

11. Home Parenteral Nutrition in Children

METHODS

Literature Search

Timeframe: publications from 1990, but single publications from 1980 onward were also considered.

Type of publications: case-control or cohort studies.

Key Words: Children, parenteral nutrition (PN), home, long-term, cost, quality of life, complications, liver disease, metabolic bone disease, catheter-related sepsis, prevention.

Language: English.

INDICATIONS

Why Start an HPN Programme?

In children, as in adult patients, long-term total or complementary PN is required to preserve nutritional status when oral or enteral nutrition cannot provide protein-energy needs, especially in diseases which impair digestive function. When a child does not need hospitalization but depends on long-term PN, home PN (HPN) is an alternative to prolonged hospitalisation and is recognized as the best option for improving the quality of life of these children and their families within the constraints of the disease.

Underlying Disease

The main indications for prolonged PN and thus HPN in children are primary digestive diseases causing intestinal failure 1. Short bowel syndrome ((2) (LOE 4); (3) (LOE 4); (4) (LOE 4)), mainly congenital, is the largest group, accounting for at least 30% of cases in the major published surveys ((5) (LOE 3); (6) (LOE 3); (7) (LOE 3)). The main other digestive indications are intractable diarrhoea of infancy ((8) (LOE 3)), chronic intestinal pseudo-obstruction ((9) (LOE 3)) and inflammatory bowel diseases, especially Crohn's disease. Primary non-digestive indications such as immune deficiency including AIDS, tumours, metabolic diseases, and end stage liver diseases before transplantation account for about 20% of patients. The need for HPN in these diseases is usually shorter than for primary digestive diseases.

Age

Age for safely commencing PN at home depends on each individual condition. Most paediatric HPN

programmes cater for children under one year old and include babies under the age of 6 months ((5) (LOE 3); (7) (LOE 3)).

Condition

Patients eligible for HPN should be in a stable condition. This includes stability of the underlying disease, fluid and electrolyte requirements, and reliable central venous access.

Social and Familial Requirements for HPN

Whatever the medical indication, some social and familial criteria have to be fulfilled before a child's HPN programme is organized. Parents have to be informed, motivated and should be able to cope with all medical, emotional and technical problems related to HPN. Family suitability for HPN must be carefully assessed by a health care team member ((10) (LOE 4)). This may include visiting the home, to examine practical details such as space for dedicated refrigerator, electricity, and connected telephone ((11) (LOE 4); (12) (LOE 4)). The assistance of a social worker, before discharge, is needed, especially the home environment is inadequate (e.g. bathroom facilities on the same level as the child's bedroom). In other cases, the professional status of both parents needs to be carefully examined, for occasionally one of them has to stop working. In one-parent households, the mother is usually the parent responsible for administering HPN. A single-parent family is not always a contraindication for HPN, but social help and home nursing assistance may become necessary ((5) (LOE 3); (6) (LOE 3)). Separated parents who share the child's care should be trained providing they each connect/disconnect the PN at least once a week to maintain their skills.

Cost Savings

HPN is an expensive technique. The annual cost of HPN per patient, including nutrients, pump and disposable equipment, was evaluated to amount to about 60,000 to 80,000 £ ((11) (LOE 4)) in England ((13) (LOE 2+)), but as much as 100,000 to 150,000 US dollar in the USA ((14) (LOE 4); (15) (LOE 4)). However, cost-benefit studies have demonstrated that HPN is about 65% more cost-effective than hospital treatment for children as for

adults ((16) (LOE 2++); (14) (LOE 4); (13) (LOE 2+)). The longer a patient survives on HPN, the more cost-effective home-treatment becomes. A paediatric study showed that HPN in the UK led to cost savings of about 2 millions euros in a single year by the decrease in the incidence of septic episodes from 1/142 days in hospital to 1/567 days at home ((17) (LOE 2+)).

Statement and Recommendation

- HPN is less costly than hospital care. **LOE 2+**
- All children who depend on long-term PN should be discharged on HPN, if familial criteria are fulfilled. **GOR D**

PREPARATION OF AN HPN PAEDIATRIC PROGRAMME

Prior to discharge, parents must undergo structured training in all aspects of care and complications ((18) (LOE 3); (6) (LOE 3); (11) (LOE 4); (12) (LOE 4), (19) (LOE 4)). The teaching programme should begin as soon as the decision to proceed to HPN has been taken. It is best undertaken during the period when at least one parent, or preferably both, is resident in the hospital, especially if the family lives far from the HPN centre. The mean duration of the teaching programme is about 2 weeks ((6) (LOE 3); (11) (LOE 4)), but the duration needs to be tailored to each family's needs. The structured teaching programme must have a written plan, step by step instructions and a method to record competence comprising theoretical and practical aspects. Written and audiovisual tools may be used. Each session is limited to learning one particular skill, and a new subject should only be introduced when parents are competent and confident in the previous one. A written record of progress should be kept (Table 11.1). Some teams recommend that the parents spend 1 to 2 nights with their child in a special "isolation" room, close to the medical unit but without any help from hospital nurses, to simulate home conditions and to assess their autonomy, just before the family returns home ((6) (LOE 3)). When parents cannot be autonomous, especially in case of a single

