Migraine Self-Management: Pathways to Learning

By

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Abstract

Background: Self-management is the cornerstone of migraine management. How women learn to self-manage is largely unexplored. Women in lower social locations (i.e., those with lower income and education) are disproportionately affected by migraine severity and disability.

Objective: To explore pathways to learning self-management of migraine in women. Methods: Part of a parent study on migraine self-management, this exploratory portion of the study used semi-structured interviews to gain insight into perceptions of how women with migraine learn to self-manage their condition. Grounded theory and content analysis were used to analyze qualitative interview data in QSR International’s NVivo 11 Pro Software (2017). Results: Women model self-management strategies as well as agency in relationship to migraine that they saw trusted family members (i.e., trusted migrainers) use early in life. These learned behaviors and attitudes may contribute to the disparity in burden of migraine among women of lower social location. It is necessary for nursing to consider the generational and familial context in which women learn to self-manage migraine.

Keywords: migraine, self-management, agency, self-efficacy, locus of control, social location, learned behavior, pathways to learning, social learning theory
Migraine Self-Management: Pathways to Learning

Migraine prevalence and burden falls disproportionately on women in the lowest income bracket and with lower levels of education (Burch, Loder, Loder, & Smitherman, 2015). Self-management is the cornerstone of migraine management (Kneipp & Beeber, 2015). The purpose of the current study is to describe the self-management learning patterns in women of varying social location.

BACKGROUND

Migraine affects over 19% of women in the United States, with the greatest prevalence and burden on women of lower socioeconomic status (Burch, et al., 2015). However, the process by which these women learn to manage their migraines has been largely unexplored.

Women are affected at a rate 2.17 times that of men (Burch, et al., 2015; Buse, et al., 2013). Migraine is a leading causes of disability worldwide and costs the U.S. economy $13 billion each year in lost work (Brandes, 2009; Stokes et al., 2011). While these numbers are staggering, migraine remains underdiagnosed and undertreated (Jensen & Stovner, 2008; Lipton et al., 2007).

Migraine symptoms can be treated with acute therapies, however, frequency of headaches is best treated by way of behavioral methods and preventive pharmacotherapy (Lipton et al., 2007). Only 1 in 5 suffers report using prophylactics, which have been shown to reduce the occurrence of migraine by 50 to 80% (Lipton et al., 2007). More than half of individuals with migraine use over-the-counter medications or none at all to relieve symptoms (Burch, et al., 2015). Thus, the vast majority of migraine management is done by individuals
without the guidance of health care professionals. It can be deduced from the literature that most women coping with migraine do so by drawing on their own non-prescription medication resources and expertise to engage in migraine self-management (Lemstra, Stewart, & Olszynski, 2002).

Self-management is the foundation of migraine management (Kneipp & Beeber, 2015). The process of learning to self-manage, however, has not been described in the literature. While the research clearly indicates that women of lower socioeconomic status carry the burden of migraine disproportionately, management strategies by women of varying social positions have not been defined (Burch, et al., 2015). Stewart, Roy & Lipton (2013) reported that while migraine incidence is higher in lower income groups, migraine remission is independent of income. Thus, if effective interventions in the initial stages of migraine onset are learned, it may be possible to reduce the burden of women in lower social locations early on. In order to assess whether self-management strategies of women of these groups are contributing to the disparity, more research is needed. Specifically, research to describe how women learn self-management strategies and whether there are social and contextual factors that contribute to management styles that may be associated with adverse migraine outcome trajectories.

A wealth of prevalence and burden research on migraine exists (Burch, et al., 2015; Lipton, et al., 2007). Research on the management of migraine predominantly focuses on pharmacologic measures and acute symptom management (Burch, et al., 2015). However, a growing body of evidence investigates non-pharmacologic means of managing migraine in the interictal, or in-between headache, period (Lemstra, et al., 2002). The literature supporting behavioral interventions for the management of migraine is expanding. Cognitive behavioral
Therapy, relaxation methods, and biofeedback have all been shown to reduce migraine severity and duration in randomized controlled trials (Lemstra, et al., 2002). Of particular interest and importance, however, is what women are actually doing without health care or research intervention. The great majority of women suffering from migraine do not seek treatment from physicians, and only 48% of women who meet the diagnostic criteria for migraine have been diagnosed by a primary care provider (Lipton, 2001). To that point, women are self-managing with a potentially limited set of resources to effectively curb their migraine episodes, severity, and potential disability. The literature fails to describe the existence of strategies being used, and how these strategies are learned at the onset and adjusted over the course of the lifetime.

