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Prevalence of Home Parenteral and Enteral Nutrition in the United States

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Abstract

Background: Malnutrition is highly prevalent and associated with increased morbidity and mortality. Studies continue to reveal significant clinical benefits with nutrition support, including improved wound healing, reduction in complications and length of stay, and mortality. Due to these benefits, the prevalence of home parenteral and enteral nutrition (HPEN) continues to increase worldwide. In the United States, given our healthcare insurance landscape, it has been very difficult to ascertain the true prevalence of HPEN. *Methods:* Medicare beneficiary data for 2013 were obtained from Centers for Medicare and Medicaid Services. Commonly used Healthcare Common Procedure Coding System codes were used for home enteral nutrition (HEN) and home parenteral nutrition (HPN). Data regarding number of patients and insurance providers were also obtained from 3 of the largest home infusion providers in the United States (Coram CVS, Option Care Enterprises, and BioScrip Inc). Based on the ratio of Medicare to non-Medicare billing, an estimate of HPEN prevalence was obtained. *Results:* For 2013, there were 6778 Medicare beneficiaries for HPN and 114,287 for HEN. The ratio of Medicare to non-Medicare was 0.271 for HPN and 0.261 for HEN, leading to an estimated prevalence of 25,011 patients receiving HPN (79 per million U.S. inhabitants) and 437,882 patients receiving HEN (1385 per million U.S. inhabitants). There are an estimated 4129 pediatric patients and 20,883 adult patients receiving HPN; for HEN, 189,036 pediatric patients and 248,846 adult patients. *Conclusion:* Compared with results from 1992, the prevalence of HEN has increased dramatically, while the prevalence of HPN has declined. (*Nutr Clin Pract*. 2017;32:799-805)

Keywords

enteral nutrition; home nutritional support; long-term care; parenteral nutrition; home care services; home care agencies; health insurance reimbursement; reimbursement

Malnutrition is highly prevalent in acute and chronic diseases, contributing to increased morbidity and mortality with longer hospital length of stay, greater risk of hospital readmission, and higher overall cost of care.[1-5] Over the last few decades, despite greater advances being made in our understanding of the importance of macronutrients and micronutrients in maintaining homeostasis, there has not been a general decline in the prevalence of malnutrition among hospitalized patients or residents of long-term care facilities.[6-9] During the same period, studies have continued to reveal significant clinical benefits from nutrition support, including improved wound healing, decreased catabolic response to injury, reduction in complications and length of stay, maintenance of gastrointestinal integrity, and an overall improvement in clinical outcomes and mortality.[10-12] This has prompted major organizations to recommend determining the nutrition risk of patients and implementing early enteral nutrition (EN) support if they are unable to meet their nutrition needs through oral intake.[6,10,13] If the gastrointestinal tract is not accessible or usable for EN, parenteral nutrition (PN) support should be implemented when appropriate.[14,15]

The high prevalence of malnutrition, with the tremendous clinical benefits and significant cost reduction associated with use of nutrition support, has led to an ever-increasing prevalence in EN and PN among hospitalized patients as well as in the home setting.[16-21] Data supporting this trend have been well published for the pediatric and adult population from many developed countries with nationalized healthcare systems.[19-22] In the United States, gathering these data is more difficult, as home EN (HEN) and home PN (HPN) are prescribed by thousands of physicians across the country and supplied by numerous durable medical

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equipment (DME) providers. Previously, these data were compiled by a national home PN and EN (HPEN) registry on a voluntary basis by providers (physicians and nutrition support teams), with data being reported for use between 1985 and 1992.[18] Unfortunately, with dissipation of this registry, data regarding HPEN use in the United States have been difficult to obtain. The aim of the present study was to estimate HPEN prevalence in the United States with available Medicare and commercial provider data.

Methods

Medicare data were obtained from the Centers for Medicare and Medicaid Services' Medicare Referring Provider DMEPOS Data CY2013, which is a database with 100% of Medicare enrollment and fee-for-service claims data.[23] After discussion with DME providers regarding their billing practices, data were obtained for the national and state Healthcare Common Procedure Coding System (HCPCS) aggregate report for calendar year 2013. For EN, the following HCPCS codes were used:

B4034: Enteral feeding supply kit; syringe fed, per day, includes but not limited to feeding/flushing syringe, administration set tubing, dressings, tape
B4035: Enteral feeding supply kit; pump fed, per day, includes but not limited to feeding/flushing syringe, administration set tubing, dressings, tape
B4036: Enteral feeding supply kit; gravity fed, per day, includes but not limited to feeding/flushing syringe, administration set tubing, dressings, tape

