Feeding through a gastrostomy button (GB) provides benefits to the families of children on chronic dialysis. But data on the transition to oral feeding following renal transplantation—especially in children under 2—is scarce. Here, we report our experience of more than 14 years in 22 children who were GB fed at under 5 years of age (median age: 1.66 years; range: 0.25 – 4.25 years). We excluded 6 children from the analysis of transition following transplantation because of factors precluding early return to oral feeding—specifically, cognitive impairment and a tongue tie. We compared 10 children who commenced GB feeding at less than 2 years (group 1) with those who commenced at 2 – 5 years (group 2, n = 6).

All 16 children made the transition to normal oral feeding by 10 months post transplantation. Median duration of GB feeding post-transplant in group 1 was 0.3 years (range: 0.1 – 1.0 years) as compared with 0.2 years (range: 0 – 0.3 years) in group 2 (p = 0.2).

Children with normal cognition and no other precluding factors who have a GB inserted at less than 2 years of age can make a successful transition from GB to oral feeding with no significant delay. Family support should be individualized during this period of potential anxiety.

Key words
Gastrostomy, transition, renal transplantation, chronic dialysis

Introduction
Enteral nutritional support has become an integral part of the management of children on dialysis whose oral food or supplement intake is inadequate (1–3). The presence of an enteral tube not only allows delivery of the nutrition prescription, but also eases administration of fluids and medications and minimizes the risk of force-feeding the child. To quote one parent from our parent support groups: “The dialysis is easy; it’s the feeding that’s difficult” (4).

The nasogastric tube has been the most frequent method of enteral support (5), but the gastrostomy route is more attractive, given the lesser need for traumatic passage of tubes, less likelihood of gastroesophageal reflux and aspiration, and better opportunities for stimulating oral motor development.

Our original experience with feeding through a gastrostomy button (GB) in children on continuous cycling peritoneal dialysis was reported in 1992, and similar positive experiences have been reported from other centers (6–9). However, one of the major concerns is that prolonged tube feeding in the young child can lead to interruption of normal oral motor development (10). Tube feeding a child during the first 2 years of life can disrupt a crucial developmental period when children learn to accept a variety of tastes and textures (11), which in turn may lead to difficulties later, when children make the transition to oral feeding after transplantation. Few reports have been published on the transition to oral feeding in gastrostomy-fed infants post renal transplantation (12,13).

Our own unit’s initial experience was positive, in that 12 of 14 children ceased using a GB for nutritional support within a mean of 12 weeks after transplantation (14). We now report our further experience in a cohort of children spanning a larger age range.

Patients and methods
We included in the study infants and children less than 5 years of age who had undergone nutritional support via a GB for at least 6 months before transplantation. We favor the Stamm gastrostomy (insertion as an open surgical procedure) rather than the percutaneous endoscopic approach, which carries a greatly increased risk of peritonitis when attempted in children on chronic
peritoneal dialysis (9). In our unit, GB insertion is routinely considered at the time of insertion of the dialysis access (15).

We divided the patient cohort into two groups, with group 1 undergoing insertion of the GB at under 2 years of age and group 2, at 2 – 5 years of age. We obtained the duration of tube feeding pre- and post-transplant and other clinical data from our prospective registry database. For the analysis of duration of GB feeding post-transplant, we excluded 6 patients (3 in each group) who had additional impediments that precluded early return to oral feeding—specifically, cognitive impairment as a result of congenital or acquired brain damage, and tongue tie (Table I).

The pediatric renal dietitian and clinical psychologist led a feeding support group for parents with the aim of having them share experiences, discuss frustrations, and make suggestions for additional support that would help with the transition to oral feeding.

Results
We prospectively observed 22 children (13 boys/9 girls) over 538 patient–months of treatment between 1989 and 2003. Mean of commencement of GB feeding in the 22 patients was 1.7 years (range: 0.25 – 4.25 years). Table I shows the causes of the renal failure, the pre-transplant dialysis modality, and the duration of GB feeding.

The median duration of GB feeding in the group 1 children was 2.9 years (range: 1.0 – 5.58 years) as compared with a median of 1.7 years (range: 0.5 – 6.0 years) in the group 2 children. The longer duration in group 1 is consistent with the policy in our unit of achieving at least 10 kg body weight before listing for transplantation.

Duration of GB feeding post-transplant
The median duration of feeding post-transplant in group 1 was 0.3 years (range: 0.1 – 1.0 years) as compared with a median of 0.2 years (range: 0 – 0.38 years)

<table>
<thead>
<tr>
<th>Patient ID</th>
<th>Sex</th>
<th>Primary renal disease</th>
<th>Treatment pre-Tx</th>
<th>Age at pre-Tx (years)</th>
<th>Total feeding duration (years)</th>
<th>Feeding duration post-Tx (years)</th>
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<tr>
<td>1</td>
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</tr>
<tr>
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<td>M</td>
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<tr>
<td>6</td>
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</tr>
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<td>HD</td>
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</table>

a Cognitive impairment.

b Tongue tie.

