Abstract

Injustice, Quality of Life, and Psychiatric Symptoms in People with Migraine

Objective: To describe and examine the relationships between perceived injustice, quality of life and psychiatric symptoms through a mixed method study design in people with migraine.

Participants and Methods: A total of 127 participants who met criteria for current migraine completed the Injustice Experience Questionnaire (IEQ), Migraine Disability Assessment (MIDAS), Migraine Specific Quality of Life Questionnaire (MSQL), Allodynia Symptom Checklist-12 questionnaire (ASC-12), PROMIS Anxiety Short-Form (PROMIS-A), and the PROMIS Depression Short-Form (PROMIS-D) for the for the quantitative component of the study. From the scores of the IEQ, 10 participants, stratified by low and high IEQ scores took part in phenomenological interviews for the qualitative component of the study.

Results: A Person's product-moment correlation revealed higher IEQ scores were strongly associated with lower quality of life (QoL; *r* = -. 676, p < .001). Higher scores on the IEQ were related to higher migraine attack frequency (*r* =.403, p < .001) and migraine pain intensity (*r* = .352, p < .001). There was no association between the IEQ and reports of nausea/vomiting during migraine (*r* = .110, p = .220). Higher levels of perceived injustice on the IEQ were associated with a higher report of allodynia symptoms (*r* = .281, p < .001). Participants who reported a migraine with aura in the past year (n = 84/127, 66.1%) reported higher IEQ scores (M = 23.4, SD = 11.4) than people with no aura in the past year (n= 43/127, 33.9%; M = 18.6, SD = 10.2; t(125) = -2.34, *p* = .02). Two Pearson's product-moment correlations and two hierarchical linear regressions assessed the relationship between (a) IEQ and PROMIS-A, and (b) IEQ and PROMIS-D. Higher IEQ scores were associated with higher PROMIS-A (*r* = .447, p < .001) and

PROMIS-D scores ($r = .495$, $p < .001$). The IEQ was able to statistically significantly predict an additional 21.2% of the variance in PROMIS-A scores $F(1, 122) = 16.43$, $p < .001$, adjusted $R^2 = .186$, $\beta = .387$, $p < .001$. Finally, the IEQ was able to statistically significantly predict an additional 25.1% of the variance in PROMIS-D scores $F(1, 122) = 23.19$, $p < .001$, adjusted $R^2 = .226$, $\beta = .448$, $p < .001$. For the qualitative results, the phenomenological interviews resulted in a set of 4 core themes describing perceived injustice and QoL with migraine: coping, loss, illness burden, and misunderstood. All of the study participants (N=10) endorsed these themes in some capacity regardless of belonging to the high or low IEQ group.

Conclusion: Higher levels of perceived injustice showed lower levels of QoL, was associated with higher headache frequency and headache attack severity, and higher rates of depressive and anxiety symptoms. People who experience migraine described their quality of life similarly, regardless of whether they reported high or low levels of perceived injustice. This knowledge could provide beneficial information to specifically target psychological treatment and prepare a multidisciplinary team for the consequences of how patients with migraine are affected. Specifically, this study provided information about psychosocial factors that contribute to poor QoL in people with migraine and provide guidance for behavioral treatment development.

Injustice, Quality of Life, and Psychiatric Symptoms in People with Migraine

By

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Dedication

To my parents and siblings, thank you for being my greatest cheerleaders throughout every step of my life. Dad and Mom, you taught me to never settle and to always chart a path so I could reach all my hopes and dreams. Thank you for helping me navigate every step and hurdle on my journey. Matthew, Katie, and Jenna, your constant and unwavering support, along with your humor, has made me succeed. I could never ask for a better ‘Core 4’.

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Finally, this document is dedicated to all of the patients who advocate for advancements in the understanding and treatment of migraine and to the clinicians and researchers who continue to instill hope and strive to attain these lofty goals. In addition, for those who have ever been defined by others based on challenges they face, do not be afraid to break the mold, do the unexpected, and keep striving to reach your full potential.

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CHAPTER I

Background & Significance

Migraine is a prevalent, painful, neurological disorder associated with high levels of disability worldwide (Leonardi & Raggi, 2013; Lipton et al., 2007; Smitherman, Burch, Sheikh, & Loder, 2013). Migraine is a disabling and burdensome chronic condition causing attacks of moderate to severe head pain, nausea and/or vomiting, and sensitivity to light and/or sound (Burch et al., 2015; “Headache Classification Committee of the International Headache Society (IHS) The International Classification of Headache Disorders, 3rd Edition,” 2018; Smitherman, Burch, et al., 2013)’.

The 2017 Global Burden of Disease study reported that migraine is the second leading cause of disability worldwide (Institute for Health Metrics and Evaluation, 2018). The prevalence of migraine is high (Burch et al., 2015). Migraine has been found to affect 28 million Americans, accounting for approximately 18% of women and 6% of men in the United States which demonstrates a gender prevalence for females 3:1 compared to males (Buse, Manack, Serrano, Turkel, & Lipton, 2010; Lipton, Stewart, Diamond, Diamond, & Reed, 2001; Stewart, Lipton, Celentano, & Reed, 1992). This translates to an impact rate of approximately 1 out of every 7 Americans annually, and roughly 1 in every 4 women will experience migraine (Burch et al., 2015; Smitherman, Burch, et al., 2013). The onset of migraine typically presents with a peak during midlife age. (Buse et al., 2010; Smitherman, Burch, et al., 2013). Migraine and headache are leading causes of outpatient and emergency room visits and remain an important public health problem, particularly among women during their reproductive years (Burch et al., 2015).

Migraine often leads to negative repercussions within social situations and the workplace, which can result in substantial costs at both the individual and societal levels (Kolotylo &

Broome, 2000; Serrano et al., 2013; Smitherman, Burch, et al., 2013). Social costs are also attributed as a consequence of migraine, such as stigma, social withdrawal, and feeling like an outcast (Leonardi & Raggi, 2013; Leonardi, 2014; Young, Park, Tian, & Kempner, 2013). Moreover, Leonardi (2014) found that social difficulties were higher among patients with migraine than other neurological disorders, including epilepsy, stroke, multiple sclerosis or Parkinson's disease because of disease burden and stage of life (Leonardi, 2014). It is evident that compared with the aforementioned neurological disorders, migraine has onsets at a younger age and affects individuals who typically engage in active social and occupational situations. Migraine is a public-health concern given the associated disability and financial costs to society. Due to the fact that migraine is most burdensome in an individual’s typical productive years (late teens to 50s), there are massive personal and financial costs in both social and occupational that are greatly compromised (World Health Organization, 2013).

Background on Quality of Life (QoL) in People with Migraine

Quality of Life (QoL) is a multi-dimensional construct that explains individual’s subjective experience of life satisfaction, including the impact of an illness and treatment on patients’ perception of their status of health, coping mechanisms, life experiences, emotional support, and disease state (Guyatt et al., 2007; Opara et al., 2010). The construct of QoL contributes an understanding of the impact of a disease on an individual and can assist with informing proper clinical care and management (Guyatt et al., 2007). Viewing QoL holistically can be useful in understanding the impact of daily living, such as health status, symptom status (including emotional, cognitive, and physical symptoms), functional status, general health perceptions, and subjective well-being, and provide a framework for how patients are adapting with their conditions (Ferrans, 2005; Guyatt et al., 2007; Wilson & Cleary, 1995). This perspective will provide insight and account for the patient’s direct experience. It is important in the decision-making process relating to disease management and illustrates the manner in which researchers and practitioners can produce different information to evaluate the efficacy of treatment as it relates to enhancing QoL (Ferrans, 2005; Guyatt et al., 2007; Wilson & Cleary, 1995).

The episodic nature of migraine contributes to a disproportionate impact on QoL compared to other pain-based conditions. When individuals have migraine attacks, their recurring pain and associated symptoms often influence the patient’s ability to function productively (Abu Bakar et al., 2016). People with migraine may be able to function at very high levels during the time between attacks; however, during an attack, physical and occupational function is typically impacted and often debilitating. Higher migraine attack frequency, higher pain severity during migraine attacks, and the presence of associated symptoms have been associated with poorer QoL in people with migraine (D′Amico et al., 2015). Additionally, common migraine symptoms, such as nausea and vomiting, allodynia, and aura have been reported to negatively impact QoL in migraine patients (D’Amico et al., 2015; Malone et al., 2015). Many patients with migraine also experience reduced productivity at work and suffer lost wages and decreased efficiency due to absenteeism in addition to the disruption of their family, social, and leisure activities (Solomon & Santanello, 2000). Increasingly, researchers and clinicians are emphasizing the need for integrative treatment of migraine that includes a multidisciplinary approach to treating the whole person with a migraine disorder and improving their QoL (Kropp et al., 2017; Witteveen et al., 2017).

Given the high proportion of years lived in disability attributed to migraine research is warranted to evaluate and expand the understanding of how patient experiences of migraine influence QoL (Leonardi, 2014). In a study that examined the relationship of disease duration and the frequency of attacks with health-related quality of life in people with migraine (n = 106), the results showed no significant correlation with the duration of migraine and with the number of attacks in the aspects that were assessed related to health-related QoL (Vladetić et al., 2017). This may show that regardless of duration and frequency of migraine attacks, health-related QoL is affected. Further, people with migraine have reported to experience decreased physical functioning and encountered role limitations because of physical health problems, bodily pain, and social functioning which are all related to QoL (Aydemir et al., 2011).

Migraine and Psychological Symptoms

Migraine causes significant limitations in daily life and compromises psychological well-being (Antonaci et al., 2011; Buono et al., 2018; Louter et al., 2015). About 25% of people with migraine meet criteria for mood and anxiety disorders, however, an even greater number of individuals experience symptoms of mood and anxiety without meeting full criteria for a specific disorder (Corallo et al., 2015; Louter et al., 2015). Psychiatric comorbidities, such as mood and anxiety symptoms, have important implications since they worsens the clinical symptoms and increase the risk of chronicity, pain frequency, intensity and the rate of treatment failure in migraine patients (Antonaci et al., 2011; Louter et al., 2015).

Background on Depressive Symptoms in Migraine

Depression is a highly comorbid diagnosis in people with migraine, with incidence rates in approximate 35-40% of patients (Guillem et al., 1999; Torelli & D’Amico, 2004). Depression is one of the most common disorders encountered by mental health professionals (Barlow, 2014). According to the National Institute of Mental Health, depressive disorders are the leading cause of disability in the U.S. for ages 15 to 44.3 (National Institute of Mental Health, 2015a). In North

America, it is estimated that one in five individuals receive a diagnosis of depression at one point in their lives (Soucy Chartier & Provencher, 2013). The incremental economic burden of individuals with Major Depressive Disorder was $210.5 billion in 2010; 48-50% attributed to workplace costs, 45-47% attributed to direct costs, and 5% to suicide-related costs (Greenberg et al., 2015). The common feature of all depressive disorders is the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect an individual's capacity to function. However, depressive disorders differ with duration, timing, and etiology (American Psychiatric Association, 2013).

Previous research indicates that the relationship between migraine and depression is bidirectional, with migraine predicting first-onset depression and depression predicting first-onset migraine (Antonaci et al., 2011; N. Breslau et al., 2000; Torelli & D’Amico, 2004). Further, this bidirectional relationship impacts subsequent attacks and episodes (Torelli & D’Amico, 2004). Two possible explanations is that depression in individuals with migraine might be a psychological reaction to recurrent disabling headache attacks and migraine and major depression might share etiologic, genetic or environmental factors. Additionally, abnormalities related to the neurotransmitter serotonin have been suggested as a neurochemical basis for both migraine and for depression (Breslau et al., 2000). One study examining comorbid disorders in migraine patients (n = 2,907) found depression to be the most commonly reported comorbid condition representing 63.8% (n = 1,411) of participants in the sample (Malone et al., 2015). However, even individuals without a known and complete depression diagnosis often experience depressive symptoms (Sheftell & Atlas, 2002). For these reasons, it is important to measure depressive symptoms in people with migraine.

Individuals who experience migraine are two to four times more likely to have depressive symptoms than people without migraine (Hamelsky & Lipton, 2006; Seng & Seng, 2016). The presence of comorbid depression among people with migraine is associated with poorer QoL and higher healthcare cost (Breslau, Lipton, Stewart, Schultz, & Welch, 2003; Breslau et al., 2000; Lipton, Hamelsky, Kolodner, Steiner, & Stewart, 2000; Pesa & Lage, 2004). Moreover, signs of depression in chronic pain populations is associated with greater pain complaints and impairment, and they have significant decreases in physical, social, and role functioning (American Psychiatric Association, 2013; Bair et al., 2003; DeGood & Kiernan, 1996).

Since the course of migraine is unpredictable, the helplessness resulting from their uncontrollability can exacerbate depressive symptoms (Lantéri-Minet et al., 2005; Sheftell & Atlas, 2002). Symptomatology, such as sensory hypersensitivities, including allodynia, are associated with higher depressive symptoms and suicidality in people with migraine (Mendonça et al., 2016).

There is no current evidence that improved control of depressive symptoms help to control migraine attacks (Minen et al., 2016). However, it is important to identify and treat these symptoms in patients with migraine because it is a significant predictor of developing chronic migraine. In a longitudinal study examining the association between migraine and major depression in a sample of young adults ages 21-30 years old (n = 1,007) over a 3.5 year period, the estimated risk for first onset of major depression in individuals with prior history of migraine was approximately 3 times higher than in individuals with no prior history of migraine (Naomi Breslau et al., 1994). Moreover, the estimated risk for the first onset of migraine in individuals with prior history of major depression was also approximately 3 times higher than in individuals with no prior history of depressive symptoms (Naomi Breslau et al., 1994). The understanding of this relationship is important since it is anticipated that people with migraine who endure depressive symptoms are more likely to be less active from engaging in migraine treatments and endure medication overuse and overall disability (Minen et al., 2016; Peck et al., 2015).

Background on Anxiety Symptoms in Migraine

Anxiety has also been found to be an established comorbidity of chronic pain. Anxiety disorders are the most common mental illness in the United States. They affect approximately 40 million adults, age 18 and older, or 18.1% of the population every year in America, and are the most prevalent mental disorders and are associated with immense health care costs and a high burden of disease (American Psychiatric Association, 2013; Bandelow & Michaelis, 2015; National Institute of Mental Health, 2015b). Up to 33.7% of the population are affected by an anxiety disorder during their lifetime. Anxiety disorders are highly treatable yet only 36.9% of those struggling with anxiety will receive treatment (National Institute of Mental Health, 2015b). People with an anxiety disorder are three to five times more likely to go to the doctor and six times more likely to be hospitalized for psychiatric disorders than those who do not experience from anxiety disorders (National Institute of Mental Health, 2015b).

More frequent pain complaints and impairment are found in patients who exhibited anxiety symptoms. Moderate to severe pain is associated with greater anxiety symptoms and lower quality of life (Green et al., 2003). Therefore, since migraine is classified as a chronic pain condition, it is important to examine anxiety symptoms within this population.

Anxiety levels are higher among people with migraine when compared with the general population, with anxiety disorders having a prevalence of two to five times greater frequency patients with migraine (Baskin & Smitherman, 2009, 2009; Minen et al., 2016; Wacogne, Lacoste, Guillibert, Hugues, & Le Jeunne, 2003). More than half of all patients with migraine will meet the criteria for at least one anxiety disorder over the course of their lifetime, and even a greater percentage will experience anxiety symptomology (Minen et al., 2016). A study examining comorbid disorders in migraine patients (n = 2,907) found anxiety to be the second most commonly reported comorbid condition (following depression) representing 60.4% (n = 1,329) participants of the sample (Malone et al., 2015).

Anxiety symptoms and migraine share many clinical features. For example, both migraine and panic, a common anxiety symptom, are characterized as episodic events that exhibit recurrent attacks (i.e. head pain in migraine and autonomic dysregulation in panic disorder) and are associated with hypersensitivity to changes in the internal environment (Seng & Seng, 2016; Smitherman, Kolivas, et al., 2013). Interestingly, trauma during childhood has been associated with the presence of migraine compared to healthy controls and other headache types (Brennenstuhl & Fuller-Thomson, 2015; Seng & Seng, 2016). Managing and controlling anxiety of patients with migraine is associated with improved quality of life, adherence to a migraine treatment plan, and effectiveness of migraine treatment (Baskin et al., 2006; Minen et al., 2016).

