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CHRONIC MIGRAINES AND COUPLES: A GROUNDED THEORY OF  
ADAPTATION TO CHRONIC MIGRAINES FOR PATIENTS  
AND THEIR PARTNERS

by

Douglas P. McPhee

A thesis submitted in partial fulfillment  
of the requirements for the degree

of

MASTER OF SCIENCE

in

Marriage and Family Therapy

Approved:

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UTAH STATE UNIVERSITY  
Logan, Utah

2018

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## ABSTRACT

Chronic Migraines and Couples: A Grounded Theory of Adaptation to Chronic Migraines  
for Patients and their Partners

by

Douglas P. McPhee, Master of Science

Utah State University, 2018

Major Professor: Dr. Dave Robinson  
Department: Marriage and Family Therapy

Chronic migraines are a leading cause of disability, worldwide. I have developed a grounded theory of adaptation to chronic migraines for patients and their partners. The impact of chronic migraines upon patients' partners has largely been ignored. Furthermore, prior to this study, very little was understood about chronic migraines' effect upon couple dynamics. Utilizing grounded theory methodology, I interviewed eight couples affected by chronic migraines. Data were gathered and analyzed using the constant comparative method. A team of seven researchers utilized open coding, axial coding, and selective coding to analyze the data. My grounded theory of adaptation to chronic migraines for patients and their partners is presented in what follows. The burdens and costs of migraines emerged as the central category from the data. Four major categories, coping, healthcare, couple dynamics, and identity, emerged as well. These major categories were the means through which patients or their partners adapted to the burdens and costs of chronic migraines. Subcategories associated with the central category and major categories are detailed. The implications of this study upon

couples dealing with chronic migraines, medical providers, and therapists are provided. As part of this grounded theory, a diagram was developed that can be used to visually demonstrate the effectiveness with which couples are able to adapt to the burdens and costs of migraines.

(145 pages)

## PUBLIC ABSTRACT

Chronic Migraines and Couples: A Grounded Theory of Adaptation to Chronic Migraines  
for Patients and Their Partners

Douglas P. McPhee

This study was completed to better understand and treat couples wherein one partner suffers from chronic migraines. I interviewed eight couples about their experiences in dealing with migraines as a patient, as a partner, and together. The interviews were transcribed and analyzed by a team of seven researchers. We developed a theory that can be used to understand how patients and their partners adapt to chronic migraines. The theory was grounded in the experiences of the patients and partners who were interviewed. We found that patients and partners alike dealt with burdens and costs associated with chronic migraines. Coping, healthcare, couple experience, and identity were found to be the means through which patients and partners adapted to their burdens. These concepts are broken down and discussed in greater detail. A model is provided that can be used to create a visual representation of how well a couple deals with migraines. Suggestions for couples who are dealing with chronic migraines, and for medical providers and therapists who work with couples affected by chronic migraines, are provided.

## ACKNOWLEDGMENTS

I am deeply grateful for the contributions of Drs. Dave Robinson, Julie Gast, and Ryan Seedall to this project. As my major adviser, Dr. Robinson read more drafts of my thesis than I care to count. Feedback from Dr. Gast and Dr. Seedall served to further refine and improve my study. I consider myself very lucky to have benefitted from the mentorship of these three wonderful scholars.

Hannah Anderson, Sergio Alvarez, Andrew Jensen, Sarah Jensen, Adam Johnson, and Emma Krygsman were the members of my data analysis team. We spent many hours together. As a group, we cared deeply about our participants' experiences and worked to analyze them appropriately. Thank you, team, for your passion, commitment, and camaraderie. I'm glad that, along the way, we became friends. I must give additional thanks to Hannah, Andrew, Sarah, and Adam for participating in the transcription process. Transcription is painstaking work, and they did it without complaint. I'm also grateful to the efforts of Alex Rawle in helping me market my study.

This project would have been impossible without the love, support, and sacrifice of my family. Space prevents me from thanking each of them adequately. I am most grateful, though, for my wife, Micael. I spent hundreds of hours away from her and our baby because of this study. She, along with my father-in-law, Roger Mann, served as my editors. On many occasions, when I was feeling inadequate and exhausted, she strengthened me and pushed me onward. She deserves as much recognition for this study as I do. To all my family members who enabled this study's completion, I express my thanks.

Lastly, I wish to thank the 16 people who let me interview them about their experiences with chronic migraines. When I began this project, I wanted badly to conduct a study that would be helpful to couples affected by headaches. As I met each of you, and learned from you, my desire to get this study right grew even more. Thank you for being my inspiration.

Douglas P. McPhee



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# CHAPTER I

## INTRODUCTION

Fifteen percent of the people in the United States suffer from migraines<sup>1</sup> (Burch, Loder, Loder, & Smitherman, 2015). The Institution for Health Metrics and Evaluation [IHME] (2013) ranked migraine as the third most prevalent disorder in the world. Migraines are classified as either episodic or chronic (Headache Classification Committee of the International Headache Society III [hereafter cited as ICDH-III], 2013). For many episodic sufferers, migraines are rare, sporadic, and do not seriously impact their lives. However, chronic migraine sufferers experience migraines with a consistency and frequency that can disable them. Migraine is the third-highest cause of disability in the world for men and women under the age of 50 (IHME, 2013). To be diagnosed with chronic migraines, one must deal with headaches on at least 15 days a month for three months and must have migraines on at least eight of those days each month (ICDH-III, 2013). The global prevalence of chronic migraines per year falls somewhere between 0.9%-5.1% (Natoli et al., 2010).

Despite voluminous medical research exploring ways to treat and prevent migraines (Chaibi & Russell, 2014; Chiang & Starling, 2017; Chiu, Yeh, Huang, & Chen, 2016; Prousky & Seely, 2005; van Dongen et al., 2017; Wang & Young, 2011), a cure remains elusive. As Wang and Young (2011) noted, treating chronic migraines is a “difficult task” that “requires multidisciplinary approaches” (p. 1508). Common

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<sup>1</sup> Medical literature typically uses the term "migraine" in the singular; e.g., "The patient suffers from migraine." Whereas the term "migraines" is more natural-sounding to a general audience, this study will refer to migraine headaches as "migraines."

treatment approaches include pharmacological treatment, Onabotulinum toxin A (BOTOX) injection, acupuncture, physical therapy, and massage therapy (Chaibi & Russell, 2014; Chiang & Starling, 2017; Wang & Young, 2011). Each of these treatments attempt to target patient physiology in order to produce migraine relief. Still, for many migraine sufferers, these treatments only produce “modest” or “unsatisfactory” gains (Wang & Young, 2011, p. 1507).

Current treatment methods usually fail to treat psychosocial-spiritual symptoms associated with chronic migraines. In addition to experiencing chronic physiological pain, migraine sufferers also cope with psychological, social, and spiritual distress that is associated with their headaches. Chronic migraine patients deal with high rates of anxiety, depression, and are at risk for suicidal behaviors (Friedman, Zhong, Gelaye, Williams, & Peterlin, 2018; Novic, Kolves, O’Dwyer, & De Leo, 2016). They also experience significant relational distress and feel that their migraines burden those they love (Nichols et al., 2017). Psychological and social distress appear to be both outcomes of and triggers for chronic migraines. Anxiety, stress, and poor sleep are well-documented triggers for migraines (Ascha, Kurlander, Sattar, Gatherwright, & Guyuron, 2017). Furthermore, depression, anxiety, poor sleep, and high stress are some of the strongest predictors of treatment outcomes for chronic migraines (Probyn et al., 2017). Thus, while psychosocial distress results from experiencing chronic migraines, chronic migraines also result from psychosocial distress. Evidence for the usefulness of more holistic chronic migraine treatment is found in a recent study that examined the effectiveness of mindfulness in treating migraines. Utilizing mindfulness produced a 50% reduction in headaches for chronic migraine patients (Grazzi et al., 2017). It is

unlikely that improving treatment for patients' psychosocial-spiritual distress will cure them entirely from migraines; however, it should improve symptoms and help them to better adapt to their illness.

Medical family therapy (MedFT) literature highlights the effectiveness of using a systemic, relational approach when providing biopsychosocial-spiritual treatment (Hodgson, Lambson, Mendenhall, & Crane, 2014). MedFT is a burgeoning field of psychotherapy. Medical family therapists (MedFTs) work in concert with physicians and other medical providers, offering patients integrated care (McDaniel, Hepworth, & Doherty, 2014). They recognize that illness is a biological, psychological, social, and spiritual experience (Hodgson et al., 2014). Furthermore, they understand that illness is not an isolated affair; entire families are deeply impacted by a patient's illness (Rolland, 2018). Thus, MedFTs include significant members of a patient's family system in the treatment process. In adult relationships, this family member is most often the patient's partner. Including the partner in therapy serves dual purposes. First, the partner's struggles are heard, validated, and treated. Second, by including the partner in treatment, the patient receives better care. The partner learns how to better support and serve his/her ill loved one. The utility of this approach to therapy is well-documented. Fischer, Baucom, and Cohen (2016) found that in some cases, using couples therapy to treat psychological disorders and chronic health conditions was more effective than treating the patient individually. MedFT research has highlighted the need for a systemic approach to treatment with couples affected by numerous illnesses, including cancer, diabetes, and Parkinson's disease, to name a few (Aamar, Lamson, & Smith, 2015;

Hodgson, Garcia, & Tyndall, 2004; Hodgson, McCammon, Marlowe, & Anderson, 2012). But, prior to this study, chronic migraines were rarely mentioned in this literature.

To achieve a more complete understanding of the chronic migraine experience and to enable better and more systemic migraine treatment, I have created a grounded theory of adaptation to chronic migraines for patients and their partners. This is the first study to explore partners' biopsychosocial-spiritual experiences as they are affected by chronic migraines. Partners of chronic migraine patients do not, themselves, experience chronic migraines, but they are impacted by chronic migraines, nonetheless. In the extant literature, the experiences of partners of chronic migraine patients have largely been ignored. Yet, in a systematic review of qualitative literature, "strained relationships" was identified as one of three major, overarching themes across qualitative chronic migraine research (Nichols et al., 2017, p. 5). Through this study, I explore how both patients and partners are affected by and adapt to chronic migraines. This is also the first study to put chronic migraines in the context of couple relationships. As such, my findings provide insight into the relational processes associated with chronic migraines. I identify how the attitudes and behaviors of patients and partners serve to minimize or exacerbate each other's distress. Thus, my grounded theory illustrates the usefulness of a systemic approach to treating chronic migraines.

In conclusion, my study aims to address two major gaps in the chronic migraine literature. First, research indicates that chronic migraines cause relationship strain and negatively influence partners (Nichols et al., 2017). However, the impact of chronic migraines upon patients' partners has never been explored. I address this gap by studying the biopsychosocial-spiritual impact of chronic migraine on patients as well as their

partners. Second, I explore relational processes that impact couples' experiences as they deal with chronic migraines. Though MedFT research highlights how valuable couples therapy can be when helping couples who are dealing with an illness (Hodgson et al., 2014), there is minimal research exploring the relational dynamics that shape chronic migraine patients' and their partners' experiences. This study helps fill this gap. My research questions address the highlighted gaps in the chronic migraine literature. The questions are as follows: *In couple relationships wherein one partner experiences chronic migraines, what is the biopsychosocial-spiritual impact of chronic migraines on both partners? In couples dealing with chronic migraines, what biopsychosocial-spiritual processes and factors affect how effectively they adapt to chronic migraines?* By seeking answers to these questions, I have sought to provide patients, partners, therapists, and other health-care providers with information that will enable better coping with chronic migraines.



## **CHAPTER II**

### **LITERATURE REVIEW**

In this chapter, I review the theories that ground my study and the empirical findings it is built upon. The biopsychosocial-spiritual model and family systems theory provide the theoretical frameworks guiding this research. I describe these theories and how they are applied within this study. Then, I elucidate past research that pertains to this project. The diagnostic classification for chronic migraines is provided and treatment options for chronic migraine patients are discussed. I next discuss research pertaining to the psychosocial-spiritual impact of chronic migraines upon patients. Finally, I review research exploring the effect of migraines upon the partners of patients who suffer from them.

#### **Biopsychosocial-Spiritual Model**

In shaping my study, I relied upon the biopsychosocial-spiritual (BPS-S) model. Engel (1977) challenged the traditional, biomedical approach to modern medicine when he presented his biopsychosocial model. Seeking to remedy the fragmentation of health-care and stressing that the medical community fails to provide patients with holistic treatment, Engel presented his comprehensive model of human health. He theorized that biology, psychology, and sociality are each vital, interconnected components of a person's overall health. Engel's model has continued to be refined and shaped since its proposal four decades ago. Spirituality has since been included by some as a fourth component of overall health (Hodgson et al., 2014). Burgeoning research indicates that spirituality is a protective factor in mental and

emotional health (Hodgson et al., 2014). The BPS-S model pushes for holistic treatment which recognizes biological, psychological, social, and spiritual factors as integral, intertwined components of a whole person and his/her well-being (McDaniel et al., 2014).

Proponents of the BPS-S model do not discount the significance of biology in human health, but they do not give biology exclusive prominence, either. Failure to address psychology, sociality, and spirituality in understanding and treating illness is reductionistic and ineffective (Engel, 1977; McDaniel et al., 2014). Extant research regarding the chronic migraine experience has done a fair job of exploring psychological impacts of chronic migraines upon patients (Friedman et al., 2018; Novic et al., 2016). Less is understood about migraines' social impact upon patients, and less, still, is understood about migraines' spiritual effects. Furthermore, the experiences of chronic migraine patients' partners have received virtually no attention in the chronic migraine literature. We know very little about their biopsychosocial-spiritual experiences as they cope with the effects of chronic migraines. With this study, I have provided couples dealing with chronic migraines a more holistic exploration of their illness experience. Efforts such as these are needed in order to more fully understand chronic migraines' impacts.

The BPS-S model also has important implications when applied to chronic migraine treatment. Treatment methods discussed within the extant literature focus largely upon physiology. Pharmacological treatment is, by far, the most common method to treat chronic migraines (Wang & Young, 2011). Other approaches to chronic migraine treatment include BOTOX, acupuncture, physical therapy, and massage therapy (Chaibi

& Russell, 2014; Chiang & Starling, 2017; Wang & Young, 2011). Each of these methods primarily utilize physiological methods to provide migraine relief. There is a dearth of research exploring the use of psychosocial-spiritual processes in chronic migraine treatment. Psychotherapy, clerical services, or support groups are rarely, if ever, mentioned in chronic migraine literature. Grounded in the BPS-S, I believe that to receive the highest-quality care, chronic migraine patients should receive effective psychosocial-spiritual care in addition to receiving physiological treatment. Thus, in this study, I have sought to identify psychosocial-spiritual processes that served to either improve or worsen how effectively couples adapted to chronic migraines. Hopefully, these findings can be useful to clinicians as they provide care to chronic migraine patients and their partners.

### **Family Systems Theory**

The lens provided by family systems theory was also invaluable in the design of my study. Family systems theory is the product of different theorists who, over the course of multiple decades, applied cybernetic philosophy to the study of families (Smith & Hamon, 2012). These theorists conceptualized families as systems of interconnected and interdependent individuals (Smith & Hamon, 2012). When patients suffering from chronic migraines are viewed through family systems theory's lens, it is obvious that migraines impact entire families. No individual suffers in isolation (Rolland, 1994). A patient's experience with chronic migraines affects and shapes the experiences of his/her family members, and vice versa. Generally, when the experiences of patients with chronic migraines have been studied, minimal attention has been paid to the patient's story as it fits within the larger context of their family experience. In this study, I

interviewed chronic migraine patients and their partners together. I studied chronic migraines within the context of couple relationships. Furthermore, when applicable, I asked about how migraines impacted their children, parents, or other family members. Thus, I took a uniquely systemic approach to studying chronic migraines.

In this study, I interviewed chronic migraine patients and their partners. I believe asking chronic migraine patients' children, parents, or siblings about their experiences is worthwhile and important. However, in most cases, it is the partner who serves as a patient's primary caregiver when he/she is disabled with a migraine. Because of this, I felt that we could improve psychosocial-spiritual treatment for chronic migraines the most by coming to understand the partner's experience, as well as the couple dynamics and processes that influence their well-being, and I chose to narrow interviews in on the partner's experience and the couple's dynamics. By coming to understand the experiences of both patients and their partners, we will be able to provide couples dealing with chronic migraines better psychotherapy.

Boszormenyi-Nagy (henceforth: Nagy) was a pioneer in marriage and family therapy who drew from family systems as he theorized about relational ethics and family dynamics; his theorizations are receiving increasing attention in recent literature (Boszormenyi-Nagy & Krasner, 1986; Meiden, Nordegraaf, & Ewijk, 2017). He theorized that couples experience feelings of trust and safety when their relationship is fair and balanced (Hargrave & Pfitzer, 2011). Nagy spoke often about what he called the relational give-and-take. In couple relationships, he believed it was imperative for partners to give to and receive from each other in a manner that they perceive as balanced (Boszormenyi-Nagy & Krasner, 1986). He stressed that relational balance did not result

from a perfectly equal ratio of giving and receiving between partners. There are times where one partner gives more to the relationship than he/she is receiving. That is okay, as long as there is an appropriate oscillation in these patterns that allows partners to feel relational balance (Hargrave & Pfitzer, 2011). Nagy believed that frustration, exhaustion, and guilt resulted when a sense of fairness and trustworthiness was absent from one's relationship (Boszormenyi-Nagy & Krasner, 1986). As I, along with my research team, collected and analyzed our data from couples experiencing chronic migraine, we<sup>2</sup> began to see evidence of Nagy's theorizations within the experiences of the couples who were interviewed. Nagy's ideas aided us in developing our grounded theory and understanding the relational dynamics our participants reported.

### **Chronic Migraines: Symptoms and Diagnostics**

In this section, I move away from my review of the theories that were used to shape my study, and I proceed to review literature pertinent to my study. First, I discuss the physiological symptoms associated with chronic migraines. Migraines are slightly more prevalent amongst women than men and can be experienced throughout the lifespan (Harms, 2005). Migraines strike suddenly, and patients cannot easily predict when an attack will strike. There are some triggers that can lead to patients experiencing an attack, such as caffeine, stress, certain foods, weather patterns, intense physical exertion, and sleep patterns (Ascha et al., 2017). Some migraines persist unpredictably, even when triggers are avoided. For some patients, migraines are accompanied by aura, “a fully

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<sup>2</sup> I am the sole author of my thesis, and throughout my paper I generally utilize first-person singular (I/my) point of view. However, when describing data analysis and presenting findings, I use first-person plural (we/our) point of view to respect the contributions of the other six researchers who worked with me analyzing the data.

reversible visual, sensory, and/or speech/language symptom” (gleam of light, blurred vision, numbness, difficulty speaking, etc.), which is followed by a migraine within 60 minutes (ICDH-III, 2013, p. 646; Napolitano, 2007). When individuals experience a migraine attack, the degree of incapacitation can be quite severe. Migraines generally make patients particularly sensitive to light and sound. Thus, for the duration of their attack, migraine patients are often incapacitated, resting in a dimly lit, quiet room as they attempt to manage the moderate to severe pain they are experiencing (Nichols et al., 2017). To be diagnosed with chronic migraines, one must deal with headaches on at least 15 days a month for three months and must have migraines on at least eight of those days each month (ICDH-III, 2013). The diagnostic criteria for chronic migraines is provided in Table 1 (ICDH-III, 2013).

