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# The Canadian Migraine Forum

Supplement Editor: W.J. Becker



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## The Canadian Migraine Forum

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### Introduction

Congratulations to all who participated in this forum. For those neurologists who thoughtfully read these proceedings, I also think you deserve congratulations. Many neurologists do not take the time and effort to go beyond a diagnostic screen, a "neuroimage", and the addition of a few medications, when they see migraine patients in their practices. This is ironic at many levels. Migraine is one of the most interesting of all the neurological disorders and has a biological basis unique in our field. It has a rich history in clinical neurology, and is suffered, many times in silence, by family members, friends and even frequently by ourselves!

So where is the dissonance here? These papers outline the problems in spades and point towards some potential actions and solutions. The patient testimonials show just how miserable people are during their migraine attacks; and yes, when they become frequent and chronic, and intermixed with numerous comorbid disorders, they become very complex. It is difficult to manage migraine and to care for the patient with migraine. Please read on carefully to the patient testimonial in the third paper, "I am grateful to my neurologist who never gives up trying to find new treatments to improve my quality of life, and who was supportive in my attempts to obtain a small disability pension. . ." Is this different from any other neurological disorder such as stroke, multiple sclerosis, Parkinson's disease or epilepsy? Are these patients asking for any more that the hundreds of patients we see throughout our careers that ask, and yes sometimes lately even demand, that we help them, not abandon them, and carry on against all odds?

The main difference is that there are over three million Canadians with migraine. They are numerically greater than the sum of all of the other disorders mentioned above. Have we forgotten them or is there something they do or say that that makes their complaints less worthy? Is it because they have pain and nothing life threatening that to some neurologists they are not 'real' patients, or that they are somehow tainted by 'psychological problems'? Or are we collectively in denial, marginalizing them and sometimes even making jokes about headache patients because we by and large feel there is little we can do but "diagnosis and adios!"

In my view the people that participated in this forum are not cynical about headache medicine and try hard to help these patients. Sometimes all they can do is provide "hope" as to date there is no cure – but someday there may well be one. This was debated recently at the Scientific Meeting of the American Headache Society in Chicago in a symposium: "Migraine – Will there ever be a cure?" The answer: It is possible, if your definition of a cure includes freedom from symptoms of disease.

Canadian neurologists are world-class clinicians. They have the talent and ability to apply their considerable expertise, knowledge, and now the biological and clinical evidence to help our patients with migraine. This forum and its participants are clear indicators that we are headed down the right road. The migraine brain is a 'sensitive' one, but none the less deserving of our attention. For the sake of our patients, the next time you see a patient with migraine in consultation, to paraphrase Sir William Osler, take those few extra minutes to learn about the "person with the disorder" as well as the "disorder in the person".

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# Migraine Prevalence, Diagnosis, and Disability

Werner J. Becker, Jonathan P. Gladstone, Michel Aubé

ABSTRACT: The goal of the Canadian Migraine Forum was to work towards improving the lives of Canadians with migraine by reducing their migraine-related disability. This paper reviews the epidemiology and diagnosis of migraine, and the effects of migraine on health related quality of life. Many patients with migraine do not consult a physician for their headaches, and when they do they often do not receive a correct diagnosis. The discussion at the Forum concluded that better education, both for physicians and the public, on issues relating to migraine was a necessary step in improving migraine diagnosis. The degree of disability caused by migraine is often not recognized by society, and can be substantial for individuals with migraine. Once again, education of the public and of the health professionals who see these patients is key, so that the best migraine management can be instituted to minimize the impact of migraine on the individual, the family, and society at large.

RÉSUMÉ: La prévalence, le diagnostic et l'invalidité dans la migraine. Le but du Canadian Migraine Forum était de s'efforcer d'améliorer la vie des Canadiens qui souffrent de migraine en diminuant leur invalidité due à la migraine. Cet article revoit l'épidémiologie et le diagnostic de la migraine et les effets de la migraine sur la qualité de vie reliée à la santé. Plusieurs patients atteints de migraine ne consultent pas de médecin pour leurs céphalées et quand ils le font, souvent le diagnostic posé est erroné. Suite aux discussions, il s'avère qu'une meilleurs formation sur la migraine, destinée tant aux médecins qu'au grand public, est une étape nécessaire pour améliorer le diagnostic de la migraine. Fréquemment le degré d'invalidité causé par la migraine n'est pas reconnu par la société même s'il peut être important pour le patient migraineux. Encore là l'éducation du public et des professionnels de la santé qui traitent ces patients est la clé du succès si on veut que le meilleur traitement de la migraine soit administré afin de minimiser l'impact de la migraine sur l'individu, sa famille et la société en général.

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The Canadian Migraine Forum was organized to discuss various aspects of migraine and its treatment in Canada. Migraine is a significant public health problem in Canada, even though migraine does not causes death, and rarely causes permanent neurologic deficits.

The impact of migraine on the individual with severe migraine is perhaps best expressed in poetry. In the poem, "A Friend Like No Other", the throbbing headaches are likened to the pounding of a hammer, and the disability and reduced quality of life is poignantly expressed in the last lines of the poem:<sup>1</sup>

"There's a man chained to me with a hammer in his hand who has stolen my life.

Do you understand?"

#### BACKGROUND

On May 13th, 2006, 30 health professionals and individuals with migraine gathered in Toronto for a unique meeting organized by the Canadian Headache Society (CHS) and

From the Division of Neurology, University of Calgary (WJB), Calgary, AB; University of Toronto (JPG), Toronto, ON; McGill University (MA), Montreal, QC,

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**Table 1: Canadian Migraine Forum planning committee** 

Dr. W.J. Becker (chair)	Calgary	President CHS
Dr. R. Giammarco	Hamilton	Neurologist
Dr. M. Aubé	Montreal	Neurologist
Dr. A. Purdy	Halifax	Neurologist
Dr. G. Shapero	Markham	Family Physician
Ms. V. South	Toronto	Sec/Treasurer HNC
D. McIntosh	Calgary	Pharmacist

summarized in three articles. This article focuses on migraine diagnosis and migraine related disability. A second article focuses on migraine treatment. The third focuses on what general approaches might be taken to reduce the burden carried by individuals with migraine and their families in Canada. Each of the three articles is prefaced by one of the migraine patient presentations at the forum. These presentations brought to the forum the real life experiences and perspectives of patients with migraine.

Headache Network Canada (HNC). The CHS is a non-profit physician organization dedicated to promoting research, education and patient care in the field of headache. Headache Network Canada is a lay organization which provides educational services to headache sufferers and their families. The forum was funded by an unrestricted grant from Merck Frosst Canada. The content of the forum was determined by a planning committee made up of members of the CHS and HNC (Table 1). The forum was held at Hart House, University of Toronto.

The goal of the Canadian Migraine Forum was to improve the lives of Canadians with migraine by reducing their migraine-related disability. The objectives included reviewing the disability suffered by individuals with migraine and the current medical care available to them in the Canada. This included the identification of gaps in current migraine care as compared to optimal care, and a consideration of what specific steps might be taken to close these gaps. The ultimate aim was to determine what could be done to reduce the burden carried by migraine sufferers and their families.

#### Forum attendees

The forum was attended by six individuals with migraine from three Canadian provinces, and twenty four health professionals from across Canada (Table 2). All the healthcare professionals had wide experience in the care of patients with migraine.

#### Forum overview

The forum included seven presentations, each of which was followed by a discussion. (Table 3). One of the presentations, (the migraine experience), included presentations by three individuals with migraine who discussed some of their experiences in the health care system, and the impact that migraine had had on themselves and their families. The presentations were followed by a "Finding Solutions" session on how the forum's goals could be met. The entire forum was recorded.

The presentations and discussions at the Forum have been

**Table 2: Canadian Migraine Forum participants** 

Patients with migraine	
Isabel Berger	Montreal
Ruth Clausen	Grimsby
Mary Anne Ewer	Stoney Creek
Rebecca Holohan	Richmond Hill
Georgina Kossivas	Toronto
Margaret McCourt	Calgary
Nurses	
Shelley Maher	Hamilton
Irene O'Callaghan	Calgary
Valerie South	Oakville
Pharmacists	
Donald McIntosh	Calgary
Nancy Simonot	Hamilton
Deb Stewart	Calgary
Irene Worthington	Toronto
Family Physicians	
Kelly Chapman	Markham
Ian Finkelstein	Toronto
Charles Schellenberg	Winnipeg
Gary Shapero	Markham
Janet Vickers	Oakville
Neurologists	
Michel Aubé	Montreal
Werner Becker	Calgary
Andre Bellavance	Montreal
Suzanne Christie	Ottawa
Marek Gawel	Toronto
Rosella Giammarco	Hamilton
Jonathan Gladstone	Toronto
Gordon Mackie	Vancouver
Stephen McKenzie	Mississauga
Occupational Therapists	
Cheryl Lake	Calgary
Healthcare Administrators	
Valerie Wiebe	Calgary
Psychologists	
Sharon Habermann	Calgary

#### Table 3: Presentations at the Canadian Migraine Forum\*

Migraine prevalence and diagnosis

Migraine and quality of life

Medications for migraine attacks

Medications to prevent migraine attacks

Non-medication treatment approaches for migraine

Medication overuse and migraine

The migraine experience

#### **Patient Experience**

I started suffering from migraines in my early teens, but was not diagnosed with migraine until my early thirties. In the meantime, I was given many diagnoses. I was told that it was just puberty, then that the headaches were caused by my hormones. I was put on the birth control pill to regulate my hormones, and was told the headaches should go away. I was diagnosed many times with the flu, then with sinusitis, and then was told I had an eating disorder. I had a brain scan to exclude a tumor. I was given over the counter medication and sent to a chiropractor. I had a lot of vomiting with my attacks, and after several trips to the emergency, I was given a prescription for Gravol by injection, so I would not have to come back. My migraines became more frequent, and I began to miss a lot of work. My employer required notes from my doctor, and this prompted him to do something. My family doctor sent me to an allergist to check for food allergies, and the allergist thought I might have migraine. He suggested I see a neurologist.

By this time my employer had identified me as a person who abuses sick time, and this was placed on my permanent file. Once the diagnosis of migraine was made, everything at work changed, and my employer became very supportive.

My family has endured many frustrating times because of my migraines. I can never get back all the things I have missed: birthday parties, graduations, several Christmas dinners, mother's days, and one missed flight home from a vacation.

My family doctor said migraines were out of his league, and wanted me to follow up with the neurologist. From that point on, I have been followed by a neurologist, with whom I have regular follow-up appointments. We have tried many different medications. Currently I am taking a preventative medication and use a triptan when my attacks occur. Finding the right treatment has been an ongoing process, and the key to all of this is a good relationship with your doctor.

#### Migraine Prevalence and Diagnosis

Migraine is remarkably common. Its prevalence exceeds that of osteoarthritis, diabetes, and asthma, and is greater than the combined prevalence of epilepsy, multiple sclerosis, stroke, and Parkinson's disease. In Canada, the lifetime migraine prevalence in women was found to be 23 % in 1992,<sup>2</sup> 24.9% in 1994,<sup>3</sup> and 26% in 2006.<sup>4</sup> In men, migraine lifetime prevalence was found to be 10% in 1992,<sup>2</sup> and 7.8% in 1994.<sup>3</sup> These results indicate that at least three million women and one million men in Canada have migraine.

