PROMOTING BETTER TREATMENT AND ADVOCACY FOR PEOPLE EXPERIENCING SEVERE MIGRAINE AND MENTAL HEALTH ISSUES

SEPTEMBER 2024

A joint project between GAMIAN-Europe
and the European Migraine and Headache Alliance (EMHA)

CONTENT

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EXECUTIVE SUMMARY

In this report, we highlight the economic and social costs of comorbid migraine and mental health and continue to share the experiences of people with this comorbid condition as in our previous report.[1] In collaboration with the European Headache and Migraine Alliance, GAMIAN-Europe convened a workshop of seven people with lived experience of this comorbidity. A small survey with 13 experts was also carried out to explore what key messages were important for the general public to know.

In this report, we highlight the economic and social costs of comorbid migraine and mental health and continue to share the experiences of people with this comorbid condition as in our previous report.[1]

Comorbid migraine and mental health refer tothe co-occurrence of migraine and a mental health condition. It is common for migraine to co-occur with various mental health conditions, particularly depression and anxiety disorders. The relationship between these two conditions is not fully understood and their treatment as a comorbid condition is often disjointed and lacking a holistic approach by healthcare services.

The economic and social costs are considerable. For example, a person aged 44 years with migraine across their lifetime costs the UK government £1379 per year in fiscal costs. Healthcare costs (admissions to hospital and medication) are similarly high, particularly for those with comorbid migraine and mental health, although there is less research on these costs. The negative impact on productivity and well-being is likely high.

The experiences of migraine and mental health problems were varied.

Many workshop participants explained the lack of understanding they often encountered and the intense pain they experienced with their migraine attacks.

These attacks were frequent, unpredictable, often lasting days and bringing their daily lives to a grinding halt. Participants and survey respondents alike knew the connection between their migraine and mental health issues. It did not always matter which came first but it was important that both were treated effectively to minimise the other.

Stigma and discrimination towards this comorbidity were a common experience, especially at work. It came largely from a lack of understanding and not believing how debilitating both conditions could be. This stretched into healthcare services where migraine attacks were sometimes minimised or misunderstood by General Practitioners.

Treatment for this comorbidity was never holistic where different specialities treated either migraine or mental health issues, but rarely considered both at the same time.

There is now a growing need to understand this comorbid condition and to campaign for better investment in its research and treatment to improve the lives of those who experience it.

BACKGROUND

In this follow-up project, we build on our last report which revealed the findings of a Europe-wide survey, workshop and webinar with experts on migraine and mental health. Here we highlight the key issues flagged in our previous report supplemented with new material from a rapid review of the literature on severe migraine and mental health, including the economic and social costs and a workshop to campaign for better awareness and investment into this comorbid condition.

Our previous report based on women with migraine and mental health issues found:[1]

77%

had a diagnosed mental health condition, mainly depression and anxiety.

76%

were aware of their triggers for migraine attacks, including flashing or bright lights, stress, noise and sounds, which also became a source of anxiety.

25%

reported their depression or anxiety was connected to their migraine attacks.

The combination of migraine and a mental health conditions were especially debilitating for women, significantly impacting their daily tasks, social life, employment, and caregiving responsibilities.

90%

took prescribed and/or over-the-counter treatments for migraine attacks.

30%

took antidepressants and/or received psychological therapy for their mental health.

83%

made lifestyle changes to avoid triggers for migraine attacks, and 45% used prevention treatment

48%

of women were in touch with a neurologist for their migraine attacks and 16% were in contact with a mental health professional

37%

reported that their healthcare professional(s) treated their migraine attacks and mental health condition separately

Women often encountered difficulties accessing health services, but emphasised the importance of a holistic approach to treating comorbid migraine and mental health conditions.

Many respondents felt their migraine symptoms were not taken seriously, even by their family doctor. Specialist health professionals (neurologists and mental health professionals) were reported to lack an understanding of this comorbid condition, and treatment was often disjointed, poorly coordinated and included long waiting times.

AIMS AND OBJECTIVE

The main objective of this report was to combine the key findings from a rapid literature review with the lived experiences and impact of migraine and mental health to be used as part of a campaign to increase awareness of this comorbid condition and its economic and social costs to promote better investment in its research and treatment.

The rapid literature review aimed to identify and provide a narrative summary of the key research on the:

Frequency of migraine and comorbid mental health conditions.

Relationship between this comorbidity and its treatment.

Economic and social costs of migraine and mental health conditions as both a separate and comorbid condition.

The workshop aimed to gather some of the key experiences and impact of having comorbid migraine and mental health issues as part of a campaign to raise more awareness of these conditions.

METHOD

Rapid literature review

The literature review focused on the above key questions to search for the most salient academic and grey literature.

The following methods were applied to identify and search for relevant literature:

Perplexity AI - to help identify the key questions and to find the most relevant literature.

