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Opinion Paper

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

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ABSTRACT

Background: Outcomes related to chronic intestinal failure (CIF) vary significantly within and between countries. While there are extensive European Society of Clinical Nutrition and Metabolism (ESPEN) guidelines on the delivery of optimal care in CIF, there are no international consensus recommendations on the structure or resources required, nor on the process and appropriate outcome measures for delivering such quality care in CIF.

Aim: The aim of this position paper is therefore to devise ESPEN-endorsed, internationally agreed quality of care standards, covering the resources, systems and standards that centres should aim for in order to deliver optimal CIF care.

Methods: Members of the Home Artificial Nutrition-CIF Special Interest Group of ESPEN proposed an initial set of quality-of-care standards which was submitted to voting amongst clinicians from international CIF centres using a modified Delphi process, with participants rating each proposed statement as 'essential', 'recommended' or 'not required'. Any statement receiving 80% of more 'not required' responses was excluded.

Results: All 30 proposed standards relating to the structure, 18 relating to the process and 16 to the outcome measures of CIF care were deemed to be essential or recommended in more than 80% of respondents.

Conclusion: This is the first paper to determine and describe internationally-agreed quality of care standards in CIF, which are now 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 multi-disciplinary team CIF care delivery. The recording of standardised outcomes should also allow internal and external benchmarking of care delivery within and between CIF centres.

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1. Introduction

Intestinal failure (IF) is “the reduction of the gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation (IVS) is required to maintain health and/or growth” [1]. IF can be further subclassified into acute (types 1 and 2 IF) and chronic (type 3 IF) conditions [1,2]. Chronic IF (CIF) occurs when patients achieve metabolic stability and can be discharged on home parenteral nutrition (HPN) outside of the hospital setting [1,2]. While the reported prevalence of CIF varies significantly between countries, it is also recognised that the approach to CIF care delivery can also differ both within and between countries [2,3].

The development of CIF can be associated with significant morbidity, with recognised complications including central venous catheter (CVC)-related complications such as catheter-related bloodstream infections (CRBSIs), occlusion and thrombosis, as well as metabolic complications, such as renal, hepatic, and bone complications [4]. An excess mortality of patients with CIF occurs as a result of such CIF-related complications, and also because of the underlying disease causal to CIF as well as non-CIF or HPN-related reasons [5]. There is evidence that some of the risks of CIF and HPN may be reduced in larger CIF centres. Data from the ESPEN CIF registry, involving nearly 3000 patients from 51 worldwide HPN Centres, demonstrated that reduced 1-year mortality, CRBSI and CVC thrombosis rates were associated with centres contributing more HPN-patients to the registry [6]. It may be possible that, by agreeing, sharing and then implementing quality standards within CIF centres of varied size (which may be a surrogate marker of centre experience), outcomes for all patients with CIF may improve.

The World Health Organisation defines quality of care as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes, highlighting that quality health services should be effective in providing evidence based-health services to those needing them, safe in avoiding harm and people-centred in providing for the needs and values of individuals [6]. The evidence base for delivering clinical care to people living with CIF has been recently extensively evaluated and described within the updated ESPEN guidelines on CIF care [4]. However, although there are national IF recommendations on the delivery of severe acute and chronic IF care [7,8], there are, as yet, no international consensus recommendations on the structure or resources required, nor on the process and appropriate outcome measures for delivering such quality care in CIF.

The aim of this position paper is therefore to devise ESPEN-endorsed, internationally-agreed quality of care standards, covering the resources, systems and standards that centres should aim for in order to deliver optimal CIF care.

2. Methods

Members of the CIF Special Interest Group of ESPEN conducted a physical meeting in January, 2023, to produce an initial set of proposed quality-of-care standards. The findings of the published ESPEN clinical care guidelines were considered. A facilitator (SL) tabulated the proposals on quality standards and grouped those in three domains: structure, process, and outcomes of care.

A modified Delphi process [9] was designed and facilitated by the ESPEN Guideline Office and distributed to CIF centres contributing to the ESPEN CIF Database [6]. Delphi methodology was chosen as traditional systematic review and meta-analysis was not possible given the lack of published data in the field of quality standards in IF care.

