



CHRONICLE



Confronting Disparities in Health Care

by Penney Cowan, Executive Director, ACPA

INSIDE

- 2 [Getting the Help You Deserve](#)
- 4 [Disparities in Pain Care Affect Quality of Life](#)
- 6 [Is Pain Care Based on Race?](#)
- 8 [An Overview of Spinal Cord Stimulation](#)
- 10 [Who We Are Affects How We Respond to Pain](#)
- 11 [ACPA Update](#)
- 11 [New Groups & Members](#)
- 12 [Book Reviews](#)
- 14 [Tributes](#)

A key component of the presidential campaign this year is health care, a problem that has been discussed in just about every circle and corner of society. No one will argue that the need to improve health care is paramount. Children, the working poor, minorities, and women are at the top of the list when it comes to needing better access and higher quality of health care. The goal must be to provide *equal* health care for every man, woman, and child.

In the United States there is an enormous gap between those with access to health care and those without. This gap increases each day, with no end in sight. The question is: where do we begin to create positive change, ensuring that everyone has access to high quality health care?

Chronic pain is difficult enough to cope with without having to search desperately for high quality and timely care.

Where you live, your ethnicity, or your race could affect the quality of care you receive. There are many reasons why there are such disparities in care and we will explore some of them in this issue.

Ideas to Close the Gaps

While we don't have the answers to solve the health care crisis, there are many things that can be done to improve the medical management of pain and health care delivery in general. We need more information,

communication, persistence, and understanding to help people with pain improve their relationships with their health care providers and possibly improve their ability to obtain quality care.

Health care providers, support organizations, educators, legislators, payers, researchers, and health care consumers all play a role in this effort. These ideas would get things moving in the right direction.



- * Implement communication tools that are standard in all health care settings; create consistent ways to communicate symptoms and factors to promote greater understanding of the symptoms and concerns of the "patient."
- * Increase requirements in pain and pain management education for health care providers.
- * Provide standards in care that must be strictly adhered to, ensuring that each and every person seeking care is treated equally

CONTINUED ON PAGE 13...

Get the Help You Deserve

Members Overcome Disparities in Pain Treatment

by Sally Price

Many of us find it challenging to communicate with our doctors about our chronic pain and get the help we need. But some of us—due to other factors over which we have no control—have extra challenges.

These factors—where we live, our age, gender, economic or educational level, or even having a prior health problem—can interfere with getting proper pain treatment.

Take Louise VanDenHoogen, for instance. An ACPA facilitator in Ontario, Canada, Louise has overcome much since being diagnosed with juvenile arthritis at age 16. Now 48, she uses what she has learned to help others.

She sees her ACPA group members struggling to get equal pain treatment because they live in a rural area without benefit of advanced education or social status. She tries to help these people with chronic pain identify their health problems and effectively report their pains to their doctor.

Louise said one of her members was told by a doctor she should just stay home and have babies and not worry about her health. It took five years for this woman to be referred to a specialist and finally get a diagnosis of fibromyalgia.

When Specialist Care is Far Away

Louise lives in Haliburton Highlands, a tourist area where most of the jobs are seasonal, earning it the distinction of being the second poorest county in Ontario. Like many rural areas, there's a shortage of doctors. Medical specialists, surgeons, and high-tech tests like CT scans are about 85 miles away, a three-and-a-half hour drive.



Because of their limited education and economic circumstances, many residents have poor vocabularies and have difficulty talking with medical professionals, said Louise.

She'll often meet with members just prior to doctor appointments—or go with them to the appointments—to make certain they are making themselves clear, so the doctors will listen and respond with appropriate treatment.

She's good at it because she has learned the hard way—by experience. For Louise, her age creates a large disparity in health care. “They don't believe my physical condition at my age unless they see test results,” she said. “My bones are comparable to a 75-year-old's. Getting around is not easy.”

Louise is used to dealing with a number of challenges. She has had constant pain and limited range of motion on her right side from thoracic outlet syndrome since a car accident in 1988. She also has fibromyalgia, carpal tunnel syndrome, temporomandibular joint disorder (TMJ), urinary stenosis,

attention deficit hyperactivity disorder (ADHD), and dyslexia, in addition to a joint replacement necessitated by the arthritis.

After repeatedly being misunderstood by medical professionals, Louise learned to explain everything she could at medical appointments. “You can't just sit and demand” proper treatment, she said. “I try to be open with my doctors so they have no excuse to treat me with disparity.”

Your Right to Fair Treatment

She has become accustomed to having to speak up for herself in doctors' offices. Once she explained to a doctor why she needed to sit on her hands. It was due to her ADHD diagnosis. “It helps me slow down. I find when I explain to them they treat me better.”

Disparities in health care can result in patients blaming themselves. They start to believe they aren't worthy of being treated well. After walking away from doctors who didn't treat her fairly, “I learned to stand up for myself and believe...that I have the right to proper care,” Louise said.

