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Family Members' Lived Experiences of Chronic Migraine

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

Chronic migraine (CM) is a growing phenomenon in the United States and has been recognized as a disabling headache disorder. CM negatively affects the quality of life not only of CM sufferers but also their family members. The lived experiences of the family member of CM sufferers has not been sufficiently investigated. The purpose of this study was to gain in-depth insight into the lived experiences of family members who lived with CM sufferers. The phenomenological approach, guided by the social support theory, was used to investigate the lived experiences of family members who live with CM sufferers through open-ended semi structured interviewing. The research participants were asked about their experiences of living with a family member who suffers with CM and their perspectives of the chronic migraine sufferers' social and professional functioning. The data gathered from the interviews was analyzed with NVivo 12 using the Colaizzi Method. The themes created from the data analyses were feelings and moods, disability and activities, functionality, and support. These themes showed that family members are burdened with the health consequences of CM associated with mood swings and functional impairment. The emotional impact of CM on the family members can also be viewed in terms of empathy and feelings of helplessness. The positive social change implications of the findings of this study are that they may help with the design and implementation of interventions that can improve the quality of life for family members and help them provide effective support to the chronic migraine sufferer, which would promote the wellness and health of the whole family.

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Dedication

To my children, Jay Courtney and Chase Isaiah Nolan. The writing process of this dissertation has been challenging for them too, but this teaches them that they can accomplish any goal with perseverance and great determination.

To my family and in memory of my grandfather, Charles Edward. Their support, understanding and encouraging words helped me accomplished this challenging goal. I really appreciate everyone who provided encouragement and high fives during these pressing times. I had motivators who helped me achieved this goal and this motivation is what helped me finished this whole challenging process.

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Chapter 1: Introduction to Study

Introduction

Chronic migraine is a type of primary headache disorder that is associated with the neurological function of the human body. Chronic migraine is characterized as an intense pulsating and throbbing head pain that is usually unilateral and accompanied with symptoms such as sensitivity to light, sound, smells, and visual aura, which may also result in nausea and/or vomiting (Diener, Solbach, Holle & Gaul, 2015). Diener et al. (2015) stated that “patients who have chronic migraines often have migraines that are bilateral, and their symptoms are not as pronounced” (p 344). Chronic migraines is just a category of migraines that can be triggered by a person’s internal and/or external environment but not subject or limited to these factors that may cause migraine symptoms: hormonal changes in women such as menstrual cycle; certain foods; food additives; alcoholic drinks; caffeinated drinks; stress; sensory stimuli such as sensitivity to lights, certain sounds, and certain smells; changes in sleep pattern; physical factors such as exercise or sexual activities; changes in the environment; and certain medications (Mayo Clinic, 2016) . The prevalence of migraines is approximately 6% in men and 15% in women and occurrences generally peak at the age of 40 years (Starling & Dodick, 2015, p. 408). Migraines are also quite common among Primary Care Physicians offices due to it being the chief complaint associated with head pain (Starling & Dodick, 2015, p 408). Chronic migraine is becoming a known phenomenon because 1%-5% patients with migraines have been categorized with chronic migraines (Starling & Dodick, 2015, p 408). I review studies concerning chronic migraines in the literature review in Chapter 2 .

Migraine sufferers often feel that no one understands their pain. They may believe that others think that a migraine is just a bad headache. For migraine sufferers, it is much more than that. It affects their productivity in work, enjoyment of life, and commitments in their family and social life. Buse stated, "If family members better understand the scope of impact that migraine can have they may better understand what their family member is going through" (as cited in Vimont, 2015, para 9). Family members' support is sometimes key to securing optimal treatment.

Background

In some literature, migraine is considered a disability or burden that affects the quality of life of the sufferer. Migraine is generally categorized into two groups: episodic migraine (EM), which occur fewer than 15 days a month, and chronic migraine (CM), which occurs more than 15 days a month (Adams et al., 2015). CM has a greater impact on the daily living activities of sufferers than EM in terms of reduced quality of life, higher rates of comorbidities, and higher medical costs (Adams et al., 2015; Buse, Scher et al., 2016). Buse, Scher et al. (2016) stated that people who live with or are related to those who suffer from CM report that CM has an adverse effect on their family life and/or social activities (p. 596). Adams et al. (2015) and Buse, Scher et al. (2016) conducted studies that included the family burden module. The family burden module focuses on quantitative answers that relate to missed family events due to CM, unfulfilled household responsibilities, impact of CM on family finances, and the impact of CM on family quality of life. The data from both studies indicated that people who suffer from CM have a disability that affects their family unit. In the study conducted by Adams et al.

(2015), the results confirmed that CM is a growing phenomenon that is associated with a lowered quality of life for the patient and as well as for family members. However, Buse, Sher et al. (2016) stated that the perspectives of CM sufferers are different from those of their spouses regarding the impact of CM on the family. Buse, Scher et al. (2016) stated that spouses of CM sufferers did experience anxiety about the headache disorder affecting the family life. It was found that CM sufferers have higher anxiety about their disorder than their spouses (Buse, Scher et al., 2016).

According to Seng et al. (2017), CM causes severe disability and with high levels of anxiety and depression. Bacher (2014) found that both CM sufferers and their spouses can experience depression due to the impact of CM on their lives. Although the study by Bacher (2014) was based only a small sample size of 20 couples, it showed that depression is prevalent among CM sufferers and their family members. Studies conducted by Buse, Powers et al. (2016) and Mohammadi et al. (2016) affirmed Bacher's (2014) findings.

Mohammadi et al. (2016) found that headache intensity and family life functioning correlate to distress or anxiety, which corroborated the findings of Buse, Powers et al. (2016), who investigated the effect of parental CM on their children. Buse, Powers et al. (2016) found that children of CM sufferers have higher anxiety due to missing school events, not receiving help from their CM parent, and missing having friends at the home. This demonstrates that CM is a burden on the family, but it does not provide further data on the lived experiences of family members dealing with CM. These studies demonstrate that CM is a burden, may cause anxiety, may cause depression, and may have a significant impact on family life, but they do not provide an in-depth examination of the lived experiences of CM family members.

There is a gap in literature regarding the lived experiences of family dealing with migraines. Current literature has provided quantitative analysis of the impact of CM on family life functioning but has not explored family perspectives, attitudes, or lived experiences regarding CM. There is no literature that states whether family members are worried, depressed, and/or anxious due to CM being in the home. It is perceived that the migraine is mostly a burden on the family from the CM sufferer perspective (Buse, Scher et al., 2016). Knowledge of the perspectives of family members is needed so that CM sufferers can be introduced to prophylactic treatment, which is known as prevention medication and/or treatment. Agostoni et al. (2019) suggests that prophylactic treatment for CM sufferers is needed but can only be introduced after understanding the CM sufferer's lived experiences with the disorder. Understanding family members lived experiences may also help with prophylactic treatment for CM sufferers. Family members may provide critical support for CM sufferers and knowing their perspectives on the disorder may help to create an effective treatment plan for the CM sufferer.

Theoretical Framework

I used the social support theory a theoretical framework for examining the lived experiences of family members with CM. Social support involves assisting others through supportive communication and behaviors (Glanz, Rimer & Lewis, 2002). The social support theory helped provide an understanding of the social relationships and interactions between CM sufferers and family members. This understanding may be valuable in designing and implementing effective interventions aimed at preventing and managing migraine attack in which family member supports are integral components of the interventions.

Social support is important in making general and mental health care decisions in which the positive interactions of family members are considered. The social support theory asserts that these interactions are generated by supportive behaviors (Glanz et al., 2002). There are four supportive behaviors that constitute social support: emotional, instrumental, informational, and appraisal (Glanz et al., 2002). Emotional support is the provision of empathy, hope, and a listening ear to the CM sufferer. Instrumental support means providing practical aid to the CM sufferer, for example, by baby-sitting their children while they are having a migraine attack. Informational support is providing facts and suggestions on treatment of CM. Appraisal support means offering encouraging words to the CM sufferer that they will soon see a day without CM pain. These behaviors are understood through the social support theory that states that social support is perceived by the recipient as any type of supportive assistance from the provider (Hupcey, 1998).

The social support theory has three perspectives on how social relationships help influence health and well-being (Lakey & Cohen, 2000.). The first is the stress and coping perspective. The stress and coping perspective states that support from others helps reduce the effects of stress on a person's health (Lakey & Cohen, 2000). Supportive actions that match the stressor are needed to promote coping. Coping means dealing with the stress effectively, often with the support of others. Providing support must be timed well and perceived as useful for a positive influence on a person’s health status. Support may be perceived negatively das insufficient or not the type of support desired (Hupcey, 1998). This can be avoided by providing support that caters to the characteristics of the recipient . Some CM sufferers may want support in the form of a family member running errands for them while others may want the family member to sit with them all day. It depends on the characteristics of the CM sufferer for the support to be perceived as positive. The second perspective of the social support theory states that promoting positive self-esteem affects health status. Self-esteem is derived through self-evaluation, and this can be influenced by others in society. Society influences the development of certain beliefs about self and others. These beliefs can be affected by the perception of support from others. Perceived support may influence self-esteem, which may lead to positive health outcomes (Lakey & Cohen, 2000). For the CM sufferer, family support may influence the sufferer to make effective health decisions. Having relationships with others is the third perspective of the social support theory. These relationships can take the form of friendship, socializing, or intimacy (Lakey & Cohen, 2000). These relationships constitute a social network with the goal of supporting the CM sufferer. These relationships can provide a sense of belonging and knowing someone cares about the CM sufferer’s well-being (Lakey & Cohen, 2000). The social support theory reinforces the understanding that family members are needed to support their loved ones through the chronic condition of migraines.

Problem Statement

CM is a debilitating condition that becomes disabling and a burden to the sufferer. There has been much research on its prevalence, burden, and treatments because it affects the quality of life. Buse et al. (2019) have found that CM affect the quality of life by interfering with family activities and quality time with spouse or significant other. This study conducted by Buse et al. (2019) was only on the lived experiences of the migraine sufferer. There is limited research on the lived experiences of CM from the point of view of family members. If family members have negative attitudes towards their loved one for having CM, this may impact the family as a whole. Diener et al. (2015) stated that CM is a “higher burden of disease” (p 348). This indicates that CM can be overwhelming for anyone who experiences it due to its disabling effects and risk of developing comorbidities (Buse et al., 2020).

There is current literature that documents the impact of chronic headache or migraines on family members but does not elaborate on these family members’ perspectives of the headache disorder. It has been found that chronic head pain can affect family functioning if the family is already dysfunctional (Mohammadi et al., 2016). Dysfunctional families tend to experience greater stress than functional families (Mohammadi et al., 2016). Even though Mohammadi et al. (2016) found that functional families can find a way to live through the pain of migraines, another study found that children of CM sufferers experience high levels of anxiety due to the great burden of missing social activities or school events and not being able to have friends visit the home because of their parents’ migraines (Buse, Powers et al., 2016). Both studies provided quantitative data that family members have some type of lived experiences with migraines. There is a need to have further understanding about CM through family members' lived experiences from qualitative data. Having a better understanding of this phenomenon may help develop strategies to improve the quality of life for family members of CM sufferers. CM sufferers need the support of their family members while living with headache disorder. Vimont (2015) stated migraine sufferers feel isolated and alone, which can lead to depression and/or suicidal thoughts due to pain from the migraine (Lin et al., 2019). Bacher (2014) stated that depression is a possible comorbidity of migraines and should be treated for the migraine sufferer and their family through counseling. There is a risk that a migraine sufferer may attempt suicide (Trejo-Gabriel-Galan, Aicua-Rapún, Cubo-Delgado & Velasco-Bernal, 2017), which is a good reason to learn more about the phenomenon. Knowledge of family members' lived experiences is needed to form a fuller understanding situation, which may lead to family support techniques or interventions for migraine care.

