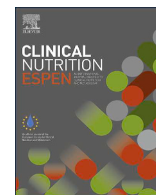
Clinical Nutrition ESPEN 70 (2025) 509–515

Contents lists available at ScienceDirect

Clinical Nutrition ESPEN

journal homepage: http://www.clinicalnutritionespen.com



Original article

Measuring quality standards in chronic intestinal failure: A pilot international survey

Maja Kopczynska [a,*], Stéphane Schneider [b], Marianna Arvanitaki [c], Nicola Burch [d], Heiko De Schepper [e], Philippe Fayemendy [f], Jorge Fonseca [g,h], Palle Bekker Jeppesen [i], Francisca Joly [j], Aníbal Marinho [k], Jessica Quayle [l], Julie Rasmussen [m], Tim Vanuytsel [n], Lars Vinter-Jensen [o], Joost Wesseling [p], Loris Pironi [q], Simon Lal [a]

[a] *National Intestinal Failure Reference Centre, University of Manchester, Northern Care Alliance NHS Foundation Trust, Salford, M6 8HD, UK*
[b] *Gastroenterology and Clinical Nutrition, Nice University Hospital, Université Côte d'Azur, Nice, France*
[c] *Department of Gastroenterology, Université Libre de Bruxelles, Hôpital Erasme, Brussels, Belgium*
[d] *University Hospitals Coventry and Warwickshire NHS Trust, Coventry, UK*
[e] *Department of Gastroenterology, University Hospital Antwerp, Edegem, Belgium*
[f] *CHU Limoges, Limoges, France*
[g] *Artificial Nutrition Team, Gastroenterology Department, Hospital Garcia de Orta, Almada, Portugal*
[h] *Egas Moniz Center for Interdisciplinary Research (CiiEM), Egas Moniz School of Health and Science, Almada, Portugal*
[i] *Department of Transplantation and Digestive Diseases, Rigshospitalet, Copenhagen, Denmark*
[j] *Centre for Intestinal Failure, Department of Gastroenterology and Nutritional Support, Hôpital Beaujon, Clichy, UMR 1149, University of Paris, France*
[k] *Department of Intensive Care, Hospital Universitário de Santo António, Porto, Portugal*
[l] *Lancashire Teaching Hospitals NHS Foundation Trust, Preston, UK*
[m] *Department of Internal Medicine, Zealand University Hospital in Køge and Roskilde, Denmark*
[n] *Leuven Intestinal Failure and Transplantation (LIFT) – Leuven University Hospital, Leuven, Belgium*
[o] *Department of Gastroenterology and Hepatology, Aalborg University Hospital, Aalborg, Denmark*
[p] *The European Nutrition for Health Alliance (ENHA), Amsterdam, the Netherlands*
[q] *Department of Medical and Surgical Sciences, University of Bologna, Italy*

ARTICLE INFO

Article history:
Received 1 August 2025
Accepted 31 October 2025

Keywords:
Intestinal failure
Quality standards
Monitoring
Survey

SUMMARY

Background & aims: It is recognised that the approach to chronic intestinal failure (CIF) care delivery can differ both within and between countries. The aim of this pilot study was to explore the utility and fulfilment of the European Society for Clinical Nutrition and Metabolism-endorsed quality-of-care standards across European CIF centres.
Methods: To evaluate differential approaches to quality-of-care delivery, lead clinicians of small (<30 current patients), medium (30–100 patients) and large (>100 patients) CIF centres from five countries were asked to complete a 139-item questionnaire. As per the standards, the questionnaire was divided into four subsections: background information concerning the CIF centre, structure and process of care and CIF outcome monitoring.
Results: The response rate was 100 % from 15 CIF centres across five countries: 20 % responses from Belgium, 26.7 % from Denmark, 20 % from France, 20 % from United Kingdom and 13.3 % from Portugal. Despite an extensive number of questions, the questionnaire was completed without any missing data, while also allowing for further comments that elaborate on centre experience. The gaps identified

