Vascular Malformations of the Brain: Diagnosis, Natural History and Management Strategies
Webcast
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Introduction

Andrew Schorr:
AVM, or arteriovenous malformation, you are born with it and may not even know it. Over time it could cause big problems in your brain, and you need to recognize it and get help. We’re going to talk about this with a leading neurosurgeon next on Patient Power.

Hello and welcome to Patient Power sponsored by Northwestern Memorial Hospital. I'm Andrew Schorr. Well, there are some things that you may be born with that are simply different and are not significant, but one thing that could cause big problems for you in the future could be if the arteries and veins in your brain, different parts of your brain, are not connected just right. This can develop over time. You can have symptoms, such as headache or seizures or even a severe hemorrhage. What are the signs of all this? What is an arteriovenous malformation?

I want to introduce you to a leading expert on this, Dr. Christopher Getch. He's a neurosurgeon at Northwestern Memorial Hospital in Chicago. He is also the co-director of the Northwestern Memorial Hospital Pediatric and Neurovascular Disease and Stroke program. He's an associate professor of neurosurgery at Northwestern's Feinberg School of Medicine. He's also president-elect of the Congress of Neurosurgeons. Did I get it right, Dr. Getch?

Dr. Getch:
That is correct.

What is AVM?

Andrew Schorr:
Okay. Tell us about AVM. What is this exactly?

Dr. Getch:
Well, an AVM, arteriovenous malformation, is one of four types of vascular malformations; sort of histopathologically that you can have in the brain. Those four are AVMs, cavernous malformations, deep venous anomalies and capillary telangiectasias, but of those four the AVM really represents the most aggressive and potentially dangerous lesion. An AVM is a congenital lesion. It is the absence
of sort of the normal blood vessel development resulting in a tangle of blood vessels which is fed by arteries and drained by veins and is located within the brain substance.

Andrew Schorr:
And because of the way they're tangled the veins are often asked to do more than they were designed to do, right? So they could sort of blow out, in a way?

Dr. Getch:
That's correct. The AVM tangle of vessels is often referred to as the nidus. The nidus has no capillary beds which usually slows down blood flow through the brain and takes some of the pressure out of it. If you don't have the capillary beds the arterial flow is passed directly through to the veins and it can cause those veins to dilate up and to bleed.

Andrew Schorr:
So high pressure in sort of low-pressure pipes, in a way.

Dr. Getch:
That is correct.

Tara’s Story

Andrew Schorr:
Well, as we'll hear, you saved the life of a patient of yours, Tara Barker, from the south side of Chicago. She works at the Northwestern Memorial Faculty Foundation. She's 32 and has a son she loves very much, 14-year-old Anthony, right, Tara?

Tara:
Yes.

Andrew Schorr:
Okay. It turn out that for many years you were having headaches, you even had some times when you fainted, and you were taking all sorts of pills for the pain. What had you been taking over the years to try to control the headache pain?

Tara:
Advil, Aleve, Excedrin.

Andrew Schorr:
Anything you could get over the counter.

Tara:
Yes.
Andrew Schorr:
And people said, well, maybe you have a migraine, you need rest. What else did they tell you?

Tara:
You're doing too much.

Andrew Schorr:
Stress.

Tara:
You're overloading yourself. Stress, yes.

Andrew Schorr:
All right. But it really wasn't that, as we will now learn. So you're taking mom to work and you're on the train with her and you're not feeling well, and then you go to work in November of 2006, not too long before Thanksgiving, and then what happened at work?

Tara:
I arrived at work, sat down and told my co-workers that I wasn't feeling well. I had a migraine that just would not stop. My head was hurting so bad I just wanted to lay down. They said, well, you need to eat something before you take the medicine. I ate a bowl of cereal, took the pills and lay my head down, but I had to go to the washroom, and as I got up to go to the washroom and got in the hallway, I passed out.

Andrew Schorr:
That scared everybody. So they called 911.

Tara:
Yes.

Andrew Schorr:
You're right near the emergency room at Northwestern Memorial, you got taken there?

Tara:
Yes.

Andrew Schorr:
And when they kind of figured out what was going on, what exam did they do and what did they see?
Tara:
When I arrived at the hospital emergency room they did a CAT scan on me and saw bleeding on my brain. They immediately called down the top neurosurgeon, which is Dr. Getch.

Andrew Schorr:
Right. Our guest today.

Tara:
Yes. Called him down and he saw the bleeding and told my mom and my family that I had to have emergency surgery, and I had to have it then.

Andrew Schorr:
And you did, and that went on for quite a while. It was sort of touch and go.

Tara:
Yes.

Andrew Schorr:
You believe Dr. Getch saved your life?

