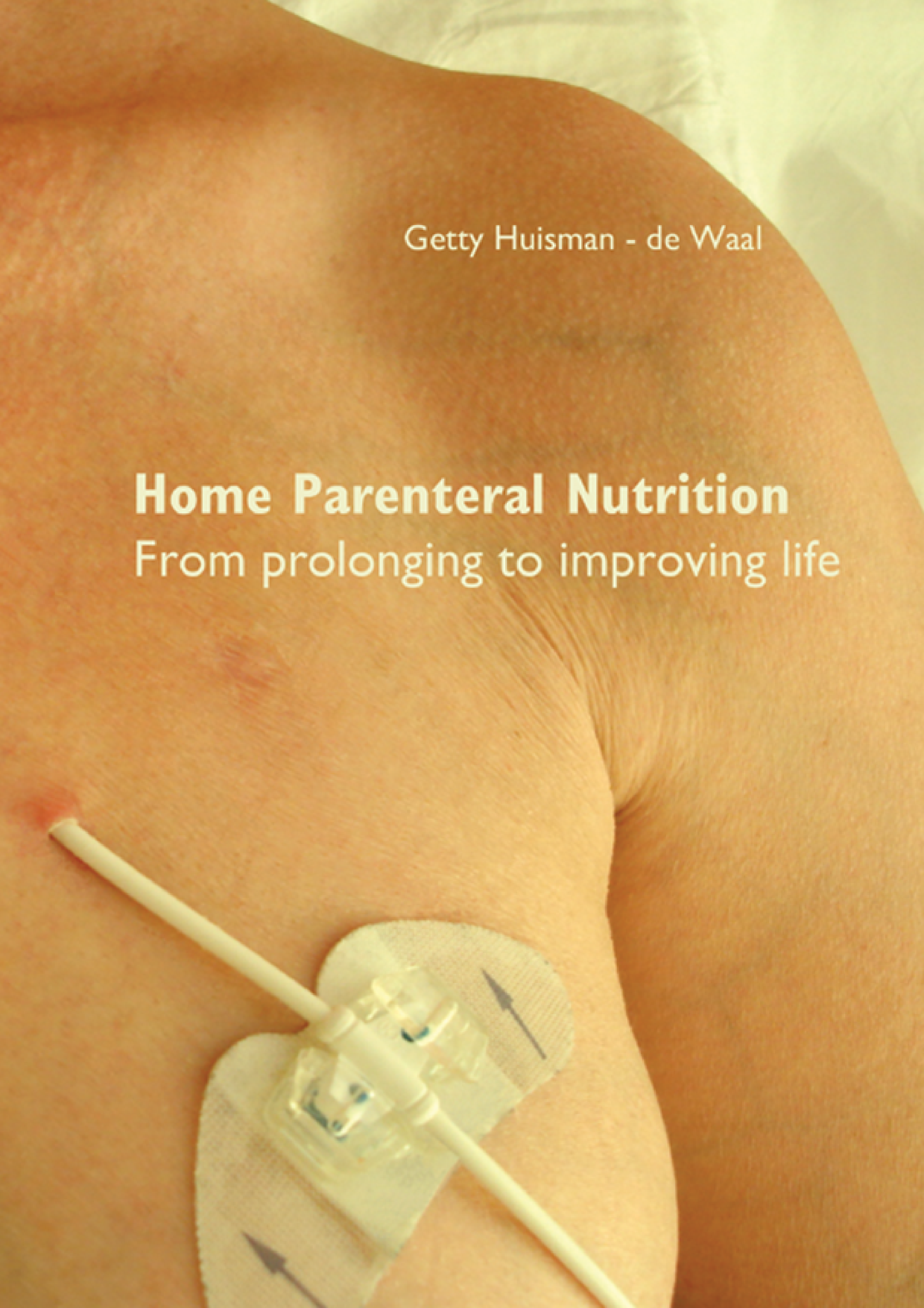

Getty Huisman - de Waal

Home Parenteral Nutrition

From prolonging to improving life

Home Parenteral Nutrition

From prolonging to improving life

The studies presented in this thesis have been performed at the Department of Gastroenterology and Hepatology and the Scientific Institute for Quality of Healthcare (IQ healthcare), both situated at the Radboud University Nijmegen Medical Centre. IQ healthcare is part of the Nijmegen Centre for Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Nijmegen.

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Nijmegen, 2010

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Home Parenteral Nutrition
From prolonging to improving life

een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

Proefschrift

Ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S.C.J.J. Kortmann,
volgens besluit van het college van decanen
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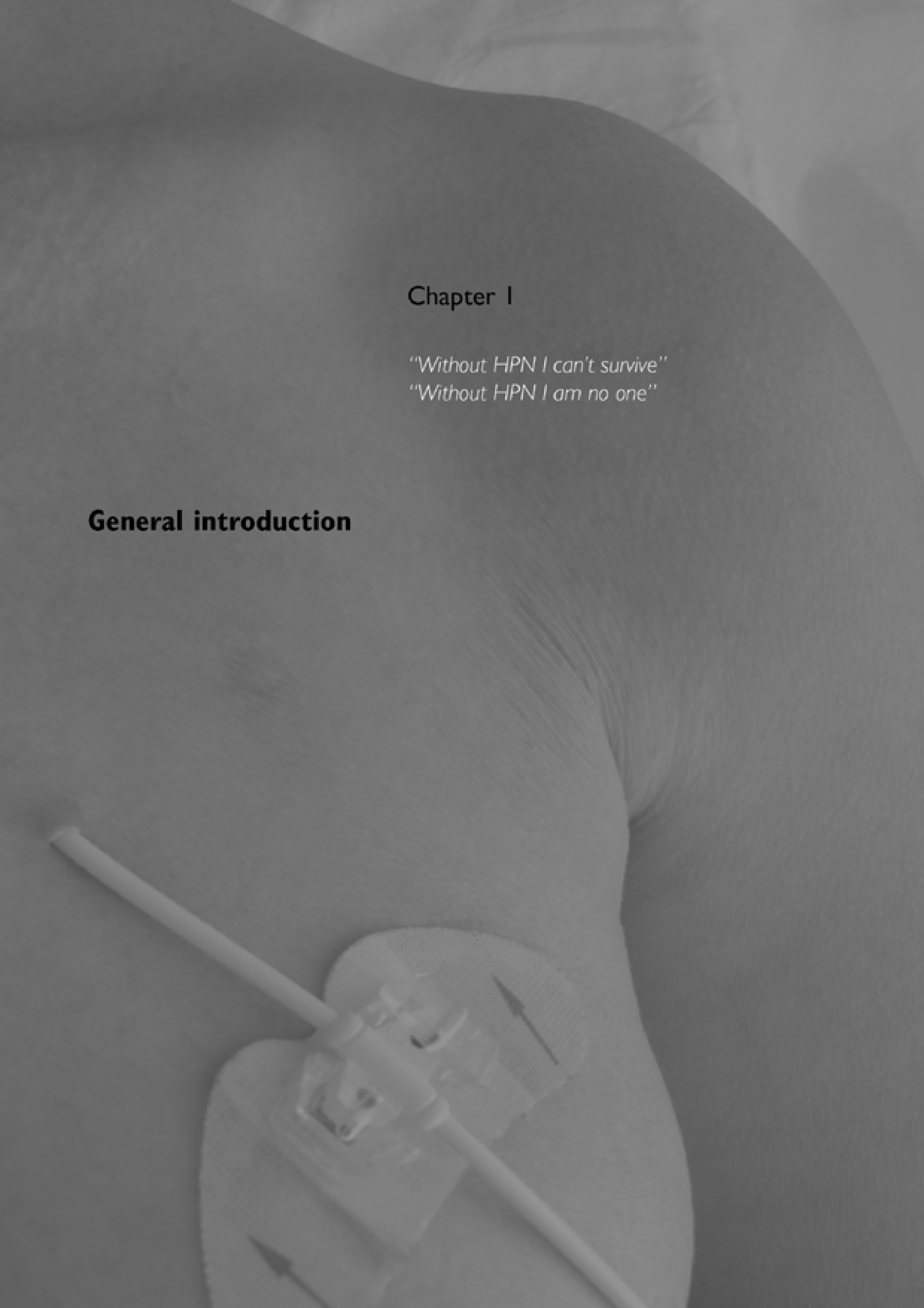


Chapter 1

"Without HPN I can't survive"
"Without HPN I am no one"

General introduction

HOME PARENTERAL NUTRITION

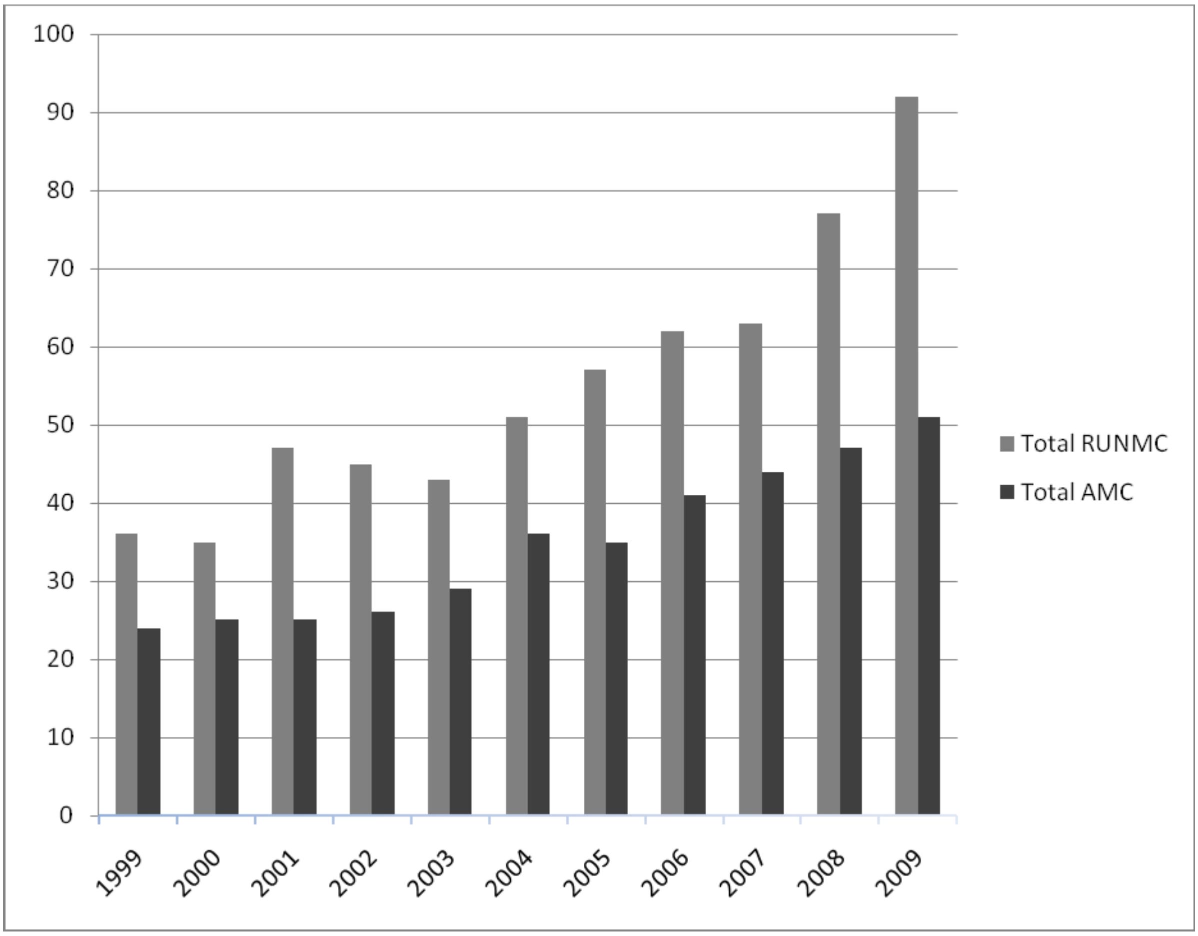
Home Parenteral Nutrition (HPN), i.e. parenteral nutrition in the home setting, was initiated by North American and European pioneers in the early seventies and was initially conceived to provide nutrition to patients who were suffering from life threatening chronic intestinal failure.[1] Parenteral nutrition involves the administration of nutrients using routes other than the gut. This could include infusion of nutrients into veins, arteriovenous shunts, subcutaneous tissue, muscle or bone. Although all of these access routes have been tried at one time or another, parenteral nutrition usually involves the intravenous route, and for patients on HPN in the Netherlands, it almost invariably involves central venous catheters, subcutaneous ports, or arteriovenous fistulae.

In the early years of HPN, the most common indication in different countries was the short bowel syndrome due to surgical resection, as sometimes found in patients with Crohn's disease and mesenteric vascular disease.[2;3] Over time, the indications for HPN have widened. In some countries, such as the USA, Japan, and Italy, 40-60% of the HPN patients suffer from malignant conditions.[4-6] However, international differences in the indications to provide HPN have become apparent, and probably also in relation to this, the prevalence of HPN varies considerably between countries.[7] Part of the differences may be explained by economic reasons, for instance in the United States of America, where there is no unified national health system. Here, hospitals financially benefit from rapid patient discharges even while this throws a burgeoning demand and cost on home care services.[8]

Since 1990, professionals from different European countries who were interested in the field of HPN have collaborated in the Home Artificial Nutrition (HAN) working group, which was officially recognised as an ESPEN (European Society for Clinical Nutrition and Metabolism) working group in 1997. The main goals of the ESPEN-HAN group are to perform epidemiological surveys throughout Europe, to harmonise the use of HPN and to formulate recommendations for good practice.

Previous epidemiological surveys carried out by the HAN Working Group of ESPEN reported a prevalence range of 0.3 (Spain) to 12.2 (Denmark) adult patients on HPN per one million inhabitants.[9;10] Incidence and prevalence in the different European countries are dependent of several factors: date of starting a HPN programme in the country, experience of HPN training centres, local incidence of some diseases such as Crohn's disease, diagnostic indications for HPN, and encouraging results obtained from the therapeutic management of patients with non-malignant digestive disease such as Crohn's disease.[9] A more recent study in Denmark reported a prevalence of 19.2 per million at the end of 2000, and the average annual incidence was 5.0 per million per year over the 5 year period studied (1996-2000).[11] Prevalence of HPN in the two major HPN centres in the Netherlands is shown in figure 1.

Figure 1 Prevalence of HPN in adults in the HPN centres in the Netherlands
RUNMC = Radboud University Nijmegen Medical Centre
AMC = Academic Medical Centre Amsterdam



A European survey by the ESPEN-HAN group between December 1998 and March 1999[12], included five European countries, and showed different benign diseases in patients on HPN. Underlying conditions were Crohn's disease (33%), mesenteric vascular diseases (25%), post-surgical complications (19%), intestinal pseudo-obstruction (8%), radiation enteritis (4%), abdominal trauma (2%), and others (8%).[12]

NUTRITION TEAM

Because HPN implies a radical change of life for the patient, relatives, and the caregiver, each potential candidate for HPN must be assessed on an individual basis using a multidisciplinary team approach. Within this assessment, several factors must be considered, including treatment suitability, assessment of home environment, duration of treatment, and psychosocial assessment.[1] HPN is a huge psychosocial strain for the patient and relatives during 24 hours a day, seven days a week. The most common criteria for excluding patients from the HPN programme in European countries are lacking intellect, social situation, physical disability, underlying disease, and age.[13] To make patient instruction successful, a specialised team is available in the two HPN centres in the Netherlands. After successful training, the patient is monitored by the nutrition team, including a gastroenterologist, an

HPN nurse, and a dietician. Patients must be able to recognise and cope with complications. A study of Wengler et al.[13] showed that in 42 centres that were engaged in the monitoring process of HPN patients nearly all of these had a dedicated multidisciplinary nutrition support team for this task. A physician evaluated all of the HPN patients in almost every centre, and a nurse was involved in monitoring in 81% of the centres. In other centres the nurse only took care of part of the patients. In 62% of all centres, a dietician was also assigned to the task of monitoring, and in 50% of the centres a pharmacist was involved. In addition, a psychologist, a social worker, a general practitioner and a community nurse were involved at the monitoring visits, if their knowledge was required.

Quality and quantity of complete professional care in HPN patients has not been well described. In the Netherlands, the Corporation Registration Enteral and Parenteral nutrition at home ('Stichting Registratie enterale En parenterale voeding Thuis; RET') reported some bottlenecks in care, but conclusions cannot be generalised to the Dutch HPN population because only 3 HPN patients were included in this study.[14]

VENOUS ACCESS COMPLICATIONS

Infectious complications are the most serious events related to vascular access devices. In patients on HPN, infections of this kind add significantly to the morbidity and mortality. The pathogenesis is generally bacterial or fungal growth colonising the catheter, with both the luminal and outer surfaces becoming contaminated. From there, pathogens can reach the bloodstream and clinical signs of infection may become evident. The hub, a broken line, or the use of the catheter for non-nutritional purposes (i.e. using the line to withdraw blood) are probably the most common endoluminal causes of infection. If micro-organisms migrate along the catheter or are introduced during the insertion, the infection is of extra-luminal origin.[1] The observed blood stream infection (BSI) rates in central venous catheter's (CVC) reported in various studies range from 0.17 to 2.19 episodes per catheter year.[11;15-20]

Next to infectious complications, catheter occlusions are also common. Occlusion rates are associated with the lifespan of the catheter, the type of catheter used, handling procedures and repeated events of blood flushing back, and possibly also the type of intravenous nutrition used.[1] Central venous catheter occlusion rates in the literature range from 0.06 to 1.6 episodes per catheter year.[3;21-25]

It is evident that the success of HPN depends on a reliable, long-term form of venous access. Loss of access is associated with prolonged periods of hospital care, deterioration in nutritional status, often painful attempts to insert a new access device and is feared by patients.[26] In addition, repeated episodes of catheter loss eventually inevitably result in the inability to obtain adequate venous access and hence provide an indication for intestinal transplantation.

PSYCHOSOCIAL PROBLEMS AND QUALITY OF LIFE

It has been demonstrated in the literature that HPN patients report alterations in physical, psychological and social functioning.[27;28] Although parenteral nutrition is a potentially lifesaving therapy, thanks to its positive effects on managing the nutritional and hydration status of these patients, the psychosocial effects are considerable. The quality of life of patients receiving HPN has been found to be lower than that of the general population and of similar clinical groups such as HPN independent patients with short bowel syndrome, those who have undergone intestinal transplantation, and those with end stage renal disease and renal transplant.[29-33] Even if the symptoms of the underlying disease have subsided, the impact of managing the technology of the HPN infusion system has a significant impact on lifestyle as well as the effect of hospital readmission for the treatment of catheter-related complications such as infections and thrombosis.[34]

There are a few studies on the quality of life of HPN patients. The interpretation of the results however, is hampered by the fact that there are numerous definitions of quality of life. In the context of health, quality of life describes health status from the patients' perspective and has evolved from the need to estimate the impact of disease and treatment to the physical, physiological, social, and somatic domains of functioning and well-being.[35]

Both HPN and the underlying disease may affect quality of life, and an evaluation of quality of life requires the separation of these two issues. For example, a patient with a history of good health who suffers from a mesenteric infarction has a massive reduction in quality of life as he suddenly becomes dependent on HPN. In contrast, someone who spent many years with Crohn's disease may have had several operations and many hospital admissions with exacerbation of disease and a substantial reduction in quality of life during the course of the disease. This patient will have had time to cope with the underlying disease and can usually accept the need for HPN or even experience benefits.

In a study of Galandiuk[36], quality of life was examined before and after HPN was started in patients with Crohn's disease, and results showed that quality of life improved on HPN. For these patients, HPN obviates the abdominal pain associated with eating. Decreased stoma output or diarrhoea may lead to a marked improvement in social activity and the general quality of life, while nutritional repletion of malnourished patients results in an increased sense of well-being.[37] Furthermore, patients with malignancy have an improved quality of life if they are provided with HPN and survive for over three months.[27] While early studies did not provide evidence for a significant improvement in quality of life in patients with malignancy[3;38], more recent studies indicate that quality of life can improve with HPN when compared to pre-HPN status.[39;40]

Little information is available about quality of life and the problems HPN-dependent patients experience in daily life. Chambers and Powell-Tuck[41] report lowest quality of life scores in the first year on HPN, especially if the patient previously was well and experienced an acute life-changing event such as a mesenteric infarct. Quality of life issues never have been systematically assessed. Furthermore, information is lacking concerning the association of venous access device-related problems and experienced psychosocial problems.

Given this lack of insight into HPN patient problems, venous access device-related complications and a possible relation between these problems, further research is mandatory. The same applies for the follow up care for HPN patients.

Our general aim is to establish a body of knowledge on topics relevant to the professional care of outpatients with HPN. This general aim is specified in three sub aims:

1) To describe available evidence on the quality of life -including somatic, psychological, and social aspects of daily life- as experienced by HPN patients;
2) To delineate the Dutch population on HPN with regard to problems experienced in daily life, venous access device-related complications, and an assessment of whether these adversities are related to psychosocial problems and quality of life;
3) To describe the quantity, quality, and content of professional care in Dutch HPN patients.

Outline of the thesis

In this thesis, six studies are reported in seven chapters. In **chapter 2**, a literature review is presented. The aim of this review was to describe the implications of home parenteral nutrition for the quality of life as experienced by patients, as well as to describe the caregiver's reactions regarding these implications. Cinahl, Medline, and Psychlit databases were searched for the period 1965 to 2005, to answer these questions. A total of 26 studies were included. A standardised record was used for data extraction, including study design, sample characteristics, HPN-related characteristics, data sources, outcome measures, recommendations, as well as strengths and methodological flaws of a study. In **chapters 3 and 4**, a survey among 48 Dutch HPN patients is described on patient problems experienced. **Chapter 3** describes a questionnaire study, to arrive at answers to the question: To what extent do long-term HPN patients experience problems? Questionnaires were based on results of two group interviews: one with patients on HPN, and one with health care workers. Questionnaires covered subjects arising from these interviews and included the Checklist Individual Strength (fatigue), the Beck Depression Inventory (depression), Sickness Impact Profile (social impairment), the Utrecht Coping List (coping), the Health Locus of Control questionnaire (health belief), the Subjective Sleep Quality Scale (sleep), the State-Trait Anxiety Inventory (anxiety), and Cantril's ladder (Quality of Life).

Complementary, interviews were held to explore which HPN treatment-related problems had a negative influence on daily life. **Chapter 4** describes this study. Data were collected during single interviews at the patients' homes. An open approach was chosen for the interviews. In order to standardise the interviews, each patient was asked the same questions in the same order. They were asked to state the 3 problems that came with the heaviest burden in their daily life with HPN. Per problem, information was obtained about the meaning and content, severity, and cause according to all patients.

Based on the results of the study in chapter 3, in which HPN patients reported fatigue as the most bothersome problem in daily life, **chapter 5** describes the course of fatigue and the predictors of persistent fatigue. In this longitudinal study 75 HPN patients were included. Patients completed questionnaires at baseline and follow up (12 months later). Measurements included fatigue, depression, functional impairment, social support, self-efficacy, coping, anxiety and acceptance. Relevant laboratory measures were obtained from the medical records. Descriptive statistics, correlations, and linear regression analysis were performed.

Chapters 6 and 7 focused on venous access device-related complications and their association with psychosocial complaints. In chapter 6 blood stream infection (BSI) and occlusion incidence rates during central venous catheter and arteriovenous fistulae (AVF) use were compared. Surgically created arteriovenous fistulae are constructed in the forearm, or, less ideally, in the lower extremity. The population consisted of 127 HPN patients in whom 343 CVC and 194 AVF access years were used. Based on biological and clinical rationales, possible confounders in the relation between access type and complication rate were identified and reported for each access type. These included the frequency of HPN administration, the underlying disease and relevant co-morbidities, the use of immune-suppressive therapy or systemic anti-coagulants and the administration of nutrition (with or without lipids) versus solely fluids and electrolytes.

The aim of **Chapter 7** was to present an overview of venous access device-related complications in the current population of patients on long-term HPN in the Netherlands and to assess whether these adversities are related to psychosocial problems and quality of life. Information on venous access device-related complications was collected from medical records, and in addition a survey was performed to characterise psychosocial problems and assess their association with technique-related complications. The questionnaires addressed general as well as HPN-related characteristics, quality of life, social impairment, depression, fatigue, physical complaints, coping, self-efficacy, social support, sexual disorders and anxiety. Pearson's correlations were used to analyse associations between venous access device-related complications and psychosocial problems and quality of life. To compare subjects with and without complications, t-tests or Mann Whitney U tests were used where appropriate.

Chapter 8 presents an overview of professional care in HPN patients. A survey among 51 HPN patients was performed, to assess contacts with professionals and possible shortcomings in care. Patients were on HPN for at least 12 months. Nursing files were screened to collect information about all contacts between the patients and the HPN nurse. Medical files were screened to check venous access device-complications and hospitalisations. HPN nurses and (specialised) home care nurses were interviewed to assess care and bottlenecks experienced.

Finally, in **chapter 9** the findings of the studies in this thesis, conclusions, methodological considerations, and implications for practice and future research are discussed.
The present thesis provides a solid overview of the concurrent situation regarding venous access-related complications and psychosocial problems that are experienced in daily life in the context of home parenteral nutrition, including their interrelation.

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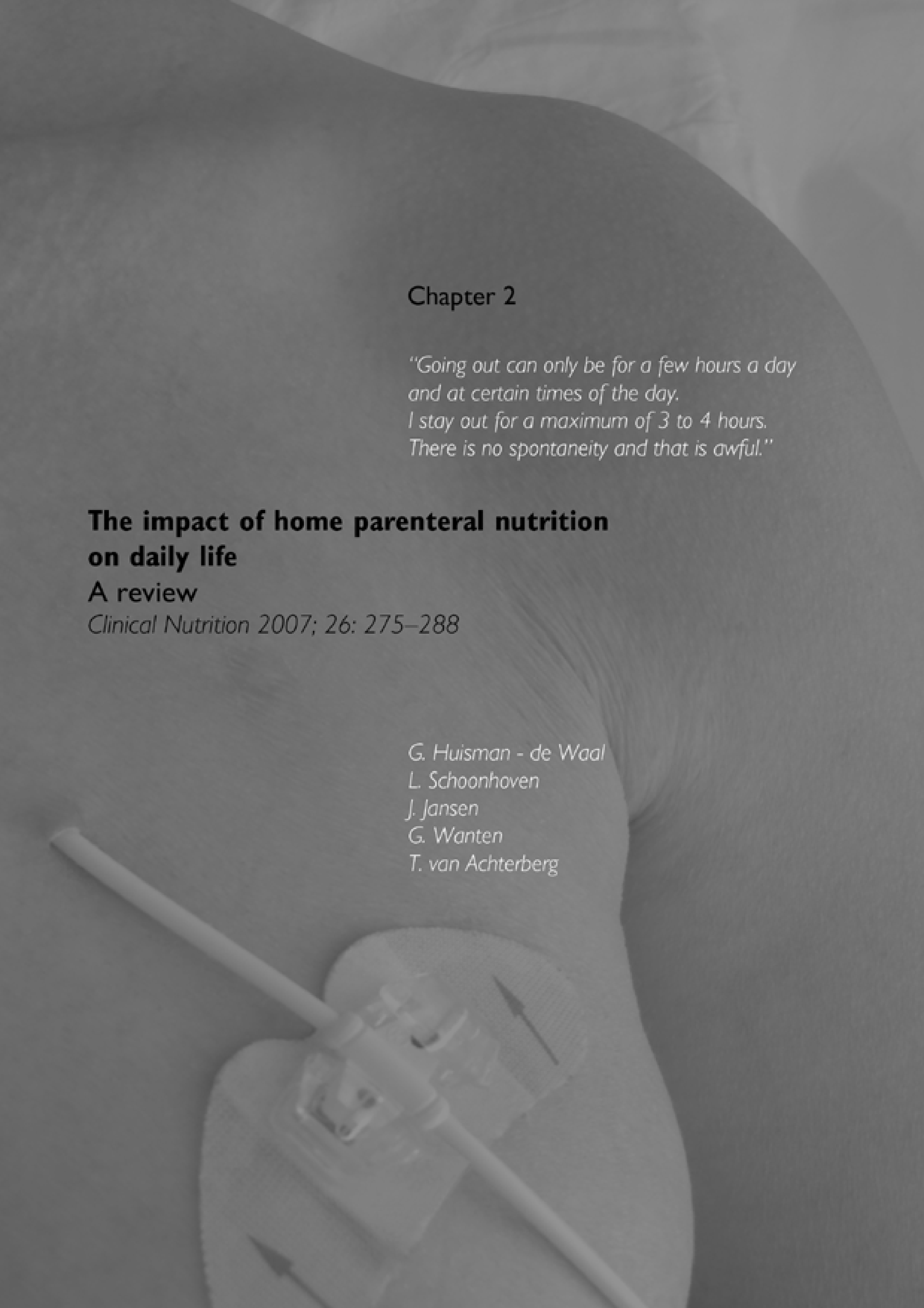

Chapter 2

"Going out can only be for a few hours a day
and at certain times of the day.
I stay out for a maximum of 3 to 4 hours.
There is no spontaneity and that is awful."

The impact of home parenteral nutrition on daily life

A review

Clinical Nutrition 2007; 26: 275–288

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Summary

BACKGROUND: Total parenteral nutrition (TPN) is a lifesaving therapy in patients with severe intestinal failure that can be administered at home. However, patients have to face complex technological nutritional support issues at home, which will influence their personal life.

OBJECTIVES: This review aims to describe the implications of home parenteral nutrition (HPN) on the quality of life, as experienced by patients, as well as to describe the caregivers' reactions regarding these notions.

SEARCH STRATEGY: A systematic review of the literature published between 1965 and 2005 was conducted. Cinahl, Medline, and Psychlit databases were searched. Systematic data extraction and narrative data synthesis were performed.

SELECTION CRITERIA: Papers were included if they described original research published in a peer reviewed journal, with a focus on adult patients on HPN and/or their family caregivers.

DATA COLLECTION (AND ANALYSIS): A standardised record was used for data extraction.

MAIN RESULTS: A total of 26 studies were included. The quality of life reported by patients was moderate to good, but psychological problems, e.g. depression and anxiety, were common. Social life was disturbed due to the venous access device, the time schedule for HPN administration, the inability to have normal oral intake, gastrointestinal mobility problems, and physical complaints. Frequently mentioned somatic problems included fatigue, diarrhoea, pain, polyuria during infusion and sleep disruption.

Despite social restrictions, depression and fatigue, caregivers reported their overall quality of life as similar to the norms for healthy populations.

Introduction

Parenteral nutrition is a lifesaving therapy in patients with severe intestinal failure. Most frequently, this failure results from extensive resections of small bowel due to inflammatory bowel disease or mesenteric thrombosis, or it is caused by loss of function because of severe motility disorders.

Total parenteral nutrition (TPN) implies that a complete aqueous food formulation is administered intravenously. Generally, total parenteral nutrition is administered overnight for a period of 12 hours. Patients feed two to seven times a week, depending on their remaining gut function. Importantly, these patients do not choose total parenteral nutrition out of their own free will, but it is usually the ultimate remaining option to maintain or improve their nutritional status.

In patients with prolonged intestinal failure, parenteral nutrition may be administered in the home setting. Home parenteral nutrition (HPN) is nowadays a commonly used procedure in many developed countries.[1] The patient population receiving HPN is small, but growing steadily.

Moving parenteral nutrition support from the hospital to the domestic setting results in a significant gain in quality of life.[2] However, patients have to face complex technological nutritional support issues at home, which will inevitably influence their personal life. HPN administration is a time consuming and intrusive procedure that requires many adjustments. Besides, the underlying disease that led to intestinal failure may also cause a variety of physical complaints, due to the presence of a stoma, altered body image, etc. These factors frequently impose restrictions on daily life regarding social, physical and psychological function. Understanding the difficulties that these patients experience is crucial in order to offer the right modalities of support. Besides, these notions may help patients as well as health care workers to anticipate to problems in the future.

The aim of the present study was to identify the implications of HPN on the quality of life (QoL), including somatic, psychological, and social aspects of daily life, as experienced by patients, as well as to describe the caregivers' reactions regarding these notions.

Method

INCLUSION OF STUDIES

A systematic review of the literature was conducted. The Cumulative Index to Nursing and Allied Health Literature (Cinahl), Medline and Psychlit databases were searched for relevant studies published in between 1965 and 2005. Subject-specific keywords used to describe patients relevant for this review were selected by using the databases' thesaurus function. We used the following keywords: home parenteral nutrition, successively combined with: depression, anxiety, quality of life, psychological, social, psychosocial, physical, pain, coping, sleeping, stress, mobility, activities of daily living, and limitations. The selected keywords were combined using the Boolean operator 'AND'. The search was also performed in free text. Additionally, the reference lists of studies were searched to retrieve relevant studies not recovered using the search terms. Also, the proceedings of the European Society of Parenteral and Enteral Nutrition (ESPEN) congresses from 1992 to 2005 were screened.

Because in some studies quality of life was measured as a general parameter, while in others quality of life was specified in somatic, psychological, and social aspects of daily life all options were checked.

Inclusion criteria of this review were: the article had to describe original research published in a peer-reviewed journal, with a focus on adult patients on HPN and/or their family caregivers.

EXCLUSION OF STUDIES

Articles in languages other than English or Dutch, or with a focus on TPN in the context of AIDS or cancer, or case reports, were excluded.

METHODS TO ANALYSE STUDIES

Two reviewers independently assessed the abstracts for fulfilment of inclusion criteria. In case of any doubts, consensus was achieved by discussion. After this first selection, the full papers were read by the first reviewer. A standardised record was used for data extraction. A second reviewer extracted data from two full papers for comparison. Data were compared and results showed consensus to a major extent.

Extracted information included study design, sample characteristics, HPN-related characteristics, data sources, outcome measures, recommendations, as well as strengths and methodological flaws of a study.

Results

SELECTED STUDIES

The search of Medline, PsycInfo, and Cinahl databases provided a total of 661 hits (duplicates included). After selecting studies by reading the abstracts, 43 studies remained. Twenty-three of these were excluded because inclusion criteria were not met. Nine of these did not describe original research, seven only reported on medical treatment and complications, two concerned patients with AIDS and cancer, one described hospital total parenteral nutrition patients, one discussed only appetite factors, one evaluated the hospital support team of HPN patients, one was a case report, and one was published in two different journals. An additional six studies that met the inclusion criteria were identified by checking the references of the relevant papers. Thus, a total of 26 studies were available for this review (Table 1).

DESCRIPTION OF STUDIES

Most of the included studies were conducted in the United States (n=15),[3–17] and in Europe (n=10),[1,18–26] only one study was performed in Canada.2 Seventeen studies had a quantitative design,[1,3–9,12,18–24,26] six had a qualitative design,[10,13,15–17,25] and three used both types of design.[2,11,14] The mean sample size of HPN dependent patients was 59±85 (range 5–347).

Studies were carried out at a single point in time (n=15)[4,6–8,10,11,15,16,19–21,23,24,26,27] or over a longer period (n=11).[1,3,5,9,12–14,18,22,25,28] Data were gathered using one or more of the following techniques: questionnaires (n=17),[3–9,11,12,14,18–23,26] interviews (n=9),[3,10,11,13–15,25,27,28] analyses of medical and nursing files (n=8),[2,3,6,19,22–24,26] unstructured monitoring during care (n=4),[1,5,7,16] and monitoring sleep.[9] Four studies gathered information from caregivers of HPN-dependent patients.[10,11,25,28] Five studies used a control group: two compared HPN patients with intestinal transplantation patients,[4,5] and one compared HPN patients with short bowel syndrome patients without HPN.[21] One study compared HPN patients with long-term medication use (opiates, benzodiazepines) with closely matched HPN patients, not dependent on these drugs.[23]

Table 1 Search outcome

HPN combined with	**Cinahl**			**Medline**			**PsycInfo**		
	Hits	Selected	Included	Hits	Selected	Included	Hits	Selected	Included
Psychosocial	0	0	0	16	6	4	2	2	1
Psychological	0	0	0	25	6	2	0	0	0
Physical	30	4	1	26	6	5	1	1	0
Social	36	13	4	58	16	10	2	2	1
Quality of life	79	18	4	163	47	14	0	0	0
Depression	23	7	1	10	8	3	1	1	0
Anxiety	8	4	1	11	6	2	1	0	0
Pain	19	1	1	55	5	2	0	0	0
Coping	15	3	0	2	2	2	0	0	0
Sleeping	1	0	0	2	0	0	0	0	0
Stress	38	2	0	6	2	1	0	0	0
Mobility	1	0	0	3	0	0	0	0	0
Limitations	14	4	1	5	1	1	0	0	0
Activities of dialy living	1	0	0	7	0	0	0	0	0
Total	**265**	**56**	**13**	**389**	**105**	**46**	**7**	**6**	**2**
Total per database without duplicates			**4**			**15**			**1**

Total included Cinahl, Medline, PsycInfo: 61
Total without duplicates: 20
ESPEN: 0
Studies found in references: 6
Total studies found: 26

One compared a group of HPN patients who were supported by an organisation with a group of non-supported patients.[3] In three other studies, adult HPN patients were part of the study population and were compared to enteral nutrition patients,[6,12] and patients with nutritional therapy.[19] One study gathered information from mothers of HPN-dependent children.[28] Details of the studies are listed in Table 2.

The age of HPN patients ranged from 17 to 87 years. Underlying diseases were Crohn's disease, mesenteric ischemia, pseudo-obstruction, radiation enteritis or other gastrointestinal failure. The duration of HPN ranged from 1 month to almost 28 years; patients were on HPN for 2–7 days a week, 7–24 h a day (Table 3).

METHODOLOGICAL QUALITY

Many of the studies had methodological flaws. For example, in several quantitative studies the sample size was very small[1,4,5,9,12,14,19,22] (≤20), and in one study quality of life of HPN-dependent patients was assessed by the author without any obvious structure.[24] The response rate was only mentioned in 14 studies[3–8,10,11,18–21,23,26] and varied from 30%7 to 100%.[18,20]

Questionnaires used were strongly heterogeneous, especially with regard to global measures of quality of life and health assessment.

IMPACT ON DAILY LIFE

We studied the impact of HPN on quality of life, somatic, psychological, and social aspects of daily life. Table 2 gives a summary of the results per study.

