



Cost of ambulatory care for the pediatric intestinal failure patient: One-year follow-up after primary discharge[☆]



Christina Kosar^a, Karen Steinberg^a, Nicole de Silva^a, Yaron Avitzur^{a,b}, Paul W. Wales^{a,c,*}

^a Group for Improvement of Intestinal Function and Treatment (GIFT), The Hospital for Sick Children, University of Toronto, Canada

^b Division of Gastroenterology, Hepatology and Nutrition, The Hospital for Sick Children, University of Toronto, Canada

^c Division of General and Thoracic Surgery, The Hospital for Sick Children, University of Toronto, Canada

ARTICLE INFO

Article history:

Received 26 January 2016

Accepted 7 February 2016

Key words:

Pediatric
Intestinal failure
Costs
Ambulatory

ABSTRACT

Background: Survival of children with intestinal failure has improved over the last decade, resulting in increased health care expenditures. Our objective was to determine outpatient costs for the first year after primary discharge. **Methods:** A retrospective analysis was performed in pediatric intestinal failure (PIF) patients between 2010 and 2012. Patients were stratified into 3 groups (1 = enteral support with no devices [7 patients], 2 = enteral support with devices (gastrostomy and/or ostomy) [19 patients], 3 = home parenteral nutrition (HPN) [22 patients]). Data abstraction included clinical characteristics and costs related to medication, enteral/parenteral nutrition, and supplies were calculated. Data were analyzed using one way ANOVA.

Results: Forty-eight patients (mean age 7.6 months; 31 males [65%]) were studied. See attached table for results. HPN patients had significantly more ambulatory visits ($p < 0.0001$), number of admitted days ($p = 0.01$), and productive days lost ($p < 0.0001$). Total cost of care was significantly higher for HPN patients (mean = \$320,368.50, $p < 0.0001$) when compared to other groups. Costs covered by the health care system were significantly higher for patients on HPN (mean = \$316,101.56, $p < 0.0001$).

Conclusion: The outpatient expenditures to care for PIF patients in the first year post primary discharge are significant. Our single payer health care system supports the majority of costs, but families are also incurring expenses related to travel and lost productivity. Children on HPN have more visits to hospital, but have access to more funding options. Children solely on gastrostomy or stoma therapy, however, have a significantly greater personal financial burden.

© 2016 Elsevier Inc. All rights reserved.

Long-term parenteral nutrition support is a common therapeutic strategy for the management of children with intestinal failure (IF) in both the inpatient and home setting. IF is defined as the inability of the intestine to digest and absorb adequate nutrients and fluid to support survival and growth [1–3]. Pediatric intestinal failure (PIF) is caused from short bowel syndrome (SBS), intestinal motility disorders and mucosal enteropathies [1]. The most common cause of PIF is SBS with an estimated incidence of 22.1 per 1000 neonatal intensive care admissions and 24.5 per 100,000 live births [4]. Mortality rates vary greatly depending on age, underlying diagnosis and length of small bowel remaining, but are traditionally estimated at 30% [5–7]. Survival

rates continue to improve with the introduction of intestinal rehabilitation programs (IRP) and novel medical therapies [8–13]. Children with IF remain at risk for a variety of morbidities including liver dysfunction, electrolyte derangement, metabolic bone disease, central line and infectious complications [8–9,14–16].

With improved survival rates more patients are requiring intensive management within the home setting for parenteral nutrition (PN), and management of enteral therapy and medications/supplements. Many studies have evaluated the cost of care, but have mainly looked at the adult population or the isolated cost of PN including both inpatient and outpatient costs [17–26]. Few studies have discussed patient or family's out of pocket expenses. Intestinal failure patients require a number of interventions that are independent of home parenteral nutrition (HPN) including enteral device therapy (gastrostomy and stoma care), specialized nutrition products, intravenous fluid and electrolyte replacements, medications and vitamin and mineral supplements. Costs also vary significantly between countries depending on the particular model of health care delivery. To date there is no information available on the outpatient costs of care for various types of IF intervention. The objective of our study was to determine the ambulatory cost of care in the first year after primary discharge in pediatric IF patients

Abbreviations: IF, intestinal failure; PIF, pediatric intestinal failure; SBS, short bowel syndrome; IRP, intestinal rehabilitation programs; PN, parenteral nutrition; HPN, home parenteral nutrition; GIFT, Group for Improvement of Intestinal Function and Treatment; CAD, Canadian dollars; ODB, Ontario Drug Benefit; REB, research ethics board; km, kilometers; SB, small bowel; LB, large bowel.

[☆] Level of Evidence: 3.

* Corresponding author at: The Hospital for Sick Children, Rm 1526, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada. Tel.: +1 416 813 7654x201490; fax: +1 416 813 7477.

E-mail address: paul.wales@sickkids.ca (P.W. Wales).

stratified by degree of medical intervention. We were interested in determining total cost of care to the health care system, as well as, the cost incurred by individual families.

1. Methods

The Hospital for Sick Children is a tertiary care facility in Toronto, Canada. The Group for Improvement of Intestinal Function and Treatment (GIFT) was Canada's first multidisciplinary team established for the management of children with IF. GIFT was established in 2002 and has representation from general surgery, gastroenterology, transplantation, nursing, nutrition, occupational and physiotherapy, social work, neonatology, and psychology. Early intervention has been the cornerstone of the rehabilitation program and our mandate has been to improve the clinical care of patients with IF and to create new knowledge through clinical and basic science research. The team is responsible for the assessment and management of pediatric IF patients in the inpatient and outpatient setting, providing patients with consistency of care.

