Benefits of Using a Low-Calorie Whey Peptide Enteral Formula in Children with Gastrointestinal Impairment, Complex Condition and Having Lower Energy Needs - A Series of Clinical Case Reports

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Abstract

Swallowing and feeding difficulties associated with Neurological Impairment (NI) can impact on children’s ability to meet nutritional requirements orally and so enteral nutrition is often required. NI can also be associated with having lower energy requirements due to restricted mobility and a lower metabolic rate. There is some evidence to suggest that the nutritional requirements of enterally fed children can be over-estimated and lead to a disproportionate accumulation of body fat. Poor tolerance of enteral nutrition formulas including symptoms of reflux, vomiting and constipation can also be problematic in this group.

This article outlines how the introduction of a low calorie (0.6kcal/ml) partially hydrolysed whey protein formula has been beneficial for four children with NI. The case study series includes children aged seventeen months to nine years old with a range of medical conditions including global developmental delay, holoprosencephaly, cystic periventricular leukomalacia and cerebral palsy. Some of the positive outcomes observed by changing their feed regimen include reduced vomiting, bloating and constipation as well as appropriate weight stabilisation and improved growth. Moving to this formula also resulted in a less time-consuming feeding regimen for parents and better quality of life for the children and their families.

The availability of a ready to feed low calorie partially hydrolysed whey protein formula has streamlined feeding regimens while appropriately meeting the nutritional requirements of children with low energy needs and poor feed tolerance.

Introduction

Children with neurological impairment, such as those with cerebral palsy often require enteral nutrition to meet their nutritional needs due to difficulties eating and drinking orally [1]. Lower levels of energy expenditure due to restricted mobility associated with their condition can result in excess fat accumulation [2,3]. There is evidence to suggest that the nutritional requirements of enterally fed children is often over-estimated and body fat accumulation can be disproportionate, impacting on appropriate growth in this population [1]. A lower metabolic rate is also associated with significant weight gain as seen in children with brain injuries and genetic neurological conditions [2].

A nutritionally complete partially hydrolysed whey tube feed containing 0.6kcal/ml has been designed to meet the needs of children with low energy requirements (Nestlé Health Science). A tolerance and acceptability trial published in 2020 showed that this formula was well-tolerated by children aged 1-11 years [4]. The following series of case studies highlight how a low energy tube feed can be beneficial for children who have low energy requirements and poor feed tolerance.

Case Study 1

Nine year old female who will be referred to as M with feeding problems and a history of chronic constipation.

Clinical case study description

M has a history of global developmental delay, epilepsy and feeding problems from infancy. She required a Percutaneous Endoscopic Gastrostomy (PEG) insertion, which was subsequently converted to a Low-Profile Gastrostomy device (LPG). This was compounded by increasing immobility due to orthopaedic surgery and increasing weight gain despite calorie restriction. Oral intake was limited and essentially for comfort measures. Enteral feeding was required to meet nutritional requirements. She presented to dietetics with a one-year history of worsening feeding tolerance, increasing Gastro-Intestinal (GI) distress and chronic constipation requiring frequent dis-impaction. In addition, parents felt GI distress was triggering seizure activity.
Medical and nutritional intervention

M was dependent on a feeding tube from a young age and her feeding plan on presentation was small amounts of oral intake, 30g low caloric grated cheese and a handful of crinkle potato crisps on occasion (estimated total of 168kcal and 8.8g protein). Her parents reported that she was experiencing periods of hunger at night time with current feed regimen and worsening GI issues of pain, bloating and discomfort. M’s parents were keen to change feed with the aim of reducing GI distress, reducing calories while ensuring satiety and reducing M’s dependency on laxative therapy.

Estimated nutritional requirements

Actual weight = 50kgs = <50th percentile (Length unavailable); Ideal weight = 32kgs 50th percentile

<table>
<thead>
<tr>
<th>Calorie Requirements:</th>
<th>Protein Requirements:</th>
<th>Fluid requirements:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated Average Requirements (EAR) = 1790kcal/day</td>
<td>RNI = 28.3g/day</td>
<td>Whey peptide-based low energy feed</td>
</tr>
<tr>
<td>Maintenance = 0.66g/kg + growth 0.90g/kg = 0.75g X 50 = 37.5g/day</td>
<td>Safe = 0.92g/kg = 46g/day</td>
<td>100mls/kg X 10 + 50mls/kg X 10 X 20mls/kg X 30 = 2100ml/day</td>
</tr>
<tr>
<td>BMR 20 X 50 + 486 = 1486kcal/day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Energy Expenditure (TEE) 6.8 X 50 = 3040kcal/day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMR 20 X 50 + 486 = 1136cals/day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current weight</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

M’s original feeding regimen was four 400ml boluses of whole protein low energy feed with fibre providing 1200kcal and 32g of protein. M was also taking some feed orally and her mum reported that she had been increasing feeds in the previous few months due to the complaints of hunger. Weight gain was a significant concern and there was an increasing need to reduce the calorie intake given the increasing level of immobility.

