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Original article

Home parenteral nutrition and employment in patients with intestinal failure: Factors associated with return to employment

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SUMMARY

Background & aims: Home parenteral nutrition (HPN) is provided to patients with intestinal failure (IF). HPN can however affect the patients' quality of life and ability to remain in employment. The aim of this study was to determine the effect of HPN on employment and factors associated with the likelihood of maintaining or returning to employment while on HPN.

Methods: Patients with chronic IF were identified from a prospectively maintained IF Unit database. A structured questionnaire was designed to probe employment both before and after starting HPN, intention to work and social welfare status (benefits & pensions).

Results: A total of 196 (62.8% females, median age 53 years) patients participated in the study of which 184 (94%) patients were in full or part time employment before their illness. At the time of starting HPN, 102 (52%) patients had the desire to return to work with 19 (18%) and 48 (47%) patients returning to full time or part time employment respectively. Multivariate analysis demonstrated that the frequency of the HPN infusion per week ($p = 0.045$) and intention to work after starting HPN ($p = 0.001$) were significantly associated with returning to work.

Conclusions: Patients on HPN can have their employment status affected. The number of days per week on HPN and the desire of the patient to return to employment are significantly associated with employment.

1. Introduction

The European Society of Parenteral and Enteral Nutrition (ESPEN) define intestinal failure (IF) 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]. It can occur acutely and or progress to a chronic condition. The causes of intestinal failure include inflammatory bowel disease, surgical resection of small bowel resulting in short bowel as well as impaired intestinal motility [2–4].

The administration of parenteral nutrition (PN) to patients with IF is lifesaving and developments over the past 30 years have enabled patients to receive this lifesaving maintenance treatment at home in such a way that patients are more able to lead an independent lifestyle [5–8] and have good survival prospects [9,10]. However there are limitations as a result of the PN infusions including hospital admissions, body image issues, complications of PN, finances and disrupted family and friends support [5,8,11–13].

Quality of life (QOL) is an important concept that is difficult to measure. Though the QOL while on HPN can still be perceived as reasonable [8], in general, patients on HPN have a poor QOL when compared to the normal population [5]. Patients can experience difficulties in their financial or social status and work environment. The ability to maintain employment can be difficult for patients on HPN for both practical and psychological reasons [5].

The psychosocial and physical burdens associated with HPN have been well explored [6,14–17]. However, there are limited studies on the ability to maintain employment while on HPN. Also,

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aspects relating to employment do not necessarily feature in the commonly used validated QOL questionnaire. The aim of this study was to determine the effect of HPN on employment and factors associated with the likelihood of maintaining or returning to employment while on HPN.

2. Methods

We performed a prospective study with a questionnaire of the current patients on HPN in our institution. The patients were identified from our prospectively maintained IF Unit database. The short questionnaire addressed issues relating to employment before and after starting HPN as well as the intention to be in employment and social welfare status (benefits & pensions). The questionnaire was developed by the authors specifically for this study. To access the ability of patients to return to employment after starting on HPN, we included patients who had been on HPN for over one year. Data on patients' demographics, aetiology of IF, duration of HPN, frequency and hours per day on HPN were also collected. Interviews were conducted via telephone or face to face conversation in clinic. Details of the questionnaire are shown in Table 1.

The study was given approval by the Research and Development Department of the institute as part of service evaluation.

2.1. Statistical analysis

Chi Squared, Kruskal Wallis and Wilcoxon Signed Rank tests were used to determine differences before and after HPN therapy. Binary logistic regression analysis was used to determine predictors of returning to employment while on HPN. A p value of <0.05 was considered to be statistically significant. Variables were tested for association with the outcome (return to work) to determine significant association. Those variables that demonstrated a significant association ($p < 0.05$) were selected and entered into a multivariate regression model. At the multivariate level, those variables that remained significant were deemed to be independently associated with return to work. All statistical analysis was carried out using IBM® SPSS®, Version 20.0.

3. Results

3.1. Patients

Three hundred and five patients receiving HPN from 2004 to 2014 were identified on the database. Of these 305 patients, 40 had died and 69 were inaccessible due to change in contact details, leaving 196 (64%) patients who agreed to participate in the study. Of the 196 patients who participated in the study, 123 (62.8%) were females and the median age was 57 years (IQR 46–67 years) (Table 2).

Table 1
Questionnaire.

Date of commencing HPN	
Were you in an employment prior to commencing HPN	Yes/No
If yes, what type of employment were you in	Full time/Part time/ Volunteer
Did you stop employment because of ill health	Yes/No
Did you stop employment because of HPN	Yes/No
Did you intend to go back to employment after commencing HPN	Yes/No
Have you being in an employment since commencing HPN	Yes/No
If Yes, what type of work	Full time/Part time/ Volunteer
Are you on any benefits	Yes/No
What benefits are you receiving	Yes/No
Are you on pensions	Yes/No
How much has HPN interfered with your employment or ability to work	

Table 2
Data on demographics and HPN.

