

Psychological Impact: The Personal Burden of Migraine

Based on a presentation by Alvin E. Lake III, PhD

Presentation Summary

Migraine patients are among the most dissatisfied groups of healthcare consumers. An intractable minority of headache sufferers accounts for the majority of this dissatisfaction, as well as for the majority of the headache-related costs to the healthcare system. A tertiary plan of multidisciplinary care for this refractory group of migraine patients—perhaps 1 in 5—has been shown to be both clinically and economically effective. Primary benefits include improve-

ment in quality of life, quicker return to work, and reduction in acute-care interventions. Managed care administrators need to be aware of their current costs for treatment of intractable migraines, as well as the potential gains in terms of member satisfaction and reduced overall treatment costs associated with a multidimensional and flexible treatment program. In some cases, this program will include biobehavioral therapy, which has been documented in many studies to be effective.

A Tale of Two Migraines

(with apologies to Charles Dickens)

It was the best of times.

It was the worst of times.

It was the age of serotonin 5HT₁ agonists.

It was the age of analgesic rebound and medication abuse.

It was the epoch of nonpharmacology.

It was the epoch of noncompliance.

It was the season to function heroically.

It was the season of disability.

It was the spring of hope.

It was the winter of comorbid depression.

The past decade has witnessed an exponential growth in understanding the neurophysiology of migraine, leading to more effective treatments. However, clinicians (and those who pay for their services) must keep in mind that migraine reflects a spectrum of illness with widely ranging personal burdens. Migraine can range from occasional, easily controlled attacks in a healthy person, to increasingly frequent, severe, and disabling headaches, with several interrelated comorbid medical and behavioral conditions. The full range of the disease spectrum—and the necessity for stratified treat-

ment—becomes clear when we consider basic questions such as:

- What are patients looking for in treatment?
- How satisfied are migraineurs with care?
- What is the impact on quality of life?
- How vulnerable are these patients to stress?
- What are the psychological comorbidities?

What Patients Want, But Don't Get

Formal surveys indicate that most patients seeking treatment for migraines are looking for understanding of their pain in addition to pain relief.^{1,2} An explanation of the pain and reassurance is rated by patients, including children, as more important for migraine than any particular type of treatment.¹⁻³ In one survey, approximately one third of patients clearly expressed a preference for drug-based treatment; one third preferred non-

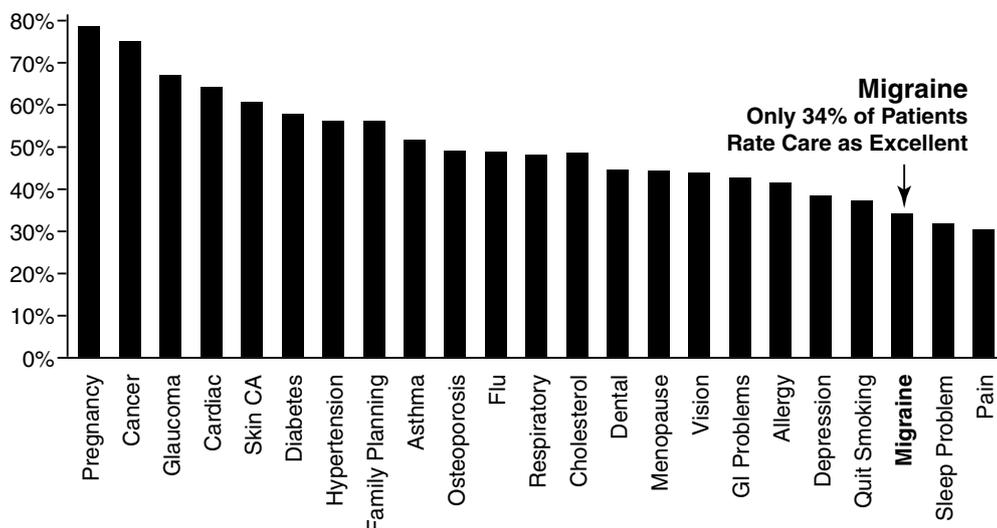
drug treatment, and one third indicated no preference.¹

