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Original article

Cost analysis of chronic intestinal failure

Emilio Canovai [a, b], Laurens J. Ceulemans [a, b, c], Guido Peers [d], Lutgart De Pourcq [a, e], Marleen Pijpops [a, e], Gert De Hertogh [a, f], Martin Hiele [a, g], Jacques Pirenne [a, b], Tim Vanuytsel [a, g, *]

[a] Leuven Intestinal Failure and Transplantation Center (LIFT), University Hospitals Leuven, Belgium
[b] Abdominal Transplantation, University Hospitals Leuven, Belgium
[c] Thoracic Surgery, University Hospitals Leuven, Belgium
[d] Financial Department, Medical Administration, University Hospitals Leuven, Belgium
[e] Department of Pharmaceutical and Pharmacological Sciences, University Hospitals Leuven, Belgium
[f] Pathology, University Hospitals Leuven, Belgium
[g] Gastroenterology, University Hospitals Leuven, Belgium

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SUMMARY

Background & aims: Chronic intestinal failure is a complex medical condition which is associated with high costs. These patients require long-term home parenteral nutrition (HPN) and costs are compounded by frequent admissions for the underlying disease and HPN. However, it is unknown what the specific costs subdivisions are and how they evolve over time. The aim of the study was to evaluate the cost dynamics of HPN care in a cohort of stable, long-term intestinal failure patients.

Methods: A retrospective analysis of our single-center long-term (>2 years), benign HPN population was performed. All relevant clinical and financial data were collected: costs of hospital admissions, diagnostics, treatments, out-patient clinics, home care, medication, materials and HPN education. The costs were tabulated and assigned by cause (HPN related, underlying disease-related or -unrelated). Patients with complicated intestinal failure (defined as impending loss of vascular access, liver failure or recurrent fluid/electrolyte disorders) were excluded. Data are presented as median (range).

Results: Thirty-seven patients (24 female; age 58.6 ± 13.3 years) were included in the study. HPN duration was 5.3 years (2.1–15.1) at 4.3 infusion days per week (1.5–7). Total cost of the first HPN year was €83,503 (35,364–256,780). HPN-related costs accounted for 69% (€57,593) vs 27% for underlying disease-related costs (€22,505) and 4% for disease-unrelated costs (€3065). HPN complications cost €16,077 in the first year and accounted for 31% of HPN costs. The total cost dropped by 15% in the second year to €71,311. This reduction was due to fewer hospital admissions and fewer HPN complications. This trend continued and by year 5 the annual cost was 40% cheaper compared to year 1 (€58,187 vs €83,503).

Conclusions: HPN related costs accounted for the majority of the total expenses in IF patients. The costs declined after the first year due to a reduction in complications and hospital admissions.

1. Introduction

Intestinal failure is defined as the loss of gut function which requires intravenous (IV) supplementation for survival or growth [[1.] Depending on various factors (remaining bowel length, age, underlying pathology, etc.) around 50% of patients will require parenteral nutrition for an extended period of time [2]. The incidence of chronic intestinal failure (CIF) has been estimated at 5–20 patients per million [3,4]. Once the underlying disease process has been stabilized, ambulatory treatment using home parenteral nutrition (HPN) is the primary treatment. The first case of HPN was

Abbreviations: CIF, chronic intestinal failure; CRBSI, catheter related bloodstream infections; HPN, home parenteral nutrition; UD, Underlying disease; UR, Unrelated disease.

* Corresponding author. Department of Gastroenterology, University Hospitals Leuven, Herestraat 49, 3000 Leuven, Belgium.
E-mail addresses: emilio.canovai@uzleuven.be (E. Canovai), laurens.ceulemans@uzleuven.be (L.J. Ceulemans), guido.peers@uzleuven.be (G. Peers), lutgart.depourcq@uzleuven.be (L. De Pourcq), marleen.pijpops@uzleuven.be (M. Pijpops), gert.dehertogh@uzleuven.be (G. De Hertogh), martin.hiele@uzleuven.be (M. Hiele), jacques.pirenne@uzleuven.be (J. Pirenne), tim.vanuytsel@uzleuven.be (T. Vanuytsel).

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described in 1970 by Shils et al. [5]. Soon after, the first structured HPN networks were set-up both in the USA and Europe [6,7]. These have evolved over time into integrated, multidisciplinary teams [18]. Recent studies have demonstrated excellent long-term results with experienced centers reporting 5 year survival of 80% in adults and 90% in children [2]. Transferring and treating the patient in an ambulatory setting not only improves quality of life [9,10] but it also reduces costs significantly [11,12]. Nevertheless, the cost of HPN treatment remains high, ranging from $ 70,000–300,000 per year [11,13–20]. Expenditures on HPN reached $2.3 billion in 2014 in the USA [21].

