

Patient and Partner Experiences with Obstructive
Sleep Apnoea and Mandibular Advancement Devices:
A Qualitative Analysis

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Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university. It is entirely my work and the library may lend or copy this work upon request.

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Summary

Aim of the study: To elucidate the experience of patients and partners who are living with Obstructive Sleep Apnoea (OSA) and undergoing Mandibular Advancement Device (MAD) therapy and examine the factors that influence adherence and acceptance of treatment. The influence of the partners' role and level of engagement in treatment was also explored.

Materials and Methods: Semi-structured in-depth interview qualitative research methodology was used. In this study two groups of patients were interviewed. The first group was for patients who have worn MADs only. The second group was for patients who were using MADs following failure to adhere to CPAP therapy. Partners of OSA patients were also interviewed to highlight their experience with their partners' condition and treatment of OSA.

Results: A total of fifteen participants were interviewed in this research. Ten of them were patients who had been diagnosed with Obstructive Sleep Apnoea (OSA) and five of their bed partners. Of the ten patients interviewed, five of them used mandibular advancement devices (MADs) following failure to adhere to Continuous Positive Airway Pressure (CPAP) treatment. The impact of OSA on patients' and partners' lives, and their perspectives on the condition were explored. Patients' experience with the diagnosis and treatment with OSA was highlighted. For patients who failed to adhere to CPAP treatment technical and psychological factors, and side effects of the treatment were explored. Facilitators and barriers to MAD treatment were analysed. Patients also reflected on their experiences with the services provided, how services

could be improved, and the possible role of support groups in treatment. Finally, the partners' roles in diagnosis, treatment and on-going management of OSA were highlighted.

Conclusion:

OSA is a shared problem between patients and partners; it affects the quality of life of patients and is an impairment to patients' work, social life, and the ability to perform daily functions. Patients diagnosed with OSA associated it with a number of psychological factors such as association with old age, depression, and impairment. Psychological factors such as locus of control, health attitudes and influence of significant others should be identified at the beginning of treatment to predict adherence to the prescribed treatment. OSA patients described that they would like to be actively involved in their own treatment. Partners' instigated the process for patients to seek medical advice, and the partner's role were not gender specific. They can have an active role in treatment of OSA. An array of roles were described; active sensitivity, passive adaptation, and direct confrontational approaches. For some partners cultural influences and classic gender roles influenced their perceived roles.

OSA should be treated as a chronic condition that requires active intervention from patients paired with regular check visits and repeat sleep studies to assess patients' progress.

Management of OSA should focus on a wholesome approach that involves incorporating healthy sleeping habits, getting patients and partners actively involved in treatment, adherence to prescribed treatment, and regular maintenance and follow up.

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1. Literature review

1.1 Sleep Apnoea

1.1.1 Definition

Sleep apnoea is a disorder of repetitive collapse of the pharyngeal walls during sleep (Jordan, McSharry et al. 2014) causing disturbance in gas exchange which leads to oxygen desaturation, hypercapnia, and sleep fragmentation (Jordan, McSharry et al. 2014). The spectrum of collapse of the pharyngeal walls ranges from partial airway collapse manifested as loud snoring and episodes of hypoapnoea, to complete blockage of the airway lasting up to sixty seconds (Young, Palta et al. 1993).

Patients with obstructive sleep apnoea (OSA) report symptoms such as snoring, witnessed apnoea, waking up with a choking sensation, excessive tiredness and sleepiness (Punjabi 2008, Jordan, McSharry et al. 2014). Other symptoms include lack of restorative sleep, difficulty in initiating or maintaining sleep, and headache. If left untreated it may lead to excessive daytime sleepiness, cognitive dysfunction, impaired work performance and affect overall quality of life (Punjabi 2008). OSA can be life threatening and is associated with extreme daytime sleepiness, automobile accidents and cardiovascular morbidity and mortality (Young, Palta et al. 1993).

1.1.2 History of the Condition

The Wisconsin Sleep Cohort Study in 1993 was a landmark for investigating OSA. Six hundred and two men and women were recruited and studied by overnight polysomnography to determine the frequency of episodes of apnoea and hypoapnoea per hour of sleep. The study defined OSA as more than five apnoeas or hypoapnoea events per hour of sleep

plus excessive daytime sleepiness (Young, Palta et al. 1993, Jordan, McSharry et al. 2014). This study estimated the age specific prevalence of obstructive sleep apnoea among middle aged men and women, and analysed the spectrum of severity, and investigated age, sex and obesity as risk factors (Young, Palta et al. 1993).

The study reported that the prevalence of OSA among men and women was 4% and 2% respectively. They identified male sex and obesity as risk factors for OSA; however age was not identified as a strong risk factor.

Despite advancements in the knowledge in relation to OSA in the last two decades, a high percentage of people affected by OSA remain undiagnosed (Young, Evans et al. 1997, Kapur, Strohl et al. 2002). Young et al. found that 93% of women and 82% of men with moderate to severe OSA had not been clinically diagnosed.

Sleep related complaints are common in the elderly population. Epidemiologic studies showed that 50% of people aged 65 years or above report sleep related problems, such as trouble falling asleep, trouble waking up, waking too early, needing to nap and not feeling rested (Foley, Monjan et al. 1995). The prevalence of obstructive sleep apnoea increases with age and reaches a plateau at 60 years (Young, Shahar et al. 2002). Researchers proposed that changes occur in the pharyngeal area, including increased fat deposition and lengthening of the soft palate. Other changes included reduction of the elastic recoil of the lung, which reduced the residual capacity of the lungs (Young, Palta et al. 1993).

1.1.3 Health Problems Associated with the Condition

1.1.3.1 Cardiovascular Disease

Polysomnography studies showed that OSA is accompanied by changes in cardiovascular parameters; namely swings of blood pressure and heart rate, which change due to hyperventilation episodes during sleep (Parati, Lombardi et al. 2012). The European and American guidelines for the management of arterial hypertension acknowledged obstructive sleep apnoea as a cause of systemic resistant hypertension (Program 2004, Mancia, Laurent et al. 2009). The prevalence of hypertension in patients diagnosed with sleep apnoea is 35 – 80%. Conversely 40% of patients with hypertension have sleep apnoea (Calhoun 2010). Apnoea and hypoapnoea episodes during sleep cause transient blood pressure perturbations, and elevations of 30 mm Hg or more in diastolic blood pressure (Morgan, Dempsey et al. 1998).

Randomised clinical trials have shown that treatment of OSA reduces arterial blood pressure (Montesi, Edwards et al. 2012). Predictors of improvement in blood pressure following CPAP treatment include adherence, young age, baseline blood pressure, daytime sleepiness and severity of sleep apnoea (Barbé, Durán-Cantolla et al. 2012). An observational study followed men with treated or untreated sleep apnoea for a mean period of 10 years. Their results showed that patients with untreated severe sleep apnoea had a higher incidence of fatal (death from myocardial infarction or stroke) and non- fatal cardiovascular events compared to patients with treated sleep apnoea and control groups (Marin, Carrizo et al. 2005). Simple snoring is not a significant cardiovascular risk factor (Marin, Carrizo et al. 2005). The effect of

obstructive sleep apnoea on cardiovascular outcomes is greater in young men compared to older men (Jordan, McSharry et al. 2014).

1.1.3.2 Diabetes Mellitus

Obstructive sleep apnoea has been linked with diabetes mellitus. A high prevalence of undiagnosed obstructive sleep apnoea was found in obese patients who had type 2 diabetes mellitus (Foster, Sanders et al. 2009). However, association between the two does not imply causality. Obesity is a common risk factor between obstructive sleep apnoea and diabetes mellitus, so this association might be a simple correlation (Jordan, McSharry et al. 2014). A randomised controlled trial showed that weight loss improved OSA signs and symptoms in obese patients with type 2 diabetes (Foster, Borradaile et al. 2009). Conversely, a controlled trial found that continuous positive air pressure treatment did not improve glucose metabolism in individuals who were obese and had moderate OSA (Weinstock, Wang et al. 2012).

1.1.3.3 Depression

Depression is a frequently reported symptom of sleep apnoea. A study by Mosko et al. reported that 67% of patients who attended a sleep disorder centre reported an episode of depression within the previous 5 years of their presentation (Mosko, Zetin et al. 1989). They reported that 26% of patients presenting with sleep apnoea, narcolepsy, and sleep related periodic limb movement reported that they were depressed at the time of presentation (Mosko, Zetin et al. 1989).

The association between OSA and depression is described as bidirectional; sleep deprivation causes mood changes in healthy subjects, conversely patients diagnosed with depression have sleep alterations

(Sanchez, Bucla-Casal et al. 2001). It was found that there is a correlation between the severity of depression symptoms and apnoea-hypoapnoea index in patients with OSA (Watson, Greenberg et al. 1987). Treatment of sleep apnoea improves the mood of patients with OSA. A study found that CPAP treatment of OSA improved depression levels at 1 month and 3 months post-treatment (Sanchez, Bucla-Casal et al. 2001). Changes in depression were measured using the Beck Depression Inventory, which is an assessment tool that collects 21 items referring to specific manifestations to depressive behaviour. These manifestations include mood, irritability, social isolation, work, decision-making, sleep alteration, tiredness and libido. The author explained that before receiving treatment many OSA patients were forced to quit their jobs, or to stop driving because of the level of tiredness and daytime sleepiness caused by sleep fragmentation. He reported that some patients reported problems in their sexual relations and they admit that they became irritable which affected their anxiety levels. They argued that once treatment is established patients started to regain employment, improve their night time sleep, their state during the day, and their social-professional relationships. This improvement was proposed to explain the decrease in depression levels.

1.1.3.4 Quality of Life

Patients with OSA have impaired quality of life, social functioning and a high prevalence of minor psychiatric morbidity (Engleman and Douglas 2004). Patients with OSA show psychosocial distress which is described as a consequence of the condition rather than a cause (Kales, Caldwell et al. 1985). Treatment of OSA improved the quality of life of patients and

their bed partners. Patients reported improved physical activity and vitality as well as mental health and social functioning (Parish and Lyng 2003).

1.1.4 Life Course

A study described the clinical course and characteristics of severe obstructive sleep apnoea for 50 adults (Kales, Caldwell et al. 1985). The onset of symptoms began at the mean age of 36 years and clustered within a few years, and eventually became chronic. Symptoms included snoring, excessive daytime sleepiness, gasping sounds and breath cessations reported by the bed partner. The first reported symptoms were snoring and excessive daytime sleepiness. OSA is linked to conditions that account for leading causes for mortality in adults such as hypertension, cardiovascular, and cerebrovascular diseases. In addition, it is also linked to neurobehavioral morbidities that are of public health and economic importance; including excessive daytime sleepiness and impaired cognitive function that contribute to motor vehicle accidents and employment related incidents (Young, Peppard et al. 2002). Untreated severe OSA increased the risk of fatal and non-fatal cardiovascular events. (Marin, Carrizo et al. 2005)

A study on the long term efficacy of oral appliances reported a general deterioration of the condition with continuous long term oral appliance use (Marklund 2016). The study included nine patients who had received oral appliances for treatment of OSA at least 15 years prior to the study. Polysomnography recordings were made with or without the sleep appliances. Five of the nine patients also had a five year short term follow up where their AHI reduced from 17.3 events per hour without the

appliance to 7.3 events per hour with the appliance. However, after long-term use the AHI was 32.4 events per hour without the device, and 35.1 events per hour with the device. The author indicated that some patients might have experienced a large scale deterioration in sleep apnoea, but she also pointed out that older people had more frequent apnoea events than younger patients (Marklund 2016). This could be explained by physiological changes in the pharyngeal wall, lengthening of the soft palate and reduction of the residual capacity of the lung (Young, Palta et al. 1993). Other explanations of increased frequency of apnoea events was weight gain, however, this did not explain the increase in apnoea event frequency in the studied sample, because participants did not gain weight during the long term treatment (Marklund 2016). Other reported changes with long term use of oral appliances are occlusal changes, decrease in the overjet and overbite, and overall mesial shift of the occlusion. This meant that the effective degree of the mandibular advancement decreased with time, and that these changes were adapted for when new devices were constructed for patients. Sleep position was another factor that affected the frequency of apnoea with sleeping in a supine position found to increase the frequency of apnoea events (Marklund, Carlberg et al. 2015). The authors concluded that regular follow ups be scheduled for patients using MADs with periodic repeated sleep recordings to avoid suboptimal or total loss of effects on sleep apnoea.

1.2 Management of Sleep Apnoea

1.2.1 Continuous Positive Airway Pressure (CPAP)

Nasal continuous positive airway pressure is considered the treatment of choice for the treatment of obstructive sleep apnoea (Giles, Lasserson et al. 2006). It was first described by Sullivan et al. in 1981 as an effective mean of preventing collapse of the pharyngeal wall, and maintaining the airway open during sleep, by maintaining a positive pharyngeal airway pressure so that it exceeds the surrounding pressure, thus maintaining the pharyngeal lumen open (Sullivan, Berthon-Jones et al. 1981).

CPAP treatment improves daytime sleepiness and subjective symptoms for patients with OSA. (Sullivan, Berthon-Jones et al. 1981). However, despite its efficacy in improving daytime symptoms and potential cardiovascular protection, adherence to CPAP treatment is suboptimal. It is reported that internationally that 5 -50% of patients diagnosed with OSA and prescribed CPAP either refuse this treatment option or discontinue within the first week, and 12-25% of the remaining patients discontinue CPAP treatment by 3 years (Engleman and Wild 2003). Adherence is defined as using the device for greater than 4 hours five nights per week (Wild, Engleman et al. 2004). Reasons for failure to adhere to CPAP treatment can be attributed to biomedical reasons or psychological reasons. Increased adherence to CPAP therapy has been associated with greater body mass index (BMI), severity of the OSA measured by AHI (apnoea-hypoapnoea index).

1.2.1.1 Psychological Factors in Adherence to CPAP

Psychological factors have been investigated to determine adherence to CPAP treatment. It was found that an internal locus of control and higher

health value scores were associated with greater CPAP adherence. Researchers have also identified determinants of low CPAP adherence or discontinuation of treatment. These factors included: female sex, age less than 50 or greater than 80 years of age, lack of obesity, low AHI, lack of symptomatic complaints, increased CPAP pressure, higher external loci of control, powerful others and coexisting depression (Wild, Engleman et al. 2004). Therefore, it has been suggested that a multidisciplinary approach to treatment, which involves educational, technical and psychological support, would increase adherence to CPAP treatment. Cognitive behavioural therapy has been used to increase patient adherence to CPAP therapy (Richards, Bartlett et al. 2007). Providing accurate information and new learning experiences can correct faulty or irrational beliefs through exposure to positive stimuli, and sharing positive experiences with individuals with real experience could improve the adherence to CPAP therapy (Bandura 1989, Richards, Bartlett et al. 2007). A randomised trial had two groups of patients; the first group patients were familiarised with the mask, encouraged to handle the machine, and provided with a 15-minute video involving real CPAP users, and an information booklet containing information about OSA. They then received treatment as usual. The control group received treatment as usual without additional training or information. At the 28-day review 77% of patients who received CBT were using CPAP for more than 4 hours five nights a week. Only 31% of patients who received CPAP treatment alone were using CPAP for more than 4 hours five nights a week (Richards, Bartlett et al. 2007). The authors concluded that CBT increased CPAP adherence and in turn could reduce the social,

economic, and health consequences of OSA (Richards, Bartlett et al. 2007).

Locus of Control and Health Value

Factors that influence patterns of behaviour vary. Some of these factors including skill and willpower are internal to the individuals, while other factors such as task demand and the actions of another person are external. When people believe that they have the required resources and opportunities and that obstacles are likely to be encountered, yet manageable, they would have confidence in their ability to perform the task and exhibit a high degree of perceived behavioural control. On the other hand, when people feel that they lack the resources and are more likely to encounter serious obstacles, they would show a lower degree of perceived behavioural control. This is applicable whether the resources and the obstacles are located internally or externally (Ajzen 2002).

The locus of control is one of complex factors that predict health behaviours, including value of health, motivation, social supports, previous behaviours, and perceived costs and benefits of specific interventions (Strudler Wallston and Wallston 1978). A locus of control is measured by using the Multidimensional Health Locus of Control (MHLC) Scale (Wallston 1992). The scale measures health specific loci of control beliefs in relation to three dimensions. Firstly: to what extent do individuals believe their health is a consequence of their actions? Secondly: to what extent do they believe their health is under the influence of powerful others? Thirdly: to what extent they believe their health is due to chance or fate? (Norman, Bennett et al. 1998). It was reported that for people who had an internal locus of control, there was

evidence of greater health information seeking behaviour (Strudler Wallston and Wallston 1978). However, the authors argued that knowledge did not lead to control. They reported that studies found no relationship between locus of control and compliance measured by appointment keeping, clinic discontinuance, or self-report of medication taking (Strudler Wallston and Wallston 1978). The relationship between internal locus of control beliefs and the performance of health behaviour is weak (Wallston 1992, Norman, Bennett et al. 1998).

Health value describes how individuals value their health, and is function of long-term experience of illness, and health habits formed in childhood. Health values change with current health status (Lau, Hartman et al. 1986). Research suggests that health value moderates the relationship between health locus of control and health behaviour (Norman, Bennett et al. 1998). Significant correlations between behaviour-specific efficacy beliefs and the health behaviours were only found among individuals placing a high value on their health (Norman, Bennett et al. 1998).

1.2.2 Surgical Management

Surgical management of obstructive sleep apnoea is indicated when there is anatomic obstruction in the area of the soft palate that can be surgically corrected. Surgical treatment plans are formulated to target the area of anatomic obstruction. Uvulopalatopharyngoplasty (UPPP) is the most common surgical procedure for treatment of OSA (Tanna, Smith et al. 2016). This procedure involves surgical removal of the uvula, tonsils, and lateral pharyngoplasty, it is completed under general anaesthetic and associated with significant postoperative pain, and possible long term complications such as nasal reflux, pharyngeal stenosis, dysphonia, and

velopharyngeal insufficiency (Tanna, Smith et al. 2016). However, it also has low success rate with a meta-analysis showing only a 40% success rate, where success was defined as reduction of the apnoea-hypopnoea index by 50% of its preoperative value (Sher, Schechtman et al. 1996). Another study reported that some patients deteriorated after the surgery. Patients with mild OSA who underwent UPPP were followed for a mean of 40.5 weeks after surgery. Polysomnography was completed before and after surgery. Subjective assessment of sleepiness was performed using the Sleep-Wake Activity Inventory. Success of treatment was determined by reduction in the Respiratory Event Index (REI) by more than 50%. Results showed that ten participants had a reduction in REI below 50% of the preoperative reading, and those who did not have reduction in REI showed increases ranging from 16.6 ± 5 to 26.7 ± 18.4 . They also reported that subjective assessment of sleepiness did not show any statistically significant improvement after surgery (Senior, Rosenthal et al. 2000).

There is no standardised test to assess the anatomic obstruction for patients presenting with OSA. The Mallampati score, as modified by Friedman, is based on observation of the palate position, where the patient is asked to open his/her mouth widely without protruding the tongue. This score helps to objectively assess the oropharyngeal space. Another classification is the size of the uvula (Friedman, Ibrahim et al. 2002). Friedman suggested a staging system for sleep disordered breathing based on the palate position, tonsil size, and body mass index. This staging system was suggested to assess patient suitability for surgery and to predict the success of the surgical procedure. Authors

retrospectively reviewed 134 patients who underwent UPPPs to correlate palate position and tonsil size to the success of UPPP based on postoperative polysomnography results. Patients were staged according to the morphology of the palate, and tonsil size. Patients with favourable palatal morphology and tonsil size showed an 80.6% success rate. They concluded that the surgery could offer high success rate for selected cases (Friedman, Ibrahim et al. 2002).



Fig 5. Tonsils, size 1, are hidden within the pillars.



Fig 6. Tonsils, size 2, extend to the pillars.



Fig 7. Tonsils, size 3, extend beyond the pillars but not to the midline.



Fig 8. Tonsils, size 4, extend to the midline.

Figure 1.1 Friedman's classification of tonsil size (Friedman, Ibrahim et al. 2002).

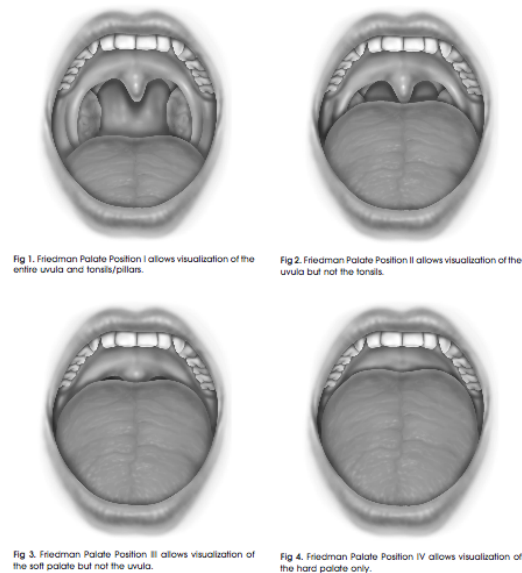


Figure 1.2 Mallampati classification of palate position (Friedman, Ibrahim et al. 2002).

1.2.3 Mandibular Advancement Devices

1.2.3.1 Principles

Oral appliances appeared as an alternative treatment to CPAP in the management of snoring and mild to moderate OSA in patients who failed to adhere to or refused CPAP treatment (Marklund, Sahlin et al. 2001). It is a simple non-invasive treatment option. Dental practitioners work as a part of a multidisciplinary team, which involves a physician and a sleep specialist in management of OSA (Dugal, Kothavade et al. 2010). Mandibular advancement devices (MADs) are prescribed by a sleep specialist who refers the patient to a qualified dentist for construction of a device.

Oral appliances function by repositioning the tongue and the mandible forward and downward to reduce airway collapse, widening the lateral aspects of the pharyngeal walls thus improving the airway patency (Kyung, Park et al. 2005). Protrusion of the mandible is required for the effectiveness of MADs. It has been reported that effective degrees of

advancement ranges from 6 to 10mm or from 65% to 70% of maximum protrusion (Barewal and Hagen 2014). Studies suggested the possibility of using a remotely controlled mandibular positioner test and a temporary oral appliance during PSG testing to determine the ideal advancement position (Dort, Hadjuk et al. 2006).

1.2.3.2 Efficacy of MADs

A study investigated the long-term efficacy of MADs on apnoeas, and the tolerability of MADs in patients with OSA (Marklund, Sahlin et al. 2001). Thirty three patients were treated with adjustable MADs. Polysomnography was undertaken twice, one night with the device, and one without the device at 0.7 ± 0.5 years and after 5.2 ± 0.4 years from the start of treatment. Success was defined as Apnoea-hypoapnoea index of < 10 events per hour, and subjective reporting of reduction of snoring. Fourteen patients were insufficiently treated with MADs and they were prescribed other treatments for OSA. However, authors did not comment on the reason of failure of treatment. The remaining 19 patients experienced satisfactory treatment outcomes. AHI was reduced from 25 ± 16 without the device to 8.8 ± 7.6 events per hour with the device. In the long term AHI was reduced from a mean of 22 ± 17 events per hour with the device to 4.9 ± 5.1 events per hour with the device. Patients who had their devices replaced or adjusted during the study period showed better long-term reduction in AHI. The authors explained that changes in the mandibular positioning or change in dental occlusion did not account for these findings. They speculated that a well-fitted device is most important for effective reduction in AHI than the exact mandibular positioning in the device within a specific range. The results of this study

concluded that the life span of a MAD is 4 to 5 years and it is important to follow up on the condition of the device (Marklund, Sahlin et al. 2001).

Another study assessed 630 patients with snoring and obstructive sleep apnoea. Six hundred and nineteen of these patients received MADs treatment (Marklund, Stenlund et al. 2004). Twenty-four of these patients did not use the device after one year, and were regarded as having poor tolerability of the treatment. These patients were interviewed about the reason for discontinuing the treatment. Patients reported that discomfort, and excessive salivation were the main reasons for poor tolerability. Other reasons included insufficient reduction in snoring, or dental problems such as temporomandibular joint symptoms or changes in occlusion with treatment. Patients who had unrealistic expectations of the treatment in terms of cured tinnitus or dysphagia also were not able to tolerate the device. The study found that female sex was a predictor of the success of treatment and that supine dependent sleep apnoea was a predictor of success in men. Men who had gained weight during the treatment had reduced their chance of treatment success and were advised to be followed up and to repeat the sleep study at a future date (Marklund, Stenlund et al. 2004).

1.2.3.3 Various Appliance Types

There are various types of oral appliances; mandibular advancement devices, tongue retaining devices, and soft palate lifters. Mandibular advancement devices are subdivided into titratable (two-piece appliances) and non-titratable (1-piece appliances), custom made and prefabricated. Most are made of polyvinyl vacuum formed thermoplastic

or heat cured acrylic material (Barewal and Hagen 2014). Fixed oral appliances are set to advance the mandible between 50% to 80% of its maximal protrusion and are fabricated in a permanent position for therapeutic use (Lettieri, Paolino et al. 2011).

Thornton Adjustable Positioner (TAP-T™)



Figure 1.3 Thornton Adjustable Positioner (Toms 2017)

TAP is an adjustable oral appliance fabricated from models made from maxillary and mandibular impressions. The device can be titrated using a screw type mechanism. Patients are instructed to advance the device incrementally to optimise therapeutic efficacy (Lettieri, Paolino et al. 2011). A retrospective study reported on 805 patients with OSA treated with adjustable or fixed oral appliances. Seventy five percent of patients had received Thornton Adjustable Positioner (TAP) devices, while the remaining 25% had received fixed appliances. Effective treatment was defined as having an $AHI < 5$ events per hour or $AHI < 10$ events per hour with resolution of sleepiness measured using the Epworth Sleepiness Scale. Patients were classified according to the degree of severity of OSA into mild (AHI 5-15), moderate (AHI 15-30) and severe ($AHI \geq 30$). Both types of oral appliances resulted in a reduction in AHI ; however it was greater in patients with mild OSA when compared to moderate and severe OSA. Adjustable oral appliances (TAP) was more superior to fixed oral appliance in their ability to reduce AHI (Lettieri, Paolino et al. 2011). Predictors of success of treatment were female sex

and using adjustable devices. In contrast, older patients with higher Body Mass Indices (BMI), higher baseline AHIs, or those using fixed appliances were less likely to achieve $AHI < 5$ events per hour (Lettieri, Paolino et al. 2011).

Herbst Appliance

The Herbst appliance consists of two parts that fit the maxillary and mandibular arches. The two parts are connected by lateral telescopic rods that guide the mandible into a protruded position while allowing limited lateral, protrusive, and opening movement (Bloch, Iseli et al. 2000).



Figure 1.4 Herbst appliance (Uninterrupted Sleep 2016)

A randomised, controlled crossover trial compared the effectiveness of two types of oral appliances; a single-piece mandibular advancement device (Monobloc), and the two-piece appliance with lateral Herbst attachments (Herbst) (Bloch, Iseli et al. 2000). Twenty-four patients who were diagnosed with OSA, and prescribed MAD treatment participated. Patients had an adaptation period to oral appliances, and then they used the Monobloc, Herbst appliance, and no appliance treatment in random

order using each appliance for one week. Sleep studies were completed at the end of each week. The authors did not define the criteria of success of treatment. They compared the level of reduction of AHI between the appliance types. The reduction in AHI indices were 8.7 ± 1.5 events per hour using the Herbst appliance, 7.9 ± 1.6 events per hour with the Monobloc, and 22.6 ± 3.1 events per hour without treatment (control). The authors concluded that both the Monobloc and the Herbst appliances were effective therapeutic devices for the management of sleep apnoea. However, the Monobloc relieved symptoms to a greater extent than Herbst and was preferred by patients (Bloch, Iseli et al. 2000).

1.2.4 Tongue Retaining Devices



Figure 1.5 Tongue retaining device (Uninterrupted Sleep 2016)

This type of oral appliance was developed in the 1980s (Dort and Brant 2008). The device contains a plastic bulb into which the anterior part of the tongue is positioned. The bulb is depressed to create a negative suction pressure and hold the tongue in a forward position (Dort and Brant 2008). The advantage of these devices is that they are not dependent on having a healthy dentition for retention, and can be used by edentulous patients or those with a compromised dentition (Dort and

Brant 2008). Tongue retaining devices are less effective in reducing sleep apnoea symptoms when compared to mandibular advancement devices (Barthlen, Brown et al. 2000). In their study, the authors compared MADs, tongue-retaining devices (TRDs), and soft palate lifers (SPLs). Eight patients participated in the study, the tolerance rate of all three devices was compared, 8/8 patients tolerated MADs, 5/8 patients tolerated TRDs, and only 2/8 patients tolerated (SPLs). One-year follow up of MADs showed statistically significant reductions in AHI, and patients reported subjective improvements. However TRDs and SPLs did not show statistical reduction in AHI. Despite the small sample size, and the short follow up period, it could be concluded from this study that TRDs and SPLs were not well tolerated by patients and they did not achieve satisfactory results in reducing subjective or objective OSA symptoms (Barthlen, Brown et al. 2000).

1.2.5 Positives and Negatives of Mandibular Advancement Devices

A long-term prospective study followed up patients with OSA for 5 years. Polysomnography was undertaken without the device, and then with the device in place following 6 months of treatment and then long term. The authors concluded that long-term effects of MADs are satisfactory provided the device is continuously adjusted or replaced when indicated. They indicated that the lifespan of these devices is 4-5 years, and that a well-fitting device is important to maintain the reduction in apnoea events (Marklund, Sahlin et al. 2001).

The primary measured outcome of the success of MADs treatment is reduction in AHI. However, studies reporting the success rates of MADs

exhibit heterogeneity due to different follow up periods, success criteria (some studies report AHI reduction below 5 as success, while other studies report that an AHI reduction below 10 as success) and different diagnostic tests for OSA (full night polysomnography versus home test) (Marklund, Sahlin et al. 2001). Reported side effects include jaw discomfort, tooth tenderness, excessive salivation, gingival irritation, mouth dryness and bruxism (Mehta, Qian et al. 2001, Gotsopoulos, Chen et al. 2002). However these side effects are usually transient and tend to resolve during the adaptive period.

MADs are contraindicated when there is an insufficient number of teeth, or the patient has periodontal disease or temporomandibular joint dysfunction or limited protrusion of the mandible (Petit, Pépin et al. 2002).

1.2.6 Cochrane Reviews and Guidelines for Sleep Apnoea Management

Oral appliance therapy is indicated in cases with mild symptomatic obstructive sleep apnoea, or for patients who refuse or cannot tolerate CPAP therapy (Barewal and Hagen 2014). The current evidence is that oral appliances improve subjective sleepiness, and indices of sleep disordered breathing over inactive controls. Oral appliances and continuous positive airway pressure both lead to improvement in apnoea-hypoapnoea indices (AHI) and subjective sleepiness when compared to baseline (Lim, Lasserson et al. 2006). Studies show that there is no consistent preference for one intervention over the other (Lim, Lasserson et al. 2006). Studies that considered patient preferences in relation to treatment response rather than baseline characteristics appeared to have a

strong preference for OA over CPAP (Ferguson, Ono et al. 1996, Lim, Lasserson et al. 2006). The American Academy of Sleep Medicine and the American Academy of Dental Sleep Medicine recommend that sleep specialists and dentists should collaborate in treatment of OSA. They recommend the use of oral appliances for patients who suffer from mild to moderate sleep apnoea and those who suffer from snoring. (Ramar, Dort et al. 2015). The American Academy of Sleep Medicine provides evidence based recommendations for addressing aspects of care for patients with OSA. The guidelines included incorporating questions about OSA into routine health evaluation. Suspicion of OSA requires a comprehensive sleep evaluation, which includes a sleep-oriented history, physical examination, objective testing and patient education. This aims to identify patients at risk, and guide them into the selection of the appropriate treatment modality. OSA should be approached as a chronic disease requiring multidisciplinary management (Force and Medicine 2009).

