



Transcript from AACIPM Fall Symposium

Equity in Access to Comprehensive Integrative Pain Management for People with Pain - September 24, 2020

13 minute transcript - accompanying video can be found [here](#).

Presenter: Nicole Hemmenway, CEO, US Pain Foundation

Findings from US Pain Foundation Survey

Cindy Steinberg, Moderator (00:00):

So next we're going to hear from Nicole Hemmenway, CEO of U.S. Pain Foundation and a colleague, on the results of the survey that we at U.S. Pain Foundation conducted and released on September 1st in coordination with Pain Awareness Month. The title was understanding the barriers to multidisciplinary care, and I think there were some really interesting findings that Nicole is going to go over. So, welcome Nicole.

Nicole Hemmenway, Panelist (00:27):

Yes. Thank you, Cindy, so very much and good morning, everyone. I am just really glad to be here today. This symposium is tackling a much needed topic and I am honored to be able to bring the patient perspective to everyone tuning in and to discuss our recent survey on barriers to pain care. Next slide, please. First, I thought it would make sense to share a little bit about the U.S. Pain Foundation. So, U.S. Pain is the largest national nonprofit for the chronic pain community. And our staff is primarily comprised of people living with pain, which means that we are deeply invested in helping patients.

Nicole Hemmenway, Panelist (01:07):

Next slide, please. We strive to help individuals through our various programs and services, the large majority of which are free. Our programs, listed here on the slide, range from a national network of support groups led by a clinical social worker, to federal advocacy efforts that include representing the patient voice on high ranking policy committees.

Nicole Hemmenway, Panelist (01:31):

Next slide, please. So, one of our primary focuses is advancing multidisciplinary pain care. And to better understand the barriers that patients face in accessing this type of care, which as we all know is best practice, the organization recently conducted a 57 question survey as part of our Pain Awareness Month initiatives. Over the course of a week, a total of 1,581 individuals with chronic pain responded.

Nicole Hemmenway, Panelist (02:04):

Next slide, please. By far, as you can see, the large majority of respondents were female, white, and over the age of 45. Some of these results might be expected, after all, women and older individuals are more likely to experience pain, but that doesn't necessarily account for them being such a significant majority or even the under-representation of people of color. So, an

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interesting area for future study could be why some populations are more likely to seek assistance from patient groups, and how patient groups can better connect with and support diverse communities. Also worth noting is that the majority of respondents indicated having Medicare, which I will go into detail on the next couple of slides.

Nicole Hemmenway, Panelist (02:57):

So, next slide, please. One item that we found promising overall was that 96% of respondents reported to having some kind of insurance. Most indicated having Medicare at roughly half, followed by insurance through an employer or a family member's employer, a little over 12% had Medicaid. Interestingly, for those with private insurance, Blue Cross Blue Shield was the leading insurer at 45%. Next slide, please. So, the reason for such a high rate of Medicare is likely that people who seek us out are typically severely impacted by pain. Nearly three quarters of respondents reported living with pain for over a decade and 82% of them considered themselves disabled. In addition, nearly half of the folks reported they received Social Security Disability Insurance, which makes them eligible for Medicare. So, it's clear that the patients we try to serve are among the most vulnerable in our healthcare system.

Nicole Hemmenway, Panelist (04:08):

Next slide, please. Patients reported experiencing pain from a large range of reasons, but most reported living with musculoskeletal conditions at 81%, followed by neurological conditions at 70%, and rheumatological conditions at 53%. Interestingly, there were 45% of respondents that said their pain was a result from a trauma or injury such as a car accident, and 29% live with a rare disease. Next slide, please. The findings from the survey really align with what we as an organization hear every day from patients. And that is, although experts agree that the best pain care is multidisciplinary, multimodal, and individualized, patients don't realistically have access to that type of care. Here are our four key takeaways, which I'm going to discuss in detail over the next few slides.

Nicole Hemmenway, Panelist (05:13):

Next slide, please. By and large, patients do not have access to multidisciplinary care. Despite their severity of pain, only slightly over half reported being seen at a pain center, and nearly a third said they cannot see a pain specialist as often as they like due to barriers to cost. For those who do receive care at a pain center, an astounding 77%, over three quarters, reported that the clinic or center only offers pain doctors and not multidisciplinary specialists like psychologists, nutritionists, physical therapists, OTs, et cetera. This really just illustrates that we're not making multidisciplinary care as accessible as we could be.

Nicole Hemmenway, Panelist (06:04):

Next slide, please. Another finding that we found interesting was looking at what patients wanted most emphasized versus what they perceive to be most emphasized by their providers. While providers typically most emphasize medications and interventional procedures, patients actually wish they placed the most emphasis on complementary or integrative health approaches, as well as restorative therapies, followed by medications. Again, this tells us that folks want to have their pain managed comprehensively, but providers aren't necessarily able to offer that whether it's because of a lack of time, resources or training.

