

Living Beyond Cancer Podcast Transcript
LGBTQ Community and the Cancer Continuum

Guest: Mandi Pratt-Chapman and Kk Naimool

Lauren Hixenbaugh (00:00):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh, the Coalition Manager for Mountains of Hope. Living Beyond Cancer is a series of podcasts created for cancer patients, survivors, and their caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and is produced by the WVU Cancer Institute's, Cancer Prevention and Control.

Today we are recording in multiple locations, so please forgive any of our tonal differences. Today's focus is on the needs and experiences of the LGBTQ community across the cancer continuum from prevention through survivorship. This topic was chosen because data shows that sexual and gender minority communities delay cancer screening and care. Many of these delays are related to past negative interactions with medical providers or their office staff. We want to explore these topics with experts, both professionally and through their lived experiences. It is my pleasure to introduce Mandi Pratt-Chapman and KK Naimool. Mandi is the Associate Cancer Center Director of Cancer Center Initiatives and Health Equity at the George Washington Cancer Center. And KK is the Director of Strategic Partnerships for the National LGBTQ Cancer Network. We're delighted to have you both today as we discuss the LGBTQ population and the cancer continuum. Let's just start off today talking about yourselves a little bit.

Mandi Pratt-Chapman (00:58):

Sure. I can get us started. I'm Mandi, I've been at GW for about 12 years, a little over 12 years. I'm a queer-identified researcher, increasingly focused on LGBTQI health and intersectionality, which we might want to get into a little bit later. And came out pretty late in life, so that informs also of a variety of perspectives that I bring to my work. So happy to be here, really excited to have this conversation.

Kk Naimool (01:35):

So I'm Kk. I am non-binary and identify as queer. I work with the National LGBTQ Cancer Network. My background is one of an educator and a social justice activist, and I get into this work simply because I've been advocating for myself for so long, that I might as well advocate for everyone else like me. And as a child who had a terminally ill parent, I can see how a disease impacts families and as a parent myself, it's been my biggest fear of a lack of rights as a queer parent, if something were to happen to my son, how would I be able to handle him navigating the health system if my partner was not around. So I do this work because it's very personal.

Lauren Hixenbaugh (02:24):

Wow, thank you both for being here today. We are so fortunate to have guests that can come and talk about this important topic. Today we're going to get started with, what does being LGBTQ have to do with the cancer continuum?

Kk Naimool (02:40):

I will say that as a queer person, at every stage of the cancer continuum, in addition to seeking care that's going to save our lives, or keep us healthy, or keep our families in support, we have the added burden of whether or not we will be rejected by our healthcare provider. Which to me is unfathomable. You're contemplating death and end of life care, or what this is going to look like if you had a history of cancer in your family, you kind of have an idea of what it looks like, and in addition to that, you have to think if the person at the front desk is going to make you feel so uncomfortable that you have to choose over lifesaving care and whether to just go into the doctor to get screened, or to do a followup.

Mandi Pratt-Chapman (03:32):

Yeah, I totally agree. I think that this is really about patient-centered care, and it's about understanding who the patient is, making the patient the priority, and understanding that we don't fit into normative or convenient boxes, but I also see the impact on the cancer care continuum, from the cellular level to the macro social level in terms of just the gaps in provider education and what we need to address. From whether someone has XX chromosomes, XY chromosomes, XXY chromosomes, whether people have certain anatomy, we see anatomy-driven in our center screenings, not gender-driven, and then support network and social and legal rights, so I think it affects cancer. In many ways, cancer care is like any other kind of healthcare, in terms of provider respect and communication, and in some ways, I think it's unique in that there are certain physical considerations toward cancer screening that should be anatomy-driven, as well as supportive partner care and functional differences, particular sexually post-treatment, that should be accounted for. So I think it's really, really relevant and we don't have a lot of comprehensive education on the topic currently for providers, so it's great that you're doing this.

Lauren Hixenbaugh (05:12):

Do you want to talk a little bit more about cancer screening?