* Corresponding author. National Reference Centre of Intestinal Failure, Salford Royal & University of Manchester, UK.
E-mail addresses: maya.kopczynska@gmail.com (M. Kopczynska), stephane.schneider@univ-cotedazur.fr (S. Schneider), marianna.arvanitaki@hubruxelles.be (M. Arvanitaki), nicola.burch@uhcw.nhs.uk (N. Burch), Heiko.DeSchepper@uza.be (H. De Schepper), Philippe.Fayemendy@chu-limoges.fr (P. Fayemendy), jorgedafonseca@gmail.com (J. Fonseca), Palle.bekker.jeppesen@regionh.dk (P.B. Jeppesen), francisca.joly@aphp.fr (F. Joly), anibalmarinho@gmail.com (A. Marinho), jessica.quayle@lthtr.nhs.uk (J. Quayle), julra@regionsjaelland.dk (J. Rasmussen), Tim.vanuytsel@uzleuven.be (T. Vanuytsel), l.vinterjensen@rn.dk (L. Vinter-Jensen), joost@european-nutrition.org (J. Wesseling), loris.pironi@unibo.it (L. Pironi), simon.lal@nca.nhs.uk (S. Lal).

https://doi.org/10.1016/j.clnesp.2025.10.035
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included (1) providing two specialist clinicians with expertise in IF restricting cross-cover arrangements; (2) access to psychology and psychiatry services; (3) access to specific ward area; (4) establishment of networks with other services; (5) patient engagement; (6) CIF outcome monitoring.
Conclusion: This pilot study clearly demonstrated the utility and fulfilment of the quality-of-care standards in selected European CIF centres. Future work will include expansion of participating centres, as well as annual reassessment of quality-of-care standards per centre.
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1. Introduction

Intestinal failure (IF) is defined as the inability of the gut to absorb the necessary macronutrients, electrolytes and water to sustain life, such that intravenous supplementation is required [1]. Type 3 or chronic IF (CIF) describes the need, reversible or irreversible, for long-term home parenteral nutrition (HPN) in metabolically stable patients [1].

Though life-sustaining, the impact of HPN on both the individual [2,3] and the healthcare economy is high [4]. HPN can lead to complications, including those associated with the central venous catheter (CVC), such as catheter-related bloodstream infections (CRBSI) or thrombosis, IF-associated liver disease (IFALD), and metabolic bone problems [5,6]. Additionally, patients with CIF are at increased risk of developing renal impairment [7], gallstones [8] and sarcopenia [9] and may require frequent hospital admissions, with up to 6.6 % of the time on HPN spent hospitalised [10]. Previous research also shows that CIF is associated with more than seven-fold higher mortality rates than for the general population and shorter life expectancies of more than 17 years [2].

It has been shown that clinical outcomes such as 1-year mortality, CRBSI and CVC thrombosis rates are associated with the number of CIF patients cared for per centre [11]. However, it also is recognised that the approach to CIF care delivery can differ both within and between countries [12,13]. A recent international survey identified a high number of unmet needs for patients with CIF including delays in patient referral, limited awareness of CIF among non-specialists, a lack or low level of access to HPN in some countries, insufficient research to drive care improvements, lack of optimal treatments and inadequate funding [13]. To address this, members of the Home Artificial Nutrition-CIF Special Interest Group of the European Society for Clinical Nutrition and Metabolism (ESPEN) proposed an initial set of quality-of-care standards aimed at forming the basis for all CIF teams to develop and monitor their service, while also informing policymakers and payers on the infrastructure required for the optimal approach to multidisciplinary team CIF care delivery [14].

This article describes the results of a pilot study that aimed to explore the utility and fulfilment of the quality-of-care standards across small, medium and large European CIF centres.

2. Material & methods

2.1. Survey

A one hundred and thirty-nine item questionnaire was designed to evaluate the ESPEN-endorsed quality-of-care standards for CIF care delivery for adult patients with type 3 IF [14]. As per the standards, the questionnaire was broadly divided into four subsections: background information concerning the CIF centre completing the questionnaire, structure and process of care, as well as CIF outcome monitoring. In order to evaluate differential approaches to quality-of-care delivery within a wide spectrum of centres, lead clinicians of small (<30 current HPN-dependent patients), medium (30–100 HPN-dependent patients) and large CIF centres (>100 HPN-dependent patients) from five countries were asked to complete the questionnaire.

The online questionnaire was administered using Microsoft Office forms. Binary (yes/no) and free-text answers were utilized to allow objective assessment of answers. Each quality-of-care standard question had a follow-up query for “Additional comments or insights” enabling more detailed elaboration. A full version of the survey is provided in the Supplementary Materials.

The invitation to participate in the survey was circulated by the Leading Intestinal Failure Equity committee of Optimal Nutritional Care for All (ONCA) to selected CIF centres within countries considered to be at varied stages of IF service development and of varied size (as indicated by the CIF patient cohort), between January and March 2025.