Perceived Injustice

For some individuals with chronic pain, such as can be involved in people with migraine, these individuals may perceive or experience injustice and ascribe external blame for their circumstances (DeGood & Kiernan, 1996; Scott et al., 2014). This occurrence may lead to these individuals encountering a loss of function and identity which can impact their QoL and psychological symptoms (Scott et al., 2014).

The construct of injustice has a broad and expansive meaning including ensuing from acts or conditions that might cause someone to suffer hardship or loss undeservedly (Sullivan et al., 2008). An example of a specific type of injustice was that found when inspecting the perceptions of injustice on the trajectory of recovery following musculoskeletal injury. For the purposes of this study, Sullivan et al. (2008) guided the perspective of injustice to be one of a health and/or injury-related to be appropriate (Sullivan et al., 2008). Therefore, injustice is operationally defined as "an appraisal reflecting the severity and irreparability of injury or pain-related loss, blame, and unfairness" (Sullivan et al., 2008 p. 259, 2011, 2012; Trost et al., 2015). Perceptions of injustice can stimulate exaggerated physical and psychological outcomes, with greater levels of disability, dysfunction, and emotional distress, both after acute injury and in the context of chronic health conditions (Scott et al., 2014; Sturgeon et al., 2017; Trost et al., 2012). There is evidence that the experience of pain-related injustice adversely influences recovery among individuals with chronic pain (Scott et al., 2014). Moreover, elevated injustice perception includes greater self-reported pain and disability, higher pain levels, and poorer outcomes following treatment recommendations (Scott et al., 2013; M. J. L. Sullivan et al., 2009, 2012; Trost et al., 2016).

The unique features of migraine as an episodic, chronic, neurologic, painful condition warrants the exploration of patients perceived injustice in relation to quality of life, migraine symptoms, and psychological symptoms. The screening and assessment of comorbidities of migraine has been strongly emphasized in recent studies to aid in the overall care and quality of life of those impacted by the disease (Abu Bakar et al., 2016; Seng et al., 2017; Seng & Seng, 2016). The following sections review in detail the importance of understanding and assessing for quality of life, migraine symptoms, and psychological symptoms in order to comprehensively assess and understand the components that may impact perceived injustice in migraine patents.

Perceived Injustice and QoL

Studies have consistently find that individuals who endorse lower levels of responsibility or externalize blame for their life situations experience poorer mental and physical health outcome (DeGood & Kiernan, 1996). Therefore, there is support for the negative impact of perceived injustice and lower levels of QoL (Trost et al., 2015).

As a result of the occurrence of injustice being an aversive experience on an individual, this can drastically alter their QoL and life satisfaction. In the context of chronic pain, specifically migraine disorders, avoidance from these adverse experiences may be visible by a negative impact on their status of health, withdrawing from once pleasurable activities, maladaptive coping mechanisms, and other undesirable QoL influencers. It is also common for individuals to interpret pain itself as a source of injustice and an unfair circumstance (Green et al., 2003; Scott et al., 2014). An injustice experience may become particularly harmful when behavior aimed at avoiding this experience interferes with engagement in life activities that are valued by the individual. Conversely, individuals who continue to participate in valued life activities despite experiences of injustice and are able to maintain a perspective that is less overwhelmed by these experiences may be less negatively impacted. Therefore, unsuccessful attempts to solve the problem of pain-related injustice may contribute to further injustice experiences, greater dissatisfaction in QoL factors, leading individuals to disengage from activities that are important to them, thus engendering further suffering (Scott et al., 2014).

Perceived Injustice and Psychological Symptomology

Greater amounts of research have inspected components of depressive symptoms in relation with the perceived injustice construct; however, in comparison, studies examining anxiety symptoms have been scarce. Mood and anxiety symptoms have established comorbidity of chronic pain; moderate to severe pain is associated with greater depressive and anxiety symptoms and lower quality of life (Bair et al., 2003; DeGood & Kiernan, 1996; Green et al., 2003). It has been suggested that emotional-related perceptions of injustice might augment the negative emotional impact of adverse events (Scott & Sullivan, 2012).

Injustice-relevant constructs, such as unfairness and victimization, have been suggested to play a central role in the development of depressive and anxiety symptoms, thereby enhancing the negative emotional impact of adverse events and derogating the individuals' sense of self (Miller, 2001; Scott & Sullivan, 2012; Sheppard, 2002). Several studies have shown that perceptions of unfairness or injustice in the general population (not effected by a particular health condition) have been associated with greater depressive symptoms and increased severity (Tepper, 2001). Since this relationship has not been explored in the migraine population, in an examination of individuals with persistent musculoskeletal pain following injury, previous research indicates that perceived injustice is associated with heightened levels of depressive symptoms (Mikula et al., 1998; M. J. L. Sullivan et al., 2008). Additionally, perceived injustice appears to be associated with problematic health and mental health recovery trajectories after the initial onset of a pain condition (M. J. L. Sullivan et al., 2012).

With the knowledge that migraine produces pronounced amounts of pain that fluctuates with duration and intensity, examining individuals with chronic pain may provide an analogous experience and an useful comparison. Sturgeon, Ziadni, Trost, Darnall, & Mackey (2017) examined the direct effects of pain intensity, pain-related perceived injustice, and pain catastrophizing on life satisfaction in an Internet-based sample with chronic pain (n = 330). Findings of this study indicated that depressive symptoms fully mediated the relationship between pain catastrophizing and life satisfaction. Additionally, depressive symptoms significantly mediated the relationship between perceived injustice and life satisfaction.

However, different and more substantial than the other study variables, perceived injustice demonstrated a significant negative relationship with life satisfaction (Sturgeon et al., 2017). The inclusion of therapeutic techniques specifically targeting perceptions of injustice may enhance the effectiveness of interventions aimed at reducing symptoms of depression for individuals presenting with strong perceptions of injustice and increase life satisfaction (Scott & Sullivan, 2012).

Perceived Injustice in Relevant Clinical Populations

Although discussions of philosophical, social, and legal issues related to injustice have a long history of presence in literature, only recently have there been efforts to study the psychology of perceived injustice in the context of injury and pain (Miller, 2001; Sullivan et al., 2012). Multiple studies have sought out to examine the impact of perceived injustice in samples that experience chronic pain as well as samples with neurological conditions, but none have inspected migraine, specifically. Since these two distinct populations of those with chronic pain neurological disorders are analogous in many respects with patients who experience migraine, a complex review of the perceived injustice literature in these populations will be examined.

Perceived Injustice in Pain Samples

Pain is viewed as centralized through maladaptive responses within the central nervous system that can profoundly alter specific brain systems and behaviors (Borsook, 2012). Due to the intense and chronic nature that pain can impact an individual, multiple studies have previously examined its relationship with perceived injustice with several populations. In a qualitative research study (utilizing phenomenological analysis methods) examining the nature and construction of justice and injustice in chronic pain, individuals (n = 15) living with chronic pain participated in a three focus groups. Participants reported upper (e.g. head, neck), middle (e.g. hips, abdomen), lower (e.g. knees, ankles), and general full-body pain. The dominant themes that were observed was ‘seeking equality’, ‘battle for quality of life’ and that there is an ‘unfair advantage of others’ (McParland et al., 2011). This study concluded that individuals who report chronic pain prioritize justice-related issues in terms of what is dominant to their social concerns and personal needs. However, it was apparently clear that chronic pain emerged to be equally a social problem as it is a medical problem. Despite the fact that individuals in this study represented a range of socioeconomic areas and social backgrounds, they all described clear concerns with social judgements of worthiness and the perceived fairness of these judgements (McParland et al., 2011).

Individuals who have sustained debilitating whiplash injuries may experience tremendous amounts of pain, which is often chronic in nature (Myrtveit et al., 2016). In a prospective study of individuals with mixed musculoskeletal injuries (i.e. back sprain, whiplash), Sullivan et al (2008) reported that high scores on perceived injustice predicted work disability at 1-year follow-up (Sullivan et al., 2008). Perceived injustice predicted work disability even when controlling for initial pain severity, post-injury functional limitations, catastrophizing, depression, and pain-related fears (Sullivan et al., 2008, 2012). Similarly, in another study involving individuals who have sustained debilitating whiplash in rear-collision motor vehicle accidents (n = 85), the analyses revealed that individuals with high levels of perceived injustice displayed more protective pain behaviors than individuals with low levels of perceived injustice (Sullivan et al., 2009). The results of this study suggest that the relation between perceived injustice and pain behavior might underlie the high prevalence of occupational disability in individuals who have sustained whiplash injuries (Sullivan et al., 2009).

Comparative to individuals with migraine, patients with sickle cell disease have a lifelong illness with unpredictable, disabling, and severe pain complications. A pilot study examined the relationship of perceived injustice with perceived stress and pain in adults with sickle cell disease (n = 52). Findings from this study showed that perceived injustice was a significantly associated with perceived stress and pain (Ezenwa et al., 2015).

Recent research has shown that some individuals who experience physical injuries, such as musculoskeletal, perceive themselves as victims of injustice (M. J. L. Sullivan et al., 2008). Scott & Sullivan (2012) investigated the moderating role of perceived injustice on the relationship between pain and depressive symptoms in individuals with persistent musculoskeletal pain (n = 107). For individuals with migraine, since there is no medical test (i.e., blood test, magnetic resonance imaging (MRI), etc.) that can conclude abnormalities or an injury, the diagnosis of migraine is based upon the presentation of symptoms. This can be frustrating and add additional challenges for the individual attempting to achieve a proper diagnosis. The results of this study demonstrated that perceived injustice strengthened the relationship between pain severity and depressive symptoms (Scott & Sullivan, 2012).

Perceived Injustice in Neurological Conditions.

As a result of the lack of existing literature on how perceived injustice impacts patients with migraine, examining other neurological conditions is valuable. Similar to migraine, fibromyalgia is characterized as a neurological disorder in which pain is a hallmark symptom of the condition (Cassisi et al., 2014). Ferrari and Russell (2014) conducted a pilot study to compare levels of perceived injustice experienced in patients with fibromyalgia (n = 62) and rheumatoid arthritis (n = 64). These patients were recruited from two adult rheumatology practices in Alberta, Canada. Participants were asked to specify how much pain they had because of their condition over the past week using a Likert scale ranging from “no pain” to “worst pain imaginable", as well as complete the Injustice Experiences Questionnaire (IEQ) to measure injury-related perceptions of injustice (Ferrari & Russell, 2014). The findings of this study showed that fibromyalgia patients demonstrated higher levels of perceived injustice compared with the rheumatoid arthritis patients (Ferrari & Russell, 2014). Since the differences appeared to be associated with higher levels of pain reported by fibromyalgia patients, and therefore may not be specific to the diagnosis, it is applicable to a migraine population since they are both neurologic-pain disorders. In addition, rheumatoid arthritis has biomarkers for the diagnosis, which allow patients to better understand their condition. Fibromyalgia is similar to migraine in that it is based off a clinical diagnosis. To date, this is the only available study examining the relationship of a specific neurologic-pain disorder in association with perceptions of injustice.

Another population that shares common diagnostic and symptomatology to those with migraine and are viewed as neurologically impacted are people with traumatic brain injury. In a sample of individuals with mild traumatic brain injuries (n = 102), perceived injustice and its correlates were examined in patients who were slow to recover from mild traumatic brain injuries (Iverson et al., 2017). The results found that greater perceived injustice was associated with greater bodily pain, post-concussion symptoms, traumatic stress, depression, and negative expectations for recovery (Iverson et al., 2017).

RATIONALE/HYPOTHESES

This study aimed to understand how perceived injustice relates to quality of life, understand the relationship of perceived injustice on migraine symptoms, and examine how perceived injustice impacts mood and anxiety in people with migraine. This is the first study to evaluate the construct of injustice in migraine. This cross-sectional mixed methods study evaluated 127 people who met current criteria for migraine based on a validated screening tool.

Participants completed an online survey that will assist in describing their experience with migraine. Additionally, this study aimed to evaluate phenomenological interviews with 10 patients, stratified by low and high perceptions of injustice

The use of phenomenological interviewing described the 10 people with the highest and lowest injustice perceptions from the previous 127 participants who completed the online survey, evaluated the participant's perceptions about migraine, and described how migraine impacted their QoL and psychiatric symptoms.

Aim 1: To understand how perceived injustice relates to the quality of life (QoL) in patients with migraine (quantitative and qualitative).

- Hypothesis 1 (a): Patients with migraine will qualitatively describe variations in perceived injustice and articulate any impacts on QoL.
- Hypothesis 1 (b): Higher levels of perceived injustice will be quantitatively associated with lower levels of QoL in 1) zero-order relationships and 2) adjusting for relevant migraine symptoms.

Aim 2: To understand the relationship of perceived injustice on migraine symptoms (quantitative).

- Hypothesis 2 (a): Higher levels of perceived injustice will be associated with higher headache frequency, headache attack severity.
- Hypothesis 2 (b): Higher levels of perceived injustice will be associated with presence of associated symptoms in migraine, including 1) nausea/vomiting, 2) aura (transient sensory disturbances which occur prior to the pain of a migraine attack in approximately 20% of people with migraine), and 3) allodynia (a neurologic phenomenon when non-painful stimuli are perceived to be painful).

<u>Aim 3:</u> To examine how perceived injustice impacts mood and anxiety in migraine patients (quantitative).

- Hypothesis 3 (a): Higher levels of perceived injustice will be associated with higher rates of depressive and anxious symptoms in 1) zero-order relationships and 2) adjusting for relevant migraine symptoms.

<u>INNOVATION</u>

Perceptions of injustice are important patient experiences in other pain populations, and are risk factors for poor pain outcomes, higher pain severity, and poor quality of life (Scott & Sullivan, 2012; M. J. L. Sullivan et al., 2012; Trost et al., 2015; Waugh et al., 2014). Characterizing the patient experience of people with migraine can help us better understand the burden of this disorder.

This study provided novel information in several meaningful areas that currently lack research. 1) Despite the high rates of prevalence, disease burden, and cause of disability status of migraine, there have been no studies to date that have assessed the impact of perceived injustice on patients with migraine. Further, there have not been any studies inspecting chronic diseases that are characterized by episodic symptom attacks conducted with the construct of injustice and/or evaluating the perceptions of injustice. 2) Consequently, no study has evaluated the relationship between perceptions of injustice and migraine-related quality of life. 3) Given that perceived injustice is a belief system that can influence health behaviors, it might influence QoL, migraine symptoms, and psychiatric symptoms. To the author’s knowledge, this was the first study examining these factors through gathering both quantitatively and qualitative data. Having this knowledge could provide beneficial information in order to know how to specifically target psychological treatment and prepare a multidisciplinary team for the consequences of how patients are affected with migraine.

CHAPTER II

METHODS

Overview of the Design

This study was a multi-site, cross-sectional, mixed-method design which examined the association between injustice, quality of life (QoL), and psychiatric symptoms in individuals with migraine using a mixed methods approach. The study data was collected from the study titled “Patient Perspective on Migraine Experience” which was approved by the Albert Einstein College of Medicine Institutional Review Board (IRB # 2018-9564: PI: Dr. Elizabeth Seng). The following study includes a portion of the primary planned analyses.

Funding

Funding for this study was supported a Foundation for Rehabilitation Psychology Dissertation Award presented to Amanda Parker.

Quantitative Methods

Quantitative Participants and Recruitment

The study population included adult patients with migraine recruited via printed flyers across multiple tertiary care headache neurology clinics in the broader New York region distributed during the summer of 2019. Patients who identified as have been diagnosed with migraine by a healthcare provider and interested in study participation emailed the research coordinator (Amanda Parker) at the email listed on the flyer (Aparker2@mail.yu.edu) and sent a link to a complete the online survey. Additionally, Clinical Looking Glass (CLG) was used to recruit participants directly from the Montefiore Headache Center, a site in the Bronx, NY (*Clinical Looking Glass from Montefiore Medical Center*, 2002). The CLG system integrates clinical and administrative datasets to identify specific targeted patients. For this study, CLG was used to identify patients with the following criteria: 1) has seen a headache provider at the Montefiore Headache Center within the past year, 2) has been given a diagnosis of migraine, and 3) is 18 years old or older. After potential participants were identified, an IRB-approved email was sent to patients containing the link to complete the survey.

