

Balancing the pressures: a review of the quality of care provided to children and young people aged 0–24 years who were receiving long-term ventilation

Assessing the quality of care for patients receiving long-term ventilation is complex given the diversity of this population (0–24 years in this case) and their differing requirements for treatment. This article details how and why such reviews are necessary.

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Introduction

The most recent report from the National Confidential Enquiry into Patient Outcome and Death, entitled *Balancing the Pressure*, reviews the care of patients aged 0–24 years who are receiving long-term ventilation, across all points of the care pathway. This includes admission to hospital for patients who are already established on long-term ventilation (National Confidential Enquiry into Patient Outcome and Death, 2020).

A definition of long-term ventilation as ‘respiratory support provided every day for a period of at least 3 months’ was used and the study included both patients who were ventilated invasively via a tracheostomy tube and those ventilated non-invasively via a face mask (Palange and Simonds, 2013).

There is huge variation in the patients receiving long-term ventilation. They range from premature babies requiring support for airway, lung or central nervous system problems, to young people with failing respiratory or neuromuscular functions. There is also variation in both the interface with the ventilator itself and the daily needs for respiratory support. As a result, care is delivered to this group of patients across a highly complex care pathway, with variations in service provision across the UK.

The long-term ventilation study methods

From the outset it was clear it was going to be difficult to identify the number of people receiving long-term ventilation. There is no OPCS Classification of Interventions and Procedures code and the way in which hospitals record the details of patients on long-term ventilation also varies. Previous research studying young people on long-term ventilation showed an increase from one patient in 1975 to an estimated 1400 in 2013 (NHS England, 2014).

In order to identify patients, study contacts were set up in hospitals to provide details of patients under the care of their long-term ventilation service as well as those who were admitted to their hospital during the 2-year study period.

There were 3061 patients reported from 113 hospitals across the UK. This is considered an underestimate because the absence of coding for long-term ventilation means there is no way to easily identify patients who are at home or who have transitioned to adult services. Just over half of patients (1710/2999; 57.0%) were admitted to hospital during the study period (Table 1).

Sampled data collection method

The clinical care provided in hospitals was assessed by taking a random sample from the study population of patients already established on long-term ventilation, who were admitted to hospital. Questionnaires that covered the long-term ventilation care by specialist and community providers and the acute admission period were sent for completion. Copied extracts of case notes were also requested.

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Table 1. Acute admissions to hospital during the study period for the total population

	Number of patients	%
Admission	1710	57.0
No admission	1289	43.0
Subtotal	2999	
Admission date given after study period	62	
Grand total	3061	

Report findings and recommendations

A total of twelve recommendations were made, five of those presented in this article related to routine hospital care. For the full findings, recommendations, and support tools please see <https://www.ncepod.org.uk/2020ltv.html>.

Emergency healthcare plans

Personal care plans have been recommended for all children and young people receiving long-term ventilation, as they have been shown to aid communication between healthcare providers and patients (Quality Review Service, 2018). Building on the recommendations that the National Confidential Enquiry into Patient Outcome and Death made in the *Each and Every Need* report (National Confidential Enquiry into Patient Outcome and Death, 2018), this study highlights the importance of emergency healthcare plans. Community teams indicated that 57/83 (38.7%) of patients had a fast-track admission plan or emergency healthcare plan. This was slightly better at the point of hospital admission, with admitting clinicians reporting that 52/75 (69.3%) of patients had an emergency healthcare plan in place. However, in the peer review of the notes, reviewers found evidence that an emergency healthcare plan was only present in 23/149 15.4% of cases.

Recommendation

Templates for emergency healthcare plans should be developed and standardised for all people receiving long-term ventilation. These templates should provide information about what to do and who to contact in an emergency situation and should form part of a patient's records. These records should be physical as well as digital and should be fully accessible to the person receiving long-term ventilation, and also parents, carers and health and social care teams.

Emergency care

In patients that had an admission to hospital, 113/148 (76.4%) did not have a pre-determined plan for urgent or emergency care. On admission, 36/139 patients (25.9%) went directly to critical care. This did not always relate to critical illness and in some cases was the only place where clinicians' competencies were appropriate to care for those receiving long-term ventilation.

Recommendation

People on long-term ventilation should be able to access age-appropriate emergency care when required.

