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Overview of migraine care, impact of the disease, and patient experience in France through patient voices: a cross-sectional and participatory survey study

Anne Duburcq¹, Manon Molins², Sabine Debremaeker³, Julie Joie³, Luna Lopes¹, Camille Nevoret¹ and Olivia Begasse de Dhaem^{4,5,6*}

Abstract

Background This study aims to improve the understanding of the patient journey via the perspectives of patients with migraine.

Methods The questionnaire was created by patients. It was based on the experiences of 24 patients with migraine and 4 members of the patient advocacy organization *La Voix des Migraineux*. Two focus groups were held to assess the various dimensions of the patient journey. This survey was accessible on the *MoiPatient* online platform between March 19th and May 17th, 2022.

Results Out of the 683 participants (average age: 41.8 years; female: 92.4%; average age at first migraine attack: 16.2 years), 95.9% had received a formal migraine diagnosis from a physician. Migraine had a significant impact on most participants (96.0% had a severe HIT-6 score and 70.7% had severe disability on the MIDAS). Unmet patients' needs highlighted in this study included diagnosis delay (mean 7.5 years), treatment delay, limited access to neurologists and/or headache specialists, long trial-and-error process of different medications (participants had tried an average of 5.6 acute treatments and 5.0 preventive treatments), numerous (7.2 side effects per participants on average) and often inadequately addressed side effects, suboptimal patient education, and the need for a therapeutic, empathic, and supportive relationship between patients and healthcare professionals. Participants had a negative perception of the care journey and experience with healthcare professionals: 36.2% described their care journey as an uphill battle ("parcours du combatant"). More than half of patients did not feel heard nor supported by healthcare professionals.

Conclusion Patients with migraine have to face a multitude of complex obstacles trying to get the care they deserve. The burden of disease is amplified by the complexity of the migraine patient's journey, both in terms of diagnosis and treatment. This study highlights specific areas in need for improvement.

Keywords Patient journey mapping, Lived experience, Headache disorders, Advocacy, Care journey, Treatment

*Correspondence: Olivia Begasse de Dhaem begassededhaem@gmail.com

Full list of author information is available at the end of the article



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Background

Migraine is the second leading cause of disability in the world [1, 2]. Migraine has a global prevalence of 14% and affects more than 10 million people in France [3]. Migraine accounts for 4.9% of global population ill health quantified in years lived with disability (YLDs) [3]. Chronic migraine has a global prevalence of 1 to 2% and affects almost 1.4 million French people [4]. Yet, migraine remains underdiagnosed and undertreated, and the migraine-related disability has not improved over time [5–8].

Studies on the migraine care journey have historically been initiated and designed by health care professionals and/or treatment manufacturers. The latest study conducted in France about the care journey of patients with migraine, FRAMIG III, was published in 2004 and conducted at the initiative of health care professionals and public authorities [9, 10]. Out of 10,532 participants interviewed over the phone, 1,179 (21.3%) had migraine. It showed that migraine management was suboptimal for 80% of patients. Its results emphasized the need for adequate medical consultations and patient education to promote patients' autonomy and empowerment. The Additional file 1 describes the French healthcare system as it relates to migraine care. Now that 20 years have passed since the FRAMIG III study, our study aims to evaluate whether the objectives stated in the FRAMIG III study (improved medical consultations, patient education, patients' autonomy and empowerment) were met from the patients' perspective. Patients' needs, concerns, and perspectives are not necessarily identical to those of the healthcare professionals. This study is novel as it was completely initiated and designed solely by patients to avoid any potential bias from prior studies, healthcare professionals, manufacturers, and policy makers. Evaluating the patients' own perceptions of their overall care throughout the course of their illness is the first step to identify areas of improvement in the delivery of care. This study aims to assess the journey to diagnosis and care of people living with severe migraine, to evaluate the impact on their quality of life, and to improve knowledge regarding their experiences of their disease and its management.

Methods

Survey design, measurements, and outcomes

The protocol of this cross-sectional study and the survey were ethically approved by the MoiPatient Scientific Advisory Board on Patients' Best Interests (Le Conseil Scientifique d'Intérêt des Patients or CSIP) [11]. The CSIP is made up of health care professionals; researchers and methodologists; specialists in digital health, health economics and digital ethics; and patients, relatives and carers.

