



Disparities in Lung Cancer Clinical Trials: Moving toward Equity and Inclusion

Diane Mulligan:

Scandal. That's what one doctor calls the medical care for lung cancer patients of color. But what can you do to help change the abysmal numbers of minority populations, getting lung cancer, screening and treatment?

Sarah Beatty:

Are there answers that will help you, your family or friends who have lung cancer?

Diane Mulligan:

The answer is yes. Here is just one example.

Doctor Osarogiagbon:

First of all, how often do people agree to go on a clinical trial when offered? It's well over 50 percent of people offered who will agree. And guess what? Suddenly gone. There is no racial difference.

Diane Mulligan:

Advances in lung cancer treatments over the last few years have made it possible to live with lung cancer for years after diagnosis, but minority and ethnic populations represent less than 5% of those getting the latest treatments in clinical trials. I'm Diane Mulligan.

Sarah Beatty:

And I'm Sarah Beatty. Today on the Hope With Answers, living with lung cancer podcast, we hear from doctors in the field and researchers on the front lines talk about the inequities in lung cancer care and how you can help yourself or a loved one get the cutting edge treatments so desperately needed with a lung cancer diagnosis.

Diane Mulligan:

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers. But first, it's a disease that affects people. The Hope With Answers, living with lung cancer podcast brings you stories about people living, truly living, with lung cancer, the researchers dedicated to finding new breakthrough treatments and others who are working to bring hope into their lung cancer experience. Sarah, I had the pleasure of discussing this topic with three of LCFA's lung cancer thought leaders. They educated me not only on where we are currently, but where we are going, so patients who are members of minority or ethnic groups get more and better treatment.



Sarah Beatty:

What I find interesting is not so much the current numbers, but the movement across the country. So many conversations are now taking place at so many more levels. An equitable medical treatment is receiving more consideration than ever before. I can't wait to hear our doctors' thoughts, experiences, and suggestions on how each of us can make a difference.

Diane Mulligan:

All right, thank you all for joining us. So today we're taking a deep dive into a topic at the forefront of discussions about healthcare equity, access to the best practices in medical care for everyone, especially minority and traditionally disenfranchised population suffering from lung cancer. We're going to look at who isn't getting access to the latest diagnostic tests, clinical trials and breakthrough treatments, but also why is this happening and what can we do to make a difference?

Diane Mulligan:

We have three guests today, Doctor Raymond Osarogiagbon, Dr. Vincent Lam and Dr. Triparna Sen. Dr. Osarogiagbon, who's kind enough to let us call him Dr. O, thank you, Dr. O, is a thoracic oncologist, a lung cancer specialist from Baptist cancer center in Memphis, Tennessee. And doctor Vincent Lam is an assistant professor of oncology at Johns Hopkins University and the recipient of the LCFA young investigator grant. And Dr. Triparna Sen is an assistant attending in thoracic oncology services department of medicine at Memorial Sloan Kettering cancer center, New York. And she's also a young investigator award winner from LCFA.

Diane Mulligan:

So hello, and thank you to all of you for joining us in this discussion today.

Dr Vincent Lam:

Thanks, Diane. Happy to be here.

Diane Mulligan:

Thank you. Okay. So my first question to whoever would like to take this is how do we define the problem of medical access to the best healthcare for minority populations? How do we define that? And we're going to get into why it's not happening, but if you had a panacea, if you had that crystal ball, what would that look like? Triparna, Would you like to start?

Dr Triparna Sen:

Sure. As you rightly pointed out, there is now very well-documented and significant disparities in lung cancer outcomes for communities of color. And that includes black African-American, Latino, Hispanic, and also native American communities. And if I had to define a healthcare disparity in lung cancer, I would say when two people who are at equal risk of having lung cancer, equal harm to benefit ratio from



a treatment and equal stage of the disease, are not getting equal treatment. I would define that, in my knowledge, as a disparity. And it is critical that we address disparity in all aspects, which includes eligibility, referral programs, healthcare access, and appropriate follow-up for lung cancer screening, and propose strategies to address each of these areas so that we can bridge this gap.

