GE – Portuguese Journal of Gastroenterology

Review Article

GE Port J Gastroenterol 2026;33:422–430
DOI: 10.1159/000551206

Received: December 17, 2025
Accepted: February 11, 2026
Published online: February 26, 2026

Chronic Intestinal Failure: Portuguese Overview and Future Perspectives

André Bargas[a] Luisa Glória[a] Jorge Fonseca[b, c] Anibal Marinho[d]
Paula Gouveia[e] Simon Lal[e]

[a]Gastroenterology Department, Hospital Beatriz Ângelo, Loures, Portugal; [b]GENE – Artificial Feeding Team, Gastroenterology Department, Hospital Garcia de Orta, Almada, Portugal; [c]Egas Moniz Centre for Interdisciplinary Research (CiiEM), Egas Moniz School of Health and Science, Almada, Portugal; [d]Department of Intensive Care, Hospital Universitário de Santo António, Porto, Portugal; [e]National Intestinal Failure Reference Centre, Northern Care Alliance and University of Manchester, Salford, UK

Keywords
Chronic intestinal failure · Home parenteral nutrition · Portugal · Quality of care · Multidisciplinary management

Abstract

Background: Chronic intestinal failure (CIF) is a rare and complex condition in which patients require long-term intravenous supplementation to maintain health and quality of life. Across Europe, initiatives led by the European Society of Clinical Nutrition and Metabolism (ESPEN) and the European Nutrition Health Alliance have sought to harmonize definitions, care standards, and access to home parenteral support. However, international differences remain significant, particularly in countries where CIF care structures are still developing. ***Summary:*** This review outlines the current landscape of CIF care in Portugal, from its formal recognition to the ongoing establishment of national standards. This review revisits the traditional difficulties of CIF patients' management, the changes that come along with the publication of Health Directive 017/2020 marking a turning point, providing a legal and organizational framework for home management and multidisciplinary nutrition support teams. Recent Portuguese and European studies highlight both the progress achieved and the continuing gaps in coordination, registry data, and specialized services. Integrating the new ESPEN quality-of-care standards into clinical practice represents an opportunity to consolidate a structured national network, promote equity of access, and align Portuguese practice with broader European benchmarks. ***Key Messages:*** CIF remains underrecognized and underreported in Portugal, highlighting the need for developing the current national registry and dedicated referral network. Legislative advances and professional initiatives represent critical first steps toward equitable, evidence-based CIF management and integration into European care models. Implementation of structured multidisciplinary teams and adherence to ESPEN quality-of-care standards are pivotal to improving safety, outcomes, and cost efficiency. Portuguese progress has been clear and significant, but there is still a long way to travel before reaching European standards of CIF patient care.

karger@karger.com
www.karger.com/pjg

Correspondence to:
André Bargas, bargasandre2@gmail.com

Insuficiência intestinal crónica: panorama geral em Portugal e perspetivas futuras

Palavras Chave
Insuficiência intestinal crónica · Nutrição parentérica domiciliária · Portugal · Qualidade dos cuidados · Gestão multidisciplinar