All participants who chose to participate were consented and enrolled by completing a single set of online surveys using Qualtrics, a secure data capture system. Figure 1 shows a recruitment study flow diagram for both quantitative and qualitative aspects of the study.

Quantitative Eligibility and Exclusion Criteria

Participant eligibility was determined by an online screen as a part of the Qualtrics survey. Inclusion criteria: Participants were included if they 1) reported symptoms consistent with a current International Classification of Headache Disorders – 3 beta diagnosis of migraine (using the AMS/AMPP screener, see measures section for details), 2) self-reported being diagnosed with migraine by a healthcare provider, 3) reported they were 18 years of age or older, and 4) reported they had capacity to consent for participation.

Exclusion criteria were 1) the participant does not speak English, and 2) the participant does not meet migraine diagnostic criteria as assessed by the AMS/AMPP screener.

Quantitative Procedure

Once participants accessed the survey within Qualtrics, they provided online informed consent. Participants interested in participating in the survey completed the AMPP diagnostic screen but the participant's whose screens did not indicate current migraine were excluded from the study during data analysis. Participant then completed a series of surveys via Qualtrics, which was designed to take approximately 20 minutes. All quantitative data was captured at a single time-point using Qualtrics. Participation was voluntary and the participants were given the option to discontinue participation at any time by closing their browser. As part of the study, after completing the online survey, participants were entered in a raffle to win one of 5 $150 gift cards. In May 2020, following the collection of all quantitative data, an online random lottery generator selected 5 participants at random who fully completed the survey to receive 1 of 5 $150 gift cards.

Quantitative Measures/Instruments

Measures were selected using materials from the National Institutes of Neurologic Disorders and Stroke (NINDS) Common Data Elements (CDE) initiative (*NINDS Common Data Elements*, n.d.). When possible, measures from the National Institutes of Health Patient Reported Outcome Measurement System (PROMIS) were selected.

Table 1 depicts an outline of the measures used during the present study and are embedded in a survey designed to last approximately 22-minutes (see Appendix A for full survey).

Demographics. NINDS CDEs were used to evaluate: Age; Gender; Ethnicity; Race; Sexual Orientation; Education Level; Marital/Partner Status; Employment Status; Household Income; Height and Weight; Overall Health; Medical History. Additionally, questions about comorbid conditions, current prescribed medication regimen, and treatment satisfaction were asked to acquire greater gain insight into associated circumstances that the individual is going through.

American Migraine Study/American Migraine Prevalence and Prevention (AMS/AMPP) Diagnostic Module. The AMS/AMPP Diagnostic Module (Lipton et al., 2007; Lipton, Stewart, Diamond, et al., 2001) is a survey based on the ICHD-2 criteria for migraine; migraine criteria remain unchanged in the updated ICHD-3b (Headache Classification

Committee of the International Headache Society (IHS), 2013). The sensitivity and specificity for migraine are 100% and 82% respectively by a neurologist diagnosis (R. B. Lipton, Stewart, Diamond, et al., 2001). This measure captured associated symptoms including nausea/vomiting and aura.

Allodynia Symptom Checklist-12 questionnaire (ASC-12). The ASC-12 (Lipton et al., 2008) is a 12-item self-report measure designed to evaluate the frequency of allodynia symptoms in association with headache attacks (Lipton et al., 2008). Individuals were instructed to answer the questions based on their most severe headache type. The ASC-12 questionnaire poses the question "How often do you experience increased pain or an unpleasant sensation on your skin during your most severe type of headache when you engage each of the following?" and states examples which include "wearing a necklace wearing earrings", "wearing glasses", "wearing tight clothes", "wearing a pony tail", "wearing contact lenses", "shaving the face", "taking a shower", "combing the hair", "resting the head on a pillow", "exposure to cold", and "exposure to heat". The response categories are "does not apply to me" (0 points), "never" (0 points), "rarely" (0 points), "less than half the time" (1 point) and "half the time or more" (2 points). ASC items are summed and yield scores that range from 0 to 24. Lipton et al. (2008) provided the criteria for evaluating allodynia symptoms and defined the ranges as: no allodynia (scores 0–2), mild allodynia (scores 3–5), moderate allodynia (scores 6–8), and severe allodynia (scores ≥9) (Lipton et al., 2008). The ASC-12 demonstrated validity and overall utility in providing information about allodynia symptoms surrounding headache attacks (Lipton et al., 2008). The sensitivity of the questionnaire was 84.8%, whereas the specificity was 52.2% (Lipton et al., 2008). In this study, the Cronbach alpha for the ASC was 0.79, suggesting fair internal consistency reliability. Other than allodynia being a prevalent symptom reported with migraine, the rational for examining it in this study is that it can be helpful as a biomarker of the disability acquired from migraine.

Migraine Disability Assessment (MIDAS). The MIDAS (Lipton, Stewart, Sawyer, et al., 2001; Stewart, Lipton, Dowson, & Sawyer, 2001) is a commonly-used 5-item survey measuring disruption experienced due to migraine. Items target role functioning and ask about lost days of house-work, job-work, and non-work activities. All questions asked about either days of missed activity (paid work, household work, or non-work activities) or days where productivity was reduced by at least half (i.e., paid work and household work). These questions captured the number of days with substantial reductions to productivity. If productivity decreased to 50% or below, the day was considered missed. Each item is an open question, allowing entry of number of days lost over 90 days). MIDAS items are summed and yield scores that range from 0 to 90. Total scores are categorized into four, graded levels of disability severity. The scores ≥ 21 will be considered “Severe Migraine Disability”, scores of 11-20 will be considered “Moderate Migraine Disability”, scores of 6-10 will be considered “Mild Migraine Disability”, and sores of 0-5 will be considered “No or Little Migraine Disability”, which are the cutoff scores that had been used in previous research. Several studies have shown the test to have good internal consistency, reliability and construct validity (Lipton, Stewart, Sawyer, et al., 2001; Stewart et al., 2000). This measure also captured attack severity and headache frequency. Two additional questions on the MIDAS questionnaire assess headache frequency and pain intensity. Throughout this paper, ‘MIDAS frequency’ refers to the number of migraine days in the past 3 months (i.e. 90 days) and ‘MIDAS intensity” refers to the average intensity of migraine pain from 0-10. The test-retest Pearson correlation coefficient for the total MIDAS score was approximately 0.8 (Stewart et al., 2000). These are not included in the MIDAS score, but provide additional clinical information and were therefore included in this study’s survey (Lipton, Stewart, Sawyer, et al., 2001). In this study, the Cronbach alpha for the MIDAS total score was 0.86, suggesting good internal consistency reliability.

Migraine Specific Quality of Life Questionnaire (MSQL) v 2.1. The MSQL (Martin et al., 2000) is a commonly-used 14-item survey measuring quality of life in people with migraine. Items comprise three subscales (Role Restriction [items 1-7], Role Prevention [items 8-11], and Emotion Function [items 12-14]) (Cole et al., 2007; Martin et al., 2000). All of the questions in the scales asked respondents to reflect upon the past four weeks and consider all of their migraine attacks when providing their answer. All domains of the MSQL are scored from 0 to 100, with higher scores indicating better functioning. Items are on a standard six-point ordered-categorical scale with choices ranging from “none of the time” to “all of the time” (Cole et al., 2007). The internal consistency coefficients ranged from 0.86 to 0.96, and the intraclass correlation coefficients ranged from 0.57 to 0.63 across the three dimensions of subscales (Bagley et al., 2012). The test-retest measures of reliability for all MSQL dimensions exceed the generally accepted test-retest criteria of 0.50. The MSQL has demonstrated adequate reliability and validity in a number of studies with migraine (Bagley et al., 2012). In this study, the Cronbach alpha for the MSQL total score was 0.97, suggesting very good internal consistency reliability. Additionally, the Cronbach alphas for the three subscales showed Role Restriction was 0.96, Role Prevention was 0.94, and Emotion Function was 0.86, all of which suggest good internal consistency reliability (Bagley et al., 2012).

Injustice Experience Questionnaire (IEQ). The IEQ is a 12-item measure designed to evaluate the extent to which people with an injury or illness experience a sense of unfairness in relation to their injury or illness (M. J. L. Sullivan et al., 2008). Some examples of items include:

"Most people don't understand how severe my migraine is", "My life will never be the same", "I am suffering because of someone else's negligence", "No one should have to live this way", and "I just want to have my life back". The IEQ has two subscales: Severity/Irreparability of Loss (sum of items 1, 2, 4, 5, 6 and 8) and Blame/Unfairness (sum of items 3, 7, 9, 10, 11, and 12). A principal component analysis (PCA) was conducted prior to examining the individual subscales. Responses are coded on a 5-point Likert-type scale ranging from 0 (never) to 4 (all the time). The IEQ total scores range from 0 to 48, with higher scores indicating a poorer level of functioning. The IEQ has demonstrated internal and test-retest reliability and validity in other pain samples (Scott & Sullivan, 2012; Sullivan et al., 2008). Cronbach's alpha for IEQ has been found in other chronic pain study samples to be as high as .92, indicating good internal consistency (Trost et al., 2016). In this study, the Cronbach alpha for the IEQ total score was 0.91, suggesting very good internal consistency reliability. Additionally, in the current study, the Cronbach alphas for the Severity/Irreparability of Loss subscale was 0.84 and the Blame/Unfairness subscale was 0.86, which suggests good internal consistency reliability for both subscales.

PROMIS Anxiety Short-Form (PROMIS-A). The PROMIS-A (Pilkonis et al., 2011) is an 8-item survey selected from a 29-item bank assessing severity of anxiety symptoms in a normative sample. Items assess frequency of anxiety symptoms in the past 7 days and include items such as: "I felt fearful" and "My worries overwhelmed me". Scoring is based on raw scores that are translated into T-scores, with higher T-scores representing increased levels of depression. T-scores can range from 38.2-81.3. The response options are evaluated on a 5-point Likert scale ranging from "never" to "always." The PROMIS-A has demonstrated validity and increased utility in providing information about depression symptoms compared to other self-report measures (Pilkonis et al., 2011, 2014; Stone, Broderick, Junghaenel, Schneider, & Schwartz, 2016). In this study, the Cronbach alpha for the PROMIS-A total score was 0.95, suggesting very good internal consistency reliability.

PROMIS Depression Short-Form (PROMIS-D). The PROMIS-D (Pilkonis et al., 2011) is an 8-item measure of self-reported depressive symptoms in the past seven days, selected from a 28-item bank assessing severity of depression symptoms in a normative sample (PROMIS, 2015). Items from this scale are derived from larger item banks developed by the National Institutes of Health (NIH) to help measure scientific study of patient-reported outcomes (PROs) for common medical conditions in a standardized manner for researchers (Cella et al., 2010; Cella et al., 2010). Items assess frequency of depression symptoms in the past 7 days and include items such as: “I felt that nothing could cheer me up” and “I felt helpless”. Scoring is based on raw scores that are translated into T-scores, with higher T-scores representing increased levels of depression. T-scores can range from 38.2-81.3. The response options are evaluated on a 5-point Likert scale ranging from “never” to “always.” The PROMIS-D has demonstrated validity and increased utility in providing information about depression symptoms compared to other self-report measures (Pilkonis et al., 2011, 2014; Stone et al., 2016). The measure has shown excellent internal consistency in large samples of people representative of the US population (Cronbach’s alpha=0.92) (Cella et al., 2010). In this study, the Cronbach alpha for the PROMIS-D total score was 0.95, suggesting very good internal consistency reliability.

Quantitative Statistical Method & Data Analysis Plan

All data from the “Patient Perspective on Migraine Experience” Study was downloaded from Qualtrics into SPSS statistical software. SPSS version 26 was used to conduct the statistical analyses for this dissertation study (*IBM SPSS Statistics 25*, 2019). To estimate the required sample size for this study, power calculations were conducted using the statistical software G*Power 3.1 and a full power analysis plan is described below. The analyses will be two-tailed with the alpha level set at .05.

Quantitative Power Analysis: The statistical program G*Power Version 3.1.9.4 was used to calculate the adequate power analysis for the proposed correlations (Faul et al., 2007, 2009). We expect each measure to be continuous and normally distributed. Specifically, our four input parameters were: (1) two-tails, (2) $\alpha = .05$, (3) power of 80% or 95%, and (4) an effect size of $r = .30$ or $r = .50$, which represents a medium or large effect size, respectively (Cohen, 1988). The below power shown in Table 2 analysis anticipates each of these potential scenarios and indicates the required sample size. The most conservative power estimate required 134 participants; therefore, we planned to collect at least 134 participants.

Prior to analysis, variable distributions were examined for normality and statistical techniques were chosen in accordance with variable distributions. Normality distributions were based upon the finding that normality can generally be assumed unless the univariate values of a given variable approach at least 2.0 in terms of skewness or 7.0 for kurtosis (Curran et al., 1996). Demographic characteristics for enrolled participants included age, gender, ethnicity, race, sexual orientation, education level, marital/partner status, employment status, household income, height and weight, overall health, and medical history. The values for these variables were summarized using means, standard deviations, or counts and percentages, based on the nature of the specific variable. The outcome (i.e., MSQL, AMS/AMPP, ASC-12, PROMIS-D and PROMIS-A) and predictor variables (i.e., IEQ) were assessed for normality, using the same criteria as detailed above. The data analysis plan for each of the specific aims is listed below. Note that for all data included in the present study, all variables were considered to be normally distributed since the skewness and kurtosis values all fell within the aforementioned required range.

In addition, since the IEQ is a relatively new measure, a series of analyses were conducted to determine how many components, if any, should be extracted from its items. First, a principal components analysis (PCA) was conducted, using the following specifications: (a) the maximum iterations for convergence was set at 30 (Field, 2013); (b) an oblique rotation was used, based on the recommendations of Field (2013, p. 681); (c) the "Promax" method of oblique rotation was used, based on Norman and Streiner (2014); (d) a covariance matrix was used, rather than a correlation matrix, in the rotation process, based on Norman and Streiner (2014). Further, a parallel analysis was conducted to determine the appropriate number of components to extract, using syntax developed by O'Connor (O'Connor, 2000).

Quantitative Analysis

Aim 1. The first aim examines how people with migraine describe their experiences with perceived injustice and how it may impact their quality of life (QoL). To evaluate this aim and determine the strength of association, a Pearson's product-moment correlation analysis was calculated, using the Injustice Experience Questionnaire (IEQ) total score and the Migraine Specific Quality of Life Questionnaire (MSQL) total score. To control for the effects of disability severity in predicting quality of life, a hierarchical linear regression was then conducted to predict MSQL total scores, entering MIDAS scores as the independent variable in the first block, followed by IEQ total scores as the independent variable in the second regression block.

Aim 2. The second aim examines the relationship of perceived injustice with several aspects of migraine symptomatology, including headache frequency and severity, as well as associated symptoms in migraine. In order to evaluate this aim, five correlational analyses, using Pearson's product-moment correlations for the 1st four and a point-biserial correlation for the fifth, were calculated. For the first analysis, the frequency subscale (i.e., the number of headache days experienced in the past 90 days ("In the last 3 months [past 90 days]…On how many full days [from the time you woke up to the time you went to sleep] were you completely free of headache pain or head discomfort?") from the Migraine Disability Assessment (MIDAS) was correlated with IEQ total scores. In the second analysis, the pain severity subscale (i.e. attack severity; "On a scale of 0 - 10, on average, how painful were these headaches? [where 0 = no pain at all, and 10 = pain as bad as it can be]) was correlated with the total calculated scores on the IEQ. The third analysis examined the correlation between the specific migraine symptoms of nausea/vomiting, using the AMS/AMPP, specifically question number five of the module (which inquiries about whether the participant's most common type of headache makes them feel nauseated or sick to their stomach) and the total calculated scores on the IEQ. The fourth analysis examined the correlation between total calculated scores on Allodynia Symptom Checklist-12 (ASC-12) and the total calculated scores on the IEQ. Finally, a point-biserial correlation was conducted to analyze the association between the dichotomous variable aura (i.e., transient sensory disturbance, occurring prior to the migraine attack, as measured by the aura item detailed above) and the total calculated scores on the IEQ.