Costs of CIF patients can be divided into three categories: HPN related, underlying disease (UD) related and costs of unrelated disease (UR) (Fig. 1).

HPN treatment requires specialized nursing care and materials such as IV lines, HPN and/or fluids, needles, pumps, IV medication and other disposables [14]. Furthermore, HPN complications such as central venous line complications, liver disease, metabolic complications and fluid/electrolyte disorders are frequent in these patients [22]. Secondly, the underlying disease will continue to require treatment. This is especially the case in the short bowel syndrome patients [18,23] which make up the majority of the CIF population [1]. Thirdly, CIF patients also require treatment for unrelated diseases which may be more challenging due to the concomitant intestinal failure.

Financial studies of chronic HPN treatment have been performed in the past in various countries, but the included costs are highly variable and hence only tell part of the story. Some researchers have focused only on the direct cost of HPN [15] while others have also included the costs of HPN complications and/or underlying diseases [16,18,20]. There are also studies that examined the cost of nursing and ambulatory treatment only [14,21]. To the best of our knowledge, no attempt has been made to calculate the total cost of CIF patients. Furthermore, most studies date back from many years ago and do not reflect the current state of HPN therapy. Finally, studies frequently include quite heterogeneous patient populations including palliative HPN in oncological cases which is a totally different population [24].

The aim of this study is to report the total annual costs of long-term adult CIF patients with benign underlying disease at our institution and to assign them to a specific category. Secondly, the evolution of costs over time will be evaluated and analyzed.

2. Materials and methods

We performed a retrospective analysis of our long-term (>2 years) single-center HPN population for benign indications who commenced their therapy between 2000 and 2013 at the University Hospitals Leuven, Belgium. We only included adult patients (>18 years) in this study. The period of 2 years as a cut-off for long-term was chosen as this is recognized as the period beyond which little further recovery of bowel function can be expected [1]. Our center is the largest of five tertiary care referral hospitals for CIF in Belgium. Patients with complicated CIF being considered for intestinal transplantation were excluded. This includes patients with impending loss of vascular access, liver failure, recurrent episodes of severe dehydration or catheter related blood stream infections (CRBSI) as defined by the Centers for Medicare and Medicaid [25]. Demographics, indication, HPN formulation, admissions, complications and survival data were collected retrospectively from our prospectively maintained database. Total costs were calculated from the billing information from both the financial department of the hospital and home-care companies. These included all costs of admissions, diagnostics, treatments, out-patient clinics, home care, medication and education. Home nursing costs were calculated by taking the nationally fixed daily tariffs and multiplying this by the number of HPN days. The costs were tabulated per patient and assigned by cause (HPN, UD or UR) (Fig. 1). If an admission was related to two causes, the costs were assigned to the clinically dominant category. In the event that a patient was admitted in another hospital, the reason for admission and details of the stay were recovered from local patient files. Costs would then be estimated based on the same tariffs as applied in our hospital. All financial data was rounded to the nearest Euro and corrected for inflation up to 2015. This was achieved by multiplying all costs in a specific year by an indexation correction factor (i.e. Corrected value = uncorrected value * (national index value 2015 * national index value year X). All patient data were updated until 31 December 2015. This study did not include indirect costs such as lost income due to reduced productivity of the patient or family. All values are presented as median (min–max range) unless stated otherwise due to the skewness of the data. Mean costs are summarized in Table 1 for comparison. For statistical analysis, Wilcoxon signed-rank test was used for paired, non-normally distributed data and Mann–Whitney U test for unpaired, non-normally

