

Online Table S5.2: CPAP/NIV adherence

Author	Country	Journal	Type of study	Number of patients	Ages	CPAP / NIV adherence results	Determinants of adherence
Waters et al. [1]	Australia	AJRCC M	Retrospective study	children with CPAP	< 15 yrs	63 (86%) continued to use CPAP after 6 m	Not specified
Marcus et al. [2]	USA	J Pediatr	Retrospective survey by questionnaires sent to centers	94 children	1 – 19 yrs	Good adherence defined by a use > 50% of prescribed hours CPAP unsuccessful in 1 patient 12/ 94 not adherent, in 50% attributed to the parents	
Massa et al. [3]	UK	Arch Dis Child	Retrospective study	49 children on long term CPAP	0- 19 yrs	Data on 42/49 children: Good adherence (use every night during whole night by parents) in 68%	Not specified
Koontz et al. [4]	USA	Sleep	Retrospective study in CPAP non adherent children	12 Behavior therapy (BT) 6 Behavior consultation (BC) 3 None (refusal)	1-15 yrs	Significant improvement in adherence in the BT (8.55h/night) and BS (8.58h/night) groups vs the None group (0.67h/night)	Behavior therapy improves adherence
Marcus et al. [5]	USA	Pediatrics	Prospective study, CPAP vs BPAP	29 children	2-16 yrs	1/3 dropped out < 6 m Mean adherence at 6 m 5.3 ± 2.5 h/night	No difference between CPAP and BPAP
O'Donnelle et al. [6]	Canada	Sleep	Retrospective study	Data on 50/71 children treated with CPAP	10 ± 5 yrs	Mean use 4.7h/night Mean use on night with CPAP 6.3h/night	
Uong et al. [7]	USA	Pediatrics	Retrospective study	46 children, data available for 27 (59%)	7-19 yrs	Mean adherence 7 h/night, 73% of week 85% used CPAP > 4h/night	Greater improvement in AHI associated with a better adherence No difference CPAP vs BPAP

Nixon et al. [8]	USA	J Pediatr	Retrospective study	32 children	9.1 ± 5.3 yrs	Mean CPAP use 4.7 ± 2.7h/night Consistent users defined by CPAP use > 1h on > 6 nights/week: 10 (33%)	The number of hours of CPAP use during the 2 nd night (and 1 st week) was predictive of the use at 2 and 3 m
Beebe et al. [9]	USA	Plos One	Prospective study	13 obese adolescents	14.8 ± 1.8 yrs	Adherence defined by a night use > 21% of sleep time 6 were adherent, 7 not	Improved attention and academic function in the adherent vs the non-adherent patients
Marcus et al. [10]	USA	J Clin Sleep Med	Prospective study	56 children randomized to CPAP or BPAP	12 ± 4 yrs	No difference in adherence between CPAP and BPAP: 24 ± 6 vs 22 ± 9 nights/m and 201 ± 135 vs 185 ± 165 min/night	No difference in adherence between CPAP and BPAP
Marcus et al. [11]	USA	AJRCC M	Prospective study	52 children with OSA	12 ± 4 yrs	Mean use 170 ± 145 min/night at M3	
Simon et al. [12]	USA	Sleep Med	Prospective study	51 children treated with CPAP (46%), BPAP (6%), auto-CPAP (48%)	8-17 yrs	Mean adherence 3.4 ± 2.8 h/night, 41% of nights with a use > 4h	The usefulness of the ABCQ (Adherence Barriers to CPAP Questionnaire) questionnaire is demonstrated: useful clinic-based tool for identifying patient-specific issues with CPAP-adherence
DiFeo et al. [13]	USA	J Clin Sleep Med	Prospective study	56 children and parents completed a questionnaire before CPAP initiation	?	Mean use 3 ± 3h/night	Greatest predictor of adherence: maternal education Adherence lower in Afro-Americans Inverse correlation with age Correlation with family social support
Nathan et al. [14]	Singapore	Singapore Med J	Retrospective study	51 children on home CPAP/BPAP	Median age 11.5 yrs	Adherence defined by a reported use ≥ 4 nights/week 21/51 (41%) were compliant	Predictors of adherence (by logistic regression): female gender, presence of asthma
Prashad et	USA	J Clin	Semi-	21 adolescents	12-18 yrs	7 good adherence (381 ±	Predictors of adherence: degree

