

Background:

- Congenital Hyperinsulinism (CHI) is the most common cause of severe and recurrent hypoglycaemia in childhood.
- Many patients require nasogastric tube (NGT) or gastrostomy feeding to meet nutritional demands and often enriched feeding is required to maintain blood glucose. When this fails, parenteral nutrition (PN) is often used.
- Non-oral feeding, nausea inducing medications and interruption of normal feeding milestones create an environment primed for feeding problems¹.
- Feeding problems are a recognised complication in CHI and affect up to 45% of patients².
- Severity of CHI is known to be a risk factor for feeding problems and these often persist beyond resolution of hypoglycaemia³.

Aims:

1. To investigate types of feeding problem and rates of persistence over three years.
2. Identify factors that predict resolution of feeding problems in CHI.

Methods:

- All patients with CHI (detectable insulin at the time of hypoglycaemia) were reviewed by specialist Speech and Language and Dietetics teams. Those with feeding problems were entered prospectively onto a database.
- Feeding problems were classed as: **sucking/swallowing problems, feed aversion, vomiting** and **requirement for non-oral feeding**.
- Patients were also evaluated for neurodevelopmental problems which were classified as none, some or severe.
- Feeding problems were assessed for persistence on a 6 monthly basis over a two year follow up period.

Patient characteristics:

- Over a 3 year period, 25 of 138 patients with CHI were identified as having feeding problems:
 - Mean age at diagnosis was 3 days (range 1 – 324)
 - Fourteen patients (56%) had a confirmed genetic mutation causing CHI (*ABCC8*, *KCNJ11* or *GCK*)
 - Six patients (24%) had focal CHI and four underwent lesionectomy.
 - Eight patients (32%) required subtotal pancreatectomy.
 - Neurodevelopmental problems were present in eight patients (32%).
 - Mean Glucose Infusion Rate (GIR) was 14mg/kg/min
 - All patients were treated with Diazoxide but 18 (72%) were not responsive and required octreotide.

Results:

- Eight patients required PN with high concentration dextrose.
- Feeding problems were common:
 - Vomiting was present in 20 patients (80%).
 - This resolved by mean 2 months post discharge.
 - Sucking and swallowing problems were present in six (24%) and two (8%) patients respectively.
 - Feed aversion was present in 17 patients (68%).
- **Feed aversion resolved slowly with a mean time to resolution of 240 days and 40% with no resolution two years later (Fig 1).**
- **Sixteen patients (64%) required non-oral feeding, with 14 still needing this at discharge.** A decrease was seen over the first 12 months but then a plateau in those coming off non-oral feeds (Fig 2).
- Subtotal pancreatectomy did not speed time to resolution of feed aversion ($P = 0.87$). However, **those who underwent lesionectomy had a much shorter time to resolution of feed aversion post discharge** (82 days vs 777 days, $P = 0.16$).
- When considering all **feeding problems as a composite, focal lesionectomy also decreased time to resolution** (30 days vs 590 days, $P = 0.009$)(Fig 3).
- None of: neurodevelopmental problems, gene mutation status, glucose infusion rate, medications or PN/non-oral feeding showed any association with time to resolution of feeding problems.

