TRANSCRIPT #: 1016

' Pain: Controlling the Narrative’'

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[00:00:10] So tonight, I have a presentation that I'll be sharing with you the title being, "**Controlling the Narrative**." And this may be a bit of a change in pace from the usual. It's not as heavy on concepts, and treatments, and data, but more along the lines of sharing pain experience from a patient perspective in a clinical window.

[00:00:39] So we'll start by confirming that I am sharing my screen. Here we go. I will introduce that "Pain: Controlling the Narrative." My name is Russell Wimmer. I'm a **physician assistant**. I work in internal medicine, family medicine, as well as addiction medicine, addiction recovery in Lebanon, Oregon, predominantly, so not as prestigious or exotic as Australia. But I am local.

[00:01:06] So, my disclosures: I'm a member of the **Oregon Pain Management Commission**. That is an unpaid position, and it is a public advisory commission. And I have no conflicts of interest for today, and I am not being paid for my time or presentation.

[00:01:20] The **agenda** for tonight and this presentation will be a couple parts. First of all, establishing that pain, as many of you probably know, is not that simple. Starting with, "I hurt," transitioning that into, "Tell me more," and then hopefully getting to, "What I hear you say is..." And then, if I've done my job, at least one of you will have your mind blown. That's the goal.

[00:01:42] This is a bit of a transition from what I'm used to. And this would be great for a lot of participation, audience kind of interaction. I'm just going to have to tell myself that you're laughing when I think I'm being funny. And that there's head nodding when I ask what are essentially rhetorical questions. So with that in mind, I'm also going to do a lot of cliche things that I always make fun of presenters for doing in their presentations. I **encourage you to laugh** because they are funny.

[00:02:07] We'll start with, "Pain: It's not that simple." So the goal is to find out how to listen and **how to be heard** in the context of the personal pain experience.

[00:02:16] So let's start with that first and foremost cliche, which is, let's define pain. So **pain: physical suffering**, or discomfort caused by an illness or injury. I can't see your faces, but here's where I would really look to see how many people are nodding and how many people are squinting in anger. Because this is an absolutely **terrible definition**.

[00:02:36] It is not simply physical suffering. It is not a physically simple discomfort caused by injury or illness. It is far **more complex** and nuanced and multifactorial.

[00:02:48] So let's get into a better definition. We're going to go with the tried and true **Merriam-Webster definition**. I apologize. But it is "a localized or generalized unpleasant bodily sensation or a complex of sensations that cause mild to severe physical discomfort and emotional distress, and typically, results from bodily disorder." now, there are a couple things that I underlined and highlighted because I think that they're on the right track. This is not a perfect definition, but it's better. In the way that we are now understanding the pain experience. This is much better. It is unpleasant. It is a discomfort, and it is often linked with emotional distress. And I think that there's more to it than this, but it's a good start.

[00:03:34] And the best word in that entire definition in my word is "typically." Because the most important part in my mind about a **pain experience is** that there's nothing really typical about it. It's **unique**, it's individualized, and it's different. Everyone experiences pain differently, and that experience is modified by a number of things that we're still identifying.

[00:03:58] And so starting with this as a general jumping point, this is the idea of pain. It's complex. It's motivated by **external and internal factors**. It's modified by things like thoughts, fears, beliefs about pain and about the source of the pain.

[00:04:15] So I'm going to use this picture. I kind of stole this story from a previous Pain Summit, but I use it a ton with patients. And I think it really lays some great groundwork. So I will be brief. There is a very **well-documented case**. Construction worker on the site

doing his job, stepped off of a step, and stepped down, and wearing proper, attire, and safety gear, and work boots, and everything, stepped on a very large metal spike.

[00:04:41] And that **metal spike** punctured the bottom of his boot, and went through the boot, and punctured all the way up through the top of the boot. And the moment he realized, of course, did what everyone would expect the typical response would be, which is a very painful reaction. You know, took the weight immediately off the foot, fell to the ground, grabbed the foot, starts calling for help.

[00:05:01] So his mates do exactly what they're supposed to, they pick him up. They get him into a car. They get him transported to the emergency room. And they come?? him into the **emergency room** with his foot in a boot with a huge metal spike saying, what now? How do we fix this?

