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CASE REPORT

Case report: nutritional management of a repaired congenital diaphragmatic hernia

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Congenital diaphragmatic hernia (CDH) is a rare diaphragm malformation that historically had low survival rates, but advances in care have improved outcomes. This case study discusses the outpatient management of an 8-month-old male infant who survived CDH but, due to a severe oral aversion, required nutritional adaptations to ensure optimal growth was maintained. Barriers experienced included volume tolerance, feeding tolerance, and the need for feeding skill development. The case emphasises the importance of individualised nutritional management.

Keywords congenital diaphragmatic hernia (CHD), growth faltering, multidisciplinary approach, oral aversion

Introduction

Congenital diaphragmatic hernia (CDH) is a serious birth defect that affects approximately 2.3 out of every 10,000 live births worldwide, with the Bochdalek hernia being the most common type.[1] CDH is characterised by a malformation of the diaphragm that allows abdominal organs to move into the thoracic cavity.[1] Nutritional complications frequently persist despite advancements in medical and surgical interventions that enable early detection and management and improve survival rates.[2,3]

Common nutritional challenges include growth faltering, gastroesophageal reflux, oral aversions, poor suck–swallow reflex, and increased metabolic demands.[3] Studies indicate that up to 56% of infants with CDH experience growth faltering within the first three years of life, with about one-third of survivors requiring a feeding tube to meet their nutritional needs.[4] As growth faltering can lead to irreversible consequences for growth and development, especially in the first two years of life, understanding nutritional strategies to improve outcomes is crucial.[5] Regular nutritional screening and treatment are believed to help mitigate growth faltering, especially between the 6–12-month period following birth to promote attainment of catch-up growth.[3]

Outpatient case study

Patient X, a male infant, seen in the outpatient setting, was diagnosed with a right-sided Bochdalek hernia (Type D defect) during a 20-week anatomy scan. At 31 weeks' gestation, his mother experienced premature rupture of membranes, yet he was only delivered vaginally at 37 weeks, with a birthweight of 2.46 kg. The hernia was surgically corrected on day three of life, and he required mechanical ventilation for 19 days.

At eight weeks of age, imaging studies revealed small bowel malrotation, but surgery was not needed as there were no obstructive symptoms. In view of severe oral aversion, a 16-F percutaneous endoscopic gastrostomy (PEG) was placed at 32 weeks of life (±7 months). An outpatient dietetic consultation was arranged, on referral from a physio- and speech therapist, to assist the infant with growth monitoring and introduction of blenderised tube feeding.

Anthropometry obtained at outpatient consultations

During the initial consultation, when the patient was 8 months (39 weeks) old, Patient X was severely underweight and stunted, indicating chronic malnutrition. From 39 to 44 weeks of age, he gained 360 g, reflecting a weight gain velocity of 10 g per day (1.5 g/kg/day). However, the nutritional regimen of fortified EBM only (1.3 g/kg/day protein and 109 kcal/kg/day energy) was insufficient to achieve the required catch-up growth of at least 10 g/kg/day.[6] Between 44 and 47 weeks of life, his weight gain velocity increased to 2.1 g/kg/day after introducing a mixture of infant formula, EBM milk feeds, and one blenderised tube feed (BTF), marking his first introduction to solid food. However, an optimal weight gain velocity had still not been reached at 47 weeks (10 months). Patient X's anthropometric measurements are detailed in Table 1.

Biochemical and clinical findings at outpatient consultations

No biochemical values were available, and no nutritional deficiencies or wasting were noted. Slight pallor was observed. The PEG site showed no signs of leakage or redness. The infant still required evening oxygen support due to recurrent apnoea episodes.

Outpatient dietary assessment and management

During the first outpatient visit it was established that the mother had been feeding the infant expressed breast milk (EBM) with thickener every three hours, with evening feeds being infused continuously over a six-hour period due to vomiting via the PEG. The mother had also been following a cow milk protein (CMP) avoidance diet related to the concern regarding a possible allergy due to the presence of occasional blood-stained stools. A week before the first nutritional consultation, the mother began administering a multivitamin, which provided 10 mg of iron.

Patient X presented with a severe oral aversion, as assessed by a speech therapist, starting around nine weeks after delivery and continuing throughout infancy. By seven months, the infant

