

Online Table S11: Therapeutic education programs for CPAP and NIV.

Author	Country	Journal	Type of study	Number of patients	Ages	Therapeutic education program	Evaluation, efficacy
Hewitt-Taylor [1]	UK	Intensive Crit Care Nursing	Survey questionnaire, descriptive study on local practice	21/35 centers responded	Not specified	Areas that were seen as important for children with complex diseases requiring CPAP or NIV are discussed Role of trained nurses A variety of health care professionals are needed	
Tibbals et al. [2]	Australia	J Ped Child Health	Longitudinal survey (1979-2008) in one center in Melbourne	168 patients	3 weeks – 19 yrs	Patients are considered early for discharge, condition must be stable, parents must be motivated. Nurses and technologists teach the parents/carers in the PICU and the ward. Social workers act as case managers in the home. Parents are trained to cope with predictable instability at home. A full set of equipment for ventilation, suctioning and monitoring (SpO ₂) with disposable items is provided. Children requiring 24-h ventilation have a spare ventilator at home	No information on eventual discharge failures
Boroughs et al. [3]	USA	Children		11 children with SMA, 6 on BPAP	6 m-18 yrs	Evaluation of caregiver skills via simulated scenario, corrections with re-evaluation after 3 and 6 m.	Training beneficial for all participants Desire for real-life scenarios Value of an on-going training for caregivers
Amaddeo et al. [4]	France	Pediatric Pulmonology	Prospective study:	31 children	0.8 - 17.5 yrs	Description of the therapeutic education program and tools: educational boards and	Compliance was excellent: mean

		1	outpatient program for CPAP initiation			cartoons, booklet, teddy bear, relaxation, distraction, follow up at home, home visits, etc.	use 8h21/night (5h45-12h20); % of night with use > 4h: $83 \pm 17\%$, median nights use/m: 25 (18-30)
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Abbreviations: m: months, yrs: years, BPAP: bilevel positive airway pressure, PICU: pediatric intensive care unit, SpO₂: pulse oximetry, SMA: spinal muscular atrophy.

References

1. Hewitt-Taylor J. Children who require long-term ventilation: staff education and training. *Intensive Crit Care Nurs* 2004; 20: 93-102.
2. Tibballs J, Henning R, Robertson CF, *et al.* A home respiratory support programme for children by parents and layperson carers. *J Paediatr Child Health* 2010; 46: 57-62.
3. Boroughs DS. An evaluation of a continuing education program for family caregivers of ventilator-dependent children with Spinal Muscular Atrophy (SMA). *Children (Basel)* 2017; 4: 33.
4. Amaddeo A, Frapin A, Touil S, *et al.* Outpatient initiation of long-term continuous positive airway pressure in children. *Pediatr Pulmonol* 2018; 53: 1422-1428.