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Quality of life in patients receiving home parenteral nutrition

P B Jeppesen, E Langholz, P B Mortensen

Abstract

BackgroundlAims—Quality of life is an important determinant of the effectiveness of health technologies, but it has rarely been assessed in patients receiving home parenteral nutrition (HPN).

Patients/Methods—The non-disease specific sickness impact profile (SIP) and the disease specific inflammatory bowel disease questionnaire (IBDQ) were used on a cohort of 49 patients receiving HPN, and the results compared with those for 36 non-HPN patients with either anatomical (<200 cm) or functional (faecal energy excretion >2.0 MJ/day (~488 kcal/day)) short bowel.

Results-In the HPN patients the SIP scores were worse (higher) overall (17 (13)% v 8 (9)%) and with regard to physical (13 (15)% v 5 (8)%) and psychosocial (14 (12)% v 9 (11)%) dimensions and independent categories (20 (12)% v 9 (8)%) compared with the non-HPN patients (means (SD); all p<0.001). The IBDQ scores were worse (lower) in the HPN patients overall (5.0 (4.3-5.7) v 5.6 (4.8-6.2)) and with regard to systemic symptoms (3.8 (2.8-5.4) v 5.2 (3.9-5.9)) and emotional (5.3 (4.4-6.2) v 5.8 (5.4-6.4)) and social (4.3 (3.4-5.5) v 4.8 (4.5-5.8)) function (median (25-75%); all p<0.05), but only tended to be worse with regard to bowel symptoms (5.2 (4.8-6.1) v 5.7 (4.9-6.4), p = 0.08). HPN also reduced quality of life in patients with a stoma, whereas a stoma did not reduce quality of life among the non-HPN patients. Female HPN patients and HPN patients older than 45 scored worse.

Conclusion—Quality of life is reduced in patients on HPN compared with those with anatomical or functional short bowel not receiving HPN, and compares with that reported for patients with chronic renal failure treated by dialysis.

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Keywords: parenteral nutrition; quality of life; sickness impact profile; inflammatory bowel disease

Parenteral nutrition is a lifesaving procedure in patients who have intestinal failure defined as inadequate intestinal function for absorption of nutrients and electrolytes. While in hospital, the patients who can be maintained on parenteral nutrition are educated in the aseptic infusion of nutrients and electrolytes, thereby avoiding the metabolic disturbances and mal-

failure. When qualified in this complex procedure, the patients are discharged for home parenteral nutrition (HPN). Intestinal transplantation on the other hand is the ultimate lifesaving option when complications impede parenteral support, such as progressive liver failure, serial septic episodes, and venous inaccessibility, most frequently seen in the paediatric population.²

Moving the parenteral support from the hospital to the home results in a significant gain in quality of life,4 and as intestinal adaptation occurs, some patients may even be weaned off parenteral supplements. Others, however, experience irreversible intestinal failure and face life-long complex technological nutritional support, which inevitably has an impact on their quality of life. HPN is a time consuming intrusive procedure, and HPN patients with intestinal failure are often troubled by the inconvenience of high intestinal output, presence of a stoma, fear of incontinence, altered body image, etc. These factors may impose severe restrictions on daily life with regard to social and leisure activities and emotional function, and the presence of malnutrition and dehydration in spite of HPN therapy may affect physical activity. In these patients the quality control of medical care must be focused towards proper control of the symptoms and complications of intestinal failure and treatment with HPN, aimed at full rehabilitation of the HPN patient.

As the results of intestinal transplantation will probably improve in the coming years, this procedure may become an alternative to HPN on the lines of renal transplantation versus dialysis, not only on vital indications, but also with the aim of improving quality of life in these patients.

In order to understand the experience of chronic illness and to describe behavioural dysfunction and problems related to HPN treatment, comparisons were made, using validated quality of life measurement techniques, between a population of patients receiving HPN monitored at the intestinal failure unit in Copenhagen in July 1997 and a group of non-HPN patients with known severe malabsorption, who managed without parenteral supplements

Materials and methods

QUESTIONNAIRES

The study was based on two validated quality of life questionnaires: the sickness impact

Abbreviations used in this paper: HPN, home parenteral nutrition; IBDQ, inflammatory bowel

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profile (SIP)⁵ and the inflammatory bowel disease questionnaire (IBDQ).⁶