If I focus on an activity, I forget about pain for awhile.

CONTINUED FROM PAGE 2...

She said most of her work with group members who experience disparities in their health care is encouraging them to believe in themselves. She also reminds them, "When you're a patient and the doctor is not treating you very well, sometimes (the doctor) is having a bad day. You can't blame yourself."

Get a New Diagnosis

Sometimes disparity in pain treatment occurs when a prior medical condition complicates getting a new diagnosis for a fresh problem. That happened to ACPA group facilitator Patrick Goertz of Wichita, Kansas. In January 2007, he found himself in an emergency room with stroke-like symptoms of numbness and tingling on one side of his body. But the ER team and the admitting neurologist focused on Patrick's pre-existing bipolar disorder. He was told his symptoms were psychological and that he was seeking drugs. Then he was sent home.

"After six months of trying to get someone to listen to me I fired the whole crowd," said Patrick. "Now I have doctors who understand that I have chronic pain. We've developed a realistic treatment plan. Being involved in ACPA as a facilitator is a part of my plan for living with chronic pain."

It turned out that when Patrick reported to the emergency room he was experiencing a rare kind of stroke, one that doesn't show up on an MRI scan for months, he said. He currently suffers from post-stroke central nervous system chronic pain, which can result from any type of injury to the brain, according to Patrick, a clinical nurse specialist. His symptoms today are a constant tightness, severe burning, and "a ripping kind of feeling" on the right side of his body.

In the emergency room with stroke symptoms, Patrick was also experiencing a daily bout of severe depression. He said, "I was in such pain, I was crying. Because I was acting emotionally, [the doctor may have thought] I was just seeking drugs."

ACPA Provides Focus and Relief

"If I can focus on some activity I can forget about it for a while. That's why the ACPA has been so helpful," said Patrick, who found the ACPA when researching pain management on the Internet. Now he is re-establishing an ACPA support group in Wichita. He said he uses ACPA relaxation tapes and the workbook in his daily life. "I try to live it," he said.

Like Louise, Patrick deals with his multiple diagnoses through acceptance and courage. Since starting medication 20 years ago, he deals with depressive symptoms that come and go. "I've had the bipolar a long time and know it doesn't last longer than a day," he said.

He also knows how the two conditions affect each other. "If I feel the depressive symptoms the pain becomes more intense because I'm just focused on

myself and I just kind of get lost in that a little bit." On those days, he said, "I give myself permission to be down. I do cross-stitch and watch old movies." He is also writing a book for children.

This author has also experienced disparities in pain treatment due to a prior diagnosis. After a spinal fusion to stop progressive scoliosis (spinal curvature) as a child, I had a difficult time getting my doctors to look beyond my curvature when I injured my back years later and experienced chronic pain.

Finally, having no diagnosis other than spinal arthritis, I had surgery (another fusion). Years later, I learned from a doctor trained in osteopathy that the injury had knocked my sacroiliac joint out of alignment. The surgery and the years of non-treatment precluded him from making any corrections. Looking back, I see that I should have left the area to find a doctor who would look beyond a prior diagnosis.

Yes, disparities do happen. And it's up to us to keep on trying and not give up.

| TOP |



Disparities in Pain Care Affect Quality of Life

by Alison Conte

While many hospitals and physicians follow set procedures for people with heart disease, diabetes, and other wide-spread health conditions, the course of treatment for chronic pain is not firmly established.

Further, researchers have found that the treatment you receive for your pain can vary because of who you are. Women, the elderly, and racial and ethnic minorities with pain may be treated differently by health professionals. These disparities in pain care can lead to more pain as well as poorer pain assessment and management, resulting in a lower quality of life.

Carmen R. Green, MD of the University of Michigan Medical School, led a team of researchers (including ACPA board members Donna A. Kaloukalani, MD, MPH and Knox H. Todd, MD) in reviewing the literature, experience, and anecdotal evidence surrounding the disparities in pain care. They published their results in *Pain Medicine* in 2003, under the title “The Unequal Burden of Pain: Confronting Racial and Ethnic Disparities in Pain.” They found differences existed in pain perception, assessment, and treatment in all settings (postoperative, emergency room, outpatient, and inpatient) and across all types of pain (acute, cancer, chronic nonmalignant, and experimental).

“The research shows minorities, women, and the elderly with pain are less likely to get attention, be properly assessed, and optimally treated by clinicians,” said Dr. Green. “Depending on where they live, they may be less likely to have their opioid analgesic prescriptions filled because their local

pharmacies don’t carry the medications they need. Overall, minorities are at risk for lesser quality care.”

Why? Disparities can be caused by:

- * The way people with pain communicate their specific needs, track their pain levels, question their doctors, and assert their rights
- * An individual’s image, attitudes, and cultural beliefs
- * The way a healthcare provider makes decisions
- * How geography and economic status influence access to pain medication, therapies, and health professionals.

