Transcript from AACIPM Fall Symposium

Behavioral Health as Part of Comprehensive Pain Care and Payment Design - November 12, 2020

25 minute transcript - accompanying video can be found <u>here</u>.

Ravi Prasad, PhD, University of California, Davis School of Medicin

Tom Norris, Lieutenant Colonel, USAF (Retired), Chronic Pain Advocate

Impact and Prevalence of Chronic Pain

Stephen Gillaspy, Moderator (00:01):

So, at this time, we're going to transition into the first section of the symposium. There's going to be a discussion about the impact and prevalence of chronic pain. As Amy said, in your symposium materials, there are full bios of all the presenters.

Stephen Gillaspy, Moderator (00:18):

So, I just want to give a quick little intro to Dr. Prasad. Dr. Prasad is a health psychologist, and recently joined the University of California Davis School of Medicine as the Director of Behavioral Health Services and Clinical Professor in the Department of Anesthesiology and Pain Medicine.

Stephen Gillaspy, Moderator (00:37):

I can tell you all kinds of stories about Dr. Prasad because he is one of those individuals who... He's involved in almost every strategic pain management initiative we have at APA. He is a wealth of knowledge in regards to pain management. And at this time, I will turn it over to him. Dr. Prasad.

Ravi Prasad, Panelist (01:00):

Well, thank you very much, Dr. Gillaspy for the introduction. Appreciate it very much. So, go ahead and we'll go to the next slide.

Ravi Prasad, Panelist (01:09):

So, I'm going to start off our discussion this morning from a 30,000 foot perspective. We'll start by putting pain in context. So, just this month, the US Department of Health and Human Services and the CDC put out a data brief characterizing the incidence of pain in the United States. They estimated that pain affects approximately 20% of the US population. Now, put in other words, what this basically means is one in five individuals around us is living with a chronic pain condition. Of these individuals, just over one third have high-impact pain. And high-impact pain is defined as pain that frequently limits life or work activities. Chronic pain, they found that it has differences. It has variations. Specifically, they found it was more prevalent in women, individuals over 65, and in non-Hispanic, White adults. And interestingly, they also found that as people move to more rural areas, the more rural that you get the higher the incidence of chronic pain.

Ravi Prasad, Panelist (02:14):

Now, even as we look at these figures, which are admittedly quite staggering, there's still an underestimate of pain in this country. And part of the reason for that is that these figures all represent just the adult population. We can certainly appreciate that once we factor in children and the pediatric population that these numbers would be just that much higher. So, clearly pain is an issue that needs to be reckoned with in this country. Next slide.

Ravi Prasad, Panelist (02:39):

So, why do we have pain? Does this pain serve any purpose or function? Well, in its most primitive form, next slide, there is a function that pain serves. So, in its most primitive form, the primary function of pain is to serve as a warning sign. It alerts us to some sort of damage occurring in the body that requires some sort of immediate action to prevent more harm from occurring to that particular part of our body. So, for example, if I'm barbecuing outside, if my hand touches the barbecue grill, I'm going to feel pain. That's going to be a warning sign for me to move my hand away from the grill so I don't have tissue damage to that part of my body.

Ravi Prasad, Panelist (03:16):

But is that true of all pain? Is all pain a warning sign that there's active damage occurring to our body, and we need to do something right now to prevent more harm from occurring? Well, the simple answer to that question is no. And this is where we start to get to the differences between two very broad categories of pain: acute pain and chronic pain.

Ravi Prasad, Panelist (03:35):

In acute pain, the pain that we experience is a sign of active harm occurring in the body, and the avoidance behavior minimizes damage to the body. And so that example of my hand touching the barbecue grill is a great example of acute pain, and the avoidance behavior of me moving my hand away decreases the damage in my body.

Ravi Prasad, Panelist (03:53):

But in chronic pain, we know that the pain a person's experiencing is real. First and foremost, that's critically important to recognize, that the pain and chronic pain is absolutely, 100% real. But we usually know from the medical workup that's occurred prior to the person coming to us for treatment that it's not a sign of ongoing damage occurring in the body that requires immediate intervention.

