

Understanding Data and Opportunities Focused on Value

A Single-Center Experience in Headache Care

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Abstract

Background and Objectives

Headache syndromes are highly prevalent, disabling, and costly. Our goals were to (1) describe headache care delivery and costs in a system and (2) identify opportunities for the system to collect, organize, or analyze health care data to facilitate value-based headache care delivery.

Methods

We performed a descriptive, retrospective cohort study using data from a large integrated health system (July 2018–July 2021). We assigned individuals into a reference (REF) or headache group based on headache-related ICD diagnoses. The primary exposure variable, applied to the headache group, was the headache specialty seen most after the incident headache diagnosis: primary care (PC), neurology (NEU), or headache subspecialist (HS). Outcomes of interest were per member per month all-cause costs, per episode costs, all-cause utilization, and headache utilization. Variables included age, sex, insurance contract, and the Adjusted Clinical Groups (ACG) concurrent risk score. We calculated univariate statistics for clinical indicators and outcomes for each group. For outcome variables, we also report these statistics after adjustment for ACG risk score.

Results

We identified 22,700 (14%) individuals in the headache groups and 138,818 (86%) individuals in the reference group (REF). Within the headache groups, 84% received care from PC, 14% from NEU, and 2% from HS. The average ACG risk scores increased across exposure groups. In both unadjusted and after risk adjustment analyses, total cost of care (TCOC) was highest in NEU and HS, and the largest drivers of TCOC were outpatient facility costs, followed by inpatient facility costs. HS had the highest pharmacy and professional costs. After risk adjustment, all-cause inpatient admissions and headache-related ED visits were roughly similar, although there was increasing use of outpatient PC and NEU visits across exposure groups.

Discussion

Individuals seen by a NEU or HS had higher medical morbidity, higher health care utilization, and higher costs than those who receive care from PC. Outcome data were either not available or not structured to determine the value of neurologic expertise in headache care or within a particular headache care pathway. To clarify neurology's value in primary headache disorders, we encourage health system leaders to adopt an economic evaluation framework.

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Introduction

Headache syndromes are highly prevalent and among the leading causes of disability worldwide. According to the Global Burden of Disease Study 2016,¹ tension-type headache was the third most prevalent disease and migraine the sixth. Migraine was the second highest cause of years of life lived with disability.

In the United States, a 2018 review of national publicly available sources showed that migraine affects 1 in 6 Americans over a 3-month period and headaches are in the top 5 reasons for an emergency department visit.² Migraine prevalence and severity are not equally distributed in the United States, with women and historically marginalized populations having the highest burden of disease.³

The economic impact of headache, especially migraines, cannot be overstated.^{4,5} Higher direct medical costs are clearly correlated with monthly headache days and headache severity,^{6,7} and the annual cost of chronic migraine is consistently and substantially higher across studies than for episodic migraine.^{8,9} Indirect costs of headache related to work absenteeism and lost productivity are even higher, accounting for more than 80% of total costs of headache in some studies.¹⁰

Although most headaches are addressed in primary care settings,¹¹ neurology providers have a prominent role in headache care, especially in complex, severe, or refractory cases. Determining the cost and value of using neurologists to provide headache care is an area of active study. In one study on a US commercial administrative claims data set, the annualized cost of migraine care increased by 66% when a neurologist was involved.¹² Another commercial claims-based study showed higher medical costs (headache-related and non-headache-related) in the first year after incident diagnosis of headache for individuals seen by a neurologist compared with those without one, with costs of neurology cases decreasing toward control in the years thereafter.¹³ A third study using the Medical Expenditure Panel Survey (MEPS) showed that while headache-related costs were higher in the group with neurology involvement in year 1, those costs were nearly equal to controls in year 2.¹⁴ Where measured, it appeared that individuals seen by a neurology provider had trends toward or significant improvement in headache quality indicators such as appropriate medication treatment, reduced headache burden, higher patient satisfaction, and higher quality of life than either their baseline or non-neurology involved controls.¹³⁻¹⁷

In the context of escalating medical costs and increased demands on limited health care resources, program evaluations and economic evaluations are increasingly being performed to inform value-based care.¹⁸ We partnered with a large integrated US health system to (1) describe the landscape of headache care delivery and costs in the system and (2)

identify opportunities for the system to collect, organize, or analyze health care data to facilitate future improvements in value-based care delivery.

