

Dr. Salvatore J. A. Sclafani, Chief of Radiology
 Kings County Hospital in Brooklyn, New York
 Professor and Chairman of Radiology at the SUNY Downstate Medical School
 Email: ccsvliberation@gmail.com
 Assistant Holly Barr: Holly.Barr@downstate.edu

ThisIsMS posts by Dr. Sclafani. Questions are from ThisIsMs users.

Source: http://www.impact-ltd.ca/dr_sclafani.doc

Base Version: 28.03.2010, 08:58:00

ThisIsMS: <http://www.thisisms.com/ftopict-10680.html>

Post from Dr. Sclafani:

Perhaps it is not appropriate to write a reply, but now that I have been outed as a physician treating CCSVI, I thought I would read what is discussed and see whether anyone would want to hear from someone on the other side of the catheter.

It was clear from reading a few posts that there are great misgivings and lots of unfamiliarity with these tests, their methodology and their use.

This evening I heard some discussions about catheter venography and thought I would try to help sort this out.

Catheter venography is the gold standard test for viewing vein anatomy. It is performed under local anesthesia. All the veins connect, so we try to enter in a safe, simple area where the vein is readily available. We would not want to enter in the neck, because it is more difficult to work from there, the vein is very close to the carotid artery and we need to see the entire vein, so putting the tube there would miss part of it.

The leg is the best location up near the groin, because the vein is just an inch or two deep to the skin and readily hit by the small needle that is used. Since we are below the veins involved in CCSVI, the jugular veins and the azygous vein, we must traverse the right atrium of the heart to get to them. Sounds scary but actually that is a relatively easy part of this generally easy procedure. The catheter (tube) we use is very thin, measuring less than a twelfth of an inch in diameter. It is visible on xray so we can find our way. The catheters have different tips with varying curvatures that help get into the veins. Because there are no pain fibers on the inside of the vein, moving the catheter in the veins is painless.

The venogram is always the first part of a treatment of CCSVI. It provides the roadmap for reaching any abnormalities. It makes no sense to divide the procedure into a venogram test followed at another time by the treatment part. They should always be done at the same time.

The dye used to see the inside of the veins is a very safe iodine containing substance. Adverse reactions are very uncommon, less common, for example, than many antibiotics or pain medications. I recently reviewed 600,000 exams of which 100,000 had xray dye injected. There were two serious reactions and 17 moderate reactions in the 100,000 exams. I will take those odds.

If I overstepped my bounds, let me know and I will lurk
 ciao for now

+++++

Post subject: HOW IS THE ACTUALLY BALLOONING DONE?

After we get the first wire into the vein through the first needle, we thread a sheath over the wire into the leg vein and then all further maneuvers and tool exchanges are done through the sheath. This reduces the wear and tear on the vein from multiple catheter exchanges, etc.

So once we identify a narrowing, we put a flexible guidewire through the diagnostic catheter and remove the catheter while leaving the wire in its place. We then thread a balloon catheter over the wire and position it with the center of the balloon in the middle of the narrowing.

The balloon catheter is a regular small catheter with a balloon attached to it. The balloon is wrapped tightly so it is a very low profile and easily goes through the sheath. The balloon catheter has a small channel that goes from the outside of the patient, through the catheter and exits the catheter where the balloon surrounds it. Through the exterior port on that channel, liquids are injected and thus fill the balloon. The balloon is made of very strong

materials that withstand very high pressures (about 30 atmospheres) that usually overcome any resistant to expansion.

Under fluoroscopic vision we follow the balloon catheter until it is in the exact proper position and inflate it. We can do this several times. Mark Stecker's blog shows a balloon inflated in the body.

When the treatment is completed, the balloon is deflated and then removed over the guidewire.

Then we exchange the balloon catheter for a regular catheter and do another venogram to see what effect we have had. Then we move on to the next vein evaluation.

+++++

Question:

When I asked a reputable interventional radiologist in the Montreal area if angioplasty was safe for CCSVI, he was not too reassuring. He said that if you dilate a vein there is a significant risk of restenosis (which we already know is about 50% in IJV's) but also a risk that the restenosis gets worse than it was initially. Do you think this is true? If so, what would the magnitude of this risk be? If this is truly the case I might have second thoughts. The second part to my question is how often can we do angio on the same vein? Can we repeat the procedure regularly, for e.g. every 6 months if it restenoses. This might be costly, but something that I would be willing to endure and pay for if it could keep my MS progression at bay.

Answer:

Restenosis occurred in 50% of Dr Zamboni's patients in the report. It is difficult to say what this means because he did not tell us details of what types of problems had recurrent narrowing.

This is a different entity that that for which angioplasty is usually used and we should not correlate the outcomes of two different entities. While it is true that veins tend to restenose with other reasons for venoplasty, the narrowings of ccsvi are very different in pathology. These abnormal veins have all kinds of bizarre narrowings unlike anything I routine deal with. Only time will tell.

The second part of the question is not how simple would it be to repeat the venograms. It is really how much time do we want to use to provide surveillance of failing vein angioplasty when there are so many patients needing definitive treatment. Using Venography to followup is going to clog up the treatment assembly line.

Look, I am coming around to thinking that venography is really the way to assess, not MRI and not ultrasound. If vein problems are present in 60-90% of patients, how can you not test with the gold standard test? The reason I am doing these other tests is to determine whether US or MRV can be used as a screening test for followup checks, not to determine whether venography needs to be performed.

Perhaps a bit radical, but I am an angiographer, not an imager.

+++++

Question:

Could it be that the neck is dense and tightly packed with muscle, jugulars, carotids, throat, etc. and that contributes to the CT/MRV/ultrasounds being unreliable? The more I've read about CCSVI, the more I'm impressed with necks....

Answer:

It is true that some of the narrowings seen on MRV do not prove to be stenoses on the catheter based venograms. While the narrowings are a sign of CCSVI, some of them are not necessarily the cause of CCSVI. If you looked at the jugular veins while standing, you would see that they are always narrowed, even in the absence of CCSVI. That is because the blood of the brain drains through the vertebral veins, not the jugular veins, when standing.

Imagine you had a flat soft hose and you ran a lot of water through it. It would distend and change shapes as it filled. If you slow the flow, the hose would partially collapse, perhaps becoming oval in shape.

The same thing happens to the jugular vein in CCSVI. Obstructions that increase resistance to drainage through the jugular veins drive the blood through the vertebral venous system. Thus as flow is reduced in the jugular vein it collapses and appears narrow. These narrowings seem to occur next to the carotid bulb and the second cervical vertebra

Nonetheless, the narrowing is a "sign" of CCSVI, even if it is not the cause of the CCSVI. Other signs include lots of small collateral vessels and large branches bypassing the areas of resistance. Big thick valves, reversed valves and poorly developed narrowed veins are other signs.

So MRV has value in screening but catheter venography is the gold standard.

+++++

Question:

[Do you believe other vascular surgeons and interventional radiologists agree with your opinion (and Dr. Dake's and many others) that jugular and azygous vein stenosis/collateral circulation is damaging to the brain and spine? Why should we be concerned with CCSVI? Even if CCSVI does not affect MS, is this condition harmful on its own?]

Answer:

Honestly, most interventional radiologists, and vascular surgeons have no idea what I am speaking about. Original opinions seemed to think that I was crazy, just like most thought that the woman who originally contacted me about getting involved in this was also crazy.

But I am used to this. I was once called the "lunatic fringe from Brooklyn" at a national meeting of trauma surgeons because I was suggesting that not all patients with injured spleens needed to have them taken out. Now saving the spleen is the standard of care ...who got the last laugh!

The more associations people see, the more they will come around. It took more than twenty years for my concepts of interventional radiology in trauma to be accepted. I will bet that you people will make this accepted far sooner. After all, who was advocating for a kid with a gunshot wound.

