

Pull Up a Seat: Engaging Patients as Empowered Partners in Health Equity Transformation

PRESENTED BY MAIMAH KARMO,¹ and AMY PIERRE,^{2,3} MSN, ANP-BC

From ¹Tigerlily Foundation, Stone Ridge, Virginia; ²Memorial Sloan Kettering Cancer Center, New York, New York; ³Flatiron Health, New York, New York

Presenters' disclosures of conflicts of interest are found at the end of this article.

<https://doi.org/10.6004/jadpro.2022.13.3.3>

© 2022 Harborside™

Abstract

At the JADPRO Live Virtual 2021 keynote interview, Maimah Karmo, CEO and Founder of the Tigerlily Foundation, spoke with Amy Pierre, MSN, ANP-BC, on her breast cancer experience and drive to establish an organization that educates, advocates for, and empowers young women of color at every stage of their breast cancer journey. Ms. Karmo and Ms. Pierre also discussed the role of the advanced practitioner in furthering patient-centered, equitable care.

As an immigrant from Liberia, Maimah Karmo has experienced disparities firsthand. Today, the CEO and Founder of Tigerlily Foundation is a leader in the field of women's health—and a breast cancer survivor. By working with members of Congress, Ms. Karmo has created and implemented national health initiatives for women and young girls and has worked tirelessly on the global stage to end health disparities of age, stage, and color.

During the keynote interview of JADPRO Live Virtual 2021, Amy Pierre, MSN, ANP-BC, of Memorial Sloan Kettering Cancer Center and Flatiron Health, asked Ms. Karmo about strategies to reduce health disparities among oncology

patients from underrepresented groups and the role advanced practitioners can play in transforming healthy equity.

TIGERLILY FOUNDATION

Ms. Karmo grew up in Liberia, where her mother was the Head of the Liberian Nurse Association. As a 13-year-old, she received life-saving advice from her mother, who taught her the importance of breast exams.

"I always say she gave me life, and she saved my life...because she instilled in me that my body is my vessel, the vessel of my life, and to know my body is to love it and to take care of it," said Ms. Karmo. "I began breast exams at 13, never, ever imagining what I would find out about my breasts 18 years later."

Eighteen years later, at the age of 31, Ms. Karmo detected an unfamiliar lump that convinced her to get a mammogram and see a breast surgeon. Ms. Karmo knew her body well enough to know that something was wrong, but the surgeon she consulted with told her she was too young to have breast cancer and to come back many years later at a more appropriate age for screening. Over the next 6 months, however, the lump doubled in size.

“The physician saw me, a young black woman, and she dismissed me,” Ms. Karmo explained. “She applied a standard of care that was not relevant for me as black woman, given significantly higher rates of aggressive breast cancers. I didn’t know these facts at the time; I just knew that the lump should not be in my breast, and I wanted it out.”

Ultimately, Ms. Karmo was diagnosed with triple-negative disease (TNBC), which at the time, had no targeted treatments and felt like “inevitable death.” She was struck by a grave sense of injustice—that her late diagnosis may have robbed her of a life as a mother to her then 3-year-old child.

“I knew that I had two choices,” said Ms. Karmo, describing her physical and spiritual transformation from cancer treatment. “One [choice] was to just lay down and let this happen to me, and the other was to ask God how I can serve others...I was bald, I was scared, I was sick and throwing up from my second round of treatment, and I knew that I couldn’t go back to life the way it was before, and so I asked God, ‘How do I serve? What do I do with this?’ And the answer was, ‘Tigerlily.’”

“Women are beautiful in every way,” said Ms. Karmo, explaining the name Tigerlily. “Our hair is our crown, our breasts feed our children, and our ovaries are how we reproduce our families. When you’re going through treatment, you may lose your flower petals, your hair may fall off, you may become infertile, you may lose your breasts, but like the flower, the Tigerlily, women can become stronger and transform through their journey. The name represents a woman’s ability to become more beautiful, strong, and transformed through her breast cancer journey.”

ROLE OF ADVANCED PRACTITIONERS

The Tigerlily Foundation was created to educate and empower patients of all backgrounds, including those at heightened risk, those facing health

disparities, and those with less access to care. According to Ms. Pierre, it’s a message that should be incorporated into the mission of every single cancer center.

“How can advanced practitioners begin to weave that type of work into everyday practice?” Ms. Pierre asked.

The first thing, said Ms. Karmo, is to be humble and to exercise humanity. Each person that a provider meets is different, but the fast pace of the modern world has become an impediment to recognizing the individual patient.