Mandi Pratt-Chapman (05:16):

Mm-hmm (affirmative), sure. When we think about cancer screening, one of the things that I find really challenging with this work is that our gold standards guidelines, our US Preventive Services Task Force guidelines are still very, use very gendered language. So when you're talking about breast screening they talk about women, right? And it's valid in that our research, which the US PSTF relies on strong research for the guidelines, our research is in women but we have consensus guidelines from the University of California in San Francisco that educate that based on provider consensus, from knowing that age and estrogen are the most significant risk factors for breast cancer, that generally at this time we think that if there's a transgender woman

who's been on estrogen or feminizing hormones for more than five years and is over the age of 50, they should be screened as a cisgender woman. Just to kind of in terms of vocabulary cisgender just means not transgender, it means you're self-identified and your gender identity are important or in alignment, which the majority of the population identifies with. So breast screening is one that we really don't have a lot of research on, we just have knowledge from what we can extrapolate from other research to say hey, we know that age and hormones are huge factors, so based on our best guess, we should be providing this care to transgender women.

Mandi Pratt-Chapman (07:04):

Likewise, even more rigorously, for transgender men or transmasculine individuals for the cervix, there is no doubt that there should be cervical screening and that could be a very challenging, painful, emotionally disturbing exam for a trans man, particular because it's involving a body part that is not aligned their gender identity. So those are two of the more significant differences, I would say. The other two things that I would mention is just that for transgender women, while we think that feminizing hormones reduce the risk for prostate cancer and prostate screening is controversial anyway, providers should still be aware that it's not impossible for a trans woman to get prostate cancer. Typically the prostate is not removed and so that is an important consideration. And then the last thing I'll say is just that for intersex individuals that span a variety of chromosomal types and have different anatomy, then a doctor typically expects a female or a male. There can be some significant differences, including a shorter vaginal canal and other considerations that are really critical for providers to be listening and not ignoring what patients are saying. So these are just kind of the most prominent things that come to the top of my head, but I do think what Kk mentioned in terms of just knowing your provider is respectful and cares and is paying attention, is also kind of the core of all of this.

Lauren Hixenbaugh (08:54):

I think that should be the core of a provider that we want to know that they are caring and that they're going to provide us with the best type of care that we need. Sorry, Kk, you were going to say something.

Kk Naimool (09:08):

I was just going to add that when you look at the individual, making that decision to go get screened is a very difficult one. For LGBTQ people, we've had a lifetime of stigma, prejudice, and rejection. And for any human being, getting a diagnosis makes things too real and so you have all of these blocks of wanting to get that answer. So getting screened is something that you want to bring a friend or a loved one with you to hear the words, to get the news. And for many LGBTQ people, their chosen family may not look like them, may not appear to be in what people expect certain genders to look like, so they may have to go alone. Which in itself means that they may not actually follow through and we know that when you receive a diagnosis and you don't have a loved one in the room, not having that person there to hold you accountable or to even hold your hand means you're less likely to follow your treatment protocol. It simply means you're not likely to do better, like to even have that support system to get you through this

hump, and so that individual fear of rejection also impacts how often we want to get screened or whether we make the decision to go ahead and take our health into our own hands.

Mandi Pratt-Chapman (10:38):

Yeah, and one other thing I was thinking of as Kk was talking, which is huge, is that we have such really prevalent gender language around certain clinics, particularly women's clinics, and many transgender men don't want to go to a women's clinic, and don't want, when everything is pink and everything is extremely gendered, it can feel really like people are looking at them and feel like this isn't for them. Interestingly, that might be more affirming for a transgender woman, but for a transgender man, it is not. So I think we're still really learning about what we should be doing in terms of environment and clinic and those kinds of things, but at the core is paying attention and checking those assumptions on who needs what service.

Lauren Hixenbaugh (11:37):

Absolutely. That's great information, and I was also wondering, as you guys were talking about it if these are similar situations that people are dealing with during treatment.

Kk Naimool (11:48):

Definitely, at every phase. Every interaction with health and human service providers, even your therapists are getting some sort of support group. You're dealing with the fear, the stigma, the rejection as well as well-intentioned but uninformed providers who might say something that basically alienates you from being able to trust them or to open up. And that's something that many LGBTQ people are hypervigilant and on the alert for, because that's how we've protected ourselves. And what that means is you may not be able to tell this healthcare provider something that's integral to your care, because you think they don't need to know this. And it could be something you do with your partner, and how that impacts your risk. It could be something that you might need to feel better and you don't ask your healthcare provider if you can continue doing this while you're in treatment. So it impacts us in every single realm of receiving care.