2.2. Statistical analysis

Responses to the survey were downloaded from Microsoft Office forms into a CSV file for further analysis. Descriptive analysis was performed, and data are presented as frequencies and percentages. While findings are presented and discussed in three distinct groups: “small CIF centres” (<30 HPN-dependent patients under the care of CIF centre), “medium CIF centres” (30–100 patients) and “large CIF centres” (>100 patients) no hypothesis testing of differences in proportions or means was performed, given the scope and design of the study. All analyses and data visualisation were performed using R Version 4.0.3.

3. Results

3.1. Participating centres

The response rate was 100 % from 15 CIF centres across five countries: 3 (20 %) responses from Belgium, 4 (26.7 %) from Denmark, 3 (20 %) from France, 3 (20 %) from United Kingdom and 2 (13.3 %) from Portugal. The median number of HPN-dependent patients under the care of CIF centres was 75 (range 6–600), with a total of 2027 patients. Overall, there were 4 (26.7 %) small CIF centres, 4 (26.7 %) medium CIF centres and 7 (46.7 %) large CIF centres. Location and size of the centres is presented in Fig. 1.

3.2. Structure of care

All included CIF centres reported that their service provided advice and, when referral criteria were met, clinical care of patients with type 3 IF. In all CIF centres the referral criteria were defined as “patients with benign disease needing or expected to need PN for more than 3 months and being considered for HPN”; however, only 9/15 (60 %) centres utilised a specific referral proforma. Further results of quality-of-care standards regarding structure of care are summarised in Table 1.

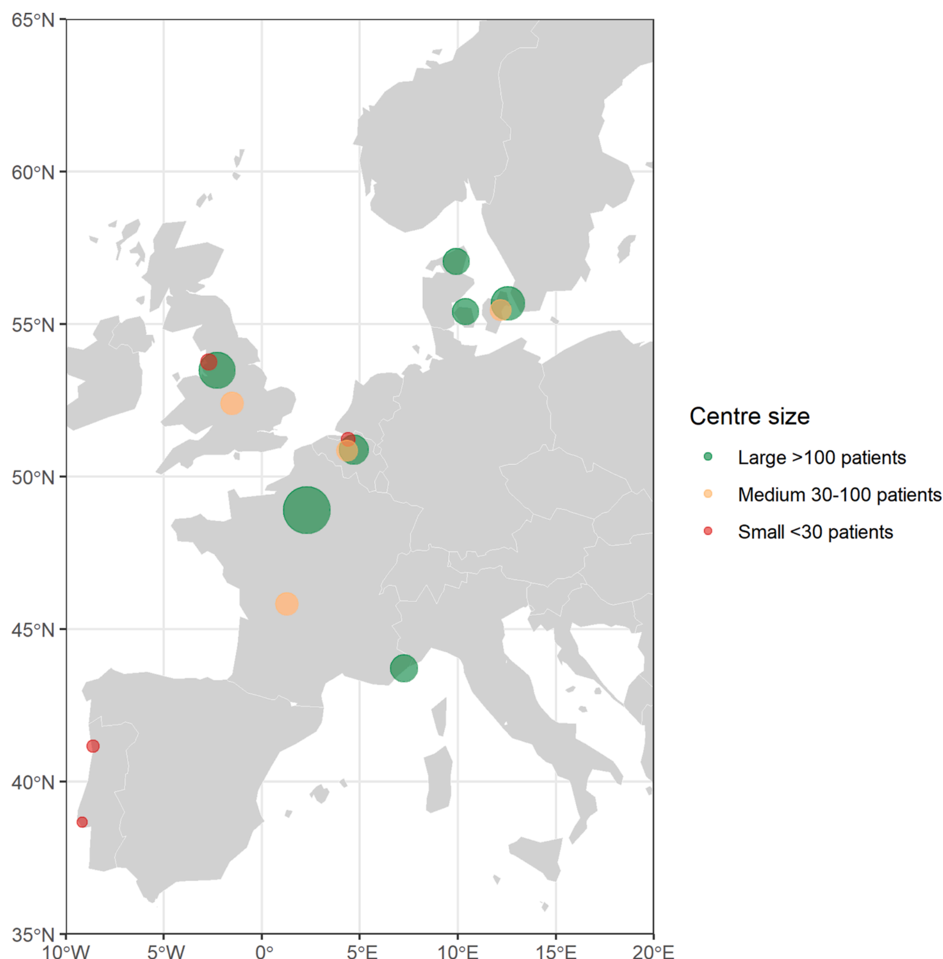

Fig. 1. Location and size of the responding centres. The size of the bubble is relative to the number of patients with CIF under the care of the centre.