Twenty-four patients with migraine and 4 methodologists collaborated to create a cross-sectional survey under the leadership and guidance of *La Voix des Migraineux*, the French patient advocacy organization for people with headache disorders. To design the survey, two focus groups took place in October and November 2021; 28 patients (3 male / 25 female; living in France and La Réunion) gathered to share their experiences and visions on their health care journey, including problems encountered before diagnosis, during diagnosis, and during disease management. During these focus groups, 11 themes were selected for the survey. The survey was created by patients and *La Voix des Migraineux* with support from *CEmka* and *MoiPatient*. It was composed of a series of 86 questions to collect data on:

- demographic and health parameters (such as age, sex, familial status, place of residency, education level, main activity, current or past occupation, family history, comorbidities, disability situations).
- migraine-related clinical characteristics (type of migraine, type of attacks, frequency and duration, age of onset, characteristics of migraine over specific time frame).
- level of knowledge about the disease.
- migraine burden (in multiple domains such as pain, regular daily activities, and work).
- healthcare journey (diagnosis, migraine management, professionals consulted (type, frequency...)).
- access to information.
- acute and/or preventive treatments received (type, frequency, efficacy, side effects, drug abuse, information, compliance) including nonpharmacological approaches.
- patient-healthcare professional relationships and overall impressions.

The migraine-related disability was assessed using:

- HIT-6 [12], which is a validated scale to assess the impact of migraine through 6 items assessing the severity of pain during attacks, the incapacitating nature of attacks (desire to lie down and inability to carry out daily activities), and the impact of migraine on various aspects (fatigue, feelings, work capacity). Score < 55: slight or moderate impact; \geq 55: significant to major impact.
- MIDAS [13], which is a validated scale to evaluate migraine-related disability, the unproductive days, and the days with reduced productivity over the 3 last months.

The questionnaire was constructed with methodological assistance from *Cemka* and piloted by the participants of the focus-groups. It was then submitted for proofreading to the President of the French Society for the Study of Migraines and Headaches (SFEMC). Finally, it has been validated the *MoiPatient* Scientific Advisory Board on Patients' Best Interests.

The survey is available in its original version in the Additional file 2 and translated in the Additional file 3.

Target population and survey dissemination

Inclusion criteria included adults aged ≥ 18 years who self-reported living with migraine. The survey was promoted *via La Voix des Migraineux* newsletter (500 subscribers) and social media channels (12,000 followers). It was also promoted *via* a migraine diary application entitled *Apomigraine* and a patient information platform entitled *Mapatho*. The survey was available online on the platform *MoiPatient*, which is a digital platform created by and for patient associations and a trusted third-party used by *La Voix des Migraineux*. The *MoiPatient* administrative board can solely be composed of patient associations. This platform collects the experiences of patients with different illnesses to enhance research and to create new indicators on health centres.

Data was collected by *MoiPatient* between March 19th and May 17th 2022 on a secure and approved health data host, ClaraNet, in compliance with the privacy standards and laws. To be able to access the survey, participants had to validate an activation link sent to them via email, which enabled them to provide consent for participation in the study.

Sample size

Using the formula for sample size calculation in a simple random sample with a Z score of 1.96 for 95% confidence level, margin of error 0.05, proportion of the population 0.14, the sample size needed is 185. Since two prior surveys recently done in France among people living with migraine had 660 participants [14] and 741 participants [15], our targeted sample size was at least 600 participants.

Statistical analysis

CEmka, a healthcare and research consulting agency, was commissioned to conduct statistical analysis of the data.

The statistical analyses were descriptive and performed with SAS[®] software (version 9.4, SAS[®] Institute Inc., Cary, NC, USA). They included a complete analysis of all survey items, on all participants, and were completed by cross-analyses according to the main demographic characteristics of the participants.

Quantitative variables were described using the following statistics: mean, standard deviations, t-tests, and ANOVA in case of normal distribution, and median, quartiles, and Mann-Whiney U in case of variables that are not normally distributed. Categorical variables were described using size and percentage of each category calculated on the expressed responses and compared using chi-squared test. All analyses were run in aggregate and no individual-level analysis was conducted.

Results

General characteristics of participants

Out of the 683 participants, only 5 (0.73%) provided surveys with missing data. Participants were on average 41.8 years old (SD 11.4). Most (631, 92.4%) were female, 49 (7.2%) were male, and 3 (0.4%) were nonbinary. The geographical distribution of participants was diverse within France and all regions were represented (Fig. 1). Most participants (500, 73.2%) lived with a partner, and 358 (52.5%) had children. Most participants (484, 70.9%) were employed, 70 (10.2%) were students or unpaid interns, 27 (4.0%) were homemakers, 40 (5.9%) were unemployed, and 11 (1.6%) were retired or pre-retired. Most (501, 73.5%) participants had a family history of migraine.

38 participants (5.6%) had a disabled allowance (Allocation aux Adultes Handicapés and/or Pension d'invalidité de la Securité Sociale,) consisting in a financial support linked to difficulties to work. 51 (7.5%) had the long-term illness status (Affection Longue Durée) meaning a better reimbursement for migraine-related care.