Diane Mulligan:

Vincent, do you mean, do you have some examples maybe where you personally witnessed the impacts of this problem?

Dr Vincent Lam:

Yeah. And thanks again, Diane, for, for having me on with this amazing panel. It's my first time actually meeting Doctor O, and so this is truly an honor. Doctor O obviously is one of the pioneers in our field, and then of course I know Dr. Sen from our previous time that MD Anderson. As part of my training actually trained at a county hospital. And then I also currently work at Hopkins, where our thoracic center was purposely located at Bayview, which is an area of Baltimore that does have a high number of patients who are under-resourced. Also a high African American population, as well as other minorities.

Dr Vincent Lam:

So we see the effects of this disparity regularly, and even previously in my training, I've seen some of these impacts. So for example, lung cancer screening. It's a big deal. We actually have an intervention that can try to catch these cancers early and thus potentially catch them at a stage where they're curable. And we know that lung cancer screening uptake in minority populations is much lower than non minority populations. And then also, just in my training, we see time and time again that there's delays in diagnosis in patients who are in under-resourced settings as well. So I think the list goes on and on, unfortunately.

Diane Mulligan:

Absolutely. I think it does. Triparna, and go ahead.

Dr Triparna Sen:

I just have something to add. So I don't see patients, Vincent can speak about his experience in seeing patients, but I work in lung cancer awareness, and that gives me the opportunity to talk to patients and their families. And something I have seen in terms of mindset is that there's often a preconceived notion, and this I've seen more in the populations from the minority communities, is that they have the sense of guilt that I have smoked, and hence, since I have a smoking history, they think that they are less eligible for either screening or treatment. And that is simply not true, but I think this is a notion or a stigma that I have seen repeatedly come up in communities from these ethnic minority groups. And that's something that my personal experience has been.

Diane Mulligan:



Absolutely. The stigma is such an issue. Doctor O, you have lived all this. What do you think is our best course of action to make sure that these communities get the best and most effective lung cancer treatment?

Doctor Osarogiagbon:

Yeah, thanks, Diane. The first thing I would say is that we need to understand the true nature of the causes of disparities. One of the challenges we displayed as a research is that, for most of its lifespan, it has been mostly descriptive, identifying who suffers, who's the victim, if you will, who's left behind, and the inadvertent effect of that sometimes is that there's this a natural human tendency to victim blame. Something wrong with you. This is not that hard. Why do you always seem to fall behind? So I think it's important for us to look etiologically, meaning at the place where the thing is caused, in order to be able to find its solution. Because what we see oftentimes is the superficial nature of something that has resulted from something else.

Doctor Osarogiagbon:

So increasingly, we push this idea of the multi level causes of disparities. There is the person level, the patient level. Which is oftentimes over black people, racial minorities, ethnic minorities, women, gender, sexual minorities, geographic, places where people live. Then there's the provider level, which begins to get uncomfortable for people like Vincent and I. What are doctors doing that contributes to the existence of avoidable difference between person and person? And then at a higher level, you have the organizational level. What are healthcare systems and other institutions doing that actually allow this to happen? And then really, at the highest level, what social policies do we have that advertently or inadvertently promote the existence of disparities?

Doctor Osarogiagbon:

I think when you take that multi-level etiology, you begin to find, first of all, there is plenty of responsibility all across the landscape. It's not just the person who is suffering who needs to deal with this. Because in actual fact, when you now start talking about solutions, you find that there is a paradox. I call it the intervention impact paradox. The more the targets for intervention, the less effected your interventions will be.

Doctor Osarogiagbon:

So for example, there are way more people at risk for disparities than there are providers who give care to them. There are way more providers that then they are institutions within which the providers work. And of course there are fewer social policies that guide how institutions and providers work. So if we really want to intervene and make the product disparities go away, what we have to recognize is that social policies are way more effective than nagging individual people, do this, or do that. Interventions that work at the organizational level are going to be more effective than interventions at the single provider level.