QUALITY OF LIFE

Ten studies used a specific quality of life questionnaire[3–5,7,11,19,21–23,26] and 12 studies used other questionnaires or interviews to evaluate quality of life.[1,6,8,12,14–16,18,20,24,25,27] In five studies, quality of life was seemed to be acceptable on average for HPN patients.[1,3,11,15,23] Some studies conclude that the majority, e.g. 70% of the patients, had a reasonably good quality of life.[2,7,8,25,26] A low quality of life was found in six other studies.[4,5,12,19–21]

HPN patients experienced a lower quality of life compared to the healthy population.[3,12,18] They scored equal or lower than patients with other nutritional therapy[6,12,19] and end stage renal disease (ESRD) patients.[6,7,11,21] Herfindal et al.[7] noticed that the difference with ESRD patients is that HPN patients tend to be isolated from other patients and health care providers. Patients suggest that health care providers should be sensitive to the psychological and technology needs of HPN patients.

Compared to intestinal transplantation patients quality of life was similar in both groups [5,26] but in one study intestinal transplant patients experienced a significant higher quality of life.[4] HPN patients depending on opiates or benzodiazepines experienced a low quality of life, i.e. 0.26 mean on a scale from 0 (worst possible quality of life) to 100 (best possible quality of life).[23]

An acceptable quality of life seems to depend on several factors such as primary disease, duration of HPN, contact with social worker, hospital admissions, presence of a stoma and employment status.[7,18,20,23,25,26]

PSYCHOLOGICAL ASPECTS

Seven studies did not assess the psychological reactions of patients on HPN. In many of the remaining studies, depression was a common emotional response to the HPN procedure (n=12). Severity of depression ranged from mild to severe and was found in 10–80% of the HPN patients.[3,13,14,26] Jeppessen et al.[21] showed that the female HPN patients expressed more feelings of depression and discouragement and they appeared to be more tearful and upset than male HPN patients. In a sample of 216 HPN patients, Smith et al.[3] found that the patients supported by an organisation had a mean score indicating none or mild depression, while the mean scores for the patients who were not supported indicated moderate depression. In the study of Richards and Irving[23],depression was reported in 70% of the HPN patients depending on opiates or benzodiazepines, compared to only 10% of the non-dependent closely matched HPN patients. Depression may have serious consequences as it might lead to less care with the aseptic technique regarding the catheter, resulting in an increase in line sepsis.[14,15]

By contrast, two studies showed little evidence that psychological health status was affected by HPN.[6,12]

Table 2 Characteristics of included studies (n=26)

Author Year	Type of study design	Sample size	Data sources	Main Outcomes
Carlson GL et al. 1995 [26]	Quantitative	47	File analysis Questionnaire : subjective QOL, the Nottingham Health Profile, SF 36	Good QOL, age and gender appeared to have little effect on QOL Many patients reported sexual and social dysfunction and most patients were unable to return to work. Almost half the patients had frequent feelings of depression or anxiety.
Carlsson E, et al. 2003 [19]	Quantitative	8 HPN, 20 nutritional therapy (SBS)	File analysis Questionnaire : Visual Analogue Scale, SF-36, Rating Form of IBD patients concerns, Jalowiec Coping Scale	Low QOL and low perceived health in HPN group The most intense concerns were being a burden, energy level, having surgery, feeling alone, and loss of sexual drive.
Detsky AS et al. 1986 [27]	Both	73 analysis 37 interview (van de 73)	Dossier analysis Structured interviews	QOL improved fast during the first year and then increased slowly. QOL specifically improved in patients who had experienced malnutrition prior to HPN
DiMartini A et al.. 1998 [4]	Quantitative	19 : 10 HPN 9 ITx	Questionnaire : Quality of Life Instrument	HPN patients reported significant worsening across many areas of QOL after becoming TPN dependent. Intestinal transplant recipients experience a significant improvement in most areas of QOL, compared to the period while on TPN.
Herfindal ET et al. 1989 [7]	Quantitative	347	Questionnaire : Campbell's Life Satisfaction [32], patient predictor's, physiologic complaints, QOL, Affect Balance Scale	HPN patients appear to adapt to most aspects of their treatment program. Overall life satisfaction is lower than ESRD patients Patients have difficulties with the isolation from health care providers, the ability to travel and sleeping.
Jeppessen PB et al. 1999 [21]	Quantitative	49 patients 36 controls	Questionnaire : Visual Analogue Scale, Sickness Impact Profile, Inflammatory Bowel Disease Questionnaire	Reduced QOL according to those with short bowel without HPN and patients with chronic renal failure treated with dialyses. HPN patients spent more time at home. They experience a large impact on their psychosocial activities, sleeping and emotional functioning. Females scored worse on QOL.
Johnston JE 1981[16]	Qualitative	Evaluating 36 patients, 26 HPN participants	Monitoring: 3 years experience (36 patients), working with 26 HPN participants	Stresses introduced by HPN involve self-image, depression, fear, hopelessness, family life, job participation, social participation, financial situation and sexual activities. Chronically ill patients adapted more easily to HPN than patients with acute gastrointestinal trauma..

Author Year	Type of study design	Sample size	Data sources	Main Outcomes
Ladefoged K 1981 [25]	Qualitative	13 patients 10 partners	Structured interview (1st 13 patients 2nd 9 patients)	70% fair QOL, 30% poor QOL. Patients were not able to work, experienced physical distress, and sexual activity had ceased completely in patients above 55 year. Leisure activity and social activities were restricted.
MacRitchie KJ 1980 [15]	Qualitative Survey	20 (2 subgroups with distinctive coping styles)	Open interview (once)	Sudden loss of bowel inevitably results in grief. Patients who already were chronically ill experience a smoother adaptation. Resultant body image alteration played an important role within the group, especially in woman.
Malone M 2002 [12]	Quantitative	12 HPN 5 HEN	Questionnaire : SF 36, symptoms, impact of nutrition on their lifestyle	Sleep, travel, and social activities were the most affected aspects of the patient's lifestyle. The general health scale showed that older patients had a better general health status score.
Mughal M & Irving M 1986 [24]	Quantitative	200	File analysis QOL (self made instrument)	Most patients were fit and independent . Those likely to do well tend to have a primary intestinal disorder. Patients with a poor QOL were older men whose mesenteric arterial occlusion is a manifestation of generalised arteriopathy.
Perl M, et al. 1980 [14]	Both (quantitative and qualitative) Longitudinal	10	Semi-structured interview Observation and report by nurses Questionnaire : Life History Questionnaire, Structured mental status examination	Patients are gratified with the new life, but most patients were at least mild depressed as a result of obvious and severe current life stresses. Common problems: fear related to realistic dangers, embarrassment, problems with not being able to eat, social discomfort, sexual problems, financial difficulties.
Pironi L et al. 1993 [1]	Quantitative	18	Monitoring QOL according to Mughal & Irving	HPN improved QOL by ameliorating the nutritional status, allowing social rehabilitation and reducing the hospital rate. The outcome of the patients on HPN is mainly determined by the underlying disease.
Pironi F et al. 2003 [20]	Quantitative	40	Questionnaire : SF 36, nutritional status, rehabilitation status according to Mughal & Irving, hospital readmissions File analysis	QOL was lower than that of the healthy population. Lower QOL in patients with pseudo-obstruction or those dependent on narcotics and sedatives. During HPN, 58% of the patients maintained the same occupational activity they had before HPN.
Pironi L et al. 2004 [18]	Quantitative	31	Questionnaire: SF 36, social demographic and general factor's, disease factor's, HPN factor's, hospital stays, rehabilitation according to Mughal & Irving	SF 36 raw scores were worse compared with the standard population. Lowest scores among older patients and those addicted to narcotic analgesics. Higher scores among those who had been treated with HPN longer.

Author Year	Type of study design	Sample size	Data sources	Main Outcomes
Price BS, Levine EL 1979[13]	Qualitative Retrospective	19	In-depth open interviews	Depression, social restrictions, sexual problems, anxiety and fear of the unknown, frustration, ambivalence and fatigue are common. Patients developed a 'love-hate' (life-death) relationship with the TPN apparatus. Every patient misses and craves food. The cosmetic effect of multiple surgical procedures was a constant source of concern.
Reddy P, Malone M 1998[6]	Quantitative	22 HPN 10 HEN	Questionnaire: SF 36, influence of therapy on lifestyle Review charts	HPN had a significant negative impact on a patient's QOL and lifestyle domains like sleep, travel, exercise, and social life.
Richards DM et al.. 1997[22]	Quantitative	20: 10 dependent 10 controls	Questionnaire: EuroQOL index, SF 36	Outcomes for opiate- and sedative-dependent patients are significantly worse than for other HPN patients (more depression, anxiety, complications). This is possibly due to a low morale, more pain, less energy, more anxiety and more central line sepsis
Richards DM Irving MH 1997[23]	Quantitative	51 patients 64 case notes	Dossier analysis: demographic and clinical details Questionnaire: EuroQOL index, SF 36, self-rated health status, change in health over the past 12 months	Fairly good QOL. No difference between patients with of without a stoma. Poorest scores in older patients and those dependent on narcotic drugs Employment rate was low (5%)
Robb RA et al. 1983[8]	Quantitative	42	Questionnaire (own development): patients predictor's, hospital admissions, physiological complaints, psychosocial interferences	Reasonable QOL; most patients believed that HPN had no effect on their self-image and a very positive effect on their overall life. Patients with chronic diarrhoea or a low annual income might be expected to have more medical and psychosocial problems
Rovera GM et al. 1998[5]	Quantitative (longitudinal)	20: 10 HPN 10 ITx	Questionnaire: Quality of Life Instrument	Little difference in QOL between ITx recipients and HPN dependent patients Improvement occurred over time in ITx recipients in domains related to sleep, anxiety, and impulsiveness/control.
Scolapio JS et al. 2002[9]	Quantitative	5	Wrist activity data Polysomnography Questionnaire: Epworth Sleepiness Scale	Reduced sleep quality in patients receiving HPN; total sleep time and sleep efficiency during HPN infusion was less than reported for controls. Sleep quality does not seem to be negatively effected by cyclic HPN infusion.
Silver HJ 2004[28]	Qualitative	9 HPN patients (6 adults, 3 children) 3 mothers of HPN patients	Structured interview (online)	Improvements in the ability to function. Fear of death, fear of complications, frustration, and anger were the most frequently expressed negative feelings. Facing social situations with family and friends when food is present appeared to be anxiety-producing.

Author Year	Type of study design	Sample size	Data sources	Main Outcomes
Smith CE 1993 [11]	Both	178 patients 178 caregivers	Telephone interview Questionnaire: QOL index, Rosenberg's Self-Esteem Scale[33] , Cantril's self anchoring scale, Batson Emotion Index, Caregiving reaction assessment scale, Mutuality (quality of relationship) Family Crisis Oriented Personal Evaluation Scale, Family Adaptability and Cohesion Evaluation Scale, Centre of Epidemiologic Studies – Depression Scale	Low QOL was associated with increasing length of time on HPN, fewer coping skills, and inability to get along income. Depression and physical fatigue were reported as most problematic for both patient and caregivers. Self-esteem was comparable to that of healthy individuals. Patients and caregivers reported missing out on activities and worrying about infection frequent.
Smith CE et al. 1993 [10]	Qualitative	20 family caregivers	Semistructured interviews	Reactions to care giving were mainly positive. Common problems: anxiety in managing the technology, depression, fatigue, less time for leisure.
Smith CE et al. 2002 [3]	Quantitative	95 large centres 121 smaller centres (controls)	Telephone interviews File analysis Questionnaire: Quality of Life Index, Centre of Epidemiologic Studies – Depression Scale	Patients supported by an organization experienced a higher QOL, less reactive depression, and a lower incidence of catheter-related sepsis.

SF 36	Short Form 36 health status questionnaire
IBD	Inflammatory Bowel Disease
QOL	Quality of Life
HIVH	Home intravenous hyperalimentation
ITx	Intestinal Transplantation

Table 3 Patient characteristics

Author	Mean age (range)	Gender	Employed	Years on HPN mean (range)	Hours on HPN/day	Hospital admissions
Price BS, Levine EL 1979 [13]	39.6 (17-60)	47% F	15,8% FT, 36,8% PT	-	At night	-
Perl M, et al. 1980 [14]	41.6 (24-66)	40% F	40% FT, 50% PT	1.8 (0.5-3.25)	Generally 24 hours	-
MacRitchie KJ 1980 [15]	44.1 (18-66)	50% F	-	1.5 (0.25-5)	-	-
Ladefoged K 1981 [25]	45.3 (24-62)	54% F	0%	Median 32 mo (3-49 months)	7.1 hours mean	Mean LOS 38.8 (0-120 days).
Johnston JE 1981[16]	(10-69)	27% F	-	-	10-12 hours overnight	-
Robb RA et al. 1983 [8]	50.1 (22-78)	67% F	11.9% working 9.5% homemaker (48% employable)	3.6 (0.5-9.5)	-	Mean 1.6 (0-7 times), 35% wasn't hospitalised last year. Only 36% of admissions were attributed to HPN complications.
Detsky AS et al. 1986 [27]	41.7 (19-75)	53% F	-	(0.5-12)	-	-
Mughal M & Irving M 1986 [24]	(0-80)	60% F	Nearly 1/3 FT 22% PT or looking at family	(0.08-6)	Usually 12 hours at night	-
Herfindal ET et al. 1989 [7]	45.8	58% F	11% FT, 6% PT, 28% retired, 15% homemaker, 50% disabled, 9% unemployed	2.9	-	3 times last year due to HPN complications (22.5 average length of stay).
Pironi L et al. 1993 [1]	45.5 (27-71)	44% F	Some patients could maintain the employment (no percentage)	1.8 (0.08-5.8)	12-18 hours overnight	0.41 catheter related complications / patient-year Catheter sepsis: 0.12 /patient-year, deep vein thrombosis: 0.1 /patient-year.
Smith CE 1993 [11]	HPN 52 (19-85)	Nearly equally divided	-	4.6 (0.08-20)	8-24 hours; majority during night time	-
	Caregivers 52.5 (21-87)	-	-	-	-	-
Smith CE et al. 1993 [10]	HPN (32-78) Caregivers (30-76)	-	30% FT , 30% PT, 30% retired, 10% unknown	0.08-8 providing home care	1-24 hours a day assistance (mean 9.95)	-

Author	Mean age (range)	Gender	Employed	Years on HPN mean (range)	Hours on HPN/day	Hospital admissions
Carlson GL et al. 1995 [26]	Median 50 (21-67)	51% F	11% FT, 3% PT, 59% unemployed, 15% retired, 11% carrying for home/fam.	4.6 (1-12.6)	-	3.0 / year HPN: patients with a positive attitude towards ITx 3.5 / year HPN: patients with a negative attitude towards ITx
Richards DM Irving MH 1997 [23]	44.4 (17-70)	62.5% F	10% FT, 10% cope with housework, 80% too ill to work	Median 4 years (0.5-15)	98% noctural	-
Richards DM et al. 1997 [22]	Dependent patients 36.2 (19-45)	80% F	-	2.7 (1-12)	-	Mean 2.2 admissions the past year (mean 29 days)
	Non-dependent 39 (24-55) C	80% F	-	3.3 (1-11)	-	Mean 0.2 admissions (mean LOS 8 days)
DiMartini A et al. 1998 [4]	HPN 37.4 (22-73)	60% F	50% totally disabled, 20% pre-TPN working status, 30% housewives	4.2 (1.2-8)	-	-
	ITx 26.6	67% F	22% totally disabled, 22% housewives, 56% student	2.6 (0.25-8)	-	-
Rovera GM et al. 1998 [5]	HPN 36.4 (27-54)	70% F	20% working, 10% student	5.3 (0.5-15.8)	Noctural basis	-
	ITx 34.2 (23-62)	50% F	0% working; 20% home maker, 20% student	2.4 (0.25-8) HPN before ITx	-	-
Reddy P, Malone M 1998 [6]	56 median (25-74)	64% F	14.5% FT, 4.5% PT	Median 6 (1-21)	-	-
Jeppessen PB et al. 1999 [21]	HPN Median 45.4 (25-75)	63% F	14% FT	Median 5 (0.2-27.8)	Generally at night; 12% day and night	-
	SBS 50.0 (44.1-60.4 = 50%)	56% F	44% FT	-	-	-
Smith CE et al. 2002 [3]	(30-70)	More woman	-	8 (2.9-16.9)	-	-
Scolapio JS et al. 2002 [9]	61.4 (40-73)	60% F	-	1.9 (0.4-5)	10 hours noctural	-
Malone M 2002 [12]	HPN 54.8	59% F (total population)	35% working, 41% retired, 24% unable to work (n=17)	7.1 (1-18) (n=17)	-	1993-1996: none of these patients were admitted to hospital as a result of HPEN related complications
Pironi F et al. 2003 [20]	42.6 (17-66) (n=40)	55% F (n=40) 60% F (n=17)	30% working/ student, 28% housewives, 18% retired or temporary suspension, 24% already uncapable due to the disease (n=40)	3.74 (0.08-11.02) (n=40)	Overnight (n=40)	Rehospitalisation's related to HPN: 0.37 ±1.02 /year of HPN (n=40, 1986-2001) Rehospitalisation related to HPN: 0.33 ±0.66 / year of HPN (n=17, 2001-2002)

Author	Mean age (range)	Gender	Employed	Years on HPN mean (range)	Hours on HPN/day	Hospital admissions
Carlsson E, et al. 2003 [19]	51 (37-57) (n=8)	50% F (n=8)	50% PT (not reduced since HPN), non workers stopped working due to disease	6.2 (4.75-17.42)	-	-
Pironi L et al. 2004 [18]	45.4 (18-74)	55% F	-	4.2 (0.2-17.6)	-	-
Silver HJ 2004 [28]	38.7	50% F	-	4.3 (2-8)	-	-

F	Female
FT	Full-time
PT	Part-time
ITx	Intestinal Transplantation
SBS	Short Bowel Syndrome
LOS	Length of Stay

Another common reaction in HPN patients was anxiety and fear for the unknown; the future, the attitude of other persons, complications and death (n=10).[4,5,13–16,21,25,26,28]

Carlson et al.[26] reported that 41% of the patients had frequent feelings of anxiety or depression. Other studies did not report percentages of anxiety and fear, but gave descriptions as "there was a high degree of anxiety and fear for the unknown",[13] "most frequently mentioned was their fear of death" and "all subjects expressed fear of liver damage".[17]

Anxiety and fear was related to realistic threats, such as catheter infection, pump malfunction, air metabolism, liver damage, etc.[13,14,16,25,28] Perl et al.[14] described fear was almost universal, especially in the early months of HPN. With the passage of time, patients became less fearful. As the level of fear became manageable, overall functioning and activity improved.

When HPN patients were compared to patients after small intestinal transplantation, anxiety levels were higher in the HPN patient group.[4,5]

Reduced physical mobility, lack of energy and optimism, fatigue, a sense of loss of control, financial instability, marital disintegrations and inability to return to an appropriate work or social setting could lead to or aggravate symptoms of depression or anxiety in total parenteral nutrition patients.[4,14–16]

A constant source of concern for almost all patients was the cosmetic effect of multiple surgical procedures and the actual location of the catheter.[13–16] Patients perceived themselves as unattractive or repulsive. MacRitchie[15] showed that especially females experienced feelings of embarrassment and shame concerning disfigurement caused by scars, the catheter and weight loss. Unlike HPN patients, transplanted patients experienced a significant improvement in appearance.[4] By contrast, in two studies patients believed that HPN had no effect on their self-image or self-esteem.[8,11]

Patients with chronic bowel disease seemed to cope more effectively than patients with acute gastrointestinal trauma.[1,13,15,16,20,21,23,24] They were usually so grateful, that they showed a better compliance and adjustment to the HPN regime. Also, they were more emotionally prepared for HPN. These patients, suffering from a chronic disease, viewed HPN as a relief from frequent hospitalisations and abdominal discomfort. Patients with acute gastrointestinal problems found their new circumstances quite devastating, had enormous fears, and they grieved for the loss of functioning.[13,15,16,23]

Patients who had been able to maintain stability in their personal lives towards employment, family support and financial security, seemed to adjust better to HPN and had a more positive outlook on the future.[16]

Other psychological problems were changes in dependence (mostly loss of independence),[13,16,21] frustration,[13,28] anger,[21,28] difficulty with concentration and memory,[5,14] some patients felt they were a nuisance or a burden to others,[19,21] some felt lack of understanding from others,[21] and some felt alone,[19] tense,[13] or annoyed.[25]

SOCIAL ASPECTS

Freedom to choose and the power to make simple decisions of daily living were sharply reduced and social contact and interaction decreased because of the catheter, the schedule of HPN, mobility problems, and physical complaints.[11–13,21] When statistics were reported, 35–43% of the patients experienced social activities as a problem due to HPN.[8,12,25] Sports, shopping, leisure, travelling, hobbies, and child care were domains where patients had to make adaptations.[4,7,8,12,14,17,25]

Depending on the underlying disease, HPN patients are either able to eat and drink normally, just a bit or not at all. Patients who can eat orally are encouraged to do so if they wish to minimise feelings of social alienation.[16] When a HPN patient is not able to eat and/or drink, friends sometimes stopped asking them over for meals or celebrations that included food.[10] Some patients felt unable or unwilling to sit down to meals with the rest of their family[26] and some had a reduced appetite.[21]

In seven studies the impact of HPN on the sexual relationship was assessed.[13–16,21,25,26] Sexual functioning reduced and this was a major concern in 27–60% of the HPN patients.[14,21,26] Lovemaking had to be timed,[13] the enjoyment of sexual relations was reduced,[14] and embarrassment and shame often led to impairment in sexual relationship.[15,26] Reasons were an altered body image, feelings of embarrassment, discomfort with the bag and pump, and the partner's fear of harming the patient. Sexual relations tended to improve after the first few months. Single patients may experience a more difficult time feeling uncomfortable in sexual situations because of their catheter. Younger patients seemed to have a more normal sex life.[25]

Going on holiday or travelling required logistic attention. Patients had to carry along adequate supplies of nutrient fluid and equipment. Despite this, in one study patients frequently made road or air trips, having their supplies sent to their destination.[14] Other studies reported travelling and going on holiday was negatively affected by HPN in 32–53% of the patients.[7,11–13,26] In a sample of 347 HPN patients, Herfindal et al.[7] found that the ability to travel was the activity most disturbed by HPN, but the longer the patients were on the HPN program, the less affected this ability was.

Patients mostly were encouraged to return to work as soon as their physical and emotional condition permitted. If a patient worked a regular day, he had to learn to schedule his employment hours around being 'hooked up' to feedings. This highly restrictive schedule left little time for any other family or leisure time activities. Because the solutions mostly run through the night and disrupt sleep, patients sometimes felt weak and tired during the day. In several studies percentages of full-time working patients were given, none of the patients in the study of Ladefoged[25] felt capable of managing a job, related to a complexity of reasons: tiredness, pain, diarrhoea, frequent hospitalisation, and the time-consuming therapy of HPN. In several studies 10–20% of the patients worked full-time,[4,6–8,23,26] and in other studies nearly 30–40%.[5,14,19,20,24] Furthermore, some patients were home makers, some were students, and some were retired. Richards and Irving[23] reported that 80% of the patients were too ill to work. The reason for this low employment rate was unclear but might be a result of illness-related financial benefits.

SOMATIC ASPECTS

The most frequently mentioned general complaint in HPN patients was fatigue (n=8).[4,10,11,13,14,19,21,22] Fatigue was seen as consistently interfering with daily activities like work, and leisure. In other studies weakness and/or tiredness was mentioned.[7,8,13,14,25] Only three studies reported statistics, 23–54% of the HPN patients experienced this problem.

Another complaint, described in five studies, was diarrhoea, for which the reason was not always clear.[4,8,11,12,21] Robb et al.[8] found that patients who complained of diarrhoea had significantly more physiological complaints than the patients who did not have diarrhoea.

Five studies reported patients suffered from different sorts of pain: bone and joint pain,[1,8] abdominal cramping or abdominal pain,[8,21] and pain which was not specified.[4,22] Four studies described skin rash in a small part (8–17%) of the HPN population.[6–8,12]

The most frequently mentioned physical complaint related to the fluid intake was polyuria during infusion, mostly at night. This problem was mentioned in eight studies and seemed to be an important reason for sleep disruption.[4,6–8,12,13,18,28] Studies using percentages reported 42–58% of the patients mentioned this problem.[7,8,12]

An overview of general and HPN-related problems that were mentioned in several studies is shown in Table 4.

CAREGIVERS REACTION

Most of the caregivers were patients' partners,[10,11,25] but in two studies there were also some parents, children, sisters and a close relative who provided care to the HPN patient.[10,11] Silver assessed the reaction of three mothers of HPN-dependent children.[28]

Caregivers reported their overall quality of life, self-esteem, life satisfaction, family cohesion and quality of the patient–caregiver relationship as similar to the norms that are published for other healthy populations. Reactions to care giving were mainly positive, although common problems like depression and fatigue were articulated.[10,11] Low quality of life was associated with increased length of time on TPN, fewer coping skills, and inability to get along on income.[11]

All four studies mentioned social restrictions: caregivers were missing out on activities, friends had stopped visiting, or asking them over for meals or celebrations that included food.[10,11,25,28]

Depression or other psychological feelings such as strain, frustration, anger, and difficulty watching the patient go through the illness, were also reported by caregivers in all studies.[10,11,25,28]

In three studies caregivers were anxious about infection, loss of venous access, liver damage, managing the technology, and death.[10,11,28]

Two studies mentioned that fatigue and tiredness consistently interfered with daily activities.[10,11] Caregivers undertook more household duties,[10,25] and more physical care.[10,17] Other problems mentioned in the studies were sexual problems,[25] role reversal, and financial dependence on insurers because of the cost of TPN.[10]

Table 4 Physical complaints

Reference	Physical complaint	% patients experiencing this problem (if reported)
4;10;11;13;14;19;21;22	Fatigue	-
7;8;13;14;25	Weakness/tiredness	23 – 54%
4;8;11;12;21	Diarrhoea	25 – 26%
4;7;8;21;22	Pain	-
4;6-8;12;13;18;28	Polyuria	42 – 58%
6-8;12	Skin rash	8 - 17%
7;8	Decreased concentration	11 – 26%
6-8;12	Ankle or feet swelling	17 – 45%
8;12	Orthostatic hypotension	17 - 25%
6;8;12	Ageusia	52%
6;8;12;34	Nausea	25 – 37%
6;12	Thirst	42 – 58%
6;12	Constipation	0 – 9%
6;12	Gas	8 – 23%
6	Dry mouth	45%
6	Vomiting	9%
6	Hyper- or hypoglycaemia	27%
6	Sore throat	5%
8	Chest pounding	19%
12	Fluid retention	25 – 50%
7;8	Nervousness or sweating	33 – 38%
7;8	Cramps in hand or feet	40 – 62%
7;8	Hair loss	15 – 24%
7;8	Shortness of breath during infusion	14 – 18%

Discussion

The aim of this study was to identify the impact of HPN on daily life as described in literature. We found that, overall, HPN patients experience a moderate to good quality of life, but many suffer from depression and fatigue. HPN also limits social activities. Caregivers reported their overall quality of life as similar to the norms that are published for other healthy populations, but common problems like depression and fatigue were articulated.

This review was conducted in a systematic and meticulous manner. In order to reduce publication bias we also searched the proceedings of the ESPEN congresses from 1992 to 2005 for studies that were presented but had not (yet) been published. Therefore, it is not likely that relevant studies were missed. However, the conclusions from this review should be treated with some caution, because of limitations in the data. Some included reports were difficult to compare because of the use of different instruments, scales, and lifestyle domains. Other studies used individually designed questionnaires that were not validated and therefore could be considered weak. Also, the methods used to conduct and interpret the interviews were not always clearly described. Another problem within the studies is selection bias. Satisfied patients may not have responded and responders may be less satisfied, or the other way around. Finally, it is sometimes difficult to evaluate whether the problems are a result of HPN use or the underlying disease. Despite these limitations most reports mention similar problems experienced by HPN patients.

While we found that overall HPN patients experience a reasonable quality of life, some issues need to be discussed. First, the interpretation of the outcome measures are quite variable between studies, both 0.51 and 0.73 on a scale from 0 to 1 were indicated as a reasonably good quality of life.[2,23] Also, part of the HPN patients is not capable to eat and/or drink normally. The value of food intake on social patterns, self-esteem, pleasure and enjoyment, and nutritional status is not considered in most generic or disease-specific quality of life tools.[29] Taking these items into account may result in a lower appreciation of quality of life.

There are some studies that yielded contradicting results in several ways. Depression is a complaint that was mentioned in 12 studies as a problem, but in two studies little or no evidence of impairment of the psychological health status was found.[6,12]

Also, in most studies only 10–30% of the patients were capable to work part-time or full-time. In contrast, in the study of Perl et al.[14] about 80% of the patients had a part-time or full-time job or retained family and homemaking activities. The reason for this difference is unclear, but it may be a result of illness-related financial benefits.

Finally, Perl et al.[14] concluded that patients are extremely gratified with the new life afforded by HPN, and seem to put up with the inconveniences with a good sense of humour. But at the same time 80% of these patients experience at least mild depression, 30% experienced several suicidal episodes, and fear was almost universal in these patients.

Conclusion/recommendations

Both qualitative and quantitative studies provided information on symptoms experienced while receiving HPN. In general, it has become clear that HPN patients suffer from a broad range of problems, of which many are social or psychological in nature. Frequently expressed problems were depression, anxiety, limitations in social activities and travelling, sexual problems, fatigue, and diarrhoea.

To minimise the impact of HPN, patients could be supported in coping with these problems from the time patients start with HPN. In order to be maintained as an active outpatient on HPN, Perl et al.[14] stated it is necessary that emotional needs be understood and that the psychological problems be handled as enthusiastically and competently as the physical problems. An annual assessment of psychological-, social-, and physical functioning might provide insight into experienced problems and the necessity to start with interventions. It is recommended to involve partners and family of HPN patients in this process.

Recently, Baxter et al.[30] carried out a review of the quality of life of adult patients on HPN. There are however several differences with this review. Baxter et al. included cancer patients while we did not, and they did not limit the study design, whereas we only included original research published in peer reviewed journals. Also, we included caregivers' experiences in our review, while they did not.

We agree with Baxter that both HPN and the underlying disease may affect quality of life, and that there is a need for a standardised, scientifically validated, treatment-specific instrument to measure quality of life in HPN patients.

In the literature Smith et al.[31,32] have published on interventions in HPN patients. The first study[31] demonstrated that Interactive and Videotaped Educational Interventions were associated with a reduction in reactive depression, catheter-related bloodstream infections, and hospitalisations because of infections. Writing in checklists and diaries, and using step-by-step problem-solving engaged subjects, prompted use of self-monitoring, activated professional partnerships for problem management, and ultimately helped maintain their satisfactory quality of life. The partnership problem solving intervention was shown to be a logical, stepwise approach for identifying problems and emotional reactions and encouraging specific communication with professionals. The second study[32] demonstrated that journal writing was acceptable to participants, effective and specific for reactive depression, and low in costs. The intervention stimulated writing and prompted mood-evaluating activities, resulting in a positive effect on patient and caregiver depression.

A specific questionnaire to evaluate the value of food intake on daily life is not available and therefore should be developed.

It is recommendable to develop, evaluate, and implement interventions which go into negative moods, anxiety, limitations in social activities and travelling, sexual problems, fatigue, and diarrhoea.

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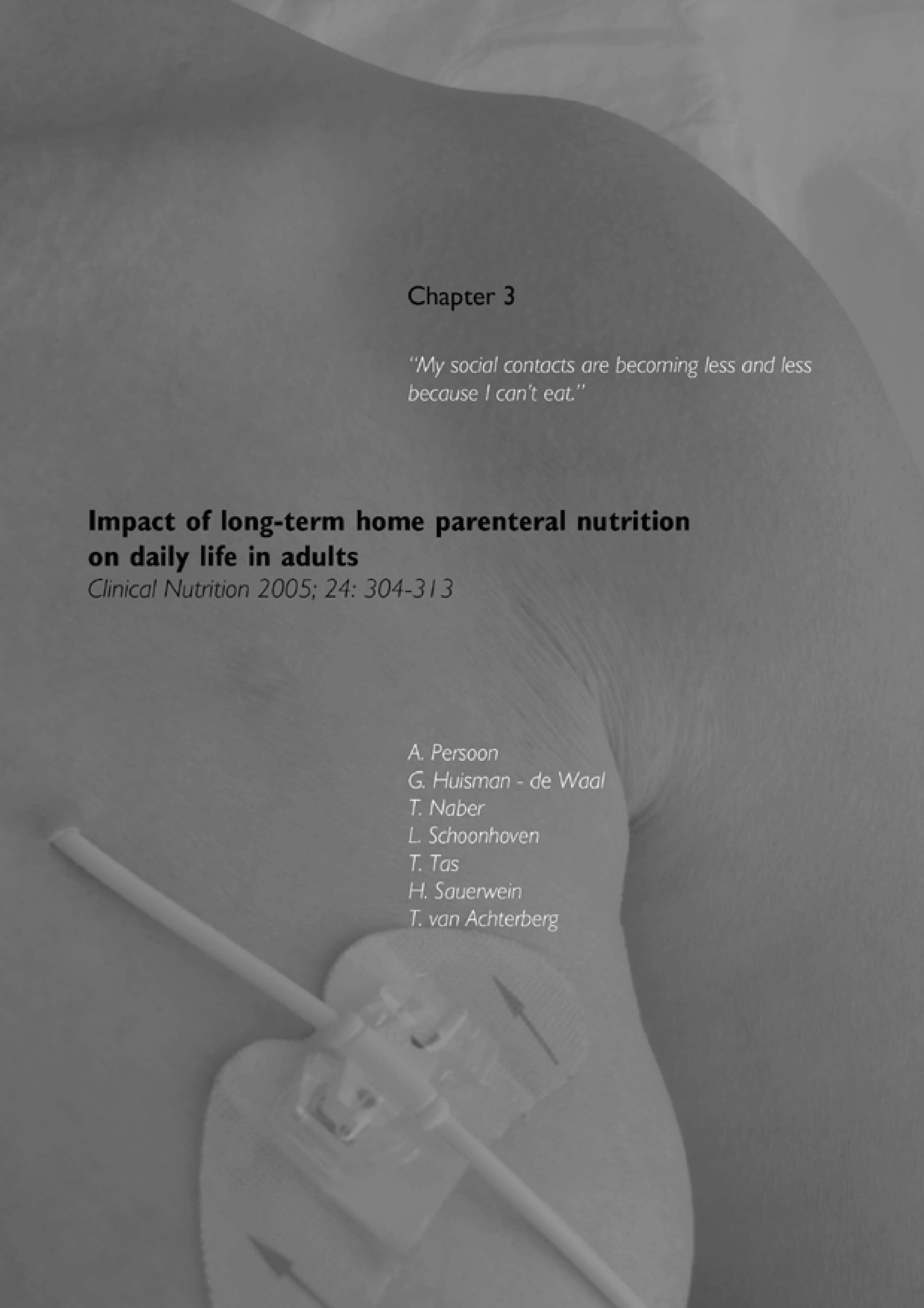

Chapter 3

"My social contacts are becoming less and less because I can't eat."

Impact of long-term home parenteral nutrition on daily life in adults

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Abstract

BACKGROUND AND AIMS: Home parenteral nutrition (HPN) is a therapy that changes life radically and often means lifelong dependence on parenteral feeding. The aim of this study was to gain insight into problems experienced by adult patients who were dependent on long-term HPN.

METHODS: A survey was performed on all patients at the ambulatory care clinics of two university centres. We used two techniques: written questionnaires and interviews. The questionnaires addressed fatigue (CIS), quality of sleep, anxiety, depression (BDI), social impairment (subscale SIP68), and sexual functioning. Data were analysed descriptively. Structured interviews inquired about the negative influence of HPN dependence on daily life. These data were quantified by content analysis.

RESULTS: The response rate was 76% (n = 48). Questionnaire results: all the respondents had multiple physical symptoms, which they attributed to the underlying disease. Furthermore, severe fatigue (63%), sleeping disorders, (severe) depression (65%), social impairment (55%), and sexual disorders (33%) were present.

Quality of life (QoL) correlated with fatigue, sleeping disorders, anxiety, depression, and social impairment ($P<0.02$). Interview results: psychosocial problems were the main complaints in daily life due to HPN dependence, e.g. negative changes in moods and feelings (including anxiety), lack of freedom, limitations in social life and being dependent.

CONCLUSIONS: Although many somatic symptoms were present, HPN-dependent patients reported primarily psychosocial problems in daily life. To improve quality of life, HPN teams should assess somatic as well as psychosocial aspects standard. Given the large proportion of patients with depressive disorders, therapies such as antidepressant medication, psychosocial support and cognitive training, should be offered.

Introduction

Home parenteral nutrition (HPN) is a life-saving therapy for patients with very serious intestinal problems. It is impossible for these patients to absorb sufficient amounts of food, even with extra enteral feeding. Inevitably, intravenous supplementation of nutrition becomes necessary. Indications for HPN are mainly the short bowel syndrome (SBS) and motility disorders. In 2003, 80–90 patients were dependent on long-term HPN in the Netherlands, which is a prevalence of 5 per 10^6. In Europe, the mean prevalence of HPN is 3 per 10^6.[1] HPN is a therapy that changes life radically. The technique consists of administering intravenous nutrient solution via a pump. In general, HPN is given intermittently, during a 10–14 hours overnight period. Depending on the underlying disease, patients may tolerate a normal quantity of oral food, or a restricted quantity in the case of motility disorders. Thus, the frequency of HPN can vary from 2 to 7 times a week. HPN treatment often means lifelong dependence on parenteral feeding.

Despite the heavy impact that HPN has on a patient's life, research has mainly focused on the physical consequences, i.e. health status and complications such as liver disease and line problems.[2,3] Some studies examined the impact of long-term HPN on daily life. These studies showed that quality of life in patients on long-term HPN is lower than that in the general population,[4–9] and lower than quality of life in closely related patient groups, e.g. non-HPN-dependent groups with severe malnutrition due to SBS,[7,10] small bowel transplant recipients,[10,11] and kidney transplant patients with end stage renal disease.[12] A few studies described problems related to HPN at home in more depth. These included problems of frequent depressive episodes, disturbed sleep, difficulty with travelling, exercise and leisure.[7,8,12–15]

Patients also reported complications that may be caused by metabolic problems, such as cramp in hands and feet, swelling of the ankles or feet, weakness and joint pain.[12,13] However, most of the studies are relatively old, they were often based on small populations, and nowadays nutritional regimes comprise all-in-one bags. We were interested to find out what problems were being experienced by long-term HPN-dependent patients. The aim of this study was to gain insight into the impact of HPN on daily life in adult HPN patients as input to improve treatment and increase quality of life. Therefore, the nutrition support team at our hospital initiated a study that addressed the following questions:

(1) To what extent do long-term HPN patients experience problems?
(2) Which HPN-treatment-related problems have a negative influence on daily life?

