## Episode - Ethics Talk: The Invisibility of Chronic Pain

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[mellow music plays]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff.

You stub your toe, and it hurts. You get a paper cut, and you're reminded of it every time you wash your hands. Pain is simple. At least that's how it sometimes seems. But in reality, pain is complex, and it's confusing. Pain experiences are informed not only by physical damage to one's body, but by a series of interactions between one's body, environment, and brain.

A 1995 British Medical Journal case recounts a construction worker who accidentally jumped onto an exposed nail. The nail pierced his boot, and the worker was in pain. A lot of pain. Fentanyl and midazolam were administered before the boot could be touched, much less removed. Amazingly, however, the nail, though embedded in the boot, had passed between the toes and made no contact with the worker's foot. Now, this worker wasn't faking his pain. His experience was very real. The visual cue of a nail sticking through a boot, the worker's background knowledge of everyday workplace hazards, and coworkers rushing to assist were enough information for this person's brain to register danger and produce acute pain.

Chronic pain can also arise from a source that isn't normally painful. This is called allodynia. Everyday activities such as putting on clothes, walking, or sitting still in a moving car can make some of us experience pain. Pain that's neuropathic, for example, is pain that does not come from physical damage to one's body, but instead, the source of neuropathic pain is disordered transmission of sensory signals themselves. And it can be nearly impossible to measure.

KIM CHRISTENSEN: And when you're in chronic pain, honestly, sometimes it gets a little foggy. Like, you're in pain all the time, so it's hard to differentiate. How much is it right this minute compared to 20 minutes ago compared to yesterday at this time? [sighs] It hurts all the time.

T HOFF: That was Kim Christensen. Nine years ago, an accident left Kim with an incomplete spinal cord injury. She has limited physical mobility, which is visible, and chronic neuropathic pain, which is invisible. She joined us to talk about her experience living with both. Kim is a nurse and lactation consultant who works at AMITA Health Resurrection Medical Center in Chicago, Illinois. In the interest of full disclosure, Kim is also my mother-in-law.

Kim, thank you very much for joining me.

CHRISTENSEN: You're welcome. Happy to be here and share what I know.

T HOFF: You experience both visible and invisible effects of your accident. There are mobility limitations, for example, that are quite visible, but your chronic pain is invisible. Has this difference influenced how health professionals respond to you and your symptoms, in your experience?

CHRISTENSEN: It has, and I'm going to start first with my colleagues as health care professionals.

T HOFF: Sure.

CHRISTENSEN: And I recall when I was being interviewed to be rehired for the same position, my team leader asked me how long I would be needing to use crutches.

T HOFF: Mm.

CHRISTENSEN: So, right there, I got a sense of they were hoping this was a temporary situation, as was I.

T HOFF: Mmhmm.

CHRISTENSEN: I would say primarily, my colleagues have been very supportive over the last 38 years. Some of them give me kudos, we'll just say, for actually working, but some of them still question how I can work if I state I'm in so much pain.

T HOFF: Mm.

CHRISTENSEN: And I think that they think that it's maybe not true or real.

T HOFF: Hmm.

CHRISTENSEN: I've never asked them about that specifically, but in my, that's what I feel is coming from them. I also work with a physician who repeatedly asks me for nine years, "Aren't you better yet?" That's shocking to me, and I just, I don't really have a great response to that anymore after nine years.

T HOFF: What was your response the first time? Was it just to treat it as a joke or what? How do you navigate something like that?

CHRISTENSEN: I said, "Well, you know, you might recall that I do have a spinal cord injury. And as of this date, there's two options for complete healing. One would be a scientific research miracle, and the second would be a miracle from God. So, those are my two options right now." And she just doesn't remember that, and I see her all the time. And so, I just kind of like smile and [chuckles]. I don't know what to say to that anymore.

T HOFF: Yeah.

CHRISTENSEN: Some of my colleagues who truly know me, the Kim before my accident and the Kim now, they really can see the true pain I'm in at some points in my day. And my colleague said to me once, she's like, "Kim, I know you're still working, but you need to go home."

T HOFF: Hmm.

CHRISTENSEN: She could just tell on my face, as I'm trying to move and navigate through the nurse's station, that I was in a lot of pain, but still carrying on, nonetheless.

The other thing is that in the professional world—and I don't care where you work—when your colleague or you pass someone in the hallway and they say, "Hey, hi. How are you?" They're really not asking "how are you?"

