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# The Long and Winding Road in Chronic Migraine

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## ABSTRACT

This article is based on a research that explored the illness experiences of 16 women with chronic migraine and the healing practices employed in their daily lives. The term “healing practices” refers here to *techniques*, *strategies*, and *adaptations* employed to alleviate or more effectively manage migraine symptoms and episodes. These practices may, in some cases, interact with and influence the use and effectiveness of pharmacological treatments, while in others, they function independently of any medication intake. We analyze, on one side, which meanings are given to these practices and why they are considered to be effective once identified; on the other, how, biomedically speaking, they can reduce the symptom severity and perception by acting on a biochemical and pathophysiological level.

**Keywords:** Chronic migraine - Illness experience - Therapeutic efficacy - Healing practices

## Introduction

This article is based on a research that integrates two analytical paradigms, namely medical anthropology and neurology, in order to investigate the healing practices mobilized by chronic migraine patients and their efficacy in the everyday disease management<sup>1</sup>.

The term “healing practices” refers here to *techniques*, *strategies*, and *adaptations* employed to alleviate or more effectively manage migraine symptoms and episodes. These practices may, in some cases, interact with and influence the use and effectiveness of pharmacologi-

cal treatments, while in others, they function independently of any medication intake. We analyze, on one side, which meanings are given to these practices and why they are considered to be effective once identified; on the other, how, biomedically speaking, they can reduce the symptom severity and perception by acting on a biochemical and pathophysiological level.

Migraine is as a neurological disease characterized by recurrent headache episodes, often unilateral and pulsating, associated with neurological and vegetative disorders. The clinical features are different from patient to patient, as does the sequence of symptoms that occur during each acute attack. In their episodic form, attacks involve different phases, with specific neural mechanisms and symptoms. A premonitory phase, prior to the onset of the actual headache, is characterized by excessive yawning, thirst, somnolence, food craving, cognitive difficulties and mood changes associated with hypersensitivity to intense sensory stimuli (such as sounds, light, smells). Transient neurological symptoms, known as migraine aura – typically visual disturbances – occur just before the actual headache begins. The postdrome phase is mainly characterized by symptoms such as fatigue, concentration/comprehension difficulties and neck stiffness.

From a biomedical point of view, triggers in migraine are no different from the factors that can cause a normal headache in apparently non-migraine sufferers. These triggers can be many, including diet and exercise<sup>2</sup>. They also change over the years: strenuous exercise or skipping meals are common triggers in young people while in adults sleep duration or problems associated with neck and teeth may be predominant. Several other factors may trigger migraine as for example stress and lack of sleep<sup>3</sup>. There are therefore several causes. We should imagine a “threshold” given by individual genetic and epigenetic factors; this threshold is lowered or raised by some “external” body components, as well as by “internal” brain changes.

Migraine is a multifactorial disease characterized by therapeutic complexity<sup>4</sup>. Although it has always been an intriguing medical research object and several studies have been developed in recent years, at present no clear physio-pathogenetic model of migraine has been identified yet. The etiological processes are still debated and not completely understood<sup>5</sup>. Significant advances have been made in characterizing migraine as a brain disorder and in identifying evolutive functional changes in different brain areas during the migraine attack. However, despite the studies on pain pathways involved during the headache phases<sup>6</sup>, the molecular changes that actually trigger migraine episodes remain unknown. Migraines also occur in people with a more sensitive nervous system; brain nerve cells are in this case easily stimulated, by producing electrical activity that temporarily disturbs several functions, such as sight, balance, muscle coordination, and speech. This can cause symptoms that precede the headache. Migraine occurs when the 5th cranial (trigeminal) nerve is stimulated. This nerve sends impulses (including pain) from the eyes, scalp, forehead, upper eyelids and mouth to the brain. When stimulated, the nerve may release substances that cause

painful inflammation in the brain's blood vessels (cerebral vessels) and in the tissue layers that cover the brain (meninges), thus resulting in throbbing headache, nausea, vomiting, light and sound sensitivity.

The pain process in migraine is likely multifactorial, involving both the activation of nociceptors in pain-sensitive intracranial structures and a dysfunction of endogenous pain-control pathways that normally modulate or inhibit pain. These processes are triggered by several elements; pain is actually a sensory and emotional experience<sup>7</sup>, characterized by affective-motivational, cognitive-evaluative, and sensory-discriminative dimensions. Although this is particularly important for the biomedical comprehension of migraine, it is not completely clear how exogenous factors can influence physical pain. We know, however, that pain can be understood by considering organic/physiological, psychological and environmental elements as well as other components linked to the personal illness experience, to the "pain-related phenomenologies" that make this phenomenon thinkable and semantic<sup>8</sup>.

From our perspective, the complex nature of pain demands a scientific approach that integrates its psychological-emotional, symbolic, and relational dimensions. This lens enables a convergence between the biomedical and the anthropological paradigms, fostering a shared conceptual framework that supports more holistic, patient-centered therapeutic and care practices. In this research context, we draw upon a specific body of knowledge that allows us to analyze how chronic headache's causes – as well as the processes determining its improvement or worsening – can be better understood by considering the body as *conscious*, as a sentient, thinking and acting psychophysical unit. Consequently, the pathological condition is conceptualized as a phenomenon in which exogenous factors may play a significant role in the etiological process: by influencing emotional states and psychological/subjective experiences, these factors can indeed affect physiological processes either in a negative (pathogenic) or in a positive sense<sup>9</sup>.

We will address these issues in the following paragraphs. Starting from data collected during the ethnographic interviews conducted with 16 women suffering from migraine, we will explore some factors that shape personal illness interpretations, as well as possible "triggers" that can impact the body mechanisms by worsening migraine symptoms or causing acute migraine episodes. We will then analyze the techniques, strategies, and adaptations which not only reduce the symptom severity but can also postpone or prevent acute migraine attacks.

### **Methodological Note**

This research lasted 12 months (March 2023 - March 2024). The ethnographic interviews were conducted with 16 female patients at a neurology and pain clinic in a hospital in northern Italy<sup>10</sup>. Interviews, although conducted by using an interview guide<sup>11</sup>, allowed the exploration of several topics, including: the illness history, from the symptoms' onset to diagnosis; medical treatments, pharmacological therapies and

their efficacy; the impact of migraine on interpersonal relationships; individual considerations about the disease and its causes, as well as the potential “triggers” that can exacerbate symptoms and/or cause migraine acute episodes. Finally, what potential “healing practices” have been identified and why they are considered effective both in decreasing the symptoms’ severity and in postponing/reducing migraine’s attacks. Interviews have been transcribed verbatim and analyzed following a thematic methodology<sup>12</sup>. Data interpretation and elaboration are considered here as an attempt, albeit incomplete, to reconstruct what happened during each interview framed as a knowledge co-construction process, being conscious that illness narratives can provide only a partial contextualization of each personal illness experiences. These narratives are thus seen as retrospective elaborated accounts which allow to represent the illness event<sup>13</sup> and, therefore, they do not fully capture the complexity of living with migraines or the circumstances and needs that occur in patients’ daily life.

Women interviewed were Italian, aged between 26 and 58 years, and had each been previously diagnosed with migraine<sup>14</sup>. Fifteen of them were employed: eight as health-care professionals<sup>15</sup>, five as office employees, and two as freelancers. One patient was unemployed after having worked for many years as administrative secretary. Seven were married/cohabiting with children, five were cohabiting without children, two were single with children, and two were single without children. The participation of only female patients reflects a gender discrepancy<sup>16</sup> that is supported in literature but which still needs to be sufficiently understood in biomedicine<sup>17</sup>.

Being aware that the involvement of 16 patients may present limitations from a quantitative and biomedical perspective – since results cannot be statistically generalized to a larger scale – we highlight how our choice was motivated by the adoption of an ethnographically oriented research methodology, with the intention of drawing on a small number of narratives which, given their richness, allow to explore and identify key themes and associations evoked in relation to the lived illnesses experiences. We also believe that this preliminary analysis can provide the basis for future research phases on a larger scale.

This study aimed to explore new topics, albeit in deep continuity with research paths undertaken by the two Authors, particularly in the field of pain<sup>18</sup>. We know that the dialogue between our disciplinary perspectives is tortuous, not only because it is complex to bring them back under a unified “science of the human being”, but also because it is difficult to blend distinct languages and conceptual apparatuses<sup>19</sup>. However, by recognizing that a “purely” naturalistic or a “purely” sociocultural explanation is insufficient to shed light on both illness and healing practices, we tried to integrate two *interpretations* starting from the necessity of denaturalizing the body, the disease and the care, and by focussing on the multiple factors that shape and transform these “processes”. Therefore, from our perspective, the aim was to investigate what happens *into the body* by considering what occurs *outside the body* (in the connections between social

situations, emotional states, and physiological changes), without assuming that this approach should yield one “objective truth” provided by a single knowledge perspective. This has often led to a methodological symmetry’s reinforcement between the so-called “hard” and “human” sciences, by hindering the development of a broader, holistic and integrated conception of health, illness and care.