Research Questions

RQ1: What are the lived experiences of the family members of someone who suffers CMs, and how does that impact their daily life?

RQ2: From the family member perspective, what are the lived experiences of the CM sufferer?

RQ3: How are the social and professional functioning of CM sufferers affected during and after a migraine attack?

RQ4: How critical is family support in managing migraine from the migraine suffers' perspective?

Purpose of the Study

Migraines not only affect the sufferer, but they can also have an impact on family members. The purpose of this study was to examine the lived experiences of family members of someone who suffers from CM. Literature states that CM is a burden to the family structure but fails to elaborate on family members' perspectives and lived experiences with the phenomenon. An understanding of family members' health, well-being, social life, family life, and daily living that is affected by CM was explored through the use of in-depth interviewing.

Assumptions, Limitations, Scope, and Delimitations

This study focused on a certain population that was difficult to access. The target population for this study included adult family members of CM sufferers. To establish this target population, protocols were put in place. At least 10 willing participants were needed for this qualitative research so that it could be meaningful. Because this was a phenomenological study, the participants answered questions that were open-ended, which left room for them to be openly honest. Their answers about their lived experiences were solely for qualitative data.. The scope of this study was limited to the lived experiences of family members of CM sufferers. The results did not include data on lived experiences of family members of those diagnosed with EMs, cluster headaches, or chronic headache.

Significance of the Study

The study of migraines is a growing phenomenon, and there is a need to gain more knowledge on this subject based on previous literature. Migraines effect the quality of life for the migraine sufferer, and it is also a burden on family members. In this study I aimed to further social change by contributing insight into possible intervention for migraine care.

This research will fill in the gap in literature in understanding the phenomenon of CM by focusing on a certain group of people who deal with CM. The true feelings of family members concerning the reality of living with CM sufferers are usually not researched. The results of this study may help develop migraine interventions that integrate family support so that migraine sufferers do not feel isolated when migraine pain attacks (Vimont, 2015). It has been found migraine sufferers who have higher frequencies of migraine are associated with suicide ideation and suicide attempt (Lin et al., 2019). It's helpful when the family members can be present for the migraine sufferer with a treatment plan that caters to their perspective and lived experiences of CM.

Definitions

Chronic headache: Head pain that can be everyday but does not have associated migraine symptoms.

Chronic migraine: Mild to moderate head pain that lasts 2-72 hours and occurring more than 15 days a month that is also accompanied with symptoms such as sensitivity to light, smells, and sound (Weatherall, 2015).

Chronic migraine sufferer: Patients who suffer from CM for more than 15 days a month.

Cluster headache: Pain around the eye that can last up to 2 months but can go into a period of having no pain at all throughout the year (Shiel, n.d.)

Episodic migraine: Migraine that occurs fewer than 15 days a month (Lipton & Silberstein, 2015)

Migraine triggers: Factors that may lead to a migraine attack such as lack of sleep, certain foods, or weather change (Kiefer, 2020).

Primary headache: Head pain that is not caused by injury or trauma

Social functioning: Ability to interact normally in society (Social Functioning, n.d.).

Social support: Important aspect of social relationships that includes receiving help from others during an adverse event that can come in the form of emotional, instrumental, informational, companionship, and appraisal support (Social Support, n.d.).

Visual aura: Any visual disturbance such as blind spots, sparkles, zig-zag lines, flashing lights, colored spots, or blindness that may accompany a migraine (Obrenovitch & Dreier, n.d.).

Summary

CM is growing phenomenon in the United States. This headache disorder can cause great disability for anyone who suffers from it. Studies have found that CM has some type of effect on family members. Even though these studies show that the disorder of CM has statistical significance with family members, the current literature lacks the perspective, attitudes, and lived experiences of family members of CM sufferers. With this study I sought to obtain in-depth information on the lived experiences of CM from family members' perspectives. In Chapter 2 I review literature that related to this study. Chapter 3 contains a description of this study's design, theoretical framework, and procedures used to gather information for this study.

Chapter 2: Literature Review

Introduction

The purpose of this phenomenological study was to investigate CM's impact on daily living from the perspectives of CM sufferers and their family members. Current literature has documented that CM has a significant impact on the sufferer (Adams et al., 2015; Buse et al., 2018; Buse, Scher et al., 2016; Buse et al., 2019; Diener et al., 2015; Lipton et al., 2017; Starling & Dodick, 2015) and it also has an impact on family members (Buse, Dodick, Manack, 2015; Buse, Powers et al., 2016; Buse, Scher et al., 2016; Lipton et al., 2017; Mohammadi et al., 2016). Quantitative studies have shown that CM is a burden for family members but there is a lack of literature that provides a qualitative analysis of family members' perspectives on the headache disorder. Family members' lived experiences are needed to achieve an understanding of what they think and how they feel, which may lead to improved techniques and interventions for migraine care.

There is much literature that pertain to many aspects of CM, and more is likely because migraine is a phenomenon that many are still trying to understand. Even though there are many studies on the phenomenon of migraine, there are limited studies on the perspectives and lived experiences of family members of CM sufferers. Studies predominantly focus on the CM sufferer, the prevalence of the headache disorder, and its disabling effect on life. The lack of an in-depth investigation of the lived experiences of family members of CM sufferers was the reason for conducting this qualitative research.

This review of literature covers the following topics that pertain to CM: prevalence of CM, management of CM, the disability of CM, and the burden of CM on the family members. A critical review of literature as pertains to these aspects of the study exposed the prevailing knowledge gap as described in the problem statement.

Literature Search Strategy

I conducted the search for literature for this review by using the following databases through Walden Online Library: CINAHL Plus with Full Text, MEDLINE with Full Text, Thoreau EBSCO search, Pub Med, ProQuest Central, and Google Scholar. The keywords used in the search were *chronic migraine OR migraine AND daily life, family, functioning, social support, work, management, family support, relationships, social relationships, family functioning, caregiver, perception,* and *family perception*.

Theoretical Foundation

The social support theory was the theoretical framework for this study because it helped me to understand the lived experiences of family members of CM sufferers. The social support theory states that resources provided by other persons will have either negative or positive effects on someone's physical, mental, and social well-being (Cohen & Syme, 1985). Social support is not intended to produce negative effects because the desired outcome is to promote new healthy behaviors through social support from others.

Social support has been utilized to change behaviors in the effort to produce better health outcomes. This is achieved through people changing their normal routine and adopting new self-perceptions and perceptions from others (Cohen & Syme, 1985). Social support from others can help people recover from physical and mental illnesses by elevating their self-esteem, providing a greater ability to cope, and providing motivation to get well (Cohen & Syme, 1985, p. 8). However, Kamenov et. al (2016) found that people who have high levels of disability due to their health condition, including those with migraines, can experience low levels of social support (p. 7). Donovan, Mehringer & Zeltzer (2013) suggests that social support is needed because it promotes self-care, self-management skills, and better family functioning among adolescents who suffer from migraines (p. e140).

Social support exists through the structure of social relationships and how these social relationships function (Cohen & Syme, 1985). The structural sense of social support pertains to the type of relationship and the number of relationships a person has in their social network (Cohen & Syme, 1985). These may be with friends, significant others, someone known through another party, or someone connected to through social media. These relationships have a social support function such as providing information or providing affection (Cohen & Syme, 1985). These functions are also the types of social support that can be given or received. There are four types of social support: emotional support, tangible support, informational support, and belonging/companionship support (Cohen & Willis, 1985). Emotional support is presented through any type of communication with others that has the goal of being a listening ear, providing compassion, and boosting self-esteem. Tangible support includes financial assistance, material information, or services (Cohen & Willis, 1985) such as cleaning and running errands. Informational support is when advice and guidance is rendered. This type of support can provide understanding and a way to cope with an illness or stressful event

(Cohen & Willis, 1985). The last type of social support is belonging/companionship support, which is presented through spending leisure time with others that has the goal of decreasing worry (Cohen & Willis, 1985).

Social support exchange is associated with personality factors. Personality plays a role on making and maintaining any type of relationship (Cohen & Willis, 1985). This can influence the sources of social support available when there is a need for it due to the situation. CM sufferers' possible personality traits of neuroticism (Muñoz et al, 2016; Davis, Kayhan & Ilik, 2016) and social introversion may result in them receiving social support that is not wanted or needed. Because CM sufferers deal with persistent head pain, it would be ideal for them to receive all types of social support from loved ones. Studies show that CM sufferers may exhibit depression or have the risk of developing depression (Hung, Lui, Yang & Wang, 2015). This depression and constant chronic pain are associated with suicidality (Campbell, Darke, Bruno & Degenhardt, 2015), suicide attempts (Trejo-Gabriel-Galan, Aicua-Rapún, Cubo-Delgado & Velasco-Bernal, 2017), and suicide due to primary headaches (Calati et al., 2017). However, Colman, Kingsbury, Sareen, Bolton, and van Walraven (2016) stated that migraine is associated with self-harm, but not suicide (pp. 137). Despite this finding, it is important for CM sufferers to obtain social support through all their social ties in an effort to prevent potential mortality.

What is Migraine?

Migraine has a social stigma of being "just a headache," which is not the case. People who suffer from migraine have disabling and debilitating symptoms that present at an unpredictable rate. Parikh & Young (2019) stated that CM sufferers experience social stigma more than other unpredictable illnesses such as epilepsy and panic attacks (Doheny, 2018). While Shapiro (2017) stated, “Epilepsy should have more stigma than migraine because it was referred as a demonic possession” (Conference presentation). Freud started the migraine stigma by stating it was the fault of the migraine sufferer due to their daily behavior (as cited by Shapiro, 2017). Migraine stigma can be external or internal. Externalized migraine stigma comes from others treating migraine sufferers differently than others due to the notion that the headache is being exaggerated (Vilanilam, Badi & Meschia, 2018) or merely an annoying problem (Shapiro, 2017). Internalized migraine stigma comes from the migraine sufferer thinking their condition is a burden for others, their suffering being dismissed by others, and negative reactions from others (Shapiro, 2017; Vilanilam et al., 2018).

Migraine is still misunderstood because there is a lack of knowledge about its main cause. Migraine diagnosis can be delayed many years due to the unique symptoms and variants of the headache disorder. Hersh & Hersh (2017) stated that people are not getting diagnosed with migraine due to symptoms such as facial pain, nasal congestion, and sinus pain that are similar to rhinosinusitis. Some migraines can present symptoms similar to sinus headaches. This may make it difficult to diagnose migraine, especially when there are several different types of migraine.