Informal questioning of patients with chronic, intractable migraine in our inpatient Headache Pain Treatment Unit has further defined patient needs. When asked what they wanted (in addition to pain relief) from their primary care physicians, the most common answers were variations on the following:

- “Believe me that I have pain.”
- “Don't dismiss my pain.”
- “Don't blame or judge me.”
- “Don't give up on me.”
- “Admit your limitations.”
- “Refer me to an expert if necessary.”
- “Don't snow me with ineffective medications.”
- “Involve my family.”
- “Don't tell me it's all in my head, or that stress is the cause.”

Given this long list of expectations linked with migraine treatment, it is not surprising that many patients are dissatisfied with their headache care.

Figure 1. Perceived Adequacy of HMO Care, 1998



Source: Adapted from Jacob JA. Can't get no satisfaction? *AMA News: Medical Markets* 1998;41:34(Sept 14).

A 1998 CareData survey of patient perception of care received in HMO settings found that while most patients were highly satisfied with treatment for conditions such as pregnancy, cancer, glaucoma, and cardiac conditions, only about one third of patients rated headache care as excellent (Jacob JA. Can't get no satisfaction? *AMA News: Medical Markets* 1998;41:34(Sept 14). (Figure 1) This was approximately the same level of satisfaction seen with depression, a common comorbid condition.

A less formal survey of 70,000 in *CONSUMER REPORTS* magazine had similar findings, with 23% of respondents saying they were dissatisfied with their care for chronic headache versus dissatisfaction rates of less than half this for heart care, prostate problems, and cancer (*CONSUMER REPORTS*. How is your doctor treating you? *CONSUMER REPORTS* 1995;60:81-88.) (Figure 2). In fact, when 16 common conditions were ranked in order of dissatisfaction, headache was at the top of the list.

Clearly, many migraine patients are demanding more attention from their managed care providers. For a sizable minority, these demands are not being met. One study found that about 60% of patients reporting with migraine in a primary care setting remained impaired at 1 year.⁴ About 20% were still impaired at 2 years. It is this intractable minority that accounts for most of the economic burden to society, including lost workdays and school absences. In fact, the major share of the direct costs of treatment and medical utilization is contributed by a minority of migraineurs—those with high frequency, severe headaches in combination with comorbid illness.⁵ This also holds true for indirect costs. For example, only 20% of a population-based sample accounted for 77% of the lost workdays due to migraine,

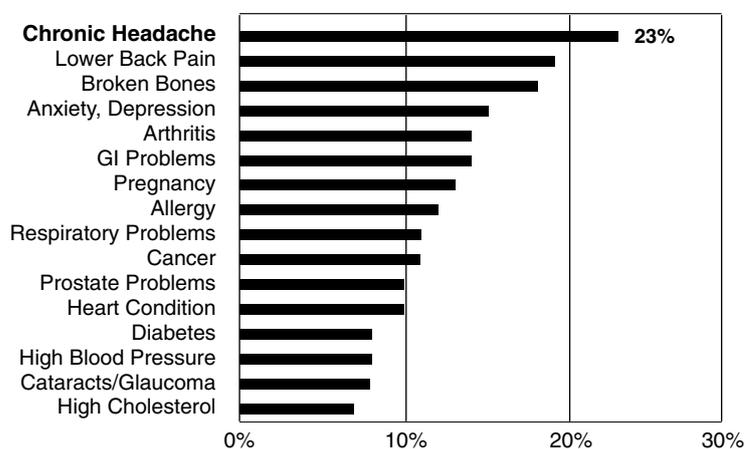
and 40% accounted for 75% of the lost workday equivalents based on reduced work efficiency.⁶

For this minority of migraine patients, a tertiary care model needs to be developed. To create that model, a full understanding of the multidimensional aspects of the disease is required.

