Innovating to Improve Patient-Centeredness

November 9, 2021 | Transcript

Sarah Dash:

Dr. Barr managed development teams in oncology and infectious diseases and became therapeutic area ahead for infectious diseases in 2013. In 2016, Dr. Barr was appointed a senior vice president in charge of global clinical development of preventative and treatment approaches to infectious diseases at Merck. Dr. Barr, thank you so much for joining us today and I'll turn it over to you.

Dr. Eliav Barr:

Well, thank you very much for the invitation. And I also wanted to extend my welcome to the Alliance for Health Policy's Advancing Patient-Centered Cancer Care Summit. And on behalf of my colleagues at Merck and the Merck Foundation, we want to extend our appreciation and thanks to you and to the entire Alliance for Health Policy team. We also would like to thank doctors Debra Barton and Christopher Friese of the University of Michigan School of Nursing who co-direct the Alliance to Advanced Patient-Centered Cancer Care National Program Office.

Now like many of you, I've seen cancer strike my own family. My mother had stage three Merkel cell cancer which required extended surgery, chemo and radiation therapy. And the impact of the diagnosis was devastating, especially because we were so worried about the prognosis. But we were very lucky to have extraordinary support from a multidisciplinary team at each stage of the workup, treatment and follow monitoring.

And I must say she ended up returning back to normal existence with a lot of support from folks. And I recognize that this sort of high quality care may not be typical. And that's why I'm so excited about participation in this event. Today's conversation presents an important opportunity to explore ways in which we as a community that includes healthcare providers, policy experts, patient advocates, and researchers can better support all people living with cancer and meet their needs.

These needs go beyond the medical care that patients receive. We're all well aware of the social and structural determinants of health and their impact on whether patients receive the high quality care they deserve. This includes, but not really limited to access to nutritious food, reliable transportation to doctors visits, psychosocial and mental support during treatment and other important factors.

And as you know, patient centered care begins with asking patients what they need and what they want, listening to what they say, understanding what we hear and then taking action to respond. We need to do this on a one-to-one basis with individual patients while also building stronger and more responsive systems for providing care. Now, I wanted to turn my attention to COVID-19 and cancer care.

I'm sure you'll agree with me that the past 18 months of the pandemic has really been challenging for all of us, and certainly for those living with cancer. Last year, many services were closed and routine visits and screenings were canceled or delayed and that means that many patients did not get the care they needed when they needed it and the care they did get looked really quite drastically different than before.

Many cancer patients were also concerned about exposure to COVID-19 and so they avoided in person care and ended up being hold up in their homes. So throughout today's meetings, I think we'll hear from colleagues who'll speak about the impact of the pandemic and what it has caused to the management of cancer. Certainly it's been devastating for anyone with a serious illness, especially those in under served communities.

Now, the challenge cancer patients continue to face are exacerbated by the economic and social follow up from the pandemic. It certainly has been quite extraordinary, a loss of income, social isolation, childcare responsibilities, and just a general fear about the risks of even seeking routine healthcare, just coming to the doctor's office or the hospital. So that leads me to think about and to talk about equity in cancer care.

Obviously this pandemic only exacerbated the differences and the disparities among patients with their ability to access cancer care. And just looking at the epidemiology, the pandemic of an infectious disease doctor, I can see and it became very clear that there were tremendous inequities in the way in which the pandemic hit different communities across the countries.

And obviously inequities and access to care and health outcomes were really laid bare by the pandemic. The stress of the pandemic brought out all of the structural problems that we see in healthcare in this country. Communities of color, of course, as usual, unfortunately, have been hit especially hard, and this again represents to me an important call for action.

So as we speak about the future of patient centered care, a key lesson from COVID-19, I think is that health equity must be front and center in the policies and programs we develop in our efforts to do better by patients. We know that there are unacceptable disparities in cancer outcomes in this country. Though cancer in its rates are similar between whites and black males and females in the United States, disparity exist in mortality rates and they persist across racial and ethnic identities.

And this is a quite important example of the access difficulties and the quality of care differences between different communities in our countries. We also see different kinds of underserved populations, those living in rural areas, those who identify like me as LGBTQ and those without insurance coverage. Health equity is really important for us to consider in the context of cancer care.

It's obviously a very, very frightening and expensive disease. People living with cancer have a unique set of needs and often face quite a few challenging obstacles getting to and staying in care. Approaching cancer care and treatment through health equity lens helps us recognize and plans for the needs of patients and their caregivers.

For me, in particular, equity and access to quality care is a really important issue because I've worked at Merck for 26 years, mostly in clinical research and it's been really a privilege to see how different countries deliver their healthcare around the world. And what I came to realize is that the way in which countries deliver healthcare is a rather telling reflection of each country's values and priorities.

So in this country, we need to challenge ourselves to enable equity of access because we as Americans value fairness and ultimately succeed when we have equality under the law and equality around the country. So the Merck Foundation is quite interested and quite supportive of improving patient centered cancer care and improving equity and access to cancer care.

So to increase timely access to patient centered care and help reduce disparities in cancer care for underserved populations, the foundation established the Alliance to Advance Patient-Centered Cancer Care. We committed $50 million over five years to support six projects based on leading academic cancer centers around the US working in collaboration with communities to provide high quality patient-centered cancer care, as well as the national program office at the University of Michigan School of Nursing.

Before the development of the Alliance, we were seeing advancements in clinical treatment of cancer with promising results for patients and care plans were becoming more complex. Certainly our clinical trials of pembrolizumab showed us that there were a lot of benefits to these drugs, certainly in terms of overall survival, but the way in which the care was administered and certainly the longer duration of followup of patients because of the happy reduction in mortality created significant challenges, new adverse experiences, new issues that had to be addressed and these are very, very important.

