

ESPEN HAN & CIF WORKING GROUP

PROSPECTIVE STUDY **PROSPECTIVE 5 YEAR FOLLOW UP OF PATIENT ON HOME PARENTERAL NUTRITION FOR CHRONIC INTESTINAL FAILURE**

Loris Pironi, Francisca Joly, Bernard Messing and Home Artificial Nutrition & Chronic Intestinal Failure Working Group of ESPEN

Background and purpose of the study.

Previous surveys of patients on long-term HPN have reported survival rates after the first 3 years of treatment ranging from 70% to 82% in adults and of about 95% in children, and have shown a trend towards lower mortality in the longer-term. Negative prognostic factors include extremes of age (older adults and very young children), and certain types of underlying disease and/or cause of IF.

A 3 year prospective survey was recently carried out on a patient population with a mean duration of HPN at baseline of about 5 years, from which patients at higher risk of death on HPN (such as those older than 65 years, and those with a major contraindication for ITx) were excluded. The results showed a survival rate of 96% in patients stable on HPN and of 87% in those candidates for intestinal transplantation. A low rate of incidence of HPN-failure (1% / year), which would be an indication for intestinal transplantation, was also observed.

The purpose of the present prospective study is to know in a larger cohort of unselected patients starting HPN for chronic intestinal failure, the 5-year mortality and HPN-failure rate and risk factors.

Material and methods

Type of study

Multicenter, European and USA; prospective questionnaire-based follow up of any new patient (adult and pediatric) who starts HPN after January 1st 2009.

End-points

Survival rate and risk factors for death and HPN failure

Selection of the participating centers

Each member of the ESPEN HAN Group will send the study protocol to all the known HPN centers managing patients with benign intestinal failure in their Country, asking for their willingness to participate. Centers that agree to participate will receive the questionnaire from the study coordinators.

Patient inclusion and exclusion criteria

Inclusion: **all the patients with benign intestinal failure who start HPN between January 1st and December 31st 2009;**

Exclusion: active cancer or AIDS;

Time of data collection:

31st December of each year of follow up; end of the survey, December 31st 2014.

Publication rules

All the participating Centers will be recognized in the acknowledgment section; CO-Authors status will be recognized to: contributing centers including > 30 patients (1 name) or > 60 patients (2 names)

Data collection

Patients' data must be collected by the **attached excel file**, aiming at gathering information about:

- Center experience (first part)
- Patient data (second part): in this section, **put the pointer of your computer on the first cell of each column; a window with the list of the possible answers will appear**; please take care that the whole window is opened; in case enlarge it in order to read the complete text

Completed questionnaires to be returned at the end of each year of follow up as attached file, by email to: loris.pironi@unibo.it

Loris Pironi, MD

Center for Chronic Intestinal Failure, St. Orsola-Malpighi Hospital, University of Bologna
Via Massarenti 9, 40138 Bologna, Italy

ESPEN HAN & CIF WORKING GROUP

TEL/FAX: +39 - 051 - 6363073