School of Economic Sciences

Working Paper Series
WP 2009-23

The Costs of a Quiet Disorder: Direct and Indirect Costs of Idiopathic Intracranial Hypertension

By

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July 2009

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Acknowledgements:

[‡]The Intracranial Hypertension Registry is a joint project of the Intracranial Hypertension Research Foundation and the Casey Eye Institute at Oregon Health & Science University

The Costs of a Quiet Disorder: Direct and Indirect Costs of Idiopathic Intracranial Hypertension

OBJECTIVE: Idiopathic Intracranial Hypertension (IIH) is a disorder with an occurrence rate of 1-3 per100000 people. Symptoms include severe headaches, visual disturbances and tinnitus, which can severely limit functional independence and quality of life. Little is known about the origin of the disorder, nor has evidence-based medicine identified the most efficient and effective treatment path. We attempt to provide some estimates of the economic costs of IIH from the societal perspective.

METHODS: This was a retrospective study using data collected by the Intracranial Hypertension Registry (IHR), the Nationwide Inpatient Sample and other publicly available sources. Data from the IHR were used to infer non-medical (indirect) IIH-related expenses for the population at large, while data from the Nationwide Inpatient Sample were used to determine direct medical costs.

RESULTS: The total costs of IIH in 2007 exceeded $444 million per year. $212 million is due to lost wages and other, non-medical expenses. $232 million is attributable to direct medical and surgical hospital expenses. In 2007 US direct hospital care averaged approximately $2314 per person. The total average direct cost per IIH admission was four times greater.

CONCLUSION: Although IIH gets little public attention, the economic costs of this disorder, which are jointly borne by those suffering from IIH and society as a whole, are quite substantial. As such, it would be very useful for the medical and policymaking communities to direct efforts towards findings ways to better treat and manage the disorder in order to reduce some of these costs.

KEY WORDS: idiopathic intracranial hypertension, economic costs, shunts, medical costs, pseudotumor cerebri

The Costs of a Quiet Disorder: Direct and Indirect Costs of Idiopathic Intracranial Hypertension

INTRODUCTION

Idiopathic Intracranial Hypertension (IIH**;** pseudotumor cerebri) is a disorder with a reported incidence rate of one to three per 100,000 people in the general population. The rate among obese females of childbearing age is approximately 20 out of every 100,000 (1,9,17,25). As its name suggests, the disorder arises from unknown causes, and manifests itself in the form of elevated cerebrospinal fluid pressure within the skull. Those afflicted with IIH often experience an array of signs and symptoms suggestive of IH, including papilledema, severe headaches, visual disturbances and pulsatile synchronous tinnitus, which can severely limit functional independence and quality of life (8,19,20).

Little is known about the origin of the disorder, nor has evidence-based medicine identified the most efficient and effective treatment path (3,21). Treatment is primarily palliative, beginning with medical therapy and progressing to surgical therapy (3,9). Medicinal treatments generally employ carbonic anhydrase inhibitors such as acetazolamide (Diamox). Alternative medications (including furosemide (Lasix) and topiramate (Topamax)) are prescribed to patients unable to tolerate acetazolamide or in various therapeutic combinations. Surgical procedures (including optic nerve sheath fenestration and neurosurgical shunts) are often performed when patients do not respond to pharmaceutical interventions and vision loss is potentially eminent. For obese patients weight loss (and in extreme cases, bariatric surgery) is prescribed in conjunction with medicinal and/or surgical treatments, and when successful usually reduces IIH-related symptoms (27). Stenting for cerebral sinus stenosis, although sometime used, remains controversial (10,11).

The lack of an efficient and effective treatment path is due to failure to understand the underlying pathophysiological mechanism of the disorder. Individuals are diagnosed with IIH after exhausting all other possible identifiable causes, such as the presence of a tumor or drug toxicity (20). Any patients without a detectable cause, and whose signs and symptoms meet the Modified Dandy Criteria, are diagnosed with IIH (9: See Table 1).