Doctor Osarogiagbon:



And the provider based interventions actually are going to be more effective than patient level interventions. So I think it's important for us to begin to recognize that we have seen the enemy, and it is us. It's not the person who's suffering this disparity. So giving you a specific example, working off what Vincent said. He used the example of screening. So we know clearly that screening saves lives. We know clearly the places where the most lives are there to be saved. So you would think that if we have screening with CT scans that save lives, and we have low dose screening CT programs that need to be deployed, a cat scan machine, radiologist to read, American college of radiology accreditation and all of that, you would think that if everything was rational, we would see that these screening programs are more heavily deployed in the places where the most lives are to be saved.

Doctor Osarogiagbon:

But what we see is a total mismatch. So what you find is that the highest density of low-dose screening programs is in the places that have the lowest per capita density of lung cancer patients. That's like looking for your keys where the light is, not where you lost them. But that's not patients saying we don't want to be screened or not. That is social policies and organizations saying, this is where we're going to invest infrastructure to save lives. So I think when you begin to look at those kinds of examples, you see where the opportunity really exists.

Diane Mulligan:

I think that's very interesting, especially when we're talking about screening. I wonder if you think, all three of you, that that also would apply to clinical trials. Because we know they're the gold standard for many advances in lung cancer, and yet, in a recent report from the US food and drug administration on its 2018 drug trial snapshots, it showed that even though black and African-Americans make up 13 point four percent of the US population, only 5 percent are trial participants, and for Hispanic and Latinos, 18 percent of the US population, but less than 1 percent are trial participants. And we also know that that on top of, are the trials in the right place? Are the screenings in the right places? There's a complicated and very real history of minority groups not being treated ethically by the medical community. And that has contributed to a lack of trust, and some people would even say fear. So how do we approach this issue and make sure that all people have access to the very best options for lung cancer care. Triparna, you want to start on that one?

Dr Triparna Sen:

Sure. As you very rightly pointed out that there is some amount of fear and stigma. So I think one important factor is to develop a cultural competence for the healthcare providers. Because we need to understand first why communities of color are not participating in clinical trials. And then we need to acknowledge that mistrust. And only then that trust can build. And it is important in terms of clinical trials, because we know over 30 drugs have been approved by the FDA only in the last five years for lung cancer. And if the minority community is not participating that, they're actually missing out on standard of care and all these novel therapies, the targeted therapies and immunotherapies, that could be potentially lifesaving.



Dr Triparna Sen:

And there is an important issue, not just of communities as a whole, but when you consider intersectionality, like women in these communities. So when you consider that factor, that gap is even wider than the statistics that you've mentioned. So I think we not only need to identify the patients for trials, but also activate them, make them more aware of what these drugs are, what biomarkers and biopsies and all of that actually means and how that can be beneficial. So I think education would play a very important role. And then I think as doctor O was mentioning, at the healthcare institutions, at the social level, private programs that could launch culturally adaptive outreach activities, that can educate them about these new therapies and then take that stigma out of enrolling in these clinical trials.

Diane Mulligan:

Absolutely. I think that, that you hit on something very important is not only is there a fear, but there is a lack of understanding. Doctor Vincent Lam, you've seen this, I'm sure, when you were dealing with patients, where words like biomarkers and liquid biopsies and targeted therapy, it just goes on and on. Do you think medical educators or even family members and friends who have some medical terminology knowledge could almost work as translators, medical translators, or mentors? Do you think that would be helpful, and do you know of any programs like that?

Dr Vincent Lam:

Yeah, that's a great point. We like to say, for a lung cancer patients these days that are newly diagnosed, it's almost like they have to obtain a degree in molecular biology just to navigate their own cancer diagnosis. You can imagine how the effects of disparities really get amplified in a situation like this. So really our advances in lung cancer, in which we're able to really split the lung cancer pie so finely and have this precision medicine that's so wonderful for everybody, unfortunately it doesn't get carried away through for everybody.

Dr Vincent Lam:

So in terms of just being able to better interpret some of these terms and these test results, yeah. Definitely, having somebody who is able to translate will be very helpful. I'm not aware of programs that are already existing, but I think this is one area where we can really tap into patient advocate organizations like LCFA, and then even the specific lung cancer subtype organizations. So I've worked very closely with the ALK group, but also, each of these subtypes have their own amazing representative group that are super active on social media. So most everybody does have some access to the internet these days, fortunately. So maybe that's one easy way to get some of this information in underrepresented populations' hands in their native language, if they don't speak English, and being able to connect them with somebody whom they trust to help them navigate their cancer journey.

