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Invisible No More: An Intersectional Approach to Understanding the Lived Experiences of People with Migraine in Lebanon

By

Farah Taleb

A thesis
submitted in partial fulfillment of the requirements
for the degree of Master of Interdisciplinary Gender Studies in Social and Education Sciences

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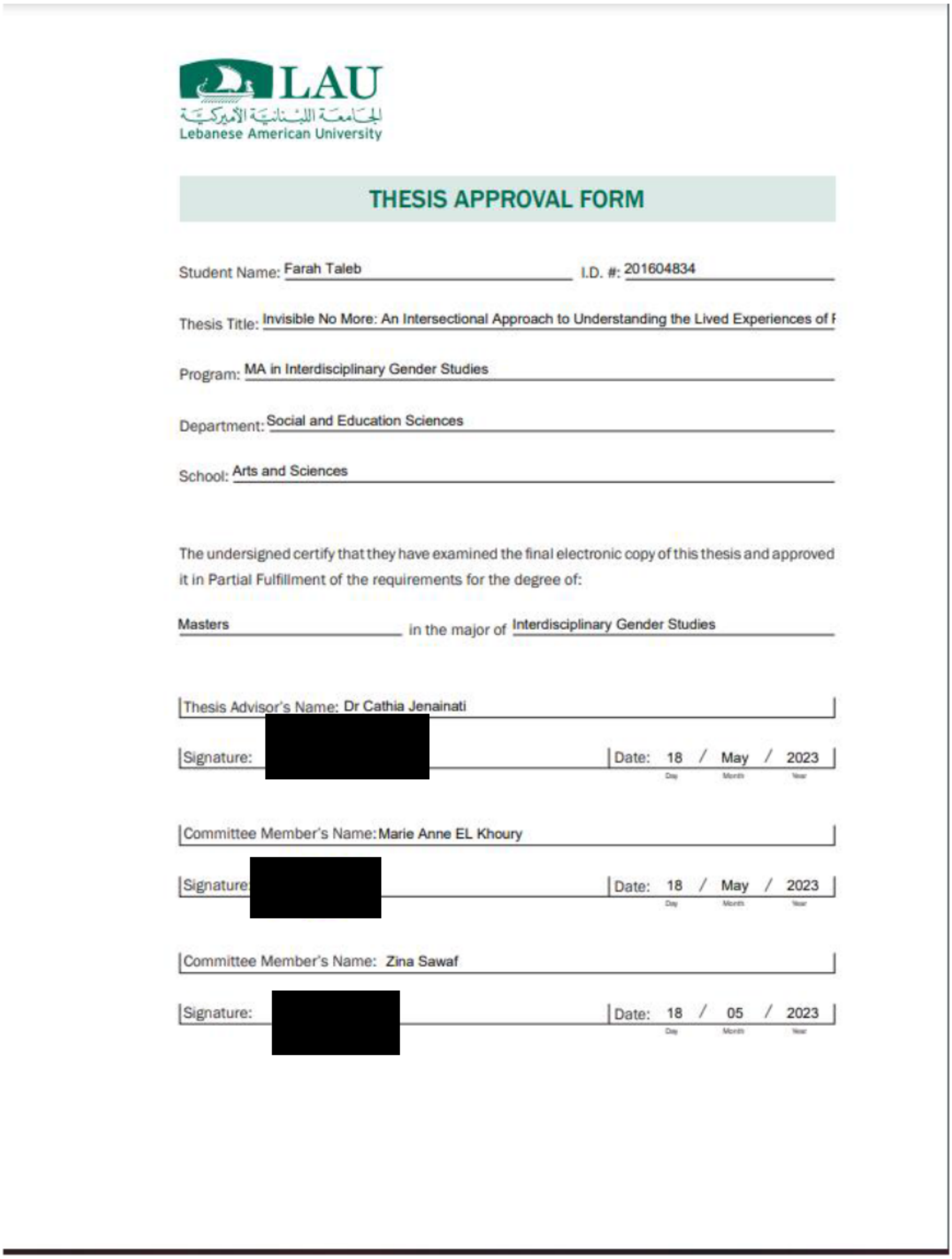

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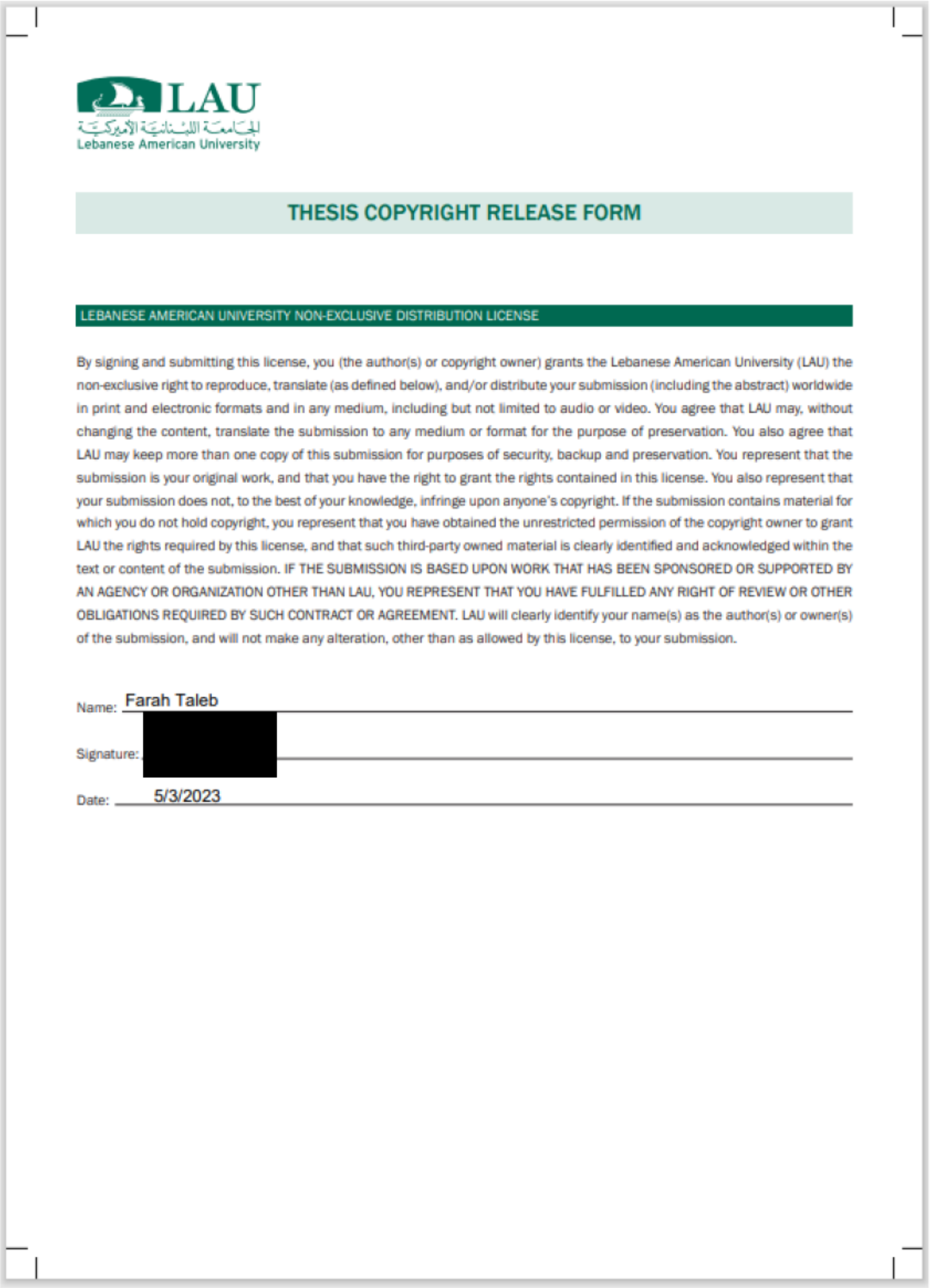

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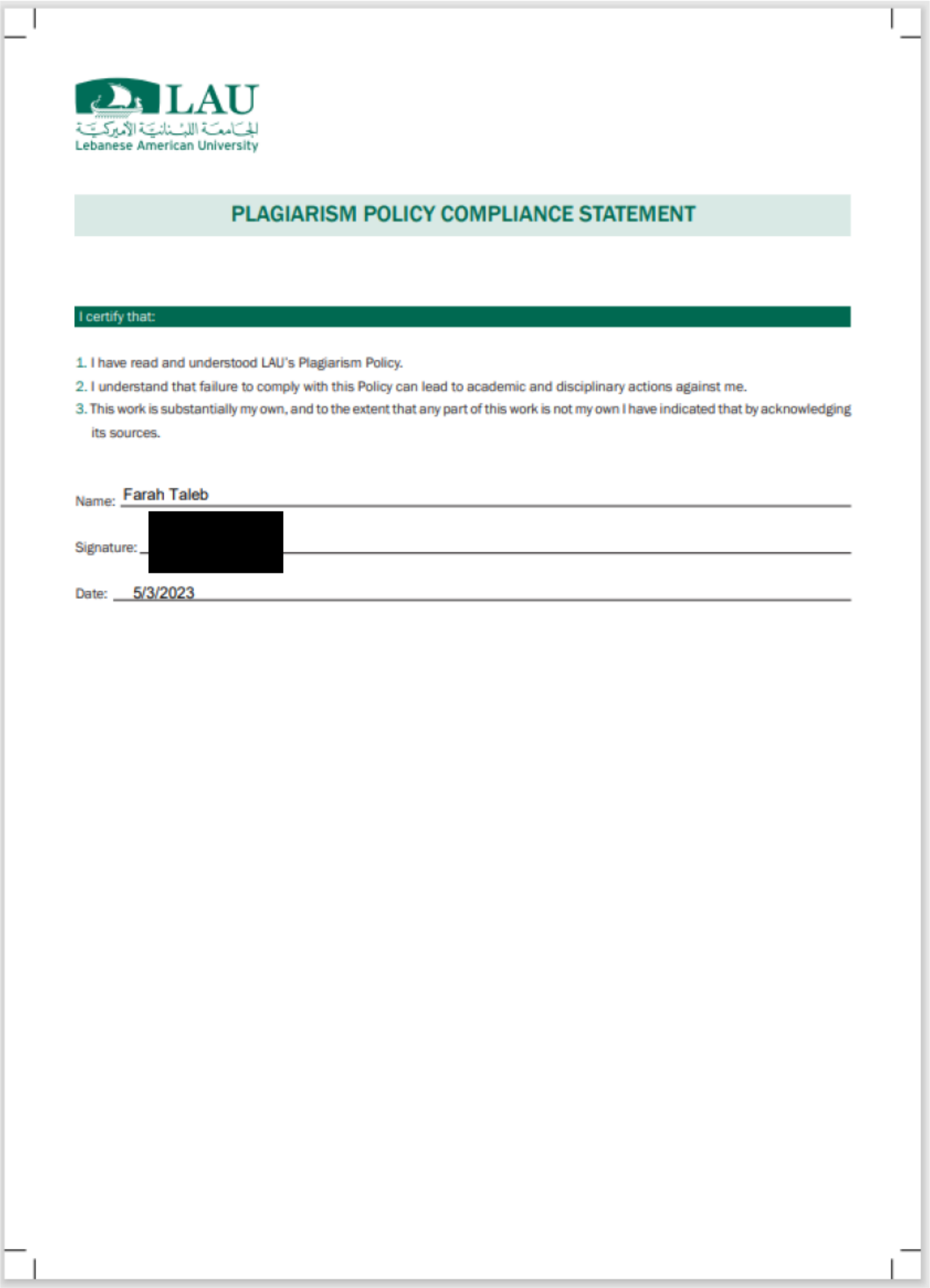

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DEDICATION

To our limbs, lungs and livers. To our hearts, heels and hands. To our brains, bones and adamant bodies. To our complex identities. May we be proud of them.

To the words that weave our tales, the silences that edify our experiences, the faces that mirror our emotions. To the power of our voices, may we fearlessly narrate our stories.

To my mother, sister, and all who live with invisible disabilities.

You are heard.

May we, as a society, do better.

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Sami, your support, words and wisdom have enlightened me, even across the miles.

Invisible No More: An Intersectional Approach to Understanding the Lived Experiences of People with Migraine in Lebanon

Farah Taleb

ABSTRACT

This thesis examines the experiences of people living with migraine through a feminist lens. Utilizing theories of feminist disability, the French philosopher Foucault's ideas on power, and intersectionality, this research aims to examine people's illness narratives of migraine and its effects on their experiences with the society around them. Additionally, this study explores people's definitions of their migraine, their perceptions of societal views of migraine, and their self-image. The methodology applied in this research is founded on a feminist post-constructionist approach which utilizes mixed-method, 4 semi-structured interviews and a quantitative survey. Key findings disclose modes of marginalization and exclusion that are experienced by people living with migraine, including feeling singled out and perceived as untrustworthy. Also, this research sheds light on the intersection between disability and gender, laying out the injustices that both men and women with migraine experience due to the gender norms, roles and expectations around them. Important findings were established about the differences between how women and men view and make sense of these gendered experiences. The study also reveals themes of empowerment and support that people with migraine experienced throughout their journeys. Overall, this study fills a gap in research about invisible disabilities in Lebanese literature, and provides insight into illness narratives of migraine, the impact of societal and gender perceptions on these narratives, and the importance of taking into consideration the intersection between gender and disability. This thesis pushes towards the inclusion of invisible disabilities into the Lebanese literature on disabilities by providing a more nuanced understanding of people with migraines' challenges and needs.

Keywords*:* Migraine – Invisible disability – Intersectionality – Gender – Societal perceptions – Ableism – Marginalization

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LIST OF DEFINITIONS AND ABBREVIATIONS

- **Disability:** In this thesis, the definition of disability does not entail framing the body as defective the way the medical model of disability defines it, nor does it mean a deviance from the norm that needs to be accommodated. The definition of disability here is based on Kafer[1]'s political/relational model in their book *Feminist, Queer, Crip*, "that sees disability as a site of questions rather than firm definitions". (2013) Hence, disability does not only have biological basis, but is also about the societal attitudes, barriers, and hierarchies that the person with disability experiences. Disability is a site of social and political struggle rather than a personal calamity. The category of disability is not fixed, but rather static and permissive.

- **Ableism:** Is a system of marginalization and oppression against people with disabilities that places them as inferior with respect to able-bodied individuals. Ableism can take many forms including physical barriers and stereotypical attitudes towards people with disabilities.

- **Gender Expectations:** Are gendered societal assumptions of what it means to be a male or a female. Such expectations differ from one time to another and from one culture to another. Often, such expectations are based on gender norms and

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[1] <Accessed on 24 April 2023>

roles that place men and women within labels that reflect femininity and masculinity. For instance, men are expected to be stoic and assertive while women are expected to be nurturing and emotional.

- **Androcentrism**: Is a system of beliefs that favors men over women. This perspective highlights men's experiences and achievements, excluding women.
- **Gynocentrism**: Is a system of beliefs that marginalizes men's experiences and focuses solely on women's views of the world.
- YLDs[2]:Years lived with disability

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[2] <Accessed on 25 November 2022> YLD: years lived with disability. It measures the amount of time people lose to diseases and injuries that degrade health but do not cause death.

CHAPTER ONE

INTRODUCTION

1.1 Positionality

Various types of knowledge that are essential for the enhancement of human life and that play an important part in improving the lives of people emanate from healthcare systems. Some of these types of knowledge are biological, which represents the basis of healthcare, and epidemiological which focuses on the reasons for and the causes of diseases, illnesses, and disabilities in order to control them. The following thesis is concerned with an important kind of knowledge that is often undermined by society at large and the medical systems in particular, yet is as equally important, and that is the subjects' knowledge; in other words, people's own experiences of disabilities, illnesses, pains, and treatments. In 2019, I fell ill all of a sudden with what now I know is a disabling disease that keeps me up at night lingering through the small space of my living room with both hands pressed against my lower right abdomen. It took me frequent visits to medical clinics and lots of struggles to accept and come to terms with it. Venturing through life with a body I felt had betrayed me, I have had several experiences where many people around me did not understand, let alone believe that I had a chronic disease that was disabling me from practicing my daily life activities. I started seeing the world through the eyes of someone who is not able-bodied, which had me thinking about disability and its nature. Being a woman who has been hovering around medical clinics for quite some time now, I have become interested in self-reflecting and analyzing my own experiences as a female with an invisible disabling disease. This thesis is born because of an interest in individuals' self-perceptions of their disabilities and diseases, scrutinized through a feminist theoretical lens that I have been acquainted with as a graduate student in Interdisciplinary Gender Studies. I wanted to explore one of the most invisible disabling diseases worldwide, that is migraine, not in a scientific framework but through narratives that would provide insights into people with migraines' experiences of their disability, their social context, and their cultural background. By writing this paper, I am not claiming to speak on behalf of people with disabilities, as I believe in the feminist definition of disability provided by Kafer in their political/relational model of disability that "neither opposes nor valorizes medical intervention". (2013) A renewed interrogation of the medical model of disability is needed, as disability is not a universal concept that could be limited to a certain set of people, it is socially constructed from biological reality (Wendell[3], 1989). Each person has a unique experience of their illness, disease, or disability from their own standpoint, determined by their interactions with the world around them. My own disabling disease is similar to migraine in the sense that both are invisible which adds a layer of struggle to a person's experiences. Conducting this research allows me to endeavor outside of solely describing my experience, into understanding the experiences of disabilities, here migraine specifically, in a larger context.

1.2 Evolution of Research/ Change in Direction

The original idea for this thesis focused solely on the gendered experiences of migraine, specifically tackling the idea of the feminization of migraine, while aiming to have a population constituting of women, men, and genderqueer. However, after conducting further research and obtaining findings, I realized that the population in both the interviews and the surveys that I have conducted constituted only ciswomen and cismen. Also, I found that a

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[3] <Accessed on 30 March 2023>

large portion of the findings focused on the disabling effects of migraine and the social marginalization that people with migraine experienced. Therefore, I decided to shift my thesis towards examining migraine as an invisible disability, without leaving behind the effect of gender on people's experiences but rather utilizing an intersectional approach that inspects the joining point between gender and invisible disability. I believe this new direction in research is essential because it provides a more comprehensive approach to women's and men's experiences of migraine. In the beginning, I ventured into the study with an inclusive mindset that wanted to acknowledge the genderqueer population's experiences of migraine as well, however, the participants in the study were males identifying as men and females identifying as women. Although the researcher recognizes that the sex and gender of an individual do not necessarily have to coincide, the following study will focus on ciswomen and cismen as a starting point for filling the gap in research pertaining to migraine, gender, and invisible disabilities, especially in Lebanon.

1.3 Situating the Problem

Migraine is a neurological idiopathic disease that ranks among the highest causes of disability in the world. According to the Institute for Health Metrics and Evaluation (IHME) GBD 2019 statistics, "headache disorders are responsible for 46·6 million (95% UI 9·77–100) YLDs, or 5·4% (1·1–10·6) of total YLDs in 2019. Migraine headache made up 88·2% (60·7–97·7) of the burden of headache disorders." (IHME, 2020)[4] In Lebanon, the prevalence of migraine in 2019 was 16.75%. The percentage of YLDs in Lebanon was 5.42% for both males and females, 6.01% for females alone and 4.62% for males. (IHME,*GBD Compare*, 2022)[5] People could suffer from either one of the two types of

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[4] <Accessed on 22 November 2022>

[5] <Accessed on 25 November 2022>

migraine: migraine with aura or migraine without aura. Migraine with aura is accompanied by "visual disturbances, followed by sensory symptoms and speech problems" and in rare cases, it "can also include motor symptoms and retinal or brain stem symptoms."(Brink & MacGregor, 2019)[6] Migraine without aura is more common and is often accompanied by a throbbing headache that could vary in intensity. Despite its debilitating effects, migraine is often stigmatized and undermined especially due to its invisibility. People who experience the invisible disability often face a double burden: having their migraine disable them from performing their everyday life activities, and having this disabling disease be undermined and normalized which leads to feelings of marginalization, exclusion, and being viewed as the 'other' (Hendry et al., 2022[7] ; Valeras, 2010[8] ; Kattari et al., 2018[9]). The world around us is designed from the perspective of the able-bodied, inevitably placing people with disabilities at a disadvantage. Gender plays a significant role in affecting people's perceptions and experiences of migraine, as gender roles, norms, and expectations entangle with ableist paradigms of youth and health to further marginalize people with migraine. Despite the fact that both disability and gender are parts of people's identities and play essential roles in shaping their experiences, stories of disability and illness are often not given the spotlight as much as gender. This thesis aims to explore the intersection between gender and disability in the perceptions of men and women who experience migraine in Lebanon.

Migraine is complex in the way that its symptoms differ from one person to another and can be triggered by a myriad of factors such as stress, insufficient sleep, light, and odors. Its chronic nature, numerous triggers, and invisibility lead to significant emotional, social, and

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[6] <Accessed on 29 October 2022>
[7] <Accessed on 18 April 2023>
[8] <Accessed on 18 April 2023>
[9] <Accessed on 18 April 2023>

physical struggles that the person with migraine has to face. Despite its severe and disabling effects on people's lives, societal and medical views of migraine often undermine and normalize it. Having their disability invalidated by friends, family, and even doctors, people with migraine feel stigmatized and isolated from their surroundings. Men and women do not experience migraine the same way, nor do people from the same gender. Hence, an intersectional lens is required to explore these different experiences in order to understand the disparities each gender faces in experiencing migraine. The following thesis aims to explore these experiences through a feminist intersectional disability framework and to investigate people with migraines' perceptions of the ways the public reacts to their migraines, their own feelings, and the obstacles they face when accessing medical help. The thesis will also shed light on the way gender roles, norms, and expectations affect these experiences within the Lebanese society and medical institutions. This study aims to raise awareness of the challenges that people with migraine often face and to contribute to the inclusion of invisible disability into disability research in Lebanon. The following study will centralize people's stories of their migraines as essential illness narratives, which Alshammari[10] describes as "in the same way that women's self-narratives challenge the male narrative of women, illness narratives challenge linear plots and the narratives of health." (2018)

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[10] <Accessed on 26 April 2023>

1.4 The Lebanese Context

1.4.1 Migraine and Invisible Disabilities

According to Combaz (2018)[11], the prevalence of disabilities has been low in Lebanon based on the Lebanese State figures, as “it claims that the disability prevalence rate stands at 2% of the population. One explanation for this rate is that Lebanon’s official statistics body uses a medical model of disability, instead of a social one (Kabbara, 2013, p. 8; Lakkis et al., 2015, p. 4).” Using a medical model to explain disability not only considers disabilities as defects that need to be ‘corrected’, but also does not consider several invisible disabilities as disabilities. Being a person with a disability in Lebanon is difficult, but having an invisible disability makes it even harder. Marouche et al.[12] write that: “In Lebanon, the situation of those with invisible disabilities is even more severe because these disabled persons are not only invisible in society, but they are completely excluded from legal protection.” (2021) Consequently, it is much harder for them to receive accommodation as well as the understanding of the Lebanese society around them. The Lebanese law 220 that was drafted in 2000 defines a person with a disability as: “A person who witnessed a decrease or even a disappearance of his capacity to: practice one or more important activity (ies), or to provide him/herself with the basics of livelihood alone; or a person who has lost the capacity to take part in social activities equally with others or to guarantee a normal personal or social life according to the common criteria of the society he lives in because of the lack in one of his functions- be it corporal, sensorial or mental, permanently or temporarily because of a defect by birth or acquired with time or because of an illness that perdured beyond medical expectations.” (Disability Hub[13]) Although the definition of a

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[11] <Accessed on 26 April 2023>
[12] <Accessed on 17 April 2023>
[13] <Accessed on 17 April 2023>

person with a disability is broad, its ambiguity does not make it easy for migraine to be considered a disability. In addition to this, the disability law focuses on 4 types of disabilities: "mobility, visual, hearing, and mental" (Disability Hub) without mentioning invisible disabilities. Hence, people with invisible disabilities are marginalized from the legislative decree of what a disability is, which makes their disabilities undermined in the eyes of the public. In the report *Forgotten and Invisible: The Impact of Lebanon's Crises on Persons with Disabilities*, the NGO Humanity and Inclusion[14] discusses the way law 220 focuses on the disability itself rather than on the issues of societal barriers, lack of accommodation, and public perceptions of disabilities. The report says "this definition is consistent with the outdated medical model. The law's content ensures a few rights (using physical environment, right to employment, etc.) but excludes services like social inclusion, political and economic participation, and legal capacity." (Humanity and Inclusion, 2022) The Lebanese Ministry of Social Affairs issued a Disability card, however, this card also follows the medical approach to disabilities and has "limited access to services by persons with disabilities, due to administrative constraints, lack of awareness, as well as limited efficiency of the services, which stopped being provided because of absence of funds." (Humanity and Inclusion, 2022)

When it comes to literature pertaining to invisible disabilities, there is a scarcity in both Lebanon and worldwide. In fact, the underfunding of healthcare systems in Lebanon and the "limited coordination between academic bodies and ministries to provide evidence-based policies, roundtables, and working groups to discuss priorities of health research with the different stakeholders including policymakers, local NGOs, International NGOs and

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[14] <Accessed on 15 April 2023>

academics" (El Achi et al., 2020)[15] have led to the under-research of several disabilities that affect people in Lebanon, including migraine as an invisible disability. In *Assessing the Capacity for Conflict and Health Research in Lebanon: a Qualitative Study*, participants such as public sector officials, specialist academics, and humanitarian workers pinpointed "'lack of research culture' as a major challenge for conducting health research in Lebanon" (El Achi et al., 2020). Living within a society whose medical and academic institutions do not recognize migraine as an invisible disability, and whose societal perceptions of this disability is 'just another headache' resembles what Pace et al., (2021)[16] describes as the power of "whole institutions and social groups … to stigmatize through laws, policy, and the built environment. Purely through the routine of their everyday operation, these institutions may perpetuate stigmatizing and discriminatory rules and practices, excluding social groups from life opportunities through stigmatization ..." In addition to this, research pertaining to disabilities in Lebanon mainly focuses on physical disabilities and disabilities that are more visible, prioritizing them over less visible disabilities. (Marouche et al., 2021)

1.4.2 Migraine and Gender

The source of most of the research done on migraine worldwide is medical quantitative research which aims to find cures to migraine. Most quantitative studies on migraine either disregard the role of gender by using 'gender' and 'sex' interchangeably or aim to explore the prevalence of migraine among a certain population. Even qualitative research focuses on migraine experienced by women mainly, disregarding both the gendered experiences of men and the concept of invisible disability. Throughout their daily lives, men and women are exposed to different factors that have an effect on their experiences of illnesses, diseases,

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[15] <Accessed on 22 November 2022>

[16] <Accessed on 7 November 2022>

and disabilities. In fact, migraines can be triggered by social and environmental factors such as experiencing gender-based violence. Studies show that “women who had ever experienced physical and/or sexual violence had a 40% increased odds for migraine compared with women who never experienced any IPV.” (Cripe et al., 2010)[17] Men are not as susceptible to gender-based violence as women, however, they are vulnerable to other types of violence. “Most assaults reported to the police, in countries with good statistics on the matter, are by men on other men.” (Connell, 2009)[18] A study that examines the connection between early childhood adversities and migraine in Canadian men and women also sheds light on the effect of social factors on migraines. Being a victim of abuse as a child could be a trigger for experiencing migraine during one’s adolescent years. In fact, it promotes the idea that “future research on this topic, which considers sex and gender, is needed not only in the analysis of data, but also in study conceptualization”. (Brennenstuhl & Fuller-Thomson, 2015)[19] People could suffer from migraines regardless of their gender, however, gender norms, roles and expectations often shape the experiences of women and men. Thus, more research within the Lebanese context about the gendered experiences of migraine as an invisible disability is needed.