97 (14.3%) had the recognition of disabled worker status (Reconnaissance de la Qualité de Travailleur Handicapé) allowing the employee to benefit from a set of measures to access a job, keep it or consider a new job. (See Additional file 1 for more information about French disability status.)

Migraine-related clinical characteristics

Among the 683 participants, 654 (95.9%) received a formal migraine diagnosis from a physician. Average age at first migraine attack was 16.2 years (SD 8.6). For 118 (21.0%) of women, the first migraine attack occurred at the same time as their first period (12.9 years; SD 1.7).

Over the last 3 months, 415 (60.9%) participants had migraine without aura, 186 (27.3%) had migraine with aura, and 81 (11.9%) had both. No definition of aura was specified in the questionnaire (question 14 in Additional files 2 and 3). Regarding monthly migraine days (MMDs), 190 (27.9%) participants had 1 to 7 MMDs, 246 (36.1%) had 8 to 14 MMDs, and 246 (36.1%) had at least 15 MMDs. Regarding the intensity of migraine attacks, 4.3% (N=29) were mild, 51.3% (N=350) were moderate, and 44.4% (N=303) were severe.

While 271 (76.3%) women described less intense pain during pregnancy and 279 (79.0%) had less frequent migraine attacks during pregnancy, about two third



Fig. 1 Geographical distribution of participants by regions in France. Number and percentage of participants

of women (631 (66.3%)) felt that they did not receive adequate migraine care during pregnancy. The perimenopausal transition was associated with an increased migraine burden. Out of 83 (41.3%) post-menopausal women, 43 (51.8%) experienced more intense pain and 45 (54.2%) felt that migraine attacks were more frequent.

Comorbidities

The main psychiatric comorbidities reported by the participants included: depression (218, 31.9%), anxiety disorders (189, 27.7%), sleep disorders (179, 26.2%), and suicidal ideation (56, 8.2%), respectively diagnosed after the diagnosis of the migraine in 73.0%, 63.3%, 67.0%, and 80.0% of cases. 26.5% of patients with depression (26,1% of patients with anxiety disorder and 24,3% of patients with sleep disorders, respectively) thought that depression (anxiety disorders and sleep disorders respectively) has negatively impacted the migraine management. (See the question number 62 in Additional files 2 and 3)

Migraine impact

The mean HIT-6 score was of 67.4 (SD 5.8). Out of 682 participants, 3 (0.7%) had headaches with little or no impact, 22 (3.2%) had a moderate impact, 24 (3.5%) had an important impact, and 632 (92.5%) had a severe impact. The mean MIDAS score was 71.5 (SD 80.4).

Out of the 680 (99.6%) participants who completed the MIDAS, 83 (12.2%) had no or little disability (Grade I), 32 (4.7%) had mild disability (Grade II), 85 (12.4%) had moderate disability (Grade III), and 483 (70.7%) had severe disability (Grade IV, lack of productivity during at least 21 days over the last 3 months). On average in the last 3 months, participants missed 8.6 (Q_2 1; IQR 0–7) days of work or school, they had 16.9 (Q_2 10; IQR 3–20) days with at least 50% reduced productivity due to the symptoms of their disease, they missed 16.0 (Q_2 10; IQR 3–20) days of housework and missed 14.8 (Q_2 7; IQR 3–20) days of family, social, or leisure activities.

The migraine care journey

Diagnosis

The migraine diagnosis was received on average at the age of 23.6 years old (SD 10). Diagnostic delay (time lag between onset of migraine symptoms and diagnosis) was 7.5 years (Q₂ 21; IQR 17–30). Out of the 654 (95.9%) participants who received a diagnosis of migraine from a physician, 337 (51.5%) received it from a GP, 277 (42.4%) from a neurologist, 18 (2.8%) from a pain center physician, and 5 (0.8%) from a pediatrician. The main reasons for seeking medical advice were "the frequency of migraine attacks" (543, 83.0% of participants), "the difficulty to manage migraine attacks" (434, 66.5%), and "the worsening of migraine pain" (404, 61.8%). Participants consulted 2.7 (Q_2 2; IQR 1–3) healthcare professionals before receiving a diagnosis of migraine. Participants' territory type (rural, semi-rural, or urban) was not associated with diagnostic delay.

Migraine follow-up over the last 12 months

Most participants (626, 92.1%) had at least one clinical follow-up for migraine over the last year. The 3 most common specialties for these visits were GP (518 participants, 82.7%), neurologists (449, 71.7%), and osteopathic practitioners (327, 52.2%). Other specialties visited included physical therapists (186, 29.7%), psychiatrists or

Table 1 Professionals consulted over the last 12 months

psychologists (146, 23.3%), pain specialists (145, 23.2%), acupuncturists (127, 20.3%), meditation professionals (67, 10.7%), and sport medicine specialists (21, 3.4%).