T HOFF: Right.

CHRISTENSEN: And nobody really wants to triage someone else's mess on a casual encounter in the hallway. So, I have trained myself to have uplifting comments like, "Oh, I'm great," or "feeling fine" or "super-duper, never been better." Because what would someone's answer be if I said, "Horrible?"

T HOFF: Sure.

CHRISTENSEN: It's not really anything they want to handle.

T HOFF: Hmm.

CHRISTENSEN: As far as working with health care, as far as being a patient—so, being with health care professionals, but they're my providers—very few have challenged what I say. I really have not had too much challenge as far as my physical pain, my neuropathic pain, or my disability.

T HOFF: Mmhmm.

CHRISTENSEN: But there are a few. I worked with an orthotist who makes my braces, and I had been back for several adjustments. And he said to me, "Listen, Princess and the pea." Yeah, that 100 percent rubbed me the wrong way. That was the last time I saw him. Because if that was how he, if he felt that way and enough to say it out loud, oh boy. It's one thing to feel that way. It's another thing to verbalize that to me.

T HOFF: Sure.

CHRISTENSEN: And another time, and this makes me sad to even remember this time or to report this again, I was down at RIC, so the biggest rehab. People come from around the world. This was before it was changed to Shirley Ryan AbilityLab.

T HOFF: Mmhmm.

CHRISTENSEN: The top doctor there in the rehab center said to me, "Well, you barely have a spinal cord injury." I was like, "Well, you didn't know me before my spinal cord injury, because this is a lot."

T HOFF: Mmhmm.

CHRISTENSEN: No, yes. Compared to the other patients I did see in that facility, perhaps I see where he's coming from. But to tell me that I barely have a spinal cord injury when I have so much damage to my body, was, it, it's...obviously, I haven't forgotten it. But it has helped me as a practitioner when my patient's in pain, and I'm assessing her, and to me, it

doesn't look that bad. But I would, I will say to her, "I am not the one experiencing your pain."

T HOFF: Mm.

CHRISTENSEN: "You are the one experiencing your pain. And we are going to proceed forward with how you feel, not how I think the case looks in comparison to what I've seen in the last 38 years."

T HOFF: Sure.

CHRISTENSEN: It's her pain, and she's going to tell me what she feels like. And everybody has a different pain threshold.

T HOFF: Yeah.

CHRISTENSEN: And I did work with a hospitalist that never read the chart before they came into my room. And actually, your wife was in the room when this hospitalist asked me to wiggle my toes. And this was in 2016, and Natalie clearly said, "Well, you clearly haven't read the chart because she hasn't been able to wiggle her toes in a couple years." So, that was disheartening as a health care provider to see health care providers. And again, this is only two out of nine years, but these are ones that stick in my head, and that it shouldn't happen.

T HOFF: Mmhmm.

CHRISTENSEN: They shouldn't, a hospitalist or any other doctor should not come in pretending to give care. Yeah. So, I mean, I've been treated well by my colleagues, and overall, I have been treated well by the physicians that I've worked with.

T HOFF: The mobility limitations that you experience seem to, at least from the outside—obviously, it's different living with them—but they seem to have these sort of clear and direct solutions. For example, the ankle-foot orthotics for stability and support or crutches or a wheelchair for ambulating. Addressing the chronic pain seems to be harder, as the solutions are more remote and harder to discern and often come with just modest promises about effectiveness in the first place. Some efforts to assuage your chronic pain that I'm aware of have included, for example, when purchasing a car, paying special attention to the suspension in that car or in various other models to reduce vibrations that might trigger neuropathic pain, things like spinal cord stimulation, and topical analgesics. The invisible symptom of chronic pain seems to demand tolerance, and I can imagine, a great degree of patience with trial and error and uncertainty about what your experience is going to be like. Can you talk a little bit about how the experience of living with chronic pain compares to the experience of living with limited mobility?

CHRISTENSEN: Yeah. So first, I did want to address the chronic pain versus the limited mobility is that I do remember in the early days, probably within the first six months of my injury, having a negotiation with God—like he was going to negotiate with me for real—that I wanted to just keep one problem. He could choose either the neuropathic pain or the disability. And I know that it was ridiculous, but at the time, it seemed like there might be an option out there.

T HOFF: [chuckles]

CHRISTENSEN: Well, of course there's not. But by far, chronic pain is worse than limited mobility.

T HOFF: Hmm.

