



Promoting safer home care for children with technology dependence



Bethan Page (PhD researcher) & Emily Harrop (Medical Director of Helen & Douglas House)

Incident analysis: feeding tubes

Priorities for improvement

- Handovers from hospital to community
- Training for family carers
- Provision and expertise of services in the community
- Availability and reliability of equipment

Original article



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Paediatric enteral feeding at home: an analysis of patient safety incidents

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ABSTRACT

Aims To describe the nature and causes of patient safety incidents relating to care at home for children with enteral feeding devices.

Methods We analysed incident data relating to paediatric nasogastric, gastrostomy or jejunostomy feeding at home from England and Wales' National Reporting and Learning System between August 2012 and July 2017. Manual screening by two authors identified 274 incidents which met the inclusion criteria. Each report was descriptively analysed to identify the problems in the delivery of care, the contributory factors and the patient outcome.

Results The most common problems in care related to equipment and devices (n=98, 28%), procedures and treatments (n=86, 24%), information, training and support needs of families (n=54, 15%), feeds (n=52, 15%) and discharge from hospital (n=31, 9%). There was a clearly stated harm to the child in 52 incidents (19%). Contributory factors included staff/service availability, communication between services and the circumstances of the family carer.

Conclusions There are increasing numbers of children who require specialist medical care at home, yet little is known about safety in this context. This study identifies a range of safety concerns relating to enteral feeding which need further investigation and action. Priorities for improvement are handovers between hospital and community services, the training of family carers, the provision and expertise of services in the community, and the availability and reliability of equipment. Incident reports capture a tiny subset of the total number of adverse events occurring, meaning the scale of problems will be greater than the numbers suggest.

What is already known?

- There are increasing numbers of children who require specialist medical care at home. Most of this care is provided by parents.
- While there are advantages of care at home, little is known about the safety of enteral feeding at home.

What this study adds?

- This study identifies a range of safety problems occurring with enteral feeding at home, many of which can remain hidden from paediatric services.
- If children with complex care needs are to be cared for safely at home, the provision of services to support families at home need improving.
- Priorities include handovers from hospital to community, training for family carers, provision and expertise of services in the community, and availability and reliability of equipment.

Artificial Nutrition Survey, it was estimated that there were 16982 children on home enteral nutrition in the UK in 2010, with an increase of 41.5% between 2005 and 2010.⁷ There are several types of enteral feeding, all of which involve inserting a device into the stomach and/or jejunum. Nasogastric (NG) tube feeding is the most common short-term solution. Surgically placed devices are required in children

Incident analysis: long term ventilation

Priorities for improvement

- Training for staff and other carers
- Maintenance and availability of equipment
- Support for families
- Co-ordination of care

Also featured in the Independent

<https://www.independent.co.uk/news/health/patient-safety-children-ventilation-community-care-nursing-nhs-a9250671.html>



Analysis of paediatric long-term ventilation incidents in the community

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ABSTRACT

Aim To describe the nature and causes of reported patient safety incidents relating to care in the community for children dependent on long-term ventilation with the further aim of improving safety.

Methods We undertook an analysis of patient safety incident data relating to long-term ventilation in the community using incident reports from England and Wales' National Reporting and Learning System occurring between January 2013 and December 2017. Manual screening by two authors identified 220 incidents which met the inclusion criteria. The free text for each report was descriptively analysed to identify the problems in the delivery of care, the contributory factors and the patient outcome.

Results Common problems in the delivery of care included issues with faulty equipment and the availability of equipment, and concerns around staff competency. There was a clearly stated harm to the child in 89 incidents (40%). Contributory factors included staff shortages, out of hours care, and issues with packaging and instructions for equipment.

Conclusions This study identifies a range of problems relating to long-term ventilation in the community, some of which raise serious safety concerns. The provision of services to support children on long-term ventilation and their families needs to improve. Priorities include training of staff, maintenance and availability of equipment, support for families and coordination of care.

What is already known on this topic

- The number of children on long-term ventilation cared for at home is rapidly increasing.
- There are significant risks in long-term ventilation that need to be carefully managed.
- Little is known about the safety of care for children on long-term ventilation in the community.

What this study adds

- This study identifies a range of problems in care and underlying factors experienced by children on long-term ventilation at home.
- Priorities for improvement are training of staff, maintenance and availability of equipment, support for families and improving coordination of care.