### “Pressure Cookers”

Despite several differences, some elements bring together the lived experiences of the women met during this research.

The first is the long and prolonged period of living with migraine. Most of the patients (14 out of 16) indeed stated that they have been suffering from headaches for as long as they can remember, “since always” i.e. during childhood or adolescence. However, migraine changed over time, typically worsening after the onset of the first menstrual period. The frequency of migraine episodes, as well as the symptom intensity and severity have also fluctuated. However, over the years, the headache progression has not been experienced as an initial sign of a lifelong condition that would characterize the patients’ biographies. Most of them stated that the headache was experienced personally and was considered by others (especially family members) as a problem of minor importance, not requiring particular attention or specific medical investigations. This especially happened when other family members suffered from migraines and, more specifically, when it appeared as a disorder “inherited” from other women, such as grandmothers, mothers, aunts or sisters.

Sometimes by following family members advices, other times and more sporadically, after the general practitioner prescriptions, patients have assumed analgesics, integrators or non-steroidal anti-inflammatory drugs (NSAIDs), by gradually increasing the dosages, and without following ongoing treatment plans or referring to medical specialized clinics. The “self-medication”<sup>20</sup> – described as what characterized a long period of ineffective medicine consumption – unifies the different patient’s illness experiences as does the diagnostic delay<sup>21</sup>. Indeed, most of the patients referred to different specialists after having *re-considered* their migraine, following several years of living with an headache which, at that point, could no longer be considered as “normal”. They consulted acupuncturists, physiotherapists and neurologists, and began testing multiple treatments and medications. Only after years this research eventually culminated in a diagnosis and in the identification of medical therapies that, although had positive effects or reduced the headache attacks’ frequency, did not provide a definitive remedy, and therefore did not guarantee a total recovery from migraine<sup>22</sup>.

Ethnographic interviews show that patients may identify what makes their daily headaches more severe or what triggers migraine attack episodes. These triggers are varied. There are several environmental factors, such as exposure to intense light, sounds, loud noises, strong smells, wind, sunlight, humidity, and temperature changes. Hormonal

fluctuations – particularly those related to the menstrual cycle – as well as changes in sleep-wake rhythms (including sleep deprivation or excessive sleep) and dietary habits (such as consuming specific foods and drinks) can also worsen or trigger headaches. Additionally, lack of rest, fatigue, and both insufficient and excessive physical activity play an important role. Alongside these triggers – widely documented in the biomedical literature<sup>23</sup> – there are additional factors which are less “manageable” in daily life through habits and lifestyle changes, as they seem to be related to the patients’ everyday lives, to the multiple spheres of their biographical histories.

Indeed, many women state that what triggers migraine should be sought in specific personal situations that drive them “beyond their limits”. These situations, as Ida<sup>24</sup> – 49-years-old woman, self-employed, suffering from migraine mixed with headache – describes, can transform into “pressure cookers”: after having accumulated so much, headache breaks out.

*I have two jobs [...] so I use my head a lot. Perhaps that's my problem, that I use my head too much. It could be. [...] I took on both of these jobs after leaving my previous one. At the time, it was my only employment, but the work environment was so inhumane that I felt forced to leave... and indeed, during that time, I had severe headaches, but even before, when I worked there, because I wasn't feeling well with myself or with other people [...] My headache is like a pressure cooker that explodes after too much has been put inside my head. We [patients with migraines] can handle a lot of things at once compared to other people. But still that much that, being human, leads to the explosion [...] I have great organizational skills because otherwise I wouldn't be able to do so many things at once and in such little time, and I think I do them quite well... not superficially, I'm definitely not a superficial person [...] and yet, evidently, too much is too much, as it is said. [...] I have this dynamic personality, and when I experience this physical collapse, because it's a total physical collapse, I'm unrecognizable, my personality changes completely. So, to those who see me regularly... it's upsetting, right? It hurts. [...] Then there are those who don't believe that you're really sick, but that's another story [...] but if someone loves you, it's clear that you're really unwell... and so they often say to me: "Ida go slowly, give up here, give up there", but for me it's impossible to do that [...] because my world is a complex one, with many people relying on me [...] with my family responsibilities to manage, with a job, actually several jobs, all mentally demanding. [...] The truth is, I still don't have a clear idea of what exactly causes my headaches. My impression, though I can't say for sure, is that it has something to do with tension, maybe an accumulation of... let's call it stress?... a physical or mental overload. That's why the only logical explanation for me lies in my entire life's experience. Is that so? I don't know. And if so, I wonder what I can do? Because, unfortunately... I live in this world, I mean, I have to go to work... should I change jobs? Change my personal life? The society? Should I distance myself from all the people in my life? I don't know... what can I do? [...] I was once told that headaches and, in general, migraine does not go away, it is a constant that will remain for your entire life. It can be mitigated, but even monoclonal antibodies are not resolute. They can attenuate but not solve the problem, which will remain for the rest of your life and that, as I said before, in my opinion is also associated with how you live and with certain personality types, like mine. (Ethnographic interview with Ida, September 2023)*

Ida's narrative is significant as it condenses and foresees numerous issues mentioned during other interviews. For example, Franca and Matilde – respectively 49 and 35-year-old women, employees, both suffering from migraine with aura – claim to be somehow “predisposed” to migraine because they *think too much*, having to deal with several complex situations, which “provoke” headache attacks:

*[...] I think too much, but it seems that this is how the brain of a migraine sufferer works, I don't know [...] I have to analyze any event that happens in my life, I have to elaborate it, maybe I'm obsessive about this. [...] If only I had some kind of tool, you know? Something like a broom to sweep all the thoughts out of my head... that would be perfect. [...] I'm convinced that this could improve the quality of my life as a migraine sufferer [...] [but] I can't do it, I think even at night, of course! I think about all the things I'm going through at work, or at home, things I need to do that keep me awake, you know [...] After that, each of us has a specific area where we somehow... we're bodies... so, we have to take out. I mean, we are a system, really... if you want, electrical with hemodynamics, and somewhere, this energy which is created by living events or things, and in mentalising over and over again has to come out [...] I mean, for sure, this really impacts the course of my chronic condition. [...] I'm usually very organized. I mean, to give you an example, I live in an earthquake-damaged house, and I cannot tell you what it meant rebuilding my house... I had to think about everything, from the first tile to the tax agency, the financial authorities, the state, and so on [...] And I took care of everything... at home I'm the reference person because they are reassured by knowing that I'm the one thinking about everything, always. [...] But when I am under a significant mental or physical stress, I get the migraine of the century. (Ethnographic interview with Franca, October 2023)*

*I never suffered from migraines before, and I can tell you that my life has always been quite complicated, given everything I've always done. But migraine only started in recent years, and... beyond hormonal changes and everything else, I think it is really a symptom of how on edge my life has become, otherwise I would've suffered from it all along, I mean, I've always had a full life but I didn't get headaches. Now I do. That means that... either I've demanded too much from life in the past and now I'm paying the price, or maybe it's simply that everything has become too much to handle now [...] I sometimes feel like as if inside, I have... like a bomb ready to explode, as if I have something inside that's ready to blow up, and that's how I feel when my migraine begins. (Ethnographic interview with Matilde, October 2023)*

The life of Matilde, married with two children, is “on edge” due to several factors: work-related rhythms and responsibilities are combined with ongoing management of the domestic life. She describes her family situation as “critical” due to financial problems that “crush” her, that break into her daily life by shaping the family relationships. This impacts her migraines:

*It's all a whirlwind in my house... I get up at six, and by seven I'm already tired because I have to do things at home, in the morning at six or in the evening at eight, before or after work... it's all so much for me that I'm exhausted, and the physical and mental fatigue I experience really exacerbates my headache. [...] I spend seven and a half hours at work, and seven hours... that is the rest of my life, at home. I have no friends, I have nothing, both of my main focuses are these and both expose me to heavy situations [...] my head just can't follow me, and I think my family environment also influences me a lot... because, well, I*

*have a borderline family situation, let's say, financially it's a disaster, and this makes me feel crushed and always in conflict with everyone... and when I think about it [...] when things related to this happen, [migraine] starts from my eye, like I realize it starts from the frustration I feel. [...] In the past, I also did a lot of yoga, I used to take better care of myself and was I more careful about many things. But now, money is tight, so I've had to cut back on many things... and this pisses me off even more... and I get a headache... just in a situation as if I'm ready to explode, as if all the stuff in my head are ready to... I mean, I'm full. This is the image I have of myself, of fullness of stuff, in short. [...] It is my body that makes me realize that there is something wrong [...] I ignore it, I put it aside and I tell myself: "No, now I have to think about this, I have to think about that" and I never think about myself... to give you an idea, I really need to listen to myself more. The headache, in my opinion, when it starts it's as if it's telling me: "Matilde, you need to stop, you've clearly reached your limit" [...] What I'm experiencing is hurting me, so I need to find something different, something in my family life... if I don't bring some peace into these parts of my life where I spend most of my time, my migraine will never go away. [...] So, I think my migraines happen because I don't have... I can't keep up with things anymore. They're bigger than me, much bigger than me. (Ethnographic interview with Matilde, October 2023)*

If material living conditions, socio-economic insecurity and vulnerability, as well as social discrimination, exclusion and isolation can act as predisposition and worsening factors in migraine and headache development<sup>25</sup>, the illness phenomenology seems here to be shaped also by further elements that refer to what is experienced by patients within broader life contexts<sup>26</sup>. Illness' meanings are so given in bodily, emotional, familial and social terms, they become meaningful when placed within a polysemous framework. In this framework, the energy's dispersion, physical and mental overload, tensions, fatigue, and responsibilities experienced in social, work or family circumstances, become crucial.

