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Self-management Experience of Nurses Living with Migraine: A Qualitative Study

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Abstract

Often considered 'only a headache', migraine is a chronic incurable neurobiological condition characterized by a constellation of unpredictable and disabling symptoms and is the second cause of disability worldwide. Migraine is most prevalent during the peak working years of an average adult (ages 22-55) and is three times more common in females than males. Migraine is prevalent among nurses, and high workplace stress and shift work are suggested as the main contributors. However, literature exploring the experience of persons living with migraine is scarce and nearly non-existent regarding nurses which has important individual and systems implications for health and wellness, job satisfaction, burnout rates, and patient safety. Self-management is essential in chronic disease management as the patient engages in various strategies to be able to live with their condition. Thus, in this study I employed interpretive description as a methodology to explore and describe the experiences of living and working with migraine among female nurses in Ontario, with particular attention to their priorities and strategies for self-management. The results revealed nurses engaged in various self-management strategies including pharmacological and non-pharmacological strategies and highlighted the role of technology in migraine self-management. Participants also described experiences of living with migraine as an invisible condition including feelings of not being understood, stigma and the absence of formal support at the workplace. The implications of these findings support the incorporation of a critical approach to relational engagement that is person-centred including non-judgemental, strength-based care as a practice approach when caring for persons living with migraines and the need to include experiential learning in nursing educational curriculums as a strategy to reduce stigma against migraines.

Keywords

Keywords: self-management, migraine, headache, stigma, nurses

Summary for Lay Audience

Migraine is a chronic condition that is a leading cause of disability worldwide. Migraine is more common among women with symptoms that occur more frequently during one's productive years (i.e., between 22-55years). Women's migraine symptoms are commonly labelled as a "woman's excuse" for avoiding responsibilities, as such, this belief has undermined the understanding of migraine and has contributed to the underdiagnosis, undertreatment and experiences of discrimination among persons living with migraine. Living with a chronic condition such as migraine requires self-management which refers to the day-to-day management of chronic conditions by individuals throughout an illness. Also, with the increasing cost and burden of chronic illness, the use of digital health or electronic health platforms (eHealth) for self-management is a growing priority. The purpose of this study is to explore and describe the experiences of living and working with migraine among female nurses in Ontario, with particular attention to their priorities and strategies for self-management. The findings highlight various self-management strategies used by nurses and reveal a potential for the adoption of technology to support the self-management of migraines. In addition, the findings also highlight nurses' experience of stigma and how they negotiate the workplace as they live with migraine and feelings of their experiences not being understood and lack of workplace support. The implications of these findings support the incorporation of a collaborative approach to care which requires exploring and assessing contextual factors that shape the experience of persons living with migraines, the need to include experiential learning in nursing educational curriculums as a strategy to reduce the stigma against migraines and improve policies to support persons living with migraines.

Co-Authorship Statement

Marionette Ngole Dione conducted this research for her master's in science thesis under the supervision of Dr. Lorie Donelle, Dr. Victoria Smye, and Dr. Deanna Befus, who will be co-authors on the publication resulting from this manuscript.

Dedication

I dedicate this work to all the participants who despite being frontline healthcare workers during a global pandemic dedicated their time to participate in this study.

Acknowledgements

I would like to express my gratitude to the many people who supported me throughout this research. I am grateful to my family, my friends and nursing colleagues who were always ready to listen to my struggles, challenges and frustrations through my studies and encouraged me daily to continue working hard. To my role models, mom and dad; thank you for believing in my dreams, however small or big - you remain my biggest motivators. You all are the reason I am where I am today.

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Chapter 1

1 Introduction

Migraine is a prevalent chronic neurobiological and potentially incapacitating disorder that is more prevalent among females than males (Steiner et al., 2018). Globally, migraine has a 12% prevalence, and is responsible for 5.6% of all years lived with disability (YLDs) (Steiner et al., 2018). Described by The European Headache Federation and World Headache Alliance as the “forgotten epidemic”, the global burden of migraine has steadily increased over the last decade as migraine moved up from the seventh most disabling condition in the Global Burden Disease 2013 to the second most disabling condition in the Global Burden of Disease Study 2016 (Abd-Allah et al., 2017; Schroeder et al., 2018; Steiner et al., 2020; Vos et al., 2015;). Although there are effective symptomatic and preventive treatments available, more evidence from research about the under-diagnosis and undertreatment of migraine is disconcerting, underscoring a major gap in the medical care for persons living with migraines (Heidari et al., 2022; Schroeder et al., 2018; Steiner et al., 2020). According to the World Health Organisation (WHO) about 50% of persons living with migraine are self-managing their symptoms (2016). The prevalence and socioeconomic impacts such as years of disability, prevalence, and financial burden as a consequence of migraine are well documented in the literature (Steiner et al., 2020; Viticchi et al., 2018; Wang et al., 2015; WHO, 2011;). However, literature on migraines have highlighted treatment gaps in the use of preventative and treatment therapy and access to timely and person-centred pain care (Lipton et al., 2016; Nahas et al., 2021; Viticchi et al., 2018). As such the purpose of this research is to explore and describe the experiences of living and working with

migraine among female nurses in Ontario, with particular attention to their priorities and strategies for self-management.

1.1 Background

Migraine is the second most common type of headache after tension headaches and is more prevalent among females (Steiner et al., 2018; WHO, 2011). This disproportionate prevalence has been related to hormone fluctuations with menstruation as a potential trigger during reproductive years (Deneris et al., 2017). Considerable progress has been made in explaining the pathophysiological mechanisms of migraine, the genetic and environmental factors that may influence susceptibility, and migraine treatment (Schroeder et al., 2018). However, the medical management of migraine remains challenging due to the variation in the presentation of migraine symptoms and migraine experiences are unique and require a person-centred and holistic approach to care (Andreou & Edvinsson, 2019).

Migraine attacks are characterized by episodic pulsating unilateral headaches which are aggravated by routine physical activity, of moderate to severe intensity, with acute episodes lasting for a minimum of a few hours up to two to three days (Dayapogu & Yildiz, 2017; Landy et al., 2011; WHO, 2011). Migraine headache is associated with other symptoms such as nausea or vomiting, photophobia or phonophobia (WHO, 2011). According to the International Headache Society (IHS) (2019), there are two significant subtypes of migraine. Migraine with aura and migraine without aura. Migraine with aura includes migraine symptoms that are preceded by completely reversible visual, sensory, speech, language, or motor symptoms (IHS, 2019). Migraine can be classified based on the severity and frequency of headaches into episodic and chronic migraine. Episodic migraine is defined as episodes that occur less than 15 days per month for three months (Deneris et al., 2017). Chronic migraine, a severe form of migraine, is

defined as headaches that occur for at least 15 days per month, with migraine features on at least eight days per month for at least three months (Deneris et al., 2017; IHS, 2019). Episodic migraine can progress to chronic migraines when undertreated (Deneris et al., 2017). Some risk factors for transitioning from episodic to chronic migraine include advanced age, female, low education, low socioeconomic status, and family history of migraine (Deneris et al., 2017).

Stigma and stereotyping are important issues that have been raised by migraine patients and remain a significant determinant of health for persons with migraine (Aydemir et al., 2011; Parikh & Young, 2019; Young et al., 2013). Stigma against migraine began around the 18th to 19th century and was rooted in the absence of objective manifestation of pain or headaches and lack of tangible anatomical and pathological features (Parikh & Young, 2019). Migraine and its symptoms are commonly labelled as a "woman's excuse" for avoiding responsibilities, and this belief has undermined the understanding of migraine as a true condition contributing to social and economic barriers to care (Parikh & Young, 2019; Rains et al., 2002). Furthermore, migraine is often not considered by the public as a severe or legitimate disorder as symptoms are episodic, not contagious, and have not been linked to mortality (Lonardi, 2007; WHO, 2011). This stereotypically feminized discourse around migraine, and people suffering from it, has contributed to underdiagnosis, undertreatment, and experiences of delegitimization and stigma among sufferers of all genders and plausibly responsible for the scarcity of literature on migraine experiences (Cevoli et al., 2009; Rains et al., 2002; WHO, 2011).

Researchers have reported migraines to be prevalent among nurses (Kuo et al., 2015; Wang et al., 2015). The risk of migraines among nurses has been suggested to be related to stress and shift work patterns (Kuo et al., 2015). However, the prevalence of migraine among nurses

may reflect the higher prevalence of migraine among females as most nurses identify as females (Wang et al., 2015).

Self-management is recommended by Canadian Pain Society as an essential strategy in management of chronic pain (Lynch, 2011). Lorig and Holman (2003) defines self-management as any cognitive, behavioural, or physical action taken by individuals with chronic disease enabling them to go about with their daily life. Self-management support has been identified as a critical strategy and primary goal of chronic pain management in Canadian primary health care services (Lukewich et al., 2015). Grady and Gough (2014), describe self-management as "the day-to-day management of chronic conditions by individuals throughout an illness." (p. 26). Nurses play a critical role in the maintaining the wellbeing of others through engaging in the treatment of and promoting the health of individuals, families, and communities (College of nurses of Ontario, 2020). Moreover, the health and wellbeing of nurses and their ability to meet their expectations at the workplace has important implications for patient care (Cuff and Forstag, 2020). As such, it is an assumption of this study that nurses with migraine are likely to engage in self-management to continue with their daily activities and fulfill their workplace obligations. As such it is important to explore nurses' experiences of living with migraines and understand their strategies for self-management.

1.2 Purpose

The aim of this study is to explore and describe the experiences of living and working with migraine among female nurses in Ontario, with particular attention to their priorities and strategies for self-management.

1.3 Theoretical Framework

A theoretical perspective is a set of related concepts that provide a systemic view of a phenomenon to explain or predict relationships (Liehr et al., 2009). According to these authors, a theoretical perspective serves to guide data collection, analysis, and conclusions, parallel to the study design. Three primary theoretical insights guide the framing of this study: the concept of self-management of chronic illness (Lorig & Holman, 2003), understanding migraine and pain as an invisible and private experience (Goffman, 1963; Vickers, 1997) and, interpretive description a practice-oriented methodology (Thorne, 2016), which will be explored in the methods section.

Self-management is a lifetime task for individuals with a chronic illness, which Lorig and Holman (2003) described to include three sets of self-management tasks and six self-management skills. According to Lorig and Holman, the first set of tasks involves medical management of the condition, which includes activities such as taking medications or adopting a specific diet. Secondly, individuals with chronic illness also engage in role management. Role management encompasses maintaining, modifying and creating new meaningful behaviours or life roles to live with the condition while optimizing their quality of life. For example, persons living with migraines may need to balance rest periods with daily activities such as taking multiple breaks while at work (McLean et al., 2012). The third task requires the individual with a chronic illness to live with the emotional sequelae. For example, people living with migraine express emotions such as anger and frustrations associated with their living experience (Pearson et al., 2019). Learning how to manage these emotions constitutes a portion of the work required to manage a chronic condition (Lorig and Holman, 2003). Self-management skills include ones' capability to carry out self-management tasks (Lorig and Holman, 2003).

Problem-solving, the first self-management skill, includes problem definition and the generation of possible solutions, how to implement the solution and the evaluation of results

(Lorig and Holman, 2003). Secondly, individuals with chronic conditions engage in day-to-day decision-making with the evolution of their disease. To make daily decisions, these individuals require the necessary knowledge that encompasses frequent changes (Lorig and Holman, 2003). For example, persons with migraine need to decide what symptoms would require complete rest or medications. The third skill is how to find and utilize resources. Self-management includes the ability to seek out appropriate and useful resources from other existing resources (Lorig and Holman, 2003). Taking action is another self-management skill. The individual makes and commits to an action plan for specific behaviour. For example, a migraine patient may decide to take at least three 30 minutes of rest sessions daily. According to Lorig and Holman (2003), successfully carrying out an action plan for a specific behaviour is related to the individual's confidence in carrying out the said action or change in behaviour. Establishing a patient-provider relationship is also an essential self-management skill. Finally, self-tailoring includes an individual's ability to adapt self-management knowledge and skills to oneself as appropriate. This conceptual understanding of self-management, as described by Lorig and Holman, informs the taxonomy of everyday self-management strategies (TEDSS), a comprehensive framework for everyday self-management strategies that are grounded in the experiences of persons with neurobiological conditions such as migraine, multiple sclerosis, epilepsy and Parkinson's disease (Auduly et al., 2019).

The TEDSS framework constitutes seven descriptive domains of self-management strategies, represented as integrated parts of a complex whole (see figure 1) (Auduly et al., 2019). Activity-based strategies include finding ways to participate in everyday activities such as leisure or work activities despite experiencing chronic disease symptoms. Internal strategies refer to activities such as meditation or relaxation techniques directed at preventing and managing

stress, negative emotions or internal distress to achieve inner calmness. Social interaction strategies refer to one's actions and behaviours, such as disclosing the condition, enabling one to manage social interactions and relationships, and allowing the individual to continue to engage in social relationships without exposure to negative attitudes or stereotypes.

Health behaviour strategies include activities performed to maintain a healthy lifestyle such as eating healthy food or staying hydrated and mitigating the risk of illnesses related to lifestyle. Disease control strategies are performed to prevent or mitigate symptoms, complications, or limit disease progression, such as avoiding migraine triggers or using complementary medicine such as magnesium oxide to prevent migraine headaches. Auduly et al. (2019) described these first five strategies as goal-oriented domains as they are directly linked to individuals' everyday goals to optimize their quality of life. Process and resource strategies were described as support-oriented domains as these represented strategies that underlie or reinforce strategies in the goal-oriented domains. Process strategies referred to strategies such as information seeking to obtain knowledge that supports individuals to make informed decisions.