The following changes to M’s regimen were recommended:

- Oral intake as tolerated in small amounts for comfort only.
- Trial with a whey peptide-based low energy feed in four 375mls boluses and one 500mls bolus of a whey peptide-based low energy feed and a sachet of protein powder which would provide a total of 1019kcal and 48.4g protein. It was advised to monitor weight closely to prevent weight gain. Symptoms of constipation resolved; M was having daily bowel movements and laxatives were discontinued.

Due to a temporary supply issue, the family reverted to their previous feed. Within 24-48 hours, symptoms of feed intolerance reappeared. When M re-commenced on the whey peptide-based low energy feed, her regimen was changed to three 450mls boluses and these symptoms again resolved. A reduction in the need for venting and gut rest was also reported.

An overview of the final regimen is as follows:

Nutritional Review of Feeding Regimen not including oral intake:

<table>
<thead>
<tr>
<th>Volume (ml)</th>
<th>Calories (kcal)</th>
<th>Protein (g)</th>
<th>Iron (mg)</th>
<th>Calcium (mg)</th>
<th>Vat D (up)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whey peptide-based low energy feed</td>
<td>1350mls</td>
<td>810</td>
<td>31</td>
<td>11.6</td>
<td>918</td>
</tr>
<tr>
<td>Protein Supplement</td>
<td>44mls</td>
<td>44</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>European Food Safety Authority (EFSA)</td>
<td>1394mls</td>
<td>854</td>
<td>42</td>
<td>11.6</td>
<td>918</td>
</tr>
<tr>
<td>Per kg (50)</td>
<td>17.1</td>
<td>0.84g</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Estimated Total Intake- note variable oral intake:

<table>
<thead>
<tr>
<th>Calories (kcal)</th>
<th>Protein (g)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enteral Feeds</td>
<td>854</td>
</tr>
<tr>
<td>Oral Intake</td>
<td>168</td>
</tr>
<tr>
<td>Total</td>
<td>2022kcal/day</td>
</tr>
</tbody>
</table>

The whey peptide-based low energy feed has been well tolerated by this child given the improvements in GI tolerance, bloating and stools. The parents are keen for their child to continue on it. This is most likely due to the peptide nature of the feed and low osmolality and osmorality. It also contains more fibre than the previous feed and also provided more than adequate levels of micronutrients, particularly calcium and vitamin D. Meeting protein requirements can be a challenge in patients with low energy requirements and so a protein supplement was required in this case. The reduction in the need for venting and gut rest is a clear indication of the improved tolerance of the whey peptide-based low energy feed.

Case Study 2

A five year old boy who will be referred to as A who requires enteral nutrition and experienced rapid weight gain.

Clinical case study description

A has a diagnosis of Cerebral Palsy GMFCS Level 5, due to meningitis during the neonatal period. He also has epilepsy, microcephaly and very low activity levels and sleepiness, possibly due to hypothermia and his medication.
Medical and nutritional intervention
A was admitted to hospital at four years nine months with poor weight gain, swallowing difficulties and constipation. Advice following a swallow assessment was to give only small amounts of puree (International Dysphagia Diet Standardisation Initiative (IDDSI) level 4). A nasogastric tube (NGT) was passed and he was referred to the ward dietitian and commenced on a whole protein feed. Due to discomfort at night and loose stools he was swapped to a 1 kcal/ml peptide feed and referred to the community dietitian for follow up at home. The peptide feed also seemed to cause discomfort, so ward staff started him on an extensively hydrolysed infant formula just prior to discharge. Discharge weight was 16.3kg, 9th centile (Height 25th centile at 4 years). Once home the formula was concentrated to meet requirements calculated as 1000kcal/day (72% for low activity level of EAR for four-year-old [2] given as 5 x 250ml pump assisted feeds).

Within 1 month his weight increased to 18.4kg (50th centile) so feeds were reduced, compromising his nutritional intake. He was taking very little orally due to being very sleepy during the day. Full fluid and nutritional requirements needed to be met via his enteral feeds. In view of previous tolerance issues experienced in hospital, he was changed to an amino acid feed for children over 1 year and he tolerated this well. At this point he was receiving 800kcal/day and meeting his requirements for micronutrients.