Inequality in Health Care Delivery

The National Institute of Health and the Institute of Medicine define health disparities as “differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions existing among specific population groups in the U.S.”

In 1999, the Institute of Medicine (IOM) of the National Academy of Sciences (NAS) described health care inequities in the delivery of health care services among racial and ethnic minorities, including pain therapies. IOM found that the legal and regulatory environment for healthcare systems, along with discrimination, biases, and stereotypes among providers, were some of the reasons that African Americans and Hispanics were more likely to be poorly assessed and treated for pain than Caucasians. However, when considering the significant burden and socio-economic costs associated with pain, the IOM directed minimal attention to disparities in pain care, especially for chronic pain.

In “Ethnicity as a Risk Factor for Inadequate Emergency Department Analgesia” (*JAMA* 1993), Dr. Todd and other researchers found that in the emergency department (ED), Hispanics with isolated bone fractures were twice as likely as non-Hispanic Whites with similar fractures to receive no pain medication during their stay. The results suggest that ethnicity might influence ED pain management by having an impact on:

- * How patients perceive pain,
- * How comfortable they are admitting their level of pain,
- * How their pain intensity is assessed, and
- * A lack of action in ordering the analgesics.

Dr. Green explained more research is needed because clinicians are still not well educated about how to assess and treat pain. They also don’t always understand how they, as well as people experiencing pain, may differ in their attitudes about their pain.

Communication Makes a Difference

Breakdowns in patient-doctor communications may be partially responsible for disparities in pain treatment, particularly in the way people prepare for a doctor’s visit. “People in pain and their families can get better care if they prepare for their visit by recording pain intensity and any associated symptoms,” Dr. Green added.

People should track their pain over time, listing variations in intensity and reaction to medications or other treatment, thereby providing their doctors with the necessary information needed to assist them in assessing the pain.

CONTINUED ON PAGE 5...

| TOP |

CONTINUED FROM PAGE 4...

This allows doctors to make better treatment decisions. On the other hand, researchers found that some cancer patients may not report pain complaints due to fear their cancer is progressing. They also don't want to be labeled as complainers or distract their physicians' focus on treating the cancer.

According to the article in *Pain Medicine*, "Many Hispanics and African Americans report stoicism and the belief that pain is an inevitable part of having cancer and must be accepted [157-159]. Hispanic and African American patients are often concerned about taking opioid analgesics because they fear that they will become addicted, develop tolerance, or experience intolerable side effects."

We know how important it is for people in pain to be active participants in their treatment decisions. Therefore it is interesting to note that "people participated more actively in treatment decisions when their physicians were of the same ethnic background [164]. Thus, ethnicity-related differences in willingness to communicate about pain may influence and impact pain care," according to the article.

People participated more actively in treatment decisions when their physicians were of the same ethnic background.

But pain scales and communication only work for those who can speak the language or communicate through other mechanisms. Thus, children, those with developmental delays, or those who are cognitively impaired, such as people with Alzheimer's disease, are at risk for poor assessment and treatment. Dr. Green said, "Physicians aren't trying

to under treat. They may lack necessary tools. We need more research so we can develop better models of care for all people."

Understanding is the First Step

Some health professionals are beginning to view chronic pain as a disease of its own and not just a symptom of something else. Pain should be treated in an interdisciplinary and multidisciplinary fashion to manage the physical, emotional, and social impact, Dr. Green explained.

She added that the ACPA and other pain groups need to encourage federal and state agencies to fund more research and develop policies to improve care and to ensure equality in pain treatment. "More specifically, pain research receives less than 1% of NIH-granted research dollars, yet it is a frequent cause of healthcare utilization and disability," she said.

Research leads to new knowledge that can lead to greater awareness and education. Increased awareness and new attitudes are the first steps to changes in policy and practices. "I'm a positive person," Dr. Green

added. "It is my belief that raising awareness is the cornerstone. We need to get the right people involved in supporting the right research and talking about the best policy fixes. The increasing burden of pain is a socio-economic issue, while the unequal burden of pain is a social injustice and human rights issue."



1 Carmen R. Green, MD, et al.; "The Unequal Burden of Pain: Confronting Racial and Ethnic Disparities in Pain." *Pain Medicine*, Volume 4, Number 3, 2003

2 Anderson GF, Hussey PS. Population aging: A comparison among industrialized countries. *Health Aff (Millwood)* 2000;19:191-203.

3 Todd KH, Samaroo N, Hoffman JR; "Ethnicity as a risk factor for inadequate Emergency Department Analgesia." *JAMA* 1993; 269:1537-9.

4 Green CR, Baker, TA, Ndao-Brumblay; "Patient attitude regarding healthcare utilization and referral: A descriptive comparison in African- and Caucasian Americans with chronic pain." *Journal of the National Medical Association* 2004; 96(1): 31-42.

5 Green CR, Ndao-Brumblay SK, West B, Washington T; "Differences in prescription opioid analgesic availability: Comparing minority and white pharmacies across Michigan." *Journal of Pain* 2005; 6(10): 689-699.

| TOP |

Is Pain Care Based on Race?

