



Making choices about CPAP: Findings from a grounded theory study about living with CPAP



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ABSTRACT

Untreated sleep apnoea incurs high societal and personal health costs. Although continuous positive airway pressure is a recognised, cost-effective treatment, concern exists that patients under-use this therapy. However, there is limited evidence regarding users' views of this treatment. Therefore, we aimed to explore experiences of living with continuous positive airway pressure from participants' perspectives.

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

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

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

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1. Introduction

People spend around one third of their life sleeping. Good sleep is restorative while sleep deprivation is distressing. In *Macbeth*, Shakespeare (circa C16th) described sleep as “chief nourisher in life's feast” (p.181). Yet many things can disrupt sleep, leading to lowered mood and daytime functioning, reduced productivity and an increased risk of errors (Sateia, 2014). Sleep medicine literature regarding the issue of non-restorative sleep highlights obstructive sleep apnoea (OSA) as a common cause of disrupted of sleep (Barbé

& Pépin, 2015; Jordan, McSharry, & Malhotra, 2014). Evidence on treatment options for OSA demonstrates that continuous positive airway pressure (CPAP) is the gold standard intervention (Giles et al., 2008; Qaseem et al., 2013). However, on-going concern with CPAP compliance highlights a gap in understanding about how to minimise non-compliance. Addressing this gap by exploring how CPAP-users successfully manage therapy adds to the literature and may provide new strategies to optimise support for CPAP-users.

A long-term condition, OSA is prevalent in 3–7% of the general population worldwide (Gislason & Sunnergren, 2014; Peppard et al., 2013). OSA is caused by the partial, or complete, collapse of the pharynx during sleep, which obstructs breathing. These obstructions, or apnoeas, may occur from five to over 100 times an hour causing hallmark symptoms that include snoring and excessive daytime fatigue (Jordan et al., 2014; Peppard et al., 2013). Untreated

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OSA is physically, socially and economically costly (AlGhanim, Comondore, Fleetham, Marra, & Ayas, 2008; Jennum, Ibsen, & Kjellberg, 2014). Consequences include increased risk for hypertension, neurocognitive dysfunction, cardiovascular disease and reduction in the quality of relationships and social life (Gottlieb et al., 2010; Marshall, Wong, Cullen, Knuiiman, & Grunstein, 2014; Vaessen, Overeem, & Sitskoorn, 2015). Additionally, rates of medical intervention and risk for accidental trauma increase while OSA remains untreated (AlGhanim et al., 2008; Mwenge & Rodenstein, 2010; Tregear, Reston, Schoelles, & Phillips, 2009).

CPAP, via nasal or face mask, pneumatically splints the pharynx open during sleep. There is strong evidence regarding the efficacy and cost-effectiveness of CPAP when used as prescribed (Giles et al., 2008; Guest, Helter, Morga, & Stradling, 2008; Qaseem et al., 2013). Yet CPAP can be challenging to use, with evidence suggesting patients under-use CPAP (Sawyer, Gooneratne et al., 2011). Interventional literature concerned with improving the use of CPAP is plentiful (Sawyer, Gooneratne et al., 2011; Wozniak, Lasserson, & Smith, 2014). To determine barriers to using CPAP, investigators have addressed issues such as self-efficacy in CPAP use and used health beliefs models to predict CPAP use (Dickerson et al., 2013; Sawyer, Canamucio et al., 2011). Studies using health beliefs and other psychological models have also examined inclination to adhere to CPAP therapy (Aloia, Arnedt, Stepnowsky, Hecht, & Borrelli, 2005; Olsen, Smith, & Oei, 2008; Sawyer, Canamucio et al., 2011). However, a recent review identified that current literature addresses problems with CPAP adherence from an 'expert' standpoint and through a problem-oriented paradigm (Ward, Hoare, & Gott, 2014). Furthermore, it appeared that while concern with the difficulties experienced by patients was evident in the literature, research into the patient experience was limited (Hu, Yu, Lee, & Tsao, 2014; Rodgers, 2014).

