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A framework to support quality of care for patients with chronic intestinal failure requiring home parenteral nutrition

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Abstract

Background: Chronic intestinal failure requiring home parenteral nutrition (HPN) is a disabling condition that is best facilitated by a multidisciplinary approach to care. Variation in care has been identified as a key barrier to achieving quality of care for patients on HPN and requires appropriate strategies to help standardize management.

Method: The Australasian Society for Parenteral and Enteral Nutrition (AuSPEN) assembled a multidisciplinary working group of 15 clinicians to develop a quality framework to assist with the standardization of HPN care in Australia. Obstacles to quality care specific to Australia were identified by consensus. Drafts of the framework documents were based on the available literature and refined by two Delphi rounds with the clinician work group, followed by a further two involving HPN consumers. The Oxford Centre for Evidence-Based Medicine Levels of Evidence were used to assess the strength of evidence underpinning each concept within the framework documents.

Results: Quality Indicators, Standards of Care, and Position Statements have been developed to progress the delivery of quality care to HPN patients.

Conclusion: The quality framework proposed by AuSPEN is intended to provide a practical structure for clinical and organizational aspects of HPN service delivery to reduce variation in care and improve quality of care and represents the initial step towards development of a national model of care for HPN patients in Australia. While developed for implementation in Australia, the evidence-based framework also has relevance to the international HPN community.

Keywords

Quality of Health Care; Standard of Care; Parenteral Nutrition, Home; Intestinal Diseases

Introduction

Chronic Intestinal Failure (CIF), also known as Type III intestinal failure, develops following significant small bowel resection or presence of gastrointestinal conditions with mucosal dysfunction or dysmotility that severely limits intestinal function [1]. (Table 1). Patients with CIF are unable to digest or absorb sufficient fluid, electrolytes, and/or nutrients to meet their basic requirements without active medical intervention including parenteral nutrition (PN) [1]. PN may be required as a temporary measure (such as while awaiting surgery to restore gut continuity, or while gut adaptation occurs), or may represent a lifelong, irreversible requirement to maintain fluid, nutritional and metabolic balance, and in children with CIF, to optimal processes of growth and development. PN is commonly administered for patients with CIF in an ambulatory setting as home parenteral nutrition [HPN].

Quality of care is an important concept in health care settings, of which HPN and CIF management is no exception. The World Health Organization (WHO) defines quality of care as “the extent to which health care services provided to individuals and patient populations improve desired health outcomes. It encompasses safety, effectiveness, patient-centeredness, timeliness, efficiency and equity” [2]. The achievement of quality care is closely linked to the avoidance of adverse clinical outcomes and patient harm [3]. In practice, quality of care is advanced through the development and implementation of evidence-based guidelines, in order to reduce variation in care and optimize clinical outcomes. Objective assessment of care against quality indicators allows key stakeholders (including patients, practitioners, auditors and payers) to evaluate care at different locations and allows comparisons between healthcare providers. It enables recognition of variation in care and identifies mechanisms aimed at improving clinical outcomes. Guidelines have been developed locally and internationally for CIF and HPN management [4-6]; however, to date there has been a limited focus placed on the standardization of care for this patient group in Australia.

In recognition of the need to minimize variation in care in HPN provision, the Australasian Society for Parental and Enteral Nutrition (AuSPEN) aimed to develop a structured approach to the delivery of quality of care for HPN in Australia through the development of Quality Indicators, Standards of Care and Position Statements (collectively “quality framework”): This is the first step towards the development of a model of care for HPN management in Australia. It is intended for practical application in clinical practice and use as an advocacy document, whilst identifying the drivers that might facilitate future changes in healthcare infrastructure to support improvements in quality of care through reduction of variation. The concepts underpinning the quality framework documents articulated in this paper, while developed for application to Australia, are also generalizable to the global CIF/HPN community.

Methods

A multidisciplinary working group of 15 clinicians managing HPN in tertiary centers in Australia and New Zealand was assembled by AuSPEN through means of an Expression of Interest to members. The working group members were selected to ensure an adequate representation of disciplines, experience and location of practice to undertake the breadth of the project required (n=5 gastroenterologists [n=2 adult, n=3 pediatric]; n=3 HPN nurses [n=2 adult, n=1 pediatric]; n=7 dietitians [n=6 adult, n=1 pediatric]; n=1 pharmacist [adult] with n=13 working in Australia across 5 States, n=2 New Zealand). Meetings were held via teleconference between December 2017 and June 2019. Further communication by email facilitated progress between meetings. Due to the broad and varying aspects associated with CIF management, the focus of this project was limited to HPN management for the treatment of CIF due to benign disease.

