Dr. Lynn McPherson:

Hello, this is Dr. Lynn McPherson and welcome to Palliative Care Chat, the podcast brought to you by the online Master of Science and Graduate certificate program at the University of Maryland. I'm very excited about our guest today, Nancy Eddy, who is a social worker with MedStar and she works in the PATCH program, which is the palliative telehealth clinic. So welcome Nancy, how are you today?

Nancy Eddy:

Thank you, Lynn. I'm thrilled to be here. I'm doing well. It's a beautiful day.

Dr. Lynn McPherson:

It is a lovely day today. So our topic today, we're going to talk about, what are we going to talk about today? Why don't you share with us [crosstalk 00:00:37].

Nancy Eddy:

Yeah, we're going to talk about the LGBT community and how we have LGBT patients and how that intersects with palliative care.

Dr. Lynn McPherson:

So first off, what are all these letters standing for? And sometimes you hear the Q, sometimes you don't hear the Q. I'm very Q-fused here. What are we doing?

Nancy Eddy:

Yeah, there are a lot of letters, it seems like alphabet soup sometimes. And I think that folks mostly know LGBT is lesbian, gay, bisexual, transgender, and Q usually stands for queer. And queer, you may know it as a derogatory term, but it's been a term that's been repurposed, and some in the community have latched onto it as an umbrella term for LGBT, instead of having to say LGBT, just saying the queer community, because it is a little more flexible. But not everyone likes the term, maybe older adults who have had that as a derogatory term or epithet, they may feel less comfortable with that term. So not everyone likes Q. There's always... It also can... You may have heard queer used for gender queer, which is someone who is not identifying with femaleness or maleness, maybe more in between gender queer or non-binary or gender non-conforming.

Nancy Eddy:

So that's another way that we hear the term, with the letter Q for queer. There's other letters too. You may have heard I, A, intersex, asexual. I think the intersex is actually pretty interesting to just actually talk about for one second. There are actually about 1 in 2000 folks who are intersex. I'm not a physician, but it's interesting. Biological sex has five different components: you've got your chromosomes and your sex hormones and your gonads reproductive glands, your external genitalia. And if some of those don't match up completely, then you're in the intersex community. So it's actually a very large umbrella term. And 1 in 2000 is a lot, that's actually more common than cystic fibrosis. So..

Dr. Lynn McPherson:

Wow. I didn't even know that. That's interesting.

Nancy Eddy:

Yeah. Yeah. And so there's lots of other letters as well. You may have heard P for pansexual, sometimes you see LGBTQ and then a plus sign to encompass the whole community. But I don't think they need to get too hung up on all the letters. You can say LGBT and I think folks will understand where you're coming from and be appreciative of you using that language.

Dr. Lynn McPherson:

I wish we were all more like the TV show Bridgerton, where everybody's equal and everybody's accepted and you don't need to have all these letters and so forth... That the world should be like Bridgerton in my opinion, I love that show. So I guess given the strides we've made with marriage equality, is same-sex marriage legal in all 50 states now?

Nancy Eddy:

Yes, yes. Marriage equality... So in 2015, the Supreme Court passed the ruling that we do have same-sex marriage or marriage equality in all 50 states. That was just six years ago. So not that long ago... [crosstalk 00:03:58]

Dr. Lynn McPherson:

No but I guess, given that, which is great progress, many people assume that LGBT folks no longer face systemic discrimination, is this true? So have the waters quieted here and everything's smooth sailing?

Nancy Eddy:

Yeah, I wish. I mean, I don't think that you can overstate how important marriage equality is, I do think that's a huge stride. Also last year, you may or may not be aware, there was a Supreme Court case that finally made it illegal to fire someone for being LGBT across the 50 states. So, in 2020 that's when that happened. There were jurisdictions and states already that had some protections for LGBT folks, but now in all 50 states, you cannot be fired for being LGBT. So that's also great and huge. But I don't know if you've been hearing the news lately, we have all these anti-LGBT and a lot of anti-trans bills all across the country right now, it's kind of a new wedge issue, unfortunately using transgender youth, not allowing them to participate in sports and not allowing them to get the healthcare they need and just really, really disquieting.