All included CIF centres provided multidisciplinary support to each patient under their care. The composition of CIF teams and access to additional teams and facilities were broadly similar between the centre sizes. The fulfilment of quality-of-care standards regarding structure of care was high with regard to the composition of CIF teams, access to additional teams and facilities, as well as provision of education/training, with the majority of standards fulfilled by more than 80 % of CIF centres. Areas requiring improvement included providing two pharmacists with expertise in IF (provided by 73.5 % of centres); referral pathway to psychology and psychiatry services (provided by 60 % of centres) as well as specific ward area to facilitate cohesive multidisciplinary team care (provided by 66.7 % of centres). Interestingly, access to psychology and psychiatry services was more common in small CIF centres in comparison to medium and large ones. On the other hand, access to specific ward was limited especially in the small centres with only one out of four of them providing this standard of care.

Another area of improvement for most CIF centres was patient engagement, with only around 50 % of all centres offering a patient forum to feedback care delivery or conducting a patient survey on care delivery. Large CIF centres were more likely to run a patient forum to feedback care delivery compared to medium and small centres but there was no substantial difference in the patient survey provision per centre size.

Additionally, access to an intestinal transplant programme was not widely available; just over 50 % of centres provided this standard of care, with no substantial differences between the centre sizes.

3.3. Process

Results of quality-of-care standards relating to the process of CIF care delivery are summarised in Table 2. All CIF centres reported having a pathway for urgent referrals and provided advice to referring units. Monitoring of elective and ‘on-hold’ waiting lists was common in large CIF centres, less so in medium centres and uncommon in small CIF centres. Three small centres and one medium centre which indicated lack of monitoring explained that there was simply no waiting list for their CIF service.

The fulfilment of quality-of-care standards regarding all inpatient processes was broadly similar between all centre sizes and high as each standard was fulfilled by more than 80 % of CIF centres. Twenty 4-h cover and specialist advice for inpatient care was reported to be generally supported by the specialist IF team in larger centres and by the combination of specialist IF, general gastroenterology and surgical teams in small and medium sized centres.

All centres offered regular face-to-face or virtual outpatient clinic reviews for all HPN-dependent patients with all appropriate disciplines being available during the clinic reviews. Access to psychological outpatient follow-up was available for all large and small CIF centres but only 50 % of medium centres.

Table 1
Distribution of structure of care quality standards, stratified per centre size.

Structure of care	Overall N = 15[a]	Large CIF centre N = 7[a]	Medium CIF centre N = 4[a]	Small CIF centre N = 4[a]
CIF team				
Multidisciplinary support	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Two physicians with expertise in IF	13 (86.7 %)	7 (100.0 %)	3 (75.0 %)	3 (75.0 %)
Two nurses/physician assistants	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
Two pharmacists	11 (73.3 %)	5 (71.4 %)	3 (75.0 %)	3 (75.0 %)
Two dietitians	14 (93.3 %)	6 (85.7 %)	4 (100.0 %)	4 (100.0 %)
Stoma therapist	13 (86.7 %)	6 (85.7 %)	3 (75.0 %)	4 (100.0 %)
Two CVC insertion experts	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Periods of leave cover	13 (86.7 %)	7 (100.0 %)	3 (75.0 %)	3 (75.0 %)
Additional teams				
Microbiology input	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
Surgical input	14 (93.3 %)	7 (100.0 %)	4 (100.0 %)	3 (75.0 %)
Interventional radiology input	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
Psychology/psychiatry input	9 (60.0 %)	4 (57.1 %)	1 (25.0 %)	4 (100.0 %)
Social services input	14 (93.3 %)	7 (100.0 %)	4 (100.0 %)	3 (75.0 %)
Facilities				
Sterile pharmacy unit access	13 (86.7 %)	7 (100.0 %)	3 (75.0 %)	3 (75.0 %)
Pharmacy access for nutritional admixture and ancillaries for safe HPN provision	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Specific ward	10 (66.7 %)	6 (85.7 %)	3 (75.0 %)	1 (25.0 %)
Intensive care unit access	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Education/training				
Nurse CVC training	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Nurse CVC re-appraisal	9 (60.0 %)	4 (57.1 %)	2 (50.0 %)	3 (75.0 %)
Following national/international guidelines	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Any deviation from national/international guidelines	2 (13.3 %)	1 (14.3 %)	0 (0.0 %)	1 (25.0 %)
Regular education for MDT members	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
Regular governance meetings	12 (80.0 %)	6 (85.7 %)	3 (75.0 %)	3 (75.0 %)
Patient engagement				
Patient forum to feedback care delivery	8 (53.3 %)	5 (71.4 %)	2 (50.0 %)	1 (25.0 %)
Patient survey of care delivery	7 (46.7 %)	4 (57.1 %)	1 (25.0 %)	2 (50.0 %)
CIF therapies				
Intestinal transplant programme access	8 (53.3 %)	4 (57.1 %)	2 (50.0 %)	2 (50.0 %)
Protocols for entero-hormonal therapy administration/monitoring	12 (80.0 %)	6 (85.7 %)	3 (75.0 %)	3 (75.0 %)