Resumo
Contexto: A falência intestinal crónica é uma situação clínica rara e complexa em que os doentes necessitam de suplementação intravenosa a longo prazo para assegurar a manutenção do estado nutricional e da saúde. Em toda a Europa, iniciativas lideradas pela Sociedade Europeia de Nutrição Clínica e Metabolismo (ESPEN) e pela *European Nutrition Health Alliance* têm procurado padronizar definições, padrões de cuidados e o acesso ao suporte parentérico domiciliário. No entanto, persistem diferenças significativas entre países, especialmente onde as estruturas de cuidados aos doentes com falência intestinal crónica ainda se encontram em desenvolvimento. ***Sumário:*** Esta revisão descreve o panorama atual dos cuidados de falência intestinal crónica em Portugal, desde o seu reconhecimento formal até ao processo em curso de definição de normas nacionais. Esta revisão relembra as tradicionais dificuldades no tratamento dos doentes com falência intestinal crónica, bem como a evolução resultante da publicação da Norma de Orientação Clínica da Direção Geral de Saúde n° 017/2020 que constituiu um marco importante, ao estabelecer um enquadramento legal e organizacional para a gestão domiciliária e para as equipas multidisciplinares de suporte nutricional. Estudos recentes, portugueses e europeus, evidenciam tanto os progressos alcançados como as lacunas persistentes na coordenação, nos registos clínicos e nos serviços especializados. A integração dos novos padrões de qualidade de cuidados da ESPEN na prática clínica representa uma oportunidade para consolidar uma rede nacional estruturada, promover a equidade no acesso e alinhar a prática portuguesa com as referências europeias. ***Mensagens chave:*** A falência intestinal crónica continua sub-reconhecida e sub-notificada em Portugal, evidenciando a necessidade de desenvolver o registo nacional e de uma rede de referenciação dedicada. Os avanços legislativos e as iniciativas profissionais representam etapas cruciais rumo a uma gestão equitativa e baseada na evidência da falência intestinal crónica, bem como à sua integração nos modelos de cuidados europeus. A implementação de equipas multidisciplinares estruturadas e a adesão aos padrões de qualidade da ESPEN são fundamentais para melhorar a segurança, os resultados clínicos e a otimização dos custos. Em Portugal o progresso tem sido claro e significativo, mas há ainda um longo caminho a percorrer até se atingirem os padrões europeus de tratamento dos doentes com falência intestinal crónica.

Introduction

Intestinal failure (IF) is defined as reduced gut function below the minimum necessary for macronutrients and/or water and electrolytes absorption, such that intravenous supplementation – termed parenteral support (PS) – is required to maintain health and/or growth [1]. Broadly, IF represents a state of impaired intestinal absorption arising from anatomical loss or functional derangement of the intestine due to surgical, congenital, or disease-related causes [1].

In clinical practice, IF is categorized into three functional types [1, 2]. Type I IF is an acute, short-term, self-limiting condition, commonly occurring in post-operative or critically ill patients, generally resolving within days or weeks with temporary PS. Type II IF is a prolonged, subacute condition occurring in metabolically unstable patients following major intestinal resection, intra-abdominal sepsis or fistula formation. Type III IF, also termed chronic IF (CIF), refers to a stable condition in which patients require long-term, sometimes lifelong, PS to maintain health. This chronic form may be *reversible* or *irreversible*, where intestinal function cannot be restored; ideally, in CIF, the PS should be administered at home (termed home PS or HPS) [1]. Types II and III therefore represent the most severe and clinically challenging forms of IF. Approximately 70% of patients with Type II progress to chronic, Type III IF [2].

CIF is a rare, life-altering, and resource-intensive disorder, where patients are metabolically stable but depend on long-term HPS to maintain health and quality of life (QoL) [3]. In fact, CIF is the rarest long-term organ failure, imposing substantial clinical, psychological, and economic burdens on patients, families, and healthcare systems, with significant risks of complications, hospital readmissions, and reduced physical performance [3].

Over the past decade, there has been growing European interest in improving awareness, equity, and quality of care for patients with CIF. Recognizing the inequity of access that exists between countries, the ATLAS initiative [4], established in 2016, brought together clinical experts, patient organizations, and policy advisors across Europe to harmonize IF care delivery. One of the first outputs of this program surveyed 119 healthcare professionals from 12 European countries and found marked disparities in CIF management and access to HPS, particularly in Eastern Europe. While improving QoL was identified as the main treatment goal, validated QoL tools were reported to be seldom used, and major unmet needs included poor disease awareness and the shortage of accredited referral centers. These findings provided Europe-wide evidence of inequality in CIF care and supported subsequent ATLAS and European Society of Clinical Nutrition and Metabolism (ESPEN) efforts to standardize multidisciplinary care and quality-of-service benchmarks across Europe. Subsequently, the European Nutrition Health Alliance (ENHA) [5] – a multistakeholder foundation established to improve nutritional care across Europe – has underlined the importance of translating nutritional care science into policy. Within ENHA's framework, the "Leading Intestinal Failure Equality" or "LIFE" initiative [6] is a specific campaign aiming to address the needs of patients with CIF. The LIFE initiative brings together clinical experts, patient organizations, and industry and policy makers with the aim of advocating for equal access to CIF care across Europe and raising awareness of the burden, inconsistencies, and disparities in care delivery [6]. By aligning with the mission of ATLAS, ENHA, and the LIFE initiative provides a broad policy-and-advocacy platform that complements the previous clinical and audit-oriented work of ATLAS, reinforcing the push for standardized, equitable, multidisciplinary care pathways in CIF across European countries.

