

# From diagnosis to long-term management: the experiences of older New Zealanders with obstructive sleep apnoea

Rosemary Gibson PhD; Angela Campbell PhD; Shelley Mather BSc, PGDip MedTech;  
Alister Neill MBChB, MD, FRACP

University of Otago,  
WellSleep Sleep  
Investigation Centre,  
Department of Medicine,  
Wellington 6242,  
New Zealand

## ABSTRACT

**INTRODUCTION:** In New Zealand (NZ), access to public sleep services is limited to people deemed with the highest need. The prevalence of obstructive sleep apnoea (OSA) increases with age, but the symptoms and the treatment pathway is expected to differ for older compared to younger patients. This study explored the experience of older people regarding diagnosis and treatment services for OSA in order to inform considerations required in primary health and sleep services.

**METHODS:** Patients who were initiated on Continuous Positive Airway Pressure (CPAP) therapy at the age of 65 years or older were invited to one of three 1.5-h focus group discussions. In total, 16 patients attended; nine were accompanied by their spouse or partner. Discussions were semi-structured and explored experiences with the OSA pathway, from diagnosis through to long-term management.

**RESULTS:** Thematic analysis highlights the key symptoms of OSA. Patients' experiences with diagnostic and treatment services were generally positive. However, there was an overarching need for greater knowledge and follow up regarding OSA and CPAP therapy. Most patients were happy with CPAP treatment. Issues associated with long-term use, comfort and daily management were highlighted, and strategies used to overcome them discussed.

**DISCUSSION:** Focus groups reported similar experiences, positively endorsing the health value of OSA diagnosis and CPAP therapy. Mechanisms and resources are required at a primary healthcare level in order to raise awareness around sleep and aging, OSA and CPAP. This would aid earlier and more appropriate diagnosis and management of OSA and help overcome some of the gaps identified in this study.

**KEYWORDS:** Aging; continuous positive airway pressure; obstructive sleep apnoea; focus groups

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**CORRESPONDENCE TO:**  
**Rosemary Gibson**  
University of Otago,  
WellSleep Sleep Investigation  
Centre, Department of  
Medicine, Wellington  
6242, New Zealand  
r.gibson@massey.ac.nz

## Introduction

Obstructive sleep apnoea (OSA) is a sleep-related breathing disorder characterised by repetitive cessations of breathing (apnoeas) during sleep caused by physical obstructions of the upper airway, creating hypoxaemia and hypercapnia. Apnoeic events are typically accompanied by loud snoring and negatively affect the cardiovas-

cular system due to dips in oxygen and surges of blood pressure. Sleep is usually disturbed to restore airway patency. Therefore, people with OSA syndrome have increased risk of cardiovascular disease and daytime sleepiness, having implications for daytime functioning and accidents.<sup>1–4</sup>

A previous New Zealand (NZ) study estimates that sleep apnoea is prevalent in 12.5% of males

and 3.4% of females aged 30–59 years.<sup>5</sup> It was also found that, with increased age, the likelihood of reporting symptoms of OSA also increased. Age-dependent changes have been verified elsewhere with larger samples and using polysomnography.<sup>6,7</sup> Heinzer *et al.*<sup>6</sup> found that moderate–severe OSA (apnoea or hypopnea index [AHI] of  $\geq 15$  events per hour) was more prevalent with each 10-year increment (between ages 40 and 85 years,  $N = 2121$ ), and that incidence of severe OSA (AHI  $\geq 30$  per hour) doubled for people aged  $\geq 60$  years compared to people aged  $< 60$  years for both men (16% vs. 32%) and women (5% vs 14%).<sup>6</sup> OSA has been associated with physiological changes to the airway, a less stable respiratory response, plus increased comorbid health conditions exacerbating sleep-disordered breathing.<sup>8,9</sup> Therefore, factors that are considered key predictors for OSA in younger people (eg being male, overweight and witnessed respiratory events) may not be as reliable with increased age.<sup>7</sup> Furthermore, Heinzer *et al.*<sup>6</sup> found that the presence of self-reported excessive daytime sleepiness with OSA actually *decreased* with age, which complicates the diagnostic process.<sup>6</sup>

