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Research Article

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The Role of Patients' Advocacy Groups to Reduce Headache Pain in the European Union: from the Italian Case History to the European Migraine Action Plan

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Abstract

From the "patients' right to avoid unnecessary suffering and pain" to the "Charter of Rights of the Cephalalgic Patient", over the years the role of the civic & patients' organisations to reduce headache pain in the European Union is increased: this research article explores the experiences of individuals affected by migraines and headaches, highlighting challenges, rights, and the need for improved healthcare support. Based on an extensive civic survey conducted at the national level by the Italian NGO Cittadinanzattiva, the study reveals the profound impact of headaches on people's lives, emphasising the lack of disability recognition and difficulties in accessing quality care. Through compelling testimonies, the article underscores the emotional, psychological, and physical burden of these conditions, and describes an innovative artificial intelligence-based tool called "EMI".

Together with many actors, since decades Cittadinanzattiva has been engaged in the fight against chronic pain for decades, both at the national and European levels. In this regard, what attention will the new MEPs (Members of the European Parliament) and the new leadership of the EU Commission DG Santé (Directorate-General for Health and Food Safety) dedicate to this issue in the wake of the upcoming European elections in 2024? From various quarters, there is a call for a European Migraine Action Plan aimed at finally placing this issue on the agenda of European political institutions, promoting a more inclusive and patient-centered vision within the European healthcare landscape, where the pain of those suffering from migraines and headaches is no longer invisible or unheard.

Keywords: Chronic Pain, Headache, European Union, Patients' Rights, Patients' Empowerment, Civic Participation, Awareness, Migraine, European Parliament, Survey, Healthcare, European Elections.

1. Introduction

Migraine is the most frequent disabling headache in the general population. In Europe, about 136 million people suffer from migraine, of which 6 million only in Italy [1]. Migraine, tension-type headache, and cluster headache are the most prevalent forms of headaches classified by the World Health Organisation as the third most prevalent disease globally and the second leading cause of disability. They are responsible for the highest number of years lost due to the disease. Women are disproportionately affected, with a threefold higher incidence than men, particularly in the 25-55 age group [2-4].

In Italy, it took many years and extensive advocacy efforts by patient associations and scientific societies to pass Law No. 81 of

2020 [5]. This law formally recognises chronic primary headache as a social pathology.

Study shows that headache disorders, and migraine in particular, are important causes of disability worldwide, and deserve greater attention in health policy debates and research resource allocation [6]. The impact on individuals' lives, their families, social relationships, employment, and education is substantial, as highlighted by a recent survey conducted in Italy by Cittadinanzattiva APS through the "Colpo di testa: Your Rights on Migraine and Headache" awareness campaign [7].

Cittadinanzattiva APS is an organisation, founded in Italy in 1978, which promotes citizens' activism for the protection of rights, the care of common goods, the support for people in conditions of weakness in Italy and abroad [8]. For decades, Cittadinanzattiva has been committed to addressing chronic pain issues, both nationally and at the European level joining the chorus of voices calling for a European Migraine Action Plan to finally place this matter on the agenda of European political institutions [9-13].

2. Materials and Methods

The civic investigation conducted in Italy by Cittadinanzattiva APS, which took place from June to November 2021, had the primary objective of gathering the experiences and journeys of people living with headaches [14]. A total of 671 individuals were interviewed. For the purpose of the survey, individuals with a diagnosis of headache were considered, as well as those undergoing clinical and diagnostic investigation, and those who, for any reason, had not taken steps to investigate the causes of their headaches.

The investigation aimed to shed light on the experiences and emotional aspects of individuals with headaches, regardless of whether they had received a formal diagnosis. This condition significantly impacts their lives, including their family, emotional, social, and work relationships. The analysis excluded individuals who only occasionally experienced headaches of such intensity that they did not disrupt their normal daily activities.