Patients were expected to manage this complexity and didn't always have the ability to do so, especially when they're facing barriers to care driven by social determinants of health so the most vulnerable were the most challenged. Similarly, physicians, although certainly expert in clinical care needed help in getting patients and their caregivers the support that they needed.

It's often through referrals to care and services that extended beyond the doctor's office. So in this new era of multidisciplinary cancer care, it's really clear that the system needed to change to support patients throughout the cancer care journey. And we saw at the Merck Foundation the need to create systems based solutions to streamline care and improve provider awareness and communications all with the patient at the center.

So we established the Alliance to respond to these major needs by first getting patients to the care that they need through navigation, support and referral to community resources. We then help to facilitate clear and respectful communications between patients and care teams, providing better information to inform decisions about cancer care. And then we next provided psychosocial support that focused on patients' mental health and wellbeing, such as screening for depression, anxiety, all this was done through the Alliance.

These critical issues are often overlooked, but they certainly do have a major impact on those living with cancer. And you can certainly vouch for that in terms of how we as a family worked to help my mother get through what was pretty brutal and difficult, but ultimately successful care for her Merkel cell. So during today's conversation, I think you'll hear from some of the Alliance's program partners, and I hope you'll learn from their experiences and take with you lessons that they discovered over the past five years.

Now, looking to the future, there's so many committed people lending their talents to help improve the lives of people living with cancer as seen by the depths of the leaders represented in today's agenda. And as a physician and scientist, I'm really hopeful that the solutions developed will get to the people that need them most.

I'd point out one thing that we talk about a lot at Merck, the best medicine is the medicine that patients can access in a timely fashion. And that is a really important point. We have all of these advances and it's really important that those advances don't end up in a medical journal, but actually end up in use in broad populations of patients and not just a select few.

So as a physician and scientist, again, I'm really hopeful that the solutions developed can get to the people that need them most. And I hope that through the work of the Alliance we will see improvements in care can be made by streamlining care systems and helping patients navigate their complexity with the support of the care team.

We're looking for ways to sustain system improvements and scale best practices through policy change, an issue that panelists today will focus on in the second panel. With that, I welcome you and really look forward to productive dialogue throughout today. I encourage you to imagine how you can continue to improve the lives of your patients and their caregivers. Thanks so much.

Sarah Dash:

Thank you so much Dr. Barr for your remarks and for sharing your story. And so from one alliance to another, it's certainly made the planning for this that fun. We appreciate your being with us and for sharing your perspectives.

Dr. Eliav Barr:

My pleasure.

Sarah Dash:

So thank you. So to our audience, thank you for joining us today. We have a really great agenda for you today. We're going to start with a panel on innovating to improve patient centeredness which will be around table discussion discussing key lessons learned from the ongoing health services intervention projects to improve patient-centeredness in cancer care. Then we'll follow that with a fireside chat, which was prerecorded with Dr. Wayne Frederick, present of Howard University.

And then finally, we will have a panel on translating lessons and successes to policy and practice. And so we hope that you'll join us for all three, but again, you will also be able to view recordings after this event is over. And so now I'd like to introduce our moderator for today's first discussion. Dr. Reginald Tucker-Seeley is vice president for health equity at ZERO - The End of Prostate Cancer.

In this role, he is responsible for the development and implement of the health equity strategy at ZERO focused on addressing regional and ethnic disparities in prostate cancer, from prevention to survivorship and end of life care. He is on leave from his academic position as the inaugural holder of the Edward L. Schneider chair in gerontology and assistant professor in the Leonard Davis School of Gerontology at the University of California.

Dr. Tucker-Seeley has a longstanding interest in the impact of health and social policy on racial and ethnic minorities and across socioeconomic groups. Dr. Tucker-Seeley, we're so glad you could join us today and I am happy to now leave this discussion in your expert hands.

Dr. Reginald Tucker-Seeley:

Thank you for that introduction. Before we start our discussion today, I'd like to offer some opening remarks and then I will introduce today's guests. At our recent National Academies of Medicine workshop focused on promoting health equity and cancer care delivery, one of my esteemed colleagues adapted a quote from Toni Morrison to apply to the cancer care delivery system.

She stated the only way to change the order is not to do something differently, but to do a different thing. That is perhaps we need a paradigm shift in how cancer care is delivered and coordinated that addresses the many barriers and how people navigate from their communities to primary care, to specialty care while recognizing that many in this country don't have a usual source of care.

So we know that the current system is not working for everyone and to achieve health equity, we must do it differently. As has been consistently highlighted during the past 18 plus months during the COVID-19 pandemic, our health is substantially influenced by the social context in which we live, and those contexts are substantially influenced by where we have been sorted to live based largely on our race and on the socioeconomic resources that we have available. As research on the fundamental causes-

Sarah Dash:

Dr. Tucker-Seeley, I am so sorry to interrupt you. We've been trying to reach you. We can't hear your audio and I deeply apologize. We're just going to take a moment, a very human moment to just recheck your audio so that we can hear everything that you're saying.

Dr. Reginald Tucker-Seeley:

Sure.

Sarah Dash:

You could maybe turn up your volume or get a little closer to your mic. And we're working on it on our end too. To our friends at home, thank you so much for just bearing with us for just a moment while we make sure we can hear Dr. Tucker-Seeley introductory remarks and then when we get to our panel. As a reminder, if you have questions that you want to submit in advance for the panel, you could take this moment to go ahead and submit some questions. And if we need to just take everything backstage for a moment, we will do that and then start again. Do you want to try again Dr. Tucker-Seeley?