Materials and methods

DESIGN

A survey was carried out in the spring of 2003. We used written questionnaires to address research question (1) and structured open-ended interviews to address research question (2).

PARTICIPANTS

All adult patients monitored by the nutrition support teams at the University Centres in Amsterdam and Nijmegen were invited to participate in the study (n=63). We estimate that these patients represent 80% of all the patients receiving long-term HPN in the Netherlands. Patients gave informed consent.

NUTRITION SUPPORT TEAMS

In the Netherlands, HPN is mainly carried out at two university centres that both have a multidisciplinary nutrition support team. Main participants are a gastroenterologist, an internist, an HPN nurse and a dietician. A 24 h telephone service is included. Main objectives of the teams are to assist the patient to gain an optimal physical condition, to prevent and treat complications, and to educate patients to master the technology and become independent. All the patients were using all-in-one bags. Professional assistance is only given when patients report severe psychosocial problems.

QUESTIONNAIRES

We initiated a pilot study to draw up a set of questionnaires to address research question 1. We planned two group interviews: one with the patients on long-term HPN and one with the health care workers. The subject of discussion was: 'What type of problems do HPN-dependent patients encounter in somatic, psychological, social or other areas of daily life?'. The procedure for participation in the group interviews was planned meticulously. Patients as well as their care providers were selected explicitly on different characteristics, e.g. patients with SBS as well as with motility disorders. The eight most important subjects which emerged from the interviews were: bowel disturbances and metabolic complications, fatigue, sleeping disorders, anxiety, depressive disorders, social impairment, sexual functioning disorders, and care provider burden. We then looked for questionnaires to cover each of these subjects (with the exception of care provider burden) thus creating a set of questionnaires to measure the extent of HPN-treatment-related problems (Table 1). The feasibility of the questionnaire set was tested in two patients. These data were not included in the study. Based on the outcome, changes were made to the layout, introduction, and sequence of questions.

INTERVIEWS

To address research question 2, all the respondents were interviewed at home. They were invited to describe in their own words any problems they were encountering due to HPN dependence, with a maximum of three. A problem was defined as an 'unwanted negative influence on daily life'.

DATA COLLECTION

The written questionnaires were sent by mail to all the participants 10 days before the interview. Completion of the set took 45–75 min. The interviewer collected the responses during the interview at home. Data verification against the medical records was only conducted to check the medical diagnoses. Two research assistants carried out the interviews.

DATA ANALYSIS

Data from the questionnaires were analysed descriptively. Correlations were calculated between patient characteristics and the presence of problems. Pearson's correlation, Spearman, t-test or Mann–

Whitney were used where appropriate. Correlations were considered to be statistically significant at a cut-point of 0.05.

Content analysis, a procedure to quantify communication material, was used to analyse the interviews. The problems reported by the respondents were listed in categories and quantified.

Table 1 Set of questionnaires

Topic	Instrument + references	Information
Patient characteristics		
General characteristics		- 12 items
HPN-related characteristics		- 6 items
Quality of life	Cantril's Ladder: [16]	- 1-item questionnaire on a visual analogue scale
Health related functioning	Sickness Impact Profile (SIP68): [17-18]	- 48 dichotomous questions, 6 subscales - validated in various populations
Coping strategy	Utrecht's Coping List (UCL): [19-20]	- assesses the coping strategy when problems are met in daily life - 47 item questionnaire, 7 subscales - validated in various populations
Health Locus of control	Multidimensional health locus of control scale: [21-22]	- measures the extent to which individuals believe that their health is the result of their own actions (internally oriented), the medical doctor, or of chance or fate - 9 items
Extent of problems		
Bowel disturbances and metabolic complications		- 18 items
Fatigue	Fatigue Severity, subscale of the Checklist Individual Strength (CIS): [23-25]	- 8 items, score 8-56 - clinically severe fatigue present when score > 35 - validated in various populations
Quality of sleep	Subjective Sleep Quality Scale (SSQS): [26]	- 15 dichotomous items, score 0-15
Anxiety	State-Trait Anxiety Inventory (STAI): [27-28]	- consists of two subscales: - anxiety state refers to the state of anxiety at the time of the test - anxiety trait reflects the predisposition of a person towards anxiety as a more stable line of anxious feelings in general - both scales comprise 20 items; score 20-80 - the STAI was tested in various groups and reliability is high
Depression	Beck Depression Inventory-21 (BDI): [29]	- focuses on a negative attitude of a patient towards him or herself - only the 14 psychological items; score 0-42 - a total score of 0 to 3 represents no depression, 4 to 13 represents depression, 14 to 42 represents severe depression
Social Impairment	Social Behaviour, subscale of the sickness impact profile (SIP68): [17-18]	- 12 items, dichotomous
Sexual disorders		- 3 items

Results

The response rate was 76% (n=48). No differences in gender, age, duration of HPN therapy and the indication for HPN were found between the respondents and the patients who refused to participate.

QUESTIONNAIRE: PATIENT CHARACTERISTICS

General patient characteristics are presented in Table 2. Mean age was 52 years, about 2/3 of the patients were women, 19% were employed, 29% had a stoma, 27% could 'eat and drink just a little', and 46% had one or more comorbid diseases besides the indication for HPN treatment. The respondents' mean Quality of life was 6.2% and 35% of the group scored below 6.

Table 2 General patient characteristics (n=48)

Characteristics	
Mean age, years	52
- Range, years	29-82
Women, %	65
Married/cohabiting, %	83
Mean quality of life 1)	6.2
- below 6, %	35
Education, in %:	
- Primary education	31
- Secondary education	52
- Higher education	17
Employed, %	19
Underlying disease, %:	
- Mesenteric thrombosis	38
- Crohn's disease	25
- Adhesions	10
- Neuropathology	8
- Radiation enteritis	8
- Volvulus	4
- CIIP*	2
- Others	5
Disease history before HPN:	
% acute (versus % chronic)	48
Comorbidity, % 2)	46
Stoma, %	29
Able to eat and drink 'just a little', % 3)	27
Medication, in %:	
- Acid suppression	65
- Analgesics	38
- Diarrhoea inhibitors	33
- Sedative drugs	31
- Antidepressive drugs	8

1) Score 0-10, where 10 represents best possible quality of life.
2) Percentage of patients who have other types of disease besides the indication for HPN.
3) Patients were asked whether they were able to eat and drink normal quantities or just a little.
* CIIP = chronic ideopatic intestinal pseudo-obstruction

The mean number of years on HPN treatment was 4.6, with a mean frequency of 5 days a week and a mean of 12.4 hours a day (Table 3). On average, the respondents had been admitted to hospital due to catheter problems 1.6 times in the past year; 38% of the patients had not been admitted at all.

Table 3 HPN-related characteristics (n=48)

Characteristics		
Years on HPN*, mean (range)	4.6	(0.1-19.0)
Hours HPN*/day, mean (range)	12.4	(4-24)
Days on HPN*/week, mean (range)	5	(2-7)
Type of catheter:		
Port-a-cath(PAC), %	43	
Long line(LL), %	34	
Shunt (in combination with LL or PAC), %	23	
Indication HPN: SBS*(vs motility disorder), %	71	
Hospital admission due to catheter problems in the past year:		
Number of admissions, mean (range)	1.6	(0-7)
No admissions in the past year, %	38	
If admitted (n=30): number of days, mode (range)	16	(1-240)

* SBS= Short Bowel Syndrome

Table 4 shows the health status of the patients (SIP-68). Raised levels were found on the subscales Social Behaviour and Emotional Stability, which were comparable with cerebrovascular accident (CVA) patients.[18] Coping strategies are presented in Table 4: when faced with a problem in daily life, the HPN group was less active in solving problems than the healthy Dutch population. However, the HPN group was less absorbed by a problem, generated more optimistic thoughts when meeting a problem in daily life, and sought more comfort and understanding from other people.[19] The results on the health locus of control scale did not indicate any specific orientation towards own strength, medical doctor or chance or fate (Table 4).[21]

Table 4 Health-related functioning, coping strategy and locus of control (n=48)

		mean	sd
Health-related functioning (range) 1)			
Somatic autonomy	(0-17)	1.5	3.1
Mobility control	(0-12)	3.3	3.3
Psychological autonomy and communication	(0-11)	1.5	2.2
Social behaviour	(0-12)	5.5	3.2
Emotional stability	(0-6)	1.4	1.6
Mobility range	(0-10)	2.2	2.5
Sumscore	(0-68)	15.3	11.3
Coping strategy (range) 2)			
Active	(7-28)	17.5	4.7
Palliative	(18-32)	17.1	3.3
Avoiding	(18-32)	15.9	4.1
Social	(6-24)	12.4	4.2
Passive	(7-28)	11.7	3.6
Expressive	(3-12)	6.2	1.7
Encouraging	(5-20)	13.0	3.0
Health locus of control/HLC (range) 3)			
Internally-oriented	(1-5)	3.5	0.9
Medical-doctor-oriented	(1-5)	3.2	0.7
Fate-oriented	(1-5)	3.1	1.1

1) higher scores indicates more health-related problems.
2) Higher scores indicate more inclination to cope in this particular way.
3) More belief in one type of orientation corresponds with lower scores.

QUESTIONNAIRE: EXTENT OF PROBLEMS

Responses to the set of questionnaires showed a multitude of problems related to bowel disturbances and metabolic complications (Table 5).

Table 5 Bowel disturbances and metabolic complications (n=48)

	Presence (%)	Severity [1)]	Due to HPN [2)] (%)
Fatigue	90	2.5	21
Diarrhoea	90	2.9	0
Feeling cold	85	1.5	17
Dry mouth	75	0.8	27
Cramp in hands/feet	73	0.8	31
Nocturia	63	1.7	77
Sleeping disorders	60	1.7	31
Abdominal cramp	60	1,4	13
Feeling warm/hot	56	2.5	33
Nausea	54	1,4	35
Bad smell (faeces)	54	1,6	27
Vomiting	50	1,1	13
Flatulence	46	1.0	5
Palpitations	40	1.4	32
Bad taste	40	2.1	37
Bad smell (nutrition fluid)	38	0.8	95
Faecal incontinence	38	0.7	6
Headaches	33	1.0	19

1) Range 0-4, 0 indicates no problems and 4 indicates severe problems.

2) When a symptom was present, respondents could indicate whether this symptom was due to the Home Parenteral Nutrition (HPN), the underlying disease or both. Only scores due to HPN are given.

Several symptoms were present simultaneously, e.g. fatigue (90%), diarrhoea (90%), feeling cold (85%), having a dry mouth (75%), and cramp in hand and feet (73%). Diarrhoea and fatigue were reported to be the most disturbing symptoms in daily life. Patients mostly attributed the symptoms to the underlying disease; only about 15–35% of the symptoms were side effects of the HPN treatment. Severe tiredness was reported by 63% of the respondents (Table 6). The mean fatigue score of 39.6 (on a scale from 8 to 56; SD = 16:1) was higher than that in healthy subjects or patients with Functional Bowel Disorder or CVA and corresponded with tiredness in patients with Multiple Sclerosis.[22,23] On average, more sleeping disorders (Table 6) were present than in the general Dutch population.[24] Surprisingly, anxiety levels in the HPN group (Table 6) matched those in the general Dutch population.[26] No depressive disorders were present in 35% of the group; 65% had depressive disorders, 17% of which were severe (Table 6). Only 1/3 of the patients whose score indicated severe depression were using anti-depressant drugs. One-third of the group stated that their sexual activities had decreased due to HPN (Table 6). About half of the respondents experienced social impairment in various social activities (Table 6).

Table 6 Fatigue, sleep, depression, sleeping disorders, and sexual impairment (n=48)

Questionnaire			
Fatigue Severity/CIS*			**%**
No or mild fatigue			37
Severe fatigue			63
Sleeping disorders/SSQS*	**(range) 1)**	**mean**	**sd***
Quality of sleep	(1-15)	8.0	4.3
Anxiety/STAI*	**(range) 2)**	**mean**	**sd***
Anxiety at present (state)	(20-80)	40.4	12.0
Anxiety in general (trait)	(20-80)	39.3	10.8
Depressive disorders/BDI*			**%**
No depression			35
Depression			48
Severe depression			17
Social behaviour/SIP*			**%**
Impairment in social behaviour			55
Sexual disorders			**%**
Diminished sexual interest			31
Not possible to relax due to HPN*			13
Sexual functioning has decreased due to HPN*			31

1) Lower scores indicate more severe sleeping disorders.
2) Higher scores indicate greater anxiety.
* CIS = Checklist Individual Strength; sd = standard deviation; SSQS = Subjective Sleep Quality Scale; STAI = State-Trait Anxiety Inventory; BDI = Beck Depression Inventory; SIP = Sickness Impact Profile-68
HPN = Home Parenteral Nutrition

We also analysed the relationship between the problems encountered and patient characteristics. Low quality of life was strongly related (P<0.02) with greater fatigue (r=-0.52), more frequent sleeping disorders (r=-0.35), higher anxiety (anxiety state r=-0.43), anxiety trait r=-0.63), more severe depression (r=-0.58), and greater social impairment (r=-0.3). More tiredness was statistically significantly related with passive coping strategies (r=0.5) and believing that good health is determined by fate (r=-0.7). More frequent sleeping disorders were related with gender (the women slept less well than the men: mean 10.5 versus 6.7). Higher anxiety was also related to gender (the women were more anxious than the men) and to younger age (r=-0.3), higher education, believing that good health is determined by the medical doctor (r=-0.4) or by fate (r=-0.3), and passive coping strategies (r=-0.4). Coping in an active way was statistically significantly related to less anxiety (r=-0.5). More severe depressive feelings were statistically significantly correlated with younger age (r=-0.3), higher education, the opinion that good health is determined by fate (r=-0.3), coping in an active way (r=-0.5), and passive coping strategies (r=-0.4).

INTERVIEWS: PROBLEMS IN DAILY LIFE

In the interviews, we asked the respondents which (three) problems they experienced due to HPN treatment. A total of 125 problems were reported: 74 problems had a psychosocial character, 30 had a somatic character and 21 were of another type (Table 7). At least one psychosocial problem was reported by 92% of the respondents, while 50% reported at least one somatic problem. Negative moods or feelings were mentioned most often among the psychosocial problems (46% of all the respondents), in particular anxiety with regard to medical complications (31%). Other negative feelings (27%) were loneliness, anger, uselessness, incapability, lack of understanding from others, and feeling ill. Furthermore, lack of freedom was reported frequently (29%), especially being bound to the pump and housebound. Limitations in social life (21%), being dependent on others and the HPN (19%) were also reported.

The two most frequently reported somatic symptoms were fatigue (17%) and not being able to eat and drink like other people (13%). Strictly speaking, the latter symptom was not due to the HPN treatment, but due to the underlying disease.

Table 7 Problems due to HPN reported in the interviews (n=48)

	number of problems	% respondents [1)]	type of problem [2)]
Negative moods & feelings	22	46	One or more of these **psychosocial problems**: 92% of the respondents (n=44)
- e.g.: anxiety	15	31	
Lack of freedom	14	29	
Social limitations	10	21	
Being dependent	9	19	
Problems related to holidays	5	10	
Unable to work	4	8	
Medical ambience at home	4	8	
Subtotal	**74**		
Fatigue	8	17	One or more of these **somatic problems**: 50% of the respondents (n=24)
Unable to eat or drink[3)]	6	13	
Metabolic symptoms	4	8	
Problems with mobility	4	8	
Diarrhoea	3	6	
General malaise	3	6	
Sleeping disorders	2	4	
Subtotal	**30**		
Problems with care providers	8	17	One or more of those **other types of problem**: 33% of the respondents (n=16)
Connecting the HPN infusion bag	4	8	
Problems related to the pump	3	6	
Financial limitations	2	4	
Others	4	8	
Subtotal	**21**		
Total	**125**		

[1)] Respondents formulated a maximum of 3 problems in their own words.

[2)] Afterwards, the problems were classified into one of the three types of problem.

[3)] This type of problem was not due to HPN, but to the underlying disease.

Discussion

In the interviews, the respondents primarily reported psychosocial problems due to HPN dependence, such as negative changes in moods and feelings (including anxiety for serious medical complications), lack of freedom, limitations in social life and being dependent. The questionnaire set showed multiple physical symptoms, which the patients believed were mostly due to the underlying disease. The respondents were severely fatigued (63%), had sleeping disorders, were (severely) depressed (65%), were socially impaired (55%), and had sexual disorders (33%). Low quality of life was related with fatigue, sleeping disorders, anxiety, depression, and social impairment ($P<0.02$).

In our study, many more psychosocial problems were reported than in the literature. This was most probably due to our meticulous data collection method. Firstly, we conducted a pilot study in which we identified the important themes and secondly, we combined the techniques of questionnaires and interviews. This combination enabled us to form a more complete impression of the HPN group than previous studies. Particularly, the fact that this was the first study that used open interviews in this patient group may explain our results. Given the fairly high response rate and the non-selective non-response, we think that the results of our study can be generalised to all HPN-dependent patients in the Netherlands. When generalising the results from our study to the American and European situation, it should be kept in mind that in the Netherlands, HPN is not indicated for cachexia secondary to cancer or AIDS as it is in some other countries.[1]

In comparing our results to the results of Van Gossum et al.,[30] a difference is found in the percentage of patients that have a full-time or part-time job. The European survey shows an employment percentage of 68%, while we found a percentage of 19%. As the populations in the studies do not differ on factors that may influence employment, e.g. age, underlying disease and duration of HPN, this large difference can only be explained by two differences between the Netherlands and other European countries. Firstly, the percentage of women with a full-time or part-time job is low in the Netherlands, compared to other European countries. As 65% of our population is female, this will result in a relatively high percentage of unemployment, regardless of HPN dependence. Secondly, the social security system in the Netherlands is comprehensive. In the past, people who were ill and only capable of a partial appointment, were declared unfit for work and received a disability pension much more often than in other European countries.

Two limitations are apparent in our study. First, due to our cross-sectional design, we cannot draw any conclusions about the causality between quality of life and psychosocial problems. Secondly, we did not focus on positive factors to explain how problems were managed in the past. Prior to developing interventions, it may be relevant to interview patients on how to cope successfully with a far reaching treatment such as HPN.

Nutrition support teams face great challenges to address the above-described psychosocial problems in HPN-dependent patients. A specific psychosocial assessment tool is needed that can unravel the association between somatic and psychosocial aspects, because different types of intervention might be necessary. An example is the lack of freedom experienced by patients caused by shortcomings of the pump, embarrassment towards showing up with a pump, or incomprehension of acquaintances. It was noteworthy that no relation was found between psychosocial problems and the number of admissions to hospital. Therefore, we can conclude that patients who are not admitted regularly are suffering to the same extent, which implies that all patients should be assessed. It was also noteworthy that no relation was found between psychosocial problems and the duration of HPN treatment. Consequently, psychosocial assessment is necessary at regular intervals throughout the years.

To improve quality of life it is important to focus on fatigue, sleeping disorders, anxiety, depression, and social impairment. In our HPN group, the anxiety levels measured by the questionnaire matched those in the general Dutch population. Conversely, one-third of the group mentioned anxiety as the main problem in the interviews, especially anxiety about the risk of serious medical complications. Apparently, the State-Trait Anxiety Inventory was not sensitive enough to measure this type of anxiety. It can be concluded that reducing medical complications will help to prevent anxiety. An impressive proportion of two-third of our HPN group had depressive disorders according to the 14 psychological items of the Beck Depression Inventory (BDI), 17% of which were severe. However, overestimation is a serious validation problem when using the BDI in a patient group that may have depression associated with the medical illness. Kathol et al.[31] concluded that the BDI only screens patients at risk for major depression, but does not diagnose depression. In the interviews, depression was not reported as such, but statements were made by almost half of the HPN group that demonstrated the respondent's negative attitude towards him or herself (Table 7). Therefore, we believe that depression is a major risk in HPN patients and should be studied in more detail by individual assessment. Various therapies, such as anti-depressant medication, psychosocial support and cognitive training, could be offered and the results monitored over time. In the study of Smith et al.[14] it was interesting that interactive and videotaped educational interventions successfully reduced infection, rehospitalisation and reactive depression.

In conclusion, despite the fact that HPN-dependent patients experience many somatic symptoms, psychosocial problems were primarily reported as having the greatest impact on daily life. Therefore, to improve quality of life, HPN teams should assess somatic as well as psychosocial aspects standard. Moreover, given the large proportion of patients with depressive disorders, therapies such as anti-depressant medication, psychosocial support and cognitive training, should be offered.

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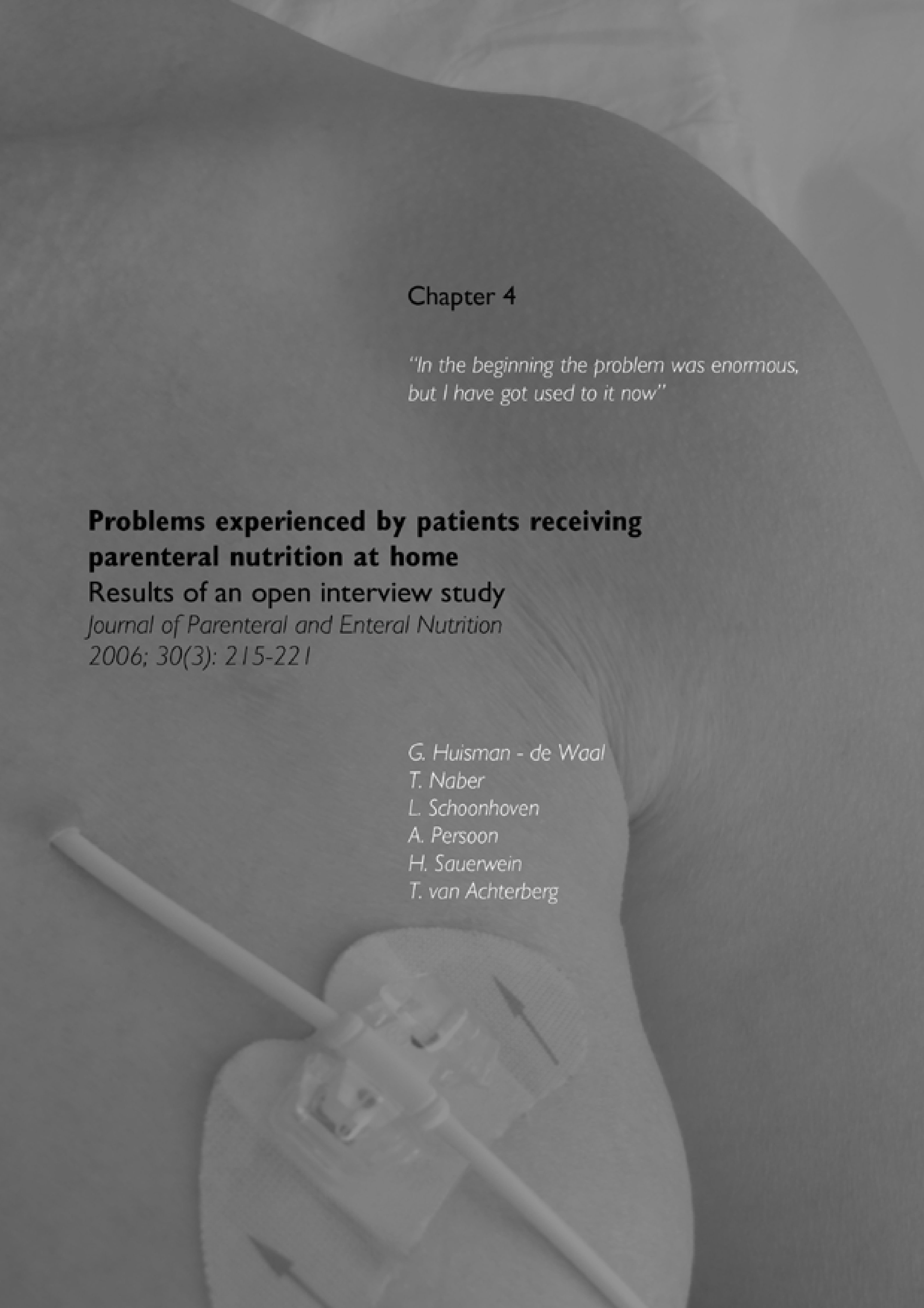

Chapter 4

"In the beginning the problem was enormous,
but I have got used to it now"

Problems experienced by patients receiving parenteral nutrition at home

Results of an open interview study

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Abstract

BACKGROUND: Home parenteral nutrition (HPN) is offered to patients who are unable to absorb sufficient nourishment from normal oral food intake or tube feeding. Major causes include severe motility disorders and limited resorption surface in the small intestine. HPN is a lifesaving therapy but has severe consequences on daily life. The aim of this study was to make an inventory of the problems experienced by patients receiving HPN.

METHODS: Open interviews were held with 48 patients from the 2 major centres for HPN in the Netherlands, centred around the question: Which 3 HPN problems have the most severe impact on your daily life? Data were analysed using content analysis.

RESULTS: The respondents mentioned 7 central problems: negative emotions, physical problems, social limitations, dependence on others, incapability, complications, and "patient-care provider problems. In addition, practical problems were mentioned: sleeping problems, financial problems, and the "hospital atmosphere" at home. The latter issues formed less of a problem for the patients.

CONCLUSION: The main underlying elements in the lives of many HPN patients appeared to be loss, longing, and grief. In contrast, a smaller proportion of the patients expressed that they had clearly adapted to life with HPN. By means of the HPN, they were still alive and enjoying all the things they could still do.

Introduction

Home parenteral nutrition (HPN) is a lifesaving therapy. Since 1968, it has developed from a rare and complicated clinical treatment into a routine therapy that can be applied at all hospitals and even at home. The patient group receiving HPN is small but growing steadily. In the Netherlands, this concerns about 100 patients in a country of 17 million inhabitants.

HPN is indicated in the case of gastrointestinal failure due to either loss of absorption area or motility disorders. Generally, HPN is administered at night over a period of about 12 hours. Patients feed themselves 2–7 times per week, depending on their nutrition needs. A proportion of patients can also cope with oral nutrition, but they are unable to derive sufficient quantities of nutrients from it.

HPN involves a heavy physical and mental burden on the patient, and it also may have considerable consequences on daily life.[1] In the literature on the influence of HPN on daily life, attention has mainly focused on the administration system and potential metabolic and septic complications. Until now, few qualitative studies about the consequences of HPN are carried out.

A small number of studies used a questionnaire to investigate the influence of HPN on daily life. The results showed that HPN patients had a lower quality of life than dialysis patients and patients with short bowel syndrome without indications for HPN. HPN patients had anxiety, depression, pain, stress, anger, negative self-image, low self-confidence, loss of control, mobility problems, low vitality, and sleeping problems.[1–4]

Van Reeuwijk-Werkhorst[5] discovered a bottleneck in the psychosocial care of HPN patients: too little attention is paid to the fact that a proportion of the patients cannot eat solid food. This has serious consequences on social activities like leisure, vacation, and hobbies. These problems are also recognised by Dutch care providers. In the Netherlands, 2 university medical centres have nutrition teams who provide support for HPN patients: Radboud University Nijmegen Medical Centre and the Academic Medical Centre Amsterdam. Major tasks for the nutrition teams include keeping the patient in optimal physical condition, prevention and treatment of complications, and instructing the patient. Despite the fact that attention is given to psychosocial problems, patients mention serious problems in this field.

It can be concluded, therefore, that the literature and daily practice show clear indications of problems in HPN patients. Until now, these problems have been insufficiently mapped, which means that no structural therapeutic measures can be taken.

The aim of this study was to gain insight into the problems experienced by HPN patients. Therefore, we conducted open structured interviews with the following central study question: What is the nature and context of the problems experienced by patients as a result of receiving HPN in the home situation?

Methods

Interviews were held to obtain data for this inventorial study. Our questions were open ended, but there was structure in the conversation line. The interviews were centred around the problems experienced by patients in their daily lives as a result of having to live with HPN.

STUDY POPULATION/INTERVIEWEES

The study population comprised adult patients who were receiving HPN at home in the period from February to July 2003. Patients under supervision of the Radboud University Nijmegen Medical Centre or the Academic Medical Centre Amsterdam were invited to participate. At the time of this study, 68 patients were under treatment at the 2 hospitals. This represented about 75% of all the adult patients receiving HPN in the Netherlands. We excluded 5 patients with insufficient knowledge of the Dutch language and patients younger than 18 years; children receiving HPN will experience different problems.

Therefore, we invited 63 patients to participate, and 48 of them agreed to be interviewed (76%). No differences in gender, age, duration of HPN, and underlying disease (acute or chronic) were found between the groups of responders and nonresponders.[6] Table 1 shows the patient characteristics.

The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre gave permission to conduct this study. Patients received a written invitation to participate, and the respondents signed an informed consent form.

Table 1 Patient characteristics

	Total (n=48)
Mean age in y (range)	52 (29–82)
Percentage of women	65
Married or living together, %	83
Patients with paid employment, %	19
Underlying disease, %	
Mesenteric thrombosis	38
Crohn's disease	25
Adhesions	10
Neuropathology	8
Radiation enteritis	8
Volvulus	4
Chronic intestinal idiopathic pseudo-obstruction (CIIP)	2
Other	5
Mean duration of HPN, years (range)	4.6 (0.1–19.0)
Mean number of days of HPN per week (range)	5 (2–7)
Mean hours receiving HPN/day (range)	12.4 (4–24)
No. of patients who could not eat and drink or could only manage a few swallows of fluid, %	27
Type of infusion line	
Port-a-Cath (PAC), %	43
Central venous catheter (CVC), %	34
Shunt, %	23
Percentage of patients hospitalised in past year due to line problems	62
Mean number of admissions in past year (range)	1.6 (0–7)

DATA COLLECTION

Data were collected during single interviews at the patients' homes. An open design was chosen for the interviews.

Two interviewers were involved in this study. Each patient was interviewed by 1 interviewer, and mean interview duration was 1 hour. In order to standardise the interviews, each patient was asked the same questions in the same order (Table 2). They were asked to state which 3 problems formed the heaviest burden in their daily life with HPN. Per problem, information was obtained about the meaning and content, severity, and cause according to all patients. Moreover, to develop a comparable and consistent interview style, at 6 out of the 48 interviews, the second interviewer was present and these interviews were evaluated.

Table 2 Interview questions

Questions
Which 3 problems form the heaviest burden in your daily life with HPN?
Can you tell me what the meaning and content of these problems are?
Can you tell me what the severity of these problems is?
Can you tell me what the cause of these problems is?

RELIABILITY AND VALIDITY

To increase the reliability of the data, questions were asked during the interviews. In addition, summaries or rephrasing of the patient's words were read back to the patient for confirmation at various intervals.[7] The notes taken by the interviewer were also read back to the patient to confirm their accuracy. Additionally, tape recordings were made of 2 interviews per interviewer (n=4). A third researcher evaluated these tape recordings, and good agreement was found between the notes taken by the 2 interviewers and the patients' words. To increase reliability in terms of checking back, we aimed to adhere as closely as possible to the patients' words in the reports, for example, by quoting their exact words in this article. To verify the quality of the interpretations, use was made of peer debriefing (i.e., interpretations were checked by colleague researchers).

Validity within a research project firstly concerns the soundness of the data that have been collected.[8] The positive reactions of the respondents contributed to the validity of the data obtained. During the interviews, the patients were able to talk about themselves, and they were listened to very closely. A number of respondents mentioned explicitly that they had found this very pleasant.

To help achieve internal validity, 2 measures were taken. First, methodological memos were made about methodological qualities, doubts, ideas, and interpretations to support memories and the analyses. Second, we used peer examination (i.e., the quality of the data analysis and preliminary results were evaluated critically by an independent researcher, and the same conclusions were drawn).

The participation rate in this study was high and covered about two-third of all the patients receiving HPN in the Netherlands.

ANALYSIS OF THE INTERVIEWS

Content analysis was performed on the data obtained during the interviews. This technique allows statements to be made about communicative messages according to objective and systematic analysis.[8] In this way, the answers to the open questions gained structure.[9] The notes made by the interviewers were typed out in full. The text was then divided into segments, and each segment was given a code. To assign a code, we adhered as closely as possible to the literal words of the respondent. Two researchers checked the codes of 15 interviews. Codes were then grouped to derive central notions.

These central notions were worked out further, and we explored whether there were underlying relationships between these notions. The computer programme Atlas.ti 4.2 (Technical University, Berlin, Germany) was used for data management and analysis of the textual data.

Furthermore, frequencies of the central notions were counted with the programme Microsoft Excel to give percentages of respondents who mentioned each particular central notion.

Results

The results of this study are presented in light of the main problems that emerged during content analysis of the interview data. The main problems are described in sequence of severity experienced by the patients. Each problem is accompanied by a table that lists all the relevant quotations. In addition, we describe underlying relationships between the problems.

NEGATIVE EMOTIONS

A negative emotion mentioned by one-third of the respondents was anxiety. In general, the respondents experienced this as a very severe problem (Table 3). In many cases, there was anxiety about the complications that can occur with the HPN. On one side, there was anxiety about complications related to the administration system, such as infections or obstruction of the catheter. Sometimes a new catheter had to be inserted, and this could also lead to complications. On the other side, there was anxiety about the complications related to the nutrition fluid itself, such as liver damage. Respondents were sometimes anxious about the need for venous puncture to administer the HPN.

Some respondents always stayed at home when they were receiving HPN because they were afraid of potential complications. This also affected holidays.

The future held uncertainty and anxiety. Some of the respondents mentioned that they were afraid of dying.

Other negative emotions that were experienced by almost half of the respondents varied widely. However, these were regarded as moderately severe problems. Some respondents remarked that they felt as if they were on their own, despite the help they were receiving. They had to deal with disappointments, lack of understanding from other people, and a shortage of friends. This often led to grief and anger.

Some of the respondents mentioned that they felt "like nothing", they had frustrations about their appearance, and one person said that his ego was suffering.

A number of respondents sometimes felt left out or that they no longer counted. They were confronted by people who did all sorts of things, and that was difficult.

A number of respondents had problems with the strongly compelling nature of their situation (e.g., "must" endure drip feeding because they would not survive without HPN). For many respondents, being compelled to "hook up" was unpleasant and a daily routine.

Respondents saw a connection between emotions and dependence. They expressed finding it terrible to be dependent, and they did not want to be a burden on others. Some of the respondents were anxious about becoming dependent. Respondents also saw a connection between emotions and social limitations. Some of them mentioned that they could no longer join socially; they felt locked up, and that caused them grief.

Table 3 Quotations

Main problems	
Negative emotions	
1	Every day I'm afraid that the IV line will become blocked or that I'll get an infection or thrombosis. I've had so many new lines.
2	HPN causes liver damage. But I also need HPN. I have to be careful not to see the HPN as my enemy. Without HPN I can't survive, but I won't survive either with liver damage.
3	I am frightened of the needle in my body.
4	I am afraid of complications with the catheter. I am afraid that I will be left on my own. Afraid that one day it will be the end; I am afraid of dying.
5	It is an awful letdown when I look in the mirror. My battered body means that I am frustrated about how I look. There are so many clothes I can't wear: I can't wear a skirt any more, and I have to wear something with a high collar.
6	I have less confidence in myself, forget lots more things. I tend to cry more easily and become angry at people around me. I find that terrible for others.
Physical problems	
7	You get up and straight away feel that you want to lie down again. The tiredness ruins your whole life. I don't have any puff for anything; I am living like a potted plant. I am willing, but unable. Even the slightest things tire me out.
8	I feel like I have the flu. For years and years, day and night. Flu and tiredness is about the size of it. I just feel more and more tired. In the summer and on holiday, you feel it the most. On days like that I'm quieter.
9	I have to feed for 18 hours at a time, and the nutrition bag is very heavy. This stops me moving around. I could hang the nutrition bag on the infusion pole, but it's really so big I can't walk around in the sitting room properly. I feel trapped in my own house.
Social limitations	
10	I don't go anywhere anymore; I don't go out shopping or visit people. That's because I'm tired and too ill. On good days I sometimes go outside for a while. It's a piece of life lost.
11	Going out can only be for a few hours a day and at certain times of the day. I stay out for a maximum of 3 to 4 hours. I plan everything and I can't do a lot; there is no spontaneity and that is awful.
12	In the beginning the problem was enormous, but I have got used to it now. Besides, I only have HPN 5 times a week at present instead of 7, which means I have some evenings off.
Dependence	
13	Life revolves around the HPN, around me. You can't go one day without HPN; that is a scary feeling. Without the HPN, I am no one.
14	Being dependent, you can't do anything any more. I always have to be home by four o'clock in the afternoon. It is no longer possible to make plans.
15	"Must" is the problem. Must hook up to the HPN; must get up in the morning to unhook even though you're tired. I want to be the one who decides when I get out of bed, not the nutrition bag.
16	I would like to be able to do everything myself, but I can't manage. That makes me so sad. I find it awful to be a burden on others, but I also feel bad that I can't do it myself any longer. I can't accept it.
Incapability	
17	I feel so useless. I would like to go out to work, to do something I'm good at, receive appreciation. I would also like to have more to offer my partner.
18	No longer being able to eat really gets me down. I miss the taste, the smell, and the enjoyment; it feels like an empty space. My social contacts are becoming less and less because I can't eat.
Complications	
19	It's always serious and unexpected. They admit me to hospital and sometimes I get a new IV line. Then I have to regain confidence in the new line.
Problems with care providers	
20	It's always a different surgeon who places the intravenous line; they underestimate it. I think that's why I have so many infections. They make me wait ages for a new line, which means that I lose a lot of weight and then that makes me ill.
Other problems	
21	I often have problems with the feeding pump. Time and time again the battery is flat, although it's been charged, and the ordinary batteries are often flat too. It makes me mad. The new pump is difficult to operate. On holiday, the pump broke down; that was a serious problem.

PHYSICAL PROBLEMS

Almost half of the respondents remarked that physical complaints and limitations formed a problem (Table 4). In the majority of cases, these problems were experienced as large and serious (Table 3).

The physical problems varied widely and were related to HPN or the underlying disease. In their heads, the respondents were capable of a great deal, but not physically.

Table 4 Physical complaints and limitation of the HPN patients

Physical Complaints	Physical Limitations
Diarrhoea	Mobility limitations caused by being hooked up to the nutrition bag, the heavy bag pack, the infusion pole, or difficulty with walking
Fatigue	
Vomiting	Limited strength
Nausea	Physical limitations caused by fatigue and feeling ill
Tiredness	
Urine incontinence	
Cramp, particularly in the hands	
General malaise	

Respondents saw a connection between the physical problems and "being incapable" (e.g., no longer being able to cope with housekeeping due to mobility problems or fatigue) and also with complications that can occur during HPN ("feeling ill when the HPN is running in").

