Advances in Blood Cancers:

NHL Treatment and Survivorship

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Transcript

INTRODUCTION

Ed Ciborowski, MLS, LCSW
Hello, I'm Ed Ciborowski, Senior Information Specialist at The Leukemia & Lymphoma Society. I'm pleased to be here today with Dr. Jonathan Friedberg, Director of the James P. Wilmot Cancer Center at the University of Rochester; and Miss Lynn Rich, Nurse Practitioner. We will be discussing non-Hodgkin lymphoma survivorship management, including treatment, monitoring, and managing side effect communication with your healthcare team, and managing long-term and late effects.

OVERVIEW/DIAGNOSING NHL

Ed
Dr. Friedberg, what is non-Hodgkin lymphoma, and why is an accurate diagnosis important?

Jonathan Friedberg, MD, MMSc
Well, Ed, first I'd like to just thank you for the opportunity to talk today. It's really a privilege, and I can't emphasize enough how much LLS has helped my patients and us as a team.

Non-Hodgkin lymphoma is really a broad term that defines a large group of diseases. There are at least 60 different subtypes of non-Hodgkin lymphoma, and these really vary in their clinical behavior. Some of the subtypes are curable, some are less curable. Some of the subtypes require aggressive emergent treatment, and sometimes we don't even have to treat the disease because it doesn't bother the patient.

The commonality of non-Hodgkin lymphoma is that all of these diseases involve problems with a white blood cell called a lymphocyte, where that white blood cell is making too many copies of itself. But each subtype has different mistakes that lead to those problems. So it's very important to get an accurate diagnosis. And the way that's done is with interpretation of a biopsy. So usually it's a lymph node, but sometimes it could be the bone marrow or other organs that are biopsied for lymphoma; and complicated tests are done to definitively subtype the lymphoma. And I would say it's critically important for patients to understand exactly the subtype of lymphoma they have in order to understand their prognosis and the appropriate treatment.

Ed
Since an accurate diagnosis is so important, what are your thoughts about getting a second opinion to confirm the diagnosis? Some people feel uncomfortable raising the question of getting a second opinion, especially when they're presently working and have a working relationship with their doctors.

Lynn Rich, RN, MS, ANP-BC
So that's a very good question. I think people very often have that insecure feeling; do I ask the provider? Do you want to try to develop a relationship? He's relatively new to you. So it's often a very uncomfortable question to bring up, but we highly encourage a second opinion.

One, it's very reassuring. We get a much better sense if the plan is exactly what you heard from the first time, that's very reassuring. If it's different, then we can tease out what is the commonality of the two visits.

What we feel though if you're going to do it, it's really important to make sure it's a place of high quality. And by that we mean you want to go to a place that has an expertise in lymphoma only. So you want a specialist not only that reads slides, but reads lymphoma slides. So getting that interpretation from a lymphoma pathology expert is important.

Make sure the doctor has your radiology which are all your CAT scans or PET scans. You want to make sure you provide those pathology slides for the pathologist to have those reviewed so that Dr. Friedberg has a much better sense. If it's read here, he's confident it is what they called it on the outside. So that reassurance also is a very validating piece of a second opinion.

Dr. Friedberg
I would just add that I don't think patients should be overly concerned about what physicians feel. I certainly am not threatened if my patients get a second opinion. I learn from second opinions myself, and I would encourage anybody who feels that would be helpful to them to seek out a second opinion

STAGING AND TREATMENT PLAN

Ed
I know that many patients are anxious when they're told they have a certain stage of NHL. What is staging and why is it important when diagnosing a lymphoma patient?

Dr. Friedberg
Well after you confirm the subtype of lymphoma, the next step in treating a patient is to figure out what stage is the lymphoma. And stage is simply a way that we define where the disease is in the body. And early stage disease, or Stage I disease, is frequently a single lymph node that's involved. Stage IV disease is when the disease is much more widespread. And the way we determine what stage the lymphoma is involves the use of things like CAT scans, PET scans, blood tests, physical exam, and sometimes other specialized tests.