Grounded theory and phenomenological studies have been published describing women with migraine and their perceptions of living with the condition (French, et al., 2000; Peters, Huijer Abu-Saad, Vydelingum, Dowson, Murphy, 2003; Ramsey, 2012). However, these small descriptive studies have yet to incorporate socioeconomic variables or discuss the implications of income or education on the burden of migraine. Additionally, the use of terms to describe social position in the literature varies and provides minimal insight into the complexities involved. For the purpose of this study, the term social location, both higher (HSL) and lower (LSL), are used to characterize where women are located in the social hierarchy based on their income and education. The present exploratory study aims to begin creating a body of literature that more adequately frames migraine self-management within its sociocultural and economic context.

Social Location: Migraine Outcomes and Management
A concerning gap in the literature is the lack of research that considers the most burdened population by migraine, women of LSL. How women occupying lower social locations self-manage, how they learn self-management strategies, and whether their efforts are different than those of higher social location, has not been explored. While it is clear that women of lower income and education have higher prevalence and migraine severity, there has been little to describe how these women may be managing in ways that are unlike than other groups (Burch, et al., 2015). Additionally, when considering how people learn health behaviors, women who are born into LSL households may be predisposed to learning self-management strategies that perpetuate the disparity (Bandura, 1977; 2001). The impact of cross-generational burden is of particular interest in this report. Jensen and Stovner (2008) identified familial disposition, lack of secondary education, and high work load as risk factors for migraine. These, among other contextual factors, such as higher levels of stress, may be contributing to the disparity among women with migraine.

Relevance to Nursing Research

The National Institute of Nursing Research (NINR, 2010) has identified symptom management as a priority for future research in the field of nursing science. In order to move toward quality literature that describes beneficial and possibly harmful methods of symptom management in migraine, and whether these differences contribute to the adverse outcomes experienced by LSL women, it is necessary to take a closer look at the possible causes of the disparity in prevalence and burden. This can be accomplished by first examining self-management as it is learned by women of differing social locations. The literature is conflicted in
terms of whether this disparity is perpetuated by the social causation model – that is, does poverty, or lower social location lead to greater migraine burden – or does severe migraine lead to disability that perpetuates low income (Peterlin & Scher, 2013). In the current study, this notion is investigated using Albert Bandura’s Social Learning Theory (1977, 2001). Bandura posits that behavior is learned and modeled by others within one’s social context. Thus, migraine self-management and perceptions that are harmful or beneficial may be perpetuated generationally. The topic of learning self-management has not been addressed in the migraine literature. Exploratory and descriptive studies are needed to lay the groundwork for future research (Grove, Burns, & Gray, 2013).

METHODS

Data were collected from participants who took part in a broader, parent feasibility study entitled Migraine Self-Management: Feasibility of Collecting EMA, Biometric, and Biomarker Data (MSM). The MSM is part of a series of smaller-scaled pilot and feasibility studies research exploring relationships between three dominant modes of symptom management strategies and contextual stress, mood, depressive symptoms, and migraine-related functional limitations in socioeconomically disadvantaged women with migraine. The present MSM feasibility study aimed to gauge the viability of collecting many types of data in this population simultaneously, and for longer periods of time. These include ecological momentary assessments (EMA), self-report questionnaires, biometric data through the use of actigraphy, venipuncture for the analysis of the biomarker brain-derived neurotrophic factor (BDNF), and semi-structured interviews. The qualitative data gathered from interviews assessed two domains: (1)
participants’ acceptability of the data collection protocol and suggestions for revising, and (2) how participants recall their initial exposure to how others manage migraine headache events, and how they have learned to use select strategies for themselves. The second domain related to how participants learn to self-manage their migraine symptoms is the focus of this paper.

Study Sample, Data Collection, and Measures: Parent MSM Feasibility Study

In the broader study, all self-reported data were collected using a questionnaire administered and stored on the Qualtrics platform and sent to participants using SurveySignal text alerts (Qualtrics, 2018; SurveySignal 2015). These methods are briefly described below as they informed much of the qualitative analysis.