The pathophysiology of migraine can be either episodic or chronic. EMs suffer fewer than 15 attacks in a month while CMs have more than 15 in a month. These migraine attacks can come in different forms. These forms are basilar migraine, cluster headaches, hemiplegia, ophthalmoplegic, abdominal migraine, retinal migraine, migraine with aura (Alice in Wonderland syndrome), aura without headache, and acute confusional migraine. Basilar migraine is experienced most frequently presenting symptoms of throbbing head pain from the occipital section of the head that has been known to cause vertigo, vomiting, tinnitus, double vision, ataxia, and slurred speech (Rothner, 2018). Cluster headaches are painful, intense, unilateral head pain that is experienced only during a brief period, such as 7 days to a year followed by weeks, months, or years of being pain free (Schenck & Andrasik, 2019). Hemiplegia is an uncommon, rare form of migraine with aura that presents as stroke-like symptoms with weakness on one side of the body, which may be caused by head trauma and/or genetically from a gene mutation that goes through a family line (Rothner, 2018; Kumar, Samanta & Arora, 2020). Ophthalmoplegic, abdominal, and retinal migraine all derive from a certain body part. Ophthalmoplegic migraine is characterized as pain and muscle weakness in the ocular cranial nerves and abdominal migraine is midline abdominal pain that is accompanied by vomiting and interferes with daily living (Rothner, 2018). Retinal migraine is ischemia of the retinal artery that cause head pain and temporary blindness (Rothner, 2018). Migraine with aura includes visual disturbances such as seeing zigzag lines and visual perception abnormalities, which increases the risk of ischemic stroke (Viana, Tronvik, Do, Zecca & Hougaard, 2019). There is also an occurrence of aura that is not accompanied by any head pain, and this aura symptom of migraine can last 5-60 minutes (He, Li & Nie, 2015). Acute confusional migraine is presented with disorientation that can last for several hours, which may cause vomiting and hallucinations (Rothner, 2018).

A few of the migraine forms are common in children: abdominal migraine, acute confusional migraine, and migraine with aura. There are also migraine variants that are characterized in children, which are benign paroxysmal torticollis, cyclical vomiting syndrome, and benign paroxysmal vertigo. Benign paroxysmal torticollis is head tilt that has symptoms of nausea, vomiting, and paleness (Rothner, 2018). Cyclical vomiting syndrome is related to abdominal migraine, but there is an ongoing occurrence of vomiting, which leads to dehydration and paleness (Rothner, 2018). Benign paroxysmal vertigo is intense dizziness that lasts for a few minutes with the absence of vomiting and migraine pain (Rothner, 2018).

Sutherland, Albury, and Griffiths (2019) stated that some forms of migraine have evidence of being a genetic disorder due to a gene mutation. This gene mutation is similar in migraine without aura, migraine with aura, and familial hemiplegic migraine (Sutherland et al., 2019). This provides evidence that there is more to know about migraine and that it is a complex headache disorder.

Prevalence of Chronic Migraine

Migraine has a significant global prevalence in which 11.7% to 13.2% is prevalent in the United States (Moriarty & Mallick-Searle, 2016). Of this percentage, 0.9% represents people who suffer from CM (Moriarty & Mallick-Searle, 2016). There have been many studies conducted in the United States that had the goal to see what demographics represents this percentage. CM sufferers are more likely to be female, white, obese, have depression, and have anxiety (Adams et al., 2015). CM is more prevalent in females than males (Guo, 2019) and highest among Whites followed by

Blacks then Hispanic and Asian (Loder, Sheikh & Loder, 2015). National Health Interview Survey (NHIS) indicates that CM is more prevalent in White females followed by Hispanics then Blacks while the American Migraine Prevalence and Prevention (AMPP) study indicates that CM is more prevalent in Hispanic females followed by Blacks and then Whites (Loder, Sheikh & Loder, 2015). NHIS indicates that White males have the highest prevalence of CM followed by Black males then Hispanics while AMPP indicates Hispanic males have more prevalence that is followed by Blacks and then Whites (Loder, Sheikh & Loder, 2015).

Risk Factors for Transformation to Chronic Migraine

CM prevalence is still being studied on why the prevalence is increasing. EM transform to CM, “in about 3% of people, annually” (May & Schulte, 2016, pp 456). The risk factors that increases the chance to transform to CM are: elevated headache frequency, overweight, psychiatric problems, medication overuse, (Bonavita & De Simone, 2015; Moriarty & Mallick-Searle, 2016) sleep related breathing disorders, excessive caffeine intake, comorbid pain, (Moriarty & Mallick-Searle, 2016), being female (Bonavita & De Simone, 2015), stress, poor treatment efficacy, (Moriarty & Mallick-Searle, 2016), major life changes, head or neck injury, lower socioeconomic status, cutaneous allodynia, (Moriarty & Mallick-Searle, 2016) and idiopathic intracranial hypertension without papilledema (Bonavita & De Simone, 2015). It has been documented in recent findings that idiopathic intracranial hypertension without papilledema (IIHWOP) is a risk factor for CM. IIHWOP is diagnosed with “elevated opening pressure and in the presence of at least three of the following: empty sella, distention of the perioptic subarachnoid space with or without a tortuous optic nerve, flattening of the posterior sclerae and transverse venous sinus stenosis" (Favoni, 2018, pp. 2)

Despite these risk factors, CM has somatic and psychiatric comorbidities and may cause cutaneous allodynia in which activities such as brushing hair or wearing a hat or watch is painful (May & Schulte, 2016). CM increases with gaining weight (Moriarty & Mallick-Searle, 2016) and sufferers are more likely to experience depression, anxiety, cardiovascular conditions, bipolar disorder, respiratory illness, (May & Schulte, 2016) and other chronic pain conditions such as fibromyalgia or arthritis (Moriarty & Mallick-Searle, 2016).

Management of Chronic Migraine

CM prevalence is evident. Current literature state that there is a need to manage CM because it has a great impact and burden for the sufferers and their family members. Starling & Dodick (2015) state that CM must be managed through a treatment plan that includes only medication that has the purpose to reduce migraine days and the severity of the migraine. Dougherty & Silberstein (2015) agree with Starling & Dodick but they also suggest that CM treatment should include improving the lifestyle with regular physical activity and sleeping patterns, gaining more knowledge on the aspect of migraine triggers and management, behavioral therapy, biofeedback, and cognitive behavioral therapy (pp. 691). Özge et al. (2018) also agrees with improving the lifestyle by losing weight, regular nutrition, avoid alcohol, avoid over usage of abortive migraine medicine, staying well hydrated, and manage triggers which all have the purpose help to avoid transformation of

CM and reverse back to EM (pp. 119). Starling & Dodick (2015) also suggested that patient education and communication with their headache specialist is key to managing CM.

There is much to consider with the management of CM. Much literature state the same as the referenced articles and they include that medication should not be overused due to risk of getting rebound headaches. Even though medication, healthy lifestyle, and behavioral therapy are good suggestions with managing CM, there is a lack of literature that provide ways for the caregiver(s) or the family member(s) to help adult CM sufferers with CM management.

Chronic Migraine as a Cause of Disability

CM can result in disability for the sufferer. Shapiro (2017) states that CM is the third leading cause of disability. This provides a notion that CM can be difficult to managed and it has a significant effect on the lives of CM sufferers and their immediate family members.

Daily Life

CM becomes a disability when it becomes refractory with high levels of pain and severity. This headache disorder will make it difficult to do the simplest daily living activities such as bathing, sleeping, eating, and going to the bathroom. Other daily living activities that are needed to survive in the United States include cooking, cleaning, working, and maintaining a healthy lifestyle. CM makes it difficult to perform these daily functions effectively and efficiently.

Migraine intensity and frequency plays a role in reducing sufferers' participation in household work, socioeconomic functioning, family activities (May & Schulte, 2016). Current literature agrees that CM is a disability that decrease the quality of life for sufferers. CM sufferers have problems of being effectively productive and participating in life. The chronicity of migraine has a great impact on a sufferer's life (Emadi et al., 2019) in which there is a poor impact on social relationships, leisure time, self-care tasks, emotions, clear thinking, and family time (Mannix et al., 2016). Despite this finding, there is a gap of literature that analyzes the quality of life of caregivers or family members of CM sufferers.

CM sufferers are found to be less educated with large pain intensity (Adams et al., 2015) which can affect their cognitive reserve (Gómez-Beldarrain et al., 2016). Cognitive reserve provides the ability to keep absorbing knowledge while aging without memory loss. Gómez-Beldarrain et al., (2016) (2014) state that CM sufferers with low cognitive reserve are more likely to experience more pain and have a worse quality of life than those who have high cognitive reserve. Since there is prevalence of low cognitive reserve among CM sufferers, this mean that there is a need for caregivers or family members to help these sufferers with daily living. There is a gap of literature that states whether CM sufferers can change from low to high cognitive reserve with the help of caregivers or family members.

Work

While having a low quality of life, CM sufferers are also limited in the workplace. Some CM sufferers are working full or part-time with presence of lost productivity time

(LPT) while other CM sufferers are not working at all due to the headache disorder disabling effects. D’Amico et al. (2015) confirmed that episodic and CM has an effect at the workplace. CM sufferers have the greatest difficulty with performing at work (D’Amico, 2015). This chronic pain from the headache disorder produces more stress for the sufferer while at work (González-Quintanilla et al., 2015). Serrano et al. (2013) found that these difficulties that CM sufferers demonstrate on the job affects the cost of lost productivity time (LPT). CM sufferers have the higher LPT than EM sufferers at every age and in both genders with it accounting to $5 billion in impaired work function costs, according to a U.S study (Agosti, 2018).

It is evident that CM has an effect on productivity at the workplace and also contributes to workplaces to losing money. Agosti (2018) state that the LPT cost is due to CM sufferers being present at work but not performing at their highest ability. This gives an indication that CM sufferers are deemed to be unproductive and will need support. Literature does not state how this affect the CM household. González-Quintanilla (2015) state that CM sufferers are burnout and stressed at work but there is no indication if this stress is work task related or related to having migraine attacks at the workplace.

Social and Family Functioning

Besides being less productive than their healthy coworkers, CM sufferers are less productive in social and family functioning. Buse, Sher et al. (2016) found that CM sufferers’ involvement or enjoyment in family events is reduced 4 times or more a month when participating in social activities and/or enjoyment time with their significant other. This finding is based on the CM sufferers’ perspective which includes their perception of being a burden to their family because of the missed activities and not operating at full capacity due to their pain (Buse, Dodick, Adams, 2015). Buse, Scher et al. (2016) also found that CM sufferers are their own worst critic when compared to their spouses' perspective. Buse, Scher et al. (2016) found that spouses of CM sufferers do not believe that CM is not much of a burden despite other studies (Mohammadi et al., 2017) stating that their migraine days has an impact on family and parental functioning.

Most literature provides the quantitative evidence that CM is burden on social and family functioning. There is a gap in literature that includes youth perspective on CM even though this study will be focusing on adults. The only adults' perspective that have been documented are spouses. Current literature does not provide qualitative analysis on other adult caregivers or family members of CM sufferers. Since CM causes a great disability, current literature does not state whether this influences the sufferer's caregiver(s) or family member(s).

The Burden of Chronic Migraine

There is a lack of literature that goes into detail on the aspects of family members' feelings toward CM. Current literature has stated that family members do realize that CM has an impact on family functioning but there is no qualitative analysis on whether they are worried, depressed, anxious, confused, and/or stressed from the presence of CM in their loved one.

