Nutritional management of a child with glycogen storage disease type Ia combined with feeding disorders undergoing gastrostomy:a case report

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Abstract

This report provides information for healthcare professionals who may be involved in the future nursing of children with glycogen storage disease type Ia combined with feeding disorders undergoing gastrostomy . Nursing interventions focus on emergency management of first aid, multidisciplinary collaboration to determine nutritional improvement plans and maintain blood glucose stability. Through targeted care, it can effectively correct metabolic disorders in children with GSD I and reduce the incidence of metabolic complications.

KEYWORDS

glycogen storage disease,case report, feeding disorders, gastrostomy

1 | INTRODUCTION

This case report highlights the course of nursing of children with glycogen storage disease type Ia combined with

feeding disorders undergoing gastrostomy.Nursing interventions focus on emergency management of first aid, multidisciplinary collaboration to determine nutritional improvement plans and maintain blood glucose stability. The whole process emphasized the importance of first aid and demonstrated that the use of multidisciplinary teams could help the child and his caregivers find appropriate ways to solve the problem. At the same time, it is also important to clarify the individualized problems of the child, maintain the stability of the child's blood sugar, and take care of her and the family members emotions. This report aims to provide information for future healthcare professionals and therapists who may be involved in treating children with glycogen storage disease type Ia combined with feeding disorders, as literature in treatment is limited

Glycogen storage disease (GSD) is a group of metabolic disorders caused by congenital enzyme defects. Its common biochemical feature is the lack of various enzymes during glycogen decomposition or synthesis, resulting in the accumulation of structurally normal or abnormal glycogen in tissues such as the liver, muscle, heart, and kidneys, leading to a series of clinical symptoms[1].Glycogen storage disease is a rare disease, which is a treatable rare autosomal genetic disease. There are 12 known types, of which type I is the most common, accounting for about 30%[2-3].Due to the lack of key enzymes regulating blood glucose level or their mediated transporters, glycogen and fat in the liver, kidney and intestinal mucosa accumulate excessively, leading to multiple systemic complications such as hypoglycemia, hyperlactaemia, hepatomegaly, and even premature death[4]. Domestic and international researches have shown that dietary nutrition intervention can effectively correct the metabolic disorder of children with glycogen storage disease type I and reduce the incidence of metabolic complications[5]. However, nursing of children with glycogen storage disease type Ia combined with feeding disorders who underwent gastrostomy surgery is rare.In February 2021, our department admitted a child with glycogen storage disease type Ia and feeding disorders who underwent gastrostomy. The child was successfully fed orally and through a gastric tube after the surgery, without repeated vomiting, dehydration, or fever. The gastrostomy site was dry and clean, without redness, swelling, or exudation. Blood glucose levels were monitored to maintain normal levels, and the condition improved significantly. The patient was discharged smoothly 13 days after the surgery. The following case introduction is reported.

2 | CASE HISTORY

2.1 | The course of treatment for the child

The patient was a 3-year-old Chinese child.In January 2021, vomiting occurred after upper respiratory tract infection. The vomitus was stomach contents, not serious. It was denied that it was accompanied by bile like and blood silk like substances, with poor expectoration, no fever and diarrhea. Therefore, they went to the local hospital for

treatment and hospitalization (2021.0104~2021.0116). During this period, the child repeatedly vomited, no convulsions, no lethargy and coma. Blood glucose monitoring showed that blood glucose was reduced (2.0~3.0 mmol/L), blood lactic acid was significantly increased, and the specific value was unknown,She was treated with lactose free milk powder and raw corn starch, corrected acidosis, and supported by high concentration sugar water rehydration. After discharge, high-concentration sugar water rehydration support continued in the outpatient clinic of the hospital, and the blood sugar level remained within the normal range.Vomiting, hypoglycemia, fever, shortness of breath, diarrhea and convulsion occurred again 1-2 days after stopping infusion support.On February 2, 2021, the child vomited again without obvious inducement. The vomitus was stomach contents, mild, without fever and diarrhea. They went to an external hospital for treatment, indicating that the blood leukocyte, lactic acid and metabolic acidosis are increased, and anti infection and fluid replacement support will be given. Later, the family came to our hospital for further diagnosis and treatment. It is proposed that "glycogen accumulation disease type Ia, hyperlactemia" was admitted to the hospital.