Participants: A total of 6 women were recruited, stratified by higher and lower levels of social location. All participants met the following inclusion criteria: (1) being between 18 and 50 years of age, (2) have episodic migraine as defined by the International Classification of Headache Disorders-II (ICHD-II) diagnostic classification, (3) report at least three migraine episodes on average per month that are not confined solely to days 15-28 of the menstrual cycle, (4) fluent in written and spoken English, (5) employed at least 20 hours per week, and (6) in possession of a smart phone capable of displaying ecological momentary assessment data collection tools using SurveySignal and Qualtrics platforms (Olesen & Steiner, 2004; Qualtrics, 2018; SurveySignal, 2015) Exclusion criteria included (1) being pregnant, within 6-months post-partum, or currently breastfeeding, (2) reported head injury in the past 6 months that resulted in loss of consciousness or new onset of headache with symptom features that differ from their typical migraine, (3) having had a stroke, (4) brain tumor, (5) arteriovenous malformation, or (6)
hypertension. Sample stratification criteria for enrolling women in lower social locations were defined by any of the following: (1) having less than a 4-year college education, (2) earning less than $16.00 hourly or salary equivalent, or (3) having received food stamps, Temporary Assistance for Needy Families (TANF), or public housing in the prior 2 years. Three participants were classified as lower social location (LSL) and three were higher social location (HSL). For the purpose of the interview data analysis, one LSL participant was moved to the HSL group. The reason for this was her current role as an undergraduate University student and her family’s history of education. While she qualified initially as LSL because she had not completed college and made less than $16.00 hourly, other contextual factors such as nearing completion of a college education led the researcher to re-assign her to the HSL group.

Participants earned a maximum of $120.00 US ($20 for each of 2 optional blood draws, $30 for each of 2 weeks of data collection, and an additional $10 for those weeks in which they wore the actigraphy watch for 90% of the time and answered 75% or more EMA prompts). Registration and enrollment were completed via Qualtrics (2018) using a computer or mobile device, after which participants signed an electronic consent form. The consent was reviewed and signed with paper and pen at the first in-person meeting with study personnel. A minimum of four in-person meetings took place with study staff and each participant. The first and last meetings, to include consent, venipuncture and interviews, took place in the UNC-Chapel Hill School of Nursing Biobehavioral Lab’s Observational Suite. The total length of participation ranged from 4.5 to 6 weeks, with a minimum of 2 weeks between intensive, week-long data-collection periods. The goal of the timeline was to collect data at different points on women’s
menstrual cycle and to assess the feasibility of 1 week of intensive data collection, repeated once over roughly a 4-6-week period.

Enrolled women completed eligibility questionnaires via Qualtrics survey software (2018) prior to consent which included demographic data and the creation of a 2-digit personal identification study ID. This study ID was used for all future surveys and EMA reports. At the beginning of each data-collection week, prior to beginning EMA data, participants completed a “baseline” questionnaire. This included items related to missed work due to personal health problems, family health problems, medications, self-management behaviors, health self-efficacy, depressive symptoms, the impact of migraine on several role domains (social functioning, family engagement, and employment), migraine symptoms (both acute and during the interictal period), and migraine triggers. Each participant completed two of these questionnaires.

Ecological Momentary Assessment (EMA) data were collected using text-alerts prompting participants to complete a very brief, 4-item EMA survey five times a day for 7 days, between the hours of 0800 and 2130. A reminder was sent after 5-minutes if there was no initial response, and the survey timed out after 30 minutes. During data-collection weeks, participants were also instructed to answer a series of questions related to their migraine symptoms and their self-management at the beginning of each acute headache “event.”

Basic gross motor activity, sleep/wake cycles, periods of rest and exposures to light were measured with Phillips Respironics Actiwatch Spectrum. The watch displays time and was worn 24-hours a day during the data collection weeks with the exception of time spent bathing or swimming. Research personnel retrieved the watch at the end of each week of data collection and downloaded data to software in the UNC-Chapel Hill School of Nursing Biobehavioral Lab
Blood samples were also collected to measure BDNF at the first and last in-person meetings. Participants were given the option of giving blood or skipping this aspect of the study. All six participants chose to take part in venipuncture. The principal investigator drew samples from the hand or antecubital vein using a small, 24-gauge butterfly needle and syringe, placed on ice and centrifuged in the BBL prior to storage for analysis. BBL personnel analyzed the samples at the end of all data collection.

Finally, and most relevant to the focus of this paper, at the final in-person meeting, a semi-structured interview was conducted. Interviews were audio recorded with the written consent of participants and downloaded onto a secure server for research data storage through the UNC-Chapel Hill School of Nursing. Interview questions were divided into two domains: study feasibility feedback, and pathways to learning migraine self-management. Henceforward, the focus of this paper is on the analysis and findings of the interview data related to the second domain: Pathways to learning migraine self-management.