Mandi Pratt-Chapman (12:58):

Two things come to mind as I was listening to Kk. One is that I recently did a formative study to inform educational training on how to support sexual and gender minority prostate, cancer survivors. In the interviews that I did with patients, one of the things that came up as a theme was not the expectation but the wish that first of all, that there were male facilitators for men who have sex with men, and that ideally, wouldn't it be great if you had a gay male facilitator or someone who you could identify with and that there were groups that had people that were more like you in those support groups. And I think that there's not necessarily an expectation for that, because in the queer community we know that we're a minority and that just statistically might not happen in terms of incidents at the same time and support needs at the same time, but just identifying kind of a gap. I do know that cancer care provides, I believe an online LGBTQ support group, so that could be, the virtual environment might be a solution for

that since geographically we might not have the same kind of sexual and gender minority cancer status in one geographic location. But I think that's a need that's often overlooked, and to the extent that we can meet that in part or in full, that would be great. And then I think another thing that frankly would benefit everyone, in my experience a lot of times oncology providers are, many oncology providers, not all, are hesitant and uncomfortable talking about sex. And that affects straight people in treatment, that affects gay people in treatment, queer people in treatment. But to the extent that providers say, hey, you shouldn't be doing this or that, which Kk was mentioning, but they know that they want to do that and so not being able to have that conversation because it's not an open conversation about what to look for, or when something's risky or when something's not I think is really, really critical in just providing that open space for people to share really what their needs are, so providers can have patients be on the lookout and not just give strict kind of do this, don't do that.

Kk Naimool (15:35):

Yes, I think it's true for all people when you talk about the taboo things that doctors and healthcare providers won't bring up because regardless of sexual orientation and gender identity, there are many couples who enjoy anal sex and if you don't talk to your doctor about that act, you're not getting informed that you should be getting an anal pap. Just knowing that and that doctors are basically afraid to, or nervous to bring that subject up in any examination makes you wonder like how much of our healthcare is being compromised because of this lack of comfort in talking to people about their bodies and affirming their identities and the activities that they may engage in.

Lauren Hixenbaugh (16:24):

Yeah, we actually did a podcast on sexuality and intimacy with three of our specialists from the WVU Cancer Institute, and really got into that topic, and it's really interesting ... There were some really interesting points brought up during the podcast.

Mandi Pratt-Chapman (16:43):

Yeah, I think again it's about checking your assumptions about what you expect someone to be or how you expect someone to behave. I know that when I was coming out, I came out really late at 32, or I feel really late at 32. And for several years, talking to my primary care provider, who I thought was probably affirming, but I wasn't sure and was even within the system where I work, I was hesitant to come out because I felt like some of the questions were anticipating that I was heterosexual and when I was asked questions about whether I was sexually active or whether I was using protection and these things I wasn't sure how safe it was to talk about those things. And eventually I just kind of several years after coming out, I was just more confident in like, okay, this is who I am so I'm going to talk about it. But even for someone with a very opinionated and strong personality, which I would describe myself as, it took me a couple of years to get to that point, so providers providing that faith to not assume I think is really important in any aspect of healthcare.

Lauren Hixenbaugh (17:55):

So do physicians at ... You talked about this just a little bit, but do physicians have any kind of specialized training to work with the LGBTQ population, or is there training they can do if they want to be more welcoming?

Mandi Pratt-Chapman (18:13):

So I'm sure Kk has a response there, I can give it a start. So GW has a free online training called the TEAM training, which stands for together, equitable, acceptable, meaningful, and it's not just focused on LGBT cancer care, but it's focused on really kind of a more intersectional approach, so we have content on historical abuses in racial and ethnic communities, and we also have spotlights on the black, Latino and LGBTQ communities, and then interpersonal and system-level strategies to advance health equity in the setting where we work. So that is freely accessible at GWCCAcademy.org, and again it's called the TEAM training. We also have training that's specific to support, as I mentioned before, supporting classic cancer survivors that identify as sexual or gender minority. And of course, in a non-COVID era, there are more in-person options. I know that Fenway Health has a lot of online options in its national education center as well. And I will let Kk talk about the resources available through the National LGBTQ Cancer Network.

