

Demographics and Clinical Features of Patients Referred to Headache Specialists

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ABSTRACT: Objective: To examine demographic characteristics and clinical features of headache patients referred to neurologists specializing in headache in Canada. **Methods:** Demographic and clinical data were collected at the time of consultation for 865 new headache patients referred to five headache-specialty clinics in Canada. The Headache Impact Test (HIT-6) and Migraine Disability Questionnaire (MIDAS) were used to measure headache impact and disability. Data were analyzed as part of the Canadian Headache Outpatient Registry and Database (CHORD) Project. **Results:** The average age of the patients was 40 years and the majority were female (78%). Most were employed either full time (49%) or part time (13%). The majority of patients were diagnosed with either migraine or tension-type headache (78%). Over a third of patients experienced headache every day, and half had experienced a headache in the previous month which was of severe intensity. Most (80%) scored in the “very severe” category of the HIT-6 and over half (55%) were severely disabled as measured by the MIDAS. **Conclusion:** Patients referred to headache specialists in Canada are severely disabled by their headache disorders. These patients are in the most productive phase of their lives in terms of age and employment. It is important to provide the best available treatment to headache patients in order to minimize the disability and impact of their headache disorders.

RÉSUMÉ: Caractéristiques démographiques et manifestations cliniques chez des patients référés à des spécialistes de la céphalée. Objectif: Examiner les caractéristiques démographiques et les manifestations cliniques de patients souffrant de céphalée qui sont dirigés à un neurologue spécialiste de la céphalée au Canada. **Méthodes:** Les données démographiques et cliniques ont été recueillies au moment de la consultation chez 865 nouveaux patients dirigés à cinq cliniques spécialisées en céphalée au Canada. Le HIT-6 et le MIDAS ont été utilisés pour mesurer l'impact de la céphalée et de l'invalidité. L'analyse des données a été faite dans le cadre du Canadian Headache Outpatient Registry and Database Project. **Résultats:** L'âge moyen des patients était de 40 ans et la majorité était des femmes (78%). La plupart avaient un emploi à temps complet (49%) ou à temps partiel (13%). La migraine ou la céphalée de tension était le diagnostic posé chez la majorité des patients (78%). Plus du tiers des patients souffraient de céphalée quotidienne et la moitié avaient eu un épisode de céphalée sévère dans le mois précédent. La plupart des patients avaient un score les plaçant dans la catégorie « très sévère » au HIT-6 et plus de la moitié (55%) étaient sévèrement invalidés selon le MIDAS. **Conclusion:** Les patients qui sont référés à des spécialistes de la céphalée au Canada ont une invalidité importante due à leur maladie. Ils sont dans la période la plus productive de leur vie de par leur âge et leur situation d'emploi. Il est important de fournir aux patients qui souffrent de céphalée le meilleur traitement possible pour minimiser l'invalidité et l'impact de leur céphalée.

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Headache disorders are disabling conditions experienced by many in the general population. Among adult Canadians, the lifetime prevalence of migraine is 7.8% for males and 24.9% for females.¹ Tension-type headache is even more common. An American study found that 38.3% of the population had experienced an episodic tension-type headache in the past year, and 2.2% had chronic tension-type headaches.² The socio-economic cost of headache disorders, particularly migraine, is enormous. For Canadians with moderate to severe intermittent migraine attacks who were participating in a triptan clinical trial, the average annual overall cost due to migraine was estimated to be \$3,025/patient, with most of this (87%) due to indirect costs (missed work, etc).³ Although many Canadians with headache, even those with migraine, do not consult a physician,⁴ many do turn to the medical profession for help. Fifty percent of American neurologists list headache as one of the foci of their practice, as

compared to 46% for epilepsy and 23% for chronic pain.⁵ In the United States, headache is also the leading condition for which neurologists indicate that they provide extended or long-term care, with over 77% indicating they provide such care for

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patients with headache.⁵ Headache may be somewhat less of a focus for Canadian neurologists, although comparable data are not available. In a 2002 survey done by the Canadian Neurological Society, only 6% of Canadian neurologists listed pain and/or headache as a specific sub-specialty interest, as compared to 15% for epilepsy and 14% for neuromuscular disorders.⁶ Nevertheless, as in other countries,⁷⁻¹⁰ headache is likely the most common reason for patient referral to a neurologist in Canada.