Interview Data Preparation for Analysis

The principal investigator of this portion of the larger study (A.M.) was the primary contact person for each participant throughout the 4-6 weeks to completion. Prolonging engagement with participants prior to interviews allows rapport to develop and enhances the study’s validity and rigor (Morse, 2015). Audio recordings were transcribed in their entirety by the researcher and reviewed once before handing off to second reviewers to ensure accuracy. By transcribing her own interviews, the principal investigator becomes deeply involved in the interpretation of the content and develops detailed memory of the data and interviews which
aids in later analysis (Wellard & McKenna, 2001). To reduce bias and increase reliability, a second reviewer compared audio recordings to transcriptions for errors (Morse, 2015; Wellard & McKenna, 2001). Transcription content was divided in half, and a randomly-selected half was reviewed for errors by a second, independent reviewer. Guidelines for errors included checking for word omissions, word substitutions, or other errors. A maximum of 2 errors that did not alter the meaning of the text were deemed acceptable a priori. No transcriptions necessitated a full review by second-reviewers. The framework for interviews is summarized in Table 1.

Table 1

<table>
<thead>
<tr>
<th>Migraine Self-Management for Semi-Structured Interview: Interview Guide</th>
</tr>
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<tbody>
<tr>
<td>So now, I'm going to ask you to think back to when you were younger.</td>
</tr>
<tr>
<td>1. Did you have any people in your family or close friends that suffered from migraines? [IF YES - ask a.i., a.ii, and b. below; IF NO - move to Question #2 below]</td>
</tr>
<tr>
<td>a. How did they manage their headaches?</td>
</tr>
<tr>
<td>i. Can you tell me a little more specifically what they did, if you remember?</td>
</tr>
<tr>
<td>ii. Did they take any medication? Did they do anything else?</td>
</tr>
<tr>
<td>b. Did they seek any services from the healthcare system? What type?</td>
</tr>
<tr>
<td>2. How old were you when you had your first migraine headache?</td>
</tr>
<tr>
<td>a. Can you tell me about what you did to relieve the headaches at that time?</td>
</tr>
<tr>
<td>3. What are you doing differently now to manage your migraines compared to how you managed them back then, and why?</td>
</tr>
<tr>
<td>4. Over the whole period of time that you've had migraines, what have been the most important things that influenced how you try to relieve the migraines now?</td>
</tr>
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Thank you for sharing your experiences with self-management to these questions. Just a few more questions now, turning to your experiences during the study.

1. What were the most burdensome and the least burdensome aspects of the self-report questionnaires / actigraphy / venipuncture?
2. If you could change one thing about the study to make it easier to participate, what would it be?
3. Now that you know what the data collection is like in this study, would you agree to participate, and/or encourage your friends to participate, if we collected 1 week of data each month for 6 months (with only blood samples taken at 0 and 6 months)?

Interview Data Analysis

Coding and analysis was done in QSR International NVivo 11 Pro (2017) within the framework of Charmaz’s guide to grounded theory methodology (2006). Charmaz (2006) outlines initial and focused coding to begin the analysis of qualitative data. The first step in initial
Coding is a line-by-line method of naming content. This line-by-line, or as Strauss & Corbin (1998) refer to it, microanalysis, was performed on a sentence-by-sentence level in order to extract meaning from participants’ responses as well as increase the objectivity of the researcher. In addition to bolstering objectivity, microanalysis allows the researcher to pick up on details and nuances in the data that may be easily lost to larger themes if this detailed coding is skipped. The results represent the best fit to the data when this initial process of coding is carefully and systematically performed, thus enhancing validity (Charmaz, 2006; Morse, 2015). Next, focused coding consisted of formulating themes in order to encapsulate as many initial codes as possible. Focused codes are a more conceptual and synthesized form of the initial codes. For example, the initial codes “use of over-the-counter medication,” “meditation,” and “isolate,” can all be labeled under the focused code, “self-management strategies.” Focused codes were created until all initial codes could be accounted for. Finally, axial coding was used to develop a structure of relationships to a category. In the example, “self-management strategies” along with other personal approaches to migraine were re-coded to surround axes of “agency,” or perception of control. From the axial codes, a diagram was created in order to visualize the relationships among categories (see Figure 1). Charmaz (2006) goes on to describe theoretical coding to begin the process of theory development, which was not included in the current analysis, given more exhaustive data is needed to achieve that goal. Due to the limited sample size, saturation was not reached. That is, while it is possible that data were nearing saturation, as consistent patterns emerged, there is simply not enough content to fully construct a new theory (Charmaz, 2006).
FINDINGS

In the small sample of six women, two consistent patterns of phenomena emerged. Agency and lasting self-management appear to be largely informed by early exposure to a trusted migraineur. The trusted migraineur was typically female, always older and always within the family. That is, our data may suggest that both utilization of specific management strategies and perception of control may be passed down generationally in families.