Each centre was asked to choose one representative to respond. Participants were asked to provide their country of origin,

profession, years of practice in CIF and the number of HPN-dependent patients currently (at the time of survey completion) under their care. Participants were asked to rate each of the proposed statements as ‘essential’, ‘recommended’ or ‘not required’; free text comments were allowed following each statement. It was highlighted to respondents that the quality standards were designed to define the optimal care that CIF centres could potentially offer, rather than to describe the current practice in any centre or minimal acceptable standards.

Any statement receiving 80% of more ‘not required’ responses was excluded. All comments were considered by the Special Interest Group, which modified the proposed statements accordingly. Retained and final statements are presented here, with the proportional expert ratings for each statement.

3. Results

The initial set of proposed standards consisted of 30 related to the structure of care, 18 to the process of care, and 16 to the outcome measures of quality of care. Thirty-five responses were received from 21 countries including Australia, Belgium, Canada, China, Colombia, Croatia, Denmark, France, Germany, Indonesia, Italy, Malaysia, Mexico, Lithuania, Netherlands, Poland, Spain, Sri Lanka, Turkey, U.K., and the U.S.A. Participants included an anaesthetist (n=1), dietitians/nutritionist (n = 6), physicians (n = 19), and surgeons (6); 3 participants did not state their profession. The median number of patients with CIF currently cared for by clinicians was 60 (range: 0 to 550; twelve participants cared for 0–20 patients; five for 21–50 patients; eight for 51–100 patients and nine for >100 patients (one participant did not specify)), while the median number of years of CIF practice amongst respondents was 21 years (range: 1 to 40).

Agreed statements and ratings received are denoted in [Table 1](#).

4. Discussion

This is the first paper to determine and describe internationally-agreed upon quality of care standards in CIF. Notably, all standards proposed by the HAN-CIF SIG of ESPEN were deemed required or essential by participants. Furthermore, the varied country of origin and the wide range of CIF experience amongst the respondents support the results of the modified Delphi as being representative of international opinion. Standards relating to CIF care structure, process and outcomes were generally considered equally important, with a significant proportion of proposed standards within each domain felt to be essential by the vast majority (more than 75%) of respondents. While there was a broad range of opinion, it is noteworthy that those with greater than 75% ‘essential’ responses were supportive of the basic and key elements required to run a CIF service. Thus, within the structural domain, essential standards included the need for clear referral criteria and multi-disciplinary support with cross-cover arrangements, as well as links to an IF surgical service. In addition, a clear structure around the placement and care of CVCs was felt to be essential, with respondents also noting the importance of training and the requirement for in-patient and out-patient monitoring of CRBSI rates as essential quality outcome measures. Furthermore, not only was the essential requirement for regular outpatient review noted, respondents also highlighted the need for 24-h, 7-day access to specialist emergency care.

4.1. Structure

There was strong support for a structured referral pathway and referral criteria, which are essential criteria for any centralised

Table 1

Responses to Quality Standards graded essential, required and not required. Statements with >75% 'essential' responses are highlighted with * for ease of reference.