Table 1: Anthropometric measurements during growth monitoring period

Age (post-delivery)	Weight (kg)	z-score (SD)	Length (cm)	z-score (SD)	Head circumference (cm)	z-score (SD)	Weight-for- length z-score (SD)	BMI (kgm^2)	z-score (SD)	MUAC (cm)	z-score (SD)	Growth velocity g/day (g/kg/day)
Birth	2.46	−2.00	46.0	−2.05	33.8	> −1, < 0	> −1, < 0	11.6	−1.52	N/A	N/A	N/A
39 wks (8 mo)	6.36	−3.02	63.0	−3.96	43.5	> −1, < 0	> −1, < 0	16.0	−0.86	13.5	> −1, < 0	N/A
41 wks (9 mo)	6.50	−2.99	65.0	−3.39	44.0	> −1, < 0	< −1; > −2	15.4	−1.34	14.0	> −1, < 0	8.5 (1.2)
43 wks (9 mo)	6.64	−2.88	66.0	−3.11	44.5	> −1, < 0	< −1; > −2	15.2	−1.34	14.0	> −1, < 0	7.8 (1.1)
44 wks (10 mo)	6.72	−2.84	66.5	−3.03	45.5	> 0, < +1	< −1; > −2	15.2	−1.45	14.5	> −1, < 0	10.0 (1.5)
47 wks (10 mo)	6.90	−2.79	67.0	−3.18	45.5	< + 0, > −1	< −1; > −2	15.4	−1.23	Not available		14.0 (2.1)
54 wks (12 mo)	7.30	−2.62	69.0	−2.73	46.0	On + 0	< −1; > −2	15.0	−1.39	15.0	> + 0, < + 1	7.8 (1.2)

Note: weight, length and BMI z-scores (SD) were generated using World Health Organization (WHO) AnthroPlus software.
Measurements were evaluated using World Health Organization (WHO) child growth standards and expressed as standard deviations (SD).
Abbreviations: BMI: body mass index, cm: centimetre, kg: kilogram; MUAC: mid-upper arm circumference; mo: months; N/A: not applicable,; SD: standard deviation; wks: weeks.

could not consume EBM or solid foods orally, leading to a referral for a swallowing evaluation.

An Omnipaque barium swallow study indicated initial reluctance to swallow semi-solid contrast. However, it showed a normal oropharyngeal phase with no aspiration or gastroesophageal reflux (GER). The infant, therefore, started feeding therapy using the sequential oral sensory (SOS) feeding approach to develop oral feeding skills. This transdisciplinary method is used to improve children's acceptance of various foods by focusing on sensory experiences, play, and gradual tasting of different foods in a non-pressuring environment.[7]

To ensure adequate nutritional support, it was initially decided to defer BTF until an evaluation by a gastroenterologist to investigate vomiting and risk of obstruction due to small bowel malrotation could be done. The thickening agent was stopped due to a lack of evidence of reflux. As the benefits of EBM provision are well documented, EBM provision was encouraged, and the infant was placed on larger volumes of EBM fed every four hours, with a continuous infusion of EBM in the evening over six hours. Due to the possible CMP allergy, the EBM fortifier containing intact cow milk protein was changed to single monomeric powders. Following these changes, the mother reported less frequent vomiting spells and the resolving of blood-stained stools.

Energy and protein targets were set to achieve a weight gain of 10 g/kg/day, with energy provision at 126 kcal/kg/day and protein at 2.82 g/kg/day.[6] Although these targets were set, it was challenging to fortify EBM sufficiently to meet them without using intact cow milk protein formulations or infant formula. The use of infant formula was debated due to frequent bouts of vomiting and malrotation of the small bowel, which was thought to potentially worsen tolerance. The infant struggled with the concentration of EBM feeds with monomeric powders as well as with initial trials of specialised infant formula, with increased bouts of vomiting and fussiness being documented. The infant was unable to tolerate a volume of more than 160 ml every 4 hours.

Following the gastroenterologist's assessment at 47-weeks of life (10 months), no obstruction was observed, and it was recommended that BTF be initiated whilst continuing SOS therapy to ensure skill development. The vomiting was attributed to a possible normal baseline of the infant. Table 2 provides a summary of nutritional prescriptions and progression. While the case study specifically focuses on the circumstances leading up to the recent introduction of BTF, the primary objective is to transition towards complete BTF feeds while preserving the recommended milk feed intake for infants aged between 6 and 12 months.

Discussion

EBM provision should be encouraged as the benefits offered are crucial in promoting growth and development and allowing the mother to bond with her infant. EBM provision, however, in the context of CMP allergy and the need to address growth faltering may prove challenging. Nutritional strategies for fortification would involve the administration of several monomeric powders, which may neglect protein provision due to the limited availability of CMP-free EBM fortifiers. The adding of several powders may not be sustainable due to the increased risk of feeding intolerance as well as the increased workload for caregivers.