Ravi Prasad, Panelist (04:16):

So, for example, many of the 150 plus individuals who are on the webinar this morning, you may be experiencing a pain condition yourself. You may have low back pain as you listen to me speak, and it may get higher the longer I talk. But we know that that pain isn't a sign of damage that requires some immediate intervention where you need to call 911 or go to an ER. But what can happen is if we start to interpret this pain as being a sign of active damage that requires immediate intervention, it can start to lead to a fear avoidance cycle where we start to have fear that the pain is a sign of active damage occurring in the body or fear of experiencing the pain itself, so we start to avoid activities. And that over the course of time will actually just worsen the pain condition.

Ravi Prasad, Panelist (05:00):

We also know that there are differences in the causes of pain. Acute pain oftentimes has a very clear pathway, and often times there's just a singular cost for that pain. Again, my example of my hand touching the barbecue grill. But in chronic pain, we know that there's a much higher level of ambiguity and chronic pain tends to be multifactorial in nature.

Ravi Prasad, Panelist (05:20):

So, first the ambiguity, what do we mean by that? Well, we can give a pain condition a name. We can say that a person has complex regional pain syndrome, a person has fibromyalgia. We can even identify a particular nerve that's responsible for the transmission of a person's pain condition.

Ravi Prasad, Panelist (05:36):

But what we can't do is we can't explain why is it that two people may have the exact same mechanism of injury, and one person goes on to develop chronic pain, but another person doesn't? Our research has shown us that there's a wide number of different factors that may predispose a person to pain, but predisposition and cause are two different things. So, we don't quite understand why it is that this false alarm continues to go off in the body, alerting us to damage, even though there's not active harm occurring in the body.

Ravi Prasad, Panelist (06:05):

But it's also multi-factorial. Chronic pain is strongly influenced by a wide range of different factors in our life. Emotional states, situational stressors, the substances we put in our body, all of these things will affect a chronic pain condition, whereas acute pain conditions aren't as impacted by these things as strongly. So, for example, the day that my hand touches a barbecue grill, if I'm behind on a deadline for work, if I have an argument with my significant other, the pain that I experienced on that day is still going to be the same regardless of those other stressors happening in my life. If I've got chronic low back pain, the presence of those other stressors will make that pain worse. And those changes aren't based on psychological factors but based on physiologic factors in the body.

Ravi Prasad, Panelist (06:49):

But all this leads to differences in the treatment course. By definition, acute pain has a fixed end point. It does go away. And in many cases, immobilization is essential for that recovery, and medications may be a part of that treatment as well, including some opiate medications may be a part of the short-term treatment for my acute pain. But in chronic pain, we don't have a fixed endpoint. We can't tell folks that if they do all the things that we tell them to do that their pain will go away. Immobilization can worsen the condition. And with medications, it's not that there's no role for medications. There absolutely is a role, but we have to have a lot more caution because now we're talking about prescribing medications for a condition that doesn't have a fixed endpoint. So, we have to appreciate the impact of issues like dependence, psychological dependence, physical dependence, tolerance, and addiction.

Ravi Prasad, Panelist (07:39):

So, we can see that acute and chronic pain are two completely different beasts, so we have to take a different approach to chronic pain treatment. And so the approach that we take is the

exact same approach that we take with any other kind of chronic health condition that doesn't have a cure, which is a management approach. We can go onto the next slide. Thank you.

Ravi Prasad, Panelist (07:57):

And so in management approaches, we focus on quality of life and functioning. And again, this is similar to the approach we take with other chronic conditions that don't have a cure like heart disease, asthma, diabetes. Go on to the next slide. I'll focus on diabetes. We know that there's no fix for diabetes. There's not a surgery. There's not an injection that just makes diabetes go away. But if a diabetic regulates their diet, checks their blood sugars, gets regular exercise, takes their medications or insulin, monitors their wounds, generally speaking, they can still have a decent quality of life.

