One year outcomes of Congenital Duodenal Obstruction – a population based study

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Abstract

Objectives

Congenital duodenal obstruction (CDO) occurs in 1.2 per 10,000 live births and is frequently associated with other anomalies, most commonly cardiac. The aim of this study was to report important outcomes to 1 year following surgical repair.

Methods

This was a prospective population-based study using the British Association of Paediatric Surgeons Congenital Anomaly Surveillance System. Cases were identified at specialist pediatric surgical centres in the United Kingdom during a 12 month period starting in March 2016. Outcomes were recorded at 1 year following surgical repair.

Results

There were 100 infants with possible follow-up at 1 year and follow-up was achieved in 80 of these (80%) of whom 76 were alive at 1 year. The remainder had been discharged home although one remained on parenteral nutrition. Five (6.1%) infants underwent repeat surgery for reasons related to CDO and overall 23 (23%) experienced at least one central venous catheter related complication within 1 year. Overall mortality either before repair or within 1 year following surgical repair was 8.4% (95% CI 2.5-14.4%), no deaths were related to CDO.

Conclusions

One year outcomes for CDO are generally very good with poor outcomes typically related to co-morbidities. These data are useful for national benchmarking and parental counselling.

Keywords

Congenital duodenal obstruction; duodenal atresia; duodenal stenosis; congenital cardiac disease.

What is known

- Congenital duodenal obstruction (CDO) occurs in 1.2 per 10,000 live births and is frequently associated with other anomalies.
- Management involves surgical repair, usually within the first few days of life.

What is new

- Overall mortality for CDO at 1 year following surgical repair was 8.4% (95% CI 2.5-14.4%).
- Twenty-three infants (23%) experienced at least one central venous catheter related complication.
- The median duration of parenteral nutrition administration, when used, was 11 (2-365) days with only one child remaining on this at 1 year due to co-existing ileal atresia.
- These outcomes from a population-based study are generally good.

Introduction

Congenital duodenal obstruction (CDO) consisting of duodenal atresia or stenosis has an estimated incidence of 1.2 cases per 10,000 live births and requires surgical repair that is usually performed within the first few days of life.[1] Associated congenital anomalies are common, with cardiac abnormalities occurring most frequently. Chromosomal anomalies are also common and trisomy 21 is seen in around a third of cases.[2] Despite this, previous reports of outcomes of CDO are generally good with high proportion of infants achieving full enteral feeds, a low reoperation rate and even lower mortality rates.[3, 4]

Existing literature predominantly focuses on single centres collecting data over long durations and therefore reported outcomes do not necessarily represent contemporary practice.[5, 6] Follow-up is often incomplete and of variable duration. The aim of this study was to report contemporary outcomes of infants at 1 year following surgical repair of CDO using proven population based methodology.

Methods

This analysis was undertaken according to a pre-specified protocol with use of the British Association of Paediatric Surgeons Congenital Anomaly Surveillance System. Ethical approval was granted by the National Research Ethics Service (NRES) South Central- Oxford A committee (ref: 12/SC/0416).

Case identification

This process of case identification has been described previously.[1] Cases of congenital occlusion or narrowing of the duodenum associated with atresia, stenosis, duodenal web or annular pancreas presenting prior to a post-conceptual age of 44 completed weeks live born were prospectively identified over a 1 year period from 1st March 2016 at all 28 specialist pediatric surgical centres in the UK. Cases of duodenal occlusion or narrowing caused by

congenital bands associated with malrotation, intestinal volvulus, duplication cyst or malignancy without an intrinsic duodenal abnormality were excluded.

Data collection

After a case was identified via a monthly reporting card a data collection form was sent for each case to the specialist pediatric surgical centre at day 28 and then 1 year following surgical repair. These forms were returned and data were entered into a database at the National Perinatal Epidemiological Unit (NPEU), Oxford. Unreturned forms were requested by the study team at least twice.

Outcomes

Outcomes of interest were defined in the study protocol and were time to achieve full enteral feeds, use and duration of parenteral nutrition, number of central venous catheters (CVCs - including both peripherally inserted and centrally inserted catheters) used, CVC related complications, anastomotic complications, duration of initial inpatient hospital stay, need for further admission / reintervention related to CDO, standardized weight gain/loss and death. Short term outcomes to 28 days have been reported previously;[1] here we report outcomes to one year following initial surgical repair.

Statistical analysis

Statistical analysis was undertaken using StataSE v15 (StataCorp LLC, Texas, USA). Fishers exact test was used for 2x2 categorical data and Chi squared was used for categorical data with more than 2x2 analysis. A Mann Whitney U test was used for non-parametric continuous data. Data are reported as median with range or number with percentage as appropriate. A Kaplan-Meier plot was constructed to investigate time to achieve full enteral feeds and statistical comparison between groups undertaken with the Mantel-Cox test. $P<0.05$ was considered significant.

