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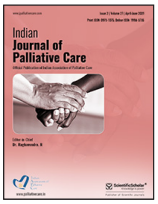

Original Article

Short-term Non-invasive Ventilation for Children with Palliative Care Needs

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ABSTRACT

Objectives: Non-invasive ventilation (NIV), namely continuous positive airway pressure (CPAP) and bi-level positive airway pressure (BiPAP), delivers mechanical ventilation without endotracheal intubation. Short-term NIV (planned for <21 days during initiation) can be used for the management of acute respiratory distress (ARD) among paediatric palliative patients with "Do Not Resuscitate or Intubate" (DNI) as the ceiling of care. This study aimed to describe the usage of short-term NIV among paediatric palliative patients in a woman and child hospital with a paediatric palliative subspecialty.

Materials and Methods: A retrospective and observational study was conducted on all paediatric palliative patients who received short-term NIV in Tunku Azizah Hospital Kuala Lumpur, Malaysia, from March 2020 to May 2022.

Results: During the study period, short-term NIV was offered on 23 occasions for 20 different children. Indications for short-term NIV include 16 (69.6%) occasions of potentially reversible ARD (NIV Category 1) and 7 (30.4%) occasions of comfort care at the end of life (NIV Category 2). The main cause of ARD was pneumonia (90.3%) due to either aspiration or infection. The modality of NIV used was BiPAP only (14 occasions, 60.9%), CPAP only (three occasions, 13%) and both BiPAP and CPAP (six occasions, 26.1%). The median duration of NIV usage was four days (minimum one day and maximum 15 days). NIV was initiated as an escalation from nasal prong, Ventimask or high-flow mask oxygen on 22 occasions and as weaning down post-extubation on one occasion. For the 22 occasions of escalating therapy, there was significant improvement at six hours compared to pre-NIV in the median heart rate (136 to 121, P=0.002), respiratory rate (40 to 31, P=0.002) and oxygen saturation (96% to 99%, P=0.025). All 17 documented parental impressions of the child's condition post six hours of NIV were that the child had improved. Adverse events during short-term NIV include five episodes (21.7%) of stomach distension, four episodes (17.4%) of skin sores on the face and one episode (4.3%) of excessive drooling. Three patients passed away while on NIV in the hospital. For the other 20 (87%) occasions, patients were able to wean off NIV. Post-weaning off NIV, three patients passed away during the same admission. On 17 occasions, patients were discharged home after weaning off NIV.

Conclusion: Usage of short-term NIV in paediatric palliative care, where children have an advanced directive in place indicating DNI, as seen in our study, can be a valuable modality of management for distressing symptoms, in addition to the pharmacological management of breathlessness. This is shown through our study to be of benefit in potentially reversible ARD as well as comfort care at the end of life. Further rigorous studies will need to be conducted for a clearer understanding of short-term NIV that would enable the formulation of guidelines to improve the quality of life and death in children.

Keywords: Paediatric, Palliative, Non-invasive ventilation, Temporary, Respiratory insufficiency

INTRODUCTION

Mechanical ventilation minimises the work of breathing and improves gas exchange, assisting the body in meeting its metabolic demands. Non-invasive ventilation (NIV), namely continuous positive airway pressure (CPAP) and bi-level positive airway pressure (BIPAP) delivers mechanical ventilation without requiring endotracheal intubation.[1] Globally, NIV is increasingly used in children.[2,3] It is indicated for long-term use (more than 21 days) in a wide range of disorders that can cause increased respiratory load, decreased performance of respiratory muscles or dysfunction of central drive.[4-7]

In the adult population, NIV is used as a palliative strategy in conditions when it is deemed inappropriate to perform endotracheal ventilation or when patients have a "do not intubate" order.[8] Indications for short-term NIV are as life support with limits intended to restore pre-admission health status or for comfort measures only.[9]

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In Tunku Azizah Hospital Kuala Lumpur, a woman and child hospital in Kuala Lumpur, the Paediatric Palliative and Supportive Care (PPSC) unit has been providing short-term palliative NIV support to children since the year 2020. There is no standard definition for short-term duration. Based on the long-term definition being more than 21 days, the institution defined short-term NIV as the provision of NIV initially planned for a duration of not more than 21 days during the initiation of NIV.

There is limited information on the usage of short-term NIV in paediatric palliative patients presenting with acute respiratory distress (ARD) or respiratory failure. This study was conducted to describe the usage of short-term NIV in a paediatric palliative setting.

MATERIALS AND METHODS

A retrospective and observational study was conducted on all paediatric palliative patients who received short-term NIV in Tunku Azizah Hospital, Malaysia, from 1 March 2020 to 31 May 2022. The study was approved with a waiver of consent by the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (NMRR ID-22-01374-IPP) on 16 August 2022. There was no conflict of interest.

All inpatient children under paediatric palliative care who received palliative NIV support were reviewed. Children who were on long-term NIV (decided to provide for more than 21 days) were excluded from the study.