Current sources of variation in care and service gaps were identified through structured discussion and group consensus obtained during teleconferences and through email communication.

A literature search was performed for guidance on existing quality indicators and standards of care relating to CIF and HPN management, as well as other chronic diseases (primarily inflammatory bowel disease) perceived to have transferable concepts of relevance [7-11]. Quality indicators were subsequently drafted from the review of the literature using the Donabedian model [12]. Outcome quality indicators were further refined in consultation with the AuSPEN working group to develop a minimum data set for the AuSPEN HPN registry and ensure integration between these complementary resources.

Standards of care were drafted from the identified evidence-based literature to guide day-to-day practice and reduce variation of care between HPN centres. These are intended to link closely with Quality Indicators, with the intention of translating established international CIF and HPN guidelines for local implementation [4-6].

Position Statements were drafted with the intention of providing strategic direction for future service development to address important aspects of HPN care not widely available or absent in Australia. The proposed position statements highlight barriers to the provision of quality of care in HPN, gaps in HPN service delivery and governance.

Two Delphi rounds refined drafts of the framework documents with the clinician working group. A further two rounds of feedback were conducted with HPN consumers who responded to an invitation circulated by AuSPEN in partnership with the consumer support group Parenteral Nutrition Down Under (PNDU). (Table 2). Over 70% agreement was considered to represent consensus [13].

The Oxford Centre for Evidence-Based Medicine Levels of Evidence was used to assess the strength of evidence underpinning each concept within the framework documents [14].

As this project falls outside of the NHMRC national statement of research, ethics committee review was not sought.

Results

The AuSPEN proposed framework documents for HPN include Quality Indicators to provide a consistent structure for service level audit practices and benchmarking (Table 3); Standards of Care, to be considered as a minimum requirement for quality care provision for HPN (Table 4); and Position Statements, aimed to present practical actions to bridge identified service gaps and progress the delivery of quality of care to this patient group (Table 5). These have been developed with a view to address the identified present sources of variation in HPN care (Table 6).

Discussion

In this paper AuSPEN has outlined a framework to reduce variation in care, and therefore enhance quality of care, for patients with CIF requiring HPN. This is the first step required for moving towards the development and adoption of a nationally implemented model of care for HPN for Australia.

An integrated health care model utilizing a multidisciplinary approach to care has been identified by the WHO as facilitating the optimal management of chronic diseases such as CIF [2]. This paper has highlighted key focuses for structural, process and outcome quality indicators and standards of care to support such an approach for HPN management. It has also brought into focus the need for multidisciplinary, age appropriate, patient-centered care to be provided as close to the patient’s home as feasible (Standard of Care 1). Access to a multidisciplinary team (MDT) for HPN management, including a clinician dedicated to HPN care coordination was identified as a key structural indicator of quality CIF and HPN care (Quality Indicator 1). Patient-centered care coordination that engages carers, HPN suppliers and primary care providers was identified as a key process indicator (Quality Indicators 1, 6-

11, 19-25). The role that consumer organizations play in the empowerment and support of patients and carers has also been emphasized as an important process indicator and may offer different dimensions of peer support than those able to be provided by the health-care system (Quality Indicators 8, 11). It is increasingly recognized that CIF has an impact on patients and their carers beyond its treatment alone [15]. The quality framework developed reinforces the need for patient-reported outcome measures, of which quality of life (QoL) was identified as being an important outcome indicator (Quality Indicator 31).

Carers and family/social supports for both pediatric and adult patients play a key and often under-recognized role in facilitating HPN. Thus, needs of carers and family members providing practical support to HPN patients must be recognized and supported. The impact of providing support to those requiring HPN has been underrepresented in the literature, resource allocation and service planning. Given the pivotal role carers and family supports play in the lives of HPN patients it is essential that frameworks for quality care consider carers' needs to a similar extent as that of the patients themselves. This is especially true in Australia where access to in-home nursing support for HPN is limited, and the patient or carer must be trained to undertake aspects of HPN and CVAD management, as well as any other aspects of CIF management (e.g. stomas, fistulae, wound care, etc.) independently to remain at home. A greater emphasis on partnership with carers and family members has been identified with specific reference to clinical decision-making, access to training, clinical and technical assistance and adequate peer support for carers (Quality Indicators 9-11; Standard of Care 4-7). The impact of and risk posed by carer burden has been acknowledged in the AuSPEN framework and it is recommended that carer burden be monitored through regular assessment including QoL measurement as a quality outcome indicator and managed through provision of HPN appropriate respite options (Quality Indicator 31; Position Statement 5-6).