Figure 1

Figure 1. Pathways of learning migraine self-management and agency. This figure depicts the central relationship of the participant and trusted migraineur and how self-management and agency are shared among them. While own research, trial and error, and health care providers may interact, they are peripheral to the impact the trusted migraineur’s self-management and agency has on the participant.
The participant and her trusted migraineur share migraine symptoms, a strong sense of trust, and space/time early in the life of the participant. Self-management strategies are learned by way of observation of the trusted migraineur as well as direct advice from the trusted migraineur. Agency, or the participants’ perceived ability to exert influence through her actions, appears to be closely linked with her trusted migraineur’s sense of agency (Bandura, 2001). Among women in the HSL group, it was not uncommon for participants to have engaged in their own research, trial and error, and asking health care providers about how to manage migraines. However, participants consistently circled back to those self-management techniques that were observed in or advised by the trusted migraineur. Of note, the two women from LSLs reported fewer alternative strategies, less sense of agency, and consistent use of taking medication and attempting to sleep in a dark quiet place. This method of “shutting down” was described in interviews as their only option when a migraine was imminent. They did not report any interictal behaviors to prevent migraines, where those from HSLs discussed “preventive strategies.”

The Trusted Migraineur

“My sister… she’s older… her knowledge of how to treat it helped me a lot when I started having them because... I thought something was wrong with me.”

Participants were asked about other people in their lives who suffered migraine, in addition to whom they sought for advice (health care providers, family, friends, and strangers). A theme of one particular person who had also suffered migraine that was the main source of support and learned behavior and attitudes arose. The researcher refers to this person as the
trusted migraineur, who in nearly all cases was a close, older, female family member. One exception was the father of a participant, whose grandmother had also suffered migraines. The participant discussed what she knew about how her grandmother managed, and what she did at the onset of her first migraine:

My grandmother was gone by that point... and my dad, after the first one I had, I called him and was like, “this is what happened to me, is this what happened to you?” And he was like, “Yeah, oh yeah, it’s exactly like that.”

The remaining five interviewees’ trusted migraineurs included a grandmother, older sister, and three mothers. While the three mothers and older sister were all present for our participants’ first migraine attack, the grandmother, like our previous participant, was not. One participant recounts her first migraine and how her sister found her:

She just actually... come in... was like, ‘What’s wrong with you?’ That kind of scenario... she helped me... telling me to lay down and cutting the lights off.

Each of the trusted individuals shared symptoms and early exposure to the participants. Whether present for the onset of migraines or not, the women interviewed spent a significant amount of their early lives with the trusted migraineur. In addition to time and space, they shared a great deal of trust and compassion with their trusted migraineur. Speaking about her mother’s pain, one participant says:

Can you imagine? ... She’ll be okay. God has already shown me what he’s going to do for her, and she’s going to be okay.

To summarize, four of six participants reported their trusted migraineur was present during their first migraine attack, one notified their trusted migraineur immediately following the initial
migraine, and one did not report this information. All shared symptoms, space, time and trust. There were no apparent differences between women in higher and lower social locations and the relationship with a trusted migraineur. The differences between social location arise when analyzing perceptions of control as well as specific management strategies.

Advised Self-Management

“My mom would ... tell me to do exactly what she did.”

Women interviewed shared that their trusted migraineur told them specifically how to manage their migraine symptoms. Regardless of social location, the advice was overwhelmingly to do just as they did:

My mom takes Excedrin Migraine... and pushes through it. [For my first migraine, I was] probably around 9 or 10... my mom gave me Excedrin. And said here take this. It will help. 15 minutes you’ll be all better. And so that’s what I continued to do. Anytime I had a migraine... I definitely push through. It’s the way [she] taught me.

One participant, when asked what her father told her when she called him about her migraine, said, “He didn’t have too much to offer except... that his went away eventually, and that it sounded very similar.” This particular participant may not have been told directly how to manage by her trusted migraineur, but evidenced in her manner of self-management, learned by observation.