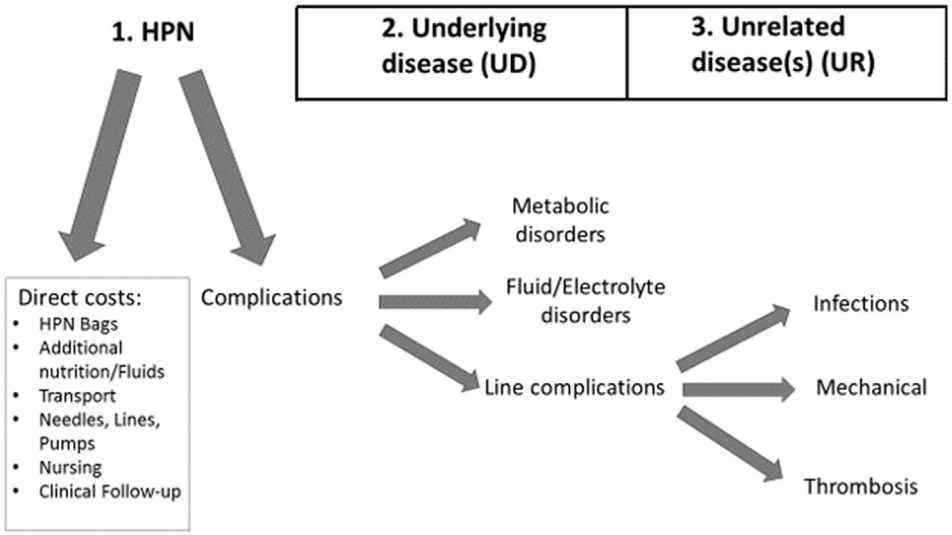

Fig. 1. Break-down of costs associated with Chronic Intestinal Failure treatment. HPN = Home parenteral nutrition.

Table 1
Median and mean costs per patient per year.

	Year 1		Year 2		Year 3		Year 4		Year 5	
	Median (min–max)	Mean (SD)	Median (min–max)	Mean (SD)	Median (min–max)	Mean (SD)	Median (min–max)	Mean (SD)	Median (min–max)	Mean (SD)
Total costs	€83,503 (35,364–256,780)	€94,828 (45,049)	€71,311 (31,955–136,657)	€72,701 (29,780)	€57,593 (29,161–238,136)	€67,842 (36,092)	€58791 (22,686–124,008)	€66,206 (27,051)	€58186 (25,049–143,988)	€68,279 (41,338)
HPN	€57,970 (29,078–145,900)	€71,219 (20,682)	€55,795 (39,622–118,555)	€62,353 (16,781)	€45,079 (32,400–75,992)	€58,119 (11,843)	€45,333 (32,627–120,341)	€60,884 (15,555)	€44,542 (33,437–157,074)	€62,975 (27,276)
Underlying disease	€22,505 (402–194,766)	€31,249 (34,071)	€13,616 (617–83,413)	€19,961 (19,706)	€11,407 (0–158,240)	€17,675 (26,803)	€10,991 (1357–40,673)	€13,651 (9988)	€11,163 (351–48,760)	€12,277 (11,706)
Unrelated diseases	3028 (754–6721)	4631 (4648)	1900 (867–17,972)	1996 (814)	2460 (849–6455)	3013 (1629)	2467 (1134–21,245)	2927 (1805)	2481 (1252–57,722)	3902 (5067)

HPN: Home parenteral nutrition.

distributed values. Paired sample t-test was used for normally distributed, paired samples. Differences between groups were considered to be significant at a P value of <0.05. Survival was calculated using the Kaplan–Meier estimate. Statistical analyses were performed with GraphPad Prism 7.0 (GraphPad Software, Inc., San Diego, CA). The study was approved by the Institutional Review Board of the University Hospitals Leuven (IRB number S60961) in accordance to the latest version of the Declaration of Helsinki.

3. Results

3.1. Patients

Thirty-seven CIF patients were included in the study. Median age was 59 (34–85) years and 67% (n = 24) were female. The median duration of HPN treatment was 5.3 years (2.1–15.1). HPN was administered 4.3 days per week (1.5–7) at a total of 6058 kcal per week (2270–11,290). Seventeen of the 37 patients (46%) required additional fluid and/or electrolytes bags in addition to calories. Additional patient demographics and data on nutritional support at the start of HPN therapy are shown in Table 2. The causes of the CIF were short bowel (59%), chronic severe dysmotility (30%), mechanical obstructions (8%) and mucosal disease (3%). Five and 10-year all-cause survival were 90% and 65%, respectively. None of the deaths were related to the HPN treatment. Three patients (8%) could still be weaned off completely of HPN after a median of 4.4 years (2.7–5.8) and switching to enteral nutrition.

3.2. Total costs

The total cost of the first year of HPN was €83,503 (35,364–256,780) (Fig. 2). The total cost dropped by 15% in the second year to €71,311 (31,955–136,657; p = 0.002). Costs decreased further by 17% for year 3 to €57,593 (29,161–238,136) and were significantly lower compared to the first year (p = 0.02). The costs stabilized by year 4 and 5 as these were very similar: €58,791 [22,686–124,008] and €58,187 (25,049–143,988), respectively (p = 0.398). Year 5 was 40% cheaper overall compared to year 1 (€58 186 vs €83 503; p = 0.001).

