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Precision Medicine Podcast, Season 6 Episode 68

#3 in the Series "Bringing Precision Medicine to Everyone"

Bringing Precision *and Compassion* to Every Cancer Journey with Dr. Arif Kamal

July 9, 2025

Karan Cushman:

Welcome to season six of the Precision Medicine Podcast, proudly sponsored by Trapelo. This is the podcast where leading voices in cancer explore how to bring precision medicine to patients everywhere.

Welcome back to the Precision Medicine Podcast. I'm Karan Cushman, your founder and host. And today I am really honored to welcome a guest whose career and personal mission truly represent why we've created this current series titled Bringing Precision Medicine to Everyone.

To kick us off today, I want to take us back a bit so that we can truly appreciate how far we've come. In 1913, the American Cancer Society was founded and by just 10 medical professionals and five businesspeople. And at that time, the word cancer, it was rarely spoken aloud and a diagnosis often meant near certain death.

As we fast-forward more than a century, the landscape of cancer care has transformed dramatically. We now have an entire podcast dedicated to talking about cancer. And the work of the ACS has contributed to a 33% drop in the overall cancer death rate in the US.

In 2021, not too long ago, the ACS appointed its first ever chief patient officer, a role created to unify and lead its patient-facing programs, which include navigation, education, lodging, transportation, and survivorship support. This happens across 5,000 communities nationwide. Today that team is driven by a team of more than 1,000 employees and led by our guest, a nationally recognized expert in oncology, palliative care, and health system innovation.

Dr. Arif Kamal, welcome to the Precision Medicine Podcast.

Dr. Arif Kamal:

Thanks so much for having me, Karan.

Karan Cushman:

Well, I really appreciate it. We have so much to talk about today, but I want to just start like a lot of our guests, your journey into oncology and your career was shaped by something deeply personal. And from what I understand, your mother's experience with metastatic breast cancer had a significant impact for you. So, I wanted to know what was that like for you as her son and how did that influence your career path towards palliative care and oncology and ultimately lead you to your role as chief patient officer at ACS?

Dr. Arif Kamal:

Yeah, I think it's important to live a purpose-driven life. And at the age of 17, I wouldn't have been wise enough to use terms like that, but as I've grown older, it's been a nice way to reflect and sort of summarize the journey that I've been on.

The reality was I didn't set out in life to become a physician. And I certainly admire people who can find their callings in different circumstances. For our family, it was really a sudden diagnosis of breast cancer. And then as it moved forward, it became cancer that recurred and became pretty clear that it was not going to be curable. As I, through my own professional journey, went from not thinking about medicine at all to wanting to cure cancer as a noble way to live one's life, it became really clear through her journey that the experience matters and that the experience is what people really take away. And that there are outcomes for many people, even more compelling than time or survival. Though oftentimes as physicians we might think that's the one and only truth, the reality is that people are complex and live their lives for many reasons. And for us as a family, quality of life was just as important as quantity of life.

And as my career shifted, I pursued palliative care to really try to understand the science and best practices in not having to make this false choice between focusing on time and focusing on quality of life. And I think that's summatively come together as my career has been about helping people, both patients and caregivers and those at risk for serious illness, live more and better days, this idea that there's a false choice between both because really our goal in medicine and really in society maybe writ large should be to help people live more and better days.

I think one of the things about being a physician and being in palliative medicine for sure is it's very humbling to learn that everyone's different and unique in their experiences and how they're driven are unique to their situation.

And listen, I've taken care of 90-olds who want to take their last breaths with chemotherapy running through their veins. And I've taken care of 30-year-olds who have foregone any type of, let's say, sort of traditional or evidence-based medicine because their goals were a little bit different.

I think that one of the challenges and opportunities for those of us in healthcare and those of us who think about the delivery of healthcare is how important humility is because it's remembering that the story is not of us as healthcare professionals. We are an actor in the play, but the play is not about us. And I think humility is one of both the hardest and yet the most satisfying components of a career in palliative medicine as an example. But a lot of what I've learned over my career is when you realize it's about someone else's story; it makes many more options okay. It makes many more conversations possible. And in fact, it facilitates the need to learn more about someone else because when you come from a humble stance, you recognize that no two people are the same, and you have to take deliberate and intentional time to learn about another human being.

