Atlas of Variance: Healthcare Professionals' Perception of Key Care Delivery Goals in Patients with Chronic Intestinal Failure in Europe

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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
- Patients with chronic IF can have symptoms such as diarrhoea, abdominal pain, fatigue and weight loss, leading to an impaired health related quality of life (QoL)^{1,2}
- Chronic IF management is complex and aims to alleviate the daily burden of the condition through maximising the remnant intestinal absorptive capacity and minimising the symptoms of malabsorption and the need for parenteral support^{1,3}
- 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 patients with chronic IF in Europe
- We report results covering healthcare professionals' (HCP) main treatment goals, and their perception of patient treatment goals, for adults with chronic IF across Europe

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
- Identifying HCP perceptions of the treatment goals of patients with chronic IF

Methods

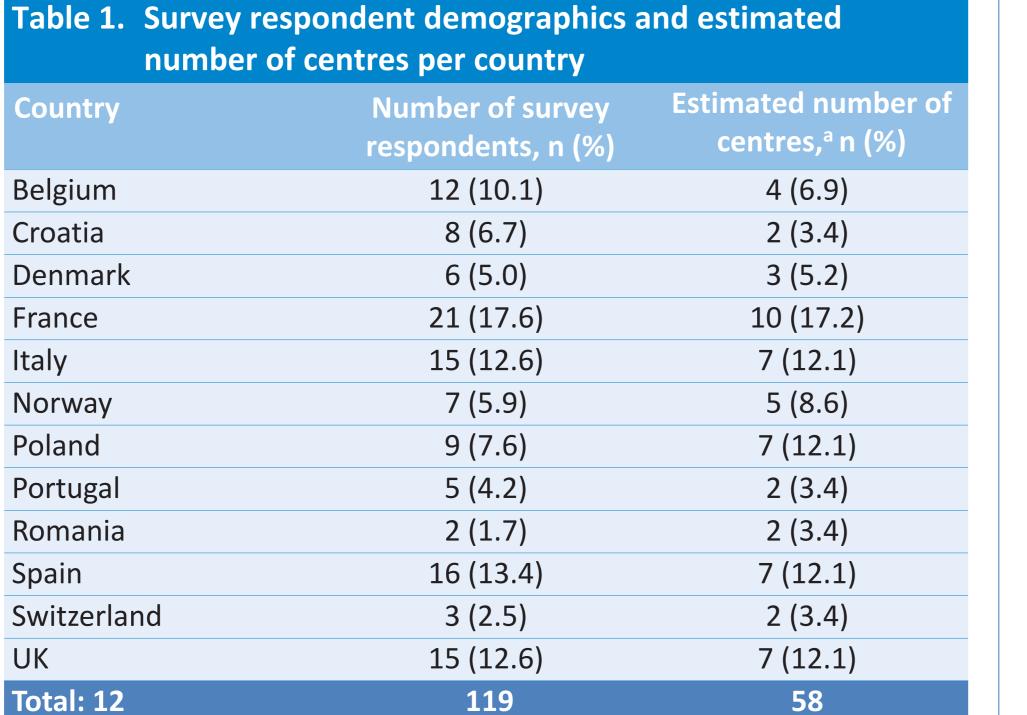
- HCPs involved in the management of adult patients with chronic IF (at least 10 patients over the past 5 years) were invited to complete an online quantitative survey during the period November 2020 to January 2021
- Data were collected from 12 European countries: Belgium, Croatia, Denmark, France, 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)

Gastroenterology was the most frequent specialty of respondents (45%) (Table 2), treating an average of 35 patients each at the time of the survey

- 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 dieticians/nutritionists (n=4)



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

Table 2. Survey respondent number per specialty	
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), Belgium (n=1), France (n=1), Switzerland (n=1)

