

Research article

## Decision-Making Around the Use of Parenteral Nutrition in Advanced Cancer: Views from a UK Roundtable Discussion

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### Abstract

Offering parenteral nutrition to improve survival and quality of life in patients with advanced cancer and malignant intestinal failure is increasingly common. A lack of good quality data to identify patients who may benefit most from this medical intervention, has resulted in a great extent of variation in practise, both nationally and internationally. A roundtable discussion of experts in the field, aimed to provide insight and guidance for clinicians involved in decision-making around the use of PN and HPN. Thematic analysis of the digitally transcribed discussion was undertaken. The panel recommended that clinical suitability based on factors such as prognosis and performance status, should be balanced with psychosocial needs, and the patient's priorities. There is crucial need for more robust patient information regarding PN/HPN, future research into quality of life on HPN, and the role of early-intervention for patients with impending, irreversible malignant intestinal failure, in order to support informed and shared decision-making. Aside from patient selection, there are significant challenges in the delivery of HPN in the United Kingdom, including resources and staffing. Cohesive working, with education and support from secondary to primary care, is required to ensure safe, good quality care and decision-making at the end of life.

Key words: Cancer, advanced cancer, parenteral nutrition, home parenteral nutrition, decision-making

### Background

Parenteral nutrition (PN) is the provision of nutrients and fluids administered intravenously [1]. The European Society of Parenteral and Enteral Nutrition (ESPEN) recommends that home parenteral nutrition (HPN) be prescribed to prevent earlier death from malnutrition in patients within chronic intestinal failure secondary to advanced cancer (AC), with the aim to improve survival and quality of life (QOL) [2]. The guidance suggests patients who have a life expectancy longer than one to three months should be assessed for HPN, regardless of whether they receive further active oncological treatment [2]. Mortality for patients with malignant intestinal failure (MIF) supported with HPN, is around 50% at three months and 75% at six months [3,4].

In the United Kingdom (UK), the number of referrals for patients with AC doubled from 12% to 27% in the 10 years from

2005, with malignancy accounting for approximately 1 in 4 HPN registrations [5]. Accurately identifying patients likely to survive long enough to benefit from HPN is challenging [6], with limited understanding of the effects of HPN on QOL [7]. Attrition rates following referral for HPN in AC are up to a third [8] and incremental cost-effectiveness ratio of delivering HPN in the palliative setting approximately six times higher than the recommended threshold per quality-adjusted life year [4]. It is unsurprising that supporting patients with MIF using HPN remains a controversial topic with wide variation of practices nationally and internationally.

### Methods

The British Specialist Nutrition Association (BSNA) hosted a roundtable discussion, chaired by two independent healthcare

professionals (ZS and CS). Twelve professionals regularly involved in the initiation and delivery of PN/HPN in AC attended, in November 2021 (Table 1).

### Objectives of the discussion

- Identify and discuss factors influencing decision-making around suitability for HPN
- Understand current challenges in provision of HPN in AC, and explore how to overcome these
- Establish recommendations on the role of PN in AC
- Consider the future landscape of PN in AC

The panel completed a survey relating to their practice around PN/HPN in AC to stimulate discussion. The session was recorded and digitally transcribed. Author and panellist RW, and author JM analysed the discussion thematically. The following themes were identified:

- Factors influencing decision-making around PN
- Education and expectations
- Current challenges in the provision of HPN in AC
- Community care: assessment and monitoring
- Discontinuing HPN at end of life

In addition to the panellists, a unique insight into the personal experiences of life with AC and HPN was presented by a patient's spouse. The pre-recorded session was shown at the roundtable meeting. Excerpts are presented at the beginning of this paper.

### A relative's perspective

Mrs A was 54 years-old when diagnosed with stage 3c clear cell ovarian cancer in January 2020. In August 2020, she was admitted to hospital with MIF and established on HPN, and died at home in December 2020. Her husband, Mr A, tells the panel of his wife's experiences of being diagnosed with MIF and living with HPN. Excerpts from the transcript are presented in table 2 and 3.

