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Original article

Needs-based quality of life in adults dependent on home parenteral nutrition☆

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SUMMARY

Background & aims: Home parenteral nutrition (HPN) provides life sustaining treatment for people with chronic intestinal failure. Individuals may require HPN for months or years and are dependent on regular intravenous infusions, usually 12–14 h overnight between 1 and 7 days each week. This regime can have adverse impact on the life of people dependent on the treatment.

The aim of this study was to establish mean values for the Parenteral Nutrition Impact Questionnaire (PNIQ) and to determine the effect of disease, frequency of infusions per week and patient characteristics on quality of life of patients fed HPN.

Method: The PNIQ was distributed to patients across nine UK HPN clinics. Data were analysed using linear regression, with PNIQ score as the dependent variable and potential confounders as independent variables. Unadjusted and adjusted models are presented. Higher PNIQ scores reflect poorer quality of life.

Results: Completed questionnaires were received from 466 people dependent on HPN. Mean PNIQ score was 11.04 (SD 5.79). A higher PNIQ score (effect size 0.52, CI 0.184 to 0.853) was recorded in those dependent on a higher frequency of HPN infusions per week. Respondents with cancer had a similar mean PNIQ score to those with inflammatory bowel disease (mean 10.82, SD 6.00 versus 11.04, SD 5.91). Those with surgical complications reported a poorer QoL (effect size 3.03, CI 0.642 to 5.418) and those with severe gastro-intestinal dysmotility reported a better QoL (effect size −3.03, CI −5.593 to −0.468), compared to other disease states.

Conclusions: This large cohort study of quality of life in chronic intestinal failure demonstrates that HPN impacts individuals differently depending on their underlying disease. Furthermore, since the number of HPN infusions required per week is inversely related to an individual's needs-based quality of life, therapies that reduce PN burden should lead to an improvement in QoL.

☆ **Ethical standards** Procedures were followed in accordance with the ethical standards of the regional committee on human experimentation and approval was obtained from the relevant committee on human subjects.

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1. Introduction

Intestinal failure is defined as 'the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth' [1]. Chronic (or type 3) Intestinal Failure (CIF) describes the need for long-term, sometimes lifelong, home parenteral nutrition (HPN), which involves infusion of intravenous nutrition via a central venous catheter (CVC) one to seven times per week, usually for 12–14 h overnight. While HPN represents a lifesaving therapy for those with CIF, it is not without risk. Complications include CVC-related bloodstream infection and liver dysfunction, which may be life-threatening [2,3]. Notably, focus of care has now broadened beyond survival to encompass quality of life (QoL). Decreased mobility, fatigue, poor sleep and psychological issues associated with the restrictive nature of HPN have been reported to affect individual's experiences [4]. Readmission to hospital with complications associated with HPN can also impair a person's QoL, as can worry over the development of such complications [2]. Furthermore, most people rarely return to full-time paid employment, adding to the sense of isolation and lack of purpose [5].

Many of the tools used to measure the impact of HPN on individuals are time consuming to use in routine clinical practice, awkward to complete and focus predominantly on treatment effectiveness [6,7]. To date, the most commonly used tools to measure QoL in CIF are the SF-36 [8] and the HPN-QoL [9]. The former is a generic measure of health status that employs items developed over 25 years ago [10]. Consequently, much of the content is unsuitable for assessing outcome in people with CIF [8]. The HPN-QoL was intended to be more specific to people with CIF. Its content was generated from the literature, clinical experts and semi structured interviews with people who receive HPN [9]. However, the HPN-QoL has 57 items so decreasing its practicality in the clinical setting where clinicians and patients are time poor. Indeed, the SF-36 and HPN-QoL focus on the assessment of symptoms (impairment) and activity limitations (disability), issues that are of primary concern to physicians. National and international health service providers are becoming increasingly interested in the concept of 'patient value' as measured by a patient reported outcome measure (PROM) [7]. Patient value can only be measured where the content of the PROM is patient-centric [11].