The most effective therapy for OSA is continuous positive airway pressure (CPAP). This device delivers air to the upper airway through a mask, at a pressure adequate to splint the airway open, preventing obstruction and collapse. When used regularly (preferably  $\geq 6$  h per night), CPAP is highly effective for improving apnoea and associated sleepiness.<sup>10</sup> Furthermore, regular use of CPAP could reduce risk of cardiovascular morbidity and mortality.<sup>11,12</sup> There are several factors that can negatively affect acceptance of CPAP. These include comorbid health conditions, psychosocial factors, mask leaks and reduced access to relevant education or support.<sup>13–15</sup>

The WellSleep, Sleep Investigation Centre is a sleep laboratory representative of similar laboratories found in the major centres around NZ. It provides both government and privately funded sleep services, including OSA diagnosis and CPAP initiation. Patients are typically referred from their primary healthcare provider to a public or private sleep specialist who then contracts the WellSleep, Sleep Investigation Centre for

## WHAT GAP THIS FILLS

**What is already known:** Continuous positive airway pressure (CPAP) is an effective therapy of obstructive sleep apnoea (OSA), but can be limited by poor acceptance rates. Older people have a higher likelihood of having OSA and risk factors that reduce CPAP acceptance. Increasing life expectancy and obesity means that primary health care and sleep services can anticipate a greater number of older patients in need of CPAP and other sleep support related to diagnosis and ongoing management.

**What this study adds:** Focus groups with older New Zealanders highlight the need for increased awareness from primary healthcare professionals regarding OSA and CPAP, as well as public awareness and education. This would enable timely identification and management of OSA, reducing the effect of symptoms on people moving into retirement. Increased information, reduced costs, and improved availability of clinical and comradery support via follow-up appointments or casual patient meetings were highlighted as important for facilitating the establishment and maintenance of long-term CPAP.

formal diagnostic and treatment services. Life expectancy is increasing; therefore, this pathway is expected to encounter more older patients.<sup>16</sup> Health professionals' knowledge regarding sleep disorders is variable, and there is a need for services tailored for older people.<sup>17,18</sup>

Previous qualitative studies have been useful for understanding the beliefs, attitudes and experiences of OSA patients, allowing for appropriate recommendations and adaptations to resources and services to be made.<sup>19–21</sup> Focus groups with New Zealanders with an average age of 47 years (30–71 years) helped identify thematic differences between ethnicities, as well as what patients considered strengths and weaknesses of their local sleep services when recently established on CPAP therapy.<sup>22</sup> However, documented experiences of older patients are lacking. Further research is required to better understand the experience of diagnosis and management of OSA for older patients, as well as to identify factors affecting acceptance of the current NZ services. The present study was designed to meet these gaps by conducting focus groups with older adults who had been through a tertiary-level pathway for OSA in NZ for the diagnosis and treatment of OSA.

## Methods

### Recruitment

We used a convenience sample recruited from patients who had previously agreed to be considered for research protocols. Inclusion criteria were that patients lived in the Greater Wellington Region and had been initiated on CPAP therapy as an older person ( $\geq 65$  years) at the WellSleep, Sleep Investigation Centre following standard clinical practice.<sup>23</sup> All eligible patients were contacted via community health providers or the WellSleep Sleep Investigation Centre by phone or email.

Participants attended one of three focus groups across the Wellington region in November 2016. One was held at a local marae (Māori meeting place), one was held at a local community centre's meeting room and another in a meeting room on site with the sleep laboratory. Participants could bring their spouse, partner or family member to join them if they wished. The study was approved by the Otago University Human Ethics Committee: category A approval. Prior to taking part in this particular study, participants received an information sheet and they gave written informed consent. It was reiterated that all data would remain anonymous. They were reimbursed for their time with a NZ\$20 supermarket voucher.

Focus groups were used as they are able to create a supportive environment in which participants feel free to share their insights and experiences. This method also allowed for free discussion on issues considered important to participants, rather than pre-defining questions using a fixed, questionnaire-based approach.<sup>24</sup>

### Focus groups and data collection

Focus groups were conducted according to standard methodology.<sup>24,25</sup> A brief introduction was given at the beginning of each session from the principal investigator, as well as from management at the venues. This also gave participants the opportunity to ask questions before audio recording commenced. Focus groups were conducted by the principal investigator (R. Gibson) only, who was a Research Officer with experience

in qualitative research as well as OSA and CPAP services. She was contracted to conduct this study as someone unknown to the participants.

