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Gerri Amori, PhD, DFASHRM: Hello, everyone, and welcome to *Healthcare Perspectives 360*, a podcast dedicated to exploring contemporary healthcare issues from multiple perspectives. I'm Gerri Amori, and today I am joined by Kris McCarty, occupational therapist with a master's in physical therapy, who is an inspired and passionate advocate, David Miller, patient experience coach from Johns Hopkins Health System, and Carleigh Zahn, a practicing board-certified internist and rheumatologist. Today, we're talking about patient advisory councils, what they are, what they do, and how they both help clinicians and patients.

But before we begin discussing this very important topic, it's my pleasure to tell you about a comprehensive white paper that has been developed by Coverys, our parent company, and that's available for a free download to anyone who listens to this podcast. The white paper details data gleaned from Coverys medical malpractice claims and offers risk management suggestions to increase your healthcare organization's patient engagement. There is a link right on the podcast landing page. We hope you'll take advantage of this resource.

And now, let's begin today's discussion. I'd like to start with you, Kris. We hear a lot about patient and family advisory councils, known as PFACs. In your experience, what is a PFAC? Where did they come from? How did they get started? Are they by service line or hospital or population? What is a PFAC?

Kris McCarty, OTR/MPT: Thank you for the question. These councils, near and dear to my heart, have evolved over time. And they were really a mechanism to involve patients and loved ones in decision making. They go back to the late 20th century when it was identified of the vitality of including patient perspective in that planning and treatment. And then they gained additional momentum in the 90s with the focus on patient-centered care.

The use of the tool can vary by health system, as they can be organized by different sectors, different service lines. And the goal of the councils is to provide input on a variety of patient-related issues, such as wayfinding, policies, program, facility design, marketing, or website review. It's a great collaboration that really, really supports patients and loved ones as partners in care.

Amori: All right. David, you are our patient coach here. And in full transparency, I have to tell you that I have been a member of our local PFAC for a number of years and a patient advisor, a volunteer patient advisor. And I started doing that when I transitioned into working part time, right? So people often think that that means I help patients with complaints, which is not what I do. That's not my role.

Can you explain to our audience, here, the differences between PFAC and a patient advocate?

David Miller: Absolutely. As Kris noted, patient and family advisory councils [are] very different than patient advocates. They're distinct from one another, and they serve different purposes in healthcare. While PFACs are those formal groups of patients, family, staff, providers, working in that partnership to improve patient experience, they offer that guidance on procedures and processes and quality improvement to achieve high quality, safe, coordinated care.

Now, if we take a look at patient advocates, these are individuals who work with patients and their families to help them navigate the healthcare system. They provide support, information, assistance to patients and their families, helping them understand their rights and responsibilities, and ensuring that their needs are met. And they can aid in a whole host of things from setting up medical appointments, to finding financial and legal resources, assisting in locating support groups.

But indeed, in some health systems, patient advocates are also patient relations. So, if at any point a patient or a family member's expectations aren't being met, they can, of course, bring those concerns to the attention of their care team or the manager of that department. But if the concerns remain unresolved, they can contact the patient relations team at the hospital for further assistance. And that's, I think, what you were referencing earlier. Those are the folks that help navigate, listen to what the concern is.

Of course, that information is then, in turn, shared with leadership, there's a formal review, and then, obviously, the follow-up to the patient and the family regarding those concerns. So, I think, essentially, that is the differentiation between the two.

Amori: So, to make sure I understand, people on a PFAC or a patient counselor, a patient-advisor volunteer at the hospital—they just give a patient perspective to whatever projects they're working on. Whereas patient advocates actually work with patients to help resolve issues. Did I get that right?

Miller: Absolutely.

Amori: All right. Great. I'm glad I got that right.

Carleigh, patient advisory councils and patient and family advisory councils have a unique perspective and a unique ability to identify system blind spots. They can also harness the power of personal narratives to affect change in the system for other patients and families because they each have their experience that, of course, those people working in the system don't see—they're blind spots, right? The lived experience of these patients and families allows them to see and feel things that providers may not even be aware of and therefore may remain overlooked and unaddressed.

So, if you work or you're going to an organization—if either if you work in one, or you're a patient at one—that doesn't have access to that patient perspective through a PFAC, how do you even get those personal perspectives for the organization? Is there any other means?

Carleigh Zahn, DO: Oh, this is a good but challenging question. If it's not feasible for your practice to have a PFAC, for some reason, eliciting those perspectives from your patients and patients' families would be a small but impactful way of kind of trying to help identify those blind spots, keeping an open door of communication, and just asking them about the challenges and experiences they've had.

If you're at a bigger institution, or you feel the passion, like most of us here do, you could also try to lobby for the formation of a PFAC. So, from a physician side of things, we actually have an educational hub through the American Medical Association for creating a PFAC. So there are resources out there. You just need to get on your platform and really help support the creation of one.

Amori: So we need to somehow go out there. I actually know that there's an organization out there for patient interaction, I believe it's called the Beryl Institute, that really works to engage patients and has all kinds of resources that are out there if your organization is not quite up to snuff.

You know—this is for you, Kris—and I can see a variety of ways in which the method for getting people on a PFAC may actually bias the type of perspectives that are shared, right? I sort of remember way back when we first started doing PFACs, patients were sort of cherry-picked by what they thought they would do. And they were only allowed to do certain things, like pick the color rug in the waiting room, right? Those days are long gone. Now patients on PFACs are...I sit on patient safety committee of our local hospital, and that's part of my role as being a patient advisor. So, things have changed.