The investigation involved the creation of a customised questionnaire. The first section of the questionnaire collected general and demographic information about the interviewees. Data were treated with anonymity and in accordance with privacy regulations. The following areas of inquiry were identified:

- Frequency, duration, and intensity of headaches.
- Strategies and pharmacological therapies to counteract headaches.
- Onset and diagnosis.
- Personal experiences of the interviewees.
- Impact of headaches on daily life.
- Rights.

Within the questionnaire, there was also a section dedicated to testimonials, where participants had the opportunity to share their stories. The questionnaire was developed by Cittadinanzattiva in collaboration with the Civic Evaluation Agency of Cittadinanzattiva (AVC) and with the contribution of the working group that validated the instrument [15]. The survey was disseminated by group members, especially by patient associations, and through Cittadinanzattiva's communication channels. This allowed for nationwide coverage.

The number of collected questionnaires does not provide a sufficiently representative sample; However, this does not diminish the civic value of the survey and this report. The document is an example of civic information, understood as the "production, by citizens and based on their point of view, of information from data collected directly or indirectly and oriented towards transforming reality in the direction of increased protection of citizens' rights and the realisation of related conditions" [16]. Therefore, the data and information in this report should not be seen as representative of the entire system but rather as indicators of critical situations, highlighting issues of greater importance for further investigation and serving as stimulus to develop improvement proposals aimed at ensuring a more citizen-centred organisation.

6.1 Survey's Main Figures

The survey "Colpo di testa: Your Rights on Migraine and Headache" data mainly highlight the **lack of disability recognition for headaches** (reported by 43,7% of respondents), the difficulty in examinations and visits **booking** in the public sector (22,8%), the medications (23,3%) and supplements' cost (22,1%), private/intramoenia medical examinations, visits' cost (19,6%) and copays (18,4%). Women suffer the most from migraines and headaches (89% of the interviewed sample). The most affected age group is the one between 30 and 55 years (69,6%), with a frequency of headaches episodes exceeding 15 times per month (for 29,8% of respondents) of variable duration from hours to days, for 39,8% of the sample. On a scale of 1 to 10, 88% of respondents report pain intensity from 7 to 10. Individuals who have received a diagnosis of a headache have waited, in 30% of cases, from 5 to 7 years and beyond.

The survey, involved 671 citizens of all Italian regions, reflecting the daily experience and the journey of three categories of people: those who received a **headache diagnosis** (88,2% of the total), those who are still in the stage of clinical and diagnostic **assessment/examination** (4,3%) and, finally, those who have **not yet taken action** to investigate the causes of their headaches (6,4%). Among those surveyed who received a diagnosis, 69,1% suffer from migraines, 12,8% from tension-type headaches, and 10,7% from cluster headaches. The survey shows that headaches significantly affect and undermine family (79,9%), social life (80,5%), and career/study path (79,3%), to the point of sometimes/often experiencing discomfort when reporting to others headaches' suffering (73,6%).

Compared to the treatment plan, Cittadinanzattiva's Survey finds that only 5% of the respondents with a headache diagnosis are included in a Diagnostic Therapeutic Assistance Pathway (PDTA) specific to the pathology, while 7,6% are not included, although the residence region would provide for it. 59,2% of those surveyed are partially or not at all satisfied with the effectiveness of drug therapies.

On their initiative, 44,1% of respondents sometimes/often take more drugs doses than prescribed or recommended in the package leaflet; 34,4% completed the prescribed treatments, while 32,9% were forced to stop them due to side effects or simply because they felt that the treatment was not effective (32,4%). 37% of respondents are unaware of innovative monoclonal therapies or find it difficult to know where these therapies are prescribed and from whom (6,6%). In a handful of cases, difficulties are met in booking an appointment to headache centers entitled to their prescription (5,2%). Similar inconveniences also arise for those suffering from cluster headaches: 14,8% do not know what oxygen therapy is, and 7,6% declare they have not received information from the neurologist or the Headache Center.

Those who suffer from migraine and headaches demand flexibility in working hours, to have the ability to work from home when needed (48,8%), a dedicated number in case of need and emergency (39,2%), qualified and up-to-date healthcare professionals (35,5%), correct and adequate information on headaches (31,2%). To support families, providing incentives or babysitters and/or caregivers' relief (19,4%), the presence of a social network and volunteering (7,4%) would help [17].

