori and Pacific Island people are over represented in mortality figures and given the societal cost of obstructive sleep apnoea this study becomes highly relevant to our communities at large and in particular to our Māori and Pacific island communities (P. Gardner et al., 2010; Ministry of Health, 2003, 2007). Improving obesity related and cardiovascular disease outcomes for Māori and our Pacific Island communities and removing inequalities between Māori and non- Māori is an important and urgent health priority (Garrett, Chen, & Taylor, 2009; Thoracic Society of Australia and New Zealand, 2004). As outlined in the Hauora: Māori Standards of Health IV and the Māori Cardiovascular Action Plan, there is substantial scope to effectively achieve cardiovascular health gain for Māori in New Zealand (Paine, Harris, & Mihare, 2007). The higher risk of developing sleep problems and the associated cardiac sequelae among Māori and Pacific Islanders suggests these peoples needs should be prioritised (Paine et al., 2007).

Exploring the personal experiences of CPAP in obstructive sleep apnoea may lead to a deeper understanding of the patients’ perspectives with CPAP therapy and in the future may become a powerful persuader in changing clinical practice to improve peoples’ experiences with CPAP and therapy and their health outcomes (Green & Britten, 1996). For the Māori and Pacific Island groups findings from this study may in the future become agent in the improvement of health outcomes for Māori and our Pacifica population (Green & Bitten, 1996). The project will advance knowledge in the care of the obstructive sleep apnoea patient in New Zealand. The findings of this study may also generate the provision of further patient education and information around aspects of their non-invasive ventilation therapy including for example, a supportive education follow up programme to facilitate understanding of their therapy. Other respiratory patients may retain enough homogeneity with obstructive sleep apnoea patients in their use of CPAP and other forms of non-invasive ventilation that findings of this study may be transferable (Dempsey & Dempsey, 2000; Stake, 1990).

A6.2 What is the potential significance of this project for the advancement of knowledge?

A literature review could identify no previous studies undertaken on this topic internationally despite its importance. The intention of this project is to provide a basis for further national and international exploration of patients’ experiences with CPAP therapy with the findings of this study informing the design of future studies. The project will advance knowledge in the care of the OSAO patient in New Zealand.

A6.3 What steps will be taken to disseminate the research results?

Data gathered from patients will be written up for publication in peer review journals in the subjects of medical, nursing and social sciences and presented at relevant national and international conferences. The findings of this study will be circulated to respiratory nursing and medical specialists locally within ADBH, regionally via the Respiratory NZNO section and via appropriate national publications and conference presentations.

A7. Publication of results

Will any restriction be placed on publication of results?  

☐ Yes  ☑ No

A8. Funding

A8.1 How will the project be funded?

The principal investigator has fees bursary scholarship from the University of Auckland to assist in the provision for data collection, analysis and report writing. All other activities will be in the investigators own time. No travel is required of the investigator or participants during data collection.

Resources required include:
- Phone interview audio recording technology & equipment - University of Auckland
- Data management computer program NVivo - University of Auckland
- Principal researcher - Own time
- Transcription - Principal researcher - Own time
- Paper, toner & photocopying/printing - ADBH
- IT equipment - ADBH
A8.2 Does the researcher, the host department, the host institution or the locality organisation have any conflict of interest, eg, financial interest, in the outcome of this research? If yes, please give details.

A9. Incentive payments

A9.1 Have you read and understood the description of incentive payments in the Guidelines?  

Note: Details about any payment (in money or kind) or reward made to participants recruited into the project are to be provided in question E10.

A9.2 Does the funding available to the project depend upon the number of participants recruited, eg, is the funding on a per participant basis? If yes, give details of the amount per participant. Where there is a significant difference between these, this incentive to recruit should be declared in the information sheet.

A9.3 Does the funding available to the project include any form of incentive (in money or kind) for the early or complete recruitment of a specified number of participants, eg, bonus payments to the researcher, host department or host institution? If yes, give details.

A9.4 Will all funding available to the project be passed through an audited research account or cost centre? If yes, give details. If no, specify why not.

There is no funding.

B. Minimisation of harm

(Operational standard paragraphs 60–68)

B1. How many visits/admissions of participants will this study involve? Clarify what is in addition to standard treatment. Give also an estimate of total time involved for participants.

No extra visits / admissions are required of the patient.

Each participant will be interviewed one to one via the phone. It is anticipated each interview will be of 30 to 60 minutes duration.

B2. Who will carry out the research procedures?

Principle researcher Kim Ward.

Kim is a registered nurse and will receive the appropriate training and support from her supervisor Professor Gott and relevant associates in conducting the interviews.

B3. What other research studies is the lead investigator currently involved with?

None.

B4. Where will the research procedures take place?

The patient interviews via phone will be made from Auckland City Hospital, ADHB. The patients’ will be in locations of their choice.
Appendices

B5. How do the research procedures differ from standard treatment procedures?

The patient group would not routinely participate in an interview.

B6. What are the benefits to research participants of taking part in the project?

There are no specific benefits of participation for the patients. However, previous experience shows that many patients enjoy sharing their own stories, particularly when these can contribute to knowledge and have the potential to improve practice.

B7. Describe any methods for obtaining information. Attach questionnaires and interview guidelines. (If National Health Index (NIH) information is used, see the Guidelines (NAFG-2009-v1).)

See attached with this application the following documentation:

- Letter of invitation for patients
- Information Sheet
- Consent Form & Reply slip indicating a willingness to participate in the study

Once informed consent has been obtained from the participant individuals will be phone interviewed. Data collection will be via interview over the phone and recorded using audio software. Interview via phone rather than face to face is a means to reduce the personal impact on the patient's time, exclude travel costs, and allow access to geographically dispersed patients (Holt, 2010). It may also reduce transferrance, prejudice, bias or judgement on the part of the participant or interviewer as a result of not seeing the other person's facial expressions or body language (Holt, 2010; Sturges & Hannahan, 2004). This may lead to deeper exploratory questioning around a particular comment rather than misinterpreting the meaning of a gesture, or allow the respondent to feel more relaxed and disclose sensitive information (Holt, 2010; Novick, 2008).

Indeed, intonation, hesitation and other paralinguistic cues may be more useful (Novick, 2008; Opdenakker, 2006). Cultural protocol requires that interviews will be offered in person to Maori and Pacific Island participants if they prefer with cultural support offered to Maori and Pacific Island people via He Kamaka Oranga and the Pacific Family Support Unit respectively. In this case body language will become an additional source of data rather than confound the data. As the interviewer does not speak Te Reo or Pacific Island languages all interviews will be in English, though it is acknowledged that many of our consumers are competent bilingual. As mentioned cultural support will be offered via He Kamaka Oranga and the Pacific Family Support Unit to foster culturally safe communication. The interviewer will record details around characteristics of the interview setting such as is outlined by the participant and can be heard in the background, behaviours of the respondents, length of the interview, interviewer's reaction, main themes, and the questions that provoked the strongest responses (Dallas et al., 2005). The data will then be transcribed verbatim and entered into computer program NVivo to facilitate data management (Dempsey & Dempsey, 2000).

The interview will be in the form of a guided dialogue starting with a general request of the participant to tell their story of what it is like needing and using CPAP for obstructive sleep apnoea. The point of using grounded theory in this way is to skillfully persuade the patient to talk about their own lives with CPAP and obstructive sleep apnoea with as little partiality from the investigator as possible. Guiding the interview with a few common questions will facilitate across-case analysis with the following questions for use to provide direction to the interview:

- Tell me what needing CPAP means to you?
- Tell me what having obstructive sleep apnoea means to you?
- How do you explain having obstructive sleep apnoea and needing CPAP to your family?
- Tell me about your sleep time routine / what pre-occupies you during this time?
- What kind of things have you done to help yourself manage with this therapy?

Once theoretical data saturation is reached no new cases will be added (Charmaz, 2006; Dempsey & Dempsey, 2000).
Appendices

B8. Briefly describe the inclusion/exclusion criteria and include the relevant page number(s) of the protocol or investigator's brochure.

Adults included in the study will be patients prescribed continuous positive airway pressure (CPAP) via face or nasal mask as a therapy for obstructive sleep apnoea that have become regular users, where regular can mean neither all right or every night. This group of patients will be recruited via the Respiratory Service at Auckland City Hospital (Murray, 2011; Whyte, 2011). (See attachment of support from Doctors Ken Whyte and Tim Christmas and Charge Physiologist Pru Murray.) As outlined by Dr. Ken Whyte the period of use for this group may be between one sleep cycle anywhere up to four to six hours per night of use (Whyte, 2011). Where the patient has not fully adhered to the prescribed therapy it will remain valuable to interview them as their comment will still inform the picture of patients' experience.

This patient group will be recruited from respiratory clinic from the beginning of August 2011 to the end of February 2012. They will be attending either their first medical clinic visit which usually falls around six weeks after the commencement of CPAP or a subsequent six month visit (Whyte, 2011). Some patients may be attending a clinic appointment additional to their first two and will also be invited to participate. Studies have shown that patients begin non-adherence to therapy as early as the fourth day of use (Terri E Weaver et al., 1997). Therefore recruiting patients from the six week appointment onwards will allow for patient experiences of starting this therapy to be fresh, yet still have had time to develop a clear understanding of perspectives around their use of CPAP with any challenges already identified by the patient along with potential coping strategies.

Exclusion criteria will be applied, with the following groups not receiving an invitation to participate: adults on non-invasive ventilation in intensive care environments where sedation may affect recall; patients with evidence of impaired cognitive impairment who are not able to give informed consent; patients on non-invasive ventilation via tracheostomy; patients with increased work of breathing who cannot tolerate being without NIV contraindicating prolonged verbal communication; and patients on NIV for other respiratory causes such as chronic obstructive pulmonary disease or cystic fibrosis are also excluded.

