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## The effects of a sensitisation campaign on unrecognised migraine: the Casilino Study

Received: 7 March 2007  
Accepted in revised form: 21 June 2007  
Published online: 24 September 2007

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**Abstract** A striking feature of migraine is the difference between the estimated migraine prevalence and the actual number of migraineurs consulting their general practitioners (GPs). We investigated the impact of a sensitisation campaign on migraine in a large cohort of patients, living in a district of Rome. The study involved 10 GPs and a population of about 12 000 people, contacted by mail and posters located in GP clinics. Both the letter and poster stressed the impact of headache on quality of life and included the Italian version of the three-item Identification of Migraine (ID Migraine) screening test, consisting of questions on disability, nausea and photophobia. If the subjects suffered from headaches, they were invited to contact their GPs for a visit and a free consultation with a headache expert. By means of this sensitisation campaign, 195 headache patients consulted their GPs. Ninety-two percent of them (n=179) were migraineurs; 73% of

them had never consulted a physician for headache. The ID Migraine test had a sensitivity of 0.92 (95% CI 0.86–0.95), a specificity of 0.75 (95% CI 0.47–0.91) and a positive predictive value (PPV) of 0.97 (95% CI 0.93–0.99) for a clinical diagnosis of migraine, according to the International Headache Society (IHS) criteria. This study confirms that a large number of migraine patients never see a doctor for their headache. This awareness campaign is likely to identify the severest cases of undiagnosed migraineurs. However, mailing campaigns do not seem to be so effective in bringing undiagnosed migraine patients into the primary care setting, and more efficient strategies have to be planned.

**Keywords** Migraine • ID Migraine  
• Sensitisation campaign

### Introduction

Migraine is a very frequent, disabling disease with a high socio-economic cost, it being one of the most common causes

of lost working days [1, 2]. It has been estimated that the total loss of workdays per year due to migraine in the general population was 270 days per 1000 persons [3]. Nevertheless, a striking feature of migraine is the difference between the estimated migraine prevalence and the number

of migraine sufferers that consult their general practitioners (GPs). In a Danish study, among subjects with migraine 56% had, at some time, consulted their GP because of migraine [3]. An Italian study on migraine prevalence showed that 25% of the subjects reported headache but only 2.6% of them sought medical advice [4]. Furthermore, Lipton et al. observed that only 70% of consulters are correctly diagnosed and a lower percentage of them receive prescription medication [5]. One of the main reasons for undiagnosed migraine is that patients themselves are unaware that they are migraineurs. Recently, it has been demonstrated that approximately 30–40% of migraine patients do not actually know that they have migraine, the result being that they frequently self-medicate or are treated inappropriately [6].

The use of simple screening tests has been proposed to obviate these problems. A screening test should be sensitive and specific as well as simple, easy to use, patient-friendly and economical [7]. The Identification of Migraine (ID Migraine) questionnaire was found to be a valid and reliable screening test for migraine for persons with headache complaints in primary care [8]. The items that were independently associated with migraine included disability, nausea and photophobia. Individuals who indicated that they had two of these three features were considered to test positive for migraine. The ID Migraine test had a sensitivity of 0.81, a specificity of 0.75 and a positive predictive value (PPV) of 93.3% for a clinical diagnosis of migraine according to the International Headache Society (IHS) criteria.

We investigated how a simple tool such as the ID Migraine test might facilitate the identification and diagnosis of migraine and help change its perception by both patients and GPs. The aim of our study was to assess the impact of an awareness campaign based on the Italian version of the ID Migraine screening test on the population of a district of Rome, thereby increasing the number of patients diagnosed in the GP setting and assessing the effectiveness of the Italian version of the ID Migraine test.

## Methods

A primary care group of 10 GPs in the Casilino district of Rome was involved in the study. The Casilino district is a well defined area, located in the suburbs of Rome, with a relatively homogeneous socio-cultural background. The GPs worked as a cooperative with approximately 12 000 registered subjects, all living in the same area.

