Monitoring of physiologic features and treatment aspects of children on home invasive mechanical ventilation”

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Abstract

Paediatric home invasive mechanical ventilation patients are a small but resource intensive cohort, requiring close monitoring and multidisciplinary care. Patients are often dependent on their ventilator for life support, with any significant complications such as equipment failure, tracheostomy blockage, or accidental decannulation becoming potentially life threatening, if not identified quickly. This review discusses the indications and variations in practice worldwide, in terms of models of care, including home care provision, choice of equipment and monitoring. With advances in technology, optimal monitoring strategies for home, continue to be debated: In-built ventilator alarms are often inadequately sensitive for paediatric patients, necessitating additional external monitoring devices to minimise risk. Pulse oximetry has been the preferred monitoring modality at home, though in some special circumstances such as congenital central hypoventilation syndrome, home carbon dioxide monitoring may be important to consider. Children should be under regular follow up at specialist respiratory centres where clinical evaluation, nocturnal oximetry and capnography monitoring and/or poly(somno)graphy and analysis of ventilator download data can be performed regularly to monitor progress. Recent exciting advances in technology, particularly in telemonitoring, which have potential to hugely benefit this complex group of patients are also discussed.

Monitoring of Physiologic Features and Treatment Aspects of Children on Home Invasive Mechanical Ventilation

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Keywords

Tracheostomy ventilation, Monitoring, Paediatric long term ventilation

Abstract

Paediatric home invasive mechanical ventilation patients are a small but resource intensive cohort, requiring close monitoring and multidisciplinary care. Patients are often dependent on their ventilator for life support, with any significant complications such as equipment failure, tracheostomy blockage, or accidental decannulation becoming potentially life threatening, if not identified quickly. This review discusses the indications and variations in practice worldwide, in terms of models of care, including home care provision, choice of equipment and monitoring. With advances in technology, optimal monitoring strategies for home, continue to be debated: In-built ventilator alarms are often inadequately sensitive for paediatric patients, necessitating additional external monitoring devices to minimise risk. Pulse oximetry has been the preferred monitoring modality at home, though in some special circumstances such as congenital central hypoventilation syndrome, home carbon dioxide monitoring may be important to consider. Children should be under regular follow up at specialist respiratory centres where clinical evaluation, nocturnal oximetry and capnography monitoring and/or poly(somno)graphy and analysis of ventilator download data can be performed regularly to monitor progress. Recent exciting advances in technology, particularly in telemonitoring, which have potential to hugely benefit this complex group of patients are also discussed.

Introduction

The population of children managed at home with ventilatory support has continued to grow worldwide.(1) This is a direct result of advances in medical care and technology, which have increased survival rates amongst children with complex medical disorders who may have co-existing chronic respiratory failure.(2, 3) Home mechanical ventilation (HMV) is now well established as a method of facilitating discharge home for this group of children, enabling them to participate in daily family activities, attend school and receive an overall improved quality of life.(4) HMV can be either invasive (IV), via a surgically inserted tracheostomy tube or non-invasive (NIV), delivered via a nasal or full-face mask interface. Whilst in children the preference is always to avoid invasive ventilation, in some instances the severity of the condition or underlying disease necessitate this method of ventilation.(5) Monitoring and safety considerations differ in children with invasive HMV compared to those receiving NIV and are reviewed in this article, in the context of advances in available technology, existing guidelines and current practice.

Indications for Invasive Home Ventilation Via Tracheostomy

The population of children managed with invasive ventilation at home has changed over time and particularly with the introduction of non-invasive respiratory support. Increasingly NIV is preferred to avoid complications that may result from tracheostomy, including acute airway blockade by secretions, accidental decannulation, tracheal injury and respiratory infections.(6) Indications for invasive ventilation in children include chronic respiratory insufficiency resulting from severe upper airway obstruction, where anatomy prevents NIV administration (e.g., facial abnormalities, bilateral vocal cord paralysis, cystic hygroma), children who have an inability to protect their lower airways (e.g., bulbar dysfunction) or cannot cooperate with a mask interface (e.g., severe neurological impairment) and in those who are deemed ventilator dependent and require ventilatory support for more than 16 hours/day (e.g., high cervical spinal cord injury, infants with congenital central hypoventilation syndrome).(6)