B9. What are the physical or psychological risks or side effects to participants or third parties? Describe what action will be taken to minimise any such risks or side effects.

There are no specific risks (psychological or physical) associated with taking part in this study. Though if a patient becomes upset they will be reminded that they can withdraw from the study at any time.

Decision on treatment for the patient will be made by their attending physician. Should the investigator have any concerns about the involvement of a study participant or around clinical safety for the patient, a referral to the appropriate services will be instigated with their consent. Provisions can also be made for a patient to be referred to the AHRB respiratory psychologist for debriefing should psychological distress be discovered and if desired by the patient (Fatten, 2002).

B10. What facilities/procedures and personnel are there for dealing with emergencies?

Not applicable for a qualitative/ interview based study.

B11. What arrangements will be made for monitoring and detecting adverse outcomes?

Not applicable for a qualitative/interview based study.

B12. If the study is a clinical trial, are participants to be provided with a card confirming their participation, medication and the contact phone number of the principal investigator?

- Yes   - No

B12.1 Do you intend to inform the participant's GP that their patient is a participant in this study? (If yes, consent from the participant is required.)

- Yes   - No

B12.2 Do you intend to inform the GP of all clinically significant abnormal results obtained during study conduct?

- Yes   - No
Appendices

B13. Is the trial being reviewed by a data and safety monitoring board (DSMB)?  
Yes  No

If yes, who is the funder of the DSMB?  
HRC  Sponsor  Other

If ‘Other’, please specify.

B14. What are the criteria for terminating the study?

Not Applicable

B15. Will participants be exposed to any potential toxins, mutagens or teratogens?  
Yes  No

If yes, specify and outline the justification for their use.

B16. Will any radiation or radioactive substances be used?  
Yes  No

Note: If any form of radiation is being used, please answer B16.1-B16.3. If no, go to question B17.

B16.1 How many x-rays or other procedures are planned for the purposes of this study, i.e., that are not part of standard treatment?

B16.2 Under whose licence is the radiation being used?

B16.3 Has the National Radiation Laboratory (NRL) risk assessment been completed?  
Yes  No

If yes, please enclose a copy of the risk assessment and a contact name and phone number. If no, please explain why not.

B17. Will any medicines be administered for the purposes of this study?  
Yes  No

B17.1 If yes, is Standing Committee on Therapeutic Trials (SCOTT) approval required?  
Yes  No

B17.2 Has SCOTT approval been given? (Please attach)  
Yes  No

B18. Does the study involve the use of health care resources?  
Yes  No

If yes, please specify:

Not Applicable

B19. What effect will this use of resources have on waiting list times for patients, that is, for diagnostic tests or for standard treatments?

Not Applicable
C. Compensation for harm suffered by participants

(Operational standard paragraphs 87–95)

(Refer also to Appendix 3 of the Guidelines (NAFG-2009-v1).)

C1. Will participants be treated by, or at the direction of, a registered health professional as part of the research? (Treatment includes screening, diagnosis, for definitions see the Guidelines (NAFG-2009-v1) pages 11-13.)

If no, go to section D. If yes, please answer questions C2-C5.4.

D. Privacy and confidentiality

(Operational standard paragraphs 48–56)

D1. How will potential participants be identified?

Appropriate patients will be identified with the guidance of the Respiratory Service Sleep physiologist by the Respiratory Outpatients’ Administrator prior to their clinic appointment.

This patient group will be recruited from respiratory clinic from the beginning of August 2011 to approximately the end of February 2012. They will be attending either their first medical clinic visit which usually falls around six weeks after the commencement of CPAP or a subsequent six month visit (Whyte, 2011). Those patients attending a clinic appointment subsequent to their first two will also be invited to participate. Studies have shown that patients begin non-adherence to therapy as early as the fourth day of use (Teri E. Weaver et al., 1997). Therefore recruiting patients from the six week appointment onwards will allow for patient experience of starting this therapy to be fresh, yet still have had time to develop a clear understanding of perspective around their use of CPAP with any challenges already identified by the patient along with potential coping strategies.

D2. How will participants be recruited (for example, advertisements, notices)?

Patients identified as eligible for the study will be handed a letter of invitation including an information sheet by clinic personnel during a visit to the ADHB Sleep Service Respiratory Outpatients’ clinic.

This will include a Consent Form and a Reply Slip addressed to the investigator indicating a willingness to participate and including the patient’s contact phone number.

To avoid risk of biasing sample selection, the investigator will not review the patient for inclusion until after the patient has been selected (Dempsey & Dempsey, 2000).

D3. Where will potential participants be approached (for example, outpatient clinic)? If appropriate, describe by type (for example, students).

Patients identified as eligible for the study will be handed a letter of invitation including an information sheet by clinic personnel during a visit to the ADHB Sleep Service Respiratory Outpatients’ clinic. (See D1 & 2)

D4. Who will make the initial approach to potential participants?

Refer D.1-3.

The letter of invitation will be signed by the principal investigator.

NB: Do not include information on storage and use of tissue samples and related information in the following questions. That is covered separately under Part 5.
E. Informed consent

(Operational standard paragraphs 29–43)

A participant’s informed consent should be obtained in writing, unless the procedures are not experimental and there are good reasons for not requiring written consent. If consent is not to be obtained in writing, the justification should be given and the circumstances under which consent is obtained should be recorded. Attach a copy of the information sheet and consent form provided to participants.

E1. By whom, and how, will the project be explained to potential participants?

A first introductory explanation will be provided to the patients by means of an invitation letter including a written information sheet.

Completing and returning the Consent Form and Reply Slip to the clinic administrator will indicate willingness to participate in the study. The investigator will then make contact to give the opportunity for the patient to ask questions and confirm consent. Opportunities will also be provided to ask questions about the study immediately prior to the interview.
<table>
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<tr>
<th>E2.</th>
<th>When and where will the explanation be given?</th>
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<tbody>
<tr>
<td></td>
<td>Written information outlining their potential involvement in the study in advance of their decision to participate will be given to patients at their outpatient appointment by the clinic administrator. Written informed consent will be obtained at this time. Opportunities to ask any further questions about the study will be provided at the start of each individual interview along with verbal confirmation of written consent prior to data collection.</td>
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<th>E3.</th>
<th>Will a competent interpreter be available, if required?</th>
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<tr>
<td></td>
<td>Yes ☑ No</td>
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<td>If no, why not?</td>
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<td></td>
<td>Patients that cannot understand and speak English may be excluded from the study. Clear communication may be compromised as there are no resources available to fund translation services. Note cultural support can be offered to Maori and Pacific Island participants via He Kamaka Oranga and the Pacific Family Support unit (ADHB) respectively and will include assistance with culturally safe communication and potentially interpretation services if funding can be arranged.</td>
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<th>E4.</th>
<th>How much time will be allowed for the potential participant to decide about taking part in the project?</th>
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<td></td>
<td>Participants will be handed an information sheet detailing the study, along with their initial invitation letter in advance of their decision to participate in the study. This will contain a reply slip. To express an interest in the study it will be up to them to return the slip at the outpatient appointment at which they were first recruited or at subsequent appointments. If they indicate a willingness to participate, they will then be contacted by the researcher. Participants will be encouraged to ask any questions that they might have prior to taking part in the study.</td>
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<tr>
<th>E5.</th>
<th>In what form (written, or oral) will consent be obtained? If oral consent only, state reasons.</th>
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<tbody>
<tr>
<td></td>
<td>Written consent will be obtained from participants to take part in the study at initial recruitment with an additional verbal confirmation of consent given once the potential participant has exercised the opportunity to ask further questions prior to the interview.</td>
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<th>E6.</th>
<th>If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings?</th>
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<td></td>
<td>Yes ☑ No</td>
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<th>E7.</th>
<th>Will data or other information be stored for use in a different study for which ethics committee approval would be required?</th>
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<td></td>
<td>Yes ☑ No</td>
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<th>E7.1</th>
<th>If yes, please explain how.</th>
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<th>E8.</th>
<th>Is there any special relationship between the participants and the researchers (for example, doctor/patient, student/teacher)?</th>
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<td></td>
<td>None</td>
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<tr>
<th>E9.</th>
<th>Will there be any financial cost to the participant, for example, travel and parking costs? If so, will such cost be reimbursed? (Refer to the Guidelines (NAFG-2009-v1).)</th>
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<tbody>
<tr>
<td></td>
<td>There are no anticipated financial costs to participants.</td>
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<tr>
<th>E10.</th>
<th>Will any payments be made to participants, or will they gain materially in other ways from participating in this project?</th>
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<td></td>
<td>Yes ☑ No</td>
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<tr>
<th>E10.1</th>
<th>If yes, please supply details.</th>
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F. Cultural and social responsibility

Section F enshrines two fundamental principles. They are:

i. Culturally safe research practice: Research involving participants from specific ethnic or socially identified groups (even when small numbers from each group are involved) must involve those participant groups in the research process as full participants. Where a particular ethnic or socially identified group is the principal subject of the research, there must be engagement with appropriate parties, and this process must be outlined in the application.

ii. If the research is in an area of health inequalities, then the researcher must demonstrate how the research will contribute to achieving equity of outcomes for those population groups most in need within the public good health system.

F1. Have you read the HRC booklet Guidelines for Researchers on Health Research involving Māori?

Yes  No

Relevance and responsiveness to Māori

F2. All health research conducted in Aotearoa New Zealand is of relevance to Māori. How relevant is a decision to be made by Māori. The researcher must be able to articulate the context and the relevance of the proposed research to Māori and the possible consequences for Māori health outcomes, and generally, the greater the degree of relevance to Māori, the greater the expectation of participation of Māori and hence consultation expectations.