To calculate standardized weight change the *zanthro* package for StataSE v15 was used to calculate weight-for-age z scores using UK WHO term and preterm growth reference charts. For infants with Down syndrome the *Zemel 2015* weight-for-age growth chart was used.[7] The weight-for-age z score, also known as SD score, is a measure of the SD of weight from the mean value of a reference population matched for gestational age and sex.[8]

Results

Infant demographics

In total there were 103 infants with CDO identified during the study period, of these one infant died prior to surgical repair and two died within 28 days of repair. This left 100 infants with potential for follow-up at 1 year and data were available for 80 (80%) of these (no data were returned for 20 infants from participating centres despite multiple reminders). Full details of the infants in this study including associated anomalies and management has previously been reported.[1] Infant characteristics, CDO type and management were similar between those with and without follow up (table 1), with the exception that those infants lost to follow-up had a younger gestational age at birth.

Outcomes

Nutritional outcomes and weight gain

An overview of outcomes is shown in table 2. Full enteral feeds were achieved by nearly 90% of infants at 28 days and all but one infant by one year post surgical repair (Table 2 and Figure 1). The median duration of PN was 11 days (range 2-365). Nine infants (9.1%) remained PN dependent at 28 days of whom 5 had co-existing gastrointestinal anomalies. These were oesophageal atresia (OA) with traceho-oesophageal fistula (TOF) (n=2), OA and anorectal malformation (ARM) (n=1), OA with TOF and ARM and ileal atresia (n=1) and ileal atresia (n=1). Those infants with an associated gastro-intestinal (GI) tract anomaly achieved full

enteral feeds later than those without (Figure 1). One infant remained PN dependent at 1 year due to co-existing ileal atresia and subsequent short bowel syndrome.

The median reduction in weight-for-age z score between birth and 1 year was less than between birth and 28 days post surgery suggesting a degree of 'catch-up' growth between 28 days and 1 year.[1] There was no significant association between the presence of another GI anomaly or cardiac anomaly and standardized weight change between birth and 1 year, compared to those without one of these anomalies (-0.70 *vs* 0.14 [p=0.06] and -0.10 *vs* -0.12 [p=0.88] respectively). Additionally, there was no significant association between the presence of another GI anomaly or cardiac anomaly and raw standardised weight-age scores at 1 year following CDO repair compared to those without one of these anomalies (-1.11[-2.09-0.62] *vs* -0.48[-2.55-1.57], [p=0.15] and -0.52[-2.55-1.44] *vs* -0.97[-2.25-1.57], [p=0.60] respectively).

Length of stay

The median inpatient length of stay post surgical repair was 20 (6-149) days. At 28 days following surgical repair 76% infants had been discharged home either from the surgical neonatal unit or from a local neonatal unit following repatriation. Those who had not been discharged home at 28 days following operative repair had a lower gestational age at birth (33.1 *vs* 37.8 weeks, p<0.0001), were more likely to have other gastrointestinal tract anomalies (32% *vs* 10%, p=0.03) but not more likely to have a cardiac anomaly (58% vs 35%, p=0.11) than those who were discharged home.

Re-operation and complications

In total there were 11 post-operative complications within 1 year of surgical repair. There were five repeat laparotomies for complications associated with CDO. Two of these were undertaken after 28 days and were both adhesiolysis and resection of a segment of non-viable jejunum for small bowel obstruction. Three babies had a repeat laparotomy before 28 days following CDO repair for small bowel obstruction (n=1, treated with adhesiolyis and duodenoplasty) or suspected anastomotic leak (n=2, proven in 1). One baby developed chest

sepsis requiring ventilation and the other complications were treated non-operatively. These were wound infection (n=3), skin dehiscence (n=1), incisional hernia (n=1) and a stich abscess (n=1).

There were 34 surgical procedures performed for reasons unrelated to CDO in 19 (24%) infants between 28 days and 1 year following CDO repair. These were esophageal atresia/ tracheo-esophageal fistula related (n=8), cardiac surgery (n=6), urology surgery (n=4), stoma reversal (n=4), posterior sagittal anorectoplasty (n=3), inguinal hernia repair (n=2), tunnelled central line insertion (n=2) and other procedure (n=5).

There were 2 infants who had not experienced a CVC related complication at 28 days who went on to have a complication by one year meaning 23/102 (23%) infants who underwent surgical repair of CDO experienced a CVC related complication.

