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Ohio Cardiovascular and Diabetes Health Collaborative

Podcast 19 - Engaging Patients in Quality Improvement Initiatives

Transcript

[Voiceover] Michael Konstan: Welcome to Cardi-OH Radio, a podcast of the Ohio Cardiovascular and Diabetes Health Collaborative, also known as Cardi-OH. This is Dr. Michael Konstan from the Case Western Reserve University School of Medicine, and I serve as a principal investigator for Cardi-OH, a statewide network of Ohio's seven medical schools. Cardi-OH is funded by the Ohio Department of Medicaid and shares best practices to improve cardiovascular health and diabetes outcomes and to eliminate health disparities in Ohio's Medicaid population. I hope you enjoy today's podcast.

Aleece Caron: I am Aleece Caron, associate professor of medicine at Case Western Reserve University and a member of Cardi-OH's team best practices. Today's podcast will explore the importance of engaging patients in quality improvement initiatives. We'll talk about what's involved in strategies to keep patients engaged. With me today is Dr. James Campbell. Dr. Campbell is professor of family medicine at Case Western Reserve University. He is also the chair of geriatrics, co-medical director of Metro Health's accountable care organization and the medical director of the Jennings Center for Older Adults. In addition to building a successful geriatric academic program at Metro Health in Cleveland, Ohio, Dr. Campbell has published numerous articles and book chapters in the areas of substance use disorder in older adults, physician home care, and geriatric trauma. His research efforts have focused on these same areas of interest, and most recently on preparing faculty and physicians in training to practice in a quality-driven patient centered model of care delivery. Quality improvement is important to me because it is my area of research and if done well, it can deliver sustained improvements in care delivery and outcomes and patient and provider experience. I appreciate you being here with me today, Dr. Campbell, to share your perspective as a primary care physician and leader in quality improvement.

James Campbell: Thank you very much, Aleece. It's my pleasure to be here.

Caron: So, Dr. Campbell, why is it important to involve patients in quality improvement efforts and what are the benefits?

Campbell: The first most important thing is that patients provide a reality check that we forget how much we need. We get involved in sort of the high flutin and the practice and the this and the that and busy with our fishbone diagrams and all sorts of things. And the patient will bring you back to the reality of well this is what that looks like when I show up in your office. This is what that looks like when I have to wander around and find a lab or do this or do that. And this is what it means if you're going to ask me to do something additional. It's those reality checks that help to transform a quality improvement project into a practice change quality improvement that is sustainable over time.

For example, if you talk to patients about blood pressure and you look at the guidelines, it says, "Oh yeah, the patient's supposed to be sitting calmly relaxing 5 minutes before their blood pressure gets checked." And you talk to the patients, they'll say, "Boy, that's never happened." Every time I've had my blood pressure checked, they call my name, scream out in the waiting room, tell me to hustle on over, get into this little room, they wrap this tight cuff around me the second I sit down, and they're off and running and checking my blood pressure. Sometimes they'll check it again. But it's important that sort of when we think we're doing X, Y, and Z because that's what's written. When you actually sit down and talk to the patients, they say, Boy, that's not true. The other thing is that it's really important because patience can help us understand the flow and the process.

And you know, for example, if you're telling people, well, I need you to come back for a repeat blood pressure in two weeks, they will ask questions about, well, I'm dependent on transportation. That's either transportation from my children or transportation from hospital or transportation from some sort of public transport. And they're trying to figure out is that possible? For example, at the place I work, in order to be able to use the hospital transportation, you have to have a scheduled appointment. You can't just say to them, "Well, I want you to come back in two weeks, and in order to make it convenient for you, we're going to say you can walk in anytime. You don't need an appointment." And the patient said, "Well, that doesn't work because if I don't have an appointment, I don't have transportation."