The most widely implemented method of evaluating patient value is the needs-based model, which is based on the premise that the disease and its treatment influence an individual's ability to fulfil his or her human needs [12]. The content for the Parenteral Nutrition Impact Questionnaire (PNIQ)© was developed by undertaking unstructured qualitative interviews with people living with CIF, to identify ways in which their human need fulfilment was impaired by HPN [13]. This content was then checked with a new sample of people dependent on HPN by means of cognitive debriefing interviews and, finally, the tool was tested for construct validity and reproducibility by means of a large-scale validation survey [13]. Hence, the PNIQ is a patient-centric measure that evaluates the impact of HPN on the individual [14].

The primary aim of this study was to establish mean values for the PNIQ and to determine the effect of disease state, frequency of infusions per week and patient characteristics that influence needs-based QoL in a large cohort of people living with HPN.

2. Method

This study was an observational cohort study with data collected using a postal survey. The PNIQ was used to assess QoL and was combined with a questionnaire (See Supplementary material A) that collected participant characteristics and clinical information, including parenteral nutrition (PN) volume, duration and underlying diagnosis.

2.1. PNIQ tool

The PNIQ comprises 20 statements that assess the QoL of people dependent on HPN [13]. Each PNIQ statement has a dichotomous response 'True' (yields a score of 1) or 'Not true' (yields a score of 0). Item scores are summed to give a total score ranging from 0 (good quality of life) to 20 (very poor quality of life).

2.2. Recruitment

Research Nurses employed by the Clinical Research Network (National Institute of Health Research) recruited participants from the National Health Service (NHS) in locations throughout England. People who met the inclusion criteria were identified by the research nurses working within HPN clinics at each of the NHS locations.

Inclusion criteria: All people with type 3 IF aged over 18 years in receipt of HPN for longer than three months. Those on HPN for less than 3 months may be at increased risk of developing issues and being readmitted after discharge [15].

Exclusion criteria: People who were unable to give informed consent or who could not read or write in English.

Individuals who agreed to participate were sent a pack which included an explanatory leaflet, the PNIQ and a questionnaire assessing participant's characteristics and details of their HPN regime. Completion and return of the questionnaires were taken as consent.

2.3. Anonymity

All questionnaires were allocated an identification number and a recruitment log was completed. This allowed for linkage back to the participant without sharing identifiable participant details with research team members.

2.4. Sample size

Given the study design, a formal comparison test suitable for a sample size calculation was not available for the main survey proposed. Hospitals managing HPN patients were identified and considered as potential sites for this study. Twelve sites were identified which treated an estimated total of 1040 people receiving HPN. A previous PNIQ validation study, with 506 people requiring HPN, conducted at Salford Royal Foundation Trust, yielded a response rate of 45% across two study sites. Consequently, the expected sample size of 468 could be achieved if all 1040 patients were approached for this study.

Given the number of subjects approached in the previous study ($n = 506$), an 80% binomial confidence interval (CI) of 43%–49% for the 45% response rate indicated 80% confidence in a response between 447 and 510, or 90% confidence of a sample size greater than 447.

2.5. Ethics committee approval

Procedures were followed in accordance with ethical standards of the regional committee on human experimentation and approval was obtained from South West-Frenchay Research Ethics Committee (16/SW/0146).

2.6. Statistical analysis

Responses from study participants were summarised and reported using standard descriptive statistics and appropriate

graphical techniques. Cross tabulations were used to display mean PNIQ scores and days on HPN. Factors influencing the primary outcome (PNIQ score) were investigated through exploratory analysis. Factors of interest included the participants' age, gender, disease state and socio-economic group. Secondary outcome measures relating to PN (including frequency of PN per week) were also investigated. In each case, the appropriate regression model was chosen according to the structure of the outcome of interest (continuous, binary, ordinal). The factors of interest were initially investigated individually in an unadjusted model and then adjusted for potential confounders chosen a priori. All appropriate goodness of fit and model assumptions were checked and measures were taken to account for any departures. Of the tests that were significant ($p < 0.05$) there were 27% unadjusted and 18% adjusted and therefore, any significant effect size was not due to random change.

