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ORIGINAL RESEARCH

Characteristics of chronic intestinal failure in the USA based on analysis of claims data

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Abstract

Background: This study investigated the prevalence, characteristics, and management of patients with chronic intestinal failure (CIF) in the United States in 2012–2020, based on parenteral support (PS) prescription claims and healthcare utilization.

Methods: Patients with CIF were identified from the Integrated DataVerse® claims database if they had at least two PS prescriptions within 6 months and a relevant diagnosis. Analysis included prevalence and characteristics of patients with CIF, their travel distance to receive PS prescriptions, and the distribution of PS providers and their prescribing history.

Results: Up to 24,048 patients with CIF were identified, equivalent to 75 patients per million. CIF affected people of all ages, being more prevalent in women than in men. Many providers signed PS orders for small patient groups over short time periods, whereas few providers signed PS orders for large patient groups long term, indicating a lack of centralization. The distribution of PS providers suggested a disparity in healthcare coverage in rural vs urban areas, leading to patients traveling considerable distances to receive PS prescriptions. This may be exacerbated by a decline of providers with expertise in CIF and nutrition.

Conclusions: Healthcare disparities for patients with CIF have likely been obscured by the lack of CIF-specific diagnostic and procedure codes, obliging providers to code for their patients under other codes. Effective policy changes, including centralized care, revision of reimbursement models, and expansion of nutrition-focused education in addition to the newly introduced International Classification of Diseases codes, are needed to provide the best care for patients.

KEYWORDS

chronic intestinal failure, claims data, parenteral support

†Deceased.

INTRODUCTION

Chronic intestinal failure (CIF) is a rare and heterogeneous disease defined as a "reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth."[1] CIF represents a clinical spectrum of severe malabsorption and can be further classified based on functional, pathophysiological, and clinical criteria.[2] Given the fragmented healthcare landscape in the United States, it has been difficult to ascertain the true prevalence of CIF. Additionally, characteristics, outcomes, and healthcare resource utilization in patients with CIF are poorly understood.

The majority of published work on the epidemiology of CIF represents data from single-center studies that may include patients with both benign and malignant diseases.[2] These studies favor home parenteral nutrition (HPN) provider data from CIF centers in Europe that are managing large numbers of patients with CIF on parenteral support (PS). They note that the prevalence of HPN for CIF in Europe is 5–80 patients per million individuals, including approximately 10% pediatric patients.[3–6]

It has been quite difficult to reproduce similar work in the United States owing to the lack of an insurance mandate for centers with significant expertise in managing patients with CIF. An estimate by Howard et al using data from Medicare as well as the North American Home Parenteral and Enteral Nutrition Registry found that 40,000 Americans (157 per million) received HPN in 1992.[7] Mundi et al utilized data from Medicare and three of the largest US Durable Medical Equipment (DME) providers to estimate that in 2013, the prevalence of patients receiving HPN in the United States had declined to 25,011 or 79 patients per million, including 16.5% pediatric patients.[8]

CIF is a devastating condition for patients, with a high burden of care for caregivers and families.[2] Management of patients with CIF is complex and often requires a multidisciplinary team with diverse expertise, caring for the underlying gastrointestinal disease, as well as providing HPN support.[1,2,9] To assess the current state of CIF management in the United States, the current study utilized Symphony Health Solutions' Integrated DataVerse (IDV) open claims database[10] to determine the prevalence, characteristics, and PS-associated travel distances of patients with CIF as well as the geographical location and PS prescribing history of PS providers in the United States.

METHODS

Claims database

The IDV database is a national administrative open claims database consisting of longitudinal data of 290 million unique deidentified US patients regarding pharmacy claims, physician offices medical claims, and hospital claims, including patients with multiple years of PS claims. It covers all payment types, including (but not limited to) commercial plans, Medicare (including Medicare Advantage), Medicaid, cash, and assistance programs. It complies with the Health Insurance Portability and Accountability Act, thus institutional review board approval was not required.