CHRISTENSEN: The limited mobility, yes, I can't do things like walk on the beach. One of the things I miss the most about my mobility is holding hands with my husband.

T HOFF: Hmm.

CHRISTENSEN: I am either holding crutches or a walker, or he's pushing a wheelchair. So, the holding hand thing is pretty rare. But so, by far, the chronic pain is worse.

T HOFF: Yeah.

CHRISTENSEN: Chronic pain does take away kind of your sense of self and who you always thought you'd be. We all think about who we're going to be going forward, especially as we were heading towards retirement time. We had plans financially, vacations, children, grandchildren. And it does, this kind of an injury does bring it to a screeching halt, and you just have to reevaluate how you're going to do it. It's not over, but it's totally not how you planned. Living with chronic pain, it's not a choice. I don't get to decide how I want it to be or what I want it to be. It's there 24 hours a day.

T HOFF: Hmm.

CHRISTENSEN: And it's not just the pain. It's a complete physical, mental, and emotional assault on my body because the pain makes you weary. The pain makes you crabby. The pain makes you [chuckles] tired. And I don't like to be that way.

T HOFF: Mm.

CHRISTENSEN: That's not me. I don't like to be difficult. And pain's not normal. It just, it reminds you of its constant presence, and I tell that to patients. Every day, I say that to someone. When she's in pain, you know, when I'm working with them, and I say out loud, "And pain's not normal. It means something wrong."

T HOFF: Hmm.

CHRISTENSEN: And what am I thinking in my head? Yeah, there's something wrong. But I'm, you know, except in the case of myself. So, I just, it's not normal. It shouldn't be there.

When you're in this much pain, there's a lot of pain at night. And so, who notices that is pretty much no one. But the habitual sleeplessness, or if you do get to sleep, you sleep for a certain amount of time until your toleration of the pain is no longer good. So then, you cannot tolerate the pain, and you just lay there at night wondering, like how many more minutes? Should I time this? Or should I just think it was a half hour?

T HOFF: Mmhmm.

CHRISTENSEN: Has it really been five minutes, or has it been an hour and five minutes?

T HOFF: Hmm.

CHRISTENSEN: The spinal cord stimulator that I had put in, in 2016, no, '14, 2014, I had that put in. My original surgeon had encouraged me to try every opportunity to fix the pain before I went to something surgical whether it's meditation, it's cannabis, it's pain medication, before surgery, because that's no return.

T HOFF: Sure.

CHRISTENSEN: So, that's what I did. So, after two years, I did seek out more help with a pain specialist. And this physician says, "Are you kidding me? You waited for two years to reach out for some good help?"

T HOFF: Hmm.

CHRISTENSEN: I said, "Well, that was what I was told to do." He's like, "But your body has, really has a different threshold and a tolerance now that it's been going on for two full years."

T HOFF: Hmm, yeah.

CHRISTENSEN: So, I did what I was told. So, we had the spinal cord stimulator put in, and it helped. However, it took me from pain to annoyance.

T HOFF: Hmm.

CHRISTENSEN: So, I don't know if most of you would all agree that that's a great tradeoff.

T HOFF: [laughs] How is it annoyance? Just the managing of it, or what was annoying you?

CHRISTENSEN: Well, the original one, you constantly feel a vibration up and down your legs and in your feet.

T HOFF: Ah.

CHRISTENSEN: So, it would be like being in a vibrating bed or sitting in a massage chair that's constantly vibrating intensely, with the neuropathic pain, and it's a bit insane.

T HOFF: Yeah.

CHRISTENSEN: But did it help me 20 percent? Maybe. And then thankfully, he knew that this upgrade was in the works. And in 2018 I had an upgrade on my spinal cord stimulator, where I don't feel the stimulation. Game changer.

T HOFF: Yeah, I can imagine.

CHRISTENSEN: Yeah. So, I don't feel that constant annoyance. I'm like, I can't say this is so much better because I did go from nonstop pain to now, I have annoyance instead. So, it helps.

T HOFF: Good.

CHRISTENSEN: What I was told is that perhaps this will help 20 percent. Perhaps prescription medications like gabapentin. And I was able to access a cannabis license. I haven't had the best response with that because I just don't feel like I've had great guidance, is part of the problem. The reality is a spinal cord stimulator, alcohol, cannabis, or prescription pain medication, none of them change the pain.

T HOFF: Mmhmm.

CHRISTENSEN: What they change is what your brain thinks about the pain.