The Stress Factor

The genetic component in migraine pathophysiology is strong.⁷ Headache triggers can vary significantly from person to person. Still, stress has long been recognized as a significant provocative factor. One widely recognized survey of the mid-1980s found that 50% of the general population reported stress to be among the top 2 or 3 triggers of headache.⁸ Most respondents in this survey said stress led to headache

Figure 2. Dissatisfied Health Consumers, 1995. *Consumer Reports* Survey of 70,000



"How is Your Doctor Treating You?" Copyright 1990 by Consumers Union of US, Inc., NY 10703-1057. Adapted by permission from *CONSUMER REPORTS*, February 1995.

more often than it led to menstrual pain or back pain.

Diary-based studies of migraine support the stress-as-trigger concept. For example, in a 2-month study of migraine, more than half (54%) of classical migraine attacks were preceded by stress.⁹ Smaller studies have also documented more “hassles” in the 4 days prior to migraine than in a comparable headache-free period,¹⁰ and a correlation between the intensity of stress and migraine occurring 1 to 3 days later.¹¹

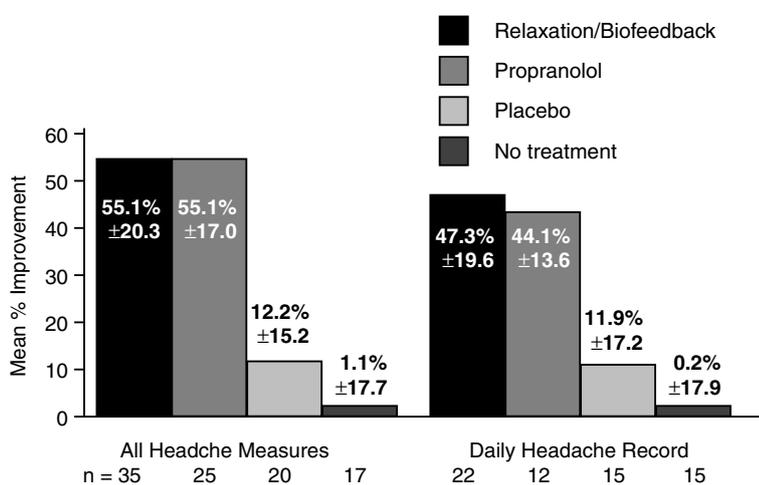
In the Michigan Head-Pain and Neurological Institute, patients have attributed about 45% of their headaches to stress,² either alone or in combination with other events. However, only about 8% said stress was the primary cause. One in 5 patients said stress played no role whatsoever in their headaches.

In a pediatric setting, 68% of children and adolescents reported ten-

sion was almost always a trigger or aggravator.³ In fact, stress was more frequently named a trigger than other commonly identified migraine instigators such as loud noises, missed meals, and bright lights.

Over the longer term, stress may also play a role in the emergence of migraine in a vulnerable individual. In a controlled study evaluating the 5 years prior to severe headache diagnosis, researchers found a significant increase in major life change in the year prior to headache onset.¹² The most common stressors were death of a close family member (25%), serious illness or injury in the family (21%), or a major personal illness (18%). In contrast, this increase in stressful life changes was not observed in patients with other neurological disorders. Similar findings have been noted in adolescents, with major family stressors such as illness, separation or divorce, or family moves preceding the emergence of a significant headache problem in some cases.¹³

Figure 3. Meta-analysis of Experimental Studies



Source: Adapted from: reference 14.

Efficacy of Behavioral Treatment

Given the established role of stress in the eruption of migraine pain, interest in the potential for relaxation-based treatments is to be expected. Several studies have documented the efficacy of behavioral therapy in migraine, even as part of an entry-level program. One meta-analysis shows a general improvement of about 50% for the combination of relaxation and biofeedback in treating intermittent migraine, a level comparable to propranolol.¹⁴ In contrast, prophylactic placebo medication led to only a 12% reduction in headache (Figure 3). When biofeedback is combined with propranolol, controlled studies show improvement rates between 70% and 74%.^{15,16} For the simplest cases, minimal contact approaches with structured treatment manuals were effective.

