Published in final edited form as:
Int J Health Care Qual Assur. 2019 February 11; 32(1): 152–163. doi:10.1108/IJHCQA-04-2017-0060.

Emergency department utilization among individuals with idiopathic intracranial hypertension

Sean Murphy,
Department of Healthcare Policy and Research, Weill Cornell Medicine, New York, New York, USA

Daniel L. Friesner,
College of Health Professions, North Dakota State University, Fargo, North Dakota, USA

School of Economic Sciences, Washington State University, Pullman, Washington, USA

Robert Rosenman,
Initiative for Research and Education to Advance Community Health, Elson Floyd School of Medicine, Washington State University, Pullman, Washington, USA

School of Economic Sciences, Washington State University, Pullman, Washington, USA

Carin S. Waslo,
Department of Neurology, Veterans Affairs Portland Health Care System, Portland, Oregon, USA

Johnathan Au,
Chicago Medical School, Rosalind Franklin University of Medicine and Science, Chicago, Illinois, USA

Emanuel Tanne
Casey Eye Institute, Oregon Health and Science University, Portland, Oregon, USA

Intracranial Hypertension Research Foundation, Vancouver, Washington, USA

Abstract

Purpose ––Idiopathic intracranial hypertension (IIH) can be a debilitating disorder that is difficult to identify and treat. Failure to adequately manage IIH symptoms may force patients to present at emergency departments (EDs) seeking symptom relief. The purpose of this paper is to empirically characterize ED use by previously diagnosed IIH patients.

Design/methodology/approach ––Patients diagnosed with IIH, and who registered with the Intracranial Hypertension Registry by 2014, were solicited for study inclusion. A survey was designed to elicit ED use during the period 2010–2012. Information on demographic and socioeconomic characteristics, IIH signs and symptoms, time since diagnosis, perspectives of ED use and quality of life was collected. Quality of life was assessed using an adaptation of the Migraine-Specific Quality of Life Questionnaire. Data were analyzed using descriptive statistics and nonparametric hypothesis tests.

Corresponding author: Daniel L. Friesner can be contacted at: Daniel.Friesner@ndsu.edu.

Findings — In total, 39 percent of IIH patients used emergency services over the study period; those that did used the services intensely. These patients were more likely to be non-white, live in households making less than $25,000 annually, have public insurance and have received a diversional shunt procedure. Patients who used the ED were less likely to live in households making $100,000, or more, annually and have private insurance. Participants who used the ED had significantly lower quality-of-life scores, were younger and had been diagnosed with IIH for less time.

Originality/value — ED staff and outside physicians can utilize the information contained in this study to more effectively recognize the unique circumstances of IIH patients who present at EDs.

Keywords

Utilization; Emergency department; Idiopathic intracranial hypertension

Introduction

Estimates indicate that a substantial amount of ED visits are likely non-urgent. A review by Durand *et al.* (2011) indicates that 34 percent (IQR 27 percent, 52 percent) is the median percentage of ED visits identified as non-urgent in a retrospective analysis using explicit criteria (e.g. vital signs and diagnostic tests from the ED). The cost of ED visits has been estimated to be as much as 2.7–5.2 times higher for comparable visits in alternative settings (Thygeson *et al.*, 2008; Mehrotra *et al.*, 2009), hence understanding what motivates ED use beyond medical need is imperative. The purpose of this study is to understand, beyond clinical signs and symptoms, the driving forces involved in ED visitation among a patient population previously diagnosed with a specific disorder, idiopathic intracranial hypertension (IIH). It is not the intent of this study to determine appropriate or inappropriate ED visitation by IIH patients. In comparing IIH patients who visited EDs to those who did not, and evaluating frequency of use among those who did, we identify whether specific individuals, as measured by physical findings and symptoms, basic socioeconomic demographics and quality of life, were more or less likely to use ED services.

IIH is an often debilitating disorder affecting approximately one to three people per 100,000 in the general population (Durcan *et al.*, 1988; Radhakrishnan *et al.*, 1993; Digre and Corbett, 2001; Kesler and Gadoth, 2001; Asensio-Sanchez *et al.*, 2007; Friesner *et al.*, 2011; Glatstein *et al.*, 2015). The symptomatic and idiopathic nature of IIH makes it difficult to identify and treat (Lueck and McIlwaine, 2005). Historically, the clinical diagnosis of IIH was established using the modified Dandy Criteria, although revised guidelines have recently been proposed (Smith, 1985; Friedman and Jacobson, 2002; Friedman *et al.*, 2013). Given its low population prevalence, all guidelines require that IIH be diagnosed residually after eliminating other possible causes (Friedman *et al.*, 2013). The disorder is much more common in obese women of childbearing age, with an incidence rate of approximately 20 IIH cases per 100,000 people (Friesner *et al.*, 2011; Liu *et al.*, 2015). The most frequent signs and symptoms of IIH include severe headaches, papilledema and visual disturbances (Friedman, 2014; Lai *et al.*, 2014). In some cases, visual injury may become permanent. IIH symptoms are similar in scope to those of severe migraines (DeSimone *et al.*, 2014). The prevalence of migraines among IIH patients has been estimated at over 60 percent, and no differences were found between IIH patients who did or did not suffer from migraines, in terms of age, gender or body mass (Sina *et al.*, 2017).

