

## THE EXPERIENCE OF PERSONS LIVING WITH MIGRAINE

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**Abstract:** The aim of the study was to describe the experience of living with migraine headache and the ways that persons cope with it. This could help specialists to get a better understanding of the patients with migraine. We used the interpretative phenomenological analysis. Being affected by a long time, participants feel that pain is a part of them, and that it will never be completely cured. Also, most of the emotions and feelings that came up with an attack are negative, for example emotions like sadness, irritability and feelings like vulnerability. The ways that participants cope with the migraine are traditional treatments (drugs), complementary treatments, use of coping strategies, both active and passive, and trying to find a cause of the attack in order to take the control over it. The findings of the study suggested that the migraine is more than a headache; persons endure both emotional and physical suffering.

## INTRODUCTION

Migraine is one of the most common diseases with a significant socio-psychological impact and was included by the World Health Organization (WHO) in 2010 as the 19<sup>th</sup> cause of disability among men and woman.

While migraine has a genetic basis, environmental and psychological factors also play an important role in the way it influences those affected. Pathophysiologic mechanism underlying migraine has been identified, but the reasons for the occurrence of migraine attacks and the causes of periodic sharp still remain unknown.

The relationship between psychological factors and headache has been observed for a long time, ancient Greeks and Romans were aware that negative states were often triggers of headaches, especially for migraine.

Since 1743, Junkerius D. noted that the main cause of migraine might be anger, especially tacit suppressed anger. In 1891 Freud S. and Breurer J. observed that in many cases of headache, the pain disappeared after experience of catharsis, or at least an improvement of the emotional state.(1)

Consequences that migraine may have for the person are extending beyond the pain itself, many aspects of a person's life may be compromised, such as education, employment, family and social life. Previous studies related to the emotional factors involved in migraine reported elevated levels of depression and anxiety.(2,3,4) Life with a chronic illness can be stressful and annoying, so in addition to depression and anxiety, people might experience other negative emotions like anger, helplessness and despair.

Most of the studies addressing this issue are quantitative studies. While they provide important information on the magnitude and the impact of migraine, quantitative studies fail in examining the unique aspects of each individual. In contrast, there are few qualitative studies, thus we have only few details about the experience of people with migraine and the ways in which they cope with it. The small number of studies conducted from the perspective of the person with migraine

requires more information about this aspect. By exploring experiences with migraine we can explain complex issues such as factors influencing the onset of an attack, how people make sense of the experience and the ways they cope with migraine.(5)

## PURPOSE

The aim of this study is to be a starting point to provide a “voice” for people with migraine, so that those involved in this phenomenon (therapist, family, etc.) to know and understand what does it mean to experience migraine, in order to identify specific treatment and provide necessary support for the affected persons.

## MATERIALS AND METHODS

Qualitative methods enables detailed examination of how individuals understand and build their lives and situations, and the researcher tries to rely on his understanding of a particular phenomenon as much as possible from the perspective of those involved in the study. Also, qualitative methods could provide a holistic picture of the phenomenon and the findings can be more meaningful to practitioners.

Following a review of the scientific literature, based on searches defined as “migraine qualitative research” in the databases PubMed, CINAHL and ScienceDirect, Ramsey A. (6) has identified between 17 to 29 qualitative studies conducted on people with migraine, and only 7 of these were chosen based on relevance and reference to some aspect on experience with migraine.

Interpretative phenomenological analysis is chosen for several qualitative research methods (discursive narrative method, Grounded Theory) based on its properties as one of the methods widely used in health psychology and having particular relevance in this research area.(7) Psychologists that work in medical field have identified the importance of understanding the perceptions of patients, the interpretation which they give to the experience of their body and also the meaning that those

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experiences provide them. Interpretative phenomenological analysis allows exploration of subjective experiences and offers the ability to describe and understand the “story” gives meaning to process by which a person experiences.

#### **Participants**

Participants of this study were recruited in collaboration with a neurologist from one of the public hospitals from Sibiu and the recruitment procedure was based on rational criteria of selection.