In addition, about 62% of those on the combined therapy actually were able to discontinue the beta-blocker at the end of one study.¹⁷ This included patients with both migraine and tension-type headache. The combination of biofeedback with propranolol and amitriptyline led to greater improvement (76%) than any other combination of the three treatments.¹⁶ When delivered in a highly structured format with clear homework expectations and aggressive follow-up, the number of sessions required can be minimized while maintaining similar rates of improvement.¹⁷ Similar positive results have been reported for pediatric and adolescent patients.¹⁸

Diminished Quality of Life

Questionnaire-based studies have found that quality of life among those with migraine is lower than for healthy individuals with no chronic disease.^{19,20} This holds true for all levels of migraine severity,²⁰ for males and females, for all ages,²¹ and even for the time periods between migraine attacks.²² Quality of life with migraine has been rated as comparable to that following recent myocardial infarction or congestive heart failure.²² It has been ranked worse than the quality of life following back pain, depression, osteoarthritis, or diabetes.^{20,22}

In children, the prevalence of frequent or severe headaches is ranked fifth of 17 chronic conditions. However, in terms of subjective distress during each episode of illness, headache ranked first.^{23,24} The fallout from this migraine pain in childhood has been measured in terms of school absence²⁵ and poor school performance during migraine (37%).²⁶ School problems were identified in 46% of the patients between ages 5 and 17 in one pediatric practice, and were more common than vomiting, dizziness, or neurological

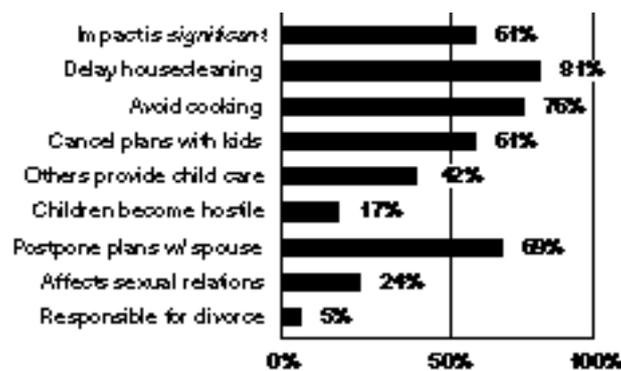
phenomena commonly associated with headache.²⁷

A large randomized study of 4000 individuals, 350 of whom had migraines, showed the disease also has a significant impact on the entire family.²⁸ As shown in Figure 4, about 6 of every 10 migraineurs reported such an effect. For example, 4 of 10 needed to seek outside help for child care while even more needed to alter daily housecleaning and cooking chores due to the disease. One of 10 families cited migraine as a primary reason for separation (5%) or divorce (5%).

Comorbidities and Consequences

Clinicians should be aware that migraine patients tend to have high levels of comorbidities, and that treatment choices should therefore be guided by the specific disease mix manifested by individual patients. Comorbidity increases in those with more frequent and severe headaches, and is associated with increased disability.²³⁻²⁵

Figure 4. Impact of Migraine on the Family: Random Sample of 4000 (350 migraineurs)



Source: Adapted from reference 28.

Depression and anxiety are two of the most common psychiatric conditions associated with migraine. In one large study of young HMO members, migraine patients had a lifetime prevalence of major depression 3 times higher than those without migraine.²⁹ In 55% of these cases, the migraine came before the depression and in another 16%, the diseases emerged together in the same year.³⁰

In the same study group of health plan members, the lifetime prevalence of anxiety disorders among migraineurs (including phobias, panic disorder, generalized anxiety, and obsessive-compulsive disorders) was double the normal rate.²⁹ These trends in comorbidity have been replicated internationally for migraine.

