

Practical Pain Management for IC Patients

Exploring The Many Options For Pain Management & Long Term Care

Featuring Dr. Daniel Brookoff, Integrative Health Center (CO)

Moderated by Jill Osborne, President - IC Network

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INTRODUCTION - Welcome to the second special event in the 2006 IC & PBS On-Line Patient Conference, the only free lecture series available to interstitial cystitis and painful bladder patients on the web. Our goal is to bring the worlds best researchers, clinicians and activists directly into the homes and offices of patients who are unable to travel and/or afford to attend a national or regional conference. Most patients have no choice but to stay home and hope to read transcripts or watch DVD's of the various IC events. The internet, however, changes this dynamic. We can now bring the conference directly to thousands of patients at one time. This would not happen without our generous sponsors, including: Akpharma (Makers of Prelief), Desert Harvest (Makers of DH Aloe), AstraTech (Makers of the Lo-Fric Catheter) & Algonot (Makers of Algonot, Cystoprotek & Prostoprotek). We thank them for their support and encouragement of IC patients throughout the world.

Tonight we welcome Dr. Daniel Brookoff, currently Attending Physician at Integrative Treatment Center in Westminster CO. Known in IC circles for his compassionate care of IC patients around the country, Dr. Brookoff has dedicated his career to advocate for the needs of patients in pain, particularly IC, cancer and sickle cell anemia patients. He is a Clinical Associate Professor of Medicine & Preventive Medicine at the University of Tennessee College of Graduate Health Sciences and formerly served as the Director of the Methodist Hospital Comprehensive Pain Institute (Memphis, TN). A review of the National Library of Medicine will find dozens of publications that he has authored or co-authored on regional pain syndromes, neuromodulation, managing cancer pain and the compassionate use of opiates. For many years, IC patients struggling with pain have flown across the country to consult with him.

His story of how he became involved in IC is telling. In the days when his practice was limited to oncology (the treatment of cancer patients), the sister of one of his cancer patients who had "come back to life" when her cancer pain came under control came to him and asked if he could help her with her pain. He asked, "*what type of cancer do you have?*" She replied that she didn't have cancer, that she had bladder pain from interstitial cystitis. At that point, Dr. B said he actually remembered the one lecture in medical school where they had mentioned interstitial cystitis (he claims to still have the notes – he thinks they're on parchment). The professor had said something to the effect that, "you try this treatment, then you try that treatment and you usually end up having to remove their bladders. But they keep complaining anyway and that's because most of the pain is probably in their heads." At that point, one of the few women in the class stood up and asked, "if you think the pain is in their heads why are you taking out their bladders?" At that point the professor ended the class, leaving the medical students with the impression that the best approach to patients with interstitial cystitis was to avoid them.

With that in mind, he told the lady with IC pain that she really should see a urologist since he only treated cancer patients. At that point, the poor woman looked him straight in the eye and said, "in that case, I wish I had cancer." Dr. B said he was so shaken by that, that he went home and started reading about IC and soon realized what a terrible illness IC was and how difficult it was for patients to get the care they deserved. That lady became his patient and she continues to do well twenty years after their first meeting. In those twenty years, he has been the leading pain advocate in the world speaking at conferences throughout the country on the needs of IC patients. Welcome Dr. Brookoff!

DBROOKOFF - Sorry I'm late but I'm very happy to be here. I have a good excuse. I was taking care of an IC patient!

ICNJILLOSBORNE - Let's start our discussion with your approach to working with patients. What are your priorities??

DBROOKOFF – Let me tell you the doctors' point of view. Pain is alarm that tells us that that something is going on. Doctors must look for meaning in the pain. What does it represent? If someone comes in with pelvic pain, I have to generate a list of possible problems that can be causing that pain. Not only do we assess for the most likely

conditions, but we also have to make sure we rule out the most dangerous conditions that could be causing the pain.

Because of this, I tell my patients we have different agendas. My patients come to me and their first priority is getting relief from their pain. And that's legitimate. But the fact is, relieving pain is the **second** thing on my agenda. My first goal is my patient's safety. We always have to take into account the disparities between what the doctors and patients are seeking and then reconcile them.

ICNJILLOSBORNE - Do you have any ground rules?

There are some general ground rules that I use. If possible, at first I like to see patients with a family member or a support person. This has to be someone who is truly helpful to the patient. This way the "patient's people" are in the majority and patients who have gone through long and frustrating treatments can feel less threatened at the prospect of seeing a new doctor. I tell the support person that his or her "job" is to believe the patient and love the patient. But they don't have to understand the patient.

I know a lot of patients get frustrated when family members don't understand them. But the whole point of getting care is not to get understood – it's to get better. A cry for understanding is the cry of someone who is drowning in their illness. A lot of times I have told a tearful patient that, *"nobody might ever understand what you're going through – not even me. But I really know that if we all work together and listen to you and believe you, you will get better. Now, at that point nobody will understand you either but that probably won't matter much to you. The real interesting thing is that you will have a unique ability to understand others who suffer. You will get better and someday someone will come up to you and will somehow know that **you** understand **them**. In some sense it's a gift – albeit a terrible one. But people who get through what you are going through have a lot of strength. And even when your sickness is gone, your strength will still be there."*

One of my key rules is that only the patient can say how she feels. The patient's story is the absolute gospel truth. **Why** she feels that way is open for discussion. At the same time, only someone who loves you can say how you look. Again, **why** you look that way is a matter for discussion. I tell people that we have two important goals for treatment – you have to **feel** good **and** you have to **look** good. If you feel good but you look like poop, we've still got some work to do. (Or, to quote Vidal Sassoon, "if you don't look good then I don't look good.")

This lets us address everybody's concerns in an honest and open and constructive way. Every day I have family members who are very upset about the pain medications that my patient is taking... even though the patient is improving. So I'll ask the family members how the patient looks and they'll say something like, *"well she's looking great...getting more active and doing more."* And before the words are out of their mouths they realize they are describing somebody who is **getting better** – and that's what we all want. We have to make sure that loving family members don't undermine the progress of a patient fighting pain because of misplaced fears. . We have to address this early in care and we have to face this in a constructive, positive way. If you say you're in pain, that's it. You're in pain and that's the truth. That's how we get started.

ICNJILLOSBORNE - How do you assess pelvic pain in new patients?

DBROOKOFF - I've come to a point now where I take a great deal of time to assess specifically where the pain may be coming from. Some IC patients have pain directly coming from their bladder lining while others have pain from others sources, such as inflamed nerves or dysfunctional pelvic floor muscles. Still others may have pain coming from other structures, often gynecological or related to bowel function. A few simple questions will help us figure this out.

As an example, I had a very nice lady come see me who had terrible pelvic pain since she was 12. She had been diagnosed with everything and was now told she had "end-stage" IC. My first question when assessing IC is *"How often do you get up at night to go to the bathroom?"* She said she usually didn't get up at all at night - maybe once at the most. Another thing I noticed is that as we spent time talking she didn't have to get up and go to the bathroom. This tells me that her discomfort does not appear to be related to hypersensitivity of her bladder to the presence of small amounts of urine – which is a definition of "classic IC". She ended up having a bowel-related problem.

To help determine if a deficiency of the bladder lining is an important generator of pain, I'll ask *"do you ever drink*

alcoholic beverages? Do they give you pelvic discomfort or burning?" In a sense, I see this as a bladder "stress test". If alcohol (or high-potassium foods such as fruit juices) irritates your bladder, then we would suspect that there is a problem with the bladder lining. In one patient's case, alcohol didn't irritate her bladder at all. In fact, it made her feel better. This made me think that therapies aimed specifically at the bladder lining, such as Elmiron or a restrictive diet, might not be especially helpful for this person.

We then explored other things that made her pain worse, such as physical activity. She offered that sexual intercourse was painful, especially afterwards when she would cramp for a day or two. This was a huge clue and suggested that she had a pelvic floor instability. This then became our target for treatment. In her case, bladder lining treatments wouldn't have helped but pelvic floor therapies did.

We've had some very positive results in treating pelvic floor dysfunction with high doses of Valium. Unfortunately, the problem with taking valium orally is that it can make you very sleepy. One solution to this problem is to use valium vaginal suppositories (which, unfortunately, have to be custom-compounded). Up to 80% of women pelvic floor dysfunction who use them have had very good relief without the drowsiness. One sign of success is when they report that they can have intercourse without spasm.

I see a lot of people with IC but I always have to be aware that I see quite a few people with chronic pelvic pain who don't have IC (they may have pain due to pelvic adhesions or endometriosis, etc.) – so I always have to keep an open mind.

ICNJILLOSBORNE - Do you believe in treating pain promptly?

DBROOKOFF - If someone is coming to me for pain relief I have an obligation to rule out dangerous things but I also feel I have an obligation to start providing pain relief **today**. There's almost never any legitimate medical reason to delay. Many doctors won't start treating the pain until a person has gone through a lot of tests and procedures to "treat the disease". For most patients with IC, the pain **is** the disease. Pain treatment has to be a priority. There is no reason to not treat pain while we're looking for other causes. Even if we suspect an infection, that's no reason to withhold treatment aimed at relieving severe pain.

ICNJILLOSBORNE – Pain medication options?

With respect to pain medications, I first ask patients what they've tried before that helped or didn't help because they usually come into my office with a lot of prior experience with pain medications. We're not going to take away something that works but we will offer additional things that can improve and optimize pain therapy.

OPIATES FOR MODERATE TO SEVERE PAIN

If you have moderate to severe pelvic pain you probably need a narcotic pain medication. For starters, I want to pick a medication that will work quickly but is also short acting to help minimize side effects. Playing the odds, I'll usually pick something strong that is tolerated by most people. Oxycodone is a reasonable first choice for a lot of people because it usually causes less nausea than some of the other narcotics and has a pretty fast onset. For most people, it hits a couple of different receptors such as the "**mu** opioid" receptors for pain, as well as "**kappa** opioid" receptors for visceral pain. Those are some of my targets to help you get out of the pain.

Some other narcotic (we actually prefer the word "opioid") medications that are worth consideration, depending upon your circumstances and/or drug sensitivities, can include: hydrocodone (e.g. Vicoden, Lortab, Norco) and codeine, which are commonly used for moderate pain. Severe pain may be treated with morphine, Demerol (meperidine), Dilaudid (hydromorphone), Levo-Dromoran (levorphanol), methadone and fentanyl. Long-Acting opioid medications include various brands of slow-release morphine (e.g. MS Contin, Kadian, Avinza), slow released oxycodone (e.g. Oxycontin), and fentanyl. Pretty soon we should have a long-acting form of oxymorphone (currently available in a short-acting form called Numorphan). This drug is a breakdown product of oxycodone and looks like it will provide excellent pain relief with fewer side effects than OxyContin.

In general, when someone says that they can't take a pain medication, such as Vicodin, there may be other medications or chemical classes of opioids that can help, such as fentanyl. Fentanyl used to only be available in a long-acting patch so it often was not used as a starter therapy. It is now available as a rapid-release sucker. Unfortunately, these are very expensive and sometimes not covered by insurance.

DARVON

If people are allergic to "all of the narcotics", one option may be propoxyphene (Darvon, Darvocet). Lots of doctors don't think that Darvon works - the party line from the pain experts is that it's no more effective than Tylenol. They always refer to one study that was done at the National Institute of Dental Health which examined of people getting their teeth pulled. They had a molar pulled and were either given Darvon or Tylenol. The participants couldn't tell the difference between the two medications. The interesting thing, though, is that none of those people had chronic pain and that none of the people participating were women because, back then, they didn't allow women in most pain studies ("too many hormones"). We now know that there are significant gender differences in response to pain medications. I have taken care of a lot of women who do respond to Darvon. It may be worth consideration.

DEMEROL

Patients who are "allergic/sensitive to/cannot tolerate" the usual opioids may get pain relief with Demerol. The problem, though, are the side effects. Demerol has a breakdown product that can last for long periods of time (i.e. 15 hours while the active medication only lasts for 4 hours). This breakdown product, called normeperidine can cause epileptic seizures. That's why we avoid long term use of Demerol.

LEVORPHANOL

There are also other other narcotics that are somewhere in between short and long-acting. One of the best is levorphanol (Levo-Dromoran). It's an extremely effective drug that is very bioavailable, which means that 90% of it will enter your bloodstream. For most opioids, that number is between 40% and 60%. It has relatively low side effects for most people and it's relatively inexpensive. It's hard to find at many pharmacies and some insurance don't cover it.

METHADONE

Another medication that is getting a lot of publicity lately is methadone. Methadone is really unique because it contains two different types of molecules, one of which appears to reverse opioid tolerance. Methadone also seems to work better the longer you take it. This makes it the opposite of a lot of narcotics which, if you're taking a certain dose, don't work as well over time. But with methadone, if you take the same dose, it seems to work better over time.

A potentially dangerous feature of methadone is that the side effects can be delayed, particularly its sedating effects. The drug can build up so you have to be worried about delayed sedation. I stay in very close contact with patients while they are starting methadone. Whenever I start someone on methadone, I seek a family member or other support person to talk to about the sedating effect so that they can monitor the patient's level of sedation and notify me of any problems so we can adjust the dose.

HYPER VS. SEDATION EFFECTS

It's important to understand that there are some narcotics that can "hype you up" where others can make you sleepy. A lot of doctors are not aware of this. For example, oxycodone (Percocet, OxyContin) will stimulate a lot of people and they will feel energized. I don't have a problem with this during the day because it can help them work, etc. But, I have a problem with that at night because it will undermine their sleep.

The most commonly used long acting narcotic is Oxycontin, which is a long acting form of oxycodone. Most people need it at least three times a day (though the PDR suggests twice a day). If it's taken in the morning, it can wear off in the afternoon. When some patients take their nighttime dose, they can get energized and might be unable to sleep. So, if OxyContin helps you but stops you from sleeping, we might try using the Oxycontin during the day and then, at bed time, we'll use methadone, which will allow you to sleep. If you just use methadone at night, it doesn't seem to build up over time and patients can get a nice night of sleep. Again these are generalizations and there are even some people who might get stimulated on methadone.

STEROIDS

Patients with IC have different types of pain and different types will respond to different medication. For example, part of the pain might be inflammatory pain. Narcotics often won't help this. Often we'll give these patients a trial dose of a high-potency steroid, such as dexamethasone, that can get into the central nervous system and to the inflamed nerves where we think the problem is. Dexamethasone is extremely strong and we caution people about the side effects. Short-term side effects might be agitation and increased appetite. Obviously we can't use this for patients with diabetes or high blood pressure. Within ten days, some people get extraordinary pain relief and others don't. If they don't, we're not going to waste their time with less potent anti-inflammatory drugs.

ANTICONVULSANTS & ANTIDEPRESSANTS

There are other classes of drugs that work enough that they deserve to be tried, such as anticonvulsants (i.e. Lyrica, Neurontin) and anti-depressants, some of which have an independent pain relieving effect.

The classic "SSRI" antidepressant drugs (e.g. Prozac, Paxil, Celexa, Lexapro) are often very good for depression but don't give significant pain relief. Tricyclic antidepressants do seem to have modest pain relieving effects as well as increased bladder capacity and can help you sleep at night (i.e. Elavil) They can also cause weight gain.

Another drug that is commonly used is trazodone (Desyrel). Effexor can be effective but can be a little tough due to side effects. It is fast acting and does confer some pain relief.

The real star of the antidepressant group is duloxetine (Cymbalta) which was developed for neuropathy pain. It really takes away a certain part of IC pain, usually the unpleasant burning, ground glass sensations in the pelvis. This type of pain is usually due to some kind of dysfunction in nerve cells and is termed neuropathic pain. Cymbalta really seems to help a lot with that type of pain.

ICNJILLOSBORNE - Are there any alternative medications that can help with pain?

DBROOKOFF - Absolutely yes! Some of the "alternatives" are versions of things that we use. There are some herbs that act like valium. Marinol (THC), which is the active ingredient in marijuana, has helped a small group of people with nerve type of pain. Aloe vera appears to be chemically similar to Elmiron.

I have no problem with "alternative medications" as long as people are using them safely. As I once said (a few minutes ago), my first priority is safety. I have a lot of patients who bring in big bags of herbs that they are taking and we will work to look them up for safety before we go any further. Then we'll keep our minds open and learn together.

ICNJILLOSBORNE - What about pain that fluctuates with the menstrual cycle? Do you recommend stopping the cycle with birth control pills?

DBROOKOFF - Great question! One of the first things we ask new patients about is the relationship of the pain with their cycle. This is often a really important feature of their illness. Some people have pain during ovulation while other may peak right before menses. We may try to find and keep them at their optimal hormone level (the time of the month when they feel the best).

ICNJILLOSBORNE - Let's talk briefly about clitoral pain. Some patients struggle with longer periods of clitoral pain, often with a persistent sensation of arousal. Any ideas for them?

DBROOKOFF – One thing I worry about is a condition called "clitorism", which is a prolonged, painful period of clitoral erection. One of the things that makes me nervous about this is that I've seen three women in which this was due to a Trazodone (an antidepressant). Their doctors, unfortunately, thought their clitoral pain was a sign of depression so they increased their Trazadone, which dramatically increased their clitoral pain. It turns out the FDA had hundreds and hundreds of reports of this. So, I'll want to make sure that they are not taking something that is making this occur. I also have to consider if it could be another condition such as pudendal neuralgia. We might use locally acting medications such as lidocaine. Neurontin or Elavil in a topical gel can provide pain relieving effects locally.

ICNJILLOSBORNE - One patient asks "Can you explain the difference between addiction versus tolerance. My doctor won't give me pain medication because he says I'll be an addict?"

DBROOKOFF - To give you my personal definition, tolerance is a biochemical happening. It means that, after a period of time, with the same blood level of the drug, you get less effect. Tolerance can be a very good thing. For example, when we are using narcotic medications, which are the mainstay for severe pain, it might have pain relief effects but it can also cause nausea or itching as side effects. Interestingly, most people will develop tolerance to the side effects way before they develop tolerance to the pain-relieving effects.

There was a big study done on people taking morphine who started losing their relief with this drug. They thought it

was tolerance but it was instead was *pseudotolerance*, which means that, over time, their livers got better at breaking it down. The treatment for that is called **opioid rotation**. If an opioid drug is no longer working for you, we'll try a new one that is chemically different. This has been studied in cancer patients where we know they frequently have to have their pain medications changed. So, we know this is biochemical, not psychological.

Addiction is compulsive abuse of a drug that means that a person uses the drug to solve a lot of **non**-medical problems. Eventually they develop a strategy of "compulsive abuse". Addiction is a profoundly awful condition that deserves concern, care and treatment.

Mislabeling a patient as an addict can be terribly damaging to them. I have gotten the opportunity to meet quite a few real drug addicts and I believe that the addiction lives in the person, not in the drug. If you're addict, if we take away your drug, you'll find another drug to take. If you're not an addict, I really can't turn you into one. People have the misconception that exposure to the drug will create addiction and that's only true in a certain type of person. The estimate of addiction in the general population is just 6%.

We have to always keep looking at why people take their drugs. Pain patients want to live and take their pain medications to improve their function and activities. An addict, on the other hand, will take pain medication so that they don't have to be functional, they want to get high and escape their responsibilities.

ICNJILLOSBORNE - Any comments about using botox to treat pain?? Seen any success??

DBROOKOFF - Yes, we've had a lot of nice results. Botox can be wonderful for treating trigger points and for patients who have spasms after sex. It can help with muscle spasm or pain in the lower back. Botox might help relieve pain for the long term.