The SIP is a non-disease specific behaviour based measure of sickness related dysfunction designed to cover patient perception of performance in areas of activity in everyday life. It contains 136 items in two main dimensions (physical (ambulation and mobility, body care and movement) and psychosocial (social interaction, alertness and emotional behaviour, communication)) and five independent categories (sleep and rest, eating, work, house keeping, recreation and pastimes). It is designed to be broadly applicable across types and severities of illness and across demographic and cultural subgroups. It has been used to collect and evaluate sickness related behavioural dysfunction in various diseases⁷ and was chosen for this study to provide a measure of the non-disease specific function of the two groups of patients. Patients were asked to endorse or check those statements that accorded with their present situation. No positive answers was equivalent to no behavioural dysfunction. The SIP percentage scores of the dimensions and categories were obtained by summing the number of positive statements to the items in each dimension and category, dividing that sum by the total sum of the possible values, and multiplying the quotient by 100. Zero per cent indicates the best possible function (absence of dysfunction), whereas 100% indicates presence of all possible dysfunctional behaviour.

At the end of the SIP questionnaire, patients were asked to mark their overall quality of life on a 9 cm visual analogue scale. At the left at 0 cm a miserable quality of life was indicated, whereas an ideal quality of life was indicated at 9 cm at the right end of the scale.

The IBDQ was developed to measure subjective health status for patients with inflammatory bowel disease. The 32 item questionnaire examines four aspects of patients' lives: symptoms directly related to the primary bowel disturbance (10 questions), systemic symptoms (five questions), emotional (12 questions), and social function (five questions). This questionnaire is disease specific and was chosen to focus on bowel related symptoms and their impact on quality of life. The response options for each question were framed as a seven point scale on which 7 represented best function and 1 represented worst function. The score of each aspect has been given as a median on the seven point scale.

EXPERIMENTAL DESIGN AND PATIENTS

In June 1997 the two questionnaires were mailed to the total cohort of 57 patients (corresponding to 75% of patients receiving HPN in Denmark) followed at the intestinal failure unit in Copenhagen receiving HPN because of intestinal failure secondary to benign disease, and to 45 non-HPN patients, who had an anatomical and/or functional short bowel defined as <200 cm of remnant small bowel (26 patients) or a daily faecal energy loss measured by bomb calorimetry exceeding 2.0

admission (37 patients). Written reminders were sent to non-responders after two months and the study was closed for inclusion at three months.

The population of patients receiving HPN in Denmark and the standardised care of these patients has been described in a recent study. None of the patients had a history of an underlying psychiatric disorder. In only one HPN patient was the impairment of quality of life evidently secondary to the underlying disease and not necessarily related directly to HPN therapy. This patient suffered from Charcot-Marie-Tooth syndrome, had intestinal dysmotility, and was partly immobilised as a result of the disease.

The HPN patients and their relatives were trained by a special team. An instruction manual was handed out, and the patients were discharged from hospital when they were able to carry out the procedures. Thus the HPN consumers were taught to be totally independent of nursing involvement with routine infusion. Home care companies delivered the HPN products, and even supplied them if the patients were away from their home town. Single-lumen catheters, inserted through the subclavian, jugular, or femoral vein and advanced to the vena caval-right atrial junction, were used. Administration was generally at night, but six patients with large stomal volumes had additional infusions of saline during the day. The recommended infusion time of standard 3 litre HPN bags was 10 hours. Infusion was by gravity in all patients.

The patients had 24 hour access to the intestinal failure unit in Copenhagen for emergencies. Nursing support at home was instituted for seven patients. All patients in this study were monitored in our outpatient clinic at intervals of about 6-12 weeks. During these visits patients were clinically assessed, weighed, and routine blood tests taken. At intervals of about one year, intestinal function was assessed using balance techniques that measured diet and faecal weight and energy content by bomb calorimetry. In the HPN patients the parenteral energy and electrolyte supplements were adjusted on a clinical basis to maintain normal body weight, hydration, diuresis, and levels of plasma albumin and electrolytes. This information was obtained from medical records, and remnant intestinal length was obtained from surgical records. The length of the colon was expressed in terms of percentage of the usual length by the method of Cummings et al. 10 Basal energy expenditure was calculated by Harris-Benedict equations using actual body weights.11

ETHICS

All procedures were performed in accordance with the ethical standards of the Helsinki Declaration of 1975, as revised in 1983. Patients gave their informed consent.