1.3 Qualitative Analysis

1.3.1 Introduction

Quantitative research seeks to provide a deeper understanding of the social world of research participants. It provides insight into people's personal perspectives and experiences. Qualitative methods are non-standardised and they adaptable to the social context of the study and can be adapted for each participant to allow exploration of emergent issues (Ritchie, Lewis et al. 2013). Data generated from qualitative research are rich and complex; it allows exploration of the meaning of quantitative data in more detail. Qualitative research is conducted in a naturalistic

setting such as home or work that resembles the social setting of research participants which allows greater understanding of the research participants natural world, especially for areas where little is understood about the nature of the research population and quantitative methodology lacks the depth and open-ended questions required (Stewart, Gill et al. 2008).

Combinations of qualitative and quantitative research methods can be applied to evaluate outcomes of different interventions, which could inform policy makers, and aid in improvement of services provided by providing a wholesome view of the effectiveness of the interventions and programs (Stewart, Gill et al. 2008).

1.3.2 Comparison with Quantitative Approaches

There is overlap in qualitative and quantitative research methodologies. Qualitative research is used to complement quantitative research findings, and interpret the findings within the social context of the target research participants.

Quantitative research begins with a theory from which a hypothesis is derived and applied. Data collected can be objectively measured and quantified. The hypothesis will then be confirmed or rejected, thereby strengthening or weakening the theory.

While qualitative research begins with the intention to explore a particular area of interest, data are collected in naturalistic settings through observation, or directly through approaching research participants through focus groups or one-to-one interviews. Inductive reasoning allows generation of ideas from the obtained data, and then conclusions can be drawn. The strength of qualitative research lies in its

validity, i.e. its closeness to the truth, while the strength of quantitative research lies in its reliability (Greenhalgh 1997). What qualitative research cannot do is measure the importance of an attitude or a belief in terms of its distribution in a population nor provide prevalence figures. However, the type of research question applicable to quantitative methods is not applicable for qualitative methods. Quantitative methods answer the question “How”, while qualitative answers “why and what” (Britten and Fisher 1993). The end product of qualitative research is an elucidation of a new concept, or mapping of a range of phenomena within the subject area, development of an explanatory framework, or foundation for a new intervention (Britten and Fisher 1993).

1.3.2.1 Quality of Qualitative Research

Critics of qualitative research argue that qualitative research data is merely a collection of anecdotal and personal impressions of people that are strongly subject to researchers’ bias. Secondly, it is argued that qualitative research lacks reproducibility and thirdly, they argue that it lacks generalisability (Mays and Pope 1995). The assumption that underlies this criticism is that quantitative and qualitative methods are essentially different in ensuring the validity and reliability of their findings. In quantitative data analysis statistical representations of phenomena are generated which may be or may not be justified. They, as in qualitative research, depend on the appropriateness of the research question asked, the analysis method and depends on the judgment and experience of the researcher. All research methods depend on collecting

evidence through the scope of particular methods, which have their strengths and weaknesses (Mays and Pope 1995). The basic strategy followed to ensure rigor in qualitative research is systematic research design, data collection, analysis, interpretation and reporting. The researcher has two aims when conducting qualitative research; firstly to create an account of method and data which can stand independently so that another trained researcher can analyse the same data in the same way and come essentially to the same conclusions. The second is to produce a credible and coherent explanation of the phenomenon under inspection (Mays and Pope 1995).

Reliability and validity are tools used to assess the repeatability and closeness to truth in quantitative research. Reliability is defined as the extent to which the results are consistent over time and are an accurate representation of the total population studied. Validity is defined as how truthful the results are. When describing reliability and validity of qualitative research these definitions need to be viewed from different perspectives (Golafshani 2003). Triangulation is a strategy that has been developed to improve the validity and reliability of research or evaluation of findings and it strengthens the study by combining methods. For example using observational fieldwork and interviews or focus groups provides a broader view of the question under observation (Barbour 2001). However some qualitative researchers conclude that comprehensiveness is a more realistic goal for qualitative research rather than internal validity (Mays and Pope 1995).

1.3.3 In – depth Interviews

1.3.3.1 Methods, Positive Features and Limitations

In-depth interviewing is a qualitative research technique that involves completion of individual interviews with a small number of correspondents to explore their perspectives on a particular idea, program or situation (Boyce and Neale 2006). It is a method for generating description and interpretation of people's social worlds (Ritchie, Lewis et al. 2013).

The key features of in-depth interviews are (Ritchie, Lewis et al. 2013):

- Combining structure with flexibility: Interviews are based on a topic guide that sets out the key topics and issues to be covered in the interview. However, this structure allows flexibility to encourage the interviewee to raise issues and shape the content of the interview.
- Interactive: the material generates interaction between the researcher and the interviewee and is facilitated by how the researcher frames the questions, which are derived by what the interviewee has already said.
- Getting below the surface: allows the researcher to explore factors that underlie participant's answer; their values, past experiences and circumstances etc.
- Generative: new thoughts and knowledge are likely to be created. Participants are encouraged to put forward ideas and suggestions on a particular topic and propose solutions for issues raised during the interview.

- Importance of language: the interview focuses on how interviewees express themselves; the language used by the participants is explored because it elaborates meaning.

Advantages of in-depth interviews:

- Provides detailed information compared to other qualitative data collection methods.
- They are carried out in a naturalistic atmosphere that encourages correspondents to express their views.

Limitations of in-depth interviews (Boyce and Neale 2006):

- Prone to bias
- Time consuming
- Interviewer must be trained in interviewing techniques
- It is not possible to generalise the results of interviews because of the small sample size and the sampling methods used.

1.3.4 Thematic Analysis

Thematic analysis is considered a foundation method for qualitative analysis. It provides skills that can be used to conduct many other forms of qualitative analysis. It is a method for identifying, analysing and reporting patterns “themes” within the data (Braun and Clarke 2006). It organises the data in rich detail, and highlights various aspects of the research topic. A theme in the data set captures an important data set in relation to the research question. It represents some level of patterned response or meaning within the data set. The importance of the theme does not rely on quantifiable measures; moreover it relies on how it relates to the main research question.

Advantages of Thematic Analysis include that it is a flexible method because it is not wedded to a pre-existing theoretical framework. It is accessible to researchers with little or no experience of qualitative research. The results are generally accessible to educated general public. It can usefully summarise the key features of a large body of data, and it can highlight the similarities and differences across the data set. It allows for generating of unanticipated insights, because the themes generated do not rely on quantifiable methods, but on how the data relates to the main research question. Thematic Analysis also allows for social as well as psychological interpretation of data, and it can be useful for producing qualitative analyses suited to informing policy development (Braun and Clarke 2006).

However, the Thematic analysis method is not without disadvantages. Many of the limitations of Thematic analysis method depend on poorly conducted analyses or inappropriate research questions. Furthermore, the flexibility of the method can be a disadvantage in that it makes developing specific guidelines for higher phase analysis difficult. Also Thematic Analysis has limited interpretative power beyond mere description if it is not used within an existing theoretical framework that anchors the analytic claims made. In contrast to other qualitative analyses approaches Thematic Analysis does not allow the researcher to make claims about language use of the fine – grained functionality of the talk (Braun and Clarke 2006).

Phases of Thematic Analysis (Braun and Clarke 2006, Ritchie, Lewis et al. 2013)

Phase 1: Familiarisation; transcribing data and reading the transcript noting down initial ideas.

Phase 2: Indexing and sorting (generating initial codes): coding interesting features of the data in a systematic fashion across the entire data set.

Phase 3: Construction of categories (searching for themes): data are grouped into potential themes; data relevant to one theme are grouped together.

Phase 4: Reviewing of data extracts

Phase 5: Data summary and display (defining and naming of themes)

Phase 6: Producing the report

1.4 Qualitative Analysis in Sleep Apnoea

Qualitative studies examined different aspects of living with OSA, starting with diagnosis of the condition, adherence to prescribed treatment and barriers to diagnosis. Results from these studies both inform health care providers and provide a basis for interventions to promote diagnosis and treatment for this population (Almeida, Henrich et al. 2013, Henry and Rosenthal 2013, Luyster 2014, Rodgers 2014).

Rodgers et al interviewed patients with a wide range of experience with OSA via face to face or telephone interviews, or through email correspondence. The study reflected the socio-psychological process of living with OSA. Participants described living with OSA as “*breaking through the limbo*” , which reflected the experience of participants as

they were struggling with the unknown. These related to delayed diagnosis, lack of knowledge before and after the diagnosis, lack of support and follow up, and the battle to adhere to prescribed treatments (Rodgers 2014). Patients had also reported that they had received support of their significant others and they had persuaded them to seek treatment. Some were concerned about intimacy and possible rejection, however most participants reported that their partners were supportive and these concerns were not realised. Some reported that the relationship had improved; they no longer had to sleep in separate rooms, or deal with the distress of witnessed apnoeas, and few recounted humorous stories regarding the condition and the equipment involved in the management of OSA (Rodgers 2014).

Adherence has been reported to be one of the biggest challenges with OSA. Some problems reported were related to the CPAP machine which required minimal adjustment, whilst other participants reported their desire to be more involved in their treatment and monitoring of their sleep (Rodgers 2014).

Another group conducted focus group discussions for patients and partners to address topics related to OSA including knowledge about OSA, perceived effects, initial experience with CPAP, and barriers and facilitators to CPAP use (Luyster 2014). Patients reported daytime effects of OSA, including tiredness, napping, irritability and morning headaches. Interestingly, partners reported that snoring and OSA had a significant impact on their quality of sleep, and that they had used earplugs, sleep medication, or altered their sleep schedule. This had caused frustration, and put a strain on the relationship which resulted in sleeping in separate

rooms (Luyster 2014). Patients also reported challenges related to CPAP use including adjustment and comfort of the mask. However, despite these difficulties, patients reported the positive response to CPAP treatment, which encouraged them to continue to use the CPAP. The authors suggested that patient-centred interventions that personalised patients symptoms and the impact of OSA on health and functioning may improve CPAP adherence, particularly among patients who are uncertain about the efficiency of treatment (Luyster 2014). Partners' description of patients' initial use of CPAP were positive in relation to improved symptoms. Partners reported providing support during the early treatment; however partners' involvement in treatment has been shown to be both a facilitator and a barrier to CPAP adherence. Partners of OSA patients reported different levels on engagement in treatment, through allowing patients to handle the condition themselves, or handling the treatment together or taking over the treatment. That study reported that emotional and technical support is a key motivator for CPAP use. They recommended a couple-oriented approach to improving CPAP adherence (Luyster 2014).

Another study looked at patient preferences and experiences with CPAP and oral appliances used for treatment of OSA (Almeida, Henrich et al. 2013). They conducted focus groups for patients who were currently using CPAP or MADs. Emerging topics were expectations and goals of treatment, benefits of treatment for patients and bed partners, side effects and inconveniences of CPAP and MADs and factors influencing the treatment choice. Expected benefits of treatment as reported were improved health, elimination or reduction of apnoeas; improved sleep,

reduction of daytime symptoms and benefits to bed partners. Reported side effects and inconveniences of CPAP were comfort of the device, fit of the mask, cleaning the machine, the noise produced by the machine and claustrophobia. On the other hand, reported side effects and inconveniences related to oral appliances were pain and discomfort of the device, impact on the users' occlusion, cleaning and durability of the device. Participants reported that the lifespan of oral appliances was 1.5 to 3 years. Interestingly, patients expressed what influenced their treatment choice and highlighted that effectiveness of treatment was a very important factor that influenced their choice of treatment. Other factors related to the patient's lifestyle; some patients preferred a portable device that is easy to pack for travelling. Other factors mentioned included embarrassment, cost, and needing a power supply to operate the CPAP machine (Almeida, Henrich et al. 2013).

Spouses or bed partners have a significant role in influencing their partners to seek and adhere to treatment regimens. Patients' understanding of their illness is shaped by their experience with the symptoms, or by how others who witnessed the symptoms described them (Henry and Rosenthal 2013). A qualitative study looked at significance of gender and partner reporting on the diagnosis, management and treatment of OSA (Henry and Rosenthal 2013). Semi-structured, in-depth interviews were conducted with OSA patients and their partners. Topics included were the perception of the aetiology and the development of symptoms, anticipated treatment outcomes, interpersonal communication, and help seeking behaviour. Interestingly, the majority of patients were unable to report their immediate experience

of their symptoms; the symptoms were often best described by someone close to them. The authors commented on the cultural status of snoring and how patients perceived it. For male patients the comic representation of snoring made it difficult to talk about it seriously, and the female partners found it difficult to convince them that their snoring was not normal. Conversely, the exact opposite occurred for women which displays the gendered expectations about what constitutes appropriate sleep for men and women (Henry and Rosenthal 2013). For women who snore and have sleep apnoea their male spouses felt compelled to be sensitive about reporting the symptoms as it was not considered something that women are supposed to do. Another area that showed gendered differences is the help seeking behaviour. Male patients sought help after insistence or direct intervention from their spouses. On the other hand some women reported that they decided to seek help on their own, and some reported that they sought encouragement to go for medical assessment (Henry and Rosenthal 2013).

In summary, previous qualitative studies about OSA looked at the socio-psychological aspects of living with OSA, and the CPAP treatment of OSA, they compared and contrasted patient preferences between CPAP and Oral Appliances, and highlighted the significance of gender and partner role in the diagnosis and treatment of OSA. However, none of the previous study highlighted the experience of patients who had failed to adhere to CPAP treatment and to explore the perceived treatment effectiveness according to them and to compare and contrast their experience with MADs.

1.5 Aims of the Study

There is increasing evidence that MADs improve subjective sleepiness compared to placebos but are less effective than continuous positive airway pressure therapy (CPAP) (Lim, Lasserson et al. 2006). They are, however, frequently preferred by patients because of their ease of use and portability and hence, are recommended for patients with mild-moderate sleep apnoea or those who are not able to tolerate CPAP (Lim, Lasserson et al. 2006).

OSA is a shared problem that can have a negative impact on patients' and partners' sleep, quality of life, and relationship. For people who suffer from chronic diseases, perceived spousal support and involvement in both treatment decisions and interventions have been associated with improvements in compliance with medical treatments and therapies (Doherty, Schrott et al. 1983, Luyster 2014, Rodgers 2014).

Qualitative research methods have been utilised to highlight the experiences of patients diagnosed with sleep apnoea. It has been described as a "limbo" by patients because of the delayed and circuitous route to diagnosis of the condition. Therefore, patients' adherence to management is often poor (Rodgers 2014).

A recent study by Luyster and co-workers described a qualitative analysis completed for patients using CPAP and their partners (Luyster 2014). They reported the importance of the partners' involvement in early CPAP treatment and recommended a couple-oriented approach to improve adherence to treatment. No study of this type has been completed to date for MADs. Our study aims to highlight the experience of patients and their partners using MADs.

In this study two groups of patients will be interviewed. The first group is for patients who have worn MADs only. The second group is for patients who are using MADs following failure to manage to adhere to CPAP therapy. Partners of OSA patients will also be interviewed to highlight on their experience with their partners' condition and treatment of OSA.

Aims and Objectives:

Aim:

The aim of this study was to answer the question : “ What are the experiences of patients and partners living with OSA and receiving treatment with Mandibular advancement devices?”.

Objectives:

- Identify barriers to diagnosis.
- Identify what motivates patients to adhere to prescribed treatment and what are barriers to adhere to prescribed treatment.
- Report on perceived treatment effectiveness of CPAP and MAD from patients and partners perspective.
- Identify levels of partners engagement in treatment.

2. Materials and Methods

2.1 Research Stages and Planning

The research stages and planning used in this project are outlined in Figure 2.1.

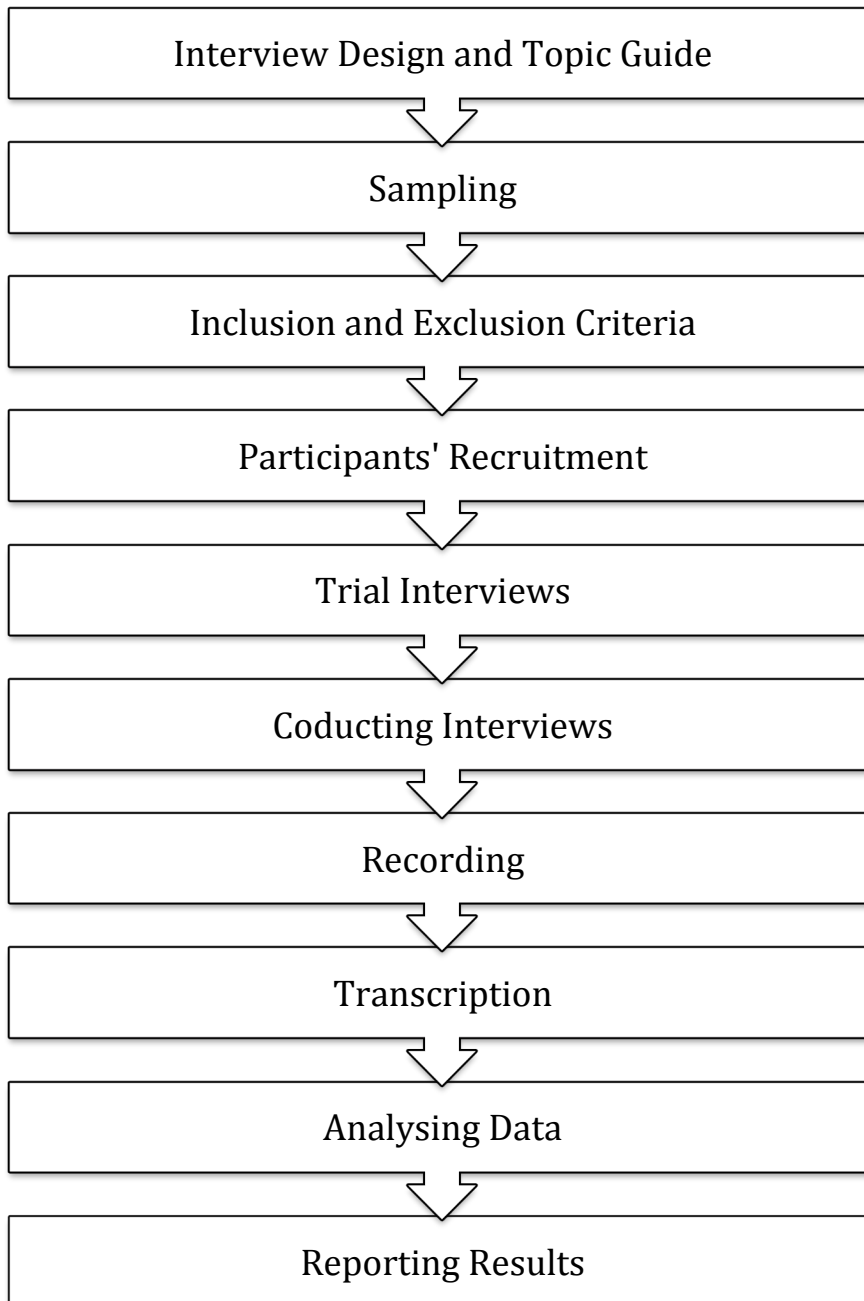


Figure 2.1 Research Stages and Planning

2.2 Ethical Approval

Ethical Approval granted from Tallaght Hospital /St. James's Hospital Joint Research Ethics Committee (REC) in December 2015 (Appendix 1).

2.3 Interview Design and Topic Guide

A qualitative study was proposed to further understand the context of what it means to live with sleep apnoea and to explore the effects of mandibular advancement devices on the quality of life of patients suffering from sleep apnoea and their partners. Qualitative data was collected through semi-structured in-depth face-to-face interviews with participants with sleep apnoea and their partners.

Two groups of patients and their partners were invited to participate in the study.

Group 1: Patients who have used MADs only for management of OSA.

Group 2: Patients who have used MADs after failure to adhere to CPAP therapy.

Qualitative research methodology was followed in this study to explore the experiences of patients diagnosed with sleep apnoea and their partner. The study aimed to compare and contrast the experiences of patients who have used MAD only and patients who have used MAD after failure to adhere to CPAP therapy. The experience of both patients and partners were detailed in this study.

Qualitative data was obtained from in-depth semi-structured interviews. Topic guides (Appendices 2 & 3) were formulated to elaborate on certain aspects that related to the research question. However, participants were

encouraged to talk about their experiences, as themes were extracted from transcripts of the interview. The topic guide was formulated based on literature review of qualitative studies that included patients and partners regarding diagnosis and treatment of OSA, CPAP and MAD therapy. Online databases (*Medline, PubMed, and Cochrane Library*) were searched. Research terms used were: *qualitative, sleep apnoea, partners, experiences, patient, mandibular advancement devices, and continuous positive airway pressure*. The process was supplemented using reference lists in Google Scholar. Selected articles were searched until April 2016. Only articles published in English were considered due to limitations in time and resources. The topic guide was formulated and revised by an experienced qualitative researcher.

The topic guide was used to elucidate upon certain aspects related to sleep apnoea: (1) initial diagnosis of sleep apnoea; (2) current experience with MADs; (3) partner's role in treatment; (4) impact of OSA on day-day life; and (5) future support. A separate topic guide was formulated for partner interviews. The topics discussed included: (1) diagnosis with OSA; (2) experience with treatment CPAP/ MAD; (3) partner's experience and effect on relationship; and (4) impact of OSA on day-day life. Appendices 2 & 3 outline the topic guides utilised.

2.4 Sampling

Determining Sample Size

Determining sample size of qualitative study is required to estimate the number of participants required to reach data saturation. Data saturation is reached when there is enough information to replicate the study, and when new information cannot be attained and when further coding is no

longer feasible (Fusch and Ness 2015). Estimating the number of participants required to reach saturation is dependent on multiple factors: (Morse 2000)

- The scope of the study: the broader the scope of the study, the larger the sample size required to reach saturation. The scope of this study was focused on patients' and partners' experiences with OSA and MAD therapy.
- Nature of the topic: the topic covered in this study was obvious and clear, and information was easily obtained from research participants through semi-structured in-depth interviews.
- Study design: including partners in this research provided a source of "shadowed data" (Morse 2000). This means that the partners provided information about the range of experiences and the domain of the phenomena beyond single participant's personal experience and provided explanation for the rationale of these experiences.
- Quality of data: quality of data obtained was rich, experiential and data saturation was expected to be achievable.

Sampling Method

Qualitative research methodology provides flexibility, and is different to quantitative research sampling methodology. Purposeful sampling in qualitative research requires a sample of participants who are articulate, reflective, and willing to share their experiences with the interviewer (Coyne 1997). Purposeful sampling aims at interviewing participants

with a broad general knowledge of the topic, and those who have undergone the experience, and their experiences are considered typical. In addition participants with atypical experiences are also sought so that the entire range of experiences are covered, and the breadth of the concept is understood (Morse 1991, Coyne 1997, Morse 2000).

In this research project, the participants were patients in the Dublin Dental University Hospital and treated by the research supervisor who had knowledge of these participants and suggested recruitment of patients with a range of experience, but most importantly, articulate and expressive and willing to share their experience with the interviewer. A total of 24 patients were invited to participate in the research. Ten of them responded positively, and five of their partners were willing to attend an interview. Therefore the richness of the quality of the data obtained was ensured and the recruitment of the partners confirmed that all dimensions of patients experience with OSA could be explored.

2.5 Inclusion and Exclusion Criteria

Inclusion criteria of patients:

- Confirmed diagnosis with mild-moderate sleep apnoea as determined by an overnight sleep study completed by the referring physician and included in the referral letter to the DDUH.
- Patients receiving therapy using a MAD appliance.
- Over 18 years old.
- Able to provide consent.

Inclusion Criteria for Partners:

- Sleep partner of patient diagnosed with sleep apnoea and using a MAD.
- Over 18 years old.
- Able to provide consent.

Exclusion Criteria:

- Patients taking medication to alter their sleep patterns.
- Pregnant women.
- Subjects who were unable to consent.

2.6 Participants' Recruitment

Research participants were recruited from patients attending the Dublin Dental University Hospital for mandibular advancement device therapy. Patients were identified from treatment lists to ensure that the population recruited consisted of patients with a range of experiences with CPAP and MAD treatment. Each invitee received a pack with a patient information leaflet to self-assess for eligibility and interest (see

Appendices 5 & 6). Each pack contained an Expression of Interest Form so that the invitee could contact the gatekeeper to ask any questions in relation to the study and indicate if they would like to participate. Once the invitee expressed interest in participation they were asked to meet the investigator at which time they were asked to provide informed consent. Invitees had seven days from receiving the study information to seeking informed consent.

If the invitee did not want to participate in the study they still received dental treatment at the DDUH in the normal manner. Subjects were free to withdraw from the study at any time and this did not affect their clinical care.

2.7 Trial Interviews

Before the actual interviews were completed, two mock interviews were conducted with three consultants with experience in both qualitative research and sleep apnoea management. Two consultants each chose a patient role to present during the trial interview. The third consultant observed the interview to reflect on the interviewing skills and techniques of the investigator, and evaluate the nature of the topic guide.

Interviews were arranged in the setting planned for the definitive interviews to ensure that the room was suitable and the recording equipment was sufficiently effective to record the interviews.

The trial interviews were conducted in the exact manner planned for the definitive interviews. At the end of the session a detailed discussion was carried out between the investigator and the consultants to provide feedback on the interviewing skills, the topic guide and questions asked.

A small number of items were changed in the topic guide to ensure that

the questions were clear and open-ended and encouraged the participants to express their thoughts. On account of feedback questions about the perceived control of the condition were added to elaborate on psychological factors of adherence to treatment and questions about barriers of treatment were expanded to ensure that a wholesome view of the topic was covered.

2.8 Conducting Interviews

Participants were invited to attend the DDUH on a day and time that suited them during the week. They were greeted in the main reception by the investigator and brought to the meeting room where the interview was to be completed. They were offered coffee, tea or water to ensure the informality of the meeting. The interview process was explained to the participants on arrival and informed consent was obtained. Any questions raised were answered prior to commencing the interview.

2.9 Recording

Data were recorded on two separate recording systems to guarantee no loss of data. Two digital voice recorders were used *Philips Voice Tracer Recorder DVT2000*, and the second device was an iPhone s6. There was no videotaping of the participants, as it was not considered necessary. Participants were encouraged to express their opinions, and to give their views on the topics discussed. Once discussion reached saturation and no more ideas emerged, the investigator summarised the overall findings. Each interview lasted in the region of 60 minutes.

2.10 Transcription

The audiotapes were transcribed using a recognised professional transcription services provider and a confidentiality agreement was

signed in relation to storage of digital and text information. Participants were given different names in the transcribed data to ensure full confidentiality. Data was anonymised and stored on an encrypted and password protected computer. Once digital recordings had been transcribed and the text documents received by the investigator all recorded data was deleted.

2.11 Analysing Data

After each interview, a transcript of the study was formatted. These transcripts were then converted to text files and uploaded to a qualitative data analysis software (MAXQDA). MAXQDA is the successor of winMAX and was developed and distributed by VERBI Software based in Berlin, Germany. The software was used for qualitative data analysis by systematically evaluating and interpreting textual data. The data were organised using Thematic Analysis approach. Where Themes were identified from data sets. A theme is defined as the main idea that captures what is important about the data in relation to the research question. It represents a level of patterned responses or meaning within the data set. The importance of the theme is not dependent on quantifiable methods.

Figure 2.2 shows the software interface.

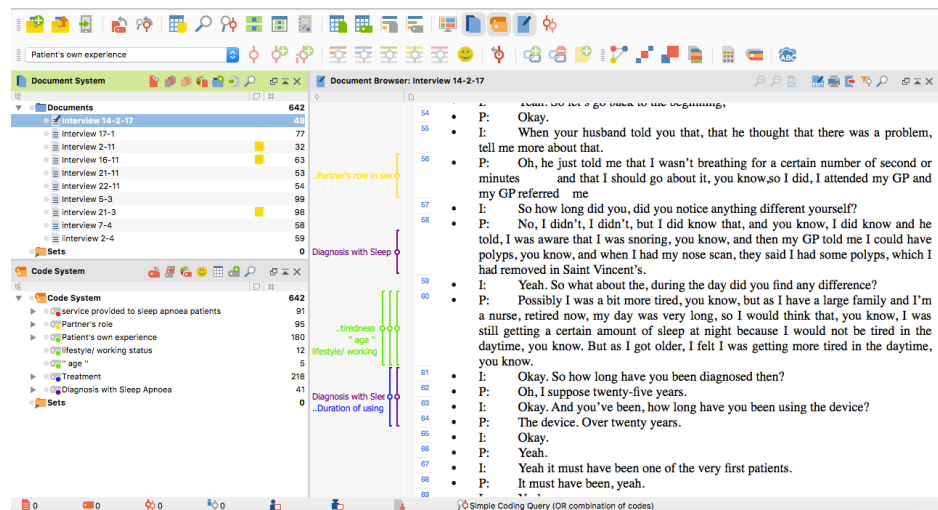


Figure 2.2 Example of MAX QDA interface

There are three main display windows that provide the following features:

1. A document system window offers options to import data (text documents, table documents, PDF files, video and audio files and images). Data files were accessed through this window.
2. A Code System Window. This allowed assignment of a code to a particular part of the document, table, image or media clip. The name of the code was given to the label attached to it. Codes were ordered into a hierarchical structure, a main code having several sub-codes.
3. A Document Browser Window. This allowed visualisation of the selected document, on which the researcher could mark text segments, attach codes or create memos.

MAXQDA provided features of data visualisation through the MAXMaps function, which enabled visualisation of coherences or connections in the data that had been established through the analysis of the data. Figure 2.5 shows a case model map with all the coded themes.

The weight of the lines reflects the frequency of occurrence of the themes in the text.

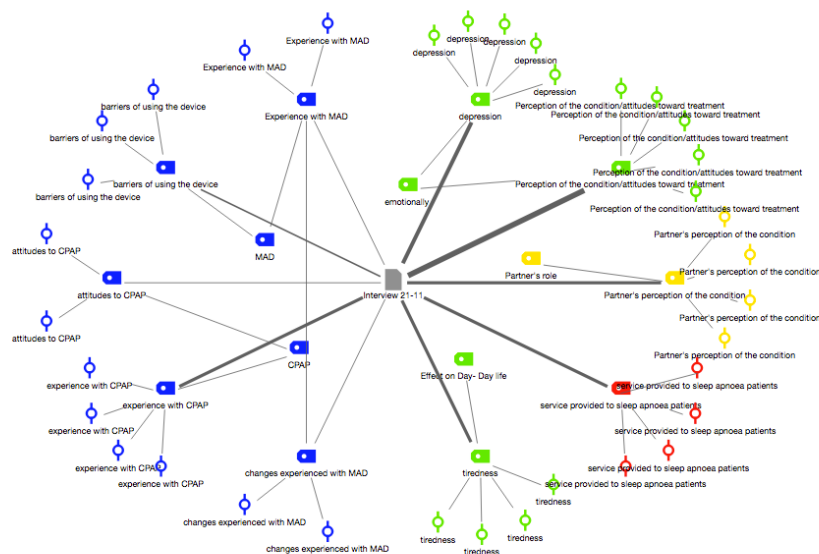


Figure 2.3 MAX QDA model map

A thematic analysis approach was followed in analysing the data (Figure 2.4). The first step of the analysis was to actively read the transcripts. The aim was to provide familiarisation with the depth and breadth of the content. Patterns and meaning within the text were identified and notes were taken for future reference. The second step was to generate the initial themes and in these steps the most basic elements of the data captured key concepts. The initial themes were then reviewed independently by two researchers with experience with qualitative research, and then the definitive thematic scheme was developed. The subsequent themes were analysed were grouped into main themes and sub themes.

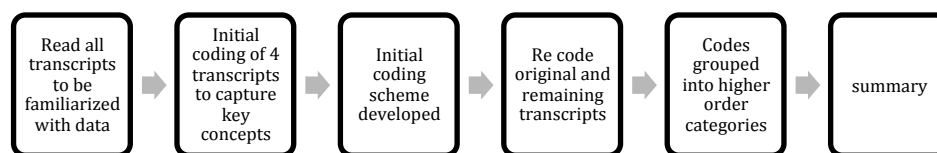


Figure 2.4 Steps of thematic analysis

2.11.1 Analysing Patient Interviews

Figure 2.5 shows a map of the initial codes grouped into five main themes. Table 2-1 details the themes and codes identified from patient interviews.

