



Perceptions and Needs of Patients With Migraine

A Focus Group Study

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■ **OBJECTIVE** This study's purpose was to identify the areas that people find most difficult in living with migraines and, in that regard, what kinds of assistance would be most helpful to them and to other people who have migraine headaches.

■ **STUDY DESIGN** Four focus groups, each consisting of 4 to 8 participants, were held. Discussions, which were recorded and organized according to category and theme, focused on problems in living with migraines and effective treatment of migraines.

■ **POPULATION** Participants were 24 people who had been experiencing 1 to 2 migraines a month, each lasting 1 to 2 days, for at least 6 months.

■ **RESULTS** Five themes emerged: (1) impact on family, (2) misunderstanding by others, (3) effect on work, (4) physician care issues, and (5) issues related to medical insurance and drug companies. A majority of participants identified early treatment as the most important consideration for new migraine sufferers. Many participants preferred to have a relationship with their physicians in which they developed a treatment plan together rather than receiving generic educational materials.

■ **CONCLUSIONS** Results suggest that patients are interested in understanding their migraines and securing relevant information in addition to obtaining pain relief. Patients desired collaborative relationships with their physicians and a team approach to treatment. Suggestions for physicians who treat patients who have migraines are reviewed.

■ **KEY WORDS** Migraine; focus groups;

KEY POINTS FOR CLINICIANS

- Migraine sufferers said they would prefer a collaborative relationship with their physician and a team approach to therapy.
- Patients reported that they often felt dismissed by their physicians, frustrated by insurance and drug companies, and misunderstood by their loved ones.
- Participants said early treatment of migraine headaches should be emphasized for new migraine patients.

physician-patient relations. (*J Fam Pract* 2002; 51:142-147)

Twenty-five to 30 million people in the United States have migraine headaches. Of these, approximately 11 million are moderately to severely disabled by their attacks,^{1,4} resulting in significant lost labor costs,⁵ substantial health care expenses,⁶ and a pervasive negative impact on overall quality of life.

Although migraine is a highly treatable disorder, almost one half of people who have migraines are not currently under the care of a physician for that condition.⁷ Further, data from the American Migraine Study II, sponsored by the National Headache Foundation, show that those who have received a diagnosis suffer at a level similar to that of those who have not. This finding suggests that effective migraine management depends not only on diagno-

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TABLE 1

IMPACT ON DAILY LIFE

Impact on family

"I'm not the mom I wanted to be. I'm short-tempered, and I don't like that. They [family members] all try to leave the house [when I have a migraine]."

"Being at home, I pretty much run the show. So if I'm not up and going, the show's not going. The show shuts down."

Impact on social activities

"Gradually, things are taken away from you. Like you can't even walk down the street on a sunny day because the sun will give you a headache."

Impact on relationships

"I think people look at you like, 'Yeah, right, everybody has headaches. They're not that bad; just get a grip and keep going.'"

Impact on work

"I always stay at work [when I have a migraine]. I try to look productive, but I'm only doing half. You get a reaction if you tell [coworkers]. After about the fourth headache in 2 months, they just don't buy it."

sis but also on ongoing treatment. The opportunity exists to reduce the indirect costs, disability, and impairment associated with this disorder. However, the primary care physician has a pivotal role in the management of migraine.

The aim of this study was to identify: (1) the areas that people who have migraines consider most problematic in living with their headaches and (2) the types of physician assistance they believe would be most helpful in managing this disorder.

METHODS

This exploratory study used a focus group format to identify topics of concern to people with migraine. Although this format has inherent limitations, its use in health science research has gained considerable acceptance in recent years.⁸⁻¹⁰ Focus groups are recognized for their ability to identify issues of the greatest importance to individuals.¹¹

The Institutional Review Board of Ohio University, Athens, Ohio, approved all procedures used in this study. Names of potential participants were obtained from a list of people who had responded to community-wide advertisements recruiting subjects for a separate headache study conducted by 2 of the authors (K.A.H. and F.J.O.). Telephone screenings were reviewed to identify those with 2 to 8 migraine days per month by self-report. Of the 59 patients

contacted, 24 attended a focus group. (The remainder did not meet criteria, were uninterested, or had transportation or scheduling difficulties.) Two thirds of the sample had 1 to 3 migraines per month. The remainder of the sample experienced more frequent migraines. Every participant met International Headache Society criteria for migraine with or without aura and had migraine as the primary headache diagnosis. Only 2 patients indicated a history of occasional tension-type headaches. All had consulted a physician about their headaches, with 60% presenting to their primary care physician exclusively and the remaining 40% consulting a neurologist at some point. Attendees were given a \$30 incentive for their participation.