[a] n (%).

Table 2
Distribution of process quality standards, stratified per centre size.

Process	Overall N = 15[a]	Large CIF centre N = 7[a]	Medium CIF centre N = 4[a]	Small CIF centre N = 4[a]
Pre-admission				
Patients fulfilling referral criteria accepted	13 (86.7 %)	6 (85.7 %)	4 (100.0 %)	3 (75.0 %)
Pathway for urgent referrals	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Monitoring of elective waiting list	10 (66.7 %)	6 (85.7 %)	3 (75.0 %)	1 (25.0 %)
Monitoring of 'on-hold' waiting list	7 (46.7 %)	5 (71.4 %)	2 (50.0 %)	0 (0.0 %)
Clinical advice given to referring unit	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Inpatient				
Daily ward round for hospitalised patients with CIF	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
24hr cover for inpatient care	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
HPN regimen establishment and training	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Pathway for admitting patients with emergency complications	13 (86.7 %)	7 (100.0 %)	2 (50.0 %)	4 (100.0 %)
24/7 specialist advice	13 (86.7 %)	7 (100.0 %)	3 (75.0 %)	3 (75.0 %)
Outpatient				
Regular outpatient clinics	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
MDT assessment during outpatient clinic	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Psychological follow-up	13 (86.7 %)	7 (100.0 %)	2 (50.0 %)	4 (100.0 %)
Education/training				
Patient/carer CVC technique re-appraisal	14 (93.3 %)	7 (100.0 %)	3 (75.0 %)	4 (100.0 %)
Patient/carer CVC technique re-appraisal post CRBSI	15 (100.0 %)	7 (100.0 %)	4 (100.0 %)	4 (100.0 %)
Networks				
Discharge to other recognised HPN services	13 (86.7 %)	6 (85.7 %)	3 (75.0 %)	4 (100.0 %)
Transition programme for HPN-dependent adolescents	7 (46.7 %)	5 (71.4 %)	1 (25.0 %)	1 (25.0 %)
Network with local hospitals where HPN-dependent patients present with CIF-related complications	9 (60.0 %)	5 (71.4 %)	2 (50.0 %)	2 (50.0 %)
Network with local hospitals where HPN-dependent patients are admitted for non–CIF–related reasons	11 (73.3 %)	5 (71.4 %)	2 (50.0 %)	4 (100.0 %)

[a] n (%).

The fulfilment of education/training of patients' and carers' catheter handling techniques was excellent among all centres, and reached 100 % for re-appraisal following acquisition of CRBSI in all centres, with additional comments stating reassessments are offered to ensure that all policies are being followed and all identifiable risks reduced following any catheter infection.

Area of improvement for most CIF centres related to establishment of networks with other services such as a transition programme for HPN-dependent adolescents, which was provided by less than 50 % of centres, and liaison with local hospitals where HPN-dependent patients present with CIF-related complications, provided by 60 % of centres; this was an issue especially in medium and small centres.

3.4. Outcomes

Overall, fulfilment of quality-of-care standards relating to CIF outcome monitoring seemed lower compared to structure of care and process standards as visualised in Fig. 2.

Around 80 % of CIF centres monitored outcomes regarding CRBSI (inpatient and outpatient), inpatient mortality and causes of death, with large CIF centres having higher fulfilment rates in comparison to medium and small centres.