There are a few important points to emphasize. The reason why we do this is that the treatment differs. So, for example, certain lymphomas you use radiation as part of the treatment if they're in early stage but you don't if they're in advanced stage. However, I want to emphasize also that a lot of patients get very nervous when they're told they have Stage IV disease. In many types of lymphoma, it is still curable if it is Stage IV disease. And the difference in prognosis and overall survival may not be that different whether the disease presents in Stage II, Stage III, or Stage IV.

Follicular lymphoma, the vast majority of patients have advance stage disease if you look hard enough.

Lynn
At presentation.

Dr. Friedberg
At presentation, exactly.

So I think the anxiety that people have about staging in lymphoma should probably be less than the anxiety maybe in some other types of cancers. And it's important to emphasize why we do this because it really dictates a therapeutic strategy.

Ed
Lynn, what else do patients ask you about?

Lynn
Well, I often meet them when they're newly diagnosed and they just kind of had a whole understanding from Dr. Friedberg and then they share with me, "Wow, this is overwhelming. What do I need to know?" And I try to tell them, "Definitely you want to understand how we're going forward. What treatments are we going to endure?" If we have certain treatments, we want to make sure we address all of the possible side effects, what are the different things we're going to worry about? Sometimes there can be annoying side effects — nausea, vomiting, diarrhea, constipation. We kind of put those in a box. Then I try to describe to them, secondly, as those that are maybe more clinically concerning. So that could be you have low blood counts or you have fever.

And what I really try to stress is your individual specific questions with your provider. Ask the doctor, ask the nurse, ask your providers, ask your team, "What do I need to be worried most about in my circumstance, my treatment regimen?"

Dr. Friedberg
And I think the concept of team approach to the care is important for patients to understand. The treatment of lymphoma as a type of cancer is far more complex now than it has been ever and certainly more complex than when I started taking care of patients with lymphoma. And it's really not appropriate for an individual to be providing that care. It's often done by a team. So teams can include physicians and physicians of different specialties like radiation oncology, surgeons sometimes, nurses, nurse practitioners or physician assistants, social workers. Lots of team members, pharmacists that can be involved in the care of patients.

So I think it's important early on as patients are getting ready to start a treatment program that they understand who the team members are, how the team communicates, and what resources each team member brings to the table in order to have their questions answered.

SURVIVORSHIP

Ed
So, Lynn, what is survivorship?

Lynn
Very good question. It's actually evolving in oncology throughout the country. Years ago survivorship really wasn't talked about, and so it's really coming much more to the center, the heart of oncology care. Survivorship is the day you've been diagnosed. So it's bringing you through the full treatment course to periods of time when you are done with treatment and maybe times when we are no longer treating you or times when we retreat again because often, as he said, with indolent cancer, indolent lymphomas, we have periods of treatment, a long period of remission, period of treatment. So to me the whole spectrum is survivorship.

Dr. Friedberg
I'll add some aspects to that. I think that a disease course of cancer, once you're diagnosed, I think it's very important for patients to think of themselves as a survivor. It helps put things in a positive light. But frequently we think about a few different time points in the disease. There's a period of active therapy; and although survivorship is a component of that, most of the energy during that time is to fight the disease and to deal with the side effects of treatment.

When we use the term survivorship, oftentimes functionally we're thinking about at the end of treatment beyond. And I think that's really what the focus of some of the things we're going to be talking about today because, historically, once treatment was over—

Lynn
We said goodbye.

Dr. Friedberg
—the feeling was, okay, now you get on with your life.

And what we realize is that there are a whole new set of issues that are brought up that are complex issues that patients with cancer, and specifically patients with lymphoma, need to deal with. And that's the survivorship component. It's a very positive way to think about how patients can thrive after treatment.

Ed
Now we have an understanding of the staging and treatment for the many subtypes of NHL, can you talk about some of the issues for patients who have completed treatment?

