Alternatives to hysterectomy for the treatment of uterine fibroids

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Paul Indman, MD: "Hi, I'm Dr. Paul Indman. I'm at the 30th Annual meeting at the AAGL, and I have with me Carla Dionne who is Executive Director of the National Uterine Fibroid Foundation - NUFF. I think you're in a very interesting place because you've been treated for fibroids and you've had several types of surgery. You started out as a lay person with very little knowledge or no knowledge of fibroids and now I think in talking with you you're far more knowledgeable than most of the physicians I've talked to. I've very impressed because I think you have good medical knowledge and not just a matter of reading so what made you decide on having alternative treatment?"

Carla Dionne: "For me it really wasn't a choice in that it was a hysterectomy or some alternative treatment. I think this actually happens to a lot of women trying to avoid a hysterectomy for whatever personal reasons. My own personal reasons accumulated over a period of time of gynecological consults where I would ask specific questions about myomectomy and not get intelligent answers from the gynecologists I was consulting with which didn't exactly lay the foundation for trust in terms of any surgical procedure with that specific gynecologist."

Paul Indman, MD: "What would they tell you about myomectomy?"

Carla Dionne: "That it was too dangerous, too risky, too much blood loss, and they couldn't do it without converting to a hysterectomy. To me with the knowledge that I have today, I really believe that all of that was nonsense. I had primarily a singularly large subserosal fibroid and in terms of myomectomy at any point in time it could have been a fairly simple myomectomy. Over time I accumulated enough information so that when I asked the questions and I received certain answers I knew instantly that the gynecologist (A) never did myomectomies or (B) just didn't just want to do myomectomies, or any number of additional reasons they might have but it didn't lay the foundation for trust. Eventually, when I did choose embolization it's interesting because the interventional radiologist who evaluated my case took one look at the ultrasound and said - you need a myomectomy. Why would you want an embolization for this singularly large fibroid? We could get rid of the bulk mass with a myomectomy, and I said - I've been to X-number, at that time fourteen gynecologists, and none of them would."

Paul Indman, MD: "You just went to the wrong place."

Carla Dionne: "I know that now which is part of why we founded as an organization - to help women sort out who the experts were for whatever treatment that they themselves would be interested in choosing and getting them to the right people on the first or second hit and not fourteen gynecologists later. So it's important to be able to understand what drives women down a certain path; I think it's important that gynecologists have a better understanding as to why women don't want a hysterectomy. I don't see a lot being presented at this particular conference nor have I seen it at any gynecology conference that really evaluates and looks at why a woman might choose some other option. Why are women choosing embolization in the thousands? I think part of the reason, which I've come to understand in the last three years of communication online with women, is it has to do with control and feeling as though you're in control of your condition to some extent. With any surgery that is currently being offered by gynecologists you're put to sleep and you have no control, and if you've received the same number of recommendations for hysterectomy and the same type of
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communication that I did over the last fourteen years there's a lot of concern over how much you can trust that physician."

Paul Indman, MD: "Help me understand this, now I'm a gynecologist, and I do lots of myomectomies. I've never done a hysterectomy on a woman who wanted a myomectomy but I tell women that's a known risk just as a plane crash is a known risk of getting on a airplane."

Carla Dionne: "Right."

Paul Indman, MD: "We can do it under regional anesthesia, numb from the waist down, so the woman's awake. Obviously, she can't be in there with her hands helping with the surgery."

Carla Dionne: "Correct."

Paul Indman, MD: "How is a myomectomy in that situation any less of control or discussing what situation we would do a hysterectomy knowing that the risk is very low of needing a hysterectomy during a myomectomy? How is that any less of control than, let's say, doing an embolization under sedation?"

Carla Dionne: "There's a couple of things at play, one of them is there are women who want to be awake even if they're not going to be able to see a darn thing during the procedure. There are women that want to be awake during that procedure."

Paul Indman, MD: "I do them; we do myomectomies awake under an epidural."

Carla Dionne: "That's very rare."

Paul Indman, MD: "But it's not a problem, if someone wants to be awake we do it that way."