Observed Self-Management

“She shuts down. She goes into her room. Lights out.”
Every participant did not share with the principal investigator whether they were directly
told how to manage their migraines by their trusted migraineur. However, each participant
discussed their observations of the trusted migraineur during a migraine. For some participants,
this was years prior to the onset of their own migraines. However, these behaviors are modeled
in the participants’ preference for self-management. Take one example, a participant from HSL
who spent summers with her grandmother who had migraines when she was a toddler and
school-aged. She recounts:

I would see her take a lot of pain relief medications... she would always try to drink coffee
to kind of use caffeine as a reliever... I think she’d try and balance it out as much as she
[could]... she wasn’t taking medication every day, so I think it was kind of like an acute
relief kind of thing... there were times that she’d just kind of sit quietly, just kind of like – I
guess meditating. I just didn’t know what meditating was when I was little.

Although the participant clearly indicates that her grandmother was using medication, caffeine
and meditation to manage her migraines, when asked question 4 from Table 1 in addition to
follow-up questions, what have been the more important things that influence how you manage,
she listed “trial and error... I try multiple things and I’ve also sought solutions... online... what
options are there, talk about it with [my doctor].” However, the self-management strategies that
she highlights in her interview as the most used are identical to her grandmother’s strategies: “I
do meditations... I try to drink coffee... using caffeine as an alternative from the pain
medications.” While she utilizes many techniques, those she uses most consistently are what she
saw her grandmother use at a very early age. Self-management strategies by the trusted
migraineur and participants are broken down in Table 2.
As depicted in Table 2, all six participants reported using identical or similar self-management strategies as those they were exposed to either at an early age by their trusted migraineur, prior to their first migraine, or whom was present at the onset of their first migraine. A few participants discussed a “trial and error” approach to self-management, but all inevitably rely again on the strategies modeled for them during their early exposure years. Of note, the two LSL participants reported taking medication and sleeping in the dark as their only option for managing migraine, excluding caffeine or “eating something.” “You know, [it gets] worse, because you know you can’t – you have to shut down,” one LSL participant explained.
Agency

“I couldn’t do anything. I couldn’t do anything other than take medicine.”

In the current study, findings related to agency are consistent with those described by Albert Bandura as “direct personal agency” (2001). Bandura (2001) discusses the “bidirectionality of influence between social structure and personal agency” (p. 6). Agency consists of intentionality, forethought, self-reactiveness and self-reflectiveness (Bandura, 2001). Intentionality means simply that agency refers to intended actions. For example, a woman with migraine intentionally drinks water as often as possible. Forethought guides individuals’ actions by planning for the future to optimize positive outcomes and minimize detrimental ones. In the example, the woman brings two bottles of water with her when leaving her house because she knows she will be without access to water for several hours. Self-reactiveness refers to internal motivation and self-regulation. That is, not only the ability to plan and think ahead, but the capacity to carry out activities and goals because of personal standards, or morality. Bandura (1991) calls this aspect of self-reactiveness moral agency. The woman who drinks two gallons of water daily does this because it may inhibit migraines, and her personal aspirations necessitate working extremely hard every day. She does drinks water to avoid migraines in order to avoid missing work days due to her internal drive, or moral agency. She was taught by her “no-sick-days-family” to “push through.” Her internal motivation to be a high achiever, as she learned from her social context, motivates her to act as an agent in her life with regard to her migraines. Finally, and perhaps most relevant to the research question at hand, agency includes self-reflectiveness. Bandura (2001) describes this as a “metacognitive capability to reflect upon oneself and the adequacy of one’s thoughts and actions” (p. 10). Within the domain of self-
reflectiveness lies self-efficacy, or the belief in one’s own ability to exert control over oneself or the environment (Bandura, 1977). Self-efficacy is central to agency, and has been described in the literature as it relates to migraine and pain (Bandura, 1982; Fenwick, Chaboyer, & St John, 2012; French et al., 2000). In the example, the woman drinks water to prevent migraines because she inherently believes that she has some measure of control over her own body and the environment in which she finds herself. In the present study, this aspect of agency – self-efficacy – is a key difference between women from HSLs and LSLs. Participants displayed varying levels and aspects of agency. Four participants discussed their migraines and the management of symptoms and interictal periods with agency. All four of these were classified as being from a HSL. On the other hand, the two LSL participants described their relationship to migraines with much less sense of agency.

