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Retraining of Home Parenteral Nutrition (HPN) users in Australasia – a pilot observational survey

ABSTRACT

Introduction

Published guidelines recommend patients and carers are trained and meet competency in certain criteria of connecting and disconnecting procedures before going home with HPN. Despite many HPN users requiring HPN indefinitely, PNDU was not aware of retraining of HPN users unless the user had recurring central line-associated blood-stream infection (CLABSI).

Objectives

To survey PNDU members on their experiences of formal retraining in HPN procedures, and how members perform one aspect of these procedures: withdraw back (into syringe), for comparison with latest expert opinion.

Methods

An anonymous on-line questionnaire was circulated to all Australasian HPN members in November 2018.

Results

There were 40 responders representing 30 adult and 10 child HPN users. Thirty-two (80.0%) responders had been on HPN for 2 or more years, receiving initial training before discharge. Just over half (57.9%) had received retraining with most (81.0%) retraining prompted by a specific event, commonly related to a suspected or confirmed CLABSI or change of medical equipment/item used to perform the procedure. Overall, 34 (85.0%) responders withdrew back into the syringe before connecting to PN, 25 (73.5%) discarded the aspirate, and 9 pushed the fluid back into the central line.

Conclusions

Few HPN users receive regular retraining as part of HPN management. Considering possible benefits in complication prevention, consequentially maintaining quality of life and reducing healthcare costs, we recommend discussion and further research into regular retraining. Additionally, more research is needed to determine best practice for withdrawal of blood, and, if required, how much drawback is sufficient and safe.

INTRODUCTION

Home parenteral nutrition (HPN) is required when there is ongoing insufficient nutrient intake through the digestive system – intestinal failure (IF). IF can be caused by a wide range of digestive diseases and congenital problems, as well as surgical misadventures. Although a life-saving therapy that can be conducted at home, HPN is highly complex, requiring central venous access and care, and bringing with it serious risks and possible complications, including central line-associated blood-stream infections (CLABSI), thrombosis, PN-associated liver disease, and loss of central venous access. Prevention and avoidance of complications reduces hospitalisations and with it, additional costs, and impact on the health and quality of life of the HPN user and his/her carer(s) and loved ones.

In 2008 the Australian Society for Parenteral and Enteral Nutrition (AuSPEN) published a guideline for the clinical practice for HPN patients in Australia and New Zealand (1). In that guideline it could not make a recommendation based on published evidence on how patients should be trained for HPN. However, by consensus, it recommended patients should be trained to meet competency in certain criteria such as the principles of asepsis. There is no mention of retraining or ongoing education in that guideline despite some users of HPN requiring this therapy indefinitely. And by extension, there is also no mention of updating HPN users in new evidence-based protocols.

Our organisation, Parenteral Nutrition Down Under (PNDU), suspected that little or no retraining or updating of HPN users takes place except if there is recurring central line-associated blood-stream infection (CLABSI). This is in contrast to the hospital environment where clinicians accredited to care for central venous access devices (CVADs), and with inherently more medical training and experience as compared to an average HPN user, are provided in-service training whenever a change in policy and/or evidence-based practice occurs, and possibly also semi-regular reaccreditation in CVAD care.

OBJECTIVES

Therefore, the aim of this survey was to identify and understand the individual experiences of formal retraining in connecting and disconnecting to parenteral nutrition in the home environment. A general search of the internet and Google Scholar did not locate any similar articles or studies. However, two studies of HPN users conducted in the United States of America (2)(3), while not primarily focused on retraining of HPN users, do make secondary conclusions in relation to the matter and are referred to in the Discussion.

The survey further sought to collect data on one aspect of the parenteral nutrition (PN) connection process, drawing back into the syringe from the CVAD before connecting to PN. We wished to see if this step was performed in accordance with the current expert opinion of the Alliance for Vascular Access Teaching and Research (AVATAR) (personal communication 2018), and whether there was any correlation between years of HPN use, retraining or lack thereof, and the use (or not) of latest recommended protocols for this one aspect of the PN connection process.