We believe that many health care organizations share similar aspirations to demonstrate value and high-quality care. Furthermore, the profession of neurology seeks to optimize headache care and the neurology provider's role in it. This study, conducted under real-world conditions (i.e., without a dedicated funding stream), represents a practical effort to approach and understand headache care delivery and costs.

Methods

Study Design and Setting

This is a descriptive, retrospective cohort study using data from a large integrated health system in the Midwest United States that provides care and insurance coverage to 170,000 individuals. The health system participates in risk contracts for subsets of its population, receives regularly updated files of administrative claims data from its health plans, and integrates those data with electronic medical record (EMR) data. For this study, administrative enrollment, medical, and pharmacy claims data were combined with data from the EMR to identify the population, create subgroups, and measure clinical indicators and outcomes.

With respect to headache care, the health system has 525 primary care providers (PCPs), 12 general neurology providers (4 physicians, 8 advanced practice providers), and 5 neurology headache subspecialists (2 physicians, 3 advanced practice providers). The headache subspecialists work in a comprehensive and interdisciplinary headache clinic alongside pain psychologists, pharmacists, and physical therapists to develop and implement a treatment plan.

Participants

The population consisted of all individuals attributed to any one of the health system's value-based contracts (Medicare, Medicaid, commercial individual, commercial group) between July 1, 2018, and July 1, 2021. Individuals diagnosed with secondary headache conditions (e.g., stroke, brain tumor) or extremely expensive medical conditions (cancer, end-stage renal disease, transplantation) within the study period or the preceding 6-month period were excluded from analysis. The remaining individuals were assigned into a headache group or reference group depending on the presence (or absence) of a headache-related ICD diagnosis (see eAppendix 1) within the study period.

Variables

The primary exposure variable, applied to the headache group, was the headache specialty (primary care, general neurology, or neurology headache subspecialist) seen most after the incident headache diagnosis date. Individuals who saw different tiers of headache specialists during the exposure

period contributed their patient-months of data to their highest exposure tier.

Four mutually exclusive groupings were created from the overall population as follows: Reference (REF)—individuals without a headache diagnosis; primary care (PC)—individuals with a headache diagnosis and who did not have a neurology office visit; neurology (NEU)—individuals with a headache diagnosis and who had at least 1 neurology office visit; headache specialist (HS)—individuals with a headache diagnosis and who had at least 1 headache subspecialist office visit.

Outcomes were characterized as either all-cause (i.e., not restricted to headache) or headache specific.

Outcomes of interest were as follows:

- Per member per month (PMPM) all-cause (i.e., not restricted to headache) costs—total cost of care (TCOC), pharmacy, inpatient facility, outpatient facility, imaging, skilled nursing facility (SNF), and professional fees
- Per episode (i.e., per single instance) costs—ED visit and inpatient admission
- All-cause utilization—inpatient admissions, PCP visits, and neurology visits
- Headache utilization—ED visits, PCP visits for headache, and neurology visits for headache

Per episode costs and utilization parameters are amassed throughout the 3-year study period and divided by the person-months represented (i.e., averaged over the study period). Utilization parameters are per 1,000 members. We additionally constructed neurology to PCP visit ratios for all-cause and for headache diagnoses.

Variables included total and median patient-months of observation, age, sex, race, ethnicity, insurance contract (Medicare, Medicaid, Commercial Individual, Commercial Group), and the Adjusted Clinical Groups (ACG) concurrent risk score. Age was coded as a continuous variable. Sex was only available as a binary variable as collected by the health system. Gender was not available. The ACG risk score is a ratio level measurement and is further explained below.

The Adjusted Clinical Group Risk Score

Individuals in a population are assigned to one of roughly 100 mutually exclusive ACG morbidity categories based on age, sex, and medical diagnoses (clinically categorized based on the expected duration, severity, diagnostic certainty, etiology, and expected need for specialty care).¹⁹ Each ACG category includes individuals with a similar pattern of morbidity and similar expected resource use, and each ACG category is converted into a weighted risk score by taking the average cost of individuals at that ACG to the average cost of all individuals in the (local health system) population. Thus, a group with an ACG risk score of 2 is expected to use twice as many resources as a group with an ACG risk score of 1. In

this study, we calculated subgroup ACG risk scores (REF, PC, NEU, and HS) by averaging individual ACG risk scores per subgroup.

Analysis

We calculated univariate statistics (means and percentages) for clinical indicators and outcomes and reported these statistics for the reference group and each headache group. For outcome variables, we report additionally these statistics after adjusting for the ACG risk score (setting the reference population to an ACG risk score of 1). Risk adjustment by ACG risk score was performed by dividing a subgroup's raw cost and utilization data by its own ACG risk score. To understand any substantial variation among subgroups, an additional breakdown of groupings was done by insurance product to determine whether membership in any specific insurance type drove outcomes.

Standard Protocol Approvals, Registrations, and Patient Consents

A determination of non-research was made by the organization's IRB administration. Review by the IRB was not required for this quality assurance and program evaluation study. Identifiable clinical information was retained within the health care operations team.

Data Availability

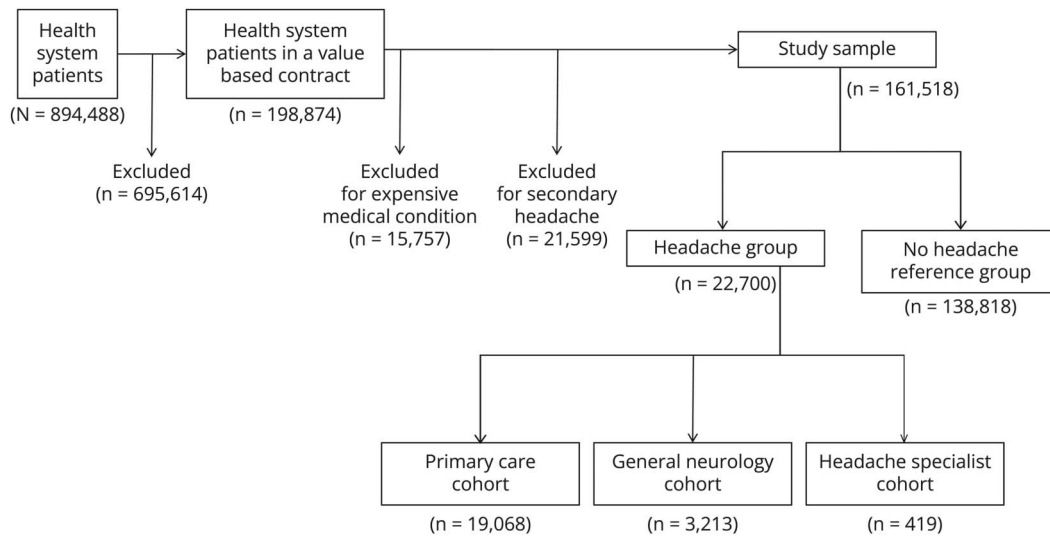
Anonymized data not published within this article will be made available by request from any qualified investigator.

Results

The Figure depicts the CONSORT diagram for this study. We identified 22,700 (14%) individuals in the headache groups and 138,818 (86%) individuals in the reference group. In the headache groups, 19,068 individuals (84%) did not see a neurologist, 3,213 (14%) saw a general neurologist, and 419 (2%) saw a headache neurologist. Table 1 reports the variables by exposure group. Female individuals made up the largest percentage of individuals with a headache diagnosis (74% among all subgroups), and notably 86% of those who saw a headache specialist were female. The distribution of individuals among insurance types within the subgroups largely reflects the distribution within the reference population, although neurologists had a higher percentage of individuals on Medicare than commercial insurance products. The average ACG risk scores increased across exposure groups, with the NEU and HS groups having morbidity close to 3 times that of the REF group and over 1.5 times the morbidity of the PC group.

In Tables 2 and 3, the outcome variables are reported raw and risk adjusted by the ACG risk score for each group. In unadjusted analysis, total cost of care (TCOC) was highest in the NEU and HS groups (\$602 and \$557 PMPM, respectively). The largest 2 drivers of TCOC across all groups were outpatient facility costs, followed by inpatient facility costs.

Figure CONSORT Diagram



Although pharmacy costs were the number 3 driver of TCOC across all groups, they were substantially higher in the HS group at \$79 PMPM compared with \$15 PMPM in the NEU group and <\$3 PMPM in the PC and REF groups. Similarly, professional costs were also substantially higher in the HS group at \$71 PMPM than \$15 PMPM in the NEU group and <\$2 PMPM in the PC and REF groups. The NEU subgroup had an unexpectedly high PMPM SNF cost (\$8.7), which is unlikely to be related to headache care.

After risk adjustment, TCOC was roughly 1.5 times as high in the NEU and HS groups compared with the PC group. Again, this was primarily driven by pharmacy costs (3 times and 17 times that of PC, for NEU and HS, respectively) and professional costs (6 times and 27 times that of PC, for NEU and HS, respectively). Imaging costs were 5 times and 4 times that of PC in the NEU and HS groups, respectively, although the absolute difference in PMPM imaging was modest at \$0.8 PMPM. After risk adjustment, the HS group had lower inpatient facility and SNF costs than the PC group. As stated above, the PMPM SNF cost for the NEU subgroup remained high compared with that of the PC group even after risk adjustment, although this cost was similar to the REF group.

Unadjusted costs per ED visit (\$643-\$964) and per admission (\$9,267-\$11,924) were similar across exposure groups. With risk adjustment, these per episode costs were lower in the headache groups than in the reference group.

All-cause inpatient admissions increased modestly across exposure groups, though were roughly similar across groups after risk adjustment. There was increasing use of outpatient PCP and neurology (sub)specialty visits across exposure groups. The ratios of neurology (sub)specialty to PCP visits

for any condition were 0.6–0.7 for the NEU and HS groups while the ratios of (sub)specialty to PCP visits for headache diagnoses were 4.6–5.3. Headache-related ED visits increased across exposure groups, albeit at a lower rate after risk adjustment.

Costs and outcomes within an exposure group did not materially differ across insurance providers (results not shown).

Discussion

Within 1 integrated health system, we found that most individuals diagnosed with a primary headache disorder do not see a neurology provider (84%) and that those individuals who do see a neurology provider or headache subspecialist have higher medical morbidity (>1.5 times) than those who receive headache care from a primary care provider. In this health system, individuals who suffer from headaches have higher utilization of inpatient and outpatient services compared with individuals without headaches, although their utilization rate generally fits with what would be predicted by their global ACG risk score.

By contrast, individuals who receive headache care from a neurology provider or headache subspecialists have higher total costs (\$57–85 PMPM or approximately 1.5 times), even after risk adjustment, than those who receive headache care from primary care. This difference is driven primarily by pharmacy costs, professional fees, and imaging costs.

Although our current analysis contains important demographic information and a sophisticated risk-adjustment parameter (the ACG risk score), it does not contain many

Table 1 Study Demographics

	Reference group	Headache groups		
	REF (n = 138,818)	PC (n = 19,068)	NEU (n = 3,213)	HS (n = 419)
Total patient-months	3,466,190	505,476	91,855	12,461
Median patient-months	31	33	33	33
Age	43	44	51	47
% Female	52	74	71	86
% Race				
White	80	82	86	84
Black or African American	4	6	5	6
Asian	2	1	1	1
Other	<1	1	<1	<1
Unknown	14	11	8	9
% Ethnicity				
Non-Hispanic	87	89	92	91
Hispanic	5	6	4	4
Unknown	8	5	4	5
% Insurance				
Medicare	24	19	36	21
Medicaid	26	31	30	27
Commercial group	44	45	31	47
Commercial individual	6	5	3	4
ACG Risk Score	1.00	1.77	2.76	2.92

Abbreviations: ACG = Adjusted Clinical Group; HS = headache specialist cohort; NEU = general neurology cohort; PC = primary care cohort; REF = reference group.

Other race includes American Indian, Alaska Native, Native Hawaiian, or Other Pacific Islander.

headache-relevant parameters. As an example, it would be instructive to know the primary headache diagnosis, as it has been shown that chronic migraine sufferers have considerably higher disease burden, medical utilization, and medical costs than their episodic migraine counterparts, even after adjusting for confounders.^{8,9} Complementary to diagnosis, details about a patient's baseline headache days per month or disease impact would help classify disease severity.

These results are in line with others, although comparing across methodologically different studies is challenging. The demographics of our sample are similar to those of other population studies. Most individuals were in their working years, and female individuals had higher rates of most primary headache subtypes.¹⁵ Similar to other studies, we found a minority of individuals receive headache care from a neurologist,²⁰ and medical comorbidity is higher in those who receive neurologic care.¹⁵ Furthermore, despite adjusting for morbidity, we continued to find higher costs and health care

utilization in our neurology and headache subspecialty subgroups than in primary care.^{13,15} As in our analysis, pharmacy costs were previously cited as a main driver of headache costs.⁹

Another principal finding of this work was that the currently available data were necessary but insufficient to determine the value of headache care within the organization. We surmise that most organizations will similarly struggle with the availability of key data and with the ability to transform existing data into information for proper evaluation and tailored interventions. Although acquiring, organizing, and analyzing more data comes at a cost, we recommend the use of an economic evaluation framework to pursue and inform value-based care initiatives. To that end, we highlight 6 key components of an economic evaluation to guide organizations on how to collect, organize, and analyze health care data to determine the value of headache care. These components align closely with the latest reporting guidance for health

Table 2 Costs and Utilization, Unadjusted

	Reference group	Headache groups (unadjusted)		
	REF	PC	NEU	HS
ACG Risk Score	1.00	1.77	2.76	2.92
All-cause				
PMPM costs (USD)				
Pharmacy	1.6	2.9	14.7	78.9
Inpatient facility	78.1	90.7	231.3	136.8
Outpatient facility	83.3	136.5	323.6	254.4
Imaging	0.2	0.4	2.7	2.2
Skilled nursing facility	2.9	1.9	8.7	1.1
Professional fees	0.9	1.5	14.9	71.3
Total	167	236	602	557
Per Episode costs (USD)				
ED visit	964	643	951	758
Inpatient admit	11,446	9,845	11,924	9,267
All-cause utilization^a				
Inpatient admits	81.9	114.8	232.8	177.2
PCP visits	827	1,220	1,687	1,629
Neuro visits	57	0	1,029	1,135
Neuro/PCP	0.07	0	0.61	0.70
Visit ratio				
HA utilization^a				
ED visits	N/A	33.5	75.8	193.6
PCP headache visits	N/A	36	42	149
Neuro headache visits	N/A	N/A	192	794
Neuro/PCP headache	N/A	N/A	4.60	5.32
Visit ratio				

Abbreviations: ACG = Adjusted Clinical Group; ED = emergency department; HS = headache specialist cohort; NEU = general neurology cohort; Neuro = neurology (any type) provider; PC = primary care cohort; PCP = primary care provider; PMPM = per member per month; REF = reference group; USD = US dollars.

^a Utilization is calculated per 1,000 members.

economic evaluations (CHEERS)²¹ and have consistently appeared in features of scoping reviews.²²⁻²⁴ The 6 components, which we detail below, are perspective, intervention, target population, costs, outcomes, and study design.

It is important to recognize that different stakeholders will have different perspectives of “value.” Improved value for one stakeholder or at one level of the socioecological model may not be universal. In our example, we analyzed data at the level of the health system because VBC arrangements attribute costs and outcomes of the system’s population to the health system. Because primary headaches have an outsized

proportion of indirect costs (e.g., loss in work productivity) compared with direct medical costs, analysis at a societal level would further highlight the importance of expert headache care to society.

Intervention

A central tenet of economic evaluations is a clearly defined intervention—and a comparator ideally—ranging from drugs to medical technologies to entire treatment programs. Our intervention was loosely defined as the use of neurology providers and headache specialists compared with primary care in headache care. Rather than assessing the value of

Table 3 Costs and Utilization, Adjusted

	Reference group	Headache groups (adjusted)		
	REF	PC	NEU	HS
ACG risk score	1.00	1.00	1.00	1.00
All-cause				
PMPM costs (USD)				
Pharmacy	1.6	1.6	5.3	27
Inpatient facility	78.1	51.3	83.8	46.8
Outpatient facility	83.3	77.2	117.3	87.0
Imaging	0.2	0.2	1.0	0.8
Skilled nursing facility	2.9	1.1	3.2	0.4
Professional fees	0.9	0.9	5.4	24.4
Total	167	133	218	190
Per episode costs (USD)				
ED visit	964	363	345	259
Inpatient admit	11,446	5,362	4,321	3,169
All-cause utilization^a				
Inpatient admits	81.9	64.9	84.4	60.6
HA utilization^a				
ED Visits	N/A	18.9	27.5	66.2

Abbreviations: ACG = Adjusted Clinical Group; ED = emergency department; HS = headache specialist cohort; NEU = general neurology cohort; Neuro = neurology (any type) provider; PC = primary care cohort; PCP = primary care provider; PMPM = per member per month; REF = reference group; USD = US dollars.

^a Utilization is calculated per 1,000 members.

headache care at an aggregated, system level, it likely would be more instructive and interpretable to determine value at the level of distinct homogeneous headache care pathways.²⁵ Examples include a first outpatient evaluation and management of a headache diagnosis or an ED visit for uncontrolled headache symptoms. Evaluation per pathway (or per intervention) facilitates more appropriate decision making and can also inform the best allocation of neurologic expertise across the health system. Unfortunately, most health systems have yet to develop data models or reports that would support analysis at this level of granularity.

Each person has a different “baseline” in terms of their clinical status, functional health status, and care expectations.²⁶ In many scenarios, that baseline status has profound effects on applicable care processes and eventual care outcomes. Unfortunately, in this study, relevant headache parameters were not available or were unreliable. For instance, it is unclear whether primary headache diagnosis followed the International Classification of Headache Disorders (ICHD-3). Many of the other primary headache diagnoses (e.g., cluster headaches) had too few cases to be meaningfully and independently analyzed. Therefore, we

analyzed the entire set of primary headache diagnoses. We encourage headache leaders and quality improvement and value-based care champions to work with clinicians to systematically collect 1–2 key parameters of headache severity so that more nuanced and cross-context comparisons can be performed.

Cost data are notoriously obscure in the health care setting. A strength of this project is the transparency around total and line-item costs (e.g., pharmacy, imaging, facility) for headache care and that we were able to segment those costs by cohort with relative ease for additional insights. However, it is a nontrivial request to identify “headache-attributable costs” from the global cost management system. We were left largely with all-cause costs and the need to estimate headache-related costs by cross-cohort comparisons and ACG risk adjustment. Because the proportion of headache-related costs (and utilization) to total costs (and utilization) is small, the precision for headache-based cost accounting is low. Therefore, management personnel may need to support registries or customize reports that more discriminatively capture headache-related costs to properly appraise the value of headache care.

