Beyond Trials and Research: A Patient's Perspective on Undiagnosed Chronic Pelvic Pain

A personal conversation with Dr. Spencer and Ms. Vollmer on the consuming impact of pelvic venous disease on a woman's life, necessary improvements in diagnosis and management, and areas of current and future research.

With Brooke Spencer, MD, FSIR, and Nichole Vollmer

Dr. Spencer: Nichole, I understand that you endured pelvic pain and other symptoms associated with pelvic venous disease for many years. Could you explain what the biggest impacts of this were on your life, marriage, and career?

Ms. Vollmer: The pain impacted all parts of my life. When you are told that your symptoms are all in your head, it eats at your confidence. As one can imagine, this had a big impact on my career. In addition to the mental impact, there is a significant physical impact of pelvic venous disease. My career requires long periods of sitting and standing, and the pain was often unbearable. In terms of my personal life, it affected my marriage because having intercourse was painful, especially afterward. With no physical explanation for this pain according to many physicians, it was hard to explain or deal with. I wondered if it was all in my head, yet I knew the pain was real.

Dr. Spencer: Overall, how much of a role did pelvic pain play in your life? How long did you deal with this before the pelvic pain diagnosis was made?

Ms. Vollmer: It consumed every aspect of my life. I wanted to have a reason for my pain, and for the longest time, I believed that and thought about it all the time. It took 22 years to get a pelvic venous disease diagnosis.

Dr. Spencer: How do you think your life would have been different if you had been diagnosed earlier?

Ms. Vollmer: I would have been happier and in a "healthy" mental state. I really feel like my confidence took a huge hit, which impacted my career. I firmly believe I could have climbed the career ladder faster had I had the confidence that I needed. Plus, when you are suffering, you sometimes put aside your aspirations. I always wanted to run a marathon but never did because I didn't think I could finish with the amount of pain I would be in from running for a long period of time. Now, I can run without pelvic pain.

Dr. Spencer: How did your life change when you realized your symptoms had an explainable, treatable cause?

Ms. Vollmer: I remember exactly where I was when I realized my symptoms were real. I almost fell out of my chair; I couldn't breathe, and my heart was racing. I felt like a weight was lifted off my shoulders, but I was cautiously hopeful.

Dr. Spencer: How did you feel going into the procedure? We had discussed that your left gonadal vein was enlarged with pelvic varices, and I felt that this was the main culprit in your case. We also needed to examine the iliac vein with intravascular ultrasound to determine if the compression was significant and if a stent was needed or not (Figure 1).

Ms. Vollmer: Honestly, I was very nervous and scared—not of the procedure but of the possibility that you might not find anything wrong. Even though I saw the MRI and read the report, I was afraid it was all a mirage. I was afraid to wake up and hear you tell me the words that I had heard over and over: "We couldn't find anything wrong with you."

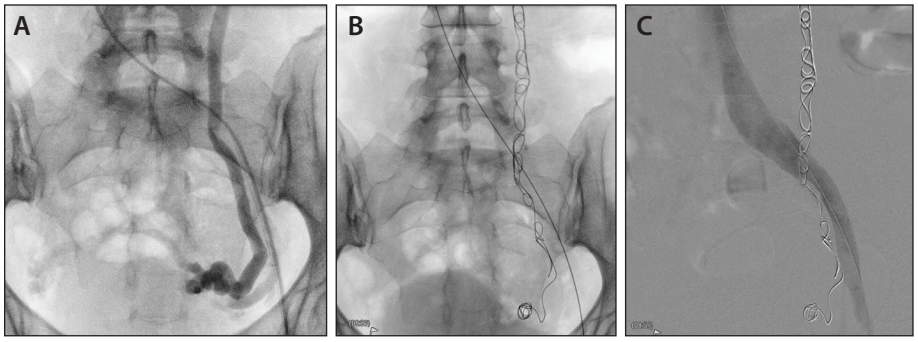

Figure 1. Classic "pelvic venous congestion." Enlarged left ovarian vein with left adnexal varices draining through the uterus to right adnexal varices (A). Postadministration of 1.5% sodium tetradecyl foam in varices from left across to the right and coiling of the left gonadal vein (B). Normal venogram of the left iliac vein confirmed with intravascular ultrasound (C).

Dr. Spencer: It is an honor to interview you, and I applaud your courage in sharing your story. Why did you want to put yourself out there and share with others these intimate truths about your struggle?