METHOD

All Australasian members of PNDU who were currently on HPN (or their carers) were invited by direct email to participate in the survey which took place over two weeks in November 2018. The survey involved completing an anonymous online questionnaire compiled by PNDU's Management Committee using the program SurveyMonkey. The survey consisted of 19 questions, and took approximately 5 to 10 minutes to complete. Ethics approval was not sought. No identifiable details were collected, and consent was implied by completion of the survey. See Appendix A for the survey questions.

Retraining was defined as:

at some point in time after initial formal training the responder was:

- given ***additional detailed oral instructions*** on all or a particular technique in connecting/disconnecting to PN; and/or
- given ***additional written instructions*** on all or a particular technique in connecting/disconnecting to PN; and/or
- given an ***additional demonstration*** on all or a particular technique in connecting/disconnecting to PN; and/or
- ***required to again demonstrate*** competence in performing all or a particular technique in connecting/disconnecting to PN.

Connecting techniques referred to preparation of the CVAD for connection to the bag of PN.

Disconnecting techniques referred to the procedure done after stopping the infusion pump to just before administering the CVAD lock (if a lock was used).

Responders were instructed not to include procedures relating to preparing a PN bag or using an infusion pump.

For analysis purposes, those HPN users younger than 18 years were classified as children.

RESULTS

Responders

There were 40 responders, representing 30 (75.0%) adult and 10 (25.0%) child HPN users.

Length of time on HPN ranged up to more than 20 years with 8 (20.0%) responders (7 adults, 1 child) being on HPN for less than 2 years.

Initial training

The earliest initial training for HPN for any of the survey participants took place in 1992 (1 adult) and the most recent initial training in 2018 (1 adult). Overall, 26 (65.0%) of the 40 responders had initial training prior to 2016 and 14 (35.0%) prior to 2011.

Thirty (75.0%) responders (24 adults, 6 child HPN users) were given written instructions during their initial training. Of the 10 who did not receive written material, 7 had initial training prior to 2016 (Fig. 1).

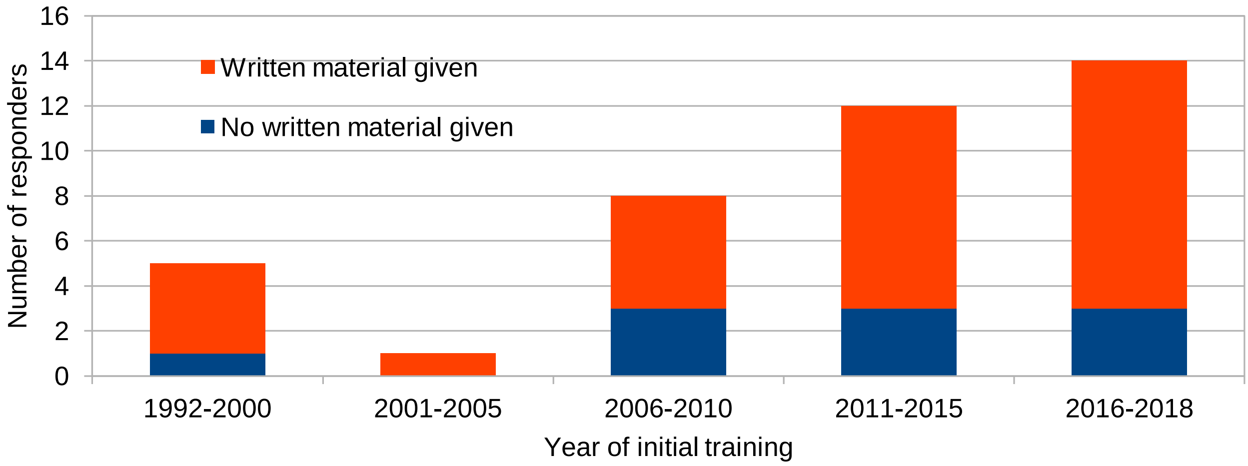

Fig 1. Year of initial training versus whether written material was given during that training.

Retraining

It was unclear whether 2 responders had been retrained in HPN procedures since hospital discharge. Of the remaining 38 responders, 16 (42.1%), including 12 adults and 4 children, did not receive any retraining. Further, of these 16 responders, 9 (56.3%) had received their initial training during 2015 or earlier including 6 receiving initial training prior to 2011 (Fig. 2).