Research into Ethnic Disparities in the Emergency Department Treatment of Pain

by Knox H. Todd, MD, MPH

Ethnic disparities in health care have been described for a number of illnesses and injuries. There is also a growing body of research literature that addresses inequalities in the treatment of pain.

The first documentation of ethnic disparities in analgesic prescribing came from an emergency department (ED) almost 15 years ago. ED clinical interactions are often characterized by a lack of patient-physician continuity, diagnostic uncertainty, and significant demands on time. These features increase the probability that unconscious bias may influence a physician's treatment decisions. A new study, funded by the Agency for Healthcare Research and Quality, suggests that the quality of pain treatment you receive in the emergency department continues to depend on the color of your skin.

In 1993, our research team published the first report of ethnic disparities in analgesic treatment, among patients with extremity fractures seen in the UCLA emergency department. In that study, Hispanics with fractures were twice as likely as other Whites to

receive no analgesic during their ED visit. While only 26 percent of non-Hispanic Whites failed to receive analgesics, fully 55 percent of Hispanics went without pain medication. We could not explain these findings based on any characteristics other than ethnicity. We thought that language difficulties might explain some part of the disparity in analgesic treatment, but even after controlling statistically for our patients' primary language, these differences could not be explained.

Assessments Accurate Across Ethnic Groups

In a second study at UCLA published in 1994, we tried to determine if there were differences in the ability of physicians to accurately assess pain in Whites and Hispanics. Our hope was that improved pain assessment might cause disparities in pain management practices to lessen or even disappear. In this study, we asked patients with a wide range of extremity injuries (sprains, strains, and fractures) to report the intensity of their pain. We asked physicians to ask the same questions. To our surprise, there was no difference in the ability of physicians to assess pain in Whites and Hispanics.

A third study by our group, at Emory University in Atlanta, found ethnic disparities in pain treatment between African-Americans and Whites with extremity fractures that were very similar to those observed in Los Angeles. By this time, a number of organizations, including the American Pain Society and The Joint Commission, had advocated for routine standardized pain assessments in many clinical settings including the ED. Importantly, in the Emory study, the ED medical records of White and African-American patients contained similar assessments of pain intensity. This finding suggested that initiatives solely designed to improve and standardize pain assessments were unlikely to help reduce racial and ethnic disparities in analgesic practice.

A number of other investigators have assessed the role of patient ethnicity in pain treatment. Ethnic disparities have been found in a wide range of clinical settings, including nursing homes, cancer treatment centers, and post-operative hospital wards. Although there are exceptions, most studies have found evidence for disparities in pain treatment and national healthcare databases have tended to support their presence.

Opioid Prescriptions Show Bias

In a recently published study from UCSF, Dr. Mark Pletcher examined data from the National Hospital Ambulatory Medical Care Survey (NHAMCS), a national survey administered by the U.S. Census Bureau to assess the provision of ambulatory care at U.S. hospitals. In this study, Dr. Pletcher and his colleagues examined ED data collected from 1993 to 2005. They determined that



CONTINUED ON PAGE 7...

| TOP |

*The elimination of analgesia-related health disparities...
should be a fundamental goal of emergency medicine practice.*

CONTINUED FROM PAGE 6...



pain monitoring and treatment in the ED had improved markedly over this 13-year period. The use of opioids for ED patients with pain increased from 23 percent in 1993 to 37 percent in 2005. However, even though emergency physicians were prescribing analgesics more aggressively, the gap between White and non-White patients' pain treatment had not changed. While 23 percent of Blacks and 24 percent of Hispanics presenting to the ED with pain received an opioid medication, fully 31 percent of Whites were treated with opioids. Differential prescribing by ethnicity was observed for all types of pain visits and was more pronounced with increasing pain severity. In commenting on his study, Dr. Pletcher suggested that although emergency physicians' unconscious ethnic bias might explain these results, many other factors could contribute to disparities in health care. His study did not attempt to determine a cause of the observed disparity.

Eliminating Ethnic Disparities

A number of measures may help us move forward toward eliminating ethnic disparities in pain treatment. Evidence-based guidelines and performance measures are promising interventions that should promote consistency in pain care. Quality assurance and improvement activities conducted at the institutional level should use patient ethnic identifiers to identify ethnic disparities when they exist. Simply supplying this feedback to health care providers may be an effective intervention.

At the regional and national levels, health plans should incorporate ethnic identifiers to determine whether pain management disparities exist. The definition of quality ED care should include the absence of such disparities. If these conditions are not met, providers should receive notice from third-party purchasers. Ultimately, third-party payers (i.e., all of us) should

demand that our costly premiums buy us top quality medical care that is free from disparities and offer to pay less if we receive unequal care.