Table 1

*Diagnostic Criteria for Chronic Migraines*

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To be diagnosed with chronic migraines, one must deal with headaches on at least 15 days a month for three months and must have migraines on at least eight of those days each month. The diagnostic symptoms of a migraine are as follows:

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1. Headache lasts 4-72 hours (untreated or unsuccessfully treated)
  2. Headache has at least two of the following characteristics:
    - Unilateral location
    - Pulsating quality
    - Moderate or severe intensity
    - Aggravation by or causing avoidance of routine physical activity (e.g, walking or climbing stairs)
  3. The patient experiences at least one of the following during the headache:
-

- 
- Nausea and/or vomiting
  - Photophobia (sensitivity to light) and Phonophobia (sensitivity to sound)
4. History, physical examination, and neurological examination do not suggest underlying organic disease
- 

### **Treatment**

Having discussed the physiological symptoms associated with migraines, I now briefly review medical treatments for migraines and their effectiveness. The gold standard in treating severe migraine is the use of triptans or other migraine-specific agents (Harms, 2005). Randomized, placebo-controlled trials have shown that topiramate and botulinum neurotoxin can effectively minimize pain and reduce frequency of migraines for patients with chronic migraines (Chiang & Starling, 2017). Yet, these prescriptions do not work for all chronic migraine patients and can possess harmful side-effects (Wang & Young, 2011). For patients who are able to utilize these treatments, their effectiveness has been described as “only modest,” and as “unsatisfactory” (Wang & Young, 2011, p. 1507). Before prescribing these medications, it is recommended that migraines be treated with pain relievers such as NSAIDs, aspirin, or acetaminophen, and caffeine combinations (Harms, 2005). But these combinations are regularly ineffective (Harms, 2005). It is clear that medicine alone is insufficient in providing chronic migraine patients with relief. As Wang and Young explained, despite medical advances, “treatment of chronic migraines remains a difficult task and always requires multidisciplinary approaches” (Wang & Young, 2011, p. 1508).

Other common, evidence-based approaches to treating chronic migraines include Onabotulinum toxin A (BOTOX) injection, acupuncture, physical therapy, and massage therapy (Chaibi & Russell, 2014; Chiang & Starling, 2017; Wang & Young, 2011). BOTOX is the most-researched of these approaches and has been approved by the Food and Drug Administration (FDA) as a valid treatment for chronic migraines (Amirlak, Sanniec, Pezeshk, & Chung, 2016). Research evaluating the effectiveness of acupuncture, physical therapy, and massage therapy in treating chronic migraine is still in its infancy (Wang & Young, 2011). However, several reliable studies have been produced for each approach, indicating that acupuncture, physical therapy, and massage therapy can help alleviate chronic migraine symptoms (Chiang & Sterling, 2017; Wagner & Young, 2011). None of these alternative methods serve as cures to chronic migraines. There are many chronic migraine patients who try all available treatment approaches, and their migraines persist.

There is some recent literature examining the benefits of mindfulness for chronic migraine treatment. One study with 107 migraine patients found that mindfulness significantly reduced pain-related stress (Feuille & Pergament, 2013). Oinonen (2017) described mindfulness as an essential component of effective chronic migraine treatment. Grazzi et al. (2017) found in their study that the majority of patients who attended weekly mindfulness training for 6 weeks and practiced mindfulness for 10 minutes a day experienced a 50% reduction in their headaches compared with baseline. Despite its significant potential to improve migraine symptoms, though, mindfulness appears to be an underutilized treatment method (Oinonen, 2017).



## **Psychosocial-Spiritual Impact upon Patients**

Having outlined a foundational understanding of the biological symptomology of migraines and how they are treated, I will now review what is known about the psychosocial-spiritual impact of migraines upon chronic patients. I address psychology, sociality, and spirituality separately. In general, research examining the psychological impact of chronic migraines and patients' social experiences are fairly robust. The effect of chronic migraines upon patient's spirituality is the least understood.

### **Psychological**

The relationship between chronic migraines and psychological distress appears to be bi-directional. Chronic migraines result in potentially severe psychological distress for chronic migraine patients. A study conducted from an Italian specialty headache clinic found that chronic migraine sufferers reported significantly lower scores on measures of quality of life than episodic migraine patients (Leonardi, Raggi, Bussone, & D'Amico, 2010). Rates of anxiety and depression are high in patients with chronic migraines (Waldie & Poulton, 2002). Furthermore, there is a strong link between chronic migraines and suicidal behavior (Novic et al., 2016). Multiple studies have confirmed that chronic migraine sufferers have abnormal rates of suicidal ideation and abnormal rates of attempted suicide (Friedman et al., 2018). The percentage of these suicide attempts that are successful is unclear; migraine-related suicide mortality is understudied in the current literature (Novic et al., 2016). Unfortunately, chronic migraines lead many patients to contemplate taking their own lives.

Conversely, research shows that psychological distress triggers migraines. The work of Probyn et al. (2017) evidenced how psychological distress appeared to affect the treatment outcomes. They conducted a systematic review of randomized controlled trials that treated chronic headaches with pharmaceuticals. They identified the predictors, mediators, and moderators that accounted for differences in patient outcomes. Depression, anxiety, poor sleep, and high stress were four of the six strongest predictors of a chronic headache sufferer's prognosis (Probyn et al., 2017). Thus, there is evidence that a patient's mental health, sleep habits, and levels of stress serve as factors that exacerbate migraines and decrease the likely effectiveness of medical care.

## **Social**

Chronic migraines tend to be associated with social isolation and guilt. Huber and Henrich (2003) found that migraine sufferers cope with their physiological pain by socially isolating themselves. During a migraine attack, they often seek a dark, isolated room where they can be by themselves. Migraine patients miss social activities they want to attend because of migraines (Lonardi, 2007). Patients worry about making plans, fearing that they might have a migraine at the time of the planned event (Tenhunen & Elander, 2005). Because of these experiences, chronic migraines have been labeled as a driver of social behaviors and a "potentially menacing ever present cloud of concern that patients have to take into account with all relationship transactions and forward planning" (Nichols et al., 2017, p. 5).

In their systematic review of qualitative chronic migraine studies, Nichols and his colleagues (2017) identified "strained relationships" as one of the three major themes of the existing qualitative literature. Chronic migraine patients struggle with feelings that

they burden their loved ones with their migraines (Tenhunen & Elander, 2005). In one qualitative study, a patient expressed that he "was causing a lot of extra work for [his] wife" with his migraines (Tenhunen & Elander, 2005, p. 402). Another social complication associated with chronic migraines is the fact that migraines are an invisible disorder (Nichols et al., 2017). Patients with migraines appear to be healthy; others cannot see the pain they are in. Consequently, patients have experiences where people think they are faking their symptoms (Lonardi, 2007). Furthermore, they worry that others will think they are exaggerating or faking their pain (Tenhunen & Elander, 2005). Buse and his colleagues (2016) found that 44% of chronic migraine patients perceived that their partner did not believe migraines were as severe as they insisted they were.

### **Spiritual**

There is a dearth of literature exploring the impact of chronic migraines upon patients' spirituality. As far as I can tell, there is essentially no research addressing the spiritual or religious experience of chronic migraine patients. A finding from a study with cluster headache patients likely applies to chronic migraine patients, though. Palacios-Cena et al. (2016) found that cluster headache patients "cried out to God" during attacks for relief from their suffering (Palacios-Cena et al., 2016, p. 1178). Efforts like this one to explore the spiritual effects of chronic migraines are needed.

While little is known about migraines' spiritual or religious impact, some research has explored how spirituality might be incorporated into chronic migraine treatment. Wachholtz and Pargament (2005) found that spiritual meditation, a form of meditation wherein individuals try to connect with God and their inner light, ameliorated migraine symptoms. Furthermore, spiritual meditation was more effective at decreasing

anxiety than secular meditation or other relaxation techniques; spiritual meditation was also shown to increase “pain tolerance, self-efficacy, daily spiritual experiences, and existential well-being” of migraine patients (Wachholtz & Pargament, 2008). Thus, it appears that, when incorporated into treatment, spirituality can produce positive outcomes.

### **Chronic Migraine's Impact upon Partners**

Few studies have explored the impact of chronic migraines upon families. As Lipton and his colleagues (2017) asserted, “Although existing data and clinical experience suggest that the impact of migraine is pervasive and extends beyond the individual with migraine, few studies have assessed the family impact of migraine” (p. 571). Several notable studies have been published exploring the impact of migraines upon families (Buse et al., 2016; Cripe, Sanchez, Gelaye, Sanchez, & Williams, 2011; Lipton et al., 2003). These studies, though, were patient-centered and did not systemically examine the experiences of patients' family members. Bacher (2014) conducted a study of men whose partners were diagnosed with chronic migraines. Using survey data, she found that her participants' quality of life scores were significantly impacted by their spouse's migraines. I have developed a grounded theory that explains the experiences of both male and female partners and helps predict how effectively they have adapted to chronic migraines. By so doing, I have addressed some of the gaps in the literature pertaining to chronic migraine patients' partners.

Literature addressing the impact of chronic illness upon partners, in general, helps us to make inferences about the experiences of partners of people dealing with chronic migraines. Partners of chronically ill patients regularly experience exhaustion because of

caregiving burdens (Sav et al., 2013). Hounsgaard, Pederson, and Wagner (2012) reported that individuals whose partners were diagnosed with Parkinson's disease experienced a diminished quality of life due to the caregiving burdens associated with the illness. Studies have shown that relationship satisfaction is also negatively impacted when dealing with chronic illness (Tompkins, Roeder, Thomas, & Koch, 2014; Woods, Priest, Fish, Rodriguez, & Denton, 2014). The relational dynamics that result in this dissatisfaction are not well understood. Literature specifically discussing couple dynamics in the context of chronic illness is largely theoretical or anecdotal and is not grounded in empiricism. It appears, though, that when coping with a chronic illness, developing a feeling of togetherness and shared meaning is beneficial. Helgeson, Jakubiak, Seltman, Hausmann, and Korytkowski (2017) found that when couples dealing with illness shared a communal perspective (viewing the illness as their problem, not just the patient's problem), coping for both partners was improved.

### **Conclusion**

The BPS-S model and family systems theory helped shape my study. Illness is a biopsychosocial-spiritual experience, and the biopsychosocial-spiritual experiences of patients and their partners dealing with chronic migraines is currently understudied. Furthermore, when viewed through the lens of family systems theory, the dearth of research exploring the experiences of chronic migraine patients' partners and the couple's relational dynamics is an oversight that should be remedied. To better treat chronic migraines, it is important to better understand the illness' relational impacts.

I provided diagnostic classifications for chronic migraine and reviewed research regarding chronic migraine treatment. Pharmaceuticals, BOTOX, acupuncture, physical

therapy, and massage therapy have all been shown to improve migraine symptoms, but, for many patients, these methods do not provide a cure. It appears that mindfulness could improve migraine treatment. I highlighted major findings regarding patients' psychosocial-spiritual experiences. Chronic migraine patients experience high rates of anxiety, depression, and are at risk for suicidal behaviors. They also experience significant relational distress. Migraines result in feelings of social isolation and misunderstanding. Little is known about migraines' spiritual impacts. Furthermore, research exploring the experiences of patients' partners or the impact of chronic migraines on relational dynamics is scarce.

### CHAPTER III

#### METHODS

The exploratory nature of my study, my interest in processes that influence how couples adapt to chronic migraines, and the usefulness of a grounded theory for clinicians and couples dealing with chronic migraines resulted in my decision to utilize grounded theory methodology to answer my research questions. My research questions are as follows: *In couple relationships wherein one partner experiences chronic migraines, what is the biopsychosocial-spiritual impact of chronic migraines on both partners? In couples dealing with chronic migraines, what biopsychosocial-spiritual processes and factors affect how effectively they adapt to chronic migraines?*

Now, I expound upon my reasons for selecting grounded theory. Grounded theory studies are generally focused on concepts that have not yet been identified or explored (Glaser & Strauss, 1967). I have found minimal research addressing the experiences of chronic migraine patients' partners in the existing literature. I have not found any research examining relational dynamics of couples as they deal with chronic migraines. Thus, the exploratory nature of this study made grounded theory a fitting methodology. Furthermore, grounded theory questions tend to be action-oriented or process-oriented (Echevarria-Doan & Tubbs, 2014). My interest in the biopsychosocial-spiritual processes and factors that affect adaptation for couples experiencing chronic migraines is an inherently process-oriented question. By using grounded theory, I was able to investigate these processes and how they were related to each other. Lastly, by using grounded theory methodology, I was able to create a theory of adaptation to chronic migraines. With this study, I wanted to produce research that would be useful for

clinicians who treat couples with chronic migraines. Clinicians, who are often discouraged by how irrelevant they find research to be, typically identify grounded theory as a methodology that produces clinically relevant research (Echevarria-Doan & Tubbs, 2014). Additionally, I wanted to produce research that would be relevant and applicable for couples dealing with chronic migraines, themselves. Grounded theory methodology was best-suited to yield relevant, applicable, digestible findings for clinicians, patients, and partners.

In what follows, I describe recruitment and provide the demographics of my participants. Then, I outline my procedures relating to data collection and data analysis. My methods and procedures were reviewed and approved by my university's institutional review board (see Appendix A).

## **Participants**

Herein, I describe how participants were recruited, outline the inclusion/exclusion criteria for this study, and provide the demographics of my participants.

### **Recruitment**

Participants in my study were recruited using several methods. Most participants learned of the study through social media. Others were found by word-of-mouth techniques. I created an electronic flier advertising my study (see Appendix B). My flier showed images of three different people, each with a different skin color, experiencing a headache. I hoped to appeal to potential participants from a multitude of ethnic and cultural backgrounds with my flier. Furthermore, because I did not want to exclude potential participants who were in the LGBTQ+ community, I did not include an image



of a heterosexual couple on my flier. My flier was shared repeatedly on Facebook. It was shared by friends and friends-of-friends on their personal Facebook pages. Furthermore, along with a team of eight university students who volunteered to help me recruit participants, the flier was shared with headache support groups. Each student on my “marketing team” was assigned a region of the United States wherein to focus their recruitment efforts. Using Facebook and search engines such as Google, members of the marketing team searched for headache support groups affiliated with their assigned regions. They contacted group administrators through Facebook messages or emails and asked to have the flier shared with persons in their support groups. By sharing the details of my study with support groups across the United States, I hoped to interview couples from diverse regions of the country. Participants were also recruited by word-of-mouth. Members of my marketing team were encouraged to identify couples they knew who experienced chronic migraines and to ask them if they would be willing to participate in my study.

### **Inclusion/Exclusion Criteria**

To be interviewed, couples had to meet the following inclusion criteria: (a) they had to be in a committed romantic relationship, wherein they had been living with each other for at least one year; (b) one partner in each couple had to have been diagnosed with chronic migraines; (c) the chronic migraine patient had to have had migraines during the last year; (d) the couple had to speak English fluently; and (e) the couple had to live within the United States.

By interviewing couples who had lived together for at least one year, I assured that participants had adequate exposure to one another’s lifestyles and experiences. Still,

my criteria allowed me to interview couples who had experienced a wide range of relationship durations. Couples who had lived together for just a year could be included in this study, as could couples who had lived together for multiple decades. I believe my grounded theory benefitted from incorporating the experiences of couples with diverse relationship lengths.

Couples wherein both patients were chronic migraine sufferers were not included in this study. My focus in this study was to explore the experiences of couples wherein one partner was a chronic migraine patient and the other partner was not. This configuration is certainly the most common in couples affected by chronic migraines. I also chose to focus my study upon couples who had been actively experiencing chronic migraines for at least one year. A major focus of this research was to explore couples' experiences with chronic migraine treatment. Participants who had experienced chronic migraines for less than a year would have had relatively little experience with treatment. Couples were required to speak English because transcribing, coding, and analyzing their interviews would not have been possible otherwise. For legal reasons, the IRB asked that only couples who lived within the United States be interviewed. Of the couples who contacted me to be interviewed, only two couples were excluded from the study. They were excluded because they lived outside of the United States. One couple contacted me to be interviewed and met the inclusion/exclusion criteria for the study but opted out due to scheduling conflicts.

Couples were not excluded based on age, race, sexual orientation, ethnicity, or gender. Couples were excluded if they did not meet the inclusion criteria for this study, reported instances of intimate partner violence (IPV), were experiencing psychological

disorders that are not associated with headache disorders, or if either partner reported experiencing other illnesses that overshadowed the impact of chronic migraines in their lives. None of the couples who contacted me to be interviewed were ruled out because of these criteria. However, to explain my reasoning behind establishing these exclusions, I address each one individually.

**Intimate partner violence.** Violent couples were excluded from this study. By participating in this study, couples engaged in rather sensitive discussions about their experiences with migraines. For violent couples, engaging in such a discussion could have heightened the likelihood of violence. The violence would have overshadowed any exploration of how chronic migraines impact relational dynamics.

**Psychological disorders.** Including participants who dealt with psychological disorders that are not associated with chronic migraines would have unduly complicated data analysis. The impact of migraines could have been overshadowed by the impact of the psychological disorders with which they struggled. Separating the impact of migraines from the impact of participants' psychological disorders would have been overly difficult. Still, not all psychological disorders resulted in exclusion. Depression, anxiety, mania, somatic symptoms, obsessions and compulsions, substance abuse, and sleep issues are associated with the headache experience. Couples affected by these disorders and symptoms were not excluded from the study. Participants who reported experiencing the following symptoms, which are not usually associated with chronic migraines, were excluded from the study: psychosis, memory loss, dissociation, and personality function (refer to the Procedures section for more details about how screening for these symptoms was done).

**Severe illness.** If participants dealt with a severe, challenging illness that overshadowed the impact of chronic migraines upon their lives, they were excluded from this study. It would have been impossible to separate the impact of chronic migraines from the impact of other, severe illnesses (explanations of screening procedures for severe illness are also described below in the Procedures section of this study).