N = 196	Number (%)
Age at start of HPN (years)	
18–40	55 (28)
41–55	68 (35)
55–70	55 (28)
<70	18 (9)
Gender	
Male	73 (37)
Female	123 (63)
Duration of HPN (years)	
≤3	102 (52)
>3	94 (48)
Frequency of HPN (days/week)	
<5	29 (15)
5–6	50 (26)
>6	104 (53)
No data	13 (7)
HPN infusion time (hour/day)	
<12	45 (23)
≥12	138 (70)
No data	13 (7)

3.2. Aetiology

The underlying causes of developing IF were inflammatory bowel disease (IBD) in 52 (27%), mesenteric infarction in 42 (21%), motility disorders in 34 (17%), surgical complications in 30 (15%), malignancy in 8 (4%) patients and other causes 30 (15%). Motility and IBD related IF were more common in patients ≤55 years while surgical complications and malignancy related IF were more common in patients ≥55 years (Table 3).

3.3. HPN therapy

The median age at the start of HPN therapy was 51 years (IQR 37–61 years). The median duration on HPN for all patients was 3 years (IQR 1–9 years). More patients with an underlying motility disorder, surgical complication and mesenteric infarction required daily HPN when compared to patients with IBD or an underlying active malignancy.

3.4. Employment

Before their illness and commencing HPN, 184 (94%) patients were in full or part time employment. At the time of starting HPN, 70 (36%) were in employment. One hundred and two (52%) patients had the desire to return to work after starting HPN. Of the 102 patients, 19 (18%) returned to full time paid employment, 48 (47%) returned to part time (paid and unpaid (volunteer)) employment. On starting HPN, 24 (13%) of 184 patients returned to their current job while 19 (10%) and 14 (8%) patients became volunteer or changed employment respectively. Three students went into employment after starting HPN and two patients who were not working took up volunteer employment. The reasons for seeking employment after starting HPN were a desire to contribute to society (48%), finance (20%) and social (17%). The return to employment post initiation of HPN is illustrated in Fig. 1.

Table 3
Patient demographics according to intestinal failure aetiology.

		IBD		Motility Disorder		Malignancy		Surgical		Mesenteric Infarct/ vascular disease		Other	
		n	%	n	%	n	%	n	%	n	%	n	%
Gender	Female	31	60%	28	82%	6	75%	17	57%	20	48%	21	70%
	Male	21	40%	6	18%	2	25%	13	43%	22	52%	9	30%
Age at start of HPN (years)	18–40	19	37%	13	38%	1	12%	6	20%	10	24%	6	20%
	41–55	18	35%	13	38%	1	12%	6	20%	16	38%	13	43%
	56–70	14	27%	6	18%	5	64%	8	27%	15	36%	7	23%
	>70	1	1%	2	6%	1	12%	10	33%	1	2%	3	10%
Number of years on HPN	3 years or less	25	48%	15	44%	5	63%	21	70%	17	40%	19	63%
	More than 3 years	27	52%	19	56%	3	37%	9	30%	25	60%	11	37%

Patients with any underlying aetiologies can be seen to have significantly decreased employment rates after starting HPN. This rate is lowest in those patients who have developed IF as a result of a surgical complication.

Univariate and multivariate analyses were performed in order to assess the factors that influence the ability of patients to gain employment (Table 3). Univariate analysis demonstrated a significant association between the parenteral infusion time, length of time that the patient has been receiving HPN, age and social benefits with employment. Multivariate analysis demonstrated that the frequency of the HPN infusion per week ($p = 0.045$, OR 2) and intention to work after starting HPN ($p = 0.001$, OR 82) were significantly associated with returning to work (Table 4).

3.5. Social welfare

One hundred (54%) and 34 (18%) patients received benefits and pension respectively. Univariate analysis demonstrated a significant association between having no benefits or pensions and return to employment ($p = 0.002$) (Table 4).

4. Discussion

This is the first paper to investigate the effect of HPN on employment and to determine factors associated with a return to employment while on HPN. Our study has shown that patients are likely to return to return to employment if they have the desire, are young and the frequency of HPN infusion is less than 5 days per week. More than half of the patients who expressed a desire to work in our study returned to either full time or part time employment. The reasons for this are not known however maintenance of social and or financial status may be a factor [5]. Other reasons are eagerness particularly in younger patients and being encouraged to work as soon as they are physically and emotionally able to work [8].