I believe that emergency medicine is an inherently egalitarian specialty, in which we strive to treat all people equally. Our profession should be guided by principles of distributive justice, and provide high quality services to all. One of our specialty's most important roles within the U.S. health care system is to promote fairness and equal access to quality medical care. The provision of superior ED analgesia, as well as the elimination of analgesia-related health disparities in our departments, should be a fundamental goal of emergency medicine practice.

Knox H. Todd, MD, MPH is director of the Pain and Emergency Medicine Institute at Beth Israel Medical Center in New York. He serves on the Board of Directors of the ACPA.

References:

- 1 Todd KH, Lee A, Hoffman JR. The effect of ethnicity on assessment of pain severity in patients with isolated extremity trauma. *JAMA* 1994;271(12):925-928.
- 2 Todd KH, Samaroo N, Hoffman JR. Ethnicity as a risk factor for inadequate emergency department analgesia. *JAMA* 1993;269(12):1537-1539.
- 3 Todd KH, Deaton C, D'Adamo AP, Goe L. Ethnicity and analgesic practice. *Annals of Emergency Medicine* 2000; 35:11-16.
- 4 Pletcher MJ, Kertesz SG, Kohn MA, Gonzales R. Trends in opioid prescribing by race/ethnicity for patients seeking care in U.S. emergency departments. *JAMA* 2008; 299(1):70-78.

| TOP |

An Overview of Spinal Cord Stimulation

by David Provenzano, MD



Spinal cord stimulation (SCS) involves the delivery of pulsed electric signals near the spinal cord to reduce and control pain for certain medical conditions. It was originally described by Shealy* in 1967. Since its introduction, major improvements and discoveries have helped us understand how SCS works, for which conditions it is beneficial, and the optimal equipment design.

Technique and Mechanism of Action

Unfortunately, the effective treatment of chronic pain cannot always be achieved with conventional and non-invasive pain treatments. SCS may be considered when medical management, surgical intervention, and physical therapy have not been effective in relieving pain.

Two stages are involved in SCS. In both a physician, guided by an x-ray, places a lead into the epidural space located within the bony spinal canal. The first stage is the trial phase which provides information to predict the success of permanent implantation.

During the trial phase, one or two leads are placed via an epidural needle in the appropriate position. This is an outpatient procedure under light sedation. Once the lead is in position, it is tested to see if the patient's painful area is covered with a tingling sensation (paresthesia). It is important that the patient is alert during the insertion and testing of the lead so they can inform the health care provider if the lead is in the appropriate position.

The lead is programmed with a computer. The patient then goes home for three to five days. He or she has an

It is important for people with SCS to involve themselves in a multidisciplinary treatment plan if they are to get the best results.... SCS treatment can be an important tool in a treatment plan and significantly reduce pain and associated limitations.

external power source and remote control that allows him or her to control the amount of stimulation being received. During the trial the patient determines if the treatment is helpful in relieving pain and improving function. At the end of the trial, the patient returns to the physician's office to discuss the results and have the lead removed.

Together, the health care provider and the patient decide whether or not to advance to permanent implantation. In this stage the lead is again placed and implanted underneath the skin with a power source the size of a pacemaker battery. Rechargeable batteries can extend the life of the battery, giving the patient up to nine years before a replacement battery must be surgically placed. The SCS recipient goes home with a remote-control and battery charger, limiting activity for about 12 weeks to allow for healing.

Medical researchers are still investigating how SCS controls pain and are considering multiple theories. One is the gate control theory, which was the originally proposed mechanism of action of SCS. This theory states that

by providing a pleasant vibratory and touch sensation via the SCS system, pain signals that reach the brain are decreased. Recently, we have discovered that spinal cord stimulation modifies the chemical makeup of the spinal cord.

It's Not for Everyone

Some people respond better to SCS than others, which is why selecting the right individuals is so important.

Prior to SCS treatment, patients should have tried more conservative therapies and have undergone psychological screening to make sure that underlying psychological conditions have been addressed and effectively treated. Furthermore, it is important for the patient and health care provider to have realistic expectations regarding treatment, with the goal being pain reduction and control rather than complete elimination.

Currently, conditions that can respond favorably to SCS treatment include:

- * Failed back surgery syndrome
- * Complex regional pain syndrome (previously known as RSD and causalgia)

CONTINUED ON PAGE 9...

| TOP |

CONTINUED FROM PAGE 8...

- * Peripheral neuropathic pain
- * Peripheral vascular disease**
- * Ischemic heart disease**

SCS has been proven to be effective for many of these conditions with lasting results in terms of pain relief, pain medication reduction, and improvement in quality-of-life indices and satisfaction scores.

For example, approximately 10 to 40 percent of people in United States that have had previous surgery for back pain continue to have significant pain. Compared to another operation for persisting back and extremity pain, SCS is often more clinically effective and more cost effective.

Although there are significant upfront costs for SCS, the treatment often reduces costs in the long run secondary to its efficacy and reduction in health care services used by patients with SCS. A significant advantage of a SCS system is that it is a reversible and nondestructive treatment option.

