

Atlas of Variance: Awareness of Chronic Intestinal Failure Versus Chronic Kidney Failure and Key Areas for Improving Care Delivery to Patients with Chronic Intestinal Failure

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Background

- Chronic intestinal failure (IF) is a rare but life-altering condition occurring from extensive surgical resection, disease associated loss of absorption or congenital diseases of the small intestine¹
- Loss in intestinal absorptive capacity can lead to malnutrition, dehydration and micronutrient depletion, which may require long-term parenteral support^{1,2}
- Chronic IF management is complex and aims to alleviate the daily burden of the condition through maximising the remnant intestinal absorptive capacity, minimising the symptoms of malabsorption, and minimising the need for parenteral support^{1,2}
- Dialysis for chronic kidney failure (CKF) can be performed in the home and treatment centres either through vascular or peritoneal access.³ Healthcare professional (HCP)/carer support and training is also available to patients with CKF⁴
- Anecdotal reports show that the management of chronic IF can vary across countries in Europe. This non-interventional study aimed to characterise the standard of care (SoC) for adult patients with chronic IF in Europe
- We report the results on awareness of chronic IF versus CKF, and areas for improving chronic IF care

Objectives

- Primary objective:
- To describe the management of adult patients with chronic IF across Europe
- Secondary objectives included:
- Describing the variation in SoC between European countries
 - Identifying the goals of treatment for chronic IF from HCP perspectives

Methods

- HCPs involved in the management of adult patients with chronic IF (at least 10 patients over the past 5 years) were invited to complete an online quantitative survey during the period November 2020 to January 2021
- Data were collected from 12 European countries: Belgium, Croatia, Denmark, France, Italy, Norway, Poland, Portugal, Romania, Spain, Switzerland and UK
- Survey data were anonymised and pooled for analysis at European and country level. Responses were summarised as frequencies, ranks and percentages

Results

- 119 HCPs completed the survey across an estimated 58 centres (Table 1). 65% of all HCPs who responded were from a referral centre for adult patients with chronic IF (N=119)
- Between countries, the numbers of respondents based in a referral centre varied greatly (Figure 1)
- Gastroenterology was the most frequent specialty of respondents (45%), treating an average of 35 patients each at the time of the survey (Table 2)
- Respondents specialising in psychology, anaesthesiology and internal medicine were low, at one respondent per specialty, at the time of survey
 - Other respondents included endocrinologists (n=17), nurses (n=14), physicians specialising in nutrition (n=11), surgeons (n=10), pharmacists (n=6) and dietitians/nutritionists (n=4)

HCPs' perceptions on disease awareness

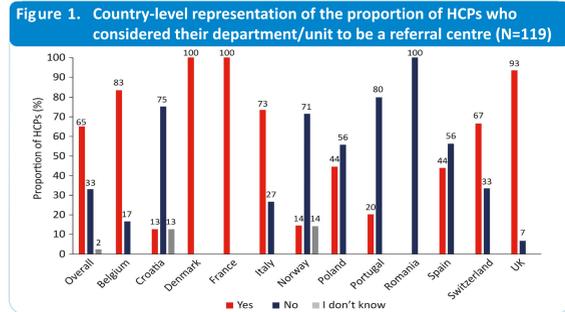
- HCPs perceived the disease awareness of chronic IF among primary and secondary care HCPs to be lower than the disease awareness of CKF among general HCPs (Figure 2)
- Mean perceived disease awareness of chronic IF in gastroenterologists not specialising in chronic IF was 5.2 on a scale of 0–10
 - Mean perceived disease awareness of CKF in general HCPs was 7.1 on a scale of 0–10
 - Primary care practitioners were perceived to be the least aware of chronic IF

HCPs' perceptions on access to treatment

- The majority of HCPs surveyed perceived that patients with CKF had better access to dialysis than chronic IF for home parenteral nutrition; only 13% perceived access as being similar (Figure 3)

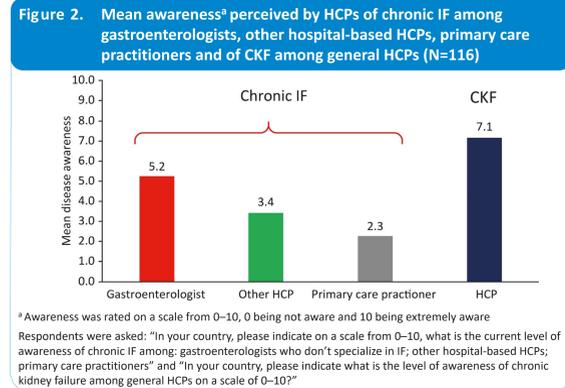
Country	Number of survey respondents, n (%)	Estimated number of centres, n (%)
Belgium	12 (10.1)	4 (6.9)
Croatia	8 (6.7)	2 (3.4)
Denmark	6 (5.0)	3 (5.2)
France	21 (17.6)	10 (17.2)
Italy	15 (12.6)	7 (12.1)
Norway	7 (5.9)	5 (8.6)
Poland	9 (7.6)	7 (12.1)
Portugal	5 (4.2)	2 (3.4)
Romania	2 (1.7)	2 (3.4)
Spain	16 (13.4)	7 (12.1)
Switzerland	3 (2.5)	2 (3.4)
UK	15 (12.6)	7 (12.1)
Total: 12	119	58