Ravi Prasad, Panelist (08:30):

Well, in chronic pain, we know that there's a similar number of features that are necessary to optimize management of that pain condition. There's medical optimization, which involves physicians, nurse practitioners, and physician assistants, which is looking at all aspects of medical care. Does a person need more medication or less medication? Are they on the most appropriate medications for their condition? Is additional workup necessary? Are they appropriate for implantable therapies or surgical interventions? Physical reconditioning is essential. Making sure that the parts of the body affected by pain are kept as toned as possible. Making sure that any compensation that people are using assistive devices, making sure that those are being used appropriately. And this is where physical therapies come in.

Ravi Prasad, Panelist (09:16):

Behavior and lifestyle modification. And this is typically where behavioral health specialists such as psychologists like myself or social workers come into play. And this is looking at everything else: the role of substances, stressors, and emotional states, which we know can influence pain. And then we have complimentary/integrative therapies: acupuncture, spiritual care that are also an essential part of the management picture. And so chronic pain management is a combination of all of these therapies working together. Next slide.

Ravi Prasad, Panelist (09:44):

In this capacity, it's very similar to diabetes management. Unfortunately, a diabetic can't pick or choose which aspects of their care they want to do. They really have to have a combination of all these things working together. Now, how much of each of these components they need varies from one person to the next, but we know that these are all essential components to diabetes management. Well, it's the same thing with chronic pain management. We know that these are the essential tools that are necessary to assist with managing pain. It's not a cure. It's not a fix that'll make the condition go away, but their tools that are essential to helping to improve functionality and improving quality of life.

Ravi Prasad, Panelist (10:20):

Now, this is not an easy thing to do. What you're going to hear today are you're going to hear about some of the challenges that we face with trying to implement this management approach. But we know that there've been individuals who are living with pain who have been able to successfully put this together, either on their own or with supportive clinicians to achieve

this optimal pain management. And it's always a work in progress. It's not something that you accomplish and you're done. And we're going to hear from one of those individuals today.

Ravi Prasad, Panelist (10:50):

So, I've had the distinct pleasure and honor of being able to work with Lieutenant Colonel Tom Norris on multiple projects now. And it is my honor to introduce him to us today to share with us some of his experiences of how he has navigated these challenges of making the transition from an acute injury to a chronic pain condition and what he's learned along the way. And so with that, I turn it over to Lieutenant Colonel Norris.

Tom Norris (11:23):

Thank you, Dr. Prasad. I'm honored to be here today as a member of this behavioral health symposium for the Alliance to Advance Comprehensive Integrated Pain Management. I'm here today as a person with chronic pain. Today, I'd like to give you a quick overview of who I am and then share my journey with chronic pain. I hope you will find examples of how pain management has changed over the years through my talk.

Tom Norris (11:50):

Just who am I? I was raised on a farm in Virginia where I learned my faith from my grandmother, patience from my grandfather, compassion from my mother, and my work ethic from both parents. Today, I'm very happily married to Marianne Muellerleile, an actor, and live in the historic West Adams district of Los Angeles. Prior to having chronic pain, I was a Lieutenant Colonel in the United States Air Force. I worked as a problem solver and manager of people, air craft, and maintenance production while holding different titles.

Tom Norris (12:28):

I was medically retired in 1993 with untreatable chronic pain after 23 years of service. My main activity these days has been advocating for people with chronic pain through the auspices of the American Chronic Pain Association.

Tom Norris (12:47):

My personal journey began while on active duty and it's very similar to others: acute pain initially, doctors tests without improvements, more visits and more medications. I started having left hip pain and difficulty walking in 1997. The military doctor told me to start taking Motrin. Every time I went to the doctor, their reaction was the same: take more medicine. Medicine didn't really help much, but I kept working. I really think that was the doctors real intent. However, the pain kept getting worse, no matter how much medication I took.