For those headache patients who do choose to seek health care professional advice regarding their headaches, it has been demonstrated in a Norwegian study that consultation with a neurologist generally results in some improvement in headache and self-perceived quality of life.¹¹ For migraine, it has been found that after evaluation and treatment by a headache specialist, patients report improved satisfaction with care and significant improvement in headache.¹² Despite these findings, it appears that many headache sufferers are not satisfied with the medical care they receive,¹³ and many Canadians with headache have either never sought medical care for their headaches, or once they have done so do not return for ongoing care.⁴ This is of concern, given the major disability caused by headache disorders.

The study reported here used a prospective cohort study design to characterize the demographics, diagnosis and selected clinical features of patients with headache referred to five neurological practices in Canada with a special interest in headache disorders. In addition, the degree of disability was quantified using standard measures. Our results show that these patients, for the most part, are at the severe end of the headache spectrum and are indeed a formidable challenge for the Canadian healthcare system.

PATIENTS AND METHODS

Subjects

Data were prospectively collected as part of the Canadian Headache Outpatient Registry and Database (CHORD) project for new patients referred to one of five neurologist outpatient practices in Canada. All neurologists involved were known in their geographic area to have a special interest in the diagnosis and management of headache. The five clinics involved in this study were in Calgary, Hamilton, Ottawa, Toronto, and the greater Vancouver area (Richmond). With the exception of the Calgary centre where patients saw one of two neurologists, all practices were staffed by a single neurologist. Ethical approval for the study was obtained at each centre. All neurologists involved worked as consultants, seeing patients upon referral. The great majority of the patients seen were referred by family physicians. In Canada, there are no specific criteria for referral of a patient with headache to a specialist, and the decision to refer is a clinical decision made by the referring physician in conjunction with the patient.

To avoid selection bias, consecutive new patients seen by the consultant were entered into the database. In some centres, data collection was interrupted for periods of time for logistical and resource reasons. At one centre (which entered 38 patients), because of limited resources and high patient volumes, patients were entered in a semi-random manner as time permitted. Some degree of selection bias in this small patient contribution cannot

be ruled out. Overall, data collection occurred over a period of just over two years from September 2001 to January 2004. The exact period of data collection varied somewhat from centre to centre, as additional centres were added over time.

Data Collection

Pre-specified data including basic demographic information, diagnosis, and other clinical characteristics were collected by the neurologist with the aid of a paper form, and the data were later entered into the database. Demographic information collected included age, gender, highest education level, employment status, marital status, and specialty of referring physician. Diagnoses were made according to International Headache Society (IHS) criteria of 1988,¹⁴ with the exception that patients with chronic daily headache (headache on 15 days a month or more) were diagnosed according to Silberstein et al.^{15,16} If patients received more than one headache diagnosis, the one considered most responsible for the referral was listed first, and this was the diagnosis used in data analysis. A determination as to whether or not symptomatic medication overuse was present was also made by the neurologist according to the criteria of Silberstein et al,¹⁵ and the type of medication overused was noted. Patients were asked to estimate the number of headache days they had per month at the time of the consultation. This was done with the assistance of headache diaries if these were available. Additionally patients were asked to rate the intensity of the most severe headache that they had experienced in the past month (none, mild, moderate, or severe). "None" was selected if patients experienced no headaches in the month prior to consultation with the headache neurologist. At the time of the consultation, patients also completed two measures of headache related disability, namely the Headache Impact Test (HIT- 6)¹⁷ and the Migraine Disability Questionnaire (MIDAS) (18-20).

