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Original Article

Adherence to continuous positive airway pressure in adults with an intellectual disability[☆]Kim A. Luijckx^a, Nele L. Vandebussche^a, Dirk Pevernagie^{a, b}, Sebastiaan Overeem^{a, c}, Sigrid Pillen^{a, *}^a Sleep Medicine Center Kempenhaeghe, Heeze, The Netherlands^b Department Internal Medicine, Faculty of Medicine and Health Sciences, Ghent University, Belgium^c Eindhoven University of Technology, Eindhoven, The Netherlands

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ABSTRACT

Study objectives: This retrospective study evaluated the feasibility of continuous positive airway pressure (CPAP) therapy in adults with intellectual disabilities (ID).**Methods:** CPAP therapy of 24 obstructive sleep apnea syndrome (OSA) patients with ID were compared to age- and sex-matched adults with normal cognitive functioning. All ID patients received an intensive in-hospital training protocol to stimulate adherence. Good adherence was defined as a use of >70% of the nights and >4 h/night. Influencing factors were assessed.**Results:** Baseline apnea-hypopnea index (AHI) was significantly higher in ID patients compared to controls (median 34/h (range 6–101) versus 17/h (range 5–50), $p = 0.013$). The required average duration of in-hospital training was four nights (range 1–8 days). At six weeks, 60% of the ID patients showed good adherence and 65% at six months, compared to 71% and 50% respectively in the control group. Mean CPAP use per night was equal in both groups both at six weeks (5 h in both groups) and six months (ID 6:30 h vs control 5 h ($p = 0.18$)). CPAP adherence correlated with baseline AHI in the control patients, but not in ID patients. There was no correlation between CPAP adherence and the level of ID or the degree of support at home.**Conclusions:** Using an intensive training protocol it is very well feasible to apply CPAP therapy in OSA patients with any degree of ID. CPAP adherence in ID patients was comparable to the control patients in this study as well as to previously published adherence numbers.

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1. Introduction

Obstructive sleep apnea (OSA) is a common disorder with an increasing prevalence over the last years. Recent data from the Wisconsin sleep cohort show prevalence rates of 3% in women and 10% in men between 30 and 50 years, increasing to 9% in women and 17% in men at an age of 50–70 years [1]. Obesity, hypotonia, craniofacial anomalies and relative macroglossia are among the factors that increase the risk of having OSA [2,3]. These factors lead

to a higher prevalence of OSA in people with an intellectual disability (ID). For example, in patients with Down syndrome OSA prevalence was shown to be 50–96% [4,5], whereas in patients with Prader Willi Syndrome, the prevalence of OSA is over 90% of whom 20% suffer from severe OSA [6].

Generally, OSA is treated with continuous positive airway pressure (CPAP), oral appliances, behavioral treatments such as weight loss or positional therapy, and in some cases surgical intervention. Although it is known that OSA can have a significant impact on daily functioning and quality of life of ID patients [4,7], studies on adherence and effectiveness of CPAP therapy in these patients have not been reported. In our experience, many physicians are reluctant to start CPAP treatment in ID patients because it is assumed that patients will not tolerate this treatment, or judge beforehand that the positive effects of treatment will not outweigh the burden of therapy. However, in our experience CPAP might be

Abbreviations: AHI, apnea hypopnea index; CPAP, continuous positive airway pressure; ID, intellectual disability; OSA, obstructive sleep apnea.

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feasible in ID patients as long as intensive guidance is provided at the start of therapy.

We developed an intensive treatment protocol to train caregivers in guiding CPAP use in order to facilitate acceptance. In this retrospective study we evaluated the results of this training protocol by studying the initiation of CPAP in 22 OSA patients with ID. We compared adherence at six weeks and six months to a group of age- and sex-matched OSA patients with normal cognitive functioning. We describe the methods used to reach optimal CPAP acceptance, in addition to the level of adherence and its influencing factors.

2. Materials and methods

2.1. Patient population

This study was performed at Kempenhaeghe, a tertiary referral center for sleep medicine in Heeze, the Netherlands. The study was approved by the local ethics committee. We performed a retrospective study including all OSA patients aged >18 years with ID in whom CPAP therapy was indicated, between January 2008 and November 2014. ID was defined as a significant limitation in intellectual functioning (IQ below 70) with limitations in conceptual, practical and/or social skills, originating from before the age of 18 years [8]. OSA was diagnosed based on polysomnography results, according to the ICSD2 criteria: apnea-hypopnea index (AHI) ≥ 5 /hour, combined with symptoms during the day [9]. Furthermore, we included a control group of age and sex matched OSA patients with normal cognitive functioning who were treated with CPAP, and randomly selected from the same time period. These patients were selected from our hospital electronic patients records, based on the diagnostic codes “obstructive sleep apnea syndrome” and “initiation of CPAP treatment.”