Dr. Reginald Tucker-Seeley:

Yes. Can you hear me now?

Sarah Dash:

Yes. Woo, we can hear you. Awesome.

Dr. Reginald Tucker-Seeley:

Oh, great, great.

Sarah Dash:

Back to you, sir.

Dr. Reginald Tucker-Seeley:

Yes. So I apologize. It worked in the AV test. So let's start this again. So I will start with my... So thanks Sarah for introducing me and start with some of my opening comments. It's a pleasure to be here with you today. Sorry for the technical difficulties. As someone who had to teach online for a year, I understand sort of all of these many challenges. And so... Oh, getting an error message here on my computer, just making sure that everything is okay.

So my opening remark started with mentioning a recent National Academies of Medicine workshop focused on promoting health equity in cancer care delivery, where one of my esteemed colleagues adapted a quote from Toni Morrison to apply to the cancer care delivery system. And she stated the only way to change the order is not to do something differently, but to do a different thing.

That is perhaps we need a paradigm shift in how cancer care is delivered and coordinated that addresses the many barriers in how people navigate from their communities to primary care, to specialty care while recognizing that many in this country don't have a usual source of care. We know that the current system is not working for everyone and to achieve health equity, we must do it differently.

As has been consistently highlighted during the past 18 months during the COVID-19 pandemic, our health is substantially influenced by the social context in which we live and those social contexts are substantially influenced by where we have been sorted to live based largely on our race and on the socioeconomic resources that we have available.

Research on the fundamental causes of health disparities has highlighted that resources such as money, knowledge, prestige, power, and beneficial social connections help to create the context where our health status is produced, and it is these resources or the lack of those resources that put people at risk of disease risk, and also influence how we manage and navigate healthcare generally, and cancer care specifically.

As we turn our attention to advancing patient centered cancer care, there are many things that the cancer research, policy and practice communities can do to promote health equity and to center patients. In particular, as we attempt to operationalize equity in the cancer care delivery system, it must be recognized that we can't move so quickly to solutions without being seen as trustworthy by the communities we are working.

And the process of showing that one is a trustworthy partner is indeed one of the first action steps, which requires genuine engagement with communities. So now I'd like to move to introducing our speakers and to get our conversations started. So first I'm joined by Mr. Michael Holtz. Michael was diagnosed with stage 3B rectal cancer in March of 2012, and has since been a passionate advocate for cancer patients, survivors, and caregivers.

He is the American Cancer Society Action Network state lead ambassador for the state of Tennessee, a role he has held for six years. Michael also is a member of the board of directors for the Cancer Support Community of East Tennessee, and is an advocate peer reviewer representing the Colon Cancer Alliance and is an active member of the Man Up to Cancer Facebook community. Next, we have Dr. Roland Matthews, medical director of the Georgia Cancer Center for Excellence at Grady Health System.

Throughout his career, Dr. Matthews' research education and clinical activities have focused on reducing disparities in underserved communities. As a gynecologic oncologist, he specializes in pre-invasive cervical disease and gynecologic cancers and serves as an attending physician at Grady. He has worked to understand protein biomarkers of cervical cancer risk and studies the gene prohibition and its functional significance as a tumor suppressor in women with gynecologic cancers.

Finally, we're joined today by Dr. Heidi Hamann, associate professor in the department of psychology at the University of Arizona and member of the cancer prevention and control program at the University of Arizona Cancer Center. She has strong training in health psychology with expertise in psychosocial and behavioral responses across the cancer control spectrum. For almost 20 years, her research has addressed early detection and survivorship issues especially among populations traditionally underserved or underrepresented in cancer control research.

So welcome. So I'd like to start the discussion by asking each of you to respond to our opening question. From your perspective, what does an equitable cancer care delivery system look like? So we talk about health equity, we talk about health disparities. And so I'm eager to hear what you think an equitable cancer care delivery system looks like. And so, Michael, I'd like to start with you.

Michael Holtz:

Sure. Thank you, Dr. Tucker-Seeley. For me, I think an equitable cancer care system looks like a system where wherever you live, whoever you are, whatever you know, you can get the care that you need. I understand social determinants of health, I've worked in public health myself in the past. And as a cancer advocate, we are working very strongly in the area of health equity and where you live should not determine if you live, particularly if you're diagnosed with cancer.

But also as a cancer survivor and someone who has had to put the pieces together for myself in some aspects of my own care, I knew because of my background in healthcare, because of my background, I worked for the American Cancer Society and the Cancer Action Network, I knew how to be a patient advocate for myself. Not everyone knows how to do that.

So if for example, while I was in treatment for rectal cancer, I'm having a side effect that I... Is this normal? Is this the way this is supposed to happen? Until I asked the question, nobody told me that what I was experiencing was normal. Oh yeah, everyone who gets radiation treatment for rectal cancer experiences leakage. Would've been great to know so that I was prepared for that before it happened instead of having to ask afterward.

So I think for me, it's a really a huge combination of all of those things. It's the knowledge, it's the location, it's the making sure if someone can't get to the medical center for treatment, that they can get there, that we overcome transportation barriers, but also making sure that they have a complete understanding of what it is they're going through.