[00:05:14] And so in the emergency room, they immediately do what they do. They triage. They put on a blood pressure cuff and a pulse ox and all the things. And they start monitoring his vitals and they see that he's hypertensive, and he's tachycardic, and he's sweating, and he's clearly writhing in pain. This man is in **really bad pain**. And as clinicians we're taught that's how we know he is in pain. He looks like he's in pain. His blood pressure, his body's compensating for these huge excitatory signals being sent from the foot, right? He's got this metal spike.

[00:05:41] It's got to be terrible, so they give him pain medication to try and **stabilize him** enough to start assessing and dealing with the problem, which is his foot, right? And the first dose doesn't really work. And then they give him a subsequent dose. And after a couple doses, multiple doses, and a patient with no historical desensitization and intolerance of these strong medications, he's "opiate naive," as we would call it. He starts calming down. It starts working. Right? The pain starts decreasing.

[00:06:09] And so they talk to him. They've got him stable. Then they say, what we're going to do is we're going to cut the boot off, all right? We're going to hold and stabilize this metal spike. And we're going to cut the boot off around your foot so we can see how bad it is. And he goes, okay. And **cut off the boot**. And what they found was that the spike had gone between his toes. It hadn't touched his foot. It hadn't punctured tissue.

[00:06:33] So the question that I have for you is, "**Was he in pain**?" Another great opportunity for audience participation that I will visualize in my head. And my answer is absolutely yes. That man was in pain. He was in pain because the pain is processed in the brain. His body used the mechanism of safety and avoiding danger and saw this metal spike and did what it was supposed to do, which is a protective sense, and said, I'm in pain. Try and stop what's causing it. Try and get away from it. Stop the source. Remove it.

Run! Whatever you gotta do. Fight or flight, the adrenaline. And that's what caused the hypertension and the tachycardia is his brain's response to survive this perceived danger.

[00:07:20] And so the **tissue damage wasn't real**, but the pain was very real. He lived the pain. He experienced it the whole time. From the time he stepped on it into the hospital, despite multiple doses of potent narcotic medication. The **pain was very real** to him. And so the idea that I really want to impress upon this point in the presentation is that we know that pain is complex, and pain is also not the body.

[00:07:46] You can have pain without damage. And you can have damage without pain. I fairly recently had a **90-year-old patient**, and this is very true, 90-year-old patient come into me who said her **hip** had been **bothering her for two weeks**. And her daughter was tired of her kind of slowly ambling around and kind of rubbing at her hip and made her come in to see me. And she walked up to my second floor office to come see me and said, "Well, they just, they made me come here."

[00:08:11] I said, "Well, let's take a look at your leg." And I start examining her, and it's pretty clear, pretty quickly that something doesn't seem right. And I convinced her to let me get an x-ray. And when I get the x-ray, I found that her **femur**, her big bone in her leg had **fractured** just below her hip and was completely misaligned. Huh? It was pushed to the side of where it should be. It should be like this. It was like this. It was completely broken. It had been for two whole weeks, and she was still walking around. She walked up to my second floor office, and she only came in because she was tired of getting nagged by her daughter.

[00:08:48] She had very real damage. She was in surgery within a couple days and has some new hardware she hadn't planned on. But she really **wasn't in a lot of pain.**

[00:08:57] And so this old concept that we've kind of married to for so long, and we've really meshed into how we've previously approached **pain** is that if you **have damage**, then you have pain. And if we can address the damage, then the pain goes away. And that's just not true. You can have damage without pain. You can have pain without damage.

[00:09:17] So I'm going to keep doing the cliche thing and I'm going to go through a couple more stories. Disclaimer, this is not my toddler. I do have a **toddler**. This is not mine. It was just a great picture online and this one's actually funnier than mine. Don't tell my wife. She will get mad about that. So I have a patient whose kid is right now she's just about turned four. And about a year and a half ago, so she's two and a half, we're talking about our kids in communication and stories. And she said the most prophetic thing that I have seen and experienced in parenting, and then it has translated into a lot

of my practice and communication. And so the scenario was that her two-and-a half-year-old daughter, she has words and she has some **language**, but she's, she's two, you know, she's got a two year old's language. Mom understands it, Dad understands it, mostly, and no one else does.