Google Scholar - to find salient literature using relevant key terms (e.g. chronic migraine, comorbid migraine and mental health/psychiatric disorders/emotional disorders/depression/ anxiety, relationship and treatment of this comorbidity, economic and social costs, financial/fiscal burden, healthcare costs).

Searches were performed between 24-28 June 2024 and included literature published between 2000-2024.

Cross-referencing key literature - to collate other pertinent literature.

Other related literature - gathered from key academic journal listings.

Based on the review findings, the social media campaign messages were generated with the aid of Perplexity AI.

The workshop

The workshop brought together seven people with lived experience of migraine and mental health issues. This was convened by GAMIAN-Europe and the European Headache and Migraine Alliance to explore the experience and impact of migraine and mental health, and what key messages would be beneficial to help others understand this comorbid condition.

The survey

A brief survey with open-ended questions was developed and sent to participants attending the workshop and others who were also invited to respond.

Thirteen respondents gave their insights into their experience of migraine and mental health and what is important for the general public to know. These responses were incorporated with the workshop findings.

PART I: FINDINGS FROM THE RAPID LITERATURE REVIEW

Comorbid migraine and mental health

Comorbid migraine and mental health refers to the co-occurrence of migraine and a mental health condition. It is common for migraine to co-occur with various mental health conditions, particularly depression and anxiety disorders, where people experiencing migraine are 2-5 times more likely to have these common mental health disorders, which also include insomnia[2]. [3]Poor sleep is also more common in people with migraine.[4]

Additionally, around a third of people with migraine that includes aura (sensory disturbances) are three times more likely to be diagnosed with bipolar disorder (BD) and a similar proportion of people with BD experience migraine.[5] Primary headache disorders are similarly associated with depressive and anxiety disorders (pooled proportions of 23% and 25% respectively).[6]

While the interplay of comorbid migraine and mental health conditions is not clear it is generally agreed to be bidirectional – in which migraine can increase the risk of developing a mental health condition and vice versa. Some authors suggest similar or potentially shared underlying mechanisms for this comorbidity, although this is not fully understood[7]. [8]The two conditions *'feed each other in a vicious circle that reduces the patient's well-being'*, where medication needs to address both the migraine pain and psychiatric symptoms.[9] The mental health side is also likely to be underdiagnosed in many people experiencing migraine.[10]

Relationship between psychiatric comorbidity and migraine

Stress is a common trigger for migraine (and its chronification), and also affects mental health conditions, particularly depression.[11] Stressors and life events can also increase the incidence and susceptibility of depression and other mental health conditions.[8]

Depression is a significant predictor of the onset of chronic migraine, and psychiatric comorbidities are more common in this group than in people with episodic migraine.[12 13]

Psychiatric comorbidities are also associated with increased migraine-related disability, poorer quality of life and treatment outcomes.[8]

Psychiatric comorbidity can affect migraine evolution, lead to substance use issues, and affect outcomes of migraine.[14]

Impact

The impact of comorbid migraine and mental ill health is far-reaching affecting mood, social activities, general quality of life and work performance. People with migraine experience poorer quality of life, greater disruption or impairment to their work and social activities and higher health service use.[15]

Treatment of comorbid migraine and mental health conditions

Several treatment approaches can be used to treat this comorbid condition. Indeed, treatment of psychiatric comorbidity, particularly depression and anxiety, can reduce both the severity and frequency of migraine attacks. Untreated psychiatric comorbidities can lead to poorer responses to migraine treatments.[16] Hence the importance of using screening tools for comorbid mental health issues during initial assessments for migraine.[17]

Controlling stress is another important way to help manage migraine, which can include learning coping strategies, especially if migraine is associated with depression, and using cognitive behavioural therapy may be helpful.[18] Mind-body interventions or alternatives to medication, such as mindfulness-based CBT (MBCT), acceptance and commitment therapy (ACT), and mindfulness-based stress reduction (MBSR) therapy are also being used to treat this comorbidity.[19]

The use of behavioural and pharmacological treatments (e.g. a combination of beta-blockers and behavioural migraine treatments) is more effective in reducing headache disability in people with comorbid depression and/or anxiety disorders than those without these comorbidities.[20] Behavioural treatments include cognitive behavioural therapy which can reduce migraine attacks by helping to manage stress and the overall impact of migraine and improve coping skills. Behavioural therapy in combination with pharmacological treatments is particularly beneficial.[21]

In a small treatment trial for severe migraine preventive treatment appears to reduce the number of migraine days and migraine-related disability in people with a mood and/or anxiety disorder than those without this comorbidity.[23]

The presence of psychiatric comorbidities usually requires a more integrated and comprehensive treatment approach.[22]

The management of both migraine and psychiatric conditions may require separate treatments for each condition, and/or behavioural therapies. Often the management of migraine with psychiatric comorbidity requires increased use of medication to manage migraine/headache and a higher risk of medication overuse.