The management of transition or transfer of care from one center to another has been identified as a source of variation in care (Standard of Care 8). The concept of transition relates to the process by which adolescents are handed over from pediatric to adult services for ongoing care [16]. Transition is recognized as a source of anxiety for many patients and their families as a new, unfamiliar set of clinicians are introduced. It is often associated with different approaches to care (e.g. care distributed between single organ specialties in adult services versus oversight by an individual pediatric gastroenterologist or pediatrician) and greater expectations of the adolescent patient regarding involvement and responsibility for the self-management of their chronic disease. This may exacerbate common challenges associated with other major (physical, emotional, social and financial) life changes associated with moving into adulthood [16]. Although no international guidelines (including age at which transition should occur) yet exist to inform this important process, suggested priorities involve checklists to assist practical aspects of clinical handover, use of a clinical coordinator for the transition process to facilitate communication, management of expectations and support aspects of transition, and psychological support to smooth the transition [16]. Transitions should be planned with introduction of the concept in early adolescence to both child and parent/carer and guided by pathways and agreed communication processes between HPN centers. Key factors in facilitating a smooth pediatric transition are also applicable to other transfers of care for HPN patients when a change to the HPN center managing their care is required.

This quality framework also seeks to address service and organizational structure for supporting quality care with position statements that highlight current gaps or vulnerabilities in the infrastructure for HPN management. The need for a clinical quality register for HPN in Australia is highlighted (Position Statement 2). Quality registries have been shown to be effective for identifying variations in care through comparison against a minimum dataset of quality indicators, detecting clinical processes associated with delivering improved clinical outcomes, and describing clinical characteristics of patients most likely to benefit from specific interventions [17]. Thus, establishment of a national quality registry for HPN care in Australia represents a crucial step required to support, monitor and guide quality improvement in the management of HPN, and to assist the strategic advancement of HPN care into the future.

Second, access to the financial resources required to provide quality HPN care remains an issue of concern for both patients and clinicians (Position Statement 2). Carey et al's consensus document identified the lack of access to allocated funding as a significant barrier to providing quality services in CIF in Australia [18]. Additional funding associated with growth in the number of patients on HPN has not consistently resulted in a proportional investment in the resources of HPN centers to adequately manage their growing service needs. Adequate funding and resourcing of CIF services is fundamental to achieving and maintaining quality of care. This is further complicated when considering HPN governance at a national level given the significant differences that exist between State-based health care systems.

Third, there remain significant inequities for CIF management compared to those available for other chronic conditions that are unlikely to be rectified by the AuSPEN framework documents or the model of care that follows from it. Other issues that warrant attention include the development of a strategic plan to address the needs of an aging HPN population, building clinical capacity in community nursing organizations and residential facilities to manage central venous access devices (CVADs) and HPN, and establishing funding programs to relieve the excessive financial burden that arises from the use HPN ancillaries not provided by HPN centers and/or consumables not covered by other subsidized access schemes required for other aspects of CIF management (incontinence aids, stomal supplies, etc.) (Position Statement 6). These issues are likely to continue to disadvantage a proportion of HPN patients without access to adequate service infrastructure and need to be addressed in order to better meet the needs of all HPN patients.

It is now imperative that the concepts delineated in the AuSPEN quality framework be translated into a national model of care for HPN management in Australia. This is the essential next step to realizing equitable and sustainable quality of care for CIF patients requiring HPN, and further exploration of a model of care that will best deliver quality of care within the Australian context needs to be undertaken. Several examples that have been implemented internationally contain elements that could be incorporated to overcome local challenges (i.e. geographical distance and population dispersion) while meeting key value aspects of the quality framework (i.e. care delivered locally).

