

# SUBJECTIVE EXPERIENCE OF MIGRAINE SUFFERERS: PSYCHOEMOTIONAL EXPERIENCE AND QUALITY OF LIFE OF SUFFERERS

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## Abstract

Migraine is a severe headache that usually occurs together with other symptoms, creating significant dysfunction in the sufferer's daily life. Taking into account its diverse impact on the patient's life, the present qualitative research aimed both at investigating the subjective experience of migraine, as well as at the perceived consequences that occur on the quality of life of the sufferers, women and men. At the same time, it was sought to enable sufferers to express their personal experience of migraine, which is often treated as an "invisible" disease. 14 people participated in the research, of which three were men and eleven were women. From the thematic analysis of the research material, three main themes emerged; the subjective experience of the sufferers, the strategies developed by sufferers to remain functional, and the impact of migraine on the various aspects of the social domain, the attitude, and way of dealing with significant others towards the patients. Based on the findings, the necessity for further investigation of the experience of migraine patients over time, as well as the need for psychological support and systematic counseling of themselves and their relatives, can reasonably be seen.

**Key-words:** migraine, subjective experience, psycho-emotional experience, quality of life

## ΥΠΟΚΕΙΜΕΝΙΚΗ ΕΜΠΕΙΡΙΑ ΠΑΣΧΟΝΤΩΝ ΑΠΟ ΗΜΙΚΡΑΝΙΑ: ΨΥΧΟΣΥΝΑΙΣΘΗΜΑΤΙΚΟ ΒΙΩΜΑ ΚΑΙ ΠΟΙΟΤΗΤΑ ΖΩΗΣ ΤΩΝ ΠΑΣΧΟΝΤΩΝ.

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## Περίληψη

Η ημικρανία είναι μία σοβαρή κεφαλαλγία που συνήθως εμφανίζεται μαζί με άλλα συμπτώματα, δημιουργώντας σημαντική δυσλειτουργία στην καθημερινότητα του πάσχοντα. Λαμβάνοντας υπόψη την ποικιλότροπη επίδραση αυτής στη ζωή του ασθενή, η παρούσα ποιοτική έρευνα στόχευσε τόσο στη διερεύνηση του υποκειμενικού βιώματος της ημικρανίας, όσο και στις αντιλαμβανόμενες συνέπειες που επέρχονται στην ποιότητα ζωής των πασχόντων, γυναικών και ανδρών. Ταυτόχρονα, επιδιώχθηκε να δοθεί η δυνατότητα στους πάσχοντες να εκφράσουν το προσωπικό τους βίωμα για την ημικρανία, η οποία συχνά αντιμετωπίζεται ως μια «αόρατη» ασθένεια. Στην έρευνα συμμετείχαν 14 άτομα, εκ των οποίων οι τρεις ήταν άνδρες και έντεκα γυναίκες. Από τη θεματική ανάλυση του ερευνητικού υλικού προέκυψαν τρία κύρια θέματα· το υποκειμενικό βίωμα των νοσούντων, οι στρατηγικές που αναπτύσσουν οι πάσχοντες ώστε να παραμένουν λειτουργικοί και η επίδραση της ημικρανίας στις διάφορες πτυχές του κοινωνικού τομέα, η στάση και ο τρόπος αντιμετώπισης των σημαντικών άλλων προς τους ασθενείς. Βάσει των ευρημάτων προκύπτει εύλογα η αναγκαιότητα για περαιτέρω διερεύνηση του βιώματος των ημικρανιακών ασθενών διαχρονικά, καθώς και η ανάγκη για ψυχολογική υποστήριξη και συστηματική συμβουλευτική των ίδιων και των οικείων προσώπων.

**Λέξεις κλειδιά:** ημικρανία, υποκειμενική εμπειρία, ψυχοσυναισθηματικό βίωμα, ποιότητα ζωής

## Introduction

Migraine is described as a rhythmic pain, usually located on one or both sides of the head.<sup>[1]</sup> Often the localization changes, i.e. sometimes one side hurts, sometimes the other, or even the whole head.<sup>[1]</sup> Migraine is divided into two main types; with aura (classic migraine) and without aura (common migraine).