Many physicians believe IIH is a diagnosis of abnormal CSF hydrodynamics made by excluding known secondary causes of intracranial hypertension and, therefore, they require that the Dandy criteria be fulfilled before a diagnosis of IIH can be made (4,12,22,24). Diagnosis can sometimes be difficult if several of the prominent features are not apparent or absent such as papilledema and pulse synchronous tinnitus or if a marginally high opening pressure reading is obtained on lumbar puncture.

We have elected to describe this as a "quiet" disorder not in reference to the symptoms of IIH patients who can be victims of unremitting, intense head pain as well as possible vision loss but rather because of three under-recognized major management factors. First, there is a problem of resource fragmentation. Professional attention tends to focus on the underlying disease and is fragmented among many different specialists, so the scope and magnitude of the IH problem is not recognized by some physicians, healthcare institutions or public policy leaders. Second, there is a problem of diffusion of responsibility in patient care. No single physician is likely to have a complete picture of any individual patient's overall history because evaluation and treatment usually involves several different specialties, none of whom are likely to have global responsibility for the patient's management. The third problem centers on unsatisfactory treatment options. After more than 100 years, IIH management remains, for the most part, unsatisfactory. Shunts to divert CSF are often of benefit in about 50% of patients, but are subject

to serious complications and require frequent revisions. Off label carbonic anhydrase inhibitors usually help some patients, but often require high doses that are poorly tolerated. No drug company appears interested in further drug development. Weight loss is helpful but only if sustained. Additionally funding for research has been very limited and there has been a paucity of basic scientists interested in entering this area. And to add to this, there is evidence that the incidence of the disorder and corresponding surgical management is increasing in proportion to the rise of obesity (7,27). Therefore, we designated IIH as a "quiet" disorder with far-reaching consequences that has been largely overlooked by the medical community, healthcare institutions, industry and government.

In the absence of identifiable causes and an optimal treatment path, one way to promote public attention to and future research on IIH is to identify the economic costs of the disorder. In doing so, one can characterize the magnitude of the effects, both direct and indirect, that the disorder has on society. Comparing these costs to other, more publicized conditions afflicting similar cohorts of individuals may induce greater effort on the part of the healthcare and medical communities to work towards finding a cure for IIH.

In this paper, we use data from the Intracranial Hypertension Registry and other publicly available sources to generate estimates of the economic costs of IIH for a societal perspective. We estimate that, in a single year (2007) alone, the total economic costs of IIH are in excess of 444 million U.S. dollars

METHODS

Data Sources

The data used in our analysis come from several sources. First, we use data from published sources to obtain an estimate on the incidence of IIH in the US population in 2007.

We combine the incidence rates provided by the medical literature (1,2,9,13,17,18,25), along with estimates of the prevalence of obesity (http://www.obesityinamerica.org) and population projections (http://www.census.gov/population/projections/nation/detail/d2001_10.pdf) by gender and age to generate an estimate of the number of individuals in the US suffering from IIH.

The second source of data was the Healthcare Cost and Utilization Project's (HCUP) Nationwide Inpatient Sample, or NIS (14), which was used to determine both hospital and procedure costs. The NIS is a hospital discharge database for the year 2005 (from the Agency for Healthcare Research and Quality). The year 2005 was the last data available from HCUP at the time of this study. NIS is the largest all-payer inpatient care database containing approximately 8 million hospital stays from 1,000 hospitals sampled to approximate a 20% stratified sample of all US community hospitals. A synopsis of the NIS can be found on HCUP's website: http://www.hcup-us.ahrq.gov/nisoverview.jsp. NIS data were weighted to estimate all non-federal discharges in the US during the year 2005.