Something that seems paradoxical and we would not have thought about patients also can feed back to you on materials, things that you're giving to them for patient education. They may not admit if they have true illiteracy, but they may be able to say, "This is pretty complicated. This is pretty hard to see." They may even for some of my patients who are older may say, "Well, this type set is just way too small. I can't see that. How am I supposed to do what it's telling me to do?" And for example, they will get an after-visit summary, and they will sort of give me the less is more lecture. And they will say there's so much here that I can't tell what's important. I can't tell. The med list says, well, these are the meds that are continue. These are the ones that are stopped. These are the ones that are historical. And they're like, I want to know what medications I'm supposed to take.

And so, they help you to understand how that all fits into their life and into their ability to process things in addition to the fact that some places will say, "Oh, well that's all available through their my chart or their personal electronic medical record." And they say, "Well, that doesn't help me because I can't access my personal electronic medical record." Whether that's because they've misplaced their password or whether that's just because they don't have high quality internet at home and are unable to access it. On the other hand, they may say, "Well, really, what I need this for is I take this home, I show this to my daughter, she tells me what it says and we work together to figure out what comes next and whether then it might actually be better for it to be on the electronic system because then it's more available to the daughter."

So, they can really help you feedback, you know, the educational materials, whether it's the right educational level, the right number of diagrams, the right size of the type, the right number of pieces of information per unit of paper. And then there's the issue around every time you put patients and patient families onto your improvement team, you get information. You get information about what's really important to them. Is it really important to them to have a blood pressure of 139 over 89? Or is it really important to them to not have a stroke? Or is it really important to them

to not be taking a diuretic at 6:00 at night and then having to wake up all night to urinate or whether that's something more fundamental. I don't want to take more than three medications. I don't want to take medications that cause me to have to stay up at night to urinate. I don't want to take medications that might cause me to be impotent.

And they can also talk to you about sort of how much or how willing they are to come in for frequent recheck visits, whether they're willing to do things like check their own blood pressure at home. You know, those are the sort of things that really help you understand what's important to them. We think their health is primary, but their health is a part of their life. It may not be as important to them as the fact that their daughter just lost her job or as important to them as the fact that their son just got arrested. There's also issues about helping health care providers embrace change as part of the process because they're able to see patience. They're able to see how the patients see that as beneficial. It takes it out of that cold world of, well, I want to improve this number. So, the next time I get a report from my boss about the number of times I've controlled their blood pressure, followed up on an abnormal blood pressure, I look better than the clinic down the street.

It actually comes down to sort of, oh, I remember Hazel's face and Hazel was talking about, well, I know that if I can do this right, I won't have a stroke like my sister Florence had and I don't want to have that stroke. All of a sudden that whole health quality improvement office quality improvement practice change environment becomes real, becomes important, becomes valuable. It also is an empowerment. It empowers patients to feel involved in their own health care. And they will not just do that for the individual. They'll talk to their friends. They'll talk to their family. They'll say, "Oh, my doctor actually involved me. He got me involved in this and then all of a sudden other patients will come in." I say, "Oh, this is a great practice. This is a practice that cares about who I am, what I mean, and what my part in the health care team is." Too often we sort of deliver health care to people instead of delivering health care with people.

Caron: So, Dr. Campbell, thank you. That was great information about why we should really involve patients and families in our quality improvement efforts. But I think one of the things we all struggle with is how do we get started on this initiative and how do we get patients and families involved?

Campbell: And that's critical because as you're assembling your quality team, first of all, you want to get a diverse set of people from your own team. You want to have providers, you want to have front office staff, you want to have telephone staff, you want to have nursing, you want to have the MTAs, you might even have transportation, whoever it is who's going to impact what the issue is that you're trying to improve. And it's very easy once you get in the habit of then saying, "Oh, we should have a patient join us." And people will say, "Oh, this guy'd be great or this lady' be wonderful." So on and so forth. And they all say, "Oh, this person really wants to help us." So, you begin by identifying potential areas that you want to improve. And it's always the hardest to take that improvement area and narrow it, narrow it, narrow it until you get to a specific measurable change where you can do an intervention and see that you've made a difference.

