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HIV Prevention in LGBT Adolescents: A New Center's Innovative Approach

Dr. Jennifer Caudle:

Lesbian, gay, bisexual and transgender patients comprise a population susceptible to disparities in health care. Although the LGBT community has the same health concerns as their heterosexual counterparts, LGBT individuals may be at higher risk for other health problems due to various factors including societal discrimination and difficulty accessing health care. But what about the health care of our LGBT pediatric and adolescent patients? I'm your host, Dr. Jennifer Caudle, and with me today is Dr. Robert Garofalo, MD, MPH, and Full Professor of Pediatrics and Preventative Medicine at Northwestern University, Feinberg School of Medicine. He's also an attending physician at Children's Memorial Hospital and he's the director of the first and only gender, sexuality, and HIV prevention center at the Anne and Robert H. Lurie Children's Hospital of Chicago. Dr. Garofalo, welcome to Reach MD.

Dr. Robert Garofalo:

Thank you for having me.

Dr. Jennifer Caudle:

I first wanted to talk about the center that you have. Can you tell us a little bit about the mission of your center and some of the work that you're doing there?

Dr. Robert Garofalo:

Sure. It's a multidisciplinary center that focuses on both clinical care and a range of sort of academic subjects that really include sexual health, gender, sexuality, HIV prevention, and health disparity is affecting sort of adolescent and young adult populations that largely are at risk of acquiring HIV. The center sort of does this through a variety of mechanisms, clinical care, research and evaluation, education, professional training, as well as some advocacy work mostly tailored toward sort of high risk adolescent populations that include but are not limited to sort of the homeless, LGBT adolescents, questioning youth, and our center really strives to sort of do our work internally at our academic center, but also to partner with likeminded sort of community-based organizations to kind of create an environment where clinicians, academics, scientists, and community health workers can really collaborate and design projects that are sort of significant for this population.

Dr. Jennifer Caudle:

What's your specific role at the center?

Dr. Robert Garofalo:

So I'm the Division Head of Adolescent Medicine and I'm also the Director of the Center. I started the center back in I think 2011, and it really was sort of organically created, and it grew out of both our clinical programs related to sort of HIV positive youths and gender non-conforming children and adolescents, as well as a fairly robust sort of NIH-funded sort of research program dedicated largely to HIV prevention but increasingly hopefully towards other disparities affecting this population.

Dr. Jennifer Caudle:

So this is something that you created the center, I mean with all of the resources that you were talking about, but I think that's quite fascinating. You talked about doing some research and special projects that you all are involved in. Are there any particular projects or research that you'd like to talk about today?

Dr. Robert Garofalo:

Sure. I mean I think our research projects tend to be community driven and community engaged, and kind of focused on hopefully the

practical solutions to problems. They are things that really help young people get through sort of certain aspects of their lives. So one example is that we have pilot tested and have an ongoing study that looks at the use of text messaging as a component of hopefully helping HIV positive adolescents successfully take their medications.

We also have a project, the first ever project that's an HIV prevention program and intervention for young transgender women that was written by young transgender women. It started with funding from the CDC, now has funding from the National Institute of Mental Health as a two city efficacy trial that we're doing with the Fenway Community Health in Boston. It's a very gritty, sort of youth driven intervention that hopefully is going to reduce the incidents or at least the risk of HIV for a very high risk population of young transgender women.

We also have sort of a longitudinal study, one of the first longitudinal studies of HIV negative young men who have sex with other men, or young gay and bisexual men aged 16 to 20 that hopefully will follow them throughout their young adulthood to look at factors related to the acquisition of HIV and other sexually transmitted infections.

Those are just sort of a snippet of some of the research that we have but we tend to be very practically focused and community engaged here with our research efforts.

Dr. Jennifer Caudle:

Right. I think it's really great. I actually was looking at your website the last couple of days and I saw kind of some of the logos even that as assigned to the projects that you were just describing, and they do seem very specific to the groups that they're working with and it's really community engaged. You get that feel from the website. I really like that.