### **Participant Demographics**

The demographics of the participants in this study are presented in Table 2. Saturation was achieved after conducting eight interviews, thus eight married couples comprised my sample ( $N = 16$ ). Each couple was heterosexual. Couples had been married an average of 11.75 years, with the range being 2-38 years. For 12 of the participants, their current relationship was their first marriage. The other four participants had each been divorced once prior to their current marriage. All the participants in this study identified as cisgender. The average age of the participants was 39 years old, with a range of 23-64. All participants were white. Couples who were interviewed predominantly resided in the Mountain West. One couple lived in the Pacific Northwest, and another couple was from the Pacific Southwest. The number of years that patients had been diagnosed with chronic migraines varied from 1 to 2 years, to over 20. All participants had received at least some college education. Seven participants did not have a college degree, five had received a bachelor's degree, and four had received a master's degree. The average approximate combined annual income of the couples was at least \$74,625. The lowest combined annual income was approximately \$27,000. Three couples reported making over \$120,000 annually. Two participants reported that they

Table 2. Demographic information of participants

	Patient/ Partner (Male/Female)	Age (in years)	Relation- ship Duration (in years)	# Years Since Being Diagnosed	Education	Combined Yearly Income (Approximate)	Religiosity/ Spirituality (None; Slight; Moderate; Very)	Children? (Y/N)
Couple 1	Patient (F)	47	3	20+	Some College	\$50,000	Very	Yes
	Partner (M)	54			Master's Degree		Moderate	
Couple 2	Patient (M)	25	3	1-2	Some College	\$30,000	Very	No
	Partner (F)	24			Bachelor's Degree		Moderate	
Couple 3	Patient (M)	53	32	20+	Bachelor's Degree	\$120,000+	Very	Yes
	Partner (F)	52			Some College		Very	
Couple 4	Patient (F)	26	4	10-20	Bachelor's Degree	\$27,000	Slight	No
	Partner (M)	24			Some College		Slight	
Couple 5	Patient (F)	64	38	20+	Bachelor's Degree	\$120,000+	Very	Yes
	Partner (M)	61			Master's Degree		Very	
Couple 6	Patient (F)	36	4	20+	Master's Degree	\$120,000+	Very	Yes
	Partner (M)	39			Bachelor's Degree		Very	
Couple 7	Patient (F)	24	2	2-3	Some College	\$80,000	Moderate	No
	Partner (M)	23			Some College		Moderate	
Couple 8	Patient (M)	36	8	10-20	Some College	\$50,000	Very	Yes
	Partner (F)	37			Master's Degree		Very	

were "slightly religious/spiritual," four reported that they were "moderately religious/spiritual," and 10 participants said they were "very religious/spiritual." Five couples had children, and three couples were childless. Two of the couples with children did not have children living at home. Two couples had young children.

### **Procedures**

Couples who were interested in participating in my study contacted me via email. They were then sent a link to an online survey. This survey can be viewed in Appendix C. The survey did not ask for any identifiable information. Respondents entered a couple-specific code that enabled me to pair their answers with their partner's. By referring to couples' survey responses, I was able to determine if they met the inclusion criteria for my study. In the survey, respondents were asked if they were 18 years old or older, if they lived within the United States, and if they had lived with their partner for at least one year. Through the survey, I was also able to determine if one of the partners in the couple had been diagnosed with chronic migraines, and if the patient had been experiencing frequent migraines within the past year. For individuals who did not meet the study's inclusion criteria, the survey concluded immediately after notifying the respondents that they were ineligible for the study. Thus, respondents who did not meet the inclusion criteria were not asked to waste time responding unnecessarily to additional questions.

The survey was also used to identify if couples needed to be excluded from my study because of intimate partner violence, psychological disorders that are not associated with chronic migraines, or severe illness. No participants who completed my study had to be excluded for these reasons. However, I detail how these exclusion criteria were

screened for with this study. Participants were asked to list any health conditions from which they suffered. Furthermore, they were asked to indicate if their condition had a mild, moderate, or drastic influence upon their lives. Participants who said their condition had "drastically" impacted their lives would have been ruled out from the study. The survey concluded with two instruments which helped me to screen for psychological disorders that are not associated with chronic migraines, and intimate partner violence. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition [DSM-5] Level 1 Cross-Cutting Symptoms Measure (American Psychiatric Association, 2013) is an assessment that specifically evaluates if respondents are experiencing symptoms of psychosis, memory loss, dissociation, or disordered personalities—the four psychological symptoms that seem to be unrelated with chronic migraines. Respondents who reported moderate-severe symptoms associated with these four categories would have been deemed ineligible for the study. The Revised Conflict Tactics Scale [CTS2] is a well-known instrument that screens for psychological and physical abuse in intimate relationships (Straus, Hamby, Boney-McCoy, & Sugarman, 1996). Partners who reported incidents of physical violence would have been excluded from the study. After completing the survey and being deemed eligible for the study, participants were contacted to schedule a date and time for their interview.

### **Data Collection**

At the heart of grounded theory research is the constant comparative method (Glaser & Strauss, 1967). This method requires a constant interplay between data collection and data analysis. Data are continually analyzed for emerging categories;

these categories are evaluated further and interrelationships between categories are explored during continuing data collection (Strauss & Corbin, 1998). For this study, the constant comparative method was utilized. For clarity and simplicity in the presentation of my methods, I have separated my procedures related to data collection and my procedures related to data analysis with distinct headings. However, it is important to note that data collection and data analysis did occur simultaneously for this study.

Interviews lasted between one and two hours and required the presence of both partners. As my grounded theory is a theory of adaptation for both patients and their partners, it was vital to have both partners present for the interview. I conducted each interview. One interview was conducted in a couple's home, another interview was conducted inside a university therapy office, and the other six interviews were conducted online through a secure video-conferencing network. Midway through the interview, I spent between 10-20 minutes speaking with partners alone. This allowed partners to speak more openly about their experiences with caregiving. This process occurred midway through the interview because it seemed like the most appropriate time to do so in the flow of my semi-structured interview guide. The rest of the interview was conducted with the couple together. Audio from each interview was recorded. A team of five people (including myself) took turns transcribing the interviews. Transcriptions were always checked for errors by a member of the transcription team.

Interviews were shaped by a semistructured interview guide (see Appendix D). I developed the interview guide with the help of my major adviser, who has extensive experience in qualitative research. To prepare me for data collection, I conducted two pilot interviews with couples who deal with migraines. The pilot interviews were not



transcribed or analyzed. My focus throughout the pilot interview process was refining my interview guide. I sought feedback regarding the questions I had asked from both couples I interviewed. Minor adjustments were made to how questions were worded in my interview guide as a result. Consistent with the constant comparative method (Strauss & Corbin, 1998), new questions were added to the interview guide over the course of data collection and analysis. While data were analyzed, questions would come up that were noted for future interviews (Echevarria-Doan & Tubbs, 2014). This iterative process refined our grounded theory and led to a greater understanding of our emerging categories and their connections with each other (Strauss & Corbin, 1998).

### **Data Analysis**

A grounded theory's findings become more trustworthy when multiple people are engaged in data analysis (Brimhall & Engblom-Deglmann, 2011). For this study, a team of seven researchers met weekly for an hour to two hours for four months analyzing data and developing our grounded theory. All researchers were university students. Five researchers were undergraduates in family science related majors, and two (including myself) were master's students in a marriage and family therapy program. Both master's students and three of the undergraduates served as the transcription team, as well. Prior to beginning our data analysis, researchers received training on qualitative data analysis and grounded theory methodology from me and my major adviser. My major adviser, a researcher with extensive experience in qualitative methodologies, was also involved in data analysis. He regularly joined analysis meetings to provide insight and answer questions. Furthermore, he systematically reviewed our findings and suggested adjustments that improved our grounded theory. Thus, his involvement in this project

helped to further strengthen the trustworthiness of the findings. To help ensure the confirmability of the findings, an audit trail of codes, emergent categories, and memos was created as we analyzed our data (Lincoln & Guba, 1985). Consistent with grounded theory methodology, analyses was performed in three distinct, but overlapping, phases: open coding, axial coding, and selective coding (Strauss & Corbin, 1998). I will outline the processes involved with each phase. These phases were not linear; they occurred concurrently (Echevarria-Doan & Tubbs, 2014).

Open coding, discussed by Strauss and Corbin (1990) as the way researchers initially "fracture" their data, was our first step of analysis (p. 97). Open coding involved a line by line analysis, wherein we studied each line of a transcript searching for categories, subcategories, actions, events, or properties within our data (Echevarria-Doan & Tubbs, 2014). As we engaged in line by line coding, we produced lists of categories and subcategories that emerged from our analysis (Hock, Timm, & Ramisch, 2012). For the first five transcripts that we analyzed, each researcher on our team conducted a line by line analysis of the transcript. We wrote codes in the margins as we read through the transcript by ourselves. Then, in our weekly meetings we would discuss the codes we had identified. Lively discussion ensued as we combined our lists of categories and subcategories. Consistent with grounded theory methodology (Echevarria-Doan & Tubbs, 2014), line by line coding was not utilized to analyze our final three transcripts. Analysis shifted primarily toward axial coding, selective coding, and upon determining if we had reached saturation as we analyzed our last few transcripts (Strauss & Corbin, 1998).

Axial coding involved the process of making connections between the categories and subcategories we identified (Strauss & Corbin, 1998). In open coding, categories and subcategories *within* each transcript were identified. In axial coding, we identified categories and subcategories that were applicable *across* our participants' experiences (Strauss & Corbin, 1998). As I conducted more and more interviews, the condensing of categories and subcategories became more challenging for us as a research team. Open coding was producing a plethora of codes for each transcript, and it was difficult to isolate the major categories and subcategories that were most important. To help us move away from open coding, and into axial coding, we would frequently discuss what categories and subcategories would be evident across our participants' experiences if we could view them from a bird's eye view. This metaphor helped us to identify categories that were common across participants' experiences. During axial coding, we considered if there was a central category in our data. Central categories are said to capture the essence of a research project (Brimhall & Engblom-Deglmann, 2011). To be considered a central category, all participants must discuss it, and it must be connected to most of the data (Strauss & Corbin, 1998). Eventually, it became clear that a central category existed in our data. The emergence of a central category helped us to better understand how identified categories and subcategories were connected to each other.

Closely connected with axial coding, the final phase of coding, selective coding, involved putting the story of the data together (Larossa, 2005). During selective coding, we proposed how the categories we identified might be related to each other. Possible explanations for how categories shaped and influenced each other were discussed and recorded. In grounded theory, these explanations are called memos (Glasser, 1998). We

recorded memos throughout our analysis and referred to them frequently. As a group, we would regularly test our memos by searching for confirming or disconfirming examples in the transcripts. It was through selective coding and the testing of memos that our grounded theory came together, moving from a list of categories and subcategories to a theory wherein the relationships between categories were understood (Strauss & Corbin, 1998).

To ensure the trustworthiness of our findings, member checking was utilized. The grounded theory we developed was sent out electronically to each of the participants in the study. In providing participants with our findings, I invited them to consider how effectively our grounded theory captured their experiences. They were encouraged to give feedback and I assured them that their feedback would be incorporated into my findings. Our participants did not suggest any changes to the model. They responded to the findings with expressions of appreciation. One participant said we had done "an extraordinary job" and asked if she could share the results with her extended family.

### **Conclusion**

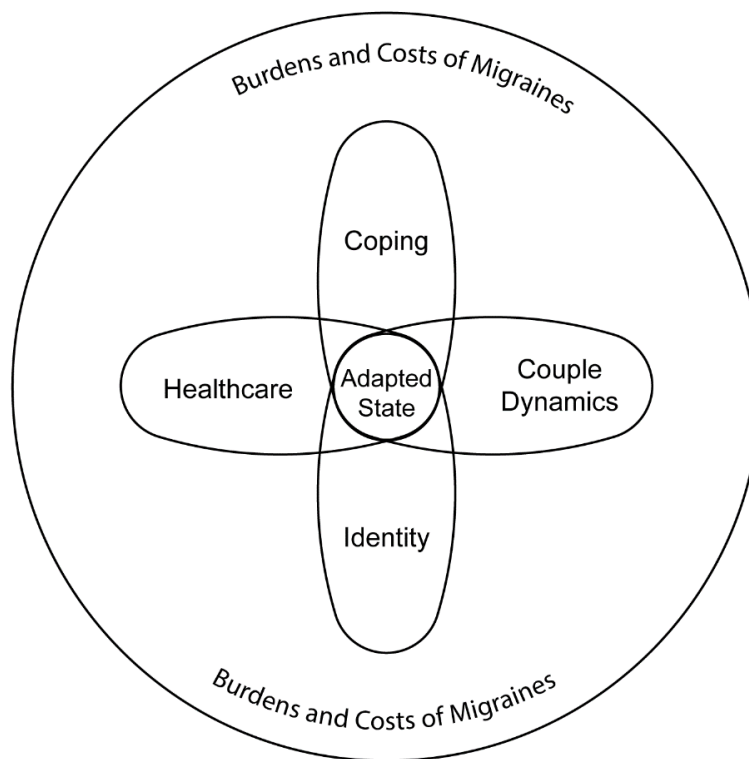
I have described the inclusion/exclusion criteria that was applied to this study. I outlined how participants were recruited and provided the demographics of the couples I interviewed. Survey procedures and interview procedures were described. Finally, I talked about how data was collected and analyzed. The constant comparative method was utilized. Interviews and analysis were done simultaneously, ensuring that questions and hypotheses developed during analysis could be evaluated in continuing interviews. With a team of seven researchers, the data were analyzed in three phases:

open coding, axial coding, and selective coding. Measures were taken throughout the analysis process to ensure our findings were confirmable and trustworthy.

## **CHAPTER IV**

### **FINDINGS**

Five categories emerged from our analyses. Each of the categories was present in all the interviews I conducted. One category, the burdens and costs of migraines, was identified as the central category of our grounded theory. The burdens and costs of migraines became a central category because it was the category upon which all other categories hinged (Strauss & Corbin, 1998). The other categories were coping, healthcare, couple dynamics, and identity. Consistent with other grounded theory research (Brimhall & Engblom-Deglmann, 2011), these four categories are referred to as "major categories," distinguishing them from the central category. These major categories are the means through which patients or their partners adapt to the burdens and costs of chronic migraines. Subcategories were also identified. Some of these subcategories applied only to patients, others applied only to partners, and others were relevant to patients and partners alike. By analyzing how our categories and subcategories impacted and shaped one another, we developed our grounded theory of adaptation to chronic migraines for patients and their partners. In the end, our grounded theory was designed to illustrate how effectively patients and partners have adapted to their migraine-related burdens. In what follows, I discuss our theory and use quotations from our participants to describe each category and subcategory.



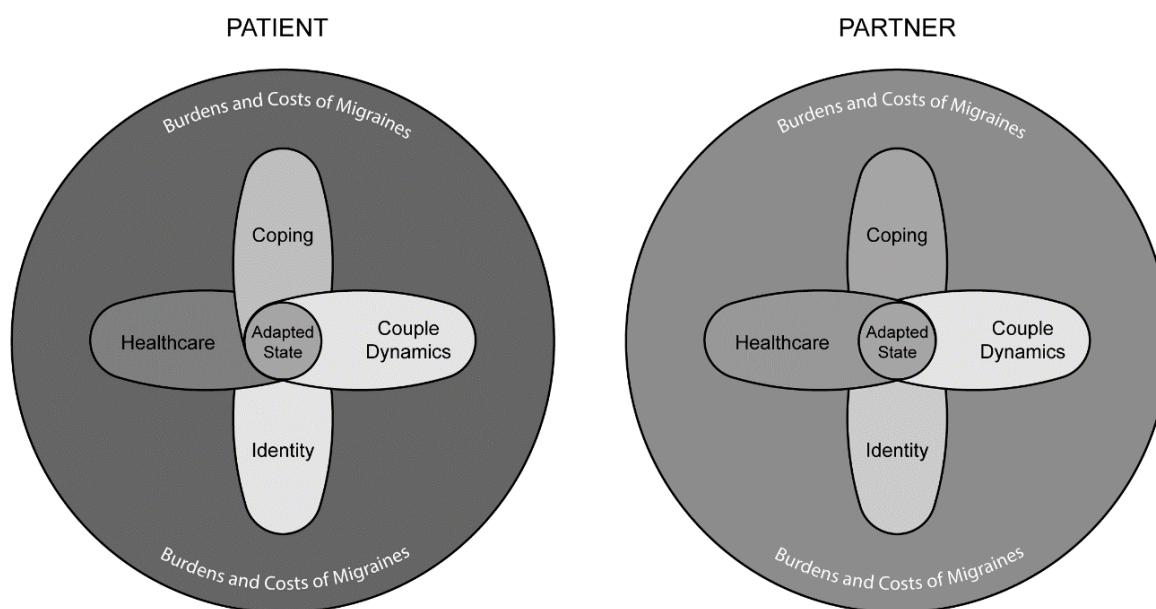
*Figure 1.* Grounded theory of adaptation to chronic migraines for patients and their partners.

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### **Elucidation of the Model**

Figure 1 depicts our grounded theory of adaptation to chronic migraines for patients and their partners. This model illustrates how well a patient or partner has adapted to the burdens and costs of chronic migraines. Our central category, the burdens and costs associated with chronic migraines, is represented by the outside circle of the diagram. The particular burdens and costs of migraines differed between patients and

their partners. The four major categories (coping, healthcare, couple dynamics, and identity) are represented by ovals situated within the central category. These major categories are the means through which patients and partners adapted to migraine-related burdens and costs. As shown in the model, each of the major categories overlapped and influenced one another. The central circle of the model, labeled "adapted state" represents the general state of wellness of the patient or partner, taking into consideration his/her costs and burdens, as well as the factors and processes (major categories) which have affected his/her ability to positively or negatively adapt to those costs and burdens.



Note: The darker the shading, the more negative the individual's experience; the lighter the shading, the more positive the individual's experience.

*Figure 2.* The model applied specifically to one of the couples interviewed.



Figure 2 (see above) represents the application of the model to one of the couples I interviewed. When applying this model, the positivity or negativity of a patient or partner's experience is represented through a continuum of shading: the more negative the experience, the darker the shading on the diagram, and the more positive, the lighter. By using the diagram in this way, couples or clinicians can gain a visual representation of how well patients and partners have adapted to chronic migraines, as indicated by the center circle, which is a composite of the shading of the other five categories. Major categories that require the most improvement can be targeted. I stress that Figure 2 is an illustration of the experience of one of the interviewed couples. Adaptation varied among couples, and Figure 2 should not be mistaken as the uniform illustration of adaptation for couples impacted by migraines.

### **Presentation of Categories and Subcategories**

Understanding the categories and subcategories of our grounded theory is critical to understanding our results. I will now individually discuss each category and subcategory that emerged from our analyses (see Table 3). I will provide quotations from our participants that illustrate these categories and subcategories. Theorized relationships between categories and subcategories is a central feature of any grounded theory. Thus, I will also comment further on the connections we identified among our categories and subcategories.