Variations in Practice Worldwide

Despite similarities in populations across countries, the proportion of children managed with invasive home ventilation does differ considerably between countries and centres. This is due to many factors that influence preference including local expertise, availability of NIV interfaces, technology, and healthcare costs. In high-middle income countries, it is estimated that children receiving invasive ventilation represent around $1/5^{th}$ of the total population of children on home ventilatory support.(1) Whilst home ventilation is certainly feasible in developing countries,(7, 8, 9) rates of invasive ventilation have been reported to be as high as 97% in some.(10) The driver to avoid tracheostomy in countries where this is possible, has come from both an increase in expertise, available technology to enable management of children non-invasively and an awareness of the potential complications from tracheostomies. Published literature estimates complication rates ranging from 19.9%(11) to 40%(12), with infection, granuloma formation, obstruction of the cannulae and accidental decannulation all more common in children than in adults.(13) Additionally, speech impairment and feeding difficulties may also occur. The negative impact of a tracheostomy on a developing child also needs to be considered.

Models of care for children receiving invasive home ventilation also differ vastly worldwide and are largely dependent on the resources available. The American Thoracic Society published comprehensive clinical practice guidelines for paediatric chronic home invasive ventilation in 2016.(14) This included nine recommendations regarding the standards of care for this complex group of children. Similar documents have been published by other countries, with some encompassing the spectrum of children on both invasive and non-invasive ventilation and other focusing more specifically on distinct groups.(15, 16, 17) All are largely based on expert consensus opinion, due to the limited quality of evidence available in this field. The commonality amongst all these guidance statements is the recognition of the high level of risk and complexity involved in delivering care to this group of children, which necessitates structured programs delivered by multi-disciplinary teams who can ensure close monitoring of these children in the home setting. Despite these recommendation, funding for such structured programs remains variable; In the US, home healthcare is generally supported by Medicaid, Medicare, or long-term insurance.(18) In the UK, the NHS largely covers the cost involved in supporting home care for children on ventilation, with the local health authorities taking responsibility for care provision.(19) In Australia and New Zealand, funding packages are provided through federal and state services but there remains an inequity amongst regions and even between centres.(15) In comparison, in Thailand, home ventilation is not covered by any of the available healthcare funding source. Patients have a right to stay in the government hospital if they still need ventilatory support, but none of the private health insurance providers offer coverage for home care.(18) This is a common situation in developing countries, where costs for both ventilation equipment and the provision of homecare are borne by parents and families, thereby presenting significant barriers to discharge from hospital.(10)

Safety Considerations

Whilst facilitating care at home for children requiring invasive ventilation has several benefits, significant safety issues can occur. In an analysis of patient safety incident reports undertaken in the UK, for children on home invasive ventilation, the most common problems in the processes of care were issues with faulty equipment and availability of equipment, factors relating to procedures and treatment and concerns around staff availability and competency.(20) Of concern, this study demonstrated clearly stated harm to the child (CPR required, emergency tracheostomy change in community setting, significant child, and parent distress) in 41% of incidents.(20) This demonstrates how crucial it is that risks and safety measures are thoroughly and systematically considered prior to discharge home of children on invasive ventilation.

Home Care Provision

In general, the recommendation is for a minimum of two trained primary caregivers at home, ideally with the support of a home care package that includes provision of an awake, trained caregiver that can be present at all times for a child who is chronically invasively ventilated.(14, 15, 16) This assists in reducing the risk of complications such as tracheostomy blockage or accidental decannulation and may prevent a fatal incident from equipment failure. However, it is also important to recognise that daily night carers in the home can have significant impact on family life and privacy.(15)

Comprehensive parent education is vital for successful discharge home of children receiving invasive ventilation. However, despite general guidelines on educational objectives, there is great variability in training between programs, and standards are lacking.(21) Most programs are heavily based on skilled nurses undertaking daily education of parents and carers whilst the child is still an inpatient, with some using digital resources and simulation techniques to supplement the face-to-face teaching. In their recent scoping review High *et al.*highlighted the need for additional research to support the design and test the effectiveness of parental education programs for children assisted by invasive mechanical ventilation at home.(21) As this population of children continues to grow, standardised education, which incorporates additional elements which go beyond the day-to-day practical skills required, such as for example, providing knowledge of the psychological and financial demands associated with caring for a child at home on invasive ventilation and strategies that may help to manage this, need to be considered to reduce long-term risks in this population of children.

