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Understanding Lymphedema

February 20, 2009

Andrea L. Cheville, MD, MSCE

ELYSE SPATZ CAPLAN, MA:

Thanks to everyone for joining us today for Living Beyond Breast Cancer's teleconference, Understanding Lymphedema. This is Living Beyond Breast Cancer's first time devoting an entire teleconference program to this very important subject that has the potential to affect every person who's had breast cancer surgery.

While we've covered this topic many times in many programs over the years to discuss some of the side effects of cancer treatment, and also in a new publication we recently produced, we are responding to feedback from many participants at our conferences and teleconferences over the years who have told us through program evaluations, or via e-mail, or on our Survivors' Helpline [(888) 753-LBBC (5222)] that you have questions about lymphedema, and you want more opportunities to access the latest information on how to care better for yourself. We're very delighted that we can bring today's program to you.

I do want to take a moment to go back and highlight this new publication, the *Guide to Understanding Lymphedema*, that LBBC recently published, to let you know that you can obtain free copies by contacting our office or by going to our Web site, lbbc.org, and clicking on our "Marketplace" to order copies. This resource contains information to help you recognize the early signs of lymphedema, how to take control of risk, some treatment methods, information on financial aspects of paying for services and your quality of life, including your emotions and the impact [lymphedema] may have [on them]. A list of useful resources is also included.

When LBBC produces our *Understanding* brochures, we engage a very active group of healthcare and consumer reviewers and advisors to take part in our work. We're very grateful to all of you who have, in some way, contributed to making sure that our outline, text and resources are current, accurate and up-to-date.

Our featured speaker today, Andrea L. Cheville, MD, MSCE, is actually a member of the advisory committee that helped us put this brochure together. What will you learn today? Whether you are newly diagnosed, are currently receiving breast cancer treatment, or have completed treatment or are many years beyond, lymphedema can affect your life at some point. It may. It may not. Today, you'll hear some about the causes and the methods of preventing lymphedema, the importance of early detection, medical and holistic treatment methods, and again, the impact that this condition can have on your quality of life.

My name is Elyse Spatz Caplan, and I'm the education director at LBBC. I will serve as the moderator for today's program. Just to review, like all Living Beyond Breast Cancer teleconferences, there will be a speaker presentation and, following that, a question-and-answer session where you may have the opportunity to ask our speaker your question.

As many of you already know, Living Beyond Breast Cancer offers an array of programs for women and families affected by breast cancer. Teleconferences are just one way we can get the word out and information out to large groups of people.

I'd like to tell you of a few upcoming programs for which more information is available on our Web site, lbbc.org. Our next teleconference will be on the subject of triple-negative breast cancer. It will be a treatment update, and we'll also be talking about healthy lifestyle choices. That date will be Tuesday, April 21, 2009. On May 6th, our teleconference will focus on understanding insomnia and fatigue, another quality-of-life concern for many women affected by breast cancer.

Next weekend, the weekend of February 27 through March 1, 2009, we will host, in collaboration with the Young Survival Coalition [<http://www.youngsurvival.org>] and Susan G.

Komen for the Cure [<http://ww5.komen.org>], our 9th Annual Conference for Young Women Affected by Breast Cancer in Dallas, Texas. If you're interested in information [on future conferences], you can visit the dedicated Web site at youngsurvivorsconference.org for more details.

Our 3rd Annual Conference for Women Living with Advanced Breast Cancer will be held in Philadelphia the weekend of April 18 through 19, 2009. Again, more details [on upcoming conferences] can be found on lbbc.org.

Just a reminder, if you need to leave today's program a little bit early, an MP3 podcast will be available on our Web site soon, and a written transcript will be posted at a later date. Another housekeeping note is program evaluations will be e-mailed to you shortly following the program, and we really do listen to your feedback. As I referenced early on in my remarks, today's program is brought to you because people told us on evaluations that lymphedema was a subject of great interest. Please be sure to take a few minutes and submit your evaluation comments to us.

I'd like to tell you a little bit about our speaker and then introduce her. Dr. Cheville is an associate professor of physical medicine and rehabilitation at the Mayo Clinic in Rochester, Minnesota. She specializes in cancer rehabilitation, lymphedema, pain management and system symptom control. In 1999, Dr. Cheville accepted the University of Pennsylvania Health Systems' invitation to develop a cancer rehabilitation and lymphedema program. During the seven years she served as the director, the program gained national recognition and expanded dramatically in clinical and research fields. In 2006, Dr. Cheville moved to the Mayo Clinic to pursue her research in breast cancer-related lymphedema, focusing on protecting the lymphatic system during primary breast cancer treatment. She has written and lectured extensively on the subject of lymphedema and is a board member of the Lymphology Association of North America



[<http://www.clt-lana.org/>] and the National Lymphedema Network's [<http://www.lymphnet.org/>] medical advisory committee. There are so many more credits to Dr. Chevillé's name, but please welcome Andrea L. Chevillé, MD, MSCE.

ANDREA L. CHEVILLE, MD, MSCE:

Well, thank you, Elyse, and everybody who's here with us today. And a big thank-you to Living Beyond Breast Cancer for creating these opportunities where we can share and disseminate very important information in a way that's convenient and relatively inexpensive for everybody.

I'm going to deliver a general overview of lymphedema, and I ask you please, please write down questions or anything that you would like further clarified as I continue, since there's no immediate audience feedback to know if I'm losing everybody.

Lymphedema is a very important issue. Despite the introduction of sentinel lymph node biopsy into mainstream primary breast cancer care, lymphedema incidence continues to be high, and we know that breast cancer survivors afflicted with lymphedema have reduced quality of life. Many of my patients have said, "You know, I could deal with the breast cancer. I knew when my treatment was going to end. There was a date, and it was over. That's not true with lymphedema." This is, unfortunately, a lifelong burden that requires an often tedious collection of maintenance activities to keep under control, so it really never goes away.

Even those survivors who do not have lymphedema, it's still very anxiety-provoking, the possibility that you might develop it. There's increasingly very, very good information available to survivors about appropriate and effective preventive strategies. I want to endorse the LBBC Understanding Lymphedema educational booklet. It's outstanding. I refer patients daily in that direction, so it's a great resource.