Aim 3. The third aim examines perceived injustice is associated with mood and anxiety symptoms in people who experience migraine. In order to evaluate this aim and determine the strength of association, two Pearson's product-moment correlation analyses were calculated. The first correlation analyzed the association between the Injustice Experience Questionnaire (IEQ) total score and the total T-score from the PROMIS Anxiety Short-Form (PROMIS-A). The second correlation analyzed the association between the Injustice Experience Questionnaire (IEQ) total score and the total T-score from the PROMIS Depression Short-Form (PROMIS-D). After conducting these correlations, a series of hierarchical linear regressions were then conducted to examine the degree to which perceived injustice predicted anxiety or depressive symptoms, respectively, after controlling for the effect of migraine disability severity. In the first hierarchical linear regression, PROMIS-A was the dependent variable, the MIDAS scores were entered as the independent variable in the first block, followed by IEQ total scores as the independent variable in the second regression block. In the second hierarchical linear regression, PROMIS-D was the dependent variable, the MIDAS scores were entered as the independent variable in the first block, followed by IEQ total scores as the independent variable in the second regression block.

Qualitative Methods

Qualitative Participants and Inclusion Criteria

Following the quantitative data collection process for the study, interviews were conducted in order to obtain qualitative data on how migraine patients are impacted by their perceptions of injustice.

Based on recommendations in the literature, 5 people in the top 25 percentile of the highest injustice perceptions and 5 people in the bottom 25 percentile with the lowest injustice perceptions were randomly selected and contacted via email (which they provided during the informed consent portion of the quantitative survey) and invited to participate in a 20-minute interview (Creswell & Poth, 2017). At this time, they provided the most convenient phone number which they could be reached. All interviews took place within a two-week period in May

2020. As previously mentioned, Figure 1 shows a recruitment study flow diagram for both quantitative and qualitative aspects of the study.

Qualitative Procedure

The current study used the framework of phenomenological interviewing, which aims to understand the meaning of a specific lived experience of a phenomenon from the point of view and perspective of the participant (Tong et al., 2007). Phenomenological interviewing is used often when qualitatively describing individuals experiences with of chronic illnesses (Lie et al., 2018; Snelgrove & Liossi, 2009).

Phenomenological interviewing evaluates patient experience related to a specific phenomenon or event, including perceptions, experiences, and decision-making rather than the outcomes of decision-making (Vagle, 2018, p. 21). Phenomenological interviewing guided interviews to evaluate the participant’s specific beliefs and perceptions about migraine, whether they feel unjustly inflicted, and how migraine impacts their quality of life. The phenomenological interview approach has successfully used phenomenological interviewing before to explore related concepts in both chronic pain and migraine populations (Palacios-Ceña et al., 2017).

As described above and in the power analysis below, a total of 10 interviews (5 people in each of the top/bottom 25 percentile of the highest/lowest injustice perceptions) were conducted with the anticipation that data saturation would be met prior to the last interview. The interviews were conducted under the guidance and supervision of Elizabeth Seng, Ph.D., who has been trained in phenomenological interviewing. The interviews were collected between May 7, 2020 and May 18, 2020.

Interviews were scheduled in one-hour blocks and conducted over the phone. The interviews varied in length from 12 minutes to 36 minutes. Laura (Libby) Sebrow, a psychology doctoral level student at Ferkauf Graduate School of Psychology, conducted all the interviews for this study and was trained on the purpose of phenomenological interviewing. Ms. Sebrow was blind to knowing if the participant scored in the top/bottom 25 percentile of the highest/lowest injustice perceptions. At the start of each interview, the objective of the study and purpose of phenomenological interviews was described to all participants. All participants provided verbal consent to answer the questions and have their interviews recorded. After the interview was completed, each participant received a $30 Amazon gift card via email. All interviews were transcribed. The interviews and qualitative portion of the study was designed to adhere to were assessed in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

Qualitative Measures

The below questions were developed for the study based on the framework of phenomenological interviewing and were asked of each participant.

1) Tell me about your first migraine experience.
2) Tell me about your most typical migraine experience.
3) During the last migraine attack that you encountered, describe how it impacted your daily life?
4) Tell me about how your migraine attacks have influenced your quality of life?
5) What do you feel is other people's understanding of your experience with migraine?
6) How do you compare yourself to others who may not experience migraine?

Qualitative Power Analysis

A brief review of qualitative analyses in similar chronic disease populations found the recommendation for phenomenological methods is to use at least three participants (Englander, 2012; Giorgi, 2009). Justification for five to twenty participants is considered appropriate because it provides appreciation for variation of the phenomenon being assessed in the study (Englander, 2012; Giorgi, 2009); 10 participants falls in the appropriate range compared to other studies utilizing the phenomenological interview approach for individuals with episodic conditions (Ramsey, 2012; Rutberg & Öhrling, 2012; Rutberg, Ohrling, & Kostenius, 2013; Yennadiou & Wolverson, 2017).. Given the novelty of the proposed study in the migraine population, we selected a sample size of 10 migraine patients prior to assessment of data saturation. These 10 phenomenological interviews were stratified by IEQ quartile such that 5 people fell in the highest quartile and 5 in the lowest quartile. Data saturation was achieved after collecting interviews from 8 participants.

Qualitative Data Analysis

A team of two doctoral students reviewed all recordings and transcripts and developed a codebook. A qualitative training was conducted for Ms. Sebrow and Ms. Parker in May of 2020 under the guidance of Elizabeth Seng, Ph.D. A background on phenomenological interviewing was provided along with appropriate steps to ensure data triangulation. Ms. Sebrow and Ms. Parker independently coded the interviews to develop a codebook and fulfill the requirements of data triangulation, which ensures that more than more than one person is involved in the data coding at each level adding credibility to the findings (Carter et al., 2014). Recruitment continued until the occurrence of data saturation, the point at which no new data emerges, was reached after 10 interviews (5 from each group). A codebook through an iterative process was created in which they each read all 10 interviews and tracked potential codes from each one. This process ensured that each interview was reviewed in detail by two separate coders.

A thematic analysis meeting occurred in July 2020 and included both Ms. Parker and Sebrow, as well as the three members of the dissertation committee (Elizabeth Seng, Ph.D, Elizabeth Hirky, Ph.D. and Frederick Foley, Ph.D,) who represent senior researchers with expertise in qualitative research, as well as chronic illness, QoL, and psychology. The attendees of the meeting demonstrated another method of data triangulation as members brought various backgrounds and expertise in different disciplines to the discussion. A codebook consisting of 4 major themes codes was approved by the team and used for the inter-rater reliability phase of the qualitative process. After the approved codebook was created, Ms. Parker and Ms. Sebrow independently reviewed each of the interviews again to ensure correct coding. Finally, Ms. Parker and Ms. Sebrow crosschecked the codes of the other person to ensure agreement through a detailed discussion.

The final product of the interviews was a set of themes and corresponding quotations that reflected the intersection between QoL and perceived injustice (Aim 1). The use of quotations is an important component of transparency in reporting major and minor themes (Tong et al., 2007). To help address respondent validity, Ms. Parker summarized responses from participants throughout each interview in order to check accuracy.

CHAPTER III

RESULTS

Quantitative Results

Participant characteristics. One hundred seventy-nine participants consented to participate in the study. Of these, a total of 132 participants met eligibility criteria, which included that they had at least 50% of the survey data completed, met diagnostic criteria for current migraine as identified the American Migraine Prevalence and Prevention Study/American Migraine Study (AMS/AMPP) calculated assumptions, and completed the Injustice Experience Questionnaire (IEQ; see figure 1 for study flow diagram). There were no significant differences in demographic between the participants included in the study and the participants who were excluded (*p*s > .05).

Table 3 presents characteristics for the total sample of 127 participants. Participants had a mean age of 42.3 (*SD* = 13.9). The majority of participants were female (*n* = 113/127, 89.0%), non-Hispanic or non-Latino (*n* = 87/127, 68.5%), White (*n* = 89/127, 70.1%), heterosexual (*n* = 106/127, 83.5%), married (*n* = 51/127, 40.2%), and had at least a bachelor’s degree (*n* = 36/127, 28.3%).

Clinical characteristics. Table 4 presents clinical characteristics for the total final sample of 127 participants. According to the AMPP/AMS and as a part of the study’s inclusion criteria, all 127 (100%) of the participants met the modified International Classification of Headache Disorders (ICHD) for migraine.

Participants had a mean age of onset of 21.1 (SD = 12.8). In terms of migraine disability and symptomatology, as displayed in Table 4, the majority of participants (*n* = 80/127, 63.0%) were described as having severe migraine disability as characterized by the Migraine Disability

Test Assessment (MIDAS). On average, participants had 30.8 (SD = 28.8) migraine days in the past 3 months (90 days) and a mean pain severity of 7.7 (SD = 2.2) on a scale of 0 to 10, with 0 indicating no pain and 10 being pain as bad as possible. According to the Allodynia Symptom Checklist (ASC-12), the mean score was 6.1 (SD = 4.8), which falls in the range of moderate allodynia.

Table 4 also includes descriptive statistics for the scales measuring the effect of migraine on the individual. Participants reported an average score of 51.0 (SD = 16.9) on the Migraine Specific Quality of Life Questionnaire (MSQL), which indicates a midpoint of quality of life impairment in the range of 1-100 with higher scores indicating better functioning and higher quality of life. In terms of psychiatric symptoms, the PROMIS Anxiety Short-Form (PROMIS-A) mean score of 49.6 (SD = 9.9) and the PROMIS Depression Short-Form mean score of 50.1 (SD = 10.2) were in line with the population average. On the PROMIS-A, it should be noted that 15/l27 (11.8%) participants endorsed clinical elevations between a T-score of 60 and 70 and 4/127 (3.2%) participants endorsed above a 70, indicating severe anxiety. On the PROMIS-D, 20/127 (25.4%) participants endorsed clinical elevations between a T-score of 60 and 70 and 5/127 (6.4%) participants endorsed above a 70, indicating severe depression.

The novel construct of this study for the migraine population is perceived injustice, as measured by the Injustice Experience Questionnaire (IEQ). 127 completed the IEQ and demonstrated a total mean score of 21.8 (SD = 11.2) which revealed overall higher than average (i.e., better functioning) in terms of their perception of injustice (Table 5). Scores ranged from a score of 1 to 44. In relation to other clinical samples (i.e. Musculoskeletal Injury), the mean of our participants was at the 56th percentile (Sullivan, 2008).

As documented in the literature, the IEQ has two subscales. The Severity/Irreparability of Loss subscale (IEQ items 1, 2, 4, 5, 6 and 8) reveled a mean score of 14.2 (SD = 5.9), with a range of scores from 1 to 24. The Blame/Unfairness subscale (IEQ items 3, 7, 9, 10, 11, and 12) reveled a mean score of 7.6 (SD = 6.1), with a range of scores from 0 to 21 (Table 3). A principal component analysis (PCA) was conducted prior to examining the individual subscales to determine whether the total scores, or subscale scores, should be used for the study analyses. The PCA with Horn's Parallel Analysis suggested that there was a single component on the IEQ which accounted for 55.3% of the variance, using percentile ranks of both 50% and 95% as recommended by (O'Connor, 2000, p. 397). Analyses below use only the total score of the IEQ.

Aim 1 Results (Quantitative): Relationship between perceived injustice and quality of life (QoL)

Person's product-moment correlation was used to assess the relationship between perceived injustice (assessed by the IEQ) and migraine specific quality of life (assessed by the MSQL; Table 6). Higher scores on the IEQ (indicating higher perceived injustice) were strongly associated with lower scores on the MSQL (r = -.676, p < .001; indicating lower quality of life impact). The three subscales (Role Restriction, Role Prevention, and Emotion Function) of the MSQL demonstrated similar results (Role Restriction: r = -.636, p < .001; Role Prevention: r = -.618, p < .001; Emotion Function: r = -.618, p < .001; Table 6).

As shown in table 7, hierarchical linear regression assessed the degree to which perceived injustice (IEQ scores) is associated with quality of life (MSQL scores) after controlling for the influence of disability, frequency, and intensity (these latter, control variables were all assessed by the MIDAS). The three MIDAS variables were entered in the first block, and IEQ was entered as a predictor variable in the second block.

The first block containing Severe MIDAS Score (>=21), MIDAS Frequency (number of days in past 3 months) and MIDAS Intensity (average intensity of migraine pain from 0-10) model accounted for 51.5% of the variance of the MSQL score, $F(3, 123) = 43.47$, $p < .001$. In this model, displayed greater migraine disability scores predicted lower quality of life. In the second block, after controlling for severe MIDAS disability, MIDAS frequency and MIDAS intensity, the addition of the IEQ was significant and associated with an additional 12.1% of the variance in MSQL scores $F(1, 122) = 82.89$, $p < .001$, $\beta = -.42$, $p < .001$ (Table 7).

Aim 2 Results: Relationship between perceived injustice and migraine symptoms.

Higher scores on the IEQ were related to higher migraine attack frequency (r =.403, $p < .001$) and migraine pain intensity ($r = .352$, $p < .001$; Table 8).

There was no association between the IEQ and reports of nausea/vomiting during migraine ($r = .110$, $p = .220$; Table 9). Higher levels of perceived injustice on the IEQ were associated with a higher report of allodynia symptoms ($r = .281$, $p < .001$; Table 9). Participants who reported a migraine with aura in the past year (n = 84/127, %) reported higher IEQ scores (M = 23.4, SD = 11.4) than people with no aura in the past year (n= 43/127, %; M = 18.6, SD = 10.2; $t(125) = -2.34$, $p = .02$).

Aim 3 Results: Relationship between perceived injustice and mood and anxiety symptoms.

Two Pearson’s product-moment correlations were used to assess the relationship between (a) perceived injustice (assessed by the IEQ) and anxiety symptoms (assessed by the PROMIS Anxiety Short-Form [PROMIS-A]), and (b) perceived injustice and depressive symptoms (assessed by the PROMIS Depression Short-Form [PROMIS-D]; Table 6). Higher IEQ scores were associated with higher PROMIS-A ($r = .447$, $p < .001$; Table 5) and PROMIS-D scores ($r = .495$, $p < .001$; Table 6).

Two hierarchical linear regressions assessed the degree to which IEQ scores predicted (a) anxiety symptoms (i.e. PROMIS-A scores), and (b) depressive symptoms (i.e. PROMIS-D scores) after controlling for the influence of disability severity, frequency, and intensity of migraine (these latter, control variables were all assessed by the MIDAS). In both hierarchical linear regressions, the three MIDAS variables were entered as predictor variables in the first block, IEQ was entered as a predictor variable in the second block, and the PROMIS-A and PROMIS-D scores, respectively, were entered as the dependent variable.

As shown in table 10, in the first hierarchical linear regression predicting PROMIS-A scores, the regression model for the first block in which the three MIDAS scores were entered as predictor variables yielded statistically significantly results, in which the model accounted for 10.5% of the variance of the PROMIS-A score $F(3, 123) = 4.83$, $p = .003$, adjusted $R^2 = .084$ and specifically, greater migraine disability scores predicted greater anxiety symptoms. In the second block, after controlling for the MIDAS variables' ability to predict PROMIS-A scores, the IEQ was able to statistically significantly predict an additional 21.2% of the variance in PROMIS-A scores $F(1, 122) = 16.43$, $p < .001$, adjusted $R^2 = .186$, $\beta = .39$, $p < .001$, and specifically greater perceived injustice predicted higher levels of endorsed anxiety symptoms (Table 10).

As shown in table 11, in the second hierarchical linear regression, which was used to predict PROMIS-D scores, the first block of the regression included MIDAS as the predictor variables, and the regression model was statistically significantly, accounting for 10.9% of the variance of the PROMIS-A score $F(3, 122) = 4.99$, $p = .003$, adjusted $R^2 = .087$, and specifically greater migraine disability scores predicted greater depression symptoms. In the second block, after controlling for the MIDAS' ability to predict PROMIS-D scores, the IEQ was able to statistically significantly predict an additional 25.1% of the variance in PROMIS-D scores F(1, 122) = 23.19, $p < .001$, adjusted $R^2 = .226$, $\beta = .45$, $p < .001$, and specifically greater perceived injustice predicted higher levels of endorsed depressive symptoms (Table 11).