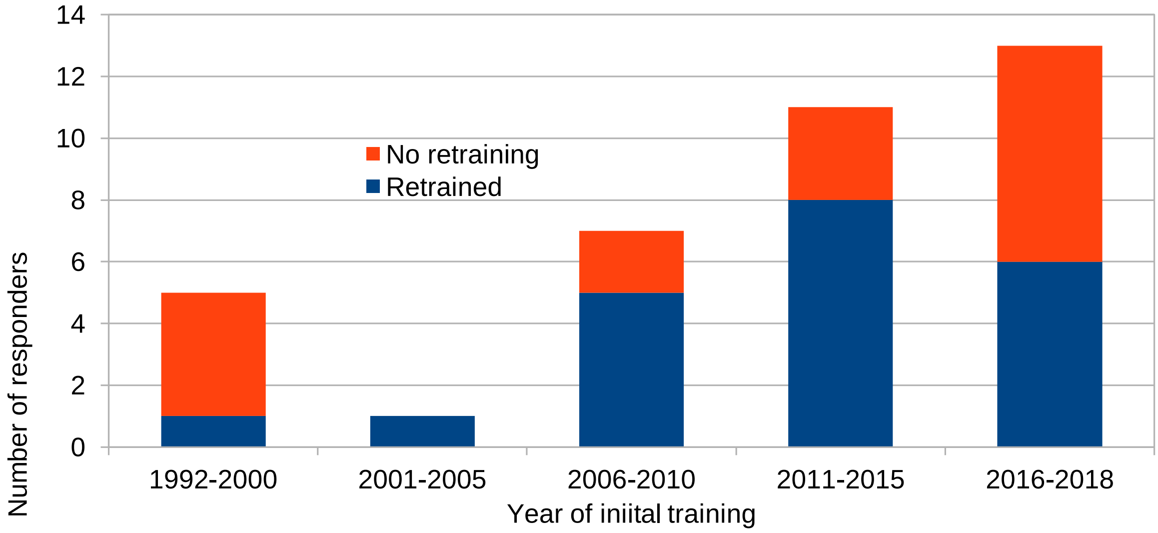

Fig. 2. Year of initial training versus retraining.

Of those 22 responders who reported receiving retraining, 16 (72.7%) had received retraining once or twice, 2 (9.1%) regularly every year, 3 (13.6%) regularly every 2 years and 1 responder could not remember how many times retraining had occurred. For those 16 reporting further training only once or twice, 2 were retrained the same year as their initial training. For the others, retraining occurred 1 to 13 years post initial training.

Of the 21 responders who could remember the type of their retraining, 8 (38.1%) reported being given retraining in more than one format. Overall, 11 (52.4%) reported being given additional detailed oral instructions, 6 (28.6%) additional written instructions, 9 (42.9%) an additional demonstration, and 9 (42.9%) required to again demonstrate competence in performing a particular technique.

Eleven of the 21 responders (52.4%) reported that their retraining involved being taught new or updated procedures in connecting/disconnecting and CVAD care, rather than a repeat of the initial training content. The new or updated procedures related to: cleaning of the line hub, flushing the line, using an antibacterial locking agent, and changing the CVAD used.

Specific events prompted retraining for 17 (81.0%) of the 21 responders. This occurred to three responders on more than one occasion. The most common events were a suspected or confirmed CLABSI (7, 41.2%) or a change in use of medical equipment or item, apart from the PN and infusion pump, used to perform the connecting procedure (ancillary item) for example locking agent, pre-filled syringes, gloves, giving set, etc (8, 44.4%) (Table 1).

Table 1. Specific event prompting retraining.

Specific event	**No. of responders (n=17)**
Suspected or confirmed CLABSI or repeated infections	4
Suspected or confirmed CLABSI and change of ancillary item	2
Suspected or confirmed CLABSI and restarting HPN after time off	1
Change of ancillary item	5
Change of ancillary item and transfer to different managing hospital	1
Restarting HPN after time off	3
Change of type of CVAD	1

Withdrawing back into the syringe before connecting to PN

Overall, 34 (85.0%) of the 40 responders reported withdrawing back into the syringe before connecting to PN. This included 24 of the 30 adults and all 10 child HPN users. Ten (8 adults and 2 children) of the 34 withdrew only until the first sight of blood in the CVAD/connector with 9 of these pushing back the fluid. Responders were not asked what sort of CVAD they used and it is noted that unlike implantable ports and PICCs, Hickman® and Broviac® catheters are opaque. This results in not seeing blood on draw-back until the blood enters either the catheter connector or the syringe.