Each focus group ran for ~1.4 h (range 0.9–1.5 h); morning tea was provided. Discussions were semi-structured to ensure the group data were comparable with regard to time and topics covered. Enquiries were designed to reveal experiences with having OSA as an older patient, from diagnosis through to long-term management with CPAP therapy. The following framework was used as a guide to areas that would be explored in the discussion and was displayed for reference during the session:

- (a) The journey to the sleep clinic;
- (b) Prior knowledge of OSA;
- (c) Prior knowledge of CPAP;
- (d) External support available during the CPAP trial;
- (e) Experience with the CPAP trial;
- (f) Experience with long-term CPAP therapy.

All participants were encouraged to contribute. Focus groups were conducted in a supportive manner to allow participants time to voice their experiences and concerns. Participants were reminded that they were free to decline answering particular questions or could leave the group at any time.

### Data analyses

Demographic and trial-based information were collated from patients' hospital records. Recordings were transcribed verbatim and a thematic analysis was conducted (audio recordings and facilitator notes were referred to as needed). The analysis was data-driven.<sup>25</sup> Transcripts were coded, which involved adding notation to each sentence summarising the central point. Basic themes were identified, and illustrative quotes noted. These were then reviewed and compared by two of the researchers (R. Gibson and A. Campbell) to identify broader patterns and then rearranged into organising themes, which were further discussed, compared and revised where necessary. Finally, all themes were categorised into broader global themes, together forming thematic networks.<sup>26</sup>

## Results

There were 25 participants in total across all focus groups: 16 were patients and nine were accompanying spouses or partners. All but one patient was male; their average age was 71 years (67–89 years). Eight identified as either NZ European or other European ethnicity (remaining participants had not disclosed their ethnicity). Socioeconomic position was gauged using NZ deprivation index quintiles based on geographic area.<sup>27</sup> This indicated that 10 of the participants lived in the least deprived quintiles (1 and 2), five in quintile 3, and one in quintile 4 and none in quintile 5, the most deprived quintile.

Most (13) of the participants had a comorbid health condition, including 11 who had a cardiovascular disease (eg hypertension or ischaemic heart disease), three had a mental health issue (eg depression or transient ischaemic attack) and 11 had other comorbidities such as cancer, arthritis or diabetes. Most (13) had been privately referred to the WellSleep, Sleep Investigation Centre and therefore funded personally or through health insurance to attend appointments and obtain the CPAP device and masks. The remaining patients were referred through the government-funded health system and had not directly funded the cost of their appointments or equipment. The biometric measurements of the participants were comparable with typical patients with moderate–severe OSA<sup>1</sup> and representative of patients who are initiated on to CPAP at the WellSleep, Sleep Investigation Centre. At completion of their trials, they were using their CPAP machines for a median of 6 h per night (4–9 h). At the time of the focus group, they had been established on CPAP for a median of 2.5 years (0.4–6.4 years).

Participants in all three groups shared their stories of service delivery, from referral and diagnosis through to long-term CPAP therapy. Some had had unsuccessful trials with alternate therapies before trialling CPAP (five had tried mandibular advancement devices or mouth guards, one a surgical procedure). The main issues discussed across groups were the symptoms of OSA and improved sleep with CPAP

therapy; the pathway to CPAP therapy, particularly struggles with the trial and ongoing issues with equipment and adherence; and the effect that CPAP was having on their quality of life. The thematic networks around these global themes are presented with example quotes in Table 1.