Tara:
Yes.

Andrew Schorr:
Well, we're going to hear about that, and also he told your family that what was really going on was not migraine headaches but was what we're talking about today, arteriovenous malformation that you were born with, right?

Tara:
AVM, yes.

Andrew Schorr:
So fortunately you had that surgery, you recovered, and then this is another kind of procedure we're going to hear about, they used another device with focused radiation, the Gamma Knife, to go back in and help you further, right?

Tara:
Yes.

Andrew Schorr:
So how are you doing? I know it's not perfect and there's effects from the bleeding, but are you doing better?
Tara: I'm doing a lot better. I have to write a lot of things down because my memory--

Andrew Schorr: You lost some short-term memory.

Tara: Yes.

Andrew Schorr: Well, the effects of the bleeding and the malformation, we're going to hear more about that from Dr. Getch. Dr. Getch, so tell us from the doctor's side of things what did you find was going on with Tara?

Dr. Getch: Tara had come to our emergency room with persistent headaches, and on workup in the emergency room with a CT scan she was found to have a temporal lobe hematoma. And we did a further evaluation and noticed that the hemorrhage, the temporal lobe hematoma, was related to an arteriovenous malformation. Now, the hematoma was large enough that it was causing significant pressure on the rest of her brain, making her quite sick, and we needed to emergently evacuate that hematoma.

Andrew Schorr: All right. And when you say hematoma, this is like blood that's pooling in the brain?

Dr. Getch: That is correct. It's blood that leaked out of the arteriovenous malformation into the surrounding brain tissue and formed a large blood clot.

Andrew Schorr: So you have to get the blood out of there, and then at some point you need to correct where the blood was coming from. That was extensive--was that open neurosurgery first that she had?

Dr. Getch: Yes, that was. So the typical strategy for someone with a life-threatening hemorrhage from an AVM, especially if you don't have time to really evaluate it fully, is to get them to the operating room, evacuate the hematoma, and you may leave a little bit behind and then stabilize them and study the AVM in more detail. What you're trying to avoid is having to take out the AVM at the same time as the hemorrhage, as the tissue planes and the bleeding are harder to control. So in her case we were able to do this in a staged fashion, stabilize her and then come back and take out her AVM surgically.
Prevalence

Andrew Schorr:
Let's back up a little bit. How prevalent is this malformation? We're all walking around, people don't know it, Tara didn't know it for many years. How common is it?

Dr. Getch:
Well, fortunately they're not one of the more common cerebral vascular problems that we see, but, still, if you have one it's very relevant to you. Typical sort of rates might be five to ten AVMs in a patient per 100,000 patients.

Andrew Schorr:
So pretty rare, and so she was told, well, maybe you have migraines or you're under stress, and all that would be more common. How would somebody know? Is there any indication Tara might have had years earlier that she needed to get worked up further to see was there something else going on?

Symptoms & Warning Signs

Dr. Getch:
Well, this is a problem we see all the time is that the cause of headaches are extremely varied. If you work through a patient's headache pattern, if you look at its onset and its characteristics sometimes you can differentiate headaches related, let's say, to migraine from AVMs. Headaches—in my experience, headaches are often associated with AVMs, but if you end up treating the AVM sometimes the headaches go away, and I don't know the exact correlation between the two.

But a headache pattern I think that is new in onset, certainly persistent and progressive is one that likely warrants a more extensive evaluation. Now, if it fits a typical migraine pattern my recommendation to patients is that they usually get an MR or imaging study at some point in their sort of medical evaluation and that they make sure that they don't have an AVM or other underlying structural abnormality.

Andrew Schorr:
So that would be the sort of super serious thing you’d want to rule out.

Dr. Getch:
Right. That's correct. I think at the end of the day what you're really trying to avoid is missing something that is potentially life threatening.

Andrew Schorr:
All right. Now, she also tells us that she had passed out sometimes too, so between the headaches and passing out, that would be another warning sign too, wouldn't it?
Dr. Getch:
Well, that's just the severity of the symptoms. It's not common for people just to pass out, and I think hearing that pattern of headaches and then syncopal episodes would probably warrant a more aggressive evaluation.

Andrew Schorr:
And what about if somebody is taking the various over-the-counter pain pills and they're not touching it, and I think she tried everything in the book but still just suffered.

Dr. Getch:
Well, that's another red flag is that a majority of people, if you have a headache and you know why you get it, it's tension related or it fits a certain pattern and is relieved with some over the counter medications, that's for the most part not a dangerous type of headache. But if it is so resistant to medical therapy and it really is associated with some other symptoms, that's one that I would suggest a more extensive evaluation.