Kk Naimool (19:35):

Thanks, Mandi. So we have an online resource library that has a wealth of information, and it's available for free. Our website is www.cancer-network.org, and in addition to that, we have a nationally recognized LGBT cultural competency curriculum for health and human service providers, which we train therapists, social workers, doctors, nurses. We also have trained LGBTQ organizations and community centers across the country so that they have a curriculum to go and train their community partners. That's what we do as a network, and GW also has the work they're doing, but sadly, what happens in medical school is almost nothing when it comes to LGBT health, and if there is any sort of LGBT health, many of them, the majority of that course is related to HIV and AIDS, and not the social determinants of health that sort of lead LGBTQ people down the path of health inequities. So that's something definitely we need to shine a light on when we talk about the same biases that someone enters med school with is the same biases they leave with, so if they're homophobic, transphobic, sexist, racist when they go through med school there's no undoing of that and no real lesson that says people have the same body parts. So when a doctor tells me that they treat everyone the same, I know that's not true, because the same biases you have when you come in are the same biases you leave, and we know for a fact that health inequities exist. If anything, COVID-19 has shown us who's getting sick and who's getting sick at greater rates, and also who are dying from this disease, and which neighborhoods they're happening in. So we definitely have to talk about the lack of LGBTQ related health classes and courses available in medical school.

Mandi Pratt-Chapman (21:45):

You know what, I feel like I could have paid Kk to say that. So just a personal highlight, my dissertation was actually on this topic, and so if you want 200 pages of reading, you can find out which institutions are doing a better job than others. But what I basically

looked at was med students' attitudes, knowledge, and sense of preparedness in caring for LGBT people, specifically at GW and then I interviewed champions at other institutions that ranged from a lecture to a complete overhaul of the curriculum to improve LGBT content and a medical nursing or pharmacy school. And there's really only a couple dozen institutions nationally that have really made a substantial effort in this space. And I would like to call out, and I have no affiliation with them, the University of Kentucky at Louisville has been phenomenal in terms of their overhaul of the curriculum and they have something called the equality toolkit. If you Google equality toolkit Louisville, it has certain content areas that folks can think about in terms of education for healthcare professionals and doctors in particular. And just as a general rule, I think that layering, what I feel like the biggest ... Well, there were several findings, but I think one of the biggest findings was layering content where it's appropriate so addressing hormones at the time when you're also addressing hormones in menopausal women, or addressing mental health challenges at the same time you're addressing mental health in all populations, diverse populations. And the specific addressing cancer screening differences, when you're talking about cancer screening, it doesn't have to be and probably shouldn't be necessarily a standalone now we're going to talk about LGBT people, but we should be talking about sexual and gender minority health concerns and the concerns of various subpopulations throughout medical school without this kind of monolithic, white male figure as the patient. So I realize that's a little bit more provider-focused, but I think it's important stuff to think about. And you know, for patients that are going into systems and maybe noticing changes, like to intake forms or why are you asking me this question. Again, we're really trying to figure this out to be more welcoming of all people, because we have been so binary in the past, and so hopefully people that are listening will see some of those changes in the months and years ahead.

Lauren Hixenbaugh (24:42):

The LGBTQ Cancer Network has a resource for providers to look at, or is that for patients?

Kk Naimool (24:50):

Both. In our resource library, we have best practices infographics, information statistics that healthcare providers can use. They're also, some of them are really beautiful, you can use to put them up in your offices because many LGBTQ people start looking around to see someone who looks maybe queer, if there are any rainbow stickers so that we sort of start saying, I can come out to this person and talk about something intimate about my health and my body. Maybe my partner can come into the room with me. We have a wealth of information for survivors and caregivers on our websites. We're working on creating a database of support groups but they're so few and far in between, it's taking us some time to look it up. But we're going to do that because our community members need support, especially in this time where social isolation is also impacting our community at alarming levels.

Lauren Hixenbaugh (25:51):

So that resource ... Go ahead, I'm sorry.

Mandi Pratt-Chapman (25:54):

Oh, I'm sorry. That just reminded me that we also have on our [GW Cancer Control Tap site](#), and I can send you the link for this, but we have something that providers or patients can use, called the "I Want You to Know Card", and it just asks about legal name, the name that you want to be called, pronouns, race, sexual orientation, gender identity, as well as people you want to be involved in your care, religion if that's relevant for you, how you want people that you've indicated involved in your care and things you might be particular concerned about. It's really brief, it's like a front and back card, and that provides an option for patients to introduce a conversation if the provider's not introducing it, or for providers to provide a welcoming environment and offer this kind of resource so that patient's feel like, oh, they care and they're interested in this information. So again, it's called the I Want You to Know card and it's available in English, Spanish and simplified Chinese, so we can send you that link so you can include that as well.