Economic and social costs[1]

Migraine

Over the past decade, several research articles have documented the significant economic cost of migraine. One of the most recent by Martins et al., (2023) calculated that migraine costs the UK public economy just over **£12 billion** annually (or approximately **£130.63** per migraine episode[23]). In the same study productivity losses in health and social care workers are estimated to be over **£2 billion**, with total annual productivity losses exceeding **£5.81 billion**. More specifically, a person aged 44 years with migraine across their lifetime incurs **£19,823** in excess fiscal costs to the UK government (or **£1379** per year).

Another recent systematic review of the economic cost of chronic migraine in OECD countries found significant direct (e.g. admission to hospital and medication expenses) and indirect costs linked to the condition, which varied across the 13 cost of illness studies examined.[24]

Older studies, such as the Eurolight study found the cost of migraine (across eight EU countries) amounted to an annual mean cost of **€1222** for migraine per person between 2008 – 2009, with the total annual cost of migraine for adults aged between 18-65 years (using a prevalence of 15%) calculated to be **€50 billion**.[25]

Another study examined the cost of chronic versus episodic migraine in patients in continuous treatment and found those with the former had **4.8** times higher costs compared with the latter; with **86.8%** (or **€1286**) going towards medications.[26]

Costs due to lost productivity, presenteeism and absenteeism have been predominantly estimated for migraine alone. In a European survey of five countries, between **77%** to 9**3%** of all migraine-related costs are attributed to work absenteeism and reduced productivity, particularly for those with severe migraine episodes.[27]

[1]*Table 1 summarises the economic costs outlined in this section.*

Costs of mental health conditions

A recent update of the economic, human (quality of life) and healthcare costs of mental ill health revealed a total cost of **£330 billion** in the UK. Losses to the economy in 2022 (due to sickness absence, presenteeism and worklessness because of mental ill health) amounted to **£110 billion**.[28] The human cost was **£130 billion** and the health and care costs **£60 billion**. Interestingly, the main economic costs are found in decreases in well-being and productivity losses rather than direct

Costs of comorbid migraine and mental health conditions

There is some evidence available for the economic costs of comorbid migraine and mental health conditions. Much of this is focused on direct healthcare costs in the US.

Direct healthcare costs

In the US comorbid depression/anxiety and migraine were found to have greater total direct medical costs - **$11,290** compared to **$3,135** for migraine alone.[29] High healthcare expenditure was also found for children with migraine and depression/anxiety costing **$9,875** a year.[30]

Using data from healthcare claims validated with telephone interviews, Lafata et al. (2004) found medical care spending was 1.3 times significantly higher in people with migraine reporting major depressive symptoms; and comorbid psychiatric symptoms were the main factors associated with increased healthcare costs.[31] A more recent analysis of claims data, published in 2020, found the medical costs for people with migraine were 1.7 times higher than controls (**$22,429** vs **$13,166**); and 1.8 times greater for mean pharmacy costs, mostly because of having more comorbid conditions, including depression/anxiety.[32]

Across Europe, healthcare costs for having migraine and psychiatric comorbidity were **1.3 times** higher for the UK, **1.5** for Germany and **1.6** for Italy.[33]

Occupational costs

Despite the very limited evidence concerning the occupational costs of this comorbidity it likely incurs greater occupational costs given the economic and social costs of migraine and depression alone. Indeed, the presence of depression and anxiety (and other psychiatric comorbidities) in people with migraine can lead to increased absenteeism, and reduced productivity, in addition to higher healthcare utilisation. However, there is minimal evidence for occupational costs of this comorbidity in Europe.[34]

Some evidence is available for lost productivity concerning headaches and depression. In one study lost productivity was associated with depression severity; the more severe the depression the more likely an employee received reduced responsibilities (e.g. military duty restrictions had been placed on those with mild, moderate or severe depression by **8.3%**, **32.5%** and **53.8%**, respectively).[35] Treating comorbid depression therefore can reduce the frequency and severity of migraine.

This same study estimated a revenue loss of **$31 million** for this comorbidity in their small cohort of 208 people in the military.[38]

Table 1: Summary of the economic cost of migraine, mental health conditions and comorbid migraine and mental health.