F2.1 Given your approach to sampling, what are the anticipated numbers of Māori participants?

As all cultures, social groups and genders are affected by obstructive sleep apnoea the cultural, social and gender mix of the sample group remains unknown. Where this study is not targeting Māori patients there may be some Māori patients in the study. Māori patients will not be excluded from the study.

Anecdotal evidence provided by the Respiratory Service team suggests that there may be an over representation of Māori and Pacific Island peoples, though the ADHB Sleep Service patient demographic has changed significantly since Counties Manukau DHB secured access to their own region’s sleep patients (Whyte, 2011). Prior to this it is estimated that approximately 40% of the patients seen by the ADHB Sleep Service were either Māori or Pacific Island. This is now estimated to be around 25% (Whyte, 2011).

Good governance, (Article one of the Treaty) carries a guarantee, not only of upholding the Crown’s Treaty Obligations, but also of providing Governance that does not disadvantage Māori (Te Puni Kokiri 1998) and does not provide inferior levels of service or policy advice, nor base its policy on inferior quality of evidence or research. With this in mind, Māori shall be offered the same opportunity to participate in this project as non-Māori. Ethnicity data shall be collected on all participants with their permission.

F2.2 What is the incidence among Māori of the health issue/disability relevant to the study?

In New Zealand Māori comprise 15% of the population. A national survey carried out by Mihaere et al (2009) revealed a higher prevalence of OSA among Māori and among men. Māori between the ages of 30 - 59 years were 4.3 times more likely to have respiratory disturbance index ≥ 15 (95% CI = 1.3–13.9). Though ethnicity was not found to be an independent risk factor the prevalence of obstructive sleep apnoea syndrome (OSAS) was conservatively estimated to be 4.4% for Māori men, 4.1% for non-Māori men, 2.0% for Māori women, and 0.7% for non-Māori women. Māori were also more likely than non-Māori to report OSAS risk factors and symptoms (Māori Medical Practitioners Association, 2000; 2009).

Note the national study was conducted with people between the ages of 30 - 59 years. It is possible patients in this study will fall outside this age range.
F3. Please explain how this research will contribute to improving Māori health outcomes and reducing health inequalities for Māori.

Improving obesity related and cardiovascular disease outcomes for Māori and removing inequalities between Māori and non-Māori is an important and urgent health priority. As outlined in the Hauora: Māori Standards of Health IV and the Māori Cardiovascular Action Plan, there is substantial scope to effectively achieve cardiovascular health gain for Māori in New Zealand (Paine et al., 2007). The higher risk of developing sleep problems and the associated cardiac sequelae among Māori suggests Māori needs should be prioritised (Paine et al., 2007). Exploring the personal experiences of CPAP in OSA may lead to a deeper understanding of the patients’ perspectives with CPAP therapy. For the Māori and Pacific Island groups findings from this study may in the future become agent in the improvement of health outcomes for Māori and our Pacifica population (Green & Britten, 1998). Anticipated outcomes for Māori patients and their professional carers may include improved patient knowledge and understanding about their condition.

F4. Describe the process by which Māori have been engaged in the conception and design of the proposed research. Please identify the group(s) with which consultation has taken place and outline their stated view about the proposed research. Please attach their letter(s) of support for this specific research project.

I have discussed the study with the Associate Director of Nursing Māori Health ADHB, Lorraine Heteraka-Stevens. Mrs. Heteraka-Stevens is of Ngāti Kahui, Ngāi Tūhoe, Te Arawa decent and is available during the course of the study as cultural advisor to discuss any issues that may arise throughout the course of conducting the fieldwork.

Mrs. Heteraka-Stevens will be able to provide advice on relevance to Māori, engagement with Māori stakeholders; processes to inform Māori health development; and appropriate dissemination pathways.

F4.1 Describe any ongoing involvement the group(s) consulted have in the project.

Cultural protocol requires that interviews will be provided in person to Māori and Pacific Island participants if they prefer. As the interviewer speaks only English all interviews will be in English. Though it is acknowledged that many of our consumers are competent bilingual cultural support will be offered via He Kahurangi Ora and the Pacific Family Support Unit to foster culturally safe communication during interview.

F4.2 Describe how information will be disseminated to participants and the group(s) consulted during and at the conclusion of the research project.

A summary sheet of findings will be prepared for each patient participant and any groups consulted.

Responsiveness to ethnic peoples

F5. What other ethnic groups will be participating in this research based on your sampling frame (for example, Pacific peoples or Asian peoples)?

We anticipate representation from Pacific and Asian peoples but cannot anticipate numbers at this stage. No patients will not be excluded from the study based on ethnicity.

F5.1 Are there any aspects of the research based on participation or the relevance of the research to specific ethnic groups that might raise specific cultural issues?

If yes, please outline. If no, go to F6.

A 1998 study outlined the presentation of the Māori and Pacific Island groups at sleep clinic were roughly one third Māori and Pacific Island to two thirds New Zealand European (Baldwin et al., 1998). The proposed study therefore has as much relevance to the Pacific Island community as it does to Māori.
F5.2 How can this research contribute to reducing inequalities for ethnic peoples in the New Zealand health system?

Māori and Pacific Island people make up 14% and 5.3% respectively of our New Zealand population (Ministry of Health, 2007). As Māori and Pacific Island people are over represented in mortality figures and given the societal cost of obstructive sleep apnoea this study becomes highly relevant to our communities at large and in particular to our Māori and Pacific island communities (P. Gander et al., 2010, Ministry of Health, 2003, 2007). Improving obesity related and cardiovascular disease outcomes for Māori and our Pacific Island communities and removing inequalities between Māori and non-Māori is an important and urgent health priority (Garrett et al., 2008; Thoracic Society of Australia and New Zealand, 2004). As outlined in the Hauora: Māori Standards of Health IV and the Māori Cardiovascular Action Plan, there is substantial scope to effectively achieve cardiovascular health gain for Māori in New Zealand (Paine et al., 2007). This can also be said of our Pacific Island peoples. The higher risk of developing sleep problems and the associated cardiac sequelae among Māori and Pacific Islanders suggests these peoples needs should be prioritised (Paine et al., 2007).

Exploring the personal experiences of CPAP in obstructive sleep apnoea may lead to a deeper understanding of the patients’ perspectives with CPAP therapy and in the future may become a powerful persuader in changing clinical practice to improves peoples’ experiences with CPAP and therapy and their health outcomes (Green & Britten, 1998). For the Māori and Pacific Island groups findings from this study may in the future become agent in the improvement of health outcomes for Māori and our Pacifica population (Green & Britten, 1998).

F5.3 Describe what consultation has taken place with specific ethnic group(s) prior to the project’s development and attach evidence of their support.

This study has been discussed with Manager Pacific Health Provider Arm ADHB, Tuliana J. Guthrie. Mrs. Guthrie is of Samoan decent and is available during the course of the study as cultural advisor to discuss any issues that may arise throughout the course of conducting the fieldwork. Mrs. Guthrie will be able to provide advice on: relevance to Pacifica; engagement with Pacifica stakeholders such as the provision of a cultural support person to attend face to face interviews with the researcher; processes to inform Pacifica health development; and appropriate dissemination pathways. (Refer to attached letters of support.)

F5.4 Describe any ongoing involvement the group(s) consulted have in the project.

Cultural protocol requires that interviews will be provided in person to Māori and Pacific Island participants if they prefer. As the interviewer speaks only English all interviews will be in English. Though it is acknowledged that many of our consumers are competent bilingual cultural support will be offered via He Kamaka Oranga and the Pacific Family Support Unit to foster culturally safe communication during interview.

F5.5 Describe how you intend to disseminate information to participants and the group(s) consulted at the end of the project.

A summary sheet of findings will be prepared for each patient participant and any groups consulted.

Responsiveness to other peoples of interest

F6. Are there any aspects of the research based on participation or the relevance of the research to specific peoples of interest that might raise specific issues for such communities (for example, for prisoners, people with disabilities, people with diverse sexual identities)?

If yes, please outline.

If no, go to F7.

F7. Will the study drug/treatment continue to be available to the participant after the study ends?

F7.1 If yes, will there be a cost, and how will this be met?

F7.2 If no, why not?

F7.3 If there was a placebo arm, what will happen to these participants at the end of the study?

Note: This information needs to be included in the information sheet.
Part 3: General

Describe and discuss any ethical issues arising from this project, other than those already dealt with in your answers above.

There is potential for the information a patient discloses to be sensitive in nature. As a result should a patient become too upset to continue with the interview, they will be reminded that they can withdraw from the study at any time. Should the investigator have any concerns about the involvement of a study participant or around clinical safety for the patient, a referral to the appropriate services will be instigated with their consent. Provisions can also be made for a patient to be referred to the ADHB respiratory psychologist for de briefing should psychological distress be discovered and if desired by the patient (Patten, 2002).

Thank you for your assistance in helping us assess your project fully.

Part 4: Declarations

Full project title: Non-invasive ventilation: the patients’ perspective. To explore via qualitative enquiry the persons’ experiences of Continuous Positive Airway Pressure (CPAP) therapy.

Short project title: Night time CPAP: the patient’s perspective.

1. Declaration by principal investigator

The information supplied in this application is, to the best of my knowledge and belief, accurate. I have considered the ethical issues involved in this research and believe that I have adequately addressed them in this application. I understand that if the protocol for this research changes in any way, I must inform the ethics committee.

