



Management of Migraine and the Accessibility of Specialist Care: Findings from an Extended Multinational Survey (My Migraine Center Survey)

Siriporn Wongsiriroj · Elisabetta Grillo · Sabrina Levi ·
Ronald Zielman · Elia Lahouiri · Marco Marchina · Marco Pedrazzoli ·
Matias Ferraris

Received: December 9, 2019 / Published online: August 7, 2020
© The Author(s) 2020

ABSTRACT

Introduction: The parent study was a survey in 28 headache centers (6 countries) which identified five potential root causes for long waiting lists that limit patient access to specialist care. Here we performed an extension of the parent study to increase the panel of centers contacted, the representativeness of the analysis, and the statistical validity of the results, and to explore the role of dedicated headache clinics, triage, and specialized nurses.

Methods: We conducted a 19-question survey using a sample of 239 headache centers (16 countries). The five-area framework identified

Digital Features To view digital features for this article go to <https://doi.org/10.6084/m9.figshare.12698417>.

S. Wongsiriroj (✉)
Novartis (Thailand) Limited, Bangkok, Thailand
e-mail: siriporn.wongsiriroj@novartis.com

E. Grillo
Novartis Farma S.P.A., Origgio, VA, Italy

S. Levi
Novartis Argentina S.A., Ramallo, Argentina

R. Zielman
Novartis Pharma B.V., Amsterdam, Netherlands

E. Lahouiri · M. Marchina · M. Pedrazzoli
LSC LifeSciences Consultants, Milan, Italy

M. Ferraris
Novartis Pharma AG, Basel, Switzerland

in the parent study was confirmed and further developed by describing treatment center archetypes according to their setting (general neurology versus dedicated clinic) and resources available within the center (number of health-care professional [HCPs] full-time-equivalent positions).

Results: In total, 474 HCPs were interviewed across 16 countries. The proportion of patients with chronic migraine and episodic migraine varied across centers and countries. There was limited access to specialized centers in this enlarged sample; with global average waiting list of 3.7 months for the first visit and 2.5 months for the follow-up visit. Long waiting lists for headache patient care is a major issue in several countries, with the waiting lists for new patient visits extending up to 14 months. The presence of a dedicated nurse was correlated positively with the use of triage for prioritization of patient access (correlation coefficient: 0.85) and completing migraine diary (0.71).

Conclusion: This study confirmed differences across treatment center archetypes in terms of patients, waiting lists, level of delegation to nurse, and patient education and compliance, and provides support for the potential benefit of dedicated clinical settings for headache patients. The survey highlighted the potential role of nurses in patient education and waiting list prioritization, consequently benefiting headache centers.

Keywords: Access; Care; Clinic; Dedicated; Migraine; Nurse; Practice; Triage; Survey; Waiting lists

Key Summary Points

Migraine is one of the leading reasons for patients accessing neurology services.

Long waiting lists are a challenge, limiting accessibility of patients with migraine to specialist care.

The five-area framework from the parent study was further developed by describing four center archetypes according to their setting and resources available within the center.

The goal was to perform a deep dive into the major roadblocks identified in previous publications surrounding headache patient management and access to specialized care.

This study confirmed issues relating to access to specialized centers for headache patients and the importance of clinics dedicated to the management of these patients.

INTRODUCTION

Headache is an extremely common neurological disorder in the general population. It is estimated that around half of people with headache are primarily self-treated, with only around 10% treated by neurologists, according to the World Health Organization 2011 Atlas of Headache Disorders [1]. Migraine is the leading cause of disability among all neurological disorders [2], and is generally managed in a primary care setting [3, 4]. Of all headache consultations, the proportion of consultations for migraine is 30% for primary care physicians and 34% for neurologists globally [1]. Erenumab, a calcitonin gene-related peptide (CGRP)

receptor antagonist, is indicated for the preventive treatment of migraine in adults. Erenumab-aooe (Aimovig™) is the most frequently prescribed anti-CGRP worldwide, with more than 300,000 patients prescribed the drug globally in the post-trial setting [5].

Specialized headache centers play an important role within structured headache services for the management of people with headache disorders [4]. These centers provide more comprehensive treatment options, a greater ability to manage refractory patients, and better patient support. This support includes migraine diary explanation, education, and treatment that requires for more time and expertise dedicated to complex cases. Recently, to improve headache service, quality performance standards for the specialized headache centers were defined [6]. The European Headache Federation in collaboration with *Lifting The Burden: the Global Campaign against Headache* [4], recommended a three-tiered model for structured headache services that includes general primary care (level 1), special-interest headache care (level 2), and headache specialist centers (level 3). The study suggested that a three-level structure should be used to differentiate patient care. Results showed that, on average, an adult migraine patient will need a 1.25-h consultation every 2 years, but there was large variability between cases due to the broad spectrum of complexity of migraine cases [4]. The authors suggested that 90% of people with headache should be consulting at level 1 and 9% at level 2 [4]. Only a limited number of the patient pool (1%) should reach that highly specialized tertiary level [4].

In addition, methods were developed for measuring headache service quality (service quality evaluation), and the Europe-wide study was the first to evaluate indicators for headache care to guide quality improvement [7]. This approach was also used for evaluating headache service quality indicators in six Italian specialist headache centres [8]. Eurolight was a European cross-sectional survey that highlighted the need to improve care for people with migraine [9].

Multidisciplinary teams are gaining importance in dedicated headache clinics [10]. Headache nurses are also important members of the

multidisciplinary team, as they can monitor the progress of patients with headache during consultations [11]. Nurses have a direct impact on patient education and care in the primary care setting [12]. In a study of 28 specialized headache centers by Kainth et al. [13], although 85% of centers had a dedicated nurse, only 29% of center nurses carried out “advanced clinical activities.”