2.2. CPAP protocol

2.2.1. Patients with ID

At the start of CPAP therapy, an intensive training program was made available, in which the degree of intensity was adjusted to the needs of the patients. If there were doubts whether the patient would accept the CPAP mask, a mask and sometimes also the attached tube were taken home to practice. Caregivers were instructed to distract the patient, for instance, by applying the mask while sitting in front of the TV, and to gradually increase the time wearing the mask (without pressured air). Only when patients were capable of wearing the mask for a couple of minutes in bed, was CPAP therapy actually initiated. At that point, patients were admitted to the sleep center for a minimum of one and a maximum of eight nights (two times, four nights with the weekend in between spent at home). It was strongly encouraged to have a parent or caregiver accompanying the patient during the hospital stay, to learn how to aid the patient in using CPAP. During admission the patient and parent or caregiver were given individual education, including information on: sleep in general and sleep hygiene, about OSA, its pathophysiology, symptoms and the role of CPAP therapy, and the use and care of the CPAP machine and heated air humidifier. At night, patients were observed using an infrared camera system and every morning there was an evaluation of the mask acceptance and CPAP use by the sleep nurse and treating physician.

2.2.2. Control group

In patients without ID, CPAP therapy was initiated with a one-night stay at the sleep center. They were educated about sleep and OSA, use and care of the CPAP machine and heated air humidifier. After fitting the mask, they practiced in the presence of experienced staff during the evening and went to sleep with the

CPAP equipment. They were also observed on camera and helped with and stimulated to use CPAP if necessary during the night.

2.2.3. CPAP protocol after admission (both groups)

Optimal CPAP pressure was determined using an automatic positive airway pressure (APA) trial of two weeks at start of the treatment. The upper and lower pressure limits of the APAP device were determined using a prediction model [10]. After two weeks of APAP therapy, the median pressure used by the device was taken as the fixed pressure for subsequent CPAP therapy. Follow-up visits were scheduled after two weeks, six weeks and six months. During these visits, objective adherence data were obtained from the CPAP device. Between the visits patients or their parents/caregivers could contact the sleep nurse if they had any troubles or questions. After the first six weeks trial period, symptoms were evaluated and the decision was made whether or not to continue. A polysomnography or polygraphy was performed in all patients without ID if the decision was made to continue therapy to evaluate the effect of CPAP. In ID patients, the decision to perform a sleep study depended on the clinical improvement, the residual AHI as indicated by the CPAP device and the burden of a sleep study for the patient.

2.3. Data collection

Hospital records were reviewed and the following data were assembled: age, sex, body mass index, neck circumference, sleep habits, co-morbidities, level of impairment, cause of intellectual disability, parameters of the baseline and follow-up polysomnography (AHI, apnea index, oxygen desaturation index 4%). If patients did not start CPAP therapy despite having a clinical indication for CPAP therapy, the reason was noted. If CPAP was started, the following parameters were obtained: duration of practice with CPAP mask at home, duration of hospital admittance, type of interface, use of chinstrap, side effects and subjective improvement of symptoms, and – if applicable, – the reason to cease therapy. In addition, the following data were obtained in ID patients: type of housing situation, degree of guidance and/or supervision available at night, degree of support and assistance needed in using CPAP, degree of mobility getting in and out of bed, and the ability to put on or remove the mask. Objective adherence data were obtained from the CPAP device after one week, six weeks and six months. These data included the mean hour of daily use, the average number of nights per week CPAP was used, the pressure fork or fixed pressure, residual AHI and median mask leak.

2.4. Data analysis

The level of intellectual disability was graded according to intelligence quotient (IQ) or developmental age as mild (IQ 50–70 or 9–12 years), moderate (IQ 35–50 or 6–9 years), severe (IQ 20–35 or 3–5 years), and profound (IQ <20 or <3 years). Severity of OSA was graded according to AHI as mild 5–15/h; moderate 15–30/h; severe >30/h. The degree of support needed to apply CPAP therapy was defined as low when the mask could be put on and removed without help and the CPAP machine could be started without help, moderate if there was needed guidance with putting the mask on and/or off, high if the CPAP mask had to be put on and removed by someone else; very high if one-on-one guidance was needed to use the CPAP. Obesity was defined as a BMI ≥ 30 .

Data were analyzed using IBM SPSS statistics version 23 (IBM, New York, USA). Descriptive statistics were used to describe the subjects' characteristics. Good CPAP adherence was defined as >70% of the nights and a mean use of >4 h/night based on the report of the CPAP device of the last 30 days. The patients with good CPAP adherence were compared to those who did not reach good

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