SOCIAL LIMITATIONS

Almost half of the respondents mentioned social limitations as one of their problems. A proportion of them experienced this as a very severe problem (Table 3).

Respondents felt that they were tied to the house when they were receiving HPN. They had to be home on time to hook up to the HPN, and afterwards they did not go out again. HPN took a long time, sometimes > 14 hours per day, and many of the respondents had to hook up 5 times a week or more. Consequently, they missed all sorts of social activities. They had not joined a club because they could not always keep appointments, and some of them paid fewer visits to their family or friends. Social contacts gradually diminished; respondents had fewer visits from family and friends.

As mentioned above, respondents saw a connection between physical problems and social limitations. There was also a connection with dependence. In some patients, the administration time of the HPN was long, or they were dependent on others to assist with the HPN, which limited the patients' social activities. Furthermore, respondents saw a connection between social limitations and no longer being capable of doing things; for example, not being able to eat, especially in patients with motility disorders of the gut, meant limitations socially: they could not go out for a meal and were reluctant to invite other people. Respondents did not join clubs, because of their physical limitations.

DEPENDENCE

Over one-fifth of the respondents remarked that they experienced their dependence as a problem (Table 3).

The respondents felt dependent in a number of respects. First, they felt dependent on the HPN: without it they would not survive. Second, the respondents felt dependent on others. In many cases, this was the partner who had to help with the housekeeping or sometimes assist with the HPN. A proportion of the respondents also required aid from third parties, such as (specialised) home help, nursing, or household help. Third, some of the respondents felt dependent in a practical respect. For example, they felt dependent on the pharmacy (respondents were "stuck at home all day when a delivery was due").

The dependence of the respondents was experienced as a severe problem by the majority of them. It was difficult to accept dependency. People wanted to "have their own hands on the reins".

Respondents saw a connection between dependence, social limitations, and emotions. This connection is described in the corresponding notions.

INCAPABILITY

Incapability can be described as "not being able to do anything". One-third of the respondents mentioned that they were experiencing this incapability, in their own words, "no longer being capable", as a problem (Table 3). The severity of this problem varied between respondents. Several of them said that the fact that they could no longer do a number of things (such as eat or go to work) was really terrible.

In their heads, the respondents could still do many things, but in reality, they were incapable due to physical problems. These issues comprised working, social activities, housekeeping, and managing the HPN procedure.

Going on holiday was also a problem sometimes. Respondents could not always spend their holidays in the way they wanted. Some of them never went away, because of the risk of complications and because many care providers are not trained in HPN. When the respondents did go on holiday, this always required enormous organisation.

A small proportion of the patients we interviewed were not able to eat and drink, and this was a serious problem. No longer being able to eat led to frustration. It was a difficult fact to live with. In addition to being a basic need, eating and drinking also are a social activity.

A proportion of the respondents mentioned that after some time, they had been able to accept the fact that there were some things that they could no longer do. They were enjoying the things they were still able to do; they were adjusting their boundaries and indicated that they were pleased with the HPN because, without it, they would die.

As mentioned above, respondents saw a connection between incapability and physical problems. There was also a connection between incapability and social limitations, as described previously.

COMPLICATIONS

One-fifth of the respondents said that the complications associated with HPN were a problem. In the majority of patients, this was a moderate to severe problem (Table 3).

These problems included complications with HPN administration. Infections were relatively frequent,[10] and one patient told us that he had received 3 new infusion lines within 5 months. Other complications mentioned by the respondents were liver disturbances, feeling unwell while the HPN was running in, and cramping in the hands.

Complications were strongly related with the physical problems that the respondents had. In addition, complications were related with anxiety; respondents were afraid of having complications, sometimes due to their own knowledge and experience.

PROBLEMS WITH CARE PROVIDERS

A small proportion of the respondents mentioned problems with the care providers. These problems were regarded as being moderate to severe. This applied to a range of care providers (Table 3).

For example, the site of entry sometimes went wrong (e.g., on the chest just beneath the nipple), and the respondents indicated that the experience of the surgeon might play a role.

Sometimes respondents had to wait a long time for a new central venous line. Also, they were not always satisfied with the communication between doctors or hospitals. In some cases, the general practitioner lacked knowledge about HPN and showed little interest in it.

OTHER PROBLEMS

Other problems mentioned during the interviews included the medical atmosphere at home, financial problems, and sleeping problems, but these were not considered to be serious (Table 3).

Conclusions

Patients who were receiving HPN at home experienced many problems. These problems mainly had a psychosocial nature.

Seven problems played a central role in the daily lives of HPN patients: negative emotions, physical problems, social limitations, dependence, incapability, complications and problems with care providers. Problems like anxiety, fatigue, physical and social limitations are also seen in haemodialysis patients.[11]

Patients had an ambivalent attitude toward the HPN treatment. On the one hand, life without HPN was impossible. They were pleased that HPN exists and that it was keeping them alive. On the other hand, living with HPN was difficult. It put a considerable burden on everyday life. Life with HPN meant limitations in physical, psychological, and social areas. Prospects for improvement or progress were usually absent.

A small proportion of the respondents said clearly that they had adapted to a life with HPN. They were particularly pleased that it was keeping them alive. Also, they were well aware of the limitations it was causing, but they had learned to enjoy the things they could still do.

The results of this study partly confirm our study using a questionnaire in the same population.[6] The results of the written questionnaire showed clearly that patients receiving HPN have problems in physical, social, and emotional areas. Our verbal interviews with open questions provided insight into which problems were experienced as the heaviest burden. For example, in the written questionnaire study, many of the patients complained of fatigue. The interviews demonstrated that the majority of patients did not experience fatigue as one of the largest problems in daily life. Also, the written questionnaire study found that the level of anxiety in HPN patients was no higher than that in healthy Dutch people,[12] whereas one-third of the HPN patients told us during the interviews that anxiety was a severe problem. Apparently, the State-Trait Anxiety Inventory (STAI) was not sensitive enough to measure this type of anxiety in the questionnaire.[6] Last, it was clear from the written questionnaire study that many HPN patients had needed to give up work. In the interviews, only a small group of patients mentioned this as a problem. A possible explanation for this difference could be the fact that patients had to give up work because of the underlying disease and not just because of HPN.

The combination of questionnaires and interviews in this patient group gave a more complete picture than that obtained in previous studies and therefore seems to be a more valuable approach.

Our results also support those of Jeppesen et al.,[1] who reported that HPN patients were experiencing many physical and psychological problems. Compared with patients with the short bowel syndrome without HPN and compared with kidney dialysis patients, HPN patients experience even more problems.

Problems that have been documented in other questionnaire surveys in HPN patients were anxiety, depression, pain, stress, urinary problems, loss of control, decreased mobility, decreased energy, sleeping problems, financial problems, not being able to work, and problems with self-image and self-confidence.[4,13] These problems were also mentioned by the respondents in our study.

In view of the high response rate, we assume that the results of this study can be generalised to the total group of HPN patients in the Netherlands.

By our method, we obtained a clear broad overview of the problems experienced by patients receiving HPN. The underlying notions that came forward in the interviews were, in our opinion, loss, longing, and grief. These notions formed the main threads in the problems of the respondents. However, as we did not conduct deep-level interviews, we cannot be sure about the latter. More research is necessary to confirm these underlying notions.

Once care providers have gained greater insight into the problems experienced by HPN patients, they can improve their psychosocial care. Our interviews showed clearly that patients were experiencing many problems in their lives with HPN. The chronic nature of the underlying disease and the negative influence of the treatment with HPN on daily life mean that professionals need to pay structural attention to the problems. Support to cope with these problems might lead to improvements in the situation. This support could comprise extensive periodical anamnesis by the HPN nurse, more coaching and guidance from an HPN nurse in cooperation with a psychologist or psychiatrist if this is indicated. Insight into the world of the individual patient can contribute to meeting their existing needs.

Several studies describe interventions in chronically ill patients.[14–18] An example of an intervention for HPN patients is interactive schooling, as described by Smith et al.[14] They showed that by means of interactive schooling, depressive reactions can be prevented and the patient's own capacity to solve problems is promoted. This intervention can also lead to fewer admissions to the hospital and a higher quality of life.[14] The positive effect of psychosocial interventions on quality of life is described in other studies, and these are most effective when incorporated into medical care.[15–17] Most powerful and lasting psychosocial interventions are combinations of education, coping skills like behavioural training and stress management, and emotional support required from trained health professionals, as well as family and friends.[18]

Research is necessary to develop psychosocial interventions for HPN patients and evaluate their effects.

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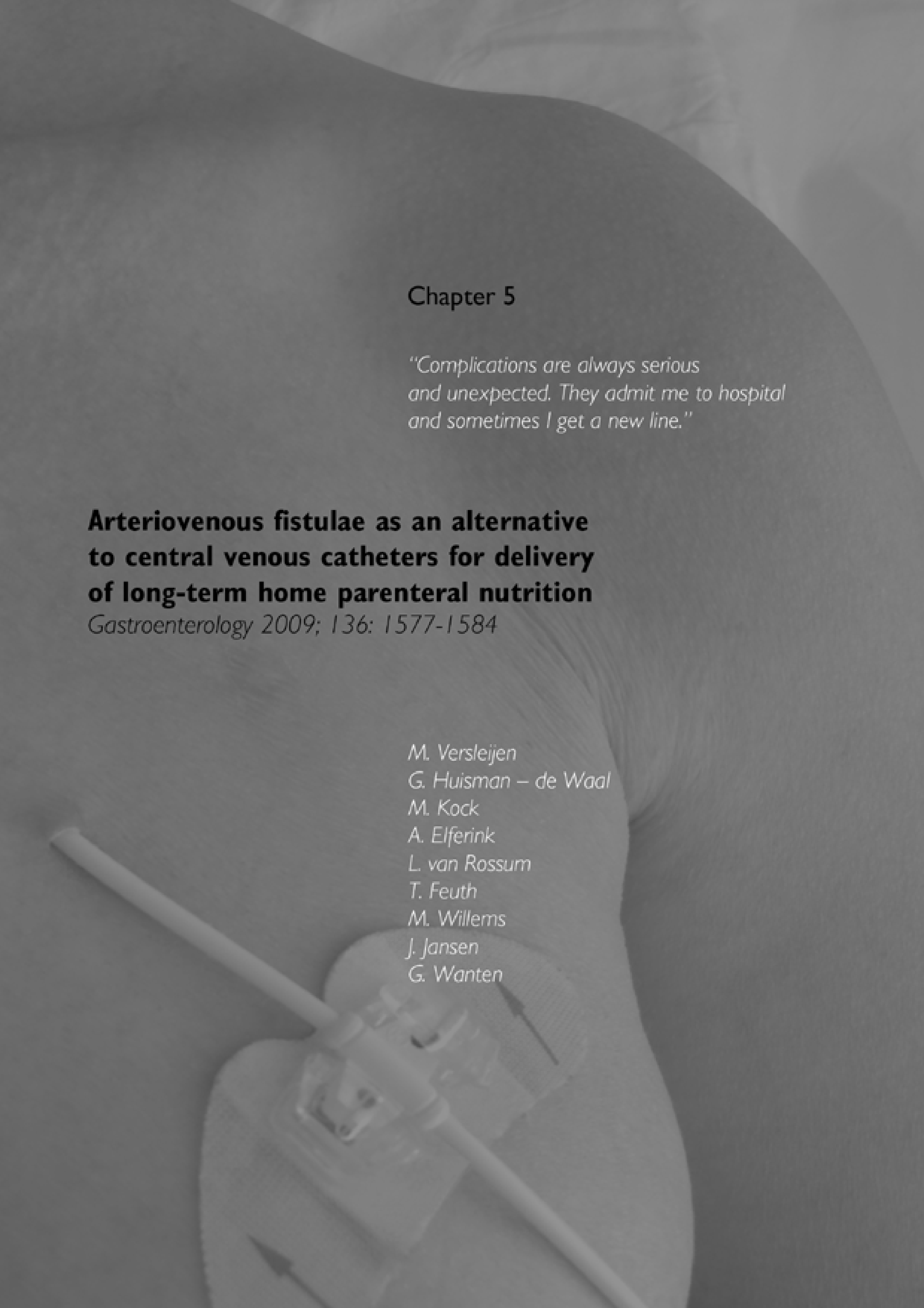

Chapter 5

"Complications are always serious
and unexpected. They admit me to hospital
and sometimes I get a new line."

Arteriovenous fistulae as an alternative to central venous catheters for delivery of long-term home parenteral nutrition

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Abstract

BACKGROUND & AIMS: The success of home parenteral nutrition (HPN) programs is compromised by complications of central venous catheters (CVCs), such as occlusions and bloodstream infections. We performed a retrospective analysis of complication rates of arteriovenous fistulae versus CVCs in patients on long-term HPN.

METHODS: Data were collected from 127 consecutive patients who received HPN between January 2000 and October 2006, comprising 344 access years of CVCs and 194 access years of arteriovenous fistulae. We evaluated access-related bloodstream infection and occlusion incidence rates (number of complications per access year) using Poisson-normal regression analysis. Complication incidence rate ratios were calculated by dividing complication incidence rates of CVCs by those of arteriovenous fistulae, adjusting for HPN frequency, medication use, infusion fluid composition, and underlying diseases.

RESULTS: Bloodstream infection incidence rates were 0.03/year for arteriovenous fistulae, 1.37/year for long-term CVCs (Port-a-Caths and tunnelled catheters), and 3.12/year for short-term CVCs (nontunnelled catheters). Occlusion incidence rates were 0.60/year for arteriovenous fistulae, 0.35/year for long-term CVCs, and 0.93/year for shortterm CVCs. Adjusted incidence rate ratios of long-term CVCs over arteriovenous fistulae were 47 (95% confidence interval, 19–117) for bloodstream infections and 0.53 (95% confidence interval, 0.31–0.89) for occlusions.

CONCLUSIONS: The occlusion incidence rate was higher for arteriovenous fistulae than for certain types of CVCs. The incidence rate of the most serious access-related complication (bloodstream infections) was much lower for arteriovenous fistulae than for all types of CVCs. Thus, arteriovenous fistulae are safe and valuable alternatives to CVCs for patients requiring long-term HPN.

Introduction

In patients on long-term home parenteral nutrition (HPN), frequently occurring vascular access–related complications continue to result in multiple hospital admissions and, in the end, these problems pose the foremost threat to continuation of therapy. Surgically created arteriovenous fistulae were the first intravenous access to be used for the administration of parenteral nutrition. However, with the development of intravenous catheters in the 1970s, the use of arteriovenous fistulae for HPN administration became rare. Ever since, it has remained common practice worldwide to administer HPN by means of central venous catheter (CVC) devices such as implantable subcutaneous ports (Port-a-Cath II [PAC], Smiths Medical MD, St Paul, MN) or externally (subcutaneously) tunnelled catheters. In addition, nontunnelled catheters are used for short-term total parenteral nutrition (TPN) administration, mostly during a hospital stay. The most frequent CVC-related complications are (potentially) life-threatening bloodstream infections and occlusions, both of the catheter and of the vessels wherein the catheter is located. Of note, the use of CVCs for total parenteral nutrition purposes has been recognised as an additional independent risk factor for the occurrence of catheter-related bloodstream infections.[1–4] Therefore, when long-term HPN is required, a reliable vascular access with a low complication profile is mandatory.

From the start of our HPN programme in the early 1970s, in addition to CVCs, we have used surgically created arteriovenous fistulae for vascular access in HPN care on a regular basis. Similar to the situation in patients on haemodialysis, this has mostly concerned arteriovenous fistulae constructed in the forearm or, less ideally, in the lower extremity. After a maturation period of 6 weeks, these fistulae are usually available for self-puncture by the patient or his or her partner. Apart from a straightforward arteriovenous anastomosis, the fistulae may be created by the interposition of autologous venous, xenologous venous, or prosthetic material (arteriovenous graft). In 1983, our group reported on a series of 7 patients using an arteriovenous fistula and concluded that these fistulae might be valuable alternatives for CVCs.[5] However, the information in the literature on the use of arteriovenous fistulae for this indication has remained anecdotal in the latest decades and solely concerns case reports or case series, with the largest series comprising only 17 patients.[6–11] Recently, we have described our oldest patient who has been using HPN over an arteriovenous fistula for 32 years without major complications in the last decades.[12] Our impression that patients using arteriovenous fistulae for HPN administration do very well, in combination with the paucity of information from other sources, inspired us to re-evaluate the feasibility of arteriovenous fistulae for long-term HPN administration and to perform a comprehensive retrospective analysis of all our data on access-related bloodstream infection and occlusion incidence rates in our own long-term HPN population.

Patients and Methods

PATIENTS

In the present investigation, we included all consecutive patients who were on long-term HPN between January 1st, 2000, and October 1st, 2006 (n=127), which comprises about 50% of all patients treated with HPN since the start of our programme in the 1970s until October 2006. Our HPN team was reorganised in 2000, and from that time a focused team of HPN nurses started to document our

HPN population in detail. Electronic patient files were also then introduced, enabling us to create a comprehensive database of our HPN population. We did not include patients after October 2006, because then we started a successful trial evaluating antibiotic catheter lock therapy with taurolidine as an alternative to heparin.[13] Including patients after 2006 would therefore induce bias because this new lock therapy was designed to counter complications.

Of the 127 included patients, 36 (28%) were already on HPN before January 2000. Excluding these 36 patients or the accesses they used before the year 2000 would have introduced a considerable source of selection bias. Therefore, and because all the necessary data for this study before January 2000 were available, we included these patients and all their accesses in our investigation.

Two independent reviewers reviewed the medical records of all patients. In each patient, all vascular accesses placed for HPN purposes between the start of HPN and October 1st, 2006, were analysed for complications. All data were entered in a database (Microsoft Access 2000; Microsoft Corp, Redmond, WA). In accordance with the European Society for Clinical Nutrition and Metabolism guidelines for parenteral nutrition, long-term HPN was defined as a requirement for TPN and/or intravenous fluid support for more than 3 months used in the home setting.

ACCESS CLEANING PROTOCOLS

In general, we pay much attention to aseptic procedures during our 1- to 2-week inpatient training period. Our access cleaning protocols are described in the following text in more detail.

For tunnelled and nontunnelled catheters, the catheter exit site is covered with a Tegaderm pad (3M Health Care, Neuss, Germany), which is replaced every 96 hours. The exit site is disinfected by circular movements from the exit site to the outer circumference. Every circle is disinfected with a new sterile swab. The first 10 cm of the catheter is disinfected with a sterile swab and chlorhexidine in ethanol. After drying, the exit site is covered with a new Tegaderm pad. After 3 weeks, the catheter cuff of tunnelled catheters has grown in the surrounding tissues and sutures for line fixation are removed. From then on, the exit site of tunnelled catheters is no longer covered with a Tegaderm pad and is cleaned by daily washing with water and soap and drying with a clean towel. The nontunnelled catheters remain fixed with a suture and covered with a Tegaderm pad, which is replaced every 96 hours, during the complete period of their use. Before TPN administration, the opening of the infusion bag as well as the (non)tunnelled catheter hub is disinfected with chlorhexidine in ethanol. After drying, the infusion system is connected to the catheter hub.

For PACs and arteriovenous fistulae, after placement, the wound is covered with sterile compresses if necessary. Before HPN administration, the skin overlying the subcutaneous port is cleaned with chlorhexidine by the described circular movement method. After HPN administration, the puncture site is covered with a sterile compress for a few minutes until (minor) bleeding ends.

Independent of the access type, the patient's/caregiver's hands are washed and subsequently disinfected with chlorhexidine in ethanol before TPN administration or cleaning of the exit site or skin.

ASSESSMENT OF VASCULAR ACCESS–RELATED BLOODSTREAM INFECTIONS AND OCCLUSIONS

Vascular access–related bloodstream infections were defined by the presence of symptoms (fever, chills) associated with positive blood cultures in the absence of other evident infectious foci that likely could explain the bloodstream infection. Episodes with fever and/or chills without positive blood cultures were considered a bloodstream infection in case blood samples were drawn under antibiotic treatment or in case patients were showing signs of sepsis (fever with cold chills, low blood pressure requiring intravenous fluid support, or oliguria) and other infectious foci that could explain the symptoms were excluded. If information could only be extracted from medical letters from referring hospitals, the vascular access was defined as being infected according to the criteria of the referring hospital.

Concerning the occlusions, the time span of development (i.e., slowly [mainly due to precipitation of infused substrates] versus acute [mainly due to thrombus formation]) was frequently undocumented and ultrasonography or contrast venography was not always performed. In this retrospective study design, it was therefore impossible to distinguish thrombotic from nonthrombotic occlusions. For this reason, and in accordance with a large investigation on CVC-related complications performed by Bozetti et al.,[14] we report overall occlusion rates.

Bloodstream infection and occlusion incidence rates (number of complications per access year) were calculated. Vascular accesses that were in situ but not used and therefore not likely at risk for complications, CVCs of which the exact type ([non]tunnelled or PAC) was not reported (defined as "unspecified CVCs"), and accesses with missing data concerning the precise utilisation period or the exact number of complications during use were excluded from the analysis.

STATISTICAL ANALYSIS

We analysed the bloodstream infection and occlusion incidence rates using random effects models with Poisson distributions for counts. The random effects for patients were incorporated in the modelling process to account for repeated vascular access periods in patients. Based on biological and clinical rationales, possible confounders in the relation between access type and complication rate were identified and reported for each access (Table 1). Complication incidence rate ratios for CVCs over arteriovenous fistulae (i.e., the complication incidence rate that occurred with CVCs divided by those with arteriovenous fistulae) were calculated and adjusted for all these confounders using Poisson-normal regression analysis. The NLMIXED procedure of SAS System for Windows version 8.2 was used (SAS Institute Inc, Cary, NC). Statistical significance was accepted if the probability of a type I error did not exceed 5%. To provide information about statistical significance, we reported 95% confidence intervals (CIs) where appropriate. We performed available case analysis because the number of missing data was limited and the missing process could be considered to be at random.

Results

DESCRIPTION OF THE STUDY POPULATION

The studied HPN population comprised 127 consecutive patients (123 adults; 46 men). The mean (± SD) age at the start of HPN was 46 (±15) years (range, 0.05–80 years). Sixty-three patients terminated HPN between 2000 and 2006 because of resumption of enteral feeding (n=35), small bowel transplantation (n=2), progressive liver failure (n=1), death (n=24; one following catheter sepsis and 23 due to progression of the underlying diseases or other non–HPN-related causes), or unknown reasons (n=1). The median duration of HPN use, counted from the start of HPN to termination or October 1st, 2006 (the end of the study period), was 2.1 years (range, 0.25–30.2 years).

Table 1 Overview of Confounders, Specified per Access Type

	Tunnelled catheters (n=374)	PACs (n=166)	Arteriovenous fistulae (n=62)	Nontunnelled catheters (n= 83)
Immune suppressive use				
Yes	58 (16)	27 (16)	8 (13)	14 (17)
No	316 (84)	139 (84)	54 (87)	69 (83)
Anticoagulant use				
Yes	204 (55)	98 (59)	58 (94)	59 (71)
No	169 (45)	68 (41)	4 (6)	23 (28)
Partly	1 (0.3)	—	—	—
Unknown	—	—	—	1 (1)
Underlying diseases				
Possible coagulative state	47 (13)	56 (34)	17 (27)	29 (35)
Inflammatory	92 (24)	38 (23)	11 (18)	8 (10)
Other	235 (63)	72 (43)	34 (55)	46 (55)
Composition of infusional fluid				
Nutrition with fat	328 (88)	139 (84)	55 (89)	68 (82)
Fat-free nutrition	26 (7)	8 (5)	1 (2)	7 (8)
Nutrition with/without fat (both partly)	7 (2)	4 (2)	—	1 (1)
Only fluids and electrolytes	13 (3)	15 (9)	6 (10)	6 (7)
Unknown	—	—	—	1 (1)
HPN frequency (times/week)				
1	3 (1)	4 (2)	—	3 (4)
2	4 (1)	2 (1)	2 (3)	—
3	18 (5)	22 (13)	16 (26)	2 (2)
4	31 (8)	19 (11)	6 (10)	3 (4)
5	32 (9)	21 (13)	11 (18)	3 (4)
6	32 (9)	19 (11)	5 (8)	5 (6)
7	251 (67)	76 (46)	22 (35)	64 (77)
Unknown	3 (1)	3 (2)	—	3 (4)

NOTE. Distribution of relevant confounders adjusted for in the analysis, presented as absolute number (%) of accesses with a certain confounder status. Relevant confounders included medication use (immune suppressives or systemic anticoagulants), underlying disease and relevant comorbidities, the administration of nutrition (with or without lipids) versus solely fluids/electrolytes, and the frequency of HPN administration (i.e., the frequency of access puncture or use per week). Underlying diseases and comorbidities were divided into 3 categories: inflammatory diseases (mostly Crohn's disease and ulcerative colitis), diseases related to a possible procoagulative state (mesenteric thrombosis and patients with >2 pulmonary emboli and/or deep venous thromboses not directly related to CVC use), and "other" diseases (mostly patients with motility disorders, pancreatitis, enterocutaneous fistulae, and so on). PACs, Port-a-Cath II.

Indications for HPN in our population mainly were motility disorders (31%) and short-bowel syndrome (46%), the latter mostly related to inflammatory bowel disease or mesenteric thrombosis (Table 2).

Table 2 Indications for long-term HPN

Indication	N=127
Motility disorder	**39**
Chronic Idiopathic Intestinal Pseudo-obstruction	9
Multiple adhesions	3
Sclerosing peritonitis	2
Sclerodermia	3
Slow transit obstipation	4
Neurogenic	3
Cause unknown	5
Other	10
High output stoma	**11**
Crohn’s disease	6
Ulcerative colitis	2
Resection; multiple adhesions	1
Resection; intestinal wall perforation	1
Mesenterial thrombosis	1
Short bowel	**60**
Mesenterial thrombosis	25
Crohn's disease	12
Other vascular/ischemia	9
Malignancy	3
Volvulus	4
Other	7
Inadequately absorbing intestinal surface	**4**
B-cell non-Hodgkin lymphoma	1
Amyloidosis	1
Radiation enteritis	2
Other	**13**
(high output) Enterocutaneous fistulae	5
Pancreatitis	5
Other	3

VASCULAR ACCESSES

Complication rate analysis was performed with 194 arteriovenous fistulae access years and 344 CVC access years, represented by 62 arteriovenous fistulae and 623 CVCs. Table 3 presents the 836 vascular accesses that were created to administer HPN in our 127 patients (i.e., a median of 5 accesses per patient [range, 1–24]) and the reasons to exclude some accesses from incidence rate analysis.

Arteriovenous fistulae

Fifty-eight patients (46%) had at least one arteriovenous fistula created at some point during their HPN treatment. During maturation of the fistula, these patients used a CVC. The median number of created arteriovenous fistulae in these 58 patients was 2 (range, 1–7). In each patient, usually multiple factors steer the decision to create an arteriovenous fistula for HPN administration. Clinically, the most important factor is whether intestinal failure is expected to be permanent and at least longer than 1 year. Additionally, patient preference is essential and usually varies over time. From the perspective of the patient, complications associated with CVC use are often critical. In 42 patients (72%), prior CVC-related complications occurred and importantly contributed to the decision for arteriovenous fistula creation. In 16 patients, fistula creation was performed independent of CVC-related complications. The median duration from the start of HPN to the creation of the first fistula was 10 months (range, 0.0 –10.6 years).

In total, 120 arteriovenous fistulae were created (Table 3). Of these, 75 (63%) became functional; 6 failed during their creation (4 immediate occlusions and 2 because of inappropriate vasculature) and 39 failed during maturation (resulting from occlusion [32], inadequate maturation [2], wound infection [2], vascular steal phenomenon [1], or unspecified reasons [2]). We excluded 16 functional fistulae; 11 fistulae were never used (because of pain during puncturing [2], a preference to continue using a CVC after adequate maturing of the fistula [5], fistula maturing at the time of analysis [1], and nonspecified reasons [3]) and for 5 arteriovenous fistulae the complication rate could not be fully ascertained. Of the 62 fistulae that were included in the incidence analysis, 32 were straightforward arteriovenous anastomoses and 30 were arteriovenous grafts (20 with autologous grafts, 2 with bovine grafts, and 8 with Gore-Tex [Goremedical, Flagstaff, AZ] grafts).

Central venous catheters

Overall, 716 CVCs were placed. In total, 671 CVCs (94%) became functional (Table 3), which is a significantly higher proportion when compared with the arteriovenous fistulae ($P<.001$); the insertion of 45 CVCs failed (due to vascular occlusion [24], malpositioning [8], failed punctures [6], and unspecified reasons [7]). Of these functional CVCs, 620 could be used to analyse bloodstream infection incidence rates and 623 could be used to analyze occlusion rates. Twenty-five and 23 CVCs were excluded because bloodstream infection or occlusion incidence rates, respectively, could not be fully ascertained and 26 were excluded because the exact CVC type was not reported (defined as "unspecified CVC" in Table 3). As a rule, catheters were single lumen and exclusively used for the administration of parenteral nutrition. In rare cases (i.e., if multiple ports were essential for the management of the patient), multiple-lumen catheters were used. The catheter tips were mainly placed in the superior (86%) or inferior vena cava (9.6%) via insertion through the subclavian, internal jugular, axillary, cephalic, femoral, or greater saphenous veins. Incidentally, the CVC was even placed in an uncommon vein such as the vena ovarica (1 CVC) or directly in the right atrium via sternotomy (2 CVCs). In 4% of the CVCs, the exact vessel used was not documented.

BLOODSTREAM INFECTION AND OCCLUSION INCIDENCE RATES

Table 4 presents the complication incidence rates. In total, 507 vascular access–related bloodstream infection episodes occurred. In 473 episodes (93%), blood cultures were positive. Eighteen episodes (4%) were counted based on information from referring hospitals without information about the results of the blood cultures (11 episodes in tunnelled CVCs, 3 in PACs, 1 in arteriovenous fistulae, and 3 in nontunnelled CVCs). In 16 episodes (3%), blood cultures were negative but the episode was defined to be an access-related bloodstream infection because cultures were drawn under antibiotic treatment (6 in tunnelled CVCs, 2 in PACs, and 1 in nontunnelled CVCs) or patients were showing evident signs of sepsis and other infectious foci that likely could explain the symptoms were excluded (3 episodes in tunnelled CVCs, 2 in PACs, and 2 in arteriovenous fistulae).

Bloodstream infection incidence rates (number/access year) were 0.03/year for arteriovenous fistulae, 1.79/year for tunnelled catheters, and 0.84/year for PACs (i.e., 1.37/ year for overall long-term CVCs).

Table 3 Created and analysed vascular accesses, per type of access in 127 patients on long-term HPN.

	No. of patients[1]	Created access per type of access[2]	Failed creation/ maturation[3]	Functional accesses, n (%) [4]	Used[5]	Missing data *exact number* BSI/OCC[6]	Missing data *exact duration* of use[6]	Included in BSI/OCC incidence analysis[7]	Access years analysed for BSI/OCC
AVF	**58**	**120**	**6 / 39**	**75 (63)**	**64**	**0/0**	**2**	**62/62**	**194/194**
Overall CVC	**127**	**716**	**45/NA**	**671 (94)**	**671**	**14/8**	**31**	**620/623**	**343/344**
Tunnelled catheter	109	412	30/NA	*382 (93)*	*382*	*1/0*	*8*	*373/374*	*184/185*
PAC	62	182	9/NA	*173 (95)*	*173*	*3/3*	*7*	*166/166*	*151/151*
Nontunnelled catheter	62	92	2/NA	*90 (98)*	*90*	*5/3*	*7*	*81/83*	*8/8*
Unspecified CVC[8]	19	30	4/NA	*26 (87)*	*26*	*5/2*	*9*	*0/0*	*0/0*
Total	**127**	**836**	**90**	**746**	**735**	**14/8**	**33**	**682/685**	**537/538**

PAC; Porth a Cath; BSI; blood stream infections; OCC; access or vascular occlusions; NA, not applicable.

[1] Number of patients with at least one created access per type of access.

[2] Includes failed creations/maturations.

[3] Failed accesses per type of access; a more detailed description of failure reasons is presented in the text.

[4] All created accesses that were technically usable for HPN administration.

[5] Eleven functional arteriovenous fistulae were not used because of reasons explained in the text.

[6] Excluded accesses per type of access due to incomplete follow-up data.

[7] Remaining number of accesses after exclusion of accesses with missing data concerning the exact number of complications and/or the exact utilisation interval.

[8] Unspecified CVCs are CVCs of which the exact type ([non-]tunnelled or PAC) was not reported.

Table 4 Bloodstream infection and occlusion incidence rates and incidence rate ratio's in CVCs compared with arteriovenous fistulae used for the administration of TPN

	BSI incidence rate[a]	Adjusted IRR CVCs/AVF[b]	Occlusion incidence rate[a]	Adjusted IRR CVCs/AVF[b]
Long-term TPN accesses				
AVF	0.03 (0.01-0.06)		0.60 (0.43-0.84)	
Overall long-term CVC	1.37 (1.14-1.66)	47 (19-117)	0.35 (1.27-0.47)	0.53 (0.31-0.89)
Tunnelled CVC	1.79 (1.47-2.18)	61 (25-150)	0.26 (0.24-0.37)	0.37 (0.21-0.67)
PAC	0.84 (0.64-1.09)	29 (12-73)	0.50 (0.36-0.70)	0.81 (0.45-1.45)
Short-term TPN access				
Nontunnelled CVC	3.12 (2.04-4.78)	89 (33-237)	0.93 (0.48-1.80)	1.27 (0.55-2.94)

[a] Bloodstream infection (BSI) and occlusion incidence rates (unadjusted for confounders) of arteriovenous fistulae (AVF) and central venous catheters (CVCs) presented as number of BSI or occlusions per access year (95% CI).

[b] Bloodstream infection and occlusion incidence rate ratio's (IRR) of CVCs over arteriovenous fistulae adjusted for the confounders presented in table 1.

Overall long-term CVCs indicate tunnelled catheters and PACs combined.

For short-term CVCs (i.e., nontunnelled catheters), bloodstream infection rates were highest (3.12/year). The bloodstream infection incidence rate ratio, adjusted for confounders, of overall long-term CVCs over arteriovenous fistulae was 47 (95% CI, 19–117). Gore-Tex grafts were applied in 13% of analyzed arteriovenous fistulae but 33% of the fistulae-related bloodstream infections (2 of the 6) occurred in Gore-Tex grafts, suggesting that the use of artificial grafts is a risk factor for arteriovenous fistula–related bloodstream infections.

Organisms responsible for the CVC-related bloodstream infections were mainly gram-positive organisms (mainly Staphylococcus epidermidis and Staphylococcus aureus; 51% in tunnelled CVCs, 68% in PACs, and 93% in nontunnelled CVCs). Less frequently, gram-negative organisms (40% in tunnelled CVCs, 28% in PACs, and 4% in nontunnelled CVCs) and fungi (9% in tunnelled CVCs, 4% in PACs, and 4% in nontunnelled CVCs) were cultured. In arteriovenous fistula–related bloodstream infections, 3 organisms were cultured (2 Staphylococcus aureus and 1 Candida albicans).

Occlusion rates were slightly lower in tunnelled CVCs (0.26/year) than in arteriovenous fistulae (0.60/year). Occlusion rates in PACs (0.50/year) did not significantly differ from arteriovenous fistula–related occlusion rates. In short-term (nontunnelled) CVCs, occlusion rates were highest (0.93/year). For overall long-term CVCs (tunnelled CVCs and PACs), the adjusted occlusion incidence rate ratio with respect to arteriovenous fistulae was 0.53 (95% CI, 0.31– 0.89).

Discussion

Vascular access–related complications remain a major problem in patients on long-term HPN. In our patients, the incidence rate of vascular access–related bloodstream infections was much lower during arteriovenous fistula use than during CVC use. The occlusion rate was slightly higher in arteriovenous fistulae, but only compared with certain types of CVCs.

Our centre is the larger of the 2 HPN centres in The Netherlands, and we take care of 60%–70% of the nationwide HPN population, which currently approximates 130 patients. The main indications for long-term HPN in our 127 analysed patients are in accordance with other studies. 15,16 The present study is by far the largest to evaluate the use of surgically created arteriovenous fistulae as an alternative to CVCs in patients on long-term HPN.

The observed bloodstream infection rates in CVCs correspond with the rates reported in other studies, ranging from 0.17 to 2.19 episodes per year.[1,17–22] In our study population, the arteriovenous fistula–related bloodstream infection rate was 0.03/year, which even in comparison with the lowest CVC-related bloodstream infection incidence rate reported in the literature constitutes a clinically relevant reduction. Therefore, also in other populations with lower bloodstream infection incidence rates, the conclusions and recommendations of our study would remain unchanged. The lower bloodstream infection rate (up to 61 times lower) in arteriovenous fistulae in comparison with long-term CVCs (PACs and tunnelled catheters) is in line with case reports or small case series that even describe a complete absence of infections related to arteriovenous fistula use in patients treated with HPN.[8,10,11] The considerably lower bloodstream infection rate observed during arteriovenous fistula use is of major importance because, in patients treated with HPN, bloodstream infection is the most frequent and most life-threatening catheter-related complication. In fact, 20%–50% of the causes of death directly related to HPN are represented by catheter-related infections.[19,23] In our population, the death of 1 patient was directly related to HPN treatment and was caused by an episode of catheter sepsis. It can be argued that the incidence rate of arteriovenous fistula–related bloodstream infection benefits from the fact that patients who have been using (multiple) CVCs before arteriovenous fistula creation have been better trained in aseptic techniques. However, all our patients who require long-term HPN receive in-hospital training on aseptic vascular access care and proper HPN administration for 1–2 weeks. They are allowed to administer TPN at home only if they can satisfactorily care for their access. We therefore do not believe that a more extended access-care experience has skewed our results in that patients with an arteriovenous fistula have a better aseptic technique. We consider it more likely that the patients who eventually end up using an arteriovenous fistula represent a selection of patients who are more vulnerable to infections. Improper access care, which more likely is a trait of character that improbably will change with a switch to a fistula, might in fact be a factor that contributes to this risk.

Although based on a low number of arteriovenous fistula–related bloodstream infections (n=6), we observed a relatively high bloodstream infection rate with artificial Gore-Tex grafts; 33% of the arteriovenous fistula–related bloodstream infections occurred in Gore-Tex grafts, while only 13% of the arteriovenous fistulae were Gore-Tex grafts. Higher bloodstream infection rates in artificial grafts compared with autologous grafts have also been shown in patients on hemodialysis.[24] Therefore, we propose that the artificial grafts, such as those constructed from Gore-Tex, might be more susceptible to bloodstream infections than the autologous grafts and that arteriovenous fistula–related bloodstream infection rates in patients receiving HPN can be decreased even further if only autologous grafts are used.