Family members are the natural supporter and caregiver for CM sufferers and are the first group of people to provide social support. A few quantitative studies have found that caregivers of people with chronic illness such as cancer, diabetes, dementia, arthritis, multiple sclerosis are burden from the caregiving role by experiencing some type of strain (DeDios-Stern, Eun-Jeong, Lee, Pieczynski & Simonetti, 2015) to where they lack the skills to cope and seek support for themselves (DeDios et al., 2015). A multicenter survey of caregivers from 22 countries agrees with the above quantitative studies but also added that family member caregivers experienced emotional burden and need adequate means to seek social support while caring for their loved one (Visa & Harvey, 2019). Despite these studies did not focus on CM, there is evidence that caregivers and family members are burden with providing social support. Kamenov et al. (2016) found that the level of disability has an influence on the level of social support. Sufferers of mental and neurological disorders have lower social support when their disability is high but people that have high disability related to neurological disorder have higher social support than those with mental disorders (Kamenov et al., 2016).

It is evident that CM is a challenge for the sufferer and for the caregiver(s) and the family member(s). CM has several comorbidities and depression is one of them. Quantitative studies have found that CM sufferers experience depression (Dindo, Recober, Marchman, O'Hara & Turvey, 2015). This combination produces a higher risk of suicide, which is a recently documented growing occurrence (Aly, Rosen & Evans, 2016). A cross sectional study (Lin et al., 2019) found that higher frequency migraine with aura is associated with suicide attempts in the presence of depression. Another study state migraine is not associated with lifetime suicide attempts after receiving help for their depression or other mental health problems (Campbell et al., 2015). A Canadian study found that one-third (30%) of people in Canada that attempted suicide are migraine sufferers in which suicide ideation is more prevalent in those who are young, white male, lower educated, lower income and unmarried (Fuller-Thomson & Hodgins, 2019). Experiencing the pain from migraine reduces social support for some which leads to stress and then later on may lead to suicide ideation (Wenzel, 2017, pp. 1609). It is very important for caregivers and family members to become educated on all aspects of CM so that they can have the tools needed for migraine care. Since they are providing social support, their need of social support is essential so they can conduct migraine care. This can only occur after examining their lived experiences and perspective of CM.

Family Perspectives

There is limited literature that pertain to the impact of migraine on family members and their perspective and lived experiences on the headache disorder. Literature from more than a decade states that migraine has an impact on immediate family members who live with a migraine sufferer. Stang, Crown, Bizier, Chatterton & White (2004) found that families with a migraine sufferer have 70% higher healthcare cost versus families who do not have migraine sufferer (as cited in Migraine Research Foundation, 2020). This is due to both EM and CM direct medical costs ranging from $9 billion to $28 billion annually according to different sources (Rich, 2019). Smith (1998) and Lipton et al. (2003) both found that migraine sufferers view their headache disorder as burden to the family and has negative impact on their immediate family relationships (as cited in Buse, Sher et al., 2016). Migraine has caused family disharmony and has a significant impact such as adolescents being neglected from parent’s care and/or missed events or activities (Buse et al., 2018), spousal or significant other feel neglected sexually, needing relationship counseling, and a few relationships has ended up separation/divorce (Buse, Scher et al., 2016). Buse, Scher et al., (2016) state there is a lack of literature on the family members' lived experiences on CM and this study has the purpose to provide the knowledge gap.

The limited current quantitative literature found that CM affects family activities and relationships (Buse et al., 2015) and children of CM sufferers have moderate/severe anxiety and are negatively affected with social and school related activities (Buse et al., 2015). It is evident that CM has some type of burden or impact on immediate family but there is a lack of qualitative information that seeks the family members' lived experiences on CM. Lipton et al. (2017) agrees with this statement based on the action of developing a questionnaire that will help to assess migraine's burden on the family dynamic. Even though this instrument scale provides only quantifiable data (Lipton et al., 2017), it is valuable because no such scale exists.

Summary

This chapter provided a literature review of relevant research that pertain to CM. Literature provides evidence that CM is a prevalent phenomenon and it has an effect on the sufferer and their family members. Although literature is limited on family members' perspective on CM, there is evidence that family members have some type of view on the subject. This study attempted to provide knowledge for the gap in literature that pertain to the lived experiences and perspective of family members who live with a CM sufferer. Chapter 3 provides a discussion on the qualitative methodology that was utilized to explore the lived experiences of family members on CM.

Chapter 3: Research Design

Introduction

The purpose of this study was to examine the lived experiences of CM sufferers and their family members. This study had the goal of investigating the impact of CM on the daily lives of family members who live with CM sufferers. It captured these family members' lived experiences of CM and how it affects their health and well-being, daily tasks, and ability to interact with the sufferer. In this chapter, I discuss research design, role of the researcher, how the data was collected and analyzed, and the trustworthiness of the study.

Research Design and Rationale

I conducted in-depth interviewing in a qualitative phenomenological approach for this study. Qualitative research methods are used to explore or gain understanding about individuals or groups that are related to a certain problem (Creswell, 2018). Phenomenology is one of the five qualitative study approaches. A phenomenological approach has the goal to describe the lived experiences of individuals who have experienced the same phenomenon (Creswell, 2018). Using the phenomenological approach was more appropriate for this study than the other four approaches because the phenomenological approach helps to describe the lived experiences of individuals, which is the main purpose of this study.

The descriptive phenomenological approach was adopted by a German philosopher Husserl (Giorgi, Giorgi & Morley, 2017). It is typically used to explain a phenomenon through the perspective of each individual by using these four steps:

bracketing, intuiting, analyzing, and describing (Greening, 2019). Bracketing has the purpose of separating the researcher’s bias, thoughts, and opinions from the study participants’ lived experiences of the phenomenon (Matua & Van Der Wal, 2015). Bracketing is used to effect an outsider’s view or ethic to prevent influencing the study participant’s perspective because the goal is to understand their reality in regard to the phenomenon (Matua & Van Der Wal, 2015). I achieved bracketing by keeping a journal on my personal notions regarding the phenomenon, which I used during the interview process to record reactions, facial gestures, and my own thoughts while interviewing each participant. Intuiting is the step that involves phenomenological reduction, which is achieved by the researcher placing themselves into position of the study’s participants (Umanailo, 2019). Intuiting is achieved by getting a sense of participants’ perspectives of the phenomenon and by reflecting on their experiences (Polit & Beck, 2020) in an unbiased way (Umanailo, 2019). Analyzing can be achieved through reading all the participants’ descriptions of their lived experiences and categorizing this data into themes that are common so that these themes can be described (Polit & Beck, 2020). Describing is the last step in this phenomenological approach, and it was achieved by describing the study’s participants’ reality with CM.

Descriptive phenomenology is the theory of science for this study. The steps were followed throughout the research process including during the data collection and data analysis of the study. I attended to bracketing throughout the research process to achieve reflexivity. Reflexivity helps to answer the research questions by keeping the researcher’s bias from the data collection and data analysis of the study (Palaganas, Sanchez, Molintas, & Caricativo, 2017). Reflexivity is important during the interviewing process; it is achieved by using a semi structured interview format and asking focusing questions instead of leading questions (Palaganas et al., 2017). The other steps of descriptive phenomenology bring thoroughness to the study by helping the researcher to get the true essence of the phenomenon through the participant's perspective (Rodriguez & Smith, 2018). For this study, the most important focus was the phenomenon of the effects of CM and not the individual. The research questions were answered by participants who met specific criteria describing their experiences as they related to CM (see Rodriguez & Smith, 2018). Doing this led to gaining a better understanding of the lived experience of the phenomenon, which was the purpose of the study.

The following research questions were addressed in this study:

RQ1: What are the lived experiences of the family members of someone who suffers CMs, and how does that impact their daily life?

RQ2: From the family member perspective, what are the lived experiences of the CM sufferer?

RQ3: How are the social and professional functioning of CM sufferers affected during and after a migraine attack?

RQ4: How critical is family support in managing migraine from the migraine sufferers' perspectives?

Role of the Researcher

My role as researcher was that of a professional nonparticipant interviewer. Unlike some ethnography or case studies where researcher participation is needed to get a feel of the participants in the study (Tracy, 2019), it was not needed for this study. In this study, I aspired to maintain a strict focus on the self-expression of the research participants to attain a better understanding of their lived experiences. I interviewed the participants and observed their reactions and gestures throughout the semi structured in-depth interviews.

The main goal of this research was to have a better understanding of the lived experiences of CM patients and their caring family members. I kept a journal to bracket any personal reactions and comments on the participants' experiences with CM.

Methodology

Participant Selection

The target population for this study included people who live with CM. The sample included adults age 18 and over who were a family member of a CM sufferer. This target population had the goal to fill the gap on the literature that pertains to the problem statement of this study. The sampling strategy for this study was purposeful sampling. This sampling strategy gives the researcher the ability to select participants based on certain criteria that reflect the purpose of the study (Benoot, Hannes, & Bilsen, 2016). For this study I only interviewed family members who lived with a CM sufferer. Descriptive phenomenology targets a certain group a people to study their lived experience with the same phenomenon (Giorgi et al., 2017).

Inclusion/Exclusion Criteria and Recruitment Sample

Inclusion criteria for the individuals of this study were: 18 years and older, speak and understand English proficiently, able to communicate in a face-to-face interview, an individual with or without CM who lives with a CM sufferer. Exclusion criteria for this study were: not able to communicate for an interview, under 18 years old, and description of experienced headache was not CM, such as sinus headache, tension headache, cluster headache, or EM.

Participants were recruited through neurology offices and headache centers located in the Dallas/Fort Worth area. Dukes (1984) stated that a phenomenological research approach can have 3 to10 participants (as cited in Creswell & Poth, 2018). In qualitative research, there is no magic number of participants needed to gain accurate results because data saturation may be reached with a just a few participants (Fusch & Ness, 2015). Data saturation is reached when rich, thick data no longer present any new themes (Fusch & Ness, 2015). To ensure data saturation, this study targeted a sample of 10 participants. Each neurology office and headache center that chose to participate responded to the letter of recruitment that allowed advertisement to be posted to recruit participants for the study.

Instrumentation

Participants were known to meet the criteria by answering a preliminary questionnaire (Appendix A) through e-mail, phone call, or text. Once I determined that they met recruitment requirements, I scheduled a face-to-face interview at a local library or community center of their choice. The face-to-face interview had the purpose of capturing nonverbal language that may cue real thoughts and feelings of the participants (Oltmann, 2016). This was achieved through qualitative interviewing using semi structured open-ended questions (Appendix B). This allowed me to follow a guide of questions tailored to the research and provided room to explore more from the participants' reactions to questions in order to elicit a better understanding (see Petrescu, Lazar, Cioban, & Doroftei, 2017). To assure a comfortable environment in which the participants would be willing to answer the questions, I allowed them to choose a site that was agreeable and safe for the interview, excluding their place of residence.

Data Analysis Plan

For novice researcher, there are many methods from which to choose to analyze qualitative data. I used computer-aided qualitative data analysis software (CAQDAS) to analyze the data for this study. The first step was to transcribe the interviews. Transcription of the data is essential to provide every word that was used by participants and the researcher during the interview process. Transcription is a tedious task, so I used Dragon Speak to transcribe the interviews. Dragon Speak was a hard software to find for a reasonable amount, so I used another software. The interviews were recorded with a digital recorder, which was helpful to use with the software of Google Live Transcribe. Google Live Transcribe can dictate voice into text. This was needed so I could see the wording of the interview. Without the full transcription of all the interviews conducted in the study, there is no way to accurately analyze the data. Transcription provides the data to analyze to understand the content and meanings as provided by the participants.