For a given hospital in the NIS, the data contains information on all hospital discharges and charges by ICD9-CM codes. As such, it can be used to provide information on the direct medical expenses that arise due to the disorder. To examine inpatient IIH-related procedures, we utilized the ICD9-CM diagnostic code of pseudotumor cerebri (intracranial hypertension code) 348.2. Similar to Curry et al. (7) to rule out cases of secondary intracranial hypertension such as brain tumors, a number of exclusionary diagnostic codes were removed. These codes were 190.x, 191.x, 192.x, 198.3, 198.4, 225.x, 237.x, 239.6, 239.7, 801 – 804, 850 – 854, and 430 – 437.

To establish the number of surgeries performed for IIH in the NIS 2005 data, ICD9-CM procedure codes for shunt placement (lumbar shunt 3.71, ventricular shunt 2.3x), shunt revision (lumbar shunts 3.97, ventricular 2.42), shunt removal (lumbar shunts 3.98, ventricular 2.43), and shunt exploration (54.95) were used. Optic nerve sheath decompression procedure codes used were 04.42 and 04.04. Unlike Curry et al.'s (7) exploration of the costs of intracranial hypertension, we included sub-temporal decompression (procedure code 01.24) in our examination. Gastric bypass for IH was established using DRG code 288 with inclusions and exclusionary criteria based on Zhoa and Encinosa (30). Inclusionary procedure codes were 4431, 4438, 4439, 4495, 4496, 4497, 4498, 445x, and 4499 if found in combination with DRG 288. Exclusionary criteria were ICD9-CM codes 1500 – 1599, 2301 – 2309. All DRG 288 discharges were also checked to ensure that a diagnosis code of obesity was present (ICD9-CM codes 27801, 2780, 28900, and V778).

In order to fully explore the yearly cost of IH, we examined the discharge-related charges and physician costs. Since hospital costs are only a portion of the total care cost, we used information provided by Medicare (15) to deduce the physician costs in 2005 dollars. Physician costs were obtained using CPT codes for shunting procedures (62220, 62223, 63740, 63741, 63744, 64746, 62230), optic nerve sheath decompression (67570), sub-temporal decompression (61340), and gastric bypass (43842, 43644). Finally, we use the consumer and producer price indices (series CPIAUCNS and NDU622110622110601, respectively) published by the U.S. Bureau of Labor Statistics to convert these 2005 dollars into their equivalent purchasing power in 2007.

Our final source of data comes from the Intracranial Hypertension Registry. The Registry is co-sponsored by the Intracranial Hypertension Research Foundation (IHRF) and the

Casey Eye Institute at the Oregon Health and Sciences University (OHSU). It contains information gathered from individuals diagnosed with intracranial hypertension (idiopathic or secondary), as well as information provided by their physicians. Patients are admitted to the Registry on a voluntary basis; however medical information from at least one or more of the patient's physicians is required for admission and confirmation of diagnosis. The Dandy Criteria (12) is used in the confirmation of idiopathic intracranial hypertension.

Similarities of Registry patients to those described in other studies tend to imply that the Registry population may be fairly reflective of the general IIH patient population (outside of the Registry). In comparing our Registry patients' major and minor symptoms and signs we found the incidence of these to be similar to previous reports (3,9,26). In a recently completed Registry study, which is in preparation for submission for publication, we found no difference in incidence, severity or type of visual field defects among Registry patients from previously published reports of non Registry patients (29). However, on initial investigation of those who have undergone shunt surgery we believe Registry IIH patients have a higher shunt failure and revision rate than non Registry IIH patients. We hope to publish this data in a future report.

This analysis uses information on individuals who were admitted to the Registry and have been diagnosed with IIH. Information from the Registry was used to identify patient gender, race, ethnicity and whether or not the patient was overweight (BMI between 25 – 29) or obese (BMI $\geq$ 30) at several points in time, including the time of diagnosis. Additionally, patients in this cohort were asked to complete a survey identifying their education and occupational characteristics, past and current earnings, IIH-related expenses and proxies for quality of life. 196 patients completed the survey. Virtually all respondents were U.S. residents, with a relatively small number of respondents (14) residing in countries such as Canada,

Australia, South Africa and the United Kingdom. For non-U.S. residents, any monetary information provided in survey responses was converted to U.S. dollars (for the year in question) using exchange rates provided by the St. Louis Federal Reserve Bank's economic database (http://research.stlouisfed.org/fred2/categories/15). The OHSU Institutional Review Board approved the survey.