The main problem in arteriovenous fistulae is the risk of fistula occlusion. In our patients, 4 fistulae could not be created because of immediate occlusion during surgery and 32 fistulae never matured because of early occlusion. However, once adequately matured, the occlusion incidence rate in the arteriovenous fistulae was only slightly higher than in tunnelled catheters, while it was not significantly different from the occlusion rate in PACs. In our study population, arteriovenous fistulae were mainly used in patients in whom CVCs repeatedly proved ineffective; in 72% of the patients, prior CVC related complications decisively contributed to the decision for fistula creation. This might have contributed to the higher occlusion rates in arteriovenous fistulae with respect to CVCs because the prior insertion of multiple CVCs may damage the proximal vasculature and make fistula creation impossible or increase fistula occlusion rates due to an already compromised blood flow. This latter hypothesis can, however, only be proven in a prospective study in which detailed data on thrombotic clot localisation are correlated to prior catheter placements in the exact same vessels. Nevertheless, we propose that arteriovenous fistulae should be considered early, if not immediately, after the decision to start long-term HPN. Alternatively, we promote the use of jugular instead of subclavian veins to place CVCs, thus minimising the risk of obliteration of the venous circulation, which might be required for future creation of an arteriovenous fistula.

The retrospective study design confers favourable as well as less favourable aspects. It caused a limited number of incomplete data concerning access use, the occurrence of complications, and covariates. It is highly unlikely, however, that bias due to incomplete data has coloured our conclusions. We reviewed both the surgical and gastroenterological records as well as all letters from referring hospitals. In addition, to further increase the reliability of data collection, 2 independent reviewers reviewed all medical records and differences in interpretation were evaluated until consensus could be reached. Eventually only a very small and in all likelihood random number of accesses could not be included in the analysis due to lacking data (3% of arteriovenous fistulae and 7% of CVCs). The retrospective study design of a study period of over 30 years was favourable because it enabled us to evaluate access-related complication incidences during more than 500 access years and to include a large cohort of unselected patients on long-term HPN. We propose that no apparent bias was introduced by the relatively long study period because medical and surgical procedures, as well as complication prevention protocols, have not changed dramatically in the studied decades. As previously mentioned, arteriovenous fistulae have been used by a selected group of our patients, mainly patients in whom CVCs (repeatedly) proved ineffective. In the present population, it is impossible to correct for this apparent selection bias, but in the absence of likely other causes, most likely these patients are more vulnerable to complications. Therefore, the arteriovenous fistula–related complication rates are probably more overestimated than underestimated. This strengthens our conclusion that arteriovenous fistulae are safe alternatives for CVCs. In our opinion, complication rate analysis of all accesses created in our entire HPN population best represents complication rates that occur in daily practice. It has been argued that in each patient only the first access should be included because inclusion of accesses that were placed in patients with prior access-related complications might bias the results.[14] However, in clinical practice, patients on long-term HPN mostly need multiple accesses, so only comparing the first accesses would probably result in decreased generalisability for a complete study population over the total duration of HPN. Therefore, instead of only 127 first accesses, we decided to include all 685 accesses in our analysis. We used a Poisson-normal regression model with account for repeated measurements to control for overrepresentation of some patients.

In conclusion, in our patients on long-term HPN, the occlusion incidence rate was higher in arteriovenous fistulae compared with some types of CVCs. The incidence rate of potentially life-threatening bloodstream infections, however, was extremely low in arteriovenous fistulae compared with CVCs, independent of CVC type. These data suggest that arteriovenous fistulae are safe and valuable alternatives for CVCs in patients in whom (life-)long-term dependency on HPN can be expected. Finally, within the limitations of a retrospective study design, we propose that the risk of arteriovenous fistula–related bloodstream infections and occlusions can probably be further decreased if only autologous grafts are used and if arteriovenous fistula creation is performed before (multiple) catheter placement(s).

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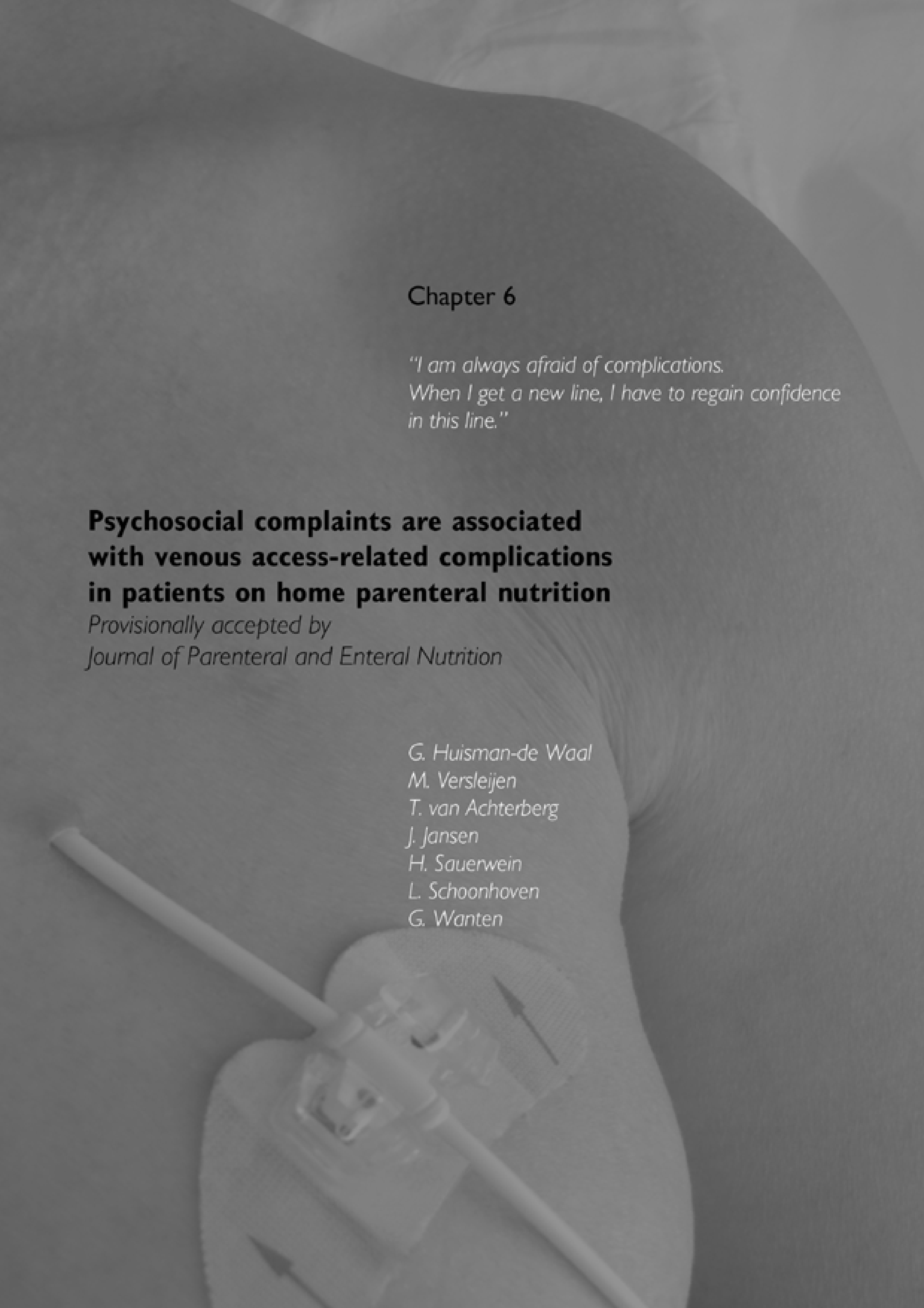

Chapter 6

*"I am always afraid of complications.
When I get a new line, I have to regain confidence
in this line."*

Psychosocial complaints are associated with venous access-related complications in patients on home parenteral nutrition

*Provisionally accepted by
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Abstract

BACKGROUND: Venous access device (VAD)-related complications remain the foremost drawback of home parenteral nutrition (HPN) support. In addition to technical issues, patients also experience significant psychosocial problems.

The aim of this study is to present an overview of VAD-related complications in patients on long-term HPN and to assess whether these adversities are related to experienced psychosocial problems and quality of life (QoL).

METHODS: Information on VAD-related complications was collected from the medical charts of all 110 adult HPN patients who were followed by the two major referral centres in The Netherlands, in Nijmegen (n=64) and Amsterdam (n=46).

In addition, a survey was performed to characterise psychosocial problems and assess their association with technique-related complications. 75 patients (75/110, 68%) responded.

RESULTS: The majority of patients (76%) had already developed one or more episodes of catheter-sepsis at some point during their HPN treatment course. The overall incidence of access-related blood stream infection (BSI) was 3 per 1000 venous access days. Incidence of venous access device occlusion was 0.8 per 1000 venous access days.

There was a highly significant association between the incidence of VAD-related complications and the occurrence of psychosocial complaints, in the form of depression, fatigue , social impairment, and quality of life.

CONCLUSION: Psychosocial complaints are associated with previously experienced VAD-related complications in patients on HPN. Although only an association, and not a causal relation is demonstrated by these findings, our results underscore the need for preventive and therapeutic measures regarding both types of problems in these patients.

Introduction

Parenteral nutrition has been used for nearly four decades now to prevent or correct malnutrition in patients with severe intestinal failure. In case of chronic intestinal failure, patients may administer parenteral nutrition in the home situation (home parenteral nutrition, HPN). In The Netherlands, HPN patients, whenever possible, are trained in the two academic referral centres in Nijmegen and Amsterdam in order to become autonomous with regard to their HPN practices and allow them to live in their own social environment.

HPN is most frequently delivered by means of a venous access device (VAD), such as a tunnelled catheter or a subcutaneous port, which is positioned in a large-bore central vessel, mostly the subclavian or internal jugular vein. Despite substantial clinical experience, VAD-related complications remain the most serious threat for both the patient as well as HPN survival as a technique.[1-3] Catheter-related blood stream infection (CRBSI) is the most common complication. For instance, Howard & Ashley[4] reported that adult HPN patients in the USA experience catheter-related BSI on average once every 2 to 3 years (0.34 episodes per catheter year). Other studies mentioned BSI rates in central venous catheter's (CVC) ranging from 0.17–2.19 episodes per year.[2,3,5-7] CRBSI could be responsible for the loss of a precious central venous access or even serious septic complications, therefore increasing morbidity and costs, or, in the most severe cases, leading to death. Additionally, in HPN patients, the loss of a VAD may complicate the clinical status in those patients for which parenteral nutrition constitutes the unique route for nutrient delivery.[6] Therefore, prevention of CRBSI is very important. A summary of our protocols for CRBSI and occlusions are given in box 1 and 2. Recently, we published an in-depth analysis of all venous access related complications of the HPN population in Nijmegen showing that the use of arteriovenous fistulae for the administration of HPN is feasible, with a significantly decreased infectious complication rate when compared with central venous catheter (Hickman-type or subcutaneous ports).[8]

As reported previously by our group, HPN patients also experience a wide range of psychosocial and physical problems in daily life besides VAD-related complications.[9,10] For instance, anxiety and fear are common reactions in HPN patients and these have been shown to be associated with realistic threats, such as catheter infection, thrombosis, air embolism and liver damage.[9,11] Anger, negative self-image, being dependent, and diarrhoea are other frequently reported problems.[4,9,12-14]

Box 1 Criteria for defining and treatment of infections

In both Dutch HPN centres, patients who are suspected of having catheter sepsis are evaluated in the clinical setting:

- Blood cultures are taken from the venous access device as well as from peripheral sites.
- TPN administration is aborted and only restarted after a period of 24 hours without fever.
- Treatment is started with broad spectrum antibiotic infusion through the catheter (i.e. flucloxacillin in hemodynamically stable patients, ceftriaxone and gentamycin in hemodynamically unstable patients).
- The therapeutic regimen thereafter is tailored according to culture results.
- In addition, in Nijmegen, patients are treated by the instillation of the fibrinolytic agent urokinase into the catheter (5.000E/2.5ml) before antibiotics are given.
- Catheters are only immediately removed in case of septic shock, with fungal infections, or with treatment failure, as evidenced by culturing the same organism from the access device within 6 weeks after antibiotic discontinuation. VAD-devices are also removed in case of tunnel- or persistent exit site infections.

Box 2 Criteria for defining and treatment of occlusion

Apart from infections, catheter- or AVF occlusion is the most common VAD-related problem, often necessitating catheter removal or AVF surgery or -angioplasty. These latter events interrupt HPN treatment and also expose the patient to the risks associated with catheter replacement as well as the loss of valuable access sites.

Occlusion of CVCs can be caused by thrombus formation, lipid deposition or drug precipitation. Thrombosis of CVCs generally results from disruption of the vein and development of a fibrin sheath around the catheter. If catheter thrombosis is unrecognised and untreated, it may lead to the need for catheter removal and long-term loss of a venous access site.
Treatment:

- In case of suspected lipid deposition or drug precipitation, patients are treated by means of sodium hydroxide (0.1mol/l, 25 mL) infusion.
- Catheter thrombosis may be treated by means of urokinase.
- If treatment is unsuccessful, removal of the catheter is necessary.
- AVF occlusion may occur during episodes of dehydration or in case of an underlying prothrombotic disease, but mostly is related to the occurrence of stenosis of the vascular anastomosis. The latter problem mostly develops gradually over time and can be suspected in case of an increased pitch of the murmur that can be heard over the AVF. Patients are therefore trained to check their AVF by means of a stethoscope. In addition, periodic ultrasonography is performed to detect any abnormalities.

Fatigue, depression, and social impairment are the most common problems and have a major impact on daily life. Typical for HPN patients, fatigue may result from a lack of sleep [15] because of the sound of the infuser pump or because of repeatedly disrupted sleep episodes as a consequence of frequent urination at night associated with fluid infusion.[16] In our previous study fatigue was the most frequently reported general complaint in HPN patients. Fatigue was seen as consistently interfering with daily activities such as work and leisure.[16]

An important underlying question that sparked the present investigation was whether the occurrence of psychosocial problems is associated with VAD-related complications, which are essentially preventable, or rather with the underlying disease that leads to intestinal failure, which mostly cannot be prevented. This is relevant, since such a notion would further bolster the indication for preventive measures in this respect.

The aim of the present study was (1) to provide an assessment and characterisation of VAD-related complications in patients on HPN in the Netherlands, and (2) to relate these complications to experienced psychosocial complaints.

Materials and methods

We included all long-term adult HPN patients who were treated in the two Dutch specialised university centres for at least 3 months, in December 2006. Their medical charts were retrospectively reviewed by two reviewers, independently. Whenever data from medical charts were unclear, nursing files were screened as well. In each patient, all vascular accesses placed for HPN purposes between the start of HPN and December 2006 were analysed for complications. Vascular access device-related bloodstream infections were defined by the presence of symptoms (fever, chills) associated with positive blood cultures in the absence of other evident infectious foci that likely could explain the bloodstream infection. Episodes with fever and/or chills without positive blood cultures were considered a bloodstream infection in case blood samples were drawn under antibiotic treatment or in case patients were showing signs of sepsis (fever with cold chills, low blood pressure requiring intravenous fluid support, or oliguria) and other infectious foci that could explain the symptoms were excluded. Concerning the occlusions, the time span of development (i.e., slowly and partial, with a spontaneous flow of less than 100 drops/min [considered to be mainly due to precipitation of infused substrates] versus acute [(nearly) complete obstruction, mainly due to thrombus formation]) was frequently undocumented and ultrasonography or contrast venography was not always performed. In this study, it was therefore impossible to distinguish thrombotic from nonthrombotic occlusions. For this reason, and in accordance with other studies on CVC-related complications[8,17], we report overall occlusion rates.

Catheters are only used for administration of parenteral nutrition or fluids for hydration.

A standardised record was used for data extraction. Extracted information included: age, sex, underlying disease, indication for HPN, years on HPN, type of CVC (external tunnelled vs. implanted port vs. AVF), co-morbidity, type of complications (infection, occlusion, others) and their treatment. For each patient, all vascular accesses placed for HPN purposes between the start of HPN and December 2006 were analysed for complications. Vascular accesses that were in situ but not used, and therefore not likely at risk for complications (n=8), and accesses with missing data concerning the precise utilisation-period or the exact number of complications during use (n=4) were excluded from the analysis.

With regard to the second aim of this investigation, a single survey was performed in October 2006, using questionnaires that were based on our previous survey in 2003.[10] All adult patients monitored by the nutrition support teams at the University Centres in Nijmegen and Amsterdam in October 2006 were invited to participate in the study (n=110). Based on previous reports, we estimate that these patients represented 85% of all the patients receiving long-term HPN in the Netherlands during that period (n= ± 130).[18] The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre approved the study protocol. All patients gave their written informed consent before inclusion in the study.

The questionnaires addressed general as well as HPN-related characteristics, medication use, quality of life, social impairment, depression, fatigue, physical complaints, coping, self-efficacy, social support, sexual disorders and anxiety (Table 1). To assess a possible relation between experienced psychosocial problems (in October 2006) and VAD-related complications, we included complications that occurred between January 1st 2005 and September 30th 2006.

Completion of the survey took 45 to 75 minutes and was accomplished by 75 of 110 patients who were addressed for this part of the study.

Fatigue Severity, a subscale of the Checklist Individual Strength (CIS-fatigue) was used to measure fatigue.[19,20] The Beck Depression Inventory–Primary Care (BDI-PC) was used for measuring the severity of depression[21], and the subscale 'Social Behaviour' of the SIP 68 (Sickness Impact Profile) was used to evaluate social impairment.[22,23]

Quality of Life (QoL) was measured with the Cantril ladder of life, a 1-item questionnaire, based on a visual analogue scale from 0 to 10, where 0 stands for the worst possible QoL and 10 for the best QoL.[24] Cantril's ladder has acceptable psychometric characteristics. Both reliability and validity were found to be reasonable.[25]

Information on hospital admissions is provided from 2002 to 2006 because of the highly improved computer registration of patient data in this period.

HPN patients who experienced VAD-related complications between January 1st 2005 and September 30th 2006, were compared with those who did not have VAD-related complications in this period.

Table 1 Set of questionnaires

Topic	Instrument + references	Information
Patient characteristics		
General characteristics	Own development	9 items
HPN-related characteristics	Own development	13 items
Quality of life	Cantril's Ladder [70]	1-item questionnaire on a visual analogue scale. Cantril's ladder has acceptable psychometric characteristics. Both reliability and validity were found to be reasonable. [25]
Extent of problems		
Fatigue	Fatigue Severity, subscale of the Checklist Individual Strength (CIS) [71-73]	8 items, score 8-56 Clinically severe fatigue present when score > 35 validated in various populations. The internal consistency of the CIS is good: Cronbach's α for 'fatigue severity' was 0.88. Convergent validity is satisfactory.
Depression	Beck Depression Inventory-Primary Care (BDI-PC)[45;74]	The BCI-PC is a 7 item questionnaire with each item rated on a 4 point scale (0-3). It is scored by summing ratings for each item (range 0-21). Items are symptoms of sadness, pessimism, past failure, loss of pleasure, self dislike, self criticalness, and suicidal thoughts and wishes. Patients were asked to describe their symptoms for the 'past two weeks including today'. A cutoff score of >4 is given a diagnosis of major depressive disorder. The internal consistency is high (α = 0.86). With regard to the convergent validity, the BDI-PC was positively associated with the diagnosis of major depressive disorders (r = 0.66, p<0.001).
Social Impairment	Social Behaviour, subscale of the Sickness Impact Profile (SIP68) [75;76]	12 items, dichotomous. The internal consistency of the SIP 68 is high, Cronbach's α = 0.92.

STATISTICAL ANALYSIS

Descriptive statistics were computed for all variables. These included means, medians, and standard deviations. Pearson's correlations were used to analyse associations between VAD complications and psychosocial problems and quality of life. To compare subjects with and without complications ,t-tests or Mann Whitney U tests were used where appropriate. ANOVA was used to analyse differences between VAD type. A p value < 0.05 was considered significant in all analyses. All statistical tests were performed using SPSS version 16.0.

Results

In total, 110 medical charts could be retrieved for review (i.e. there were no missing records). Patients recruited were treated at the Radboud University Medical Centre Nijmegen (n=64) or at the Academic Medical Centre Amsterdam (n=46) in the Netherlands. In October 2006 sixty-six percent of these were female, mean age was 51 years (sd 12.4; range 18-81) (Table 2). The cumulative duration of HPN treatment in these 110 patients was 567 years, i.e. 206.955 VAD days, with a mean of 5.1 years (sd 5.6; range 3 months to 30 years). Three patients (4%) only used fluids for hydration, all other patients (n=72) used parenteral nutrition, from which 37 patients used parenteral nutrition combined with fluids. Two patients used antidepressants.

Table 2 Characteristics of HPN patients

	N = 110
Mean age (years)	51 (sd 12.4)
Women N	72 (65%)
Underlying disease N (%)	
- Mesenteric thrombosis	39 (35%)
- Crohn's disease	19 (17%)
- Radiation Enteritis	7 (6%)
- CIIP*	10 (9%)
- Others	35 (32%)
Indication HPN: short bowel syndrome (versus motility disorders) (%)	57 (52%)
Comorbity N (%)	38 (35%)
Years on HPN, mean (range)	5.7 (sd 5.6)
Type of venous access at start HPN	
- Central Venous Catheter (CVC) %	47 (43%)
- Port-a-Cath (PAC) %	35 (32%)
- Arterio Venous Fistulae (AVF) %	17 (15%)
- Other	11 (10%)

* CIIP, Chronic Idiopathic Intestinal Pseudo-obstruction

The majority of patients (76%, n=84) had experienced infectious complications at some point during their HPN treatment (n=391). The overall incidence of access related BSI was 3 per 1000 venous access days (3/1000). Access-related BSI were mainly caused by Gram-positive bacteria (54%, mostly Staphylococcus sp.). Gram-negative bacteria, mostly Escherichia coli or Klebsiella sp., were found in 25%. Fungi, mostly Candida sp., were responsible for access-related BSI less often (5%) (Table 3).

Table 3 Pathogenesis of infections

Pathogens	**n**	**%**
Gram positive bacteria	194	50
Gram negative bacteria	82	21
Gram positive bacteria and gram negative bacteria	20	5
Fungi	14	4
Gram positive bacteria and fungi	6	2
Gram negative bacteria and fungi	3	1
Unknown	72	16
Total	**391**	**100**

In 54% (n=211) of all catheter infections urokinase was used as part of the treatment protocol, with the intention of eliminating a potential thrombus. Ninety-five percent of all episodes (n=371) had been treated with antibiotics, and in 5% the catheter was removed immediately (n=20). In 57% of all infections (n=223), the VAD was eventually replaced.

Access device occlusions occurred in 42% of patients (n=46/110) and the overall incidence of access device occlusions was 0.8 per 1000 venous access days (0.8/1000) Eighty-four percent of these access occlusions (n=176) were treated by infusion of a caustic solution (0,1M sodium hydroxide, NaOH)[26]

(Box 2). In 44% of all catheter occlusion episodes (n=92), this strategy failed to open the catheter and a new catheter had to be placed.

Almost one third of all patients (n=34/110) experienced a range of other complications, such as accidental removed (n=12) and tearing of the catheter (n=9). These latter complications occurred 0.65 per 1000 venous access days (0.65/1000). In 69% of these cases (n=84), placement of a new catheter or AVF was mandatory.

Table 4 shows our data on hospital admissions due to venous access-related complications. The mean length of stay in days per patient per year in the hospital significantly decreased over these years from 21.5 (sd 34.9) to 8.9 (sd 17.5) (p<0.001).

Table 4 Hospital admissions 2002 to 2006

Number of patients under treatment	2002 n=46	2003 n=53	2004 n=64	2005 n=81	2006 n=110
Mean no. of admissions per patient per year (sd)	1.61 (1.5)	.77 (1.2)	1.05 (1.4)	1.0 (1.5)	.71 (1.1)
Total no. of admissions per year	74	41	68	83	79
Mean length of stay in days per patient per year (sd)	21.5 (34.9)	9.5 (22.1)	10.1 (17.0)	10.9 (19.3)	8.9 (17.5)
Total length of stay in days per year	987	505	656	879	986

PROBLEMS EXPERIENCED

The response rate in our survey was 68% (n=75/110). No evidence for selection bias, as suggested by differences in gender, age, duration of HPN therapy and the indication for HPN, was found in respondents or patients who refused to participate.

Severe fatigue was reported by 66% of all respondents (Table 5). There was a significant association between the severity of fatigue and the occurrence of VAD-related complications (r = 0.30, p = 0.009). Fatigue severity was not associated with the number of hospital admissions.

Table 5 Problems experienced by HPN patients

	Mean (sd)	Range
CIS-Fatigue	39.61 (13.30)	9-56
BDI-PC	3.65 (3.32)	0-18
SIP-Social Impairment	5.68 (3.48)	0-12
Quality of life	5.70 (1.72)	1-10

According to the BDI-PC, almost 57% percent of the HPN patients had depressive disorders (Table 5). There was a significant association between depressive disorders and the number of experienced VAD-related problems (r = 0.30, p = 0.011). In addition, depression was clearly associated with the number of hospital admissions due to VAD-related problems (r = 0.43, p = 0.002).

The results of the SIP 68 questionnaire showed raised levels on the subscales Social Behaviour (Table 5). There was a highly significant association between social behaviour and VAD-related complications (r = 0.34, p = 0.003). We also found an association between social impairment and the number of hospital admissions due to VAD-related complications (r = 0.31, p = 0.026).

For quality of life, patients scored a 5.7 on average (sd 1.72). Forty-three percent of the patients scored below 6. Quality of life was clearly associated with the number of VAD-related problems (r

= -0.38, p = 0.001) and the number of hospital admissions due to these problems (r = -0.41, p = 0.002). In case of more VAD-related problems and related admissions, patients reported a lower quality of life. A low quality of life was also strongly related ($p < 0.02$) with more intense fatigue (r =-0.59), more severe depression (r = - 0.68) and greater social impairment (r =-0.45).

The length of hospital stay did not show a significant relation with quality of life or experienced problems, except with social impairment (r = 0.04, p = 0.291).

There were no significant correlations between the type of venous access (AVF vs. implanted port vs. CVC) and quality of life, depression, fatigue, and social impairment.

Patients without VAD-related complications between January 1st 2005 and September 30th 2006 (n=29) experienced significantly less psychosocial problems and reported a better quality of life compared to those who did have VAD-related complications in this period (n=46) (Table 6).

Table 6 Comparison VAD-related complications vs. no complications

October 2006	VAD-related complications between Jan 1st 2005 – Sept 30th 2006 Yes (n=46) No (n=29)	Mean (sd)	t-test	p-value
Quality of life	Yes	5.4 (1.7)	-2.22	0.029
	No	6.2 (1.7)		
BDI-PC	Yes	4.4 (3.6)	2.59	0.012
	No	2.4 (2.5)		
CIS-Fatigue	Yes	43.1 (11.8)	2.991	0.004
	No	34.1 (13.9)		
SIP-Social impairment	Yes	6.6 (3.0)	2.994	0.004
	No	4.2 (3.8)		

Discussion

To our knowledge this is the first study that shows that in a substantial (70%) proportion of HPN patients, at least in the Dutch situation, the number of access-related complications and hospital admissions due to these complications is strongly associated with an impaired quality of life and the presence of depression, fatigue, and social impairment.

In our opinion these data underscore the need for adequate measures to prevent access-related problems and, if possible, treat psychosocial problems. We also confirm that venous access device-related complications are being experienced at some point by the vast majority of these patients despite the fact that all these patients or their caregivers in the home setting have been trained to perform HPN administration in accordance with current practice guidelines.

In our two major Dutch HPN referral centres, specialised TPN nurses teach all patients to work in an aseptic manner and also to recognise relevant symptoms of all vascular access related complications in an early stage, thus enabling adequate treatment in an early stage of any problem. Patients can contact their total parenteral nutrition centre on a 24/7 basis. The CRBSI rates in our HPN population are comparable with those in some recent studies showing incidence rates between 0.44–6 per 1000 venous access days[2,3,5-7] Occlusion rates in other studies are also comparable with our finding of 0.9/1000 catheter days.[26-28]

Evidence indicates that the risk of CRBSI is reduced for example by the use of tunnelled and implanted catheters, proper education and specific training of the staff, an adequate policy of hand washing, and regular change of administration sets.[29] Recently, the use of an antibiotic lock solution containing 2% taurolidine was compared to our previous standard practice and has been shown to dramatically (>90%) reduce the recurrence of CRBSI.[30] In due time we will evaluate whether this policy translates into an improved quality of life as well as psychosocial outcome measures.

Several implications of our findings for clinical practice can be noted. Apart from measures to decrease access-related complications, other therapeutic options to improve quality of life are at hand. For instance with respect to fatigue. Fatigue is a major problem in HPN dependent patients to a degree that is similar to the level seen in patients on haemodialysis and Multiple Sclerosis[31], and higher compared to fatigue in patients with Functional Bowel Disorder or Cerebrovascular Accident patients.[20] Anti-fatigue therapy should be the standard care for most chronic conditions associated with fatigue.[15] Yurtkuran et al.[32] evaluated the effects of a yoga-based exercise program on sleep disturbance and fatigue in haemodialysis patients. They concluded that a modified yoga-based exercise regimen for half an hour twice a week improves sleep disturbance and fatigue amongst other things. Liu[33] reported that there were two significant predictors for fatigue in haemodialysis patients; depression and age. Findings suggest that identifying the existence of depression routinely as suggested by Wuerth et al.[34] and providing adequate treatment for depression might be an effective strategy for decreasing levels of fatigue.[33] O'Sullivan concluded that as physical functioning increased fatigue decreased.[31] The results from this study highlight the importance of focusing nursing care on fatigue and physical functioning ability in practice. To our knowledge, studies looking at the effect of psychosocial interventions on clinical outcomes in HPN dependent patients were not previously performed.

Social impairment has a major impact on the daily life of HPN patients. In our previous study, 35 to 43% of the HPN patients experienced social impairment as a problem due to HPN.[16] HPN administration takes a long time, sometimes more than 14 hours per day, and many of the respondents had to hook up 5 times a week or more. Freedom to choose and the ability to make simple daily life decisions were sharply reduced and social contact and interaction decreased because of the catheter, the schedule of HPN, mobility problems, and physical complaints.[16] Skerrett et al.[35] has shown that the ways in which patients interpret and respond to their symptoms as part of their underlying disease (coping style), have a significant impact on the level of social impairment. Most important correlates of social adjustment were embarrassment cognitions and avoidance/resting behaviours (for example "when I experience symptoms, I rest") To compare these results with ours, continued investigation in our HPN patients is needed. Skerrett et al. [35] also found that depression explained a moderate amount of the variance in social impairment levels as well as fatigue.

Depression also can have a marked impact on many aspects of life. Depression is often accompanied by impairment in one's functional capacity to work and in role functioning in non-work domains as well.[36] Our previous review showed that depression was a common emotional response to HPN treatment in many studies.[16] Severity of depression ranged from mild to severe and was observed in 10–80% of the HPN patients.

Limitations of the present investigation have to be considered. The retrospective character of the study carries a risk for misinterpretation of documented relevant data. We tried to overcome this by using two reviewers independently, both with a medical background and with expertise in this field.

Given the design used, we cannot be sure that psychosocial problems truly resulted from complications. Firstly, data on psychosocial problems were collected following the collection of data on VAD complications. While this suggests a favourable time order, complications could have been resolved at the time of data collection. Furthermore, part of these psychosocial problems may be due to the underlying disease. However, Carlsson et al.[12] showed that short bowel syndrome patients on HPN experience a lower quality of life compared to short bowel syndrome patients without HPN, and HPN patients worry more about fatigue and feeling alone. In this study, patients without venous access device-related complications also experienced significantly less psychosocial problems and reported a better quality of life compared to those who did have venous access device-related complications. Although not allowing firm conclusions on causal relationships in this study, the results support our hypothesis that venous access device-related complications do contribute to psychosocial problems.

Another limitation is the small patient population. Therefore, subgroup analyses were sometimes not feasible. Despite this small patient population, a strength of this study is the high response rate in the survey. Therefore, we assume that the results of this study can be generalised to the total group of HPN patients in the Netherlands. Another strength is that several validated scales were used to assess psychosocial problems. Future research should include new HPN patients to determine whether psychosocial complaints are mainly caused by the underlying disease, or, as we think, are deteriorated by access-related complications.

Taking the limitations of our studies into account and given the before mentioned questions regarding the interpretation of our data, the correlations identified in our data still stand. Taken together, the results from the present study show that in patients on HPN, depression, fatigue, social impairment, and the experienced quality of life is closely related to previously experienced venous access device-related complications. This notion should bolster our efforts to prevent such adversities and further optimise the quality of HPN care.

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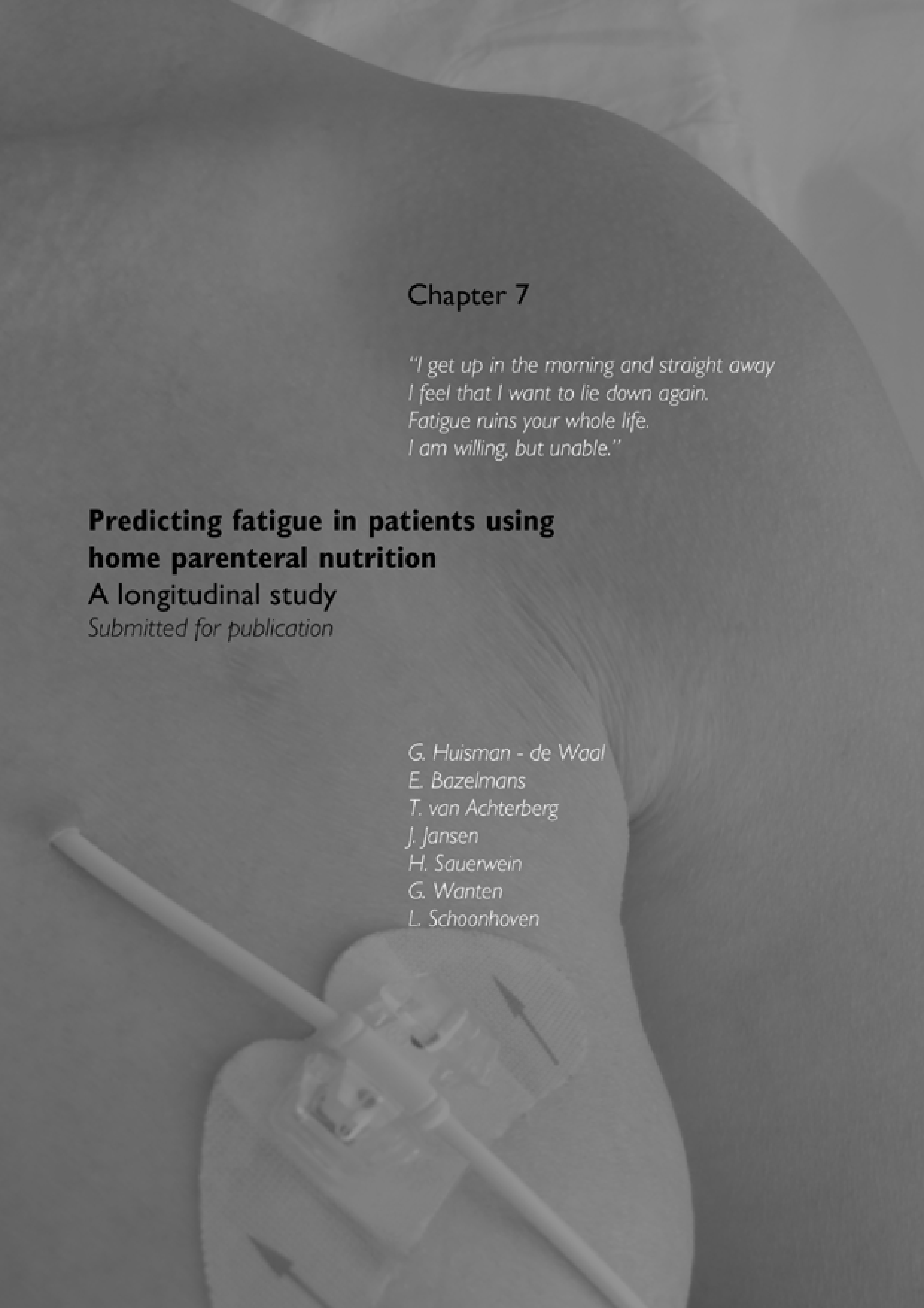

Chapter 7

"I get up in the morning and straight away
I feel that I want to lie down again.
Fatigue ruins your whole life.
I am willing, but unable."

Predicting fatigue in patients using home parenteral nutrition

A longitudinal study

Submitted for publication

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Abstract

OBJECTIVE: Home Parenteral Nutrition (HPN) is a life-saving therapy for patients with diseases that preclude adequate oral or enteral food intake. HPN has a large impact on daily life. Many patients suffer from fatigue and depression, and they experience limits in social activities. This all contributes to a lower Quality of Life (QoL). Fatigue is the most frequently mentioned problem in Dutch HPN patients. Therefore, we studied the prevalence, course, and predictors of fatigue in these patients.

METHODS: All HPN patients treated at the two Dutch HPN centres were asked to participate. Patients completed questionnaires at baseline and follow-up (12 months later). Measurements included fatigue, depression, functional impairment, social support, self-efficacy, coping, anxiety and acceptance. Laboratory measures, including total bilirubin, creatinine, albumin, and haemoglobin levels, were obtained from the medical records. Descriptive statistics, correlations, and linear regression analysis were performed.

RESULTS: The response rate was 71% (n=75). Sixty-five percent of the patients were severely fatigued (n=49). Eighty-nine percent experienced persistent fatigue. Baseline fatigue predicted 57% of the variance of fatigue at follow-up, and avoidance was responsible for 3% of the variance. No significant correlations between fatigue and laboratory measures were found. A cross-sectional analysis showed that 46% of the variance of fatigue was explained by functional impairment, self-efficacy, and depression.

CONCLUSION: Severe fatigue is a persistent problem for HPN patients. Baseline fatigue was the strongest predictor of fatigue at follow-up. Functional impairment, self-efficacy, and depression are strongly related to fatigue. Early recognition and treatment of fatigue are important.