Dr. Zamboni's theory makes a lot of sense to me and I think that others will come around to understanding his elegant and simple concept. If you have resistance to outflow from the brain, you will develop reduction of inflow. Inflow to the brain is a good thing. The Buffalo group has determined that there is reduction of blood flow in MS. So I look at treating CCSVI as first and foremost a strategy to reduce resistance to blood flow in the brain. How else can you explain the sudden clinical symptom improvements one sees in some patients with MS? Reduction in cogfog, loss of tingling in a matter of an hour makes no sense unless it is related to improving blood flow.

Personally I suspect that the insufficiency leads to upstream effects that may result in the clinical manifestations called MS. Whether treatment of the CCSVI will make a difference in the long term needs to be determined and that is why long term expensive trials are required.

+++++

Question:

Post subject: valves

My question for you is, now that we are beginning to see after-op problems from ballooning the valves. Should folks with pathologic valve problems wait for additional research in this area BEFORE undergoing angioplasty?

Answer:

Another tough question, sort of the same question as "should anyone undergo angioplasty before additional research"

I do not think that reflux up the jugular vein is really the pathophysiology of this entity. Dr. Zamboni suggests that it the obstruction that is the real problem. This leading to reversal of flow through small vessels not designed to take that kind of flow. I do not think the problem is pressure or reverse pressure. It is flow

I worry that these valves are going to be a real bugger, incomplete treatments, and recurrent obstructions. One gets the sense that something will be ultimately needed to fix the abnormal valve against the wall and stop it from restricting blood flow. Perhaps stents are the answer, or some endovenous procedure that resects the valve, or some other technique beyond my imagination at the moment. Surgery on veins, I am told by my vascular surgical colleagues is not without failure.

This is all so new.

So my answer is rather philosophical.

You are all pioneers and are looking for answers at the front of the wave. If it were neurosurgery, I might say, wait awhile. But jugular venoplasty and valvuloplasty is not particularly dangerous. So I think the decision is about how far out into the frontier you want to travel. Me? I would venture forth and look for a solution to some future recurrence or complication when I see it.

+++++

Question:

My question is that my left vein was treated with angio (pathologic valve)(see CCSVI tracking thread as I have pics there) and now it seems that a problem has manifested in my right vein valve (which was not there pre-CCSVI treatment. Can some stenosis can come and go??

Answer:

Just a guess, but I would bet that the valve was present but not detected the first time around.

+++++

Question:

Specifically, could you please expand on the effects of the reduction of "in flow?" What effects could be/would be felt from a lack of in-flow? Could it be that the in-flow is just as an important piece of the puzzle as blocked drainage?

Answer:

Consider the brain to be like a barrel with two openings.
Take two hose and place them in the openings
Push water into one hose and let it drain through the other hose
By regulating input and output you can get a steady state to keep the fluid in the barrel to the same level

Now block the drainage.
Either less water can go into the barrel or the barrel will explode.

In the body, if you reduce the amount of blood getting out of the skull, then the amount of blood that gets into the brain must be reduced.

Reducing the blood flow into the brain is a bad thing most of the times. Flow in the carotid and vertebral arteries is essential for brain life.

Why? Because oxygen and nutrients get to the brain via the carotid arteries so reducing inflow to the brain leads to inadequate oxygen to the brain. That can lead to cell death or dysfunction.

+++++

Question:

Specifically, could you please expand on the effects of the reduction of "in flow?" What effects could be/would be felt from a lack of in-flow? Could it be that the in-flow is just as an important piece of the puzzle as blocked drainage?

Answer:

Consider the brain to be like a barrel with two openings.
Take two hose and place them in the openings
Push water into one hose and let it drain through the other hose
By regulating input and output you can get a steady state to keep the fluid in the barrel to the same level

Now block the drainage.
Either less water can go into the barrel or the barrel will explode.

In the body, if you reduce the amount of blood getting out of the skull, then the amount of blood that gets into the brain must be reduced.

Reducing the blood flow into the brain is a bad thing most of the times. Flow in the carotid and vertebral arteries is essential for brain life.

Why? Because oxygen and nutrients get to the brain via the carotid arteries so reducing inflow to the brain leads to inadequate oxygen to the brain. That can lead to cell death or dysfunction.

+++++

Question:

My wife has some concerns, her main one being - if ballooning is done on a stenosed vein and it has collaterals, we understand the collaterals will wither up. Then suppose a few months later the stenoses re-occurs. Since the collaterals are gone, would this make the blockage even worse than before the procedure?

Answer:

You are on a highway. The road ahead is blocked by an accident. So you get off and take a service road around the accident. You are not the only one so the traffic on the service road grows.

Then the accident is cleared and the road is clear sailing again.

The service road goes back to little traffic.

Unless you permanently barricade the service road, it will again be used to bypass delays.

Same with the veins. They will shrink but they generally will not evaporate

Have a nice trip!

+++++

Question:

Thanks for your answer to my question. It's so hard sometimes to make these kinds of decisions. The only surgery I've ever had was an emergency surgery, never an elective one

Answer:

Dear ruthless

I cringe whenever I hear anyone refer to the surgeries. This is as much standard surgery as a tuna fish sandwich is sushi

Did you notice that I never used the word cutting, scalpel, general anesthesia, blood loss, retractors or cautery. Did anyone hear transplant, excision, or anastomosis?

This procedure is performed through a needle the size of a safety pin without any cutting. As the wheelchair kamikaze said to me tonight, he cannot find the spot through which I placed my instruments.

So, while it is true that the dictionary defines surgery as the treatment of disease by instrumentation or manipulation, treatment of ccsvi is as much a surgical procedure as lighting a firecracker is a space launch.

+++++

Question::

In the absence of any pressure, the vein walls will collapse to their natural position. But in many of the venogram images, the jugular vein is obstructed in one particular location, caused by some external force, such as a bony protrusion, malfunctioning valve, etc. These images still show blood flow above and below the narrowing. Shouldn't the image show no blood flow below the narrowing, if the vein was to collapse in the absence of any flow?

Also, if blood blow is being driven to the vertebral veins, in the presence of flow resistance in the jugulars, why is CCSVI a problem? Aren't the vertebral veins capable of handling this blood flow like when the person is supine?

Answer:

Those MRVs are a static image taken after the gadolinium has percolated through the area. If you take a snapshot you might see what you expect, but there is slow flow rather than no flow.

Good question about the vertebral vein flow. I see that you will make me think by this exercise and I will figure things out or need to learn things along the way.....we really are partners in crime, eh.

I would postulate and argue that these vertebral veins have extra flow that they are not prepared to handle. And not all the blood can exit as fast as necessary. The theory is that this "breakdown" in the blood brain barrier leads to problems.

You guys are tough and insatiable.

+++++

Question:

Venogram is the gold standard for diagnosing CCSVI in IJVs and azygous you say and of course it makes sense. What about vertebral plexous problems? Atresia, agenesis or whatever. Would you suggest a specific test (like ct scan or MRV) just to make sure especially when venogram is not indicative for CCSVI?

I know it s early days, but given the fact that blood drains from the vertebral veins when in upright position isn't imaging of these veins also, of special importance?

Answer:

I asked the same question on Sunday to a certain well known investigator. Awaiting an answer

These vertebral veins are pretty small. I wonder whether they would stay open after angioplasty.

+++++

Post subject: using port for access for liberation

Question:

Perhaps the port could be used to access my right internal jugular, but if a wire was put in my port, it would exit the catheter into my right atrium and it would have to turn right back and trace along the catheter in my left subclavian to reach the base of my left internal jugular.

Answer:

The port can be injected with contrast media but one would never try to perform a liberation procedure through the port. Technically impossible

+++++

Question:

Do you think that low blood pressure would reduce mean transit time of blood through the brain and increase hypoperfusion?

Answer:

Low pressure might increase transit time and increase hypoperfusion
However the body adapts to low blood pressure by clamping down some arterial beds to protect others like the brain.

+++++

Post subject: vertebral veins angioplasty

Question:

Venogram is the gold standard for diagnosing CCSVI in IJVs and azygous you say and of course it makes sense. What about vertebral plexous problems? Atresia, agenesis or whatever. Would you suggest a specific test (like CT scan or MRV) just to make sure especially when venogram is not indicative for CCSVI?