COLPO DI TESTA
I tuoi diritti su emicrania e cefalea
INDAGINE CIVICA

Figure 1: Report on Civic Survey "Colpo di testa: your rights on migraine and headaches" awareness and information campaign. Cittadinanzattiva APS, 2020/2022.

6.2 The issue of pain in the European Charter of Patients' Rights

The European Charter of Patients' Rights was drafted in 2002 by the EU branch of Cittadinanzattiva- Active Citizenship Network in collaboration with citizens' & patients organizations from 12 different EU countries [18-21]. The European Charter of Patients' Rights states 14 patients' rights that together aim to guarantee a "high level of human health protection" (Article 35 of the Charter of fundamental rights of the European Union) and to assure the high quality of services provided by the various national health services in Europe [22].

The 14 rights are an embodiment of fundamental rights and, as such, they must be recognised and respected in every country. They are correlated with duties and responsibilities that both citizens and health care stakeholders have to assume. The Charter applies to all individuals, recognising the fact that differences, such as age, gender, religion, socio-economic status etc., may influence individual health care needs. Drafted in 22 languages, it has become a reference for EU citizens' rights in health care and a milestone for other EU Charters.

Art.11 of the European Charter of Patients' Rights clearly establishes the Right to Avoid Unnecessary Suffering and Pain: *"Each individual has the right to avoid as much suffering and pain as possible, in each phase of his/her illness"* [23].

European Charter of Patients' Rights
PATIENTS' RIGHTS HAVE NO BORDERS

Figure 2: "European Charter of Patients' Rights", draft in 2002 by Cittadinanzattiva-Active Citizenship Network.

6.3 From the "Charter of Rights of the Cephalalgic Patient" to the "EMI" Tool

Just after the the European Charter of Patients' Rights, it was written the "Charter of headache patients' rights" following the suggestions of the International Headache Society and the platform - established by Active Citizenship Network - that drafted the European Charter of Patients' Rights in 2002 [24,25]. In particular, in Italy in 2003 this new Charter was proclaimed with the naim of "Manifesto of headache patients' rights" by AIC-onlus e OUCH-Italia in collaboration with Cittadinanzattiva-Tribunale per i Diritti del Malato and with the support and endorsement of LIC-Lega Italiana Cefalalgici [26-30].

The document highlite that the patient with headache has the right to:

- Access healthcare facilities focusing on prevention.
- Be heard and taken seriously when reporting their suffering.
- Have unrestricted access to the most qualified facilities, using specific emergency channels if necessary and adequately advertised.
- Freely choose their healthcare provider or facility for any

potential treatment.

- Receive a proper and relevant medical history collection, thorough physical examination, and clear diagnostic, behavioural, and therapeutic indications (quality standards).
- Maintain adequate privacy and confidentiality in the physician-patient relationship.
- Be accurately informed about the diagnosis, nature of the disorder, prognosis, and treatment options.
- Receive personalised treatment, considering individual circumstances and specific needs.
- Provide informed consent before undergoing any examination, procedure, or therapy deemed necessary.
- Undergo examinations and therapies under the highest possible safety conditions.
- Avoid unnecessary suffering and pain.
- Demand from society and medical professionals to conduct research on headaches to improve knowledge and future treatments.
- Obtain proper recognition of their condition in the workplace, family, and any other social setting, with an evaluation of the actual degree of disability.
- Express dissent and complaints towards facilities and/or healthcare providers without compromising the possibility of receiving care.
- Receive concrete assurances that a guarantor can apply strict sanctions against those who violate these rights, if needed.