Mortality

There were 4 deaths between 28 days and one year post CDO repair in addition to the previously reported[1] 3 deaths either prior to or within 28 days of repair (cause of death: bilateral chylothorax, hypoxic ischaemic encephalopathy and multiple associated anomalies including pulmonary hypertension) giving an overall estimate of one year mortality rate of 8.4% (95% CI 2.5-14.4%). Of these late deaths, two were due to sepsis, one was sudden death in infancy and one was cause was unknown. Of the babies who died of sepsis, one had pneumococcal septicaemia and one had severe sepsis following cardiac surgery involving a Blalock–Taussig shunt for tetralogy of Fallot. All those infants who died had an associated cardiac anomaly and four had trisomy 21. No deaths were reported to be related to CDO.

Discussion

This population-based study of CDO using proven BAPS-CASS methodology aimed to report important outcomes at 1 year following surgical repair of this condition. Despite a high incidence of associated anomalies with CDO the outcomes found in this study are generally

good. These data can be used to counsel parents in which CDO is suspected on antenatal ultrasonography or following postnatal diagnosis.

The one year follow-up rate in this study (80%) is similar to the rate achieved in other BAPS-CASS studies (70-88%).[9, 10] We found that the gestational age at birth of those infants followed up was greater than those lost to follow-up which is not something reported by previous similar studies.[10-13] It is possible that the reduced number of infants followed-up at one year is due to unreported mortality related to prematurity although we have no data to support this and no mechanism to investigate it further. In all other aspects the two groups of infants were similar, including presence of associated anomalies, hence we believe the risk of bias in these data is relatively low.

In this population with a high incidence of associated anomalies, the mortality rate at 1 year was 8.4% but of note none of the deaths were related to CDO. In the existing literature a mortality rate of between 3.4% and 22% is reported.[14, 15] This wide variation in survival may be due to disparity in methodology and variable follow-up duration between studies. Death related to CDO in the literature is extremely rare with this complication only described in a handful of infants.[5, 16]

Another important outcome, particularly for families, is length of hospital stay. This is infrequently reported, perhaps because this outcome is so variable depending on whether other congenital anomalies are present or not. The median of 20 days post-surgical hospital stay in this study is similar to a mean of 22.5 days reported by *Mustafaw et al.* but is higher than a single centre study in the UK that reports a length of stay of just 14 days.[3, 17] In such a heterogeneous group of infants it is hard set standards for length of stay but stay beyond 28 days was associated with other co-existing gastrointestinal tract anomaly or prematurity.

We have previously reported feeding outcomes to 28 days, demonstrating variation in post-operative feeding strategy. With this longer duration of follow-up we provide more accurate epidemiological data on feeding outcomes. Of note almost all infants are fully enterally fed by

1 year; failure to achieve full enteral feeds is related to other gastrointestinal anomalies rather than CDO. These longer term data also remind surgeons of the ongoing risk of CVC related complications with further episodes occurring beyond 28 days and an incidence of adhesional small bowel obstruction following neonatal laparotomy. Overall the gastrointestinal outcomes for infants born with CDO are extremely good but of note nearly one quarter of all infants experienced at least one complication related to a central venous catheter.

This study is limited by its observational nature and relatively low sample size due to the rarity of the condition but reports important outcomes for both families and clinicians from a prospective population based study at 1 year following CDO repair.

Conclusion

Outcomes for CDO are generally good and complication rates related to surgical repair are low. These data can be used by individual centres to benchmark outcomes and to inform parental counselling. Further work to confirm these positive outcomes into later childhood would provide further reassurance.