The literature on ED use by IIH patients is scant. Jones *et al.* (1999) described the clinical presentation of 52 patients (1987–1996) in a retrospective analysis. Glatstein *et al.* (2015) examined ED use among children afflicted with IIH at Dana-Dwek Children's Hospital in Tel Aviv, Israel between 2000 and 2008. Three-fourths of patients reported headache as the primary symptom, followed by blurred vision. Koerner and Friedman (2014) conducted a retrospective chart review of 51 adult patients who were diagnosed with IIH, and who presented for care at Strong Memorial Hospital's affiliated EDs, over an 11-year period. Virtually all patients (96 percent) presenting at the ED reported headaches, while more than half of patients (53 percent) reported changes in vision. Approximately, 43 percent of patients presented at the ED due to recurrent symptoms. Most pertinent to the present paper, the authors found that the number of ED visits for IIH symptoms doubled over the study's time frame. During the same period, the total number of ED visits in the USA increased only 26 percent (McCaig and Ly, 2002; National Center for Health Statistics, 2012). Aside from the studies just discussed, the most relevant literature on the determinants of ED utilization is likely that which pertains to those who suffer from migraines and severe headaches, which in the US account for over 4m ED visits a year (Burch *et al.*, 2018). Previous work in this area has indicated that gender, age, race, disorder severity and socioeconomic status were all associated with ED use among patients who suffer from migraines (Minen *et al.*, 2014). Liu *et al.* (2015) examined the clinical management of IIH patients who visit the ED. They found that most of the patients underwent computed tomography scans during their ED visits. But, 96 percent of the scans led to no change in pathology, and 81 percent did not result in a change in the management of IIH. This implies that a better understanding the factors that lead patients with IIH to visit the ED may also provide opportunities to effectively manage care for IIH patients who visit the emergency room while simultaneously reducing the costs of providing that care.

Data from the Intracranial Hypertension Registry (IHR), the largest active source of complete information on individuals with IIH, provide a unique opportunity to examine important factors spurring ED utilization in a patient population suffering from a single, often incapacitating, idiopathic condition, IIH. The findings among this population, while important for physicians managing patients specifically with IIH, may also generalize to other conditions and represent the factors leading to general utilization of US hospital emergency departments (EDs).

Materials and methods

Study design and data source

This study adopts an exploratory, survey-based research design. Individuals identified for inclusion in this study were drawn from the IHR, which is co-sponsored by the Intracranial Hypertension Research Foundation and the Casey Eye Institute at Oregon Health & Science University (OHSU). IHR enrollment procedures require previously intracranial hypertension diagnosed individuals to complete an enrollment questionnaire, detailing demographic and clinical information, and consent to medical record collection. A diagnosis of IIH is confirmed according to the Modified Dandy Criteria, following a thorough review of the participant's medical records by medical staff (Smith, 1985). Patient information is annually updated in the IHR as resources and available patient information permit.

The IHR provided demographic and surgical information, collected during enrollment procedures, and also generated and administered a supplemental survey to enrolled individuals in order to gather further information of interest, such as ED utilization and insurance-related and basic household financial information. The OHSU Institutional Review Board approved the methods used in this manuscript.

Study subjects

At the time of the survey's administration in 2013, a total of 1,067 IHR enrolled individuals were confirmed as meeting the Modified Dandy Criteria for IIH. A total of 332 of the 1,067 individuals returned a partial or complete set of useable survey responses. This results in an effective response rate of 31 percent.

Survey data collection

Between the summer of 2013 and early 2014, confirmed IIH individuals enrolled in the IHR were asked to complete an IHR generated survey, which focused on several critical concepts relating to IH treatment and management: quality of life with IH, primary- and outpatient-care experiences, ED use during the previous three years (2010–2012), common IIH-related signs or symptoms experienced over the six months prior to completing the survey, economic and financial consequences of IH, and treatment and management experience in the ED.

Data management

The primary outcome variable of interest was the number of ED visits during the study's time frame. This was not only collected as a count variable (number of ED visits per year), but was also transformed into a binary variable characterizing whether, or not, an individual sought out ED care at least once during the period of the study's time frame. This allowed for an examination of who, among IIH study participants, used ED services as well as an examination of the intensity with which participants used these services.

Several variables were selected to characterize the clinical, economic and humanistic characteristics of the sample. For clinical indicators, binary variables were created to identify the presence or absence of common IIH signs and symptoms over the six months prior to the survey's completion, including the presence of headaches, pulse synchronous tinnitus (PST), swollen optic nerves (papilledema) and a lumbar puncture with an opening pressure measurement exceeding 250 mm H_20. Similarly, a binary variable was created to identify if a patient had ever received a cerebrospinal fluid (CSF) diversional shunt surgery before 2013.