Twenty- four (70.6%) responders withdrew the line lock or a quantity of blood. These 24 all discarded the fluid withdrawn (Fig. 3).

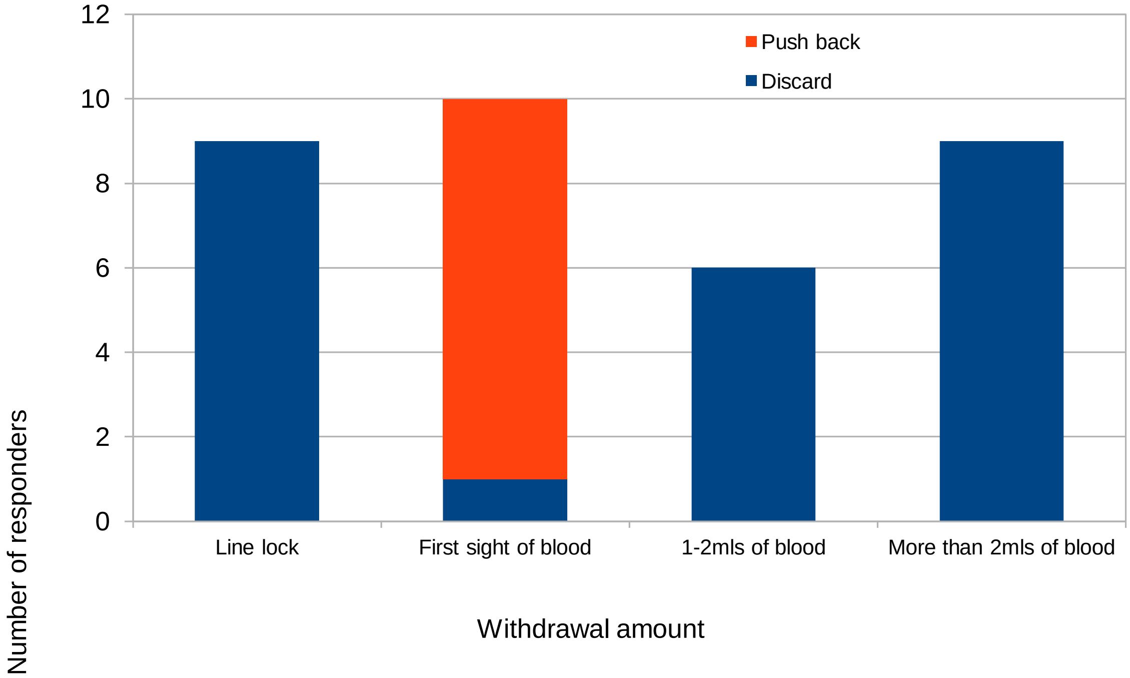

Fig. 3. Withdrawal versus push back or discard.

Thirty (76.9%) of 39 responders currently used the same drawback procedure (or no drawback) as taught before first going home from hospital on PN. This included 4 who did not drawback and 26 who did. The reasons for the 9 responders changing the drawback procedure included: 3 being retrained by the medical team; 2 being told by their medical team to change but not receiving detailed retraining; 2 changing the technique without the medical team knowing (reason not stated); 1 due to having to remove blood clots; and 1 commencing using a line lock.

Of the 9 (8 adults, 1 child) responders who withdrew more than 2 mL, 5 (4 adults, 1 child) had received their initial training prior to 2014. Further, of the 9 responders, 5 had received some form of retraining and 7 used the same drawback procedure as taught when first going home on PN.

DISCUSSION

HPN is a life-saving, yet complex, therapy which some users require for many years, and others even for the rest of their lives. Therefore it is vital that patients are trained in competent management of HPN, including the connecting and disconnecting procedures and care of the CVAD, in order to prevent complications.