1.1. Study design and study population

A retrospective cohort study of pediatric IF patients was completed to evaluate patients managed by our multidisciplinary intestinal rehabilitation team. Patients included in the study were discharged from hospital after their primary admission between January 1, 2010 and December 31, 2012 with one full year of follow-up. Patients were stratified into three groups: *No medical device* (reached full oral enteral autonomy prior to discharge, but may have required various medications, supplements or formulas), *Enteral device* (reached full enteral autonomy prior to discharge, but was discharged with a feeding enterostomy tube [gastrostomy or gastrojejunostomy] and/or the presence of an ostomy), *Home Parenteral Nutrition* (patients discharged on parenteral nutrition, but may have also possessed a medical device such as a feeding enterostomy or ostomy). Patients were followed for one year following their primary discharge from hospital. Patients were excluded if they did not have one full year of follow-up, were not Ontario residents or underwent organ transplantation.

1.2. Determination of cost of care

Data were collected using the electronic patient chart, as well as health records. Demographic data collected included gestational age (weeks), gender, etiology of IF, category of IF (SBS, dysmotility, mucosal enteropathy), duration of primary admission and distance from hospital to home (in kilometers [km]). Additional data collected included readmissions to hospital within one year post discharge (including number of admissions and number of admitted days). Ambulatory data collected included costs associated with clinic visits, bloodwork appointments and diagnostic imaging.

Ambulatory visit expenses represented out of pocket expenses incurred by families related to return visits to hospital. After accounting for the distance the patient traveled for appointments, transportation costs were determined, including mileage [27] and parking rate of \$12 per visit. Overnight accommodation at our affiliated hotel with parent rate for patients traveling greater than 200 km was included at a rate of \$100 per night. For parental meals while readmitted to hospital we included one food voucher valued at \$8 Canadian dollars (CAD) daily.

We estimated productive days lost for one parent. Many parents may be initially on maternity/paternity leave when the patient is first discharged home, but often have to return to work during that first year. Often both parents are present at clinic appointments or take shifts during readmissions. While this likely impacts ability to work and personal income, we did not include a monetary value to our findings owing to the lack of precision in making these estimates.

Medication expenses included both prescription and "over the counter" therapies that patients were receiving. The cost/dollar value of the medications, supplements and enteral nutrition products were obtained from the Ontario Drug Benefit (ODB) fee schedule and outpatient pharmacy price list, along with standard dispensing fees.

Device expenses related to enteral therapy (feeding enterostomy supplies, enteral feeding pump and ostomy appliances) were determined. Expenses were based on outpatient provider information and catalogues provided to families.

Nutritional expenses were calculated for both enteral and parenteral nutrition. Enteral nutrition costs included type of formula, daily volume and method of administration. Parenteral nutrition expenses included parenteral solutions, vitamin injections, hydration solutions, administration supplies, pump rental and miscellaneous costs associated with PN administration. Parenteral nutrition costs were obtained from an outpatient pharmacy based on their average charges under the Ontario Drug Benefit program and supply charges covered by Community Care Access Centre. Solid or table food lists were not collected owing to extreme variability and is an expected family maintenance cost.

1.3. Data analysis

Analysis was based on patient level data and expenses were adjusted to 2014 Canadian dollars (CAD). The calculated costs included the overall total cost of all outpatient expenses, cost to the government and out of pocket cost to the family. Canada has a single payer health care system with universal access and health care is provincially funded. The costs to the family were calculated based on what was not covered under provincially funded drug benefit programs and subsidy programs if they qualified and general "out of pocket" expenses. Some families may have additional extended coverage depending on private insurance, but this was not included in our analysis.

Baseline and patient outcome data were compared using appropriate summary statistics and continuous variables were presented using means and standard deviations and groups were compared using one-

Table 1
Patient demographics.

	No medical device (n = 7)	Enteral device (n = 19)	HPN (n = 22)	P-value*
Age at discharge (mo)	4.4 (2.1)	6.7 (2.5)	9.3 (11.6)	0.329
Gender, male (%)	5 (71.4)	13 (68.4)	13 (59.1)	0.757
Birth weight (g)	2786.4 (878.6)	1607.7 (738.9)	2154.8 (932.5)	0.008
GA (wk)	34.9 (3.7)	31.3 (4.2)	34.1 (3.8)	0.042
IF category (%)				0.284
Short bowel syndrome	6 (86)	17 (89)	20 (91)	
Dysmotility	1 (14)	2 (11)	0	
Mucosal enteropathy	0	0	2 (9)	
Percent SB remaining	67.9 (22.4)	74.2 (22.3)	35.5 (29.8)	<0.001
Percent LB remaining	79.3 (36.1)	87.6 (30.3)	70 (32.9)	0.23

Values are expressed as means with standard deviation.

% represents frequencies with percentages.

* Hypothesis testing performed using one-way ANOVA or chi square where appropriate.

Download English Version:

<https://daneshyari.com/en/article/6216581>

Download Persian Version:

<https://daneshyari.com/article/6216581>

[Daneshyari.com](https://daneshyari.com)