parent family, the help of a community nurse is required ((6) (LOE 3); (12) (LOE 4)). In some countries, candidates for HPN can be referred to outside service organizations, which use nurses who sometimes meet the family in the hospital for the first encounter and then visit the patient at home to complete the training given at the hospital. Community health professionals should be involved in all aspects of discharge planning and subsequent shared care ((11) (LOE 4); (20) (LOE 4); (21) (LOE 4)). The physician and the teaching nurse from the HPN centre should inform staff from the patient's local hospital about guidelines for emergencies such as fever, pump or line failure ((11) (LOE 4)). This may be done by holding a discharge planning meeting attended by parents and all professionals involved in the child's care. It is best held at the patient's local hospital. Those attending may include the child (if old enough), parents, members of the specialist nutrition team, local paediatrician and a nurse from the local hospital, community nurse and the patient's general practitioner.

Recommendations

- Parents should undergo a structured teaching and training programme, conducted by a nurse from the HPN centre's nutrition support team. **GOR D**
- Parents' skills and knowledge should be checked before home discharge. **GOR D**
- Community health professionals and staff from the local hospital should be involved in all aspects of discharge planning and subsequent shared care. **GOR D**

TECHNIQUES

Vascular Access

Children on HPN require a reliable central venous access (see chapter on venous access). No data is available to compare implanted ports with Broviac-type catheters for paediatric HPN use in terms of quality of life and complications. Extensive thromboses are a possible problem in patients who receive HPN over long periods of

TABLE 11.1. Parents' knowledge required before home discharge on HPN

Parents' knowledge	Handling	Catheter and line	Pump	Child
Current care	Hand washing technique Preparation of sterile field	Flushing or heparinisation Initiation and termination of infusion	Operation Maintenance	Catheter exit site Temperature
Emergency What to do? Who to contact?	Drawing up solutions into syringe Materials missing	Blockage of line Breakage/split catheter Air in the line	Alarms	Exit site Infection Fever Digestive problem

time. In these circumstances, alternative sites for venous access may need to be used. Rarely, arterio-venous fistulae can be used for long-term HPN programs, especially in the case of repeated catheter complications ((6) (LOE 3)).

The Infusion Cycle

HPN is based on cyclical (10 to 18 hours per day) parenteral infusion of nutrient formula ((6) (LOE 3); (11) (LOE 4)). Children, like adults, almost always tolerate a nocturnal infusion over a period of 10 to 12 hours, especially when oral or enteral feeding is possible. Cyclic infusion has metabolic, physical and psychologic advantages. In infants, especially when enteral feeding is not tolerated, or in children with major digestive fluid and electrolyte losses, a longer period of infusion is required (14 to 18 hours). When PN is initially started in hospital all children are infused continuously 24 hours per day. They then undergo a period of adaptation, during which time the rate of infusion is gradually increased and the infusion period decreased, usually from 24 to 12h per day, and in exceptional circumstances to a maximum of 18 hours. A progressive increase and decrease of infusion rate during the initial and final hours of infusion should be considered to avoid hypoglycemia and hyperglycemia in some patients ((6) (LOE 3)).

Pumps, Equipment and Ancillaries

A pump is essential for parenteral infusion in children. Pumps for PN at home should reach a good compromise between safety and comfort. The main requirements for safety are: volumetric accuracy in wide range of flow rates, no risk of sudden discontinuation of infusion (reliable battery), no risk of free flow, "keep vein open" status, audible and written alarms (e.g. for air bubbles in line, empty container, occlusion, change in pressure, dose limit or low battery) and child proof ((20) (LOE 4)). Other requirements are also important for the quality of life: simplicity to prime the set and clear air, pre-selection of infusion rates and of programmed stepwise increased and decreased flow rates at the onset and end of the infusion times, minimum false alarms, minimum motor noise, minimum weight and volume with carrying handle and binding on IV poles. Portable pumps are now more widely available and can have a major impact on improving quality of life. Any faulty pump should be replaced within a reasonable time span (e.g. 4 hours), or a second pump should be available at home. Pumps should be annually serviced.

The supply of equipment and ancillaries should be delivered to the home. Families should not have to collect equipment from different sources ((20) (LOE 4)).

