# CHANGES IN ADULT HOME PARENTERAL NUTRITION PRACTICE OVER 25 YEARS

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## ABSTRACT

Background and Aims

Home Parenteral Nutrition (HPN) is the established treatment of intestinal failure. This study considers the changes in practice in a single UK centre over the past twenty-five years.

Methods

Data was culled from a database used for clinical care and maintained prospectively.

Results

Two hundred and five patients were included from 1993-2018. Patient numbers increased from 22 during 1999-2003 to 158 during 2014-2018. The median age at discharge increased from 52 years during 1999-2003 to 59 years during 2014-2018. Thirty percent of patients discharged during 1999-2003 had Crohn's disease, reducing to 14% during 2014-2018. Fifteen percent of patients discharged during 1999-2003 had small bowel fistula or obstruction in comparison to 44% during 2014-2018. Only 18 patients were treated with palliative intent, the majority in recent years. An increasing number of patients required help with HPN care over the years.

Survival in non-palliative patients was 85% at 1 year, 67% at 3 years, 53% at 5 years and 42% at 10 years. The majority of deaths were due to underlying disease and only 5 of 55 deaths were attributed to HPN alone. HPN dependence in non-palliative patients was 73% at 1 year, 59% at 3 years, 56% at 5 years and 43% at 10 years. Fifty eight patients stopped HPN after reconstructive surgery.

Patients experienced 5.1 admissions/1000 HPN days (64.7 admission days/1000 HPN days). Admission rate did not change over the years though the percentage due to catheter problems fell from 52% to 40% while the percentage due to underlying disease or unrelated cause rose.

Conclusions

The increase in numbers, age and dependency of HPN patients requires increasing resource and consideration of new models of service. Many patients with short bowel syndrome now survive to old age and the care needs of the HPN patient who has become elderly can be complex. A significant proportion of patients are being referred for HPN as a bridge to reconstructive surgery after surgical complication and this requires close involvement of gastrointestinal surgeons in HPN teams. The need for hospital admissions remains a burden for HPN patients and there is scope for changes in service provision to try to reduce hospital days.

**KEY WORDS**

Intestinal failure

Home Parenteral Nutrition

## INTRODUCTION

Since the first report describing parenteral nutrition by Dudrick in 1969 (1) and of home parenteral nutrition (HPN) by Jeejeebhoy in 1973 (2), HPN has become established as an essential treatment for intestinal failure. Indeed intestinal failure is defined as "the long-lasting 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" (3).

Although a small number of adults were treated with HPN in Glasgow in the 1980s and 1990s, the service has developed considerably in the past 25 years. This study aimed to assess the changes in our HPN practice over this time, examining both patient characteristics and outcomes.

## METHODS

For many years, most of the adult HPN patients cared for by Greater Glasgow and Clyde Health Board (GGC) have attended Glasgow Royal Infirmary. A small number of patients who attended other Glasgow hospitals had their care transferred to Glasgow Royal Infirmary in 2015. A number of patients who live in other health board areas have been referred to Glasgow over the years.

Patients were initially assessed as inpatients. Sepsis and acute intestinal failure was managed until the patient was stable and it was clear that parenteral support was needed. Appropriate venous access, suitable intravenous prescription and training was instituted. The majority of patients had tunnelled Hickman or Broviac catheters inserted, with a small number using implanted ports. Intravenous electrolytes only were appropriate for a few patients who were included in this report with those requiring nutritional supplements as the management is the same and some patients moved from one formulation to the other. The majority of patients were trained to self-manage their HPN by hospital specialist nutrition nurses. Some patients had the aid of relatives and a few patients had district nurse visits to connect and disconnect their infusions. From 2000 to 2012, there was a Managed Clinical Network for HPN in Scotland (4) and from 2006 a homecare service for supply of intravenous solutions, hardware, ancillaries and some nursing services has been commissioned by NHS National Procurement Scotland. Patients were followed up in a multidisciplinary outpatient clinic

at three monthly intervals. Open access to phone the ward at Glasgow Royal Infirmary was arranged for urgent admissions and patients were admitted directly to the ward if needed.

Since 1998, data about HPN patients has been collected on a prospective basis in an Access database which is updated at every inpatient or outpatient episode of care. Nine patients who started HPN prior to the database had their data included retrospectively (three started between 1993 and 1998, the others prior to 1993).

We have examined the data from this source to December 2018. Data was exported in Excel spreadsheets as appropriate and the following used to calculate statistical parameters - Kruskal Wallis test to compare numerical data; Chi squared+/- Yates correction or Fischer's exact test to compare categorical data(https://www.socscistatistics.com/); Kaplan Meier statistics to establish and compare survival. Descriptive statistics were described as median and range.

In total 217 patients had records available on the database. Four patients was excluded completely from analysis as they had been started on HPN in other hospitals and had significant missing data.

Data was collated for age, sex, health board of residence, underlying disease, indication for HPN and whether HPN followed operation or followed unpredicted post-operative complications. Underlying disease described the pathological process causing the patient's illness. "Other" underlying disease included a variety of pathology, including diverticular disease, complex abdominal wall hernias and mucosal disease. Indication for HPN described the mechanism of intestinal failure rather than the underlying disease. HPN following operation was defined as HPN following operation during the same admission period as the start of HPN. HPN following post-operative complication was defined as occurring in patients who had unpredicted surgical complications after operation (e.g. anastomotic leak, peritonitis or fistula) which led to the requirement for HPN. Short gut which was predictable at the time of operation (eg due to resection for ischaemia) was not included as a post-operative complication. Functional small bowel length was as recorded at any previous operation. Patients treated palliatively were defined as those in whom cancer was not curable. Other patients had intestinal failure following treatment for malignancy which was curative. This included some patients with post-operative complications and others in whom resection of neuroendocrine tumour or sarcoma or emergency resection had left only a short length of bowel in circuit. The total number of patients treated each year were calculated, in addition to the number of new starts; number stopping and the reason for stopping, including the cause of any deaths. Cause of death was established from the treating clinician.

