



Original/*Nutrición parenteral*

Twenty five years of outsourcing home parenteral nutrition: experience of the La Paz University Hospital, Madrid

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Abstract

Introduction: For the last 20 years, most adult patients following home parenteral nutrition (HPN) under the care of the Clinical Nutrition and Dietetics Dept. of the La Paz University Hospital (*Unidad de Nutrición Clínica y Dietética del Hospital Universitario La Paz*), Madrid, Spain, have received their nutrition formula via a catering system (Nutriservice) responsible for its preparation and home distribution.

Aim: To assess the clinical characteristics, quality of life and degree of satisfaction with the care received, of patients undergoing HPN who received their nutrition formulae via the named catering service.

Materials and Methods: The characteristics of the patients who received HPN via this service between 1992 and 2013 were retrospectively collected. Those patients still undergoing treatment completed a quality of life questionnaire, plus a survey of their satisfaction with the catering system and the care provided by our department.

Results: Seventy eight patients were examined; 57.7% were men. The mean age of the patients was 53.1±14.3 years. The most common underlying disease was cancer, both in advanced stage (33.8% of all cases) and in stages in which active treatment was being provided (34%). The most common indication for HPN was intestinal obstruction (46%). The median duration of HPN treatment was 96 [1-5334] days. The most common complication was catheter infection (72%). For the analysis of the results, the patients were divided depending on disease type: those with advanced stage cancer, those with cancer under active treatment and with a better prognosis, and those with non-oncological disease. The patients undergoing active oncological treatment believed the quality of their lives to have been improved by the Nutriservice catering system, and rated the care received by our department positively.

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VEINTICINCO AÑOS DE OUTSOURCING DE LA NUTRICIÓN PARENTERAL DOMICILIARIA: EXPERIENCIA DEL HOSPITAL UNIVERSITARIO LA PAZ DE MADRID

Resumen

Introducción: La mayoría de los pacientes adultos con nutrición parenteral domiciliaria (NPD) que dependen de la Unidad de Nutrición Clínica y Dietética del Hospital Universitario La Paz, reciben desde hace más de 20 años la fórmula de nutrición a través de un sistema de catering que elabora y distribuye directamente al domicilio del paciente.

Objetivo: Evaluar las características clínicas, calidad de vida y grado de satisfacción con la atención recibida de los pacientes con nutrición parenteral domiciliaria que recibieron las fórmulas de nutrición mediante el sistema de catering: Nutriservice.

Material y métodos: Se recogen retrospectivamente las características de los pacientes que utilizaron fórmulas de nutrición parenteral en su domicilio a través de Nutriservice, desde el año 1992 hasta la actualidad. Los pacientes en tratamiento activo realizaron un cuestionario de calidad de vida y encuesta de satisfacción sobre el sistema de catering y la atención prestada por nuestra Unidad.

Resultados: Se registraron 78 pacientes, el 57,7% eran hombres y la edad media 53,1±14,3 años. La patología de base más frecuente fue el cáncer, tanto en estadios avanzados (34%) como en tratamiento activo (34%). El motivo principal de indicación fue la obstrucción intestinal (46%). La duración del soporte nutricional tuvo una mediana de 96 días (1-5334). Las complicaciones más frecuentes fueron las infecciones relacionadas con el catéter (72%). Se analizaron los resultados, clasificando a los pacientes según la enfermedad de base: cáncer en estadio avanzado, cáncer en tratamiento activo y mejor pronóstico y patología no oncológica. Los pacientes en tratamiento activo consideraron afectada su calidad de vida y valoraron positivamente el servicio ofrecido por Nutriservice y la atención recibida de la Unidad de Nutrición.

Conclusión: En nuestra experiencia, los pacientes oncológicos son los que con mayor frecuencia tienen nutrición parenteral domiciliaria, siendo muy frecuente su indicación en estadios avanzados de la enfermedad. A la gravedad de la patología de base se une la complejidad de

Conclusion: In our experience, patients with cancer are those who most commonly receive HPN, especially those with advanced disease. Given the seriousness of their conditions, and the complexity surrounding the use of HPN, catering systems appear to offer a means of improving their quality of life.