Nearly a third of participants who had consulted a healthcare professional for migraine over the last year (190, 30.3%) did not see a neurologist. The most common reasons were the excessive wait time to see a neurologist to the point that they had given up seeing one (49 participants, 33.6%) and the absence of neurologist specialized in migraine in their geographic area (33, 22.6%). The time between follow-up appointments was between 3 and 6 months for 190 (42.3%) participants. The mean duration of an appointment was 25.4 min (SD 12.5).

145 participants (23.2%) had had a consultation at a specialized center for the study and the treatment of pain.

About half of participants (355, 53.5%) considered their physician to be very/somewhat available for emergencies. Table 1 lists the types of professionals consulted over the last 12 months Between 66.7% and 92.3% of professionals were attentive to possible pain or side effects of treatments (medications, procedures or other), particularly osteopaths (92.3%), acupuncturists (88.9%), and meditation practitioners (88.1%). Follow-ups were deemed most helpful with the neurologist, psychologist/psychotherapist, and pain centers (Table 1, question 63 in Additional files 2 and 3).

Each patient had consulted an average of 3.3 (SD 1.7) different kinds of healthcare professionals for the management of their migraine over the last 12 months, 1.8 (SD 0.7) different kinds of physicians with prescription capacity (such as neurologist or general practitioner) and 1.5 (SD 1.4) different kinds of health care professionals (such as psychologist or acupuncturist). This number significatively differs depending on migraine frequency (p-value = 0.022) (Fig. 2). Indeed, the annual number of different healthcare professionals consulted was on average 2.9 (SD 1.6) for patients with 1–7 MMDs, 3.2 (SD

Professionals consulted in the last 12 months	Consulted following recommenda- tions from a professional	Able to listen to complaints of pain and of possible side effects	Follow-up considered as effective or rather effective
GP	70 (13.6%)	413 (80.4%)	281 (54.6%)
Neurologist	333 (74.5%)	375 (83.5%)	292 (65.5%)
Osteopath	161 (49.8%)	301 (92.3%)	178 (54.4%)
Physiotherapist	146 (79.3%)	28 (75.7%)	10 (35.7%)
Psychologist/ psychotherapist	94 (64.4%)	165 (88.7%)	110 (59.5%)
Pain center	118 (81.9%)	120 (82.8%)	85 (58.6%)
Acupuncturist	58 (45.7%)	112 (88.9%)	47 (37.9%)
Other	37 (40.2%)	87 (93.5%)	61 (66.3%)
Meditation professional	39 (58.2%)	59 (88.1%)	36 (53.7%)
Sports professional	13 (61.9%)	14 (66.7%)	12 (60.0%)



Fig. 2 Number of different kinds of healthcare professionals consulted over the last 12 months according to the number of attacks per month

1.7) for patients with 8-14 MMDs, and 3.7 (SD 1.8) for patients with at least 15 MMDs (p-value = 0.0004).

Among the 54 participants (7.9%) who did not see a healthcare professional for migraine over the 12 last months, the most common reasons for not following up included (1) never having had clinical follow-ups for migraine (22 participants, 40.7%), (2) giving up on the follow-ups (13, 24.1%), (3) not having energy anymore to seek follow-ups (12, 22.2%), (4) not requiring active follow-ups due to amelioration of the disease with or without an effective treatment (7, 13.0%), (5) not having the means anymore to be able to follow-up (4, 7.4%).

Treatment

Respectively, 655 (97.0%) and 675 (99.0%) participants had taken at least one treatment over the last 3 and 12 months. Most (413, 61.2% and 598, 87.7%) took both acute and preventive treatments, 229 (33.9%) and 73 (10.7%) took only acute treatments, and 13 (1.9%) and 4 (0.6%) was on preventive treatment exclusively. More than a third of participants (289, 43.1%) experienced medication overuse with an acute treatment.

Among the 671 (98.4%) of participants who took acute treatments, migraine attacks stopped within 2 h in half the cases (317, 49.4%), whereas in the absence of treatment 21 (75.0%) the attack lasted more than 12 h. The first acute treatment was taken on average 7 (Q_2 5; IQR 1–11) years after the first migraine attack and at the age of 23 years old (SD 9.5). It was generally taken about 6 months before the diagnosis.

Oral triptans were the most taken acute treatments (538 participants, 83.8%) followed by two Nonsteroidal Anti-Inflammatory Drugs (NSAIDs), ketoprofen taken by 232 participants (36.1%), and ibuprofen taken by 192

participants (29.9%). There were followed by acetaminophen, opioids, and aspirin (Fig. 3).

Participants had tried 5.6 (SD 4.2) different acute treatments and an average of 5.0 (SD 4.0) different preventive treatments. Respectively, over the 3 and 12 last months, 426 (71.0%) and 602 (88.3%) participants had taken at least one preventive treatment.