Atlas.ti (2019) was the CAQDAS that I used to analyze the transcribed data produced from Google Live Transcribe. It can take the text from a transcription and interpret it by using coding and annotating activities (Atlas.ti, 2019). Atlas.ti was too difficult to use, so I used NVivo 12 to code the transcription without losing any context.

These codes were then put into code families, which helped with interpretation to answer the research questions. The code families helped to group together what was said in the interviews to see if there was a common theme among the participants. These common themes helped to describe the responses from the participants so that the research questions were answered.

Issues of Trustworthiness

To achieve trustworthiness in qualitative research, multiply standards of quality such as credibility, transferability, dependability, and confirmability need to be taken into consideration. It has been said that there is a question of trustworthiness in qualitative research (Korstjens & Moser, 2018), but trustworthiness can be achieved. Credibility provides internal validity which represents how well the research is conducted. In other words, Korstjens & Moser (2018) states that it establishes whether the data collected from the participants of the study is original with correct interpretation (pp. 121). Credibility was reached in this research by doing member check. Member check has the purpose to get rid of subjectivity from the researcher by having the researcher do a follow up with the participants on the findings of the research (Kornbluh, 2015). The researcher interprets the information provided from each participant and then follows up with each participant to make sure the interpretation matches their intended feelings and thoughts (Kornbluh, 2015).

Transferability provides external validity of whether the research can be generalized to other situations or other people. This research reached transferability by providing thick description of the study. Korstjens & Moser (2018) states that thick description provides a way for other researchers to replicate the study (pp. 122), which means there is a need to distinctively described all the actions used to collect and analyze the data in this research.

Dependability refers to the reliability of the study. It represents consistency (Korstjens & Moser, 2018) and it is supported by the data obtained from the participants in the study (Amankwaa, 2016). Ary et al. (2019) state that dependability can be achieved with the code-recode strategy. This research utilized this strategy by coding the same data twice with a two-week resting period between the two coding (Ary et al., 2019, pp. 447). If the result of both coding is similar, then dependability is achieved (Ary et al., 2019).

Confirmability refers to objectivity or lack of bias in the study. In other words, it ensures that the findings and the interpretation of the data is tailored around the responses from the participants (Amankwaa, 2016). This was achieved by using theory triangulation. Theory triangulation is the usage of two or more theories to analyze the data so that the study has validity. Descriptive phenomenology with a reflexive journal and CAQDAS are the theories used to interpret the data in the study. Colaizzi method was added as another method to interpret the data. The Colaizzi method is an eight-step approach that has the goal to answer the research questions. The following steps was followed: 1) Transcribed the data from the participants' interviews which be assisted through the usage of Dragon Speak, 2) Extract statements that relate to the phenomenon or experiencing the phenomenon, 3) Create formulated meanings from the extracted statements, 4) Create themes from the formulated meanings, 5) Develop a description from the themes, 6) Interpret symbolic representation notated during the interviews, 7)

Identify the structure of the phenomenon that is revealed from the description, and 8) Obtain validation by returning to participants for clarification on what was found (Suryani, Welch, Cox, 2016).

Ethical Procedures

It is essential in any research study that involve human participants that it protects their anonymity and confidentiality by doing no harm. The American Psychological Association (APA) Code of Ethics state that all researchers must respect their human participants and provide privacy with the insurance that their information confidential through an informed consent (Barrow & Khandhar, 2020). The participants of this study were provided an informed consent that stated the purpose of this research, participating in this study was completely voluntary and they had the right to refuse participation, confidentiality was protected by excluding all personal information out of the findings, their participation entitles them to the findings of the research, coercion was not used for this study, and participation in this study allows them to discuss any questions and concerns to the researcher. Informed consent was provided to participants who had signed the form with mental capacity of understanding their rights written out in the form. This study required the participants to do a total of three interviews. The first interview was a 1-hour initial interview which includes the participant answering semi-structured questions. The second interview allowed the researcher to verify the findings from the first interview and discuss it with the participant. The participant was asked questions that pertain to getting a better understanding of what was found from their first interview. The third interview reported final individual findings to the participant by providing this information in writing to the participant, if asked. This third interview also ensured that their privacy was protected, and everything collected during the study will be destroyed in five years. All participants of this study were given a $10 Wal-Mart gift card for their participation in this study. This incentive showed appreciation of the participant’s time and effort for this study and participants received this incentive at the end of the first interview.

Data collection of this study was 100% confidential so it was not tampered or damaged during the study. All documents, audio recordings, electronic media, and flash drives were protected in a locked storage box with a code only known to the researcher. The flash drives used stored all documents, electronic media, and data related to this study and has an encrypted password that is only known to the researcher. After 5 years, all data pertaining to this study will be destroyed.

Summary

In this chapter, a detailed description of the research design and methods are provided. It remarked that a qualitative research paradigm with phenomenological approach and purposeful sampling strategy was used. Description of the study population, inclusion and exclusion criteria, and sample size were provided. Data analysis plans, strategies for ensuring quality and ways of adhering to the ethical requirements of conducting research on human subjects were discussed. In Chapter 4 presentations and descriptions of the results and analyses of the collected data are highlighted to answer the stated research questions.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to explore the lived experiences of family members who live with CM sufferers. In this study I tried to capture the impact of CM on the daily tasks, feelings, and well-being of the family members. This was achieved through in-depth face-to-face interviews. The semi structured interviews were used to answer the following research questions:

RQ1: What are the lived experiences of the family members of someone who suffers CMs, and how does this impact their daily life?

RQ2: From the family member perspective, what are the lived experiences of the CM sufferer?

RQ3: How are the social and professional functioning of CM sufferers affected during and after a migraine attack of the migraine sufferer?

RQ4: How critical is family support in managing migraine from the migraine suffers' perspective?

In this chapter I present the results of the collected and analyzed data and describe and the methods used to ensure trustworthiness. The chapter concludes with a summary that transitions to Chapter 5 in which I make interpretations of the observed results, social change implication of the observed findings, conclusions, and recommendations based on the observed results.

Research Setting

For this research study, I used face-to-face interviews to allow for the observation of facial expressions and gestures. This goal was achieved, but it took a long time to locate eight qualified people willing to do one preliminary questionnaire, one in-depth recorded face-to-face interview, and two interviews through phone or e-mail. These methods were approved by the Walden Institutional Review Board (IRB).

All eight participants had their face-to-face interviews conducted in a private room in a public setting. The interview space had to be one that allowed for limited interruptions and noise so that the interview could be recorded. I used reserve rooms at a local library as the interview space, which were free for 2-hour blocks of time. Libraries were selected by the participant so that they did not have to travel far for the face-to-face interview. Having this private room allowed freedom to record the interviews with a handheld digital voice recorder with ease. There was no background noise to deal with or any other distractions. The goal was to have the initial interview to be relaxed so it was like having a regular conversation. This was needed so that the follow up interviews were comfortable and easy to conduct. The second and third interviews were conducted through e-mail for six of the participants while the follow-up interviews for the other two participants were conducted by phone.

There were no budgetary complications for this study. There were no problems with obtaining items for the study. Funds were set aside to purchase the gift cards and buy materials needed to conduct the interviews. Each participant was made aware during the preliminary questionnaire and informed consent that only their time and conversation was needed for this study.

Demographics

All participants for this study were family members who lived with someone who suffer from CM. There were eight participants for this study even though the target sample was 10. Data saturation was reached at eight, so there was no need to have a total of 10. This study used purposeful sampling because a certain population was being explored. To make it easier, the sample was obtained in the area in which I currently reside. Therefore, all eight participants lived in the Dallas/Fort Worth area. Finding the eight participants was a tedious process, which led to a change in the recruitment process. The first proposed recruitment process did not produce participants, so a change was approved in December 2018, and eight participants were recruited by the end of July 2019.

The sample for this study were family members who lived with CM sufferers. It did not matter if the sample was diverse, but it ended up that way. Each participant identity was protected by naming them FM1 and so on. Table 1 presents the demographic information of each participant by stating the gender, race/ethnicity, age, marital status, whether the participant suffered with CM, and the participant’s relationship to the CM sufferer.

Table 1

Demographics of Participants

Participant	Gender	Race/Ethnicity	Age Group	Marital Status	Suffer from CM	Relationship to CM sufferer
FM1	Female	Black	25-44	Married	No	Wife
FM2	Female	White	25-44	Single	No	Sister
FM 3	Female	Hispanic	18-24	Cohabitating	No	Girlfriend
FM 4	Female	Black	18-24	Single	No	Niece
FM 5	Male	Black	25-44	Married	No	Husband
FM 6	Female	Black	25-44	Married	Yes	Mother
FM 7	Female	White	45-64	Divorced	Yes	Mother
FM 8	Male	Hispanic	25-44	Divorced/ Cohabitating	Yes	Boyfriend

Data Collection

The IRB application was approved on February 16, 2018, with approval number # 02-16-18-0155650. With this application, I proposed to recruit participants by sending letters to neurology offices or headache centers asking if it was acceptable to post recruitment flyers at their place of business. I sent letters by mail and e-mail by the end of February 2018. I received no response, so the process was repeated in March 2018, and I waited until the end of April 2018, for a response. I received no response from any of the centers and offices that I had contacted. By the end of July 2018, I had left messages at all centers and offices that were contacted by e-mail and mail. Nobody answered any of the messages, so there was a need to find out why. Someone finally answered the phone around August 2018, and I was told that the process will take a long time due to them needing to follow a procedure that included contacting their IRB and board of directors even though there was no need to look at any patient's information or chart. Having permission to post the recruitment flyer on the door was the only goal. However, because the flyer was for recruitment for dissertation research, they would have needed to contact their IRB and board of directors. Therefore, this halted the recruitment process for this study, and the recruitment process had to start from the beginning.

I conducted a search in the Walden Library to read dissertations on how other students recruited for their research. Many students recruited through posting flyers at different business establishments. I decided that this study must do the same so that participants could be found to complete the data collection process. I contacted the IRB on December 4, 2018, to request a change on the procedures for recruitment. Recruitment flyers were needed to be posted at churches, community centers, libraries, grocery stores, coffee shops, Facebook, and via e-mails. The request for change in procedures was approved on December 20, 2018.

At the first of 2019, the new recruitment flyer was printed and posted at several business establishments. My son posted the recruitment flyer at his college and their different campuses in Fort Worth, TX. The recruitment flyer was also posted at different community centers, churches, Starbucks, and grocery stores. In addition to having it displayed at different establishments, it was posted on Dallas/Fort Worth Craigslist and Facebook. Despite posting the recruitment flyer at many places, it took a while to obtain participants for the study.

The data collection process lasted 7 months because that is how long it took to obtain 8 participants. Two data collection instruments were used: the preliminary questionnaire, given through e-mail after participants made the initial contact from the recruitment flyer, and the semi structured interview. The preliminary questionnaire was a demographic questionnaire that also had a very important question of whether they lived with a CM sufferer. If they did not live with a CM sufferer, they could not be a participant of the study. Fortunately, everyone who made the initial contact lived with a CM sufferer. After completing the preliminary questionnaire, the interviews were scheduled. All eight of the participants had the opportunity to schedule their first interview at a local library of their choice and at any time they desired. Each interview started the same, but all were different because the interview was conducted as a regular conversation.