MIGRAINE COSTS

DETAILS	COST	LOCATION
UK Public Economy	£12 billion annually (£130.63 per episode)	UK
Productivity Losses (Health & Social Care Workers)	Over £2 billion (Total: £5.81 billion)	UK
Lifetime Fiscal Costs (Per Person, UK)	£19,823 (or £1379 per year)	UK
Chronic Migraine in OECD Countries	Significant direct and indirect costs	OECD Countries
Eurolight Study (8 EU Countries, 2008-2009)	€1222 per person annually; Total: €50 billion	8 EU Countries
Chronic vs. Episodic Migraine (EU Study)	4.8 times higher costs for chronic migraine	EU
European Survey on Migraine-Related Costs	77% to 93% attributed to absenteeism/productivity loss	5 European Countries

MENTAL HEALTH COSTS (UK)

DETAILS	COST	LOCATION
Total Cost of Mental Ill Health	£330 billion	UK
Losses to Economy (2022)	£110 billion	UK
Human Costs (Quality of Life)	£130 billion	UK
Healthcare and Care Costs	£60 billion	UK

COMORBID MIGRAINE & MENTAL HEALTH

DETAILS	COST	LOCATION
Direct Healthcare Costs (US)	$11,290 (comorbid) vs. $3,135 (migraine alone)	US
Healthcare Costs for Children with Comorbidity (US)	$9,875 annually	US
Medical Spending Increase with Comorbid Depression (US)	1.3 times higher	US
Medical Costs with Comorbidity (US, 2020)	$22,429 vs. $13,166 (controls); Pharmacy: 1.8 times higher	US
Healthcare Costs in Europe	1.3 times higher (UK), 1.5 (Germany), 1.6 (Italy)	UK, Germany, Italy
Lost Productivity (Headaches & Depression)	Revenue loss of $31 million in a small cohort of 208 people	US

PART II EXPERIENCES AND IMPACT OF MIGRAINE AND MENTAL HEALTH

Seven experts by experience attended the workshop.
Their demographic and health profiles are listed in Table 2 on the next page.

Table 2:
Demographic and health profiles of workshop participants

AGE	
41-45	2
46-50	1
56-60	1
61-65	2
66-70	1

COUNTRY	
Ireland	2
UK	2
Germany	1
Italy	1
Spain	1

EMPLOYMENT STATUS	
Employed:	3
Retired:	1
Unemployed:	3
Self-employed:	1

SEVERE MIGRAINE	
Yes	6
No	1

COEXISTING MH CONDITION	
Yes	4
No	3

AVERAGE YEARS SINCE DIAGNOSIS OF:	
Migraine	25
Mental health	27

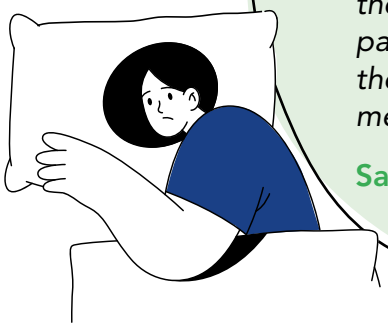
Understanding migraine and mental health

Experience of migraine attacks

The experience of migraine attacks is often varied. Participants and respondents to the survey described their migraine as lasting anywhere between a few hours to several days with a range of different symptoms, such as seeing flashing lights, partially losing vision, pain, less aura, fatigue and lack of concentration.

> *[My migraine attacks] last from 6 hours to 6 days. I experience cognitive problems, speaking problems and of course a lot of pain - mostly. Photophobia [light sensitivity] and problems with almost every sound. Ice is my best friend during an attack. I try to meditate to ease the pain, it works sometimes. And sometimes it helps me sleep which is a good help. Salty food, water with electrolytes and painkillers - triptans and other strong medicines I have from my neurologist.*
>
> **Emma**[2]

Other people do not always know or can relate to the intense level of pain and distress migraine attacks can bring.



> *Nobody ever asked me what my migraines are like. Everybody assumes they know and… they'll tell you things that might help you…but [most people] say my migraines are my fault… The perception is [during a migraine attack] that you go to bed for a few hours and suddenly the migraine lifts. For me and many people, I'm pacing the room sometimes hitting my head on the wall. Sometimes my husband has to restrain me from doing this.*
>
> **Sarah**

[2]*The names in the report have been changed to maintain anonymity.*

> *When I have frequent, unexpected attacks that affect my family and work obligations, I get more anxious and can feel depressed.*
>
> **Samantha**

Migraine attacks were sometimes erratic, making it challenging to plan normal day-to-day activities.

It was also common that participants with migraine had to keep going regardless of the intense pain they experienced from their migraine attacks.

> *Whilst people were considerate at work, I don't think everyone always understood the pain I experienced by a migraine attack. I always felt that I had to work through the pain and would only have left work on a handful of times when the pain was so bad. At one stage I was experiencing 2-3 attacks each month.*
>
> **Jasmine**

MIGRAINE
AND MENTAL HEALTH

PREVALENCE
People with migraine are **2-5 times** more likely to experience **depression and anxiety**.

MIGRAINE AND MENTAL HEALTH
Both go **hand in hand**, with one affecting the other.

TREATMENT
Both conditions must be **treated effectively** to minimise the other.

