

Recommendations for improving the quality of services provided to HPN patients: a consensus statement from PN-DU*

Introduction:

*Parenteral Nutrition - Down Under (PN-DU) is a support group for adults and parents/carers of children on Home Parenteral Nutrition (HPN) in Australia and New Zealand.

In June 2012, PN-DU conducted an on-line survey of its members' opinions on the levels of compliance, by Australasian HPN centres, with the Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) Clinical Practice Guidelines for HPN Patients in Australia and New Zealand (Nutrition 2008) (the guidelines).

This consensus statement is based on the data collated from our pilot survey. The survey results have been provided to major stakeholders, such as AuSPEN and commercial providers of HPN products, and have been accepted for presentation at multidisciplinary scientific conferences of health professionals, at the 3rd National Nutrition and Hydration Summit in Australia, November 2012 and at Clinical Nutrition Week in USA, February 2013.

Description:

The survey was devised and conducted by patients for patients and included questions with 'Yes/No/Don't Know' answers, relating to the 10 aspects of HPN addressed by the guidelines.

The aim was to ascertain consumer perspectives of their standard of homecare, to complement any future survey of clinicians involved in HPN management by AuSPEN, before the next revision of the guidelines. Participation was voluntary, anonymous and confidential.

Results:

A total of 15 consumers/carers started the survey with 13 completing all questions. Just over half (53%) were adults dependent on HPN, with the remainder being parents/carers of a child on HPN; all referred to as "patients".

10 patients have been HPN dependent for at least 5-10 years, 4 of these for >10 years. 71% reported their care involved a nutrition support team (NST) but only 1 team included a pharmacist.

All patients reported being closely involved in the decision to go home on HPN, however, 21% of patients felt they did not have the risks and benefits of HPN explained to them, and 1 (7%) felt they did not have all treatment options explained nor the opportunity to ask questions. 29% reported that their HPN centre did not confirm any aspect of their home set-up prior to discharge.

Practical training was given to all, but less than half reported receiving advice on high risk events (line blockage 36%, febrile episodes 43%). Notably only (43%) received written information to assist in expedited hospital triage.

All HPN pumps were reported easy to operate and clean, but less than half of the respondents (46%) had been required to demonstrate competence, before discharge.

Of concern is that only 23% have contact details for a 24/7 pump troubleshooting service and none reported being able to access an after-hours service.

Discussion:

Our pilot survey suggests overall most HPN centres comply with the guidelines, doing best at selecting/placing a central venous access device (CVAD) and training patients before going home.

However, there is a need for more concerted efforts in relation to:

- training in the management of emergency situations and life-threatening complications associated with HPN and/or a CVAD, with provision of emergency repair kits
- confirming patients have suitable home environments before discharge
- providing written information, to facilitate rapid triage and treatment in the event of emergency hospitalisation
- assuring patients that a multidisciplinary NST is coordinating their care
- providing information on after-hours technical support for pumps
- more involvement of pharmacists to advise about HPN and drug interactions.

Conclusions:

Options for improving HPN practices might include:

- development of checklists to empower patients to advocate for the best possible care
 - what patients should expect before discharge
 - what sort of monitoring should occur and with what frequency
- parallel checklists for clinicians within HPN centres may be useful.

Although not statistically valid in terms of the total Australasian HPN patient group, these data nonetheless serve as a useful pilot snapshot.

Our results highlight areas where a wider survey could provide more valuable comprehensive insights into HPN practices and care management that may need improvement.

PN-DU would appreciate and value feedback on our survey results and our recommendations for service improvement, from relevant health professionals and other stakeholders, involved with HPN.



Parenteral Nutrition - Down Under™

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