Name of Principal Investigator (please print): Kim Ward

Signature of Principal Investigator: ____________________________

Date: 26 April 2011 Amendments: 20 June 2011

2. Declaration by Head of Department in which the Principal Investigator is located or appropriate Dean or other Senior Manager

I have read the application, and it is appropriate for this research to be conducted in this department. I give my consent for the application to be forwarded to the ethics committee.

Name (please print): Judy Kilpatrick (Refer also Deans Cover Sheet for University of Auckland Human Subjects Ethics Committee signed by Dean School of Nursing, Judy Kilpatrick 21 04 11)

Signature: ____________________________ Institution: University of Auckland

Date: ____________________________ Designation: Dean School of Nursing, FMHS

- Where the Head of Department is also one of the investigators, the Head of Department declaration must be signed by the appropriate Dean, or other senior manager.
- If the application is for a student project, the supervisor should sign the Head of Department declaration.
- Submit a declaration by the principal investigator for each site.

3. Locality organisation approval

Locality organisation approval is being sought/is attached from the following locations:

Auckland District Health Board. Park Road, Grafton.
Locality Assessment by Locality Organisation

Refer to pages 13-15 of Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project (NAFG-2008-v1).

Locality organisation sign off

Ethics committees review whether investigators have ensured their studies would meet established ethical standards if conducted at appropriate localities. Each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.

Please note that the locality organisation may have additional requirements to be met before a study may commence at that locality.

Part One: General

To be completed by the principal investigator for this locality.

<table>
<thead>
<tr>
<th>Full project title:</th>
<th>Non-invasive ventilation: the patient's perspective. Does the drowning man like being saved? To explore via qualitative enquiry the patients' experiences of Continuous Positive Airway Pressure (CPAP) therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short project title:</td>
<td>Nighttime CPAP: the patient's experience.</td>
</tr>
<tr>
<td>Locality to be assessed:</td>
<td>ADHB</td>
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</tbody>
</table>
| Brief outline of study: | This study aims to explore patient perspectives about the experience of using non-invasive ventilation (NIV) therapy in the form of continuous positive airway pressure (CPAP) via nasal or face mask for obstructive sleep apnoea (OSA).

A large body of research has explored the reasons for a patient’s use or refusal to use their NIV therapy and looked at interventions to aid the person in their use of the therapy. In these studies however, people were not asked directly about their experience of NIV or for their thoughts on how delivery could be improved. Equally, how this therapy affects home and social life and whether these factors influence compliance were not explored.

To develop a deeper understanding of a patient’s experience with NIV CPAP therapy participants will be interviewed via the phone to allow them to describe their own experience of their OSA therapy. Using grounded theory themes will be developed from patient accounts to provide an explanatory framework for their experience.

Exploring the personal experiences of NIV in OSA may lead to a deeper understanding of the patients’ perspectives with NIV therapy and in the future may change clinical practice to improve peoples’ experiences with NIV therapy and their health outcomes. The findings of this study may be used to develop and focus patient education and information on use of non-invasive ventilation including for example, a supportive education follow up programme. Other respiratory patients may retain enough similarity with the patients in this study that the findings may be transferable.

Principal investigator (for this locality): Kim Ward

Contact details: Nurse Educator NETP ADHB & University of Auckland Masters student. Nursing Development Unit, Level 15, Support Building, Auckland Hospital Private Bag 92 024 Grafton.

09 630 9943 ext. 23378
mobil: 021 406 081  kward@adhb.govt.nz
Part Two: Locality Issues

To be completed by the principal investigator for this locality and signed by the authorised locality representative. (See the Guidelines (NAFG-2009-v1) (pages 13–15) for more information and examples.) Identify any local issues and specify how these issues will be addressed.

1. **Suitability of local researcher**
   - For example, are all roles for the investigator(s) at the local site appropriate (for example, has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?
   - Syn: Yes  No

2. **Suitability of the local research environment**
   a) Are all the resources (other than funding that is conditional on ethical approval) and/or facilities that the study requires appropriate and available (for example, is staffing adequate? Is this site accessible for mobility-impaired people where necessary)?
   - Syn: Yes  No
   b) Have all potentially affected managers of resources such as patient records, or laboratory managers been notified?
   - Syn: Yes  No

3. **Have issues such as cultural issues specific to this locality or to people being recruited at this locality been addressed?**
   - Syn: Yes  No

4. **Have the local investigator contact details and other important contact details been provided to the locality organisation for checking?**
   - Syn: Yes  No

Part Three: Declaration by locality organisation

I am authorised to complete locality approval on behalf of this locality organisation. I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the principal investigator and then the relevant ethics committee should this occur.

(Questions 1–4 at Part Two above must be completed prior to signing.)

I confirm the organisation has sufficient indemnity/insurance to compensate participants for harm that does not qualify for compensation under the Injury Prevention, Rehabilitation and Compensation Act 2001.

---

**Signature:**

**Date:**

**Name:** Dr Mary-Anne Woodnorth

**Position:** Manager Research Office

**Contact details:** 09 307 4949 Extn 23854

mwoodnorth@adhb.govt.nz

---

References


Chowdhury, M., Adama, S., & Whellan, D. J. (2010). Sleep-disordered breathing and heart failure: Focus on obstructive sleep apnea and treatment with continuous positive airway pressure. Journal of Cardiac Failure, 16(2), 184-174. 10.1016/j.cardfail.2009.06.006


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Mchsenin, V. (2001). Sleep related breathing disorders and risk of stroke. Stroke, 32(6), 1271-1276. 10.1161/01.STR.32.6.1271

Murray, P. (2011, 8th March). [Discussion and advice given by Pru Murray, (Charge Physiologist, Sleep Laboratory) regarding logistics of and support for the study 'Nighttime CPAP: the patient’s experience' from the Respiratory Service (ADHB)].


Appendices


Whyte, K. (2011, 2nd June). [Discussion and advice given by Dr. Ken Whyte, Respiratory Physician - Respiratory Service ADHB, regarding logistics of and support for the study "Night time CPAP: the patient's experience"].


# Appendix 1.2. Locality ethics application documents

**APPLICATION FORM FOR APPROVAL OF A RESEARCH PROJECT at ADHB**

<table>
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<th>Ethics Number</th>
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## Section A. General Summary

**Full project title**: Non-invasive ventilation: the patients’ perspective. To explore via qualitative enquiry the patients’ experiences of continuous positive airway pressure (CPAP) therapy.

**Short project title**: Night time CPAP: the patient’s experience.

**Principal Investigator’s name and position**: Kim Ward, Nurse Educator NETP Coordination & Workforce Development ADHB & University of Auckland Masters Nursing student.

**Physical address**: Nursing Development Unit, Level 15, Support Building, Auckland Hospital Private Bag 92 024 Grafton

<table>
<thead>
<tr>
<th>Work phone No.</th>
<th>Emergency No. *</th>
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<th>E-mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>09 630 9943 ext. 23378</td>
<td>021 406 081</td>
<td>+64 9 375 4374</td>
<td><a href="mailto:kward@adhb.govt.nz">kward@adhb.govt.nz</a></td>
</tr>
</tbody>
</table>

**ADHB Co-investigator names and addresses**: 1. None

**Coordinator name**: None

**Contact details for communication if not via Principal Investigator or coordinator**

**Contact name**: Merryn Gott - Professor of Health Sciences & Director of Research Masters Thesis Supervisor to Principal Investigator

**Contact details**

<table>
<thead>
<tr>
<th>Work phone No.</th>
<th>Emergency No. *</th>
<th>Fax</th>
<th>E-mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>(09) 923 1655</td>
<td>+64 9 367 7158</td>
<td></td>
<td><a href="mailto:m.gott@auckland.ac.nz">m.gott@auckland.ac.nz</a></td>
</tr>
</tbody>
</table>

**ADHB Contact name (Required for non-ADHB researchers)**

**Contact details**: Researcher is ADHB employee carrying out the research as a University of Auckland student.

**Signature**

<table>
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<th>Work phone No.</th>
<th>Fax</th>
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</table>

**Scientific Review Documents Attached**: Yes

**Conflict of Interest**: None

**Describe**: This project has been reviewed by my supervisor Professor Merryn Gott and via the ethics advisor during the University of Auckland School of Nursing research review process. This project is also under full review by the National Ethics research review committee (copy of form attached).
## Section B: Proposed Research

### Brief Abstract

This study aims to explore patient perspectives about the experience of using non-invasive ventilation in the form of continuous positive airway pressure (CPAP) via nasal or face mask as therapy for obstructive sleep apnoea (OSA).

Little evidence exists of the patients' voice in the literature when considering the impact of CPAP and obstructive sleep apnoea in their lives (1). Indeed most data available is positivist and related to interventions to improve compliance with prescribed mask ventilation therapy for obstructive sleep apnoea (1-9). In past studies people were not asked directly about their experience of CPAP or for their thoughts around if or how their experience could be improved. Equally, how this therapy affects home and social life and whether these factors influence the patient experience were not explored. Where we know, for example, compliance to be an issue, to gain an understanding of why this might be we must first see this in context by exploring and seeking to understand the patient's whole experience.

To develop a deeper understanding of a patient’s experience with CPAP participants will be interviewed via the phone to allow them to describe their own experience of their OSA therapy. Using grounded theory themes will be developed from patient accounts to provide an explanatory framework for their experience (10, 11).

Exploring the personal experiences of CPAP in OSA may lead to a deeper understanding of the patients' perspectives with this therapy and in the future may change clinical practice to improve peoples' experiences with NIV therapy and their health outcomes (12). For example the findings of this study may be used to develop and focus patient education and information on use of non-invasive ventilation, or to develop a supportive education follow up programme. Other respiratory patients may retain enough homogeneity with the patients in this study for the findings to be transferable (13, 14). Additionally it is hoped that data from this qualitative enquiry will provide complementary information to offer different aspects of approach for subsequent qualitative and quantitative research on this topic (15, 16).