2.11.2 Analysing Partner Interviews

Following completion of all patient interviews, their partners were approached. They were contacted by phone and asked if they would like to attend the DDUH for a personal interview. Once they expressed their interest they were sent a package containing information leaflet about the research (see Appendices 5 & 6). Five partners expressed interest and were invited to DDUH at a time that best suited them to conduct the interview. The same thematic analysis approach was followed for conducting the interview, recording, and transcription as was employed for the patient interviews. Figure 2.6 shows a map of initial codes identified. Table 2-2 summarises the coded themes employed.

2.11.3 Strategies to Ensure Rigour

Strategies to ensure rigour in qualitative research were followed to protect against bias and enhance the reliability of the findings.

Systematic research design, data collection, interpretation and communication were followed.

Sampling

The recruited sample of participants consisted of males and females who were >45 years of age, lived in Dublin and were treated in the DDUH for OSA with MADs. Recruited patients had a range of experiences. We ensured recruiting patients who had failed to adhere to CPAP , and who were first time users of MADs, who had mild to moderate OSA. The researcher had not provided any treatment for these patients prior to meeting them for the interview.

Ensuring the reliability of the analysis

A topic guide was formulated prior to conducting the interviews based on a review of the literature and covered the aspects related to living with OSA and CPAP and MAD treatment, and items that were specific to the research question being asked. The topic guide was “ tested” in the trial interviews stage, and items were reviewed to make sure that they cover the aspects of interest in this research.

All interviews were transcribed and a Thematic Analysis method was used as described by Braun and Clarke. The transcripts and the initial analysis were reviewed by skilled qualitative researchers to ensure agreement on the analysis.

Validity

To ensure the reliability of data and their closeness to truth “

Triangulation” is an approach of data collection which refers to seeking evidence from a wide range of different independent resources by different means. Another validation strategies used in qualitative research to feed the findings back to the participants to see if they regard the findings as a reasonable account of their experiences and to use

interviews or focus groups with the same people so that their reactions to the evolving analysis become part of the emerging research data.

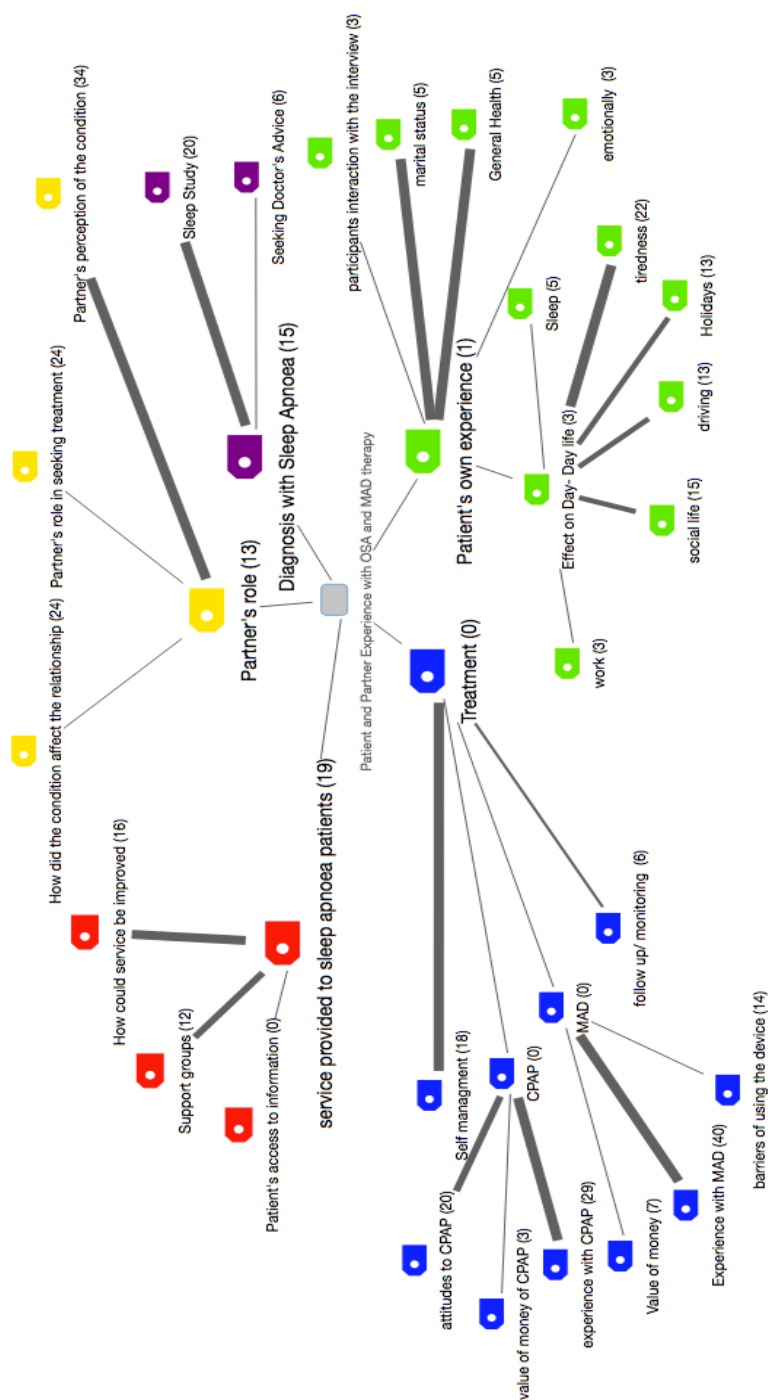


Figure 2.5 Summary of themes generated from patients' interviews

Table 2.1 Summary of themes generated from patient interviews

Theme	Sub-themes	Labels
Patients experience	Effect on day-day life	Social life
		Sleeping
		Driving
		Holidays
		Tiredness
		Work
	Psychologically	Fear of the unknown
		Using the condition as a crutch
		Depression
		Perception of the condition
Diagnosis with OSA	Sleep study	Sleep study
	Seeking medical advice	Seeking medical advice
Treatment	Self-management	Self-management
		Follow up and monitoring
	CPAP	Attitudes to CPAP
		Value for Money
		Experience with CPAP
	MAD	Value for money
		Experience with MADs
		Barriers of using MADs
Partner's role	Partner's perception of the condition	Partner's perception of the condition
	Partner's role in seeking treatment	Partner's role in seeking treatment
	How the condition influenced the relationship	How the condition influenced the relationship
Service provided	Patient's access to information	Patient's access to information
	Support groups	Support groups
	How could services be improved?	How could services be improved?

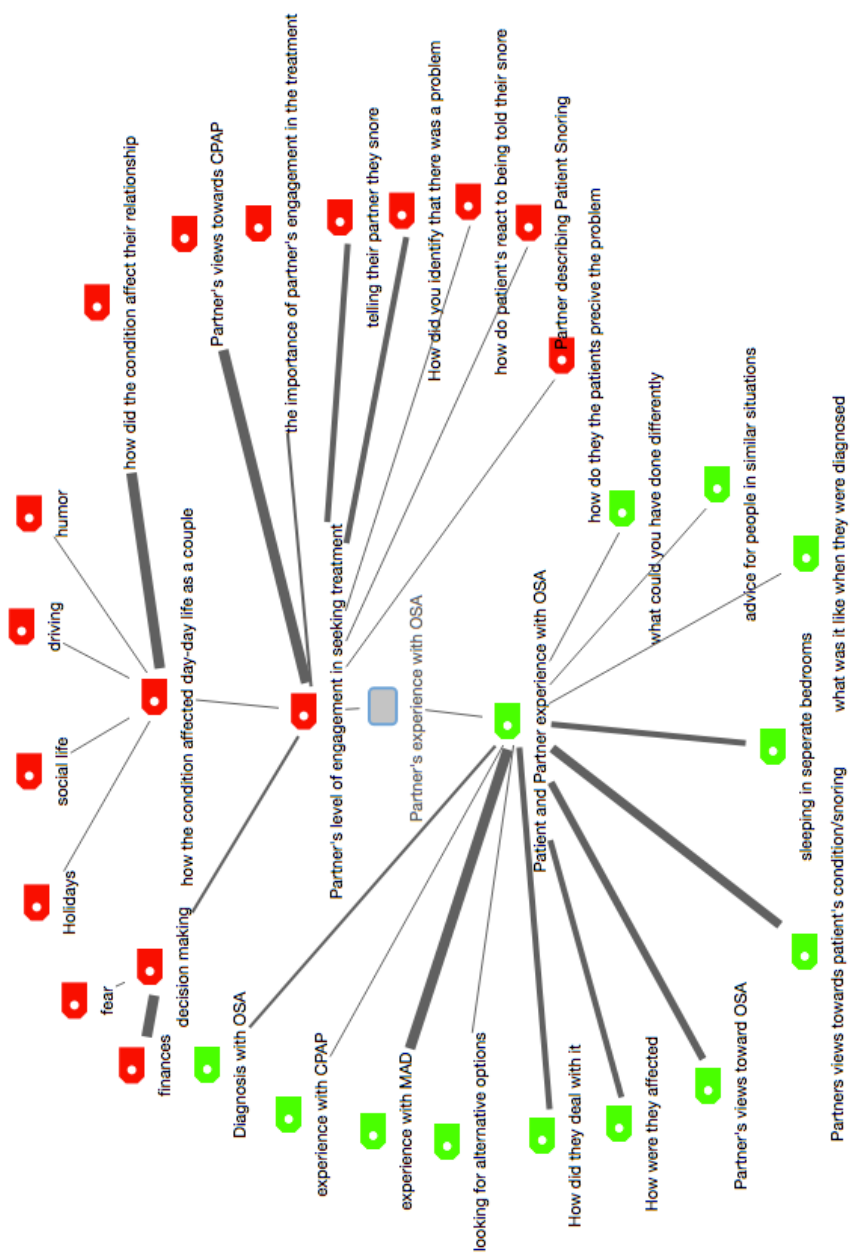


Figure 2.6 Summary of themes generated from partners' interviews

Table 2.2 Summary of themes generated from partners' interviews

Theme	Sub-theme	labels
Partner's experience with OSA	How they perceived the problem	
	Describing patient snoring	
	Coping strategies with OSA	Sleeping in separate bedrooms
		Alternative treatment options
	Attitudes toward treatment	CPAP
		MAD
	Effect of OSA on day to day life	Social life
		Holidays
		Driving
		Humour
		Relationship
Level of engagement in treatment	Importance of partners engagement in treatment	
	Decision making	Finances
		Fear

3. Results

3.1 Introduction

A total of fifteen participants were interviewed in this research. Ten of them were patients who had been diagnosed with Obstructive Sleep Apnoea (OSA) and five of their bed partners. Age range of participants recruited was 45-70 years old. Of the ten patients interviewed, five of them used mandibular advancement devices (MADs) following failure to adhere to Continuous Positive Airway Pressure (CPAP) treatment. The MADs were all of the TAP design.

Table 3.1 Summary of gender distribution of research participants

Research Participants	Patients	Partners
Male	5	2
Female	5	3

Table 3.2 Summary of distribution of patients' group

Patients	Used MADs following failure to adhere to CPAP	Used MADs Only
Male	3	2
Female	3	2

3.2 Patients Interview Analysis

3.2.1 Patient Experience with OSA

3.2.1.1 Describing Symptoms

Sleep apnoea clearly had an impact on patients' day-to-day lives. It seemed that their understanding of their nighttime symptoms was

through their daytime effects. Patients would rely on reports from bed partners about their nighttime symptoms such as snoring or interrupted breathing. They themselves described daytime symptoms such as tiredness, lack of concentration, and daytime sleepiness. (Figure 3.1)

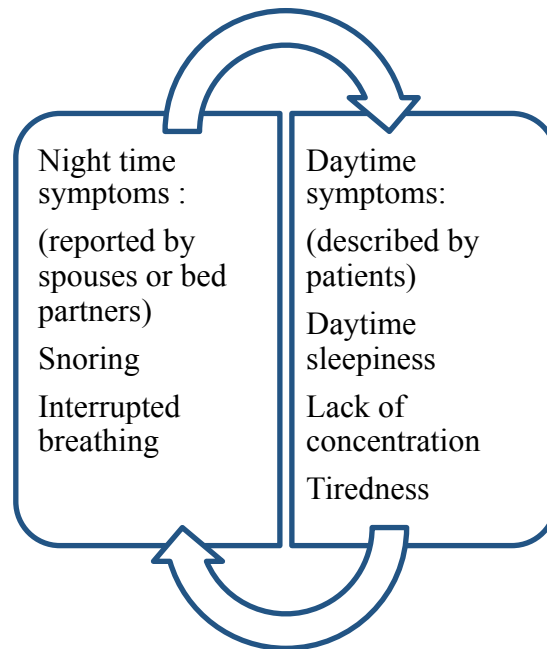


Figure 3.1 Patients' description of OSA symptoms

“I was getting tired quite a lot and I had no concentration. I’d be in a meeting and after two minutes I was somewhere else, I just, I couldn’t focus on anything. Now I was still working and I was still doing things but my concentration totally went, and I was forgetting a lot of things.”
(Male 48 years old)

“I was quite tired all the time at home and any time, even when I got from bed and I’d get up, do a bit of work, I’d fall asleep. I’d be asleep quite quickly, if I sat down I’d be falling asleep, which I didn’t believe, my husband kept saying I was a very heavy snorer. I’d wake up sometimes feeling a choking sensation.” (Female 55years old)

“I was really, really tired all the time and I always remember it got to the stage where I’d be having meetings with staff and sitting down and, and I, I’d be falling asleep” (Male 48 years old)

“They say wake up refreshed, couldn’t tell you what that is. Like I wouldn’t be able to explain wake up refreshed, I’ve never, I’ve never felt getting up in the morning being refreshed.” (Male 68 years old)

“I was so tired. Now that was unusual, but I would find myself having to pull in when I would be driving on long journeys and have a nap, because I was just, and it wasn’t a normal tiredness. I imagine normal tiredness is a grading down, mine was [snaps fingers] like that.” (Female 65 years old)

3.2.1.2 Effect on Day-to-Day Life

Obstructive sleep apnoea had an impact on patient’s daily life and activities such as family life, holidays, and daily activities such as driving an automobile. (Figure 3.2)

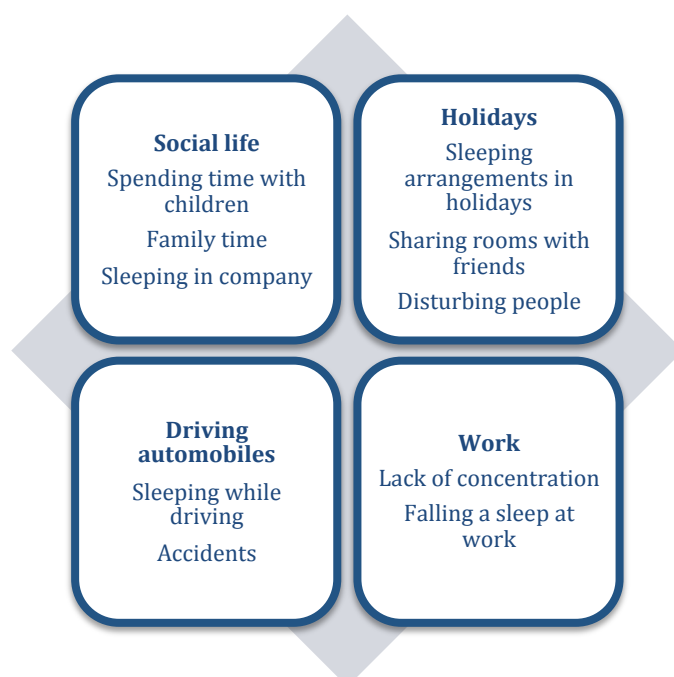


Figure 3.2 OSA effects on day-day life

“When my children were young, just even last night I was looking at the photographs and I’m in them, no matter where we are, where they’d be at the seaside, up the mountains, at home, I’m asleep. The bulk of the photographs, I’m asleep in the chair.” (Male 68 years old)

“We went on holiday one year, and sure they all wanted to kill me by, by the week was up because we were out every night, having a few beers and drinking and, and I came home, snored the house down, you know. So from that point of view, other people are affected by it, you know, so it’s, that kind of does annoy me because you know, you want other people to have their sleep as well.” (Male 48 years old)

“About probably a year before I got diagnosed... I was driving along. It was about two o’clock I’d say because we were up early, and I think she (wife) could have been asleep in the passenger seat, I think she could have fell asleep and the next minute I heard thump-thump-thump-thump-thump, I actually fell asleep and I actually went that way instead of the other way and I was hitting the cats’ eyes, you know the, the bumps on the road? I was hitting them, that’s what woke me up, and I was heading actually for the ditch on, on one of the motorways. So it did frighten me...” (Male 48 years old)

“It affects my life in the sense that I don’t like driving. I don’t drive long distances anymore because I have the fear of, of falling asleep... I actually fell asleep that I know of three times while driving. And that’s very frightening, you know, but luckily enough I didn’t crash, I had, my wife was in the car twice and another chap was in the car another time so, you know, once I start dozing and going off they just woke.” (Male 68 years old)

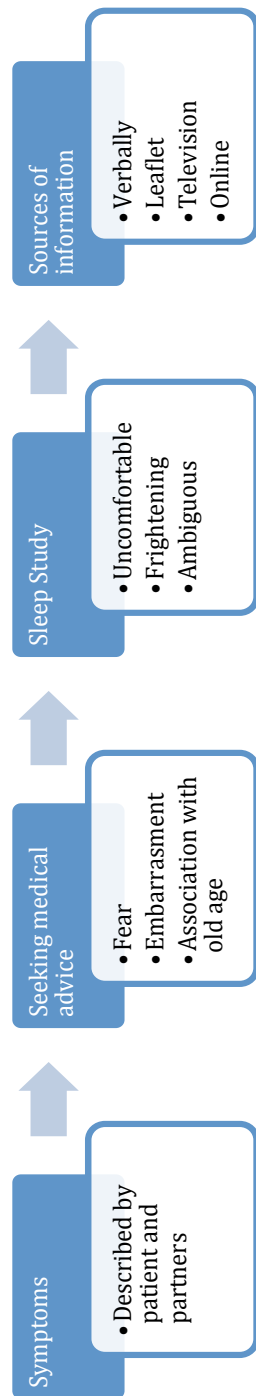


Figure 3.3 Patient's journey in diagnosis with OSA

3.2.2 Diagnosis with Sleep Apnoea

Figure 3.3 summarizes patients journey in diagnosis with OSA as described by patients. It begins with reporting symptoms, followed by seeking medical advice at the instigation of the partners, followed by their description of the sleep test, and the information provided to them.

3.2.2.1 Symptoms

Patients' reports on how they knew they had sleep apnoea were recollections of their spouses relaying to them that they snored with descriptions of their behaviour during sleep. Many were unaware of the fact that they snored at night.

'I couldn't understand, I was always a very lively person and I found myself extremely tired, and I didn't know what it was and I, you know, you don't hear yourself in bed at night. It's somebody else who hears you, and of course discretion being the better part of things, my husband wasn't going to say anything because his life might have depended on how he said it, so, [laughing].' (Female 65 years old)

"I was quite tired all the time at home and any time, even when I got from bed and I'd get up, do a bit of work, I'd fall asleep. I'd be asleep quite quickly; if I sat down I'd be falling asleep. which I didn't believe, my husband kept saying I was a very heavy snorer. I'd wake up sometimes feeling a choking sensation." (Female 55 years old)

"Because my wife, when I'd be snoring, right, she'd be sitting, she'd say she was going to kill me, but then I'd stop breathing, and then she thought I'd be dead. So she'd lie in the bed waiting and I wouldn't be breathing, and she said oh, I'd better check, and as soon as she'd go to check then, I'd go into another snore, and off again. But that was the

start of it, it was her who said, you know, there's something wrong, you're not breathing, you know, you're going asleep and you're, well .. I'm either then snoring or not breathing, one or the other, that's the way she put it at the time." (Male 68 years old)

3.2.2.2 Seeking Medical Advice

The occurrence of persistent symptoms such as tiredness and daytime sleepiness had led patients to seek medical advice at their partners' instigation. Snoring on its own was not a symptom that concerned patients. It became an issue when snoring was accompanied by interrupted breathing as reported by spouses and daytime symptoms such as tiredness, sleepiness and lack of concentration.

"I always did snore, even when, well as a kid obviously I don't remember, I can't remember, but when, when I was in my twenties my mother would say the noises coming out of, out of my bedroom at night." (Male 48 years old)

One patient reported that seeking medical advice conveyed a sense of embarrassment and fear.

"I: So what would embarrass you? Why is it embarrassing?"

P: I don't know. You might think you're weak, especially when you get, when you're younger, like twenty year ago or even fifteen year ago, sure I can't be sick, like I'm only a young man. Old people get sick, you know? That's the way I felt about it, not anymore. If I was sick in the morning I'd go straight away, I wouldn't be told to go, I, I'd go." (Male 48 years old)

"I: So what would you be afraid of as well? You mentioned fear."

P: Probably if they found something wrong that could be something out of this world. Not out of this world, but like cancer or like something like that, do you know? And then you find, even when I was younger, going to the doctor, it wasn't the done thing.” (Male 48 years old)

“I was worried until I went to my doctor because like, I suppose in your, in your forties you're aware of that. I think up until you're forty, you're kind of invincible in a lot of ways, you kind of think you're young and your body can take a lot, and it was one of the first things that I remember thinking God, what if there's something really wrong with me?” (Male 64 years old)

3.2.2.3 Sleep Study

Patients stated that following their reported symptoms, witnessed snoring and interrupted breathing they had sought medical advice. Subsequently they were referred for a sleep study, which they described as “uncomfortable” or “frightening” because they were not prepared to it, and had been provided with very little information beforehand.

“Well it's not the most comfortable or glamorous situation you could find yourself in, believe you me, and I don't know how they really test it so well because it's not a comfortable situation to be in, as you well know, and you're trying to get to sleep to make it work and you're anxious because you want to make it work, etcetera, etcetera. I think that hit me the first time that I, I didn't relax down into it, but I, the, the second time worked.” (Female 65 years old)

“I couldn't actually sleep because I was so conscious of it. So eventually I did fall asleep and I always, I just remember that it was nineteen times a minute was what they diagnosed me at.” (Female 45 years old)

‘‘ I: So why do you think it’s frightening, then?

P: Oh, when they wire you up to all the machines and everything, I found that was, you know, frightening, but you know, maybe if I knew more about it, I wouldn’t be as frightened, you know, going into it and that. But otherwise now it was grand, and then I got my brace then after that. ’’ (Female 45 years old)

‘‘I was told very little about it when I was going in to have it done, I, I only really found out what was going to happen when I got there and the technician, very, very nice guy, but he made it very, very clear he wasn’t discussing anything about anything with me, so it was kind of, I kind of went out thinking what was all of that about?’’ (Female 65 years old)

3.2.2.4 Sources of information to patients about Obstructive Sleep Apnoea

Patients had access to information directly through their treating doctor, or by leaflets that were given to them at the hospital, through television, or by online access to information.

‘‘I wasn’t familiar with the term sleep apnoea, so in my head I’m saying it and saying it and saying it and wondering what it is and I, I remember as well, gosh, the first time I travelled with that horrendous mask, at the airport they stopped me and asked me what it was for, I couldn’t remember what the name of the thing was that it was there to cure, and they didn’t recognize it at the airport either, they weren’t going to let me through with it. ’’ (Female 65 years old)

‘‘I was given a leaflet to read about it, and it was pretty conclusive, it was pretty clear and informative and it was explaining how my, my, my

understanding or my perception of sleep apnoea is that it's a condition which interferes with a person having good sleep.' (Male 59 years old)

"I watched a programme on television and it was a, a man describing sleep apnoea, it was the first time that I had heard about it," (Male 64 years old)

"Oh, well because, it was, we knew there was something wrong, you know, with this not breathing, that's, you know, that's not normal. That's the way we looked at it, and I think we actually, I, I actually Googled it and had a look and, and I seen sleep apnoea come up and I said oh, I better go and see about this." (Male 68 years old)

"I would read up about sleep apnoea on a regular basis online, just out of interest to see like what, are there any new developments and there's a there are, sort of every couple of months there's somebody has a brand new something or other." (Male 64 years old)

3.2.2.5 Patients Knowledge about Sleep Apnoea

Patients' description of OSA was simple. It included a description of interrupted breathing due to closing airways, and they mentioned the health implications and consequences of OSA.

"Sleep apnoea is this thing that causes the airway to narrow, which is what we call snoring and of course that raises you from being down deep in uninterrupted, smooth flowing sleep to being up into that sort of area where you're not quite awake but your heart rate increases." (Male 59 years old)

"I was noticing was, and my understanding is that with sleep apnoea, you probably get down into that first level of sleep but you don't get down lower to where you really need to be to have a renewing,

refreshing, restorative sleep which is so necessary to function properly, and therefore that was the cause of me not really getting the kind of level of renewal from a night's sleep that I should have had, and hence this hangover into the day where you're tired." (Male 59 years old)

"I think the emphasis should be okay, sleep apnoea is serious but these are the things you can do about it, but a lot of the information is, you know, you put pressure on your heart, your palate, your blood pressure and risk of stroke, all of this kind of stuff is there as possible, like you could fall asleep driving and kill somebody or kill yourself, all of this stuff is, is listed but I think, I suppose I should say for me, more positive messages work. You have this, this is what we can do about it, or you have this, this is how you look after yourself around it." (Male 48 years old)

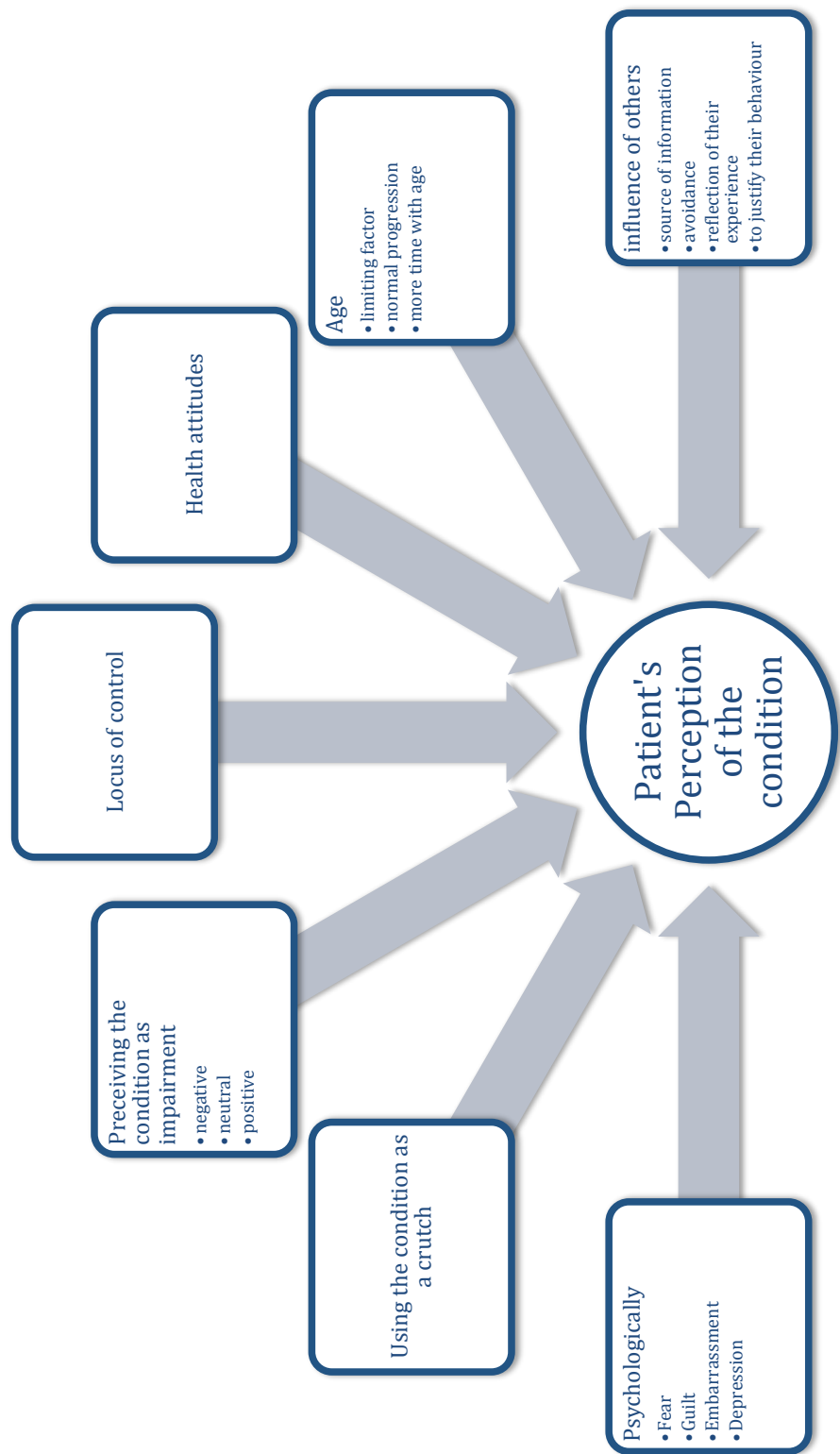


Figure 3.4 Patient's description of the condition

3.2.3 Patient's perception of the condition:

Figure 3.4 illustrates a visual summary of patients perception of the condition, i.e Obstructive Sleep Apnoea. Patients described an array of emotions towards having OSA, some described using the condition as a “crutch”, and degrees perceiving the condition as impairment, we refer to patients locus of control and health attitudes, and how they linked having OSA with Aging. And finally the influence of powerful others on their experiences.

3.2.3.1 Psychologically

Despite the fact that patients were well informed about their medical condition, their perception of the condition displayed an array of views on the psychological level. They described feelings such as fear, guilt, embarrassment, and depression.

Fear

Fear was described as an emotion on different levels. Fear of the fact that their breathing stopped at night, and fear of the condition as an impairment or something that is limiting to their lives.

“It is very daunting, because you know when somebody says to you that you stop breathing and then you wake up, you say oh my god, you know? You’re afraid then to go asleep at night, I think that was a lot as well, I was afraid to go asleep at night in case I wasn’t going to wake up.”

(Female 65 years old)

“But this profound tiredness is scary, if it takes over, if it gets a grip on you, it is very scary. You know, so you’d want to be, and I would say to anybody who feels that level of tiredness and fatigue, chronic, constant fatigue that just won’t go away, and that’s what I had, then you’ve got to

do something about it ... It's scary because basically it tells you you're in a new phase of your life, you're in a more sedate phase of your life, you're in a phase of your life where you no longer can do things." (Male 59 years old)

Guilt

Feeling guilty implies that patients felt somehow responsible for getting the condition. They might think they must have something to cause it as in gaining weight or not leading a healthy lifestyle. They also mentioned that they were guilty because they were causing discomfort for their spouses, or that the condition had prevented them from leading a life where they could spend more time with their families.

"I took it so badly, because part, I blamed myself for it; because I have put on weight and that's one of, though it's not the only factor, as you know, a lot of very slim people have it as well. But I thought have I done something in my life, and this was stupid to get this, etcetera, and he said I think it would be a good idea if we got you the, the mask and that." (Female 65 years old)

"You know. I used to think oh god, there's something wrong with you, you know, I used to think there was something, well there is, but you know the way. There's something really bad wrong with me, that's the way I used to feel." (Female 45 years old)

Embarrassment

Some patients reported that they were embarrassed by the condition.