You know, usually we all try to boil the ocean and it's hard to break it down and figure out, no, we just want to figure out how does this one area get a little bit better. As you're setting your overall goals and aims, that's a great time to have a patient on board because they can help you phrase and put those aims together in a way that makes sense. Not only to a provider population but also to a patient population and you'll be interesting because what'll happen is that then you'll see whether it's the nursing or the MTA for an office staff whoever they're all patients as well somewhere and you'll empower the patient voice and they will start to give you patient feedback not just feedback of oh well this is what it's like to answer the phone they'll say well yeah when I

go to my doctor he does this and this feels better than what we do here and all sudden you're like, "Oh, well that's great information. I would never have known that." But you got to that because you said the patient's voice matters. The patient's voice is a part of the process, a part of quality, a part of improvement. So, as you're setting your goals for the project, your patients and your advisors will contribute to not only how those goals are written and what those goals sound like, they will actually help you decide what that goal is. Is your goal to say we're going to improve blood pressure control or is your goal to say we want to try to have a healthier patient population with less strokes and less people going on dialysis? You then have to stop and choose a method of engagement. Your method of engagement may be different depending on the population you're working with. If you're working with significantly older people, 75, 85, you may have more trouble with doing any sort of virtual type process.

Consider how you're going to engage those patients to help focus your quality efforts and then just asking them to just help develop it and implement it but having them there right at the beginning so they feel ownership of the process right from the start. They feel like they were part of determining the goal. They were part of determining the specific quality initiative that was going to be put together. They were part of designing it, part of figuring out how we're going to test it, part of talking about how we'll even implement it and then essentially their input is usually critical on how to sustain it. The patients will help you on what is the focus you have chosen. For example, if you're focusing on improving the communication with patients, patients will give you critical information.

So, when you're engaging patients in your quality improvement effort, make sure that you have sort of a good sense in your mind and you can communicate with them which part of the process are they helping you with? And you may want them to help with the whole process, but are they there at the process of just getting started, just trying to figure out what quality improvement initiative will be worked on, or are they at the phase where you're really looking at designing and testing solutions, or are they at the phase where you're looking at implementing and sustaining change? You may want them in all three phases, but helping them to understand, you know, did they get on halfway down the bus? Did they get on the train halfway down the track? Or are you putting them in right at the beginning? They'll be okay with either one. They just want to know. The patients will help you on what is the focus you have chosen.

For example, if you're focusing on improving the communication with patients, patients will give you critical information in terms of what's the best way to communicate with them. Is it verbally? Is it written? Is it text messages? Is it e messages through their electronic personal medical record or is it a multitude? Usually the answer is not one, the answer is multiple. And how do you actually find out? We're going to try to even put it for patients. Well, their method of learning of choice is X. So that when we go back to them, somehow the chart says, oh, this person is happy to get a text message, whereas this other person may say, this person can only deal with the telephone or you know, we have patients with aphasia or other issues.

And you say, you really have to figure out because you have to communicate with their family and have their family communicate with you because they may be able to communicate when they're with you face to face and you can take time but their aphasia may be bad enough that the telephone becomes a nonuseful device. What methods will allow you to investigate the patient experience? How are you going to get them to share? How are you going to get them to open up? First of all, you have to be nonjudgmental and non-defensive. You have to really call out the first time one of your patient advisors says, you know, that doesn't sound like the good idea or, you know, that doesn't

actually sound like the way things really happen. And you quickly stroke them and say, “Thank you so much for giving us that feedback. That’s exactly what we need.” And that opens up the door for the other patient advisor or family advisor or the other members of your team to start to give you more clear feedback because whether or not you know it, if you’re sort of the boss of the team, if you’re the provider on the team, if you’re the team leader for the clinic, you have an inherent power in a conversation. That power role can block communication. It can block people from giving you good feedback on what’s really happening, giving you good feedback on how to actually change things. Then you have to think about what are the patients you really need to hear from. For example, if you’re focusing on reducing barriers to providing input, you’ll want a method that allows you to engage with patients who may have perceived or experience those barriers.

