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

Module 19.2
Training and Monitoring

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Learning Objectives:
• Understand the importance of training and monitoring patients on home parenteral nutrition;
• Learn about common practice in training and monitoring;

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Key Messages:
• Training patients for home parenteral nutrition is best carried out by specialised personnel usually working together in a team;
• Patients are trained in hospital before discharge and/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 can be carried out by the specialised team at the hospital, by a home care agency or by community nurses;
• Intervals between monitoring visits for the stable patient are 2-3 months;
• Parameters monitored at each visit should include biochemical variables and anthropometry; measurements of trace element and vitamin status and bone mineral density should be done every 6 to 12 months;
• Studies of the effect of monitoring are needed to support development of guidelines.

1. Training for HPN

1.1 Introduction

The goal of HPN training is to teach patients and their caregivers all aspects of home infusion to ensure independence in its administration and to decrease complications of vascular access devices and of long-term parenteral nutrition (PN) itself. When patients receive HPN, the education is generally more complicated and requires a focus different from routine infusion of intravenous medication. In addition, the management of an HPN patient is different from a hospitalized PN patient because the needs and goals of HPN patients vary from those of hospitalized patients. Educating HPN patients so that goals and outcomes can be achieved effectively while allowing the patient to remain as independent as possible and to reduce PN complications is a challenge. The provision of parenteral nutrition in the home requires collaboration between many 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 all the 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 taking a multidisciplinary team approach, in which the gastroenterologist or nutrition expert is involved. Important factors that should be taken into consideration include:

- 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 those who are to be responsible all the necessary procedures, so that the patient, a family member or a caregiver can safely carry out parenteral nutrition in the home. Also patients must be educated in all relevant complications that may occur and learn how to handle them. Overall the teaching programme also should focus
on how the patient may return to as normal a lifestyle as practicably possible. The training programme aims for the best possible quality of life and the lowest rate of complications with HPN.

Before starting a training programme for a patient, the nutritional team should define some objectives with the patient’s agreement:

- Definition of requirements in the acquisition of skills of self-care
- Definition of the minimum amount of self-care necessary to obtain therapeutic safety
- Advantages and disadvantages of self-care in comparison to recourse to a specialist nurse
- Definition of the minimal acceptable knowledge in relation to the principal complications of HPN
- Definition of patient and/or family actions related to a specific HPN complication (such as fever)
- Strengthen the acceptance of the disease

To summarize, training for HPN may include the following items:

- 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 patient’s capabilities before sending the patient home is essential
- Periodic or on-demand surveys of the patient’s capabilities should be considered

1.4. 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 and 95 patients on HPN, 63% of centres having fewer than 10 patients. Not all patients with intestinal failure will be able to cope with HPN, and in the survey one or more criteria, were used by 62% of 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, sometimes with more than one patient 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 recognizing 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

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. There should be a formal teaching programme for the patient and/or carer. The teaching programme should include catheter care, pump use, and preventing, recognizing and managing complications. Experienced nurses
are usually best placed to take responsibility for the teaching programme. From the European survey we know that centres use different methods for training, including instruction manuals with illustrations of the procedures, and some centres use videotapes. Training sessions usually involve 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 their individual pace. Training is usually carried out in an in-patient setting, but training at home can be considered.

1.6. Role of Nutrition Support Team - in practice

The nutrition team should determine, for each patient, the skills needed by the patient after the therapeutic education programme. The group will determine the methods and techniques of participatory learning. The content will be based on the type of venous access but also the type of care. Prior thought will be essential for planning sessions within the constraints of place (local availability) and time of dedicated staff (availability of health professionals), but also the needs and preferences of the patient. The nutrition team will explore the possibility of realization of individual and group sessions. The nutrition team should consider the resources available for the training programme including all tools and teaching techniques such as interactive lectures, case studies, roundtable discussions, brainstorming, simulation from the analysis of a situation or a book of monitoring, work practices, workshops, simulations of actions and techniques, sports, role-play, documentary evidence, etc. “Educational diagnosis” will require educational assessment:

- Professional constraints
- Constraints related to the disease and its treatment.
- The profile of the patient will be evaluated, including personal and social resources, the potential for learning, motivation and interests.
- The living conditions are a factor for parenteral nutrition, infusion requires a work plan, and a specific room.
- Factors increasing vulnerability.
- Drivers of fragility (eg advanced age, disabilities).
- These chronic diseases are often accompanied by an anxiety-depressive syndrome that should be systematically sought.