Most migraine sufferers have headaches that are frequent enough to potentially interfere significantly with their activities. Approximately 60% have one or more headache attacks per month, and 25% of migraineurs have attacks at least once a week.<sup>5,6</sup>

#### Table 4: Diagnostic Criteria for Migraine\*

Recurrent headaches

Last 4-72 hrs untreated

At least 2 of the following

- unilateral
- pulsating
- mod-severe intensity
- aggravated by (or causes avoidance of) exertion

At least 1 of the following

- nausea +/- vomiting
- photophobia + phonophobia

No evidence on history or physical of another cause

Migraine is generally under diagnosed. A recent Canadian survey found that 48% of women with migraine had never consulted a physician for their headaches. When a diagnosis of migraine is made by a primary care physician, it is usually accurate, but one in four patients with migraine receives another diagnosis. Research has also shown that over 80% of patients with recurrent headaches without fever or purulent nasal discharge, with a self diagnosis or physician diagnosis of sinus headache have migraine headaches instead. It has been concluded that the vast majority of patients consulting their physician with disabling episodic headache as a primary or secondary complaint suffer from migraine. Such headaches

<sup>\*</sup> All presentations were followed by a discussion period, and once all presentations were completed, a final "finding solutions" discussion completed the forum.

<sup>\*</sup>Summarized from IHS diagnostic critieria.9

Table 5: Three questions to assist in the rapid diagnosis of migraine\*

Strongest predictors of migraine diagnosis

- Nausea

Are you nauseated or sick to your stomach when you have a headache?

- Disability

Has a headache limited your activities for a day or more in the last 3 months?

- Photophobia

Does light bother you when you have a headache?

2 out of 3 symptoms: 93% PPV for migraine 3 out of 3 symptoms: 98% PPV for migraine

should probably be diagnosed by default as migraine in the absence of contradictory evidence.<sup>7</sup>

Simple diagnostic paradigms for migraine have been developed for primary care physicians, based upon the detailed International Headache Society diagnostic criteria (IHS). Both of these screening methods are not meant to replace a detailed clinical evaluation, but could serve to alert physicians to a high possibility of migraine. One of these, the PIN criteria (Table 5), consists of only three questions: does light bother you when you have a headache (Photophobia), has a headache limited your activity for a day or more in the last three months (Interference with activity), and are you nauseated during a headache (Nausea). The presence of two of these three symptoms has a 93% positive predictive value for a diagnosis of migraine. 10

Another simple diagnostic system consists of three questions which were found to allow diagnosis with a positive predictive value of 0.96: 1) do you have headache every day, 2) is your headache only on one side of your head (during an attack), and 3) does your headache stop you from doing things. Patients with intermittent migraine would answer "no" to the first question. If they answered "yes" to the second question, they would be diagnosed with migraine. If they answered "no" to the second question, but "yes" to the third question, they would also be diagnosed with migraine. Patients with chronic migraine or with migraine, medication overuse, and chronic daily headache would be missed by this method, but such patients would require detailed evaluation in any case.

It is important that more patients with migraine be diagnosed appropriately. In a U. K. population based study, 60% of those with migraine who had never been diagnosed suffered from

substantial migraine related disability (defined as  $\geq 5$  lost day equivalents in the last year) as compared to 80% of those who had been diagnosed with migraine.<sup>12</sup>

In summary, migraine is very common in the general population, and continues to be under diagnosed by physicians. This contributes to inadequate treatment and unnecessary suffering.

#### FORUM DISCUSSION SUMMARY

In the discussion, it was apparent that there are additional barriers to migraine diagnosis. Headache is so common, that everyone thinks they know about headache, and don't appreciate that some patients with migraine suffer marked disability from their headaches. Diagnosis of migraine, also carries a certain stigma. There are few jokes in our society about epilepsy or Parkinson's Disease, but jokes about headache abound. Perhaps because of this, many patients don't want to accept a diagnosis of migraine from a physician, but argue instead that they have sinus headaches or some other headache type. Those who may know more about migraine, and who may have had relatives suffer badly from migraine, may also go into denial of their migraine diagnosis because migraine can be a very frustrating disorder to treat, and may require much effort from the patient for successful management. Other patients appear to have a misconception of what the range of migraine headache is. They feel that if a headache does not completely incapacitate them and does not result in repeated vomiting, it cannot be a migraine.

Once some physicians have become satisfied that the patient does not have a sinister headache, they lose interest in the patient's headache. Physicians need to realize that for many patients with headache the challenge is not diagnosis, but management. The first thing that should be done is to kill forever the concept that migraine is a psychological disorder. It results from brain malfunction and is a neurological problem.

There are many barriers to effective migraine management. Some patients with a family history of migraine have the attitude that headaches are their lot in life and nothing can be done. They do not seek out the best management possible. When patients have been diagnosed with disabling migraines, they are not always receptive to taking the best treatments. Some feel that the triptans are very strong medications, and fear their potential cardiovascular side effects. One solution may be to make the point that the triptans are very safe medications in patients without cardiovascular disease, and are migraine specific medications as opposed to "strong" medications.

Better information and education for patients and for health professionals was felt to be a major part of any solution to improve migraine diagnosis and treatment. Public lectures, television interviews and spots, and more time in professional educational curricula would all be helpful. Some of the patients present felt it important to include patients with migraine in educational efforts and support groups, as individuals with migraine can relate more to information from others with migraine. Well informed pharmacists could also be part of the solution. Patients frequently come to pharmacists with over the counter medications they intend to purchase, and ask, "Is this the best there is?" Pharmacists need to be aware that there are many other treatment options besides OTCs, and advise patients to see their physicians about these.

<sup>\*</sup> Sometimes referred to as the PIN criteria (Photophobia, Interference with Activity, and Nausea). PPV: Positive Predictive Value

In short, much could be improved. One reason why patients do not seek out effective therapy is that they may give up after seeing physicians who use a step treatment paradigm and initially try therapy in patients with severe migraine which are unlikely to be effective.

#### Migraine and Quality of Life

Quality of life is defined in a subjective way, and depends upon an individual's perception of his or her state of well being in multiple areas (social, emotional, physical, etc). A reduced quality of life represents the gap between an individual's actual life experiences and that individual's expectations.<sup>13</sup> Health related quality of life refers to the impact of a disorder on the individual's ability to lead a fulfilling life, and therefore has a relationship to illness related disability.<sup>14,15</sup>

Many aspects of migraine may lead to significant disability, including the pain, nausea, vomiting, photophobia, phonophobia, osmophobia, aura symptoms, and cognitive dysfunction related to an individual's migraine attack. Migraine management may include lifestyle adjustments, and the avoidance of specific migraine triggers. The unpredictable nature of migraine attacks contributes to disability beyond that imposed by the actual symptoms of the attacks.

Most migraine attacks are relatively severe. In a population based study, 87% of migraine sufferers usually experienced attacks with at least grade 7 / 10 pain, and 43% of all migraine sufferers usually experienced grade 9 or 10 pain.<sup>6</sup> Untreated migraine attacks last more than 24 hours in the majority (approximately 60%) of patients.<sup>6</sup> Individuals with migraine show in general a significant reduction in HRQoL as compared to controls, and a greater reduction in HRQoL than people with asthma.<sup>16</sup> Migraine is very common, and the World Health Organization ranks it as 19th overall among medical disorders in terms of causing years lived with disability (2001). Among women, migraine ranks 12th.<sup>17</sup>

Almost all individuals with a migraine attack experience some disruption of their activities. A Canadian population based study found that regular activities were limited in 78% of migraine attacks. Is In the migraine population, missed work time is concentrated in a sub-population, presumably those who are more severely affected, as 40% of migraineurs account for 100% of lost workdays and 75% of lost workday equivalents (time spent at work with reduced productivity). Based upon a population based study, it was estimated in 1992 that seven million working days are lost annually in Canada as a result of migraine. A

One aspect of the migraine attack which can contribute to disability is the cognitive dysfunction which can be associated with migraine attacks.<sup>20,21</sup> Recent work indicates that patients with left sided migraine attacks suffer more from left hemisphere dysfunction such as verbal disabilities, and patients experiencing right sided headache attacks suffer more from right hemisphere dysfunction.<sup>22</sup>

Migraine related disability is very marked in patients referred to headache specialists in Canada, as measured by the HIT -6 and the MIDAS. For patients with migraine on  $\leq 15$  days a month, 77% showed very severe impact of headache on their lives as measured by the HIT -6, and 51% showed severe disability on the MIDAS. For migraine patients with > 15 days

of headache / month 91% showed severe impact on the HIT – 6, and 77% showed severe disability on the MIDAS. $^{23}$  These data are consistent with an Italian study which showed a greater reduced of HRQoL in patients with chronic daily headache as compared to those with episodic migraine. $^{24}$ 

A 2005 Canadian population based study<sup>4</sup> confirmed that migraine causes significant disability in the general population. When 300 individuals with migraine were asked to estimate on how many days their migraines incapacitated them, including missed work days, difficulty doing housework and/or caring for children, the average number of days given equated to 21 days per year of total or partial incapacitation. Sixty one percent of the same population of migraine sufferers when asked, "How do you usually deal with your migraine/bad headache" indicated that this included, "Staying in bed until it's over".

In summary, migraine brings with it a huge cost for many individuals with migraine and for society, with absenteeism and reduced productivity estimated to cost the American economy 13 billion dollars per year. <sup>25</sup> A study of American migraine sufferers from the general population who reported migraines of moderate or severe intensity found that individuals with migraine had higher direct and indirect costs related to medical disorders than a control group without migraine. Individuals with more severe migraine had the highest costs, with direct and indirect costs averaging \$1,656.00 for these individuals over a six-month period. The authors concluded that, "Migraine is an expensive illness and two-thirds of the financial burden is linked to indirect costs. Consequently, individuals with migraine, employers, and insurance companies all have an economic stake in reducing the migraine burden."

#### FORUM DISCUSSION SUMMARY

The area of migraine related disability is a difficult one for the practicing physician because many patients try to ignore the impact that migraine is having on their life. If they kept diaries for a time and recorded the impact, they would be dismayed with the impact their migraine is having on them. These do not include just missed work, but also disruptions in the patient's personal life, like missed birthday parties, and Christmases spent in bed. Once the headache is gone, life goes on, and patients don't want to admit to the problem because of the stigma attached to migraine. It is the doctor's responsibility to ask about disability, and it is the patient's responsibility to document it. This will often result in changes in the treatment plan. The degree of disability suffered by the patient influences the treatment. Physicians may avoid discussions of disability because it may mean the need to complete forms, and there is no objective way to quantitate the disability in migraine.

For treatment to reduce migraine related disability, patients may need to come in early in the course of their migraine disorder, as they do in diabetes, for example. They need to schedule a visit to discuss their migraine rather than have the discussion as an add on to a visit for some other illness, and they need to bring in diaries. Even when a patient accepts the diagnosis of migraine, and recognizes the impact that migraine is having on their lives, family physicians still often find it hard to get them to undertake an appropriate treatment plan. It can be hard to change ingrained ways that patients have of reacting to their migraines, including the therapies they use. This is likely

not unique to migraine, and has been the case with asthma in the past as well. Education has the potential to slowly change that.

Patients with difficult migraine often have inappropriate expectations about themselves and their migraine, perhaps because of general societal attitudes towards headache. They often feel that they should not have to take prescription medications, and that they should not need daily prophylactic medications. They may also feel that they should not be impaired by their headaches and should not need to take time off work or call in sick. These expectations do not reflect reality, and when these negative things do happen, the patients feel anxiety and depression.

The cognitive impairment during migraine attacks is an issue for many patients, and may be one of the first symptoms of the attack. It was felt by some present that treating with good symptomatic medication very early in the attack can prevent the cognitive dysfunction.