3. Results

Of the twelve NHS Hospitals in England initially identified, nine were recruited to take part in the study. A total of 906 questionnaires were sent out, with 466 (51%) returned, of which 451 were included in the analysis. Fifteen participants returned questionnaires with 4 or more missing responses to the PNIQ and were excluded from the study.

The mean PNIQ score for the total population (n = 451) was 11.04 (SD 5.79; range from zero (good QoL) to 20 (poor QoL)). Table 1 summarises the PNIQ score and provides information on use of HPN.

Participants self-reported the underlying diagnosis that had resulted in the need for HPN. Short bowel syndrome (35.9%) and Crohn's disease (20.3%) were the most frequently reported diagnoses (Supplementary material B). Due to low sample sizes in some diagnostic categories (e.g. post radiotherapy), diagnostic groups were redistributed and combined into one category; for example, Crohn's disease and ulcerative colitis were relabelled to form a combined category of inflammatory bowel disease. This led to a decrease from nine to six diagnostic categories (Table 2). Out of the six diagnostics groups, participants reporting surgical complications as their underlying disease had the highest mean PNIQ score, indicating worse QoL, of 14.15 (SD 4.94), while participants reporting severe gastro-intestinal dysmotility as their underlying disease had the lowest mean PNIQ score, indicating better QoL, of 9.04 (SD 5.51).

Standard linear regression was performed to determine the relationship between PNIQ and respondent characteristics. Table 3 reports effect estimates and 95% CI for the direct unadjusted relationship and adjusted for analysis of confounders of age, gender, time since HPN commencement, frequency of HPN per week, underlying diagnosis leading to HPN need, education, marital status, and income. Diagnostic goodness of fit assessments indicated that the model fit and assumptions of normality were acceptable. An effect estimate approaching zero indicated no effect, greater than zero indicated an increase in the outcome (worse QoL) per unit increase (PNIQ score) and an effect estimate less than zero indicated a decrease in the outcome (better QoL) per unit decrease. From 466 respondents 448 returned data for both PNIQ score and frequency of HPN per week. Results denoted that for a one day change in frequency of HPN in a week, PNIQ score alters in the unadjusted analysis by 0.58 (95% CI 0.255 to 0.908) and in the adjusted analysis by 0.52 (95% CI 0.184 to 0.853) (Table 3). A mean clinical importance difference has been calculated from the difference in PNIQ score between 1–3 and 6–7 nights, as 2.4 (Table 4). Results also demonstrated that those with an underlying condition of surgical complications had a significant mean increase in PNIQ score in the adjusted analysis of 3.03 (95% CI 0.642 to 5.418), compared to those with severe gastro-intestinal dysmotility who had a significant mean decrease in PNIQ score again in the adjusted analysis of −3.03 (95% CI −5.593 to −0.468). Those with an underlying condition of cancer had a similar average PNIQ score in the adjusted analysis of −0.417 (95% CI −2.577 to 1.742) as those with short bowel syndrome −0.472 (95% CI −1.917 to 0.974) (Fig. 1). Gender, time since starting HPN, education, and marital status did not influence the PNIQ scores (Table 3).

4. Discussion

This is the largest study of needs-based QoL in individuals dependent on HPN reported to date. The novel PNIQ outcome measure was applied to a large cohort of individuals dependent on HPN from multiple U.K. centres.