Since the illness, the child had been in good spirits, without significant weight loss, and no obvious abnormality in urine and urine.After admission, the nutritional status of the child was improved by correcting acidosis, feeding her with oral sugar free milk powder and raw and raw corn starch, placing stomach tubes, performing gastrostomy, and combining oral feeding with gastrostomy. The general condition of the child recovered well after surgery, eating gradually regularly, maintaining metabolic indicators at normal levels, and getting better and better after discharge.

2.2 | Various nursing measures

2.21 | Emergency management of first aid, discovering acidosis and correcting electrolyte disorder in time

The child repeatedly vomited and had difficulty feeding before admission.The lactic acid value in the external hospital was 9.87mmol/L, and the blood gas analysis showed that BE was -7.8mmol/L, pH was 3.73, HCO3- was 18.4mmol/L, and blood glucose was 2.0-3.0mmol/L.It indicated that metabolic acidosis, hyperlactaemia, hypoglycemia. Studies have shown that complications of severe metabolic disorders caused by the disease can lead to acute encephalopathy, liver disease, renal insufficiency, pulmonary hypertension, heart failure, and even death [6].After admission, the child was immediately given a supine position, kept warm, 24-hour ECG monitoring monitored vital signs. At the same time, the child was given to keep the airway open and give oxygen early, consciousness, pupils, and signs of both lungs were closely observed to prevent cerebral edema and pulmonary edema. The nurses drawsed venous blood in time to keep abreast of blood gas and electrolytes. According to the blood glucose value was 4.3 mmol/L, BE- value was 4.3 mmol/L, 15 ml of concentrated sodium and 5 ml of 10% potassium chloride were added into 10% high concentration glucose water to maintain the treatment of slow

continuous intravenous infusion. The rate of fluid replacement was maintained at 20～55 ml/h (the sugar rate was 1.75~4.8 mg/kg. min), sodium bicarbonate was used to correct acidosis, and the blood sugar was maintained at 5~8 mmol/L[7]. Blood gas, blood lactic acid, sodium, potassium, chloride and other blood indicators were reviewed regularly.

2.2.2 | Comprehensive nutritional diet assessment and multidisciplinary consultation to determine the nutrition improvement plan

Comprehensive assessment of nutritional status

Before admission, the metabolic control index of the child fluctuated unstable, hypoglycemia was frequent, and blood glucose was maintained at 2.0~3.0mmol/L combined with hyperlactic acidemia, metabolic acidosis, abnormal liver function, abdominal Penglong, and liver ribs 7 cm.In the growth and development indicators, the child was 3 years old and 3 months old, with a weight of 18.55kg and a height of 89.5cm. According to the child nutrition assessment form designed by Professor Cai Wei of our hospital, the child was in malnutrition status[8], and his height was lower than two standard deviations of the same age, sex, and race.In addition to raw corn starch, the child's diet was only lactose free milk powder for a long time in the past, and only liquid and semi liquid drinks were allowed. It was difficult to add complementary foods from 6 months after birth.

Clarification of dietary management issues

Due to the particularity and various restrictions of diet, the children's diet often did not follow the normal feeding schedule, and there was a delay in introducing solid food, resulting in a delayed transition of food conversion, which caused long-term mastication and swallowing with feeding difficulties. The complementary food was not added on time, the children's oral teeth had not been properly trained, and the mastication function was seriously poor,Many factors not only caused unbalanced nutrition matching of children, affected growth and development, but also aggravated metabolic disorder.The GSDI diagnosis and management guidelines in 2014 recommended that carbohydrate accounts for 60%~70% of the dietary nutrients, protein accounts for 10%~15%, and the remaining energy comes from fat (the fat intake of children aged 2 years and above should be less than 30%)[9].During the course of the disease, the child repeatedly vomited, less oral completion, and decreased appetite, failing to meet the above requirements.The Child often had symptoms of hypoglycemia such as trembling and cold sweat, and parents often fail to deal with them correctly in time. Pediatric endocrinology,metabolism specialists and nurses paid close attention to the feeding situation of the child, helped the child to insert a gastric tube to improve the feeding problem, but the feeding problem of the child was not significantly improved by the nasal feeding milk Q3H, 100ml/time.The Nutrition Department, Pediatric Digestion and Nutrition Department and Anesthesiology Department were invited