Filters

The importance of filtration to reduce the risk of precipitates reaching the patient has been emphasized

Recommendations

- Single lumen catheters should not routinely be used for blood sampling. However, to reduce stress and trauma to the child blood sampling from single lumen catheters may be considered when connecting or disconnecting PN on an individual basis. **GOR D**
- Flow control should be provided by a pump with free flow prevention, air alarm, occlusion alarm and lockable settings. **GOR D**
- HPN delivery should be cyclic. A progressive increase and decrease of infusion rate should be considered to avoid hypo-/hyperglycaemia. **GOR D**
- Filters should be used to avoid the risk of precipitates/particulates. **GOR C**

((22) (LOE 3); (23) (LOE 2++)). Filters should be 1.2 μm air-eliminating filters when an all-in-one, lipid-containing formula is delivered, in contrast to 0.22 μm air-eliminating filters usable for non-lipid-containing PN.

FLUIDS AND NUTRIENTS

Requirements vary depending on age, weight, underlying disease, hydration status and environmental conditions. When PN is not the sole source of protein-calorie intake, intestinal absorptive function should be estimated. Digestive tract losses due to diarrhoea or from stomas should be measured (volume and sodium concentration), replaced and the patient should be on a stable regimen before starting a HPN programme.

Vitamins and Trace Elements

Each PN infusion should provide vitamins and trace elements, according to patient's age, weight and specific needs. In certain circumstances, e.g. patient weaning from PN, vitamins and minerals may be given enterally (will also reduce the cost of the bags). Vitamins will need to be given separately if it is not possible to obtain stability in the PN, e.g. if PN bags can only be delivered on a monthly basis.

Nutrition Mixtures for Paediatric HPN

Binary mixtures including glucose, amino acids, electrolytes, trace elements and vitamins (lipids being administered separately on a Y-line) or all-in-one mixtures are provided to children on HPN. Mixtures may be

manufactured and delivered to patients with ancillary equipment weekly, fortnightly or monthly. Vitamins or drugs added to nutrient mixtures might impair their stability and, on the other hand, availability of drugs and vitamins might be reduced when introduced into PN mixtures ((24) (LOE 3)). Thus, depending on these limiting factors, the “safe” duration of PN bag storage varies from about 8 to up to 30 days. Bags should be stored at 4 C from their production to their delivery to patients. Home care companies should provide the families with dedicated refrigerators for PN bag storage. Special mixtures should be prepared according to individual requirements ((6) (LOE 3)). The so-called standard PN mixtures compounded by pharmaceuticals companies, usable only

Recommendations

- The patient should be on a stable regimen before starting PN. **GOR D**
- Standard PN mixtures are usually not suitable for long-term PN in infants and young children. Therefore, PN solutions providing macro- and micro-nutrients for paediatric HPN should be compounded according to individual patients needs. **GOR D**

for adult patients on short-term and/or complementary PN, cannot meet children’s nutritional requirements and are free of vitamins and trace elements. The use of non paediatric-standard PN formulas in children at home can lead to severe metabolic complications. Currently, no standard formulas are suitable for children on HPN.

ORGANISATION - MONITORING AND FOLLOW UP

Management of children on PN at home should be undertaken by specialist multidisciplinary hospital nutrition support teams that include physician(s), pharmacist(s), nurse(s), dietitian(s), social worker(s) and psychologist(s). HPN centres should have adequate

expertise and resources to ensure a good standard of care. Physicians should be trained and qualified to be responsible for the appropriate use, prescription and follow-up of patients on HPN programmes. Nurses who are responsible for parents’ teaching and training should evaluate their capacities to deal with all medical and technical issues related to the child’s treatment. Pharmacists should ensure safety of compounding and storage of the PN mixtures.

Once discharged from hospital, a regular out-patient follow up is planned to check clinical and biologic parameters (Table 2). Visits are planned according to each individual situation, initially at monthly intervals,

Recommendations

- Centres caring for infants and children on HPN must have adequate expertise and resources, including multidisciplinary nutrition support teams, trained and qualified to be responsible for use and prescription of HPN in children and a 24 hour telephone hotline. **GOR D**
- Paediatric HPN patients must be followed-up by an experienced team on a regular basis. **GOR D**

more frequently if necessary, especially in infants. A 24 hours hot-phone contact should be provided by the hospital nutrition support team ((18) (LOE 3); (6) (LOE 3); (20) (LOE 4); (21) (LOE 4)). A close connection with general practitioners and local non specialized hospital units is indispensable in an emergency.

