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Long-Term Home Parenteral Nutrition: It Takes an Interdisciplinary Approach

ABSTRACT

Home parenteral nutrition (HPN) is indicated for adults and children who cannot digest and absorb food and who are able to receive therapy safely outside of a hospital. How successful this therapy is depends on the patient's support system and ability to learn and independently administer medically complex procedures. Transition to home is facilitated by identifying all necessary therapies, obtaining information to demonstrate medical necessity, establishing central venous access, reaching goal infusion rate, identifying who will write HPN orders, and coordinating care among all home care providers. An interdisciplinary team provides the most successful process to ensure safe HPN.

Key words: home parenteral nutrition

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INTRODUCTION

The successful provision of parenteral nutrition (PN) at home in 1968 established a model to safely deliver technology-dependent therapies in the home environment when hospitalization is no longer needed. Home care services have lower health care costs when compared to typical daily charges in a hospital or skilled nursing facility.[1] Successful home care, however, greatly depends on the patient's support system and ability to learn and independently administer medically complex procedures. Providing personalized care at home enables individuals to take an active role in their own care, in addition to having family members and caregivers take part in caring for loved ones.[2] Home nutrition support therapy is positively associated with survival, economic, and quality-of-life outcomes.[3] Furthermore, technological advances in home care allow individuals to avoid prolonged hospital stays or repeated hospitalizations for nutrition therapies. An interdisciplinary team provides the most successful process to ensure safe PN at home.

INDICATIONS FOR HOME PARENTERAL NUTRITION

Home parenteral nutrition (HPN) is indicated for adults and children who cannot digest and absorb food and who are able to receive the therapy safely outside of an acute care setting.[4,5] Diagnosis and clinical conditions generally requiring HPN include but are not limited to intestinal failure or dysfunction, short bowel syndrome, malabsorptive disorders, chronic bowel obstruction, Crohn's disease, radiation enteritis, intestinal and pancreatic fistulae, pancreatitis, and gastrointestinal malignancy in adults; and short bowel syndrome, necrotizing enterocolitis, gastroschisis, Hirschsprung's disease, intestinal atresia, motility disorders, and failure to thrive in children. Severe, life-threatening malnutrition independent of the above-designated disease states is also an indication for long-term home nutrition therapy.

Candidates for HPN should have their primary disease and clinical condition stabilized. Infants and patients who live alone—as well as those patients who have diabetes or glucose intolerance, congestive heart failure or pulmonary disease, hyperemesis gravidarum, or high-output ostomy, fistula, or wound drainage—may present challenging conditions for management of HPN as the result of alterations in fluid balance, glycemic control, and acute electrolyte or acid-base abnormalities. The need for repeated blood work or acute clinical monitoring at home may pose difficulties and should be considered before discharge.

DISCHARGE PLANNING

Patients who require HPN usually are discharged from an acute care or rehabilitation care setting; however, a small percentage of patients may begin nutrition therapy at home.[6] Factors that should be assessed as part of the discharge planning process include insurance coverage, a home safety evaluation, and a physical, nutritional, and psychological needs assessment. The discharge planning process should begin early. Hospital personnel can facilitate the transition to home by identifying necessary home therapies, obtaining required diagnostic tests and procedures to demonstrate medical necessity, establishing central venous access, reaching the goal infusion rate, identifying who will write the home PN orders, and coordinating care among the home infusion provider, home care nursing agency, primary care physician, and other physician specialists.[2] To the extent possible, it is important to paint a realistic picture of what the patient and caregiver or family responsibilities will be while the patient is receiving PN at home, including the time needed for preparation and administration of PN and self-care of the access device.[7] While leaving the hospital usually indicates health improvement and stability, the onset of new responsibilities for HPN may be overwhelming and add new stress for both the patient and the caregiver.[2]