For Sara, a 31-year-old nurse, acute migraine episodes are mainly related to what happens in her "stressful" working environment:

*I don't really associate headache with a specific triggering event or a period of life... I can associate it with a certain period when there's more stress. [...] For sure in a much more rushed period, that yes, having perhaps... less peace, so to speak. Obviously, during that time, headache is more likely to be triggered, so it comes more often, but there's no period when I don't have it, basically. [...] What at present can mostly cause my migraine is my job. Turnover has a great impact. [...] Our work shifts are very irregular, we often skip rest after having worked during the night. Obviously, for me, those are headache triggering factors [...] [I work in] the emergency ward... so of course I think headache worsening is also due to my job, as I work in a highly stressful environment, with constant stimulation and pressure, you have to be 100% focused all the time, stay on the ball [...] Obviously in a hospital ward like this, after having worked during the night shift without resting, I'm bound to get an headache. [...] I had just moved to a new region during the Covid pandemic and I was really lonely. [...] I went through a change of work life, I changed everything, colleagues, hospital ward... so it was definitely a long adjustment period, also because of Covid, which was also very stressful on its own [...] This caused more frequent migraine attacks [...] [During that period] I felt like I had to spend so much energy, and obviously, for me, it ended up in recurrent headaches. (Ethnographic interview with Sara, September 2023)*

Anna doesn't refer to the impact that Covid-19 pandemic has had on healthcare professionals' experiences<sup>27</sup>; however, she states that the stress lived at her workplace has a clear effect on her body and often triggers migraines. Lea shares the same idea. During our interview, she described herself as "happily unemployed" after having worked as an executive assistant and a commercial secretary for several companies over the years<sup>28</sup>:

*I realize that when I'm particularly stressed at work, I get really stiff, even in my shoulders. I bend in a posture that is always bad. Another reason is that I can never switch off my mind when I'm stressed; there's always something I'm thinking about, so I can't stay too relaxed. I feel all that tension in my shoulders, and that's when I get headache. There might be other minor factors, but for me, the main cause is this. (Ethnographic interview with Anna, September 2023)*

*So, as I told you, it's part of my character to... to face things as if they were all personal to me, both personal and work-related... I tend to take on too much, and I really feel it inside me, there's this effort, also physically, especially in my head... it's a real physical strain inside my head, which is greater than what is required, especially when things don't go the way I want, and this leaves me with an after-effect that has triggered my migraines over the years. [...] [My way of being at workplace] isn't aggressive, it stems from a kind of inner drive, from the urge to resolve things, or from the need to carry forward a battle you believe in blindly [...] There is a tension and energy build-up inside that... is exaggerated perhaps in relation to the situation, then... it always depends... there are situations in which you cannot let off steam in your own way... so, all these thoughts you have to keep inside like a in a pressure cooker. You can't let the steam out, and obviously, it pushes against the walls [of the head]. And there... I mean, I find myself like my head is exploding. There the only way to deal with this is just to close everything off, close the door, no contacts and go to bed. (Ethnographic interview with Lea, September 2023)*

As a somatic condition that mediates and shapes the relationship between the self, others, and the surrounding context and, simultaneously, as an "object" through which this very relationship can be examined and represented, migraine – precisely because it affects a central and symbolically part of the body, the head – is narrated through both individual and collective histories. These accounts unfold within specific "semantic networks"<sup>29</sup>, in which terms such as "home", "kids", "family", "time", "commitments" and "work" structure discourses that primarily reflect *feminized* experiences.

*Monica: Also my mom suffered from migraine, and as I told you before... I don't have a great relationship with my mom, I don't know if it's because of the migraine or not, I don't think so... now I joke about it... but obviously I've always said it's due to a genetic factor, just like for my cousins, my aunts, and so on, because we all suffer from these types of headaches. However, I often look for a different answer.*

*Chiara: Did you find this answer?*

*Monica: Not really. Well, to be honest... I've never really thought about it, but if I had to think about it now... I think of my life as a very frenetic one... I mean, at my place, we wake*

*up at six in the morning, I have two kids... the breakfast... it's a nuthouse... the schoolbag, one thing and another... but I think a lot of families are like that... right? Then, two kids, one plays football, the other dances, you have to organize, driving them here and there... the planning you have in your head... anyway... so I try to think that it's not my kids, for heaven's sake, but... it's also my current life. [...] My husband and I are both alone, we don't receive help from anyone, and we both work. Actually, if I imagine a life a little bit more... no light... a bit slower, with a little more help. [...] If I had had the chance to run my life a little slower, at a slower speed, with work and home better balanced, maybe, I don't know... I can't say if that would have helped me with my headaches, but it would have definitely made me feel better. Let's put it this way, it would have helped me to reach my well-being. (Ethnographic interview with Monica, September 2023)*

*[...] I've made a clear connection: I feel terrible when I'm stressed and when I don't sleep. And in my job, not sleeping is just part of the deal, and my body really feels the impact of that. I mean, you take that sleep away, but eventually your body asks for it and when you don't give it what it needs, it starts to break down [...] So, in short, I've clearly understood that fatigue, lack of sleep, and stress are triggering factors for my migraines. [...] What you do at your workplace is mixed with what you have to do at home, and with two young kids you've got a lot of work to do [...] I mean, is it normal... migraine is the least you can get! [...] Because the famous woman... who still does everything, I do it too because culturally, coming from the South [of Italy], it's almost unconscious that the woman does the cooking, the dishes, the grocery... so finally the woman works twice... always, and here is the point! So, it's almost an illusion to think a woman can really go to work when she also has to work at home. And if she's a mother, and there's family to take care of, it's even harder... but time is one, the day has 24 hours, and we fill it with 48 hours' worth of stuff. And I think you get a migraine afterwards, because the body holds its minimum, my body holds this minimum. It could be that for someone else... everyone knows what its minimum is, but when it is exceeded it is exceeded [...] The human body, my human flesh, needs a human rhythm, and I think we are working now in an inhumane manner. (Ethnographic interview with Camilla, September 2023)<sup>30</sup>*

Migraine emerges as a phenomenon that gains meaning when framed within particular social settings and configurations that shape specific gender interactions and relations. Looking at the Italian historical and sociocultural context, these configurations still strongly structure an unequal distribution of domestic and care work that often falls on women<sup>31</sup>. While this results in the difficulty (if not impossibility) of daily balancing productive and reproductive work<sup>32</sup>, it equally exposes women more than men to experience overwork, stress and fatigue – i.e., crucial factors in the migraine' etiology<sup>33</sup>. The way sociocultural contexts and settings mold gender differences and inequalities “impacts” women's bodies and health<sup>34</sup> also strengthening the migraine misrecognition processes, precisely because this disease is considered to be *primarily* experienced by the female population<sup>35</sup> and is, therefore, shaped by gender biases that eventually also decrease healthcare access possibilities<sup>36</sup>.

However, migraine delegitimization also occurs outside the biomedical context, and social relationships seem to play a key role in this process. Literature frequently highlighted how migraine patients perceive their health problem as discredited within fam-

ily, work and interpersonal relationships<sup>37</sup>. Ethnographic interviews show how it is often challenging to make people understand the nature, severity, and effects of migraine, both due to the predominance of self-reported symptoms (including pain, nausea, visual disturbances, fatigue) compared to the more visible one (such as vomiting, dizziness, sweating, etc.), and because migraines are often confused with regular headaches, that is, with a “common” condition. Cloe and Bruna<sup>38</sup> express this as follows:

*[The headache] in a sense didn't exist as a problem because I didn't show it much, maybe [other people] didn't even notice. Those who did might have seen it in my eyes, my eyes tend to shrink when I have a migraine, but especially in the beginning, it wasn't perceived as a real disease... because around me there wasn't... I mean, I didn't really understand myself that having migraines was actually a disease. I thought it was just something personal, something I was somehow responsible for, something that lacked the dignity of being considered a medical condition [...] I think headaches are still not understood, it's not understood that it's a disease just like breaking a bone. Many people think it's just the common headache we all get. (Ethnographic interview with Cloe, September 2023)*

*Well, when you say you have headache, people never really understand the gravity, because everyone has had a headache at some point, or a migraine experience, or some sort of headache in their life. The difference that most people don't understand is that there are migraines and migraines, there are headaches and headaches, and that mine, like others who suffer from tension headaches, isn't just a headache, it comes with powerful and disabling symptoms. So, the lack of understanding is something that has always bothered me and also made me suffer, because it almost seemed like I was trying to take advantage of this, for example, at my workplace. Or that I wasn't strong enough to bear it... they say: “Oh, come on, what's a headache? Really? You have to stay home because you're sick?”... this is definitely something that stresses me out [...] because... just being perceived as cunning... or like I'm a liar, or someone who can't tolerate pain, as if I'm being judged, right? (Ethnographic interview with Bruna, September 2023)*

For Bruna, as well as for Paola<sup>39</sup>, migraine is a condition that can be fully understood only by those who experience it firsthand. This gap between public narrative/representation and private illness' experience produces several effects.