Nicole Hemmenway, Panelist (06:47):

Next slide, please. So, all the barriers we explored in our survey, including knowledge of options, concerns about side effects versus risks, geographic location, insurance issues, et cetera, direct

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out of pocket cost was by far the largest obstacle. Over three quarters indicated cost prevented them from accessing one or more treatment options. In addition, nearly 52% stated that high copays prevented them from accessing treatments. Cost aside, insurance limits and requirements present barriers to patients as well.

Nicole Hemmenway, Panelist (07:28):

Next slide, please. So, this graph lists the treatments respondents most commonly couldn't access because of cost, complementary and integrative health approaches, as well as restorative therapies lead the pack with massage at 53%, acupuncture at 39%, and physical therapy at 29%. This does make sense though, massage and acupuncture are rarely covered by insurance, so those costs are typically entirely out of pocket for patients. In regards to physical therapy, it's possible that even though copays per visit may appear affordable on the surface, over multiple visits, which someone with a chronic illness most likely will need, the financial burden adds up and they are unable to afford it.

Nicole Hemmenway, Panelist (08:17):

Next slide, please. For the 96% of individuals with insurance, we see the results of our questions about costs echoed again. Massage, PT, and acupuncture are the three therapies most commonly prohibited by copays, followed by chiropractic care, and counseling and talk therapy. Aside from costs, issues like prior authorization, and annual visit limits, most often presented barriers to accessing physical therapy, massage, chiropractic care, acupuncture, and, interestingly enough, opioids. Again, and I know I've been saying this over and over, but it really is worth noting that restorative therapies comprise the majority of answers here. We consistently see these emphasized as integral to effective pain management, and yet patients are struggling to access them.

Nicole Hemmenway, Panelist (09:16):

Next slide, please. If there's one silver lining from the pandemic, it has to be the leaps and bounds made in increasing the availability of telehealth, and 90% of patients report they want telehealth to be an option beyond COVID-19. The convenience is vitally important for people with pain who live in rural areas or have mobility issues as it allows them more options for obtaining care.

Nicole Hemmenway, Panelist (09:46):

Next slide, please. I wanted to share this graph to show really the breakdown of mobility issues. Difficulty driving, by far, is the most common mobility issue our community faces, which obviously is going to cause challenges when trying to schedule doctor's appointments, visit healthcare providers, or even get to the pharmacy. I really think it is important to highlight because even if a patient can afford a particular therapy, perhaps they simply can't get to it.

Nicole Hemmenway, Panelist (10:20):

Next slide, please. Finally, the survey shed light on gaps in addressing our behavioral health as part of a multidisciplinary approach to pain care. Slightly over a quarter reported wishing mind-body and behavioral health therapies were emphasized more by their providers. And almost 20% wish they had the ability to see or see more of a mental health professional, but barriers like costs, again, prevented them from doing so. As an organization that provides support groups to patients, we were interested to see that those in rural areas most commonly found their location a challenge in terms of accessing support groups, and not necessarily what we thought would

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be the most common challenge, which would have been restorative therapies or interventional procedures.

Nicole Hemmenway, Panelist (11:17):

Next slide, please. By and large, the study clearly underscores the enormous gaps between best practices in pain management, and the pain care that is currently affordable and accessible to patients. Much more must be done to reduce those barriers to care and here are some of our recommendations. First, we must incentivize the creation of multidisciplinary pain centers through value-based models of care. If we truly want to improve pain care, especially for individuals with complex and disabling health issues, payments should be tied to health outcomes and not services.

Nicole Hemmenway, Panelist (12:00):

Next, we need to improve insurance coverage of multidisciplinary therapies, particularly massage therapy, acupuncture, physical therapy, chiropractic care, exercise programs, and counseling or talk therapy. And this also ties into what Kirk was talking about a little bit earlier, this is both in terms of lowering out of pocket costs, but also in terms of rules and limits on things like the number of visits per year, or unwieldy authorization paperwork just to get to the right provider. And finally, we have to provide more education to providers and patients on the value of multidisciplinary care, specifically that it is best practice to find the right combinations of therapies for the management of each individual pain. In particular, we are huge advocates for the national dissemination of the HHS's recent best practices and pain management reports.

Nicole Hemmenway, Panelist (13:01):

Next slide, please. Well, thank you guys so much for having me here today. This is a much needed conversation and we really do appreciate the opportunity to include the patient perspective. For those that would like to read more about our findings from this survey, please look at this link that's on the slide and you can download the report. I'd also like to thank our sponsor of the survey, Sunbeam, and especially the AACIPM for inviting U.S. Pain Foundation to partner on this symposium. Thank you so much. And Cindy, I'll turn it back over to you.

Cindy Steinberg, Moderator (13:35):

Thanks, Nicole. Great job summarizing a sort of complex report, but the report's available like Nicole said, so hope you all take a look at it, both on our website, and I know Amy is going to make it available as well. (<https://uspainawarenessmonth.com/access-survey/>)