Possessing agency. The avoidance of triggers or preparing for the inevitability of triggers may be classified by possessing agency. For example, one participant from a HSL explains:

*I think one of the triggers might be changes in humidity and temperature and things like that so I try to avoid, like if I know that I’m going to be outside for a long time I’ll try to like make sure I bring extra water, and go inside, and cool down every once in a while... so I guess that’s a preventative measure that I take... and then there’s other things that I know like they might cause a headache like if I don’t eat for a while... or if I’m going to go to... something that’s really loud and... stimulating... sometimes not go, but for the most part, just be aware that if I feel a headache coming on it’s probably going to progress into something worse. It’s hard to tell because I feel like I still don’t have it down pat. Like, I know this is a migraine, or I know this is a trigger... I’m still trying to figure that stuff out.*
But I know... generally like they seem to kind of be synced up with my periods, and things like that, so in that kind of sense... but for the most part I’m still trying to figure out everything.

The process described includes all four aspects of personal agency: intentionality, forethought, self-reactiveness and self-reflectiveness (Bandura, 2001). While this participant has not yet “figure[d] out everything,” she possesses the agency or self-efficacy to believe she can figure it out and is working toward doing so. She appears to be exhibiting agency that she saw modeled by her trusted migraineur.

**Lacking agency.** On the other end of the spectrum, the two LSL participants showed less agency than their counterparts. One displayed some intention, forethought and action:

* I stay out of the sun. Even on vacation, I know what my limit is. You can feel it coming on.
* And it’s time to go back in... when it starts to come on, I need to go ahead and lay down.

The same participant expressed a desire to do more to prevent her migraines:

* I wish I knew, how to prevent them, you know? And I’ve looked into like trying to research it myself and there’s really just – [shrugs shoulders] – it’s out there... I wish I would – what do I need to do or what do I need to eat? That’s what I feel like – like my body is needing something – I don’t know what it is.

Here, the aspect of agency, self-efficacy, is evident. She perceives her self-efficacy, or the “power to produce effects” by her actions as possible, but struggles with diving further into problem-solving and the belief that she can find the answers, or that there are solutions, to cope. Bandura (2001) describes self-efficacy as impacting other determinants and beliefs in individuals’ lives, such as whether one is optimistic or pessimistic. These beliefs are then self-enhancing or self-
hindering. The participant describes some self-efficacy, but perhaps not enough to inhibit the self-hindering mentality that may dominate (Bandura, 2001). Her descriptions of her self-management and attempts to find solutions indicate a greater level of agency than the next participant, who also identifies triggers, “the stress would contribute... dehydration, sunlight, stress, all of it.” However, this participant describes a more passive relationship with migraine self-management, and less agency in terms of finding more effective approaches: “Take the medicine and lay down until it kicks in no matter what you have to do.” Recalling an experience with her reverend two weeks prior in church, she said:

...he lined us all up, and I felt God was there, and before he got to me, like three people down he said “migraines” – he said migraines! – “Somebody’s gonna be healed of migraines” – I said, “Lord, is that me?” And he came and touched me. With that one finger. And I felt an inferno... it was so hot. It felt it was cleaning me up of something. So I have not had a migraine since... God is good.

In this account, the participant describes her migraines being removed, and later discusses how neither she nor any health care professional could help relieve her migraines:

...for my headaches? I don’t think they could have figured out what was wrong with me...

God didn’t touch my head, he touched this [neck, chest, back]... I’m sure nobody would have been able to figure out what was wrong.

Her descriptions of management prior to this event, “I couldn’t do anything. I couldn’t do anything other than take medicine,” and her experience with God removing her migraines, exemplifies a lack of personal agency as well as external locus of control. External headache locus of control (EHLC) is the belief that migraine development and progression of symptoms is
outside of one’s own control. Internal headache locus of control (IHLC) refers to the belief that one’s behavior has an impact on headache progression and severity. EHLC has been linked to greater disability and higher migraine-related quality of life impairments (Grinberg & Seng, 2016). Consistent with social learning theory which states the two perceptions are related but distinct, the participant displays low self-efficacy as well as external locus of control (Bandura, 1997). The participant’s experience at church was not intentional or displaying forethought – she did not go to church to see this reverend in order to have her migraines relieved. Nor did her management style prior to the event contain forethought, intention, or actions and self-reflection. She describes her relationship to migraine as though she is a prisoner to them, as she said, “I was married to it and didn’t know it.” In light of the experience at church, she is still not the agent in the situation, rather, God is. She displays external headache locus of control.