Several socioeconomic characteristics, including respondent gender, age and race (white vs non-white), were collected and included in the analysis. The annual income of the respondent’s household in 2012 US dollars was also recorded, which was subsequently characterized into five categories: less than $25,000 annually, $25,000–49,999, $50,000–74,999, $75,000–99,999 and $100,000 or more. Finally, the respondent’s insurance coverage was recorded: uninsured, privately insured/non-HMO, privately insured by an HMO, Medicare or Medicaid.

Given the similarities in symptoms between those who suffer from IIH and those who suffer from severe migraines (DeSimone *et al.*, 2014; Burch *et al.*, 2018), humanistic characteristics were measured using an adapted version of the Migraine-Specific Quality of Life Questionnaire (MSQ) (Version 2.1) instrument (Bagley *et al.*, 2012). The MSQ includes three scales: restricted role functions, preventive role functions and emotional functions. Questions in our adapted MSQ were drawn directly from Bagley *et al.* (2012) with all references to “migraines” replaced with “IH-related symptoms.” There are 14 items in the survey, each of which asks respondents to rate their functioning, over the previous four weeks, on a six-point scale where a response of 6 indicates that a symptom interfered with functioning “none of the time,” a score of 3 indicates “a good bit of the time” and a score of 1 indicates that the symptom in question interfered with functioning “all of the time.” Thus, higher scores for each survey item indicate a higher quality of life for the respondent. Bagley *et al.* (2012) found that these 14 items could be used to construct three basic quality of life scales which we employed in this study: restricted role functions (items 1–7), preventive role functions (items 8–11) and emotional functions (items 12–14). Each scale is constructed by adding up the total number of points available in each scale, and converting that score to a percentage of total points in the scale.

Patients who utilized the ED were asked to answer a set of questions regarding their experience. Specifically, they were asked about how they were treated and perceived by ED staff, ED staff knowledge regarding IIH and whether they were prescribed narcotics. Other data collected included a set of questions, for each ED visit reported, detailing information on which symptoms lead patients to seek the ED.

Another variable of interest consists of the open responses to the survey question: “If you haven’t been to the Emergency Department or Urgent Care in this time period, why not?” Answers to this question were categorized into six common themes by three IHR researchers. Discrepancies in scoring between researchers were discussed and consolidated.

To ensure that survey responses were both accurate and consistent with available information, self-reported responses were cross-referenced against patient medical records available in the IHR.

Statistical analysis

The relationships between the discrete ED use and patient-characteristic variables were analyzed using Fisher’s exact tests, while Kruskal–Wallis tests were used to examine the relationships between the discrete ED use and continuous patient-characteristic variables (Aparasu and Bentley, 2014). The relationship between the number of ED visits and the categorical patient characteristics was also assessed using Kruskal–Wallis tests. The remaining quantitative variables were analyzed using Spearman correlations, which measure the strength of the monotonic relationship between two variables. A Spearman correlation of ± 1 indicates a perfect monotonic relationship. Nonparametric, rank order analyses (Spearman correlations, Fisher exact tests and Kruskal–Wallis tests) were used in place of their parametric counterparts (Pearson correlations, Pearson χ^2 tests and analysis of variance) because the number of ED visits was unlikely to be normally distributed. If no answer was provided by the patient, the data for the question were considered missing and were removed from the relevant statistical analysis. Statistical significance was set at $\alpha = 0.05$. Analysis was conducted using Stata statistical software (Version 13.1; Stata Corp, College Station, Texas).

Results

Study population characteristics

Population characteristics, stratified by ED use, are presented in Table I. Of the 332 respondents included in this analysis, approximately 92 percent ($n = 306$) were female, a finding that is generally consistent with the literature (Friedman and Jacobson, 2002;Sinclair *et al.*, 2011; Liu *et al.*, 2015), and 91 percent ($n = 299$) were of Caucasian ancestry. At the time of this study's implementation, the typical respondent was about 40 years of age and had been diagnosed with IIH for almost nine years. Respondents reported a relatively even income distribution with approximately 24 percent ($n = 77$) living in households making less than $25,000 annually, 22 percent ($n = 69$) with household incomes in the $25,000–49,999 range, 21 percent ($n = 67$) living in households with incomes in the $50,000–74,999 range, 13 percent ($n = 40$) with household incomes in the $75,000–99,999 range and 21 percent ($n = 66$) living in households earning $100,000 or more annually. The majority of the study population carried a non-HMO delivered private insurance policy (48 percent). Mean quality of life scores for restrictive-role, preventive role and emotional functioning (which are normalized to a percentage basis) were 50.5, 60.1 and 50, respectively, which suggest moderate quality of life among these respondents.

Relationship between ED use and population characteristics

Approximately, 39 percent ($n = 128$) of respondents reported visiting the ED during the 2010–2012 study time frame, while the remaining 61 percent ($n = 204$) did not present at an ED (Table I). Among those who visited the ED, there was a significantly larger proportion of participants who were non-white, lived in households making less than $25,000 annually, insured by Medicare or Medicaid and had received a CSF diversional shunt procedure than among those who did not utilize the ED ($p < 0.05$). A significantly smaller proportion of participants who used the ED had incomes of $100,000 or more and had private, non-HMO insurance. Also, participants who used the ED had significantly lower quality-of-life scores, were younger and had been diagnosed with IIH for less time.