A care plan is great, but what are the side effects that I'm going to experience? Is this normal? Should I be experiencing this? And then in life aftercare, I'm a 9 1/2 year survivor. It seems like almost every year something comes up that is a result of side effects from my cancer treatment, from non-pressure glaucoma to a little cyst that I had several years after. As a cancer patient, anytime something goes wacky, you worry that you're having a recurrence. And so having someone that you can call on to help you put those pieces together, that you can trust would also be beneficial.

Dr. Reginald Tucker-Seeley:

Thank you for that, Michael. And I can definitely relate to the part of even when you know how the system works, sometimes you still struggle with how to go through it. I've been a researcher in this space for many years and every time I enter the cancer care... Whenever I enter the healthcare delivery system, I'm always surprised by how much about it I don't know. So thank you. So next I'd like to hear from Dr. Matthews. So Dr. Matthews, what does an equitable cancer care delivery system look like?

Dr. Roland Matthews:

Well, I think Mr. Holt sort of outlined a lot of what needs to be said around that, I'll just add a few points. The fact is we are all individuals. And a cancer care delivery system has to take that into account. So each patient will need different things to achieve that ultimate healthcare that they will need in their cancer care. So as he mentioned, whether it be transportation, we have food insecurity, financial insecurity, actually different levels of health literacy, right?

All these things are there that we need to make sure that the patient understands and each individual patient has these areas addressed for them so that they can achieve the ultimate care and results for their cancer. And that's what we need to do. So we need to build a team within the system to do exactly that for the patients. I mean, simple things. You'd be surprised, even "patients with insurance", there's different levels of insured.

So I mean, just navigating that and you'd be surprised most people don't understand that until they're in the system itself. So you can imagine when you do get that diagnosis. You have fears, you have concerns and you want both the social, the clinical to be taken care of. And so if we are able to do that, no matter where you live, rural, urban, your background in terms of ethnicity, and you have to folks who understand and can speak to the patient on all those levels no matter your education, all that must be taken into account to make a system that is equitable for everyone.

Dr. Reginald Tucker-Seeley:

Yes, thank you for those comments, Dr. Matthews. I think at the beginning there you were highlighting the classic struggle in public health and healthcare delivery, that is how do we go from the population to the individual and how do we do that in such a way to where we can take the lessons that we've learned from our population level research and what we know in populations to make that specific to the individuals. And then also, how do we ensure that those individuals are highly health literate, highly health insurance literate, so that navigating that system is equitable for everyone? Thank you for those comments. And next we have Dr. Hamann.

Dr. Heidi Hamann:

Great, thank you so much for including me in this panel. And I echo all the excellent comments that have been made so far. And I think adding to this related to patient centered care from a cancer center perspective, it's often making sure that we have that infrastructure and that capability to address those barriers as they come through. And I know we'll be talking a little bit later about how do we both sustain and expand the scope of the work that's being done so that no matter what sort of cancer center care environment people go into, they have that infrastructure to access.

I know for us and our research group being in Southern Arizona, one of the aspects that we focus on a lot is language. And so many of our individuals who are diagnosed with cancer in our region, Spanish is their primary language. And so the importance of really being able to not only address concerns in the preferred language, but also have a sense of cultural competence and community focused care, I think also becomes important.

And for those of us who are researchers, we often think about, well, how can we expand the work? And part of it is it's not going to be the same approach everywhere, right? Like each region, each community is going to have different aspects, different needs and so the importance of being very community focused in our cancer care, I would just add that to the excellent conversation.

Dr. Reginald Tucker-Seeley:

Thank you so much for those comments. And I think one of the things that you've highlighted especially now that we're having this discussion across the country around how does the healthcare delivery system, how does the cancer care delivery system address social determinants of health and social needs, in your comments about language access, it's not just about figuring out what is the social need that we need to address, but how do we then implement that in such a way to where it's equitable across our patient population.

So thank you all for setting the stage and offering us sort of what an ideal state of the cancer care delivery system that we should be striving for. So let's dive into some follow up questions, and I'd like to also remind our audience that you can submit your own questions via the chat box. So let's start with one of our first questions. Let me get that up here. So after we've figured out what the best tools and strategies are to reach and care for cancer patients, what comes next? So how do we scale models or pilots that we've seen work well in one setting? How do we help build up those for the larger cancer care delivery system?

Dr. Heidi Hamann:

Well, I think at least from the work that we have done at Grady through the Alliance, it is clear to me that we learn very well from each other. Just amongst the Alliance members, we have taken things that others are doing and implement them in our system to great success.

So I think there has to be a way or a forum to communicate across county lines, state lines and the like to have best practices out there that can work for systems similar to ours and just in general, to be able to take from others. So communication, as we see is vital here. And I don't know what the forum ought to be but there must be a way for these systems to get together and collaborate in delivering some of these cares that we have determined at individual system levels.

Dr. Reginald Tucker-Seeley:

Any of the other panelists want to comment on either the question posed or the comments just made by Dr. Matthews?

Michael Holtz:

I think similar to what Dr. Matthews was talking about with the creation of centers of excellence or something where one health system can train another health system, or one group of providers can train other providers so that you can scale up and you can... If someone's doing the best practice in Texas, the same thing is happening in Washington or in Tennessee, wherever. But so that there's a way to communicate where improvements in the system are happening.

Dr. Heidi Hamann:

And I agree. I think having best practices and having different systems, being able to share with each other. And I would also add, I sometimes struggle with this. I think part of what we're talking about too, is an organizational change amongst healthcare systems in terms of what they value as outcomes and how we as researchers, clinicians, advocates, really lift up our voices to be able to say patient centered care and all the pieces that go along with it really need to be important outcomes for the environment.

