

[Community Health Workers get an up-close view of the ways that patients experience healthcare. Insights from a patient-centered vantage point.](#)

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With new payment models further complicating a difficult situation, are some Kentucky residents struggling to get the care they need and the respect they deserve from rural healthcare systems that are under increasing strain? Dr. Rose Gonzalez explores the patient perspective with Amanda Goolman, a community health worker with Kentucky Homeplace, a Center of Excellence in Rural Health, providing essential care and support in a region with high levels of cancer, heart disease, hypertension, asthma, and diabetes.

Dr. Gonzalez: Hello and welcome back to the Health Disparities Podcast, a program of the Movement Is Life Caucus. Movement Is Life, is an initiative that aims to reduce health disparities, particularly in the areas of musculoskeletal disease and related conditions, such as heart disease and mental health with a focus on those disparities, we see in women, black and Latino communities and populations living in rural areas. Let me just mention that all views and opinions expressed in the discussion today are the participants own and do not necessarily reflect those of their respective organizations or those of Movement Is Life. I am Rose Gonzalez, a registered nurse in Virginia and I had the great honor to serve on the Movement Is Life Caucus executive steering committee, where I constantly advanced the nurse and patient perspective.

The podcast continues to build on our previous discussions, focused on value-based models of care. We produced a Movement Is Life value monograph, which provides a nice overview of how payment systems impact the provision of care, especially to high-risk vulnerable populations. And you can download this form from our website at [movementislifecaucus.com](http://movementislifecaucus.com). Now this episode will take a quick look at the impact of value-based models of care from the patient perspective and that's a perspective we rarely hear from, the receivers of most of the care. Today, it's my pleasure to welcome Amanda, who is a part of the Kentucky Homeplace Team. Welcome Amanda, welcome to our podcast, how are you today?

Amanda Goolman: I'm doing great, thank you for having me here.

Dr. Gonzalez: Why don't you tell us a little bit about yourself and also a little bit about Kentucky Homeplace.

Amanda Goolman: I am a mother of three. I am a community health worker with the Kentucky Homeplace program, and we have a 30-county range that we cover in Kentucky and we help people get access to like medications, eyeglasses, dental care, discounted dentures, all kinds of different services that maybe they would not have access to, maybe their insurance

don't cover that, or they just can't afford it. So, we have different programs that are available for mostly people that are within 100 to 133% of the federal poverty level. That's mostly the range that we serve. We don't charge any money for the services that we provide. We don't have an age range that we do cover. So, anyone can be served through the Kentucky Homeplace Program, no matter what age they are.

Dr. Gonzalez:       What I do remember about Kentucky Homeplace, when I first went to Hazard, Kentucky to do the operation change program was talk of supplying someone a refrigerator because there was no place to refrigerate their insulin. And it's incredible in this day and age to think somebody may not have a refrigerator to store their insulin, but that's the sad reality of our country today. So, I'm so glad for the work that you do at Kentucky Homeplace and the services you provide. I've already learned about how extensive you are. So, as you work at Kentucky Homeplace, talk to me a little bit about the kinds of patients you typically see in any given day or week.

Amanda Goolman: Most of our population that we see are the neediest of the needy. They are barely scraping to get by, they can't afford sometimes their \$8 copay.

Dr. Gonzalez: I know about copays because I remember hearing from someone in rural Virginia, how they save for two months to gather up enough funds for copay for a primary care visit just to get their meds filled. So, the poverty is extreme and where you live in the beautiful mountains in Hazard, Kentucky, it's hard to get around. And even gas is costly to be able to afford, you have to plan your trips. So, poverty is a huge impact there and isolation.