* Estimation based on email addresses of individuals directly contacting the study team regarding survey completion (N=79)



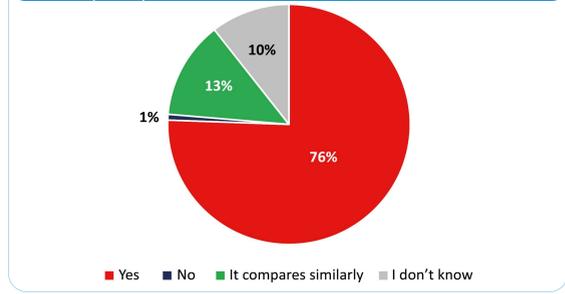
Specialty	HCPs per specialty, n (%)
Gastroenterologist	54 (45.4)
Endocrinologist ^a	17 (14.3)
Nurse	14 (11.8)
Physician specialising in nutrition	11 (9.2)
Surgeon	10 (8.4)
Pharmacist	6 (5.0)
Dietician/Nutritionist	4 (3.4)
Psychologist	1 (0.8)
Anaesthesiologist	1 (0.8)
Internal medicine	1 (0.8)
Total	119

^a HCP per specialty per country: Spain (n=14), Switzerland (n=1), France (n=1), Belgium (n=1)



^a Awareness was rated on a scale from 0–10, 0 being not aware and 10 being extremely aware. Respondents were asked: "In your country, please indicate on a scale from 0–10, what is the current level of awareness of chronic IF among: gastroenterologists who don't specialize in IF; other hospital-based HCPs; primary care practitioners" and "In your country, please indicate what is the level of awareness of chronic kidney failure among general HCPs on a scale of 0–10?"

Figure 3. HCPs' views on whether patients with CKF have better access to dialysis than patients with chronic IF have to parenteral nutrition (N=115)

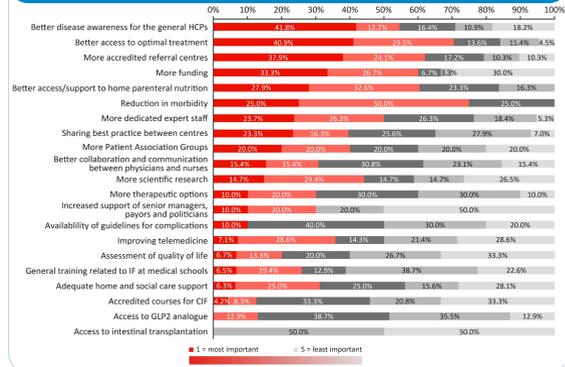


Improvements to patient care in chronic IF

Four key areas of improvements to patient management and care in chronic IF were identified (Figure 4):

- Better disease awareness for HCPs (42%)
- Better access to optimal treatment (41%)
- More accredited referral centres (38%)
- More funding (33%)
- Better access/support to HPN (28%)
- Increased support of senior managers, payors and politicians and access to intestinal transplantation were identified by 50% HCPs as the least important areas of improvement

Figure 4. Areas of improvement in the management of/care for patients with chronic IF, identified by HCPs and ranked as most to least important (N=115), represented at an overall, all countries level. HCPs were asked to select up to five options and rank them accordingly. The percentages shown indicate the proportion of responses for each option, at each rank



HCPs from all countries identified improving chronic IF disease awareness for HCPs as an area to improve patient management and care (Figure 5). Where this area was ranked as the most important, alignment in responses were seen between:

- Poland and Portugal (67%)
- Belgium, Croatia and Switzerland (50%)
- Spain and the UK (38%)
- Denmark, France and Italy (33%)