al. [15]		Sleep Med	structured interviews ado and caregivers	and 20 caregivers (17 mothers)		80min/night), 7 low use (30 ± 24 min/night) and 7 no use	of structure at home, social reactions, mode of communication among family members, perception of CPAP benefits
Jambhekar et al. [16]	USA	Respir Care	Prospective study: adherence at baseline and after a respiratory therapist intervention	46 children	11-18 yrs	12 (26%) baseline adherence 0%, 12 (26%) baseline adherence 0-50% of nights, 22 (48%) baseline adherence > 50% of nights (> 4 hours/night) Significant improvement (+22-24%) in adherence in children using CPAP < 50% of nights	An (1) extensive therapeutic education session performed by a skilled respiratory therapist in pediatric CPAP improves the objective adherence in children using CPAP < 50% of nights.
Ramirez et al. [17]	France	Sleep Med	Retrospective study	62 children treated with CPAP or NIV	2-18 yrs	Mean adherence 8h17 \pm 2h30/night, 72% used CPAP/NIV > 8h/night, Mean number of nights with use 26 ± 5 nights/m	No effect of mode (CPAP vs NIV), age, interface, duration of CPAP/NIV
Ennis et al. [18]	Canada	J Clin Sleep Med	Semi-structured interviews in children and caregivers	7 dyads of youth-caregiver (4 NMD, 3 obesity) + 2 caregivers	> 12 yrs	Children treated with BPAP: mean use 6.04 ± 3.47 min/night (range 0.53-11.10min/night)	Better adherence when: previous encouraging experiences with therapy, subjective symptom improvement, familiarity with medical treatments, understanding of nocturnal hypoventilation and its consequences, family and health-care team support, early adaptation to treatment Poorer adherence when: previous negative experiences with therapy, negative attitude towards therapy, difficulty

							adapting, lack of support from family and health-care team, fear-embarrassment regarding treatment, technical issues, side effects, lack of subjective symptom improvement
Hawkins et al. [19]	USA	J Clin Sleep Med	Retrospective analysis of objective adherence over 1 yr	140 children	12 ± 5.7 yrs	Good adherence: > 4h/nights > 70% nights. 69/140 (49%) good adherence: 7.4 ± 1.9h/night, 94 ± 0.8% of nights	Adherence is poor: female sex and developmental delay are associated with a better compliance No effect of AHI, residual AHI, CPAP pressure, age; ethnicity, insurance status
Adeleye et al. [20]	Canada	Canadian Respir J	Retrospective study	92 infants < 12 m with PSG, 49 were prescribed CPAP	1-12 m	Objective adherence in 20/49: 25% of days with > 4h/use per night	Of the 92 infants (no details on those treated with CPAP), 35 Down syndrome, 9 prematurity, 9 Pierre Robin Sequence, 3 pulmonary hypertension, 6 achondroplasia, 2 Prader Willi syndrome, 2 genetic disease + 25 other
Machaalani et al. [21]	Australia	Sleep & Breathing	Routine clinical care over 2 yrs	55 children treated with CPAP and 44 with BPAP	0.4-18 yrs	Adequate adherence > 4h/night > 70% of nights Adequate adherence in 75% of CPAP and 91% of BPAP users	Better adherence with BPAP than CPAP, adherence maintained over time
Puri et al. [22]	USA	J Clin Sleep Med	Retrospective chart review	56 children treated with CPAP	1.6-18 yrs	Mean adherence at 3 m: 2.8 ± 2.4h/night	Better adherence in children with a family member using CPAP (3.6 ± 0.6h/night on all nights and 4.8 ± 0.6 on nights used)
Xanthopoulos et al.	USA	Sleep	Prospective study	Questionnaire given at CPAP	4 m-18 yrs	Pediatric modification of the Self-Efficacy Measure for Sleep	Adherence correlated to caregiver-reported self-efficacy