All other standards of care relating to CIF outcomes were fulfilled by less than 80 % of centres overall. Particular areas of improvement included monitoring of waiting list mortality, CVAD placement timing, inpatient length of stay, readmission rates and quality of life across all centres. Additionally, medium CIF centres were unlikely to monitor outpatient CVC thrombosis and small CIF centres were unlikely to monitor entero-hormonal therapy outcomes.

4. Discussion

This is the first paper to assess the utility and fulfilment of the ESPEN-endorsed, internationally agreed quality-of-care standards [14] in selected European CIF centres. Despite an extensive number of questions, the questionnaire can be completed without any missing data, while also allowing for further comments that elaborate on centre experience. Thus, the quality-of-care standards appear to be appropriate for assessment of centres of all sizes and allow comparison between different CIF care practices over Europe.

The quality-of-care standards in CIF care were designed to form the basis for new and established teams to develop and monitor their service, while also providing clarity to payers on the infrastructure required for optimal multidisciplinary care delivery [14]. The recording, assessment and comparison of standardised outcomes between different centres should allow benchmarking of care delivery among CIF centres, both within the same country and across international borders. It is also a way to identify areas for improvement that the CIF multidisciplinary team may address through quality improvement projects aimed at increasing efficiencies, enhancing clinical standards and delivering improved patient-centred care.

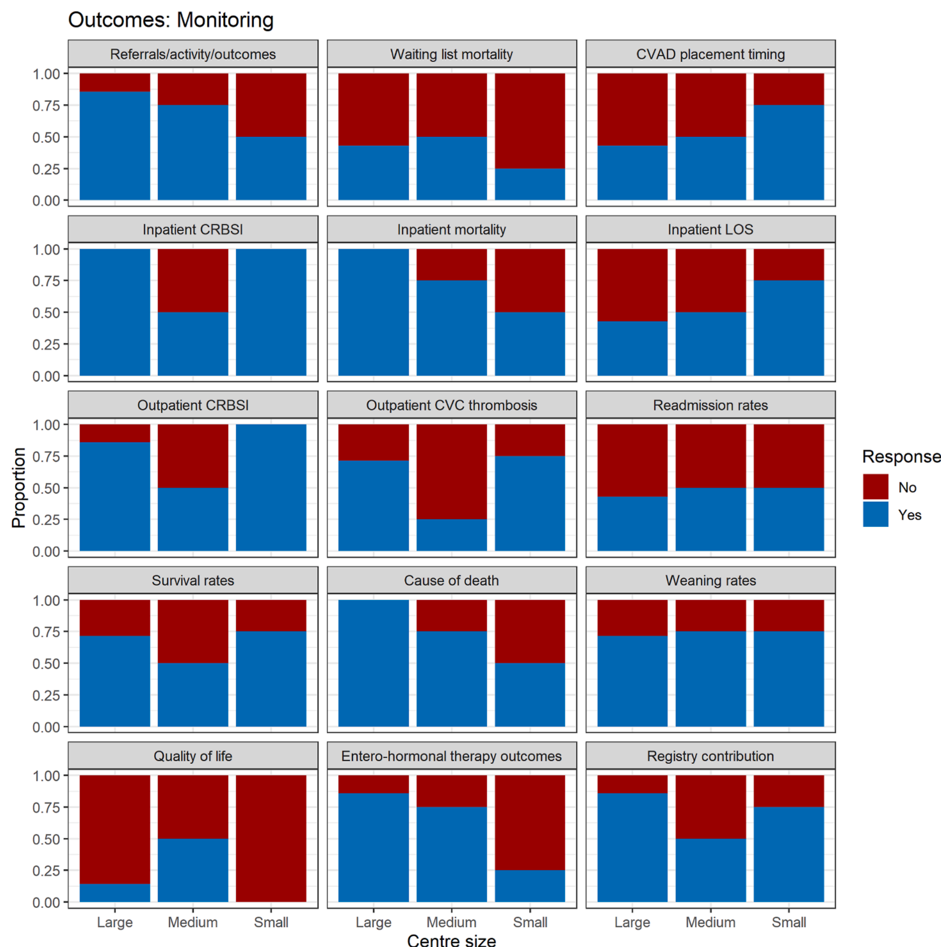

Fig. 2. Distribution of outcomes quality standards, stratified per centre size.