Lauren Hixenbaugh (27:05):

Yeah, that's a great tool to show that a provider is affirming. Is there any other way that patients would know that?

Kk Naimool (27:14):

On our website, if you just go to cancer-network.org, the front page has these little square call-outs that you can see what each topic is, and we have a national database of LGBT-friendly, low cost or free screening facilities and treatment facilities. So we literally have someone calling these facilities and going through lists of best-practice interview questions with them and sort of assessing whether or not they're friendly. And I put this, and we're really proud of the work we've done this, but the caveat I'll put is that maybe the person we interviewed was very well informed and that's why that facility is on that database, but sadly, it is not part of organizational culture to create LGBTQ-friendly facilities. That is also something we list in our best and promising practices, which we share with all of these facilities once we do an interview. We're like, you sound great and this is where we hope you are. And sadly, due to lack of funding, we can't get into those places and say we will help you get there. I know that HRC has their health equality index, and that is another way to hold hospitals accountable for saying that they're LGBTQ-friendly and what that might look like. So those are what I know that's out there.

Mandi Pratt-Chapman (28:39):

And I think that knowing those resources that the patient or caregiver is important because it's one thing for people like me and Kk to go to institutions and providers and say, hey, this is a really good idea, you should do this. And it's another thing if a patient or caregiver says, have you thought about participating in HQI, the Healthcare Quality Index, or did you know there is this resource from the National LGBTQ Cancer Network, and do you do these things? That might be really hard for someone diagnosed with cancer, but for a caregiver or someone who is at some point, at whatever point in their experience, I did a webinar yesterday with some interview participants just doing some

member checking on another study that I'm doing and one person said that they just feel like every provider is against them. This was a transgender diverse group of people. I encourage them to kind of advocate and give that feedback. I don't know that providers always realize that, but that's a lot of pressure to put on people too, so I recognize that. I'm just suggesting that for those who are comfortable and for caregivers of those affected, that knowing these resources exist can also be helpful.

Lauren Hixenbaugh (30:02):

Absolutely. So that kind of leads me into an article that I read recently that says that the inability to disclose sexual identity to cancer care providers results in poor health outcomes. Can we talk about that a little bit?

Kk Naimool (30:24):

Thanks, Mandi. I think that's what we have been talking about because if you're trapped in the closet, you're not sharing who you are with someone who needs to know how to take the best care of you. And we also know that if you have a good relationship with your healthcare provider, it actually has an exponential impact on how well you do as you follow treatment protocol. So basically, if you like your doctor, you're going to get better. And so if you have mistrust and you're withholding and you're watching your pronouns when you talk to your doctor, or you're nervous to take your loved one in with you, you've already jeopardized whether or not you can follow this treatment and feel healthier or move towards something that looks like a better quality of life. And that's because you're not coming out, you're not able to be your full authentic self in that space, but what I've been telling doctors is you need to come out as an LGBTQ-friendly provider, and you need to do that loud so that people don't have to, while they're contemplating the end of life or what this might be, and how this means to their family and how scared they are, they don't also have to think, "Do I have to come out to this person? Again? How many times do I have to do this?" And so really, the onus shouldn't be on the patient or their loved ones to have to struggle with this additional burden. It should be the healthcare providers recognizing that human beings are diverse in the ways that we identify and partner and how we live our lives. And demonstrate that by saying what their pronouns are, having some visible cues that this is a safe space. Having gender-neutral language on their intake forms. And there are ways to do that.

Mandi Pratt-Chapman (32:17):

I think that the words that really resonated with me as Kk was talking were authentic self. And this is a non-cancer, non-LGBT specific example, but I took my 13-year old to her wellness checkup yesterday, and I watched and she is straight, despite having a lot of gay friends and feeling like ... She's like, "Wish I was gay, just am not." But she was kind of animated and talking to her doctor, and then her doctor said something that totally shut her down, and was like, and out of respect for her privacy, I won't share what that was but I watched her body language just completely change and after that, it was "I'm going to say whatever you want to hear." You know what I mean? I think that that kind of being your authentic self and being heard and having that space to be able to say, "Hey, this is what's important to me," is relevant for all people. And the reason we're highlighting our sexual orientation or gender identity is because it's been taboo

and hidden as something that we haven't been able to talk about. There are many, many other things that make people authentic, and we just need to be able to have that kind of openness to allow patients to be their authentic selves and listen. Just wanted to share that, it was a really interesting moment for me.