Research about women’s struggles has recently been put under the spotlight worldwide, where more NGO reports and academic articles are flourishing in light of women’s issues. On the other hand, such progress in acknowledging the injustices that women face does not include women with disabilities, even in Lebanon. “The suffering of women with disabilities in the Arab world multiplies for reasons of their disability, as they suffer from social norms imposed on women in general, as well as more suffering for being

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[17] <Accessed on 12 November 2022>
[18] <Accessed on 11 November 2022>
[19] <Accessed on 12 November 2022>

handicapped in terms of exclusion and social isolation (Al-Thani, 2009).” (Abu Al Rub & Al Ahmed, 2014[20])

1.5 Medicine: On Migraine as a Female Deficiency

A large number of quantitative and qualitative research studies and articles mention in their introduction the following statement: “Migraine is a common and often disabling disorder that occurs in three times as many women as men”. (Peterlin et al., 2011)[21] It is true that migraine predominantly affects females, however, feminizing migraine has major disabling effects on both women and men. Historically, “a negative, feminized view of the person with migraine has persisted since, whether migraine was viewed as a psychological defect or as the result of an excitable, feminized brain.” (Young, 2018[22]) Ever since the beginning of medicine, socially constructed gender roles have seeped into the medical field resulting in several gender inequities and reinforcing gender roles on both women and men. Migraine has been gendered throughout its medical history, via medical institutions as well as the society itself by sustaining social hierarchies that categorize patients into able-bodied or disabled. During the 19th century, physicians realized that migraine affected more women than men, thus they sought to feminize it through equating disability to women, and seeking to explain it through gender norms. Perhaps one of the most prominent physicians during the early twentieth century was Harold G. Wolff (1898-1962), a neurologist at the New York Hospital Cornell Medical Center, who created the concept of the “migraine personality” which he described as an ambitious and perfectionist man who is over-tense. This patient that Wolff has invented was an embodiment of a masculinized middle-class man who is so

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[20] <Accessed on 13 April 2023>
[21] <Accessed on 9 November 2022>
[22] <Accessed on 14 April 2023>

intellectually gifted and exquisitely responsible to the point where he is cursed with migraines. On the other hand, women who experienced migraines were described by Wolff "as unwilling to accept the female role, particularly in sexual relations". (Kempner, 2014) Physicians like Wolff framed their female patients, who had migraines, within the context of reproduction and sexuality. Women who had migraine were described as reluctant to pursue their marital duties of sleeping with their husbands and becoming mothers. On the other extreme, a physician called Walter C. Alvarez (1884–1978), a gastroenterologist, treated women with migraine as naïve beings who needed guidance. Alvarez utilized a technique, that today is called medical gaslighting, through sitting the female patient down and "'talking over her life problems and … showing her how to live more calmly and happily, [better] than in making useless examinations.'" (Kempner, 2014) In his writings, he even described the women as "'petite, full-breasted, and with a nice figure,'" yet became quickly tense and fatigued. Research on men with migraine has been scarce, as MacGregor, a clinician specializing in headache and women's health at Barts Health NHS Trust in London, says that culture, society, and psychology contribute to "how people cope with migraine or decide to seek care" (Eisenstein, 2020)[23] . In addition to these gendered expectations, expressing that one is in pain is viewed as a characteristic of females in many societies. For instance, it is more acceptable for a woman to talk about her pain and to seek healthcare, than it is for men. Men are expected not to show signs of pain because it is perceived as a weakness. Hence, the under-representation of males in research could also emanate from the effect of the social pressures that force men not to seek treatment for their migraine. Everyday life can be impaired by the chronic pain that accompanies migraine. Men and women living with this chronic pain experience major life-style changes, be it

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[23] <Accessed on 8 November 2022>

physical, psychological, or both. Experiencing sudden waves of chronic pain can alter the way one communicates with their surroundings, and the way they see themselves. Living in a society that is filled with gender norms, roles, and expectations places obstacles for people from different genders to seek help. In light of this sexist history of migraine, updated research is needed to assess whether such gender norms and expectations still persist within the Lebanese society at large and the medical institutions, what forms they take, and how men and women living with migraine perceive them in the context of an ableist-dominant world.

1.6 Research Questions

There are two essential research questions, each containing two sub-questions:

1- What are the experiences of people who live with migraine?
  a- How does the invisibility of migraine influence the experiences of individuals living with the disability?
  b- How do men and women who experience migraine perceive the effect of their gender on their experiences of migraine?
2- What are the societal perceptions of migraine, and how do these perceptions impact the experiences of people with migraines?
  a- How do able-bodied people react to people who have the invisible disability?
  b- How do institutions, including healthcare, education and workplace, react to people with migraine?

This thesis aims to provide a deeper understanding of the often-silenced narratives by shedding light on the experiences of the invisible disease migraine. Such a study can be a first step towards creating support for people with invisible disabilities and might help lead to generating better policies regarding invisible disabilities and healthcare, workplace and education. This thesis also reveals the various unique experiences of women and men through an intersectional lens that provides an analysis of how gender and disability intersect to form challenges in people’s lives. Such an intersectional study could contribute to the development of inclusive policies and laws which take into consideration the diverse needs. Lastly, this thesis aims to give voice to people who live with migraine and consequently challenge the dominant ableist and sexist narratives, thus empowering people with invisible disabilities to voice out their concerns.

CHAPTER TWO

LITERATURE REVIEW

The following section is a literature review of the studies that align with the content of this MA thesis. The literature that seeks to investigate and analyze people's experiences of migraine, in general, is considerably high. On the other hand, research on migraine as a disability is not as abundant, as (Kattari et al., 2018) puts it, "Although ableism is insidious and apparent in all aspects of society, little research has been conducted to understand the lived experiences of ableism by disabled individuals, nuanced disabled identities (such as those who have invisible/less obvious disabilities), and intersections of other marginalized identities with disability identities." The following literature review will discuss the most common themes related to the study at hand. Three main headlines were extracted from the studies as a result of the search that was conducted to organize the following literature review. Themes found in the literature that align with this MA thesis focus on people's experiences of invisible disabilities (Hendry et al., 2022 ; Valeras, 2010 ; Kattari et al., 2018 ; Olney et al., 2005[24]). A remarkable number of studies exploring only women's or men's experiences of invisible disabilities (Michelle Jean Yee, 2013 ; Olkin et al., 2019[25] ; Barber & Williams, 2021[26] ; Korn, 2017[27]) is an important theme to consider. Such a wide abundance of research tackling migraine outside the frame of disability and gender is very essential and has definitely added insight into the experiences of people with migraine worldwide (Velasco et al., 2003 ; Peters et al., 2005 ; Peters et al., 2004 ; Khan et al., 2015 , Befus et al., 2019 ; Scaratti, 2018 ; Morgan et al., 2016 ; Pearson et al., 2019 ; Leiper et al.,

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[24] <Accessed on 15 April 2023>
[25] <Accessed on 14 April 2023>
[26] <Accessed on 10 April 2023>
[27] <Accessed on 10 April 2023>

2006 ; Estave et al., 2021) and in the MENA region (El- Metwally et al., 2020 , Bamalan et al., 2021, Al-Hashel, 2014). Also, a section on migraine, gender and disability is provided where part of it tackles research on migraine as a disability (Gurley-Green, 2021[28]), and the other part focuses on disability and migraine research in Lebanon (Combaz, 2018; Marouche et al., 2021 ; Chahine et al., 2022 ; Hatem et al., 2022). This MA thesis seeks to tackle both men and women's experiences of migraine as an invisible disability.

2.1 Invisible Disabilities

Research pertaining to the experiences of people with invisible disabilities is often scarce when compared to literature that focuses on the experiences of visible disabilities "despite evidence that there are higher numbers worldwide of people with invisible disabilities. As such, persons with invisible disabilities can feel under-represented in disability literature." (Hendry et al., 2022) One of the main aims of the World Health Organization for the 2030 SDGs is implementing SDG 3, which promotes a healthy life for people with disabilities. The WHO aims to increase and strengthen the collection of data on disability internationally, as well as to encourage research on disability. WHO pledges "to leave no one behind, including people with disabilities and other disadvantaged groups, and has recognized disability as a cross-cutting issue to be considered in the implementation of all of its goals." (WHO)[29] Therefore, more research on disability is needed, specifically on invisible disabilities. Most studies about invisible disabilities did not focus on gender as an important aspect in analyzing the experiences of people who have them. A 2022 research titled *"I Just Stay in the House So I Don't Need to Explain": A Qualitative Investigation of Persons with Invisible Disabilities* by (Hendry et al., 2022) was conducted in Scotland in the form of two

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[28] <Accessed on 15 April 2023>
[29] <Accessed on 17 April 2023>

studies. It aimed to explore the experiences of people with invisible disabilities, regardless of what the disabilities were. Study one conducted a focus group that constituted 18 participants (9 males and 9 females) where participants were asked about the influence of their invisible disabilities on their social lives. In the second study, 7 one-on-one interviews were conducted to explore the effects of these disabilities in the workplace. The findings of the two studies each revealed themes of their own. The first study showed 'social life findings' where participants discussed the incongruity between what they look like on the outside in the eyes of those around them, and what they are actually experiencing from their disability. This theme also tackled topics like people with disabilities' interactions with others who do not understand them, as well as trying to adapt to this new identity. Concerning the workplace findings, research previewed themes such as disclosing their disabilities, feeling (un)supported and (un) accepted by others, and feeling discriminated against in the workplace. Overall, the authors recommended more research on the topic of invisible disabilities. This research did not take into consideration the intersectionality of disability with gender and other factors. Another study that focused on hidden disabilities was the one written by Valeras (2010) titled *"We don't have a box": Understanding Hidden Disability Identity Utilizing Narrative Research Methodology.* This study extracted self-narratives from 3 men and 3 women who had a hidden physical disability through snowball sampling in the US. The major themes for this study revolved around disability identity, with the participants either accepting, rejecting, or being in the middle concerning considering their hidden disability a disability. Other themes entailed non-disabled people 'othering' those with disabilities, people with disabilities passing as nondisabled people, hiding away the fact that they are disabled, and maintaining the able-bodied persona. Overall, this study presented narratives of people with hidden disabilities living in gray areas where they created their own bi-ability identity, defying the ability/disability dichotomy with not much emphasis on gender. Kattari et al. (2018) shed light on microaggressions that people with invisible abilities often face in their study *"You Look Fine!": Ableist Experiences by People With Invisible Disabilities* conducted in a metropolitan city in the Southwest. The authors identified migraine as one of the invisible disabilities tackled in this study. The participants included 10 women, 2 men, 1 transgender man, and 1 nonbinary gender individual. The emerging themes of the study were as follows: policing of bodies where participants often had their bodies commented on by others and expected to perform better, tension in roles where participants either felt the need to educate those around them on how not to be ableist or decided not to, and desire for justice where participants expressed their frustration and anger, and the last theme was internalized ableism. Overall, this research provided insight into the experiences of ableism of people with invisible disabilities.

2.2 Invisible Disabilities and Gender

The studies mentioned previously provide insightful information on the topic of experiences of invisible disabilities that is often rarely tackled in disability research. On the other hand, most such studies either merely provide a hint of the relationship between disability and the participants' gender, disregard the intersectionality between disability and gender altogether, or tackle disability focusing only on one gender's experience, mainly women's experiences. Only one research study, to the best of our knowledge, was found to take intersectionality into consideration when examining invisible disabilities between men and women. The study titled *The Impact of Visibility of Disability and Gender on the Self-Concept of University Students with Disabilities* by Olney et al. (2005) highlighted differences in experiences of both visible and invisible disabilities among 25 university students constituting of men and women participants in the US. Four main themes were established: the first was participants' self-perceptions where the authors found that women spoke about their experiences in a more personal way than men, self-presentation where most men spoke about hiding their disability more than women, meta perception where participants shared how others viewed them in terms of their disabilities, and perceived support where the authors found that men participants had more support from those around them than women. Overall, this study was comprehensive in the sense that it looked at both genders' experiences of visible and invisible disabilities.

Since literature on invisible disabilities is itself scarce, research on women's and men's experiences of invisible disabilities is even more limited, however, as will be seen in the following sections, research on women with invisible disabilities is greater in number than those on men.

2.2.1 Women with Invisible Disabilities

A study titled *Lived Experiences of Women with Hidden Disabilities: A Phenomenologically Based Study* by Michelle Jean Yee (2013) explored women's experiences of marginalization, inclusion, and exclusion due to their non-visible disabilities and how they articulated these experiences. The researchers conducted 3 90-minute interviews with 4 women where several themes were established. Themes entailed: getting support from those around them, self-advocating, passing, inclusion using technology, feeling marginalized and excluded by the medical system, redefining disability, and future hopes. All in all, the study presented thorough research on women's experiences and perceptions of invisible disabilities. Another study titled *The Experiences of Microaggressions against Women with Visible and Invisible Disabilities* by (Olkin et al., 2019) used a mixed-method approach to explore women's experiences of both visible and invisible disabilities. This study mentioned that migraine is one of the invisible disabilities included. 30 women participants were involved in 90-minute focus groups, where 77% had visible disabilities and 33% had hidden disabilities, also, a questionnaire was presented to determine how many participants experienced microaggressions due to their disabilities. The researchers found that women with disabilities felt like second-class citizens and were disrespected and denied. Other themes included women feeling denied their personal identities, having their disabilities downplayed, denial of privacy where the participant is asked too many questions, others assuming that the participants needed help, people expecting praise in return for helping some of the participants, being treated like a child, and desexualization where women were considered unsuitable to have partners. The authors added two more themes that were major in their studies which were: medical professionals undermining women's disabilities that led to delayed diagnosis, and women having their disabilities denied due to how they appeared. This study provided input into women's experiences of several invisible disabilities in a mixed-method approach. Quantitative research by Barber & Williams (2021) titled *Invisible Chronic Illness in Female College Students* highlighted women's experiences of invisible disabilities in the context of college. 105 female students took part in an online survey. Although this study tackled a wide variety of invisible disabilities, the majority of women reported having chronic migraines (24.8%). 67.7% of the participants viewed their chronic illness as serious and 92.7% reported that it had greatly influenced their life. Another major theme that was presented was avoiding social occasions because of their chronic condition (89.6%). Overall, the study provided quantitative research which revealed patterns in females' experiences of invisible disabilities and how they navigated college with their chronic illnesses.

2.2.2 Men with Invisible Disabilities

Literature about men's experiences of invisible disabilities is much lower in number than those that focus on women's experiences. Charmaz writes: "To date, the sociological literature has not explicitly addressed the special circumstances that chronically ill men face…Nor have earlier researchers looked at these men's experience from the standpoint of gender-based conceptions of masculinity.” (1994) The only study found was *Being a Man with an Invisible Disability: College Men's Experiences* by Korn (2017) which explored how men made meanings of their experiences of invisible disabilities in terms of masculinities and within the context of college. In-depth interviews with 22 males identifying as men were conducted. The first theme found was embodying masculinity through which the participants defined what masculinity meant to them, the second theme entailed experiences of losing their masculinity such as when seeking help due to their disabilities, and the third theme was preserving their masculinity. The last theme was cultivating masculinity by which the participants made sure to still do men’s activities. This study provided a whole different insight from men’s perspectives of invisible disabilities and how they coped with them in the context of their own masculinities.

2.3 Migraine

2.3.1 Outside the framework of Disability and Gender

There has been extensive research on migraine experiences not necessarily within the framework of disability and gender. Most of these studies shared, with the disability literature, the theme pertaining to the major influence of migraine on people’s everyday lives. A 2003 study titled *Quality of Life in Migraine Patients: A Qualitative Study* by Velasco et al. (2003)[30] conducted in Spain aimed to explore the impact of migraine on patient’s lives and to identify the most negatively affected areas of their well-being. The study conducted six focus groups and nine personal interviews with 33 migraine patients, where the majority were females. The study findings revealed the following themes: self-

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[30] <Accessed on 3 March 2023>

medication, social aspects including the effects of migraine on people's lives at work and school and within their interpersonal relations. The themes mainly focused on the marriage life of people with migraine. Overall, the study highlighted the significant impact of migraine on patients' quality of life and the need for effective interventions to improve outcomes. The authors suggested that a more patient-centered approach to migraine management is needed, considering the unique experiences and needs of individual patients. Other studies centered on the management strategies of migraineurs specifically. *The Patients' Perceptions of Migraine and Chronic Daily Headache: A Qualitative Study* by Peters et al. (2005)[31] is a study conducted in the UK that sought to gain insights into how people with migraine managed their chronic daily headaches. Through semi-structured and tape-recorded interviews with 13 participants (9 females and 4 males), themes were identified where participants voiced out their concerns about their migraines in comparison with other chronic daily headaches. Interestingly, although participants described their headaches as disruptive to their everyday lives, they considered them as not serious enough to bother their doctors with. *Migraine and Chronic Daily Headache Management: a Qualitative Study of Patients' Perception* is another study by Peters et al. (2004)[32] which conducted semi-structured interviews in the UK with 13 participants (9 females and 4 males). The study found that there are 5 areas of management that migraineurs maneuver through in order to relieve their own migraines: healthcare use, medication use, alternative therapies, social support, and lifestyle and self-help. By the end of the study, the researchers suggested the importance of understanding patients' own perspectives of diseases and illnesses especially when it comes to migraine and chronic daily headache (CDH), and to follow the UK Department of Health's advocacy for the 'Expert Patient' method "as a new

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[31] <Accessed on 3 March 2023>

[32] <Accessed on 3 March 2023>

approach to chronic disease management for the twenty-first century". (Peters et al. 2004) A number of research studies explored migraine in relation to the use of medications as one of the management techniques. A study conducted in Ontario, Canada by Khan et al. (2015)[33] titled *Access to Triptans for Acute Episodic Migraine: A Qualitative Study* recruited 3 participant groups: people with migraine, physicians, and pharmacists. The group of people with migraine consisted of 19 participants (15 females and 4 males). The aim of the study was to explore the experiences of people with migraine in accessing triptans, a medication commonly used to treat migraine attacks. The study identified themes including the impact of migraine on daily life, the patients' experiences of accessing triptans, and the use of alternative treatments and self-management strategies. In the study, *Nonpharmacological Self-Management of Migraine Across Social Locations: An Equity-Oriented, Qualitative Analysis*, Befus et al. (2019)[34] aimed to look at the experiences of individuals with migraine in managing their condition using non-pharmacological self-management strategies. The study was done in the US consisting of 30 participants (25 females and 5 males). It showed the importance for healthcare providers to be more aware of the social and cultural factors which impact the management of migraine and to provide culturally sensitive care. Another study titled *A Qualitative Study On Patients With Chronic Migraine With Medication Overuse Headache: Comparing Frequent And Non-Frequent Relapsers* by Scaratti (2018)[35] in Milan, Italy looked at the experiences of people with migraine who relapsed due to their addiction to migraine medication. The participants were 16 in number (13 females and 3 males). The findings of the study showed that frequent relapsers often reported a higher effect of migraine on their daily life, which included more

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[33] <Accessed on 27 October 2022>

[34] <Accessed on 11 November 2022>

[35] <Accessed on 3 March 2023>

increased disability, severe pain, and a greater need for medical care. Morgan et al. (2016)[36] examined people's perceptions of specific management tools for migraine, away from drug treatment, which incorporated therapy, post-intervention, and relaxation techniques in their study *Patients' Experiences of a Behavioral Intervention for Migraine Headache: A Qualitative Study* in the UK. They recruited 21 participants (14 females and 7 males). The findings of the study suggest that patients who participated in the behavioral intervention reported significant improvements in their migraine headache symptoms, as it helped them manage stress and anxiety, which in turn reduced the frequency and severity of their migraine headaches. Consequently, the behavioral intervention helped to improve participants' quality of life as they felt less stigmatized and isolated. The study also found that behavioral intervention was difficult for some participants. Overall, the study by Morgan (2016) provided evidence that a behavioral intervention can be an effective approach for managing migraine headaches. This study highlighted the importance of patients to be educated about their migraines.

Some studies shed light on the negative impact of the stigmatization of migraine on people's self-image. A study titled *Not Just a Headache: Qualitative Study About Web-Based Self-Presentation and Social Media Use by People with Migraine* by *Pearson et al. (2019)*[37] in the UK examined the experiences of people with migraine as they engaged in web-based self-presentation and social media use. The study was based on semi-structured interviews with 20 individuals with migraine (17 females and 3 males), who were asked about their experiences with social media use and how their migraine affected their online self-presentation. The study found that individuals with migraine often felt stigmatized, and that social media provided a space where they could connect with others who understood

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[36] <Accessed on 3 March 2023>

[37] <Accessed on 3 March 2023>

their experiences. On the other hand, some participants reported feeling pressure to present themselves in a positive light on social media, which could exacerbate feelings of isolation and stigma. In fact, some felt that they had to present themselves as "normal" online to avoid being stigmatized. Others, however, felt that it was important to be open about their condition to raise awareness and reduce stigma. In *Experiences and Perceptions of People with Headache: a Qualitative Study*, Leiper et al. (2006)[38] conducted semi-structured interviews with 17 participants (8 females and 9 males) in the North-East of Scotland, UK where they extracted 3 themes: The first theme was the impact of headaches on daily life, the second theme was similar to the ones discussed above and that is how much knowledge patients had about their condition, and their feelings of shame and guilt as well as frustration with physicians. The third theme, also mentioned in other studies, was about how participants managed their migraines. All in all, this study also shed light on the importance of patient-centered treatment of migraine. Estave et al. (2021)[39] had similar findings even though the study was conducted in a different region, the US. Their study titled *Learning the full impact of migraine through patient voices: A qualitative study*, consisting of mostly female participants, also highlighted the importance of education and support for individuals with migraine because participants discussed that there was lack of understanding from the physicians as well as the society around them, which often increased the stigma around migraine.

In terms of existing literature that pertains to research on migraine in the **MENA region**, fewer studies are found. A study titled *The Epidemiology of Migraine Headache in Arab countries: A Systematic Review* by El-Metwally et al. (2020)[40] focused on assessing the

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[38] <Accessed on 10 November 2022>

[39] <Accessed on 27 October 2022>

[40] <Accessed on 10 November 2022>

prevalence and risk factors of migraine in Arab countries by undergoing a systematic review of studies published between 1990 and 2019. A total of 23 studies were included in the analysis, covering the countries: Saudi Arabia, Egypt, Kuwait, Bahrain, Qatar, Oman, Iraq, Syria, Lebanon, Morocco, Algeria, Sudan, Libya, Tunisia, and Jordan. The authors in this study shed light on the fact that migraine headache is often underdiagnosed and undertreated in Arab countries, which may further contribute to the burden of migraine. This study highlighted the need for further research to better understand the factors contributing to the high prevalence of migraine in the region. A considerable number of studies about migraine in the MENA region focused on the impact of migraine on students' lives. In *Prevalence of Migraine among the General Population, and its Effect on the Quality of Life in Jeddah, Saudi Arabia* Bamalan et al. (2021)[41] conducted a questionnaire-based study in Jeddah, Saudi Arabia, consisting of 2058 participants most of whom were females. The study found that migraine was highly prevalent in females, and especially among students. Also, the study showed that the most frequent triggers of migraine were anxiety and sleep deprivation. Another study by Al-Hashel et al. (2014)[42] done in Kuwait and titled *Migraine among Medical Students in Kuwait University* recruits 621 students (437 females and 184 males). The study found that the severity and frequency of migraine increased among students in Kuwait University, especially during the final 2 years of education. This study also highlighted the fact that even though menses was the migraine trigger for 20% of the females, the most triggers for students were related to stress, anxiety, and lack of sleep.

2.3.2 Migraine, Gender and Disability

Very little research pertaining to studying migraine as an invisible disability is found. A thesis done by Gurley-Green (2021) titled *Invisible Chronic Illness in College: Faculty*

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[41] <Accessed on 4 March 2023>

[42] <Accessed on 4 March 2023>

Perspectives and Student Narratives Surrounding Accommodations sheds light on chronic migraines. The study aimed to examine the impressions of college students with chronic migraine concerning accommodations, highlighting their experiences and expectations of the accommodation process. Also, this research assessed the faculty's impressions of accommodations while examining students' expectations of the faculty's responses. 94 students including 59 women, 22 men, and 3 non-binary individuals, and 40 faculty members answered the survey. The findings of this quantitative research were as follows: first, students considered accommodations such as "(distraction-free testing, extra test time, and deadline flexibility) more positively than the rare attendance flexibility accommodation." (Gurley-Green, 2021) A second finding was students' agreement to the importance of providing them with more information about their chronic migraine. Giving this information was viewed through a more positive lens when it is the Office of Accessibility Services who is providing it rather than the students themselves. The author of the study also found that the students perceived the faculty as less inclusive in their methods of teaching, than the faculty reported having. Overall, the study provided much insight into the experiences of students who have migraine concerning accommodation within the context of education. On the other hand, it disregarded the intersections between disability and gender and did not provide extensive information on migraine as a disability experienced by students.

Although knowledge about disability has been flourishing around the world lately which represents an essential step towards the fulfillment of the rights of people with disabilities, research about their experiences in the Lebanese context is important to provide a uniquely social and cultural background. In their report *Situation of Persons with Disabilities in Lebanon*, Combaz (2018) writes that "much of the academic literature is medical, and focuses on documenting the prevalence of disabilities, its manifestations (e.g. capacities), and its immediate medical causes (e.g. nutrition, genetics). Conversely, academic references offer fairly little by way of producing or considering data on access to services, contextual conditions (e.g. economic, political, social, or legal).” In fact, none of the studies in Lebanon examined migraine as an invisible disability to the best of our knowledge, but rather shed light on its prevalence specifically among students. Literature about migraine experiences in Lebanon is significantly rare. Only two studies were found about migraine experiences in Lebanon, both of which were quantitative. A study done by Hatem et al. (2022)[43] titled *Prevalence and Risk Factors of Migraine Headache among University Students: A Cross-sectional Study in Lebanon* aimed to investigate the risk factors that associate migraine among the Lebanese University students in Lebanon. The study was conducted among 1144 university students (321 females and 89 males), and data were collected through interviews using a uniform questionnaire. Several risk factors were identified, including a family history of migraine headache, smoking, and irregular sleep patterns. The study also found that the presence of stress and anxiety was significantly associated with migraine headache. In their study *Migraine Attacks among Lebanese University Medical Students: A Cross sectional Study on Prevalence and Correlations*, Chahine et al. (2022)[44] aimed to determine the prevalence of migraine attacks among medical students in a Lebanese university and to identify correlations with demographic and lifestyle factors. The study was conducted among 471 medical students (275 females and 196 males), and data was collected using a self-administered questionnaire. Several connections were identified with migraine, including students with a family history of migraine. Also, students with a higher BMI were more likely to have migraine attacks. The study found that stress and lack of physical activity were also linked to migraine attacks.

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[43] <Accessed on 4 March 2023>

[44] <Accessed on 4 March 2023>

Based on this, there is a lack of qualitative research on migraine, let alone on migraine as an invisible disability. In addition to this, most research on disabilities in Lebanon and worldwide "address gender merely by disaggregating analysis between women, men, girls, and boys, with a few references even seemingly just conflating 'gender' with 'women and girls'. Very few references analyze gender as a socially constructed relationship of norms and practices. This leaves issues such as masculinities and femininities, and their implications for persons with disabilities in Lebanon, under-examined." (Combaz, 2018) Also, research on disability is highly biased in Lebanon "and skewed towards certain trends… The diversity of disability types as well as differences in context and experience make overgeneralization dangerous for disability research and service provision – driving invisible disabilities further into darkness." (Marouche et al., 2021) Marouche et al.'s study *Lebanon Literature Review* "highlighted a gap in academic research around disability especially in the field of social sciences, arts and humanities. Most of the existing research comes from NGOs." They also shed light on the fact that intersectionality between disability and other layers is overlooked in academic research which further leads to the marginalization of people with disabilities. "Moreover, research efforts need to be more inclusive of diverse disability types including less visible and invisible disabilities including mental health." (Marouche et al., 2021)

2.4 Reiterating the Gaps

I believe that this thesis brings about the unique gendered experiences of migraine and fills a gap in scholarly resources that tackle migraine as an invisible disability in the Lebanese community. The above literature paved the way for my research to flourish in terms of research questions and methodology. While these studies consider unique experiences of people with migraine, a more nuanced study that tackles the intersection between gender and disability in affecting such experiences is needed. Allowing a participant-centered approach in my research where participants can freely talk about their experiences of migraine and how they manage the invisible disability, how they perceive others to see them, and how ableist paradigms around them influence their decisions are all important questions to ask my research participants. On the other hand, exploring how patients from both genders experience migraine, and how gender norms and expectations around them affect these experiences is worth investigating. As the disability movement in Lebanon is starting to tackle issues that people with disabilities face, this is a great opportunity for such a research topic to flourish and contribute to a wider body of literature concerning invisible disabilities and gender in the Lebanese context.