Nancy Eddy:

So that is... We are far from being discrimination free even in our laws let alone our attitudes, right? So... There was a poll done last year by GLAAD, the Gay and Lesbian Alliance Against Defamation, I think that's what they used to be called, they're LGBT organization. And actually the acceptance for LGBT folks declined in 2019 for the first time in many years. So there are internal biases and discrimination that continues, there's additional... Hate crimes against LGBT folks were increasing as well. So, we have a lot of strides. The societal discrimination... You think about homelessness rates and job discrimination, suicide rates are much higher, much, much higher in the trans community. There is a survey done, it was in 2010, but of the transgender community and 41% of transgender folks have attempted suicide. And-

Dr. Lynn McPherson:

Oh, my goodness!

Nancy Eddy:

Responded to the survey. Thinking of that in terms of the general population, it's enormous. So it is staggering. So these disparities, they multiply when you... If you're a LGBT folk and you also are a person of color, all these disparities just kind of can be even more difficult. So it's an ongoing fight.

Dr. Lynn McPherson:

I think I was sharing with you earlier in our pharmacy school, I know several years ago we'd have activities called a fishbowl where students work on some clinical situation as a group and so forth. And we had one specifically on transgender patients and the students were a little uncomfortable because no one wants to be offensive on purpose. At least I hope not. But they really struggled with what do you do with someone who doesn't want to identify as either man or woman? You can't say, "can I help you ma'am?" if you don't want that label. So is it rude to say, how do you self-identify? How would you like me to refer to you? What's the best protocol to do to not be offensive, but to be sensitive.

Nancy Eddy:

Sure. I think that ideally you can first kind of align yourself with them by saying, "Hi, my name is Nancy. I use she/her pronouns. How can I refer to you? What would you like to be called?" So it's quick. If you haven't practiced that it might not slip off your tongue very easily. But you're right, there are a lot of folks who don't feel they have a home in the gender binary. And I think that that is that's something that is really increased in the last few years I would say, especially among youth, because I think that they are feeling the ability to really kind of create and be who they really feel they are internally and express that externally.

Nancy Eddy:

In a very non-scientific study, I asked my neighbors, who are college professors who have about a hundred students in their classes, how many are transgender? How many are non-binary? And there was, I think, one transgender student and there were like 15 non-binary. I mean, this is... Yeah. So I think it is something that we can't just kind of push off to the side. It really is present, it's going to be even more present I think in the coming years. I think it's really cool. I think it does take some time and thought to use they/them pronouns or that's... It doesn't come off our tongues easily, so I think it takes practice. And I think you have to think it in your head first and use it. So...

Dr. Lynn McPherson:

I recall that the standardized patient we had, who actually was a non-binary self-identified individual said, "if you're really stuck, call me friend: hi friend, what can I help you with today?", so I thought that was a good tip. And the other query I have is, probably about 10 or 12 years ago, we had a patient on hospice who was transgender but had not made a physical transformation. And I don't for the life of me remember which way they were going, but they wanted to be... They self-identified as the non-birth gender and the hospice nurse refused to do that. So the patient had changed their name, but the nurse refused, not legally. And I remember the rest of the team wanted to kind of kill the nurse for being so insensitive. Have things gotten any better? I mean, I know there was an article published last May about the experiences of LGBT patients and their families in hospice and care. What's the upshot of that?

Nancy Eddy:

Yeah. I mean, I think that your story I think illustrates it quite well. You know, we're not immune in hospice and palliative care. Our patients are LGBT and they are not always being treated respectfully. Who knows how much hurt that caused that person at the end of their life in hospice-

Dr. Lynn McPherson:

Horrible. It was horrible.

Nancy Eddy:

You know, when you're vulnerable and someone's coming in to take care of you and you have put yourself out there to be out to that person. And then them not respect that, that just makes me really sad. Yeah. The survey that they did in this article, they surveyed over 865 hospice and palliative professionals, so social workers, nurses, physicians, pharmacists, and asked them have they seen discriminatory care or would they expect that a LGBT person would be treated similarly to a straight person?

Nancy Eddy:

And it was really eye-opening. I think one of the most stark statistics was that it was almost 43% of the folks who responded said they had seen, directly observed, not just hearsay, but directly observed discriminatory behavior towards a patient's caregiver or loved one or spouse, not taking them seriously, eye rolling, maybe not actually following through with their care decisions. That's our bread and butter, your decision-making and if you're not respecting someone who's been appointed as a healthcare agent or you're not respecting the spouse as that person because they're gay or lesbian. Yeah. We have work to do.

Dr. Lynn McPherson:

Yeah. You would think hospice and palliative care, we would be doing a better job. You would think-

Nancy Eddy:

Yeah.

Dr. Lynn McPherson:

You're leading the flock here.