Andrew Schorr:
So what about a cause? So is it anything mom did during pregnancy, or do we have any idea where this comes from?

Dr. Getch:
Well, in general it's not anything that your parents contribute to. It's just a process in the embryological development of the fetus and the development of the blood vessels, and there's nothing that is really linked with the formation of these, other than that process.

Andrew Schorr:
And nothing that runs in families.

Dr. Getch:
No.

The Effect of AVM

Andrew Schorr:
So here's Tara, she's 32 now but this was going on for a while, but, still, she doesn't remember it so much from childhood. When does this show up, and why would it show up later in life?

Dr. Getch:
Well, typically the peak sort of age where these show up is in the 30s to 40s, and I think that has to do with the hemodynamic or blood flow effects on the AVM over time, meaning that the AVM begins to expand the blood vessels. It has time to develop some of the hemodynamic side effects, such as flow-related aneurysms. It
has time to steal blood away from the normal brain. As the brain gets bigger, it's more noticeable. So I think they typically will show up in the 30s and 40s because of all of the cumulative effects that occur from birth.

**Andrew Schorr:**
Now, we were saying earlier that the veins aren't always built for this higher pressure. So is there sort of wear and tear over many years on the veins?

**Dr. Getch:**
Right. What happens is just the high flow through the AVM thins the walls of the AVM vessels, and they get more fragile over time. In fact, you can develop what are called intranidal aneurisms, which are thought to be the point of rupture, and those aneurysms represent dilatations of the abnormal blood vessels that eventually go on to rupture. And you can develop these flow-related aneurysms on some of the feeding vessels as well, which are more obvious, but usually in the AVM over time the stress on these vessels creates these points of rupture, and that's where they bleed from.

**Andrew Schorr:**
Now, the capillaries are feeding blood to the tissue, like in the brain, right?

**Dr. Getch:**
Well, the capillaries are just where the exchange of gases occur, and they represent the very smallest vessels, and that's where the exchange of gas and nutrients occurs. An AVM does not have those.

**Andrew Schorr:**
Right. So is part of your brain over many years sort of being starved of a process?

**Dr. Getch:**
Well, the AVM nidus, itself, that tangle of vessels, does not contain any normal brain within it. So really the way to look at it is that the AVM has displaced normal brain tissue and does not contain any tissue within itself. Now, how an AVM affects normal tissue is that if it has a high enough flow rate it can steal normal blood flow away--or blood flow away from the normal brain, and that way it can affect tissues around it. But in general it has no normal tissues inside it so it's not really stealing anything from brain tissue there.

**Andrew Schorr:**
Now, we talked about these more dramatic symptoms, severe headache or seizures perhaps or passing out, like Tara did. Could there be any subtle symptoms just over many years? Could it affect your movement or your speech in subtle ways?

**Dr. Getch:**
I think the more common presentations, as you mentioned, are acute hemorrhage without really any warning, a seizure, and then something where it begins to draw
the blood away from the normal brain tissue, and that can be presented in a more subtle way, like numbness or tingling or weakness developing slowly over time.

**Andrew Schorr:**
And that depends on where this malformation is in the brain?

**Dr. Getch:**
That is correct.

**Andrew Schorr:**
And they can be in a number of different places.

**Dr. Getch:**
They can occur virtually wherever brain tissue is.

**Andrew Schorr:**
Well, we have a lot more to talk about. What we'll do in our next segment is learn what to do about it, what are you doing at Northwestern, how do different specialists come together to see what's right for an individual patient. I know you have several approaches that can be used now. We'll have much more with Dr. Christopher Getch when we continue discussing AVMs right after this.

**Approaches to Treatment**
Welcome back to Patient Power sponsored by Northwestern Memorial Hospital. We're talking about not a common condition, arteriovenous malformations that you can be born with. It doesn't affect a lot of people, but it is very risky for people who find out they have it because their first sign of it could be a hemorrhage in their brain, and they are rushed to the emergency room. We heard about Tara, that happened to her, although maybe she had some warning signs over the years, but many people don't.

So, Dr. Getch, help us understand when someone comes to the emergency room what might be going on there and what needs to be done to see what you are dealing with.

**Dr. Getch:**
Well, when a patient comes to the emergency room and they have a neurologic change, either altered mental status or a focal neurologic deficit, and they undergo an imaging study in the ER, let's say a CT scan, and they're noted to have a hemorrhage or a blood clot in the brain. Initially, the first thing you need to do is make sure that they're stable, meaning that they're awake, their airway is protected, their blood pressure is under control, and that the condition is not rapidly deteriorating.