Information on demographic data, clinical information, NIV usage and NIV outcome were collected from the case notes. Clinician and parental impressions of the child's improvement six hours post-NIV initiation were collected if it was documented in the case notes following the institution's operating procedure. Monitoring as per hospital protocol is after NIV initiation and every 4–6 hours until cessation of NIV. Hence, six hours was chosen as the time for review.

Short-term NIV For paediatric palliative patients

The PPSC unit of Tunku Azizah Hospital offers NIV support for children with life-limiting illnesses who develop ARD. The NIV support can be initiated in the emergency department or the paediatric wards. A standard operating procedure guides the whole process, including selection criteria, NIV provision (initiation, maintenance, weaning and stopping) and patient monitoring (effectiveness and complications). All ward staff, especially the nurses, have to be briefed and trained on the protocols and monitoring methods before starting these services.

Before starting palliative NIV, there are a few principal criteria that must be fulfilled. First, the patient, parent and primary health team have discussed and agreed that the option "Do Not Resuscitate or Intubate" (DNI) is the ceiling of care according to the advanced care plan from before this current episode. Advanced care plans are rediscussed every 6–12 months. Second, verbal or written consent has been taken from the parents, with a proper explanation of the indication and side effects of NIV. Finally, the staff nurses and doctors in the paediatric ward must be educated on the usage of NIV and be comfortable with monitoring patients on NIV.

Two main indications for palliative NIV are differences between the selection of NIV modality and monitoring. They are for potentially reversible ARD (NIV Category 1) or for symptom management and comfort measures at the end of life (NIV Category 2).

NIV Category 1 consists of patients with "Do Not Resuscitate or Intubate" (DNI) as their ceiling of care who present to the hospital with acute respiratory failure due to conditions such as pneumonia and heart failure. The provision of NIV for NIV Category 1 functions as an alternative to providing invasive endotracheal ventilation. NIV is provided to improve oxygenation and ventilation. The NIV modality of choice would be BiPAP with the nasal mask with good interface sealing for at least the first 24 hours. The patient would be monitored for improvement in dyspnoea and work of breathing. If there is intolerance to NIV or worsening of respiratory failure after one hour of NIV, changing to comfort measures and palliation of symptoms without NIV is considered. If there is improved oxygenation and ventilation after 24 hours, the NIV is progressively weaned down.

NIV Category 2 consists of patients with end-stage respiratory failure, such as patients with severe lung metastasis of cancer, end-stage renal failure with pulmonary oedema or withdrawal from invasive ventilation support during the end of life. NIV is provided for symptom relief and comfort. CPAP with the nasal mask is the preferred modality. BIPAP is considered if NIV is given on extubation from the paediatric intensive care unit. Comfort and NIV tolerance are prioritised for this indication. The patient is monitored for comfort and reduction in dyspnoea or breathing effort. For patients intolerant to NIV, palliative measures without NIV are considered. If improvement of symptoms is noted, consideration to wean down the NIV settings is done after 24 hours.

For both categories, vital signs and adverse events are monitored one h after NIV initiation and every 4–6 h until cessation of NIV.

Statistical analysis

All data were collected and analysed using Microsoft Excel. Results were presented as frequencies and percentages for categorical variables and as median (minimum and maximum) for continuous variables. Wilcoxon ranked sum test was performed for analysis of non-parametric data.

RESULTS

During the 26-month study period, short-term NIV was offered on 23 occasions for 20 different children. Three children had received short-term NIV during two separate admissions. Table 1 shows the demographic characteristics of

the 20 patients recruited in the study. Half of the patients who received short-term NIV were from the paediatric neurology team. Ages ranged from 2 months up to 18 years old, with a median of 6 years old.

Table 2 describes the details of NIV provided. Most of the patients (69.6%) were started on NIV for potentially reversible ARD. The main cause of ARD leading to NIV use was pneumonia (90.3%) due to either aspiration or infection. BIPAP was used in 87% of cases. The median duration of NIV usage was four days (1, 15).

Table 1: Demographic details of paediatric palliative patients receiving short-term non-invasive ventilation (*n*=20).

	Frequency	Percentage
Malaysian	20	100
Gender		
Male	10	50
Female	10	50
Race		
Malay	19	95
Dusun	1	5
Primary team		
Paediatric Neurology	10	50
General Paediatrics	3	15
Paediatric Cardiology	3	15
Paediatric Oncology	2	10
Paediatric Nephrology	1	5
Paediatric Gastroenterology	1	5

NIV was initiated as an escalation from nasal prong, Ventimask or high-flow mask oxygen on 22 occasions and as weaning down post-extubation on one occasion. Table 3 shows that for the 22 occasions of escalating therapy, there was significant improvement at six hours compared to pre-NIV in the median heart rate, respiratory rate and oxygen saturation.

Concurrent medications given include intravenous infusion (IVI) midazolam (4 cases), glycopyronium (1 case), morphine (3 oral, 1 IVI), chloral hydrate (7 cases), haloperidol (1 case) and clonidine (1 case).

There were only 22 entries of clinician impressions and 17 entries of parental impressions of the child's condition post six hours of NIV. All documented impressions were that the child had improved after starting NIV.