And so that kind of... And I think organizations are often doing well with that, but sometimes I still see the main outcomes related to issues that potentially aren't highlighting some of the patient-centered care aspects that we're discussing.

Dr. Roland Matthews:

I think we-

Dr. Reginald Tucker-Seeley:

And so... Oh, sure. Dr. Matthews?

Dr. Roland Matthews:

Well, yes. I totally agree with that. I think we have to find a way to get the "public" involved in what we are trying to do here. And I think everyone, I think can appreciate how important it is to deliver good healthcare. And we need to communicate what that is and how that can be done to the public so that they can also advocate.

I mean, I don't have to remind us what we are going through with regard to the pandemic and how communication, good or bad has affected that. So we need to utilize some of that. And it's not just publishing in the journals that folks around the table here read, but to get it out there so that the public understands what we are trying to do. And I think they will buy in once they're here.

Dr. Reginald Tucker-Seeley:

I think that's a great point because I think as we think about traditionally what our outcomes are especially for those on the tenure track and sort of thinking about what the deliverables are for that process is the published manuscript or getting the grant and sort of how does that then translate to patient-centered and equitable care. So how are we getting all of the great information that we have in our published literature, how are we getting that to the healthcare delivery system and to the patients that are impacted by the research that is happening?

And also, how do we share that information? Not just behind paywalls of sort of academic journals, but how do we actually share that with the public? And also as Dr. Matthews mentioned, sort of create partnerships with the public in terms of what we're trying to do here. I imagine that no clinician assumes that he or she is providing inequitable care.

I think everyone is hoping that they are providing equitable care, but I think sort of figuring out what does that look like? What does that look like in the context of providing care to patients? And so that leads me to my next question, that we talk a lot about centering patients in their day to day care, but that's not the only opportunity there is to include patients and caregivers. Can you tell us more about how to involve these groups and the design and implementation of tools and strategies to improve care?

Dr. Roland Matthews:

Well, I can start quickly and mention to you that one of the things that we did through the Alliance work and at our cancer center at Grady is to start what we call a PFA, which is a patient centered, a group of patients, providers, staff, but mostly patient and caregivers to help advise the system as to what makes sense for the patient.

And I tell you, of all the things we did and I think we had some pretty innovative things, I think that proved to be the most important thing that we did in the health system, as far as I'm concerned. Because the patients and their providers were so engaged and they were detailed about what is needed and why it's needed. And the great thing is also is that they also reach back into the community to give back both to the system, as well as to their own community.

So I think that patients and their caregivers are always ready to help and to give information if we just asked. And we started to ask, and they started to advise us as to what would be best for them as patients and as people taking care of patients with illness.

Michael Holtz:

I'm lucky that I have the ear of the COO of my cancer treatment center because he's a really good friend of mine and he was before I was a cancer patient, so we talk a lot. But also a piece of legislation that I'm particularly passionate about is called the Palliative Care and Hospice Education and Training Act, which is legislation we've actually been trying to get past for [inaudible 00:40:39].

But it's legislation that one, educates people on the difference between palliative care, which I think is the definition of patient centered care and hospice. And it trains medical professionals, but it also educates the public so that members of the public when they hear those words, "You have cancer," they know what to ask for. They know that hopefully at their treatment center, there's a team that is not only going to focus on the medical aspects of their care, but what are the psychosocial aspects?

Are there food insecurity issues? Do you have transportation? One of my issues was I lost a hundred pounds over two years before my diagnosis and A, that's how I knew there was a problem to seek a colonoscopy, but through the course of treatment, I gained all of that weight back because my nutritionist basically said, "Eat whatever you can tolerate," which was like giving a fat guy the keys to a bakery, no offense to anybody.

But I didn't eat healthy food because I didn't have someone, not that anyone held a gun in my head, but I didn't have someone sort of helping me keep track. I was fatigued from chemo so I didn't move a lot, which was a bad combination. So just having all of those pieces together so that you can still be physically active, so that you can be monitoring your nutrition, getting acupuncture if you needed, all of those things would be critical.

And I think just patients knowing that that exists in the treatment center, if it does, is extremely helpful. So I think sometimes it's even just a function of my cancer treatment center offers this. I didn't, for example, know that my cancer treatment center had healing touch until I was about three quarters of the way through treatment. Would've been great. It would've been great from early on, but if someone's not telling you this is available on a consistent basis. So I think just some of it's really simple, I think.

Dr. Reginald Tucker-Seeley:

Dr. Hamann?

Dr. Heidi Hamann:

I think that's really interesting considering this two-way communication process. A lot of times as a researcher, we tend to focus on how can we make sure we're getting information from stakeholders and community members, but it's also being able to come back and say, "Here's what we've learned from you. Here's how things have changed, here's what the services available are," and making it a constant communication process rather than like a one time focus group or something like that.

And also showing that meaningful communication and the need for... I think for me, particularly as a researcher to recognize we're asking a lot from people to not only be going through this cancer care experience but then to participate and help us understand. And so whatever we can do to meet patients, caregivers, other stakeholders where they are. Even if that's before COVID physically like going to places so we're not asking people to come in to the medical center again and just being responsive to what some of those needs might be.

Dr. Roland Matthews:

It's really... There's a whole sense, a few things that I just have to comment on. And you're so right, Dr. Hamann because we need to provide complete care. I know for example, we put into our system a exercise coach and a dietician. And I often ask, I am glad that the system leadership has decided to continue these beyond our grant because in medicine we are so used to this figuring, okay, let's take care of that tumor, right? But it's a whole patient.