Dr. Robert Garofalo:

Yeah. We have one hopefully that we'll get, I mean this is...you never know with the NIH, but we do have one project that's a collaborative process with Children's Hospital Los Angeles, University of California San Francisco, and Harvard Boston Children's Hospital, which would be the first national study of the impact of medical interventions such as pubertal blockers or cross-sex hormones on gender non-conforming children and adolescents. So that grant is currently pending at the National Institute of Child Health and Development, and we're very hopeful that that might receive funding because it would be a very important non-HIV oriented study that I think would really move the field forward with regard to the medical care of transgender children and adolescents.

Dr. Jennifer Caudle:

You know, going back a little bit to some of the projects that you have that are focused on the HIV risks in the LGBT community, can you talk to your listeners a little bit about some of the risks, maybe some of the numbers or statistics with regards to LGBT youth and HIV risk?

Dr. Robert Garofalo:

The numbers are kind of hard to pinpoint. I mean we do know that upwards of two thirds of new infections occur among men who have sex with men, an overwhelming majority of those at least increasingly tend to occur in younger populations. So we do know that it's a significant health disparity that continues to affect at least young men and really men who have sex with men across the ages. Over the past probably five to seven years I would say it's really, the HIV epidemic has increasingly become one that affects younger and younger ages. So it's really that younger demographic group, maybe ages 16 to 24 or 16 to 29 of young men who have sex with men, particularly those of color and particularly those in the African American or black community that are increasingly becoming affected and represent the, I don't know about the new face, but increasingly the face of this sort of epidemic as we begin to combat it in now the third decade. So that's one group.

Transgender women, I think represent another unique risk group with regard to the acquisition of HIV, and their risk of acquiring HIV tends to be greater than even that of gay men. I don't think we know population based numbers or population based estimates because we don't necessarily have good epidemiologic data on transgender women that we collect in a systematic way, the way we would collect information on say males or females sort of in this country. I don't think we do a very good job of systematically collecting data on transgender individuals and that's going to be very helpful as it begins to define health disparities for this population. But for transgender women, we know that they face unique risk factors with regard to their acquisition of HIV and it's complex. I mean, I think for transgender women there's sort of an odd or dual risk factor related to their gender identity. I think it's sometimes very hard for them to find sort of romantic or sexual partners that sort of validate their gender identity as women, and then they also face oftentimes sort of economic hardship or marginalization with regard to sort of economic stability which for a subset, certainly not all, but a subset of transgender women may lead them to things like commercial sex work or prostitution as a way of sort of seeking or gaining economic stability that can otherwise be elusive for them. So for transgender women they face some really tricky risk factors with regard to HIV that very much contribute to the disparities we're seeing with HIV.

Dr. Jennifer Caudle:

If you are just tuning in, you are listening to Reach MD. I'm your host, Dr. Jennifer Caudle, and I'm speaking with Dr. Robert Garofalo, a national authority on LGBT health issues, adolescent sexuality, and HIV clinical care and prevention. Can you maybe talk a little bit about the health disparities in general or health problems in general that we might see in adolescent or pediatric LGBT or questioning patients?

Dr. Robert Garofalo:

I think to a large extent they're poorly understood. We know that there are disparities with regards to things like HIV and sort of the acquisition of other sexually transmitted infections, but we don't necessarily have a good feel of whether there are health disparities in other areas like heart disease or depression or diabetes, things that we might otherwise look at health disparities in other populations such as ethnic minority youth or males versus females. We don't necessarily collect good data on sexual minority populations such as LGBT youth to really fully understand where the health disparities may lie.

So we tend to think of health disparities in this population across what I tend to call a spectrum of dysfunction which is sexually transmitted infections, homelessness, substance use, perhaps issues around depression or suicide, yet I'm always careful to think that that spectrum, that spectrum of dysfunction in no way captures the very strengths that this population has. You know, in my clinical population I think the LGBT youth today here are some of the strongest, some of the most resilient, some of the hardest young people that really navigate, I think, the difficult road of adolescence in some ways a much more robust way than some of their peers because they've had to. I'm reticent to talk about sort of the health disparities that are often framed from within this perspective of dysfunction because I just don't think that it captures the whole picture of sort of LGBT youth that I think we're going to need to take a look at if we're really going to begin to combat the health problems that this population has. So I think we need to look at both the strengths and perhaps some of the disparities, if that makes any sense.