There were two cases of failed NIV. One child had desaturation with hypersecretions, and the NIV was discontinued after 24 hours. She was able to be discharged home after one week. The other child did not have reversibility of respiratory distress because he was in the end-of-life phase. However, the symptom burden was reduced after starting NIV, and thus, NIV was continued until he passed on.

The main complications noted were stomach distension ($n = 5$) and skin lesions ($n = 4$). Overall, three patients passed away while still on NIV in the hospital. Patients were able to successfully wean off NIV on the remainder 20 (87%) occasions.

Table 2: Description of NIV provision for paediatric palliative patients (*n*=23).

	Frequency	Percentage
Indication for NIV		
Cat 1 – Potentially reversible acute respiratory distress	16	69.6
Cat 2 – comfort care at end of life	7	30.4
Cause of acute respiratory distress		
Aspiration pneumonia	10	43.5
Pneumonia (due to RSV, COVID and unspecified)	11	47.8
Sleep hypoventilation	1	4.3
Acute pulmonary oedema	1	4.3
NIV modality		
CPAP only	3	13
BIPAP only	14	60.9
Both BIPAP and CPAP	6	26.1
Complications		
Stomach distension	5	21.7
Skin lesions (nasal sores or sores in other skin area)	4	17.4
Excessive drooling	1	4.3
Outcome		
Passed away on NIV	3	13
NIV stopped but passed away during same admission	3	13
NIV stopped and patient discharged	17	74

NIV: Non-invasive ventilation, COVID: Coronavirus disease, CPAP: Continuous positive airway pressure, BiPAP: Bi-level positive airway pressure, RSV: Respiratory syncytial virus

Table 3: Vital signs before initiation and 6 h post-initiation of non-invasive ventilation (*n*=22).

	Before initiation median (min, max)	6 h post initiation median (min, max)	*P*-value
Heart rate	136 (69,200)	121 (85, 163)	0.002
Respiratory rate	40 (14–80)	31 (16, 50)	0.002
Oxygen saturation	96 (80–100)	99 (90, 100)	0.025

DISCUSSION

This study showed that palliative short-term NIV used during the escalation of respiratory support for distressing symptom management improved vital signs, namely heart rate (P = 0.002), respiratory rate (P = 0.002) and oxygen saturation (P = 0.025).

Other studies have reported that NIV reduces respiratory rate and is associated with greater reductions in dyspnoea and heart rates than standard oxygen therapy.[10,11] Thus, respiratory support for children under palliative care should not be limited to only standard oxygen therapy and should be escalated when necessary.

Dyspnoea or breathlessness is associated with poor quality of life for the patient and caregivers.[12] Improvement of the child's respiratory distress would increase comfort, either in the acute episode or during the end of life. The majority of clinicians and parental perceptions of the child's condition after six hours of NIV were that the child's condition had improved. This could improve parental distress; however, a formal pre- and post-parental distress assessment needs to be done to confirm this.

Complications experienced by the patients receiving NIV in this study include stomach distension (21.7%), skin lesions over the nose and face (17.4%) and excessive drooling (4.3%). These are some of the minor NIV complications. The incidence of stomach distension or gastric insufflation globally is between 5% and 40%.[13] Nasal skin lesions increase with longer NIV durations, occurring in 5–50% of patients after a few hours and almost 100% of patients after 48 hours of mask NIV. There was less skin irritation and stomach distention among our patients, possibly due to using a nasal mask instead of a full face mask.

NIV was able to help patients tide through the acute respiratory episode while waiting for the definitive treatment, such as antibiotics, chest physiotherapy and nebulised medication to work. This was evidenced by the fact that many patients were able to wean off the NIV before being discharged home.

There were a few limitations faced while conducting the study. The study was retrospective and not a randomised controlled trial. Thus, many of the parameters could not be standardised or controlled. The respiratory support was provided according to clinical practice and could have differences between practitioners. Oxygen supplementation given concurrently with the provision of NIV could not be standardised between the different subjects. Concurrent medications such as midazolam and morphine could have contributed to the improvement of the vital signs.

Future studies suggested include a study on the quality of life of the patients and parental distress scores before and after starting NIV for the patients.

CONCLUSION

Usage of short-term NIV in paediatric palliative care, where children have an advanced directive in place indicating DNI, as seen in our study, can be a valuable modality of management for distressing symptoms, in addition to the pharmacological management of breathlessness. This is shown through our study to be of benefit in potentially reversible ARD as well as comfort care at the end of life. Further rigorous studies will need to be conducted for a clearer understanding of short-term NIV that would enable the formulation of guidelines to improve the quality of life and death in children.

Acknowledgment

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Ethical approval

The research/study was approved by the Institutional Review Board at Medical Research and Ethics Committee, Ministry of Health, Malaysia, number NMRR ID-22-01374-IPP, dated 16 August 2022.

Declaration of patient consent

Patient's consent are not required as patient's identity is not disclosed or compromised. Waiver of consent was obtained from the Medical Research and Ethics Committee, Ministry of Health, Malaysia.

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the

writing or editing of the manuscript and no images were manipulated using AI.

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