### Key symptoms of OSA that improved with CPAP therapy

Participants reported that snoring or disrupted breathing, daytime sleepiness and generally disturbed sleep were their key symptoms of OSA. Typically, it was their partner who reported symptoms and who had initiated the diagnosis. For most, symptoms had been alleviated through CPAP therapy. Many noted that they did not appreciate the magnitude of their symptoms until treated. They reported sleeping more calmly and no longer snoring or ‘fighting for breath’ [Group 3, Pt2]; there was a reduction in daytime sleepiness plus improved mood, energy and waking function. Partners were happy:

‘First night he had the CPAP machine and I never heard a peep out of him. He never got up. In fact, I was nudging him to see if he was still breathing! And it has been brilliant ever since. I sleep better than ever!’ [Group 2, Pt2]

### Pathway to long-term CPAP therapy varies

Degrees of awareness of OSA and CPAP varied for participants, partners and for their general practitioners. Many had experienced symptoms of OSA for years before raising the problem clinically. A key theme was that identifying and understanding OSA requires assistance. For most, the referral process had been quite straight forward. But others felt that a faster process or information would have helped. Most expressed disappointment with the expense of CPAP and lack of support from the public health system or medical insurance.

There were also mixed experiences with the CPAP trial. Some felt an unbelievable and immediate improvement, but many took more time to adjust or feel any benefits. Problems during this

Table 1. Summary of thematic networks arising from focus groups

Organising themes	Basic themes	Supporting quotes
<b>Global theme: There were key symptoms of OSA that improved with CPAP</b>		
1. Disrupted breathing		
1.1 Snoring disturbing sleep	Heavy snoring, waking self, disturbing partner	'She said 'It wasn't a light snore, you were away like a truck going up a hill!' [Group 1, Pt3]
1.2 Witness apnoeas	Poor breathing at night; partner worry/checking at night; partner's sleep disturbed	'She kept nudging me at night and I'd say 'what's wrong?' She said, 'you've stopped breathing'. This went on for about two years before I decided to do something about it.' [Group 1, Pt4]
1.3 Noisy breathing affects quality of life	Affects sleeping arrangements; affects social life	'I'm a keen fisher man. On the fishing boat, as you know, a lot of males are all together. They used to just push me up the front of the boat, as far away as possible. I used to wake everybody up and I was banned from fishing. So when I retired, that was one of my hobbies and I was banned.' [Group 2, Pt2]
2. Daytime sleepiness		
2.1 General tiredness	Very tired; no energy/enthusiasm; headaches	'Every time he sat down he wanted to go to sleep... he was tired when he woke up, he was tired when he went to bed.' [Group 1, Pr5]
2.2 Sleepiness affecting daytime functioning	Falling asleep during the day, at work; or driving affected; fell asleep in public; modified behaviour to stop falling asleep during the day	'I'd feel myself drifting. I do think I used to do things to keep myself awake...like get up and move around, instead of always sitting down and talking, I used to stand up and look out the window. It is amazing how you modify what you are doing in order to overcome your problem.' [Group 1, Pt3]
3. Disturbed sleep		
3.1 Poor general sleep	Restlessness; excessive movement	'He was terrible before he had it [CPAP], his arms would be flying and he was snoring.' [Group 1, Pr5]
3.2 Disruptions in night	Waking multiple times; disturbing partner	'He used to wake up and it was as though someone was suffocating him..... It was terrible.' [Group 2, Pr3]
<b>Global theme: Pathway to long-term CPAP varies</b>		
4. Identifying OSA requires knowledge and assistance		
4.1 Lack of awareness regarding OSA/CPAP	Limited knowledge; negative connotations; disbelief that OSA could affect them	'I didn't have any knowledge of it at all. I didn't know what they were talking about, to be honest. When the doctor said you must be suffering from sleep apnoea and he explained it. I thought, how can that be?' [Group 1, Pt4]
4.2 Knowledgeable about OSA/CPAP	Aware of risk factors and outcomes of OSA; family or friends with OSA	'My father had had the same problem. You would constantly hear him with these great snorts and moments of silence during the night.' [Group 1, Pt4]
4.3 Another person drives referral	Symptoms noted by others (partner, hospital staff, friend, audio recording); spouse/partner initiated diagnosis; patient denial of symptoms	'Then I had to have an appointment with the doctor. He said, 'what are you here for?' I said, 'just to prove [to my wife] that I'm not snoring and not stopping breathing!' [Group 1, Pt2]
4.4 GP's knowledge affects referral process	Provided useful information and referred appropriately; sleepiness associated with age; lacked knowledge regarding sleep or OSA	'But our old doctor he said 'he is just getting older, he's just getting older'. And I kept saying, 'no, it was abnormal.' [Group 1, Pr5]
5. Experience of diagnostic night		
5.1 Diagnosis was straight forward	Happy to have diagnostic night at home; staff useful and supportive; slept better than expected with equipment	'I was never apprehensive at all about the whole process. Never. I just felt that it was going to be good.' [Group 2, Pt6]
5.2 Diagnosis was challenging	Anxiety of sleeping with equipment; embarrassment of being seen with equipment; set up more extensive than expected; sleeping in alternate environment difficult	'I didn't know how I was going to try and stay with all those wires for that long.' [Group 3, Pt3]