Finally, resource strategies involve actively seeking or managing needed supports (formal or informal) such as social care support, financial support or navigating formal healthcare or organizational systems to receive treatment or equipment needed for disease management. These domains within the TEDSS framework are often intertwined, meaning that individuals self-manage by employing multiple strategies (Auduly et al., 2019).

Based on the conceptualization of self-management by Lorig and Holman (2003) and the TEDSS framework, persons living with migraine would engage in several self-management strategies to achieve goals related to their quality of life. Within the TEDSS framework, self-management strategies are represented as integrated parts of a complex whole. As such nurses

living with migraine would engage in the various self-management domains either simultaneously or in an interactive way such that the self-management strategies in one domain serves as a foundation for the successful engagement in strategies of another (see figure 1). Also, strategies in one domain could serve as a springboard for activities in another domain. Using this illustration, the domains within the TEDSS framework would be co-dependent. For example, one may have to practice good sleeping habits in order to engage in social activities. Studying the lived realities of an invisible illness and discriminatory illness such as migraine necessitates the exploration of the multiple contexts in which these experiences are embodied (Krieger, 2012). Employing a holistic approach towards understanding migraine self-management, an individual might engage in various activities depending on their priorities for self-management and their socioecological context i.e., the workplace, sociopolitical or social environment (community) in which they are positioned. As such, self-management strategies may reflect their goals at a specific time or context in which they live.

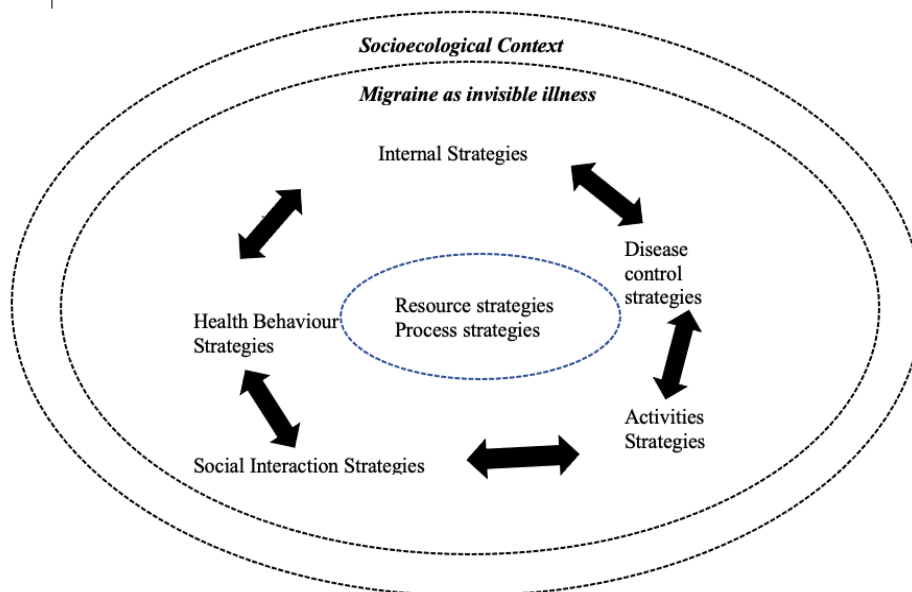


Figure 1: Illustration of TEDSS framework as conceptualized for this study

The experience of living with some chronic illness such as chronic pain, fibromyalgia, and migraine are often not perceptible, noticeable or evident to others (Palacios-Ceña et al., 2017; Vickers, 1997). Vickers (1997) described this phenomenon in which a condition is unseen by others as an "invisible" chronic illness. Lonardi (2007) explained that persons living with migraine often appear physically healthy and tend to adopt outwardly normal behaviour defined by their culture and communities, which the author described as "private suffering." A chronic illness trajectory is often an unpredictable route with periods of unwellness interrupted by disease exacerbation and remission (Vickers, 1997). At different stages of the chronic illness, invisible symptoms may be reflected during acute episodes or chronicity (Vickers, 1997). According to Lonardi (2007), the absence of apparent symptoms has influenced the social representation and understanding of invisible diseases. For example, the experience of migraine headaches is sometimes likened to regular non-migraine and less severe or benign headaches that subsides with over-the-counter pain killers or minimal intervention. Lonardi highlights that comparison undermines the severity of migraine headaches and leads to negative stereotypic reactions such as blame and discrimination from those external to migraine experiences.

Persons living with an invisible condition are often faced with a dilemma to disclose or withhold their diagnoses from their social network (Vickers, 1997). Theoretically, individuals living with an invisible illness can control whom they would disclose their diagnosis to or not (Vickers). These individuals also tend to negotiate their social identity between their known self (to the social network) and actual self (true to oneself) (Goffman, 1963; Lonardi, 2007; Vickers, 1997). Disclosure of the diagnosis exists along a continuum, from complete secrecy to complete information (Goffman, 1963). According to Goffman (1963) and (Vickers, 1997) depending on their circumstance, individuals may employ passing and covering as techniques while

negotiating their disclosure to avoid negative stereotypical. These authors also explained passing as any behaviour employed by an individual presenting as one without a stigmatizing condition while covering is a behaviour employed to mask any evidence of a stigmatizing condition to be made known to others. The central issue is whether to disclose or not to disclose and the consequences that come with either decision, i.e., to be a victim of stigma and other stereotypic behaviours or experience positive social acceptance

Successful passing comes with a price. According to Goffman (1963), one can pretend to be normal, which involves avoiding disclosure and self-management of disease symptoms such as pain. Pretending to be normal precludes others from knowing about the condition (Lonardi, 2007). As such, the individual would learn to live like they do not have the disease and conceal their symptoms, thereby creating an ambiguous self-representation that does not align with one's true self. Individuals may choose to discriminate during the disclosure of their symptoms, adopting different strategies in different social contexts (Goffman, 1963; Vickers, 1997). For example, the patient may be sincere and completely disclose a chronic condition among family and close friends while keeping the condition a secret at work. Failure at passing would compromise one's credibility and lead to the lack of healthcare support for that condition because the individual is believed to be affected by a disease that does not exist (Lonardi, 2007).

Vickers (1997) described reasons for disclosure could be related to the illness, such as severe chronic conditions requiring multiple visits to medical specialists or rehabilitation centers for treatment. Absence from the workplace often mandates an explanation; thus, the individual discloses their condition to receive appropriate support at the workplace or social networks. Individuals also disclose to receive support from their community and increase the other's

understanding of their condition. The central reason for the non-disclosure of an invisible illness: fear of negative attitudes and discrimination and consequently decreased self-esteem.

1.4 Significance

Migraine, a chronic pain condition is potentially incapacitating to the individual and remains a priority issue among employers due to significant loss of productivity in the workplace related to migraines (Befus et al., 2019; Steiner et al., 2015; Vos et al., 2015; WHO, 2011). Migraine is prevalent among nurses, and high workplace stress and shift work are suspected as the main contributors (Kuo et al., 2015; Shields & Wilkins, 2006; Smyth et al., 2016; Wang et al., 2015). In the most recent national survey on the work and health of nurses in Canada, migraine ranked as the third most common chronic condition among female nurses and the eighth-most common among male nurses (Shields and Wilkins, 2006). Migraine is most prevalent during one's peak working years of an average adult (ages 22-55) (Land et al., 2011; WHO, 2011). In Canada, migraine accounts for about 7 million workdays lost annually (Gilmour & Wilkins, n.d.). In the United States, indirect cost related to migraines has been estimated at \$19.3 billion with 81% of this cost resulting from loss of workdays or absenteeism (Yucel et al., 2020). In addition, González-Quintanilla (2015) reported that migraine patients experience increased burnout, reduced personal accomplishments, and reduced positive interaction towards colleagues in the workplace. Burnout, an occupational hazard, further contributes to absenteeism and increases nurse turnover, negatively impacting the quality of care (Lu, 2007). The resulting loss of workdays due to migraine attacks can further worsen the ongoing shortage of nurses in the Canadian healthcare service (Canadian Nurses Association, 2020).

Most persons living with migraines report self-managing their migraines (WHO, 2016). In the United States, only about 40% of individuals with chronic migraine seek consultation and

about 10% of this sample received a diagnosis, while only half of those who were diagnosed received evidence-based treatment (Schroeder et al., 2018). In addition, researchers surveyed Canadians and found that for every 100 employees, 25 reported having migraine while only 12 had been diagnosed by a health care provider (Migraine Canada, 2022). Enabling patient self-management is a core element in the chronic disease care model and self-management support have been linked to improved disease outcomes (Grady and Gough, 2014). Understanding the self-management of migraine is also essential. Medical management of migraine is complex, limited access to migraine specialists, and variable patient response to medical treatment of migraine which includes medication side effects and medications do not always fully relieve migraine symptoms (Canadian Nurses Association, 2020). More so, exploring the self-management experiences of nurses living with migraine has the potential to generate insights to care approaches for migraine.

Given the implications of these findings to practice, in this study I will employ an interpretive description as a research methodology to explore the self-management experiences among female nurses living with migraines in Ontario. Interpretive description as a research methodology has effectively been used to better understand complex interpretations of experiences and generate knowledge essential for practice settings (Thorne, 2016). Employing interpretive description to exploring self-management experiences among female nurses with migraines will provide a framework for an extensive examination of this phenomenon, which will rely on interpretations of the data generated to provide opportunities to inform current practice and stimulate knowledge generation.

1.1 Research Question

The purpose of this research is to explore the experiences of living with migraines among female nurses in Ontario with attention to their self-management strategies. The study question is: Among female nurses living with migraine in Ontario, what are the experiences of living and navigating life with migraine, with particular attention to their strategies and priorities for self-management?

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Chapter 2

2 Self-management experience of nurses living with migraine:

A qualitative study.

Migraine is a chronic condition that is a leading cause of disability worldwide (WHO, 2011). Migraine is more common among women with symptoms that occur more frequently during one's productive years (i.e., between 22-55years) (WHO, 2011). Migraine symptoms are commonly labelled as a “woman’s excuse” for avoiding responsibilities, as such, this belief has undermined the understanding of migraine as true condition potentially contributing to the underdiagnosis, undertreatment and experiences of discrimination among persons living with migraine (Schroeder et al., 2018). A high prevalence of migraine has been reported mostly among nurses identifying as females (Wang et al., 2015). While Kuo et al (2015) observe that the risk of migraine among nurses is related to stress and shift patterns. However, studies exploring the experience among persons living with migraine is scarce and non-existent among nurses. This is important as living with migraine has implications for work productivity and impacts the health of individuals.

Living with a chronic condition such as migraine requires self-management which refers to the day-to-day management of chronic conditions by individuals throughout an illness (Grady and Gough, 2014). Also, with the increasing cost and burden of chronic illness, the use of digital health or electronic health platforms (ehealth) for self-management is a growing priority. This study aims to explore and describe the experiences of living and working with migraine among nurses in Ontario, with particular attention to their priorities and strategies for self-management.

2.1 Background and Significance

The disabling nature of migraine and its adverse socioeconomic effects make migraine a vital health concern (Buse et al., 2013; Steiner, 2018). Persons living with migraine have reported decreased efficiency at work, during their studies, and performing family roles such as caring for their children (Ruiz de Velasco et al., 2003; Rutberg & Öhrling, 2012). Dayapogu and Yildiz (2017) highlighted that 70% of migraine patients experience moderate to severe pain that affects their ability to perform activities of daily living (ADLs). The effects of living with migraine goes beyond the individual; e.g., there can be a disruption in family dynamics and community relationships (Lonardi, 2007). Persons living with migraine report deteriorating relationships with friends and family due to involuntary social isolation as a self-management technique, which involves avoiding migraine triggers such as noise and light (Dayapogu & Yildiz, 2017; Lonardi, 2007).

There is increasing evidence that supports the roles of gender and sex in migraine risk, the pathophysiology, the manifestation of signs and symptoms, diagnosis and management of migraine (Rutberg and Ohrling, 2012; Schroeder et al., 2018; WHO, 2011). Migraine prevalence is higher in women than in men and research suggests that cyclic fluctuations of female sex hormones play a role in the gender differences in migraines. In addition, according to Schroeder et al. (2018), women are more likely than men to experience moderate to severe pain, and experience longer and more intense migraine attacks. Comorbidities of migraine such as depression and anxiety are associated with more frequent migraine episodes and are more prevalent in females than males. Unfortunately, research and medical care for migraine patients have been overlooked in the women's health agenda; researchers argue this may be because migraine symptoms are episodic, not contagious, and migraine is not listed as one of the

significant causes of adult mortality (Rutberg, 2012; WHO, 2011). For example, migraine receives minimal funding from the National Institute of Health (NIH) a major research organisation (Schroeder et al., 2018). The lack of investment on migraine research negatively affects treatment and management options. More research into understanding the experience of women living with migraine would increase awareness, aid in eliminating discrimination and stereotypes towards people with migraines and inform migraine policy and treatment (Rutberg and Ohrling 2012; Schroeder et al., 2018; WHO, 2011).

