Online Table S5.1: Follow up of CPAP and NIV

Author	Country	Journal	Type of study	Number of patients	Ages	Follow up and outcome
Tan et al. [1]	Australia	J Pediatr Child Health	Retrospective study	61 sleep studies in 45 children: 29 CPAP, 14 BPAP, 2 tracheotomy	0.4 - 18.6 yrs	Children on CPAP/NIV > 3 m, stable condition, 1/3 PSG, 2/3 PG 51% of children had a sleep study in the previous 6 m 40 (61%) studies resulted in a change of setting: 12 increase in CPAP, 12 increase in BPAP, 1 decrease in CPAP, 4 decrease in BPAP, 2 discontinuation of CPAP, 8 need to continue CPAP (no weaning) Necessity of systematic PSG/PG in children treated with CPAP/NIV
Paiva et al. [2]	France	Intensive Care Med	Retrospective study	50 children treated with NIV (40) or CPAP (10): 23 NMD, 2 lung, 23 upper airway disease	8.5 ± 5.2 yrs	Routine follow up, none of the patients had SDB symptoms Overnight SpO_2 + $PtcCO_2$ with CPAP/NIV: 21 (42%) had a nocturnal $PtcCO_2 \geq 50$ mmHg ≥ 10% recording time or ≥ 5 continuous min, 18/21 had normal daytime PCO_2, and all had a nocturnal $SpO_2 > 90\%$ Necessity of systematic overnight $PtcCO_2$ recording during CPAP/NIV
Felemban et al. [3]	France	Pediatr Pulmonol	Prospective study	24 children treated with NIV: 11 NMD, 3 lung disease, 9 upper airway anomaly, 1 central hypoventilation	4 -19 yrs	29 pairs of home/hospital overnight SpO_2 + $PtcCO_2$ recordings/24 pts Feasibility: 1 SpO_2 failure in hospital Results similar between home vs hospital at lower cost Value of a home overnight SpO_2 + $PtcCO_2$ recording during NIV with trained technicians (home care provider)
Griffon et al. [4]	France	Respir Care	Retrospective study	79 children treated with NIV/CPAP/HFNC	1.5-14 yrs	Routine follow up, none of the patients had SDB symptoms Overnight SpO_2 + $PtcCO_2$ with NIV (n=52, 47%), CPAP (n=43, 39%), HFNC (n=2, 2%) or spontaneous breathing (n=13, 12%) Quality of recording excellent in 81%, more $PtcCO_2$ failures > SpO_2 failures

						11 abnormal recordings in 11 patients: 6 hypercapnia, 3 hypocapnia, 2 hypoxemia, corrected by change in settings/equipment Value of a home overnight SpO_2 + $PtcCO_2$ recording during NIV follow up with trained technicians (home care provider)
Caldarelli et al. [5]	France	Intensive Care Med	Prospective study	39 children treated with NIV: 13 NMD, 15 OSA and 11 lung disease	1 – 18 yrs	Systematic PG during NIV in stable NIV patients Unintentional leaks, patient ventilator asynchronies, decrease in ventilatory drive, upper airway obstruction with or without reduction of ventilatory drive, and mixed events were observed in 27%, 33%, 10%, 11%, 12%, and 3% of the patients, respectively. A predominant respiratory event was observed in all patients. Mean duration spent with respiratory events was 32±30% (range 3 to 96%) of total recording time. Unintentional leaks were the most frequently associated with AA whereas patient ventilator asynchronies were rarely associated with AA or 3% desaturation.
Widger et al. [6]		Sleep & Breathing	Retrospective study	25 children on CPAP, 17 on BPAP	11 ± 6 yrs	2 pairs of titration studies: 41 CPAP + 30 BPAP Changes in settings recommended in 27/41 (65%) of CPAP studies and 11/30 (36%) BPAP studies Changes were implemented by physicians in 55% of cases Titration studies led frequently to changes in settings
Amaddeo et al. [7]	France	Sleep Med	Prospective study	26 children treated with CPAP	7.8±6.2 yrs	Systematic PG during CPAP (use 10.6±14.4 m) in stable patients. Median index of total respiratory events 1.4/h (range 0-34). Mean number of different types of respiratory events per PG was 2±1 (range 0-4), with always a predominant event. Partial or total upper airway obstruction without decrease in ventilatory drive was the most frequent event and was the most frequently associated with an oxygen desaturation (in 30% of the events) and an AA (in 55% of the events).
Khirani et al. [8]	France	Sleep Med	Comparison of AHI scoring	15 children treated with CPAP	1.5-18.6 yrs	Comparison of scoring of AHI on -built-in software of a CPAP device (Resmed) + integrated SpO_2: automatic analysis and manual scoring on a breath-by breath analysis

