Adherence to Home Long Term Non-Invasive Ventilation in Children

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Introduction

Home long term non-invasive ventilation (NIV) is increasingly used to treat a range of paediatric conditions. Until recently our hospital relied on parental reporting to assess NIV adherence. However newer machines can store and download usage data.

Aim

We aimed to objectively assess the adherence of our patients to NIV and compare parent reported NIV usage with that from machine downloads.

Methods

The parents of 62 children (Table 1) who were admitted to the Children's Sleep and Ventilation Unit from March 2014 to March 2015 for follow up sleep studies were asked to complete a questionnaire. Questions included how many nights their child had used the machine in the past week and number of hours used each night. Their responses were compared to the machine data.

Results

15 (24%) of parents over reported whilst 3 (5%) under reported the number of nights their child had used NIV the preceding week. The actual mean number of hours used per night correlated well with the number of hours NIV was reported to be used ($p<0.0001$, $r^2=0.6$). However, parents tend to slightly overestimate the time spent on NIV (Figure 1).

Children on NIV for nocturnal hypoventilation (NH, comprising 22 patients with neuromuscular disease, 4 with central apnoeas and 6 with other causes of nocturnal hypoventilation) were more adherent than children on respiratory support for obstructive sleep apnoea (OSA, 30 patients). When good adherence was defined as average daily use >4h, 23/32 (72%) children on NIV for NH had good adherence, compared with 14/30 (47%) of children on respiratory support for OSA.

Conclusion

Some parents over report the NIV usage of their children. We need to improve adherence in around 30% of children with nocturnal hypoventilation and around 50% of children with OSA on NIV in our patient population.

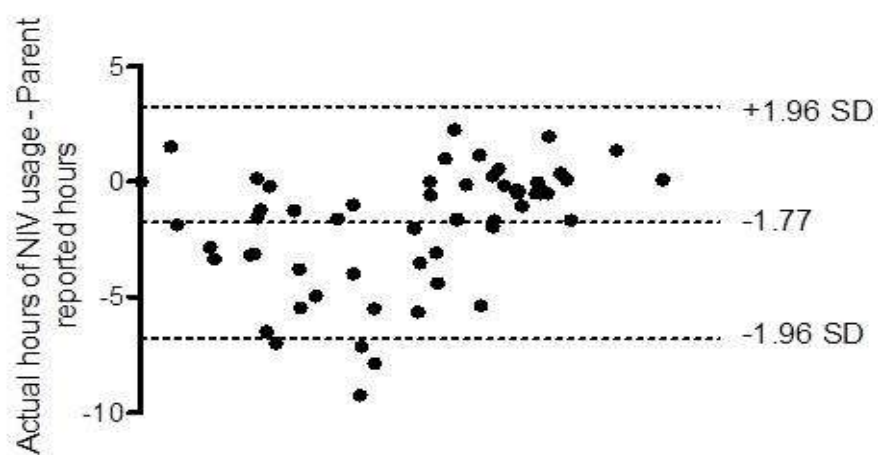| Patient Demographics	
Sex (male:female)	39:23 (63%:37%)
Age (mean (SD; Range))	9 (+/- 4.7; range 1.2-16.7) yrs
Mode of Ventilation (BiPAP:CPAP)	44:18 (71%:29%)
Diagnosis (OSA:NH)	30:32 (48%:52%)

Table 1: Patient Demographics

Figure 1: Bland Altman plot depicting actual hours of NIV use minus parent reported hours.