Dr. Friedberg
So I'll focus on probably the number one complaint, at least initially, that patients have is the concern over disease recurrence; and how do I know that the lymphoma is really gone, and how do I know that it isn't going to come back?

So the first concept there is to make sure that patients actually understand what the goal of the initial treatment was. As I said, a subset of lymphomas are curable. In that situation, the goal of the treatment was to have the disease go away and have it never come back. That's what a cure is.

Many lymphomas are not curable. So the expectation is, even after treatment, at some point the disease may recur. That might be years later. So it's important to understand that. And then given that information, an individualized disease surveillance plan is created with the physician. And that often includes periodic imaging studies, physical exams, and visits to make sure that the lymphoma isn't coming back.

Historically, we used to do a lot of scans. We're doing many less now because we realize that if you do too many scans, you might be exposing patients to radiation that can cause other problems. So today oftentimes with lymphoma, we rely a lot on physical examination, patient history, reporting of any new complaints, and blood work.

Lynn
It's kind of an evolution certainly in lymphoma care that we're really trying to step back about, with so many scans.

Dr. Friedberg
Exactly. And I think the other point about the disease surveillance is the reason why we are following patients is because the cancer and the lymphoma at that point, even if it recurs, may still be very treatable and even potentially curable. So it is important that the patient stay involved with an oncologist for a period of time to make sure that things remain under control.

I think it’s a fine line though between being involved with the oncologist and being almost physically or psychologically paralyzed by fear that the disease will come back.

And that’s been clearly a concern that many patients have. And I think what we really have to do as oncologists and as a whole team with the patient is to try to help the patient compartmentalize these concerns such that when we have the visit, we can review everything and provide a sense of reassurance that everything is stable so that in between the visits the patients can live as healthy, normal lives as possible. That can be a challenge certainly at the beginning, but it’s something that’s very important.

I think the bottom line is patients have to have confidence in their treatment team and know that if the scans or the visit goes well and things are okay, things are okay.

Lynn
It really is, yeah.

Dr. Friedberg
And they can go on in between visits. And, obviously, personality of patients differs. Some patients even need psychological support. Some patients benefit from some groups where they can talk to other patients who have been through similar situations.

TREATMENT SUMMARY AND CARE PLAN

Ed
Lynn, can you tell us about your center’s survivorship program?

Lynn
Sure. We have a coordinator of our survivorship program. Her name is Alicia and she pulls together actually throughout the whole cancer center each of the different diseases. Nurse practitioners pretty much are representatives of the survivorship, so essentially patients who have recently finished treatment will be referred to a survivorship nurse practitioner. And we basically go through different things.

So I greet them, “Tell me about your experience,” and then I actually go through what we call a Treatment Summary. And it’s a one-page. We treat that as a very formal document that I suggest that they bring that to whomever may care for them themselves as well as bringing it to their other providers. It could be other oncologists if they were to move out of the area. If they went to their primary care physician, bring that paper with them.

And what that paper is, is a one-page description of their experience. It gives their oncology team, all the different members that he talked about, the diagnosis with histology. Not just non-Hodgkin lymphoma, but one of those 60 that we referred to with a very specific subtype so that it’s clear. Then we go through the stage. We then discuss whether or not they were on a clinical trial.

Then I actually go through the medications. So this paper describes it to them. Gives each of the chemotherapy medications, the dosage they got, the frequency, whether there was a delay or not, how many cycles they got altogether, the dates when they started, the date when they finished. Whether or not they had radiation. How much treatment did they get under what time frame, where on their body they were radiated. All those pieces are pulled together on this one page. So I think that’s a really good tool. Patients have really appreciated that.

Dr. Friedberg
I think that’s so important and whether it’s in the form of a tool like we make or it’s something that the patients make themselves, I think it’s very important for a patient to be able to know what treatment they got and what disease was being treated and what the intent of that treatment was.