Introduction

Home Parenteral Nutrition (HPN) has been used for the management of intestinal failure since the late sixties of the previous century. This treatment modality is life-saving for patients with an inadequate oral or enteral food intake of nutrients and fluids. Most patients suffer from intestinal failure due to short bowel syndrome, or motility disorders.[1] HPN is used alone or in conjunction with oral feeds. The support of patients on HPN requires a dedicated multidisciplinary team. This team should be available for instructions to patients, advice and treatment of complications on a 24/7 basis. During their training period, patients who are fit to perform HPN administration become knowledged and skilled in the performance of aseptic techniques, catheter care, and the intravenous administration of nutrients. Also importantly, these patients are trained to contact their treatment centre in case of suspected catheter infection or - occlusion or other problems due to the therapy.[2]

Several studies describe that HPN is associated with medical complications.[3-5] These complications may be related to the central venous catheter or to the nutrition formula.[6;7] However, HPN also has a major impact on daily life and many patients suffer from fatigue and depression.[8-13] Not unexpectedly, HPN also limits social activities and impairs quality of life.[10;11]

A Dutch study showed that fatigue is the foremost and most frequently mentioned problem in HPN patients. Sixty percent of the HPN patients were severely fatigued, and fatigue was reported by 90% of these patients as a main problem in daily life (n=43).[11] It was found that HPN patients were more fatigued when compared with patients suffering from functional bowel disorder or cerebro vascular accident and fatigue scores corresponded with those seen in patients with multiple sclerosis. More specifically, a higher level of fatigue was related to the presence of passive coping strategies and believing that good health is determined by fate. Depressive symptoms were present in 65% of 48 HPN patients, 17% of whom experienced severe depressive symptoms.[11] Social impairment also was a commonly reported problem. Almost half of the respondents mentioned social limitations as a problem in daily life. Increased social impairment was strongly related to a lower quality of life. Social impairment was more often reported when compared to patients on haemodialysis, cancer patients, and patients suffering from rheumatoid arthritis.[14]

Fatigue is a common symptom in various chronic diseases. It has mostly been studied in patients with chronic fatigue syndrome, cancer, multiple sclerosis, Parkinson's disease, renal disease, and after stroke.[15-20] Physical as well as psychosocial predictors have been reported in the literature. Vercoulen et al.[19] found that 85% of included patients suffering from multiple sclerosis, and 100% of Chronic Fatigue Syndrome patients felt fatigued at least once a week. In the same study only 13% of the healthy individuals experienced fatigue at least once a week. Several studies show that persistent fatigue is predicted by the presence of fatigue at the baseline measurement.[21-23] Vercoulen et al. (1994) developed a multidimensional assessment method for Chronic Fatigue Syndrome (CFS) and other chronic disorders.[19;24] Nine relatively independent dimensions of CFS were identified, namely psychological well-being, functional impairment in daily life, sleep disturbance, concentration problems, physical activity, social functioning, social support, causal attributions and self-efficacy.

In CFS patients, fatigue severity was related to impairment in daily life and low sense of control. Other predictors of fatigue in chronic diseases are depression and anxiety[18;25;26], psychological general well-being, high impairment in role functioning, disability, acceptance, self efficacy, and problematic social support.[18;22;26-29]

Besides psychosocial factors, physiological factors may be related to fatigue. For example McCann and Boore (2000)[15] found that malnutrition causes fatigue in renal failure patients. Srivastava [30] and Piper et al. [31] found that anaemia affects the reported levels of fatigue. Other studies however, did not find these associations.[15;32-35]

So far, longitudinal studies regarding fatigue in patients on long-term HPN are lacking. The current study presents the longitudinal data of a cohort of HPN patients during a 12-month period. Based on the literature in other chronic patient groups, fatigue in HPN patients might be predicted by the presence or absence of disease activity, depression, self-efficacy, coping, acceptance, anxiety, functional impairment and social support. The aims of this study were 1) to describe the prevalence and course of fatigue, and 2) to evaluate baseline fatigue and the fore mentioned set of psychosocial and physiological factors in the prediction of fatigue.

Method

PATIENTS

All 106 HPN patients treated at the Radboud University Nijmegen Medical Centre or the Academic Medical Centre in Amsterdam at the start of the study in October 2007 were asked to participate in this study. These patients represent about 90% of all patients receiving long-term HPN in the Netherlands. Patients had to be on HPN for at least three months at T1 (baseline). We excluded patients younger than 18 years. The regional committee on Research Involving Human Subjects waived the need for review of the study because we used questionnaires and medical records only. Patients received a written invitation to participate.

PROCEDURE

After obtaining written informed consent, questionnaires were sent to the patients (T1). Participants were asked to complete the questionnaires within two weeks and return them in a prepaid envelop to the hospital. After one year, a second questionnaire was sent by mail (follow-up, T2). Only fatigue was measured. In case of missing data, patients were contacted by telephone to complete the questionnaires. Patients who had discontinued HPN at follow-up still were asked to fill in a questionnaire. Results of these patients were analysed separately. Laboratory measures (taken during regular check-ups at the outpatient clinic) were obtained from the medical records at T1 and T2.

MEASUREMENTS

The questionnaire addressed general and HPN related characteristics.

Fatigue

The subscale 'Fatigue Severity' from the Checklist Individual Strength (CIS) is an 8-item questionnaire and measures fatigue during the previous 2 weeks.[36] Each item was scored on a seven-point Likert scale. High scores indicate a high level of experienced fatigue. Severe fatigue was defined as a CIS-fatigue score equal to or higher than 35.[24] A score between 27 and 34 indicates high experience of fatigue. In this study a score of 35 or above at baseline as well as at follow-up was seen as indicating 'persistent severe fatigue'. The CIS has been tested thoroughly among patients with different chronic diseases and healthy controls.[19;24;36] The internal consistency of the CIS is good: Cronbach's α for the total CIS was 0.90, and for the subscale 'fatigue severity' 0.88. Convergent validity was satisfactory.[37]

Depression

The Beck Depression Inventory for Primary Care (BDI-PC) was used to assess depression. The BDI-PC, does not contain questions concerning physical aspects of fatigue and the somatic symptoms of depression.[38;39] The BDI-PC has seven items and consists of cognitive and affective symptoms. Each item is rated on a 4-point scale ranging from 0 to 3. A score of 4 or more indicates clinical depression. This score was found to correctly classify patients as being diagnosed with or without major depressive disorders (MDD) according to DSM-IV. The internal consistency is high ($\alpha = 0.86$). With regard to the convergent validity, the BDI-PC was positively associated with the diagnosis of MDD ($r = 0.66$, $p < 0.001$).[39]

Functional impairment

The Sickness Impact Profile short form 68 (SIP-68) was included in our study as it is a widely used measure of the impact of disease on an individual's physical and psychosocial functioning.[40] Patients are required to read through a list of conceivable difficulties and to identify which of these apply to them using a yes/no response format. Scores range between 0 and 68, a higher score indicates more functional impairment. The internal consistency is high, Cronbach's $\alpha = 0.92$.[40;41]

Social support

The Van Sonderen Social Support Inventory (SSL) was used to assess social support.[42] Total scores of the SSL-I (amount of social interactions) range from 34 to 136, a higher score meaning more social support. Subscales are emotional interactions, emotional support problems, esteem support, instrumental interactions, social companionship, and informational support. The SSL has good reliability (Cronbach's $\alpha = 0.93$ for SSL-I) and content validity.[43]

Self-Efficacy

Self-efficacy, a sense of control over fatigue symptoms, was measured with a Self-Efficacy Fatigue Questionnaire. Seven items measured sense of control with respect to fatigue. Total scores range from 7 to 28, a higher score meaning a patient experiences more sense of control with respect to fatigue.[20] Cronbach's α reliability coefficients range from 0.70 to 0.77.[21;44]

Coping

The subscales avoidance and problem-focused coping of the UCL (Utrechtse Coping List) were used to assess coping.[45] A high score on a subscale means that the individual uses that coping style often. The internal consistency is moderate to high ($\alpha = 0.66$ for avoidance, $\alpha = 0.78$ for problem focused coping).[46]

Anxiety

In a previous study[9] the State-Trait Anxiety Inventory[47;48] was not sensitive enough to measure specific anxiety in HPN patients. Therefore, a specific questionnaire was used to measure anxiety. Based on interviews in a 2003 study, six questions specific for anxiety in HPN patients were developed. These items were scored on a 4-point scale ('not at all' to 'almost always'). Total scores ranged from 6 to 24, a higher score meaning a patient experiences more anxiety with respect to HPN complications or hospitalisations, future or even death.

Acceptance

Acceptance was measured with a subscale of the Illness Cognition Questionnaire (ICQ). This questionnaire measures different cognitions about the way patients think about and give meaning to their chronic illness. The items are rated on a 4-point scale (1, not at all, to 4, completely), a higher score meaning better acceptance. The reliability (Cronbach's $\alpha = 0.90$, test-retest reliability 0.76) and validity of acceptance were found to be high.[49]

Laboratory measures

Relevant laboratory measures were obtained from the medical records. We evaluated liver function (total bilirubin), renal function (creatinine), inflammation (albumin), and haemoglobin levels (Hb).

STATISTICAL ANALYSIS

Data analyses were performed using the Statistical Package for Social Sciences for Windows version 16.0. Variables were normally distributed, and therefore, parametric tests were performed. Descriptive statistics as mean, standard deviation and range were used to describe the participants and to evaluate laboratory measurement outcomes. Paired sample t-tests were performed to analyse differences between baseline and follow-up scores. P-values < 0.05 were considered statistically significant.

Associations between potentially predictive variables at baseline and fatigue at follow-up were examined by calculating the Pearson's correlation coefficient. Pearson's correlation coefficient was also used to analyse relations between the predictive variables at baseline to identify possible multi-collinearity.

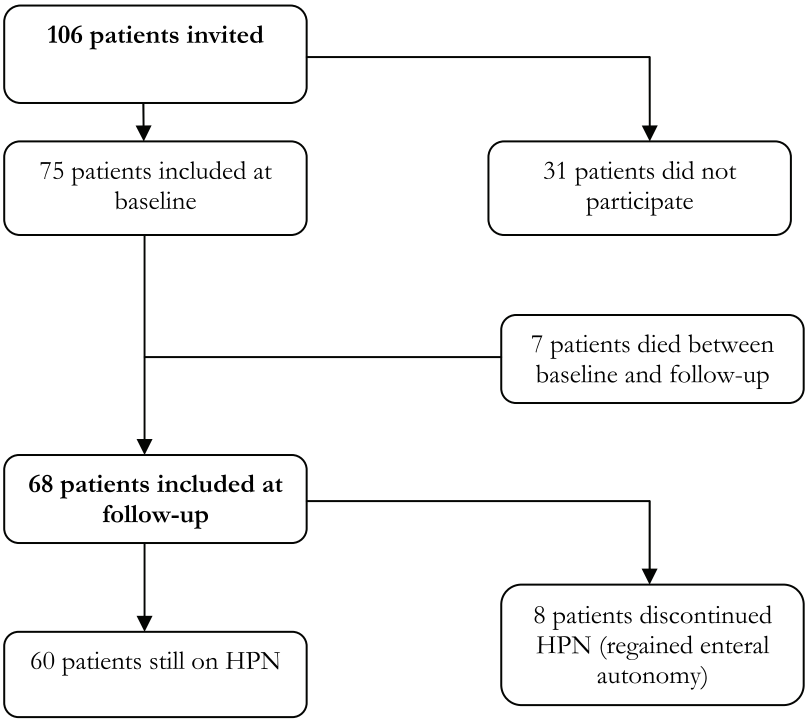
We performed a longitudinal linear regression analysis in which we entered variables which possibly are connected to fatigue at follow-up as independent variables, and fatigue at follow-up as dependent variable (model 1). Subsequently, we performed a cross-sectional backward stepwise linear regression analysis with fatigue at baseline as dependent variable, and potentially predictive variables for fatigue from baseline as independent variables (model 2). This second model was added because of the risk that persistent fatigue is predicted by the presence of fatigue at baseline alone.[26] Therefore, model 2 might give information on other important variables explaining fatigue. Predictive variables were removed from the model when they met the removal criterion of P> 0.05.

Results

PATIENT CHARACTERISTICS

The response rate at baseline was 71% (i.e. 75 out of 106 patients). No differences in gender, age, duration of HPN therapy or the indication for HPN were found between the respondents and the patients who refused to participate. At follow-up, 68 out of 75 patients were able to fill out the questionnaire again (Figure 1). Eight patients discontinued HPN, but filled out the questionnaire at follow-up. The reason for discontinuing HPN in all patients was being able to eat sufficiently again due to adaptation of the remaining small intestinal mucosa. All follow-up analyses pertain to the 60 patients still on HPN. The 8 patients who discontinued HPN were analysed separately.

Figure 1 **Patient flow chart**



At baseline, patients' median age was 56 (range 19 to 81), 63% were women, 80% were married or cohabiting, and merely 20% was employed. Indications for HPN were short bowel syndrome, mostly related to inflammatory bowel disease or mesenteric thrombosis (n=41, 55%) and motility disorders (n=34, 45%), Table 1. Patients were on HPN for median 2 years (range 3 months to 30 years). Almost 75% was able to use solid or liquid food to some extent.

Serum haemoglobin, creatinine, albumin and bilirubin were in accordance with the reference ranges (Table 1), and therefore did not indicate the occurrence of fatigue in the patient population. These laboratory measures were not included in our analysis because they did not correlate significantly with fatigue.

Questionnaires that were completed by patients were checked, and in case of missing data, patients were contacted to complete the questionnaires. Because of no missing values, all 60 cases were included in the analysis.

Table 1 Patient characteristics

			N = 75
Mean age (years)			53.1 (sd 12.8)
Women N			47 (63%)
Indication HPN: short bowel syndrome (versus motility disorders)			41 (55%)
Years on HPN			5.0 (sd 6.2)
		T1	**T2**
Haemoglobin	Mean (sd)	7.4	7.4
	Percentiles 25 - 75	7.1 - 8.0	7.0 - 7.9
Albumin	Mean (sd)	35.8 (4.9)	36.9 (4.9)
	Percentiles 25 - 75	36.5 - 41.0	34.0 - 40.0
Total bilirubin	Mean (sd)	10.5 (10.9)	8.6 (6.7)
	Percentiles 25 - 75	5.0 - 12.0	4.0 - 12.0
Creatinine	Mean (sd)	77.8	85.2
	Percentiles 25 - 75	58.8 - 87.0	62.0 - 91.5

Reference ranges (from included hospitals): Haemoglobin 7.5 – 10.0, Albumin 35-50, Total bilirubin <17, Creatinine 65-95

PREVALENCE AND COURSE OF FATIGUE

The baseline fatigue score was 37.9 ± 13.6 (mean, sd), and 62% of all patients scored 35 or higher. At follow-up the mean fatigue score was 38.8 ± 13.2 (difference 0.9, $p = 0.45$), 63% of the patients scored 35 or higher. The correlation between baseline and follow-up CIS-fatigue scores is 0.75 ($p < 0.001$). Eighty-nine percent of the patients that were identified as severely fatigued at baseline were also severely fatigued at follow-up (Table 2).

Patients who discontinued HPN at follow-up (n=8) had a mean age of 44 ± 12 (median 47), 5 of them were women, 5 were married or cohabiting, and 5 of them were employed. They showed a mean fatigue score of 43.1 ± 10.0 at follow-up. This did not differ from their baseline fatigue score (mean 43.8, ± 10.3, $p = <0.001$). Five of these were identified as severely fatigued at baseline and follow-up.

Table 2 Course of fatigue

T2 T1	Severe fatigue at follow-up	Heightened fatigue at follow-up	No fatigue at follow-up
Severe fatigue at baseline (n=37)	33 (89%)	2 (5,5%)	2 (5,5%)
Heightened fatigue at baseline (n=8)	3 (37,5)	2 (25)	3 (37,5)
No fatigue at baseline (n=15)	2 (13,3)	5 (33,3)	8 (53,3)

The course of fatigue: numbers and percentages of patients that were classified as severely, heightened or not fatigued at follow-up, on basis of their classification as severely, heightened or not fatigued at baseline

PREDICTORS OF FATIGUE

The correlations between the predictive variables and fatigue at follow-up are presented in Table 3. There was multi-collinearity between depression and acceptance ($r = -0.651$) and between depression and anxiety ($r = 0.628$). Based on these results, acceptance and anxiety were excluded, and avoidance, social companionship, functional impairment, self-efficacy, and depression were included in the regression analysis.

Table 3 **Pearson Correlations between possible continuous predictors at baseline and fatigue at follow-up**

	Fatigue
Coping	
- Active problem solving	-.098
- Avoidance	.330**
Health cognitions	
- Acceptance	-.369**
SSL-I (amount of social interactions)	
- Total	-.157
- Emotional interactions	-.214
- Emotional support problems	-.022
- Esteem support	-.185
- Instrumental interactions	.048
- Social companionship	-.257*
- Informational support	-.166
SSL-N (negative interactions)	.230
SIP – Total	.511**
Self-efficacy fatigue	-.443**
Anxiety	.369**
BDI-PC	.444**
CIS – Fatigue	.745**
Laboratory measures	
- Haemoglobin	.086
- Albumin	-.139
- Total bilirubin	-.242
- Creatinine	-.036

*p=<0.05 **p=<0.01

The longitudinal analysis with fatigue at follow-up as dependent variable and fatigue, depression, self-efficacy, avoidance, functional impairment and social companionship at baseline as independent variables showed that 60% of the variance of fatigue was predicted by fatigue and avoidance. Fatigue was responsible for 57%, and avoidance was responsible for 3% of the variance (Table 4, model 1).

Tabel 4 **Linear Regression of complete model and final model**

Model 1					
Complete model		**B**	**SE B**	**β**	**P-value**
	Constant	13.926	11.333		.224
	Fatigue baseline	.653	.106	.659	.000
	Social companionship	.262	.371	0.65	.483
	Avoidance	.537	.309	.149	.087
	Functional impairment	.110	.502	.088	.400
	Depression	-.245	.502	-.053	.627
	Self-efficacy	-.704	.394	-.167	.079
Final model		**B**	**SE B**	**β**	**P-value**
	Constant	1.777	5.231		.735
	Fatigue baseline	.714	.082	.720	.000
	Avoidance	.597	.298	.165	.049

Cross-sectional, the analysis with baseline fatigue as dependent variable and depression, self-efficacy, avoidance, functional impairment and social companionship at baseline as independent variables showed that 46% of fatigue was explained by functional impairment, self-efficacy, and depression. Functional impairment was responsible for 31% of the variance, self-efficacy for 11%, and depression was responsible for 4% (Table 4, model 2).

Model 2					
Complete model		**B**	**SE B**	**β**	**P-value**
	Constant	50.408	10.833		.000
	Social compagnionship	-.158	.425	-.038	.711
	Avoidance	.040	.355	.011	.911
	Functional impairment	.463	.138	.364	.001
	Depression	1.041	.568	.218	.071
	Self-efficacy	-1.062	.402	-.269	.010
Final model		**B**	**SE B**	**β**	**P-value**
	Constant	49.472	7.742		.000
	Functional impairment	.465	.136	.366	.001
	Depression	1.102	.535	.230	.043
	Self-efficacy	-1.100	.385	-.279	.006

Discussion/conclusion

We found that severe fatigue is a persistent problem in daily life of HPN patients. This finding has also been reported in other patient categories, such as (disease-free) breast cancer patients[26], chronic peritoneal dialysis patients[16], and patients suffering from rheumatoid arthritis.[50] For HPN patients, no predictors of fatigue were available from the literature. Our first longitudinal analysis showed that fatigue is the most important predictor for persistent fatigue. This result has also been found by Servaes et al. in disease-free breast cancer patients.[26] Our second cross-sectional analysis, showed that functional impairment, self-efficacy, and depression explain a considerable part of fatigue at baseline.

While fatigue is a frequent symptom in HPN patients, it has received no attention in research. As HPN patients may suffer from anaemia, problems with fluid intake/diarrhoea, renal disease or liver disease, it is reasonable to assume that fatigue is related to somatic problems. However, our results show no correlations between relevant laboratory measures and fatigue. This is in accordance with several studies in patients on haemodialysis and in patients with primary biliary cirrhosis, where no association was found between anaemia, albumin- , creatinine-, and bilirubin levels and fatigue.[15;32-35]

As in our study, other studies in patients suffering from rheumatoid arthritis show that the relationships between psychosocial variables are often much stronger than ‘objective’ measures of disease severity or inflammatory markers, like laboratory values, swollen joints or deformities.[51-53] Riemsma et al.[28] showed that laboratory measurements like haemoglobin concentration and erythrocyte sedimentation rate are not significantly related to fatigue, while psychosocial aspects like self-efficacy and problematic social support are the most important variables in explaining fatigue.

With regard to the results for functional impairment, it can be concluded that HPN patients experiencing more functional impairment have higher levels of fatigue. Regarding self-efficacy, a lower sense of control with respect to fatigue complaints is associated with an increase in experienced fatigue. Both these findings are consistent with results of studies with chronic fatigue syndrome patients, multiple sclerosis patients, and patients with rheumatoid arthritis.[20;28] In these patient populations, a negative self-efficacy was found to have a direct negative causal effect on fatigue severity. It is known that improving self-efficacy can be enhanced by self-management courses and it may thus be possible to decrease symptoms of fatigue.[28] Self-efficacy is also an important aspect of cognitive behaviour therapy in CFS patients. Prins et al.[44] found that patients with a greater sense of control at baseline had a larger decrease in fatigue severity after cognitive behaviour therapy, than patients with lower sense of control.

For CFS patients, cognitive behaviour therapy (CBT) has proven to be successful in reducing fatigue complaints.[44;54-56] Besides reducing fatigue severity, CBT also had a positive effect on functional impairment.[44] A systematic review of Neill et al.[57] showed the effectiveness of non-pharmacological interventions for fatigue in chronic diseases. Exercise appears to be an effective, appropriate and feasible non-pharmacological intervention for reducing fatigue in people with MS, RA, and Systemic Lupus Erythematosus (SLE). This is consistent with recommendations for cancer-related fatigue and chronic fatigue syndrome. In addition, a range of behavioural interventions, like energy conservation, may be helpful in reducing fatigue in MS, RA, and SLE.[58-60] Educational interventions also produced statistically significant reductions in fatigue.

The finding that depression partly explains fatigue is also confirmed by other studies on fatigue. Leserman et al.[61] showed that depression results directly in fatigue. Lui [25] found that depression was the most important predictor of fatigue in haemodialysis patients. Although this remains to be proven in future research, in our opinion the adequate identification and treatment for depression might also prove to be an effective strategy for decreasing levels of fatigue.[25;62] In HPN patients, a study by Smith et al. [63] showed that by means of interactive education, depressive reactions can be prevented and the patient's own capacity to solve problems is promoted. This intervention also led to a higher health related quality of life.

Surprisingly, fatigue also was a main problem in patients who discontinued HPN. Their fatigue scores were higher compared to patients still on HPN. This can possibly be explained by having less energy because of their nutritional status. These patients have to eat often during the day, to maintain their body weight.

Importantly, we included about 70% of all Dutch HPN patients who were treated according to very similar protocols. The 30% not included did not differ in gender, age, duration or indication of HPN. Therefore, the sample seems representative of the whole population of HPN patients in the Netherlands. Unfortunately, reasons for not participating are unknown. We used validated questionnaires. Another strength of our present study is that there were no missing data. With exception of the patients who died, there was no loss to follow-up in 2007. A weakness of this study is that, although we included about 70% of the Dutch HPN population, the sample size as a whole remains relatively small. Due to this problem, we could only include the total SIP-68 score in our analysis, instead of different subscales. Based on these notions, an additional longitudinal, and ideally multicentre international study, including these factors is recommended.

The importance of identifying modifiable factors to predict fatigue is that these can help in the prevention and treatment of this problem.

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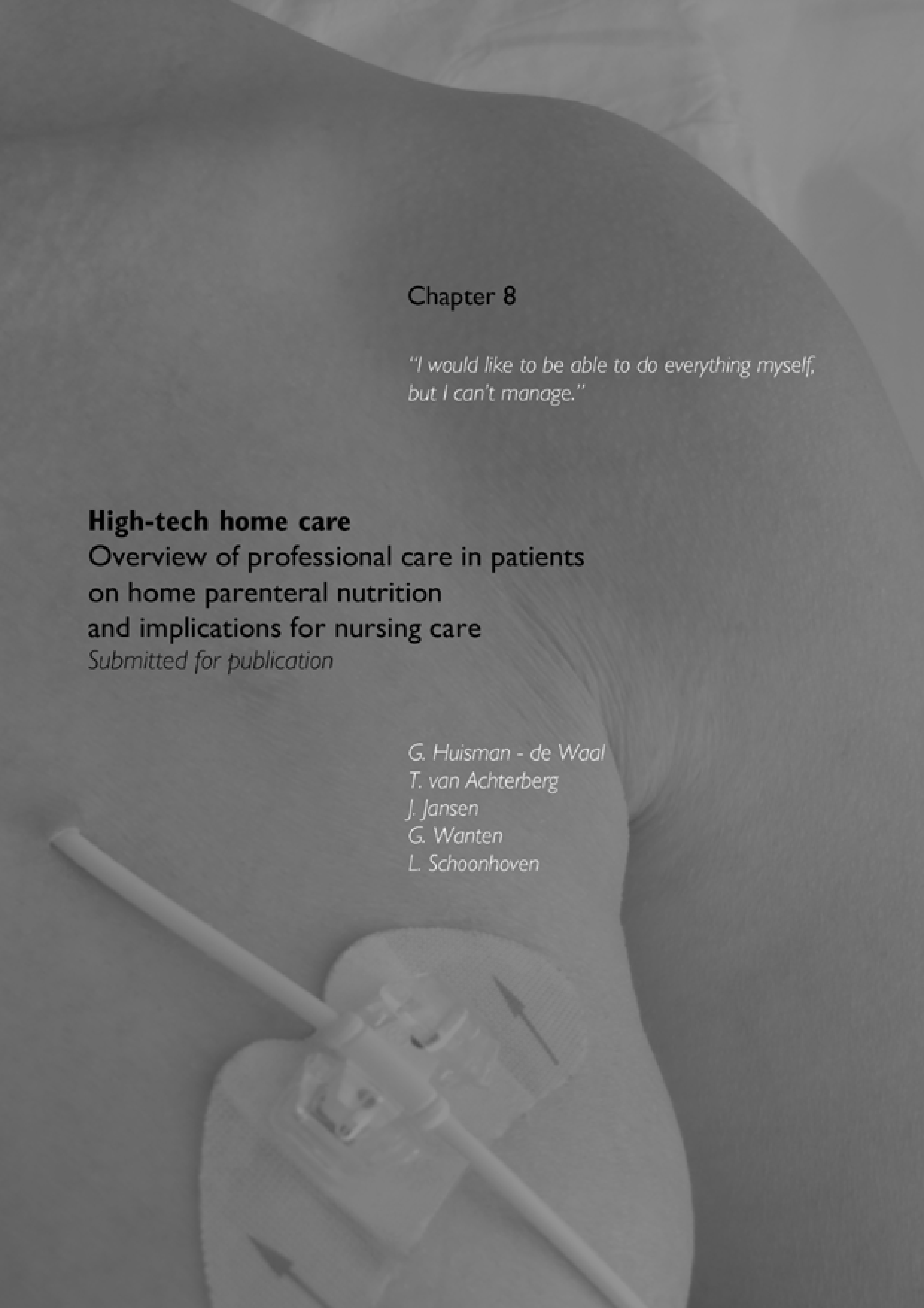

Chapter 8

"I would like to be able to do everything myself, but I can't manage."

High-tech home care

Overview of professional care in patients on home parenteral nutrition and implications for nursing care

Submitted for publication

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Abstract

BACKGROUND: Home parenteral nutrition (HPN) is a lifesaving treatment for patients who cannot eat or cannot eat sufficiently, due to serious chronic intestinal failure. Very little is known about follow-up care after initial instructions during a hospital stay. Yet this is an important aspect of care as patients, although well trained, must cope with high-tech skills at home. Also, complications, and psychosocial complaints can occur.

OBJECTIVES: The aim of this study is to describe the quality, quantity, and content of care given to HPN dependent patients by various professionals in the Netherlands, and to detect potential shortcomings.

DESIGN: A descriptive survey.

PARTICIPANTS: Adult patients from the largest HPN centre in the Netherlands, who had been on parenteral nutrition in the home-setting for at least one year.

METHODS: A survey was performed, using a patient questionnaire to assess contacts with professionals and possible shortcomings in care. Nursing files from HPN nurses were reviewed for information from all contact moments. HPN nurses and (specialised) home care teams were interviewed to assess nursing care and to detect whether they experienced bottlenecks in daily care.

RESULTS: HPN patients visit several professionals. The nutrition support team, at our centre comprising a gastroenterologist, dieticians and HPN nurses, was primarily responsible for the HPN care. In daily practice, HPN nurses were contacted most frequently. Physical complaints like abdominal pain or nausea, and venous access problems like fever were discussed most often. Patients were satisfied about the nutrition support team, but both the patients as well as the HPN nurses reported that relatively little attention was paid to psychosocial problems. Furthermore, the included patients visited their General Practitioner (GP) 11 times per year on average (range 1 to 104). Patients experienced a bottleneck with respect to the GP’s knowledge of HPN-related matters.

CONCLUSION: HPN patients visit the nutrition support team and their GP most frequently, and a lot of attention is paid to medical and physical problems. Psychosocial problems, however, were only discussed in a minority of patients and this was experienced as a shortcoming. Patients' concerns must be integrated in contact moments, to enhance quality of life.

Introduction

Home parenteral (intravenous) nutrition (HPN) is a lifesaving treatment for patients with severe intestinal failure who cannot meet their fluid- and or nutrient needs by means of a normal enteral diet. Chronic intestinal failure is a serious complication of a number of gastrointestinal diseases ranging from inflammatory and vascular disease to radiation enteritis and motility disorders.[1;2] HPN can provide a patients' total nutritional requirements and/or can be a supplement to oral or enteral intake. Therefore, the frequency of HPN administration can range from 2 to 7 times a week. HPN has allowed more patients to be discharged from hospital who would otherwise have remained in hospital with increased healthcare costs.[3] HPN may be administered as a 'cyclic' infusion over a number of hours per day (mostly overnight for a 12-14 hour period). A night-time cyclic infusion is preferred, because it frees the patient from carrying an infusion pump during the day, thus offering a more normal lifestyle, resulting in lower frequency of parenteral nutrition-associated liver disease.

Patient education is a crucial nursing intervention in ensuring successful outcomes for the patient on HPN.[4] HPN education aims at the care of the central venous access device, administration procedures, and monitoring for complications such as infection, occlusion, or central vein thrombosis. Sometimes, a partner or other caregiver is educated during the same training sessions. In some cases, when the patient and/or partner is not able to learn or perform all procedures, for instance following a neurologic event, home care nurses are engaged to assist with, or carry out the HPN procedures once the patient is at home.

Research indicates that because of the complexity of Total Parenteral Nutrition (TPN) therapy, a high level of knowledge and expertise is required in the management of these patients.[5] Evidence demonstrates that physicians have minimal training and experience in this area of nutrition support[5], and consequently this has led to the development of specialised multidisciplinary nutrition support teams in many health care facilities.[6] It could be expected that outcomes of a multidisciplinary nutrition support team are influenced by the combined disciplines of the TPN team members, and their knowledge and expertise.[6;7] A multidisciplinary team can be expected to be able to assess the patients' nutritional status, prescribe the nutritional requirements, and reduce the incidence of complications through regular monitoring.[8;9] Several studies show that a multidisciplinary team is a way of providing efficient service, and it can improve health outcomes and the quality of patient care.[10-12]

So far, however, little is known about the quality, extent and content of the professional care given to HPN patients. These are important aspects of care as patients, although well trained, must cope with high-tech skills at home as well as possibly life-threatening complications such as central line related infections, access occlusions, as well as a broad range of psychosocial problems.[13-15] Therefore, it is crucial to characterise professional care, in order to deliver effective, and patient-centred supervision.

The aim of this study is to describe the quality, quantity and content of care given to HPN dependent patients in the Netherlands by the major academic HPN centre, and to point out potential shortcomings.

Method

DESIGN

A survey was performed between January and April 2009, using a patient questionnaire, patient file analysis, and interviews to detect contacts with professionals and possible shortcomings in care for the year 2008.

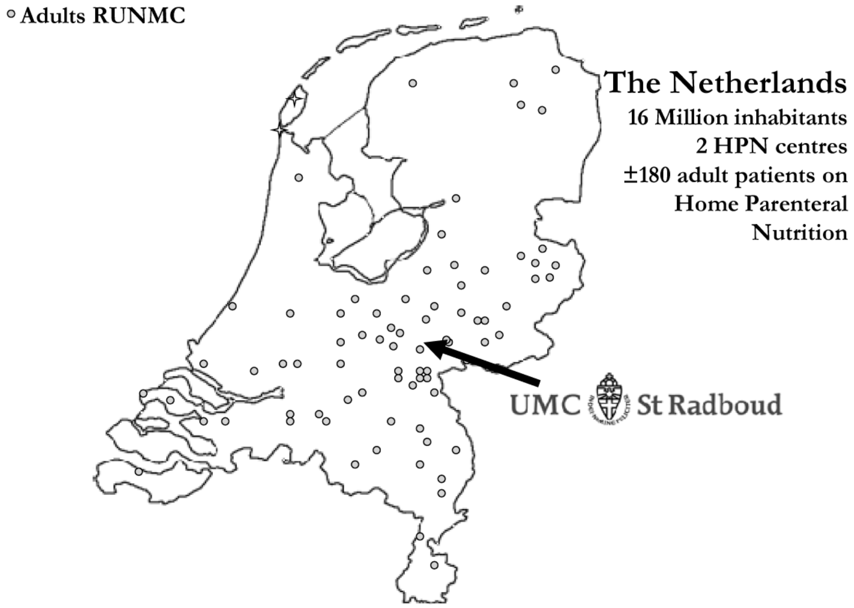
PATIENTS/PARTICIPANTS

Adult patients from the Radboud University Nijmegen Medical Centre (RUNMC) in the Netherlands were included in January 2009 if they had been on parenteral nutrition in the home-setting for at least one year (n=64). Patients gave written informed consent.

SETTING

In the Netherlands, the care for the approximately 180 patients on long-term (> 3 months) home parenteral nutrition is mainly carried out by the multi-disciplinary nutrition support teams of two university centres, in Nijmegen (currently 105 patients) and Amsterdam (ca. 50 patients). Figure one shows the geographical spreading of HPN patients in the Netherlands, treated in Nijmegen. In our HPN centre in Nijmegen, this multidisciplinary nutrition support team is responsible for the HPN patients and comprises a physician (gastroenterologist), a dedicated HPN nurse and a dietician. Patients are generally hospitalised in one of these specialised centres for about two weeks, in order to obtain all knowledge and master all skills necessary for safe HPN, using protocols. If a partner or other caregiver is involved, this person too is educated during this two week period.

Figure 1 Geographical spread of HPN patients treated by the Radboud University Nijmegen Medical Centre (RUNMC) in the Netherlands



When new HPN patients are discharged from the hospital, a home-visit by the HPN nurse is a standard procedure (n=16 new patients in 2008). Issues that are discussed during home visits include physical, psychosocial, emotional, economic, and practical aspects. After this first visit, follow-up home visits only take place when indicated by the HPN nurse. In these visits, mainly physical and psychosocial problems are discussed.

In some of the HPN patients, a specialised home care team is involved in case the patient cannot master all HPN procedures. Training for members of this team is given when a new HPN patient is hospitalised. This education is given once by the HPN nurse, especially in teams who have no other HPN patients in care.

FILE ANALYSIS

Nursing files kept by HPN nurses were reviewed for data over the year 2008 with a standardised record for data extraction. Two reviewers independently collected information, including age, sex, underlying disease, indication for HPN, years on HPN, type of CVC (external tunnelled vs. implanted subcutaneous port vs. Arterio Venous Fisulae (AVF)), venous access complications, and frequency and content from all contact moments between patient and the nutrition support team, and other contact moments with the nurse. For each patient, venous access complications and hospitalisations due to these complications were checked in the patients' medical files as well.

INTERVIEWS

HPN nurses were interviewed to assess whether they experienced bottlenecks in daily care (n=4). We used an interview topic list based on the aims of this study. This list included content of outpatient clinic visits, telephone/e-mail contacts, home visits, and contact with other relevant professionals. We started the interviews with a general question about qualities and bottlenecks experienced in HPN care. Further questions were based on what the respondent said. At the end of the interview the researcher checked whether all topics had been covered.[16] Information from these interviews complement information from the file review.

Primary responsible nurses from (specialised) home care teams were interviewed by telephone (n=13). A topic list was used, also based on the aims of this study. Patients gave consent to contact primary responsible nurses. Interview topics were frequency and content of care, protocols used, education, contact with nutrition support team and shortcomings experienced. All interviews took place in April 2009.

QUESTIONNAIRE

Patients received a written questionnaire by mail. Completion of the set took about 30 minutes. We evaluated general characteristics (3 questions), TPN characteristics such as HPN duration and indication (7 questions), frequency and content of professional care (51 questions), and satisfaction with contacts with professionals (17 questions). Satisfaction was evaluated for all different professionals with two questions, 'are you satisfied with ..?', and in case the patient was not satisfied, 'why are you not satisfied?'. The Sickness Impact Profile short form 68 (SIP-68) is a widely used measure of the impact of disease on an individual's physical and psychosocial functioning.[17,18] For every subscale, patients were asked if they had experienced problems, and if there had been a need for professional help (12 questions). Finally, frequency and satisfaction with home visits by HPN nurses were evaluated (3 questions). The feasibility of the questionnaire set was tested in two HPN patients.

These data were not included in the study. Based on the outcome, changes were made to the layout and introduction.

STATISTICAL ANALYSIS

File analysis/questionnaire

Descriptive statistics were used for all variables. These included means, medians, and standard deviations. All statistical tests were performed using SPSS version 16.0.

Interviews

The notes made by the interviewer during the interviews were typed out in full. After the interviews, a member check was done by giving the report to the interviewee in order to check the authenticity of the work. The comments served as a check on the validity of the interpretation.[19] Content analysis was performed on the data obtained during the interviews. Central topics were summarised from the interviews.

Results

An overview of patient care will be given. First the patients' general characteristics, results for the Sickness Impact Profile, and hospitalisations are described. Secondly, results for quantity and content of care are reported. Finally, quality of care and experienced bottlenecks are presented.

HPN PATIENTS

The HPN population studied comprised 64 patients of which 22 were males. The mean age was 53 (±14.7) years (range 18-77 years). The mean duration of HPN use, counted from HPN start until December 31 2008, was 6.4 years (range 1.1-32.3 years). Indications for HPN in our population were mainly motility disorders (36%) and short-bowel syndrome (59%), the latter mostly related to inflammatory bowel disease or mesenteric thrombosis. Patients had three types of catheters, a Port-a-Cath (PAC, 35%), a central line (Hickman catheter, 41%), or an arteriovenous fistula (AVF, 24%). Most patients were independent in all HPN procedures (63%), in 16% a partner was involved, and (specialised) home care teams were involved in 21% of all patients (table 1).