In parallel, the ESPEN has played a pivotal role in standardizing the clinical approach to CIF. Building upon its guidelines and recommendations for CIF and HPS delivery [3, 7, 8], the Home Artificial Nutrition and CIF Special Interest Group of the ESPEN recently published internationally agreed quality-of-care standards [9], outlining the essential resources, structures, and outcome measures required for optimal CIF care. Collectively, initiatives such as ENHA and ESPEN underscore a continent-wide effort to transform CIF care from a fragmented, country-specific practice into a coordinated European network driven by shared standards, data, and patient advocacy.

Despite increasing European initiatives to harmonize IF care, Portugal still faced a significant knowledge and structural gap regarding CIF [10]. The main reason for the gap in CIF support in Portugal was the lack of legal support for HPS that existed until recently. Parenteral nutrition was legislated for exclusive hospital use, and only hospitals with home hospitalization programs provided HPS. In 2020, the Portuguese health authorities (Direção-Geral da Saúde) issued Norma 017/2020 [11], establishing the regulatory framework for home management of CIF. This regulation defined the organization and responsibilities of the Nutrition Support Teams (NSTs), set standards for HPS delivery and monitoring, and promoted a transition of stable patients from hospital-based to ambulatory care settings. Following this legal development, the Special Interest Group in Nutrition of the Portuguese Society of Gastroenterology (Núcleo de Nutrição em Gastrenterologia: NNG-SPG) published two articles with recommendations and guidelines, as well as proposals for the organization of reference centers at the national level [10, 12]. Also, the largest Portuguese CIF center published its clinical experience as an example of patients' diversity and organizational model in the national context [13]. Nevertheless, there are no formalized national protocols for referral, multidisciplinary follow-up, or quality benchmarking, unlike in other European countries [14–16] with established CIF registries and referral systems. Recently, the NNG-SPG introduced a national registry collection initiative that is currently underway, aiming to characterize the epidemiology, clinical outcomes, and care models of CIF across the country. Although in its early stages, this effort represents an important first step toward establishing a comprehensive national CIF registry and standardizing care pathways.

Epidemiology and Prevalence

Recent data confirm substantial geographic variability in the prevalence of CIF across Europe and globally. According to the global review by Khokhar et al. [17] which synthesized national registry and survey data from 61 countries, the estimated prevalence of adult short bowel syndrome leading to CIF (SBS-IF) in 2024 ranged from 0.12 to 2.74 per 100,000, and in children from 0.09 to 1.67 per 100,000. Complementary data from European registries and national reports illustrate a similar heterogeneity in the prevalence of patients receiving HPS, ranging from around 80 per million in Denmark [14, 18], 62 per million in

France [19], and 36.1 per million in the UK [20], to around 6 per million in Spain [21].

In Portugal, the PARENTERAL Study [22] provided the first national estimate, identifying only 31 patients (11 adults, 20 children) on stable HPS across multiple hospitals – corresponding to an apparent prevalence of around 3 per million inhabitants, far below the 20–80 per million range considered realistic for other European CIF cohorts. Notably, the cohort was predominantly composed of anatomically defined short bowel syndrome (SBS), with 45.5% of adults classified as having SBS and 36.4% as having ultra-SBS, while the remaining 18.4% had functional IF without major resection; in the pediatric cohort, 60.0% had SBS and 40.0% ultra-SBS, with no identification of other CIF etiologies [22].

Beyond benign CIF, recent evidence indicates a growing yet heterogeneous use of HPS in patients with advanced cancer across Europe, particularly among patients with malignant bowel obstruction. Naghibi and colleagues [23] recently surveyed 220 clinicians across 36 countries and found marked geographical variation in the use of HPS in advanced malignancy, with Southern and Central Europe reporting a higher use compared to Northern or Eastern regions. Reported barriers to HPS initiation in this cohort with malignancy included the lack of local expertise, objections from oncology doctors, and funding constraints. Notably, there are limited data on HPS use in this setting in Portugal.