[00:10:04] And her daughter is trying to communicate that she really needs something that's by the fridge. I want it. I need it. And she's using words and she's using motions and Mom is not understanding it. And it's something that she doesn't just want, it's something she feels she needs. And so she starts getting more and more upset, and she starts melting down. And any one of you that have had kids, hopefully, have ingrained in you the trauma that I live with every day of having a toddler meltdown. It's terrible. And the **kid starts melting down**, and Mom becomes more desperate to try and fix it and finally connects the dots of what her daughter's trying to communicate.

[00:10:36] And she gets, I think it was just a cup of water. It was a **sippy cup of water** and hands it to her and says, honey, is this what you want? And her daughter hugs it and says yes. And just maintains eye contact with Mom. And totally stops the meltdown. And it was at that moment that she said, "It was like my daughter has been doing everything in her power to communicate with me for two and a half years. And I've been doing everything in my power to understand anything that she's trying to say. And at **that moment i**t was like I finally got her, finally heard her for the first time. And this is what two and a half years of struggle for this tiny little human being who's so dependent on me. It's finally paid off, and we were both relieved." And she said, "I have been chasing that moment and it's finally getting easier."

[00:11:24] And that really struck home with me with how difficult some **patient experiences** are to describe, how difficult they are to explain, and how important communication and just feeling heard can be in every context.

[00:11:42] This is **the brain of a six y**ear old. They did an amazing study through Brown University. They called it the baby imaging lab. They're really smart people. They're not good at creative titles, clearly. A child's vocabulary grows from the time that they're about two years of age until the time that they're four at an even growth. That part of the brain doesn't go up and down based on how much vocabulary they're exposed to or how many words they learn. It just keeps growing at the same rate, at the same speed. They're constantly absorbing, no matter what.

[00:12:15] And at about a year they have 50 words in their vocabulary. At six, two years after that growth has stopped, but they're starting to really make more complex connections, they have 5,000 words. In five years that part of their **brain**. I guess you can kind of see me pointing, but not at the screen, so that's less helpful for me to do. But

each one of those colors represents a different measurable timeline along that one year to four years that they scanned. And it **just keeps growing** and growing in as a 100-fold increase, which is just massive.

[00:12:53] And that really hits home to me how important it is for communication to exist in us as human beings as early as possible. I mean, they're barely walking at 12 months old, and they're already starting to communicate. And then by the time they're six, I mean, they're not driving, they're not voting, hopefully, possibly. I don't know. But they have 5,000 words. It's incredible. At the age of two, they have the intelligence of most dogs, and I know a lot of smart dogs. But **four years later**, they have this massive amount of communication skill.

[00:13:26] Last story, probably, I have a patient that I see in addiction and recovery. And let me start by saying she's not an addiction patient. She had a number of abdominal surgeries. And **after** those **abdominal surgeries**, which were merited, there was real reason to do them, she **developed chronic pain**. And that pain continued to evolve, and despite more surgeries and interventions specifically to fix her post-procedural pain, it didn't work. And her function was affected, and her life was affected. And it went from, "I was pain free, but I had some stuff that needed to be addressed surgically" to "I have some pain", to "I live with a lot of pain." And so eventually the determination was made to put her on opiate medication. It helped. It helped her function better. It helped her feel better. She, she was able to regain some of her function.

[00:14:18] But, after a number of years on that medication, she had changed clinicians a few times because practices had changed or someone had left. And at some point, one of her clinicians decided to put her on **methadone**. And methadone is a really potent opioid medication that is classically reserved for substance use and dependence. It's used because it has a high potency. It's very titratable. It's difficult to abuse. It has a lot of good benefits for that cause, but can also be used for pain, largely because of its potency. And it has a long duration. So you can dose it once per day, and it'll last for a 24-hour period. But there aren't many people that will prescribe it, even though it's available for clinicians that can prescribe controlled medications. Methadone is perfectly within our rights to prescribe. Not many people do.