In the differential of a blood clot in the brain, and certainly someone in their 30s and 40s, but you can see in the pediatric population and in older patients as well.
You want to make sure that it's not a ruptured vascular malformation. And what we'll typically do is at the same time as the plain CT scan is obtained we'll obtain what's called a CAT scan angiogram. And the CAT scan angiogram is obtained very rapidly on a CT scanner. It doesn't take long to get the images, and it can give us some idea if we are dealing with a vascular malformation and give us the location and rough size. It doesn't give us all the information we need, but certainly it clues us in to what we potentially could be dealing with.

**Andrew Schorr:**
So somebody who has the most common form of stroke is where there's a clot blocking blood flow to some part of the brain, and one of the tools that's used in the emergency room, if it's early enough, is some clot busting drug. But if somebody is bleeding you wouldn't want to do that at all because you already have a bleeding problem, so you have to determine which situation you're dealing with. And then is it where something ruptured, right?

**Dr. Getch:**
Right. If you want to take a step back then, stroke is a general term. And under that generalized term there are really two types of stroke. There's ischemic stroke, which represents probably 85 percent of strokes, and that's the typical blood vessel occlusion by a clot that requires the clot dissolving drugs given in the ER or treatments up in the interventional angio suite.

The hemorrhagic strokes represent about 15 percent of strokes, and within that are strokes related to high blood pressure that result in bleeding into the brain, AVMs and ruptured aneurysms, for example.

**Andrew Schorr:**
All right. So with the AVMs, somebody has this congenital malformation, so we want to get the blood out of there like we did with Tara, and then stabilize them, as you talked about. Then what? Then you have different approaches to trying to correct the rupture. Tell us about how you evaluate that at Northwestern and what do you do.

**Dr. Getch:**
Right. In the case of a patient that comes into the emergency room and you've stabilized them and either removed the hematoma surgically or didn't need it and they are up in the ICU, the next step is to perform a digital subtraction angiogram, which is a more extensive angiogram than the CAT scan angiogram. It shows you clearly with high resolution the arteries, veins, the nidus, and really the dynamics of how an AVM is filling and where it's draining to.

And all that information that comes from a cerebral angiogram, digital subtraction angiogram, is important. You need to see if there's any flow-related aneurysms. You need to see the arteries that are feeding the AVM. You need to see if there's any intranidal aneurisms, perhaps the site of rupture, and you need to see the venous drainage pattern, whether it drains up superficially in the brain or deep.
And the reason why those factors are all important is because each one of those gives us some idea of the natural history risk of that AVM going forward, meaning that if we didn't treat it what would be the risk to the patient.

**Andrew Schorr:**
So you're getting, if you will, a road map of the entire brain. So you're seeing the interstate highways, the secondary roads, the dirt roads, the bumpy roads, and do they go where they're supposed to go.

**Dr. Getch:**
That is correct. And you can differentiate those normal blood vessels from the abnormal blood vessels and really begin to understand the nature of the problem much more clearly.

**Andrew Schorr:**
Now, one of the things one might wonder, could you have some malformation and you don't need to do anything?

**Dr. Getch:**
Well, that's correct. And again this gets into really understanding all of risk factors for that patient, which I mentioned some of the ones that are derived from an angiogram. Also it's related to age and other medical conditions of the patient that may make treatment more risky. So there are a number of factors that go into deciding not only whether to treat an AVM but also how to treat an AVM.

**Andrew Schorr:**
Let's go through the how. So one approach could be there are some drugs that could be used in a mild situation. Am I right?

**Dr. Getch:**
Well, let's say a patient presents with a seizure. Well, of course there's medications to treat the seizures which don't really treat the underlying AVM but certainly block its ability to create seizures. Once you get into the treatment of the actual AVM nidus itself, there are no real medications you can take that will get rid of the AVM. You can again treat the symptoms, let's say it's headache, with headache medications, but to really get rid of the AVM there's no medical therapy.

**Andrew Schorr:**
So we talked about typical neurosurgery you think of--and I watch *House* M.D., and the same guy does all the surgeries, and sometimes he's opening somebody's head and doing brain surgery, but you have other approaches as well. Help us understand the different approaches and the team you have at Northwestern to put your heads together to see what's right and also how one patient may need more than one different type of procedure over time.
Dr. Getch:
Right. And this is really where the management and treatment of AVMs requires a team that brings many different skills to the table, and I'll go through the tools or strategies we have for managing AVM and then sort of give you a sense of how they interact, when you would use one or a combination of one and another.