Data Analysis

All information collected was entered into the CHORD computer database which was specifically designed to collect data from patients with headache disorders. All data were

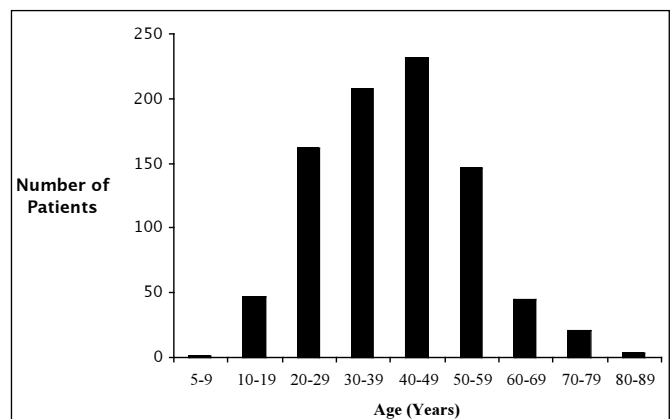


Figure 1: Age distribution of patients.

stripped of specific patient identifiers before they left each of the five headache clinics, and analyzed centrally. Descriptive statistical analyses were performed using SAS for Windows (release 8.02; SAS Institute Inc., Cary, NC, 1999-2001).

RESULTS

Data were collected on 865 patients seen in the five headache centres. The number of patients (and data collection periods) for each of the five centres were as follows: Centre #1: 357 patients (Nov 2001 – Feb 2003); Centre #2: 276 patients (Dec 2002 – Jan 2004); Centre #3: 119 patients (Sept 2001 – Oct 2003); Centre #4: 75 patients (May 2003 – Dec 2003); Centre #5: 38 patients (June 2002 – Jan 2004).

Demographic Features

Demographic features of the patient population are shown in Table 1. The mean age was 40.3 years (SD \pm 13.7). As shown in

Figure 1, most patients were between the ages of 20 and 60, while the 40-49 age group was the most populated in our sample. The majority of the patients were female (n=672; 77.7%), and approximately half of the patients who were referred were married or living common law (n=471; 56.2%).

Almost 90% of our patients had at least a high school diploma, and 22% (n=164) were educated to a Bachelor degree level or higher. More than half of the patients were employed outside of the home (n=491; 61.9%), either full time (n=391; 49.3%), or part time (n=100; 12.6%). A further 11.3% (n=90) identified themselves as full time home makers. Only 5.4% (n=43) of the patients were receiving disability benefits because of their headache disorder, but an additional 4.9% (n=39) were receiving a disability pension for other reasons. Only 9.3% (n=74) gave their work status as unemployed.

The vast majority of patients seen (n=729; 84.3%) were referred to the headache specialist by a family physician, although 5.3% (n=46) were referred by other neurologists.

Diagnosis

Patient diagnoses are shown in Table 2. The majority of patients referred to the headache specialists in our study were given a migraine diagnosis (n=606; 70.4%). Of these, approximately a third (n=216; 25.1% of the total patient population) were given a diagnosis of transformed migraine. Approximately half of the patients with transformed migraine (n=104; 48.1%) had medication overuse.

In only 7.9% of patients (n = 68) was tension-type headache considered the diagnosis most responsible for the patient's referral. The majority of these patients (n = 46; 67.6%) were specifically sub-classified as suffering from chronic tension-type headache. Only eight (n=8; 17.4%) of these chronic tension-type headache patients were considered to have medication overuse and 24 patients (52.2%) were specified not to have medication overuse. In the remaining patients, their status with regard to medication overuse was not specifically coded and is therefore not known.

The diagnosis of new daily persistent headache was given to 5.1% (n = 44) of patients. These diagnoses were made before the 2004 IHS diagnostic criteria²¹ were available, and reflected primarily the mode of onset of these continuous headaches.¹⁵ Twenty-five percent of these patients (n=11; 25%) were specified to have medication overuse.

