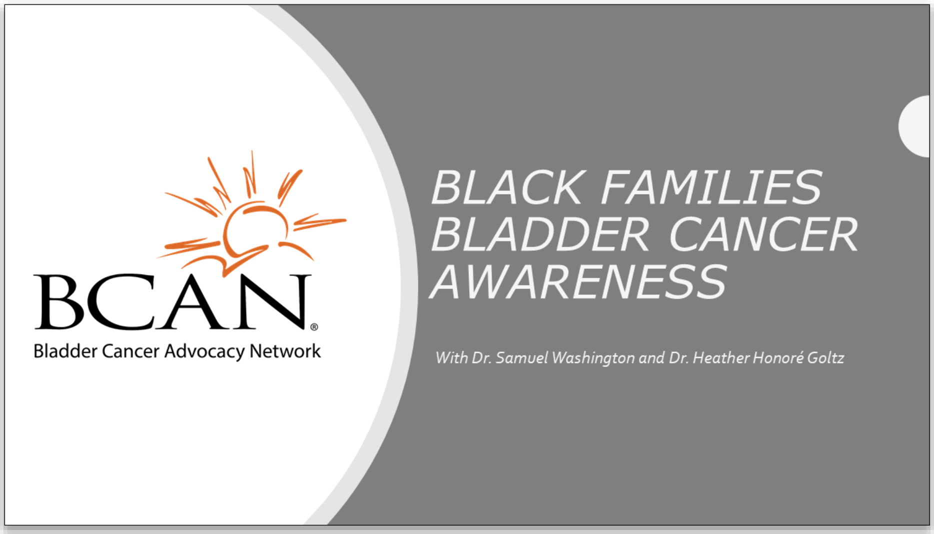


BCAN Bladder Cancer Advocacy Network

BLACK FAMILIES BLADDER CANCER AWARENESS

With Dr. Samuel Washington and Dr. Heather Honoré Goltz

Question and Answer

Stephanie Chisolm: Thank you so much, Dr. Goltz and Dr. Washington. I think this is a really great discussion and I invite people to turn on their videos now at this point if you'd like to. If you could keep your audio off, unless you have a specific question, but there are a couple of questions that have been submitted. Again, I welcome everybody to participate and to share your experiences.

This has been really enlightening in that I think we have seen some gaps, some resources that maybe people don't know from the psychosocial and social determinants of health, as well as from our general understanding. **I would like to just open it up for Dr. Goltz and Dr. Washington, as you were putting this together, was there anything in particular that surprised you?**

I know it's a trick question. Or is there something in particular that really pains you because you knew it and we know this and why is it still happening this way? What is it that struck you like that? Maybe didn't surprise you because you know this, but what are you surprised hasn't changed?

Dr. Goltz, why don't you start?

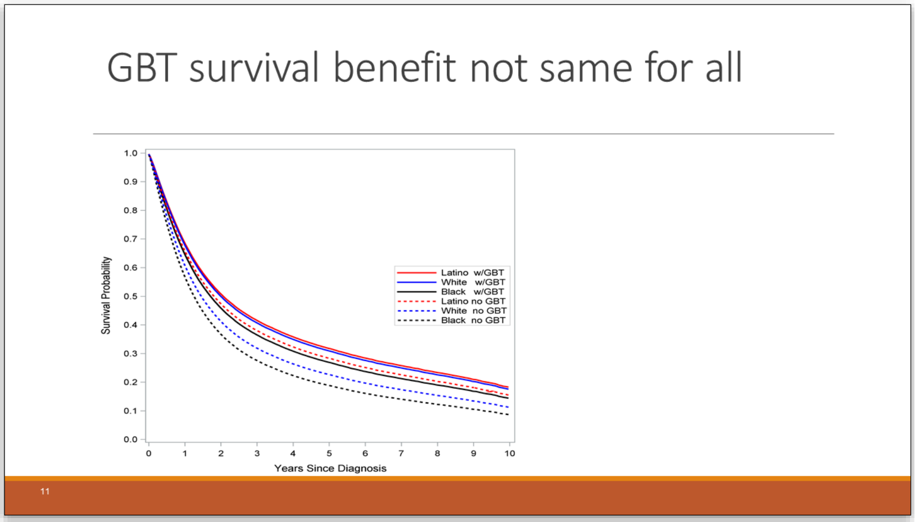
Dr. Heather Honoré Goltz: I'm always pained, that's a good word for it. I'm always pained. I came into bladder cancer research in roughly 2008, so we're well over a decade later and the stats really aren't changing for Black people in America, they really aren't. I literally, if I could talk to my 2008 self, I'd be saying the same thing to her that I'm saying to you now, and that's both surprising, but unsurprising. We need to do more.