CHAPTER THREE

METHODOLOGY

The following chapter constitutes the methodology, it provides a detailed overview of the theoretical considerations, methods, scope, limitations, and ethical considerations of the study.

Restatement of the Purpose of the Study

The purpose of this mixed-method study was to explore the lived experiences of people with migraine as a disability. This study depended on an IPA approach to examine how people with the invisible disability articulate and make sense of their experiences.

Research Questions:

This study attempted to answer the following research questions:

1- What are the experiences of people who live with invisible migraine?

a- How does the invisibility of migraine influence the experiences of individuals living with the condition?

b- How do men and women with migraines perceive the effect of their gender on their experiences of migraine?

2- What are the societal perceptions of migraine, and how do these perceptions impact the experiences of persons with migraines?

a- How do able-bodied people react to the invisible disability?

b- How do institutions, including healthcare, education and workplace, react to persons with migraine?

3.1 Theoretical Foundations

The purpose of this study is to explore how men and women with migraine experience the disabling disease, how they navigate their social interactions and medical treatments, and make sense of the intersections between their disability identity and their gender identity. The following study is based on a feminist framework that links the knower, the known, and the process of knowing following a post-constructionism approach. In their article *The Timeliness of Post-Constructionism*, Lykke[45] defines feminist post-constructionism as an umbrella term that aims to"…neither push feminist thought back into the traps of biological determinism or cultural essentialism, nor make feminist theorizing leave bodily matter and biologies "behind" in a critically under-theorized limbo." Lykke (2010) Feminist post-constructionism was created in order to bridge the gap between positivists and constructionists, in other words, to merge quantitative and qualitative research to reach feminist goals. In fact, one of the most notable pioneers of feminist research, Donna Haraway [46], points out that considering 'sex' the basis of all knowledge as per biological determinism disregards feminist social constructionists' concepts of gender as socially constructed and having different meanings. On the other hand, Haraway says that neglecting the biological accounts of sex which started with its binarism, "seems to be to lose … the body itself as anything but a blank page for social inscriptions, including those of biological discourse." (Haraway, 1988) Consequently, this paper depends on a mixed-method approach that converges qualitative and quantitative research methods as per feminist post-constructionism, rather than disregarding one and adopting the other.

The epistemological perspectives of feminist post-constructionism start at the core of believing that as long as the partial position of the researcher subject is acknowledged, there is a possibility of speaking about the "real world". Haraway writes "only partial perspective

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[45] <Accessed on 28 March 2023>

[46] <Accessed on 28 March 2023>

promises objective vision.” (1988) Consequently, a form of partial objectivity is established here. Unlike postmodernist feminists who believe that there is an inseparable relation between the knower and what they know, feminist post-constructionists rely on the idea that “the researcher can momentarily construct a provisional and momentary “cut” between knower and known that will allow her/him to give a partially objective, reliable, and ethically committed account of the world “out there”/“in here”.(Lykke 2010) This momentary cut allows for the utilization of a mixed-methods approach with overarching qualitative research as its foundation and a hint of quantitative research that supports it. Haraway writes that “feminist objectivity means quite simply situated knowledge” (1998), which highlights the importance and dominance of qualitative approaches including interviews and narratives. On the other hand, due to this momentarily cut, integrating a hint of positivist quantitative approach is essential. It is eye-opening to be able to compare between men and women’s experiences of disability, and to study how people with migraine make sense of their disability and gender identities. This paper rejects the idea of universal truths and instead focuses on the individual experiences of men and women with migraine, and at the same time provides statistics of trends that could solidify the qualitative results. Consequently, I understand that there is no one true essence of how men and women experience their migraines, that the knowledge produced from their experiences is influenced by their own biases, and that their gender and disability identities are socially constructed. On the other hand, I acknowledge that specific gender patterns could be obtained from accumulating survey responses about these experiences of migraine. People’s accounts of migraine as a disability within their everyday lives and the healthcare system could be understood through the existing gendered roles, norms, expectations and power hierarchies. The following paper relies on a mixed-method approach that is qualitatively dominated. The researcher’s aim is to attain social change through combining quantitative and qualitative methods, which could create a platform that gives a more powerful voice to these people's experiences of migraine, while demonstrating patterns of injustice and inequalities. A mixed-method approach is essential to use in research because it allows to "understand the holistic picture from meanings obtained from interviews or observation to the prevalence of traits in a population obtained from surveys, which add depth and breadth to the study." (Wasti et al., 2022)[47] This method was selected because it permits the assimilation of two approaches which will enrich our understanding of the phenomena being analyzed, that is the experiences of migraine as a disability. The same way that this research adopts a feminist post-constructionist stance and rejects the dichotomy of quantitative/qualitative approach, it also rejects the androcentric/gynocentric dichotomy. In their article *Epistemology of Critical Studies on Men and Masculinity: Perspective of a Boy from France, After 25 Years of Research on These Topics*, Welzer-Lang(2017) writes about two degrees of androcentrism in research. The first degree of androcentrism "made us think of the male as being normal, general, and the female as being particular, specific." Therefore, the word human has historically coincided with men, while women were considered a lower version of what a man was. This has led to studying men, and women's relation to them, in the frame of heteronormativity, leaving out other genders. The second degree of androcentrism, as Welzer-Lang(2017)[48] describes it, came as a backlash to the first and focused on women's studies, viewing men from a specific standpoint which "allows researchers to better define general and specific forms of domination, but tends to provide less information on what men really experience," while trivializing and silencing men's experiences; also known as gynocentrism. The following study aims to criticize both androcentric and gynocentric approaches to research, while focusing on a more gender-

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[47] <Accessed on 25 November 2022>

[48] <Accessed on 28 March 2023>

sensitive and aware approach to understanding both men's and women's experiences of migraine within the gendered norms, roles, expectations and power hierarchies.

The theoretical foundations of this research study are based on the feminist theories of disability, Foucault's theory of power, and intersectionality, all of which align with the overarching method of IPA. In their article *Toward a Feminist Theory of Disability*, Wendell (1989) provides an explanation for why we need a theory of disability as feminists. They demonstrate how women and people with disabilities share similar experiences of feeling pressured to fit into a male-dominated / able-bodied society, seeking equality with men/able-bodied people, and having their own knowledge disregarded as they are considered untrustworthy. Feminists have always been fighting for the emancipation of the body from cultural attitudes that created categories of what is considered normal and what is abnormal. This study aims to examine migraine, not as "a biological given", but rather as a disability that is "socially constructed from biological reality" like gender. (Wendell, 1989) Consequently, studying migraine as a disability in this paper "begins and ends with the subjective impressions of the individual who experiences the world through her body." (Adams et al., 2015)[49] Focusing on the individual truths of the people who experience this disability, as well as on their own interpretations of these experiences during the study is the main focus of this paper which is, in fact, parallel with the goals of IPA. Utilizing Foucault's theory of power espouses that governments and institutions, including medical, aim to exert power over bodies, especially non-conforming ones. A Foucauldian lens allows me to examine how power and hegemony influence the lives of people with migraine, and how contextual factors affect the way they perceive and describe their disabilities. It is also essential to investigate the participants' interactions with medical physicians and the power

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[49] <Accessed on 30 March 2023>

play that takes place between them. Foucault's ideas are not specifically concerned with disability, however, they center on concepts of 'power' and 'normalization', both of which could be spoken of in terms of disability. Foucault's ideas on 'normalization' could explain how society including its institutions tend to control people's bodies in attempts to 'fix' their disabilities. Also, power hierarchies play a role in the way a person with migraine experiences interactions with able-bodied people and medical doctors, as migraine is an invisible disability. Intersectionality theory allows for the exploration of how possessing two identities, gender and disability, contribute to the privilege or oppression of men and women in their experiences of migraine. The term 'Intersectionality', first introduced by Kimberley Crenshaw in 1989, "is a cornerstone of multicultural feminist and social justice approaches and typically refers to the complex interactions among social identities experienced by individuals, such as race/ethnicity, nationality and language, sexual orientation, religion, gender, disability, colorism, and age." (Enns et al., 2020[50]) Using an intersectional lens in this paper will allow me to identify the various oppressive forms of disability, gender, and socio-economic status. This intersectional approach will aim to explore the intersection of disability and gender and to understand how the experiences of men and women are shaped by gender norms and expectations around them. Also, intersectionality provides a lens through which we can inspect how ableism and sexism interact to form challenges on men and women experiencing migraine, in terms of barriers,

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[50] <Accessed on 16 April 2023>

inaccessibility, societal attitudes, and negative stereotypes. Disability intersects with other forms of disenfranchisement that often shape the experiences of people with migraine.

3.2 Research Method(s)

Beetham & Demetriades[51] write "that there is not one specific method or combination of methods that necessarily makes research 'feminist,' but rather that the research comes from an approach that is considerate of the multifaceted nature of gender". (2007) The following outlines the research design that is implemented in this study. The mixed-methods approach in this study is characterized by the following equation 'QUAL + quan' which is based on Johnson and Onwuegbuzie[52]'s mixed-method design matrix (2004). It shows the concurrency of qualitative and quantitative methods with a high priority to the qualitative over quantitative.

3.2.1 Qualitative Method(s)

3.2.1.A Semi-structured Interviews (IPA)

Qualitative research allows researchers to acquire a deeper understanding of and a better insight into people's experiences of complex phenomenon. In this research, it is essential to understand the gendered experiences of migraine in order to give voices to men and women with migraine as well as to inform the healthcare systems about patients' preferences within the medical context. This would help "shape clinical practice; develop patient education programs adapted to the patients' coping and problem-solving strategies and their willingness to change; and encourage further research efforts (both qualitative and quantitative) into issues that are important to the headache patient" (Peters et al., 2004). I understand that being a feminist researcher means it is important to step away from the

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[51] <Accessed on 8 December 2022>

[52] <Accessed on 28 March 2023>

position of the ableist and gender-biased institutions and instead give voice to people with migraine as a way of giving them authority over their own bodies and minds. Qualitative research allows people with migraine to be participants in the production of knowledge about their own bodies (and minds) and aims to make them aware of these gendered experiences, thus creating awareness for those with similar experiences. This study aims to highlight the known's (participant) experiences of migraine, while the knower (researcher) carefully listens to them. The core of this feminist research is the known, who takes on the role of the knower, and possesses the 1st person knowledge which is portrayed in their physical, emotional, and mental experiences of migraine. The process of interviewing the participants is part of awareness itself. Qualitative methods are able to capture aspects of the research that are otherwise not captured by numbers, hence can assist in interpreting the quantitative data.

Interpretative Phenomenological Analysis (IPA) is used for the purpose of discovering, in details, how people with migraine are actively engaged in making sense of their own gendered experiences of migraine. IPA consists of two types of interpretation: the subject's own interpretation of the phenomenon and the researchers' attempt to decode the meanings behind the participant's interpretation. Hence, "IPA synthesizes ideas from phenomenology and hermeneutics resulting in a method which is descriptive because it is concerned with how things appear and letting things speak for themselves, and interpretative because it recognizes there is no such thing as an uninterpreted phenomenon." (Pietkiewicz & Smith, 2014)[53] Therefor, IPA is inductive which means a pre-existing hypothesis is not possible. In addition to this, IPA depends on ideography which requires an in-depth analysis of single case studies in order to understand this subject's particular experience of migraine rather

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[53] <Accessed on 25 March 2023>

than to generalize findings. On the other hand, “comparing multiple IPA studies on a particular problem may provide insights into universal patterns or mechanisms.” (Pietkiewicz & Smith, 2014)

This study is concerned with how men and women experience migraine and live with it rather than how scientific books discuss migraine, as “phenomenological studies… focus on how people perceive and talk about objects and events, rather than describing phenomena according to a predetermined categorical system, conceptual and scientific criteria.” (Pietkiewicz & Smith, 2014)

3.2.1.B Sampling and Recruitment Process

In order to recruit people with migraine who meet the criteria, a mixture of online and in-person snowball sampling methods are utilized. Since this is IPA, I aim to produce an in-depth examination of the lived experiences of migraine, rather than generalizing the results (Pietkiewicz & Smith, 2014). Also, due to some restrictions including time constraints, access to people with migraine, and migraine being a rare disease especially among men, the sample size chosen for this study is small in number (4 participants), “samples in IPA studies are usually small, which enables a detailed and very time consuming case-by-case analysis.” (Pietkiewicz & Smith, 2014) It is through the accumulation of similar studies over time that IPA can contribute to more generalizable findings. The selection of the participants is done purposively since the target audience are people who have migraine. A flyer was posted online (Appendix B: Interview Poster) as a method of sampling, which included: 1- information about the study, 2- the inclusion criteria, 3- an encouragement for all genders to participate, 4- the Institutional Review Board stamp, 5- the researcher’s contact information. Another flyer included the survey which had a small section at the end calling for volunteers to participate in a one-on-one interview by contacting the researcher via email or phone. The researcher surfed Instagram and Facebook for pages that posted about migraine and messaged potential participants who shared comments about their migraine publicly. In most cases where individuals did not express readiness to participate in one-on-one interviews, I shared the questionnaire link with them. After these recruitment methods, three of the participants contacted me via Instagram to volunteer, and I contacted the fourth via snowballing.

3.2.1.C Settings

Due to some interviewees' busy schedules, or because of currently living outside Lebanon, three of the individual interviews were conducted online, and one interview occurred in-person as originally planned, where all the participants were in their own comfortable environments. During the online interviews, I sat in an empty room with air pods on to ensure the confidentiality of the interviewees' identities. One interview was conducted through Zoom with the interviewee's camera turned off, and the other two were done through WhatsApp voice call. During the in-person interview, I made sure to find a quiet place where the interviewee felt comfortable to conduct the interview anonymously. All four interviews were recorded as per the interviewees' consents.

3.2.1.D Participants

The inclusion criteria required that the participants: 1- be individuals who have been diagnosed with migraine, 2- residents of Lebanon who are attending/have attended a doctor's clinic in Lebanon about their migraine, 3-males, females, and gender queer people are welcome, 4- aged 18 or over.

3.2.1.E Data Collection

The main role of the researcher in IPA is to elicit in-depth accounts of the men's and women's experiences of migraine using semi-structured interviews. As (Pietkiewicz & Smith, 2014) put it, "semi-structured interviews allow the researcher and the participant to engage in a dialogue in real time. They also give enough space and flexibility for original and unexpected issues to arise, which the researcher may investigate in more detail with further questions.” I had previously created a list of questions suitable to IPA that focus on the interviewee’s memories, thoughts, associations, and perceptions of migraine(Appendix D: Interview Questions). Each interview took around 55-70 minutes. I understood that it is essential to leave my presumptions at the door before heading into the interview, to actively listen, and prompt for further details. I began by building rapport with the interviewees through having warm up discussions, and then asking open-ended questions while allowing them to think and feel comfortable in the silence.

All online interviews were audio-recorded on two recording devices (the device itself using screen recorder option or application, and another device which is laptop or mobile phone), while the in-person interview was recorded using both laptop and mobile phone. All the interviews were transcribed verbatim. I immediately downloaded the audio recording from Zoom, and the other three from the laptop onto a Microsoft Word document where they were transcribed then moved to a flash memory, which was then encrypted with a password. The audio files, transcriptions, and consent sheets were all stored with a pseudonym for each participant.

Potential participants contacted me through social media direct messaging or I contacted them through snowballing, then I introduced them to the study and answered any questions they had. The potential participant and I then decided on a suitable place and time for conducting the interview in a safe and comfortable way. A reminder of the date and time of the interview were sent before the meeting. The consent sheet was sent to the participants prior to and sometimes during the interview after reading it together. The interviewees were provided with a small list of demographic information to complete at the beginning, and were told that they can decline any question that they do not wish to answer. Either I sent the list with the reminder before the interview, or the participant answered the list at the beginning of the interview. As soon as the interview ended, the researcher added the list to the flash memory and asked each to choose their own pseudonym. A password protected excel sheet on the flash memory was created which contained the actual names with the corresponding pseudonyms of the participants. A follow-up question was sent to the participants via WhatsApp chat to answer the question 'do you think of migraine as a disability?' which they answered through a voice note.

3.2.1.F Data Analysis

One of the main characteristics of IPA is that it is iterative, meaning that data collection and analysis occur concurrently. Pietkiewicz & Smith (2014) write that "the researcher moves between the emic and the etic perspective" during data analysis, which means that I step into the participants' shoes to understand their perspective, but I also analyze their perspective through the application of the three theories: feminist disability, Foucault, and intersectionality. Based on Pietkiewicz & Smith's (2014) steps of analyzing IPA qualitative research, the initial step was "multiple reading and making notes". After each interview, initial thoughts concerning the participants were written down, followed by a close listening, and reading of the audio-recordings. During this stage, interviews were transcribed which helped recall the settings of the interviews and allowed me to pick up any non-verbal cues and silences from the participants. During this stage, note-taking took place on the margins of the papers using a pen. The second stage was transforming notes into themes and subthemes. An inductive approach took place where themes were extracted from the notes that were taken for each interview. After that, connections were made between themes from the four interviews where some themes were in common among all participants, some were dropped, and some were similar only between men or women participants. A Microsoft word document was then created which included the headlines of the themes and subthemes under which quotes of the participants were pasted. Lastly, a short introduction was added for each theme and subtheme, supported by the participants' quotes and the analysis that is related to theories and previous articles from the literature review, followed by links that relate one theme to another.

3.2.2. Quantitative Method(s)

3.2.2.A Cross-Sectional Survey

The positivist epistemology is "an epistemology of the fact" (Sprague, 2016)[54] that depends on statistics and numbers for the possibility of replication. The importance of quantitative research is to complement the qualitative findings by grounding them in data such as numbers and statistics. Here, one survey (Appendix C: Survey Poster) is used to collect data from a wider audience who have experienced migraine as a way to complement the qualitative data. A specific number of structured questions (Appendix E: Survey Questions) are found in the survey. Carvalho (2022) mentions that "quantitative data in mixed methods research is more likely to be regarded as reliable and valid, and thus be heard in the policy arena, hence contributing to convince non-feminist decision makers more easily."

3.2.2.B Sampling and Recruitment Process

The survey in the form of a flyer was posted around LAU Beirut campus, as well as on social media (Instagram, Linkedin and Facebook) and reshared by friends and family members for non-LAU volunteers to participate. Initially, the survey was only in English, however, after being informed that many did not fill it because it was in English, the researcher created another version in Arabic and attached its link to the English version. The flyer included: 1- information about the study, 2- the inclusion criteria, 3- an encouragement for all genders to participate, 4- the Institutional Review Board stamp, 5- the researcher's contact information, 6- A QR code to scan and a link to copy. In addition to this, I spent a

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[54] <Accessed on 26 March 2023>

full day at LAU Beirut campus asking students who qualify to fill the survey or hand it out to people they know who fit the criteria. A Red Cross event was taking place during that day, so a couple of flyers were kept at their booths. Also, the link was shared online through direct messaging with social media users who agreed to fill the survey. The survey included Yes/No, multiple choice, and a scale (1-5) questions. The number of participants collected from this questionnaire is 28 participants.

3.2.2.C Settings

The surveys were created via google forms.

3.2.2.D Participants

The characteristics of the survey participants were similar to those of the interview: 1- be individuals who have been diagnosed with migraine, 2- residents of Lebanon who are attending/have attended a doctor's clinic in Lebanon about their migraine, 3-males, females, and gender queer people are welcome, 4- aged 18 or over.

3.2.2.E Data Collection

Data was collected through the English and Arabic versions of the survey.

3.2.2.F Data Analysis

The results of the survey were later transformed into a Microsoft Excel document as a table. The Arabic results were translated to English and accumulated in the same table. After that, information was converted to charts such as graphs and pie charts, and numbers were rounded to percentages.

3.3 Ethical Considerations

Firstly, informed consent was taken from the participants prior to conducting both the interviews (Appendix F: Consent sheet) and the survey (Appendix E). Participants were informed that they have the right to withdraw from both the interviews and survey at any time, and that their participation is voluntary. Concerning anonymity and confidentiality, the interview participants were asked to provide a pseudonym that will be used instead of their names in the study. In addition to this, all their data including audio-recordings, transcripts, demographic information documents, and their real names were stored securely on a flash memory which was password protected. For the survey participants, their anonymity was secured through the researcher choosing the option of not collecting the email address or any other information about who the participant was. When discussing the gendered experiences of migraine with some of the interview participants, certain sensitive topics surfaced such as sexuality or negative relationships with families. The interviewees were listened to carefully, and prompted for further details upon their consent. I also acknowledged that there are often power dynamics between the researcher and the researched, hence I strove to create a safe environment for the participants where they could share their thoughts freely rather than be intimidated by the idea of being asked bombarding questions from a researcher. The participants were given the lead to speak up their minds and sometimes even steer the conversations within the topic of migraine. Gender biases were a major consideration in this research, as they should be avoided especially when conducting research that specifically tackles the gendered experiences of migraine as a disability. I understand that as a female researcher who identifies as a woman, men might be hesitant to share their experiences especially if they contained feelings of shame, hence I strove to establish rapport with them. In addition to this, caution should be taken to avoid making assumptions about men and women participants which could bias the analysis and results of the study. Finally, during data presentation, quantitative and qualitative data are interpreted transparently instead of forcing quantitative data on the qualitative results and vice versa.

3.4 Scope

This study was conducted in a specific country that is Lebanon to examine the gendered experiences of migraine as a disability. Hence, participants were required to be Lebanese citizens who have visited at least one doctor and were diagnosed with migraine. Participants who come from backgrounds other than Lebanese but are living in Lebanon, or are living abroad but were Lebanese citizens at a point in their lives were eligible to participate. The sample size of the interviews was only 4 participants in order to focus on an in-depth analysis of their experiences, which represented "a fairly homogeneous sample" (Pietkiewicz & Smith, 2014) , this allowed an in-depth analysis of the participants' experiences of migraine using IPA. For homogeneity, all participants were in their twenties, where every two shared a similar gender identity: two were women and the other two were men. The participants in both the interviews and surveys were cismen and ciswomen, hence people identifying as other genders were not included. The study focused on people's definitions of migraine, their social interaction with families, friends, and medical doctors, and their perceptions of the relation between their gender as men and women and migraine. This study utilized in-depth interviews with participants who have experiences migraines, and a survey was used to collect quantitative data on the effect of migraine on people's lives, making a distinction between men and women experiencing migraine. The scope of the socio-economic background of my participants was kept open due to the fact that I wanted to discover, throughout the interviews, the extent to which it affects certain aspects of their migraine.

3.5 Limitations

This research is subject to some limitations. First, the sample sizes of the interviews and survey were relatively small which might limit the study's generalizability unless other research builds up on it. The 4 participants in the interviews would not be representing the whole population in Lebanon but rather contributing to a field of knowledge that is limited. Also, depending on participants' memories may produce biases as some might have difficulty remembering their exact experiences of migraine. Also, due to the vulnerability of the gender minority population in Lebanon, only cisgender participants were willing to participate, which lead to a study that is still within the binarism of sex and gender. Due to the anonymous nature of questionnaires, the results are not often 100% reliable hence comparing them with the results of the qualitative interviews and other similar quantitative data in Lebanon could give us a more comprehensive idea of the gendered experiences of migraine. Despite these limitations, the findings of this study provided valuable insights into men's and women's experiences of migraine as an invisible disability, and informed research on invisible disabilities within the Lebanese context.

CHAPTER FOUR

FINDINGS AND ANALYSIS

Restatement of the Purpose of the Study

The purpose of this mixed-method study is to explore the lived experiences of persons with migraines as a disability. This study used the IPA approach to understand the way in which men and women with invisible disability perceive and make sense of their experiences.

Research Questions:

This study tackles the following research questions:

3- What are the experiences of people who live with migraine?
    c- How does the invisibility of migraine influence the experiences of individuals living with the disability?
    d- How do men and women who experience migraine perceive the effect of their gender on their experiences of migraine?
4- What are the societal perceptions of migraine, and how do these perceptions impact the experiences of persons with migraines?
    c- How do able-bodied people react to people who have the invisible disability?
    d- How do institutions, including healthcare, education and workplace, react to persons with migraine?

This chapter presents the findings of this study which are organized into themes and subthemes. It starts with a general profile that introduces each participant, including a table that reveals their demographics. Because of the nature of Interpretative Phenomenological Analysis as idiographic, this study examines the experiences of people with migraine through their individual descriptions of migraines, in a detailed representation of their words and actions. As a way to give voice to the participants, excerpts from the interviews are provided where most of them are in the form of quotes.

4.1 Quantitative Finding

The survey aims to provide quantifiable data on the experiences of migraine and to investigate the relationship between gender and those experiences. The quantitative survey was administered to 28 participants asking about the effects of migraine on their everyday life experiences. The survey included the following sections: general information, the migraine disability assessment test (MIDAS), perceptions of migraine and self-image, gendered experiences of healthcare encounters, migraine and management/medication, migraine and everyday life, and depth of knowledge about migraine. The sample consists of 71.43% women/females and 28.57% men/males, with the majority of the sample's age (32.14%) being less than 25. The educational background of most survey respondents is higher education (92.86%), including 50% working full-time jobs followed by 21.43% students. Most participants who answered the survey reside in cities (85.71%). The results of the MIDAS questionnaire showcase a high number of migraine as it causes 46.43% of moderate disability and 32.14% of severe disability among the sample population. 50% of the overall respondents usually seek information first from the internet regarding their migraine. Interestingly, the majority of men seek information from the internet rather than from family, friends, or physicians which represents 75% of the men surveyed. 60% of the women surveyed agree with the fact that they believe that being a woman puts more pressure on them than people from other gender identities in seeking help. The majority of the survey respondents (82.14%) chose 25 as the age at which migraine started. 75% of the respondents have not previously completed the MIDAS questionnaire, or any other migraine questionnaire at a doctor's clinic. 64.29% of the total respondents chose yes as an answer to the statement ‘I was prescribed anti-depressants upon first/second visit to a doctor’s clinic’, including a large number of the women respondents (65%). Doctors do not describe the side effects of the migraine medication to 32.14% of the respondents. Similarly, 57.14% answered ‘not at all’ to the statement ‘the doctors prescribe alternatives to pills before prescribing the pills such as alternative treatments’. Out of the whole respondents, 67.86% answered that they have been self-medicating. 75% of the participants can not go outside their homes unless they are equipped with the medication for a migraine breakout and 78.57% know what triggers their migraine so they try to avoid it. The majority of the participants do not express that they are in pain around friends and family where 25% answered 1 (not at all) and 28.57% answered 2. Also, 39.29% of the participants agree to the statement that their friends and family underestimate their migraine pain. The trigger scoring the highest among participants is stress (15.86%) followed by insufficient sleep (15.17%).

4.2 Qualitative Findings and Overall Analysis

4.2.1 Participants

Four participants took part in this study, each in a semi-structured interview that lasted 55-70 minutes. In order to protect the anonymity of the participants, they will be referred to by their pseudonyms: June, Alissar, Flapjack and Mango. The brief list of demographic information that was provided to the participants at the beginning to complete contained the following: 1- Pseudonym / 2- Sex / 3- Gender / 4- Sexuality /5- Age / 6-Socio-economic Status / 7- Highest Educational Background / 8- Previous - Current Partner(s) / 9- Children. Participant demographics are found in the proceeding table, reported the same way participants wrote them down or answered them verbally.