New Zealand's National Intestinal Failure Service (NIFS) was established in 2015 and delivers specialist CIF care via a shared care hub and spoke model in which the 'hub' (Auckland City Hospital and Starship Child Health) in Auckland, provide clinical support to 'spoke' facilities (District Health Services) throughout New Zealand. NIFS functions by supporting and developing clinical capacity of clinicians in local facilities managing patients on HPN: It does not provide additional human resources to deliver direct patient contact. NIFS has defined a comprehensive national standard of care for patients with CIF [11] and initiated a national HPN registry to provide accurate data on HPN use.

The Home Intestinal Failure Network (HIFNET) in the United Kingdom utilizes a model of networked centers organized by region. In the HIFNET model, different aspects of CIF and HPN care are delivered by facilities meeting specific criteria commensurate with the complexity of management required. For example, both 'Intestinal Failure HPN Centers' and 'Integrated Intestinal Failure Centers' provide an ongoing clinical service to patients in the community receiving HPN; however, only the latter have the ability to provide complex surgeries and medical management for Type II and Type III intestinal failure, and as such represent the highest degree of specialization for CIF/HPN management. The Integrated Intestinal Failure Centers also provide clinical oversight and professional support to the HPN Centers in their regional network. [19, 20]. Complementary to and informing this service is the British Association for Parenteral and Enteral Nutrition's Intestinal Failure Registry, which commenced in 2016 [21, 22].

The experience gained from the implementation of these models of care may serve to inform the process for determining how an Australian model may function. Key learning points from the implementation of these models, for example, may assist in answering important questions such as:

- How many facilities should provide specialist oversight to HPN provision in Australia, and how should these be organized at a national/State/Territory level?
- How should existing facilities providing HPN be integrated into the model of care? Would a credentialing or assessment process, similar to that used by HIFNET, be required to ensure adequate structural, process and outcome indicators are in place to meet service requirements?
- How would national governance for HPN management be integrated into the function of the model of care?

The implementation of a coordinated model of care for Australia will require a commitment at the level of both Federal and State/Territory health ministries to guarantee an appropriate investment into the health service infrastructure. At a facility level, engagement and support from all stakeholders including health service administrators, existing HPN centers, local hospitals, clinicians, patients and their family supports/carers, consumer and professional associations (PNDU, AuSPEN, Gastroenterology Society of Australia, etc.) will be required to support the adoption of the model at the point of care, and to identify and advocate for areas where service improvement is further required.

While implementing changes to current practice will inevitably bring challenges, the risks associated with delaying or failing to progress a coordinated model of care are considerable. At an individual patient level, a reactive, *ad hoc* approach to care has the potential to result in the development of avoidable HPN related complications (i.e. loss of vascular access sites, catheter related blood stream infections and intestinal failure associated liver disease), which can have a devastating impact on quality of life, morbidity and mortality for HPN patients. Such complications are associated with significant financial costs associated with HPN management at an organizational level. While data specific to CIF/HPN are not available, it has been demonstrated in other chronic diseases that avoidance of reactive, crisis-driven care is associated with a reduction in disease burden and decrease in the use of acute care services and their related costs [23].

Conclusion

Achieving quality care for patients with CIF requiring HPN is essential to optimize clinical outcomes and maximize patient quality of life. The quality framework proposed by AuSPEN is intended to provide a practical structure for clinical and organizational aspects of HPN service delivery to reduce variation in care and improve quality of care. It represents the initial step towards development of a national model of care for HPN patients in Australia and should become a focus for all stakeholders seeking to progress quality of care for this population.

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Table 1 – Examples of Causes of Chronic Intestinal Failure

Adults[1]	Pediatrics[24, 25]
Short bowel syndrome following extensive surgical resection for conditions such as • Mesenteric infarct • Crohn's disease • Intestinal volvulus • Abdominal trauma, etc. Intestinal Fistula Intestinal dysmotility disorders • Chronic intestinal pseudo-obstruction • Hollow viscus myopathy Mechanical obstruction Extensive small bowel mucosal disease such as • Autoimmune enteropathy • Radiation enteritis	Short bowel syndrome following extensive surgical resection for conditions such • Gastroschisis • Intestinal atresia • Intestinal malformation • Volvulus • Necrotizing enterocolitis, etc. Congenital disease of enterocyte development • Microvillous inclusion disease • Tufting enteropathy • Intractable diarrhea of infancy Severe dysmotility disorders • Total or subtotal aganglionosis • Chronic intestinal pseudo-obstruction

