Gastro-oesophageal reflux disease in the paediatric patient with disability

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Introduction
Symptoms of gastro-oesophageal reflux disease (GORD) are frequently observed in children with developmental disability. Gastro-oesophageal reflux (GOR) refers to the passage of gastric contents into the oesophagus, with or without regurgitation and vomiting, and is considered a normal physiological process. Conversely, GORD, refers to the troublesome symptoms and/or complications that develop secondary to persistent GOR. Children with developmental disability are at increased risk of developing GORD and generally experience a greater number of complications associated with the disease than their otherwise healthy counterparts. Thickening feeds represents one means by which symptoms of the disease may be managed in children, however, there is limited evidence to support this line of treatment in those with cerebral palsy, epilepsy, autism spectrum disorder and other forms of developmental disability. The potential side-effects associated with long-term use of feed thickeners should not be overlooked and the financial implications of their use in enteral feeds requires consideration. A lack of published recommendations and national guidelines for managing this patient group has led to variance in practice between dietitians who treat such children in Ireland.

GORD in developmental disability
Episodes of GOR are usually caused by transient relaxations of the lower oesophageal sphincter (TLOS), which normally allow excess gas to escape from the stomach. In those with developmental disability, the development of GORD is likely to be due to altered gastric motility, altered oesophageal motility, or an increase in the number of TLOS, all of which may occur secondary to central nervous system and enteric nervous system dysfunction. Up to 75% of this patient group experience symptoms of the disease. Moreover, the type of GORD commonly observed in these children is severe and chronic in nature, and increases these patients’ risk of developing associated complications, which may include; erosive oesophagitis, Barrett’s oesophagus and adenocarcinoma. In children with neurological impairment, recurrent vomiting is the objective hallmark of GORD, although haematemesis, anaemia, rumination and regurgitation have also been observed in increased frequency in this patient group. Other signs and symptoms that may be indicative of GORD are outlined in Table 1.
Management

Management of GORD generally involves aspects of positional, nutritional, and dietary modification, with use of pharmacological agents as required. Thickening feeds represents one dietary modification by which symptoms of GORD may be managed. Commercial thickening agents include carob bean gum, maltodextrin, modified maize or rice starch, sodium carboxymethyl cellulose, pectin and cellulose. In children with GOR who are otherwise healthy, it appears that feeds that are thickened with these agents reduce the frequency of overt regurgitation; however, they have not consistently been shown to reduce the actual number of oesophageal reflux episodes, as measured by oesophageal pH monitoring. Nonetheless, their use may provide a welcome improvement in symptoms for parents and carers of these children.

Only one small trial has investigated the effectiveness of thickened feeds for managing GORD in children with developmental disability. Miyazawa et al. investigated the effects of a pectin-thickened enteral feed on symptoms of GORD and oesophageal parameters in 18 children with cerebral palsy. Results revealed a reduction in the number of vomiting and coughing episodes and improvements in some, but not all, oesophageal pH parameters.

A medical position statement commissioned by the European Society of Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) suggested that the lack of observed effect of some thickened formulas may be due to slower clearance of thickened acid refluxate from the oesophagus when ingested orally. Hence, in the study carried out by Miyazawa et al., had the thickener been administered orally, it is possible that the results for oesophageal parameters and symptoms of GORD may have differed.

Lack of clinical guidance

There is no algorithm or clinical guideline available on the use of thickened feeds for managing GORD in children with developmental disability. The National Institute for Health and Clinical Excellence (NICE) have recently proposed the development of guidelines for managing GORD in children and young people. These guidelines aim to give special consideration to children with neurodevelopmental disorders; however, they are not due to be published until October 2014.

The lack of clinical guidance in this area has been highlighted by a recent survey of dietitians practising in Ireland who have experience managing GORD in children with disability. The main finding from the survey was that significantly more dietitians working in tertiary (n=11) and general hospitals (n=11) than in the community (n=3) reported recommending thickened feeds to manage symptoms of GORD in these children (p<0.01, p<0.001 respectively). In addition to this, 20 dietitians reported observing thickened feeds being used in conjunction with enteral feeds in practice, and three reported observing these agents being used in post-pyloric feeds.

NICE guidelines for the prevention and control of healthcare associated infections in the community state that reconstituted feeds should be administered over a maximum period of four hours. Additionally, they state that administration sets and feed containers should be discarded after each feeding session when this approach to feeding is being undertaken. Despite this, only 7 out of 17 question respondents were of the opinion that giving sets should be changed every 4 hours when used with thickened enteral feeds. Of these dietitians, only three believed that the NICE guidelines are being implemented in practice where feed thickeners are being recommended. These findings further highlight the need for published guidelines in the area to promote consistent standards of care and to optimise treatment of GORD in this patient group.