[00:15:05] And so she was put on methadone and it was okay. It wasn't better than what was before. It was probably not quite as good. But she was told by her clinician, "This is a better option." And so she stuck with it. And then once again, after about a year, her clinician left the practice. And she inherited a new clinician for her primary care. And they said well, "I've gotta send you somewhere else for your pain." And she didn't understand. And she said, "Well, why? I mean, you've been managing my pain in this practice for, for years. I, nothing's changed. I don't understand." And they said, "Well, I

don't deal with addiction." And she was very confused and said, "I don't understand. I don't have addiction." And they said, "Well, you're on methadone. And the **only reason to be on methadone is addiction.**"

[00:15:44] And so she ran into an impasse. She said, " Can you review my history? I've never had addiction issues. I've never had dependency issues. I just have chronic pain. And, I didn't ask for this. I was put on it. I don't know what to do." And they said, "Well, I can't help you. You **need to find someone else** who will prescribe for you."

[00:15:58] And so now I manage her. And I have for about a year and a half. And so despite the fact that she has persistent pain through no fault of her own, and she lives with that experience. And she didn't make the choice to initially become a patient that was managed on that level of medication, and she definitely didn't make the informed decision to start methadone. She was following the advice that she was given and kind of doing what she was told. **She has been labeled** a pain patient, and she's been labeled an addict, and she's neither of those things. Hmm.

[00:16:32] And so to give you **a bit of a happy ending** for that, and it will segue into what I'm hoping to achieve here, one of our audience, who I'm going to put on the spot because she's the one that got me here, Sharna Prasad, has worked with this individual. And I will tell you that it took a number of appointments with this patient. And I would say probably six, and I see her once a month, six appointments. And the first appointment or two, I just got to know her and let her know that my job was to help whatever she needed. I acknowledged that she was not a patient seeking addiction and recovery services, that that is not what she needed, and that's not why she was there. She was there through no fault of her own. She was there to be managed, to have her medications maintained. And she had accepted that that was the best it was ever going to be.

[00:17:20] And so I asked her to tell me about her pain experience, **her story**. And she told me her story. And over 4, 5, 6 months, I was able to convince her that there may be someone else who'd like to hear her story. And that person may be able to let her see her pain in a different way that might be modifiable. And I was very clear. I am not trying to send you to a new therapist that's new and awesome and a new treatment. And I am not going to solve your pain and neither is she. But I do think that you have been a victim of the classic model for a long time, and that model has failed you. And I think that there are people that understand pain the way that I do that are much more open-minded that will see where you are at in your experience and may be able to give you some hope.

[00:18:08] And I will not disclose a whole lot of details, but I can tell you that she is still a patient with a persistent pain experience, but **her life is very different**. And she has a lot

more influence on how she feels. And she has a lot of good days. And she knows that there will be bad days, and she's okay with that because she knows that she's got a lot more of a part in it than she ever thought she did. And that all came from my approach of, "I just want to know your story." And then her having the courage to be vulnerable when we actually formed some trust.

[00:18:43] So with all of that said, w**hy is pain so difficult to communicate?** And in my experience, there are two personal patient experiences that if you haven't lived them, you can't explain them. If someone hasn't experienced it, no amount of eloquence or token-esque ability to write and paint a scene will be able to get them to experience what it means to live that way and to feel that day in, day out. And the nuances. These are both very lived experiences. And one of those is substance use dependence, or what some people coin addiction. And the other is chronic pain or the persistent lived pain experience. They're both lived experiences. They're both things that include lots of factors and nuance that occurred day in and day out. And if you haven't experienced all of those nuances, you just have to accept it on face value. And man, and that's hard.

[00:19:40] And the idea that it, yeah, it just hurts, and that's where it ends is really hard to break. So there's the end of my presentation. I hope it was helpful. I'm kidding. I basically **highlighted the problem**. So here's the challenge. Here's the difficulty in all this. Now what, right?

[00:19:59] One of the simplest things is **to be able to communicate "I hurt"** and hear all the nuances and seek care and support, but man is that difficult. Right? And I want to get us to the point where I can empower patients to go from, "I hurt" to, "Tell me more," from the other side. The average patient with a lived pain experience has experienced it for years. And many, many, many of the patients I've run into have been living with this for a decade or more. And they've gone through clinician after clinician. And every time they try and have this conversation, it runs into a brick wall of someone saying, "I get it. You just want pain meds." Or, "Yeah, you hurt. I can't fix you." Or, " Another surgery's not going to work." And it ends the conversation.

