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## Becoming a team: Findings from a grounded theory study about living with CPAP

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### ABSTRACT

Untreated sleep apnoea incurs significant health costs. Continuous positive airway pressure (CPAP) is a recognised, cost-effective treatment that can be challenging for users and about which there is limited evidence from the users' perspective. Therefore, we aimed to explore experiences of living with this therapy from participants' perspectives using constructionist grounded theory.

Adult participants (n = 16) were recruited through a main-centre respiratory service in New Zealand. We used semi-structured interviews, and data were analysed until theoretical saturation was reached.

This paper reports the first of three main categories from the grounded theory: *bargaining and balancing life with CPAP*. The first category, *becoming a team for good-sleep*, emphasises that partners are not simply bystanders, but integral to using CPAP. Indeed, it was apparent that users and partners formed a team with the mutual goal of achieving a good sleep. Partners experienced and bore witness to consequences of untreated sleep apnoea, prompting the snorer to seek treatment. Joint problem-solving and decision-making facilitated successful therapy management. Conversely, un-collaborative partners hindered this process.

Findings provide new insights that illustrate how CPAP may successfully be used at home and strategies for promoting effective sleep apnoea management. Therapy-users' designated partners should be formally incorporated into the treatment process, including nurse-led and clinician clinic consults, to increase the probability of successful therapy management at home. Further research, including intervention studies, should explore the role of partners in successful positive airway pressure management and other long-term therapies.

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### 1. Introduction

Untreated sleep apnoea negatively affects physical health, work life and home life. The cause and consequences of the chronic condition obstructive sleep apnoea (OSA) are internationally recognised and well documented in the literature, as are the high personal and societal costs of untreated OSA (AlGhanim, Comondore, Fleetham, Marra, & Ayas, 2008; Gottlieb et al., 2010; Jennum, Ibsen, & Kjellberg, 2014; Kendzerska, Gershon, Hawker, Tomlinson, & Leung, 2014; Marshall, Wong, Cullen, Knuiman, & Grunstein, 2014; Tregear, Reston, Schoelles, & Phillips, 2009; Vaessen, Overeem, & Sitskoorn, 2015). Continuous positive airway pressure (CPAP)

via face or nasal mask is an internationally recognised and cost-effective therapy for OSA (Giles et al., 2008; Kakkar & Berry, 2007). However, the device can be challenging for users and studies have reported concern with poor adherence (Galetke, Puzzo, Priegnitz, Anduleit, & Randerath, 2011; Sawyer et al., 2011). The association between OSA and obesity suggests that the global increase in obesity may herald a worldwide health and economic matter if treatment for OSA is unsuccessful (Parekh, Green, & Majeed, 2012). Therefore, exploring factors that support CPAP use at home is important.

To address concern with poor adherence to CPAP, studies have extensively explored supportive interventions that may aid the CPAP-user (Dickerson et al., 2013; Smith & Lasserson, 2009; Smith, Nadig, & Lasserson, 2009; Sparrow, Aloia, Demolles, & Gottlieb, 2010; Wozniak, Lasserson, & Smith, 2014). However, a recent review identified limited evidence about experiencing CPAP for OSA from the users' perspective, determining that current literature

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addresses concerns with adherence through a problem-oriented paradigm (Ward, Hoare, & Gott, 2014). Moreover, Ward et al., identified that partners and other family members influenced CPAP-users' experiences. This view is supported by two subsequent studies. Hu, Yu, Lee, and Tsao (2014) focused upon the process of seeking medical help for OSA and identified family as a source of information regarding sleep apnoea symptoms. However, this study did not explore the role of partners in the process of using CPA Rodgers (2014) focused on the process of being diagnosed with OSA and identified partners as an important source of support for sleep apnoea sufferers as they pursued treatment. The current study extends these findings by incorporating participant views about the role of partners and by identifying processes that explain how partner support occurs.

Evidence regarding how couples cope with chronic illness supports the role of partners in long-term therapy care (Hemphill & Berg, 2012; Hemphill, Stephens, Franks, & Rook, 2012). Indeed the inclusion of family members is credited with improved long-term condition management (Conway et al., 2006; Leape et al., 2009; Marks, Allegrante, & Lorig, 2005). However, evidence on the role of partner involvement and other family members in the management of CPAP is limited (McDowell, 2011; Troxel, 2010; Wozniak et al., 2014). It is within this context that the present study used grounded theory to explore living with CPAP to understand success with this therapy, by asking, what is it like to live with CPAP for sleep apnoea? This paper presents an important component of the findings focusing on the first main category, becoming a team for good-sleep, which incorporates participants' perspectives about the role of the partner and significant others.