Jeppesen [24] previously highlighted that in Denmark, the approximate point prevalence of patients receiving HPS and renal replacement therapy (RRT) for end-stage kidney disease, irrespective of etiology, in 2010–2012, was 80 and 800 patients per million population, respectively – yielding a ratio of 1:10 between HPS and RRT [24]. Indeed, the author recommended that for any country, the prevalence of HPS should ideally be 10% that of RRT [24]. Applying this ratio to the Portuguese context, where national registry data report an RRT prevalence rising from 998 per million in 2010 to 1,286 per million in 2016, the expected prevalence of HPS would be in the range of 100–130 patients per million. The observed data therefore indicate significant underdetection of Portuguese CIF/HPS cases.

Clinical Burden and Health Resource Utilization

Despite the low number of identified CIF patients in Portugal, their management represents a substantial healthcare resource utilization burden. The PARENTERAL Study [22] demonstrated that care is a resource intensive, even in a small cohort (n = 31). Over a 12-month period, each patient required a mean of 8.7 ± 5.1 medical consultations/year in adults and 10.2 ± 5.3 in children, as well as around 38 visits/year to other health professionals (mainly nursing and dietetic consultations) [22]. According to ESPEN's Practical Guideline, stable CIF patients should undergo medical review every 3–6 months, supplemented by contact with the NST if needed [7]. This standard equates to 3–4 physician consultations/year for stable patients, far fewer than the nearly 10 annual visits observed in the Portuguese cohort [22]. Hospitalization rates were also high, averaging 1.9–2 admissions/year with a mean length of stay of 31 days, and around 80% of admissions were due to catheter-related complications [22]. In two other Portuguese single-center cohorts, both with 13 patients, one reported a 61.5% hospitalization rate due to catheter-related complications, mainly infections, over a mean 28.8 ± 29.2 months of follow-up, with an average of 2.25 admissions/patient and a mean hospital stay of 24.5 days [25]; the other center reported an incidence of central venous catheter-associated bloodstream infections (CRBSIs) of 0.46 per 1,000 catheter-days, with four deaths related to HPS-related complications, including catheter-related sepsis (n = 2), endocarditis with cardiac failure (n = 1), and hepatic failure (n = 1) [26]. These figures contrast with those reported by a dedicated IF center in the UK, where unplanned hospital readmissions averaged only 0.33 per patient-year and CRBSI rates were as low as 0.199 per 1,000 catheter-days [27].

Several organizational and management factors may contribute to the relatively high rate of catheter-related complications reported in Portuguese cohorts. These include the heterogeneity in NST composition across centers, variable experience related to low patient volumes, and the absence of fully standardized national catheter-care protocols. In addition, patient and caregiver training programs, follow-up intensity, and access to specialized nursing support may differ between institutions, potentially influencing adherence to aseptic techniques and early detection of complications.

International evidence consistently supports the benefits of structured, multidisciplinary NSTs in optimizing outcomes associated with PS. A recent systematic review and meta-analysis [28] showed that across ten studies reporting in-hospital infection rates, NST introduction reduced CRBSI rates by 68% compared with standard care, corresponding to a reduction of 8 CRBSIs per 1,000 catheter-days. Moreover, NST-led care was associated with a 6% absolute reduction in 30-day mortality (IRD = −6%; 95% CI: −11% to −1%),

highlighting the role of specialized teams in preventing life-threatening complications in patients receiving PS. Beyond infection control, NST implementation significantly improved metabolic safety and quality of PS delivery. Notably, NSTs also reduced inappropriate PS prescriptions – whether due to incorrect indication or excessive duration – by 18–21%, demonstrating a critical stewardship role in avoiding unnecessary or prolonged PS exposure. Collectively, these improvements were consistent across hospital settings and regions, with moderate-quality evidence supporting their generalizability. These findings confirm that NSTs significantly enhance the safety, efficiency, and cost-effectiveness of PS through coordinated, multidisciplinary, evidence-based care [29].