Each interview was recorded with a handheld digital recorder and was started with the same question from the semi structured interview questionnaire. In addition to recording the interviews, I kept a reflexive journal to write down notes from the interview so that facial expressions, body language, and gestures that were observed were documented. After each interview, the interview was transcribed through Google Live Transcribe. I had previously proposed to use Dragon Speak for transcription, but Google Live Transcribe was free to use. Google Live Transcribe has the feature to put the transcribed files into a Word document. The Word document was used in a CAQDAS to analyze the data. The CAQDAS used was NVivo 12, even though Atlas.ti was initially proposed. NVivo 12 was easier to use and understand what was being analyzed. Along with using NVivo 12, I used the Colaizzi Method to code the transcribed interviews.

Data Analysis

According to Creswell & Creswell (2018), qualitative data analysis uses an inductive and deductive process by creating themes from the raw data and then looking at the themes to see whether more information can support them (pp. 181). I accomplished this by using a reflexive journal with the NVivo 12 software and then conducting member checking by going back to the participants to see if the results matched what they were trying to portray. Two or more weeks later, I conducted the Colaizzi Method as the second method of data analysis.

I used the reflexive journal as an observation protocol. Observation protocol is for recording information that was observed by writing down notes during the interview (Creswell & Creswell, 2018, p. 190). These notes may be about facial expressions, gestures, time and place of interview, body language, and the researcher's impression of the participants (Creswell & Creswell, 2018, p. 190). Having the opportunity to observe the participants during a face-to-face interview provided an opportunity for a more in-depth look at their lived experiences. Observing allowed me the freedom to ask other questions based on their facial expression and/or body language. Every participant was unique in sharing their lived experiences. One participant showed great sadness for her husband who suffered from CM. Another participant showed confusion while stating she was annoyed. Another participant was nonchalant to a point where it was a challenge to extract his opinions while another participant was happy and very talkative.

Despite the uniqueness of each participant, nodes were created for each research question so that NVivo 12 can conduct auto-coding. The nodes created were Lived

Experiences-Family member for RQ1, Lived Experiences-Perspective of Family Member for RQ2, Functioning for RQ3 and Family Support for RQ4. NVivo 12 created auto coded themes from the nodes.

To use the auto coding feature in NVivo 12, nodes were labeled based on the research question and imported the transcribed interview responses to the questions that related to each research question. This resulted in many auto-coded themes to emerge. Besides having the auto-coded themes to interpret the results, NVivo 12 provided other ways to interpret the results. Word frequency queries, word clouds and group node queries can be conducted. Group node queries were used to see what themes emerged from the four created nodes. After getting the results from the queries and auto coding, I went back to the participants to ensure the findings.

After two weeks or so, the Colaizzi method was conducted as a second data analysis method. The Colaizzi method is a seven-step process that aids in answering the research questions. The following are the steps that were followed: 1) Transcription of the interviews was conducted with Google Live Transcribe, 2) Extracted the statements from the transcribed interviews that related to the phenomenon of CM, 3) Created formulated meanings from the extracted statements, 4) Create themes from the formulated meanings, 5) Develop an exhaustive description from the themes, 6) Identify the fundamental structure of the phenomenon that is revealed from the description, and 7) Revisit back to the notes from doing member check after the NVivo 12 analysis so validation can be obtained and have verification of the findings (Morrow, Rodriguez & King, 2015, p 2).

Evidence of Trustworthiness

Proving trustworthiness by relying on the findings from the methods used was vital for the study. Lincoln & Guba (1985) states that trustworthiness produces strength to a qualitative research study and can be achieved through credibility, transferability, dependability, and confirmability (as cited in Amankwaa, 2016). Trustworthiness was established through different techniques. Two instruments were utilized: a preliminary questionnaire and a semi-structured interview questionnaire. A reflexive journal was used to document the researcher's impressions and reflections of each interview and another journal that documented the Colaizzi method. Besides the Colaizzi methods, a CAQDAS called NVivo 12 was used.

Credibility

Credibility was reached when there is confidence in the findings (Amankwaa, 2016). Lincoln & Guba (1985) states that is can be reached by doing member check which is "the most crucial technique" when establishing credibility. Member check was conducted by doing second interviews with participants. This second interview consist of going over the results of NVivo 12 with the participant to ensure that the findings are what they wanted to portray.

Transferability

Thick description was the way to provide transferability to the study. Amankwaa (2016) states that Lincoln & Guba describes that thick description provides external validity by providing rich details of the study (pp. 122). Details of the study is displayed throughout the chapters. Research setting, data collection, data analysis, and the results are greatly described to where the readers can replicate the study.

Dependability

As stated in Chapter 3, Ary et al., (2019) stated that dependability can be achieved with the code-recode strategy. This was achieved by coding and creating themes from extracting statements of the transcribed interviews through the Colaizzi method that was conducted two or more weeks after the data analysis using NVivo 12. Dependability was achieved when the results from both ways of coding are similar, which is displayed in the results.

Confirmability

Amankwaa (2016) state that confirmability is achieved when the results of the study comes from the participants and does not include any type of bias from the researcher (pp. 121). This can be achieved by using triangulation, which is conducting different data collection methods. Confirmability was achieved by doing two methods of data collection. I used two methods of data collection and two methods of data analysis. I used a reflexive journal with observation and conducted interviews as the two methods of data collection. Using these two methods has provided confirmability to the study.

Results

Themes

Many themes emerge from the auto coding results of NVivo 12. NVivo 12 provides a way to look at each node to see what auto coded themes emerged (Table 2).

Table 2

Nodes/Auto Coded Themes

Nodes	Auto coded themes
Lived Experiences-Family member	Things
	Pain
	Migraine
	Kids
	Headaches
	Difficulty
	Daily
	Chronic Migraine
	Activities
Lived Experiences-Perspective of Family Member	Pain
	Noise
	Migraine
	Family
	Chronic Migraine
	Changes
	Activities
Functioning	Time
	Migraine
	Leisure Time
	Family
	Family Time
	Family Vacations
Family Support	Support
	Family
	Chronic migraine

The auto coded themes from NVivo 12 had sub themes, which helped to create main themes for each research question. These are the themes that were created from the NVivo 12 and Colaizzi Method results:

- Daily Impact for RQ1 what are the lived experiences of the family members of someone who suffers CMs, and how does this impact their daily life?
- Burden for RQ2 from the family member perspective, what are the lived experiences of the chronic migraine sufferer?
- Functionality for RQ3 how are the social and professional functioning of chronic migraine sufferers affected during and after a migraine attack of the migraine sufferer?
- Support for RQ4 how critical is family support in managing migraine from the migraine suffers' perspective?

Daily impact. RQ1 had the goal to explore the lived experiences of the family while they live life with a CM sufferer. In order to answer this question, the family member was asked questions that pertain to them witnessing CM, discussing the worse CM ever witnessed, and how the ways of their life are impacted from the sufferer having a CM.

Based on the group query in NVivo 12, auto coded sub themes (Table 3) emerged to help create the main theme for RQ1. These sub themes described the participant's lived experience while living with a CM sufferer. The participant's direct statements extracted for the Colaizzi method explained the sub themes.

Table 3

Lived Experiences-Family Member Node

Auto coded themes	Auto coded sub themes	Main theme
Things	Sure things	Daily impact
Pain	Kids things	
Migraine	Certain things	
Kids	Various pain	
Headaches	Sharp pain	
Difficulty	Excruciating pain	
Daily	Menstrual migraine	
Chronic migraine	Daily Migraine	
Activities	Barometric migraine	
	Helping kids	
	Sinus headaches	
	Slight headaches	
	Real difficulties	
	Caused difficulty	
	Daily routines	
	Daily migraines	
	Daily activities	
	School activities	
	Normal activities	

With the Colaizzi method, the interviews were transcribed first. Second, statements were extracted from the transcribed interviews that related to the phenomenon. These are the direct statements of the participants that relate to RQ1:

- “During a migraine, a helpless feeling comes over me… Not many chores or errands are handled because migraine paralyzes my husband. There is always a sadness when my husband suffers from a migraine” (FM1)
- “This (migraine) happens so sporadically…. The worst lasted a week… and nothing seemed to help…I stay with him as much as I can to help during an attack. This (dealing with CM from a loved one) has made me more empathetic towards others because you never know what hardships they face” (FM3)
- “I deal with menstrual migraines and barometric migraines. Sometimes lose sleep because I check on him constantly when he is having a migraine. I feel overwhelmed and irritable when my son suffers a migraine even though I know exactly what he is going through cause I suffer from them too” (FM6)
- “I am unable to do certain things because my sister is having a migraine and it stops her from doing things. You can’t do things when you want because the pain is there. I feel empathy when she is sick but sometimes it can get annoying to cater around her..” (FM2)
- “I suffer from migraines occasionally. It puts a strain on daily activities. Sometimes it is an everyday occurrence. Activities are slowed down… I feel sad when she is hurting so everything stops in our household” (FM8).

- "In the past I suffered from migraines but taking Topiramate daily prevents so I have the occasional slight headaches. I feel their mood swings.. I help out by doing more chores… I feel helpless cause I can't magical take the pain away" (FM7).
- "I have more responsibilities such as cooking and helping the kids with homework when there is an active migraine attack. I have to step my game up and take over the household. I have to make sure it is the way she will do it…. I was the only one financially responsible because she was unemployed for 2 years due to the migraines" (FM5).

Step 3 and 4 of the Colaizzi method, formulated meanings were extracted from these statements in which it created the theme of daily impact. The 8 participants described their life while living with a CM sufferer to answer RQ1, therefore it seems fitting to use this as the theme for RQ1. Some have to change their ways so that they can do extra chores or errands while others do not do anything different. One stated that they cannot do anything while their loved one is having a migraine while one stated that it just puts a strain on them. Most of them feel helpless, sadness, and empathy while only a couple felt annoyed or irritated because life must change or stop because of their love one suffering from a CM.

Burden. Research question 2 had the goal to explore CM through the perspective of the family member based on the CM sufferer's activity. This was achieved by asking questions in the interview that ask the family member how they thought their loved one felt during a CM, how do they know when their love is suffering from a CM, and how difficult is the loved one while suffering a CM.

Based on the group query in NVivo 12, auto coded sub themes (Table 4) emerged to help create the main theme for RQ2. The sub themes in the table described the participants perspective of the phenomenon. These words of the sub themes describes the CM sufferer's burden of the disorder. The direct statements from the participants used for the Colaizzi method provides more understanding on why the sub themes emerged from the auto coding.