“I’ve had doctors come into the room to meet me the first time, and they’re looking at the device in their hand as they ask me questions, and their back is turned to me most of the time,” said Ms. Karmo. “I literally will say, ‘I would like you to look at me and see me. I’m not just a person you had before or the person after me. I am one unique person with the culture and history and needs that demand and deserve your attention. Would you look at me?’”

The system may be overburdened and there may be a time limit on the patient-provider interaction, said Ms. Karmo, but recognizing each patient’s uniqueness is essential. Secondly, advanced practitioners should “lean into” their patient, especially those who may not instinctively trust a physician because of past experiences.

“People of color may not trust people in a uniform, whether they’re blue or white,” said Ms. Karmo. “Everybody who is touching the patient along the entire continuum has the opportunity to embrace that patient and transform their health-care experience. Listen, lean in, and learn from the patient. You’ve taken an oath to protect your patient, and that means listening to them, learning from their experiences, and asking them what they need to feel safe with you.”

As Ms. Karmo explained, Tigerlily has been involved in powerful activities around engaging providers and patients. These activities invite patients of color to share their experiences with advanced practitioners of all fields in a safe environment. The first part of the experience is simply watching and listening. The second part is co-creating solutions that can help better patient care and provider support throughout the cancer care journey.

ENGAGING COMMUNITIES OF COLOR

Given the potential for mistrust of the medical community, Ms. Pierre emphasized the need to better engage communities of color. She asked Ms. Karmo to discuss tangible steps that advanced practitioners can take to improve engagement.

According to Ms. Karmo, relationships are more important than recruitment, and this type of relationship building ideally should take place outside of the health-care setting.

“It’s important to meet people in their community first before you ask them to be in a trial or a treatment protocol,” said Ms. Karmo. “I would encourage practitioners to engage with the community on a regular basis.”

At Tigerlily, Ms. Karmo and colleagues routinely conduct roundtables called ‘listening summits’ in different cities to explore unique opportunities for engagement.

“Even as a nonprofit leader who is a black patient, I practice what I preach,” said Ms. Karmo. “I listen, I learn, I lean in, I am authentic, and I show compassion, and based on the input from the community and all that we learn in summits, we then create programs.”

Ms. Karmo also underscored the importance of community ambassadors. Through their Angel Advocate Program (tigerlilyfoundation.org/programs/angel), Ms. Karmo and colleagues train black women to become patient advocates in the community.

“We give these black women the tools to go back into the community and build programs to help their members and their loved ones,” she said.

IMPROVING DIVERSITY IN CLINICAL TRIALS

As Ms. Pierre explained, diversity in clinical trials has long been an issue in oncology, with African Americans comprising less than 5% of oncology clinical trial participants despite a high incidence of cancer and disproportionately high mortality rates. Ms. Pierre asked Ms. Karmo what steps need to be taken to improve diversity in clinical trials.

As Ms. Karmo summarized, the history of racism and abuse in the US has instilled in black people a deep mistrust for the medical community.

“You’re asking a person to take part in a trial that historically may not have helped people of color,” Ms. Karmo said.

Simply discussing potential biases and actual biases, said Ms. Karmo, can create opportunities to heal within the medical system and within people of color.

“It’s one thing to talk about the importance of [clinical] trials,” she continued. “Before you offer a clinical trial, it’s important to build a relationship of trust with your patient and ask them what their perceptions are about trials.”

ADVOCATING FOR FUTURE PATIENTS

Ms. Karmo and colleagues at Tigerlily also advocate for health care as being a lifestyle option. From 5Ks to jewelry events to reaching patients on social media through Twitter, TikTok, Instagram, and Facebook, the goal, she said, is to educate young women before they get cancer.

“Just like my mom did with me, it’s critical to educate young women early about their bodies so that they can be empowered patient advocates and educate their peers about breast health,” said Ms. Karmo.

With that goal in mind, Tigerlily is partnering with different pharmacies across the country to distribute information about the importance of a healthy lifestyle and how to reduce risks and overcome health disparities.

“Our job is to give people data at the right time to make the right choices to keep them here longer and to have happier and healthier lives,” said Ms. Karmo. “Health care is not always about coming to a doctor when you’re sick. It’s about maintaining a healthier lifestyle, and for some communities, that’s not always easy to do.”

“When you invest early, however—when you stay committed, when you listen, learn, and build that relationship—then down the road when you ask to be in a trial or talk about the importance of adhering to a better lifestyle regimen, it can be an easier conversation,” she concluded.

More information about Ms. Karmo and her work can be found at mimah.com and [Tigerlily Foundation.org](https://TigerlilyFoundation.org), including an inclusion pledge (tigerlilyfoundation.org/inclusionpledgeforblackwomen) and barrier toolkits (tigerlilyfoundation.org/barrier-toolkits). ●

Disclosure

The presenters had no conflicts of interest to disclose.