I know it's early days, but given the fact that blood drains from the vertebral veins when in upright position isn't imaging of these veins also, of special importance?

Answer:

I cannot think of a reason why venography would not be indicated for CCSVI. The incidence of CCSVI in MS is so high and MRV does not adequately assess the azygous vein, I would perform venography on anyone.

It has been suggested that vertebral venography and angioplasty has no role. Personally I am not sure yet

+++++

Post subject: vertebral veins

Question:

You answered to my question, and of course you should perform venogram on anyone by all means! I was trying to say that venogram cannot access those tiny vertebral veins, so if a venogram doesn't lead to a CCSVI diagnosis this doesn't mean that someone has no vein problems. Maybe he should undergo other tests also

Answer:

Dear Costumena

At the present time, in a phase of discovery, all the tests should be performed to determine 1. Whether a screening test adds value, is accurate and is reproducible. 2. Figure out which is going to be the gold standard

The vertebral veins are not that small and the catheter can enter them

What to do is a different question.

+++++

[drscifani wrote: the vertebral veins are not that small and the catheter can enter them. what to do is a different question.]

Question:

Exactly...

I didn't have a clue that vertebral veins can be accessed by catheter. This sounds promising!!! Let's hope no one will have to go that far though...

Answer:

Who said it hasn't been done? I did it twice today.

Both verts were abnormal.

But what to do is a different question

+++++

Question:

When angioplasty is performed on veins to correct inverted (or sticky-faulty-valves) or to remove membranes from the lumen of these, are there any debris released and if so, what is their fate?

Answer:

The valves are connected to the wall of the vein. The angioplasty is trying to stretch and shear the attachments to the wall but it is unlikely that a valve or web or membrane or septum could be completely detached. If it did detach, it would go with the flow. Where would that be?

The flow would be into the right atrium of the heart, through the right ventricle of the heart and lodge in the pulmonary arteries that cause gas exchange in the lungs. The amount of tissue that might be released would be minor and would not have significant effect on lung or heart function.

+++++

Question:

A few TIMsers reported accessory nerve damage after stent placement high up in the IJVs: is this unavoidable ? Is balloon angioplasty safer for interventions high up there with regards to accessory nerve damage? What are the probabilities for the vein to stay open without stent placement in this location?

Answer:

I have been told that if the flow in the jugular veins is obstructed lower down, then flow is diverted to the vertebrals and that leads to collapse of the upper part of the vein. At the level of the carotid bulb, and the high IJ near the skull base.

I didn't realize it when I first got involved with ccsvi but I am a quick learner. I was planning to treat the high IJ on the kamikaze based upon a CT venogram but by the time he was scheduled for his procedure, I had learned and didn't treat that area.

I look at the area with intravascular ultrasound (IVUS) and watch it phasically increase and decrease in size, proving it is not real stenosis.

I am not saying that there are no occasions where a stenosis is seen there but I haven't had to treat that area. That area is a really crowded one, with nerves and veins and arteries competing for space. I can imagine that stretching the nerve or compressing it by stenting could be a problem so I am very reluctant to stent that area

+++++

Question:

However, since she found out that this procedure involves going thru the heart she has become very apprehensive about having the procedure done. Other than her mild ms, my wife is in excellent health, and bikes an hour a day. However her father died at age 27 of a coronary, which is the cause of her concern. Are there any risks to the heart in this procedure?

Answer:

All good things go through the heart
Seriously, the catheter goes through the heart over a floppy guidewire. This is done for many reasons every day. I think it is very safe

+++++

Question:

I still wonder though if the better results are coming from those treated for higher stenosis at Stanford. Dr Dake saw on my MRV that my veins were flattened at C2. When I went to Poland I had an area of stenosis lower down on the left as well (also seen by Dake) but the right was untouched. Now I have been told there are issues with the right and I am wondering whether I just need both sides treated at C2.

Answer:

I am happy to discuss the merits of your post, but it gets a little sticky to be advising you personally on the forum, without a formal consultation. One doesn't get the real flavor of other physicians' rationale from such short messages and without analyzing the imaging.

So let's try to stay theoretical for the moment.....

I am not aware of long term results other than Dr. Zamboni's article on clinical outcomes. I do not know that treating higher stenoses at Stanford will result in better outcomes. I do not know the incidence of cranial nerve trauma associated with high angioplasty or stenting. So we will just have to see. Frankly, as I have said before, so far all the high narrowings are dynamic and the vessel expands and closes down. I think that assessment of upper narrowings should only be done after the central obstructions are relieved. Then we can tell if there is something substantive.

Anyway, maybe my idea of intravascular ultrasound is brilliant! I've had the instrument for many years and didn't find a really good use for it, so I tried it here and it really makes me feel comfortable with my diagnoses.

+++++

Question:

If I have a problem with valves, could a catheter venography detect this problem? Could a ballooning operation solve valve problems?

Answer:

The catheter venogram has the precedent of being considered the gold standard imaging test of the anatomy of the veins. Flow issues can be assessed subjectively but other tests, such as ultrasound and MRvenogram should be more accurate for specific velocity and flow rates.

There has never been a blinded study comparing the accuracy of ultrasound, MRV and catheter venography. Thus we must presume that Catheter Venography remains that gold standard until such time as head to head (or should I say neck to neck) comparison is made.

Venography is the injection of opaque contrast media (dye) into the interior of the vein. The dye outlines the walls and the structures inside the vein. It says nothing about the wall of the vein itself. When the vessel is narrow, the dye column also appears narrowed. The cause of the narrowing can be stricture or developmental narrowing, a big thick valve protruding away from the wall, or other abnormalities like twists. Sometimes you can see the thickening moving in and out suggesting that it is a valve.

Sometimes the webs and valves are too thin and very difficult to recognize. This is especially true if the dye is too dense.

So even the gold standard is unlikely to be 100% accurate. Only way to tell that is to compare venograms to their gold standard, which is examination of the tissue by a pathologist. AND WE DON'T WANT TO DO THAT, DO WE

I got to go, late for meeting

+++++

Question:

Will this treatment be more difficult for those whose veins roll and collapse?

Answer:

That's an interesting question. Never occurred to me since the veins we put IVs in are not the veins we are treating or accessing to start the procedure. This experience is great. It is helping me understand the patient point of view.

Wiggly veins in the hand and arm used for putting in IVs are still challenging to me. Despite almost 40 years of putting needles and catheters in these veins, I still find them more challenging than doing the actual procedure. I admire the nurses and technicians who are better at it than I.

The veins we access for the procedure are the femoral veins. These are much larger, deeper, surrounded by stronger tissues than flimsy superficial veins of the hand and arm. They are not visible but we know where they are by feel (they are just to the midline of the femoral artery whose pulse I am sure most of you can feel). If still not found, ultrasound is useful in seeing exactly where the vein is.

Because of the femoral vein's strong fixation to the tissues, accessing it with the thin needle (about the diameter of a safety pin) takes just a few minutes. Putting in the conduit through which all the instruments go is pretty routine and then we do not touch that vein any more.

The jugular veins and azygous vein are large veins with substantial wall thickness surrounded by tissue that holds them in place. They do not wiggle or roll. Even if they did, we are inside the vein so it wouldn't matter.

So a short question still has no answer!

I would say that the answer is NO, it would not be difficult to do the procedure if you had roly veins.

+++++

Question:

Some skeptics on CCSVI claim that solving stenosis by ballooning is only temporary, and all the improvements noticed will fade away, since veins will return to their "old position"(i.e. collapsed, flattened) after an avg. 3 weeks.

What do you think?

Answer:

Please ask the skeptics the number of patients on whom they have performed venous angioplasty. Ask them the indications for the treatments they have done. If they do not have personal experience, ask them for the literature on which they base their opinions.

Dr. Zamboni showed that about 50% of patients had recurrence of outflow obstructions after 18 months. I am not aware of any other literature on angioplasty of CCSVI.