So their psychosocial needs have to be taken care of, their diet has to be taken care of whether they're exercising, has to be taken care of. They can afford to get to the visits, we have to make sure that is happening. So you need really a whole team of people to do that and to do it well. And it has to be a real team where everyone is at the table for all the decisions for that patient. So I think those are good points.

Dr. Reginald Tucker-Seeley:

So what I'm hearing is the importance of bringing patients to the decision making table around some of the issues that are going to be relevant as they are navigating care, but also how do we create all of the wraparound need, or how do we address all of those wraparound needs that aren't just focused on medical care delivery.

And how I've been framing this within my own organization at ZERO is how do we prepare patients and caregivers to expect equity? What are the tools that are needed so that patients expect equity and then get equity as they are navigating the care delivery system, which leads me to my next question, which is, and also I want to remind the audience, if you have any questions, please put them in the chat and we'll try to integrate those into our discussion.

And so our next question is from the patient and caregivers perspectives, what tools or strategies work best to connect with patients and to center them in their care? And then did you find that there was a significant learning or acceptance curve to these strategies? Because it might require sort of educating on patient's perspectives. When they are expecting to enter the care delivery system and you start talking to them about addressing social needs, that might not be what they're expecting as they are entering that particular system.

Dr. Roland Matthews:

Yeah, I think for us, if I understand the question, I think for us, the patients have been very much appreciative of being able to have the significant input that we have given them into how their care is delivered. And I think part of what made that work well, at least in our system is that we employed navigators to help us with that. And I tell you, they know the system, they know the issues, they understand a lot.

Some of our navigators were survivors themselves. And so that really helped us to connect well with the patient and to... Because these are people that they get to trust and they know that these folks care about what happens to them. And so that helped us to deliver the type of care that I think is patient focused and person focused in my opinion.

Michael Holtz:

I agree with what Dr. Matthews just said about navigation. I mean, having a patient navigator who gets the system, who understands what's going on, who can help you put all of the pieces together is critical. And if your health system doesn't have that, every few weeks I was in a chemo chair for eight hours, just to have someone pop by and say, "Hey, how are you doing?" A social worker, whoever it is.

How are things going? Do you have any needs? That sort of thing would have been great. Now I got great care. So I'm still alive when I wasn't supposed to. I'm not supposed to be here, I get all of that. And my complaints are minor compared to a lot of other people. But just to have sort of that regular check in that isn't just focused on the medical issues would have been wonderful, I think.

Dr. Roland Matthews:

Very important.

Dr. Heidi Hamann:

I'm interested to hear the other panelists' perspectives related to something that was brought up about information and how to communicate information. Different people that I've talked to no matter what their level of kind of knowledge going in have often said, "When I was diagnosed with cancer, I heard about the first 15 seconds of what was being said and then the rest was just... It might as well have been speaking a language I don't understand."

And so for me as a clinical psychologist, I often think about kind of how we process information and thinking about being able to share and discuss information throughout the course of treatment. It's not going to be something right where the clinician just says everything at the very beginning, the patient remembers it, and then they're fine going on.

And kind of that need whether that be through navigators, whether that be through other professionals who are consistently checking in with patients to get a sense of what's your understanding of what's going on, how can I be helpful, what resources do you need, I think is important.

Dr. Reginald Tucker-Seeley:

So you raised a really good point about because in healthcare we often talk about getting the right care at the right time. And so the question that you're referencing was actually one of our first audience questions, which is, is there a lack of information or is it that information is given at the wrong time? And so do we need to think about how do we get information to patients as they need it, but also as Dr. Hamann just mentioned and when they can hear it?

So maybe it's not in that initial meeting that all of the information gets presented. So I'd love to hear comments from the panel about sort of is it a lack of information or is information given at the wrong time that sort of does not necessarily center patients as they are navigating cancer care?

Dr. Roland Matthews:

It's very funny. Our PFA helped us with that because we had a new patient sort of packet that we used to give to our patients. And they helped us redesign that because to the point, it has to be given in almost the right time, the right place. And they helped us to understand that. I think what probably will be a good thing is if we can institute that care partner idea where each patient has someone with them to help them at that visit. That I think is a good start.

But the other thing is that I mentioned before that it's a team of people, right? So we have to make sure at one point our exercise coach and our dietician, they couldn't access and get to certain part of the chart. We have to make sure all the folks that interact with our patient can tell us something about the needs of the patient and they have to be able to communicate to everyone in the team about the patient.

So I've gotten information about my patient that's relevant to the care of the patient from the dietician, from the exercise coach, from the social worker, certainly from the navigator. And those people are even involved in our tumor board to make sure that this happens. So a little bit of both in terms of when to deliver the information. But I think most time the information is there but I think it's when and who is listening that is the key factors in deciding what the patient absorbs.

Michael Holtz:

And I think where the patient is in the treatment process.

Dr. Roland Matthews:

Exactly.

Michael Holtz:

So I have two thoughts and sort of two tracks. My oncologist was excellent in distilling the severity of my cancer over time. So it was sort of like peeling an onion. Yes, you have stage 3B rectal cancer and this is how we're going to treat it. I didn't know until about halfway through six rounds of chemo that the cancer had actually gotten into my lymph nodes and was about to break through the capsule of the lymph nodes.

Because if I knew all of that on the front end, I probably would've freaked out. And who knows what would've happened? So there's that. On the other hand, the center gives me as a patient, a warning stick binder full of dust on the day that I start chemo. That's just an overwhelming amount of information on a day that I'm already nervous because I don't know what to expect and even though I'm going to be there for the whole day, that's not what I want to read while I'm sitting there trying to figure out what's happening.