STATISTICAL ANALYSIS

A non-parametric Mann-Whitney rank sum test was used for the comparison of patient



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Table 1 Demographics of patients on home parenteral nutrition (HPN) and those not

HPN (n = 49)	Non-HPN $(n = 36)$	p Value
31/18	20/16	0.62†
(31/8/10)	(30/6/0)	0.01†
45.4 (37.7-56.9)	50.0 (44.1-60.4)	0.16*
167 (163–174)	170 (162-175)	0.47*
57.4 (51.3-64.9)	63.2 (56.1-69.3)	0.03*
20.8 (18.9-22.8)	22.2 (20.0-24.0)	0.046*
140 (74-233)	200 (148-246)	0.03*
0 (0-64)	29 (0-86)	0.21*
38	17	0.008†
8.12 (6.30-10.17)	11.49 (9.13-13.56)	<0.001*
1941 (1505-2429)	2745 (2182-3238)	
72 (50–94)	127 (113–150)	<0.001*
1.87 (0.95-2.80)	1.25 (0.67-1.71)	0.03*
	31/18 (31/8/10) 45.4 (37.7-56.9) 167 (163-174) 57.4 (51.3-64.9) 20.8 (18.9-22.8) 140 (74-233) 0 (0-64) 38 8.12 (6.30-10.17) 1941 (1505-2429) 72 (50-94)	31/18 (31/8/10) (30/6/0) 45.4 (37.7-56.9) 50.0 (44.1-60.4) 167 (163-174) 170 (162-175) 57.4 (51.3-64.9) 63.2 (56.1-69.3) 20.8 (18.9-22.8) 22.2 (20.0-24.0) 140 (74-233) 200 (148-246) 0 (0-64) 29 (0-86) 38 17 8.12 (6.30-10.17) 11.49 (9.13-13.56) 1941 (1505-2429) 2745 (2182-3238) 72 (50-94) 127 (113-150)

Results are expressed as median (25–75%). *The Mann-Whitney rank sum test or the $\uparrow \chi^2$ test was used for comparison between groups. CD, Crohn's disease; MD+OP, patients with intestinal resections because of mesenteric vascular disease or complications of intra-abdominal surgery. BEE, basal energy expenditure calculated by the Harris-Benedict equations using actual body weights.¹¹

scores on the visual analogue scale in the SIP questionnaires, and the medians between groups in the IBDQ questionnaires. The χ^2 or Fisher exact test was used for comparison of the frequencies of confirmatory answers in the SIP questionnaire. The statistical software used was SigmaStat for Windows Version 2.0 (copyright 1992–1995; Jandel Corporation, Erkrath, Germany). p<0.05 was considered to indicate statistical significance.

Results

PATIENT DEMOGRAPHICS

Forty nine (86%) of the HPN patients and 36 (80%) of the non-HPN patients returned completed questionnaires; table 1 gives the demographics of these patients. The median duration of HPN treatment was 5.0 (range 0.2–27.8) years. The HPN patients were given a median of 2.23 (range 0.2–5.5) litres of parenteral fluid per day and 3.97 (range 0.0–10.5) MJ/day (~948 (range 0–2508) kcal/

day) corresponding to a median of 73% of their basal energy expenditure. The HPN was infused for a median of seven (range four to seven) nights on a cyclic nocturnal basis, but six patients had saline supplements during daytime. The two groups did not differ significantly with regard to sex ratio or age. Significantly more of the patients receiving HPN had a dysmotility disorder. Body mass index was lower in the HPN patients because of a lower body weight compared with the non-HPN patients. The remnant small bowel was significantly shorter and the presence of a stoma more predominant in the HPN patients compared with the non-HPN patients. In spite of a lower dietary energy intake, the HPN patients had a higher faecal weight than the non-HPN patients. The energy absorption in relation to the basal energy expenditure was 72% and 127% in the two groups respectively (p<0.001).

SIP SCORES

Figure 1 gives a comparison of the overall SIP scores, dimensions, and categories between the HPN and non-HPN patients. A score of 0% indicates the best possible function (absence of dysfunction), whereas 100% indicates presence of all possible dysfunctional behaviour. The patients receiving HPN scored worse (higher scores) in all areas of activity. All 136 questions were individually compared in order to identify differences among the HPN and the non-HPN patients.