Table 3

*Central Category, Major Categories, and Subcategories*

<b>Central Category: Burdens and Costs of Chronic Migraine</b>		
<i>Patient Specific</i>	<sup>a</sup> <i>Both</i>	<i>Partner Specific</i>
Loss: Lost time and loss of normalcy	Social and recreational loss	Costs associated with caregiving
Invisible Disorder	Financial burden	Questioning/ doubting severity of partner's migraine
Guilt, fear, and anxiety		Less sex
Shutting down and escaping		
Experiencing hopelessness and depression		
<b>Major Category #1: Coping</b>		
<i>Patient Specific</i>	<i>Both</i>	<i>Partner Specific</i>
Pain tolerance and grit	Acceptance	Embracing opportunities to provide support
Finding purpose	Becoming expected	Trusting one's partner
Managing stress	Humor	Shutting down
	Avoiding triggers	
<b>Major Category #2: Healthcare</b>		
<i>Patient Specific</i>	<i>Both</i>	
Giving up. Starting over.	Trying to find a cure; searching for alternative treatments	
Lack of understanding from medical professionals	Positive and negative effects of insurance	
Comorbid conditions complicating treatment		
Access to headache specialists		
<b>Major Category #3: Couple Experience</b>		
<i>Both</i>		
Perceived balance/imbalance of giving and taking in the relationship		
Connection and disconnection		
Resilience and strength		
<b>Major Category #4: Identity</b>		
<i>Both</i>		
Gender		
Family values and expectations		
Anxiety		
Religiosity/Spirituality		
SES		

<sup>a</sup> Subcategories in the "Both" category apply to patients and to their partners

### **Central Category: Burdens and Costs of Chronic Migraine**

Burdens and costs of chronic migraine is the central category of this analysis. Patients and partners were forced to adapt to their illness because of the burdens and costs of chronic migraines. The four major categories represented how patients and partners adapted. Burdens and costs were fairly consistent across our participants' experiences. What varied was how well patients and partners had adapted to their burdens and costs.

The couples we interviewed talked often about the severe toll chronic migraines have upon their lives. When asked, "What are the first words that come to your mind when you think of your chronic migraines?" one patient responded without hesitation, "Hell." Her partner agreed with the statement, but then added that it was also "just [their] normal." Another patient shed light on how painful and burdensome his chronic migraines are when he revealed he had elected to experience kidney stones in the hope that it would decrease the frequency and intensity of his daily headaches:

Ya know, the number one side effect from this medication [I'm taking to reduce my headaches] is kidney stones. . . But, for me, I know what kidney stones are, I've had them several times. I'm willing to take kidney stones twice a year if it reduces my headaches every day. And, for me, that was a fair trade. I had to talk [my doctor] into putting me on the medication, because he said, "No, no, you don't want to do kidney stones. Those are painful." I said, "Daily headaches are painful!"

The burdens and costs of migraines also greatly affect the partners of those who suffer from migraines. One partner explained, "You just get tired, you get exhausted from the constant pattern of this being part of your lives. It becomes daunting." Another partner, referring to how pervasive and constant her spouse's migraines are said simply,

“I married migraines.” For her, and the rest of the partners I interviewed, migraines were not a minor footnote in their lives. Migraines were a major part of their married life.

The couples we interviewed experienced burdens that were physical, psychological, social, spiritual, and financial. These diverse costs will be reviewed as I discuss each of the subcategories associated with the burdens and costs of chronic migraine. Some burdens or costs applied only to chronic migraine patients, others applied to only their partners, and some applied to both patients and partners.

### **Patient-Specific Burdens and Costs**

Some of the burdens and costs identified in this study applied only to patients. These subcategories were identified as loss; invisible disorder; guilt, fear, and anxiety; shutting down and escaping; and experiencing hopelessness and depression. I address each one.

**Loss: Lost time and loss of normalcy.** The patients I interviewed commonly shared a feeling that chronic migraines resulted in major loss. They talked often about how chronic migraines resulted in “lost time.” One patient talked about how she woke up almost every morning with a migraine. Explaining that she had to lie down for a few hours each morning as a result before she could even start her day, she said:

“The hardest thing for me, [becomes emotional and starts crying] I used to be a morning person, and I've hated that my mornings have been taken away. So that's been very hard for me. I used to get so much done in the early morning, and I just can't do that... that's hard.”

Another patient, reflecting on all the time she has lost because of her chronic migraines, said she realized, prior to our interview that she had been dealing with chronic migraines for 21 years. She remarked, “[my migraines] dominate a lot of what we do and how we do it.” She then said, “[and it has] for such a long time!”

In addition to losing time because of chronic migraines, the patients I interviewed said they had also lost the ability to live a “normal” life. One patient talked about how she had missed one of her best friends’ weddings because of a migraine. She then remarked, “[migraines] ruin things. Migraines [have] ruined a good share of events in my life.” Another patient adequately summarized the feelings of many of the patients I interviewed when he said, “Until medical technology for understanding migraine brings us to a point where we can cure or have freedom from migraines, those of us with migraines will never experience the way of life that others have.”

**Invisible disorder.** The patients I interviewed frequently talked about how chronic migraines are an “invisible disorder.” One patient explained, “[Chronic migraines are] not like having a broken leg or a broken arm where people can see that you are hurt. It is one of those things that’s invisible.” There are heavy social burdens associated with the disorder’s invisibility. One patient reflected on how family members and friends used to always act like he was “faking it” when he got migraines as a kid. He said, “Growing up, there was always the looks or the questions of, ‘What’s wrong with you? Why? It’s just a headache.’ . . . There was a lot of judging . . . [people who haven’t suffered a migraine] don’t understand.”

**Guilt, fear, and anxiety.** The patients I interviewed reported experiencing guilt, fear, and anxiety because of their chronic migraines. These feelings tended to feed off each other. For example, one woman talked about how she would stress herself out to the point of having a migraine, then she would feel guilty and blame herself for her migraine. After talking about having to miss events she had planned to attend because of migraines, she reported, “[I] feel guilty! I feel it eating inside of [me], and I feel like a

worthless person. Am I imagining these things? Am I causing these things? Why can't I be there? And it just makes the migraines worse." Other patients reported similar sentiments. The guilt patients reported was primarily rooted in their feeling that migraines were burdening people they love. In tears, one patient explained, "There's a lot of lost time. . . There's some guilt with that. . . [I tell myself that] it's my fault somehow. It's because of my migraines. . . I'm burdening [my partner]. I'm a burden."

Several patients talked about feeling guilt and fear when they thought about passing chronic migraines on to their children. One patient explained:

I'm pregnant now with a girl . . . And so, just today, I'm driving home, and I was like, Oh my gosh, like, if this is passed down to her. . . it's just gonna keep going." I felt guilty . . . Cause no one wants their child to be in pain, and when it's your genetics that are causing it, like, that sucks!

Other patients reported feeling guilty because they had adult children who were afflicted with chronic migraines. They blamed themselves for their children's suffering. In addition to the psychological burdens associated with possibly giving their children chronic migraines, patients worried that chronic migraines prevented them from being "good" parents. One patient recalled an experience wherein she became "hysterical" thinking about caring for her baby while she was experiencing a migraine:

"When we had our first son, um, and [my husband] had gone back to work and it was just me and an infant. . . and I got a migraine I remember. . . I had a human depending on me, and I couldn't even, like, take care of myself. So, I remember being absolutely terrified. Um, and like, hysterical because I was like, 'If this continues to happen, I can't be a good mom.' Like I remember telling myself like, 'I can't be a good mom with migraines.'"

All the patients I interviewed talked about how, to some degree, their chronic migraines led them to experience guilt, fear, and anxiety in their familial relationships.

**Shutting down and escaping.** Each patient I interviewed said migraines caused them to shut down and isolate. One patient talked about getting away at work and taking breaks because of his headaches. He said, “There are times [at work] when I need to go find a dark room and lock the door and just go and sit there for 15-20 minutes. Or [I’ll go] out in my truck in the parking lot.” Shutting down and escape behaviors were not confined to work. One patient talked about how she was able to “push through” her workday with a migraine, but said that she would come home, sit on her reclining chair, and “be done for the day,” not moving until morning. Patients described feeling like exposure to anything or anyone hurt when experiencing a migraine. “It’s just like everything hurts me. Whether it’s talking, whether it’s light, whether it’s a car driving by outside or something, it’s just like everything. I just want to, like, shut it down.” Several patients explained that, in part, they shut down when they had a migraine to avoid acting snappy, grumpy, and mean. One patient remarked, “When I get a migraine, I just get quiet. I just don’t do anything. And it’s because I don’t want to be mean and I don’t want to snap, and I don’t want to say something I’ll regret.” Finally, one patient talked about how he spent a lot of time on his computer, because he felt that it helped to escape into a fictional world. He explained:

“I try to absorb my soul in mind-numbing activities . . . My thing for the last eight years has been Manga and Anime (laughs). Ya know, involving myself in a story, um, and just trying to escape from my, from the pain in my world by just immersing myself in some other imaginary world.”

For the patients I interviewed, it was clear that migraines resulted in isolation and withdrawal during attacks.

**Experiencing hopelessness and depression.** All interviewed patients struggled, to some degree, with feelings of hopelessness and depression associated with their

migraines. Several patients reported being officially diagnosed and treated for depression. Others denied having diagnosable depression but still reported times of deep sadness and feelings of hopelessness. After a long, tearful pause, one patient said, “Sometimes it feels hopeless. Like, [I] feel trapped, like, kind of stuck like this.” Another patient disclosed that he struggled with depression and said he knew other chronic migraine sufferers who struggled with depression, too. “From my own experience and many others, [chronic migraines] tears families apart, it drives people apart, a lot of individuals face a lot of depression from it. I myself have had a lot of depression and self-esteem issues.” A patient who was unable to work and whose first wife divorced him, in part, because of his migraines, spoke very frankly about how hopeless and depressing his illness is. He went as far as to say that he might prefer having cancer to having chronic migraines. He stated:

But, when you have something that affects your life so wholly as migraines do. . . [Migraines are] a physical disability that prevents [people] from being able to take care of themselves, or to go to work . . . . I mean, in some respects, I would almost have cancer with the hopes of being able to be a survivor. And I mean, that’s sad to say, but those in remission have a higher quality of life (becoming emotional) than I and my family have because I know- and I’m not trying to downplay the severity of cancer or other potentially terminal illness- but migraines can get to the point of virtually being terminal. I mean to those who sink so deeply into depression, it becomes terminal. It is terminal to marriages and relationships. And it is definitely terminal to employment.

Some patients spoke in their interviews about how “there are others who have it much, much worse.” Thus, some disagreed with this patient’s stance. Nonetheless, this patient spoke poignantly, from his own experiences, of how depressing and hopeless chronic migraines can be. While the degree of depression and hopelessness varied in our participants, such feelings were reported by all the patients I interviewed.



### **Partner-Specific Burdens and Costs**

The identified subcategories relating to the burdens and costs of migraines that applied only to partners were as follows: costs associated with caregiving; questioning and doubting the severity of partner's migraine; and less sex.

**Costs associated with caregiving.** Throughout the interviewing process, patients' partners had misgivings about using the word "caregiver" to describe the role they played with their partner when he/she was experiencing migraines. They talked about how they did not bathe or bandage their spouse and spoke of how their relationship was not a nursing relationship. Yet, all of them agreed that elements of caretaking and caregiving existed in their experience as a chronic migraine patient's partner. Some partners took on much bigger caregiving roles than others. Two partners reported that they did very little caregiving. They reported experiencing "guilt" as a result. The others were very involved in caregiving. Caring for their spouse produced heavy burdens and costs for them personally. One partner explained that when her husband was having a migraine, she was "more of, like, a caretaker than a wife." She also explained that although she tried to help him, there was not "really anything [she] could do," to alleviate his pain. She said that it was "very hard" for her to "watch him suffer." Another partner talked about how exhausted she was by her caregiving role. She explained that she worked full-time because her husband could not work with his migraines. She also explained that she took care of him when he was having migraines, took care of their children, and took care of the house. She stated:

It gets really draining. It gets very exhausting. . . When I'm not feeling well, it makes things really hard, because he will be absolutely down and can't do anything. . . And I just wish that I could go lay down. It's tough just thinking,

“Well at least you get to take a nap.” Ya know? And he’s like, “I wish I wasn’t taking a nap.”

This woman revealed that she was “drained” and that she was tired of always being the caregiver, explaining that sometimes she would like to be the person who got to lie down. Yet, she also implied that this feeling resulted in guilt, because she knew her husband was in pain and she did not want to envy him.

**Questioning/doubting severity of partner’s migraine.** Partners also reported that they sometimes doubted or questioned the severity of their partner’s migraines. One partner wondered if his wife was just using her migraines to “get out of” spending time with him. Another partner talked about how she “tries so hard” to understand her husband’s migraines and how severe they are. But she reported experiencing an “internal battle” because “deep down” she believed her husband was using migraines as an excuse and was stuck in a victim-playing role. Thus, she struggled to know if she should trust her husband’s reports, or trust her own gut-feelings. Some partners discussed struggling to believe that their spouse’s migraines were as severe as he/she was saying they were.

**Less sex.** All partners in this study talked about how their spouse’s chronic migraines resulted in less sex. When asked about how migraines had impacted their sexual relationship, one partner quickly responded, “Yeah the old- the old joke, ‘Not tonight honey, I have a headache.’ Multiply that times ten!” Some partners were not as light-hearted as they spoke of their sexual experience. One explained:

I kinda get in the mood and wanna [have sex], but she’s just not feeling it [because she has a migraine]. . . Then I keep trying, even though I should stop trying cause she’s obviously told me that I should just stop trying. . . Then I just end up getting depressed and then rolling over to the other side of the bed.

He said he felt guilty for trying to have sex with his wife when she was in pain. Yet, he was clear that the impact of migraines on their sex life was, for him, the illness' biggest cost.

A different partner revealed thinking that his wife was using migraines as an excuse to not have sex. He said:

For the longest time I would [assume that when she] wasn't in the mood or didn't want to [have sex] that it was just an excuse. And so, it would create a lot of tension. I would always see it as her way of getting out of having sex.

His feeling that his wife did not want to have sex with him and that she was using migraines to avoid sex created tension. It weighed on him, leading him to resent his wife for her migraines.

### **Burdens and Costs that were Present in Both Patients' and Partners' Experiences**

Now, I address the subcategories related to the burdens and costs of migraines that were present in both patients' and partners' experiences. The two subcategories were social and recreational loss, and financial burden.

**Social and recreational loss.** Social and recreational losses were some of the most oft-discussed costs associated with chronic migraines. Each couple we interviewed reported living less social, less active lives because of chronic migraines. One partner, as she reflected on what chronic migraines have cost her, explained:

I think that we have faced life very seriously. I think we [didn't have] as much fun with our children. . . And, to me, that is a huge cost that we had to give up. I see that as I see other families being very physically active, and camping, and hiking and doing all of those kinds of things that our kids didn't experience. We had to do what we had to do to just um, I don't want to say survive, because that sounds really drastic, but ya know, just to cope.

Agreeing, her husband said that social and recreational loss was the biggest cost of all from his migraines. He talked about how he would exhaust himself during the work-week, pushing through his migraines to provide for his family. This process took so much out of him that he rarely had energy for “family-fun time.” He said:

Ya, I would say the same thing. Um, it felt like a lot of times, ya know, when I got to Saturday, um, rather than a fun Saturday afternoon outing, it would be, ‘I don’t, I don’t really have anything left in the gas tank.’ And so, rather than us packing up and going to somewhere fun for an outing, we didn’t. We would just hang around the house and do something locally. And so we missed out on going to the beach, or going for a drive up into the mountains, or things like that. Maybe we didn’t do enough fun family things because I was just exhausted by the weekend. That was maybe the biggest cost.

A different couple talked about how their evenings were wasted because of migraines. Like the patient who was just quoted, the patient in this couple would work despite her migraines. By the time she came home, though, she was too exhausted to do anything. Thus, she and her partner rarely did anything social or recreational in the evenings. Her husband explained:

But, as far as the evenings, especially the nights that she works, we’re pretty well home now. We don’t go out too much. Maybe we’ll see a movie or something, but most times she’ll sit there and watch and fall right asleep, ya know, she’s so worn out.

Our patients and their partners reported pervasive social and recreational impacts from chronic migraines. Dealing with migraines was so exhausting, they reported, that they often missed out on opportunities to have fun.

**Financial burden.** Several couples spoke of the financial burdens associated with chronic migraines. He then talked about how much he has had to budget for medical expenses since getting married to a chronic migraine sufferer. He explained:

So I get very frustrated because it is like a normal monthly bill that I gotta now budget for that I've never even had to think about. And so . . . that's probably the most frustrating part is, um, we've got a bill for \$130 for a chiropractor, it's like "what the hell?" (laughs). Why did this, why do we have- and that's after we paid all the co-pays. So, um I yeah, I get very frustrated about that.

Another couple spoke of the guilt associated with medical expenses:

Husband: It's taking the medication or filling the prescription all the time, the cost and expense of it, that we could use that money for something else. I know that makes her feel guilty.

Patient: That's always made me feel guilty. The cost of it has always made me feel bad.

One couple spoke of not being able to afford the treatments that doctors suggested. The partner explained, "We're just poor college students so [the doctor is] like, 'I suggest you do this \$2,000 thing,' and we're like, 'Well, we have negative \$2,000. How do you expect us to do that \$2,000 thing?'" For them, it was deeply frustrating to not have the funds required to treat migraines appropriately. For several couples, in various phases of the lifespan, chronic migraines created heavy financial burdens.

### **Major Category #1: Coping**

Having outlined our theory's central category, I move into discussing our theory's four major categories. The first major category was coping, through which patients and partners adapted to chronic migraines' burdens and costs. Some coping strategies were present in each of our participants' experiences. Others were utilized by only a majority. Some strategies were bonadaptive, others were maladaptive. In this section I discuss each of the subcategories that were identified as a coping subcategory.

One couple had just detailed the burdens they dealt with because of their chronic migraines when I asked how they coped with it all. The partner responded, "We just, we get through it." Like the subcategories that emerged regarding burdens and costs of

migraines, our coping subthemes are divided into three categories. In our analysis we found subthemes that were specific to patients, subthemes that were specific to partners, and subthemes that applied to both patients and partners.

### **Patient-Specific Coping**

Identified subcategories that applied only to patients were as follows: pain tolerance and grit; finding purpose; and managing stress. Each of these strategies were bonadaptive. However, all patients reported struggling to effectively manage stress.

**Pain tolerance and grit.** In response to the immense physiological pain of migraines, patients reported developing higher pain tolerances and spoke of “gritting” their way through work and other activities despite their migraines. One patient talked about how she used to not be able to work through migraines but said that over time she got to the point where she could work through them. She explained:

I will usually still go to work. And work the day. Get through my work day- which would have never happened before. But I get home and I’m pretty done. I don’t want to do anything else. Especially the last year, I think he (husband) can attest to that. I’m surviving through a work day and that’s pretty much it.