## Results / Themes

### Factors influencing decision-making around PN

Sixty percent of the panel indicated using an individualised approach to decision-making around suitability for HPN, compared to 30% using a published framework. Decision-making was considered complex, and the panel recognised individualised care

**Table 1.** Panel members

Charlotte Boddie: Clinical Excellence Manager, Calea Homecare
June Davis: Allied Health Professional Advisor, Macmillan
Alison Green: Consultant Dietitian
Angela Halley: Consultant in Palliative Medicine
Simon Lal: Consultant Gastroenterologist
Charlene Leak: Calea Homecare
Mani Naghibi: Consultant Gastroenterologist
Ruth Newton: Senior Colorectal Pharmacist
Zena Salih*: Consultant Medical Oncologist (gynaecology)
Clare Shaw*: Consultant Dietitian
Rebecca Wight: Advanced Nurse Practitioner (gynaecology)
Hannah Winn: Specialist Oncology Dietitian
*Co-chair

and use of clinical guidelines are not mutually exclusive.

### Prognosis

The panel discussed the complexity of predicting prognosis in patients with AC, due to rapidly changing physiology. Offering HPN to patients who did not know their prognosis can be challenging, and a contraindication according to ESPEN guidance [2]. Patients should be able to weigh up the commitment of hospital stay to set up HPN, in the context of their prognosis. Support from the multi-disciplinary team (MDT) such as palliative care specialists, can help facilitate discussions with both patient and family members in challenging situations where patients may be reluctant to discuss prognosis. Despite all panel members identifying patients as part of the decision-making process, research in this area has demonstrated that while some patients feel involved in decision-making [9], others felt that their oncologist made the decision [10]. In contrast, patient choice to have HPN despite poor prognosis can often override medical advice, due to the ethical controversy of withholding nutrition and fluids or stopping

**Table 2.** The setting up of HPN and expectations

“Unexpectedly and suddenly, she developed symptoms of bowel obstruction. I was unable to attend any of the initial consultations in hospital because of covid-19 restrictions. The NG tube was placed without me fully knowing the circumstances. It would have helped if more robust communication methods were in place virtually, so that I could have supported her through the process”.

“TPN was presented as a necessity, that there was no other alternative, the chances of spontaneous resolution of her condition was very small”.

“It may have been helpful/useful for us to have some kind of video, so we knew what to expect...”

“[she] was in hospital for nearly 4 weeks, before everything was in place for her to return home...there was a little bit of frustration in the delay of everything being set up, but there was an acceptance that we needed to be ready. In hindsight, and I don't know whether this is possible, I wonder if there would have been a way for her to return home and then fine-tune her nutritional requirements, but with the covid situation at the time, it probably was the best it could have been.”

PN that had already been initiated.

### Performance status and QOL

European guidance recommends that in AC patients, PN should be utilised if there is potential to improve performance status (PS) or QOL [11]. Whilst 100% of panellists considered prognosis to be important when assessing suitability for HPN, they recommend considering prognosis alongside PS, as patients with short prognosis (<3 months), may still benefit from HPN with PS>2. Guidance suggests that patients PS≥3 are unlikely to benefit from nutrition support [12]. PS 3 is considered to correlate with poorer QOL on HPN [13]. The panel highlighted that this is not a linear relationship; therefore PS 3 should not be a complete contraindication to HPN.

Robust data on QOL and understanding of how this is defined by individuals with MIF is lacking [13]. PS assessment on admission to hospital may not be reflective of a patient's functional ability due to symptom burden and medical interventions. The panel suggested assessing what PS was prior to the acute episode may be more reliable when assessing suitability, as PS can improve with nutritional optimisation and management of symp-

**Table 3.** The experience

“What would have made our experience better?...Well, if set-up had have been quicker, delivery of equipment, nurses etc. One issue was that there was a lot of waste. We had situations where [she] was readmitted to hospital, where they refused to use any of the supplies we brought in. There was also quite large deliveries [of TPN], even after we had stopped feeding, and I know a lot of that was disposed of.”

“Overall, the experience was good. I was very quickly trained to disconnect [her] every morning. I was also trained to connect her in the evening, but we opted to have the TPN nurses to come in every night...the advantage of the TPN nurse, really this was where we felt there was a huge benefit, was that most of the time it was the same nurse, enabling us to build up a relationship with her. She was very quickly able to assess any changes in [her] condition, any fluid retention or hydration levels...in her final days we were able to agree small adjustments of fluid volume and rate to keep her as comfortable as possible.”