Pseudonym	June	Alissar	Flapjack	Mango
Sex	Female	Female	Male	Male
Gender	Ciswoman	Female	Man	Male
Sexuality	Heterosexual	Heterosexual	Homosexual	Straight
Age	25	29	21	23
Socio-economic status	It is complicated to define that these days. My answer might be biased, but upper-middle	Low-middle	Middle	Middle
Highest educational background	Masters degree	Higher Education	Bachelors	Bachelors
Previous / current partner(s)?	Previous 2-year long relationship	Yes	Yes	No
Children?	No	No	No	No

June is a 25-year-old female residing in Lebanon who identifies as a heterosexual ciswoman. June is a translator and an instructor who was diagnosed with migraine at the age of 13. After the first interview with June, I wrote down that she was very enthusiastic and passionate in the way she spoke about her migraine. June visited several doctors for her migraines, some of whom undermined her pain.

Alissar is a 29-year-old female residing abroad and who identifies as a heterosexual female. It is relevant to note that Alissar is a nurse, hence she uses numbers throughout the interview to quantify and explain migraine. Some of her ideas concerning migraine are influenced by medical and scientific discourse. She was diagnosed with migraine at the age of 14. Alissar was eager to share her experiences of migraine as I realized that she wanted to share more about her life and what affects her migraine episodes. Alissar has had a long journey with medical health professionals concerning her migraine, many of whom had prescribed her with anti-depressants during her first visit.

Flapjack is a 21-year-old non-Lebanese male residing in Lebanon who identifies as a homosexual male, but insinuates during the interview that he is not open about his sexuality around his family. He is a university student pursuing a Bachelors degree. His migraine episodes started when he was in grade eight. I realized that Flapjack looked worried at the beginning of the interview, but later felt at ease and began talking more freely after rapport was established with him. Flapjack discusses his journey with only two doctors, a psychiatrist and a neurologist in Lebanon. His experiences mainly focus on his interactions with university professors and friends concerning his migraine episodes.

Mango is a 23-year-old male residing in Lebanon and who identifies as a straight male. He works in an international NGO and shares that he has a gender focal point. He experienced his first migraine episode at the age of 9. Mango was excited to share many stories as examples on how his migraine episodes affect his everyday life activities, and showed that he is an easy-going man. Mango shares that he only visited the family doctor for his migraines, and did not follow up. His experiences mainly focuses on the severity of his migraine and how they influence his daily activities.

4.2.2 Data analysis and Discussion

In this section, the participants' experiences and narratives are highlighted according to 7 themes, where some of them contain subthemes.

A. Migraine: The Invisible Disability

A.1 Description of Migraine and its Challenges

Following Kafer's concept of "collective affinity", the researcher did not want to define which type of migraine and what symptoms a person has to show for their migraine to be considered a disability. On the contrary, the researcher is "play[ing] on identifications that have been attributed to individuals by their societies, and that have served to exclude them or subordinate them." (Kafer, 2013) In other words, listening to the participants' own definitions of migraine allows this study to highlight shared struggles and experiences between people living with migraine, despite the uniqueness of each experience which could contribute to a sense of affinity and support. In an attempt to privilege the voices of people with migraine, the researcher asked them to define migraine in their own terms by answering the following questions:

(1) Describe migraine in 3-5 words or expressions.
(2) Do you think of migraine as a disability?

Answers to the first question were provided verbally during the interviews, whereas those of the second question were sent through a voice note message, a couple of days after the interview. As a response to the first question, all the participants defined migraine within its disabling influence on their lives, as they used words that have negative connotations, and most of them referred to the pain that accompanied their migraine. In fact, the severity of migraine is strongly expressed through the results of the survey where 75% of the participants answered that they can not go outside their homes unless they are equipped with the medication for a migraine breakout (figure 1). Alissar talked about the severity of migraine pain and its hindering influence on her everyday life activities. She said:

> It's an extreme, (pauses) painful, (pauses) stinging pain. It's so sharp, it's painful…It's so strong to a degree where I can't do my daily activities. I can't sit with people. I can't talk with people. I can't see light. I feel nauseous. I vomit sometimes, not sometimes frequently. Yes, you can't handle the pain. It's so, so extreme. Out of ten, it's ten out of ten.

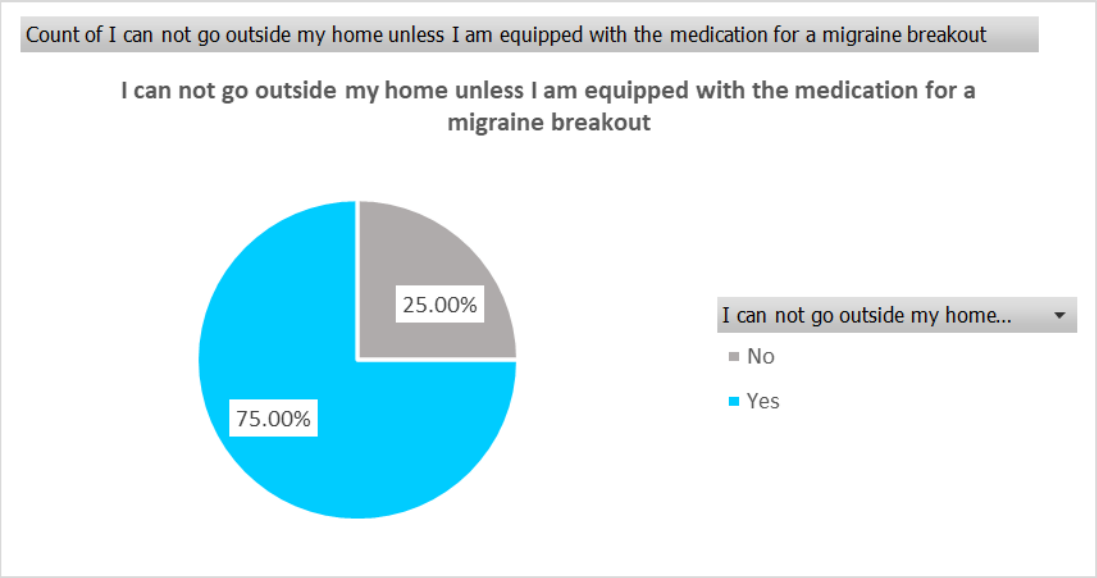

Figure 1

In addition to this, Alissar said: “they (migraines) make me so weak. I feel so weak when I have migraines.” In fact, all the survey respondents (100%) chose the option ‘weak’ when completing the statement ‘My migraine makes me feel’. Similar to Alissar, June’s definition of migraine entails information about the pain that accompanies it. She said: “It's definitely an obstacle. It makes basic easy stuff sometimes almost impossible to do… I mean, I would use painful as well, they are extremely painful.” June continued: “I'm like in a constant state of migraines if that makes sense.”

Flapjack also used negative words to describe his migraine as “horrible nasty migraines.” The fourth participant, Mango, provided two analogies about migraine and its severity. In the first analogy, he described migraine as “my enemy and my friend.” Mango was the only participant to mention the positive side of migraine when asked to define it, which he declared had increased his endurance for pain. The other analogy captured the sudden outburst of his migraine episodes where he said: “You can consider migraine like a volcano, if anything is thrown at it, it erupts literally. This is the most accurate description of migraine.”

The above section provides an overview of the participants' descriptions of their migraine episodes in their own words. Although each participant has their own definition of migraine, these definitions converge at times, especially in relation to the sharp pain that often accompanies migraine and disables them from performing everyday tasks. As discussed earlier, this study aims to give voices to people who live with migraine, hence the findings will portray their experiences in their own words, without attempting to frame them as either victims or heroes. Utilizing Kafer's political/relational model of disability gives notice to the pain and the debilitating effects of migraine on the participants' lives, because "admitting to struggling with our impairments or wanting a cure for them" should not be seen "as accepting the very framings we are fighting against" (Kafer, 2013), rather, should be acknowledged and unsilenced. Hence people with disabilities are not supposed to deny their own feelings of pain.

Within the context of disability, migraine is perceived differently, regardless of its severity in the eyes of the participants. When society labels certain people as disabled, this does not entail the idea that they ought to define themselves as such. Regardless, people with disabilities are often viewed by those around them as disabled even if they do not see themselves as such. Hence, a part might be offended if considered disabled, on the other hand, another might be struggling to be considered as such due to society unrecognizing their disability as a disability. Wendell writes: "These people often long to be perceived as disabled, because society stubbornly continues to expect them to perform as healthy people when they cannot and refuses to acknowledge and support their struggles." (1989) In light of defining migraine as a disability, all the participants in this study agreed with this definition. The researcher recognized participants' hesitancy regarding defining migraine as a disability, whether through their words or their silences. One of the reasons why people with invisible disabilities tend to undermine their own disabilities is the notion that their "claims do not rise to the level of disability" especially when society rejects these disabilities by comparing them to more visible ones, considering the latter more 'serious'. Alissar said:

> I do think that migraine is a disability where it limits your daily activities, your normal (stresses on it) daily activities. Like if you have a meeting with friends, or work, the normal (stresses) work that your coworkers do, it might limit your effort. (pauses) Yea it is a disability. (pauses) …

By pausing before and after stating that migraine is a disability, Alissar took some time to rethink her answer well before proceeding. In addition to this, she provided a brief comparison between herself living with migraine and her able-bodied coworkers and also stressed on the concept of 'normality', which her migraine did not allow her to pursue in her everyday life. This showcases "compulsory able-bodiedness/able-mindedness", that Kafer (2013) discusses, in which people with disabilities feel they need to fit into.

In her reply, June provided a similar comparison between herself and able-bodied people in order to justify her answer. She said:

> I do think that migraines umm (pauses) I mean personally do classify them as a disability. To be honest, I don't know if the WHO or the CDC or the health organizations or like institutes if they … uhh if they consider them as a disability, sorry. (pauses) But like the definition of the word disability, it means a condition whether it's physical, mental or neurological or anything, something that prevents you from engaging in normal daily activities…And personally, my experience with migraines, they have prevented me from showing up to work sometimes, from being productive. Sometimes I just lay in bed all day because I can't get myself to get up and function as a normal human being so in a way, they are like you know, limiting my daily normal activity, as compared to someone who doesn't suffer from

> migraines or like who doesn't have these sorts of disabilities. So yea it is, of course it is…

In this excerpt, June decided that migraine is a disability due to its impeding effects on her life regardless of the health organizations' definitions of disability. It is interesting to note how June's lexical choices changed throughout her answer. She began by using words such as 'I think' and 'I personally' to more certain words like 'so yea' and 'of course' which mirrors her hesitancy at the beginning. However, recalling the disabling effects of migraine made her answer more definite at the end.

Flapjack utilized a comparison as well, but here between people with migraine and people with disabilities to back up his answer. He said:

> So I do consider the chronic type of migraines which debilitate your lifestyle and working habits or like how you pursue your life normally… Well I mean definitely it's not as we would consider the physical disabilities like people in wheelchairs or people who can't see. However, I mean, I don't know how to say it honestly. Umm I mean without the treatment, without the medications, definitely the same influence would be on both people. I mean if it's a person in the wheelchair, without the means to continue their life, they wouldn't be able to go on and live productively, and the same thing for migraines. So that's why I would consider it a disability because if we're not giving them the medications or the ways to cope with it, it would definitely ruin their lives or it would impair how you can go on to live normally.

Flapjack hesitated when defining migraine as a disability, as he undermined it in the presence of other physical disabilities that society often believes as more disabling. However, he related migraine disability to physical disabilities by tackling the essential point of access and accommodation. At this point in his definition, the problem of disability does not only reside in the chronic pain that migraine causes but also in the "unequal distribution of resources, status and power within a biased social and architectural environment" (Kafer, 2013) as put by Rosemarie Garland-Thomson. Hence, Flapjack believes that the inaccessibility of resources that could assist people with disabilities is what defines a migraine as a disability.

Mango's answer was received in two voice notes, one on the same day that the question was asked and the other six days later. His initial answer was a partial rejection of migraine as a disability, as he believed it depended on one's case.

He stated:

> Now, we can't totally consider migraine as a disability but depends upon cases, as in sometimes it disables you from doing a lot of things, so it depends from case to case. Sometimes there are cases where they can't walk anymore as I told you, they can't attend any event, to go out, to do a lot of things. So maybe it's kind of a disability with a small percentage. As well as the fact that it's not a disability for some people…

Mango decided that migraine is not completely a disability, acknowledging the fact that not everyone would define it as such. However, having a migraine episode later reminded him of how disabling it could be. He shared the story of how his migraine started at 5 am and continued throughout the day. He said:

> … The partial pain in the left side was deadly. I am sending you this voice note now while my eyes are closed and my head is tied. But I thought I should tell you before I sleep … I will try my best to sleep now and hopefully it works. So you came to my mind in the morning and I thought I should tell you about my pain. It really is a disability (laughs) it'ski something super harmful. This is the life of a migraineur.

Reliving a migraine experience made Mango realize the severity of this disabling disease, and decided that migraine is a disability after all.

The participants' verbal and nonverbal hesitations to describe migraine as a disability reflect how they internalized society's image of disability as mainly physical. Due to the medical model of disability that frames it as physical, we often grow up to believe that our invisible disabilities are not, in fact, disabilities. The hesitation or even sometimes "rejection of the word 'disability' is a byproduct of growing up entrenched in the attitudes and behaviors that the very word symbolizes (Zola, 1993a)." (Valeras, 2010) Either due to considering disability as a characteristic that makes one inferior to others, or due to perceiving one's own disability as 'not enough of a disability', many people with invisible disabilities might reject this notion, indirectly affected by society's own definitions of disability. Due to the debilitating effect of migraine on their lives, many of the participants try to dissociate themselves from when they experience migraine, leading to what I named the 'migraine identity' in the proceeding section.

A.2 The Migraine Identity

Three out of four participants shared phrases that showed a clash between their identity when they were not experiencing a migraine episode and their other identity when they had a migraine episode. Similar to the participants in Hendry et al.'s study, those here "emphasize or de-emphasize aspects of their identity." (2022) At a certain point during the interviews, participants talked about themselves as having two identities: the able-bodied identity and the disabled identity. For instance, June described these identities, and how her friends noticed the differences between them. She used words such as "very hyperactive person", "overachiever", "full of energy and focused", "super excited to get something done" and "the comedian of the group" when discussing her able-bodied identity, but switched to using words with negative connotations when describing herself with migraine such as "struggling", "suffering from a migraine", "can barely make a joke" and "the polar opposite of June without migraines".

Similarly, Flapjack described his disabled identity based on how he perceived it is formed in the eyes of others. He discussed how migraine stood in his way of attending his regular classes at school. He stated: “I became the person who's known with the highest, umm, I mean the least attendance, as in most absences.”

Flapjack realized that his migraine identity led to the creation of this other identity or image of him as being a slack-off in the eyes of his classmates and teachers. In another excerpt from the interview, Flapjack said: “…Because you look like this person that you need to get to the hospital. Most of the time people would want to call 911.”

This is another example of separating one’s able-bodied identity from the disabled identity, which here is represented by Flapjack relating his disabled identity to being perceived by others as a sickly person. This is similar to Hendry et al.’s finding of the theme ‘incongruity between looking and feeling’, where they highlight the fact that “the visibility of their (people with invisible disabilities) disability appears to be a factor in how seriously their disability is considered.” (2022)

Throughout the whole interview, Mango repeated that he is usually a person who endures pain even when at work, however, having a migraine does not allow him to be that person anymore. Mango shared: “I was someone who usually endures, I’m not someone who quickly uff doesn’t feel well, so I was normal but sometimes I can’t anymore...”

Mango’s use of the word ‘normal’ in relation to his able-bodied identity signifies the idea that he considers his disabled identity as ‘abnormal’. In fact, normality here is associated with his ability to be the person who usually endures pain, thus is in control of his own body. Valeras discusses a similar example of a participant in their study who pushed themself despite their pain because “for persons with a hidden disability, upholding a nondisabled public presentation often means hiding discomfort in the pursuit of appearing able-bodied.

Limitations of the body are often ignored or minimized, frequently leading to exacerbation of the condition (Matthews & Harrington, 2000; Fitzgerald & Paterson, 1995).” (2010) Whether around friends, at school or university, or in the workplace, the migraine identity appeared at a time that they did not expect. In the next section, an overview of the participants’ interpretation of what often triggers their migraine will be discussed.

A.3 Number One Trigger: Stress

Stress is the most common trigger discussed by all the participants. In fact, the survey results show that stress is the number one trigger for people with migraine, scoring the highest percentage 15.86% in relation to other triggers (figure 2). It is important to have an overview of what people with migraine consider as their triggers in order to provide them with the suitable accommodation.

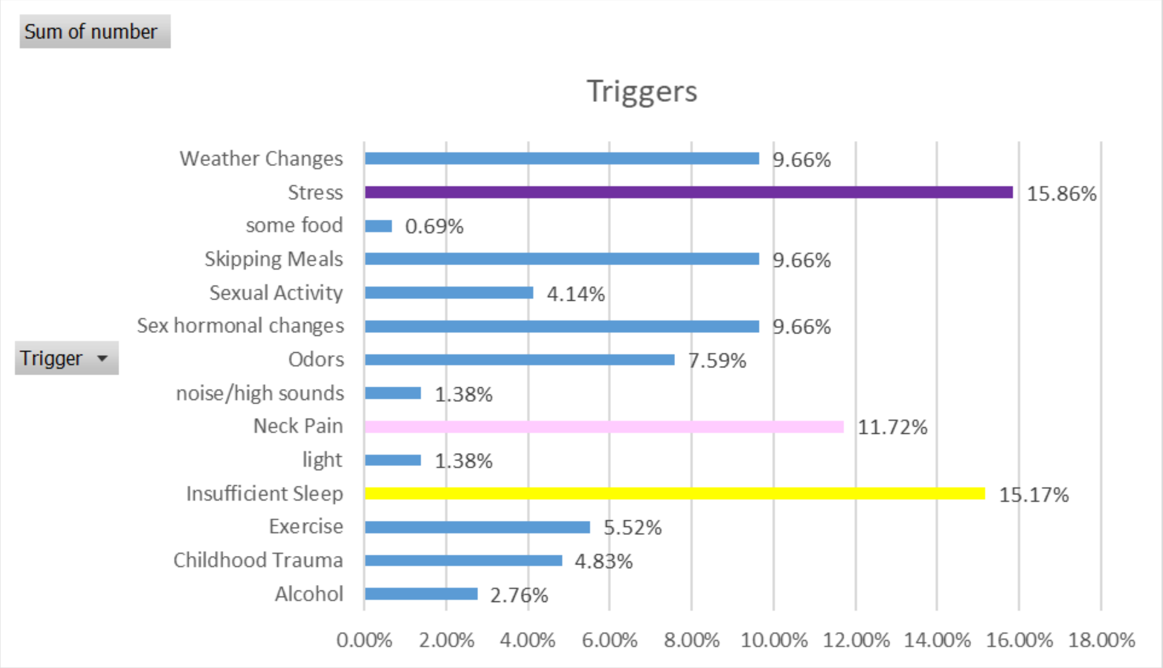

Figure 2

Both June and Mango related their migraine episodes to stressing over academics. June explained the origin of her stress as stemming from education and life choices at the age of

18, when she was looking for programs at universities. She described her migraines as "drowning" her. Mango also shared that his migraine is triggered during major academic pressures. He said: "I remember at uni once I had migraines for 4 days I slept in bed. I had at the time a senior project, so for graduation, I finished them, then came and slept literally for 4 days with headache. I couldn't anymore." In fact, educational stress is a main factor contributing to migraine due to the high levels of anxiety, depression, and insomnia that students might face. (Chahine et al., 2022)

On the other hand, Alissar believed that stress from her work as a nurse, as well as feeling upset both triggered her migraine. She highlighted the fact that her migraine is sometimes triggered by her low moods. Flapjack also considered stress a major factor in initiating his migraine, however, he believed that "stress is just an umbrella", as there are several stressors in one's life. He shared times when he was stressed out but surprisingly did not experience migraine, and other times when he felt at ease but still experienced it. He asked himself: "…So what kind of stress even? Is it academic? No. Is it social? No? So what is it really? I haven't figured."

Since Flapjack shared that he identifies as a homosexual, the researcher asked whether there was a relation between his sexuality and his migraine, to which he answered:

> … As in sexuality, usually it's in grade 8-9, even before, that's when I also started facing migraines. I think maybe deep down as in feeling that it's always like this and that you're confined somewhere some place. In my interactions, I don't feel the need to express anything, or explain anything to anyone. I don't have any weight from it, but I think it does affect because ironically… (pauses and then talks looking above as if thinking) It could be. Maybe. Very nice I mean I wouldn't have reached one of these conclusions.

Even though Flapjack shared later that he acknowledged the fact that his migraine is not solely initiated by his stress from fear of others knowing about his sexuality, he said that he sometimes used to get severe migraine when he traveled back home during the winter break. He continued: “But I do think that once I'm at a level where I can feel this inner peace, maybe I will not have the migraines. (laughs)” At a certain point, Flapjack linked his migraine to finding inner peace with his sexuality. In fact, “research shows that disclosing a hidden facet of one's identity, including disability, sexual orientation, and mental health issues, can promote a sense of self-acceptance, self-esteem, and self-efficacy, create the opportunity to connect with a community, and improve physical and psychological health and well-being (Corrigan et al., 2013; Corrigan et al., 2016; Elliot & Doane, 2015; Taniguchi, 2020). Gurley-Green (2021) Research also shows that sexual minority stress is associated with stigma and barriers that often worsen migraine. (Pace et al., 2021) Flapjack’s exacerbation of migraine especially when being around family could be explained through Foucault’s concept of surveillance. Foucault believes that the private sphere does not always represent a space where one can express their autonomy, but rather could be an area for surveillance and control over one’s sexuality by the family. The private sphere is where gender norms, roles and expectations play a huge role in controlling individuals. This control seems to be the trigger of Flapjack’s disability at some point.

Having people with migraine think about what triggers it is very essential in keeping track of their own health. If such criteria were to be followed by doctors and if governments took responsibility, resources would be provided for people with migraine which would help decrease the triggers. The following section provides more information and explanations about governments and societies in the frame of disability and power.

B. Disability and Power

In this section, I am referring to the French philosopher Michel Foucault's theories on power and social control in the frame of invisible disability. People's perceptions of disability originate from the societal power structures and norms that are rooted in social practices and medical institutions. According to Foucault, power is possessed by a group of individuals over the other, but is also present in the institutions and governments around them. In his book *Discipline and Punishment: The Birth of the Prison*, Foucault [55] explains the way the authorities exert control through a double mode "that of binary division and branding (mad/sane; dangerous/harmless; normal/abnormal); and that of coercive assignment, of differential distribution (who he is; where he must be; how he is to be characterized; how he is to be recognized; how a constant surveillance is to be exercised over him in an individual way, etc.)." (1995) Disability is one of the many areas where power dynamics play a role, as persons with disabilities are marginalized by society which is tailored mainly for the able-bodied individuals. Societies tend to create and define the meanings of disability, categorizing certain people as either able-bodied, hence the 'normal', or people with disabilities as the 'abnormal'. The manifestation of such power dynamics and inequalities is portrayed in people's behaviors around individuals with migraine. When it comes to invisible disabilities such as migraine, Foucault's ideas are specifically relevant in this context because people's experiences of living with such an invisible disability are often influenced by how society defines disability. Many people with migraine live with this invisible disability that often is mysterious to others, hence unless its symptoms are apparent on the person who has it, people around them often do not understand. In the following section, examples of people's perceptions and behaviors around individuals with migraine

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[55] <Accessed on 15 May 2023>

are provided. Through the societal and the institutional attitudes, “the tactics of individualizing disciplines are imposed on the excluded; and, on the other hand, the universality of disciplinary controls makes it possible to brand the 'leper' and to bring into play against him the dualistic mechanisms of exclusion. The constant division between the normal and the abnormal…”. ((Foucault, 1995)

The split between the public and the private reinforces the power dynamics and control exerted by societies over people’s bodies. Able-bodied individuals often see themselves as the norm in public spaces tailored for them, which enables them to make assumptions about people with disabilities. Women and people with disabilities are usually assigned to the private spaces, away from the public world, that is the world which is built on paradigms of health and youth. Wendell writes: “Coming into the public world with illness, pain or a de-valued body, we encounter resistance to mixing the two worlds; the split is vividly revealed.” (1989) In terms of the public/private distinction, Foucault believes that setting boundaries between the public and the private is a modern way of controlling individuals; “it was an effort to adjust the mechanisms of power that frame the everyday lives of individuals; an adaptation and a refinement of that machinery that assumes responsibility for and places under surveillance their everyday behavior, their identity, their activity, their apparently unimportant gestures; another policy for that multiplicity of bodies and forces that constitutes a population.” (1995) Creating this public/private separation is a method of regulating the population’s behaviors and identities. Such control helps make it easier for governments and societies to categorize people and to manage their multiplicity as a way to preserve social order. Therefore, people with disabilities might navigate these boundaries in a more difficult way, because their experiences of disability and pain might be undermined and rejected. Such control expects them to conform to the dominant able-bodied expectations, which often reinforces the public/private boundaries.

B.1. Public Perceptions of Migraine

B.1.1 Normalizing Migraine

One of the major themes that overarches all four participants' stories is people's neutral or negative reactions to their invisible disability. In fact, migraine was considered a private personal problem for people with migraine and their families to deal with. When it comes to disability, societies do not take responsibility in providing resources for people with disabilities, considering disabilities an issue that should be dealt with within the confinement of their private homes. Wendell writes that "disabled people are often expected to overcome obstacles to participation by their own extraordinary efforts, or their families are expected to provide what they need." (1989) This is present in the way many institutions handled the participants' migraine episodes which resembles perpetuating keeping the invisible invisible. Kattari et al. and Olkin et al.'s studies label such acts of the implicit perpetuation of ableism as "microaggressions" that spread myths of normality, where "frequent exposure to microaggressions, including ableist microaggressions, can result in higher incidence of negative mental health outcomes, feelings of being excluded, and lower positive outcomes including reduced academic performance (Khattari, 2017; Nadal, Griffin, Wong, Hamit, & Rasmus, 2014)." (Kattari et al., 2018)

One of the ways that people often react to disability is by normalizing it. Normalizing disability has major negative effects not only on the individual but also on the general disability community. All participants shared their experiences of having their migraines normalized by those around them which lead to the assumption that people with disabilities are like everyone else, hence their needs and experiences were neglected, sometimes even from close family members. Alissar provided an example of how her family normalized her pain by undermining it:

> Not all take it seriously. I tell some of my family I should sleep 8 hours without hearing noise or seeing light…They say (her voice becomes louder and sterner) ‘you are exaggerating’. And some say when I tell them I have migraines ‘Ohh, we all have headaches’.

This misconception that migraine is just a headache often frustrates people with migraine because it undermines their experiences and normalizes a disability that often restricts them from conducting their everyday life activities. June confirmed this by saying:

> … Anyone would just say I have a migraine I have a migraine, and no, you just have a headache. (laughs) There’s a huge difference between a migraine and a headache. And people are not aware of the difference between the two, which makes it easier for them to, underestimate the pain ...

Flapjack shared a similar view within the context of university. His university professors undervalued the crippling impact of migraine on his academic productivity. In discussing how his university professors reacted to him, he said: “… they told me to toughen up, like just collect notes and do what you can and go read the material. So what? We all have migraines.” The university professors considered it solely Flapjack’s responsibility to catch up with the class material, which has triggered a cycle of him explaining himself to every professor so they understand the severity of his pain. Another example that Flapjack provided was the reaction of his family, friends and partners who, with time, proved to care less in a way that normalizes his migraine. He said about his relationship with a partner:

> You expect every time the other person to have the same reaction. But then you see that this amount of attention is like highly fading… so as if it became like a habit or like a normal thing. Not like it's a constant experience, as it’s painful.