STATEMENT	RESPONSES (n (%))		
	Essential	Recommended	Not Required
STRUCTURE OF CARE			
There is a service that provides advice and, when referral criteria are met, clinical care of patients with type 3 IF.*	31 (94%)	2 (6%)	0
The referral criteria are patients with benign disease needing or expected to need parenteral nutrition (PN) for more than 3 months and being considered for Home PN (HPN).	24 (73%)	9 (27%)	0
Services should have a referral proforma available to local hospitals and linked to the patient's records to ensure consistency of clinical details and aid transfer of care.	19 (58%)	14 (42%)	0
Chronic IF services should have at least 20 ongoing HPN-dependent adults in order to maintain the multi-disciplinary team's (MDT) skill base. This should include a minimum of 10 new patients per year.	13 (40%)	14 (42%)	6 (18%)
The service provides multidisciplinary support to each patient under the care of the service. Patients receiving home parenteral nutrition (HPN) should be cared for by a multidisciplinary nutrition support team with expertise in Chronic IF and HPN.*	30 (91%)	3 (9%)	0
The service has at least two identified specialists with expertise in artificial nutrition and intestinal failure, at least one of whom is a gastroenterologist with expertise in intestinal failure.	21 (64%)	8 (24%)	4 (12%)
The service has at least two identified specialist nurses or physician assistants with expertise in IF.*	26 (81%)	6 (19%)	0
The services ensures that all nurses handling the patient's central venous catheter are trained to do so according to the local standardised catheter care protocol for the administration of safe PN.*	31 (94%)	2 (6%)	0
Nursing staff should undergo annual re-appraisal of catheter handling techniques.	16 (49%)	17 (52%)	0
The service has at least two identified pharmacists with expertise in IF.	10 (31%)	16 (50%)	6 (19%)
The service has at least two identified dietitians with expertise in IF.	20 (61%)	11 (33%)	2 (6%)
The service has on-site stoma therapists with expertise in IF.	21 (64%)	10 (30%)	2 (6%)
The service has identified input from microbiology or infectious disease services.	18 (55%)	15 (46%)	0
The service has direct links, including multi-disciplinary team patient discussion, with an acute IF surgical service, for managing acute surgical complications as well as the elective restoration of bowel continuity and intestinal lengthening procedures.*	25 (76%)	8 (24%)	0
Each discipline should have cross-cover arrangements in place during periods of leave.*	26 (79%)	7 (21%)	0
The service has at least two identified specialists on-site with expertise in placing central venous access devices, including peripherally inserted centra catheters (PICCs), tunnelled and subcutaneous central venous port catheters.*	27 (82%)	6 (18%)	0
The service has access to interventional vascular radiology for patients with limited vascular access and/or managing complications.*	28 (85%)	5 (15%)	0
The service has access to a production-certified sterile pharmacy unit.	20 (61%)	10 (30%)	3 (9%)
The service can provide or has links to a pharmacy and appropriate healthcare service to offer the prescribed nutritional admixture and ancillaries for safe HPN provision.*	26 (79%)	7 (21%)	0
The service has an identified referral pathway to psychology and psychiatry services, ideally with experience in caring for patients with IF.	14 (42%)	17 (52%)	2 (6%)
The service has an identified referral pathway to social services.	12 (36%)	19 (58%)	2 (6%)
Where appropriate, particularly for larger services, patients should be admitted to a specific ward area to facilitate cohesive multi-disciplinary team care and foster peer support amongst patients.	14 (42%)	17 (52%)	2 (6%)
The service is in a hospital with an intensive care unit.	23 (70%)	9 (27%)	1 (3%)
The service has a patient forum that meets regularly with staff members and address feedback to improve care delivery.	8 (24%)	22 (67%)	3 (9%)
The service conducts a patient survey of care delivery and endeavours to improve care delivery on the basis of the survey, wherever possible.	9 (27%)	24 (73%)	0
The service should follow national (where available) or international guidelines for the management of HPN/CIF-related complications. Where the service may deviate from such guidelines, there should be locally-agreed written protocols for the management of these complications.	21 (64%)	12 (36%)	0
The service should ensure regular education for continued professional development in chronic IF for each multi-disciplinary team member.	23 (70%)	10 (30%)	0
The service conducts regular governance and service review meetings.	21 (64%)	12 (36%)	0
The service has established links, including multi-disciplinary team patient discussion, with an intestinal transplant programme.	12 (36%)	16 (49%)	5 (15%)
The service has established protocols for the administration and monitoring of patients receiving pro-adaptive, entero-hormonal therapy, where these medications are available.	21 (64%)	11 (33%)	1 (3%)
PROCESS			
All patients fulfilling specific referral criteria are referred to a type 3 IF service.*	25 (81%)	5 (16%)	1 (3%)
The service provides a contact pathway for urgent referrals and consultations.*	25 (81%)	6 (19%)	0
The service monitors its elective waiting list and ensures that all accepted referrals are transferred to its site within 2 weeks or managed remotely within 24–48 h of receipt of referral containing all required clinical information from the referrer.	16 (52%)	14 (45%)	1 (3%)
The service monitors all patients placed 'on-hold' on the waiting list in situations where it is deemed by the service's multi-disciplinary team and the referrer that it is not in the patient's best interests to be immediately transferred to the IF centre.	9 (29%)	19 (61%)	3 (10%)
The service provides clinical advice as needed to the referring unit prior to transfer.	21 (68%)	10 (32%)	0
The service provides daily ward rounds and urgent attention at all hours for in-patients, including those readmitted with HPN/CIF-related complications. This can be provided in collaboration with another service, such as gastroenterology.	22 (73%)	7 (23%)	1 (3%)
The service can establish patients on a HPN regime and can train patients or family members/carers to be independent with their procedures, where appropriate.*	27 (87%)	4 (13%)	0
The service conducts re-appraisal of patients' and carers' catheter handling techniques on a routine basis. The service also reappraises catheter handling techniques of patients and carers at the time of any acquired catheter-related blood stream infection.	20 (65%)	10 (32%)	1 (3%)