*When I have these severe headaches, I tend to avoid meeting people, to not talk... I isolate myself. So, [migraine] hasn't allowed me to live... a peaceful life... because I always felt disabled, because no one around me had this problem with headaches. Not at home... they were rare, my mom sometimes had headaches, but rarely, and even my friends, no one had this problem, so I didn't... I was actually a little ashamed because I thought: “Oh God, I'm always the one with the headache”... and so sometimes I would take a pill and try to pretend I was fine, but it was like having a nail in my head that hurt, so... I tried to be present but it was an endless struggle for me. [At that time] I also felt obligated to socialize and so it was a nightmare. (Ethnographic interview with Bruna, September 2023)*

*Paola: I believe that headaches are... how can I say? A physical problem, you can't really say, a disease that's not socially recognized, so in almost 90% of the people I've met, I've found a lot of superficiality in this regard. When I say: “I can't come to work because I have*

*headache” they say: “You’re staying home for the headache?” ... sometimes I’ve been hurt by jokes or playful situations... “What’s up? You have headache?” ... yes... this thing really upset me because... you know, when the relationships then become deeper and maybe they see me with my face... after three days of migraine, when I’m destroyed and they ask me: “What did you have?”, [I reply] “Migraine”, [They say] “Oh, I didn’t think it was that kind of thing”.*

*Chiara: Does this happen only at your workplace or also elsewhere?*

*Paola: With my family too. For example, my brother still hasn’t understood this thing... he still doesn’t really understand the problem I have. In fact, it really bothers me because he still takes it as an excuse, the fact that I [...] give up things that we decided to do together the day before that I know will trigger my headache. (Ethnographic interview with Paola, October 2023)*

Social relationships transform migraine into a “shared” and public phenomenon, or conversely, in a “private affair” confined to the individual dimension. They become what *materializes* symptoms, making them sometimes visible and other times invisible (credible or unthinkable, real or unreal). Given the impact that migraine has on the quality of life<sup>40</sup>, patients seek to manifest their condition; however, these communication attempts often fail and eventually result in a kind of secrecy around the symptoms severity and perception. Many women, for fear of not being understood or believed, or because they think they suffer from a disease that is strongly stigmatized<sup>41</sup>, tend not to “socialize” it. However, they experience every day the difficulty of keeping “hidden” something that, indeed, has shaped the self-perceived identity over time: “In my view, I don’t have a disease”, Sara states, “For me, it’s something that is part of me and my life, always and forever”; “I only know myself this way. Since I can remember, I’ve always known myself with migraines, I believe that is part of me. I would struggle to think of myself without that” adds Bruna.

Nevertheless, interpersonal relations also play an important role in a further sense: they can themselves negatively impact on the migraine severity and frequency. For Bruna, Monica and Franca, it is mainly what happens at the workplace that can trigger migraines episodes:

*I’m convinced that many people don’t believe me and haven’t believed me. [...] For sure, this has happened many times at work... you know when you have to call at five in the morning to say you’re not coming because you can’t get out of bed and knowing that, on the other side, they say: “Oh, you’re not coming because you have headache?” it’s definitely something that causes me anxiety, and this automatically makes my headache worse. (Ethnographic interview with Bruna, September 2023)*

*When I have headache, I stay alone because there’s no point in trying to explain what’s wrong anyway. Over time, many people haven’t believed me and this made me nervous and irritated. This could be another reason for stress, which, as I told you before, makes my headache explode. [...] When your headache is really strong, you expect people to understand. But sometimes, you can’t even find the right words to express yourself. At*

*work, for example, you try to explain, you think you've made your point clearly, but maybe you didn't. Or maybe others just didn't get it for their own reasons. I don't know. What I do know is how much effort it takes to communicate when I have a headache. It's a huge effort! And that makes me even more upset, because I think: "Damn, I'm still here, pushing through despite the pain". And that frustrates me. Because in the end, everything affects the headache, good things, bad things... it's a vicious cycle. (Ethnographic interview with Monica, September 2023)*

*I've noticed that when someone around me makes me angry, it directly worsens the pain. If something upsets or stresses me out, I can literally feel my head start to throb, it intensifies the migraine. For example, if I'm in a meeting and already dealing with a migraine, I might take a pill ... but then, if someone irritates me or there's some kind of conflict, the pain gets worse. I can feel it escalating. I become more uncomfortable, and it feels like I lose whatever little control I had over it.*

*Chiara: A control over it... in which sense?*

*Franca: In the sense that it seems like even the effect of the pill disappears, like it's no longer working, and so I feel that it's getting worse and I feel myself getting worse [...] Afterward, of course, I have a specific time for taking medicines, so I wait for the right time to take it again. (Ethnographic interview with Franca, October 2023)*

For Giada some other relationships can cause tension by clearly affecting her migraines:

*[...] I have always been a sunny and active person... and when you change from one day to the next... some friends don't understand, and there were even some arguments... like: "You can't even come out for my birthday?" and I couldn't explain: "I can't even get out of bed, and if you can't understand this, I'm sorry". We had many tensions, because they thought I was exaggerating or just being selfish. They couldn't understand what I was going through. And I couldn't find a way to explain that the pain was so intense, so overwhelming, that I was completely at its mercy. I couldn't do anything else... I went through very difficult situations [...] I felt very stressed, I was stressed because I couldn't understand what was happening to me [...] I kept asking myself: "I wonder what everyone thinks of me. Do they think I'm pretending to be sick?" and this really upset me, and I think this also caused more pain, for sure. [...] [For me] any external input, things that happen with other people may cause an emotional imbalance. I externalize it with physical pain [...] I'm not prone to being depressed or anxious... I'm much more likely to experience physical pain than mental pain. This is what I think... I've realized that this is my way of expressing emotional imbalance. [...] physical pain is my way of expressing negative emotions (Ethnographic interview with Giada, October 2023)*

Giada's narrative echoes some elements that have emerged during several ethnographic interviews. For Cloe, what happens in family or working contexts can lead to conflict situations that "subject the body to tension", thus causing headaches. For Camilla, migraine is "emotional", is triggered during stressful social and interpersonal situations. Exhaustion, fatigues, pressures, disappointments, and negative emotions thus bring the headache to "harbor" silently before "exploding", as if "something un-

fair to you, and that has hurt you inside, messes you up and, for sure, you feel it all in your head” (Ethnographic Interview with Camilla, September 2023). Monica explains that “recurring thoughts” tied to “dysfunctional” relationships often lead to a sensation of “head heaviness” which she describes as a kind of early warning signal, a “calling card” for an oncoming migraine. The weekly migraine episodes recurrence is, for Bruna, connected to some “toxic” interpersonal relationships; negative energies are released in specific circumstances, they act as a “fuse”, triggering the onset of the migraine: “I may be someone who gets touched by everything, as if I had a skin with too wide pores, so it’s like I absorb more than normal people... but the toxicity of some discussions leaves a trace even after, when certain thoughts creep in my head, I get fatigued and my headache breaks out” (Ethnographic interview with Bruna, September 2023). For Paola, migraine is “the alibi to disconnect” from heavy situations, a kind of “escape route” to completely withdraw after getting fatigue and stress. Finally, for Rita a combination of factors triggers migraine where, once again, social relations and situations experienced with other people become central:

*Rita: Getting little sleep, stressing my body a lot, and not being understood or supported when these difficulties occur... my body lets me know, it rebels by giving me these crazy headaches.*

*Chiara: So, in your opinion, is the headache a kind of physical reaction to these situations?*

*Rita: Yes, of course [...] let’s say the headache is a reaction to what happens to me, because I am the type of person who has difficulty letting things slide off, and I think that’s the cause of the autoimmune diseases I suffer from, in addition to migraines, because it’s a battle against myself... it’s like a self-sabotage, almost like a suicide, because the antibodies no longer recognize parts of your body as part of your body [...] the symbol of my entire life, an ongoing battle against myself. [...] In relationships, I tend to blame myself a lot... “I was wrong, I did it... me, me, me” and this overthinking stress me out, increases cortisol, I get bloated, I get a headache, it increases and it doesn’t go away. So... it’s all a combination of situations, but it’s all socially based. It is not the headache that affects my social situation, it is the social situation that affects my headache. (Ethnographic interview with Rita, October 2023)*