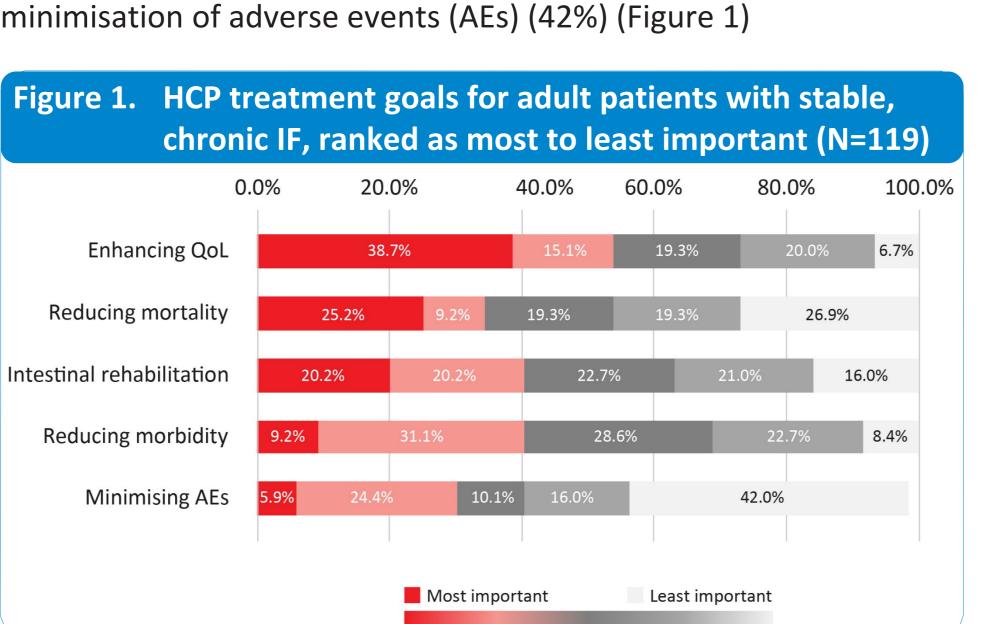
HCP and patient treatment goals

39% of HCPs stated that their most important treatment goal in adult patients with stable chronic IF was to enhance the patient's QoL (Figure 1)

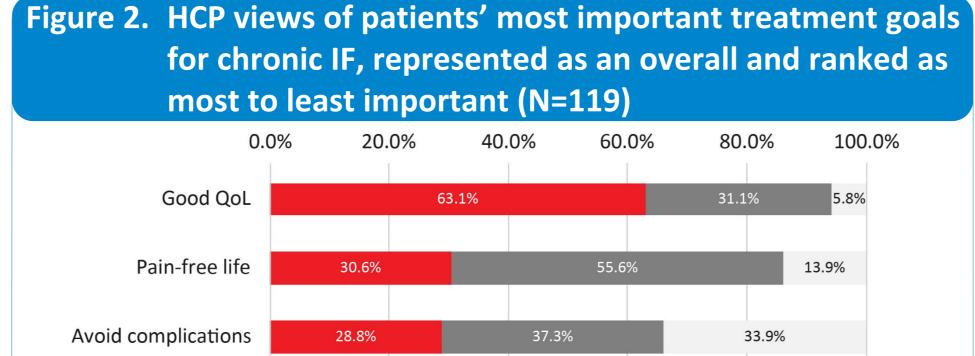
 Most HCPs (63%) regarded good QoL as the patient's most important treatment goal (Figure 2)

Reducing mortality and intestinal rehabilitation were considered the most important treatment goals by 25% and 20% of HCPs, respectively (Figure 1)

The least important treatment goal reported by HCPs was the minimisation of adverse events (AEs) (42%) (Figure 1)



HCPs considered that the least important patient-described treatment goals were avoidance of AEs and reduced hospital visits (35% and 69%, respectively) (Figure 2)



QoL as a treatment goal

goal was to enhance QoL (Figure 3)

Belgium (n=12)

Denmark (n=6)

France (n=21)

Norway (n=7)

Portugal (n=5)

Romania (n=2)

Switzerland (n=3)

Only three countries had >50% of HCPs (Norway, Portugal and Belgium) ranking enhancing QoL as the most important treatment goal (100%, 80% and 58%, respectively) (Figure 3)

 Conversely, >50% of HCPs in nine out of 12 countries considered that the most important patient described goal was to enhance QoL (Figure 3)