Dr. Sam Washington: I think in researching and looking at this and other studies, we have a clear sense of what we don't know in that we use cancer registry data, which gives us a broad overview of what's going on. And we can try to drill things down to the facility, but when it comes to specifics, how long it takes for someone to get diagnosed after a hematuria evaluation, we know broad ideas that there are differences there, but it's hard for us to drill down the drivers.

And some of that's just due to the type of data that's available and the type of data that's available on a broad scale. So I could say drivers are things that may be impacting care locally from an anecdotal standpoint or a single institutional standpoint. But we don't have that granular data from multiple centers across the country showing a clear breakdown of that pipeline from diagnosis to treatment to survival for each facility. And that's where we need to get to, because that's really when people ask, "Well, how do you intervene to change some of these differences?"

You need to know where the potholes are and broadly we have a sense, but we don't know specifics. And that's the same across multiple diseases where we see similar disparities and we've described them quite well, but not all the potholes. So intervention becomes that much harder.

Stephanie Chisolm: I did want to just pop up a slide really quick because I felt like this slide that you showed, Dr. Washington, where you were really working at guidelines-based treatment and the survival benefit. If it's following guidelines, what are your thoughts on, **"Should we be looking at specific guidelines, changes to the guidelines? What's going on that you think that the Black Americans with bladder cancer don't do as well as Latinos who aren't even getting guidelines-based therapy? What is going on there and where do we need to focus a little bit in the future?"**



GBT survival benefit not same for all

Dr. Sam Washington: I think this analysis mirrors a lot of what we know, which is that when we look only at our clinical data and broad proxies for socioeconomic status and social determinants of health being access to quality care, access to timely care, and then all of the other social factors that are not included on our cancer registries, it tells us that there's something else going on. And I think that's the highlight from that slide. And I think it really takes more nuanced, drilled down, mixed methods type studies to really get at that.

But I think also understanding that what happens at say San Francisco VA may be different than what happens in Baylor or UCSF for that matter. So some of these specific factors to each institution are going to be the things that make up that difference, and that's just the part that we don't have a clear sense of yet.

Dr. Heather Honoré Goltz: Okay. To piggyback on that, the slide where it's got that figure about what's happening in the community and those social determinants of health, these academic cancer centers and hospitals don't occur in isolation. So a lot of those social determinants that happen in the area around those hospitals can help us in terms of explaining what's going perhaps with those disparities in access or the outcomes from guidelines-based treatment versus non. We've described bladder cancer quite a lot.

I echo Dr. Washington's sentiment that it's time for intervention, but we really need to be looking at what is happening in Black lives within communities that forms those potholes or how Black America intersects with those potholes that may prevent them from timely acquisition and access to care of guidelines-based treatment.

Stephanie Chisolm: Jim, you just raise your hand. Do you have an additional question?

Jim: Thank you so much for this, and I apologize, I'm in my car. **But I wanted to ask doctors, in your research and in your studies, have you had anyone, and I do have more information on this either way you reply, address the implicit biases that exist amongst doctors?** And all of us are born with biases, so I'm not picking on anyone or anything like that, but I have some real case information here from Physician's Weekly and from the National Academy of Sciences where they are studying this and looking at it.

Because they have pointed out in the Physician's Weekly where African American, Black patients are going into emergency rooms and are less likely to receive painkillers as someone Black who goes in. So I have to believe that someone coming in with bladder cancer who is of color may get treated differently than a White person coming in. So could you speak to that please?

Dr. Sam Washington: I guess I can start as a clinician. I definitely acknowledge that there are a lot of studies looking at this, looking at pain management and long bones fractures, cardiac or angio catheterization in patients with cardiac symptoms. Looking at maternal mortality rates and looking at these things that often we broadly try to attribute to the individual, but really are more attributed to the health system in which I consider myself part of that system.

So I think that's definitely something that is... the impact of that is misattributed to the patient when it should be explored on the health system and provider side. Now, I think the way to get to that is complicated, and some of that we can clearly see just with discussions of structural institutional racism within our country broadly, but also that is in our own backyard. Now you're talking about other urologists and implicit biases, and that takes a level of, I think, insight and comfort with uncomfortable situations.