Table 1 (continued)

STATEMENT	RESPONSES (n (%))		
	Essential	Recommended	Not Required
The service can discharge patients who need long-term parenteral fluid and/or nutrition support to recognised home parenteral nutrition services.	23 (74%)	8 (26%)	0
The service has a pathway for admitting patients with emergency HPN/CIF-related complications.*	29 (94%)	1 (3%)	1 (3%)
Where appropriate, particularly for larger services, patients should be admitted to a dedicated ward area to facilitate cohesive multi-disciplinary team care.	16 (52%)	13 (42%)	2 (7%)
The service should provide clear pathways for patients to receive emergency specialist advice 24-h per day, 7 days per week.*	26 (84%)	5 (16%)	0
The service offers regular face-to-face or virtual clinic reviews for all HPN dependent patients, generally on a three to six-monthly basis for stable patients or more frequently if required for patients with acute needs.*	26 (84%)	5 (16%)	0
All appropriate disciplines are available for all HPN out-patient clinic reviews, including a physician and dietitian and, where required, a nurse and/or pharmacist.*	24 (77%)	6 (19%)	1 (3%)
The service has identified access for psychological outpatient follow-up for HPN-dependent patients, where required.	14 (45%)	15 (48%)	2 (7%)
The service offers a transition programme for HPN dependent adolescents in collaboration with local paediatric centres.	18 (58%)	11 (36%)	2 (7%)
The service has close networks of care with local hospitals where HPN-dependent patients are likely to present with HPN/CIF-related complications. This may include dissemination of appropriate management protocols and development education networks for local nutrition support teams and provision of advice for immediate treatment or arrangement for timely patient transfer to the chronic IF service where required.	13 (43%)	17 (57%)	0
The service has close networks of care with local hospitals where HPN-dependent patients admitted for non-CIF/HPN-related reasons, including provision of advice for the continued safe provision of parenteral support until the patient is discharged.	16 (52%)	15 (48%)	0
OUTCOMES			
The type 3 IF service maintains a prospective electronic audit of all referrals, activity and outcomes.	16 (53%)	10 (33%)	4 (13%)
The service should contribute to a national or international registry.	14 (47%)	15 (50%)	1 (3%)
The service monitors the mortality rate on its waiting list for primary admission.	16 (53%)	12 (40%)	2 (7%)
The service monitors the time to CVAD placement from request.	12 (40%)	17 (57%)	1 (3%)
The service monitors its in-patient catheter-related blood stream infection rates.*	25 (83%)	5 (17%)	0
The service monitors HPN catheter salvage rates.	18 (62%)	11 (38%)	0
The service monitors in-patient mortality rates.*	24 (80%)	6 (20%)	0
The service monitors in-patient length of stay for new admissions and readmissions.	15 (50%)	15 (50%)	0
The service monitors its out-patient catheter-related blood stream infection rates.*	24 (86%)	4 (14%)	0
The service aims to achieve an out-patient catheter-related blood stream infection rate that is less than 1 episode per 1000 catheter days*	23 (77%)	6 (20%)	1 (3%)
The service monitors its out-patient catheter thrombosis rates.	19 (63%)	11 (37%)	0
The service monitors 1- and 5-year survival rates for patients.	22 (73%)	7 (23%)	1 (3%)
The service monitors causes of death, differentiating HPN/IF-related complications (catheter-related blood stream infection, central venous catheter thrombosis, IF-associated liver disease); complications from underlying diseases; and causes unrelated to HPN and IF.*	24 (80%)	6 (20%)	0
The service monitors 30/60-day readmission rates for newly discharged HPN-dependent patients.	15 (50%)	11 (37%)	4 (13%)
The service monitors HPN weaning rates and associated timeframes, detailed according to underlying pathophysiological mechanism and, where appropriate, intestinal anatomy.	16 (53%)	12 (40%)	2 (7%)
The service monitors the quality of life of patients using a validated tool.	8 (27%)	19 (63%)	3 (10%)
The service monitors the entero-hormonal therapy outcomes, including:	20 (67%)	10 (33%)	0
Proportion of SBS-IF patients treated; Response rates, Significant adverse events			