(Continued)

Table 1. (Continued)

Organising themes	Basic themes	Supporting quotes
<b>Global theme: The pathway to long-term CPAP varies (continued)</b>		
6. Adjusting to CPAP		
6.1 Positive trial experience	Immediate improvement of symptoms; happy with CPAP choices; straight forward trial; staff supportive and informative	'The next morning, I couldn't believe how I felt...I could take the world on!' [Group 1, Pt3]
6.2 Took time to adjust to CPAP	Didn't notice immediate improvement; struggled with mask comfort or leak; issues with machine/humidifier; anxiety related to breathing; negative waking symptoms from CPAP	'I just can't tolerate anything on my face – I don't know why. I tried and tried and I just couldn't make the grade. So I am one of those.' [Group 2, Pt3]
6.3 Recommendations for trial	More information on OSA and how CPAP works; opportunity to try more mask or machine options; more information on sleeping with and managing CPAP	'There is not a lot about the actual - what we are actually doing with this machine, apart from making us breathe properly?... I wonder how this is actually working. Is there a... well there is a medical reason why we're doing it, but how does the process actually work?' [Group 2, Pt4]
7. Factors associated with long-term success		
7.1 CPAP is expensive	Surprised or concern about costs; disappointed that public health service does not support treatment for all; disappointment that medical insurance does not cover OSA	'The public system is miserable because there is only a certain amount of money in the till. But I think there are people out there who are just pensioners and they don't have anything else. How do these people cope? They don't use them, they don't have it, they just have apnoeas and die I suppose' [Group 2, Pt3]
7.2 Group or individual follow up desirable	Opportunity to meet others with same condition; appointments to reassess symptoms; address unanswered questions; maintain machine and mask	'... I had my calls and in that first few weeks, but then there was nothing...I had a whole lot of queries.' [Group 3, Pt3] 'I felt a little bit left alone in that.' [Group 3, Pt1]
7.3 Happily independent	Happy to use machine data for support; knows how to research and access equipment	'That is the advantage of the [brand name], you can read yours. Each night you can read them'. [Group 1, Pt5]
7.4 Sleep is also affected by other factors	Comorbid health conditions; age-related changes; environmental factors	'I don't think we can really talk about sleep as just an isolated entity, because there are so many different issues that have to be factored in.' [Group 1, Pt1]
<b>Global theme: the effect of CPAP on quality of life</b>		
8. CPAP is a routine part of life		
8.1 Happy with CPAP	Become routine part of life; happy with outcomes	'My grandchildren have seen me in mine, and I'm not the slightest bit worried...I gave them very clear instructions about 'grandpa's elephant nose!' [Group 2, Pt2] 'It has been marvellous. I actually love it.' [Group 2, Pt6]
8.2 Dedicated users	Care for machine and equipment; travel with CPAP; compliant users; only inadvertent behaviours affecting compliance	'One thing I do know, I do now – once you get used to it I take it everywhere. Even if I go away the machine goes everywhere I go.' [Group 3, Pt3]
9. CPAP problematic		
9.1 Negatively effects quality of life	Impact on relationship; negative connotations of CPAP; travel with CPAP arduous	'I don't care what anyone says, there is vanity and we are all vain in one way or another and we don't want to be seen by our grandchildren wearing them. That is a protection exercise. I think we have to acknowledge that.' [Group 2, Pt1]
9.2 Ongoing issues affecting compliance	Still sleepy; mask and comfort problems; feels sleep is better without CPAP; partner disturbed by noise; sore sinuses; need strategies/aids to successfully use	'It is a bit of a love hate relationship with plenty of issues I have...' [Group 3, Pt3] 'I just think that is the machine and the leaking, but it is not a very 'health and safety' good issue for the other person.' [Group 1, Pt2]