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Key words: home parenteral nutrition, catering systems, malnutrition, cancer

Abbreviations

Parenteral nutrition (NP)
Home parenteral nutrition (HPN)
Home and outpatient artificial nutrition (HOAN)
Spanish Society of Parenteral and Enteral Nutrition (SSPEN)
Quality of life questionnaire related to nutritional status (QLQrNS)
Subjective overall score (SOS)
Peripherally inserted central catheter (PICC)
Percutaneous endoscopic gastrostomy (PEG)
Body mass index (BMI)
Arm muscle circumference (AMC)
Ticipital fold (TF)
Karnofsky index (KI)

Introduction

An adequate nutritional status is vital to the maintenance of health. Malnutrition worsens the clinical course of disease, increases the number of complications suffered, increases mortality, and reduces patient quality of life.

Patient nutritional support covers everything from the oral diet and dietetic recommendations through to more complex processes such as the use of enteral or parenteral nutrition (PN). Parenteral nutrition is the intravenous administration of nutrients. It can be total or partial, and therefore can be used to supply all or some of a patient's nutritional needs. The nutritional formula used must be stored under adequate conditions, and provide the necessary quantities of macro- and micronutrients, electrolytes, vitamins and minerals according to the physiological and clinical condition of the patient. Parenteral nutrition is indicated when the gastrointestinal tract fails to function or is inaccessible, as well as in certain clinical situations in which the patient's nutritional needs are not covered by oral or enteral intake. When PN is provided in the patient's home it is known as home parenteral nutrition (HPN); this might be needed for a determined period of time or be required indefinitely.

la NPD. Los sistemas de catering podrían ser una alternativa eficaz para mejorar la calidad de vida en algunos de estos pacientes.

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Palabras clave: Nutrición parenteral domiciliaria. Sistema de catering. Malnutrición. Cáncer.

Home parenteral nutrition is a safe and effective way of maintaining an optimal nutritional status and of improving the quality of life of patients who require it. Patients who receive it should be selected by a multidisciplinary clinical team. They should also receive HPN education from specialised nursing staff, and be carefully monitored either at a hospital or at home¹.

The first data regarding HPN and its relationship with quality of life were published in 1975². Moving PN out of the clinic and into the patient's home was reported to provide important gains in this area. It was in 1988 that the first patient indicated to receive HPN at our hospital was so treated; this was the year in which such cases in Spain were first described¹. However, it was not until 1992, with the creation of the Home and Outpatient Artificial Nutrition Group (HOAN; in Spanish the *Grupo de Nutrición Artificial Domiciliaria y Ambulatoria*, a body ascribed to the Spanish Society for Parenteral and Enteral Nutrition [SSPEN; in Spanish the *Sociedad Española de Nutrición Parenteral y Enteral*]), that the characteristics of those undergoing such treatment became better known via the annual register that the Group maintains^{3, 4}. With its 25 years of experience in the field, our department has been a full participant in the improvements in survival and quality of life that HPN has allowed.

Traditionally, patients undergoing HPN have had to go to hospital pharmacies to collect their PN bags. To alleviate this inconvenience, catering services were set up with the responsibility of making and taking the nutritional formula to patients' homes. The aim of the present work was to assess the accumulated experience of our department with respect to the use of such catering services.

Materials and Methods

All adult patients of the *Hospital Universitario La Paz* who received HPN between 1992 and 2013, and who did so via the Nutriservice catering system, were identified and their age, gender, main diagnosis and indication for HPN recorded. Note