It can also be effective for inoperable peripheral vascular disease (PVD). In the United States more than eight million people are affected by PVD. In some of these individuals, SCS may improve microcirculation (i.e. blood flow), reduce pain, increase walking distance, and promote ulcer healing. However, one must remember that PVD is often a progressive disease.

Associated Risks and Complications

As with other implantable devices, SCS has associated risks and complications. With improvement in technology and implanting techniques, the risks have often been reduced. Some of the complications associated with SCS include subcutaneous hematoma (collection of blood and fluids), headache, nerve injury, infection (typically requiring removal of the system), lead migration with loss of coverage, and hardware failure. People with SCS implants cannot have MRI studies, although computed tomography and x-rays can be performed.

The Beginning of a Long-Term Relationship

Effectively treating pain by implanting an SCS system requires a responsive, long-term relationship between the person with pain and his or her health care provider. Occasional re-programming will be needed to optimize coverage of the painful area.

As with most treatments for chronic pain, it is important for people with SCS to involve themselves in a multi-disciplinary treatment plan if they are to get the best results. In appropriately selected individuals, SCS treatment can be an important tool in a treatment plan and significantly reduce pain and associated limitations.

David Provenzano, MD, is Medical Director of the Pain Treatment Center, at Ohio Valley General Hospital in Pittsburgh, Pa. He is on the ACPA board of directors.

* Shealy CN, Mortimer JT, Reswick, JB (1967). "Electrical Inhibition of pain by stimulation of the dorsal columns: Preliminary Clinical Report." *Anesth Analg* 46: 489-91.

** Not FDA-approved indications



Who We Are Affects How We Respond to Pain

In this issue of *The Chronicle* we've reported on researchers who are exploring how race, gender, and other traits influence how pain treatment is delivered. We know that individuals vary in the way they perceive, track, and report their pain to a physician. These studies show that physicians in various settings also respond differently to people, based on their ethnicity and other factors.

Here are some of the many factors that might influence how people manage their pain and communicate with the health care providers.

- * **Language:** How do people in pain describe pain in their native tongue? How well can their healthcare providers understand them? How do we account for words that mean different things to different cultures?
- * **Education:** Can they research new treatments and carefully document their pain?
- * **Literacy:** Can they read directions and medication instructions?
- * **Culture:** What does an ethnic group believe about illness and pain?
- * **Gender:** Are a man's complaints treated differently than a woman's?
- * **Ethnicity/Race:** Do people relate better to a medical professional of the same race?
- * **Religion/Spirituality:** Who do people believe has the power to heal them?
- * **Geography:** Do they live close to pain centers, pharmacies, and physicians?
- * **Economic Status:** Are they insured? Can they afford care givers to help at home?
- * **Status:** Are they unemployed, in jail, under psychiatric care, in a nursing home?
- * **Age:** How well is the pain of children or the elderly understood?

- * **Disability:** Are there mental or physical challenges or sensory disabilities that make it hard to assess pain?
- * **Illness:** Do pre-existing conditions mask new causes of pain?

Disparities in pain care exist, but who is responsible, the health care providers or the person with pain? In fact, responsibility is shared by both.

Providers must be aware of their own bias when treating people with pain. But disparities also can happen if a person with pain is not literate in the language of health care, able to read and act on medical instructions, and other health information.

Unfortunately, more than half of the U.S. population lack these very skills, skills that often lead to longer and improved quality of life.

Disparities Found in Treating Cancer Pain

The Intercultural Cancer Council shares information about how disparities in health care affect those with cancer pain in their brochure, *Pain and Cancer*. It discusses disparities in clinical assessment and patient/provider communications, including these findings about how different ethnic groups react to pain.

- * Religion and faith are important ways in which Hispanic patients cope with cancer and pain.
- * African-Americans with chronic illness use more pain coping techniques that employ distraction, praying, or hoping, while Whites use more pain techniques that involve ignoring pain.



- * Attitudes and cultural beliefs about coping with pain may explain why Asian patients are less likely to request an opioid or cease its use prematurely even when there is some pain relief.

- * Patients who are less educated or who have lower incomes are significantly more likely to hold beliefs that may be barriers to effective pain management.

Understanding these issues is the first step to education and advocacy, so that agencies and government can develop positions to curtail disparities and encourage equal treatment.

Use these online resources to learn more:

National Institute of Health, Clear Communications
<http://www.nih.gov/icd/od/ocpl/resources/improvinghealthliteracy.htm>

Healthy People 2010
<http://www.healthypeople.gov>

Health Exchange
<http://www.health-exchange.net>
 (for health care providers)

Intercultural Cancer Council,
 713-798-4617, info@iccnetwork.org or
<http://iccnetwork.org>

ACPA Update

New ACPA Groups

Welcome to our new groups and facilitators.