Nancy Eddy:

Yeah. I agree with you. And I think we have an opportunity to do that. I think we have an opportunity to lead the flock and I think, it... We can't just say, "oh, we mean well" and go that way. You know, I think we really have to do the work and train staff and kind of be aware of our blind sides. If folks are fearing discriminatory treatment, then they're going to delay their treatment, right? And they're not going to be doing any advanced care planning. So all these things that we really care about are affected by discriminatory treatment or the fear of it.

Dr. Lynn McPherson:

Yeah. Well when I think of the LGBT community, I tend to think of adolescents and younger adults, but what about this population as older adults? What do we have to be mindful of and what are some tips in dealing in hospice and palliative care with the older community?

Nancy Eddy:

Yeah. There's a special place in my heart for LGBT older adults. That's kind of why I got into this in the first place. I was always interested in older adults. And then when I came out as lesbian, I realized that there were these elders who had gone through so much, and then at the end of their life, they're going through transitions and maybe having to go back in the closet because they're scared to go to a nursing facility or they're scared to have someone come in and take care of them and be open about who they are, what if they pray over them? What if they abuse them? What if they neglect them? So I think that if you think about a person's life, somebody who's 70+, they were alive during bar raids, where police would come in and not just break up the party, but arrest people and put their names and their addresses in the paper the next day. Not... Like these are real newspapers that did this.

Nancy Eddy:

And then what would happen is they'd lose their job. So there was a reason that people were scared and thinking about carrying that with you, what if you have dementia and you're kind of going back into prior times in your life? You may be more scared about being out. Also you may have lived through the AIDS epidemic and seen loved ones and have some medical trauma around that, right? Maybe you were a partner to someone who died and you weren't able to be at the bedside, maybe their family swooped in and made all the decisions and you were cut out. You know, I mean, that happened very, very commonly. So, and they could be victims of discrimination or violence in the past. So I think not everyone is going to come with this baggage or come with this in their history.

Nancy Eddy:

But I think it's good to be aware of the possibilities and kind of be open to learning about someone and their history like that. So then, also gay elders or LGBT elders are much more likely to be single, much more likely to live alone. And it's like four times as likely to not have children. So when you're thinking about caregivers and community and support when you grow older, they really may need those long-term care facilities and they need us to help kind of create a good plan for them.

Dr. Lynn McPherson:

Well I know as a social worker, I have many dear friends who were social workers who had taught me so much about best practices in hospice and palliative care. Things like when you meet a patient, listening with an open heart and the spirit of curiosity. What are some best practices that we can apply to addressing this entire population?

Nancy Eddy:

Yeah. So, we talked a lot about terms at the beginning and I know that there's a lot of anxiety over messing up. I would caution folks to think of these terms as labels to be placed on someone. You know, you want to get a fluency with terms just so you feel more comfortable, but we're always here to come to that individual, come to that individual in the bed or in the home and meet them where they are. These are real palliative care best practices, right? So I think we can do this. We know what we're doing to do real personalized care. But part of that is adopting someone's language, mirroring their language, don't assume based on appearance.

Nancy Eddy:

When you're writing a note, so when you're documenting, write what the person wants to be called in your note. You can say, "Oh, I met with this... Met with Sally, a transgender woman," and then use she for the rest of your documentation. Also when you're talking with your colleagues about the patient,

talk respectfully, even if they can't hear you. Use the correct pronouns, you can be an example for others that this is not a joke and that this is something to be taken seriously and that they can do it too. Intake forms: do you have sexual orientation or gender identity questions on your intake forms?

Nancy Eddy:

If you... These pronouns are... People get really hung up on the pronouns and worried about them. If you make a mistake, that's fine, correct yourself and just move on. You don't have to belabor the point. And if you hear a colleague making a mistake in front of the patient or not in front of the patient, correct them, because if you don't correct them, you're leaving that onus on the marginalized person to correct them. And if you don't correct them, you're saying that's not important. So, you can just say, "Oh, Dr. Smith, Alex goes by she pronouns or uses she pronouns" and move on.

Dr. Lynn McPherson:

Absolutely. I could see not adopting that as a best practice ranges anywhere from annoying to downright hurtful. And my only example is my name is Mary Lynn McPherson. And I go by Lynn, but there are people who persist on calling me Mary, which is annoying. I can't imagine if it's much more personal, like your gender identity. Oh my gosh, that could be so hurtful, like that one patient we had in the hospice. So excellent points. What can we do specifically? Any ideas for creating a welcoming or safe space in our palliative care teams and for our patients? What are your thoughts?

