

Patients' experiences with home parenteral nutrition: a literature review

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ABSTRACT

Aim The aim of this review is to summarise the literature relating to patients' experiences with home parenteral nutrition (HPN).

Method This literature review is based on searches of CINAHL, PubMed, Web of Knowledge and Web of Science for articles published between 1970 and 2013. Additional studies were included from Department of Health publications, NICE clinical guidance, UK patient support group with interests in HPN or intestinal failure (IF).

Results Patients with severe IF have been successfully treated with HPN since the 1970s. Early published studies evaluated clinical outcomes such as catheter-related infections, metabolic complications, thrombosis of the catheterised vein and liver impairment. Since the 1980s questionnaire studies were used to evaluate the quality of life (QoL) of patients treated with HPN. These early studies used QoL assessment tools which were not validated for patients treated with HPN. Internationally, there were published qualitative research studies which explored the experiences of patients treated with HPN.

Conclusions The long-term outcome of patients treated with HPN continues to attract research interest. The review of the literature did not identify any published qualitative studies on the experiences of patients treated with HPN in the UK, suggesting a gap in the research. The UK National Health Service advocates a patient-centred approach for service design and delivery in primary and secondary care. This literature review has highlighted opportunities for qualitative research into the experiences of patients living with HPN to achieve better understanding and awareness of the rehabilitation of these patients.

INTRODUCTION

Parenteral nutrition (PN) is an admixture consisting of sterile and nutritionally balanced macronutrients and micronutrients for intravenous administration.¹ This form of artificial nutrition can save lives in patients who have intestinal failure (IF).² IF is a condition associated with extensive loss of absorptive function and capacity of the small intestines.³ There are many different causes ranging from obstruction,⁴ abnormal motility, major surgical resection, congenital defects and severe inflammatory bowel disease.⁵ The main problem in IF is the failure of the small bowel to absorb nutrients (fat, protein and carbohydrate), water, minerals and vitamins from the diet to maintain health or sustain life.⁶

Parenteral nutrition

Patients with IF develop a range of health problems and the term 'short bowel syndrome' (SBS) is used to describe the clinical consequences caused by IF.⁷

Before the discovery of PN in the 1960s patients would die from starvation caused by chronic malnutrition.⁶ During the 1970s and 1980s clinicians in the USA started to provide parenteral nutrition at home to adults who suffered chronic IF due to non-malignant diseases.⁸ Home parenteral nutrition (HPN) involves the delivery and administration of a sterile admixture containing optimally balanced macronutrients, micronutrients and electrolytes in a single infusion bag at the patient's home. The patient has a long-term indwelling central venous catheter for administration of the feed admixture. Patients or their main carers have to learn the skills and aseptic techniques needed to set up the infusion and to connect to the catheter at home overnight. In some cases patients receive help from specialist nurses, who look after the central venous catheter and carry out the connection and disconnection of the HPN feed. Once they are clinically and metabolically stable with the infusion during hospital stay, they continue with HPN following discharge. Patients receiving HPN can continue oral diet and fluids but they need to follow a low residue diet advised by dieticians and take oral medications to reduce losses from ileostomies or chronic severe diarrhoea.⁹ Patients with severe chronic malnutrition become dependent on lifelong treatments. They live with these healthcare interventions in the same way as those with chronic conditions.

Demand for HPN

In the UK the first patient was discharged home on HPN from St Marks Hospital, London in 1976 and from Salford Royal Hospital (formerly Hope Hospital) in 1978.¹⁰ Over the years many patients were offered this ambulatory treatment and HPN is now widely used in Western countries.^{11 12} The North American HPN Patient Registry reported a prevalence of 120 per million population for HPN between 1989 and 1992.¹¹ In 1993 a European retrospective survey from 13 countries and 75 centres, involving adult patients with non-malignant primary disease receiving HPN reported an incidence of 0.2–4.6 and a prevalence of 0.3–12.2 patients per million population per year.¹³ In 1997 a UK health technology assessment identified differences between countries in the underlying diseases for which HPN is indicated. It reported that HPN was offered to more patients with an underlying malignancy in Italy and the USA than in the UK (40–70% vs 8%).¹⁴ In 2008 the UK National Commissioning Group reported that 18 adult patients per million population require prolonged management of IF in hospitals,



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and 14.6 adult patients per million population need HPN on discharge from hospital.¹⁵

In 2011 the British Artificial Nutrition Survey (BANS)¹⁶ published data collected from 2000 to 2010. The reported UK HPN point prevalence was 8.40 per million population during 2010. This survey also found that SBS was the most common reason for HPN (54.4% new cases; 58.9% established cases). Crohn's disease, small bowel ischaemia and pseudo-obstruction were the major indications for new HPN cases (18.4%, 9.7% and 11% respectively) and established cases (29.3%, 15.3% and 15.1%).

