# New trends in understanding the burden of migraine: Semantic analysis of the voice of Russian patients – users of Web 2.0

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*Migraine is the second leading cause of disability, and the burden of migraine is determined, among other things, by its impact on work ability, social activity and family relationships.*

***Objective:** to identify the patterns of behavior of Russian patients with migraine, factors affecting their quality of life, and their level of awareness of the disease based on a semantic analysis of messages in Web 2.0.*

***Patients and methods.** The study is based on the results of semantic processing (automatic analysis of natural language texts taking into account their meaning) of anonymized posts from 6,566 patients and their caregivers from social networking websites and forums (over 73 thousand messages posted between 2010 and 2020). In addition, the study was carried out exclusively according to the data indicated in the messages. In this regard, complete data for several parameters was not available for analysis. No personal data about the authors of the messages was collected or used. The gender was determined based on the text of the analyzed message. Only open data from the Internet from social networks and forums were used for this study.*

***Results** and discussion. A landscape of problems of persons complaining of migraine issues was formed Factors affecting the quality of life (QoL) were combined in 4 main groups ("Restrictions imposed on lifestyle by triggers of migraine attacks", "Loss of work capacity", "Serious psychological problems", "Family planning issues"); additional, rarer, but acute problems were identified as well. The results show that the average number of days with migraine is 9.4 per month; 21.8% of patients report daily migraine; most of patients have been suffering from attacks for 10 years or more and 9% of patients for 30 years or more. The analysis of diagnostic patterns showed that in most cases patients seek additional examinations on their own, while only 13.1% of patients had experience of adequate preventive therapy.*

***Conclusion.** The study revealed the presence of a wide range of unmet needs, QoL problems both in patients themselves and their caregivers, as well as a significant social and economic burden of this disease (including a long-term burden on the economy, which can be used as arguments for reimbursing migraine therapy costs) based on the text of migraine-associated messages in open sources on the Internet.*

***Keywords:** migraine; migraine burden; quality of life; semantic analysis; natural language understanding technologies; Web 2.0.*

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***For reference:** Tabeeva GR, Katsarava Z, Amelin AV, et al. New in understanding the burden of migraine: semantic analysis of the voice of Russian patients P users of Web 2.0. Nevrologiya, neiropsikhiatriya, psikhosomatika = Neurology, Neuropsychiatry, Psychosomatic. 2021;13(6):73–84. DOI: 10.14412/2074-2711-2021-6-73-84*

## Introduction

Migraine is a chronic neurological disease affecting about 1 billion people worldwide (1). Overall, the prevalence of migraine is 14,4% (13,8% to 15,0%) in the general population (2). According to a large Russian epidemiological study conducted among 2,725 adult individuals from 18 to 65 years old, disease prevalence is 20.8% (3). The burden of migraine as a chronic disease is associated not only with the severity of its attacks, but is also largely determined by its impact on work capacity, social activity and family relationships (4). Migraine is the second most significant cause of disability, and it leads to more significant impairment of functional activity than all other neurological disorders (5). The Global Burden of Diseases study (GBD2019) reports that headaches are generally the first in terms of YLD parameter in the group of working-age population (15–49 years), and migraine takes the leading position on this parameter among women of working age (15–49 years) (6). At the same time, the analysis of data from recent epidemiological studies shows a steady increase in migraine cases in the population, especially among young people and school-age children (6).

It is known that the rate of visits for medical help among patients with migraine is extremely low, so most migraine patients never receive a diagnosis from professional physicians, and they practice self-diagnostics and self-treatment. Thus, according to a large population study, a French

Nationwide Population-Based Survey (FRAMIG 3) (7) conducted in France, only 60% of people with migraine have ever sought medical advice for their headache, 34% of patients underwent active follow-up by a specialist, and only 8% received treatment prescribed by a physician. About 60% of patients with migraine were not aware of having this disease, and the average time between the onset of the disease and the first consultation was 3.7 ± 5.8 years. 78.6% of the respondents had to take acute medications for every migraine attack. Of these, only 38.6% used medications recommended by their physicians, and 51.1% took medicinal products not recommended for migraine treatment (7). In general, more than 50% of patients experiencing migraine attacks never consult a doctor, and only 20% of patients have an established diagnosis of migraine (8).

Patient awareness of the disease, its course and effective strategies for behavioral therapy and pharmacological treatment remain unsatisfactory. Overall migraine awareness remains low despite its high prevalence (9). In both the US and Europe, health information is one of the most requested topics on the Internet (10). Today, many patients consider the Internet as a valuable and reliable source of health-related information, and use it before seeking professional medical attention (10). CF Mullins et al. (11) analyzed Twitter and included several relevant pain-related keywords in their search. 941 tweets from 715 authors were found within a 14-day period only. The most common keywords were headache (n = 321), migraine (n = 147), and back pain (n = 123) (11).

Studies of the use of social networks by people with migraine show that this platform has great potential to improve understanding of the disease (12, 13). This approach is not limited to formal patient reports and allows analysis of many aspects of the disease. Thus, the influence of stressful events on the course of migraine is well-known, which is reflected in user posts, but is not always detected during a routine interview with a doctor (15–17). Based on data from Google Trends search for over 12 years (from January 1, 2004 to August 15, 2016), S.M. Burns et al. (14) showed the role of several repeated social factors prompting users to search for migraine-related information. On the other hand, mentions of migraine in the media can increase interest in and awareness of this disease, and lead to an increase in the number of searches (15). From this point of view, the use of web-based technologies, such as search engines and social networks, makes it possible to detect hidden problems of social factors influence on the course of migraine.