Migraine has been identified as prevalent among nurses. Kuo et al. (2015) described that the high risk of migraine among nurses is related to stress and shift patterns. With most nurses identifying as females, there is also a possibility that the prevalence of migraine among nurses reflects the higher prevalence of migraine among females (Wang et al., 2015). The incidence and symptoms of migraine peaks during the most productive years, between 22 and 55 (Landy et al., 2011). For this reason, indirect costs related to workdays lost due to migraine are enormous. In Canada, migraine accounts for about 7 million workdays lost annually (Gilmour & Wilkins, n.d.). In the United States, indirect cost related to migraines has been estimated at \$19.3 billion with 81% of this cost resulting from loss of workdays or absenteeism (Yucel et al., 2020). Migraine has been reported as a predictor of burnout among nurses due to the negative impact of its symptoms on the quality of life (Lu, 2007). Migraine also has severe impacts on the psychosocial aspects of individuals. Durham et al. (1998) also described migraine interfering with home activities or life roles. Literature exploring experiences of living with migraine is scarce and virtually non-existent regarding nurses. There is a need to develop a better understanding of the management of this morbid health condition with the possibility of augmenting wholistic care approaches.

Living with a chronic condition such as migraine requires self-management. Self-management support has been identified as an essential strategy and primary goal of chronic pain management in Canadian primary health care services (Lukewich et al., 2015). Grady and Gough (2014) describe self-management as "the day-to-day management of chronic conditions by individuals throughout an illness." (p. 26). According to the WHO (2011), about 50% of individuals with headaches globally are primarily self-treating without contact with health professionals (WHO, 2011). Similarly, a survey among employees in Canada revealed that 25% reported having migraine and only about half of them had been diagnosed by a physician (Migraine Canada, 2022). These data do not only indicate a gap in the medical management of migraines but underscores the importance of self-management as an approach to caring for individuals with migraine.

Understanding the self-management of migraine is also essential for various reasons. Medical management of migraine is complex, and the medical treatment is sometimes not effective in improving migraine symptoms (Canadian Nurses Association, 2020). Furthermore, the high cost of purchasing migraine medications, and their corresponding side effects, limited access to neurologists or migraine specialists, and limited understanding of migraine and its management by physicians have created the necessity for self-management (Matthews & Kneipp, 2020; Palacios-Ceña et al., 2017; Parikh & Young, 2019; Peters et al., 2004; Ruiz de Velasco et al., 2003; Varkey et al., 2013; Viticchi et al., 2011). Understanding self-management would also provide insights for clinicians to explore alternate comprehensive approaches other than the biomedical approach that are appropriate to caring for persons living with migraine.

With the increasing cost and burden of chronic illness, digital health and electronic health platforms (eHealth) for self-management are a growing priority (Bundorf et al., 2006; Yi et al.,

2018). eHealth refers to using the internet and electronic communication technology such as mobile phone applications, websites, and web-based sites to deliver health services or health information to improve health (Lancaster et al. 2018; Eysenbach, 2001). eHealth serves as a platform to enhance patient engagement in their chronic condition, provide person-centred care and ultimately improve patient outcomes (Eysenbach, 2001). Living with migraine often requires the patient to record headache episodes and other symptoms and identify triggers to actively engage in its management (Mosadeghi-Nik et al., 2016). Despite the promising features of digital health technology to enhance patient engagement in migraine management, more remains to be known about how migraine patients employ digital health technology to actively engage in self-managing their condition.

2.2 Research Question

This study aims to explore and describe female nurse's experiences of living and working with migraine in Ontario, with particular attention to their priorities and strategies for self-management. Aligning with this purpose, the researcher will explore the following research question: Among nurses living with migraine in Ontario, what are the experiences of living and navigating life with migraine, with particular attention to their strategies and priorities for self-management?

2.3 Literature Review

This literature review provides a synthesis of the research literature on the impact of migraines and the experiences of persons living with migraines and self-management strategies. An electronic search was conducted using the following databases Proquest, PsycInfo (Ovid), PubMed, Scopus and CINAHL. These databases were chosen with the intention of including diverse perspectives beyond health-related experiences of migraines. Reference lists of relevant

articles were further hand searched to obtain potentially relevant articles. The search terms used were *Migraine, self-management, females, nurses, and stigma*. This literature review was limited to peer reviewed articles written in English, published within the last 10 years from 2002 to 2022. The following three themes resulted from the literature review: the epidemiology of migraine among nurses and healthcare workers, migraine and stigma, self-management of migraine and the role of technology in self-management of chronic pain or chronic disease.

2.3.1 The Epidemiology of Migraine among Nurses and Healthcare Workers

Migraine is a prevalent chronic illness reported by nurses (Shields & Wilkins, 2006; Smyth et al., 2016; Wang et al., 2015). In the most recent national survey on the work and health of nurses in Canada, migraine ranked as the third most common chronic condition among female nurses and the eighth-most common among male nurses (Shields and Wilkins, 2006). Eighteen percent of female nurses reported migraine as a chronic condition, compared to eight percent of males (Shields and Wilkins, 2006). Though not remarkably different, the prevalence of migraine among female nurses (18.3%) was significantly higher than that of all employed females (17.1%) (Shields and Wilkins, 2006). Wang et al. (2015) and Xie et al. (2020) reported a higher prevalence of primary headaches among nurses in China than the general population. In Australia, migraine was reported among the top three highly prevalent chronic conditions among nurses and midwives (Smyth et al., 2016).

Healthcare workers were identified to be at higher risk of developing migraine with nurses having the highest risk relative to physicians due to stress and shift work rotating day and night shifts (Durham et al., 1998; Kuo et al., 2015; Lin et al., 2007; Xie et al., 2020). Significant work-related stress sources include work overload and working overtime (Lin et al., 2007).

Also, greater number of night shifts and the resulting poor sleep from altered normal sleep circadian rhythm has been associated with a higher prevalence of headaches (Bjorvatn et al., 2018; Wang et al., 2015). The relationship between poor sleep and the development of migraine has been anecdotally described as bidirectional (Bjorvatn et al., 2018). Wang et al. (2015) reported that alternating day and night shifts and the presence of headaches were independent risk factors for poor sleep. Hence, perturbed sleep as a result of shift work is a likely trigger for acute migraine episodes.

Bartolini et al. (2014) evaluated the diagnostic timeline for migraine among healthcare workers compared with the general population, hypothesizing that health care workers are theoretically more aware of health problems than non-healthcare workers. Interestingly, the average time for a correct diagnosis of migraine to be made among healthcare workers with headaches was significantly higher (15 years) than for outpatients (12 years). These findings reinforce the issue of delays in migraine diagnosis and raise concerns about the impact of migraine on nurses' health and how nurses living with migraine cope or self-manage while remaining productive. Research is needed to inform evidence-based employee health and wellness interventions that allow for prompt referral and migraine diagnosis among hospital staff.

2.3.2 Migraine and stigma

Stigma is described as negative attitudes and behaviour (such as avoidance of the individual or inferior treatment) that discredit individuals, leading to discrimination and prejudice of the stigmatized individual (Aydemir et al., 2011; Young, 2018). Stigma against migraine is rooted in the absence of objective manifestation of pain or headaches and lack of tangible anatomical and pathological features (Parikh & Young, 2019). The stereotyping

gendering of migraine began socially, as migraine was sometimes associated with ladies of fashion or young female martyrs or described as a disorder of low-class women who often experienced poor sleep and hardship (Kempner, 2016; Parikh & Young, 2019). As a result, migraine was often disregarded as an excuse to avoid responsibility (WHO, 2011). Raffealli et al (2021) explored the perception of ten random migraine images on the internet by migraine patients and healthcare workers. Both groups rated photos with male and older models as more realistic than photos with females and younger models. The authors, argued from a feminist perspective, that pain expressions of females are often taken less seriously than that of males and the reality of pain among women is often questioned. Appallingly, the stereotypic representation of migraine has persisted to current times (Raffealli et al., 2021).

Internalised and enacted stigma against migraine were described in the literature. Internalised stigma refers to the individual cognitive, emotional and behavioural effect that results in holding a negative attitude regarding a disease and directing these negative attitudes to oneself (Kane et al., 2019; Parikh & Young, 2019; Young et al., 2013). For example, a person with migraine may become overly suspicious that others may not believe their symptoms are real (Nichols et al., 2017). Enacted stigma or attitudes that discriminate against persons, influences structural resources available to persons with migraine. Persons living with migraine have described that physicians often did not understand patients' symptoms or showed little empathy, or did not take patients seriously (Belam et al., 2005; Palacios-Ceña et al., 2017; Varkey et al., 2013; Parikh & Young, 2019). Also, persons living with migraines have reported a lack of understanding among their work colleagues and managers who tend not to believe their migraine symptoms (Palacios-Cena et al., 2017).

2.3.3 Self-management of migraine

Living with a chronic condition such as migraine requires self-management. Self-management is a skill in which the individual can continuously engage in problem-solving and decision-making to find a better solution (Lorig & Holman, 2003). Effective self-management encompasses the ability to monitor one's condition and the cognitive, behavioural, and emotional responses necessary to maintain a good life (Lorig & Holman, 2003). Munir, Leka and Griffiths (2005) describe self-management of chronic disease as recognizing and responding to symptoms, managing acute episodes, managing relations, obtaining support from significant others, and using medications or other non-pharmacological activities towards living with a chronic illness. According to these authors, self-management is influenced by factors such as one's social network, family support, healthcare providers, and the physical environment. Self-management of migraine described in the literature can be summarised into the following themes: disease preventing strategies, disease controlling strategies, and social interaction strategies.

Disease prevention strategies. Varkey et al. (2013) and Chang et al. (2021) explored migraine experience from the patient's perspective, focusing on how patients prevent migraine episodes. Activities aimed at preventing migraine episodes included: avoiding migraine triggers or using migraine inhibiting strategies. Avoiding migraine triggers involved planning one's life or activities to avoid stimuli or activities that increase the risk of an acute episode, including certain foods and scents, or working less (Varkey et al., 2013). Migraine inhibiting strategies are activities intended to improve wellbeing and optimize both physical and mental health, which includes self-care activities such as eating a healthier diet, exercise.

Disease controlling strategies. Disease controlling self-management strategies include pharmacological, non-pharmacological or complementary therapies (Audulv et al., 2019). The most common medications include non-steroidal anti-inflammatory drugs, acetaminophen,

ergotamine, triptans and, less commonly, opioids (Brusa et al., 2019; Cevoli et al., 2009; Ozkan et al., 2018). In their study, Ozkan et al. (2018) found that persons living with migraines reported that their medication choice was influenced by the medication's ability to relieve pain, physician recommendation and ease of access.

Complementary or alternative therapies used for managing migraine include supplements such as magnesium, coenzyme 10, vitamins (riboflavin) (Weiss et al., 2008). Non-pharmacological methods include massage therapies, physical therapy, relaxation techniques, yoga, reflexology, acupuncture, physiotherapy, chiropractic treatment and lifestyle modifications such as drinking plenty of water, a healthy diet, consistent sleep, use of sunglasses, sleep in a dark room (Befus et al., 2019; Peters et al., 2004; Varkey et al., 2013; World Health Organization, 2011).

Social interaction strategies. To maintain their social relationships with minimal inferences from their condition, migraine patients described how they managed their social interactions with physicians, significant persons, or community within their social network (Auduly et al., 2019). Persons with migraine continuously negotiate their social interactions to maintain healthy social relationships with significant others, colleagues at work and the community (Auduly et al., 2019). Befus et al. (2018), using a system thinking approach, illustrated the complex negotiations between self, one's social network, and migraine symptoms as persons with migraine engage in self-management activities. These negotiations sometimes involved trading off one activity for another.

Self-disclosure of migraine symptoms and diagnosis is identified as a self-management strategy in maintaining relationships within one's social network (Lonardi, 2007; Munir et al., 2005). Pearson et al. (2019) highlighted the concept of self-disclosure on social media where

participants described having multiple personal profiles and posted information about their migraine only in private migraine forums rather than on their personal social media accounts to control who saw their migraine-related content and concern for how they were perceived by others. These findings point to internalised stigma and how persons living with migraines negotiate their social identity in their environments. Munir et al. (2005) described two types of self-disclosure: partial self-disclosure, which is the disclosure of chronic illness and full self-disclosure that includes disclosure of how the illness affects the individual. Self-disclosure of chronic illness is influenced by factors such as stigma, type and severity of chronic illness, and access to social support (Munir et al.). In addition, considerations for disclosing chronic illness include a balance between the benefits and risks. Some benefits of disclosing a chronic illness at work are access to workplace interventions such as work adjustments, modified working hours, reduced work pace or adjustments to physical working pace, social integration, and professional identity (Munir et al.).

Conversely, disclosure may result in negative attitudes such as social rejection, discrimination, and loss of social support and employment (Munir et al., 2005). Fear of such reactions is a plausible reason for the lack of disclosure of a chronic illness (Munir et al.). For example, Palacios-Cena et al. (2017) reported that migraine patients described withholding diagnosis from colleagues and managers for fear of being discredited and losing their jobs. However, with no known study exploring factors influencing self-disclosure of migraine among nurses, our knowledge of self-management of migraine and insights on self-disclosure suggests that nurses living with migraine may negotiate self-disclosure within their social network based on factors such as the severity of their condition, the attitude and behaviour of those within their social network, workplace culture and their perceived ability to self-manage their condition. A

greater understanding of self-disclosure as a self-management strategy among nurses is needed to tackle discriminatory attitudes, inform workplace support, and improve care access for these nurses.