Patient population

Claims data were analyzed from October 2012 to June 2020. Patients of any age were included if they received at least two PS prescriptions within 6 consecutive months and had a relevant surgical or nonsurgical diagnosis. A PS interaction was defined as a claim with a given patient and physician and a corresponding PS code. These criteria were selected to exclude patients who received a single PS prescription and those with short-term intestinal failure, which typically refers to patients receiving PS for only a few days or weeks. All codes used for definition of the CIF patient population are listed in full in the Supporting Information.

Data analysis

CIF patient number

The number of patients with CIF in each US state per million individuals was calculated from the number of patients with CIF from each state in the database and the total number of patients in the database over the 8-year data set.

Patient characteristics

Data on the CIF population were categorized by sex (men or women), current age group (0–17, 18–44, 45–64, and ≥65 years of age), insurance type (commercial, Medicare, Medicaid, other) and geographic region (Northeast, Midwest, South, and West). The states included in these regions and a brief background on US health insurance models are available in the Supporting Information).

PS provider location

Each provider's ZIP code, converted to a latitude and longitude, was used to plot PS providers on a US map as a function of the number of patients the provider had at least a 12-month PS interaction history with. Providers were grouped based on the number of patients they had (1–4, 5–9, 10–19, and ≥20) over the 12-month period.

PS provider numbers over time

PS provider data were analyzed for the number of patients the providers had prescribed PS for over a period of at least 2 months

and up to 12 months. Providers were grouped based on the number of patients they prescribed PS for over the respective time period (time difference between the initial and final PS prescription).

Patient travel distance

Travel distances were analyzed for each PS interaction that happened outside of a patient's ZIP3 area code, converted to a latitude and longitude. The associated distance between the patient and provider was calculated from the center of the patient's ZIP3 area code and their provider's full ZIP code, using their most recent location information.

Additional methods are included in the Supplementary Materials.

RESULTS

Characteristics of patients with CIF

The estimated number of patients with CIF of all ages identified was 24,048, equivalent to an estimated prevalence of 75 patients with CIF per million US inhabitants (based on the US population estimates for 2012–2020[11,12]).

The number of patients with CIF per million individuals in the IDV claims database is displayed in Figure 1A for each US state. Maine, Pennsylvania, and New Jersey had the highest number of patients per capita, whereas the lowest number was noted in the states of Vermont, Mississippi, and Louisiana.

Of the estimated 24,048 patients with CIF, 9% were 0–17 years of age, 16% were 18–44 years of age, 39% were 45–64 years of age, and 35% were 65 years of age or above. In all adult age groups, the majority (60%) of patients with CIF were women (Figure 1B).

Health insurance coverage included commercial health insurance for 56% of patients, followed by Medicare for 33%, Medicaid for 10%, and other forms of insurance for 1% of patients. Commercial insurances provided the majority of coverage for healthcare costs in all age groups (Figure 1C).

With regard to geographical distribution, 31% of patients with CIF were in the South, 29% in the Northeast, 23% in the Midwest, 17% in the West, and for 1% the location was unknown (Figure 1D). The South and the Northeast comprised the highest proportion of patients with CIF in all age groups. The highest proportion of pediatric patients with CIF was in the South (35%).

Geographic location of PS providers

Figure 2 shows a map of the geographic location of providers in the United States who prescribed PS for each of their patients for at least 12 months. The plot exhibits a high number of PS providers in the East of the United States, particularly in the Northeast, where hubs with providers prescribing for large patient populations were colocated with large population centers. The data reveal a larger number and higher density of PS providers in the Northeast than in other regions of the country. The Midwest, South, and West display a lower PS provider count and density overall, as well as fewer hubs with providers prescribing for large patient populations. Most of the PS providers in these regions were providers who had PS interactions with a small number of patients (1–4 patients, blue dots), with the excetion of high prescriber hubs such as Rapid City in South Dakota and Salt Lake City in Utah (red dots, Figure 2).