The use of the Internet by patients suffering from chronic diseases is not limited to the search for relevant information. Patients and their caregivers visit various forums, groups on social networks, platforms for communication with doctors and leave messages there describing their condition, including symptoms, peculiarities of diagnostics and treatment, access and QoL problems. Such "patient voice" messages are a unique source of data: as compared to surveys, interviews and focus groups, in these messages there is no influence of researcher on patients; patients donXt need to answers questions in a socially approved manner and talk about what they really care about. For a number of issues, passive "listening" to patient messages (subject to user agreements of such resources, using only open sources on the Internet, analyzing only the texts of messages from authors with ensured anonymization) can form the basis for collecting objective data and real insights.

**The aim of this study** was to study the level of awareness, needs and strategies of behavior (in particular those related to diagnostics and therapy, including pharmacological treatment) of Russian migraine patients, based on their messages in open social networks and forums. The novelty of the study is associated with the application of new methods: "listening" to messages on the Internet with using techniques of artificial intelligence and deep semantic analysis of texts.

## Patients and methods

The study design presupposed the use of "patient voice" data from the Internet.

The general diagram of the study design is shown in Fig. 1. Estimates of the general population and the representative sample of patient messages from open Internet resources are based on the statistical and epidemiological data discussed below.

Patient messages were collected and analyzed in anonymized form in accordance with the requirements of the General Data Protection Regulation (GDPR; European Union Regulation 2016/679) and Federal Law No. 152-FZ "On Personal Data" of July 27, 2006. Only relevant message fragments related to the description of patient journey and experience were analyzed. This approach allows carrying out the study activities in accordance with the requirements of regulatory documents on protection of personal data and intellectual property.

In the Russian Federation, the prevalence of migraine among the working-age population aged 18 to 65 is 20.8% [3]. As of January 2021, the population of the Russian Federation numbered 145.9 million peoples; therefore 17.1 million of these peoples suffer from migraine [16]. Considering that the level of Internet penetration in Russia is 85%, and that the number of users of social networks has already reached 99 million peoples, and about 17.0% of such users are interested in health-related issues (17), we can make an upper-bound estimate of the number of users of medical social networks and forums at 16,8 million people in all nosologies, and the number of patients with all forms of migraine in social networks and forums can be estimated as 2.5–3.5 million peoples.

Considering that not all migraine patients post their messages in the social networking sites and forums where they are signed up, although one patient can have on average 5 ± 2 posts, we can expect 500 to 700 thousand patients with all forms of migraine signed up on specialized social networks and forums. At the same time, as the studies show (18), only 20% of patients visit doctors to diagnose chronic migraine. Therefore, it can be assumed that the same proportion will be observed in social networks and forums and, consequently, 140 thousand posts can be accepted as an upper-bound estimate of the general population of patients with chronic migraine in Russia presented on specialized networks and forums.

Therefore, to assess the size of the representative sample in this study the authors used AltmanXs nomogram method (19, 20). In this case, we recorded (based on previous experience and medical studies) a level of significance = 0.05, a level of credibility of the analysis results = 0.99, and a standard deviation = 0.1. Using the chosen parameters, the size of the representative sample in accordance with Altman's nomogram was about 7,000 posts.

The next step in the design of this study was to define the criteria for selecting posts. Relevant sites for carrying out crawling (collecting original messages for further processing, with their anonymization in accordance with the requirements of the GDPR and the Federal Law No. 152-FZ "On Personal Data" of July 27, 2006) and typical requests for the crawler were identified. As a first step, all messages were selected (i.e. "posts" of users ion forums and social networks, with no personal data) from open sources (i.e. indexed by search engines and available to all Internet users) containing the terms "migraine", "migrainous" and other relevant expressions, as well as their synonyms. Then all the messages were analyzed using semantic analysis techniques (i.e. "by meaning"). Based on the results of this analysis, only the messages related to migraine in the medical sense (since in Russian the word "migraine" can also be used as a metaphor) were selected. Moreover, there were the messages where proven or suspected "migraine" diagnoses were mentioned. Message authors were either patients themselves or their caregiver (this was also determined on the basis of message texts). At the same time, messages related to specific author were grouped into a single "story" based on structural features (for example, within the same discussion ("thread") on the forum).

Based on these criteria, scanning of relevant web-sites with filtering by typical search requests resulted in a representative sample of 5,319 anonymous target patients writing about migraine experience. In addition, another 1,247 people were included in the representative sample who did not directly report the diagnosis of migraine, but were members of specialized support groups for patients with migraine. In total, the overall number of patients diagnosed with migraine and/or suspected of having migraine was 6,566 authors, which is close to the theoretical estimate of the representative sample size. The total number of messages posted by patients and their caregivers exceeded 73000.

The final step in the study design was semantic processing of the selected posts from the representative sample and analyzing the obtained results discussed below.

### Study results

In their messages on the Internet, patients touch upon a variety of aspects concerning their experience. Within the framework of the current study all problems of concern to patients and their "unmet needs" were combined into several groups, including disease prevention issues, therapy, etc. The article deals primarily with those aspects for which the patient voice is the main (if not a unique one) data source: QoL and disease burden, perception and description of symptoms by patients, specific diagnostics and therapy patterns.

***Demographic data, burden and quality of life.*** As noted above, the final analysis of the collected information based on more than 73,000 posts, including the responses from patients and their caregivers, made it possible to select a representative sample of 6,566 authors from the most regions of the Russian Federation. The analysis of patient distribution by age and gender was conducted across 2,641 patients who provided information about themselves. Age information was also extracted directly from patient messages (from constructs like "I am 40 years old and have been suffering from migraines for 10 years") or message metadata (without collecting any personal data). Hereinafter, sample sizes for specific research questions may differ taking into account the number of authors who provided relevant information in their posts. The mean sample age was 30.1 years, of whom 63.5% were females and

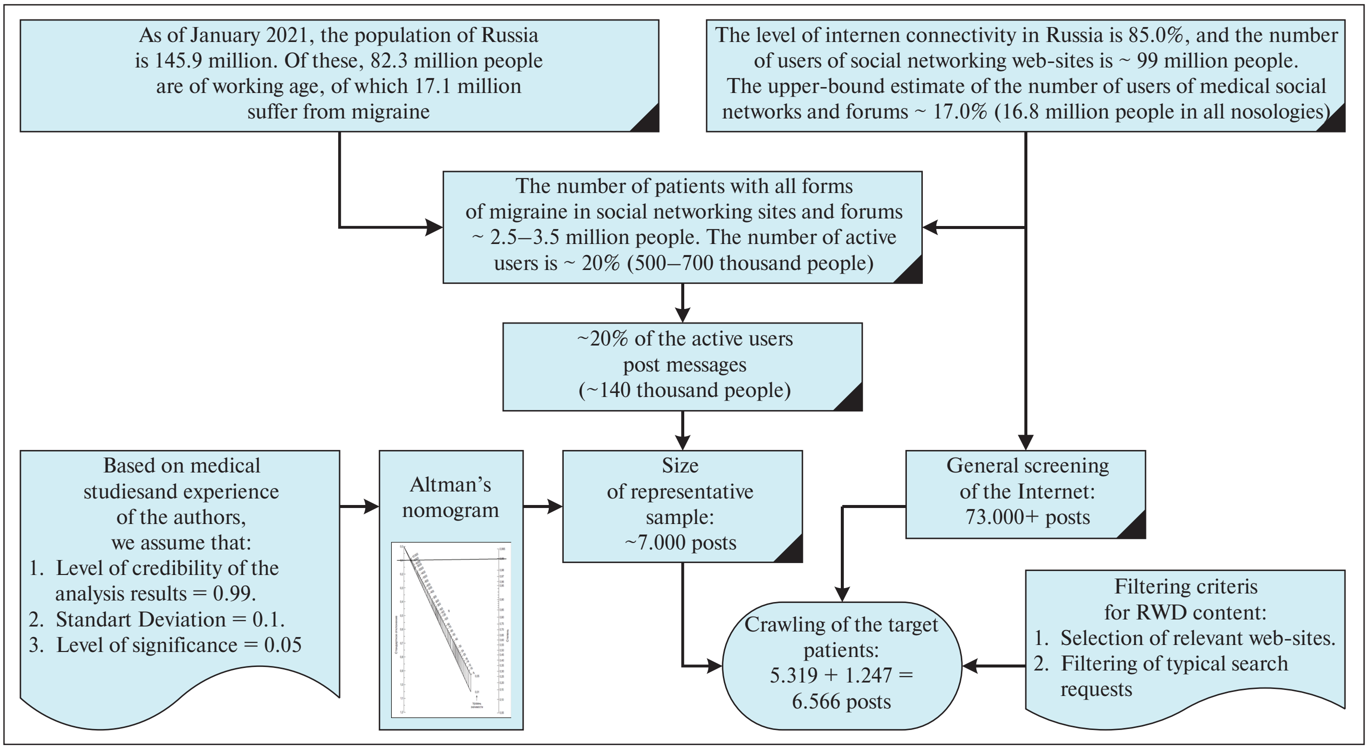

**Fig. 1.** *Study design flow-chart*

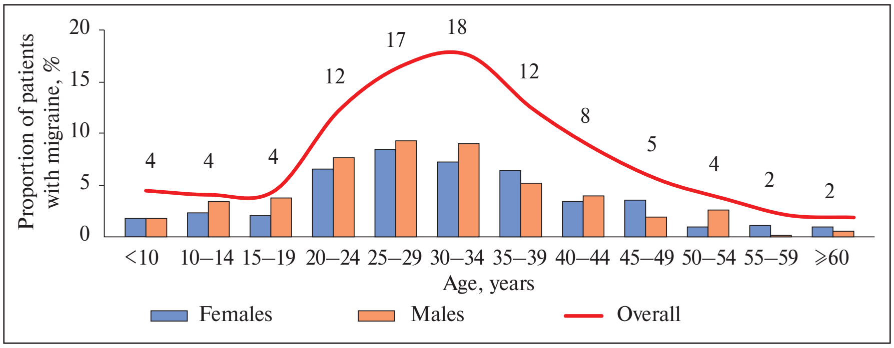

**Fig. 2.** *The proportion of patients with migraine in different age and gender groups*

36.5% were males. Distribution of the study population by age (Figure 2) demonstrates that the most active authors are patients aged between 20 and 40 (more than 60% of all patients) and the maximum representation of posts is accounted for by the authors aged between 30 and 35 (17.6% of all patients). It should be noted that not all patients indicated their age (the number of such authors is less than the number of those who indicated their gender or for whom the gender could be determined based on message texts). In this regard, men predominate in Fig. 2 although there are more women in the sample as a whole (see above).

Since the purpose of this study was to analyze Patient Voice (the “voices” of patients and their caregivers) on social networks (the fact of belonging to the group of patients or their caregivers was determined based on message texts, depending about whom the author writes about – himself or his/her loved one), data on the most active information resources in this area are of interest. When interpreting the data, the level of internetization in the regions of the Russian Federation was taken into account.

As shown in the analysis of the most active information resources, the largest number of posts was found on the social networks, while the share of online consultation forums is about 25% in the total volume of posts, which indicates that patients first of all prefer communicating with each other rather than seeking medical advice.

The sample of patients who reported their type and form of migraine was 5,280 people. At the same time, 73% of authors do not report whether the diagnosis was confirmed by a physician, and only 22% of the patients claim that their diagnosis was established by a medical specialist. Based on the form of migraine, patients were distributed as follows: migraine – 85.4% (n = 4509), migraine with aura – 11.1% (n = 586), migraine without aura – 3.4% (n = 181), status migrainosus – 0.1% (n = 4). It should be noted that the patients who mentioned the diagnosis of migraine included cases where the author did not use the term “aura”, but could use other phrases when describing ocular events. Most of the patients were employed people (68.4% with migraine in general, 63.0% with aura and 75.9% without aura), the proportion of university students was 9.0%, 11.1% and 10.3 %, respectively.

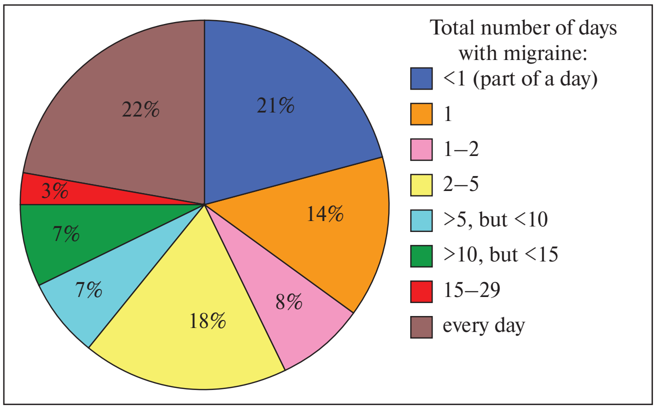

**Fig. 3.** *Days with migraine per month (in total)*

Analysis of the subjective posts of potential patients showed a significant polymorphism of clinical manifestations of both headache attacks, prodrome events and aura symptoms. In a sample of 3,752 patients who reported clinical manifestations of the disease, the most common symptoms of migraine were identified. The most common symptoms included: headache (90.7%), nausea and vomiting (25.8% and 23.7%), dizziness (17.1%), aura (14.6%), heaviness in head, back of headб stomach (9.2%), pulsation (8.0%), tinnitus (7.8%), edema of the face/eyelids (6.8%), cramps (6.4%), fever (6.1%), fainting (6.0%), drowsiness (5.6%). It is noteworthy that only 2.7% of patients complained of photophobia. 2,012 patients mentioned prodrome manifestations of migraine attacks, among which the most frequent were: weakness (29.9%), numbness (26.7%), increased emotional stress (21.7%), fatigue (19.0%), pulsation (14.9%), tinnitus (14.6%). The following manifestations of a visual aura were common: floaters (20.5%), blind spots (11.5%), lines/lightnings (9.0%), flashes of light (6.0%), shimmering (5.7%).

According to the posts from 686 patients the average disease duration in this group was 12 years, and in 8% of cases the disease duration did not exceed 1 year; in 30% of cases it varied from 1 to 5 years; in 10% of individuals it ranged from 5 to 10 years and in 52% – more than 10 years. The largest share of patients falls on the disease duration of 10–15 years, which again emphasizes the importance of analyzing migraine as a chronic disease with a tendency to long-term persistence of headache attacks. About 9% of all patients report having migraine for more than 30 years.

Data on the frequency of attacks based on all possible wordings was used to estimate the monthly migraine days,: “once a week”, “2–3 times a month,”, “5 times a year” etc. Data on the distribution of migraine attacks by frequency were analyzed across 353 patients who provided relevant information (Figure 3). 21% of patients reported rare attacks (less than 1 day per month). 22% of patients claimed that they suffered from migraine “every day”, in some cases implying “very often”. Mean number of monthly migraine days was 9.4.

Among patients with a potential diagnosis of migraine, in 913 cases there were characteristic descriptions of headache effect on general well-being, social and daily activity and work productivity. About 15% of patients reported an effect of migraine on their QoL. The following problems were among

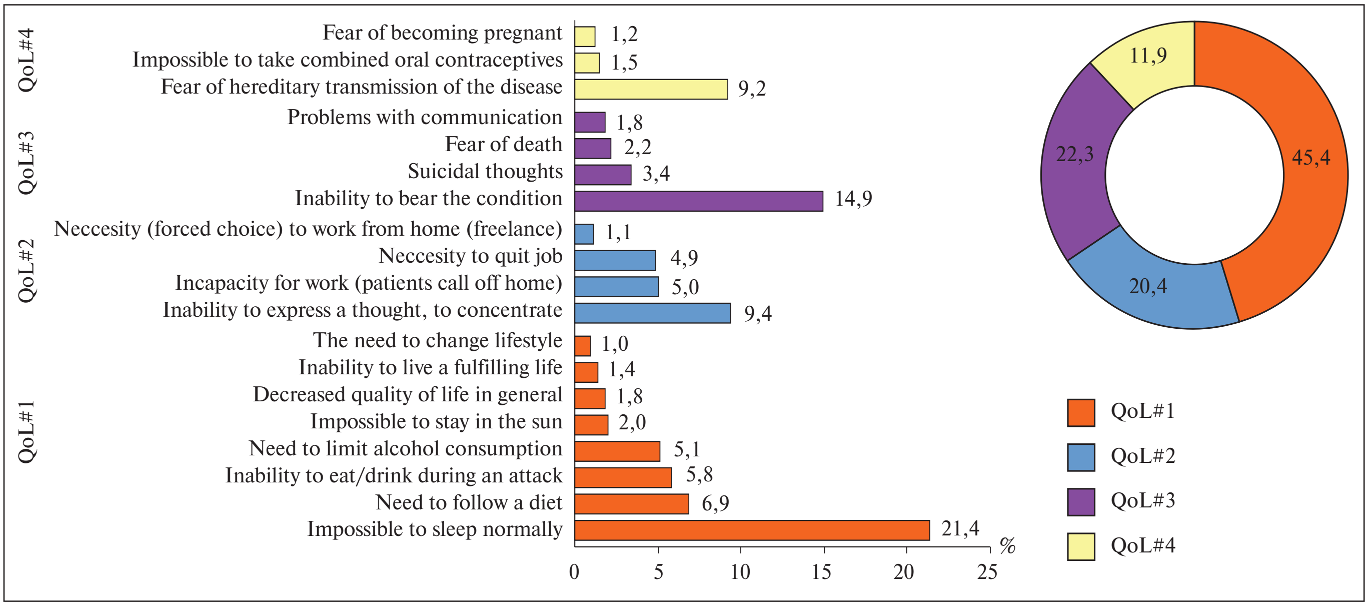

**Fig. 4.** *The most significant quality of life problems in the patients by QoL categories and subcategories*
*The diagram displays data on the main quality of life aspects in the patients, obtained from a sample of 913 QoL-related quotes by 4,599 by the authors of the posts. At this: QoL#1 is the category "Restrictions imposed on lifestyle by triggers of migraine attacks", QoL#2 – "Loss of work capacity due to the disease", QoL#3 – "Serious psychological problems caused by lifestyle changes due to the disease", QoL#4 –"Family planning issues".*

the most common: impossibility to have normal sleep – 21.4% (n = 195), inability to bear the condition – 14.9% (n = 136), inability to express a thought or concentrate – 9.4% (n = 86 ), fear of hereditary transmission of the disease – 9.2% (n = 84), need to follow a diet – 6.9% (n = 63), impossibility to eat/drink during an attack – 5.8% (n = 53), need to limit alcohol consumption – 5.1% (n = 47), incapacity for work (they call off work) – 5.0% (n = 46), necessity to quit job – 4.9% (n = 45).

One of the important study results was to identify in patient posts a migraine effect on the QoL and, in particular, on the ability for successful work and career growth. A classification of QoL aspects was formed, which were divided into four categories. In its turn, the most frequent subcategories were identified in each category (Fig. 4)2. Fig. 5 presents integrated data on work-related aspects of QoL. As the analysis showed, about 15% of the patients explicitly reported about the effect of migraine on quality of life, many others complained of feeling severely unwell (mostly in terms of medical aspects). At the same time, sleep disturbances were ranked first (21% of the patients).

As a rule, posts about work-related (see Fig. 5) issues are associated with the fact that migraine patients complain of misunderstanding with friends, relatives and acquaintances who consider them "faking an illness". At this, patients live in constant fear of having an attack at a crucial moment, or not having time to take treatment before the attack begins; they blame themselves if an attack begins. This leads to 24*7 self-control and makes patients further suffer from migraine-associated stress. In their messages the authors also describe work-related strategies in case of migraine attacks. Despite the significant effect of migraine on work productivity, only 12.3% (n = 18) take time off (at their own expense or in lieu of vacation pay), and in 72% of cases, patients are forced to be present at the workplace during a headache attack. At the same time, 6.8% of the patients reported that they had to change their job to a "quieter" one, 4.1% – work as a freelancer/as needed/if possible, and 2.7% – quit their job. It should be noted that cases of job loss, forced transfer, switching to freelance and other options are typical for patients with high frequency of migraine attacks per month. This suggests that patients go to extremes if they suffer from severe migraine (in total, 9% of all cases). Younger patients with migraine, including students, also experience similar problems,

Some descriptions from patient experience are provided below to illustrate specific QoL subcategories. At the same time, thoughts of suicide, fear of death; as well as the inability to take COCs are among the most significant problems since they lead to a worsening of patient condition, which, in turn, leads to stress and despair because of emerging barriers in family planning or, conversely, fear of becoming pregnant; communication problems at work and in the family. In particular, the following facts are mentioned:

- patients write that because of long-lasting pain (for example, within the last six months) they do not leave suicidal thoughts;
- many patients call migraine with aura a "hell" and say that during an attack they want to "kick the bucket";
- some patients cannot adequately treat comorbid conditions: because of increasing migraine or appearance of an aura, they have to cancel a therapy of concomitant conditions ;
- other patients note that they cannot communicate to children and engage in bringing them up since they feel permanent strong irritation and / or loss of strength on the days they have migraines.

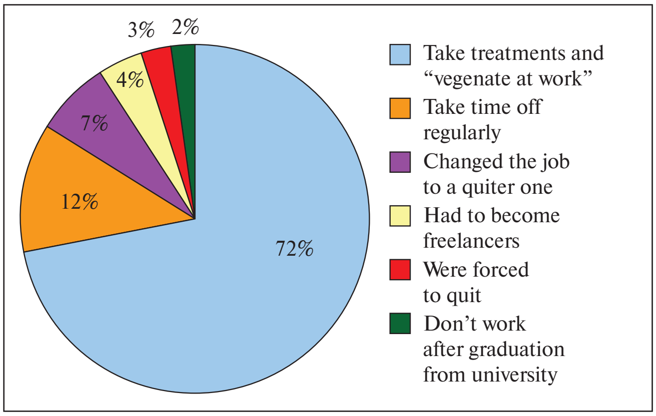

**Fig. 5.** *Impact of migraine on career growth*

As part of this study, more common but severe problems were identified in patients with migraine (Table 1). As in previous cases, spelling and style have been left unedited in the citations. Examples are given to display the variety of unmet needs which patients with migraine have.

***Diagnostic patterns.*** The results of the study (Figure 6) show that the principal medical specialist visited by patients with headache is a neurologist – in 56% of cases during the initial visit. It is also noteworthy, that there is an increasing use of a range of specialized doctors from the first to the third visit. General practitioners holds the third position as "sought-after" for initial visit, and an ophthalmologist holds the second position (in 14% of cases).

Table 1. *Unmet patient needs*

| Additional problems in migraine patients | Problem description |
|---|---|
| Weight problems after an attack | Patients write that they cannot regain body weight after several days of migraines: they cannot eat after an attack or even think about food during attacks. Moreover, their state of health is such that they would not be able to eat even if they have such a desire |
| Impossible to tidy up hair | Patients (primarily women) cannot wear hairstyles they like. The head begins to ache even more when using hairpins, braiding, etc. Bouffant is also not good for some women as the pain passes off "due to coldness". |
| Vision problems | Some patients cannot wear glasses during seizures, Classes also lead to attacks since patients have to strain eyes, which, in turn, leads to additional restrictions in the lifestyle and profession selection. |
| Poor sleep quality. Night attacks | In addition to poor sleep quality per se, some patients suffer from nightmares. Moreover, upon awakening, they experience a strong attack, which cannot be eliminated by medicines |
| Difficulties in transport, including problems with driving a car | Patients complain that an attack may unexpectedly overtake them when they driving a car creating risks for them and for those around them. In this case they try to slowly, focusing on the road, drive home and go to bed |
| Difficulties with hospitalization | It is not uncommon for doctors to misdiagnose patients even when they are in a day patient department at a clinic, since, according to doctors' comments, migraine cannot be the basis for planned hospitalization or inpatient treatment under compulsory medical insurance.<br>The only possibility is emergency aid in case of an extremely bad (in terms of pain severity or duration) attack. |

The study results show (Figure 7) that the diagnosis of migraine at initial visit was established in 71.3% of cases, which is a very positive indicator. In rare cases, the number of required visits to specialists reaches 8 (0.1%). The mean number of visits required to make a diagnosis is 1.46.

At the same time, the majority of patients in the sample have a positive experience with neurologists (64%). Negative experience is more often associated with the fact that "no one can help" (48.7% from the sample of 232 negative feedbacks).

Among examinations undergone by the patients, the first position is held by hematology and blood chemistry and the second position by MRI of the brain. There is a great interest in self-administering of diagnostic procedures – only 63% of them were physician-initiated.

A feeling of stigmatization in the patients' attitude to their disease is noteworthy – the patients believe that their relatives and doctors may consider them "faking an illness".

***Treatment patterns.*** An analysis of 5,193 patient posts regarding migraine treatment was conducted. Among acute migraine medications, NSAIDs and combined analgesics are mentioned most often (36.1%), followed by triptans (20.2%). At the same time, 23.7% of patients noted that they were using combined analgesics, 15.6% were administering a combination of acetylsalicylic acid, paracetamol and caffeine, and 8.1% were taking combined analgesics containing analgin. Among the references to NSAIDs for acute migraine treatment, ibuprofen (21.9%) is the most common, with rarer posts about acetylsalicylic acid (8.3%) and ketorolac (7.4%).

Interestingly, among all groups of medications the frequency of mentioning well-proven preventive migraine treatment is 13.1% (anticonvulsants 5.2%, antidepressants 4.7%, β-blockers 3.2%) that is comparable to ineffective "vascular" therapy – 11.5% (nootropics 4.4%, cerebral blood flow correctors 4.1%, vasoprotective drugs 3.0%). The results of the analysis of the most popular anticonvulsants and antidepressants in terms of the number of mentions used by patients with migraine are presented in Table. 2.

Opinions of patients and doctors regarding various migraine treatment options were analyzed in the framework of the study. Despite the wide range of drugs mentioned, more often patients were not satisfied with the ongoing migraine treatment (64% vs 36%). Dissatisfaction with treatment equally applies both to acute and preventive migraine therapy. Patients actively discuss adverse drug reactions associated with the treatment, with the most common of which are the following: weakness 14.9%, malaise 13.3%, high blood pressure 8%, nausea 7.6%, vomiting 6.4%, drowsiness 5.2%, weight loss 4.8%, insomnia 3.2%, dizziness 2.4%, and weight gain 2.0%. About 20% of patients say they use non-pharmacological treatments for migraine prevention. The most common of them are massage (39.2%) and non-pharmacological prevention 45.3%, while 9.8% of patients note they administered methods of traditional medicine.

Analysis of patients' opinions showed that the main problems in migraine treatment are a decrease or lack of efficacy (33% in total), side effects (10.3%) or, at least, a fear of their occurrence (1.4%), and a fear of long-term medication usage (7.5%).

Analysis of physician opinions regarding acute and preventive treatment of migraine (2,891 mentions) was conducted. It is of interest that among physicians, triptans are more often noted as medications of choice for acute migraine treatment (34.5%) as compared to NSAIDs or combined analgesics (20.7%). At this, there are practically no mentions or recommendations for the use of combined analgesics containing analgin. At the same time, when preventive migraine treatment is mentioned, drugs with antidepressants (10.1%), anticonvulsants (8.0%) and β-blockers (5.4%), drugs with unproven efficiency ("cerebral circulation correctors") are also mentioned – (8.8%). About 80.6% of physicians recommend non-drug migraine treatments, in most cases massage (39.9%), medicinal baths and physical therapy (33.0%).

The opinion of physicians and patients regarding dissatisfaction with the ongoing drug treatment for migraine practically coincides (mainly because of a wide range of adverse drug reactions and poor efficacy).

## Discussion

Internet sources are being increasingly used for analysis, disease diagnosis and in predicting human behavior in relation to health problems. This use of the Internet is called infodemiology, a concept presented by G. Eysenbach (21). Infodemiology studies and information surveillance (infoveillance) studies use data from the Internet, and have become an integral part of health informatics methods over the past decade (22).

Health information is one of the most popular topics on the Internet. Web-based technologies such as search engines and social networks have made it possible to manage user-generated data in real time in the form of infodemiology studies. The field of infodemiology is becoming more and more popular; it uses innovative methods and approaches for assessment of health and needs of potential patients. The use of web sources which provide information of a unique volume inaccessible for traditional studies allows solving problems arising from the complexity of traditional methods (22). The main advantage of using data from the Internet is the ability to evaluate information in real time, whereas traditional epidemiological studies may process data over years. Another significant advantage of information surveillance is anonymity In addition, traditional epidemiological studies involve the use of survey tools with structured questions and clearly worded responses that can often cause difficulties in many respondents when choosing responses. The data on the Internet are a reflection of the "voice" of a potential patient posting materials regarding the most pressing issues (22, 23). The infodemiology approach provides unique opportunities for real-time analyses of large amounts of data related to health, medical needs of potential patients, and thereby provides evidence-based information (24, 25).

The main disadvantage of using Internet sources in the analysis of information is the issue of representativeness of the analyzed population. When it comes to a disease such as migraine, the diagnosis of which is established solely clinically, it is important to obtain information about the key manifestations of the disease, which suggests that the study sample is representative. Thus, LA. Lenert et al. (26) conducted a comparative analysis of capabilities to diagnose migraine in 109 subjects. By analyzing the posts on social networks, the authors compared their data with diagnostic criteria for migraine according to ICHD-3. Subsequently, the patients were examined by a neurologist, and information was obtained from the patients' attending physicians to confirm their diagnoses. The authors found a significant compliance between the diagnostic approaches: the majority of patients with a reliable diagnosis of migraine reported the characteristic quality of pain (97%), associated symptoms (92%). The findings from a neurologist's consultation confirmed the diagnosis of migraine in 97% of cases, and the attending physicians confirmed the diagnosis in 90% of patients (26).

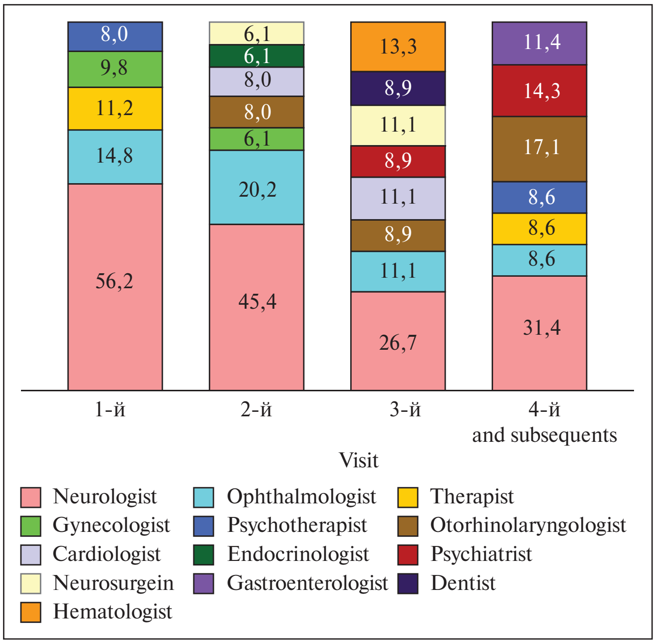

**Fig. 6.** *Specialties of doctors visited by the patients on their way to diagnosis*

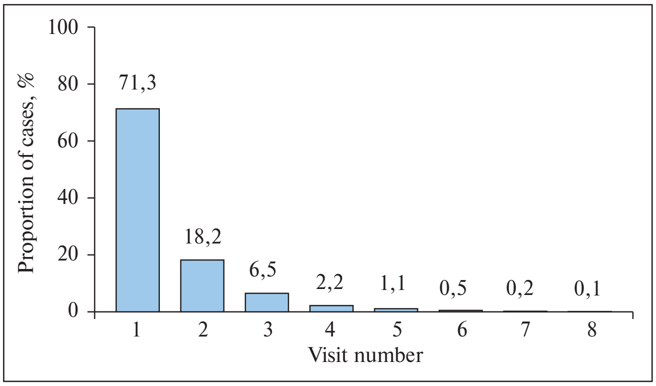

**Fig. 7.** *Diagnostics (during which visit the diagnosis is made)*

In our study, the search for target patients was based on selection of the authors of the posts who specified the diagnosis of migraine, and, thus, over 73 thousand posts were found. The selection of relevant web-sites with filtering by typical search requests provided a representative sample of 5,319 target patients with a diagnosis of migraine and 1,247 people who did not directly report the diagnosis of migraine, but who were the members of specialized support groups for patients with migraine. A detailed analysis of clinical manifestations made it possible to interpret the analyzed sample as representative.

The analysis of demographic parameters showed that among 1,641 patients females (63.5%) and young people aged 20–40 years old (more than 60%) prevailed that generally corresponds to the demographic profile of patients with migraine (27, 28, 29). Disease duration parameters were similar: with a duration of 12 years, 30% of participants reported the duration of 1 to 5 years, 10% – 5 to 10 years, and 52% – more than 10 years. Among 353 patients who provided data on the frequency and duration of headache attacks, only 21% of patients reported rare attacks (less than 1 day per month), 22% of patients reported having pain almost every day, and the mean monthly migraine days was 9.4. These data clearly show predominance in the population of persons with a long-term persistent migraine and a high frequency of attacks. This can potentially be a result of 'selection' bias P people who suffer more are more likely to share their experience and/or seek advice in social media.

Analysis of the impact of migraine on the quality of life revealed that despite the fact that only 15% of patients clearly reported a significant decrease in the quality of life, the proportion of people who noted an effect on work productivity was high: 6.8% of patients reported that they had to change their job to a “quieter” one, 4.1% – to work as a freelancer/as needed/if possible, and 2.7% – quit their job. At the same time, despite the decreased work productivity, 72% of patients had to be present at the workplace during a headache attack. This parameter clearly reflects the burden of migraine in people of working age, and in our study it does not differ from the findings from other studies, where the proportion of these subjects ranged from 57% (30) to 89% (31, 32, 33).