In the previously mentioned study by Kainth et al. [13], the authors performed an in-depth investigation of the roadblocks impeding access to specialized headache care. This parent study [13] assessed the magnitude of the problem of access to specialized headache care in terms of waiting lists times. It also identified good practices in the management of headache patients across a variety of settings and countries. The study showed that the delay in access to specialist care was due to issues in regulating patient inflow, resulting in a longer waiting list (> 3 months) (first visit [61% of patients] and follow-up [36%]) [13]. The study highlighted five potential root cause areas leading to long waiting times for migraine patient management: appropriate patient referral, triage and priority allocation, dedicated clinics and resources, nurse role and task delegation, and follow-up management.

The parent study was a starting point, and we expanded on these data by increasing the number of centers involved. In this study we explored, in detail, the role of the dedicated clinics, the impact of triage on patient pools in these centers, the role of specialized nurses in the care of headache patients, and the potential they have in the efficient management of headache services. The three objectives were to evaluate previous findings using a more robust sample, to record existing good practices in 16 different countries and in different center archetypes and settings, and to identify promising areas of interest to improve patient journeys in the respective countries.

METHODS

Sample

The total sample was expected to include more than 200 centers across more than 20 countries. Sample size (for binary outcomes) calculations indicated that 200 centers were needed to produce a two-sided 95% confidence interval with a maximum width of 0.143 (precision = 0.072) when the sample proportion was 0.5.

Centers were selected for this study if they were headache centers officially recognized by scientific societies, and based on the number of patients who visited per year. The headache specialist and/or neurologist who had direct involvement in migraine care consented to participate prior to the survey. The healthcare professionals (HCPs) were both physicians and nurses in the case of centers that had both, or physicians only when there were no nurses within the center. In some cases, students, administrative personnel, and pharmacists were also interviewed. The sample comprised a heterogeneous group of headache centers that varied in location, size, presence of dedicated migraine/headache clinic or general neurology clinics, and type of setting (department of neurology in the general hospitals, specialized headache centers/migraine units, and office-based neurology practices and pain clinics).

Data Gathering

The survey was conducted by LifeSciences Consultants (in June 2017) and Novartis personnel (in March 2019), using a 19-question survey. Data were collected via field interviews with HCPs. All the interviews were conducted face-to-face according to a 19-question survey developed from the conclusions of the parent study [13]. The interviews were conducted in the local language. Each in-depth interview lasted between 30 and 60 min. The survey covered areas of interest in migraine patient management and addressed potential access issues in each center. All 28 centers in the parent study were included in the sample. Data were inputted in a tailored Microsoft Excel® repository,

and analyzed using Microsoft Excel® spreadsheets.

Centers involved in the survey were not equally distributed across the countries analyzed. For this reason, the sample was unbalanced, with the center concentration skewed towards a few countries. To mitigate this issue, the sample's global average was calculated as the mean of each country's average. This calculation redistributed statistical weight across countries and increased the reliability of global results.

The five common types of biases in data collection from the parent study [13] were also applicable to the extension study (participant's self-selection bias, single responder bias, single interviewer bias, country interviewer bias, and sponsor bias). Please refer to the previous publication by Kainth et al. [13] for details regarding biases in data gathering.

Participants gave informed consent to voluntarily participate in the study. All participants had the right to withdraw from the interview at any time. This article involves an assessment of interview questionnaires and does not contain any studies with human or animal subjects performed by any of the authors.

RESULTS

The global survey involved HCPs from 239 centers in 16 countries across Asia Pacific and the Middle East, Europe, Latin America, and North America (Table 1). In total, 474 HCPs were interviewed across 16 countries: Albania ($n = 11$), Argentina ($n = 22$), Australia ($n = 18$), Canada ($n = 31$), Colombia ($n = 5$), Croatia ($n = 9$), Germany ($n = 19$), Ireland ($n = 25$), Italy ($n = 155$), the Netherlands ($n = 19$), Pakistan ($n = 45$), Spain ($n = 46$), Switzerland ($n = 1$), Thailand ($n = 53$), Turkey ($n = 10$), and the United Kingdom ($n = 5$).

The Framework of Analysis and Definition of Center Archetypes

From analysis of the parent study [13] there emerged five areas (Fig. 1) along the patient

journey into which issues in migraine patient management were grouped. In our study, we also used an analysis framework supported by the larger sample, which detects major issues concentrated in these five areas (appropriate patient referral, triage and priority allocation, dedicated clinics and resources, nurse role and task delegation, and follow-up management). The framework was further developed by the definition and inclusion of four archetypes (Fig. 2). The archetypes were defined according to setting (general neurology versus dedicated clinic) and resource availability inside the center (number of full-time-equivalent [FTE] HCPs).

Type I: Fully dedicated clinics with full-time personnel available and at least two FTE HCPs

Type II: Dedicated clinics with full-time personnel available and 1–2 FTE HCPs. This archetype represents specialized clinics with at least one full-time HCP available.

Type III: Dedicated clinics with part-time personnel and < 1 FTE HCP. This archetype represents specialized centers where the clinic is only open a few days a week. Generally, only one specialist runs the clinic without the support of other HCPs.

Type IV: General neurology without time dedicated to headache alone

Framework Area 1: Appropriate Patient Referral

On average, 51% of patients referred to headache centers suffered from episodic migraine (EM; 4–14 migraine days per month, with < 15 headache days per month [14]), consistent with the parent study (52%) [13]. Significant variations were reported across centers, with results ranging from 0 to 90% EM (Fig. 3). Patients under migraine management were usually not screened (72%), and centers accepted patients with every degree of severity.

Table 1 Sample characteristics by country

| Country | Centers (number of centers interviewed) | Size (number of migraine patients managed) | | |
|----------------|---|--|-------------------|----------------|
| | | Small (< 600) | Medium (600–1000) | Large (> 1000) |
| Switzerland | 1 | 0 | 0 | 1 |
| Australia | 4 | 2 | 1 | 1 |
| United Kingdom | 5 | 1 | 2 | 2 |
| Colombia | 5 | 2 | 0 | 3 |
| Canada | 5 | 1 | 1 | 3 |
| Germany | 6 | 1 | 2 | 3 |
| Spain | 6 | 0 | 3 | 3 |
| Croatia | 9 | 5 | 3 | 1 |
| Turkey | 10 | 4 | 3 | 3 |
| Albania | 11 | 8 | 3 | 0 |
| Ireland | 15 | 9 | 5 | 1 |
| Netherlands | 16 | 10 | 5 | 1 |
| Argentina | 22 | 14 | 0 | 8 |
| Italy | 26 | 6 | 8 | 12 |
| Pakistan | 45 | 25 | 7 | 13 |
| Thailand | 53 | 37 | 12 | 4 |
| Total | 239 | 125 | 55 | 59 |

Differences in the patient pool were also present between different settings. General neurology (type IV centers) had a higher percentage of patients with EM, at around 55%. Conversely, in fully dedicated clinics (type I centers), patients presenting with EM constituted around 45% (type II centers, 51%; type III centers, 57%).