Migraines still had their impact. After working, she was done for the day. Yet, through grit and an increased pain tolerance, she was able to maintain employment. Talking about her resilience and strength, the patient’s husband said, “She’s really a trooper . . . She goes through and she does a lot of things when she’s in a lot pain, and won’t let you know.” Another patient expressed similar sentiments. She spoke of how her daily headaches and migraines had “essentially become background noise.” She said she felt like she “[lived] with them pretty well.” She said still had to take “half-days off” to rest frequently but said her ability to live well despite her migraines had improved over time as she had become better able to tolerate her pain.

**Finding purpose.** Half of the couples talked about how finding purpose and engaging in meaningful, purpose-driven experiences helped to make their migraines less painful. Speaking about his wife who experienced chronic migraines, one man explained that taking care of her grandkids helped alleviate his wife's pain. "She loves those grandkids. So [when she goes to take care of them], it takes, whatever pain she's in, having them hug her and talk to her, it makes her forget about it, or something." Another couple talked about how taking care of children and grandchildren has helped the patient to better cope with her migraines. They explained that their daughter-in-law had just been hospitalized with a serious medical condition. As a result, the patient I interviewed had been going over to take care of grandkids every morning, even though she had a headache each morning when she woke up. Her husband explained:

Lately, with [my daughter-in-law]'s condition, boy it's been- my wife is there every single day. She gets up and goes over there in the morning. She stays until dinner time when [their son] gets home from work. So, she has that, that, I don't want to call it a distraction, but she has that purpose of helping take care of those kids. It gets her off her feet in the morning, perhaps a little sooner than she otherwise would. I'm not saying she feels any better, but that she has something to do to distract her.

Adding to her husband's statement, the patient said, "It's true, and it does help me to focus on other things, focus outside of myself. It's a good thing."

One patient talked about how being busy at work made his migraines more bearable. He stated:

If I'm busy, [the headache is] not nearly as bad as if I'm not. . . In meetings and interactions with people demanding from me has one kind of a pull on me emotionally, but idle time and sitting at my desk trying to respond to emails and other things is actually all a lot harder for me.

Being engaged in meaningful activities helped patients to better cope with migraines.

**Managing stress.** Most of the patients I interviewed talked about trying to

manage their stress as a way to decrease the severity and frequency of their migraines. Yet, they also repeatedly talked about how complex their stress was and how difficult it was to know how to best manage it. Thus, while they wanted to effectively manage their stress, their inability to do so often made them feel more stressed. This sequence was illustrated in the following quote from a chronic migraine patient, wherein he compared his many stressors to a multi-variable equation and said that he's never really sure if he's "solving" the right stressor. He stated:

It's always going to be a multi-variable equation to solve. And a condition like mine, it's always going to be that way. Where work is going to be stressful, home is going to be stressful, church is going to be stressful . . . and so, you know- one is spiking when the other is going down . . . So, it's really just, you try to balance things out, and you try to solve one thing at a time, but you're not really positive if you're solving the right thing at the right time to help keep the waves from crashing on each other.

Another patient spoke about how managing her stress had felt like a frustrating balancing act. She said:

When I do get a migraine I sleep like an enormous amount, which is also hard then because I don't want to like fall behind in school or anything else that I'm doing. And so, it's hard to kind of balance that because that stresses me, but I know that at the same time, if I do get more stressed out like my migraines are just going to get worse.

Our patients felt that managing stress was an important way to cope with their migraines. Yet, they were not confident in their stress management abilities. Some stated that their failed attempts to balance their lives actually made them feel more stressed.

### **Partner-Specific Coping**

Partners were found to cope with migraines by: embracing opportunities to provide support, trusting their spouse, or shutting down. The first two subcategories were



bonadaptive. All partners reported struggling at times to cope in these ways. Some partners reported rarely embracing opportunities to provide support or trust their spouse. Shutting down was found to be maladaptive.

**Embracing opportunities to provide support.** For partners, learning to embrace opportunities to provide their spouse with support was a valuable coping strategy. This mindset led them to see their partner's migraines as an opportunity for growth and self-improvement. For example, one husband talked about how his wife's migraines had taught him how to serve. He said:

I've learned to serve. I needed that. So, I've learned a lot of things that I needed to learn out of this deal. It's been a great learning experience for me. . . . Being more aware of what she needs, and trying to anticipate –cause like today, I come home from work and I got the apple juice, orange juice, and butter, and she goes, 'How did you know I need that?' Now she doesn't have to stress or worry.

For him, picking up items at the store that his wife needed was not so much a caregiving burden as it was a chance to make his wife happy. By viewing chronic migraines as an illness that could make him a better person, he was better able to cope with his wife's illness. A different partner spoke of a similar learning process. He explained:

When she is feeling incapacitated, I've realized that there isn't a lot I can do clinically to help her recover more quickly from the headache. But, there are a lot of things I can do to ease the burden around the house. I can do some additional housework and make sure the kitchen is cleaned up. I can make her a sandwich . . . Plus, [I've learned] to recognize when she's going through it in an acute phase [in a social setting] and [I] help her [leave] gracefully so that we can let her put her head down.

There was satisfaction for this man in helping to ease his wife's burdens. Embracing their role as a caregiver helped partners to better cope with their spouse's chronic migraines.

**Trusting one's partner.** A couple of partners spoke of learning to trust their

partner as an important part of their journey through chronic migraines. One partner said she used to question her partner when he was experiencing migraines. She tried to force him to take certain medications or do certain things she thought would alleviate his pain. He would rarely follow her instructions and it frustrated her. After explaining this cycle, she spoke of how she had eventually learned to just trust him and his judgements.

She said:

One of the biggest things is, I just have to trust (husband's name) and understand what he wants to do and what he feels comfortable with. And let him do that, instead of trying to force what I think I know on him. 'Cause he knows his body and how his headache is affecting him better than anybody else, and so I think, just like listening him, and just kinda letting him know, like, 'I'll do whatever you need, just kinda tell me how you're feeling.' Trust them in that process."

She found that instead of fighting with him about how to take care of himself, it was best to trust him and support him in the ways that he wanted.

**Shutting down.** Interestingly, a several partners reported shutting down during their spouse's migraines more often than they supported him/her. Thus, while embracing opportunities to serve was the more common coping strategy for partners, shutting down was also a relevant technique. One partner explained:

I think I almost shut down with her . . . That's when all hell will break loose in the house, the kids running wild, dinner is not cooked, because I just don't, I don't have the ability just to do it, you know? . . . A lot of times I'll just lay in the bed with her and I'll just watch TV, or I'll just hang out and I won't do anything.

Later, when asked to talk more about how he responds when his wife has a migraine, he said:

Truth is that I just become numb and I have zero sympathy for when she gets one. I don't feel bad anymore, I don't feel like I need to take care of her. I don't feel like I need to make it better . . . As a husband and as a man, you know, you always want to fix it. You want to be a fixer. And now, I just don't even process it. I've just learned to just shut down.

He used to try to fix his wife's migraines. But, he had stopped processing his failure to fix his wife's pain. He had learned to "just shut down."

### **Coping that was Present in Patients' and Partners' Experiences**

Finally, some coping subcategories were applicable to patients and partners. These subcategories included: acceptance, expectation, humor, and avoiding triggers. Acceptance, becoming expected, and humor were all bonadaptive coping strategies. Avoiding triggers was bonadaptive for patients, as it helped them to avoid getting a migraine. For partners, though, it was more complicated. Some partners reported being very frustrated by having to avoid certain triggers.

**Acceptance.** One of the most oft-repeated methods for coping with chronic migraines was learning to accept chronic migraines as a long-term part of life. Patients and partners alike talked about acceptance as a process or journey. They said that when they first began dealing with migraines, they would try to fight against the chronic illness and retain a sense of normalcy. But, with time, they said they came to accept that their lives were different because of chronic migraines. One patient talked about how she had had to "derail" her plans "many times" because of migraines. She said eventually she learned that because of her migraines "[she] wouldn't get to have [her] plan A" most of the time. Instead, she would have to go with "plan B, or plan C," and that was "okay."

One couple talked about how they fought a lot more during the weeks where the husband was having constant migraines. The partner reported, "It's just like, we understand that that week is like, sort-of like a crap week, and we just kinda, you know, we accept that that's how it is." The positive impact of acceptance in couple dynamics was made more evident by one patient we spoke to who had been married twice. She

spoke of how her current husband was very patient with her condition, which helped her to feel loved and valued. In contrast, she explained that her ex-husband “got very impatient with [her] about the migraines” and “got burned out by them.”

Acceptance, and its impact in couple relationships, was also relevant in the bedroom. Some partners in the study spoke of changing their sexual expectations to accommodate for their partners’ migraines. As one partner explained:

I’ll just be fair, [sexual] expectations have been lowered on my part in order to accommodate the reality of how she’s feeling. The last thing I want to do is try to work on my personal gratification at her expense when she hurts. So that has required adjustment, but it hasn’t been damaging to the relationship, it’s just been- again- part of [our] evolution.

For this patient, having less sex became less burdensome once he decided to change his sexual expectations. Acceptance was a powerful coping tool that improved individual well-being for the patients and partners I interviewed.

**Expectation.** One partner, when asked what words came to mind when he thought of his wife’s migraines responded, “Routine. For me, it’s just the routine.” Each couple we spoke with talked about how migraines had become routine for them. They developed patterns and routines that helped them to cope with the migraines the best they could. One patient, speaking about the mornings where he woke up and felt a migraine coming on, said, “Ya know, it’s not a surprise. I wake up in the morning and I go right to taking my medications.” For both him and his partner, these mornings had become predictable. He was able to tell when he woke up if a migraine was coming, and he was in the habit of immediately taking his medications if one was. His wife, likewise, had developed a routine- on mornings where his head was hurting- of giving him space. She no longer inquired if something was wrong. It was all expected and normal. Couples

came to expect and anticipate migraines which helped them to better cope with them.

**Humor.** I was surprised by how often the couples I interviewed were laughing and joking as I asked them questions about their migraines. Every couple I interviewed talked about using humor to cope with their migraines. One couple described it this way:

- Wife: That's the other thing too. Having a sense of humor . . . You learn how to laugh through a lot of these things, because otherwise you would just sit at home and cry-
- Patient: It's laugh or cry.
- Wife: So, if [other couples in our shoes] don't have a sense of humor, [they] need to develop one. Because it is bumpy without one. We laugh a lot, and we make fun of each other, and we do those kinds of things because that's what eases that burden a lot of the times too.

Another couple expressed similar sentiments:

- Patient: Keep up your relationship, talk to each other a lot, spend as much time together as you can, and laugh! (To husband) Right?
- Husband: That's right.
- Patient: Yeah, don't take yourself too seriously.

By learning to laugh, and by not taking themselves "too seriously," the couples I interviewed were able to better cope with the burdens they were carrying from chronic migraines.

**Avoiding triggers.** Avoiding migraine triggers was another important coping strategy. This involved both partners, as demonstrated by the following exchange:

- Patient: Light is one of my things that I really don't like when I have really bad headaches. I like to go sit in the dark.
- Husband: She makes me brush my teeth in the dark!

Light was a common trigger for the patients I interviewed. A different partner talked about how he had to avoid creating bright light for his wife, too. He said, "I have to be more cautious because I can't make loud noises, I can't do bright lights. Just different

activities I would normally do, I have to avoid [because they trigger migraines for my wife].” In addition to lights and sounds, other triggers mentioned included: lack of sleep, gluten, stress, scents, and exposure to the sun for long periods. One patient who was triggered by scents talked about how “really strong perfumes or colognes” gave her headaches. She said she was grateful her husband did not wear colognes. Patients and partners in this study were both careful to avoid patients’ triggers. For some partners, this practice was somewhat frustrating.

### **Major Category #2: Healthcare**

Another major category that emerged in our analyses centered upon our participants' experiences seeking healthcare for chronic migraines. This category served to either aid or frustrate patients' and partners' efforts to adapt to chronic migraines. For most participants, their experience with healthcare was largely frustrating. The following exchange serves as an appropriate introduction to our participant’s feelings about the healthcare they have received:

Interviewer: What’s your experience been with treatment?  
 Husband: Frustrating.  
 Patient: I was just gonna say that. Beyond frustrating.

Much of this frustration centered upon how doctors seemed to “experiment with medications” that “never seemed to work” for them. One patient explained that after 21 years, she still had not found a treatment that worked. She said, “I have been on so many medications. I’ve just trusted the neurologist and the doctors and [they’ve put me] on so many medications [that haven’t worked].”

Still, patients’ feedback for the medical community was not entirely negative. A couple patients spoke of how they felt like their doctors and nurses “always cared” and

“tried their best.” One patient said her headaches “used to be a lot worse” than they were currently, and credited pharmacological advancements- particularly, the development of triptans- for her improved outcomes. I will now review the healthcare-related subcategories that emerged during our analyses. Three subcategories were specific to patients and three subcategories applied to both patients and partners. There were no partner-specific subcategories affiliated with this major category.

### **Patient-Specific Healthcare Subthemes**

Three healthcare subcategories emerged that were specific to just chronic migraine patients. Patients spoke about giving up on medical treatment and then starting over again. They discussed how their comorbid conditions complicated treatment, and some reported that they struggled to receive care from headache specialists because of limited access. Each of these subcategories were largely maladaptive in patient's lives.

**Giving up. Starting over.** The patients I interviewed described patterns of giving up on doctors and not seeing them anymore, then starting over again with new medical providers. They talked about feeling extremely frustrated with their doctors’ lack of solutions, leading them to quit on doctors altogether, at times. Eventually, hoping that a new doctor would have new answers, or needing refills on prescriptions that helped alleviate their pain to an extent, they would seek care again. For some, this pattern was repeated many times. One patient summarized this process, stating:

I know most of the neurologists in this county, I’ve been to most of them. Every couple of years, I’ll give up and I’ll say, “I’m done for now!” I’ll quit going to neurologists, because I think they don’t know how to help me. And many of them, their go-to solution is to try different medications with me, and I’m not interested in them experimenting to see if one sticks and one works. And I’ll tell them that, I’ll say ‘Look, if your solution is to try an antidepressant to see if it helps, I’m not interested in doing that.’ And, and, I was really excited when a

couple of those guys said, ‘Okay, I don’t think I can help you.’ You know, they saved me four months of visits with them.

Like he described, patients were frustrated with their perception that doctors were always “[trying] different medications” on them that never seemed to work. Patients appreciated doctors that listened to them and who responded to their questions and desires in an upfront manner. The consistent experience of starting treatment with a new provider and finding that (like their previous providers) he/she did not have solutions was one of the greatest frustrations patients reported.

**Comorbid conditions complicating treatment.** Without exception, each of the patients in this study had comorbid conditions that complicated their treatment. These comorbid conditions included epilepsy, benign tumors, back pain, allergies, generalized anxiety, and depression, to name a few. One patient with back problems spoke about having a surgery to replace a screw in her back. This surgery reduced the pain in her back, but it greatly exacerbated her migraines. Another patient talked about how he had struggled to get good treatment for his migraines, because the neurologists he met with were so focused on his epilepsy. His wife added, “So, we’ve tried to get attention to the headaches because of how bad they can get, but no one’s really able to focus on it because they’re more worried about the epilepsy.” The chronic migraine patients I spoke with had a complex interaction of symptoms associated with comorbid conditions that made treating their migraines very difficult.

**Access to headache specialists.** Another challenge that patients reported was getting access to neurologists or other headache specialists. One patient, living in a suburban area, said she waited over nine months to get into her local headache clinic. She then exclaimed, “That’s a long wait! I just think there are so many people



who suffer, there is just a huge waiting list to get in.” Another patient, living in a more rural location, explained that she had not been able to get in to see a neurologist. Her husband said that “she [was] trying to get in to see a neurologist, but there [were] no neurologists” in the area where they lived. Then, she added, “And I’ve, like, tried calling other places . . . I could never even get into a neurologist anywhere. I was looking like all the way down to [a place 3 hours away].” Many patients in this study struggled to access healthcare from headache specialists because of long waiting lists and long distances to travel.

### **Healthcare Subthemes that were Present in Patients’ and Partners’ Experiences**

The partners I interviewed expressed that it was their spouses who were impacted the most by the healthcare they received. Partners usually did not go to their spouses' medical appointments. Yet, three healthcare-related subcategories emerged from our analyses that applied equally to both patients and partners. I discuss these subcategories in what follows.

**Trying to find a cure; searching for alternative treatments.** The patients and partners I spoke with frequently talked about searching for a cure to chronic migraines. Speaking of her hope for a cure, one partner said, “You know, we’re always looking for answers from people or whatever. And, of course, we pray for answers and those kinds of things, and hope that maybe some new technology comes along.” Another partner shared his reaction when his wife first began experiencing frequent migraines. He immediately began trying to find a cure. He explained:

I was in the fix it mode: let’s get this fixed, let’s get it taken care of. Let’s find out what medicine is gonna take this away from you. Or, is it a medicine you are

taking that is causing this and we need to get you off of it? Or is it stress related? Do we need to de-stress your life?

In pursuit of a cure, or at least in pursuit of more effective treatments, patients and partners often sought out alternative treatments. Couples rarely felt like the medical treatments they were receiving were adequate and searched for their own for answers. Several partners talked about how their spouses were “always searching,” “not settling,” and “looking for something else to try.” One partner talked about how his wife’s constant search for better treatment was something he “appreciated.” Still, this constant searching often led to even more disappointment. One partner said her husband had tried everything there was to try and none of it had worked. She explained:

He has . . . done everything. We’ve gone to every kind of doctor . . . He’s had Botox, he’s had everything done possible. Um, acupuncture, been to all kind of specialists, headache clinics, sleep studies, there’s nothing left to do, that’s just the way it is.

The search for alternative treatments was not always unfruitful. One patient spoke of going to a chronic pain management class, and said it was one of the most helpful things she had ever done to treat her migraines. She said:

You know, I think that one of the best things that I did . . . was going to a class on, um, chronic pain management. Because it helped me to . . . find other solutions [that didn’t involve medications] . . . To find other ways [to cope with the pain] like exercise and self-talk and things like [that]. So that was very helpful to me; I appreciated that very much. And I feel like I probably should have started with all of that and then worked into the medicines after that.

For her, using exercise and positive self-talk were some of her most effective pain-management strategies. There were several patients we interviewed who reported feeling like migraine treatment is too focused on pharmacology and said they wanted to be introduced to other methods to manage their pain. Furthermore, partners also felt an urgency to find solutions to their spouses’ suffering.