Education has great potential to improve the lives of migraine sufferers. It is ironic that much of the migraine information that patients receive today through the media involves advertising of over the counter medications. Largely missing is public education about migraine as a disorder, about migraine related disability, and about specific migraine treatments. This education must also involve the workplace, and include the employers. It is important for the employer that employees with migraine receive optimal migraine education and care. Without education, people around the migraine sufferer just don't understand the migraine experience. Some programs in the UK involving rapid treatment of patients with migraine attacks at work were supported by employers and proved very successful. At the same time, the whole issue of migraine related disability is potentially a doubleedged sword. Greater awareness has the potential to benefit the migraine sufferer, but might also result in migraineurs being considered unreliable when employees are being hired.

#### **DISCUSSION COMMENTARY (FORUM CHAIR)**

Better education on issues relating to migraine both for physicians and the public is a necessary step in improving migraine diagnosis. It is important that all realize that migraine is a biological disorder of the brain and not basically a psychological phenomenon, even though psychological factors can influence migraine, as they can the symptoms of many pain disorders. Other health professionals also need to become more knowledgeable about migraine.

Because a very small minority of patients with headache have serious underlying disease, assessment of the patient with headache involves a careful history and physical, and it is hard to find time for that in a busy primary care practice.<sup>27</sup> If misdiagnosis of migraine as tension-type headache and sinus headache can be eliminated, it will go a long way towards improving migraine diagnosis.

The degree of disability caused by migraine is not recognized by society, and sometimes not fully appreciated by the patients themselves. Because the degree of disability present does help guide treatment, it is important that physicians ask patients with migraine about the impact migraine is having on their lives, and that patients take the time to document this. Education of the public and of the health professionals who see these patients is key, so that the impact of migraine on the individual, the family, and society at large can be minimized.

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## **Migraine Treatment**

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ABSTRACT: The goal of the Canadian Migraine Forum was to work towards improving the lives of Canadians with migraine by reducing their migraine-related disability. This paper focuses on migraine treatment in its many aspects, including symptomatic therapy of individual migraine headache attacks, prophylactic drug therapy, non-pharmacological interventions, and diagnosis and management of symptomatic medication overuse. Many patients with difficult migraine experience significant frustration in trying to obtain the help they need from our current medical system. Although many symptomatic medications are available for use in migraine, migraine specific medications are still underutilized. An ideal migraine preventative medication does not yet exist, but currently available preventatives do have utility, and are also thought to be underutilized. Behavioral approaches to migraine management as an adjunct to medication therapy show promise, but the availability of programs to bring these to patients is limited, and more research is needed on their efficacy. Symptomatic medication overuse in migraine sufferers remains a large problem in Canada, and better defined treatment paradigms and programs are needed both to prevent and to treat this problem. Such programs should include strong elements of public, patient, and health professional education. A potential solution to some of these problems may be to develop treatment approaches to migraine similar to those that are being developed for other chronic medical disorders. For patients with severe migraine, these would optimally include multidisciplinary teams so that the multiple facets of migraine management can be adequately addressed.

RÉSUMÉ: Le traitement de la migraine. Le Canadian Migraine Forum avait pour mandat de chercher à améliorer la vie des Canadiens qui souffrent de migraine en diminuant l'invalidité reliée à la migraine. Cet article est axé sur le traitement de la migraine sous tous ses aspects, dont le traitement symptomatique de la crise migraineuse, la médication prophylactique, les interventions non pharmacologiques et le diagnostic et le traitement de la surutilisation de médicaments symptomatiques. Plusieurs patients qui souffrent d'accès de migraine pénibles éprouvent beaucoup de frustration dans leur quête de soins dans notre système de santé actuel. Bien que plusieurs médicaments pour traiter les symptômes de la migraine soient disponibles, les médicaments spécifiques de la migraine sont encore sous-utilisés. La médication préventive idéale n'existe pas encore, mais les médications préventives existantes sont utiles et on pense qu'elles sont également sous-utilisées. Les approches comportementales comme traitement d'appoint à la médication pour la migraine sont prometteuses, mais la disponibilité de ces programmes est limitée et la recherche sur leur efficacité est insuffisante. La surutilisation de la médication symptomatique chez les migraineux demeure un gros problème au Canada. Nous avons besoin de paradigmes de traitement plus précis et de meilleurs programmes de prévention et de traitement. Ces programmes devraient comporter d'importants volets éducatifs destinés au public, aux patients et aux professionnels de la santé. On peut envisager comme solution à certains de ces problèmes de développer des approches de traitement de la migraine qui sont semblables à celles qui sont actuellement développées pour d'autres maladies chroniques. Les patients sévèrement atteints devraient être pris en charge par une équipe multidisciplinaire afin que les multiples aspects du traitement de la migraine soient abordés de façon optimale.

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On May 13th, 2006, 30 health professionals and individuals with migraine gathered in Toronto for a unique meeting, the Canadian Migraine Forum, organized by the Canadian Headache Society (CHS) and Headache Network Canada (HNC). These included six individuals with migraine from three Canadian provinces, and 24 health professionals from across Canada. For more information on organization of the forum and its participants, please refer to the first paper in this series.<sup>1</sup>

The presentations and discussions at the Forum have been summarized in three articles. The first focused on migraine prevalence, diagnosis, and migraine related disability. The second, this paper, is focused on migraine treatment. The third paper in this series focuses on the general approaches that might

be taken to reduce the burden carried by individuals with migraine and their families in Canada.<sup>2</sup>

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One of the objectives of the forum was to review the medical care available to migraine patients in the Canadian healthcare setting. To help meet this objective, the forum included four presentations focused on migraine treatment: one on symptomatic treatment of acute migraine attacks, one on migraine preventative medication use, one on non-pharmacological approaches to migraine management, and one on migraine and medication overuse. This paper summarizes these four presentations and the discussion that followed each one.

Each of the three articles which report on the forum is prefaced by one of the migraine patient presentations at the forum. These presentations served to bring a strong patient perspective to the discussions at the forum.

#### PATIENT EXPERIENCE

My migraine experience has been in part a struggle to lead a normal life. To do this, I have struggled to have as much control as possible over my migraines, rather than being entirely controlled by them.

One of the most frustrating aspects of migraine is the lack of understanding and sympathy shown migraine sufferers by those without migraine. Migraine is not considered a real or serious disability by many. The fear of not being taken seriously prevents many migraine sufferers from seeking help, or in continuing to seek help if they are not successful at the beginning of their quest.

When medications prescribed for me failed to work or caused disabling side effects, the reactions of some neurologists was a terse, "Sorry, that's all I can do for you." I was made to feel an inconvenience to them rather than a serious concern, and made to feel that somehow I was not trying hard enough.

During my work life of 38 years, I was in a continuous battle to prevent my disability from turning me into an invalid. Eventually, a neurologist interested in migraine explained to me what is known about the pathophysiology of migraine, and that migraine attacks are due to a malfunction of the brain. With this understanding, I was given a better perspective, and this allowed me to adjust better to my condition. We embarked on a journey to help me learn how to live as full a life as possible by understanding what factors triggered and fed my migraines, and what I could do to gain some measure of control over them. At one time, I became very dependent on sumatriptan, and it was necessary for me to stop it for a time. I have also tried preventative medications, mainly without success. My neurologist continues to urge me to listen to my pain, and to make the lifestyle and work changes that could improve my quality of life. He has convinced me that if I don't use a total lifestyle approach, combined with preventative medications, I will be trapped in an ever increasing number of migraines.

#### MEDICATIONS FOR MIGRAINE ATTACKS

Many medications are available for the symptomatic treatment of acute migraine headache attacks. The migraine specific drugs include egotamine, dihydroergotamine, and the triptans (Table 1). Canadian migraine treatment guidelines published in 1997<sup>3</sup> promoted tailoring the symptomatic

Table 1: Specific migraine drugs used for symptomatic therapy: Commonly used formulations only\*

Drug	Formulation and Dose	Max. Dose in 24 Hours	Other Considerations
Ergotamine	Tablets 2mg dose	6 mg	Can cause prolonged arterial vasoconstriction. Each 1 mg tablet Cafergot contains 100 mg caffeine
Dihydroegotamine	Nasal spray 2mg Injection 1mg	4 mg 3 mg	For the spray, only 50% is absorbed.  Spray can cause nasal irritation.  Dihydroergotamine has a long half life.
Sumatriptan	Injection 6 mg Nasal spray 20mg Tablets 50 or 100 mg	12 mg 40 mg 200 mg	DF tablet available for rapid absorption (Imitrex). Sumatriptan tablets available in generic form.
Naratriptan	Tablets 2.5 mg	5 mg	
Zolmitriptan	Tablets 2.5 mg Wafer 2.5 mg Nasal spray 5 mg	10 mg 10 mg 10 mg	Wafer (Rapimelt) not absorbed through buccal mucosa, must be swallowed in saliva. Nasal spray has significant absorption through the nasal mucosa.
Rizatriptan	Tablet 10 mg Wafer 10 mg	20 mg 20 mg	Wafer (RPD) is not absorbed through buccal mucosa, must be swallowed in saliva. Reduce dose (use 5 mg formulation) for patients on propranolol.
Almotriptan	Tablet 12.5 mg	25 mg	, 1 1 1
Eletriptan	Tablet 40 mg	40 mg	80 mg tablet has been used safely in clinical trials. Plasm levels may be raised by CYP3A4 inhibitors (ketoconazole, clairithromycin, etc.)

<sup>\*</sup>For general use only. Consult product monographs for specific prescribing information. Not all tablet sizes, etc, are listed.

medication used to the usual severity of the patients headache attacks. In this scheme, which presaged the later concepts of step and stratified care, 4.5 analgesics (eg acetaminophen) and NSAIDS (eg acetylsalicylic acid and ibuprofen) were recommended for mild attacks, and NSAIDS and if necessary ergotamine and the triptans were recommended for attacks of moderate severity. For the outpatient treatment of severe attacks, dihydroergotamine and the triptans were recommended. Attack severity was defined in terms of the degree of disability suffered by the patient during the migraine attack.

There are currently six different triptans available in Canada, and multiple formulations (tablets, wafers, nasal sprays, and injectables) exist for some of these. Although the six triptans are relatively similar pharmacologically, individual patients may respond much better to one than another.<sup>6,7</sup> It is therefore necessary to try a number of triptans before deciding that this drug class is ineffective for a given patient, in keeping with the Canadian Guidelines<sup>3</sup> which state that "The medication of choice (for an individual patient) is often individual and idiosyncratic".

The concept of stratified care is now supported by most headache specialists, and also by some scientific evidence.<sup>4</sup> This concept recommends that rather than subject every migraine sufferer to sequential treatment trials of symptomatic medications, perhaps organized in terms of side effects or cost, the symptomatic medication prescribed should be tailored to the patient's headache severity and disability. Therefore, according to the guidelines<sup>3</sup> and the stratified care paradigm, if a patient presents with migraine headaches which usually result in severe disability and render the patient temporarily bedridden, medication appropriate for severe migraine attacks, namely a triptan or dihydroergotamine, should be used. Some patients will tend to use a "stepped within attack" approach,5 where an NSAID may be tried first, and symptomatic therapy escalated to a triptan after an hour or two if this initial therapy fails. While this approach may work for some patients, patients should be made aware that most symptomatic migraine medications, including the triptans, work better if taken early in the attack.8-10 The reasons for this likely include the development of central sensitization in second order sensory neurons in many patients as the migraine attack progresses. 11 Stepped within attack therapy may jeopardizes the ultimate efficacy of the migraine specific treatment. Patient decision making as to which drug to take and when to take it during a migraine attack is a complex process, and inappropriate drug use may occur because of misinformation, inappropriate attitudes, and other barriers. 12 Better patient education has the potential to improve patient medication use.