The treatment of AVMs can be sort of broken down into a traditional open surgery, radiosurgery, or Gamma Knife radiosurgery is a very commonly known system. Endovascular therapy, meaning where you place a catheter up from the femoral artery into the actual AVM feeding vessels and inject a glue-like substance which then fills the AVM blood vessels and blocks the flow through it. And so, given those available tools, when you look at an AVM off of the cerebral angiogram and off from the MRI scan which is often obtained in the evaluation of these patients, you begin to think of, is this one that's amenable to surgery, is this one that needs embolization before surgery, or is this deep and inaccessible and may need radiosurgery. So we begin by looking at the location in the brain, its size, its feeding arteries and taking into account patient age and risk factors. We then begin to design a treatment paradigm using these tools.

Andrew Schorr:
Now, let's talk about some of the specialties that come into play. So you're a neurosurgeon. I know there's something called an interventional neuroradiologist, I think.

Dr. Getch:
That's correct. Sometimes they're one and the same. A neurosurgeon may do traditional open surgery, or if they're dually trained they may be able to do the endovascular treatment as well as the surgical treatment, or you have your radiologists who are specialized in interventional techniques. So depending on the training the team members can be either neurosurgeons or radiologists.

Andrew Schorr:
And talking about the teams, we talk about multidisciplinary teams a lot, certainly at the university medical centers such as yours. So you all talk about a case, right? Because you have to come to some agreement as to what might be best.

Dr. Getch:
Right. Because the management of these lesions is so complex and has many different options, the way we do it at Northwestern is we often present these cases at a multidisciplinary cerebrovascular conference where neurologists, neurosurgeons, interventional radiologists are all in attendance, and we go through the imaging findings and the clinical picture and try and come up with the best treatment, an individualized treatment plan for that patient.

Andrew Schorr:
Now, such a group doesn't exist everywhere, so this would be typically at major centers such as yours?
Dr. Getch:
That's right. I think in order to really offer a patient the sort of optimized treatment you need to have every one of the components, radiosurgery, endovascular and open surgery, all available to that patient because oftentimes you require a combination of these techniques, and you're really trying to optimize the treatment of the AVM, meaning complete resection or removal or obliteration, and minimize the risk. And I think in centers that have each one of those modalities, you'll pick ones that offer the lowest risk and highest success.

Andrew Schorr:
Now, you mentioned this term "embolization," so that's where you're going up from the groin, right, with catheters, and you're injecting the material in to try to seal the AVM off. But I understand that sometimes that's done as a first step to make the open surgery more effective.

Dr. Getch:
Yeah, that's correct. It can be a stand-alone technique where if the AVM is small, it has a single arterial feeder or maybe just two arterial feeders, it's a fairly simple AVM. Embolization can be used as a first-line treatment to completely glue the nidus, stop the flow and treat the AVM without any further intention.

When an AVM is more complex and has multiple feeders, multiple arteries leading into the nidus or the tangled vessels, then your strategy is often more of knocking out some of the blood flow to it in anticipation of surgery later. It makes the surgery much easier because of less chance of blood loss during the procedure.

Andrew Schorr:
And safer, I imagine.

Dr. Getch:
Yeah, much safer. And there's some benefits of embolization. One of them is that each one of those little arteries if it has the glue in them can almost serve as a road map so you know exactly where you are in the surgical field.

Andrew Schorr:
Just so people can kind of visualize this. So a lot of people are familiar with like angioplasty to unclog heart arteries, and they know that's sort of done in a lab, and there are all these TV screens watching the catheter get to where it needs to go. Is that the way it goes for this sort of, I guess you'd say, minimally invasive brain surgery, same sort of approach?

Dr. Getch:
Yeah, the embolization procedure is done in an angiogram suite, and those angiogram suites, as you mentioned, are quite sophisticated. They have a lot of flat panels to see the pictures as they're working, and it's a fairly state-of-the-art looking facility.
Andrew Schorr: Now, the patient is asleep for that.

Dr. Getch: In general. For the diagnostic angiograms they can be awake, but for any interventional procedure which involves migrating a very, very fine catheter all the way up into the AVM, the patient is asleep. It's just any movement would distort the images.

Andrew Schorr: How long does a surgery like that take?

Dr. Getch: Well, an embolization procedure, depending on how many vessels or how many pedicles you're trying to eliminate, it may take a couple hours to do that.

Andrew Schorr: But you're basically plugging pipes that shouldn't be there, right?

Dr. Getch: That's correct.

Andrew Schorr: All right. Now, then when you go through open surgery are you cutting something out or sewing something closed, or what are you doing with the open surgery?

Dr. Getch: Well, the goal of the open surgery is to actually take out the tangle of blood vessels. So the typical strategy is once the AVM is exposed you systematically go, disconnect whatever arteries haven't been embolized, and then you work very gently down around the AVM, the tangle of vessels, and remove that entirely.