Kk Naimool (33:47):

Thanks, Mandi. That makes me think about the ways in which patients who do come out are still harmed by their healthcare providers. There are many people with breasts. Some of them identify as women, who if they have to undergo a double mastectomy, will tell their surgeons that they want to remain flat-topped, that they want their chest to be flat, they don't want reconstruction. And there are many instances of these surgeons hearing this from their patient and then ignoring it and leaving these flaps of skin in case these patients change their minds. So imagine that you are trusting this healthcare provider, and they ignore a simple request while they're sleeping. It violates that patient trust, and these aren't members of the LGBTQ community alone, these are cisgender and heterosexual woman-identified people who are saying, "I don't want reconstruction." And being denied. There are movements of these people with breasts saying, "Our healthcare providers need to listen to us." And it's also very sexist in assuming that these people will be changing their minds at the last minute. So even if we do come out, it's no guarantee that our whole authentic selves can be there. Just this, it's not even members of our community, it's like anyone with breasts can say "This is what I want." Imagine the trauma of waking up and finding that someone did something to your body you didn't want, and you signed away, said yes, I trust you, do this. It's a huge violation. I'm not going to go back for care. I would just be like "No, I don't think I trust any doctor at this point."

Mandi Pratt-Chapman (35:40):

I think that speaks to the problems of how much social conditioning we have as a society and how gender [crosstalk 00:35:48] are, and not just gender but in terms of racial expectations, gendered expectations. During the pandemic, there have been a few things that I've re-embraced, or newly embraced. One of them is gardening. Another is meditating, and one of my favorite meditation teachers often says "You think you're thinking your thoughts, but you're thinking the culture's thoughts." And I think that the example that Kk is giving in terms of doctors assuming people want reconstruction or want to look a certain way speaks to that, that we think, oh, we think that we're thinking unique thoughts, but we're so socially conditioned and the healthcare system isn't exempt from that.

Lauren Hixenbaugh (36:42):

So what suggestions do you guys have to improve this cancer survivorship for folks? It sounds like people are advocating and sometimes it's still not working, so what can we do?

Kk Naimool (36:57):

I think it starts with education and some of that education has to be with unlearning. We know that there are medical textbooks that still say that African American women have higher thresholds for pain. That's not true. It's absolutely not true. Human beings have varying thresholds for pain and it's not race-based. And there's a lot of unlearning to do. It's going to take more than three or four hours in your seven to fifteen years of however long you're going to be in medical school, depending on your discipline. And we need to have these uncomfortable conversations because healthcare providers should be there for all human beings.

Mandi Pratt-Chapman (37:45):

Yeah, and I would say when I'm talking to people I used to do a lot more actually before everything was at home, but the two really important takeaways I would say for people that are working with patients, whether you're a healthcare clinician or healthcare staff or health worker. The two takeaways, I would say, are one, we're all biased. We are socially conditioned people, we are human beings, and our environment, our education, how we were raised, what we've been exposed to, affects us. So it's helpful, I think, to realize it's not that you're biased and I'm not, we're all biased. The point is to understand what our immediate reactions are to things and whether that's in service to the patient or the outcome that we really want to achieve. So being reflective of hmm, this is my initial impulse. How am I going to land with that? How is this going to land for the patient, and kind of continually reflecting on that and learning and listening? And then the second thing I would say, which actually I learned from the founder of the National LGBT Cancer Network, Liz. She made this point when she was doing some training at GW several years ago. She said ... I'm not going to get it exactly right. My daughter says my recollection of storytelling is awful, but we all make mistakes. If we're trying we're going to make a mistake. So mistakes are a reflection of getting out of your comfort zone. So if you make a mistake, that may mean that you're trying and that's okay. Apologize briefly, listen, move on. But don't be afraid of making mistakes. That is part of the process of learning about things that are not your own experience. So those are the things I think are most critical in terms of the learning process and continuing to try to improve, that we all have a bias, you're not alone. We all have it, I have it, everyone has it. It's just it varies, depending on life experience, and we all make mistakes. So it's the process of listening and committing to lifelong learning, I think that is the point.