So, for example, if your hospital is very invested in electronic communication and you have a series of patients who say whether it’s due to poverty or learning or just unfamiliarity that they are not good at electronic communication. Find a way to get them in the party and so that they can be involved in saying, “Well, how do you get my voice? How can I tell you that those actually are barriers? Those turn me off. Those make me think you’re just not listening.” And help them to understand how extensive do you want the engagement to be. Sometimes it may be a very simple, short, please help us get this change underway. We got to get it kicked off. We’re going to have it all looked at in 3 months.

Otherwise, they’re like, “Well, if I start to do this and I start to get too involved, am I going to have to do this for another year?” So, if you set an expectation, you know, we did an advisory group at one point and we said to everybody, the first thing we said is this meeting will by definition stop in six months. So, give us your all for six months and then we’re going to let you all go back to your lives. Should provide a reasonable opportunity for patients to share their experiences, share their expectations, share what they think.

They can do what they, you know they often will think they don’t have much to offer and you have to help them understand oh you have much more to offer than you have any idea and they can give you a set of perspectives that you may have totally lost track of. We all get so deep in the weeds of trying to figure out this and that particularly on the medical side—I’m going after my own profession—that we forget putting this all into perspective of their daily life. If they’re having trouble putting food on the table or if they’re having trouble keeping their heating going in their house, we have to be very clear about how much we can ask them to do to try to improve their blood pressure and how are they going to comment on the issues which you’re seeking feedback. Give them an exact recipe. This is how I want to hear from you. This is how I want you to give me information. And then frequently seek information for them to say, did that work for you? Did you feel like you got to speak up? Did you feel like we were listening?

So, we talked about how much time they’re going to be involved with the team, but we also have to remember time is money. How much time are they going to be able to donate to this project? How much money are we asking them? Are they going to have to pay for parking? Are they going to have to pay for transportation? Be wary that there’s often hidden costs in being involved in something like this. Are there in-kind resources that they can be utilized to sort of help them feel like this is of value to them? Have coffee. Have cookies, whatever it is, so that there’s a way that this is not just a full out them giving and getting nothing back. What’s the organizational commitment? How well is your organization going to support having patients involved in bringing patients in? Will they support transportation? Will they support parking? Will they support helping people achieve reasonable

internet access? And be realistic about your engagement strategy. Be clear about what your patient advisers can expect.

Some methods of engagement include one-on-one debriefs, interviews right after a meeting, saying, “How did that go? Did that work for you? How was it?” Do it right in the moment because if you wait too long, they will forget. Surveys are valuable partially because they can be anonymous. Always ensure that the survey, even if it has some Likert scales and some yes/no questions, at least one place where that they can put in open-ended feedback. What else do we need to know? What did we forget to ask you? And teams and task force for quality improvement projects, you know, figure out the quality committee. Explain the quality committee to the patients. How do they fit into that quality committee? They’re mentors. They’re educators. They’re reality checkers. They’re the feedback loop that tells us what that quality change really looks like.

Caron: So, Dr. Campbell, clearly, there’s a lot involved in getting started on your quality improvement project and doing a lot of planning to get your quality improvement project started so you can be successful. But how would you go about selecting a patient or a family member to participate in your quality improvement effort?

Campbell: There’s lots of little tricks in the trade that’ll help you. The first and more important is to make sure you have somebody who’s willing to be vocal. You don’t want to basically have, oh, I’m going to take Susan because Susan loves this practice and Susan loves her provider. And Susan just says good things about us all the time to everybody. That’s great. That’s wonderful. But you want somebody who’s going to be able to say, you know, you guys are super, but you need to know this. And you need to have somebody who sort of says, you know, I can say that and I won’t get that you guys will understand. You won’t mind. You’ll still take care of me. Finding somebody who feels like they can voice what they have to say safely, openly, and repeatedly. Somebody who values their own opinion can be difficult when you’re trying to voice that opinion to your provider. Again, the provider has a position of power. Even if you don’t wear the white coat, even if you don’t do all the trappings that sort of put the distance between you and the patient, there is still a power relationship. You have control of their records. You have control of what time their appointment starts and stops. You have control of access to be able to listen to their hearts, touch their bodies. Those are inherently things that give you control. And when you’re trying to flip that and say, “Well, now that we’re in this quality committee room and we’re talking together, you as the patient are the person in charge.” You’re the educator. You’re the person giving us information. You’re the person who’s determining what the story needs to be and they’ll say, “Oh, okay. That’s interesting. Thanks.” Make sure you have someone who actually has time to attend the meetings.