T HOFF: Mm.

CHRISTENSEN: So, and going back to my neurosurgeon, he said there is no cure for neuropathic pain. None. I didn't really believe him at the time. I thought that was a ridiculous statement. But it was true. It's right.

T HOFF: Yeah.

CHRISTENSEN: So, there's really nothing out there right now that does fix the pain. But every little part can take 5 percent, 20 percent, 15 percent. And considering that compared to zero percent?

T HOFF: Mmhmm.

CHRISTENSEN: I'm good as I can be.

T HOFF: Yeah. Part of the difficulty of living with invisible illnesses is explaining to others who are used to expecting disability to be apparent in some way. What strategies do you find to be most helpful for communicating to others, and perhaps especially people who are not health care professionals, about what they can't see about your chronic pain?

CHRISTENSEN: You're right. It is difficult to communicate that there's no blood, there's no scar, there's no rash. There is muscle wasting in the lower limbs just because I'm not, I'm using them, but they're not being, the nerves aren't telling the lower legs what to do.

T HOFF: Mmhmm.

CHRISTENSEN: But I try to explain it in ways that you could appreciate, in that if you wear shoes that are too small, it's painful. I wear those every day. Now we're going to put some gravel in those shoes because that's what my feet feel like every day.

T HOFF: Mm.

CHRISTENSEN: And then in your sock, I'm going to put a zester. And every step you take, the zester's going to run up the inside of your ankle and outside of your shin.

T HOFF: Mm.

CHRISTENSEN: It's every day. And doing some simple things like taking a shower, which then requires taking off my clothes, putting on my clothes, using a towel, putting on lotion. Anything that touches those lower limbs, it makes it unbearable. When I'm on vacation

with my family—I'm kidding, but I'm not—I recommend that they put their sunscreen on their lower limbs with sandpaper, preferably a higher grit sandpaper, so you can feel like what that feels like.

T HOFF: Wow.

CHRISTENSEN: Because there's no way for them to see it. But people that really know me, like my husband, my kids, they know by my face and when I'm struggling. And recently I was with my mom for a while, and we were cooking. And I sat down, and I just had this probably very painful look on my face. And she says, like, "What's wrong with you?" "Oh, my gosh. My left leg is just screaming." And I kind of got a [sharp exhalation], you know, breath out of her.

T HOFF: Mm.

CHRISTENSEN: And my sister said, "I thought you take that medication." I said, "Oh, that only helps about 20 percent." She said, "Then why do you take it at all?" So, even the people that love me sometimes and they're with me, pre-pandemic, they want to see the Kim they know. They don't want to, not that they don't trust me in it. I don't know. They just, they don't see it.

T HOFF: Mmhmm.

CHRISTENSEN: And I think I also would like to say to people that don't, can't see my pain—obviously, like you're saying, it's invisible—is that if you're seeing me enjoying myself, it doesn't mean I'm not in pain.

T HOFF: Mmhmm.

CHRISTENSEN: That it's still there. And one of my pain specialists described it to me perfectly, how I can explain to other people is, if you think of we each get 50 poker chips to start our day.

T HOFF: Mmhmm.

CHRISTENSEN: I can spend— We'll each take a shower. That costs you 5; it costs me 15. So, it's just I'm going to use them up faster. If I work today, if I grocery shop today, I just go through all these. Whatever someone without an injury does, it takes me, it's twice as hard for me at the end of the day. I have to plan activities in advance. Like, you know, when my children got married, I've got to plan that weekend out knowing where I have to save the bulk of my energy for. If I'm home for a weekend but I plan on doing a lot of cooking, I have to plan accordingly to save my energy. If I'm planning to go out, I have to plan ahead. I can only dress once for the day because getting dressed and undressed is painful. So, it's...people don't think about those things. You just change your clothes. No, I don't. I have to find the right shoes to fit with the braces. And but planning out the day and energy conservation. If they watch me, they can see where I'm trying to conserve energy. Like, I'll ask someone to get me something.

T HOFF: Mmhmm.

CHRISTENSEN: But I haven't come up with a great way to really get people to understand it, I don't think.

T HOFF: Yeah.

CHRISTENSEN: Because there's still my family that doesn't get it. And just getting people to understand that fatigue is different than tired.

T HOFF: Mm.

CHRISTENSEN: The whole year, I was home for a year after the accident, and I did lay down almost every day. And I can say I probably did not nap 12 times, didn't sleep.