Qualitative Results

Participant characteristics. Of the total sample of 127 participants included in the quantitative analysis, a total of 10 interviews (5 people in each of the top/bottom 25 percentile of the highest/lowest injustice perceptions based on the IEQ) were conducted to gather qualitative data. Table 12 presents demographic characteristics for the 10 participants that were interviewed and shows if they belong to the group of the top/bottom 25 percentile of the highest/lowest injustice perceptions based on the IEQ total scores. Participants had a mean age of 46.6 (*SD* = 13.1). The majority of participants were female (*n* = 9/10, 90.0%), non-Hispanic or non-Latino (*n* = 6/10, 60%), White (*n* = 5/10, 50%), heterosexual (*n* = 9/10, 90%), never married (*n* = 5/10, 50%), and had completed some college (*n* = 4/10, 40%). Data saturation was met after the 8th interview.

Clinical characteristics. Table 13 presents relevant clinical characteristics for the 10 participants that completed qualitative interviews. Qualitative participants reported an average total score of 51.3 (SD = 21.5) on the MSQL, which indicates a midpoint of quality of life impairment in the range of 1-100 with higher scores indicating better functioning and higher quality of life. Additionally, while examining the high and low IEQ groups independently, the scores were in line with expectations; the high IEQ group had a mean score of 32.2 (SD = 7.0) indicating lower QoL, while the low IEQ group had a mean score of 70.4 (SD = 8.8) indicating higher QoL. The three subscales (Role Restriction, Role Prevention, and Emotion Function) of the MSQL demonstrated similar results. Finally, on the IEQ which was the quantitative scale that determined the high/low injustice groups, qualitative participants reported an average total score of 20.6 (SD = 16.3); the high IEQ group had a mean score of 35.6 (SD = 4.8) and the low IEQ group had a mean score of 5.6 (SD = 3.5).

Aim 1: To understand how perceived injustice relates to the quality of life (QoL) in patients with migraine.

After examining each interview independently, Ms. Parker and Ms. Sebrow attended a joint meeting with the project's committee members, Elizabeth Seng, Ph.D, Elizabeth Hirky, Ph.D. and Frederick Foley, Ph.D in June 2020. Together, codes were combined, moved, or removed if not agreed upon. Ms. Parker and Ms. Sebrow reviewed the interviews again with a line-by-line process of coding interviews to ensure consistency of themes/subthemes. After reviewing all of the codes and illustrative quotes, a total of 4 themes emerged from the interviews.

Theme One: Coping (Table 14 & Table 18)

> "I had to start learning how to cope with it. This is a part of me and so I listen. When I feel a migraine coming on or headache coming on, I have to shut everything down and just lay there until it passes and sometimes it comes like a wave. Or it'll just go through your body, I had to learn how to shut myself down. I just let the waves go and then I'm okay. But if I don't shut it down then it becomes so bad that I start feeling nauseous and start wanting to throw up. And that's really bad…"
>
> (Participant #163, High IEQ Group)

In both groups, the most commonly used terms and concepts related to this theme included the impact on their relationships (both being able to rely on others and hindering relationships), trying to be positive and optimistic, and the manner in which they have altered certain behaviors to help with their migraines. A majority of patient's commented on the need of understanding, both personally and by others, which aided in the process of coping.

Theme Two: Loss (Table 15 & Table 19)

> "…they've (migraines) influenced my quality of life as far as not being able to do a lot of things… family functions and stuff like that. I've missed out on many of them. There are times I've had to cancel out and it even affects the pocket because there are times when I've bought tickets to go and do something and things like that. And the last minute, I can't do it. … So, it's hurt me as far as family functions. It's hurt me as far as losing money over it. It's hurt me as far as even taking on little events and stuff. I used to go to a church on every other Sunday, I think it was. Or once a month, twice a month. And just help them out by feeding the homeless people and stuff like that. And I can't even commit to things like that anymore because they count on a certain amount of people to be there. And there's times where I could be on my way and all of a sudden, a migraine hits. And I know I'm not going to be able to do that and I have to cancel on them… Sometimes it stops me from everyday things like food shopping, anywhere where I have to drive because I can't drive when I'm like that."
>
> (Participant #158, High IEQ Group)

The most commonly referenced concepts related to this theme was the loss of the ability to enjoy life and everyday activities. Participants in the high IEQ group specifically mentioned a loss of social interaction due to their migraine, and often expressed disappointment from others. Participants seemed to share that they discontinued specific activities because of migraine that has impacted their life.

Theme Three: Illness Burden (Table 16 & Table 20)

> "It's disruptive for sure. It's disruptive to my life when I get them. They take me out. I can't do anything when I have them. I just have to lay in a dark room until they pass...I couldn't take care of my son. I couldn't do anything. I couldn't eat. I couldn't do things around the house...There's definitely been times where I have to leave work or not go to work because of one...it's made me lose work days, it's interrupted my ability to care for my son, it's interrupted my ability to do leisure activities."
>
> (Participant #189, Low IEQ Group)

The subtheme of "Disruption" had the greatest number of illustrative quotes across all the themes. "Disruption" and "Symptoms" were the only two subthemes that contained illustrative quotes from all 10 interviews. Across all the interviews, it was evident the aspects of illness burden interfered with quality of life. Some participants in the low IEQ group described improvements as they aged, while participants in both groups described greater disability and mental health effects due to their experience with migraine.

Theme Four: Misunderstood (Table 17 & Table 21)

> "They don't see migraine. Someone can tell you, I'm sick, this hurts, that hurts, but the person that you're telling it to, they don't feel it. So, they don't know what you're going through. People that don't experience migraines definitely don't

> understand a person that gets chronic migraines, that's for sure. I think they just have to take your word for it, including the doctors…”
>
> (Participant #178, High IEQ Group)

The majority of illustrative quotes for this theme came from participants in the high IEQ group. Participants felt misunderstood with friends, family co-workers, and professionals. The feeling of being misunderstood led participants to feel alone and upset about their migraine journey.

CHAPTER IV

DISCUSSION

The current study is the first to examine perceived injustice in a sample of individuals with migraine. Growing literature within other medical and disability samples have found perceived injustice to be an important construct in how they relate to what they are enduring (Scott & Sullivan, 2012; Sullivan et al., 2009; Trost et al., 2015). As such, inspecting the effect of perceived injustice within the migraine population was the novel endeavor that this study inspected. This cross-sectional survey study points to perceived injustice as an important component of the patient experience of migraine and is strongly associated with migraine outcomes. The relationship of perceived injustice was explored as an important factor influencing quality of life, symptomatology, and psychiatric symptoms in people with the condition. With the utilization of mixed methods, the data collected for this study is among the first to focus on the multidimensional aspects of the perceived injustice experience associated with migraine.

This study suggests that perceived injustice played a role in influencing people with migraine's life in a significant way. Within this migraine patient sample, perceived injustice appeared to be associated with poorer QoL, as consistent with previous research in some disease state (Trost et al., 2015). This finding was also supported by phenomenological interviews, where participants with high perceived injustice described poorer quality of life and more avoidance from valued activities and withdrawing from once pleasurable activities than people with low perceived injustice.

In considering our findings of perceived injustice, increased nocebo rates should have been considered with how perceived injustice relates to negative expectations of a patient because of their treatment satisfaction. Therefore, we post-hocly examined the relationship between treatment satisfaction and perceived injustice total scores. Treatment satisfaction was self-reported by the participant and evaluated on a 5-point Likert scale from “extremely satisfied” to “extremely dissatisfied” (lower scores indicated higher satisfaction). Results showed that participants with lower perceived injustice had higher treatment satisfaction (r = .330, p < .001). This finding may suggest that treatment satisfaction should be a component that is considered as a part of individuals injustice experience. Further research should inspect these results with the migraine population.

The themes of coping, loss, illness burden, and being misunderstood emerged from the qualitative interview as influential factors that impact people with migraine and their QoL. These themes are consistent with previous literature. Overall, the theme of coping was endorsed by the high and low IEQ group similarly, while loss, illness burden, and feeling misunderstood emerged with greater frequency from the high IEQ group. Functionally, participants in our study endorsed the inability to work/needing disability accommodations at work, inability to complete household roles/chores, and impact of social events. It was also common for individuals in our study to interpret pain itself as a source of injustice and an unfair circumstance, which has also emerged in other previous studies involving perceived injustice and QoL.

As established in previous perceived injustice literature, two factors have been conceptualized and believed to contribute to perceptions of injustice (i.e., severity/irreparability of loss and blame/sense of unfairness) (Monden et al., 2016, 2020; Sullivan et al., 2009). Although the quantitative aspect of this study showed that perceived injustice is an experience of migraine patients, the important information that the quantitative interviews may suggest is that for individuals living with migraine, perceived injustice may be less related to fault and blame but instead more closely related to a lack of understanding of their disorder. This finding is similar to the quantitative finding for those with spinal cord injury (Monden et al., 2020). Participants reported being misunderstood, in the context of their migraine disease, as a common experience. Within our study, the high IEQ group more frequently reported being misunderstood, which also contributed to feeling isolated and angry, but several members of the low IEQ group also endorsed similar thoughts. It may also be important to gain an understanding of the construct of stigma. Stigma refers to the negative attitudes expressed by other individuals that are experienced by an individual with devalued characteristics (Molina et al., 2013). The role stigma plays in the lives of people with migraine may be related to aspects of QoL, as well as be an influencing factor of perceived injustice (Aydemir et al., 2011; Rao et al., 2009; Seng & Seng, 2016; Waugh et al., 2014; Young et al., 2013). It has been shown to restrict individual's participation within the community and workplace due to the attitudes of others (Molina et al., 2013). However, future research should also determine the ways in which injustice and stigma overlap. No study to date has examined injustice and stigma in migraine, specifically, or within another pain population.

It is important to consider that perceptions of injustice are not merely mental constructions of individuals but might emerge from a reality that is characterized by some degree of injustice. In other words, the individual's perceptions of injustice might be completely justified, anger or social isolation may be important components, and should be evaluated in future studies (Sturgeon et al., 2017). Conducting in depth interviews may be a productive way to evaluate this in the future.

Although perceived injustice may be an aspect of mental health, our study found that perceived injustice is different from psychiatric symptoms. This is illustrated by the fact that the correlations were not aligned. As suggested by theory, perceptions of injustice might intensify the negative emotional impact of adverse events (Scott & Sullivan, 2012). However, in this study we found a clear distinction between perceived injustice and psychiatric symptoms. Perceived injustice was associated with higher depression and anxiety. Future studies should work to replicate this finding in both migraine as well as other disease populations. Future research should work to develop and evaluate interventions, include specific psychoeducation protocols, and target perceived injustice as it could play a role in reducing depression and anxiety symptoms which are prevalent and disabling in people with migraine. Future research should evaluate if interventions targeted depression and anxiety, could that have an impact on other distinct outcomes.

There are a number of empirically supported therapies for pain disorders, including cognitive-behavioral therapy (CBT) and third-wave therapies such as acceptance-based commitment therapy (ACT), which could be considered in the multidisciplinary treatment of the experiences patients with migraine endure, such as the perception of injustice (Probyn et al., 2017; Sharpe et al., 2019). The emphasis in ACT of psychological flexibility (encompassing acceptance, cognitive diffusion [i.e. one’s ability to observe thoughts as just thoughts and ultimately transient] , present moment awareness, self-as-context, values and committed action) could be beneficial to individuals with migraine given the level of uncertainties and unpredictability that participants expressed during the quantitative and qualitative components of this study (Hayes et al., 2006; Hughes et al., 2017; Martel et al., 2017). Within ACT, individuals are encouraged to experience some level of pain in order to partake in activities of value, which may allow them to decrease the blame and unfairness burden that they are attributing to their health-related situation. By taking this approach coping route, people with migraine may positively affect their quality of life and lower their symptoms of anxiety and/or depression. Future studies should examine perceived injustice as a potential treatment target for empirically supported therapies for migraine and other pain conditions.

Limitations

This was a cross-sectional study; therefore, we can make no causal attributions regarding the direction of relationships between injustice and symptoms/QoL. Participants were recruited at specialty care locations, so these individuals may experience more frequent and severe migraine episodes (i.e. higher levels of disease and disability) this study cannot generalize to the full range of the migraine patient population. However, as this was the first study examining perceived injustice in people with migraine, we selected a population where the perceptions could be expected to be prevalent. Future studies should evaluate the role of perceived injustice in people with migraine who present in primary care settings, and who do not present in medical settings for care. The participants were recruited non-consecutively, therefore they likely had high motivation to complete the study. However, the study was generically labelled “The Patient Migraine Experience Study” therefore we do not think that this motivation was specifically related to injustice perceptions.

It is important to note that the majority of the data collected for this study was gathered during the COVID-19 global pandemic. This may have affected both the recruitment of participants, as well as their symptoms in ways that cannot yet be understood. It is possible that participants had more flexible schedules (e.g., office closures, remote working, unemployment, etc.) and were, therefore, more willing to participate than during normal circumstances. Additionally, at the present time, effects of quality of life, migraine symptoms, and psychiatric symptoms remain unknown. Since data for this study were collected during a vulnerable time, it is possible that the effects of the pandemic (both from illness and psychological) could have impacted the study's data. Participant's impact of COVID-19 was not assessed in this study.

In terms of demographic information, it is typical that people who experience migraine are frequently from a White and educated background (R. B. Lipton, Stewart, Diamond, et al., 2001; Stewart et al., 1992). In this study, the sample included individuals from more diverse backgrounds that anticipated. Although this is not typical for studies involving migraine, it may be considered a strength of the study. However, the sample was predominantly women and only one qualitative interview participant was a man. How perceived injustice differs between gender has yet to be determined in the available literature, and unfortunately our own study is limited in an ability to contribute to an understanding of gender differences (Ishii et al., 2020). Additional differences between the low and high perceived injustice groups can be found in Table 10. Future studies should match participant groups on more established criteria to determine between group differences, but this study is able to remain a baseline or a blueprint for racial and ethnic disparities.

This study did not examine the quantitative or qualitative impact of perceived injustice in individuals under the age of 18, even though migraine can have a younger age of onset. The present study limits our findings to adult participants. Our study findings in an adult population are still important in capturing the perceived injustice experience, as many participants in the study reported an age of onset during childhood or adolescence. Moreover, during the qualitative interviews, participants also described experiences of migraine during childhood and/or adolescence. Future research should explore the perceived injustice experience in younger migraine patients as an important area of both qualitative and quantitative research.

In terms of the study procedures, the recruitment locations were all in the Northeast, United States; therefore, this study is primarily generalizable to individuals who are in a large urban/metropolitan area. Data was collected at a single time point, which results in significant limitations in interpretability, especially since migraine is a condition of episodic attacks and individual's symptoms can fluctuate. Since this study involves completing an online survey, proficiency and sufficiency of utilizing technology is required, as well as having an established internet connection to access the survey.

All of the measures included in this study relied exclusively on self-report assessment. Depending on the study, collecting data from solely self-report may add and detract from the data quality. For our study, both possibilities are feasible. Further, we evaluated measures of psychiatric symptoms rather than psychiatric disorders. Future research should evaluate associations between perceived injustice and psychiatric disorders in people with migraine. Using more complex diagnostic measures in future research studies, such as the Structured Clinical Interview (SCID), would provide a more definitive diagnosis of psychiatric symptoms and pathology. This would also provide more established cutoffs for assessing psychiatric factors. Furthermore, since symptoms in this study were asked about retrospectively (i.e. using self-report measures), future studies may consider utilizing diaries which can allow participants to document their symptoms and experiences in the present moment.

The measure of Migraine Specific Quality of Life Questionnaire (MSQL) does not capture all aspects of an individual's quality of life. Therefore, measures that encapsulate more aspects that can influence QoL may be beneficial, such as family functioning, finances, and other important life domains (Dawn C. Buse et al., 2009, 2019).