"I didn't know what I had, it makes sense now what happened, but at the time it was, when you couldn't tell people what you had, it was embarrassing, it was, you kind of feel guilty about it in a sense though,

with the kids, you didn't spend much, that much time, or not, I won't say that much time but not enough time with them because you'd be narky, you'd be tired, you know, leave me alone, you know." (Male 68 years old)

*"I didn't want to ask a lot of people about it either, **I was kind of being covert about it.**"* (Female 65 years old)

Depression

It has been described in the literature that the relationship between depression and sleep apnoea is bidirectional; as in sleep deprivation causes mood changes in healthy individuals, and depression causes sleep disorders (Montesi, Edwards et al. 2012). This patient's description of the depression and sleep apnoea is a representation of that.

"The depression and the sleep apnoea were still there, but this was a start and maybe that gave me the positive energy in my mind to finally deal with the sleep apnoea thing and the depression thing, and all of these things, it's like all the lines came back into focus again, you know, if you were looking at a picture and it's out of focus, the lens of my life came back into sharp focus." (Male 59 years old)

"I was always a bit anxious in my life and always a little bit, I won't say depressed but I was always a bit out of sorts, and I always, my disposition was always a little bit negative and a little bit anxious, and I was never a person who could completely let go and just enjoy the moment, I always felt some level of guilt or pessimism about things." (Male 59 years old)

“ There are days when I’m out working, driving the bus and doing the work with the people and all of that and I just say to myself I’m actually happy. I’m actually happy. [laughing]

I: Okay, so what, what do you think changed that then?

P: I’m optimistic. I think the medication to a great degree, but also the fact that I’m not tired all of the time. Right? The fact that I have more energy than I had, you see the lack of energy is something we would associate with old age.” (Male 59 years old)

Depression was mentioned at another level, as this lady describing how she tried to cope with CPAP treatment and how she nearly went into depression (in her words) over the fact that CPAP was unsuccessful for her.

“I invested in that and I hated every single second of it. I felt revolted by it, I felt unattractive, well obviously unattractive in it, and my husband was very, very understanding, he said look, it’s for both of us, it’s for the good of your health, it’ll be this, I definitely nearly went into a depression over it.” (Female 65 years old)

Using the condition as a “crutch”

For this man having OSA was an excuse he used for being tired or lacking the energy to do normal chores around the house. It became a method of avoidance of tasks that he preferred not to complete.

“I say to myself, Jesus, have I sleep apnoea at all, am I just, is it just something I have that I’m so tired, you know what I mean? Or, or am I using that as a crutch at times? Do you know what I’m saying? Am I using the sleep apnoea, oh well, that’s my excuse for I, I’m tired, leave me alone, you know, I have to, you know, it’s...” (Male 68 years old)

I: Yeah. So what do you mean, you use it as a crutch...?

P: I mean am I using it as an excuse, do I,

I: Yeah. For what?

P: Am I using it as an excuse? Well, if, if the wife wants something done, ah no, I'm too tired, you know, the, you know. You know, where, where I didn't have sleep apnoea the wife could say get up off your backside, you know, that type of thing, you know.

I: Yeah.

P: That's what I mean. Taking advantage of it, if I wanted to. Do you know what I mean?" (Male 68 years old)

3.2.3.2 Perceiving OSA as impairment

Perceived daytime effect of OSA were tiredness, lack of concentration, and sleepiness. However, on a deeper level patients were asked to what extent the condition had an effect on their day-day life and whether they thought it was impairment. The responses varied and ranged from negative views on the condition where it was perceived as an impairment, while others were neutral and did not think that OSA was limiting them from practicing their normal lives, and the third view was an optimistic view where the patient expressed strong feelings about how she handled the situation.

Negative view

"It's a problem for anybody that has it, it's a severe problem, what, what, I don't say severe because depends on the degree to which people have the condition, but for me it was a bad problem, yes, and an impairment is an understatement." (Male 59 years old)

Realistic perspective

“I live with it, you know, I do everything everybody else does, you know, and I would know if I didn’t sleep, if I hadn’t a good night’s sleep, that I might be more tired or I’d doze or fall asleep in the middle of the day, which isn’t, at my age, is quite, I’m sure it’s quite normal. But you know, I don’t feel it any burden to my life, you know. The only thing I don’t want to be annoying my husband, anyhow he can go, all our children have fled now, he can go to the room next door, you know [laughing].”

(Female 62 years old)

“I suppose it hasn’t slowed me down anything, you know, touch wood. I’ve had, I have a good life, but I look after myself, you know, I make sure I don’t, you know, my weight is in proportion to my body and my exercise, I go to the gym or I have a walk, I have an hour’s walk most days, every day nearly, most days, and you know, I eat healthy, I drink in moderation, a glass of wine maybe once a week, and really there’s nothing else, you know. I have to live with my condition, I’m aware of that, and I don’t get depressed about it.” (Female 62 years old)

“I don’t treat it as an illness.” (Male 48 years old)

Optimistic perspective

“I’ve a very positive outlook and I, I was, this wasn’t going to beat me. This wasn’t, this was going to be good and it was going to be right, and it was going to work, and that’s exactly what happened.” (Female 65 years old)

3.2.3.3 Health attitudes

Patients expressed positive health attitudes. They expressed that they had regular check-ups with their general medical practitioner and were willing to spend money on their health.

“I’m a firm believer, you get your car serviced every year, pay five or six hundred quid, you might as well get your body done.” (Male 48 years old)

“I’ve two doctors, everybody can have one doctor but I have actually two doctors. I have one doctor who’s a medical doctor and I have another doctor who is, he’s an osteopath and a homeopath as well as a medical doctor.” (Male 64 years old)

3.2.3.4 Age

The age range of patients who were interviewed was from 42 to 69 years old. Their views about the condition and how it related to age varied. Age was perceived as a limiting factor by some and a reminder that life is finite.

“Again, I suppose people in general, when you come into what is described as middle age, and I’m coming out maybe to the elderly end of that now, right, but when, when you’re middle aged, you suddenly find that, people find this in life, that there’s a difference between, everybody you meet in life is younger than you. The doctors, the policemen, everybody. Right? And suddenly you’re a senior person and you know, your own children are adults and you weren’t noticing, but suddenly you’re in a different disposition. I always remember a life where I was young, and suddenly I’m not young, so those things are depressing, and then this preoccupation about not being young anymore, not that I want to pretend to be young, right, or anything like, that’s a vanity issue, it’s not that. It’s just that hold on, your life is limited, there are things you can’t do, and maybe this tiredness is part of this older age, but yet I only lost my father two years ago and he was ninety-five, and he never had

this. So I knew that there was something, it, it wasn't old age. Do, do you know what I'm saying?" (Male 59 years old)

"I feel that, it's not that I feel younger, I feel as I think I ought to feel at my stage in life. But so many people, and the doctor told me this, that so many people at my stage in life, he said life was different years ago, but so many people now have so much more to cope with than they had years ago.

I: Okay. So how are you supposed to feel at your age then?

P: Well, I think I feel the way I'm supposed to feel. I have, you see we're, we're human beings and you know, you look at dogs, you look at cats, you look at other animals, they don't have these problems because they don't know, the fundamental difference being a human being, you are finite. You know, I know I'm fifty-nine, I know you're probably twenty-five or something, right?

I: Twenty-seven.

P: Well, we're close; you're the same age as my daughter, then, right?

I: Yeah.

P: So you're at a different stage in your life, you're young, you have so much in front of you, but the shock that you're going to feel between where you are and where I am, because I got married when I was your age, it all telescopes into nothing." (Male 59 years old)

"I think quite often depression or anxiety does come with age, although I had it when I was younger, much younger, when I was still of a reasonable age, even, even when I was, you know, back in my twenties, I

had a tendency towards an anxiety and a fundamental lack of sureness of myself, you know.” (Male 59 years old)

“I was worried until I went to my doctor because like, I suppose in your, in your forties you’re aware of that. I think up until you’re forty, you’re kind of invincible in a lot of ways, you kind of think you’re young and your body can take a lot, and it was one of the first things that I remember thinking God, what if there’s something really wrong with me?” (Male 64 years old)

“You might think you’re weak, especially when you get, when you’re younger, like twenty year ago or even fifteen year ago, sure I can’t be sick, like I’m only a young man. Old people get sick, you know? That’s the way I felt about it, not anymore.” (Male 42 years old)

“When I was, when I was diagnosed that night there was five of us in the room that night, and I was the youngest one there. Like I was only thirty, thirty-one or thirty-two, so everyone else was probably over fifty.” (Male 42 years old)

Others perceived old age as a normal progression of the life course and that with old age there is more time and more control of their lives. Some associated their symptoms with old age such as sleepiness or tiredness and thought it was “normal”.

“Now I know an awful lot of people my age do fall asleep and it’s probably normal, coming to my age, for people without sleep apnoea. But I still put it down to the sleep apnoea, you know what I mean?” (Male 68 years old)

“I have that so I can’t do that, you know, I have sleep apnoea, you know, but, but as I say to you, like at my age now with, I have no real

responsibilities now, you know, so I, I can control my life now because it's got, the things we do are smaller, you know, there's only me and her now... I have a lot more control of my life because I have more time, more freedom, you know. Where, younger, I don't know. I don't know what way I'd be now if I was younger." (Male 68 years old)

"P: I, I think it's an age thing. I don't sleep as well as I used to, but then I think it's an age thing.

I: Okay. How come it's an age thing, then?

P: I don't know, but they say old people don't need as much sleep as young people."

(Female 69 years old)

"I'd doze or fall asleep in the middle of the day, which isn't, at my age, is quite, I'm sure it's quite normal." (Female 65 years old)

3.2.3.5 Locus of Control

Locus of control describes how people believe that they have control over their lives. People with an internal locus of control believe that they are responsible for their treatment and they would try to make treatment successful and persevere to make it work.(Wild, Engleman et al. 2004)

"I've a very positive outlook and I, I was, this wasn't going to beat me. This wasn't, this was going to be good and it was going to be right, and it was going to work, and that's exactly what happened." (Female 65 years old)

At the other end on the spectrum there were people with external loci of control who believed that external factors would affect their treatment and they expect to be told what to do as this man describing that doctors did not "force" losing weight to improve his lifestyle.

“And yet they never forced it, they never, they just said your weight is a problem, but they never said to me ah, you better make sure. Whether they do it now or not I don’t know, but I know no-one ever said to me get that weight down.” (Male 68 years old)

3.2.3.6 Influence of Other People

“Other people” in patients’ lives had an influence on the way they dealt with OSA. For some “others” were a source of information.

“Well it’s just by chance we were talking one day and she said oh, she said she had been on holiday with her sister, her husband hadn’t gone, my brother hadn’t gone with her, and she said my sister kept saying to me, you, you know, you fall asleep and I’m afraid you’ll never wake up. So that’s how she came to know about it.” (Female 62 years old)

For some other people’s experiences were alarming and they were avoiding being in the same situation.

“I had a friend who was diagnosed with lung cancer when I was thirty-nine, and she ended up with half of her lung being taken out. She’s still smoking, she has emphysema, she has all kinds of things, and I just decided no, I don’t want to be that person.” (Male 64 years old)

On the other hand, this man’s family experience with OSA had conditioned him into being realistic about it.

“It’s not the end of the world for me. It doesn’t really affect it, my family are used to it, they know it. My sister has it, my father had it, because my father would be up in bed and we’d be downstairs and we’d hear him snoring, and he had a similar build to me, and my older sister, who’s not, she’s not over, she’s not skinny but she’s not overweight, she has it but

she does nothing about it, and she won't do anything about it, so it seems to be in the, in my family."

(Male 48 years old)

Some used other peoples' experiences to compare it to their own, and gauge where they stood in terms of their health, which they might think that would place them in a better position.

"I have a brother, an elder brother who has significant apnoea as well, and, but he doesn't do anything about it. He's sixty-one years old, and unlike me they say sleep apnoea comes with weight." (Male 59 years old)

Finally, some used other people's experiences to reflect on their own and to try to justify their own behaviours, such as this man who had stopped using CPAP and mentioned that two of his friends have decided to stop using it and were not doing anything about having OSA.

"I know two other people with sleep apnoea and both of them have stopped using the mask."

(Male 68 years old)

"I haven't met anybody who's actually got a hundred per cent out of, that has been cured, or not even been cured but controlled." (Male 68 years old)

3.2.4 Patient's experience with CPAP and MAD

Two groups of patients participated in the research. The first group had used mandibular advancement device following failure to adhere to a continuous positive airway pressure machine (N=6), and the second group had received mandibular advancement device treatment only (N=4).

3.2.4.1 Patients' experience with CPAP

Patients who had had experienced CPAP therapy described difficulties with using CPAP machines. The difficulties were classified into technical such as discomfort related to the mask, and psychological challenges, side effects and other problems such as travelling with the CPAP machine.

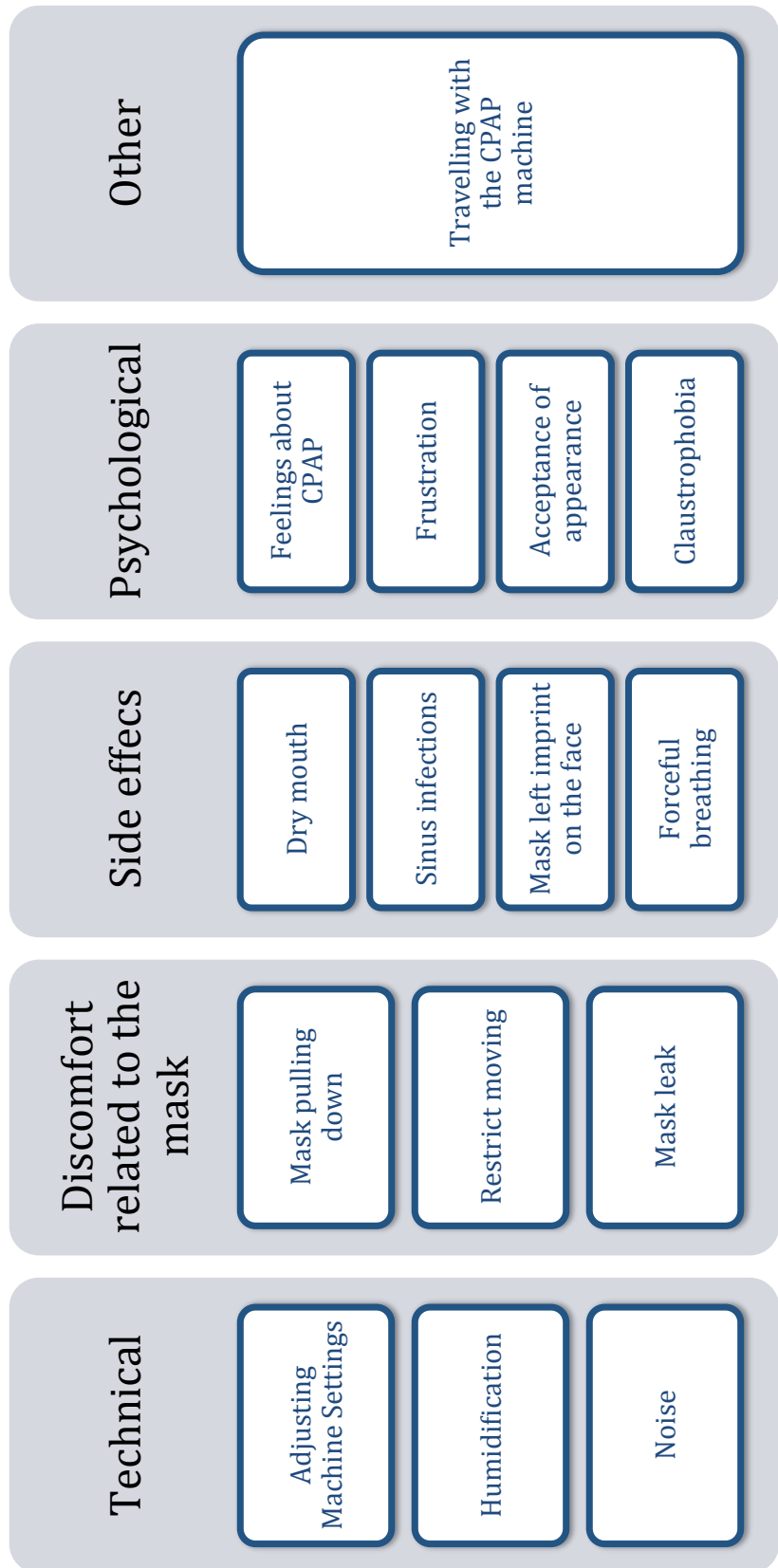


Figure 3.5 Patients' experience with CPAP

Technical issues with the CPAP machine

Technical difficulties described by patients were related to adjusting the pressure settings of the machine, the need to use a humidifier and noise of the device.

Adjusting the CPAP Machine Settings

Patients reported that they had the machine set in the hospital, and that they were not able to change the pressure settings. As this man reported, he would have preferred to set the device to his preferred settings at home.

“You’d put water into it, you turn it on, you hear a humming noise from it and obviously there was different levels on it, but I couldn’t actually change the level, you had to have a code or something to change it, and you’re meant to use this company who supply it. But I just couldn’t get used to it. I’d get, I could put it on, I could use it, I could go asleep, but I, I’d wake up because I’d move around quite a bit and, and like it’s a big mask over your face and like talk about social kind of thing, you don’t want that, you know what I mean? Like it’s, it’s like you’re going deep-sea diving when you have it on and, so I tried it for about three, three months and...” (Male 48 years old)

“I mean even trying the different pressures, you know, they’d alternate the pressure, oh well we’ll, we’ll up your pressure a little bit. Now, as I said the wife said I was not snoring, which was the biggest advantage of the mask, yes. But to me, it wasn’t worth it.” (Male 68 years old)

Humidifier

Many sleep specialists prescribed the use of a humidifier to prevent dryness of the air. In spite of this, patients reported that this was unsuccessful for them, and they still experienced dryness.

“I’d say I tried it for about three weeks, every night was the same, I was just ripping it off. So they put a humidifier in the room with me at home, still didn’t work...I couldn’t get used to having something on my face while I was asleep like.” (Male 42 years old)

“They said okay, when we get you this humidifier, this will keep the, the air moist and your mouth won’t dry up, but it still dried up.” (Male 68 years old)

Noise

Patients described that the machine was noisy, however that was not a significant problem for them because, as this man describes, it was not as loud as his snoring.

“I tried that and it was very difficult at first and eventually I, I got used to it, but I have to say it was a horrible experience. And what, what was happening was I’d wake up every day and my face, the mark, the, the imprint of the mask was on my face, it was like someone had ironed my face, big red mark of the mask and broke out in a rash on my face from it and it was, and plus the noise of it at night.” (Male 48 years old)

“Now it was a little noisy, but the noise, the noise was an awful lot less than, than me snoring.” (Male 68 years old)

Discomfort Related to the Mask

Patients described that they had used masks that covered the nose and mouth. Difficulties experienced with the mask were that the mask would move if the patient turned on his/her side while sleep, and that it leaked

air which caused dryness and soreness of the eyes, and that the mask would leave an imprint on the face.

Mask Kept Pulling off the Face

“Could not get used to it at all, just couldn’t, kept pulling it off at night time, the full mask.” (Male 42 years old)

Mask Leakage

“I couldn’t stick the mask because it was leaking and it was, it was giving me sore eyes and I just couldn’t get it under control, and it was very uncomfortable.” (Male 68 years old)

Mask Imprint on the Face

“I’d wake up every day and my face, the mark, the, the imprint of the mask was on my face, it was like someone had ironed my face, big red mark of the mask and broke out in a rash on my face from it.” (Male 48 years old)

Side Effects

Side effects reported by patients were dryness of the mouth and eyes, one patient reported that she had repeated sinus infections, and that breathing was forceful with CPAP.

Dry Mouth

“I started off with just a nose mask, now that I think of it, just a nose, and then the, and then with the mouth being open and drying up, they said we’ll try the full mask, but that still, I still ended up with the dry mouth. I could be up maybe twice or three times and into the bathroom, and I’d be actually brushing my tongue with a toothbrush because it felt like sandpaper, you know rough sand.” (Male 68 years old)

Sinus Infections

“I couldn’t tolerate it, my sinuses kept getting infected and I kept constantly having to go back for, to the doctor and she’d have to give me antibiotics.” (Female 69 years old)

Forceful breathing with CPAP machine

“The CPAP machine is a two-man job because the minute I stop exhaling I found that it was pushing the air into me. So that meant I had to consciously think oh, inhale now, because otherwise my mouth was being crowded out with this, or my nose was being crowded, you know, if I didn’t open at the back, down in the airway to let it through. So what I felt about the CPAP machine was it required me to constantly pull and push the saw, right?” (Male 59 years old)

Psychological

Psychological difficulties described by patients were feeling of frustration, fear of closed spaces, and difficulties of accepting the appearance of the device.

Frustration

“In my mind I was saying hold on, I’m working at this, I want to go asleep, and I’d wake up two hours later and I said, I’d just take the thing off in a fit of anger. Right? Frustration. And then I’d go asleep, albeit snoring and God knows what else, but I’d get better sleep.” (Male 59 years old)

Claustrophobia

“I was brought in for one week, one week into Vincent’s Hospital, and there I thought I would die because I got this awful phobia of smothering. I couldn’t tolerate it at all, my heart would absolutely jump out of my

chest. One night was worse than the other, so anyhow.” (Female 62 years old)

Acceptance of Appearance

Patients described the machine using terms like “elephant”, “hose”, and “as if going deep sea diving” and they said they felt unattractive to their spouses.

“I just always remember waking up and having this big red circle on my face. mouth and nose and under the eyes, but I’d literally have big red like, like someone had an iron on my face. And like, like you know when you get a wind burn like on your lower, it was all here and then here, and so I was putting cream on my face, I couldn’t put up with it, so. I’d rather be tired than go around like that, you know what I mean?” (Male 48 years old)

“Well from a vanity point of view, well I mean you try, you dress, you have a shower, you wash your hair, you do this, you do that, you try to look as good as you can and you go to bed at night and you put on this elephant’s face, not on, not for me. Definitely not. I’d rather do without anything than use it.” (Female 65 years old)

“So I invested in that and I hated every single second of it. I felt revolted by it, I felt unattractive, well obviously unattractive in it, and my husband was very, very understanding, he said look, it’s for both of us, it’s for the good of your health, it’ll be this, I definitely nearly went into a depression over it.” (Female 65 years old)

“I have to admit I only rented the machine, I didn’t buy it, but it didn’t work. My wife used to wake up in the night and see me with this big thing looking like an elephant. [laughing] Now that’s just joking, but it didn’t

work, it was ridiculous, it just did not do the business for me.” (Male 59 years old)

Other Challenges with CPAP

Travelling with the CPAP Machine

“I’d a letter to tell, to tell Ryanair that they had to give it to me for free or, you know, to carry this thing that it was a, but the thing is the hassle of carrying it anyway was just a pain.” (Male 59 years old)

“At that time I was travelling the world quite a bit with my job, and the thought of dragging this thing around with me.” (Female 65 years old)

“I remember we went on holidays, now just thinking about it, I had to carry an extension lead in my bag because when you go to a hotel, you couldn’t guarantee you had a socket to plug it in near enough to bed.” (Male 68 years old)

3.2.4.2 Perceived Efficacy of the CPAP machine

Despite the fact that patients were not able to tolerate the CPAP machine, it was efficient at reducing snoring. However, the challenges expressed by patients prevented them from adhering to treatment.

“It did improve a little bit, yeah. Now I wouldn’t, as I said it wasn’t a miracle cure, you know, but it did, it did improve a bit, but, but I still never woke up, they’d say, you know, you wake up refreshed, still never woke up like that.” (Male 68 years old)

“But it did stop the snoring. Now, or controlled the snoring or whatever way you want it, but I’m, I had sore eyes all the time and I just couldn’t cope with it.” (Male 68 years old)

3.2.4.3 Attitudes Towards CPAP

Patients' attitudes toward CPAP varied. One patient expressed strong feelings of rejection about the CPAP machine and could not tolerate it.

While others stated that they have tried to use it could not get used to it.

"I have to say it was a horrible experience" (Male 48 years old)

"I said we can't afford that, we'll have to do something, he (husband) said no, well we'll get it, we'll get it, so we got it, and it's now hanging in a place of disgrace up in the attic." (Female 65 years old)

"I think I still have it, it's up in the attic." (Male 48 years old)

"He said that he didn't think he, he described the mask over the face thing, CPAP machine, and I just said to him immediately my first reaction is no, I couldn't do anything like that, I don't like anything anywhere near my mouth." (Male 64 years old)

"It's not that I gave up trying to wear the CPAP, I just couldn't." (Male 48 years old)

"I just was not going to wear that mask, no matter if they had been the Pope of Rome. It didn't make any difference. I was not going to go down that road, and I found, I found them, talk, I, I found the kind of attitude with people talking and, and all of that, I didn't want to enter into that. I just wanted to push it away and not be involved, and that's why the Sleep Apnoea Association didn't work for me, because I found the whole thing, to be honest, I suppose the word I'm going to use is too strong, but it's the only one I can think of, I found it all repulsive, all of this, having to put this on at night, that's how strongly I felt." (Female 65 years old)

"I gave it a try every night, I was always optimistic, I was always thinking it'll work tonight, it'll work tonight, it didn't work. Every night I

ended up just taking the thing off just because I want to go to sleep.

Right?” (Male 59 years old)

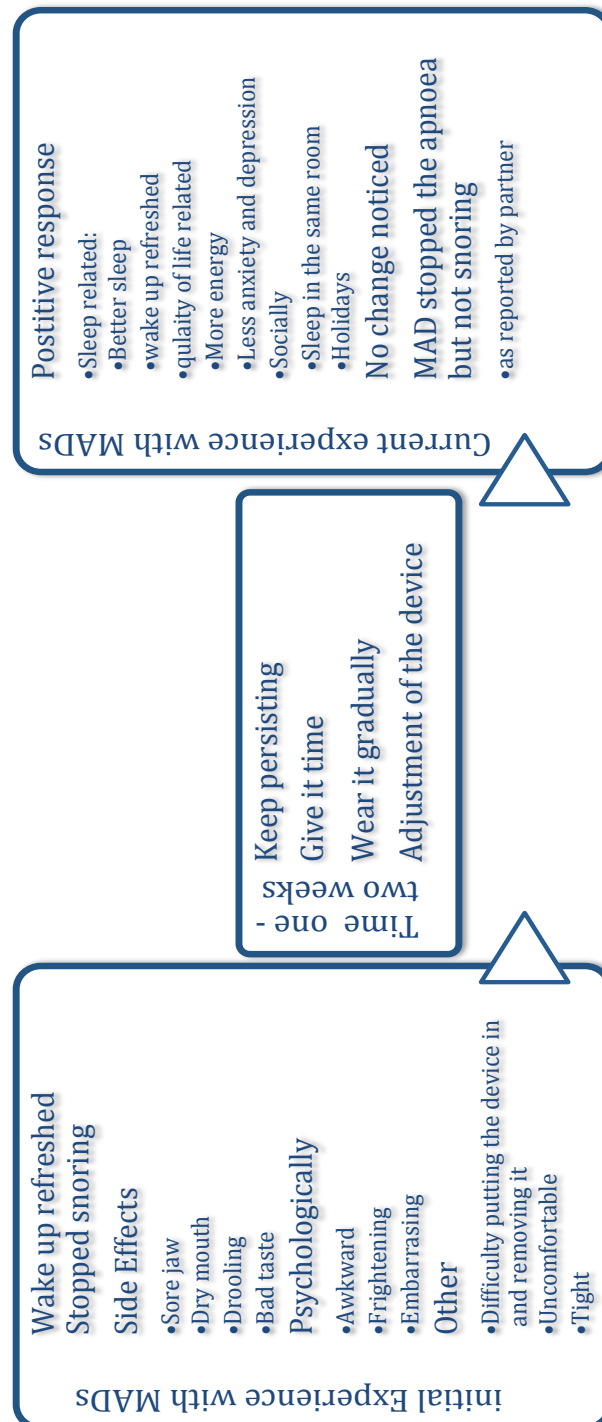


Figure 3.6 Patients' experience with MADs

3.2.4.4 Patients Experience with Mandibular Advancement Devices (MADs)

Patients' experience with MADs were highlighted. As described by patients, their experience could be divided into three phases: the initial experience with MADs, adaptation period, and current experience with MADs.

Initial Experience with MADs

Patients reported that initially MADs were uncomfortable; they acknowledged that they needed time to get used to them, and that initial discomfort decreased with time. Reported symptoms included discomfort, jaw pain, drooling, and difficulty with placing and removing the device.

"A bit uncomfortable, you know, to get used to it you know, that was the thing, you know, just getting used to it. You wouldn't sleep as well, you know, and your mouth was dry and a few things, but I'd always have a drink or moist, you know, that I just squirt in and that serves the purpose." (Female 62 years old)

"I got that device here on the Friday and I used it that night and I woke up the next day a different person. I swear to God, because I obviously slept all night, there wasn't a murmur out of me... I always remember the next day I woke up, I was like a new person." (Male 48 years old)

"When I woke up that morning, she (wife) said to me you know what happened last night? And I said no. You didn't snore, and I said what do you mean? You didn't snore whatsoever. She said I never heard you all night. She said I got the best sleep in years." (Male 42 years old)

“From the first night I didn’t snore, but once I put it in and then maybe it took about a week or a week and a half just to get used to it, I had sore jaws and sore bones from it, but I can, I kept persisting with it and now it’s just natural. It just goes in at night time and I don’t feel any pain whatsoever. From the start then you were, you had to adjust it maybe every two to three weeks because your jaw was coming out so much every time, so you’d actually start snoring again and you just turned the lad a bit and I have it set now that it’s, it’s just perfect for me.” (Male 42 years old)

“Once I put that in the first night, when I woke up that morning, my mouth was in bits from the pain. But the following night, I put it in again and just kept going and going, and there was some nights that it was so paining, I actually took it out and left it down. And I snored, and I got a poke, are you putting them in tonight or what? And I picked them up, back in, do you know?”(Male 42 years old)

“I suppose it was a bit, it was like a bit frightening, it was a, just as though you’ve, you know, felt it so tight on your teeth, just not used to having something in your mouth constantly, and I’d still find that now because even with being asleep I actually do remove it during the night, you know, so even now I find that I, I get a very dry mouth and lips and I always take, you know what I mean, I have to remove it.” (Female 55 years old)

“It was overnight I felt better. Overnight, I actually felt more refreshed getting up in the morning. Now it, it was a progression from there. Okay, but I could see immediately, immediately the change. And the first morning after, not so much with the mask because I was so un--, unhappy

with that, but with the dental thing, once I got it right, the first morning that I had a really good night's sleep I knew I was on my way, and from there on was, it just, it's part of my life. I don't even think about it." (Female 65 years old)

Adaptation period to MADs

Patients described that the adaptation period patients mentioned that they were proactive about their treatment. They got the device adjusted , and they persisted with the treatment until they felt that it was working well for them.

"The first night wasn't good, nor the second, nor the third, nor the week, but as I got it adjusted because it was rubbing on my gums and different things, but as I got it adjusted, I said this has to work. There was no other choice, has to." (Female 65 years old)

"I was a bit rejecting, inclined to reject it. I was having trouble going to sleep with it but I said to myself, right, this has to work. Right?... I said I'm giving this my absolute best, and after three nights I was happy that I could sleep with this thing, and I've used it ever since." (Male 59 years old)

"Oh, the first, yeah, it was, it was just awkward, I mean, and getting it in, it's embarrassing, you know, but it's, it was, like I can't get the two, that's why I had to put the two together and then put them in, because I can't put one in and put the other and then connect when it's in my mouth. I have to get them done first, you know, and then put it in. But, and then with the little screw I'd adjust it." (Male 68 years old)

"It was terrible. The taste of the stuff, but you know what? It was well worth it. But it took me about a week before I got into it. Sometimes even

during the night I wanted to take it out, I just felt, I used to take a glass of water beside me, take it out, just take a sip of water, and then try and put them back in again and clip it up and clip it down.” (Female 45 years old)

“For several weeks, you know, I’d wear it and I’d try and make it last longer and longer and longer, and I think I would have been wearing it for maybe two weeks before it stayed in all night.” (Male 64 years old)

Current Experiences with MAD

Patient’s current experiences with MADs ranged from no reported differences to a positive response and reported improved sleep, with some reporting that the MAD did not stop the snoring.