RESULTS

Estimating the Number of IIH Cases

Table 2 contains our estimates of the number of IIH cases in the U.S. Panel A shows general estimates of the U.S. population by gender and age are taken from the U.S. Census Bureau's population projections for the year 2007. Because of the link between IIH and obesity (which we define as a body mass index whose value is greater than 30), we also collect data on the estimated prevalence in obesity in America by age and gender. These values can be combined to generate point estimates for the number of obese and non-obese individuals in the U.S., disaggregated by age and gender. Panel B uses incidence rates from the established literature (8,9,20,21), to arrive at a point estimate for the number of new IIH cases in the U.S for 2007. Given that age, gender, and obesity have a differential impact on the occurrence of IH, utilization of various incidence rates was appropriate (2,6,9,13,16,18). Panel C uses the traditional formula (prevalence = incidence * duration of disorder) to create point estimates for the prevalence of IH in 2007. The duration of the disorder was estimated using the 196 patients from the IH Registry. Of the 196 patients, 117 (59.6 %) were confirmed by their physicians as still under treatment for IH with a follow-up range up to 24.8 years. The average duration of illness was 4.3 years (*SD* = 5.1). For simplicity (and due to a lack of evidence suggesting

otherwise), we assume that the duration of IIH is constant across age, gender and obesity-related cohorts.

One difficulty associated with estimating the prevalence of IIH by gender, age and obesity is a paucity of IIH incidence rates for each of these cohorts. As such, we are forced to employ a pair of additional assumptions, which are consistent with what is known about the disorder, to allow us to estimate IIH populations for each cohort of individuals. First, there are no known IIH incidence rates for females over the age of 45 which are stratified by whether an individual is obese. Because obesity is thought to disproportionately increase the likelihood of IIH, we assume that the incidence among obese females is three times that of the corresponding non-obese rate. Second, there are no available estimates of IIH for males, especially when stratified by whether a male is obese. Since both obesity and being female are thought to increase the likelihood of developing IIH, we assume that the incidence among obese males is roughly half that of obese females and five times that of non-obese males. While these assumptions are admittedly ad hoc, an examination of Table 2 suggests that the estimated number of individuals in these categories suffering from IIH is relatively small. As such, even if our assumptions are improper, the error introduced from these assumptions is unlikely to significantly impact our overall estimates of the disease cost.

In total, we estimate that there are 6,041 cases of *new* IIH in the U.S. in of 2007, 5,194 of which are female and 4,531 of which are obese. Moreover we estimate that 4,575 individuals of working age (i.e., between the ages of 20 and 64) developed IIH in 2007. Of these working age individuals, 4,027 are female. Since the average duration of IIH is 4.3 years, we estimate that there are 25,976 total cases of IIH in 2007, 19,673 of which are of working age and 22,334 are female.

Estimating the Direct Medical Costs of IIH

To estimate the economic costs of IIH from a societal perspective, we used a multi-step process. First, we used the 2005 NIS to identify the direct medical costs associated with the disorder. We used 2005 data because it represented the most current NIS data at the time this study was conducted. Assuming population growth (which would also imply the growth of IIH) these numbers represent conservative estimates of the direct medical costs of the disorder. Table 3 contains both surgical procedure information retrieved from the 2005 NIS and the corresponding physician charges as well as the hospital charges. The most common surgical treatments for IIH were lumbar or ventricular shunts for CSF diversion (19). Panel A contains the number and typical physician costs for a variety of shunting procedures used to treat IIH. In 2005, the NIH data report at total of 1,880 shunt surgeries, approximately half of which are new placements (899) and slightly less than half of which are revisions and removals (796). Slightly more than one thousand (1,006) of these were ventricular shunts. The physician costs for each of these procedures are, not surprisingly, proportional to the number of shunting procedures performed. While the Medicare physician cost data were unavailable for ventricular shunt removals and shunt explorations (which makes these estimates conservative), the remaining 1,626 procedures lead to nearly $1.25 million in physician costs in 2005, or in 2007 terms, nearly $1.33 million.