In January 2003, we started an awareness campaign addressed to all the patients enrolled in the cooperative by:

- sending a letter with a copy of the ID Migraine screening test to all the households;
- placing posters in the GPs' waiting room.

Both the letter and poster stressed the impact of headache on

quality of life and included the Italian version of the three-item ID Migraine screening test, consisting of questions on disability (missing 1 or more days at work in the previous 3 months owing to headache), nausea and photophobia. If the subjects suffered from headaches and wished to seek advice, they were invited to contact their GPs for a visit and free consultation with a headache expert.

More than 8000 letters were delivered to households. Patient consultations started the following month. A preliminary diagnosis was made by the GP while an independent confirmatory diagnosis was made by the headache specialist from the Headache Centre of the "La Sapienza" University of Rome, during a consultation in the GP's office. A standardised clinical record, obtained for each patient, included the following: demographic data, past medical history, headache characteristics (severity, location and pain type, accompanying symptoms, aura, duration and frequency of attacks, therapy). Headache diagnosis was made according to IHS criteria (1988) [9]. In addition, headache disability was assessed by the Headache Impact Test (HIT-6) [10].

## Results

From February to June 2003, 195 headache patients consulted their GP (Table 1) because of the sensitisation campaign. Ninety-two percent of them ( $n=179$ ) were migraineurs (mean age:  $40.5\pm 15.8$  years, 84% female, education:  $8.4\pm 3.2$  years, average age at onset:  $20.2\pm 10.9$  years). Migraine with aura was present in 23% ( $n=41$ ) of the cases. The mean number of days of headache per month was  $8.4\pm 9$ , the mean pain intensity (on a scale 0–10)  $8.6\pm 1.5$ , the mean (SD) headache duration  $36.4\pm 25.1$  h and the mean (SD) HIT-6 score  $61.5\pm 7.6$ .

Seventy-three percent of the patients were diagnosed for the first time. There was no difference in the occurrence of aura between previously diagnosed or undiagnosed migraineurs (22% vs. 25%). In this study, the ID Migraine test displayed a sensitivity of 0.92 (95% CI 0.86–0.95), specificity of 0.75 (95% CI 0.47–0.91) and a PPV of 0.97 (95% CI 0.93–0.99) (Table 1).

Twenty-two percent (39/179) of the patients used triptans. These 39 patients comprised 41% (20/49) of the

**Table 1** ID Migraine screening test: results of the validation study (Lipton et al.,<sup>\*</sup> 2003) and the Casilino study (LR, likelihood ratios; values and 95% CI are reported)

	Casilino study	Validation study
Sensitivity	0.92 (0.86–0.95)	0.81 (0.77–0.85)
Specificity	0.75 (0.47–0.91)	0.75 (0.64–0.84)
LR positive	3.68 (1.57–8.62)	3.25 (2.69–3.93)
LR negative	0.10 (0.06–0.17)	0.25 (0.22–0.28)

patients with a previous diagnosis and 15% (19/130) of the patients with undiagnosed migraine. There were no differences between migraineurs using and those not using triptans in headache pain intensity, days of headache per month and HIT-6 (Table 2).

## Discussion

Migraine disorders are, despite the heavy burden they impose on individuals and society in general, largely unrecognised and untreated. Assuming a migraine prevalence of approximately 11.6% [4], in a general population of 12,000 subjects exposed to posters and contacted by mail we expected to be contacted by 1300–1500 migraineurs, whereas approximately only 15% (195 patients) contacted us. This low percentage is disappointing even though it fits in with the results of similar general awareness campaigns by mail, for other common diseases [11]. Those migraineurs who did contact us were probably only those with very severe headaches, a hypothesis supported by the high HIT-6 score as well as the number of days of headache. In this regard, Rasmussen and Olesen showed that the frequency of attacks was positively correlated with the consultation rate [12]. Furthermore, subjects who seek medical advice because of headache might differ in personality from those who do not consult a doctor [13].