“ [HPN] kept [her] at home, this was a huge positive, especially since there were such drastic covid restrictions in place at the time preventing visiting in hospital, and we desperately wanted to avoid [her] being admitted to a hospice all this made her feel her life still had a purpose...She took short visits from friends and family, and even now, I’m discovering how short texts and messages she sent have had such a positive impact [on family and friends].”

“In [her] final weeks, she was able to prepare myself and our two sons, she was able to live these days with dignity and with purpose, in the comfort of her home, and for that, I’m very grateful”.

toms.

### The emerging role of early intervention

Medical management of MIF, such as bowel rest, nasogastric drainage, high dose steroids, analgesia and anti-emetics, may resolve symptoms of MIF and improve intestinal function. Recurrent episodes of MIF, which may necessitate recurrent hospital admissions, can result in nutritional deterioration, reduced PS, and physiological instability that can complicate establishing PN. Early intervention for symptomatic patients may enable establishment of supplementary HPN over a proportion of the week for those still able to tolerate some enteral nutrition and fluids. With appropriate monitoring and expertise, HPN can be adjusted for patients who become unable to continue eating, without the need for further hospitalisation. Current difficulties with outpatient management were highlighted, such as lack of outpatient dietetic services, and experience of community dietetics to deliver and monitor PN. The need for collaborative working between oncology and dietetic services was identified as crucial for successful development of HPN services [8].

The Complex and Recurrent Gynaecology Oncology service at The Christie, Manchester, is the first dedicated specialist service for management of MIF in gynaecological cancers in the UK. Panel members ZS and RW discussed the aims of this novel unit, which identifies patients developing early symptoms of MIF. Educating patients on symptom management, and facilitating early discussions and initiation of HPN, can optimise medical management and promote shared decision-making before the patient starts experiencing high symptom burden and nutritional deterioration. Internationally, similar models of care have been shown to reduce hospital admissions and improve patient experience and outcomes [14].

### Oncological treatment – gynaecology perspective

The panel discussed continuation of systemic anti-cancer therapy (SACT) in MIF. Many patients will develop recurrence, with the disease-free interval becoming progressively shorter, and often culminates in MIF. Surgery for MIF is rarely indicated due to diffuse intraperitoneal disease and high peri-operative risk [15]. Patients may resist commencing PN if they hold hope that symptoms caused by MIF will resolve with further SACT, thus delaying initiation of the HPN process. Chemotherapy is rarely successful in reversing established MIF in patients with platinum-resistant disease [16,17]. Risk of toxicity-associated

complications whilst establishing HPN may prolong admission if chemotherapy is given concurrently. Continuing active treatment with chemotherapy in this setting, can make discussions around prognosis, initiation of PN and advanced care planning more difficult.

In contrast, patients presenting with MIF at diagnosis of AC are considered to be candidates for PN/HPN irrespective of PS, if systemically well prior to diagnosis, facilitating nutritional optimisation during the delivery of first-line chemotherapy.

### Education and expectations

#### Clinicians

The panel discussed varying knowledge amongst healthcare professionals regarding indications for PN/HPN in AC. Patients may be introduced to the concept of HPN without the clinician considering suitability, or fully understanding the logistics of delivering HPN. It can be unclear who should co-ordinate decision-making across teams, particularly in hospitals with no established nutrition support team. HPN for patients with poor oral intake and no known gastrointestinal pathology, is currently not standard practice in the UK. Across Europe, HPN prescription for AC patients with cachexia or anorexia is far more common [18]. Further evidence is required to support PN use among early cachectic non-IF patients, before considering changing practice in the UK.

Development of education programmes and dedicated support groups to facilitate safe practice involving the MDT and patients was discussed. It was agreed that education should include a standard set of principles nationally for clinicians’ reference when considering HPN referral, with the aim of improving the decision-making process and reducing inequality across tumour types.

#### Patients and relatives

The importance of managing both patient and relative expectations was highlighted during the discussion. Whilst patients with MIF would ‘wish’ to have nutrition, which is fundamental to preserving life, HPN was seen as ‘medicine’ without sufficient understanding of the clinical and logistical complexities of establishing and delivering HPN. There is a lack of information on HPN for patients with AC and their families. The panel acknowledged that decisions are often made without including family members, however guidance states patients should be

asked if they wish to involve family in decisions around their care and should be provided with information [19]. Developing podcasts with patient stories to provide insight into practicalities and adaptation to life on HPN was suggested. However, patients are usually faced with the decision on whether to commence HPN following emergency admission to hospital whilst acutely symptomatic of MIF. Symptom burden and psychological distress during this time may inhibit a patient's ability to process and retain information. Therefore, focussing on early education of those at risk of developing MIF may support patients to consider their future management.