The percentage of patients with EM varied among countries. For example, 80% of patients in Switzerland presented with EM, versus only 18% in the United Kingdom (Fig. 4). Nevertheless, there was limited variation in terms of the proportion of EM to chronic migraine (CM) across all countries, as global variance averaged only 2%.

Framework Area 2: Triage and Priority Allocation

The parent study [13] highlighted the importance of triage for prioritizing patients and effectively managing the demand for migraine consultation. Triage is performed in almost all centers for urgent cases, such as patients with acute attacks or with suspected tumor/stroke, thus avoiding the waiting list. However, in the centers we performed more advanced triage to differentiate access priorities among non-urgent cases, which represent the vast majority of patients. Such procedures help guarantee access for severe cases and limit waiting lists for patients with CM or more complex cases.

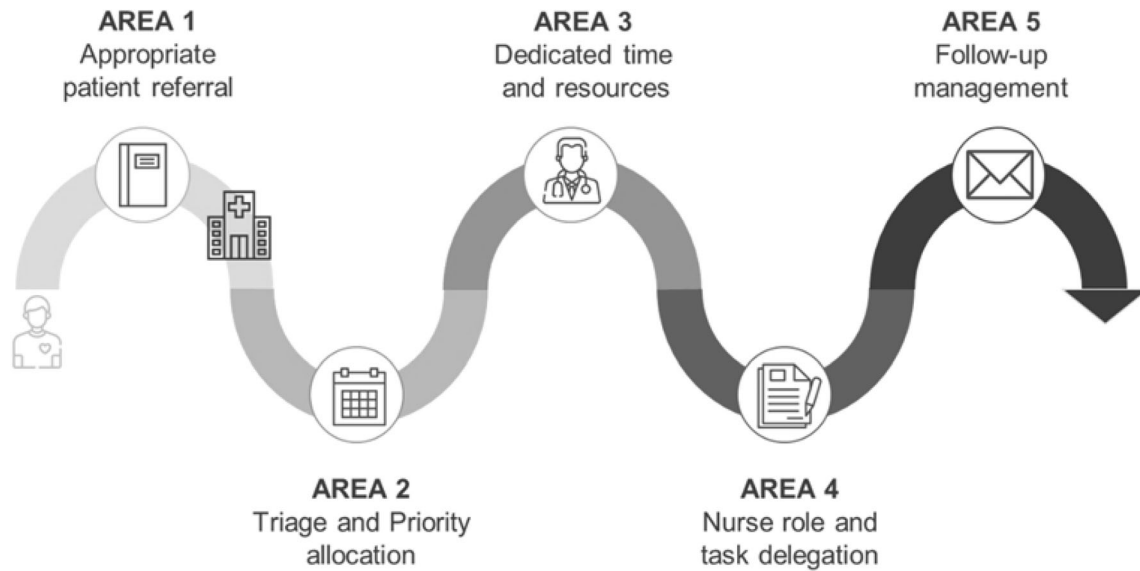


Fig. 1 Framework of analysis. Adapted from Kainth et al. [13]

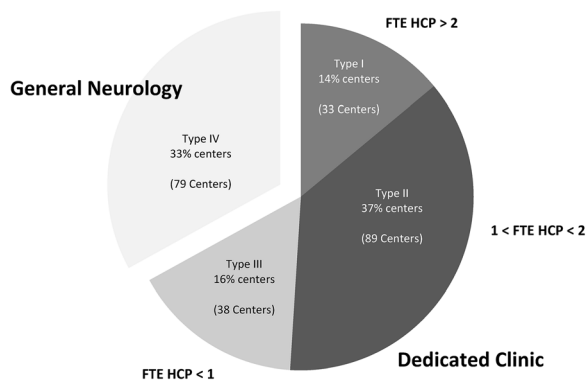


Fig. 2 Archetype identified according to setting and resources available. *FTE* full-time equivalent, *HCP* health-care professional

The global survey tested the existence of two main types of triage: triage that decides whether to allocate patients to dedicated clinics or general neurology departments, and triage for patient prioritization (e.g. longer versus shorter waiting lists).

Triage that classified patients as needing general neurology versus a dedicated clinic was available in 16% of centers. It was most prevalent in the Netherlands, where the rate was around 56%. The absence of triage for distribution of patients leads to unfiltered access to specialized care and more patients with EM in

specialized centers (including patients sent by the primary care physician and treated with triptans in a single visit). Moreover, only 13% of centers leveraged triage procedures to prioritize more severe patients with severe migraines. In fact, even when triage was utilized, it was not used for both patient distribution and prioritization in around 9% of centers.

Triage was usually not performed in type IV and III centers, and there was higher utilization in dedicated type I (used in 50% of centers) and type II (used in 25% of centers) centers. Triage was performed mainly in dedicated centers, as they have enough resources to allocate HCP time to this activity. The impact of triage on the patient pool of dedicated centers is highlighted by the different proportions of EM across the identified settings. In fact, type I centers performed triage in around 50% of cases and had 45% of patients presenting with EM, whereas type III and IV centers had 57% and 55% of patients presenting with EM, respectively.

In the dedicated clinics cluster, the waiting list for centers where triage was leveraged to distribute patients between general neurology and dedicated clinics was around 3.3 months. There was a reduction of approximately 1 month in wait time versus the centers that did not perform any triage.