But Dr Zamboni was acting cautiously and responsibly on the first go around. We have yet to stratify the abnormalities that resulted in recurrences. Moreover some of us have elected to try to avoid stents on the first go around, like Dr Z. A second intervention may be needed and no one has reported on this SECONDARY PATENCY yet.

The largest experience with venous angioplasty comes from treatment of dialysis grafts and fistulas in the arm. We have done that for more than 20 years. This is definitely different disease than ccsvi so we cannot use that experience as a mirror image. Dialysis grafts are punctured every couple of days, often there is synthetic material, etc.

Nonetheless, we know that venous angioplasty and venous stenting of dialysis stenoses do not have the long term patency of arterial plasty and stenting. But to assert that the dilation of the veins of ccsvi will result in only three weeks of relief is irresponsible.

+++++

Question:

Could ballooning solve valve problems?

Answer:

The valves are leaflets of tissue that are attached to the wall and close periodically by coming together. In ccsvi some of the valves are thickened mounds of tissue that do not open and close at all, some just do not open all the way, some do not close all the way, some seem to have the leaflets fused partially or completely. , some form pockets adjacent to the lumen and balloon up some times. In all situations they restrict the flow of blood coming out of the neck and brain.

Angioplasty attempts to tear the valve's attachment to the wall or split apart any fusion of the leaflets, or stretch wall adjacent to it. So it is not one question, one problem, or one solution. I do see improved flow, but we will have to wait to understand the natural history of the treatments.

We have a long way to go to understand these problems and determine the best way of treating the various problems. Bottom line, stay tuned. And keep asking the good questions.

Does that help you?

+++++

Question:

Is there no possible better solution then to vein stenoses that might lengthen patency? Any ideas for a better treatment solution? Has this been explored in dialysis stenoses at all?

Answer:

Yes, there are many things attempted

- Angioplasty
- Ultrasound surveillance followed by earlier aggressive repeated angioplasty
- Stenting
- Resections
- Covered stents
- Funnel shaped stents
- Reducing the number of synthetic grafts used.

While dialysis graft and shunt problems are different from ccsvi, they are also long term problems that require ongoing treatment....remember loss of all the veins leads to inability to perform dialysis and that is not compatible with life. We are constantly searching for answers for old and new questions.

No reason to thing anything different for ccsvi

+++++

Question:

If you have resistance to outflow from the brain, you will develop reduction of inflow. Inflow to the brain is a good thing." But I still do not understand, if no reflux (= underlying theory of CCSVI), what could be the damaging impact for MS of such a condition?

Would you think that intervention in this case can bring chances for improvement?

step1: go to Poland for MRV, venography and if they find stenosis only angioplasty (without stent) as a first step
- step2: monitor potential improvements Cool
- step3A: in case none, well at least I tried Wink
- step3B: should improvements be vanishing after a while, when going for check-up to Poland after 6 months they would detect whether restenosis has occurred, and if so, only then go for a stent.
- step3C: should improvements not be vanishing Very Happy or only be vanishing in around 1-2 years , get later-on as soon as it's my turn within the 1200 Exclamation people Bologna/Ferrara waiting list follow-up in Ferrara..

Answer:

Those are complicated questions. I have committed to answering questions in a general way rather than a personal one. It is far too complicated to make specific recommendations on individual patient issues without knowing a great deal about your history, presentation, progression, imaging, neurological assessment, age, attitudes, etc.

QUESTION ONE:

So let me address the first issue you ask, namely the confusion about flow and reflux
REFLUX. Slow flow or no flow leads to vicarious drainage of the brain's blood through different pathways. The theory suggests that this large flow leads to harm to smaller vessels in the brain and that this leads to exposure of brain tissue to immune cells and to iron, leading to brain damage that leads to demyelination and inflammatory plaques. This leads to electrical conduction problems that lead to symptom complexes called MS.
SLOWFLOW If there is resistance to outflow from the brain, this may lead to reduced inflow to the brain. That may lead to reduced oxygen delivery to the brain and cellular function may be compromised without oxygen. And it may ultimately be the cause of diminished brain size. Perhaps it is improvement in blood flow after angioplasty that explains the very rapid improvements in neurofunction that some patients experience. Clarity, return of sensation, etc sometimes are seen before leaving the hospital. Of course it could be placebo, but it could also be improved brain function because of improved brain flow.

QUESTION2

Namely the debate of stenting and angioplasty. Firstly, we do not have ideally designed stents, there are concerns about migration because of the dynamic and considerable ability of these veins to dilate, and we do not have clarity of their long term outcome. It is therefore reasonable to attempt angioplasty first as it is safe and relatively simple. Repeating it is not a problem as the risk of the procedure is low.

Therefore I am inclined to treat by angioplasty alone first. See how things go. If symptoms recur, if stenosis recurs, then comes the decision making process that must be a plan devised by patient and doctor. If a patient's symptoms have improved after angioplasty, cog fog, numbness, etc, then the decision is really a quality of life issue.

+++++

Question:

Dr Sclafani, I am wondering if you have done any looking in the lumbar plexus area yet. Dr Zamboni has mentioned a problem in some PPMS patients regarding veins down there that have never developed at all, thus there is no way to treat. What do you think about this problem and have you seen it yet?

Answer:

I have not really focused on lumbar veins yet. I have seen some abnormal veins there but not complete absence of these veins.
I think that the drainage of the lower spine is very different from the upper spine and am studying this area more closely to answer someone's question but I don't want to speak about this yet

+++++

Question:

Deleted my silly question. Found a pic that makes it obvious. It is the IJV's that drain blood from the cervical spine.

Answer:

Your silly question led me to read about this yesterday. It appears that you are NOT correct. See, that is why I joined this forum, to try to clarify, modify and correct some of the ideas patients have.

The spinal cord has an interesting venous drainage. There are small veins that exit the spinal cord and enter venous plexuses that surround the spine and vertebrae. (A venous plexus is a tangle of very small venous channels and lakes.) These plexuses connect up and down the spine. Some then drain out into larger more defined veins. These veins can drain upward into the brain and then back down the venous sinuses to the jugular vein. There are also veins that connect the cervical plexuses to the upper jugular vein itself. The cervical venous plexus also drains into the vertebral veins and they connect to the subclavian or innominate veins. Lower down in the thoracic spine these plexuses drain into veins that connect to intercostal veins and hemiazygous and azygous veins. Lower down still there are veins that connect the vertebral venous plexuses to lumbar veins, ascending lumbar veins, and the inferior vena cava and lots of other veins.

+++++

Question:

I get the feeling you think it more prudent to try angio first and then stent which might have higher possibility of complications. Honestly I'd be happy to sign a waiver for the stent but if I have to come back a couple times to get it right if the vein restenosis after angio so be it. I am just happy to get a chance to feel better. Engineering wise if you put a slight flare on the end going towards heart one would think that would help to avoid movement. But I'm just thinking plumbing.

Answer:

That's me, Joe the plumber

Your feeling is correct. Stents are designed to go into straight tubes that taper gently as they go to the periphery. First designed to bridge bile duct narrowing caused mostly by cancers around the liver, they expanded their application into arteries in the heart, extremities, kidneys and more recently the carotid arteries as a treatment of arteriosclerosis in those arteries. Applications also extended into veins, notably for dialysis grafts and fistulas designed to enable hemodialysis for kidney failure and more recently for the treatment of deep vein thrombosis of the legs and abdominopelvic veins.

The technique of stenting is to pick a diameter of stent that is about 10-20% larger than the diameter of the blood vessels. The stents stay in place because they exert radial force against the blood vessel wall.

Since atherosclerosis occurs in older people whose life expectancy is not that long, very long term performance of stents is not as critical as in MSers who, we hope, will live long, albeit challenged lives.