Diane Mulligan:

That's a very good point. LCFA has an entire podcast and a video on some of this terminology on the website, which is LCF America dot org. So doctor O, this is the hope with answers podcast. So I'm going



to ask you, do you think we have some advances? Have we made any advances? Are we making any progress? Is there any hope here?

Doctor Osarogiagbon:

Diane, you know the answer is, of course, yes. So we are in about the most exciting age in lung cancer. It's an age of rapid fire discovery. I mean, every six months there is a new drug, just about. A new biomarker or a new drug. The best treatment is a clinical trial. We say this as a mantra. We have said it for a long time, and when people have challenged us, we have now started producing scientific evidence to support that notion. Essentially, what I tell healthcare administrators who ask me, what's the purpose of research? I say, it's the opportunity to give tomorrow's treatment today. Especially when you're in an age of rapid fire discovery.

Doctor Osarogiagbon:

So the question is, what is the problem? Because that's where your solutions are going to come from. You have to understand the problem in order to be able to solve it. So let us first lay out the problem. In adult oncology. The scandal of adult oncology in America is approximately, we think, guesstimating, it's about five, six, maybe, percent of adult oncology patients who wind up in a clinical trial. that's the way it's been for many years. People will dispute that. Some people say if you count all the different types of clinical trials, not just therapeutic drug trials, maybe it's higher than that. Even maybe as high as 20 percent. In pediatric oncology, it's 60 to 80 percent of children with a cancer who wind up in a therapeutic drug trial. No wonder they have streaked so far ahead, right.

Doctor Osarogiagbon:

But we're talking about disparities. And yes, indeed, the challenge of disparities in access to clinical trials is horrible. Let me just give you a quick snapshot. Recently, we published a paper in JNCI spectrum. Joe Unger, who's done some dynamic work in this space and a number of our colleagues put this together. Where we looked at clinical trials that led to FDA approvals of treatments, and we categorize them as industry sponsored and NCI sponsored clinical trials, and then compare that to the population distribution.

Doctor Osarogiagbon:

So it was barely, what was it? Three, four percent of industry sponsored trials that had African-Americans in them. NCI sponsored trials, it was much higher. It was about eight, nine percent. But the population of African-Americans obviously is in the 12 to 14 percent range. And it didn't matter which disease you were talking about. Even when you were talking about prostate cancer, which is proportionately higher, more frequent in black people, you still have that relationship. Even worse, if you look at lung cancer trials, immunotherapy trials, and targeted therapy trials that led to approvals, it's actually consistently just about 1 percent of those people who have been blank. What's going on?

Doctor Osarogiagbon:



Okay. Let me give you some objective evidence of what's going on. If you asked the question, why is it that people don't wind up on a clinical trial? It turns out the most common reason is, there are no clinical trials in the place I seek care. So it's as simple as that. Sounds simple, but it takes actually measuring correctly to be able to see that. 66 percent of the time. And this is a meta analysis of 13 studies that were done at institutions that had clinical trials infrastructure. Which tells you that that 66 percent is actually a gross under estimate, because if you expand it to everybody, you will find that even more of those places that have no clinical trials infrastructure, of course they have no clinical trials. Who goes to those places? It tends to be the disadvantaged. It is rural, poor, racial minorities, gender, sex, minorities, and so on and so forth.

Doctor Osarogiagbon:

Now, another piece of that pie, about 20 something percent, it is that, yes, the patient is at any institution that has a clinical trial, but the eligibility criteria are so stringent, they disqualify them. So one of the areas that we have been working hard on with ASCO, the FDA, friends of cancer research, is to work with clinical trial designers like this and to say, look, this is not the kingdom of heaven. You don't have to pass through the eye of a needle to get to a clinical trial. You're going to do a trial, it's going to be successful, and then you're going to turn around and tell everybody to come get it? Why don't you make your clinical trials realistic in their eligibility criteria to match up with the population, right? So that's another effort.