The campaign "Colpo di testa: Your Rights on Migraine and Headache" only reaffirms Cittadinanzattiva's long-standing commitment to the issue. This commitment recently led Cittadinanzattiva to introduce "EMI," an innovative AI-powered tool designed to provide essential information and support to individuals experiencing migraines and headaches. This cutting-edge resource is accessible through the campaign's webpage and social media platforms, aiming to raise awareness and deepen understanding of migraine and headache disorders [31,32]. By harnessing the power of AI technology, the artificial intelligence tool created by Cittadinanzattiva “EMI” empowers individuals with knowledge about their rights, helping them manage their conditions and navigate their healthcare journey confidently.

Carta dei diritti
del paziente cefalalgico

Preparata sulla base dei suggerimenti della Task Force dell'IHS e della piattaforma per la Carta Europea dei Diritti del Malato, presentata a Bruxelles nel novembre 2002 da Cittadinanzattiva - Active Citizenship Network.

Figure 3: The "Charter of headache patients’ rights" dates back to the early 2000's.

6.4 Testimonies

The testimonies collected during Cittadinanzattiva's campaign "Colpo di testa: Your Rights on Migraine and Headache" have been remarkably touching and revealing [33]. Individuals from various regions of Italy shared their personal experiences, offering an intimate glimpse into their lives with migraines and headaches.

“I remember the night when I had my first 'cluster headache' attack. Since then, I haven't had a single day without pain. During that time, I was living with my parents, and my hell became theirs as well. Over the years, I consulted numerous neurologists, and none of them ever diagnosed cluster headaches, which were unknown to me until then. I underwent all kinds of tests, with negative results. I was as healthy as a fish, but I suffered in an indescribable manner”.

“Many times, it wakes me up at night and stays there, pounding my temple, foreboding a terrible day ahead. Almost every time, it comes along with its friends: nausea, vomiting, photophobia, and phonophobia, forcing me to stay in the company of another friend named 'bed”.

Many testimonies highlighted the profound impact these conditions have on people's daily lives.
“My migraines started tormenting me when I was 4 years old, and I'm about to turn 38. A lifetime, in short. There were moments when I deeply hated and cursed it, moments when I tried to accept it, moments when I attempted to look at it from a different perspective, hoping to create something good from my pain. To banish it from my life is not possible; I am now aware of that”.

Patients described the agony and despair experienced during painful attacks, often destabilising their family, social, and work life.

“As a child, they used to treat me with wet cloths soaked in water and vinegar... afternoons spent in pain, waiting for it to ease a little so I could do my homework." "The excruciating pain made it impossible for me to breathe. I staggered, unable to stay still, not even lying down. I moved back and forth like a mad person.”.

“It caught me in my sleep, and I thrashed and contorted, waiting for the attack to pass. Unimaginable pain! I jumped out of bed, running around the table, fearing I might go insane. And so it went on that night, the next night, and many more”.
The constant and debilitating pain undermined their quality of life, creating emotional and psychological challenges beyond mere physical discomfort.

“My mom is ill; she has a terrible headache. Her head isn't broken because there are no visible cuts, but it hurts just the same. When I ask her why it hurts, she says she doesn't know, and even the doctors don't know. Mom is always very sad, and many days, she can't even go to work because she can't get out of bed”.

Difficulties in obtaining accurate diagnoses and accessing proper care were a common theme among the testimonies.

“Over 15 years, I consulted various doctors, headache centers, chiropractors, and 'magicians,' anyone who seemed to have 'the solution' to relieve me of this pain that affected my work and private life”.

“I tried everything: lithium, cortisone, opioids, cannabis, pain therapy, antiepileptics, beta-blockers, estrogens, triptans, dopaminergic agonists, melatonin, magnesium, anti-inflammatories, ketogenic diet, often with no positive results, other times with too many side effects. A new antiepileptic, monoclonal antibodies for chronic migraine, and a medication for paroxysmal episodes make the pain more bearable, but my ordeal continues.”.

Many reported feeling neglected by the healthcare system and forced to live with pain without a suitable solution.