Positive Response

“It changed my life, I was able to get back into, go back into the room with my husband. I was able to go away on holidays. As I say, I got up the next morning feeling much more refreshed. I wasn’t exhausted. I knew when I went to bed at night that I was going to get a good night’s sleep, you know, that I wasn’t going to get up the next morning exhausted.”

(Female 45 years old)

“I am getting an actual better sleep with it, but I mean, you do have to adjust it because sometimes he’d (husband) say I, I had snored a bit, while it was in.” (Female 55 years old)

“But here’s the big, the big plus is that, and I’m only noticing it now, the days when I have not had the brace in the night before, I can be drowsy, but if I put the brace in and I go to sleep with the brace in, I am fresher

and I'm more alert the next day, and so from that point of view I can say without a shadow of doubt." (Male 59 years old)

"I'm in a better position now, and so I'm, I'm pretty happy overall, and I do believe that my anxiety levels and my depression that I did have, no, I'm only, I'm still taking five milligrams of Lexapro, the GP said take it for the rest of your life and don't worry about it, and so I do." (Male 59 years old)

"I don't feel tired during the day at all anymore. I get probably eight or nine hours sleep at night anyway, but even before, I was getting eight or nine hours of sleep but it was just, half twelve, one o'clock, even up to two o'clock, I'd just conk off. If I was sitting at all for a few minutes, I'd just , I'd be gone like. And sometimes the snoring was that bad I was actually waking myself up." (Male 42 years old)

"But the difference between then and now is completely different, because for one, I'd say we haven't slept in a separate bed for ten year. For two, she's getting a good night's sleep and I'm getting a good night's sleep. For three, we're having sex once or twice a week. And for three I'm happy, I presume she is, she hasn't said she's not, so do you know? Big difference. Big difference in, in what was going on. Some of this is hard to talk about, you know. What was going on before and, and now like. I think there's a big difference anyway." (Male 42 years old)

No Change Reported

"I don't really see any change. I mean maybe I'm not as tired as I used to be, I don't know. I'm a tired kind of person, I'm always tired. I work, it's nothing got to do with, people say oh, it's no wonder you're tired, you work hard. But I'd be twice as tired if I didn't work, you know what I

mean? If I didn't, wasn't doing anything I'd be even more tired, or just sitting around." (Female 69 years old)

Still Snoring with MADs

Some patients reported that MADs have stopped the apnoeas (as reported by their partners, but not the snoring.

"It didn't stop me. I would have been happy if it had to stop me snoring and I was, still left me feeling tired, you know, I would have been happy, but it didn't even do that ... it's not giving me the quality of sleep that I thought I would have got, neither the mask nor the mandibular... All I know, for me, it never gave me what I thought it would have gave, you know. That quality of sleep, I won't say quality of life, quality of sleep, so that then I could make changes to my quality of life after that, if you know, if that makes sense to you." (Male 68 years old)

"I'm not really getting the same as I was when I first started using it, and I, I put it down to having more, having more weight on me. And so I, and it, in the last kind of six months my, my wife has been noticing I'm, I'm louder again." (Male 48 years old)

"I suppose it does help because the wife at the time never complained about my stopping breathing. She said I was snoring alright, but she never said I'd stopped breathing, where when I'm not using it now and I'm just using that little gum shield, she's telling me I, I'm stopping breathing again with that, you know. So obviously the mandibular is helping in that sense, you know, but it would be nice if it had done both, [laughing]." (Male 68 years old)

“Sometimes I still snore, A___ (husband) would say to me, whatever I hold my mouth, whatever it is, sometimes I still snore and A___ (husband) would always kind of give me a nudge and say you’re snoring terrible, and I’ll turn around or something and then that’ll be fine.”

(Female 69 years old)

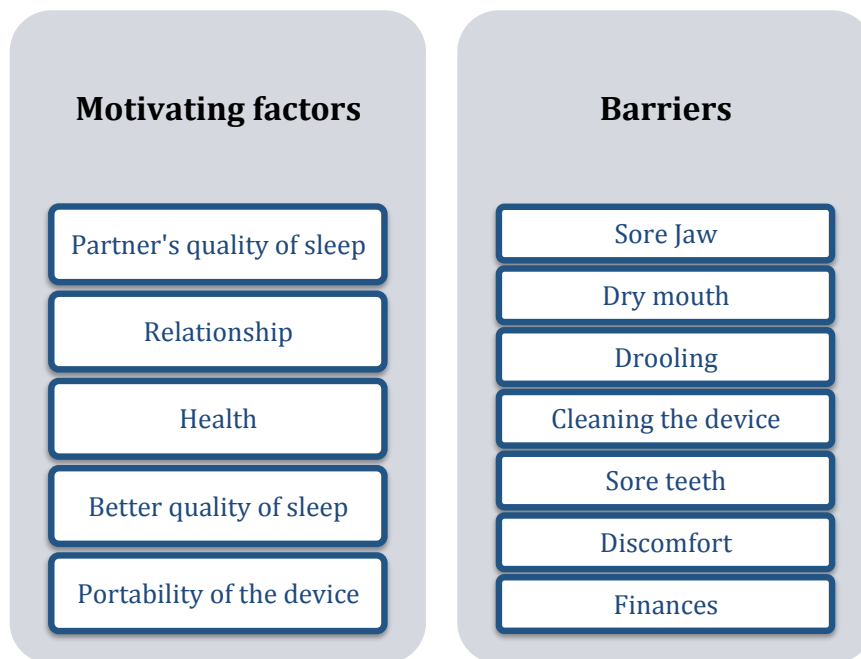


Figure 3.7 Motivating factors and barriers to using MADs

3.2.4.5 Motivating Factors and Barriers to Using MADs

Motivating factors to Using MADs

Partner’s Quality of Sleep, Relationships, Health, and Better Quality of Sleep

Patients highlighted what motivated them to use the device. They were considerate about their partners, they wanted their partners to get good quality sleep, and they did not want to sleep in separate rooms. Another factor was the relationship between them and their partners.

Health-wise patients were aware of the long-term sequelae of OSA and wanted to prevent potential complications of the condition such as

hypertension. They perceived that MAD treatment was a non-invasive option that did not have the potential side effects of sleep medications. Finally, patients' priorities were to improve their sleep and overall quality of life.

"I definitely need it because when I don't have it my wife can't stay in the same room as me."(Male 48 years old)

"Oh, boxes in the head from the woman. Ah no. She's probably the main factor; well not the main factor but she is one of the factors. She needs a good night's sleep as well like, and relationship is than it ever was, do you know? And then health-wise, I feel healthier. I'm not tired during the day, I can do my job every day, and that's, that's a good thing." (Male 42 years old)

"Once you're on this, the gum shields, you're not taking tablets for keeping yourself awake or you're not on medication to stop your snoring or anything like that. So it's a good thing that way." (Male 42 years old)

I: So what motivates you then to use the device?

P: Not having to go into another room to go asleep.

I: Yeah?

P: And getting, getting a better sleep and, yeah, I suppose it just, as, as a fear of, you know what I mean, I'll get a, I'll get, well my husband gets I suppose more of a relief than I do because I didn't realise I was that way. But I don't wake up with the sensation of I can't breathe, I can't, I'm choking like, I don't get that sensation." (Female 55 years old)

"Because I knew that if I didn't I was going to either end up found dead in bed in the morning or that we were going to be sleeping apart forever,

or that I was going to have to go back on the mask and the mask wasn't an option, not at all." (Female 65 years old)

"You need a night's sleep and the need for a better quality of life, and you know, it, it made me, it, it made me kind of, it restored a certain level of confidence and calm and, you know, positivity in me, which had kind of gone missing, because you, you know that tiredness or extreme fatigue is not generally coexisting with happiness and optimism." (Male 59 years old)

"I'm hoping, you know, I'm hoping that my overall health won't be adversely affected by the sleep apnoea because I'm using it, you know what I mean? I hope, you know, that my blood pressures not getting any worse or my, my cholesterol levels, but they did say that does affect those things, the sleep apnoea." (Female 69 years old)

"I would hope that if it, if, if not getting a proper amount of sleep affects your general health, although at this stage of my life I don't want anything to affect my general health, you know what I mean, I want to stay as healthy as I can for as long as I can." (Female 69 years old)

"And I find it's good, and you, and you know, I'm not keeping everybody awake at night, and that I would encourage anybody that can use it to use it. You get up the next morning, you're feeling better, and you have a better relationship I think with your husband as well, you know."
(Female 45 years old)

"P: I suppose it's that I, I know I have to.

I: You have to?

P: Yeah.

I: How come?

P: *You know, that like, because if I, if I don't I'm not going to sleep well, I'm going to snore, I'm going to wake up in the morning not feeling well, so it's now part of the routine of going to bed.*" (Male 64 years old)

Portability of the Device

"That's a whole different ballgame now because I just take the, the sleeping device in my handbag and take it through with me." (Female 65 years old)

"The great thing about it is it's only a little thing, you can carry it in your luggage when you go on Ryanair on your holidays or wherever you're going, you can bring it with you." (Male 59 years old)

"You just put it in your bag, it fits in your bag, you're not carrying around this big machine around with you, and you can bring it and nobody has to know that you have a brace or whatever." (Female 45 years old)

Barriers to Using MADs

Challenges described by patients were initial discomfort as sore jaws, and teeth, drooling, dry mouth, cleaning the device and finances.

Sore Jaw

"But [pause] might be one or two little things that would irritate you about it. I don't get, I used to get sore jaws and sore gums and this, that, but I don't get them anymore. I used to get the odd mouth ulcer in, especially on the bottom, but I think that was from not cleaning it enough." (Male 42 years old)

"So there was jaw pain initially, but now that I'm so used to this thing, I don't get jaw pain and my jaw, my mandible position adjusts from a night time position where I have my, my jaw bone thrust forward a little

bit because of the device to receding slightly as it should do.” (Male 59 years old)

Need to Adjust

“I had to get it redone because I’ve lost teeth. Now I don’t know if it’s loosening my teeth because of all, you know, my teeth and, you know, when you lose a tooth, you have to go get it adjusted because it wouldn’t be fitting correctly?” (Female 55 years old)

Dry Mouth

“I just find that now a very, just getting a dry, dry mouth, you know, might have to get up and get water or something.” (Female 55 years old)

“In the beginning I suppose I was afraid of the, when you’re clipping it together I was afraid I wouldn’t be able to open it again.” (Female 55 years old)

“The mouth would be still bone dry so I’d still have to go into the bathroom at night time, do the, do the tongue and put it back in and back into bed. So it was breaking the sleep, you know, a few times during the night.” (Male 68 years old)

Drooling

“I was a bit discouraged first, which sounds a bit negative, which it was, in actual fact, because you drool in the, initially with it, and I was saying I have to get this sorted because that, that can’t be right, talked it over with the, the lads and they said look, you might, this might be a condition of it, that because it’s a device in your mouth, etcetera, etcetera, and it was, it was pretty bad now, I felt, and I used to get face cloths in Dunnes, you know the cheap ones, and put them on the pillow, I don’t need that any more, that wore away. The other, the other thing that I found initially

a bit of a pain in the neck was your jaw is sore, tired, to get back in again, but because of the usage I don't have any of that at all now, none." (Female 65 years old)

"One of the possible side effects is an occasional little bit of drool, if I may say so, saliva escaping." (Male 59 years old)

Not Being Able to Wear the Device While Ill

"The only thing that would prevent me wearing it, if I get a cold. My nose is blocked up, and I do suffer a bit from that. I can't wear it because I, I feel I'm going to choke, smother, you know what I mean? So that's the only time I wouldn't wear it, if I had a bad cold, bad congestion in my head." (Female 69 years old)

Cleaning the Device

"To clean the braces is just unbelievable. The smell from them, you know, if they can get some solution that'll clean them would be great. That's another thing, if they get a solution that will clean it off, it would be great because you know, you take it out in the morning and the smell from them, oh my god, it's terrible. And you've that taste in your mouth, so the minute I take it out in the morning I wash it out and I would brush my teeth." (Female 45 years old)

Loose teeth

"Oh there'd be nothing that'd keep me from using it. Nothing. The only thing would stop me from using it if I thought my teeth were getting loose and that I couldn't use it, you know. That would be the only thing." (Female 62 years old)

Discomfort

“I think the discomfort in my mouth would be the biggest one, the fact that I feel my, my teeth being pressurised, and I also think that the, that would be it, I think. That would be the only one. Like, it’s, it’s almost like you’re, you’re clamping the lower part of your face.” (Male 64 years old)

Speaking with the Device in Place

“You know, it’s grand. The only thing is you can’t talk with it in, you have to take it out.” (Female 45 years old)

Finances

Patients mentioned that the device was expensive, and they had to pay privately for it, they suggested it should be covered by Drugs Payment Scheme because to them it is important for their health, and there should be a scheme to secure the fees of the device.

“Well they’re very expensive, you know. It’s very, I mean I’m an OAP now and I find it very expensive, but I’m not so sure if we should be charged for them, you know.” (Female 62 years old)

“Well back then I was, I was in a good job and I had the money to pay for it, but anyone that didn’t have the money to pay for it and they were depending on, now the, the medical card crowd did, the social welfare did pay for mine but I had to fight for it.” (Male 42 years old)

“I had have lived in Dublin, because I have a full medical card I would have got it on my medical card, but because of where I’m living I don’t get it, so it was an expensive piece of equipment to get.” (Female 55 years old)

“It should either be able to be tax-deductible or there should be a grant towards it, because in medicine, if you go to a hundred and forty-four euro a month on medicine, the rest of your medicines are free for that month under the Drugs Payment Scheme. So if they said look, you have to get a device, we can only, do the way they do with, with these elasticated stockings that people get, you only get one pair per year, so you have to look after them.” (Female 62 years old)

Value for Money

Despite limitations and challenges patients expressed that MADs were good value for money and they were willing to pay for the treatment.

“Well I suppose it is what it is, I mean you know, it costs what it costs, and I don’t think you can put a price on your health.” (Male 64 years old)

“Without a doubt. I don’t think you can put a price on happiness, relationships, yeah? And your health, probably health should come first. It’s all about a good night’s sleep... I’d find the, I’d find the money somewhere but I know for a fact that I have to be wearing them. If I went back to the way I was, I don’t think I’d survive. For one I probably wouldn’t be working, and for two your health. For three, probably be divorced. Probably. You never know. And for four, if I’m divorced I’m only seeing my kids once or twice a week. So regardless of what they cost, doesn’t come into it.” (Male 42 years old)

3.2.4.6 Attitudes Toward MADs

Patients expressed that MAD use is part of their daily routine and they use it every day.

“ I spend a bit of time over in the, in the UK and travelling and I bring it with me even when I’m on my own, so I feel like it’s essential to me, it’s part of, it’s like putting my socks on.” (Male 48 years old)

“It’s like religion now, it’s just when I go to bed at night it’s just going straight in. I’ve got so used to it that it’s in the box on the locker, I collects that, goes to the bathroom, brushes my teeth, cleans that, and it goes straight into my mouth before I come out of the bathroom and it’s into the bed.” (Male 42 years old)

“Totally, utterly changed my life. It’s part of me, I’ll never go anywhere far away without it. If I think I’m even going to be overnight, I take it with me. I take very good care of it as well, wash it every day without fail and dry it.” (Female 65 years old)

“It did, not only did it improve my sleep, I wanted it to improve my sleep, I really wanted it to because I thought if I was going to go down that ugly road, that there would have to be some payback time, and it did, I felt better getting up in the morning ... I was determined to make it succeed, I was determined.” (Female 65 years old)

“It’s part of the routine when I get up in the morning, you know, that I go into the bathroom and I clean it, you know, and dry it and put it back in its box, it’s, it’s like shaving, like it’s just what you do in the morning, and it’s just part of the routine of going to bed at night, it’s just on the, in its container in the drawer” (Male 64 years old)

“I just wish the mandibular worked, you know. Definitely worked, because I reckon anybody out there with sleep apnoea would rather use the mandibular than the mask because it’s so much less cumbersome, it’s so much easier to carry with you.” (Male 68 years old)

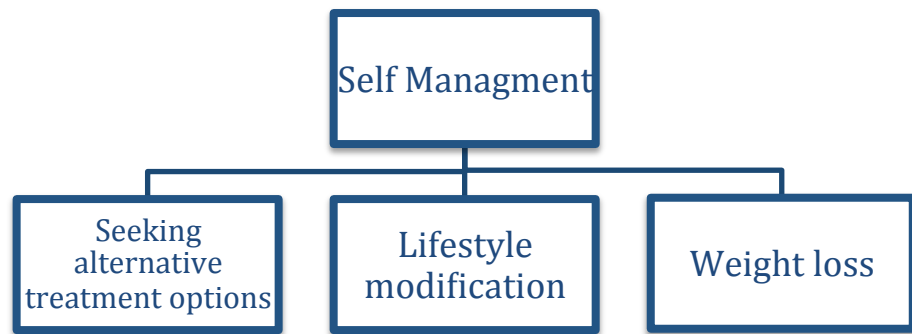


Figure 3.8 Self – management strategies described by patients

3.2.4.7 Strategies for Self-Management

Patients expressed strategies for self-management of the condition such as seeking alternative treatment options, modification of their lifestyle, and weight loss.

Seeking Alternative Treatment Options

“And I bought something over the internet, similar to, well, I’ve tried a few things, I found a spray then, it I tried the clips on your nose, I tried gum shields, stuff like that, but nothing actually worked.” (Female 55 years old)

“I would read up about sleep apnoea on a regular basis online, just out of interest to see like what, are there any new developments and there’s a there are, sort of every couple of months there’s somebody has a brand new something or other.” (Male 64 years old)

Lifestyle Modification

“He said now you have to do this, I mean, he had me not eating after five o’clock kind of thing, you go to bed by nine o’clock, you get into a pattern. Now I don’t know anybody who is in a pattern like that. Do you know what I mean?” (Male 68 years old)

“They said weight, so I’m keeping an eye on my weight, wouldn’t be, you know, drinking would be a lot of snoring as well, so I do exercise as well

because your, I just keep myself I suppose a bit more of a healthy situation?” (Female 55 years old)

Weight Loss

“I think what my issue here is I need to lose weight. That seems to be the problem, because it seems to be getting worse as I get older.” (Male 48 years old)

“Like they say that being overweight as well doesn’t help, but yet I never tried too hard to lose the weight either.” (Male 68 years old)

“I think they put everything down to weight, so they advised me to lose weight so I did lose a bit of weight, but then it sort of crept back on again, you know, and I find when I have the weight on, it’s worse.” (Female 45 years old)

3.2.4.8 To What Extent do Patients Feel That They are in Control of the Condition?

Patients considered themselves as being in control of the condition when they use the MAD every night, monitoring their general health, and through check-ups with their doctors.

“I am in a hundred per cent in charge of the condition now, I’m, it’s up to me to make sure that I’m using the device because if I don’t, it just will be a, it’s a thing, it’s only threatening your health and stuff like that. But I’ve got it, it’s, to me now to, to make sure I keep myself, weight-wise and, not that I was big or anything, just to, you know, small little things to keep yourself healthy, keep, I mean we have, have the device now, so to use it.” (Female 55 years old)

“I feel I am in control of it. You know, again, you don’t, I’m not qualified to say what difference it made, I just know that I’m fine at the moment and I’m presuming that the reason for that is that I’m using it.” (Female 69 years old)

“I wouldn’t say I’m in control, but I’m living with it. You know, I’m living with the condition. Well I’m using the device, I’m doing all the things they say to do, you know, lie on your side with your mouth moist, you know, and attend your physician or whoever is kind of looking after you and keep an eye on your general health, really, your blood pressure and all the rest, you know.” (Female 62 years old)

3.2.4.9 Follow Up and Monitoring

Monitoring of patients use of CPAP

Respondents suggested that CPAP use could be monitored through sensors in the device that could indicate the frequency and the duration of use.

“They plug it into the laptop and they know, they downloaded all the stuff off it.” (Male 42 years old)

Monitoring of MADs

Patients were relying on their partners to report improvement of symptoms, and two of them had a repeat sleep study to monitor the improvement in the condition.

“The appliance I found very good, very good, you know, and I found, my husband never complained about snoring, and of course I had the polyps gone, you know, and all the rest, you know, and I use the appliance all the time, except maybe when I forget them going away or something.”
(Female 62 years old)

“I came here, I got the device, I went home and I used it, I don’t know, I’ve never had any sleep test or anything since.” (Female 69 years old)

“I went back after six months and I had another sleep test wearing the, the mandibular advancement device, and the consultant, whose name has just floated out of my head, may float back, just said that, that it was working and that, my breathing was normal and I wasn’t, I wasn’t sort of any longer suffering from sleep apnoea.” (Male 64 years old)

“I’m not talking to anybody about it. I come here every two years and get a new device. I haven’t been tested in eight years, I don’t know if it’s getting better, if it’s getting worse, I, you know, I, I’m not seeing anyone about it, so to me that’s a bad thing. Like I went to James’s, they told me to come back in two years.” (Male 48 years old)

“Actually sometimes I do think, I wonder what’s my situation now, if I had the sleep test again. I do wonder about that, would it be a good idea.” (Female 69 years old)

3.2.5 Services Provided to Patients with OSA

Patients were asked to reflect on the services provided to patients with OSA. Three areas were discussed, patients access to information, how could services be improved, and what would they advise people in a similar situation.

3.2.5.1 Patients’ access to information

Please refer to section (3.2.2.4)

3.2.5.2 How Could Services be Improved?

Patients suggested that a focus for health care providers should be on keeping patients informed and updated about their condition and to

increase awareness about sleep apnoea, and seek financial support for patients seeking treatment.

“To notify the clients as, if there’s any update on services as well, you know. If there’s any talks, if there’s anything going on, if drug companies have something now to offer, you know, that they make them aware of it.” (Female 62 years old)

“If there is a sleep apnoea specialist out there who I can go and see and who can do tests and maybe do another sleep study, I’d be quite open to doing that kind of thing, you know.” (Male 48 years old)

“Well the way it was explained to me was it’s a matter of life and death because, this is the way I was told anyway, that I was stopping breathing twenty-five times every hour and it’s putting stress on your heart. So I think the health providers should advertise it more. Now they probably, anyone that snores, you could have ten people that snore, maybe only three of them could have sleep apnoea, but you don’t know you have it until you get tested for it.” (Male 42 years old)

“Well if I were making that decision I would go, I would find out who had the sleep apnoea and what degree. I would also have a, a meeting with them and say look, this is something that you have to deal with, it’s crucial to your life, to your wellbeing, to everything about you, and not only to you but to the people around you. It’s crucial that you deal with this and deal with it well and in a style that suits you, alright? And then I would say we have this, this, this and this, some people, they suit this, this, we’ve had reports women particularly don’t like this, but we can move on to that if you have your, I would put such a positive spin on it, that I would enthuse them to go down that road.” (Female 65 years old)

“If there’s some dental company out there, they should think about sponsoring an ad about, an ad on the media that says are you tired all the time? Have you a problem, are you frustrated, do you need to go to bed during the day just to keep going? Ask all the questions, all the stuff that you and I have just discussed here, right? You know, go for keynote points. Could you have sleep apnoea? You don’t have to live with this, talk to your GP. There are ways of dealing with these matters.” (Male 59 years old)

“I suppose the relationship with, with the, the, the, the patient is very important, I mean that the patient is working with somebody that they feel has the knowledge and has the interest in them for them to get better, I think that’s for them to manage it, I think that they’re, they’re, that the, the patient has that message, I mean that this is somebody who has the expertise that I need in order to manage this condition.” (Male 64 years old)

3.2.5.3 Support Groups

Views on Support Groups – How Can They Help?

Patients expressed that support groups would help in making them feel as a part of a community where they could share experiences and as they expressed is “not to feel isolated” and that hearing others peoples’ experiences would help them face their own problems.

“I hated it, I absolutely hated it. I was distraught by it, distraught is the word I would use. It upset me to that extent, and I went to the Sleep Apnoea Association because I felt that I would get solace from other people who were in the same situation, and when I got there I just, I just couldn’t talk, I just started to cry because I thought this is useless, it’s

hopeless, I'm here and I, everybody was sharing experiences and all and, and I just couldn't, couldn't do it. It really hit me very hard." (Female 65 years old)

"I suppose you could nearly put it like Alcoholics Anonymous. I mean they need support groups, you know what I mean? And it's the same thing, sleep apnoea, it's something you can't control, being an alcoholic, as far as I know, you can't control if you're an alcoholic, you've no control over your drinking. So having sleep apnoea, no control, so I suppose, you know, support groups would help that, yeah, you know."
(Male 68 years old)

"If one person was able to tell you it's definitely working for me, that would be a help, right? And if someone else could say yeah, well I had your problem with the eyes, but because I done this or I done that, I solved it or maybe not have solved it but the crowd who supplied my mask is now looking into getting me a different mask or whatever. Just keep you, giving you that little bit of hope all the time. I, in that sense it would, it would kind of, to me it would have to kind of help you." (Male 68 years old)

"Support from people who have it is better than any support you'll get from any doctor. Do you know what I mean? Because they're the person who has it, I mean a doctor doesn't have it, so if a person over there says yeah, I have that and I have it worse than you, and I'm doing this and it's helping, in that sense support would definitely work." (Male 68 years old)

"If I was about forty or younger, def--, yeah, I'd probably go now because of the family life , and still hope that okay, something might be

there to help with the family life, but because of the situation I'm at now, I, as I said, I've so much free time and I can control my life much easier now." (Male 68 years old)

"I don't suppose it would have changed the fact for me that I couldn't tolerate it, you know, I suppose for it getting the sinus infections all the time and having to get antibiotics you know, it wouldn't have changed that." (Female 69 years old)

"To say well no, you're okay, you're not on your own, there is other people here that have it, that you'd go to a group, people could talk about it, you know, maybe they're only diagnosed, a month later or something, go and talk and say well there is other people out there, you're not on your own, and you do get nights, like there's some nights you're in the spare room, some nights you're in your own room, you know, or whatever, you know, holidays, I've gone through that, being away on holidays, you know, that would be a very good idea to have something like that. I'd say it would help an awful lot to learn more about it, and to know and I'd say you would get much more people that didn't realise that they had it, and they would come to that group, and they could talk out, you know, what, you know, their problems with it and how they were finding and how they're coping with it and that, you know?" (Female 45 years old)

"Well I suppose it's like anything else, when you see somebody like yourself, you don't feel as isolated." (Male 64 years old)

Advice for people in similar situation

Patients were asked about what advice they would give to people in similar situation. They acknowledged that OSA has a significant impact on general health and day-to-day life. They recommended that management of OSA is approached from three angles; seeking medical advice, lifestyle modification and keeping the weight under control and finally to be patient and persevere with the treatment.

“I would certainly advise them if it interferes with them, their driving or their work, to go and see the GP first, and from there take it, you know, and follow up on it, because there, there are problems, there are problems that it causes but there are problems that can, that can be alleviated by using a device or the CPAP machine.” (Female 62 years old)

“I feel, most of the people who have sleep apnoea are overweight and when I get heavy here it gets a lot worse. And I’d advise them to lose weight first, because I think it makes a huge difference.”(Male 48 years old)

“I’d just say go to your GP, and he’ll send you to the sleep clinic and they’ll send you to the Dental Hospital, because it, improves your lifestyle, you know, your everyday life, you’re not as tired, you’re not as, just feeling drained.” (Female 55 years old)

“I would recommend it to anybody who could use it, and I would also recommend it with a couple of little words of advice, and the words of advice from me would be make it work. Be patient. If you’re patient with it, it’ll treat you good. It’s as simple as that.” (Female 65 years old)

3.2.6 Partner's Role in Treatment of OSA: Patients' Perspective

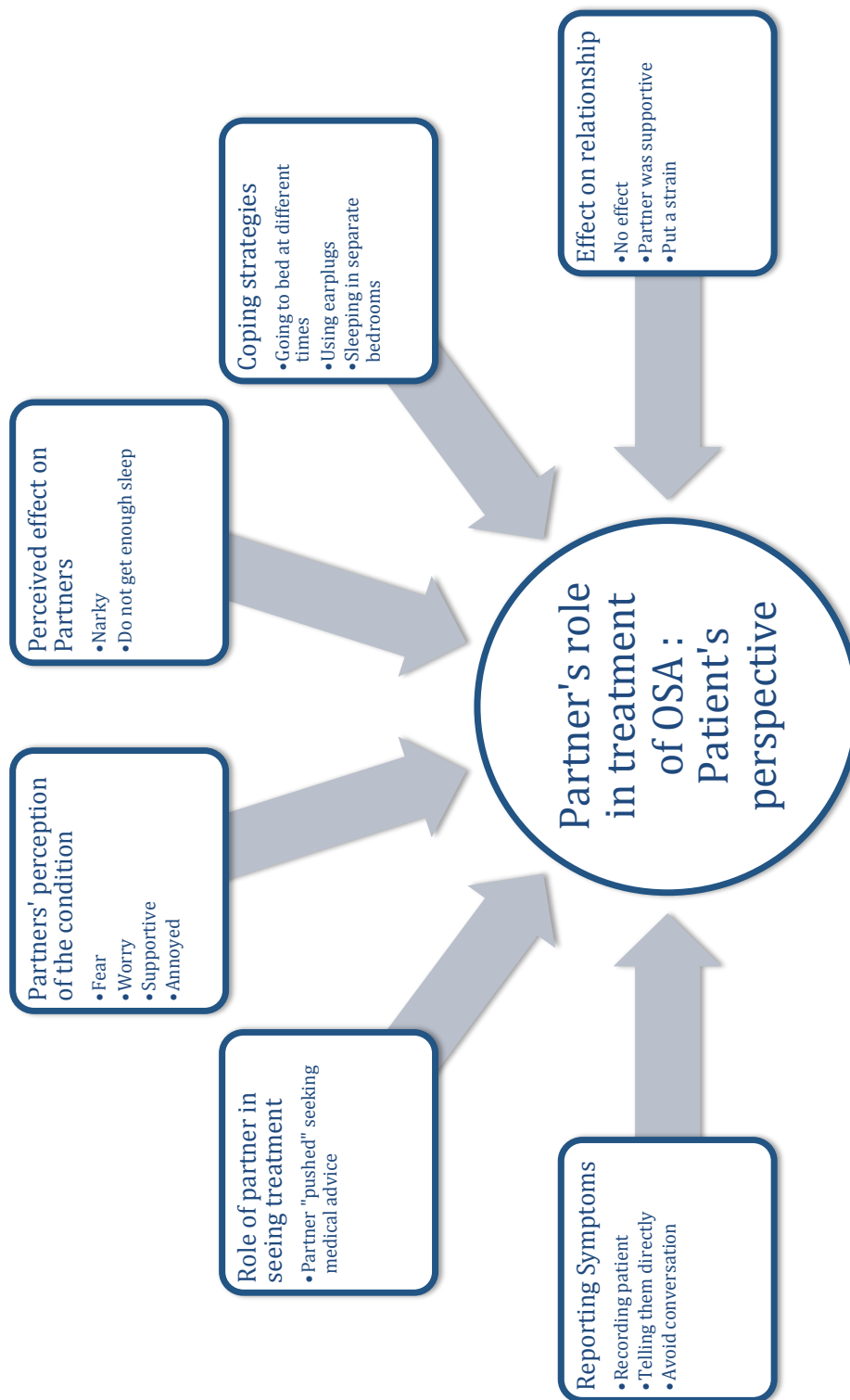


Figure 3.9 Partner's role in OSA treatment: Patients' perspective

Patients highlighted their partner's role in treatment. Topics discussed included: reporting symptoms, partners level of engagement in treatment, partners' perception of the condition, perceived effect on partners, coping strategies, and effects on the relationship.

Reporting Symptoms

Patients reported that it was their partners who told them that they snored. Some partners would be direct and would have an open conversation with patients regarding their snoring, whereas others would record the snoring because they believed that patients denied that they snored, and others would avoid conversation about the topic and would not mention it.