I’ll often see patients who might be new to Rochester who were diagnosed ten years ago with lymphoma and just need some follow-up. And if I ask them, you know, what they had, if they don’t know, that’s a concern because a lot of the late effects and issues that can come up are individualized depending on specific treatments and specific diseases. So if a patient knows that, they can be more proactive in their health in the future. So it’s important at least in one place to have all that information so that should another medical issue occur, you’ll have easy access. And I think having patients play that proactive role will serve them well in the future.

Lynn
They feel empowered by it, and I’ve seen that change, and it’s a nice transition that I’ve seen.

After we go through the Treatment Summary, we do something called the Care Plan. And this is more guidance about how to proceed in the future. I can’t tell you today, “Don’t do A, B, and C to prevent the lymphoma from coming back.” But what I can suggest are certain everyday healthy habits — “Eat well, eat your vegetables.” Fatigue is one of the biggest issues that we talk about, and exercise has been one of those small pieces that I can just suggest to them.

I have one example of a patient who, 80s or so, had been golfing, went through treatment and really was wiped out. He really thought so. He said to me, “Lynn, I’m never picking up a golf club again. I’m not going to be able to do it.” and I said, “Well, let’s see what we can do.”

We got him to a trainer. He worked hard. He did his treadmill every couple of days. And by the end of the summer, he was on the golf course shooting a club. So I think there’s ways to really help people transition from, “Oh, I was sick” to “Oh, I’m getting healthy.”

Also in that Care Plan we talk about, go back to your primary care, continue with your primary healthy maintenance tests that you need — cholesterol and your heart and all those basic everyday things that your primary care would normally do. We want to not own that. We say, “We’re sharing that. Your primary care knows what you’ve gone through. We want to make sure they pick up and are part of this piece also.”

Dr. Friedberg
I think that’s particularly important now that our treatments have gone on for a lot longer. I mean, historically in lymphoma, you’d be treated for a couple of months of chemotherapy and maybe radiation. Now many of our treatment programs can go on for months to years based on these new maintenance approaches and things that are being used. So keeping up with routine medical care is very important.

I think one other area that is very important is emotional and mental health. I think we underestimate the toll that lymphoma diagnosis and treatment takes on patients. And as Lynn was saying earlier, the transition from the intensive energy around therapy to suddenly we’re not going to see you for three months can be very traumatic for patients.

A recent patient of ours who was able to work all through his treatment and he would leave the chemotherapy infusion room to go to a board meeting and do all of those things. And he told me recently that the hardest time for him was when we were finished with treatment. He became depressed, and it was just very hard for him to adjust back to a normal routine without being anxious about the disease coming back and so forth.

And that’s a pretty typical story. It’s something that I think, you know, no matter how conditioned physically somebody is, it’s a big toll that lymphoma takes on people’s lives. So an appropriate intervention has to be individualized for patients. And there are a lot of resources that are available, and I think we just have to encourage patients to understand that this is a normal challenging transition and ways to get through—

Lynn
Yeah, I was going to say I think patients are surprised by this.

When you tell them, “Oh no, this is a very common experience,” they kind of are taken aback and like, “Oh, something’s not wrong with me?” And that’s very reassuring to say, “No, this is what we see. This is how we’re going to help you get through this.”

Dr. Friedberg
You’d think it’s the best time. You’re in remission, we’re done with treatment.

Lynn
Yeah, woo-hoo!

Dr. Friedberg
And, you know, it’s true, we celebrate it. But then all of a sudden they go home and they feel I think a little abandoned. Not in the sense that they want to come back and get more chemotherapy, but in the sense that their whole care team and all of the energy around treating the cancer is gone.

Lynn
We’ve been rooting for you and all of a sudden we kind of say, “Good bye. Good luck.”

And they’re not really ready for that. So I think acknowledging at this survivorship visit, “We know this may happen. These are the things we’re going to do. If that happens to you, these are the things we’re going to do.” And we give them resources — the supports groups in the community, calling LLS and say, “I’m not sure who to call, what do I do?” That’s a great resource. I think people forget or aren’t aware of that, and I think it’s really important that we bring that to the surface to seek out that help, that it’s okay. And in time, it gets better.