The groups were conducted by a moderator (C.K.C.) and an assistant (S.E.W.) using an interview guide. Eight questions were addressed during each meeting: (1) What is the biggest problem you have encountered in trying to manage your migraines? (2) What is the most important lesson that you have learned in trying to manage your migraines? (3) Where did you get your ideas regarding how to manage your migraine headaches? (4) Where and how do you think would be the best way to get information? (5) What types of information or skills do you think would be most useful to you and others for managing migraines? (6) (Of the information gathered) what topics do you think are most important? (7) If topics had to be eliminated, which ones could go? and (8) What other advice do you have for us?

The moderator elicited comments from quieter participants by specifically inviting their views on discussion topics. To prevent the opinions of especially verbal participants from receiving undue attention, the moderator probed for differing experiences from other group members. Each discussion took approximately 2 hours.

All sessions were audiotaped and transcribed. Transcripts were read independently by 2 of the authors (C.K.C. and S.E.W.), who arranged comments into categories and themes. Disagreements were resolved by mutual agreement and validated by 2 other authors (K.A.H. and F.J.O.). Typical statements were selected for inclusion in this report.

RESULTS

Participants' comments on migraine management fell into 6 primary categories. Representative comments are provided in Table 1.

Effect on Social Functioning

Group discussions indicated that all aspects of social and recreational activities were hampered by

migraines. In particular, avoiding food triggers was reported to be difficult because in some situations, there was no way to determine whether the food had been prepared with additives that might trigger a headache. This was an especially difficult barrier because food often plays a central role in social activities.

Effect on Family Functioning

Although participants regretted, and sometimes resented, being unable to participate in social activities because of their migraines, the effect on family, particularly children, was especially troublesome. Many participants felt they were less available and less understanding as parents as a result of migraine-induced irritability, feeling emotionally and physically drained for days after a migraine, and feeling “drugged” from taking medications.

Further, being forced to place restrictions on their children’s activities left many parents feeling that they and their children had been “cheated” by the migraines. Many participants expressed guilt about their inability to prepare meals, help with homework, or complete other routine household chores. Finally, some were frightened at the possibility that they might have a migraine when away from home but still retain responsibility for caring for the children. Both the migraine itself and the medication used to treat it left many feeling they should not drive, even when they had no alternative.

Effect on Work

The predominant emotions evident during discussions of job functioning were fear and guilt. Most participants expressed apprehension about the possibility of losing their jobs if they missed work because of their migraines. Those who went home with a migraine reported lost pay or fewer vacation or personal days to enjoy when feeling well. Thus, participants reported often trying to “just keep going” in spite of the headaches. These efforts contributed to lost productivity, feelings of guilt for not carrying a fair share of the workload, and, in some cases, decreased pay because of failure to meet job quotas.

Effect on Relationships

Participants’ comments suggest that others’ reactions to migraines are associated with shame, anger, and frustration. Most participants verbalized an unwillingness to tell others when they were experiencing a migraine, reporting that people were unsympathetic. The consensus was that most people dismissed migraines as insignificant and “think you’re embellishing it.”

Issues Related to Physician Care

Some group members were happy with the medical care they received. Identified as important behaviors were a physician’s willingness to consider alternative treatments, to “sit down and listen,” and to “pull out a book and look it up.” However, significant frustration related to medical care was evident as well (Table 2). The most emotionally laden issue in this category was the feeling of being “dismissed” by physicians who did not appear to take complaints of headache pain seriously. Some participants reported that they had endured years of frequent migraines since allegedly being told to “live with it” by a physician.

The majority of group members perceived that they had to take responsibility for researching new treatment options, including medications and alternative therapies, and to take suggestions to their physicians. Some, especially women considering pregnancy, were dissatisfied with a perceived emphasis on drug therapy. Many participants were concerned about possible long-term complications from taking potent medications and believed that their health care providers addressed their concerns inadequately.