Relationship between frequency of ED use and population characteristics

Those who responded to the frequency of ED use question ($n = 123$) averaged nine ED visits over the three-year study period, a somewhat intensive use of ED services. The frequency of ED use among those who reported visiting an ED, stratified by patient characteristics, is presented in Table II. Respondents who had undergone a CSF diversional shunt procedure any time before 2013 also visited the ED significantly more often than those who had not received a shunt surgery ($p < 0.01$).

The same sets of insurance variables associated with ED use, not having private (non-HMO) insurance and being on Medicare or Medicaid, were also associated with significant higher frequency of ED use. Additionally, having an annual household income of $25,000–49,999 was significantly associated with higher ED use.

Table III reports the results from the Spearman correlation analysis, which characterizes the relationship between the frequency of ED use among respondents with at least one ED visit and various quantitative patient characteristics. Greater ED use was significantly and negatively correlated with the number of years, since the respondent had been diagnosed with IIH, age and all three quality-of-life indexes. All three quality of life indices are highly (and positively) correlated, with correlation coefficients exceeding 0.86. Correlations between each of the three quality of life measures and the ED use variable are statistically significant from 0, and moderate in magnitude, ranging from 0.41 to 0.45.

Patient perspectives of ED treatment

Patient perspectives of ED experience, among those who reported going to the ED and answered at least one of these questions, are presented in Table IV. In total, 47 percent (n = 57) of respondents indicated feeling that ED physicians did not treat them with respect and dignity, while 23 percent (n = 29) of patients reported the same feeling about ED nurses. Approximately, 21 percent (n = 25) of patients reported the perception that the ED staff was familiar with Intracranial Hypertension and only 26 percent (n = 32) reported that the staff understood how to treat their condition. About 61 percent (n = 76) of patients reported receiving prescriptions for narcotic medications at the ED, while almost 50 percent (n 62) reported the perception that they were being treated as a drug seeker. Only about 36 percent (n = 44) felt that their symptoms were taken seriously and 54 percent (n =66) believed that ED staff perceptions of the respondent’s appearance influenced the care they received. Health insurance helped cover the cost of the visit for just under 90 percent (n = 111) of respondents.

Reasons for using the ED

Among those who utilized the ED between 2010 and 2012 (n = 128), 89 patients reported more detailed information about their ED visits (total of 206 visits) including the symptoms that led them to seek treatment at the ED. These responses are summarized in Table V. For each symptom, Table V reports the number of ED visits for which patients identified experiencing a particular symptom. Additionally, Table V reports the number (and percentage, expressed using the total number of ED visits in which patients reported the symptom in question as a denominator) of patients who identify that symptom as a major reason for the ED visit. Headache was listed as a reason for visiting the ED for almost 90 percent (n = 160) of the ED visits, while abdominal pain (16 percent, n = 29) was the least common reason for ED usage. Among the 85 visits due to “other” symptoms, pain in general (neck, eyes and arms) was most common (11 percent, n = 20), followed by nausea/vomiting

(9 percent, *n* = 16), cognitive/speech problems (5 percent, *n* = 9), lumbar puncture complications (5 percent, *n* = 9) and shunt complications (5 percent, *n* = 9).

Reasons for not using the ED

Among those who did not utilize ED services during the study period (*n* = 205), 163 respondents gave at least one reason for not seeking ED care. Of the 163 responses, 49 percent (*n* = 79) said that they did not have a need for ED services, 35 percent (*n* = 57) reported that they had private medical care options for symptom management and approximately 24 percent (*n* = 39) reported that they managed symptoms with home remedies or medication. About 12 percent (*n* = 20) said that they did not use the ED due to financial cost, 10 percent (*n* = 16) stated that they felt that the ED could not help them and almost 4 percent (*n* = 6) said that they feared prejudice from ED staff.

Residual IH signs and symptoms after ED utilization

IH signs and symptoms reported during the six months before survey completion, among those who utilized the ED, were also reported. Among those who utilized the ED between 2010 and 2012 (*n* = 128), 2 percent of respondents reported having no IH symptoms percent months prior to survey completion, while headache was reported by 94 percent (*n* = 120), papilledema by 41 percent (*n* = 52), PST by 70 percent (*n* = 89), an opening pressure measurement of > 250 mm H_2O by 20 percent (*n* = 25) and other IH symptoms (e.g. nausea and neck pain) by 70 percent (*n* = 90).

Discussion

Utilization of US EDs is of significant interest to ED medical workers, hospital administrators, policy makers, politicians and patients. This study includes information from 332 individuals with IIH enrolled in the IHR, and aims to understand the influence that untreated/undertreated symptoms and socioeconomic factors have on the use of ED facilities. There are several important findings.