Carla Dionne: "But really it begins back in the consult - how much of the procedure you're going to communicate to them and how much you open up the dialogue for asking questions and not just waiting to see what their questions are but actually inciting questions specifically. Do you want to know what I'm doing here, do you want to know what I'm going to do here, or do you want to know what kind of stitches I'm doing? Women write to us feeling very violated after they wake up and find out they have a certain kind of incision or they used staples instead of sutures and none of that was communicated prior to the procedure. That's really sad because now we have a patient who may have had a wonderful outcome from a procedure but is very distrusting of her physician because he never told her he was going to do that. So there's a lot of detail in preparing for the surgery that's very important in terms of communicating with a patient. But in terms of being awake, that is a very important issue because the number one thing that I hear over and over about the embolization procedure for those under conscious sedation who remember it all, they are ecstatic because from what I can tell it has to do with having some sense of control that this isn't going to convert to a hysterectomy right before their very eyes, and there is a sense of wonderment as well as control over that. I don't know if that could be mirrored with a myomectomy or even a hysterectomy for those who would choose hysterectomy but I certainly know we've answered questions from women who want to know why they can't be awake or want to know why their surgeon isn't talking to them specifically in detail."

Paul Indman, MD: "So what can women do to find a physician who is going to meet those needs? I get e-mails from around the country - do you know someone in Timbuktu? I can only refer to surgeons who I've seen operate so those who I've seen take out myommas, I'm happy to refer to them. I haven't seen many people do it so how would you tell a woman to go about finding somebody?"

Carla Dionne: "We're in a tricky position there too because we certainly get phone calls from all over the U.S. and even outside the U.S. from women calling for referrals because they want to come to the U.S. for treatment. It is a very difficult position to be put in so instead we've taken the approach that we'll help you try to decipher the information, we'll help you figure out using physician databases online and resources like the reproductive medicine physician finder, and the board certification verification online. The fact is every state medical board has access to a license for
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Paul Indman, MD: "Those are sort of minimal, that means you haven't lost your license."

Carla Dionne: "Right, those are very minimal but then cross-referencing which professional organizations they belong to so you can get a feel of what their peer review participation is both in terms of obtaining additional education along the way. For instance, one of the road maps that I have on the list is if you're looking at laparoscopy have you checked the AAGL website to determine whether or not your physician is a member because at a minimum that's a good starting point. Then do they have any sort of accreditation now and that will only get you a small pool of names, from there you have to be able to open up communication yourself and be willing to ask key questions."

Paul Indman, MD: "One thing that amazes me in this day and age of airplanes and travel, obviously it's inconvenient to travel but if this is something that is important to a woman as wanting to be in control of her uterus and wanting to have the surgery done in a manner that she's comfortable with, it doesn't cost much to get on an airplane and go anywhere in this country. Certainly if I were having major surgery on something that was important to me I'd go anywhere if I thought I'd have a better experience because I've got to live with that for the rest of my life."

Carla Dionne: "I would agree with that, and I think a lot of women do agree with that but there is also something much deeper especially where fibroids are concerned and that is the acculturation of the hysterectomy. It's very well imbedded among many generations of family members who've had hysterectomies to just stay where you're at and have the hysterectomy. Even when women don't want a hysterectomy and they want to avoid that treatment or they even want to avoid surgery period, they don't want a myomectomy either, the acculturation of hysterectomy is so intense that it's really frowned upon. If you have to leave the area, it can't be that good. If you have to get treatment somewhere else, it can't be that great because the majority isn't doing that. In reality, a great many women do exactly that, they get on planes and they go wherever and we can certainly help there as well because we have some affiliation with organizations that allow for low rental of rooms to stay in the area for an extra week or so after a procedure. Definitely in very extreme cases we have some affiliation to get you there via air fare if that's what you want but, again, our organization is about individual choice so we try to help them be able to determine what that choice is and find a practitioner in their area first."

Paul Indman, MD: "That's logical, if you can find someone in that area. Ultimately, I think women need to find someone they're comfortable with and not accept if someone's giving you something that doesn't sound right, check it out."

Carla Dionne: "Right, absolutely."

Paul Indman, MD: "Thank you very much. I'm Paul Indman here with Carla Dionne from the AAGL meeting in San Francisco."

For more information on Fibroids and Myomectomy please see Dr. Indman's web site Myomectomy.net

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