The composition of CIF teams and access to additional services were broadly similar between the centre sizes. Nevertheless, not all CIF centres provided the aspirational level of multidisciplinary cover such as two physicians, two pharmacists or two dietitians with expertise in IF. This could create concerns regarding cross-cover arrangements in periods of absence and ability to provide specialist advice at all times. Of particular concern is the fact that only 60 % of CIF centres were able to offer referral pathway to psychology and psychiatry services for this complex group of patients, who have high rates of anxiety and depression in addition to experiencing social isolation and psychological problems associated with the highly regulated lifestyle [3]. Moreover, access to a specific ward area was not always available, especially in small CIF centres. When a designated ward area is not available, it is recommended to cohort patients on a single bay to ensure a cohesive patient management approach, particularly regarding CVC care. This also fosters peer support amongst patients, facilitating ways to connect with other patients and obtain help to answer practical questions.

Monitoring of elective and 'on-hold' waiting lists differed substantially between centre sizes, however, this was primarily explained by the lack of waiting list in four out of five centres which indicated no need for monitoring. When waiting lists are in use, close monitoring of patient activity should be undertaken in order to minimise transfer time wherever possible and appropriate, as it has been previously demonstrated that a reduction in waiting times had a significant impact on improved patient outcomes [15]. This pilot study also highlighted a frequent lack of established networks between the CIF centres and other services such as local hospitals where patients can seek help with CIF and non-CIF related emergency issues. The development of close networks of care including sharing of CIF protocols with other services is an important step in optimising the overall care of patients, particularly in regions or countries where CIF services are centralised. A recent paper from the UK demonstrated that CRBSIs can be effectively managed in patients' local hospitals, enhancing care closer to home, but reliant on the development of networks and sharing of protocols between the centralised IF centre and local hospitals [16]. On the other hand, hospital reorganisation and high turnover of nursing teams with recruitment of nurses lacking experience in CVC care has been shown to be associated with increased rates of CRBSIs [17], which again highlights the need for regular nursing training, stability of the nursing team and protocol sharing.

Overall, fulfilment of quality-of-care standards regarding outcomes was lower than structure of care and process standards. Apart from CRBSI and mortality outcomes, which have specific quantifiable metrics, monitoring of other outcomes was reported to be undertaken by less than 80 % of centres, without specific differences between centre sizes. Monitoring of outcomes is the first step in identifying unmet needs and effective implementation of quality standards and ultimately improved clinical and patient centred outcomes.

The strength of the pilot study is the involvement of CIF centres of different sizes across five European countries in addition to no missing data regarding each of the quality standards. The main limitation is the small number of centres which meant statistical analysis of differences in care provision was not possible; however, this was a pilot study primarily aimed at assessing the utility of the quality-of-care standards as well as the ease of use of the questionnaire in order to asses any modification required prior to involving more centres. In the future work, we aim to include a wider range of centres including ones located in Eastern and Southern Europe, as well as the rest of the world. Moreover, more detailed investigation of the reasons for differences among centres, including country's health policies, organisation of care or access to funding, in addition to centre size, will be undertaken.

5. Conclusion

In conclusion, this pilot study clearly demonstrated the utility and fulfilment of the quality-of-care standards in selected European CIF centres. Future work will include increasing the number of participating centres, as well as annual reassessment of quality-of-care standards per centre. Engagement of policymakers in regions and countries where CIF care quality is identified to be limited, or locations where access to care may even be lacking, should also help improve HPN service delivery in the long-term.

Author contribution

Conceptualization: SL, SS, PJ, FJ, AM, TV, JW, LP; Data curation: SL, SS, PJ, FJ, AM, TV, JW; Formal analysis: MK, SL, SS, PJ, FJ, AM, TV, JW; Funding acquisition: SL, SS, PJ, FJ, AM, TV, JW; Investigation: SL, SS, PJ, FJ, AM, TV, JW, MA, NB, HD, PF, JF, JQ, JR, LV; Methodology: SL, SS, PJ, FJ, AM, TV, JW; Project administration: SL, SS, PJ, FJ, AM, TV, JW, MA, NB, HD, PF, JF, JQ, JR, LV; Resources: SL, SS, PJ, FJ, AM, TV, JW; Visualization: MK; Writing - original draft: MK, SL, SS, PJ, FJ, AM, TV, JW; Writing - review & editing: all authors.

AI statement

Artificial Intelligence was not used for preparing or the writing of the manuscript.