First, socioeconomic and health insurance factors play an important role in ED utilization. Consistent with recent ED literature, our results showed that respondents who were non-white, lived in households with incomes below $25,000 and were insured by Medicare or Medicaid were not only more likely to use the ED, but also used it much more frequently than those in higher socioeconomic households (Trzeciak and Rivers, 2003; Stevenson, 2008). A suggested relationship between healthcare access and ED utilization is supported by our finding that about 35 percent of respondents who did not use the ED reported that they did not seek ED services because they had private medical care options for symptom management. This was the second most frequent reason given after “no need for ED services.”

A second implication of our analysis is that IIH patients are utilizing ED facilities for symptom relief. Among the IIH participants in this study, 39 percent utilized emergency services during the three-year study period and averaged nine visits. Headaches were reported as a reason for seeking ED treatment in 90 percent of the ED visits for which this information was reported, while blurred vision was a reason given for 43 percent of such visits to the ED. CSF shunting procedures and complications with such procedures were additional factors associated with ED utilization. Over half of respondents who had received a CSF diversional shunt at some points used the ED, which may suggest insufficient symptom control or an adverse reaction. While CSF shunting procedures can be beneficial for some IIH patients, there are potential complications, such as infection, over-drainage and malfunction. These complications can lead to numerous shunt revision procedures with their own potential complications (Sinclair *et al.*, 2011). In fact, 24 percent of patients reported “shunt pain,” with another 11 percent reporting a “shunt complication,” as being a reason for their ED visit.

Third, in general, IIH patients seeking care in the ED found it to be inadequate or unsatisfactory. IIH symptom management is complex and only 21 percent of patients utilizing the ED reported that ED staff was familiar with IH or IH treatment, and only 36 percent felt that their symptoms were taken seriously. Often, the only services ED staff can offer IIH patients are a lumbar puncture in selected circumstances to temporarily decrease the CSF pressure, narcotics for pain, or referral based on findings and general lack of response to treatment. Repeat lumbar punctures introduce opportunity for many serious complications, such as infection and low-pressure headaches, while narcotics may not effectively reduce pain in IIH patients and may lead to dependency (Friedman, 2004). Over 60 percent of respondents reported that they received a narcotic from ED staff; however, approximately half of respondents felt that they were perceived as being drug seekers. We were not able to obtain information on the number of lumbar punctures or referrals given in the ED.

Many participants who had utilized the ED during period of focus (2010–2012) continued to experience issues around the time of survey completion. When participants were asked about symptoms they experienced six months prior to survey completion, approximately 94 percent of ED users reported headache, 70 percent reported having PST and 41 percent reported having papilledema. Participants who utilized ED services also tended to have significantly lower quality of life across all three constructs compared to those who did not use these services. The frequency of ED use was also significantly and negatively correlated with all three constructs.

Finally, a longer time-since-diagnosis period was associated with significantly fewer ED visits. Participants who used the ED had, on average, been diagnosed with IIH within the seven years prior to the survey being administered. Those who did not use ED services during the period of the study had 9.6 years since IIH diagnoses. This finding may indicate that more recently diagnosed patients have less experience dealing with IIH symptoms and, consequently, are more likely to use the ED.

Strengths and potential limitations

The IHR data are assembled from both participant-reported questionnaires and abstracted information from periodically collected medical records. This represents the largest collection of medical data on individuals with chronic IH. All information used for research projects was reviewed for accuracy and consistency and medical records abstraction was performed by medical staff and reviewed by IHR research coordinators.

While our study utilizes a large sample with a carefully constructed data set, certain limitations exist that merit further consideration. First, the data are drawn from a survey of IHR participants, and as such may over-represent those individuals in the IIH patient population who have the time, money and family support necessary to manage the disorder (Friesner *et al.*, 2011). This also means that Registry data may underrepresent that part of the patient population with undiagnosed or improperly managed symptoms, the very sub-population that is most likely to use ED services. As such, the results presented in this manuscript must be considered as conservative.

Second, because the survey was administered over a period of approximately one year, and because the outcome is dependent on the participants' ability to accurately report their past ED utilization, there is the potential for recall bias if those who completed the survey early on were more likely to accurately remember their ED visits. We believe that we remedied this concern, however, by examining the outcome as both a continuous frequency variable and a more general binary variable characterizing whether, or not, the individual sought out ED care at least once during the period of the study's time frame.

Third, responses to several open-ended survey questions were scored by IHR research staff, introducing the possibility for bias. We believe that we remedied this, however, by having three IHR researchers independently score responses and then address discrepancies in scoring through discussion.

Fourth, as with all research dependent on participant-reported data, missing data in returned surveys introduce concern for bias and appropriate analysis and interpretation. Results were calculated with the denominator equaling the total number of responses, while the total number of possible responses is indicated in the tables. Due to the exploratory nature of this study, we did not think it appropriate to use more sophisticated methods of missing data management.

Conclusions

This study highlights several key factors related to ED utilization among patients with IIH. While this study profiles ED use by IIH patients, it does not address the clinical, humanistic or economic outcomes of emergency services provided to these patients. Future research, utilizing more sophisticated (e.g. regression based) statistical methods is necessary to identify whether visiting the ED leads, or does not lead, to immediate symptom relief and to elucidate which IH symptoms, or combination of symptoms, are more likely to lead to ED use.