A notable finding was that the greater the number of nights individuals require HPN through the week, the worse the PNIQ score (QoL). This finding concurs with clinical and patient experience. It is well established that patients with CIF may have a poor QoL because of the restrictive nature of HPN [4]. However, there is little published evidence that the number of HPN nights required per week has a negative impact on QoL. A study of 48 patients with CIF demonstrated that patients reducing their frequency of infusions showed an improvement in physical functioning, as measured by the Short Form-36 questionnaire, but not in seven other aspects of health status covered by the measure [16]. A smaller study demonstrated a worsening of Short Form-36 scores in 10 of 31 patients over a 10-month period [17]. Finally, a more recent study investigated the effect of a recombinant glucagon-like

Table 1
Parenteral Nutrition Impact Questionnaire (PNIQ) and details of home parenteral nutrition.

	Males n = 168 Mean (SD) [Range]	Females n = 296 Mean (SD) [Range]	Total n = 466 Mean (SD) [Range]
Total PNIQ score	11.10 (5.97) (n = 163) [0–20]	10.98 (5.70) (n = 285) [0–20]	11.04 (5.79) (n = 450) [0–20]
Age (years)	56.77 (13.29) (n = 168) [18–82]	59.86 (19.07) (n = 296) [22–92]	58.31 (14.73) (n = 464) [18–92]
Time since HPN commencement (months)	79.81 (78.15) (n = 166) [3–375]	71.70 (75.09) (n = 287) [4–420]	74.66 (76.09) (n = 455) [3–420]
Frequency of HPN per week (days)	5.60 (1.59) (n = 168) [2–7]	5.53 (1.65) (n = 293) [1–7]	5.60 (1.59) (n = 463) [1–7]

Table 2
Mean Parenteral Nutrition Impact Questionnaire (PNIQ) score according to diagnosis group.

Diagnosis	Mean PNIQ score (SD)	95% Confidence intervals
Inflammatory bowel disease[a] n = 101	11.04 (5.91)	9.87 to 12.20
Short bowel syndrome n = 160	10.64 (5.67)	9.76 to 11.53
Severe gastro-intestinal dysmotility n = 25	9.04 (5.51)	6.77 to 11.31
Other[b] n = 97	11.42 (5.88)	10.24 to 12.61
Surgical complications n = 27	14.15 (4.94)	12.20 to 16.10
Active cancer n = 39	10.82 (6.00)	8.88 to 12.76

Higher score indicates worse quality of life.
[a] Includes Crohn's disease and ulcerative colitis diagnoses.
[b] Includes Ischaemia and radiation diagnoses.

Table 3
Linear regression models.

Independent variable (PNIQ = Constant)	Unadjusted		Adjusted	
Factor of interest	Effect size	95% CI	Effect size	95% CI
Age (years)	−0.022	−0.053 to 0.009	−0.013	−0.049 to 0.023
Gender	−0.142	−1.261 to 0.977	−0.559	−1.697 to 0.578
Time since HPN start (months)	−0.005	−0.012 to 0.002	−0.004	−0.011 to 0.004
Frequency of HPN per week	0.582	0.255 to 0.908*	0.518	0.184 to 0.853*
Diagnosis: Reference category − Inflammatory bowel disease				
Short Bowel Syndrome	−0.393	−1.823 to 1.038	−0.472	−1.917 to 0.974
Severe gastro-intestinal dysmotility	−1.996	−4.517 to 0.524	−3.030	−5.593 to −0.468*
Surgical complications	3.112	0.668 to 5.556*	3.030	0.642 to 5.418*
Cancer	−0.386	−2.493 to 1.721	−0.417	−2.577 to 1.742
Other	0.386	−1.215 to 1.988	0.155	−1.426 to 1.736
Education: Reference category − No post-school formal qualifications				
NVQ/College	−0.22	−1.614 to 1.569	−0.024	−1.641 to 1.688
University	−0.461	−2.171 to 1.249	−0.069	−1.752 to 1.891
Did not wish to answer	1.062	−1.362 to 3.486	0.505	−1.930 to 2.940
Marital status: Reference category − Married				
Single	0.495	−0.988 to 1.978	−0.639	−2.174 to 0.895
Living with partner	0.698	−1.410 to 2.806	0.489	−1.573 to 2.551
Separated/Divorced	1.358	−0.325 to 3.040	0.601	−1.291 to 2.218
Widowed	−0.351	−2.489 to 1.786	−0.737	−2.887 to 1.454
Did not wish to answer	7.274	−4.138 to 18.685	8.301	−2.204 to 20.402
Income: Reference category − Above minimum wage				
Minimum wage or below	2.107	0.711 to 3.502*	1.675	0.734 to 3.803*
Did not wish to answer	0.252	−0.157 to 0.660	0.177	−0.161 to 0.712
Employment: Reference category − Employed				
Unemployed	1.551	0.938 to 2.164*	1.209	0.539 to 1.878
Retired	0.774	0.316 to 1.231*	0.800	0.310 to 1.291
Did not wish to answer	1.192	0.289 to 2.096*	0.761	−0.207 to 1.728