But how can we make sure that our PFACs aren't being cherry-picked in a way that they actually only greenlight initiatives that may not actually represent important perspectives or rarely address true needs? So how could they bias initiatives in the system? And how can we ensure that we have a more representative, diverse PFAC?

McCarty: That is a great observation and, again, true by historical function. I think as organizations work to establish the PFACs, it should be noted that the representation of the PFAC should very closely resemble that service line that they are representing. You want the demographics to match those that you are serving.

That being said, it's also important to get a cross-sectional representation to really look and challenge, to ensure that you don't have those biases occurring unintentionally, and, you know, practicing that pause and being reflective to say, we may have this new member, but we really need to get this particular voice at the table.

So, I think it's very, very important to ensure all of those elements, that you're getting all these different healthcare lenses adequately sharing because it's not always the loudest voice, but also a clear voice.

Amori: Yeah, I like that. Thank you a lot. I'm having some thoughts, so I'd like to kind of bounce this out to all of you. And one of those thoughts is that often the people in underserved populations are those voices that we're missing on our PFACs, right? And sometimes they aren't even our largest contingent of users, but definitely it's harder to get them to join a PFAC, for goodness sakes, because they're busy with their jobs. And I mean, it worries me. It kind of scares me. I want to have everybody at the table because we do serve everybody, and we've got to meet everybody's need in our community.

So, thoughts about how we recruit maybe people from minorities, a variety of minorities, how do we make it palatable to them?

McCarty: When you're soliciting voices and looking at that, it's no different than a personalized care plan. You've got to meet them where they're at. So maybe they can't make that PFAC meeting that is 1 o'clock in the middle of the day, but are there elements of discussion that you can get their information and feedback that can impact care in a different way? No different than our individual work with patients, it's meeting them where they're at and getting those important lenses looking at the variety of care issues.

Amori: Okay. Carleigh.

Zahn: I think something to consider, as well, is—you kind of hit it on the head before, Geri—you mentioned the word cherry-picking. We cherry-pick those that are engaged or compliant with—I have a huge issue with that word—but compliant. We cherry-pick these patients. A simple first step might be, are we even engaging those who are of different socioeconomic barriers? Are we even approaching them? That might be a question that we're not even asking ourselves in our own PFACs.

Amori: That's a good question. Yeah, David, what are your thoughts on this?

Miller: I think a couple of key words that we've heard so far, community and trust, and I think in partnering and building and being a real presence outside of the hospital in the community strengthens that. And that just fosters a better relationship we have with patients and families within the hospital.

Amori: So, by doing some more outreach, we kind of let people outside of our usual circle here know that we do care, we do want to hear their opinion and their voice, and we're going to listen. So it might take more outreach to get people representative. I've watched organizations go through that.

Sometimes we're blinded by, you know, since most of the people in our catchment are pale, we don't think about the fact that everybody on the PFAC is pale. So we need to reach out. All right, that's good. Thank you.

David, I did also want to ask you, the majority of the existing research done on PFACs indicates that implementation of patient advisory councils, patient family advisory councils, has a positive effect on healthcare initiatives and promotes more patient-

centered care within the organizations. It's even been said that patient advisory councils positively affect patient safety. Do you see this at your organization?

Miller: I do. And much like what we've discussed, it's that partnership with the PFACs, it's hearing those voices, and then having that diversity with respect to culture, race, religion, preference sexually, socioeconomic, all the educational background, all of those different voices. Getting that perspective, we can not only build, but we can actually improve existing programs and services.

So, for example, there was an initiative about improving handwashing education and understanding and practice. So, there was a whole piece about handwashing best practices and educating patients and families that it's okay to ask. And in implementing that, if a provider has washed or sanitized their hands, that just allowed that safety component to improve.

Amori: All right. Good.

Carleigh, how do you imagine that patients that are under your care—you know your patient load—would contribute to a PFAC?

Zahn: I'll be honest. I don't think every patient is a good fit for a PFAC. And that's okay. I think to truly be an advocate, you need to be open to challenging your own biases and to challenging others' biases. And that may be hard for some people to do. So I think PFACs are unique in that it's a group of people that are all in on this. They're dedicated for this. And that may not be every patient.

Amori: Okay. So, you have to kind of look and see who might be right and who might not be right. And those people that want to be engaged, you ask them to be more engaged, right? That sounds good.

So, we're coming to the close of today's episode, and I'd like to ask each of you our usual ending question. So, what is the one thing you'd like our listeners to take away from each of your perspectives on the idea of PFACs? Kris, you want to start us?

McCarty: You know, as a healthcare provider, recognize the absolute value that that diversity of voice and thought can bring to how we provide care. We look at life through our own lens. And when we look at those transactional interactions in healthcare through the lens of different eyes, it can be highly impactful how we change and how we learn and grow as healthcare professionals.

Amori: Thank you. David, you want to give us your one thing?

Miller: Sure. From the patient end: getting involved, having your voice heard, being able to join a PFAC—it's empowering. It gives you a perspective in new initiatives and improvements. And then from the provider end, it's that relationship. It's listening.

Listening to hear, not listening to respond. Really taking that into consideration whenever you are implementing whatever that project is.

Amori: Okay. Good. And Carleigh.

Zahn: As a medical professional, we have a unique platform we can use to advocate for change. The biggest thing we need to bring is willingness and time. The evidence is already there for PFACs. There are websites and resources. So, I would tell my peers to really consider being advocates for this change in supporting our patients on all levels.

Amori: Thank you. Thank you so much.

This has been an amazing discussion today on patient involvement in the process of PFACs and patient and family advisory councils. So I'd like to thank you, our panelists, for joining us today and our audience. I look forward to seeing you next time in *Perspectives 360*.

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