In 2010 there were 228 new adult patients registered for HPN, compared with 148 in 2009 and 157 in 2008, representing a rise in clinical demand in the UK.¹⁶ In contrast, 3430 adults were newly registered for home enteral tube feeding in 2010.¹⁶ The number of newly registered adult patients receiving HPN was low in comparison to other common chronic conditions, such as hypertension and diabetes. Therefore, only a very small number of GPs are likely to come across a patient treated with HPN in their practices.

Patients living with HPN

The latest BANS report¹⁶ also explored the HPN patients' 'ability to manage' and their 'activity level'. It found that 60.1% and 71% of newly registered adult patients were described as 'independent' and 'fully independent' respectively for 'ability to manage' following discharge from hospitals. For 'activity level' it found that only 68% of patients were described as 'fully active', whilst nearly 40% required 'some help' or 'total help' at home. From this latter group, 'limited activity' was reported by 28.5%, with 3.5% and 2.5% remaining house bound or bed bound respectively. The report did not give details on what help was needed by these patients, or who provided the help. All the data were submitted by healthcare professionals of the nutrition support teams (NSTs) from 21 HPN centres. They assessed the patients and then directly submitted the data onto collection forms. The data represented limited insight into the patients' experiences with HPN.

Patients' experiences with the National Health Service

In 2008 Lord Darzi's report 'High quality care for all'¹⁷ highlighted the importance of the entire patient experience within the National Health Service (NHS). In 2012 the National Institute for Health and Care Excellence (NICE) provided the NHS with clear guidance on the components of a good patient experience. It emphasised the need for service providers to ensure services are designed in a way that they respond to the needs, preferences and values of the patient. It recommended that service providers should encourage the patients to give feedback about their care, and the providers should respond to any feedback given.¹⁸

Patient representation on the HPN framework committee provides a valuable contribution to the design and commissioning of HPN services across the UK. The availability of published qualitative data on patients' experiences with HPN could support the Clinical Commissioning Groups when making decisions on the provision and improvement of IF and HPN services for adults in England. The aim of this review is to provide an account of patients' experiences with HPN following discharge from hospital.

METHODS

Search strategy

CINAHL, PubMed, Web of Science and Web of Knowledge were searched for relevant articles published between 1970 and 2013. All included studies have been published in the English language. Additional studies were included from reference lists of eligible papers, including Department of Health publications, NICE clinical guidance, UK charities, and patient support/self-help groups with interests in HPN or IF, and NHS England publications.

Inclusion criteria

Qualitative studies that assessed or evaluated HPN and adults' experiences with PN at home respectively were included. Eligible patients were those who could eat and drink but were also partially or fully dependent on HPN (with or without additional intravenous fluids, with or without antimotility drugs) for chronic malabsorption and malnutrition problems, and lived in the community (privately or in residential/nursing homes). All causes of IF in patients with non-malignancy were included.

Exclusion criteria

Studies which examined the clinical issues of HPN, involved children as participants, and those published in a language other than English.

Search terms

HPN, IF, patient experiences, adults, quality of life.

RESULTS

The results are now presented as thematic areas identified within the literature.

Mortality of HPN

During the 1970s and 1980s the clinical outcomes of HPN were studied by many researchers in the UK, the USA and European countries. They reported on the prevention of certain death,¹⁹ reduction in hospital stay,²⁰ remission of bowel obstruction due to Crohn's disease, weight gain and improved biochemical profiles.²¹⁻²³ The focus was on keeping these patients alive and monitoring for side effects of treatment, such as catheter-related infection episodes⁸ and liver abnormalities.²⁴

Living a life with HPN

One study used a qualitative methodology to observe 19 patients treated with HPN at home. The researchers found that these patients experienced psychological problems of anger, anxiety, depression, loss of ability to eat, negative body image and relationship problems.²⁵ Another study which observed 10 patients receiving HPN over 2 years reported similar findings of depression, fear, anxiety, body image distortion, marital stress and sexual difficulties.²⁶ These discoveries led to changes in the research paradigm with subsequent investigations into the impact of HPN on patients' quality of life (QoL).

