

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Impact of Disparity: Navigating Treatment Equality in Cancer Care'

Description:

In this episode, we sit down with Dr. Bilal Abid from University of Texas Health Science Center in Houston to discuss how healthcare disparities have an effect on cancer care — especially when it comes to cutting-edge treatments such as stem cell transplantations and CAR T-cell therapy. We discuss how race, socioeconomic status, education, and geographic location can determine a patient's access to cancer care. With travel, insurance, and systemic barriers in the mix, we explore what patients can do to navigate these challenges, and how treatment centers and policymakers are contributing to ensure equitable access to care for all patients.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today, we will be speaking to Dr. Bilal Abid about healthcare disparities. Dr. Abid is a clinical researcher in the Medical Oncology Department at the University of Texas Health Science Center in Houston, Texas. His research interests include CAR T-cell therapy, stem cell transplantation, adoptive T-cell transfer, cancer immunotherapies, and infectious diseases.

We also recently spoke to Dr. Abid about CAR T-cell therapy on our first episode of our video podcast, *Bloodline Breakthroughs: Innovations & Inspiration*, so be sure to check that out using the link in the show notes. Welcome Dr. Abid.

Bilal Abid, MD: Hi, Elissa. Hi, Lizette. Thank you for having me again.

Elissa: So nice to have you back. So, our episode today is on healthcare disparities or gaps in healthcare. Could you explain to our listeners what that means?

Dr. Abid: Disparities from an aerial view means differences. Now, differences can happen in general life where one day sort of spill into the healthcare sector. When we use this term healthcare disparities, to put it simply, it means that there are measurable, tangible differences in healthcare outcomes between populations that are preventable.

Elissa: So, essentially, patients of all different types aren't necessarily getting the same access to healthcare?

Dr. Abid: Pretty much what it means. That's right, Elissa.

Elissa: So, before we get into healthcare disparities, when you and I first talked, I could tell you were very passionate about this topic. Could you tell us a little about your background and why you are personally invested in addressing healthcare disparities?

Dr. Abid: Interesting question. So, since you asked this question, it occurs to me that it probably had to do with my upbringing and the community that I grew up in, the travels and places I lived at with my family growing up, probably drove that inclination and sort of affinity towards doing work in underserved communities when I grew up.

So, I was born in an urban coastal city of Pakistan, which is in Southeast Asia. Then I did elementary schooling in East London. Then I did part of my high school in a southern state of America, which may not be ethnically diverse, in a small town in Mississippi.

Elissa: Oh.

Dr. Abid: I went back to attend medical school in Pakistan, and then I returned to America, started part of my residency in a uni-town urban setting in Pennsylvania. The East side. And then went to Singapore for additional research and clinical training. Lived there for a number of years and was exposed to this very distinctive type of healthcare infrastructure – sophisticated, streamlined, high quality, and high-efficiency type of healthcare infrastructure.

At that time, I got married. My wife and I, driven by some laboratory research passion, decided to move to a city called Bristol in the Southwest of England, very close to Wales and also next to the City of Oxford. And I was inexperienced as well. We lived there for over a year at uni in Bristol, and that was part of my clinical training as well there in hematology and cell therapy. Then we moved to the Midwest, in Milwaukee, Wisconsin, and lived there for a number of years before coming down to Texas.

So, I grew up in different cultures because of my father's profession, different places. I got to experience diverse cultures, and I understood a couple of things there. First, people bring in their distinctive attributes to a community, to a neighborhood; and each one of these distinctive stories that they bring in, their family, their nurturing, their backgrounds strengthens our community, our society. But at the tail end, all of them deserve same healthcare, irrespective of several other determinants that we talk about all the time. So, that's one thing that I noticed firsthand.

A second thing was, when I was in second year of medical school in 2005, and there was a large, ginormous earthquake in the northern areas of Pakistan, and I got to go there and help out firsthand. And then, when I started residency in my intern year, there was an earthquake in Haiti. I couldn't go there in person, but I did some work staying back in Pennsylvania, some groundwork in logistics and stuff and support. So, I think since you asked, it does occur to me that nurturing and growth in the communities you're exposed to, do end up driving your passion and future activities, really.

Elissa: Yeah. I can see that all of those different countries and areas have very different healthcare systems, so I'm sure they have definitely different levels of access for patients that need healthcare.

Dr. Abid: That's right. That's what I learned.

Lizette: Yeah, and every country must do it in a different way. In the United States, really getting into healthcare disparities, since we do have a lot of different people that live in the United States, different races, different ethnicities, so with healthcare disparities, what are different ways that people may have disparities when getting cancer care?

