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Original Article

Paediatric emergency department presentations due to feeding tube complications in children with cerebral palsy

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Abstract

Aim

To describe the characteristics of emergency department (ED) presentations due to complications from gastrostomy or [gastrojejunal](#) feeding-tubes among children with cerebral palsy (CP), the complexity of complications and the management approaches taken.

Methods

The Victorian CP Register was linked to the ED databases of Victoria's two tertiary paediatric hospitals and data on presentations due to feeding tube complications were identified based on discharge diagnosis codes. Additional data on presentations were extracted from medical records.

Results

Over five years, there were 234 ED presentations due to feeding tube-related complaints among a CP cohort (n=2183). ED notes were located for 183 of the 234 presentations. The majority of presentations (90%) involved children with severe gross motor impairment. Forty-six percent of presentations (n=84) was triaged as lower urgency and 68% (n=124) took place between 8am and 6pm. The most common presenting complaint was tube dislodgement (n=105; 70%). No investigations were recorded in the majority of cases, and in almost 90% of cases, the feeding tube was successfully replaced in the ED, usually by an ED physician (n=74), and less frequently by a surgeon (n=9), gastroenterologist (n=2) or nurse (n=8). Nine percent (n=17) resulted in a hospital admission.

Conclusions

Most ED presentations due to feeding-tube complaints in children with CP are in children with severe gross motor impairment yet are able to be managed in the ED. As such, it is likely that caregivers and other health professionals could manage some of the complications experienced in primary health care settings closer to home.

Key words

cerebral palsy, emergency department use, feeding tubes

What is already known on this topic

1. Approximately one in three children with cerebral palsy (CP) with severe gross motor impairment use a gastrostomy tube for feeding.
2. Gastrostomy tubes are associated with a number of benefits for children and their families, but also have risks associated with tube placement and maintenance.
3. Feeding tube complaints are a common reason for presenting to the emergency department (ED) in this group.

What this paper adds

1. In Australia, the most common feeding tube-related complaint seen in the tertiary paediatric ED is tube dislodgement.
2. Most dislodged tubes can be safely managed in the ED by an ED physician and do not require further intervention or hospital admission.

Cerebral palsy (CP) is the most common cause of childhood physical disability, affecting approximately two in every 1,000 live births.¹ It is an umbrella term for a group of permanent disorders of movement and posture that are caused by a disturbance to the developing brain.² Compared to typically-developing children, children with CP, particularly those with severe gross motor impairment, are more likely to experience feeding difficulties.³ Abnormal oro-pharyngeal anatomy,⁴ poor oro-motor function,^{5, 6} gastroesophageal reflux,⁶ and suboptimal seating posture during feeding (due to poor truncal tone)⁵ contribute to feeding difficulties in children with CP. In turn, feeding difficulties can contribute to poor nutrition and growth,³ constipation,⁷ oesophagitis leading to bleeding and pain,⁸ and pulmonary aspiration⁹ all of which cause significant morbidity for this group of children.^{4, 10}

Gastrostomy tubes (g-tubes) and gastrojejunal tubes (gj-tubes) have become important management options for children with CP who have feeding difficulties. Among all children with CP, the prevalence of g-tube feeding is estimated to be approximately 11%; however, this increases to 32% among children with severe gross motor impairment.¹¹ Benefits of gastrostomy feeding in children with CP include better weight gain and nutritional status, ease of feeding, improved medication compliance and decreased symptoms of gastroesophageal reflux.¹² Risks associated with g-tubes and gj-tubes, however, include complications due to tube placement (anaesthetic risk, peritonitis, sepsis, gastrointestinal bleeding, intussusception) and tube maintenance (dislodgement, obstruction, leakage, tube site infection).^{12, 13}

Saavedra *et al*¹⁴ describe g-tube related complaints in a paediatric emergency department (ED) at a single paediatric hospital in the United States of America (USA) and found that tube dislodgement was the most common presenting complaint (65%), with most being replaced by ED physicians. Showalter *et al*¹⁵ retrospectively reviewed the notes related to 237 paediatric ED presentations due to dislodged g-tubes that required replacement, and concluded that confirmatory imaging of g-tube position was of no clear benefit in prevention of complications and was associated with a considerably longer length of stay in the ED. These studies did not focus specifically on children with CP.^{14, 15}

A previous study found that 6% of tertiary paediatric ED presentations in children with CP were due to feeding tube complications.¹⁶ This study did not report on the types of feeding tubes involved, the exact complications, or how they were managed. The primary aim of the current study was to describe in detail the characteristics of ED presentations due to g-tube or gj-tube

complications among children with CP. A secondary aim was to determine the complexity of the g-tube and gj-tube complications and the management approaches taken.