Problems with Insurance and Drug Companies

A great number of participants expressed anger with

TABLE 2

ISSUES RELATED TO CARE
<p>Physicians’ failure to take migraines seriously “I remember the first doctor I went to. He said, ‘Oh, just take a couple of Tylenol and go on with it.’”</p>
<p>Desire for referral “When you go to a clinic and they can’t help you, it’s like you’ve fallen off the face of the earth. Where do you go from there?”</p>
<p>Undesirable focus on medications “I don’t want to be on a bunch of drugs. But they’re not willing to do anything else. If you can’t treat it with a chemical, you can’t treat it. Forget it!”</p> <p>“I worry about getting pregnant. I’d like to make sure I have a healthy baby, so I don’t want to pollute myself. What if I’m already pregnant? Should I take a pregnancy test before I take my [name of drug]?”</p>
<p>Issues with drug companies “I can’t afford to pay \$75 to treat a headache, so sometimes I go without the medication. I only use it if it’s a severe one with the nausea and the vomiting.”</p>

insurance and drug companies, viewing them as barriers to effective treatment. They were frustrated by “the bureaucrats” in managed care companies who mandated their choices of physicians and medications. This situation was particularly infuriating for those who had spent significant time and effort finding a physician with whom they felt comfortable or a medication that worked for them, only to be told that because of a change in insurance coverage, they had to change physicians, medications, or both. The primary complaint about pharmaceutical companies was the steep cost of medication.

DISCUSSION

It is important to note this study’s limitations. The focus group format is an effective method for soliciting issues of greatest importance to the individuals in attendance, but does not provide information on the prevalence of those opinions in the population. Because patients experiencing up to 8 migraine days per month were included in the study, our sample may have included those who had obtained insufficient relief from treatment and were, therefore, dissatisfied with that treatment. The information provided in the discussions may have been influenced by the fact that individuals who volunteer to participate are likely to have different views from those who do not participate in such groups. The small sample size limits the authors’ ability to generalize about these findings. Thus, the experiences and views reported here cannot be considered representative of all migraine sufferers. Finally, patients report interactions with physicians as they remember them. In some cases, their recollections may not reflect the true nature of the interactions.

Nonetheless, these participants resemble the migraine sufferers most likely to seek headache treatment. The typical participant in this study, a white female aged 25 to 49 years who experiences 1 to 2 migraines per month, each lasting 1 to 2 days, is a counterpart to the migraine patient seen in the primary care setting. In fact, 60% of participants had consulted only in the primary care setting. Thus, the experiences and opinions reported here might be typical of migraine patients who present management difficulties for primary care physicians. Being aware of these patients’ concerns may help physicians provide more effective treatment and improve patient satisfaction.

Focus group members reported migraine-related concerns across a range of life experiences. These concerns can be divided into 2 primary categories: (1) impact of migraines on daily functioning and

(2) perceived barriers to effective care.

The impact of migraines on quality of life has been well documented.^{2,5,12-20} Previous studies have shown that the bodily pain, nausea, and vomiting that occur during attacks result in impairments in job and role functioning.²⁰ Migraines have also been shown to interfere with family and with social and recreational activities⁵—resulting in less pleasure in life and less energy between attacks—and to disturb sleep.¹⁸

Many of the problems of daily life that are encountered in experiencing frequent migraines, as reported by study participants, result from perceived barriers to treatment. Lipton and colleagues⁷ described 3 levels on which barriers occur: the failure of migraine sufferers to consult physicians, failure to receive correct diagnoses in those who do consult physicians, and failure of correctly diagnosed patients to receive effective therapy.

Participants’ comments reveal a fourth level on which barriers to effective migraine management can occur: correctly diagnosed consulters for whom effective treatment has been prescribed but who are unable or unwilling to implement the prescribed treatment. Among focus group participants were individuals who had consulted a physician, received the correct diagnosis, and obtained what is generally accepted as effective treatment. Yet some experienced difficulty in implementing that treatment.

Comments by group members indicate several factors that can interfere with a patient’s ability to follow treatment recommendations. For example, avoiding known dietary triggers by consistently identifying preservatives and additives used in food preparation can be arduous. In addition, the high cost of abortive medications may make it difficult, and in some cases impossible, for patients to buy such medications, especially if they do not have prescription insurance coverage. Insurance companies’ limits on the types and amount of medication covered and on which physicians a subscriber may see can also interfere with effective migraine management. In addition, behavior patterns among migraine sufferers may interfere with obtaining effective therapy. Examples included patients’ reports of their reluctance to “accept that the migraine is coming” and take the necessary steps to ward it off.