The fact that migraine is invisible and often unrecognizable on one’s physical appearance, makes many people think of migraine as not a disability. Sometimes, those who care about you get sucked into this world of normalizing disabilities to an extent where they start considering it a habit. Hence, having his migraine normalized by the closest people to him made him feel abandoned. According to Wendell, “people with unrecognized illnesses are often abandoned by their friends and families.” (1989)

Mango also said: “Rarely would people know how annoying and painful it is to have migraine. If you say migraine in front of anyone, they be like ‘okay’.” He also shared the first time he informed his family about his migraine, to which they reacted normally. It is important to note that migraine is hereditary in Mango’s family, from both his mother and father’s sides, hence it was normalized within the family in this case. He stated: “It was like it’s okay, it’s headache, it’s migraine, okay we take medication and if it works it works, if it doesn’t work then (pause)” It is interesting to see the extent to which Mango believed in the normality of his migraine episodes, which consequently influenced his decisions in seeking medical help later in his life. Omitting what is to be done in case the medication does not work could be seen as a sign of Mango’s uncertainty about a plan B for treating his migraine. “The entire physical and social organization of life, assumes that we are either strong and healthy and able to do what the average able-bodied person can do, or that we are completely disabled, unable to participate in life.” Wendell (1989) According to Wendell, society has two ways of perceiving people with disabilities: either as unproductive members, relating their productivity to a defect which hinders their ability to function, or as ‘normal’ people who are just like anyone else, thus expecting them to be as productive as others.

Both June and Flapjack provided examples of being expected to accomplish their jobs just like the others. June’s excerpt shows how people around her expected her to fulfill her duties at work even when having migraine. She shared:

> They don't know how severe it could actually be and how it forces you to pause everything and this happens on a daily basis… Maybe it's lack of awareness or something. So this is probably the main issue with it that you're expected to be a fully functioning human being. I've had someone tell me one time something along the lines of ‘yeah, but when I have the flu, I can still work.’ But the flu is not migraine…but this is not the same thing. Like I cannot be as productive as I usually am...

For June, the issue is lack of awareness among those around her which usually allows them to undermine her pain and equate it to other temporary illnesses like the flu. People at her workplace expected her to provide as much effort as anyone else. Flapjack tackled the same point by highlighting the fact that institutions have always been time-sensitive, which required him to lift his pace to be able to meet such expectations of productivity. He explained:

> I have always thought the world, as in institutions can stop being time sensitive by trying to turn things into task-based instead of time-based because this way you would know that you're not forcing someone into limits and boundaries.

Due to the time-based nature of the work industry, several workplaces prefer hiring able-bodied people who could finish tasks on time. In light of this, people with disabilities were the first to be dismissed at the beginning of the 2019 economic crisis in Lebanon. “Although the Lebanese Law 220/2000 stipulates that private sector businesses hiring more than 60 employees should hire at least 3% of persons with disabilities, 79.6% of persons with disabilities were unemployed in 2019, and they became more likely to be the first ones dismissed from income-generating activities." (Humanity and Inclusion, 2022)

Another example on companies choosing to hire able-bodied individuals is the excerpt from Alissar:

> In my previous work, the director of nursing, he told me that 'if I knew that you had migraines, I wouldn't have given you the post of nursing here.' I was in shock. I mean you are a director of nursing, you should understand more than normal and regular people.

This information is supported by the findings of the study done by Hendry et al. where one of the participants shared that once they disclosed information about their invisible disability in 2 interviews, the interviewers "were already going from 'we like this candidate' to 'no you're not for us.'" (2022) In a society that idealizes fast-paced productivity, a person with a debilitating migraine is a constant reminder of pain, disability and less productivity. It is important to note that Alissar's boss did not suffer from migraines. In another section, we will be discussing the advantages of having a boss who has experienced a similar disability (*check section F titled 'Those who Understand Migraine'*) Avoidance is another way of reacting to people with disabilities, and will be tackled in the following section.

B.1.2 Avoiding Migraine and People with Migraine

People with disabilities sometimes meet others who try to avoid them or their experiences of migraine. Wendell writes, "disabled people learn that many, perhaps most, able-bodied people do not want to know about suffering caused by the body." (1989) Although Wendell was discussing these concepts in the frame of physical disability, such ideas can be applied to invisible disabilities like migraine. Avoiding disabilities could be due to what Wendell describes as fear of not being able to control one's own body. The modern world around us encourages perfection and individualism, both of which could lead to obsession over ideals, that in turn becomes obsession over taking control of your own body. In this frame, societies' emphasis on perpetuating the ideal of ableism through encouraging the body's self-discipline and self-control is another type of social control. Such ideals are not limited to appearance, but also extend to ideals about health and productivity. In such a society, people with migraine are often marginalized because they do not reach those cultural standards. Lessing (1981) writes: "The disabled person is not seen as unique among humankind to be cherished for her gifts of differences. Instead she poses a symbolic threat, reminding us how very tenuous that imaginary model of perfection really is -- a thought from which most people want to run. It is through this fear and denial that attitudes of repulsion and oppression are acted out on disabled people, in ways ranging from over solicitous good intentions to total invisibility and isolation." (Lessing, 1981) Telling an able-bodied individual you are in pain because you are having a migraine episode often reminds them that pain exists and that the body is imperfect. Hence, able-bodied people tend to either avoid discussing it with the person living with migraine, or avoid them altogether.

Flapjack shared his experience of being avoided, he said: "They trivialize it or they just don't talk about it at all. I don't know how to describe it exactly" and "I don't know they either want to stay away or they wanna act like it's okay." Alissar also shared a similar experience specifically with her friends, she said: "Some friends we like to party, they say (changes voice) 'oh we can't take you because you have migraine.' They don't cancel the party and come sit with me and make our own party."

Most of the participants expressed that they often recognized how able-bodied people rejected and marginalized them and the topic of migraine. Consequently, feelings of being viewed as the 'other' and as an untrustworthy person could also arise in such interactions.

B.2 Feelings of Marginalization and Exclusion

B.2.1 Singled out as the 'other'

Flapjack and Alissar shared that they felt singled out and were viewed as the 'other' by those around them. For instance, Alissar expressed her feelings of being abandoned and considered unable to tag along by her friends. She said: "Sometimes I feel left out by some of my friends…That makes me somehow hurt." Flapjack also said: "even if for example maybe I think if there's something you'd be out of it. And that's it, as in 'oh he is having his migraines', you feel like as if it became normal and life moves on without you."

Flapjack also shared a long story about how he was perceived as the 'other' in the eyes of people who witnessed the symptoms of a horrible migraine episode. The lexical choices he used to describe the incident portray a sense of alienation that he felt from those around him. He narrated a story from when he was at university and had a severe migraine that led him to try to press random things on his eye to put pressure and stop the pain. Describing the way people viewed him, he said: "So I had to just put a huge bin next to me (to vomit) and then someone would just see this guy laying on the floor", "it was kind of traumatizing for people", "my friends got scared from seeing me like that", "so after that it felt awkward".

The above excerpts are similar to Valeras's study findings where they mention that one of their participants explained how people often stared at someone who showed signs of disability. Valeras stated that "disability … is an identity category any person can enter at any time." (Valeras, 2010) Able-bodied individuals often try to avoid thinking of their bodies as not fixed, which leads them to illusion and "false comfort of everlasting health, strength, and well-being." (Valeras, 2010)

At other times, Flapjack was singled out by some of his university professors whenever he could not catch up with the material in class, he shared a story of a time when he was late to class due to a migraine episode:

> …Then she (the professor) cracked a joke, so I smiled. And then she's like 'all the students in the class are allowed to laugh except for you, I don't want to see you smiling.' That was one of the repercussions as in I didn't want it to diverge into me again going to the instructor, 'I have this, I have this, I have that'. Here's the report. Here's this, here's that…I had to take this embarrassment in front of the class just like keep it brief.

The professor's remark made a distinct separation between Flapjack and all his other classmates, which increased his sense of alienation to a degree where he felt embarrassed to explain his disability to her. In their study, Gurley-Green (2021) writes that feeling safe to disclose their own disabilities in the classroom makes it easier for students living with disabilities to participate regularly, as their stress levels form hiding their disability decrease. However, one of the many reasons that students hide their disabilities is stigma which "can be so powerful as to reduce someone "from a whole and usual person to a tainted, discounted one" now to be perceived as having a "spoiled identity" (Goffman, 1963, p. 3)." , (Gurley-Green, 2021) Being singled out often increases feelings of stigma and isolation from what is considered 'normal'.

B.2.2 Untrustworthy

At other times, most of the participants talked about how they were perceived as untrustworthy when they shared their experiences. People often did not take their experiences seriously, or questioned them skeptically, especially since migraine is an invisible disability. The findings of Olney et al. (2005) are analogous with the following findings concerning others' perceptions of the participants as unreliable. "… those with hidden disabilities thought that others saw them as minimally disabled or nondisabled… Conversely, those with hidden disabilities expressed concern that others didn't believe them to have a disability." (Olney et al., 2005)

June shed light on the fact that unless her mother informed the school, the administration would not have believed her. She said: "…It's different when the parents tell the administration that their kid, … suffer from migraines instead of the other way around, like they tend to believe the parents and not the kids." June provided a concrete example on being perceived as untrustworthy when she shared the following: "But you know, like the extended friends or like groups of friends, it seems like I'm just making an excuse just to avoid or skip an outing..."

It is important to note that June's close circle of friends understood the disabling effects of migraine on her life (*see section F under the title 'Those Who Understand Migraine')*, but it is the extended group who did not. Alissar gave another vivid example on this issue, but here in the context of her workplace as a nurse. She said: "… The administration saw me and told me 'you are always sick? You are always having migraines?' That made me feel that I am a liar. I wasn't lying, that was the truth." The administration's statement questions signify that they already knew the answer to the questions which proves their disbelief as well as their ridicule towards Alissar's migraine episodes.

In the context of university, Flapjack narrated a time when he had an exam on a Wednesday, which he attended, but the professor decided to postpone it till Friday at 1:00pm. He had a migraine on that day and was only able to reach class at 1:35pm, hence he had 15 minutes for the exam. He shared:

> She (the professor) told me 'you won't make it'. Anyway I did it. But when I handed it over, she told me 'by the way, I felt that it's rude for you to come in', and I told her 'I'm sorry I'm sick' and she was like 'Yea, we know' (he said it with sass)… Everyone doesn't realize so it's been so tiring.

Being met with all these different scenarios, and as a result of the negative societal attitudes towards invisible disabilities, people with disabilities might internalize such oppressive acts.

In the section below, the participants shared information about their internalized oppression which manifested in different ways.

B.2.3 Internalized Oppression

Scenarios of being alienated and underestimated might lead many people with disabilities to internalize such oppressions and sometimes even blame themselves for their own disabilities. Wendell states that most people with disabilities "will censor what they tell or say nothing rather than expose themselves repeatedly to such deeply felt invalidation. They are silenced by fear and confusion." (1989) Some people with migraine might feel ashamed only for showing symptoms of the disability in front of others due to past experiences of being alienated or underestimated. For instance, Alissar expressed that she felt ashamed every time she had to throw up in front of her partners, because most people reacted repulsively when it happened before.

Also, June shared that having her disability underestimated by the medical doctors she visited resulted in her doubting herself. She questioned herself: "…They (migraine and tachycardia) were so trivialized to a point that I was just like (changes voice) okay, maybe I am overreacting. You know, it makes you doubt that am I in that much pain or am I, you know, overreacting?"

While interviewing Flapjack, his words reflected a kind of blame towards himself. He said:

> I think if I was able to kind of manage the trigger, the stress, and track the material and all of that, I could have stayed on, and I felt like I have the responsibility of actually keeping myself together because there's no one else there to pull me, I have to keep my s*** together. Because you know, who would do it otherwise?

The participants portrayed what many people with disabilities often experience and that is blaming oneself. Sometimes this internalized oppression leads people with disabilities to participate in keeping the invisible invisible themselves. Wendell states: "Disabled people can participate in marginalizing ourselves…We can feel trapped in the negative body; it is our internalized oppression to feel this.” (1989) Notably, only the men in these interviews expressed their need to hide away their disability, even though they were unaware of the effect of gender on their decisions (*check section D.3 under the title ‘Men: A General Idea of Gender’*). Flapjack explained that he was living alone during the time the interview was being conducted, thus he decided not to inform his family, especially his mother about his migraine. He said: “…I saw it like tear down their energy levels. As in it was very emotionally draining, them seeing me in the episodes. Because the scenery, the darkness, the vomiting. the screeching on the bed and stuff, like trying to reach out for something...” In fact, the majority of the survey respondents answered that they do not express that they are in pain around friends and family where 25% answered 1 (not at all) and 28.57% answered 2 (figure 3). Also, 39.29% of the participants chose 4 (all the time) when answering that their friends and family underestimate their migraine pain (figure 4).

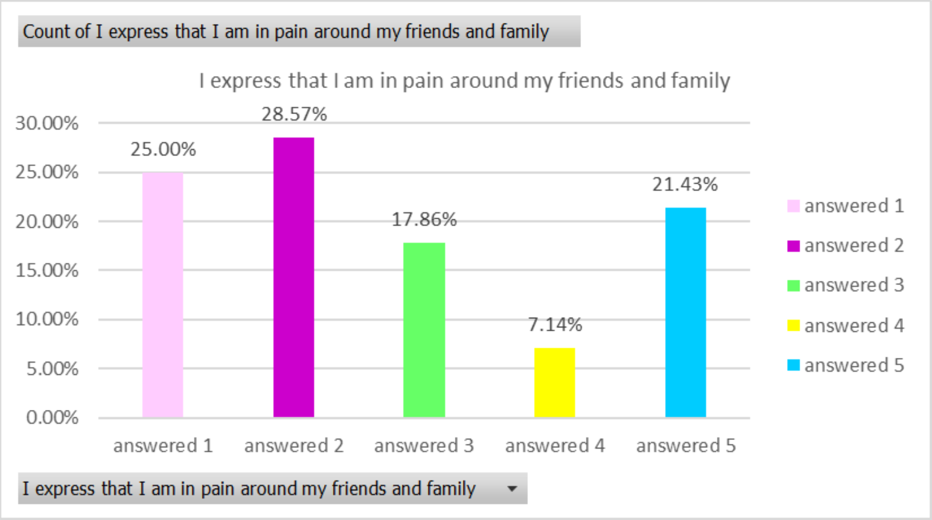

Figure 3

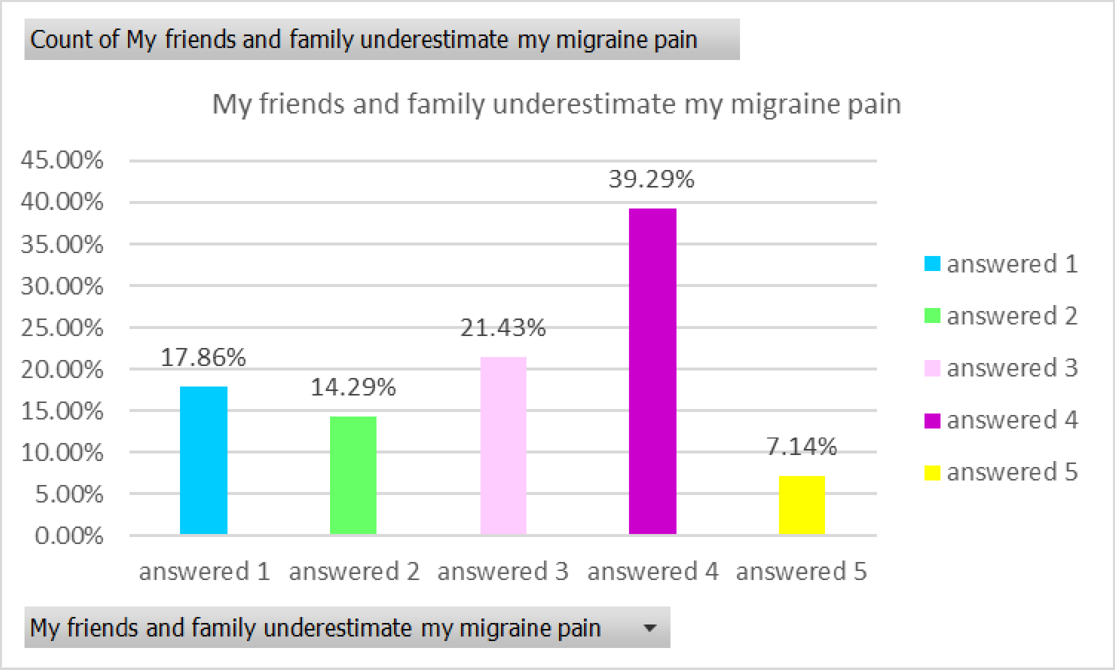

Figure 4

People with invisible disabilities often try to keep their experiences hidden from those who love them, especially when pain is involved. By refraining from informing his mother about his migraine episodes, he felt that he needed to be responsible and careful not to let himself and the others down, as he does not want to disappoint. Flapjack reported that he also felt ashamed of experiencing migraine when people are over at his place, “because then whoever is in the room might tell them to go to the other room and they need to be quiet.”

C. Migraine and Modern Medicine

C.1 The Medical Gaze, Control, and Flaws

In previous sections, a discussion of the influence of people’s perceptions of disabilities on people living with migraine was conducted. In the proceeding sections, the power of medical institutions will be tackled specifically through highlighting their perpetuation of ableist and sexist narratives. The same way such institutions shape ableist perceptions of disability, cultural myths about the body seep into the walls of these institutions, which maintains several stereotypes and modes of oppression. Hence, medical institutions render ableism as the norm and preserve the idea that the body which is disabled can be and must be corrected. A clear example of this is the medical model of disability which "views disability as a defect within the individual. Disability is an aberration compared to normal traits and characteristics. In order to have a high quality of life, these defects must be cured, fixed, or completely eliminated. Health care and social service professionals have the sole power to correct or modify these conditions." (UCSF)[56] For medical institutions, disability is a pathology that needs to be fixed, rather than a reflection of human diversity. Such a model neglects the complex layers of identities including disability and gender that intersect to either enfranchise or disenfranchise people. Consequently, many medical doctors fail to recognize the importance of their patients' unique experiences of disabilities, especially invisible disabilities such as migraine. People often believe in the 'natural truths' of medicine, thus many of us view medicine as value neutral, and its medical doctors as more knowledgeable about our own bodies than ourselves. The power of medical institutions lies in people's perception of medical knowledge as 'objective', which gives birth to disproportionate power hierarchies between the doctor and their patient. Foucault coins the concept of 'medical gaze' which he describes as "no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with power of decision and intervention." (1963) Several medical doctors view their patients through this medical gaze in which the patient becomes the object of medical examination. This power hierarchy becomes specifically dangerous when doctors use their power to discredit their patients, such as when having invisible disabilities like migraine. In light of

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[56] <Accessed on 15 April 2023>

this, these next sections provide examples of flaws within the medical system from the participants’ points of view.

Different stories that portrayed the power dynamics between the participants and their doctors were portrayed through the participants’ narratives. One of the issues that Flapjack faced with the psychiatrist he visited was feeling as if he was being labelled. People with disabilities, illnesses and diseases often get their conditions re-described by medical doctors in a way that is perceived to be more ‘objective’. “The objectively observable condition of your body may be used to determine the severity of your pain, for instance, regardless of your own reports of it.” (Wendell, 1989)

Flapjack shared that one time he was prescribed Tryptizol, a strong anti-depressant by a psychiatrist, which was a result of one visit to the doctor, where she attempted to label and place him in a box; in other words viewing him through the medical gaze as a set of pathologies that need to be fixed. According to the survey results, 64.29% of the respondents answered that their doctors have prescribed them with anti-depressants upon their first/second visit, which portrays the fact that many doctors disregard the negative side effects of anti-depressants (figure 5) In fact, “ it is common clinical experience that some patients are more prone to relapse into MOH (medication overuse headache) and to need further treatment after a shorter period than others”. Scaratti (2018) Flapjack elaborated:

> … Psychiatry was disappointing… I felt she had like a fill-in-the-blank kind of way. So ‘are you eating for example, yes or no? Yes or no? Okay, these are symptoms of this, here’s the medication. let's have another visit after six months…it was like that classical case for her…

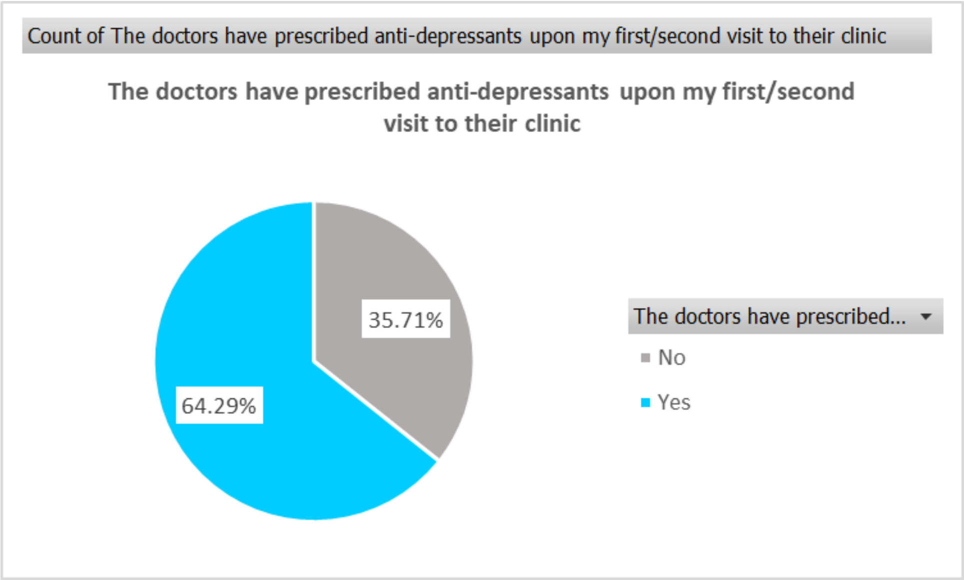

Figure 5

Mango on the other hand shared that he has been self-medicating ever since he knew he had migraine. When the family doctor prescribed him Panadol during the first visit, Mango realized that it was not working anymore. He changed his own medication from Panadol, Advil, Maxifen, Panadol Migraine, and lately to Dorixina, saying that with time, his body would stop reacting to the medication. He also mentioned “an old school way” that he applied where he bandaged his head with a piece of cloth and slept. He shared: “it might be something harmful, but I use it honestly, because it helps a lot.” When asked for the reason behind not visiting other doctors, Mango explained:

> Because it’s known. You’ll visit a doctor and he’ll give you pain killers. You know? He won’t give you a magical solution… I totally believe in science and doctors, but lately honestly I am not liking it because you feel like all of them want to make a trade or a deal.

Mango continued by providing an example of a time when he visited a doctor for his knee and ended up being sent to another. He had two opposite opinions from the doctors, hence he stopped going and decided to self-medicate. In fact, Mango’s statement resembles June’s who also discussed how her cardiologist referred her to a psychiatrist. June was prescribed Topamax right from the beginning. She shared the story on how it happened: "…the first neurologist I went to see he was like, "okay, your mom is taking Topamax, take Topamax. I don't think that he put a lot of thought into it..."

In light of these two examples, patients prefer having doctors who are willing to see them beyond the medical gaze, as humans with feelings rather than as organs that need to be fixed. They long to be treated seriously and to feel that they are cared for rather than just a body which doctors transcribe their previous medical knowledge onto. It is relevant to mention that a Lebanese study titled *The Psychological Attitude of Patients toward Health Practitioners in Lebanon* (2015) emphasizes that the traits most desired by patients from their doctors are empathy (90%) followed by professionalism (87%). In fact, "a sorting by precedence of the desired empathetic qualities showed that the Lebanese public perceived being polite and gentle (99%), showing interest in the patient's illness (97%), being compassionate (93%), and asking about patient's symptoms (90%) as the most important characteristics in a doctor." (Ayoub & Fares, 2015)

C.2 Advantages / Disadvantages in Acquiring Medication

A pattern of self-medication among most participants, those with low-middle socio-economic background, was recognized. In fact, out of the whole survey population, 67.86% answered that they have been self-medicating (figure 6). The socio-economic status of the participants had major effects on the way they dealt with their migraine, as it either enabled or disabled them, especially in the absence of resources provided by the government. June, the only participant who comes from an upper-middle class, shared that she visited a therapist who helped her manage her migraines.

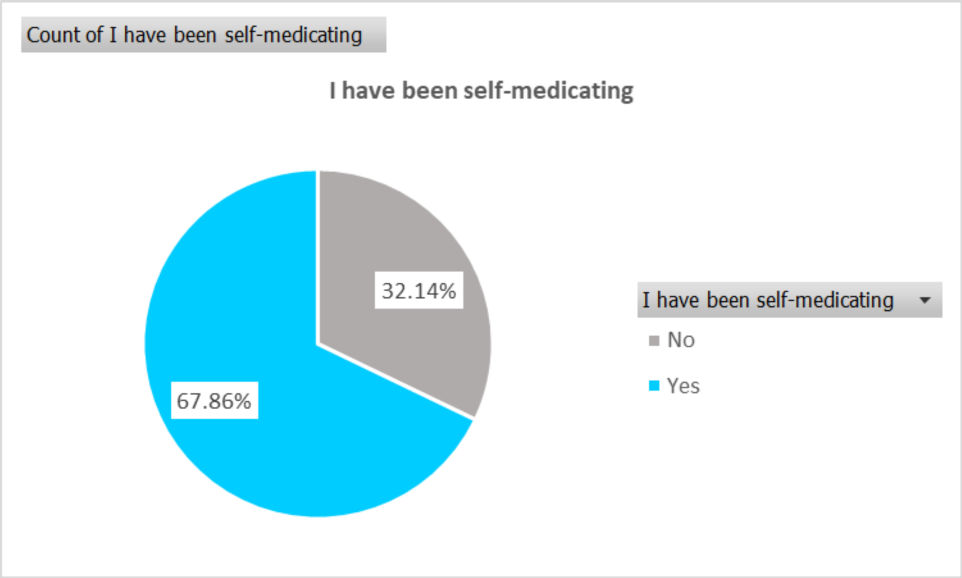

Figure 6

She said:

> … We're doing these organizational therapy things, something like that. So that I would like prioritize the tasks that I need to do, keeping in mind that I might one day wake up with a migraine, etcetera, you know, so it's just time. I'm trying to, you know, to work my way around it.

Similarly, Flapjack mentioned that the insurance coverage from his university enabled him to visit doctors at a prestigious hospital.

Conversely, when asked why she did not try alternative medicine like massage, Alissar who came from low-middle socio-economic status shared: “Because here financially, even if you are a nurse in your hospital, you have to pay for that...” In fact, Yee (2013) also sheds light on the “material factor of economics” and how it limits participants from seeking what they view as better options and treatments. In light of this, it is relevant to note that one of the main reasons why Alissar decided to move abroad was Lebanon’s economic collapse. The socio-economic crisis in Lebanon has had major debilitating effects on the Lebanese population as a whole, and on people with disabilities specifically. A Baseline Evaluation

Report conducted by MedGlobal in July 2022 assessed the situation of people with disabilities and the elderly for the last 12 months. The report found that “most of the respondents 81% (n=156) indicated that they were either not able to afford any of the medical services be it purchase of medicine or payment for treatment, medical consultations, or admission to the hospital.” Taking into account the intersection between participants’ socio-economic status with disability allows us to further understand most participants’ advantages or disadvantages to accessing what they view as the best course of medication for them. It is essential for the Lebanese government to utilize an intersectional lens rather than combine all people with disabilities into one group in order to ensure their rights.