According to the population based 2005 Canadian Women and Migraine (CWM) survey,<sup>13</sup> only 10% of Canadian female migraineurs took no medication. The 8% that listed a triptan as their main migraine medication were dwarfed by the 38% who used ibuprofen, and the 21% who used codeine containing analgesics. Only two thirds of women indicated that they were pain free two hours after taking their medication, and one quarter could not function normally at two hours (Table 2). Finally, 19% indicated that they were not comfortable enough with their medication so that they were able to plan their daily activities. The same survey also showed that 5% of Canadian women with migraine were very unsatisfied with how effective their migraine medication was, and a further 9% were unsatisfied to a lesser

Table 2: Canadian Women and Migraine Survey: How well does medication currently used by Canadian migraine sufferers work for them?

Questions	Yes	No
When you take your treatment:	%	%
Does your migraine medication work consistently in the majority of the attacks?	78	20
When you take your treatment:  Does the headache pain disappear within 2 hours?	62	36
When you take your treatment: Are you able to function normally within 2 hours?	75	25
When you take your treatment?  Are you comfortable enough with your medication to be able to plan your daily activities?	80	19

<sup>\*</sup> Questions are from the Migraine Assessment of Current Therapy tool (46). The Canadian Women and Migraine Survey was done by Barometre (13) and was a Canadian national population based survey which included 300 individuals with migraine.

extent. Given that there are four million migraine sufferers in Canada, these figures mean that there are 200,000 migraineurs in Canada whose medication works so poorly for them that they are very dissatisfied. Surely this is a disease burden that cannot be ignored.

For patients with migraine who are referred to headache specialists in Canada, the Canadian Headache Outpatient Registry and Database (CHORD) study found that 49% were taking a triptan at the time of referral, while 38% were taking an NSAID, and 39% were taking an opioid containing medication. For this same population, the headache specialist recommended that 97% either stay on or start a triptan. This would suggest that many patients who could benefit from a triptan are not taking these medications.

#### FORUM DISCUSSION SUMMARY

The medical profession needs to approach the treatment of migraine in the same way that other chronic disease, like hypertension and diabetes are managed. These patients need to be monitored, annual reviews need to be done, and all available medication classes need to be used as appropriate to achieve control. "Do you have headaches?" needs to be part of the routine review of systems, and more details obtained as necessary. The family physician should not take the patient's word for the type of headache disorder they have, but rather take the time to get more details. Patients with migraine need to learn early about the importance of early treatment of the migraine attack, and at the same time need to know what constitutes medication overuse and its significance. Medication overuse needs to be caught early in its course by the physician. Pharmacists are often the first health professionals consulted by the patient with headache, and they could play a larger role both

in advising patients to consult a physician where appropriate, and to educate patients about the proper use of medications and the problems that can be caused by medication overuse. Patients need to be aware of the triptan drug class, and use these drugs when appropriate. Depending on how well their headaches respond to a triptan, they may also need to know that they may be able to achieve better headache relief by taking their triptan together with an NSAID. Patients need to be empowered with sufficient knowledge so that they can avoid common migraine triggers and use medications effectively.

Triptans are expensive, and this is a potential barrier. There is a lot of variability from province to province in how available triptans are to patients. In Quebec all six available triptans are covered by government plans. In others, this coverage is not nearly so extensive. Poorly informed private insurers also at times erect unreasonable barriers that are not appropriate for some patients, with unreasonable limitations on the number of triptan tablets per month that will be covered.

Headache patients require a lot of time, and family doctors don't have a lot of time. Inclusion of migraine in the chronic disease billing codes that exist in some provinces could be helpful. For patients with difficult migraine, multidisciplinary disease clinics should be available, as they are for many other chronic disorders. Over 200,000 migraine sufferers are highly dissatisfied with their current migraine treatment. This needs to be improved, and significant progress can be made through better utilization of current therapies.

#### Medications to prevent migraine attacks

The goal of migraine prophylaxis with preventative medications is to reduce migraine frequency by 50% or more. These medications should be used when migraine headaches are causing significant disability despite the use of appropriate symptomatic medications, or when symptomatic use is so frequent that the patient is at risk of developing medication overuse headache.

Based on headache frequency in population studies, it would appear that at least 25% of migraine sufferers might benefit from prophylaxis.<sup>15</sup> Preventative medications do have side effects, however, and the actual number which would show an overall benefit is uncertain. In general, preventative medications for migraine are considered greatly underutilized.<sup>16</sup>

Currently used migraine preventative medications include beta-blockers, tricyclic antidepressants, anticonvulsants, calcium channel blockers, serotonin antagonists, and others (Table 3). The mechanisms whereby these drugs reduce migraine

Table 3: Commonly used drugs for migraine prophylaxis\*

Drug	Usual starting dose (mg)	Daily dosage range (mg)	Other Considerations
Propranolol	20 bid	40 - 320	Increase dose gradually every few weeks, dose twice a day, once a day with long acting formulation.  High CNS penetration.
Atenolol	50 od	50 - 200	Less CNS penetration.
Amitriptyline	10 hs	10 – 70**	Increase dose by 10 mg weekly, all given at bedtime, or an hour before.
Nortriptyline	10 hs	10 - 70	Fewer side effects than Amitriptyline, but less evidence for efficacy.
Divalproex sodium	250 daily	750 - 1500	Twice a day dosing. Increase daily dose by 250 mg every week. Consider teratogenic side effects, very rare liver toxicity.
Topiramate	15 or 25	50 - 200	Increase daily dose by 15 or 25 mg every week to avoid side effects, more slowly if necessary. Usual target dose 100 mg daily Usually dosed bid, but long half life suggests once daily at bedtime adequate.
Gabapentin	300	900 - 1200	Evidence for efficacy less than for the other anticonvulsants.  Dose three times a day.
Verapamil	80 bid	240 - 320	Contraindicated with second and third degree heart block, and with beta-blockers.
Flunarizine	10	10	Use hs. Stop if depression occurs. Contra-indicated in patients with history of depression.
Pizotifen	0.5	1.5	May dose tid or just od at bedtime.

<sup>\*</sup> Not all drugs are listed. Not all drugs listed have clinical indication for migraine prophylaxis (are used off label). Not all side effects and contraindications are listed. Consult the product monograph for more complete prescribing information. The Headaches, 3rd Edition, Olesen J, Goadsby PJ, Ramadan NM, Tfelt-Hansen P, and Welch KMA (Eds), Lippincott Williams and Wilkins, 2006, Philadelphia was used for reference for this table, and may be consulted if more information is needed. \*\* Patients differ greatly in how rapidly they metabolize tricyclic antidepressants. For intractable patients, much higher doses can be used.

frequency in some patients is unknown, and this current lack of understanding hampers the development of new more effective migraine preventatives. In terms of prophylactic benefits with tolerable side effects, current evidence is strongest for the betablockers, the tricyclics, and the anticonvulsants (valproate and topiramate). 17,18

For patients referred to headache specialists in Canada, the CHORD study showed that amitriptyline was the most commonly used prophylactic drug used in this patient population, both by referring physicians and by the neurologist headache specialist.<sup>14</sup> For the specialists, topiramate and nortiptyline were the second and third most commonly used prophylactic drugs. At the time of specialist consultation, 31% of patients were taking a preventative drug. Once seen by the specialist, a preventative was recommended or prescribed for 70% of patients.

In summary, preventative drugs would appear to be underutilized in Canada. No currently available drug is ideal. Preventative drug trials do have a sizeable placebo effect, <sup>19</sup> and it is important to take advantage of this in practice by providing a helpful and positive consultation. <sup>20,21</sup> Patients should receive the best possible advice regarding general migraine management, be encouraged to keep diaries, and should be seen in follow-up. Patients should also have realistic expectations, and understand that preventative medications will not usually eliminate migraine attacks completely. Optimal symptomatic migraine management should be used to complement preventative therapy.

#### FORUM DISCUSSION SUMMARY

There are many potential barriers to prophylactic therapy. Patients are easily discouraged, if they do not understand that a 50% reduction in migraine frequency is success. Many patients are reluctant to take medication every day for migraine, even though their migraines may be quite frequent. Patients must understand that a preventative should not be abandoned, except for side effects, until they have tried it for at least six to eight weeks. Patients and physicians find the lack of predictability when a prophylactic is used frustrating. The response of migraine patients to prophylactic drugs is individual and idiosyncratic. On the other hand, because the effect is so gradual, some patients do not realize that they are receiving benefit from a preventative drug until they stop it. Other barriers to the use of preventative drugs include side effects, particularly weight gain, and the preference of some patients for natural compounds as opposed to pharmacological agents. Natural substances like magnesium, feverfew, and coenzyme Q10 can be used if patients prefer "natural" substances. Magnesium may be better tolerated if a preparation which is combined with calcium is used.

Comorbid conditions are important in the choice of a preventative drug for a given patient. Tricyclics can be helpful for insomnia, anxiety, and depression, and if well tolerated, doses above the 20 to 40 mg daily usually used for migraine prophylaxis can be used. Beta blockers can also benefit anxiety, but they are contraindicated in patients with asthma, and will likely reduce exercise tolerance in athletes. Verapamil and beta blockers can be useful for hypertension. Divalproex sodium and topiramate can be helpful as mood stabilizers, but the use of divalproex is problematic in females of child bearing age

because of its teratogenic effects, and topiramate is relatively contraindicated in patients with a history of renal calculi.

From a family physician point of view, it would be very helpful to have a plan which can be presented to the patient, so that the patient knows what needs to be done. Currently, treatment plans seem much better developed for other chronic diseases like hypertension and diabetes, where the family physician seems to get more help from specialists, disease societies, and the pharmaceutical industry. Because of the variability in how individual migraine sufferers respond to different treatments, such a plan would have to build in significant flexibility.

In summary, there are many reasons why preventative medications are underused in Canada. Family physicians may not recommend them often enough, and many patients would like to avoid daily medications for their migraine. Neurologists interested in headache may not be as accessible to patients in all parts of Canada as they should be. Current prophylactics also are not all that effective, have side effects, and there may be reluctance to use preventative medications in women of child bearing age.

When prescribing a preventative drug, good communication is important. As with all chronic medications, compliance is an issue, and if the patient is not convinced that taking a medication every day is something they should do for their migraine, it is unlikely that a course of prescribed preventative medication will be effective.

#### Non medication treatment approaches for migraine

Non medication approaches and medications for migraine are complementary. For example, headache diaries assist in choosing appropriate medications, assessing headache response to medications, and in determining the importance of different potential migraine triggers for a patient. Patients need to become educated about migraine, and determine what works for them.<sup>22</sup> For optimal management, many patients with difficult migraine need to learn specific skills. These include self monitoring to learn what factors influence their migraine, and pacing their activity so that they can get things done without triggering or exacerbating their migraine. Many patients find relaxation techniques helpful both in preventing migraine attacks and in dealing with individual attacks.<sup>23,24</sup> Cognitive restructuring so that catastrophic and negative thinking is avoided is important. The anticipation of a migraine event can be almost as disabling in terms of planning activities as actually having a migraine. Many patients find learning better ways to communicate with family and friends about their migraine helpful. Finally, as stress is the migraine trigger reported most often by patients as a factor in their migraines, 25 stress management techniques are also often helpful.23,24

A key concept is self management,<sup>26</sup> and this includes taking medication appropriately (Table 4). Self management programs have proven effective in other chronic disorders.<sup>27</sup> To be successful, patients must take an active role in their management, and they can be a better partner for their physician if they are knowledgeable about their condition. For some patients, this may entail significant changes in lifestyle and expectations. Over 50 years ago, John Graham, perhaps America's first headache specialist, put it this way in his 7th

Table 4: Patient Self-Management - Patients can become more involved in actively managing their migraine if they learn and apply the following skills:

- Self-monitoring to identify things that bring on migraine attacks and influence pain.
- Relaxation techniques to avoid migraine attacks triggered by increasing tension and stress, and to better cope with attacks when they occur.
- 3. Pacing their activity to get things done but at the same time avoiding triggering or exacerbating migraine.
- 4. Cognitive restructuring to avoid catastrophic/ negative thinking.
- How to communication effectively about their pain with family, etc.
- Stress management techniques to avoid triggering migraine attacks and to cope with them when they occur.
- 7. How to identify migraine triggers, and developing strategies to avoid them, including special care to avoid adding triggers they can control at times when other triggers they cannot control are operative.
- 8. Lifestyle skills: Sleep hygiene, appropriate diet and exercise, and the maintenance of a regular schedule with regard to sleep and meals
- Appropriate use of medication, including both symptomatic and prophylactic medications.

commandment for living with migraine, "The most rewarding long-term therapy will result from an adjustment in patient's means of living within his or her capacities, rather than an endless round of medication." <sup>28</sup>

There is evidence that some of the non-medication skills listed above are effective for patients with migraine, particularly relaxation techniques and cognitive behavioral therapies.<sup>23,29</sup> Situations where non-medication management therapies may be particularly appropriate include patients in whom pharmacological treatments are ineffective, poorly tolerated, or contraindicated; and patients on pharmacological therapy who require additional therapeutic gain. They may also be particularly useful in patients who are planning a pregnancy, are pregnant or are nursing; and in patients who have significant stress but deficient stress management skills.