Methods

Study design, cohort and setting

This was a retrospective review of the medical records of children with CP who presented with a feeding tube related complaint to the two tertiary paediatric EDs in the Australian state of Victoria between 2008 and 2012. These presentations were identified through a previous data linkage study, the methodology of which is described in detail elsewhere.¹⁷ In summary, the Victorian CP Register was linked to the hospital episode databases of Victoria's two tertiary paediatric hospitals, and data were obtained on 3,631 ED presentations over a five year period (2008-2012) by children with CP who were born between 1993 and 2008 (n=2,183). Routinely collected data were extracted and the main reason for each ED presentation was summarised using the recorded discharge diagnoses. Through this process, it was found that, of the 3,631 ED presentations, 234 (6%) were due to feeding tube complications. These ED presentations due to feeding tube complications are the focus of the current study.

This study was approved by the Human Research Ethics Committees of the Royal Children's Hospital, and Monash Health, Melbourne.

Data collection

Data collected as part of the original data linkage study included date and time of arrival at the ED, triage category and discharge destination. Each ED presentation was triaged using the Australian Triage Scale (ATS), a five-level classification system describing the urgency with which a patient should be treated.¹⁸ For this study, presentations triaged as 1, 2 or 3 according to the ATS were considered higher urgency presentations, while category 4 and 5 presentations were considered lower urgency. A standard data collection form was created to record supplementary information related to the feeding tubes. For each ED presentation, data were extracted from the child's medical record, including, the specific tube type and, if available, the date of initial tube insertion. Additional data were extracted on the chief presenting complaint (dislodgement, obstruction, malfunction, leakage, tube site infection, bleeding), ED management and investigations performed.

Clinical data extracted from the Victorian CP Register on each case comprised date of birth, epilepsy status and Gross Motor Function Classification System (GMFCS) level. The GMFCS is a five-level classification system that describes the gross motor function of people with CP on the basis of their self-initiated movement. Children classified as functioning within GMFCS levels I and II are independently ambulant, whereas those classified as functioning at GMFCS level III ambulate with walking aids. Children classified as functioning within GMFCS levels IV or V are generally limited in their ability to move around independently and require a wheelchair for transport.¹⁹

Data analysis

Data were manually entered into a REDCap database²⁰ and exported into Stata (version 14)²¹ for analysis. Descriptive statistics were used to summarise the characteristics of the cohort and the ED presentations, including the main presenting complaints, investigations, and complications. Chi-squared analysis was used to test for differences between included presentations and those excluded due to lack of availability of detailed documentation, and for differences between ED presentations that resulted in a hospital admission and those that did not. *P*-values were used to estimate the likelihood of differences being due to chance alone; a value of less than 0.05 was considered to provide strong evidence of difference.

Results

Detailed ED notes were located for 183 of the 234 (78%) ED presentations classified as feeding tube related. (Figure 1) Eighty-seven children with CP accounted for these 183 ED presentations. One-half (n=45) had a single ED presentation for a feeding tube related complaint over the five-year period, 18% (n=16) had two, 9% (n=8) had 3, 13% (n=11) had 4, and 8% (n=7) had five or more presentations. In some cases, the entire medical record could not be obtained and in other cases we were unable to locate notes pertaining to the specific ED presentation. Comparison of included and excluded groups show that the excluded group were relatively more likely to live in metropolitan Melbourne and to be triaged as less urgent.

The majority of presentations involved children classified as functioning at GMFCS levels IV or V (n=164; 90%) and aged nine years or younger (n=122; 67%). More than half (58%) those who presented to one of the EDs were residing in outer Melbourne (n=80), regional Victoria (n=24) or interstate (n=2). Forty-six per cent of presentations (n=84) were triaged as lower urgency

(ATS 4 or 5), 9% (n=17) resulted in a hospital admission, and 68% (n=124) took place between the hours of 8am and 6pm. (Table 1)

Overall, 83% of presentations were due to g-tube complications (n=151), 6% to gj-tube complications (n=10) and 10% to complications with other tube types, predominantly nasogastric and nasojejunal tubes (n=18). (Table 1) Forty-four per cent of presentations involved a child who had their initial feeding tube inserted more than two years prior to the presentation. Fewer than 5% (n=9) had their initial tube inserted within the month prior to the ED presentation. (Table 1)