ROLE OF HOME CARE PROVIDERS

Many health care professionals are involved in the management of HPN. A.S.P.E.N.'s standards of practice recommend that this interdisciplinary process be collaborative between the referring physician, home care provider, and nutrition support practitioners.[5] Additionally, the role of each health care professional should be well defined, and each clinician should have clearly designated responsibilities.[5] Ideally, the patient and caregiver receive a predischarge teaching visit in the hospital, at which time there is a demonstration of equipment and procedures and an opportunity for the home infusion nurse to assess the patient's and caregiver's ability to learn and manage PN at home. The ability to safely perform HPN-related procedures prevents complications and hospital readmissions.[8] Extra time spent for 1-on-1 teaching care and management of HPN results in increased patient satisfaction and compliance.[9]

After discharge, the home infusion nurse conducts an in-home patient physical and psychosocial assessment. This nurse has a very active role in teaching both the patient and caregiver how to safely administer the PN therapy, including initial certification and periodic reassessment and recertification of skills.[2] When beginning HPN, the nurse also teaches the patient and caregiver to reliably monitor weight, hydration status, and blood and/or urine glucose, recognize early signs of infection, and care for the access device and site. The home infusion nurse also performs access site care, collects blood specimens, provides medication oversight, and evaluates compliance and response to nutrition therapy.[10] Often the eyes and ears for all other clinicians, the home infusion nurse's role is the cornerstone of this interdisciplinary process. The home infusion nurse should provide regular reports to the prescribing physician and the hospital-based nutrition support team if this mechanism is in place for long-term HPN monitoring and care. We have found that establishing a routine weekly reporting time helps facilitate this communication. In the absence of a hospital-based nutrition support team, the nutrition care plan may be developed and implemented by the home infusion nurse in collaboration with the home infusion provider's pharmacist and dietitian.

The home care pharmacist compounds the PN formula and dispenses the solution, equipment, and supplies.[11] The pharmacist also evaluates each nutrition therapy prescription, the potential for drug-drug, drug-nutrient, and nutrient-nutrient interactions, and monitors laboratory data and clinical response. In view of the current national drug shortages that affect PN components and additives, the pharmacist has a key role in communicating alerts and recommending alternative methods of meeting nutrient requirements to the physician and nutrition support team. Detailed information concerning PN-related shortages can be found at http://www.nutritioncare.org/Professional_Resources/Drug_Shortages_Update/.

The registered dietitian (RD) may be involved in the care of the patient receiving HPN as an employee or a consultant of the home infusion provider, home care nursing agency, or the hospital-based nutrition support team. The RD assists in the development of the nutrition care plan, establishes energy and macro- and micronutrient requirements, assesses adequacy and appropriateness of nutrient delivery and intake, and may perform a nutrition-focused physical examination and monitor laboratory data and response to nutrition therapy.[12] For those patients at home who will transition to enteral nutrition or an oral diet, the RD plays a key role in helping to taper or wean PN and in evaluating tolerance and adequacy of the diet.

Home PN patients may have many physician specialists involved in their care. It is important to identify which physician will have the responsibility for prescribing PN. This designated physician will initiate, modify, supervise, evaluate, and coordinate the HPN plan.[13] Physicians also interpret diagnostic testing, review laboratory data, and evaluate changes in the patient's medical condition. In some large academic medical centers, the physician also directs the hospital and homecare nutrition support team.

For all of the nutrition support clinicians involved, being certified by a reputable certifying body in the area of specialization adds credibility and assurance to the patients. Specialty certification can be obtained through the Infusion Nurses Certification Corporation, the National Board for Nutrition Support Certification, the Board of Pharmacy Specialties, or the American Board of Physician Nutrition Specialists.