Simple instructions from the physician may not accomplish a significant behavior change in the patient. This was recognized long ago by John Graham, when he stated, "Changes in psychological attitudes become real only through actual practice, not through repetitive verbal instruction". Physicians often do not have the time or the expertise to teach these non-medication skills and to provide the necessary practice. A multidisciplinary team involving non physicians has the potential to do this successfully and economically. For patients with chronic disorders like migraine, teams can address problems that no single individual can solve. <sup>30</sup>

At least two Canadian studies support the use of multidisciplinary teams in migraine management. One tested the

effectiveness of a group multi-disciplinary intervention compared to standard medical care with the family physician in patients with an average of 20 headache days per month. The team approach was found generally superior to standard medical care, and the study concluded that positive outcomes could be obtained in migraine with a low cost group multidisciplinary intervention.<sup>31</sup> A second study compared a cohort of patients with headache followed in a neurologist specialty clinic with another cohort who were treated in a multidisciplinary chronic pain center with a neurologist as part of the team. The patients in the pain center program showed more improvement in health related quality of life.<sup>32</sup>

#### FORUM DISCUSSION SUMMARY

Patients with migraine want someone to listen to them and provide education and advice.<sup>33</sup> Family physicians simply do not have sufficient time for this, and non physician health professionals could help.

For many patients with migraine, as with many other chronic diseases, the emphasis needs to be on management and not cure. Many are best managed with the self management model, with emphasis on the necessary knowledge and skills so that they can change their behavior as necessary.

Not all patients are ready for a self management program, and a way of determining who will benefit from such programs is needed so that resources are not wasted. Such programs can also be more affordable if much of the necessary therapist – patient interaction occurred in a group format. The resources that are required might be counterbalanced by savings elsewhere in the system. For example, many patients in the Calgary Headache Assessment and Management Program report an enhanced ability to deal with and manage their headache attacks, and this could translate into less use of resources elsewhere in the system, like emergency departments.

Multi disciplinary programs are not available to most patients with difficult migraine in Canada, and if they are there is often considerable cost to the patient. If we are to work towards more such programs in the Canadian public healthcare system, we need to gather more systematic evidence that such programs are effective, and that the effects are long lasting. Such evidence is available for some other chronic pain conditions like low back pain, 34,35 and more evidence needs to be obtained for migraine. Exercise, particularly aerobic exercise, was felt to be very beneficial for many migraine patients. This is generally available to patients, although about 14% give exercise as one of their migraine triggers. This may be avoided in some patients by proper hydration before exercise sessions are started.

Patients must be encouraged to take an active role in their own care. Physicians need to outline a plan for how they are going to work together with the patient, rather than have the physician take all the responsibility for treatment. If patients are referred to non physician health professionals, they should be referred for active therapies which they can carry on themselves long term, rather than for passive treatments. For most patients, significant modifications in lifestyle are an important aspect of migraine management.

#### Medication overuse and migraine

Thomas Willis described progression of migraine from an intermittent to a chronic daily headache pattern as early as the 17th century, although he made no mention of medication overuse. Hennox, almost a century ago, drew a relationship between symptomatic medication overuse and increasing migraine frequency. Today, patients with medication overuse still make up a very significant proportion of patients attending specialty headache clinics. In the Canadian CHORD study, 21% of patients referred to headache specialists who received a migraine diagnosis had symptomatic medication overuse. Por patients referred to a headache clinic in Denmark, 25% were reported to have medication overuse.

According to the International Headache society (IHS) diagnostic criteria,<sup>38</sup> a diagnosis of medication overuse headache (MOH) requires headache on at least 15 days a month, medication overuse for at least three months, and improvement in headache frequency within two months of cessation of medication overuse. For most medications, including triptans, ergotamines, and combination analgesics, use on ten days a month or more is defined as overuse. For acetaminophen and NSAIDs, the corresponding figure is 15 days a month. Frequency of use in excess of these frequencies is considered by the IHS to place patients with headache at risk for increasing headache frequency. MOH can be considered to be an interaction between a susceptible individual and excessive use of a therapeutic agent. Patients with migraine seem susceptible to the development of MOH.<sup>39,40</sup>

Not all patients with migraine who develop chronic daily headache do so as a result of medication overuse. In patients referred to headache specialists in Canada, 37% of those with migraine had transformed migraine (headache on 15 days a month or more). Only half of these patients were medication over users.<sup>14</sup>

Virtually every symptomatic medication is overused by at least some migraineurs in an attempt to control their headaches.

In patients with migraine referred to headache specialists in Canada, opiate containing analgesics were overused by 42% of over users, while triptans were overused by 22% (Table 5).<sup>14</sup>

Headache on 15 days a month or more (CDH) is relatively common in the general population. In most countries where this has been studied, the prevalence of CDH is approximately 4%, and about 30% of these patients are medication over users.<sup>41</sup>

The cornerstone of MOH treatment is patient education regarding the disorder, and cessation of medication overuse (Table 6). Both abrupt withdrawal and a tapering withdrawal over several weeks have their proponents. If the patient is overusing barbiturate containing medications, slow withdrawal or temporary use of phenobarbital is necessary to prevent barbiturate withdrawal seizures. Stopping or greatly reducing symptomatic medication use can be a daunting task for many patients, and patients need to understand that this is a necessary part of therapy. Headache usually becomes temporarily worse before improvement occurs, and various bridging therapies including steroids, NSAIDs, and dihydroergotamine have been used as a temporary measure to assist patients in stopping medication overuse. Triptan over users usually show major improvement within a week of drug withdrawal, whereas improvement is often much slower in patients overusing analgesics.42

Most patients who are undergoing treatment for MOH require a preventative medication and careful attention to their symptomatic migraine medications, as most will continue to have migraine attacks. Although outpatient treatment is appropriate for the majority of patients with MOH, they may require considerable follow-up and support during treatment. Inpatient withdrawal may be appropriate for some patients, but this is often difficult to achieve in the Canadian setting.

Not all patients with medication overuse improve when their medication overuse is stopped, and not all patients can be successfully withdrawn from their medication overuse. In a Danish study, of 106 patients with medication overuse, only 74

Table 5: Medication types overused by patients with migraine referred to headache specialists in Canada\*

Overused Medication	% of over users overusing this med.**
Acetaminophen/ NSAIDs	67
Opiates	42
Triptans	22
Barbiturates	8
Others	8

<sup>\*</sup> Modified from the Canadian Headache Registry and Database Study (14). Data is derived from an analysis of 125 medication over users with migraine. \*\* Many patients overused medications in more than one category simultaneously. As a result, the figures in the table add up to more than 100%. Only 6.4% of over users overused an opiate alone, and 13% were overusing a triptan only.

Table 6: Management principles for migraine patients with medication overuse headache

- 1. Patient education re migraine management and the potential consequences of medication overuse.
- Stopping medication overuse, either by a slow taper or abrupt withdrawal, depending upon the dose, type of medication overused, and other circumstances.
- Provision of a plan for the symptomatic management of severe migraine attacks, including frequency limitations on the medications used.
- Provision of a migraine prophylactic medication where appropriate.
- Consideration of a short term "bridging therapy" during the medication withdrawal period, depending on individual circumstances.
- 6. Patient support and follow-up.

patients (70%) were successfully withdrawn from their medication overuse in a multidisciplinary headache clinic, and of those successfully withdrawn, only 47% had a reduction of 50% or more in their headache days per month.<sup>43</sup> The rate of improvement may be somewhat higher, however, in patients with underlying migraine as opposed to other headache types, particularly if they are overusing triptans or ergotamine.<sup>37</sup>

Most patients with MOH have severe migraine, and their long term prognosis is guarded. However, a recent study from a tertiary headache center concluded that almost all MOH patients benefit to some extent from drug withdrawal. These benefits included direct headache improvement from withdrawal of the overused medication, and also becoming more responsive to other headache treatments after withdrawal.<sup>44</sup>

#### FORUM DISCUSSION SUMMARY

Stopping medication overuse can be a very difficult experience for a migraine patient with CDH, but often after two or three weeks things begin to slowly improve. However, even if withdrawal is successful in improving their headache problem, some patients will once again relapse into medication overuse. There may be many reasons why this happens. Most migraine patients with medication overuse have a significant underlying headache problem which was present before the overuse, and this will continue. Various stressors, psychosocial factors, and psychiatric comorbidities may contribute to resumption of medication overuse. An internal locus of control may be important in preventing relapse of medication overuse.

Some patients get into medication overuse in the first place, or suffer a relapse of medication overuse after withdrawal, because of fear that they will get a migraine attack. They feel they are too busy to have a headache, and will medicate almost automatically at the first sign of anything wrong, perhaps a little fogginess in the head, in order to preemptively treat a possible migraine attack. Such attitudes and habits can be hard to change.

It is important that we tell patients with migraine and medication overuse that they are not drug addicts. This certainly is true for the great majority. There is evidence that actual drug addiction is no more common in the migraine population than in the general population despite their recurrent pain and symptomatic medication use. The patient should also be given realistic goals, and instructed that they have about a 50% chance of major improvement with stopping medication overuse. It may also be the case, although evidence for this is not available, that CDH from medication overuse may be harder to reverse after it has been present for a long period of time. This might be because of increasing degrees of central sensitization as the duration of CDH increases. If true, this would imply that there is some urgency in the diagnosis and effective treatment of MOH.

In the patient with migraine, medication overuse, and CDH, the medication overuse is not always the driver of the CDH. The patient may have chronic migraine, and the medication overuse may be secondary to that rather than the cause of the increase in headache frequency. On the other hand, a patient with migraine may have medication overuse headache, and this may improve with medication withdrawal. However, the underlying migraine may eventually progress to chronic migraine, which then might become associated with medication overuse again, but, now the medication overuse is no longer the cause of the CDH. Whether

a period of CDH caused by medication overuse contributes to the eventual development of chronic migraine is not known, but this might be a possibility given that central sensitization of pain systems is likely important in both conditions.

Migraine patients are often advised to use their triptans or other medications early in their attacks, as this provides better relief. There is danger that this advice might lead to medication overuse. Patients must be advised about the dangers of medication overuse at the same time that advice about early treatment is given. Regular follow-up by the family physician with review of patient diaries can aid in identifying patients who are becoming at risk for medication overuse. Such regular follow-up is common place in many other chronic illnesses such as diabetes, asthma, and hypertension.