Surprisingly, about a quarter of survey participants were not given written instructions on connection/disconnection procedures before hospital discharge. Connecting and disconnecting to PN involves a number of steps such as: how to handle the CVAD in an aseptic manner; method of cleaning the catheter valve; method of flushing; and whether to draw back into the syringe before connecting. A set of written step-by-step instructions might be expected to aid retention of procedures and be helpful as a reference for the HPN user or carer, especially in the early weeks after discharge from hospital. Recent guidelines of the European Society for Clinical Nutrition and Metabolism (ESPEN) (4) while recommending training of the patient for HPN be patient-centred and include written guidelines concluded that the evidence for this was very low. This is expected as the rarity of IF necessitating HPN results in difficulty in obtaining good quality evidence, including from randomised controlled trials, for many of the recommendations.

As many patients remain on HPN long-term, it is also reasonable to expect that some further training or repeat demonstration of competency by the HPN user would reinforce good practice, and that the HPN user would benefit from being updated in the latest evidence-based procedures as part of that retraining. However, retraining is not addressed in the AuSPEN (1) guidelines. In our study, 42% of participants did not receive retraining, although just over half of these had received their initial training three or more years earlier. Further, most of those who were retrained reported that the retraining was prompted by a specific event, commonly a suspected or confirmed CLABSI or a change in an ancillary item. These are reasonable causes for re-education and fit with the guidelines of ESPEN (4), which recommend re-education of the HPN patient if repeated CLABSI occur. The evidence for this was also considered low, however, again, this is expected due to the rarity of IF necessitating HPN.

By extension, the secondary findings of two American studies of HPN users (2)(3) challenge this omission of HPN user retraining from HPN guidelines. Konrad, Roberts, Corrigan et al (3), looking at the education and treatment of dehydration in users of home parenteral support (HPS) (encompassing both parenteral nutrition and intravenous fluids) conclude “these patients [that is patients with >1-year therapy] still had documented episodes of dehydration, and the patient with the most episodes was receiving HPS for 10 years. This demonstrates the ongoing need for patient education no matter how long a patient has been receiving a specific therapy.”

Smith CE, Curtas S, Kleinbeck SVM et al (2) undertook a study of long-term HPN users to evaluate Interactive Educational Videotaped Interventions (IEVI) designed, amongst other purposes, to prevent CLABSI. The results demonstrated “that IEVIs, when added to experienced patients’ standard care education and prescribed medical regimen, were associated with reduced CRBSIs, reactive depression, and rehospitalization because of infection.” While this study evaluated a specific mode of patient education – IEVI, the findings “were notable because these were long-term users of HPN, and a majority of the patients had histories of CRBSIs and reactive depression”.

Few of PNDU’s survey participants received retraining as part of regular management of HPN. While we would encourage and welcome further investigation into the benefit of regular retraining, including demonstrating continued competence in CVAD use and care, what form retraining should take, the frequency of retraining, the cost, and who would conduct this retraining, these two American studies readily indicate value and benefit in retraining HPN users, including retraining in the prevention of adverse events, in particular, CLABSI.

An opportunity to address the lack of retraining of HPN users is now being taken by AuSPEN by way of the inclusion of regular retraining as an element in the HPN care framework currently under development (personal communication, December 2018).

Regarding the specific aspect of the connecting to PN procedure this survey looked at, most of the survey participants withdrew back into a syringe before connecting to PN. Nineteen of these withdrew back in accordance with the recommendation of AVATAR (personal communication, 2018), that is, to draw back only until the first sight of blood in order to check catheter patency and/or removal of a line lock. It should be noted however that this recommendation is based on expert opinion rather than evidence which is lacking. Of note, a further nine responders withdrew more than 2 mL of blood and seven of these had not changed their withdrawing procedure since hospital discharge. It would be interesting to know why these responders were instructed to withdraw this volume, whether it was due to a valid clinical reason, since it is likely that the volume of line and connector combined is significantly less than 2 mL. It would also be interesting to know if this volume of blood withdrawal occurred daily and if it impacted negatively on the iron levels of the HPN users, especially the sole child responder. In light of the long term and possibly indefinite nature of HPN for HPN users, more research and resulting evidence-based protocols on this small but necessary part of the connecting up procedure would be welcome.

Limitations

Our study sample was small so the results cannot be generalised to all HPN users. Further, the survey relied on patient recall and although we attempted to define the term ‘retraining’ interpretation may have varied amongst the responders.