Panel B in Table 3 provides a more expansive set of costs based on hospital discharges we attribute to IIH (as opposed to procedures which are depicted in Panel A). As indicated in Panel B, the vast majority of patients (7803 out of 9821, or 79.5 percent) admitted for IIH were treated using non-surgical approaches. Shunting represents the most common invasive inpatient

treatment for IIH with 1696 admissions and a mean cost in excess of $60 million. We note that the number of admissions (1696) is less than the number of procedures performed (1880) because in some instances a single admission will result in several procedures performed. In those cases, the physician costs associated with that admission reflect only the primary CPT code, making our estimates of physician costs conservative. In addition, a number of alternative and/or complementary treatment paths including bariatric surgery, sub-temporal decompression and optic nerve sheath decompression (ONSD) are also used. Since most ONSD surgeries are done as outpatient, our number of ONSD is expectedly low. These together account for 322 admissions and generate costs of over $13.6 million.

Taken in total, these 9821 admissions amount to hospital costs of $218.5 million in 2005. Our data also show that physician costs represent only about a tenth of this total, with the remainder of these costs accruing to hospitals. When we use the producer price index (Series NDU622110622110601 for general medical/surgical hospitals treating diseases and disorders of the nervous system) or the consumer price index (Series CCPIAUCNS) published by the U.S. Bureau of Labor Statistics to convert these values to 2007 dollars, we find that the total increases to approximately $232 million.

To provide some perspective on this figure, in 2007 the US spent an estimated $2.26 trillion on health care or $7,439 per person (5). This per person cost represents total healthcare costs including professional office visits, outpatient care, dental services, nursing and home care, prescription drugs and medical equipment. US hospital care was $696.7 billion or approximately $2,314 per person (based on US population). The total hospital care cost per IIH admission in 2007 was $8,931 or almost four times greater.

It is interesting to consider why the direct medical costs of IIH are so high, given that we estimate about 26,000 people are afflicted with the disorder. The information in Table 3 indicates that the answer can be traced to two, related sources. First, the fact that fewer than 26,000 individuals generate over 9,800 admissions clearly implies a relatively high usage of hospital services. Examining Panel A of Table 3, we can also infer that much of this activity comes from either i) shunt revisions, removals and replacements or ii) non-surgical treatments. The latter likely occur when the patient is admitted for diagnostic procedures, management and stabilization of symptoms, surgical complications, potential vision loss, and/or other functional impairments.

IH Registry Patient Characteristics

As mentioned earlier, our primary source for non-medical expenses come from the IH Registry. Table 4 contains some basic descriptive statistics for our sample of IH Registry patients. Consistent with the established IIH literature, the vast majority of respondents were female (92 percent), of Caucasian and non-Hispanic heritage (92 percent) and either overweight or obese, both prior to diagnosis (68 percent) and at the time they apply to the Registry (80 percent). Nearly three-fourths of respondents have a high school or college degree, and over half (54 percent) have some vocational or college training. Eighty-two percent of respondents were employed prior to being diagnosed with IIH, and nearly half (46 percent) were employed in professional occupations. Over sixty percent of individuals reported that their occupation has changed since their (or their children's) diagnosis with IIH, many of which report that they are unemployed or unable to work full time. All but three of the respondents reporting a career change identified IIH-related symptoms as the primary impetus for the change. We see a

relatively even distribution of respondents who report a given year as the last one in which they were able to work full time, free of IIH-related symptoms.

Calculating Lost Wages Due to IIH

Having identified the prevalence of IIH, as well as the direct medical costs of the disorder, the next step is to estimate lost earnings (in 2007 U.S. dollars) due to IIH. Because IIH is a severely debilitating condition, it is often the case that an individual will not be able to perform his or her job-related duties, and thus will leave the workforce. Similarly, parents of young children with IIH may also incur lost wages in order to provide care for their children. As such, lost wages due to IIH-related symptoms are likely a significant component of the costs of the disorder.