* Statistically significant $p < 0.05$. PNIQ-Parenteral Nutrition Impact Questionnaire, CI-Confidence intervals, HPN-Home parenteral nutrition, NVQ-National vocational qualification.

peptide 2 analogue on parenteral support requirements in 86 people with an underlying diagnosis of short bowel syndrome [18]. The study showed that despite a reduction in HPN requirements associated with the drug, there was no difference in health status between active treatment and placebo groups. It would be interesting to evaluate the effect of such novel therapies on QoL when using a patient-centric measure such as the PNIQ.

Table 4
Frequency of home parenteral nutrition and Parenteral Nutrition Impact Questionnaire (PNIQ) mean score.

Frequency of HPN per week	n	PNIQ score mean (SD)
1–3 nights	66	9.20 (5.90)
4 nights	52	9.63 (6.15)
5 nights	73	11.08 (5.64)
6–7 nights	257	11.78 (5.60)

P = 0.002; HPN: Home Parenteral Nutrition.

The data also demonstrate that HPN impacts differently on individuals depending on their underlying disease. The higher mean PNIQ score in participants reporting an underlying diagnosis of surgical complications and the lower score in those with severe gastro-intestinal dysmotility merit consideration. The former finding may be explained by the sudden onset of intestinal failure that occurs in patients with surgical complications. Patients typically present after multiple surgeries with acute, type 2 IF, and, after prolonged periods of in-patient stay, are discharged home to recuperate on HPN [19,20]. Such patients are often devastated by a relatively rapid deterioration in their QoL. By contrast, patients with chronic intestinal severe gastro-intestinal dysmotility have typically had a long period of ill-health with deteriorating

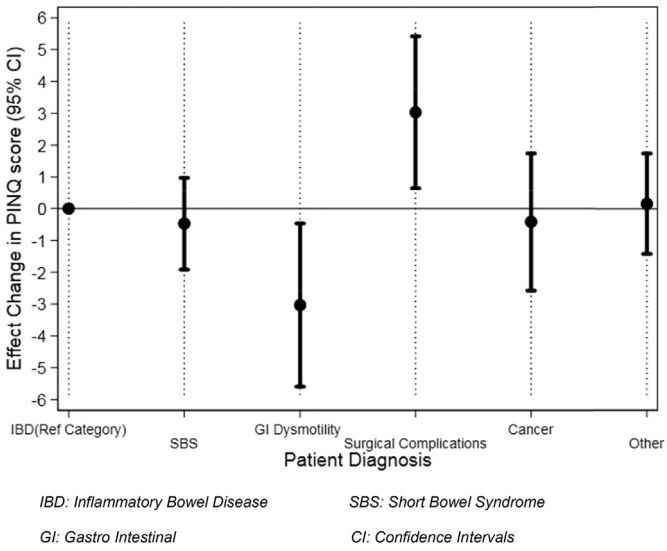

Fig. 1. Plot of the adjusted change in Parenteral Nutrition Impact Questionnaire (PINQ) score associated with respondent's diagnosis where the reference category is Inflammatory Bowel Disease.

nutritional status, often with a protracted delay in diagnosis and therefore management [21–23]. Such patients may then find it a relief to be placed on HPN with an improvement in QoL, compared to their pre-CIF state. These suggested explanations are supported by earlier data from the U.K. demonstrating that QoL is often worse in patients presenting acutely with intestinal failure [5] compared to patients with a long term chronic condition.