## 2. Methods

Given limited previous research in this area, we used semi-structured individual interviews and a constructionist grounded theory (GT) approach, as described by Charmaz (2014) and Birks and Mills (2011). GT is used to address gaps in knowledge by using participant accounts to construct an explanatory theory about their actions (Birks & Mills, 2011; Charmaz, 2014). Accordingly, the coding framework was inductively derived from the data. This report uses the consolidated criteria framework for reporting qualitative studies (Tong, Sainsbury, & Craig, 2007).

### 2.1. Setting and participants

This study was situated in a main city respiratory clinic in New Zealand. People with sleep apnoea who meet nationally established diagnostic criteria are eligible for a CPAP device free of charge. Mihaere et al. (2009) identified that prevalence of sleep apnoea in New Zealand aligns with international evidence, and that prevalence increases as body mass index increases. Initial participant sampling was purposive with a focus on recruiting adults with a personal knowledge of using CPAP. As the study progressed, new participants were sampled theoretically based on information they might provide (Birks & Mills, 2011; Charmaz, 2014). In total sixteen participants were recruited (women n = 7, men n = 9; see Table 1)

Theoretical sampling led to a second interview with one participant, to compare experiences of CPAP over time, and inclusion of partners<sup>1</sup> (n = 4) of CPAP-users in the study, who were invited to participate by mail. People aged seventeen years and under, or those prescribed CPAP for other illnesses were excluded.

**Table 1**  
Participant demographics at the time of interview.

| Demographics at time of interview                              | Number of participants                                        |   |
|----------------------------------------------------------------|---------------------------------------------------------------|---|
| Age band                                                       | 25–35                                                         | 2 |
|                                                                | 36–45                                                         | 4 |
|                                                                | 46–55                                                         | 2 |
|                                                                | 56–65                                                         | 6 |
|                                                                | 66+                                                           | 2 |
| Ethnicity                                                      | NZ European                                                   | 9 |
|                                                                | Maori                                                         | 1 |
|                                                                | Samoan                                                        | 1 |
|                                                                | Indian                                                        | 3 |
|                                                                | NZ European plus other                                        | 2 |
| Time since CPAP initiation** (CPAP-users n = 12 <sup>±</sup> ) | “a while”                                                     | 1 |
|                                                                | 1 year or less                                                | 5 |
|                                                                | 2 years or less                                               | 2 |
|                                                                | 3 years or less                                               | 2 |
|                                                                | 5 years or more                                               | 3 |
|                                                                | Pete* abandoned CPAP after “about a year.”                    |   |
|                                                                | Hal interviewed twice, at 11 months and at 2 years, 11 months |   |
| CPAP use ** (CPAP-users n = 12)                                | Each night, all night †                                       | 6 |
|                                                                | Each night, not all night †                                   | 2 |
|                                                                | Not every night ‡, but all night                              | 1 |
|                                                                | Not every night, not all night                                | 3 |

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

### 2.2. Ethical considerations

National and local ethics committees (reference NTX/11/06/048/AMO2) provided ethical approval for the study. Prior to clinic, the lead physiologist identified potential participants. Clinic staff provided each potential participant with an information pack that outlined reasons for and details of the study, including written consent to complete if they chose to participate. At each contact point, KW re-confirmed consent to protect participants' right to consider participating and their confidentiality.

### 2.3. Data collection and analysis

In total, KW conducted, audio recorded, transcribed and coded seventeen individual in-depth, semi-structured interviews during ten months ending in late 2014. The average interview duration was 52 min, the shortest being 24 min and the longest 82 min. Although interviews were offered in-person if preferred, all participants chose to be interviewed by telephone (Ward, Gott, & Hoare, 2015). Interview data and interview notes were stored and managed using QSR NVivo10. Interviews began with open-ended questions, or prompts, to elicit information relevant to the participant regarding CPAP. These included: tell me about your CPAP, and about your night-time routine, what does CPAP mean to you, and how do you explain sleep apnoea or CPAP to others? Semi-structured dialogue enabled KW to follow new avenues of inquiry as new categories were constructed from the data (Birks & Mills, 2011; Kvale & Brinkmann, 2009). Subsequent questions focused on exploring and developing main categories.

Data collection and analysis occur concurrently in GT (Birks & Mills, 2011; Charmaz, 2014). Therefore, analysis commenced with line-by-line coding of the first transcript to identify initial constructs (Birks & Mills, 2011; Charmaz, 2014). Further coding

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

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