Karan Cushman:

So true. It's so true. Well, so how did you decide to leave that role of bedside, if you will, working and supporting patients directly and make that move to something that's a little bit more distant, but maybe cancer at scale, if you will, for patients? How did you decide to pivot to that point in your career and why?

Dr. Arif Kamal:

I think that all of us have a really important role to play. And I think that's when a lot of us are maybe professionally even sort of reborn, is when you figure out what your highest and best use

is to play in the world. There are plenty of my colleagues who are absolutely every single day taking care of patients and at the 3-foot level are making change at scale that is lifelong and will never be forgotten by a patient and family, and there's a ton of nobility to that.

And then at the same time, there are roles clearly in medicine that think about making change at a different scale. One is not better or worse than the other, but we're all rowing in the same direction just from different parts of the boat. The role at ACS was interesting, one, because as a teenager taking care of my mom, we actually stayed at the American Cancer Society Hope Lodge in Kansas City. I grew up in a very small town in kind of the middle of nowhere Missouri. And I think part of that experience was understanding what are the experiences that others face when coming from rural areas or just geographically distant.

You think about even the concept of food deserts and nutrition deserts and things like that is that we live in a very, in the United States, a very large country. And we have one of our secret sauces as a country is that we have diversity of thought and diversity of population and diversity of geography. It is why this country is so great in so many different ways.

And so having spent time in American Cancer Society Hope Lodge and then growing up through this experience of cancer and then ultimately losing my mom and learning about palliative care and thinking about how do we take this vision of a kinder, gentler, more person centric version of healthcare to scale, the American Cancer Society came knocking and their vision was to create a unified and scaled approach to compassion across the country because the American Cancer Society is wonderful in so many different ways. It's a well-known brand, been around for 115 years. So much going for it as an organization. And yet for many people in the public, the perception of what it does, the organization does, to help the everyday person have a better experience to and through cancer was unclear for many people.

Dr. Arif Kamal:

And in my journeys in this role for nearly four years, I've found that to be true, as I've asked people what do they consider the role of the American Cancer Society to play. And I think it's one of the least known things we do, is focusing on patients and caregivers and communities and healthcare professionals. We do a lot as an organization, but until this role kind of existed, there wasn't sort of a unified team, a unified leadership structure, a unified strategy that give crystal clarity to where does suffering exist, where can the organization play its highest and best use, and where can it act in a way to bring compassion?

The way I've brought that to the organization, but I think I've also learned it from a lot of other colleagues too, is that we've operationalized a very simple, I would say simple to explain, but harder to execute formula, which is that compassion equals empathy plus action. And so, to be a compassionate organization, in our case, a nonprofit that delivers supportive services to nearly 111 million people per year, not only in the US but across the globe, that compassion, that goal of bringing that compassion involves those two components, empathy and action.

Empathy is the qualitative and quantitative understanding of the experiences of others, right? It is the ability to step outside your own shoes and understand the experiences of people going through a journey that you may not have ever gone through. And that means both understanding people's stories, understanding the data, understanding where gaps exist in care. It's putting all of that together to then guide the right action. And when done together, you equal compassion.

And I think in a lot of ways, my title is chief patient officer, but also I lead a team that is sort of the compassion team, not only the American Cancer Society. I think we also serve as a model to others and as a collaborator to others because we can't get our work done on our own.

Dr. Arif Kamal:

And I think that when we elevate the standard for compassion in the United States, whether we use a big brand like ours and partner with others, it raises the level of what we should expect from healthcare, what we should expect from other community-based organizations, what we should expect from nonprofits, including our own, and what we should expect from each other so that once we raise the visibility of issues like social isolation, loneliness, food insecurity, access to care, these really critical issues, when there's a collective voice around it, then everyone sort of wins. Because until the American Cancer Society was talking about food insecurity or social isolation or caregiver support or clinician burnout, it wasn't getting maybe the attention that it could get. I feel really privileged that as an organization, when we start talking about something, it brings attention to something. And I see that as a really important responsibility for the organization to be empathic to where the areas of suffering can be and then to take the right action.

