Nutritional Support outside the Hospital: Home Parenteral Nutrition (HPN) in Adult Patient

Module 19.2

Training and Monitoring

Learning Objectives

• Understand the importance of training and monitoring patients on home parenteral nutrition;
• Learn about common practice on training and monitoring.

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Key Messages

• Training patients for home parenteral nutrition is carried out by specialised personnel usually working together in a team;
• Patients are trained in hospital before discharge or in their home;
• Training and educating patients significantly reduces the rate of complications and improves the quality of life with HPN;
• Official guidelines for training are not available and clinical studies of different training regimes are warranted;
• Monitoring of patients on HPN is important to support the patient and to prevent and treat complications;
• Monitoring is carried out by the specialised team at the hospital, by a home care agency or by the community nurse;
• Intervals between monitoring visits for the stable patient are 2-3 months;
• Parameters monitored at visits should include biochemical variables, anthropometry; at every 6 months or yearly, measurements of trace element and vitamin status and bone mineral density;
• Studies of the effect of monitoring are needed to support development of guidelines.
1. Training for HPN

1.1 Introduction
The provision of parenteral nutrition in the home requires the collaboration between more players including the patient, relatives, the discharging hospital, the community nurse and general practitioner and in some cases also a home care agency. Before being able to cope with parenteral nutrition patients or family members must be trained to manage necessary procedures. Although only few studies are available, the best approach is to launch the process using a multi-disciplinary care team with expertise in intestinal failure. Collaboration with the family of the patient and with community nurses is very important. No official guidelines on training for HPN are available.

1.2 Patient suitability
Teaching patients about HPN and training them to administer it at home takes a lot of nursing time and commitment from those involved including the patient. Before starting it is important to assess the suitability of the individual in a multidisciplinary team approach, in which also the gastroenterologist or nutrition expert is involved. Important factors that should be taken into consideration:
- Physical ability;
- Mental status, intellect, social status, family support;
- Age;
- Underlying disease;
- The patient’s home, facilities for preparing and storing nutrition bags.

1.3. Training Objectives
The aim of the training programme is to teach the patient procedures so that provision of parenteral nutrition can be carried out safely by the patient, a family member or a caregiver. Also patients must be educated in all relevant complications that may occur and learn how to handle. Overall the teaching programme also should focus on the patients return to as normal lifestyle as practically possible. A training program aims at the best possible quality of life and the lowest rate of complications with HPN.
Training for HPN may include the following:
- Teaching patients essential anatomy, physiology, basics of nutrition;
- The complications occurring during treatment with HPN;
- Practical issues, initially by demonstration, followed by hands on exercises;
- The use of hand-out material is recommended and used by many centres;
- Patients previously trained may support education;
- Testing the patients capabilities before sending the patient home is essential;
- Periodic or on demand surveys of the patients capabilities should be considered.

1.4. The teaching practice in Europe
To gather information about how patients are taught the necessary procedures to undertake HPN a questionnaire about HPN teaching practice was circulated to centres in 7 European countries via representatives on the ESPEN HAN working group in 2001.
Responses were obtained from 51 centres in 7 countries. Centres ranged in size from 18 to 203 beds and had between 0-95 patients on HPN, 63% of centres having less than 10 patients. Not all patients with intestinal failure will be able to cope with HPN and in the survey one or more criteria, was used by 62% centres to exclude patients from their HPN programme. These included intellect (33%), physical disability (24%), social situation (25%), underlying disease (18%) and age (16%). All centres had a nutrition support team and 96% followed guidelines, usually locally developed. Generally training was carried in an inpatient setting over 1-2 weeks with one or more patients simultaneously. The personnel involved were hospital nurses/clinical nurse specialists (84%) and/or doctors (39%).
The centres reported that teaching included catheter care (100%), preventing and recognising complications (98%), most common mistakes (92%), pump care (92%), managing complications (90%), adding vitamins (55%), bag preparation (51%), iv-medication (50%), compounding (18%). Quality of care was assured by periodic surveys (47%) and re-checking the teaching process (33%) following the occurrence of complications. There was no significant variation between the large and small centres for either exclusion criteria or teaching methods.
This survey highlighted common teaching practice across seven European countries. Local or national guidelines underpinned practice in the majority of centres.

1.5 Training methods
From the European survey we know that centres use different methods for training, including instruction manuals with illustrations of the procedures, some centres use video tapes. Training sessions usually involves more patients, team members and the patient’s family, if required. It is important that only key designated members of the nursing staff provide the training. Training should start when the central venous access has been obtained, if the patient’s condition allows. No time limits for training should be set allowing patients to make progress at individual pace. The literature on training regimens is scarce and there are no studies showing which training regimen is the best in terms of complications or quality of life.

