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# Eating Difficulties in the Pediatric Small Bowel Recipient: The Role of the Nutritional Management Team

S. Staschak-Chicko, K. Altieri, M. Funovits, J. Kovalak, J. Reyes, B. Nour, O. Bronsther, A. Tzakis, J. Fung, S. Todo, and T.E. Starzl

INTESTINAL transplantation has become a feasible option for total parenteral nutrition (TPN)-dependent patients with short gut syndrome. Crucial to the long-term success of small intestine transplantation is the recipient's ability to maintain an adequate oral intake. It was of particular concern that some pediatric patients would not eat postoperatively and therefore required enteral feeds for total nutritional support. The objectives of this study were to identify factors that influence postoperative eating difficulties in pediatric intestine transplant recipients and the development of therapeutic approaches to improve oral nutrition.

### PATIENTS AND METHODS

Between July 1990, and March 1993, 22 children with intestinal failure underwent isolated small intestine transplantation (n=5), combined liver/small intestine transplantation (n=15), or multivisceral transplantation (n=2). Of the total, 6 patients died and 1 had removal of the graft for rejection. The remaining 15 pediatric patients were studied for their preoperative and postoperative eating patterns with follow-up ranging from 3 to 36 months.

#### RESULTS

An eating difficulty was defined as refusal to eat for greater than 90 postoperative days in the presence of a functioning graft. A graft was considered functional when the patient became independent of TPN. Six patients (40%) were identified as having eating difficulties. None of these 6 children were eating preoperatively. Of these 6 patients, 1 child has a rejecting graft and posttransplant lymphoproliferative disease, and another child has severe dysmotility of the proximal native gastrointestinal tract. The 4 remaining patients received intensive intervention which included individual and group feeding therapy as well as continuous family support. Of the 4 patients who received feeding therapy, 2 have begun to eat, and the other 2 patients continue to refuse to eat. The other 9 patients without eating difficulties did experience initial hyporexia; however, they had attained satisfactory eating habits, such that 4 of these patients are completely free of supplemental feedings. Five patients still require supplemental enteral feedings, which are slowly being weaned.

#### DISCUSSION

While intestinal transplantation has achieved technical success trestoration of normal small bowel anatomy and

independence from TPN), it does not necessarily equate with the ability of the recipient to sustain adequate oral nutrition. The factors we identified as influencing postoperative eating were age/duration of TPN, patients who had a lack of experience with eating pretransplant, and the presence of siblings as role models. We observed several similarities in the group of pediatric recipients who did not eat posttransplant, but the single most significant factor was the lack of experience with eating pretransplant. As a result, a Nutritional Management Team was formed to encourage postoperative eating, which consisted of a clinical nurse specialist (ie, feeding specialist), occupational therapist, dietitian, and the clinical transplant coordinator. The team worked closely with the children on an individual as well as group basis.

The dietitian chose developmentally appropriate menus with particular attention to taste and texture, monitoring the child's nutritional needs and calculated caloric requirements. The occupational therapist and the feeding specialist performed developmental assessments and taught swallowing and chewing techniques. The liver transplant coordinator was responsible for assessment and evaluation of outpatient follow-up and progress on a long-term basis. A daily food diary, patient's height and weight, and laboratory parameters were obtained to provide ongoing evaluation of the recipient's progress.

As a direct outcome of our early experience with post-transplant eating difficulties, we have modified our preoperative nutritional teaching. Presently, all new candidates for small intestine transplant are assessed by the feeding group as part of the routine candidate evaluation. This dietary assessment identifies the patient's baseline eating habits and allows for development of an individualized feeding plan. This plan strongly encourages all patients to eat pretransplant unless medically contraindicated. Other strategies stress the importance of patient and family education about continued oral feedings, and the encouragement to eat pre- and posttransplant. Professional education is aimed at the same nutritional goals.

From the Pittsburgh Transplantation Institute, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.

Address reprint requests to Dr Thomas E. Starzi, MD, PhD, Pittsburgh Transplantation Institute, University of Pittsburgh Medical Center, 3601 Fifth Avenue, 5C Falk Clinic, Pittsburgh, PA 15213.

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Our experience suggests that though independence from TPN was achieved with intestinal transplantation, factors that may affect eating difficulties include age/duration of TPN, experience with eating pretransplant, and the presence of role models. Our conclusions suggest the importance of the awareness of this possibility and the possible

risk factors, encouraging eating pretransplant and the use of a nutritional management team.

## **REFERENCES**

1. Abu-Elmagd K. Fung JJ, Reyes J. et al: Transplant Proc 24:3, 1992