With regard to the rarer primary headache syndromes, three patients were given a diagnosis of hemicrania continua,

Table 1: Demographic features of patients seen by headache neurologists in Canada. (n=865)

Age (mean \pm SD)	40.3 \pm 13.7
Gender	
Male	193 (22.3%)
Female	672 (77.7%)
Race	
White	735 (93.8%)
Education*	
Elementary-Secondary Only	340 (46.3%)
<i>Less than High School Diploma</i>	77 (10.5%)
<i>High School Diploma or Equivalent</i>	263 (35.8%)
Trades Certificate/Diploma	56 (7.6%)
Community College	142 (19.3%)
University	196 (26.7%)
<i>Some University</i>	23 (3.1%)
<i>University Certificate Below Bachelor's Degree</i>	9 (1.2%)
<i>Bachelor's Degree</i>	122 (16.6%)
<i>University Certificate Above Bachelor's Degree</i>	6 (0.8%)
<i>Medicine, Dentistry, Veterinary Medicine, Optometry</i>	2 (0.3%)
<i>Master's Degree</i>	30 (4.1%)
<i>Doctorate Degree</i>	4 (0.5%)
Employment Status**	
Full Time Outside of Home	391 (49.3%)
Part Time Outside of Home	100 (12.6%)
Full Time Homemaker	90 (11.3%)
Unemployed	74 (9.3%)
Retired From Work Outside of Home	46 (5.8%)
Disability Due to Headache	43 (5.4%)
Disability For Reasons Other Than Headache	39 (4.9%)
Welfare/Social Assistance	10 (1.3%)
Marital Status***	
Married/Common Law	471 (56.2%)
Single	261 (31.1%)
Divorced/Separated	90 (10.7%)
Widowed	16 (1.9%)
Referral	
Family Physician/GP	729 (84.3%)
Neurologists	46 (5.3%)

*Education status was unknown in 131 patients; % totals are out of 734

**Employment status was unknown in 72 patients; % totals are out of 793

*** Marital Status was unknown in 27 patients; % totals are out of 838

Table 2: Diagnoses of patients seen by headache neurologists in Canada (n=860)*

Diagnosis	No. (%)
Migraine	390 (45.3%)
MO**	21 (5.4%)
Transformed Migraine	216 (25.1%)
MO	104 (48.1%)
Tension-Type	68 (7.9%)
MO	10 (14.7%)
NDPH***	44 (5.1%)
MO	11 (25.0%)
Headache Associated With Head Trauma	31 (3.6%)
MO	10 (32.3%)
Headache Associated With Cervical Spine Disorder	30 (3.5%)
MO	7 (23.3%)
Cluster	23 (2.7%)
MO	2 (8.7%)
Other	58 (6.7%)
MO	12 (20.7%)

*No diagnoses was listed for 5 patients; % totals are out of 860

**MO=Medication Overuse

***New Daily Persistent Headache

there were five cases of idiopathic stabbing headache, and three cases of chronic paroxysmal hemicrania.

If medication overuse was excluded, the most common secondary headache types seen were headache associated with head trauma (n = 31; 3.6%), and headaches associated with disorders of the neck (cervical spine) (n = 30; 3.5%). Sinus-related headache as the most important diagnosis leading to referral was rare and diagnosed in only two patients. A diagnosis of low spinal fluid pressure headache was also given to only two patients.

Clinical Features

Over a third of patients (n = 310, 36.4%) had headache every day. Just over half of all patients, 55.1% (n=471) had headache on 15 days per month or more. As shown in Figure 2a, the

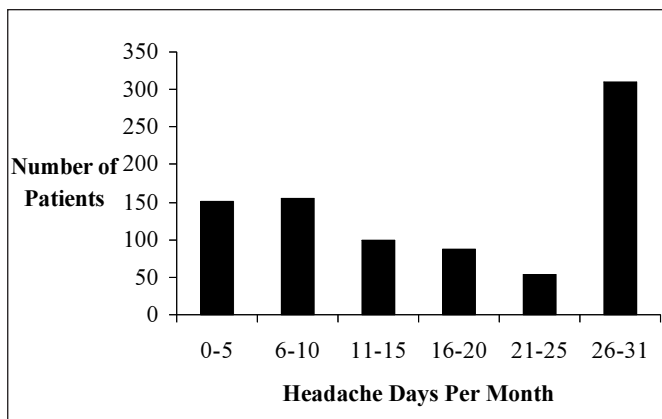


Figure 2a: Number of headache days per month (n=855)

majority of the patients who had headaches on more than 15 days a month had headache essentially every day.