Only 87 (12.9%) of the participants never had side effects to migraine treatment, 62 (9.2%) rarely, 174 (25.9%) sometimes, and 275 (40.9%) often. The number of side effects over the last year is shown in Fig. 4. Out of the 586 (87.1%) of participants who had side effects, the mean number of different side effects was 7.2 (SD 3.9).

The most common side effects were concentration difficulties, memory difficulties, digestive problems, and sleep disorders (Fig. 5).

Some of the participants changed doses and/or discontinued their treatment on their own. The proportions and the reasons given are listed in Table 2.

Out of the 3,662 self-reported side effects, 2,330 (63.63%) were discussed with a physician and the association between the side effect and the treatment was confirmed in 1,490 (40.7%) cases. All side effects combined, participants felt that their reporting of side effects were adequately addressed by their healthcare professional in 304 (8.30%) cases. Some side effects (such as migraine worsening, sleep disorders, and weight gain) were easier for patients to report to healthcare professionals than others (such as anger/irritability). Participants also felt that some side effects (such as digestive issues) were more easily addressed by healthcare professionals than others (such as migraine worsening or weight gain).



Fig. 3 Acute treatments used during attacks by the participants



Fig. 4 Number of side effects due to migraine treatment over the year

499 (73.4%) of the participants said they had not used any non-medication treatments. Among other participants, some reported using:

- transcutaneous electrical neurostimulation (TENS) (105, 15.4%), of which 16 (15.4%) were satisfied or very satisfied, and 67 (64.5%) were dissatisfied or very dissatisfied.
- CEFALY (91, 13.4%), of which 16 (17.6%) were satisfied or very satisfied, and 62 (68.2%) were dissatisfied or very dissatisfied.

Patient education

At the time of diagnosis, 367 (56.1%) patients received information about migraine; for 252 of them (68.7%) this information was clear and sufficient to understand the



Fig. 5 Migraine treatment side effects in the last 12 months

Table 2 Treatment adherence in their lifetim	٦e
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	Acute treatment	Preventive treatment
Number of treatments already tested (lifetime)	5.6 (SD 4.2)	5.0 (SD 4.0)
Number of participants who changed the treatment dose themselves	260 (38.5%)	183 (30.4%)
Number of participants who discontinued the treatment themselves	257 (38.1%)	361 (60.0%)
Main reasons for changing doses	Lack of treatment efficacy: 224 (87.2%) Side effects: 113 (44.0%)	Side effects: 138 (75.4%) Lack of treatment efficacy: 112 (61.2%)
Main reasons for discontinuing	Lack of treatment efficacy: 194 (76.1%) Side effects: 177 (69.4%)	Side effects: 293 (81.4%) Lack of treatment efficacy: 272 (75.6%)
Number of patients informing their care teams of the dose modifications / discontinuation	 203 (79.6%) for the dose modification 212 (85.1%) for the discontinuation	 153 (85.5%) for the dose modification 312 (88.9%) for the discontinuation

Table 3 Proportion of healthcare professionals providing migraine patient education at the time of diagnosis

	GP	Neurologist	Pain center physician	Pediatrician	Other
Migraine education provided	151 (44.8%)	194 (70.0%)	14 (77.8%)	3 (60.0%)	5 (29.4%)

diagnosis. A significant difference was observed according to the physician consulted (Table 3).

About two third of participants (457, 67.0%) felt that they had enough information about their treatment plan (such as maximum number of acute treatments and number of trial weeks for the preventive treatment to possibly reach its effectiveness), 482 (70.7%) about lifestyle habits that could help mitigate migraine attacks, 313 (45.9%) about potential side effects.

When asked to rank 10 possible sources of migraine information in terms of importance to them, personal search came first followed by neurologists (Fig. 6).

Relationships between patients and healthcare professionals and shared medical decision-making

Participants overall had negative feelings about their care and their relationships with healthcare professionals. More than half of participants felt the healthcare professional did not listen to them (364, 53.6%), nearly half did not feel they received any support from their healthcare professional (332, 48.8%), and the majority did not receive guidance from their healthcare professionals (550, 80.9%). On average, they rated the understanding and support of healthcare professionals at 6.1 (SD 2.5) on a scale of 1 to 10 (10 corresponding to the highest



Fig. 6 Mean score of source information importance. 10 possible sources of information about migraine were proposed to the participants, who were asking to rank the sources from the less important source to the most one