Doctor Osarogiagbon:

Now, if you start with the segment where we have clinical trials infrastructure, we have a clinical trial and you are eligible. And you now ask, first of all, how often do people agree to go on a clinical trial when offered? It's well over 50 percent of people offered who will agree. And guess what? Suddenly, there is no racial difference. Gone. So if we're talking about solutions, yes, it's important to be culturally competent, it's important to educate patients and so on, but if I give you the example of my healthcare system, I've been in my healthcare system, Baptist, now for what? About 10 years? The health care system is about 110 years old. Our first oncology clinical trials were open a few years after I came here. This is the highest volume healthcare system in a high volume pathology region. So basically, the moment somebody walked in the door, they were guaranteed previously to have no access to clinical trials. You can educate them all you want. They will not get on a clinical trial.

Doctor Osarogiagbon:

And so, as you start saying, okay, we want review clinical trials access. Guess what you run into? The doctors begin to say things like, look, I'm in private practice. I'm not an academic oncologist. If I wanted to do clinical trials, I would have gone to Johns Hopkins. I am here at Baptist. Leave me alone. It's not the patient level. It's provider, institution, and our social policies that only now are beginning to encourage dissemination of clinical trials access. You wanted an example.

Doctor Osarogiagbon:



I'll give you the example of the NCORP. NCI's community oncology research program. Because all NCORP has done is said, okay, we know that there are all these research powerhouses, that see all those patients, and they do a wonderful job designing and executing clinical trials. But we know that it's only 15 percent of patients who go there. 85 percent go elsewhere, to community health care systems. So we are going to invest in the rollout of clinical trials, research infrastructure, in such places. And not only that, but they actually also specifically carved out certain institutions they call minority underserved NCORPs. I happened to be PI of one such. The Baptist system. That's what allowed me to be able to begin to build out infrastructure into Mississippi, Arkansas, and Tennessee, which were places that used to be research deserts. So those are some examples.

Diane Mulligan:

That's extremely hopeful, but at the same time, I'm sitting here thinking that so many of the people that are listening to this podcast today are patients. So my question to any one of you who wants to answer this is, this is called hope with answers. What can patients do to make a positive impact to advocate for themselves, or what can their family members do to advocate? Doctor O?

Doctor Osarogiagbon:

I will tell you real quick, the best treatment is a clinical trial. Ask about clinical trial, and if the guy tries to talk you out of it, go get a second opinion.

Diane Mulligan:

I love that. I love that. And what about if you're in a situation as a patient or a family member, and you see a situation in your community where you think people are getting substandard care? What do you suggest they do? Who should they call? Dr. Triparna Sen, any ideas on that?

Dr Triparna Sen:

I think first they should talk to, though I don't see patients, I'll say that, but I think they should talk to their primary care doctor, and then seek help from specialists if they have access to a comprehensive cancer center. And as Doctor O rightly pointed out, go and talk about clinical trials to that comprehensive cancer center. And I think there are some large organizations, like yourself, that are designed for everyone living with lung cancer to have those resources. And as Vincent pointed out, there is social media.

Dr Triparna Sen:

But there are minority specific organizations who actually the advocate for these disparity issues, and there are several websites out there. And another place is lung dot org, which is American lung association. They put out the state of lung cancer every year, and there is a special minority disparity section on that page that gives you resources. So I think going to these webpages will give you a basic idea, but I think there are minority driven websites and resources that are available right now, because



disparity is now a huge issue, and people are getting more and more educated about this. And I think there are resources out there.

Dr Vincent Lam:

Yep. And Diane, if I may, just to briefly circle back on some of the organizational and systemic changes that need to be made to help affect and improve this problem. This is hope with answers, right? And so along with the NCI NCORP program that Dr. O. Has mentioned, that's truly needed to try to improve the ability of, and the infrastructure of sites in these upper underrepresented areas to run clinical trials. Hope also looks like some of the other changes that are afoot, which include, for instance, this trend towards allowing more remote consents for clinical trials, and also trying to decentralize our clinical trial procedures and assessments.

Diane Mulligan:

Also explain what a remote consent means, just for somebody who's listening and might not know what that means.