A limitation of the current data was the lack of headache-specific outcomes. Although we reported generic utilization parameters (e.g., ED visits, inpatient admissions), they are not sensitive to the expected results of proper vs suboptimal headache care. Commonly cited and more sensitive headache outcome metrics include headache days per month, the Migraine Disability Assessment score, or the Headache Impact Test (HIT-6).^{6,7,9,27} We recommend the parsimonious selection of a feasible number of outcomes that can be measured regardless of care delivery location or treatment modality to facilitate comparisons across interventions or care pathways. One proposal is hours lived with disability averted as an intuitive measure that would be responsive to both acute and preventative therapies and across headache subtypes.²⁸ In addition, compared with pain levels, this outcome may be more clearly linked to work absenteeism and health care utilization.

Economic evaluations have different study designs and model structure. Full economic evaluations measure the costs and outcomes for competing interventions. The type of evaluation depends on how costs and outcomes are expressed (e.g., cost minimization, cost benefit, cost effectiveness). Partial evaluations, which may measure only costs, only outcomes, or only have 1 intervention, can still be insightful and may be sufficient depending on organizational context.²⁹ This study involved a snapshot of costs and utilization of headache sufferers across different provider groups. Assignment of patients to a provider type was not random, so selection bias is expected. Despite these threats to causality, signals of value can still be ascertained. As an example, future steps might look at the variation of costs and outcomes within a provider type because those are expected to be involved in similar care (sub)pathways as a means to identify problematic or promising deviance. Another example is looking at how cost and utilization change over time. This is a method of benchmarking against self, such that trends show improvement over time. If headache metrics and methodologies align, an organization (or specific headache program) could also benchmark against other care delivery systems. In fact, we hope a beneficial byproduct of this project is that the cost and utilization data presented here will be available for others to use in their benchmarking efforts.

The above components are not an exhaustive list for a successful economic evaluation, but they do illustrate a gap between the maturity of currently available data and the desire to illustrate the value proposition for neurologic expertise in headache care.³⁰

We note that there are non-neurology providers who may specialize in headaches (e.g., pain teams) and subspecialty neurologists who *will not* address headache care. Improving these exposure misclassifications would likely increase the reported differences between cohorts. Second, we did not perform cost indexing for this 3-year study. Reported costs approximate the median time point (~2,020 US dollars). Third, there is endogeneity between insurance status,

potential and actual access to care (including neurologic care), and likelihood of receiving a headache diagnosis. Given potential selection bias with this observational study, we do not propose causal links. Fourth, we collected and adjusted for a limited number of observed confounding variables. In part, this is because larger studies have exhaustively adjusted for confounding variables and similarly found that these adjustments did not fully explain the higher morbidity or costs seen in headache subspecialty clinics. Fifth, we attributed all of an individual's cost data from the entire study period to their highest headache provider exposure tier. Another approach would be to attribute costs and outcomes at a monthly interval to a lower exposure group, and only assign them to a higher headache specialty provider subsequent to that exposure. Sixth, these results come from one tertiary, integrated health system, which may not be representative of other health systems.

In summary, within a large integrated health care system, we found that primary headache disorders were prevalent and generally seen by primary care. Individuals who receive headache care from a neurology provider or headache specialist have higher medical morbidity, higher health care utilization, and higher costs than those who receive care from primary care. Despite these findings, data were either not available or not structured to determine the value of neurologic expertise in headache care or within a particular headache care pathway. Given the trend toward VBC arrangements, we encourage health system leaders to adopt an economic evaluation framework to help the system clarify their data and analytic needs and select study designs to reach more definitive conclusions. In particular, systems that standardize data collection, ease the burden of data collection, and organize data for valid performance measurement will be well suited for VBC arrangements and improvements. With this framework, we anticipate health systems will be able to determine neurology's value in diverse areas such as the identification of primary vs secondary headaches, the prevention of episodic migraine transforming into chronic migraine, and the de-escalation of chronic headaches.

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