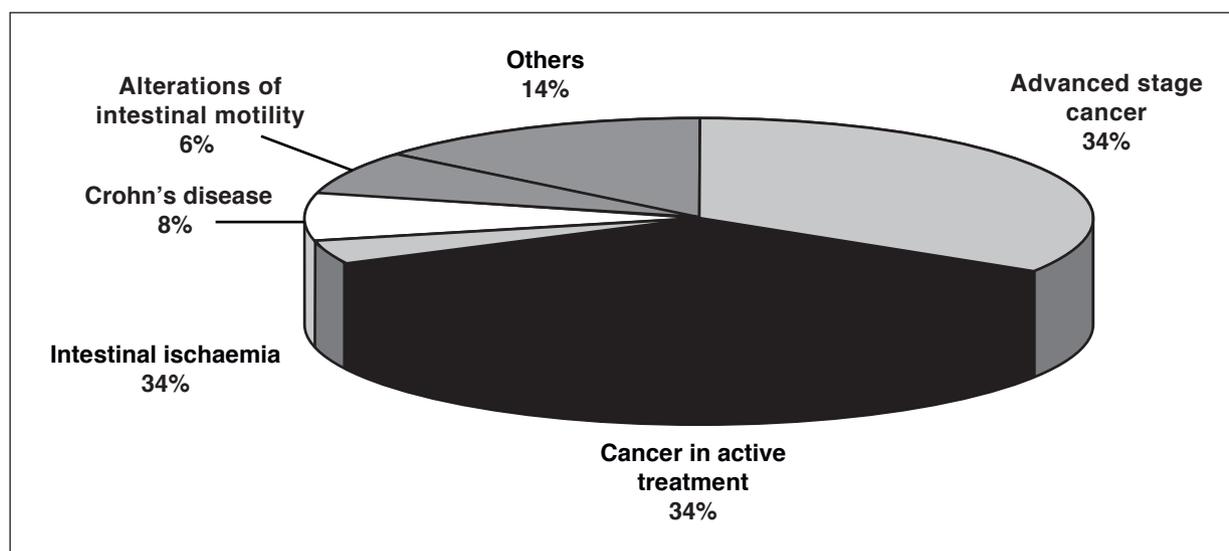


Fig. 1.—Underlying disease associated with indication for HPN.

was also made of whether the patient was still receiving HPN treatment, the reason for its withdrawal if such was the case, and the duration of HPN treatment. The type of venous access used was recorded, as were any complications (thrombotic, bone and liver problems, and infections), and the number of PN bags used. Finally, each patient was registered as either a candidate or non-candidate for intestinal transplant.

Anthropometric and blood variables related to nutritional status (albumin, prealbumin, haemoglobin, total lymphocytes and transferrin) were recorded for those patients who were still receiving HPN treatment at the time of the study. Those also taking food orally/enterally completed a three day food questionnaire to determine the mean daily intake of energy and the distribution of macronutrients.

Quality of life was assessed using the quality of life questionnaire related to nutritional status (QLQrNS)⁵. Nutritional status was determined using the Subjective Global Assessment (SGA) method. Finally, patients were surveyed regarding their satisfaction with the care provided by our department and the catering offered by Nutriservice.

The results were analysed with respect to patient disease type: those with advanced stage cancer, those with cancer under active treatment and with a better prognosis, and those with non-oncological disease.

Results

General characteristics of the patient sample

Seventy eight patients who had received HPN between 1992 and 2013 were identified. Some 57.7% of

the population was male. The mean age of the patients was 53 ± 14 years. The median duration of HPN was 96 [1-5334] days. In 22% of the patients it lasted longer than 2 years.

Advanced stage cancer and cancer for which active treatment was being received were the main problems underlying the indication for HPN (33.8% of the patients in each case) (Fig. 1). Intestinal obstruction was the most common indication (46% of all cases) requiring HPN be prescribed, followed by short bowel syndrome (22%) (Fig. 2).

All patients received infusion via a long-term indwelling catheter. Some 62% had been fitted with a Hickman-type tunnelled catheter, 33% with a Port-a-Cath system, and 3.9% with a peripherally inserted central catheter (PICC).

The majority of complications were related to catheter infection. Some 72% of patients experienced at least one such infection (including local infections, bacteraemia, and sepsis [specific frequencies not distinguished]). The median number of infections was 1 [0-21]. Bone complications were recorded in 33% of patients, liver complications in 24%, and thrombotic problems in 15%.

The main liver complications were cholelithiasis (42% of patients), followed by abnormal liver function (21%), biliary sludge (21%), and fatty liver (16%).

Over the entire study period, 18,657 PN bags were used.