Similarly, the number of hospital admissions (all cause) was the highest in the first year at a average of 2.3 (0–7) admissions per patient per year and declined each year afterwards (Fig. 3).

There were no differences in costs between the underlying conditions (data not shown). As an example, the first year total costs of short bowel syndrome were €92,192 (35,364–169,146) and €79,606 (44,224–256,780) for chronic dysmotility disorders (p = 0.36).

3.3. HPN related costs

3.3.1. First year

Patients were admitted at the time of the start of their HPN treatment (if not already admitted for their UD) and received the necessary education by specialist nurses and training to connect and/or disconnect in case the patient was able and willing to be trained. If necessary, a local home nursing team was contacted and their staff was trained by a specialized HPN home care company if necessary. In specific cases, the home care company made extra visits to the patients at home to inspect if all procedures were being followed correctly. In the first year, HPN and associated complications accounted for 69% of total costs (€57,970, (29,078–145,900)) (Fig. 4). Of these direct costs, 68.1% (€26,511 (12,064–42,284)) was spent on parenteral nutrition bags,

Table 2
Demographics and parenteral nutrition characteristics.

Variable	Median (Range; min – max)
Age	58.6 years (34–85)
Gender	24 Female, 13 Male
Median duration of HPN	5.3 years (2.1-15.1)
Number of infusions per week	4.3 days (1.5-7)
Mean Total kcals per week	6058 kcal (2285–11,290)
Mean Glucose kcals per week	3528 (1365–7322)
Mean Lipid kcals per week	1659 (399–3598)
Mean Volume per week (Liters)	5.9 (2–14)
Type of access	Tunneled catheter: 30 (81%)
	Totally implantable venous access device (ports): 7 (19%)

HPN: Home parenteral nutrition.

disposables and transport of materials, 23.2% on home nursing (€9259 (0–18,491)) and 8.7% on ambulatory treatment (such as (re)placement of access, consultations and technical investigations) (€4158 (251–7747)).

The remaining 31% of the HPN costs in the first year were due to complications (€13,050; (0–86,718)). There were 21 complications requiring admission in 16 patients (46%) in this first year (average of 0.62 per patient per year) (Fig. 3). The median duration of hospital stay for HPN complications was 17 days (1–61) and cost €16,077 (3500–57,683). The vast majority (n = 19, 90%) of these admissions where due to suspected or confirmed CRBSI, requiring hospitalization for IV antibiotic or antimycotic treatment. Of the infections, 90% were of bacterial origin. There were 2 cases (10%) of *Candida Glabrata* infection. In 32% of infections, the catheter could not be salvaged by local (line locks) and systemic antibiotics. Half of these infections occurred in totally implantable venous access devices (ports) which were then always replaced by a single lumen tunneled line. The incidence of CRBSI was higher in ports compared to tunneled lines (1.18/1000 vs 0.3/1000 catheter days, p = 0.02). Two cases were hospital-acquired line infections in year 1 with a cost of €16,849 and €52,340. The remaining 10% of HPN admissions were for interventions for refractory in-line occlusions or thromboses. There were no admissions in the first year for fluid/electrolyte or metabolic disorders.

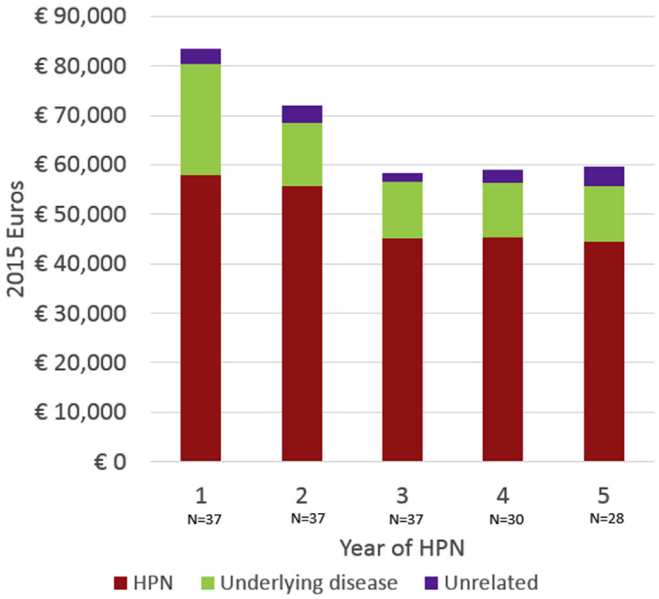

Fig. 2. Annual Median cost per patient. HPN = Home parenteral nutrition.