for consultation, pointing out that the current oral stomach tube and oral feeding could not meet the nutritional requirements of the child. It was confirmed that the child had indications for gastrostomy. After completing the preoperative inspection and full preparation, gastrostomy was performed, and the gastrostomy tube was retained after the operation.

2.2.3 | Developing individualized diet strategy to maintain stable blood sugar

Before fistulation, sugar free milk powder and raw corn starch were fed 35g/time. Raw corn starch was prepared with 20~25℃cooled boiled water five times a day, and a small amount of semi liquid complementary food was fed. The total calorie was about 1300kcal. The family members of the child were instructed to record their daily diet according to the diet record table (Table 1) designed by the our department to ensure that the diet nutrients structure was reasonable.A continuous glucose monitoring system (CGMS) was installed on the children's arms to observe the changes of blood glucose at any time, record the blood glucose of the children's fingers before and after meals and at 2:00 in the morning, and be alert to the occurrence of hypoglycemia. In case of hypoglycemia, the doctor should be notified and dealt with in a timely manner. The child had a fast meal and no water fasting the night before the gastrostomy operation, and no water at 6 am on the day of the operation.

The child was fasted from food and water for 6 hours after surgery, and was given omeprazole acid suppression and hemostatic sensitive gastric treatment, actively rehydrated, and recorded the 24-hour intake and exit to ensure the accuracy of fluid and energy supply. On the day after the postoperative day after the recovery of eating and the first day after the operation, 40ml lactose-free milk powder was pumped into the gastrostomy tube for 1 hour, once every 3 hours and 40ml sugar saline gastrostomy tube was pumped continuously for 1 hour, and it was conducted at Q3h.10% GS maintained intravenous fluid infusion to maintain stable blood glucose, and blood glucose was monitored at Q3h.During this period, nurses needed to observe whether the child had vomiting and whether there was retention, bloating, diarrhea, etc. before each pump. The second day after surgery, the child vomited twice, the amount was 5~10ml, the vomit was milk lumps with yellow liquid, the sugar-free milk powder pump was stopped, and the sugar saline (90ml/time, Q3h) was used to feed by mouth, and the vomiting of the child was continued to be observed.On the third day after operation, the child still vomited in the morning, vomited once, which was stomach contents, about 10ml, and was pumped into the gastrostomy tube with sugar saline (90ml/time, Q3h).The blood glucose was monitored at Q3h in the first three days after operation to be alert to the occurrence of hypoglycemia and maintain the blood glucose above 4-5mmol/L.Once the child had symptoms of hypoglycemia such as mental depression, pale face, fatigue, palpitations, tremors, cold sweats, etc, the doctor should be notified immediately and treatment should be carried.

Table 1 Diet Record of Pediatric Endocrinology and Genetics Department of Xinhua Hospital

Name: Gender: Age: Weight: (hot calorie kcal: 1g carbon water * 4 1g protein * 4 1g fat * 9)

Target:	Total hot card:	Energy of Carbon water：	Grams of Carbs:	Energy of Fat：	Grams of Fat:	Energy of Protein：	Grams of Protein:	Special amino acids(mg)	Special amino acids(mg)	Special amino acids(mg)

Date/ Eating time	type Milk/Complementary food	Input ml	Output ml	weight （g）	Carbon water (Food quantity * coefficient)		Fat (Food quantity * coefficient)		Protein (Food quantity * coefficient)		Special protein	Natural protein	Total hot card (kcal)
					g	kal	g	kal	g	kal	g	g	
Total for the whole day													
Proportion of hot card													