Dr. Abid: Sure, so again, historically, we know that groups of people and communities have had less than others. In terms of education, socioeconomic status, insurance coverage, and even a sense of belonging, such a basic need.

And we look at, from an aerial view, there are parts of the world which struggle for clean water, housing, education for girls, just some very basic fundamental requirements. So, now when we talk about disparities in healthcare and specifically in cancer, there are reasons why these exist. The large regions could be bucketed into lack of understanding, which means enough research has not been done and disseminated to learn what those are.

Second is practice and policies. So, once those have been learned, just the gaps have been identified, practices and policies have not been made to address those. And then if they were made, they have not been put into practice. So, I think this type of a triangle office is important from an aerial perspective, that disparities in cancer care exist. We know that. there's enough evidence now based on gender, orientation, age, race, ethnicity, insurance coverage, neighborhood in which one might reside, federal poverty level, disability, educational status. So, disparities exist in different varieties, different formats. And each needs to be addressed in a strategic manner separately and so our policies can be made accordingly addressing each one of them.

Lizette: And since you've lived in so many different parts of the United States, you've probably seen firsthand the differences just within the different regions that you've lived in.

Dr. Abid: That is very true. We can see that there are communities, counties, and states or residential areas that fall below a certain federal poverty level, are populated more by a certain race or ethnicity, and/or may be populated more frequently by a certain education level, which is below a certain education status. We would identify through research that those communities would not have equal access to healthcare.

Lizette: And are there certain groups that are more likely to experience these disparities in healthcare?

Dr. Abid: Ethnic minorities, non-Hispanic African Americans, as we call them when we do our research.

Lizette: Okay.

Dr. Abid: Hispanics, Asians, folks who do not have education beyond high school, folks who fall below the federal poverty level, folks who don't have commercial insurance. We could talk more about how Affordable Care Act (ACA) with the Medicaid expansion really helped curb some of those access issues directly and impacting population at large. That's a great example of how policy changes can directly impact healthcare outcomes and bridge these healthcare gaps.

Elissa: How did the ACA and the Medicaid changes help bridge those gaps?

Dr. Abid: So, a good example is our policymaking and policy changes impacting healthcare outcomes at large and at the grassroots level is expansion of Medicaid through the Affordable Care Act. We saw that that policy chain directly impacted healthcare outcomes by increasing access to healthcare homogeneously across race and ethnicities. It allows access to insurance to more and more populations and individuals.

Lizette: I'm really glad that we're having this discussion with healthcare disparities because a lot of times people talk about inequality or disparities just when it pertains to other types of socioeconomic issues. But I don't think that people realize we're all patients when we go into our medical appointments. We don't always realize that these disparities can really impact us within the healthcare system. It's not something I don't think that is top of mind for folks, so I'm really happy that we're having this discussion so we could recognize that this might happen; and I know in our conversation we could talk about certain things that can help us realize what we could do if this does happen.

Dr. Abid: I'm glad that we're having this conversation here because I do think this is an important conversation; should be conducted on and on repeatedly, get the message out; allow people to understand that healthcare disparities exist. We want to talk about them, and I am thankful to LLS for conducting this very important conversation.

Elissa: Yeah, absolutely. And I can say as being a part of the young adult cancer community and young adults with cancer are very much facing healthcare disparities. And I had recognized that even though I seemed to have an easier time, I still had some difficulties. But a lot of my friends with cancer were having very difficult times. They were living much farther away from the hospital than I did. They couldn't find rides. They couldn't get there. They were having insurance issues. They might have lived very, very far away from home or family; and so even if you're in that community and not experiencing those difficulties yourself, you can still see that other people have experienced real difficulties with getting the same access to care with the same diseases. And so, I think it is really good to talk about and recognize what other people are going through, even if you haven't gone through that same thing.

Now, I mentioned in the introduction that we recently spoke to you about CAR T-cell therapies on our video podcast; and you were also highly involved with other cellular

therapies like stem cell transplantation. Could you discuss the disparities patients may face when getting these types of therapies?

Dr. Abid: Sure, sure. Elissa, you made a great comment; and, I want to quickly just add a point to that. When we talk about CAR T, ASTCT, NMDP, so ASTCT is American Society of Transplantation, and NMDP is National Marrow Donor Program. They have this joint initiative called ACCESS Initiative. They did some research, and they actually showed that non-Hispanic African Americans are less likely to have access to CAR T-cell therapy; and one of the reasons identified was they're more likely to live farther away from the treatment center. You alluded to travel, and that was one of the things which is very clearly identified.