Addressing the issues of healthcare access and effective symptom management in private healthcare settings may reduce ED utilization among IIH patients. Importantly, future research efforts should lead to more effective clinical treatment plans, both medical and surgical, that can better accomplish improved CSF pressure control. Ultimately improved pressure control reduces pain management and increases preservation of vision, which should in turn significantly decrease the need for IIH patients to seek ED treatment.

Further efforts to reduce ED use would be the development of new pharmaceutical agents and ancillary advances such as non-invasive pressure measuring which would contribute to reduction of shunt surgery with its relatively high rate of failure, revisions and complications. Innovative strategies that both educate and care for those patients identified in this study with high potential ED use might include the development of medical services for home care supported by telemedical access to available multispecialty teams.

Acknowledgments

A special thank you to Ralpha Newton, Senior Volunteer Research Coordinator (IHR), Veda Varada, IHR research intern and the entire IHR group for their help in compiling the data contained in their Registry. Dr Murphy was supported by the National Institute on Drug Abuse (P30DA040500).

References

Aparasu R and Bentley J (2014), Principles of Research Design and Drug Literature Evaluation, Jones & Bartlett Publishers, Burlington, MA.

Asensio-Sanchez VM, Merino-Angula J, Martinez-Calvo S, Calvo M and Rodriguez R (2007), “Epidemiology of pseudotumor cerebri”, Archivos de la Sociedad Española de Oftalmología, Vol. 82 No. 4, pp. 219–222. [PubMed: 17443426]

Bagley C, Rendas-Baum R, Maglinte G, Yang M, Varon S, Lee J and Kosinski M (2012), “Validating Migraine-Specific Quality of Life Questionnaire v2. 1 in episodic and chronic Mmigraine”, Headache: The Journal of Head and Face Pain, Vol. 52 No. 3, pp. 409–421.

Burch R, Rizzoli P and Loder E (2018), “The prevalence and impact of migraine and severe headache in the United States: figures and trends from government health studies”, Headache: The Journal of Head and Face Pain, Vol. 58 No. 4, pp. 496–505.

De Simone R, Ranieri A, Montella S, Cappabianca P, Quarantelli M, Esposito F, Cardillo G and Bonavita V (2014), “Intracranial pressure in unresponsive chronic migraine”, Journal of Neurology, Vol. 261 No. 7, pp. 1365–1373. [PubMed: 24781838]

Digre K and Corbett J (2001), “Idiopathic intracranial hypertension (pseudotumor cerebri): a reappraisal”, The Neurologist, Vol. 7 No. 1, pp. 2–67.

Durand AC, Gentile S, Devictor B, Palazzolo S, Vignally P, Gerbeaux P and Sambuc R (2011), “ED patients: how nonurgent are they? Systematic review of the emergency medicine literature”, The American Journal of Emergency Medicine, Vol. 29 No. 3, pp. 333–345. [PubMed: 20825838]

Durcan PJ, Corbett J and Wall M (1988), “The incidence of pseudotumor cerebri: population studies in Iowa and Louisiana”, Archives of Neurology, Vol. 45 No. 8, pp. 875–877. [PubMed: 3395261]

Friedman D (2004), “Pseudotumor cerebri”, Neurologic Clinics, Vol. 22 No. 1, pp. 99–131. [PubMed: 15062530]

Friedman D (2014), “Papilledema and idiopathic intracranial hypertension”, CONTINUUM: Lifelong Learning in Neurology, Vol. 20 No. 4, pp. 857–876. [PubMed: 25099098]

Friedman D and Jacobson M (2002), “Diagnostic criteria for idiopathic intracranial hypertension”, Neurology, Vol. 59 No. 10, pp. 1492–1495. [PubMed: 12455560]

Friedman D, Liu G and Digre K (2013), “Revised diagnostic criteria for the pseudotumor cerebri syndrome in adults and children”, Neurology, Vol. 81 No. 13, pp. 1159–1165. [PubMed: 23966248]

Friesner D, Rosenman R, Lobb B and Tanne E (2011), “Idiopathic intracranial hypertension in the USA: the role of obesity in establishing prevalence and healthcare costs”, Obesity Reviews, Vol. 12 No. 5, pp. e372–e380. [PubMed: 20804521]

Glatstein M, Oren A, Amarilyio G, Scolnik D, Ben Tov A, Yahav A, Alper A and Reif S (2015), “Clinical characterization of idiopathic intracranial hypertension in children presenting to the emergency department: the experience of a large tertiary care pediatric hospital”, Pediatric Emergency Care, Vol. 31 No. 1, pp. 6–9. [PubMed: 25207755]

Jones J, Nevai J, Freeman M and McNinch D (1999), "Emergency department presentation of idiopathic intracranial hypertension", The American Journal of Emergency Medicine, Vol. 17 No. 6, pp. 517–521. [PubMed: 10530526]

Kesler A and Gadoth N (2001), "Epidemiology of idiopathic intracranial hypertension in Israel", Journal of Neuro-Ophthalmology, Vol. 21 No. 1, pp. 12–14. [PubMed: 11315973]