2.3.4 | Encouragement of oral feeding and training of feeding behavior

On the fourth day after the operation, the child was encouraged to gradually transition from gastrostomy tube feeding to oral feeding of sugar free milk powder 100ml with raw corn starch 27g, five times a day, with three meals of semi liquid complementary food added, and the gastrostomy tube was pumped with sugar saline, and the child's completion and blood sugar fluctuations were noted.Since then, the child did not vomit frequently, and her blood sugar was stable. Later, the child's milk volume was increased to 600ml, five times a day. At the same time, the child was given a multivitamin supplement and continued to record a diet record table.On the 10th day after the operation, the child vomited again, and the oral feeding was poorly completed, so the oral feeding was stopped and the original gastrostomy tube was used to pump sugar free milk powder, raw corn starch and complementary food. During this period, the diarrhea of the child increased, up to 7 times, and montmorillonite and bifidobacterium were given to regulate the bowel therapy, and the treatment improved.Once again, it was changed to oral feeding. At the same time, under the joint guidance of the rehabilitation department and the nurse of the department feeding specialist team, the child's oral sensation and motor function were trained, including 1/3 massage/press on the orbicularis muscle around the lip, masticatory muscle, lingual body side and tongue front, rubbing and swallowing inside and outside the cheek, and using cotton swabs to stimulate the child's oral cavity once a day. The goal was to promote the recovery of oral function in the child [10].The patient tolerated oral feeding, had good food intake, and was discharged after improvement.The whole diet adjustment process of the child is shown in Table 2:

Table 2 Diet adjustment during hospitalizatio

time	Feeding food	Feeding mode	Completion	Blood glucose monitoring frequency
Before operation	Lactose free milk powder feeding and raw and raw corn starch 35g/time Small amount of semi liquid complementary food	Oral/5 times a day	vomit	Before going to bed and 2:00 a.m. before and after three meals
Evening before operation	Fasting without water	Oral	/ /	Before going to bed and 2:00
Operation day: 6am	Water deprivation	/	/	a.m. before and
6 hours after operation	Fast from food and water	/		after three meals
The first day after operation	40ml lactose free milk, 40ml sugar brine	Gastrostomy tube pumping shall be maintained for 1 hour and conducted at Q3h	vomit	
The second day after operation	Stop using lactose free milk, 90ml sugar brine	Oral, Q3h	vomit	Q3h
The third day after operation	Stop taking sugar and saline	Gastrostomy tube pumped with saline and sugar	Tolerable	

The fourth to ninth days after operation	Lactose free milk powder 100ml+raw corn starch 27g Small amount of semi liquid complementary food	Oral/5 times a day	Tolerable On the tenth day, vomit
Day 10	Lactose free milk powder 100ml+raw corn starch 27g Small amount of semi liquid complementary food	Gastrostomy tube pumping	Tolerable
The 11th day after operation~discharge	Milk volume increased to 600ml/day+27g raw corn starch Small amount of semi liquid complementary food	Oral	Tolerable

2.2.5 | Nursing care of gastrostomy

Nutrients can enter the gastrointestinal tract directly through nutrition tube, and direct feeding through stomach is more suitable for human physiology. In case of poor oral feeding, it is the first choice for tube feeding[11].Gastrostomy is the application of endoscopic technology to establish a channel between the abdominal wall and gastric cavity, so that drugs or food can enter the stomach directly. It is applicable to children with dysphagia, who cannot take all or only part of their food orally, and who need continuous nasal feeding and enteral nutrition[12-13].For this child, the feeding speed was strictly controlled during the use of gastrostomy tube, and the infusion pump was used to maintain the feeding control at about 1h each time.To keep the fistula unobstructed, 10ml warm boiled water should be used to flush the tube after taking food through the gastrostomy tube each time.The child's lactose free milk and other nutritional liquids should be prepared on the spot, especially the raw rice starch powder. The nurses also needed to pay attention to keeping the equipment clean, strictly implement the handwashing system before operation, and use a set of equipment to change every day. Doctors and nurses checked the area around the ostomy daily for exudate, kept the surrounding skin clean and dry, and changed dressings regularly.On the first day after operation, the skin around the gastrostomy stoma and the surface of the external nutrition tube close to the stoma were sterilized, and the external nutrition tube was held in hand, extending 1~2 cm into the stomach cavity to make the PEG pad in the stomach leave the stomach wall. After rotating the nutrition tube, the PEG pad was pulled out to make it cling to the stomach wall, so as to avoid the occurrence of adhesion and fixer implantation syndrome[14].The fistula was fixed on the chest and abdomen wall, properly fixed, avoid shaking, and prevent patients from discomfort or pain caused by slippage and traction. Nausea, vomiting and other abnormalities were observed during the whole eating process, and nurses would notify the doctor in time if there was gastrointestinal discomfort.