T HOFF: [chuckles]

CHRISTENSEN: I'm not a day sleeper. I'm not tired. I'm fatigued. So, that's one, another thing that people need to understand is, with the invisible illness, again, you can't see it, but I'm fatigued from putting the effort in with the crutches and the walker and stuff.

T HOFF: Yeah. And it's not even just that physical effort. It's the mental effort that you're talking about before of all of this advanced planning and everything like that.

CHRISTENSEN: Right. And trying to appear happy. My mom and dad don't want to see me miserable. They don't.

T HOFF: Mmhmm, yeah.

CHRISTENSEN: So, I really try not to display that in their company. Not that I purposely display it in anyone else's company, but I really put extra effort. This injury was especially painful for my father, who has polio. So, he's been disabled most of his whole life. He got it when he was 16, and he's 82. So, to see his daughter struggle, it's really painful.

T HOFF: Yeah.

CHRISTENSEN: And my mom, I'm sure.

T HOFF: Right. Hmm. Well, hopefully turning to a little bit more of an uplifting area of this conversation of how your experiences have helped you specifically in your professional work as a lactation consultant. And you spoke a little bit about this before, about making sure that essentially to believe your patients. When they say they're in pain, you say, "This is your experience. So, we'll deal with that as a starting point." Are there other ways that your experience has informed the way that you interact with parents of a newborn?

CHRISTENSEN: Well, I was very, I was nervous. I was out a year or so. I was very lucky. The very first patient I went to see, her sister was with her, and I was there for both of their last babies. So, we already all knew each other. So, the first encounter was, just gave my heart a smile because I thought, okay, I can do this. I didn't know how patients would receive me, if patients would trust me. I think just as a practitioner, too, it really has allowed me or made me have to get the dad more involved where before, it's much faster for me to do a diaper change. But now I kind of, you know, the balance and everything for me, standing and balancing. I just use crutches when I go into a patient's room. I don't use a power chair or anything, but it has made me a better practitioner in that I do involve the family more. I do less.

T HOFF: Yeah.

CHRISTENSEN: Because I can do less. Which is actually better for my patients because I'm teaching them more, making them do more hands-on. Like, just in, you know, when I'm busy, it's easier for me to do it myself, but hopefully that's helping them.

T HOFF: Yeah. Finally, to wrap up, as we often do on this show, what's something that you would like health professions students to know about visibility and measurability when they begin caring for patients?

CHRISTENSEN: I was very happy to see this question, because being an experienced practitioner, and now I got the side of being the patient, that I think health care providers should really listen to their patients.

T HOFF: Hmm.

CHRISTENSEN: Let them report their problems. And unfortunately, some patients aren't great historians, but many are. But listen. Actively listen to what they're telling you. Most people are honest, so most patients are telling the truth. And for someone with chronic pain like myself, it is difficult to be a great historian 24/7.

T HOFF: Mmhmm.

CHRISTENSEN: Because what happens is you go to the doctor, you meet with the health care professionals, and they say, they ask you to rate your pain right now. I'm sitting. A two! Have me walk to the park-, through the parking lot to my car? A six. Well, the computer doesn't have that option. The computer will give you one response. It's either two or six. So, listen to the story and appreciate that the computer's not going to give you the whole story.

T HOFF: Sure.

CHRISTENSEN: And then always ask the patient what they have already tried...before you recommend something they have tried!

T HOFF: Mmhmm.

CHRISTENSEN: I try to be really calm when someone's like, "Have you, you should just try topical cannabis." I've tried that. "You should just swim."

T HOFF: Mm.

CHRISTENSEN: Okay, how do I get from the locker room to the pool with no orthotics on? And remember, it hurts my legs to be in movement. Well, in water, they're moving. So, always ask them what they've tried. In my work as a breastfeeding consultant, if someone calls up with pain, I'm like, "What have you tried so far?" Otherwise, it makes no sense for me to rattle off ten things that she has already done.

T HOFF: Sure.

CHRISTENSEN: So, ask them. It saves time for the health care provider and also decreases the frustration of the patient.

[mellow music returns] But then lastly, I am what the person looks like who has an invisible illness. If you just see me sitting here, I don't look any different than anybody else.

T HOFF: Well, thank you very much for the time and for your expertise. I really appreciate you joining us today. And hopefully, we'll get to talk to you again soon.

CHRISTENSEN: All right. Thanks a lot, Tim. Have a good afternoon.