It was recognised on analysis of the responses that the year ranges offered as answer options to the questions of age and length of time on HPN were overlapping, creating possible ambiguity. As a result, we could only definitively state the number of HPN users younger than 18 (child) and those 18 or over (adult), and therefore only reported adults and children rather than different age categories. Also we could only definitively state the number on HPN less than 2 years and the number 2 years or more. However we were able to convey long time HPN use by some by stating the range since first HPN training.

This latter limitation impacted on our ability to investigate any correlation between length of HPN use, retraining or lack thereof, and use (or not) of latest recommended protocols, when looking at one small part of the PN connecting-up process – withdrawing back into a syringe. This component of the survey investigation was also impacted by the absence of evidence-based protocols for withdrawing back into the syringe, and the resulting question of the value of expert opinion versus evidence-based protocols.

References

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Thank you also to members of PNDU who participated in the survey.

Appendix A – Survey Questions

Q1. Are you currently on Home Parenteral Nutrition (HPN)?

Yes
No

Q2. How old are you (at your last Birthday)?

0-7 years
7-12 years
12-17 years
18 years and over

Q3. How long have you been on HPN ie living at home on Parenteral Nutrition?

Less than 2 years
Over 2 years but less than 10 years
Over 10 years but less than 20 years
Over 20 years

Q4. In what year was your initial training to go home on Parenteral Nutrition? (enter 4-digit year; for example, 2010)

Q5. With your initial training in connecting/disconnecting techniques before going home, were you given any written procedures and/or written advice to follow once at home?

Yes
No
Can't remember

Q6. Since your initial training in connecting/disconnecting technique before going home on HPN, have you ever had any further training or updating by your medical care team? (tick as many as apply)

Yes, I've been given additional detailed oral instructions on all or a particular technique in connecting/disconnecting to PN; and/or
Yes, I've been given additional written instructions on all or a particular technique in connecting/disconnecting to PN; and/or
Yes, I've been given an additional demonstration on all or a particular technique in connecting/disconnecting to PN; and/or
Yes, I've been required to again demonstrate my competence in performing all or a particular technique in connecting/disconnecting to PN?
No
Can't remember

Q7. How many times have you had further training or updating since first starting on HPN?

Once or twice
Regularly every year
Regularly every 2 years
Other (please specify)

Q8. In what year(s) did this further training or updating take place? (enter 4-digit year(s); for example, 2012 (and 2016))

Q9. Was any of your further training or updating undertaken because of a specific event eg suspected or confirmed central line associated bloodstream infection (CLABSI), change of ancillary items used, restarting HPN after a period off, or other medical problem?

Yes
No

Q10. What was the specific event(s) which led to you receiving further training or updating? (Tick as many as apply)

Suspected or confirmed CLABSI

Change of ancillary item(s) used
Restarting HPN after a period off
Other medical problem
Can't remember
Other reason altogether (please specify)

Q11. How many times have you had further training or updating because of a specific event(s)?

Once
Twice
Three times
Four times or more

Q12. During retraining, have you ever been taught new or updated procedures or techniques in connecting/disconnecting and CVAD care?

Yes
No
Can’t remember

Q13. What was/were the new or updated procedures or technique(s) you were taught during this retraining (short description eg a new way of cleaning the hub, or flushing the line with 20mls saline rather than 10mls)?

Q14. Do you ever draw back into a syringe before connecting the CVAD to the administration/giving set of a bag of PN?

Yes
No

Q15. How much do you usually draw back?

Just enough to withdraw the line ‘lock’
Only until the first sight of a flash of blood in the CVAD/connector ie to ensure the line is clear.
I’m not concerned about
withdrawing line ‘lock’
1-2mls of blood
More than 2mls of blood

Q16. What do you do with the blood you have withdrawn from the CVAD?

Discard it
Push it back in to the central line

Q17. Is how you carry out this drawback procedure (or not drawback at all) the same as you were taught by your hospital when you first went home on HPN?

Yes
No

Q18. Why has your technique for this procedure changed?

My medical care team retrained me in this technique
Someone in my medical care team told me to change it, but I did not receive formal retraining (ie detailed oral instructions; written instructions; a demonstration; nor was I required to demonstrate it myself).
I changed my technique without my medical care team knowing
Other (please specify)

Q19. Thank you from the PNDU team for completing this survey! Please provide any other comments below in respect of retraining of connecting/disconnecting procedures.