### Research Design

<table>
<thead>
<tr>
<th>Research Design (max 4 pages)</th>
<th>Much information is available in the literature around the use of interventions to improve the patient experience with CPAP (1-9). However little information exists on the topic of patient point of view on using CPAP. As a result very little material is available on which to base a questionnaire as might be employed with a quantitative study. In considering specific interventions to study past researchers have needed to make assumptions on what the patient would think and feel about having obstructive sleep apnoea and using the night time CPAP mask in its various forms. In this study no assumptions are made; rather it is an opportunity to uncover what the patient really thinks and feels and what their motivations are in the use of this therapy. Since the patient’s experience is key in this study Glaser &amp; Strauss’ (1967) qualitative method of grounded theory is most obvious as a means to explore, discover and develop a deeper understanding of patients’ experiences with CPAP (11, 17-19). Grounded theory allows the investigator to remain ‘grounded’ in the data – the patients’ story. The intent is to retain the integrity of their story without the addition of the investigator’s preconceived ideas of what their story includes. For example, where a brief literature review on health beliefs occurred prior to undertaking this study a full in depth review would be undertaken only after the data analysis to prevent confounding bias which may cause the investigator to inadvertently lead patient responses during the interviews (10, 11, 20). The point is to skilfully persuade the patient to talk about their own lives with CPAP and obstructive sleep apnoea with as little partiality from the investigator as possible. Here the constant comparative methodology of grounded theory using Charmaz’s (2003(21)) constructivist paradigm will be used by the investigator whereby transcribed text from each interview will be coded into categories, categories from each subsequent interview will be compared with the categories from previous interviews and then interpreted to form summary themes and progress on to develop an explanatory framework of the patients’ experiences (10, 15, 22-24).</th>
</tr>
</thead>
</table>
Adults included in the study will be recruited via the Respiratory Service at Auckland City Hospital (25, 26). (See attached letter of support from Dr. Ken Whyte and Charge Physiologist Pru Murray.) Participants will be patients prescribed continuous positive airway pressure (CPAP) via face or nasal mask as a therapy for obstructive sleep apnoea that have become regular users, where regular can include not all night or not every night. As outlined by Dr. Ken Whyte the period of use for this group may be between one sleep cycle anywhere up to four to six hours per night of use (25). Where the patient has not fully adhered to the prescribed therapy it will remain valuable to interview them as their comment will still inform the picture of patients’ experience. Though it may come up during the interview it is not imperative for the researcher to have prior knowledge of whether the patient has or hasn’t adhered to therapy as exploring specifically this issue is not the purpose of this study. Equally as this study explores the patient experience from their view not how the health sector measures their experience researcher knowledge on the patients’ quality of life scores such as the Epworth sleepiness score is also not essential though again it may be discussed during interview.

This patient group will be recruited from respiratory clinic from the beginning of August 2011 to the end of February 2012. They will be attending either their first medical clinic visit which usually falls around six weeks after the commencement of CPAP or a subsequent six month visit (25). Those patients attending a clinic appointment subsequent to their first two will also be invited to participate. Studies have shown that patients begin non-adherence to therapy as early as the fourth day of use (4). Therefore recruiting patients from the six week appointment onwards will allow for patient experiences of starting this therapy to be fresh, yet still have had time to develop a clear understanding of perspectives around their use of CPAP with any challenges already identified by the patient along with potential coping strategies.

Research Design (max 4 pages)
The sample size in this grounded theory study is that required to obtain theoretical data saturation where no new information is being uncovered (27). It is anticipated that up to but not limited to 15 individuals may be included in the study. This is a typical sized sample for a qualitative study (10, 13, 22). Note that this number may increase if the data gathered continues to provide new themes. Once no new themes are emerging from patient interviews then no further patients will be recruited. As all cultures, social groups and each gender is affected by obstructive sleep apnoea the cultural, social and gender mix of the sample group remains unknown as no patient will be excluded based on these factors. Anecdotal evidence provided by the Respiratory Service team suggests that there will likely be an over representation of Maori and Pacific Island peoples, though the ADHB Sleep Service patient demographic has changed significantly since Counties Manukau DHB secured access to their own region’s sleep patients (25). Prior to this it is estimated that approximately 40% of the patients seen by the ADHB Sleep Service were either Maori or Pacific Island. This is now estimated to be around 25% (25). A 1998 New Zealand study outlined the presentation of the Maori and PI groups to the whole Auckland region Sleep Disordered Breathing Clinics were at that time roughly one third Maori and PI to two thirds New Zealand European (28). Demographic data suggest that the gender mix will be predominantly male (29-31).

Exclusion criteria will be applied, with the following groups not receiving an invitation to participate: adults on non-invasive ventilation in intensive care environments where sedation may affect recall; patients with evidence of impaired cognitive impairment who are not able to give informed consent; patients on non-invasive ventilation via tracheostomy or who cannot understand and speak English; patients with increased work of breathing who cannot tolerate being without NIV contraindicating prolonged verbal communication; and patients on NIV for other respiratory causes such as chronic obstructive pulmonary disease or cystic fibrosis are also excluded.
Guided interviews via telephone will be used to explore and gain an understanding of each patient’s view of having CPAP therapy in their lives. Interviews will be offered in person to Maori and Pacific Island participants if preferred with cultural support offered to Maori and Pacific Island people via He Kamaka Oranga and the Pacific Family Support unit respectively. An open-ended approach using semi-structured interviews will be used starting with a general request of the participant to tell their story of what it is like needing and using CPAP for obstructive sleep apnoea. The point is to skilfully persuade the patient to talk about their own lives with CPAP and obstructive sleep apnoea with as little partiality from the investigator as possible. Each interview will be a guided dialogue using a few common questions to facilitate across-case analysis.

The following questions will be used to provide direction to the interview:
- Tell me what needing CPAP means to you?
- Tell me what having obstructive sleep apnoea means to you?
- How do you explain having obstructive sleep apnoea and needing CPAP to your family?
- Tell me about your sleep time routine / what pre-occupies you during this time?
- What kind of things have you done to help yourself manage with this therapy?

When informed consent has been obtained from the participant individuals will be contacted via phone to arrange a mutually convenient time for interview. Data collection will be via interview in most cases over the phone and recorded using audio software. Interview via phone rather than face to face is a means to reduce the personal impact on the patient’s time, exclude travel costs, and allow access to geographically dispersed patients (32). It may also reduce transference, prejudice, bias or judgement on the part of the participant or interviewer as a result of not seeing the other person’s facial expressions or body language (32, 33).

This may lead to deeper exploratory questioning around a particular comment rather than misinterpreting the meaning of a gesture, or allow the respondent to feel more relaxed and disclose sensitive information (32, 34). Indeed intonation, hesitation and other paralinguistic cues may be more useful (34, 35). Cultural protocol requires that interviews will be provided in person to Maori and Pacific Island participants if they prefer. In this case body language will become an additional source of data rather than confound the data. As the interviewer does not speak Te Reo or Pacific Island languages all interviews will be in English, though it is acknowledged that many of our consumers are competent bilingual. As mentioned cultural support will be offered via He Kamaka Oranga and the Pacific Family Support Unit to foster culturally safe communication. The interviewer will record details of behaviours of the respondents, length of the interview, interviewer’s reaction, main themes, and the questions that provoked the strongest responses (36). The data will then be transcribed verbatim and entered into computer program NVivo to facilitate data management (14).

As usual with the methodology of grounded theory data analysis will be concurrent with the data collection. The transcribed text of each guided dialogue will be coded by the investigator. Codes from each interview will be compared with codes and text from preceding interviews and sorted into categories (10, 14, 37). These categories will be interpreted and used to formation of summary themes which will form a background theoretical framework to ease coding subsequent data into themes (23). This process will continue after data-collection finishes until no further themes emerge (10, 14, 37). The summary themes will then lead to the development of an explanatory framework for the patients’ experiences (15, 22, 23). Categories and themes derived from codes will remain grounded in the words of the patient about how this therapy affects their lives. Concurrent data collection and analysis will also allow revision and adaptation of interview questions (11, 14, 38). In this way grounded theory allows the investigator to elicit a wide range of information around the subject that could then be further investigated in a later study using, for example, a survey questionnaire (36). Once theoretical data saturation is reached no new cases will be added (14).
More than 3500 New Zealanders die each year from obesity related disease, approximately ten times the annual road toll (30, 31, 39-42). The estimated cost of obesity is between 2-7% of a nation’s annual health budget equating to approximately $460 million for New Zealand (43, 44). These figures incorporate health care costs from obesity associated conditions including obstructive sleep apnoea (40, 45). In 2010 the estimated total annual societal costs of obstructive sleep apnoea for New Zealanders aged 30–60 years were around $40 million or $419 per case, with accidents being the major contributor (46). A 1998 Auckland study outlined the presentation of Māori and Pacific Island groups at sleep clinic were roughly one third Māori and Pacific Island to two thirds New Zealand European (28). A national survey carried out by Mihaere et al (2009) revealed a higher prevalence of obstructive sleep apnoea among Māori and among men. It was found that Māori between the ages of 30 – 59 years were 4.3 times more likely to have respiratory disturbance index $\geq$ 15 (95% CI = 1.3–13.9) (47)). Though ethnicity was not found to be an independent risk factor the prevalence of obstructive sleep apnoea syndrome was conservatively estimated to be 4.4% for Māori men, 4.1% for non-Māori men, 2.0% for Māori women, and 0.7% for non-Māori women. Māori were also more likely than non-Māori to report obstructive sleep apnoea syndrome risk factors and symptoms (28, 47-49).