Elissa: Absolutely, because when we're looking at CAR T-cell therapy, right now, is it really only at the very large cancer centers or research institutes?

Dr. Abid: That is correct. It's available only at larger academic centers in a 30-story building and so on. And even the small/medium size academic centers are unable to onboard a CAR T-cell platform just yet.

Elissa: So, what happens when somebody may live say, several hours away or on the opposite side of the state or a state over and they need CAR T-cell therapy or stem cell transplantation?

Dr. Abid: It does two things. So, one is, it increases the financial burden. It increases the caregiver burden. Imagine me in need for a transplant. My treating doctor has already determined that CAR T-cell therapy or allogeneic transplantation is the next-best therapy for me, which will prolong my survival. I have to get a loved one to come with me to travel 120 miles to get to the center, stay there for a number of days, sometimes weeks and months. Majority of the times, at least a month or so; and bear some out-of-pocket costs for that lodging and boarding and transportation while I'm away from home.

Caregiver also not working, so that's a financial burden. Caregivers' availability. And I think that all of this put together is enough of a toll on one individual that a lot of times folks might just think, maybe let's just not do it.

And that will directly impact their survival. So, there's a clear link between access and survival outcomes. If we identify that certain racial or ethnic groups or minority groups or education groups, socioeconomic groups that have less access to life-prolonging or potentially curable cancer treatment, and we do identify that some of these have less access to those life-prolonging curable therapy, then we're clearly saying that if they don't get access to it, their survival is going to be shorter. And that is disappointing. That's something that we all need to work together towards a common goal.

Lizette: Yeah, and even with our blood cancers, there have been studies in regard to healthcare disparities that have said that there have been certain populations that are not really educated about clinical trials. And for our blood cancers, clinical trials are a very viable treatment option. It's not just an option after you've tried other things. It could be an option even for first-line therapy for patients, and it has proven to be very beneficial for many patients to be on a clinical trial.

But there's been studies that have found that a lot of our patients aren't even given the choice of a clinical trial. So, is that something that also impacts certain populations and makes more of a gap there in treatment for certain folks.

Dr. Abid: Absolutely. Sometimes it's the stem of the problem. Lot of times, actually. So, if minority groups are not included into a clinical trial, then once that product or drug or platform gets FDA approval and become commercially available, the practice also mimics the trial design.

So, invariably, what happens is if clinical trials are not inclusive, it impacts clinical practice downstream. Hence, this recent initiative and national drive to make clinical trials more inclusive is imperative. It should have happened long time ago. But to

make the clinical trial designs more homogenous, more inclusive, is just something that, we just can't live without.

Lizette: So, what comes to my mind also is implicit bias when I look at that example of clinical trials. Could you speak to that a little bit about implicit bias and how that can be an issue and actually cause more disparities within healthcare?

Dr. Abid: Great question again. One of the things in cellular therapy landscape and getting access and impacting outcomes is early referral to the treatment center. Multiple studies have identified in transplant setting, and more recently in CAR T-cell setting, independently, that outcomes are inferior and access is also lower in ethnic minorities because the referrals are not made in a timely manner.

One of the reasons could well be the implicit bias that exists within all of us, that we constantly need to keep working on, that when the referrals are made homogeneously in a hypothetical world where nobody had any implicit bias, then they would be referred early to the treatment centers, irrespective of any type of status that they have, any race or ethnicity they might belong to, they would be referred and plugged into care early.

Now, the other thing, obviously, is that you have CAR T outcomes and access and decreasing time to apheresis, improving CAR designs and so on. But I think implicit bias does play a role into access issues.

Elissa: Yeah. Now, with all this discussion of these incredible treatments like CAR T-cell therapy, stem cell transplantations that are so effective for many blood cancers and then clinical trials, it's hard to think about all this amazing research being done and then patients not being able to access it for whatever reason – for insurance coverage or travel, or just being able to get to the treatment center. I mean, it's so good to be able to talk about these things so we can really see what we can do to affect the change.

Dr. Abid: Absolutely. We could never talk about it enough times.

Elissa: Yeah, so you mentioned then that, patients will sometimes say, “Hey, it’s not worth it for me to go do this treatment. I can’t do CAR T-cell therapy. I live too far away” or “It’s too much of a burden on my caregiver.” Is there anything that’s being done by the treatment team or the hospital or even government policy like you mentioned to help address these disparities?

Dr. Abid: Well, at the institutional level, we can certainly say that almost all majority academic centers have created some degree of philanthropy. Charitable houses like Ronald McDonald Houses® have been created close to the medical center for folks to come in and receive their transplant, CAR T-cell therapy at, no cost – logistics, boarding, lodging.

