Online Table S8: Role of CPAP and NIV in palliative care

Author, year	Country	Journal	Type of study	Number of patients	Ages	Palliative care
Chatwin et al. [1]	UK	Arch Dis Child	Retrospective study	13 SMA I	4 – 24 m	All treated with NIV + MI-E NIV used for palliation of symptoms in 4 patients
Chong et al. [2]	Malaysia	Singapore Med J	Retrospective of children referred to a hospital inMalaysia for palliative care	137 patients 72% malignancies 80% died at home	2-250 m	CPAP in 5 children (without details on diseases)
Kherani et al [3]	Canada	Pediatr Pulmonol	Retrospective study on all infants < 1 yr treated with long term IV and NIV in Sick Kids (Toronto) between 1991-2014	51 infants 25 NIV: 14 musculosketal, 8 deaths	< 1 yr	8/25 deaths in the NIV patients, in 4 infants, NIV was used as a palliative treatment
Tabone et al. [4]	France	Am J Med Gen A	Retrospective study	7 children with mucolipidosis	0.3-17.4 yrs	All patients were treated with CPAP or NIV, one patient had NIV as part of palliative care (2 have died since)

Abbreviations: m: months, yrs: years, CPAP: continuous positive airway pressure, NIV: noninvasive ventilation, IV: invasive ventilation, SMA: spinal muscular atrophy, MI-E: mechanical insufflation-exsufflation

## References

- 1. Chatwin M, Bush A, Simonds AK. Outcome of goal-directed non-invasive ventilation and mechanical insufflation/exsufflation in spinal muscular atrophy type I. *Arch Dis Child* 2011; 96: 426-432.
- 2. Chong LA, Khalid F. Paediatric palliative care at home: a single centre's experience. Singapore Med J 2016; 57: 77-80.

- 3. Kherani T, Sayal A, Al-Saleh S, *et al.* A comparison of invasive and noninvasive ventilation in children less than 1 year of age: A long-term follow-up study. *Pediatr Pulmonol* 2016; 51: 189-195.
- 4. Tabone L, Caillaud C, Amaddeo A, et al. Sleep-disordered breathing in children with mucolipidosis. Am J Med Genet A 2019; 179: 1196-1204.