COMPLICATIONS

Catheter-Related Sepsis

Although the incidence of catheter related sepsis (CRS) in HPN patients is lower than in hospitalized patients ((17) (LOE 2+)), CRS is the most frequent complication of HPN in children. Its incidence varies from 1 to 4 per 1000 days HPN among published studies

TABLE 2. Clinical and biologic monitoring in children on long-term home PN

Intervals	Clinical assessment	Other investigations
1 to 3 months	<ul style="list-style-type: none"> • Weight • Height • Clinical examination • Dietetic assessment 	ALT, bilirubin, GGT, alkaline phosphatase, Blood chemistry, including Ca, P, Mg, urea, creatinine Blood count Clotting tests Urinary electrolytes (Ca, Na, K) Ferritin Zinc Thyroid function parameters
6 months to 1 year		Plasma vitamins A, E and D Liver and biliary tract ultrasonography Bone densitometry

((6) (LOE 3); (25) (LOE 3); (26) (LOE 3); (27) (LOE 3); (17) (LOE 2+); (28) (LOE 3)). The risk of CRS is higher at young ages ((25) (LOE 3); (26) (LOE 3) which may partly explain the higher incidence of sepsis during the first two years of HPN as compared to later years ((26) (LOE 3); (17) (LOE 2+)). All studies have shown that some children have more than one infection over the period of study whilst others remain infection free. Risk factors, except for young age are uncertain. Underlying disease, ostomy, and the socio-economic level of the family have not appeared to be discriminant. A recent study showed that the increase in HPN duration was associated with a lower incidence of CRS and suggested that early occurrence of the first episode of CRS after starting HPN was a predictive factor for later infections ((28) (LOE 3)).

Coagulase-negative Staphylococci accounted for at least 60% of sepsis in several large studies ((6) (LOE 3); (25) (LOE 3); (28) (LOE 3)). However, the incidence of *Staphylococcus aureus*, gram-negative bacilli and fungal catheter infections was higher in other paediatric surveys ((26) (LOE 3); (27); (17) (LOE 2+)). The cost of infectious complications is about 10,000 € per episode, corresponding to 10 to 15 days in hospital, more in case of catheter replacement ((13) (LOE 2+); (17) (LOE 2+)). Parents should be taught about the signs of CRS. They have to contact their general practitioner and the hospital (referring local hospital and/or HPN centre) in case of fever or any signs of infection (See chapter on Complications).

Other Complications

Children on long term PN are at risk of pulmonary emboli (29,30). Catheter displacements or obstruction are discussed in the venous access chapter. Parenteral nutrition associated liver disease and metabolic bone disease are discussed in the chapter on complications.

Quality of Life

Although one of the aims of HPN is to give recipients and families the "best possible" quality of life, the burden of care on the parents is enormous. Assessments of quality of life using validated techniques have been rarely performed. Several surveys have mentioned that most children on HPN have normal physical activity ((31) (LOE 3)), are able to attend a regular school, to practice sports and that families can take holidays with their child on HPN ((6) (LOE 3); (32) (LOE 3); (11) (LOE 3); (33) (LOE 3)). However, sleeping is frequently impaired by nocturia and pump alarms. In a survey of children on HPN in Sweden, children and adolescents with HPN were found to be quite distressed psychologically ((34) (LOE 3)). A recent survey in parents of children with chronic intestinal failure requiring HPN showed that child's illness was associated with

Recommendation

- The nutrition support team should provide nursing assistance and psychologic assistance for children on HPN and their families. **GOR D**

significant deterioration, compared to controls, in the social life, family life, sex life and work in these parents, who were also more likely to be physically tired ((35) (LOE 3)). Therefore, nursing assistance and psychologic assistance should be provided to children on HPN and to their families when possible and acceptable to the family.

LONG-TERM OUTCOME: THE ROLE OF CENTRALISED HPN EXPERT CENTRES

The largest paediatric surveys ((5) (LOE 3); (6) (LOE 3); (7) (LOE 3)) reported a mean HPN duration of about 2 years with an upper duration longer than 15 years. Children on HPN have better survival rates and greater likelihood of resuming full enteral nutrition after 1 year than older patients ((15) (LOE 3)). About 50% of paediatric patients can be weaned from HPN, the functional prognosis being better for congenital short bowel syndrome and inflammatory bowel diseases than for other indications ((6) (LOE 3); (7) (LOE 3)).

In children with chronic intestinal failure who cannot be weaned from PN, small bowel transplantation might be an alternative to lifelong HPN, according to each individual situation (complications of long-term PN, tolerance of the family). Since the first isolated small bowel transplantations using cyclosporine A, major advances have result from use of new immunosuppressive treatments ((36) (LOE 4)). When liver structure and function are impaired by long-term PN, a combined small bowel and liver transplantation should be considered. However, the timing of referral and criteria for isolated intestinal or combined transplantation is still a matter of debate ((36) (LOE 4); (37) (LOE 4); (38) (LOE 4); (39) (LOE 4)). The role of expert centralised HPN centres is to improve the quality of HPN and thus to decrease the number of transplantations which are due to, or precipitated by PN-associated complications. Therefore, early referral of patients on long-term PN to specialized HPN centres, and especially before irreversible liver failure occurs, might increase their quality of life and survival and reduce the cost of care.

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