Support for families on long-term ventilation care

Children on long-term ventilation need an extensive care package to provide long-term medical,

Academic Health Science Network (AHSN) programme

- Regional training booklet for children with PEGs and gastrostomy buttons
- Thames Valley Pathway for children on long term ventilation

<https://www.patientsafetyoxford.org/wp-content/uploads/2018/12/Thames-Valley-LTV-Pathway-and-Standards.pdf>

- Regional multidisciplinary training days for long term ventilation and gastrostomy care



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Specialised paediatric care



The aim of our Specialised Paediatric Programme is to improve safety and outcomes along the care pathways of children with technologically dependent complex needs who are looked after at home, while enabling them to lead as normal a family life as possible, and reducing unscheduled admissions to hospital.

It also aims to foster improved collaboration between different stakeholders from the point of initial referral to surgical management of patients, and subsequent follow up and long-term care in the community including transitional care to adulthood.

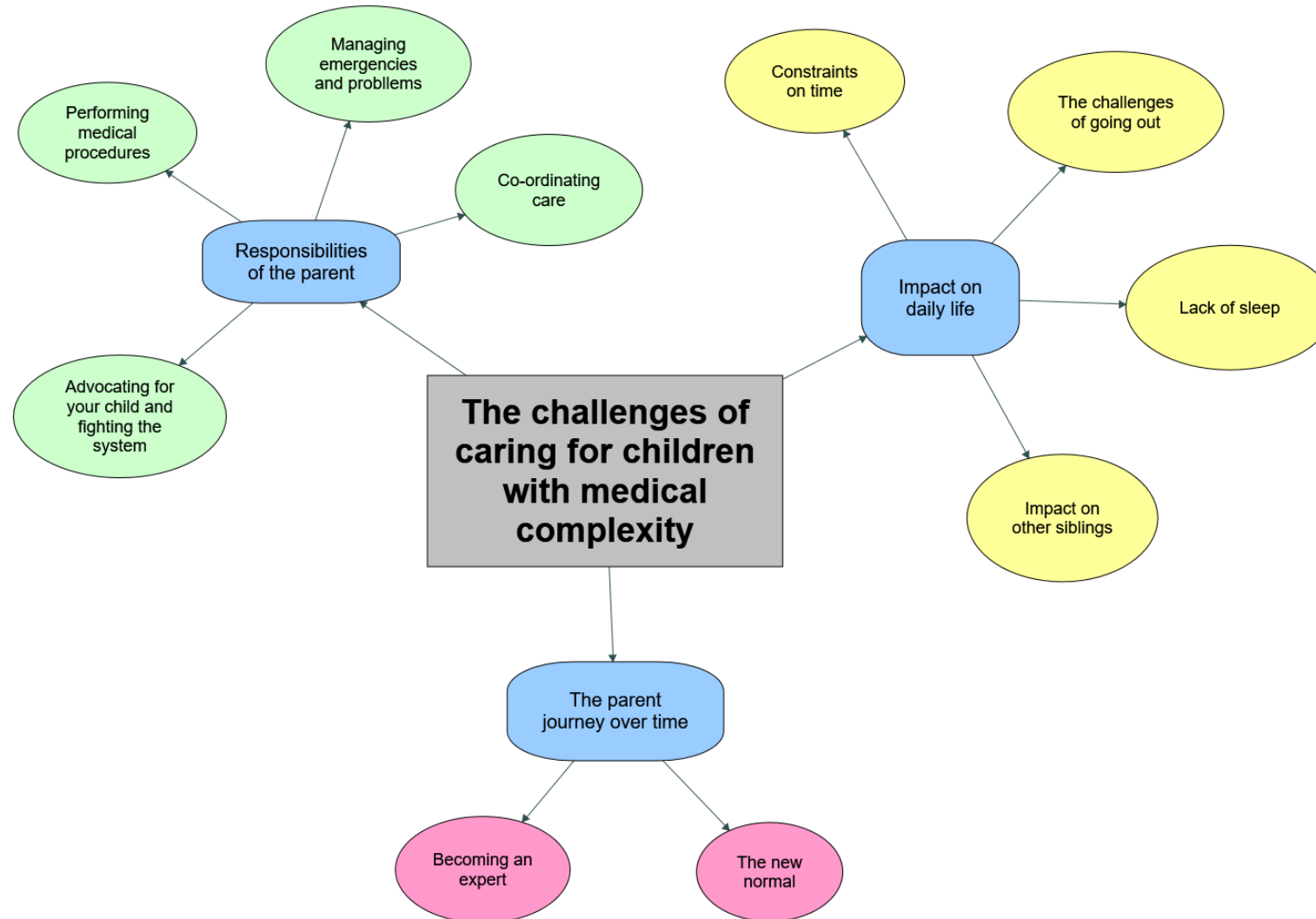
It has two projects; one for children with gastrostomies [PG] who are dependent on enteral feeding, and one for children who are dependent on long term ventilation [LTV]. Engagement in the programme is fully regional and multi professional