There's a lot of erroneous information also available on the Internet, informal patient-to-patient discussions and truths that are not fully fleshed out. My experience has been that many patients are appropriately anxious, asking, "What should I be doing?" Sometimes the advice seems to be conflicting: "I was told never to lift more than 10 pounds ever with my arm, and yet I'm being told to exercise. And how do I reconcile those apparently conflicting recommendations?"

We'll try and address some of that as we go on today. Certainly, if there are any specific questions, we can address those towards the end. It's helpful to start off with a very brief discussion of lymphatic anatomy and physiology, and unfortunately, we don't have pictures to refer to. If you think of the lymphatic system as the body's drainage ditch, or sometimes I use a kind of unglamorous metaphor of the body's sewage system, it's responsible for waste removal, and that involves both fluid and particulate waste. Our cells, like we do, generate garbage. It's the lymphatic system's responsibility to constantly cleanse the tissue.

The fluid constituent of lymph is fluid that leaks across the walls of our blood vessels. Very normal occurrence. It's part of how the body delivers nourishment to the cells. Our blood is constantly circulating, and, as it penetrates the web of tiny capillaries, the smallest blood vessels, fluid leaks out.

Most of that fluid returns in the venous end of those capillaries, and it's carried out of our tissues. However, between five and ten percent of that fluid that has leaked out of the little blood vessels remains in the tissue, and it's the lymphatic system's responsibility to absorb or sequester that fluid, along with debris, solid debris.

The lymphatic system and the venous system job share, to a degree. They both are responsible for eliminating fluid from our tissue. What the lymphatic system does that the venous system cannot is removing large molecular waste, big molecules, big proteins, big fatty acids, and the lymphatic system is exquisitely designed to handle these large molecules. When it's not working very well, those molecules can build up in the tissue and cause real problems, as we see in lymphedema.

The lymphatics are capillaries, tiny little vessels that absorb all this fluid and this waste. They converge into larger and larger vessels, the lymph vessels that run up the inner side of both the arms and the legs. Since this is a breast cancer conference, we can kind of restrict our focus to the arm. Those vessels run up the inner side of the arm. They converge and eventually terminate in lymph nodes in your axilla.

The reason that breast cancer patients are unfortunately placed at increased risk of lymphedema is because, during primary breast cancer treatment, lymph nodes are almost always removed from the armpit. The goal of that is twofold. One, to accurately stage the cancer,

because it has very important implications for further treatment whether those lymph nodes contain tumor cells or not. We want to accurately stage the cancer. We also want to achieve local control. If there is any cancer in those nodes, we want to get it out of there. Lymph nodes are removed, usually surgically, but they can also be further damaged through radiation, and we'll talk a little more about that later. The lymph vessels converge in those nodes.

The nodes have a number of jobs. They play a number of roles. One thing they do is regulate how thick or thin the lymph is. If it's coming in too thick, they'll make it thinner. Vice-versa, they can make it thicker, so that's one job. They also remove useless waste, things that the body has no further use for or may be harmful. The third thing they do, that is very, very important, is that they detect the presence of any harmful microbes, predominantly bacteria.

Most of us get little cracks in our skin around the cuticles. It's very, very common. Bacteria enters the body, and it's the lymphatic system's job—again because these bacteria are, from the body's point of view, large molecular garbage—to absorb those bacteria, transport them back to the lymph nodes where, for the first time, the immune system becomes aware, "Aha, intruder. We may need to do something about this."

I suspect we all have had swollen lymph nodes in our necks or under our chins. It's because the nodes in our necks drain our oral cavity. Often, there's bacteria that overgrows. When that bacteria reaches a lymph node, the immune system is alerted, "You need to do something. Houston, we've got a problem here." That's where antibodies are developed and lymphocytes proliferate. They increase in number so that we can fight off the infection, so that's what the lymph nodes do.

We'll come back to the risk of cellulites and the risk of infections. I'm sure many of the breast cancer survivors with us today have been advised to avoid infection, avoid skin cuts. It's precisely because, with the removal of your lymph nodes, your body is less able to detect bacterial overgrowth in its early stages.

Ultimately, the immune system does become aware, "Hmm. We've got a real problem here." Unfortunately, many times that's late in the process, so the bacteria—or the infection, rather, has progressed much farther than it would have otherwise.



We're at the lymph nodes. The lymph vessels converge. They end in the lymph nodes, and normally the lymph transits multiple lymph nodes because, eventually, that lymph is going to be returned to your arterial venous circulation, to your blood flow. The body wants to be absolutely sure that it's not introducing anything harmful when that lymph reenters the system and then is distributed throughout the body. Often the lymph is serially filtered in multiple nodes and eventually returns to the system.

One important aspect of the lymphatic system anatomy that bears directly on lymphedema after breast cancer is the drainage territory of the lymph node, kind of the lymph node clusters. We have six clusters of lymph nodes in our body, or what we call superficial lymph nodes. [These are] the nodes that drain the skin, the muscles, not the organs. Those are located on both sides of our neck.

Most of the lymph nodes in the body are in the neck, again because it's draining the oral cavity, which is very chronically bacterially infested. We have two lymph node clusters in the neck. We have two clusters under our armpits in the axilla, and those are the ones that are affected in breast cancer treatment. We have two clusters in our groin on either side of our genitalia. Each of those lymph node beds, or lymph node clusters, drains a defined territory of the body.

For the axillary, or the armpit nodes, they drain the arm, but they also drain the front and the back of the chest. On the front of your body, if you think of your collar bone, that's the top part; your sternum, your breastbone, is the middle, the midline; [then there is the area above] your waist. All of that territory, including your breast, or reconstructed breast, those are all drained by the lymph nodes in your armpit, and the same territory on the back of your body are drained by those nodes. Those are the areas where you're at risk for lymphedema.