“My experience with physical and psychological pain dates back to when I was 6 or 7 years old. Every 2-3 months, I had severe headaches that led to vomiting, sharp pain that sometimes eased with simple painkillers. I only discovered it could be migraine attacks many years later when, in the grip of anxiety and depression, in addition to physical pain, I decided to turn to a Headache Center where they diagnosed me with migraine without aura and tension-type headache. Gradually, I found myself in a torment of physical and psychological pain, excruciating and devastating, driving you to exasperation. You always live with the anxiety that a headache might strike, the kind that would even terrify physically strong people and is difficult to endure. Not even the various medications I took for prevention, symptomatic relief, and anti-migraine treatment during acute attacks helped stop the disease, which worsened over the years and became chronic. I even ended up receiving treatment in the pain therapy unit for terminal cancer patients for many months! A very impactful experience, even in my professional life”.

The costs of therapies and medications proved to be a significant obstacle for some, limiting their ability to manage the condition effectively.

“My university years were the worst: I felt really ill, with highly disabling attacks, especially after exams, to the point where I couldn't even enjoy good grades. I studied, worked, and spent almost all my money searching for any treatment that would allow me to have a normal life”.

However, many testimonies also expressed hope and gratitude for the introduction of "EMI", the artificial intelligence tool created by Cittadinanzattiva. Participants highlighted how EMI provided them with valuable information, helping them better understand their condition and feel more confident in managing their health. Patient empowerment emerged as a fundamental theme, underscoring the importance of providing tools that enable individuals to make informed decisions about their health.

The collected testimonies demonstrated the great need to raise awareness among the general public, policymakers, and healthcare professionals about the importance of understanding, supporting, and protecting the rights of people affected by migraines and headaches both at a national and European level. Cittadinanzattiva continues to work diligently to ensure that the voices of those facing these conditions are heard and that significant changes are promoted at the policy and healthcare levels to improve the quality of life for all living with migraines and headaches.

Figure 4: Communication materials related to the “Colpo di testa: your rights on migraine and headaches” awareness and information campaign. Cittadinanzattiva APS, 2020/2022.

6.5 Migraine’s Impact on European Citizens

Cittadinanzattiva is also engaged at the European level through its Active Citizenship Network, which has been dedicated for years to selecting and promoting best practices in the fight against pain [34-36]. And precisely with this intent - in partnership with the European Headache Alliance (EHA), Active Citizenship Network organized in the European Parliament the meeting titled: “Making Visible the Invisible on Headache Pain: sharing successful experiences across Europe” With the support of the MEPs Interest Group “European Patients' Rights and Cross-border Healthcare” and in the presence of experts, leaders of patient associations, and European institutions [37-39]. In this regard, to what extent the commitment of the European Institutions in the fight against pain can help in improving the condition of headaches patients? Among the rights listed in the "Charter of headache patients’ rights ", what are the less respected? What recommendations, resulting from the collaboration between experienced patients and professionals, can be addressed to policy makers and relevant stakeholders? These are just some of the pending issues on the subject to which attempts have been made to provide answers, starting from the fact that health economic studies have documented that the costs of headache disorders are huge; the costs only for migraine amounting to €27 billion in the EU countries, and the cost for other headaches are probably as large due to reduced productivity and work days lost [40]. This highlights the importance of addressing headache disorders and implementing effective strategies to support and improve the quality of life for sufferers [41].

Figure 5: Event “Making Visible the Invisible on Headache Pain: sharing successful experiences across Europe” realized by Cittadinanzattiva-Active Citizenship Network at the European Parliament on January 24, 2018, Bruxelles.

7. Discussion and Conclusion

Although migraine has been recognised under Law n.81 of 2020 as a chronic disabling disease, progress must be made in Italy to ensure greater protection and rights for citizens suffering from it. First and foremost, this can be done by strengthening and extending the diagnosis and treatment centers throughout the territory (1/3 of the respondents requires greater capillarity) and by investing particularly in general practitioner’s training to make sure that some signals are not underestimated, and an early diagnosis of the disease is possible.

