

THE FUTURE OF INTESTINAL FAILURE SERVICES IN ENGLAND AND WALES

Introduction

Intestinal failure services for children are currently managed regionally. Improvements in paediatric intensive care, medical and surgical facilities in the past twenty years has resulted in much greater numbers of children receiving parenteral nutrition for prolonged periods in hospital and at home.

Birmingham is currently the single provider for small bowel transplantation in the UK with greater than 50% long term survival. The service is funded by the National Specialist Commissioning Advisory Group (NSCAG) who fund national services or specialised services for rare diseases.

The current service agreement with NSCAG covers the cost of assessment for potential transplant candidates, the transplant episode and follow up.

The current contract does not include the management of those children with complex intestinal failure in whom small bowel transplantation may not be necessary. In recent years such management has included isolated liver transplantation rather than combined small bowel and liver transplantation in children with short bowel syndrome.

This has led to consideration of setting up supra-regional units for the management of children with complex intestinal failure as such patients are small in number and require concentration of expertise.

NSCAG has asked the BSPGHAN to comment on the need for supra-regional centres for the assessment and management of patients with complex intestinal failure. We have not been asked to comment on whether there should be more than one unit performing small bowel transplantation.

Potentially there may be increased funding for children with intestinal failure, and possibly the development of additional supra-regional centres.

The size of the problem

We do not have accurate knowledge of the numbers of patients requiring long term parenteral nutrition (PN) nationally, and 'complex intestinal failure' is even more difficult to delineate.

If intestinal failure is defined as the need for PN for greater than four weeks there are clearly many patients already being managed in regional centres by gastroenterologists and/or surgeons, often through the agency of multidisciplinary nutritional care teams. If the definition is arbitrarily extended to 6 (or even 12) weeks of PN, the numbers will be less.

For the management of children with intestinal failure complicated by liver disease, regional paediatric units will need either to have hepatology services on site or close links with supra-regional liver units.

Consultation, and report back to NSCAG, September 2004

We are now in the period of a consultative process, involving both members of the BSPGHAN and the British Association of Paediatric Surgeons (BAPS), with feedback to NSCAG scheduled for September 2004. We are therefore requesting your view as a member of the BSPGHAN on this important issue and would be grateful for any comments in relation to how services for intestinal failure should develop.

Specific questions to be addressed include:

1. Is intestinal failure (when separated from bowel transplantation) a specialised and vulnerable service that is appropriate for NSCAG designation?
2. What kind of patients should be referred (i.e. what constitutes 'complex' intestinal failure)?

Possible examples of patients that might be referred include:

- Patients with intestinal failure in whom diagnostic uncertainty persists (eg protracted diarrhoea, motility disorders)
- Short gut patients not making reasonable progress with enteral feeding (e.g. tolerating <50% of their nutritional requirement enterally after 6 months of PN)
- Patients with progressive liver dysfunction (rising conjugated bilirubin after three months on PN; not tolerating an increase in enteral feeding)

- Patients in whom venous access is difficult and there is a real possibility that PN cannot be maintained in the near future
- Patients with short gut in whom surgery aimed at bowel lengthening or improving motility (gut tapering) might be considered as a means of establishing full enteral nutrition
- Patients with recurrent episodes of life threatening catheter related blood stream infection

3. How many supra-regional intestinal failure units would be ideal (1, 2, 3?) (it is likely that location would be the subject of a formal bidding process)

Our initial view is that a strong case can be made for more than one intestinal failure centre, but that further development should not be at the cost of weakening current regional services.

The role of the supra-regional intestinal failure unit as part of a managed clinical network could be

- To assess and advise on the management of the small number of complex cases
- Collaborate in the development of management protocols
- Aid in diagnostic difficulty
- Evaluate new treatments
- Support regionally based services
- Facilitate research

The majority of children with intestinal failure would remain within region as now.

In addition, the supra regional unit may also facilitate the standardisation of home parenteral nutrition (HPN) services, although we would not anticipate the need for all HPN patients to be referred to a supra-regional intestinal failure centre. One could therefore envisage most children managed within region with a register of children on home parenteral nutrition . There would be a facility for children from centres with only small numbers of children on HPN to be seen for review in the larger unit if appropriate.

On behalf of the BSPGHAN Council, therefore, we would like to ask for your views on this topic as outlined above.

In addition to general views we would also be interested in a number of specific responses including number of children who were PN dependent for 4 weeks or more (and 12 or more) in your centre, and how many home PN patients you managed, during 2003 if these data are available.

In your feedback could you please give your views upon

What constitutes Complex Intestinal Failure (time frame, clinical condition)

Whether you feel such patients should be managed in conjunction with a supra regional centre

What facilities/expertise should be available at such a centre

We are grateful for your input so as to ensure that views expressed represent the society's view on this important topic

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