“ We need to recognize that these forgings have always already been inflected by histories of race, gender sexuality, class and nation”. (Kafer, 2013) In the next section, the intersection between disability and gender will be analyzed to understand the gendered experiences and perceptions of migraine.

D. Intersection between Disability and Gender

According to Olney et al (2005), “There is disagreement concerning whether gender or disability is more salient to an individual’s self-concept. In a review of the literature, Fowler and her colleagues (1992) noted that while some authors claim that disability has a greater impact on self-concept than other attributes, other authors suggest that the relationship between gender and self-concept is stronger.” In the following study, both gender and disability identities had impact on participants’ self-concepts, however, what was apparent on the surface was that gender had greater impact on women’s constructions of the world around them, whereas disability dictated men’s self-concepts more.

D.1 Narrating the Migraine Journey through a Gender Lens: An Overview

One of the most prominent themes that distinguished women from men experiencing migraine in this study is the unique experiences of gender roles and expectations portrayed in their narratives. Alshammari writes: “The silence around disability and women with disabilities is staggering. To consider disability, we cannot ignore gender or race. A disabled individual is not genderless, and personal circumstances are not separate from gender and race.” (2018) This theme tackles the participants’ narratives about the first time they experienced migraine, and how they reacted to it.

All four participants shared that they had their first migraine at a young age. In fact, 82.14 % of the whole survey respondents answered that their migraine started at an age less than 25-years-old (figure 7). When asked to provide a history of their migraine from when it started, women participants decided to share hints of their experiences regarding doctors’ biases against women with migraine, whereas men participants opted for a more linearly narrative story of their migraine.

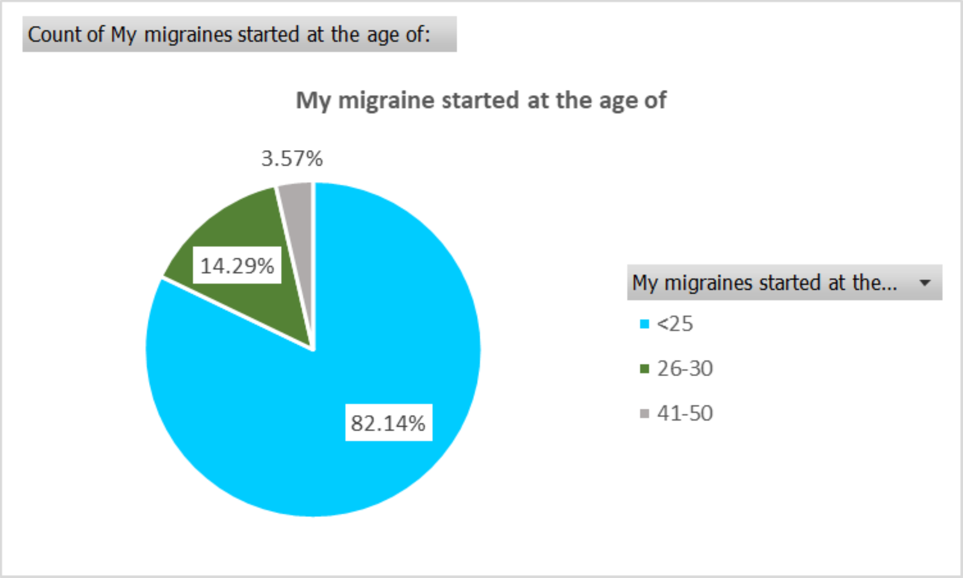

Figure 7

June shared that she got a full diagnosis for her migraine at the age of 13 for the first time, shedding light on the fact that she had been living with migraine way before she was diagnosed. Choosing to discuss her experience of having this disabling disease be dismissed by the medical doctors when asked to provide background about her migraine could be viewed as her awareness of the injustices that women often face by the medical staff. June said:

> And then the second time I got dismissed (laughs) by the doctor, and then the third time I finally got diagnosed by another neurologist… So well, it doesn't go away … like the medication is supposed to make the symptoms or make life a bit more easier, but that's not the case…

Similarly, the other woman participant, Alissar, who was diagnosed back in 2009 tackled the doctors’ treatment of women with anti-depressants. Alissar shared:

> I was at school, I had an English class. I had a sudden aura, I didn’t know what’s the meaning of the thing that is happening to me …then I told my mom the same day, she took me to the doctor the first time after one week, and there he told me I had migraines, and he was the first one who gave me anti-depressant drugs that I think was ‘Zoloft’ or ‘Solotik’ (changes voice sarcastically)…

Alissar’s nonverbal cue that was resembled in changing her vocal tone was how she chose to pinpoint the fact that she has been prescribed anti-depressants ever since the beginning. In fact, 65% of the total of women respondents answered ‘yes’ to the statement ‘the doctors have prescribed anti-depressant among my first/second visit’ in the survey (figure 8).

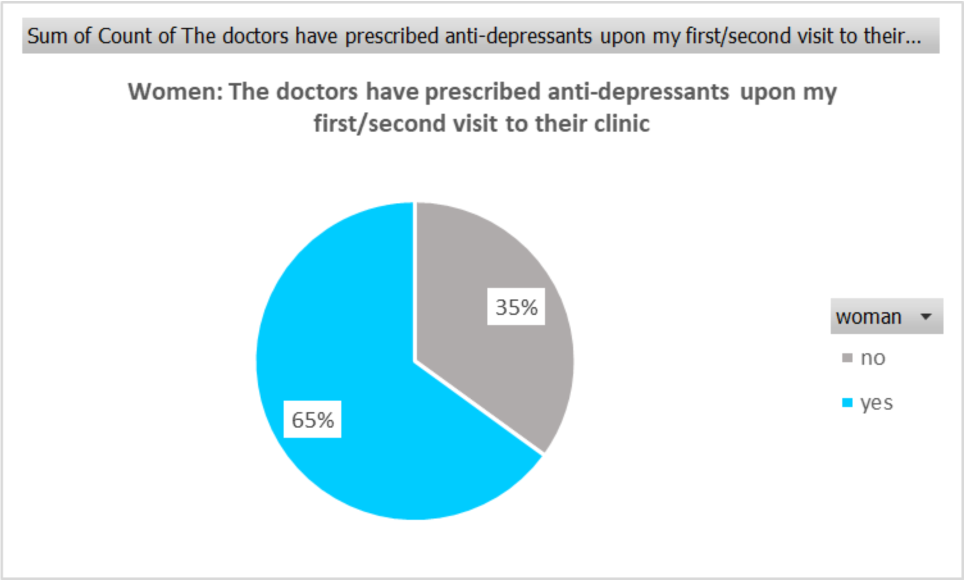

Figure 8

On the other hand, Flapjack and Mango did not mention the medical treatment of doctors towards them as men who have this invisible disability. Flapjack revealed that his migraine started when he was in grade 8, middle school. He said:

> …and then it started like once a month and it was unknown headaches, and then it got more severe, it got more frequent. By high school, by grade 11,12, it became debilitating, as the current form that I have. In Grade 11 I started to consult doctors until first year of uni...

Although Flapjack's brief introduction about his migraine journey does not portray a gendered experience in relation to medical doctors, it reflects a gendered narrative. His quote is proof that he did not quickly seek medical help when he had his first migraine, but rather 3-4 years after having recurrent episodes. In fact, according to the results of the survey, 75% of the men respondents usually consult the internet rather than their physicians or their family members first (figure 9) which showcases that men opt to postpone visiting a doctor for their migraine. This is also shown in Hunt et al.'s study titled *Do women consult more than men? A review of gender and consultation for back pain and headache* where they performed a narrative review of publications that examined men and women's doctor consultation patterns. They wrote that "none of the 11 publications suggested that men were *more* likely to consult for headache". (2011)

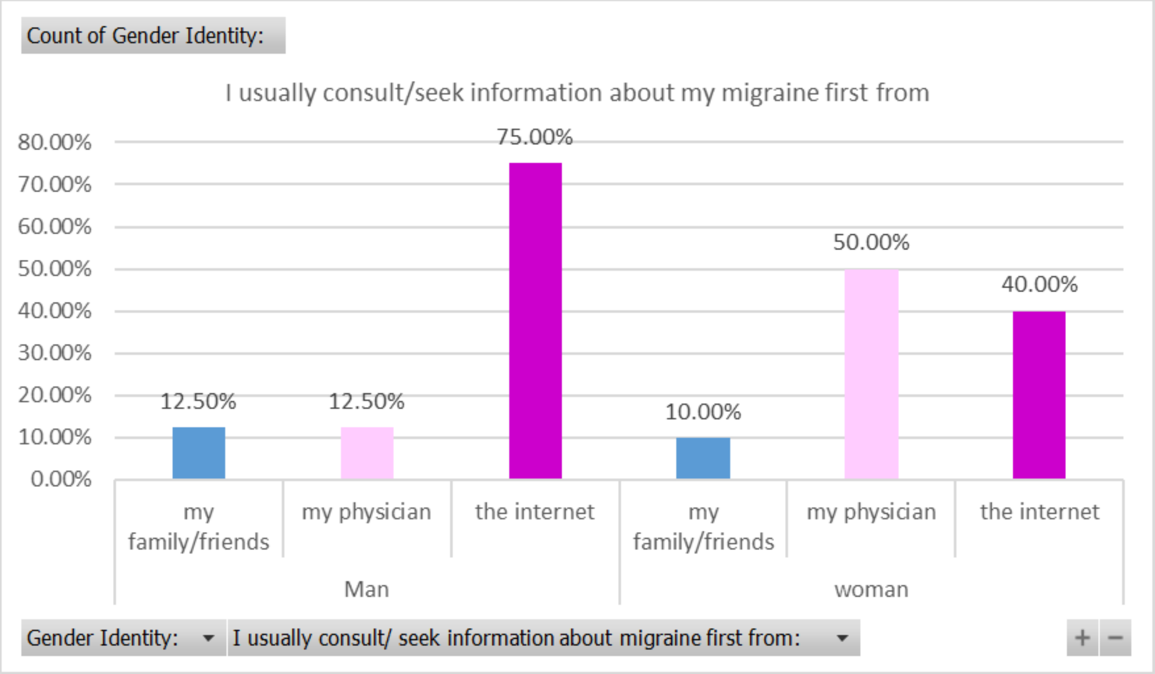

Figure 9

Mango chose to explain his migraine as hereditary, linking it to an incident that took place when he was nine years old.

> Basically it's by heredity we have it, migraine. My dad has it, my sister has it. And basically from both sides, my mom and dad. So they all have migraines, so I'm the one who's fits are the strongest… I was nine years. I was in grade 4 approximately and I had a sunstroke, the sun plays a huge role by the way in migraine…uff at that time I died…

Discussing his migraine as hereditary without mentioning his first doctor appointment foreshadows the fact that Mango only visited the family doctor once for his migraine. He depended on the fact that everyone in his family had migraines. Mango later shared that the family doctor asked for X-rays but he did not follow up with him. This could be viewed within the idea that several men avoid asking for help because it is considered less masculine to do so (Korn, 2017). A large number of men not only postpone seeking medical help, but some also avoid it altogether. Charmaz writes that "a man may take enormous risks with his health to remain active, independent, and dominant. At each turn, trying to maintain former identities may take more effort while potential social, psychological, and physical losses simultaneously multiply." (1994)

D.2 Women: Gender Stereotyping in the Medical Field

Although both men and women with disabilities are often marginalized, women with disabilities suffer more than men "from the demand that people have "ideal" bodies, because in patriarchal culture people judge women more…" (Wendell, 1989) Firstly, the women participants shared their experiences of having their migraines normalized and undermined by medical doctors because of their gender as women. This has been a recurrent theme in literature where women expressed having their invisible disabilities underestimated by medical physicians based on gender stereotypes and assumptions (Yee, 2013; Olkin et al., 2019). In fact, 60% of the women survey respondents agreed to the fact that they believe that being a woman puts more pressure on them than other gender identities in seeking help (figure 10) June shared a list of examples on how doctors underestimated her migraine, she said:

> When I first went to see a neurologist, when I was like maybe 10 or something. He just brushed it off…He told my mom that I just want attention and that this is why I'm overreacting. I've had a similar thing with another, you know, health professional, not just a neurologist. I have a heart condition … until eventually I was diagnosed with tachycardia which is not a stress-related thing.

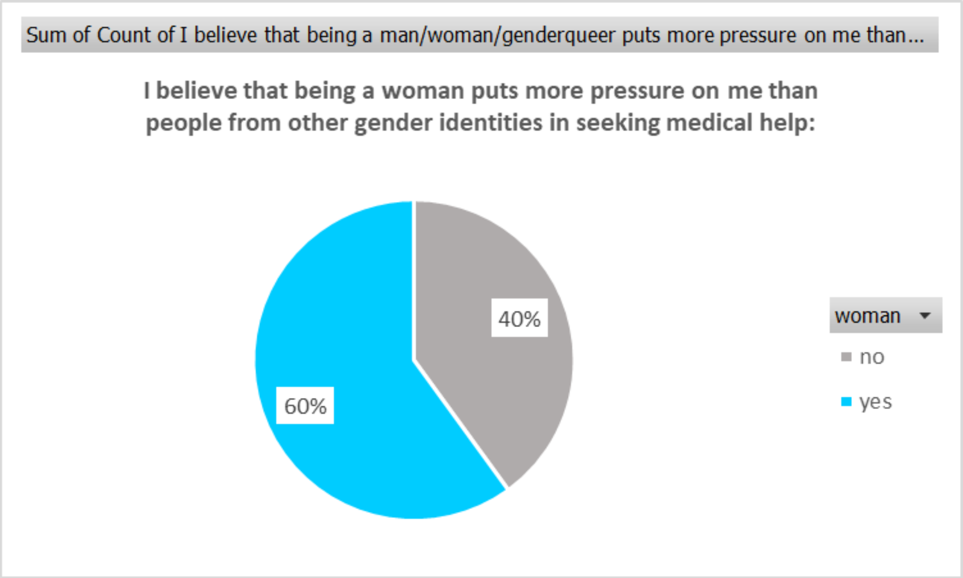

Figure 10

She also said about another doctor:

> The doctor told my mom that I was just, you know, being a drama queen (laughs) or something, so he dismissed me. The other doctor said that this is related to the sinuses and something like that which wasn't the case, and I was prescribed, well, medication for allergies (laughs) and for sinusitis and stuff like that, which also wasn't the case up until when I was at school.

In another excerpt she said: "…So basically my mom has migraines, my grandfather used to have migraines as well… which was supposed to make my diagnosis way easier (laughs). But of course, it didn't."

In these excerpts, June stated that the doctors she visited labelled her as a woman who 'wants attention', 'is overreacting', and 'is a drama queen' in response to her migraine experiences. A study done by Eriksson et al.[57] strongly supports this finding as the researchers conduct a literature review on doctors' gender biases in the treatment of male and female patients. Various studies that they found reveal that doctors employ the gender expectation of

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[57] <Accessed on 28 April 2023>

endurance to men because they are “tolerating pain, denying pain, and taking health risks even when they lead to increased pain…being autonomous, in control, avoiding seeking health care, not talking about pain, and avoiding talking about the possible relation between pain and psychic well-being.” (Eriksson et al., 2018) On the other hand, the study found that doctors view women “as more sensitive to pain and more willing to report pain than men” (Eriksson et al., 2018). Gaslighting and accusing women of over-exaggerating their pain has led June to seek one doctor after another, which resulted in wrong diagnoses, and eventually the extension of her journey with the disabling disease. Moreover, pinpointing the fact that she was not diagnosed with migraine sooner could be a reflection of doctors’ inattention to their patients’ background stories. Through the medical gaze, doctors tend to assign not only their previous knowledge of illnesses, diseases and disabilities onto the bodies of their patients, but also ascribe already innate gender stereotypes on the bodies of their female patients. As Kafer puts it: “medical beliefs and practices are not immune to or separate from cultural practices and ideologies.” (2013)

Alissar reported that doctors usually prescribed her antidepressants because she is a woman and is considered more prone to being emotional than men. She said: “You can say (started counting on her fingers) out of seven doctors, six told me to take antidepressant upon 1st visit.” Alissar also disclosed a very recent memory of a Lebanese doctor who underestimated her migraine pain. She shared:

> He's a professor. I went to him and there is a doctor sitting beside him. I told him I was so so much in pain. He told me (changes voice) ‘what do you have?’ like this. And his facial expressions didn’t make me feel comfortable. You look at him, you're not comforted because of him. He was like this. Like he knows better than anyone. I told him I had migraines, he said, ‘what migraines? There’s no such thing as

> migraines' and he looked at the doctor beside him and he said (changed voice) 'huh migraines.'

She continued:

> I told him (the neuro-surgeon) pain, 'okay', headache, 'how does it start?' … 'Ah okay. You know you have nothing. Take Cipralex' which is a very strong antidepressant. I told him give me muscle relaxant, something to help the triggers of the migraine (changes voice again) 'No, no, no. antidepressants. Cipralex, 10 milligram.' That's all without telling me like go sit in a green space, meditate or go have massage for these triggers… …You say this point is a trigger and this is a trigger. (changes voice) 'No no. We try our way, we try how we know'. I get frustrated and angry and. And I don't go anymore."

These short narratives reveal the different ways doctors underestimate women's pains, either through prescribing them with anti-depressants as the first course of action basing this on the assumptions that women are emotional beings, or disregarding their pain by hearing rather than listening to them.

Alissar, June and Flapjack all mentioned their mothers when narrating their experiences, whether it was for taking them to see a doctor, informing the school about their migraine, or even expressing their worry about their children's pain. This is similar to Olney et al's finding concerning their own participants where many of them "identified a specific woman—a mother, sister, aunt, wife, or girlfriend—who provided support to them." (2005) The following portrays that the caregivers are often women of the family, here specifically mothers, which resembles the society's reinforcement of the gender roles, considering women's care work as a normal act that is expected of them to do.

D.3 Men: A General Idea of Gender

The men participants in the study did not share specific personal experiences that reflect disenfranchisements they faced from medical doctors or from society at large for being men. A very interesting finding that was established is the fact that the men participants were unaware of the effect of their gender on their experiences of migraine. When asked about their experiences as men who experienced migraines, the following were their replies:

Flapjack said:

> I don't see myself in the lens of a guy. It's the first time I look at myself in the lens of a guy, as in how would they look at me with migraine?" and "I can't say from male (perspective) because I'm still the same person.

Mango also shared: "What do you mean exactly? You mean as gender wise? For example, when they tell us come on it's not that hard and stuff like that?"

> Researcher: Do they tell you this?
>
> Mango replied:
>
> …It's very rare for me to show that I am tired because as I told you I am someone who endures, you know? I continue my day normally until I reach my home and here that's it, this would be my weakest point uff I break down…Usually I'm someone who isn't the typical Eastern guy much. Even I have a gender focal point at work, I work in an international NGO. So I have a gender point. So I'm not an Eastern person and I'm not one of those masculine groups, so you know? So, how do I say it, I hear a lot of words but I don't care honestly I don't give a s*** what they say, what they do, so when my head is hurting, I wouldn't be in the mood of talking…

Similar to two male participants in Korn's (2017) study, Mango did not want to associate himself with the traditional definition of masculinity that he views as bad. However, he embodied particular traditional traits. Flapjack and Mango's replies to the question about their gendered experiences of migraine portray different answers from those provided by the women. At a time when the women participants readily expressed the relation between being a woman and their experiences of migraine and how they were treated by the medical doctors, the men in this study talked solely of their disabled identity, without being aware of their gender identity and how it affected their interactions with doctors. In light of this, I would like to discuss Kimmel et al.'s ideas on power and its visibility. Kimmel et al. write in the introduction of their book *Men's Lives* the following: "…men often think of themselves as genderless, as if gender did not matter in the daily experiences of our lives. Certainly, we can see the biological sex of individuals, but we rarely understand the ways in which gender – that complex of social meanings that is attached to biological sex – is enacted in our daily lives." (2010)

Therefore, the researcher decided to phrase the question differently, in a way where the male participants could share their perceptions of how people from their gender, as men, experience their migraines. While Flapjack and Mango did not feature a similar type of masculinity, they "expressed awareness of society's expectations of masculinity." (Korn, 2017) The conversations went as follows:

Researcher: So why do you think men don't talk about their migraines?

Flapjack answered: "In my case, I think because I would need people to take care of me… So imagine like those who are close to you seeing you just like that. Like super weak."

When asked whether migraine is hereditary, in his family, Flapjack replied*:*

> I have my uncle who experiences migraines. But I have no idea about how it goes with him. It feels like it's a mystery cause what we know is that he lives abroad. So when he used to come during the summers, if we know that he has migraine, just no one there visits him. That's all we know. And we didn't try to get into contact to

> know what medicine he uses or even he doesn't like to talk about it. I don't know, there’s this stigma about it. that’s about that from his side.

Flapjack shared the fact that personally, he did not talk about his migraine pain because it portrayed him as weak in front of others, especially those close to him. This, in fact, resembles Mango’s previous excerpt about not expressing his pain in front of others. Although each has his own reasons for not talking about how disabling migraine is, both showcase men’s tendency to hide their disability and pain in order not to seem weak. This goes hand in hand with Flapjack’s story about his uncle who never discussed his migraine with anyone. As Flapjack put it, the gendered experiences of migraine for men are a mystery. In fact, this is similar to what June said about men and migraine: “…I honestly don't know like except for my grandfather, I don't know anyone who's had migraine, a man that had migraine. I don't know why (laughs) I never met a man who had migraine…” In their studies, Valeras (2010) and Olney et al. (2005) presented male participants who, similar to the males in this study, were more concerned about hiding their disabilities from others around them than women were. “Hypervigilance of bodily performance and bodily appearance is common [around people with disabilities] but particularly those with an unapparent medical condition…” (Valeras, 2010) At a time when Valeras explains this from a disability and ableism point of view, I see this hypervigilance through the lens of an intersection between migraine disability and gender of being a man. The men in this study are engaging in preserving their masculinity. “In keeping their invisible disability hidden, participants maintained a sense of control over their image they projected to the world, helping them avoid further losses, and minimized feelings and experiences of stigmatization.” Korn (2017) Chronic illnesses and disabilities often threaten both men and women’s self-identities, however, they threaten “men's taken-for-granted masculine identities and lead to identity dilemmas that can reoccur again and again.” (Charmaz, 1994)

The researcher asked Mango: "… Do men go through this as well?" (having their pain underestimated)

Mango:

> Yes, yes, sure, sure. Sorry for my words but they say 'balā miḥin̊', 'kẖalaṣ̊ kẖifaⁿ̃ạ ʿalaẙnā' , and 'mā t̊kwn ktyr nāʿim̊'. Yes a lot a lot. If not for me, I'm pretty sure it is said to others…As in don't be this delicate and stuff and 'balā dalaʿ …

Mango on the other hand decided to provide examples of what he perceived as gender biased phrases that he thinks many men often are told in case they expressed their pain. However, he kept reinstating the point that such phrases do not bother him because he does not care. Kimmel et al. (2010) also shed light on the idea that similar to femininities, we cannot define masculinity as a singular term, rather we "must examine masculinities; the ways in which different men construct different versions of masculinity." In the context of the men participants in this study, Flapjack and Mango do not share one type of masculinity, because masculinity differs from one person to another and through one time to another. In addition to this, intersectionality has great impact on how men experience their masculinities. Mango's answers differed from Flapjack's in the sense that they reflected what some of the men in Olney et al's study portrayed and that is "talk[ing] in more performance-oriented terms. They discussed what they were good at and, on the surface, came across as more confident. These men put a positive spin on their failures and weaknesses". (2005) Perhaps this could be also understood in terms of reflexivity by looking at the relation between the men participants and I, a woman researcher. In a study titled *Issues of Gender, Reflexivity and Positionality in the Field of Disability Researching Visual Impairment in an Arab Society* by Ahmed et al., the authors shed light on the importance of taking the cultural and social context into consideration when conducting research in the Arab world. Perceptions of gender in the Arab world differ from those of Western societies, in Lebanon like in

Bahrain, “being a female researcher may encourage female interviewees to be more open as they may assume shared assumptions and experiences (Riessman, 1994)” (Ahmed et al., 2010) whereas men, such as in Mango’s case, might not identify with or feel comfortable enough to share their own experiences, especially if these experiences include feelings of stigma or shame.

D.4 Gender Expectations

Through their multiple narratives, most participants shared stories about the gendered expectations that society has of them as men and women who experience an invisible disability. Unlike able-bodied people who face the obstacle of conforming to gender expectations of them, men and women with disabilities face an additional obstacle that is fitting into the normative able-bodied expectations.

The women participants provided concrete examples of how they felt they were somehow not fulfilling sociocultural expectations of being a female (Michelle Jean Yee, 2013). In Lebanon, stories about men with disabilities or illnesses getting married are more accepted than those about women with disabilities, and that is due to the gender expectations of what a Lebanese woman is supposed to do in the household. Alshammari writes that “disabled women fail to maintain Middle Eastern society’s ideal image of womanhood, (married, mothers, able to balance between work and family) and as such, their quality of life is affected…Women are expected to reproduce, take care of children, to carry multiple burdens. If a woman is disabled, her ability to be a caretaker is questioned. This social stigma further destroys one’s self-image and ability to function in society.” (2018)

Alissar shared how her family discussed her love life as a woman which was entangled with the fact that she experienced migraine. If a society considers it a necessity to a woman’s ‘normal’ role to be a wife, then a woman with migraine is not to disclose information about her disability to the men she meets. Alissar explained:

> Some words from my family are ‘if you have a guy in your life, don't tell him you have migraines.’ For me it’s the other way around. I have to tell him. They say that the guy will say ‘I don't need her’, that ‘she has migraines’…In their imagination, the woman should be a perfect woman. But I don't think all guys think that way… They should understand what you are going through...

According to a study done by Olkin et al., this is a type of microaggression which they called “desexualization”. It is when people with disabilities have their sexuality denied and their value as a partner minimized. The women in Olkin et al.’s study discussed similar experiences as Alissar where they were desexualized due to their disability. Olkin et al. writes: “over two thirds indicated experiencing desexualization on the Disability Microaggressions Scale, with one third indicating it happened often or very often, and almost 75% finding it bothersome or very bothersome.” (2019) When it comes to being in a relationship, women with disabilities are often met with a range of stereotypes. Alissar’s family warned her from telling her partner about her migraine, as they believed a man would not be willing to marry a woman who is disabled or ill, equalizing disability to dependability and the incapability of taking care of herself. Also, women with disabilities are often viewed as asexual, thus misconceptions that strip them away of their intimacy and relationships arise. Such stereotypes of women with disabilities are built on ableist assumptions of the perfect woman, entrenched with gender roles and expectations.

On another note, Alissar shared that the positive aspect of her migraine is portrayed in the way it allows her to conform to the society’s ideas of thinness and beauty. Once asked to elaborate, she said:

> Cause when I eat, I feel regret and remorse because I get fat. So I can not wear my outfits, and mom keeps taunting me, that I am fat. I ask her sometimes why she hates fatness and she says 'I was thin when I gave birth to you.'

This could be explained through the standards of beauty that have been passed down from the mother to her daughter. In fact, "maternal control in weight management is associated with higher levels of body dissatisfaction among daughters, whereas maternal autonomy support in weight management is associated with lower levels of body dissatisfaction." (Shao et al., 2023) Women have always been expected to have fit, if not thin bodies, and these expectations are internalized by many of them. A Lebanese-based study found "striking gender differences in ''trying to lose weight,'' especially among those with normal weight, [which] suggest that thinness is becoming more desired in Arab society" especially among women more than men. (Khawaja & Soweid, 2004) Hence, Alissar considered her invisible ability as enabling her to follow the visible beauty standards imposed on women in the Lebanese society.

June discussed similar expectations from the society concerning her productivity as a working woman. She elaborated:

> … it's like we're supposed to tolerate any kind of pain. You know, we're just expected to do that. If it were a man, they would be like, (changes voice sarcastically) 'oh no, he has a migraine and he can't function.' And I'm like yeah, I can't function either (laughs), but why do you expect me to be productive and all of that and you wouldn't expect a man to be as productive. So it's just like the standards are not equal for work performance you know.