We placed the most emphasis on lymphedema in the arm because that's the most common site of lymphedema. It's the most challenging area for the body to drain lymph from, since it's quite far from the trunk and the lymph node beds. We're learning more and more that lymphedema of the breast is not at all uncommon. Lymphedema of the area under the armpit, the axilla, is a common and problematic occurrence for breast cancer survivors. Just to review, it's that area on the front of your body, below the collarbone, to the outside of your breastbone or sternum and above your

waist, on the front and the back of the body, as well as your arm. That's the location you have to worry about swelling or lymphedema.

Swelling in any other area of the body is not due to your breast cancer surgery, and you shouldn't attribute it to that. It may represent another medical problem that should be worked up. Lymphedema related to breast cancer is only on the side where you had lymph nodes removed, be it right or left, and the territory that we discussed.

That brings us to the end of lymph anatomy and physiology. If I've not been clear, if you'd like more elaboration, please jot down a question, and we'll address at the end of my presentation.

The question comes up, "What happens in lymphedema?" Lymph nodes many times are surgically removed or irradiated, and we're learning that radiation is, perhaps, [as] problematic [as] the surgical compromise of the lymphatics in contributing to lymphedema. A paper's in the process of being published that shows that one of the principal risk factors for progression of lymphedema after it's developed—this is not the initial presentation, but for patients who have lymphedema—one of the strongest predictors of whether that lymphedema will progress is irradiation to the nodes above the clavicle, above the collar bone. Radiation-induced damage can continue to progress over time, and we think this may be why some patients develop lymphedema years after their treatment because of progressive radiation injury that only injures the lymphatic system sufficiently five years after initial treatment. Hopefully I've been clear on that. If there are questions, please bring it up toward the end.

The lymphatics in the armpit are compromised through surgery and radiation, which makes it challenging [...] for the lymphatic system to remove fluid and solid waste from the arm. We don't have a good explanation for why it takes a year, two years, three years. Most women will develop some suggestion. They'll have an episode of swelling within three years of their primary breast cancer treatment, so the vast majority of women who will ultimately develop lymphedema are aware of that within three years.

Why there's such a delay, we really truly don't understand. The current explanatory model goes as follows.

The lymphatic system is unable to remove solid debris: proteins, long chain fatty acids. These are tiny particles, but, from the body's perspective, from the tissue perspective, they're

on the big side. The lymphatic system, little by little, falls behind in sequestering and removing that debris from the tissue, and it accumulates. Slowly, slowly, it accumulates.

Those molecules don't just sit there. Many of those proteins cause inflammation. They may cause pain, which is why recent research has shown us that many women develop symptoms. Before they note any swelling in the arm, they'll note symptoms—heaviness, achiness, not focal pain.

This is a real pearl, or something I would like everybody to take away from this teleconference. Lymphedema, except for very rare circumstances, does not cause focal pain. Heaviness throughout the arm, yes. Achiness, feelings of a foreignness, but not significant, severe, localized pain in a wrist, in an elbow. That [pain] should not be ignored and should be worked up separately.

In my clinical experience, these focal problems—a common occurrence is a woman comes in with severe elbow pain. Physicians have written it off as lymphedema and kind of assumed it was there to stay when, in fact, it was an inflamed tendon that was placing the woman at risk for lymphedema. It's very important, if there is local inflammation in the arm, we need to treat that quickly so that it doesn't cause chronic inflammation and overload the lymphatic system.

Back to the onset of lymphedema. We have this pertinacious debris, little by little, building up in the tissue, which causes discomfort, symptom sensations in the arm, may cause inflammation, and eventually it leads to scarring. The body knows something's wrong. It's not quite sure what to do about it, so it does the best it can.

It sends in inflammatory cells, what we call neutrophils, but they're white blood cells that penetrate the tissue. They're trying to solve the problem, but, unfortunately, they cause more problem because they perpetuate the inflammation and the scarification, the scarring process, which can cause further compromise because this fibrosis, this scarring, can encompass the lymph vessels that are still in the arm, that are still working, and thereby worsen the lymphedema.

We get into a vicious cycle of more debris accumulation, more inflammation, more scarring, more compromise of the lymphatic system. Eventually, this reaches a critical level at which the system cannot remove the debris and the fluid that is accumulating in the arm, and the arm swells.

At that point—and Elyse touched on this in the introduction—[it's a] very critical point. Once



an arm swells—and it may be just in the hand, it may be very subtle—it's not uncommon for women simply to have their fingers involved or the area between the thumb and the index finger either on the back or the palmar surface of the hand.

Sites that are particularly problematic in lymphedema are the back of the hand; the forward side, the palmar; the side of the forearm that has the softer skin [that] usually is not sun exposed, we call it the volar forearm; and the area around the elbow, on the inner side of the elbow. Very commonly, those are the first sites where lymphedema [appears].

Another plug for information that I think is very helpful, the American Cancer Society [<http://www.cancer.org>] has created a book on lymphedema. There are some nice illustrations in that that demonstrate a self-exam and—just for serial independent screening for lymphedema—the most effective ways that you can detect lymphedema at its early stages.

Any episode of swelling in the arm indicates that the lymphatic system has been overwhelmed. [There is] more fluid, more debris is in the arm than the system can handle, and it indicates that the woman, the patient, has lymphedema.

Too often, my patients, they have an episode of swelling, and they think, "Ugh, but it's getting better. It's going away." Lo and behold, it does. Usually the first indication, the first episode of swelling happens after a period of overuse. Sometimes it may be a very hot summer day. More blood is going to be flowing through the arm. The little blood vessels are going to be dilated so that more fluid leaks into the tissue. A very hot day, a woman uses her arm vigorously.

We often will have some patients that first notice a problem after spring cleaning. They go nuts, vacuum their whole house, overuse the arm and, lo and behold, it swells. Often, once that episode of more intense activity or heat exposure or whatever the situation is, is over, then the lymphatic system can get control again. Little by little, it removes the excess fluid, and the arm goes back to normal.