Due to this study involving a mixed method design, the qualitative component should be interpreted within the context of the qualitative nature of this enquiry. The results are based on discussions with 10 individuals. Even though 10 was the intended sample for the qualitative components based on power in the existing literature, the results may not be generalizable to all individuals with migraine or other groups who experience chronic pain. Additionally, the data collected from the interviews was be subject to the researchers' interpretation and may have been interpreted in a different way by another researcher groups. This study utilized data triangulation and in-depth agreement during the thematic analysis meeting with expertise in qualitative research to agree on the interpretation so that the analysis was not the responsibility of a sole researcher.

This study did not examine acceptance of circumstances, such as disability identity. This may be an important factor to examine that could potentially influence perceptions of injustice. Previous research has found that disability identity mediated greater satisfaction with life among individuals with chronic health conditions (Monden et al., 2016). In one study, Disability identity was also associated with lower anxiety and depression among people with MS (Bogart, 2015). Future research should investigate the role of disability identity on perceived injustice, specifically within the migraine population.

Clinical Implications

Presently, there are no interventions that specifically target appraisals of injustice. There is limited research upon which to recommend clinical interventions to diminish the impact of perceived injustice on quality of life and psychiatric symptoms. However, several relevant interventions may be useful for practicing clinicians to help frame and explore the experience of perceived injustice with migraine patients. Nevertheless, it should be noted that many clinicians fail to refer their migraine patients to seek behavioral healthcare as an option.

In the context of chronic health conditions, such as migraine, perceptions of injustice may be difficult to avoid, as unfairness and significant losses often characterize the patient experience. As such, as mentioned above in the discussion section, acceptance and commitment therapy (ACT) may be well suited to address injustice concerns (Hayes et al., 2006; Hughes et al., 2017; Monden et al., 2016). ACT aims to improve function and QoL through the enhancement of psychological flexibility. Psychological flexibility represents the capacity to persist with or to change behavior in a way that incorporates conscious and open contact with difficult thoughts, feelings, and bodily sensations in a manner that serves one's goals and values (Monden et al., 2016). Rather than attempting to change an individual's perceptions of injustice, ACT aims to help individuals succeed in terms of their own personal values, even when confronted with debilitating physical symptoms and maladaptive thoughts. thus, ACT promotes adjustment in a manner that is inherently validating of individuals' experiences, and supportive of psychological strengths. With the migraine population, ACT may be a particularly helpful psychological intervention as the unpredictability and severity of symptoms is often challenging for individuals to cope with, while maintaining hope and productivity.

Conceptualizing patients within a biopsychosocial framework will also assist with other contributing social and psychological factors for people with migraine. Optimal management and treatment of perceived injustice among people with chronic pain also requires consideration of the social context within which perceptions of injustice are likely to arise and be maintained. For example, studies have shown that people with pain experience unfairness in their interactions with their employers, medical providers, family members, and society at large (Martel et al., 2017). Therefore, in addition to implementing interventions to facilitate pain acceptance at the level of the individual, the implementation of strategies may need to include social and systems-level sources of injustice are likely needed to optimally mitigate the impact of the injustice experience among people with migraine. Psychoeducation may be a particular useful tool in this context. Some useful psychoeducation elements that may be relevant are briefing patients about the course of migraine, eliciting problem-solving techniques, providing insight into the illness, dispelling stigma around the experience with the illness, and indicating how and when to seek appropriate treatment. Providing psychoeducation can be effective within an individual, group, and family setting (Sarkhel et al., 2020).

Conclusions

Our study found that perceived injustice is a central and pervasive component of the patient experience of migraine. The experience of perceived injustice was related to quality of life, migraine symptoms, and psychiatric symptoms. Both the quantitative and qualitative components of the study demonstrated the multidimensional aspects of the perceived injustice experience of migraine patients. As researchers and clinicians turn to focus on the components of perceived injustice as a crucial patient-centered outcome, it is important that these findings be incorporated into the selection of appropriate patient experience measures, or the develop of a new measure that fully captures the experience of migraine-related perceived injustice, such as invisible or unpredictable factors of migraine. Measures ensure independent aspects of the perceived injustice experience that do not overlap with quality of life or psychiatric symptoms. Rather, it may be valuable to consider perceived injustice as an aspect of mental health which can be targeted with specific treatments. For example, utilizing a cognitive-behavioral or acceptance approach in psychological treatment may target the specific unjust thoughts that a patient is thinking and teach them how to change or adapt their maladaptive thoughts. A multidisciplinary approach between neurologist, pain management specialists, and psychologists will also help to address many of the current gaps in our treatment of this important symptom and component of the disease.

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TABLES

Table 1

Outline of Survey

Variable Measured	Measure	Reference
Demographics (age, gender, ethnicity, race, sexual orientation, years of education, marital status, employment status, household income, height and weight, headache history) Comorbid Conditions, Current Prescribed Medication Regimen, and Treatment Satisfaction	National Institute of Neurological Disorders and Stroke Common Data Elements (NINDS CDEs)	---
Migraine Diagnostic Criteria	American Migraine Study/American Migraine Prevalence and Prevention (AMS/AMPP) Diagnostic Module	Lipton, Diamond, Reed, Diamond, & Stewart (2001)
Allodynia Symptoms	Allodynia Symptom Checklist-12 question (ASC-12)	Lipton et al. (2008)
Aura Symptoms	American Migraine Study/American Migraine Prevalence and Prevention	Lipton, Diamond, Reed, Diamond, & Stewart (2001)

	(AMS/AMPP) Diagnostic Module	
Migraine Disability	Migraine Disability Test Assessment (MIDAS)	Lipton, Stewart, Sawyer, & Edmeads (2001)
Quality of Life	Migraine Specific Quality of Life Questionnaire (MSQL) v 2.1	Martin et al. (2000)
Injustice	Injustice Experience Questionnaire (IEQ)	Sullivan et al. (2008)
Anxiety	PROMIS Anxiety Short-Form (PROMIS-A)	Pilkonis et al. (2011)
Depression	PROMIS Depression Short-Form (PROMIS-D)	Pilkonis et al. (2011)

**For compilation of the ‘Patient Perspective on Migraine Experience’ survey see Appendix A*

Table 2

Power analysis possibilities anticipating each of the potential scenarios with corresponding sample size

Statistical Test	Number of Tails/ Significance Level	Power	Effect Size	Sample Size Required
Correlation	Two-tails/ α = .05	80%	*r* = .30 (Medium)	82 Participants
Correlation	Two-tails/ α = .05	80%	*r* = .50 (Large)	26 Participants
Correlation	Two-tails/ α = .05	95%	*r* = .30 (Medium)	134 Participants
Correlation	Two-tails/ α = .05	95%	*r* = .50 (Large)	42 Participants

Table 3

Demographic Characteristics for Quantitative Participants

Variable	Total N = 127 N(%)
Age (n = 124)	42.3 (13.9)
Gender	
Male	14 (11%)
Female	113 (89%)
Ethnicity (n = 126)	
Not Hispanic or Latino	87 (68.5%)
Hispanic or Latino	35 (27.6%)
Prefer not to Say	4 (3.1%)
Race (n = 126)	
White	89 (70.1%)
Black or African American	20 (15.7%)
Asian	3 (2.4%)
American Indian/Alaska Native	3 (2.4%)
Prefer not to say	6 (4.7%)
Unknown	5 (3.9%)
Sexual Orientation	
Heterosexual	106 (83.5%)
Gay/Lesbian	5 (3.9%)
Bisexual	4 (3.1%)
Unknown	2 (1.6%)
Other	3 (2.4%)
Prefer not to say	7 (5.5%)
Marital Status (n = 125)	
Never married	42 (33.1%)
Married	51 (40.2%)
Domestic partnership/living with partner	18 (14.2%)
Divorced	7 (5.5%)
Separated	4 (3.1%)
Widowed	2 (1.6%)
Prefer not to answer	1 (0.8%)
Education Level	
12th grade or less, no diploma	6 (4.7%)
High school graduate	2 (1.5%)
GED or equivalent	3 (2.4%)
Some college, no degree	18 (14.2%)
Associate degree	9 (7%)
Bachelor's degree	36 (28.3%)
Master's degree	34 (26.8%)
Professional school degree	9 (7.1%)

Doctoral degree	9 (7.1%)
Unknown	1 (0.8%)

Note. N = 127.

Table 4

Clinical Characteristics for Quantitative Participants

Variable	Total N = 127 M(SD) or N(%)
Met migraine criteria via AMPP/AMS	127 (100%)
Age at first migraine attack (n = 125)	21.1 (12.8)
Days in the past month of most severe headache type (n = 125)	7.8 (8.0)
MIDAS	
No or little migraine disability	11 (8.7%)
Mild migraine disability	9 (7.1%)
Moderate migraine disability	27 (21.3%)
Severe migraine disability	80 (63.0%)
MIDAS frequency	30.8 (28.8)
MIDAS intensity	7.7 (2.2)
ASC-12	6.1 (4.8)
Aura	
Yes	84 (66.1%)
No	43 (33.9%
MSQL	51.0 (16.9)
Role restriction subscale	24.3 (8.2)
Role prevention subscale	16.1 (5.3)
Emotion Function subscale	10.6 (4.6)
PROMIS-A (raw score[a])	18.8 (8.2)
PROMIS-A (T-Score)	49.7 (9.9)
PROMIS-D (raw score[a])	15.9 (8.3)
PROMIS-D (T-Score)	50.1 (10.2)
Self-Reported Comorbid Conditions	
Anxiety	52 (40.9%)
Depression	48 (37.8%)

Note. N = 127; AMPP = American Migraine Prevalence and Prevention Study; AMS = American Migraine Study; EMR = Electronic Medical Record (accessed from Montefiore Medical Center) MIDAS = Migraine Disability Test Assessment; MIDAS frequency = Migraine days in the past 3 months (i.e. 90 days) reported on the MIDAS; MIDAS intensity = Pain severity as assessed by MIDAS; ASC-12 = Allodynia Symptom Checklist-12 question; Aura = Reported >1 migraine with aura in the past 12 months
MSQL = Migraine Specific Quality of Life Questionnaire (version 2.1); IEQ = Injustice Experience Questionnaire; PROMIS-A = PROMIS Anxiety Short-Form; PROMIS-D = PROMIS Depression Short-Form.

[a] In the present study, T-scores for these data were calculated and used in all subsequent analyses. They are presented here in raw scores for descriptive purposes only.

Table 5

Perceived Injustice Data for Quantitative Participants

Variable	Total N = 127 M(SD)
IEQ Total	21.8 (11.2)
Severity/Irreparability of Loss Subscale	14.2 (5.9)
Blame/Unfairness Subscale	7.6 (6.1)

Note. N = 127; IEQ = Injustice Experience Questionnaire; Severity/Irreparability of Loss = Items 1, 2, 4, 5, 6 and 8 on the IEQ; Blame/Unfairness = Items 3, 7, 9, 10, 11, and 12 on the IEQ. The IEQ total scores range from 0 to 48 and each subscale scores range from 0 to 24.

Table 6

Bivariate Relationships between Perceived Injustice, Allodynia Symptoms, Quality of Life, Anxiety, and Depression

Variables	1	2	3	4	5	6	7
1. ASC-12							
2. MSQL	-.333**						
3. MSQL - Role restriction subscale	-.334**	.966**					
4. MSQL - Role prevention subscale	-.313**	.942**	.883**				
5. MSQL Emotion Function subscale	-.265**	.862**	.744**	.728**			
6. IEQ	.281**	-.676**	-.636**	-.618**	-.635**		
7. PROMIS-A[a]	.257**	-.526**	-.497**	-.477**	-.497**	.447**	
8. PROMIS-D[a]	.209*	-.617**	-.583**	-.606**	-.527**	.495**	.727**

**$p < .01$.

Note. Person's product-moment correlation analyses were used for all correlations. ASC-12 = Allodynia Symptom Checklist-12 question; MSQL = Migraine Specific Quality of Life Questionnaire (version 2.1); IEQ = Injustice Experience Questionnaire; PROMIS-A = PROMIS Anxiety Short-Form; PROMIS-D = PROMIS Depression Short-Form.

[a] T-scores for these data were used in the analyses, as detailed in the Method section.

Table 7
Linear regression predicting quality of life from perceived injustice, while controlling for disability severity, frequency, and intensity of migraine (*N* = 127)

	b	95% CI	SE *b*	β	*p*-value
Step 1					
Constant	92.62	84.4, 100.8	4.13		<.001
MIDAS Severity	-5.03	-7.7, -2.4	1.35	-0.28	<.001
MIDAS Frequency	-0.20	-0.3, -0.1	0.04	-0.33	<.001
MIDAS Intensity	-3.06	-4.1, -2.0	0.53	-0.40	<.001
Step 2					
Constant	93.93	86.8, 101.1	3.60		<.001
MIDAS Severity	-4.14	-6.5, -1.8	1.18	-0.23	.001
MIDAS Frequency	-0.11	-0.2, -0.03	0.04	-0.19	<.001
MIDAS Intensity	-2.08	-3.0, -1.1	0.49	-0.27	<.001
IEQ	-0.63	-0.8, -0.4	0.10	-0.42	<.001

Note. R^2 = .52 for Step 1; ΔR^2 = .12 for Step 2 (*p*s < .001).

b = Unstandardized regression coefficient; β = Standardized regression coefficient; CI = Confidence interval.

Table 8

Bivariate Relationships between Perceived Injustice, migraine frequency, and migraine intensity

Variables	1	2	3
1. IEQ			
2. MIDAS frequency	.403**		
3. MIDAS intensity	.352**	-.003	

**p < .01.

Note. N = 127. Person's product-moment correlation analysis were used for all correlations. IEQ = Injustice Experience Questionnaire; MIDAS = Migraine Disability Test Assessment; MIDAS frequency = Migraine days in the past 3 months (i.e. 90 days) reported on the MIDAS; MIDAS intensity = Pain intensity as assessed by MIDAS

Table 9

Bivariate Relationships between Perceived Injustice and migraine symptomatology

Variables	1	2	3	4
1. IEQ				
2. Nausea/Vomiting	.110			
3. ASC-12	.281**	.272**		

**p < .01. *p < .05.

Note. N = 127. Person's product-moment correlation analysis used for variables 1, 2 and 3 correlations;

IEQ = Injustice Experience Questionnaire; Nausea/Vomiting = Reported from the AMS/AMPP (i.e. question number five); ASC-12 = Allodynia Symptom Checklist-12 question;

Table 10

Linear regression predicting anxiety symptoms from perceived injustice, controlling for disability severity, frequency, and intensity of migraine (N = 127)

	b	95% CI	SE b	β	p-value
Step 1					
Constant	38.88	32.4, 45.3	3.26		<.001
MIDAS Severity	0.001	-0.03, 0.03	0.02	0.01	.936
MIDAS Frequency	0.07	0.001, 0.14	0.04	0.21	.047
MIDAS Intensity	1.11	0.33, 1.89	0.40	0.25	.006
Step 2					
Constant	37.67	31.6, 43.8	3.08		<.001
MIDAS Severity	-0.003	-0.03, 0.03	0.01	-0.02	.834
MIDAS Frequency	0.02	-0.05, 0.09	0.04	0.07	.527
MIDAS Intensity	0.52	-0.27, 1.31	0.40	0.12	.196
IEQ	0.34	0.18, 0.51	0.09	0.39	<.001

Note. R^2 = .11 for Step 1; ΔR^2 = .11 for Step 2 (p < .001).

b = Unstandardized regression coefficient; β = Standardized regression coefficient; CI = Confidence interval.

Table 11

Linear regression predicting depression symptoms from perceived injustice, controlling for disability severity, frequency, and intensity of migraine (N = 127)

	b	95% CI	SE *b*	β	*p*-value
Step 1					
Constant	39.89	33.31, 46.48	3.33		<.001
MIDAS Severity	0.01	-0.02, 0.04	0.19	0.07	.480
MIDAS Frequency	0.07	-0.003, 0.14	0.04	0.19	.060
MIDAS Intensity	0.97	0.17, 1.77	0.40	0.21	.018
Step 2					
Constant	38.46	32.37, 44.55	3.08		<.001
MIDAS Severity	0.01	-0.02, 0.03	0.01	0.04	.677
MIDAS Frequency	0.01	-0.06, 0.08	0.04	0.03	.755
MIDAS Intensity	0.27	-0.52, 1.06	0.40	0.06	.502
IEQ	0.41	0.24, 0.57	0.09	0.45	<.001

Note. R^2 = .11 for Step 1; ΔR^2 = .14 for Step 2 (ps < .001).

b = Unstandardized regression coefficient; β = Standardized regression coefficient; CI = Confidence interval.