Amanda Goolman: And then, I've heard countless of times, some of the clients that came into my office like you said, they save for their copays. They tell me, I either buy my medicine or I ate this month. And it's truly sad that it's come down to either improving their health outcomes or they feed themselves. And sadly, that's the way sometimes that comes out to be, and we as community health workers, we try to fight that barrier for them and we search for resources and if they come in for one thing, like medication, by the time we get done talking with them, we may realize like they may need something else. So, we kind of like breakdown and get their trust, so by the time they are done talking with us, they know that our doors are open. They can call us at any time and not be ashamed or scared to open up to us and let us know that they need help.

Dr. Gonzalez: Because I think it's hard to ask for help and there's a certain amount of pride that's involved. And you have to kind of bridge that gap,

you have to get that connection to build that safe place. So, it's so appropriate, Kentucky Homeplace, that safe place, so that conversation, there but for fortune go you or I, right? So, it can happen to anyone and there's nothing wrong with asking for help and needing help at this point in time, in our journey called life. So, I bet you, your clients almost see you as friends and angels.

Amanda Goolman: Yeah, we have a close connection with our clients and they feel like family to us. It's the closeness that we have and most of us is community health workers. We serve the counties and communities that we grew up in Beth County, that I'm a community health worker in, I grew up there. So, I have that trust in the community, everyone knows me, and they know that I'm wanting to help people. I have a heart to serve and they know that they can call me if they have a problem or something that they need and I'll do my best to try to help someone.

Dr. Gonzalez: I want our listeners to understand that trust is paramount, right? Trust is at the top and because you already live in that community and people know you, and you're a reputable organization, people trust you because there's always somebody out there trying to take advantage of people and as you get older, you're more susceptible to that, right? So, you come in and have that trust relationship and then the journey begins

for them to get health care. So, talk to me about the types of clients you see.

Amanda Goolman: We do some home visits for people that cannot get out, of course that was before COVID, we're not able to do that, right now. So, in Menifee County, I serve that county also, it's more up in the mountain area. A lot of people, there's no transportation there and transportation there is a huge barrier for people, they're not able to get out and go get things. So, I did a lot of home visits in that county. Some of the conditions that people have found their selves in, they do the best that they can, and they don't know really what to do or who to call. We get donations sometimes at medical spas. There's a lot of people that need incontinent supplies. When we get those, we donate those, we give those to clients. We deliver those to a lot of people because they're not able to get out and come pick those up. I do a lot of the home visits for the elderly population, especially like the wintertime so that they don't have to get out and be in the cold and things like that.

Dr. Gonzalez: And do you deliver food, too?

Amanda Goolman: I've had people call that have been out of food and I've taken food to people. I don't typically deliver food on a regular basis. It just depends on the situation commodities that the counties give out, they normally go

and pick those up on their own. If there's a certain problem that someone can't get out to go pick those up because of the transportation, I can, as long as they give permission for those to be picked up and brought to them, I'm willing to take those out to the people. I have at different times, had people actually right in the beginning of the COVID, I had a gentleman call me and he asked if I knew any food banks in the area. He had just moved and he said, I'm running low on food and I'm going to be a while before I get any more money. And I told him some food banks and something just kind of tugged at me and told me to ask him how much food do you have, do you have enough food to get you through a day or a couple days? And he just opened up to me and just let me know that he only had a few crackers and like a little thing of noodles. I just knew that I had to do something, I had to find something for this gentleman. So, I started making phone calls and by that evening I had a lot of food to just take and drop off to him. Like it was amazing how people came together and helped him out and I was able to take those to him, and it was just a huge blessing, and he was so appreciative, and I've built that that connection with him. And I still call and check on him every now, and he then calls, and he'll just see how I'm doing. It's just those connections that we make along the way, that it's a friend for life.

Dr. Gonzalez:       And it sounds like you have that inner sense after working in this arena for a while and knowing your community to feel just over a phone or

whatever, right, just to feel, oh, I'm not sure I have the whole story and you go one step further. That's a testament to your experience and knowledge and working in this arena and really understanding people who need services but are afraid to kind of really totally open up and share the whole story. So, you've tuned into him and were able to identify a real need and then be able to provide it. Now he has a contact. He's not alone and he knows who to reach out to. So, that's wonderful for you to be able to do that because I could feel, as you were telling the story, I could feel your heartstrings going into that experience and yet how wonderful for that man to have found you that day, so that is great. Now, how have those experiences changed with COVID, where maybe you can't go out to visit or has that changed a lot with your clients are they expressing concern?