[00:20:42] And so **they just stop trying**, and that is a horribly isolating and disempowering feeling. So both of those conditions and both of those stories, I was hoping to illustrate that that lack of communication, that lack of feeling heard, it's a barrier to connecting with one another as human beings. You can't form an alliance. And it is just this impassable brick wall to improve the wellness.

[00:21:07] So my goal and my encouragement is to just **start with what your goal is**. And rarely is that goal "I want to be fixed." So there are two parts to this. There is the lived experience, which is the persistent lived patient experience of pain, and that is a story.

It's not simple. It didn't just happen when I dropped the hammer on my foot, and my foot's hurt ever since. There's a lot to it. Usually there's surgeries and there's years, and there's things that were up and things that were down. And it affects your sleep and your emotion, your fatigue. Those things are really hard to communicate, and I know that that's not easy.

[00:21:44] **It takes vulnerability**, and that's scary. And so what I'm hoping is to make it a little softer and to develop a better rapport with this, which is I want you as a patient, if you live this and you're trying to bridge this conversation with a family member or ideally you know, a clinician, because this is where my peers and I have to be better. Start that with "I want you to understand." And on the other end, we have to want to understand, we have to want to bridge that gap. And it's difficult to understand something we haven't lived, you know? How do you describe color to a dog? How, how do you describe something that you've never seen, you don't know exists from someone who has, it's very challenging.

[00:22:29] So I'm going to encourage you to just start at the beginning. If you're going to walk into that room, start at the beginning and view it as a story, and you're going to start as simply and as comfortable as you can by saying, "Today I'm hoping to tell you about my pain and have you understand a little bit of what that means to me." It's not just the pain exists. It's not just the hurt. It's what does that hurt do? What does it mean? How does it affect who you are as a human? Because that's really **the origin** of what a persistent lived pain experience is. It's all of that profile. It's not just a back hurts. It's the feelings and the emotions and all of the things that go along with the impact of that pain all day, every day, and ebbs and flows and ups and downs.

[00:23:18] And, "**I want you to hear how this affects me**," right? Communicating all those pieces. It's also okay to say, "This is hard for me to talk about." And that may be helpful. It's okay to not know what happens next. If you just start with that, it's okay because the provider probably doesn't know either. The course forward takes a team approach, and the team starts with one person, the person behind the pain, and then it grows.

[00:23:52] So if you aren't feeling heard, it's okay to say, "I don't feel like you're hearing me." Or, "I don't know that I'm communicating what I meant to." It's okay to say, "This is challenging and scary, and I feel like I've tried this a lot, and no one really seems to understand. **I'm hoping you can understand.**" It's okay to say that that conversation is failing. Because if you do and you try and communicate that it's challenging and difficult, and it's complex and you haven't been heard before, and there's a lot to it. At some point, hopefully, the other person is going to, and that other person in this context may

be me, put down the pen, put down the notepad, take their eyes off the computer screen, and go, "What do you mean?"

[00:24:39] And that's the hook. That's **the bridge** because sharing the story opens the opportunity for more people to be involved, more characters to become part of that story. And then change the ending of that story. And that's ultimately the way that we improve wellness for anyone that deals with persistent pain experience. It takes community. It takes people from multiple disciplines because no one has the right answer.

[00:25:06] And that should be absolutely supported by the fact that many people with persistent pain experiences have done this for years, and years, and years. And **they've seen lots of people over those years**, and it kind of all ended up the same. And in my patient with persistent abdominal pain, the chronic pain, it was multiple surgeries. It was multiple primary care clinicians. It was multiple physical therapists. It was multiple, insert any level of provider you can think of.

[00:25:34] She tried it. It wasn't that she wasn't open to being better, she desperately wanted to be better. No one had the right idea. And part of that was that **no one was really hearing** what she was saying. And part of that was that the old model is still prevalent. But the one thing that has quite literally changed her life is one amazing provider that has laid a seed in this community, who has taught me a lot of the vocabulary and the terminology, and broken down my old beliefs of pain. And made a change.

[00:26:06] And that change continues to sow more and more and more productivity and more benefits through lots and lots of people. And that program that I work with, and I'm still talking about Sharna, has grown. And the first time that **I met Sharna**, she gave me a quiz. **I asked to shadow her**, and her first day was that she gave me a quiz. And it had 20 different statements about pain. And she said, I want you to check every one of these that you know, is correct. And I checked three of them, and she turned it over and she said, well, you only failed a little. There are none of them that are correct. And we talked about it.