For PN, the following HCPCS codes were used:

B4168: PN solution; amino acid, 3.5%, (500 mL = 1 unit)—homemix
B4178: PN solution: amino acid, >8.5% (500 mL = 1 unit)—homemix
B4189: PN solution; compounded amino acid and carbohydrates with electrolytes, trace elements, and vitamins, including preparation, any strength, 10–51 g of protein—premix
B4193: PN solution; compounded amino acid and carbohydrates with electrolytes, trace elements, and vitamins, including preparation, any strength, 52–73 g of protein—premix
B4197: PN solution; compounded amino acid and carbohydrates with electrolytes, trace elements and vitamins, including preparation, any strength, 74–100 g of protein—premix
B4199: PN solution; compounded amino acid and carbohydrates with electrolytes, trace elements and vitamins, including preparation, any strength, >100 g of protein—premix

For EN and PN, data in number of supplier beneficiaries column were combined to generate total number of Medicare beneficiaries.

Beneficiary data from 3 of the largest DME providers for HPEN in the United States were subsequently obtained (Coram CVS Specialty Infusion Services, Denver, CO; Option Care Enterprises, Deerfield, IL; and BioScrip Inc, Denver, CO).[24] As part of release of these data, confidentiality agreements were required, and data for each company individually could not be released. Instead, data for all 3 companies are provided in aggregate with ratios of percentage Medicare, Medicaid, and commercial insurance beneficiaries being averaged. Data from DME providers allowed us to generate a ratio of Medicare to non-Medicare beneficiaries. This ratio, with the total number of Medicare beneficiaries obtained from the Centers for Medicare and Medicaid Services data, was used to estimate the total number of patients receiving HEN and HPN in the United States for 2013. The total number of pediatric versus adult patients was estimated by multiplying the ratio of pediatric to adult patients obtained from DME providers to the total estimated number of patients receiving HEN and HPN.

Results

In 2013, there were a total of 6778 Medicare beneficiaries receiving HPN from 6703 referring providers and 1970 suppliers. There were 114,287 Medicare beneficiaries receiving HEN from 73,770 referring providers and 9101 suppliers (Table 1). Based on 2013 U.S. Census Bureau data, this amounted to 21 Medicare beneficiaries per million U.S. inhabitants for HPN and 361 for HEN (Figure 1).[25] Mississippi had the highest number per population of Medicare beneficiaries receiving HEN, at 803 per million inhabitants, with Alaska having the lowest, at 90 (Figure 2A). For HPN, the District of Columbia had the highest number of Medicare beneficiaries, at 77 per million inhabitants, with Montana, North Dakota, South Dakota, Rhode Island, Wyoming, and Vermont reporting no Medicare beneficiaries for 2013 (Figure 2B).

Although market share data were not available for 2013, we were able to obtain market share data published by Harris Williams & Co in June 2014.[24] These data revealed that Coram CVS Specialty Infusion Services had a 10% home infusion market share, with Option Care Enterprises having 6% and BioScrip Inc having 5%. The remaining market share per Harris Williams & Co analysis was divided among Express Scripts, which had a 5% market share, and independent DME providers, who controlled 74% of the market share.

In aggregate, the 3 DME providers (Coram CVS Specialty Infusion Services, Option Care Enterprises, and BioScrip Inc) serviced 16,193 patients for HPN (4388 Medicare, 2141 Medicaid, and 9664 with commercial or other insurance) and 98,550 patients for HEN (25,722 Medicare, 20,862 Medicaid, and 51,966 with commercial or other insurance). The respective ratio of Medicare to non-Medicare insurance was 0.271

Table 1. Prevalence of Home Parenteral and Enteral Nutrition.[a]

Category	Parenteral Nutrition	Enteral Nutrition
Medicare beneficiaries		
Total	6778	114,287
Per million U.S. inhabitants	21	361
Referring providers	6703	73,770
Suppliers	1970	9,101
DME provider patients	16,193	98,550
On Medicare	−4388	−25,722
On Medicaid	−2141	−20,862
With commercial or other insurance	−9664	−51,966
Ratio of Medicare to non-Medicare insurance	0.271	0.261
Patient estimate		
For 2013	25,011	437,882
Per million U.S. inhabitants	79	1385
Infusion company, %		
Pediatric patients	16.5	43.2
Adult patients	83.5	56.8
Patient estimate by age		
Pediatric	4129	189,036
Adult	20,883	248,846

DME, durable medical equipment.
[a]Values are presented as No. unless noted otherwise.

for HPN and 0.261 for HEN. Using this ratio with the total number of Medicare beneficiary data, we estimate that 25,011 patients in the United States received HPN (79 per million inhabitants) and 437,882 received HEN (1385 per million inhabitants) in 2013. Combining the ratio of pediatric to adult patients from DME providers revealed that 43.2% of patients receiving HEN were pediatric (189,036) and 56.8% were adults (248,846). For HPN, 16.5% were pediatric (4129) and 83.4% were adults (20,883).