Amanda Goolman: I do have some clients that where I'm not able to have that one-on-one with them. We do a lot of phone visits now because of the contact part of it. They miss that in-person connection and a lot of them, they don't have family. Sometimes, I would have clients just come in because they were just maybe lonely, they just wanted someone just to talk to and not really even needed anything. They wanted to just stop in and say hi. Now that we're not able to have that in-person visit, it's harder, we do porch drop offs now. If people are needing supplies or like a shower chair, things like that, then we will do like the visit over the phone, or like a Zoom visit. And then, we will do a porch drop-off, so that we can keep that social

distance. So, we're still able to try to meet the need the best that we can, but we're not able to have that complete connection that we did before, and I think it's making it hard on some of them that they don't have that social aspect that they did before. They feel like they're alone.

Dr. Gonzalez: So, I want to go back to 2019 when we were doing Operation Change in Hazard, Kentucky, and we really were working on this monograph to talk about value in healthcare. And Amanda, you were part of a focus group that Keisha convened to help us understand, from your perspective and from the clients that you serve, what does healthcare look like for them and what they valued in healthcare and we had a whole group, I think we had about maybe 10 or 15 people at the most, that many probably closer to 12, I think that really came together and we had some structured questions that we ask and really ask for feedback from you, and a lot of your colleagues about what their clients viewed as a value or the kind of healthcare they wanted to see and then we talked about you. So, let's talk first about some of the things we discussed about what the clients feel is important to them when they go to a healthcare encounter. Because I remember hearing a lot of missed appointments, long waiting, those kinds of things that happen to your clients who really, like you said, save up, they save up for their copay, they get to the office and things go wrong.

Amanda Goolman: I feel that a lot of my clients, when they go to the doctor or see a provider, they don't feel like they're being heard or listened to and they're being rushed. Like you said, they have saved up for their copay for that visit, a lot of our Medicare people have a lot more of out-of-pocket costs than the Medicaid people do. They're not being listened to, like they feel like they should, they may be being rushed to the visit. I know that providers have an allotted time that they can spend with each patient, and then, of course, the long wait to get an appointment. You'll call, your sick that day, but it's a week or two before you're able to get in to see a doctor. The biggest part is probably just not being heard; they feel like they're just not being listened to.

Dr. Gonzalez: In that vein of discussion where they feel they're not being listened to and many of them like you said, shared that they had long waits and I think being passed over. You shared a personal story with us that was very moving, really showed us how the system fails individuals.

Amanda Goolman: Well, from my past experience, I was looked over and not listened to, by a set of doctors. I had been diagnosed after the fact with breast cancer at age 30. In the beginning, I knew that something wasn't right. I knew something was wrong and I wanted further testing and I was told no, because of my age. Even after my mother had already been diagnosed with breast cancer, even with a family history, I was still told no.

Something wasn't right, and I knew that I wanted further evaluation. I knew something needed to be done but I could not get them to listen. It wasn't until my mother was diagnosed a second time with breast cancer, that they finally took me serious. She was diagnosed with a different type of breast cancer the second time and I was finally able to get a mammogram. They did biopsy and it came back cancer. So, what I have learned from my experience, and I've tried to advocate is if you feel like something is wrong or you feel the need to get a second opinion, if you feel like something's just not right, we know our bodies better than anymore, go and get the second opinion. If the first doctor will not listen, take the time to listen to your concerns, go to someone else because I honestly feel like if my mother had not been diagnosed the second time, then I would probably have been very advanced in my cancer diagnosis. Luckily, mine was found at an earlier stage than most people. I was able to have surgery and I didn't have to have treatments because of the surgery that I've chose to take. I have the cancer gene, so does my mother, so we have that going for us also. So, it's very important, if you take anything from me that I say today, don't let anyone ever tell you that you don't deserve that second opinion or that you don't need to go get that testing because even if they tell you that it's not anything that's piece of mind for you.