The patient will be able to express their needs, expectations, concerns, and challenges. At the end of evaluation, the following will have been identified with the patient:

- The needs and skills to be developed by the patient and possibly his relatives:
  - Self-care skills and adaptation to his situation;
  - Skills that are designed to permit coping with and adapting to circumstances and consequences of the disease in daily life
  - Skills needed for safety and security
- Specific skills based on the needs of the patient.
- The proposed monitoring
  - educational timing,
  - medical monitoring with timing of biological follow up,
- When and how to contact the specialist hospital team
- The coordinates of the contact person who will be responsible for coordination.

1.7. Training for home parenteral nutrition and avoiding 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 line handling and prophylactic measures regarding line infec-
tions. The overall catheter infection rate was 14% corresponding to 1.7 episodes yearly. Conventionally tunnelled lines had fewer infections than implanted ports. The rate of infections was reduced by 50% in those who had the detailed instruction supporting the observation that training is an important factor.

1.8. Conclusions: training for HPN

- Training patients for HPN make take place in hospital and/or in the home of the patient.
- Careful selection of the patient is needed before starting training
- Nutritional support teams and instruction manuals are essential elements in the process.
- Hardly any studies on the effect of different training regimens or the impact of training on complication rate are at hand.
- Many centres adhere to guidelines, but these have been developed locally and are 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 on the mood of the patient. Involvement of a nutrition support team (NST) is required to manage HPN safely. It normally includes a specialized nurse, dietician, pharmacist, physician and surgeon, ideally trained in both nutrition and gastroenterology, plus a social worker, caregiver and general practitioner, the patient and family being at the heart of this medical sphere (3-4).

The NST has to:
- identify appropriate candidates;
- develop a nutritional plan of care acceptable to the patient and care giver;
- devise a prescription appropriate for the home setting;
- properly train the patient/care giver
- monitor efficacy of therapy

According to ASPEN the standard but “minimally required” care for HPN patients is a standardized method for “ordering and monitoring HPN support”: this is necessary because US physicians with various academic training may order home artificial nutrition support. It is also highly recommended that “disease specific pathways” are used for obtaining laboratories values and organizing patient visits and formal communication between home care staff and the relevant general practitioner.

An HPN survey in the eighties in French approved HPN centres, showed a significant increase in the probability of survival according to the date of inclusion: the number of deaths being higher during the first 3 years of treatment than during the two subsequent 3-year periods. Contribution of an NST specialized in chronic intestinal failure is a prerequisite for running a safe and effective HPN programme. The learning curve observation showing improvements in long term health outcomes in HPN pleads now for the development of intestinal failure units covering and integrating expertise in all medical and surgical aspects of chronic intestinal failure treatment (3-4). A recent european study, demonstrated that the risk of death decreased and the causes of death changed with time on HPN. These data confirm the observations from previous retrospective studies of survival on HPN, adding the information about the causes of death in relation to time on treatment. Overall only one third of deaths which occur on HPN were related to the treatment. The risk of death during the early years of HPN was mainly attributable to the underlying disease, whereas in long-term survivors, the risk due to HPN-related complications prevailed (5).
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. 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 of 934 patients 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 (6).

2.2.1 Guidelines

Of the 42 centres 92% had an HPN team and 66% had written guidelines for monitoring HPN. The guidelines generally were locally developed, to some extent based on national guidelines.

2.2.2. 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, and community nurse or home care agency. Stable patients on HPN for more than 12 months were monitored at the discharging hospital (73%), at a local hospital (12%), by the General Practitioner (11%) or by a home care agency (4%). 90% of the centres reported that the main responsibility for monitoring was assigned to a specific person [Fig. 1 and 2]. The interval between monitoring visits for the stable HPN patient was in the range 1-6 months, and 52% of the centres reported intervals of 2-3 months [Fig. 3].

Figure 1. The figure shows at which location the HPN-patients were monitored after discharge from the hospital with HPN.

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1 Home Artificial Nutrition – Chronic Intestinal Failure Group
Figure 2. shows which personnel are involved in monitoring the HPN-out-patient after discharge from hospital.