**Lack of understanding from medical professionals.** Speaking of the healthcare his wife had received, one partner said, “I remember her doctor- literally 95% of the dialogue was the doctor talking. Like, how much information can you get if you're talking the entire time? Doesn't the doctor want to know the actual problems?” Multiple patients shared feeling like their doctors did not listen to them, care about them, or trust them. Speaking of the value of listening to patients and learning what has worked for them in the past, and what has not, another partner said:

It helps a whole lot to first listen to what's already been tried and to what extent it helped, and then start from there . . . There were several times when a provider tried to take her off of everything, all the medications, the diet coke, and to cleanse the system, get it all out of her—it literally put her to bed for two months. You know, doing that, it completely took away any relief mechanism she was getting from her headaches and she was incapacitated for an extended period of time . . . There were those that blamed her current regiment, blamed caffeine, blamed the medication she was on and felt like by stripping that all out she would magically heal. It always made things worse.

This couple encouraged doctors to care more about their patients' actual lived experience, instead of blindly following current medical protocols or theories.

Beyond not listening to their patients, our participants complained that doctors assumed migraine patients were “just drug-seeking,” when in fact they were experiencing severe pain. One patient explained, “Emergency room doctors just think you're looking for meds- like you're drug seeking . . . . So that's probably the worst.” Another patient said that she, gratefully, was never accused of drug-seeking. But, she sympathized with chronic migraine sufferer friends who had experienced drug-seeking accusations. She said:

I've had friends who've had doctors who thought they were just there for drugs, or when they went to the ER they thought they were just there for drugs. Um... I always worried about that when I went to the ER. Are they going to think that I

just want pain killers? And I'm in so much pain, it's like, "I *am* here for pain killers!"

The patients and partners I interviewed reported many experiences which left them feeling like the medical community did not understand the severity of chronic migraine symptoms. Furthermore, they felt that the medical community often did not know how to treat chronic migraines, either.

**Positive and negative effects of insurance.** Quality and affordability of one's insurance had a profound impact upon the care patients received. For some couples, insurance enabled desired treatment. For other couples, insurance was a major contributor to financial burdens and prevented access to wanted medical care. The following quote illustrates how, for some couples, insurance was an invaluable aid. A patient explained, "I've been really, really lucky that my headache condition didn't happen until we moved to [state they live in]. And, the whole time I have been employed by [the same corporation] and I have had fantastic health insurance coverage." Other couples did not feel so "lucky" with regard to their coverage. One patient said, "I was looking [for a neurologist everywhere] and everyone was, like, booked, or not covered by my insurance, and it was just gonna be an enormous amount of money." Because of their insurance's limited network of paneled headache specialists, this patient was unable to get treatment.

Insurance also impacted how couples approached employment. For one couple, the patient stayed home and took care of children, in-part because his wife's job had better health benefits than the insurance offered by his former employer. He said this was hard for him, as he had always planned to be the provider for his family. In other couples, the patient had to work because health insurance he/she was offered through

his/her employer was drastically better than the insurance options his/her partner could provide. In one such couple, the patient talked about a headache support-group held at the headache clinic where she received medical care. She said that some of the people in the support-group had quit working because of their migraines, but she said that was never an option for her. Her family was reliant upon her for health insurance. “There’s a group that meets, and a lot of [patients in the group] have lost jobs and they just stopped going to work. And, for me, that’s not really an option because I have to keep my health insurance.” In this study, insurance impacted patients’ access to medical care, family finances, and couples’ decisions concerning employment.

### **Major Category #3: Couple Dynamics**

Couple dynamics emerged as another major category during our analyses. We found that, like coping and healthcare, a couple’s dynamics served to either improve or worsen patients’ and partners’ adaptation to chronic migraines. One of the patients we interviewed was uniquely qualified to speak of how couple dynamics influence adaptation. She had been married twice. Speaking of her current husband, she said:

He lifts a lot of burdens. He does. Which is, it kind of blows my mind, actually. That was not my first experience, with my first husband. He tended to give you burdens. He tended to do the opposite of that.

She appreciated that her current husband helped to ease her burdens. Her first marriage, an unhealthy, distressed relationship that ended in divorce, had only added to her burdens. In what follows, I address the three subcategories related to couple experience that were identified during our analyses.

### **Perceived Balance/Imbalance of Giving and Taking in the Relationship**

We found that the couples in our study oscillated between feelings of balance and imbalance regarding what each person gives and takes in their relationship. No couple in our study always felt that their relational give-and-take was perfectly balanced, and no couple felt that it was always lopsided, either. Still, we found that some couples felt that their give-and-take was largely balanced, while others felt that their relationship was largely imbalanced or unfair.

One partner shared his feeling that he did not receive from his partner nearly as much as he gave to her. He talked about how he did his best to take care of her while she was having a migraine but said he did not feel that he got the same care and concern from her in return. He said:

I need just as much help as she does with stuff in my life . . . And, um, I, like, can't get that from someone who has a migraine. It's more [of] a one-way thing. I know how to help her really well . . . When she has an issue with school, or migraines, like, I can figure out the problem and help her with it. But that's not translated, like, vice versa. It's a lot harder for her to help me when [she has] migraines all the time . . . It feels a little uneven.

His wife responded immediately to this statement, saying: "It's like I try, and I want to of course be there and help whenever I can, but I think a lot of times I'm in a lot of pain and I just can't. And I'm, like, exhausted." She said that she and her husband had discussed this issue many times. She recognized that their relationship felt "uneven," but she was not sure how he expected her to care for him when she was in pain.

Another partner said that because of her husband and his chronic migraines, she basically did "everything" for the family. "I was in my master's, I was our provider, I was, ya know, everything. It was a lot. . . there were a lot of times where I was crying,

and angry, and trying to understand, but not understanding.” Yet, she said, she did not always feel that way. She reported occasions where she became quite sick and said that her husband did “an amazing job” taking care of her. He cared for her even as he was experiencing migraines.

The partners we spoke with did not always feel that they gave without receiving in return. Several of the partners talked about how their spouses helped to ease their burdens by taking care of children or grandchildren. Others talked about how their spouses “were troopers” and were able to do a lot of things around the house. Or, they were grateful that their spouses were employed despite their chronic illness. Conversely, the patients we interviewed often felt grateful for their spouse’s compassion, patience, and kindness. Yet, there were also many times where they felt frustrated with their partners’ lack of understanding, impatience, or selfishness. Thus, most couples struggled with frequent feelings that there was an imbalance of giving and taking in their relationship, while also feeling, at times, that they were giving and taking from each other in a fair manner.

### **Connection and Disconnection**

We were surprised during our analyses at how couples reported experiencing both connection and disconnection because of chronic migraines. Couples spoke in great depth about the discord and tension chronic migraines caused, but then discussed migraines as something which had brought them closer together as well. One partner spoke about how she fights more with her husband when he is having a migraine. She said:

I think we fight more that week. And it’s not like, you know, crazy, yelling, knock down furniture. But I think, like, petty arguments increase . . . I’m frustrated because it’s just so stressful, and I’m dealing with everything. And he’s frustrated because he has a pounding, aching headache. And so I think we’re just on each other’s nerves a lot more . . . [It] makes for, like, a tense kind of feeling in the house for, like, a week. . . We’re keeping each other at arm’s length for a little bit . . . I think that is a big thing.

Just a few minutes later, this same woman reported that she thought migraines had

“actually brought them closer together.” She talked about how they had learned to “just

let things go,” and said that they felt like they could “get through anything together” because of the experiences they had with chronic migraines.

Each couple we interviewed agreed that, to varying extents, their chronic migraines had brought them closer together. One partner explained, “I’ve become more connected with her. I feel we’re a closer couple in a lot of ways, because I’ve had to change what I look at and become more involved in what she needs.” A patient who had been the recipient of her husband’s gentleness and kindness talked about how her migraines had only increased the feelings of gratitude that she had for her partner. She explained:

One thing that has been really nice is, I’ve been really grateful for the way that he has responded to me. It hasn’t been an issue of anger, ever. It’s never been an issue of, “Why don’t you just get up off that couch?” or anything like that. He’s always been very gentle, very understanding, very patient. And, I mean I couldn’t ask for a more ideal situation than I have. If I have to go through this, I’d rather go through it with him than with anybody else.

This report was unique. All the other couples reported—to varying degrees—moments of anger, misunderstanding, or impatience, as well as feelings of connection.

### **Resilience and Strength**

Because of their experiences with chronic migraines, most of the couples we interviewed reported feeling that they were resilient and strong. Couples spoke of being “able to work well together during crises,” or they spoke of being “able to get through anything.” One partner said he and his wife had kept their relationship strong, despite all the frustration and stress her chronic illness had put them through. He said that they had learned to rely on each other, and that “after 24 years of marriage, [they were] still doing pretty well.”



### **Major Category #4: Identity**

During our analyses, it became apparent that factors associated with one's identity helped to shape how patients or partners adapted to chronic migraines. Along with coping, healthcare, and couple experience, identity was one of the central factors that shaped how effectively patients and partners responded to the burdens associated with chronic migraines. I will outline the subcategories associated with identity that emerged from our analyses. Each subcategory had both bonadaptive and maladaptive effects. All subcategories associated with this major category applied to patients and partners alike.

#### **Gender**

For our participants, gender scripts played a major role in shaping their experience with chronic migraines. Two of the male patients I interviewed struggled to reach out to their wives for support with their migraines. They felt the need to be "masculine" and "tough," instead. A wife of one these patients remarked, "My husband is kind of like a 'suffer through it in silence' kind of a guy." She said it was very difficult for her to help him when he was in pain because he would respond by isolating himself and pushing her away. Furthermore, these perceptions of toughness often affected treatment. One male patient said that he regularly failed to take his pain relievers early enough to prevent the onset of a migraine. His wife explained that because he valued toughness so much, he only took his medications when he was in "a lot of pain" and would not take them at an attack's onset. However, she also felt that there was a silver lining associated with his perception of manhood. "He doesn't quit, he doesn't stop," she

said. His perceptions of toughness and manhood helped him “to work and to keep going” when “other people would have quit.”

Females with chronic migraines were more likely to ask for their partner’s support and help than the male patients we interviewed. Several male partners expressed the belief that it was masculine and noble to care for their wives. Despite this, male partners were more likely than female partners to “shut down.” In one case, the female chronic migraine patient was more of a caregiver to her husband, than her husband was to her. Her husband did not suffer from any illnesses that required caregiving, aside from normal colds and illnesses. She said:

If he’s not feeling well or whatever, like, I’m always like his mom, so to speak. And so, you know, I’m making sure he’s taking medicine, I’m making him go to bed, I’m, ya know, like he said, I’ll go to the store and get different food or whatever the case may be. . . [But] you’ve seen that commercial that’s like, “Moms can’t take a sick day”? Like, it’s true. [I] just can’t cause [I’m] stuck with this guy whose mom is always taking care of him, so he, he doesn’t know how to do that for me.

She felt that she had a responsibility to care for and “mother” her husband. The husband, according to her, was unable to take care for her because of how he had been raised. Gender dynamics were unique and varied in the couples I interviewed, but it appeared that concepts of gender affected and shaped how couples adapted to chronic migraines.

### **Family Values and Expectations**

Another identity factor that impacted adaptation was family values and expectations with which patients and partners were raised. One patient credited her upbringing for her pain tolerance and resilience. She said:

I mean, I grew up playing sports and stuff like that. And so, like, I've always, like, had that mentality of, "If you're not bleeding, you're fine." . . . That's just, like, how I grew up . . . If I got hurt or something my mom would be like, "Are you bleeding?" and I'd be like, "No." And she's like, "OK, you're fine." So, I've just kind of, like, learned to just push through.

Similarly, one partner talked about how her husband had grown up with very similar values. She said, "His dad was a very hard worker. I mean, and so is [my husband]. . . They don't quit, they just function through it." Another woman talked about how she grew up with a "function through it" mentality as well. However, she said that her husband, who suffered from chronic migraines was not raised the same way. She explained that, consequently, she was frequently fighting the feeling that her husband just needed to be "tougher." She struggled to know if she should be sensitive and supportive with her husband, or if she should push him and challenge him, instead. Thus, the values and expectations patients and partners were raised with influenced their experiences with chronic migraines.

### **Anxiety**

Earlier, I spoke of how chronic migraines created anxiety for the migraine patients I interviewed. We also found that many of our patients reported being "highly anxious, naturally." An anxious predisposition proved to be another identity factor that shaped the migraine experience for patients and partners. For patients who were naturally anxious, their high anxiety worsened their headaches. One patient explained, "My anxiety and my stress are out of control. And I'm sure they play a large role into why I have such frequent migraines." One partner, with some frustration in his tone, said, "Well, one thing to know about [my wife] is, her anxiety and stress is non-stop. It doesn't end." He was "sure" that his wife's anxiety made the headaches worse.

### **Religiosity/Spirituality**

Religiosity and/or spirituality was another identity factor that impacted participants' adaptation to chronic migraines. The impact was diverse and varied. Some of the effects of religiosity/spirituality were challenging or negative. Some patients talked about how their activity in their church community just created more stress for them, exacerbating their headaches. One partner talked about how her husband's migraines always occurred on days where they were supposed to be going to church as a family. She wondered why her husband was not trying harder to accompany them to church. Patients and partners talked about praying for a cure and described experiencing frustration and doubt when those prayers were never answered. One partner said, with some emotion, "There are times where [I ask myself], 'Why aren't my prayers getting answered?'" It feels like the more I pray for him, the worse his migraines get."

Conversely, couples also shared encouraging and healing experiences relating to religiosity and/or spirituality. Patients and partners talked about receiving support from people in their church communities. One patient said he had found a neurologist who "actually helped him" through one of his friends at church. One partner talked about how she found "tremendous strength and comfort" by praying and engaging in other spiritual activities when she was feeling overwhelmed. One couple talked about how they were able "to be patient," and to "try and figure out what [they] are supposed to learn from all of [their suffering]" by maintaining their religious perspective.

Several couples talked about acceptance as a spiritual process. They spoke of praying and hoping for a cure and eventually coming to accept that they were not "meant" to have the illness cured. Speaking of this process, one partner said:

Now, now we're [in] full acceptance of the fact that there probably isn't going to be a cure, unless...unless the Lord sees fit . . . but, uh, we just have come to accept the fact that this is part of her mortal existence. And so, we'll do our best to cope and manage it within the limits of our own ability.

Similarly, one patient spoke about how he used to think he needed to have more faith, so he could get cured from his migraines. He said, though, that he realized it was best not to rely upon false hope. "Ya know, from a [religious] perspective, you don't, you don't want to show a lack of faith, but at the other time, false hope doesn't get you anything." Consequently, he had chosen to accept that chronic illness was a long-term part of his life. Several couples said spirituality was vital in helping them cope with their chronic migraines.

### **Socioeconomic Status (SES)**

Lastly, the SES of the couples we interviewed was another factor that shaped their migraine experience. Social and economic standing dictated what healthcare was available to patients. The financial costs of chronic migraine treatment weighed most heavily upon couples who struggled financially. One patient aptly summarized how SES affects chronic migraine patients and partners when he said:

We are a "normal," every-day, working class family. And, ya know, migraines affect everyone. [They] have no boundaries in status. But, those who suffer the most [with migraines] are those in the working class, and those who can't afford the absolute best care.

### **Conclusion**

I have presented our grounded theory of adaptation to chronic migraines for patients and their partners. Our grounded theory illustrates that each patient or partner affected by chronic migraines deals with related burdens and costs. The effectiveness

with which patients or partners adapt to chronic migraines is determined by how effectively he/she copes, the healthcare he/she receives, couple dynamics, and factors associated with identity. I provided quotes describing each subcategory that emerged from our analyses. Quotations were used throughout the presentation of my findings to ensure that they were grounded in the actual data our participants provided.

## CHAPTER V

### DISCUSSION

With this study, I<sup>3</sup> created a grounded theory that couples dealing with chronic migraines and clinicians can use to understand how to best adapt to chronic migraines. In developing this grounded theory, I explored chronic migraines within the context of committed, romantic relationships. Lipton and his colleagues (2017) drew attention to how little we know about the impact of migraines on families and called for research investigating this topic. I helped to fill this gap in the literature by studying the impact of migraines on partners, and by exploring how migraines affected romantic relationships. My grounded theory has important implications for couples dealing with chronic migraines and clinicians. I will discuss these implications later. First, I discuss my grounded theory as it relates to the BPS-S model and family systems theory. Then, I situate my findings within the existing literature, discuss my study's limitations, and provide suggestions for future research.

#### **My Grounded Theory, the BPS-S Model, and Family Systems Theory**

My grounded theory is situated within the larger theoretical framework provided by the BPS-S model and family systems theory. Seen through the lenses provided by these theories, one realizes that: (a) a person's health is the product of his/her biology, psychology, sociality, and spirituality, and that these domains affect one another; (b) that

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<sup>3</sup> In the findings section, I utilized first-person plural point of view to honor the contributions of the other researchers who analyzed the data alongside me. In this section, as the sole author of this project, I return to using the first person-singular point of view.

families form an interdependent, interconnected system (Engel, 1977; Hodgson et al., 2014; Smith & Hamon, 2012). The BPS-S model and family systems theory are theories that are broad enough to be applied to anyone (Hodgson et al., 2014; Smith & Hamon, 2012). My grounded theory is an extension of these theories; it is specific to how patients and partners dealing with chronic migraines adapt to illness. In other words, my grounded theory helps to confirm the universal concepts of the BPS-S model and family systems theory within the specific context of couples and chronic migraines.

With my theory, I isolated various experiences that chronic migraine patients and their partners experienced and illustrated how they were connected. Categories and subcategories associated with each of the domains of the BPS-S model were present in my grounded theory. Furthermore, the experiences of chronic migraine patients and partners were found to be interdependent upon one another. Relational dynamics shaped how effectively patients and partners adapted to their migraine-related burdens. Thus, I found that the BPS-S model and family systems theory provided an appropriate framework for this study. Yet, it should not be assumed that my grounded theory was unnecessary. With my grounded theory, I explained and predicted adaptation to chronic migraines for couples with a degree of specificity and detail that was previously unfounded.

### **My Grounded Theory in the Extant Empirical Literature**

My grounded theory features the burdens and costs of chronic migraines as its central category. In the extant literature, the burdens and costs of migraines for patients are much better understood than partners' migraine-related burdens. My findings regarding patients' burdens were very consistent with findings in the existing literature



(Nichols et al., 2017). In addition to experiencing physical pain, chronic migraine patients in my study suffered social misunderstanding and feelings of isolation because their illness was invisible. Patients also reported feelings of loss, hopelessness, depression, and high levels of stress and anxiety.

My findings regarding partners' burdens and costs as they dealt with chronic migraines appear to be a new addition to the chronic migraine literature. My grounded theory makes clear that partners deal with migraine-related burdens and costs, and that they, like patients, must adapt to chronic migraines. Partners and patients alike were less social and less physically active than they wanted to be because of migraines. Partners also regularly provided care for their spouse during migraines. Caregiving was said to be exhausting, time-consuming, difficult, and unexpected. These findings were consistent with previous research that has examined caregiving burdens for chronically ill patients' partners (Tompkins et al., 2014; Woods et al., 2014). But, to my knowledge, this study was the first to highlight that chronic migraine patients' partners experience caregiving-related burdens. By including partners more fully in treatment, clinicians could alleviate their burdens while helping them to provide better care to their spouses. My grounded theory indicates that a more systemic approach to chronic migraine treatment would be useful.