June's explanation of how her pain was perceived in comparison to her male colleagues could be seen as the result of either one of two views: women can endure pregnancy pain thus they can endure all pains or women are so fragile that they cannot endure any pain. As

(Sheppard, 2018)[58] states: “women are cast as capable of enduring more pain (as assigned female bodies have the capacity to go through childbirth) but also as being more inclined to complain about minor pains and as tending towards hysteria (Bendelow, 1993; Hoffman and Tarzian, 2001). Men, on the other hand, are cast as more stoic and less inclined to complain but also less capable of enduring pain (Bendelow, 1993).”

In addition to this, June talked about the societal expectations of her to be talkative and friendly even when she is experiencing migraine pain, because she is a woman. As such, people around June are practicing both ableist and gender stereotypes.

June said:

> And if let's say that I'm a bit, you know, I'm not going to use the word angry, but let's say that it's just a very severe migraine and I'm just like, not in the mood to talk to someone or like to be social or anything like I would be expected, you know, to put on the brave face and the sociable, the very talkative girl face. But for a man it would just be like, (changes voice into male voice) ‘he’s having a headache.’

The fact that June did not want to use the word angry to express her emotions reflects her fears of being called emotional and over-reacting the same way the medical doctors called her before. Also, June recalled once when a doctor claimed that being a woman, she should know better to live with pain. She said:

> I've had a physician as well tell me that I should be used to it because you know we get our periods every month and there are cramps and we should be used to this kind of pain. But like no, I don't want to be. No, they kind of equal being a woman to being in pain the entire time, no.

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[58] <Accessed on 2 December 2022>

Many doctors tend to relate women’s invisible disabilities to the biology of female bodies. Here, the doctor related June’s migraine to the fact that she gets menstrual cycles. Yee(2013) describes a similar assumption made by doctors concerning one participant’s diagnosis with Addison’s disease. Both doctors had a “default assumption” that these women had invisible disabilities due to their biology as females. Historically, women’s bodies were equated to inferiority with respect to men’s bodies. Beauvoir et al discuss this extensively in *The Second Sex* where she explains that it has been perceived that “a man’s body has meaning by itself, disregarding the body of the woman, whereas the woman’s body seems devoid of meaning without reference to the male. Man thinks himself without woman. Woman does not think herself without man…He is the Subject; he is the Absolute. She is the Other.” (2015) Therefor, women’s bodies are expected to have disabilities because they are perceived as the second inferior sex to men.

The researcher realized another interesting similarity between the two women and that is their resistance to and unacceptance of these ableist gender expectations. Alissar strongly expressed her disapproval of hiding her disability from her partners because she believed that her partner must be a supporter. Also, June condemned living her life with the idea that she should accept pain because she is a woman, she assertively says no to that.

In terms of gender expectations of men, Mango discussed this idea but in a broader sense rather than a personal experience. He said:

> “…Yes yes, maybe for men it’s even more annoying, for women it’s usually as they say she is ‘nạʿmi’ but when you’re a guy and in pain it becomes like iff you can’t express your feelings. It’s more annoying.

When the researcher asked what he meant by ‘more annoying’, Mango’s tone changed as if what he was about to say was obvious:

> I mean as anything, I mean our standards as men ‘you do not feel pain, nothing happens to you, you walk into a wall and break it down’. So imagine saying I’m in pain and being delicate and calm. Of course, it will annoy you because you aren’t a person who is in the box of the norms that they have created… but for someone who knows themselves and what they are, from my side I don’t care. If someone tells me this, I don’t care. (laughs)

Mango gave examples of how men experiencing pain are expected to behave within the gender norms by staying stoic. Once again, Mango reinstates the fact that he himself does not care about what other people think of him, but the men who do, as he says, definitely get annoyed for not being able to express their pain.

It is interesting that these findings about men and women participants are closely related to Olney et al.’s study findings. Olney et al. mentions that “women often revealed information about themselves in a personal way, whereas men were more likely to talk about their philosophies or worldviews.” (2005)

D.5 Thoughts/Expectations of the Other Gender

In an attempt to explore men and women’s thoughts on the other gender’s experiences of migraine, I asked the question “How does your experience differ from that of a man/woman with migraine?”

June shared:

> Funnily enough, I don't know if the statistics like if medicine was able to prove or like to show that mainly the women are affected, you know, like are suffering from migraines, way more than men are. I've never seen a man suffer from migraine. (laughs) I don't know.

Although June had previously used comparisons to showcase the inequality between how men and women with migraine are perceived, she acknowledged different reasons for why she hasn’t met a man who had migraines before. She continued: “… I don’t know if men actually dismiss their pain because you know I'm a tough guy and I'm not going to deal with that, or like they don't know that what they're having is migraines.”

Alissar speculated that men are also exposed to gender stereotyping. She said: “I think they tell them (men living with migraine) to man up. (changes voice) You're a man go jog, go to the gym, go out. (sarcastically)”. She also said that both men and women go through stress in their lives, but women have it worse. She reported:

> I think stress is stress whether you are a woman or a man…we (women) have more feelings … In my opinion, hormones interfere like in premenstrual cycle, you have your hormones going up and down. So stressed that you didn’t do it (the period) on your own, it comes on its own because you are a girl and you have premenstrual cycle… I also think lifestyle, family, all trigger the migraine of a woman. okay, it does affect men but I think women are affected more.

It is important to recall the fact that Alissar was a nurse and much of her knowledge came from the medical environment she worked in, which was also entrenched with gender biases. Therefore, Alissar related female sex hormones to experiencing more feelings leading to more stress for women than men. While discussing this, Alissar mentioned an essential point that reflects doctors’ gender bias towards women more than men. She stated:

> I know my cousin, he has migraines. He (the doctor) didn’t prescribe him medication quickly. He gave him muscle relaxants. He told him to sleep better. But no, he didn't give him antidepressants. It’s the same doctor I went to.

The same doctor who prescribed Alissar anti-depressants did not prescribe them to her male cousin. It is interesting to see how Alissar framed women’s menstruation as causing them a disadvantage due to what it entails in terms of hormonal changes and more stress for women. Mango, on the other hand, perceived women’s periods as an advantage to them. He said:

> … I've asked many people, men and women, so what I know is that women's symptoms are less than men because usually migraines often come from blood pressure, sometimes you'd have pressure which leads to pain. Usually, women have periodic cycles in their bodies so there isn't the same pressure of blood for men. I feel like men are more affected by migraine.

He further explained it:

> … even its duration as a migraine fit, it's not as much as us. For example, I experienced a migraine fit for 12 days continuously. So I asked more than one person, and none were this much, I mean like men…

In addition to this, Mango believed that experiencing migraine is more annoying for men because it is more acceptable for women to express pain. Mango explained that women are allowed to express their migraine pain more, considering the stereotype of being 'delicate/feminine' as another advantage to them, whereas stereotypes around men's masculinity stand in their way of expressing their pain.

Flapjack acknowledged women's experiences but also mentioned that he believed women to have more advantages. He said:

> It would differ I think maybe more support? friend support for the women. Maybe even more institutional support it. Generally, I don't want to discredit their experience, I think it's the same experience. I think it would just be, it's about the people around us who would be different and have different reactions, let's say. But of course, I think the symptoms would be just the same. Horrible nasty migraines.

E. Migraine Lessons

Although participants shared experiences of struggling with their migraines, most of them "also shared ways in which they viewed their disabilities or aspects of their disabilities more positively." (Korn, 2017) For instance, three participants discussed how migraine gave them a different and more positive perspective. Mango talked about his high endurance for other types of pain because he has been through migraine pain which he perceived as the worse, he said: “so sometimes when I’m in pain I say I have reached the extreme pain that is migraine, so I can endure other pains, so I can adapt to more pain.”

Flapjack shared the same ideas as Mango, he also discussed how the good thing about migraine is that it built some kind of strength in him. He said:

> Now I finished the exam and went out and discussed answers with the rest of the people, that I don't think any of them, not any of them of course … So it takes a lot (stressing on a lot) of energy and effort for me to do this, so hopefully a result comes out if it. So you feel like proud or a sense of achievement over a very small exam, maybe it would be trivial for others, but it took a lot of mental health from me to finish.

June also shared:

> …I always try to see the positive aspect of things. So like when I don't have a migraine, it helps me appreciate. You know when they say if you are in a good health, it's the most important thing. So it makes me appreciate that…when I don't have migraines I’m like, thank God, it's just that, and not something that could have been more chronic, more severe, more intense, you know? Like it makes me in a way appreciate or be thankful for the fact that I have medication… instead of it being some sort of rare, you know, unknown disease with no cure or something like that. So I'm trying like to find the word that's like the middle ground between ‘thank God it's not much more than that’, but at the same time you know, it's like your pain in the a**.

June’s migraine changed her mindset concerning her health, as she now has a positive perspective towards her health. Alissar mentioned that migraine has helped her know who her actual friends are, those “who stand by my side when in pain.”

F. Those who Understand Migraines

The participants faced several misunderstandings and marginalization from people around them, however, the women mentioned getting support from others around them.

F.1 Support from Others

In terms of support, women were the ones to discuss getting more care from those around them. This, in fact, came as a surprising finding dissimilar to Olney et al’s (2005) results in their study. Unlike their findings, female participants in this study received more support especially from their friends. Both Alissar and June shared similar experiences of having close friends understand their pain, even when these friends have not experienced migraines themselves.

Alissar said:

> Some of my friends, my old friends, used to lower this pressure on me. I'm gonna cry when I remember. Uh, they put me in a car, they take me out, they take me to green places… They used to (stresses on ‘used to’) listen to me.

Similarly June shared**:**

> The thing is that my very close circle of friends, they are also very understanding. They understand how it genuinely affects everything that I do. So I've never had a problem with my very close circle of friends …

Interestingly, the women also talked about the support of their previous partners.

June said:

> … My partner was a doctor. (laughs) So like he knows what a migraine is and how it can affect you know, your daily life activities, how it could like literally just drain

> you out of energy and all of that. So I never had a problem with that. Or like trying to explain this to him or like anything because you know…he was super understanding and I mean I've never had a problem with this in my relationship.

Alissar also shared about her previous partners: "Their reaction was good. And if I had a migraine attack, they helped me... they go and buy me medicine, and cold water."

These two excerpts provide interesting insight into the relationships of these women. In fact, the findings here are similar to those written by Yee (2013) who provided examples on how their female participants felt compassionately supported by their partners especially during the diagnostic periods of their invisible disabilities.

F.2 Others' First-hand Experiences of Migraine

Most participants realized that being a person with migraine allowed them to both understand and be understood by others who have also experienced migraine. Experiences of understanding migraine involved support from those around them, especially those who experience or have lived with the disabling disease themselves. In fact, for a society to decide whether a disability is considered a disability and whether it is its responsibility or that of the family to provide the resources to accommodate this disability depends on "whether the majority can identify with people who need the resource." (Wendell, 1989)

Both Mango and June's migraines were hereditary, which meant that the family members who experienced migraines understood their experiences of it. In their book, Kafer writes "those who have been most vocal in imagining my future as ripe with opportunities have been other disabled people, who are themselves resisting negative interpretations of their futures." (2013)

Mango said: "So they (family) now knew I was like that. But it wasn't like a taboo thing as they say."

June also pointed out:

> I've already said that before, in my family, we have a history of migraines. So, like my parents were, I don't know if the verb accepting suits my situation here because they know what it's like. Like my dad knows because my mom has migraines. My mom herself, you know, she's just like me, so we haven't had any misunderstandings about it at home.

June also shared her experience of being understood at the workplace. She pinpointed the fact that her boss became aware of the disabling influence of migraine after experiencing them themselves. Hence, before experiencing migraine, her boss was looking at the world through the eyes of an able-bodied person. She said:

> They understand actually for one reason, actually two reasons. First, we've had a coworker in the past who also suffers from migraines. And before my boss became, you know, the boss, she was working closely with this person who had migraines, who still has migraines. So she knows. She experienced it first hand and how, her performance changed etcetera. And because she wasn't a boss back then, she was more understanding of it. So, she could wrap her head around it. I think this helped a lot. And the second thing is it happened very recently … She texted me … and she was like,' oh my God, I've had a migraine all day long, and I haven't been able to get out of bed. How do you do this?' … I wouldn't want you to experience that, but I'm glad because you know (laughs) it's really impeding in a way, I mean migraine. Like a weekend or so, she's been very understanding…

June also highlighted the correlation between power and understanding disability when she discussed the fact that her boss became more understanding after experiencing migraine herself. This is apparent in another study by Kattari et al. where one of the participants shared that once she was diagnosed with disabilities, she had more empathy towards other people with invisible disabilities during her position as a disability examiner for the state. (2018)

Flapjack also shared: "… Most of the instructors were (more understanding) the females ones maybe because they also said they have experienced migraines too…"

These findings are similar to the ones from Gurley-Green's study about the perceptions of students with chronic migraines and professors of the accommodation. Gurley-Green writes: "The findings of this study suggest that if professors have more information about the diagnosis and/or illness impacts, they might be more understanding and more willing to accommodate." (2021)

F.3 People with Migraine Supporting People with Migraine

The two participants Mango and Flapjack demonstrated their support of others who have experienced the disabling disease. Mango explained that nobody actually knew what a person with migraine is going through, unless they experienced the pain. He said: "when someone tells me they have migraine, I give them an exception because it's something that is really not easy."

As a demonstration of this, Mango provided an example of his work colleague who also experienced migraines. He said:

> We have the same symptoms the both of us. When he gets a migraine fit, I take up most of the work pressure to reduce his, and try to support him, and when I get a fit I usually don't talk but he understands if I told him 'Uff my head is starting to hurt.' So we understand this, maybe this is helpful.

A strong bond has been created between Mango and his colleague, which developed into a kind of work ethics and strategy that ensured their productivity as a team in the workplace. The other participant, Flapjack, showed his support of people with disabilities through his interaction with the researcher. After Flapjack explained the severity of his migraine, the researcher wanted to build rapport with him. The conversation went as follows:

> Researcher: Sorry to hear that
>
> Flapjack: It sounds so nasty. No? (laughs)
>
> Researcher: No absolutely, I haven't been personally through it. But I've seen my mom and my sister go through it, which is really really hard, yeah…But I have another condition, a digestive problem. So for example, I can't go out without having my little medicine kit with me, you know. If I want to eat anything I need to take a pill that helps me digest it because without it, it hurts. (Flapjack seemed concerned)
>
> Flapjack: I think this is the perfect thing for **us** (ushering and the researcher then himself), which is I wish I reach your level as to take care of myself and know the medicines to know the right combinations of things and factors that will avoid situations with migraines.
>
> Researcher: Yeah, makes sense. The thing about me is that we know it's digestive and it's related to food, you know, so it's easy for me to be like, you know, I should stop eating burgers and fast food. I should start eating veggies. Migraines are much harder, I acknowledge that. There are a lot of triggers for migraine. There are different types of migraine. Yeah.
>
> Flapjack: Yea but it goes like some people are like "ah one has the components" so really you don't know what to eat, what to do.

In this excerpt, Flapjack felt that both the researcher and him shared some form of connection to diseases that are disabling, hence he used the inclusive first-person plural pronoun 'us' which induced a sense of rapport and unity between him and the researcher. Even when the researcher was acknowledging the fact that migraine is more disabling and even harder than her own disabling disease, Flapjack did not want to undermine her experience of her disabling digestive disease. This showcases a form of connection that people with disabilities might feel with each other even if the disabilities were different.

G. Putting their Foot Down

Although migraine has been disabling to the participants, many of them expressed their unacceptance of following what the society tries to label them with. For instance, when Alissar talked about her previous partners, she stated that: “if he doesn't understand, ‘allh mau’.” Alissar’s words reflected her disapproval of settling for someone who would not understand her migraine episodes. June shared a similar view of friends who are not willing to understand why she cancelled plans:

> And I'm genuinely not interested in, you know, like explaining myself or making them understand. Like, if you wanna understand, welcome. It's fine, it's great. But if you don't wanna understand that if you don't want to see things from my perspective, I'm not interested in making that effort to see it.

Flapjack said that he has recently stopped having the stigma of migraine because he has already suffered too much for him to even care. He stated: “If others want to understand what it means to have migraines, they can open Google and can try to relate, I’m not there to be a compass.”

CHAPTER FIVE

CONCLUSION

5.1 Reflection

After conducting interviews with June, Alissar, Flapjack, and Mango, I realized the importance of this study which was articulated through the ways the participants responded to it. Almost all participants expressed the need to be listened to and understood which was apparent through the texts they sent via WhatsApp in order to update me about their migraines, how they are feeling, and their views on migraine, or even to inform me of the importance of having consecutive interviews. I realized that many of them wanted to be heard, and I, or perhaps my WhatsApp platform, somehow took the form of a diary for the participants to keep track of their migraine, what triggers it, and any new experiences related to it. Hence, I figured it would be valuable to propose an online migraine diary that allows people with the invisible disability to document their experiences, and perhaps even links members of the migraine community to each other. This could help reduce feelings of marginalization and exclusion, and people with migraine could have a safe space to share their experiences. In fact, writing about one's own disability could be a form of a 'companion text' which Alshammari explains is a term coined by Sara Ahmed, borrowed from Donna Haraway, "a text whose company enabled you to proceed on a path less trodden. Such texts might spark a moment of revelation … they might share a feeling or give you resources to make sense of something beyond your grasp'". (2018) Such narratives seek to oppose the grand medical narrative of disability and to focus on people's stories of their migraines from their own perspectives. By collecting people's experiences, narratives, and memories of their disabilities on this online platform, a form of solidarity is born, not one that speaks in the name of all disabilities but rather one that inspires people to openly express their experiences. Alshammari encourages the “unveiling of the wounded storyteller’s voice, not concealing it, but rather calling attention to it, labeling it.” (2018)

5.2 Participants’ Recommendations

The recommendations in this section are informed by the participants’ insights and feedback. By incorporating their recommendations, this research aims to amplify the voices of people with migraine and center their needs and experiences. All the participants expressed the need to be listened to, whether by family members, friends, or even strangers. Due to the various negative encounters that they have had with those around them, many of the participants discussed the need for educating people about migraine in order to understand and accept them. The participants talked about the ways people around them would not take the time to listen, and instead accuse them of lying or exaggerating their pain. Some participants even felt stereotyped as they explained how they were often viewed as lazy, unproductive, or even intellectually lower than able-bodied people because of their migraines. Hence, awareness about migraine is necessary to be provided if not by medical institutions, by Lebanese health and disability NGOs. One of the things that all the participants shared was the difficulty of continuing their every-day activities due to severe pain. Hence, institutions, such as workplaces and academic organizations, should be equipped with proper accommodations tailored to people’s needs. Some participants even discussed the importance of having task-based rather than time-based duties. For many of the participants, time seemed to escape from them whenever they had responsibilities that they could not fulfill due to migraine. Thus, a task-based approach is preferred for people who experience migraine, and disabilities in general, because it allows them to focus on completing tasks without having to stick to specific deadlines in case they had chronic migraine episodes. In institutions like schools for instance, “there should be a focus on both supporting students to disclose in an illness-affirming way and bolstering faculty development and awareness about disability justice and ableism.” Gurley-Green (2021) Medical institutions must also acknowledge the disabling effects of migraine, and ask more questions about the patient’s life to get better insight into the factors that might trigger their migraines including patients’ financials, environments, triggers, lifestyles, partners, jobs, and previous lab tests. The women participants shed light mainly on recommendations for medical doctors which entailed recognizing the experiences of women with migraine and acknowledging that they are not superhuman creatures who are supposed to endure pain. Also, doctors need to shed aside gender stereotypes when treating patients with migraine, especially women.

5.3 Recommendations for Future Research

Although this study has provided valuable insight into the experiences of women and men with migraine as an invisible disability, future research would do well to expand on and build upon these findings. There is a need to explore the way migraine is experienced by people from different gender identities and sexual minorities and to expand outside the gender dichotomy of man and woman because research has shown that gender minorities experience ‘minority stress’ which often is a trigger for migraine.(Pace et al., 2021) Another recommendation for future research would be a more disability-centered approach where questions about migraine focus on migraine as a disability to investigate the people with migraine’s perspectives of passing as able-bodied in the Lebanese culture. Perhaps surveys with an increased number of people experiencing migraines could help generalize the results of this study. More studies are needed to examine the relations not only between disability and gender, but also other factors as well such as socio-economic status, race, ethnicity, and religion especially since Lebanon is a sectarian country which might provide results unique to this area. In addition to this, research that takes into account other people's perceptions of migraine as a disability could provide more insight into the friends, family members, and even disability NGO's perceptions of migraine to further understand the cultural ideas surrounding disability. It would also be interesting to conduct research on medical physicians' views and perspectives of what disability is, and their knowledge about invisible disabilities like migraine.

5.4 Conclusion

Based on the research conducted in this thesis, it can be concluded that migraine is an invisible disability indeed, that hinders people's lives. Despite these disabling effects, several friends, families, and even doctors tend to underestimate migraine either by normalizing it, avoiding it, or deeming the person with the disability as untrustworthy. People with migraine often find themselves stereotyped as lazy and unproductive. The experiences of people living with migraine showcase intersections between disability, power and gender. Through these narratives, this thesis highlighted how one's gender affects their experiences of migraine, especially in light of society's gendered expectations of men and women. Finally, this thesis provided a glimpse of the way people with migraine spoke out, and the shortcomings of the government and institutions in providing the necessary sources and accommodations for people living with migraine.

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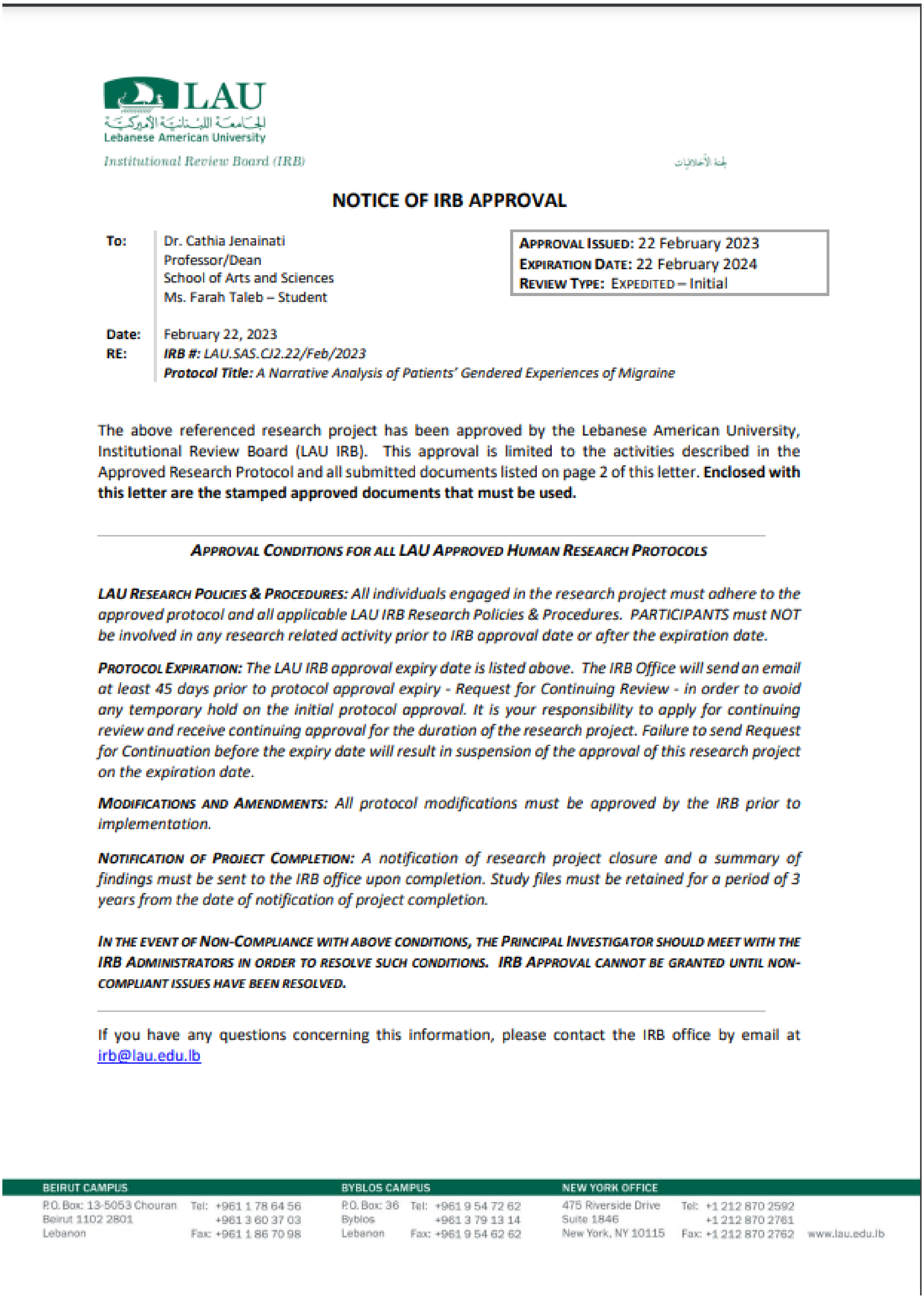
APPENDICES

APPENDIX A : IRB APPROVAL OF RESEARCH



LAU
الجامعة اللبنانية الأميركية
Lebanese American University

Institutional Review Board (IRB) لجنة الأخلاقيات

NOTICE OF IRB APPROVAL

To:
Dr. Cathia Jenainati
Professor/Dean
School of Arts and Sciences
Ms. Farah Taleb – Student

Approval Issued: 22 February 2023
Expiration Date: 22 February 2024
Review Type: Expedited – Initial

Date: February 22, 2023
RE: ***IRB #:*** *LAU.SAS.CJ2.22/Feb/2023*
Protocol Title: *A Narrative Analysis of Patients' Gendered Experiences of Migraine*

The above referenced research project has been approved by the Lebanese American University, Institutional Review Board (LAU IRB). This approval is limited to the activities described in the Approved Research Protocol and all submitted documents listed on page 2 of this letter. **Enclosed with this letter are the stamped approved documents that must be used.**

APPROVAL CONDITIONS FOR ALL LAU APPROVED HUMAN RESEARCH PROTOCOLS

LAU RESEARCH POLICIES & PROCEDURES: *All individuals engaged in the research project must adhere to the approved protocol and all applicable LAU IRB Research Policies & Procedures. PARTICIPANTS must NOT be involved in any research related activity prior to IRB approval date or after the expiration date.*

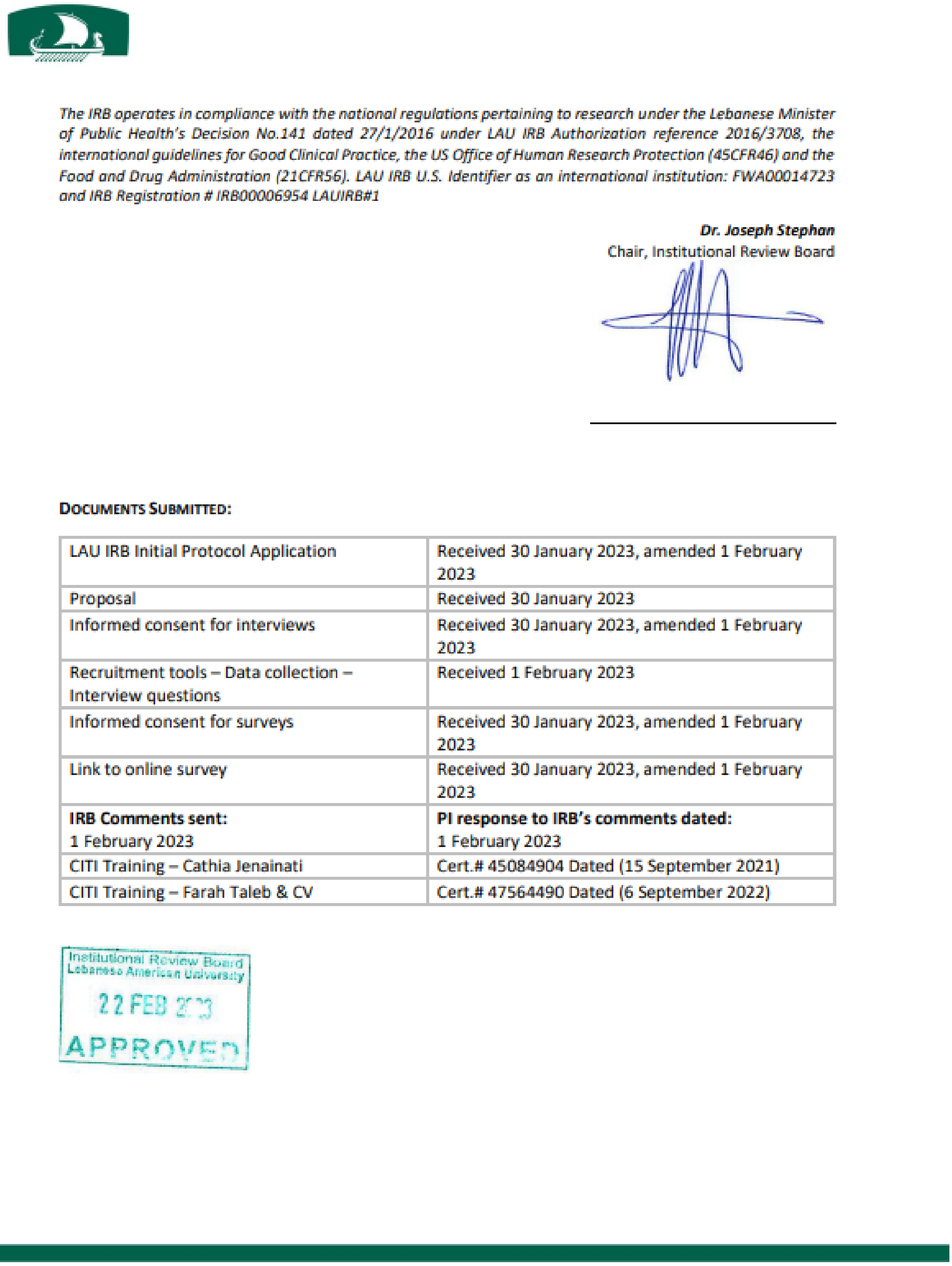
PROTOCOL EXPIRATION: *The LAU IRB approval expiry date is listed above. The IRB Office will send an email at least 45 days prior to protocol approval expiry - Request for Continuing Review - in order to avoid any temporary hold on the initial protocol approval. It is your responsibility to apply for continuing review and receive continuing approval for the duration of the research project. Failure to send Request for Continuation before the expiry date will result in suspension of the approval of this research project on the expiration date.*

MODIFICATIONS AND AMENDMENTS: *All protocol modifications must be approved by the IRB prior to implementation.*

NOTIFICATION OF PROJECT COMPLETION: *A notification of research project closure and a summary of findings must be sent to the IRB office upon completion. Study files must be retained for a period of 3 years from the date of notification of project completion.*

IN THE EVENT OF NON-COMPLIANCE WITH ABOVE CONDITIONS, THE PRINCIPAL INVESTIGATOR SHOULD MEET WITH THE IRB ADMINISTRATORS IN ORDER TO RESOLVE SUCH CONDITIONS. IRB APPROVAL CANNOT BE GRANTED UNTIL NON-COMPLIANT ISSUES HAVE BEEN RESOLVED.