"Now my husband tells me now, sometimes I make a noise, you know. So that's it."(Female 69 years old)

"Well, my husband recorded me. He actually, because he was so fed up with it, he recorded me because I, I kept saying oh, there's no way I can, I, I don't feel I'm snoring, you know, all this, and when he recorded it."
(Female 55 years old)

"Well, he, more with your, with nudges in the back or a slight kick in the leg and kept saying will you stop snoring and then I'd, then I'd be, we'd be having an argument saying I didn't snore, I don't do this. So then one, next morning he just said look, well listen to this. And I, you know, the usual, I, I was annoyed but then realized it wasn't, he wasn't doing it to upset me, he was, he was trying to get me to recognize there was a problem."(Female 55 years old)

"P: you don't hear yourself in bed at night. It's somebody else who hears you, and of course discretion being the better part of things, my husband wasn't going to say anything because his life might have depended on how he said it, [laughing]

I: So why do you think your husband did not mention anything about snoring?

P: Because he wouldn't hurt me for the world. He wouldn't. He wouldn't upset me and he would know that something like that would upset me, and he wouldn't go down that avenue ever.

I: How did that make you feel?

P: Very precious. Very much cared for." (Female 65 years old)

"I go home to bed, my wife would say oh god, you were like a thunderstorm all night, snoring and rumbling. And my wife, obviously she snores as well, but you know the two of us are so used to each other, we're like a pair of, what do you call, bay trees, we've grown into each other." (Male 59 years old)

"I used to frighten her because she didn't know whether I was dead or not, lying, I just wouldn't move, I mean, and I wouldn't be breathing, and she'd be listening and listening and listening, and then of course the nearer she came to see and if she'd touch me then I'd just and I'd start, and I'd be off snoring again, and she'd say she was sorry she woke me, you know what I mean, sorry she should have let me die, messing."

(Male 68 years old)

"Well it's much easier to monitor when you're living with somebody because they wake up in the morning and they tell you were snoring last night." (Male 64 years old)

Partners' Level of Engagement in Seeking Treatment

Patients reported that partners were supportive when they sought medical treatment, and it was the partner who would frequently “push” them to seek medical advice.

“It was A ____ (Wife) who pushed me to go and get something, because I’d wake up, well, we’d no kids, we had a three bedroom house, and I’d say after, there was times, four nights a week I’d wake up and she’d be in the spare room because I’d be waking her up.” (Male 48 years old)

Partners' Perception of the Condition

Patients reported that their partners were relieved when they received a diagnosis. However, some reported that partners were concerned, and were supportive of them in seeking treatment.

“Well my husband gets I suppose more of a relief than I do because I didn’t realize I was that way.” (Female 55 years old)

“I don’t know. He never said that, now well he, he did say it to me, sometimes he would give me a nudge and say wake up, especially after he heard I had sleep apnoea, he used to say, he’d wake me up when I’d snore a lot because he’d say, he’d be afraid I would die. [laughing]. But he never complained, he’s that kind of person.” (Female 69 years old)

“My husband was very, very understanding, he said look, it’s for both of us, it’s for the good of your health, it’ll be this, I definitely nearly went into a depression over it.” (Female 65 years old)

“Occasionally I’ve gotten lazy, and when I get lazy and I go to bed, I brush my teeth and floss and all that thing, oh, put this damn thing in, I don’t bother, you know, so I go to bed and my wife’s, every so often I’m

getting nudges, oh God, so then I get up out of bed in the middle of the night.” (Male 59 years old)

“Well, my wife was, to be fair, and still is pretty supportive and she’s not negative. I do think that at one stage she became rather annoyed at me going to bed, because then she was doing more work in the house than I was... So you know, we have kind of roles together... and she was a little bit annoyed and I think she had every right to be. And she tended to perceive me going off for a nap, I think, I don’t know because I think she perceived it as some sort of a, a self-indulgence on my part, and if I step outside myself and I look at things, try and imagine things from her perception, and she keeps going all day and I don’t, fair enough, I understand why she might feel that way. It’s not fair...and she always says well, life is a man’s world, it’s a man’s world we live in, and she’s right about that too.” (Male 59 years old)

“He’d just really, we worry that, you know, I was going to die, that would be his main thing that he’d say, you know, because say you stop breathing for a second or whatever, then you wake up, you know, but apart from that he, he didn’t mind one way or the other.” (Female 69 years old)

Perceived Effect on Partners

Patients’ main concern regarding their partners is that they were not getting good night sleep.

“Sometimes I wake up, my wife is gone, even when I have it on. But it’s give and take, it depends. When I’m really, really tired, apparently I snore a lot.” (Male 48 years old)

“Just she’d be very narky with me because she got no sleep, you know, which, which would be, and most of the time, ah look, she gets over it, we’re together twenty-odd years, twenty-five years, so we know each other a long time so she’s well used to me.” (Male 48 years old)

“I feel that if I, if I did lose a stone and a half and I was a lot fitter, I wouldn’t, I wouldn’t be half as bad as what I am. But, and I’m just being lazy about it. I should go and do something about it, and I’m actually trying at the moment.” (Male 48 years old)

“My husband gets I suppose more of a relief than I do because I didn’t realise I was that way. But I don’t wake up with the sensation of I can’t breathe, I can’t, I’m choking like, I don’t get that sensation.” (Female 45 years old)

“Because I would just, it was draining me, and my husband couldn’t sleep with my snoring.” (Female 45 years old)

“I’d say her life weren’t great in that aspect of things, because, now it wouldn’t be every night that you’d be snoring. You’d probably, I’d say for a year before it was a real bad time, or even eighteen months before I got diagnosed with it was probably the worst time. That was, that was when the spare bed came into it, that she was, she was or I was going or, or some nights I wouldn’t even go to bed. I’d be asleep on the sofa like at eight o’clock and she’d just leave me there some nights.” (Male 42 years old)

Coping Strategies

Patients mentioned three strategies that they and their partners use to deal with snoring; going to bed at different times, using earplugs when going to sleep, and sleeping in separate bedrooms.

Going to bed at different times

“I let her go to bed about two hours before me so that she’s in a deep sleep when I go to bed, because if she’s not, when I start snoring, she’s up but if she’s in a deep sleep, now she also sleeps with her earphone in, with the radio off the, off the phone, because that kind of drowns it out a little bit, you know. But if she’s in a deep sleep she’s grand, you know. If she’s not, she’s up and I wake up and she’s gone. And I say why don’t you wake me to go, and she says you, you were in a deep sleep, there’s no point in wakening you up, and she gets up and goes into the other bedroom.” (Male 68 years old)

Using Earplugs

“H___ wears earplugs at night, because he worked nights when he went working first, he was on night duty, so trying to sleep during the day, he started wearing earplugs, he’s always worn earplugs. So I buy him his earplugs. [laughter].” (Male 64 years old)

Sleeping in Separate Bedrooms

Patients’ views about sleeping in separate bedrooms varied. Some patients said that their partners would get a better quality sleep, so they did not mind sleeping in separate bedrooms. Some said that they missed their partners in the morning and preferred if they would sleep in the same room. Some felt guilty about having their partners move out of the room, and some believed that sleeping in separate bedrooms put strain on the relationship.

“I: Does that upset you in any sense?”

P: Not really, no, you know, it doesn’t, it’s peaceful. [laughing]”

(Male 48 years old)

“As long as he gets his sleep, that’s very important for me, you know. You know, and that I get off to sleep as well. Because if he’s in the bed and I’m conscious that, if I’m, if I’m, you know, if I was annoying him I wouldn’t sleep then. So it would be easier for him to go next door or me to go next door and sleep, and fall asleep, you know. So that’s all.”

(Female 62 years old)

“It’s very important that he’s happy, you know. If that’s what he wants, you know, it’s very important for me that he’s happy, that he gets his night’s sleep, because that’s more important than say him being in the bed awake all night and me awake because he can’t, because if I’m keeping him awake, so that would, that might, you know, wear me out.”

(Female 62 years old)

“Now I’d miss him in the bed in the morning, you know, I’d put my hand over and nobody in the bed, I would, I would miss him.” (Female 62 years old)

“See about getting up in the morning on your own in a bed, do you know, that’s, that’s a strain on us, for both of us, probably, you know? Don’t know what else to say now.

I: So what is it about waking up on your own in the morning?

P: Well sure, you’re a married couple, you’re supposed to wake up together, aren’t you? If you were married, you’re supposed to wake up, you know? If, if, how would I put it? If you, if you married someone and you love them that much, and you wake up in the morning and they’re not there, then you say ah, that’s my fault. Okay? So you apologize or whatever, sorry for snoring. Yeah, yeah, I had a good night’s sleep anyway so don’t worry about it, or you could get yeah, I didn’t sleep at

all because I miss you. So you're one or the other. Sometimes, sometimes you get ah, I had a good night's sleep, probably sleep in here tonight as well. So that puts a strain on your marriage." (Male 42 years old)

"When I had to move out of the room at night, that upset me an awful lot, you know, and I felt, you know, it's not fair on him not being able to sleep and having to move out of our bedroom and go into the spare room or something, you know, that sort of affected me, affects me, you know. But that was really the only thing now that really." (Female 45 years old)

Relationship

When asked how the condition had affected their relationship, some patients said that they were well used to each other and the condition did not affect their relationship, and that their partners were very supportive of them, while others said that it put a strain on the relationship.

"It's the way life works. So we're a long time together, we're thirty, oh God, we're nearly forty years together really, a long time. But the point is her snoring wouldn't keep me awake and mostly mine wouldn't keep her but mine was more difficult, so now she says that I, I sleep silently, which is brilliant, right. That means for me that I go into a deeper sleep." (Male 59 years old)

"She used to go to sleep in the spare room or I'd go to the spare room, if I, if she was poking me that much that I was snoring, I'd just get out of the bed and go, or she'd go if I wouldn't wake up. But relationship-wise, it was putting a strain on it like. So I think she just got to the final straw that week we went away to Scotland, that she, we were in a room and she couldn't go to a spare room, do you know? So she was up every night, she was up the whole, the five nights and didn't sleep at all. So she just

said when we, when we got back onto the boat to come back, because we got the boat over to Scotland, she says you're going to the doctor in the morning, make an appointment and that's it, she says. You either go to the doctor or I'm gone." (Male 42 years old)

"P: It puts a strain on your marriage.

I: So how did you deal with it?

P: We didn't deal with it. She just, it was going on constantly, that the strain was there, and then once I got diagnosed and we knew what the problem was, we worked through it, and then we tried the CPAP, that didn't work, that put more, a little bit more strain came back into the marriage, and once I got the gum shields, just went back to normal. Do you know?

I: Yeah.

P: And she, I think she actually rang Michael two or three days after the first night, yeah, I think she did actually, because she was looking for the number, and I says what do you want it, I want to thank him, she says." (Male 42 years old)

" Took a while to get back the way we were. Stress in a marriage is not good like, so I'd say maybe about six months after, maybe three, maybe four months after I got the device, the fun came back into it. Do you know?

I: Yeah.

P: We were getting, we were getting sleep at night, we were having sex at night. Sex stopped, actually, I should have mentioned that, sex stopped, because she was in one room and I was in another, so there was, there was no sex for probably two year, and on and, you know, not

that there weren't sex for two year, you'd, you'd probably get to have sex maybe and then it could be six months down the line. So that's stress, that's stress-related like, but since, since the gum shields, I presume at the, at, on average about once or twice a week since the gum shields, so that's good. We've two kids to prove it anyway, so, two more kids, but yeah, it's been good. Been good so far." (Male 42 years old)

"I was waking up in the morning and the sweat was all around me, it was absolutely awful, horrendous, dreadful, demeaning, and I said to him I, with the best intentions in the world, I don't think I can do this. I just don't think I can do it. And we have a large house in, and, thank goodness we're lucky enough to have that, and I said it's going to be, maybe we just at night time, just separate and, but he said that doesn't cure it for you, you're still going to be tired. And that's when we took the others, wasn't I lucky to be in at the very beginning? Was I?" (Female 65 years old)

"I think we're strong, that we've, you know, it kept us together, you know, we had loads of hurdles before that, so I think it sort of, it held us together, we can get through this, this was sort of, you know, a minor sort of, after losing my mam and then A___ (Husband) was very sick as well so it sort of, we, we seemed to get on, gel together." (Female 45 years old)

3.3 Qualitative analysis of Partner's interviews

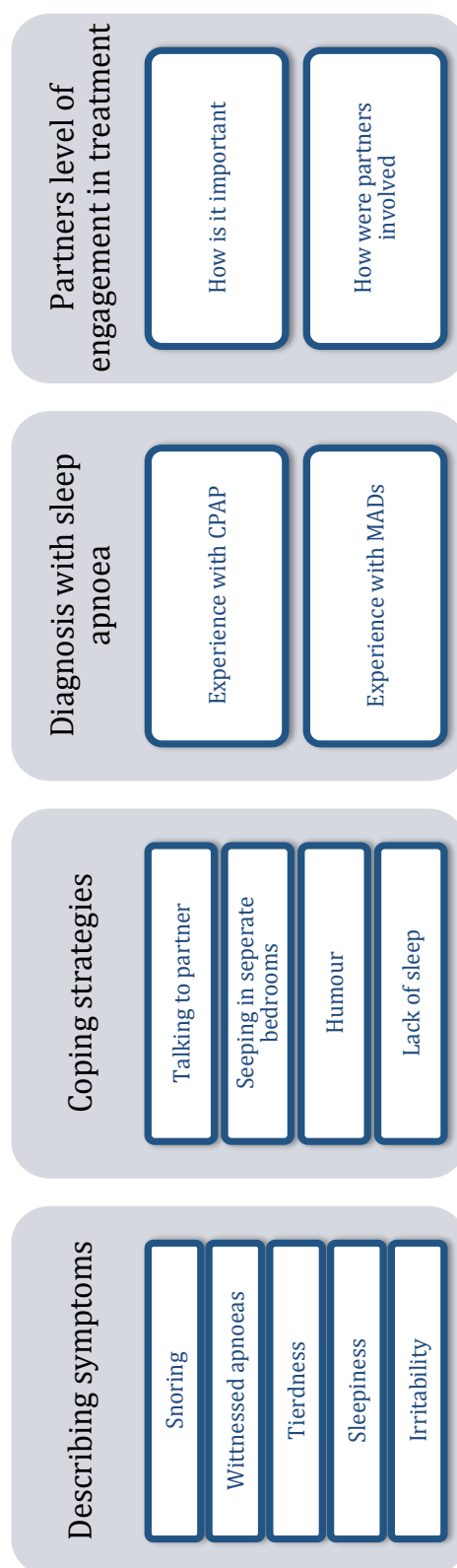


Figure 3.10 Partners' experience with OSA and CPAP and MAD treatment

Participants were approached through their spouses who had OSA and were using MADs. Patients were contacted after the interview, and were asked if their partners would be interested in participating. If so, they were sent a package containing information leaflet and expression of interest forms. Five partners responded to the invitation, and were interviewed individually at a time of their convenience in the DDUH. Partners' experiences were highlighted through the interview. Topics discussed were partners experience with OSA, in particular reporting symptoms, diagnosis with OSA, and their experience with CPAP and MADs therapy. In addition the partners' level of engagement in treatment was explored.

3.3.1 Partners' Experience with OSA

Partners experience with OSA began with relaying the patients' symptoms to them. They elaborated on how they identified that there was a problem, how were they affected and what strategies they followed to cope. The second part in the experience began with the diagnosis of sleep apnoea for their partner and their experience with CPAP and MAD therapy. The following topics were discussed: their initial experience, their current experience, and the barriers to treatment.

3.3.1.1 Describing Symptoms

Partners reported a range of symptoms. They reported that partners snored, that they would stop breathing and that they would "listen to their breath" at night. They also reported daytime symptoms like tiredness, sleepiness and irritability.

"Sometimes he would stop breathing, I shake him so he started again, snoring but at least he was breathing." (Female 40 years old)

“I: Yeah, so now you mentioned earlier that he says that he does not sleep. How do you think this affects him?”

P: He’s tired. He’s always tired, he always feels his eyes are heavy and he just, he just sits down and he’ll slump down in the chair and you can see him, he’s ready to go. And you say are you alright and he’ll say no, I’m just tired. And he shouldn’t be tired all the time.” (Female 62 years old)

“A___ snored his brains out for years and years and years and it nearly drove me mad. Now really snoring, this is not just snoring, everybody snores or, I know what happens when you fall asleep, everything relaxes, but he was horrendous. I mean we used to go camping and when you’d pass by the tent in the summer, the kids all laughed because you could nearly see the tent going in and out with the snoring, it was horrendous. But at night time you’re lying awake, you can’t sleep with the noise, the snoring was horrendous, and I think I’ll kill him, I’ll smother him, I’ll stab him, I’ll kill him, you know, aah, and then it’d stop and I’d say oh thank God, that’s grand, he’d stop. But then kind of nothing would happen and you’d be looking and you’d be half-sitting up and then you’re kind of up ready to jump, what’s wrong with you? And he’d, oh, snorting would start all over again, I’d say I should have smothered him. [laughing]” (Female 62 years old)

“He was tired all the time and saying that he hadn’t had a proper night’s sleep, even though he was in bed all night for a long night. So that’s really how he started, he didn’t seem to be getting proper sleep. So, also he had a lot of snoring and he seemed to be tired all the time and in bed all the time and one time he came back from the USA and he thought that

he had jetlag and a month later he was still going to bed at every opportunity, thinking you know, I've got jetlag but of course it wasn't jetlag. Not after a month. [laughing] So that's really how it started."

(Female 60 years old)

"Being frank and honest about it she was, oh God, the term was in my head a second ago and it's gone, irritable. Right? And that's, that's one of the, that's one of the signs of sleep apnoea, is irritability. You know, and she would have been irritable." (Male 70 years old)

How is Snoring a Problem?

Partners reported that snoring was a problem because it interfered with them achieving a good quality sleep at night. They would be repeatedly woken during the night, and that in turn would affect their own daily activities. A man described it as a "stumbling block" in marriage.

"I know it seems like the smallest thing, you know, it's just snoring, it's not a big deal. But like when you can't sleep it's not, yeah, it's not nice, and to be honest I also had my own, unfortunately, my own problems, I'll say family problems as well, so I had reasons to be awake at night if you know what I mean..." (Female 40 years old)

"Sleeping maybe once a week together is one thing, but when you have, you share every night, it becomes like, it's a nightmare to be honest. It was like, it was hard." (Female 40 years old)

"The snoring was a problem since the start because, basically as soon as the relationship became more serious so we would share the same bed, there were many sleepless nights, like I'll literally wake up maybe ten times per night, so it was, like in the morning I was, I wasn't very able to function, let's say. And it went on for a year like that, more or

less, and then we started looking into possible solutions.” (Female 40 years old)

“I: So who was first that identified that there was a problem?

P: Me. I said, like even when we were going out together, like I remember the first time we went away and it was the first time sleeping together. I was lying in the hotel bed and here we are, I’m looking, counting the stars, she flaked out, and I turned around and I says God, if I ever get married to her, this is going to be a stumbling block in our marriage. But I never really did, I never did let it be a stumbling block, but it was me that was the one that, that said it to her, said Jesus, you’re going to have to get I says you’re going to have to get something done.”
(Male 50 years old)

3.3.1.2 Effect of OSA on Partners

Partners reported that their sleep would be interrupted during the night, and that in the morning they would not be able to function properly and that they would be irritable. Some mentioned that they were not really affected, because they were well used to their partner snoring that it would not annoy them.

“I couldn’t function in the morning, I mean I had to go to work, he would wake up sometimes, wake himself up sometimes, you know, with the, with the noise, but then he would fall asleep again, but I couldn’t sleep because it’s like, like a train, [laughing] basically, like sleeping beside a train.” (Female 40 years old)

“I knew for a long time, and I would have very broken sleep. Sometimes I would have gone to the spare room, and I never said anything to A_____

but I think A___ was aware that I was going to the spare room some nights.” (Male 70 years old)

“I: And how did that affect you then?

P: It irritated me a bit, you know. And especially if we’re going out at night time, he’d have to have what he would call, I’d have to go, he, he does say I have to go for a kip before I go out. It’s a taken thing, he has to go for a sleep before we go out or he wouldn’t last the night, you know, and that’s not right either, you know. And he knows it. [laughing]

I: So why does it irritate you then?

P: He shouldn’t have to go for a sleep just because we’re going out? The minute that we’re going out, well now, I have to get this done, I have to do this because I have to go for a kip before I go out. Why? You’re only going out for a chat and a drink and a meal or something. Sleep on in the morning or something. It just irritates me. I don’t know, maybe it’s just me, probably is just me.” (Female 62 years old)

“I would have been irritable during the day because I hadn’t had a full night’s sleep myself, and we used to put it down to the fact that teaching was a very, a very tough job, you know.” (Male 70 years old)

“Just not sleeping, basically, that’s how I coped. I would sleep maybe two hours, then be awake an hour and then sleep two, it was like, now I’m exaggerating a bit but it was like having a baby, if you know what I mean ... and then obviously in the mornings like, yeah, it was hard.” (Female 40 years old)

“I was wakening during the night and trying to get back to sleep and, and not wanting to, to disturb A___, do you know what I mean like? But I, then I learned later on that if she was lying on her side away from me,

if I did a little, you know, nudge in her back it would stop for maybe five minutes, but then it would start again.” (Male 70 years old)

“Not really, not hugely. I mean I wasn’t awake all night or anything, I must say, and I’m sure he wasn’t awake all night either but you know when you wake up a few times in the night, you think you haven’t slept at all, even though you’ve been asleep for maybe six hours, you know. So he was tired all the time and heading to bed and this, this had been going on for a long time.” (Female 60 years old)

How was the Relationship Affected?

The effect of the condition on patients and their partners’ relationship varied. Partners described frustration, anger, and sleeping in separate bedrooms, which put pressure on the relationship. While others mentioned that they were supportive of their spouses and that the relationship was not affected they described it as *“they grew into each other’s ways”* meaning that they were used to each other’s habits.

“I didn’t know how to basically sleep together anymore... I remember one night, okay, [laughing] I feel bad now, I say look, we have to do something because otherwise I, I can’t go on, like it was, it, it got to that point, it was like either we live separately or I don’t, I didn’t know what to do.” (Female 40 years old)

“No, no, no, no, no. It wasn’t A___, it wasn’t A___’s fault. I mean it’s, it’s, the only way it had an impact was that the two of us became irritable because we weren’t getting a good night’s sleep. A___ and I have always been close, that sort of thing would not interfere in our relationship at all.” (Male 70 years old)

“We’re together a long time and even in the early stages of the marriage like, I could put up with it, but it’s just gone so bad now I just, I can’t.”

(Male 50 years old)

“I’d just grin and bear it, that’s all I done. I’d just grin and bear it, just for, because she feels bad, that it’s her problem, you know what I mean.

That’s what she feels, like oh, this is my problem and everything else and she thinks that it’s causing, because it’s not causing us any problems in the marriage.” (Male 50 years old)

“It created a bit of tension, you know what I mean, like having to wake someone and say can you put in this thing that is going to make you sore for three or four hours the next morning, it’s not the nicest thing.”

(Female 40 years old)

“I get annoyed because he’s snoring and keeping me awake. I do get annoyed sometimes, but that’d be all. It doesn’t affect our relationship, I still love him. [laughing].” (Female 62 years old)

3.3.1.3 Coping Strategies

Partners described how they were affected, and described the coping strategies they employed. They described talking to their partners, moving to a separate bedroom, taking sleeping tablets, or being humorous about the snoring.

Telling their Partners That They Snored

How Did They Feel About Telling Their Partners They Snored?

Despite the fact that partners’ perceived snoring as a problem that was affecting them, they had reservations about being confrontational with their spouses about telling them they snored. Some described that they were embarrassed to tell them, yet they had to as it was a serious problem

for them. Some avoided conversation about the topic and mentioned that they would move out of the room at night in preference to confrontation. Some said that they had no problem directly discussing the topic, and they were willing to seek advice and seek solutions.

Being Embarrassed

“Once again, you feel like you’re giving out about something that is not that important, let’s say, it’s like, because, how to explain? It’s not something that is immediately, I didn’t even know there was a way to measure the apnoeas or to measure the noise or whatever happens, you know, I didn’t know, so I thought like in the end I’m just saying oh, there is a lot of noise and that’s all, that’s all I can say, there is no scientific, you know, data to it basically.” (Female 40 years old)

“It’s, not that he thought I was making it up but like oh, you’re making a big fuss out of a small thing.” (Female 40 years old)

I: How did you talk to, to A___ about it then, in the beginning?

P: [laughing] It’s a bit of, yeah, it’s not the nicest subject I suppose. It’s not very nice to have to say look, it’s a problem... I remember one night, okay, [laughing] I feel bad now, I say look, we have to do something because otherwise I, I can’t go on, like it was, it, it got to that point, it was like either we live separately or I don’t, I didn’t know what to do.” (Female 40 years old)

Being Direct and Confrontational

“I: So was it difficult then to bring up the subject, to point out that it, that there’s a problem?

P: Was it difficult?

I: Yeah, for you to bring up the topic.

P: Oh no, no, I just say it, say it as it is, you know, I won't go behind, sometimes I think that's my, my problem. I speak too freely, you know, I mean where, instead of taking it nicely, I just go all ahead about it, and out straight, and that's what I done." (Male 50 years old)

Avoiding the Conversation

"I: So why didn't you tell her anything about it in the beginning?

P: I didn't want to embarrass her. You know, it was just one of those things." (Male 70 years old)

"I think A ____ became more and more aware, because she was waking up in the morning and I would either be in the spare bed or I would already be up, you know, so she probably became aware." (Male 70 years old)

Patients' Reaction to Being Told They Snored

Partners mentioned that their partners were upset to be told they snored and that they felt guilty for keeping their partners awake at night. However, they acknowledged that this was out of their control and it is not their fault. On the other hand, they mentioned that their spouses did not perceive their complaint as a real problem, or that they would have an argument over the topic.

"I: Yeah. So tell me what happened then after you, you had the conversation.

P: He wasn't very happy because sure, it's not something that depends on your will, you can't control it so you feel like, sure he felt kind of, he told me he felt kind of guilty in a way, but he had no control over it, so it's, yeah, it was, it did make us have more than one argument, not, not bad arguments but we had a few discussions because you know,

he's like what can I do, and I'm like please try and find something"(Female 40 years old)

"He's a man. [laughing] He didn't understand what I was saying, he couldn't see, because he wasn't experiencing it, you know. He didn't know he wasn't breathing, but like, so it took a while to convince him that he'd have to say it, so." (Female 62 years old)

Sleeping in Separate Bedrooms

Partners mentioned that sleeping in separate bedrooms was a way to avoid the noise at night in order to ensure that both they and their spouses go at good night sleep. Some mentioned that it was a relief and peaceful for them to sleep in separate beds. Others said that for them as it was not normal in a marriage to sleep in separate bedrooms and that put a strain on the relationship.

"I remember one night, okay, [laughing] I feel bad now, I say look, we have to do something because otherwise I, I can't go on, like it was, it, it got to that point, it was like either we live separately or I don't, I didn't know what to do." (Female 40 years old)

"If A___ is unwell for any reason and she doesn't want to put the appliance in, then I go for the spare room, and the two of us have a, I have a good, I sleep like a log. I go, I'm a very, very sound sleeper and I just get into bed, fall asleep and that's it." (Male 70 years old)

"We do talk about it, you know, to try and get something done because like it's not right, she in one room, me in another room, you know, it's, it's not part of a marriage at all....I'd give anything just to have her back, but it's just so bad." (Male 50 years old)

"It does annoy me, but the way I look at it is I'm getting a night's sleep, you know, I mean like A___, like to me, like when we were together, I'd be punching her, I'd be digging her and I says, I'd be twisting and turning, jumping, and then nine times out of ten she'd say ah here, I'm getting out and she'd even move to let me have a sleep, and the thing is, as soon as she is gone, bang, I'm asleep because I know, peace, quiet."

(Male 50 years old)

"So when you go up to bed, you go to bed, you go asleep or you read a book and like that's what I miss, you know what I mean, our little, cozy little chats or whatever." (Male 50 years old)

"P: I mean many nights I've slept on the couch, like if we had, when we had the kids at home because they'd no, no extra bedroom, but now I have two bedrooms I, so you never know where I'd be, but I won't be in my own bed. You know, I'm often gone and as a matter of fact the night before last I slept in the, in the back bedroom because I couldn't, I just couldn't stay any longer, you know."

I: So, how does it affect you, to have to sleep in a separate bedroom?

P: Well I wouldn't like to have to do it all the time, you know. But I like my own bed. Tried, I don't, wouldn't be happy having to do it all the time but there is the odd time when I have to, I just can't take any more. I have to sleep and, you know."(Female 62 years old)

"I: So some people say that they sleep in separate bedrooms if the noise is annoying."

P: We never did that, but I'm sure if it got really bad, yes, that would have been a good idea. Would have been a good idea."

I: Yeah, why haven't you done that?

P: I didn't think of it, you know, probably, I didn't think of doing that. It's all habit I suppose. It's all habit and I didn't think of, of doing that. I can't recall that I ever moved out of the bed or moved into another room, I don't think so. Maybe once or twice, if I was really bothered, but it wasn't, it wasn't a problem really. It didn't become too much of a problem, you know.

I: Okay. why wasn't it a big problem for you?

P: Well I, you know, you just kind of put up with it. You grow into each other's ways, you know, you just get on with it, yeah.” (Female 60 years old)

Taking Sleeping Tablets

“I tried sleeping tablets, everything. Now the sleeping tablets worked but then A___ said I was like a different person in the morning, whatever the effects, the tablet, now not a nasty person but just very quiet or just, and now it just takes a while, must be the wearing off of the sleeping tablet.”
(Male 50 years old)

Humour

Partners mentioned that they would be humorous about snoring, to avoid making it a problem for themselves and their spouses.

“We often joke about it... I didn't make a big issue of it but I did say it to her, you, you, you were, you were really going for it last night, weren't you? The snoring, and we would have laughed about it at different times and then it just, you know, as I said to you, it wasn't every night.” (Male 70 years old)

“We laugh it off ,well we know it’s a problem but we laugh it off. That’s just the way it is.” (Male 50 years old)

3.3.1.5 Diagnosis with Sleep Apnoea

Delay in Obtaining Medical Advice

Despite snoring being a problem for partners, some reported delays in seeking medical advice, because of their lack of knowledge about the condition, and they thought that snoring was not “a real problem” or an “illness” that required medical attention.

“I don’t know how long is it now that he has this, but it took a good few years to finally decide to go the medical way, proper medical way.”

(Female 40 years old)

“We didn’t even know something like that existed, It was very much a like, yeah, okay, let’s see online, okay, there is this spray, there are a few other things we didn’t try like a nose ring, I remember we said maybe the doctor, and also we said something like the doctor will think we’re crazy, you know like, why do you come to me for snoring? You know, we thought it is not a proper problem or an illness or anything, so, but then yeah, we decided yeah, we needed to talk with someone because it wasn’t right, you know what I mean. So initially it was like no-one can do anything, like we’re going to seem silly because we’re going to the doctor about snoring, it’s nothing major, you know.” (Female 40 years old)

Seeking Medical Advice

Partners mentioned being with their spouse when they went to the doctor, yet they felt embarrassed about going to the doctor about it because they did not have enough information about the condition before they went.

“P: I remember being embarrassed, yeah.

I: What were you embarrassed about?

P: Once again, you feel like you're giving out about something that is not that important, let's say, it's like, because, how to explain? It's not something that is immediately, I didn't even know there was a way to measure the apnoeas or to measure the noise or whatever happens, you know, I didn't know, so I thought like in the end I'm just saying oh, there is a lot of noise and that's all, that's all I can say, there is no scientific, you know, data to it basically, so I'm like I'm just going to seem like someone that is just annoying and giving out a lot and something, so yeah. I think he, he was surprised and then he went for the analysis and they kept him overnight in Vincent's and, with all the, recording him and also the sensors and stuff and they came back saying yes, I think, like we think you are in need of something to help because you have had several apnoeas during the night and stuff, like he was surprised because I don't think up to then he believed me completely. I know it's bad to say, but it's, not that he thought I was making it up but like oh, you're making a big fuss out of a small thing, you know." (Female 40 years old)

3.3.1.6 Diagnosis with Sleep Apnoea

Partners mentioned that they felt relieved when their spouses were diagnosed with OSA. Because they reasoned that there was a clear problem that they could target, and that treatment was available. On the other hand, they felt worried about the consequences for their spouses' health in the longer term.