Often, patients will think, "Hmm. This is great. Okay. Maybe I'm—maybe we're done with this. I don't have to worry about it anymore." The usual story is that that is the first indication of what is going to be a lifelong chronic problem, and the sooner that the patient can see a trained therapist certified by the Lymphology Association of North America [<http://www.clt-lana.org/>]

once they can get to well-trained and experienced help, the better.

There is a serious under-shortage of physicians that are experienced [and] adequately exposed to lymphedema, so the best thing a woman can do, if she feels, "Uh-oh. You know, I think this is it. I think I've got lymphedema," is to certainly inquire from her oncologist, her surgeon, her radiation oncologist, whoever her ongoing breast cancer team is, "Do you know of a certified therapist, a trained therapist that I can get to?"

If not, there are resources on the Internet. The National Lymphedema Network Web site [<http://lymphnet.org>] has a list of trained therapists. That's an outstanding resource. Also, the website for the Lymphology Association of North America [<http://www.clt-lana.org>] can direct you to trained therapists.

Perhaps if there are additional questions about this, we can come back to it toward the end of the presentation. The most appropriate and most effective thing a woman can do, if she has any suspicion, is get to a trained physical or occupational therapist.

Back to the onset of lymphedema. The story that we tell—that I just told—is one of gradually accumulating debris, inflammation, scarring, further lymph compromise leading ultimately to lymphedema. It's probably more subtle and complex than that, but we simply have not done the research to gain better understanding of the processes involved and how we might intervene early in the—what we call the subclinical phase, before a woman has developed frank swelling or sensations in the arm, to prevent lymphedema.

I want to spend a little bit of time talking about risk avoidance. Here again, we don't have great, great research. There are a lot of don'ts that you'll encounter out there:

- Don't lift more than 10 pounds.
- Don't get sunburns.
- Never get a cut.
- Be careful of bug bites.

All of those are based on theory. That's not to say they're wrong or appropriate in any way, but nobody has done rigorous research, appropriate clinical research, to define what we should be telling our patients. What are the most effective ways for them, the most effective practices they can engage in to protect themselves from lymphedema?

What I find is most helpful, rather than giving patients a whole laundry list of dos and don'ts, is to help them understand the rationale behind these

precautions. What we want to avoid, given what I've shared with you about lymphatic anatomy and physiology and the way we currently assume that lymphedema develops, [is] anything that allows bacteria access to the system, and that's predominantly cuts.

We tell our patients, if you develop a cut, wash it quickly with antibacterial soap, or just any soap. You don't have to be too compulsive here. Use an antibacterial salve. Most of the commercially available ones are absolutely fine: Neosporin, Polysporin, triple antibiotic ointment. Any of those are absolutely okay.

Wash, put some salve on it, keep an eye on it. If you see redness, progressive discomfort, swelling in the area, then you may want to contact a primary physician or whoever you have a clinical alliance with, whoever you feel comfortable seeking, and get quick medical assistance from [this person]. We want our patients to avoid giving bacteria access to the tissue at risk for lymphedema. Avoiding cuts is a biggie.

Another is, in dry or cold weather, avoiding cracks in the skin. The truth is, the vast majority of my patients that develop a cellulitis or an infection related to bacterial overgrowth in the arm, we never identify a cut. We never figure out how the bacteria got in. Some of it occurs because the skin gets dry and it develops microfissures, tiny, tiny little cracks that allow bacteria entry into the system and overgrowth. [It's] important to use soap. Don't over-dry the skin with excessive washing or an overly drying soap. Dove is great. It's inexpensive. It has a moisturizer in there.

Certainly, if you're in a cold climate or a very dry climate, like Arizona, you want to make sure that the skin is adequately lubricated with a daily moisturizer, ideally perhaps applied twice a day if you're really in a cold or a dry period.

We recommend, in lymphedema treatment, to use a low pH lotion because we believe that the lower pH discourages bacterial growth on the skin. Whether that's effective or not, we honestly have no idea. It's more of a theoretical recommendation. Eucerin is one. Most drug stores offer a generic and cheaper alternative to Eucerin, but, that said, if you simply keep the arm or the area at risk moist, you're fine.

Many women will have been told to avoid manicures. Well, that's not necessary. It's nice to have pretty fingernails. But, what you do need to do is avoid cutting back your cuticles, and it's good to maintain well-moisturized cuticles. You can do



this by pushing them back after a shower. Getting a cuticle oil or ointment that you [apply] three times a week is fine, but keep those nice and moist, because that that is another opportunity for bacteria to enter the system. [...] We don't want to give bacteria any way to penetrate the skin and place our patients at risk for infection.

We want to avoid circumstances associated with lymphatic overload. I talked about how the lymphatic system removes excess fluid and solid debris from the tissue. Certain situations cause the amount of lymph produced in the arm to increase, and this is where the, apparently, conflicting recommendations about exercise come in because, when you exercise, you significantly increase the amount of lymph that is produced in your arm.

If you think about it, the muscles are hungering for oxygen. Your blood vessels will dilate, and your heart is pumping faster. A lot more blood is being circulated through the arm and, consequently, more fluid is leaking out into the tissue. That's where the precautions, the encouragement to avoid exercise, come from. All of that increased lymph production is not very good. We don't want that to place the system at risk for lymphedema.

However, on the flip side, your lymphatic system functions best when you're exercising, for many reasons. Your muscles are pumping, and the lymph vessels are very responsive to the contraction and relaxation of the muscle. That's very stimulating to the lymph vessels. The part of the nervous system that controls the contractility, the activity of the lymph vessels, is stimulated when you exercise.

Also, your diaphragm massages the thoracic duct, which is a big, big lymph vessel running down the center of your body. You breathe faster when you exercise, and so the diaphragm massages the thoracic duct, all of which, we believe, contributes to improved lymph removal during exercise.

Exercise is a very tricky topic, and there's not one truth for everybody. Some patients without compression actually benefit from exercising. The pros, again, more lymph removal, outweigh the greater lymph production.

However, the opposite is true for some patients. They produce much more lymph than the increased absorption and transport of the system can accommodate. It's a very individual thing whether you'll reap benefit or harm the lymph through exercise.