Andrew Schorr: That sounds like a long surgery.

Dr. Getch: Well, it can be, depending on the complexity of the AVM. It can be relatively straightforward if the AVM is small with very few feeding arteries, or it can take all day.

Andrew Schorr: Lot of time on your feet, I imagine, as a surgeon. Now, you mentioned radiosurgery and the Gamma Knife and I've seen that. So let's describe that. There's been a lot of physics and plotting exactly where you need to fire gamma radiation, right?
Dr. Getch:
Right.

Andrew Schorr:
So now you're trying to get at a certain point. Now, why would you do that? Would that be because they're deep in the brain or you want to be less invasive?

Dr. Getch:
Right. So radiosurgery is a nonsurgical way of obliterating an AVM, and really the ideal candidate is someone with a deep AVM where in order to reach that AVM with a surgical technique you might have to go through some normal brain just to arrive at the tangle of vessels. So someone with a deep AVM and it's clinical course is relatively benign might be a good case for radiosurgery.

Essentially when you have a patient who is a radiosurgical candidate you look at the size of the AVM. There are some limitations. If the AVM is larger than approximately three centimeters in diameter or 10 cubic centimeters, it is hard to treat radiosurgically. We have some advanced strategies for doing that, but in general that is a cutoff point. The goal is to direct, using stereotactic coordinates derived from MRI and angiogram, direct beams of radiation onto the abnormal tangle of blood vessels causing them to scar over time.

Now, when you treat AVMs radiosurgically the effect is not immediate. It is a delayed effect, and it usually causes the AVM to scar up over about a two- to three-year period, and we call that period the latency period. And so when we talk to patients about treating them radiosurgically we do tell them this is not an immediate effect. You'll have to live with this AVM a little bit longer until the scarring process is complete.

Andrew Schorr:
Wouldn't somebody worry that they have a ticking time bomb. Like I know with aneurysms, I had a friend where an aneurysm was diagnosed, it ran in her family and she elected to go into surgery because she was worried it was going to rupture. When somebody is a candidate for Gamma Knife treatment, is it that it's more benign, as you said, and you're not that worried about that?

Dr. Getch:
Right. Well, that's one of those points again, depends on how the AVM presents, what its risk factors are right up front. If it has some flow-related aneurysms it may be a little bit riskier, and it may be better to take out. Now, when they're deeply located and really you don't have a good surgical option because the risk of surgery is too high, you simply have to accept the natural history risk of that AVM bleeding during radiosurgery. The natural history risk of an AVM that is unsecured is typically around four to six percent, and it can be a little bit higher in AVMs that have presented with previous hemorrhage, so that's risk of hemorrhage per year. So if you look at the risk during their latency period, while they're waiting for the AVM to go away, it's fairly low any given year.
Andrew Schorr:
Now, one question about Tara. My understanding is that subsequent to her open surgery you did Gamma Knife, and we've talked about how different procedures can be combined. What would be the reason after open surgery to go back later on with Gamma Knife?

Dr. Getch:
Well, in her particular case she had a very unusual finding. She actually had an AVM nidus that ruptured which we removed surgically, and she had another more remote nidus that was located a little bit more in front of where her other AVM was. So we ended up deciding not to go back surgically because it was her dominant hemisphere and just treat that small new AVM with radiosurgery. In general, radiosurgery can be used, and we've done this before, where you take out an AVM and there's a piece left in a region that you felt was too hard to reach. You can treat that with radiosurgery. So it can be used for a separate nidus or a residual nidus.

Andrew Schorr:
And that brought up one other question for me. So for someone like Tara or other patients you see you have this hemorrhaging nidus, as you call it, AVM, but what's the chance that they have another tangle somewhere else in their brain?

Dr. Getch:
Very unusual, and that's what makes Tara's case somewhat unique, is that in fact she has a couple abnormalities, additional abnormalities which don't have AV shunting like an AVM but there are some other tangled vessels. So I think her situation is a little bit unique.

Andrew Schorr:
We have more questions for you when we come back with more of our Patient Power discussion with Dr. Christopher Getch, neurosurgeon at Northwestern Memorial Hospital. Stay with us.

Evaluation

Andrew Schorr:
Welcome back to Patient Power as we continue learning about arteriovenous malformations. You're born with it, you find out you have it, you haven't had a rupture, you didn't go to the emergency room, but it was discovered somehow, and there you are sitting across from Dr. Getch. Maybe you're a younger person, maybe you're not.