NUTRITION CARE PLAN

The A.S.P.E.N. Home Care Standards recommend that the nutrition care plan be interdisciplinary and involve the patient, the patient's referring physician, homecare provider, and any other health care professionals involved in the care of the patient as appropriate.[5] The objectives of this care plan should include immediate and long-term goals of nutrition therapy, anticipated duration of therapy, and patient education. Additionally, this nutrition care plan shall include nutrition goals; route for administration; prescribed nutrients; infusion schedule; drug-nutrient interactions; specialized techniques of preparation and administration; care of access device, equipment, solutions, and formulas; monitoring frequency; and a plan to implement if problems related to infusion access devices and equipment or patient symptoms develop.[5]

The nutrition care plan is developed following nutrition assessment and includes determination of energy and nutrient requirements. Patients who are allowed nothing by mouth or have abnormal fluid losses will likely need additional fluid. For the HPN patient, the PN volume is based on the desired total daily fluid volume, keeping in mind that this may require a specially compounded formulation rather than a premixed solution. Good tolerance includes achieving euglycemia and acceptable urine output. Careful supervision of changes to the formula in the hospital setting may prevent the need for frequent formula changes in the home, which occur at weekly rather than daily intervals.

The patient and caregiver's preferences should be carefully considered when determining the infusion cycle. Minimizing the number of hours needed to infuse PN allows the patient freedom to resume normal activities. Work or school schedules and other family obligations may warrant flexible scheduling. Varying the start time further allows freedom day-to-day to accommodate family obligations or social events.[2] Parenteral nutrition always requires controlled pump delivery. Based on volume and formula tolerance, infusion may be as few as 8 or as many as 24 hours per day. If the patient is able to tolerate oral hydration or requires only supplemental PN, the infusion may be less than 7 days a week. It is not uncommon for HPN-dependent individuals to report impaired sleep due to pumps and equipment alarms, fear of catheter dislodgment, need for extra storage space, and complaints of carrying heavy backpacks.[14–18] Polyuria and nocturia due to large volume infusions, typically overnight, are known to affect quality of sleep.[7,19] Furthermore, being hooked up to a pump while trying to sleep introduces noise in the home environment and may be an additional source of irritation. Severe fatigue, associated with functional impairment and depression, is also a recognized problem with HPN dependency.[20]

PREVENTING COMPLICATIONS AND HOSPITAL READMISSION

There are numerous reports of the social and psychological burdens of HPN care affecting quality of life.[5,16,20–22] Patients worry about their ability to manage and troubleshoot problems; coordinate their schedules to accommodate many home nursing visits and medical appointments; and handle life-threatening side effects, such as catheter sepsis and liver failure, along with financial and economic constraints. Home infusion nurses have an important role in identifying clinically relevant psychosocial distress among their patients and providing appropriate referrals and community resources to help maintain and improve quality of life.

Long-term PN is often associated with numerous complications, including catheter-related infections and vascular access/thrombosis issues.[23] In a study of 80 families managing adult HPN, 29% had 34 separate hospitalizations for HPN-related care; 50% of these admissions were due to catheter-related blood stream infection and 20% were due to catheter occlusion or need for replacement.[24] Zhao and colleagues reported their single-center experience in which 101 adult HPN patients who had 12 877 catheter days and 6655 PN infusion days developed 245 infectious episodes.[25] More than half of these events were attributed to bloodstream infection requiring hospitalization. Patients who had a peripherally inserted central catheter (PICC) had a significantly higher rate of infection in this series.[25] Buchman et al examined the risk factors for catheter-related bloodstream infection among HPN patients receiving services from 1 national home infusion provider.[26] Use of a subcutaneous infusion port, frequency of intravenous fat emulsion infusion, obtaining blood from the venous access device, and infusion of additional medications other than PN via the central line were associated with higher risk of catheter-related bloodstream infection. There appears to be substantial benefit in avoiding blood draws from central lines used for long-term PN.