Māori and Pacific Island people make up 14% and 5.6% respectively of our New Zealand population (50). As Māori and Pacific Island people are over represented in mortality figures and given the societal cost of obstructive sleep apnoea this study becomes highly relevant to our communities at large and in particular to our Māori and Pacific Island communities (39, 46, 50).

| Research Design (max 4 pages) | Improving obesity related and cardiovascular disease outcomes for Māori and our Pacific Island communities and removing inequalities between Māori and non-Māori is an important and urgent health priority (51, 52). As outlined in the Hauora: Māori Standards of Health IV and the Māori Cardiovascular Action Plan, there is substantial scope to effectively achieve cardiovascular health gain for Māori in New Zealand (53). The higher risk of developing sleep problems and the associated cardiac sequelae among Māori and Pacific Islanders suggests these peoples needs should be prioritised (53).

Exploring the personal experiences of CPAP in obstructive sleep apnoea may lead to a deeper understanding of the patients’ perspectives with CPAP therapy and in the future may become a powerful persuader in changing clinical practice to improve peoples’ experiences with CPAP and their health outcomes (12). This project will advance knowledge in the care of the obstructive sleep apnoea patient in New Zealand and for the Māori and Pacific Island groups findings from this study may in the future become agent in the improvement of health outcomes for these populations (12). The findings of this study may also generate the provision of further patient education and information around aspects of their non-invasive ventilation therapy including for example, a supportive education follow up programme to facilitate understanding of their therapy. Other respiratory patients may retain enough homogeneity with obstructive sleep apnoea patients in their use of CPAP and other forms of non-invasive ventilation that findings of this study may be transferable (13, 14). A literature review could identify no previous studies undertaken on this topic internationally despite its importance. The secondary intention of this project is to provide a basis for further national and international exploration of patients’ experiences with CPAP therapy with the findings of this study informing the design of future qualitative and quantitative studies.

This study has been discussed with the Associate Director of Nursing: Māori Health ADHB, Lorraine Heteraka-Stevens and Manager Pacific Health Provider Arm ADHB, Tuliana J. Guthrie. Mrs. Heteraka-Stevens is of Ngāti Kahu, Ngāi Teraingi, Te Arawa decent and Mrs. Guthrie is of Samoan decent. Both are available during the course of the study as cultural advisors to discuss any issues that may arise throughout the course of conducting the fieldwork. Mrs. Heteraka-Stevens will also be able to provide advice on: relevance to Māori; engagement with Māori stakeholders; processes to inform Māori health development; and appropriate dissemination pathways. Mrs. Guthrie will be able to provide advice on: relevance to Pacifica; engagement with Pacifica stakeholders such as the provision of a cultural support persons to attend face to face interviews with the researcher; processes to inform Pacifica health development; and appropriate dissemination pathways. (Refer to attached letters of support.)
### Appendices

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<tr>
<td>Duration of project in New Zealand</td>
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Describe reasons if no budget attached

The principal investigator has fees bursary scholarship from the University of Auckland to assist in the provision for data collection, analysis and report writing. All other activities will be in the investigator's own time. No travel is required of the investigator or participants during data collection.

Resources required include:
- Phone interview audio recording technology & equipment
- Data management computer program NVivo
- Principal researcher
- Transcription - Principal researcher

Source / availability
- University of Auckland
- Own time

Describe ADHB resource impact

Resources required include:
- Paper, toner & photocopying/printing
- Computer
- Cultural support for Māori and Pacifica peoples

Source / availability
- Investigators work area
- He Karaka Oranga & the Pacific Family Support Unit

Clearly describe what care is standard and what is extra for Research

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<th>Non-standard care</th>
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<tr>
<td>None</td>
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<td>The patient group would not routinely participate in an interview. Each participant will be interviewed one to one via the phone. It is anticipated each interview will be for a total of one hour.</td>
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Resource impact (e.g. clinic space, access to facilities, potential savings)
None
### Breakdown / Explanation of Budget -

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<td>Study visits and CRF completion Own time</td>
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### Section D: Contracts and Legal

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<tr>
<td>Current Insurance Certificate</td>
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Section E: Approval Signatures

Clinical Director / Manager / Leader / Medical Director / Nursing Leader (etc.): I am assured that
The study design and methodology are sound, and it appears ethically sound; Clinically feasible/appropriate; Staff Workload acceptable; Resource use adequately identified; Funding adequate; Are PI and/or team members or planned members suitable to do the study? That the potential group of patients/clients are not over researched already? Can department/service area manage the research in the time frame suggested? Are there any conflict of interest issues that need declaring/addressing? I also agree if savings or use of operational money are identified for use/transfer. Legal issues being addressed.

1. Name: Di Roud
   Comments or qualification?: Nurse Advisor – Professional Development ADHB Researcher’s Manager
   Signature
   Date

2. Name: Dr. Tim Christmas
   Comments or qualification?: Respiratory Service Clinical Director, ADHB
   Signature
   Date: 03 June 2011
   Refer to attached letter of support

3. Name: Dr. Ken Whyte
   Comments or qualification?: Respiratory Physician of the ADHB Respiratory Service with OSA expertise.
   Signature
   Date: 03 June 2011
   Refer to attached letter of support

4. Name: Pru Murray
   Comments or qualification?: ADHB Sleep Service Charge Physiologist
   Signature
   Date: 03 June 2011
   Refer to attached letter of support

Service Manager: I am assured that
The project has been clinically evaluated and ok’d by CD/CL/MD; ADHB policy compatible; HR requirements identified for non-ADHB personnel i.e. screening & ID & confidentiality; Aware of Conflicts of interest and accepted. All resources/costs identified and accounted for (quotes obtained), financially viable; Payment schedules noted and appropriate. I also agree if savings or use of operational money are identified for use/transfer. Legal issues being addressed.

1. Name: Taima Campbell
   Comments or qualification?: Executive Director of Nursing ADHB Researcher’s second up manager
   Signature
   Date
   As per previous submission

Section E: Clinical Trial Registration

Clinical Trial Number
Trial Website
Comment
Not applicable
References


25. Dr. Whyte K. Discussion and advice given by Dr. Ken Whyte (Respiratory Physician) regarding logistics of and support for the study 'Night time CPAP: the patient’s experience' from the Respiratory Service (ADHB). In: Ward K, editor. Auckland2011.


ADHB Research Amendment Form

A+ No. 5120 Date 07 April 2013

Please describe the changes that have been made to the protocol

The following changes have been made:

Including spouses of CPAP users:
Data from interviews to date indicate the importance of the participant spouse in the management of CPAP at home. Inclusion of this group therefore has relevance to the study.

Extension of the study until 30 November 2014:
This study commenced as a masters project which was successfully converted to a PhD project April 2012. Subsequently the timeline is altered to accommodate PhD scholarly activity. It is anticipated that interviews will be more in-depth and include spouses of CPAP users, which will extend the timeframe.

Documents updated include:
Participant invitation
Participant information sheet
Consent Form
Amended forms provided.

Please provide a list of all documents that were updated in this amendment

Please provide details of the expected impact of these changes to the aspects of safety, ethics, scientific merit and budget.

Impact of these changes on safety, ethics or budget are anticipated.
Data from interviews to date indicate the importance of the participant spouse in the management of CPAP at home. Inclusion of this group therefore has relevance to the study. Scientific merit will be increased by incorporating this group.

Research Office Use Only
Appendix 1.3. Participant information, invitation and consent from

Invitation

07 April 2014

Dear Sir / Madam,

As you, or your partner, are using a night time nose or a face mask for continuous positive airway pressure (CPAP) I would like to invite you to take part in a research study. You, or your partner, probably use a nose or face mask when sleeping to help with difficulties with breathing or snoring at night. This study will give you the chance to share with me your experience of night time CPAP.

Little research has been done looking at patients’ and partners point of view when using a night time nose or face mask. What you can tell me will help improve the care we give to patients using CPAP.

For this study I will be carrying out interviews on the phone with patients, and partners of patients, who use a night time nose or face mask at times during the night. Your involvement includes talking to me, the researcher in a single interview on the phone for between 30 to 60 minutes. The interview will be taped by me as we talk.

On the other side of this sheet is information describing the project in more detail. If you have any questions please feel free to contact Kim Ward (Researcher) on the number or email below.

Should you be interested in taking part please complete the accompanying Consent Form including the Reply Slip and return to the clinic reception. I will then make contact with you to answer any of your questions and to arrange a time to talk.

Your participation will be greatly appreciated.

Warm regards,

Kim Ward
Registered Nurse
Telephone 09 923 2265
Email k.ward@auckland.ac.nz

THIS STUDY HAS RECEIVED ETHICAL APPROVAL FROM THE NORTHERN X REGIONAL ETHICS COMMITTEE ON 14 June 2011 for a period of 3.4 years, Reference Number NTX/11/06/048

INSTITUTIONALLY APPROVED BY THE ADHB RESEARCH REVIEW COMMITTEE ON 27 June 2011, Reference Number 5120

Please keep this sheet for your information

Version 5 Page 1 07 04 2013
Participant Information Sheet

Night time CPAP: the patient’s experience.

You are invited to take part in this study to talk about what it is like to use CPAP (continuous positive airway pressure) via a nose or a face mask while sleeping. You, or your partner, use a night time face or nose mask for help with difficulties breathing while sleeping or with snoring. It might not be used every night or all night. This research is being undertaken as part of a Nursing PhD Degree with the University of Auckland.

Why are you being asked? / What is it all about?