2.3.4 The role of technology in self-management of Migraine or chronic pain diseases

Advances in information technology have created a platform through which individuals with chronic illness obtain information, and seek social support (Mosadeghi-Nik et al., 2016). In a review of mobile applications for migraine Mosadeghe-Nik et al. reported that mobile applications were mainly used as electronic diaries to regularly document information and monitor the participants' conditions. Patients documented information such as migraine triggers, headache patterns, medication, and the impact on their daily life. Some mobile applications (*MyMigraines* and *MyMygarinesPro*) were interactive and allowed headache specialists or healthcare providers to access patient's headache diaries and interact with patients via messages. Clinicians used interactive mobile applications to effectively identify migraine trigger factors among patients and analyze the association between trigger factors and clinical characteristics of headache.

From qualitative research interviews, Pearson et al. (2019) identified that persons with migraines use social media to acquire information to better comprehend their condition and treatment options. In their study, participants described social media groups as a safe space where their migraine symptoms were acknowledged and given meaning and helped patients normalize their experience as they found assurance through another's story. Participants reported that social media use enabled them to be more actively involved in managing migraine and enhanced their confidence when communicating with health care providers. These results

indicate that the use of technology for managing migraines is a developing area that can be used as a channel for shared decision-making and recommendations between clinicians and patients, support self-management with the potential for improved health outcomes.

2.3.5 Literature Review Summary

The literature review revealed persons living with migraines experience challenges related to migraine management which included a prolonged gap period from when they first experienced symptoms to when they obtained a medical diagnosis (Bartolini et al., 2014; Migraine Canada, 2022; Schroeder et al., 2018). Persons living with migraines rely on a composition of self-management strategies and non-pharmacological strategies to manage their migraines (Audulv et al., 2019). In addition, persons living with migraine managed their migraines primarily using disease controlling strategies, disease prevention strategies, social interaction strategies, and may rely on technology applications for support, or information regarding self-management (Audulv et al., 2019; Befus et al., 2019; Chang et al., 2021, Mosadeghi-Nik et al., 2016; Munir et al., 2005; Peters et al., 2004; Varkey et al., 2013; Varkey et al., 2013; World Health Organization, 2011). The misrepresentation of migraine and stereotypes persist to present date (Kempner, 2016; Parikh & Young, 2019; Raffealli et al., 2021). As such this underscores a need for studies exploring how stigma interplays to create inequities to care for persons living with migraines.

Scholarly literature exploring migraines focused on assessing its prevalence among sub populations such as healthcare workers and those assessing self-management were descriptive, using survey- like approaches for data collection. Of the studies reviewed most assessed self-management interventions or the effect of migraines on work and life using quantitative descriptive or survey approaches (Shields and Wilkins, 2006; Smyth et al., 2016; Wang et al.,

2015; Xie et al., 2020). However, most of the studies reviewed involved large sample sizes which may have limited an in-depth interpretive analytical description of migraine experiences. Lesser attention was paid to understanding how individuals living with migraines navigate work and live and the dynamics of self-management. These aspects require more scholarly attention to examine migraines experiences while recognising the multiple contextual factors may influence migraine self-management.

Generally, no known study was found that employed methodologies to explore and reveal potential clinical practice insights that may further inform approaches to caring for people with migraines. There remain opportunities to further develop knowledge about and from persons living with migraines regarding how they navigate work and life and their experiences of managing their migraine. In this current research I will employ an interpretive description research methodology to address these knowledge gaps by exploring the experiences of nurses living with migraines.

2.4 Methodology

The interpretive description methodology used to guide this study supports the exploration of the self-management experiences of nurses living with migraine. This methodology serves as a framework that extends beyond simple description to interpretation, from what is evident and accessible to the subjective consciousness to the "so what" (Thorne, 2016 p. 36) that drives all applied health disciplines (Thorne, 2016; Thorne et al., 1997). Thorne, Stephens and Truant (2016) state that research questions within nursing's disciplinary philosophy are informed by critical reflection, the awareness of what is already known about the phenomenon, and the notion that the current understanding of the phenomenon is shaped by past and current knowledge within the discipline which will inform future understandings of this

phenomenon. These theoretical underpinnings of interpretive description were most appropriate to scaffold this study and ensured that an in-depth exploration of the self-management experiences of nurses remains central in this research.

Thorne (2016) reinforced that the goal of interpretive description research is not to generate theory but rather guide the researcher to inductively explore a phenomenon of interest to gain new ways of understanding that can inform practice or advance the understanding of the phenomenon. Understanding migraine management remains a challenge as migraine experiences are unique and require a person-centred approach to care (Andreou & Edvinsson, 2019). Thus, specifically in this research, interpretive description provided an orientation towards inquiry that sought to better understand the complex nature of migraine self-management and explore the nuances within individual and collective nurses' self-management experiences (Teodoro et al., 2018). These tenets of interpretive description guided the researcher through participant sampling and in drawing interpretive, and analytic conclusions from the data, that were reflected within both individual and collective representations of the data, demonstrating how individual nurses' self-management experiences contributed to the general pattern observed among participants. Ultimately, interpretive description assisted in understanding the significance of each participant's subjective and experiential knowledge, including assessment of similarities and differences between their experiences as a source of insight to the self-management of migraine. Similar to other traditional qualitative methodologies, interpretive description affirms the importance of understanding the time and context within which human expressions and behaviours are enacted in the analysis process (Thorne, 2016). In this study, temporality helped the researcher to analyse how the length of time living with migraine has shaped nurses' self-

management experiences while context incorporated the various social, political, and ecological factors and how these elements relate and are expressed within participants' experiences.

Interpretive description acknowledges that the researcher and participant interact and engage in a systematic process of co-constructing the meaning of the phenomenon (Thorne, 2016). Interpretive description methodology recognises that the researcher must be aware of and regularly scrutinize disciplinary and personal preconceptions and conceptual frameworks from personal and experiential reflections that they bring into the study to ensure these do not unintentionally influence their observations and interpretation of the data (Thorne, 2016; Thorne et al., 2004). Therefore, engaging in active self-reflection was an essential part of this research process, particularly in my position as a nurse and journey towards self-awareness and attaining my own understandings. I am aware that as a researcher I have personal and professional experiences that may potentially influence this study design and analysis and I recognise that my experiences may shape my understanding of the findings of this research. Throughout the research process, I used reflective journaling to track initial observations, decision points and for testing various conceptualisations from the data (Thorne, 2016). The sequence of self-awareness and actively reflecting on my position allowed me to identify as a curious learner, establish a relational space and serve as a facilitator for authentic and transparent dialogues with participants (Thorne). In this study, this process fostered the development of knowledge and mutual understandings by an increased in-depth conversation through clarifying questioning as the researcher further explored evolving interpretations about the relevance of self-management experiences in nurses' narratives (Thorne).

Engaging in self-reflection allowed me to consider my various identities including my professional practice lens as a registered nurse. My interest in researching about migraine

experiences began with my own experience of caring and creating care plans for persons living with chronic pain and chronic pain syndromes and persons experiencing acute pain from surgical procedures. I have observed the challenges in the medical management of pain and how research evidence and personal beliefs influence pain management. I have collaborated with patients and advocated for person-centred care plans and witnessed the various sociopolitical challenges that patients can face while transitioning from acute care to community. I believe exploring patient's experiences of managing their pain is essential in creating care plans that reflect their needs and goals. As an acute care nurse, it is possible that I may be familiar with some of the experiences shared by the participants in this study. Firstly, I had to reconcile that although I am a practicing registered nurse, my role in this study is as a student researcher. Also, I had to understand that being a nurse would not mean I have gained privy into participants' experiences, neither to make recommendations or question their self-management strategies. This led me to disclose my professional status and clarify that my role in this study is that of a student researcher and curious learner.

2.5 Ethics Approval

The study protocol was reviewed by the university's research ethics committee (see appendix D). All participants provided consent prior to participating in the study. Interviews were hosted via a unique and secured Zoom link. All data were encrypted and stored on a secured system. Anonymity and confidentiality of participants was maintained throughout the study.

2.6 Sampling and Recruitment

Purposive and theoretical sampling techniques were used to recruit study participants. Purposive sampling allowed for the selection of participants (i.e., female nurses living with

migraine) with the potential of answering the research question of this study (Thorne, 2016). Theoretical sampling was identified as an appropriate sampling strategy as it involves simultaneous data collection and data analysis process, which guides and informs further data collection, enhancing the possibilities of in-depth interpretations of the experiences of nurses living with migraine and how they engage in self-management (Coyne, 1997; Thorne, 2016). Maximal variation, a unique element of theoretical sampling, also allowed the researcher to recruit participants across a broad range of demographic characteristics or with varying experiences of self-management of migraines to further explore hunches about patterns and themes that are observed during the initial phases of data analysis (Sandelowski, 2000; Thorne, 2016; Thorne et al., 1997). Study advertisements were posted and shared on social media platforms such as Facebook, Instagram, Twitter and Kijiji. Eligible participants contacted the researcher via the email or telephone number shared on the study advert. The researcher shared a unique personalised link to the letter of information via email and collaborated with each participant to provide any clarifications and responded to questions. The participants and researcher collaborated to choose a mutually suitable time for the interview.

Informed by the literature review, nurses were included in this study if they met the following criteria: 1) were employed full time, part-time or casual in a clinical environment, 2) identify as women, 3) were fluent in spoken English and 4) had either medical diagnosis or self-report migraine or migraine-like symptoms. The exclusion criteria for this study were a) persons who identify as male nurses, b) persons who have a brain tumour c) persons who do not speak English and d) nurses who did not work in Ontario in either an acute care or community setting. At the start of each interview the researcher verbally clarified that participants did not meet any of the exclusion criteria and were eligible to participate in the study.

2.7 Data Collection

Data were collected through semi-structured interviews via video call at a scheduled date and time of mutual agreement between each participant and the researcher. The primary reason for using virtual interviews was related to the COVID-19 global crisis and the importance of respecting the Public Health Agency of Canada's (PHAC) mandate of maintaining physical distancing at the time the data was collected. Demographic and occupational characteristics, and questions in relation to migraine symptoms were collected using an online questionnaire (see appendix A). A semi structured interview guide (see appendix B) was used to conduct the interviews which lasted between 45 to 60 minutes. A conversational approach was employed to allow participants to provide rich description of their experience of living with migraines. At the end of each interview the researcher shared the contact information of a local Canadian Mental Health Association support services with each participant should they need support. The interviews were audio-recorded and transcribed verbatim by the researcher. Following each interview, memo notes and personal reflections (which included any thoughts or emotional reactions, analytic reasoning and considerations, and decisional processes made throughout data collection and data analysis) were documented to assist with further data collection and data analysis process (Thorne et al., 1997; Thorne 2016). Memo documentation allowed for critical self-reflection in relation to the study objectives and was used as a reminder to ensure that the contextual whole is preserved for ongoing analysis (Thorne et al., 1997). A \$5 coffee or tea e-gift card was offered to participants at the end of each interview as a gesture of gratitude, acknowledging their time.

2.8 Data Analysis

Consistent with the interpretive description methodology, a thematic analysis of the interview data, as described by Braun and Clarke (2006), was conducted. Thematic analysis enables the researcher to explore beyond the semantic content of data to identify underlying assumptions and conceptualizations within data that inform the semantic content (Braun & Clarke, 2006; Thorne et al., 2004; Thorne, 2000, 2016). Concurrent data analysis and collection also constituted the analytic process to further explore initial ideas and clarifications of developing themes from the data (Thorne, 2004; Thorne, 2016). Data analysis was done with the assistance of NVivo (QSR International Pty Ltd., 2020) in sorting and organization of data to facilitate the identification of patterns.

Thematic analysis consisted of a non-linear six step guide which includes familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining themes and producing a final report (Braun & Clarke, 2006). In keeping with Braun and Clarke's approach to data analysis, these six steps included familiarizing myself with my data which included transcription of data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and reporting my findings. Following each interview, I (the researcher) reflected on the interview process and wrote memo notes. I then transcribed each interview verbatim which helped facilitate the initial appreciation of underlying concepts from each interview (Thorne, 2016). Following transcription, each transcript was read multiple times and segments of texts were coded to maintain the context within which the data was created (Saldana, 2009; Sandelowski, 2000). Initial codes were descriptive features in the data of interest to the researcher which allowed the researcher to further explore the underlying meaning in the data (Braun & Clarke, 2006). I (the researcher) paid close attention to strategically identifying patterns, test, explore, and expand on conceptualizations observed particularly in relation to

contextual and social factors reflected in the self-management experiences of nurses allowing for further refinement of the data collection process (Sandelowski, 2000; Thorne et al., 2004; Thorne, 2016). Questions such as "what will this structure illuminate that the other will not?" (Thorne, 2016, p.186) enhanced cognitive reasoning and stimulated the generation of new insights (Thorne). Throughout the data analysis I continued to engage with the data to ensure that codes and themes accurately represented the meaning of participants experiences. This approach of data analysis reflects interpretive description which emphasizes the contextual nuances that are embedded within experiential narratives of nurses living with migraines. All names of individuals were changed to pseudonyms and quotes were edited for readability.