It is imperative for all health care professionals to follow provider-specific guidelines and national organization standards of care in the handling and treatment of the venous access device. From the perspective of the HPN patient, this central line is "not just an IV," rather this central line is "a lifeline."[5] It is well documented that patients fear being hospitalized because of a greater risk of infection and the necessity of having to be on guard to be sure the staff wash their hands and administer their infusions correctly.[27] Matheny described her own experience as a patient and a student nurse noting, "I am extremely overcautious with sterile technique … but what I have noticed … is that nurses each have their own definition of the word sterile …. There is nothing worse than a nurse or healthcare provider mishandling my central line and jeopardizing the five years of work that I have put into keeping it patent and free of infection."[28(p47)] HPN-dependent adults in a study by Winkler shared similar experiences indicating "this is not the first time that I've had to stop someone and say, look I would really prefer that you do it this way…."; and, "every time I'm in the hospital you really have to be your own advocate as far as the care of those lines."[29]

Prevention of complications and hospital readmission and early intervention are key to successful transition from hospital to home. Education is the foundation for success and avoids procedure and therapy-related complications.[30] Clearly, not all complications can be prevented; however, there are known strategies that minimize risk. Reasons for complications within the first 90 days of HPN include inadequate training, patient and caregiver noncompliance, prescription error, health care worker error, and equipment malfunction.[31] Recognition of the signs and symptoms of complications promotes early treatment intervention. Two ways of efficient management of complications are early recognition and use of standardized protocol interventions. One example is the use of standing orders to obtain blood cultures and complete blood count in the event of a febrile course.[2] Empowering patients with verbal and written references to recognize signs and symptoms will enable appropriate action in the event of serious complications, such as fever or dehydration.

ROLE OF FOOD

Food is important in the lives of HPN-dependent adults and children, even though food may not be providing absorbable nutrients and energy. Eating is something people often take for granted until faced with a situation in which they are unable to eat. The loss of the ability to eat is similar to any loss experienced in life. HPN-dependent individuals may have a prolonged period of grief and bereavement associated with the loss of the ability to eat.[32] Home infusion nurses should recognize the potential for social isolation related to HPN dependency and the inability to eat. Most patients who receive HPN, especially those who have short bowel syndrome, are strongly encouraged to eat small amounts of food to promote intestinal adaptation and potentially reduce PN dependency.[33] Still others learn to balance their food intake with their gastrointestinal symptoms. Patients receiving HPN have described many strategies to learn new limits for what, and how much, they can eat. Some strategies for restaurant eating include eating a little bit from the plate of a spouse or friend, selecting an appetizer instead of an entrée, ordering a child's portion, asking for a "to-go" box or "doggie" bag, or bringing half home and eating it the next day.[32] Others may need to learn that it is entirely acceptable to sit at the table and not eat at all. While this may make family members, relatives, or friends feel uncomfortable at meals, the HPN-dependent individual can enjoy the social aspect of being with others even if she or he is unable to eat.

Home PN-dependent children should also interact with food. Food may provide oral stimulation and nonnutritive sucking and may promote chewing skills. Children should be exposed to different textures, tastes, and colors and develop food-related games to increase their familiarity with foods and mealtimes. Handling food and playing with food and utensils encourages oral-motor skill development. Setting the table for the rest of the family is an important and necessary social skill. Children can also set the table for their dolls or stuffed animals and role-play. Older children should participate in shopping, food preparation, and cooking. Mealtimes should be maintained for socialization and to allow children to watch others eat. Most importantly, including everyone at the table creates a supportive eating environment for the entire family.

TRANSITION AND DISCONTINUATION OF THERAPY

Adequate nutrient intake from an oral diet should be demonstrated prior to discontinuing PN.[5] When appropriate, PN should be gradually decreased as oral intake increases so that overall adequate nutrient intake is sustained. Monitoring should confirm the ability to chew and swallow safely or document the absence of gastrointestinal symptoms and pain with eating. It is helpful to have the patient record the amount of fluid and foods she or he is consuming in a food diary to guide the transition. Patients should demonstrate the ability to maintain weight, hydration status, electrolytes, and nutrient balance prior to discontinuing PN.