Dr. Getch, help us understand, because you're a neurosurgeon. Neurosurgery is scary to somebody, they'll say, oh, my god, I need it now, like Tara did, please help save my life. But what if there's this malformation you have to evaluate, do you really need to do something and when? Take us through that.
Dr. Getch:
Here's the thing. I think if you present with an AVM, it's found incidentally. So you had some headaches or you fell and had your head worked up with an MRI or CT scan and they noticed on the imaging that you had an AVM. You're in a reasonably good position because there's no emergency to treat this AVM and you have time to really, one, have it evaluated, and, two, really work through the options to minimize the risk and decide whether it should be treated or not.

So when a patient comes in and they have an AVM in the brain and it has not presented in an aggressive way we really can spend a lot of time evaluating that AVM. Getting the proper studies and then looking at the risk/benefit of each modality that we can bring to bear on this AVM and working with the patient to decide should it be treated and how it should be treated.

Andrew Schorr:
All right. Now, where does age come into play?

Dr. Getch:
The natural history of AVMs is really a risk over time. So there's been a number of natural history studies on AVMs looking at their risk of bleeding over time, and that risk of bleeding is generally in the range of about four percent per year so that it's a cumulative risk. So that four percent, like a probability any given year that this will bleed, is cumulative, it's additive over time. So if you're younger your risk over your lifetime of this AVM hemorrhaging is higher than if you're older.

Andrew Schorr:
And, as we said, those veins that are being challenged by higher pressure blood flow, they get some wear and tear on them.

Dr. Getch:
Right. So if you're younger and you're approaching that period that you're maybe 35 to 40, which is the more common time these AVMs hemorrhage, then you may want to have your AVM treated before you reach that higher risk period in your life.

Andrew Schorr:
All right. If you have the treatment, you go through one form of neurosurgery or another, and I know it's going to vary where how big was the AVM, where was it in the brain, but what can you expect for a quality of life going forward because here you may have somebody, as you said, it was discovered incidentally, maybe they're very active. Maybe they're a runner or a weight lifter or something even that might have spikes in their blood pressure, and they say, well, I want to continue with that life. What about going forward?

Dr. Getch:
Where we usually address those issues is in the younger male athlete, female athlete, and the young lady who wants to have children, for example. Pregnancy has been associated with an increased chance of rupture of an AVM during their
third trimester of pregnancy. So when we're counseling patients who have an AVM and have not had children, that is certainly a factor that we take into account in recommending treatment or not. And if they're expecting to have a family then oftentimes you want to get that AVM treated before they start their family.

Andrew Schorr:
So let's take that situation. Unfortunately just last week I was talking to a gentleman, and he has a second family, and he explained to me that he lost his first wife eight months into a pregnancy, exactly what you're describing. She died tragically. The baby was saved. So they didn't know that situation even existed. But let's say we're lucky enough that mom is told, prospective mom, that you have this and you need to get this taken care of. Then they can go on with a healthy pregnancy. Can they go on with an active life?

Dr. Getch:
Well, with the AVM treated?

Andrew Schorr:
Yes.

Dr. Getch:
Absolutely. I think once the AVM has been addressed, oftentimes there's really no restrictions on what they can do. We generally recommend that patients avoid the extremes of activities, but in general, for a normal lifestyle, it's fine.

Andrew Schorr:
So if you get rid of the tangle and you want to be a runner or you're an active mom now, you've gone ahead and had the baby and have to chase the two-year-old all around, you're good to go?

Dr. Getch:
Good to go.

Andrew Schorr:
Wow. Now, what about recovery from surgery like this. First of all, the less invasive Gamma Knife or the embolization, what about recovery from that? And what about from open surgery, and I guess it varies where the malformation was, but help us understand that.

Dr. Getch:
Right. And also it depends a little bit on how they presented. If they presented with a hemorrhage obviously recovery is going to be a little bit longer and more difficult. But if it's a Gamma Knife procedure, for example, which is an outpatient procedure, by--let's say they had it on a Friday. By Monday they can be back at work. So the recovery from that procedure really isn't significant. Where the side effects show up is usually anywhere from six months to 18 months after treatment on average. That's where there may be some other sort of medical therapy required
to get them through the post-treatment period. But in general following radiosurgery patients can go back to their normal activities and work quite rapidly.

Embolization is very similar. If embolization is used primarily to treat the AVM usually once they’re up and around after the procedure there’s really no limitation in terms of activity, other than strenuous activity to let the puncture site in the artery, in the femoral artery heal, and then they can go back to their normal activities.

Surgery is a little bit different, and again it depends on where the AVM is located, how they did after surgery, neurologically, if they are well. A typical pattern for a straightforward AVM might be they’re in the hospital for three or four days, they are back in clinic for sort of a wound check at anywhere from ten days to two weeks and then are able to conduct their sort of daily activities but no real strenuous activities until they are fully healed. And usually I release patients back to their full activities, depending on what they had done and how they're doing, at about three months where there's really no restriction.