Good ventilation care and clinical leadership

On admission to hospital, the accurate documentation of respiratory rate, oxygen saturation and ventilation settings is fundamental to the provision of safe, quality care. In this study, ventilator settings were not documented in 38/148 (25.7%) cases; oxygen saturation was not documented in 9.8% of cases and respiratory rate was not recorded in 18/135 (13.3%) of cases. In addition to this, there was evidence of blood gas analysis being undertaken in only 68/141 (48.2%) cases. Case reviewers stated there was evidence of clinical leadership during the admission in the case notes of 82/137 (59.9%) people. This was

based on evidence of regular senior review and planning of care in hospital, and managing discharge. Leadership was more likely to be apparent if the admission was related directly to long-term ventilation care (41/462, 66.1% in long-term ventilation admissions, 41/75, 54.7% in non long-term ventilation admissions).

Recommendation

When patients on long-term ventilation are admitted to hospital for any reason, they should have a standard clinical and respiratory assessment. If the patient is not admitted under the care of their usual long-term ventilation team, this team should be involved in the patient's care. Identifying clinical leadership is key in delivering high quality healthcare.

Discharge arrangements

Case note reviewers found evidence in the case notes of discharge planning in 64 out of the 126 (50.8%) sets of notes reviewed. Case reviewer data also indicated there was evidence that the usual community team was involved in discharge planning in only 30/103 (29.1%) cases and the usual long-term ventilation team in 45/113 (39.8%) patients. However, a discharge summary was provided for 94.5% of patients and a revised care plan was provided at discharge for 43/124 (34.7%) patients.

Recommendation

Ensuring high quality discharge arrangements is key for people who are already established on long-term ventilation and are admitted to hospital. Planning should start on admission to hospital and be clearly documented in the case notes. It should also include the community and the usual long-term ventilation teams and continuously document any changes to care made throughout admission.

Optimise the frequency of clinical review

An acute admission to the same hospital in the previous 6 months had occurred in 68/145 (46.9%) people. Data showed patients who had been on long-term ventilation for less than 2 years were more likely to have had an unplanned admission to hospital in the previous 6 months (34/54) compared to those patients who had been receiving long-term ventilation for more than 2 years (20/54).

Recommendation

The frequency of review will vary from patient to patient based on a number of factors. These include the severity of the underlying condition and the length of time they have spent ventilated. This should be optimised on an individual basis for patients on long-term ventilation who are at increased risk of admission. Such at-risk patients include those established on long-term ventilation for less than 2 years and those who have had an admission in the previous 6 months.

Key points

- All children and young people receiving long-term ventilation should be provided with a standardised emergency healthcare plan.
- All children and young people receiving long-term ventilation should be able to access age-appropriate emergency care when required.
- Standard clinical and respiratory assessment for children and young people on long-term ventilation when admitted to hospital needs improvement.
- Ensuring high quality discharge arrangements for children and young people, already established on long-term ventilation, who are admitted to hospital is key.
- The frequency of review should be optimised on an individual basis for children and young people receiving long-term ventilation who are at an increased risk of admission.

Conclusions

The data in the report represent a profile of a population with complex and chronic healthcare needs. Many of the patients in the sample were admitted with acute illness or because their respiratory requirements or long-term ventilation needs had changed. Focusing on the clinical data in the report will enable all services providing routine care to patients receiving long-term ventilation to reflect on the care they are able to provide and to make improvements where necessary. This applies not just to centres providing specialist long-term ventilation care but to all hospitals where this group of patients may be admitted.

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References

- National Confidential Enquiry into Patient Outcome and Death. Each and every need. 2018. https://www.ncepod.org.uk/2018report1/downloads/EachAndEveryNeed_FullReport.pdf (accessed 5 August 2020)
- National Confidential Enquiry into Patient Outcome and Death. Balancing the pressures. 2020. https://www.ncepod.org.uk/2020ltv/LTV_Full_Report.pdf (accessed 5 August 2020)
- NHS England. Children who are long term ventilated - Pathfinder project: engaging with families and children/young people. An independent quality improvement review by the patient experience network. 2014. <http://patientexperiencenetwork.org/resources/report/Paediatric%20Long%20Term%20Ventilation%20Report-v12%20-%20final.pdf> (accessed 5 August 2020)
- Palange P, Simonds AK. European respiratory handbook of respiratory medicine. 2nd edn. Sheffield: European Respiratory Society; 2013:178
- Quality Review Service. Quality Standards – Long-Term Ventilation for Children and Young People V4.1. 2018. <https://qualityreviewservice.nhs.uk/standards/page/2/> (accessed 5 August 2020)