T HOFF: Next is Dr Natalie Hoff. Dr Hoff is a Physical Therapist at the Diamond Headache Inpatient Program at AMITA Health St. Joseph Hospital in Chicago, where she works with patients experiencing chronic migraines. She joins us to discuss the role that physical therapy can play in an interdisciplinary approach to chronic pain management. As sharpeared listeners might've gathered from her being briefly mentioned in the last interview, Dr Hoff is my spouse.

Dr Hoff, welcome to Ethics Talk. [music fades out]

DR NATALIE HOFF: Thanks for having me on, Tim.

T HOFF: So, if you hear somebody say something like, "Well, migraines are just headaches, right," how do you respond?

N HOFF: "No." Migraines are really complex neurological conditions with a wide variety of associated symptoms besides just intense pain in the head. Some of these symptoms are primary, or directly related to the migraine, and others are secondary impairments that can come as a result of headaches or migraines. The secondary impairments include things like occipital or trigeminal neuralgia, sometimes the cervical derangement or dysfunction, hemiplegia, oculomotor impairments, dizziness, mobility impairments, even weight gain associated with being stuck in bed with migraines. So, more than just a headache.

T HOFF: At the Diamond Headache Inpatient Program where you work, migraine headaches are treated as neurological conditions that can be intensely painful, and migraine pain can be mitigated through physical therapy or PT. But many folks don't see the connection between neurological healing and good PT care. So, what should people understand about why PT is a treatment for migraine or other kinds of invisible pain?

N HOFF: Well, the cervical spine, the neck, is one of the most overlooked contributing factors to headaches and migraines. Sometimes this is related to the cervico-trigeminal pathway. The trigeminal pathway is housed in the cervical spine. So, if there's some kind of issue in the cervical spine, that can disrupt the trigeminal pathway and then cause migraines. Other types of cervical dysfunction in general can be excitatory to the nervous system, which can be a breeding ground for migraine as well. That being said, PTs are neuromusculoskeletal experts, and we're really uniquely suited to treat impairment of the cervical spine.

Personally, I use an assessment based on the McKenzie Method of MDT to decide what direction I want to take their treatment approach for the individual that's in front of me. Sometimes we work on treating the migraine directly: which movements, which positions might yield a positive response from the symptoms. Other times we're addressing the pain through more global function with headaches and migraines. We're discussing my patients' activity, tolerance. What do you need to be able to do to get back to work, to

achieve your goals? Whether that's taking care of your home, taking care of your family, getting back to hiking or yoga, for instance. Improving my patients' function can give the brain some kind of alternative stimuli to process, which can inhibit the progression of the migraine itself. So, that indirect approach can be really effective for pain management, pain reduction as well.

T HOFF: Speaking of a more global approach, a key part of your PT practice is yoga. And for those who are suspicious that yoga is not quote "allopathic" enough to be regarded as a legitimate part of Western health care, what are key intersections between PT and yoga that you use to help people with migraine pain?

N HOFF: I think this is an important time to bring up the biopsychosocial model. As we know, pain is not as simple as just real or potential damage to the tissue. There's a lot of factors that make up the pain experience, from biological tissue damage to visually what you can see as dangerous, your past experiences with this potential danger, and even the way that your environment, the people around you, react to this potential danger. Breath and movement both activate the parasympathetic nervous system, which is the goal for pain management. Breath and movement is yoga.

Yoga can be really beneficial for my patients with chronic pain. It is noncompetitive by nature. By definition, you're not competing with others. Most of all, you're not competing with yourself: what you think you ought to be able to do, what you could do in high school, what you could do yesterday. In yoga, we practice focusing on just the present moment, on what you can do today. Before any of the movement or poses, yoga poses, yoga is a mindfulness practice and a breathing practice. The yoga poses are meant to be layers on top of that clear mind and steady breath work. This is particularly helpful for my patients at Diamond because one day may be really different from the next, and that's okay. Our yoga practice helps us work on being okay with that and not judging ourselves one way or the other. And that's a hard thing for all of us, chronic pain or not.

T HOFF: Mm. Inpatients of the Diamond Headache Inpatient Program are cared for by physicians, by pharmacists, dietitians, psychologists, and all sorts of other interdisciplinary colleagues. With all of these different disciplines, how do you collaborate when it's unclear what's working and what's not working for a patient?