healthcare system, providing clarity for both referrers and specialised centres on the clinical condition and nature of patients deemed appropriate for that service. Similarly, more than 90% of respondents agreed that CIF and HPN administration require multi-disciplinary expert care and most felt that a minimum number of 20 existing and 10 new patients per year was essential or required to maintain the multi-disciplinary team's (MDT) expertise; notably a small minority did not feel exposure to a minimum number of HPN-dependent patients was required. Clearly, as new centres develop, perhaps evolving services should aspire to attract referrals and gradually increase their patient numbers, not least since there is now strong supportive evidence that centres caring for more patients are likely to achieve better outcomes [6]. However, we should emphasise that, while any quality standard is aspirational and aimed at increasing the likelihood of desired health outcomes, it is also important to meet an individual country's or region's needs, which can be influenced by a number of factors such as geographic location, population density and resource allocation.

There was general consensus about the composition of the MDT, with particularly strong support for the role of nurses in CVC care. Similarly, the majority of respondents felt that at least 2 physicians should be recommended, although some comments received highlighted that the standard should not necessarily mandate a gastroenterologist and that other physicians or surgeons may be equally competent. Clearly, there may be a need to adapt any standard according to local resources and expertise availability, but the overriding requirement of any member of the MDT is to be able to work cohesively and to demonstrate that they are able to achieve the requisite quality outcomes for patient-centred care, with associated harm avoidance. The breadth of disciplines required for the MDT was clearly acknowledged by respondents, as was the need for regular education and cross-cover arrangements in periods of absence. There was strong support that pharmacists, dietitians and psychologists/psychiatrists with appropriate expertise should be recommended to be part of the CIF MDT, although some respondents commented that it was not always possible to recruit

all of these disciplines to their service. Again, quality standards are aspirational and aimed at describing the optimal service for patient care, noting that there is a reasonable evidence base for having expert input from multiple disciplines in published CIF and HPN guidelines [4,10].

Outside of the core CIF MDT, the need to have direct links and access to intensive care, microbiological, interventional radiology, surgical (including transplant), pharmacy and social services was clearly recognised. Other operational considerations receiving support included the need for a designated ward area (for larger services), agreed protocols, governance review, and delivering a patient-centred service, with the majority agreeing with the importance of patient forums and feedback to improve care. Indeed, the importance of all health care services having systems to regularly audit, review and improve patient care cannot be understated in any document on quality standards, emphasising that it is only the ability to embed such systems and processes within a CIF service that will ultimately allow the MDT to improve outcomes, minimise harm and offer the patient-centred care that these quality standards aspire towards.