The final sample was consisted of four female participants diagnosed with migraine without aura that met the inclusion criteria: the diagnosis of migraine according to the classification provided by the International Headache Society: having a migraine diagnosis over one year; no other physical disabilities and no other psychiatric disorders; age of participants between 20 and 60 years. Number of migraine attacks might vary among participations, from one attack once a week or every two weeks to one attack every other day. Migraine headache started with at least 5 years prior in the case of all the participants, given the long period of migraine in their life none of the participants remembered exactly when they had their first migraine attack. All four participants were informed by the aim of the study first after that they agreed to participate and signed an informed consent form.

#### **Data collection**

Data collection was made using a semi-structured interview schedule. The interview was chosen as the most appropriate method due to the qualities that it has to access experience of the participants. Smith J.A. et al (8) confirms the “natural fit” between semi-structured interview and the purpose of qualitative research by providing an overview of perception and experience of people on a particular phenomenon, in this case migraine as questionnaire does not possess. The final form of the interview consisted of 17 questions. Data collection procedure was extended on a period of four months, including early identification of subjects available and interviews. Interview duration was ranging between fifty and sixty-five minutes. Informed consent was sought and granted in all patients interviewed and participants’ anonymity and confidentiality were ensured. All interviews were audio-taped with the participants’ permission and lasted between fifty and sixty-five minutes. Few days after each interview, the interviewer transcribed verbatim the texts. The audio tape and transcripts were marked with different names from the real one of the participants to ensure anonymity and were stored securely to maintain confidentiality.

#### **Analysis**

The interviews were analyzed using the Interpretative Phenomenological Analysis, and following the analysis stages proposed by Smith J. A., Flowers P., and Larkin M.(8)

The first step involves reading and re-reading the transcript. The second step of the analysis is to examine the semantic content and language used by the participant, this process ensures familiarity with the text and lead to identifying specific ways in which the participant speaks, understands and thinks about an issue. In the third stage of interpretation, comments exporting from the precedent steps are analyzed in order to extract the emerging themes. Focus moves from the transcript to the notes made in the previous step, but it takes into account the text. Transformation of the notes into themes involves initial attempt to produce concise statements about what is important in the comments attached transcript. Step four involves identifying connections between the themes shown in prior. After identifying topics themes are written in chronological order and grouped according to their meanings in clusters.

## **RESULTS**

Results of the study describe the experience of people with migraine, and this instance means to live in constant uncertainty about the next attack and intensity of the pain and trying to take control. This uncertainty is hard to understand if the real experience of a migraine attack is not well known.

#### *The themes*

After analyzing the transcripts, we identified five common themes to the four participating namely: “experiencing an attack”, “part of the person”, “invisibility pain” “emotions and feelings aroused” and “coping with migraine”. Each of these themes has associated a number or sub-themes.

*Experiencing an attack.* Experiencing an attack means that the person is besieged by pain and other physiological and emotional symptoms which lead to inability to function normally. An attack is perceived as an obstacle in the way of their plans, an obstacle to happiness leading to isolation from other person for a certain period of time, and the actual pain is hard to bear. The pain is amplified by light and sounds that make the person stop other activities if possible and try different methods to relieve pain. Nausea, vomiting and dizziness are other symptoms associated with migraine, which can sometimes be more disturbed than the pain itself.

*Part of the person.* Study participants live the pain associated with migraine for a long period of time, so the pain is seen as a part of the self. If the pain is not present for a long period of time the person believe that something is wrong because migraine attacks had become something normal in their lives. In contrast to acute pain, wherein the pain is equivalent to a recent and obvious damage, chronic pain actually means life. These descriptions are presented by patients with cancer that seem to embrace pain as a reminder that they are still alive.

One of the subtopics here refers to migraine as the opposed to a peaceful life. Current lifestyles involving stress and other factors with negative meanings tend to contribute to the emergence and intensification of attacks, so for participating life without migraine attacks means living a quiet life without stress and other problems.

The second subtopic called, *permanence of pain*, refers to the familiarity with regular attacks. Thus, the participants considered that there is little chance that the pain can be completely healed and that it will permanently remain in their lives. Medical treatment and changes in their actual lifestyle, according to the participants, may lead only to a decrease in the intensity of the attacks. This perspective may occur either due to the participant’s habit with recurrent pain or from the examples they may have from friends or family members with similar issues.

*Emotions and feelings aroused.* A migraine attack brings changes in mood making persons more irritable, verbal aggressive, while experiencing emotions such as sadness and frustration. This theme consists of the following four sub-themes “irritability”, “sadness”, “feelings of vulnerability” and “need for affection”.