Robin Arena
West Palm Beach, FL

Jannie White
West Detroit, MI

Rosalind Ballard
Sterling Heights, MI

Felisha Starkey
Saint Louis, MO

Edwin W. Kitzes
Las Cruces, NM

Jan McNamara
Cleveland, Ohio

Carolyn Rains
Yakima, WA

Partners Against Pain® Website

Purdue Pharma L.P. has redesigned its Partners Against Pain® website at www.partnersagainstpain.com. Information for people with pain, caregivers, and healthcare providers on pain assessment, documentation, advocacy, pain education, integrative medicine, and other resources are now easier to find. Partners Against Pain® works to alleviate unnecessary suffering by leading efforts to advance standards of pain care through education and advocacy.



Board Member Named to Professorship

Steven D. Feinberg, MD, medical editor of *The Chronicle*, has been named an Adjunct Clinical Professor, Stanford University School of Medicine, Stanford, California. Dr. Feinberg serves on the Board of Directors of the ACPA and is our Medical Advisor.

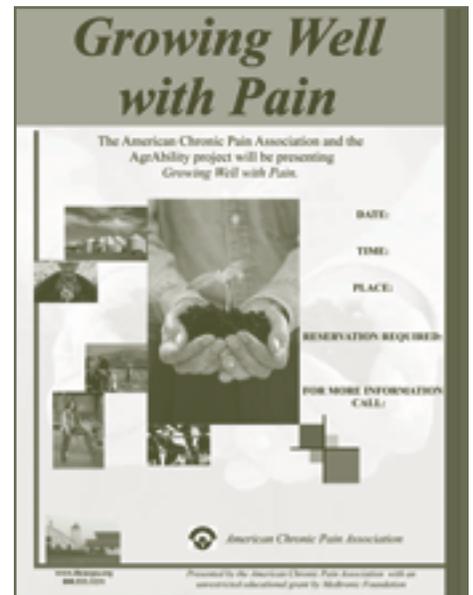


AgrAbility Helps Agricultural Workers

Growing Well with Pain is a program that encourages people in rural communities to actively manage their pain. It will be presented by the American Chronic Pain Association and the AgrAbility project in 12 states.

“We received funding for eight presentations but we are doing 12 because the need is so great,” said Penney Cowan, Executive Director, ACPA. “The focus of this educational campaign will be unique. It will build awareness of chronic pain

among agricultural workers—most of whom do not have any health care insurance.” Working within rural communities, ACPA hopes to provide these workers with the coping skills they need to allow them to begin to take an active role in managing their pain, improve the quality of their lives, and reduce their sense of suffering. The events will be held in conjunction with the state AgrAbility projects in Utah, Wyoming, Kansas, Maryland, West Virginia, Pennsylvania, Colorado, Mississippi, Missouri, Virginia, Idaho, and Michigan.



“We will work to empower people with chronic pain and their caregivers and families, giving them information, resources, and tools to help them manage their pain,” said Cowan. The campaign is also designed to foster productive dialogue between people with chronic pain and their health care providers to facilitate better diagnosis and treatment.

For more information on AgrAbility go to: <http://www.agrabilityproject.org/>.

Book Reviews

You've Gotta Fight Back! Winning with Serious Illness, Injury, or Disability

by Dirk Chase Eldredge

Reviewed by Samantha Nagy,
ACPA Michigan Regional Director

This book was based on the life-threatening illnesses that have struck certain people and the people who took care of them. The author shares many stories of people with cancer, spinal cord injuries, and ALS, etc. Some of these people survive and some don't, which I found very depressing. It does not discuss the problems of people with Fibromyalgia, back problems, or migraines.

I feel that this book would be more useful for a person with cancer or another life-threatening illness and their family members, than someone with, say Fibromyalgia or lower back pain (something that is not life threatening).

In the last chapter, the author writes about his son's battle with alcoholism and speaks a lot about AA meetings—not what I consider to be appropriate in a book about chronic pain. However, the author shared a few interesting websites and sprinkled a very few tips here and there about how to deal with chronic pain.

The book does not provide any coping skills or exercises, so I walked away from it none the wiser, only depressed by the stories of people's deaths (which I felt was very inappropriate in a book about "fighting back.")

You've Gotta Fight Back! Winning with Serious Illness, Injury, or Disability, by Dirk Chase Eldredge, \$16.46, Loving Healing Press; paperback: 288 pages, ISBN-10: 1932690344
<http://booksbydirk.com/>

Live Well with Chronic Pain: A Journey of Discovery

By Liza H. Leal, M.D.

Reviewed by Evelyn Cooper

This book followed my line of thinking as it promotes a way of living with pain that does not rely primarily on drugs. The way it is written, mostly as a conversation, made it easy for me to read and understand.

I would recommend this book to someone with chronic pain. Here are a few quotes that illustrate the author's point of view: "The only real disability people have is a negative attitude." "Show me a person, young, old, or in-between, who is inactive and without goals, and I will show you someone who is unhappy."

I learned new and useful things from this book. It helped me see the need to do more to manage my pain.