Equipment

Choice of equipment is often dependent on the preference of individual centres and requirements for a specific child. For invasively ventilated children this will include both what is required for tracheostomy care as well as ventilatory equipment. For details of this, readers are referred to the existing National guidelines, which provide excellent summaries of this aspect of care.(14, 15, 16, 22) In brief, 1-2 preferred ventilators are recommended, so that workers are familiar with the capabilities, limitations, and operation of those ventilators. A back up machine and sufficient alternate power source are important to consider for patients who are ventilator dependent. This is to ensure that in the event of equipment failure or power failure ventilation can continue to be provided through an alternate device or with a battery source or back-up generator. Strategies to address potential equipment failure include regular maintenance and servicing of home equipment as well as regular re-education of the patients and caregivers. With this approach, risks from ventilator equipment failure can be reduced and are less likely to lead to a severe adverse event than tracheostomy complications. (14, 23)

Monitoring at Home

Optimal monitoring strategies for the home environment continue to be debated. In-build ventilator alarms are often inadequate and insensitive to the small tidal volumes seen in paediatric patients, necessitating additional external monitoring devices to minimise risk. Commonly, centres will opt to provide pulse oximeters at home for children on invasive mechanical ventilation. Others have used cardiorespiratory monitors, end-tidal CO_2 monitors or rely on direct observation by a nurse 24hr a day. Both The American Thoracic Society and Canadian Thoracic Society clinical practice guideline provide an excellent summary of the rationale for pulse oximetry as the preferred monitoring method for this population of children over other options.(14, 16) However, it is also important to remember that continuous oximetry monitoring may be difficult to undertake in some children and has the potential to falsely alarm or even falsely reassure parents and carers. Therefore, the data needs to be interpreted in the context of the clinical situation and by those with the experience to determine its reliability.

In recent times, the role of home carbon-dioxide monitoring in children on invasive ventilation has been raised, recognising that this is an important measure to gauge effectiveness of ventilation. Non-invasive capnographs and capnometers that can measure either end-tidal carbon dioxide ($EtCO_2$) or transcutaneous CO_2(TCM) have become increasingly available and are attractive for use in children, who often cannot tolerate regular invasive blood gas monitoring.(24) Foster *et al.* recently evaluated the potential of a portable endotracheal capnograph (EMMA^{TM} Capnograph) for measurements of $EtCO_2$ at home in children on home invasive ventilation. Overall, this device was demonstrated to show promise for spot-checking carbon dioxide levels in this population of children, but it has not been evaluated for continuous home monitoring purposes.(24) Similarly, there is little evidence for the use of ambulatory transcutaneous carbon dioxide monitoring (TCM) in children on home invasive ventilation. One study has been undertaken in children with neuromuscular disease to determine if ambulatory TCM monitoring could be used for early screening and diagnosis or nocturnal hypoventilation.(25) However, this study did not demonstrate sufficient accuracy for this tool to be used for this purpose, despite patient preference for this option over in-lab polysomnography. Therefore, at present further research is required before non-invasive CO_2 monitoring of any type can be recommended as part of routine home continuous routine monitoring.(24)

The exception is in congenital central hypoventilation syndrome, a genetic condition where there is absent or abnormally reduced ventilatory responses to hypercapnia and hypoxia, in the context of systemic autonomic dysfunction. These patients fail to display the typical responses to hypoxia and/or hypercapnia such as increases in respiratory rate or effort. Here, home CO_2 monitoring can identify early hypoventilation in times of illness or stress. Which in turn enables parents to institute a predetermined escalation plan such as a ventilation ladder or a second program on the ventilator to better reflect the increasing need for respiratory support. This can avert attendance or admission to hospital. Furthermore, many emergency departments do not have ready routine access to non-invasive CO_2 monitoring relying on CO_2assessments taken by capillary or arterial blood gases. The pain/ arousal generated by these procedures often alter sleep state and breathing, rendering results potentially less reliable. There has thus been a movement towards providing these patients with home CO_2 monitoring, albeit funding can be an issue.

Follow up

It is important for children receiving home ventilation to receive regular follow up at specialist respiratory centres with experience in looking after these children. This may be in the form of an overnight hospital stay, an out-patient visit, a home visit, via telemonitoring or telemedicine, or a combination thereof. Clinical evaluation, nocturnal oximetry and capnography monitoring and/or poly(somno)graphy and analysis of ventilator download data are recommended as part of routine monitoring. Gas exchange, delivered pressure, tidal volumes, inspiratory: expiratory ratio, leak, residual respiratory events, and patient ventilator synchrony ideally should be assessed. Follow up should be provided by a multidisciplinary team, members of which include a pulmonologist, long term ventilation/ tracheostomy nurses, respiratory therapists, physiotherapists and ENT surgeon.