Koerner J and Friedman D (2014), "Inpatient and emergency service utilization in patients with idiopathic intracranial hypertension", Journal of Neuro-Ophthalmology, Vol. 34 No. 3, pp. 229–232. [PubMed: 25136774]

Lai L, Danesh-Meyer H and Kaye A (2014), "Visual outcomes and headache following interventions for idiopathic intracranial hypertension", Journal of Clinical Neuroscience, Vol. 21 No. 10, pp. 1670–1678. [PubMed: 24974193]

Liu A, Elder B, Sankey E, Goodwin C, Jusue-Torres I and Rigamonti D (2015), "The utility of computed tomography in shunted patients with idiopathic intracranial hypertension presenting to the emergency department", World Neurosurgery, Vol. 84 No. 6, pp. 1852–1856. [PubMed: 26283484]

Lueck C and McIlwaine G (2005), "Interventions for idiopathic intracranial hypertension", The Cochrane Database of Systematic Reviews, Vol. 20 No. 3, p. CD003434, doi: 10.1002/14651858.CD003434.pub2.

McCaig L and Ly N (2002), National Hospital Ambulatory Medical Care Survey: 2000 Emergency Department Summary, Advance Data, Vital and Health Statistics, Centers for Disease Control and Prevention, Atlanta, GA.

Mehrotra A, Liu H, Adams J, Wang M, Lave J, Thygeson N, Solberg L and McGlynn E (2009), "Comparing costs and quality of care at retail clinics with that of other medical settings for 3 common illnesses", Annals of Internal Medicine, Vol. 151 No. 5, pp. 321–328. [PubMed: 19721020]

Minen M, Tanev K and Friedman B (2014), "Evaluation and treatment of migraine in the emergency department: a review", Headache: The Journal of Head and Face Pain, Vol. 54 No. 7, pp. 1131–1145.

National Center for Health Statistics (2012), National Hospital Ambulatory Medical Care Survey Factsheet: Emergency Departments, Centers for Disease Control and Prevention, Atlanta, GA..

Radhakrishnan K, Thacker A, Bohlaga N, Maloo J and Gerryo S (1993), "Epidemiology of idiopathic intracranial hypertension: a prospective and case-control study", Journal of the Neurological Sciences, Vol. 116 No. 1, pp. 18–28. [PubMed: 8509801]

Sina F, Razmeh S, Habibzadeh N, Zavari A and Nabovvati M (2017), "Migraine headache in patients with idiopathic intracranial hypertension", Neurology International, Vol. 9 No. 3, pp. 69–70.

Sinclair A, Kuruvath S, Sen D, Nightingale P, Burdon M and Flint G (2011), "Is cerebrospinal fluid shunting in idiopathic intracranial hypertension worthwhile? A 10-year review", Cephalalgia, Vol. 31 No. 16, pp. 1627–1633. [PubMed: 21968519]

Smith J (1985), "Whence pseudotumor cerebri?", Journal of Clinical Neuro-Ophthalmology, Vol. 5 No. 1, pp. 55–56. [PubMed: 3156890]

Stevenson S (2008), "Pseudotumor cerebri: yet another reason to fight obesity", Journal of Pediatric Health Care, Vol. 22 No. 1, pp. 40–43. [PubMed: 18174088]

Thygeson M, Van Vorst K, Maciosek M and Solberg L (2008), "Use and costs of care in retail clinics versus traditional care sites", Health Affairs (Millwood), Vol. 27 No. 5, pp. 1283–1292.

Trzeciak S and Rivers E (2003), "Emergency department overcrowding in the United States: an emerging threat to patient safety and public health", Emergency Medicine Journal, Vol. 20 No. 5, pp. 402–405. [PubMed: 12954674]

Table I.

Study population characteristics, stratified by ED use (count (%))

Variable	**Total responses**	**Characteristic present**	**Cases (ED use)**	**Controls (no ED use)**	***p*-value**
Total *n* (%)	332	–	128 (38.6)	204 (61.4)	–
Sex (male)	332	26 (7.8)	9 (34.6)	17 (65.4)	0.83
Race (white)	327	299 (91.4)	108 (36.1)	191 (63.9)	0.01 *
Shunt	332	118 (35.5)	67 (56.8)	51 (43.2)	< 0.01 *
Annual income	319				< 0.01 *
< $25,000		77 (24.1)	43 (55.8)	34 (44.2)	< 0.01 *
$25,000–49,999		69 (21.6)	29 (42.0)	40 (58.0)	0.68
$50,000–74,999		67 (21.0)	26 (38.8)	41 (61.2)	1.00
$75,000–99,999		40 (12.5)	10 (25.0)	30 (75.0)	0.06
$100,000 or more		66 (20.7)	18 (27.3)	48 (72.7)	0.02 *
Insurance					
No insurance	332	27 (8.1)	11 (40.7)	16 (59.3)	0.84
Private	332	160 (48.1)	46 (28.8)	114 (71.2)	< 0.01 *
HMO	332	65 (19.5)	26 (40.0)	39 (60.0)	0.78
Medicare	332	76 (22.9)	39 (51.3)	37 (48.7)	0.01 *
Medicaid	332	42 (12.6)	26 (61.9)	16 (38.1)	< 0.01 *
Mean restrictive index score (SD)	328	50.5 (37.8)	34.9 (26.3)	60.2 (32.6)	< 0.01 *
Mean preventive index score (SD)	328	60.1 (37.8)	43.0 (28.6)	70.7 (32.4)	< 0.01 *
Mean emotional index score (SD)	328	50.0 (37.7)	29.9 (29.9)	62.5 (36.7)	< 0.01 *
Mean age (SD)	332	40.4 (12.5)	37.5 (11.4)	42.3 (12.9)	< 0.01 *
Mean years since Dx (SD)	320	8.7 (6.1)	7.3 (5.3)	9.6 (6.4)	< 0.01 *