Table 4

Lived Experiences-Perspective of Family Member Node

Auto coded themes	Auto coded subthemes	Main theme
Pain	Pain meds	Burden
Noise	Pain manage	
Migraine	Excessive pain	
Family	Noise complaints	
Chronic migraine	Loud noise	
Changes	Migraine hit	
Activities	Migraine attack	
	Migraine action plan	
	Family member	
	Family activities	
	Major changes	
	Lifestyle changes	
	Normal activities	
	Family activities	

Extracting direct statements from the participants helped create the theme of burden. The participant more or less described their perspective of when their family member had a migraine from the following statements:

- "The mood changes when the migraine disappears .You know when a migraine hits because all the lights are off and he may be balled up in fetal a position. Life changed because plans has to be handled when there is no migraine. My husband wants to be alone and not be interrupted and sometimes plans are not handled until they can be handled" (FM1)."Migraines changes her mood badly. She is very short tempered. Wants quietness and can't enjoy activities" (FM4).
- "It (migraine) prevents him from eating or even showering some days. He becomes angry in one instant. He refuses to leave his room for a few days. He is more moody and stressed because of this" (FM 3).
- "She is very irritable when she has a migraine and wants to sleep more, the temp cold and a dark room. She takes detox baths with Epsom salt and peppermint oil… She has no appetite due to being very nauseated. She is very moody and irritable. Less social… drinks more water than having alcohol" (FM 5).
- "My son has an attitude and is irritated when he has a migraine and ends up missing school and his activities such as football and baseball. Ended up in the ER because he didn't want to stop his activities because of an active migraine.

Has no major changes to his life because he follows a migraine action plan at home and at school" (FM 6).

- "Doesn't participate in family activities. Most of the time everything stops, and she stays in bed and becomes very grouchy. He has persevered through this disorder" (FM 7).
- "Life is put on hold because she is too sick to do normal activities. Lay around most of the time and is sometimes disoriented from the pain meds…Has become more angry and bitter…My sister looks lethargic, tired, and sensitive to lights with having noise complaints that comes off as being whiny" (FM 2).
- "I know she is in pain from her facial expressions. Everything stops and it brings on depression She makes me depressed because she is depressed" (FM 8).

Formulating the meanings from these statements created the theme of burden. The 8 participants have stated that their loved one are burdened from the disorder. They are burdened because it makes them moody, irritable, whiny, depressed, grouchy. They also cannot do certain things and have to medicine or follow a plan. Life stops for the CM sufferer and some of them spend time in quiet, dark rooms while having an attack. Most participants stated that their loved one do not continue with doing any type of activity or movement when in an attack. One participant did state that when the CM sufferer continued with activity, they ended up in the Emergency Room.

Functionality. Research question 3 asked probing questions about how the CM sufferer functions through life such as their work life, productivity, and social life. The 8 participants had to answer these questions from their perspective by sharing what they have witness and experience with their love one with being active and productive.

The auto coding from NVivo 12 created themes and sub themes (Table 5) from the participants' responses for RQ3. These sub themes helped create the main theme for RQ3. These sub themes emerged based on how the participant responded to the questions. The direct statements used for the Colaizzi method explained the sub themes.

Table 5

Functioning Node

Auto coded themes	Auto coded Subthemes	Main theme
Time	Time work	Functionality
Migraine	Leisure time activities	
Leisure time	Leisure time	
Family	Full time	
Family time	Family time	
Family vacations	Migraine attack quietness	
	Migraine attack	
	Social activities	
	Family vacations	
	Family time	
	Family members	

Extracting the following direct statements for the Colaizzi method helped create the main theme of functionality for RQ3:

- "He is outgoing until a migraine strike. He works but sometimes it's difficult to work due to his pain. We don't go out as much as we use to because bright lights and loud noises can start a migraine. We don't have time for vacations" (FM 3).
- "He takes a long break when he has a migraine at work. It's hard for his eyes to stay open when he has one at home…He piles up on the pain meds when he has one (migraine) if interrupts something I want to do…" (FM1).
- "She doesn't work full time. Her leisure time is sleeping. She leaves early from family time all the time" (FM 4).
- "She doesn't drink socially. The weather depends on whether we plan a trip. Sometimes have to reschedule plans to another day. Basically, she changes her work schedule and plans if she has a migraine at work. I play video games or take the kids out the house so she can get peace while having a migraine" (FM 5).
- "When at school, he follows a plan… He gets extended time to complete his work at school when he had migraine. During family vacations he will chill out and not do anything if it is really hot outside. He doesn't do anything when he has a migraine, not even his PS4" (FM 6).
- "He works full time but sometimes do not complete all his tasks due to a migraine. He doesn't socialize that much. During an attack, she withdraws

from socializing such as not participating in family time or watching TV. Family vacations are less enjoyable. Goes back to being productive at work after a migraine attack" (FM 7).

- "Social life is non-existent, and working is not consistent" (FM 2).
- "We have leisure time such as going to the movies and going out together despite her migraines. She works part time. She has good working habits but if she has a migraine at work she gets in a bad mood and is not very responsive We have family vacations, but migraine meds are on deck" (FM 8).

These statements are straight forward and discusses the functionality of the CM sufferer. It is described that the CM sufferer has limited function in all aspects. A few of the CM sufferers work while some do not work at due to the pain. CM disrupts social life, leisure time, and vacations. Not one of the CM sufferers' functionality is at full capacity while experiencing an attack. CM is very disabling and lessens the activity of the CM sufferer. They can function in life while not experiencing a CM but when the attack is active, their function is very limited or non-existent.

Support. Research question 4 had the goal to explore family support from the perspective of the family member. In order to get a sense of their perspective, the interview questions ask the participant how critical is family support, who provides caregiving to the CM sufferer, how is support is provided to the CM sufferer, how important is support for the CM sufferer, and what type of support is needed and wanted by the CM sufferer.

The auto coding from NVivo 12 created auto coded sub themes (Table 6) from the participants' responses for RQ4. These sub themes helped create the main theme for RQ4. The direct statements used for the Colaizzi method explained the sub themes.

Table 6

Family Support Node

Auto coded themes	Auto coded Subthemes	Main theme
Support	Physical support	Support
Family	Much support	
Chronic migraine	Huge support	
	Family support	
	Emotional support	

The Colaizzi method extracted the direct statements of responses for RQ4. These statements created formulated meanings which were used to create a main theme for RQ4. The theme that emerge from this was support. The following statements from the participants help create the theme:

- "You have to provide physical and emotional support… Having support from family is very important because it keeps her from being depressed" (FM 2).
- "Emotional and physical support is the support that my auntie gets. I do anything to make her better" (FM 4).

- “Family support is extremely important. Very important in managing migraines…People have not been trained properly in how to manage a migraine” (FM 1).
- “. She doesn’t like to be dependent on no one….I try to comfort her when she is feeling bad. Without proper care and management, quality of life would be intolerable” (FM 5).
- “I trust his dad and grandma to take care of him when I cant. It is highly important to have support…He needs the support of someone advocating for him” (FM 6).
- “I make sure he knows it is not his fault. His mother has been a huge support at this time because she knows what to do for being a nurse” (FM 3).
- “I provide her support by helping her, soothing her, and providing her with her meds and food. My wife needs the best care and support so she can be motivated to move and not let the pain affect them as much” (FM 8).
- He is supported through helping him with things, providing his meds, and emotional support…I do not trust others to take care of him. I don’t know what level of support he needs but I do know CM is very debilitating” (FM7).

Exhaustive Description

The fifth step of the Colaizzi method is the development of an in-depth description of the phenomenon that includes the themes that were created. This description is just a comprehensive description of CM that was expressed from the participants (Morrow, Rodriquez & King, 2015). The statement of description is organized by the themes that emerge from the formulated meanings and represents the detail integration of the results.

- Despite the family member not physically experiencing CM, they somehow feel helpless just like the CM sufferer. The family member can go on with their daily living activities, but they have empathy for their family member who suffers from CM. Their daily routine may change because the sufferer is having a CM, but it is not a bother for most of the participants of the study. One participant stated that they are annoyed sometimes when they have to do extra because the CM sufferer cannot do anything. One participant is overwhelmed while the rest are sad because their love one is in pain and they cannot physically take that pain away.
- CM is found to be a disabling headache disorder due to the pain and symptoms experienced. The participants of this study agree that CM is disabling because the CM sufferer does not participate in any activity during an attack. The family member knows that the CM is present based on facial expressions, attitude, and/or physical ability. One participant stated that the CM sufferer will ball up in fetal position while other participants stated that the CM sufferer will just lay down and sleep. Due to the CM sufferer not doing anything, the family member may need to aid to the CM sufferer. When this occurs, some of the participants state that everything stops, and nothing gets done which is overwhelming for one participant while another is not bothered when everything stops.

- Functionality during CM is quite hard based on family members' perspectives. CM is disabling that it affects CM sufferers' productivity and attendance. They often miss family time and have no social life. The CM sufferer avoid certain activities. If they work, their productivity is lessened or is non-existent due to taking a break to rest and take medicine. Family vacations are not affected by the CM sufferer because they bring meds and it is not a stressful thing like work and socializing.
- Support is provided in a few ways for CM sufferers. CM sufferers mostly experience emotional and physical support from their family members. Family members ensures love and assumes that this very important for the CM sufferer. Family members provides help and wants to provide help if needed due to understanding that the CM sufferer is in pain that is difficult to manage. The CM sufferer has not complained about their level of care because some of them like to be independent. Family members have to remind the CM sufferer that they are there to help and will provide anything that is needed so that the quality of life is managed.

Fundamental Structure

The fundamental structure is the sixth step of the Colaizzi method. In this step, a statement is derived from summarizing the exhaustive description that describes the elements of the phenomenon. The fundamental structure of lived experiences of chronic migraine from the perspective of family members is that the headache disorder creates empathy among family members because sufferers are in pain that is disabling and limits their activity to where family member feel helpless and sadness despite providing the sufferer with emotional and physical support because it is known that support is important while managing CM.

Validation

The seventh and final step of the Colaizzi method is to validate the findings. This is achieved by going back to participants and go over the results. For this study, participants were revisited after conducting the NVivo analysis. Each participant did a second interview to go over the results. All of them validated the findings and did not add anything to the findings. The notes from the second interview was used to validate the findings after conducting the Colaizzi method.

Summary

In this chapter, the results of the study were discussed. It included a description of the research setting, participants, data collection methods, data analysis, trustworthiness, and the results that include findings from a NVivo 12 data analysis and findings from using the Colaizzi method.

Chapter 5 includes a final discussion and conclusions of this study. This is achieved by going over the results through interpretation, state the limitations of the study, provide recommendations, and state the implications of social change.

Chapter 5: Discussion, Conclusion, and Recommendations

Introduction

The purpose of this study was to examine family members' lived experiences of CM. There is much literature on CM from the sufferer's perspective, but there is a lack of literature on CM from family members' perspectives. This study gained a sense of family members' perspectives by using a descriptive phenomenological approach with the social support theory as the theoretical framework. A phenomenological approach is used to explore the lived experiences of certain individuals, while the social support theory provides an understanding of the lived experiences.

The purpose of understanding the perspective of family members who live with CM sufferers was to gain a better understanding of the phenomenon of CM. The results of this study may help to create migraine interventions that integrate family support as understood through the social support theory. The social support theory states that social support promotes better decisions that may lead to better health.

The following research questions helped guide the study and accomplish its purpose:

> RQ1: What are the lived experiences of the family members of someone who suffers CMs, and how does this impact their daily life?
>
> RQ2: From the family member perspective, what are the lived experiences of the CM sufferer?
>
> RQ3: How are the social and professional functioning of CM sufferers affected during and after a migraine attack of the migraine sufferer?

RQ4: How critical is family support in managing migraine from the migraine suffers' perspective?