Figure 3. The figure shows the distribution of intervals for monitoring of the stable HPN patient

2.2.3. Which parameters were monitored?

Fig. 4 and Fig. 5 show the main results regarding which parameters HPN patients had evaluated at monitoring visits in this European study.
Parameters evaluated at monitoring visits.

**Figure 4.** The figure shows which parameters that were evaluated at monitoring visits for HPN-patients.

**Figure 5.** The figure 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. At every visit 37 (88%) of the centres evaluated the state of hydration and 31 (74%) of the centres asked patients about oral intake. The mood of the HPN-patient was considered at 36 (86%) centres at every monitoring-visit.

Regarding blood tests the following results were obtained. At every monitoring visit: 39 (93%) centres measured haematology, in 36 (86%) centres biochemical tests for liver-function, in 40 (95%) centres creatinine and electrolytes, in 39 (93%) centres Ca\(^{2+}\), Mg\(^{2+}\), Phosphate, in 34
(81%) centres glucose, in 20 (48%) centres cholesterol / triglyceride, in 20 (48%) centres albumin. Eight (19%) centres measured trace-elements, and 6 (14%) centres analyzed vitamins A, E, D, B12 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 (5).

2.2.4. HPN and handling complications

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

2.3. Monitoring HPN – in practice

Biochemistry and anthropometry should be measured at all visits; measurement of trace elements and vitamins are recommended at intervals of 6 months. Bone mineral density assessment by DEXA scanning is recommended at yearly intervals (3)

2.3.1. Assessment of biochemistry

Monitoring every month to every three to six months, depending on the stability of the disease and the patient (the reviews will be more frequent in the case of important digestive losses) including:
- Liver function, ferritin, lipid profile, albumin, C-reactive protein (CRP), ionograms (blood and urine), phosphorus, magnesium, calcium, haemogram, platelets

Unless there are specific indications, the following checks can be further apart (six months to one year):
- vitamins (A, E, 25-OHD3, folic acid, B12, possibly vitamin B1)
- trace elements (zinc, copper, selenium).

Micronutrient deficiencies may compromise the effectiveness of anabolic renourishment. In prolonged parenteral nutrition, additional contributions may be necessary in addition to routine supplementation, particularly of zinc (eg 10 mg/day) and selenium (50 to 100 mg/d), in cases of jejunal stoma or fistulae.

Chromium deficiency, an element not measured in normal practice, which can be seen (rarely) during prolonged parenteral nutrition, may be responsible for difficult-to-control hyperglycaemia (chromium overload can also occur).

2.3.2. Assessment of liver disease in HPN

HPN-associated liver disease is related to the composition of the HPN and to the underlying disease or coexisting liver disease (7). Chronic cholestasis was significantly associated with the subsequent occurrence of home parenteral nutrition–related liver disease. Cavicchy et al, demonstrated that almost all patients who developed this disease had had abnormalities on liver function tests indicative of cholestasis, occurring after a median of 6 months after the start of parenteral nutrition. The median time to development of clinical and histologic features of severe home parenteral nutrition–related liver disease was 17 and 27 months, respectively. This study presented objective data indicating that home parenteral nutrition–related liver disease may be related to a primary intrahepatic cholestatic disorder that may evolve into extensive fibrosis or cirrhosis. In this study, two factors were strongly associated with the occurrence of complicated home parenteral nutrition–related liver disease: parenteral lipid input of more than 1 g/kg per day and chronic cholestasis.
Early hepatic dysfunction is asymptomatic. Chronic biochemical cholestasis is the most frequent biochemical alterations. However, in most of HPN patients, chronic cholestasis is considered to be mild to moderate (less than 5 times the upper limit of normal). In children, persistent elevation of serum bilirubin (>200µmol/L) has an adverse prognosis (8).

Up to now, the assessment of hepatic disorders was based on clinical and biochemical features and finally on liver biopsy (transparietal or transjugular).

Prevention of chronic cholestasis is of utmost importance. If chronic liver abnormalities are present
- a liver ultrasound remains necessary (ultrasound is usually normal and most likely underestimates liver damages).
- and a liver biopsy can be discussed if case of persistent elevation of serum bilirubin and if chronic liver abnormalities remains present after PN composition changes and/or individuals treatments (bacterial overgrowth treatment, enteral feeding etc...)

