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EPISODE 3 V2 BREAK APART

MTT NHL & HL

Loretta Nastoupil, MD: Welcome to this *Med Table Talk*™ series on Lymphoma: The power of the community translating innovations into care in non-Hodgkin and Hodgkin lymphoma.

This is Part 3 of a 4-part series entitled, "Taking a Team Approach: Community-based Practices at the Forefront of Non-Hodgkin and Hodgkin Lymphoma Care." My name is Dr. Loretta Nastoupil from the University of Texas, MD Anderson Cancer Center. Welcome back to my fellow colleagues. Would you please quickly reintroduce yourselves.

Ann LaCasce, MD: Hello, and thank you for including me. My name is Dr. Ann LaCasce at Dana-Farber Cancer Institute in Boston.

Amitkumar Mehta, MD: Hi, happy to be here. I'm Amitkumar Mehta. I am at the University of Alabama at Birmingham.

Dr. Nastoupil: Let's get started. So, we've been discussing some of the latest breakthroughs for the management of relapsed/refractory non-Hodgkin lymphoma, two of which are CAR T-cell therapy and bispecific antibodies that are really promising in terms of the efficacy we're observing, including the potential for very durable remissions for high-risk patients.

That would not have been possible if not for patients and caregivers' willingness to participate on clinical trials, many of which were done at large academic centers that had transplant capacity. And so we're still missing a large population of patients that are not making it onto these clinical trials, and we're hopeful that these small groups are really going to be representative of the general population, both in terms of efficacy but also safety. But that's a major assumption.

It would be best if we had better representation on these prospective trials from patients that had the same demographics as our general population. And so how do we improve upon access to clinical trials, particularly as it pertains to these novel effective strategies, not just first-in-human Phase I studies where we're identifying the optimal dosing strategy.

Dr. LaCasce: So, I would say, you know, just what you said. We need to take the therapies to the patients; and I, I think expecting that patients, even with a lot of resources, are going to be able to come to academic centers to participate in clinical trials is just not going to happen for a lot of patients.

I think the cooperative groups may do a better job at opening clinical trials broadly in, in areas that are, may serve more underrepresented minorities. And I think, as you mentioned, we really need to push back on the eligibility criteria. We have very strict eligibility criteria for patients. And then when we go to try to generalize our results to the patients that we care for, we find that it doesn't match up because those patients would have never been eligible for this study. So I think really looking at, you know, do you really need to have a creatine clearance of X in order to participate in a study in a drug that is not nephrotoxic? I think that's one thing that we need to really, really examine and push back so that we can be treating more- So, our real world and our clinical trials data aren't so vastly different, which is what we see time and time again.

Dr. Mehta: Eligibility criteria is one of them. Second is there are a definite proportion of patients who we enroll under clinical trials at 30% of minority. So, even if you have, once you have 70% enrollment from the general, you know, category, 30% if they're not enrolled, the trial just enrolls some minority patients. So there are many factors that go in.

In, in my catchment area, the patient navigator approach has worked very well in clinical trial setting too. And that has helped our center and clinicians to connect with the patients and understand their needs and requirements to run a clinical trial.

At the end of the day, I feel it's education, education, education everywhere. Right from those who are designing clinical trials to all the way in the community and community doctors. Everybody's responsibility is, is aligned. Then we'll even be able to have more minority patients on clinical trial.

Dr. Nastoupil: I absolutely agree, and I think definitely where we have a role, such as informing clinical trial design, we absolutely should be advocating for more inclusive features.

I think the other part where it becomes quite challenging is how did we provide the support to generate the infrastructure to do clinical trials in centers that are providing care for underrepresented population or underinsured populations? Because oftentimes they're functioning at, you know, very low resource situations, and so we have tried utilizing granting mechanisms from various organizations to try and provide that infrastructure.

I think another area that definitely warrants some discussion is are there better tools for assessing patient quality of life? We're all familiar with these surveys that are incorporated near several of the large, randomized, Phase III studies, frequently underrepresented in those earlier phase studies, often lead to accelerated approval for drugs in lymphoma.

And there's still limitations for these tools in that oftentimes there's a large quantity of missing data. And you worry that those that are failing to complete the survey are the sickest patients. And then separately, oftentimes quality of life is strongly associated with disease. And so a more effective therapy might improve the quality of life vice versa.

And so there are a number of strategies that we can employ to try and improve our capture of what is the impact of quality of life of our therapy, and how can we again help incorporate this into our shared decision-making?

One way to do that is better utilization of our interdisciplinary teams. I think, at least in my practice, it is obvious to me that patients will reserve certain conversations for my outstanding nurse or nurse practitioner and then have very different conversations with me that are oftentimes tied more to, "Well, let's choose between these therapies." Or they may be more willing to discuss specific side effects or concerns with some of my support staff.

And so can we do a better job of incorporating a multidisciplinary team to ensure that we're, again, providing a comprehensive approach to patients but also being able to acknowledge where they have questions and concerns where each team member may have a different strength in addressing those.