Table 2: Recommended nutritional prescriptions and nutritional progression

							Initial		Progression					
Nutrient	**Recommendations***	**Nutrient range per 100 ml of EBM**		**Average EBM content in 100 ml**	**Nutritional content of 900 ml of EBM**	**MVT (1 ml)[2]**	**Nutrient provision (900 ml EBM with BMF + MVT)[3]**	**Percentage of requirement met (%)**	**Nutrient provision (900 ml EBM with one monomeric fortifier energy, fat, and CHO + MVT)[4]**	**Percentage of requirement met (%)**	**Nutrient provision (900 ml EBM with two monomeric fortifier energy, fat, and CHO + MVT)[5]**	**Percentage of requirement met (%)**	**Nutrient provision (two formula feeds of partially hydrolysed formula, six EBM feeds and 1 x BTF)**	**Percentage of requirement met (%)**
Energy (kcal)	793.8	65	70	67	603.0	0	637.4	80.3	626.6	79	684.2	86	446	56
Carbohydrate (g)	**95**	6	7	6.5	58.5	0	60.9	64.1	62.0	65	76.4	80	50.85	54
Total protein (g)	*17.8*	0.8	1	0.9	8.1	0	11.3	63.5	8.1	46	8.1	46	10.2	57
Total fat (g)	**31**	3.5	4	3.75	33.8	0	35.4	114.0	34.8	112	34.8	112	20.1	65
Iron (mg)	*11*	0.03	0.07	0.065	0.6	10	14.6	132.6	10.6	96	10.6	96	3.21	29
Calcium (mg)	**200**	20	25	22.5	202.5	0	353.7	176.9	202.5	101	202.5	101	366.9	183
Phosphorus (mg)	*275*	12	14	13	117.0	0	205.0	74.5	117.0	43	117.0	43	224.7	82
Magnesium (mg)	*75*	3	3.5	3.25	29.3	0	37.3	49.7	29.3	39	29.3	39	36.6	49
Sodium (mg)	**370**	15	25	20	180.0	0	252.0	68.1	180.0	49	180.2	49	162	44
Chloride (mg)	**570**	40	45	42.5	382.5	0	446.5	78.3	382.5	67	382.5	67	339.3	60
Potassium (mg)	**700**	40	55	47.5	427.5	0	524.3	74.9	427.5	61	427.5	61	396	57
Selenium (mcg)	**20**	1	2.5	1.75	15.8	0	15.8	78.8	15.8	79	15.8	79	0.3	1.5
Copper (mcg)	**220**	0.01	0.03	0.02	0.2	0	0.2	0.1	0.2	0	0.2	0	0.3	0.1
Zinc (mcg)	*3*	0.1	0.3	0.2	1.8	0	3.4	113.3	1.8	60	1.8	60	2.7	90

Abbreviations: BTF: blenderised tube feed; CHO: carbohydrate; CMPA: cow's milk protein allergy; EBM: expressed breast milk; MVT: multivitamin.

* Based on dietary reference intakes of Food and Nutrition board, Institute of Medicine, National Academies. ** Adequate intakes in bold. *** Recommended dietary allowance in italics. **** Energy calculated using 126 kcal/kg/day to achieve 10 g/kg/day weight gain, ***** Protein calculated using 2.82 g/kg/day to achieve 10 g/kg/day weight gain.

[1]Based on reference values of Kim SY, Yi DY. Components of human breast milk: from macronutrient to microbiome and microRNA. Clin Exp Pediatr 2020; 63(8): 301.

[2]An MVT with 10 mg added iron. Provided 400 IU of Vitamin D3.

[3]EBM was fortified with 8 g of hydrolysed whey breastmilk fortifier.

[4]EBM was fortified with high-energy, low-electrolyte monomeric feed (balanced blend of fat and CHO with 35% MCT related to possible CMPA).

[5]EBM was fortified with high-energy, low-electrolyte monomeric feed as well as high-energy CHO supplement related to possible CMPA.

The severity of the oral aversion also supported the use of PEG feeding. However, this PEG was only placed at 32 weeks (+/– 7 months) of life. One might question whether more timely placement of a PEG should have been encouraged to promote adequate nutritional status, especially as oral aversions affect about 70% of CHD survivors by the age of one and are more common among those who have undergone patch repairs. Furthermore, it is noted that up to 47% of CHD survivors still exhibit oral aversion by the age of two.[8]

In this case study, the duration required to achieve nutritional adequacy was hindered due to the complexities associated with the prescription of nutrients and the subsequent implementation, which faced various obstacles. From the perspective of healthcare professionals, these barriers encompassed concerns regarding the potential strain on parental resources (including the prescription of ineffective supplements or those that might exacerbate tolerance issues and increase the frequency of follow-ups), apprehension concerning the possibility of feeding regression, the time required for comprehensive investigations, and the necessary monitoring to ascertain the effectiveness of the nutritional strategy. From a parental perspective, barriers included the time commitment required to sustain breastfeeding amid the demands of daily activities, the necessary skills to implement effective strategies, and perceived feeding intolerances that necessitated alterations in nutrient administration.

Conclusion

This case study highlights that achieving nutritional goals for CDH patients may be complex, and nutritional management cannot be done in isolation. A multidisciplinary approach incorporating medical, nutritional, and developmental support is essential to optimising outcomes for infants with CDH who experience growth faltering. It would be beneficial to further research how nutrition adequacy could be promoted with the use of fortified EBM in the context of potential CMP and introduction of solids using a BTF feeding modality.

Consent for publication

Informed written consent for publication was obtained from the patient's parent.

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