Despite regular reductions in feed volume his weight continued to increase to 20.8kg (>75th centile, height 50th centile) over the next 2 months and parents were very concerned. He was now receiving just 600kcal per day. This current feed was not meeting his requirements for protein (16.6g = 0.84g/kg, minimum safe level 0.86g/kg [5]), or essential vitamins and minerals. A video fluoroscopy at this stage demonstrated an unsafe swallow to IDDSI level 4, so parents were advised to give only tastes for pleasure.

In view of the rapid weight gain, the decision was made to trial whey peptide-based low energy tube feed. As symptoms were mild on the previous peptide feed, parents were willing to trial it, but guidance was given to mix this feed with the current feed and slowly increase as tolerated and at a pace they felt comfortable with. Parents started with 50% in one feed per day, increasing each day until all four feeds were the same. Once confident that he was comfortable, parents then increased the whey peptide-based low energy feed to 100% of current feed volume and then finally to the final volume required (900mls per day). This provided 504kcal, 19.3g protein (= 0.91g/kg, minimum safe level= 0.85g/kg [5]) and continues to meet requirements for micronutrients. This feed enabled the further reduction in calories with the aim of at least maintaining weight during growth, if not weight reduction. There were no tolerance issues during the process of transitioning the feeds. Standard vitamin drops were discontinued as no longer required.

Outcome
A’s weight stabilised for several weeks but possibly due to a further reduction in activity levels, weight began to increase again to 21.1kg (75th centile). Feeds were therefore reduced further to 840mls/day. This provided 504kcal, 19.3g protein (= 0.91g/kg, minimum safe level= 0.85g/kg [5]) and continues to meet requirements for micronutrients.

This feed has been a success for A by reducing the rate of weight gain, but still ensuring he meets his nutritional requirements. A hydrolysed feed was necessary for him to prevent GI disturbances experienced with whole protein feeds. This has reduced parent’s anxiety and the process of preparing feeds is also much easier and less time-consuming, improving quality of life for the whole family.

Case Study 3
The following case study is about a three-year-old girl who will be referred to as H who is experiencing severe reflux.

Clinical case study description
H was diagnosed with Holoprosencephaly, a brain condition resulting from failure of the forebrain to divide into two hemispheres [6]. It is a life-limiting condition and spasms and seizures occur in up to 40% of cases [7]. H was also diagnosed with multifocal epilepsy. Infants and children with holoprosencephaly often present with feed difficulties and Gastro-Oesophageal Reflux (GOR), as was also the case for H.

H was diagnosed in infancy with diabetes insipidus which was managed by careful fluid management, sodium restriction, and Desmopressin. At six months of age, H underwent a Ladd’s procedure to correct a bowel malrotation. Due to having an unsafe swallow; H was fed via a nasogastric tube from birth.

Medical and nutritional intervention
Following her Bowel surgery coupled with low tone, H was prescribed prophylactic antibiotics to protect her chest. This, coupled with low tone, resulted in gut dysmotility and feeding challenges, with significant reflux on standard whole protein infant formula. The usual treatments for GOR (positioning, continuous feeds, Proton-Pump Inhibitor therapy) were not fully effective and she remained symptomatic. Due to severe reflux and poor tolerance of feed volumes, a thickener was initially added to H’s feed. This however, resulted in constipation and so a 1 kcal/ml whey peptide-based formula was chosen. Anti-reflux medication remained prescribed and reflux was largely better controlled.

On review by dietetics at eighteen months of age, H had experienced significant weight gain. Her weight had increased over two and half centiles since birth and was now plotting on the 91st centile. Her length was on the 25th centile and so there were concerns about her growth being disproportionate. A decision was made to introduce a feeding regimen to meet 75% of H’s energy requirements. This was achieved by alternating H’s milk feeds (495ml divided over 3 feeds) with water boluses (360ml divided over 2 feeds) containing a powdered multivitamin to meet micronutrient requirements. To not unduly increase the care burden, a powdered formula alternative was not chosen.

Weight gain of 1.9kg in six months was observed prior to H’s dietician review at three years of age, despite having a feeding regimen meeting 50% Estimated Average Requirement for her actual age. At this point her weight was plotting on the 75th centile and length on the 25th centile. A recommendation was made by the dietitian to change H’s feed to a whey peptide-based low energy feed as it was a ready-to-hang formula which would reduce the need for water boluses in H’s current regimen. This would allow her parents to reduce the time spent feeding and was less labour intensive. H was fed 5 times per day, a total of 800ml in 24 hours divided across the bolus feeds, at a rate of 118ml/hr. She had an additional 160ml water over the course of the day as flushes. A change was also made to H’s micronutrient supplement to an age-appropriate alternative.
H was reviewed again just over 2 months later where her weight had remained stable and plotted between 50th to 75th centiles. The aim to achieve appropriate weight gain and increase linear growth was met as weight and length were in proportion. Reflux symptoms remained well controlled. At a further review 4 months later, H had gained 800g weight, which tracked between 50-75th centiles and in total she had gained 2.2kg and 5cm linear growth in 13 months.