Discussion

The current study is the first to look at the prevalence of HPEN in the United States in >20 years. To our knowledge, the last peer-reviewed article that evaluated the estimated prevalence of HPEN in the United States was published in 1995, and it revealed that in 1992 approximately 40,000 and 152,000 patients in the United States received HPN and HEN, respectively.[18] Our study reveals that the estimated prevalence of HPN has actually declined to 25,011. This decline is even more significant since the population of the United States has increased from 254,782,555 in 1992 to 316,204,908 in 2013, leading to a reduction in the estimated prevalence of HPN from 157 to 79 per million inhabitants.[25,26] For patients receiving HEN, there has been a significant increase in estimated prevalence, going from 152,000 patients in 1992 (597 per million) to 436,874 in 2013 (1382 per million).

Similar to our study design, Howard et al utilized Medicare data to extrapolate overall estimated prevalence.[18] They noted that from 1986–1993, Blue Cross/Blue Shield of South Carolina was 1 of 2 national carriers responsible for determining the HPEN eligibility of Medicare beneficiaries and carried approximately 75% of the Medicare HPEN workload. The authors subsequently used data from the North American Home Parenteral and Enteral Nutrition Registry to estimate overall prevalence with spectrum of disease and outcomes with HPEN. This registry collected yearly information for >12,000 patients treated with HPEN, with outcomes data reported on 9288 patients from 217 home nutrition support programs nationwide. The authors reported that Medicare was the largest single payer, accounting for 10,000 patients receiving HPN (39 per million U.S. inhabitants) and 73,000 patients receiving EN (287 per million) in 1992. Our study found that the percentage of the U.S. population receiving HPEN covered by Medicare has declined for PN (21 per million U.S. inhabitants) and increased slightly for EN (361 per million). Given that Medicare accounted for 27% and 46% of the PN and EN registry patient sample, respectively, they were able to estimate the prevalence of HPEN in the United States for 1992.

Although the overall design of our study was similar, we did not have the benefit of using data from a national registry of patients receiving HPEN and instead relied on information from 3 of the largest DME providers in the country who service patients throughout the United States. This gave us the advantage of having a larger sample size, as our DME providers managed 114,743 patients receiving HPEN, compared with the 12,000 in the North American Home Parenteral and Enteral Nutrition Registry. These data were actively gathered by each company based on claims filed (ie, not self-reported, as in the registry), thereby providing increased accuracy.

We were able to perform an additional check of the accuracy of our findings using independent market share data from Harris Williams & Co,[24] which indicated that the 3 DME providers in our study combined for 21% of the home infusion market share, based on a report from June 2014. On the basis of our estimate of 462,893 patients receiving HPEN in the United States in 2013, our 114,743 patients managed by the 3 DME providers would account for 24.7% of the market, which is quite close to the 21% estimated by Harris William & Co. We also verified our results against data from the Sustain registry, a voluntary research database maintained by the American Society for Parenteral and Enteral Nutrition.[27] This database enrolled 1251 patients from 29 sites between August 2011 and February 2014. Although its methodology was different from ours, in that it depended on volunteers providing information regarding their patients (similar to the North American Home Parenteral and Enteral Nutrition Registry), we did find similarities. It reported that 85% of patients receiving HPN were adults, quite similar to the 86% in our data. In terms of insurance coverage, 58% of patients from the Sustain registry had private insurance, 26% had Medicare, and 23% had Medicaid,

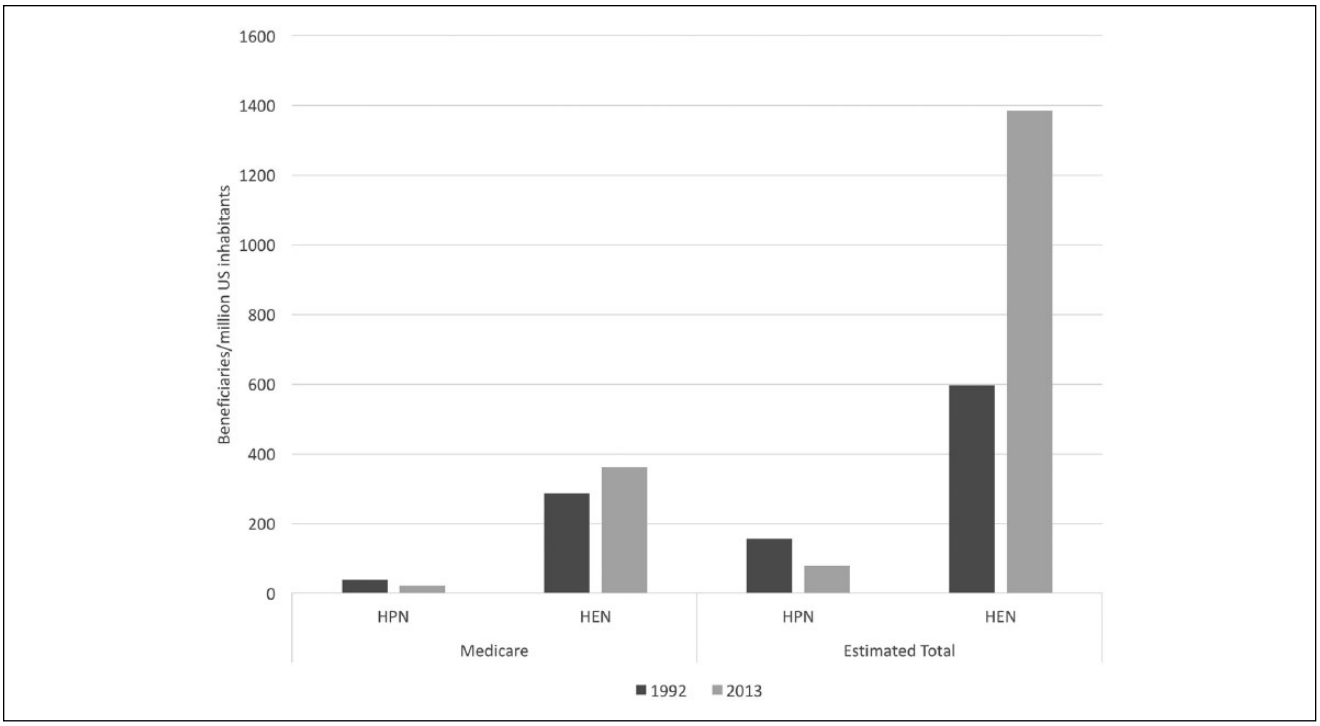

Figure 1. Prevalence of HPN and HEN for Medicare and estimated total beneficiaries per million U.S. inhabitants for 1992 and 2013. Data for 1992 extrapolated from Howard et al.[18] HEN, home enteral nutrition; HPN, home parenteral nutrition.

very similar to our findings of 59.7% commercial or other, 27.1% Medicare, and 13.2% Medicaid.

Our data did differ significantly from previous registries in terms of number of referring providers.[18,27] We obtained data directly from the Medicare "Number of Referring Provider" column, which listed 6703 referring providers for 6778 HPN beneficiaries (1:1 ratio) and 73,770 referring providers for 114,287 HEN beneficiaries (1.5 patients per provider). We wanted to ensure the integrity of this finding, as the North American Home Parenteral and Enteral Nutrition Registry reported data from 9288 patients supervised by 217 home nutrition support programs, for a ratio of 42.8 patients per program.[18] The Sustain registry enrolled 1251 patients from 29 sites, for a ratio of 43.1 patients per site.[27] Our HPN Medicare data were instead describing close to 1 patient per provider. Part of this could be explained by the fact that the North American Home Parenteral and Enteral Nutrition Registry and the Sustain registry were reporting data submitted by programs or sites, whereas the Medicare provider number was being generated from claims records. Each site could have multiple providers signing for the nutrition support orders. Additionally, both registries were gathering data from volunteer centers, who were more likely to be from larger nutrition programs with providers that had significant experience in nutrition support and were thus likely managing a larger number of patients receiving HPN. Providers managing just 1 or 2 patients are less likely to belong to national organizations centered on nutrition support and thus not likely to submit their data to national registries.

However, this certainly would not explain all of the difference that we noted in the ratio of patient to provider, leading us to contact our participating DME providers to obtain additional information. One DME provider was able to pull data regarding the number of providers who referred, and it noted a ratio of 1.6 patients per HEN provider and 1.8 patients per HPN provider—values much closer to our Medicare-reported data than the 2 other registries discussed. Another DME provider noted that for its Medicare patients receiving HPN, the ratio of patient to provider was 1.35. It also reported that 89% of its providers managed only 1 patient, whereas 11% managed >1. These data were confirmed by the remaining DME provider, which noted that 80.8% of its providers managed just 1 HPN patient, 16.8% managed 2–5 patients, and only 2.4% managed >5 patients. Again, since these data are from the 3 largest DME providers, it is conceivable that smaller providers could have differing ratios of patient to provider. However, we believe that, most likely, smaller sets of DME data will point in the other direction, given the trend for major centers to work with a small set of DME providers that tend to have national presence.

As mentioned, similar studies have been reported by major developed nations in Europe. Data from multiple European surveys indicate that the prevalence of HPEN is lower in Europe than the United States per million inhabitants.

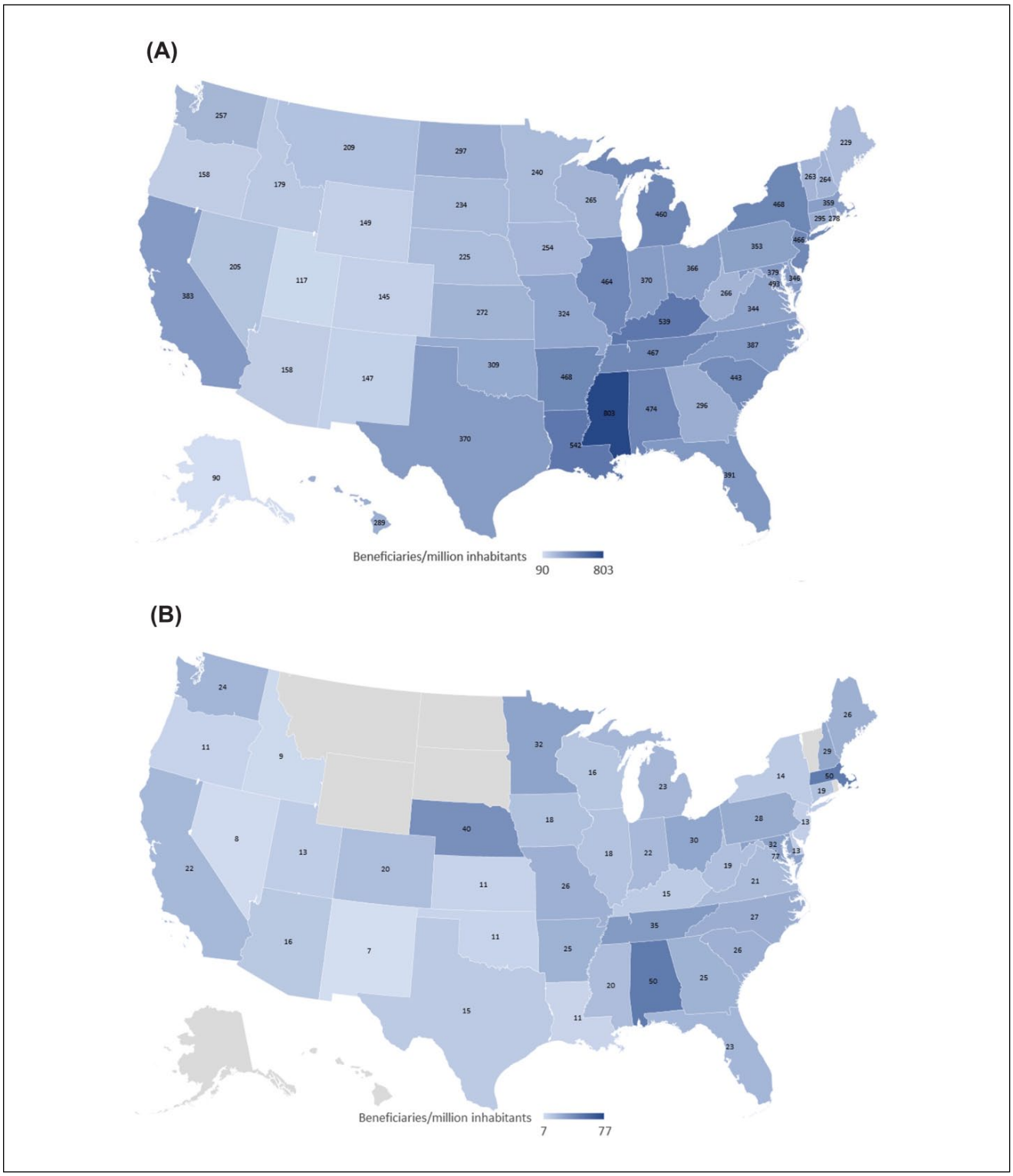

Figure 2. Number of Medicare beneficiaries per million inhabitants per state for (A) home enteral nutrition and (B) home parenteral nutrition. States in gray did not have information available. Maps were generated using Microsoft Excel.

Hebuterne et al published a survey of 1387 patients from 23 centers in Belgium, Denmark, France, Germany, Italy, Poland, Spain, and the United Kingdom and noted that the median incidence of HEN in 1998 was 163 patients per million inhabitants

(range, 62–457).[28] The British Artificial Nutrition Survey from 2005 reported an ongoing increase in HEN for adults, from 16,890 in 2003 to 18,260 in 2004 and 18,686 in 2005 from 333 centers in United Kingdom.[29] For 2005, the prevalence per million inhabitants was 384 for England, 371 for Scotland, 465 for Ireland, and 386 for Wales—a significant increase in prevalence when compared with 1998 data. Adult HPN prevalence per million was noted to be quite low, at 11.1 for England, 14.6 for Scotland, 5.4 for Ireland, and 5.4 for Wales.

Although the exact reason for lower HPEN prevalence in Europe versus the United States needs to be explored further, we do note many differences in healthcare practices especially pertaining to HPEN. HPN in Europe tends to be managed through specialized intestinal failure centers, in direct contrast to the United States, where the majority are managed by primary providers outside of specialized centers. This was quite evident from the earlier discussion yielding almost 1 HPN provider per HPN Medicare patient and 1.5 HEN Medicare patients per provider. We also think that there is more drive to discharge patients to the home setting in the United States, which can also contribute to the higher prevalence of HPEN.

Despite these significant findings, our study did have some limitations. Our overall prevalence was an estimate based on data from large national DME providers that accounted for 24.7% of market share. As evident from Harris Williams & Co market share data, close to 75% of the HPEN market is controlled by independent providers who may not all be Medicare certified, leading to differing ratios of insurance providers. We also chose to be very conservative with the billing codes utilized to gather Medicare data, to avoid any possibility of duplication. We discussed billing practices with DME providers and then chose to utilize amino acid codes in an effort to ensure that no patients were counted twice. As an example, patients who just receive intravenous fluids would not be counted through this methodology. We believed that this was important since Medicare does not typically cover intravenous fluids at home. Counting these patients could have led to a significant error in our ratio, since they would not have been present in the Medicare data set. A similar conservative approach was used for HEN and certainly could have resulted in an underestimation of the true prevalence of HPEN use.

Another limitation is that our data are based on benefit claims and do not actually account for use of HPEN. In the case of HEN, there may be a subset of patients who purchase their formula or use blenderized tube feeding (BTF) and thus may not be making insurance claims or using DME providers. In a survey of our patients, we found that approximately 55% of them were using BTF in some capacity, with a median use of 4 days per week.[30] A survey partnering with the Oley Foundation found that 89.6% of pediatric patients and 65.9% of adult patients used BTF in some capacity.[31] Certainly, additional studies into BTF are needed, but high prevalence of use could indicate that perhaps our estimation of HEN use is an underestimation.

Conclusions

Overall, with significant data revealing the benefits of nutrition support, the prevalence of HPEN continues to increase worldwide. U.S. HPEN prevalence data have been difficult to obtain given the lack of a single-payer system present in many developed European countries. Using available Medicare HPEN data with data from 3 of the largest DME providers in the United States (≈20%–24.7% market share), we were able to estimate a prevalence of 25,011 patients receiving HPN (79 per million) and 437,882 patients receiving HEN (1385 per million) for year 2013. The use of HPN has actually decreased as compared with 1992, whereas the use of HEN has increased significantly.

Statement of Authorship

M. S. Mundi and R. T. Hurt contributed to the conception/design of the research; A. Pattinson, M. T. McMahon, J. Davidson, and M. S. Mundi contributed to the acquisition, analysis, or interpretation of the data; M. S. Mundi drafted the manuscript; and A. Pattinson, M. T. McMahon, J. Davidson, and R. T. Hurt critically revised the manuscript. All authors agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

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