Of the 151 presentations due to g-tube complications, 114 (76%) were related to problems with low-profile g-tubes (usually balloon retention devices), whereas 18 (12%) were due to problems with long g-tubes (usually initial type tubes). The most common presenting complaint was a dislodged tube (n=105; 70%). (Table 5) No investigations were recorded in the majority of cases, and failed attempts at re-insertion in the ED were recorded in 17 (11%) cases. (Table 2) In almost 90% of cases, the dislodged g-tube was successfully replaced in the ED, usually by an ED physician (n=74), and less frequently by a surgeon (n=9), gastroenterologist (n=2) or nurse (n=8). (Table 3) The presenting problem was able to be identified in 8 of the 10 ED presentations relating to gj-tubes. As expected, a higher proportion of presentations with gj-tubes required investigations in the ED which is illustrated in Table 2.

ED presentations due to gj-tube complications were more likely than presentations due to g-tube complications to require an overnight admission to hospital (40% vs 7%; $p=0.001$). (Table 4) The four presentations due to gj-tubes that resulted in an admission required replacement via interventional radiology, which is a service primarily available during standard working hours. ED presentations in which the chief presenting complaint was tube dislodgement were least likely to result in a hospital admission (6% vs 12-33% for other presenting complaints). The six admissions that resulted from dislodged g-tubes involved initial type g-tubes that required reinsertion, three of which required reinsertion in the operating theatre.

Discussion

To our knowledge, this is the first study to report on ED presentations due to feeding tube complications specifically in children with CP. By using a population CP cohort identified from a CP register, we were able to report on a large number of feeding tube related ED presentations

to Victoria's two tertiary paediatric hospitals over a five-year period. The main findings were that 1) more than two thirds of g-tube related presentations were due to tube dislodgement, and 2) the majority of dislodged g-tubes were successfully replaced by an ED physician in the ED. *Of note, a number of ED presentations* due to dislodged tubes involved initial type g-tubes. In Victoria, g-tubes are usually initially inserted by either gastroenterologists or paediatric surgeons. Most patients' g-tubes are inserted percutaneously with endoscopic assistance by a gastroenterologist unless there is a risk of complications. Non-balloon, long g-tubes are primarily used as the initial g-tube when the procedure is performed by a gastroenterologist. The initial type g-tube is then changed over to a low-profile g-tube, typically after 12 months. The low-profile g-tube is usually replaced every 6-12 months depending on the type of tube. Gastrostomy tracts are more likely to be immature and to close if dislodgement has occurred within 8 weeks of initial placement.²² This has implications for the type of education provided to carers after initial tube insertions. Specifically, carers need to be made aware of what to do in the case of tube dislodgement and, provided with education on basic tube care and prevention of tube dislodgement.

Our results are consistent with the findings of Saavedra *et al.*¹⁴ Despite the fact that most children who presented to the ED were classified as functioning at GMFCS level IV or V, 92% of presentations due to g-tube complications and 60% of presentations due to gj-tube complications did not lead to a hospital admission. This raises the question of whether dislodged g-tubes in children with CP could be effectively managed elsewhere other than a tertiary centre. Given that more than half of the total cohort of children with CP who were included in this study resided in outer metropolitan Melbourne or regional Victoria, it is likely that attendance at one of the tertiary hospital EDs required significant travel time.

Although there are only two tertiary paediatric EDs in Victoria, there are multiple other EDs across the state that care for children, including those in metropolitan and regional general hospitals. Community-based healthcare settings, many of which are run by highly experienced general practitioners and nursing staff, are also available. *It is not clear whether staff at these facilities consider themselves equipped to attend to basic gastrostomy issues in children with CP, and whether families are aware of their options for urgent care when a problem arises with their child's feeding tube. Further research in this area could focus on assessing the competency of emergency physicians in non-paediatric EDs in managing feeding tube related complaints in*

children with complex needs. More information on the proportion of parents and guardians who are trained to reinsert g-tubes, the proportion who feel confident, and the perceived barriers to learning this skill would be useful. There may be potential to restructure education, training and g-tube community support programs to help build parent and community providers' confidence. The establishment of g-tube education and support teams could strengthen state-wide education in emergency g-tube management for both children and adults. Providing parents with information about EDs or other community-based providers that are confident in managing g-tubes in children with complex needs may be helpful for families and could also provide guidance when they are considering where to present for urgent care. Ambulatory care such as g-tube/ gj-tube drop-in clinics and utilisation of Hospital-In-The-Home (HITH) services may also be important resources in feeding tube complication management in these children. Management of g-tube complications closer to home would mean decreased travel burden on families and more efficient use of tertiary hospital ED resources.