The findings of this study were based on the answers to the research questions from the eight participants who were over 18 in age and lived with a CM sufferer. It was revealed that CM has an impact on the sufferers' family members. This finding is interpreted further with a discussion of the limitations of the study. This chapter concludes with recommendations and implications for social change.

Interpretation of Findings

Several open-ended questions were used in the semi structured interviews that had the goal of answering the four research questions. The four research questions aligned with four themes that emerged. The following are the themes that were created from the results for the research question:

- The theme for RQ1 was Daily Impact.
- The theme for RQ2 was Burden.
- The theme for RQ3 was Functionality.
- The theme for RQ4 was Support.

Daily Impact

All participants of the study described their lived experience of CM by stating how it impacted their daily living. Some stated they have empathy for the CM sufferer while having the feeling of being helpless. While experiencing this feeling of helplessness, they take up the slack of their loved one by doing extra chores around the house. Two participants did not like doing the extra chores of the house, therefore everything that needed to be done in the household stopped when the CM sufferer had a CM. Hence, this caused the feelings being overwhelmed and irritated. According to the social support theory, most of the participants displayed emotional support when sharing their lived experiences of CM by having empathy. The findings from the two participants who admitted irritation and being overwhelmed aligned with the study that stated family members are emotionally burdened (Visa & Harvey, 2019).

Burden

All participants stated that they witnessed CM causing disability for the sufferer. The sufferer slept often, did not eat, avoided bright lights, despised certain noises and smells, and went into a state of isolation with depression. The sufferer often avoids activities, is not in a good mood, and does not attend to household responsibilities. They may close themselves off from everyone or even ball up in a fetal position. This finding aligned with Emadi et al. (2019) who stated that CM has a great impact on the sufferer's emotions, social activities, and self-care tasks. According to the social support theory, family members provide tangible support because the sufferer is disabled and has limitations with doing errands and any type of cleaning. With that said, CM disables sufferers while they are experiencing CM, and their activities are limited due to not wanting to move and to the desire to isolate themselves while experiencing CM. They are only inactive during the CM. When CM sufferers are not in active CM, their activities may still be limited due to experiencing CM quite often. They also limit their activity due to having the fear that activity will create CM.

Functionality

All the family members stated that the sufferer cannot function during or after a migraine attack socially or professionally. Only a few of the CM sufferers worked regularly. Of the ones who worked, all but one did not go to work when there is an attack. The one who went to work followed a special regimen that resulted in being less productive, and coworkers and/or others had to cater to this regimen. A few of the participants stated that the sufferer does not have a social life and often misses or leaves early from family functions. The sufferers who do have a social life have limitations to it. They avoid certain things and only participate in certain activities socially. Family vacations are attempted with the sufferer having their medications and only doing things that do not cause a migraine. Based on these findings, CM sufferers' functionality is very limited even though some can work but cannot function very well while suffering CM. Hence, these findings support Agosti (2018) who stated CM sufferers are less productive at work and with Buse, Sher et al. (2016) who found that CM sufferers are less productive socially.

Support

The participants of this study stated that they understand that the CM sufferer should have family support. A few of the participants were aware that support is needed so the sufferer does not get depressed while others stated that support provides a way to improve care and the quality of life. Therefore, they provide support to the sufferer because they know it is important. According to the social support theory, social support is needed because it can lead to better health outcomes. This supports the Canadian study that social support is needed so CM does not lead to attempted suicide (Fuller-Thomson & Hodgins, 2019).

Limitations of the Study

There are limitations to conducting qualitative research. Qualitative research is designed to explore the feelings, opinions, and perceptions of targeted participants concerning a phenomenon. Qualitative research has the limitations of data volume due being selective and small (Rahman, 2017), bias from the researcher, and difficulty to maintain thoroughness due to subjectivity (Ross & Bibler, 2019). This qualitative research's targeted participants were a limitation due to selection bias and sample size bias. The sampling strategy used was purposeful sampling, which meant the participant had to meet certain inclusion criteria. The participant had to be over 18 years old, live with a CM sufferer, and reside in the Dallas/Fort Worth area. Because this was the case, many people were excluded from this study. The people who were excluded were those under the age of 18, people who did not reside in the Dallas/Fort area, and people or family members who knew a CM sufferer but did not live with them.

The results of this study were limited to eight participants who were family members who lived with CM sufferers, which limited the scope of this study. Based on the inclusion criteria, children who lived with a CM sufferer were excluded. Therefore, the results of the study are limited to a very small population of people who have lived experiences of CM.

Recommendations

As previously stated, there is a gap in qualitative literature on the lived experiences or perspectives of family members of CM sufferers. Current quantitative literature has found that CM is a burden to family members but does not elaborate on how it is a burden. This study found that CM affects family members' emotions, their way of daily living, and activities during a migraine attack. Because this study has limitations, recommendations for further research are based on these limitations.

There is a need for research that goes further than this research. I recommended that researchers study the perspectives of children who live with CM sufferers. Children may provide a different perspective than those who are 18 years and older. I also recommend that researchers study different regions of the United States. Perspectives of family members might be different based on regional cultural norms. Researchers can also go a further by studying people who are family members of a CM sufferer but do not live with them. This may also provide another perspective of CM.

Implications for Positive Social Change

The positive implications of social change for this study are to lessen the stigma of migraine through better understanding of the phenomenon from the lived experiences of family members and to develop interventions or treatment plans that may improve the quality of life for the family members and CM sufferer. Stigma of migraine refers to external or internal negative response to the disorder. Shapiro (2017) stated that stigma of migraine started from Freud who stated that migraine is the fault of the sufferer due to their daily behavior. Freud's statement is an example of external stigma. External stigma is a form of mistreatment from others, which can be others treating migraine as an exaggeration of symptoms (Vilanilam et al., 2018), stating that it is an excuse to get out of something, or not treating it as a disabling headache disorder. Internal stigma refers to the sufferer anticipating how others view their headache disorder (Parikh & Young, 2019).

CM sufferers can be helped efficiently when there is limited stigma. Stigma can be decreased when there is a better understanding of the phenomenon. This study provides a better understanding of CM through the perspectives of family members. Family members stated that CM is a burden and causes alterations in life. Despite these alterations, family members stated that they know support is greatly needed so their loved one can get better. Therefore, interventions and treatment plans can be developed for CM sufferers that involve the help of their family member. This support from the family member can contribute to improving the quality of life for the sufferer.

Conclusion

CM is a misunderstood phenomenon that needs further research. Many suffer from the disorder by experiencing the pain or witnessing someone else going through the pain. This study gained some insight of the phenomenon through the lived experiences of family members who live with CM. The results indicate that family members are impacted by CM. They feel helpless while their loved one is going through a pain that disables them, and they try to provide support for them. These findings indicate that family members well know that CM is more than a headache. It takes great support to manage CM, including support from the family. People who suffer from CM are less likely to attempt suicide when there are understanding family members to provide support.

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Appendix A: Preliminary Questionnaire

The following questions has the goal to gain demographic information and whether you meet the criteria to be included as a participant.

Name: ____ (will be coded as FM#1 or so on for privacy)

Gender: ________________

Marital Status: a. Single b. Cohabitating c. Married d. Divorced e. Widowed

Educational Level: a. Less than high school b. High school diploma or GED c. Some college, no degree d. Undergraduate degree e. Graduate degree

Employment Status: a. Employed b. Self-Employed c. Student d. Unemployed e. Retired/Disabled

Race/Ethnicity: ______________________

Age group: a. 18-24 b. 25-44 c. 45-64 d. 65+

Do you live with someone who suffers from any type of headache? _________

What type of headaches do the sufferer experiences? (select all that apply) (for definitions of headaches, please see below) a. sinus headache b. tension headache c. cluster headache d. chronic headache e. episodic migraine f. chronic migraine.

IF CHRONIC MIGRAINE IS NOT SELECTED, PLEASE STOP HERE

Do you suffer from chronic migraine? ____________

Relationship to chronic migraine sufferer: ______________________

Definitions

Chronic headache – head pain that can be everyday but does not have associated migraine symptoms

Chronic migraine – mild to moderate head pain that lasts 2-72 hours that is also accompanied with symptoms such as sensitivity to light, smells, and sound in which this pain occurs more than 15 days a month

Cluster headache – characterized as pain around the eye that can last up to 2 months but can go into a period of having no pain at all throughout the year (Medicinenet.com, 2016)

Episodic migraine – migraine that lasts for only less than 15 days a month

Tension headache – mild to moderate dull throbbing pain on both sides of head that affects head, neck and behind the eyes (Higeura & Cherney, 2015)

Sinus headache – Facial pain and pressure in the sinuses that is caused by inflammation in the sinuses that is accompanied with nasal congestion, discolored nasal discharge, cough, fever, and headache (Hutchinson, 2016).

Appendix B: Semi structured Interview
(With Prompts)

Questions asked during the interview will tailored to answer the research questions. These will be prompts and interview questions to help the participant along with answering the research question.

1.What are the lived experiences of the family members of someone who suffers chronic migraines and how does this impact their daily life?

Do you personally suffer from any type of headache? If so, which type?

What is your definition of a chronic migraine?

How long have you witnessed the attacks of chronic migraine with your family member?

What was the worse chronic migraine attack have you witness with your family member?

When your family member is suffering from a chronic migraine attack,

How do you feel?

How does it impact your daily activities?

How does it affect your mood?

Describe how do your daily routine changes when this occur. (such as chores, running errands, hygiene, eating, sleeping)

Describe a time when there was difficulty in daily life because of the attack.

In your opinion, what do you think caused the difficulty?

2. From the family member perspective, what are the lived experiences of the chronic migraine sufferer?

From your perspective, how do you think the chronic migraines affect your loved one?

Is there any way you know the person is in pain from a chronic migraine? If so, how do you know?

How does the chronic migraine affect the daily routine of your family member? (such as chores, running errands, hygiene, eating, sleeping)

How does the chronic migraine affect the mood of your family member?

How does the family member act during a chronic migraine attack?

Describe a time the family member was difficult to handle due to a chronic migraine attack.

Why do you think this difficulty occurred?

Over the time the family member suffered from chronic migraine attacks, how has their life changed?

3. In your experience, how are the social and professional functioning of chronic migraine sufferers affected during and after a migraine attack of the migraine sufferer?

How does a chronic migraine attack affect your family member's social life?

How does a chronic migraine attack affect your leisure time with the family member? (such as doing social activities like movies, going out together)

How does a chronic migraine attack affect family time?

How does a chronic migraine attack affect family vacations?

How does a chronic migraine attack affect the family member's productivity at work?

If they do not work full time, how does suffering from chronic migraine stops them from working full time?

If they do work, how does a chronic migraine attack affect them with completing tasks and projects at work?

After a chronic migraine attack,

- How does it affect their leisure time?
- How does it affect their family time?
- How does it affect their productivity at work?
- How does it affect your time with them?
- How does it affect them during a family vacation?

4. Based on your experience, how critical is family support in managing migraine from the migraine suffers' perspective?

What type of support is provided to your family member to care for their chronic migraine? (help with things, providing their meds, emotional support)

Who are the main caregivers of the family member who suffer from chronic migraine?

Are there any others that you trust to take care of this family member when you are not available?

How important do you think managing the chronic migraine is for your family member?

Why do you think that this is their level of importance?

How does the family member think about their level of family support?

What type of family support do you think your family member wants or needs?

Why do you think this type of support is wanted or needed by your family member?