Dr. Friedberg
So in the past, on the visit that we would have celebrating somebody’s remission and saying, “You’re done with treatment. I’ll see you in a few months.” I would try to spend time myself going through these issues, but a lot of my energy was spent on the disease surveillance issues that I discussed at the beginning.

I continue to do that. We’ve now added this second visit in the context of the survivorship visit. And what’s fascinating is that that’s booked as a 30-minute visit, and many patients go way beyond that. And we’re not talking at all about disease surveillance. We’re talking about all of these other issues. Which in the past I think we just didn’t bring up.

This isn't unique to us by any means. This is a national trend. There's a lot of literature that's being written about this. I think we're understanding it more and more. And I think part of it is that we've become much more successful at treating diseases like lymphoma.

Lynn
We have the survivors.

Dr. Friedberg
So we have many more survivors where this becomes a real issue.

SURVIVORSHIP MANAGEMENT – LOOKING AHEAD

Ed
I know there are many developments in lymphoma therapy. How do you think they impact survivorship management in the future?

Dr. Friedberg
Yeah, I think that's a great question. It's perhaps the most exciting time in the drug development of new agents for lymphoma. You know, many of the new agents that are being developed are not chemotherapy at all. They're these targeted agents or pills that you take that have very few side effects and really focus on specific subtypes of lymphoma and are, at least in early stage clinical trials, really effective.

So I think the whole landscape and the whole approach to lymphoma treatment is evolving; and it's very possible that in the next five to ten years patients who are diagnosed with lymphoma will not need to take chemotherapy at all and will just be on cocktails of these new agents.

So on the one hand, some of the late effects that we were just talking about may not occur because if we get away from chemotherapy and radiation, we may solve some of those issues. However, I would predict that there will be some new issues that occur with these agents. And it'll be important that we continue to have programs like we just discussed to help ease the transition into the survivorship period.

I think the other exciting point I will make is that in the interest in clinical survivorship there's also a lot of research that's going on about survivorship. And we now have registries and other types of studies where we follow patients, we determine what these issues are and how best to prevent or treat them.

And the third area that is of great interest is the area of really supportive care and research in that area. So ways to prevent fatigue, the concept of “chemo brain” or a feeling of fogginess after treatment. There are now many studies going on to figure out how to prevent that or treat it if it exists. So I think there are a lot of opportunities for patients to continue to be involved in the research mission, even after their lymphoma therapy is complete.

Ed
So that’s an excellent point. I mean, I think the importance of clinical trials not only being treatment but for monitoring and long-term care issues, and those kind of trials become so important right now.

Dr. Friedberg
You know, fortunately, this is becoming really an emphasis of the National Cancer Institute. There are sections of the NCI that are really focused on these late effects. And I think with that and with resources being put into that area, as far as national investment and research investment, we can look forward to a lot of interesting results.

Ed
Well thank you.

So Dr. Jonathan Friedberg and Lynn Rich, we’d like to thank you for joining us today and your comments and insights about survivorship considerations have been very, very valuable. And we really appreciate the time you took to share with us.

Dr. Friedberg
I want to thank you and thank the LLS for this important educational program as well as for everything that they do.

Lynn
Thank you.

Ed
We hope this program will help guide your discussions about lymphoma treatment and survivorship decisions. The Leukemia & Lymphoma Society, as well as your healthcare team, are valuable resources for information and support. If you'd like to learn more information about what you've heard or for other educational materials or support, including disease and treatment information, clinical trial searches for your diagnosis, questions to ask your healthcare team, or financial and insurance information, including the new Affordable Care Act, we encourage you to contact the information specialists at The Leukemia & Lymphoma Society by calling 1-800-955-4572, or you can visit us at www.lls.org

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On behalf of The Leukemia & Lymphoma Society, thank you for joining us today. We wish you well.