That said, with the use of a compression sleeve, exercise is virtually always beneficial because

you're tipping the balance in favor of lymph removal. I want to come back to use of what we call prophylactic or preventative sleeves in a minute, but the topic I'm hopefully clarifying is why we want our patients to avoid situations associated with more lymph production.

In addition to exercise, what are some other examples? Sunburns are one. The red flush that develops after a sunburn is because your capillaries, those tiny little blood vessels, are now dilated. More blood is moving through them. More fluid is leaking into the tissue.

Immersing your arm in a hot tub is not a great idea if you're really at high lymphedema risk, because the heat will cause dilation of your blood vessels. More fluid will leak out into the tissue. It's fine to immerse the rest of your body, the part that is not at risk for lymphedema, so that's really from the waist down. No problem immersing that in a hot tub, but we are concerned about the increased lymph production that may occur if you put your arm in a hot bath or hot tub for an extended length of time. We're trying to avoid allowing bacteria into the tissue, again, protecting the skin boundary. We're trying to avoid situations with increased lymph production.

Another one of those that I touched on earlier was any inflammation in the arm—I mentioned how some of my patients presented with elbow pain, and it turned out to be what we call a tennis elbow or a lateral epicondylitis, which is an inflammation of the tendon. In fact, that's what triggered their lymphedema, because they had a chronic inflammation in the arm that was causing more blood flow, more fluid, to leak across into the tissue and, consequently, the tissue around the elbow became swollen. Any source, local pain, chronic inflammation in the arm, you want to address with medical help, and those are the primary rationale. We want to avoid inflammation, avoid breaking the skin boundary and avoid increased lymph production.

The other thing we want to avoid is spaghetti bra straps, elastic sleeves, elastic closure to your sleeves—anything that constricts the arm and can potentially create a tourniquet and block lymph flow.

Again, the lymph vessels are very superficial. They're just beneath the skin, so anything that is constrictive, a tight watchband, bracelets, that could theoretically block the flow of lymph. [There is] no data, no research behind that, but it's kind of a common-sense approach.

[...] Some women, who are truly at risk for lymphedema [have had] all of their nodes in the armpit removed. You'll have patients with 20, 30 nodes removed, aggressive radiation, and yet, they don't develop lymphedema. We believe that's, in part, because the collateral vessels—these are lymph vessels that run from the arm up into the lymph nodes above your collarbone—[drain the arm]. Remember how earlier we talked about there are lymph nodes in the neck? These extend down into the area just above that hollow above your collarbone, your clavicle. We believe that that's an auxiliary or a secondary route by which we can drain the arm. If you carry a heavy handbag on the affected side [or wear] spaghetti bra straps that are going to cut into your shoulder, theoretically [that] can block the return of lymph from your arm and place you at risk for developing lymphedema.

An issue that I just realized I passed is airplane travel. Why all the concern about airplane travel? That has to do with increasing the lymphatic load. When we're in an airplane, even though the cabins are pressured, they're still at lower pressure than we experience at sea level. Historically, the belief has been that in an airplane cabin at [an] altitude [of] 36,000 feet, the ambient pressure, the pressure that surrounds the arm, is reduced, and therefore there's less resistance, less impedance, for fluid to leak across the walls of the small blood vessels, and so more fluid accumulates in the arm. Witness the swelling that most of us get in our feet. If we take a transatlantic or transpacific flight, we believe it's because, with the reduced pressure in the cabin, there's less of a barrier for that fluid to leak across your blood vessels and into your tissue.

There are other things that happen during air travel that are also provocative that can place a woman at risk for lymphedema. These include being sedentary, sitting without moving for a long time. As I mentioned before, the muscles are very, very important, the contraction and relaxation of the muscles for normal lymphatic flow. When we don't move for a long period of time, our lymph flow becomes sluggish.

Certainly, if you're thinking about using a sleeve for a precaution during air travel, you absolutely want to move that arm. Squeeze and release your fist, your hand a few times. Get that elbow moving, so we make sure the muscles are moving.



The other thing that happens in air travel, or used to happen when we were actually given food during airplane flights, is you're fed very salty food. That will cause the body to retain water and produce more lymph.

Also, many times women are carrying luggage, carrying heavy bags, so they're using their arm in a vigorous and noncustomary way, which is potentially going to increase lymph load. They may be carrying luggage with heavy shoulder straps that cut off that collateral circulation. There are a number of things that all relate to the conditions that place a woman at risk for lymphedema.

Just to review, those are: breaking the skin—anything that breaks the skin; anything that causes inflammation; anything that increases lymphatic load; and anything that potentially constricts or blocks the lymphatic system. Again, that's where the no blood pressure comes from. We're worried that the blood pressure cuff can potentially cause a tourniquet effect and trigger lymphedema.

I'm going to move on from the precautions. I'm going to move into treatment, and the current international standard of care for lymphedema is what we call complete or complex decongestive therapy. I suspect that many of our participants on the line today who have developed lymphedema have gone through this system of care.

It was developed almost concurrently, actually simultaneously in Germany, Austria and Australia. There were different groups of clinicians in each of those countries that pioneered, somewhat ironically, similar systems of managing lymphedema.

They all have the same elements. Some type of massage. Usually we refer to it as manual lymphatic drainage [MLD], which is a very gentle massage that stimulates the flow of lymph from congested areas into areas with normal lymph flow so that it can be removed. Just a little addendum there: manual lymphatic draining is a skill that really takes years, arguably, to master, and it's worth seeking out practitioners who are skilled in MLD. [One school that promotes MLD is] the Vodder School of North America; you can go to their website at <http://vodderschool.com>. They, in their training of lymphatic therapists, very, very strongly emphasize manual lymphatic drainage. Vodder-trained therapists have to recertify every two years, so they really preserve that skill set.

The components of this multimodal therapy program include manual lymphatic draining [and] compressive bandaging. We use special, what we call "short stretch" bandages. They're different

from an ACE bandage, which is very, very stretchy. An ACE bandage can be stretched to 300 percent, or three times its length, where a short stretch bandage can only be stretched by 50 percent. They're a bit thicker. We use those to apply multilayer bandaging to the arm or the breast, and we instruct the patient in skin care because we want to go to pains to reduce bacterial overgrowth on the skin and thereby protect our patient from developing cellulitic infections.