2.9 Trustworthiness

Trustworthiness of this study was informed by Thorne's (2016) guidelines (epistemological integrity, disciplinary orientation and relevance, contextual awareness, and pragmatic obligation) which extends beyond the consideration of respecting methodological procedures and toward examination of what meaning can be made of research findings. The criteria used to evaluate trustworthiness of this study include credibility, dependability, confirmability, and transferability (Thorne, 2016; Sandelowski, 1997; Nowell et al., 2017). Credibility refers to trust in the data and interpretation such that interpretation of findings is evident in the data. Credibility in study was maintained through transcription of data, immersing myself in the data, and reflexivity which is similar to Thorne's (2016) contextual awareness. Reflexivity involves being aware of one's beliefs and previous knowledge and how this impact data analysis (Thorne). I employed a process of using memo notes to reflect on my nursing knowledge and beliefs throughout the research process. I audiotaped and transcribed each interview after which I coded fragments of text to capture the context and sought to ensure

credibility of participant's experiences in the research process. During each interview I asked for clarity through paraphrasing the participants experiences and asked for feedback to ensure I captured their reality. Transferability refers to providing thick descriptions such that other researchers can evaluate whether study reports may be transferred to their settings. Dependability refers to ensuring the research process is traceable. In this study, I maintained transferability and dependability by describing analytic logic in this chapter.

2.10 Findings

Twelve semi-structured interviews were conducted with nurses from Ontario who met the inclusion criteria for this study. Participants were recruited from clinical practice areas including both community and acute care practice environments in Ontario. Participants included both registered nurses (RN) and registered practical nurses (RPN). These participants also completed a demographic form which included descriptive questions of their migraine symptom characteristics. Of the 16 participants who expressed their interest in participating in this study, one participant declined to schedule an interview after signing the consent as she could not find potential dates and times to schedule an interview due to her busy schedule. Three participants did not respond to the researcher's subsequent emails to review the letter of information and potentially schedule an interview. Most participants were single females, aged between 20 years and 29 years and identified as white. A majority of the participants rated their migraine headaches to be moderate or moderate to severe and had lived with migraine for at least ten years. The table below represents the demographic characteristics of the study's sample.

Table 1: Participants demographic information

Demographic characteristic	Frequency
Age	
20 - 29	8
30 - 39	3

40+	1
Length of living with migraine	
Less than 10 years	4
10 to 19 years	4
20 to 29 years	4
Marital Status	
Single (never married)	6
Married	3
Common-law	3
Length of being a nurse	
Less than 5 years	5
5 – 14 years	6
15 – 24 years	1
Employment status	
Part-time	9
Full time	3
Average hours worked weekly	
20 - 39 hours	4
40 hours	5
40+	3
Health care sector	
Acute care	11
Community care	1
Level of Education	
Diploma	2
Bachelor's degree	5
Master's degree	5
Ethnicity	
White	10
African	1
Asian	1
Self-Reported Migraine Intensity	
Mild	1
Moderate	11
Severe	6

2.10.1 Physical manifestation of migraines

All the participants in this study described having consulted a physician for their migraines. All but one participant had received a medical diagnosis for their migraine.

Participants described their headaches as throbbing or pulsating headaches, located on one side

of the head ranging from moderate to severe intensity. Symptoms accompanying migraine headaches included photosensitivity, visual disturbances, phonophobia, nausea or vomiting, sensations of pins and needles or numbness, muscle weakness. Other symptoms included generalized fatigue, alterations in thought process such as slowness in expressing themselves, loss of appetite and difficulty sleeping.

Furthermore, participants shared their experiences in relation to living and working while experiencing migraines and how they engaged in self-management. The following three themes and associated subthemes were constructed from participant's reported experiences: 1) Self-management strategies with four subthemes: pharmacological strategies, non-pharmacological strategies, learning as you go and technology as a tool for self-management; 2) Living with an invisible condition with two subthemes: feelings of not being understood and It [Migraine] is very debilitating; and 3) Negotiating the workplace with three sub-themes: stigma, developing resilience through suffering and lack of formal workplace supports. To protect the privacy of participants and to maintain confidentiality, all the names used to quote participants experiences in this research are pseudonyms and do not reflect any participant's real name.

2.10.2 Self-management strategies

Participants described various self-management strategies that they employed to manage their migraines. These strategies were influenced by participants' ability to gain knowledge to inform their strategies. Overall, participants described not relying on only one strategy but engaging in multiple strategies to help provide symptom relief and to prevent worsening of symptoms.

The use of these strategies was not mutually exclusive but rather participants engaged in combining various strategies simultaneously to help relieve their symptoms. The use of these strategies also depended on their environment, that is whether they were at home, at work or at a

social event. These strategies are reflected in the following four subthemes: Pharmacological strategies, non-pharmacological strategies, learning as you go and technology as a tool for self-management.

Pharmacological strategies

The use of either prescription or over-the-counter medications to manage migraines was described by all participants. Ethel explained

If I start taking Tylenol (acetaminophen) and Advil (ibuprofen) like right away when I first start having a headache, I can catch it [headache] and it [headache] will go away in a couple of hours. But if I am busy doing things or I don't have access to the [medications], it can last up to two days.

Sonia also explained: So, once I get a migraine as soon as I can from the initial onset take Rizatriptan and go lay down immediately because I am not going to be coherent for that time anyways...have a four-hour nap and then usually good to get back to my regular day and it seems to work very well. The additional things I have done in the prevention stage is I am taking Vitamin B2 every morning and magnesium every evening.

Prescription medications usually were taken as ordered by the doctor and included triptans, beta blockers and non-steroidal anti-inflammatory medications such as ibuprofen and naproxen which could also be taken over the counter. Participants described using both prescription and over-the-counter medications to provide symptom relief rather than as a prevention strategy. Most participants who used pharmacological strategies relied on over-the-counter medications and described lesser side effects and ease of access as their reason of choice. These participants also reported good pain relief if over-the-counter medications are taken early at the start of a migraine episode.

Non-pharmacological strategies

Participants described using non-pharmacological strategies to either prevent migraine symptoms, provide symptom relief or maintain their overall wellbeing.

Ella explained: so, when I have a migraine, sometimes I just like to lay on the couch and turn out the lights because I find I don't like being in bright spaces, or looking at phones or computers aggravates it [migraines]... Sometimes if the [migraine] is little bit longer, I would put a cold cloth on my head, and put some peppermint oil, its cooling effect helps.

The non-pharmacological strategies used for preventative purposes included pacing activities such as spacing tasks with periods of rest between, improving sleep schedules, and staying hydrated. In addition, participants described avoiding migraine triggers they had identified. Katie explained:

I have also cut out MSG from my diet entirely and anytime that I am having processed foods like pepperoni, hot dogs, those tend to be a trigger as well. So, I have tried to avoid processed foods.

These triggers included bright light from screens, foods preserved with monosodium glutamate (MSGs) such as pepperoni, some red wines, loud environments, strong scents, weather fluctuations and sudden changes in barometric pressure, poor sleep, and stress. To avoid bright lights from screens some participants described dimming the brightness or using blue light protector eyeglasses or screen.

Stress was also frequently identified as a trigger for migraine among participants as Sonia explained:

I get more like mild headaches. They come more during times of stress I have noticed at work. So, like when I have a really sick patient or if a patient just coded, I find that after the fact headaches start to come up...Like I said stress triggers them [Migraine] for me...

Rowe explained: usually, it [Migraine] will come when I have some major event in my life coming up. So, like a big test or something like that. I am a very emotional person, so let's say if there's just something going on that I am really nervous or I'm excited or upset about ...whenever I start to calm down from my emotion is usually what will trigger it.

Participants described stress as having many tasks to carry out within a short period of time, high-intensity situations such as a day at work when caring for a complex patient with multiple medical challenges and an unpredictable outcome and situations involving managing multiple social responsibilities such as dealing with a relationship, children and work simultaneously. Participants reported managing stress through relaxation exercises such as yoga and pacing.

Participants also described managing acute migraine episodes by seeking social isolation as they manage their symptoms as Kathy explained:

I think like the worst part about them for me is like having to like to seclude myself. You know, because I just like, can't function with anything around me you know, so I'm going to lock myself away and even like shut off my communication.

Seeking a quiet space during acute episodes was a consistent strategy across all participants.

Participants described going into space with minimal light or noise stimulants, laying down and wanting to be left by themselves until symptoms are tolerable or relieved.

Learning as you go

Improved understanding of self, migraine symptoms, and management techniques was revealed through the participants' years of living with migraines. Participants described their ability to better identify and prevent migraine triggers and engage in activities that promote general health such as staying hydrated, and sleep hygiene that also helps prevent migraines. As Ella explained:

So, when I was younger, I had a little more time to just rest, lounge. I did not have as many responsibilities, so I didn't really do much for my headaches, I just kind of would rest and wait for them to go away. Now I do try, like I said I dabble the peppermint oil, those I find they help. Just little things that I mentioned already, I have been doing them so that I can cope with the headache and still go about my responsibilities. So, think that is kind of how it changed. I started to try to kind of use natural alternatives that work for me just to try to alleviate it so that I have more functioning.

Participants described increased interest in learning as a function of getting older and the awareness to improve their life as migraine is a lifelong condition. Establishing and building supportive relationships was at the centre of their learning experience. For example, Ethel recounted her conversation with her family physician below:

Having a family doctor that actually understands how debilitating the migraines and the headaches kind of changed the management. Because she was the one who was like let's try prescriptions. Let's try physio, let's try massage and ...the fact that she's willing to try different regimens and it did help.

Participants shared their migraine experiences with friends, family, their primary care provider, who also may have suggested or discouraged various strategies to assist participants in managing their migraines. Ethel explained:

One of my old employers, she was a migraine sufferer, so when I started experiencing the auras, I did reach out to her and asked her what her experience was when she has migraines and what helped her, and she is the one who told me about peppermint rollers...

Rowe also explained: Discussing with my neurologist, we've removed a bunch of things and obviously seen results. For example, for fluctuations in hormones, they put me on birth control for three consecutive months, rather than having a regular menstrual cycle to prevent fluctuations.

For some participants, knowledge about their management strategies was gained from family members such as parents who experienced migraines and perceived themselves as successful in their management techniques.

Technology as a tool for self-management

Most participants described using internet search engines to support them in regard to their migraines as a channel to information about migraine available online. A participant Katie, explained:

[...] I actually didn't know there was a migraine with an aura. I have always had migraines, but I didn't know that the visual disturbance came with that. No one has ever spoken to me that could happen. So I searched on google "zig pattern", "left peripheral vision" and the result was migraines with auras explaining the symptoms[...]I would search for images of migraines with auras and what the visual field would look like and there were many that came up that was exactly what I experienced[...]I wouldn't say I

went into any specific web pages, I would search everything and anything and I would read all of it and then just make an informed decision about what I was experiencing from there[...]I was just looking for that reassurance for myself more than anything else, I guess that's why I was going on the internet trying to make sure that it wasn't anything serious.

Another participant Ernestine, described:

I've used like a Google a lot like, especially before I started with my medication.

I'm just looking up other ways to get rid of it. Trying to prevent myself from using medication for it, so I find that I was on Google a lot trying to figure out stuff like that.

Intentionally seeking more knowledge about alternative management methods was a predominant theme among participants' stories. Participants acknowledged using technology as a tool to access information about migraine symptoms or potential strategies for relieving migraine symptoms. Participants who relied on technology for information primarily used a search engine such as Google to search for information related to migraine symptoms, triggers, or to learn about alternative strategies to managing their migraines. In addition, a few participants passively sought information through migraine-related content that comes up on their feed on social media pages such as Instagram, TIK TOK and Reddit. Katie explained:

So, on Reddit, I have found a lot of conversations about it [Migraine]. There was a conversation, where people would ask like a professional (a gynecologist) who spoke about recent research about hormones, the [menstrual] cycle and the influences on headache...So yeah it [Reddit] was not academic but it gave me some reassurance.

Participants also described relating to the experiences of others shared in social media which provided some reassurance to their experience. Few participants described using technologies

such as migraine tracking applications, electronic calendars on their mobile phone to track headache, symptom patterns, and to identify potential triggers based on recorded symptoms.

2.10.3 Living with an invisible condition

Participants described their experience as difficult to share with others or difficult to be understood by others because their condition was not always visible to others. These experiences are reflected in two themes: a) Feelings of not being understood b) It [Migraine] is very debilitating

Feelings of not being understood

Participants expressed personalizing their migraine experience and not wanting to share their experience with others. For example, Vanessa described:

...I think it's something that a lot of people don't necessarily always understand... So, I think it's one of those things that sometimes it's hard when you are already feeling that way and then on top of that then maybe, like the people that you work with, don't always appreciate, or understand that 'cause it's hard if you haven't had that experience yourself, right?

Ella also described a similar experience:

I would talk to people more that experience migraines. I think because, like I said in the past when I say I have really bad headaches and people will say like oh just take a Tylenol. I think it kind of dismisses how you are feeling. So, I don't really mention it to anyone other than like I said like my husband.

Participants perceived others to have a limited comprehension of the depth of their experience and suffering or the observed reactions from others to their experiences did not acknowledge their true experience of living with migraine.

Also, Sonia explained: In my own personal experience, I find it's usually men who don't get migraines are the ones that believe you the least and not very empathetic towards your experience. However, I find older women who have suffered migraines their whole life are usually the ones that are very empathetic of your experience which makes you feel validated because you can't ever prove to someone that I have a really bad headache right? it's not like someone can gauge by looking at you. It's not like a cut right?

Many participants recollected the sharing of their experience with others, or relying on them as support, as dependent on their perception of whether the other person responded with empathy. i.e., participants selectively allowed others into their migraine experience. As such participants selectively allowed others into their migraine experiences such as other migraine sufferers or those within their social support circles such as significant others, close friends, and colleagues.