Economic and Humanistic Impact

The Portuguese PARENTERAL Study [22] is, so far, the only work that has quantified the economic footprint of CIF in Portugal. It showed that even with very few identified patients, the mean annual direct cost per patient was EUR 47,857.53 for adults and EUR 74,734.50 for children, with PS and hospitalizations identified as the main cost drivers. These figures sit within the broad European range reported in other economic evaluations of CIF and HPS; in the multicenter study by Canovai et al. [30], initial annual costs averaged EUR 83,503 per patient in the first year of HPS but decreased progressively over time, reaching EUR 58,187 by year 5, equating to a reduction of approximately 40%, which, in itself, suggests that structured and long-term multidisciplinary management can significantly reduce treatment costs. Another systematic review by Arhip et al. [31] demonstrated that although HPS represents a high-cost therapy, it is overall cost-saving compared to prolonged hospital-based PS [31].

An important methodological point in the Portuguese study is that only direct medical costs were counted (PS bags and disposables, medical consultations, laboratory monitoring, and hospitalizations for catheter-related or metabolic complications), while indirect costs (productivity loss of patients/caregivers, travel costs, informal care) were not included. The authors explicitly state that given the functional limitations and caregiver dependence of many CIF patients, true societal costs are likely to be higher than those reported [22].

From the humanistic side, the Portuguese data mirror what large ESPEN-led international studies have shown: HPS clearly prolongs survival and maintains nutritional status, but it [13] is also associated with a persistent physical, social, and psychological burden [3, 22]. In the PARENTERAL cohort [22], children and adults showed clinically relevant impairment of physical and social domains compared with Portuguese normative data, despite being clinically stable on HPS. Interestingly, in children, school functioning scores were consistently lower even when compared to children with other chronic diseases. The authors interpret this, at least partly, as a coping/adaptation phenomenon – a pattern that Baxter et al. [32] also described in the international validation of the HPN-QoL® instrument, where patients reported acceptable global QoL but worse scores for body image, sleep, fatigue, and social activities. Recurrent hospitalizations and the anticipation of catheter-related sepsis are repeatedly cited by patients as impacting on QoL, not only the admissions themselves, a finding also underlined in the aforementioned UK series on hospital readmissions [27].

These Portuguese data have to be read alongside the newer European policy/organizational literature. The 2024 ESPEN position paper on quality-of-care standards in adult CIF suggests that cost containment and QoL improvement should not be competing goals: both depend on structured, multidisciplinary services, with defined follow-up frequency, nurse-led training, and standardized catheter-care protocols [9]. Data from the ESPEN CIF Registry clearly demonstrate that larger center size (centers that are more likely offering centralized CIF care) is associated with lower mortality and lower catheter-related complications, i.e., they have fewer expensive HPS-related complications [33]. The Portuguese situation, as described in the PARENTERAL Study and with the larger center reporting 23 patients [13], is almost the opposite configuration: few patients, high contact rate, and higher proportion of catheter-related admissions, therefore likely a higher cost/patient. Organizing CIF care into dedicated teams is therefore not just a clinical recommendation but a health-policy measure to reduce admissions, standardize PS prescriptions, and push part of the monitoring to the community, thereby reducing the heaviest cost blocks.

Finally, because Portugal has so far reported fewer CIF cases than expected for its population, the present economic burden likely reflects under-detection and several CIF patients without adequate treatment. As Jeppesen [24] suggested for Denmark, where the HPS-to-RRT ratio is approximately 1:10, increasing national recognition and referral of CIF cases will inevitably raise absolute healthcare costs. However, with structured multidisciplinary CIF networks following

ESPEN-aligned quality standards, such costs can be mitigated by reducing preventable hospitalizations and sustained improvements in QoL [9].

Quality of Care: The ESPEN 2024 Standards

The 2024 ESPEN Position Paper on *Quality-of-Care Standards in Adult Type III Intestinal Failure* [9] established the first unified European framework for implementing and assessing the quality of CIF and HPS services. The document, endorsed by the ESPEN CIF Special Interest Group, emphasizes that HPS provision should meet clearly defined *structural*, *process*, and *outcome* standards to ensure safety, optimize clinical results, and enable benchmarking across centers.