Funding statement

This work was coordinated by the Optimal Nutritional Care for All (ONCA) Leading Intestinal Failure Equality (LIFE) initiative(SL, SS, PJ, AM, TV, JW) which received unrestricted grant funding from Fresenius Kabi, Baxter, Hanmi and Ironwood. No author received any direct funding for this work.

Conflict of interest statement

No conflict of interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clnesp.2025.10.035.

References

[1] Pironi L, Arends J, Baxter J, Bozzetti F, Peláez RB, Cuerda C, et al. ESPEN endorsed recommendations. Definition and classification of intestinal failure in adults. Clin Nutr 2015;34(2):171–80.
[2] Kopczynska M, Hvas CL, Jepsen P, Teubner A, Abraham A, Burden ST, et al. Standardised survival and excess life years lost in patients with type 3 intestinal failure. Clin Nutr 2022;41(11):2446–54.
[3] Burden S, Hemstock M, Taylor M, Teubner A, Roskell N, MacCulloch A, et al. The impact of home parenteral nutrition on the burden of disease including morbidity, mortality and rate of hospitalisations. Clin Nutr ESPEN 2018;28:222–7.
[4] Arhip L, Serrano-Moreno C, Romero I, Camblor M, Cuerda C. The economic costs of home parenteral nutrition: systematic review of partial and full economic evaluations. Clin Nutr 2021;40(2):339–49.
[5] Allan P, Lal S. Intestinal failure: a review. F1000Research 2018;7:85.
[6] Dibb M, Teubner A, Theis V, Shaffer J, Lal S. Review article: the management of long-term parenteral nutrition. Aliment Pharmacol Ther 2013;37(6):587–603.
[7] Mathiesen SM, Fuglsang KA, Ranzato G, Scheike T, Jeppesen PB. Renal function in patients with intestinal failure receiving home parenteral support. JPEN J Parenter Enteral Nutr; 2021.

[8] Appleton ND, Lal S, Carlson GL, Shaw S, Stevens P, Peristerakis I, et al. Cholelithiasis and related morbidity in chronic intestinal failure: a longitudinal cohort study from a national specialized centre. J Gastrointest Surg : Off J Soc Surg Aliment Tract 2019;23(10):2002–6.
[9] Skallerup A, Nygaard L, Olesen SS, Køhler M, Vinter-Jensen L, Rasmussen HH. The prevalence of sarcopenia is markedly increased in patients with intestinal failure and associates with several risk factors. Clin Nutr 2018;37(6, Part A):2029–35.
[10] Fuglsang KA, Brandt CF, Scheike T, Jeppesen PB. Hospitalizations in patients with nonmalignant short-bowel syndrome receiving home parenteral support. Nutr Clin Pract 2020;35(5):894–902.
[11] Pironi L, Steiger E, Joly F, Wanten GJA, Chambrier C, Aimasso U, et al. Intravenous supplementation type and volume are associated with 1-year outcome and major complications in patients with chronic intestinal failure. Gut 2020;69(10):1787–95.
[12] Lal S, Teubner A, Shaffer JL. Review article: intestinal failure. Aliment Pharmacol Ther 2006;24(1):19–31.
[13] Geransar P, Lal S, Jeppesen PB, Pironi L, Rzepa E, Schneider SM. Survey of healthcare professionals' experiences of care delivery in patients with chronic intestinal failure: ATLAS of variance. Clin Nutr ESPEN 2023;54:157–65.
[14] Lal S, Soop M, Cuerda C, Jeppesen P, Joly F, Lamprecht G, et al. Quality-of-care standards in adult type 3 intestinal failure caused by benign disease: a European society of clinical nutrition and metabolism (ESPEN) position paper. Clin Nutr ESPEN 2024;63:696–701.
[15] Donaldson E, Taylor M, Abraham A, Carlson G, Fletcher O, Varden J, et al. Improving quality in a national intestinal failure unit: greater efficiency, improved access and reduced mortality. Frontline Gastroenterol 2015;6(3):182.
[16] Bond A, Conley T, Teubner A, Taylor M, Abraham A, Romero Salazar F, et al. Management of home parenteral nutrition catheter-related bloodstream infections in hospitals outside of a specialized intestinal failure center. J Parenter Enteral Nutr 2022;46(7):1731–5.
[17] Mirabel-Chambaud E, N'Guyen M, Valdeyron ML, Quessada T, Goudable J, Loras-Duclaux I, et al. Dramatic increase of central venous catheter-related infections associated with a high turnover of the nursing team. Clin Nutr 2016;35(2):446–52.