In our country, patients do not tend to visit their primary care providers for headache [4]. As the majority of our patients had severe and disabling migraine, it is surprising that over two thirds consulted their GPs for headache for the first time only after the awareness campaign. This finding is indicative of the fact that migraine is perceived as “just another headache”, and not as an actual disease. In our population, this lax attitude was not related to migraine characteristics, not even aura. This is in accordance with a previous study, which showed that aura does not influence the GP consultation rate for migraine (50% vs. 62%, with and without aura, respectively) [12].

**Table 2** Use of triptans in migraineurs: pain intensity, HIT-6 and days of headache per month

Triptans	Users	Non-users
All (N=179) % (n)	22 (39)	78 (140)
Diagnosed migraine (N=49)	41 (20)	59 (29)
Undiagnosed migraine (N=130)	15 (19)	85 (111)
Pain intensity (0–10)	8.6±1.6	8.5±1.5
Days of headache per month	6.6±7.6	8.9±9.3
HIT-6	63.7±7.5	61±7.5

It has to be stressed that the majority of people living in this suburb had low education and income levels. Neither of these features have been correlated with migraine prevalence and consultation patterns [14, 15], whereas they might represent risk factors for medication overuse and chronicity [16]. In this regard, Rasmussen showed that none of the sociodemographic variables: marital status, cohabitation, educational level, occupational category or employment status were significantly associated with migraine [13].

As a matter of fact, few patients had received prophylaxis therapy and only one fifth were being treated with triptans before our awareness campaign. The use of triptans was not linked to a greater severity of or disability due to headache. Surprisingly, 15% of migraineurs diagnosed for the first time had already used triptans. Triptans in Italy are paid for completely by the National Health Service and require a doctor's prescription. It is reasonable to assume that this is a form of self-treatment not only due to a mere exchange of information between people but also involving pills themselves sharing. This datum highlights the risk of over-exposing patients to drugs owing to the absence of any medical supervision to determine whether someone is deemed to be at high risk for an adverse outcome.

Finally, ID Migraine in our population had an even higher PPV than the ID Migraine validated study (Table 1). This self-administered screening test may represent an ideal tool for campaigns aimed at making unknowing migraine sufferers aware that they have migraine.

This study confirms the high number of undiagnosed migraine patients in those recruited. A previous study showed that the principal reason why the burdens attributable to headache persist, and indirect costs remain so high, is failure of health-care systems to provide awareness of the problem [17]. However a sensitisation campaign in the form we have undertaken is rather ineffective in bringing undiagnosed headache sufferers into medical care. While this awareness campaign is likely to identify the severest cases of migraineurs, it did not disclose the large number of expected migraineurs.

The key factor for a sensitisation campaign is education at every level. Probably, a preliminary training programme involving GPs as well as other health-care providers and health-policy makers could be helpful. Explanatory materials for various audiences should be prepared accordingly, as suggested by the project of the Global Campaign to Reduce the Burden of Headache Worldwide [17]. Mailing campaigns might be followed; if there is no response to the mailed invitation, by telephone contact. Finally, it also requires health service delivery and organisation that generally depend upon local health organisation to plan and implement locally appropriate health-care solutions [17].

Our approach does not seem to be very effective in bringing migraine patients into the primary care setting and more

efficient strategies have to be planned in order to improve the effectiveness of sensitisation campaigns; this can probably be achieved by acting on different levels, heightening the awareness of the population, general doctors and health policy makers of the socioeconomic burden of migraine, and of the benefits of correct management.

**Acknowledgments** The authors wish to thank G. Bruti, R. Cerbo, G.L. Lenzi and C Mostardini for their helpful advice and comments. We are grateful to Pfizer for providing fellowships for the data collection (G.B. and C.M.) and partially funding the study with an unrestricted grant.

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