You know, if you get somebody who’s very busy and you’re working with a somebody who works in the tax business and you’re trying to do your quality improvement project in March and April, it’s not going to work. Somebody who works with tax returns is no time in March and April. You know, make sure that they’re going to be able to come to the meetings and come to the meetings on a regular basis because then they become a part of the team and once they become a part of the team they become much more able to give you feedback and do they have time to review the materials and are they willing to provide feedback and have you given them a format for that feedback? Send me a note, send me an email, whatever you want some way so that they can get their feedback back to you in a safe and efficient way. The level in participation is going to vary depending on the needs of the team so set up things will work for specific projects. It’s not going to be the same for every project.

Set up conference calls for those who can't use the computer so that you don't lose that whole segment of the population. You're going to get a different perspective if you're using a virtual meeting and distance technology from people who are comfortable with virtual meetings and distance technology than people who are not comfortable with virtual meetings and distance technology. So, you have to make sure that you have multiple formats in order to be able to allow that patient advisor to give you feedback on what the story is and how that project is going. It's oftentimes very helpful if you can select a patient who has the condition the project is focused on. If the project is focused on diabetes, get a patient who has diabetes, whether it's a new patient, an established patient, long-standing patient, and they can help you understand and address the barriers they're trying to eliminate whether that's cost, whether that's pharmacy, whether that's complexity of regimen, whatever it is, they're going to be able to give you feedback that's going to be very, very valuable. And don't forget, you can always have more patients on the team. You don't have to have just one. You can include somebody who's identified with this disease, that disease, multiple diseases. It's good to have perspectives from both men and women. And it's especially valuable to have patient advisors from different ethnicities. The whole concept of a different understanding of health and disease in different populations is massive. And unless you have some representation, say your clinic has 30% Hispanic individuals, have somebody from that population to help you understand not just the language but also sort of, you know, if you're dealing with sort of end-of-life issues. What is sort of the ethnic understanding of end of life among Hispanic population.

And again, you can always say anytime you use some terminology like Hispanic. Hispanic is not like A and white is B. Hispanic is A through F and A through Z because it's different for someone who is Puerto Rican versus Peruvian versus Dominican Republic versus Mexican as their origin. So, and you know, it's also when people say, well, we'll get we'll have one old person. Well, you know, you now spend a third of your lifespan being over the age of 65. It's unlikely that all of a sudden when you got to 65, everybody took all their various needs and their various understandings of the world that they developed over the last 65 years and all became one unified mass of people who say, "Oh, now I see the world through the lens of an old person." And so, once I have an old person, I could understand one old person. I understand all old people. Encourage patients who represent the population or the clinic that you're working in.

If you're working in a population where you're taking care of patients in the jail, you're going to have patients who are incarcerated are going to be your patient advisors. If you have a population with hepatitis C, you may need to have people there who have active or treated substance abuse. If you have looking at a population with a high rate of depression, you got to make sure you're looking at all that you can use patient councils, family councils, advisory councils so that it's not just all labeled on one person and there is a power of the group. You know, if you put a set of people together, they'll feed off of each other, and you'll get even more information.

Caron: So clearly there's a lot to consider when you're selecting a patient to participate in your quality improvement activities. But how would you go about inviting a patient or a family member to be involved?