The last and very essential component of treatment is exercise. I've kind of dwelled on that—the importance of the muscles, the contraction and relaxation of the muscles. You'll hear of remedial exercises. It's an unfortunate term, but that's the technical term for lymphedema exercises. They're simply activities that encourage the serial contraction and relaxation of the muscles so that that pumping action stimulates the lymphatics. [Some ways to do this are] balling up, ("making a fist" and extending the fingers); doing wrist curls; [and] punching so that the elbow is extended and then flexed, extended and flexed. Those are all very classic remedial exercises, because we're trying to get the muscles in the territory affected by lymphedema to contract and relax to stimulate lymph flow.

That's decongestive therapy, which occurs in two phases classically. The first phase is what we call reductive. We're trying to make an arm smaller. Done appropriately, a woman is wrapped 24/7. With the exception of bathing and treatment, she's continuously wrapped. It is a drag. It interferes terribly with work and family social activities. But to really achieve nice reduction, the more continuously the patient is wrapped, the better our outcome.

Fortunately, that only lasts for two weeks to a month. Once we've achieved what we would call "optimal volume reduction," or we have returned to normal anatomy so that the arm looks the same as the other side, then we switch to phase two, or a maintenance phase, where the woman typically wears a compression garment, often a sleeve and glove or compression bra, during the day and may or may not require some form of nighttime compression.

There are a variety of nighttime compression devices. The recommendation is for women to wrap every night. It's very, very hard to maintain. I can honestly say, with no exception, I've never had patients who could keep this up. As a lifetime activity, it's very, very tedious.

Fortunately, they've developed what we call "alternative compression devices," things like the ReidSleeve [and] CircAid. Medi is a similar device. Solaris [is] a company that makes what are called Tribute Garments. These are alternatives to nighttime wrapping, much easier to don. They are bulky. Usually they are bulky. I have found that [it's best] if my patients can alternate [this treatment with] bandaging because being able to bandage well is a really essential skill set in long-term lymphedema control. Like anything, if you don't do it on a regular basis, you lose your edge. Do bandaging two, three, four nights a week, and then alternate that with use of a compression device that is much, much easier to don, and then [use] MLD as needed.

MLD is not covered on a chronic basis by typical insurance coverers, so patients that have the financial resources unquestionably benefit from weekly, biweekly, monthly MLD sessions. It's not cheap, unfortunately. That is the classic therapeutic recommendation.

There are many, many other things out there, some more fringy than others. Low-level light therapy is something that Dr. Neil Piller's group in Australia has published on. This is administering infrared light, and there are a lot of explanations for how it may work. They're all theoretical and speculative, but that's where infrared light is applied to the armpit, the axilla, theoretically simulating the nodes and improving delivery of blood flow to that area.

I may not be doing this justice because it's speculative, but low-level light therapy is something that's becoming increasingly available through lymphedema therapy establishments. It's non-harmful. It may or may not be helpful. I would argue the data is not currently sufficient to justify recommending this as standard of care, but it certainly will not cause any harm.

Medications. Currently, there are none that I feel comfortable endorsing for my patients. You may have heard about benzopyrone [brand name: Coumarin] or the rutosides. These are compounds that we believe help to sequester and remove waste material from the lymphedematous area. We do not recommend them for lymphedema associated with breast cancer because, in a trial performed here at Mayo actually, in 1999, Dr. Charles Loprinzi found that they did not offer patients any benefit and six to seven percent of the patients developed liver toxicity. Those are not commonly recommended, and Coumarin has been withdrawn



by the equivalent of the FDA in Australia and France because of some associated deaths.

Horsehair chestnut—extract of horsehair—[it] is something that again has not been adequately studied. It seems to be helpful in venous insufficiency. There have been no trials in lymphedema related to breast cancer. [It's] not harmful. [It's] unclear whether it's more beneficial to apply it topically or ingest it orally, but again, [it's] not harmful.

Butcher's broom [*ruscus aculeatus*, a type of evergreen shrub] is another naturopathic substance with some promising data. [It] has never been truly rigorously tested in clinical trials, but [it is] something that [is] generally not harmful, and the data is a bit promising.

Acupuncture. I am a certified acupuncturist, and [I have] tried acupuncture on some of my patients. [They] did not find it to be beneficial. We really worry about putting needles in [because of] the potential for introducing bacteria into an arm affected by lymphedema. However, acupuncture's effects are systemic, so treating the opposite unaffected arm [or] putting needles in the feet may be effective.

In my experience, it was not efficacious, but acupuncture is a very clinician-dependent modality, and [...] there are some reports that it is beneficial. It's not something I think we can endorse in a widespread way.

I think I've touched on most of the potential therapies that have been written about of late. There is a technique, lymph node transplant, a surgical technique. It's actually a microsurgical technique where the surgeon harvests lymph nodes from another area of the body, introduces them and connects them to the vessels—the blood vessels and lymph vessels in the armpit. [The] results are promising. [There have not been] trials. This has not really been studied. It is not currently widely available.

In the states, I spoke at the last National Lymphedema Network Meeting. I spoke to one of the surgeons that is doing these procedures, and she was very hopeful, but did not have long-term results on many patients. What we really would like to see is what happens a year, two years out, but I think it's something that's encouraging and, on the horizon, may hold promise.

Liposuction. Dr. Hakan Brorson in Sweden has pioneered, and very strongly advocated, liposuction as a treatment for established lymphedema. It is effective. For reasons that we

do not understand, the body has a greater tendency to deposit fat in lymphedematous territories, or areas affected by lymphedema. He found that in women that did not respond to that complex or complete decongestive therapy, the wrapping, the massage—if they had gone through a truly appropriate course of that multimodal therapy and achieved insufficient reduction of their arm volume, he found that he could, with liposuction, achieve a dramatic improvement. That said, the only way to sustain those benefits was through ongoing, indefinite compression. Even though those patients now have smaller arms, to maintain those results, they have to wear sleeves during the day and some compression at night. With that, I want to leave plenty of time for questions, and I fear I've run on too long as it is.