When the patient no longer benefits from PN or the burden outweighs the benefit, PN should be terminated.[5] Patients and/or their designated representative (according to the patient's competence) should be involved in decisions regarding the withdrawal of PN. It is recognized that artificial hydration in the case of a terminally ill patient can lead to discomfort due to fluid overload, pulmonary and generalized edema, and shortness of breath. As such, intravenous therapy may be discontinued on clinical and ethical grounds and in accordance with existing laws with the consent and consensus of the patient and decision makers.[34]

Nutritional care goals usually promote weight gain or improvement in body composition, prevent or correct nutritional deficiencies, and treat malnutrition. Outcomes for nutritional care therefore include survival. In contrast, palliative care goals focus on reducing human suffering by decreasing discomfort caused by symptoms of disease and promoting spiritual, psychosocial, and emotional well-being.[35] Outcomes for palliative care include symptom improvement and patient satisfaction. Comfort feeding may ultimately be a desirable approach when the decision to withdraw PN is made. This approach focuses on feeding the patient as long as it is not distressing. Comfort feeding also promotes continuous interaction with the person through mouth care, therapeutic touch, and communication.[36] End of life decisions require interdisciplinary collaboration among each health care provider, the patient and family.[34]

COMMUNITY RESOURCES

Many organizations provide important outreach services, free educational materials, and emotional support to individuals, families, and caregivers.[14] The Oley Foundation (www.Oley.org), established in 1983, is a national, nonprofit education, self-help, and research organization for home parenteral and enteral nutrition-dependent individuals and their families and caregivers, and clinicians. Some of the educational resources available through the Oley Foundation include a video library, equipment and formula exchange, bimonthly newsletters with articles about medical advances and personal experiences, and the My HPN online education modules ("Take Charge," "Catheter-Associated Infection," "Fluid Balance," "Glucose Control"). The organization holds an annual clinician/consumer summer conference. An important resource is an Internet link to other national and international organizations related to home nutrition support; gastrointestinal societies; disease- and condition-specific societies and foundations; home care agencies; equipment and products; infection control and safety; insurance and disability benefits; discount and free prescription services; government agencies; and parenting and caregiver resources. Parents of children and those who live with TPN may enjoy participating in an online Facebook site (Living Life on Total Parenteral Nutrition).

SUSTAIN A.S.P.E.N.'S NATIONAL REGISTRY FOR NUTRITION CARE

A.S.P.E.N. launched Sustain, its National Patient Registry for Nutrition Care (www.nutritioncare.org/sustain/), a comprehensive, Web-based tool that allows clinicians to enter HPN patient data, measure and analyze results, benchmark outcomes, and publish findings. The purpose of Sustain is to maintain a prospective, longitudinal nutrition therapy patient registry to improve patient outcomes.[37] Since passing the 2-year anniversary of Sustain's inception, A.S.P.E.N. can report the following facts:

- Sustain has data for more than 1100 HPN patients.
- There are currently 62 participating sites (medical centers, hospitals, and home infusion agencies); 33 sites are actively submitting patient data in the registry.
- Sustain is listed in the Agency for Healthcare Research and Quality's (AHRQ) ClinicalTrials.gov under the new program, AHRQ's Registry of Patient Registries. The study is listed as the Sustain Home Parenteral Nutrition Registry.
- Sustain is approved by the New England institutional review board (IRB) for those sites that may not have access to a local IRB for project approval.
- Current publications include 2 research abstracts and 2 papers in the *Journal of Parenteral and Enteral Nutrition*.
- The Web site http://www.nutritioncare.org/Sustain has additional information for hospitals, institutions, or home infusion agencies that would like to enroll or learn more.

CONCLUSION

Home nutrition support involves more than simply transferring PN from the hospital to the home setting. Home infusion nurses play a key role in teaching the skills and providing education to ensure patients receive and administer safe and effective HPN. Ongoing clinical monitoring is essential to prevent complications and promote successful achievement of nutritional outcomes, as well as patient satisfaction and comfort. Interdisciplinary collaboration among the prescribing physician, hospital-based nutrition support team, home infusion provider, home infusion nurse, and any additional home care nursing agencies is necessary for successful management of long-term home parenteral nutrition.

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