The main limitation of this study was its retrospective design. The presentations took place prior to the implementation of an electronic medical record, and as such, data relating to the tube complications had to be manually extracted from the medical records. Complete data were not always available, and there was notable variability in documentation, consistent with findings from other studies.^{14, 15} A prospective study, including active participation of patients and their families, may provide more information. Our sample size was reduced because detailed ED notes for 22% of presentations could not be located. Although inability to locate whole medical records was likely to be a random occurrence, missing notes for ED presentations may have introduced some selection bias. Our comparison of included and excluded presentations suggests that we are likely to have unreported presentations triaged as less urgent and presentations of children from areas local to the tertiary centre. The results of the sub-group analysis should therefore be interpreted with caution.

This study included data from the state's two tertiary paediatric EDs only. While key findings of this study will be applicable in many other settings, the out of hospital management and the concept of the medical home for complex patients will vary in other countries and jurisdictions. It is possible that children from the CP cohort presented to other EDs and healthcare settings with feeding tube related complaints over the study period. Data from the CP register show that approximately 13% of children with CP have a feeding tube in place, which would equate to a

total of 284 children in the CP cohort included in the original study. As such, the 87 children who accounted for the ED presentations included in the current study may not be representative of all children with CP who use a feeding tube. Finally, due to the study design and the identification of feeding tube related ED presentations according to the assigned discharge diagnoses, it is possible that some ED presentations associated with feeding tube complications were missed.

Conclusion

Ninety percent of tertiary paediatric ED presentations for feeding tube complications in children with CP were among children classified as functioning at GMFCS levels IV or V. Despite this, 91% of these presentations was able to be managed in the ED and did not require a hospital admission. As such, it is important to examine if caregivers and other metropolitan, regional and rural health professionals can be supported to manage some of these complications closer to the child's home.

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Tables

Table 1: Description of the 183 ED presentations

	n	(%)
Patient characteristics		
GMFCS level		
I	2	(1.0)
II	7	(3.8)
III	4	(2.2)
IV	36	(19.7)
V	128	(70.0)
Unknown	6	(3.3)
Epilepsy		
No	58	(31.7)
Yes	124	(67.8)
Unknown	1	(0.5)
Age at presentation		
0-4 years	73	(39.9)
5-9 years	49	(26.8)
10-14 years	48	(26.2)
15-19 years	13	(7.1)
Area of residence		
Inner metropolitan Melbourne	77	(42.1)
Outer metropolitan Melbourne	74	(40.4)
Regional Victoria	19	(10.4)
Unknown	13	(7.1)
Tube characteristics		
Tube type		
G-tube	151	(82.5)
GJ-tube	10	(5.5)
Other tube	18	(19.8)
Unknown	4	(2.2)
Time since initial tube insertion		
< 1 month	9	(4.9)
1 – 6 months	23	(12.6)
7 – 12 months	19	(10.4)
13 – 24 months	20	(10.9)
>24 months	81	(44.3)
Unknown	31	(16.9)
Presentation characteristics		

Time of presentation		
08:00 - 17:59	124	(67.8)
18:00 - 07:59	59	(32.2)
Triage category		
ATS 1	0	
ATS 2	1	(0.6)
ATS 3	98	(53.6)
ATS 4	61	(33.3)
ATS 5	23	(12.6)
Departure disposition		
Admitted	17	(9.3)
Home	165	(90.2)
Failed to wait	1	(0.6)

ED emergency department; GFMCS, gross motor function classification system; G-tube, gastrostomy tube; GJ-tube, gastrojejunostomy tube; ATS, Australasian Triage Scale

Table 2: Description of 161 presentations known to be due to gastrostomy and gastrojejunostomy tube complications: main presenting complaints, investigations and complications in the emergency department

