emphasizes the importance of vaccination, especially in infants and young children.

**259 CLINICAL, ECONOMIC AND HUMANISTIC IMPACT OF SHORT BOWEL SYNDROME – INTESTINAL FAILURE IN PORTUGUESE PAEDIATRIC PATIENTS (PARENTERAL STUDY)**

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Short Bowel Syndrome – Intestinal Failure (SBS-IF) is a rare, chronic, and debilitating disease, requiring patient-tailored complex management and comprehensive care. Parenteral nutrition (PN) remains the standard-of-care due to its life-sustaining nature. This study aimed to assess the clinical, economic and humanistic impact of paediatric SBS-IF in Portugal.

This was a retrospective cohort study, with a cross-sectional component for the quality of life (QoL) evaluation, including paediatric SBS-IF patients (≥1-18 years) with stable PN over at least six months. Data collection included patient chart review over a 12-month period and patient/caregiver self-report and PedsQL questionnaires with 6- and 1-month recall periods, respectively. Main endpoints included clinical and PN characterization, healthcare resource utilization (HRU), direct medical and non-medical costs, and patient QoL. Unit costs were obtained from national databases/decrees, retailers, and patient/caregiver. Costs were standardized using the 2019 consumer price index and annualized assuming constant use of resources.

A total of 20 patients were included with a mean age (SD) of 7.5 (5.0) years, 50.0% female, and a mean time since diagnosis of 6.6 (4.2) years. The three leading causes of SBS-IF were volvulus (40.0%), intestinal atresia (35.0%), and necrotizing enterocolitis (10.0%). PN was administered for a mean of 6.6 days/week, in 90.0% of cases at home for a mean of 10.8 months/year. Nevertheless, 60.0% had PN administered at least once in an inpatient setting for a mean of 1.8 months/year. HRU was high, including a mean annual frequency of 10.2 (5.3) medical visits, 29.8 (85.3) visits with other health-care professionals (including nurse, dietitian, psychologist), 3.0 (2.5) emergency visits, and 2.0 (1.5) hospitalisations. A total of 40 hospitalizations were reported, with a mean annual length of stay of 29.4 (32.3) days, of which 85.0% due to catheter-related complications, including septicemia, local central venous catheter infection, and mechanical complications. Mean annual direct costs (95%CI) per patient amounted to $74,734.5 C (74,614.8-74,854.4), with PN and hospitalization as the main cost drivers accounting for 57.3% and 21.0% of overall costs, respectively.

Patient QoL assessment showed a PedsQL™ mean total score slightly below the Portuguese norm (73.3 vs. 75.6), but with a notorious deterioration in the school functioning domain (57.5 vs. 72.6).

Paediatric SBS-IF management is characterized by a substantial therapeutic burden and HRU, translating into high direct costs and QoL deterioration, mainly in school performance. There is a clear unmet need for therapeutic alternatives that lower SBS-IF burden. This research was funded by Takeda.