Physical dimension

The responses to questions on ambulation and mobility showed that the HPN patients used public transport less frequently (41%) than the non-HPN patients (11%) (p = 0.006). The HPN patients reported that they spent more

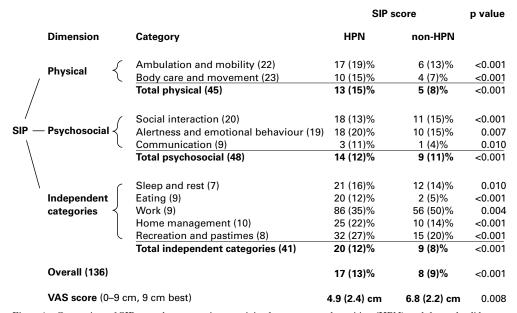


Figure 1 Comparison of SIP scores between patients receiving home parenteral nutrition (HPN) and those who did not. Results are expressed as mean (SD). Frequencies of confirmatory answers in the SIP questionnaire were compared between groups using the χ^2 test or alternatively Fisher's exact test. The VAS scores were compared using a Mann-Whitney rank sum test. The values in parentheses in the category column give the numbers of items in each category. Zero per cent indicates the best possible function (absence of dysfunction), whereas 100% indicates presence of all possible dysfunctional



Table 2 Inflammatory bowel disease questionnaire (IBDQ) scores for patients on home parenteral nutrition (HPN) and those not

	HPN	non-HPN	p Value
Bowel symptoms			
Bowel movement frequency	7.0(4.0-7.0)	7.0(4.0-7.0)	0.57
Loose bowel movements	1.0 (1.0-6.2)	3.0 (1.0-4.0)	0.02
Cramps in abdomen	7.0 (3.0-7.0)	7.0 (6.0-7.0)	0.19
Pain in abdomen	4.0 (2.0-7.0)	7.0 (5.0-7.0)	0.01
Passing gas	7.0 (5.0-7.0)	7.0 (3.0-7.0)	0.16
Abdominal boating	7.0 (3.3-7.0)	7.0 (3.3-7.0)	0.99
Rectal bleeding	7.0 (7.0-7.0)	7.0 (7.0-7.0)	0.47
Bathroom though bowel empty	7.0 (7.0-7.0)	7.0 (7.0-7.0)	0.59
Accidental soiling of underpants	7.0(4.0-7.0)	7.0(4.0-7.0)	0.85
Feeling sick to the stomach	5.0 (4.0-7.0)	7.0 (6.5-7.0)	0.02
Total	5.2 (4.8-6.1)	5.7 (4.9-6.4)	0.08
Systemic symptoms			
Feeling of fatigue/tiredness	4.0 (2.0-5.0)	4.0(3.0-7.0)	0.047
Feeling of energy	3.0 (2.0-4.0)	3.3 (3.0-4.0)	0.056
General unwell feeling	4.0 (3.0-6.8)	4.5 (3.0-7.0)	0.20
Poor sleeping or frequent wakening	3.0 (1.0-7.0)	4.0 (3.0-7.0)	0.02
Problems to maintain weight	7.0 (6.0-7.0)	7.0 (7.0-7.0)	0.42
Total	3.8 (2.8-5.4)	5.2 (3.9-5.9)	0.008
Emotional function			
Frustrated, impatient, restless	5.5 (3.0-7.0)	7.0(4.0-7.0)	0.11
Worries of new surgery	7.0 (5.0-7.0)	7.0(4.5-7.0)	0.45
Fear of not finding washroom	7.0 (4.8-7.0)	7.0 (4.0-7.0)	0.83
Feeling depressed or discouraged	5.0 (3.0-7.0)	7.0(4.0-7.0)	0.11
Worries of cancer or illness	7.0 (6.0-7.0)	7.0 (7.0-7.0)	0.26
Relaxed and free of tension	3.0 (1.0-5.8)	4.0 (3.0-6.0)	0.057
Embarrassment due to bowel disease	7.0 (7.0-7.0)	7.0(4.0-7.0)	0.13
Feeling tearful or upset	6.0(4.0-7.0)	7.0 (6.0-7.0)	0.066
Anger due to bowel disease	6.0 (3.0-7.0)	7.0 (6.3-7.0)	0.01
Irritability	5.0 (4.0-7.0)	5.5 (4.0-7.0)	0.44
Lack of understanding from others	7.0 (4.0-7.0)	7.0 (6.8-7.0)	0.41
Feeling satisfied, happy, pleased	4.0 (3.0-5.0)	5.0 (4.0-5.0)	0.046
Total	5.3 (4.4-6.2)	5.8 (5.4-6.4)	0.04
Social function			
Work	1.0 (1.0-1.0)	1.0 (1.0-7.0)	0.15
Delay/cancel social arrangements	7.0 (4.5-7.0)	7.0 (7.0-7.0)	0.15
Difficulties in leisure/sports activities	5.0 (1.0-7.0)	7.0 (2.5-7.0)	0.12
Avoiding events with no washroom close at hand	7.0 (7.0-7.0)	7.0 (7.0-7.0)	0.42
Limitations in sexual activity	1.0 (1.0-6.0)	1.0 (1.0-6.0)	1.00
Total	4.3 (3.4-5.5)	4.8 (4.5-5.8)	0.03
Overall	5.0 (4.3–5.7)	5.6 (4.8-6.2)	0.03
		<u> </u>	