Karan Cushman:

Well, that was quite an answer. I love everything you said. I think what you're driving towards is this concept of experience, but a personalized experience, which as we talked about in my monologue a little bit, like we've come so far from this time where we didn't even talk about it, to now we are an experience and trying to create what seems such an odd thing to say, but to create the best cancer experience, whatever that might be for every patient, right?

And so, unpacking that a little bit, that brings us into the precision medicine of things too. So, as we think about the concept of personalized medicine and that personalized experience, within that is precision medicine. And that's where we are today, where we can truly, based on a person's and individual genetic makeup, their cancer makeup, precisely test and treat their cancer and provide a longer-term life than maybe they would've had certainly back when the ACS was formed.

It's an exciting time. And I think we talk sometimes in different episodes about the moral injury that is occurring right now because I think some patients feel like precision medicine is happening. Yes, of course, I'm getting the right test and the right treatment because that's just the way things work now. But in the reality of things, it's not yet standard of care. So that goal feels more urgent than ever. And particularly for somebody in your shoes, right, I think, Dr. Kamal?

Dr. Arif Kamal:

Mm-hmm. Absolutely. And I think about both the concept of precision medicine, and as I was talking about compassion, the concept of precision compassion. And I mean, I've been oncology for over 15 years, and I think about a time where the most compelling issues we faced were really around availability. And what I mean by that is that we were looking for more available treatments, that we'd have a bigger pipeline of things to manage melanoma and lung cancer and these things, pancreas cancer where we just didn't have a ton of options. But we also were trying to figure out what are the available tests to understand someone's... the biology of their tumor a little bit better. What's the available strategies to take? And really it was a need for more availability.

And I think that in many respects, not all of them, but in many respects, we've pivoted to where the compelling issue of our time is one of accessibility. And so, to that issue of precision medicine in and of itself as a concept can only get so far because it's answering the question of what, but then we have to answer the question of who and how often and when and in what ways and what is the accessibility solutions to that that I think is really important.

Dr. Arif Kamal:

And I would say, what an amazing time to be alive where we're talking about precision delivery of care, let's say, in oncology as an example, where we've got both things to solve for at the same time. And yet we've solved a lot of the availability issues and we're really then thinking about, "Well, yeah, complex problems are complex to solve." And so, if we're going to move forward, we have to think about how we get these things to people, make sure that our clinicians who... Listen, I've been an oncologist for 15 years. I think I stopped counting at 300. I belong to membership societies that send me emails, and I get these updates on how often there's been a new indication, a new drug approval, black box warning, any sort of major change. And I think I stopped counting at like 300 and I was like, "Okay." Because I kept putting these emails in a folder that said, "I'll catch up to them when I can."

And so I think that the burden of knowledge is both a wonderful thing to celebrate and also a bit of the tax that we have to pay and account for, which is that there is so much excitement happening in the delivery of precision healthcare that the ability to, one, as a clinician to remember all of it and activate upon all of it is we can't oversimplify that and say that humans will just get better memories and they'll just become more thoughtful and intentional. I think we started a place that say, "Listen, we're operating the best we can, and we are being as deliberate, intentional, and thoughtful as we can frankly muster. And so whatever gaps exist or not, bad apples, let's make the right thing easier to do and we got to figure out what that is."

And so, I think there's a certain component of the compassion equals empathy plus action that really brings the concept of empathy to our clinicians and the clinical team and the ecosystem of healthcare delivery. Every person from the front desk staff who is saying, "Gosh, it's really hard to see suffering." And I say it to colleagues, it's like standing next to a waterfall and thinking you're not going to get a little bit wet. I mean, when you're a front desk person and you're hearing these stories of people in their difficult times, it's hard to not internalize some of that.

And I think that if you think about all the people in healthcare delivery itself, and obviously we think about patients and caregivers too, is there's a component there where everyone needs some amount of compassion, right? It's everyone needs some amount of compassion.

Karan Cushman:

Right.

Dr. Arif Kamal:

And so, the action for the front desk person might be to talk through what makes it difficult, to hear areas of suffering that other people have that you may not be in a position to fix.