Patients need to develop good self monitoring skills, including the monitoring of their medication use. Headache diary sheets can be downloaded from the internet (headachenetwork.ca). This website also contains information for patients and the public on migraine, including information on medication overuse and its management.

Because migraine preventative medications may not work well if patients are medication over users, taking patients down a long road of migraine preventative trials may be futile until the patient is withdrawn from medication overuse.

There are migraine patients who have been medication over users for years, who seem to be quite functional, and who appear satisfied. Should these patients have a course of medication withdrawal? Some of these patients may be satisfied, but they may have low expectations of what their options are. Probably all should have a trial of medication withdrawal before the status quo is accepted. If their headaches do not improve with withdrawal, then that would indicate their diagnosis is chronic migraine, and that the medication overuse is not the driver of their CDH. It must be recognized, however, that there are psychosocial situations and times in patient's lives when attempts at medication withdrawal have little chance of success. The physician should educate the patient as to the options, but some degree of flexibility must be maintained depending upon the circumstances. A small minority of migraine patients seem to require daily opiates to achieve optimal function. This minority is small, and this therapeutic option is a last resort.

Medication overuse has its own medical hazards and safety issues, for example gastritis and gastrointestinal bleeding from NSAID overuse. These need to be a factor in the medical decision making with the patient.

#### DISCUSSION COMMENTARY (FORUM CHAIR)

The patient presentation above poignantly outlines how difficult it can be for a patient with difficult migraine to obtain satisfactory treatment, and how not all physicians are perceived as helpful. Migraine treatment is complex and has many facets. Some of these extend beyond the pharmacological orientation of much of modern medicine. Because migraine can be disabling, and can extend over many decades, we need to take more of a chronic disease management approach to reduce migraine-related disability. Unfortunately, migraine preventative drug therapy is not yet mature, and ideal preventative drugs do not exist. Nevertheless, it is important that physicians treating migraine have a defined plan for each individual patient, so that

the patient knows what is expected, and can be an effective partner in care.

Behavioral therapies for migraine are relatively unavailable to patients in Canada. These do have promise, <sup>45</sup> but for these programs are to be successful patients need to become informed, participate acitively, and take significant responsibility for their migraine care.

Symptomatic migraine medication overuse remains a large source of disability in Canada, and this problem will diminish only once we have better informed doctors and a better informed public. It also demonstrates how difficult migraine can be to treat. Comprehensive team-based programs may be the best way to prevent this problem by providing patients approaching medication overuse with a number of treatment modalities in addition to symptomatic medications so that they can control their headaches sufficiently to allow them to function. In addition, they may be the best way to bring patients with difficult migraine and medication overuse back to a more functional status once medication overuse is present.

More research is needed to improve migraine care. This includes basic science research which could lead to better migraine preventative drugs, and clinical research to better define the effectiveness of our medications and the effectiveness of non-pharmacological treatment approaches.

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# Moving Forward to Improve Migraine Management in Canada

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ABSTRACT: The goal of the Canadian Migraine Forum was to work towards improving the lives of Canadians with migraine by reducing their migraine-related disability. Migraine has been ranked 19th by the World Health Organization among causes of years of life lived with disability. To improve management of migraine in Canada, the participants in the forum identified several important needs and strategies. There is a need for more leaders in the field of migraine to work with other stakeholders to obtain funding and develop treatment programs across Canada. Leadership is also required to address the under use of both migraine specific symptomatic medications and prophylactic medications in Canada. More non-physician health professionals are required to work with physicians in migraine treatment teams. This could assist with a shortage of physician resources, and could also help to better meet the needs of the migraine patient. Individuals with migraine need to be identified who could work with health care professionals to help meet the needs of the migraine patients in our communities. Application of the chronic disease management model for migraine treatment was also seen as an important factor for the management of migraine. Programs are needed to promote earlier diagnosis, long term follow-up, comprehensive patient education, and the use of multidisciplinary treatment teams where appropriate. Also considered important was the need to increase knowledge about migraine through public awareness campaigns, websites, medical education, and appropriate reading material for patients. The public needs to be aware that migraine is a biological disorder that can cause significant disability and suffering. Lastly, there is a pressing need to promote more migraine research, including careful outcome assessments for treatment programs that involve non-pharmacological treatments and a team based approach to migraine management. There are many challenges that must be overcome if we are to be successful in reducing migraine related disability in Canada. Success will depend upon the joint efforts of physicians, other healthcare professionals, individuals with migraine, and the public at large.

RÉSUMÉ: Impulsion pour améliorer le traitement de la migraine au Canada. L'objectif du Canadian Migraine Forum était d'agir pour améliorer la vie des Canadiens qui souffrent de migraine en diminuant leur invalidité due à la migraine. L'Organisation mondiale de la santé classifie la migraine au 19e rang parmi les causes d'années de vie vécues avec une invalidité. Les participants au forum ont identifié plusieurs besoins et stratégies importantes afin d'améliorer le traitement de la migraine au Canada. Nous avons besoin d'un plus grand nombre de chefs de file dans le domaine de la migraine pour travailler de concert avec d'autres parties prenantes dans ce domaine afin d'obtenir des fonds et de développer des programmes de traitement à travers le Canada. On a besoin de leadership pour corriger la sous-utilisation des médicaments symptomatiques spécifiques de la migraine et des médicaments prophylactiques au Canada et d'un plus grand nombre de travailleurs de la santé qui ne sont pas des médecins pour travailler avec les médecins dans les équipes de traitement de la migraine. Cette stratégie pallierait le manque de médecins et pourrait également aider à mieux combler les besoins des migraineux. On devrait identifier certains patients qui travailleraient avec les professionnels de la santé pour aider à combler les besoins des patients migraineux dans la collectivité. On a également considéré que l'application du modèle de prise en charge des maladies chroniques pour le traitement de la migraine sera un élément important dans le traitement de la migraine. Nous avons besoin de programmes pour promouvoir le diagnostic plus précoce, le suivi à long terme, l'enseignement aux patients et l'utilisation d'équipes de traitement multidisciplinaires le cas échéant. On a également établi la nécessité d'augmenter les connaissances sur la migraine par des campagnes de sensibilisation du public, des sites Internet, de la formation médicale et du matériel didactique approprié pour les patients. Le public doit savoir que la migraine est un dérèglement biologique qui cause une invalidité et une souffrance importantes. Finalement, il est urgent de promouvoir la recherche dans le domaine de la migraine, particulièrement en ce qui concerne l'évaluation minutieuse des résultats de programmes de traitements non pharmacologiques et l'approche basée sur l'intervention d'équipes multidisciplinaires. Il y a plusieurs obstacles à surmonter si nous voulons réussir à diminuer l'invalidité due à la migraine au Canada. Le succès dépendra des efforts conjoints de médecins, d'autres professionnels de la santé, de patients migraineux et du grand public.

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On May 13th, 2006, 30 health professionals and individuals with migraine gathered in Toronto for a unique meeting, the Canadian Migraine Forum, organized by the Canadian Headache Society (CHS) and Headache Network Canada (HNC). These included six individuals with migraine from three Canadian provinces, and 24 health professionals from across Canada. The health professionals present included: five family physicians, three nurses, one occupational therapist, four pharmacists, one psychologist, nine neurologists and one healthcare administrator. For more information on organization of the forum and its participants, please refer to the first paper in this series.<sup>1</sup>

The presentations and discussions at the Forum have been summarized in three articles. The first focused on migraine prevalence, diagnosis, and migraine related disability. The second focused on migraine treatment. This paper, the third paper, focuses on the general approaches that might be taken to reduce the burden carried by individuals with migraine and their families in Canada, based upon the discussion in the "Finding Solutions" session at the Forum.

The goal of the Canadian Migraine Forum was to work towards improving the lives of Canadians with migraine by reducing their migraine-related disability. The objectives were to review the disability suffered by individuals with migraine and and to review the current medical care available to them in the Canadian healthcare setting. This process included the identification of gaps in current migraine care in Canada as compared to evidence based optimal care, and a consideration of what specific steps might be taken to close those gaps. The ultimate aim was to determine what could be done to reduce the burden carried by migraine sufferers and their families in Canada.

Disability can be defined as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.<sup>3</sup> The World Health Organization has recognized that headache disorders generate a substantial disability burden and classifies them among the major public health disorders. Migraine is ranked 19th among all causes of disability in terms of causing years lived with disability.<sup>4</sup>

Migraine related disability has many facets including social, economic, and personal factors. Migraine impacts the family, the employer, and the entire social circle of the migraine sufferer. Disability is not only related to the attack itself, but also is created by the ever present possibility of an attack, particularly in those with frequent migraines.

Reducing migraine related disability involves many challenges. These include time constraints on the part of the family physician, and addressing the communication gap between the migraine patient and the physician. Patients with migraine often refrain from discussing their disability with their physician unless specifically asked. Too often they are not asked. At the same time, the degree of disability experienced should be a major factor in medical decision making with regards to migraine treatment. There are other related questions which the physician must take the time to ask, for example, how long it takes for the patient's symptomatic medication to work. The right information must be obtained and utilized in the treatment of the patient with migraine if patient disability is to be addressed and reduced.

Each of the three articles which report on the forum include a presentation by one of the migraine patients at the forum. These

presentations served to bring a strong patient perspective to the discussion.

#### PATIENT EXPERIENCE

Migraine can cause many frustrations. Despite trying every medication and treatment available over twenty years, my headaches are still not under good control. Every day has the potential to end in excruciating pain. My headaches do still control my life and that is a real frustration. There are others. I loved teaching, and was good at it, but for me that profession is only a memory. I have spent weeks planning a wonderful Christmas day for my family, only to spend it in bed with headache and nausea. Another frustration is having someone say to you, "When I get a headache, I take Tylenol and keep on working. I don't let a little headache stop me."

My problem with migraine began 35 years ago when I started the birth control pill. I began to get a few bad headaches a month. My family doctor thought they were tension headaches brought on by the stress of teaching. Several years later my husband and I started a family. When I mentioned to my family doctor that I had had no severe headaches during my pregnancies, he concluded I must have migraine.

I have many migraine triggers. I have learned to avoid cheese, citrus fruits, and processed meats. I have stopped drinking wine completely, and I make sure I do not skip meals or get thirsty. I have many other triggers, many of which I am unable to avoid or control. Changes in barometric pressure or weather fronts will cause a headache. So will hot and humid weather, or becoming overheated from exertion. I have to leave strenuous household and yard chores to others. I avoid driving at night because car headlights will start my pain, and I am always very light sensitive. I carefully avoid any emotional upsets, because they too will trigger a migraine. In short, I have to limit myself to a very restrictive lifestyle.

I am working with a skilled neurologist to manage my migraine. I am on daily preventative medication, and my headache attacks do respond to the triptans. I do everything I can to avoid migraine attacks because I have been cautioned to limit my triptans to two days a week in order to avoid medication overuse headache. I have made exceptions, however. When we went on a Carribean cruise for my 50th birthday our vacation was almost ruined by daily migraines triggered by the hot humid weather. I took my rizatriptan every day of our holiday to avoid being miserable in our cabin the whole time.

My migraine has affected me professionally, economically, socially, and personally. We became a one income family because I had to give up teaching. It was also hard on my self esteem when some of the many medications that I tried resulted in weight gain. I have struggled with depression over the years because of the chronic pain and the effects it has had on my life. Over the years, I have missed Christmas dinners, evenings at the theatre for which we had tickets, and birthday celebrations. If I am entertaining, I must be very organized days in advance. I am unable to leave too much until the last minute because I must avoid stress which would set off my headache. I have to live day to day. I never quite know how each day will turn out, no matter how careful I am. It is difficult to live a productive life when you must be ready to stop everything as soon as you recognize that the pain is starting. Ignoring the initial symptoms only guarantees a full blown migraine headache and another wasted day.