The diagnostic criteria taken into account are the duration (4 - 72 hours), its form, i.e., if it is a holo-cranium or migraine, if it is contralateral, throbbing, moderate to severe or aggravated by movement, combined with nausea, vomiting, photophobia or phonophobia, and finally the combination with aura (visual or sensory warning symptoms).<sup>[2]</sup>

Some of the key points to pay attention to when taking a migraine history, in addition to those mentioned above, are onset, frequency, warning signs and triggers, exacerbation or exacerbation (e.g., activity, bending), relief from treatment or other measures, systemic sequelae (weight loss, scalp tenderness), and family history.<sup>[2]</sup>

Based on the World Health Organization,<sup>[3]</sup> it is estimated worldwide that the percentage of adults who present, even symptomatically, some headache episodes amounts to 50%. It occurs in a ratio of 3:1 in women over men, with 90% of cases without aura and manifests mainly between the ages of 25–50 years.<sup>[4]</sup>

In addition, migraine is now considered the third most common disorder and the third most common cause of disability in women and men over 50 years of age.<sup>[3]</sup> Migraine is the sixth leading cause of lost work hours due to disability, while overall headache disorders are the third most common cause.

Regarding the Greek data, there are more than one million people who suffer from migraine, while the percentages are higher for women.<sup>[1]</sup> In a study by Kouremenos et al.,<sup>[5]</sup> 610,000 patients reported migraine episodes. Patients reported a decrease in functional ability about three times a month. A point that causes concern is the fact that only 1/5 of Greeks seek medical help and the greater percentage do not take preventive measures to deal with migraine.

Quality of life is a term that is closely related to any disease. It is often defined as the individual's subjective perception of his position in life, in the context of the values and cultural characteristics of the society in which he lives, in relation to his personal goals, interests, expectations and criteria he has set.<sup>[3]</sup> Regarding the connection of migraine with the quality of life, the first burdens the sufferers significantly, causing a reduction in both their daily activities in view of migraine episodes, and more general limitations in the way of life before the onset of such episodes. The impact of migraine appears to negatively affect all social aspects of patients.

Taking the above into account, the present quali-

tative research focuses both on the investigation of the subjective experience of migraine, as well as on the perceived consequences that occur on the quality of life of the sufferers, both women and men. It also attempts to show the aspects of daily life that are affected by the occurrence of migraine episodes, to identify ways of supporting and dealing with migraines, as well as the psycho-emotional changes observed in individuals. At the same time, it seeks to give sufferers the opportunity to express their personal experience of migraine, which is often treated as an "invisible" disease.

The aim of the research is to answer the following research questions:

- 1) How do patients define the subjective experience of migraine at a psycho-emotional, cognitive, physical and social level?
- 2) In what ways do sufferers manage the symptoms during migraine and also preventively?
- 3) What is the attitude of significant others towards sufferers during a migraine attack?

## Method

### Research design – Sampling

The method followed to investigate the above questions is the qualitative one, through which it is sought to conduct a more extensive study as well as an in-depth understanding of the personal migraine experience of each of the sufferers. The individual semi-structured interview was used to collect the data, so that a global and in-depth understanding of the personal experience of migraine was possible. In the semi-structured type of qualitative interview, a set of questions is planned that will act as a guide for the topics that are sought to be covered.<sup>[6]</sup>

### Participants

The survey, which lasted from November 17, 2020 to December 4, 2020, involved 14 people, three of whom were men and eleven women. Their ages ranged from 20 to 73 years (with an average age  $M=42.36$  years) and they came from different regions of Greece. The selection of the sample was random, provided that they were adult patients with a medical diagnosis of migraine.

### Data Collection Process

The interview process was carried out remotely using audio-visual media, due to the restrictive measures put in place in view of the Covid-19 virus, and its duration was approximately one hour. Complete anonymity and coding of names was observed when writing the research results for the protection of personal data, while all information provided is confidential and the confidentiality of the conversation was strictly observed.

Before starting the interviews, the participants were informed about the ethical principles governing the research process. Specifically, they were informed about the objectives of the research and the ways of utilizing the research material. Furthermore, they were informed and there was a mutual agreement regarding the right they had not to report information or not to answer questions they do not want, as well as the right to withdraw their participation from the research, if they considered this to be desirable. After it was clarified that anonymity, confidentiality and protection of personal data are guaranteed as a result of an ethical commitment, the consent of the participants for their voluntary participation in the research process was also ensured.

### Data analysis method

As a research and data analysis method, thematic analysis was used, which is a particularly widespread method of qualitative research in psychology, as due to its nature it forms the basis for many of the other qualitative data analysis methods.<sup>[7]</sup>

### Results

Through the data analysis, some main themes emerged regarding the subjective experience of migraine and sufferers' quality of life, which were broken down into sub-themes. The first refers to the subjective experience of patients, i.e. the way each individual experiences each migraine episode, the thoughts he has as soon as he feels the first symptoms, the feelings he has during and after the end of the migraine, the way he acts, the observed emotional changes as a result of accepting the illness and living with it. The second concerns the strategies that sufferers develop to remain functional, the ways in which they support themselves and manage migraines, either during an attack or preventively. The third theme is related to the effect of migraine on the various aspects of the social domain, the attitude and way of dealing with patients in the family, professional and friendly social circles, as well as the emotional changes observed between these two.

### Subjective experience during the occurrence of a migraine episode

The definition of personal experience is difficult to define. In this research, the experience is defined by the psycho-emotional state during a migraine episode, the psycho-emotional state after the migraine attack, physical well-being, perceived triggering factors, and cognitive processing of the illness.

According to the narratives of the participants, the experience of migraine causes various and mixed emotions such as: irritation, feeling of helplessness,

helplessness, disability, impasse, exhaustion, fatigue, suffering, frustration, fear, and sense of senseless loss of days of life, or even guilt about their situation.

The emotional change of sufferers after a migraine attack seems equally important, as positive feelings usually return: relief, euphoria, feeling of rebirth, spiritual upliftment, liberation, happiness, insatiable energy and strength, calmness, and relaxation are some of the predominant responses of patients.

Another aspect in which migraine seems to have a catalytic effect is the physical well-being of sufferers. All participants emphasize the experience of pain, with some considering that the effect of migraine is more pronounced on physical than on mental well-being.

Patients have often linked migraine to various triggers they have observed. Many sufferers associate migraine with stress as a trigger, while some argue that they are not affected by stress, or at least not consciously. Menstruation and various hormonal issues are also a common cause for almost the entire female sample.

Regarding the cognitive processing of the disease, the difficulty of moving sufferers from denial to acceptance is observed. Some sufferers refer to the mental work they have accomplished with themselves to understand, accept, and ultimately come to terms with the idea of migraine as a chronic illness. In some cases, however, there was a period of time where the patients were in complete denial, as it was impossible for them to perceive and accept the chronic nature of the disease.

After the attacks of pain, it is observed that review and evaluation of the important things in life and the appreciation of life, of the day that passes without pain, often follows. In the context of getting used to, reconciling with, and accepting the chronicity of the disease, the development of mental resilience emerges from the words of the participants.

### Self-care and ways to treat migraines

Through the narratives of the participants, it is also seen how they try to both accept the chronic nature of the disease and to handle the symptoms and the multiple changes it brings about in their lives.

The primary concern for most sufferers in their daily lives is self-care. They engage in continuous self-care to minimize the effects of chronic disease on their health. In addition, all sufferers seek and pursue, often and in combination, a form of self-medication, that is, ways to relieve themselves at least temporarily from the pain. The combination of self-care with mental work seems to partially help sufferers, giving them strength to cope and not lose hope in finding possible, more effective

healing methods.

Preventive management of migraine attacks is mainly achieved through immediate medication, which also appears to help balance physical and mental well-being. Using a diary also appears to help sufferers identify and prevent possible aggravating factors of a migraine attack.

Regarding strategies to control and cope with migraine attacks, various forms of meditation and mental imagery seem to contribute to a first contact with the pain and temporary relief from it.

### **Impact of migraine in the social domain**

Based on patients' narratives, social life and daily relationships are an important aspect of their struggle with migraine to find and maintain balance. When patients were prompted to talk about the coexistence of their social life with migraine, several mentioned the family and professional domains respectively as the main ones affected, while many claimed that both aspects were equally or almost equally affected. Sufferers also spoke of an effect on friendships and personal domains.

The family, which is one of the basic aspects of everyday life, is significantly affected by migraine attacks. The occurrence of migraine episodes implies the absence of the patients from various activities and events, family and non-family. Based on the narratives, the conflict of the multiple roles that sufferers play every day is perceived, with migraine making them dysfunctional, even for achieving simple things. Nevertheless, they continue to make maximum efforts to cope.

At the same time, migraine seems to affect the attitude and reactions of the patients' family. From their answers, a perceived support from the family is observed. The main reason for the positive attitude seems to be the personal experience of the family circle of patients with a migraine episode, as almost everyone reports a family history of migraine, usually on the mother's or father's side. Nevertheless, some patients, particularly women, talk about less supportive family contexts, referring mainly to the difficulty of understanding on the part of the husband.

Similarly, a significant effect is also observed in the wider personal and friendly sphere of the patients, themselves making daily restrictions, such as social isolation or stopping favorite activities due to the fear of triggering a migraine attack. Regarding the attitude of the friendly environment towards the sufferers, their opinions differ. Some speak of support while others report a lack of understanding of both the seriousness of the disease and the impact it has on sufferers' lives.

As far as the professional field is concerned, sufferers try to find balance, as the low functionality caused as a consequence of migraine attacks, makes

work obligations difficult.

When participants were asked to talk about the desired attitude of significant others toward them during migraine episodes, they referred to a need for more understanding and a willingness to help. References were made to all the social contexts to which they belong: family, friends, work. The desire for empathy and support also becomes apparent, with sufferers expressing a sense of grievance.

### **Discussion**

Considering the aims and objectives of the present research, a brief commentary on the findings follows.

Important findings of the work that emerged from the narratives of the patients are the change in the psycho-emotional state after a migraine episode, the desire to make use of the time lost due to a migraine attack, the feeling of fear for the next attack, the physical fixation, and the intense pain experience.<sup>[8-9]</sup> The last finding is considered important as, through the interview, the expression of each individual patient was achieved in terms of the way they personally experience pain. Regarding the cognitive processing of the disease, sufferers talked about the stages they have gone through, from denial to understanding, reconciliation, and finally, acceptance of migraine.<sup>[10]</sup>

Prevention is cited as another means of improved seizure management, particularly with prompt medication.<sup>[11]</sup> Notable aspects of the work are also the testimonies of the patients, who speak of a review and reassessment of life, and the day that passes without physical pain.<sup>[12]</sup>

On the other hand, as the effect of migraine on the social sphere as a whole seems enormous, the negative feelings possessed by the sufferers, as well as their personal need for a better understanding from the closer relatives.<sup>[8-11]</sup>

### **Limitations, challenges and directions for future research**

As any research effort, this study is subject to some limitations. One of them could be considered the sample which consists of a relatively small number of participants due to the qualitative nature of the research. In addition, there was relatively low heterogeneity in the sample in terms of gender, as the participants were mostly female. This is of course partly justified by the fact that migraine occurs mainly in the female sex with a ratio of 3:1.

It also has to be considered that due to the conditions of the COVID-19 pandemic, it was impossible for the interviews to be conducted in person.

Considering the above conditions, it would be

interesting to investigate the experience of migraine patients longitudinally in order to see the effect of the COVID-19 pandemic and confinement over time. In addition, further research is suggested in a larger population sample to enrich our knowledge of the migraine experience and the resulting needs of patients.

### Conclusion

Summarizing the conclusions of this paper, the conclusions drawn reveal the complexity of the subjective experience and experience of migraine patients. At the same time, the investigation of this experience offers the possibility for a deeper understanding of the difficulties faced by the sufferer, as well as an effort to inform and raise awareness of the general population as to the nature and severity of the disease.

### Conflict of Interest

The authors declare no conflict of interest.

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