With regard to survival and HPN dependence, six other patients were excluded from analysis as they had been started on HPN prior to 1993 and we have no records of other patients from this period. Including only the survivors would skew the results. Two patients transferred from paediatric care were also excluded from this analysis. This left 205 patients. Survival was assessed for 121 patients who remained on HPN either at the time of death or at the end of the study period on 31 December 2018. Palliative patients were excluded from survival (other than palliative vs non-palliative) and HPN dependence analysis.

Kaplan Meier curves were drawn for survival and HPN dependence. The factors examined with regard to outcome were time period of first discharge (in 5 yearly intervals); age at first discharge; presence of other illness; underlying disease leading to HPN; indication for HPN; functional small bowel length; weight at discharge; BMI at discharge; palliative treatment; whether HPN followed operation; whether HPN followed operative complication . These factors were compared over the time period (using five yearly intervals) to assess whether significant changes in the characteristics of the HPN population had occurred. Age for each patient was taken at the mid-point of each five year interval.

Other outcomes were compared using the same 5 yearly intervals – number stopping HPN with and without surgery, number of admissions; days of admission; reason for admission; deaths related to HPN. The reason for admission was categorised as related to the catheter if a problem was confirmed or suspected with no other cause identified. Infection and other catheter related complications had been examined in a previous paper (5). Episodes which had included part of more than one time period were included in the time period of the admission date. For admissions, 213 patients were included, with data from those coming into GGC care later than their HPN start date being included only from the date commencing GGC care.

# RESULTS

## Patient characteristics

Descriptive statistics include 205 patients. 127 patients were female and 78 male. The median age at discharge was 56 years (range 15-85). Median functional small bowel length in 97 patients with a record was 75cm(range 0-280).

Table 1 shows clinical details of these patients.

Table 1 – Clinical details of 205 patients included in the study.

| **Underlying disease** | n | Percentage |
|---|---|---|
| Crohn's | 40 | 19% of 205 |
| Ischaemia | 47 | 23 |
| Malignancy | 37 | 18 |
| Motility disorder | 14 | 7 |
| Radiation enteritis | 18 | 9 |
| other | 49 | 24 |
| **Indication for HPN** | | |
| Fistula | 35 | 17% of 205 |
| Malabsorption | 7 | 3 |
| Obstruction | 39 | 19 |
| Short gut | 118 | 58 |
| other | 6 | 3 |
| **Other illness** | | |
| Other illness recorded | 80 | 39% of 205 |
| No other illness recorded | 125 | 61 |
| **Initial intent of treatment** | | |
| Palliative | 18 | 9% of 205 |
| Non palliative | 187 | 91 |
| **HPN follows operation** | | |
| Follows operation | 137 | 67% of 205 |
| Not following operation | 68 | 33 |
| **HPN follows post-op complication** | | |
| Follows post-op complication | 53 | 39% of 137 |
| Follows surgery but no complication | 84 | 61 |

Figure 1 shows the total number of patients treated each year and the number starting and stopping HPN. Numbers have increased from a total of twenty-two patients being treated from 1999-2003 to 158 patients treated during 2014-2018. Numbers from Health Boards other than GGC have increased proportionately with 36% of patients discharged between 2014 and 2018 coming from outwith Greater Glasgow and Clyde catchment area.

Figure 1 – patients being treated with HPN each year from 1998 to 2018. Shows all patients treated, patients who started HPN during that year and patients who stopped HPN during that year.

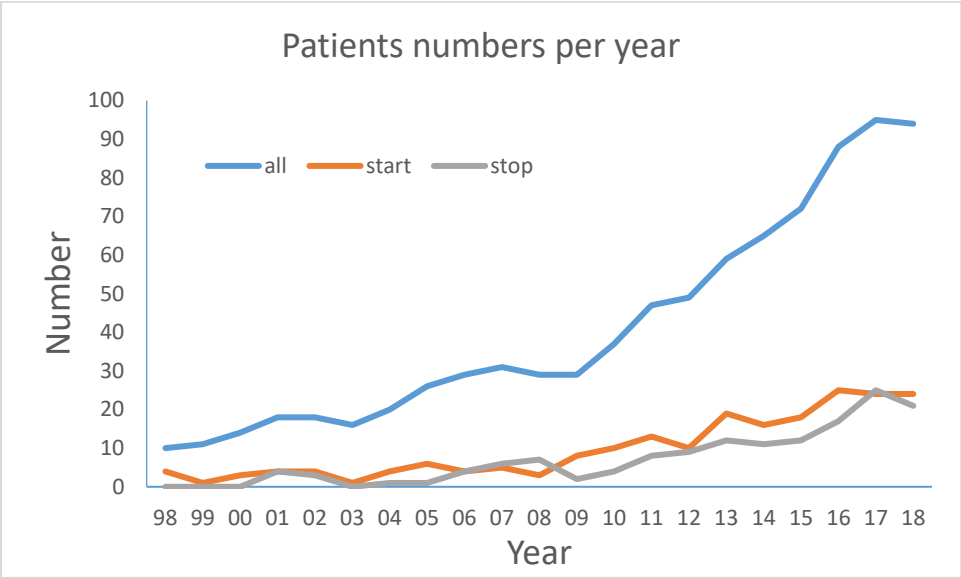



Table 2 shows the changes in patient characteristics over the time period. The age of all patients being treated and age at first discharge increased (Kruskal Wallis p=0.023 and 0.017 respectively). Fewer patients had Crohn's disease while more malignant and palliative patients were seen (Chi squared p=0.014). The percentage of patients who had ischaemic bowel remained static. The percentage of patients whose indication for HPN was short gut reduced in comparison to those who had fistula or obstruction(Chi squared p<0.01). There was no change in the weight or BMI at discharge, the percentage of patients with other illness or the functional small bowel length.