Tom Norris (13:31):

I have to mention as an aside that during this time, I was very lucky that I met Marianne. I would not have survived this entire journey without her steadfast love and support. Within a year of the onset of pain, the hip pain got much worse. And then my abdomen and back joined in the chorus. The pain now is at a point where it prevented me from concentrating on my job.

Tom Norris (14:01):

Evidently, the Air Force accepted plan treatment for chronic pain was nothing but bedrest. In one year, I spent three months of bedrest in three different hospitals. Yeah, that's 270 days flat on my back with no other treatment besides continuing to take whatever medicine the doctor ordered. Usually the doctors never even bothered to check in with me. I would get out of the hospital, return to work for a couple of weeks, and continue to be in debilitating pain.

Tom Norris (14:38):

Now, my lower back became the main source of pain. The Air Force doctors had no clue of the cause and appeared to have absolutely no idea how to resolve or even relieve the chronic pain. Daily life was dedicated to visits to the doctors, always carrying a pile of x-rays and records, bedrest, and taking more and more medications with very little time spent working.

Tom Norris (15:08):

Over time and many visits to the doctors, someone decided I might have bladder cancer, so they sent me to a urologist. This time, the doctor actually looked at my x-rays. She discovered the source of my pain. I had tons of scar tissue from the left hip to the pubic bone and up my spine for about 12 inches. That was a familiar pattern. In 1984, while stationed in Saudi Arabia, I discovered a hardening of my left testicle. When I got to Walter Reed Hospital for examination six months later, this tumor had grown to the size of a small basketball. I had an emergency orchiectomy and 30 days of radiation treatment. The pattern this urologist found matched the pattern of the radiation used in this cancer treatment. Evidently, I had received too much radiation and the scar tissue was the result.

Tom Norris (16:06):

Now, her finding the cause of pain actually brought me no relief. Pain was so omnipresent that it now caused me to have to change jobs from traveling the world with the Air Force inspector general team, to sitting at a desk as the executive officer for the Chief of Air Force Safety. Even with less activity, my pain continued to worsen. Again, I seemed to live in doctor's offices. I take more and more medication just to keep going.

Tom Norris (16:41):

A year later, I was again sent to a major Air Force hospital. Through a series of x-rays, they determined my lower back pain was caused by a series of degraded discs due to the radiation and that the best option for pain relief was surgery. Needless to say, I subsequently was diagnosed with failed back surgery syndrome.

Tom Norris (17:05):

Finally, the Air Force determined that I could no longer do any job. And after a military tribunal in which I could not even remember my address or social security number because of the medication I was on, I was medically retired. I was still in severe, debilitating pain without any hope of relief, and now I had no doctor.

Tom Norris (17:28):

Oh, yeah. The Air Force told me at the tribunal, "You will never be able to do anything." My response was, "Hide and watch." After retirement, I spent most of my time in bed taking Gabapentin and Flexeril.

Tom Norris (17:45):

Marianne was searching for a civilian doctor. At that time, there was no real internet, so Marianne was dependent upon recommendations from friends and other doctors. We tried doctor after doctor without finding anyone covered by our insurance, and we have good insurance coverage, or who would tackle my case. We finally found a doctor who really thought outside the box and was covered by our insurance. For the next couple of years, I was treated with electricity, magnets, heat and coal, biofeedback, bee stings, bee honey, hands-on praying, remote praying, and epidurals.

Tom Norris (18:30):

As the treatments progressed, as I began to find some quality of life again. Soon I started and ran from our home and yard, a neighborhood afterschool program for at-risk children. I taught 35 children for the next five years, everything from survival skills, reading, writing, covering preschool through high school. I was determined to find some sense of accomplishment and actually help others. There was an obvious need in our neighborhood for support and education. And I tried to fill it.