Thickening agents in enteral feeds

Results of the aforementioned survey that surround the use of thickened enteral feeds are also of concern. Children with developmental disability are at risk of undernutrition. Additionally, poor nutritional status is a risk factor for many infectious diseases. Therefore, children with developmental disability who are at increased risk of acquiring infections may be at further risk if proper aseptic technique is not being adopted when enterally fed. This may be further exacerbatd if thickening agents are added to jejunal feeds, in which case, the stomach’s acid defences are being bypassed.

Conversely, if the NICE best practice guidelines for preventing infection in the community are to be implemented, the economic consequences of using thickening agents in enteral feeds becomes a major issue. Thickening agents themselves are relatively affordable, ranging from €3 to €8 (as per General Medical Scheme GMS prices; November

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2012). However, if thickening agents are being administered with decanted enteral feed, best practice guidelines would necessitate changing giving sets and feed reservoirs every four hours, which vastly increases the cost of feeding. Case scenarios 1 and 2 outline the estimated cost difference of administering unthickened versus thickened enteral feed.

**Case scenario 1:** administration of enteral feed (ready-to-use)  
**Example:** 5 year old patient with cerebral palsy; estimated energy requirements: ~700kcal  
**Total feeding time:** 14 hours @50ml/hr (standard 1kcal/ml fibre-enriched enteral feed)  
**Total feeding volume:** 700ml enteral feed

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<th>Item</th>
<th>Cost per item (€)*</th>
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<tr>
<td>Fibre-enriched enteral feed (200ml)</td>
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<td>Fibre-enriched enteral feed (500ml)</td>
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<td>Giving set</td>
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*Price of feeds based on GMS prices (November 2012). Cost of giving set estimated from €250 for 30 giving sets. Weekly total includes cost of one syringe (~€7.50).

**Case scenario 2:** addition of thickening agent to enteral feeding  
**Total feeding volume:** 700ml decanted feed + 24g standard feed thickener per day (4 scoops per 200ml)

<table>
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<tbody>
<tr>
<td>Fibre-enriched enteral feed (200ml)</td>
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</tr>
<tr>
<td>Giving set</td>
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<td>Feed reservoir</td>
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<td>Feed thickener (6.8g)</td>
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*Price of enteral feeds and thickening agent based on GMS prices (November 2012). Estimate from feed thickener (135g box): €3.00. Cost of giving set estimated from €250 for 30 giving sets. Cost of feed reservoir estimated from €66 for 30 feed reservoirs. Total includes cost of one syringe (~€7.50).

Administering ready-to-use formula permits safe feed delivery over 24 hours without need to change giving sets and removes the need to use a feed reservoir. Therefore, in the previous case scenarios, using a thickening agent would increase the daily cost of enteral feeding by around €36 per day and €250 per week.

It is important to consider the financial burden that using these agents in enteral feeds places on families of children as well as the financial burden they are likely to place on the State. Anti-reflux medication ranges from €4 to €15,20 thus provision of appropriate medical agents appears to be a more appropriate strategy than recommending thickened enteral feeds to manage these children’s symptoms.

**Thickened feeds: potential side-effects**  
The long-term effects of consuming thickened feeds have not been investigated and the potential allergenicity of commercial thickening agents warrants further research.7 Side-effects reported with short-term use include diarrhoea, increased coughing episodes and an increase in gastric emptying time.21-24 In vitro studies suggest that the bioavailability and intestinal absorption of carbohydrates, fat, calcium, iron, zinc and copper may be reduced by feeds thickened with non-digestible carbohydrate.5,25 An increased risk of developing complications associated with GORD by using thickeners should also be considered. For instance, if thickened feeds only reduce symptoms of GORD but do not reduce actual oesophageal reflux as indicated by the majority of studies, their long-term use in children has the potential to mask persistent GOR that could otherwise be treated with anti-reflux medication. In such a scenario, prolonged use of thickened feeds could further increase these children’s risk for developing serious complications associated with GORD.

**Medical therapy for the management of GORD**  
The North American Society of Paediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) and ESPGHAN recommends that anti-secretory therapy should be optimised in children with GORD and neurological impairment (including those with developmental delay).7 Whilst the risk of side-effects also accompanies the use of anti-secretory medication, there are nutritional and clinical consequences of uncontrolled symptoms of GORD. At present, there is a greater evidence base to support the use of proton pump inhibitors in children with underlying disability and GORD than that which favours thickened feeds for managing these children.4,25-27 Additionally, where enteral feeding is indicated, medication represents a cheaper, more practical means by which symptoms can be managed.

**Conclusion**  
Further research is warranted to determine the effectiveness of thickened feeds in managing children with GORD and underlying disability. Until then, the potential side-effects associated with using thickened feeds should not be overlooked, nor should the serious financial burdens they place on families of these children when used in enteral feeds. Future guidelines that reflect the relevant literature are required in order to promote consistent standards of care and ultimately optimise the quality of treatment for GORD in children with a disability.
Let them know before they go!

Avoiding contaminated food and water is good advice, but they don’t always remember it.

ViATIM® protects for up to 36 months against both hepatitis A and typhoid fever.
References