2.2.6 | Doing a good job of psychological response and home rehabilitation guidance

Children with this disease are characterized by growth retardation, short stature, and fat on the cheeks and buttocks,

which is "doll-like". The child's family had low self-esteem and anxiety, and the medical staff encouraged the child's parents to "feed correctly" to reduce acute attacks. At the same time, praise and encouragement were given in a timely manner to help children regain confidence in life. Because the disease process is long, children and their families were prone to some negative and depressive emotions, doctors and nurses taked the initiative to care for and stabilize the emotions of their families, and gave the children and their families maximum understanding and psychological support. At the same time, similar cases of better recovery were shared to build confidence in overcoming the disease.

The child and her families were informed to insist on regular follow-up, continue to feed lactose free milk powder and raw corn starch, 27g/time, 4-6 times a day, gradually add complementary food, give priority to oral feeding, and the remaining amount can be pumped through the stoma. And they needed to keep a diary of the child's diet, including the time and amount of raw corn starch, the type of food intake (especially the proportion of carbohydrate, fat and protein), amount and meal time, and vitamin/mineral supplementation. They also needed to be aware of gastrointestinal symptoms (eg, nausea, vomiting, abdominal pain, diarrhoea) and be alert for serious complications. Medical staff recommended that the child's family continue to use cntinuous glucose monitoring system (CGMS), or routinely use fingertip blood glucose meters to monitor blood sugar, focus on monitoring blood glucose before meals, raw corn starch before consumption, be vigilant against hypoglycemia. When the child was at home, the child should adjust the diet plan, raw cornstarch dosage or time in time according to the fluctuation of blood sugar, and If the child developed hypoglycemia, sugar can be taken orally in time. Finally, the child should also regularly monitored blood routine, liver and kidney function, blood lipids, blood lactate, blood gas analysis and other indicators, and later we used the department's cloud follow-up platform to regularly follow up supervision, and the child's general condition was stable after one month.

3 | DISCUSSION

We all know that glycogen storage disease is a rare disease, and for the disease itself, the control of the child's diet is very important. If it is not well controlled, it will lead to multiple systemic complications such as hypoglycemia, hyperlactaemia, hepatomegaly, and endanger the lives of children.When children have feeding disorders, how to adjust the diet well, maintain blood sugar stability, and reduce the occurrence of complications is a major challenge. Throughout the course of nursing, our team recognizes the importance of multidisciplinary collaboration and individualization of the child.The medical team of the Department of Endocrinology of our hospital, together with the Department of Nutrition, the Department of Rehabilitation, and the Department of Pediatric Gastroenterology, provided targeted care through the emergency management of first aid, discovering acidosis and correcting electrolyte disorder in time, comprehensive nutritional diet assessment and multidisciplinary consultation to determine the nutrition improvement plan, developing individualized diet strategy to maintain stable blood sugar, encouragement of oral feeding and training of feeding behavior, nursing care of gastrostomy, doing a good job of psychological response and home rehabilitation guidance, to promote the improvement and recovery of the child and provide reference for how to realize the nursing care of these children.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

WQP:conceptualized the initial content and structure of the manuscript. WQP,BY,HM: drafted the manuscript. GXH, YQ and LLL: revised and edited the manuscript substantively. All the authors: read and approved the final manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Not applicable.

CONSENT FOR PUBLICATION

Written informed consent to publish this information was obtained from study participants.Informed consent for publication had been obtained patient's parents via institutional consent form. The manuscript contains no identifier or personal or clinical details that will compromise anonymity.

DATA AVAILABILITY STATEMENT

Not applicable. Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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