I am grateful to my neurologist who never gives up trying to find new treatments to improve my quality of life, and who was supportive in my attempts to obtain a small disability pension. My application was denied by the officials at Canada Pension because my suffering did not meet their definition of "severe and prolonged". I am grateful also to the honest people at my tribunal hearing who, upon hearing the extent of my migraines, overturned that ruling.

Living with chronic migraine has taught me many valuable lessons. The most valuable assets you have are not just a successful career. They are your family and friends who are there for you not only during the good times but during the tough times as well.

#### FORUM DISCUSSION SUMMARY

We need to turn to patients and their families for help in finding solutions for the problems faced by patients with migraine. We need their perspectives to determine what is needed in terms of resources.

Multidisciplinary teams can offer something more beyond the care of a neurologist expert in migraine. Teams allow patients more time to tell their story. There is great therapeutic value in that. Teams can also offer patients more education, and can collaborate with them in goal setting and in the development of skills to help them manage their migraine.

Patients with difficult migraine often benefit from a more multi-faceted approach, and physician appointments are often very medication focused. Multidisciplinary teams can help to approach the patient's migraine problem from many different angles. In the group workshops, patients learn skills and receive support from the group. Group interaction and peer support is critical because many patients with difficult migraine feel very isolated and alone.

#### **Finding solutions**

This part of the forum followed the formal presentations which have been summarized in the previous two papers. All participants were invited to share their views on how migraine management in Canada could be improved. The contributions of each participant are summarized below.

Family physician: There was a lot of information presented today, but how do we go forward from today and who do we approach? The options would include our hospitals, public health departments, and industry.

Chair: You have challenged us as to where we can find resources for some of the things that are needed. What we have heard is that despite the best efforts of family physicians and neurologists, some patients retain significant disability. Where do we find the resources to improve quality of life for patients with migraine?

*Neurologist:* There are so many people with headaches that if we inform them in an effective way, they will push politicians to do something. We can go to TV, radio, public conferences, but we have to go directly to the ones who are suffering. They in turn will put pressure on the people who are able to do something about it

*Chair:* Given the disability that migraine causes, it's not receiving its fair share of the health care dollar, relative to many other conditions.

Migraine patient: We should work towards developing multidisciplinary support groups in the various Canadian migraine centers. Each support group would consist of: a neurologist specializing in migraine that would lead each group, a scientist doing research in migraine, a psychologist who specializes in behavior modification, a nutritionist, a relaxation therapist, someone knowledgeable in stress management, and several patients. This would be done on a volunteer basis, and the rewards would be obvious to everyone. For each group of sessions, a core of patients would need to commit to attend. Each support group would need a coordinator working in conjunction with the neurologist heading the group, and that coordinator should be a patient. Each group would send a neurologist/patient team to the next migraine forum to report on the progress of their support group. These reports could be followed by a general discussion on how such groups could be made even more effective. Ultimately, you could do an appropriate analysis of their effectiveness. This program could be started almost immediately and patients would gravitate towards this because there would be other patients there. If patients are afraid to speak up because they feel isolated or feel they wouldn't be taken seriously, they will still talk to other patients.

*Neurologist:* That's an excellent idea. I agree it would be best to have a patient coordinator, and a core group of patients. The neurologist would attend on a volunteer basis. Funding needs would be minimal. Letters would be sent to other neurologists in the community who see patients with migraine to let them know there is a support group. Monthly or bimonthly meetings would be coordinated, and arrangements would be made to have a speaker: for example a nutritionist or a massage therapist.

Neurologist: Organizations who have tried to implement similar programs in the past have failed, for example the Migraine Foundation and the Migraine Association of Canada. You need a commitment on behalf of an organization to support programs like these. There is interest in government to develope programs for chronic disorders. Women's College will be the first ambulatory, chronic care hospital in Ontario, and is trying to determine how best to proceed. These discussions include the use of psychologists and nurse coordinators and other aspects of managing patients with chronic disorders.

*Chair:* There may be a real opportunity to develop the necessary programs in several parts of Canada. Let's turn to our panel.

Health care administrator: The "Canadian Pain Coalition" may have well established infrastructure in place to support and advocate for migraine sufferers The Canadian Pain Coalition, a public not for profit organization is responsible for initiatives such as "Pain Awareness Week", "Pain Hurts Canada" and "Pain Management is a Human Right". The Coalition is also linked to the Canadian Pain Society and to the Canadian Council of Health Services Accreditation (CCHSA). The Canadian Pain Society and the CCHSA have played a key role in promoting the importance of adequate pain management as a human right and as a safety and quality issue.

In terms of non-pharmacological modalities for migraine pain management, a gap exists with respect to education, knowledge, skills, available services and also perhaps the right type of research. Perhaps research methods for non pharmacological therapies needs to be different from clinical trials. For example, perhaps qualitative research over time may be needed to demonstrate efficacy of non pharmacological approaches. How can interdisciplinary approaches be supported? Resources are essential. While it is important to elicit the support of politicians, their role is to deliver the budget to health care regions. It then becomes the responsibility of the decision makers within each region to allocate those resources.

How one can obtain the needed resources from the overall resources available for health care is the question. The strategy used in Calgary was to establish a Regional Pain Program Steering committee. This committee achieved far reaching influence since membership included broad representation across the health care continuum. The role of this committee was to explore and make recommendations on how to achieve an integrated coordinated system of pain services. The broad representation facilitated a system-wide approach. The success that was achieved in obtaining funding for the program resulted from the system wide approach with input and "buy-in" from a wide range of stakeholders along the continuum of care.

In applying for funding for management of migraine headache it may be beneficial to engage representatives from other departments that are impacted by migraine sufferers in addition to neurologists. Stakeholders from emergency departments would likely be most supportive of allocating resources for quality evidence-based migraine management. They have first hand experiencing in trying to meet the needs of migraine sufferers experiencing headache crises in a less that optimal environment. Physicians in primary care would be supportive as they face challenges related to managing patients with migraine headaches. They are likely as frustrated as the patients and all of you are with the lack of resources. They only have seven minutes and no other support to provide comprehensive quality care to a patient with a complex chronic condition. Other supportive groups might be pharmacists, Child Adolescent and Women's Health Programs, Mental Health, and Home Care. Public representation from the Canadian Pain Coalition and other corporate bodies impacted by migraine could also provide a valuable perspective to service planning. Endorsement from a broad range of stakeholders across the continuum of care may help to convince decision makers and administrators to allocate resources in this

The initial step is to compile a strategic list of stakeholders and to develop a steering committee with clearly defined goals and objectives. These objectives could include identifying gaps across the continuum of care. The information being collated at this forum would benefit such a committee. Statistics that have been presented at this forum could impact resource allocation and policy making at the upper leadership level in the health care system. Once a strategic plan is developed with broad support, funding is more likely to be allocated by the institution or health region. It would also be important to demonstrate the link between adequate pain management and the commitment of the institution or health region to wellness, safety and accreditation. The CCHSA has developed ambulatory care standards which enable health care organizations to assess their pain management strategies. Inadequate pain management is considered to be a safety risk and this would help to encourage administrators to provide resources.

Chair: We have been considering an intravenous therapy room for our headache programs in Calgary to treat headache crises during working hours for patients known to the clinic. Some of our emergency doctors were very supportive, as they agree the emergency room is not the best place for patients with migraine. Treating patients with migraine elsewhere could also free up emergency rooms for medical emergencies. We should be able to obtain support from various groups for our migraine initiatives

Pharmacist: The Arthritis Society has events for newly diagnosed patients, including seminars every month. We work with them and give all newly diagnosed patients a brochure so they can contact the Arthritis Society, and most of them do. The Society has "Lunch and Learn" groups that have been effective in helping new patients deal with their diagnosis. Pharmacists can work cooperatively with organizations. The Arthritis Society faxes us a copy of their schedule of events, and we make sure that patients have access to them.

Chair: It will be hard for us to go forward successfully unless we develop a strong lay organization to work on behalf of headache. Lay organizations support work in many other neurological disorders such as multiple sclerosis, stroke, and Parkinson's disease. It has been difficult to establish and maintain such groups for the long term for headache in Canada.

*Neurologist:* It is important for migraineurs to form organizations where they can obtain detailed and up to date information about their condition. If they know they have support from other groups, they will organize as necessary. A French speaking group in Quebec, Migraine Zero, already exists.

Health care administrator: The Calgary Health Region Regional Pain Program is open to sharing information and to assist other health care groups to develop coordinated integrated plans for pain management.

Neurologist: We might achieve education of the general public about migraine by copying the model provided by asthma educators. They use nurse practitioners or public health nurses to provide information and set up small clinics. If we worked through health networks such as we have in Ontario now, and obtain support from these local health initiatives, we could disseminate knowledge and information about migraine very efficiently. Physicians are limited by time and interest. We could give lectures to the public, but we could reach a much broader audience by disseminating knowledge through local health initiatives and non-physician health professionals.

Chair: The asthma model is an interesting one. I've wondered whether headache is ready for a similar model, because treatment in headache is not as well defined as it is in asthma. In headache, the treatment sequence is less evidence based, and more individualized.

Health care administrator: Alberta has organized groups of physicians called "primary care networks". These networks are groups of physicians who are collaborating with the Calgary Health Region's Chronic Disease Management initiative. The region provides a clinical resource nurse to work alongside the physician. When the physician identifies a patient with a specific chronic condition (i.e. low back pain, diabetes) the nurse and the physician follow an evidenced based pathway. The physician may flag the need for patient education, or other related services. The nurses provide follow-up for the patient, provide education, screen for other needs according to the pathway and coordinate care in collaboration with the family physician.

We are also exploring effective ways of providing physician education. A physician to specialist telephone consult provides "just in time learning" Although including pain education in medical school is critical, surveys show that many family physi-

cians also have identified learning needs in the area of pain management.

Additionally, an interdisciplinary working group from the Regional Pain Program has developed evidence based algorithms for several common pain conditions i.e. low back pain, neuropathic pain, whiplash etc. We learned that in order to be useful the pathways must be concise and easily accessible. A four-page handout was too long, it had to be a one-pager with several key points. This further demonstrates the importance of exploring how to deliver education to physicians in the most effective way. The algorithms are available on the Calgary Health Region Website (see resources).

*Neurologist:* Another way to pass along information about migraine is to work with large corporations. They all have employees that suffer from migraine, and are quite interested in headache. We also need to work with insurance companies so that they know what migraine really is.

*Neurologist:* Hospitals and health centers have many female employees in the age groups where migraine is the most common. We could approach our health care organizations and work with them to get appropriate migraine management in place for their employees in order to minimize disability.

*Family physician:* Does the Canadian Headache Society put out a publication to provide information to patients?

*Chair:* At this time, our only direct patient information service is our website, in conjunction with Headache Network Canada (see resources).

*Neurologist:* Written newsletters and publications cost money to produce and distribute. The Migraine Association of Canada had good newsletters, but patients seemed to lose interest in that way of receiving information. We should concentrate on the website and make it more flexible and interactive.

With regard to treatment of patients with a migraine crisis, an emergency department is the worst place to go if you have a migraine. It's bright, stressful, and noisy, and you have to wait for hours. In a better treatment setting, patients might get better with much less medication.

Chair: The emergency department is probably the worst place for the migraine sufferer, but what's the alternative in Canada? There is none as far as I know, except for those family doctors who will see their patients with a severe migraine episode during office hours and give them emergency treatment as best they can in the office.