Most of the doctors I have met are not closed to new treatments.	10.8	8%	35.1	1%	22.7%	6 <mark>22.2</mark>	.% <mark>9.3%</mark>
In general, healthcare professionals take into account my overall state of health when providing clinical follow-up for my migraines.	10.3	<mark>8%</mark>	36.6	5%	<mark>5</mark> .3%	33.1%	14.6%
Generally speaking, healthcare professionals are kind to their migraine patients.	10.1	%	39.	7%	8.2%	32.1%	9.9%
Most of the doctors I have met are well-informed about migraine.	4 <mark>.0%</mark>	18.5%	<mark>3.1%</mark>		51.9%		22.5%
Generally speaking, doctors have no difficulty adapting to each migraine patient.	5 <mark>.1%</mark>	27.	5%	7.8%	42.	.4%	17.2%
	0.0%	20	.0%	40.0%	60.0	1% 80.0)% 100.0 ⁰
Strongly agree Agree No c	opinior	D D	isagre	e 📕 St	rongly dis	agree	

Fig. 7 Patient-healthcare professional relationship. Participants' level of agreement with the different proposed statements

satisfaction score). 120 (17.6%) of participants had a score between 1 and 3, 229 (33.5%) between 4 and 6, and 334 (48.9%) between 7 and 10. Figures 7 and 8 show the level of participants' agreement regarding the understanding and support of healthcare professionals when coping with migraine.

The monthly migraine days over the last 3 months was higher in participants feeling that their healthcare professionals were not treating them properly: 27.5% of participants feeling that their healthcare professionals were treating them properly had at least 15 MMDs

compared to 46.3% of participants feeling that their healthcare professionals were not treating them properly (p-value = 0.0370). Acute treatment self-discontinuation was also more frequent in participants with lower satisfaction: 47.4% for those with a satisfaction score of 0 to 3 vs. 41.0% for those with a score of 4 to 6, and 32.8% with a score of 7 to 10 (p-value = 0.0054). Participants with lower satisfaction were also less likely to inform their healthcare professionals about their medication self-discontinuation: 73.1% for those with a score of 4 to 6, and 300 score of 0 to 3, vs. 84.6% for those with a score of 4 to 6, and 300 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 300 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 0 to 5, vs. 84.6% for those with a score of 4 to 6, and 500 score of 6 to 6 to 500 score of 6 to 6, and 500 score of 6 to 6 to 500 score of 6 to 6 to 500 score of 6 to 6 to 500 score of 6 to 500 score of 6 to 6 to 500 score of 6 to 500 score of



Fig. 8 Shared medical decision-making. Participants were invited to assess the situations lived during their experience as a patient with migraine, that they have come across with one or more healthcare professionals

Table 4Ranking of expressions defining the overall patientexperience

The obstacle course / uphill battle	246 (36.2%)
Quest for the Grail	143 (21.1%)
Abandonment, loneliness	97 (14.3%)
Complex, tortuous	59 (8.7%)
Caring support	38 (5.6%)
Difficult to access	35 (5.2%)
Норе	30 (4.4%)
Coordinated, effective support	17 (2.5%)

91.5% for those with a score of 7 to 10 (p-value = 0.0091). Participants' satisfaction was also associated with taking treatment (acute or preventive) in accordance with the physician's recommendations: 75.0% of participants with a satisfaction score of 0 to 3 followed the physician's recommendations vs. 82.4% with a score of 4 to 6, and 90.1% with a score of 7 to 10 (p-value = 0.0002). The frequency of migraine medication side effects was also associated with participants' satisfaction: 43.6% of participants with a satisfaction score of 0 to 3 had frequent side effects vs. 43.7% of participants with a score of 7 to 10 (p-value = 0.0445).

Most participants (85.5%) have had to navigate a challenging and difficult journey to get medical care. Table 4 lists the expressions used by participants to define their overall experience with migraine care.

Discussion

A survey on patients' lived experience completely designed by patients

To our knowledge, this is the first study on the migraine care journey completely run by patients to be published in medical literature. Because of all the necessary steps to publish in the scientific literature (such as ethical approval, consent, secure platform to collect health data, methodology, and statistical analysis), most of the patient-led surveys remain in the grey literature. La Voix de Migraineux, the French patient advocacy organization for people with headache disorders, designed the survey based on feedback they received from patients and from the results of two patient focus groups. Independent methodological, statistical, and scientific writing help was only solicited to ensure compliance with ethical, privacy, methodological, and scientific standards to be able to share the patients' lived experience in the scientific literature. The authors hope that this study will serve as a blueprint for other patient advocacy organizations to overcome the barriers to publishing in the scientific literature and making their voices heard.

Migraine impact

This is a survey study of people with moderate or severe migraine, and/or with more than 8 MMD's. Hence, most participants had severe disability scores. Regarding the impact on people's ability to work, despite more than two thirds (70.7%) of participants with severe disability according to the MIDAS, 70.9% of participants were employed and only 5.9% were unemployed. Consistent with prior studies [6], participants with prioritized their work over other aspects of their lives (housework and family/social lives).