[00:26:46] But **it takes a whole team to start to make chan**ge when the model that we've worked on for so long is so wrong. And so by sharing your story in the beginning and breaking through some vulnerability and opening up, even though it is hard and scary and challenging, and you have no idea what comes next. And the person on the other side of the table, myself or some of my peers, probably don't either. That's okay because it starts by admitting we're not really sure how to move forward. But we're going to keep looking.

[00:27:16] Sometimes the best action is nothing. Just listen. And that has been true for me as a clinician ever since I started. **Sometimes the best approach is** to just shut up and listen. When it's obvious that the goals cannot be reached, you don't adjust the goals, you adjust the action. And that is important for everyone.

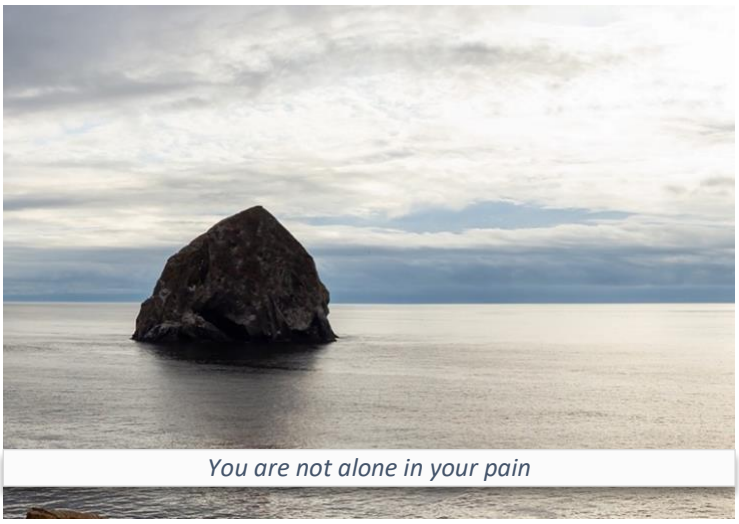
[00:27:42] The goal is wellness. The goal is improved quality of life. The **goal doesn't change**, but the way that we address it, the action, the way that it's received, should and can. I'm going to use a mantra that is not mine, that I have stolen from peers. Probably heard it before, but, "All pain is pain. All pain is real. All pain can be modified." Not all **pain** can go away, but it **can change over time**. And because it's individualized, those modifiers are individualized, too. And it starts with opening up and **sharing what pain is to you**, what it means to you, how it feels, and then starting to work with people as you build alliance to identify them and find ways that they can be changed.

[00:28:27] I'll leave you with one of my last quotes. I am a huge nerd, so I, of course, quoted Tolkien: " Go back is no good at all. Go sideways is impossible. **Go forward is the only thing to do.** On we go." And the we in that statement is the most important. Many patients with this lived experience have tried sideways, and they've tried backwards, and they've tried everything. But if we are to move forward, starts with we, and that starts with your story. And that is what I have.

About Pain Science Life Stories

Formed in 2018, the Oregon Pain Science Alliance (the Alliance) is an all-volunteer nonprofit 501(c)3 corporation. Our members come from the health care community, their patients, and others who follow pain science research.

We seek to share current information on how pain experiences are formed in the brain and influenced by biological, psychological, and/or social factors. Through community education events, health care workers describe how pain-science-based practices have changed their interaction with and care for patients, and patients tell stories about their experience with learned pain science tools used to help master chronic pain. We can now share these collected and curated stories, and other unique features, through the Alliance "story website" launched in early fall of 2022.



You are not alone in your pain

How to get involved?

Do new Pain Science insights and practices resonate with you?

We welcome anyone interested in collaborating to find or produce good stories and insights, then curating them to display on our website. Sharing in our discoveries and making them broadly available is both personally positive, and mutually satisfying.

The phone number or email address below will get you more information about us; then use the website link to the Member page for the steps to become an Alliance member, if that makes sense to you.

If you have a story using pain science tools and practices, and would like to share it with the larger community through our website, please send us an email. We would love to hear from you.

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