### Current challenges in the provision of HPN in AC

#### Accessibility to HPN – the postcode lottery

Patients often require referral to a dedicated IF centre with transfer or remote discharge to establish HPN. The panel discussed current UK development of nutrition support teams and procurement of IF centres with remote discharge pathways which will improve the accessibility of HPN. Each region will have one or two IF centres linked to HPN centres with remote discharge pathways to ensure greater accessibility to HPN services. Dissemination of information with memorandum of understanding of the referral process will be crucial to their success.

#### Length of hospital stay; the covid 19 pandemic

Eighty percent of panellists identified reducing length of stay (LOS) as the biggest challenge we face in the provision of HPN, and the most significant improvement we can make to patient experience. LOS is determined by length of time to referral, time to metabolic stability to facilitate safe and appropriate HPN prescription, and sourcing private home care nursing to administer HPN. The covid 19 pandemic significantly affected LOS for HPN, due to prolonged wait time for compounding of PN and shortages in community nurses able to administer PN. The panel recognised the psychological burden placed on patients and families deciding whether to continue with PN or discharge without.

Consideration should be given to adapting practices to counter delays, such as reducing the number of nights on HPN for patients who can tolerate sufficient oral fluids without GI losses.

Practice changes have included a move from the use of compounded PN\*(UK gold-standard), to pre-mixed, multi-chamber bags\*\* (MCBs). Prescribing MCBs can be challenging in the palliative setting due to specific electrolyte requirements. There is anecdotal evidence that patients feel less well on MCBs, likely due to electrolyte content not matching their requirements. Long-term data suggests micronutrient deficiency with MCB, which is less of a concern in the palliative setting. Patients who survive longer and can have some oral intake, a soluble multivitamin is suitable to prevent deficiency. The risks of long-term MCB use are unknown. Despite multiple connections (PN, supplementary fluids and multivitamins) with multiple circuit-breakers, there is currently no evidence to suggest an increase in catheter-related bloodstream infections with use of MCBs rather than compounded PN [20].

Internationally, services have published much shorter LOS, with in-hospital training of patients and relatives to self-administer PN, reducing the need for community nursing care [21]. Whilst self-training to administer PN in-hospital may reduce

LOS, the panel recognise the value of specialist homecare nurses. The literature supports the positive experiences of patients and carers due to the support they provide [8]. Nursing expertise enables assessment of patient's clinical condition, findings actioned promptly, prescription changes requested where necessary, thus reducing need for hospital re-admission. The panel acknowledged that whilst reducing nursing visits can help with the feeling of 'intrusiveness', having a family member manage nutrition can potentially impact negatively, changing the dynamic of relationship. The change in dynamic and roles within the family is well documented [9,22-24]. However, funding and recruitment of homecare nurses is an increasing challenge, with growing reliance on patients and family members to relieve pressures by managing HPN. The panel questioned the need for senior nurses to administer PN, particularly in the context of non-healthcare professionals such as patients and family being able to train and administer HPN. There may be a role for nursing associates, to be trained to support the HPN service, regulated by the NMC, ensuring robust training and competency that will not compromise quality and safety. The prospect of a fast-track discharge pathway for AC patients was discussed, however it was recognised this will impact on benign IF discharges and patient flow. It was agreed this concept should be carefully considered in the future.

### Community care

#### Assessment and monitoring

Upon discharge from hospital, it may be unclear who is responsible for monitoring and assessing patients for adverse effects related to PN. Standard follow-up in IF clinic is six weeks post discharge, however AC patients may be physiologically unstable due to disease burden and side-effects such as dehydration or fluid overload. There is benefit therefore in community professionals, often palliative care teams, assessing symptoms that may be exacerbated by HPN. This is particularly true where patients are self-administering HPN, or the patient is not undergoing active oncological treatment, therefore not under regular follow-up. As ongoing management of HPN requires multidisciplinary input, there is a crucial need to integrate hospital and community teams.