COSTS

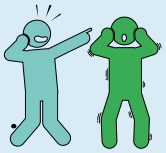
HEALTHCARE COSTS
In Europe, migraine and psychiatric comorbidity **increases healthcare costs by 30-60%*.**

Migraine costs the EU €50 billion annually**

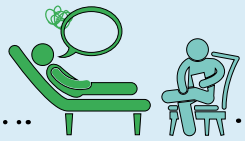
ECONOMIC COSTS
Each migraine attack is **expensive**.

EMPLOYMENT COSTS
Presenteeism and absenteeism due to migraine have a **massive economic impact.**

PREVENTION
is **key** to ensuring one doesn't affect the other.



STIGMA AND DISCRIMINATION
No one is to blame for having migraine and mental health problems.



ACCEPTANCE
Understand migraine and offer **support**.

INVESTMENT
into more **research** and **treatment** for better health and support.

** Bloudek LM, Stokes M, Buse DC, et al. Cost of healthcare for patients with migraine in five European countries: results from the International Burden of Migraine Study (IBMS). J Headache Pain (2012) 13:361–378. DOI 10.1007/s10194-012-0460-7*

***M. Linde, A. Gustavsson, L. J. Stovner, T. J. Steiner, J. Barré, Z. Katsarava, J. M. Lainez, C. Lampl, M. Lantéri-Minet, D. Rastenyte, E. Ruiz de la Torre, C. Tassorelli, C. Andrée. The cost of headache disorders in Europe: the Eurolight project. European Journal of Neurology Volume 19, Issue 5 p. 703-711. doi.org/10.1111/j. 1468-1331.2011.03612.x)*

Advice from others

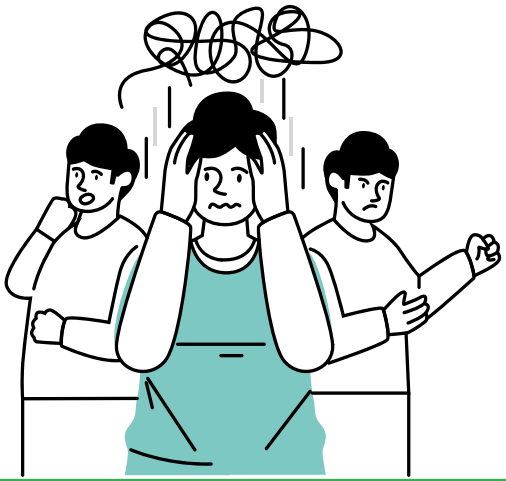
While trying to be helpful advice from other people who do not experience migraine can be misguided. Instead, listening and hearing what the person is trying to explain is far better.

The offer of help and support instead of giving advice can also be more constructive, but the assumption that a migraine could be just fixed by taking a pill could be annoying.

> *People give advice based on what they think migraine is, but they don't really know what it is and means. Listening is essential and to believe what people tell you when you have a migraine attack. When I have a migraine attack believe I cannot work, go outside and pick up my kids, go to your social event or go into the sun and enjoy the beach.*
>
> **Anna**

> *I tend to go "off the grid" during the attacks because I know people will say to take a pill and move on...*
>
> **Carlos**

Dismissing migraine attacks as a headache was also unhelpful.



The connection between migraine and mental health

Participants described a range of experiences with migraine and how it affected their mental health. Migraine attacks sometimes leave a person feeling low.

Often, participants described the connection between the two and how they exacerbated each other.

The important idea referred to here is that the stress of chronic pain can impact mental health. But it can go both ways, as mental health can also impact migraine.

> *I've had depression longer than migraine. The migraine definitely makes [the depression] worse. I suspect when I go through a bad episode of depression that makes the migraine worse too. It's a vicious cycle.*
>
> **Susanna**

> *The relationship between migraine and mental health problems can arrive in two directions. One is a person with a mental health problem that also has migraine … And the second one is a person that has migraine and as a consequence, can develop a mental health problem such as stress or anxiety or depression.*
>
> **Maria**

Another participant reiterated this idea pointing out that her mental health improved when they had fewer migraine attacks. They described a pattern of reactive depression after each migraine attack which left them in despair for days. This cycle shows how migraine attacks can compound mental health issues so the conditions magnify each other's impact.

Participants were commonly asked to identify which condition had come about first. Two participants specifically pointed out that their migraine attacks had preceded their mental health issues.

> *My mental health improves a lot when my migraine attacks decrease. I also have reactive depression. Any time after a migraine attack for two or three days. I have this condition where I don't want to do anything… life has no meaning.*
>
> **Anna**

Others noted their migraine came before their mental health issues and some considered the former a cause of the latter condition.