Now look at the problems in the jugular veins. The vessel gets larger as it goes in the direction of flow. The vessel can expand in diameter by 50% or more because of pressures applied in the venous blood, or increased flow.....it is what we call a high compliance vessel. Also there is a lot of movement in the neck and this bending and twisting is a lot of force to apply to a stent for a long time. Will the metal fatigue. Will that lead to failure?

Finally stents become incorporated in the wall of the vein by growth of the inner level of blood vessel cells called endothelium over the wire mesh. ENDOTHELIALIZATION takes a couple of months. It ain't coming out if the stent clogs off.

Yes funneling the stent so it enlarges as it gets closer to the heart sounds like a good idea, but we will probably see a lot of good ideas on how to keep the stent in place.

So, as a work in progress, I prefer to treat by angioplasty for the time being and rework with stents after angioplasty failure or stenosis recurrence, especially if symptoms worsened. More work, but a bit more cautious. If I find down the line that Zamboni's outcomes were better than mine, then I might change my mind.

+++++

[drsclafani wrote:

Nonetheless, we know that venous angioplasty and venous stenting of dialysis stenoses do not have the long term patency of arterial plasty and stenting.]

Question:

Is there no possible better solution then to vein stenoses that might lengthen patency? Any ideas for a better treatment solution? Has this been explored in dialysis stenoses at all?

Answer:

Yes there is a new stent that is covered to avoid metal against the vein wall and funneled to improve flow. I immediately thought of it for ccsvi but remain concerned that the covered nature of this stentgraft will work against us, sliding out too easily

+++++

Question:

Do you know if any md, researcher or pharmaceutical company is working on developing stents specifically designed for venous use in ms? I suspect that because the potential market for this is potentially huge someone is doing this already. If so, after how long to you think they will be in clinical use.

Answer:

I know of no such stents being designed. But it would probably be kept secret at this point. Any MSeer venture capitalists interesting in designing such a thing?

I would guess that five years would be the minimum time to market, maybe less if a old design were modified

+++++

Question:

The patch was obviously more risky because of the amount of stitches but better in the long term. He had the patch procedure and has done well. So is there a reason why some of these procedures aren't considered for veins. I'm wondering if the tissue is more delicate and stitches won't hold up. I know it is far more invasive but is there another reason that these ideas aren't considered?

Answer:

Surgeons tell me that operating on veins does not have the success rate of surgery on the heart and the arteries. Perhaps the slower flow, the compressibility, and the compliance all act against these surgeries. My first life was as an interventional radiologist taking care of patients with injuries such as car accidents and gunshot wounds. We always looked pessimistically on vein injuries because the repairs did not stay open like arterial repairs.

+++++

Question:

Dr. Sclafani, so could this suggest that the slow flow venous issue would not necessarily be linked to MS plaques but to simply a separate blood circulation problem - or as an interaction with MS neurologic issue, worsening certain MS symptoms?

Answer:

Good question, but like most of this there are more good questions than answers. It could be that all of what you say is true

The pathology suggests that CCSVI is related to the development of inflammatory processes in the brain. Perhaps even the autoimmune process is initiated by the venous insufficiency too.

The venous outflow problem may worsen the situation because it may be the culprit behind the cerebral atrophy and diminished blood flow through the brain.

Many a career will be made answering these questions
I wish I were younger

+++++

Question:

My questions is about angiograms. Strictly in terms of acquiring a CCSVI diagnosis, is there any reason that going up through the arteries, and sending dye through the brain and back down the jugular veins, wouldn't be just as effective in finding problems as going up through the veins.

Answer:

One definitely sees the jugular veins when you do a brain angiogram. However the dye is diluted and the view is not so clear as when dense contrast media is injected. the view in the venogram is much much sharper and more likely to see some of the subtle webs, septum and valves

There are other reasons NOT to try it through the arterial tree

Going into the high pressure arteries has a greater risk of causing bleeding at the puncture. Also damage to the artery has a distinct but small risk of causing loss of blood flow down the leg.

Also injecting the dye through the arteries into the brain has the added risk of sending debris, arteriosclerotic plaque, blood clot or air up into the brain and that can lead to a transient ischemic attack (TIA) or stroke. We want to avoid that. A little bit of those things going out of the jugular vein is pretty safe.

So I applaud your though process and understanding of the flow dynamics, but stay out of my arteries, thank you very much.

+++++

Question:

I have a question about pressure gradients. I have been told that they are not meaningful if measured over large distances in veins. In particular, if there's a pressure gradient of, say, 3 mmHg over the length of such a collapse (say 3 cm), would you consider this reason to treat such an area?

Answer:

I really do not think that minor pressure differences are going to make a real difference. After all, the arterial pressure exposed to the brain is more than 100 mm higher than the pressure in the veins. I think it is flow, not pressure related.

+++++

Question:

Genesis (Johnson & Johnson) is "made of stainless steel and has a closed-cell configuration". It seems to have a "superior crimpability, flexibility, and comparable radial strength to the Palmaz iliac stent, and superior crimpability and radial strength and comparable flexibility to the IS LD series."

Answer:

First of all, device manufacturers are no different that pharm. they use whatever selling point they can think of. It is trials that make a difference in deciding this. As I said we are no where near deciding if any stent has superiority over any other in ccsvi.

I prefer nitinol to stainless steel. until endothelialization, those big magnets used in MRI can have effects on ferromagnetic devices. Nitinoll does not. You do get MRIs once in a while don't you?

Also crimpability is a negative anywhere that someone can exert force on them. Banking your neck in the wrong way against something might cause the stent to crimp.

+++++

Question:

What about the use of filters in the Superior Vena Cava (normally employed for embolisms, and such) to "catch" any transient stents? And, would these filters catch fragments of any stents that might fracture?

My question about endothelialization was ultimately answered, but I still wonder if that means that the stent might have to be excised at some point, if the stent was causing untenable contra-indications (nerve pain, callousing, thrombosis, etc.). Is endothelialization a desired process in stenting?

Answer:

Placing a filter would prevent a rouge stent from going to the heart, but you would end up with a bunch of junk in the superior vena cava and that could lead to clotting of the entire superior vena cava. I would not think that having superior vena caval syndrome on top of ccsvi would not be a pretty picture

Stents have risks of thrombus formation until they are incorporated into the wall of the vein. That happens via endothelialization. Taking a stent out if it is endothelialized would not be a pretty picture. The vein would have to be excised.

Stents have a variety of patterns of the metal that make them more or less rigid and able to withstand motion stress. I have seen stents that fracture but continue to do their job.

+++++

*****NEW FROM HERE ON*****

Question:

What if the IR encounters an IJV valve that has formed a pocket and is ballooning up restricting flow...what is the approach to correct the problem?"

Answer:

Why do I think this is a known lurker who wants to know how I will treat the second time around. Nice try!

This is an unusual finding that amazed dr zambni when I showed it to him. I wish I had an easy answer, we would not have to do a second procedure if I did!

I think that a stent makes the most sense right now since all the surgeons I offered this vein to, demured with thanks. it is kind of a valve that formed a pocket and that pocket balloons out on ivus to occlude the main lumen. I think we need to permanently compress the valve against the wall.

If I knew how to show pictures here, I would.

sorry madame lurker....we will find out in a few weeks

+++++

Question:

So is undergoing a procedure doing anything more than satisfying his intellectual curiosity?

If you are looking for certainty, you will be disappointed. This is an age of discovery and we just do not have sufficient data and trials to answer this.

we are in a time sort of reminiscent of the age of the automobile. The benefits and the dangers of cars were not apparent at the beginning. Lots of horse and buggies traveled the highways for quite some time. Who could predict 50,000 deaths a year on highways and who would have predicted the freedom they would bring.

Forget his curiosity. what about yours? You are in this together.

+++++

I started this thread one week ago. I had visited the site to hear what patients thought about ccsvi. I was troubled by some assertions that were misleading or inaccurate. I saw a community that was as desperately seeking answers as I was.

I decided to weigh in thinking that a few answers might set things straight. The response was far more than I imagined. I was humbled by the appreciation that came forth and I was proud of the inspiration I was bringing and receiving.