ELYSE SPATZ CAPLAN, MA:

I just want to let you know that the presentation has really covered so much valuable information including the early signs, some of the treatment methods, the tried and true, the proven. You've ended with some of the more novel approaches that are in the research arena that we can all keep our eyes and ears open for. It's a wonderful place to draw this to a close, for the moment, and then turn back to our operator and allow some time for participants to get their questions answered.

OPERATOR:

Thank you. Our first question comes from Branford, Connecticut.

CALLER:

My question pertains to the success rate of a reconstruction following mastectomy of an already lymphedematous breast. I needed, after my initial treatment, a stereotactic in my breast. It was already affected by lymphedema. I originally had a partial mastectomy. I was told that reconstruction wouldn't have been feasible.

ANDREA L. CHEVILLE, MD, MSCE:

I don't know that that's true. It's a balance. There's no question that having surgery, you're creating an opening for bacteria. It usually is a non-issue because we can deliver antibiotics during surgery and after so that we neutralize that issue.

The question is, will the reconstructed breast be adequately drained. The fact that there's some lymphedema in the breast now suggests that that could be a problem. I think it depends on how much you want it. I would say, if it's important to

you and the surgery occurs in a center where there's good lymphedema treatment available, you'd need good post-operative compression, ideally MLD, to decongest. What kind of reconstruction was under question, a tram or an implant?

CALLER:

An implant.

ANDREA L. CHEVILLE, MD, MSCE:

Okay. We recommend MLD for patients getting implants because, if there's a problem with drainage, always with implants, we worry about scarring encasing the implant. This is theoretical, but doing some MLD immediately after and while the area is healing, to remove molecules that could cause inflammation, seems to result in better outcomes for our patients.

I would think that [it would be okay] in the hands of an adequately trained team, a surgeon that is cognizant of the lymphatic drainage and would respect that and try and protect that as much as possible during the procedure, [if you] get MLD and compression going as soon as possible, and probably use of some kind of compression long-term.

OPERATOR:

Our next question comes from Montague, California.

CALLER:

When you talked about liver toxicity, I have lymphedema in my right arm, in my right side. And right now, I have fat on the liver, and I've been trying to lose weight, but what do you mean by liver toxicity?

ANDREA L. CHEVILLE, MD, MSCE:

Oh, I'm sorry. Maybe I wasn't very clear.

That's only with a medication that used to be used—actually it was never approved. The government never said it was okay to use it in this country, but lymphedema patients in Europe and in Australia were given a medication, a pill called Coumarin, that may or may not help the lymphedema, but it was never used in this country because it causes damage to the liver.

In the study that they did here at the Mayo Clinic where patients received it, the rate of liver toxicity was just too high. But, if you've never taken the medication, which is called Coumarin, or 5,6 benzopyrone—that's the chemical name—you wouldn't be at any risk for that.



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CALLER:

There are some medications that they have me on that they're watching my liver to make sure nothing happens, but could medication that can affect the liver cause lymphedema?

ANDREA L. CHEVILLE, MD, MSCE:

I'll add a point, because you helped me very much bringing up something important. Medications are a very common source of liver damage, and it's great that you are being vigilant and watching. I suspect they're taking blood tests to make sure your liver's okay. That's great. They're doing the right thing.

Is there a potential for medications to trigger lymphedema? Some medications alter the way that our body handles fluid. Anti-inflammatory drugs can cause the body to retain fluid. So, if you're finding, after starting a medication, that you develop lymphedema or your lymphedema is more difficult to control, something very important to discuss with a medical professional is, "Could my medication be making this worse?"

CALLER:

I just have a quick [question]. Six months [after] I was diagnosed, I found out I had lymphedema. It's in my right hand. I write with my right hand, and I like doing crafts. I'm under a lot of stress. I find even with cooking and stuff, that my hand and my arm start hurting really bad.

ANDREA L. CHEVILLE, MD, MSCE:

It's really important that you continue your crafts and the things that you love. This is something I can't emphasize enough for patients. If you're not working with a good lymphedema therapist that can help you figure out a way of compressing the arm, controlling the lymphedema so that you're able to do the things you love, [it's] important [to find one]. I would encourage you to utilize some of the Internet-based resources to find good help.

In terms of your arm hurting, you may find if you're not overusing the arm, then most patients don't have trouble with pain. If you're really getting into trouble, I would suggest that you take a break, because where the lymph fluid can start to build up is when we use the arm for a long, long period of time, even if it's a customary activity.

After Thanksgiving, we may or may not get a few patients who come in because they're used to cooking for two or four people every day, but then Thanksgiving comes and, lo and behold, they cook for 30. They're using their arm in a common way,

but the duration is much, much longer, and then they get into trouble.

What I would suggest for you is maybe break up your craft periods so they're a little bit shorter. Let the arm relax. Do some gentle stretches and flex your fist, or flex your fingers, straighten your elbow. Get that lymph flowing and then come back to it, and hopefully you'll be able to find a length of time where you don't start to experience that pain.

OPERATOR:

Our next question comes from Wayne, Pennsylvania.

CALLER:

What do you do when you have lymphedema, and you also have metastatic breast cancer in your subclavian lymph nodes? Can you still do the lymphatic massage?

ANDREA L. CHEVILLE, MD, MSCE:

You bring up a great issue. This prohibition against massage in patients who have had a history of cancer.

If the breast cancer is metastatic, there's no suggestion whatsoever that the manual lymphatic drainage will accelerate the spread of your cancer. Whether cancer cells spread to your bones, [or] any other body parts is determined almost entirely by the genetics of the tumor cells, not by the massage. Exercise, movement—it's less strategic, but it can be a more profound way of mobilizing your lymph fluid. There's never any suggestion that exercise encourages the spread cancer. Absolutely, there's no contraindication to having manual lymphatic drainage if you have metastatic cancer.

OPERATOR:

Our next question comes from Boulder, Colorado.

