



## Original article

# Current practices and experience of transition of young people on long term home parenteral nutrition (PN) to adult services – A perspective from specialist centres



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## SUMMARY

**Background:** There has been an estimated fivefold increase in the number of children receiving parenteral nutrition (PN) at home in the past 10 years with some children approaching the age when they should be referred to adult services whilst still on treatment. Models of care for moving young people onto adult providers of PN at home are not yet well developed, and transition is a potentially dangerous time for young people with complex health needs.

**Methods:** A questionnaire to ascertain current experience and practices of transition in the context of home PN services was dispatched to 170 consultant gastroenterologists who were members of the British Association of Parenteral and Enteral Nutrition (BAPEN) and also to all 40 members of the Nutrition and IF working group of the British Society of Paediatric Gastroenterology and Nutrition (BSPGHAN). Anonymised returns were received from 12 adult and 18 paediatric centres.

**Results:** We estimate about 50% paediatric IF centres, and the three largest adult IF centres responded to the survey. We identified 14 young adults already transitioned and 43 currently in transition. The practices and processes of transition reported were highly variable. Time taken to achieve transition ranged from under 6 months up to 2 years. The most frequent concerns to be identified were confusion around care routines and psychological problems at the time of transition (in one third of respondents).

**Conclusions:** We conclude that a transition pathway and service standards for adolescents on home PN should be developed, consideration should be given to checklists for practical aspects (e.g. pumps), key worker and psychology input to enhance emotional resilience of the young people and carers.

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## 1. Introduction

The availability of parenteral nutrition (PN) over the last two decades and improvements in managing patients on PN have dramatically increased the survival of children with intestinal failure (IF). The number of children discharged home on PN appears to have increased fivefold in the last 20 years [1]. Although the majority develop intestinal autonomy with increasing age, a group of these children are approaching the age when they should be referred to adult services. Transition describes the process by which

medical care for adolescents with chronic disorders is handed over from the paediatric to the adult team. Home PN services for children in the UK are organised regionally with 15 expert centres (defined as a centre with 4 or more patients on home PN) providing initial training, referral to home care teams and long term medical supervision. Depending on the patient's geographical proximity to the specialist centre, shared care arrangements with local hospitals are undertaken.

Typically during childhood PN at home is supplied by a commercial homecare company. The PN is administered by parents/carers who have undergone a formal training programme. The parents/carers are also responsible for administering other medications, for attending medical appointments and for over-seeing the activities and well-being of their child. Whereas patients on

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### Abbreviations

BAPEN	British Association for Parenteral and Enteral Nutrition
BSPGHAN	British Society of Paediatric Gastroenterology, Hepatology and Nutrition
BIFA	British Intestinal Failure Alliance
IF	intestinal failure
PN	parenteral nutrition
SBS	short bowel syndrome

home PN are aware of their condition and do grow up with various restrictions to their activities, they can develop “a level of resilience, maintain a positive outlook and cope well with illness related demands” [2]. Children attend school and participate in usual childhood activities other than contact sports. Nevertheless adulthood poses certain challenges for them as they take on the responsibility of administering the PN themselves. They will need to be trained in the administration of home PN and to clearly comprehend what poses a risk to their health and well-being. At the same time the young person is having to deal with the usual challenges of taking on responsibilities and might be moving away from their family to work/attend university.

For the above reasons, transition is a potentially dangerous time for young people with complex health needs and can be associated with excess mortality [3]. This survey was undertaken jointly by BAPEN and BSPGHAN. The aim was to ascertain current experience and practices of transition in the context of home PN services and gauge future demand for transition services. A secondary aim was to raise awareness in the adult and paediatric sectors of the growing number of young people likely to need home PN support from adult services in the near future.

## 2. Methods

A questionnaire was designed using the electronic Survey Monkey Format and dispatched via e-mail in April 2013 to 170 British Intestinal Failure Alliance (BIFA) members (a special interest group within BAPEN of gastroenterologists with expertise in managing intestinal failure (IF)), and to all 40 BSPGHAN (British Society of Gastroenterology, Hepatology and Nutrition) members of the Nutrition and IF working group. Please see Table 1 for the details of the questionnaire. It was composed of ten questions and the respondents had space to add in free text comments for each question. Replies were received anonymously.