So a week later and almost 11,000 hits. As someone told me, that was more than even the Kamikaze gets!

It is a bit frightening to realize the role I have taken as a medical professional helping answer some questions and concerns. Damn good ones too.

I guess I am in this for the rest of my career so thanks to all who have made me involved in this, including Michelle , Marc , Mitch. Neen, Cheryle, Jason and holly

have a great night

+++++

Question:

Given the fact I have cervical lesions (c2 and c4-c5) and no brain lesions (yet) would it be safe to make the assumption that the problem lays somewhere there IF CCSVI applies to me? Especially for the C4-C5 problem, from what you told us, it is more likely to connect with the azygous and NOT the Jugular veins. Goodbye doppler haha

On the other hand, you wrote: There are also veins that connect the cervical plexuses to the upper jugular vein itself. What's the deal?

Umm, maybe upper cervical spine drains to the Jugs and lower to the Azygous? Couldn't God make it a bit more simple?

I wish it were that simple or there were hard and fast rules.

imagine that the jugulars were blocked. Flow from the brain veins would have to traverse through the jugulars and that might increase the flow through the veins of the spine.

so it is possible that your lesions are due to jugular problems. Just as easily it could be that all of your flow from the thoracic and lumbar spine had to bypass the azygous and travel up to get back to the heart

Ralph Waldo Emerson said people see what they are prepared to see. I would like you to be prepared for all the variations that can occur.

God simple.....I don't think so

+++++

Question:

why should only two type of veins (jugular and azygous) be affected in CCSVI? - very likely more other veins will be stenosed, just that we do not know as protocols not worked out for those yet.

eureka

one sees only what one is prepared to see.

looking in the periphery beyond those big large rivers, there are small lakes and tributaries and surprise surprise there are abnormalities of the small vessels that look like the bigger problems only smaller

the body is a beautiful thing, but when it decides to go haywire, it really knows how to mess up

+++++

Question:

I have had the doppler scan, and there is a stenosis, yet I am not scheduled until the 11th of May for my consultation with the Prof (I'd imagine the procedure would follow fairly soon after the initial consultation). Is there anything I can do in the meantime to address the stenosis?

a short hiatus from your accolades was essential to hold my ego in check. I needed a breather too.

I can imagine how frustrating it must be to find someone to treat the ccsvi but have to wait 6-8 weeks longer. I certainly cannot diminish your fears that an exacerbation might precede your treatment.

I am certainly no expert on MS. I have heard from several patients that elevating the head of the bed makes them feel improvement. I might do that.

Why should elevating the head of the bed result in improvement? I doubt it has anything to do with getting a good nights sleep, or dreaming better. From the CCSVI theory, I can imagine benefits of an elevated bed.

We should all remember that the drainage of the blood out of the brain has two normal pathways. When lying down, blood drains out of the brain through the jugular veins. When standing up, the jugular veins collapse and blood returns to the heart through the vertebral veins.

These facts astound me. I have asked a few dozen physicians, including sleep experts, vascular surgeons, cardiologists, neuroradiologists and interventional radiologists to tell me how blood drains from the brain and NO ONE got it right...making this physiology a most common hidden secret.

So how do I explain the benefit of an upright bed. If you lie down and the increased flow through the jugular veins is counteracted by the jugular obstructions, then it would seem best to enhance blood flow through the vertebral veins. So put yourself closer to upright.

Just a theory

+++++

Question:

I am curious about this as well...I guess my question would be: What causes restenosis? And are any of the possible causes of restenosis preventable?

There are many causes of restenosis, including elastic recoil, intimal hyperplasia, neointima, thrombus,

Elastic recoil is likely happening in patients with CCSVI . Also the hypertrophied valves may get pushed against the wall, but then slowly or quickly retain their original shape and cause obstructions.

neointima, thrombus formation are more common after stenting. in this situation, there is a reaction to the metal, to the shear forces, to the abrupt change in velocity of the vessel. The endothelial cells begin to proliferate and then other cellular and chemical substances in the circulation accumulate in and around the stent. This thickened area results in a decrease in the diameter of the blood vessels

So how do we deal with restenosis.

There are drugs that can reduce the intimal hyperplasia. Some (serolimus) are placed on the surface of the stent to reduce that response. Other techniques include freezing the endothelial cells, platelet inhibition can be accomplished by anticoagulation, antiplatelet agents such as aspirin and plavix, reangioplasty is done sometimes, covered stents reduce the risk as well.

in CCSVI we are dealing with abnormal tissue development so restenosis can occur because of elastic recoil of that tissue. also restenosis can result when the valve that is pushed against the wall of the vein, begins to return to its original shape and orientation.

+++++

Question:

But then if stents are placed in jugular(s); too much blood (?) is drained out of the brain during daytime (standing/seated), stents preventing their collapse Question (not sure I express myself correctly here, pardon me)

you express yourself quite clearly to me, thank you very much.

I would not worry about blood draining too fast from the brain. the limiting factor of draining the brain is what goes in. the capillary between the artery and the vein is the limiting factor in getting the blood out.

Also the stent is placed where the narrowing of the veins is. the remainder of the vein, I would presume, will still collapse when you stand up.

hope this helps

+++++

Question:

After having balloon angioplasty, could we take any measures to prevent or postpone restenosis? For example, quit smoking if we smoke, take vitamins and antioxidants, reduce stress, follow a healthy diet, etc. Do you think that this could help the venous wall be more healthy?

do not forget that some doctors who perform stenting and/or angioplasty will put patients on anticoagulation. Vitamin K counteracts the Coumadin. so make sure you discuss this with your physician when he puts you on Coumadin to see whether you should stop vitamin k or reduce your intake of foods with vitamin k

+++++

Question:

Today, I had the Doppler ultrasound, and it was revealed that my jugulars do not collapse when I am upright. I have not had any intervention, so that is my "natural" state. There was a lot more interesting about the US, and even the skeptical-about-CCSVI Dr. thought that there might be some kind of blockage below the clavicle.

Careful about the interpretation of ultrasounds. it is a steep learning curve. hopefully you had someone with experience.....

Why would the jugulars not collapse? If there is vertebral vein outflow obstructions, then blood must flow through the jugularsits got to get out somehow.

The bottom line to me is that all these tests are interesting, but you need a catheter venogram to sort everything out. and that also has a steep learning curve

+++++

Question:

Dr Sclafani,

Andrew Fletcher has a thread here at TIMS re: Inclined Bed Therapy--bed raised 6 inches at head, even incline down to none at foot of bed.

Many of us are doing this, and report great results in resolving to different degrees issues of circulation (myself included).

How do you see his theory in relationship to CCSVI?

I could guess.....

- 1. there is insufficient pressure to get adequately brain venous outflow. Raising the head of the bed might allow better gravity flow?
- 2. upright position increases vertebral blood flow. If the jugulars are not flowing, perhaps we get more favorable vertebral blood flow when upright

I am sure there are more guesses than there are answers
more flow through the vertebrae

+++++

Today I learned something new in my treatments. I thought I would share.

I have been concerned about incomplete dilatation of the veins when using venous angioplasty, especially when I think the problem is incompletely opening valves. Sometimes even with very large balloons, I have been dissatisfied with the amount of widening I achieve.

Today I added a cutting balloon to my armamentarium of tools for use in liberation. This balloon has some sharp edges of metal attached to the balloon. When the balloon is opened, the metal presses into the tissues. it creates an indentation. After creating the creasing of the vein or valve, I then went to my usual 14 millimeter high pressure balloon and the vein dilated so easily and smoothly. it was like buttah! and created a very large venous confluens.

Is this a consistent benefit? Is there any new risk? Will this reduce recurrent stenosis?

time will tell but I got really excited about this one.

+++++

Question:

Dr. Sclafani,

Please clarify something for me. When someone talks about a vein narrowing by 50%, are they talking about diameter or area ? (I'm doubting it's circumference). Is this standardized in the medical community or should I liken it to marketing (Say whatever to sell something) ?

