Gastroparesis: a patient's experience

Valerie L Wilson

Introduction

Gastroparesis (also called delayed gastric emptying) is a disorder caused by automatic neuropathy in which the stomach takes too long to empty. It often occurs in people with type 1 and type 2 diabetes and is caused when the vagus nerve, which controls movement and digestion of food to the stomach is damaged or ceases to work. The stomach and intestinal muscles do not function properly as a consequence, slowing down or stopping the movement of food. This makes it difficult to manage insulin requirements and can cause erratic swings in blood glucose levels. This article outlines the symptoms, diagnosis and treatment of gastroparesis. It also describes from a patient's perspective how gastroparesis affects quality of life and strategies that are used to cope with it.

Diabetes can cause damage to the vagus nerve if blood glucose levels are constantly high over a long period of time. High blood glucose levels cause chemical changes in the nerves which damage the blood vessels that carry oxygen and nutrients to the nerves. If food lingers in the digestive tract it can result in bacterial overgrowth from the fermentation of food. Food may also harden into solid masses (bezoars) which may cause nausea, vomiting and obstruction that requires surgical intervention (National Digestive Disease Information Clearinghouse, 2003). Feeding by parenteral nutrition has also been documented by Jacober et al (1986).

Symptoms of gastroparesis

Symptoms of gastroparesis include:

- Heartburn and nausea.
- Vomiting of food which has not been digested.
- A feeling of bloating after eating a small amount of food.
- Weight loss.
- Abdominal pain.
- Erratic blood glucose levels.
- Poor appetite.
- Gastroesophageal reflux.

Gastroparesis makes the management of diabetes difficult, because of unpredictable blood glucose swings. These are caused by the delay in food entering the small intestine from the stomach and a sudden rise in glucose levels as it is absorbed. Stomach emptying is therefore difficult to determine and it is hard to match insulin needs and working times to the rate at which food is digested.

Causes of gastroparesis

According to the National Digestive Diseases Information Clearinghouse (2003) gastroparesis is most often caused by:

- Diabetes.
- Post-viral syndrome.
- Anorexia nervosa.
- Surgery to the stomach or vagus nerve.
- Medication (such as anticholinergics and narcotics – drugs which slow the contractions of the intestine).
- Smooth muscle disorders (amyloidosis and scleroderma).
- Diseases of the nervous system (such as Parkinson's disease).
- Metabolic disorders (e.g. hyperthyroidism).

Diagnosis of gastroparesis

My diagnosis of gastroparesis was delayed because the symptoms are similar to those of irritable bowel syndrome. I had suffered many of the symptoms previously listed for many years. My diabetes had been uncontrolled in childhood and adolescence. In late adolescence (after having had type 1 diabetes for 8 years) I had a barium enema

ARTICLE POINTS

1 Severe gastroparesis has a high mortality rate.

2 Diabetes can cause damage to the vagus nerve if blood glucose levels are constantly high.

3 Damage to the vagus nerve means that the digestive process slows down, causing unpleasant symptoms and erratic swings in blood glucose levels.

4 Symptoms can be eased and blood glucose levels controlled by insulin pump therapy use.

KEY WORDS

- **Insulin pump therapy**
- **Glycaemic control**
- **Nerve damage**
- **Chronic complication**

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1 The endocrinologist diagnosed gastroparesis almost immediately from my symptoms, erratic blood glucose patterns and by listening to my stomach with a stethoscope.

2 The slow and unpredictable absorption of food as a consequence of gastroparesis affects glycaemic control and insulin requirements.

3 I found that by using pump therapy and spreading my insulin dosage over several hours after I had eaten, my blood glucose levels were more controlled.

4 I found that smaller meals were easier to manage and that if I was going to have a problem with hyperglycaemia, it was after an evening meal when I had calculated the bolus of insulin for a larger meal.

examination. This did not show the cause of the symptoms as the procedure does not examine the upper digestive tract. As a consequence the symptoms continued into my thirties.

In 2000, after having diabetes for 23 years and gastroparesis for approximately 20 years, gastroparesis was finally diagnosed. My diabetologist had thought that it was irritable bowel syndrome and did not connect my erratic blood glucose swings with the possibility of gastroparesis. I had read about gastroparesis in my position as a nuclear medicine technician, whereby stomach emptying studies were performed to establish digestive function. I was sure the symptoms applied to me. As I was waiting for a referral to an endocrinologist to begin insulin pump therapy, I did more research.

The endocrinologist diagnosed gastroparesis almost immediately from my symptoms, erratic blood glucose patterns and by listening to my stomach with a stethoscope. He heard 'swishing noises', apparently common in patients with gastroparesis due to food fermenting in the stomach. The endocrinologist ordered a radioisotope gastric emptying scan which would give a more precise emptying time. Coupled with insulin pump therapy to tailor insulin requirements to my needs, this was the turning point in establishing what my symptoms were and treating them.

The gastric emptying scan involved eating mashed potato and drinking orange juice laced with a radioisotope to show up on the scan. An hour after consuming these, the scans were taken. This was repeated for 5 hours in my case, but showed that the food was not moving very quickly. (Nuclear medicine scans for gastric emptying are normally performed for 2–3 h as 3 h is the normal stomach emptying time after a meal. If it is suspected that the stomach nerves are not working correctly, a scan is performed every 1 h to around 5 h.) An estimation of 8 h for complete stomach emptying was suggested and the endocrinologist was then able to work out insulin dosages using pump therapy. He also prescribed a drug treatment (a motility stimulant), but this did not work for me.