Results for patients with advanced stage cancer

Patients with advanced stage cancer made up 33.8% of the sample ($n=26$). Their mean age was 55 ± 10 years. The median duration of HPN treatment in these patients was 33.5 [1-246] days; in

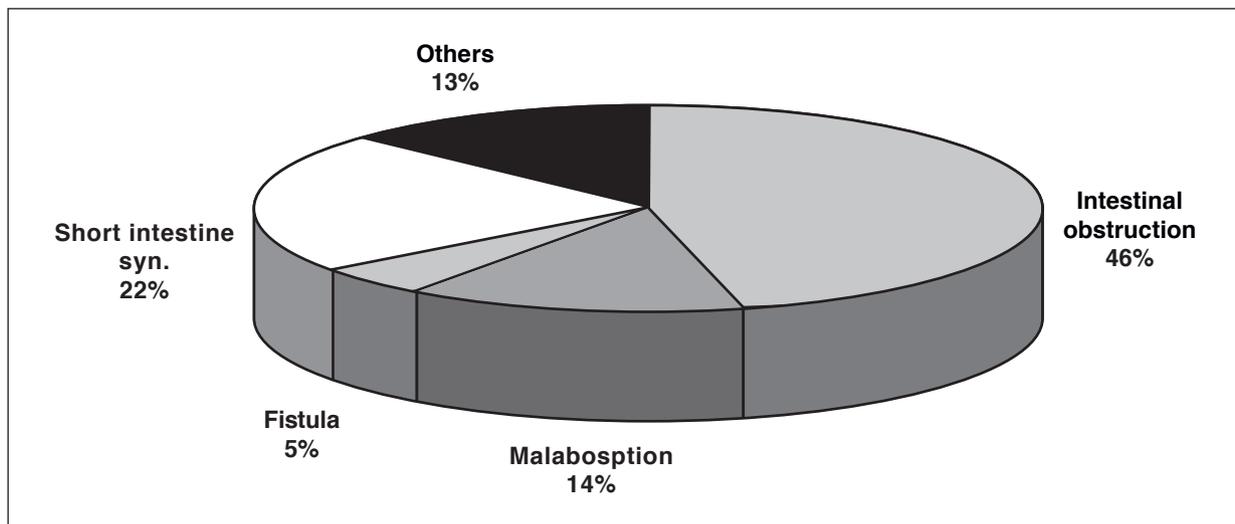


Fig. 2.—Condition indicating need for HPN.

some 30.7%, HPN treatment lasted longer than 3 months. The median number of infections experienced was 1 [0-3]. In all cases the reason for withdrawal of treatment was worsening clinical condition or death.

Results for patients undergoing active oncological treatment

Patients with cancer but with a better initial prognosis and undergoing active oncological treatment made up 33.8% of the sample (n=26). Among these, 8 patients (30.8%) had short bowel syndrome resulting from intestinal resection, and 9 (34.6%) had radiation enteritis. The mean age of these patients was 57±12 years. The median duration of HPN was 169 [5-2201] days. The median number of infections associated with HPN treatment was 2 [0-9]. The main reason for withdrawal of HPN treatment was death (67.5%), but in 25% treatment was ended because adequate oral or enteral tolerance was achieved. Treatment stoppage due to transfer to another centre was recorded for 7.4% of patients.

Results for patients with non-oncological disease

Patients with non-oncological disease made up 32.5% of the sample (n=25). Five had problems related to abnormal intestinal motility, 3 had intestinal ischaemia, 6 had Crohn's disease, and 11 had other diagnoses. The mean age of the patients in this subgroup was 46±17 years. The median duration of HPN treatment was 154 [1-5334] days. The median number of HPN-associated infections was

3 [0-21]. The main reason for withdrawal of HPN was death (52% of cases). In 40% of cases, however, adequate oral or enteral tolerance was achieved. Treatment stoppage due to transfer to another centre was recorded for 8% of patients. Only 8 patients (32%) were considered candidates for intestinal transplant.

Results for patients undergoing HPN treatment at the time of the study

General characteristics

At the time of the study, 12 patients (15.4%) were receiving HPN. Of these, 7 were men and 5 were women. Their mean age was 49±18 years. The most common diagnosis was cancer for which active treatment was being provided (7 patients) (Table I); the main indication for HPN was short bowel syndrome (42%) (Table II).