Coping was identified as my theory's first major category. The way patients or partners coped with migraine-related burdens and costs helped determine how effectively they adapted to the illness. I found that acceptance was vital for both patients and partners dealing with chronic migraines. A burgeoning body of research has found acceptance as an important component of treatment for chronic migraine patients (Feuille

& Pargament, 2015; Grazzi et al., 2017). My findings indicate that acceptance could help partners to deal with their burdens, too. When a patient had a migraine, some partners in our study would frequently shut down. While this was useful to an extent, I found that partners who would shut down, instead of embracing and accepting their role as a caregiver, dealt with greater feelings of guilt and relational distress. For those partners who consistently provided caregiving during migraines, I found improved well-being for both patients and partners. The degree to which partners were able to embrace their role as a caregiver seemed to positively impact coping for the couple. My study extended findings regarding acceptance and chronic migraines to patients' partners, and found that accepting one's role as a caregiver had powerful effects upon well-being for both patients and partners.

Consistent with past research that has found overall medical care for migraines to be unsatisfactory (Wang & Young, 2011), I found that patients in my study were frustrated with the medical care they had received. It is unfortunate that my participants experienced healthcare was so often a source of negativity and maladaptation. My grounded theory identified healthcare as one of the four categories that shaped how patients and partners adapted to chronic migraines. Efforts to improve chronic migraine treatment are worthwhile. As healthcare for chronic migraines becomes better, patients and partners should experience a greater sense of well-being. In my study, the perceptions of patients and partners regarding healthcare for chronic migraines was explored. This represents a novel contribution to the chronic migraine literature.

Patients in my study spoke of doctors experimenting with medications that rarely seemed to work and reported feeling like their doctors did not listen to them. Many

patients tried pairing alternative treatment methods- such as acupuncture, massage therapy, chiropractic services, or specially-tinted sunglasses- with their pharmacological treatment. They experienced some success with these pairings but reported only modest gains (Wang & Young, 2011). Partners were less involved with healthcare than patients. But, partners reported trying to find a cure to their loved one's migraines and experienced frustration with their inability to do so. Later, I will discuss the clinical implications of these findings.

There is a dearth of research exploring how relational dynamics are affected by chronic migraines. My grounded theory addressed how chronic migraines influenced my participants' relational dynamics. Furthermore, I found that relational dynamics influenced how effectively patients and partners adapted to chronic migraines. Current literature that specifically discusses couple dynamics in the context of chronic illness is often theoretical or anecdotal. More studies empirically examining couple dynamics in the context of chronic illness are needed.

The couples I interviewed oscillated between feeling that their relationship was balanced (in terms of what each partner was giving and receiving from the other) and imbalanced. At times, patients and partners felt that they were giving to and receiving from their partner in an appropriate measure. At other times, patients and partners felt that the relationship was imbalanced—that one partner was giving disproportionately more than the other. In part, migraine's unpredictability might be accountable for this oscillation. When migraine patients are not incapacitated, it is more likely the give-and-take will feel balanced for both patients and partners. While patients are experiencing a migraine, it is likely that the partner begins to feel like he/she is giving more than he/she

is receiving. Yet, this explanation is incomplete. In some cases, partners talked about feeling grateful for the way spouses would “push through” their migraines. Thus, in some cases, a patient’s ability to give to his/her partner in the midst a migraine, might help couples to feel relational balance. Furthermore, in couples that had embraced the partner’s role as a caregiver, relational give-and-take seemed to be more balanced than in couples that had not accepted the partner’s caregiving role (Helgeson et al., 2017). Thus, it appears that perceptions of caregiving- not just the amount of caregiving, alone- affected relational balance.

The oscillation between relational balance and imbalance helps to explain another related finding. Chronic migraines resulted in both connection and disconnection for the couples in our study. Couples reported that migraines created relational tension and/or increased fighting (Tenhunen & Elander, 2005). Yet, they also reported that chronic migraines brought them closer together and made them stronger. Perhaps, during times of perceived relational imbalance, relational distress and disconnection were the result. Feelings of togetherness and connection, on the other hand, might have been the result when couples perceived that their relational giving and receiving was balanced. The importance of these findings will be discussed later, as I outline the study’s implications.

The fourth major category in my grounded theory was identity. I found that factors such as gender, family values and expectations, and religiosity/spirituality influenced how well patients or partners adapted to chronic migraines. The existing chronic migraine literature, minimal attention has been paid to how gender affects psychosocial coping. However, some research has been devoted to how gender scripts

impact pain management. For example, Flurey and her colleagues (2018) discussed how gender scripts affected male coping with rheumatoid arthritis. I found that gender scripts impacted our participants' psychosocial experiences. For example, some of the male patients in my study believed they were required to be tough and to avoid support-seeking from their partner because they were men. Some female patients struggled with the fact that their husbands did most of the housework. They felt like it was their responsibility to do the cooking and cleaning. Thus, gender scripts were one of the factors I identified that influenced adaptation.

Another aspect of identity that influenced how couples adjusted to chronic migraines was the family values and expectations with which they had grown up. This is a topic that has received scant attention in the current literature. Some patients or partners in my study had grown up with the expectation that they had to continue working even when they were sick or did not feel well. Others grew up with the expectation that when one does not feel well, he/she should rest and recover. These expectations shaped how patients responded to migraines. Furthermore, in couples where the patient and partner grew up with opposite expectations, conflict resulted. For example, in one couple, the patient insisted that he had to rest when he was experiencing a migraine. His partner felt otherwise and tried to get him to demonstrate more toughness. Both partners resented each other's approach to pain management.

Religiosity and spirituality were other factors that shaped the experiences of couples we interviewed. Extensive prior research has found that spirituality and religiosity can improve health outcomes for various diseases, including asthma, sickle-cell anemia, diabetes, and others (Clayton-Jones, Haglund, Belknap, Schaefer, &

Thompson, 2016; Cotton et al., 2012; Rivera-Hernandez, 2016). In this study, the majority of participants reported that religiosity and/or spirituality helped them to feel peace, acceptance, and meaning. Yet, they also reported that religiosity and/or spirituality was at times a source of pain and confusion. Some patients and partners talked about praying for a cure to chronic migraines, only to see the migraines get worse. A study of patients with cluster headaches reported a similar finding (Palacios-Cena et al., 2016). I will further discuss the implications of gender scripts, family expectations, and religiosity/spirituality upon treatment when I provide this study's clinical implications.

My theory is the first of its kind. With it, I have added new and important findings to the chronic migraine literature. Foremost among these contributions, I have called attention to the benefits of a more systemic chronic migraine treatment. I have highlighted that chronic migraines impact both patients and partners. Furthermore, I have found that relational dynamics can improve adaptation to chronic migraines for patients and partners.

### **Limitations**

I will now discuss the limitations related to my study. First, all participants in this study were white, heterosexual, cisgender, and most were middle to upper middle class. Therefore, my model of well-being must be applied cautiously to: people who are racially or culturally diverse, couples of the same sex, people who are transgender or gender fluid, and people from different social or economic classes. Future research should involve more diverse samples. Second, I did little to account for the influence of time within my grounded theory. Our sample involved diverse relationship durations.

Some couples in the study had only been together for a couple of years; others had been together for several decades. Furthermore, the number of years that patients had experienced chronic migraines in our study also varied. While I believe my grounded theory benefited from having the perspectives of couples with varying relationship lengths and illness durations, I believe more nuanced research examining the effects of time on the couple chronic migraine experience could be valuable. Third, my model was developed specifically for couples dealing with chronic migraines. Thus, extending my grounded theory to couples affected by other headache disorders should be done cautiously. It would be interesting to examine the relatability of our findings to couples who deal with chronic tension-type headaches or cluster headaches.

### **Suggestions for Future Research**

I now provide suggestions for future research. First, with this study I only interviewed couples who were married. By interviewing couples affected by chronic migraines who were divorced, separated, or broken-up, researchers could gain a richer understanding of how chronic migraines affect patients, partners, and couple dynamics. Second, with this study I have suggested that couples dealing with chronic migraines should seek therapy. I believe that therapy could help ameliorate migraine symptoms. Therapy would also improve couples' psychosocial coping with chronic migraines. These claims should be evaluated and tested in future studies. Third, more research exploring how children are affected when their parents deal with chronic migraines is needed. Fourth, I found that couples tend to oscillate between feelings of relational balance and relational imbalance. Relational balance seemed to produce connection, while imbalance seemed to result in disconnection. While all relationships

oscillated to a degree, some couples reported feeling much more balanced than others. I theorized that couples' acceptance of their illness and of the partner's role as a caregiver helped to facilitate relational balance. But, this theorization should be evaluated further. There is still much to learn about processes of relational balance and/or imbalance in the context of chronic migraines.

### **Recommendations for Couples dealing with Chronic Migraines**

My grounded theory was developed specifically for chronic migraine patients and their partners. Drawing from these findings, I now make recommendations to couples dealing with chronic migraines. First, I address treatment. Then, I address coping and couple dynamics.

#### **Treatment**

The findings of this study should not deter couples from seeking medical care. Pharmaceuticals served as my patients' best form of pain relief. Chronic migraine patients should seek medical attention. But, patients need to advocate for themselves when seeking treatment. While patients cannot force medical providers to listen to them, they can at least insist upon working with providers who do. Patients should also know that the use of triptans is the gold standard in pharmacological treatment for chronic migraines. They should feel comfortable bringing up triptans with their medical provider and seeking his/her expert opinion on them.

Couples dealing with migraines should also consider pairing alternative treatment methods with their pharmacological care. Several patients referred to wearing specially-tinted glasses, receiving massages, or physical therapy as being particularly helpful in



ameliorating some migraine symptoms. One patient attended a chronic pain management class. She said that it had been one of the most useful treatments she had ever received. None of our participants spoke of seeking therapy to help them deal with their symptoms. But, psychotherapy has potential to improve the lives of couples dealing with chronic migraines. In therapy, patients could learn strategies to reduce their anxiety and stress. By so doing, it is probable that their migraines could improve. I recommend that couples dealing with chronic migraines seek out couples' therapists. In addition to teaching individual coping strategies and stress-reduction techniques, couples' therapists would include patients' partners in treatment. Our findings indicate that it would be beneficial for couples dealing with chronic migraines to receive therapy that addressed their relational dynamics and patterns of caregiving.

### **Coping**

I now speak to couples dealing with chronic migraines about the importance of acceptance in coping. While I do not discourage couples from hoping for a cure, I also strongly encourage patients and partners to accept that they might never find one. The couples I interviewed found that when they did so, their burdens became a bit lighter, and their well-being improved. They stopped berating themselves for not being "normal." They came to accept that their lives would be different than they had once expected. They altered their rules and their expectations to accommodate for chronic migraines. Acceptance, for our participants, did not represent giving up hope, or surrendering to chronic migraines and becoming miserable. Acceptance allowed them to live the best lives they could as they dealt with chronic migraines. Couples might experience more complete acceptance as they examine previous expectations and try to

alter them appropriately. Furthermore, tapping into religious or spiritual resources could also help couples to more fully accept chronic migraines. It is important to realize that the process of acceptance applied to both patients and partners. Chronic migraines alter partners' lives too, thus acceptance is required by both people.

### **Couple Dynamics**

Couples should be aware of how chronic migraines can impact their relational dynamics. It appears common for couples to oscillate between feelings of relational balance and imbalance as they deal with migraines. Consequently, couples experience both connection and disconnection during the process. Simply knowing this could be helpful for couples. They can be assured that, in the context of chronic migraines, patterns of oscillating balance and imbalance, and experiencing both connection and disconnection are a normal experience. Furthermore, as they are conscious of these dynamics, and work to create relational balance, couples can experience less distress and more connection. In my study, partners who embraced their caregiving opportunities seemed to enjoy a feeling of greater relational balance and greater connection with their spouse than partners who did not. On the other hand, patients should do their best to give back to their partners, when possible, and should avoid relational dynamics wherein they are always the one receiving care from their partner. While chronic migraines pose relational challenges, couples should know that there is hope for their relationship. Some couples dealing with chronic migraines report having happy, deeply intimate relationships.

## **Clinical Implications**

Couples in my study spoke about their experiences seeking healthcare for chronic migraines and discussed their ideas for improving treatment. In what follows, I summarize the implications of this study for medical providers and therapists. To both medical providers and therapists, I recommend that my grounded theory be utilized. Clinicians could go through my model with patients and/or partners, shading it to capture how well patients and/or partners have adapted to chronic migraines. Categories that are shaded the darkest could become the categories that are targeted in treatment. In a subsequent session, the model could be shaded once more to measure progress. I feel confident that this approach to chronic migraine treatment would improve the quality of care provided to chronic migraine patients and their partners.

### **Recommendations for Medical Providers**

My findings indicate that chronic migraine patients might receive more effective care if medical providers took a more holistic approach to treatment. Pharmaceuticals are vital to treatment and should continue to be emphasized. But, medical providers should also consider if changes in diet, sleep, or exercise could improve migraine symptoms (Harms, 2005). Furthermore, considering past research that has demonstrated the benefits of mindfulness in migraine treatment (Grazzi et al., 2017), medical providers could consider asking patients to practice mindfulness. Medical providers usually have limited time with patients, and do not specialize in psychosocial-spiritual treatment. Thus, medical providers should not hesitate to refer chronic migraine patients

to therapists, support groups, or classes that will provide them with psychosocial-spiritual resources.

My participants spoke often about doctors who did not listen, and doctors who accused them of drug-seeking. Medical providers should recognize that some chronic migraine patients have been suffering with migraines for many years and have tried many different treatment approaches. Thus, providers should listen to their patients, gather a full treatment history, and respect their patients' wishes. Furthermore, providers should be sensitive to the severe pain migraines can cause. Caution should be used when determining if a patient reporting migraine-like symptoms is drug-seeking. When one realizes that chronic migraine patients deal with chronic pain that can at times be severe, and that they are seeking medical care to alleviate this pain, the patient's request for drugs that minimize pain might not seem unreasonable. Medical providers need not comply with all their patients' wishes. But, they should at least help chronic migraine patients to feel understood and valued.

Medical providers should remember that chronic migraine patients' partners are often searching for cures to chronic migraines and trying to fix their loved one's symptoms. Their opinions and experiences should be valued. Including partners in appointments could be valuable. They could get answers to questions and receive insight into how to best care for their partners.

### **Recommendations for Therapists**

Therapists could use a myriad of modalities to effectively treat couples who deal with chronic migraines (Gutterman, Mecias, & Ainbinder, 2005). Whatever the therapist's model, though, I stress the importance of taking a biopsychosocial-spiritual

approach to treatment. Grounded in the findings of this study, therapists should realize that many couples deal with great frustration as they seek medical care for their chronic migraines. Therapists can help couples to process these frustrations. Furthermore, therapists can: encourage couples to continue seeking medical care, help couples to advocate for themselves with their medical providers, and, when needed, therapists can contact medical providers and advocate for their clients. Therapists can also explore the impact of sleep, diet, and exercise upon client's migraine symptoms.

Therapists should be aware of the high rates of anxiety and depression associated with chronic migraines. They should assess appropriately for anxiety-related disorders and depression. Knowing that thoughts of suicide are common in chronic migraine patients (Friedman et al., 2018; Novic et al., 2016), therapists should be careful to screen for thoughts of self-harm. Helping couples learn to better manage stress should become an important cornerstone of treatment. Incorporating mindfulness, with its focus on acceptance and being present, would be especially useful with chronic migraine couples. Therapists should encourage couples to accept that they might never find a cure, and that they might need to accommodate their life's plans and expectations. Religiosity and/or spirituality can serve as a resource in couples' journeys toward acceptance.

Where applicable, therapists should include patients' partners in the therapeutic process. By including partners in therapy, therapists can enlist the partner's help in reducing the chronic migraine patient's stress. Furthermore, therapists should be sensitive to the fact that patients often feel like they burden their partners. These feelings can be processed. With the therapist's help, partners can respond to the patients' expressions of guilt and provide them with reassurance. As our findings indicate, it is

possible that gender scripts and family expectations or values- specifically concerning pain management- could complicate a couple's relational dynamics. Thus, I encourage therapists to explore the couple's gender scripts. Therapists should also ask about the family values and expectations concerning pain that each partner grew-up with.

This study's findings concerning relational-balance can be used to help guide treatment. Therapists should assess how each person perceives their relational give-and-take. Therapy can become a process wherein patients and partners work toward feeling that their relationship is balanced. But, this process cannot be seen as a tit-for-tat experience. Therapists should push partners to embrace caregiving opportunities. Therapists should also work with patients to help them identify ways they can give to their partner. As both partners work consciously to give to the other partner in desired ways, relational balance and feelings of connection should result.

### **Conclusion**

I have proposed a grounded theory of adaptation to chronic migraines for patients and their partners. Patients and partners experience burdens and costs associated with migraines. Coping, healthcare, relational dynamics, and factors of identity all combine to shape how patients and partners adapt to their burdens. The implications of my findings upon couples dealing with chronic migraines, healthcare providers, and therapists have been outlined. With this study, I have aimed to provide couples dealing with chronic migraines and clinicians with useful, pertinent information that can help to improve chronic migraine treatment.

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APPENDICES

**Appendix A**

**IRB Certificate of Exemption**

Wednesday, November 15, 2017 at 11:37:20 AM Mountain Standard Time

**Subject:** Approval letter from USU IRB  
**Date:** Wednesday, November 15, 2017 at 11:36:37 AM Mountain Standard Time  
**From:** noreply@usu.edu  
**To:** Dave Robinson, douglaspmcphoe@gmail.com, adammj113rus@gmail.com

## Institutional Review Board

USU Assurance: FWA#00003308



Exemption #2



### Certificate of Exemption

FROM:

Melanie Domenech Rodriguez, IRB Chair

Nicole Vouvalis, IRB Administrator

To: W Robinson, Douglas McPhee, Adam Johnson  
 Date: November 15, 2017  
 Protocol #: 8883  
 Title: Lived Experience Of Couples Affected By Incapacitating, Recurring Headaches

The Institutional Review Board has determined that the above-referenced study is exempt from review under federal guidelines 45 CFR Part 46.101(b) category #2:

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (a) information obtained is recorded in such a manner that human subjects can be identified, directly or through the identifiers linked to the subjects: and (b) any disclosure of human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

This exemption is valid for three years from the date of this correspondence, after which the study will be closed. If research will extend beyond three years, it is your responsibility as the Principal Investigator to notify the IRB before the study's expiration date and submit a new application to continue the research. Research activities that continue beyond the expiration date without new certification of exempt status will be in violation of those federal guidelines which permit the exempt status.

