



Original Article

Trends in paediatric home parenteral nutrition and implications for service development

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SUMMARY

Background & aims: The demand for home parenteral nutrition (HPN) services for children has risen over the past 20 years. To plan a strategy for delivery of care at regional level, we carried out a national point prevalence survey of HPN during February 2010.

Methods: Paediatric gastroenterologists in 33 hospitals known to have provided HPN services were identified from their membership of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition and participation in the British Intestinal Failure Survey (BIFS). Anonymised data were collated by the BIFS administrator and results compared with a similar study performed by the British Paediatric Surveillance Unit in 1993. Trends in underlying diagnosis were explored using the BIFS database for 2006–2009.

Results: 139 children on HPN were reported; a fourfold increase since 1993; six of these were older than 16 years. The regional point prevalence of HPN varied from 1.76 to 41.4 per million, with a mean of 13.7 patients per million. Short bowel syndrome had increased from 27% to 63% of cases.

Conclusions: The large overall increase in numbers of HPN patients suggests that a national strategy needs to be developed for the management of chronic IF.

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1. Introduction

Parenteral nutrition (PN) is life saving in intestinal failure (IF), with an estimated 1200 children each year in the United Kingdom (England, Scotland, Wales and Northern Ireland) needing this intervention for at least one month.¹ The most common indication for short and long term PN is Short Bowel Syndrome (SBS), increasingly prevalent from improved survival of preterm infants with necrotizing enterocolitis, and the near tripling of gastroschisis cases.² Ideally, such a complex and technical treatment should be provided from within appropriately staffed specialist centres³ including a multidisciplinary nutrition support team (NST). Despite NSTs having been shown to reduce the incidence of

complications and to be cost effective,^{4,5} they are still found in only a minority of paediatric units.⁶ Improving services for children with IF should reduce complications of PN and is a priority for paediatric gastroenterologists in the United Kingdom.⁷ Although the majority of patients discontinue PN after a period of rehabilitation, home parenteral nutrition (HPN) must be considered for any patient likely to be dependent on PN for more than three months. In addition to the psycho-social benefits for the child and family, it is associated with lower risks of catheter related blood stream infection (CRBSI), and probably as a consequence, a decreased risk of intestinal failure associated liver disease (IFALD); the latter being the main indication for small bowel transplantation.⁵

For families who agree to care for their children with intestinal failure in the home environment the demands are immense, and the need to provide education, training and support effectively means that this can only be achieved by specialized hospital nutrition support teams working collaboratively with community services. Although many children with short term intestinal failure may be managed in a variety of hospital paediatric settings, those with long term IF who are suitable for HPN will have to be transferred to a specialist unit. In order to inform the development of a national strategy for IF, we carried out a census of children

Abbreviations: BIFS, British Intestinal Failure Survey; BSPGHAN, British Society Paediatric Gastroenterology, Hepatology and Nutrition; CRBSI, Catheter related blood stream infection; HPN, Home Parenteral Nutrition; IF, Intestinal Failure; IFALD, Intestinal failure associated liver disease; NST, Nutrition Support Team; PN, Parenteral Nutrition; SBS, Short bowel syndrome.

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receiving HPN, in conjunction with colleagues in the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), and the British Intestinal Failure Survey (BIFS).⁸ Case identification was facilitated by utilizing the professional networks developed through BSPGHAN and BIFS which is already collecting data on paediatric intestinal failure cases. The aim was to comprehensively determine the number and geographic location of paediatric PN patients in the United Kingdom, either already at home or imminently to be discharged from hospital for HPN, and to compare with the last national survey of long term PN carried out by the British Paediatric Surveillance Unit in 1993.⁹

2. Material and methods

An excel spreadsheet was sent electronically to the local investigators for the BIFS at the 33 NHS hospital Trusts in Scotland, England, Wales and Northern Ireland who have a paediatric gastroenterologist with a full or part time commitment to paediatric gastroenterology and who are already cooperating with the British Intestinal Failure Survey. Data were requested for children at home on PN (or being trained for imminent discharge for HPN) as at the 5th February 2010 including patient initials, year of birth, and first half of home postcode. The information from the postcode was used to identify patients by their family's place of residence, rather than hospital providing PN, in order to obtain a more accurate regional prevalence and exclude the possibility of double counting. Replies from the participating Trust were anonymised by the BIFS administrator; a follow up reminder was sent by email on 3rd March, and in nine cases a personal phone call enabled completion of the census data.