Dr. Jennifer Caudle:

It does. It makes perfect sense, and it's quite inspiring, and I think it's appropriate. Absolutely. Let's shift the conversation to physicians. We've got a lot of physician listeners and taking what you just said, not just health disparities as you mentioned, but the strengths of our LGBT pediatric and adolescent patients, how can physicians, how can we better reach our patients? How can we better support our LGBT, questioning adolescent and pediatric patients? What are some tips for us?

Dr. Robert Garofalo:

I think the first thing is that I often hear from doctors or nurses or providers at conferences that I speak at, they often come up to me and say, "You know, I think I do a really good job of reaching this population, but none of my patients ever come out and tell me that they're gay or lesbian," and I always think to myself, well that's kind of the wrong bar to set. I mean many young sort of LGBT patients have very good reasons for not necessarily coming out to their providers. So I wouldn't have that expectation that all your patients that are gay or lesbian are necessarily going to come out with their gender identify or their sexual orientation to a provider because they may have very realistic fears about either inadvertent or advertent disclosures of their sexuality within the context of the health care environment and the implications that that could have on other aspects of their lives, including things at home, things with their families, things related to housing, things related to their own economic stability. So I think sometimes that's a false bar that we set, like having this expectation that our patients are going to come out to us.

I do think that we should let the general guidelines for pediatric and adolescent care guide us with regard to our clinical management. So it's not about their identity per se, it's really about their own individual behaviors or their own individual feelings about who they are. So for instance, it's not being a gay man per se that should necessitate a certain test for HIV or STI, it's really your engagement in sort of some specific risk behaviors that should really guide our clinical practice, if that makes any sense. I'm sort of...

Dr. Jennifer Caudle:

It makes perfect sense, which is you're advocating and you're talking about treating the patient as a patient and not defining them, we should treat people according to our guidelines and what's appropriate for our patients.

Dr. Robert Garofalo:

Yeah. I mean I also don't think we should pigeon hole young people. I think sometimes for instance we may think if we have a young lesbian patient, for instance, there may be a tendency on clinicians to not ask that young woman about the need for things like birth control or some aspects of sort of sexual health, and yet it may be very important that at least periodically, per our guidelines, we continue to ask our patients regardless of what they might have identified as six months ago or a year ago, at least general questions regarding their behavior to guide whether they might need some preventive health services around either STI testing or family planning. So it's important not to sort of buy into say stereotypes and where they may lead us. It's really important to take an individual history from each individual patient and then use that history to guide our diagnostic evaluation.

Dr. Jennifer Caudle:

This has been a great discussion about your center, about HIV in the LGBT population, about other health issues, and some of your thoughts. Are there any other things that you'd like to add to the conversation? Any other final thoughts that you might have for our listeners?

Dr. Robert Garofalo:

I think in general we're doing a better job of conceptualizing and caring for sexual minority youth that identify as lesbian or gay. I think the new frontier for pediatricians tends to be this area of gender non-conforming children and adolescents. You know, I think this is a new and evolving area, I think there will be centers popping up across the United States that begin to do this work, ours is one of them now, but I definitely think that this is a relatively new clinical area that I think you're going to see pediatricians and clinicians needing to become more adept at dealing with, and I'm talking about children that present at younger ages with sort of gender non-conforming...conditions that are gender non-conforming and may require an added type of clinical care that's sort of multidisciplinary, and that may occur at earlier ages. So you know, we think of sexual orientation as an adolescent construct, but gender identity might occur and can occur at younger and younger ages.

Dr. Jennifer Caudle:

Many thanks to our guest, Dr. Robert Garofalo, for helping us to advance our health in the adolescent LGBT community. Thank you so much.

Dr. Robert Garofalo:

Thank you. I appreciate the opportunity to be on the show.

Dr. Jennifer Caudle:

I'm your host, Dr. Jennifer Caudle. You've been listening to Reach MD, and to download this podcast and others in the series please visit us at ReachMD.com. Thank you so much for listening.