So to that first question, yes, the information is there, but I think not only is it when do you deliver it and at what stage in the patient's treatment, but you might have to do it more than once. You might have to tell me more than one time that this service is available or you need to talk to this person or maybe it's time to talk to the social worker, whatever, to help me understand and navigate the system.

Dr. Heidi Hamann:

Absolutely. And I think a couple of points that were made, this is asking a lot of clinicians, right? To be able to work individually with each patient and to try to understand what their needs are. And so anything that can be done to have these case conferences in which there's a lot of different aspects and people who are involved in care coordination, right? That's a term that a lot of us use, but in the day to day, it really is a level of communication and some consistency throughout. And I think those are important pieces as well.

Dr. Reginald Tucker-Seeley:

So I'm hearing the need for a team based approach, the importance of care coordination, the importance of figuring out when to deliver the right information. And some of these might be a bit costly for the healthcare delivery system and the cancer care delivery system to implement and sustain. So one of our questions is, has anyone developed a consistent model of the cost that might be needed to add this level of support to primary care or to the cancer care delivery system? Anyone have any strategies of success in the space of managing costs?

Dr. Roland Matthews:

I think at least in our system, certainly I am absolutely convinced and there is some data within our system that we reached out to our financial folks to gather that says that if we do some of these things we are talking about, the cost is actually reduced. The patient, if you can talk to the patient or the navigator, reach out to the patient or the patient can reach someone to say, "I'm having symptom X, Y, and Z," maybe that patient won't utilize the emergency room for that, right?

And I think that as we work with patients on survivorship and those sort of issues they can maybe get back to working earlier, all these different things within the system, I'm not so sure. And I don't know the numbers is probably what I should say. But from my limited experience, I think that getting the patient in for care early, having an efficient system to deliver that care, I think in the end will reduce cost. So yes, we would like to look at that, at least regarding the program we have put in for the period of time we have done that to see how that affects overall cost of healthcare within our system. But I am thinking that it will reduce it.

Dr. Heidi Hamann:

This is such an excellent question. And I think those of us who have dealt with sustainability, often the first should we get from the administrators is, "Well, how much is this going to cost me?" And I am not a health economist, I'd like to learn a lot more. But I do know that there are some really good aspects out there, at least in terms of the particular domains, like what is the cost effectiveness of adding psychosocial oncology to the team in the long term?

The round table, the navigation round table has done some really good cost effectiveness data. So while I haven't seen pieces that integrate a lot of the different aspects together, my sense is that there are some really good resources out there to show just what Dr. Matthews was discussing, and to also broaden our idea of what it means to be cost effective, right?

Because we focus on quality of life and enhanced quality of life is cost effective, but we have to make sure we're showing that it is. So sorry, lots of different pieces there, but this is a question that I'm really interested in as well.

Dr. Reginald Tucker-Seeley:

Well, I think too it's definitely going to present many challenges for the healthcare delivery and cancer care delivery system, that is how do we perhaps save money in one part of the system? So if we reduce cost in one area, that's going to reduce revenue in another area. So if we sort of reduce utilization, then perhaps, the example that Dr. Matthews mentioned, then our emergency departments may not necessarily be receiving those resources.

So how do we have a conversation around how do we reduce costs, but then how do we so respond to those fewer financial resources in those areas that were relying on the brokenness of the healthcare delivery system as folks are navigating it? So then again, to encourage questions in the chat from our audience, we're happy to incorporate those. But until I see another question, I'm going to move to our questions. So next is what should providers, researchers, and sort of intervention designers in this space that are trying to center patients, what should they understand about changing or updating interventions to better suit patient needs?

Dr. Roland Matthews:

I can take a quick stab at that. I think that one thing I've figured out is that in terms of researchers, for example, I'll use that, the patients I take care of, at least in our system, there's this idea that they are not interested in participating in research, and that's not true. So patients are interested, at least cancer patients for sure, in clinical trials, whether they're economically disadvantaged or not, they are.

And I think just as much as patients who are not, the same thing in terms of education level, the same thing in terms of ethnicity. They're all interested in participating in research for instance. So we have to make sure that we deliver those opportunities to all our patients, no matter where they live or where they get care. We have to make sure the research is outside of the great university centers and ends up in some of the areas within our country that actually most cancer patients get care.

And we need to make sure we start doing that at least certainly on the research side and quite frankly, also in terms of the clinical care. So we need to figure out how we can get folks to collaborate more. The universities with the rural centers, for instance, with the community organizations. I don't know how we do that, but I think with good collaboration, we will make the system better. And that's what I know our system is trying to do. And I think if everyone does that across the country, I think our system will be better for cancer care.

Dr. Reginald Tucker-Seeley:

Any of our other two panelists want to address, how do we, or what should providers, researchers, interventionists understand about how best to update interventions to suit patient needs?

Michael Holtz:

I think for me, it's simple. Talk to the patients, get their feedback, get their opinions on how they felt either from the past perspective or a current perspective, how their care went, how it's going so that you can adjust if necessary.

Dr. Reginald Tucker-Seeley:

So I think a consistent theme is just making sure that patients are at the table. What's that famous Washington DC saying? If you aren't at the table, then you're on the menu. So making sure that you are sort of at the table where decisions about you are being made and how that is important to centering patients and the care process.

Dr. Heidi Hamann:

Can I extend that metaphor a little bit from this side of our instead of our research world, which is, I think for us, we have a responsibility to make sure that that table's accessible, right? That we're not creating this closed environment and saying, "Oh, you must come to us in this particular way," but that that table fully accessible to those and whether that's helping information or just making sure that we're asking people questions at a time that's convenient to them. I think to me, that's an important extension of that.