The connection between depression and migraine has also been noted in adolescents. One long-term epidemiologic study of young people between 11 and 21 years of age found that 1 in 10 had chronic headache sufficient to prevent normal activity. When those with chronic headache were reassessed 7 years later, 24% met the criteria for major depression. Further, those identified as having major depression in adolescence had a 10-fold increase in risk for migraine or chronic headache within 7 years.^{31,32}

Borderline personality disorder is another psychiatric diagnosis that has been associated with migraine. Individuals with this disorder display a constellation of problems, including affective mood swings, self-injurious behavior including suicide attempts, impulsive/reckless behavior, and an internal sense of emptiness. These people can shift from very gentle demeanors at one moment to angry, difficult-to-manage behaviors the next. One study of 112 sequential patients undergoing psychiatric evaluation who were diagnosed with borderline personality disorder found the overall prevalence of severe headache

to be 60%—about 3 or 4 times higher than might be expected based on epidemiological data in the general population.³³ Documented cases of migraine in this study were associated with histories of suicide attempts, violent outbursts, and substance abuse.

Rates of attempted suicide are also higher in migraine sufferers than in the nonmigraine population. One study reported a suicide rate of 15.6% in migraineurs versus 2.5% in a reference population.²⁹ In those patients with combined migraine with aura and major depression, the suicide rate was 38.5%. These extremely high rates are congruous with data projections showing higher rates of completed (ie, “successful”) suicide in populations with chronic pain (23.3 per 100,000) versus the general US population (13/100,000).³⁴

Given the diminished quality of life associated with headache pain, and the increased likelihood of conditions such as depression and anxiety, an increased likelihood of addictive behavior in this population may not be surprising. Epidemiological research has found higher-than-usual rates of smoking, alcohol addiction, or dependency, and illicit drug use in HMO members with migraine.²⁹ Further, one study found that 21% of primary care patients were probably overusing headache medications.³⁵ Such medication overuse can lead to iatrogenic progression of the illness through the mechanism of analgesic rebound.³⁶ In such cases, attempts at prophylactic medical or behavioral treatment remain ineffective until the patient is withdrawn from the overused medication.

Multidisciplinary Management for Patients with High-Acuity, Intractable Headache

Because migraine is a multidimensional disease, a system of stratified care for migraine patients is needed. Even those dissatisfied patients with

intractable migraine combined with chronic daily headache cannot be presumed to be similar in terms of pain severity, level of functioning, and disability, psychological or physical comorbidities, and drug use or medication abuse.

A tertiary system of chronic pain treatment that can be clinically and economically successful has been documented most recently in a review of 65 published studies involving 3089 patients.³⁷ In this analysis, 45% to 65% of patients with chronic pain who received tertiary treatment returned to work; only 20% of those not getting tertiary care returned to work. In addition, those receiving tertiary care required about one third the number of hospitalizations of those receiving conventional treatment. However, chronic pain programs typically address a broad array of pain problems and are not necessarily oriented toward the unique needs of the headache patient.

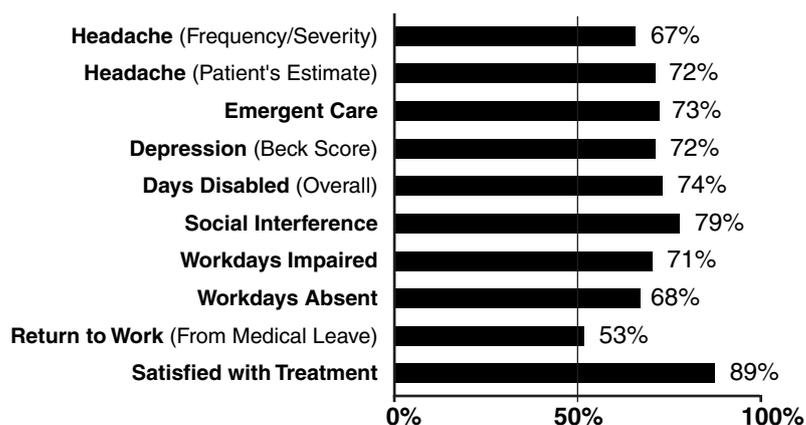
Since publication of this inpatient treatment data in 1993, we have seen a tendency toward increasing frequency of severe headaches. The total number of headaches in these patients has remained constant, at about 6.5 per week. In 1992, however, these tertiary care inpatients averaged 3 severe or very severe incapacitating headaches superimposed on this daily headache pattern while our patients in 1997 had a mean of 5 such incapacitating headaches each week. These high-acuity headache patients have failed to respond to the typical insurance-approved pharmaceutical-oriented approach, and require an advanced, comprehensive level of care. Despite the increasing acuity, roughly 7 out of 10 continue to report significant headache relief at the time of discharge from the hospital.