N HOFF: Yeah. Firstly, we have weekly meetings regarding each patient to discuss specifically what's working, what's not working, how our interventions might intersect and affect each other either positively or negatively. And this interdisciplinary, multidisciplinary approach is, I think, what sets the Diamond Headache Inpatient Program apart. We can and do collaborate very easily with each other. The Physician's Assistant can ask me what I think about an assistive device for a patient. I can share my findings and recommendations as well as put in orders for anything else the patient might need at discharge. For example, one of the behavioral health therapists stopped by my office the other day to ask what my goals were in PT for a particular patient so that she could work on addressing and carrying out those goals in her session with the patient.

On the flip side, it is sometimes challenging to determine what's working when a patient improves. There's really a lot of moving parts. When a patient starts to feel better, it's often, is it this medication or that medication? Is it what we did in PT? Was that the acupuncture that you had? And then not only is it which intervention worked, but what about it worked for the patient, and how did it improve their pain experience?

It's especially challenging for me as a PT because my treatment approach is among the most conservative end of the spectrum. I don't have any drugs to give my patients. I don't have any needles to stick in them. And oftentimes, the treatment that they're working on with me is mostly independent. I try not to do too much to them, do too much for them. My goal is to partner with my patient to find something that they can do to themselves for some relief. To empower my patients to have some kind of control over their own body rather than trying to fix them with my hands, which won't be there for them in a week or two after they're discharged.

It is a successful approach, but sometimes I will ask my patients to just hold onto this treatment strategy until their discharge. Sometimes there are so many moving puzzle pieces that we can't figure out is this even working? I don't even know right now what's working. So, I'll ask them to pause the PT treatment for now. This is the one movement that we want to assess, go home, settle back into your normal routine, and then try that on for size. When you can have just one variable, limit confounding variables, then it's easier to figure out, oh, hey. Yeah, this is actually working. I can tell a difference on a day when I prioritize my PT treatment versus on the days when I don't. So, sometimes that's an option too, for those confusing cases where we're not sure what's to blame or what's working.

T HOFF: Mmhmm. For invisible symptoms like chronic pain, assessing treatment outcome success relies heavily on patients' self-report of how they feel. And while patient self-report is often criticized as subjective, sometimes it's all you have, and it's all your patient has. So, how do you make the most of what patients tell you about what they're experiencing and use what they know about how they feel about themselves to modify a care plan or make a new treatment goal or make other professional judgments about how to help them?

N HOFF: So, one of the ways is motivational interviewing. It's a particular type of gathering a subjective history to, again, empower the patient more. My mentor says, "Be a guide by their side, not a sage on the stage," which actually came from an educator for the gifted student back in the '80s. It's still relevant for me, though, as a guide for my patients with chronic pain. I like to couple my patients' self-report of pain, tension, discomfort, whatever, with something called concordant signs. So, I observe some kind of movement that's been bothering them, something functional to them, something important in their life: maybe their golf swing, reaching behind them in the car, picking up their kid, holding their phone between their ear and their shoulder. I do a pretest and a post-test of that movement with the intervention, the little exercise, if you will, in the middle. And then we can use that concordant sign, that functional movement that's relevant to their life, to give us more data about the effects of a particular forced application. I think that's the most important thing that we can do for our patients, is just to listen to them, to listen to our patients. Even if I think that this intervention will work, if they don't think it will work, it probably won't.

T HOFF: Mm.

N HOFF: Like, if they don't buy into this, if they're like, "This is garbage. This isn't going to work for me," even if it would, it won't in this situation. [mellow music returns] And so, that has to be a big part of defining their treatment plan, is to listen to them and listen to what they want and what they need.

T HOFF: Dr Hoff, thank you very much for joining me this week and for being a special guest on the podcast.

N HOFF: Thanks so much for having me. Pleasure to be here.

T HOFF: That was Dr Natalie Hoff. Dr Hoff is a Physical Therapist at the Diamond Headache Inpatient Program at AMITA Health St. Joseph Hospital in Chicago, Illinois, where she works with patients experiencing chronic migraines. That's our episode for this month. Thanks to Kim Christensen and Dr Natalie Hoff for joining me for this family edition of *Ethics Talk*. Music was by the Blue Dot Sessions. To read our full July issue, *Illness, Invisibility and Measurability*, visit our site, <u>JournalOf Ethics.org</u>. And for all of our latest news and updates, follow us <u>Twitter</u> and Facebook <u>@JournalOfEthics</u>. And we'll be back next month with an episode on economic decision modeling in health care. Talk to you then.