Ethnographic interviews show that it’s not the stress *per se* that can trigger migraine symptoms or headache frequency episodes. “Positive” stress – i.e. related to situations that, although demanding, are considerate as pleasant (such as spending time and energy with one’s children or at the workplace) – is not perceived as a “shocking” or an impacting factor. Headaches are triggered when some events and experienced circumstances result in an energy dissipation, an accumulation of responsibilities, tension, fatigue, tiredness, emotional states that cause a “negative” stress. While, on the one hand, these factors can provoke physical and mental overload that worsens migraines or triggers acute headache episodes, on the other hand, they acquire specific meanings that ultimately prompt a reflection on the relationship between the body, the

self, and the broader social and relational context. Perceived symptoms thus become linguistic facts, symbolic constructions that allude to a biological dimension but also allow a range of situations, emotions, and conflicts to be verbalized through a “migraine language”, which is potentially understandable to other people. Yet patients do not exclusively refer to biomedical knowledge to find a migraine relief; indeed, they believe that some techniques, strategies and adaptations are equally effective in dealing with the symptomatology severity and acute migraine attacks.

### **Listening in silence: techniques, strategies, and adaptations in chronic migraine**

The women we met during this research have spent several years searching for the “right” migraine pharmacological treatment. However, medical examinations often ended in the prescription of medicines that have lost efficacy over time, despite the exponential dosages increase. Navigating the labyrinth of the healthcare system – both public and private – represents a similar and yet distinct experience, especially concerning the identification of an effective preventive treatment for migraines. Some patients describe how such research eventually led, after various attempts, to the identification of a daily therapy consisting of medicines (such as monoclonal antibodies, triptans, or anticonvulsants) that can make migraine attacks disappear for months, while not acting on the daily perceived symptomatology. Others stated that these same medications only reduced the attacks’ frequency or that they have acted solely on the attack severity without, however, altering their frequency. Although, in most cases, the identification of a more effective medication marks a clear “before” and “after” in the illness history, interviews show that pharmacological substances, on the one hand, provide a temporary relief but, on the other hand, do not guarantee a complete recovery<sup>42</sup>. The relation with these care objects also changes from case to case. Several patients take medication only when it becomes essential during the most acute phase of a migraine attack, while others choose to postpone its use until the attack has persisted for several days. Others, despite the ongoing migraine crisis, take medicines only in certain circumstances, for example, when they are able to isolate themselves while waiting for the pill to take effect; medicine actually seems to be depowered – to lose its therapeutic force – if consumed in spaces where distractions, noises, lights or other triggers (including stress) that usually exacerbate symptoms are present, strengthening headaches. It has already been highlighted that, in the management of pain, patients often assume responsibility for their own care by independently managing their prescribed medications<sup>43</sup>. What, however, seems particularly interesting here is rather another point, namely that the medication intake appears to be combined by several actions, that we first call here *techniques*, which somehow enhance the therapeutic efficacy of the pharmacological substances. Patients spoke about these techniques during the ethnographic interviews:

*When I have a headache, the most effective response is immediate: I need to turn off the lights, remain in complete silence, avoid speaking, lie down in the dark, and take my medication. Ideally, I sleep, and although I wake up a bit slow or groggy, this routine usually works well for me. The challenge, however, is that it's not always possible, especially when I'm at work. Sometimes the migraine improves within twenty minutes, sometimes it takes longer; it really depends on whether I'm able to carry out these steps. The problem is that it's not always logistically feasible. For instance, if I'm having dinner with friends, I can't just excuse myself and isolate in a dark room. In those situations, I still take the pill, but it tends to be less effective, and relief takes much longer to arrive. (Ethnographic interview with Cloe, September 2023)*

*In bed, without pillow, lying on my back, with my eyes closed, in the dark and in silence, so no noise at all, an ice pack on my head, medicine, and I stay there for at least a couple of hours. No smells, because they disturb me terribly, and I wait for the pain to become more tolerable... because I go through an intense phase at the beginning, which is very strong, and it feels like something inside is beating and trying to get out. So, it makes me feel better to think, like pressing my head as if I need to contain it. Because it's like something is trying to burst out, I mean It's hard to explain, but applying pressure to my temples with my hands, almost as if squeezing them, seems to bring some relief. (Ethnographic interview with Bruna, September 2023)*

The act of seeking darkness and silence while waiting for the medicine to take effect, seems to reinforce the pharmacological outcomes in terms of efficacy; this kind of technique emerged in many other interviews. In addition, patients interviewed may perform various self-regulating actions – such as manipulating the body to release muscle tension, or applying pressure, constricting, or covering the painful side of the head or face to alleviate the symptom severity. Franca, for example, states that she presses the fingers into her eyebrow arches for feeling less pain, while Monica, since she was young, takes the pill, lies down in bed in the dark, and wraps the bathrobe tie around her temples because she believes that this pressure, combined with the pharmacological substance, somehow reduces the pain. Clara, instead, places a handkerchief on the head/face spot where she feels pain since she feels the need to “cover it”.

*The first thing I absolutely do is lie down, not in a complete darkness but in a dimly lit space, without talking, and place a handkerchief or even just my hand on the spot where it hurts, because I really need to cover that area... with something, so I just stay there without pressing. I need something to cover that painful area. I don't know where this need or idea of protection comes from. (Ethnographic interview with Clara, September 2023)*

Breathing techniques also contribute to bodily relaxation, thereby enhancing the efficacy of the pharmacological treatments:

*I take the medication and I lie down. But there has to be absolute silence! I can't have people asking me things or talking to me... the dinner, the soccer bag, etc. In fact, when the pain is strong, I ask someone to take care of the kids, for example, because I don't want to hear anything. As if I'm not there! Otherwise, it doesn't make sense taking the pills. [...] One*

*thing I often do is control my breathing, like slowing it down and relaxing my body... and a somewhat strange thing, but it seems that this helps me to follow the pain, almost visualize it... it's a kind of self-hypnosis, when I lie down, it's like I can focus so much on my breath that I disconnect from my body and so the body doesn't hurt anymore... and I almost don't feel it anymore... usually, this is the prelude to a sleep and rest phase that helps me a lot. (Ethnographic interview with Camilla, September 2023)*

*I tend to avoid taking medicines, but even when I do, I lock myself in the room without anything that could disturb me, with my eyes closed, and I try to relax. I do this especially during the acute phase, or if it's a milder pain but that could worsen, I try to not think about it, I try to think as little as possible about it... I focus on my breathing, or maybe I think about something positive... a good moment I've lived through, something that helps me relaxing. [...] This way, I can keep it under control and not let it go crazy. (Ethnographic interview with Anna, September 2023)*

Framed as intimate resources capable of providing relief<sup>44</sup>, the techniques are mobilized and performed almost “ritually” during a migraine episode, precisely for activating the pharmacological efficacy and reducing the symptom severity. This rituality emerges as a result of several elements: the first aspect concerns the standardized and repetitive nature of a sequence of ordered actions and behaviors, which follow a structured pattern aimed at ensuring a successful outcome. Secondly, they take place within a time and a space that are detached from everyday life and routine contexts. Rituality also refers to a set of ideas/beliefs that are somehow “reinforced” and “confirmed” by the ritual itself, and it has a precise aim: to reproduce an event, to make something happen again. It involves a perception which is activated through every sense, i.e., auditory, tactile, visual and olfactory channels, and condenses specific meanings around gestures and procedures. Finally, the objects employed are re-signified as powerful symbols, essential to the ritual's efficacy; among these, the medication assumes a central role, with its effectiveness being “constructed” and activated precisely within this ritualized framework. Therefore, migraine relief is influenced not only by the pharmacological substance and its active ingredients, but also by the contextual factors surrounding the act of taking the medication. These factors can, depending on the circumstances, either diminish – or even completely suppress – the therapeutic effect of the pill, or enhance it, contributing significantly to its effectiveness. Among these factors, not least is the presence or absence of other people, which operates through a form of implicit agreement that enables the “socialization” and “legitimization” of the patient's need for isolation. Taking medicine is, therefore, a therapeutic act that appears to condense both empirical and symbolic efficacy, as it takes place within a context shaped by trust and patient expectations<sup>45</sup>.