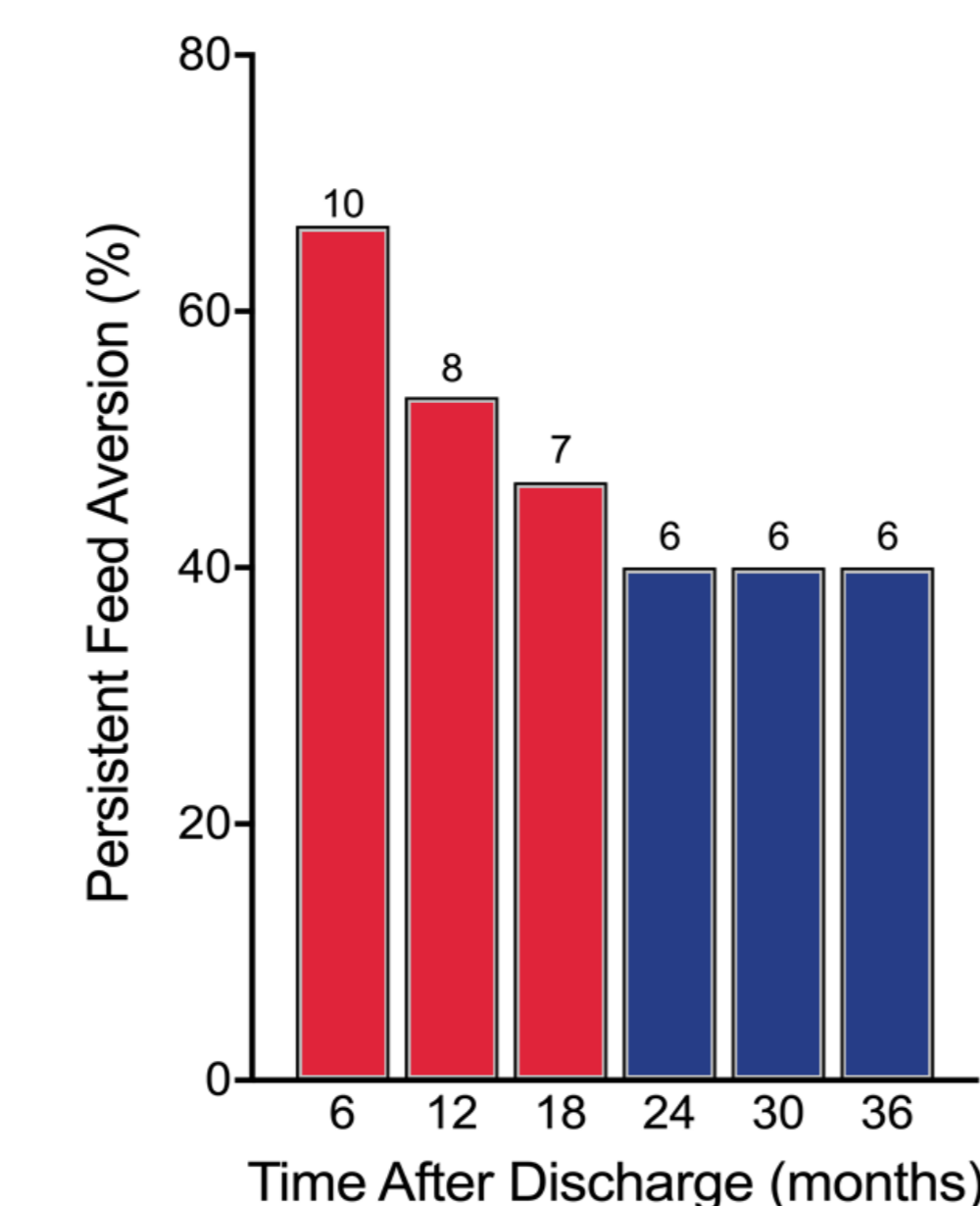


Figure 1. Persistence of feed aversion post discharge

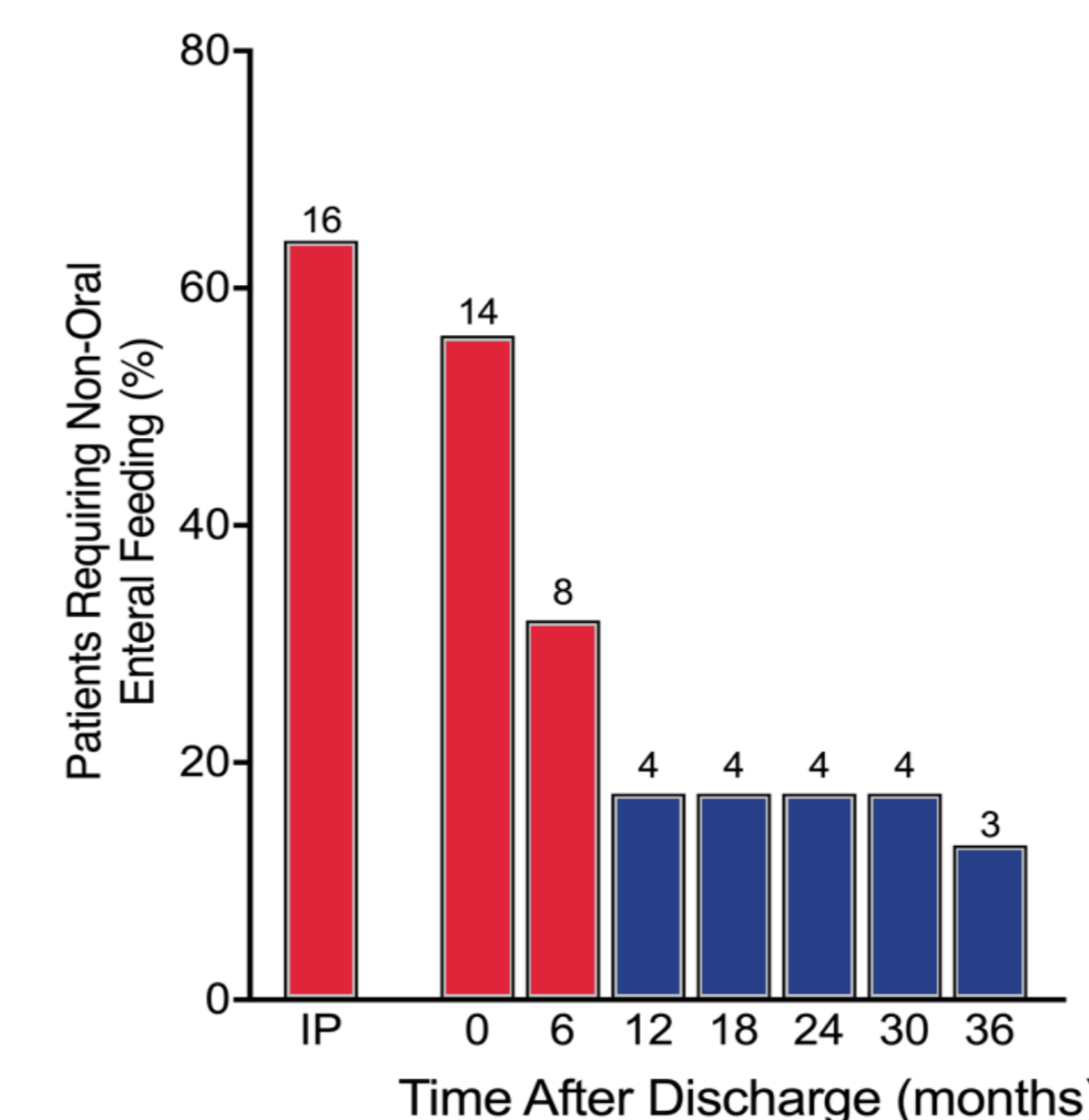


Figure 2. Patients requiring non-oral feeding post discharge

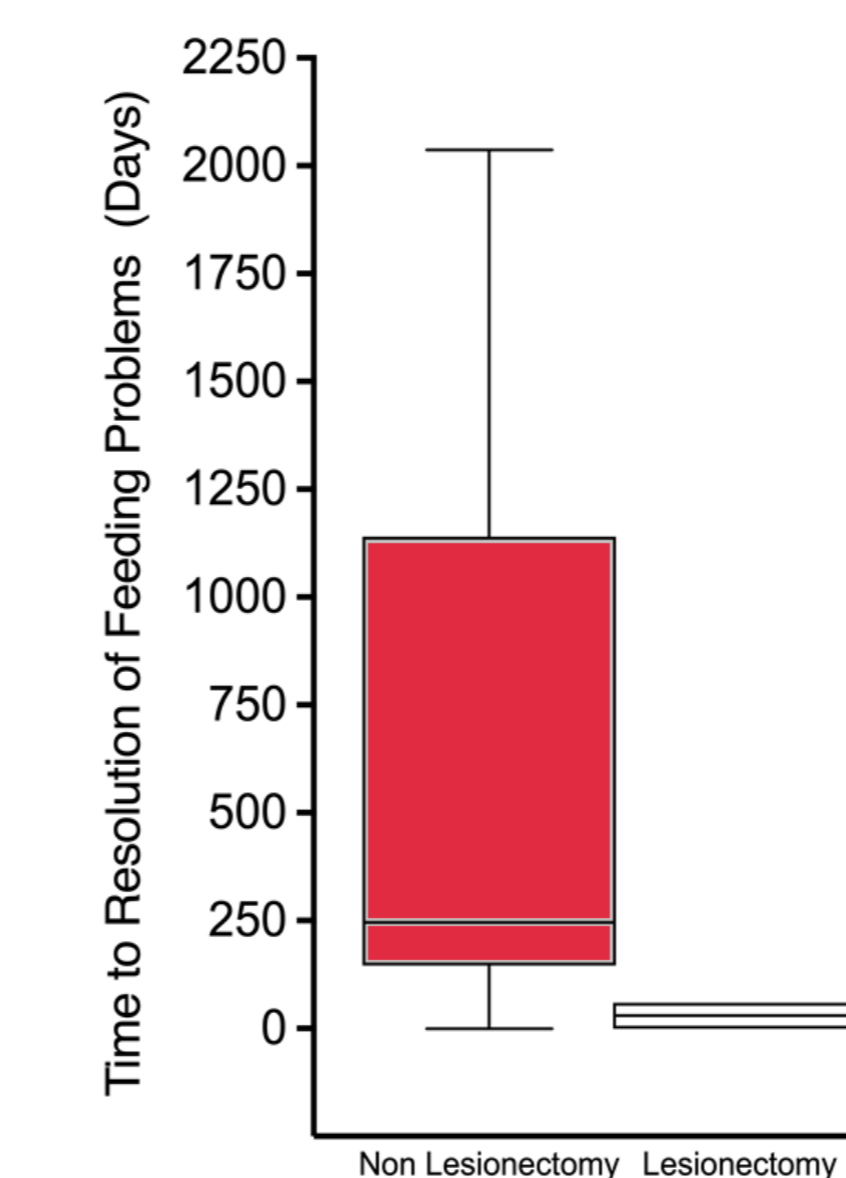


Figure 3. Time to resolution of feeding problems by surgical state

Conclusions

- **Feeding problems are common in patients with CHI.**
- **Certain feeding problems, such as feed aversion, may take years to resolve.**
- **Curative lesionectomy is the only identified positive prognostic factor for resolution of feeding problems.**

References:

1. Hall C, Banerjee I. Humana Press Inc. 2019. doi 10.1007/978-3-030-02961-6_13
2. Al-Shanafey S, Alkhudhur H. Journal of Pediatric Surgery. 2012. doi 10.1016/j.jpedsurg.2012.03.002
3. Banerjee I et al. Front Endocrinol. 2016. doi 10.3389/fendo.2016.00008