More palliative patients were treated later in this series. Patients unable to self-care were significantly older (median age 64, range 19-84 cf median age 59, range 21-80: Kruskal Wallis p=0.024). Forty-five of 107 patients discharged during 2014-18 were not self-caring for their HPN at discharge in comparison to less than 5 during each previous time period. Eight of these were palliative patients but six other palliative patients were discharged self-caring.

With the passage of time, the percentage of patients who started HPN immediately following an operation increased (Chi squared p=0.017). The number of patients who started HPN because of unpredicted post-operative complications also increased but the percentage of post-operative patients who had sustained an unpredicted complication did not increase significantly (Chi squared p=0.79)

Table 2 – changes in patient characteristics over the study period.

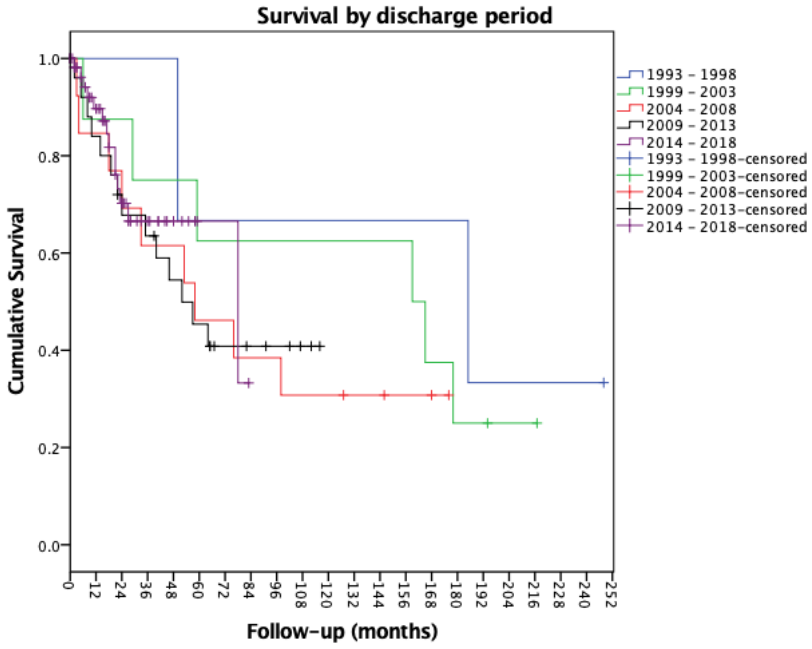
| **Age of entire group treated** | | | | | | | *P =0.023* |
|---|---|---|---|---|---|---|---|
| **Time period** | | | **No of pts** | | **Median age** | | **Range** |
| 1993-98 | | | 9 | | 45 | | 29-69 |
| 1999-2003 | | | 22 | | 49 | | 15-78 |
| 2004-8 | | | 39 | | 55 | | 20-79 |
| 2009-13 | | | 79 | | 56 | | 20-79 |
| 2014-18 | | | 158 | | 59 | | 18-84 |
| **Age at first discharge** | | | | | | | *p =0.017* |
| **Time period** | | | **No of pts** | | **Median age** | | **range** |
| 1993-98 | | | 3 | | 45 | | 35-49 |
| 1999-2003 | | | 13 | | 52 | | 15-78 |
| 2004-8 | | | 24 | | 52 | | 19-73 |
| 2009-13 | | | 58 | | 54 | | 20-78 |
| 2014-18 | | | 107 | | 59 | | 18-84 |
| **Underlying disease of patients discharged** | | | | | | | *p =0.014* |
| **Time period** | **Crohn's** | **ischaemia** | **malignancy** | **motility** | **radiation** | **other** | **total** |
| 1993-98 | 3 | 0 | 0 | 0 | 0 | 0 | 3 |
| 1999-2003 | 4 | 3 | 4 | 1 | 0 | 1 | 13 |
| 2004-8 | 5 | 6 | 2 | 4 | 1 | 6 | 24 |
| 2009-13 | 13 | 15 | 5 | 5 | 9 | 11 | 58 |
| 2014-18 | 15 | 23 | 26 | 4 | 8 | 31 | 107 |
| **Indication for HPN of patients discharged** | | | | | | | *P <0.01* |
| **Time period** | **fistula** | **malabsorption** | **obstruction** | **other** | **Short gut** | **total** | |
| 1993-98 | 0 | 0 | 0 | 0 | 3 | 3 | |
| 1999-2003 | 1 | 0 | 1 | 0 | 11 | 13 | |
| 2004-8 | 4 | 1 | 3 | 4 | 12 | 24 | |
| 2009-13 | 10 | 3 | 7 | 1 | 37 | 58 | |
| 2014-18 | 20 | 3 | 28 | 1 | 55 | 107 | |
| total | 35 | 7 | 39 | 6 | 118 | 205 | |
| **Palliative intent** | | | | | *p = 0.098* | | |
| **Time period** | | | **palliative** | **other** | **total** | | |
| 1993-98 | | | 0 | 3 | 3 | | |
| 1999-2003 | | | 2 | 11 | 13 | | |
| 2004-8 | | | 0 | 24 | 24 | | |
| 2009-13 | | | 2 | 56 | 58 | | |
| 2014-18 | | | 14 | 93 | 107 | | |
| total | | | 18 | 187 | 205 | | |
| **Follows operation** | | | | | *p = 0.08* | | |
| **Time period** | | | **operation** | **No operation** | **total** | | |
| 1993-98 | | | 0 | 3 | 3 | | |
| 1999-2003 | | | 8 | 5 | 13 | | |
| 2004-8 | | | 14 | 10 | 24 | | |
| 2009-13 | | | 37 | 21 | 58 | | |
| 2014-18 | | | 78 | 29 | 107 | | |
| total | | | 137 | 68 | 205 | | |
| **Follows complication** | | | | | *p = 0.79* | | |
| **Time period** | | | **complication** | **operation** | **Total** | | |
| 1993-98 | | | 0 | 0 | 3 | | |
| 1999-2003 | | | 2 | 8 | 13 | | |
| 2004-8 | | | 4 | 14 | 24 | | |
| 2009-13 | | | 16 | 37 | 58 | | |
| 2014-18 | | | 31 | 78 | 107 | | |
| total | | | 53 | 137 | 205 | | |