Therapeutic efficacy is also shaped by a range of *strategies* implemented both during acute migraine episodes and as preventive measures aimed at reducing or postponing future attacks. Besides managing the diet differently (Clara, Cloe, Paola, and Giada),

strategies include doing pleasant activities (Monica, Franca, Rita, Lea), being alone and in quiet (Sara and Ida), take a walk or exercising (Sara, Bruna, Anna). These actions allow to “discharge” energies, to release tensions caused by stress, and to prevent headaches from worsening. They seem to be body-centered, as they are identified thanks to the perception of body signals and reactions. Also resting or sleeping play a crucial role in this sense, as these actions allow to “stop” and to “disconnect”. Camilla states:

*My headache is caused by the lack of sleep. In fact, by sleeping I resolve the problem. I need at least fifteen minutes of sleep every day... I go into a kind of catalepsy and then I feel better... Over time, I've come to understand that without this daily rest, I end up running on reserve energy until evening, which leaves me feeling utterly depleted and unwell. As a result, I've begun to structure my day around this need. Even at five in the afternoon, if I have time, I rest... now [after years], except for this constant basic headache and this little fog in the head, I have no critical episodes... I know myself, so I know when the pain comes from my body, I pay attention to it and try to understand it. (Ethnographic interview with Camilla, September 2023)*

For Camilla, it is equally essential to protect herself from obligations and physical or mental fatigue, as these are recognized triggers that can precipitate acute headache episodes:

*You know, all those things you tell yourself you have to do during the day and that don't allow to rest?... those things make you tired. So, now, if I know that something bothers me, I don't do it. But this took time, after getting angry with myself and with other people because I realize I've really abused my body. Another strategy I've adopted to preserve my wellbeing is slowing down at work. At a certain point, I simply couldn't keep up with the demands of my job, my home, and my children. I concluded that physical health takes precedence over financial gain. There is a clear connection between how you stress your body, allocate your time, and think about money, and how all of that relates to headaches. I've seen this in others too... a friend of mine, in a similar situation, works constantly under stress and ends up spending most of her money on therapy and medication... and I ask myself: “What's the point of making money?”... I'm very practical about money. I know, for example, that if I sleep, my muscles relax, the headache doesn't get worse, and I don't need a therapist. Period. (Ethnographic interview with Camilla, September 2023)*

Exploring symptoms and trigger factors is crucial for keeping headache intensity and attacks under control. As Cloe pointed out, the recurring question – “Why do I get these headaches?” – was accompanied by a “strong desire to understand the underlying causes, why I have these reactions, to find what is good for me and see what is bad for me, try to increase what can help and decrease what can hurt” (Ethnographic interview with Cloe, September 2023). This meant looking at the negative impact that some relationships have on her health condition and to avoid specific situations in order to reduce, or to postpone, migraine episodes. Likewise, Matilde tries to prevent conflicts; changing her family and economic situation is, in her opinion, what could positively impact on headaches:

*Cloe: There has always been constant conflict within my family... and that has undoubtedly had an impact on me. Even now, despite leading a more peaceful life and maintaining physical distance from them, they continue to create problems that affect me. I'm still quite sensitive to it... I absorb things easily. Over time, however, I've developed coping strategies. For instance, instead of engaging in prolonged arguments that could last an hour, I now limit those interactions to five minutes. This has made a significant difference because the shorter exchanges are far less draining. I consider this a personal tool for managing... almost like a form of alternative medicine.*

*Chiara: What do you mean?*

*Cloe: At some point, you come to realize that the other person's intention isn't to understand or support you, but rather to dominate, manipulate, or impose their own rules. With time... because it does take years [...] you begin to accept this and learn to shield yourself from the harm it can cause. In my experience, understanding the root of the problem helps, but eventually, for your own well-being, you choose to step back. You avoid the situation in order to preserve yourself [...]. Looking back, I can see that my first migraine episodes were closely tied to family conflict. Of course, I later discovered there were also physiological factors at play. For example, after a gym workout, if I develop a headache, I now suspect it's linked to vitamin deficiencies. My metabolism is fast... I burn a lot of energy, so even though I eat well, my body may still be lacking certain nutrients. And I believe that much of my energy used to be consumed by those emotional conflicts. Now that I've distanced myself from those dynamics and reduced the emotional strain, my migraines have decreased significantly. The ones that do occur seem more clearly connected to physical causes, such as hormonal fluctuations during the menstrual cycle or vitamin deficiencies (Ethnographic interview with Cloe, September 2023)*

*I believe that now the only beneficial effect [on my migraines] [...] would be to take a stable decision regarding my family situation. That's the only thing that could really make sense for my headaches [...] Beyond rest, yoga, or setting aside time for myself, what truly makes a difference is gaining clarity about the direction my life is taking and, perhaps even more importantly, achieving a sense of security, particularly financial. I believe that when I'll feel truly secure in my surroundings, I'll also feel more emotionally and physically stable. Right now, this ongoing sense of instability makes it difficult to live well... it disrupts my sleep almost immediately. I tend to lose sleep the moment the problems arise; it's an automatic response. One strategy I've developed when I feel overwhelmed is taking evening walks because in this way I avoid conflicts... I know, it sounds silly [...] but it's been essential for me. I often return home from work quite late, and instead of sitting down for dinner, which is typically a high-tension moment prone to conflict, even with my children... I sometimes choose to skip dinner altogether. I eat alone and go out for a walk... In doing so, I avoid conflict situations and I often succeed in preventing a headache from developing. (Ethnographic interview with Matilde, October 2023)*

Beyond techniques and strategies, what emerges here are the processes we refer to as *adaptations*; these are “reshaping processes” involving specific life domains and which are based on the subjective experience’s reconstruction and on the identification of factors that, at different degrees and levels, can positively or negatively impact on migraine and acute episodes. Therefore, adaptations underline, in a sense, the connec-

tions and mutual influence between lived situations, relationships, emotional states, and physiological changes: by giving a name and a meaning to the disease, actions and “adjustments” on individual and social circumstances acquire a therapeutic power since they shape a new subjectivity, an “existential renewal”<sup>46</sup> that affects, to some extent, the body’s endogenous (biological) recovery. Such interventions are therefore “effective” since they reduce/remove negative influences that trigger headache, by impacting on the symptom’s perception and by bringing a “positive” effect. From this perspective, the decision of whom to spend time with may hold a therapeutic value:

*I don't dislike being alone, but I also appreciate the presence of others, even when I'm unwell. In fact, spending time with friends and being around others can be beneficial, as it helps me relax... headaches are inherently stressful, so even when the pain is mild, I tend to not think about it and being with other people can serve as a distraction... of course, it also depends on who you're with... not everyone has a calming or positive effect. The quality of the interaction matters. (Ethnographic interview with Anna, September 2023)*

*Monica: [...] for me it's all about the... it's all about what makes me feel good. So, in my opinion there are some people... who make me feel good or make me feel bad, or worse, maybe they could even give me a headache or make it worse. Yes, I think so... spending time, I don't know... like being with a friend who knows me and understands, and doesn't ask questions... organizing an afternoon together... or go for a walk, or whatever... yes, absolutely!*

*Chiara: Why do you think this could have a positive effect on your headache?*

*Monica: Partly because you don't think about it, you get distracted, and also because if you are with someone that knows you well... I don't know... it's like you don't have to explain anything... she/he understands this and, still, is there with you. (Ethnographic interview with Monica, September 2023)*

It has been shown that social interaction opens up an alternative space that allows migraine patients to shift their attention and, in some way, to reduce the worry and suffering associated with migraine symptoms and attacks<sup>47</sup>. Spending time with people who understand the headache severity also permits to “share”, in some way, the illness’ condition. Interpersonal relationships seem thus to impact positively not only when migraine is recognized as a “real” health problem but also when the suffering person perceives forms of support from other people, especially during acute migraine episodes. Franca, Bruna, and Giada claim:

*Respecting the fact that I need to disappear during those moments... this has a positive effect on my headache. It doesn't always happen, but most of the time, if people around me respect the need that I have of being on my own, that has a positive effect on my migraine. (Ethnographic interview with Franca, October 2023)*

*Banally, if someone says to me: “Come on, I'll do an IV so you feel better”, or “Don't worry, I'll handle it, you rest”, like taking care of things like groceries etc. ... this understanding, this support network makes me feel better; because I'm relaxed when I get a migraine. I*

*know it's understood, so I can abandon myself in it peacefully... I can surrender to it peacefully. [...] Being able to calmly manage the migraine acute phase, without thinking: "Oh, I need to do this or that", means I can take the time I need to feel better... I think it leads me to a... how do you say? Not a recovery, but... a faster crisis' ending, because otherwise I drag it, that is, if there are days when I can't really physically stop, because I have to work or I can't stay home from work and so I go there anyway, then I carry it. So being able to rely on people helps me a lot. Absolutely... because sometimes, when it's really bad, I can't do much of anything. So, knowing that I have someone who helps me is very reassuring. (Ethnographic interview with Bruna, September 2023)*

*It's not that other people can reduce the intensity or frequency of migraines in the long term, but in moments when even getting up to take a shower feels impossible, the presence of someone, your partner, your mother, or whoever who says: "Come on, let's go together" can make that small act achievable. So, it's not necessarily an impact on the pain itself, but it's on my perception of what I can still do while suffering in that moment... I don't know if I'm clear... when this happens, it makes it a little better... what I perceived as completely disabling pain becomes less disabling... at 80% no longer at 100% (Ethnographic interview with Giada, October 2023)*

Two distinct experiential domains seem to arise: on the one hand, there is a solitary space, often situated within the domestic sphere and where patients try to manage headaches by listening to their body and employing techniques and strategies that, to varying degrees, influence both pharmaceutical consumption and its therapeutic efficacy. On the other hand, a social domain emerges in which avoiding demanding situations and relationships, as well as the possibility of spending time with some people rather than others, "sharing" the one's illness experience and finding support can reduce the frequency of acute migraine episodes and/or provide symptom relief when such attacks occur. When viewed through the lens of these experiential domains, the "language of migraine" appears as dually articulated: at times, it remains concealed within the private sphere; at others, it shifts from inner subjectivity to inter-subjective expression. This language may adopt biomedical terms to make the illness experience communicable and socially recognizable, or it may generate alternative vocabularies that articulate the subjective significance of migraine within other symbolic frameworks.