QoL indicators

WHO defines QoL as:

an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social

relationships, personal benefits and their relationship to salient features of their environment.²⁷

Away from the healthcare setting, Calman²⁸ believes that 'the quality of life can only be described and measured in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions'. He advocates that 'quality of life must include all areas of life and experience and take into account the impact of illness and treatment'.

In 1989 a written questionnaire survey carried out by a major US home care company reported that half of the 347 patients receiving HPN were less satisfied with life as a whole in comparison to the overall US population and to those with end-stage renal disease.²⁹ Carlsson *et al*³⁰ studied patients with IF due to SBS and they found that patients who were dependent on HPN rated a lower QoL than those without HPN. The authors echoed Calman's statement in their discussion and concluded that when asking a subject to rate personal QoL we must appreciate what this concept means to him/her.

Most studies with patients receiving HPN used generic quantitative assessment tools to evaluate QoL. Ladefoged³¹ used a simple ordinal scale of 'poor, fair or good' to measure QoL. Detsky *et al*³² measured the QoL in terms of quality-adjusted survival. Others used existing generic or disease-specific sickness impact profile (SIP),³³ the inflammatory bowel disease questionnaire³⁴ or the short form health survey (SF-36).³⁰⁻³⁵ All these studies assessed participants against descriptive criteria chosen by the researchers. In other words the researchers made decisions on what information they wanted to ascertain from participants.

Persoon *et al*³⁶ reported that patients receiving HPN experienced a number of psychosocial problems in everyday life. These ranged from anxiety, lack of freedom to limitations in social life caused by HPN dependence. Richard *et al*³⁷ found that some patients receiving HPN, who were already taking opiates and benzodiazepines to control pain and anxiety from their underlying diseases, developed more episodes of catheter-related infection. Other studies found that patients treated with HPN described depression as the most common psychological problem.³⁸ Female patients receiving HPN often experienced depression and discouragement, and they appeared more tearful and upset than male patients.³⁴ It is becoming evident that HPN can have a significant negative impact on a patient's life style and QoL.³⁹

In 2005 a systematic review published by Baxter *et al*⁴⁰ criticised the three QoL instruments commonly used for measuring health outcomes in patients receiving HPN (see table 1).

SF-36 is disease specific for inflammatory bowel diseases only; the EuroQoL EQ-5D consists of non-validated questionnaires. SIP is the only one which involves patient interviews but it is not HPN specific. Baxter *et al* were concerned with the lack of standardisation in their use for measuring QoL in health outcomes. They found that patients receiving HPN continued to

have symptoms caused by the underlying disease which had resulted in the need for HPN. They concluded that when assessing patients' QoL, it is important to ask questions that are relevant, pertinent and sensitive to issues that are most important to them. Orrevall's⁴¹ quote from a woman, whose husband had recently begun HPN, illustrated the need for health researchers to re-think how we should assess the patients' QoL:

You can say that it gives quality of life to the rest of the family and to the patient if you can turn a negative spiral around like this ... I can only say that I'm happy about the drip, that he gets such energy and strength, and with that comes pleasure and yes, there's certainly a kind of harmony from it.

This qualitative study discovered that the most positive aspect of HPN was 'a sense of relief and security that nutritional needs were met'. It also found that the most negative effect of HPN was related to the 'restrictions in family life and social contacts'. Both the participants and their family members experienced physical, social and psychological benefits from HPN treatment.

An open interview study in the Netherlands reported that patients receiving HPN experienced negative emotions, physical problems, social limitations, dependence on others, incapability, and patient-care provider problems.⁴²

A qualitative telephone interview of patients receiving HPN and their family carers found that both patients and carers experienced loss of friends, loss of employment and depression.⁴³ Another qualitative study used online semi-structured interviews and it discovered six major themes: affirmation of life, infusion-related complications, lifestyle adaptations, self-worth, isolation, and food intake.⁴⁴ This provided insights into the daily lives and experiences of patients treated with HPN.