Tx = transplantation; F = female; APD = ambulatory peritoneal dialysis; M = male; HD = hemodialysis; PTx = pre-emptive transplantation.
in the older children of group 2 ($p = 0.2$). The 16 children with normal cognition and without limiting anatomic factors made the transition to complete oral feeding by 10 months post-transplant. Of the 16 children, 9 (56%) made the transition by 3 months post-transplant, 4 (25%) by 5 months, and 3 (19%) by 10 months.

**Transition to oral feeding in children with poor cognition or limiting anatomic factors**

Two of the 5 children with cognitive defects (patients 14 and 15) made the transition to complete oral feeding at 8 and 3 months respectively. The remaining 3 children (patients 3, 5, and 21) continue to rely on enteral feeds to provide most of their nutritional requirements.

In 2 of the 3, GB feeding provides up to 53% of energy requirements, and 1 patient drinks Nutrison Concentrate and Nutrini Energy Multi Fibre (Nutricia Clinical Care, Trowbridge, Wiltshire, U.K.) to provide 57% of his energy requirements. Several attempts were made to withdraw the enteral feed without a concomitant increase in oral intake. Hence the feeds were recommenced by parents when they feared possible weight loss.

At 16 months post transplant, one other child (patient 11) was recognized to have a significant tongue tie that prevented her from consuming textured, lumpy foods. Since receiving treatment, this child has made good progress, but at present still requires 32% of her energy requirements to be given via the GB.

**Feedback from the feeding support group**

Four parents reported their experience with 3 children (4, 5, and 9 years) who were still receiving GB feeding post-transplant.

Barriers to successful transition to oral feeding suggested by the parents included these: “She is too keen to play ... too busy to eat ... catching up [for time spent in hospital and on dialysis].” Feeding-behavior problems were commonly encountered (“she often retches when offered food”), and parents admitted that the food their child would eat was often not ideal (“because he is so fussy with food, sometimes he gets what he asks for ... chocolate bar for dinner”). Feeding behavior can affect siblings (“her twin sister stopped eating!”) and strain relationships in the home (“shouting at the kids because they won’t eat ... we fight about it all the time”).

Parents found social activities difficult (“parties are embarrassing; you are forever explaining yourself ... we don’t go back to other mums’ homes ... she just won’t eat”). Anxieties about reducing the GB feed were discussed, with one parent commenting about the “fear of jeopardizing the transplant by not giving enough feed.... Overnight feeding is a security.” One family commented about the importance of having a routine and remaining firm and consistent, even if this involves “obsession ... sticking with the same foods.”

**Discussion**

Our long-term experience suggests that children with no cognitive impairment or other disabilities will make a successful transition from GB to oral feeding. This transition is usually achieved in most children by 3 months post-transplant and is slightly delayed in children who started GB feeding at less than 2 years of age (mean: 0.4 years) as compared with children who commenced GB feeding at 2 – 5 years of age (mean: 0.25 years). These results would tend to support the findings of Kamen, who stated in her 1990 paper that children who are tube fed during the first 2 years of life are at risk of impaired development of normal oral motor patterns (10).

We previously suggested a policy whereby GB feeding would be discontinued at the time of renal transplantation to stimulate appetite as renal function is restored and when stimulants such as corticosteroids were being administered (14). We now adopt a more individualized approach, because younger children in particular may not be equipped with the oral motor skills to manage and “trust” their own oral mechanisms to “handle” the increased demands (10). They may need to be re-taught how to eat, because the process is not automatic. In addition, concerns arise about adequate fluid intake and medication, and many parents wish to delay removal of the GB in those situations.

It used to be convenient to remove the GB at the same time as the peritoneal dialysis catheter in children treated with automated peritoneal dialysis post-transplant. Because most peritoneal dialysis catheters are removed within 3 – 6 weeks post-transplant (16), the timing may be too soon for removal of a GB, which requires a formal closure of the tract in all patients who have had the GB in place for longer than 6 months (17).
Removal of the GB is delayed until the child is taking more than 50% of the nutrition prescription from oral diet. Parents need to be forewarned about the expectations with a GB at all stages of the child’s progress from pre-dialysis to post-transplant (12). The families require not only regular clinic assessments by the pediatric renal dietitian, but also additional support, with regular telephone contact and access to members of the multi-professional team such as play therapists and a clinical psychologist (18). Speech therapists may also have a role in supporting the families.

If a GB is in place, simultaneous tube feeding and oral experience is encouraged: The child can be put to the breast or can mouth food or try other oral intake to help make a firmer association between mouth movements and reduction of hunger (19). Touch and movement can be used in a highly communicative, interactive fashion during feeding sessions. Establishing a regular meal pattern, involving the child, and encouraging time for interaction with other family members are other useful strategies.

We emphasize to parents that mealtimes are a pivotal learning opportunity for children. Even if they play with food or hold it in their mouth for a time before discarding it, their involvement is a learning experience of social interaction and development. Parents derive much support from other families in similar situations, which is the aim that our feeding support group for parents tries to foster.

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References

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