Patients narratives show how migraine becomes a phenomenon that cannot be conceptually confined within the boundaries of the body; its causes and the remedy efforts acquire meaning by bringing together multiple existence domains, the personal and interpersonal ones.

## **Conclusion**

Ethnographic interviews show how the substantial efficacy of any therapeutic intervention also relies on the ability to make the disease *thinkable*, i.e. to name and represent it<sup>48</sup>. This process entails a cognitive, emotional, and affective re-orientation – a

form of “creative” labor undertaken by the individual in pain to reframe and manage the suffering experience<sup>49</sup>.

It has been shown how, in this sense, “stress” plays a central role in the headache development and progression: conceived as a term behind which are hidden several discourses referring to multiple elements (such as an accumulation of responsibilities, fatigue, and tensions), stress refers to experienced events and situations that can trigger bodily ache and discomfort by exacerbating symptoms and causing acute migraine episodes. This also makes sense from an “organic” perspective: the neuronal and hormonal changes associated with stress and stress responses can indeed have multiple relations with migraine. Stress can be a risk factor for the onset of migraine and headache, it can amplify the severity of symptoms, and even contribute to the development of chronic migraine<sup>50</sup>. Stressors indeed activate both the autonomic nervous system and neuroendocrine mechanisms; the activation of the hypothalamic-pituitary axis produces a complex series of sometimes contradictory effects in nociceptive responses, that include both pain relief but also central sensitization and hyperalgesia<sup>51</sup>. Both peripheral and central sensitization appear to be important pathophysiological factors, contributing to many of the clinical features of migraine, including throbbing pain, sensitivity to movement, and allodynia<sup>52</sup>. The brain and body respond to potential/actual stressful events by activating hormonal and neural mediators, and modifying behaviors to adapt. Such responses help to maintain physiological stability (“allostasis”), but when stressors are frequent and/or severe, allostatic responses can become dysregulated (“allostatic load”). Allostatic load may alter brain networks both functionally and structurally; when the brain responses to continued or subsequent stressors is “abnormal”, behavior and systemic physiology are altered in ways that can, in a vicious cycle, lead to further allostatic load<sup>53</sup>. Migraine would therefore be the result of the interaction with environmental and external triggering conditions/factors, and the response to repeated homeostasis perturbations. Additionally, for many patients, the painful experience of the headache episodes and the anticipation of future attacks can provoke a state of worry that persists throughout the period. Harold G. Wolff was the first who truly understood psychophysiological disorders such as headaches and developed innovative methods to observe the physiological responses of people coping with stressors<sup>54</sup>. Unfortunately, Wolff’s approach to the headache study is often forgotten in today’s biomedical practice, where in a 10-minute clinical visit the main focus is on identifying the best medication to prescribe.

In our view, the reduction of time allocated to clinical examinations results not only in a limited understanding of the stress responses, but also in a missed opportunity to investigate the range of meanings that the concept of “stress” may hold for the patient. We could indeed argue that “stress” becomes an influential factor in headaches only after it has been “meaningfully” interpreted according to the individual life experience in social and relational contexts. It is precisely this meaning-making

process that leads to the identification/implementation of the *adaptations* employed and discussed by the patient we met during our research. Such elements arise from the ethnographic interviews but often elude (quantitative and, often, qualitative) biomedical researches that rely on the inclusion of a large number of patients and which do not foresee an investigation of *how* this concept is articulated and employed, both to investigate illness causes and to identify possible remedies. We therefore believe that the concept of “stress” should be employed with more caution in migraine research and studies, and better examined during the clinical and therapeutic relationship, in order to deeply understand which factors positively and negatively influence migraine progression and patterns.

Meanwhile, we believe that the influence and the impact of social relationships on migraine is a crucial factor to consider. It has been shown how the illness delegitimation or, more generally, what, can occur within the interpersonal relationships (in any sphere of life) are factors that impact on cognitive and emotional states, either amplifying the symptoms’ perception or triggering migraine’s episodes, especially when these relationships are experienced as “harmful”, “dysfunctional” and “toxic”. Once again, this has a “physiological” reason. An increasing number of biomedical studies shows how emotions (such as worry, anger, sadness, and fear), understood as signals through which we respond to the environment, play an important role in the experience and perception of migraine’s symptoms<sup>55</sup>. It has also been observed that while the suppression of emotions has biological repercussions – such as increased activation of the cardiovascular and sympathetic nervous systems<sup>56</sup> – emotion awareness and understanding can reduce stress and positively influence the frequency of migraine attacks<sup>57</sup>. This can be further explained by considering how emotional states affect the central nervous system, by causing organic and physiological reactions through the hypothalamus and the neuro-endocrine system mediation<sup>58</sup>. Other studies<sup>59</sup> show the relationship between pain and emotional awareness, expression and processing, and suggest that both sensory (intensity) and affective (unpleasantness) components of pain are influenced by emotion regulation processes. The interplay between pain and emotion is reflected in their overlapping representation within central brain structures. Both pain and emotion activate a broad network of cortical and subcortical regions, with significant overlap in areas such as the insula, cingulate cortex, thalamus, amygdala, and caudate nucleus – structures involved in both nociceptive and emotional processing<sup>60</sup>. Migraine may thus be characterized by a more generalized alteration in brain processing of aversive stimuli, rather than being limited to specific sensory stimuli. This alteration may be an inherent feature of migraine or may be a consequential alteration produced by the ongoing and repeated nature of migraine. Regardless of its sequelae, increased functional responses in cortical and subcortical regions may play a key role in migraine pathophysiology, reflecting a heightened sensitivity to aversive stimuli that facilitates the onset and persistence of attacks, and may contribute to their chronification<sup>61</sup>.

However, acknowledging the central role of cognitive and emotional states in migraine should not be interpreted through a “negative” or reductively “psychosomatic” lens, nor should it imply that patients are passive victims of their emotions or, implicitly, “responsible” for their own suffering. Interviews highlight how it is precisely through the elaboration of perceived emotions that migraine is “signified” – it acquires meanings – thus allowing the adaptations and some strategies to be identified as effective. If it is true that “emotions can speak the language of the organs”<sup>62</sup>, we have shown how paying attention to cognitive and emotional states, allows patients to reduce or to avoid situations that trigger forms of discomfort and distress, by therapeutically acting on the headache itself. Indeed, if negative emotions can exacerbate migraine, positive ones can reduce it. In this sense, the quality of specific social relations, by allowing patients to “share” their condition and to extend the recovery time from migraine, affects the symptom perception. Perceived forms of social support also act therapeutically, in a positive sense. Several studies focused on migraine and on other conditions have demonstrated that social support is crucial not only in a protective and preventive sense but also in creating a disease adaptation<sup>63</sup>; in addition, “safety network” accelerates the healing process by affecting the pharmacological treatments’ efficacy<sup>64</sup>. The techniques and strategies adopted by patients appear to be additional factors influencing both the consumption and the efficacy of pharmacological treatments. Practices such as isolating oneself, seeking silence and darkness, resting, engaging in bodily self-care, pursuing enjoyable activities, and avoiding distressing situations all acquire a therapeutic function in the management of migraine. Some of these techniques are carried out ritually during the migraine acute episode phase, by enhancing or weakening the pharmaceutical effect and power. Other strategies seem to have a positive effect as they can activate mechanisms that support the mitigation of migraine episodes in the absence of pharmacological treatment. Taken together, techniques, strategies, and adaptations can be understood as “practices” connected to cognitive and emotional states, as well as to meanings and symbols that, in varying ways and degrees, influence physical recovery. Often identified independently by patients, these “counter-measures”<sup>65</sup> underscore the impact of illness phenomenologies and psychological dimensions (psychism)<sup>66</sup> on human biology. Their relevance lies in the psycho-sensory charge they carry, which holds a therapeutic potential and may contribute to a more favorable progression of the disease.