Dr. Gonzalez: Thank you for sharing that story. And from your interactions with these providers, do you have a sense why they wouldn't listen to you?

Amanda Goolman: They kept saying I was too young. They didn't feel like I met the requirements to have cancer. I was angry for a long time, like before I was finally able to get a mammogram done. My mother, she was upset, she's like I've had cancer, I don't know why they're not taking you serious. And my mom, she even said, I would go through it again, just to know that you was able to find your cancer. I just call it a God thing, how it happened, the day that my mother found out that she had cancer and had the cancer gene, I worked next door to where I go to the doctor, so I walked over on my lunch break and I told him I need to get scheduled for a mammogram as soon as possible. The receptionist looked at me because she knows my family and she said, you're not going to believe this. She said, our mobile unit is coming today, I can fit you in on your break this afternoon, she said, if you can walk over on your break, we'll squeeze you in this afternoon. Like I get chills thinking about it. It was just, amazing how all the pieces came together. Everything just started just fondly coming together for me. And then it was like two days they called and they're like, we feel like something's wrong with this mammogram, you need to go to whoever your mom is seeing, you need to go see them. And then, I went and had the diagnostic mammogram then and they decided to do the

biopsy. And it was just a God thing, that's all I can say, it was the God thing.

Dr. Gonzalez: In many ways, it sounds like you said, like divine intervention, right. All these things came together at once, but what I think seems frustrating and I wonder if it's an outcome of value-based care that, you didn't fit into the parameters of the disease process and the age group it manifests itself in, right. So, they're kind of like looking at you, like you can't have it, you're not in the parameters instead of looking at you and what you were saying, because you're absolutely right. Nobody knows their body better than themselves. I know what my body feels and for a provider to just go through guidelines maybe, and just kind of focus on guidelines rather than on the patient and I think that's one of the things I heard at that focus group, they're not looking at me as the patient, as the individual coming in with the problem. They're looking at a guideline, oh, this can't be, no you don't fit into this. No, please, somebody don't just type that you saw me in the computer, but can you look at me and listen to me and really heed what I'm saying? So, in our discussions, I think we realized that some of these payment systems with parameters like that, that said, oh, we can't give you a mammogram. Or we don't even listen to that because we have these guidelines that are just like one size fits all, you're outside of that. You're you and you have a history of it, and then you are coming in with something is not right, a red flag and they don't pay attention. I hope

somebody gave you an apology somewhere along the way, but I'm really glad that you had some divine intervention. It shouldn't happen in today's healthcare system to anybody. So, I thank you for sharing that story, we heard a lot about care and how maybe the providers don't have enough time because they're limited with time. So, we went through this exercise when we were there, where we had the ladies talk about in the focus group, what would be their ideal health system. I'm going to ask you that question from all your experience in working with all your clients and your own personal experience, if you had to describe or create an ideal health care system, what are the big takeaways that you would suggest needs to happen in healthcare?

Amanda Goolman: First thing would be more affordable, more affordable for especially our Medicare people. They have the hardest time. I think over anyone being able to afford their medicines. Insulin is a big thing. We see that daily, people struggling to get insulin, \$200 to \$300 a month even with their insurance sometimes and they just cannot afford to pay that. There's no way and then being able to have more time with the provider that would be ideal.

Dr. Gonzalez: Do you think that the clients feel respected by their providers and do you think they have a trusting relationship like they have with you, with their providers?