#### Stopping HPN at the end of life

In a situation where HPN has been offered to an AC patient and subsequently during admission clinical condition deteriorates thus resulting in the need to withdraw PN, this can be difficult. Guidance suggests that discussion regarding stopping HPN at end of life should be had during the establishment phase [6]. A recent international survey of healthcare professionals identified that the majority discussed stopping HPN with patients prior to commencing HPN; furthermore, the UK are more proactive in discussing stopping HPN than other countries [4]. However, the panel reported the difficulty in determining when it is appropriate to facilitate discussions around stopping HPN with AC patients, and the importance of sensitivity. During initial phase of establishing HPN patients may be overwhelmed by symptom burden and adaptation to life with MIF, to fully engage with discussions regarding withdrawing HPN. Co-ordinated communication between all teams including referring centres, IF centres, community teams and hospice is paramount. The panel

recognise the benefits of HPN must outweigh the burdens, acknowledging indications for reducing or stopping HPN such as fluid overload, which is one of the most common triggers for discussions regarding discontinuing HPN in AC [25]. Weaning PN towards the end of life to manage symptom burden was discussed, however with acknowledgement that this requires dedicated support from community teams and the IF centre, with availability for community blood monitoring. However, in many cases, this is not feasible. HPN cannot always be facilitated in all settings which may force discussions around stopping HPN, for example if a patient requires transfer to hospice where HPN cannot be supported.

## Discussion

### The future landscape of HPN in advanced cancer

This paper identifies the multifaceted complexities of the initiation and delivery of HPN to patients with AC. The unique insight into a spouse's experience of HPN highlights that there is consensus between both professionals and those experiencing HPN, as to the aspects of a patient's journey that are invaluable, and those that require improvement. The following suggestions are made by the panel, to guide healthcare professionals supporting patients with AC and MIF. As a result of this roundtable discussion, a steering committee will be established to inform research and develop future guidance and support nationally.

- When assessing patient suitability for HPN in AC, prognosis and PS should be considered in conjunction with consideration of effects on both QOL and survival, rather than survival alone.

- Clinical guidelines are useful to support clinicians' decision-making, however, a focus on individualised care is advocated, aligned with patient's values. Considerations include patients' wishes, family wishes, home circumstances and treatment plan

- Development of education programmes, protocols and guidance from current experts in the field of HPN in AC to support clinicians and patients considering HPN. This will enable clinicians to manage expectations of both patients and relatives, promoting shared decision-making, and may optimise healthcare utilisation.

- Patients with a new diagnosis of AC and MIF, which is not amenable to surgery, should be considered for PN/HPN if receiving SACT.

- Early intervention with HPN for patients with progressive symptoms of MIF should be considered to preserve nutritional and functional status.

- To counter limitations in national aseptic capacity, limitations in home care nursing capacity and current effects of the pandemic on delivery of HPN, clinicians should consider adaptations to PN, such as flexibility in prescribing, use of MCBs and self-administration of HPN.

- Service development opportunities to reduce hospital LOS for AC patients awaiting HPN are welcomed. The UK gold-standard of care must be maintained, without compromise of safety or experience.

- Patients receive significant input from primary care teams following discharge from hospital with HPN. Support and edu-

cation is crucial, to ensure safe and effective care.

- Conversations around reducing or withdrawal of PN at the end of life should take place when establishing HPN, or if not appropriate, should take place at the earliest opportunity by the oncology or palliative care team.

- There is a crucial need to understand how HPN can affect QOL in AC. High-quality, prospective data is required to explore this concept which will support shared decision-making.

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## Author's Contributions

CS and ZS chaired the discussion and organised digital transcription. RW and JM performed thematic analysis and coding of discussion transcript. CS and ZS reviewed the themes from coded transcripts and manuscript. RW and JM wrote the manuscript. CS and ZS provided final review and edits of manuscript.

## Ethics Approval and Consent to Participate

Ethics approval not required. All members of the panel, and contributing relative provided written consent for their view to be recorded and published. The final manuscript was forwarded to all members of the panel for review and comments prior to submission for publication.

## Data Availability

The digital transcription of the panel discussion is held by the BSNA.

## Competing Interests

The authors declare no conflict of interest.

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