Table 12

Demographic Characteristics for Qualitative Participants

Variable	Total N = 10 M(SD) or N(%)	High IEQ N = 5 M(SD) or N(%)	Low IEQ N = 5 M(SD) or N(%)
Age (Total n = 9, High IEQ = 4)	46.6 (13.1)	42.0 (13.2)	50.2 (13.2)
Gender			
Male	1 (10%)	0 (0%)	1 (20%)
Female	9 (90%)	5 (100%)	4 (80%)
Ethnicity (Total n = 9, Low IEQ = 4)			
Not Hispanic or Latino	6 (60%)	2 (40%)	4 (80%)
Hispanic or Latino	3 (30%)	3 (60%)	0 (0%)
Race			
White	5 (50%)	1 (20%)	4 (80%)
Black or African American	3 (30%)	2 (40%)	1 (20%)
Prefer not to say	2 (20%)	2 (40%)	0 (0%)
Sexual Orientation			
Heterosexual	9 (90%)	5 (100%)	4 (80%)
Prefer not to say	1 (10%)	0 (0%)	1 (20%)
Marital Status			
Never married	5 (50%)	3 (60%)	2 (40%)
Married	4 (40%)	1 (20%)	3 (60%)
Prefer not to answer	1 (10%)	1 (20%)	0 (0%)
Education Level			
Some college, no degree	4 (40%)	3 (60%)	1 (20%)
Bachelor's degree	2 (20%)	0 (0%)	2 (40%)
Master's degree	2 (20%)	1 (20%)	1 (20%)
Professional school degree	1 (10%)	0 (0%)	1 (20%)
Unknown	1 (10%)	1 (20%)	0 (0%)

Note. N = 10.

Table 13

Relevant Clinical Characteristics for Qualitative Participants

Variable	Total N = 10 M(SD) or N(%)	High IEQ N = 5 M(SD) or N(%)	Low IEQ N = 5 M(SD) or N(%)
Met migraine criteria via AMPP/AMS	10 (100%)	5 (100%)	5 (100%)
MSQL Total	51.3 (21.5)	32.2 (7.0)	70.4 (8.8)
Role restriction subscale	25.0 (10.8)	15.8 (4.8)	34.2 (5.2)
Role prevention subscale	15.0 (6.4)	9.4 (1.9)	20.6 (3.0)
Emotion Function subscale	11.3 (5.3)	7.0 (3.8)	15.6 (1.8)
IEQ Total	20.6 (16.3)	35.6 (4.8)	5.6 (3.5)
Severity/Irreparability of Loss Subscale	12.5 (8.5)	20.2 (2.6)	4.8 (2.8)
Blame/Unfairness Subscale	8.1 (8.1)	15.4 (3.8)	0.8 (1.1)

Note. N = 10; AMPP = American Migraine Prevalence and Prevention Study; AMS = American Migraine Study; MSQL = Migraine Specific Quality of Life Questionnaire (version 2.1); EQ = Injustice Experience Questionnaire; Severity/Irreparability of Loss = Items 1, 2, 4, 5, 6 and 8 on the IEQ; Blame/Unfairness = Items 3, 7, 9, 10, 11, and 12 on the IEQ

Table 14

Theme One: Coping

Subthemes	Total	High IEQ	Low IEQ
Relationships	4 (4 codes)	2 (2 codes)	2 (2 codes)
Optimism	5 (6 codes)	1 (1 code)	4 (5 codes)
Behavior	4 (5 codes)	3 (4 codes)	1 (1 code)
Toleration	3 (6 codes)	2 (4 codes)	1 (2 codes)

Table 15

Theme Two: Loss

Subthemes	Total	High IEQ	Low IEQ
Social impact	7 (14 codes)	5 (12 codes)	2 (2 codes)
Avoidant	3 (3 codes)	2 (2 codes)	1 (1 code)
Trigger	7 (10 codes)	3 (6 codes)	4 (4 codes)

Table 16

Theme Three: Illness Burden

Subthemes	Total	High IEQ	Low IEQ
Disruption	10 (19 codes)	5 (9 codes)	5 (10 codes)
Social impact	4 (5 codes)	4 (5 codes)	0 (0 codes)
Overwhelming	7 (10 codes)	4 (7 codes)	3 (3 codes)
Exhaustion	2 (2 codes)	1 (1 code)	1 (1 code)
Symptoms	10 (14 codes)	5 (7 codes)	5 (7 codes)
Changes due to age	2 (2 codes)	0 (0 codes)	2 (2 codes)
Scared/Fear	2 (2 codes)	1 (1 code)	1 (1 code)
Anxiety	4 (4 codes)	1 (1 codes)	3 (3 codes)
Depression	8 (10 codes)	5 (6 codes)	3 (4 codes)

Table 17

Theme Four: Misunderstood

Subthemes	Total	High IEQ	Low IEQ
Isolated	5 (5 codes)	3 (3 codes)	2 (2 codes)
Anger	1 (1 code)	1 (1 code)	0 (0 codes)
Co-opting	7 (10 codes)	5 (6 codes)	1 (1 code)

Table 18

Theme One: Illustrative quotes

Theme One: Coping	Participant/ Group	Illustrative quotes
Relationships	Study ID #163, High IEQ Group	"Just having people that are there for you, having people who understand you and having people understand that something is wrong, something is going on with you, is just important; When you're around people that have an understanding of what you live on a daily basis, every day and there to help you cope, then it's worth fighting for, it's worth living for… You have a family that's supporting you and wants you to keep on fighting…"
Optimism	Study ID #161, Low IEQ Group	"You can't be so negative about it because some people have worse things than you."
Behavior	Study ID #185, High IEQ Group	"Whenever I do have free time, I try to get everything done in the morning because I notice in the morning that's when I feel most productive and that's usually when I have the least chance of a headache."
Toleration	Study ID #159, High IEQ Group	"A lot of times I kind of power through it because I kind of have migraine activity all the time."

Table 19

Theme Two: Illustrative quotes

Theme Two: Loss	Participant/ Group	Illustrative quotes
Social impact	Study ID #159, High IEQ Group	“I'm not as social as I once was. Kind of, I've lost touch with a lot of friends and relationships that I had in the past; It puts a strain on relationships I have with family; My migraines have affected our relationship. I shouldn't mention that. We haven't been able to get married because of my migraines and finances and health insurance and things like that...”
Avoidant	Study ID #163, High IEQ Group	“I have to learn not to eat things that's salty, not to eat things that's oily. I can't read for a long period of time; I can't recap the book. I can't eat salty things or oily things. Sometimes the weather is cold, I'm not going to go outside because the cold weather will trigger a headache; I live in a different way. I don't go to events; I don't go to anything with loud music. I don't eat any kind of salty foods or high fat foods or anything like that. I can't scream and yell. I can't read for a long time; I want to read a book. Even using the phone, like Instagram or Facebook, I can't do it for too long because then it starts to bother my eyes…”
Trigger	Study ID #178, High IEQ Group	“Back then, it was the menstrual that used to trigger it. It always came around when I was going to have my period or during my period; I try the AC at 77 where it doesn't affect my head, because of the cold air, when it hits me, it also triggers a migraine... I moved from New York, because I couldn't even take the cold air; if I have a drink or a glass of wine, the likelihood that I'm going to get a migraine is 100% because it triggers it.”

Table 20

Theme Three: Illustrative quotes

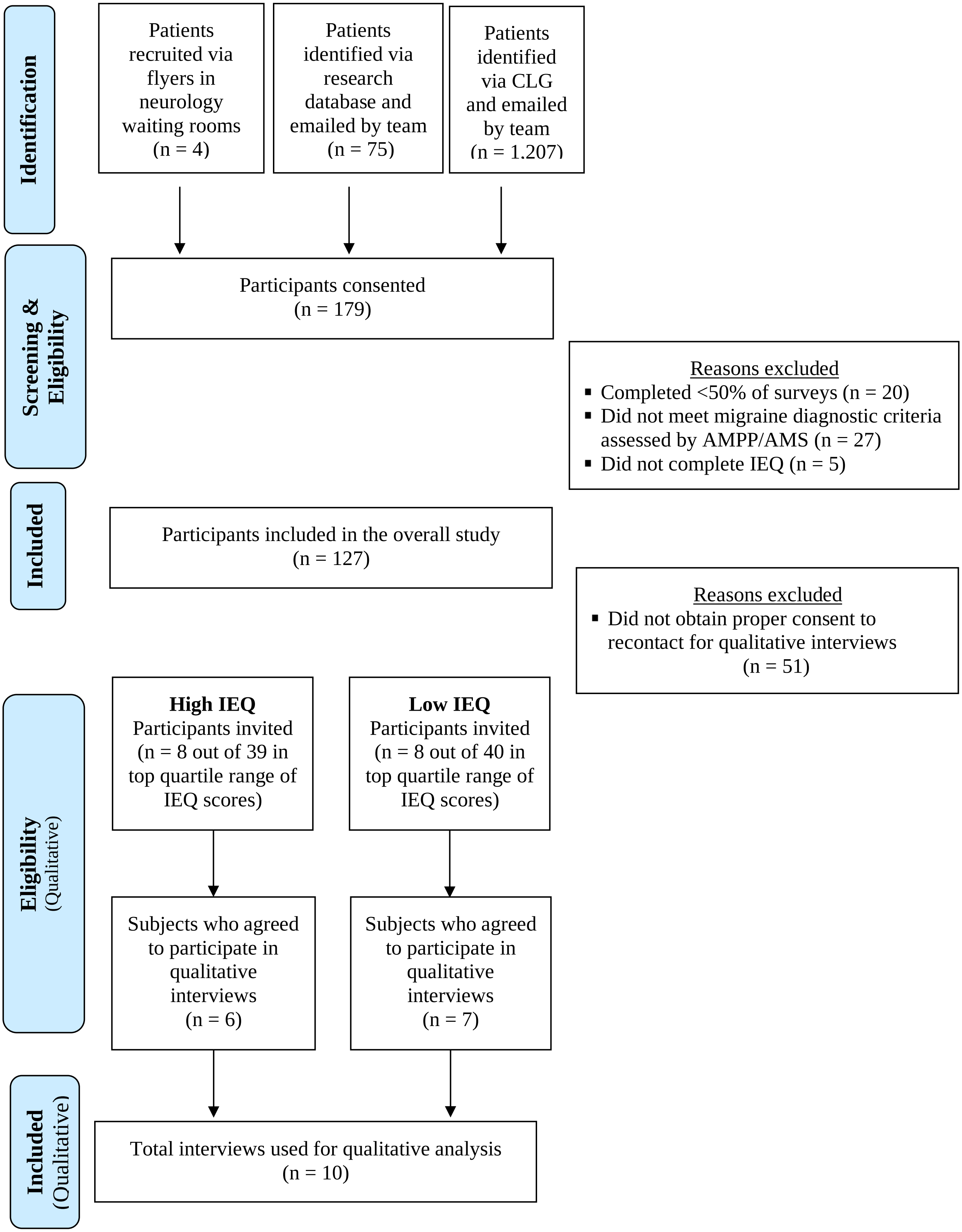
Theme Three: Illness burden	Participant/ Group	Illustrative quotes
Disruption	Study ID #190, Low IEQ Group	"It just makes it hard to just function. I mean you just can't focus; when I get home then I don't cook, I don't do anything. I just kind of shut down; Like when I need to go out and do some shopping maybe a little bit after work I can't; I don't feel like I can do the laundry even."
Social impact	Study ID #163, High IEQ Group	"I think about my life, different from everybody, all the time. People get out and go shopping, go out to eat, take vacations, been partying, those things that I can't do..."
Overwhelming	Study ID #161, Low IEQ Group	"You just feel like your world's coming to an end; ... It feels like your whole world is crashing down. It feels like the end of the world because the pain is so bad. You just want it to go away, but it's not going away. You just lie there; you take your meds and you just pray for the best. That's what it feels like…"
Exhaustion	Study ID #190, Low IEQ Group	"I just want to go home and sit and do nothing… I don't feel like I can do the laundry even. Just your daily tasks that you feel like you need to do, you don't really do because you just want to, you take your pill and you just lay down again."
Symptoms	Study ID #163, High IEQ Group	"Right now, I'm never headache free. Never. I have to learn my limits and live according to what my headaches would be. On the right side of my head there's always pressure there, there's a lot; I know when it's coming on. When I start seeing squiggly lines or black and white shapes or things creeping up the wall, I know one is about to come on. Sometimes they are so debilitating, just even laying on a pillow will hurt. I can't even comb my hair. I can't even touch my scalp because the nerves in my scalp is like, on fire; I can't see with my eyes when migraines are bad. I can't even see out of my right eye. It's ringing in my ear. It's going down my neck and to my shoulders, it's like I'm paralyzed and that I can't even move. The whole right side is like, I'm paralyzed, and I can't even move and that is really scary......like somebody's taking a drill gun and drilling into my head."
Changes due to age	Study ID #170, Low IEQ Group	"I'm hopeful. I mean, I'm 65 years old and with age maybe less. Is it all the medication or is it a function of aging that it's gotten somewhat better…"

Scared/Fear	Study ID #161, Low IEQ Group	Sometimes, I get scared because I don't know if this is how an aneurism feels, that pulsing in my head where that vein is, right there by your pulse by your eyes. Is this an aneurism? That's how bad it really can hurt. I hope it's not an aneurism. Then again, you don't know. That's the worry part that comes in, too.”
Anxiety	Study ID #161, Low IEQ Group	“Sometimes, you get that worry, especially for me when the summertime comes because that's when it's really bad in July; I get worried about them when I actually have them. How long is it going to last? The thing I worry about the most is how long is it going to last…”
Depression	Study ID #190, Low IEQ Group	“I’ve had a really significant period where I was very depressed … Like, my kids would say, "Mom, you’re not the same person anymore." And I’m not. I was a very, very, very happy person. Always enjoyed life and whatever, and after all these things that happened I just kind of ... I never bounced back to the happiest person I was, but I was fine, so I was able to come back around, and I don’t need any anti-depressants or any of that kind of stuff anymore and I was doing fine and everything was good. I do get some depressive things. It tends to be easier once in a while, but I’ve been very good. And now that the headaches and the stress and everything now again, I’ve noticed that I seem to be more on that little ... Not nothing like I had gotten but I tend to be more of that depressive tone again, like that negative ... I don’t know if it’s depressive or just a negative tone. I’m not as peppy.”

Table 21
Theme Four: Illustrative quotes

Theme Four: Misunderstood	Participant/ Group	Illustrative quotes
Isolated	Study ID #159, High IEQ Group	“I'm kind of a little isolated from friends and family; people just kind of moved on because no one wants to be around. If you're young, you don't want to be bogged down with illness or this type of thing. So, they kind of just moved on. They want to be around positivity, and being chronically ill, that's not really positive; I'm sure others have expressed this before, when it comes to the people who they feel abandoned by. I kind of felt that way. I felt that I was there for them, why aren't they here for me?”
Anger	Study ID #15*8*, High IEQ Group	“I feel like it makes me angry a little because I hate to have that feeling of, "Why me?" That kind of thing, it drives me crazy. So, it angers me at the same time that it just the debilitates me so badly.”
Co-opting	Study ID #185, High IEQ Group	“…my parents and I have gotten into disagreements of like, oh, I haven't done anything today. And I'm like, I really did try because migraines. They try to understand, but sometimes they just happen so suddenly it seems to the outside perspective that I'm just very melancholy and depressed. And. of course. they want to know what's going on. I keep telling them it's literally just migraines. And my dad is sort of old school, so he is like, "It's a headache. So how bad could it be?" I'm like, "Oh, quite bad.".... For other people that don't really know what I'm exactly going through, they're pretty much just pretty dismissive like, "Oh, it's a headache. How bad could it be?" And yeah, it's very little understanding…”

Figure 1: Patient Perspective on Migraine Experience Study Flow Diagram/Recruitment



Appendix A: Quantitative Survey

Patient Perspective on Migraine Experience Study

I have read the consent form and I understand that it is up to me whether or not I participate. I know enough about the purpose, methods, risk, and benefits of the research study to decide that I want to take part in it. I understand that I am not waiving any of my legal rights by agreeing to participate.