Notes:

* Indicates statistical significance. Significance level set at $\alpha = 0.05$

Table II.

Frequency of ED use among respondents with at least one ED visit who reported on frequency, stratified by patient characteristics (mean number of ED visits (SD))

Characteristic	Characteristic present	Characteristic absent	*p*-value
Sex (male)	6.78 (5.65)	9.54 (10.40)	0.72
Race (white)	8.86 (9.17)	13.59 (14.67)	0.18
Shunt	12.40 (11.63)	6.21 (7.22)	$< 0.01^{*}$
Annual income			0.02^{*}
< $25,000	12.19 (12.89)	7.85 (8.07)	0.18
$25,000–49,999	12.67 (10.10)	8.40 (10.01)	0.01^{*}
$50,000–74,999	5.16 (4.34)	10.40 (10.92)	0.08
$75,000–99,999	4.60 (5.32)	9.75 (10.37)	0.06
$100,000 or more	6.47 (7.48)	9.79 (10.46)	0.27
Insurance			
No insurance	12.73 (12.92)	9.00 (9.84)	0.72
Private	6.33 (6.48)	11.06 (11.43)	0.03^{*}
HMO	6.67 (6.18)	9.98 (10.81)	0.41
Medicare	13.26 (13.31)	7.58 (7.83)	0.03^{*}
Medicaid	12.88 (10.82)	8.47 (9.84)	0.02^{*}

Notes: $n = 123$.

*Indicates statistical significance. Significance level set at $\alpha = 0.05$

Table III.

Spearman correlations among respondents with at least one ED visit

	edvisits	**timesincedx**	**restrictiveindex**	**preventiveindex**	**emotionalindex**	**age**
edvisits	-	−0.22*	−0.41*	−0.45*	−0.44*	−0.21*
p-value		< 0.01	< 0.01	< 0.01	< 0.01	< 0.01
timesincedx		-	0.11	0.11	0.13*	0.39*
p-value			0.06	0.06	0.02	< 0.01
restrictiveindex			-	0.92*	0.88*	0.09
p-value				< 0.01	< 0.01	0.13
preventiveindex				-	0.86*	0.06
p-value					< 0.01	0.28
emotionalindex					-	0.09
p-value						0.10
age						-
p-value						

Notes: $n = 128$. A Spearman correlation of ± 1 indicates a perfect monotonic relationship

Table IV.

Patient perspectives of ED treatment, among respondents with at least one ED visit (count (%))

Question	Total responses	Yes	No
The nurses treated me with respect and dignity	125	96 (76.8)	29 (23.2)
The physicians treated me with respect and dignity	122	65 (53.3)	57 (46.7)
The staff understood how to treat my pain and other symptoms	125	32 (25.6)	93 (74.4)
The staff was familiar with my problems and the disorder of intracranial hypertension in general	122	25 (20.5)	97 (79.5)
I felt like my problems and symptoms were taken seriously	124	44 (35.5)	80 (64.5)
The staff prescribed or treated me with narcotic medications such as Vicodin, codeine or Percocet	125	76 (60.8)	49 (39.2)
The staff made me feel as if I was seeking drugs	125	62 (49.6)	63 (50.4)
I believe that the staff’s perception of my appearance especially my weight, influences the care I received for my symptoms	122	66 (54.1)	56 (45.9)
I had a health insurance policy which covered some of the visit’s bill	124	111 (89.5)	13 (10.5)

Table V.

Reasons for using the ED, among respondents with at least one ED visit who reported on associated symptoms (Count (%))

Symptom	Total ED visits	Visits due to symptom
Total *n* (%)	206	
Headache	178	160 (89.9)
Blurred vision	178	77 (43.3)
Abdominal pain	178	29 (16.3)
Shunt pain	178	43 (24.2)
Black/white/gray outs	178	38 (21.3)
Other	179	85 (47.5)
Cognitive/Speech problem	179	9 (5.0)
Lumbar puncture complication	179	9 (5.0)
Shunt complication	179	9 (5.0)
Nausea/Vomiting	179	16 (8.9)
Dizziness/Balance	179	6 (3.4)
Paralysis	179	7 (3.9)
Pain	179	20 (11.2)
Tinnitus	179	3 (1.7)
All Other Symptoms	179	6 (3.4)

Note: *n* = 89