It [Migraine] is very debilitating

A common theme was feelings of frustration towards the unpredictability of living with migraines. This is reflected in Eunice's experience:

So, really having migraines to me like what it means is...that it's very debilitating. I know that I've cancelled so many plans in the past that sometimes I feel bad [...] I honestly hate having migraines because there's a lot of things that I kind of feel like I missed out on...I have to think ahead like am I gonna get a migraine? I always have to pack extra things to manage my migraine if it were to come on. So, it's like I'm planning my life around having migraines as well, cause everywhere I go, I'll like pack like some medications or like non-therapeutic intervention kind of stuff like icy hot.

The inability to be able to predict when a migraine episode would occur often left participants in a predicament when planning social events or scheduling work. Participants used words like

frustration, scary, feeling debilitated, devastating and expressed the inability to focus on their activities and guilt because migraine interfered with their ability to carry on their lives and daily activities.

For all participants, the consequences of their pain transcended their physical suffering to impact their social sphere. The absence of pain was seen as the gateway towards gaining functioning and normalcy without interruptions from the migraines. As Sheila explained:

[A] couple [of] times recently within the last two months I've like thought about shaving my hair off because that even feels painful and I'm like I just don't wanna live in pain like this. So that I think would be the most distressing thing to me[...]

Sheila's experience was reflected in all other participants as they described pain or migraine headaches as the most significant and challenging symptom that impedes their ability to carry on their activities. Participants expressed navigating past migraine headaches as a priority outcome to their management strategies. The quality of pain was not only in its characteristic discomfort associated with the experience but also its unpredictability.

2.10.4 Negotiating the workplace

Participants describe days having to work while having an acute migraine episode. During this experience participants described how they go through a mental self-assessment process which includes assessing the severity of their symptoms, the availability of resources or supports at the time and their ability to manage these symptoms and go on with work. Participants' stories are reflected in three subthemes: stigma, developing resilience through suffering, and lack of formal workplace supports.

Stigma

Some participants described receiving negative stereotypic responses and attitudes from others regarding their migraine experience. As Ella explained:

So, I remember leaving work one time early. I remember coworkers saying “well if you have vision problems you shouldn't be driving”, which I agree with [...] I would never drive if I am currently having the vision changes. I remember that co-worker said, “as long as you're not just using that as an excuse to leave early”, and she said, “I remember one nurse who said they were having a migraine and said they couldn't see, then they drove home” overall, speculating whether they were even having a migraine or not. So that kind of got to me a little bit because I remember, I think I mentioned ...people just think well, she's just making it up or something, right?

These responses included the questioning of the authenticity of their symptoms and other remarks participants perceived also were dismissive of their lived experiences. Most participants described experiencing these negative connotations primarily in the workplace.

Another participant Ethel described

[...] I think it would be a problem if I called in sick as often as I need to. So, I work with severe migraines more often because I've seen it happen to other people. I've seen it and heard a conversation of, you know, this person oh they have migraines again. I think I function so much with mine being as bad as they are sometimes because I don't want to be the topic of conversation, I don't want to have the attendance management letters sent to me. It's a lived experience that I've seen other people go through.

An outcome of perceived stigma by participants was negotiating the disclosure of their symptoms at work. Disclosure was based on their perception of support from their colleagues and the organization.

Developing resilience through suffering

While at work participants managed their migraines by living through the experience while finding strategies to improve their symptoms so they could continue to work. As Sonia explained:

At work, like I mentioned, depending on the severity of the headache, depending on you know it's a lot of different variables depending on the headache, the staffing, the ability of how acute my patients are, depending on how able I am to go leave my patients for 20 minutes but sometimes you can't always do that. I'll go sit in the break room and just close my eyes.

Participants described relying on over-the-counter medications. As Ethel explained:

So, at work, I can't do things the same way I would do at home, but I do carry my peppermint roll with me in my purse, so I do have that at work. So, if I am experiencing a headache, I just quickly roll them on my temples, behind my ears, and then I have taken Advil at work before. Just kind of to get me through the day. Just to kind of alleviate a bit of my headache.

However, the goal of these strategies was not to completely relieve symptoms but to make symptoms tolerable so that the nurses could continue performing their role in the workplace.

Participants described some challenges with working while having a migraine episode. Ella explained:

It's very different because at work you're limited to what you're able to control in terms of your environment. But also, not just that, it's the amount of time you have available. I have also equally bad migraines sometimes. Let's say I'm at the bedside right now and in that particular role, if I have a bad migraine and in the environment that I

mean, my partner is busy and the person next to me is busy and there's an admission coming on, I don't have 30 minutes to go and sit somewhere and eat food. It's very common that I won't be able to go eat when I'm hungry or I won't be able to go drink water or when I feel like I need to do that in order to get a grip of my migraines or make my headaches better. To have the flexibility of being able to well, to do what I need to do is very different when I'm at work versus at home.

Participants found that at work it was not always possible to fully avoid their migraine triggers, or they did not always have the opportunity to engage in multiple strategies to prevent or improve their migraine symptoms like they would if they were at home. Participants described what considerations they made to return home or continue to work during a migraine episode. As Ethel explained:

Migraines come so unexpectedly, then you know there's that 'oh well she called in sick late'. But I have no control over that and so, I think of the nurses, the shift and the team aspect, and there's a bit of guilt that unfortunately I can't go to work and so I'm letting my team down.

Thora also explained: I had a migraine that came on one day, I did have to go home sick I remember, and it was because my vision started to change. So, I started to see black spots and was really foggy, I couldn't focus on anything and obviously, in a critical care setting, you have to be able to think critically, so that made me quite nervous. So, that was part of the reason that I did go home. Because I had a pretty sick patient, and I didn't want anything to happen to them. So yeah, I would say that itself is kind of scary.

As such, the decision to continue to stay at work or return home while experiencing an acute episode involved assessing their ability to provide safe patient care and feelings of guilt over perceived lack of dedication to service and colleagues.

Lack of formal workplace supports

Participants described supports at work to come from coworkers or colleagues and identified limited formal supports in place to assist them specifically with their migraine. As Rowe explained:

And I don't feel like I have any support at work for sure. Uhm honestly, I just keep going and it's not even like positive self-talk or anything. It's just I don't have any other choice and so I just keep doing my job like my co-worker will need help with a boost or I need to give that next medication, or I need to go talk to the family. There are really no supports. Like it's Tylenol, Advil, drink some water and just keep going and that's it. (

However, also, most participants had not informed their leaders about their migraines as they perceived they were managing their migraines well and did not find the need to search for any additional supports. Few participants identified supports to include organisational wellness programs such as ergonomic assessments, and occupational health services. However, they described these resources as beneficiary but not specific for their migraines.

2.11 Discussion

In this study I explored the experiences of living with migraines among nurses in Ontario with attention to their self-management experiences. Participants shared common experiences reflected in the three overarching themes including, i) self-management strategies, ii) living with an invisible condition, and iii) negotiating the workplace, that revealed new insights and supports beyond what is already known from the scholarly literature. These themes illuminated the need

for a more relational and person-centred approach to the treatment and support for persons living with migraines. Participants described self-management approaches to include both pharmacological and non – pharmacological strategies. The majority of the participants relied on non-pharmacological strategies for both prevention and management of acute migraine episodes which included self-management skills and the use of technology to access knowledge needed to self-manage their migraine. Participants also described how their experience of living with an invisible condition, experiences of stigma and the influence of their work in managing their migraines.

Self-management strategies

Participants in this study described relying on the ability to self-manage their migraines to cope with the debilitating nature of the condition. This finding reinforces the importance of self-management as an essential concept in chronic pain and chronic disease management. The patient is responsible for their daily care over the length of their illness (Lorig and Holman, 2003). The findings in this study elucidate the known challenges of under-treatment of migraines as all participants in this study described self-treating their migraines using multiple self-management strategies including both pharmacological and non-pharmacological strategies (Schroeder et al., 2018; Steiner et al., 2020; Heidari et al., 2022, WHO, 2016). In this study, participants described their self-management strategy as dependent on their context i.e., work or at home, the severity of their pain and their access to self-management strategies. Participants described improved pain relief with over-the-counter medications during acute episodes. Over-the-counter medications were used as first-line management for acute episodes at work.

At work, participants did not often have access to their other non-pharmacological strategies such as a quiet space or the ability to avoid noise triggers. Out of work, participants

generally relied on a combination of pharmacological and non-pharmacological strategies to relieve pain. Participants described improvement of their acute symptoms with over-the-counter medications, but not complete relief. These findings suggest that using a single self-management strategy did not always provide a relieve for symptoms of migraines. Similar findings were described by Chang et al., (2021) who reported that most participants also relied on multiple self-management strategies, including alternative therapies for migraine relief. The use of multiple self-management strategies to relieve migraine symptoms may indicate synergistic effects between pharmacological and non-pharmacological strategies in migraine management. The variation in self-management strategies with participants' contexts highlights the role of various spatiotemporal factors in the role of self-management. Chang et al. (2021) discussed the importance of cultural norms as a contextual factor that influences the preference between pharmacological and non-pharmacological strategies as they found participants in their study often relied on alternative or traditional therapies as first line of treatment during migraine acute episodes. Their study was conducted in China where the use for traditional Chinese therapy is a cultural norm.

The experiences of participants highlighted knowledge about migraines and the role of digital health literacy in the self-management of migraine. Participants in this study described using internet search engines such as Google to research for information about their migraines or to inform their self-management strategies. According to Lorig and Holman (2003), individuals require knowledge to be able to make decisions in response to the changes in their disease condition. Self-management interventions for chronic conditions incorporating educational resources for persons living with migraines have shown increased engagement and successful self-management outcomes (Patel et al., 2019; Probyn et al., 2017). Fewer participants in this

study described using technology to track their migraines or seek social support or collaborate with their health care provider. However, the use of digital technology such as mobile applications or web pages to track headache patterns, and migraine triggers to facilitate migraine diagnosis has been described in the literature (Pearson et al., 2019). Lorig and Holman (2003) described improved self-management outcomes with the support of web-based informational sources. Thus, existing evidence suggests that educational resources and technology are important resources that need to be integrated into health care delivery to enhance patient engagement in self-managing their migraines. Also, our participants were nurses who often have busy schedules and do shift work. The benefits of the adoption of mobile applications to facilitate documentation of migraine characteristics and facilitate communication is recommended among shift workers.

An established professional relationship of trust between the participant and their healthcare provider facilitated self-management strategy development as participants were able to explore unique options to find strategies that worked for them in collaboration with their healthcare provider. Participants without an established relationship with their health care provider relied on the internet for information or someone they considered knowledgeable within their social network, including an older family member with more experience in managing migraine. Befus et al. (2019) and Matthews & Kneipp (2020) reported similar findings in which women experiencing migraines relied on their physician, trusted family member or close friend from whom they learned their self-management strategies. However, these findings specifically highlight the importance of the development of trust in professional healthcare provider-patient relationships fostering self-management abilities for those living with migraines. Also, previous studies on persons living with migraines have identified the presence of social support as an

important strategy in the successful management of migraine symptoms and improved quality of life (Lui et al., 2020).

Living with an invisible condition

Participants found that the nature of the experience was often not understood especially by those who do not experience migraines. Participants also described feelings of frustration surrounding the unpredictability of migraines and having to plan their lives around their migraines. Nichols et al., (2017) reported similar findings in their systematic review in where participants described headaches as a driver of their behaviour including medication overuse or avoidance to plan events. Heidari et al. (2022) also highlighted lack of understanding of participants as a major theme. The findings of Heidari et al. also elucidated the unmet mental and emotional needs and the psychosocial burden of migraine on the lives of individuals. Studies have described poor mental outcomes with comorbidities such as depression and anxiety among persons living with migraines (Nichols et al., 2017; Martelletti et al., 2018). However, current migraine management strategies focus on preventative management and treatments for acute episodes reflecting a mainly biomedical understanding of migraine (Lui et al., 2020).

Participants described pain as the most significant and challenging symptom with psychosocial impacts on their life. The participants in this study described their experiences of living with migraines using words such as scary, frustration, and debilitating reflecting the emotional suffering associated with having migraines. Younas (2020) described the concept of patient suffering as a personalized negative response and a multidimensional experience that can threaten a person's physical, emotional, and psychological well-being. In this study, participants' experiences illuminate the need for a biopsychosocial approach to exploring the impacts of migraines and in its management. Relational practise as a biopsychosocial approach to healthcare

delivery for persons living with migraines allows healthcare providers to gain a deeper understanding of patients' experiences beyond recognizing physical suffering to understanding patients' emotional and psychological suffering (Younas). Relational inquiry requires the healthcare provider to critically examine the relational experiences of individuals which includes intrapersonal factors (i.e., factors within the patient and within the healthcare provider such as their beliefs or personal experiences), interpersonal factors (i.e., between and among the healthcare provider, the patient, and their environment), situational contexts and knowledge to inform their care models (Doane and Varcoe, 2021). Relational practice creates a milieu that facilitates communication, compassionate care, and person-centred exploration of the patient's needs (Younas).

Pain relief was the most significant outcome described by participants, which possibly explains participants the use of multiple self-management strategies during acute episodes to provide pain relief. According to Peters et al. (2004) patients would decide on management options and engage in self-management behaviour from which they expected to achieve the best outcome. Patients integrated their knowledge, experiences, and perceptions to make decisions about management strategies and to adopt behaviours that suited their individual needs and preferences (Peters et al.).