> *If you have migraine and mental health problems, there's always the question, what was first? For me, the migraine was first. And the migraine gets worse, and then the mental health problems came.*
>
> **Carlotta**

> *I have mental health problems because of my migraine.*
>
> **Anna**

One respondent felt that her anxiety had become much worse because of their migraine attacks and other problems.

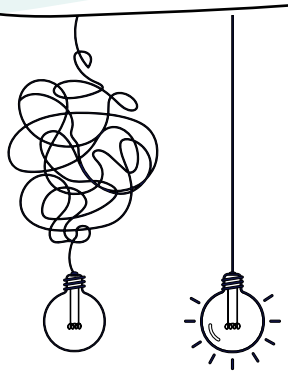
Others stressed that migraine had a debilitating effect on every aspect of their life. During a migraine attack some participants were not able to function for days at a time. Time was also needed, sometimes days to recover. This placed an added strain on their mental health which was further compounded by physical pain.

> *My anxiety is my worst enemy. When I was chronic my anxiety was with me every day, at every hour. Over the last year, I experienced a long period of depression because of personal troubles and my migraine, and despite my preventive treatment, they increased in frequency.*
>
> **Carolina**

This was distressing for participants and difficult to manage in their daily lives and also the realisation that migraine and mental health could be connected.

> *There are days when you can't get up, you can't function. You can't, so that's not a mentally healthy functioning scenario.*
>
> **Joanna**

> *It was like a lightbulb moment only five years ago that I realised I've been living with migraine all my life. And then there was the mental health part of it, which has always been there, but never I realised that the two could be connected.*
>
> **Jean**



The physical effects of migraine attacks had an obvious impact on mental health, especially when these attacks happened frequently and regularly.

> *When I vomit with migraine and have to stay in bed, I feel very low. Very hard to bounce back especially when you know that between a week or ten days, you'll be in the same position again. Feel low when I have to cancel appointments, planned outings or family gatherings.*
>
> **Maragaret**

Self-blame, stigma and discrimination

Participants talked about feeling blamed or responsible for their comorbid condition and said they often received limited consideration, sympathy, or sensitivity from others.

This was compounded by the sense that they could feel personally responsible for their condition; that they had somehow caused it. Several participants talked about feeling responsible for their migraine, and this added another dimension of stress.

> *There's very little sympathy for people with migraine outside of those who understand ... you're always cautious about events in case you're going to get a migraine.*
>
> **Joanna**

> *Sometimes you feel like it's all your fault, you should sort both of them out [the migraine and mental health issues]. And if you sorted yourself out, you'd be fine.*
>
> **Susanna**

Some participants were concerned they may have made their condition worse or that their migraine attacks happened because they had not been managing their triggers well enough.

However, despite this, some participants were able to work through feeling responsible for their comorbid condition by understanding that they were not to blame or the cause of it.

> *I was really convinced that I was the cause of my migraine attacks, that it was because of my mental health condition that I had migraine. And that I was the cause of the pain that I experienced.*
>
> **Anna**

The experience of stigma and discrimination was considerable. This was largely because of a lack of understanding of what migraine and mental health problems are about. Participants were aware of the negative consequences that might occur if they disclosed their comorbid condition, especially to colleagues or employers at work.

> *I tend to attribute the cause [of my migraine] to myself. Now I have this new mental health condition and I'm again the cause of it. So, I have to really spend time with myself to say, 'No, this is not your fault. It's a mental health issue or a health issue or, yeah, sorry.' The fault is there to think I did this.*
>
> **Anna**

> *You hide that you have anything wrong. People don't understand either condition and don't believe they are real. I have never disclosed this to an employer. The one time my mental health was known by a colleague it was used against me to push me out of a job.*
>
> **Jean**

Some employers were accommodating and allowed those with migraine attacks to work flexibly, where they could take time off and make up the time when they had recovered. Although hiding the migraine pain or battling through it was a regular occurrence for many participants/respondents.

Living with both migraine and mental health issues was not easy, often resulting in a 'double edge' of stigma and discrimination. The mental health side was sometimes more difficult to disclose than the migraine.

> *Whilst people were considerate at work… I always felt that I had to work through the pain and would only have left work on a handful of times when the pain was so bad…*
>
> **Jasmine**

> *[I tell people] I have the condition and have to apologise for being 'unpresent' more often than [not]. It's better to say [it's because of my] migraine than my mental health. I hide the latter as much as I can.*
>
> **Astrid**

Not being believed

Occasionally one or two respondents described being surrounded by people who are supportive and aware of migraine and mental health issues. However, for the majority not being believed came from all quarters and was a common experience.

Another participant talked about the stereotypes she had encountered about people using migraine as an excuse to not do something or to take time off work.