Campbell: It's best to start with somebody who has a well-established relationship with that patient. Maybe that's the clinic nurse. Maybe that's their primary provider. Somebody who can say, "Oh, you and I, we've been seeing each other in this office for the last seven years. I need to ask you a favor. We're trying to improve blood pressure control, and we were wondering if you could help us figure out how we could do a better job of taking care of your blood pressure for the patients in this practice because if it's a one-on-one personal relationship, the person's much more

likely to say yes, and they're going to feel fairly honored." They're going to say, "Oh, you really want my opinion? That's great. Thank you very much." And everything takes off from there. Explain why you want them on the team. Explain how important they are. Explain how much their feedback is going to drive what you do and don't do. You're going to have to explain to them what is quality improvement? What's that all about? That we don't just do things. We try to figure out how to do things better. And we sort of continuously are trying to improve things because the world changes around us. As we've all seen in the last two years, we had to change all our processes to wrap around the fact that COVID changed the way we took care of patients. Also, figuring out exactly how those things relate to your project and give them specific examples of how they may be able to help. Boy, you can help us understand how to look at materials we're handing out and see if they're useful or not useful. You can help us understand what do you have to do after we ask you to do things in the office. And then make sure you talk openly about the logistical questions. How do we set up the meetings? How do we make sure they're at a time you'll be able to come? How do we figure out how you're going to attend? Whether that's in person on the phone to a conference call. Address potential barriers. If there's a transportation issue, say you're doing a population of quadriplegics, you may have to do a lot of things around addressing barriers to them being able to participate. Patient advisors need to be provided feedback on the background. If they're going to be a partner and help co-lead a quality improvement initiative, they need to understand what the quality initiative is about, why you're doing it, what's the driving force? Remember, they are experts in their own lived experience, but they may not be experts in health policy, quality improvement, the science, or really what the whole blood pressure, diabetes, whatever it is, is all about. And always be very acknowledge and grateful that that person is taking time—time away from their family, time away from their job, their driving, they have to come to you. They have to take time out on the phone and they will prepare. They will take this very, very seriously. Make sure you carefully protect an advisor's privacy. Make sure that you tell them not to disclose personal information. That person's personal information is private.

Caron: So, Dr. Campbell, how do you keep patients and families involved in your quality improvement initiatives?

Campbell: It's really a matter of checking in frequently. You know, if you're doing a three-month project, checking in once a month, that's like checking in three times during every meeting and saying, "Oh, I see that, you know, Tom, you haven't told me anything lately. Why don't you tell me what you think about this?" Or "You know, Fred, I see that you have some thoughts. It looks like you're about to say something. Please say that." And always at the end of every get together, do a quick debrief to say, "Did you all feel like that was valuable? Is it too long? Too short? Did you feel like you had a chance to talk? Did you feel like there was openness to allow you to talk?" Send reminders before meetings or call before meetings. Check in between meetings to ensure they're comfortable and feel useful. That's especially important because if you're having a group, many people don't feel comfortable speaking in a group and you may need to check on them one-on-one in between and say, "Was that okay for you? Did that work for you?" Particularly if you notice somebody going silent. If they go silent, that's a red flag that something went wrong. Encourage the patient to speak up. The patient perspective is important and there's no way to get that information without a patient being involved in the discussion. Avoid being defensive. We all tend to try to say, "Well, but we really aren't doing that bad a job, are we?" That's not what they're saying. They're just saying, "We think you can do better. We think there's ways to do better." Don't try to explain away what's going wrong. Just listen, hear them, and even ask them if this was being done differently, how would that look to you? How would that feel if we created a different environment? Make sure

the environment in each meeting is welcoming to feedback. Statements like “everybody has a different lens, everybody sees this differently. Fred, how do you see that?” The patient perspective on the process is invaluable and close the loop with the patient and family members. Let them know how their contributions got incorporated. Let them know what happened to the project because you may go back to them in a year later with a second project or one of their friends.

Caron: Dr. Campbell, thank you so much for joining me today and sharing your useful and informative perspectives.

Campbell: I appreciate the time. Thanks, Elise.

Caron: And a special thank you to you, our listeners, for tuning in to Cardi-OH Radio.

[Voiceover] Konstan: This concludes today’s podcast. Be sure to visit Cardi-OH.org to learn more about the Ohio Cardiovascular and Diabetes Health Collaborative.

[Jazzy instrumental outro music]

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