	Tube type	
	G-tube (n=151)	GJ-tube (n=10)
Tube type		
Low profile g-tube: balloon retention device (e.g. Mic-Key)	114 (76.0)	- -
Long g-tube: initial type PEG	18 (11.9)	- -
Long g-tube: balloon retention device	6 (4.0)	- -
Low profile g-tube: soft retention flange (e.g. bard button)	5 (3.3)	- -
Other/Unknown	8 (5.3)	- -
Main presenting complaint		
Tube dislodged/fallen out	105 (70.0)	2 (20.0)
Tube leakage	15 (10.0)	2 (20.0)
Tube obstructed/clogged	5 (3.3)	3 (30.0)
Tube malfunction NEC	4 (2.7)	1 (10.0)
Tube site infection	3 (2.0)	0
Tube site granulation	3 (2.0)	0
Tube site bleeding	3 (2.0)	0
Other/Unknown	13 (8.0)	2 (20.0)
Investigations in the ED		
Establish vascular access	5 (3.3)	2 (20.0)
Laboratory study (e.g. blood culture, urine analysis)	5 (3.3)	2 (20.0)
Radiographic study (e.g. fluoroscopy)	11 (7.3)	2 (20.0)
Attempt to flush tube with water or other substance	21 (14.0)	1 (10.0)
None recorded	108 (72.0)	4 (40.0)
Complications in the ED		
Failed attempt/s at tube re-insertion	17 (11.3)	0
Bleeding	1 (0.7)	0
Displaced tube	1 (0.7)	0
None recorded	115 (76.7)	10 (100.0)

ED, emergency department; G-tube, gastrostomy tube; GJ-tube, gastrojejunostomy tube; PEG, percutaneous endoscopic gastrostomy; NEC, not elsewhere classified

Table 3: Management of dislodged g-tubes

	G-tube (n=105)
Consult required	
Yes	30 (28.6)
<i>General surgery</i>	13
<i>Gastroenterology</i>	12
<i>Other</i>	5
No	75 (71.4)
Tube replacement	
Replaced in the ED	94 (89.5)
<i>ED physician</i>	74
<i>Surgeon</i>	9
<i>Gastroenterologist</i>	2
<i>ED nurse</i>	2
<i>Gastro/PEG outreach nurse</i>	6
<i>Other</i>	1
Replaced in an operating theatre	3 (2.9)
Other	1 (1.0)
Unknown	5 (4.8)
Tube not replaced	2 (1.9)

ED emergency department; G-tube, gastrostomy tube;

Table 4: Description of ED presentations due to g-tube or gj-tube complications that resulted in a hospital admission compared to those that did not

	All	Admitted to ward	Not admitted	
	n	n (%)	n (%)	p-value
All	161	15 (9.4)	146 (90.6)	
Tube type				0.001
G-tube	150	11 (7.3)	140 (92.7)	
GJ-tube	10	4 (40.0)	6 (60.0)	
GMFCS level				0.235
I-III	13	0	13 (100.0)	
IV-V	142	14 (9.9)	128 (90.1)	
Unknown	6	1 (16.7)	5 (83.3)	
Triage				0.854
ATS 1-3	93	9 (9.7)	84 (90.3)	
ATS 4-5	68	6 (8.8)	62 (91.2)	
Chief presenting complaint				0.001
Tube dislodged	107	6 (5.6)	101 (94.4)	
Tube leakage	17	2 (11.8)	15 (88.2)	
Tube obstructed/clogged	8	1 (12.5)	7 (87.5)	
Tube site infection	3	0	3 (100.0)	
Tube site granulation	3	0	3 (100.0)	
Tube site bleeding	3	1 (33.3)	2 (66.7)	
Other/unknown	11	5	7	
Consult required				<0.001
Yes	59	15 (25.4)	44 (74.6)	
No	102	0	102 (100.0)	

G-tube, gastrostomy tube; Gj-tube, gastrojejunostomy tube; GMFCS, gross motor function classification system; ATS, Australasian Triage Scale

G-tube type	Long g-tube: initial PEG	Long g-tube: balloon retention	Low-profile g-tube: balloon retention	Low-profile g-tube: soft plastic retention flange	Unknown	Total
Main presenting complaint						
Tube dislodged	9	5	86	1	4	105
Tube obstructed	2	0	3	0	0	5
Tube malfunction	0	0	4	0	0	4
Tube leakage	2	1	11	0	1	15
Tube site infection	1	0	2	0	0	3
Tube site granulation	1	0	1	1	0	3
Tube site bleeding	0	0	0	2	1	3
Other	3	0	7	1	2	13
						151

Table 5: Description of 151 presentations with gastrostomy complications and the main presenting complaint according to gastrotomy tube type.

G-tube, gastrostomy tube; PEG, percutaneous gastrostomy

Figures

Figure 1: Flowchart

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