Ms. Vollmer: When you asked me to do a patient testimonial at the American Vein & Lymphatic Society 2021 meeting, I didn't realize how impactful it would be. I received a lot of feedback from practitioners that it was important for them to hear the patient perspective. I really hope attention to this issue will help increase venous procedures. I'd like to see an increase in new technologies as well. It is upsetting being a part of industry and knowing the financial impact of performing or not performing these procedures but seeing that we are not doing more. You wouldn't question treating a patient with critical limb ischemia and a 5-year life expectancy, but young women are having organs removed and being told they are "crazy." Then, if they are diagnosed with ovarian vein reflux, the only option is to pay tens of thousands of dollars to have it treated, even with insurance. Ultimately, it angers me that it takes so long to make a diagnosis of pelvic venous disease. So many women go through an astronomic number of imaging studies, multiple procedures/surgeries, and have their organs removed in a desperate search to get a diagnosis. This is a huge strain to our health care systems, insurance companies, and patients. We need more education, research, and funding to support pelvic venous disease/pelvic congestion syndrome (PCS) diagnosis.

Dr. Spencer: Help us understand the financial impact this has had on you. How many studies and surgeries did you endure, and can you estimate the direct cost of those to you/insurance?

Ms. Vollmer: I have had 18 CT scans totaling $7,200, two MRIs totaling $1,200, 22 emergency room visits totaling $44,000, and 12 surgeries totaling at least $18,000. This is not to mention the doctors' visits and time lost at work.

Dr. Spencer: How long did it take for you to stop looking for a diagnosis?

Ms. Vollmer: It took about 12 years. Honestly, when I found out I was pregnant with my first child, I stopped searching for a diagnosis. I knew I needed to focus on getting prepared for the first of my children. I wanted to focus my time and energy on being a mother. It took "luck" for me to finally be diagnosed. I interviewed for a medical education specialist position with a focus on venous disease. I wanted a challenge because I knew a little about devices and not a lot about venous disease. Had I not had this chance, I may not have ever been diagnosed.

It angers me that so many women are not being diagnosed, and if they are, they often can't afford the treatment they need for their pelvic venous disease. I am fortunate enough to have been able to pay out of pocket for my procedure, but there are so many women who can't. Imagine the women who have become addicted to legal or illegal drugs because they can't get their pain under control, or those who turn to drugs to numb the mental pain of not being believed their symptoms are real. How many women have turned to suicide? We don't know because there is little research in this area. We need to get the medical institutions and insurance companies to pay attention. With how far we have come in the medical field, there is no reason that women should be suffering from pelvic venous disease.

I want people to know that I am doing this outside of Philips on my own time—much like you are Dr. Spencer. I never realized how exhausting this can be. There are times when I want to stop advocating and go back to the million other things going on in my life, but I don't because I am passionate about this and I want things to change. They need to change. Dr. Spencer, you know this because you have been advocating for way longer than I have. If we start to join forces with other advocates, we can change the world.

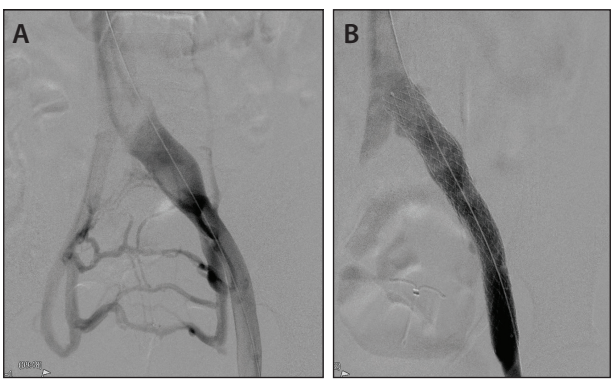

Figure 2. Iliac vein compression. Venogram showing funneling of the left common iliac vein with impression from the crossing artery and collateralized flow via the left ascending lumbar vein, retrograde flow into the internal iliac vein, and transsacral flow to the right internal iliac vein (A). Poststent restoration of normal flow (B).

Ms. Vollmer: Dr. Spencer, I have a few questions for you. Why do you think that pelvic venous disease is underrecognized as a cause of pelvic pain and not accepted by obstetricians/gynecologists and insurance companies?