Structural Standards

ESPEN defines structural standards as the core resources and organizational requirements necessary for a CIF service. Each center should care for a minimum of 20 active HPS-dependent patients to maintain clinical expertise and procedural competence. Services should be delivered by a multidisciplinary team (MDT), ideally comprising physicians, nutrition nurses, dietitians, and pharmacists, with established referral pathways to psychological and psychiatric support and appropriate cross-cover within disciplines. Access to surgical and interventional radiology expertise, as well as administrative and data management support, is also recommended. Regular MDT meetings should be held to review clinical outcomes and safety indicators, supported by audit processes and participation in national or international registries.

Process Standards

Process standards define how CIF care is delivered and coordinated. According to the recent ESPEN position paper, all CIF centers should provide 24/7 emergency access for patients with HPS-related complications and deliver standardized central venous catheter training to patients and caregivers prior to home discharge. Education in aseptic technique, catheter handling, and early recognition of infection or thrombosis is mandatory.

Centers should also implement formal referral pathways with regional hospitals to ensure continuity of care and equitable access to specialized CIF services. In addition, regular face-to-face or virtual clinic follow-up should be offered to all HPS-dependent patients, typically every 3 to 6 months for stable individuals, or more frequently when clinically indicated. These measures are closely aligned with the ESPEN Guidelines which underscores training and standardization as critical to reducing complications and readmissions [7].

Outcome Standards

All centers should systematically monitor hospital and home catheter infection rates, aiming for an incidence of fewer than one episode/1,000 catheter-days. This indicator represents a key benchmark of patient safety and a core quality metric for HPS programs. Similarly, centers are expected to record in-patient mortality rates, with adjustment for case mix and underlying disease severity, and to track readmission rates at 30 and 60 days after discharge for newly established HPS-dependent patients, to ensure service efficiency.

Beyond these parameters, mature CIF programs should evaluate long-term survival, HPS weaning rates, and patient-reported QoL. Participation in national or international CIF registries – allowing for consistent reporting of CRBSI, mortality, and readmission data – is strongly encouraged, as it represents a hallmark of transparency, accountability, and service maturity.

Alignment and Opportunities for Portugal

It is clear that Portugal has made progress with Norma no. 017/2020 from the Direção-Geral da Saúde [11]. However, current Portuguese CIF care is characterized by a small number of patients, fragmented follow-up, and heterogeneous MDT composition. Establishing specialized CIF centers meeting the ≥20-patient threshold, with full MDT staffing and 24/7 on-call capability, would allow Portugal to move toward centralized care delivery and potentially enhance associated quality metrics.

Comparative European Context

Across Europe, the organization of CIF care varies widely. Denmark and the UK are generally regarded as benchmarks for CIF service organization. Both countries operate centralized national networks of reference units that collectively support the majority of HPS-dependent patients. In Denmark, adult CIF cases are referred to a small number of dedicated IF centers, such as the Copenhagen IF Unit, which also manages the national HPS registry [14].The UK follows a similar centralized model with a nationally commissioned tiered referral structure. The UK's IF Registry aims to collect standardized data on patient outcomes,

complications, and survival, supporting continuous service improvement and policy oversight.

By contrast, Spain represents an emerging but still heterogeneous system. The NADYA Group (*Nutrición Artificial Domiciliaria y Ambulatoria*), operating under the Spanish Society for Parenteral and Enteral Nutrition (SENPE), maintains a multicenter registry of adult and pediatric HPS patients, providing valuable epidemiological data and fostering reference center development [21]. However, significant regional variability persists, with marked differences in CIF prevalence, referral practices, and MDT availability across Spanish regions [34].

In Portugal, the structure remains comparatively fragmented. While several tertiary hospitals provide HPS to a small number of patients, there is no fully implemented national registry, no designated reference centers, and limited coordination among teams. Governance is largely local, and MDT composition varies between institutions.

At the European level, initiatives such as ENHA and ESPEN provide frameworks for cross-country collaboration, knowledge sharing, and benchmarking. The ATLAS Programme identified substantial disparities in CIF management across Europe. In the subsequent ATLAS of Variance survey [35], two-thirds of respondents experienced delays in referral to specialist centers, most often due to late recognition or lack of defined pathways. The most frequently cited unmet needs included a general lack of disease awareness among non-specialist clinicians (46%), an insufficient number of accredited referral centers (41%), and limited funding (33%). Collectively, these findings underscore the fragmented nature of CIF service provision across Europe and the need for harmonized standards and structured referral networks to ensure equitable access to high-quality care [35]. ESPEN's and ENHA's endeavors, through guideline and quality standard development, as well as raising IF awareness amongst the public and policymakers, present an opportunity for Portugal to align with European standards, implement structured referral pathways, and develop a national CIF registry capable of supporting both clinical governance and policy planning.