Analysis of the patientsX content in the context of social and economic burden and quality of life showed that the majority of patients with migraine are of working age. At the same time, a significant proportion of quality of life problems are related to work and career, including the following aspects: downshifting or need to become a freelancer; impossibility to choose a profession in accordance with the level of education and experience, impossibility to study at a university due to the disease; lack of career growth due to inability to concentrate or difficulties with speech (expression of thoughts), difficulties when working with a computer; the need to quit a favorite job; frequent absences from work, including those without a sick leave (doctors do not provide, and employers do not accept sick leave certificates due to migraine); low work productivity, lack of work productivity – even in the case of formal presence at work. There are no comprehensive pharmacoeconomic studies on this topic. However, the present study shows the following: mean monthly migraine days: 9.4; 21.8% of patients who mentioned the frequency of attacks reported having daily migraine attacks; the majority of patients have been suffering from attacks for 10 years or more, and 9% of patients have been suffering from attacks for 30 years or more. All of the above indicates a long-term economic burden that can be used as reasons for reimbursing treatment costs.

Table 2. *Popular anticonvulsants and antidepressants*

| Active Substance (INN) | Trade Name | The share of a trade name among all the mentions, % | Share of the INN among all the mentions |
|---|---|---|---|
| | *Anticonvulsants* | | |
| Topiramate | Topamax | 55,1 | 36,3 |
| | Topiramate | 33,7 | |
| | Topiromax | 8,2 | |
| Carbamazepine | Finlepsin | 60,4 | 17,8 |
| | Carbamazepine | 33,3 | |
| | Tegretol | 4,2 | |
| Acetazolamide | Diacarb | 100 | 12,6 |
| Valproic acid | Depakine | 48,1 | 10,0 |
| | Convulex | 18,5 | |
| | Depakine chrono | 18,5 | |
| | Valproic acid | 14,8 | |
| Gabapentin | Gabapentin | 45,0 | 7,4 |
| | Tebantin | 20,0 | |
| | Convalis | 20,0 | |
| | Neurontin | 15,0 | |
| | *Antidepressants* | | |
| Amitriptyline | Amitriptyline | 100 | 37,7 |
| Escitalopram | Cipralex | 60,6 | 13,5 |
| | Escitalopram | 18,2 | |
| | Elicea | 12,1 | |
| | Selectra | 6,1 | |
| Sertraline | Zoloft | 71,0 | 12,7 |
| | Sertraline | 12,9 | |
| | Serlift | 9,7 | |
| Venlafaxine | Venlafaxine | 38,9 | 7,4 |
| | Velafax | 33,3 | |
| | Velaxin | 22,2 | |
| Fluoxetine | Fluoxetine | 86,7 | 6,1 |
| | Prozac | 13,3 | |
| Duloxetine | Cymbalta | 84,6 | 5,3 |
| | Duloxetine | 15,4 | |

The study results clearly show the fact that the principal medical specialist visited by patients with headache is a neurologist – in 56% of cases during the initial visit. This is due to higher availability of neurological care in the Russian Federation, and it differs significantly from the model of care for patients with headaches that is assumed in Western countries, where the primary contact for such patients is a general practitioner in 90% of cases, and only difficult cases are referred to a neurologist (34). It is also noteworthy, that there is an increasing use of a range of specialized doctors from the first to the third visit. In addition, weXd like to note that based on the results of processing our sample, a general practitioner holds the third position as "sought-after" for initial visit, and an ophthalmologist holds the second position (in 14% of cases), probably due to the presence of an ocular aura. Though 64% of patients report a positive experience of communication with neurologists, the overall experience with the Health care system is negative: 48.7% of patients mention that "no one can help". This data is in line with the findings of BK Kim et al (35) who showed that, in general, only 29.5% of patients with migraine were satisfied with their relationship with doctors. These data can be the result of both insufficient quality communication between a doctor and a patient, and, as a consequence, overestimated patient expectations from treatment, and a lack of effective treatments.

Analysis of diagnostic patterns shows that in most cases patients seek additional examinations on their own, among which the first position is held by hematology and blood chemistry, and the second position P MRI of the brain. Only 63% of these exams were performed based on the physicianXs recommendations. This may indicate both a lack of confidence in the diagnosis and health care management, and a lack of awareness in patients about the primary nature of most headaches, which has been repeatedly shown in other studies (36, 37). Among acute headache medications, NSAIDs (most often ibuprofen, 21.9% of patients) and combined analgesics (36.1%) are mentioned most often, followed by triptans in the second place (20.2%), which confirms the adequacy of migraine verification in our sample and correlates with data from other studies (35, 38, 39, 40). In our study, only 13.1% of patients mentioned the experience of adequate preventive treatments that is in full agreement with the data from population studies (41, 42, 43). Meanwhile, our study demonstrated a high (11.5%) frequency of using drugs with unproven efficacy as preventive treatment (nootropics 4.4%, cerebral blood flow correctors 4.1%, vasoprotective drugs 3.0%), which we have previously shown earlier (44). It is not surprising that about 70% of physician mentions of migraine treatment are unsatisfactory.

Although population-based studies significantly expand our understanding of migraine, they are based on structured surveys, which do not always provide a complete picture of the real experiences, behavior and needs of the patients. This raises the need for a paradigm shift in migraine studies to a new level (45). The use of modern web-based technologies, such as search engines and social networks, provide a unique opportunity to hear patients' "voices" and are a promising direction in the study of key aspects of migraine.

## Conclusion

Thus, the study revealed the presence of a wide range of unmet needs, QoL problems both in patients themselves and their caregivers, as well as a significant social and economic burden of this disease (including a long-term burden on the economy, which can be used as arguments for reimbursing the cost of migraine therapy) based on the text of migraine-assocaited messages in open sources on the Internet.

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Received/Reviewed/Accepted
19.10.2021/01.12.2021/03.12.2021

**Conflict of Interest Statement**

This article has been supported by Teva. The authors have not received any funding for the preparation of the article. There are no conflicts of interest. The authors are solely responsible for submitting the final version of the manuscript for publication. All the authors have participated in developing the concept of the article and in writing the manuscript. The final version of the manuscript has been approved by all the authors.

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