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Short communication

# Presentation of a nationwide multicenter registry of intestinal failure and intestinal transplantation☆,☆☆

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SUMMARY

*Background & aims:* Exact data on Dutch patients with chronic intestinal failure (CIF) and after intestinal transplantation (ITx) have been lacking. To improve standard care of these patients, a nationwide collaboration has been established. Objectives of this study were obtaining an up-to-date prevalence of CIF and characterizing these patients using the specially developed multicenter web-based Dutch Registry of Intestinal Failure and Intestinal Transplantation (DRIFT).
*Methods:* Cross-sectional study. CIF was defined as type 3 intestinal failure in which >75% of nutritional requirements were given as home parenteral nutrition (HPN) for ≥ 4 weeks in children and >50% for ≥3 months in adults. All patients with CIF receiving HPN care by the three Dutch specialized centers on January 1, 2013 and all ITx patients were registered in DRIFT (https://drift.darmfalen.nl).
*Results:* In total, 195 patients with CIF (158 adults, 37 children) were identified, of whom 184 were registered in DRIFT. The Dutch point prevalence of CIF was 11.62 per million (12.24 for adults, 9.56 for children) on January 1, 2013. Fifty-seven patients (31%) had one or more indications for ITx, while 12 patients actually underwent ITx since its Dutch introduction. Four patients required transplantectomy of their intestinal graft and 3 intestinal transplant patients died.

*Abbreviations:* CIF, chronic and/or irreversible intestinal failure; CIPO, chronic intestinal pseudo-obstruction; CRBSI, catheter-related bloodstream infection; CVC, central venous catheter; DRIFT, Dutch Registry of Intestinal Failure and Intestinal Transplantation; ESPGHAN, European Society for Pediatric Gastroenterology, Hepatology and Nutrition; HPN, home parenteral nutrition; IF, intestinal failure; ITx, intestinal transplantation; PN, parenteral nutrition.

☆ 13th International Small Bowel Transplant Symposium, June 26–29, 2013 Oxford, UK, First results of the Dutch online Registry of Intestinal Failure and Intestinal Transplantation (DRIFT).

☆☆ Dutch Society of Gastroenterology, March 20, 2014, Veldhoven, the Netherlands, First results of the Dutch Registry of Intestinal Failure and Intestinal Transplantation (DRIFT).

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*Conclusion:* The multicenter registry DRIFT revealed an up-to-date prevalence of CIF and provided nationwide insight into the patients with CIF during HPN and after ITx in the Netherlands. DRIFT will facilitate the multicenter monitoring of individual patients, thereby supporting multidisciplinary care and decision-making.



## 1. Introduction

Intestinal failure (IF) is characterized by the inability to maintain protein-energy, fluid, electrolyte and/or micronutrient balance, resulting from anatomic reduction or functional failure of the gut [1]. Patients with chronic and/or irreversible IF (CIF) depend on parenteral nutrition (PN) to survive, which can be provided at home. Home parenteral nutrition (HPN) is rare with a European prevalence ranging from 2 to 40 per million in adults [2] and 0.34–8.92 in children [3]. The treatment of IF requires a multidisciplinary approach which includes members specialized in (pediatric) surgery, (pediatric) gastroenterology, dieticians and nurse specialists. Intestinal transplantation (ITx) has become an alternative for patients with life-threatening complications of PN. Due to the lower survival rates after intestinal transplantation (ITx) than on HPN, HPN is still the treatment of choice. A good collaboration between centers for HPN and transplant centers is the cornerstone of the management of patients with CIF. It has been shown that early referral to the transplant center is related to higher survival [4]. However, the optimal timing to refer is difficult to determine by caregivers in HPN centers, while the exact medical status including detailed documentation of complications is often unclear to the transplant professionals. To improve standard care of these patients, a nationwide collaboration has been established. The last registration of patients with CIF in the Netherlands has been performed in 2004, with a prevalence of long-term PN of at least 5.1 per million adults and 0.6 per million children [5]. An up-to-date registration including an actual overview of the individual patient is therefore necessary. For this purpose the web-based Dutch Registry of Intestinal Failure and Transplantation (DRIFT) was developed. The objectives of this study were to obtain an up-to-date prevalence of CIF and to characterize the Dutch patients with CIF and after ITx by using the multicenter registry DRIFT.

## 2. Methods

### 2.1. Study design

HPN care in the Netherlands is coordinated by three specialized centers, located in Amsterdam (Academic Medical Center) and Nijmegen (Radboud University Medical Center) for adults and children and in Rotterdam (Erasmus Medical Center-Sophia Children's Hospital) for children only. Adults and children with CIF receiving HPN care provided by these centers on January 1, 2013 were included in DRIFT. Patients from Maastricht University Medical Center were only taken into account for the calculation of the Dutch CIF prevalence, since this center does not participate in the nationwide collaboration because of geographical reasons. CIF was defined as type 3 IF: chronic IF requiring long-term nutritional support in the form of HPN [6]. We specified this adding that >75% of nutritional requirements had to be given as HPN for ≥4 weeks in children (in line with the definition of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)) and >50% for ≥3 months in adults [7]. Patients who were receiving HPN in the absence of IF or as a bridge to a gastrointestinal continuity procedure were excluded. All patients who underwent ITx in the single Dutch transplant center (University Medical Center Groningen) were included.

### 2.2. Data collection & registration

Data for this cross-sectional study were obtained using medical patient records. Data known on January 1, 2013 were registered in DRIFT. This registry is available online in English at https://drift.darmfalen.nl (see Supplement). Figure 1 shows how data are displayed in DRIFT. Patient safety was ensured according to ISO-27001 and Dutch Data Protection Act standards.

### 2.3. Data definitions

- Catheter-related bloodstream infection (CRBSI) was defined as a positive central venous catheter (CVC) blood culture or positive peripheral blood culture in patients who met the clinical criteria of sepsis, while another focus was highly unlikely.
- Critical loss of vascular access was defined as occlusion of ≥2 from the 4 primary veins (jugular and subclavian) for the placement of a vascular access, confirmed by ultrasound or phlebography [7].
- We used total bilirubin (along with information of the last hepatic ultrasound and liver biopsy) as documented at last follow-up to assess liver dysfunction, since this value is also used in the ITx criteria. Patients who were clinically unstable or with liver dysfunction unrelated to PN were excluded for the analysis.
- Potential ITx candidates were identified using the indications defined by the USA Center for Medicare and Medicaid Services [8] and the American Society of Transplantation [9]. We specified the definitions of pending liver dysfunction (total bilirubin > 50 μmol/L), overt liver failure (signs of portal hypertension, liver fibrosis or cirrhosis) and CIF with high morbidity (≥3 hospitalizations per year, with each a minimal duration of 7 days) since the description of these indications could be interpreted in various ways (Supplementary Table 1).

### 2.4. Statistics

Patients were categorized in two groups, adults (≥18 years) and children (<18 years). The national point prevalence was calculated from the latest estimate for the population in the Netherlands (Statistics Netherlands). Data were described as mean and standard deviation (if distributed normally) and median and range (if not distributed normally) it continuous and absolute frequencies and percentages if categorical. Analyses were performed using SPSS version 20 for Windows (IBM, Armonk, NY, USA).

## 3. Results

In total, 195 Dutch CIF patients (158 adults and 37 children) were identified. (Supplementary Fig. 2). This provides a point prevalence

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