**Outcomes**

During the study period, 55 patients died, while 70 stopped HPN, 58 after surgery. Four patients were transferred out of our care and ten patients had HPN withdrawn. In four cases this was because of poor compliance (2) or recurrent infections(2) but the others were palliative patients for whom HPN was no longer considered appropriate.

This gave a survival in non-palliative patients of 88% (SE3) at 1 year; 67% (SE5) at 3 years; 53% (SE 6) at 5 years and 42% (SE6) at 10 years. Survival did not relate to date of first discharge (Figure 2, p=0.74), indication for HPN (p=0.07), age at first discharge (p=0.87), BMI at discharge (p=0.65), length of remaining small bowel (p=0.76) or whether HPN followed operation (p=0.37) or post-operative complication (p=0.35). Figure 3 shows that survival was better in patients with Crohn's disease and motility disorders than those with ischaemia or malignancy (p=0.025). Of the 18 patients who were treated with palliative intent, 12 died at a median of 2 months (range 1-9). Of 21 other patients with malignancy, 10 died at a median of 16 months (range 1-59) and 6 stopped HPN after reconstructive surgery within the first year after discharge.

Figure 2 – Survival of non-palliative patients related to the period of first discharge. p=0.74



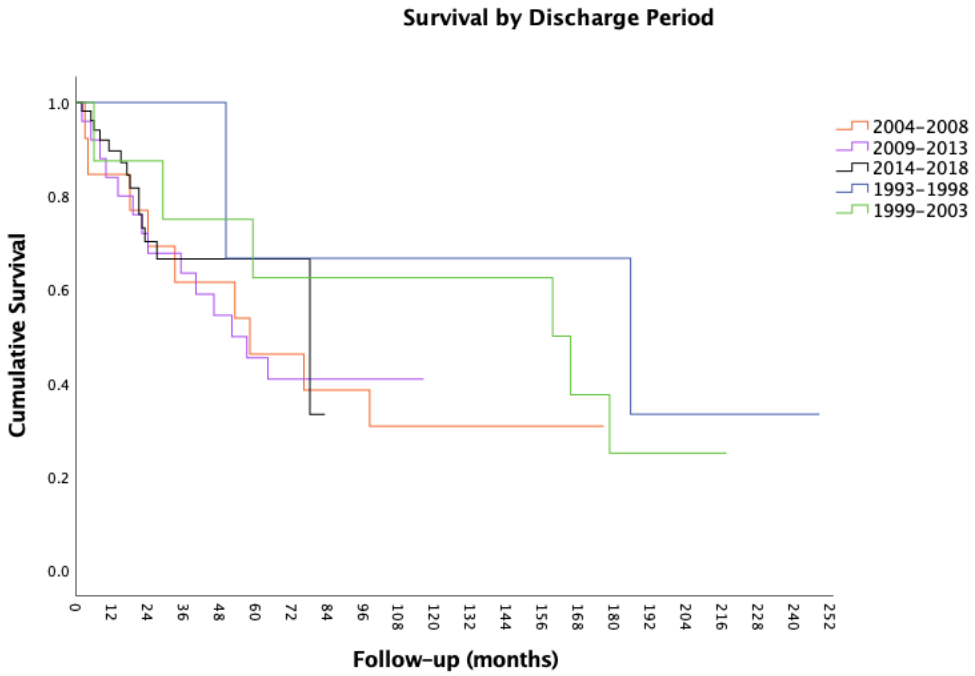
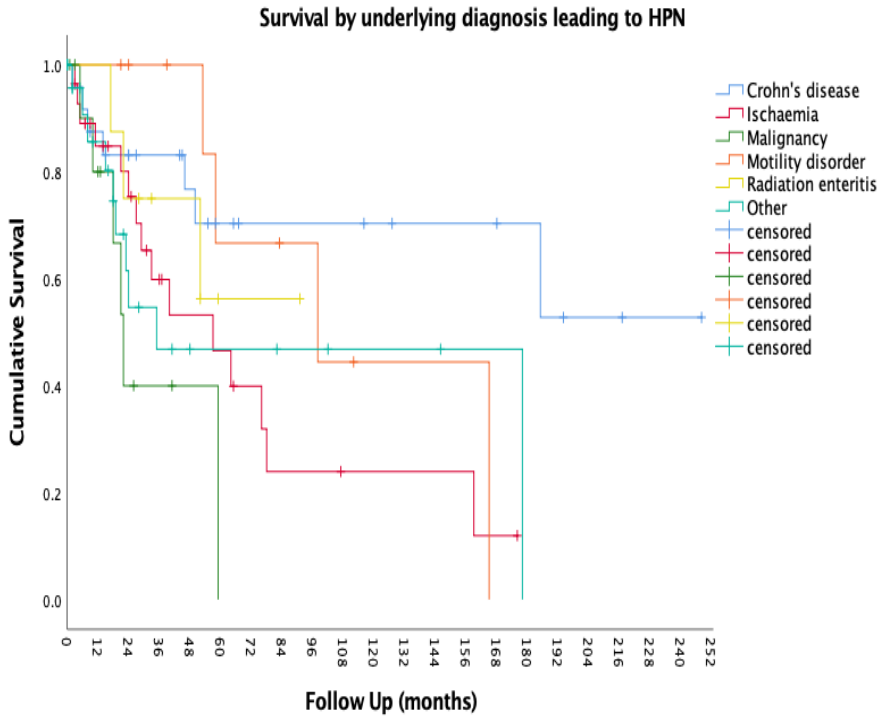
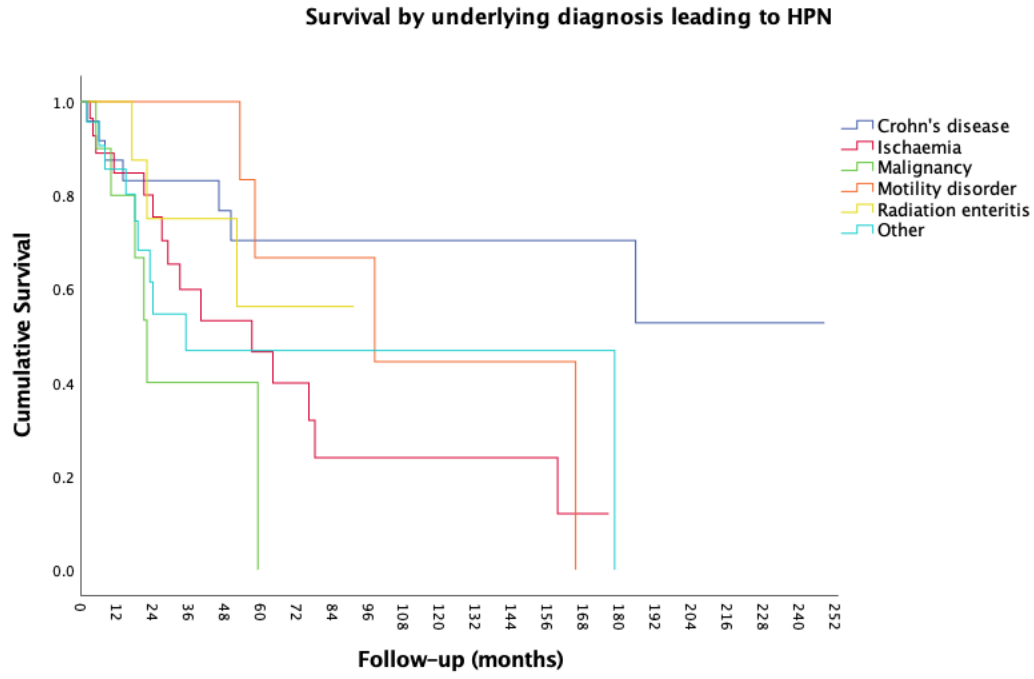

Survival by Discharge Period
Cumulative Survival
1.0
0.8
0.6
0.4
0.2
0.0
0
12
24
36
48
60
72
84
96
108
120
132
144
156
168
180
192
204
216
228
240
252
Follow-up (months)
2004-2008
2009-2013
2014-2018
1993-1998
1999-2003

Figure 3 – Survival of non-palliative patients related to the underlying disease leading to HPN. p=0.025



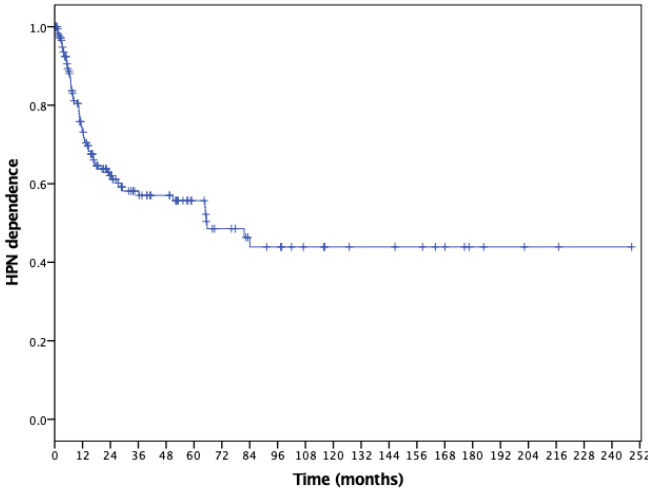

Death was due to HPN alone in 5 patients (2 catheter related sepsis and 3 liver disease, though one of the latter deaths was in an 83 year old lady who had been on HPN for 15 years). Twenty seven deaths were due to the underlying disease and seventeen were unrelated. Five patients died due to a combination of liver dysfunction and their underlying disease and one patient due to a combination of liver dysfunction and unrelated disease.