Talking in general terms for ease of math, a tube that is 1" in diameter is half the diameter of a 2" tube. The area of a 2" tube is much larger than twice that of a 1" tube.

It makes a big difference when we are talking about something this critical.

Answer:

Wow, things were pretty quiet for a few days other than discussions about bed inclination so I thought that the questions were dying down, that I had answered all the questions. How I underestimate your thirst for understanding

IRs talk about narrowing in percentages. We can speak about the percentage of the diameter or we can speak about the percentage of the cross sectional area. Area is more accurate.

its been a long time since geometry, but area is πr^2 . No, I am not a nerd. Let me translate for those non-nerders the area of a circle is 3.14 times the radius times the radius(r squared)

so if the vein above the narrowing measures 12 mm and the narrowed area measures 6mm , then the percentage of narrowing is $3.14 \times 3 \times 3$ divided by $3.1 \times 6 \times 6$ or about 28 divided by about 100 or about 28% narrowing. Some will speak about 6/12 or 50% narrowing of the diameter but cross sectional area is most important.

after all in said, actually be careful that your doctor does not define comparison to normal based upon the findings commonly seen in atherosclerosis where 70% narrowing is considered significant. Because of the low pressure changes in cross sectional diameter are exaggerated.

+++++

Question:

Is this a consistent benefit? Is there any new risk? Will this reduce recurrent stenosis?"

My one thought concerned the health of the lining of the veins. If the endothelial lining isn't strong and you put sharp little edges in it, could it weaken the vein? I'm not trained in the sciences so my apologies if this question is a foolish one. (P.S. I'm on your list as well.)

Answer:

No question is a foolish one.... otherwise it would not be asked.

I did one case! you have got to be patient as one case is only a glimmer. We need more data to answer your question. otherwise it is just opinion. my opinion is that the vein looked like flow was enhanced.

with regard to weakening the wall, that is absolutely true. The malformation of the vein is generally stiff and that stiffness prevents distension of the vein. the cutting balloon just makes it easier to dilate the vein...I will keep you all informed of this

+++++

Question:

Ought we to be confident that any competent vascular surgeon, interventional radiologist, etc., would see bad valves, stenosis, etc., as something to be treated? There was the doctor in Australia who went in, and backed out without treatment.

Answer:

would you trust a air traffic controller on his first day on the job?

I think that the procedure is the easy part. the hard part is determining what is abnormal. its not like a clown comes out and dances around with a placard that says " Hi, I am abnormal. please come treat me."

so the answer to your question is yes, it makes a difference. I am far better now than during my first case....sorry angel. Everyone should go to Zamboni, but alas he is way too busy. most patients getting the procedure done in the US are pioneers. if you don't have the courage to take on that role, then wait it out.

+++++

Question:

What would your reaction be if you performed a venogram on an MS patient and the only problem you found was that one of the internal jugular veins had a 40-50% narrowing at one point, there was a moderate patchwork of small collaterals near the narrowing, plus a large collateral above the narrowing that connected to the nearest external jugular vein, but the internal jugular vein was still dynamic in the area of the narrowing (e.g., the vein expanded when dye was released nearby)? Would you consider a balloon angioplasty in that case? Would you consider any other options?

Answer:

I would be skeptical about the degree of expansion of the vessel/ I would also doubt that the venogram was interpreted correctly. I would put an ivus in to see whether there was a something subtle and ultimately if I found nothing else, I would perform angioplasty. no sense not giving it a chance

+++++

Question:

Dr. Sclafani, I want to thank you and everyone for this great thread -- educational, eye- opening, and who could have guessed it could be so emotional and funny.

I think that somewhere in here you indicated that the venogram is a steep learning curve. By that, do you mean it's success is going to be dependent on the experience of the person doing it? I think what I'm asking is, if a person has a venogram to assess for CCSVI, how critical is it to go to someone who has already been working with this issue?

Answer:

if you cannot laugh at yourself, you might as well take a sabbatical.

Of course it is better to work with an experienced IR. all two of them. it is very critical to work with someone of experience. However we are all pioneers and if you can have the courage to take a chance, then work with the "good doctors" to get through the learning curve. pay it forward

+++++

Question:

Hello Dr Sclafani,
I have a quick and simple question...
Since jugular vein drainage occurs in the prone position... does, or could, a persons 'sleep position' effect performance? Say you sleep on your stomach with your head twisted to the side?

Answer:

prone means lying on your stomach, supine means lying on your back. both should improve blood flow in the jugular vein in the normal patient
I cannot tell you how that would affect blood flow in a patient with MS

+++++

Question:

I just gotta love a Doctor who uses a word like "armamentarium", with the confidence that the patient is not incapable of understanding (or at least, looking it up - such as I did).

I wonder, Dr. Sclafani, are these discoveries and innovations - such as you are making - disseminated in the IR, Venous Doctor, etc., community, or is that something that needs a peer-reviewed paper?

The Doc. who did my US today was remarking on anomalies in my valves, but he is not involved with treatment, and after Ricci's catastrophic experience in having had a valve ablated, I might be a bit querulous with having my own valves trashed. In your view, ought one be cautious in messing with valves? Apparently, Dr. Von Schelling warned against it.

Answer:

there are many ways that doctors receive information in the case of ccsvi is so new that word of mouth and ad hoc phone advice, peer to peer discussions are really valuable. internet is helpful, not only for the data, but also for understanding of patient experience. That is why I searched until if found this site. you all have taught me a lot

+++++

Question:

With the thought of genetics and the goal of MS prevention, if CCSVI is the cause of MS, and since twisted or stenosed veins are congenital and therefore present in childhood, do you think a child of someone with MS could prevent developing the disease if CCSVI were detected and treated in childhood?

Answer:

yes

however research in children is more difficult because the patient cannot advocate for themselves and thus research requirements are more stringent.

I have already begun the process of stimulating pediatricians and ophthalmology into this topic

+++++

Question:

I emailed Euromedics to find out what they were made from and they replied saying that they were made from Cobalt.

I think that I am allergic to Nickel but am not 100% sure, can you advise me as to what to be asking? Maybe I need a blood test to see what it is exactly that I am allergic to, if so I can ask my GP?

Answer:

I am sorry, this is not my expertise. I suggest that you speak with your allergist first to get some advice.

+++++

Question:

As an 18 month old I underwent a heart operation for the closure of an ASD. It was a simple straightforward operation. I am now in my mid twenties.

Do you think that this will prevent me from undergoing balloon angioplasty of the internal jugulars?

Answer:

as you know, I am reluctant to speak about specifics with just a little bit of information. My goal here is to educate.

an ASD is an atrial septal defect, or a hole in the septum that separates the right and left atria of the heart.

so the risk in this situation is that blood or small blood clots could go from one side of the heart to the other side of the heart through any residual hole. If the air bubbles or blood clots went from the right heart (where we are working) to the left side, it could flow into a vital organ such as a kidney the heart of the brain. That could case troubles that you do not want.

In such a situation I would think that a consultation with the cardiologist is important. an echocardiogram would be helpful for making that determination in such a patient.

if the defect is still closed, then I would pursue

+++++

Question:

What is your view on the significance of pressure gradients across narrowings? Let's say, hypothetically, that the 40-50% narrowing of an internal jugular vein was accompanied by a small (i.e., close to 0) pressure gradient. Does that impact the decision on how to proceed?

Answer:

I think that pressure gradients are not that important in this highly compliant part of the circulation. Pressures are usually low to begin with.

I think the more valuable concern is flow and resistance to flow.

I would balloon if I found even a 40% narrowing

+++++

Question:

"Because we are talking dissipating veins (is that the correct translation? Draining veins?). This is an area that we do not know much about. There is a lot of knowledge about using arteries and also about ballooning these arteries. That's is a simple procedure and there is a lot of experience in it.

On the other hand, there is less experience in ballooning dissipating veins and no knowledge on what the effects in the long run will be."

My question is simple: is this true? Do we know less about dissipating veins and ballooning them? Is that really a different ballgame?