Table 2 – Results of Delphi Rounds

	AuSPEN clinician working group (n=15)	*Consumers (n=23)* *(self-selected via consumer group expression of interest)*
Round 1		
Purpose	Refine content and wording of quality indicators; priority and content of standards of care and position statements	Obtain consumer feedback on draft of documents developed from the two Delphi rounds by working group
Commenced	24 October 2018	10 December 2018
Duration	2 weeks	2 weeks
Response rate	87% response rate	82% Response rate Responders: n=13 patients and n=6 carers; n=17 Australia, n=2 NZ
Consensus achieved	> 70% agreement on 73% (37 of 50) of items proposed *New material suggested* • Quality indicators: shared care arrangements; access to respite care; gut adaptation/rehabilitation; CVAD breaks, numbers; hospital admissions unrelated to PN; monitoring specifics including DEXA, endoscopies, liver scans. • Position statement for promotion of research • Position statement for consideration of financial	>70% consensus on 100% of items proposed including • 89% for both including model of care considerations across the lifespan (i.e. aged care planning) and consideration of financial challenges for HPN patients *Additional material suggested* • Routine reassessment CVAD and HPN management for patients/carers • Separation of timely clinical and timely technical

	challenges of HPN patients • Model of care considerations to include accommodation of HPN requirements in aged care facilities	care into 2 separate items as these represent different issues • Appropriately experienced cover arrangements/ succession planning for MDT members
Round 2		
Purpose	Refine and agree on drafts of quality indicators, standards of care and position statements following first Delphi Round	Obtain consumer feedback documents incorporating final revisions by working group, incorporating consumer feedback from first consumer Delphi round.
Commenced	6 November 2018	25 January 2019
Duration	1 week to review	3 weeks to review
Response rate	87% response rate	27% response rate (N=5 of 17 who participated in Round 1 and indicated they would like to be further involved) (additional demographic information not requested)
Consensus	100% agreement on revised wording of quality indicators, standards of care and position statements 69% agreement on priority of standards of care and position statements 85% agreement on inclusion of research position statement <70% agreement on inclusion of other proposed	100% consensus on drafts circulated

	indicators/position statements

CVAD = Central venous access device; DEXA = dual-energy X-ray Absorptiometry; HPN = Home Parenteral Nutrition

Table 3 – AuSPEN Quality indicators for HPN/CIF management

Category	*Indicators*	*Oxford levels of evidence*
Structural Indicators	1. Access to a multidisciplinary nutrition support team for HPN management, including a clinician dedicated to HPN care coordination.	Grade 4/5
	2. Availability of appropriate HPN products and components to meet individual physiological requirements	Grade 5
	3. Availability of clear guidelines, protocols and procedures for evidence based HPN management	Grade 5
	4. Access to timely clinical support	Grade 5
	5. Access to timely technical support	Grade 5
Process Indicators	***Concerning patient***	
	6. Has appropriate CVAD access	Grade 5
	7. Has demonstrated competence and confidence in self-management of CVAD and HPN (where appropriate)	Grade 5

8. Aware of consumer organization for support and contact with fellow HPN patients if desired	Grade 5
Concerning carers and family support	
9. Has demonstrated competence and confidence in management of HPN and CVAD (where appropriate)	Grade 5
10. Support, including HPN appropriate respite where applicable, is available for carers of HPN patients	Grade 5
11. Aware of consumer organization for support and contact with fellow HPN patients if desired	Grade 5
Concerning HPN centers	
12. A multidisciplinary approach to HPN care is adopted	Grade 4
13. Each HPN patient has individualized plans for HPN therapy developed, including • intestinal rehabilitation plan, • symptom management for routine CIF care, • emergency management planning, and • advanced care planning	Grade 5

14. Communication of management plans occur between the HPN centers and patient, carer, family member/support person, patient's local hospital (if appropriate), GP and any other relevant health care providers	Grade 5
15. Nutritional assessment including review of nutritional prescription and intestinal rehabilitation plan at least every 6 months	Grade 5
16. Medication review at least every 6 months	Grade 5
17. Annual monitoring of other clinical parameters (i.e. biochemistry) for stable, established patients	Grade 5
18. Liaise with other specialties as required to optimize HPN care and clinical outcomes (including psychological support, medical/surgical specialties and referral for intestinal transplantation where appropriate)	Grade 5
Concerning supplier of the HPN	
19. Performing correct delivery of HPN and consumables/ancillaries (timely, right place, right amount, right transport conditions)	Grade 5
20. Maintains communication with the patient/carer –regarding their orders, changes to usual delivery plans or product availability	Grade 5