As shown in Figure 2b, 51.4% (n=372) of patients had experienced at least one headache of severe intensity in the previous month, and a further 37.7% (n=273) had experienced a headache of at least moderate intensity. Only 10.8% (n=78) had experienced only mild headaches or no headaches in the month prior to the consultation.

Disability

Table 3 demonstrates the level of disability experienced by our sample of headache patients, shown by diagnostic categories. Headache patients experienced substantial impact and disability as a result of their headaches as indicated by HIT-6 and MIDAS scores (Table 3). The majority of patients across all diagnostic categories scored in the “Very Severe” range with the HIT-6. Similarly, over half of all patients in each diagnostic category were severely disabled by their headaches as indicated by MIDAS scores (Table 3). According to the HIT-6, the diagnostic categories in which patients were most impacted by their headaches were transformed migraine, headache associated with head trauma, and headache due to cervical spine disorder. Similarly, these same three diagnostic categories showed the highest mean disability scores on the MIDAS.

DISCUSSION

Consistent with the epidemiology of headache, the majority of patients referred to the headache specialists in our study were female. According to a Canadian population based epidemiological study,¹ migraine is just over three times as common in females as in males, and migraine was the dominant diagnosis in our referred patient population. The female to male ratio in our overall referred population was 3.48 to 1, accurately reflecting the prevalence according to gender in the general population. Our population of patients was also similar to other clinic-based studies of headache in terms of age and various demographic features.²²⁻²⁵

Given the episodic nature of headache and the lack of mortality associated with this disorder, headache typically has

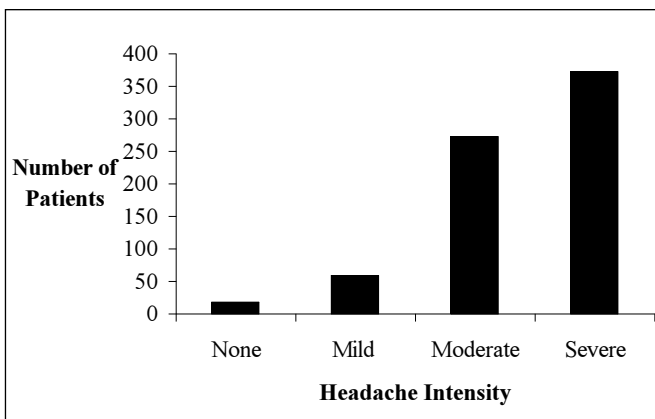


Figure 2b: Headache intensity in previous month (n=723)

Table 3: Disability in patients seen by headache specialists in Canada, separated by diagnostic categories