Dr. Roland Matthews:

I couldn't with you more. And we must be open to also changing our process to accommodate the community and the patient, right? I mean, sometimes some of us are very rigid about what we need to do and how we need to do it. And if you're going to ask the patient what he or she thinks, you must be willing to accept the responses and take them into account as you design what you're designing for them.

Dr. Reginald Tucker-Seeley:

Yes. And we're seeing this, we're also in this country having the discussion around health disparities but we're also having a discussion around the importance of diversity, equity and inclusion in our workspaces. And so as we're talking about this table where patients must be included, having a diverse membership around the table is one step, but making sure that patients are included and they feel that they belong at the table so that they can actually contribute to the conversation and that they're heard in the conversation as things are being implemented that directly impact them.

So we have another question from the audience and that is how do we continue recalibrating, redefining or deconstructing how we've always defined patients so that we're ensuring there's equity and representation across all the services and needs? So for example, that the things that we are providing are things that all patients can use. So for example, textured hair prosthesis for patients of color.

Dr. Roland Matthews:

Well, I think that question almost answers itself. I mean, we have to recognize that each patient is an individual and their needs, we need to find out what they are and provide for them, right? Whether it's textured hair or the kind of chemotherapy that they're going to make a choice about based on side effects and what concerns them, whether they want to do surgery versus radiation.

All these things are individual decisions that when you sit with the patient and his or her caregiver, family members and others that you make individual decision about each patient. Of course, those will be based on best practices and so forth. So I'm not saying that at least on the clinical care that you're going to go way off base, but there are a lot of decisions that get made that are based on the needs of the patient and their opinions can be taken into account. But the system must make sure that the patient's voice is being heard.

Michael Holtz:

Anything from our other two panelists on that comment or on that question?

Dr. Heidi Hamann:

One of the aspects that I'd be interested in thinking about discussing is we often think about the patient as an individual, but especially when we think about cultural aspects of inclusion and the importance of family and how we consider family and caregivers in the way that we address care. And that I think is an important piece.

I know in the work that we've done, I've learned a lot from our different patients, our navigators and some of our other team members about cultural representations of family in the face of an illness and how important the family is in that process. So I think for me, that's another redefinition of patient, not just as an individual, but as the group that's around that individual providing support.

Dr. Reginald Tucker-Seeley:

And so we have only, we have about five more minutes left and so I think I'll end with our last question here, which is for cancer patients, the journey does not end with final treatments. They still have significant follow up in monitoring care, with interprofessional care teams. How can the principles of patient centeredness and tools be translated and used in the long term to continuously support patients and their families?

Dr. Roland Matthews:

I think that's the whole idea of survivorship, at least the way we are implementing it. In fact, the patients will make sure that they have a primary care provider and to at least help them with all the issues that are not cancer that are medical, which we oftentimes don't think about. And I can tell you as a gynecologist that is very, very important to the patient.

And we see that quite often and we make sure that that happens and so we need to continue to do that. And at least in our center, we continue to follow the patients in the center so they have access to the things that I spoke about earlier in terms of all the other team members while they're in their survivorship portion of their care. So I think that's very, very important actually because the patient spends more time there than in active treatment. So I think it's very important that we have a robust survivorship program after cancer treatment.

Michael Holtz:

I loved what Dr. Matthews said about primary care physicians because there needs to be, and there was in my case, there needs to be a strong handoff. The day that my surgeon freed me from his care after five years was both the best day and the worst day of treatment because he was kind of a linchpin in my follow up care. Even though I have a great radiation oncologist and I'm on my third oncologist at this point, but I still do my annual checks.

But my primary care physician knows how I was treated, what I was treated with so that if I come to him with an issue that has arisen now, for example, my calcium is running really high and that typically means one of two things, one of which I don't want to think about. But we're working through that process. So we're we're getting the calcium measured in Thursday.

I'm actually going back to my cancer center so that they can run labs so that they can get a better idea of what's happening with my blood levels. So to have someone who he was always part of my care team. I mean, he understands what happened to my body physically during treatment. He treated me for the high blood pressure that came with chemotherapy and all of those things. So he understands and he can help me put the pieces together, even if it doesn't happen with some of the other providers in my world.

Dr. Reginald Tucker-Seeley:

Dr. Hamann, any final comments?

Dr. Heidi Hamann:

I mean, I just appreciate all the comments that have been made and thank you so much for moderating this really important discussion.

Dr. Reginald Tucker-Seeley:

Well, and too, I would like to thank the three of you for this very, very enlightening discussion around patient centered care. A few of the themes that have come out have focused on the importance of a team based approach and how that can help us sort of also keep the population and the individual level perspective as we are helping patients as they navigate care and also how do we create or the need to create an inclusive decision making table that includes that team in addition to patients to ensure that patient centered care is at the core as we attempt to operationalize equity.

So I think we're at time for this session. So let me look at my... So again, thanks everyone for the important insights. I want to thank our speakers for joining us this afternoon and for sharing their experiences, thoughts, and expertise. So next, our next presentation in about five minutes will be a fireside chat with Dr. Wayne Frederick who's the president of Howard University. And Michael, Dr. Matthews and Dr. Hamann, thank you so much for joining us today for this conversation.

Dr. Roland Matthews:

Thank you for having us.

Michael Holtz:

Thank you very much.

Dr. Heidi Hamann:

Thank you.

Dr. Reginald Tucker-Seeley:

Thanks.