Ethical approval for the survey was not required as no patient identifiable data were collected.

## 3. Results

### 3.1. Characteristics of home PN providers and referring patterns

Responses were received from 30 different centres, 12 adult and 18 paediatric. The adult centre respondents were either gastroenterology consultants ( $n=8$ ) or nurse specialists ( $n=4$ ). The paediatric replies were from paediatric consultants ( $n=12$ ), paediatric nurse specialists ( $n=4$ ) and dietitians ( $n=2$ ). None of the respondents were pharmacists.

The second question looked at the interaction of the respondent's unit with other care providers. For all 30 respondents their unit provided PN and home PN services. Twenty-five of the

30 were the specialist centre providing the PN at home and five shared care. Seventeen used a single home care company to formulate and deliver the PN to the home whereas 12 used more than one company.<sup>1</sup> Seven of the respondents replied that they share care home PN patients with specialist units and 11 replied that they share care home PN patients with non-specialist units. Thirteen of the 18 paediatric respondents had referred patients to an adult specialist unit. Twenty-two of the 30 adult and/or paediatric had referred patients to an intestinal transplant centre.

### 3.2. Home PN patient demographics

Question 3 and 4 asked about the age distribution of the patients and aetiology of IF. The centres were asked to report on the size of the centre and the age range of patients cared for in one year, rather than precise figures (i.e. 0–4, 5–9, 10–20, 21–50, >50 pt) – (see Table 2). The bold numbers in the cells represent numbers of centres, e.g. 12 centres report they have 1–4 patients each (12–48 in total) within the age bracket of 11–19 years, 1 centre reports 5–9 patients within the same age bracket and another one centre reports 10–20 patients. We would estimate that a minimum of 27 patients to a maximum of 77 are at the age of 11–19 years and are therefore soon to require or are undergoing transition. The main underlying cause for IF was short bowel syndrome ( $n=378$ , 61.8%); enteropathy ( $n=96$ , 15.7%); Motility disorder ( $n=84$ , 13.7%) and other ( $n=54$ , 8.8%) – total patients with IF reported on was 612.

### 3.3. Centres' experience of transition

Sixteen paediatric professionals (89%) reported that they had initiated transition for 43 patients in the last 5 years and the 12 adult professionals had received 14 referrals from paediatric services to continue PN at home. Twenty-eight respondents (both adult and paediatric) reported that 41 patients had completed the process of transition in the last 5 years.

Twenty-one respondents reported on the average length of the transition process for their centre. For four (19%) it was less than 6 months, for 7 (33.3%) it was 6 months to 1 year, for 7 (33.3%) it was 1–2 years, for 1 (4.8%) it was more than 2 years and for 2 (9.5%) it was something other than the above time frames.

Question 7 addressed the issues of complications occurring during the transition process, based on their experience with patients that had been transitioned. The respondents had to decide if the listed complications happened “hardly ever”, “sometimes”, “more than expected” or “frequently”. The seventeen responses to this question are shown in Table 3. Psychological problems and confusion about catheter care and administration of PN between the adult and paediatric centre (4 respondents) were considered frequent (2/16 and 4/17 respondents respectively). The most common problems to occur more than might be expected were hospital admissions and psychological problems (3/17 and 4/16 respondents respectively). Two respondents thought academic performance had deteriorated more than might be expected and 2 respondents thought there was more than confusion about changes in management of care than would be expected. Frequency of catheter related blood stream infections was not greater than expected by

<sup>1</sup> By ‘company’ we mean a homecare company that manufactures and distributes PN to patients on treatment at home. The manufacturing unit can obtain stability for 21–28 days on certain individually formulated/bespoke prescriptions and usually delivers the PN with the necessary ancillary equipment to the home on a 2 weekly basis.

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