Kk Naimool (40:10):

I would also like to add those politics aside, I will say that policies that discriminate sort of give people permission to behave badly. And that could be organizational policies, it could be state policy, federal policies, but when you have policies that discriminate against members of specific populations, it sort of trickles down and turns into bad behavior. It's like your parent gave you permission because I do this, you can do this too. And we see that time and time again in history and currently. So part of this conversation and this education is that if you really want to do no harm, is to understand what things actually bring harm to community members. So the ways in which even access to insurance prevents partners from supporting their partners with their insurance policies that they have through work impacts your health, and we need to

consider what this impact looks like as a healthcare provider and the oath that doctors take to do no harm.

Lauren Hixenbaugh (41:24):

Thank you both, that's great. Great information. As we kind of, I'm going to shift gears just a smidge, and let's talk about the caregiver side of this. What do they need to know? What questions should they be asking? I really like the term you said earlier, Mandi, about supportive partner care, which I think we should touch on too.

Mandi Pratt-Chapman (41:47):

Yeah, I think caregivers can be the ears and eyes and advocate for patients that may be overwhelmed, and I don't know that that is LGBTQ-specific. I think the relevant point is something that both Kk and I said earlier, that including the appropriate social support so that the right person can be those eyes and ears and advocate is what's critical. I guess the other thing I would say and again, this is informed by my own personal coping in the COVID era is just the importance of caregivers taking care of themselves and making sure that caregivers are really paying attention to their own signs of health and distress so that they can continue to be a support for the patient. So I think those are the big things that come to mind for me.

Kk Naimool (42:52):

So in terms of LGBT caregivers, firstly, when we look at the patient, the person that this caregiver is hoping to give care to, if you're excluded from the process it's very difficult to be able to advocate and ask those questions. We also know that more than any other population, out of the general population, LGBT people are more likely to be caregivers in general, of either an LGBT partner or former partner or friend or community member, or of the same family that rejected them, because LGBTQ people are less likely to have gotten married and had kids, and so they're that sibling that has to go back and take care of a parent or a sibling that rejected them. So LGBT caregivers need significant support for their own self-care. We also know that LGBT caregivers are also at higher risk for chronic illness. So we're sick LGBTQ caregivers taking care of our sicker LGBT partners or chosen family members. And there is probably I think one support group for LGBT caregivers, and it's not consistent and it's based on people's capacity to facilitate and who can attend. So when we say caregivers it's not just this one benevolent family member or spouse that's there for you. We're not allowed in the door, and when we are we might be taking care of someone who's continuing to harm us while we take care of them. In addition, we're also coping with illnesses while we're taking care of others with a lack of resources to support us in that process. And so LGBT caregivers are a population that sadly are in need of a lot of visibility and a lot of support.

Lauren Hixenbaugh (44:52):

Wow. Kk, thanks for saying that. We do have, Living Beyond Cancer has a [Facebook support group](#). Now it's not specific to LGBTQ, but it's for caregivers, family, and survivors. And we do try to be welcoming and we'll talk a little bit more about that when we talk about resources, but I just wanted to mention that. Are there any other

resources that you can think of that caregivers need to know about? We know that if they aren't getting self-care they can't give good care, so what can we do for them?

Kk Naimool (45:30):

I think it's the same thing when Mandi was talking about we have to learn how to talk about specific cancers and specific body parts and not treat them as gendered. There might be someone who's giving care and supporting someone who has prostate cancer and saying she or her in a support group can alienate that person. Saying that this person is my husband or wife, and it doesn't quite match a hetero-normative couple, alienates that person. So I think you have the support group specifically putting the language that says that while this is not exclusively LGBTQ, you train your facilitators or their resources for people who identity based on their sexual orientation or gender identity. Or we have caregiver resources, but again, we don't have the capacity to run support groups. And so we do have caregiver resources. Cancer Care is a great resource, we recently partnered with them and we put articles there. We're trying to figure out ways to boost our community to start creating these spaces on social networks like Instagram, Facebook. We are seeing a lot of interesting public health materials come out on Instagram and so we see our community members creating things for other community members and we're trying to figure out the best way to disseminate that information. But organizations like yourself can just take everything from a resource library, adapt it to the work that you do, reach out to us, info@cancer-network.org, email us. If we have resources we will give them to you. They are free. You can adapt them to what your programs are already doing. We're not asking you to reinvent the wheel, and we will support your work.