Hickman-type tunnelled catheters were the venous access most commonly used (92%), followed by the Port-a-Cath system (8%). The median duration of HPN treatment was 1296 [51-4539] days; nine patients (75%) were treated for more than 3 years. The most common complications were, again, catheter-related infections (75%), bone complications (50%), liver complications (33%) and thrombotic problems (17%). The median number of infections experienced was 2 [0-7] over the treatment period, and 1.4 [0-10,9] per 1000 days of treatment. A total 8904 PN bags were used (median per patient 935 [107-2001]). The mean number of HPN bags used per week was 4.9±1.7, with a mean volume of 2287±298 ml. The mean ω-3 fatty acid content per bag was 8±2.5 g. Some 17% of this group of pa-

Table I
Main diagnoses for the patients receiving HPN at the time of the study

Diagnosis	n	%
Cancer, for which the patient was undergoing active treatment	7	58
Crohn's disease	1	8.3
Abnormal motility	1	8.3
Others	3	25

Table II
Indication for HPN

Indication	n	%
Short bowel syndrome	5	41.7
Intestinal obstruction	3	25
Malabsorption	2	16.7
Fistula	1	8.3
Others	1	8.3

tients also took oral supplements. Two patients were subjected to percutaneous endoscopic gastrostomy (PEG) to remove accumulated fluids. Only 8% of

this group of patients were candidates for intestinal transplant.

Nutritional assessment

The SGA analysis showed that 75% of the patients currently receiving HPN treatment were well nourished, while 25% were at risk or moderate malnutrition.

Table III shows the anthropometric data collected for these patients and compares them to reference values for the same gender and age. The women patients showed a greater depletion of fat and muscular mass.

Table IV shows the results of the blood analyses performed on these patients as a means of determining their nutritional status. All results fell within the normal range.

Table V shows the mean energy and macronutrient intakes as determined using the 3 day food record. It should be noted that more than 1000 kcal/day were taken orally or enterally in 75% of subjects.

Quality of life and satisfaction with medical care and the Nutriservice catering system

All patients receiving HPN treatment completed the QLQrNS⁵. This questionnaire records patient perception of general health, physical activity, emotional status/state of mind, social and family relationships, and pain and/or discomfort. The mean score was 107±21 points (range 26–156, with the lower the score the better the perceived quality of life). Some 42% of the patients were in active employment.

Table III
Anthropometric data

	BMI	TF	% of the p50 for the TF	AMC	% of the p50 for the AMC
Men	22.5±4.9	12.6±5.9	>100%	23.48± 2.94	>100%
Women	20.5±1.6	13.5±5.0	54%	18.78± 3.09	85%

BMI: body mass index; AMC: arm muscle circumference (cm); TF (mm): tricipital fold. Results are means±standard deviation.

Table IV
Results of blood analysis

Albumin (g/dL)	4.1±2.5
Prealbumin (mg/dL)	28.1±11.33
Haemoglobin (g/dL)	12.5±2.0
Lymphocytes (x10 ³)	1.48±0.5
Transferrin (mg/dL)	317.4±56.4

Results are means±standard deviation.

Table V
Intake of energy and nutrients per day

Energy intake (kcal)	1566±836
Protein (g)	63±29
Protein (%)	17±3
Carbohydrates (g)	199±111
Carbohydrates (%)	50±10
Lipids (g)	47±30
Lipids (%)	27±7

Results are means±standard deviation.

Seven patients completed an anonymous telephone survey performed by trained third party personnel regarding the care offered by our department and the service offered by Nutriservice. All were happy with the care they received from the department. All patients received instruction on how to manage their HPN; none reported it to be difficult, and all reported that they had received adequate information. All seven patients reported having a particular place in their homes where they prepared their PN, and that they were confident regarding its correct use. No help was needed from family members by 71%. Further, all reported that, in the case of complications, they enjoyed easy access to the department. Four patients stated that the catering system had improved their ability to enjoy their weekends and holidays; two said that it had not affected their quality of life, and 14% that it had affected it very little. All the patients reported their PN bags to arrive on time and in good condition. Three of the seven surveyed patients had received their PN bag at another address when required, with no problems.

Discussion

Home parenteral nutrition is a complex treatment that has been used for over 25 years at our hospital and indeed at others across Spain. The number of patients receiving this treatment is growing.

Starting HPN is a stressful experience for patients and is associated with a considerable economic cost for health systems. When its indication is considered, medical teams should bear in mind aspects such as family support, the quality of life that can be achieved, and (especially in patients with cancer) the chances of survival.

The present results show that, at our hospital, cancer was most common disease underlying the indication for HPN. Indeed, compared to earlier papers^{4, 6-12}, an increase was seen in its indication among patients with advanced cancer.