Dr. Arif Kamal:

There's also something a lot more humbling, which I think the Palliative Care Fellowship for me taught me something really important as a clinician, which is not all suffering is fixable or reversible as much as we would like to. I think oftentimes clinicians, we see ourselves as fixers and we make identities around this concept of being a fixer. I think there's really something humbling about also taking action when you can, but being an ally, being a good listener and being present all the time. And that there's a false choice between the two things. We can be an ally all the time, we can be good listeners all the time and then figure out when we can take action is a large part of, I think, the maturation of any person who's in the clinical field because otherwise it's a bit of a fool's errand, is if you walk into oncology, for example, thinking that you're going to fix everything, you'll get frustrated really quickly.

Dr. Arif Kamal:

Now, what I always love is when patients share with me or caregivers share with me, "Remember, Dr. Kamal, when we first met six years ago, you said X." And I don't have that good of a memory, so probably I don't remember what I said, but what I can see in their face is how what was said made them feel. And I think that quote from I think Maya Angelou and others have been attributed to is that people don't remember how much you know, they remember how much you make them feel. And when I talk to mentees and others all the time, I say, "Our job can't be that we always know the right answer. Our job is to care. And what people will take away even when we're wrong, because we will be wrong, is that we cared enough to try and we cared enough to investigate and to go ask another opinion. And that if we were wrong, we care enough to address whatever we were wrong about."

Dr. Arif Kamal:

And I think fundamentally, the contract between a patient and a caregiver and a clinician is around care. That if we all believe that there's a democracy around care, that I care about you and you care about... Patients show their care in lots of different ways. Them spending an entire day to come to my clinic to park and walk through the parking garage, they demonstrate their care to me all the time. You just have to see it, right?

Karan Cushman:

Yes. Mm-hmm.

Dr. Arif Kamal:

Yeah, exactly.

Karan Cushman:

Right.

Dr. Arif Kamal:

So, they care and I care. And that trust exactly what you're talking about is the contract that we're in, and that's what we have to action against. And that's what I think we are really put in a position to do.

Karan Cushman:

So, we're in this place where clinicians and patients all together striving for this new ideal, this new standard of care that we're grasping for. And there's gaps that exist. And the ACS is known as a patient advocacy organization, but just as you alluded to, we're all in this together. And what are some of the ways that ACS is supporting clinicians directly, obviously in your train of thought there, but I'm curious what some of the resources look like and how clinicians are interacting with ACS, whether it is through journals or through other transactional types of events and support and such? Can you dig into that a little bit, Dr. Kamal?

Dr. Arif Kamal:

I can. And I love talking about this space because it is oftentimes sort of the least understood component of what we do as an organization. Yeah, we're a patient advocacy organization. And

yes, my title is Chief Patient Officer, but patients are sometimes the target of the intervention, but they are always the impact of an intervention, right?

Dr. Arif Kamal:

So, when the American Cancer Society does something that may be a patient program, we are either trying to impact on the patient or impact on the clinician to improve the quality of life of the patient. And we do that every single day. And our approach, from the patient support lens, has been around a capacity building and technical assistance and quality improvement lenses. What I mean by that is one of our superpowers is to convene people and to share lessons learned. We oftentimes use a model like ECHO or learning collaboratives or QI collaboratives to then recruit organizations who are looking through a sense of community to solve a compelling problem. And oftentimes we become the convener of that, the introducer of subject matter experts to the organizations who may not have that expertise in their locale and to help broaden their network, so they know who to pick up the phone and call, if not us, that their colleagues who share in a similar problem as what they're trying to accomplish.

We also, as you mentioned, we have three journals. And I say with a certain amount of pride, the most read and cited scientific publication manuscript in the history of science is actually put out by the American Cancer Society. For those who read the oncology literature, oftentimes you'll read a report, a manuscript, a notorial, original research that starts with, "Every year 2 million people will be diagnosed with cancer." Well, that article is actually put together by scientists at the American Cancer Society. And so oftentimes, the world's report on the state of cancer care comes from us.

And then as we go forward, we end up becoming the... We are the largest funder of cancer research outside of the federal government. And so, we have funded or been a part of the funding journey of 51 different Nobel Prize winners. And so, to the issue of supporting researchers, particularly for those Nobel Prize winners, we were oftentimes one of their first funders. So, to help people launch their scientific careers, we have oftentimes kind of been there for people. And it's a ton of pride to hear scientists who aren't big deals in the field say, "Oh my gosh, when I first got started, the American study helped us do that."