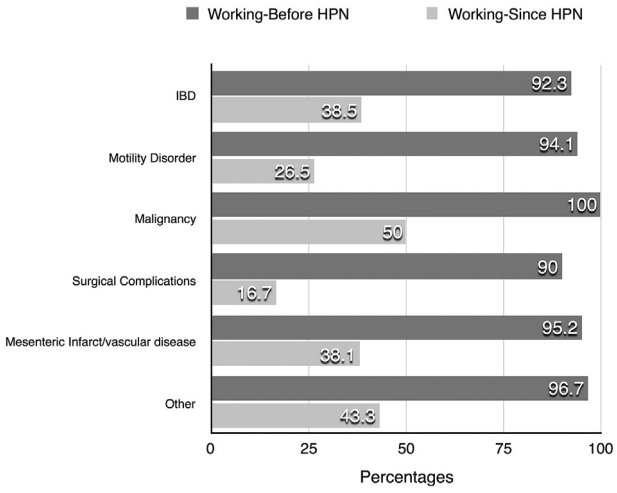

Fig. 1. The return to employment post initiation of HPN.

The impact of HPN on employment is well documented with (70–90%) of patients not able to return to work while on HPN [6,8,12,17,18]. It has been shown to relate to the length of time for the parenteral infusion, fatigue, diarrhoea/high stoma output and frequent admission [17]. In our study, 64% of the patients were not able to work after commencing HPN, however our study has not explored the factors related to this.

Approximately 10–50% of patients on HPN return to full or part time employment according to previous studies [8,11,12,16,17]. Our results are within this range with 34% of patients returning to employment. A multicentre European study performed in 1989 [11] demonstrated that 30% patients recovered their pre-HPN full time occupational status and 22% recovered their pre-HPN occupational status as part time employment. In our study, most of the patients who returned to work were in part time employment. This is likely to be due to the fact that patients were not able to cope with their previous workload [17]. Our study also shows that 19% of patients return to full time work and this corresponds to the studies by Irving and Richard [16] and Jeppesen et al. [17].

A QOL assessment includes the social, occupational, emotional and physical aspects of the patients' lives [13]. HPN has an impact on the quality of life of patients and their families [5]. Patients on HPN have a reduction in quality of life with quality of life scores ranging from 0.2 to 0.6 [16–18]. QOL is lowest in the first year of having HPN and peaks by the third to fifth year. A strong self-esteem and or family support can help in the patients coping with a loss of employment [13].

Baxter et al. [5], Waal et al. [8] and Malone [12] have highlighted the role of both the underlying illness and HPN affecting quality of life and employment. Many patients in our study expressed concern regarding their underlying illness contributing to an inability to work. It is certainly likely to be that both the underlying illness and HPN may affect a patient's ability to gain employment.

Malone et al. [12] demonstrated that patients prefer fewer HPN infusions allowing them more freedom to be engaged in social activities [13]. We also demonstrated that the number of infusions per week affect employment status at both univariate and multivariate analysis. The duration of the parenteral nutrition infusion was significant as well on univariate analysis but it is likely that this is a dependent factor and therefore was not significant on multivariate analysis. The duration of the parenteral infusion will depend on the infusion volume, stoma losses, underlying aetiology as well as the number of infusions per week. It is important that clinicians appreciate the impact HPN has on patient QOL and they should attempt to minimise the impact of HPN (by minimising the HPN

Table 4
Binary logistic regression of factors associated with return to work after the commencement of HPN.

Variable	Sub-groups	Univariate	Multivariate	Odds ratio (confidence interval)
Age	18–40 41–55 55–70 <70	0.001	0.054	1.95 (0.98–3.85)
Sex	Male Female	0.235	–	–
Aetiology	IBD Motility disorder Malignancy Surgical complications Mesenteric infarction Others	0.986	–	–
Duration of HPN	≤3 years >3 years	0.003	0.408	–
HPN frequency	<5 times/week 5–6 times/week >6 times/week	0.001	0.045	2.26 (1.02–5.02)
HPN infusion time	<12 h/day ≥12 h/day	0.003	0.778	–
Work before HPN	Yes No	0.225	–	
Type of work before HPN	Full time Part time None	0.557	–	
Intention to work	Yes No	0.001	0.001	82.69 (9.03–756.47)
Benefits/pension	No Yes	0.002	0.095	–

frequency and infusion time) as this will facilitate the possibility of returning to work in a patient who is motivated to work again.

This study is limited by the non-validated questionnaire. In order to explore this theme in depth and establish a questionnaire, a prospective qualitative study is needed. However, this was a pilot study to probe employment status and associated factors and based on current data a future study could explore this further including quality of life scale.

In conclusion, patients on HPN can have their employment status affected. The age of the patient, number of days per week on HPN and the desire of the patient to return to employment are significantly associated with employment.

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Statement of authorship

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

Conflict of interest

None of the authors or author's institution have received payment or support in kind for any aspect of the work submitted.

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