The benefits of intensive therapy

The slow and unpredictable absorption of food as a consequence of gastroparesis affects glycaemic control and insulin requirements. The MiniMed 508 insulin pump has a 'square wave' facility whereby insulin dosage can be spread over many hours and which the patient programmes into the machine. This method of insulin delivery reduces the risk of postprandial hypoglycaemia (Fredrickson, 1995).

I found that by using pump therapy and spreading my insulin dosage over several hours after I had eaten, my blood glucose levels were more controlled. Prior to pump therapy I used to take multiple daily injections of a fast-acting insulin as soon as I ate at mealtimes. The insulin started working immediately and had no food to act on, resulting in severe hypoglycaemia an hour after my evening meal (blood glucose levels of 1–2 mmol/l). A combination of delayed digestion and 'bounce back' (a rapid rise in blood glucose levels) after hypoglycaemia meant that I would then experience hyperglycaemia (18–20 mmol/l) 3–4 hours after meals.

Improved control

Once I started to use pump therapy and when I had established my insulin needs, my blood glucose levels became more normal (5–10 mmol/l after eating). This was due to the 'square wave' option on the MiniMed 508 which allowed me to have my meal bolus of insulin spread over 4–5 h (sometimes longer for larger meals) to match my rate of digestion. Obviously this differed with different foods and meal sizes. I found that smaller meals were easier to manage and that if I was going to have a problem with hyperglycaemia, it was after an evening meal when I had calculated the bolus of insulin for a larger meal. Although I did not see a dietitian, I decided that several smaller meals a day suited me.

When using pump therapy, the patient learns to gauge the correct rate of insulin for certain foods due to carbohydrate content. If foods are not eaten on a regular basis, it can be easy to forget the bolus rate of insulin and underestimate the

carbohydrate content. This is often the case when eating out, as it is difficult to know what carbohydrate content certain foods have if you are unsure of the ingredients. Regular blood glucose tests are obviously necessary to avoid long-term hyperglycaemia and to reduce the risk of diabetic ketoacidosis (Davies et al, 1995).

Psychological effects of gastroparesis and coping strategies

The effects of gastroparesis mean that eating out and social occasions become extremely uncomfortable, due to bloating of the abdomen after food and unpleasant side-effects of excessive wind. This is similar to irritable bowel syndrome and can lead to the individual preferring isolation to facing such embarrassment when with friends and family. Gastroparesis is debilitating and depressing, causing avoidance of social occasions, excuses regarding offers of food and difficulty for the individual in partaking in normal daily activities involving eating.

My coping strategies involve maintaining good control of my diabetes via insulin pump therapy. This does not cure gastroparesis but attempts to prevent further autonomic neuropathy. Monitoring food intake and knowing which foods tend to worsen symptoms makes things easier. Eating six small meals a day rather than three larger ones helps to avoid over-filling the stomach. Liquid meals also allow the stomach to process the food more quickly while providing nutrients. I avoid high fat and high fibre foods which are difficult to digest and can cause blockages.

The future

I realise that gastroparesis cannot be cured as it is a chronic condition, but I am able to control my destiny to a certain extent with the use of the insulin pump to prevent the condition from becoming worse. I also know that I have severe gastroparesis because it was undiagnosed for so long and my blood glucose levels remained erratic until pump therapy was initiated. After reading everything that I could about the condition I feel lucky that I had not reached the stage of only being able to eat via a feeding tube or through parenteral nutrition (when nutrients delivered directly into the bloodstream via a catheter into a chest vein).

Advances in technology are attempting to combat the debilitating effects of gastroparesis. Medtronic (the company who have taken over MiniMed) have developed a gastric stimulation system, an implantable device which uses the electrical stimulation of the stomach to treat patients with severe, often life-threatening gastroparesis. This is available on a limited basis to people with gastroparesis and has been shown to reduce nausea and vomiting and improve patients' quality of life.

Conclusion

As a result of the increasing availability of information about gastroparesis on the internet, it is easy to keep up to date with new treatment options and technological advances. With the aid of insulin pump therapy, it is also possible to keep blood glucose levels within normal limits most of the time to avoid further nerve damage and delay the progression of other complications of diabetes. Gastroparesis is a paradoxical condition which makes it difficult to manage diabetes; it is caused by poor blood glucose control and results in erratic swings in blood glucose levels. With the use of pump therapy, people with gastroparesis and diabetes can take control and have hope for the future. ■

Davies MJ, Rathbone BJ, McNally PG et al (1995) Management of severe gastroparesis diabeticorum. *British Medical Journal* **310**: 1331–32

Fredrickson L (1995) *The insulin pump therapy book.* MiniMed Technologies Education Department, California

Jacober SJ, Narayan A, Stroudel WE, et al (1986) Jejunostomy feeding in the management of gastroparesis diabeticorum. *American Journal of Gastroenterology* **85**: 1120–22

Medtronic (2000) News release: '*Gastric stimulator system receives humanitarian device exemption from FDA*'.

National Digestive Diseases Information Clearinghouse (2003) *Gastroparesis and diabetes*. NH publication Number 03-4343. nddic@info.niddk.nih.gov

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