And then when it comes to technical assistance, I mentioned things like ECHO and learning collaboratives. We also have a very unique grassroots team member approach. So, the way I explain this is we've got about 200 team members in patient support who live and work in their communities across the country. They are locally-based, and their job is to serve as a liaison between the American Cancer Society and clinical and research and administrative professionals in their community. So, whether that's an organization of a one doc operation or a very large integrated multi-specialty practice, we have relationships with nearly all of them. And as I mentioned before, one of the ways we get our work done as an organization is to not live on an island.

I mean, the American Cancer Society, yes, has been around for more than a hundred years, but since our founding, the way we've been able to make change in the country is through partnership, whether that's with government, community-based organizations or health systems, we've done that in that way. And the only way to make that happen is to sit in the rooms with the people who are facing a compelling problem. This is getting back to this issue of empathy. It's hard to empathize how to walk in someone's shoes unless you've actually done it. And so, what that means is every single day American Cancer Society professionals, many of them who are on my team, are sitting in meetings with health system professionals and leaders and clinicians to hear about their concerns.

Dr. Arif Kamal:

Now in a collaborative way, this is not like a town hall where you're telling the American Cancer Society what's going on, this is together, shoulder to shoulder talking about, yeah, if we need more people to get precision diagnostics because understanding the root cause of the growth of their cancer or the fuel source of their cancer is going to help identify the right treatment and we're facing this challenge that not everyone's getting, let's say for example, the right testing, let's say pre-treatment, the American Cancer Society is there to stand shoulder to shoulder with that health system and say, "Yep, we are here because we presume everyone has good intent. We presume we're all trying to do the right thing, but sometimes the right thing is a little difficult to accomplish. How can we help you?" And that might be everything from a toolkit that we've created and are there to disseminate it.

That might be creating a connection, "Oh, you're trying to solve a problem that we know our team in Maine solved with the cancer center there and you're in California. What if we connected you two?" And we might also just say, "Why don't we bring a learning collaborative together and bring all the different institutions in the country who are sharing with the American Cancer Society that you've got this challenge, bring you all together with some national experts and work through a process where we might even give you a grant? So, we might buy some time and space for you to focus on this problem. We might give you the runway to do that," and then you work on it together.

And that means in any given day, we are working with nearly 200 health systems on a funded, that means a grant-funded, either implementation science or quality improvement project where we are the funder and the convener and/or technical assistance provider. And so that goes from merely saying we believe that care has to improve at a systems level to actually investing in that. That happens through wonderful partnerships we have with Pfizer. In the Change the Odds program, we have it with the NFL. In the Crucial Catch program with Merck and several others who've invested in our ability to bring those system changes to health systems. And it really has been a game changer for us for the last 30 years or so.

Karan Cushman:

The Precision Medicine Podcast will return right after this.

With the explosion of new discoveries in precision medicine, how can clinicians keep pace to know which biomarkers will guide cancer treatment decisions? Trapelo knows. Trapelo is the only decision support platform used by oncologists, labs, and payers to resolve the complexities of precision medicine in real time, eliminating treatment gaps for patients. Trapelo knows who to test, when to test, which tests to order, the preferred labs to use, and how to connect biomarker results to the right therapies. It also knows which tests and treatments align with health plan policies, streamlining prior authorization, reducing delays in costs, and unlocking the full promise of high-quality personalized cancer care. Visit trapelohealth.com to learn how you can give cancer patients the most appropriate evidence-based treatment options when time matters most.

Karan Cushman:

You just mentioned the Change the Odds campaign, which is supported by Pfizer and features... It's really a storytelling series and it's hosted by Patrick Dempsey. It really brings us back to rural America and how something as basic as where you live shapes your entire cancer journey. And earlier we were talking about access. So, access to precision medicine, personalized medicine, all the concepts we're talking about here largely depends on where you live, maybe who your doctor is, what you can afford. Can you talk about a few of the barriers that this campaign is focused on and what that actually looks like for a patient in a rural area?

Dr. Arif Kamal:

Yeah, I mean, for us as an organization, it's really one of the most impactful collaborative campaigns we've entered into. And it's realizing, as my good colleague Dr. Rob Winn says, is that oftentimes survival is based on someone's Z and A, as in zip code, right? And it's very humbling to find that people who live blocks apart from each other can have different outcomes from relatively the same cancer.