*Live Well With Chronic Pain:
A Journey of Discovery (Paperback)*
by Liza H. Leal M.D. Available
for \$12.95 through <http://www.amazon.com/>



Mayo Clinic Guide to Pain Relief

Editors: B. Bruce and W. M. Hooten

Review by Patrick Goertz RN, MSN,
CNS, Facilitator, Wichita Chapter

This book is the best primary resource I have seen for explaining the many aspects of living with chronic pain. It presents complex concepts in easy-to-understand language. It explains the physical, financial, and social effects that chronic pain has on individuals and their families. More importantly, it offers hope.

It provides useful techniques that people can use to lessen and begin to control their pain. The Mayo Clinic's multi-disciplinary pain treatment team offers this book as a tool that people with chronic pain can use to regain their lives.

I am a clinical nurse specialist and I live with chronic post-stroke central nerve pain. I highly recommend this book from both these perspectives. As a nurse I could use this book as a primary resource to teach people about the medical aspects of the causes, diagnostic procedures, and treatments for chronic pain.

I wish this book had been available when I began dealing with my own symptoms. It would have helped me deal with the overwhelming fears and frustrations that come with the diagnosis of chronic pain.

This book would make an excellent primary text for use in any pain treatment program. It would take the person with pain and family members step-by-step from diagnosis to learning to live with chronic pain.

CONTINUED ON PAGE 13...

| TOP |

CONTINUED FROM PAGE 12...

In addition physicians and healthcare providers in other disciplines could use it to help explain pain related concepts to their patients.

I also appreciated the list of organizations that provide more information about chronic pain and associated conditions.

Mayo Clinic Guide to Pain Relief, How to Manage, Reduce and Control Chronic Pain, B. Bruce and W. M. Hooten, \$29.95 from the Mayo Clinic bookstore. <http://bookstore.mayoclinic.com>



Take A Break

We know tension increases pain. When you need a time out from the stress of your day, visit www.theacpa.org and try our new five-minute relaxation exercise.

Like the longer relaxation CDs, this quick de-stresser takes you through a progressive relaxation process aimed at helping you let go of the tension that can build in muscles in the course of the day. Just follow the link on the home page and enjoy!

Confronting Disparities CONTINUED FROM PAGE 1...

- * Use an evidence-based medicine model that would integrate clinical expertise, patient values, and the best evidence into the decision-making process of patient care.
- * Push for clinical trials that include a cross section of people from all ages, races, genders, and health status. This would establish a greater understanding of the way medications work on all people rather than a select few.
- * Work to improve the health literacy of every consumer/patient so he or she can share in health care decisions.
- * Involve consumers in developing culturally appropriate training materials, media, and educational tools for a range of diverse audiences.
- * Practice preventive medicine: treat acute pain and diagnose its symptoms before it becomes chronic.
- * Consider multiple health issues, treatment goals, and preferences when deciding which treatment is appropriate.

- * Provide consumers information that clearly explains—in terms they can understand—the choices and costs of all treatments. The chance to make an informed decision about health care can have a positive impact on a person's attitude about the possible outcome of an illness or disease.

Perhaps addressing the issues of disparities in care is like living with pain: you must start out by taking the first step and remain focused on your goal. We need to start somewhere if we are to improve health care for everyone and provide the right medicine at the right time for the right person.

One of our basic rights is to be treated with dignity and respect. Let's hope those who practice medicine will keep this in mind.

Ensure that every person seeking care is treated equally

The Chronicle is published quarterly by the American Chronic Pain Association.

We welcome essays, poetry, articles, and book reviews written by people with chronic pain or their families.

Please send inquiries to:

The ACPA
P.O. Box 850
Rocklin, CA 95677

EXECUTIVE DIRECTOR:
Penney Cowan

**PRESIDENT,
BOARD OF DIRECTORS:**
Nicole Kelly

MEDICAL EDITOR:
Steven Feinberg, M.D.

COPY EDITOR:
Alison Conte

SPECIAL FEATURES:
Sally Price

Thank You!

Special thanks to these corporate sponsors:

KING PHARMACEUTICALS *as an Ambassador level corporate sponsor*

ALPHARMA INC. *as an Educator level corporate sponsor*

THE MEDTRONIC FOUNDATION

for a Patient Link Leadership Development Award that was awarded to support a retreat for ACPA Regional Directors

ABBOTT LABORATORIES

in support of the ACPA Medication Supplement DVD/Web Project

ENDO PHARMACEUTICALS

in support of the ACPA Medication Supplement DVD/Web Project

PFIZER

in support of the ACPA Medication Supplement DVD/Web Project

ROCHE PHARMACEUTICALS

in support of the ACPA Medication Supplement DVD/Web Project

PFIZER *for the Fibromyalgia campaign*

THE MEDTRONIC FOUNDATION *in support of the AgrAbility project*

The ACPA appreciates the support of the corporate donors who share our values and make our work possible by underwriting key outreach projects.

The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain.