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Bridging the Gap conference
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A Clinical Care Model for Spinal CSF Leaks

So I'm going to talk a little bit about our, our model here for CSF leaks. I think it's, it's interesting that I follow Dr. Rau. You know, she refers patients to us and, or I have conversations with her about our patients, and I feel so honored that she would trust me with her patient.

And it's, I, that relationship that we build in this community, both with our patients and our provider colleagues across the country, is incredibly important to me. So I feel honored to follow up her really amazing talk with with mine. I have disclosures here. I'm on the medical advisory board of the Spinal CSF Leak Foundation and I do consultant work with Eli Lilly pharmaceuticals.

We have learned today, and we are all aware, that this condition is much more than an orthostatic headache. There are so many clinical symptoms that confound the diagnosis and make these patients bounce around to so many different doctors before they arrive at the appropriate place. But I'm going to make the case today that radiologists have to rethink their role, their traditional role, of being just image interpreters and clocking out after not seeing patients, because we because there is a call to action here in this disease.

Your patients may have seen neurology, primary care, pain, medicine, rheumatology, and psychiatry, and maybe one of those providers or ordered an imaging test. They said, maybe there's something going on here. Maybe I should get an MRI of your brain. And so I think my radiology colleagues might be frustrated with me because I'm ruining our job where we get to clock in and clock out, go home at five and just read those studies.

But as radiologists, we might be the first ones to suggest this, this condition. Often, we have the procedural skills to localize these leaks and to treat these leaks. So we have an obligation to our patients to change our roles slightly than maybe what we thought we were getting ourselves into, if we have these skills.

I'm also going to make the argument that the traditional radiology proceduralist model where we are just simply a technician arriving, performing a procedure without knowing the patient, and then leaving and never seeing them again does not work for this condition. By the time a patient who has a CSF leak arrives at our clinic for a procedure, they don't trust us, probably.

They don't understand fully what we're going to do to them or to their body. And they have skepticism and fear that we believe what's going on and that we're going to be giving it our all. All of these things are set, are set up for, for failure, for the treatment or diagnosis to not work. By the time that you, the provider, arrive for the procedure in a traditional model, you don't fully understand what the patient's symptoms are, so you won't understand if they get better.

You also probably haven't sat down and said, what can we optimize non invasively to increase the success of our procedure? Have I ordered every possible test? Did we get the right protocol on their MRI spine? Did I do everything I could to make my procedure, give it the best chance of success? And you probably don't have an appropriate infrastructure for follow up.

I know before I had our wonderful team that we've been building here, I was just trying to do all the follow up by myself, you know, on my own time, which is not a sustainable model. I want to remind everyone of this quote, which I think is very important, um, from Hippocrates, that it is far more important to know what person the disease has than what disease the person has.

And this is incredibly important, because this, this disease affects our patients in very different ways. What happens when a person gets referred to our program? We need everything that's happened to you medically in our system so that we can review it. All prior imaging, tests, procedures, an MRI brain, and a total spine at minimum, and ideally with a CSF leak protocol.

But if that hasn't happened, and it's going to be financially prohibitive to do so, we will take what you got. We start with a clinic visit, okay? Before we do a procedure or put a needle in you, we try to see you and have a conversation with you. We want to obtain a complete medical history. We want to start from the beginning.

We've had patients who have a certain perception of what is going on with them, and they may still be leaking, but it may actually be a completely different etiology than they realized, and you can't actually get there unless you say, we have to start from scratch, from the very beginning, the first day that you felt normal to the first day you felt abnormal, and go from there, right, we can't just make assumptions or inferences about what's happened so far. Go over the imaging together, right, sit down at a computer and say, these are the things I'm looking at, these are the things I see and the things I don't see, this is an incredibly important part of the, the healing process or the diagnostic process, the understanding process with our patients. Explain, what do these tests mean? I'm going to try to do a little bit of that today. What does it mean to get a CT myelogram? Dr. Rau just said that a conventional CT myelogram isn't good, but now you're going to, you just said, Dr. Callen, you want me to do a CT myelogram. I thought that's bad? I thought I needed DSM. What do these things mean? What are the treatment options? What are their risks? What are their benefits? What are their alternatives? And like Dr. Houk pointed out, obtaining validated health metrics, not just for research, but as kind of standardized baselines to compare to in the future,

so we know where we are and we know where we've been. One of the most important things we've done and established here is, is, is our CSF leak multidisciplinary conference. Um, I have two of my most valued colleagues sitting in the front row here, um, and we get together as neurologists, neuroradiologists, and neurosurgeons, and we discuss our patients without a straightforward clinical or imaging presentation.

And frankly, that's most of our patients. And we need to sit down together and say, listen, I think this person might have a leak. They don't fall—you know, they didn't read the textbook, so to speak. What should we do next? And we come up with a, with a consensus. We document that recommendation in the patient's chart, just like a tumor board of a patient, you know, with a, with a brain tumor, they need input from the neuro-oncologist, the neurosurgeon, the radiation oncologist.

Same concept here. Our, our patients benefit from, from this multidisciplinary discussion. Okay, I want to talk about a point that I think is, is a big stress point for a lot of our patients. What if my imaging is normal? I have the symptoms of a leak, but my brain MRI does not show it. What do I do now? I think a lot of us are familiar with the sort of numbers that get thrown around, anywhere from five to 20 percent—some people think it's higher—of people with leaks who have a normal MRI of the brain. This is a very famously quoted meta analysis that came out recently that cited that 19 percent of our patients have a normal brain MRI. I'm citing, um, my, one of my favorite mentors and people, um, from my training who loved to say that radiology is not a complete blood count.

Okay? We're not a machine that spits out a number. There's a person behind that, that, that computer interpreting that image and all of their biases and everything, you know, is going into your report. Right? So. Let's talk about what the normal brain looks like in, in SIH or in a, in a CSF leak, let me just say, um, not just SIH to the very astute comment made by one of our earlier virtual attendees.

There are true negatives. There are negatives that nobody could look at and say, I see evidence of a leak here. There are false negatives. There are negatives where the radiologist misinterpreted the scan, and we'll look at a couple examples of that. And then there's normalization over time. And, we'll see some examples of that too.

So here's an example of a true negative, okay? No pachymeningeal enhancement, minimal prepontine cistern narrowing, no subdural fluid collection, massive fluid collection in the spine. Patient—there was a question earlier about the size of the leak and the symptomatology. The brain MRI being normal in the context of leak does not mean the leak is subtle or small necessarily.

This is a massive leak, a leak that was surgically confirmed, surgically repaired. Okay? We found it on a dynamic CTM. There's the intraoperative and there's the resolution of that fluid collection afterwards. Okay? So these can be truly negative and they can be really big. Here's another example, a false negative.

The impression of this radiology report read no evidence of SIH. And perhaps to the uninitiated, you might look at this brain MRI and say, yeah, I don't know. I don't see any pachymeningeal enhancement. But let's apply the Bern score. Suprasellar distance of one millimeter. Mamillopontine distance of 4. 8.

And prepontine of three. There's no dural thickening, subdural fluid collection, or venous engorgement here. But that's a Bern score of four. Intermediate probability of finding a leak and this patient had a very large CSF venous fistula on the left. Okay. Finally, this concept of normalization over time. I think one of our, one of our attendees might recognize this, this imaging.

In 2018, had classic findings of a leak, brain sag, subdural fluid collections, a massive spinal epidural fluid collection, received non-targeted epidural patching. Partial symptomatic improvement, but not not complete. The brain MRI on its own in isolation in 2023 does not show evidence of SIH, but the spinal fluid collection is still there.

Thank goodness it was still there because now we know for sure that she has a leak and that it's not something else and getting chased down a bunch of other, you know, a long other diagnostic path. This leak was surgically repaired, which resulted in an immense improvement in this patient's clinical symptoms.

And there's the, there's evidence of that on the post operative MRI, the fluid gone. We heard a beautiful presentation earlier from Dr. Houk, and I just want to remind everyone that the Bern score is the likelihood of finding a leak on CT myelography. It is not the likelihood that you have a leak. It is, this score is a reflection of the sensitivity of our exam.

You may be leaking and our exam might not be able to find it. That is what the Bern score is talking about. It is not a reflection of your clinical severity. It is not how disabled you are from your leak. It is not a likelihood that you are going to respond to patching. If you have a low Bern score, this does not mean that you will not feel better after a patch.

It is a useful tool. And I think our patients are, you know, there's, there's some stigma behind it and, but it's a specific tool in this specific context. So important, I believe, that we have implemented standardized reporting on every brain MRI that comes here, um, for the context of a leak. We think, we found that when we did a study on this, we found there's decreased discordance between an expert blinded reader.

There's less false negatives and no false positives when we do this testing, and that radiologists just aren't good at seeing subtle narrowing of these distances, these prepontine, distances. Okay, let's move on to myelography. Not all myelograms are created equal. Okay? There's like an alphabet soup, a word salad of CT myelogram, dynamic CT myelogram, DSM, photon counting CT, MR myelography. These are

incredibly confusing. This is a patient who in 2016 had a conventional CT myelogram, and were told they did not have a leak, and then had a dynamic decubitus and there's their CSF venous fistula at this very same level.

Okay, so it's important for us to define what these terms mean. What is a conventional CT myelogram? This is a, this is a study that's been done for a very long time in the context of radiology. A conventional CT myelogram is where a, where dye is injected into the spinal fluid space, usually under x-ray.

That dye is allowed to diffuse around, the patient is rolled around, sometimes the bed is tilted up and down, and then maybe 30 minutes or 60 minutes later, we just get one CT scan of the, of the whole spine. The patient may be laying on their back or face down, and you'll see, like in this patient, that there is, there may be a leak, okay?

There's a big epidural fluid collection. Is there a role for this particular study in the way that I just described in the context of leaks? Probably not. So, you know, when you take a special spine protocol, what we've kept referring to is 3D, T2 fat-saturated MRI. Some people refer to it as non-contrast myelography.

It turns out you can see these collections without ever having to puncture this person's dura. And with this conventional myelogram, you don't know where that leak is coming from. And you also don't know that based on the MRI. But at least you know that the fluid is there without subjecting them to a procedure, which does not localize specifically where the leak is.

What about digital subtraction myelography? So a conventional CT myelogram, again, for temporal resolution, we're imaging one time, 30 to 60 minutes after the injection. Pretty good spatial resolution, but you get to see the whole spine. And you can also assess whether there's an osteophyte impinging on the dura, other contributory anatomy.

A DSM where contrast is injected under fluoroscopy, live x-ray, and imaged in real time has excellent temporal resolution. You see the dye moving. You see the dye leaving the dura. You know where the leak is. It also has excellent spatial resolution. But it has a limited field of view because where you point the camera is where you're imaging.

You don't get to see the whole spine. There's superimposition artifacts, particularly at the level of the shoulders, which make it very challenging to see subtle things like a little CSF venous fistula, often requiring anesthesia support with an endotracheal tube for breathing. And we now know that breathing is a really important part of this exam.

We don't want positive pressure ventilation. A lot of the times that might be hindering our study. What if we combine the best of both worlds here and a

dynamic CT myelogram? We're going to inject on the CT table. We're going to scan immediately and acquire multiple phases of imaging that makes our temporal resolution better.

We're going to use sub-millimeter slices. And if you had an institution with a photon counting CT, you can even get, you know, three times thinner slices than a typical CT. So even more, even smaller, that gives you excellent spatial resolution. Gives you large field of view. You get the contributory surrounding anatomy and you get the ability to treat in the same setting.

So this is what, this is our exam of choice. There's also been a recent paper that came out that kind of looked at DSM and CTM head-to-head looking for CSF venous fistulas. And that study came away with the conclusion that CTM was superior in that regard. There's downsides to everything, um, to every test, but this, this is the way we do it here.

I mentioned briefly that breathing is important when it comes to CSF venous fistula. Inspiration is important. Taking a deep breath in increases the conspicuity of CSF venous fistulas. This is important work that came out of Duke. Resistant inspiration, where a patient takes a deep breath in through a little straw, we know now this is also very important.

It drops venous pressure. It raises CSF pressure. We know, we understand now that what we're trying to do is help these really shy fistulas show themselves by increasing that gradient between the CSF compartment and the venous compartment. Okay, a unique part of the lecture that I tried to add here is just, these are one of the frequently asked questions for patients when they're going to get a CT myelogram.

What can we, what does almost every single patient ask me? I try to consolidate it here. Will I get put to sleep? No, we won't. We're not going to put you to sleep. Um, we do these exams with local anesthesia with lidocaine. We can use moderate sedation through the IV. There's two really important reasons for that.

Number one, using general endotracheal anesthesia has risks. Number two, we need you to participate in the exam, to take a deep breath in through that little straw. If we put a tube there and force air into your lungs, you can't do that, and it may in fact be doing the opposite. What about postural puncture headaches?

You just said you're looking for a leak and now you're going to put a hole in my dura. We don't take that lightly, right? This is the biggest catch-22 of my job. We perform all of these exams with a non-cutting spinal needle, if at all possible. And if you develop a new or worse headache afterwards, we will patch you after your dynamic CTM.

And when patients come here from out of state, we often plan a patch after the CT myelogram just as a backup for this very reason. Does it hurt? It's not comfortable. Two parts of the exam can be very uncomfortable. So, the numbing of the skin, that little bee-sting of the lidocaine, can be very uncomfortable.

The needle entry and manipulation. Also, as that dye moves up the spine very quickly, when it goes into the head, some patients get a very bad headache. It's often on the side that you're laying down. It really is irritating. We do our very best to avoid that. We put a lot of pillows under your head.

Usually this headache goes away in about 30 minutes. But these are the two points that could be very uncomfortable during the exam. Does it require two days of testing? I heard that when I do a DSM, I need two days for my DSM. So DSM does require two days. We can often get a good bilateral exam on dynamic CTM, and we can usually tell based on the quality of that first exam if we need a second exam.

There was a wonderful paper that came out of the UK from one of our speakers today that looked at this specifically. Here's an example of two CSF venous fistulas that we discovered just by rolling the patient over and getting that dense contrast to go into the other side of the spine. Um, and so we don't, we don't always need a second day.

Sometimes we do, if we have very high suspicion, we'll repeat the exam. So what does it look like when you have a, um, a fast leak, so to speak, a big fluid collection on your spine? We are going to position you in this funny way, okay? You're going to be laying face down and we're going to elevate your hips.

And we're going to inject contrast and immediately begin whole spine CT. We're looking for that transition point where contrast is leaving the, the intrathecal space into the epidural space. That specific point that I can tell my, my surgical colleague, Dr. Lennarson, this is where the leak is, so he can do the most minimally invasive surgery possible.

Here's an example of that on, on one of our patients here. It's very challenging to position the patient this way. Okay. A lot of times, you know, we were essentially building pillow forts with wedges and pillows, getting the patient up. And if the contrast doesn't move the right way, you've, you ruined the exam.

You've basically, you know, the contrast didn't move correctly. Now you've punctured their dura. You didn't get a diagnostic exam. It's incredibly frustrating. We got so frustrated building, building these pillow forts on the CT table that we built a device to, to do this for us. So, it's not a torture device.

Um, it's a device to help move the contrast in a safe, predictable way. We've had incredible success with this. Here's an example of us doing that with one of my poor fellows, uh, modeling this, this here. How do we do a dynamic CT myelogram

for, uh, looking for a fistula? So we're going to put our needle in the intrathecal space.

We're going to measure opening pressure, not because that there is diagnostic important diagnostic information there, but I like to raise the pressure, the intrathecal pressure a little bit, and I like to do so in a safe, safe fashion. So if it's already very high, I'm not going to infuse a lot of saline, but if it's normal or low, I will safely infuse saline until we get to a level, um, which is, which, which the patient, which you can tolerate.

We're going to put at least three pillows under the head to sort of prevent that contrast from getting back up into the head, if at all possible. We're going to elevate the hips, infuse five to 10 cc's of contrast, do two full length scans in succession, during which the patient is taking a deep breath in through that little straw, infuse the remainder of the contrast, turn the patient over and re scan.

And that's what it looks like to get a, to get a, um, a CTM for CSF-venous fistula. Why do we get two? Why do we get back-to-back, right? Well, it's important to increase that temporal resolution. Um, so here's a couple examples where we see the fistula only on that early phase, but the subsequent immediate delayed phase, the fistula is completely gone.

Here's an example of a patient where the first image didn't show the fistula and then the second image did, so if we had obtained only the delayed image in these first cases, or only the early image in the second case, the study would have been falsely negative. Okay? We're going to publish, we've, these findings are in press in the AJNR and they're coming out very soon.

Sometimes you just have to repeat the exam. You did everything right. You have an exam that looks very good, no motion artifacts, and it just, you couldn't find anything that you really think that there's a fistula there. You just have to try again. This patient, same level. Here at right T89, nothing. Next week, for some reason we were able to find this fistula, and sometimes there's just a little bit of luck involved too, okay, and you just have to persist.

This patient had a large fistula and had onyx embolization, still felt symptomatic. We repeated the dynamic CTM and on the other side there was a tiny little fistula at the level below. Okay, so these fistulas can reoccur even after treatment. This is a very important point. If the patient's still having symptoms afterwards, yes, it's potentially, um, you know, sensitization or desensitization, but

it's also possible they just have a new leak and you have to go looking for it. What are treatment options for these CSF venous fistulas? There's three main ones. Fibrin occlusion, we can perform the same day as the dynamic CTM. So we offer this to most patients. We just published some multi-site data that shows that we can get about a 59 percent cure rate with this procedure.

We think that needle placement really, really matters for this procedure. We, we can do it right then with no waiting, no anesthesia. Onyx embolization with transvenous access is an incredibly exciting and important treatment option as well with a very high cure rate, but there's less multi-site data, so we're waiting to see as more sites perform this, how effective it can be.

And then of course, surgical ligation. So we're going to get nice examples of that in a couple minutes. You know, we think that this is close to 100 percent cure rate. It can require nerve root ligation, which if the nerve root is an eloquent root is a very important consideration. But again, closing it off surgically is as close to an assured thing as we have right now.

Okay, let's get into less, um, you know, sort of more the art of medicine, maybe, than the science of it. Myelo or a patch first. A lot of patients ask me this. Should I get a myelogram? Should I get a patch? If we have a very high probability MRI situation, the Bern is greater than or equal to five. I say 100%.

You have a leak and I'm going to find it. Um, then I think it's important to do the myelogram. Because I'm going to find the leak, what kind of leak it is, and where it is, and then I can tailor the treatment to that specific leak location. What type of treatment follows? That's a shared decision making process talking about the risks and benefits of all options: patching, embolization, surgery, depending on the type of leak.

Also, we like to refer concurrently to neurosurgery, and I want to thank our neurosurgical colleagues for talking to our patients, even if surgery isn't necessarily on the table. We think it's really important, right, to understand what those options are, and you need to have that conversation with your surgeon who'd be doing that surgery,

um, if that's if that's on the table for you. Here's an example of a 35 year old gentleman with a history of SIH. He had two prior non -targeted blood patches, had a large ventral epidural fluid collection. We localized that leak with dynamic CT myelography to the T 12 level, um, and we were able to target patching here using a very long needle into the front of the spinal canal with an, with an epidural patch.

And after two non-targeted patches, this resulted in resolution for this patient. So knowing where that leak is specifically in certain cases can be very effective. What if 'reour intermediate probability, you know, you're sort of, let's say Bern three or four, and there's no fluid on the spine. If we're going to do myelography, we're going to suspect that you have a CSF venous fistula because we don't see a fluid collection or potentially a slowly leaking meningeal diverticulum.

And if we don't find anything, we're still going to offer you patching and we're going to patch what we call soft targets. Okay? So things that we know can leak or lead to leaks, but we don't see leaking right now. That means large meningeal diverticula,

maybe an area where there's osteophytes, like in this example here, um, trying to put blood and/or fibrin glue in these regions to see if we can make you feel better, even though we couldn't prove that that's where the leak is. Perhaps the most controversial and, and, um, differing practice depending on where you go: what if their brain is totally normal? There's no fluid on your spine. Where do we start?

So if the clinical symptom, um, you know, symptomatology fits, we are going to work you up. And what we're going to do to work you up really depends on your goals and sort of where you fit into this. So, you know, this myelogram, if you have a low Bern score, has a low chance that we're going to find something.

Okay? Doesn't mean we're not going to, and we do myelograms on these patients all the time, but there's a low chance. We are also subjecting you to a needle puncture and a lot of radiation. So if this is a very young patient, if you have connective tissue disease, you know, we say, maybe we should start with a patch, right?

See how you do. Maybe patching can get you to a place which is, which is helpful, you know, or maybe there's some diagnostic information there that makes us think that we should do a myelogram. There's no right answer here. Everyone's going to have a different answer to this, but this is the way that we think about it.

For follow up, at minimum, we perform follow up at one week and one month post intervention, usually longer. We have an established relationship because, as we're going to learn about today, recovery process is not just a singular moment. It's a long, long period of time. It's important for us to be involved in that.

Um, we repeat imaging at that one-month time period if the pre-intervention imaging was at all abnormal to see if there was any change, and then we figure out next steps. Do we need another patch at a different level, or the same level with a different volume? Do we need a new diagnostic study? Is it time to refer to one of our colleagues to figure out if they can help, um, here?

Okay. In conclusion, radiologists are really important and central to the care of patients with CSF leaks. And sorry, colleagues, but you need to, uh, get out of the reading room. And, uh, if you can perform these procedures, you need to change the way you think about your procedural practice to be more patient-centered, because this is what our patients need.

This traditional proceduralist model does not work for CSF leak care. We need to establish relationships with our patients in order for effective diagnosis and treatment. And multidisciplinary collaboration and longitudinal follow up are absolutely keys for success. And I just want to say thank you to my entire, my entire department and, and, and, um, the amazing people I work with, but particularly to these two individuals without whom, um, I would not be able to do this at all.

So thank you so much.