CALLER:

I have no symptoms of lymphedema, but only recently had surgery, and I had 18 lymph nodes removed. I'll be starting radiation soon, and I wondered if there was anything I could ask of the radiation oncologist or instruct them to reduce my risk of lymphedema.

ANDREA L. CHEVILLE, MD, MSCE:

Are you going to get radiation to your axilla and the lymph nodes above your collar bone?

CALLER:

What she said was the left chest wall. Super clavicle. Clavicular lymph nodes and axillary region.

ANDREA L. CHEVILLE, MD, MSCE:

You are going to receive radiation to those lymph nodes. I think they're delivering that radiation because they're concerned that there may be residual cancer cells in those lymph node beds, and the most important thing is to protect you from the cancer coming back. You're getting what we called four-field radiation to the chest wall, and then the armpit node, and the nodes above the clavicle, which, unfortunately, does increase your risk of lymphedema. But it's important. We want to protect you, and that's the goal of treatment.

There's not much, per se, that the radiation oncologist can do. However, there has been some interest in the possibility that initiating manual lymphatic drainage during radiation, immediately after radiation, can help. I talked about those collateral vessels. They're sort of those secondary pathways to drain the lymph fluid. There was actually a study in France that found it to be effective if they delivered or administered the manual lymphatic drainage massage after treatment. It seemed to protect women from developing lymphedema, because it stimulates development of those drainage pathways. If I were going to encourage you in any direction, it would be to find a therapist skilled in manual lymphatic drainage.

CALLER:

When you say immediately after, do you mean the same day?

ANDREA L. CHEVILLE, MD, MSCE:

I don't think it's important to be really compulsive about that. You'll get red, and the skin will be irritated. We don't want to manipulate or massage over an inflamed area, but they can work on your back. They could work down your side, your flank, and direct the lymph into the lymph nodes in your groin. I would say during radiation and afterwards, but don't make yourself anxious about the timing. Just to the degree that you can.

OPERATOR:

Our next question comes from Birmingham, Alabama.

CALLER:

I wanted to ask you about the complication of postherpetic neuralgia. I've had so much pain when wearing sleeves and with the wrapping. My therapists say that my PHN makes the therapy ineffective because it does cause so much pain to me. Is there any help?



ANDREA L. CHEVILLE, MD, MSCE:

Well, treating the postherpetic neuralgia—for listeners that may not be familiar, this is very common. I've actually been a victim, too. It's the Herpes Simplex Virus or the varicella zoster. It's shingles. It involves the nerve, and it causes an outbreak of vesicles, little blisters, in the distribution of that nerve. Unfortunately, afterwards, because of damage to the nerve, it can cause intense pain. I think the key is getting good pain control for your postherpetic neuralgia. There are blocks that can be done. There are a variety of medications. Have you seen a pain specialist?

CALLER:

No. I take duloxetine HCl (brand name: Cymbalta) with the SSRI as the SNRI. Also a little bit of klonopin (brand name: Clonazepam).

ANDREA L. CHEVILLE, MD, MSCE:

I would encourage you to seek out a pain management specialist because it can go both ways with pain in the distribution of lymphedema. Sometimes the wrapping actually helps and the sleeve helps. What we call the counter stimulation of having something else creating sensory input in the area reduces the experience of pain. Unfortunately, sometimes, as in your case, it goes the other direction, and it's very hard to tolerate. Some sleeves are less abrasive than others.

CALLER:

I have a ReidSleeve, which I wear when I'm flying.

ANDREA L. CHEVILLE, MD, MSCE:

Sometimes a cotton stockinet that you have next to the skin is very helpful. Lidoderm patches [may help]—they're Lidocaine impregnated. Unfortunately, I don't have any brilliant insights at all. The best thing is to find somebody who can take you through medication trials and try and get control of the herpetic neuralgia. TENS, Transcutaneous Electrical Nerve Stimulation, might help, and certainly finding approaches to compression that offer the least irritation to the skin and flare that the least. Those would be my recommendations.

ELYSE SPATZ CAPLAN, MA:

I need to jump in because, believe it or not, our 90 minutes have come up. I would very much, on behalf of Living Beyond Breast Cancer, like to thank Dr. Cheville for all her time and expertise and all of you who tuned in and the women that got to ask their questions for their very important and good questions. We hope that you got some information to take back to your oncologist and others caring for you so your quality of life can be improved in the short term and for the long run.

With that, I just want to remind everyone to fill out your evaluation forms. Remember, if you want to go back and listen to something that you need clarity on, an MP3 podcast audio recording will be available on lbbc.org very soon.

For those that want to connect with peers, with other women who've gone through breast cancer treatment for peer emotional support, please take advantage of our toll free Survivors' Helpline at (888) 753-LBBC (5222). You can talk to other women who've gone through this experience that may be really effective supporters for you. I would also like to ask Dr. Cheville if you had any closing comments.

ANDREA L. CHEVILLE, MD, MSCE:

One thing that I did not touch on was about axillary pain, meaning pain in the armpit, pain in the breast area. There's what we call post mastectomy pain syndrome, which can occur after a lumpectomy or an axillary dissection. Lymphedema in that area can be quite uncomfortable.

My experience, much more than the arm, patients with mild lymphedema in that distribution can really suffer. Trying manual lymphatic drainage [and] getting connected with a good lymphedema therapist is certainly worth a trial. If it's really bothering you, please identify a pain specialist, because you really don't have to live with that. There are effective treatments available.

I thank you, Elyse and LBBC, for the opportunity to speak, and I hope it was helpful to our audience and appreciate the questions. Thank you all.

ELYSE SPATZ CAPLAN, MA:

Oh, you're so welcome. To remind everyone, the *Guide to Understanding Lymphedema* is available by contacting LBBC if you'd like to get a copy of that brochure, and keep in mind our Web site also has message boards.

If you'd like to continue your dialogue on the subject of lymphedema, please feel free to post a message and listen to what some of your peers have to say about what was helpful for them.

With that, I'd like to thank the operator and all the participants, and have a good day.

[END OF TRANSCRIPT]