Lauren Hixenbaugh (47:24):

That's great. I really appreciate how supportive this community is of one another, and I think that's something special. As I begin to wrap up today, is there anything else that you'd like to address?

Kk Naimool (47:38):

I don't think we talked enough about this pandemic, because we know that people are coming into hospitals with more advanced cancer care needs, because of needing to quarantine. And we know that LGBTQ people, many of us work in the service industry, and so having the time and access to even do the self-care before this pandemic was already difficult, and so we know during this time, people are really struggling. And if you can, I would encourage your community members, or everyone, to please figure out what's available, screen, figure out ways to de-stress in this time so that you are giving yourself some self-care because I know that this is just an added burden to a community that's already overwhelmed.

Mandi Pratt-Chapman (48:31):

Yeah, I think also that regardless of whether you're a sexual or gender minority the pandemic has created a backlog and fear in terms of cancer screening, and that's something that's going to have long-term impacts on cancer staging and outcomes and

collectively, smartly trying to make sure that where we're focusing on screening that things are safe, environments are safe, will be important to make sure that as a society we are making sure we curb the worst outcomes and are finding things as early as possible.

Kk Naimool (49:15):

And Lauren, if I may, I just want to make a plug. In the next couple of weeks, we'll be launching out the National Cancer Survey. It's a survey for LGBTQ people, by LGBTQ people, and we really want our LGBTQ cancer survivors or caregivers to tell us about their cancer care experience. Because the survey that we did five years ago is still being used all over the country to advocate for LGBTQ affirming cancer care and this survey will help us to continue that work with more recent statistics, especially as we know that including LGBTQ identities in most data collection is a bit of a struggle, and without the numbers to support why that we exist and that we exist as significant portions of the population, it makes it harder for us to advocate for affirming care. And so follow us on social media. LGBT Cancer Network on Twitter, Instagram, Facebook, and when we put out that survey, if you're a member of our community and you have this experience with cancer, please fill out our survey. We need your voice.

Lauren Hixenbaugh (50:33):

If listeners were to remember one tip out of today's podcast, what would you hope it would be?

Mandi Pratt-Chapman (50:39):

Yeah, I think I tried to convey that earlier in terms of us all having implicit bias and us being okay making mistakes and moving on, so frankly those are the things that to me are most critical in moving the needle on advancing care for all of us, with all of the various ways that we identify. Just checking assumptions, making sure that we're not assuming things about another person that is true for ourselves or true for a majority, and continually committing to learning and reflection and growth.

Kk Naimool (51:20):

I will say the main takeaway that I want people to have is that it is your right to have affirming healthcare, and you should be able to come out to your healthcare provider. You should be able to come out to your doctor, and if your doctor needs support in providing you with care, you can give them our website. So it's www.cancer-network.org. They can go on our website and go to our online resource library and find a wealth of information available for providers, including two sample intake forms so they can see the best way to affirm people's gender identities and relationship status. You as a cancer patient, a cancer survivor, can go to our website and on our home page there are links to caregiver resources, an opportunity to share your cancer story, so you can talk about what it is you've experienced and what you would like to see maybe in the future for other cancer survivors going through the same process. So visit our website, www.cancer-network.org and we're here to provide for our community. We are also here to provide support to doctors, nurses, health and human service providers

across the spectrum of all of the ways in which these professions care for our community members, and just reach out to us. Info@cancer-network.org, and I'm actually really excited to hear this podcast.

Lauren Hixenbaugh (52:50):

Good, I'm glad. We were pretty excited about this topic as well. Thanks, Kk, those were some really great resources. In addition to that, we talked about earlier the [Living Beyond Cancer Facebook support group](#). If you want to check out the support group all you have to do is search Living Beyond Cancer in your Facebook search bar and it should pop up for you. We have a really supportive community that we'd love for you to join. To find out more about Living Beyond Cancer, visit moh.wv.gov or wvucancer.org. Living Beyond Cancer would sincerely like to thank Kk and Mandi for joining us today, as well as our listeners. We hope that you'll continue to join us.