Negotiating the workplace

The workplace as a context that shapes migraine experience was consistent among all participants. Healthcare environments sometimes include potential migraine triggers such as lights, beeping sounds from patient monitor alarms and some complexities surrounding patient care may sometimes be stressful. Participants described how they negotiated the workplace to continue to function through migraine episodes. Participants described developing resiliency to

continue to work during acute episodes as they expressed potential feelings of guilt if they had to leave their workplace understaffed by returning home during an acute episode. From our findings the potential factors that may have influenced participants' decision whether to stay at work during migraine symptoms included personal factors i.e., perceived severity of migraine, perceived ability to manage symptoms and feelings of guilt or perceived stigma, and workplace factors i.e., available supports, workload and concerns about the ability to provide safe care. Participants who explained having to leave work during a migraine episode described severe symptoms that they perceived would have impeded their ability to work and provide care safely. The concept of presenteeism where individuals continue to work despite being sick or distracted by others' (e.g., family member) has been given lesser attention than absenteeism (Malmberg-Ceder et al., 2020). However, research suggests that presenteeism is highly associated with decreased health status and lower workplace productivity (Malmberg-Ceder et al., 2020; Wong et al., 2020; Shimizu et al., 2021). Presenteeism has been attributed to worsening health conditions of individuals and eventually leading to being absent from work. Similar to participants' experiences, barriers for persons continuing to work when sick has been associated to workload and difficulty finding replacement staff (Martinez & Ferreira, 2012). These findings echo the results from (Onwuekwe et al., 2014) who reported minimal disability, work absenteeism and loss of productivity time despite the high prevalence of migraine among healthcare workers in Nigeria. Similarly, Landy et al. (2011) reported low absenteeism related to migraine among persons living with migraine who work in healthcare settings in the United States. This current study contributes to the existing literature on the prevalence of presenteeism among persons living with migraine and the need to provide organizational work support for persons living with migraines.

Despite advances made in the neurobiological understanding of migraine, it's lack of obvious clinical signs still affects the social representation and understanding of migraines. In this study, we found that disclosure of migraine symptoms was influenced by the context. At work most participants described only disclosing their migraines to immediate colleagues in order to receive supports form them. However, most participants did not feel the need to disclose their migraine symptoms to the organizational management authorities as they felt they were able to manage their migraine without influence on their work. Conversely, few participants highlighted they did not fully disclose the severity of their migraine to their employer due to concerns about their job status being questioned.

The experience of stigma was mostly described within the context of the workplace. Participants also described both enacted and internalized stigma in this study. Participants experienced negative connotations and reactions from their colleagues questioning the authenticity of their symptoms. These findings add to the literature on stigma toward migraine patients (Shapiro et al; 2014; Young et al., 2013; Parikh et al., 2021). Studies also have described stigmatising attitudes toward persons living with migraines by healthcare professionals (Belam et al., 2005; Palacios-Ceña et al., 2017; Varkey et al., 2013). Participants described internalizing stigma and as a result, did not disclose their migraines at the workplace or continuing to work despite having an acute migraine episode. Research suggests that internalized stigma negatively correlates with the ability to work and increases with absenteeism (Young et al., 2013; Shapiro et al., 2014). As such, a migraine patient with higher functional ability might feel less stigmatized than someone with lesser functional ability (Young et al., 2013).

Participants in this study also identified a lack of organizational support and a lack of awareness of organizational supports regarding their migraine. It is possible among participants

that there is a bidirectional relationship between disclosure of their symptoms and their perceived lack of organizational support. Access to work compensation for time lost due to the debilitating nature of migraines continues to be a challenge for many persons living with migraines (Schroeder et al, 2018; Steiner et al., 2018). These findings highlight the ripple effect of the absence of migraines in global policy debates (Schroeder et al., 2018). The consequence is migraine is not recognised as a debilitating condition and thus it is not included in some social compensation policies (Schroeder et al., 2018). Although participants highlighted there are other supports such as wellness programs that promote overall health, they were not aware of any strategies directly for migraines. However, most participants described not disclosing their migraines to their managers or organizational human resources. As such more research exploring healthcare work environments and organisational supports for persons living with migraines can reveal greater insights into some structural implications for migraine management.

2.12 Conclusion

Some of these findings such as stigma and self-management strategies are similar to findings in the existing literature. Others such as resilience through suffering has added contextual insights regarding why workplace absenteeism is less among persons living with migraine. Findings describing the experience of living with an invisible condition also contributes to the literature; emphasizing participants experience of not being understood and their feelings of hopelessness. This study also has highlighted information technology as tool for self-management of migraine and suggested ways in which technology can be employed. This study has also provided more context to previous quantitative reports on the importance of workplace as a context when exploring migraine management approaches. The implications from

this study have the potential to inform new approaches to caring for migraine and have potential to influence new areas of research for caring for people living with migraines.

2.13 Limitations

This research has provided insights into the experiences of nurses living with migraines. However, I recognise that there are some limitations to this study and the need for more research on experience of living with migraine and self-management. One main limitation is the nature of the sample of this study. The participants in this study included female nurses from urban areas, who are English speaking, and majority worked in an acute care setting. As such the influences of various situational contextual factors such as geographic locations (i.e., urban areas or rural areas) or type of workplace environment (i.e., exploring acute care, community care, long-term care and virtual care settings) on the experiences of living and working with migraines could not be explored this study. More research exploring the experiences of nurses living with migraines across a diverse demographic is needed.

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Chapter Three

3 Implications

The purpose of this research was to explore the experiences of nurses living with migraines with particular attention to their self-management strategies. With respect to the findings, this research helps to increase awareness of the experiences of nurses living with migraines and their self-management strategies. The findings of this study illuminate the personal and psychological impact of living with migraine and demonstrated how nurses navigate work and life while self-managing migraine. The nurses also described a process of learning through their self-management experiences and highlight the need for social support through self-management of migraines. This study also reveals the use of information technology to support self-management of migraine as an underexplored area with a potential for improving self-management skills and access to knowledge. These findings can inform self-management interventions for migraine for workers and inform occupational health nurses in the assessments and care for workers living with migraines. In addition, the result of this research has important implications for nurses and may contribute to the holistic assessment and care for persons living with migraine by strengthening education, practice, research, and policy.

3.1 Implications for nursing education

The implications for nursing education stem from the perceptions of migraine as an invisible illness and experiences of stigma shared by the participants in this study. Stigma leads to inequitable access to healthcare resources and is associated with poorer physical and mental health outcomes among people who are stigmatised (Public Health Agency Canada, 2019). Lack of knowledge about a disease and its effects is described as one of the origins of stigmatising behaviours (Public Health Agency Canada, 2019). This has implications for nursing pedagogy to

include headache disorders into the nursing educational curriculum and explore these conditions using a holistic approach i.e., physiological, psychological, and sociological aspects of these conditions. Nursing education that educates nurses on stigma pathways i.e., how various types of stigmas (such as race, gender, mental health, and stigmatised diseases) intersect to create health inequities and engage students in self-reflective practices may challenge current beliefs about migraines and provide new and important knowledge to inform practice. Parikh et al. (2021) recommends educational programs or knowledge-based interventions targeting inaccurate stereotypes and challenging negative public perceptions and replacing them with facts. Within the academic setting, opportunities for experiential learning in the form of simulations, where nursing students interact with a person living with a stigmatised disease has been shown promote changes in negative attitudes (Parikh et al., 2021; Alipanopoulos et al., 2020). Alipanopoulos et al. (2020) described experiential learning as a pragmatic education that integrates lecture-type educational lessons with case studies, and opportunities for students to engage in critical self-reflective exercises to evaluate and challenge personal values and beliefs that may result to stigmatising behaviours. In experiential learning students, would interact with persons living with migraines and engage creating care plans. Some examples of experiential learning include internships for nursing students at headache care centres or simulations in nursing laboratories.

Migraine is a chronic disease and requires lifelong adjustments. Various chronic disease models exist and are composed of different elements to inform chronic disease management. Educating nurses about chronic disease models will stimulate critical evaluation of chronic pain models, enhance knowledge development with potential improvements to approaches to care strategies.

3.2 Implications for nursing practice

The knowledge gained from this study prompts nurses to reflect on current care approaches and to consider a relational orientation that is person-centred when caring from persons living with migraines (Doane and Varcoe, 2021). Study participants expressed feelings on not being understood and experiences of stigma among their peers. The Canadian Nurses Association (2017) Code of ethics for Registered Nurses emphasizes that nurses must abstain from judging, labelling, stigmatising or humiliating behaviours towards persons within their care and towards other colleagues and stresses the need to promote social justice. This finding has important implications for nursing that upholds a building trust and therapeutic relationship between the client and the nurse ensuring collaborative, open and non-judgemental dialogues and relationships for care. A relational orientation to nursing practice allows the nurse to care for and about the client and involves a critical assessment of the clients' experiences and the situational contexts that shape their experiences (Doane and Varcoe, 2021). It involves exploring interpersonal factors and intrapersonal factors that influence a therapeutic nurse client relationship (Doane and Varcoe). Employing a relational orientation to nursing practice when caring for persons with migraine will require the nurse and nursing colleagues to explore intrapersonal factors by engaging in critical self-reflection; examine their prior personal experiences and knowledge and question their prior knowledge and understanding of migraines (Doane and Varcoe). This would allow the nurse to challenge their personal beliefs and become self-aware of potential stigmatising attitudes that could interfere with their relationship with the patient.

Participants expressed feelings of frustrations and expressed a lack of understanding of their experience by the other. These findings elucidate the dominant biomedical model of migraine management which tend to focus on physical injury and disease. The participants

expressed how migraine impacts their physical, social, and professional life. To explore the impacts of migraine on one's life, nurses need to employ a biopsychosocial framework such as the social determinants of health that allow the nurse to investigate how various environmental, cultural, social, and political factors interplay to shape the client's experience. This framework of holistic assessment allows the nurse to develop a deeper understanding of patient's suffering and collaborate with the client to identify their unique needs. A biopsychosocial approach to patient assessment would aid occupational health nurses to assess the holistically the impacts of migraine on workers.

3.3 Implications for Policy

Enacted stigma and structural barriers challenge to access care and supports for persons living with migraines (Young et al., 2013). Participants in this study described stigma from colleagues and the absence of formal supports at the workplace. In addition, participants also described continuing to work despite having a migraine attack and some described having to leave work due to the severity of their symptoms. These findings add to the literature of presenteeism and absenteeism as contributing factors to the financial burden of migraines with important implications for the retention of healthcare human resources. Nursing leadership have advocacy and promotion of safe working environments as core principles. This study also highlights a need for the development of policies that recognise migraine and promote access to supports in the workplace for those experiencing migraines.

3.4 Implications for research

Study participants described using alternative therapies such as peppermint oil to help relief their migraine symptoms. Participants described using these alternative therapies often in adjunction with other self-managements strategies described in this study. The role of

complementary and alternative therapies in chronic pain management is a developing area and further research on its application and effectiveness in managing migraine symptoms is needed.

This study highlights how contextual factors such as the workplace shapes self-management experiences of nurses. Some authors have described the role of other factors such as culture in pain management strategies (Chang et al., 2021). As such research examining the influence of ethnocultural background in shaping the use of self-management strategies is needed to inform self-management interventions for persons living with migraines. Furthermore, research exploring the multiple diversities such as geographical locations (urban or rural environments) or various healthcare settings (i.e., acute care, long term care, home care and virtual care settings) and their intersection is needed to understand how these factors influence nurses' migraine experiences and self-management strategies. Research in healthcare workplace settings exploring the influence of migraines on presenteeism, quality of care and patient safety is needed.

3.5 Conclusion

This study employed interpretive description a practice-oriented approach and revealed practice insights into the self-management experiences of nurses living with migraines. The implications practice included a relational orientation and the consideration of the social determinants of health when caring for persons with migraines. Experiential learning was also highlighted as a strategy to reduce migraine stigma. Policy implications included the need for the creation of safe workplace environments and the development of policies to support persons living with migraines. More research on the use of complementary therapy and the role of various contextual factors that shape self – management experiences is needed. Other scholarly research with qualitative data collection approaches such as grounded theory, critical exploratory

approaches related to migraine self-management and their associated data collection strategies can further help theorise migraine self-management strategies and inform practice.

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Appendix A**Letter of Information and Consent Form****Study Title**

Self-management experiences among nurses living with migraine

Principal Investigator:

Lorie Donelle, RN, PhD
Associate Professor,
Arthur Labatt Family School of Nursing,
Western University
Contact: XXX

Student:

Marionette Ngole Dione, RN, MScN Candidate
Arthur Labatt Family School of Nursing,
Western university
Contact: XXX

Co-Investigators

Victoria Smye RN, PhD
Director and Associate Professor
Arthur Labatt Family School of Nursing,
Western University
Contact: XXX

Sponsor: Who is funding this study?

All costs are covered by the principal investigator.

Conflict of Interest

There are no conflicts of interest to declare related to this study.

Introduction

My name is Marionette Ngole Dione. I am a student in the Master of Science in Nursing program at Western University, and this research is being carried out to meet the requirements of a graduate thesis.

I am conducting a study about the experiences and perspectives of nurses who have migraines. You are invited to participate in this research study to learn about the experiences of female nurses who are living with migraines. Furthermore, I am also interested in your experiences on how you navigate life and work while living with migraines as well as the strategies you use to manage your migraine. You are invited to take part in this study because you work as a nurse in Ontario, are fluent in English, self-report migraines and have been living with migraine for at least three months.