Few HCPs from Italy and Spain (13%) ranked enhancing QoL as being the most important HCP treatment goal (Figure 3) HCPs in four countries regarded enhanced QoL as being their least

and UK (7%) (Figure 3) HCPs from three countries (France, 16%; Italy, 18%; Denmark; 20%) considered that the least important patient described treatment

important treatment goal: France (14%), Italy (20%), Romania (50%)

QoL monitoring

Only 33.6% of HCPs measured QoL in chronic IF with validated questionnaires (N=116). Of those, most HCPs (53%) used them in research studies only, 35% used them systematically in clinical practice, 12% used them in other ways* (n=40)

closed to the psychologist. Also completed in between these time frames as appropriate to the individual

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

Figure 3. HCP responses to importance of enhancing QoL as a treatment goal for adult patients with stable chronic IF and their views of

patients' regard to enhancing QoL, represented on a country level and ranked as most to least important (N=119)

This is the first study of its kind to investigate the SoC for adult chronic IF across multiple European countries

~30 HCPs had a direct input into the survey design through qualitative preliminary assessment

66.7%

69.2%

- HCPs from participating countries came from different specialties
- HCP perspectives on the unmet needs and treatment challenges in chronic IF, were also captured in this study

Conclusions

- Key goals for HCPs in the treatment of patients with stable chronic IF were enhancing QoL, reducing mortality and increasing intestinal rehabilitation
- HCPs perceived key treatment goals described by patients were good QoL, pain-free life and avoidance of complications
- HCP treatment goals for patients with stable chronic IF, and their views on patient goals identified improving QoL as a key area
- Between countries, HCPs were partially aligned on the importance of enhancing QoL as a goal in the treatment of chronic IF
- Although QoL was considered important, utilisation of validated questionnaires was low, particularly in routine clinical practice

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 P268: "Awareness of chronic intestinal failure versus chronic kidney failure and key areas for improving care delivery to patients with chronic intestinal failure"

Disclosures

This study was sponsored by Takeda Pharmaceuticals International AG Medical writing support was provided by Sarah Bailey at Parexel International, funded by Takeda Pharmaceuticals International AG

S Schneider: Grant/ Research Support: B Braun, Takeda, VectivBio, Zealand Pharma; Consultant: Axium mTech, Baxter, Nestlé Health Science, Takeda; Speaker Bureau: Biocodex, Fresenius-Kabi, Laboratoires Grand Fontaine, Nestlé Heath Science, Takeda, Theradial. S Lal: Consultant: Baxter, Takeda, VectivBio, Zealand Pharma; Speaker Bureau: Baxter, Takeda, VectivBio, Zealand Pharma; Research Support: Takeda. P Geransar: Other: Employee: Takeda Pharmaceuticals International AG, owns Takeda stock and has Takeda stock options. E Rzepa: None declared. L Pironi: Consultant: Baxter, Takeda; Speaker Bureau: Baxter, Takeda. P Bekker Jeppesen: Grant/Research Support: Albumedix A/S, ArTara Therapeutics, Bainan Biotech; Baxter, Coloplast, Ferring, Fresenius Kabi, GlyPharma, Naia Pharma, Novo Nordisk Foundation, NPS Pharmaceuticals, Protara, Shire, Takeda, Therachon, Zealand Pharma, VectivBio; Consultant: Albumedix A/S, ArTara Therapeutics, Bainan Biotech; Baxter, Coloplast, Ferring, Fresenius Kabi, GlyPharma, Naia Pharma, Novo Nordisk Foundation, NPS Pharmaceuticals, Protara, Shire, Takeda, Therachon, VectivBio, Zealand Pharma; Speaker Bureau: Albumedix A/S, ArTara Therapeutics, Bainan Biotech Baxter, Coloplast, Ferring, Fresenius Kabi, GlyPharma, Naia Pharma, Novo Nordisk Foundation, NPS Pharmaceuticals, Protara, Shire, Takeda, Therachon, VectivBio, Zealand Pharma

This poster is intended for healthcare professionals only

References

20.0%

33.3%

Least important

30.8%

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Acknowledgements

Special thanks to Andrew Worsfold for his contributions into the overall study design and development of the survey questionnaire, and Caterina Hatzifoti for her significant input at the concept stage of the study



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