Dr. Spencer: I think that the gonadal vein embolization literature has been extremely variable in demonstrating efficacy, likely due to the underrecognized role of iliac vein compression as an additional cause of pelvic pain in women. We are starting to amass data demonstrating that for many patients, iliac vein stenting could be more beneficial than embolization of the gonadal veins alone when both issues are present.[1] In your case, your gonadal vein and the varices were massive, and the iliac compression was just under 50% (Figure 2). We opted to treat the classic "pelvic congestion" issue first, and given your pain resolution, this proved to be the right approach. However, in many women, if there is also a more severe iliac obstruction, the elevated venous pressures are not relieved by embolization and foam sclerotherapy alone.

Ms. Vollmer: In your opinion, what is the most important barrier to improving the understanding, diagnosis, and payment for treatment of this disease entity?

Dr. Spencer: There is no question that well-funded prospective randomized trials are needed. We are currently conducting a prospective trial that is attempting to associate myriad other symptoms with pelvic venous disease. In this study, known as the Survey of Co-Morbidities of PCS Patients Pre and Post Treatment, women complete the International Pelvic Pain Society

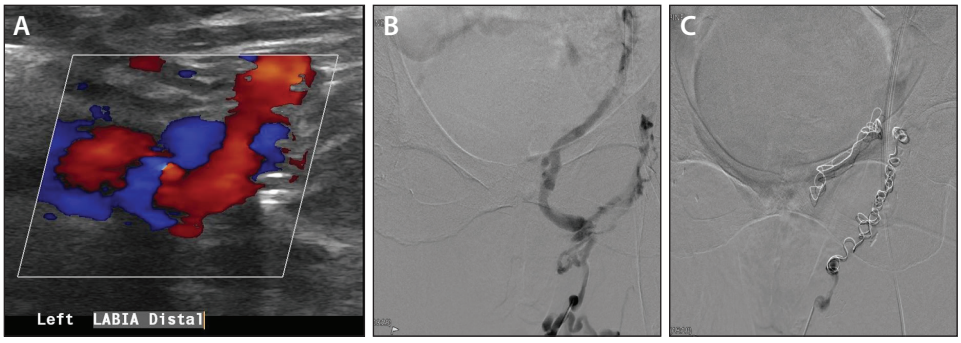

Figure 3. Residual pelvic floor/labial varices. Perineal ultrasound of large left paralabial varices (A). Direct stick venogram of deep left labial varices accessed under ultrasound with two large draining veins, the obturator and gluteal veins to the presacral plexus (B). Postmicroselection from the internal iliac vein with coil embolization and subsequent administration of 1.5% sodium tetradecyl foam (C).

questionnaire, PCS score, pelvic pain/urinary frequency score, Orthostatic Hypotension Questionnaire, modified ROME III criteria for irritable bowel syndrome, and associated symptom scores both pre- and post-treatment with follow-up out to 1 year. We have also just submitted an abstract reporting on patients aged ≤ 25 years treated with iliac stenting, and we are currently working on a grant for a randomized trial. Others have published retrospective data and are working on prospective studies as well. Additionally, I think it has historically been far too easy for the medical community to label women as histrionic and dismiss symptoms as psychiatric when we are not able to find a physical diagnosis. We need to stop dismissing physical complaints in women and start working harder on making diagnoses and advancing research in the areas that we do not fully understand.

Ms. Vollmer: Through your studies in the past few years, have you learned anything new that is exciting for the future?

Dr. Spencer: In the last 6 months, we have realized that patients with persistent symptoms and/or residual pelvic floor/rectal symptoms often have varices not seen on conventional ultrasound or cross-sectional imaging that are leading to these symptoms (Figure 3). These are even missed on venography of the internal iliac veins. Patients are being sent for colonoscopy, gastrointestinal workups, and urogynecology, and no source is found. We have developed a labial/perineal ultrasound protocol that can identify these patients and have begun performing direct stick of deep paralabial varices with venography and foam sclerotherapy with excellent early results, and we plan to publish this in the future. I liken this to treatment of superficial venous disease with ablation alone. Many patients do not achieve full relief of pain and swelling until the residual varices have been treated with phlebectomy or foam. It is the same with pelvic venous disease with stenting of the iliac vein and/or gonadal vein embolization. We should not dismiss these procedures as ineffective when symptoms are only partially resolved or recur; rather, we need to look for and treat the residual varices, and then we often achieve complete relief. ■

1. Santoshi RKN, Lakhanpal S, Satwah V, et al. Iliac vein stenosis is an underdiagnosed cause of pelvic venous insufficiency. J Vasc Surg Venous Lymphat Disord. 2018;6:202–211. doi: 10.1016/j.jvsv.2017.09.007

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