3.3.2. Year 2–5

In the second year, the total HPN costs dropped slightly but not significantly to €55,795 (39,622–118,555; p = 0.16). However, the proportion of HPN costs increased to 78% of total costs due to significant reduction of the latter from year 1 onwards. Over the following years, this proportion remained stable, accounting for around 77% of total costs.

By year 3, the total costs of HPN dropped by 22% compared to year 1: €45,079 (32,400–75,992; p < 0.0001) after which they remained quite stable (year 4: €45,333 (32,627–120,341) and year 5: €44,542 (33,437–157,074)). The number of HPN complications declined significantly in year 2 and 3. In year 2, 10 patients (27%) had 16 complications at €10,685 (1569–18,343) per admission while in year 3, 5 patients (14%) had 6 complications accounting for €9323. Because of this, the annual cost of complication per patient dropped by 85% by the third year (From €13,050 to €2,758, p = 0.004).

The direct costs of HPN increased by 15% from €39,850 (12,092–82,719) in year 1 to €46,867 (28,394–885,599) in year 2 (p = 0.006) after which they stabilized to €42,265 (20,909–170,748) by year 3 (p = 0.42 compared to year 2). This was a result of a 41% increase in the costs of home nursing and ambulatory treatment between year 1 and 2 (€13,417 (2160–23,960) to 22,739 (0–43,062); p < 0.0001)). This was due to patients spending more time at home, thereby increasing these costs.

The majority of patients (n = 30; 81%) had some form of home nursing at the end of the study period. Most relied on nursing to connect and/or disconnect the bags. This added to the total cost burden as each day of HPN therapy costed €51 (flat rate for

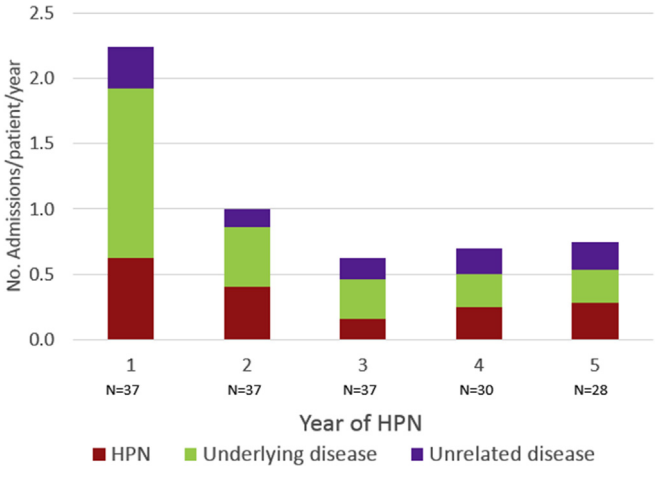

Fig. 3. Mean number of admissions per patient per year and its underlying causes. HPN = Home parenteral nutrition.