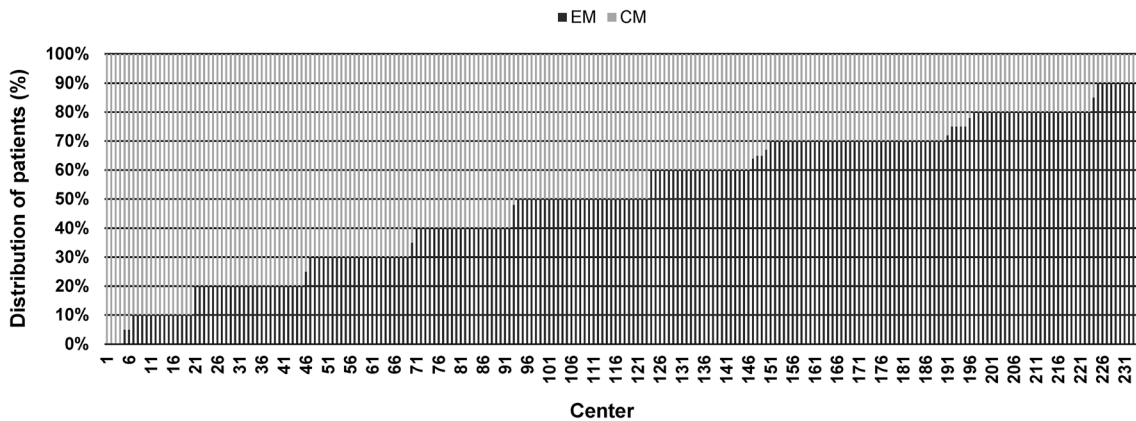


Fig. 3 Proportion of patients with chronic migraine versus episodic migraine within each center. *EM* episodic migraine, *CM* chronic migraine

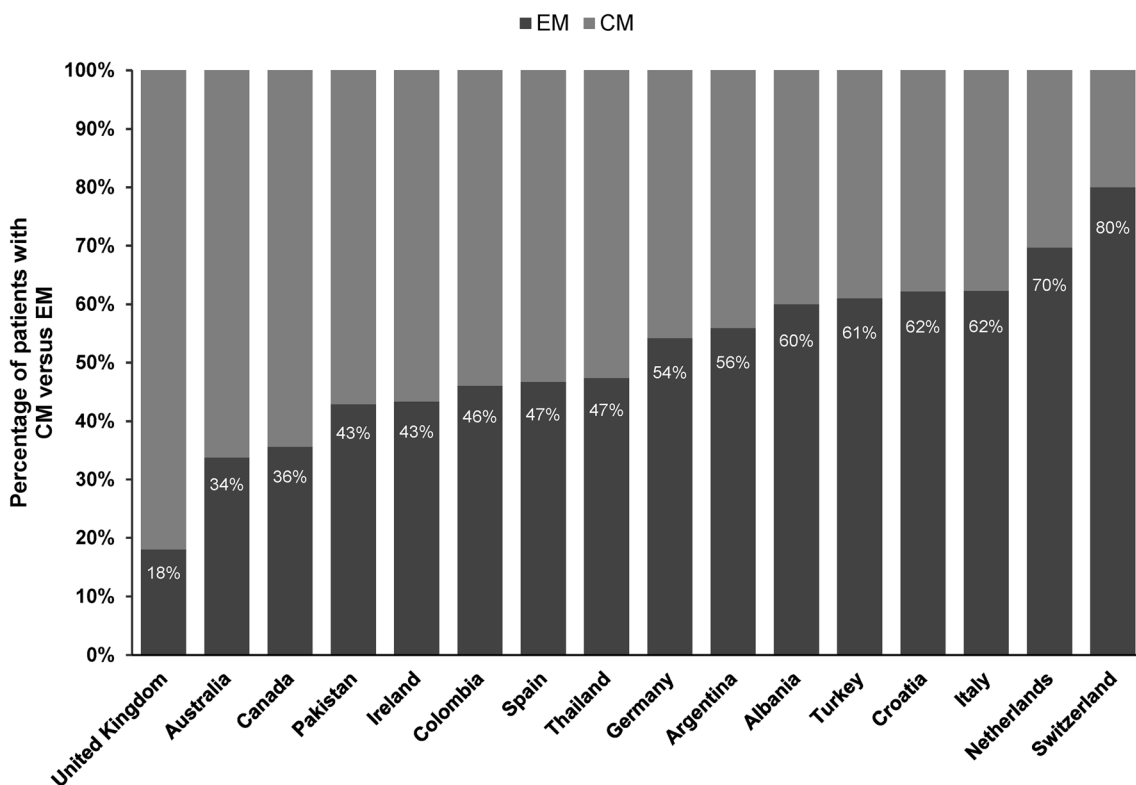


Fig. 4 Proportion of patients with chronic migraine versus episodic migraine within each country. *EM* episodic migraine, *CM* chronic migraine

Framework Area 3: Dedicated Clinics and Resources

The reference study [13] detected a significant access issue due to the long waiting lists for

headache patient care. Our study in this enlarged sample confirmed limited accessibility to specialized centers as a major issue in several countries, with waiting times for new patient visits of up to 14 months in Canada (no waiting list in Pakistan). On average, patients waited for

3.7 months for the first visit and around 2.5 months for follow-up visit. In the general neurology archetype (type IV), the waiting list was around 2.2 months for the first visit. This is the result of more available resources, shorter visit lengths (26 min on average versus the average of 39 min between type II and III), and a geographic concentration of this archetype in countries with systemically shorter waiting lists (e.g. Germany). Focusing on countries that are members of the Organisation for Economic Co-operation and Development (OECD) as a more homogeneous cluster, the top three countries in the sample averaged less than 1 month (e.g. Turkey, Albania, and Pakistan), and the bottom two countries average around 9 months (e.g. Canada and Ireland), with a global average of 3.7 months (Fig. 5).