The scores of each aspect are given as median (25-75%) on a seven point scale. 7 represents best function and 1 represents worst function. The Mann-Whitney rank sum test was used for comparison between groups.

time at home than the non-HPN patients (43% v 19%, p = 0.04), and social events and visits were shorter (35% v 8%, p = 0.01). In response to questions on body care and movement, 17% of the HPN patients reported needing help for difficult movements—for example, getting into a car and getting out of the bath—compared with 0% in the non-HPN group (p = 0.04), and the HPN patients had more difficulty in maintaining their balance (14% v 0%, p = 0.04).

Psychosocial dimension

The HPN patients experienced a large impact on their psychosocial activities. As mentioned above, their social interaction was affected because of problems with mobility. The responses to questions on social interaction showed that the HPN patients less frequently paid social visits to others (49% v 17%, p =0.004), participated less in social arrangements $(41\% \ v \ 17\%, p = 0.03)$, and were more often alone (29% v 5%, p = 0.02) than the non-HPN patients. Concerning alertness and emotional behaviour, the HPN patients in general scored worse (higher score) on questions about emotional stability and self confidence. Some 18% of the HPN patients felt that they were a nuisance to others compared with 3% of the non-HPN patients (p = 0.04). However, when asked about their prospects, the answers from the HPN patients were not more futile than am tha man IIDNI matianta C

of the HPN patients reported to have reduced sexual activity, but this did not differ from the non-HPN patients (42%, p = 0.91). No significant differences for individual questions on communication were found between the two groups.

Independent categories

The HPN patients in general had greater sickness related dysfunction with regard to sleep and rest, but none of the differences in the answers to individual questions between the two groups reached statistical significance. For the questions on eating, 41% of the HPN patients reported having a reduced appetite compared with only 6% of the non-HPN patients (p<0.001). Only 14% of the HPN patients were in full time work compared with 44% of the non-HPN patients (p = 0.004). In questions about home management, 59% of the HPN patients reported carrying out less of the housework compared with 33% of the non-HPN patients (p = 0.03) and significantly less did the shopping (84% v 100%, p = 0.02), cleaning (76% v 94%, p = 0.04), and heavy, demanding work at home (47% v 86%, p<0.001). In questions on recreation and pastimes, the HPN patients spent less time out enjoying themselves (45% v 19%, p = 0.03) and socialised less (43% v 11%, p = 0.003). They also did less physical training and exercise than the non-HPN patients (41% v 17%, p = 0.03).

On the 9 cm visual analogue scale measuring the overall feeling of quality of life, the HPN patients had a lower score (median (25-75%) 4.9 (3.0-7.2) cm) than the non-HPN patients (median (25-75%) 6.8 (4.8-8.2) cm) (p = 0.008).

IBDQ SCORES

Table 2 gives a comparison of the IBDQ scores between the HPN and non-HPN patients. The response options for each question were framed as a seven point scale on which 7 represented best function and 1 represented worst function. Not only regarding the overall scores, but also in areas of systemic symptoms and emotional and social function, the HPN patients scored worse (lower score) than the non-HPN patients. Significance was not reached for overall bowel symptoms $(5.2\ v\ 5.7,\ p=0.08)$.