Outcome

The change in feed improved H’s growth trajectory within a seven-month period. She was reviewed monthly on starting the feed change and changes in weight were noted within 2 months. The introduction of whey peptide-based low energy feed was less labour intensive for the parents than the previous regimen which meant that they could spend less time with feed preparation, impacting positively on quality of life. In this case report, rapid weight gain was having a significant effect on day-to-day care due to moving and handling and made meeting fluid requirements more difficult due to her fluid sensitivity and Diabetes Insipidus. The stabilisation of weight gain as a result of the feed change not only improved her nutritional status but aided moving and handling at home.

Case Study 4

The following case study is of a seventeen-month-old girl presenting with Bronchogenic cysts who will be referred to as R.

Clinical case study description

R was born prematurely at twenty-eight weeks gestation. Her birth weight was 1.48kg (75th centile). She was diagnosed with several complex medical conditions in early infancy. This included bronchogenic cysts with left main bronchus suppression. Bronchogenic cysts are abnormal growths of tissue that are present from birth. These cysts have thin walls and are filled with fluid or mucous. Most bronchogenic cysts are found in the mediastinum which is part of the chest cavity that separates the lungs [8]. Brain Magnetic Resonance Imaging found Cystic Periventricular Leukomalacia (PVL). This is a severe manifestation of white matter injury. White matter injury is the most common form of brain injury in premature infants and is associated with cognitive disability and visual impairment as well as cerebral palsy [9].

Due to her prematurity and complex diagnoses, R spent the first six months of her life as an inpatient in an acute paediatric hospital. Here she underwent bronchoscopic laser therapy twice and cardiopulmonary bypass due to re-accumulation of the bronchogenic cysts. She also commenced Continuous Pulmonary Airway Pressure (CPAP) which continues overnight. In addition, she had significant Gastro-Oesophageal Reflux Disease (GORD). During this hospital stay she received input from a variety of specialist teams including neonatal, respiratory and gastroenterology teams.

Medical and nutritional intervention

R was referred to the local community enteral nutrition team on discharge from hospital at six months actual age. On assessment her weight was 6.04kg (tracking below 75th centile), length was - 55.3cm (tracking 9th centile) and head circumference was -37.5cm (tracking 9th centile). On discharge from hospital R had a NGT insitu. She was receiving continuous pump feeding with a Farrell Valve in situ to help decompress the stomach whilst feeding. The feed of choice was a 1kcal/ml extensively hydrolysed infant formula at 38ml/hr - for 16 hours. Including water flushes, this nutritional care plan provided (110ml/kg, 101kcal and 2.6g protein/kg).

On discharge R was also prescribed esomprazole and domperidone for management of GORD. Due to GORD, total fluid volumes could not be increased further. However, despite the low fluid volumes this nutritional plan had a positive impact on R’s growth and weight continued to track at the 75th centile. Over the coming few weeks feed plans were adjusted in an effort to aid tolerance as vomiting and unsettled behaviour continued. As R was receiving CPAP overnight it was decided to pragmatically increase daytime feed volumes as parents felt feeds were better tolerated during the daytime. The feed plan was amended to provide two, three-hour feeds and a ten-hour overnight feed. Despite these changes however, vomiting and discomfort continued.

On review at eight months of age, poor feed tolerance continued. This included increased retching, irritability and sleeping difficulties. A decision was made to trial Naso-Jejunal (NJ) feeding as a planned admission in an effort to improve feed tolerance.

On admission R was reviewed by both gastroenterology and neurology teams and medications were also reviewed. Doses of esomprazole and domperidone were increased. A course of alimemazine was also commenced to help reduce retching episodes. The neurology team commenced nitrazepam due to suspected infantile spasms.