Eighty percent of all HPN patients completed the questionnaire (n=51). According to scores on the Sickness Impact Profile (Table 1), patients experienced most problems in the subscales social behaviour, psychic autonomy and communication, and emotional stability. Patients spent limited time visiting friends and family, joining sport clubs or other leisure activities. Somatic autonomy (e.g. general daily care, making transfers, walking) and mobility control (e.g. dressing, walking on the stairs) were also problematic.

Almost half of the patients (47%, n=30) were hospitalised due to HPN complications in 2008 (table 1). The most common complications were catheter related blood stream infections (CRBSI) and AVF occlusions. In all patients CRBSI was treated with antibiotics. In 45% of the infections, the catheter had to be removed, and a new catheter had to be inserted. AVF occlusions were treated with Percutaneous Transluminal Angioplasty in 86% of all cases. About one third of the patients (31%, n=20) were hospitalised due to their underlying diseases in 2008. Frequently reported reasons were abdominal pain and abdominal surgery.

Table 1 Patient characteristics

Patient characteristics		
Mean age, years (range)	53 (18-77)	
Woman, %	66%	
Married, cohabiting, %	81%	
Patients with paid employment, %	21%	
Years on HPN, years (range)	6.4 (1.1-32.3)	
Hours on HPN/day, mean (range)	12.8 (4-24)	
Type of catheter:		
Implanted port , %	35%	
Tunnelled catheter, %	41%	
AVF (in combination with tunnelled catheter or implanted port), %	24%	
Hospital admission due to catheter problems in 2008:		
• Admitted, % (n)	59% (30)	
• If admitted, number of admissions, mean (range)	1.9 (0-4)	
• If admitted, number of days, mean (range)	21 (0-161)	
Hospital admission due to the underlying disease in 2008:		
• Admitted, % (n)	39% (20)	
• If admitted, number of admissions, mean (range)	2.0 (0-7)	
• If admitted, number of days, mean (range)	6 (0-60)	
Sickness Impact Profile – 68	% patients that experienced many or very many problems in this area	% patients that already have professional help (% patients who lack, but would prefer professional help in this area)
- Somatic autonomy	34.3	28.6 (5.7)
- Mobility control	40.0	17.1 (2.9)
- Psychic autonomy and communication	17.1	17.1 (5.8)
- Social behaviour	55.9	23.5 (5.9)
- Emotional stability	20.6	12.0 (5.9)
- Mobility range	35.3	17.6 (5.9)

QUANTITY AND CONTENT OF CARE IN HPN PATIENTS

Nutrition support team

HPN patients visited the outpatient clinic, where they simultaneously saw their gastroenterologist, HPN nurse and a dietician (n=156 thirty-minute visits in 64 patients in 2008). The mean number of these visits in 2008 was 2.52 (sd 1.83, range 0-8). Most patients were seen every three to four months. Clinical parameters monitored during these visits were body weight, oral intake, hydration, and body temperature. Most frequently discussed subjects were physical complaints, venous access related problems, and there was communication about the composition or frequency of administrating of the parenteral nutrition (table 2). Only in 14% of all visits (n=22), nurses reported patients' overall well-being, in terms of 'he/she is doing well/reasonably well etcetera'. In 4% of the visits (n=7), psychosocial problems, like anxiety, depression, and finding new ways to cope with HPN were discussed. Seven patients did not visit the nutrition support team at the outpatient clinic in 2008, because they were treated by another gastroenterologist.

In 2008, five follow-up home visits were made by the HPN nurse. In all visits, patients' physical complaints like nausea and diarrhoea were discussed. In 4 out of 5 visits, psychosocial issues like depressive feelings and ways of coping were the most important issues discussed. In December 2008, the most recent visit was 2.5 years ago on average (sd 1.4, range 0.6-6.0 years).

Table 2 Subjects discussed during contact with multidisciplinary nutrition support team

Subjects discussed		**Outpatient clinic** *n = 64 patients* *n = 156 contacts (gastroenterologist, HPN nurse, dietician)*	**Consultation (HPN nurse) by telephone/e-mail:** *n = 64 patients* *n = 219 contacts by telephone n = 25 contacts by e-mail*
Overall well-being	n	22	0
	%	14% of all visits (17 pat)	
Physical complaints	n	132	58
	%	85% of all visits (56 pat) • Abdominal pain • Nausea • Fatigue • Stoma leakage • Cramps hand/feet	24% of all contacts (31 pat) • Abdominal pain • Nausea • Fatigue • Diarrhoea • Vomiting
Venous access-related problems	n	55	83
	%	35% of all visits (25 pat) • Exit site infection • Difficulties AVF puncturing • Crack in catheter	34% of all contacts (39 pat) • Fever/cold chills • Symptoms exit site infection • Difficulties AVF puncturing • Crack in catheter
Parenteral nutrition composition / frequency	n	49	29
	%	31% of all visits (24 pat) • Weight change • Blood tests	12% of all contacts (11 pat) • Weight change • Complaints after nutrition change
Test results	n	36	13
	%	23% of all visits (20 pat) • Bone density measurement • CT scan • Laboratory measures	5% of all contacts (5 pat)
Medication	n	19	24
	%	12% of all visits (8 pat) • Acid suppression • Analgesics • Diarrhoea inhibitors • Sedative drugs	10% of all contacts (12 pat) • Acid suppression • Diarrhoea inhibitors • Antibiotics
Practical problems	n	6	28
	%	4% of all visits (4 pat) • Pump dysfunction • Accu problems	11% of all contacts (18 pat) • Pump dysfunction • Vacation • Order problems
Psychosocial problems	n	6	5
	%	4% of all visits (4 pat) • Anxiety • Depression • Coping	2% of all contacts (3 pat) • Stress • Anxiety
Contact other professionals	N	0	14
	%		6% (6 pat) • General practitioner • Home care teams

In total, 244 other contact moments documented in the HPN nursing files (n=219 telephone calls, n=25 e-mail) were analysed. In 2008, patients called or e-mailed with the HPN nurse for an average number of 3.9 times (sd 4.2, range 0-22). Most contacts were because of venous access device-problems such as fever, cold chills or symptoms of an exit site infection, physical problems such as abdominal pain, nausea or fatigue, or about weight change (Table 2). HPN nurses told that telephone contacts often ended with more psychosocial counselling, but this was not registered in the HPN nursing files.

Other professionals

Apart from the outpatient clinic visits, patients visited other professionals. In 2008, the general practitioner (GP) was seen by 84% of the patients (n=43), with a mean of 10.6 times per year (sd 22.4, range 1-104). The type of care provided by the GP was very diverse (Table 3).

Sixty-three percent of the HPN (n=32) patients also visited other medical specialists in 2008. The sub-specialisms that were most frequently reported were vascular surgery, internal medicine, rheumatology, and cardiology. Twelve percent of the HPN patients (n=6) received counselling from a psychologist or psychiatrist. About 16% of the patients (n=8) had contacted peers during especially organised 'patient days' or by telephone.

Table 3 Contacts with professionals

Professional	% patients seen by this professional	Mean frequency (per year)	Satisfied, %	Provided care
Gastroenterologist	94%	3.35 (sd 1.4, range 1-6)	93%	• Monitoring clinical parameters • Answering patient questions
HPN nurse	86%	4.47 (sd 3.1, range 2-12)	92%	• Instructions • Patient questions • Advice
Dietician	67%	2.8 (sd 1.0, range 1-4)	94%	• Body weight • Parenteral nutrition composition
Other medical doctor	63%	2.8 (sd 2.1, range 1-7)	93%	• Monitoring by different specialism's
General Practitioner	84%	10.6 (sd 22.4, range 1-104)	92%	• Blood tests • Treatment of complaints • Psychosocial support (7%)
Psychologist / psychiatrist	12%	12 (sd 15.3, range 1-40)	100%	• Psychosocial support (e.g. depressive feelings, anxiety)
Peer support contact	15%	Median 1 (3x 1, 1x24, 1x70)	100%	• Patient meetings • Problems in daily life
Domestic help	30%	84.5 (sd 45.6, range 26-156)	100%	• Housekeeping
Home care team	6%	278 (mean 5.3 times a week) (sd 150.7, range 104-365)	100%	• Stoma care • Support with showering
Specialised home care team	14%	339 (mean 6.5 times a week) (sd 258, range 14 – 730)	100%	• (support in) HPN procedures

A small group of patients (n=13, 20%) were supported by (specialised) home care nurses in 2008. Three patients had received help with showering or stoma care (home care). In the other patients

(n=10), nurses had carried out HPN procedures, like preparing and (dis)connecting the parenteral nutrition formulation or they had supported the patient doing the procedures themselves (specialised team). Nine out of ten specialised teams had used protocols from the nutrition support team, and they were all educated by the HPN nurse. On average, patients saw 8 different nurses at home (range 2-16), and care was provided from two times a day to once in four weeks. Most patients (n=9) saw nurses daily.
Domestic help was given in 30% of the patients (n=15).

QUALITY OF CARE

Nutrition support team

According to the questionnaires, HPN patients were satisfied about the professionals of the nutrition support team (table 3). However, almost a quarter of the respondents was not satisfied about the frequency of the home visits made by the HPN nurse. All of these patients reported it was too long ago. Two patients mentioned the idea of group meetings at the outpatient clinic instead of home visits. In group meetings they would like to discuss problems and concerns due to HPN use, and hear from other patients how they cope with some problems.

The results from the interviews with the HPN nurses (n=4) showed that they were very positive about the nutrition support team. Accessibility was one of the most important strong points noted. There were two-weekly meetings with all members of the nutrition support team, also including a pharmacologist, and there was a weekly combined outpatient clinic visit. Experienced bottlenecks mentioned in the interviews with HPN nurses were the waiting list for a surgeon (in case of the need for a new venous access device), and the considerable turnover in (relatively inexperienced) surgical trainees. Furthermore, registration of all contacts (especially e-mail contact) was only partial, and communication with other hospitals in case of hospitalisation of HPN patients elsewhere was very limited. During instruction, hospitalisation or outpatient clinic visits, psychosocial issues were only occasionally discussed. HPN nurses would prefer a more frequent home visit, due to the lack of time for psychosocial support during other contacts.

Other professionals

Almost all patients who saw their General Practitioners were satisfied (92%). One remark that was made by some patients (n=5) concerned a lack of knowledge regarding HPN practice of some GPs.
All patients were satisfied with their home care teams. However, two patients mentioned that they were previously supported by a specialised home care team. Because of the considerable number of nurses and the various different ways in taking care of hygiene issues during the HPN-related procedures, these patients decided to care for their HPN care themselves in 2008.
All of the (specialised) home care teams (n=13) were satisfied about the accessibility of the nutrition support team (mostly HPN nurse). No bottlenecks were noted by the teams.

Discussion

HPN patients and their family members (caregivers) face many lifestyle changes as they adjust to technology-dependent therapies such as Home Parenteral Nutrition. So far, this is the first study that shows part of the quality, quantity and content of care given to HPN dependent patients and as provided by various professionals of the multidisciplinary nutrition support team, (specialised) home care teams, general practitioners and other medical doctors.

HPN patients visited a broad range of professionals, of which the nutrition support team (in our setting in Nijmegen comprising a gastroenterologist, HPN nurse, dietician) was primarily responsible for the HPN care. Most patients were seen three or four monthly. These results were also found in a European study in 42 centres.[20] Besides the outpatient clinic visits, in practice, HPN nurses were frequently consulted by telephone or e-mail. Physical problems and venous access problems were main topics during outpatient clinic visits and HPN nurse consultation. Severe catheter related complications were nearly always handled by the nutrition support team in our centre.

Furthermore, most patients visited their general practitioner or another medical doctor for a broad range of problems.

HPN patients were satisfied with the care provided by their professional caregivers. However, some comments can be made. In the first place, the frequency of home visits was not satisfying in almost a quarter of the patients. On average, a home visit had been made 2.5 years ago, but for some patients this period was 5 to 6 years. Since the patients reported a substantial need for this kind of care it could be considered important to aim to visit each patient once every one to two years. Patients and HPN nurses mentioned that psychosocial care sometimes is missing during hospitalisation and other contacts, due to a lack of time. According to the HPN nurses, home visits give the best opportunity for patients to discuss patient concerns like fatigue, and social or emotional problems. In haemodialysis patients, such regular contact with health-care professionals and other patients has been shown to contribute to better life satisfaction.[21] Providing support for psychosocial adaptation to HPN and anticipatory guidance for integrating this care into a person's lifestyle is an important aspect of the nurse's role. [22]

Some patients were not satisfied with their general practitioner's knowledge of the HPN treatment and - procedures. Malone (1988)[23] tried to resolve part of this problem by introducing an information package, including background information, HPN training, complications of HPN, arrangements for a particular patient, and hospital management of HPN. Overall, the booklet was very well accepted by GPs. This kind of information could be developed for the Dutch GPs as well.

Finally, some specialised home care team comprised more than ten individual nurses, leading to differences in the performance of HPN procedures because of lacking experience. Such problems also might promote the occurrence of venous access complications. For specialised home care teams in the Netherlands, HPN remains a somewhat exotic treatment modality, and therefore, these teams may benefit from retraining by HPN nurses.

HPN nurses aim to educate new HPN patients to perform all HPN procedures autonomously. Carlsson et al. (2001)[24] concluded that the confidence a patient gets from handling his own HPN is one of the main factors giving positive self-control. In our centre, only a small group of HPN patients was supported by (specialised) home care teams.

Other patients were supported by their partner or other caregiver. Caregiving requires learning an extensive amount of information about illness, symptoms, medications, and technologic treatments.[25;26] Reactions to caregiving are mainly positive, but common problems like depression, social restrictions, strain, frustration and anger are mentioned.[27;28] In our centre, caregivers of adult patients were only involved in the education process at the start of the HPN programme. Home visits, made by the HPN nurse, should involve caregivers too, and experienced problems of caregivers should be assessed.

The strength of the present study is that we collected information on almost all persons involved in the provision of HPN patient care. We collected data from nursing files, interviewed HPN nurses and nurses from (specialised) home care teams, and we also invited patients to evaluate care. We included 80% of all our patients, and therefore we assume that the results of this study can be generalised to the total group of HPN patients in our centre. A 12 month period was evaluated, and therefore a relatively complete picture of the content of care can be expected to be given. A limitation of our investigation was the presence of certain lacks of information in the nursing files. HPN nurses reported that especially e-mail contact was very poorly documented. In practice, they sometimes e-mailed with patients two times a week, and most of these contacts were not summarised in their files. A second limitation relates to the questionnaire. Most questions were developed by our research group, because no validated questionnaire was available. Finally, we did not interview the general practitioners and other medical specialists involved in the care for these patients with their various underlying diseases, and therefore we do not know whether they experienced bottlenecks in HPN care.

In conclusion, the findings of this study provide insight and direction for clinical practice regarding medical and psychosocial support in HPN patients. While there was ample attention for medical and physical problems, there seems room for improvement by more discussion of psychosocial issues by the nutrition support team, or by the HPN nurse during other contacts. Patient concerns should be integrated in the follow-up contacts to enhance quality of life.[28-30] The participation of a social worker or psychologist in the nutrition support team appears a strategy that might well lead to improved patient outcomes, but further research in this area is clearly needed.

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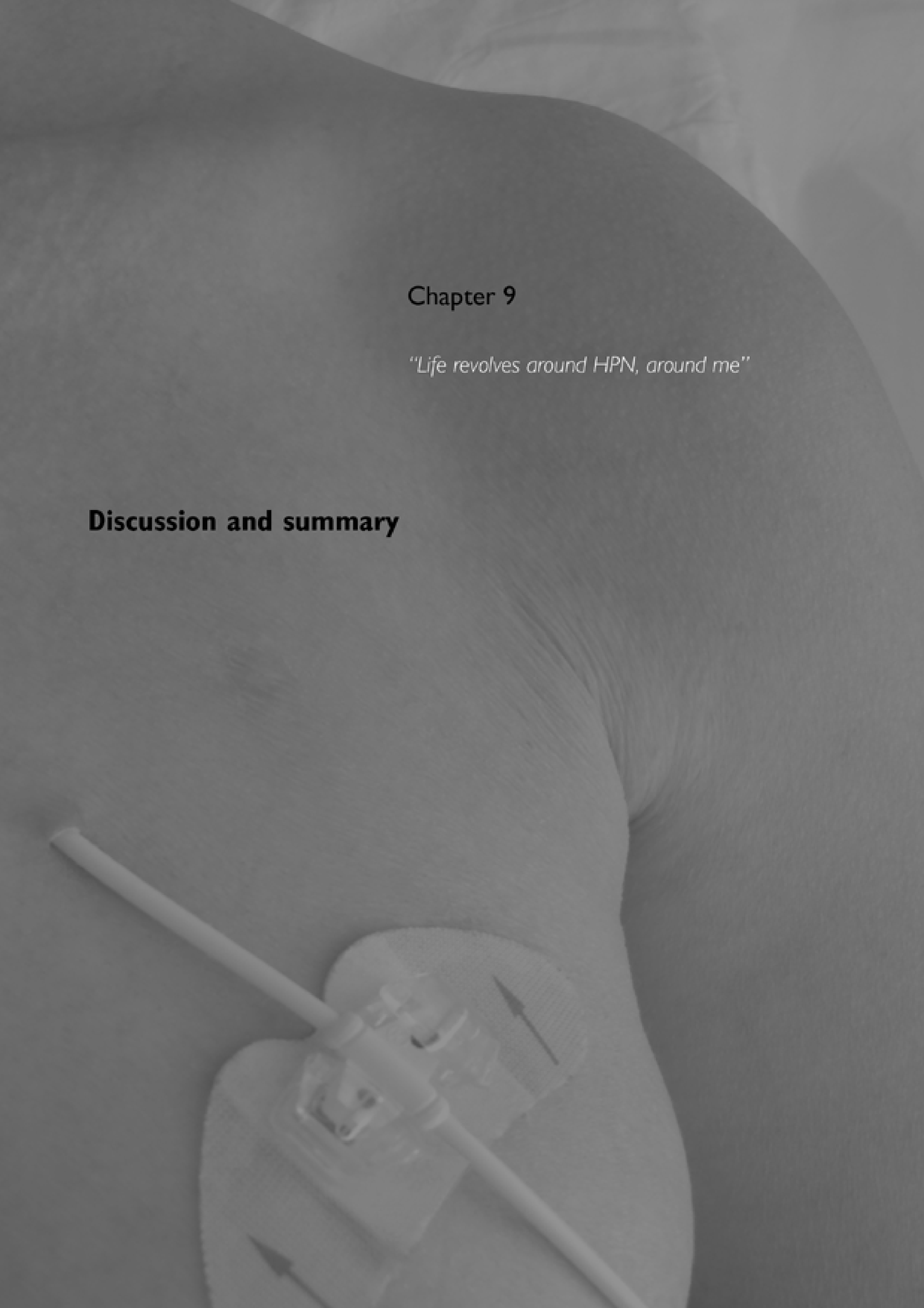

Chapter 9

"Life revolves around HPN, around me"

Discussion and summary

Total Parenteral Nutrition is a lifesaving therapy in patients who have severe chronic intestinal failure, defined as an inadequate intestinal function for the absorption of sufficient nutrients, electrolytes and water.[1] Total Parenteral Nutrition in the home setting (HPN) is a complex technology involving the intravenous infusion, performed by the patient or by another caregiver, of a sterile aqueous nutrition formulation directly into a large-bore central vein. Without the intravenous infusion of nutrients and electrolytes, there is an almost inevitable progression from metabolic disturbance and malnutrition to death in HPN patients.[2] Unfortunately, Venous access device (VAD)-related infections and occlusions remain very common and patient- and technique-threatening complications in HPN treatment so far. As such, VAD complications are the major challenge for HPN patients and professionals in that they are the foremost cause for HPN programme failure and the most high-ranked reason for renewal of the venous access.[3]

In order to transfer the care to the home, the patient and/or caregiver is taught to manage the complicated sterile routine. HPN is a time-consuming routine which may be required for many years or, in some cases, for the rest of life. It has a severe impact on the patient's life and any alteration from the daily routine requires planning. Indeed it has been shown that HPN directly affects the quality of life experienced by both the patient and his or her family.[4] A study of Baxter et al.[5] concluded that clinicians have serious concerns regarding the quality of life of their HPN patients and are in need of guidance concerning the assessment of this problem. Another important reason for assessing quality of life in HPN patients is that information concerning experienced problems can be brought back to professionals as well as patients and help to anticipate on and understand the consequences of HPN treatment.

The overall aim of the present thesis was to establish a body of knowledge on the quality of life, including somatic, psychological, and social aspects of daily life, as experienced by HPN patients. Furthermore, we described the concurrent Dutch population on HPN with respect to venous access related-complications and the interrelation with psychosocial problems and quality of life. Finally, we evaluated the quantity, quality and content of professional care for Dutch HPN patients.

This final chapter provides an overview of the included studies in this thesis, and discusses the main findings as well as methodological issues. Also, conclusions and suggestions for future research and practice are provided.

Summary of results

In **chapter 2**, various databases were searched for relevant studies on implications of HPN for the quality of life as experienced by patients, as well as caregivers. A total of 26 studies were included in this literature review. Results showed that HPN patients experience a moderate to good quality of life, but psychological problems, e.g. depression and anxiety, were common. Social restrictions because of the venous access device and the time schedule for HPN administration were also common. Furthermore, patients experienced gastrointestinal motility problems and physical complaints such as fatigue. Some of the patients were not able to have normal intake. Caregivers (e.g. partners and spouses) experienced social restrictions, depression and fatigue in daily life, but quality of life reported was similar to the norms for healthy populations.

Chapters 3 and 4 presented a survey on 48 Dutch HPN patients. A questionnaire was used to arrive at answers to the question: 'To what extent do long-term HPN patients experience problems?' Complementary, patients were interviewed to explore which HPN-treatment-related problems had a negative influence on daily life.

The questionnaires showed different physical problems such as diarrhoea, nausea, and vomiting, attributed to the underlying disease. Physical problems related to the HPN were fatigue, an odour (nutrition fluid), and nocturia. Psychosocial problems comprised depression, social impairment, and anxiety. The interviews clarified that psychosocial problems were the main complaints in daily life due to HPN dependence. Negative moods and feelings (e.g. anxiety, depressive feelings), limitations in social life, lack of freedom, and fatigue were most commonly reported. Patients had an ambivalent attitude towards the HPN treatment: on the one hand, life without HPN was felt to be impossible, on the other, living with HPN was hard and a considerable burden on everyday life. Some of the patients, though, had adapted to a life with HPN. They were particularly pleased that it was keeping them alive and although well aware of the limitations it was causing, they had learned to enjoy the remaining pleasures of life, while others felt restricted because of the physical or HPN-associated limitations (schedule, anxiety). This work shows that to improve the quality of life it is important to focus on fatigue, sleeping disorders, anxiety, depression, and social impairment. Despite the fact that HPN patients experience many somatic symptoms, psychosocial problems were primarily reported as having the greatest impact on daily life.

The success of HPN programmes is compromised by complications of venous access devices, such as bloodstream infection and occlusions. These problems result in multiple hospital admissions and, in the end, pose the foremost threat to continuation of HPN therapy. In **chapter 5** we compared blood stream infection (BSI) and occlusion incidence rates during central venous catheter and arteriovenous fistulae use. From the start of our HPN programme in the early 1970's, in addition to central venous catheter's, our centre has used arteriovenous fistulae (AVF) for vascular access in HPN care. Data were collected by reviewing the medical records. The population consisted of 127 HPN patients for whom 343 central venous catheters and 194 arteriovenous fistulae access years, represented by 62 arteriovenous fistulae and 623 central venous catheters, were analysed. In total, 836 vascular accesses were created to administer HPN in our 127 patients (median 5 per patient, range 1-24). Of the 120 created arteriovenous fistulae, 75 (63%) became functional; 6 failed during creation, and 39 failed during maturation, mostly due to occlusions. In functional arteriovenous fistulae the occlusion incidence rate was slightly higher compared with some types of central venous catheters. Independent of central venous catheter type, the incidence rate of the most serious access-related complication, i.e. blood stream infection, was extremely low in arteriovenous fistulae compared with central venous catheters. These results suggest that arteriovenous fistulae can be safe and valuable alternatives for central venous catheters in certain patients on long-term HPN.

The aim of **chapter 6** was to present an overview of venous access device-related complications and to assess whether these adversities are related to experienced psychosocial problems and quality of life. Information on venous access device -related complications was collected from the medical records of all 110 adult HPN patients who were followed by the two major referral centres in the Netherlands. In

addition, a survey was performed among this group to characterise psychosocial problems and assess their association with technique-related complications. Seventy-five of the 110 patients (68%) responded. The overall incidence of access-related blood stream infection was 3 per 1000 venous access days. Venous access device occlusions had occurred 0.8 per 1000 venous access days.
Severe fatigue was reported by 66%, almost 57% percent of the HPN patients had depressive disorders, and the results of the SIP-68 questionnaire showed raised levels on the subscales Social Behaviour, meaning high social impairment. For quality of life , patients scored a 5.7 on average, on a visual analogue scale from 0 to 10, where 0 stands for the worst-, and 10 for the best quality of life.
There was a highly significant association between the incidence of venous access device -related complications and the occurrence of psychosocial complaints. Taken together, the results from this study showed that in patients on HPN, depression, fatigue, social impairment, and the quality of life experienced are closely related to previously experienced access-related complications. This notion should bolster our efforts to prevent such adversities and further optimise the quality of HPN care.

In our interviews, HPN patients reported fatigue as the most bothersome problem in daily life. Therefore, **chapter 7** describes the course of fatigue and the predictors of persistent fatigue. Patients completed questionnaires at baseline and follow up (12 months later). Measurements included fatigue, depression, functional impairment, social support, self-efficacy, coping, anxiety and acceptance. Relevant laboratory measures were obtained from the medical records at baseline and follow up. At baseline, sixty-five percent of the patients were severely fatigued (n=49). Eighty-nine percent of them experienced persistent fatigue. Serum haemoglobin, creatinine, albumin and bilirubin did not explain the occurrence of fatigue in this patient population. Baseline fatigue predicted 57% of the variance of fatigue at follow up, and the coping style avoidance was responsible for 3% of the variance. A cross-sectional analysis showed that 46% of the variance in fatigue was explained by functional impairment, self-efficacy, and depression. The importance of identifying modifiable factors to predict fatigue is that these can help in the prevention and treatment of this problem. We therefore recommend a treatment programme to reduce functional impairment and depression, as well as increase self-efficacy.

In our final study, presented in **chapter 8**, our aim was to describe the quality, quantity and content of care given to HPN dependent patients by various professionals in the Netherlands, and to detect potential shortcomings. To answer our questions, a survey was performed, using a patient questionnaire to assess contacts with professionals and possible shortcomings in care. Nursing files from HPN nurses were reviewed for information from all contact moments between patient and HPN nurses in 2008. HPN nurses and (specialised) home care teams were interviewed to assess nursing care and to detect whether they experienced bottlenecks in daily care. Sixty-four patients visited the outpatient clinic for 156 times in 2008 (mean 2.5, range 0-8). HPN nurses had 244 contact moments with HPN patients in 2008, mostly by phone. Major issues during outpatient clinic contact and telephone contact with the HPN nurse were venous access device-related problems like fever or symptoms of an exit site infection, and physical complaints like nausea and diarrhoea. Overall, patients were satisfied with care provided by professionals. Despite this fact, several patients mentioned that their general practitioner had a lack of knowledge, and some of the patients as well as the HPN nurses experienced bottlenecks in psychosocial care. Providing support for psychosocial adaptation to HPN and anticipatory guidance for integrating this care into a person's lifestyle seems an important aspect of the nurse's role.

Discussion of the main findings

The main findings of the studies in the present thesis can be categorised as follows: 1) quality of life and problems experienced by HPN patients in daily life, 2) venous access device-related complications, 3) the relation between problems experienced by HPN patients and venous access device-related complications, and 4) bottlenecks in professional care.

1) QUALITY OF LIFE AND PROBLEMS EXPERIENCED BY HPN PATIENTS IN DAILY LIFE

The mean quality of life scores in our studies are about 6 on average, based on a visual analogue scale from 0 to 10, where 0 stands for the worst possible quality of life and 10 for the best quality of life. More than one third of the HPN patients (35-42%) scored below 6. Results from other studies reported quality of life scores in HPN patients, varying from 'low' or 'poor' quality of life, to 'moderate' or 'good' quality of life.[4,6,7] A study by Carlsson et al.[8] used an almost similar quality of life scale as ours. The Visual Analogue Scale from 0 to 100 mm (0 = worst possible quality of life, 10 = best possible quality of life) was given to HPN patients, and their median score was 48.

Our review and survey showed that HPN patients had multiple physical symptoms, such as diarrhoea, abdominal cramps and nausea. Poor physical functioning has been reported in other studies too, and this influenced quality of life.[7,9] Psychosocial problems mentioned by HPN patients were fatigue, depression, and social impairment. These problems were also common in other studies.[8,10-12] Our results showed that a low quality of life was strongly related to an increment in fatigue, higher anxiety, more severe depression, and greater social impairment. Furthermore, there was a good correspondence between results from the review and our survey, with regard to physical and psychosocial problems, and quality of life.

The literature provides documentation that quality of life is poorer in individuals receiving HPN compared with normal populations and with patients with intestinal disease not requiring nutritional support.[12] Patients with end-stage renal failure (ESRF), treated with haemodialysis or peritoneal dialysis, have been shown to have problems similar to those treated with HPN.[13] Both patient groups are dependent on a technology for survival that affects daily activities. Psychosocial problems in ESRF-patients were comparable to those found in our studies. Depression, limitation in activities, and fatigue were reported as major psychosocial stressors in patients with ESRF.[14-16] Both groups of patients experience similar medical complications, for example septicaemia, electrolyte disturbances and venous thrombosis. There are, however, also differences, which account for a higher satisfaction of patients with end-stage renal failure. In particular, the more regular contact these patients have with health-care professionals and patients with similar problems, seems to contribute to better life satisfaction.[13] These differences may also be responsible for the differences in reported visual analogue scale scores. In patients with end-stage renal failure means between 59 to 86 on a scale from 0 to 100 mm were reported. Quality of life in our HPN patients is lower, with means between 5.7 and 6.2 on a scale from 0 to 10.

2) VENOUS ACCESS DEVICE RELATED-COMPLICATIONS

Venous access device related-complications were a major threat in the HPN population studied in this thesis, although, blood stream infection rates and occlusion rates were comparable to those reported in other studies.[17-21] Consequences of venous access device-related complications are access removal and subsequent replacement. Frequent replacement of the venous access device, eventually seriously compromises the possibilities to obtain central venous access and can necessitate small bowel transplantation.[22] Intestinal transplantation (ITx) is the only curative therapy for irreversible intestinal failure and it is the ultimate lifesaving option when complications impede parenteral support.[23,24] Intestinal transplantation, however, most certainly is not the solution for all patients depending on HPN. Since its beginnings in the late 1980s, the 1-year graft survival rate in ITx improved from 30% before 1991, to 80-90% between the years 2005 and 2007.[25] Intestinal transplantation continues to be one of the greatest challenges in solid organ transplantation and to date remains a relatively uncommon procedure with approximately 1300 transplants performed worldwide.[26] In the Netherlands, patients are listed for transplantation in case of severe or recurrent life threatening line sepsis, progressive liver disease, and/or loss of conventional venous access. The experience with ITx in our country remains limited: so far only five procedures (some multivisceral) have been performed. The successful emergence of intestinal transplantation as a curative alternative has provided many patients with bowel failure to be independent from infusions on a daily basis. A review by Sudan et al.[27] concluded that available (limited) data suggest that quality of life was reasonably good after intestinal transplantation and perhaps similar to that of normal individuals. Others found that most patients had few re-hospitalisations or complications. A high proportion of patient underwent successful social and occupational rehabilitation.[28-30]

To become the standard treatment for intestinal failure, transplantation must offer better survival, better quality of life, and lower costs than TPN. Considerable progress has been made towards these goals, but further refinements are needed before bowel transplantation becomes a routine surgical procedure.[26] Therefore, intestinal transplantation is only offered in case of HPN treatment failure.

Evidence-based interventions which effectively reduce the risk of catheter-related blood stream infection therefore are very important, and are implemented in our daily practice. These include the use of single lumen, tunnelled or implanted catheters, use of 2% chlorhexidine as skin antiseptic, appropriate dressing of the exit site and regular change of administration sets.[31] Furthermore, various substances for flushing and locking the catheter for the purpose of reducing the colonisation of the device and/or reducing the risk of catheter related blood stream infection are studied. Some studies are promising,[32,33] but at this point, there is not enough evidence to give recommendations in this regard.

3) THE RELATION BETWEEN PROBLEMS EXPERIENCED BY HPN PATIENTS AND VENOUS ACCESS DEVICE-RELATED COMPLICATIONS

The majority of patients experienced venous access device-related complications at some point during their HPN treatment, and hospital admissions were often necessary. Psychosocial problems, manifesting as depression, social impairment and fatigue, were also reported by the majority of HPN patients. In our study, we found that venous access device-related complications and psychosocial problems were strongly associated. Furthermore, HPN patients with more venous access device-related complications and related admissions reported a lower quality of life. Psychosocial problems were more common in patients who did experience venous access device-related complications. Therefore, we assume psychosocial problems are a result of venous access device-related complications. To our knowledge, no other studies looked at this relationship, making comparisons impossible. From our earlier interview study[34] we know that some of the patients are anxious because of earlier venous access device-related complications experienced. This risk of new complications, is the reason they do not go outside when they are hooked-up to the parenteral nutrition. For some patients this means they are not able to join social activities. From literature, it is known that social inactivity is a risk factor for depression.[35,36] Other patients told us that mobility is a problem during infusion, because of the weight of the nutrition bag and pump. Patients were on parenteral nutrition for a mean of 14 hours a day, not including HPN procedures like preparing the nutrition bag, and (dis)connecting the parenteral nutrition. Because of this time-consuming therapy and a decreased mobility, they also miss social activities. With this information on social inactivity in mind, we assume that a decrease in venous access device-related complications will lead to a better quality of life, and therefore, prevention of venous access device-related complications is very important. Novel strategies to improve the quality of the remaining small bowel during the adaptation process after major resection, such as the use of the intestinal trophic hormone GLP-2 (glucagon-like peptide-2) or its synthetic analogues (e.g. Teduglutide) might in the near future provide tools to lower the frequency and volume of the TPN formulation that has to be administered, but currently these agents have not yet been accepted as a mainstay of treatment.

4) BOTTLENECKS IN PROFESSIONAL CARE

The final study in this thesis provided insight in professional care given to HPN dependent patients in the Netherlands. In literature there were no studies reporting an overview of professionals contacted and the content of these contact moments. Neither was information on the content of care from (specialised) home care teams available. Our study showed that in our country the nutrition team is primarily responsible for HPN care. Recently published guidelines from the European Society on Parenteral and Enteral Nutrition (ESPEN), state that the impact of a nutrition support team in the management of HPN is likely to be significant.[37] Centres with a nutrition support team are likely to use monitoring protocols, allowing the patient to be independent from hospital with improvement in quality of life. Adequate, careful training allows the patient to become the 'expert' patient, thereby reducing the frequency of venous access device-related complications and consequent readmissions to hospital. The nutrition support team should provide both physical and psychological or emotional support for all patients on HPN.[37] Within the nutrition support team included in our study, HPN nurses were contacted most frequently. Main topics during these contact moments were physical problems and venous access related-problems. Because we know psychosocial problems are common in this patient group,[34,38,39] and patients reported a need for psychosocial support, there seems room for improving psychosocial care. HPN nurses seem to appropriately fulfil this important task, but involvement of a social worker or psychologist may be valuable to improve quality of life. Although a study by Perl et al.[40] from 1980 already reported that quality of psychological support appeared to affect the patient's mental, physical, and social wellbeing significantly, nowadays, this support is still not a standard part of the treatment.

Methodological considerations

We started our research programme with a review on the impact of home parenteral nutrition on daily life. This review was conducted in a systematic and meticulous manner. However, there were limitations in the data of included studies, most of them being descriptive, and some of the included studies were difficult to compare because of the use of different instruments, scales, and lifestyle domains. Furthermore, almost all studies included small samples of patients, possibly leading to a limited generalisability. In our own studies, the included patient group was rather limited in size too, but included significantly more patients when compared with other studies in HPN patients.[34,39,41-43] Importantly, we included a very significant proportion (about 75%) of all the Dutch HPN patients in our studies. Despite these limitations, we feel that it was possible to give an adequate overview of the problems experienced by HPN patients.

A strength of all studies presented in this thesis, is that patients' and professionals' opinions were the starting-point of our studies. At the beginning of the studies presented, a pilot study was performed to draw up a set of questionnaires to address the question: 'To what extent do long-term HPN patients experience problems?' Two group interviews were performed, one with patients on long-term HPN, and one with professionals involved. Patients and professionals were explicitly selected to have a variety of characteristics. The most important topics which emerged from the interviews were included in our studies, e.g. bowel disturbances, complications, fatigue, sleeping disorders, anxiety, depressive disorders, social impairment, sexual functioning disorders, and care provider burden.

Furthermore, in this thesis, we used a combination of research methods in which both surveys and longitudinal studies, and qualitative and quantitative studies were performed to arrive at our overall aim. Several advantages of these methods can be mentioned. First, these study methods are complementary to one another. Second, this integrated approach gave us an extensive insight into the problems experienced by HPN patients, and in professional care given to these patients. In our interview study we audio-taped all interviews. To increase the reliability of the data, summaries of the patients' words were read back to the patient for confirmation. The notes taken by the interviewer were also read back to the patient to confirm their accuracy. Peer debriefing was used to check interpretation by colleague researchers, and peer examination was used to evaluate data analysis by an independent researcher.

From the literature we know that it is hard to distinguish between problems resulting from the underlying disease, and problems related to the parenteral nutrition treatment. Therefore, we always asked patients to state the problems in their daily life they felt were due to the HPN treatment. However, for patients it is sometimes hard to make this distinction . Nevertheless, we found that patients with different underlying diseases experienced the same problems. For example, patients with a mesenteric thrombosis experience less complaints due to their underlying disease compared to patients with motility disorders. Our results however, did not show a difference in psychosocial problems experienced by these patient groups. This might be due to the fact that we always asked patients to state whether they considered problems to be due to the HPN treatment. Therefore, we think that HPN largely impacted on problems experienced in daily life.