In 2010 Winkler *et al*⁴⁵ published the findings of a qualitative study which explored the QoL and experiences of living with HPN in adults with IF in the USA. The authors used content and the interpretative phenomenological analysis method and they discovered that these patients viewed HPN as a 'life-line' and 'nutritional safety net'. Participants in this study defined QoL as 'enjoying life', 'being happy, satisfied, or content with life', and 'being able to do what you want to do, when you want to do it'. They described their QoL as 'good' to 'wonderful' and they all wanted 'normality in life'. The authors believed that qualitative research methodology provides new insights and richness of data from patient treated with HPN. In the same year researchers from Scotland published a validated tool, 'HPN-QOL', to assess the QoL of patients receiving HPN.⁴⁶ They recommended that this questionnaire should form part of the routine clinical management of patients treated with HPN.

UK experience

In 1989 the Nutrition Unit at Salford Royal Hospital (formerly Hope Hospital) published its findings on the effect of HPN on the lifestyle and employment of 30 patients using a standard

Table 1 Instruments and methods used to measure quality of life in patients on home parenteral nutrition⁴⁰

Generic instruments	Disease-specific instruments	Non-validated instruments
Short Form 36 (SF-36)—assesses functioning in eight domains*	Inflammatory Bowel Disease Questionnaire (IBDQ)	Time trade-off/category scaling and direct questioning
EuroQoL EQ-5D—a single score on a quality of life scale (0 worse to 100 best)	Quality of life inventory	Non-validated questionnaires
Sickness Impact Profile (SIP)	Quality of life index Rotterdam symptom checklist	Patient interviews

*The eight domains are: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain and general health perception.

questionnaire designed for the study.⁴⁷ These researchers found that patients receiving HPN experienced unemployment, sleep disruption, travel limitations and had reduced satisfaction with social and family lives. In 1993 the first UK HPN patient questionnaire survey was carried out by the organisation 'Patients on Intravenous and Naso-Gastric Nutrition Therapy' (PINNT). This survey collected information from members of PINNT about the service from the patients' perspectives.⁴⁸ The survey reported that most patients were happy with the commercial home healthcare companies, and patients who required the shortest feed infusion time experienced minimal interruptions to daily routines at home.

In 2001 the first BANS report published results from annual questionnaires completed by NST from more than 200 UK centres each year between 1996 and 1999.⁴⁹ This was the first time that detailed information on patients' experiences with HPN had been collected by NST. They found that 74% of patients had disrupted sleep during overnight feed infusions. Noise was a problem and 21% of patients found that the infusion pump and its alarm were too noisy, while 8% found the refrigerator used to store the feed solutions was too noisy. Seventeen percent of patients disliked the inconvenience of having to keep hospital-style infusion equipment at home. Over 60% of them stated that the drip stand, the infusion pump and the stainless steel trolley took up too much space, restricting mobility within the home. Over the years technological improvements have led to the use of smaller, portable infusion drip stands and pumps. Today HPN equipment occupies much less space within the home than it did three decades ago.

In 2005 Fortune *et al*⁵⁰ investigated the significance of emotional distress experienced by patients with IF treated with HPN. They reported two predictors for emotional distress: the lack of control over aspects of their underlying condition and treatment, and the perception that the condition and treatment make little sense to them.

CONCLUSIONS

HPN is an established treatment modality for patients with malabsorption and malnutrition from chronic IF. Early studies focused on the clinical outcomes and complications associated with this treatment. This literature review identified a number of published studies which examined the non-clinical outcome of adults living with HPN. Researchers used a range of instruments and methods to assess the psychological and social impact of HPN and their QoL (see table 1). However, these assessment tools, questionnaires, surveys and scales were not validated for patients receiving HPN. Following the publication of a validated tool, 'HPN-QOL', to assess the QoL of patients treated with HPN,⁴⁶ we have not come across any published research studies in this patient group using the HPN-QOL questionnaire.

This small-scale review included studies conducted in the UK, the USA and European countries. There are very few published studies of patients' perception of living with this ambulatory treatment in the UK. This provides a strong rationale for further qualitative research studies providing the opportunity for patients receiving HPN to have a voice in such an intervention. The experiences of these patients should be made available to clinical commissioning groups who are responsible for service development in local communities.

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