And one key area is social determinants of health, and so it is very complicated, and it's probably a major reason why we do have inequity in a lot of our novel therapy studies. Socioeconomic status clearly has an impact on whether or not patients can miss work, can travel to work, can have caregivers available to them during these resource-intensive therapies.

I think age also factors in in both regards. Sometimes young people have to prov-, be the caregiver either for parents or children, and so missing work or not being able to be that caregiver can have implications for their own health.

Education level, the amount of community support for patients, and then also there are cultural truths that also factor in. And we know that for, you know, many reasons, patients of minorities have distrust of the healthcare system, particularly as it pertains to clinical trials or clinical investigations. So, can we do an optimal job to address communication in the form where it's readily received, transparency in terms of what are the research questions that are being asked and answered, and also taking into account again some of the social barriers that clearly impact whether or not patients are willing to participate?

So, I'm going to pause here, and clearly I want input from my colleagues because this is an important topic. How do you view social determinants of health, and how does that factor into your approach in the clinic with the patients but also in terms of the infrastructure of your institution? Ann?

Dr. LaCasce: Yes, so I think as Amit said, that having a nurse navigator really helps; and I think having nurse navigators who the patients can relate to. So, I think in some of the underrepresented populations, I think, you know, our center also, you know, although that we have a relatively diverse group of patients nearby, we're not seeing the referrals from a lot of those, for a lot of those patients, and I think really trying to pare with the community folks and try to establish that trust that we're going to take care of those patients.

I think, you know, the rural patients is another area where I think, you know, we see a lot of that because we are, you know, the only transplant center for several states in the Northeast, transplant and CAR center. So, you know, I think it's, again, it's that education. I think maybe there's a way to incorporate more virtual care or virtual shared care. You know, I, I saw a patient from the tip of Northern Maine who doesn't have a computer; but he was able to go to his local oncologist where they actually set him up for a virtual visit, so he didn't have to drive 7 hours to Boston, literally. And his oncologist popped in, and, during the visit. And I thought, you know, this is something that really could, we really need to think about because it allows us to really have that hands-on sort of collaborative care as opposed to phone calls or, you know, then you really feel like you know the providers, you know the patients. And then when they actually come down to see you for the first visit for consenting or whatever, there's already this familiarity and this level of trust that wouldn't, wouldn't normally be there. So, I, I think we have a lot of work to do on this, and we need, we need more resources and people to think about how we do this best.

Dr. Mehta: Well, I totally agree. I think technology can be of immense help, you know, as Ann mentioned. I, I talked about patient navigator program which has actually helped us a lot.

We also have Community Outreach and Engagement office. We call it COE office, and they on a routine basis have programs in the community with community leaders and oncologists or clinical trialists who chair this meeting, have roundtable discussions with the patients and caregivers. That way we spread the information about research and clinical trials.

The other way that we were able to engage the community is through the patient support program. We have say multiple myeloma group or a lymphoma group, and they have gatherings and, and people share their stories in those gatherings. So that way, people know about the, the program at a center as well as physician and clinician, as well as their support staff.

And that brings up the, the clinical trial office itself. You know, the, the CRCs or research coordinators, those who actually are engaging with the patient on a regular basis, they should also have training in that regard understanding the patient's need and how they can support. There are many resources that the clinical trials many times provide, and they are all able to offer that to the patient.

We have a Facebook group where we have, you know, thousands of people on that who had participated in clinical trials for their multiple myeloma group. There's a lymphoma group or a brain cancer group, and they communicate with each oth-, with each other. I have younger patients with Hodgkin's lymphoma. They get their information, believe it or not, on TikTok and Instagram. So, there are so many ways that we can, we can spread that information daily to the patient's age and, and generation.

Dr. Nastoupil: Yeah, I like both of your thoughts about making sure that we're thoughtful about how we use technology and experience from former patients to communicate that we really do want to serve our community at large.

I think that one other thing I might add is we're in the US where a lot of patients are dependent on their employer to have access to healthcare. And so are we doing an adequate job making sure that we're engaging the groups that employ the largest number of minority patients in our communities?

So, let's shift gears a little bit and talk about missed perceptions about CAR T-cell therapy, and I'm sure we all have lots of stories about this. I think some of the challenges lie in that the toxicity associated with CAR is unique. It can be intense for some patients, and it does require referral to specialized centers and the need to keep these patients within a two-hour radius for the first 28 days. And so I know that generally has led to a number of patients that are probably considered for alternative therapies because this is not something that's readily available.

But I want both of your perceptions, and then we're going to have the opportunity to get Dr. Caitlin Murphy's unique perspective on how do we address the misperceptions about CAR T-cell therapy because, again, I think we're all very excited about this therapy. How do we help others become equally excited? Ann?

Dr. LaCasce: So, I think as, as it's been mentioned already, it's all about communication. So, it's communication to the providers who are referring these patients. It's, you know, conversations with, locally about CAR T. You know, I'll mention the Lymphoma Research Foundation has really great patient support, and they run these, you know, patient education symposia where people can really learn about these different therapies and see other patients who are going through these treatments.