We explored patient problems and venous access device-related complications extensively. We included predictors of one of the main problems, fatigue, and furthermore, the relationship between psychosocial problems and venous access device-related complications was analysed. Venous access device-related complications were obtained from the medical records from HPN patients. A disadvantage of using medical records is the possibility of missing data, given that underreporting is a common problem. We tried to tackle this problem by including nursing files in the study. Therefore, we think a near-complete picture of venous access device-related complications is given. Furthermore, in these studies, data collection was carried out by two reviewers independently, both with clinical experience in the field of HPN.

HPN patients were very willing to participate in the studies presented. During our studies, patients were frequently asked to participate and fill out extensive questionnaires. Patients were well informed and results were given back to them. In most studies, both Dutch HPN centres were included. Given the fairly high response rates and the non-selective non-response in the studies, we think that the results of our studies can be generalised to all HPN dependent patients in the Netherlands. When generalising the results from our studies to the American and European situation, it should be kept in mind that in the Netherlands, HPN is not indicated for cachexia secondary to cancer or AIDS as it is in some countries.[44] In the last study, presented in chapter 8, only one HPN centre was included. We acknowledge that there might be small differences in care provided by the two Dutch HPN centres, for example in the instructions to new HPN patients.

In the studies presented in this thesis several validated instruments were used, for example the Sickness Impact Profile-68,[45,46] the Beck Depression Inventory,[47,48] the Utrecht's Coping list,[49] de Checklist Individual Strength,[50] the Stait-Trait Anxiety Inventory,[51] the Social Support List,[52] and Cantril's Ladder of Life.[53] Most questionnaires were validated and used in various populations. We used the subscale Fatigue of the multidimensional Checklist Individual Strength (CIS) to measure fatigue in our population. The CIS demonstrated sensitivity to change, and therefore, was included in our longitudinal study. Although, the CIS-fatigue has not been tested for reliability or validity in HPN patients, it was previously used in patients with many different diseases and showed good reliability, discriminative validity, and sensitivity to change.[54-56] In our first survey, the Stait-Trait Anxiety Inventory (STAI) was used, based on a high reliability.[51,57] Surprisingly, anxiety levels in the HPN group matched those in the general Dutch population. In the interviews, taken at the same time, anxiety was mentioned as a very severe problem by one-third of all patients. Apparently, the STAI was not sensitive enough to measure the relatively high anxiety experienced by HPN patients. Therefore, in the following study, we used our own anxiety questionnaire, based on the interviews. Unfortunately, this questionnaire was not tested on forehand.

Conclusions

- Quality of life of HPN patients reported in literature was moderate to good, but psychosocial problems are common, due to the HPN treatment.
- In our Dutch HPN population, patient problems experienced in daily life were mainly psychosocial, including fatigue, depression, and social impairment.
- Amongst physical problems, fatigue and diarrhoea have a major impact on daily life.
- The venous access device is literally a patient's 'lifeline'. In the Dutch HPN populations, catheter-related blood stream infection and occlusions are common complications. These complications are an important cause of hospitalisation and patients often need a new venous access device.
- Arteriovenous fistulae are safe and valuable alternatives for central venous catheters in patients on long-term HPN. This is of major importance, because blood stream infection is the most frequent and most life-threatening catheter related complication in HPN patients.
- Despite venous access device-related complications, HPN is fairly safe these days. Therefore, attention to quality of life has increased over the last years. One of the goals of HPN is to improve this quality of life.
- Psychosocial problems and lower quality of life are associated with previously experienced venous access complications.
- The main problem in HPN patients, fatigue, is a persistent problem and baseline fatigue is the strongest predictor of fatigue one year later. Functional impairment, self-efficacy, and depression are strongly related to fatigue.
- HPN patients visit a broad range of professionals, including the nutrition support team and their general practitioner. Physical complaints and venous access device-related problems were mainly discussed, but next to these topics, there is a need for more psychosocial support.

Implications for future research

Several implications for future research can be deducted from the results of the present thesis.

First, weak study designs have been a major bugbear in many investigations into the effectiveness of HPN. Many studies are hospital based, and therefore, samples are small. Randomised controlled trails are unique in quality of life studies. Larger, multicentre studies should be performed. They should be prospective, with a clearly defined aim. Comparative studies should have a control group and be randomised. In different countries, different protocols and training techniques are used in HPN treatment in. Therefore, it is difficult to include HPN centres from different countries. Because of the relatively small samples, and various underlying diseases, it is also difficult to randomise patients to a control or intervention group. Mostly, the numbers in the groups are too small for statistical analysis. International collaboration is needed to resolve these limitations in study design.

Second, with respect to venous access device-related complications, catheter removal is often necessary. This raises problems with venous access for patients on long-term treatment and can be associated with significant morbidity and mortality.[4] Arteriovenous fistulae therefore, can be a safe and valuable alternative for patients requiring long term HPN. Recent positive results on an antibiotic lock solution however, raise the question whether new arteriovenous fistulae have to be created, considering the main problem in arteriovenous fistulae of occlusion. In this study, the use of an antibiotic lock solution containing 2% taurolidine was compared to our previous standard practice where we used low-dose (150 U/ml) heparin to lock CVC's. Taurolidine has been shown to dramatically (>90%) reduce the recurrence of catheter related blood stream infection in patients who had presented with such an infection shortly before and who were able to continue HPN administration, either with a new or with their old access device (Hickman® catheter or subcutaneous port).[22] Based on these results we have changed our clinical practice and use taurolidine on a regular basis in high risk patients. In due time we will evaluate whether the new policy with taurolidine translates into improved long-term outcomes in regard to venous access device-related complications. Moreover, we want to study the effect of reduced catheter related blood stream infection on quality of life as well as psychosocial outcome measures.

Third, the current literature on quality of life in HPN patients is quite difficult to interpret because of the limited number of studies, the wide variety of instruments that were used, and the lack of patient participation in part of the studies. There is a growing demand for an HPN-specific quality of life measure for use in routine clinical practice (Chambers & Powell-Tuck, 2007).[58] Recently, a European study started with the aim to complete a large-scale population study to validate the HPN-QUALITY OF LIFE© for use in an international population and to define the quality of life of patients receiving home parenteral nutrition for chronic intestinal failure, using the HPN-QUALITY OF LIFE©. This instrument will be validated using recognised psychometric methods. The use of this questionnaire in practice will ultimately provide considerable benefit to HPN patients because it identifies issues of relevance to HPN patients and it will be sensitive to issues that are of particular importance in this patient population.[5] Both Dutch HPN centres are included in this study.

Fourth, further evaluation of quality of life is necessary in several other HPN patient groups. Quality of life should be assessed in patients with malignant diseases in the Netherlands, to evaluate the value of this treatment in improving quality of life. Furthermore, survival and quality of life after intestinal transplantation in the Netherlands should be evaluated and compared with survival and quality of life of patients receiving Home Parenteral Nutrition. Moreover, in the Netherlands, quality of life in children on HPN has not been evaluated. From foreign studies, during the last three to four decades, use of parenteral nutrition has been successful in supporting survival and normal growth in paediatric patients with severe intestinal failure. Children receiving HPN for short-bowel syndrome and Crohn's disease, may have a better probability of survival (89% after 5 years)[59,60] than adults (60-75% after 5 years).[61-63] Children can now survive to adulthood.[59,64] Quality of life of HPN-dependent children and siblings is not different from that of healthy children, suggesting that these children actively use effective coping strategies. In contrast, the quality of life of parents of HPN-dependent children is low.[65] Evaluation of quality of life in this patient group is necessary for caregivers, as this particular group is growing. Furthermore, in the Netherlands, no information is available on this topic. In practice, it is important for nutrition support team members that they can fit their professional care to the patients' needs.

Finally, research is necessary for developing and evaluating psychosocial interventions in HPN patients. Interventions should focus on the main problems HPN patients experience in daily life: fatigue, social impairment, and depression. In relation to fatigue, a systematic review showed that there was limited evidence that psychosocial interventions during cancer treatment were effective in reducing fatigue.[66] However, part of the included studies showed that brief nursing interventions including education, self-care, coping techniques, and activity management were effective.[67-69] Godino[70] also found a significant effect of an individualised and structured nursing intervention with education in oncology patients. In this study, there was a decrease in the level of fatigue in the experimental group, whereas the group of patients that did not receive this intervention showed an increase in fatigue level along the treatment. For chronic fatigue syndrome patients, cognitive behaviour therapy has proven to be successful in reducing fatigue complaints.[71-74] Besides reducing fatigue severity, cognitive behaviour also had a positive effect on functional impairment.[73]

With respect to depression, Pariser and O'Hanlon[75] conducted a study to detect the results of a minimal nursing intervention (i.e., written information, goal-setting, and action plans) on positive changes in self-efficacy and depression in older adults with arthritis. In HPN patients, a study by Smith et al.[76] showed that by means of interactive education, depressive reactions can be prevented and the patients' own capacity to solve problems is promoted. This intervention also led to a higher health related quality of life.

For social impairment, Skerrett et al.[77] have shown that the ways in which patients interpret and respond to their symptoms (coping style), have a significant impact on the level of social impairment. The most important correlates of social adjustment were feelings of embarrassment and avoidance/resting behaviours (for example "when I experience symptoms, I rest") Based on results from literature, research in our HPN patients is needed to develop and evaluate suitable interventions.

Implications for practice

Because intestinal transplantation is not the standard treatment for intestinal failure, it is important to develop preventive methods for the number one complication, e.g. blood stream infection. Therefore, our Nijmegen HPN centre, recently compared taurolidine with heparin. As previously mentioned, taurolidine lock dramatically decreased catheter-related bloodstream infections when compared with heparin.[22] However, the long-term use of taurolidine, and its effect on blood stream infection and occlusion must be evaluated in practice. Also, taurolidine cannot be used in patients who administer parenteral nutrition by means of an arteriovenous fistula. In the mean time, taurolidine has become the standard of care in the two major referral centres in the Netherland. A key issue that remains to be solved is whether it is necessary to use special catheter locks in all HPN patients, i.e. including those who have never developed catheter-related infections. It appears prudent to mention that a proper catheter care at this point has the most established effect on central line survival.

Besides attention for venous access-related complications, a psychosocial assessment is necessary at regular intervals throughout the years. The most relevant information on quality of life comes directly from the patient, so preference is given to periodical assessment of patient problems experienced, during outpatient clinic visits. Psychosocial and quality of life issues must be incorporated in the goals of the nutrition support team.

Furthermore, in the nutrition support team, there seems to be room for improvement, i.e. psychosocial issues could be addressed more systematically and more in-depth. HPN nurses may be the right persons to provide psychosocial support, because of their frequent contact with HPN patients. HPN patients feel a need for this kind of care. Home visits would be appropriate to pay attention to psychosocial problems. In practice, home visits already are introduced, but should be performed once every one to two years, dependent on problems that the patient experiences. Furthermore, many studies have shown the effects of support groups in terms of significantly improved physical condition, social support, and quality of life in patients with cancer and haemodialysis.[78-80] This kind of support group may be beneficial to HPN patients.

The management of fatigue, being one of the main problems in HPN patients, represents a major challenge for HPN nurses. The nurse's role may include patient assessment to identify patients with (severe) fatigue and patients at risk for developing fatigue, evaluating potential causes of fatigue, and implementation of interventions to manage fatigue. Assessment of fatigue could be done with a short instrument. Interventions may include patient and family education, self-care activities, coping training, counselling, and interventions based on the principles of cognitive behaviour therapy.[81] HPN nurses are in the position to help patients manage the symptoms of the underlying disease and HPN, for example fatigue. Until specific interventions for the treatment of fatigue in HPN patients are available, the nutrition support team should be more aware of this problem, and offer more general fatigue interventions like supportive listening and education on fatigue (e.g. explanation of the feelings of fatigue, causes, pattern, and consequences) Information can help the patient understand what is happening and can increase the feeling of control and thus may have a positive effect on the symptom.[82]

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Samenvatting
Abbreviations
Dankwoord
Curriculum Vitae

Samenvatting

Totaal parenterale voeding (TPV) is een levensreddende behandeling voor patiënten met ernstig darmfalen. Deze patiënten zijn zelf niet in staat om voldoende voedingsstoffen en water op te nemen uit het voedsel. De meest voorkomende onderliggende aandoeningen zijn het kortedarmsyndroom, als gevolg van uitgebreide darmresecties, bijvoorbeeld bij de ziekte van Crohn of als gevolg van mesenteriaal trombose, en motiliteitsproblemen. TPV wordt toegediend via de veneuze bloedbaan, meestal in de vorm van een centraal veneuze catheter (Hickmancatheter), een geïmplanteerde onderhuidse poort (Port-a-Cath), of een arterioveneuze fistel (shunt). Sinds het eind van de jaren ’70 kan TPV ook in de thuissituatie toegepast worden (Thuis-TPV). Patiënten worden in dat geval in het ziekenhuis getraind door speciaal opgeleide verpleegkundigen. De patiënt en/of partner leren alle handelingen rondom het toedienen van TPV zelfstandig uit te voeren. Wanneer dit laatste niet mogelijk is wordt een specialistisch team van verpleegkundigen in de thuissituatie ingeschakeld.

Patiënten kunnen volledig afhankelijk zijn van TPV, maar in veel gevallen betreft het een toevoeging op orale en/of enterale (sonde)voeding. Ongeveer een derde deel van de patiënten is zelf geheel niet in staat om te eten en drinken. Afhankelijk van de behoefte van de patiënt, wordt TPV 2 tot 7 keer per week toegediend. Over het algemeen voeden patiënten thuis 's nachts, gedurende een periode van 12 tot 14 uur, zodat zij overdag 'vrij' zijn van de voedingszak en –pomp. Dit cyclische voeden is ook van belang om TPV-gerelateerde complicaties, zoals leverfunctiestoornissen en het risico op infecties, te verminderen.

In de afgelopen jaren is er veel aandacht geweest voor de diverse aspecten van het medisch-technische handelen in deze patiëntengroep. In schril contrast hiermee is er echter weinig informatie beschikbaar over de kwaliteit van leven en de problemen die TPV-patiënten ervaren in het dagelijks leven. Complicaties van de toegangswegen komen bij deze patiënten regelmatig voor en leiden vaak tot ziekenhuisopnamen. We weten niet goed of deze medische complicaties invloed hebben op ervaren problemen en is er onduidelijkheid over de zorg die TPV-patiënten ontvangen nadat zij geïnstrueerd zijn.

Het doel van dit proefschrift is het verkrijgen van kennis met betrekking tot verschillende onderwerpen die relevant zijn voor zorgverleners die betrokken zijn bij de zorg voor TPV-patiënten in de thuissituatie. Ons algemene doel is in drie subdoelen gespecificeerd:

1) Het beschrijven van beschikbare kennis over de kwaliteit van leven, inclusief somatische, psychologische en sociale aspecten van het dagelijks leven, zoals dat ervaren wordt door TPV-patiënten
2) Het beschrijven van de problemen die worden ervaren door TPV-patiënten in Nederland, de complicaties van de toegangswegen, en een evaluatie van een mogelijke relatie tussen deze complicaties en psychosociale problemen en kwaliteit van leven
3) Het beschrijven van de kwantiteit, kwaliteit en inhoud van de zorg van professionals aan Nederlandse TPV-patiënten.

In dit proefschrift worden 6 studies beschreven in 7 hoofdstukken. In **hoofdstuk 2** wordt een literatuurstudie gepresenteerd met als doel het beschrijven van de invloed die TPV heeft op de kwaliteit van leven van patiënten en mantelzorgers. Verschillende databases, zoals Pubmed, Cinahl en Psychlit zijn doorzocht om een antwoord te krijgen op onze vraag. In totaal werden 26 studies geïncludeerd. De resultaten laten zien dat TPV-patiënten een redelijke tot goede kwaliteit van leven ervaren, maar tonen ook dat psychosociale problemen, zoals depressie en angst, vaak voorkomen. De toegangsweg en het tijdschema voor het toedienen van TPV zijn belangrijke belemmeringen in sociale contacten. Daarnaast ervaren patiënten lichamelijke klachten zoals buikpijn en vermoeidheid die vaak samenhangen met de onderliggende aandoening die het gebruik van TPV noodzakelijk maakte. Een deel van de patiënten is daardoor ook niet in staat om zelf te eten of te drinken. Mantelzorgers (bijv. partners en echtgenoten) geven aan een goede kwaliteit van leven te hebben, maar ook zij ervaren problemen zoals depressie, vermoeidheid en sociale beperkingen.

In hoofdstuk 3 en 4 wordt een onderzoek onder 48 Nederlandse TPV-patiënten gepresenteerd. Centraal stond de vraag: 'Welke problemen ervaren TPV-patiënten in het dagelijks leven?' In Nederland is hiernaar niet eerder onderzoek gedaan. In **hoofdstuk 3** worden de resultaten van een enquête weergegeven. De gebruikte vragenlijsten waren gebaseerd op resultaten van twee groepsinterviews: één met TPV-patiënten, en één met zorgverleners. De vragenlijsten hadden betrekking op verschillende onderwerpen, waaronder lichamelijke klachten, vermoeidheid, depressie, copingstijlen, angst, ziektegerelateerde disfunctie, slaapproblemen en kwaliteit van leven. De meest voorkomende lichamelijke klachten bij TPV-patiënten zijn misselijkheid, braken en diarree. Deze problemen zijn vooral een gevolg van de onderliggende ziekte. Klachten als gevolg van de TPV zijn vermoeidheid en 's nachts vaak moeten plassen. Psychosociale problemen zoals depressie, sociale beperkingen en angst komen vaak voor. **Hoofdstuk 4** beschrijft de resultaten van interviews die zijn afgenomen bij deze 48 TPV-patiënten. Patiënten werden thuis geïnterviewd. Aan patiënten werd gevraagd om de drie problemen te noemen die de grootste invloed hadden op het dagelijks leven ten gevolge van de behandeling met TPV. De resultaten laten zien dat psychosociale problemen de grootste invloed hebben op het dagelijks leven. Negatieve stemmingen, gevoelens van angst en depressie, sociale beperkingen, gebrek aan vrijheid door de TPV behandeling en vermoeidheid zijn de meest voorkomende problemen die genoemd werden tijdens de interviews. Patiënten hebben een ambivalente houding ten opzichte van de TPV: aan de ene kant is leven zonder TPV onmogelijk, maar aan de andere kant is het leven met TPV moeilijk en een behoorlijke belasting in het dagelijkse leven. Sommige patiënten hebben zich aangepast aan het leven met TPV. Zij zijn blij dat ze dankzij de TPV nog leven en alhoewel ze zich bewust zijn van de beperkingen, hebben zij geleerd om te genieten van de dingen die ze nog wel kunnen. Andere patiënten voelen zich met name beperkt vanwege de lichamelijke klachten of TPV gerelateerde beperkingen zoals het tijdschema of angst voor complicaties.

Dit onderzoek heeft laten zien dat het belangrijk is voor zorgverleners om zich te richten op de meest voorkomende problemen, vermoeidheid, angst, depressie en sociale beperkingen. Ondanks het feit dat TPV-patiënten veel lichamelijke klachten ervaren, vinden zij dat de psychosociale problemen het meeste invloed hebben op het dagelijks leven.

Het succes van de behandeling met TPV wordt voor een groot deel bepaald door het uitblijven of optreden van complicaties van de toegangsweg, zoals infecties en verstoppingen. Deze problemen zijn aanleiding voor ziekenhuisopname, de toegangsweg moet eventueel worden vervangen, en uiteindelijk zijn deze complicaties een bedreiging voor het continueren van de behandeling met TPV. In **hoofdstuk 5** zijn infecties en verstoppingen van verschillende toegangswegen (centraal veneuze catheters vs. shunts) vergeleken. De populatie bestond uit 127 TPV-patiënten bij wie het optreden van complicaties bij 623 centraal veneuze catheters (CVC's) en 62 shunts zijn geanalyseerd. In totaal werden er 836 toegangswegen gecreëerd bij 127 patiënten (mediaan 5 toegangswegen per patiënt, range 1-24). Van de 120 shunts die werden aangelegd, werden er 75 (63%) functioneel; 6 shunts mislukten tijdens de aanleg, en 39 shunts rijpten niet tot een bruikbare veneuze toegang. Bij de goed ontwikkelde shunts was de incidentie van verstoppingen slechts iets hoger vergeleken met verschillende typen CVC's. De incidentie van de meest voorkomende en mogelijk levensbedreigende complicatie, namelijk infectie, is extreem laag bij shunts in vergelijking met CVC's. Deze resultaten laten zien dat shunts veilig zijn en een waardevol alternatief zijn voor CVC's in bepaalde patiënten die TPV thuis gebruiken.

Het doel van de studie in **hoofdstuk 6** was het presenteren van een overzicht van lijncomplicaties en het analyseren van een mogelijke relatie tussen deze complicaties en psychosociale problemen en kwaliteit van leven. Informatie betreffende de lijncomplicaties werd verzameld uit de medische dossiers van 110 volwassen TPV-patiënten, die in de twee TPV centra in Nederland onder behandeling waren. Daarnaast werd er een vragenlijst afgenomen om psychosociale problemen in kaart te brengen, en om te evalueren of deze problemen mogelijk gerelateerd waren aan lijncomplicaties. Vijfenzeventig van de 110 patiënten (68%) vulden de vragenlijst in. De incidentie van lijninfecties bleek 3 per 1000 catheterdagen en de incidentie van verstoppingen 0.8 per 1000 catheterdagen te bedragen.

Ernstige vermoeidheid werd gerapporteerd door 66% van de TPV-patiënten, bijna 57% had last van depressiviteit en patiënten meldden veel sociale beperkingen. TPV-patiënten scoorden gemiddeld een 5.7 wat betreft hun kwaliteit van leven, op een schaal van 0 tot 10, waar 0 staat voor de slechtste kwaliteit van leven, en een 10 voor de beste kwaliteit van leven. Er was een significante associatie tussen de incidentie van lijncomplicaties en de aanwezigheid van psychosociale problematiek. De resultaten laten zien dat lijncomplicaties gerelateerd zijn aan depressieve gevoelens, vermoeidheid, sociale beperkingen, en een lagere kwaliteit van leven. Het is daarom belangrijk onderzoek te doen naar de mogelijkheden om lijncomplicaties te voorkomen en zo de kwaliteit van zorg voor TPV-patiënten te optimaliseren.

In onze interviews gaven TPV-patiënten aan dat vermoeidheid het meeste invloed had op het dagelijks leven. Daarom hebben we in **hoofdstuk 7** een studie beschreven die het verloop van vermoeidheid en de voorspellers van aanhoudende vermoeidheid weergeeft. Patiënten vulden op twee momenten vragenlijsten in (baseline en follow-up, 12 maanden later). Deze vragenlijsten omvatten vragen over vermoeidheid, depressie, functionele beperkingen, sociale ondersteuning, self-efficacy, copinggedrag, angst en acceptatie. Daarnaast werden relevante bloeduitslagen opgezocht in de medische dossiers van de patiënten. De baseline gegevens laten zien dat vijfenzestig procent (n=49) van de TPV-patiënten ernstig vermoeid is. Negenentachtig procent van hen was tijdens de follow-up meting nog steeds ernstig vermoeid. Hemoglobine, kreatinine, albumine en bilirubine verklaren de aanwezigheid van vermoeidheid bij deze patiënten niet. Een longitudinale regressie-analyse laat zien dat baseline vermoeidheid 57% van de variantie van follow-up vermoeidheid verklaart, en dat de coping stijl 'vermijden' verantwoordelijk is voor 3% van de variantie. Een cross-sectionele analyse laat zien dat 46% van de variantie wordt verklaard door functionele beperkingen, self-efficacy en depressie. Het belang van het identificeren van deze factoren is groot omdat dit kan bijdragen aan de preventie of behandeling van vermoeidheid. Een behandelprogramma met als doelstelling het verminderen van functionele beperkingen en depressie, en het verbeteren van self-efficacy, zou positieve resultaten ten aanzien van vermoeidheid op kunnen leveren.

In onze laatste studie, die beschreven is in **hoofdstuk 8**, was onze doelstelling het beschrijven van de kwaliteit, kwantiteit en inhoud van zorg die de TPV-patiënten ontvangen van de verschillende betrokken hulpverleners in Nederland. Daarnaast waren we geïnteresseerd in mogelijke knelpunten in deze zorg. Om onze vragen te kunnen beantwoorden hebben we een survey uitgevoerd, waarin we vragenlijsten voor patiënten hebben gebruikt om het contact met hulpverleners te evalueren. De verpleegkundige dossiers van het voedingsteam van TPV-patiënten werden gebruikt om informatie te verzamelen over de contacten met de TPV verpleegkundigen. TPV verpleegkundigen en verpleegkundigen van de (gespecialiseerde) thuiszorg werden geïnterviewd om verpleegkundige zorg te evalueren en mogelijke knelpunten te inventariseren. Patiënten onder behandeling van het UMC St Radboud werden uitgenodigd voor dit onderzoek.

Vierenzestig TPV-patiënten bezochten 156 keer de polikliniek van het UMC St Radboud in 2008 (gemiddelde 2.5, range 0-8). TPV verpleegkundigen hadden telefonisch en via de e-mail 244 contactmomenten met TPV-patiënten in 2008. De meest besproken onderwerpen tijdens polikliniekbezoeken en contacten met de TPV verpleegkundigen waren lijnproblemen, zoals koorts, koude rillingen of symptomen van een infectie van de uittredeplaats van de catheter. Daarnaast werden lichamelijke klachten, zoals misselijkheid en diarree, veel besproken. Over het algemeen waren TPV-patiënten erg tevreden over de zorg van verschillende hulpverleners, maar enkele knelpunten werden genoemd. TPV-patiënten gaven aan dat de huisarts (te) weinig kennis had van de behandeling met TPV. Daarnaast gaven zowel de TPV-patiënten als de TPV verpleegkundigen aan dat de psychosociale zorg verbeterd kan worden. Psychosociale ondersteuning is nodig bij het accepteren en aanpassen aan een leven met TPV en bij het integreren van de TPV in het dagelijks leven. Deze ondersteuning zou door TPV verpleegkundigen gegeven kunnen worden.

In **hoofdstuk 9** is een Engelstalige samenvatting van dit proefschrift gegeven en worden de belangrijkste bevindingen bediscussieerd. De belangrijkste bevindingen uit het proefschrift zijn onderverdeeld naar vier onderwerpen:

1) Kwaliteit van leven en ervaren problemen van TPV-patiënten in het dagelijks leven.
   De kwaliteit van leven van TPV-patiënten, gerapporteerd in internationale tijdschriften, is matig tot goed. De kwaliteit van leven van Nederlandse TPV-patiënten is matig. Ruim een derde deel van de TPV-patiënten vindt de kwaliteit van leven onvoldoende. Psychosociale problemen drukken de grootste stempel op het leven van alledag.

2) Complicaties van de toedieningsweg voor TPV.
   De toedieningsweg is voor de patiënt een 'levenslijn', door de TPV blijven zij in leven. De meest voorkomende complicaties zijn infecties en verstoppingen. Deze complicaties zijn een belangrijke oorzaak van ziekenhuisopnames en patiënten hebben vaak een nieuwe lijn nodig.
   In Nijmegen worden, als enige centrum in Europa, ook regelmatig shunts gebruikt voor het toedienen van TPV. Uit ons onderzoek is gebleken dat deze shunts veilig zijn in het gebruik en dat infecties, de meest voorkomende en soms levensbedreigende complicatie, veel minder vaak voorkomen bij shunts in vergelijking met centraal veneuze catheters en port-a-caths.
3) De relatie tussen ervaren problemen van TPV-patiënten en lijncomplicaties.
   Psychosociale problemen (vermoeidheid, depressie en sociale beperkingen) en kwaliteit van leven hangen samen met ervaren lijncomplicaties. Eén van de doelstellingen van de behandeling met TPV is het verbeteren van de kwaliteit van leven. Dit zou mogelijk zijn door het aantal lijncomplicaties te verminderen, en meer aandacht aan psychosociale problematiek te schenken.
4) Knelpunten in zorgverlening aan patiënten met TPV.
   Er is behoefte aan meer psychosociale ondersteuning vanuit het voedingsteam.

Aanbevelingen voor verder onderzoek

Internationale samenwerking is nodig om grotere aantallen patiënten te kunnen bestuderen. Op die manier is het mogelijk om gerandomiseerde onderzoeken uit te voeren, waarin een controlegroep wordt opgenomen en het effect van interventies kan worden onderzocht.

Zulk onderzoek zou zich bijvoorbeeld moeten richten op mogelijkheden voor het verminderen van complicaties van de toegangsweg, een voorbeeld hiervan is het gebruik van antimicrobiële middelen zoals taurolidine, om de katheter mee af te sluiten na het toedienen van de TPV. Daarnaast is onderzoek naar kwaliteit van leven in diverse patiëntpopulaties nodig, zoals bij TPV-patiënten met een kwaadaardige aandoening, bij kinderen met TPV en bij (ex TPV) patiënten die een darmtransplantatie hebben ondergaan. Tenslotte is er onderzoek nodig om psychosociale interventies te ontwikkelen en uit te testen voor de belangrijkste problemen bij TPV-patiënten (vermoeidheid, depressie en sociale beperkingen). Te denken valt aan verpleegkundige interventies met betrekking tot educatie, copingstijlen, cognitieve gedragstherapie en activiteitenmanagement. Uit onderzoek bij andere patiëntgroepen is gebleken dat dergelijke interventies positief van invloed kunnen zijn op psychosociale problemen.

Aanbevelingen voor de praktijk

Dunnedarmtransplantatie is op dit moment nog geen standaard behandeling bij ernstig darmfalen, ook al omdat patiënten met deze techniek tot nog toe minder lang overleven dan bij gebruik van thuis-TPV. Gezien de frequente medische complicaties van de behandeling met TPV is het wel van groot belang om strategieën te blijven ontwikkelen om vooral problemen met betrekking tot de veneuze toegangsweg te verminderen, c.q. te voorkomen. Op dit moment wordt er een studie gedaan naar de effecten van taurolidine op lijninfecties, waarin onder andere wordt gekeken naar de lange-termijn effecten. Tot de resultaten van deze studie bekend zijn hebben de twee TPV centra in Nederland (UMC St Radboud en AMC Amsterdam) ervoor gekozen TPV-patiënten met een centraal veneuze catheter of poort standaard te behandelen met taurolidine. Daarnaast blijft het uiteraard van het grootste belang veel aandacht te besteden aan de juiste zorg voor de toegangsweg, omdat dit waarschijnlijk de grootste invloed heeft op de levensduur hiervan.

Verder moet er een periodieke evaluatie van psychosociale problemen bij TPV-patiënten worden uitgevoerd. Dit kan tijdens polikliniekbezoeken, waar ook psychosociale problemen kunnen worden besproken met leden van het voedingsteam. Daarnaast zouden thuisbezoeken met meer regelmaat moeten plaatsvinden, afhankelijk van de problematiek van de patiënt. Mogelijk kunnen ondersteuningsgroepen positieve effecten hebben op psychosociale problemen, en dus zouden mogelijkheden hiertoe moeten worden uitgezocht.

Het meest voorkomende probleem, vermoeidheid, verdient daarbij speciale aandacht. Periodieke evaluatie met behulp van een standaard vragenlijst is hier van belang. Zolang er geen interventies zijn ontwikkeld voor TPV-patiënten die ernstig vermoeid zijn, is het belangrijk dat TPV-verpleegkundigen zich meer bewust zijn van dit probleem, informatie kunnen verstrekken en het bespreekbaar kunnen maken met de patiënt.

Abbreviations

AVF	Arteriovenous Fistula
BDI	Beck Depression Inventory
BDI-PC	Beck Depression Inventory Primary Care
BSI	Blood Stream Infection
CBT	Cognitive Behaviour Therapy
CFS	Chronic Fatigue Syndrome
CIIP	Chronic Idiopathic Intestinal Pseudo-obstruction
CIS	Checklist Individual Strength
CRBSI	Catheter-Related Blood Stream Infection
CVA	Cerebro Vascular Accident
CVC	Central Venous Catheter
ESPEN	European Society for Clinical Nutrition and Metabolism
ESRD	End Stage Renal Disease
HAN	Home Artificial Nutrition
Hb	Hemoglobin
HLC	Health Locus of Control
HPN	Home Parenteral Nutrition
GP	General Practitioner
IBD	Inflammatory Bowel Disease
ICQ	Illness Cognition Questionnaire
ITx	Intestinal Transplantation
MS	Multiple Sclerosis
NaOH	Sodium Hydroxide
PAC	Port-a-Cath
RA	Rheumatoid Arthritis
RET	Stichting Registratie enterale En parenterale voeding Thuis / Corporation Registration enteral And parenteral nutrition at Home
SBS	Short Bowel Syndrome
SF 36	Short Form 36 health status questionnaire
SIP	Sickness Impact Profile
SLE	Systemic Lupus Erythematosus
SPSS	Statistical Package for the Social Sciences
SSL	Social Support List
SSL-I	Social Support List -Interactions
SSL-D	Social Support List -Discrepancies
SSL-N	Social Support List-Negative interactions
SSQS	Subjective Sleep Quality Scale
STAI	Stait-Trate Anxiety Inventory
TPN	Total Parenteral Nutrition
QoL	Quality of Life
UCL	Utrecht's Coping List
RUNMC	Radboud University Nijmegen Medical Centre
VAD	Venous Access Device
VAS	Visual Analogue Scale

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Een hectische tijd is voorbij nu dit moment is aangebroken. En toch is het snel gegaan. Binnenkort zal ik mijn, ons, project verdedigen. Samen met jullie leef ik naar dit moment toe. Een moment waarop ik zenuwachtig zal zijn, maar met name een moment waarop ik met trots ons werk mag presenteren. De afgelopen jaren waren voor mij zeer boeiend en heb ik met veel plezier aan dit proefschrift gewerkt waarbij ik veel heb geleerd van anderen.

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De start van het onderzoek

Mijn eerste promotor, prof. dr. Theo van Achterberg, stond aan de wieg van het project. Samen met Anke Persoon, Peter Verbroekken en Ton Naber schreven we het onderzoeksvoorstel voor de TPV patiënten, dat werd gesubsidieerd door de Maag- Lever- Darm Stichting. Anke begon als onderzoeker aan de eerste studie waarbij ik haar ondersteunde als onderzoeksassistent. Toen Anke besloot om bij de afdeling Geriatrie als expert verpleegkundige te gaan werken, kreeg ik de kans, ondanks het feit dat ik mijn opleiding Gezondheidswetenschappen nog niet had afgerond, als onderzoeker het project verder uit te voeren.

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Promotores / copromotores

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Prof. dr. Theo van Achterberg, mijn promotor van afdeling IQ healthcare

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Maag- Darm-Leverziekten
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Scientific Institute for Quality of Healthcare (IQ healthcare)

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Vrienden en familie

Ik ben heel blij met mijn vrienden en familie en wil jullie allemaal bedanken voor de gezellige en ontspannen momenten!

Barbara en Mirelle, fijn dat jullie naast mij willen staan op een bijzondere dag. Studeren was meestal gezellig, maar bijkletsen over allerlei andere dingen nog veel leuker. Mirelle, de vele autoritjes naar Maastricht hebben me ondanks de afstand nooit verveeld. Barbara, heerlijk is het nu als we met onze kleintjes bijkletsen en terugkijken op onze 'pubertijd'.

Pap, mam, Henk en Tonnie, jullie wil ik bedanken voor jullie steun en liefde. Jullie zijn er altijd om ons te helpen waar nodig: het maakt niet uit of het gaat om het opvangen van Fenne, een huishoudelijke klus, zwaar werk tijdens onze verbouwing of de verzorging van de paardjes. Ik geniet ervan als ik zie hoe jullie met veel enthousiasme genieten van onze kleine meid. Met een gerust hart kan ik naar mijn werk wetende dat het thuis goed gaat.

Mariska, met jou en de kinderen heb ik regelmatig op mijn vrije dag tussen de middag een boterhammetje gegeten. Even lekker bijkletsen, genieten van de kleintjes (nou ja, bij jullie worden ze al weer groot…) en een bezoekje aan het dorp of de kinderboerderij. Even geen werk.

Liefste Maarten, jou wil ik speciaal bedanken. Met jouw zorgzaamheid en liefde heb je mij onvoorwaardelijk gesteund. We zijn ons halve leven al samen en niets is zo bijzonder als onze liefde voor elkaar. Samen stappen, samen eindexamen, samen op vakantie, samen afstuderen, samen leuke dingen doen, samen klussen en tenslotte van samen naar met zijn drieën. Ruim twee jaar geleden is ons lieve meisje Fenne geboren. Na een minder leuke tijd rond mijn zwangerschap, konden we samen genieten van dit kleine wonder! Wat heerlijk is het om na een dag hard werken met jullie te knuffelen en alle andere dingen te vergeten.

Dank jullie wel voor heel veel!

Curriculum Vitae

Getty Huisman – de Waal werd geboren op 29 april 1978 te Winssen. In 1996 behaalde zij haar HAVO-diploma aan het Pax Christi College te Druten. Vervolgens startte zij met de opleiding HBO-Verpleegkunde aan de toenmalige hogeschool Nijmegen. Met het verpleegkundig diploma op zak ging Getty in 2000 werken als verpleegkundige op de afdeling Maag- Darm- en Leverziekten (MDL) van het UMC St Radboud te Nijmegen. Naast haar werk als verpleegkundige begon zij met de opleiding Gezondheidswetenschappen aan de Universiteit Maastricht. In 2004 studeerde zij af in de richting 'Zorgwetenschappen'. Haar afstudeerscriptie richtte zich op angst en copingstijlen van patiënten die Totale Parenterele Voeding (TPV) gebruiken.

Na haar afstuderen werd de combinatie van zorg en wetenschap voortgezet. Als verpleegkundige werkte zij nog een aantal uren op de afdeling MDL, en als onderzoeker werkte zij bij de WOK (Werkgroep Onderzoek Kwaliteit), nu IQ healthcare, van het UMC St Radboud in Nijmegen. Getty ging verder met onderzoek bij TPV patiënten, waarbij de focus lag op psychosociale problemen, kwaliteit van leven en complicaties van de toedieningsweg. Het onderzoek kreeg na de eerste studie de status van promotieonderzoek. Naast haar promotieonderzoek werkte zij ook aan een studie over het bevorderen van gezond gedrag, waarin stoppen met roken, voldoende bewegen en een gezond dieet centraal stonden.

Ondertussen werden de werkzaamheden als verpleegkundige omgezet in een functie van verpleegkundig expert voor de afdeling MDL, die tot op het heden wordt uitgevoerd. Momenteel werkt Getty tevens als onderzoeker / docent op de afdeling IQ healthcare.

Getty deelt haar leven met Maarten Huisman, en hun dochter Fenne (2008) in Winssen.