Resource availability influenced waiting times. Type I and II centers had an average waiting time of 4.5 months, which contrasts with 5.4 months in type III centers. There were systematic differences across different countries. In some countries, patients consistently waited a long time for treatment, while in other countries patients usually experienced short waiting times (e.g. waiting list in the Netherlands was around 1 month and Canada 14 months). The waiting lists for the follow-up visits for type I, II, III, and IV centers were 3.3, 3.0, 2.8, and 1.7 months, respectively.

With regard to time dedicated to patient visits, dedicated clinics performed longer visits averaging 10 minutes longer than in other settings. This is probably a consequence of a different patient pool, more patients with CM, and the higher level of specialized visits performed in these clinics.

Framework Area 4: Nurse Role and Task Delegation

The nurse's role in headache management varies significantly across countries. There are different levels of nurse engagement in patient management, and there is a need to identify opportunities to improve/re-evaluate the role of nurses in caring for patients with migraine. In the sample, 31% of countries did not have a full-time dedicated nurse available in any center (i.e. Albania, Pakistan, Turkey, Italy, and Spain). In these countries, nurses were usually shared with other specialized clinics or with the general neurology department. On average, globally, only 30% of centers had a dedicated nurse. However, this percentage varied widely by country—for example, 9% in Argentina and 100% in the United Kingdom and Switzerland (Fig. 6).

The nurse's role varied across countries according to legal constraints and each

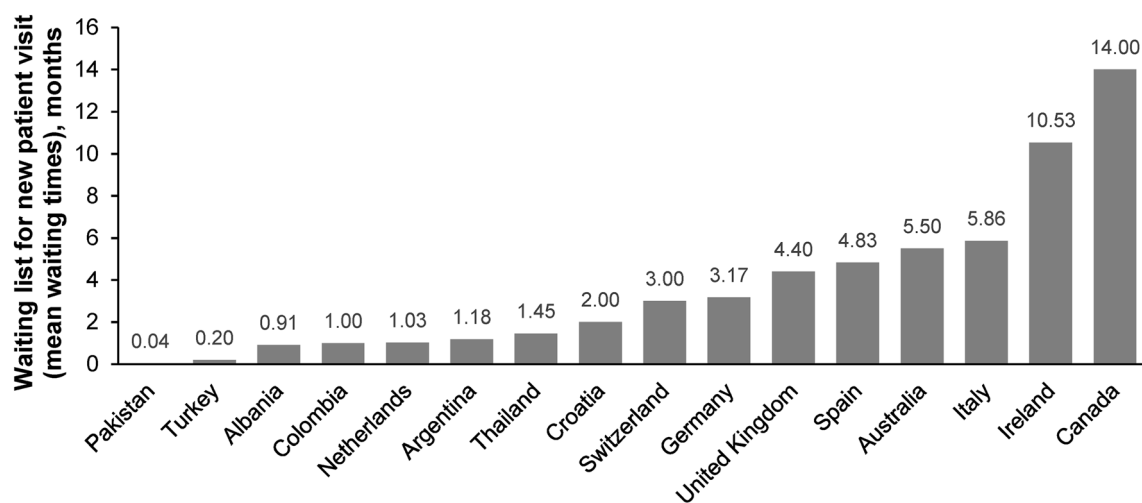


Fig. 5 Waiting list in OECD countries for new patient visits (mean waiting times). *OECD* Organisation for Economic Co-operation and Development

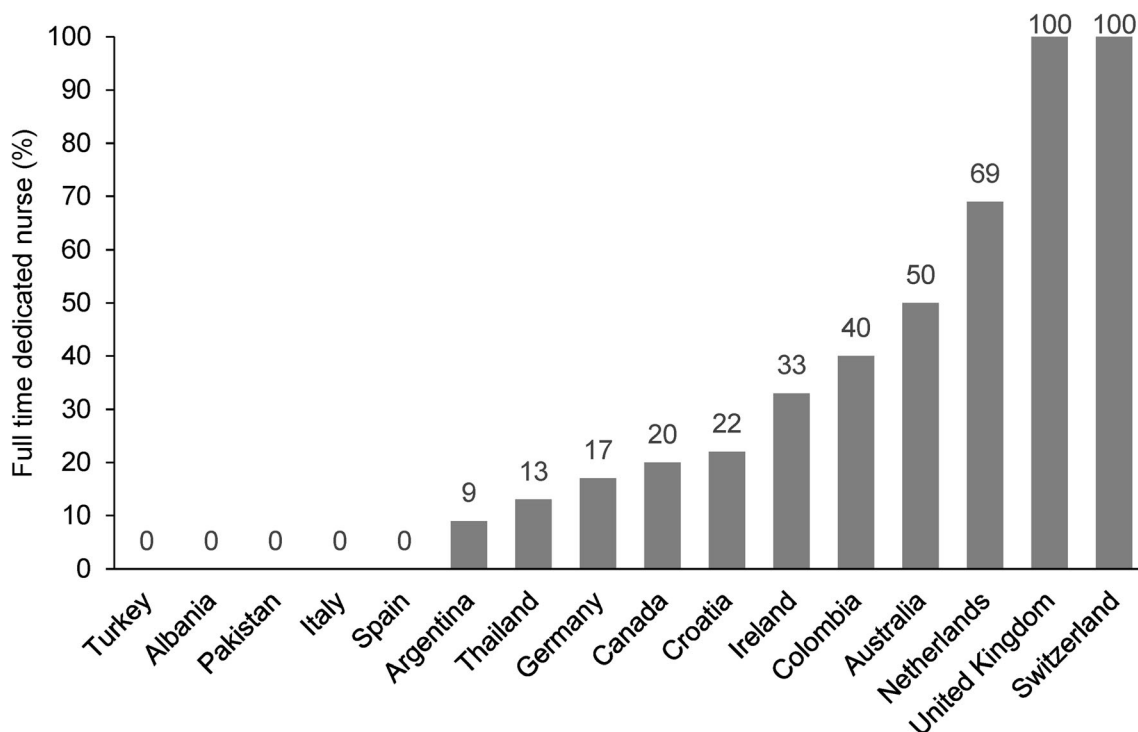


Fig. 6 Dedicated nurse distribution in headache clinics across countries

country's peculiarities (Table 2). The level of delegation also varied among centers in the same country. In the global survey, a scale of 1–3 was used to define the level of delegation, with 1 indicating the minimum level of delegation (the nurse mainly performs administrative activities) and 3 representing the maximum level of delegation (the nurse performs part of the visit, supports the specialist in treatment administration, and supports patients remotely during follow-ups). Table 2 shows the maximum level of delegation identified in the sample for each country (right column) and the average level of delegation across all centers in the country. The table highlights the potential for increasing task delegation to the nurse in most of the countries analyzed.