Impact of Advances in Technology

During the recent COVID-19 pandemic, many centres experienced severe problems in initiating home mechanical ventilation promptly and in delivering regular follow up.(26) Telemedicine was rapidly introduced into both adult and paediatric practice as a solution to this problem, aided by the ability of some ventilators to provide remote monitoring through wirelessly transmitting usage and performance data to cloud-based web servers for remote access by participating clinicians. These enabled clinicians to review ventilation parameters and trends of domiciliary therapy, including information on adherence, air leaks, pressure, and flow waveforms.

Onfofri *et al.* published their experience of using a combination of teleconsultation and telemonitoring in 21 children on long-term ventilation (including 8 patients on invasive mechanical ventilation) during the pandemic period.(27) They demonstrated the effectiveness of this approach, describing how this facilitated home adjustment of ventilation parameters, identified the need to change interface and enabled them to respond to patient symptoms and concerns promptly during lockdown.(27)

Trucco et al performed a 2 year multicenter telemonitoring trial of children and young people with neuromuscular disease on home mechanical ventilation, 7 were invasively ventilated, 41 non-invasively ventilated.(28) Home overnight monitoring of oximetry and heart rate were transmitted weekly and there were weekly scheduled phone calls to the patients, who were questioned on symptoms such as cough, dypsnoea, and temperature. The information was scored, with a deviation of >3 from baseline considered an exacerbation, prompting the clinician to be alerted and medical advice given. The telemonitored patients had fewer hospitalizations and their median length of hospitalization was also significantly shorter than control patients. It was the high severity invasively ventilated patients who benefited the most. Feedback from caregivers regarding the telemonitoring was also very positive.

Muñoz-Bonet et al have described their experience of telemedicine to facilitate discharge home of 12 children on invasive mechanical ventilation.(29) The same team also found telemedicine helped facilitate diagnosis and early treatment of medical events, 13 out of the recognised 141 medical events were classified as potentially life threatening. Of these, 9 were resolved telemedically, 4 required transfer to hospital of which 3 required hospital admission.(30)

Such successful reports have encouraged the adoption of telemonitoring into routine care for paediatric patients on home mechanical ventilation and demonstrate how advancing technology can improve the provision of home care for this cohort of patients. It is likely that in time, these approaches will be refined further, developing even easier methods of remote care delivery.

Vo *et al.* recently published a novel approach for supporting decision making around paediatric invasive mechanical ventilation, which again highlights the way in which technological advances can be utilised to benefit this complex patient group.(31) They described how a parent-to-parent-web-based tool was developed to support parental decision making, based on interviews and feedback from parents. Evaluation of this tool by other families who had experienced caring for a child at home on invasive ventilation provided positive feedback, with all participants suggesting it would have helped their decision making about home ventilation.(31) Innovative studies such as this, which take advantage of newer web-based technology, have a key role in facilitating impactful changes in practice to improve the experiences of families who are faced with the prospect of home invasive ventilation for their child in the future.

Summary and future directions

In summary, children on home invasive mechanical ventilation are a complex patient group requiring close monitoring and multidisciplinary care. The expansion in NIV threatens to turn invasive ventilation into more and more a niche concern. However, maintenance of the knowledge base and clinical expertise for this select but high-risk cohort of patients will continue to be vital for the foreseeable future. There is considerable variation in worldwide practice in terms of models of care and home care provision. Choice of equipment and monitoring are primarily dependent on individual patient requirements, but the preference of individual centres, often reflecting the nature of the health care system they are situated in, also plays a role. As a general guide continuous pulse oximetry is the preferred minimum standard monitoring method at home. In some situations, as described, the addition of home CO2 monitoring is recommended and may help to improve patient care, preventing hospital visits at times. Children should be under regular follow up at specialist respiratory centres where clinical evaluation, nocturnal oximetry and capnography monitoring and/or poly(somno)graphy and analysis of ventilator download data can be performed regularly to monitor progress.

Advances in technology, for example in telemonitoring and web-based applications have the potential to greatly benefit this complex group of patients where travel to specialist hospitals can be challenging especially if geographically distant. These advances and their implementation have been accelerated by the SARS-CoV-2 pandemic. Whilst very exciting, we need to be mindful of some of the attendant issues such as data security and lack of legal clarity in certain scenarios. The European Respiratory Society statement on tele-monitoring of ventilator-dependent patients(32) described very presciently, both the opportunities and the challenges inherent to telemonitoring, highlighting that formal guidelines incorporating ethical, legal, regulatory, technical and administrative standards, need to be developed. More research identifying and refining the role of telemonitoring continues to be urgently needed.

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