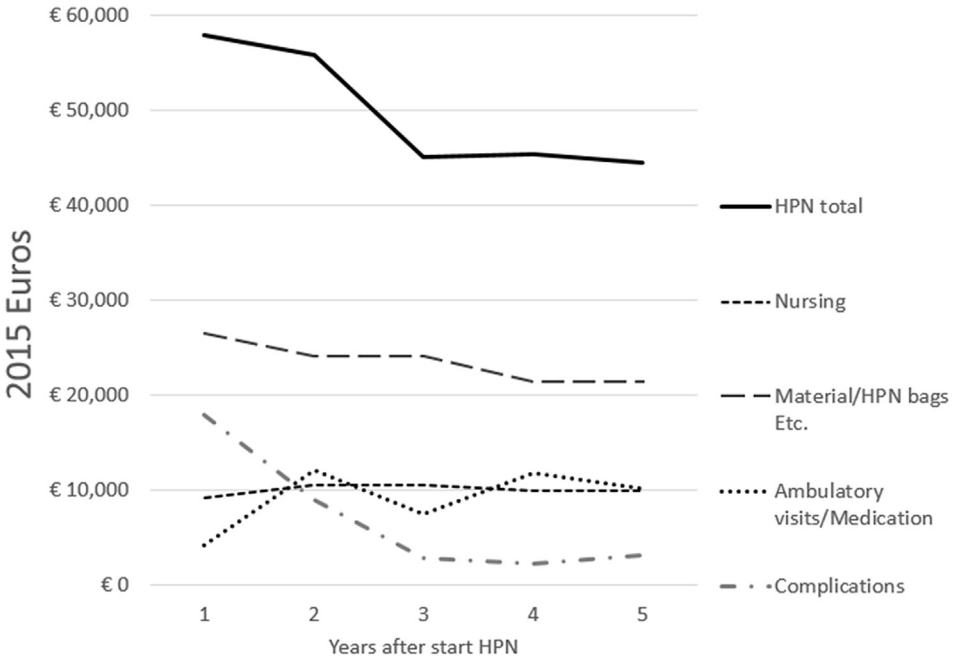

Fig. 4. HPN costs evolution over time with the component costs shown. HPN = Home parenteral nutrition.

nursing costs per day). The proportion spent on nursing accounted for 16% of the whole HPN budget in the first year (€9259; (4115–14,403), 19% in the second year (€10,566 (0–21,132)) and 23% in the third year (€10,586 (0–23,461)). Although this was a proportional increase, it was not significant in absolute value ($p = 0.26$, Y1 vs Y2).

3.4. Underlying disease related costs

In the first year, 27% of the total cost was spent on UD related costs (€22,505 (402–194,766)) (Fig. 2). Of these, 73% costs were incurred for admissions which accounted of €16,552 (0–134,538) per patient. After discharge, 65% of patients ($n = 24$) had 46 admissions for treatment of the UD in the first year. This amounted to a mean of 1.3 (0–6) admissions per patient. The majority of admissions was due to surgery followed by obstructions and admissions for observations/re-evaluations (see Table 3). The median cost of a single UD admission was €6265 (264–130,191) and lasted 8 days (1–131). Both of these factors (cost and duration) where significantly lower compared to HPN related admissions ($p < 0.0001$ and $p = 0.0022$ respectively). The most expensive reason for UD admission was surgery which cost €13,623 (1427–130,191). There was a trend for surgical admissions to last longer at 18.5 days (2–131) than for other reasons (median 7.5 days [2–42]), although this difference was not significant ($p = 0.1$). Similarly, there was a trend towards other UD related admissions (obstructions, infections, observation or other causes) being cheaper although, again this was not statistically significant ($p = 0.06$). The remaining 27% of expenses were for ambulatory treatment which amounted to € 5983 per patient (215–48,636). This included fees for outpatient clinics, ambulatory treatments, laboratory testing and imaging.

Table 3
Overview of the admissions in the first year after start of home parenteral nutrition.

Category	Median cost per admission	Mean cost per admission	Sub-category	Number of admissions (% of total)	Median cost per admission	Mean cost per admission
HPN	€16,077 (3500–57,683)	€21,456 (15,689)	CRBSI	19 (90%)	€17,462 (7215–57,683)	€22,759 (15,841)
			Non-CRBSI	2 (10%)	€9073 (3500–14,645)	€9073 (5573)
Underlying disease	€6280 (264–130,191)	€12,818 (22,281)	Surgery	12 (26%)	€13,623 (246–130,191)	€28,148 (37,488)
			Obstruction	12 (26%)	€5972 (701–31,664)	€7972 (7651)
			Infections	6 (13%)	€8903 (2071–14,766)	€8680 (4744)
			Observation/re-evaluation	9 (20%)	€1639 (120–37,505)	€1184 (11,254)
			Other treatments	7 (15%)	€5777 (148–14,226)	€4991 (4672)
Unrelated disease	€10,177 (3734–19,084)	€10,584 (4582)	Infections	5 (46%)	€13,081 (7988–19,084)	€13,457 (4116)
			Pulmonary	2 (18%)	€8633 (4182–13,084)	€8633 (0)
			Cardiac	1 (9%)	€3734	€3734
			Trauma	1 (9%)	€11,286	€11,286
			Urological/Gynaecological	2 (18%)	€8427 (7706–9148)	€8427 (721)

HPN: Home parenteral nutrition; CRBSI: catheter-related bloodstream infection.