Dr Vincent Lam:

Absolutely. So oftentimes, because a clinical trial is a formal study, you do have to, if a patient is interested in participating in this study, they have to give formal consent. And that is done by signing an informed consent document, which outlines what the trial entails and what the potential risks and harms may be, and then what the potential benefits are.

Dr Vincent Lam:

And so oftentimes this is required to be done in person. But as we know, participating in a clinical trial requires a lot of logistics, including things that people overlook, like expenses of transportation and parking, and maybe I work during the day seven days a week, I can't actually go take some time off. Or at least I want to try to minimize my time away from my work, because I need to keep my health insurance to participate in this trial. So being able to do as much of the clinical trial procedures, including consenting, including maybe blood draws, that you can actually get closer to home, as opposed to having to travel again to your academic center. All of these are part of the answers to try to really roll out more of these programs in areas that people really need the most.

Diane Mulligan:

So what I hear from each one of you is that there is hope, and that we are making strides to move forward with people of minorities, ethnic backgrounds, who maybe before weren't thinking about this. I know there's a lot more to do, but do you think... I'm going to go back to you, Doctor O, because we talked about this at the top. Do you really think we're making the kind of progress that we should be making, or do you think that we have a long way to go?

Doctor Osarogiagbon:



We're making progress, but we have a lot to do. Because we have not tackled this problems comprehensively in the past. We were really blinded previously to the enormity of the impact. So I'll give you one example. One of the things that I noticed is that pharmaceutical companies are beginning to wake up to the fact that there is no business case to be made by locking out whole segments of your potential market. One of the things that, in the past, maybe they had a pass where you prove your drug worked, and then you could go use it for everybody. But now the FDA is beginning to ask questions. Because we're beginning to see that we are missing huge opportunity. I'll give you two very specific examples.

Doctor Osarogiagbon:

Again, immunotherapy, big game changer, Nobel prize won because of immunotherapy just a few years ago. It's transforming all of oncology. Not even just lung cancer. The clinical trials, it was only about 1 percent of people who were black. Now, as we're analyzing large data sets, we're finding that black lung cancer patients actually derive a greater benefit from immunotherapy than other racial groups.

Doctor Osarogiagbon:

So what does that mean for a pharmaceutical company? Well, if you knew that early, maybe it would have cost you less money to run your clinical trial, and maybe your results would have been better, and maybe your market share would be even bigger. So people are beginning to wake up to the fact that health equity, and this is my real key take home point, it's not doing somebody a favor. It's not altruism entirely. It is actually at the heart of our self interests, no matter who we are, because it's not a zero sum game.

Doctor Osarogiagbon:

Whether we are a body politic or an institution that is rewarded for providing high quality care or a provider who is rewarded for encounters with patients, or a pharmaceutical industry that wants to sell you highly effective treatments. What's there not to push for? We all stand to win by expanding equitable access to high quality care.

Diane Mulligan:

And I think that's a great take home, is that we all stand to win from having discussions like these and looking for opportunities. Yes. Doctor Triparna Sen, go ahead.

Dr Triparna Sen:

I'd just like to add one point from the research perspective, and progress that I've been seeing is that there's a lot more funding and grants now dedicated towards research in health disparity. And I think that's a very important step in the right direction, because earlier, people used to not have so much research capital to be dedicated into analyzing these political sample data. Like the data that you're getting that the black people are actually, they are responding well to clinical trials. And so now I think there's a lot more drive, not just from the NIH, but also from private institutions that fund lung cancer,



that there are funds dedicated to the disparity studies. And I think that's a really step in the right direction. And I think that will help a lot for lung cancer researchers now to go back and do those kinds of studies and to have more data to convince people that this is actually an area that can be improved a lot.

Sarah Beatty:

So the bottom line is that there is hope, and we are making strides, but we still have a long way to go.

Diane Mulligan:

Yes, what I realized is that, as a patient or patient advocate, we each have the power to make a difference in health disparities by educating ourselves on the steps to take, asking our doctors questions, and looking for information on websites like LCF America, to get the latest information.

Sarah Beatty:

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Diane Mulligan:

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