OSA (obstructive sleep apnea); CPAP (continuous positive airway pressure therapy).

adjustment period were mostly associated with mechanical and mask issues. Participants had attempted to overcome these issues, some noting they had ‘tried the lot’ [Group 1, Pt4], or that it was an ongoing journey or ‘battle’ [Group 2, Pt4]. Mental barriers to a successful trial included negative connotations of CPAP or anxiety. Others had experienced negative physical symptoms such as discomfort in their chest or gut.

Most felt happy with the support provided by the sleep laboratory during their trial, reporting that they had been given sufficient information and options for becoming established, or that the whole process was straight forward:

‘... It is one of those things where you never look back at it. I have had a good journey, basically, all the way through.’ [Group 2, Pt6]

A reoccurring theme regarding long-term management was that participants would appreciate more follow up. Either routine one-on-one or group appointments were desired to support equipment and servicing needs, reassess status of OSA, clarify information or to meet other people with OSA. This was considered important, as some noted that they did not feel comfortable in asking for assistance once discharged and on long-term CPAP due to being unfamiliar with the sleep service staff. However, some of the participants did not feel the need for clinical follow up. These independent participants noted that they knew how to access equipment and use their CPAP machine’s data to self-monitor their hours of use, AHI, pressure or leaks.

In all three groups, it was acknowledged that sleep was affected by factors other than OSA or CPAP. Some had comorbid health issues that negatively affected their sleep. For example, diabetes, cancer, pain or a co-existing sleep problem. Others associated poor sleep with age-related changes, including increased need to use the toilet at night, feelings of general tiredness or decreased need for sleep with age. Through the conversations, it was also clear that participants had a decent awareness of how their environment or behaviours (eg temperature, pets, timing of physical activity) could affect their sleep.

### Effect of CPAP on quality of life

For most patients, the overall experience with CPAP therapy was positive and the device was welcomed into routine life. However, some were still facing issues with adapting, accepting or feeling the benefits.

Most seemed dedicated CPAP users, not wanting to go without it now accustomed, with just the odd night being affected by accidental behaviours such as forgetting to turn it on, inadvertently changing settings or taking equipment off while asleep. There were also in-depth discussions in all groups regarding travel with their machines and caring for, replenishment and cleaning of CPAP equipment. Participants seemed to enjoy these unscheduled conversations, finding the sharing and comparing of routines and techniques interesting and useful.

Some were still having problems with their CPAP machine or equipment, or generally considered it an inconvenience. Issues included finding it hard to sleep comfortably, embarrassment or anxiety, difficulties sleeping or breathing, discomfort in the sinuses during the day or that it was simply ‘a pain in the butt’ [Group 1, Pt5]. The most common theme concerning long-term problems was mask fit. Noise associated with leaks or the sound of the CPAP equipment were also widely discussed and appeared to be a key issue for partners. Participants discussed the strategies they had devised to address problems or maximise their experience with CPAP therapy. These included being mindful of positioning (of themselves or equipment), making careful mask and machine choices or using supplementary methods to improve breathing or sleep while using CPAP equipment (eg nasal sprays, specialist mattresses or pillows and sedative medications).

### Discussion

Understanding the journey from diagnosis through to long-term CPAP therapy management is an important step for informing sleep services in this community sector. To our knowledge, this is the first qualitative study exploring the experience of older CPAP patients. Our findings support previous research with younger groups<sup>19,22</sup>

while adding insight into the knowledge, experience and expectations of older patients. A broad range of themes were raised; these were grouped within three networks concerning the underlying symptoms of OSA, the variable nature of the pathway from diagnosis to management, and the effect that CPAP has on quality of life.

The study sample were representative of patients who are initiated on CPAP at the WellSleep, Sleep Investigation Centre (apart from their age which was an inclusion criteria). They reported underlying symptoms of OSA, which we would expect with the syndrome.<sup>1</sup> These symptoms, particularly daytime sleepiness, may be less easily detected or reported within an older population.<sup>7,8</sup> This was not reflected in the current sample; however, participants were still relatively young and well.