Nancy Eddy:

Yeah. I mean, we're asking them to open up to us, right? So I think that they deserve for us to meet them and create a safe space. I think that being aware of who else is in the room, right? Someone may not want to open up to you if their mother is in the room or someone else. Just kind of use your spidey sense, right? And leave crumbs to show that you're LGBT friendly. If there's one thing that folks take away from this podcast, I think that understanding the process of coming out is huge. So you don't come out once in your life and then you're out and you don't have to worry about it anymore. You know, I, as a 42 year old lesbian come out probably three or four times a week and I have to make a decision every single time, is this safe?

Nancy Eddy:

Is this some... Is this where I want to go? Am I going to hit backlash if I say this? And I mean, simple things like going to the car mechanic. The car is in my wife's name. When I come in, do I say, oh, I'm my wife's name? Or do I say, "oh, you know, it's under my wife's name, it's this". Do I out myself? And I think about those things every day through every interaction. So you can imagine something very small like that you think about and then going into the hospital, the person who's coming in to change you, who's coming into to help make a decision about your care. I want to know if they're going to accept me. And it's really nice if I know before I say something, right? So if they have a pin that has a rainbow flag on it, that makes me go, "oh, okay. That's okay. I'm okay with this person".

Nancy Eddy:

Or a gender pronoun pin or if they come in and say, "hi, my name is Alex. I use she, her/she are my pronouns". If someone says that to me, even if I think it's obvious, you do look like you use she/her pronouns, of course you do, saying that to me allows me to then be open and makes me feel more comfortable. So I think if there are ways that you can show that you're LGBT friendly. A lot of people now, like on their Zoom or on their emails, they will put their pronouns. And I had a colleague say, "well,

I'm didn't put my pronouns because I thought it was obvious". But the reason you're putting the pronouns is so that you are showing others that it's okay for them to say their pronouns too.

Nancy Eddy:

You know, it's okay, you're accepting. So leaving those crumbs can help create a more friendly space. And I think you mentioned saying friend, using more gender neutral language is always good. You know, who's important to you? Do you have a friend or a partner or a spouse? If someone came and said that to me and said the word partner or a friend or spouse, That would make me feel like I can share more information with them than if they said, are you married or who's your husband, do you have a husband or something like that? One of the things that I'm trying out right now is not walking into a room and saying Mrs. X or Ms. X and Mr. Y; just coming in and saying, "hi, I'm a social worker. Are you [full name]? How would you prefer me to call you?", instead of defaulting to Ms or Mr.

Nancy Eddy:

And then some of the things that we do without thinking about it, like family meeting can even be off-putting to someone. They may think of... If you're an older LGBT adult, you may think of your family as something really specific that doesn't relate to you. But if you say we're having a care planning meeting, or who's really important to you in your life, who could be at this meeting to help plan for your care? Things like that. So...

Dr. Lynn McPherson:

Wow. Those were excellent tips. And that's really an eye opener, I guess I never really thought about me sharing my pronoun preferences as much for other people as it is, or even more so, than for myself, sort of like getting vaccinated for COVID. So it is largely used for the greater good. That's an eye-opener. I appreciate you making these points. And I think this has really helped to heighten awareness. So as we wrap up here Nancy, is there anything else you want to share? Any final to-go points here you want folks to hear?

Nancy Eddy:

Yeah, I could talk for days, I think, and there's so much to learn and say, but I think that self-reflection is really important. I think we all have our own internal biases and I think really thinking about that, where are you uncomfortable and doing some work around it. You know, reading a book, watching movie, doing something that's going to give you some more comfort maybe in this topic. And I think that, as I said, we're palliative practitioners, this is what we do; we talk about hard things. We talk about death. We can talk about death, we can talk about this. We can do this. So I just want to encourage everyone and the opportunity for our palliative care is to really make a difference I think here, to be educators and leaders, and want to encourage everyone to do that.

Dr. Lynn McPherson:

Yeah. I think palliative care has done a good job teaching the rest of the world so many other skills. We should be a leader here as well.

Nancy Eddy:

Yeah.

Dr. Lynn McPherson:

So important.

Nancy Eddy:

Absolutely.

Dr. Lynn McPherson:

Well, again, we've been speaking with Nancy Eddy, a social worker with Union, well started at Union but MedStar altogether together, the PATCH program, telehealth talking about the LGBT community and best practices, and we're very appreciative for your time and your insight, Nancy, thank you so much.

Nancy Eddy:

Thank you, Lynn. It's a pleasure.

Dr. Lynn McPherson:

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