4.2. Process

The standards for CIF process were designed to reflect the patient pathway and received strong support at each step. Thus, the importance of a contact pathway for urgent referrals and close overview of the waiting list prior to a patient's admission to the CIF centre received strong support from respondents. Indeed, minimising transfer time wherever possible and appropriate can improve patient outcomes, as previously demonstrated in quality improvement work undertaken in a national IF reference centre, where a reduction in waiting times had a significant impact on harm reduction [11]. The key requirement for regular and urgent in-patient care provision for HPN-dependent patients was recognised, as was the need for 24-h/7-day access to emergency advice. Clearly, the ability to establish and train patients or family members on HPN administration is a pre-requisite for any CIF centre discharging patients home. Meticulous and appropriate training in CVC handling is vital to minimise CVC infections [4,10], and although the majority would recommend reappraisal of patients' or carers' handling techniques, some commented on the lack of resources to do so. We would reiterate the aspirational nature of these quality standards and perhaps teams should aim towards being able to reappraise of CVC techniques on a routine basis, possibly through the use of novel technologies to reduce the workforce burden of CVC training, such as on-line video material or even virtual reality techniques.

Multi-disciplinary monitoring of patients after discharge received strong support, and this included appropriate access to psychological outpatient clinics. The long-term psychological needs of HPN-dependent patients is well recognised in the literature and associated guidelines [4], and endorsement of the need for psychological input from the multi-national and multi-disciplinary clinicians completing this survey suggests that the key role of a psychologist in CIF care has now gained international acceptance. There is no doubt that HPN can adversely impact the quality of life of HPN-dependent patients, and this includes any readmission to hospital with HPN or CIF-related complications, as well as, of course, worries about such readmission. Establishing networks with a patient's local hospital can help with such readmissions, with a recent paper demonstrating that CRBSI management and CVC salvage is feasible in patients admitted to their local, non-specialised hospital, albeit with a lower salvage rate than that reported in the specialised CIF centre [12]. Hence, as recognised by respondents, the development of close networks of care, and

sharing of CIF protocols, with local hospitals where patients may present with CIF and non-CIF related issues is an important step in optimising the overall care of patients, particularly in regions or countries where CIF services are centralised.

4.3. Outcomes & next steps

The need to monitor outcomes is clearly mandatory for any quality standard to be implemented effectively, such that it is unsurprising that the outcome statements received strong support from respondents. Once measured, the challenge for the CIF team is, of course, to achieve improvements, not only in clinical outcomes such as mortality or CVC-related complications, but also in efficiencies in care delivery, not least because a more efficient service should ultimately lead to improved clinical and patient-centred outcomes. As outlined earlier, quality improvement work in a national IF reference centre reduced waiting times for admission, with an associated reduction in harm [11]. It is important to note that this did not happen in isolation such that, as would be expected, reduced waiting times for first admission to the CIF centre were helped by a reduction in the length of stay of hospitalised patients on the IF ward, thus freeing up beds for new patients to be admitted. If a patient with any illness is discharged from hospital sooner, it is important to ensure that they are not readmitted shortly after going home because the initial discharge may have been too speedy; hence the importance of monitoring the so-called 'balancing measure' of readmission rates to hospital. Inclusion of such balancing measures forms the basis of any quality improvement methodology aiming to improve efficiencies and quality outcomes.

Other than outcomes where there is general agreement (e.g. CRBSI rates [8,10]), specific quantifiable metrics have not been placed against all of the outcome measures in Table 1, not least since CIF centres will likely be at different stages of development and may, therefore, need to set different metrics according to their own contemporary requirements. However, a key next step for any centre is to review their current practice and collect baseline data in order to then to set tangible outcome targets that are specific to their needs, either within an individual centre or as an agreed metric aimed at benchmarking practice across a wider regional or national network of CIF centres.

In summary, it is hoped that these internationally agreed upon quality of standards in CIF care can form the basis for new and established teams to develop and monitor their service, also providing clarity to payers on the infrastructure required for optimal MDT care delivery. The recording of standardised outcomes should allow internal and external benchmarking of care delivery within and between CIF centres, and provide a baseline for the CIF MDT to then implement quality improvement methodology aimed at improving efficiencies, enhancing clinical standards and delivering patient-centred care.

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Authors contribution

Conceptualization – SL, MS, LP; Designing Delphi questions – All authors; Writing - original draft – SL; Writing - review & editing – all authors.

Declaration of competing interest

None declared.

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