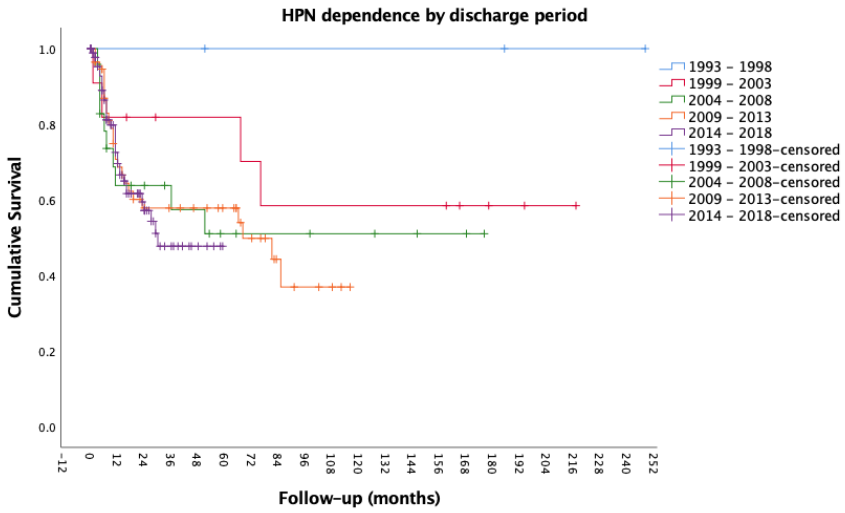
When all the deaths are considered by the period during which death occurred, there is no statistically significant difference in age of death (1999-2003 median 43 years range 42-51; 2014-18 median 63 years range 23-83) or days of HPN at death (1999-2003 median 537 days range 91-1510; 2014-18 median 674 days range 132-5444) and the ratio of all HPN related deaths to all non-palliative deaths did not change significantly.

When all the deaths are considered by the date of first discharge, there is no difference in median age at death (1999-03 median 57years range43-83; 2014-18 median 59years range 23-78). The ratio of all HPN related deaths to all non-palliative deaths appeared to fall over the years (1999-03 0.66; 2004-08 0.22;2009-13 0.29; 2014-18 0.08) but this was not statistically significant when the study period was divided into the first and second ten year period (p=0.16).

Figure 4 shows HPN dependence in non-palliative patients. This was 73% (SE 3) at 1 year, 59% (SE 4) at 3 years, 56% (SE 4) at 5 years and 43% (SE 6) at 10 years. There was no significant change over the years.

Figure 4 - Overall HPN dependence in 187 non palliative patients and HPN dependence by discharge period




p=0.389

Although the total number of patients stopping HPN after surgery increased over the time period, the percentage of patients did not increase (Table 3 Chi squared p=0.73)

Table 3 – the number of patients stopping PN after surgery, shown related to all patients in each time period and related to the patients who started HPN in each time period.

| | Total pts | Stopped after surgery | *p=0.8* | Start pts | Stopped after surgery | *p=0.73* |
|---|---|---|---|---|---|---|
| 1999-03 | 22 | 3 | 14% | 13 | 3 | 23% |
| 2004-08 | 39 | 7 | 18% | 24 | 7 | 29% |
| 2009-13 | 79 | 14 | 18% | 58 | 14 | 24% |
| 2014-18 | 158 | 34 | 22% | 107 | 34 | 32% |

There were 1073 admissions in 182 patients between 1998 and 2018(5.1 admissions/1000 HPN days). This amounted to 13580 admission days during 209864 days of HPN :ie 64.7 days/1000 HPN days. The median number of admissions per patient was 5.5 per 1000 days of HPN (range 0-100). Thirty one patients had no admissions and seventeen other patients only had admissions relating to surgery with a view to stopping HPN. In contrast, sixteen patients had more than 20 admissions per 1000days of HPN. Figure 5 demonstrates that the majority of patients had a small number of admissions with a small number of patients accounting for many admissions. Eighteen patients spent more than one third of their HPN days as inpatients (more than 333 days/1000 days of HPN). 794 of 1073 admissions(74%) were as an emergency. 523 admissions(48%) related to HPN, 417 of these due to catheter related problems.

Figure 5 – The number of patients plotted against the number of admissions per 1000 days of HPN.

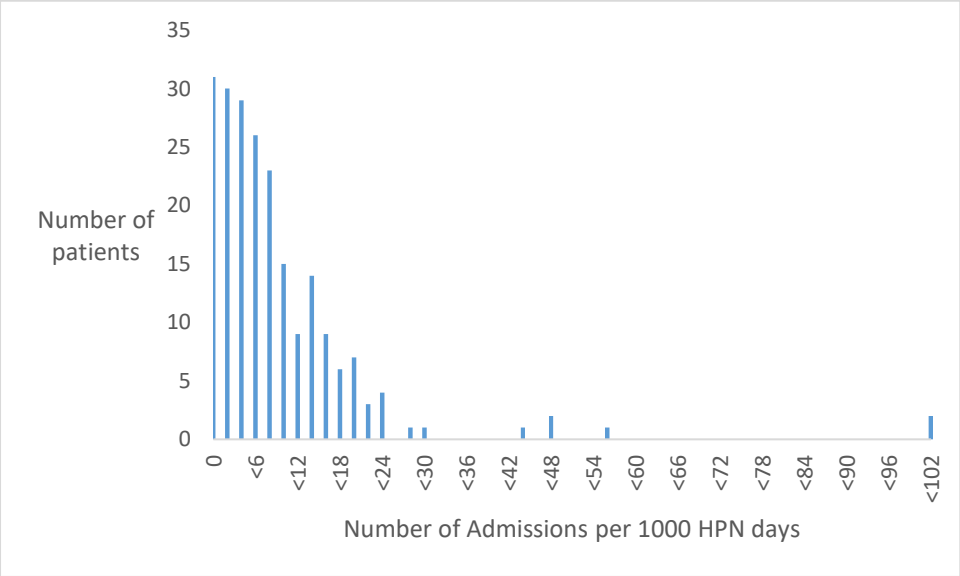



Table 4 shows that the number of admissions per patient and admission days per patient did not change over the years.