	21. Maintains communication with the HPN center – regarding HPN patient orders under their care, changes to usual delivery plans or product availability	Grade 5
	Concerning general practitioners	
	22. Engagement in shared care management arrangements, where applicable	Grade 5
	23. Engagement in provision of preventive health care	Grade 5
	24. Access to clearly defined guidelines on indicators/alerts for when to refer to hospital or HPN center	Grade 5
	25. Access to patient's individualized management plans, including intestinal rehabilitation plan, symptom management for routine CIF care, emergency management planning, and advanced care planning	Grade 5
Outcome Indicators	26. Incidence of catheter related blood stream infections	Grade 4
	27. Incidence of catheter obstruction	Grade 4
	28. Incidence of central vein thrombosis	Grade 4
	29. Incidence of infection at the insertion site of the catheter	Grade 4

30. Incidence of rehospitalization for HPN/CIF related issues	Grade 4
31. Quality of Life during HPN treatment (patient and carer)	Grade 4
32. Nutrition status - appropriate growth in pediatrics; weight and other relevant anthropometric measures in adults	Grade 4
33. Prevalence of Intestinal Failure Associated Liver Disease (cholestasis; impending liver failure; overt liver failure; liver biopsy/fibroscan)	Grade 4
34. Prevalence of osteoporosis (DEXA)	Grade 4
35. Mortality (Survival)	Grade 4

CIF = Chronic Intestinal Failure; CVAD= Central venous access device; DEXA= dual-energy X-ray Absorptiometry; HPN = Home Parenteral Nutrition

Table 4 – AuSPEN Standards of Care for HPN/CIF management

	Domain	*Standards of Care*	*Oxford levels of evidence*
1	HPN Service - local care	Patients requiring HPN should have PN and CIF management overseen by an experienced HPN center, while receiving care as close to home as possible.	Level 5
2	HPN service - MDT management	HPN centers should adopt a MDT approach and nominate a clinical lead with the skills, authority and resources to realize improvement in care.	Level 4
		The core MDT should at a minimum draw on the skills of medical, nursing, pharmacy and dietetic staff with knowledge and experience in the provision of HPN/CIF management.	Level 4
		Referral and communication pathways should exist to facilitate timely access and transfer of information to other services such as, but not limited to, psychology, psychiatry, stomal therapy, social work and primary care providers (i.e. GPs) as appropriate.	Level 5
3	HPN service – specialist access	HPN centers should have access to supportive and timely specialized services to facilitate the ongoing management and maintain quality of care for patients requiring HPN. These include, but are not limited to, vascular access, interventional radiology, microbiology, relevant medical and surgical specialties (including referral pathways to intestinal transplant services), and other allied health input that may be required.	Level 5

4	HPN service - Clinical Support	HPN centers should develop avenues to ensure timely clinical support is available to HPN patients and their carers.	Level 5
5	HPN service - Technical Support	HPN centers should develop avenues to ensure timely technical support is available to HPN patients and their carers. This includes developing strong links with HPN providers to ensure timely support for help resolve issues that may arise with infusion equipment, access to PN solutions or ancillaries.	Level 5
6	HPN Education and training – patients	Patients and/or carers of patients requiring HPN will receive education and support to enable safe HPN management. This should include the provision of written information, and re-training in HPN protocols at planned intervals and in the event of infective CVAD complications.	Level 5
		Guidelines and protocols for HPN care - including but not limited to CVAD and medication management, HPN training protocols and consumer education materials - should be reviewed and updated periodically to reflect advances in the evidence.	Level 5
7	HPN Consumer engagement / Consumer experience	Emphasis should be placed on aspects of care that increase quality of life for recipients of HPN and their families/carers. These should be informed by the active involvement of patients, their families and carers in decisions that affect their ongoing management. This should occur both at the level of individual health care decision making as well as the planning, implementation and evaluation of CIF and HPN services.	Level 5
8	Transition to	Models of care for pediatric home parenteral nutrition should include access to transition	Level 5

adult services-MOC	support services and planning as they enter adolescence and young adulthood.