In the most recent outcome study of our individualized, tertiary care model, we followed a systematically selected representative sample of 218 patients for 6 months.³⁹ The majority

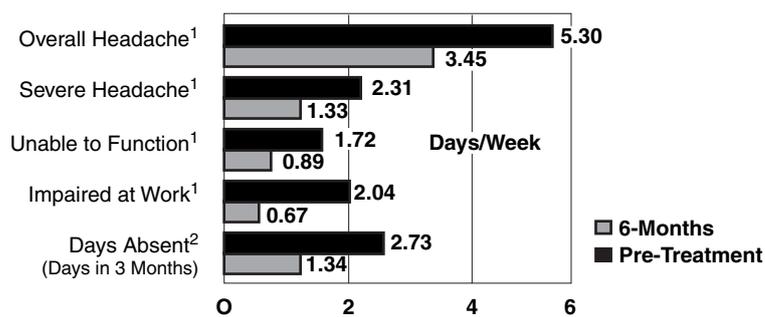
(177 or 84%) received outpatient services only, while 33 (16%) also received inpatient treatment. As shown in Figure 5a, between 67% and 74% of these patients had significant reductions (ie, >50%) in headache, depression, social disruption, days disabled, workdays impaired, work absenteeism, and use of emergency care. The mean number of days with headache and disability pre- and post-treatment are depicted in Figure 5b. Projected savings in lost labor

Figure 5. Outcomes of 6-Month Comprehensive/Tertiary Headache Care

a. Percentage of Patients with >50% Improvement



b. Reductions in Days with Pain and Disability Improvement



¹P<0.00001 ²P<0.0026

Source: Adapted from reference 39.

costs based on these measures were \$5145 per year per patient, based on the median salary in Michigan during the period of study. For those patients who were initially relying on emergency care for acute headaches, the projected yearly savings in reduced urgent-care costs were \$1666 per patient. In addition, 53% of those on nonretirement medical leave returned to work within 6 months. Overall satisfaction with the care received was reported by 89%.³⁹

Unfortunately, most individuals in this highest echelon of pain and disability cannot access the integrated-care approach that has proved most effective. Many primary care providers are adequately treating the majority of migraine cases with a mix of pharmaceuticals and, where appropriate, simple behavioral techniques, including stress reduction or trigger avoidance. However, a one-size-fits-all treatment approach works only for the majority. Without prompt triage of intractable migraine cases to multidisciplinary specialists, the overall personal and societal burden of migraine will remain unrelieved.

The solution is to match intensity of care to the severity of illness. At the entry level, structured short-term behavioral treatment can be effective for many patients, can reduce medication costs, and should be made more accessible by managed care systems. At a secondary level of intervention, patients may need to be triaged to multidisciplinary specialists. In intractable, complex cases, tertiary referral to comprehensive headache centers can in fact be quite effective, and can reduce costs over the long term.

... DISCUSSION HIGHLIGHTS ...

Dr. Mondell: Most insurance companies still view the cost of psychological intervention or specialty clinics as

prohibitive. Dr. Lake, how do you make the case for tertiary care in specific patients?