Not all CPAP-users are non-compliant, and do manage to use CPAP successfully. We argue that focusing research efforts on adherence and not accounting for experiences of CPAP from the users' perspective constrains understanding (Sawyer, Gooneratne et al., 2011). It is within this context that the present study explored participants' experiences of CPAP using grounded theory to provide insight into factors sustaining CPAP use at home. This paper presents an important component of the findings focusing on the second main category from a grounded theory study and incorporates the processes employed by participants that comprise **making choices about CPAP**.

2. Methods

We employed a qualitative design using constructionist grounded theory (GT), and semi-structured individual interviews (Charmaz, 2008, 2014; Mills, Bonner, & Francis, 2006). GT addresses gaps in knowledge by using participants' accounts about their experiences to construct an explanatory theory about their actions. Therefore, the coding framework was inductively derived from the data. This paper uses the consolidated criteria for reporting qualitative studies (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

2.1. Setting and participants

A respiratory clinic in a main city of New Zealand provided the recruitment setting. People who meet nationally established diagnostic criteria for OSA, are eligible for a CPAP device free of charge, which includes participants in this study. The prevalence of OSA in New Zealand reflects international evidence and aligns with findings that prevalence increases as body mass index increases (Mihaere et al., 2009; Peppard et al., 2013). Initial purposive sampling focused on recruiting adults aged eighteen years or older

with personal knowledge of using CPAP for OSA. In total sixteen participants were recruited (women n = 7, men n = 9; see Table 1).

As data analysis progressed, participants were sampled theoretically, which is a characteristic of GT whereby participants are selected based upon knowledge they might provide to aid theory construction (Birks & Mills, 2011; Charmaz, 2014). Participants included adults using CPAP for OSA via face or nasal mask (n = 12). Theoretical sampling led to a second interview with one participant, to compare experiences of CPAP over time, and inclusion of partners¹ (n = 4) of CPAP-users in the study, who were invited to participate by mail. Ethical requirements determined that participants self-selected independent of the researcher and it is unknown how many declined to participate during initial sampling. One partner-participant declined during theoretical sampling. People using CPAP for other conditions or aged seventeen years and under were excluded.

2.2. Ethical considerations

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

2.3. Data collection and analysis

We chose semi-structured interviews to generate data and since no participants opted for an in person interview they took place via telephone. A recent study suggests that qualitative interview via telephone is an acceptable method of data collection (Ward, Gott, & Hoare, 2015). Over ten months ending in early 2014, KW audio recorded, transcribed, anonymised and coded seventeen individual, in-depth interviews. Interview data and interview notes were stored and managed using QSR NVivo10.

We developed questions or prompts to elicit data relevant to the participant regarding CPAP that were loosely structured during early interviews. These included: tell me about your night-time routine, and about your CPAP, how do you explain sleep apnoea or CPAP to others, and what does CPAP mean to you? Semi-structured dialogue allowed the exploration of information as new categories were constructed from the data (Birks and Mills, 2011; Kvale & Brinkmann, 2009). Thereafter, questions focused on developing the main categories.

Data collection and analysis are concurrent in GT, and analysis commences with the first transcript (Birks & Mills, 2011; Charmaz, 2014). Analysis began with line-by-line coding to immerse KW in the participants' stories and to identify initial constructs (Birks & Mills, 2011; Charmaz, 2014). Coding enabled clustering of data into categories using gerunds² to identify action. Lower-level codes and categories were subsumed by main categories and then integrated into the final theory (Charmaz, 2014). Constant comparison is a hallmark of a GT project (Charmaz, 2014). Constantly comparing on-going coding with earlier data facilitated the evaluation of each code and category against the participants' words. Constant comparison also generated increasingly focused questions, which were adapted and developed as analysis progressed to explore new ideas

¹ 'Partner' describes bed- and/or life-partner.

² Gerunds are nouns formed from verbs by adding 'ing' and are useful to pinpoint action and sequence. For example, be (as in be quiet) becomes being.

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