From the IIH survey we have information on respondent's earnings the last full year worked prior to IIH symptoms affecting work life, and earnings from last year, both of which are converted to 2007 U.S. dollars. We also have information on whether IIH induced an occupational change. For those respondents that reported an occupational change due to IIH, we simply look at the difference between what they earned the last full year they worked without IIH affecting their work lives and what they earned last year. For individuals that did not change occupations, we use the percent of work missed due to IIH and earnings from last year to identify the amount of wages lost due to the disorder. All losses are adjusted to 1997 values. These calculations allow us to infer both the sample incidence with which respondents fall into these categories (no lost wages, lost wages but no occupational change, lost wages with an IIH-induced occupational change) as well as sample mean and median earnings for each of these

groups. These values can be combined with our population estimates in Table 2 to infer the number and monetary value of lost earnings due to IIH.

Table 5 contains these calculations. Of the 196 respondents, 135 individuals (or 69 percent) reported earnings and labor force participation prior to IIH. After converting all values to 2007 dollars using the consumer price index, we find that these individuals exhibited median earnings of $33,037 per person per year. 93 of these respondents reported lost wages due to IIH, 60 of which reported lost earnings and IIH-induced occupational changes median = $23,816 and 33 reported lost earnings without an occupational changes (median = $1,886).

Having created per person, per year lost wage estimates, we are now in a position to use this estimate to measure total lost wages for the U.S. IIH population. From Table 2, we know that there are 25,976 cases of IIH. The data from the IH Registry indicate that 17 percent of these individuals, or 4,416, have lost wages without changing occupations due to the disorder (Table 5, Panel B). If, at the median, these individuals lose just over $1,886 per year, this implies that in 2007 U.S. dollars, the average lost wages for this cohort equate to just over $8 million. Concomitantly, 31 percent of respondents lost wages and experienced an IIH-induced occupation change (Table 5, Panel C). At the median, these individuals lose just over $23,816 per year, implying that in 2007 U.S. dollars, the average lost wages for this cohort equate to just over $191 million. On total, median lost wages due to IIH are in excess of $200 million (Table 5, Panel D). Combining this with the direct medical costs of the disorder, the total costs of IIH are over $430 million.

The numbers predicted from the IHR may be biased upward, since the socio-demographic information from the Registry implies that a majority of individuals afflicted with IIH tend to have relatively high levels of education and many work/ed in professional settings

prior to being diagnosed with the disorder. As a robustness check, we also measured the average wage loss if IH sufferers on average earned the national average but lost proportionately similar income shares. From Table 5, Panel A the weighted average lost earnings was $20,756 of an average pre-impact earnings of $39,831, or about 52% resulting in $ 259,010,870 total estimated loss. With the national average wage of $31,510 (US Bureau of Labor and Statistics: http://www.bls.gov/news.release/archives/realer_01162008.pdf), an average loss is $16,385. Based on the estimated number of individuals loosing income from the IHR means that 12,469 people can be expected to incur this loss, producing a total loss of $204,304,565. Since this number is greater than the median income figure ($ 200,118,824) provided by the IHR data, the latter impact may be a more conservative estimate of lost income. As such, we used the median lost wage estimate produced solely by using the IHR data. It is the most conservative of the three estimates, and thus is the one we include in our total cost calculations.