Invitation and Study purpose: Why is this study being done?

The purpose of this study is to explore the experiences of female nurses navigating work and life while living with migraines and also learn about the strategies these nurses use to manage their migraines. Information from this study will help us understand how nurses manage migraines and can be used to improve resources and supports at work for nurses living with migraines.

Study procedures: what will happen during this study?

If you decide to participate in this study, you would be asked to participate in individual interviews with the researcher through Zoom telephone video call lasting about 45 minutes. The interview will be scheduled at a date and time of mutual convenience. The interview will be digitally audio-recorded, and the researcher will take notes during the interview. This information will be transcribed (i.e. written out) with your permission. You will be asked questions about your experiences and perspectives of living and working with migraine. You will be asked about the strategies you have employed to manage your migraine. Examples of questions you may be asked include: what does living with migraine mean to you? And how do you manage your migraine? You may choose not to respond to any questions. Should the need arise the researcher may request a follow-up interview. The audio-record of interviews would serve as primary data for this study. If you would prefer not to be audio recorded, you would not be able to participate in this study. You will be given a unique verification code during your initial contact with the researcher. Upon providing consent you will be provided with a link to some introductory questions about your migraine and demographic information. These questions should take about 5 minutes for you to complete. You will be asked to enter the verification code. This code ensures your data remains unidentified and helps to protect your privacy. The researcher will also send you a copy of the completed consent form through your email.

If you would like the information you provided during this study to be used for other research studies, please, consider providing consent below.

What are the risks and harms of participating in this study?

There are no significant risks associated with participating in this study. However, we realize talking about your experiences of living with, and managing migraines may be emotional. If

concerns arise during the interview, you may share them with the researcher. The researcher will also have resources for you to have access to trained personnel should need be. If you feel you need to talk to someone please, follow-up with your primary care provider or contact your local Canadian Mental Health Association (CMHA) support line to speak with trained personnel. Here is a link to assist you in finding a CMHA resource closest to you <https://cmha.ca/find-your-cmha>. If you are in the Middlesex region, here is the local CMHA-Middlesex support line number 519 601 8055 or 1 844 360 8055 for you to speak with trained personnel. This service is available 24 hours daily, seven days a week.

What are the potential benefits of participating in this study?

You may not find any direct benefits from your participation in this research study. The information you will provide us from participating in this study will help the researcher to learn about nurses' experiences of living with migraine and their self-management strategies. This information may help inform future supports and resources to nurses or other workers who are living with migraines. This information could also help inform future policies on providing appropriate accommodation for nurses or other workers living with migraines.

Voluntary Participation and can participants choose to leave the study?

Your participation in this study is entirely voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later.

If you decide to withdraw from the study, the information that was collected prior to you leaving the study will be destroyed provided you let the researcher know before the data analysis phase.

Confidentiality: how will the participant's information be kept confidential?

All the information you and other participants will provide will be kept confidential. Your identity and participation in the study will be kept strictly private. A secured Zoom link using the university's corporate Zoom will be provided to ensure only you and the researcher are participating in the interview. The interviews will be digitally audio-recorded, and the digital audio file will be encrypted and stored on a secured project site on the university's learning management system (OWL) drive which is protected behind the institutional firewall. The project site will be password protected. At the end of the consent you will be provided with a link to some introductory questions about your migraine and demographic information. You will be asked to enter a verification code that will be provided to you during your initial contact with the researcher. This code ensures your data remains unidentified and help to protect your privacy.

Only the researchers listed above will have access to the digital audio files. In addition, Western University Health Sciences Research Ethics Board has reviewed this application and may require access to identifiable study information to monitor the conduct of this research. Your name will not be recorded on digital audio records or notes. You will be reminded not to use real names during the interview. With your permission, the audio recording will be transcribed. This means that the words on the recording will be written out. Transcribed interviews will be stored on a

secured university-sanctioned server (OWL). Short quotes and interview passages may be used in published reports and presentations, but you will not be identified by name. Pseudonyms or pronouns will be used instead of your real names or anyone else mentioned in the interviews. The information you would provide will be retained for 7 years and we will be accountable to keeping your information secure and confidential as per Western University data protection policy. After this period all of your information will be permanently destroyed as per the information security guidelines at Western University.

While we do our best to protect your information there is no guarantee that we will be able to do so. The inclusion of your profession in the dissemination of the results may allow someone to link the data and identify you.

Study results

The findings of this study will be presented in the Western University library as a thesis. These findings may be presented in conferences in Canada or internationally and published in academic journal articles. If you are interested in having a copy of the published articles from this study, a copy can be sent to you either electronically or a hard copy by mail.

Are participants compensated to be in this study?

You will receive a \$5 electronic gift card in appreciation of your participation. If you do not complete the entire interview you will still be compensated with a \$5 gift card.

Whom do participants contact for questions?

It is very important that you understand that your participation in this study is entirely voluntary and based on a clear understanding. If you have any questions or would like further information with respect to this study, you may contact the researchers, Marionette Ngole Dione, at XXX or by phone at XXX or Lorie Donelle at XXX

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844-720- 9816, email: ethics@uwo.ca. The Research Ethics Board (REB) is a group of people who oversee the ethical conduct of research studies. The Health Science Research Ethics Board (HSREB) is not part of the study team. Everything that you discuss will be kept confidential.

This letter is available for download below for future reference.

Consent Form

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

I agree to be audio-recorded in this research.

YES **NO**

I agree to be contacted for a follow-up interview if needed.

YES **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research.

YES **NO**

I agree to have my other indirectly identifiable information such as professional title, general classification of workplace type (acute care or community, or clinic) used in the dissemination of this research.

YES **NO**

I consent to the use of my data for future research purposes.

YES **NO**

I consent to receive the completed signed consent form through email.

YES **NO**

Participant's full name: -----

Participant's signature: -----

Date (DD-MMM-YYYY) -----

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Signature: _____

Print signature: _____

Date (*DD-MMM-YYYY*) _____

Appendix B

Semi-structured Interview Guide

Establishing Rapport

Interviewer: Good (time of the day), thank the individual for participating, confirm participant meets eligibility criteria, review letter of information and consent form and document consent. Review participant's response to online questionnaire. Explain the interview process, respect for confidentiality and anonymity, clarify my role as researcher and not nurse [Confirm if the participant will like to proceed with the interview]

- 1) What prompted you to participate in this study?

Background information: migraine experience

- 2) Please, describe your experience of living with migraine?

Prompts:

- How would you describe your migraine?
 - How long have you had migraine symptoms and when were you diagnosed?
 - How has your migraine evolved over the last few years?
 - Headache characteristics: please describe the intensity of your headache at its worst and when it is not at its worst; location, frequency of migraine attacks in two weeks? How long does an episode last? What are some other symptoms you experience when you have migraine?
 - What triggers your migraines?
 - What aspects of migraine is most relevant to you?
- 3) How does migraine influence your daily activities (to access the intensity and impact of migraine - this could reflect their decision for various SM strategies)?
 - 4) What does having migraine mean to you?

Migraine self-management

- 5) How do you manage your migraine?

Prompts:

- Is your treatment prescribed or over the counter?
 - [So, you described taking prescription/over counter medications for your migraine] What other things do you do to help with your migraines?
 - How have these changed over time?
 - Have you tried using non-pharmacological therapies for your migraines?
If yes, please describe them
 - Have you ever seen a migraine specialist for your migraine?
- 6) What do you do to avoid migraines? or what are your thoughts when it comes to preventing migraines.

Prompts:

Are there other methods of preventing migraines that you are aware of and have no personal experience of?

- 7) Describe a day at work when you had a migraine episode.
- 8) Would your migraine self-management differ if you were at home or at work? Tell me how you manage your migraine in different settings.
- 9) Who do you share your migraine experiences with? Tell me about the conversations you have with your colleagues, friends or significant persons about your migraine (explores the social context).
- 10) Have you ever had any experience with discrimination at work? Would you have any supports at work as someone living with migraine?
- 11) How has the recent events of COVID -19 shaped your migraine experience?

Role of technology

- 12) Can you talk about any health technology platforms such as social media, google you have used specifically related your migraine?
- 13) Please, can you describe how you use social media or mobile applications in the context of your migraine?
- 14) How has the information you obtained influenced your experience with migraine?
- 15) How would you describe your experience in communicating with someone online?

Interviewer: Is there anything that I have not asked you that you would like to add in relation to your migraine experience. Also, if you think of anything else you would like to let me know in relation to the study or if have any questions, please do not hesitate to contact the me at...

I understand that sharing your migraine experiences may have been stressful if you feel you need to talk to someone please follow up with your primary health care provider or contact your local Canadian Mental Health Association (CMHA) support line.

Canadian Mental Health Association-Middlesex support line number 519 601 8055 or 1 844 360 8055 to speak with trained personnel in case they experience any emotional distress. This service is available 24 hours daily, seven days a week.

The researcher will use this link (<https://cmha.ca/find-your-cmha>) to assist participant in locating their closest CMHA support resource.

Appendix C

Migraine Symptoms and Demographic Characteristics of Participant

This section will explore your migraine symptoms.

- 1) What symptom(s) best describe your headache? Please, select all that apply.
 - a. Headache on one side of the head
 - b. Throbbing or pulsating headache
 - c. Mild intensity
 - d. Moderate intensity
 - e. Severe intensity
 - f. Other. Please, specify _____
- 2) What symptom(s) accompany your headaches? Please, select all that apply.
 - a. Nausea or vomiting
 - b. Discomfort or pain in the eye when exposed to light (photophobia)
 - c. Intolerance or increased sensitivity to sound (phonophobia)
 - d. Speech disturbances e.g., slurred speech, difficulty talking
 - e. Visual disturbances
 - f. Sensations of pins, needles, or numbness
 - g. Other. Please, specify _____
- 3) How long have you been living with migraine? _____
- 4) Have you consulted a physician for your migraine? Yes or No
- 5) Has your migraine been diagnosed medically? Yes or No

Demographic information

- 6) What is your gender?
 - Male
 - Female
 - Please describe if not any of the above _____
- 7) What is your age? _____
- 8) How would you describe yourself?
 - White
 - Black or African American
 - Asian
 - Aboriginal
 - Native Hawaiian or Pacific Islander
 - American Indian or Alaska Native
 - Latino or Hispanic
- 9) What is the highest degree or level of school you have completed?
 - a. Diploma
 - b. Bachelor's degree
 - c. Master's degree
 - d. Doctorate degree
- 10) What is your marital status?

- a. Single
 - b. Married
 - c. Common-law
 - d. Widowed
 - e. Divorced
 - f. Separated
- 11) How long have you been a nurse? _____
- 12) What is your current employment status?
- Full time
 - Part-time
 - Casual
- 13) Averagely, how many hours do you work weekly? _____
- 14) What option best describes the health sector you work in?
- a. Acute care or hospital
 - b. Community care
 - c. Ambulatory clinic
 - d. Other. Please specify _____

Appendix D

Ethics Approval from Western University, Ontario



Date: 26 January 2021
To: Dr. Lorie Donelle
Project ID: 116511
Study Title: Self-management experience of nurses living with migraine
Application Type: HSREB Initial Application
Review Type: Delegated
Meeting Date / Full Board Reporting Date: 09/Feb/2021
Date Approval Issued: 26/Jan/2021
REB Approval Expiry Date: 26/Jan/2022

Dear Dr. Lorie Donelle

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Semi structured Interview Guide, November 10, 2020	Interview Guide	10/Nov/2020	1
Research_Protocol_Migraine_Experience_Among_Nurses , January 10 2021	Protocol	10/Jan/2021	2
Online Questionnaire, January 10 2021	Online Survey	10/Jan/2021	2
Recruitment_Advert, January 10 2021	Recruitment Materials	10/Jan/2021	2
Research Participant Letter of information and Consent form, January 10 2021	Written Consent/Assent	10/Jan/2021	2

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
Reference_List_Rationale, November 10 2020	References	10/Nov/2020	1
Zoom Technology Risk Assessment report _Western Technology Services_Security and Zoom, January 10 2021	Technology Review document	10/Jan/2021	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

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Sincerely,

Patricia Sargeant, Ethics Officer (psargean@uwo.ca) on behalf of Dr. Philip Jones, HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix E

Curriculum Vitae

Name	Marionette Ngole Dione
Post-secondary Education and Degrees	Western University London, Ontario, Canada 2016 – 2018 BSc.N University of Buea Buea, Southwest Region, Cameroon 2007 – 2010 BSc. Biochemistry
Honours and Awards	Diane Y. Stewart Endowed Scholarship London Health Sciences Centre May 2022
Related Work Experience	Registered Nurse London Health Sciences Centre May 2018 to Present Research Assistant Western University, Ontario September 2020 – August 2022 Teaching Assistant Western University, Ontario September 2020 – April 2021 Clinical Student Preceptor London Health Science Centre September 2021 to April 2022

Publications:

Donelle, Hall, J., Hiebert, B., Shelley, J. J., Smith, M. J., Gilliland, J., Stranges, S., Kothari, A., Burkell, J., Cooke, T., Long, J., Shelley, J. M., Befus, D., Comer, L., Ngole, M., & Stanley, M. (2021). Digital technology and disease surveillance in the COVID-19 pandemic: A scoping review protocol. *BMJ Open*, *11*(10), e053962–e053962.
<https://doi.org/10.1136/bmjopen-2021-053962>