The national point prevalence was calculated from the latest estimate for the population < 16 years of age in England, Wales, Scotland and Northern Ireland ($n = 11,721,722$ representing 18.8% of the whole population)¹⁰. Regional point prevalence was based on 2008 data using the 18.8% ratio to estimate regional paediatric populations.¹⁰ According to the report from Office of National Statistics¹⁰ the proportion of children under 16 years in England, Wales and Scotland reflects the UK as a whole; the exception is Northern Ireland where the proportion of boys and girls is 22.6% and 20.6% respectively. The diagnosis underlying the reason for PN was not requested in this census, but diagnoses recorded by the BIFS database (approved by MREC reference no. MT/AB/MREC.01/7/18a) allowed for comparison with the BPSU findings.⁹

Separate ethics approval for the survey was not required as patient identifiable information was not gathered and the design fulfilled the criterion of an activity audit.

3. Results

Colleagues from all 33 (100%) Trusts responded (Table 1): 167 patients were reported of whom 139 were already established on HPN, four times as many as in 1993 (see Table 2), and 28 were about to be discharged home for the first time. Two patients were reported twice by different centres who had shared care arrangements; the patients were assigned to the bigger centres, but since the centres in both cases were in the same region this duplication made no difference to the calculations of regional prevalence. There was a marked regional variation in the prevalence of HPN from 1.76 patients per million children in Wales and 3.2 patients per million children in the South West (the two lowest regions) to 41.4 patients per million children in Greater London (Table 3). In addition to regional variations in prevalence, there are marked differences in activity between gastroenterology centres (Fig. 1). The relative frequency of SBS has increased strikingly since 1993, from 27% to 63% (see Table 4). The proportion of children with the most

Table 1

Participating centres in 2010 survey $n = 33$ (100% of centres surveyed).

Addenbrooke's Hospital Cambridge
Alder Hey, Liverpool
Barts and the Royal London
Bassetlaw District Hospital
Birmingham Children's Hospital
Bristol Royal Hospital for Sick Children
Chelsea and Westminster Hospital
Children's Hospital for Wales Cardiff
City General Hospital, Stoke on Trent
Great Ormond Street Hospital
Hull and East Yorkshire Women and Children's Hospital
John Radcliffe Hospital Oxford
Kings College Hospital
Leicester Children's Hospital
Ninewells Hospital Dundee
Norfolk and Norwich University Hospital
Queen's Medical Centre, Derby Road, Nottingham
Royal Aberdeen Children's Hospital, Grampian
Royal Belfast Hospital for Sick Children
Royal Gwent Hospital
Royal Free Hospital
Royal Hospital for Sick Children Edinburgh
Royal Hospital for Sick Children, Yorkhill, Glasgow
Royal Manchester Children's Hospital
Royal Victoria Infirmary Newcastle
Sheffield Children's Hospital
Singleton Hospital, Swansea
Southampton University Hospital
St George's Hospital University of London
St Mary's Imperial College Healthcare Trust
Sunderland Children's Hospital
The General Infirmary at Leeds
University Hospital Lewisham

intractable forms of IF, has reduced from 36% to 24.4% but the overall numbers have risen and we estimate that of the 167 patients identified in this survey just under a quarter ($n = 40$) have a disorder of motility or enteropathy. Six patients (3.6%) were aged 16–22 years, and twenty-four (14.6%) were below 1 year of age.

4. Discussion

The four fold increase in HPN patients since 1993 reflects both increasing numbers and survival of patients with SBS, in addition to developments in home care. Although the regional point

Table 2

Number of children and families being trained for HPN or at home on PN, in 1993 and 2010.

	1993 Candy et al BPSU survey	2010 BSPGHAN National survey
Target group	All children on PN for greater than 6 weeks (includes in and out patients)	All children on HPN or families being trained for imminent discharge on HPN
Response rate	90.7% paediatricians by BPSU card	100% (33/33) Trusts known to provide treatment for chronic intestinal failure
Total no. reported	66	167
Number of children being managed on HPN	34 (51.5%)	139 (83%)
Number of children and families receiving training for HPN	12 (18.2%)	28 (17%)
Number aged <1 year	19 (28.8%)	24 (14.5%)
Number aged > 16 years	0	6 (3.6%)

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