> *No one really believes you have migraine or you say you have a migraine and they say, 'Oh, sure, yeah, you'll be fine'. I have them every day and you're looking at the person saying, no, you don't.*
>
> **Jean**

> *[I've heard people say at work], 'Oh, those people that have this migraine attack or menstruation every Friday to get a long weekend …*
>
> **Maria**

Some participants faced contrasting attitudes towards migraine and sometimes this occurred even within their own family. This was seen as an echo of the more widespread attitudes and stigma. One participant found empathy, understanding, disbelief and dismissal within their own family. In their case, some individuals who had experienced migraine assumed their experience was the same as theirs and as a result, did not believe the severity of their experience.

> *There's migraine in the family on my dad's side. I can sit down and have a conversation with my aunts, uncles and cousins… It was interesting to see all the varying types [of migraine] we had… But my mom's family don't believe I have migraine.*
>
> **Jean**

Social impact, family and friendships

Some participants also felt the impact of not being able to maintain their social lives because of their migraine and that they were not able to participate in social activities.

Some participants understood the impact their migraine attacks had on close family members, especially children.

> *You do have to constantly talk to yourself about not feeling guilty for being unable to go to your friends [to do] whatever or even just to sit out in the sun with your neighbours.*
>
> **Jean**

> *I was a full-time mum to special-needs children. When problems occur, it's sometimes assumed that I'm overreacting to them. The people who are close to me are usually very supportive, trying to understand both conditions, but it is hard for my young grandson to understand migraine in particular, and he tends to write me out of any plans, 'You can't come. You have headaches.'*
>
> **Susanna**

Although participants were able to reconcile these difficulties, others talked about losing friends who couldn't understand why they persistently kept missing social engagements.

The negative impact of migraine attacks on social engagements also affected one respondent's mental health.

> *I have a friend I haven't heard from her for ages now because I had to keep cancelling on her…and she'd say, 'give those headaches a talking to'. Like, if I could I'd have done that. I would have done it 30 years ago… It's the idea [that] you could really sort yourself out if you tried. Again, it's almost a blame thing.*
>
> **Susanna**

> *I can't plan anything that includes others since I don't want to risk cancelling. That means almost no friends anymore… I don't tell others about my condition. Friendships just fade out. I have developed social anxiety and I am mostly at home inside my apartment.*
>
> **Freja**

Work

The interaction between migraine and mental health has profound implications for a person's work life, often leading to disruptions and challenges in maintaining employment. Sometimes the severity of symptoms forced participants to take time off work or to stop working altogether.

One participant talked about how chronic migraine led them to apply for disability benefits but despite their debilitating migraine, it was ultimately her depression that qualified for this, not the migraine.

> *The doctor asked me if I needed to [apply for] disability [benefits] because I couldn't even go to work... In the end, they gave it to me because of the depression... Nobody could understand that my migraine was itself an important reason to [grant me] a disability or incapacity to work.*
>
> **Maria**

> *You're grieving the loss of the job, you're grieving the loss of companionship through the job, you're grieving the life that you used to do and have. And then accepting that what is happening, you have to allow your body to adjust and not fight it all the time.*
>
> **Jean**

For others, the physical pain from migraine attacks along with the emotional strain of losing a career and social connections were a major challenge. One participant described their sense of grief and loss after having to leave work because of their comorbid migraine and mental health issues.

Those who were able to work often had to make adjustments to prevent migraine attacks and sometimes work colleagues were not sympathetic. This included having the option to work flexibly but also practical considerations to avoid triggers for migraine attacks, such as exposure to bright or flickering lights.

> *I have to be really careful of flickering lights from presentations. So, when you're at a work event like a conference and you're sitting at the back of the hall with dark glasses on to [avoid the lights] ... people ask very strange questions.*
>
> **Joanna**

Stigma in the care systems

Minimising migraine

One area of stigma participants experienced was in their interactions with health services. One participant described how the impact of their migraine was sometimes misunderstood by their General Practitioner (GP).

> *I was diagnosed with migraine as a child and then I developed mental health issues in my teens. But it was in my 40s that I got my migraine properly treated. It was always thought to be dietary-related [with dairy being a trigger] … My GP treated me for sinus headaches, [but a neurologist explained] that these headaches had nothing to do with sinus [problems].*
>
> **Jean**

Such misunderstanding and minimisation of migraine can lead to incorrect treatment and support, and even more distress.

Disconnected treatment and care

The failure of medical professionals to recognise the connection between migraine and mental health occurred both at individual and institutional levels. Seeing separate specialists (e.g. a neurologist for migraine and a psychiatrist for a mental health condition) led to a disconnect in care.

Although participants had first-hand experience of the mutual impact of migraine on mental health, they often found health professionals did not fully appreciate the interrelationship.

> *When you do get to see a neurologist … they don't seem to consider that the migraine is affecting your mental health. They want to see a diary of pain. They don't want to see any other symptoms that you have … I don't think it occurs to them…that this could be affecting your mental health.*
>
> **Susanna**

Sometimes the health services themselves were structured in such a way that migraine was not considered the priority. The compartmentalised services presented further challenges for participants as they had to negotiate with decompartmentalised health services.