Migraine care journey Overall impression of care

Most participants (85.5%) have had to navigate a challenging, long, painful, and difficult journey to get medical care. This study identified barriers to care similar to the ones listed in the CaMEO-I survey: only 11.5% (955/8,330) of participants were able to traverse the 3 barriers of (1) consulting a healthcare professional for headache, (2) receiving an accurate diagnosis, and (3) and receiving appropriate pharmacologic treatment [22]. This study sheds light on the migraine care journey from the patients' perspective in France to identify specific areas for improvement and hopefully encourage interventions and systemic changes for better and more compassionate, effective, and equitable care.

Diagnosis and treatment delays

It took an average of 7.5 years and consultations with an average of 2.7 healthcare professionals between first migraine symptoms and diagnosis. The European Migraine and Headache Alliance survey found comparable delays; the most frequently reported unmet need was the long delay between the first visit and migraine diagnosis: 34% of participants had to see at least 4 specialists before being correctly diagnosed, and between the diagnosis and treatment prescription: >5 years in 40% of cases [16]. The American Migraine Study highlighted that about 56% of people with migraine are not diagnosed including 24% who consulted for it [17]. Migraine remains largely underdiagnosed and hence undertreated in France too.

Unsurprisingly, the time to first acute treatment and age at first acute treatment are consistent with the delay in diagnosis. Delay in appropriate diagnosis and care has significant consequences: it negatively impacts the quality of life as well as mental and emotional wellbeing of about 89% patients with migraine and negatively impacts the work life and career of about 72% with migraine [18]. It contributes to migraine chronification and hence a higher burden of disease [19–21].

Limited access to neurologists and specialty care

Even in this sample with significant migraine burden, most participants receive a diagnosis (51.5%) and follow-up migraine care (82.7%) from their general practitioners. It is important to note where most patients are receiving their care to help develop future interventions. In addition, since only neurologists can prescribe the newer migraine-specific medications in France, the limited access to neurologists is a significant barrier to care. Nearly a third of participants who regularly follow for their migraine had not seen a neurologist in the past year mostly due to the excessive wait time to the point they have given up on seeing one or to the absence of a neurologist specialized in headache medicine in their geographical region. Given the current barriers, some patients give up on seeking or following with neurology, and some patients do not have the energy or means to continue seeking migraine care anymore.

Treatment and side effects

Most participants were taking both acute and preventive treatment. The high proportion of participants on preventive treatment (88%) and using oral triptan (83.8%) most likely reflects the frequency and severity of the disease within this study sample, their education regarding migraine including its management principles, and their access to treatments. The high proportion of participants in this study on both acute and preventive treatment is encouraging.

However, the lived experience of the study participants highlights (1) the long trial-and-error process in finding migraine treatment that is effective and tolerated and (2) the exposure to many treatment side effects. Participants had tried on average 5.6 different acute medications and 5.0 different preventive medications. Participants experienced an average 7.2 different side effects. In addition to experiencing a high number of side effects, participants felt that the side effects they reported to healthcare professionals were adequately addressed in less than 10% of cases. It is also important to be aware that some side effects (such as migraine worsening, sleep disorders, and weight gain) are easier for patients to report to healthcare professionals than others (such as anger/irritability). Participants also felt that some side effects (such as digestive issues) were more easily addressed by healthcare professionals than others (such as migraine worsening or weight gain).

Patient education

This survey also highlights the need for healthcare professionals to provide their patients with education about the disease, treatment, and potential side effects. Patient education is not reliably provided, and when it is, it tends to be focused on potential lifestyle modifications rather than the diagnosis and treatment plan. A little more than half of participants received information about migraine at the time of diagnosis. About a third that felt they did not have enough information regarding their treatment plan and more than half did not receive information about potential treatment side effects. More than two this is for the second se

third of participants received enough information about lifestyle habits that may help mitigate migraine attacks, emphasizing the weight placed on patients' shoulders.

Patient-healthcare professional relationship

Participants did not feel adequately supported by healthcare professionals. More than half did not feel that they were heard, nearly half did not feel they received any support from their healthcare professional, about half felt that their healthcare professional was available in case of emergency, and the majority felt that they did not receive guidance from their healthcare professionals. The monthly migraine days correlated with the perceived lack of support from healthcare professionals.