Calculating Non-Medical IIH Expenses

The last major component of the economic costs of IIH consists of non-medical expenses; that is, transportation, child care, and other ancillary costs that must be incurred as a direct consequence of the disorder itself, or in an attempt compensate for the impairments caused by the symptoms of the disorder. The data from the IH Registry provide some basic estimates of these costs, which are summarized in Table 6. Since the survey was administered in 2007 and asks about expenses in the current (and typical year), we do not adjust for the effects of inflation. Fifty-six percent of individuals completing the survey indicated that they incurred positive non-medical expenses. Thirty-seven percent of individuals reported expenses ranging between $0.01 and $500.00, while nearly six percent report expenses between $500.01 and $1,000.00. Seven

percent of respondents report expenses between $1,000.01 and $2,000.00, and five percent report expenses ranging from $2,000.01 to $5,000.00. Only three individuals (1.5 percent) report non-medical costs exceeding $5,000 over the past year. If we use the midpoints of the lower expenditure categories, as well as the minimum value of the largest expenditure category, we find that the average individual in the IHR sample spends $873 per year on non-medical expenses. If there are 25,976 individuals in the U.S. affected by IIH, then the prevalence available in our sample imply that 14,547 individuals incur non-medical expenses in a given year (which we assume is 2007). Multiplying our population projection times the mean non-medical expenses per individual yields total non-medical expenses of over $12.6 million annually.

CONCLUSIONS

The purpose of this paper is to provide some estimates of the economic costs of idiopathic intracranial hypertension or IIH. Using a variety of publicly available sources, we find that the economic costs of the disorder exceed $444 million annually (as measured in 2007 dollars) in the U.S. alone. Table 7 summarizes the distribution of these costs across direct medical expenses, lost wages and non-medical expenses. Clearly, direct medical expenses play the dominant role in the costs of the disorder, followed by lost wages. However, even the smallest of these costs (non-medical expenses) is a very large number, at over $12.6 million.

The direct medical expenses specific to IIH illustrate a larger set of economic and financial issues within the U.S. health care system.. When examining the direct medical costs of the disorder, either a large number of individuals were admitted to the hospital at least once each year or many patients had multiple admissions; ostensibly when those individuals had a recurrence of symptoms, surgical complications, or a failed shunt. This represents a substantial

opportunity cost to hospitals and their staffs, since treating a relatively small number of IIH patients diverts scarce (but substantial) resources away from other patients with other maladies. It stands to reason, then, that if the medical community devoted greater effort towards finding a cure for the disorder, or as a second best solution, an optimal treatment path, many of these IIH-related re-admissions could be avoided. Hospitals and other health care providers would also have greater resources and flexibility to treat other patients with other, disorders and/or injuries. Unfortunately, IIH is not the only "quiet" disorder that exists. A myriad of different maladies (whether idiopathic or otherwise) are currently plagued by the three-fold problems of resource fragmentation, a diffusion of responsibility in patient care and unsatisfactory treatment options. Future research that quantifies the magnitude of these costs for similar "quiet" conditions would provide a valuable contribution to the medical management literature. Like our this analysis, our hope is that these future studies bring more attention to these diseases and disorders, and ultimately lead to efficient and efficacious treatment paths for each of these maladies.

As with all studies, our analysis is subject to a number of limitations. First, our estimates are specifically designed to be conservative, and thus should underestimate the true costs of IIH. Moreover, we restricted our analysis to those economic costs that were most apparently quantifiable. Other economic costs were only indirectly included by the extent to which they indicate additional costs. Unplanned changes in a career for example, indicates a reduction in the quality of one's life. Since our goal is to provide some conservative estimates, this is not of significant concern for this study. However, future research that added these costs (and intended to provide less conservative estimates) to those included in our study would likely find the costs of the disorder to be much higher. Finally, a portion of our data comes from a sample of the IH Registry. As with most surveys based on fixed populations such as the Registry, sample

selection may be an issue. We have made the case that our data are consistent with the population of IIH sufferers at large, and if there is a bias it does so in a way that makes the estimates conservative.

Currently little is known about IIH, nor has evidence based medicine identified an optimal treatment path for the disorder. Clearly, the economic costs of this disorder, which are jointly borne by those suffering from IIH and society as a whole are quite substantial. As such, it may be very useful for the medical and policy making communities to direct efforts towards finding ways to better treat and manage the disorder in order to reduce some of these costs.

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