	Migraine	Transformed Migraine	Tension Type	NDPH	Trauma	Cervical Spine	Cluster	Other
HIT-6	n=371	n=213	n=64	n=44	n=29	n=29	n=22	n=57
Score *	63.1 (62.4-63.7)	64.8 (64.2-65.4)	63.4 (61.8-65.0)	63.3 (61.3-65.2)	66.1 (63.4-68.9)	64.7 (61.8-67.6)	64.1 (61.2-67.1)	59.2 (56.6-61.8)
None/Little	11 (3.0%)	1 (0.5%)	3 (4.6%)	2 (4.6%)	---	2 (6.9%)	1 (4.6%)	11 (19.3%)
Some	31 (8.4%)	6 (2.8%)	2 (3.0%)	2 (4.6%)	3 (10.3%)	1 (3.5%)	---	5 (8.8%)
Substantial	45 (12.1%)	13 (6.1%)	9 (13.6%)	6 (13.6%)	2 (6.9%)	---	4 (18.2%)	8 (14.0%)
Very Severe	284 (76.6%)	193 (90.6%)	52 (78.8%)	34 (77.3%)	24 (82.8%)	26 (89.7%)	17 (77.3%)	33 (57.9%)
MIDAS	n=373	n=208	n=64	n=44	n=31	n=29	n=68	n=56
Score *	30.5 (27.1-34.0)	67.3 (57.1-77.5)	42.1 (28.5-55.7)	53.8 (27.3-80.3)	107.5 (60.4-154.7)	62.7 (35.5-89.9)	57.0 (17.9-96.0)	31.7 (19.0-44.4)
None/Little	61 (16.4%)	20 (9.6%)	16 (25.0%)	10 (22.7%)	3 (9.7%)	7 (24.1%)	6 (26.1%)	26 (46.4%)
Mild	41 (11.0%)	7 (3.4%)	4 (6.3%)	5 (11.4%)	2 (6.5%)	1 (3.5%)	1 (4.4%)	3 (5.4%)
Moderate	81 (21.7%)	21 (10.1%)	8 (12.5%)	7 (15.9%)	5 (16.1%)	3 (10.3%)	3 (13.0%)	7 (12.5%)
Severe	190 (50.9%)	160 (76.9%)	36 (56.3%)	22 (50.0%)	21 (67.7%)	18 (62.1%)	13 (56.5%)	20 (35.7%)

*Mean score (95% confidence interval)

not been on the forefront of public health initiatives. Nonetheless several lines of research have demonstrated that headache gives rise to significant disability, substantially impacting both work and family life of headache sufferers. Gerth et al²⁶ reported that migraineurs in North America are absent from work approximately 17 days each year. In this same study, migraine sufferers indicated that, in the four weeks prior to being surveyed, they had worked approximately 13 hours with migraine and were only 46% effective while at work with migraine symptoms.²⁶ Von Korff et al²⁷ reported headache-induced decreased work effectiveness, while working with headache, in the order of 41% for migraine and 24% for other headache types. In an American study, Hu et al²⁸ have estimated that indirect costs incurred by employers because of migraine is \$13 billion annually, with \$8 billion due to migraine-related missed workdays. Almost 85% indicated a reduced capacity to perform housework or chores.²⁹

With regard to leisure activities and family relationships, studies have reported that over 40% of migraineurs reported missing family or social activities as a result of their headaches,³⁰ while 32% avoided making plans for these same types of activities.²⁹ Lipton and colleagues²⁹ reported that both migraineurs and their household partners indicated that migraine had a negative impact on communication and increased the number of arguments. Forty-three percent of migraineurs in their study felt that they would be better parents without their

headaches. As demonstrated by these studies, headache has a profound debilitating impact on both work and family life.

In our patient population, the great majority of patients referred to the headache specialists were in their potentially most productive years of life, between the ages of 20 and 60. The majority were working outside the home and an additional 11% were full time home makers. Only 16% were either unemployed, retired, or on social assistance. The highest educational levels attained by the headache patients in our sample were similar to the general Canadian population. Based on 2001 statistics, 45% of Canadians attained an elementary or secondary education only compared to 46% of patients in our sample. Twenty seven percent of our sample had completed some university compared to 26% of Canadians.³¹ Over half of our sample population was married or living common law. Coupled with our data on the degree of disability suffered by these individuals, our data paints a picture of a population severely affected by their headache disorders, and struggling to remain productive in society. Additionally, given the previous literature regarding the repercussion of headache on family relationships and activities, there is potential for headache to have a major negative impact on immediate family members. In light of the impact headache has on people's lives, the importance of our health care system delivering the best medical care possible for this patient population in order to prevent disability cannot be overemphasized.