Table 4 – the number of admissions per patient and admissions days per patient during each time period.

| | No of admissions | Total no of pts | Admissions/pt | Days of admission | Days/pt | Median days per admission | range |
|---|---|---|---|---|---|---|---|
| 1999-03 | 71 | 22 | 3.23 | 776 | 35.3 | 7 | 1-105 |
| 2004-08 | 160 | 39 | 4.1 | 2054 | 52.7 | 9 | 1-122 |
| 2009-13 | 302 | 79 | 3.82 | 3174 | 40.1 | 8 | 1-108 |
| 2014-18 | 540 | 158 | 3.42 | 7698 | 48.7 | 8 | 1-222 |

Details of catheter related complications over the period to the end of 2017 have been reported previously(5). The catheter related infection rate fell over the period. The percentage of admissions related to all catheter problems fell from 52% in 1999-03 to 40% in 2014-18 while the percentage due to disease increased from 18 to 30% and the percentage due to unrelated cause increased from 10% to 20% (Chisquared p=0.00001).

## DISCUSSION

### 1. Changes in the HPN population

There has been a significant increase in patients and change in patient characteristics over the past twenty years. The precise prevalence clearly depends on the population base but assuming that this population base includes all of Greater Glasgow and Clyde, all of Lanarkshire and all of Dumfries and Galloway, our population base would be approximately 2 million (6). Some patients from Forth Valley and Ayrshire and Arran Health Boards are seen in Glasgow because of surgical issues and this would increase our population base to 2.6 million. The period prevalence of HPN has therefore risen from 3.8-5/million to 35-45/million, a ten-fold increase. This is consistent with the estimate of prevalence in the British Artificial Nutrition survey in 2016 (7). The number of referrals from other Health Boards has risen in a similar fashion to those within Greater Glasgow. It is not possible to know how many patients were not referred for HPN over the years but it seems likely that more patients are being considered for this treatment. These patients would presumably have died or had very long hospital stays in the past.

This increase in numbers and turnover of patients, with patients coming from a wide geographical area, has impacted significantly on the workload of our nutrition team. Although the staff resources of the team have increased somewhat over the years, the increase in workload has been greater and so new ways of working have had to be developed. During the first ten years of this study, the initial home visit could be made by the hospital nutrition nurse, but this is now in the

remit of the homecare company nurses. The Scotland wide HPN contract was changed to accommodate this. Our multi-disciplinary team was regularly involved in the award of contract. Our clinic organisation has changed from a group consultation with each patient to a rotation of the patient to see the dietitian, doctor, nurse and pharmacist, controlled by our administrator and debriefed electronically after each clinic. Non-medical prescribing has enabled us to cope with PN prescribing. Although the unique skills of each team member are still needed for the complex problems, we are moving towards a model where many tasks can be undertaken by more than one healthcare professional. For example, routine outpatient review might not always require one of the doctors and could be undertaken by dietitian, pharmacist or specialist nurses. The use of technology for remote consultations can improve the efficiency of clinics and avoid some patient travel. The increase in new referrals has led to more pressure on inpatient beds and resources. We do not have the option to train patients at home as the UK National Centres have done(8,14), because the geographical spread of the Scottish population has meant that patients needing HPN nursing care are looked after by district nurses in most areas and the homecare nursing service is limited. Using remote consultations for advice may reduce some urgent admissions though patients may still need investigations and there remains a need for timely admission to specialist care.

As described by other groups (7,8,9) the age of both our new patients and our overall population of HPN patients is increasing. Our impression is that our patients are also becoming more complex but we have been unable to confirm this from the very limited data on other illness which has been collected over the years. More patients now require help with their HPN management and this may indicate increased frailty. Some of our elderly patients are struggling to manage at home but there is no easy solution to their care within the residential care environment. The size of this group is likely to increase in the future.

There is no doubt that there has been a change in patient characteristics, moving from younger patients with short gut due to Crohn's disease to older patients with malignancy and/or post-operative complications, with an increase in patients with fistula or obstruction. This may reflect increased referral of such cases, together with more aggressive treatment of advanced malignancy, bowel ischaemia and some abdominal emergencies. More palliative patients have been treated recently, in keeping with trends across the UK. The proportion of patients with post-operative complications is high (26.3% of 205 patients) and seems higher even than that described by the Salford group (8), but this

may be due to a difference in categorisation of patients. Dibb et al have included post-operative complication as one of the underlying disease categories, while we have assessed this as a separate field, so our group of post-operative complications includes patients with several different disease processes and includes some with Crohn's disease and radiation enteritis as well as those who had complications following for example, complex incisional hernia repair or diverticular disease. Although the percentage of patients who started HPN in the same admission as an operation is increasing, it is reassuring than the percentage due to unpredicted post-operative complications is not increasing. We suspect that there is now more awareness of intestinal failure and of HPN and that surgeons are referring patients more readily.