**DISCUSSION**

The sample size of the current study is small but the findings that have begun to emerge are compelling. The consistent learning pathway for participants with migraine was this: the young participant is exposed to a family member with migraines, their trusted migraineur, observing their demonstrated agency and how they self-manage. Later, the participant experiences her first migraine. Either her trusted migraineur was present with her (in 4 cases) and tells her explicitly what to do, or she called on them immediately following the episode (1 case). In all cases, she describes her current management style as nearly identical to the behaviors observed when she was younger, whether directly making this connection herself or not. Women from HSLs discussed doing their own research online, talking with friends or others who have
migraines, and seeing health care providers for their migraines. The two women from LSLs took fewer actions related to problem-solving in between headaches. Their disposition related to migraine was describe with more passivity. Regardless of these additional strategies for seeking solutions to their migraine, participants came back to similar migraine management techniques as their trusted migraineur.

The complex mechanism of learning self-management behavior can be framed within Bandura’s social learning theory. Social learning theory encompasses the cognitive processes of the learner (to include agency) that is filtered through a sociocultural context (Bandura, 1977, 2001). Bandura postulates that behavior is learned by way of example, symbolically stored in memory, and mediated by external factors as well as cognitively. These data support Bandura’s process of learned behavior. The data suggest that observations of the trusted migraineur and their response to pain and migraine are engrained in the participants’ mind. Then, with years of experience and reassessing one’s own response to different behaviors, are reinforced as the strategy to fall back on. We found that women self-manage in the same or similar ways that they saw their mothers, grandmothers, and sisters self-manage. We also found that women modeled similar agentic behavior as their trusted migraineurs. Participants from HSLs had higher levels of agency, which has been shown to correlate with more positive coping styles (French et al., 2000). Participants from LSLs described less agency related to their migraines and used a more passive self-management approach during headaches. Low self-efficacy has been linked to greater migraine disability (French et al., 2000). When considering the implications of these findings for women in LSLs, it is clear that this may contribute to disparities we see in migraine
burden, particularly when we include the type of self-management we found in women occupying LSLs.

Recent and ongoing pilot studies by the principal investigator of the parent MSM study have uncovered a group of self-management strategies including consistent use of medication and sleep that correlate with worse depressive symptoms and functioning in between headaches (Kneipp & Beeber, 2015). As indicated in the data presented, these are the exact self-management strategies being used by the two women from LSLs. Research is currently being proposed to further examine this link and its relationship to social location. While not yet conclusive, further investigation into the role social location plays in determining self-management strategies and perceived agency are needed. As the data suggests, women from LSLs appear to possess less agency as well as possibly display more external loci of control. In women with migraine, lower self-efficacy and external locus of control are correlated (French et al., 2001). If agency and self-management strategies are passed down generationally in women, the implications for the migraine burden falling heavily on women from lower social locations are great. Generation after generation of self-hindering perceptions related to migraine as well as detrimental self-management strategies may only compound the greater disability burden we see in less advantaged groups.

Relevance to clinical practice

Nursing may use this qualitative analysis to gain deeper understanding of the pathways to learning self-management and strengthen clinical practice. Identifying women from LSLs and looking for aspects of agency may assist in better management of migraine. If clinicians are able
to pinpoint which clients lack the perceived control over their migraine management, they may educate and implement effective interventions. Sensitivity to the impact that family and particularly older women in the family play in health can strengthen assessments and proposed interventions in the nursing profession. In addition, understanding these links may help clients identify areas for improvement or change. For example, a woman who has migraine and saw her mother self-manage by “shutting down” may be doing this herself. In the clinic, perhaps her nurse does a careful assessment of her migraine-related agency, self-management and pathways to learning (how her mother managed). The nurse explains the possible generational link between self-management styles and the potential correlation with other negative health consequences such as depression. The client has a daughter of her own, and motivated by her drive to improve her daughter’s health, she may show greater willingness to engage in self-efficacy improvement interventions or health behavior interventions. Nurses may be empowered to confront the perception of agency as well as specific management styles that may be self-hindering. Open and honest conversation about motivations behind health behavior can be to the benefit of the client and generations following. Using identified ways to improve self-efficacy and self-management, clinicians can play a key role in empowering women from lower social locations with migraine to better manage their condition, and contribute to the health of our current and future populations.
References


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