Over 90% of the patients referred to our headache specialists fell into seven diagnostic categories, with two diagnostic categories, migraine and transformed migraine, accounting for over 70% of referrals. Although tension-type headaches are more common than migraine in the general population, they made up a much smaller proportion (7.9%) of the referrals. It is of course likely that a significant proportion of our migraine population may have had tension-type headaches as well, but their migraine was considered the main reason for the referral. The fact that all the headache specialists in our study were neurologists may have influenced the type of patients referred significantly, as migraine is generally considered a neurological condition, whereas patients with headache associated with head injury and with neck problems may have been preferentially referred to other specialists.

As might be expected, the great majority of the patients referred had at least moderate or severe headache attacks, and were still actively suffering from their headache disorder. However, a small minority of patients had not had such headaches in the past month. Although not specifically documented, there are a number of possible reasons for the referral of such patients, including concern about infrequent but problematic migraine auras, and patients with episodic cluster headache who were not in a cluster at the time of referral.

The degree of disability suffered by our patients was very significant. We utilized both the HIT-6 and the MIDAS measurement tools to determine the level of impact and disability our patients experienced because of their headaches. In all diagnostic categories except for "other", fully three-fourths of patients were in the severe impact category on the HIT-6, and over half were in the severe disability category on the MIDAS. Our headache impact results, as measured by the HIT-6, are within the range of results of previous studies on headache patients. Fifty percent (50%) of migraine sufferers³² and 66% of episodic headache patients (including migraine)³³ seen in primary care clinics presented with very severe HIT-6 scores. Among patients in a headache specialty practice, the majority (87%) was in the severe impact range.³⁴ The MIDAS data, however, indicate that patients captured in our study were more disabled by their headaches compared to patients in other previously published studies, including a population-based study of migraine patients¹⁹ and headache clinic-based studies of both episodic and chronic migraine.^{22,24,35,36} Based on these comparisons, one explanation for this difference may be that headache patients in Canada may be experiencing delays in referral to headache specialists until a point at which their headache disorders are quite advanced. As well, this indicates that primary care physicians are selective in terms of the patients with headache they refer to specialists.

Our study was completed before publication of the second edition of the International Classification of Headache Disorders of the International Headache Society (IHS).²¹ We therefore used the transformed migraine designation¹⁶ in our study for patients with migraine and chronic daily headache, as we felt this was the most appropriate classification available for these patients at that time. Broadly speaking, most patients in our study with transformed migraine without medication overuse would meet diagnostic criteria for chronic migraine in the new IHS classification, while patients with transformed migraine with

medication overuse would fall into the probable medication overuse headache category.

There are potential limitations involved in our study. Firstly, our study sample was drawn from patients who were seen in headache specialty clinics by neurologists who specialize in headache. Therefore our findings cannot be generalized to the headache population as a whole. Furthermore, not all headache clinics in Canada participated in this study and therefore our results are not population-based and may be subject to referral bias. Given the headache frequency and disability experienced by the patients in our sample, it is likely that our study sample represents the severe end of the headache patient spectrum, comprised of patients who may have posed a treatment challenge to primary care physicians. However, we endeavoured to include specialty headache clinics across Canada and therefore our results are most likely an accurate representation of patients seen by headache neurologists in Canada. It is also likely that our patient population is not very different from patients with headache referred to general neurologists in many parts of Canada, as many areas do not have significant numbers of neurologists sub-specializing in headache.

In conclusion, the patient group referred to headache specialists in Canada is dominated by migraine. It is important that more recognition be given both by physicians and by society at large to the disability produced by migraine disorders. In addition, the high prevalence of symptomatic medication overuse, particularly in the migraine population, needs to be emphasized and addressed by the medical profession. In the overall headache referral population, the high headache frequency found is also noteworthy. Over a third of the patients referred have headache every day. Although most referred patients are in an age range where people are generally in the healthiest and most productive phase of their lives, the patients with headache analyzed in this study were characterized by high degrees of headache related disability. This was the case for all diagnostic categories, and underlies the importance of providing the best possible treatment for this patient group to reduce the impact of headache disorders on the individual, their families, and on society. Future research should also focus on patients with less severe headache problems, particularly patients with migraine, to explore whether progression to a more severe stage can be modified by early effective treatment.

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