1.6 Training for home parenteral nutrition and catheter related infection
This has been investigated prospectively in one study (2). 221 patients on HPN were consecutively followed and patients were divided into two groups that received either standard or detailed instructions with regard to handling and prophylactic measures regarding line infections. The overall catheter infection rate was 14% corresponding to 1.7 episodes yearly. Conventionally tunnelled lines had fewer infections compared to implanted ports. The rate of infections was reduced with 50% in those who had the detailed instruction supporting that training is an important factor.

1.7 Conclusions for training in HPN
• Training patients for HPN make take place in hospital or in the home of the patient;
• Careful selection of the patient before starting training;
• Nutritional support teams and instruction manuals are essential elements in the process;
• Nearly no studies on the effect of different training regimens or the impact of training on complication rate are at hand;
• Many centres adhere to guidelines, developed locally and not underpinned by quality assurance studies.

2. Monitoring HPN
2.1 Introduction
The purpose of monitoring is to secure and improve the quality of life of patients managed in the home with parenteral nutrition. Although well trained, patients must cope with complications, infections, and mechanical problems with the catheter, venous thrombosis as well as metabolic disturbances. Being complex and an every day task, dealing with HPN also may impact the mood of the patient.

2.2 How is the monitoring of HPN patients carried out in Europe?
This has been investigated in 2002 using a questionnaire about HPN monitoring practice, that was circulated to HPN centres in 8 European countries through the representative of the ESPEN HAN-working group (1). Centres were asked about guidelines, home visits and how monitoring and handling of complications were managed. 42 centres in the following 8 European countries completed the questionnaire: UK n=14, France n=9, Belgium n=4, Italy n=4, Poland n=4, Denmark n=4, Spain n=2, Germany n=1. The HPN-experience of the centres was in the range 2-30 years and ranged in size from 0-125 HPN-patients representing a total number of 934 of whom 54% had received HPN for more than 2 years. The primary disease was non-malignant in 90% whilst 10% had been diagnosed with active cancer.

2.3 Guidelines
Of the centres 92% had a HPN team and 66% had written guidelines for monitoring HPN. The guidelines generally were locally developed, to some extent based on national guidelines.
2.4 Who monitored the patients and at what intervals?
Home visits after discharge for monitoring purposes were carried out by 31 of the centres involving the HPN team, general practitioner, community nurse or home care agency. Stable patients on HPN for more than 12 month were monitored at the discharging hospital (73%), at a local hospital (12%), by the General Practitioner (11%) or by a home care agency (4%). Of the centres 90% reported that the main responsibility for monitoring was assigned to a specific person (Fig. 1 and Fig. 2). Fig. 1 shows at which location the HPN-patients were monitored after discharge from the hospital with HPN. Fig. 2 shows which personnel are involved in monitoring the HPN-outpatient after discharge from hospital.

The intervals between monitoring visits for the stable HPN patient (Fig. 3) was in the range 1-6 months, 52% of the centres reported intervals of 2-3 months. Fig. 3 shows the distribution of intervals for monitoring of the stable HPN patient.

2.5 Which parameters were monitored?
Fig. 4 and Fig. 5 present the main results regarding which parameters HPN patients had evaluated at monitoring visits in this European study. Fig. 4 shows which parameters that were evaluated at monitoring visits for HPN-patients. Fig. 5 shows the pattern of blood tests and BMD measurements at monitoring visits. Bodyweight or anthropometry was measured at every visit in all centres and 20 (48%) centres assessed blood pressure and pulse at every visit, but 14 (98%) centres only did this in case of problems.
(48%) centres s-cholesterol/triglyceride, in 20 (48%) centres s-albumin, 8 (19%) centres measured trace elements, 6 (14%) centres analyzed vitamins AED, B-12 and folic acid. The rest of the centres did this regularly, but not at every visit or only in case of problems.

One centre evaluated the bone mineral density (BMD) of the patient at every visit and 27 (64%) centres did this 1-2 times per year. Seven centres measured the BMD only in case of problems and from 1 centre there was no information available.

2.6 HPN and handling complications

In case of complications 76% of centres reported that patients got in touch with the HPN-team, 2% the local hospital, 5% the home care agency, and 17% other. Re-admission to hospital was usually to the HPN-centre and only occasionally to a local hospital.

2.7 Conclusions for monitoring HPN

- Monitoring usually takes place at the discharging hospital with access to the specialised team. Monitoring can also be carried out by a home care agency involving the hospital or the general practitioner;
- Intervals between visits vary, being on average 3 months. Do not forget that the unstable patient may need more attention;
- Assignment of responsibility for monitoring is probably very important for the quality of the process. The questionnaire based study indicated that in general responsibility is assigned to a specific person most often associated with the specialised team in hospital;
- Biochemistry, anthropometry should be measured at all visits, trace elements, vitamins and BMD only occasionally, yearly intervals are recommended;
- Official guidelines for monitoring are not available and prospective studies on the impact of different monitoring regimens on outcome including the quality of life of HPN patients are warranted.

References