> *I was never validated in the symptoms that I had... nobody ever talked to me about this connection between migraine and mental health conditions.*
>
> **Anna**

> *I had to find a psychotherapist to deal with my mental health issues and go to the neurologist to treat my migraine. I had many psychological issues, but nobody ever talked to me about the connection between migraine and mental health. I was never really helped to understand I could take care of both. It was always separated.*
>
> **Susanna**

Some employers were accommodating and allowed those with migraine attacks to work flexibly, where they could take time off and make up the time when they had recovered. Although hiding the migraine pain or battling through it was a regular occurrence for many participants/respondents.

One participant had experienced both migraine and cancer services and contrasted how cancer services were fully aware of the mental health impact of cancer.

> *When you have cancer, they're very worried... about your mental health... but with migraine, they don't.*
>
> **Susanna**

Holistic health services

Given the two-way connection between migraine and mental health problems and how each affected the other, participants talked about the need for more holistic and integrated health services. These services would consider both the physical and mental health aspects of comorbid conditions, which would be highly beneficial.
One participant described this approach that they had received.

> *My GP referred me to a psychologist who specialises in helping people with mental health problems who have long-term physical health problems. And he was actually quite helpful.*
>
> **Eve**

DISCUSSION AND CONCLUSION

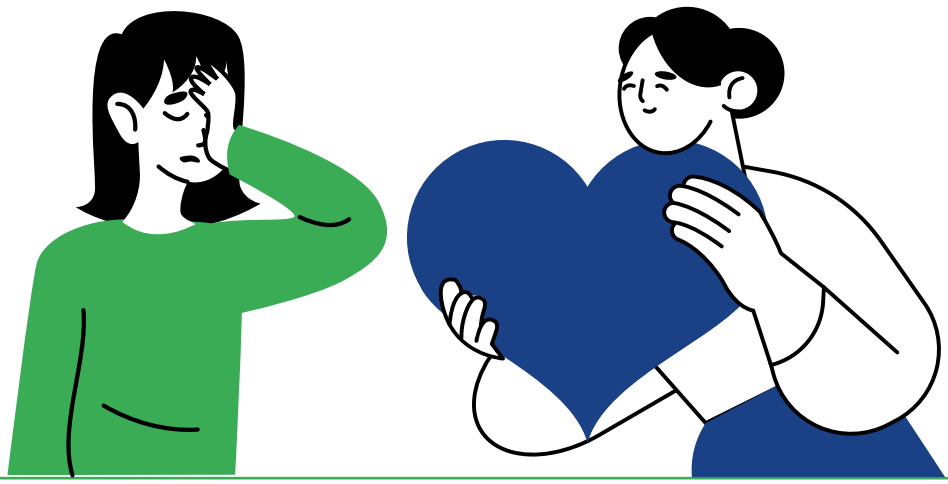
Findings from the literature review demonstrate the huge economic, human and social costs of migraine and mental ill-health as separate conditions. There is relatively little literature on the economic and social costs of comorbid migraine and mental health problems, despite recognition of its high prevalence, impact on quality of life and negative effects on treatment outcomes if both are not managed effectively.

The two-way relationship between comorbid migraine and mental health issues is gaining more attention in the research literature despite a limited understanding of its underlying mechanisms. It is likely mental health conditions in migraine patients are underdiagnosed, which makes it difficult to calculate the full costs of this comorbidity. Any such calculations may well underestimate the true costs of comorbid migraine and mental health conditions.

Researchers suggest the need for healthcare professionals to use screening tools to assess for any potential mental health issues in people with migraine. Prevention treatment, stress management, talking therapy, and healthy lifestyles tailored to the individual can help towards more effective treatment of this comorbid condition. These factors now need to be integrated into healthcare services.

The workshop and survey revealed the considerable negative impact of comorbid migraine and mental health problems. The challenge for many experiencing this comorbidity was the lack of understanding of what it is like to live with the pain and distress. Self-blame or blame from others adds to the challenges and difficulties of living with this comorbidity. Migraine attacks for many were unpredictable and frequent making it virtually impossible to plan or conduct their day-to-day activities. More constructive and flexible working conditions are crucial for those with this comorbidity. The impact on work, friends, family and children was equally difficult, creating tensions in many relationships.

This comorbidity takes much understanding that can be generated by raising the level of awareness to create a better world for those who experience its challenges.



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CONTACT US

GAMIAN-Europe

Avenue Marnix 17, 1000 Brussels, Belgium
www.gamian.eu

EMHA

Rue d'Egmont 11, 1000 Brusels (Belgium)
www.emhalliance.org