			on the built-in software and a PG			-PG during CPAP in hospital Strong correlation between the AHI scored on a manual analysis of built-in software and a PG: useful for cheap and simple follow up
Al Iede et al. [9]	Australia	Sleep Med	Retrospective study	148 children started on CPAP	1 week-16.8 yrs	65 primary airway disease, 33 chronic lung disease (18 BPD), 20 CHD, 12 CHD + airway anomaly, 5 congenital diaphragmatic hernia, 4 interstitial lung disease Mean CPAP 7.3 cmH_2O 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)
Liu et al. [10]	China	Sleep & Breathing	3 case reports	3 children	2 m - 5 yrs	1 OSA + PHT (CPAP), 1 Pierre Robin Sequence (BPAP), 1 laryngomalacia Home monitoring with TELETREK: home base remote monitoring system via telephone that records SpO_2, heart rate, CPAP use, leaks
Zhou et al. [11]	China	Int J Pediatr Otorhinolaryngol	Retrospective study 2009 - 2011	17 patients:	1 m - 12 yrs	TM: no details on what data is transmitted: ventilator data (pressure, leaks). Remote monitoring system activated by parents. Parents uploaded the data on 93.3% of days. No system or device failure Less time to upload the data (5.7 ± 3.1 min) compared to the travel time to hospital (371 ± 182 min) Cost was 59% lower than a hospital visit System convenient and easy to use for > 80% of parents
Trucco et al. [12]	Italy	J Telemed Telecare	2-year longitudinal multicentre TM trial	48 children with NMD + controls without TM	median 16.4 yrs (8.9-22.1)	TM trial protocol: patients' weekly overnight home-recording of SpO_2, heart rate and ventilation with transmission to each TM centre the following morning. Overnight data were reviewed by non-physicians and calls to families made to assess clinical condition. If necessary, unscheduled transmissions or calls were activated and managed by non-physicians or medical team according to severity Exacerbations in TM patients did not differ (59 versus 53; $p = 0.15$)

						from controls. Hospitalisations were reduced in TM patients when compared with those prior to TM (11 versus 24, $p = 0.04$) and to controls (11 versus 21, $p = 0.03$). Median hospitalisation length was lower in TM patients than controls (6 versus 7 days, $p = 0.03$). Caregivers satisfaction was excellent with no changes in Caregiver Burden Inventory
Casavant et al. [13]	USA	J Telemed and Telecare	9-m prospective study	14 patients (children and adults) with BIPAP or ventilated through tracheostomy: NMD, lung diseases + other	16 m - 35 yrs	Families completed questionnaires about clinical management before the addition of TM and 2–3 months after they had used TM Families reported higher confidence in clinical care with TM compared to telephone. The TM encounters supported clinical decision-making, especially in patients with active clinical problems or when the patient was acutely ill. The TM encounters prevented the need for 23 clinic visits, 3 emergency room visits, and probably 1 hospital admission.
Perrem et al. [14]	Canada	Pediatr Pulmonol	Review of the NIV device data reports to guide clinical care			This review provides a structured approach to the interpretation of CPAP/NIV device data reports to augment the clinical management of pediatric sleep-disordered breathing. It provided an overview of the data available from devices and their interpretation such as: check the settings, adherence and usage patterns, leak, treatment efficacy; for BPAP only: check that the back-up-rate is optimized; whether the inspiratory time settings are optimized for comfort and efficacy; BPAP is synchronous with patient respiratory effort; adherence and AHI in presence of optional pressure relief setting.

Abbreviations: m: months, NIV: noninvasive ventilation, CPAP: continuous positive airway pressure, BPAP: bilevel positive airway pressure, HFNC: high flow nasal cannula, NMD: neuromuscular disease, OSA: obstructive sleep apnea, CHD: congenital heart disease, BPD: bronchopulmonary dysplasia, PSG: polysomnography, PG: respiratory polygraphy, AHI: apnea-hypopnea index, AA: autonomic arousal, SDB: sleep disordered breathing, SpO_2: pulse oximetry, $PtcCO_2$: transcutaneous carbon dioxide pressure, TM: telemonitoring.

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