"I: So how did you feel when you got the diagnosis?

P: We were relieved, yeah. I felt relieved. The fact that it was real, like it was obvious to other people as well, I felt relieved. It's, maybe it's bad to say, I don't know, but on the other hand I felt a bit worried

because yeah, so even having like some nights where five, six times during the night, to have sleep apnoea.” (Female 40 years old)

“I was very relieved that it was diagnosed what the problem was, you know. I’m not saying, I didn’t know that it was to do with her sleeping and the way she was lying and things like that at different times.” (Male 70 years old)

“We were both relieved to find out that, what the problem was. You know what I mean, we were delighted to say that, when we got the results back to say that she does have the sleep apnoea and we’ll get something done about it.” (Male 50 years old)

“So he spoke to some other people who said they had similar difficulties, so that’s how he really found out about sleep apnoea. Well I think his sister-in-law told him that it can be fatal, so that was a bit frightening, so I think he decided then it, it could be serious enough.” (Female 60 years old)

Partners’ Perception of the Condition

Partners perceived OSA as a serious problem that affected their spouses and themselves. Their priority was to seek and pursue treatment. They mentioned that they were worried and afraid, and that they would be awake at night “listening for breath” because they would be worried when their partner stopped breathing at night. Some thought of it as their responsibility because it affected their partner’s daily activities so it was their priority that they seek treatment and for their partners to get good quality sleep at night.

OSA as a Serious Health Condition

“It’s very much like oh, the person is snoring, hahaha, like it’s, like it’s a silly thing but it’s not really, if it gets to the point where you have sleep apnoea, the person, people you live with don’t sleep, it’s not like, it’s not a joke anymore, if you know what I mean. Yeah, so that’s, yeah, that’s maybe the only thing I, like that’s the main thing I learned from this situation because I didn’t think it could affect me so much, I thought, like at the start and then he is, I was, sure, I’m going to, it’s going to be okay but it’s not, yeah, it’s, yeah, it’s not a super-easy situation to be in, both psychologically from both, for both people, and also it’s a physical problem, you know, it’s a physiological problem.” (Female 40 years old)

Listening for His /Her Breath

“And you don’t like to see your partner suffering, you don’t like to feel that they’re unwell whenever things can be sorted out.” (Male 70 years old)

“I still listen to see if he’s breathing properly at night time, and when he, when he’s very quiet it worries me. And, you know what I mean, I’m not happy when he’s snoring, but I’m not happy when he’s very quiet either, when he’s too quiet, because you’re, you can’t hear him and when somebody is very quiet and you’re looking and you’re sitting up in the bed to see if his chest is rising up, because if I touch him and wake him, that’s not fair, you know, because then he won’t go back asleep properly, he’ll be tired. So I just sit up and watch for a little while, and maybe move in the bed and he might move and then I’ll know he’s alright.”

(Female 62 years old)

Fear

“How would anybody feel if you were afraid somebody wasn’t going to breathe beside you? Scared, very scared. Anyway, I told A_____ when I married him, when I met him and married him all those years ago that I’m dying first, he’s not leaving me on my own, I’m going first, so he’s not allowed stop breathing. I’m going first, I’m not staying on my own.”

(Female 62 years old)

“That is scary. Even now, it’s not nice even now to think that, because he still has a certain amount of episodes and you’re wondering will the day come when he doesn’t, you know, start off, and that’s scary. You shouldn’t have, you shouldn’t have to be frightened of your husband dying beside you in the bed from a sleep problem, you know?”

(Female 62 years old)

“It’s still frightening because you don’t know which one might do damage, you know, might stop him. I don’t know whether this all makes sense to you because I don’t, I’ve never spoken to anybody about it.”

(Female 62 years old)

“Well when he’s, when he’s so quiet, how could you not after, after all those years of listening to the noise and listening to him stopping breathing and knowing that this is not really working, that he’s still snoring when they said he shouldn’t snore, so therefore it’s not working, and they’re saying he hasn’t got sleep apnoea, and I know he stops breathing at times, so he does have sleep apnoea. So I don’t know the answer. I wouldn’t know what to do, except panic if he doesn’t start breathing again.”

(Female 62 years old)

Responsibility

“He has a bit of responsibility because he’s driving a coach with a group of tourists, so he’s a driver and a guide, so there’s, he must get a, a night’s sleep, a proper night’s sleep because it’s a lot of responsibility.”

(Female 60 years old)

“If it was solved, the main problem would be that we’d be back together in the one room, that neither of us would have to be either lying on the couch or on a fold-down bed. That would be one of our main aims, is to get back together.” (Male 50 years old)

“You shouldn’t have, you shouldn’t have to be frightened of your husband dying beside you in the bed from a sleep problem, you know.”

(Female 62 years old)

“Wished I’d noticed it sooner. It would have stopped me worrying a lot, for years and years, looking at him falling asleep like at the car or when visitors, Christmas Day, one day he fell asleep at the dinner table. Now that irritated me, you know, I’d be huffing and puffing and giving out, you know, but not so, if you were there you wouldn’t notice I was annoyed but he would notice I was annoyed, you know.” (Female 62 years old)

3.3.2 Partners’ Experience with CPAP

Partners mentioned that their spouses stopped snoring when they used the CPAP machine, that they found the noise of the machine reassuring, and that they were happy that their spouse was using it. However, for their spouses the machine was uncomfortable and many were not able to use it. Partners mentioned that despite that fact the CPAP machine worked in reducing the snoring and the apnoea, they could not persuade their

spouses to continue to use it. Some mentioned that they were “amused” by the machine and did not understand how it worked, or why their spouses had to use it.

“He didn’t snore, he’d, he’d make funny sounds like a gurgling sound, but there was, there was nothing, I mean that’s, everybody makes noise when they sleep, it wasn’t, he wasn’t, he wasn’t snoring with it, no, but he found it difficult because his mouth was drying and he, seemingly you’re supposed to get a good night’s sleep with this sleep mask. He didn’t sleep, he still doesn’t sleep, he still wakes himself, so he never feels rested, even now he never feels, he gets up in the morning tired.”

(Female 62 years old)

“He never felt it worked, no. It, it stopped the snoring for me, it stopped, I liked the machine because it stopped the snoring, but it, he never felt it was doing, and it did start, the only thing I didn’t like was he’d turn towards you, the breeze that’d come out would blow your, you could feel the breeze on your face, but that, I’d just give him a nudge and he turns, but it used to pull at his eyes, you know, he felt his eyes were, and you could see the eye drooping, you know, from the breeze that would come up, you know.” (Female 62 years old)

“He had a breathing apparatus, and it didn’t really work. Now it probably didn’t work because he didn’t persist with it, he didn’t, he didn’t persevere with it for long enough, so I’d say that’s, that’s why. Now he had it for a long time, he used to rent it, but he, he wasn’t, he didn’t persist with it enough. So then he decided eventually it wasn’t working so he gave that up, so then he went on to get the other, the brace.”(Female 60 years old)

“And she was on one of those, the machines that put the pressure, the, you put the mask on and the pressure and all the rest of it. It didn’t work, it wasn’t, it wasn’t comfortable for her at all, and intermittently she would use it, and when she didn’t use it.” (Male 70 years old)

“It was good and it wasn’t good. It was extremely uncomfortable for A _____. Now it made a difference to the snoring to a certain extent, but it was extremely uncomfortable because with that you can’t toss and turn, you can only lie on one side, and you might be able to lie on your back a little bit or half on your back, but you can’t turn over with it, you know?” (Male 70 years old)

“It, it stopped the snoring for me, it stopped, I liked the machine because it stopped the snoring... it eased my mind, he knows it eased my mind but it wasn’t, he didn’t feel it was doing him any good.” (Female 62 years old)

“I was happy with the sleep apnoea mask the CPAP mask but he wasn’t, but he knows that I missed the reassurance of the machine in the corner, the noise from the machine, it wasn’t, I couldn’t say it was a noise, it was a hum, but that never bothered me because I like white noise at night time, you know. So, so I don’t know what else anyone could do.” (Female 62 years old)

“I found it quite strange, the whole apparatus and, and you know, I used, in the beginning I found it really strange, I used to laugh and say what are you doing? [laughing] So, but you know, he, he tried it for a while but he just, he found it, I think he found it a bit awkward and uncomfortable to use it all night... I was more amused really, you know. [laughing] I was more amused. I, I didn’t fully appreciate, you know, the

problem he had. I think I was just preoccupied with other, other things.”

(Female 60 years old)

3.3.3 Partners’ Experience with MADs

3.3.3.1 Initial Experience with MADs

Partners described their spouses’ initial experience with MADs. They mentioned that it took them time to adjust the device and to get used to it, but they noticed improvement and the partners stopped snoring.

“Not exactly first night because we, it was, we needed to understand how tight and stuff and stuff like that. I’d say two, two or three days, it takes to find the right point and, yeah, but it was already better from the first night as in he snored much less, but you know, it took a little bit to understand,” (Female 40 years old)

“It made a massive difference to A___ with regard to being able to sleep and to sleep properly. And it took a little bit of getting used to because there’s all that tightening and, and untightening and getting it to sit right in her mouth and all the rest of it.” (Male 70 years old)

I: So what was that like for you then?

P: Oh, a, a good night’s sleep?

I: Yeah.

P: [laughing] It was a Godsend.” (Male 70 years old)

Current Experience with MADs

Some partners mentioned that their spouses still snore occasionally when using the MAD. However, it is not thought to be as negative an issue as snoring was worse without the appliance.

“To be quite honest about it and I’ve, and again I’ve never said to A___ because I didn’t know if it was me or her or whatever, but at times I

would feel very strongly that even with the appliance, A___ still makes noise when she's sleeping.... Not all the time, but sometimes, it's not as, it's not as pronounced now as it used to be." (Male 70 years old)

"I: Yeah. So what is it like now? Do you think he's in control of the condition?

P: I think he probably is. Yeah, I think that he is, he's much more aware of, of, of it and he knows he is in a routine now, he has to put in the brace and he knows, he knows it's important, and I think it's working for him so it's okay. He, he has to persevere with it and use it so, and he brings it away if he's travelling anywhere, if he's going anywhere he brings it away with him. So I suppose we can't talk once the brace goes in, so that's the biggest drawback for me. [laughing]" (Female 60 years old)

"He snores a bit, you know, from time to time, I tell him, I say you're snoring, if you're keeping me awake, I'll just tell him you're snoring, you're keeping me awake and he's aware of it. I think generally speaking he's, he's much better." (Female 62 years old)

"Wonderful. [laughing] I know it's bad to say but it made a huge difference, because it's, it's adjustable, it's one thing. In the morning he may be sore for an hour, maybe half hour when he wakes up and that's it, and the rest of the day he can have, he can have his meals and stuff without suffering, and so I felt less conscious about asking him to use it." (Female 40 years old)

"I know she wears the brace all the time but she finds the brace helps her because if she doesn't wear it at night time, she doesn't feel right in the morning, you know. So, but, like she wears it all the time but it's just not

working... Now I have to say the brace did work ... I don't know is the brace the problem or is she just getting gradually worse." (Male 50 years old)

"But he has the mandibular now and he is quiet with, he still snores but when he's quiet it still scares me, you know, because you're, you shouldn't have to sit up in the bed and look and see is he breathing, you know. That's frightening." (Female 62 years old)

"Well the mandibular isn't working for him. He's still snoring, it's, to me it has changed the shape of his face even, his teeth, I can see his bottom teeth all the time... You never could before, so it has changed the shape of his mouth and that irritates me... It has damaged his teeth as such and his bottom teeth are going down in, in the middle." (Female 62 years old)

"I was happy to see that he was doing something about it, you know, if it's going to be serious, we're both aware that it could be serious, so it's important to, to get it seen to and do whatever you can to, to sort it out, and also he was going to get a better night's sleep and so was I, so there's benefits for both of us." (Female 60 years old)

Limitations to Using MADs

Partners described the MAD as being an unsociable and a passion-killer, and expensive.

"P: I have, I have something to say to you and I hope you're not offended by it.

I: No, please do.

P: It's a passion-killer. [laughing]

I: [laughing]

P: *It's a real passion-killer... But there, there won't be any; there won't be any kissing whenever the lights go out. [laughing]*" (Male 70 years old)

"P: *It's a bit unsociable.*

I: *Is it a one-sided conversation?*

P: *Yes, it's the end of the conversation once the brace goes in and that's fine. [laughing] That's fine...*

I: *So how do you make up for that then, not being able to talk at night?*

P: *Well I have to talk to him, try and talk to him earlier in the day if I can, but there's so many distractions now ...*

I: *So how does it make you feel?*

P: *Well I accept it, you know, I accept it. In the beginning I had to get used to that, but it's important. It's important, and we're getting older, we're both sixty this year so he needs to, you know, he needs to mind himself."* (Female 60 years old)

"Now, like the only trouble we have with it, because we aren't in the best economic situation, but, is that it's a bit of a, it's expensive, like you know, it's not a cheap solution let's say. But yeah, it's been, I think it has been worth it because, definitely made the difference." (Female 40 years old)

3.3.4 Level of Engagement in Treatment

3.3.4.1 Partners' Views on Partner's Level of Engagement in Treatment

Partners expressed that culture could have an influence on the level of partners' engagement in treatment. They explained that they thought that

years ago spouses would be more reserved about discussing their private matters openly, and they would be reserved when they discussed bedroom matters. Others said that communication between spouses is important, and they needed to express their feelings and concerns openly so that the relationship could stay healthy, and to avoid creating tension or stress in the relationship. Others saw the importance of the partners' role is in reporting symptoms. They also mentioned that partners could be supportive by providing reassurance to their spouses, and attending their medical appointments.

Cultural influence

I: To what extent do you think partners' engagement in the treatment is, is helpful for patients who have sleep apnoea?

P: I would say in Ireland the whole sort of male /female thing is not as dominant as it was say fifty years ago, okay? So I would, I would suggest that a lot of partners would be very supportive of their wife or their husband or, you know, whenever they have to have a, a device, or the, it would be discussed a lot more than it would have been say even twenty years ago, you know?

I: So how do you think male female dominance would, would influence that? Or would change it?

P: I would say, I would say women would be quicker to say it to men than men would be to say it to women." (Male 70 years old)

Communication

I: So how could a partner be supportive of their husband, wife or whatever it is, their significant other?

P: Just talking. We have a good relationship, we talk about anything and everything, you know, we don't have, we have our arguments like every other couple but we don't hold grudges or, you know, always talk about things and

I: Yeah. So you think that talking helps?

P: Well if you don't talk you get huffy and you get annoyed and irritated and you hold a grudge and you're angry. Well I would be if I didn't talk about it. I'd probably nag him to talk. [laughing] Have to ask him that now." (Female 62 years old)

Reporting Symptoms

I: So do you think that a partner's help is important in the management of sleep apnoea?

P: I think unless you really wake up breathless that, like often enough that you realise it's, it's happening every night, a few times, you're not going to know, I don't think, you know. You don't, you don't realise, you wake yourself up and fall asleep immediately after, I think it can be important to have someone to kind of say look, this is happening during the night and maybe let's look into it and yeah." (Female 40 years old)

Attending Medical Appointments

"I think that what should happen is the partner should be there to listen to what the doctor is saying, you know, and get to understand it and, of

the treatment... I always think it's, it's good to have your partner there with you, for support and there if any questions that you can't really answer, she would be able to answer for you, and I think it's a good thing to have somebody there with you at all times. You know, like there's no point in going in on your own." (Male 50 years old)

3.3.4.2 How Were Partners Involved in Treatment?

Patients mentioned that they supported their spouses by providing reassurance, attending medical appointments, being involved in decision-making and by "pushing" them to seek treatment. However, one patient highlighted that their circumstances would affect their level of support.

"We've always stood by one another, even, she stood by me through all my ailments and everything else, you know, now as, at the moment now I'm going through an awful lot of medical issues now myself at the moment, but she's with me, any time she has a doctor's appointment I'm with her, or if she has to go, if I have to go anywhere, she's with me."
(Male 50 years old)

"He didn't really find it kind of user-friendly I suppose, and he didn't persevere, and then you know, there were nights passing and he wasn't using it and he was paying for rent, so there's no point in, I said to him why are you paying rent if you're not using it? It's crazy. So in the end he kind of just gave up." (Female 60 years old)

"So basically how I helped is I annoyed him until it is something, like yeah, I had to insist, in fairness, and I looked up online and while I'm looking, yes, also I did look up online what could we do." (Female 40 years old)

"P: I just encouraged her, I didn't get involved in it.

I: Now why, why is that?

P: Why is that? Well, I don't know to be quite honest with you. I suppose there are some things, do you see whenever you're younger you don't get, I respect A___ so you know, she goes to the doctor, she gets sorted out and whatever medication or whatever has to happen, I, I support her all the way, but I don't have to be there." (Male 70 years old)

"A___ would be a little bit conservative. She would say well you don't want to know that or, you know, she just wouldn't discuss things with me. But now we're, it's not that we're a lot closer but it's that A___ needs a lot of reassurance, you know. So whenever she needs that reassurance I'll go with her." (Male 70 years old)

"It was a matter of support, you know, I was, prepared to support A___ in the same way that A___ was able, was prepared to support me whenever I was, you know, recovering from the, the operation." (Male 70 years old)

"I: So you mentioned earlier that you, that you supported her when she went to the GP. So what sort of support were you, were you giving?

P: It was just to help her in any way in decision-making... A___ doesn't worry about money as much as I do, and like A___ would always, sometimes say to me, she says when I'm worried then you get worried, but I says if I'm not worried, you don't be worrying. So I'll just leave A___ in control of the shillings now because, you know, I bring in the wages, we get to pay the mortgage, bits and pieces, and that's the way we do it." (Male 50 years old)

"She done that Slimming World thing to try to lose weight. The two of us joined it together, like that's how motivated now that we were to try, and she says that she wanted to get the weight down and she says it might help with the, with the snoring, and I says right, we do this, we do it together. So we joined Slimming World as a couple and she lost a stone, I lost a stone and a half, but then I had to stop because I was having problems ... But A___ wouldn't continue it on because I wasn't there."

(Male 50 years old)

I: Yeah, so how did you convince him to go?

P: Nag.

I: [laughing]

P: Keep, just keep telling him like, and he knew I was worried. When he knew I was really worried, then he went, you know. But he didn't go just for that, he went for something else and mentioned it to the doctor."

(Female 62 years old)

"I'm with him all the way, whatever he wants to do. No, I didn't influence him in any way with either. But, but I influenced him to go to the doctor originally, yes I did, I nagged until I got him there." (Female 62 years old)

"I hadn't huge influence on him really because I was busy minding elderly parents who have since passed on and I was preoccupied with, with a lot of that, so I left him to deal with it himself really, to be honest with you, I wasn't, I wasn't a huge support to him because there were bigger things going on." (Female 60 years old)

Advice for People in a Similar Situation

Partners were asked to reflect on their experience with OSA. They mentioned that they would encourage partners to be more open and to push the matters earlier on. They would also encourage their spouses to persevere with the treatment. They also mentioned that there should be more awareness about OSA.

“I would say yeah, let’s go to the doctor and maybe after six months or three months even to see what they say, and then we can think about it and make an informed decision, but I waited a year and then I waited maybe another year of different remedies that didn’t work.” (Female 40 years old)

“Oh definitely force the issue. I know I said I didn’t want to force it and I had a lot of respect and all the rest for A____ and didn’t want to upset her, but no, I would force the issue. I would. I would, I would advise them very strongly, if I had to go through it again I would force the issue. I would say look, this, this can’t continue.” (Male 70 years old)

“To go and see about, make, make him go and see about it or make her, whichever partner has to go and see about it, because you couldn’t be living with somebody and see that happening and not worry. You had to be worried. I can’t, I can’t see a situation where the partner wouldn’t be worried because you’re seeing what’s happening, you’re seeing them stopping breathing, you see them tired, you know. But I don’t know what else can be done for A____ because he’s still very tired, he’s still not getting his night’s sleep, he’s still not rested, you know. So, but I would advise anyone to go and keep going, find out.” (Female 62 years old)

“Well I’d advise them to seek help, and when they get help then to persevere with it, instead of going at it in a half-hearted fashion. And you know, people should know that it can be fatal, they should know that it can be serious, because most of the time we laugh, you know, we don’t take it too seriously but it can be, can be serious if somebody stops breathing, you know. So I think that people should be encouraged to do something about it, if it’s going to affect your sleep and your working day and your working life, I think definitely it’s worth doing something about, particularly when there is help available.” (Female 60 years old)

“It’s worth doing something about it, if you spend a third of your life in bed, it’s worth doing something about.”

4. Discussion

4.1 Introduction

This study is a qualitative descriptive study that involved a descriptive summary of the informational contents of the data which was organised in a logical manner. The study employed a qualitative research methodology, namely semi-structured in-depth interviews, to describe both patients and partners experiences with OSA, CPAP and MAD treatments. The impact of OSA on patients and partners lives, and their perspectives on the condition were explored. Patients experience with the diagnosis and treatment with OSA was highlighted.

For patients who failed to adhere to CPAP treatment technical and psychological factors in addition to side effects of the treatment were explored. Facilitators and barriers to MAD treatment were analysed. Patients also reflected on their experiences with the services provided, how could be services improved, and the possible role of support groups in treatment. Finally, the partners roles in diagnosis, treatment and on-going management of OSA were highlighted.

4.2 Patients and Partners Experience with OSA

4.2.1 Reporting Symptoms and effect on Day-day life

Patients gave detailed accounts of their experience with OSA. They described the effect of their nighttime symptoms on their day-to-day lives, and how their partners were also affected. Patients and partners accounts of OSA were mirrored; patients understanding of their night time symptoms was through their daytime effects, whereas their partners described nighttime symptoms such as snoring and witnessed apnoea events. As one patient described that *“he never woke up refreshed”*,

despite the fact that he slept for sufficient hours during the night, and took an afternoon nap during the day, which his wife described as a “*kip*”. Interestingly, this complaint was previously described in the literature where a study about sleep satisfaction in the elderly reported that freshness after awakening was the most important positive factor for the elderly. They explained that elderly people adapt to new adjustment habits such as afternoon napping habits, which increase with age (Zilli, Ficca et al. 2009). Partners description of patients snoring was very illustrative, and consistent with OSA symptoms that have been reported in the literature. (Henry and Rosenthal 2013, Luyster 2014) They described periods of loud snoring, followed by intermittent cessation of breathing, a period of quiescence, and then the cycle starting all over again. Partners mentioned that during the snoring that they would be agitated, giving their spouses nudges in the back to get them to change their sleeping position. However, when they suddenly stopped breathing they expressed worry and fear, so they described checking to make sure that they were alive and still breathing. They described peace of mind yet worry at the same time when their spouses were quiet, until it all started again. Partners relayed that this kept them awake all night anticipating the next phase of snoring and apnoea. This interrupted sleep pattern clearly affected partners daytime functioning and they described that they were constantly tired and irritable during the day.

Patients reflected on how these symptoms were impairments to their work, ability to drive and how apnoea altered their social lives. More than one patient admitted that they fell asleep while driving, and were nearly involved in road traffic accidents. Sleepiness and fatigue are a

serious risk for road traffic accidents and they account for 16% of major roads accidents and 20% of motorways accidents. There are three peaks for road traffic accidents caused by fatigue and sleepiness, late at night, early in the morning, and mid-afternoon (Horne and Reyner 1995). Patients with OSA are three times more likely to have a road traffic accident than the general population (Teran-Santos, Jimenez-Gomez et al. 1999). The Irish National Driver Licence Service released Medical Fitness to Drive Guidelines and specific guidelines in relation to OSA and driving. The guidelines encourage patients to seek diagnosis and treatment, and to notify the NDLS of their diagnosis. They reassure patients that treated patients do not pose an increased crash risk provided that they are followed up by their medical general practitioner (RSA; <http://www.rsa.ie/RSA/licensed-Drivers/Safe-driving/Medical-Issues/>).

Patients and partners described how they coped with sleep related issues. Sleeping in separate bedrooms seemed the strategy that was used by most couples. They described how that affected their intimacy and put a constant strain on their relationship. This seemed to be a greater problem for younger couples, and not so much for older couples. The latter described that “*they grew into each other*” meaning that they were well used to each other, and sleeping in separate rooms did not seem to have the same negative influence on them as for younger couples. Patients and partners description of symptoms was consistent with evidence from previous qualitative and quantitative studies (Foley, Monjan et al. 1995, Luyster 2014, Rodgers 2014). Another coping strategy described by patients and partners was humour. Snoring might be a sensitive topic to be confrontational about so humour may be an easier way to deliver a

message without hurting their spouses' feelings. One partner said that he took sleeping tablets, but reported that it had a systemic effect on him, so he stopped taking them. Others described the use of earplugs with limited success. Patients' and partners' struggles with symptoms seemed universal, as has been described previously by other spouses living with OSA (Luyster 2014, Rodgers 2014). Furthermore, other studies have shown the adverse effect of OSA on the quality of life of patients and partners (Kales, Caldwell et al. 1985, Engleman and Douglas 2004).

4.2.2 Seeking Medical Advice

Patients reported that they sought medical advice at the instigation of their partners. Seeking advice caused embarrassment for patients and partners. This may have been for a number of reasons including the fear that the doctor might trivialise the complaint, or that the complaint may be of no health importance. For these reasons some partners may have felt that they were in a very difficult position where they could be susceptible to adverse comments and actions. One partner described that she attended the first appointment with her fiancé, and described that they were both embarrassed. She described that she believed that it was not an important matter that deserved medical attention, in spite of the fact that it was causing a lot of frustration and irritability. Some patients described that they did not believe their spouses' complaint about their snoring, and they were inclined to deny the problem. However, some partners were proactive with one patient describing that her husband recorded her snoring as proof. In contrast, others were vocal and confrontational, and they described that they will just be direct and "*say it as it is*".

Patients and partners described delays in seeking medical advice because of a lack of knowledge about OSA. Many of them described that they had not heard of the condition before they were diagnosed. Another factor that delayed seeking help was fear. Patients described that tiredness was profound and alarming that they were afraid they might have a serious or life-threatening condition like cancer, as one patient described. Patients also described strategies to alleviate the snoring, such as using over the counter products such as nasal strips, sprays or pillows. The effectiveness of these approaches was limited, and that was what finally motivated them to seek medical help.

Patients said that what motivated them to seek advice was the insistence and direct intervention from their spouses. Their reasons to seek treatment were the well-being of their partners, and in many cases not related to their own health. Patients did not want their bed partners to be disturbed by their snoring or to be worried about them having repeated apnoea events at night. They also did not want to affect their partners health and day to day life. No distinct gender differences were noted among the sample population interviewed in this research. Male and female patients agreed that it was their partner who encouraged them to seek help. However the degree of intervention among partners varied and was not gender specific. The second factor that motivated patients to seek help was their own experience with daytime symptoms, and their concerns about their own health.

Partners roles in seeking treatment differed. Some partners mentioned that they had supported their spouses by attending the GMP appointments with them. Their role served to report symptoms and to ask

for information about the condition and the required interventions. While other partners mentioned that they were supportive, however they did not attend GMP appointments, but mentioned that they provided reassurance and would make sure that spouses would adhere to prescribed treatment. Previous studies have reported a high prevalence of undiagnosed OSA among adults. It is estimated that 93% of women and 82% of men with moderate to severe OSA remain undiagnosed (Young, Evans et al. 1997, Kapur, Strohl et al. 2002, Finkel, Searleman et al. 2009). Furthermore, diagnosis with OSA was often delayed. It has been reported that the average time between initial patient awareness of major OSA features and referral for definitive diagnosis and treatment was over seven years (Rahaghi and Basner 1999). The authors explained that the delay was due to delays in reporting symptoms, as patients might not associate snoring with a serious medical problem, and a lack of recognition of these symptoms by health care providers. (Rahaghi and Basner 1999). Findings from qualitative research help to explain these phenomena, and to identify help seeking behaviour of patients and level of partners' involvement. This study identified that lack of knowledge and lack of resources were the principle reasons identified to delay seeking help. These findings were consistent with findings from similar studies (Almeida, Henrich et al. 2013, Henry and Rosenthal 2013, Luyster 2014, Rodgers 2014). However, one study reported gender differences in help seeking behaviour and they found that men sought help after direct intervention and insistence from their spouses, while women needed encouragement from their spouses or decided to seek treatment on their own without intervention (Henry and Rosenthal 2013). This study did not

find any gender differences but this may have been due to the small number of participants.

4.2.3 Diagnosis with OSA

Patients described an array of emotions about their diagnosis with sleep apnoea. They described embarrassment and fear of “*waking up dead in the morning*”, and fear of the profound tiredness. Some described guilt, and thought that it something that they had brought on to themselves, such as through gaining weight or not leading a healthy lifestyle. Partners, on the other hand, expressed relief and worry at the same time regarding their patients being diagnosed with OSA. They were relieved because for them the snoring and apnoea were problems that demanded solutions and the diagnosis gave them reassurance that there was an issue that could be resolved. It also provided the patients with a target to focus on to resolve the symptoms and their consequences. For those who reported that snoring and sleep apnoea was putting strain on their relationship treatment of OSA gave them a chance to bring their relationship back together. On the other hand, they expressed worry and fear, as one partner described that as she “*listens to his breath*” and worried that her husband might die because of OSA. For these partners treatment of OSA was reassuring, and in some instances even the snoring was reassuring because they would know that he or she was alive and breathing.

4.2.4 Patients and Partners Perception of the Condition

4.2.4.1 Patients Perception of the Condition

Patients perceptions of the condition was a collection of a number of influencing factors; their feelings, how they associated OSA with getting

old, their perception of OSA as impairment, their perceived locus of control, their health attitudes, and the influence of “*others*”.

Patients associated OSA symptoms such as tiredness and daytime sleepiness with increasing age. However, the impact of this view differed among participants. Some patients accepted it as part of the normal aging process and stated that they now had more control over their time and that it did not affect them as much as in the past. Others associated it with frailty, and a preoccupation about not being young anymore. For these patients this translated into being weak and restricted and that there were things that they could not do because they were constantly tired. For one patient this preoccupation was so daunting that he associated it with depression. He described his preoccupation with the idea of being finite, and that the limiting tiredness he was experiencing at the time was overwhelming for him, and that he could not cope prior to treatment. He described that depression and OSA “went on together”, that treatment of OSA had improved his depression state, and how the increase in his energy levels had improved his life. The relationship between OSA and depression has been reported in the literature previously (Mosko, Zetin et al. 1989). It was described as bidirectional; sleep deprivation causing mood changes in healthy subjects, and patients who have depression suffer from sleep alterations, and that OSA treatment improved anxiety and depression levels with OSA patients who suffer from depression (Sanchez, Buela-Casal et al. 2001). The possibility of concomitant OSA and depression should be borne in mind by health professionals working with this patient group.

OSA as Impairment

Patients perception of OSA as an impairment was linked to their perceived locus of control and their health attitudes. Some patients reported that OSA was not an impairment, and they did not treat it as an illness. These patients said that they had a positive outlook and had control over the condition by continuing to adhere to prescribed treatment and leading a healthy lifestyle which included keeping weight under control, regular exercise, healthy eating and moderate alcohol consumption.

On the other hand there were patients who described OSA as an impairment. One patient described that he was asleep in all family photographs when his children were younger. He said that he was constantly tired and fatigued and he put it all down to having OSA. This patient expected a “*miracle cure*” to OSA. He reported feeling guilty about not knowing about it earlier. Interestingly, he used his diagnosis with OSA as a *crutch*, a method of avoidance of tasks he did not want to complete. Another patient described that the profound tiredness associated with OSA was an impairment, and that had prevented him from leading a normal life, causing him to age prematurely and develop depression. In a previous qualitative study about living with OSA, patients described living with OSA as being in a “limbo”, and the consequences of OSA posed challenges to health, functioning and emotional well-being of the affected individuals (Rodgers 2014).

