Lay summary of patient and family experience of the pathway for glucagon-like peptide 2 analogue study

This study looked at how patients with short bowel syndrome and intestinal failure experience taking a medication called teduglutide (a glucagon-like peptide 2 analogue) and following the required monitoring. These patients are unable to get enough nutrition from food alone, so they rely on artificial feeding through a vein called parenteral nutrition.

Teduglutide has been approved for use in these patients because it might help them absorb more nutrition from food and rely less on parenteral nutrition. However, taking the medication means patients need to be closely watched by their healthcare team at a specialized unit for intestinal failure.

Not much research has been done on how patients and their families feel about taking this medication and going through the monitoring process. That's what this study aimed to find out.

The study took place from 2019 to 2023 at Salford Royal hospital. To participate, patients had to be treated at the hospital, have short bowel syndrome, rely on parenteral nutrition at least twice a week, and agree to inject themselves with teduglutide. Patients were also asked if they had family members or friends involved in their care, and if so, they could nominate them to participate in the study too.

A total of 10 patients and 6 family members took part in 32 interviews to share their experiences with the medication and the required monitoring.

The patients found the monitoring process for teduglutide to be difficult, and not all of them were able to follow it completely. Only one patient was able to stop using parenteral nutrition altogether. The other patients experienced only minor improvements and had many side effects, so they decided to stop taking the medication.

Despite the challenges, the patients didn't regret trying teduglutide. They wanted to explore every possibility of reducing their reliance on parenteral nutrition and improving their lives. Teduglutide offers another treatment option for intestinal failure and gives patients a chance to reduce their need for parenteral nutrition.

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