**2. <u>Survival</u>**

Our survival data is similar to other reports (8,11). We were somewhat disappointed that we could not demonstrate improved survival over time. It would be logical to assume that increased experience would improve outcomes and some years ago a group from one Scottish centre reported a reduction in complications as the team became more experienced(12). We have also recently reported a reduction in catheter related complications over nearly twenty years of care in our own unit(5). However from 2000 to 2012 Scotland had a Managed Clinical Network for Home Parenteral Nutrition which produced guidelines for care, organised educational events, and encouraged networking between professionals. This may have reduced the learning curve for HPN care in our department. An audit of outcome across the Scottish network (13) was not able to demonstrate a difference in survival between two large centres and centres with a smaller number of patients and this would imply that networking influenced outcome. Dibb and colleagues have reported that increased age reduces survival in HPN patients (8) and it may be that our ability to maintain survival rates despite an increasingly elderly and heterogenous patient population is effectively an improvement in outcomes. We did not demonstrate a reduction in survival in older patients.

The majority of deaths in this series were due to the underlying disease process and a large number of patients also died of unrelated cause. This is similar to previous reports (8,11). The number of HPN related deaths was low. Although the numbers are small HPN deaths in comparison to the deaths from other causes may have reduced over the years, which is reassuring. Brandt has reported 40 years of HPN experience in Denmark (9) and has also noted a reduction in HPN related

deaths in the most recent decade. It is interesting that with increasing numbers of patients, Denmark has moved from a single HPN centre to a network system for management of HPN.

HPN dependency seems to be lower than other reports (8,11) and the most common reason for stopping is surgery. It seems that surgeons in the West of Scotland are referring more patients with major post-operative complications for a period of HPN followed by further operation. It is reassuring that the percentage of patients with complications is not increasing although the numbers are going up. One might speculate that some of these patients might not have survived in the past or were not offered HPN. It is likely that there is a strong influence from surgeons who have trained locally, nearly all of whom will have worked in our unit and therefore the knowledge of HPN as a means of rescuing seriously unwell patients will have increased. In many areas of medicine the ability to "rescue" a patient from complications has improved in recent years and has become a quality indicator (10). There has also been increased emphasis on the management of intestinal failure within the surgical community which has raised awareness of this treatment option (15).

### 3. Admissions

The number of admissions seems to be high in comparison to a recent report from one of the UK national Intestinal Failure centres (14) who reported 1.77 admissions per 1000 HPN days in comparison to our figure of 5.1/1000 HPN days. The reason for this likely relates to logistics. We have been fortunate to be able to give open access to our wards for our HPN patients and the great majority of our admissions are direct. We tend to be informed quickly of any patient admitted elsewhere and transfer virtually every patient, so it is likely that very few admissions are not recorded. We also have a low threshold for advising admission. Burden's report appears to have a remarkably low percentage of emergency admissions (33%) while we find that 74% of our admissions are as an emergency or urgent. Perhaps this is explained by the nursing service via a homecare company which is available in Salford and may avoid some admissions. We suspect that most intestinal failure services could also demonstrate that a small number of patients are responsible for much of the inpatient activity.

Although the number of admissions per patient did not reduce significantly in the study period, the catheter infection rate has fallen (5). More admissions are due to either the underlying disease or unrelated causes. The reason for the relative increase in admissions due to the underlying disease is not clear. Our impression is that we are treating patients

with more complex problems but we cannot provide data to support this impression. The increase in admissions from unrelated cause would be expected in a more elderly population.

One unmet need for our patients who do develop catheter infection would be the ability to finish their course of intravenous antibiotics at home. Although clearly any patient with systemic sepsis requires inpatient treatment initially, once they are stable and HPN has been re-instated without complication, there is generally a period of ongoing intravenous antibiotics of up to two weeks. Although an outpatient intravenous antibiotic service is available in Glasgow, the protocols do not fit well with HPN requirements. The inclusion of intravenous antibiotics in the HPN contract might enable earlier discharge.

## 4. Limitations

This study is observational and although the data was collected prospectively the analysis is retrospective. Because the number of patients was low during the initial years analysis is limited and type 2 errors may have occurred. Despite this, the dramatic changes in patient numbers are very clear and many of the changes are consistent with other reports.

## Conclusion

The increasing number, age and dependency of the HPN population has significant implications for the organisation and resource for HPN care. A greater number of patients may necessitate changes in the organisation and funding to allow both expert care and the development of skills local to the patient. The problem of elderly HPN patients who require increased community support at home or in residential care will need to be addressed.

HPN has widened its scope from a lifelong treatment for young people with catastrophic Crohn's disease to include rescuing patients who have serious post-operative complications. Although it is impossible to assess the numbers who did not survive such complications in the past, it seems likely that some patients are now surviving illness which would have been fatal. Clinicians~~Surgeons~~ need to be aware of HPN as a possible treatment but the HPN service must be able to supply an efficient, low complication solution.

Relatively frequent admissions remain a problem for HPN patients. Systemic sepsis is life threatening but in some circumstances our patients could have a reduced length of stay if adequate community resource was available. Community investigation of more minor possible infective episodes would reduce the number of admissions. We need to develop a means of identifying those who truly require admission and a better system for community care.

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Author Contribution –

**McKee**: conceptualisation, methodology, validation, formal analysis, data curation, writing (original draft), writing (review + editing)

**Knight:** formal analysis, writing (review and editing)

**Leitch:** data curation, writing (review + editing)

**Stevens:** data curation, writing (review + editing)

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