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Figure legend

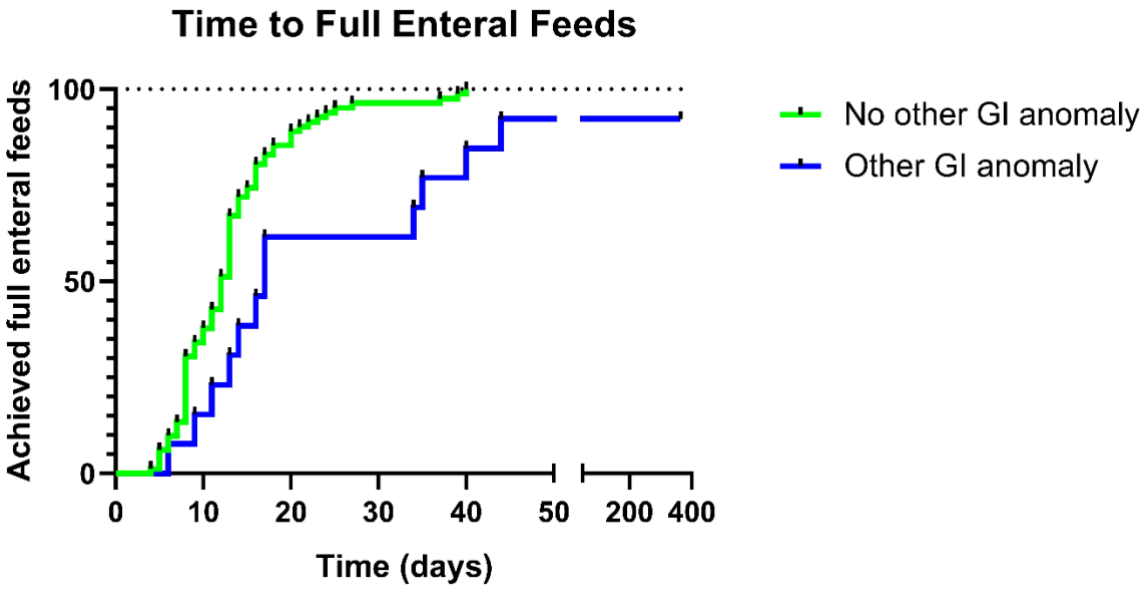

Figure 1 – Kaplan-Meier plot of time to full enteral feeds in days. Infants with associated gastrointestinal anomaly are in blue and those without, in green. Data were censored if full enteral needs had not been achieved at 1 year (n=1) and infants who died were excluded. Associated GI anomalies were anorectal malformation (n=6), oesophageal atresia with tracheo-oesophageal fistula (n=5), isolated oesophageal atresia (n=4), Meckel's diverticulum (n=2), ileal atresia (n=2) and cloaca anomaly (n=1). There is a significant difference between the two groups on Mantel-Cox test (p=0.002).

		One year follow-up (n=80)	Lost to follow-up (n=20)	P
Male, n (%)		45 (56)	9 (45)	0.37
Gestational age at birth, weeks (range)		36.9 (25.6-42.3)	33.7 (27-38.6)	**0.001**
Birthweight, grams (range)		2535 (800-4320)	2195 (1490-3600)	0.08
Associated anomalies, n (%)		55 (69)	13 (65)	0.75
Atresia type, n (%)	I	28 (35)	11 (55)	0.29
	II	5 (6.3)	0 (0)	
	III	31 (39)	5 (25)	
	Not reported or not identified	16 (20)	4 (20)	
Site of obstruction, n (%)	Pre-ampullary	21 (26)	4 (20)	0.32
	Post-ampullary	37 (46)	7 (35)	
	Not reported or not identified	22 (28)	9 (45)	
Age at surgery, days (range)		2.5 (0-75)	2 (1-22)	0.83
Repair type, n (%)	Duodenoduodenostomy	64 (80)	13 (68)	0.50
	Duodenojejunostomy	11 (14)	3 (16)	
	Membrane incision	1 (1.3)	0 (0)	
	Membrane resection	2 (2.5)	2 (10.5)	
	Duodenoplasty	2 (2.5)	1 (5.3)	
TAT used, n (%)		37 (46)	6 (30)	0.19
PICC/CVC used, n (%)		71 (89)	18 (90)	0.87
PN used, n (%)		71 (89)	17 (85)	0.64

Table 1 – Characteristics and management of infants with and without known follow-up status at 1 year following CDO repair*. TAT = trans-anastomotic tube, PICC = peripherally

inserted central catheter, CVC = central venous catheter, PN = parenteral nutrition. *those who died by 28 days following repair excluded (n=3).

Outcome	Number of infants n (% of those with data) or median (range)
Achieved full enteral feeds at 1 year	67 (99%)
Time to full enteral feeds post op (days)	13 (4-365†)
PN at 1 year post op	1 (1.3%)
PN duration (days)	11 (2-365†)
Discharged home at 1 year	69 (100%)
Inpatient stay post op (days)	20 (6-149)
Repeat surgery related to CDO	5 (6.1%)
PICC/CVC related complication	23 (23%)
Change in standardised weight score (z score) - birth to 1 year	-0.12 (-2.57-2.56)
Standardised weight score (z score) at 1 year$	
Between 2 and -2	50 (91%)
Between -2 and -3	5 (9.1%)
Mortality	7 (8.4%)

Table 2 – Outcomes at one year following surgical repair of CDO. PN = parenteral nutrition, PICC = peripherally inserted central catheter, CVC = central venous catheter, CDO

= congenital duodenal obstruction. † Includes 1 infant remaining on PN at 1 year and hence not fully enterally fed. $ Standardised weight data available for 55 infants.