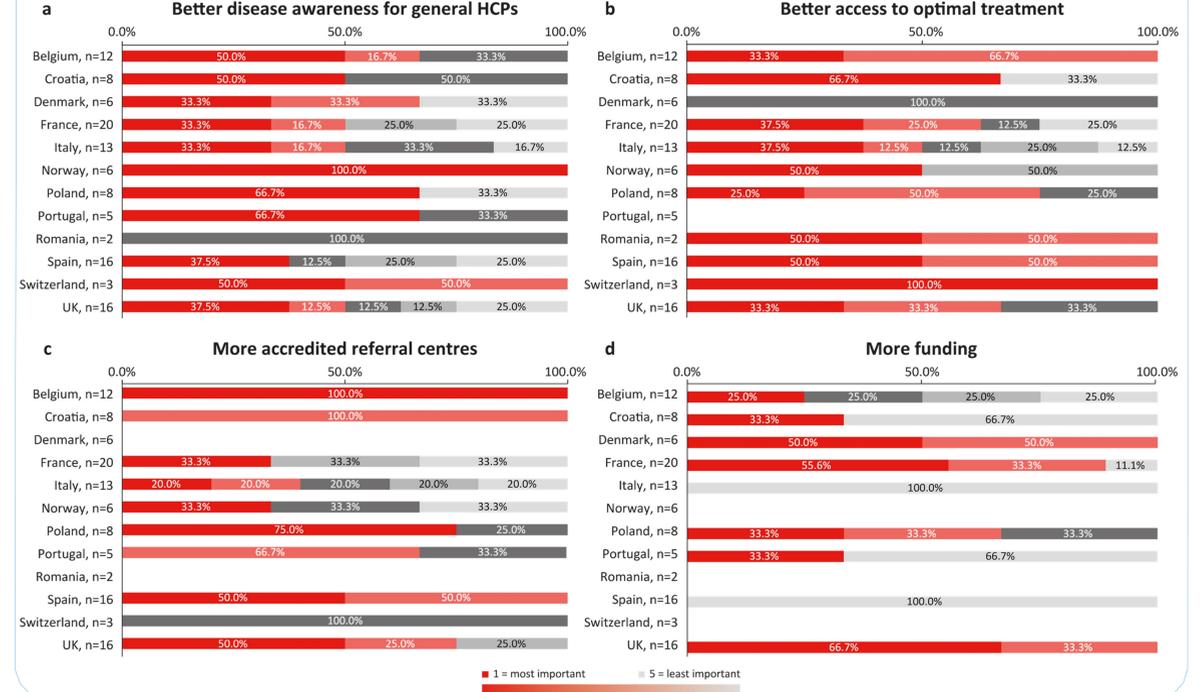
HCPs from Romania were the only respondents not to rank this area as the most important. HCPs from Portugal did not view better patient access to optimal treatment as important (Figure 5)

Better access to optimal treatment was considered as being either most or second most important by:

- 100% HCPs from Belgium, Romania, Spain and Switzerland
- >66% HCPs from Croatia, Poland and the UK
- ≥50% HCPs from France, Italy and Norway

There was little alignment between countries, concerning the importance of increasing the number of accredited referral centres and funding (Figure 5)

Figure 5. Country-level representation of the proportion of HCP respondents reporting the four most common areas of improvement in management of/care for patients with chronic IF. Responses are ranked most to least important (N=115)



Limitations and Strengths

Limitations

This study is limited by the cross-sectional survey methodology, whereby a physician reports their experiences and perceptions at a single time point only

There is a potential selection bias:

- HCPs recruited for the study were recognised for their involvement in chronic IF and often worked in chronic IF centres of excellence
- HCPs who treat chronic IF outside of these centres of excellence may be under-represented

The scope of the study covers 12 European countries only, and therefore cannot be generalised to countries that were not considered part of this study

Strengths

- This is the first study of its kind to investigate the SoC for adult chronic IF across multiple European countries
- ~30 HCPs had direct input into the survey design through qualitative preliminary assessment
- HCPs from participating countries came from different specialties
- HCPs perspective on the unmet needs and treatment challenges in chronic IF, was also captured in this study

Disclosures

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Conclusions

- Awareness of chronic IF among primary and secondary care HCPs was perceived by HCPs specialising in treating chronic IF as lower than general HCP awareness of CKF. Improvement was identified as a key area in advancing patient management and care
- Access to parenteral nutrition for patients with chronic IF was viewed as inferior to access to dialysis for patients with CKF, and the need for improvements in access to optimal treatment was identified
- Improving disease awareness and access to optimal treatment are key areas for which some alignment between countries exists and can be further developed
- Although an increase in the number of accredited referral centres was identified as important across Europe, for individual countries there was less alignment, perhaps due in part to the differences in the number of respondents from referral centres themselves

Further Atlas of Variance data are presented at this congress on posters P264: "Evaluation of care delivery to patients with chronic intestinal failure in Europe; a focus on home parenteral nutrition" and P284: "Healthcare professionals' perception of key care delivery goals in patients with chronic intestinal failure in Europe"

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