Strategic Opportunities for Portugal

Improving CIF care in Portugal requires coordinated, policy-level action, grounded in ESPEN 2024 standards and aligned with current European frameworks. First, the establishment of an ongoing national CIF registry is fundamental. This process is already underway under the supervision of the NNG-SPG [10]. The registry will operate on the Cerega platform (Centro Nacional de Registo de Dados em Gastrenterologia), initially focusing on adult CIF patients, but now including pediatric patients, and employing data fields similar with other European registries. Once completely implemented, it will enable national benchmarking and international collaboration within ESPEN and ENHA networks.

Second, Portugal could develop a structured network of referral and reference centers meeting ESPEN structural and process criteria. According to Vara-Luiz et al. [10], an optimal national configuration would consist of three to five adult referral centers closely linked to local NSTs, supplemented by two to three pediatric centers [10]. These centers should maintain a minimum caseload of ≥20 active HPS-dependent patients and a core MDT, as well as provide 24/7 emergency access [1, 2].

Third, training and accreditation programs for CIF-focused MDTs require prioritization. As demonstrated by Iyer et al. [36], a recent survey of US gastroenterologists revealed significant gaps in knowledge of CIF, underscoring the general lack of formal training in this field. Integrating CIF-specific modules into national medical, surgical, and nutrition curricula, together with continuing-education initiatives endorsed by ESPEN and SPG, would help address these disparities and enhance overall service quality.

Fourth, a national quality-assurance system would allow tracking and public reporting of standardized indicators: CRBSI incidence, unplanned readmissions, mortality, and patient-reported QoL outcomes. Linking these data to the national registry will ensure transparency and continuous improvement.

Fifth, contributing to European registries and collaborative platforms such as the ESPEN CIF Registry will facilitate cross-border benchmarking, shared protocols, and multicenter research. This collaboration has already begun, and a recent article on quality standards in CIF includes Portuguese data [37].

Finally, strengthening patient involvement and advocacy is essential for all specialized services. The development of patient associations and patients and caregiver participation in service evaluation will foster a patient-centered, participatory model consistent with European priorities for chronic disease management.

Together, these strategic steps – many of which are already in motion – will enhance CIF care in Portugal, promoting equitable access and measurable improvements in outcomes and QoL.

Conclusion

CIF remains a rare but highly demanding condition, requiring multidisciplinary and long-term care. Over the past decade, European initiatives have driven major progress toward harmonized definitions, quality standards, and benchmarking frameworks. Nonetheless, significant inequities persist between and within countries.

In Portugal, CIF management is still characterized by low case identification and a lack of recognized reference centers. However, recent advances – including the publication of the Health Directive and the development of the national CIF registry under the Portuguese Society of Gastroenterology – mark important milestones toward organized, data-driven care. These initiatives will align Portugal with the broader European movement to standardize CIF management and enable benchmarking through shared outcome indicators such as infection rates, readmissions, and QoL.

Investment in training, accreditation, and MDT development is essential to ensure safe, cost-effective, and patient-centered CIF care. Establishing a coordinated network of reference and support centers, integrated into European registries and quality frameworks, is critical to improving outcomes, reducing complications, and enhancing patients' QoL. Portugal is now in transition to a mature, equitable, and high-quality national CIF care system.

Statement of Ethics

This review does not require an ethical approval according to national laws due to the lack of patients' inclusion.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Funding Sources

This study was not supported by any sponsor or funder.

Author Contributions

André Bargas and Simon Lal performed the literature review, study selection, and manuscript writing. Luísa Glória, Aníbal Marinho, and Jorge Fonseca critically reviewed the manuscript. All authors approved the final version of the manuscript.

Data Availability Statements

All data generated or analyzed during this study are included in this article. Further inquiries can be directed to the corresponding author.

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