Patient: Many other disease areas have produced handbooks for patient education. A patient who has just been diagnosed with migraine could be given a handbook which could list the website and other resources. They could then better understand what the diagnosis means, learn about management, and plan future treatment.

Health care administer: These pamphlets should be available in emergency departments and elsewhere where migraine patients are seen. Provincial Health information phone lines which provide information about health issues could identify appropriate websites for migraine patients.

Chair: What are the main gaps in our health care system today that we need to fill?

*Neurologist:* What's missing is a more holistic approach to the patient with migraine. This requires doctors but other disciplines as well. This is essential for any chronic disease.

Nurse: One of the major barriers to success in the past has been the stigma of migraine. This has been a problem for many of our goals, including improvement of physician and patient education, changing reimbursement, and changing the approach that insurance companies take. We have failed over the years to change the attitude of decision makers. We have been unable to change the fabric of society's belief about migraine. We need to change the "rap" that this disorder has if we are to be successful. I believe that that could be done with a public awareness campaign through mass media. It would have to be much better than any we have done before. I don't think that we've really tried to do that in the past independent of therapeutic products. I don't think many other countries in the world have either.

*Neurologist:* Do you think women's organizations could be of support?

*Nurse:* Perhaps not, because it's not only a woman's disorder. As a society, we've managed to frame domestic violence, we've managed to change the face of schizophrenia, of mental illnesses, and of many other things. Yet little has been done regarding migraine, although the triptan companies have made small efforts. Other pharmaceutical companies have done a lot of advertising, about their over the counter products. A happy 30-year-old model-like woman is surrounded by her perfect children. She reaches for an Advil and the sun comes out. This is not realistic and I think improvements are needed.

Family physician: A gap exists with respect to providing evidence demonstrating the efficacy of a multidisciplinary approach.

Patient: I struggle with the current image of a migraine sufferer in the public awareness. Years ago at the Migraine Association we discussed the question, "Who best represents migraine sufferers?" No high profile people who have migraines are profiled, in contrast to many other chronic diseases. It would be beneficial if well known names and faces were associated with migraine as part of a public awareness campaign. In my business interactions people often ask me about migraine because my previous work with the Migraine Association is on my resume. I am finding high profile people who could potentially support migraine in their communities. One of the awareness solutions would be to get people talking openly about migraine. In time, these spokespeople could generate a more serious discussion about migraine, rather than it being primarily a subject of jokes.

*Neurologist:* Other disease associations recruit individuals to their association, and solicit donations. Once you have resources, interested parties compete to bring funding to their treatment centre or research program.

Family physician: Right now we don't have enough family doctors and specialists to deal with the needs of patients with migraine. If we start uncovering the iceberg by increasing migraine awareness and encouraging more migraine patients to seek care, who is going to look after them?

*Chair:* Could non-physician health professionals help meet our resource needs in migraine management?

*Family physician:* Asthma education programs have received significant funding from pharmaceutical companies. Should we involve them more in headache education programs?

*Chair:* Pharmaceutical companies have helped with educational programs and other initiatives related to migraine. The limiting factor has often been the ability of the headache commu-

nity to propose initiatives and carry them through. This is a challenge to those of us who work in the migraine field, and we must do better. We have to be more forward thinking and meet the challenges more than we have in the past, instead of primarily seeing patients day to day as physicians often do.

Family physician: A few years ago one of our physicians gave regular public lectures, and the response from the public was overwhelming but this requires physician initiative and a lot of energy. The structure of family practice is changing now, and with the new organizations like family health groups and networks, we will become more of a family health team. We may have more time to give to patient educational efforts. We will have nurse practitioners, dieticians, and psychologists. There may be more education available to patients in the future.

Family physician: Primary care reform in some parts of Canada is well on its way. It may be helpful for educating patients, and reaching out to the public more.

Chair: Some doctors feel threatened by the team concept.

*Neurologist:* There are changes occurring in health funding policy. While our ALS clinic was at one time threatened with closure, two years ago there was a major change in policy, and now we have a fully funded multidisciplinary clinic.

*Neurologist:* The ability of physicians to provide information to headache patients is limited by time constraints. Well trained non-physician health professionals working as part of headache treatment teams could help with this.

Chair: We are building up a cadre of headache trained nurses in our center. One of our nurses is now doing a master's degree in pain. In Canada, we do have a funded national headache fellowship position for physicians through the Canadian Headache Society, funded by the pharmaceutical industry. At times it has been difficult to attract physicians to this position. Perhaps we could establish training positions in headache care for interested nurses and other health professionals.

Health care administrator: No one answer exists and a multipronged approach is needed. Interdisciplinary care models including nurse practitioners, occupational therapists, physical therapists, psychologists, and others are becoming more common in Calgary. These teams can provide important services to patients with headache. In order to sustain this momentum, it is essential that these programs be evidence based. We must evaluate the duration of the benefits of interdisciplinary care. Interdisciplinary management may include pharmacologic and non-pharmacological therapies, and measuring the benefits of relaxation techniques as compared to amitriptyline may require different evaluation tools.

*Nurse:* We have heard that migraine is under diagnosed and under treated at many levels. We have run preceptor workshops with family physicians that spent a day at the headache clinic with us to learn more about migraine and its treatment. They have contact with many patients with migraine so they will reach many people.

*Neurologist:* Preceptorships are certainly well received and I think they are very positive. I've started doing these on a regular basis with our neurology residents as well. I'm hoping that we can generate more interest in headache.

Patient relative: In Ontario we tend to rely on health professionals to provide leadership and to deliver new initiatives in health care. There is competition for health care dollars. Many people who have personal experience with migraine would like-

ly volunteer their time to support a patient-led initiative which was supported by health professionals who also volunteered some of their time. But we would need to generate strong public interest in order to get something like this off the ground.

Health care administrator: "Row Your Own Boat", a component of the Chronic Disease Management program in Calgary educates the public to be lay leaders for chronic illness support groups. There is a whole framework on their website (see resources) for chronic disease management, and headache would fit into that realm. Additionally the Chronic Pain Centre is also developing family physician preceptorships in the specialist's office. To carry that one step further, as interested family physicians are recruited for pain workshops and a preceptorship, we will also be offered a training seminar to prepare them to conduct small group workshops in their clinics or Primary Care Networks as a way to efficiently spread their knowledge.

Neurologist: Insurance companies could use their funding much more effectively in treating patients who have headache after motor vehicle accidents and other trauma. Many of these patients have migraine. We should dialogue with the insurance companies and encourage them to set up more appropriate treatment programs which might prevent disability in patients who suffer from migraine.

Chair: I now have to draw our session to a close. Our job is not finished and a lot more could be said, but we have made a start. I would like to thank all the participants at this forum, and we will use the ideas generated by this Forum as a first step to achieve our goals.

#### **DISCUSSION SUMMARY (FORUM CHAIR)**

The "Finding Solutions" discussion at the Canadian Migraine Forum provided direction as to how those individuals and organizations working in the field of migraine should proceed to reduce migraine related disability in Canada. These can be summarized as six broad essential initiatives:

- 1. We need to develop more leadership in the field of migraine, both nationally and at the local level. Leadership is necessary if we are to obtain the necessary support and funding for the needed migraine treatment programs. As part of this process, we will need to better define the natural history of migraine, and what constitutes appropriate management. Local leaders will need the skills to form strategic alliances with other stakeholders in migraine care, and to develop concrete proposals for moving migraine care forward so that the necessary resources can be obtained from local health care institutions. Leadership is also required to promote the availability of migraine specific medications for patients with migraine, and to address the under use of both migraine specific symptomatic medications and prophylactic medications.
- 2. We need to use the energy and talents of non-physician health professionals more to work with physicians in migraine treatment teams. They could play key roles in education of the patient with migraine, and provide the patient with the necessary skills for successful migraine self management. They could also help to fill the gap created by scarce physician resources. Non-physician health professionals, specialist physicians, and primary care networks could work together to bring the necessary education and care to the migraine patient and the patient's family.

- 3. We need to develop and promote the chronic disease management model for migraine. Such models are being used successfully for other chronic disorders like diabetes, and could likely benefit many migraine sufferers. Important features of such models are early diagnosis, regular long term follow-up, patient education, and multidisciplinary treatment teams. A migraine chronic disease management model could include alternatives to the emergency department for the treatment of headache crises that do not respond to the patient's usual medications.
- 4. We need to use the energy and talents of individuals with migraine more, and work with them in an organized fashion to meet the needs of those with migraine in our communities. This could include the development of strong lay organizations to provide programs and educational resources for patients with migraine. Experienced individuals with migraine could also work with health care professionals and play key roles in regional migraine self management and support groups.
- 5. We need to close the knowledge gap about migraine through public awareness campaigns, websites, medical education, and appropriate reading material for patients. The public needs to be aware that migraine is a biological disorder that can cause significant disability and suffering. There also needs to be a wider appreciation that although migraine can be influenced by psychological factors, it is not primarily a psychological disorder. Recruitment of high profile individuals with migraine in our society to speak openly about their migraine could be helpful in achieving this goal.
- We need to promote more migraine research, including careful outcome assessments for treatment programs that involve non-pharmacological treatments and a team based approach to migraine management.

The discussions at the Canadian Migraine Forum identified a number of barriers which will need to be overcome to reduce migraine related disability in Canada. These include:

- 1. Diagnosis: Although it is clear that migraine is a biologically based neurological disorder, migraine is still seen by many as largely a psychological phenomenon. There is still a certain stigma to the diagnosis of migraine in our society, as evidenced by numerous headache jokes. Individuals with occasional tension-type headaches may not be aware that individuals with migraine may have much more disabling headache attacks. The broad clinical spectrum of migraine is also a problem. Many people know individuals with infrequent migraine attacks, and do not realize that the same diagnosis also includes others with much more frequent and disabling headaches.
- 2. Disability: The degree of disability which can be produced by migraine is frequently not recognized. Employers and coworkers need to understand that migraine can at times interfere with ability to work. Migraine sufferers need to understand that a long term complex treatment plan in which they will need to play an active role is often needed. As is the case for many chronic disorders, they may need to limit their activities at times, take appropriate medication, and make other lifestyle changes.

- 3. Symptomatic medications: The role of migraine specific medications as opposed to non-specific analgesics needs to be increased. Increased awareness of the risks of medication overuse in inducing more frequent headache is needed, while at the same time the benefits of early treatment in the course of the migraine attack need to be emphasized.
- Prophylactic medications: Patient response to prophylactic medications is idiosyncratic and usually incomplete. Family physicians need better guidelines on how to progress through prophylactic therapy options.
- 5. Non-pharmacological treatment approaches: These can be a good complement to medication approaches. Coordinated multidisciplinary treatment for headache is not generally available in our health care system, and when available often results in significant cost to the patient. Non-pharmacological approaches also often involve significant behavioral change and require active participation by the patient. With all the dramatic advances in modern medicine, many patients with migraine are looking for a "high technology" solution, and do not see behavioral approaches as an important part of their treatment program.

If we are to reduce migraine related disability in Canada, we must overcome immense challenges. Success will depend upon the joint efforts of physicians, other healthcare professionals, individuals with migraine, and the public at large. Reducing migraine related disability will be a complex undertaking. Strong leadership will be essential to reach this goal. It will be necessary for the Canadian Headache Society, Headache Network Canada, and other Canadian organizations active in the field of migraine to provide some of this leadership if progress is to be made.

#### RESOURCES

- 1. Information on pain treatment algorithms. (www.calgaryhealthregion.ca/clin/cme/cpg/index.htm. and click on "pain management").
- 2. Patient information from the Canadian Headache Society (headachenetwork.ca).
- 3. Information on a framework for chronic disease management (http://www.calgaryhealthregion.ca/cdm/).

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