I am looking for facts to reply with.

Answer:

I do not know what dissipating veins are. I suspect that your second translation, draining veins, is more accurate. we know a lot about veins, Our group has been doing angioplasty of the veins of the upper extremity for more than thirty years. True, they are different kinds of veins that jugular veins. jugular flow is higher, arm veins have higher pressures but are smaller. . we know that veins generally do not do as well with surgery as arteries. Clotting of veins happens more frequently than arteries when repaired after injury for example.

+++++

Question:

More and more of us MSers are going abroad to get treatment. What is the typical follow-up procedure after angioplasty, so we can educate our doctors after our trip overseas

Answer:

Followup is clinical. if things are going well, I like to see the patients in six months as that is when the stenoses in dr Zamboni's report started to develop restenosis. I am looking for a good test to noninvasively assess but currently do not like to rely upon them. I have not been treating patients that long yet so I have some time to think about it some more.

I would think that the only noninvasive test would be a doppler sonogram to look for flow changes. but I would probably do another venogram

it is good to educate and familiarize your doctors with what is happening. I think it might be a good idea for a group to find a few select imaging labs that all patients go to. This will allow a few to become expert rather than many missing the boat.

+++++

Question:

Dr. Sclafani, have you treated anyone yet who is in the early stages of m.s.? If so did you find the CCSVI to not be as bad as those in worse shape with the m.s. (or with higher EDSS scores)?

Answer:

I have treated relatively young and recently presenting ms patients. I have not noticed much difference in the character of their vein abnormalities. but the numbers are too small to make anything of it yet.

If as we think, this is a congenital malformation of these veins and their valves, then the process is not time related, except perhaps in the development of collateral veins, those veins bypassing the obstruction

+++++

Question:

It appears that the people who have had continued remission of symptoms are primarily the ones who were stented. Any thoughts??

Answer:

there is only one paper peer reviewed to my knowledge the rest is unverified. So we need more information

+++++

Question:

What is the number of MS patients you have looked for CCSVI in and what is the number you have found have CCSVI ? How many of these do you perform in a week?

Thought you could use a couple easy ones.

Answer:

I would prefer not to get into that kind of detail on the forum. shall I just say that I have found problems in every patient so far. some are very subtle findings.

+++++

Question:

Will this history of epileptic seizure preclude me from undergoing balloon angioplasty?

Answer:

There are no data on your question. However, I can think of no contraindication to venoplasty in a patient with a history of seizures.

+++++

Question:

I didn't realize that angioplasty of veins was not new. Is this for dialysis patients alone where the experience has come, or...? That gives me some comfort to know that IR's are familiar with manipulating veins to some degree and their expertise hasn't been limited to arteries alone.

Answer:

In a generic sense, the procedure I am performing for ccsvi is angiography and angioplasty of veins. Venous angioplasty has been performed at our institutions since about 1979.; Our report (Glanz S, Gordon DH, Butt KM, Hong J, Adamsons R, Sclafani SJA: Treatment of stenotic lesions in upper extremity dialysis access fistulas by transluminal angioplasty: Four years experience. Radiology 152: 637-642, 1984) was among the first in the United States.

The most common indications are

- 1.the treatment of vein stenoses caused by hemodialysis catheters
2. the treatment of venous obstructions caused by cancers.
3. treatment of stenoses of jugular veins resulting from repeated dialysis catheterization and causing massive swelling of the head and face and microhemorrhages in the brain.
4. venous narrowings caused by malformations of veins, including Budd Chiari syndrome stenoses of the inferior vena cava and hepatic veins and the May Thurner syndrome, stenosis of the iliac vein.

Other types of venous malformations at our hospitals are treated by embolization and sclerotherapy.

In CCSVI (chronic cerebrospinal venous insufficiency) a malformation occurs mostly in the region of the confluens of the jugular vein and the subclavian vein. It has been shown that such veins and valves have an abnormal type of Actin. Fused valve leaflets, inverted valves, webs, septae and hypoplasia are seen. In 2009, the College of Phlebology, with representatives of more than fifty countries, voted unanimously to define this malformation.

It is often seen in patients with symptoms of multiple sclerosis, but is also seen in other patients without the diagnosis of MS. These patients have been found to have reduced cerebral blood flow and cerebral atrophy, potentially ischemic in nature, is postulated to be caused at least in part by the outflow problems.

Our procedure calls for percutaneous femoral vein catheterization under local anesthesia, followed by catheterization and angiography of the veins draining the brain and spinal cord, namely the jugular veins and the azygous veins. Occasionally catheterization of the vertebral veins is also performed. These procedures are comparable to the treatments for other venous malformations.

If venous stenoses, slow flow, reflux or collateral flow through the brain and spine are identified, angioplasty of the jugular veins or azygous vein is performed after confirmation of stenosis by intravascular ultrasound. Patient recovery is short with discharge about one hour after the procedure. No sedation is necessary.

As stated above, venous angioplasty is an accepted procedure with a very low complication rate. While no complications were reported by Zamboni, they do occur when venous angioplasty is performed in other veins, including thrombosis, perforation that are minor and usually self limited, and restenosis. Restenosis may have a role in management of restenosis, although the stents were not designed for ccsvi.

Stent placement is also a component of most other venous angioplasty procedures either as an adjunct, as a primary form of overcoming elastic recall or as a secondary procedure to reverse restenosis. These have been safe. There is one anecdotal report in the lay press of a migration of a stent from the jugular vein into the heart that required operative removal; stent migration has been reported during other venous stenting procedures but these are uncommon.

+++++

Question:

do you think that reflux in the vertebrobasilar arterial system (and possible associated slowing of blood flow into the brain) can exacerbate MS symptoms? If so, what options would you consider to fix the reflux in the vertebrobasilar arterial system?

Answer:

If I understand your question, you are speaking about reflux in the vertebrobasilar ARTERIAL system. Reversal of blood flow in the VB system is usually referred to as Vertebrobasilar insufficiency and is often part of the subclavian steal syndrome.

This is a very different entity. For a variety of complicated reasons, there is INFLOW obstruction to the arm arteries. The body gets blood to that limb by reversing the flow in the vertebral artery as a bypass of blockage. GO back to the highway analogy. The cars will find a way around the traffic jam.

When blood flow reverses in the vertebral artery, it is possible to STEAL blood from the brain (Not good). In a patient with already reduced cerebral blood flow, this is not helpful.

Does that help. And when do you want to take your medical school exam

+++++

Question:

What would your reaction be if you performed a venogram on an MS patient and the only problem you found was that one of the internal jugular veins had a 40-50% narrowing at one point, there was a moderate patchwork of small collaterals near the narrowing, plus a large collateral above the narrowing that connected to the nearest external jugular vein, but the internal jugular vein was still dynamic in the area of the narrowing (e.g., the vein expanded when dye was released nearby)? Would you consider a balloon angioplasty in that case? Would you consider any other options?

AND

Answer:

Those collaterals are telling us something. I would dilate a 40-50% narrowing. I did so this past week. When the balloon was inflated there was an obvious stenosis

as I said before, lesser percentages of narrowing in veins may be significant because they are low flow systems.

+++++

Question:

I was wondering if you might give a GENERAL impression of what you might do with this - my stenoses, of course, with the understanding that things might look different in a venogram

Answer:

if I recall, you were speaking about a situation in which your veins showed some narrowing, but the vein dilated with flow and the ultrasound was asserted to be normal. Is that correct?

well, in a general sense, I come at this with the presumption that you all have abnormal veins until proven otherwise. Usually, the narrowing is very low in the jugular vein at its confluens with the subclavian vein. This area is not visible on most ultrasound exams.

I work really hard to exclude and find narrowings, using ultrasound, multiple views of the venogram, valsalva, deep breathing, pressure measurements and even inflation of the balloon to look for resistance to symmetrical inflation. If none of it turned up a finding that convinced me, I would stop. But I expect that to be infrequent.

Whew...I need a break. This is Doctor Whiplash, I am out to lunch.

+++++