Table 2 also gives responses to the individual questions in the IBDQ. The HPN patients reported more episodes of loose bowel movements and abdominal pain than the non-HPN patients, and they had more nausea and vomiting. Systemically the HPN patients felt more fatigue than the non-HPN patients, and they tended to score worse (lower score) with regard to energy for everyday activities. The HPN patients reported having more problems sleeping than the non-HPN patients. With regard to emotional functions, the HPN patients felt more anger as a result of their bowel problem than the non-HPN patients, and when asked how satisfied, happy, or pleased they were with their personal life, they scored worse (lower than the man IIDNI matiante Niana of the



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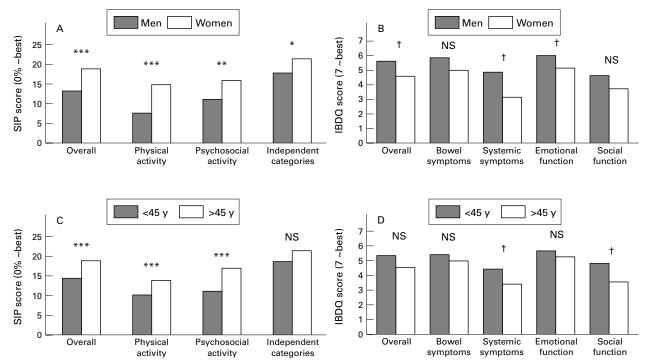


Figure 2 Mean sickness impact profile (SIP) scores and median inflammatory bowel disease questionnaire (IBDQ) scores according to sex (A and B) and age (C and D) in the patients on home parenteral nutrition (HPN). χ^2 or Fisher exact test: *p<0.05; **p<0.01, ***p<0.001. Mann-Whitney rank sum test: †p<0.05.

differences in responses to individual questions on social function reached statistical significance, but an overall worse score (lower score) was seen in the HPN patients compared with non-HPN patients. No differences were seen between the two groups with regard to limitations in sexual activity. Some 55% of the HPN patients and 53% of the non-HPN patients, however, reported that their bowel problem had reduced their sexual activity.

EFFECT OF SEX AND AGE ON SIP AND IBDQ SCORES To evaluate the effect of sex and age on the SIP and IBDQ scores, the HPN patients were divided according to sex and age below and above 45 years. Eighteen patients were men and 31 women, and 23 patients were less than 45 and 26 were more than 45.

Sex

The median age in the male and female HPN population was 45.4 and 46.1 years respectively (p = 0.55). Figure 2A, B gives the SIP and IBDQ scores respectively arranged by sex. The female HPN patients scored significantly worse (higher score) overall and for the physical and psychosocial dimensions and the independent categories. An analysis of the physical dimension showed that the female HPN patients had worse SIP scores (higher score) with regard to both ambulation and mobility (22% v 10%, p =0.002) and body care and movement (12% v6%, p = 0.002) compared with the male HPN patients. In the psychosocial dimension no significant difference was seen between sexes with regard to social interaction, but the female patients scored worse (higher score) in areas of alertness and emotional behaviour (22% v 11%, p = 0.009) and communication (5% v 1%, p =

With respect to the individual categories, no differences were seen between the sexes with regard to sleep and rest, eating, work or recreation and pastimes. The female HPN patients, however, scored significantly worse (higher score) with regard to home management (30% v 16%, p<0.001).

When considering the 9 cm visual analogue scale for overall feeling of quality of life, the female HPN patients tended to score worse (lower score: median (25-75%) 4.6 (2.2-7.0) cm) than the male HPN patients (6.6 (4.5-7.4) cm) (p = 0.068).

With regard to the IBDQ scores, the female HPN patients scored significantly worse (lower score) overall as well as in the systemic symptoms and emotional function categories. No differences could be shown for bowel symptoms and social function between the sexes (fig 2B). Analysis of the responses to the individual questions on bowel symptoms, however, showed that the female HPN patients scored worse (lower score) in the question on pain in the abdomen (3.0 v 7.0, p = 0.004) and abdominal bloating (5.0 v 7.0, p = 0.04). The female HPN patients scored significantly worse (lower score) in all individual questions on systemic symptoms, except when asked about problems of weight maintenance. Looking at emotional function, the female HPN patients felt more depressed and discouraged $(4.0 \ v \ 7.0, p = 0.01)$, more tearful and upset (5.5 v 7.0, p = 0.003), more lack of understanding from others (7.0 v 7.0, p = 0.02), and in general less satisfied, happy, or pleased $(4.0 \ v \ 5.0, p = 0.01)$.

Age

The male/female ratio in the HPN patients



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