The same psycho-sensory charge and therapeutic dimensions have been observed in sacred, so-called “traditional” or magical-religious healing practices, rituals, and self-healing experiences that have been studied since the 20th century<sup>67</sup>. In both biomedicine and cultural anthropology, this analysis has focused on the mechanisms that can mobilize and stimulate healing processes by shaping emotional states and mental orientation. These mechanisms are influenced by symbolic logics and by factors rooted in both supernaturalistic and realistic orders, and are sometimes fostered by the strong

relationship between “therapists” and “patients”. In cultural anthropology, James Mooney (1896), Raymond Prince (1982) and Gilles Bibeau (1998) studies on the therapeutic efficacy<sup>68</sup>, as well as Claude Lévi-Strauss’s investigations on the symbolic efficacy in shamanic practices ([1958] 1966) – then further re-elaborated<sup>69</sup> – have explored these topics. Likewise, researches focused on ritualistic procedures based on mythical or religious-therapeutic traditions, such as those in tarantism<sup>70</sup>, in miraculous healings<sup>71</sup>, in the “faith healing” within Christian charismatic movements liturgies or neo-religious and neo-magical movements<sup>72</sup> have focused on these aspects. Despite different historical periods and empirical contexts, these researches have explored the therapeutic efficacy by considering the sick person as a *unit* where “the different levels of functioning – social, emotional and affective, neuro-hormonal, and physiological – are interdependent and connected by mediating structures”<sup>73</sup>. This mediation always involves multiple organic systems, as also shown by studies that have investigated the interdependence of the endogenous opioid system, immune and endocrine/hormonal systems in the *meaning response* and in the placebo analgesia<sup>74</sup>. The healing practices observed among the migraine patients we interviewed are neither rooted in sacred or magical-religious framework, nor developed within a formal therapeutic relationship. Although these practices do not directly activate what are conventionally termed “endogenous self-healing mechanisms,” they stem from a personal process of naming and interpreting the illness. Through this process, they engage physiological systems and regulatory functions that can reduce the symptom severity and, to some extent, influence the recurrence of acute migraine episodes.

This leads us, in conclusion, to highlight several relevant points. The first entails a reconfiguration of the biomedical notion of “efficacy” to include patient-driven therapeutic practices, which often emerge through the renegotiation of the embodied subjectivity within a broader socio-relational context<sup>75</sup>. This allows to consider what is happening “outside the organism” for promoting a deeper understanding of all the factors that can impact positively (or negatively) on organic and physiological processes and mechanisms. Secondly, we believe that, precisely because of their efficacy, such practices should be further investigated and considered within the clinical relationship, in order to promote a more comprehensive and nuanced reconstruction of the illness experience and to identify possible remedies and therapeutic solutions; indeed if: “the essential goal of medicine is healing the sick person with no distinction on the therapeutic process that should be pursued”<sup>76</sup>, it is important to recognize both their *actual* and *real* efficacy, as well as the patients’ knowledge<sup>77</sup>, competences and expertise that allow these practices to be identified and “refined” over time.

The role of exogenous factors in shaping health and disease trajectories ultimately calls for a critical reconsideration of the doctor-patient relationship, by considering that any therapeutic intervention can be successful when they activate a psychic healing expectation that acts on a biological/organic level. Indeed, as evidenced in the

context of ritual and “traditional” therapies, the communication between the patient and the practitioner allows this latter to intervene therapeutically by operating within the same subjective world in which the patient illness’s attitudes and interpretations are situated<sup>78</sup>. As a charismatic agent, the healer operates within a psychically meaningful domain, wherein the alleviation of distress and anxiety is further sustained by the anticipatory reassurance conferred by expectation of the therapeutic efficacy. Such dynamics activate positive energies that intervene upon both the therapeutic process and the disease condition<sup>79</sup>. Efficacy thus depends, in part, on the patient’s healing expectations shaped by the trust in the practitioner’s competence and by the emotional intensity that characterizes the therapeutic relationship. Such trust would facilitate the therapeutic process in the biomedical and clinical relationships too.

As Oliver Sacks (1992) pointed out, each migraine patient faces either a shortcut or a long road: the shortcut entails a rapid diagnosis, a prescription, and a consolatory gesture; the long road calls for a deeper engagement with the meaning and complexity of the illness<sup>80</sup>. Ultimately, what we propose is to undertake this more demanding path together.

## **Bibliography, references and notes**

1. The title of the research is “Taking care of the oneself. Healing strategies in female patients with chronic tension headache and chronic migraine: a multidisciplinary and qualitative study”. CM and GB have contributed equally to the conception and design of the study. Ethnographic interviews, data analysis and interpretation were conducted by CM. Article Conceptualization: CM; Writing – original draft preparation: CM wrote the article, GB contributed in drafting the introduction and conclusion; Writing – review and editing: CM and GB. Authors have read and agreed to the published version of the manuscript. No financial support was provided for this research and publication. Authors declare that there is no conflict of interest regarding the article and its publication.
2. Although biomedical research in recent years has provided strong evidence, the association between diet and migraine remains unclear. It has been observed that delaying or skipping meals, by causing low glycaemic levels, can trigger migraine. Likewise, some foods rather than others seem to cause migraine attacks. Intense exercise can also trigger migraine due to neurovegetative changes in the homeostatic balance.
3. The stress influence will be discussed in the conclusion of this article. For what concerns the connection between sleep problems and headache, it has been observed that decreased sleep quality can increase a reduced pain tolerance risk and trigger hyperalgesic responses. It is also important to note that the relationship between headaches and sleep disturbances is bidirectional: headaches can trigger sleep problems, and sleep problems can, in turn, trigger headache attacks. Despite this evidence, the connection between sleep problems and migraine still remain today inadequately investigated and understood.
4. Medical treatments employed are multiple. In short, the most prescribed drugs are anticonvulsants, beta-blockers and anti-epileptics, calcium antagonists, monoclonal antibodies, tricyclic antidepressants, opioids, triptans, analgesics and non-steroidal

- anti-inflammatory drugs (NSAIDs). Despite a significant number of treatments are now available, unmet treatment needs remain a reality in migraine patients' lives and it has been shown that a combination of pharmacological and non-pharmacological approaches is more effective in achieving positive outcomes. For more details see: Lemstra M, Stewart B, Olszynski WP, Effectiveness of multidisciplinary intervention in the treatment of migraine: a randomized clinical trial. *Headache* 2002;42:845-854; Holroyd KA, Cottrell CK, O'Donnell FJ et al., Effect of preventive (blocker) treatment, behavioural migraine management, or their combination on outcomes of optimised acute treatment in frequent migraine: randomised controlled trial. *BMJ* 2010;341:c4871-1; Bentivegna E, Galastri S, Onan D et al., Unmet Needs in the Acute Treatment of Migraine. *Adv Ther* 2024;41(1):1-13; Guerra F, Di Giacomo D, Ranieri J et al., Network analysis of negative emotions in patients with episodic migraine: need for a multidisciplinary perspective. *Front Neurol* 2024;15:1418188.
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  10. Before each interview, information about the research has been provided. The consent form has been sent, clarifying that the study was voluntary, with the possibility of withdrawing the consent at any time with the consequent data destruction. Consent form also stated that the interviews would be audio-recorded, verbatim transcribed and data dissemination would be aggregated by using a coding system and pseudonyms, in compliance with the current legislation on the protection of sensitive data and privacy regulations. The consent form, as well as the research design and protocol, has been approved by the CE AVEC - USL Bologna on 28/04/23.
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15. Four nurses, three physiotherapists, one developmental psychomotricity therapist.
16. Epidemiological studies suggest that, before puberty, men and women are equally affected with approximately 6% of 7-year-olds reporting migraine. After puberty, particularly in migraine without aura, the prevalence increases to peak during the early 40s. During the reproductive years there are marked sex differences in migraine prevalence, with migraine without aura affecting more women. In general, in adult women, migraine is three to four times more frequent than in men. The sex disparity in migraine, as well as in all primary headaches' disorders, is believed to be partly explained through fluctuations in ovarian steroid hormones, especially estrogen and progesterone. During puberty (when estrogen levels increase), migraines become much more common among girls. Many women report being more susceptible to migraine attacks during the menstrual period. Some studies suggest that between 60 % and 70% of migraineurs experience improvement in migraine during pregnancy, particularly during the second and third trimesters, due to a more stable estrogens levels during pregnancy. The perimenopause marks a time of exacerbation of migraine for many women as menstruation becomes a more prominent trigger with regularly monthly migraine attacks. Although estrogen appear to trigger migraines, the exact mechanisms are not yet completely understood. For more details: Vetvik KG, MacGregor EA, Sex differences in the epidemiology, clinical features, and pathophysiology of migraine. *Lancet Neurol* 2017;16:76-87; Al-Hasany L, Haas J, Piccininni M et al., Giving Researchers a Headache - Sex and Gender Differences in Migraine. *Front Neurol* 2020;1:549038; Rossi MF, Tumminello A, Marconi M et al., Sex and gender differences in migraines: a narrative review. *Neurol Sci* 2022;43(9):5729-5734.
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