If you have any questions concerning this information, please contact the IRB office by email at irb@lau.edu.lb



The IRB operates in compliance with the national regulations pertaining to research under the Lebanese Minister of Public Health's Decision No.141 dated 27/1/2016 under LAU IRB Authorization reference 2016/3708, the international guidelines for Good Clinical Practice, the US Office of Human Research Protection (45CFR46) and the Food and Drug Administration (21CFR56). LAU IRB U.S. Identifier as an international institution: FWA00014723 and IRB Registration # IRB00006954 LAUIRB#1

Dr. Joseph Stephan
Chair, Institutional Review Board

DOCUMENTS SUBMITTED:

LAU IRB Initial Protocol Application	Received 30 January 2023, amended 1 February 2023
Proposal	Received 30 January 2023
Informed consent for interviews	Received 30 January 2023, amended 1 February 2023
Recruitment tools – Data collection – Interview questions	Received 1 February 2023
Informed consent for surveys	Received 30 January 2023, amended 1 February 2023
Link to online survey	Received 30 January 2023, amended 1 February 2023
IRB Comments sent: 1 February 2023	**PI response to IRB's comments dated:** 1 February 2023
CITI Training – Cathia Jenainati	Cert.# 45084904 Dated (15 September 2021)
CITI Training – Farah Taleb & CV	Cert.# 47564490 Dated (6 September 2022)

Institutional Review Board
Lebanese American University
22 FEB 2023
APPROVED

APPENDIX B : INTERVIEW POSTER

LAU
الجامعة اللبنانية الأميركية
Lebanese American University

“Alice trod the path of a wonderland well known to her creator”

Did you know that Lewis Carroll was inspired by his experiences of migraines when he wrote Alice in Wonderland?

WHAT ABOUT YOU?
DO YOU SUFFER FROM MIGRAINES?

Participate in my Research to voice out your concerns!

Participants will be asked to volunteer in **one-on-one interviews** related to their experiences with migraine, gender, and health.

Who can Participate?

(All these conditions should apply)

- Individuals who have been diagnosed with migraine
- Residents of Lebanon who are attending/have attended a doctor’s clinic in Lebanon about their migraine
- Males - Females - Gender Queer people are welcome
- Aged 18 or over

Questions? Contact me on:
farah.talib@lau.edu

Institutional Review Board
Lebanese American University
23 FEB 2023
APPROVED

APPENDIX C : SURVEY POSTER

LAU
الجامعة اللبنانية الأميركية
Lebanese American University

“Alice trod the path of a wonderland well known to her creator”

Did you know that Lewis Carroll was inspired by his experiences of migraines when he wrote Alice in Wonderland?

WHAT ABOUT YOU?
DO YOU SUFFER FROM MIGRAINES?

Scan the QR Code or copy the link:
https://forms.gle/x3SKX5A
and Participate in my Research to voice out your concerns!

Who can Participate?

(All these conditions should apply)

- Individuals who have been diagnosed with migraine
- Residents of Lebanon who are attending/have attended a doctor’s clinic in Lebanon about their migraine
- Males - Females - Gender Queer people are welcome
- Aged 18 or over

Questions? Contact me on:
farah.talib@lau.edu

Institutional Review Board
Lebanese American University
28 FEB 2023
APPROVED

APPENDIX D : INTERVIEW QUESTIONS

1- Could you tell me about your migraine journey from when it started?

2- Could you tell me about a time when you felt stigmatized or marginalized as a man/woman with migraine?

3- How has migraine affected your mental health? Your physical health?

4- How has migraine affected your every day life?

5- How have your interpersonal relations been affected by migraine? Friends / family / partner(s) / work colleagues and boss / people in general?

6- How do you think your experience as a man/woman with migraine differ from that of a man/woman?

7- What medication have you taken? What medication are you on now? Have you ever self-medicated? What do you think about alternative medication?

8- What recommendations do you have for the society around you as a man/woman with migraine?

9- Describe migraine in 3-5 words or expressions.

10- What would you like to tell the society around you as a person who experiences migraine?

11- Do you think of migraine as a disability?

APPENDIX E : SURVEY QUESTIONS

A Narrative Analysis of Patients’ Gendered Experiences of Migraine

للاستبيان باللغة العربية, اضغط هنا

A Questionnaire for Patients

I would like to invite you to participate in a research project by completing the *

following questionnaire. I am a student at the Lebanese American University and I am completing this research project as part of my Masters Thesis in Interdisciplinary Gender Studies. The purpose of this questionnaire is to investigate the ways in which patients’ gender identities (man/woman/queer) and the existing gender norms that are present around them affect their experiences of migraine.

There are no known risks, harms or discomforts associated with this study beyond those encountered in normal daily life.

The information you provide will be used to fill gaps in the literature pertaining to gender, migraine, and medical health practices in Lebanon. Your experience as a (male/female/genderqueer) patient who lives with migraine can contribute much to our understanding of local health knowledge and behaviors.

You will not directly benefit from participation in this study. The study will involve 3040 participants. Completing the survey will take about ***10-15 minutes*** *of your time.*

Who can participate?

- Individuals who have been diagnosed with migraine

- Residents of Lebanon who are attending/have attended a doctor’s clinic in Lebanon about their migraine

-Males - Females - Gender Queer people are welcome

- Aged 18 or over

Participation is voluntary. There are no negative consequences for not participating or for withdrawing from the study. All your responses will be kept anonymous and confidential within reasonable limits. Only those directly involved with this project will have access to the data.

By continuing with the questionnaire, you agree with the following statements:

1. *I have been given sufficient information about this research project.*

2. *I understand that my answers will not be released to anyone and my identity will remain anonymous. My name will not be written on the questionnaire nor be kept in any other records.*

3. *When the results of the study are reported, I will not be identified by name or any other information that could be used to infer my identity. Only researchers will have access to view any data collected during this research however data cannot be linked to me.*

4. *I understand that I may withdraw from this research any time I wish and that I have the right to skip any question I don’t want to answer.*

5. *I understand that my refusal to participate will not result in any penalty or loss of benefits to which I otherwise am entitled to.*

6. *I have been informed that the research abides by all commonly acknowledged ethical codes and that the research project has been reviewed and approved by the Institutional Review Board at the Lebanese American University*

7. *I understand that if I have any additional questions, I can ask the research team listed below.*

8. *I have read and understood all statements on this form.*

9. *I voluntarily agree to take part in this research project by completing the following questionnaire.*

If you have any questions, you may contact:

Name (PI): Farah Taleb

Email address: farah.talib@lau.edu

If you have any questions about your rights as a participant in this study, or you want to talk to someone outside the research, please contact the:

Institutional Review Board Office,

Lebanese American University

3rd Floor, Dorm A, Byblos
Campus Tel: 00 961 1 786456
ext. (2546) irb@lau.edu.lb

This study has been reviewed and approved by the LAU IRB

IRB tracking number: LAU.SAS.CJ2.22/Feb/2023

1. ☐ I agree to participate in this questionnaire

2. Educational Background: *

☐Primary education

☐Secondary education

☐Higher education

☐Not in formal education

3. Employment Status: *

☐Full time

☐Part time

☐Retired

☐Unemployed

☐Unable to work due to health problem

☐Student

☐Stay-at-home parent Other:

4. Residing in a: *

☐City

☐Village

5. Do you have a partner(s)? *

☐Yes

☐No

6. Do you have any children? *

☐Yes

☐No

II. The Migraine Disability Assessment Test (MIDAS)

This section is optional

Know the severity of your migraines:

“In 1999, Stewart and Lipton developed the Migraine Disability Assessment Questionnaire (MIDAS), a 5-item questionnaire designed to evaluate disability within the most recent 3 months.” (Peng & Wang, 2012) The following MIDAS questionnaire was taken from the Innovative Medical Research 1997 and aims to measure the impact of your migraine on your everyday life. The information in this test "is also helpful for your primary care provider to determine the level of pain and disability caused by your headaches and to find the best treatment for you."

Instructions:

Please answer the following questions about **ALL** of the headaches you have had over the **last 3 months**. Select the most appropriate answer next to each question. Select zero if you did not have the activity in the last 3 months.

1) On how many days in the last 3 months did you **miss work or school** because of your headaches?

____

2) How many days in the last 3 months was **your productivity at work or school reduced by half or more** because of your headaches? (Do not include days you counted in question 1 where you missed work or school.)

____

3) On how many days in the last 3 months did you **not do household work (such as housework, home repairs and maintenance, shopping, caring for children and relatives)** because of your headaches?

____

4) How many days in the last 3 months was your **productivity in household work reduced by half or more because of your headaches?** (Do not include days you counted in question 3 where you did not do household work.)

____

5) On how many days in the last 3 months did you **miss family, social or leisure activities** because of your headaches?

____

Result:

After you have filled out this questionnaire, **add the total number of days** from questions 1-5.

Based on the total score, you have:

☐0-5 Little or no disability

☐6-10 Mild disability

☐11-20 Moderate disability

☐21+ Severe disability

III. Perception of Migraine and Self-image:

6) My migraine makes me feel: *

☐ weak

☐strong

7) My family has a history of migraine (hereditary) *

☐Yes

☐No

8) I usually consult/ seek information about migraine **first** from: *

☐the internet

☐my family/friends

☐my physician

9) I believe that being a man/woman/genderqueer puts more pressure on me than* people from other gender identities in seeking medical help:

☐Yes

☐No

10) Provide explanation if possible:

11) My migraines started at the age of: *

☐<25

☐26-30

☐31-40

☐41-50

☐50<

IV. Gendered Experiences of Healthcare Encounters:

Answer the following regarding your visits to doctors about your migraines

12) I have had at least one bad experience with a doctor because I am a * man/woman/gender queer

☐Yes

☐No

13) Being a man/woman/genderqueer at the doctor’s clinic makes me feel nervous *

Not nervous Very nervous

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

14) Provide explanation if possible:

15) I often feel judged by the medical staff, nurses, and/or doctors because I * am a man/woman/gender queer seeking help

Not judged at all Extremely judged

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

16) I often do not follow up with my doctor concerning my migraines because I do not * feel safe or comfortable as a man/woman/genderqueer revisiting the clinic

☐Yes

☐No

17) I usually go to the clinic *

☐alone

☐with a trusted person

18) I have previously completed the MIDAS questionnaire, or any other Migraine questionnaire similar to the one above at a doctor's clinic *Mark only one oval.*

☐Yes

☐No

19) The doctors ask about my gender during consultations (in documents or verbally) *

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

20) The doctors often assume my gender based on my apparent sex *

☐Yes

☐No

21) The doctors often say comments about how I can not handle migraine pain/I am weak because I am a female

☐Yes

☐No

☐Not applicable

22) The doctors often say comments about how I can handle migraine pain/I am * strong because I am a male

☐Yes

☐No

☐Not applicable

23) The doctors explain in detail the cause(s) of my migraines *

Not at all All the time

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

24) The doctors ask for additional tests before prescribing medication *

Not at all All the time

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

25) The doctors have prescribed anti-depressants upon my first/second visit to their Clinic*

☐ Yes

☐No

26) The doctors describe the side effects of the migraine medication *

Not at all All the time

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

27) The doctors prescribe alternatives to pills before prescribing the pills such as *
alternative treatments (acupuncture…)

Not nervous Very nervous

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

28) I often speak up if I were unhappy with the doctors' results *

Not nervous Very nervous

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

V. Migraine and Management/Medication:

39. Currently I am on the treatment of: *

☐Pain relievers

☐Triptans

☐Anti-depressants

☐I stopped taking the medication for reasons other than being cured

☐I am cured

☐Other:

40. I have faced **obstacles** in acquiring medication and/or treatment for my migraine due to my **gender identity/expression**. *

☐Yes

☐No

41. I have faced **advantages** in acquiring medication and/or treatment for my migraine due to my **gender identity/expression** *

☐Yes

☐No

42. I have faced **obstacles** in acquiring medication and/or treatment for my migraine due to **my apparent sex** *

☐Yes

☒No

43. I have faced **advantages** in acquiring medication and/or treatment for my migraine due to **my apparent sex** *

☐Yes

☐No

44. I have been self-medicating *

☐Yes

☐No

45. I would consider going to see an alternative specialist for my migraines * (acupuncture / homeopathy...)

☐Yes

☐No

46. I can not go outside my home unless I am equipped with the medication for a * migraine breakout

☐Yes

☐No

47. I know what triggers my migraine so I try to avoid it *

VI. Migraine and Everyday Life:

48. My migraine affects my participation in every-day life activities *

Not nervous Very nervous

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

49. I often cancel plans with friends/family due to my sudden migraine attacks *

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

50. I have lost jobs due to my migraine*

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

51. I express that I am in pain around my friends and family*

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

52. I feel ashamed of expressing my migraine pain around strangers *

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

53. My friends and family underestimate my migraine pain *

Never Often

1 2 3 4 5

☐ ☐ ☐ ☐ ☐

VII. Depth of Knowledge about Migraine:

54. I feel like I know enough about my migraine *

☐Yes

☐No

55. I believe that taking my gender into consideration could help doctors explain the triggers of my migraine *

☐Yes

☐No

56. I have realized that the following factor(s) trigger my migraine *

☐Stress

☐Sex hormonal changes

☐Childhood trauma

☐Weather changes

☐Insufficient sleep

☐Odors

☐Neck pain

☐Alcohol

☐Exercise

☐Sexual
Activity

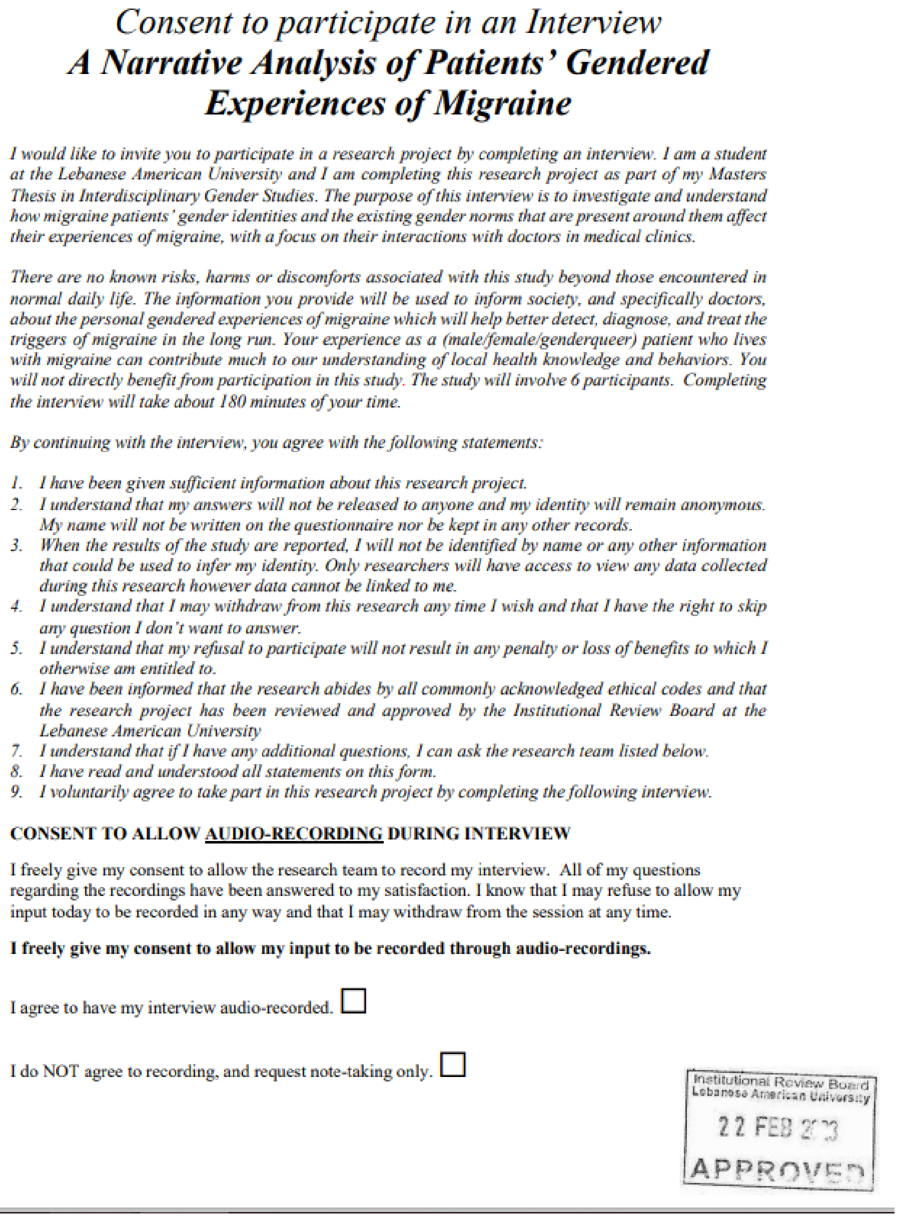
☐Skipping
meals

☐Other:

Oher comments that you would like to share which you have not discussed above

If you would you like to participate in a one-on-one interview and share your gendered experiences of migraine, kindly contact me on farah.talib@lau.edu or +96171103695

APPENDIX F : CONSENT SHEET



Consent to participate in an Interview

A Narrative Analysis of Patients' Gendered Experiences of Migraine

I would like to invite you to participate in a research project by completing an interview. I am a student at the Lebanese American University and I am completing this research project as part of my Masters Thesis in Interdisciplinary Gender Studies. The purpose of this interview is to investigate and understand how migraine patients' gender identities and the existing gender norms that are present around them affect their experiences of migraine, with a focus on their interactions with doctors in medical clinics.

There are no known risks, harms or discomforts associated with this study beyond those encountered in normal daily life. The information you provide will be used to inform society, and specifically doctors, about the personal gendered experiences of migraine which will help better detect, diagnose, and treat the triggers of migraine in the long run. Your experience as a (male/female/genderqueer) patient who lives with migraine can contribute much to our understanding of local health knowledge and behaviors. You will not directly benefit from participation in this study. The study will involve 6 participants. Completing the interview will take about 180 minutes of your time.

By continuing with the interview, you agree with the following statements:

1. *I have been given sufficient information about this research project.*
2. *I understand that my answers will not be released to anyone and my identity will remain anonymous. My name will not be written on the questionnaire nor be kept in any other records.*
3. *When the results of the study are reported, I will not be identified by name or any other information that could be used to infer my identity. Only researchers will have access to view any data collected during this research however data cannot be linked to me.*
4. *I understand that I may withdraw from this research any time I wish and that I have the right to skip any question I don't want to answer.*
5. *I understand that my refusal to participate will not result in any penalty or loss of benefits to which I otherwise am entitled to.*
6. *I have been informed that the research abides by all commonly acknowledged ethical codes and that the research project has been reviewed and approved by the Institutional Review Board at the Lebanese American University*
7. *I understand that if I have any additional questions, I can ask the research team listed below.*
8. *I have read and understood all statements on this form.*
9. *I voluntarily agree to take part in this research project by completing the following interview.*

CONSENT TO ALLOW <u>AUDIO-RECORDING</u> DURING INTERVIEW

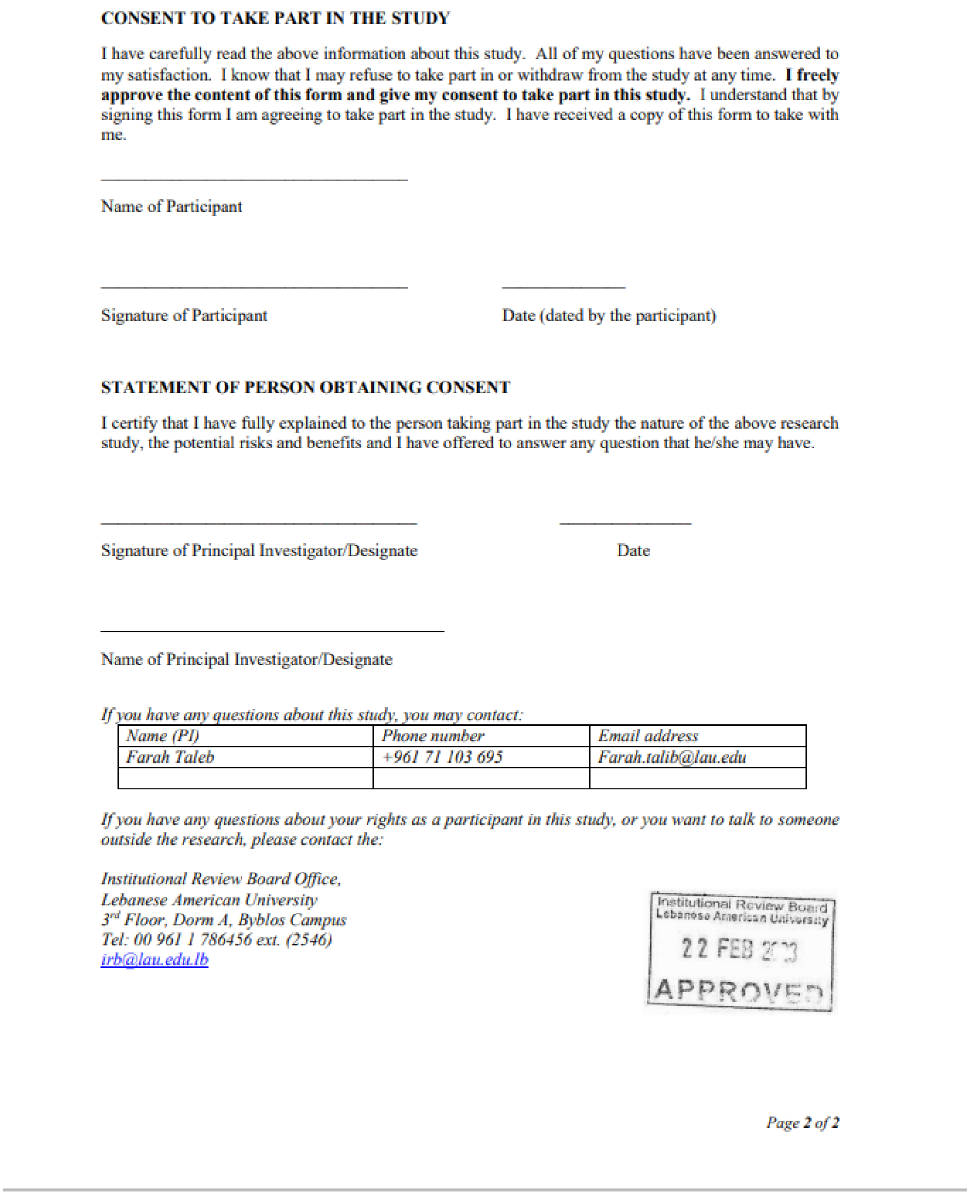
I freely give my consent to allow the research team to record my interview. All of my questions regarding the recordings have been answered to my satisfaction. I know that I may refuse to allow my input today to be recorded in any way and that I may withdraw from the session at any time.

I freely give my consent to allow my input to be recorded through audio-recordings.

I agree to have my interview audio-recorded. ☐

I do NOT agree to recording, and request note-taking only. ☐

Institutional Review Board
Lebanese American University
22 FEB 2023
APPROVED



CONSENT TO TAKE PART IN THE STUDY

I have carefully read the above information about this study. All of my questions have been answered to my satisfaction. I know that I may refuse to take part in or withdraw from the study at any time. **I freely approve the content of this form and give my consent to take part in this study.** I understand that by signing this form I am agreeing to take part in the study. I have received a copy of this form to take with me.

____

Name of Participant

____________________________________ ______________

Signature of Participant Date (dated by the participant)

STATEMENT OF PERSON OBTAINING CONSENT

I certify that I have fully explained to the person taking part in the study the nature of the above research study, the potential risks and benefits and I have offered to answer any question that he/she may have.

_____________________________________ _______________

Signature of Principal Investigator/Designate Date

____

Name of Principal Investigator/Designate

If you have any questions about this study, you may contact:

Name (PI)	*Phone number*	*Email address*
Farah Taleb	*+961 71 103 695*	*Farah.talib@lau.edu*

If you have any questions about your rights as a participant in this study, or you want to talk to someone outside the research, please contact the:

Institutional Review Board Office,
Lebanese American University
3rd Floor, Dorm A, Byblos Campus
Tel: 00 961 1 786456 ext. (2546)
irb@lau.edu.lb

Institutional Review Board
Lebanese American University
22 FEB 2013
APPROVED