Differences in delegation level are also present across archetypes. Type I centers have the highest level of delegation to the nurse, and this contrasts with a low level of delegation in all other settings.

The analysis showed the role of the nurse in improving ancillary activities such as triage and diary explanation. The presence of a dedicated

nurse was positively correlated with the use of a triage procedure to prioritize patients according to the severity of their condition (correlation coefficient 0.85). Moreover, a correlation coefficient of 0.61 was found between the presence of a dedicated nurse and the distribution of patients between specialized headache clinics and general neurology centers.

Patient education in chronic disease management is essential and widely accepted among the scientific community. Nurses in particular play an important role in educational activities in different therapeutic areas, which helps to improve patient care. Regarding education within the centers, there was a positive correlation of 0.71 between dedicated nurses and patients with a complete diary. In those centers where there was a dedicated full- or part-time nurse, patients received a more detailed education, and diary use increased.

A deep-dive examination of patient compliance with the migraine diary showed that around 20% of patients came to visits with a complete migraine diary. Migraine diary compliance correlated negatively with the no-show

Table 2 Mean and maximum level of delegation across country

| Country | Mean level of delegation to the nurse role (1, low; 3, high) | Maximum possible level of delegation to the nurse role |
|----------------|--|--|
| Turkey | 0.00 | 0 |
| Albania | 0.00 | 0 |
| Pakistan | 0.00 | 0 |
| Argentina | 0.14 | 2 |
| Thailand | 0.21 | 3 |
| Australia | 0.25 | 1 |
| Croatia | 0.33 | 2 |
| Ireland | 0.53 | 3 |
| Colombia | 0.60 | 2 |
| Netherlands | 1.31 | 3 |
| United Kingdom | 3.00 | 3 |
| Switzerland | 1.00 | 1 |
| Canada | 0.00 | 0 |
| Germany | 0.00 | 0 |
| Italy | 0.00 | 0 |
| Spain | 0.00 | 0 |

rate at the center, around -0.35 , highlighting that patients with higher compliance in filling out the diary tend to demonstrate greater adherence to scheduled visits. In our study, the center analyzed was able to reduce the time dedicated to patient history during the visit by 33%, and to reduce the number of visits needed to define the appropriate treatment plan from 3 to 1.8.

Framework Area 5: Follow-Up Management

On average, 67% of the patients referred to headache centers were followed up in the clinic. Significant differences in follow-up practices were identified across different countries, from a minimum of 4% in Pakistan to 90% in Switzerland (Fig. 7).

On average, migraine patients were followed up every 3 months, with limited cross-country differences. Analysis of variations among archetypes revealed a higher percentage of internal follow-up of migraine patients at dedicated clinics, around 74%. Conversely, general neurology tended to refer out more patients, with around 60% of patients internally followed up.

DISCUSSION

The Chronic Migraine Epidemiology and Outcomes (CaMEO) study showed that patients with CM traversing all three barriers (consultation, diagnosis, and treatment) to receive care for headache constituted less than 5% of the sample [15], mainly due to long waiting lists.

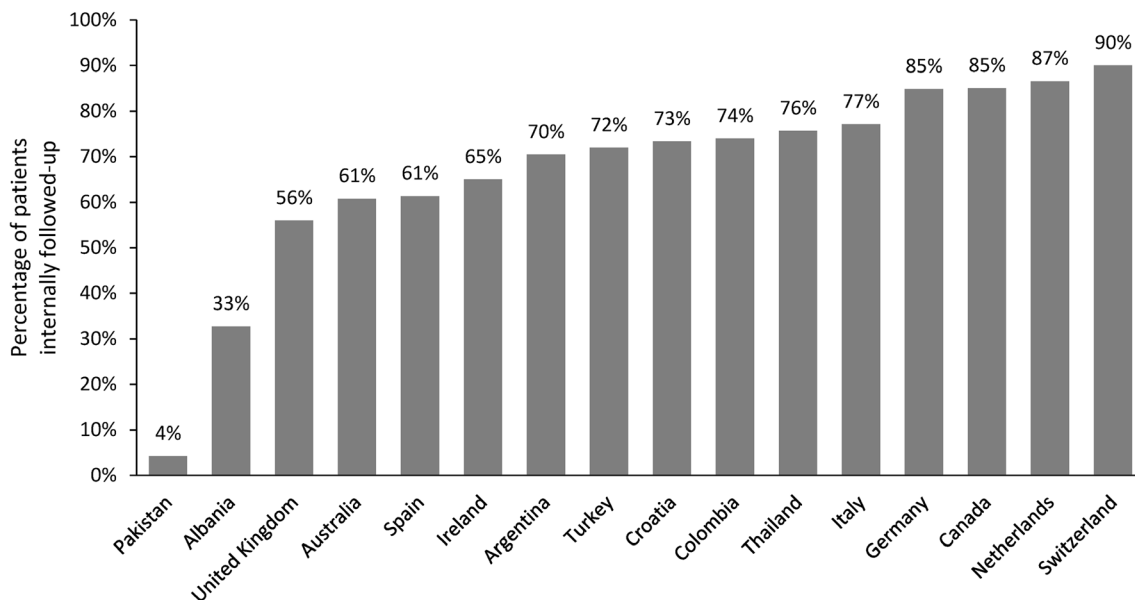


Fig. 7 Internal follow-up of patients

The findings from the parent study [13] confirmed that waiting lists were an issue in many headache centers. On average patients waited 6 months for a first/new patient visit, but this could be as long as 18 months in some cases [13]. Patients' access to specialist care was delayed due to regulation of patient inflow, resulting in longer waiting lists (> 3 months) (first visit [61%] and follow-up [36%]) [13]. Our study showed that analysis of the larger sample confirmed issues relating to access to specialized centers for headache patients.