Study limitations

There are several limitations that should be noted, and which are inherent to this type of studies. First, there is a risk of reporting and recall bias with using survey results in studies. Although this was a cross-sectional survey asking people with self-reported migraine to participate, the majority (95.9%) had a formal diagnosis of migraine by a physician. Of note, that the survey was confidential, diminishing the incentive to misrepresent one's reporting. Second, the survey was only available online, which may have restricted access to underserved segments of the population such as elderly, institutionalized, and those with severe comorbidities and disabilities. As the survey was distributed via newsletter and social media channels of a patient advocacy organization, the participants most likely had received education on the symptoms and diagnosis of migraine. The participants are therefore likely to be better informed about their disease than the general population. Most of the participants of this study had moderate or severe migraine and/or more than 8 MMD's, which limits the generalizability of the results to the general adult population. The survey did reach participants from all regions of France. The participants' characteristics are in line with other similar studies such as My Migraine Voice survey participants in terms of age (41.8 vs. 39.4 years) and type of migraine, and an overrepresentation of female (92.4% vs. 75%) and of family history (73.5% vs. 54%) [23]. The overrepresentation of female is found in other studies such as the recent European Migraine and Headache Alliance survey, which administered online to an adult migraine population in European countries counted 90% of females [16]. The survey asked about the number of side effects Page 12 of 14

experienced as part of the general patient experience. More specific questions on side effects such as whether they were attributed to acute or preventive medications and the number of medications they were attributed was out of scope of this study and should be addressed in further studies.

Conclusions

This study demonstrates, not only with data but also with words, the reality of the long and distressful patient journey to migraine care. The results show the complexity of the migraine patient's journey, both in terms of diagnosis and treatment, and highlight unmet needs for future interventions. Unmet patients' needs highlighted in this study included diagnosis delay, treatment delay, limited access to neurologists and/or headache specialists, long trial-and-error process of different medications, numerous and often inadequately addressed side effects, suboptimal patient education, and the need for a therapeutic, empathic, and supportive relationship between patients and healthcare professionals. More than half of participants described their migraine care journey as an uphill battle or quest for the Grail. This study highlighted unmet patients' needs. It is now time for patients, healthcare professionals, and policy makers to collaborate on interventions for a patient-centered approach to comprehensive headache care.

Abbreviations

AAH	Allocation aux Adultes Handicapés
AHDA	Alliance for Headache Disorders Advocacy
ALD	Affection Longue Durée
CaMEO	Chronic Migraine Epidemiology and Outcomes
CGRP	Calcitonin Gene-Related Peptide
CMU	Couverture Maladie Universelle
CPAM	Caisse Primaire d'Assurance Maladie
CPP	Comité de Protection des Personnes
CSIP	Conseil Scientifique d'Intérêt des Patient(e)s
GP	General Practitioner
HIT	Headache Impact Test
IQR	Interquartile Range
MIDAS	Migraine Disability Assessment
MMDs	Monthly Migraine Days
NSAID	Nonsteroidal Anti-Inflammatory Drugs
OVERCOME	ObserVational survey of the Epidemiology, tReatment and
	Care of MigrainE
PAI	Projet d'Accueil Individualisé pour raison de santé
Q ₂	Median
RQTH	Reconnaissance de la Qualité de Travailleur Handicapé
SD	Standard Deviation
TENS	Transcutaneous Electrical Neurostimulation
YLDs	Years Lived with Disability

Supplementary Information

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Supplementary Material 1	
Supplementary Material 2	

Supplementary Material 3

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Author contributions

AD, CN, LL, SD, MM, and JJ conceived and designed the study. AD, CN, and LL analyzed the data. AD, CN, LL, SD, OBD, and JJ interpreted the results and helped draft the paper. All authors read and approved the final manuscript.

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Data availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics declarations and consent for publication

This study required the informed consent of participants according to the GDPR. Participants had to confirm online their consent at the end of the study before any data was saved so as to make sure they saw all the questions and were reminded of the purpose of the data collection.

Consent for publication

All authors consent to publish the results presented here. Consent was obtained from the patient for the publication of the results of this study.

Competing interests

AD, CN, and LL are CEmka employees. MM is MoiPatient employee. JJ and SD declare no conflict of interest. OBD receives a stipend for her work as Executive Editor of the Pain Medicine journal, book royalties from Oxford University Press, and consulting fees from Pfizer. She received consulting fees from the Mable virtual neurology clinic.

Author details

¹CEmka – Healthcare Consulting and Research, 43, Boulevard du Maréchal Joffre, Bourg-La-Reine 92340, France

²MoiPatient – Participatory Research Platform, 29 Bis, Rue Buffon, Paris 75005, France

³La Voix des Migraineux – Patient Association, 7 B Impasse des Rosiers, Eragny-Sur-Oise 95610. France

⁴Department of Neurology, University of Connecticut, Farmington, CT, USA

⁵Institute for Headache and Brain Health, 1275 Summer Street Suite 306, Stamford, CT 06905, USA

⁶Global Patient Advocacy Coalition for Headache (GPACH), Brussels, Belgium

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