In the second year, there was a 43% reduction in UD costs to €13,616 (617–83,413; p = 0.04). This accounted for 19% of total CIF costs. The number of admissions declined sharply to 17 admissions in 11 patients. This resulted in an average of 0.46 (0–4) admissions per patient per year. However, the cost per admission went up by a factor of 2.5 (€15,564 (1188–56,908; p = 0.004). This was due to increased severity of conditions with a higher proportion of surgical interventions and subsequently doubling of hospitalization days (8 (1–131) vs 15 (2–63); p = 0.01). Meanwhile, annual ambulatory costs dropped by 62% to €2289 (316–41,282; p = 0.02) per patient.

From year 3 onwards, the total costs remained relatively stable around €11,000. Admissions costs dropped annually until reaching €4826 by year 5, which was significantly lower compared to year 1 (p = 0.0401). There were only 0.3 admissions per patient per year and both the length (12 days (range 2–12)) and costs (€10,814 (2178–22,163)) of admissions declined further. In contrast, by year 4, ambulatory costs increased and accounted for the majority of UD related financial burden by this time (66%).

Three of the 8 patient deaths in our cohort were related to the UD which were progression of amyotrophic lateral sclerosis (ALS) causing respiratory failure, recurrent bowel infarction and fatal sepsis from an abdominal source.

3.5. Unrelated disease costs

In the first year, 4% of total costs were due to UR (€3028; 754–6721) (Figs. 2 and 4). Eight patients (22%) had a combined 11 admissions. This resulted in 0.3 admissions per patient with a median hospital stay lasting 12 days [4–21] at €10,177 (3734–19,084). Of these admissions, 46% were for non-GI infections (such a pyelonephritis and skin and soft tissue infection) while the other causes were pulmonary problems, acute coronary syndrome, gynecological bleeding, urological problems and a skeletal fracture.

In the following years, costs due to UR remained only a fraction of the total costs: 3% in year 2 (€1900 (867–17,972)) and 4% (€2460 (849–6455)) in year 3. In year 2, there were only 5 admissions in 4 patients. In this year, the cause of admission was cardiovascular in 3 cases, 1 urological problem (placement of stents) and pneumonia requiring IV antibiotics. Patients spent 5 days [3–9] in the hospital at €5084 per admission (1896–13,538). By year 3, the costs per admission had further declined to €3228 (2534–5898) with a hospitalization lasting for 4 days [2–7]. Five out of eight deaths (63%) were related to UR. Death occurred at a median of 5.4 years after start of HPN (2.5–7.4). The UR deaths were caused by acute myocardial infarction, aspiration pneumonia, complications after trauma and two cases of depression leading to refusal of continuation of HPN therapy in one and suicide in another.

4. Discussion

This study investigates the total cost and evolution over time in a cohort of CIF patients. When analyzing the potential *cost-effectiveness* of new therapies, such as glucagon-like peptide-2 (GLP-2) analogues, the entire cost including non-HPN medical therapy needs to be taken into account.

Overall, €83,503 was spent in the first year which is comparable to the UK (£55,000 (€60,000)) [19] and the Netherlands at €90,928 [20]. This figure is lower than USA data ($150,000–250,000) [11,13–18] as HPN is supplied by private companies [19] and price negotiations are forbidden [26]. Other studies [20,27] also confirmed that year 1 was more expensive than subsequent years. However, HPN volume and complication rate was assumed to remains constant in the subsequent years. In contrast, our study shows that the first two years were more expensive due to higher costs of the underlying disease (UD) and complications.

In all years, the majority of costs were HPN related. Similar to literature, it accounted for around 70–85% of total expenditures [11,16,20,27]. However, direct costs (bags, disposables and nursing) was €39,850 in the first year and remained stable. This is cheaper than home hemodialysis treatment in Belgium (a recognized organ replacing therapy) which costs are around €48,350 per year [28]. In contrast, dialysis is 40% cheaper in the US than the lowest estimate of HPN therapy ($87,945 [29] vs $150,000 per patient annually). This could be due to the Belgian policy of national price negotiation.

In the first year, 31% of HPN costs were complication-related. More than half of our patients had at least 1 serious complication in the first two years. After year 2, this dropped to 10% which is comparable to other studies [11,20]. Therefore, the stabilization period of the first two years should be viewed separately [30].

In the first two years, most HPN admissions were catheter related. As expected, CRBSI admissions were more expensive than non-CRBSI complications. The costs of in-hospital CRBSI was comparable to international data [31]. Gillanders et al. [32] estimated the costs of vascular complications at €6480 which is cheaper than our data. However, this study had more non-CRBSI complications (occlusions, dislocations etc.) compared to our cohort (26 vs 10%). This was probably because this was a cross-sectional study whilst our data were longitudinal. After year 2, HPN complications became less frequent which led to a significant decline in cost. In our study, all deaths were due to UR or UD. This is in line with other series, confirming the safety of HPN [15,33].