Dr. Lake: It is true that the intensive in-clinic sessions are still relatively expensive, although you need to remember that these sessions are only recommended for the most intractable migraineurs, the patients who are already consuming the most resources in terms of office visits and pharmaceuticals. Certain treatments involving professional time may at the outset appear to be expensive. But over time the treatment outcomes for many, if not most of these patients, can be significantly enhanced, and therefore costs may be cut.

Dr. Mondell: Is there anything we can do to make biofeedback techniques themselves less expensive?

Dr. Lake: Minimal contact approaches using structured treatment manuals can make biofeedback more cost effective. Streamlining the therapy can be part of this. For example, perhaps the patient is seen just three times with intervals of a month between sessions. A key to success in these pared-down approaches will be clear record-keeping, clear instructions, and proactively maintaining contact with the patient.

Dr. Brown: Are you aware of any computerized telephone programs for intervention when patients have symptoms?

Dr. Lake: No, the only telephone interventions I am aware of are direct-care provider-to-patient calls regarding issues of compliance with therapy and progress reports. This is more a prophylactic or follow-up approach than an acute intervention.

Dr. Stewart: You described drug overuse as one dimension of intractable headache medication abuse?

Dr. Lake: Generally, abuse occurs when patients are using more than the physician has authorized them to use. It could mean they are multi-sourcing, going to the emergency department for an injection and receiving a prescription for 20 Tylenol #3s without mentioning they are already being treated by another doctor. At the extreme, they may be falsifying prescriptions. In contrast, the more common issue of drug overuse can occur when a patient is following a doctor's orders, but relying on a given medication several times a week—frequently enough for analgesic rebound to become part of the problem.

Dr. Mondell: Most physicians realize that all patients develop headaches for different reasons, that they are individuals, but how would you convince them that certain severe headaches cannot always be handled according to some standard treatment algorithm involving DHE or a triptan?

Dr. Lake: I would first assure them that most migraine headaches actually can be handled right in their own offices. The patient who comes back again and again is the only one who may require a specialist.

I often ask primary care physicians to consider 2 different patients: one patient uses a combination analgesic with a sedative 2 days per week, complains of some neck and back pain, and shows signs of mild to moderate depression; she works full-time and has no absences. In the same waiting room is a patient taking a codeine medication every 4 hours, her urine drug screen shows cocaine, she has severe depression and borderline personality characteristics, and her record shows 2 ruptured disks, asthma, anemia, and unemployment due to disability. Both patients have migraines, yes, but I would argue that in the second patient's complex level of overlapping psychological issues

and comorbidities, a multidimensional approach is warranted.

Dr. Mondell: So how would you shape a special care program for that latter patient?

Dr. Lake: First, since compliance with therapy is a major concern, we would insist that she sign a treatment contract or we would not pursue further treatment. After this, we would begin a hospital stay during which she is detoxified, her depression addressed, and her cocaine abuse confronted. At the same time we would initiate appropriate prophylactic migraine therapy. Involvement in ongoing counseling, including substance abuse treatment, would be spelled out in the contract.

Dr. Ward: What are the main barriers in getting most patients into behavioral therapy?

Dr. Lake: Some patients feel awkward about seeing a psychologist. However, the economic issue is always a large one. Many times, if insurance does not pay for it, the patient will not pursue it. In some cases, the medical doctor needs to put some leverage on the patient to take that extra step. On the other hand, if a session is authorized by certain managed care organizations, I am often left with 30 minutes of paperwork and no guarantee of a follow-up session. We need a more efficient system that allows the primary gatekeeper to choose and authorize tertiary treatment or psychologist care.

Dr. Ward: Because this nonpharmaceutical therapy is coded as psychiatry, many of the people who need it most have the hardest time getting it.

Dr. Parham: But if a plan does allow access to a psychologist, how can that level of care be defined and outcomes measured?

Dr. Lake: The whole definition of best practices in treating intractable migraine still needs definition. But many of the studies I described were performed in precisely this high-acuity population. We can learn from these stratified approaches.

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