They have some degree of emotional support as well. There are support groups that they get plugged into. But I would still call them ad hoc. Things still need to be done at the policy level, at the federal level, universal insurance coverages for life-prolonging therapies, policy change translating into practice change.

There are initiatives by American Society of Transplantation Cell Therapy, American Society of Hematology (ASH), and they are continuing to work with the Feds (United States Federal Government). We hope that things become more homogeneous in the very near future.

Elissa: Several years ago, I went to Australia; and I met with the Leukaemia Foundation over there. And because they have a universal healthcare, they have a very different healthcare system over there. So, the Leukaemia Foundation was there to of course, raise money for research but also spend their money on helping patients get that access to care. So, they had worked with partners to build, essentially apartment buildings to be able to get people there. Because if you think of Australia, you have this whole wide swath of land, and not very many large cities that will have those treatment centers there. And so, people would come from 20 hours away to be

able to go to their local centers. So, they had to provide these ways to get people there and allow them to be able to stay.

And so, it was fascinating seeing the differences between Australia and the US in how they're able to reduce those gaps for those people that live so far away from the treatment center and make it easier for their caregivers. The whole families could come with them, their children, and stay in these apartments that were very close to the treatment center. And they'd work with them to be able to get that care.

Dr. Abid: Absolutely.

Lizette: Yeah. And now that we know that hospitals and government agencies, as well as advocacy organizations can really try to help and close those gaps for patients and caregivers, is there anything that patients and caregivers can do if they do experience these types of disparities?

Dr. Abid: I think that it's important for them to be proactive. It's important to know that this is something which is happening. Know the treatment options that are available. For example, if they are unable to access CAR T-cell therapy, they could certainly well be candidates for bispecifics, which are readily available, and they're there when patients need it.

So, education empowers. So, I would say be very well-informed and identify if they're experiencing disparity, bring it up to their team and their nurse navigator who's working with them and know alternate treatment options that might be there. I mean patients are already very well-read these days, lately. But it's important to bring these issues up if they do experience such a situation.

Lizette: Yeah, and that's why we continue doing what we're doing. We want to empower patients and their caregivers to be able to ask questions, to give them questions, to give them that information so you feel like you can ask questions.

One of the biggest things from most of our programs is when patients and caregivers let us know that we've informed them of another treatment or we've informed them of another support service that they didn't know about, so they can go and ask about it and have more treatment options.

Dr. Abid: Absolutely. Absolutely.

Elissa: So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to patients and their loved ones who may experience disparities to give them hope after a diagnosis of cancer?

Dr. Abid: I want to assure them that all clinicians and clinical investigators are driven towards curbing disparities. Substantial work is being done in researching disparities in transplant and CAR T-cell setting. I can tell you that we, last year published large CIBMTR analysis, over 100,000 patients, time-trend analysis, and we showed that overall survival has improved over time across all races, across all ethnic minorities, as well.

The utilization has increased among non-Hispanic African Americans, among Blacks. But we do need to do some work in allogeneic transplant setting to improve outcome amongst Black. But certainly, there is evidence that things are moving in the right direction.

At the national hematology and oncology society level, this is one of the major topics that are discussed across all national meetings. American Society of Transplantation Cell Therapy Meeting is upcoming next month in Hawaii; and there's a dedicated half-day to specifically discuss this ASTCT/NMDP ACCESS Initiative.

Specifically in transplant, we know that, that folks of European descent have a much higher chance of finding a donor as compared to ethnic minorities. But, good news is that unmatched haploidentical, called haploidentical donors, which are sort of HLA-



disparate donors types, have really started to do exceptionally well lately; and that gives a lot of hope to our populations of ethnic minorities.

So, I want to give listeners the hope that we as clinicians and investigators are committed to researching, keep working with policymakers in curbing those disparities. And as you can see that The Leukemia & Lymphoma Society is committed to doing the same by keep talking about this. The more we talk about it, the more we discuss this, the more impact we can cumulatively create.

Elissa: Absolutely. Yes, we can all work together to make sure that patients are getting equal access to care and getting the best possible outcomes.

And so thank you very much, Dr. Abid, for joining us again for our program; and we really appreciate you, talking all about this and making sure people understand the issues that are faced with trying to get access to care and how we can all work together to make that better. So, thank you so very much for being here with us.

Dr. Abid: Thank you, again, for having me Lizette and Elissa. It's great working with LLS.

Lizette: Thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out our Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.



In addition to the Lounge, we could use your feedback to help us continue to provide engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you, and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email TheBloodline@LLS.org.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. These links and more will be found in the show notes or at TheBloodline.org.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.