- Type Name ____
- Date ____
- Email Address ____

If you do not wish to take part in the study, please close your browser window. Thank you for your time.

What is your age (in years)? ______________________________________

What is your gender?

- Male
- Female

Ethnicity (select ONLY one with which you MOST CLOSELY identify):

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown
- Prefer not to say

Race category (choose all that apply):

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Unknown
- Prefer not to say

Sexual orientation

- Heterosexual
- Gay/Lesbian
- Bisexual
- Unknown
- Other
- Prefer not to say

Education Level (What is the highest grade or level of school the completed or the highest degree obtained?)

▼ Never attended/ Kindergarten only ... Unknown

What is your **current** marital status? **(Select ONE Response)**

☐ Never married

☐ Married

☐ Domestic partnership/living with partner but not married

☐ Divorced

☐ Separated

☐ Widowed

☐ Prefer not to answer

What is your current work/ school status? (Check ALL that apply)

☐ Employed full-time (35 or more hours/week)

☐ Employed part-time (less than 35 hours/week)

☐ Self-employed

☐ Student- full time

☐ Student- part time

☐ Homemaker

☐ Retired

☐ Volunteer

☐ Temporary Medical disability or maternity leave

☐ Disabled/ “on Disability”

☐ Unemployed/Not employed

☐ Other

What was your total annual **household** income for 2018? **(Select ONE Response)**

— Less than $15,000

— $15,000 to $24,999

— $25,000 to $34,999

— $35,000 to $49,999

— $50,000 to $74,999

— $75,000 to $99,999

— $100,000 to $124,999

— $125,000 to $149,999

— $150,000 to $199,999

— $200,000 and over

— Prefer not to say

Please answer the following:

— What is your height in inches? (1)
____

— What is your weight in pounds (lbs)? (2)
____

About how old were you when you had your first attack of your most severe headache? (Write in years) ____

What is your most common type of headache? ________________________________

About how old were you when you had your first attack of your most common type of headache? (Write in years) _________________________________

Tell us about your headaches. (Check all that apply)

	I have this headache type	I have been diagnosed by a healthcare professional with this headache type	I am currently under treatment by a healthcare professional for this headache type
Migraine (any type: with aura, a.k.a., “Classical migraine”, without aura, menstrual migraine, hemiplegic migraine	—	—	—
Tension-type headache	—	—	—
Cluster headache	—	—	—
New Daily Persistent Headache	—	—	—
Post-traumatic headache (headache due to traumatic brain injury or concussion)	—	—	—
Other (please specify)	—	—	—

Many people have more than one type of headache. How many different types of headache do you have (by type of headache, we mean headaches that may differ in how they begin or the location of the pain, not necessarily pain severity)?

Specify number (#) of headache types: ______________________________

For the following question, please consider your most severe type of headache and ALL headaches you may have. Please enter the number of <u>days with headache</u> you have. If a headache lasted more than 1 day, count each day. **(Write in numerical number)**

	Days In Past Month	Days In Past 12 Months

	(#)	(#)
Most severe type of headache:		
Headache of any type or intensity (including most severe type of headache):		

Considering your **most severe type of headaches**, please answer how the following statements describe your pain and other symptoms

	Most Severe Type of Headache			
	Never	Rarely	Less Than Half the Time	More Than Half the Time
The pain is worse on just one side.	___	___	___	___
The pain is pounding, pulsating or throbbing.	___	___	___	___
The pain has moderate or severe intensity.	___	___	___	___
The pain is made worse by routine activities such as walking or climbing stairs	___	___	___	___
You feel nauseated or sick to your stomach.	___	___	___	___
Light bothers you (more than when you do not have headaches).	___	___	___	___
Sound bothers you (more than when you do not have headaches).	___	___	___	___

On a scale of 0 - 10, on average, how painful are your most severe type of headaches? (where 0 = no pain at all, and 10 = pain as bad as it can be.)

▼ 0 ... 10

What was your age when you first experienced your most severe type of headache? (in years)

____

Have you had at least one headache in the **past 12 months** that **WAS NOT** caused by a head injury, hangover, or an illness such as a cold or the flu?

▼ No ... Yes

How often do you experience increased pain or an unpleasant sensation on your skin during your most severe type of headache when you engage each of the following?

	Does not apply to me	Never	Rarely	Less than half the time	Half the time or more
Wearing a necklace:	___	___	___	___	___
Wearing earrings:	___	___	___	___	___
Wearing glasses:	___	___	___	___	___
Wearing tight clothes:	___	___	___	___	___
Wearing a pony tail:	___	___	___	___	___
Wearing contact lenses:	___	___	___	___	___
Shaving the face:	___	___	___	___	___
Taking a shower:	___	___	___	___	___
Combing the hair:	___	___	___	___	___
Resting the head on a pillow:	___	___	___	___	___
Exposure to cold:	___	___	___	___	___
Exposure to heat:	___	___	___	___	___

Have you ever had vision changes just prior to or with any headache? **(Select ALL That Apply)**

— Yes spots, stars, lines, flashing lights, zigzag lines, or “heat waves”

— Yes, loss of vision or partial loss of vision

— No

— Don’t remember

If yes to the question above, how many times have you experienced these visual changes in the past 12 months? **(Select ONE Response)**

— No times in the past 12 months

— One time

— Two to four times

— With most of the headaches

— With every headache

— Don’t remember

How many times have you experienced these visual changes with headache in your life? **(Select ONE Response)**

— One time

— Two to four times

— With most of the headaches

— With every headache

— Don’t remember

— Never

Have you had at least 1 headache in the last year with these visual changes?

- No
- Yes

How often do you have these changes in vision with your most severe type of headache?

- Not at all
- Rarely
- Sometimes
- Often
- All the time

How long do these changes in your vision last on average? (Number of minutes) ________

Have you ever had a feeling such as numbness or tingling in any part of your body or face (that was not associated with treatment) just prior to or with **any** headache?

- Yes
- No
- Don’t know

How many times have you experienced these sensory changes with headache in your life? **(Select ONE Response)**

- One time
- Two to four times
- With most of the headaches
- With every headache
- Don’t remember

Because of your headaches, on **how many days** in the last 3 months … (**Write In Number Of Days For EACH**)

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?: _______

Total : ________

Q38 In the **last 3 months** (past 90 days)… On how many days did you have a headache of any type or intensity? If a headache lasted more than 1 day, count each day.

▼ 0 ... 90

On a scale of 0 - 10, on average, how painful were these headaches? (where 0 = no pain at all, and 10 = pain as bad as it can be.)

▼ 0 ... 10

In the **last 3 months** (past 90 days)…
On how many **full days** (from the time you woke up to the time you went to sleep) were you completely free of headache pain or head discomfort?

▼ 0 ... 90

Q62 Have you been diagnosed with any of the following? (Check all that apply)

☐ Alzheimer’s Disease

☐ Amyotrophic Lateral Sclerosis (ALS)

☐ Anxiety

☐ Arthritis

☐ Asthma

☐ Ataxia

☐ Autism

☐ Bipolar

☐ Brain aneurysm

☐ Cancer

☐ Cerebral Palsy

☐ Dementia

☐ Depression

☐ Developmental delays

☐ Diabetes mellitus

☐ Dystonia

☐ Eating Disorder

☐ Eczema

☐ Endometriosis

☐ Epilepsy

- Fibromyalgia
- Gastroparesis
- Heart disease
- Insomnia
- Intracerebral hemorrhage
- Ischemic stroke
- Mild Cognitive Decline (Memory Loss)
- Multiple Sclerosis (MS)
- Obesity
- Obsessive-compulsive Disorder (OCD)
- Painful Bladder syndrome/Interstitial Cystitis
- Polycystic Ovary Syndrome (PCOS)
- Post Traumatic Stress Disorder (PTSD)
- (Pre)eclampsia
- Raynaud’s Syndrome
- Restless Leg Syndrome (RLS)
- Schizophrenia
- Sleep apnea
- Substance Abuse Disorder
- Systemic lupus erythematosus (SLE)
- Thyroid Disease

- Tourette’s Syndrome
- Traumatic brain injury
- Tremor
- Vertigo
- Other, please specify: ______________________________
- None

Please list all **proscribed medications** that you are currently taking for headache or migraine attacks:

____

Please list all **over-the-counter medications** that you are currently taking for headache or migraine attacks:

____

Q64 How satisfied are you with your current headache treatment?

- Extremely satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Extremely dissatisfied

While answering the following questions, please think about all migraine attacks you may have had in the past 4 weeks.

In the past 4 weeks, how often has migraines interfered with how well you dealt with family, friends and others who are close to you?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often has migraines interfered with your leisure time activities, such as reading or exercising?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often have you had difficulty in performing work or daily activities because of migraine symptoms?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often did migraines keep you from getting as much done at work or at home?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often did migraines limit your ability to concentrate on work or daily activities?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often has migraines left you too tired to do work or daily activities?

— None of the time

— A little bit of the time

— Some of the time

— A good bit of the time

— Most of the time

— All of the time

In the past 4 weeks, how often has migraines limited the number of days you have felt energetic?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often have you had to cancel work or daily activities because you had a migraine?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often did you need help in handling routine tasks such as every day household chores, doing necessary business, shopping, or caring for others, when you had a migraine?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often did you have to stop work or daily activities to deal with migraine symptoms?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often were you not able to go to social activities such as parties or dinner with friends, because you had a migraine?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

Q33 In the past 4 weeks, how often have you felt fed up or frustrated because of your migraines?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often have you felt like you were a burden on others because of your migraines?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

In the past 4 weeks, how often have you been afraid of letting others down because of your migraines?

- None of the time
- A little bit of the time
- Some of the time
- A good bit of the time
- Most of the time
- All of the time

Migraine can have profound effects on our lives. This scale was designed to assess how migraine has affected your life. Listed below are twelve statements describing different thoughts and feelings that you may experience when you think about your migraine. Using the following scale, please indicate how frequently you experience these thoughts and feelings when you think about your migraine.

	Never	Rarely	Sometimes	Often	All the time
Most people don't understand how severe my migraine is.	___	___	___	___	___
My life will never be the same.	___	___	___	___	___
I am suffering because of someone else's negligence.	___	___	___	___	___
No one should have to live this way.	___	___	___	___	___
I just want to have my life back.	___	___	___	___	___
I feel that this has affected me in a permanent way.	___	___	___	___	___
It all seems so unfair.	___	___	___	___	___
I worry that my migraine is not being taken seriously.	___	___	___	___	___
Nothing will ever make up for all that I have gone through.	___	___	___	___	___
I feel as if I have been robbed of something very precious.	___	___	___	___	___
I am troubled by fears that I may never achieve my dreams.	___	___	___	___	___
I can't believe this has happened to me.	___	___	___	___	___

Below you will find a list of statements. Please rate the truth of each statement as it applies to you based on your experience with headache.

	Not at all	Rarely	Sometimes	Often	All the time
Because of my illness, some people seemed uncomfortable with me:	—	—	—	—	—
Because of my illness, some people avoided me:	—	—	—	—	—
Because of my illness, I felt left out of things:	—	—	—	—	—
Because of my illness, people were unkind to me:	—	—	—	—	—
Because of my illness, people avoided looking at me:	—	—	—	—	—
I felt embarrassed about my illness:	—	—	—	—	—
I felt embarrassed because of my physical limitations:	—	—	—	—	—
Some people acted as though it was my fault I have this illness:	—	—	—	—	—

Below you will find a list of statements. Please rate the truth of each statement as it applies to you based on the pain you experience from headache.

	Not at all	Rarely	A moderate amount	Often	All the time
I worry all the time about whether the pain will end:	___	___	___	___	___
I feel I can't go on:	___	___	___	___	___
It's terrible and I think it's never going to get any better:	___	___	___	___	___
It's awful and I feel that it overwhelms me:	___	___	___	___	___
I feel I can't stand it anymore:	___	___	___	___	___
I become afraid that the pain may get worse:	___	___	___	___	___
I think of other painful experiences:	___	___	___	___	___
I anxiously want the pain to go away:	___	___	___	___	___
I can't seem to keep it out of my mind:	___	___	___	___	___
I keep thinking about how much it hurts:	___	___	___	___	___
I keep thinking about how badly I want the pain to stop:	___	___	___	___	___
There is nothing I can do to reduce the intensity of the pain:	___	___	___	___	___
I wonder whether something serious may happen:	___	___	___	___	___

Please respond to each question or statement by marking one box per row.
In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
I felt fearful	___	___	___	___	___
I found it hard to focus on anything other than my anxiety	___	___	___	___	___
My worries overwhelmed me	___	___	___	___	___
I felt uneasy	___	___	___	___	___
I felt nervous	___	___	___	___	___
I felt like I needed help for my anxiety	___	___	___	___	___
I felt anxious	___	___	___	___	___
I felt tense	___	___	___	___	___

In the past 7 days... (Please mark one box per row.)

	Never	Rarely	Sometimes	Often	Always
I felt worthless	___	___	___	___	___
I felt helpless	___	___	___	___	___
I felt depressed	___	___	___	___	___
I felt hopeless	___	___	___	___	___
I felt like a failure	___	___	___	___	___
I felt unhappy	___	___	___	___	___
I felt that I had nothing to look forward to	___	___	___	___	___
I felt that nothing could cheer me up	___	___	___	___	___

Below you will find a list of statements. Please rate the truth of each statement as it applies to you.

	Never True	Very Rarely True	Rarely True	Sometimes true	Frequently True	Almost Always True	Always True
I must limit my activities to avoid anything that might trigger a headache:	___	___	___	___	___	___	___
I avoid making plans if I think I might get a headache:	___	___	___	___	___	___	___
I avoid putting myself in situations where I might get a headache:	___	___	___	___	___	___	___
My headaches keep me from trying to be productive:	___	___	___	___	___	___	___
I would gladly sacrifice important things in my life to better control my headaches:	___	___	___	___	___	___	___
I am doing my best to live a normal life with my headaches:	___	___	___	___	___	___	___

Below you will find a list of statements. Please rate the truth of each statement as it applies to you.

	Never True	Very Rarely True	Seldom True	Sometimes true	Often True	Almost Always True	Always True
I am getting on with the business of living no matter what my level of headache is:	—	—	—	—	—	—	—
My life is going well, even though I have headaches:	—	—	—	—	—	—	—
It’s okay to experience headache:	—	—	—	—	—	—	—
I would gladly sacrifice important things in my life to control this headache better:	—	—	—	—	—	—	—
It’s not necessary for me to control my headaches in order to handle my life well:	—	—	—	—	—	—	—
Although things have changed, I am living a normal life despite my headaches:	—	—	—	—	—	—	—
I need to concentrate on getting rid of my headache:	—	—	—	—	—	—	—
There are many activities I do when I feel headache:	—	—	—	—	—	—	—
I lead a full life even though I have headache:	—	—	—	—	—	—	—
Controlling headache is less important than any other goals in my life:	—	—	—	—	—	—	—

My thoughts and feelings about headache must change before I can take important steps in my life:	___	___	___	___	___	___	___
Despite the headache, I am now sticking to a certain course in my life:	___	___	___	___	___	___	___
Keeping my headache level under control takes first priority whenever I’m doing something:	___	___	___	___	___	___	___
Before I can make any serious plans, I have to get some control over my headache:	___	___	___	___	___	___	___
When my headache increases, I can still take care of my responsibilities:	___	___	___	___	___	___	___
I will have better control over my life if I can control my negative thoughts about headache:	___	___	___	___	___	___	___
I avoid putting myself in situations where my headache might increase:	___	___	___	___	___	___	___
My worries and fears about what pain will do to me are true:	___	___	___	___	___	___	___
It’s a relief to realize that I don’t have to change my headache to get on with my life:	___	___	___	___	___	___	___
I have to struggle to do things when I have headaches:	___	___	___	___	___	___	___