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

Module 19.2

Training and Monitoring Patients on HPN

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Learning Objectives

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

Contents

1. Introduction - Training for HPN
   1.1. Patient suitability
   1.2. Training objectives
   1.3. The teaching practice in Europe
   1.4. Training methods
   1.5. Role of Nutrition Support Team: in practice
   1.6. Training for home parenteral nutrition and avoiding catheter related infection
   1.7. Conclusions

2. Introduction - Monitoring HPN
   2.1. How is the monitoring of HPN patients carried out in Europe?
   2.2. Guidelines
   2.3. Who monitors the patients and at what intervals?
   2.4. Which parameters are monitored?
   2.5. HPN and handling complications
   2.6. Monitoring HPN: in practice
   2.7. Biochemistry assessment
   2.8. Liver disease in HPN assessment
   2.9. Bone mass assessment
   2.10. Management of underlying disease

3. Summary

4. References

Key Messages

- Training patients for home parenteral nutrition is carried out by specialist 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 is carried out by the specialist 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. Introduction - Training for HPN

The goal of HPN training is to teach patients and their caregivers all aspects of home infusion to ensure independence in therapy administration and to decrease vascular access device complications and long-term parenteral nutrition (PN) complications. When patients receive HPN, the education is generally more complicated and requires a focus different from routine intravenous medication infusion. In addition, the management of an HPN patient is different from a hospitalized PN patient because 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 maintain as independent as possible and reduce PN complications is a challenge. 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 multidisciplinary 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.

1.1 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 the gastroenterologist or nutrition expert is also 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.
1.2 Training Objectives

The aim of the training programme is to teach the procedures so that the patient, a family member or a caregiver can carry out provision of parenteral nutrition safely. Also patients/caregivers must be educated on all relevant complications that may occur and learn how to handle them. Overall the teaching programme also should focus on the patients return to as normal a lifestyle as practically possible. A 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 self-care needed to obtain therapeutic security
- Advantages and inconveniences of the self-care with regard to recourse to the specialist nurse
- Definition of minimal knowledge related to principal HPN complications
- Definition of patient and/or family actions related to a specific HPN complication (for example in the case of 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 patients’ capabilities before sending them home is essential
- Periodic or on-demand surveys of the patients’ capabilities should be considered.

1.3 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 (1). 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 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, 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 out 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 practices across seven European countries. Local or national guidelines underpinned practice in the majority of centres. Recent ESPEN guidelines suggest that HPN patients should be encouraged to join non-profit groups that provide HPN education, support and networking among members. This may be beneficial to patient consumers of HPN with respect to quality of life, depression scores and catheter infections (2).

1.4 Training Methods

The literature on training regimen 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; some centres use videotapes. Training sessions usually involve patients and 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 definitive 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.

1.5 Role of Nutrition Support Team: in Practice

The nutrition team should determine, for each patient, the skills needed by that patient after his or her 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. Thinking will be essential for planning sessions within the constraints of place (local availability), the 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 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, roleplay, 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, as infusion requires a work plan, and a specific room.
- Factors of vulnerability.
- Drivers of fragility (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, challenges. At the end of evaluation these should have been identified with the patient:

- The needs and skills to be developed by the patient and possibly his/her relatives:
  - Self-care skills and adaptations to his/her situation;
  - Skills that are designed to cope with and adapt to circumstances and consequences of the disease in daily life;
  - Skills to ensure safety.
- Specific skills based on the needs of the patient.
- The proposed monitoring: educational and medical. Criteria for return to the host intestinal failure centre or criteria for referral to complementary specialists.
- The contact details of the contact person who will undertake the coordination task and the 24 hour contact details if these are not accessed via the same numbers.

1.6 Training for Home Parenteral Nutrition and Avoiding Catheter Related Infection

This has been investigated prospectively in one study (3). 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 by 50% in those who had the detailed instruction, supporting the case that training is an important factor.

1.7 Conclusions - Training for HPN

- Training patients for HPN may take place in hospital and/or in the home of the patient.
- Careful selection of the patient should occur before starting training.
- Nutritional support teams and instruction manuals are essential elements in the process.
- Hardly any studies on the effects of different training regimens or the impact of training on complication rates are at hand.
- Many centres adhere to guidelines, but ones developed locally and not underpinned by quality assurance studies.

2. Introduction - Monitoring HPN

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, and venous thrombosis as well as metabolic disturbances. Being complex and often a daily task, dealing with HPN also may impact on the mood of the patient. A nutrition support team (NST) is required to manage HPN safely. It includes specialist nurse, dietician, pharmacist, physician and surgeon ideally trained in both nutrition and gastroenterology, plus social worker, caregiver and general practitioner, patient and family being at the centre of this medical sphere (4, 5). Recent guidelines (2) have been published and recommend that
patient/caregiver training for HPN management is patient-centred with a multi-disciplinary approach, together with written guidelines. HPN training may take place in hospital or at home.

The NST has to:
- identify appropriate candidates;
- develop a nutritional plan of care agreeable to the patient/caregiver;
- devise a prescription appropriate for the home setting;
- properly train the patient/caregiver;
- 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 physicians with various levels of academic training may order home artificial nutrition support. It is also highly recommended that “disease specific pathways” are used to obtain laboratory values, to plan patient visits, and to organize formal communication between home care staff and the general practitioner concerned.

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: number of deaths being higher during a 3-year run-in period than during the two subsequent 3-year periods. NST(s) specializing in chronic intestinal failure are a prerequisite for running HPN programmes safely. The learning curve observations showing long term health improvement in HPN outcomes pleads strongly now for designation of intestinal failure units covering and integrating expertise in all medical and surgical aspects of chronic intestinal failure treatment (3, 4). The recent ESPEN guidelines (2) recommend regular contact with patients by the HPN team, scheduled according to patients’ clinical characteristics and requirements.