Co-design: working with and for families



How parents felt in the first few weeks of caring for their child at home

Interviews with parents on the challenges of caring for children who need complex care at home



A few quotes from families on the challenges they face

“And over time, just the exhaustion of trying to [um] look after him just got increasingly tough and unmanageable and, actually, to the point of being quite dangerous because, obviously, you have to be awake and alert and ready to change his [tracheostomy] tube or give him suction at any time.”

(ID01_exomphalos)

“There has been days where I, where I’ve gone ‘Enough. If I don’t leave this house for five minutes and go and get some fresh air I’ll actually not come back’ because there’s so much in your head and the times where you do have five minutes to sit down and relax you’re on the exomphalus support group checking up on other people’s kids... so the time when you do have as you’re down time, my respite care, I spend most of my respite care running to and from school dealing with my other children.”

(ID19_exomphalos)

£30,000 funding awarded from Q Exchange (Health Foundation)



Exchange

Supporting parents to care for children with medical complexity

Families are doing complex healthcare procedures at home (e.g. feeding tubes and ventilation). Our project will pilot and spread ways to train parents and carers of children with medical complexity.

Download Idea as PDF

 Print Idea

 Read comments 70



<https://q.health.org.uk/idea/2019/supporting-parents-to-care-for-children-with-medical-complexity/>

Secondment opportunity

- We are looking for a nurse to work on this project 1 days a week, for 9 months.
- To read more about the project:
<https://q.health.org.uk/idea/2019/supporting-parents-to-care-for-children-with-medical-complexity/>



Secondment opportunity

An opportunity has arisen for a 0.2 WTE (1 day a week) nurse to work on a project for 9 months to improve preparation and support for parents caring for children with medical complexity. The hours and days worked are flexible. The project is funded by the Health Foundation, through the Q Exchange programme: <https://q.health.org.uk/idea/2019/supporting-parents-to-care-for-children-with-medical-complexity/>. The grant holders are Bethan Page (PhD researcher at Oxford University), Dr Helen Higham (Director of Oxford Simulation, Teaching and Research Centre OxSTaR), Dr Emily Harrop (Consultant in Paediatric Palliative Care & Medical Director at Helen & Douglas House), Mr Alex Lee (Paediatric Surgeon) and Alison Sharrard (Paediatric surgical gastro nurse).

Key duties

- To lead on the development of a training package for parents and staff caring for children with gastrostomies, utilising co-designed videos and simulation training.
- To liaise with families and healthcare professionals from the community and hospital to co-produce the package.
- To run training sessions with families and carers new to gastrostomy care.
- To contribute to the evaluation of the training package.
- To raise awareness of the project amongst relevant community and hospital teams.
- To contribute to presentations, reports and potentially academic papers on the project.

Essential criteria

- A strong nursing background, with significant experience of working with children with medical complexity and their families.
- A good understanding of the experiences of families and other carers who look after children with medical complexity at home and in the community.
- Extensive knowledge about enteral feeding, especially gastrostomy care.
- A proven track record of working successful within a multidisciplinary team.
- Ability to work independently.
- Able to travel to the John Radcliffe hospital for meetings and to pilot training with families.

Desirable criteria

- Experience teaching families and staff
- Experience and knowledge of patient safety

To express interest, contact Mr Alex Lee alex.lee@paediatrics.ox.ac.uk and Dr Helen Higham helen.higham@ndcn.ox.ac.uk by Weds 12th Feb

THANK YOU

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Thank you to all our collaborators across the region