Perceived Locus of Control and Health Attitudes

In an attempt to understand patients’ health behaviours, and what made them adhere to prescribed treatment, this study explored their perceived

self-efficacy, loci of control and health values. All these three components are integrated and help explain and predict health behaviours. Self-efficacy refers to how confident people feel that they are capable of performing a certain task. It refers to the degree of control over the task itself, not the outcome of the task (Ajzen 2002). This is influenced by a number of factors, which might be internal to the person, such as their skill, knowledge, and willpower, or external to the person such as the actions of other people. Classifying people into internal loci of control and external is an oversimplification of the factors that predict health behaviour. It was found that the relationship between internal locus of control beliefs and the performance of health behaviour is weak, and the locus of control is not predictive of the health behaviour (Wallston 1992, Norman, Bennett et al. 1998). Health value moderates the relationship between loci of control and health behaviour (Norman, Bennett et al. 1998). In our interviews patients perceived degrees of control over the condition that were quite varied. Some patients expressed that they were in control of the condition, by maintain a healthy lifestyle and a positive attitude towards the condition and treatment. People with internal loci of control expressed positive outlooks toward treatment, and mentioned perseverance. While people with external loci of control described that they were doing what they were told to do because they understood the risks and benefits of treatment. Both groups reported that they were adherent to treatment. One patient described that he expected to be cured of OSA and that neither CPAP nor MADs have given him the quality of sleep he was hoping he would achieve. He was aware that changing lifestyle and

following sleep hygiene regimens as described by his treating physician would improve his symptoms. However, he commented that “*they did not force it enough*” or that he did not know anyone who followed “*sleep hygiene*”. He said he managed the tiredness by simply taking a nap during the day, and he was not using neither CPAP nor MAD at the time of interview.

However, all patients expressed the desire to be in control of their condition, and to be able to monitor their condition. Patients said that they had no method of monitoring their OSA other than relying on their spouses for reporting in improvement of nighttime symptoms, and their subjective assessment of daytime sleepiness and tiredness. Only two patients mentioned that they had received a repeat sleep study after their long-term use of MADs. This preference was expressed in another qualitative study, which reported that participants wanted to be involved in the selection of the CPAP machine and delivery interface (Rodgers 2014). These findings were consistent with the self-management theory, and the management of other chronic illnesses (Lorig and Holman 2003). When dealing with chronic illnesses the role of the health care provider becomes a combination of a teacher, care provider and professional supervisor. Description of compliance with prescribed treatment implies that patients do what they are instructed to do. More recently the term “compliance” has been replaced by “adherence” to imply that the focus of medical intervention is to get patients to be involved in their own treatment, and a shift in the medical community toward tailored interventions (Lorig and Holman 2003). The self-management theory consists of three tasks; medical management, which involves taking the

medication and adhering to specialised diet or exercise. The second task is self-management, which involves maintaining, changing, and creating new meaningful health behaviours, and the third is emotional management task which involves dealing with the emotional outcomes of dealing with a chronic illness (Lorig and Holman 2003). Four steps achieve self-management: (1) performance mastery, by working on improving patients perceived self-efficacy, and giving them the tools to improve their skills and knowledge about their condition; (2) modelling by showing people with similar conditions showing positive experiences with the condition and the treatment, through audio and video information. It can be achieved by having peers share their experiences, and for people who are newly diagnosed to be paired with people who have experience; (3) interpretation of symptoms: to help patients find alternative explanations for their symptoms, and identify reasons to try new self-management behaviours; and (4) social persuasion through using group education to demonstrate positive effects of interventions and to encourage patients to engage in positive behaviour (Lorig and Holman 2003). The Sleep Apnoea Self-Management Program (SASMP) employed the self-management theory and targeted increasing participant's knowledge, skills, perceived self-efficacy and outcome expectations. It was designed to be run in a group format utilising different activities including short lectures, discussions, demonstrations, practice and brainstorming. A pilot study showed promising results is improving CPAP adherence, and improved symptoms pre- and post-intervention. However, a larger scale trial is required to evaluate the SASMP approach in improving CPAP adherence and OSA outcomes

over a sustained period (Stepnowsky, Palau et al. 2007). It was noted that these programs focused on CPAP treatment of OSA, and there is no such data available for those undergoing MAD therapy.

The Influence of “Others”

The influence of powerful others such as spouses or acquaintances varied. For some they were a source of information, whereas others saw reflections of others experiences on their own, and they either wanted to avoid being in their situation, or used their experiences to justify their own behaviour. The influence of social support on self-management of chronic illness has been reported in the medical literature. Social support might be influential, either directly through providing hands-on help or self-management tasks, or indirectly by facilitating self-management activities. However, it might be a negative influencing factor due to misconceptions, or lack of understanding (Gallant 2003). Potential negative influences stem from different factors such as social environment influences, including difficulties presented by social events or special occasions, family responsibilities and obligations that took precedence over disease management, unrelated stress experienced by other family members and finally behaviours from family and friends that were perceived as unsupportive (Gallant 2003). Social support could be a double-edged sword; having both positive and negative aspects. Concerns expressed by family and friends although appreciated might make patients feel singled out or restricted (Gallant 2003).

4.3 Patients and Partners Experience with CPAP

Patients reported that CPAP was effective in reducing nighttime symptoms of OSA such as snoring and repeated apnoea events according

to their partners. However despite its efficacy in reducing nighttime symptoms some described that they were not able to adapt to it. Adherence is reported to be one of the biggest challenges with treatment of OSA (Engleman and Wild 2003).

Reasons for failure to adhere to CPAP were explored. They were classified into technical reasons (adjusting the device, the need to use a humidifier, noise of the machine), discomfort related to the mask (the mask pulling down, restriction of movement, and mask leak), psychological factors (frustration, acceptance of appearance, and claustrophobia.), side effects (dry mouth, sinus infections, imprint of the mask on the face, and forceful breathing), and other factors such as difficulties travelling with the device. These findings support existing evidence on reasons of failure to adhere to CPAP treatment (Wild, Engleman et al. 2004). Data from qualitative research suggested that patients using CPAP showed a desire to be more involved with their care, and to be able to monitor their own sleep (Rodgers 2014). Partners reported that the CPAP machines were effective. It was remarkable however that when patients were not able to use it properly partners did not try to influence them to persevere with CPAP. Instead they encouraged them to seek alternative treatment options like MADs. It might be possible that partners' role in treatment could be adversely affected by difficulties faced at the beginning of treatment. Some of the negative influencing factors might include limited effects of the treatment modality, practical or psychosocial problems, and inappropriate initiation of treatment (Elfström, Karlsson et al. 2012). As a result the treatment was perceived (by the partner) as a negative

experience from which the patient would not obtain any benefit, so the partners did not encourage prolonged adherence to the prescribed treatment.

4.4 Patients and Partners Experience with MAD

Patients interviewed were long-term users of MADs who gave accounts of their experience with MADs. Their experiences were divided into three stages: their initial experience with MADs, an adaptation stage and their current experience with MADs.

Patients experienced challenges with MADs initially and mentioned side effects such as sore jaws, dry mouth, excessive drooling, and bad taste. Psychologically some mentioned that they felt awkward and embarrassed initially.

During the adaptation phase, patients mentioned that they needed a one to two weeks to adapt and that what made it work for them was perseverance. They also mentioned practical measures they undertook such as adjustment of the device and that titration of the hours that they used the device every night until they would wear it for a full night's sleep.

Patients reported that MADs improved their symptoms and that they stopped snoring at night. Many also reported that their energy levels improved. However, it seemed that this effect was not sustainable over the years, as some of them reported that the level of improvement was not as good as when they started treatment, and that the MAD would stop the apnoea but not the snoring. Oral appliances showed reductions in AHI and sleepiness scales provided that the device was continuously adjusted or replaced when needed. That study indicated that the life span

of these devices was 4 to 5 years (Marklund, Sahlin et al. 2001). Surprisingly, a study of the long-term efficacy of oral appliances found that the severity of the condition increased with long-term use of oral appliances. Possible explanations included age, weight gain, occlusal changes, decreased overjet and overbite, reduction of degree of mandibular advancement and sleeping in a supine position (Marklund 2016). The authors recommended scheduled follow up visits and repeat sleep studies to prevent suboptimal treatment outcomes (Marklund 2016).

Patients reported that they relied on their partners to report improvements in symptoms. However, they mentioned that following receiving the device, they had not received a repeat polysomnography (sleep test) to assess the improvement. As a result some expressed concerns as to whether they were improving or not. Partners said that after a period patients still snored with the device in, and they thought that the device interfered with intimacy and was unsociable because they were not able to converse once they put the device in.

Perceived success of treatment by patients and partners was subjective. While clinicians measure success by improvement in AHI or sleepiness index, patients' and partners' measures of success were different. Cessation of snoring and a good night sleep were not the only factors that reflected the success of treatment for patients and partners. They highlighted that being able to sleep in the same bedroom with their spouses, which had restored the intimacy in the relationship, had a positive impact on their health and relationship with their spouses. This was most pronounced for those where lack of intimacy was a problem

that put stress on the relationship. They also mentioned that their social lives improved and they were less embarrassed when going on holidays, as they were not worried about keeping everybody awake at night. Some mentioned that treatment had improved their anxiety level and depression states.

Motivating factors and barriers to using MADs were explored. Motivating factors for patients were good quality sleep for them and their partners, restoring the intimacy in the relationship, better health, and the portability of the device. Barriers of using the device were sore jaw, dry mouth, drooling, keeping the device clean, teeth movement, discomfort and finances. Partners mentioned that the advantages of the device is that it is small, portable, and adjustable, the disadvantages were that the device interfered with intimacy, as one man described it as a “*passion-killer*”, and unsociable because they could not talk once the device is in. The cost of the appliance was an issue for some. Our findings were consistent with findings of a qualitative study about patients’ preference with CPAP and oral appliances (Almeida, Henrich et al. 2013).

4.4.1 Partners Role and Level of Engagement in Treatment

Patients said that their partners’ major role in treatment was in reporting symptoms, as their partners were the first to report symptoms, and they encouraged them to seek treatment. Some were grateful and used their partners report as a barometer of success of their treatment. Partners highlighted that their role was in providing support by attending doctors appointments with them, and communicate with their spouses about their concerns regarding the condition.

Henry and Rosenthal argued that the beliefs of patients and partners are shaped by their experiences, and influenced by dominant cultural narratives about weight, male snoring, the romantic intimacy of bed-sharing, and the gender appropriate styles of sleep (Henry and Rosenthal 2013). Interestingly, in their study they found that gender played a significant part in affecting how patients and spouses described symptoms and perceptions. In this study no distinctive gender differences were identified. However, three partner roles were identified, but they were not gender specific. Two female partners showed *sensitive activity* where they noted that they would stay up all night keeping watch over their partners' sleep. This could be attributed to the woman's protective social role, yet they described that they were active about forcing patients to seek help. One female partner and one male partner showed an *adaptive passive* role. The female partner attributed her behaviour to other commitments that prevented her from being actively involved in her husband's treatment. She explained that she did not understand the seriousness of the condition initially, was amused by the CPAP machine and did not understand how it worked or its purpose. On the other hand, the male partner attributed his role to cultural influences. For him snoring was a sensitive topic, and it was embarrassing for his wife, even during the interview he would refer to snoring as "*making noises*". He was protective of his wife's feelings in that he would subjugate his own sleep need to his wife's needs. The second male partner, on the other hand, showed an active role, in which he would employ a range of very active strategies to force his wife to seek help, such as vocalising his displeasure, banishing her from a shared bedroom, and developing an

independent social network. These roles were also identified in Henry and Rosenthal's work, however, the difference is that their description of partners' accounts was gender specific, while our findings did not find that partners' roles were gender specific (Venn 2007, Henry and Rosenthal 2013, Coppock, Haydon et al. 2014).

4.5 Services Provided to Patients with OSA

Three areas were highlighted regarding services provided to patients with OSA. The included patients access to information, how could services be improved, and support groups.

Patients reflected that they had little knowledge about OSA before they were diagnosed. They mentioned that they accessed information about the condition directly from the treating doctor, through leaflets provided, from TV infomercials, and through online resources. Patients and partners agreed that there should be more public awareness about OSA. Some mentioned that they educated people around them about the condition, and they encouraged them to seek medical attention and diagnosis. Some mentioned that messages delivered to the public should be positive and focus on the benefits of treating OSA rather than focusing on its association with cardiovascular diseases or high incidents of automobile accidents.

Patients highlighted that there should be a follow up schedule following receiving treatment to monitor their progress of treatment. This is consistent with findings from research focusing on treating OSA-like chronic diseases such as diabetes or arthritis, promoting a self-

management protocol that focuses on patient education and skills in managing their own condition, and also on follow up schedule to monitor the progress of the condition (Lorig and Holman 2003, Stepnowsky, Palau et al. 2007).

Patients elaborated on the role of support groups in management of OSA. Some mentioned that they would like to be a part of a focus group because they would feel a part of a community where they could share experiences, and not feel isolated. They would also learn from the experiences of other people about management of the condition, and that would help them face challenges related to the condition. The self-management model included an element of modelling when new users are paired with old users to improve patients' adherence to prescribed treatment (Lorig and Holman 2003).

4.6 Strengths and Limitations

The in-depth semi-structured interview is a qualitative research technique that allows exploration of peoples' perspectives on a particular idea, topic or situation. Conduction of the interview allowed structure and flexibility, depending on the interaction between the interviewer and the correspondent. This research was completed on patients who had received MAD treatment in the DDUH, and their bed partners. The use of this technique allowed an insightful look into patients' experiences with OSA, CPAP and MADs. Participants in this research were articulate, expressive and were all willing to share their experiences openly. They had confidence and trust in the service provided to them in the DDUH, and that encouraged them to participate and share their experience. The unique strength of this study is that it shed a light on an

area in which little is known about, and it revealed new perspective of living with OSA as patients described gutt and using the condition as a crutch which was not described in the previous literature. One more strength is that the study included the experience of patients who had failed to adhere to CPAP and compared that with their current experience with MADs. Which was unique to this study.

Limitations of this study include small sample size, as participant recruitment was a challenge that was faced when conducting this study. Recruitment involved identifying eligible participants who were articulate, expressive, and willing to share their experience. The study was explained to the potential participants, and consent obtained. The number of partners who were willing to participate was small, and was insufficient for conducting focus groups. So interviewing partners individually was the method employed. The disadvantage was that it made the gathering of data time consuming. However, this allowed for more in depth information and a richer content of data, as the participants and their partners were very willing to engage and share their experiences. It appeared that the one-to-one interviews worked very well as patients were very articulate and had wanted to share their experiences.

Other limitations were lack of triangulation and lack of member checking, however, rigour was ensured in this study through purposive sampling, and analysis by multiple qualitative researchers to ensure the validity of the results. However, the findings were unique to the sample included in this study, as it was a group of Irish adults who were all over 40, who had been diagnosed with OSA for a long time and have been

long time users of MADs and attendees to the DDUH. It would be interesting to explore the perspective of younger patients, who are short term users of MADs in future research.

4.7 Implications

This research utilised the unique perspective of patients and partners in the management of OSA. It helped understand the challenges, motivators and barriers to prescribed therapy, whether CPAP or MADs. Some of the patients interviewed in this research had previously failed to adhere to CPAP, which is not uncommon, and a universal issue in the management of OSA. Some of these were able to adhere to the alternative treatment option, which is MAD therapy, but some still faced challenges.

Identifying patient and partner profiles that will adhere to prescribed treatment is key in the management of OSA and other chronic conditions. It may help target patients who will be successful in treatment and improve patient outcomes, and help those identified as not suitable for treatment, to help modify their behaviour and get them to adhere to treatment or simply seek alternative treatment options. This study identified that patients with positive outlooks, who take responsibility of their own health, and who are proactive about improving their health and well-being were adherent to treatment. The partners influence on the adherence cannot be overlooked. Partners who were caring and persistent had a positive role in “*pushing*” their partners to seek treatment, and actively reminding them to use the appliances and creating a positive environment that would encourage them to adhere to treatment. Factors such as regular adjustment of the device, monitoring their nighttime

symptoms, attending appointments with their partner, and providing financial support were all positive indicators.

However, we identified that partners involvement in treatment is subject to cultural influences and classic gender roles as set by the society, which differ through the generations. In the sample interviewed as part of this research, we identified that younger couples were different in their perception on the level of partners' involvement in treatment than older couples. The word "*support*" also appeared to mean different things to different people. For older couples, it seemed that the degree or level of partner involvement was dependent on how much the patient allowed, and included cultural influences and personal traits of the patients and partners and the dynamics of the relationship between the couple. While for younger couples, it seemed that the spouses were more forceful and proactive in their approach. However, this cannot be generalised, as partners' level of engagement in treatment was limited to how much the patients' believed that treatment was successful for them, and the patients' had autonomy and freedom of decision when it came to deciding how successful the treatment is, and the partners' role was secondary. In cases where patients were convinced that treatment was unsuccessful, (for example patients who failed to adhere to CPAP) partners had little or no influence in persuading them to adhere to treatment. The opposite scenario occurred when patients were satisfied with MAD treatment, and if partners mentioned that the MADs did not stop the snoring, partners had little influence in getting them to seek an alternative treatment option. Getting partners' involved in the treatment has its advantages, as in creating a positive environment that would

encourage patients to adhere to treatment, and provide monitoring for progression of the condition.

OSA should be treated as a chronic disease, as neither CPAP nor MADs *cure* the condition. They are treatment modalities that help patients live with the condition and prevent adverse effects on general health.

Therefore OSA treatment should focus of a wholesome management approach that involves healthy sleeping habits, adherence to prescribed treatment, and regular maintenance and follow up of the condition. The main concern patients reported with MAD treatment was that they were not able to monitor the progress of their condition over time. Patients reported a lack of follow up, which might lead to undesirable treatment outcomes. There was no current protocol for follow up and maintenance of OSA patients in the DDUH. Patients are seen for the first time for a consultation appointment and the appliance is fitted on the second appointment. Patients are further reviewed a week later and again until they are satisfied with the appliance. Follow up is determined by the patient depending on their treatment needs. Recall appointments were not scheduled due to the high number of failed appointments. This may be as a result of the appliance working successfully or patients not complying with treatment. We recommend that future management protocols should focus on treating OSA as a chronic disease, focusing on getting patients and partners actively involved in treatment. Increased collaboration between the DDUH and the sleep specialists for follow up and monitoring of these patients is also indicated.

4.8 Future Research

The focus of future research should be on the long-term efficacy of MADs and further identify factors that would improve patients' adherence to prescribed treatment. This would be in order to identify the psychological factors that improve adherence to treatment, and to direct programs into involving patients more in their own treatment and allow them to monitor their condition. This could be measured by combining qualitative and quantitative approaches, by measuring adherence versus patient reports by using devices that track MAD use, through integration of electronic microelectronic sensors into the MAD. These sensors measure the intraoral temperature at 15-minute intervals, and can be transferred electronically to the analysis computer and software and converted into wear time and non-wear time parameters (Schott and Ludwig 2014).

Future research should focus on follow up protocols for OSA patients, and to identify the timing of repeat sleep study and when to intervene to change treatment from MADs to CPAP if indicated.

Future research should consider constructing a self-management protocol based of evidence from the social cognitive behaviour therapy which focuses on providing patients with information, knowledge and skills to manage their condition and getting partners actively involved in treatment.

Finally, future research should assess the methods of transferring information for patients and first time users, through conventional methods as leaflets and TV infomercials or incorporating new media to teach patients about their condition. This could take the form of websites

or mobile applications that will keep patients actively involved in their own treatment, and allows clinicians to access patients' information to facilitate communication between patient and clinician.

5. Conclusions

In our study, we elucidated patients and partners experiences with OSA, CPAP and MAD therapy. The influence and effect of partners was explored, and the factors that influence adherence to prescribed treatment were identified. Finally, suggestions to improve compliance and provide the support to increase treatment acceptance and uptake were made.

Suggestions include providing patients with tools to assess their progress in the condition, and close monitoring by clinicians through a follow up schedule.

OSA is a shared problem between patients and partners; it affects the quality of life of patients by causing daytime sleepiness, tiredness, affecting cognitive function, and increased risk of cardiovascular disease and increased risk of road traffic accidents. In addition, OSA impairs patients work, social life, and the ability to perform daily functions.

Patients diagnosed with OSA associated OSA with a number of psychological factors, such as association with old age, depression, and impairment. Psychological factors such as locus of control, health attitudes and influence of significant others should be identified at the beginning of treatment to predict adherence to the prescribed treatment.

Patients who failed to adhere to CPAP failed due to technical problems, discomfort related to the mask, psychological factors, side effects, and portability of the device. OSA patients described that they would like to be actively involved in their own treatment.

OSA also affects partners through interrupted sleep pattern, and agitation caused by loud snoring leading to inability to perform daily functions because of sleep deprivation. Both patients and partners described coping

strategies to dealing with OSA, the most common is sleeping in separate rooms, which for some put a strain on the relationship. Partners instigated the process for patients to seek medical advice, and the partner's role were not gender specific. Partners can have an active role in treatment of OSA. In our study partners described an array of roles, active sensitivity, passive adaptation, and direct confrontational approaches. For some cultural influences and classic gender roles influenced their perceived roles.

There was a delay in seeking medical advice with regards to OSA symptoms, patients and their partners attributed that to lack of knowledge, or embarrassment, and fear of trivialising the problem.

Service provided to patients could be improved by:

1. Improving public awareness about OSA,
2. Focusing on a positive message on media,
3. Informing patients about alternative treatment options according to the degree of disease severity,
4. Providing a follow up schedule and repeat sleep study,
5. Promoting self-management protocol for treatment of OSA (one that is specific to MADs),
6. Support groups for first time users.

Finally, OSA should be treated like chronic condition that requires active intervention from patients paired with regular check-up visits and repeat sleep studies to assess patients progress.

Management of OSA should focus on a wholesome approach that involves incorporating healthy sleeping habits, getting patients and

partners actively involved in treatment, adherence to prescribed treatment, and regular maintenance and follow up.

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Appendix 1: Ethical Approval Letter

MOS

THIS NOTEPAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie



**THE ADELAIDE & MEATH
HOSPITAL, DUBLIN**
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND
TELEPHONE +353 1 4142000

Dr. Michael O'Sullivan
Director of Teaching and Learning (Postgraduate)
Dublin Dental University Hospital
Lincoln Place
Dublin 2

11th December 2015

**RE: Patient and Partner Experiences with Obstructive Sleep Apnoea and
Mandibular Advancement Device Treatment: A Qualitative Analysis**
REC Reference : 2015-12 Chairman's Action (5)
(Please quote reference on all correspondence)

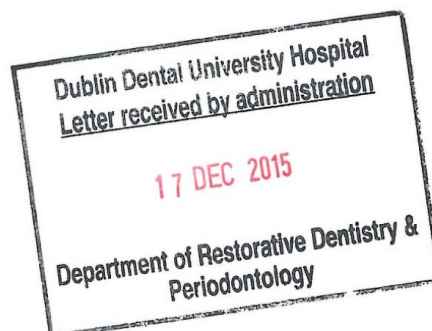
Dear Dr. O'Sullivan,

Thank you for your application to SJH/AMNCH Research Ethics Committee in which
you queried approval for the above referenced study.

The Chairman, on behalf of the Research Ethics Committee, has reviewed this
application and has granted ethical approval.

Yours sincerely,

Claire Hartin
Administrator
SJH/AMNCH Research Ethics Committee



Appendix 2: Patients' Interview Topic Guide

Patient and Partner Experiences with Obstructive Sleep Apnoea and
Mandibular Advancement Device Treatment: A Qualitative Analysis
Designing Fieldwork – Patients' interview topic guide

Objectives:

1. Identify the effect of OSA on the QoL of patients
2. Identify the effect of MADs on the QoL of patients
3. Identify what motivates patients to use MADs
4. Identify the barriers of using MADs
5. Identify how MADs are different from CPAP from patients' perspective
6. Identify the partners' role in management of OSA
7. Identify how could the management of OSA become more effective from patient's point of view

Notes:

This topic guide contains eight topics with subheadings marked as bullet points, they are written in the format of short sentences.

1. Introduction

- Introduction to the researcher
- Study topic
- Explanation of the aims and objectives
- Explain the confidentiality and anonymity
- Explain the recording length 1 hour, nature output reporting of data, and storage
- Consent issues: they may withdraw at any time from the interview as a whole and don't have to answer any question they would prefer not to; this will not affect their treatment.
- Check whether they have any questions
- Check that they are happy to continue

2. Background information

- Household composition and personal relationships
- Working, non-working status (working pattern)
- Current health

3. Diagnosis with OSA

- How did they find out that they have sleep apnoea
- How long did it take to get a diagnosis

- How do they know if they snore
- How do they monitor it
- Is it an impairment
- What were they told about treatment options
- How did they decide to use MAD
- First night using MAD
 - ◆ How long did they wear the device for
 - ◆ How was their experience
 - ◆ Self-management of the condition

4. Current experience with MADs

- How long they have been using MADs
- How did it affect their day – day life
- What encourages them to use MADs
- What are the barriers to using the device (finance , value of money)
- For patients who have failed CPAP
 - ◆ What were the barriers of using CPAP
 - ◆ How is MADs different

5. Partners' Role in the experience

- Partners' role at the diagnosis with OSA
- For patients who failed CPAP
 - ◆ How did s/he affect your decision to stop using CPAP
 - ◆ How did s/he affect your decision to start using MADs
- How do you think that your condition affects her day – day life
- How did OSA affect your relationship

6. Other impacts of OSA on day-day life

- Social life
- Interpersonal relationship
- Extent to which they currently feel that they are in control of the condition
- How do they think it is different from the time they first started using the device

7. Future

- What is your advice to someone who is just diagnosed with OSA
- How do you think patients should be familiarised with MADs
- Future support that should be available , what should the priorities be when managing sleep apnoea
- Any other points you would like to raise

8. Conclusion

- Thank You for your time

- Interview will remain confidential
- You are welcome to contact members of the study team to ask questions later if you wish
- END RECORDING

Appendix 3: Partners' Interview Topic Guide

Patient and Partner Experiences with Obstructive Sleep Apnoea and
Mandibular Advancement Device Treatment: A Qualitative Analysis
Designing Fieldwork – Partner's interview topic guide

9. Introduction

- Introduction to the researcher
- Study topic
- Explanation of the aims and objectives
- Explain the confidentiality and anonymity
- Explain the recording length (1 hour), output reporting of data, and storage
- Consent issues: they could withdraw at any time from the interview as a whole and did not have to answer any question they would prefer not to and that this would not affect their partner's treatment.
- Check whether they had any questions
- Check that they were happy to continue

10. Background information

- Household composition and personal relationships
- Working, non-working status (working pattern)

11. Diagnosis with OSA

- When did you first notice that your partner snored or had apnoea events?
- What made it a problem?
- How did you cope with it? How long did you cope with it?
- How did you bring the subject? How did your partner respond?
- How did you feel when your partner was diagnosed with sleep apnoea?
- Did they use CPAP? What was it like for you?
- What came after CPAP? Why did your partner change therapy?

12. Current experience with MADs

- How do you influence your partner to use the device at night?
- Does it make a difference if they put it on or not?

13. Partner's experience / effect on relationship

- Do you think your partner's condition has affected your social life at all?
- Do you think that the condition affected your relationship?
- So do you think you have hindered it at all- what would you differently? WHAT DOES THIS MEAN?

14. Other impacts of OSA on day to day life

- Extent to which they currently feel that they are in control of the condition
- How do they think it is different from the time they first started using the device?

15. Future

- What is your advice to someone whose partner is just diagnosed with OSA?
- To what extent do you believe that partner engagement in the treatment of OSA is important?
- Any other points you would like to raise

16. Conclusion

- Thank you for your time
- Interview will remain confidential
- You are welcome to contact members of the study team to ask questions later if you wish
- END RECORDING

Appendix 4: Consent Form



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

CONSENT FORM

Title of Research Study:

Patient and Partner Experiences with Obstructive Sleep apnoea and Mandibular Advancement Device Treatment: A Qualitative Analysis

This study and this consent form have been explained to me. My doctor has answered all my questions to my satisfaction. I believe I understand what will happen if I agree to be part of this study.

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

PARTICIPANT'S NAME:

PARTICIPANT'S SIGNATURE:

Date:

Date on which the participant was furnished with this form:

Statement of investigator's responsibility:

I have explained the nature, purpose, procedures, benefits, risks, or alternatives to, this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely give informed consent.

Dentist's Signature:

Date:

(Keep the original of this form in the investigator's records and give one copy to the participant.)

Appendix 5: Information Leaflet

Title of the Study:

Patient and Partner Experiences with Obstructive Sleep Apnoea and Mandibular Advancement Device Treatment: A Qualitative Analysis

Introduction:

I would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

I am Dr. Lina Khasawneh from the Dublin Dental University Hospital. I am conducting a research about sleep apnoea. I would like to discover more about your personal experience of living with sleep apnoea and I would like to invite you to join this research study.

Study Details:

I would like to meet with you and ask a few questions about your views and experiences of living with sleep apnoea and the use of the mandibular advancement device. This interview will take no more than an hour of your time and I will meet you in the Dublin Dental University Hospital on a day and a time, which is most convenient for you. I would like to make an audio tape recording of the interview so that I can listen to what you are saying without having to write everything down at the same time. This tape recording will remain confidential information as part of the study but you are welcome to request a written version of the interview afterwards if you so wish. Recordings of interviews will be deleted upon transcription.

Eligibility:

To take part in this study you need to be over 18 and have mild to moderate sleep apnoea and use mandibular advancement device.

Risks and Benefits:

There is no risk involved in this study except of course the taking up of your valuable time. You may of course, refuse to answer some or all the questions if you don't feel comfortable with any of them. I shall not be carrying out a dental examination.

You will not directly benefit from this study, but what you tell me will be used to understand how the use of mandibular advancement devices for management of sleep apnoea affect the quality of life of patients and their partners. It will help future patients communicate their experiences. It will also help us as clinicians to predict the quality of treatment we

provide to our patients. The results of the study will also be published in journals or conferences.

Confidentiality:

Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the research study group. All data will be anonymised in any reports I write and no individual will be identified.

Voluntary Participation:

It is up to you to decide whether to take part or not. If you decide to volunteer to participate in this study, you may withdraw at any time without giving a reason. If you decide not to participate, or if you withdraw, you will not be penalised and it will not affect the standard of care you receive. Should you decide to withdraw from the study you need to do so before the 28th of February 2017 when the final results will be written up.

Further information:

If you have any questions or require more information about this study, please contact Ms Rosaleen Glackin using the following contact details:

Ms Rosaleen Glackin
Dublin Dental University Hospital
Lincoln Place
Dublin 2
Tel: 01 612 720
Email: rosaleen.glackin@dental.tcd.ie

Appendix 6: Approach letter

Dear Sir/Madam

We would like to invite you to consider taking part in a study, which Dr Lina Khasawneh from the Dublin Dental University Hospital (DDUH) is undertaking. She wants to learn first-hand about people's experience of living with sleep apnoea. Dr Khasawneh is looking to talk to adults with mild to moderate sleep apnoea who are using mandibular advancement devices and ask a few questions in an interview format about their views and experiences of living with this condition.

You can read more about the study in the information sheet provided and if you want to ask some questions about the study, Dr Lina Khasawneh contact details are supplied below. If you are interested in taking part then Dr Khasawneh can meet you in DDUH on a day, time that is most convenient for you. You can contact Ms Rosaleen Glackin by:

- (1) Telephone contact 01 612 7200
- (2) Email Rosaleen.glackin@dental.tcd.ie
- (3) By post, put the slip below, in the envelope supplied.

Thank you for your interest in this project

I am interested in taking part in taking part or learning more about the study with

Dr. Lina Khasawneh and I am willing for her to contact me:

NAME

Telephone Number

Email

Signed

Date