At the moment there is little research on this topic. Having made use of this therapy for a time you and your partner will have begun to develop clear thoughts around the use of CPAP during sleep.

Tell Your Story

I would like you to have the chance to share with me your experience of using CPAP, or being the partner of someone using CPAP. You will be able to talk to me, the researcher, in a single interview over the phone for between 30 to 60 minutes. The interview will be recorded by me as we talk. The interview will include some simple questions to help you describe your CPAP experiences. We will use this information to help us better prepare patients to use CPAP and improve their ongoing care.

Participation

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and your decision to participate or not participate in the study will in no way affect medical treatment. If you do agree to take part, you do not have to answer every question asked.

Where the interviews will be conducted in English, cultural support will be available for participants from the Pacific and Maori communities via Mata Forbes of He Kamaka Oranga or the Pacific Family Support Unit including the offer of a face to face interview if preferred.

Confidentiality

By completing the Consent Form and Reply Slip you are giving consent to take part in this study. In addition you are showing that you understand that your responses during the interview will be anonymous. All information collected (including audio-recordings, individual interview transcripts and additional research notes) will be stored in a locked filing cabinet in the investigators locked office or in a password-protected database and accessible only to the researcher and researcher’s supervisor. The information will be retained on The University of Auckland server for a period of no more than two years beyond the end of the project.

Independent Advocacy Service If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate: Free Phone 0800 555 050 or e-mail advocacy@hdc.org.nz

This study has received ethical approval from the Northern X Regional Ethics Committee on 14 June 2011, Reference Number NTX/11/06/048. If you have any questions please feel free to contact one of us. Contact details for the researcher and researcher’s supervisor are:

Researcher Kim Ward
k.ward@auckland.ac.nz
09 923 2265

Researcher's supervisor Merryn Gott - Professor Health Sciences
m.gott@auckland.ac.nz
09 923 1655

Please keep this sheet for your information

Version 5  Page 2  07 04 2013
Consent Form

Night time CPAP: the patient’s experience.

Name of Researcher:  Kim Ward
Name of Supervisor:  Merryn Gott

- I have read and I understand the Information Sheet dated 07 April 2014 for participants about the above study. Where I have taken the opportunity to discuss and ask questions about the study I am satisfied with the answers I have been given. I agree to take part in the study.
- I understand that taking part in this study is voluntary and that I may withdraw myself or any information traceable to me at any time. My withdrawal from the study will in no way affect my medical treatment.
- I understand that information gathered from the interview may be included in academic publications and that all information will remain strictly confidential. No material that could identify me will be used in any reports on this study.
- I understand that interview will be audio-recorded and afterwards written down.

Name of Participant               Date               Signature

Name of Researcher                Date               Signature

Reply Slip

I understand in signing the above consent that I give permission for the researcher to telephone call me on the below number in order to arrange a mutual time to conduct the interview and for me to ask any questions I might have. The researcher will sign and return the consent form to you on the below address.

Telephone mobile:  
Telephone land line:  
Your postal address to return signed consent  

Please return completed form in reply paid envelope. Many thanks.

This study has received ethical approval from Northern XRegional Ethics Committee, June 14th 2013.
Appendix 1.4. Letters of ethical approval and support

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unileys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 590 9001
Mailing Address:
Private Bag 92 522
Wellesley Street
Auckland 1141
Email address:
northernx_ethicscommittee@mh.govt.nz

Ms Kim Ward
Nursing Development Unit
Lvl 15, Support Building
Auckland City Hospital
PB 92 024 Auckland 1142

Dear Kim

Re: Ethics ref: NTX/11/06/048 (please quote in all correspondence)
Study title: Non-invasive ventilation: the patient’s perspective. A study to explore the
patient’s experiences of continuous positive airway pressure (CPAP) therapy:
Prot. 28/04/11; PIS/Cons V#4, 25/6/11
Investigators: Ms Kim Ward
Supervisor: Prof Merryn Gott

Thank you for your response, the letter of support from MRRC and amended documents received
30 June 2011. The above study has received full ethical approval. A list of members of the
Committee is attached.

Approved Documents
— Information sheet/Consent form version [4, dated 25/06/11]

This approval is valid until 30 November 2012, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations
All significant amendments to this proposal must receive prior approval from the Committee.
Significant amendments include (but are not limited to) changes to:
— the researcher responsible for the conduct of the study at a study site
— the addition of an extra study site
— the design or duration of the study
— the method of recruitment
— information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports
The first Annual Progress Report for this study is due to the Committee by 7 July 2012. The Annual
Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if
you do not provide a progress report by this date, ethical approval may be withdrawn.

http://www.ethicscommittees.health.govt.nz
Tēnā koe

Re: A Study to explore the patient’s experiences of Continuous Positive Airway Pressure therapy.

To whom it may concern,

I have read and understood the research protocol for the proposed study “Non-invasive ventilation: the patient’s perspective. A study to explore the patient’s experiences of Continuous Positive Airway Pressure (CPAP) therapy.”

I endorse support this specific research project and believe that the researcher Kim Ward will continue to seek advice on matters pertaining to relevance to Māori and their whānau; engagement with Māori stakeholders including but not limited to Iwi, Hapu; processes to inform Māori health development; and appropriate dissemination pathways. Improving obesity related and cardiovascular disease outcomes for Māori and their whānau, and removing inequalities between Māori and non- Māori is an important and urgent health priority.

This study may lead to a deeper understanding of the patients’ perspectives on CPAP therapy and in the future become a powerful persuader in changing clinical practice to improve peoples’ experiences with this therapy and their health outcomes in particular for Māori.

If you have any further queries in regards to my letter of support, please feel free to contact me directly.

Noho ora mai

Lorraine Hetaraka Stevens
Ngāti Kahu, Te Arawa, Ngātirangi
Associate Director of Nursing – Māori Health

E-mail: LorraineHS@adhb.govt.nz
021 2258540
Appendices

Appendix 2. Questions used in this study

Appendix 2.1. Scripted interview memory aids

First call memory aid:

Hello [NAME]. My name is Kim Ward. If you recall, I am the nurse who invited you to take part in my University of Auckland masters research about your night-time CPAP… face mask / breathing machine / etc…

Thank you for taking the time to complete the consent form and have it returned to me. Is now a convenient time for this call to check your details and to arrange a telephone interview? ....... Are there any questions you need answered about this study before we carry on? ....... (Have info sheet handy & go through consent form questions /points....)

What I shall now do is sign the consent form myself, keep a copy for my records and send your copy to your home address for you to keep. (Check address / spelling etc –seek demographic data.) Thank you for that.

Now, to explain a little about the process, I have a number of people to interview for this study and need to interview you all one at a time. This means that I need to make a time to talk to you in a few days/ weeks’ time. I’ll need to talk with you over the phone for about an hour about your CPAP. What would be a convenient day of the week and time of the day to do that? So let’s plan a date now? … Would you like me to text or e-mail [date] and [time] to you for your diary?

That’s great. So I shall be in touch with you the day before to confirm the interview time, and we’ll go from there. If you have any questions in the meantime, please feel free to give me a call. Thank you very much for your time today. Bye.

OR

This means that I need to make a time to talk to you in about a months time. Are you happy to wait that long? … So I’ll need to talk with you over the phone for about an hour about your CPAP. What would be a convenient day of the week and time of the day to do that? … So shall we plan a date now? – arrange interview OR time to call back to arrange …
That's great. So I shall be in touch with you in a couple of weeks to arrange the interview time, and we'll go from there. If you have any questions in the meantime, please feel free to give me a call. Thank you very much for your time today. Bye.

Day Before Confirmation:

Hello [NAME]. This is Kim Ward. If you recall, I am the person who invited you to take part in my research about your night-time CPAP...

We’ve arranged XX o’clock tomorrow for me to call to interview you about your CPAP. Is this still OK? It will be for around an hour – are you still happy with that? And just to remind you that I’ll be recording our chat but that I’ll write our talk up afterwards so I can listen to you properly… Is that still OK?

Great, now are there any questions you need answered before tomorrow? …..

I’m looking forward to talking tomorrow. Have a great evening. Bye.

The interview memory aid:

Hello again [NAME]. This is Kim. Are you comfortable and ready for our interview? Are there any questions you’d like to ask first or are you happy to carry on? Great –

So just to remind you I used to work for the Respiratory Service as a nurse and that’s how I became interested in respiratory medicine. So I’ve taken the opportunity through my University study to look at what it is like for people like yourself who need to use a night-time face or nose mask. Now I know we can’t see each other so to set the scene I can tell you that I am in a closed office, so no one else can hear you or know who I’m talking to.

So I have questions to ask to help us get started talking about your CPAP. – there are no right or wrong answers to anything I ask – and don’t be afraid to ask me to explain a question if I don’t make sense. But why don’t you begin by telling me about your CPAP? …

Closing the interview:

Thank you very much for your time today – I appreciate your frankness and willingness to talk to me… If in time you wish to add something you are very welcome to call me back – my mobile is on the information sheet you have. Also, can I ask whether you are happy for me to call you back if there is anything I need to check with you about what you’ve said to me today?

It will take about 12 months for me to put together what you and the other participants have said into a report. Once done I shall send a copy to you.