CIF=Chronic Intestinal Failure; CVAD=Central Venous Access Device; GP= General Practitioner; HPN=Home Parenteral Nutrition; MDT = Multidisciplinary team; MOC=Model of care

Table 5 – AuSPEN Position Statements for HPN/CIF management

	Domain	*Position Statements*	*Oxford levels of evidence*
1	Funding	Government funding for HPN should be directed to individual HPN departments to ensure they are equitably and adequately resourced to support safe and efficacious HPN and CIF management. Resource distribution for HPN and CIF management should facilitate patients obtaining treatment as locally as possible, therefore resourcing for regional areas as well as metropolitan centers need to be considered.	Level 5
2	Data / Audit / Quality improvement	At a National level, a systematic method for the collection and reporting of Australia specific data on the prevalence and treatment course of those with HPN requirements is essential to inform ongoing quality in care.	Level 5
3	HPN Education and training - clinicians	Clinical staff of all disciplines caring for HPN patients should have access to training programs/packages for the clinical management and monitoring of HPN and CIF patients.	Level 5
		HPN centers should provide clinical leadership in building clinical capacity for HPN/CIF management both within and outside of HPN centers, through support of training and learning opportunities to non-specialist clinicians.	Level 5
4	Reduction in variation	Clinical networks should be fostered between HPN centers and other hospitals (including	Level 5

	of care	regional and remote) who manage HPN patients, with a view to standardize practice and to facilitate the ongoing development of service infrastructure for quality HPN care in Australia.	
5	Carer burden / respite - MOC	Carer and family burden must be assessed and included in models of care for home parenteral nutrition, including access to family focused respite services with appropriately trained carers.	Level 5
6	Closing current service gaps - MOC	Advocacy and lobbying for reduction in identified service gaps and inequities for those requiring HPN is required. This should be undertaken by HPN key stakeholders. Areas of action include, but are not limited to • Access to home nursing services with competency in CVAD management and PN provision • Availability of suitable residential care facilities or other aging in place initiatives to accommodate HPN requirements • Subsidies for excessive out of pocket expenses associated with HPN and/or CIF management	Level 5
7	Research	HPN centers should actively engage in research to identify best practice for enhanced patient care, improved quality of life and decrease long term HPN related complications	Level 5

CIF=Chronic Intestinal Failure; CVAD=Central Venous Access Device; HPN=Home Parenteral Nutrition; MDT = Multidisciplinary team; MOC=Model of care

Table 6 - Identified barriers to achieving quality care in Australia

Variation in care	
Limited high-quality evidence to guide clinical CIF practice locally	• Strong levels of clinical evidence lacking due to low prevalence of CIF • Limitations with available clinical guidelines o are not tailored to the Australia clinical environment, o presently outdated o lack practical guidance for bedside application.
Limited communication	• Treatment plans and/or clinical handover not consistently communicated to all parties involved in HPN patient care • No processes for transition and transfer of care between HPN centers
Limited infrastructure for CIF care	• HPN centers operating in isolation • No established referral pathways for HPN services • Lack of overarching governance for HPN management • Isolated purchasing agreements for HPN solutions/ancillaries
Variation in HPN service resourcing	• Variable MDT representation in HPN teams
Challenges Geography / Location of care	
Impact of geographical distance	• Equity of access to care between metropolitan and regional locations • Poorly articulated shared care arrangements between HPN centers and local hospitals. Resulting challenges include: o Communication of roles and treatment plans, o Ownership of financial costs associated with HPN

Impact of structure of State/Territory based health care systems	• Variation in definition of health care catchment areas and ownership of patient care within and between states • Inequity in access to HPN services between regions and States/Territories
Resources	
Funding	• Unclear method of distribution of IPHA funding – not translated into adequate HPN service resourcing • Lack of awareness around HPN funding • Differences in HPN accessibility in the private vs public sector • Inadequately funded/resourced HPN MDTs
Clinical expertise	• Failure to recognize CIF/HPN indications in less experienced centers • Limited opportunity to develop expertise in CIF/HPN o Absence of specialized professional training o CIF rare and managed primarily in specialized centers • Variation in access to MDTs experienced in HPN provision • No formalized support networks regarding CIF/HPN management
Data	• No national HPN registry in Australia

CIF = Chronic Intestinal failure; IPHA = Independent Hospital Pricing Authority; HPN = Home Parenteral Nutrition; MDT= Multidisciplinary Team