The challenge is to ensure, throughout the national territory, access to innovative medicines as well as uniform criteria for the assessment and possible recognition of civil disability. Data collected in Italy highlight that there is still an issue of underestimating the disease: some individuals do not seek medical attention at all, delay their initial visit, or have their symptoms not immediately recognised, thus prolonging the time to a potential diagnosis and treatment. Stigma surrounding the condition is still prevalent, and individuals often feel uncomfortable discussing their condition with others. Organisational and bureaucratic difficulties, costs and expenses borne by individuals (and families), the need for greater workplace flexibility, the presence of a social support network, increased training of healthcare professionals, and better information about headaches all emerge as challenges.

Regarding rights, much more needs to be done. The enactment of the already mentioned Law 81/2020 is not a final achievement but a starting point to ensure the fundamental rights of patients: safety, fair and timely access to services and care, innovation, personalised treatments, information, and inalienable rights that the National Health Service must promote, protect, and guarantee. In light of all this, Cittadinanzattiva, patient associations, scientific societies, and healthcare professionals can advocate for the needs of individuals with headaches when interacting with institutions to bring about concrete and meaningful changes expected after the law's enactment.

Given that this issue is not limited to the national level, similar attention must be given at the supranational level. In this regard, what commitment will the new MEPs and the new leadership of the EU Commission DG Santé dedicate to the issue in the wake of the impending European elections in 2024? To raise awareness among European Institutions in November 2023 it is planned a policy workshop around migraine, with key stakeholders in the field (among others Active Citizenship Network has been invited with European Brain Council, European Migraine and Headache Alliance, European Federation of Neurological Associations, Pain Alliance Europe) to work together towards the drafting of a EU Migraine Action Plan [42-44]. This document would call out policymakers to action ahead of the 2024 elections and new EU Commission mandate, and will provide concrete policy recommendations to implement at the EU and national levels.

As the new European elections approach, from one hand Cittadinanzattiva continue to be committed on awareness, education, and empowerment initiatives at the national level; for another hand, Cittadinanzattiva aims to ensure that the incoming Parliamentary Members at the EU level actively engage in addressing the issue of headache disorders. For this reason, the EU branch of Cittadinanzattiva, Active Citizenship Network, is committed to promote the third mandate of the already mentioned MEPs Interest Group “European Patients' Rights and Cross-border Healthcare”, established in 2014 at the EU Parliament to strengthen the protection of patients’ rights in the European framework [45]. By working together with the new members of the European Parliament, Cittadinanzattiva endeavours to promote better understanding, research, and care for patients dealing with the challenges of headache disorders.

As Europe moves forward, it is imperative that policymakers, healthcare providers, and society at large heed the collective call for increased awareness, education, research, and compassionate care, ultimately forging a more equitable and empathetic future for individuals grappling with migraines and headaches. Together, let's create a brighter future for headache patients.

Figure 6: Logo of the MEPs Interest Group “European Patients' Rights and Cross-border Healthcare”, officially launched at the EU Parliament in Bruxelles on 02 December 2015.

8. Ethic Statement

The authors have worked in full compliance with the Code of Conduct of Cittadinanzattiva APS [46].

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“Colpo di testa: Your Rights on Migraine and Headache” campaign, realized in Italy by Cittadinanzattiva, was promoted thanks to Teva’s unconditional contribution and launched in 2020 with the publication of an e-book with stories and valuable suggestions for patients.

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38. MEPs Interest Group. (2008). European Patients' Rights and Cross-border Healthcare" website: The Journal of Headache and Pain 9, Impact of headache in Europe: a review for the 40 Eurolight project, 139–146.
39. The European Migraine & Headache Alliance: "the burden of repeated headache attacks and the fear of future episodes can disrupt family, social, and work life. The 2006 Cost of Brain Disorders in Europe paper revealed that migraine alone costs the European economy €27 billion annually due to reduced productivity and work days lost".
40. Official website for the European Brain Council www.braincouncil.eu
41. Official website for the European Federation of Neurological Associations www.efna.net
42. Official website for Pain Alliance Europe https://pae-eu.eu
43. Towards the establishment of the new MEPs Interest Group "European Patients' Rights and Cross-border Healthcare".
44. Repositary of the official document of Cittadinanzattiva

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