ICNJILLOSBORNE - How would you suggest that patients find a doctor who will treat their IC pain??

DBROOKOFF - The best source of information are often other patients, so if there is an IC support group in your community that can identify doctors who can be helpful, that's probably the best way to proceed.

ICNJILLOSBORNE - What are your thoughts on Ultram?

DBROOKOFF - Ultram is a really interesting drug that works differently in different people. We don't really know the complete mechanism of action for it. It acts partially like a narcotic and partially like a tricyclic antidepressant (e.g. Elavil). If it works, it usually works quickly. A lot of people get nauseated on it and I've seen others get very euphoric on it. While some patients have gotten pain relief with it I haven't found it to be very effective in IC. I'm also worried about its association with epileptic seizures – especially when used along with medications such as Elavil.

ICNJILLOSBORNE - A lot of patients complain of unrelenting pressure. Is this neuropathic pain?

DBROOKOFF - Pressure can come from different sources of pain and some pain medications should help with this.

ICNJILLOSBORNE - Any comments about trigger point injections?

DBROOKOFF - I just spent all week doing them. A simple definition of a trigger point is that when you press on it, it sends pain somewhere. A lot of people get relief with treatment that is focused on their trigger points. This could be using a needle with no medication, or injecting a drug like lidocaine, or a steroid or botox. We examine everyone for trigger points and treat them.

ICNJILLOSBORNE - What are you excited about in terms of treating pain?

DBROOKOFF - One of the really neat things that we've seen are the new external interferential stimulators. For patients with a very high pelvic muscle tone this can massage the pelvic floor electronically. These electronic units just use sticky pads on the front and back and require no invasive therapy. I'm really excited about this. We've cancelled surgeries and trigger point injections because of the success with these stimulators. For a lot of patients this is all that they need. We think it's duplicating some of the effects of the implanted stimulators without having to put patients through surgery. The trial just takes 15 minutes and, when it works, it really works. I had three new patients today that got significant relief with it.

ICNJILLOSBORNE - What advice do you have to help pain patches stay on?

DBROOKOFF - Make sure you're putting it on clean, dry skin. No moisturizers! There should be nothing else on the skin. Also, there are different types of patches with different levels of stickiness. Matrix patches are thin tape and they stick with varying levels. Sandoz reservoir patches have different glues. So we try different types of patches with different patients. The most important thing about patches is that they have to be flat on the skin. You can use first aid tape over the top of it to keep it flat.

ICNJILLOSBORNE - One person asks about low back pain and IC.

DBROOKOFF - Certain people can have problems in their spine that can give them pelvic pain without any pelvic disease so its' certainly worth have a good orthopedic exam to rule out other back conditions. It's not a common cause but it's worth thinking about especially if they aren't responding to treatments aimed at other structures (e.g. bladder, pelvic floor).

ICNJILLOSBORNE - What is the best way to explain IC pain to others, especially when they can't see it?

DBROOKOFF - One of the things that IC patients do is that they work really hard to show that they aren't in pain and try to hide it. The best thing that I like to do is invite patients to bring family with them, especially ones that are not supportive, so that we can talk about this. We'll give them literature and explain things like pelvic floor dysfunction. The material that Dr. Moldwin has written is very helpful and validates the patient. I try to be patient and answer the questions of family members. I wish that we had a picture of IC that we could share but we're not there yet. Many people cannot relate to that because they have never had this experience of pain before. Women can relate better because many have had bad bladder infections. We often say "make believe you have a bad bladder infection that lasts forever". Men, often, just can't relate.

There's a very famous story of a urologist at Stanford University who wanted to know what IC pain felt like. He had his nurse put protamine in his bladder. Protamine totally wipes the bladder lining and that person will have IC-like pain for weeks. In his case, he finally understood the desperation that his patients felt. He didn't sleep for several weeks... due to the pain.

ICNJILLOSBORNE - Dr. Brookoff, you have given us two hours of your time tonight and we are so grateful for your knowledge and compassionate approach to treating IC pain. Thank you for being here and for helping so many.

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