But I think it's, it, it requires a comprehensive team of people, including social workers. You know, that's part of any consult we have is to make sure that they are really aware of the day-to-day issues that may come up when you're receiving one of these therapies.

Dr. Mehta: Yeah, I would add to that technology, as I was mentioning, that support groups out online, they have been a good source for information. That they, the misperceptions can be eliminated or answered, as a matter of fact. And so as the patient ambassadors, you know, if you have patients who have gone to the CAR T, that way we can address the specific needs because many times the patients are looking for specific questions that they have, what they will, they will feel going through the treatment.

So, those are the important resources that eventually needs to be channelized or easily available for the patients to kind of access information.

Dr. Nastoupil: And I'm really excited to have an opportunity to talk with Dr. Caitlin Murphy. So Caitlin, you have a unique perspective on this. Where, where do you think we're maybe falling short about, you know, misperceptions that, that we may not even be aware of for patients that, you know, may be residing currently in a community oncology practice?

Dr. Caitlin Murphy, DNP: Yeah. You know, I think that there's not a clear understanding of kind of the, the financial implications of kind of our healthcare system and how people are insured in general or underinsured and, and kind of that access point.

One thing that kind of struck me is that, you know, oftentimes our, our, our people of color are diagnosed at later stages.

And it may not be that they didn't initially present for care. It's just that they may, you know, they may be a more transient population. They may go to an urgent care that is staffed by a rotating clinical team. And so kind of that continuity that, you know, those subtle little things that I think impact getting people to the diagnosis and then kind of on this whole trajectory of the care in which we are fully invested in. I think it starts when they come to us initially.

And I think that that's where a lot of our community outreach navigation partnerships can be absolutely essential. And I think that that builds a lot of trust in the community of, of the healthcare system but also in the community in which all of these people reside. And, and there's a huge element of that trust that I think will translate into clinical trials, all, all of their, all of their care.

I think another key element is, is that we have these conversations, you know, with the patient in their native language. I think that's another piece that we haven't highlighted in terms of not everyone is fluent. We talked about health literacy, and health literacy is very different than, than any other type of, you know, exposure to all of these new terminologies and acronyms and so I think, you know, speaking to them with their native language, even if they're very fluent conversationally.

These are nuanced conversations that really need to be articulated well, and so having that opportunity to kind of redirect around the, the language barrier and all of, you know, these patient education materials being in a language that they can read.

So, I think that's the other piece. Whether it's their consenting, whether it's their instructions for homecare or the caregiver piece, that can also be another element of how we address health literacy but also some of these social determinants of health that will kind of sort out the best treatment paradigm for them.

Dr. Nastoupil: And I think there's another key aspect to making sure the family members and caregivers are also very comfortable with these plans given some of these new therapies do require some monitoring and giving up of their time as well. And so all of these strategies, I think, are going to be critically important moving forward.

So, with that, I'm curious to get all of your sort of key takeaways and then again, in a perfect world, what can we do better? And Ann, we'll go ahead and start with you this time.

Dr. LaCasce: So, I think we all have to be really aware of these social determinants of health and things, these barriers that our patients have to being referred in and cared for in centers that can provide these types of therapies. And I think we've heard a lot of good suggestions from outreach, from social media, from other patients giving support to, you know, nurse navigators.

But, it's clearly a team approach, and I think we all have to be thinking about this as we live in our own communities to think about how we can better serve those who, who we aren't seeing and get them in for treatments that are, really can be so life-changing.

Dr. Mehta: Ann summarized it very well, and I- Yeah, one thing that I would add is, you know, it's important that, you know, as, as she mentioned about the team, the team needs to be aware of this; and many times it's better to educate them about this. Caitlin mentioned that, you know, having a consent form in a particular language or having a device that you can communicate in the language with a patient. Those are minor but very, very critical points in establishing that trust with the patient. The trust is the key to, you know, trust the system, trust the treatments, everything.

Dr. Nastoupil: Caitlin?

Dr. Caitlin Murphy: Going to the community and, and meeting people where they are and kind of whether that's their knowledgebase, whether that's where they live, whether it's, you know, the rural or the urban, I think in a perfect world that would be, we being a bit more mobile and the patient access kind of coming along with that as well.

Dr. Nastoupil: And so I appreciate all those comments, and I think the only thing I will add is that we all need to be stewards of these trials and make sure that we're always leveraging what little power and influence we have to ensure that we're doing our job to be as inclusive as possible so that we're not creating barriers for the patients that are already in our centers.

That was a great discussion, and thank you to our special guest, Dr. Caitlin Murphy; and thank you for joining for Part 3 in this series.

If you haven't seen Parts 1 and 2 in this series, be sure to check those out. Stay tuned for our final episode, "Checkpoint Conversations: Integrating Immune Checkpoint Inhibitors in Hodgkin Lymphoma." For additional resources, please see the activity website. To claim credit, please complete the post-assessment questions and evaluation. Take care.

END OF EPISODE 3