Finally, participants indicated that dissatisfaction with the perceived attitude of their physicians had contributed to their lack of treatment follow-through. Attendees reported a perception that some physicians do not understand their problem or take it seriously. These findings are consistent with those of a previous study with migraine patients,²¹ as well as

studies with other health care consumers, both healthy and ill.^{22,23}

Recurring themes of fear, anger, and frustration were associated with both the impairments in quality of life and perceived barriers to effective care. However, while participants were eager to discuss the pain, functional disability, and management problems associated with migraines, they denied emotional distress. This denial is surprising, considering the emotional charge obvious in many of their statements (eg, "I'm not the mom I wanted to be," "I feel like I'm letting everybody down") and the important role that emotional distress plays in chronic tension-type headaches.²⁴ Possibly participants did not differentiate emotional distress from the physical disability caused by migraines or were inclined to emphasize pain and disability but minimize emotional reactions in an effort to legitimize frequent migraines as a serious medical problem.

Participants' comments suggest interventions that could be taken by physicians to improve their understanding of patients' headaches and needs and to develop the collaborative relationship that people who have migraines appear to desire.

First, physician behavior in response to migraine concerns is important. Patients want their physicians to indicate that they are listening and taking their concerns seriously *before* offering treatment. One means of indicating understanding is to reflect the concerns that the patient has expressed (eg, "It sounds as if these headaches are really interfering with your daily life, your work, and taking care of your children") and to ask the patient what he or she expects treatment to achieve. Such an exchange could initiate a mutually beneficial collaborative relationship: The patient feels understood and heard while the physician gains a better understanding of what the patient desires in treatment. Ultimately, the result may be greater success with therapy.

Physicians should listen for clues related to the severity and impact of headaches on patients' lives. A patient's complaint of "headaches" might inadvertently be dismissed unless the physician determines whether the headaches are actually migraines and the extent to which they interfere with daily life.

Consistent with other findings,^{25,26} the patients in this study seemed to be as interested in being offered the time to ask questions about headaches and medications as they were in obtaining pain relief. Some people who have migraines need general information about migraines and migraine management. Maintaining brochures from the National

TABLE 3

SELECTED INTERNET RESOURCES FOR MIGRAINE MANAGEMENT

Evidence-based guidelines for migraine headache, American Academy of Neurology Web site

<http://www.aan.com/public/practiceguidelines/01.pdf>

American Council for Headache Education (ACHE)

www.achenet.org

National Headache Foundation (NHF)

www.headaches.org

Headache Foundation, the American Council for Headache Education, or the American Headache Society in waiting rooms and directing patients to these resources may be helpful. However, generic information is merely a first step in meeting patients' needs. Periodically reviewing the patient's headache diary with an eye for patterns, possible triggers, and responses to treatment can provide the basis for a specific, individualized migraine management plan.

Providing abortive drug samples so that patients can determine whether a medication is effective and tolerable before paying the high cost of a prescription is extremely helpful for many people, especially those without prescription insurance coverage. Participants in this study and others^{21,22,27} also want physicians to maintain an open mind with regard to complementary and alternative treatments for migraine. This is especially the case for women in their reproductive or child-rearing years, who may be concerned about the side effects and risks of medications.

Time constraints may make these ideas difficult to implement. Migraine patients may require a longer appointment or may need a second appointment if the complaint is voiced as an afterthought during an unrelated visit. Working as a team, however, the physician and patient can do a great deal to reduce the disability and cost associated with migraines.

The understanding of migraines and the availability of tools to aid in their treatment have increased considerably in recent years, particularly with the advent of the Internet (Table 3). This information is useful only when both physician and patient are involved. Future studies should focus on developing a greater understanding of barriers to effective migraine management and efforts to eliminate them.

CONCLUSIONS

Results of this focus group study suggest that people are interested in understanding their migraines and

securing relevant information about it as well as in obtaining pain relief. Participants desired collaborative relationships with their physicians and wanted a team approach to treatment that involved both physician and patient.

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