The maintenance of a good nutritional status in patients with cancer is very important. Many factors influence the risk of malnutrition in such patients, including intense anorexia, gastrointestinal abnormalities, and mucositis etc. A deterioration in their nutritional status may oblige the postponement or withdrawal of oncological treatment. Efforts to maintain a good nutritional status are therefore vital.

The need for HPN in patients undergoing active oncological treatment is often conditioned by the consequences of medical and surgical actions on the digestive tract. The present results clearly show how post-surgical short bowel syndrome and ra-

diation enteritis condition the indication for PN in many patients. In some such patients it is the only option available for their nutrition. Some studies report HPN to be associated with an improvement in their overall cognitive function, that it allows them to maintain their body weight, to increase their muscular strength, and to better tolerate physical activity; it therefore allows them to better cope with the activities of daily living¹³.

Although cancer is commonly the main disease underlying the indication for HPN^{11, 12, 14-16}, its use in patients with advanced and terminal disease has been somewhat controversial. The present results for such patients differ somewhat from those previously published¹⁸ in that the mean age at treatment was lower and the median duration of treatment shorter.

Soo et al.¹⁷ assessed survival in patients with cancer for whom HPN was indicated. The Karnofsky index (KI) was determined at the start of treatment, and it was seen that those with a KI of >50 survived for longer (about 6 months) than those with a KI of <50 (about 3 months). It would thus appear that the indication for HPN in the latter subgroup is more complex; medical teams therefore need to take care in arriving at treatment decisions. Consensus exists in that the expected survival of a patient should exceed 3 months, that the KI should be >50, and that family support should be adequate. A multidisciplinary team should have the responsibility of taking the final decision, and this should be in line with the patient's wishes. It should always be clear that the aim is to improve the quality of life; if this goal is not attained, the need to withdraw HPN should be considered.

The present results show the venous access most commonly employed involved a tunnelled Hickman-type catheter; the literature reports similar results¹². Port-a-Cath systems were mostly used in patients who already had a venous access available due to chemotherapy treatment.

In agreement with that reported in other studies¹⁹, the most common complications were related to catheter infection. The present rate of infection was, however, higher than that mentioned in other reviews^{11, 12}. This might be due to the retrospective nature of the study; data were not always available on the type of infection, which therefore covered everything from sepsis and bacteraemia down to the isolation of bacteria from the catheter but which had no clinical significance. The present analysis also included two patients who suffered multiple infections during HPN treatment. Thereafter these patients received taurolidine²⁰ systematically to maintain catheter bacteriological quality; this prevented any further episodes. This treatment, of course, improved the overall catheter infection rate. The rates for other types of complication were similar to those reported in other studies^{21, 22}.

The main reason for the withdrawal of HPN was patient exitus associated with the underlying disease. Although the present withdrawal rate of 68% is higher than that reported in recent studies^{11,12}, this might be explained in that, over the years, HPN has become a more common treatment for patients with advanced stage cancer. The percentage of patients in whom it was eventually possible to end HPN due to an adequate oral or enteral intake being achieved, was much higher among those whose underlying disease was not oncological (40%).

In order to maintain the functionality of the gastrointestinal tract and prevent the atrophy of the intestinal villi, patients undergoing HPN should, as far as possible, also receive at least a minimum amount of food via the oral or enteral routes. This will facilitate the recovery and rehabilitation of the intestine. Among the subjects who were undergoing HPN at the time of the present study (75% of whom had been receiving such treatment for >3 years), 75% managed to take >1000 kcal orally or enterally.

The use of a catering service to facilitate HPN came about as an idea for improving patient quality of life. At the time a growing number of patients were receiving HPN by catering in Spain²³. Our department has been using a catering service for over 20 years, and the results show that it is positively valued by patients. Quality of life is improved since patients no longer have to constantly visit a hospital to pick up their PN bags. This improves family and social life, and allows the possibility of going away on holiday. In addition, the use of the catering service ensures optimum transport conditions, preventing any deterioration of the PN bags and their contents.

In conclusion, patients with cancer were those who most commonly received HPN treatment. The use of such treatment in patients with very advanced cancer remains questionable; in such patients it is unlikely that any quality of life improvement will be possible. The complexity of HPN treatment adds to that of managing the patient's underlying disease. The use of a catering system, however, can reduce some of the negative impacts (e.g., frequent travelling to a hospital to pick up PN bags) HPN has on patients, and is valued highly by them.

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