Amanda Goolman: I think some feel that connection with their providers. I personally, with my provider, she is wonderful, and I feel during my cancer, she was great. She actually fought trying to get me a mammogram and of course, insurance kind of kicked back on that because she wasn't a specialist. So, I do feel like some of my clients feel like they have a connection with some of the providers, but then there's also some clients that feel like they spend more time with the nurses than they do the actual provider. And it's like, they're in the door and back out and they sit and type on the computer the whole time. I've actually heard, actually my parents have said they didn't even look up from the computer. He never looked at me the whole time. It's kind of sad, I mean, to not have that eye contact, that personal experience with the patient.

Dr. Gonzalez: It sounds like if you're able to speak out for yourself, and finally take a stand and create that communication link with the provider, some people may have better relationships, but it doesn't sound like the system is focused on that link. It sounds like the system is focused, like in your case, the individual you were seeing couldn't even order the mammogram, their insurance was beating back because they weren't a specialist and that you didn't fill these parameters. So, why should you need it, so the system, these payments systems, and the way this functioning, where people are so eager to put data and computers and not even really

listening to the patient. And so, if a patient is easily intimidated and can't speak out for themselves. It's kind of like they saved this money, and \$8 is a lot of money for them to go to this visit that's rushed through, and maybe they haven't been heard and that has to feel so frustrating for individuals who are looking for answers and that's a function of the system that we have right now. And I'm sure that since you're in rural community, it's not that easy to find a specialist.

Amanda Goolman: From where we live, we have to travel for certain specialists about an hour, some of the other areas, even longer that they have to travel. Transportation for some of the clients, that's a huge problem and sometimes they don't meet the qualifications for the transportation. Like even Medicaid people, they may not even meet the qualifications to get the transportation. They have to give a certain amount of time for their appointment, if they forget to schedule transportation, they have to miss that appointment. And there's just different qualifications that you have to meet for certain transportation. It's hard to be able to even go see a specialist.

Dr. Gonzalez: I can only imagine how hard it must be to see a specialist with so few and then traveling a long distance and trying to navigate that. Do you feel that you and your colleagues at Kentucky Homeplace serve as

navigators for these individuals frequently as they interact with the healthcare system?

Amanda Goolman: Absolutely, we help them navigate through a lot of the healthcare system. We help them with their insurance, a lot of the different healthcare needs that they have. We help them sign up for insurance, when it's open enrollment, if they want to change their insurance plan, we can assist them with that. Even down to calling the doctor with them, if they need to call and sometimes people just need that little bit of a push to be able to have someone to kind of be there for them, for them to speak out. We're kind of the support system that they need to feel like that they can speak up for themselves.

Dr. Gonzalez: Amanda, we're so grateful for the kind of work you do, you're very special to do that work, because I know it has to be challenging. Healthcare is really a partnership, it should be a partnership, right? It should be a partnership between me, the patient and the provider and we should be able to have the trust that you are able to have with your clients in Kentucky Homeplace, right, to enable that trust relationship, so people are put on a healthier journey in life. So, they can find out maybe what they need to do, what could they need help with and how could I feel better, right? Because we all want to feel better. So, there's much that we have to do in our system to change that and part of that is really speaking

out on podcasts like this, to bring attention to it. So, first of all, I'm so grateful to you today, Amanda, for sharing your story, for talking to us about Kentucky Homeplace and the work you do and for the clients who served, I'm sure you're a blessing to them and it sounds like you do incredible work in the mountains of Hazard. And I appreciate you for coming on today and sharing.

Amanda Goolman: Thank you for allowing me to be here with you all today, I appreciate it.

Dr. Gonzalez: And I also want to thank our listeners for joining us today for another discussion about health disparities. You'll be able to access a transcript of the podcast on our website, [movementislifecaucus.com](http://movementislifecaucus.com), remember to subscribe to us on any of the Spotify, Stitcher, Google, or Apple podcasts. Please be safe, be well, let's keep working to achieve health equity, let's keep those doors open. Amanda, thanks again, have a great afternoon, so appreciate it. Until the next time, bye everybody.

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