As part of the IRB's quality assurance procedures, this research may be randomly selected for continuing review during the three year period of exemption. If so, you will receive a request for completion of a Protocol Status Report during the month of the anniversary date of this certification.

In all cases, it is your responsibility to notify the IRB prior to making any changes to the study by submitting an Amendment/Modification request. This will document whether or not the study still meets the requirements for exempt status under federal regulations.

Upon receipt of this memo, you may begin your research. If you have questions, please call the IRB office at (435) 797 1821 or email to [irb@usu.edu](mailto:irb@usu.edu).

The IRB wishes you success with your research.

4460 Old Main Hill

Logan, UT 84322-4460

PH: (435) 797-  
1821

Fax: (435) 797-  
3769

WEB: [irb.usu.edu](http://irb.usu.edu)

EMAIL: [irb@usu.edu](mailto:irb@usu.edu)

**Appendix B**

**Flier**



**WITHIN THE LAST 3 YEARS, HAVE YOUR OR YOUR PARTNER EXPERIENCED MIGRAINES OR CLUSTER HEADACHES?**

**ARE YOU AND YOUR PARTNER IN A COMMITTED ROMANTIC RELATIONSHIP, WHEREIN YOU HAVE LIVED TOGETHER FOR AT LEAST 1 YEAR?**

**PLEASE PARTICIPATE!  
WE NEED YOUR VOICE!**

**START BY FILLING OUT OUR ANONYMOUS SURVEY. CLICK ON THE FOLLOWING LINK TO ACCESS OUR SURVEY:**

[https://usu.co1.qualtrics.com/jfe/form/SV\\_1FU9qMyq0kz6m7b](https://usu.co1.qualtrics.com/jfe/form/SV_1FU9qMyq0kz6m7b)

**NEXT, EXPRESS INTEREST IN BEING INTERVIEWED BY EMAILING:**

**[CouplesNHeadaches@gmail.com](mailto:CouplesNHeadaches@gmail.com)**

**WE WANT TO INTERVIEW COUPLES AFFECTED BY RECURRING, DEBILITATING HEADACHES**

**INTERVIEWS CAN BE CONDUCTED ONLINE OR IN-PERSON**

**BY PARTICIPATING, YOU WILL HELP US LEARN HOW SEVERE MIGRAINES OR CLUSTER HEADACHES AFFECT FAMILIES**

THIS STUDY HAS BEEN APPROVED BY UTAH STATE UNIVERSITY'S IRB, EXEMPTION #8883

**PRINCIPAL RESEARCHER:**

Douglas McPhee

**COMMITTEE:**

Dave Robinson, PhD

Julie Gast, PhD

Ryan Seedall, PhD

TO CONTACT THE PRINCIPAL INVESTIGATOR, EMAIL:

[Douglas.McPhee@aggiemail.usu.edu](mailto:Douglas.McPhee@aggiemail.usu.edu)

**Appendix C**

**Survey**

### Introduction and Purpose:

You are invited to participate in a research study conducted by Dr. Dave Robinson, a professor in the Marriage and Family Therapy Department at Utah State University, and Doug McPhee, a graduate student in the same department. The purpose of this research is to study the impact that recurring, debilitating headaches have on couple relationships.

This form includes detailed information on the research to help you decide whether to participate in this study. Please read it carefully and ask any questions you have before you agree to participate.

### Procedures:

Your participation will involve filling out this survey, which should take approximately 15-30 minutes to complete. The purpose of this survey is to gather data about your relationship and your experience with recurring, debilitating headaches. Both you and your partner need to fill out this survey individually. If you and your partner are willing to be interviewed for 60-90 minutes about your experience as a couple with recurring, debilitating headaches, you will be provided with the researchers' email address. You are encouraged to email them if you are willing to be interviewed. In which case, you will be contacted by Doug McPhee; he will determine if you meet the inclusion criteria for the study and will work to set up a time to interview both you and your partner. Interviews will be conducted online via a secure video-conferencing server, or in-person at the Family Life Center, on the campus of Utah State University. In all, your total participation in this project is expected to be 90 minutes. We anticipate that 16-30 people will participate in this research study.

### Risks:

This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those you encounter in everyday activities. The foreseeable risks or discomforts include potential emotional discomfort as you answer questions about your experience with headaches, whether as a patient or as a partner. In order to minimize those risks and discomforts, should you experience any discomfort, contact information for Dave Robinson is provided. After contacting him, he will aid you in finding resources for emotional support for both yourself and your family if necessary. If you have a bad research-related experience or are injured in any way during your participation, please contact the principal investigator of this study right away at 435-797-7431 or Dave.R@usu.edu.

### Confidentiality:



The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study. However, it may be possible for someone to recognize your particular experiences.

We will collect your information through surveys, phone and/or email conversations, and recorded interviews. This information will be securely stored in a restricted-access folder on an encrypted, cloud-based storage system, and in a locked drawer in a restricted-access office. If you choose to be interviewed, the audio recording of those interviews will be deleted promptly once a transcription of your interview is completed. All other data collected for this project will be free of identifying information.

It is unlikely, but possible, that others (Utah State University, or state or federal officials) may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so. If the researchers learn that you are a threat to yourself or someone else, or if you disclose participation in child abuse or elder abuse, state law requires that the researchers report this behavior to the authorities.

The research team works to ensure confidentiality to the degree permitted by technology. It is possible, although unlikely, that unauthorized individuals could gain access to your responses because you are responding online. However, your participation in this online survey involves risks similar to a person's everyday use of the Internet.

#### Voluntary Participation, Withdrawal, & Costs:

Your participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by exiting out of this survey, or by informing Doug McPhee that you are no longer interested in meeting with him for an interview. If you choose to withdraw after we have already collected information about you, the information you've provided will not be included in the study. If you decide not to participate, the services you receive or may want to receive from the Marriage and Family Therapy clinic at Utah State University will not be affected in any way. The researchers may choose to terminate your participation in this research study if you and your partner do not meet the predetermined criteria for participation, or if the time frame for collecting data has expired (November, 2017- August, 2018). If your participation is terminated by the researchers after being contacted for an interview, they will contact you to inform you of the termination.

### Findings:

If you choose to be interviewed, once all analysis is completed, the researchers will email you with a link to an anonymous survey. This survey will detail the researchers' overall findings. You will be encouraged to anonymously review the findings, commenting on how accurately they capture your experience.

### IRB Review:

The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator at 435-797-7431 or Dave.R@usu.edu. If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or irb@usu.edu.

### Informed Consent:

By clicking "agree" below, you agree to participate in this study. You indicate that you understand the risks and benefits of participation, and that you know what you will be asked to do. You also agree that you have asked any questions you might have, and are clear on how to stop your participation in the study if you choose to do so. Please be sure to retain a copy of this form for your records.

- Yes, I am over the age of 18, live in the United States, and agree to participate. (1)
- No, I am not over the age of 18, do not live in the United States, or do not agree to participate. (2)

*Skip To: End of Survey If Introduction and Purpose: You are invited to participate in a research study conducted by Dr. Dav... = No, I am not over the age of 18, do not live in the United States, or do not agree to participate.*

---

Q59 Please download the Letter of Information for your own records!

---

**Q49 The point of this survey is to gather preliminary data about couple's experiencing headaches. After completing the survey, we would like to interview you and your partner as a couple about your experience with headaches. These interviews can be conducted in-person, or online. If you are willing to be interviewed as part of this research project, please email [CouplesNHeadaches@gmail.com](mailto:CouplesNHeadaches@gmail.com) expressing your interest! Because this survey is anonymous, we will have no way of contacting you. If you are interested, you must email [CouplesNHeadaches@gmail.com](mailto:CouplesNHeadaches@gmail.com).**

All of your answers on this survey are anonymous. To protect the anonymity of you and your partner, we will be assigning you a code, that will help us to pair your responses on this survey with your partner's.

Please insert the month in which you were born, the city where you and your partner met, and then the month that your partner was born. If Sally was born in December, met her partner in San Francisco, and her partner's birth month was October, she would input the following: **12SanFrancisco10**. Her partner's code would be: **10SanFrancisco12**.

**Please Insert Your Code Here:**

---

*Q27 For how long have you and your partner lived together?*

- We do not live together (1)
- Less than a year (2)
- Less than 2 years (3)
- Between 2-3 years (4)
- Between 3-5 years (5)
- Between 5-10 years (6)
- Between 10-20 years (7)
- More than 20 years, please specify (8)

---

*Skip To: End of Survey If For how long have you and your partner lived together? = We do not live together*

*Skip To: End of Survey If For how long have you and your partner lived together? = Less than a year*

---

Q3 Are you the patient who experiences recurring, debilitating headaches? Or the patient's partner?

- I experience headaches (1)
- My partner experiences headaches (2)

*Skip To: Q2 If Are you the patient who experiences recurring, debilitating headaches? Or the patient's partner? = I experience headaches*

*Skip To: Q9 If Are you the patient who experiences recurring, debilitating headaches? Or the patient's partner? = My partner experiences headaches*

---

Q2 *What kind of headaches have you been diagnosed with?*

- Episodic Migraines (1)
  - Chronic Migraines (2)
  - Episodic Cluster Headaches (3)
  - Chronic Cluster Headaches (4)
  - Tension Type Headaches (5)
  - Other, please specify: (6) \_\_\_\_\_
-

Q5 *When were you first diagnosed with your headache disorder?*

- Within the last year (1)
  - 1-3 years ago (2)
  - 3-5 years ago (3)
  - 5-10 years ago (4)
  - 10-20 years ago (5)
  - 20+ years ago (6)
- 

Q6 *Are you still experiencing headaches? If not, when was your last attack?*

- Yes, I currently experience headaches (1)
- I have not experienced a headache within the last year, but have experienced headaches within the last 3 years (2)
- I have not experienced a headache within the last 2 years, but have experienced headaches within the last 3 years (3)
- I have not experienced headaches for over 3 years (4)

*Skip To: End of Survey If Are you still experiencing headaches? If not, when was your last attack? = I have not experienced headaches for over 3 years*

---

Q8 *What treatments have you used to try and treat your headaches? Please describe the effectiveness of these treatments.*

---

---

Q7 *Approximately how many days a year do you/ did you experience headaches?*

- Less than 10 (1)
  - Between 20-10 (2)
  - Between 30-20 (3)
  - Between 45-30 (4)
  - Between 60-45 (5)
  - Between 100-60 (6)
  - Between 150-100 (7)
  - More than 150 (8)
- 

Q11 *Of those days, on how many days are your headaches severe enough that you are somewhat debilitated during the attack?*

- Less than 10 (1)
- Between 20-10 (2)
- Between 30-20 (3)
- Between 45-30 (4)
- Between 60-45 (5)
- Between 100-60 (6)
- Between 150-100 (7)
- More than 150 (8)

---

Q12 Describe your normal response when you experience an attack.

---

*Skip To: Q14 If Describe your normal response when you experience an attack. Is Displayed*

---

Q9 Does your partner currently experience headaches? If not, when was your partner's last attack?

- Yes, my partner currently experiences headaches (1)
- My partner has not experienced a headache within the last year, but has experienced headaches within the last 3 years (2)
- My partner has not experienced a headache within the last 2 years, but has experienced headaches within the last 3 years (3)
- My partner has not experienced headaches for over 3 years (4)

*Skip To: End of Survey If Does your partner currently experience headaches? If not, when was your partner's last attack? = My partner has not experienced headaches for over 3 years*

---

Q14 **Both patients and partners should respond to ALL of the following questions:**

---

Q15 *In which age range do you fall?*

- 18-29 years of age (1)
  - 30-39 years of age (2)
  - 40-49 years of age (3)
  - 50-59 years of age (4)
  - 60-69 years of age (5)
  - 70-79 years of age (6)
  - 80+ years of age (7)
- 

Q16 *Sex:*

- Male (1)
  - Female (2)
  - other, please specify: (3) \_\_\_\_\_
- 

Q18 *Sexual Orientation:*

- Heterosexual (1)
- Gay (2)
- Lesbian (3)
- Other, Please Specify (4) \_\_\_\_\_



---

Q19 *Racial or Ethnic Origin:*

- American Indian or Alaskan Native (1)
  - Asian or Pacific Islander (2)
  - African-American/Black (3)
  - Caucasian/White (4)
  - Mexican-American/Hispanic (5)
  - Biracial (specify) (6)
  - Other (specify) (7) \_\_\_\_\_
-

*Q20 Highest Level of Education Completed*

- Grammar school (1)
  - High school or equivalent (2)
  - Vocational or Technical School (2 year) (3)
  - Some College (4)
  - College Graduate (4 year) (5)
  - Masters Degree (6)
  - Doctorate Degree (PhD) (7)
  - Professional Degree (MD, JD, etc.) (8)
  - Other, please specify (9) \_\_\_\_\_
-

Q21 *Yearly Income (Please indicate your combined yearly income with your partner):*

- Under \$5,000 (1)
  - \$10,000-\$5,000 (2)
  - \$20,000-\$10,000 (3)
  - \$35,000-\$10,000 (4)
  - \$50,000-\$35,000 (5)
  - \$75,000-\$50,000 (6)
  - \$100,000-\$75,000 (7)
  - \$120,000-\$100,000 (8)
  - Greater than \$120,000 (9)
- 

Q22 *Do you work? What is your occupation?*

---

---

Q23 *What's your religious preference?*

- Muslim (1)
  - Protestant (2)
  - Catholic (3)
  - Latter-day Saint (Mormon) (4)
  - Jewish (5)
  - Buddhist (6)
  - Hindu (7)
  - Non-religious (8)
  - Other, please specify (9) \_\_\_\_\_
- 

Q24 *You consider yourself to be:*

- Not religious/spiritual (1)
  - Slightly religious/spiritual (2)
  - Moderately religious/spiritual (3)
  - Very religious/spiritual (4)
- 

Q25 *Have you ever been diagnosed with any mental health disorders? Please specify.*

\_\_\_\_\_

---

Q26 List any medical conditions or illnesses that you currently experience. Please rate how big of an impact these conditions have on your life using the following scale: Mild, Moderate, or Drastic.

---

Q28 How many children do you have? Please specify their ages.

No kids (1)

1 (2)

2 (3)

3 (4)

4 (5)

5 (6)

6+ (7)

If applicable, please specify your children's ages (8)

---

Q31 During the past **2 WEEKS** how much (or how often) have you been bothered by the following problems?

	None. Not at all. (1)	Slight. Rare, Less than a day or two. (2)	Mild. Several days. (3)	Moderate. More than half the days. (4)	Severe. Nearly every day. (5)
Little interest or pleasure in doing things? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling more irritated, grouchy, or angry than usual? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleeping less than usual, but still have a lot of energy? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Starting lots more projects than usual, or doing more risky things usual? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling nervous, anxious, worried, or on edge? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling panic or being frightened? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoiding situations that make you anxious? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexplained aches and pains (e.g., head, back, joints, abdomen, legs)? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling that your illnesses are not being taken seriously enough? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoughts of actually hurting yourself? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Hearing things other people couldn't hear, such as voices even when no one was around? (12)

Feeling that someone could hear your thoughts, or that you could hear what another person was thinking? (13)

Problems with sleep that affected your sleep quality overall? (14)

Problems with memory (e.g., learning new information) or with location (e.g., finding your way home)? (15)

Unpleasant thoughts, urges, or images that repeatedly enter your mind? (16)

Feeling driven to perform certain behaviors or mental acts over and over again? (17)

Feeling detached or distant from yourself, your body, your physical surroundings, or your memories? (18)

Not knowing who you really are or what you want out of life? (19)



Not feeling close to other people or enjoying your relationships with them? (20)

Drinking at least 4 drinks of any kind of alcohol in a single day? (21)

Smoking any cigarettes, a cigar, or pipe, or using sniff or chewing tobacco? (22)

Using any of the following medicines ON YOUR OWN, that is, without a doctor's prescription, in greater amounts or longer than prescribed [e.g., painkillers (like Vicodin), stimulants (like Ritalin or Adderall), sedatives or tranquilizers (like sleeping pills or Valium), or drugs like marijuana, cocaine or crack, club drugs (like ecstasy), hallucinogens (like LSD), heroin, inhalants or solvents (like glue), or methamphetamine (like speed)]? (23)

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Feeling more irritated, grouchy, or angry than usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Feeling more irritated, grouchy, or angry than usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Feeling more irritated, grouchy, or angry than usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Feeling more irritated, grouchy, or angry than usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Sleeping less than usual, but still have a lot of energy?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Starting lots more projects than usual, or doing more risky things usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Sleeping less than usual, but still have a lot of energy?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Starting lots more projects than usual, or doing more risky things usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Sleeping less than usual, but still have a lot of energy?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Starting lots more projects than usual, or doing more risky things usual?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Sleeping less than usual, but still have a lot of energy?*

*Skip To: End of Survey If During the past 2 WEEKS how much (or how often) have you been bothered by the following problems? = Starting lots more projects than usual, or doing more risky things usual?*

---

Q33 *Here is a list of things YOU might have done when you had a conflict or disagreement with your partner or a family member. Please indicate how often YOU did each of these things during the past year.*





Q34 *Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you or another family member. Please indicate how often YOUR PARTNER did each of these things during the past year.*



*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threw something at a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Pushed, grabbed, or shoved a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member but not with anything hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member with something hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threw something at a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Pushed, grabbed, or shoved a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member but not with anything hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member with something hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threw something at a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Pushed, grabbed, or shoved a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member but not with anything hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member with something hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threw something or smashed something (but not at your family member).*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threatened to hit or throw something at a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Threw something at a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Pushed, grabbed, or shoved a family member.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member but not with anything hard.*

*Skip To: End of Survey If Here is a list of things YOUR PARTNER might have done during a conflict or disagreement with you... = Hit (or tried to hit) a family member with something hard.*

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**Appendix D**

**Semi-Structured Interview Guide**

Can you both tell me about your experience with migraines?

- Is there a history of migraines in your family? Who else in your family experiences them?

Tell me about a typical headache experience from each of your perspectives?

- What does each person do? What do kids do (if any)?

For each of you, when you think of migraine headaches, what are the first words that come to mind?

How (if at all) have migraines impacted the following aspects of your couple relationship:

- Impact on the relationship/family
- Emotional connection
- Communication
- Physical relationship

Healthcare:

For each of you, what has your experience been as you've sought medical treatment/relief for migraines?

- Frustrations and/or positive experiences
- Financial impact?

For the partner: Do you feel you like serve as a caregiver to your spouse? Or not so much?

What, if any, positive things have come out of your experiences with the headaches?

For each of you, what has been the biggest cost or burden you have experienced dealing with headaches?

What advice would you give couples who are just beginning this journey of dealing with headaches (not medical treatment specifically, but individual, couple, and family coping)?