**Risks & Complications**

**Andrew Schorr:**
Let's just take a second to talk about risks and complications. Obviously, if you need a procedure and you don't have it, it could be a fatal event. So obviously you want to head that off. But what about from having the procedures, what could happen?

**Dr. Getch:**
I'll start with radiosurgery first. At the time of the treatment of the AVM with radiosurgery you do undergo a cerebral angiogram, and if there's any risks related to that procedure it's usually a low risk of causing a stroke or a dissection of a blood vessel or a hematoma or blood clot around the site of puncture in the femoral artery. The radiosurgical procedure itself, the complications at the time of treatment are virtually negligible. It's a frame on the head, and you may get some soreness at the pin sites, but that's about it.
The effects of radiosurgery--or side effects of radiosurgery usually show up in a delayed fashion. It's usually related to the irritation of the radiation--irritation of the normal brain by the radiation. That shows up depending on where the AVM is as headaches or focal neurologic deficits or seizures and may require steroid treatment.

In terms of embolization, the risks are really related to the catheter threading up into the brain vessels and the release of the glue into the nidus. If that glue extends into a draining vein it can cause some bleeding. If the catheter irritates some of the normal blood vessels you can have some problems related to that. But in general the risk of embolization for an AVM is low, and we're getting better with improved technology every year. So the risk might be in the range of perhaps two to three percent per embolization procedure.
Andrew Schorr:
What about the neurosurgery?

Dr. Getch:
Well, the surgical risk really boils down to the opening of the skull and then the work within the brain itself. So the risks can be broken down by sort of the approach. You can have a wound infection. You can have a meningitis, aseptic meningitis, which is a nonbacterial meningitis. You can have a blood clot form post surgery underneath the bone flap. You can have bleeding during surgery requiring a transfusion. You can have stroke related to clipping off of the blood vessels. You can have a seizure post-op, or you can have a blood clot post-op within the bed of the AVM you've resected out. So there are a number of things that can occur. Fortunately they're not all that common.

Andrew Schorr:
I'm glad to hear that. I wanted to get just a final comment from Tara. What would you say to someone who maybe has been having what others thought were headaches or they have some kind of spells or seizures of fainting, and it's just unexplained and they've tried all different sort of things? What would you say?

Tara:
Take it further. Do not constantly pop some pills. Do not let a doctor tell you that it's one thing and it's another. Go further and see a neurologist. Do some CAT scans, MRIs, take it further to see what's going on because somebody's head shouldn't be hurting like that constantly.

Andrew Schorr:
Right. Absolutely. Tara Barker, we wish you well. I want to thank you for being with us. We're glad you're with us. And anything you want to say to Dr. Getch publicly here?

Tara:
I love him. I love that doctor. He saved my life that day. I will never, and when I say never, I will never forget him. A good doctor over here at Northwestern and I talk about him all the time.

Andrew Schorr:
Tara Barker, thank you so much for being with us on Patient Power. All the best to you for a long, healthy future.

Tara:
Thank you so much, and any time you need me, I'm here.

Andrew Schorr:
All right. You've helped a lot of people today.
Tara:
Thank you.

Andrew Schorr:
Dr. Getch, Tara thinks you walk on water. It must make it worthwhile what you do.

Dr. Getch:
Oh, absolutely. It's a privilege to have patients--well, it's a privilege to treat any patient, and also it's an honor to have their confidence in me to do what I need to do. It's an incredibly rewarding thing to be able to help people, and having a patient who is engaged and invested in really understanding all the issues is so important and makes my job so much easier. Tara was an ideal patient in that sense in that we would have very detailed discussions about each one of the risks and benefits of the procedures going through them, and she really understood the process and worked well with me to get this thing tackled. So she was a super patient.

Andrew Schorr:
Well, we call this program Patient Power and Tara is a great example of a powerful patient. And you're a great example of a very dedicated doc. Thank you for explaining not a common but certainly a serious condition and complicated condition. Dr. Christopher Getch from Northwestern, thanks for being with us on Patient Power.

Dr. Getch:
Thank you so much.

Andrew Schorr:
This is what we do is help you understand these significant health problems, serious health problems and connect you with leading experts such as today, Dr. Getch and inspiring patients like Tara. I'm Andrew Schorr, remember, knowledge can be the best medicine of all. Thanks for joining us.

For more information or to schedule an appointment with a Northwestern Memorial physician, please contact our Physician Referral Service at 1-877-926-4664 or visit us online at www.nmh.org.

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