This study found no difference in PNIQ scores between people with an underlying diagnosis of cancer and those with other underlying disease states such as IBD. The incidence of HPN being prescribed for patients with advanced cancer varies considerably between countries. Lower prescribing countries may have concerns about clinical benefit, cost-effectiveness and the perceived burden that home intravenous feeding may have on individuals with palliative care needs [4,24,25]. A recent observational study of 221 patients with advanced cancer receiving HPN demonstrated a 35% survival rate at 6 months [26]. Most of the patients included in the present study with underlying cancer had an advanced malignancy with palliative care needs. The data from this study are supportive of HPN being no more burdensome on QoL in this patient group than with people with other underlying benign conditions such as IBD.

A limitation of this study is that participants self-reported their underlying diagnosis, which included potentially overlapping conditions such as short bowel syndrome and Crohn's disease. However, employing the person's own perspectives of their diagnosis and condition was in keeping with the theme of a patient-centric study. Diagnostic categories and mechanisms leading to both acute and chronic IF can be complex [1,20] and it is important not to over-medicalise studies aimed at evaluating needs-based patient value. In addition, not all centres that were eligible to take part responded to the invitation. Furthermore this study only takes an assessment of one moment in time in the life of a person on HPN, which may be misleading due to the long term dependency of the sample. Future research will consider changes in QoL over time, especially from initiation and at periodic intervals over the course of HPN dependency.

5. Conclusions

This article reports PNIQ data from a large cohort of individuals living with CIF. Not only is the PNIQ the first patient-centric measure of patient value available for use in the CIF population, it is also easy and quick to use and, therefore, can be integrated seamlessly into clinical care; as evidenced by the good response rate to the postal survey. Embedding the PNIQ into routine clinical practice will help healthcare institutes evaluate the effectiveness of CIF service provision. As payers and providers move gradually from a fee-for-service model towards outcomes-based commissioning and reimbursement, there will be an increasing reliance on measures such as the PNIQ. Using the PNIQ in daily clinical care will enable IF centres to benchmark their services so fully accounting for patients' views, while evaluating changes in patient value over time.

Statement of authorship

The authors approve the final copy of this article and certify that they comply with the ethical guidelines for authorship and publishing.

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Author contribution

SB: Established the conception and design of the study and aided in data interpretation, contributed to the drafting and revision of the manuscript; and provided final approval of the version to be submitted.

DJ: Acquired, analysed and interpreted the data; drafted the full paper and revised after co-author feedback; and provided final approval of the version to be submitted.

SL: Contributed to the conception of the design; aided in drafting and revising of the paper; and provided final approval of the version to be submitted.

MG: Provided support for statistical analysis and write up; contributed to the drafting and revision of the paper; and provided final approval of the version to be submitted.

JA, CM, JT-P, CD, FL, TB, SG, FR, SPM, JW, AH, and PA contributed to the drafting and revision of the paper; and provided final approval of the version to be submitted.

Conflict of interest

Sorrel Burden, Debra Jones, Matthew Gittins, Joanne Ablett, Christopher Mountford, Jonathan Tyrell-Price, Clare Donnellan, Fiona Leslie, Tim Bowling, Simon Gabe, Farooq Rahman, Stephen McKenna, Jeanette Wilburn, Alice Heaney, Philip Allan, and Simon Lal declare no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.clnu.2018.06.964.

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