These medical interventions alongside the commencement of jejunal feeding had a positive impact on feed tolerance and significant weight gain was observed despite no increase in feed volumes. On discharge R continued to receive extensively hydrolysed feeds with additional oral rehydration solution to support electrolyte intake on a reduced feed intake. Over the four month period when R received NJ, weight gain continued despite a feed reduction. Weight gain continued to increase from the 75-91st centiles despite receiving only 57kcal/kg/day and 1.48g protein/kg/ day. This was an overall 44% reduction in calories. Concerns were raised at this time due to the overall nutritional adequacy of the nutritional plan. Although R was growing well, the feed plan was only meeting lower reference nutrient intake requirements for micronutrients and not meeting sodium requirements despite additional oral rehydration solutions.

At one year of age R was tolerating NJ feeding well. She was readmitted to hospital for a trial of gastric feeds to ascertain whether long term jejunal feeding should be considered. As R was now one year of age (actual age) and weighed 10.5kg, it was agreed a trial of a whey peptide-based low energy feed would be an appropriate option. This feed change would allow a rationalised feed plan that met nutritional requirements without the addition of oral rehydration solutions. A full nutritional screen was performed at this time and R was noted to have a low serum copper (6.6umol/L - range 12.5-23.5umol/L). Since jejunal feeding bypasses the site of copper absorption, jejunal feeding increases the risk of copper deficiency and its associated complications both haematological and neurological [10].

R commenced 800ml of a whey peptide-based low energy feed via a nasogastric tube which provided 94ml/kg (including flushes), (54kcal/kg, 1.85g protein/kg,1.75mmol/kg sodium and 2.4mmol/kg potassium) and provided 25% more copper than the previous nutrition plan.
Outcome

At seventeen months R continues to tolerate gastric feeds well with no vomiting. She remains on a sixteen-hour feed and is tolerating gradual increases in daytime feed rates to allow more time off pump feeding. The change to a whey peptide-based low energy feed has allowed for a simplified feed plan which can be provided without any additional electrolyte supplementation in a closed system, which is sterile and negates the need for decanting feeds.

Parents report that R has occasional retching; however this is more associated with management of secretions than reflux. She does have episodes of increased flatulence which has been well managed with short courses of metronidazole. She is due for a sleep study to trial cessation of overnight CPAP which may also aid feed tolerance if permanently discontinued.

R receives regular reviews with speech and language therapy and is tolerating very small smears of purées on her lips and enjoying this sensory experience. She is awaiting placement of a gastrostomy tube for long term feeding. Her weight and height are tracking along the 75th centile and this continues to be monitored monthly. R undergoes routine monitoring of nutritional bloods to access copper status.

Discussion and Conclusion

Children with complex medical needs often have reduced energy requirements due to low tone and reduced voluntary movements, coupled with gut dysmotility, constipation and reflux [1]. Their degree of swallowing function can vary considerably. Whilst supplementary enteral feeding is often essential for adequate growth and development, it should be acknowledged that there are many other components to a child’s care, such as respiratory support. Furthermore, enteral feeding regimens should be adapted and take into consideration parental abilities and the family situation. Other aspects of the child’s life such as travel, school nurse training, carer support all need to be taken into consideration when devising an acceptable feeding regimen.

Due to hypotonia and reduced energy expenditure, many children with neuro-disabilities have considerably reduced energy requirements. This can be further reduced if they require respiratory support. It can also be increased during times of involuntary movements (e.g. seizure activity). Rapid weight gain is a well reported concern within this patient group [11]. It has been recommended to use weight for height [12] and estimate requirements to 75% EAR, but best practice is to find a starting point and monitor closely. Protein intake should at least meet the minimum safe requirement [13].

There is a risk of overfeeding when initiating feeding with enteral nutrition due to a potential shift from negative to positive energy balance, which results in fat accumulation [1]. Indeed, due to lower than average physical activity levels, children with neurological impairment have lower daily total calorie requirements compared with typically developing children [2] leading to a risk of overfeeding with standard/high-calorie feeds (1.0-1.5 kcal/ml) [14].

One approach would be to reduce the volume of standard-calorie formula administered to children with neurological impairment requiring enteral nutrition and who have reduced energy needs, to prevent overfeeding/excessive weight gain, but this may put the child at risk of macro- and micronutrient deficiencies [15,16]. As illustrated by the clinical cases reported in the present article, feeding the child with well adapted complete whey peptide-based formula, has shown to be well tolerated and effective in improving child overall health and growth trajectory.

Feeding the complex needs child requires a multi-disciplinary approach. Getting the balance right with the correct enteral nutritional support not only maximises nutritional status but can better treat underlying issues such as reflux and poor gut motility. The availability of a ready-to-feed, low calorie hydrolysed whey peptide-based formula for use in the paediatric population has helped to streamline feeding regimens and meet nutritional requirements within a group of patients for whom small increases in calorie provision can have a profound impact on weight gain.

References

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