2.3.3. Assessment of bone mass

A low bone mass and negative bone balance may occur in adult patients receiving HPN. In our French HPN centre, 88 adults with intestinal failure were prospectively studied. At the first bone mineral density determination (baseline), the prevalence of osteoporosis was 67% in this population (median age, 52 years). Ten percent of the patients with osteoporosis experienced fragility fractures. Osteoporosis was independent of age and gender but occurred earlier in patients who had received corticosteroids. At baseline, the lumbar Z-score was positively correlated mainly to body mass index and the age when intestinal failure occurred; these two parameters explained 34% of the Z-score abnormalities. Repeated measurements were performed in 56 patients during long-term HPN (mean duration, 5.5 +/- 1.2 years). Changes in Z-score at the lumbar spine were dependent on the age when intestinal failure occurred and on the duration of HPN, with a synergistic effect between them (9). Initially considered to be a manifestation of aluminium toxicity which followed massive contamination with the element of the solutions used in PN, metabolic osteopathy during PN is currently considered a multiformal syndrome, with a multifactorial pathogenesis, which may manifest itself with vague or clear clinical pictures. Other causes of osteoporosis related to parenteral nutrition include abnormal calcium absorption-PTH release and possible vitamin D toxicity. During and in the immediate postprandial periods, PTH level decreases; it rises during the interprandial periods and during sleep. Typically, in patients receiving cycle home parenteral nutrition (HPN), this rhythm is disturbed. PTH levels decrease throughout the PN infusion period to low levels and increase after the infusion, thus causing abnormalities in bone turnover. Other predisposing factors for osteoporosis (hypercalciuria, acid and sodium loads, copper, boron) have also been reported. Intravenous biphosphonates are becoming more frequently an integral part of the treatment of osteoporosis.

The bone assessment depends on:
- Bone mineral density assessment by DEXA scanning is recommended at yearly intervals.
- Bone resorption can be assessed by urinary levels of free pyridinoline (fPyr) and deoxypyridinoline (fDPyr) crosslinks at yearly intervals.
- Osteoblast function can be assessed by serum levels of procollagen 1 extension peptide (P1CP) and by bone-specific alkaline phosphatase at yearly intervals (BSAP).
- Vitamin D deficit seems very frequent and probably underestimated. Vitamin D level can be assessed more frequently

In our experience, intravenous biphosphonates (Palmidronate) seems generally well tolerated but severe symptomatic hypocalcemia and hyrophosphatemia can occur, and physicians must be aware of these potential hazards that may be prevented by additional oral calcium and vitamin D supplements following IV pamidronate treatment. Some patients may need longer treatment period than others before observing a beneficial effect. In treated patient the monitoring remains at yearly intervals.
2.3.4. Management of underlying disease

Underlying disease related factors must be strictly controlled, by treating inflammation and minimizing the dosage of (for example) bone damaging drugs. At all visits, practitioner should verify the adequacy and appropriate correlation between the current intestinal status and the nature and quality of the parenteral nutrition (3-4,10). Two principles can be applied to obtain the minimum required level of PN dependence for a given patient:

- avoid, as much as possible, exclusive or total IV feeding and
- implement, as much as possible, enteral feeding

We try to reach, step by step, a minimum number of cycles per week, water/electrolyte needs being dissociated from energy/protein needs. To adapt the parenteral nutrition some parameters remains necessary:

- Evaluation of ingested nutrients (by an experimented dietician)
- Evaluation of the degree of malabsorption

2.4. Conclusions – monitoring HPN

- Monitoring usually takes place at the discharging hospital with access to the specialist team.
- 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.
- Biochemistry and basic anthropometry should be measured at all visits, trace elements, vitamins every 6 months, and for DEXA yearly intervals are recommended.
- Liver complications are probably undiagnosed or underestimated and require our particular attention
- Monitoring the underlying disease should be planned
- Adaptation of HPN support requires regular evaluation of oral autonomy
- Current guidelines for monitoring are not precise enough, and prospective studies on the impact of different monitoring regimens on outcomes including the quality of life of HPN patients are warranted.

3. References

home parenteral nutrition (HPN) in Europe. A questionnaire based study on monitoring practice in 42 centres.