[23]				initiation to 59 children and 138 caregivers		Apnea questionnaire given to children treated with CPAP and their caregiver	(p=0.007)
Ai-Iede et al. [24]	Australia	Sleep Med	Retrospective study	148 children using CPAP at home for non OSA		Adherence 116/130 (89%) > 4h/night	65 primary airway disease 33 chronic lung disease, 32 congenital heart disease, 5 congenital diaphragmatic hernia, 4 interstitial lung disease No details on those < 24 m Mean CPAP 7.3 cmH2O Follow up: telephone call, cardiorespiratory monitoring (?) at 2 weeks, CPAP titration PSG after 3-6 m 30% stopped CPAP during a 15 m follow up (various reasons)
Amaddeo et al. [25]	France	Pediatr Pulmonol	Retrospective study	31 children started on CPAP in an out-patient setting	0.8 -16.8 yrs	4 (3 T21) not adherent, for the others: median compliance 8h21min/night, median of 25 nights/m	3 patients weaned from CPAP
Trucco et al. [26]	UK	Pediatr Pulmonol	Retrospective study	60 children with Down syndrome, 42 had SDB, 18 started on CPAP + 7 on NIV, rest on oxygen	0.7 -5.3 yrs	After 1.9 yrs, 11/24 had satisfactory adherence to CPAP/NIV (average 8h/night)	2 children weaned from CPAP and 1 switched to NIV
Perriol et al. [27]	France	Sleep & Breathing	Observational cohort	78 children with OSA type I on home	10.4 ± 3.4 yrs	Mean CPAP adherence at 1, 3, 6, 12, 24 m was 6.1 ± 2.8h, 6.2 ± 2.6h, 6.2 ± 2.8h, 6.3 ± 2.8h, and	No significant predictor of adherence

		ng		CPAP		7.0 ± 2.7 h	
Pascoe et al. [28]	USA	Pediatr Pulmonol		42 boys with Duchenne muscular dystrophy	mean age 15.1 ± 20.2 yrs	% days NIV use: 56 ± 39% % days with a use > 4h: 46 ± 41% Average use 5.6 ± 4.2h/night	Better compliance with high AHI at baseline and change vital capacity from baseline Adherence barriers: internalizing problems (anxiety, depression)
Mendoza-Ruiz et al. [29]	France	Sleep Med	Prospective study	6 CPAP non-adherent children	5 ± 5 yrs	Use of a table based on token economy, adherence evaluated after 1 month	Mean adherence improved from 1 ± 0.33h/night to 4h31 ± 1h12 at 1 m A token economy table is effective
Bergeron et al. [30]	USA	Laryngoscope	Prospective single-blind randomized controlled trial	Shared Decision-Making Tools given at CPAP start to 24 families + 26 controls	6.9-10.6 yrs	Adequate adherence = > 4h/night	Use of SDMT associated with a better adherence 57% for study patients vs 27% of controls.
Kang et al. [31]	USA	J Clin Sleep Med	Retrospective study	103 children with developmental disability (DD) and 137 typically developing (TD) children treated with CPAP	~3.2-16.1 yrs	% of nights use was higher in DD children at 3 m (86.7 vs 62.9) and 6 m (90 vs 70.7) vs TD Hours of usage at night was similar: (5 vs 4.6) at 3 m and at 6 m (6.4 vs 5.7) for DD vs TD, respectively	% of nights use was higher in DD children at 3 and 6 m Hours of usage on nights used at 3 and 6 m were similar Adherence improved in both groups over time Higher income and titration at or before 6 m were associated with a better adherence

Abbreviations: m: months, yrs: years, CPAP: continuous positive airway pressure, BPAP: bilevel positive airway pressure, NIV: noninvasive ventilation, OSA: obstructive sleep apnea, NMD: neuromuscular disease, SDB: sleep disordered breathing, AHI: apnea-hypopnea index.

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