And I'm not sure we are there yet as a group, but we are working towards, because it's a definite impact. And I think that's a part of the thing that you can't measure in a cancer registry that always gets missed, but should be discussed. And it shouldn't be the last sentence of a discussion section of a paper, it should be the whole paper, if that makes sense. But the best way to get to that, I'm not sure yet.

Dr. Heather Honoré Goltz: We have a lot of information not just from Black and Hispanic and LGBTQIA+ populations about how they interact with medical and health and allied health providers, and how that leads to medical mistrust, lack of confidence, decisions to forego care in certain institutions. I can tell you that a lot of the institutions that I'm involved in, and of course these conversations happen, are happening all across the country in terms of how do we do cultural and linguistic humility?

Not just competence, but humility training, where providers admit that they are not experts and they need to listen actively to patients and create more of a welcoming open space. But these conversations should not be one-off, they should be ongoing and policy and procedures need to follow these conversations, so that these are safer places for people of color and people of various other identities to be able to enter these spaces.

But we have decades of research that of course says that implicit bias impacts whether people either receive guidelines-based treatment or feel comfortable interacting and accessing care in a lot of settings.

Stephanie Chisolm: Rick, I know you had a couple of questions that you had submitted. Do you want to summarize and maybe get to some key points that you'd like to hear from Dr. Washington or Dr. Goltz?

Rick: Yeah. For Dr. Washington, the guidelines are clearly very troubling. **So do we have any granularity on what's driving the specifics of the guideline problem?** If we knew that it was a timing issue or that there was a specific treatment not being chosen, what's the level of granularity? And maybe there isn't yet enough granularity and it needs to be studied, but I was curious as to whether or not there was any guidance you could provide on one click down from guidelines.

Dr. Sam Washington: Yeah. I would say that it's all of them actually. I guess the approach that's commonly taken, and it's a way that even I use to wrap my brain around it is, we'll look at one factor. So we'll look at just race and control for everything else, or we'll look for timing of treatment and ignore everything else. So we have clear definitions of someone should get treatment within 90 days of diagnosis and we see outcomes that are worse after, or we'll say, "Rural patients have this."

But the issue and the difficulty with that is it's really not just one factor, it's factors layered upon other factors. So if you look at guidelines on how to interpret and report healthcare disparities that were put out by a combination of AACR, ASCO, and other groups, it's really the multi-level interactions between all these that ends up with what we see. So I'd say the long-winded answer is basically... Or I guess the short answer would be we distill everything down to one factor.

But we can't really do that because then we're going to miss all the others. So I would say from the question in the chat where it mentioned things like timing, time for cysto, time to chemo, time to cystectomy treatments, all of these things tie into one another, and that gives you the end result that we see. Does that make sense? So I wish it were just timing of diagnosis to treatment, but unfortunately there's more factors there.

Rick: **I had a question for Dr. Goltz on the distress research and whether or not that it had been done for high versus low grade or a little more specificity, one click down from non-muscle invasive and muscle-invasive, kind of before or more stage kind of breakdown?**

Dr. Heather Honoré Goltz: That's a great question. The answer is, not really. We got a little bit more detail from the qualitative components and what we found in just analyzing across those interviews really was, if you had higher grade, you were much more concerned and distressed than if you had lower grade. But that really needs to be followed up with quantitative surveys and really true mixed method studies that would specifically look at that question.

Part of what's happening is, and Dr. Washington and I have talked about this a lot, is that the field of bladder cancer research started as a very epidemiologic-based field. And that's how many new cases, how many deaths in the five-year, 10-year survival rates, et cetera. That's a very epidemiologic type data and sets of questions. Only over the last 10, 15 years have we really begun to ask the questions related to access to care, quality of life, symptom management and so on.

And so, our science within bladder cancer in terms of these types of questions is still in its infancy and the tools that we use as researchers, we're still growing them. So the skills that it takes, the methodological skill it takes to design studies that can really do those nuanced multi-layer, multi-systems, multi-dimensional studies at one time is really complex and it really takes an interdisciplinary team of researchers to do that work properly.

One of the happiest days of my life as a researcher, NIH just announced that they're looking at just they're going to fund these types of studies. They're doing a call right now to look across systems, across dimensions at that kind of data and begin to be able to help answer just the questions you all are asking today for people of color. And so, a number of us are talking about it, but how to respond to that. But the next three to five years are going to be extremely enlightening in terms of that granular detail, Rick, that you're talking about.

Rick: So I know what a couple of you are going to be doing after you get off the call!

Stephanie Chisolm: Well, thank you all so much for joining us. We really appreciate your expertise, Dr. Goltz and Dr. Washington.

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