The majority of patients had at least partial home nursing on every HPN day. However, 50% of these patients were able to disconnect alone. This was mainly due to the lack of financing to teach self-administration until 2010. This led to additional costs (11–17% of total costs) which could be avoided without impacting quality of care [32–34]. We estimate that if we could get 50% of patients to self-manage, we would save around 9% per patient (+/−€4000). Increasing the proportion of patients self-managing HPN is one of the priorities of our center. Nevertheless, certain patients could not be discharged safely without home nursing and ambulatory nursing is still cheaper than continued hospitalization. Also, this allows family members to work, improving family income and quality of life [35–37].

In addition to the HPN costs, we demonstrated that UD accounted for 27% of costs in year 1 (€22,505) and then dropped to around 18% (€12,771) for the remaining 4 years. This is significantly higher than other chronic abdominal diseases such as Crohn's disease ($8265) and ulcerative colitis ($5056) [38], which underlines the severity of CIF. In fact, during the first year, UD admissions were more frequent than admissions for HPN related causes. However, the former were shorter and cheaper by comparison. The exception was for surgical UD admissions where costs are comparable to UK data on CIF patients [23]. In subsequent years, UD costs stabilized and hospitalization became less frequent. Therefore, treatment of the UD contributes significantly to overall costs.

We also examined the UR costs. These only accounted for 3–4% of total costs in any year. This low figure is unsurprising as CIF dominates the overall health situation. Despite this, UR was the main cause of mortality in our cohort: 5 of the 8 patient deaths. This may be explained in the excellent results in managing HPN complications [33]. The causes for UR admissions varied broadly from infections, heart- or lung disease among others. It is known that chronic intestinal diseases are associated with a higher risk of cardiac events [39] and infections [40]. Two patients died due to depression which is a known complication in this population [41,42].

For this study, we selected long-term benign CIF patients. Most cohorts often also contain short-term HPN patients (oncological, post-surgery etc.). For example, HPN in terminal cancer patients is more expensive due to more frequent admissions and shorter survival 'gains' [24]. We excluded these patients in order to create a homogenous group. Moreover, we aimed to describe costs in a population, which would be potential candidates for disease-modifying treatments such as GLP-2 analogues.

Despite the strengths of our study in providing insight in the costs associated with CIF there are some limitations to acknowledge. First, the retrospective nature of the study makes it difficult to exclude missing data although this seems unlikely as all treatments are billed. We only had data from our hospital while the cost at other institutions was estimated. However, this was rare as patients were transferred to our center soon after admission elsewhere. Furthermore, in Belgium medical costs are fixed and thus do not vary significantly between centers. Indirect costs, such as lost income, were excluded however this can be significant and clinicians should be aware of this [36]. If admissions were caused by two different causes, all costs were assigned to the dominant one. In theory, it would be possible that this was not the most expensive part of the hospitalization. However, this was never the case in this cohort. Moreover, less than 5% of admissions had a double cause for admission.

Finally, the health care organization in Belgium may be different compared to other nations. GLP-2 analogues are not yet available in Belgium and hence do not influence the costs. However, this makes the data suitable as a benchmark for these novel treatments. Furthermore, our patient population continues to be treated at our institution along with the primary care physician. This allows early identification of problems and prevents emergency admissions. Moreover, the centralized structure made it possible to capture data effectively. Finally, even though the absolute costs may differ, the evolution and cost distribution are likely to be similar across different health care systems.

5. Conclusion

This study investigated the total cost of treatment of chronic intestinal failure patients. We showed that the costs were the highest in the first two years with frequent admissions. Most admissions were related to treatment of the underlying disease rather than HPN, however the costs of HPN complications were higher overall. After the first two years, costs stabilized and admissions and complications became rare. HPN treatment itself did not lead to any of the deaths in our cohort, which demonstrates it is a safe treatment and at our institution costs are roughly the same as chronic dialysis treatment, another organ replacing therapy.

Statement of authorship

EC, GP, JP and TV designed the study. EC, GP, MP and LDP collected data. EC, GP and TV analyzed the data. EC and TV wrote the first draft of the manuscript. EC, LC, GP, LDP, MP, JP, GDH, MH and TV contributed to the discussion and critically reviewed the manuscript. All authors read and approved the final manuscript.

Conflicts of interest

There are no conflicts of interest to report from any of the authors.

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