Have you any final questions?
Appendix 2.2. Question progression schematic for interviews 1-8, including ending questions

<table>
<thead>
<tr>
<th>Interview 1</th>
<th>Interview 2</th>
<th>Interview 3 &amp; 4</th>
<th>Interview 5</th>
<th>Interview 6</th>
<th>Interview 7 &amp; 8</th>
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<tbody>
<tr>
<td>Tell me about your CPAP.</td>
<td>Tell me about your CPAP.</td>
<td>Tell me about your CPAP.</td>
<td>Tell me about your CPAP.</td>
<td>Tell me about your CPAP.</td>
<td>Tell me about your CPAP.</td>
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<td>What was your life like before having a CPAP machine...?</td>
<td>What was your life like before having a CPAP machine...?</td>
<td>What was your life like before having a CPAP machine...?</td>
<td>What was your life like before having a CPAP machine...?</td>
<td>What was your life like before having a CPAP machine...?</td>
<td>What was your life like before having a CPAP machine...?</td>
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<td>So how did you feel when you got your sleep study results?</td>
<td>So how did you feel when you got your sleep study results?</td>
<td>So how did you feel when you got your sleep study results?</td>
<td>So how did you feel when you got your sleep study results?</td>
<td>So how did you feel when you got your sleep study results?</td>
<td>So how did you feel when you got your sleep study results?</td>
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</table>

<p>| When and how have you been asked to use your CPAP? | - | - | - | - | - |
| Tell me about your sleep time routine / what pre-occupies you during this time? | Tell me what pre-occupies you while you are getting ready for bed? | (Moved later *) | (Moved later *) | (Moved later *) | (Moved later *) |
| Tell me what needing CPAP / OSA means to you? | Tell me what needing CPAP / OSA means to you? | (moved earlier *) | (moved earlier *) | (moved earlier *) | (moved earlier *) |
| How do you feel about having to use the machine? | How do you feel about having to use the machine? | How do you feel about having to use the machine? | How do you feel about having to use the machine? | How do you feel about having to use the machine? | How do you feel about having to use the machine? |</p>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>What thoughts went through your mind / How did you feel when you first saw the machine?</strong></td>
<td><strong>What thoughts went through your mind / How did you feel when you first saw the machine?</strong></td>
<td><strong>What thoughts went through your mind / How did you feel when you first saw the machine?</strong></td>
<td><strong>What thoughts went through your mind / How did you feel when you first saw the machine?</strong></td>
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<td><strong>What thoughts went through your mind / How did you feel when you first saw the machine?</strong></td>
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<td>[wall of silence from docs etc]</td>
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<td>[wall of silence from docs etc]</td>
<td>[wall of silence from docs etc]</td>
<td>[wall of silence from docs etc]</td>
<td>[wall of silence from docs etc]</td>
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<td><strong>What do you think of your health / wellness versus sickness – definition of??</strong></td>
<td><strong>How does having sleep apnoea change how you think of your health / wellness versus sickness – definition of??</strong></td>
<td><strong>How does having sleep apnoea change how you think of your health / wellness versus sickness – definition of??</strong></td>
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<td><strong>How do you explain having obstructive sleep apnoea / needing CPAP to your family?</strong></td>
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<td><strong>How does your [wife] feel…</strong></td>
<td><strong>How does your [wife] feel…</strong></td>
<td><strong>How does your [wife] feel…</strong></td>
<td><strong>How does your [wife] feel…</strong></td>
<td><strong>How does your [wife] feel…</strong></td>
<td><strong>How does your [wife] feel…</strong></td>
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<td><strong>How does your wife feel about the machine?</strong></td>
<td><strong>What makes it hard to use, what makes it easy/easier to use?</strong></td>
<td><strong>Do you think you’d feel differently about it if you were single (or had a partner) – depending on current status?</strong></td>
<td><strong>Blokes – idea of weakness? Body image ques</strong></td>
<td><strong>What makes it hard to use, what makes it easy/easier to use?</strong></td>
<td><strong>Do you think you’d feel differently about it if you were single (or had a partner) – depending on current status?</strong></td>
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<td><strong>Women – idea of attractiveness - Body image ques</strong>&lt;br&gt;Strength of relationship ques</td>
<td><strong>Women – idea of attractiveness - Body image ques</strong>&lt;br&gt;Strength of relationship ques</td>
<td>Do you feel you would like to hide that you have the CPAP machine or sleep apnoea?</td>
<td>Do you feel you would like to hide that you have the CPAP machine or sleep apnoea?</td>
<td>Do you feel you would like to hide that you have the CPAP machine or sleep apnoea?</td>
<td><strong>Women – idea of attractiveness - Body image ques</strong>&lt;br&gt;Strength of relationship ques</td>
</tr>
<tr>
<td>* What kind of thoughts go through your mind when you are getting ready for bed?<em>&lt;br&gt;Do you generally keep it on all night? (getting away with it idea…)</em>&lt;br&gt;One participant mentioned that he couldn’t talk to his wife at night like he used to. Do you mind telling me - How has this machine affected your relationship / intimacy?</td>
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<td>How do you feel you sleep with the mask / without the mask? OR What do you feel about the sleep you have with the mask / without the mask? (vis a vis concept of good sleep)</td>
<td>How do you feel you sleep with the mask / without the mask? OR What do you feel about the sleep you have with the mask / without the mask? (vis a vis concept of good sleep)</td>
<td>How do you feel you sleep with the mask / without the mask? OR What do you feel about the sleep you have with the mask / without the mask? (vis a vis concept of good sleep)</td>
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<td>One participant has talked about having good sleep – tell me what goes through your mind when you think about good sleep?</td>
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<td>One participant has talked about having good sleep – tell me what goes through your mind when you think about good sleep?</td>
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<td>How has using the machine affected you physically / mentally? (memory improved etc)</td>
<td>How has using the machine affected you physically / mentally? (memory improved etc)</td>
<td>How has using the machine affected you physically / mentally? (memory improved etc)</td>
<td>How has using the machine affected you physically / mentally? (memory improved etc)</td>
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<td>What kind of things have you done to help yourself manage with this therapy?</td>
<td>What kind of things have you done to help yourself manage with this therapy?</td>
<td>What kind of things have you done to help yourself get used to your CPAP?</td>
<td>What kind of things have you done to help yourself get used to your CPAP?</td>
<td>What kind of things have you done to help yourself get used to your CPAP?</td>
<td></td>
</tr>
<tr>
<td>Getting used to it is one of the phrases all of the people I’ve spoken to so far have used. What kind of things does that mean to you – getting used to it? Is snoring a masculine problem? Embarrassment??</td>
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### Appendices

#### (Charmaz, 2006) pg 30 – ending questions

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<td>Tell me how your actions have changed since you started using CPAP</td>
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Appendix 2.3 Partner-participant questions: third partner interview

PARTNER questions 16 06 2014…

So I’ve got some questions to ask to help us get started talking about your CPAP. - no right or wrong answer to anything I ask - don’t be afraid to ask me to explain a question if I don’t make sense.

Why don’t you start by describing what’s around you and if you are doing anything while we’re on the phone? …..

What was life like before CPAP? -

Tell me about the beginning and what it all meant to you.

How did you draw his/her attention to that? What things changed that made him/her seek help?

(Good sleep - witnessing and negotiating good sleep…)

How did you feel about the machine when you first saw it? How do you feel about it now?

Comparing

Tell me about your concerns/triumphs.

Tell me about the part you’ve played in the whole process of getting the machine and also his/her use of the machine.

What has having the CPAP machine meant to you / and your partner?

And when the machine appeared in your bedroom how did you feel about that, what kind of thoughts went through your head?

How do you feel about the machine? / did you feel when you first saw it?

If the tables were turned and you were the one with the CPAP how would you feel? How would things play out?

How do you feel about the CPAP machine now?

Have you found it helpful to compare before and after? – Why?

Can you tell me about anything that has been good / not so good about having CPAP?

I get a sense that users of CPAP balance a number of things in order to come to terms with using it –
Tell me what you think about that? What are they?

One participant has described needing to master CPAP. What do you think about that?

Getting used to it is a common phrase people have used. What does that mean to you – getting used to it?

Looking back over the time with CPAP what kind of things do you think have happened to help him/her get used to CPAP?

What hasn’t helped?

How have you influenced that process? – (have you done this together?)

How do you think you affect the choice to use the machine each night?

What kinds of things help/hinder him/her to use the machine?

One participant has described how the strength in the relationship has contributed to their use of CPAP.

What do you think about that? Strategies together?

What has altered about how you see your partner… how you are with your partner…?

What thoughts have you had about how attractive they are to you now they use CPAP? How have things changed with your hubby/wife since he got the CPAP?

How do you think it would be if you didn’t like the machine? If your wife/husband/partner hid under the covers to hide the mask on what would you think?

Tell me about / how did you feel about getting the diagnosis of sleep apnoea…Is there a difference in how OSA is perceived as a mechanical illness or a chronic condition –

How does his/her using CPAP impact on you?

Someone described it as an addiction – what do you think?

Do you think that your partner feels ashamed that they need this CPAP – that they are perceived as unwell?

What are the bad consequences of using CPAP? Are there any unhappy consequences of using CPAP? (To explore some of the fear code – what are they and to what degree are they felt?)
If I describe this whole process as a route to getting good sleep, what thoughts do you have?

And based on everything you’ve told me does the phrase establishing the need for CPAP and making choices to work CPAP into our lives adequately capture what you’ve experienced?

What do you think you have learned about yourself or your partner/wife/husband through all of this?

So given your experiences with your CPAP, what advice would you give to someone just given a CPAP machine? To their spouse?

Is there anything while we’ve been talking that’s occurred to you that you haven’t ever thought of before?

Have you surprised yourself with anything you’ve said?

Is there anything else you think I should know to understand your life with CPAP better?

PROMPTS...

That’s interesting...

Could you explain that a little more...

Let’s see, you said...

Just how do you mean that...

How do you feel about ......?

Do you mind telling me...

Well, in general what would you say...

Taking everything into consideration what do you think?

On the basis of the way things look to you now what do you think?