Here we identified long waiting lists and limited resource availability as the main roadblocks to patient access. While the global average wait time was 3.7 months for the first visit and 2.5 months for the follow-up visit, in 43.7% of countries the average wait for new patient visits was longer than 3 months, and in some centers it was as long as 14 months (e.g. Canada).

More significant differences were present between countries with a low number of neurologists and centers per capita (e.g. Australia [2.0 neurologists per 100,000 population] and Canada [2.8 neurologists per 100,000 population]) and countries where neurologists and centers are more common (e.g. Italy [12,399 neurologists (60.5 million population)] and

Germany [6810 neurologists (82.7 million population)]) [16–19]. In the former, the level of CM per center was higher due to additional difficulties experienced in accessing specialized care. In the latter, the centers were able to manage all patients and prioritize (sometimes in specialized clinics) the more severe/chronic cases.

The analysis confirms the importance of dedicated clinics in the management of headache patients. From the survey, four archetypes were identified according to setting (dedicated clinic versus general neurology) and resources available (full-time versus part-time centers). The analysis by archetype highlighted differences in terms of the following:

Patient prioritization Triage and patient prioritization tools are available only in dedicated clinics. In around 50% of type I centers, there are enough resources to perform triage and to prioritize more severe patients. Nevertheless, only 9% of the centers leveraged triage to both prioritize more severe patients and allocate patients into a specialized clinic, thus limiting the positive effect of this activity. This highlights the suboptimal use of a tool already in place in clinics and reduces the potential benefit of triage to the patient pool in the specialized

centers. Ultimately, this delays the rapid management of more complex/severe cases.

Patient pool Type I centers have the highest percentage of patients with CM (65%) of all dedicated centers. This is mainly an effect of the triage procedure implemented in half of these clinics.

Nurse task delegation Nurses have a higher level of delegation and involvement in patient care in specialized clinics. In these clinics, they are more involved in advanced clinic activities (like preliminary visits, remote follow-ups, treatment administration support), and specialists delegate more tasks to them. Also, they have an important role in patient education, as shown in the example of migraine diary explanation to the patients. In fact, in dedicated clinics, diary compliance is higher (around 26% of patients).

Dedicated clinics, especially when more than two FTE HCPs are present, are crucial for improving headache patient care, treating more complex cases, prioritizing patients, increasing patient support through education, and allowing for longer and more detailed visits.

As further confirmation of the previous study, the survey points to triage as an important factor in the efficient management of headache clinics. The survey confirmed the positive impact of nurse availability on headache clinic and center efficiency. Nurse presence is positively correlated with triage performance in the center, as the availability of nurse resources allows specialists to delegate roles, and triage can be utilized. The presence of a dedicated nurse and the utilization of triage has a positive correlation of around 71%. The presence of dedicated nurses also affects the number of patients who come to their visits with a completed diary. This further stresses the central role that nurses play in the education and support of their patients.

Findings from an OECD study [20] showed that more than 75% of doctors and nurses were over-skilled for their job tasks. Although the nurse is an important HCP in headache patient management, our data suggest that potential delegation to nurses was not fully leveraged. The long waiting lists may be reduced by delegation of activities to nurses, thereby increasing

specialists' capacity to treat patients. Most centers have suboptimal task delegation to the nurse, and they burden specialists with tasks that could be completed by nurses, or reduce or remove some of their core activities (e.g. patient education and triage). In a pilot study [21], nurse practitioners developed a comprehensive treatment plan for individuals with migraine that improved patient satisfaction and reduced overall health care utilization. Results from a non-randomized controlled prospective study [22] of patients with migraine showed that a headache nurse supervised by general practitioners in primary care resulted in fewer referrals to the neurologist. Globally, there was a significant difference between the average level of delegation and the maximum level available, meaning there is potential for improvement in the nurse's role in headache patient management across all countries in the sample. A digital solution could improve patient management and transform the hospital patient experience, for instance, by engaging patients during the wait time (active waiting) and reducing visit time by completing patient history and questionnaires (digital nurse).

Limitations and Implications for Further Studies

There are limitations inherent in this study. The differences in the waiting lists were site-specific and were due to heterogeneity among sites, leading to the need for optimized migraine management. First, although the sample was larger than that of the parent study [13], it was still relatively limited in some countries. Although some countries (e.g. Thailand and Pakistan) were well represented and the results were statistically reliable, others (e.g. Colombia and Switzerland) had a limited sample size. Second, the inclusion of centers and countries within the sample was not based on statistical considerations. Third, practices may limit the generalizability of the results, as they may not be representative of a country's practices, and the results in selected countries may not be directly applicable to other countries. Fourth, in a survey-based study, self-assessment biases in

data collection are implicit. More robust data and additional insights could be obtained by combining survey results with analyses of databases internal to centers. Finally, single responder bias is present in the analysis. Only one HCP was contacted in each center, and it was not possible to factor out inconsistencies in the information collected.

CONCLUSION

This extension study in a larger sample confirmed issues relating to access to specialized centers for headache patients, and the importance of dedicated clinics in the management of patients with headache. The study confirmed the differences across archetypes in terms of patient pool (CM versus EM), waiting list, level of delegation to the nurse, patient education, and patient compliance, and it provides support for the potential benefit of dedicated clinical settings for headache patients. Moreover, it highlights the potential role of nurses in performing patient education and waiting list prioritization, and the consequent benefit in center efficiency.

ACKNOWLEDGEMENTS

We thank the participants of the study.

Funding. The study and Rapid Service Fee were funded by Novartis Pharma AG, Basel, Switzerland.

Authorship. All authors had full access to all of the data in this study and take complete responsibility for the integrity of the data and accuracy of the data analysis. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

Medical Writing and Other Editorial Support. Editorial assistance for this article was provided by K. Ananda Krishna, PhD (Novartis

Healthcare Pvt Ltd, Hyderabad, India) and was funded by Novartis Pharma AG, Basel, Switzerland. The authors acknowledge HCPs who took part in the survey.