The emotions felt by participants at the time of an attack are mostly negative, sadness is one of these, also the participants described moments when the migraine attack awakens feelings of yearning, absence of loved ones is also felt as pain.

*Living with an invisible pain.* The invisibility of pain associated with migraine makes it unpredictable, so that affected people tend to believe that the emergence of a migraine attack is not under their control, which leads to frustration and helplessness.

Lack of control brings the concept of learned helplessness proposed by Seligman M. (9), the basic idea of

helplessness is that the person thinks that he/she does not have control over events which can lead to learned helplessness which is closely related to depression. Invisibility of pain and permanence of it leads participants to believe that they do not have control over migraine attacks.

Study participants describe that although others know about their experience with migraine, the changes that migraine produced in their behaviour and mood are not always being understood. This misunderstanding of others and the fear of being considered weak or judged as vulnerable due to illness, make participants describe that they are often reluctant to discuss with others their suffering.

*Coping with pain.* The fourth theme concerns the methods by which study participants cope with pain. All the four participating uses various coping strategies, including conventional treatment, complementary methods and a number of other specific behaviours aimed to reduce the pain.

Searching for a treatment means mostly the search of a conventional medication and all the four participants followed this type of treatment prescribed by a neurologist.

Taking medication without consulting a therapist has made participants often to abuse and to reach a high level of tolerance. Inefficiency of self-prescribed treatment was one of the reasons that led them to consult a specialist. There have been a number of positive effects regarding the use of medication, which often helps relieve symptoms and pain, but some of the participants expressed also some concerns. Fear of abuse of drugs and the side effects they can have on health make them reluctant about their usage. Fear of drugs abuse was also found in the study conducted by S. Rutberg, Öhrling K. (5), participants describe that they hesitate before taking a drug, but finally feel they have no alternative because of pain intensity, things that have been identified in jacks for the front.

As complementary methods, relaxation, rest and sleep are also the common ways to cope with pain described by the four participating. Only one of the participants provides a number of other behaviours aimed at improving pain, such as mental imagery, autosuggestion and distraction from pain through discussions with other persons.

The need to seek causes of migraine is also present, most often participants describe that they are trying to explain what led to migraine and the attacks, and all of the participants describe that the main causes of migraine is stress, fatigue and personal problems that they face.

## DISCUSSIONS

The results related to experiencing an attack are similar to other two qualitative studies.(5,6) Ramsey A. (6) interprets the pain of an attack as torture, that interpretation is performed based on the description of pain by participants as a "freight train passing through" ("freight train coming through"), "like a storm coming into my head" ("like a storm entering my head"), and most often as found in paper, feeling explosive head, "head would explode" ("head would explode").

Disclosure dilemma of migraine attacks is attributed to the fact that people tend to hide from the others that they are experiencing a headache because most of them consider migraine as insignificant and are being suspicious, considering that those experiencing symptoms tend to exaggerate.(10) The attitudes of close persons are of particular importance in the process of accepting the pain, which means being understood and believed would provide the opportunity to reveal symptoms and may have beneficial effects on wellbeing and also, on the frequency and intensity of the pain.

Coping with migraine includes a number of coping strategies including passive and active strategies such as

conventional treatment, complementary treatment and a number of other specific behaviours as relaxation, recreation, mental imagery, autosuggestion etc. Also, another way to cope with pain is trying to find the causes of the attacks, the aim is to take control of pain by identifying the factors that triggers an attack so that they can be avoided.

Experiencing migraine involves living a changed life, a vulnerable self in front of the attacks, excruciating pain, negative emotions valence, low expectations about the healing and various attempts to cope with the experience. Thus, the results of the study address a gap in the literature to capture the depth and breadth of human experience with migraine and the ways to cope with pain associated with migraine.

## CONCLUSIONS

The research aim was to describe the experience of people with migraine and how they cope with migraine, the results are based on the description of people with migraine and should be understood as possible ways to be and live with migraine.

Having a migraine attack is more than just a headache. Experience of an attack can be understood as being overwhelmed by pain and other physical and psychological symptoms. An attack is described as an obstacle in the personal plans, a hindrance to happiness and leads to isolation from the others for a certain period of time. While it is impossible to fully understand the experience of another person, incapacitation and pain caused by an attack can be imagined.

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