An important theme associated with the treatment pathway was that a third party was considered important for identifying OSA symptoms and initiating diagnosis. This theme has been highlighted previously<sup>19</sup> and indicates that health professionals and family members need heightened awareness in order to capture and manage OSA in a timely manner to maximise quality of life.<sup>28</sup> With advancing age, more people are living alone or in residential care.<sup>29</sup> These people are at increased risk for sleep problems and comorbid conditions, which may further affect their experience.<sup>30,31</sup> Additional studies focusing on experience and management of CPAP for older people living in such situations is warranted.

The journey from diagnosis to trial to long-term CPAP therapy is not always straight forward. Many issues, both common and individual, mechanical and psychosocial, were shared. However, overall participants' feedback was positive regarding the effect CPAP had on symptoms and its adoption into routine life. New patients need to be made aware that such issues are not abnormal or unmanageable in order to encourage resilience and acceptance with using CPAP long-term.

It was clear that OSA may not have been the only thing affecting the sleep and quality of life of these older patients and their partners. Other sleep problems (eg insomnia and restless legs syn-

drome) and health issues affecting sleep (eg pain and depression) also increase in prevalence with aging.<sup>32</sup> Therefore, CPAP therapy was not considered necessarily a miraculous fix for all. This highlights a need to increase public and health professional awareness regarding factors affecting sleep in general, as well as expectations around CPAP. Information regarding sleep, OSA and CPAP requires tailoring to the demographic being addressed. Public information is also required to help inform and reduce risk factors for OSA in the first place (eg reduction of excess weight, use of sedating medications and adaptation of sleeping positions) in an effort to minimise the effect of mild or undiagnosed OSA on health.<sup>28</sup>

Obstructive sleep apnoea is a chronic condition, so regular review is considered good practice in terms of care models.<sup>33</sup> Patients highlighted some key areas concerning ongoing support for using CPAP therapy. These included reducing costs for pensioners, increased information to be made available throughout, and the opportunity for routine follow up, either with a clinician or a patient support forum. These themes corroborate themes identified by others.<sup>22</sup> This sample mostly comprised participants of middle- to high-socio-economic status and they mostly considered the pathway of being diagnosed and treated for OSA as overly expensive. This is a matter of concern. With the high cost of private health care and CPAP, plus the long waiting periods using the public pathway, people of marginalised status are likely to be disadvantaged and not receiving the appropriate level of care for OSA in NZ.<sup>34</sup> Relationships between the patient with their community and health service providers, including primary care, need to be strong and cohesive for the successful management of OSA.<sup>33</sup> More person-centred support may be necessary across the board, as a variety of biological, psychological and social factors can affect acceptance of CPAP.<sup>14</sup> This confirms that at least providing opportunities for patients to meet and discuss OSA and their CPAP experiences with one another would be welcomed.

A limitation of this study is that populations who are considered at increased likelihood of having OSA or challenges with CPAP therapy were not represented; for example, patients who

were of Māori or Pacific islander ethnicity, of lower socioeconomic status, advanced age or with substantial age-related comorbidities such as dementia or arthritis.<sup>34–36</sup> This was because of the convenience sampling method used for the study, having age as the primary focus, plus the underrepresentation of these populations in NZ sleep services.<sup>34</sup> Strategically designed qualitative research is warranted with such populations to highlight methods for identifying and managing symptoms of OSA and improving CPAP acceptance in more diverse populations. Female patients were also underrepresented here. The presentation of OSA, as well as the beliefs, expectations and experiences of using CPAP, are likely to vary by gender, also warranting further exploration.<sup>37</sup> Furthermore, an adjunct study pertaining to central sleep apnoea is of interest as, with advancing age and increased neurological conditions, central respiratory events are also more common.<sup>8,38</sup>

The themes from these focus groups will be used to develop resources to support older people during their journey from diagnosis to management; for example, tailored information regarding sleep and aging, as well as mechanisms for patients to support one another. The findings play an important role in identifying areas of service delivery that could be adapted to improve patient experiences and ability to maximise long-term outcomes with CPAP therapy.

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#### COMPETING INTERESTS

None.