Disclosures. Siriporn Wongsiriroj is an employee of Novartis (Thailand) Limited. Elisabetta Grillo is an employee of Novartis Farma S.p.A. Sabrina Levi was an employee of Novartis Argentina S.A. at the time the study was performed. Ronald Zielman is an employee of Novartis Pharma B.V. Matias Ferraris is an employee of Novartis Pharma AG. Elia Lahouiri, Marco Marchina, and Marco Pedrazzoli are employees of LifeSciences Consultants.

Compliance with Ethical Guidelines. This article involves an assessment of interview questionnaires and does not contain any studies with human or animal subjects performed by any of the authors. All participating countries confirmed no ethical considerations for this survey, as no research in humans was involved.

Data Availability. The data sets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Open Access. This article is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License, which permits any non-commercial use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

- World Health Organization. Atlas of headache disorders and resources in the world. 2011. URL: https://www.who.int/mental_health/management/who_atlas_headache_disorders.pdf. Accessed Oct 1, 2019
- Steiner TJ, Stovner LJ, Birbeck GL. Migraine: the seventh disabling. *J Headache Pain*. 2013;14(1):1.
- Silberstein SD. Considerations for management of migraine symptoms in the primary care setting. *Postgrad Med*. 2016;128(5):523–37.
- Steiner TJ, Antonaci F, Jensen R, Lainez MJ, Lanteri-Minet M, Valade D. European Headache Federation; Global Campaign against Headache. Recommendations for headache service organisation and delivery in Europe. *J Headache Pain*. 2011;12(4):419–26.
- Novartis Q3 and 9M 2019 Condensed Interim Financial Report—Supplementary Data. <https://ml-eu.globenewswire.com/Resource/download/54b44cbc-188b-48a6-bf59-7a844c1bcd87/>. Accessed Nov 30, 2019.
- Steiner TJ, Göbel H, Jensen R, Lampl C, Paemeleire K, Linde M, Braschinsky M, Mitsikostas D, Gil-Gouveia R, Katsarava Z. European Headache Federation and Lifting The Burden: the Global Campaign against Headache. Headache service quality: the role of specialized headache centres within structured headache services, and suggested standards and criteria as centres of excellence. *Headache Pain*. 2019;20(1):24.
- Schramm S, Uluduz D, Gouveia RG, Jensen R, Siva A, Uygunoglu U, Gvantsa G, Mania M, Braschinsky M, Filatova E, Latysheva N, Osipova V, Skorobogatikh K, Azimova J, Straube A, Eren OE, Martelletti P, De Angelis V, Negro A, Linde M, Hagen K, Radojicic A, Zidverc-Trajkovic J, Podgorac A, Paemeleire K, De Pue A, Lampl C, Steiner TJ, Katsarava Z. Headache service quality: evaluation of quality indicators in 14 specialist-care centres. *J Headache Pain*. 2016;17(1):111.
- Pellesi L, Benemei S, Favoni V, Lupi C, Mampreso E, Negro A, Paolucci M, Steiner TJ, Ulivi M, Cevoli S, Guerzoni S. Quality indicators in headache care: an implementation study in six Italian specialist-care centres. *J Headache Pain*. 2017;18(1):55.
- Katsarava Z, Mania M, Lampl C, Herberhold J, Steiner TJ. Poor medical care for people with migraine in Europe—evidence from the Eurolight study. *J Headache Pain*. 2018;19(1):10.
- Gaul C, Visscher CM, Bhola R, Sorbi MJ, Galli F, Rasmussen AV, et al. Team players against headache: multidisciplinary treatment of primary headaches and medication overuse headache. *J Headache Pain*. 2011;12(5):511–9.
- Jensen RH, Rasmussen A. Multidisciplinary team approach to headache care. *Clin Pract*. 2012;9(2):181–8.
- Cady R, Farmer K, Beach ME, Tarrasch J. Nurse-based education: an office-based comparative model for education of migraine patients. *Headache*. 2008;48(4):564–9.
- Kainth P, Murphy N, Rossi S, Talabardon JN, Pedrazzoli M, Mascagni L, et al. Management of migraine and the accessibility of specialist care—findings from a multi-national assessment of 28 healthcare networks. *Eur Neurol Rev*. 2018;13(2):103–10.
- Headache Classification Committee of the International Headache Society (IHS). The International Classification of Headache Disorders. *Cephalalgia* 2018; 38:1–211.
- Dodick DW, Loder EW, Manack Adams A, Buse DC, Fanning KM, Reed ML, et al. Assessing barriers to chronic migraine consultation, diagnosis, and treatment: results from the Chronic Migraine Epidemiology and Outcomes (CaMEO) Study. *Headache*. 2016;56:821–34.
- Canadian Medical Association 2018. Available from: <https://www.cma.ca/sites/default/files/2019-01/neurology-e.pdf>. Accessed Nov 6, 2019
- Neurology 2016 Factsheet. <https://hwd.health.gov.au/webapi/customer/documents/factsheets/2016/Neurology.pdf>. Accessed Nov 6, 2019
- <https://www.pkegroup.it/html/blog/quanti-sono-i-neurologi-in-italia.asp>. Accessed Nov 19, 2019
- https://www.bundesaerztekammer.de/fileadmin/user_upload/downloads/pdf-Ordner/Statistik2016/Stat16AbbTab.pdf. Accessed Nov 19, 2019
- Colombo F. Health workforce policies: right jobs, right skills, in the right places: The 6th International Jerusalem Conference on Health Policy. 2016. Available at: www.oecd.org/health/health-systems/Health-workforce-policies-Colombo-May2016.pdf. Accessed Oct 1, 2019

Blumenfeld A, Tischio M. Centre of excellence for headache care: group model at Kaiser Permanente. *Headache*. 2003;43:431–40.

22. Veenstra P, Kollen BJ, de Jong G, Baarveld F, van den Berg JP. Nurses improve migraine management in primary care. *Cephalalgia*. 2016;36(8):772–8.