### 2.1 How is the Monitoring of HPN Patients Carried out in Europe?

In 2002 this was investigated using a questionnaire about HPN monitoring practice that was circulated to HPN centres in 8 European countries through the representatives of the the ESPEN HAN-working group (Home Artificial Nutrition - Chronic Intestinal Failure 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 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 (6).

### 2.2 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.

### 2.3 Who Monitors the Patients and at What Intervals?

Home visits after discharge were carried out by 31 of the centres for monitoring purposes and involved 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%). Of the centres 90% 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, 52% of the centres reported intervals of 2-3 months (Fig. 3).

**Fig. 1.** The figure shows at which location HPN patients were monitored after discharge from the hospital.

**Fig. 2** This shows which personnel are involved in monitoring the HPN-out-patient after discharge from hospital.
**Fig. 3.** The figure shows the distribution of intervals for monitoring of the stable HPN patient.

### 2.4 Which Parameters are Monitored?

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

**Fig. 4.** The figure shows which parameters that were evaluated at monitoring visits for HPN-patients.
Fig. 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 s-creatinine and electrolytes, in 39 (93%) centres s-Ca, s-Mg, s-Phosphate, in 34 (81%) centres s-glucose, in 20 (48%) centres s-albumin; 8 (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 (6).

2.5 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.

2.6 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 (4).
Recent ESPEN guidelines recommend regular monitoring of signs and symptoms of dehydration, fluid balance, laboratory test, and 24-h urine output as well as a timely adjustment of fluid supplementation.

2.7 Biochemistry Assessment

Testing is recommended every month to every three to six months, depending on the stability of the disease and the patient in general (the intervals will be shorter in case of important digestive losses) including:

- Liver function, ferritin, lipid profile, albumin, CRP, ionograms (blood and urine), phosphorus, magnesium, calcium, haemogram, platelets...

Due to the possibility of renal failure, blood urea nitrogen and creatinine levels as well as urine output and body weight should be monitored frequently, especially early in the HPN course, with decreasing frequency during a stable HPN course (7).

Serum concentrations of chloride and bicarbonate should be routinely measured in patients on long-term HPN for chronic intestinal failure to monitor acid-base balance, because either metabolic acidosis or metabolic alkalosis can occur. Unless specific contexts dictate otherwise, the following estimations 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 in addition to routine supplementation, zinc (10 mg / day) and selenium (50 to 100 mg / d) may be necessary, particularly in cases with jejunal stoma or fistulae.

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

The recent ESPEN Guidelines (2) suggest that baseline serum vitamin concentrations are measured at the onset of HPN and then at least once per year. An early report of laboratory analysis of 63 patients on HPN identified 24% to have subnormal vitamin A levels, 30% low vitamin D levels, and 45% had decreased vitamin C levels. Vitamins B12 and folate were subnormal in only 7% and 0% respectively (8). Similar results were reported from France (ref 166 guidelines) and in other countries. In none of these studies were clinical signs of symptoms described. Thus, these appear to be subclinical findings and warrant regular monitoring of biological assays. According to the various guidelines (ASPEN, ESPEN and home artificial working group of ESPEN), these vitamin parameters should be monitored every 6 months or annually.

In regard to trace elements, the recent ESPEN guidelines (2) suggest that baseline serum trace element concentrations are measured at the onset of HPN and then at least once per year.

2.8 Liver Disease in HPN Assessment

HPN-associated liver disease is related to the composition of the HPN and to the underlying disease or coexisting liver disease (9). Prevention of chronic cholestasis is of utmost importance.

Recent ESPEN guidelines recommend that for prevention of intestinal-failure associated liver disease:
- sepsis is prevented and/or managed if present
- attempts are made to preserve small intestinal length and retain the colon in continuity with the small bowel
- oral/enteral intake is maintained
- PN is cycled (ie not continuous infusion)
- PN overfeeding is avoided
- the dose of soybean-oil based lipid is limited to less than 1g/kg/day.

If chronic liver abnormalities are present, a liver ultrasound remains necessary and a liver biopsy can be discussed. However liver biopsy carries risks including haemorrhage. Therefore, alternatives to liver biopsy can be used. However a recent study demonstrated correlation between elastography and cholestasis rather than with hepatic fibrosis or cirrhosis (10).

2.9 Bone Mass Assessment

A low bone mass and negative bone balance may occur in adult patients receiving HPN and is reported in several studies. An ESPEN multicentre survey (11) of 165 patients evaluated the prevalence of metabolic bone disease by DEXA. In 84% of the patients, the bone mineral density T-score of the femoral neck spine was lower than -1. And 41% of the patients presented with osteoporosis, with a T-score below -2,5.

Diagnosis of metabolic bone disease is based on combination of bone densitometry scanning (dual-energy X-ray absorptiometry DEXA) and biochemistry (minerals and biochemical markers of bone turnover such as PTH and vitamin D). It is recommended that the HPN population is monitored routinely by these two techniques at yearly intervals.

2.10 Management of Underlying Disease

At all visits, practitioners should verify the relationship between the current intestinal status and the parenteral nutrition prescription (4,5,12).

Two principles apply in obtaining the minimal required level of PN dependence:

- 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 appropriately some parameters remain necessary:

- Evaluation of nutritional ingestion by an experimented dietician
- Evaluation of degree of malabsorption.

3. Summary

- 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 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 sufficiently precise and prospective studies on the impact of different monitoring regimens on outcome including the quality of life of HPN patients are warranted.

4. References