Tom Norris (19:07):

During this time, I had my first heart attack, attributed to the pain. That doctor I was seeing soon retired, so Marianne and I began the search again. After several months, we found a chronic pain management clinic in-house that would take our insurance. Here, I was treated to physical therapy education about medications, biofeedback, occupational therapy, and attention diversion therapy. Every day for the 30 days I was in the hospital, the staff would verify for me that my insurance covered the treatment. They actually verified with my insurance every day.

Tom Norris (19:51):

I couldn't walk when I started this in-house treatment. Within three weeks at the start of the treatment, I was walking without a cane and was able to come home for a weekend and actually cooked dinner for us for the first time in many years. It was during this treatment that a nurse recommended that I contact the American Chronic Pain Association and join one of their peer-led support groups.

Tom Norris (20:17):

At the conclusion of the treatment, I really felt I was on my way to having a life again. I started attending an ACPA support group, and within three weeks, was co-facilitating it. When I went for my first follow-up appointment with a pain management clinic, as soon as I signed in, I was given a bill for \$35,000 for the stay and treatment at the clinic and was told I had to pay it that moment. Evidently, the clinic's office personnel and my insurance had miscommunicated about the treatment being covered. Of course, I refused to pay that bill and immediately went home and immediately went to bed.

Tom Norris (21:01):

Needless to say, my stress level was pretty high. Within a week, I was back on crutches and in very high pain. The legal battle on the bill grew more and more intense. My condition worsened. Within two months, the clinic finally withdrew the bill. By that time, I had lost much of the recovery I gained from the clinic. I continued my ACPA support group. I was now a facilitator but had to fight to maintain a positive attitude.

Tom Norris (21:37):

The doctor search began again. A month later, I found a doctor who met the insurance requirements. By this time, I was back in a wheelchair due to the pain. This doctor prescribed fentanyl for pain management. This actually covered much of the pain but left me drugged. I continued to see this doctor over seven years because he was the only doctor we found who was willing to treat me. I received ever increasing amounts of fentanyl to deal with the pain. I feel I lost years of my life during this treatment. I was never pain free, but it felt there was a thick blanket between me and the pain. I was very dizzy most of the time and prone to falling. I hallucinated frequently. Oh, yeah. I developed diabetes during this time and had two more heart attacks.

Tom Norris (22:37):

While this was going on, I spent years in therapy dealing with problems in my childhood. Marianne made sure I stayed socially engaged by inviting people to a party where they were encouraged to talk to me while I was in bed. I can now brag that I've had as many as six people on the bed with me at the same time. I finally was able to look at my questionable quality of life with fentanyl and say, "I want more out of life."

Tom Norris (23:05):

During a long trip with Marianne, I made a decision that fentanyl and I were going to part ways. Marianne supported that decision as did my cardiologist and endocrinologist. My pain doctor didn't want me to stop taking the medication, but on my insistence, agreed to change the dosage so I could self-detox. I didn't leave the house for six months while the detox process was going on, but my pain doctor never even bothered to check on me.

Tom Norris (23:37):

I still have horrible pain, but was able to live with it using the tools I'd learned. I was able to relax, meditate, use biofeedback, divert my attention from the pain, deal with each and every pain crisis, and have fun on a quiet, higher quality of life than before. Soon, I was able to become more active and help others deal with their chronic pain.

Tom Norris (24:04):

These days, every day the pain gets worse and is now in my attire back from neck to coccyx, both hips, lower abdomen, and left leg. But I am now more adept at handling it with the help of epidurals, virtual reality, physical therapy, water therapy, and meditation. I could have reached or exceeded this increased quality of life and productivity much sooner if I'd had early access to behavioral health and other non-pharmacological therapies. I had to pull all these options together on my own.

Tom Norris (24:44):

If I had support for navigating those options and the providers who understood a comprehensive approach, this journey would have been much easier. I believe with this help, I could have returned to the workplace in some capacity with all my management experience.

Tom Norris (25:02):

I credit my faith, Marianne's love and support, and all the lessons I've learned about pain management for my being alive and functioning. This is who I am and how I became a person with chronic pain who advocates for people with chronic pain. Thank you for your time and your attention.