PS providers over time

An assessment of the number of providers who signed PS orders for their patients for various time periods of up to 12 months demonstrates that the number of physicians who had PS interactions with their patients generally decreased over time, irrespective of the number of patients they were managing. There was a relatively high number of physicians (n = 21,004) who signed orders for at least two PS prescriptions for a small number of patients with CIF (1–4 patients) over a relatively short period of time (ie, 2 months). This number dropped by 47% over 12 months, indicating that only a little over half (n = 11,205) of physicians still prescribed PS for their individual patient or small patient group after 1 year (Supporting Information: Figure 1).

Considerably fewer physicians signed orders for at least two PS prescriptions over at least 2 months for 5–9 patients with CIF (n = 648) and even fewer for 10–19 and 20 or more patients with CIF (n = 176 and n = 83, respectively) (Supporting Information: Figure 1). After 12 months, only 37% of physicians with 5–9 patients (n = 237), 44% of physicians with 10–19 patients (n = 78), and 33% of physicians with ≥20 patients (n = 28) still prescribed PS for their patient pool.

Travel distance for PS prescriptions

We analyzed the median distance patients with CIF traveled outside of their ZIP3 area to receive PS prescriptions. Patients traveled a median of 63 miles (range = 1–5107 miles) outside of their ZIP3 area to receive their PS prescriptions.

However, we observed substantial differences depending on the residing region. Patients in the Northeast traveled considerably less distance (median 34 miles [range = 1–5107 miles]) outside of their ZIP3 area compared with patients in other regions of the country. With a median distance of 102 miles (range = 3–4569 miles), patients in the West traveled the furthest distance outside of their ZIP3 area to receive their PS prescriptions, followed by patients in the South (median 85 miles [range = 2–4719 miles]) and Midwest (median 85 miles [range = 3–4509 miles]) (Figure 3A).

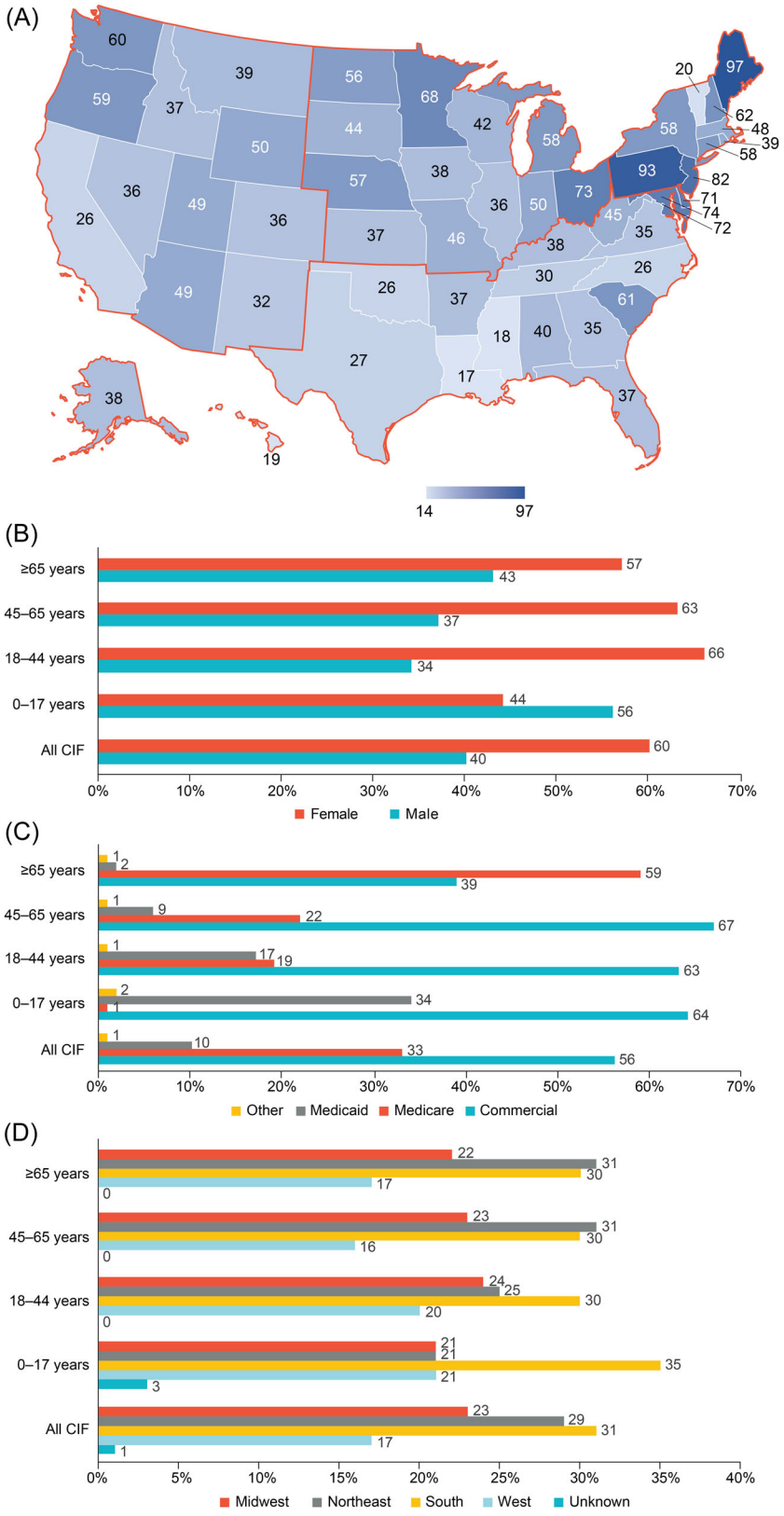

FIGURE 1 Characteristics of patients with chronic intestinal failure (CIF). (A) Number of patients with CIF for each US state per million individuals in the Integrated DataVerse claims database, (B) sex, (C) insurance provider, and (D) region, categorized by age group

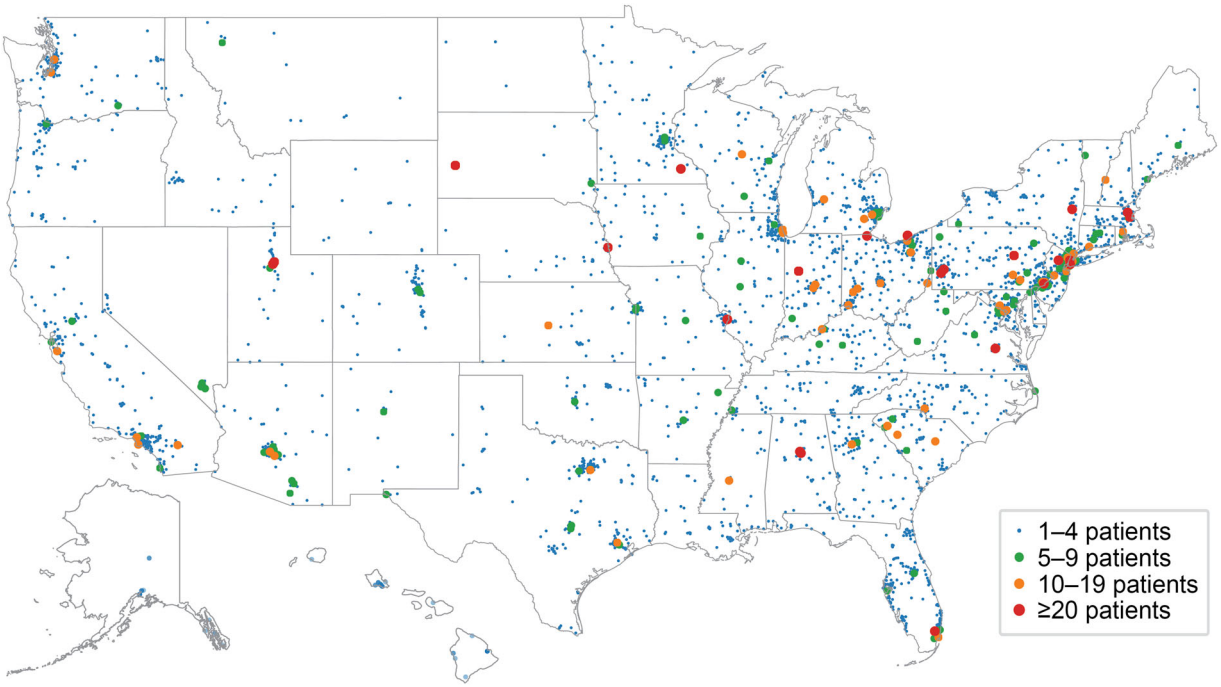

FIGURE 2 Geographic location associated with parenteral support (PS) providers in the United States. The color represents the number of patients each provider had PS interactions with that were at least 12 months apart. Each dot represents one physician who signed orders for PS prescriptions at the respective geographical location associated with their ZIP code. Providers with higher patient counts took priority over providers with lower patient counts at each ZIP location

The distribution of the average distance all patients with CIF with available location data (n = 16,449) traveled outside of their ZIP3 area to receive PS prescriptions indicates that approximately half of the patients traveled between 10 and 100 miles for their PS prescriptions (55%), yet a notable proportion traveled between 100 and 1000 miles (33%) (Figure 3A). Of note, patients in the pediatric age group (0–17 years of age, n = 1667) traveled further on average (median of 77 miles) than adult patients (n = 14,942, median of 62 miles) (Figure 3B).

DISCUSSION

To our knowledge, our study is the first comprehensive analysis of CIF prevalence and state of patient management in the United States that is based on PS prescription claims and medical utilization data. The IDV claims database provided valuable insights into the characteristics associated with this severe condition, whose impact may be underappreciated by the lack of uniform Healthcare Common Procedure Coding System (HCPCS)[13] and International Classification of Diseases (ICD)[14] codes.

Our study identified up to 24,048 patients with CIF in the United States between October 2012 and June 2020, with this overall number being similar to that of patients receiving HPN (n = 25,011) reported in a previous study.[8] Our finding of approximately 75 patients with CIF per million individuals compared with the data reported from 2013 (79 per million)[8] indicates that CIF prevalence has remained relatively stable. This consistency could be reflecting improvements in the management of diseases associated with CIF. Immunotherapeutic agents for the management of cancer and inflammatory bowel disease may be resulting in the need for less surgical interventions and thus lower prevalence of short bowel syndrome, the primary underlying cause for CIF, while at the same time, the life expectancy of patients with CIF has increased owing to improvements in care.

Overall, we found that women were more affected by CIF than men, as was noted in previous studies.[15] The predominant age group was adults >45 years of age. In our data set, 9% of patients with CIF were children or teenagers, slightly lower than noted in previous US studies,[8,16] but similar to those from European centers.[6] In terms of healthcare coverage, most patients relied on commercial health insurance. Medicare was the most important provider for patients 65 years of age or above and Medicaid was the second most important provider in the pediatric age group, as would be expected from the eligibility criteria of the two programs.

In terms of prescribing characteristics, most providers signed orders for PS prescriptions for a single patient or small patient group over a short period of time. Often, these prescriptions are being guided by DME providers who are delivering PS to patients, as many PS prescriptions have the ability to have DME provider actively manage PS.[8] Although the DME providers may be managing PS for a significant number of patients,[8] they are not able to provide wholistic CIF care for individual patients. There were only a small number of

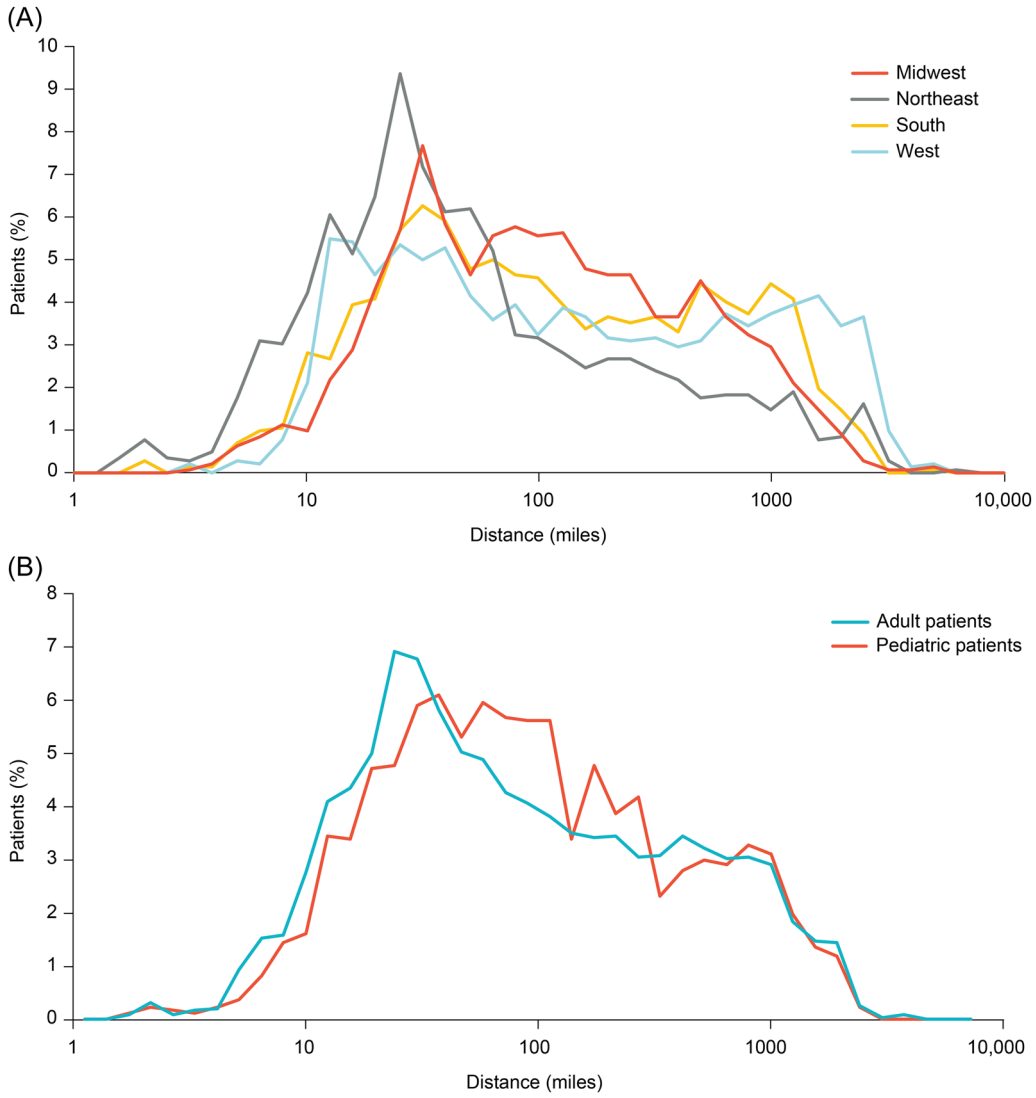

FIGURE 3 Distribution of the distance patients traveled to a different ZIP3 area code for parenteral support (PS) prescriptions. (A) The distribution of all patients by US region. (B) The distribution of adult and pediatric patients. Overall, 16,449 patients who had chronic intestinal failure, for whom precise ZIP3 code data were available, and who had at least one PS prescription provided outside their ZIP3 area were included in this analysis

physicians ($n = 28$) who signed orders for PS for a large cohort of patients (20 patients or more) long term (12 months), presumably indicating more stable patient populations at well-established medical centers specializing in the care of patients with CIF. Previous evaluations of the US HPN population have had similar findings, with analysis of 2013 Medicare data noting a 1:1 ratio between patients and number of providers signing PS orders.[8] These findings highlight a stark difference in the management of patients with CIF in the United States compared with other developed nations.

Even though PS orders were signed by providers who managed a small number of patients, presumed to be primary care providers, patients still traveled up to 100 miles to receive their PS prescriptions. This indicates that, although patients were able to have their PS orders filled locally, they often had to travel considerable distances to visit with the provider who wrote the original PS prescription. A large proportion of patients traveled >100 miles, indicating a substantial inequality in healthcare coverage throughout the country. Importantly, children and teenagers had to travel further on average than their adult counterparts. The need for patients to travel long distances to visit their provider has also been observed by the Oley Foundation,[17] an advocacy organization for those living with home intravenous nutrition and tube feeding.

These findings were especially evident in rural communities as most hubs with PS providers prescribing for large patient populations colocalized with highly populated areas, mostly in the Northeast, but also in other parts of the country. On the other hand, there was less coverage in the rural areas of the Midwest, South, and West, where the majority of providers prescribe PS for individual patients or small patient groups. For this reason, patients in rural areas presumably had to travel considerably longer

distances to receive PS prescriptions than their urban counterparts.

Having to travel these long distances with a severe condition like CIF to receive a PS prescription is a considerable burden on patients, especially on young patients. The need to find public restrooms due to high stool frequency and abdominal pain would make long-distance travel extremely challenging.[18] Furthermore, these results suggest a wider impact on patients' families and caregivers, who would regularly have to take time away from work and other duties to accompany or deliver patients to visits with their physician, resulting in lost productivity and potentially considerable out-of-pocket expenses for travel.[19]

Despite advances in the management of CIF, including dietary interventions, oral rehydration solutions, antimotility agents, and novel drugs targeting intestinal mucosal growth, the fragmentation of care for CIF in the United States appears to be worsening over time. From 2012 to 2020, we observed a general decrease in the number of physicians with long-term PS prescribing history. This trend is likely multifactorial but may be explained in part by fewer providers focusing on developing an expertise in the management of CIF. In addition, primary care providers may take on patients on PS in the short term and then refer them elsewhere when their condition becomes chronic, or as patients stabilize over time. However, this cannot fully explain the presence of only 28 providers signing PS orders for 20 or more patients for 12 months.

Other factors contributing to this trend could be a lack of physicians developing expertise in nutrition, augmented by the decline in nutrition-focused education in medical schools and residency programs.[20–22] Surveys of US medical schools found that only 25% require a dedicated nutrition course providing an average of 19.6 h of nutrition education, a reduction from 30% and 22.3 h noted 6 years earlier.[21] The data are not much better for postgraduate training programs, in which only 26% of programs had a formal curriculum for nutrition and 77% of program directors indicated that education goals for nutrition were not met.[22] This development is confirmed by the Oley Foundation,[17] which has noted with concern that access to providers with expertise in CIF and HPN management is declining as clinicians committed to the field are retiring and no one is stepping up to replace them.

This decline is exacerbated by the current reimbursement model for healthcare in the United States. In contrast to many other developed countries with government supported single-payer healthcare systems, the United States still has an employer-based healthcare system often with multiple payment models available depending on cost. These plans often reimburse significantly more for surgical interventions or procedures, such as endoscopy, than for office visits focusing on disease prevention. In this reimbursement model, many physicians tend to focus their practice on management of acute issues rather than chronic care, especially oversight of PS prescription.

To date, a central problem in caring for patients with CIF was that there were no specific HCPCS[13] and ICD[14] codes for CIF. Over decades, this situation has complicated clinical practice and forced healthcare providers to use a variety of other diagnostic and treatment codes for their patients with CIF. Appropriate codes for intestinal failure and short bowel syndrome have been added to the 2022 release of the ICD-11[14] and are under discussion for the ICD-10-CM[23] for use in the United States as well. The authors hope that future iterations of the ICD and HCPCS applicable in the United States will include these codes to facilitate management of, and reimbursement for, patients with CIF. The lack of a uniform coding system to date has not only limited an assessment of the true prevalence of CIF in the United States, it also hampered analysis of healthcare resource utilization and other characteristics associated with CIF, which would enable the establishment of appropriate regulations and frameworks for its management.[2]

LIMITATIONS

This study has several limitations (additional limitation details are included in the Supporting Information). First, the IDV claims database contains duplications of patient data that may arise if patients moved to a different state or if there were changes to their demographic information, such as a change of name. For this reason, the number of patients with CIF identified may include an unknown number of duplications and, thus, the prevalence of CIF stated is an estimate. This may also affect the decline in PS providers we observed over time, as some patients could be duplicated and appear as two patients with partial PS histories. Second, the IDV claims database does not include all claims made in the United States for the period investigated. This may affect especially the Western region of the United States, as claims covered by one of the large insurers in the Western states are not included in the database. Third, the definition of the CIF patient population relies on receipt of PS prescriptions over a defined period of time, which may exclude patients who have been weaned off PS or who fall outside of this time period. Fourth, for the assessment of patients' travel distance, we used the center of patients' ZIP3 area code, which is not identical with the patients' exact location. Furthermore, only the current location of the patient and physician were available, which is not necessarily their location at the time of the PS interaction. As a result, the very large travel distances identified are likely artifacts. In addition, some of the PS interactions may have taken place via telehealth solutions instead of in person, which may also contribute to producing artifacts.

CONCLUSION

CIF is a rare disease with up to 24,048 patients and an estimated prevalence of 75 per million in the United States. CIF affects individuals of all ages, with a higher prevalence in women than in men. Our study suggests a noticeable disparity in healthcare coverage for patients with CIF in rural compared with urban areas, which is most notable in the Northeast compared with other regions of the country. Despite CIF management being complex and

requiring a multidisciplinary team with diverse expertise, a relatively large number of physicians who sign PS prescriptions do so for a small number of patients. Only relatively few physicians sign PS prescriptions for large patient groups long term, indicating a need for greater centralization to secure management by highly experienced multidisciplinary teams throughout the United States. This leads many patients to travel great distances, presumably contributing to a worsening of the overall disease burden on patients and their families and caregivers. This trend may be exacerbated by a general decline of providers with expertise in CIF and nutrition over time. To date, these health inequalities for patients with CIF have likely been obscured by the lack of unique HCPCS and ICD codes for CIF, forcing healthcare providers to code for their patients under a variety of other diagnostic and treatment codes. Along with the ongoing introduction of unique ICD and hopefully HCPCS codes for CIF and associated diseases, centralized care, revision of reimbursement models, and expansion of nutrition-focused education are needed to provide the best possible outcomes for patients.

AUTHOR CONTRIBUTIONS

Manpreet S. Mundi, David Mercer, Kishore Iyer, Lis B. Zimmermann, Mark Berner-Hansen, and Douglas L. Seidner participated in the conceptualization and design of the study; Lis B. Zimmermann and Mark Berner-Hansen obtained funding for medical writing and editorial assistance; Daniel Pfeffer analyzed the data and provided the methods; Daniel Pfeffer, Manpreet S. Mundi, David Mercer, and Mark Berner-Hansen reviewed and verified the data; all authors interpreted the data; all authors reviewed the manuscript critically for important intellectual content; all authors approved the final version for publication, with the exception of Douglas L. Seidner, who sadly passed away before final manuscript approval.

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CONFLICT OF INTEREST

Manpreet S. Mundi has received research grants from Nestlé, Fresenius Kabi, and Real Food Blends. He is also a consultant for Baxter and part of an emerging experts SBS group with Zealand Pharma, outside of the submitted work. David Mercer is a consultant and principal investigator for Zealand Pharma, outside of the submitted work. Kishore Iyer has received grant support from Takeda and Zealand Pharma, outside of the submitted work. He has also been scientific advisor for Zealand Pharma (outside of the submitted work), VectivBio, Takeda, and Hanmi Pharmaceutical. Lis B. Zimmermann and Mark Berner-Hansen are employees and shareholders of Zealand Pharma. Daniel Pfeffer and Joan Bishop have no competing interests to declare.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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