And so, I do think about cancer as big as it's getting, right? We've got 200 different diseases we call cancer. We've got more drugs than ever before. We've got more diagnostics than ever before. But as big as it seems, cancer care is actually getting smaller. And what I mean by that is there's a time where we did clinical trials where... I explain this to patients all the time. Oncologists are terrible marketers. We should not do marketing. So, we saw lung cancer cell under the microscope decades ago, and we said, "Boy, that cell is small." So, we called it small cell lung cancer. And then when we looked at it under a microscope and we said that cell is big, we called it non-small cell lung cancer or large cell lung cancer.

And so, at a time when we had two or three lung cancers, now we have at least 50 different kinds because we've identified the fuel source. It's like saying, "That's a car." And you say, "Okay, but that's a car that runs on 93 octane and this car runs on 87 octane and this car runs on diesel." Well, now you've defined precision around the concept of a car. And because then when you've defined it as 93 octane or 87 octane or diesel, when you put regular unleaded in a diesel car, what's going to happen? The car will stop working. And so, what you've found is once you've changed up the fuel source, once you understood the fuel source, you changed up the fuel source, you could change the future of something growing or in the case of a car going forward.

So, if you have 50 different types of lung cancer, it stands to reason that you're going to have clinical trials and treatment and diagnostics that are going to be specific to lung cancer number 49, which will be different than lung cancer number 38, which would be different than lung cancer number 2. And that means that you might have to travel to enter into a clinical trial for lung cancer number 49 because lung cancer clinical trial number 1 through 48 are in your backyard, but 49 is in a city far away from you.

And so, what that means is that this issue of accessibility is, as we've gotten to precision, what we've not gotten to is yet the ability to democratize that precision. Sometimes the precision requires... It introduces a challenge to accessibility, either distance, knowledge, capacity, expertise, something happens. So, we might say, "Oh, we just developed a brand new engineered cellular technique to potentially cure lymphoma in the second line setting."

"Great, can I get that in Warrensburg, Missouri where I grew up town of 15,000?" The answer to that is clearly no.

"Okay, well great, Arif. Then you just have to travel an hour and a half to Kansas City to go get that."

"Oh, that's simple, right? Well, wait a minute. That means I have to what? Take off a full day from work?"

Dr. Arif Kamal:

"Yep."

"You have to pay for gas to get there?"

"Yep."

"That means you have to have a working car because there's no bus that goes that distance?"

"Yep."

And then you're going to have to find a clinician that can do it?"

"Yep."

"And then wait, what about insurance status?"

And so, the complexity, I think it's really important for people to understand that as care has gotten precise, it doesn't mean it's gotten easier. And as some medications and interventions have gotten more tolerable, let's say, from a symptomatic or side effect perspective, it doesn't mean it's gotten more feasible to administer.

And I think that that is the interesting paradox that exists is that we would want to believe that as things get more innovative, that they get cheaper. That's not necessarily the case. And oftentimes this is not the case. That because things get more precise, that they may be more available. And that is oftentimes the paradox that they're not. And so, I think it's important to remember that we have to work on both things, that we have to work on innovation and we have to work on compassion, which I think is oftentimes expressed by accessibility. Because what is more compassionate than telling someone there's a thing and you get to have it? There are few things more compassionate than that, but I think we have to work on both because if you look at the history of cancer care, if you look at the history of cancer care, there has always been a step forward on the supportive care accessibility side that matched the innovation on the treatment side.

We came out with all these amazing treatments, and then what we figured out, for example in the 1980s is that's great. We've got all this really fancy chemotherapy. Everyone is vomiting all over the place, and that is the rate limiting step to taking the medication. And then we went, "Wait, okay. Now let's work on accessibility." The availability is we can give you four chemos at one time. The accessibility is how do we get you to come back because it feels so terrible after the first cycle you're not going to come back.

Karan Cushman:

Wow.

Dr. Arif Kamal:

And then what we did, we developed next generation anti-medics, right? Those are the 5-HT3 blockers, and we developed those medications. And so, every time we've taken a step forward on the treatment space and the diagnostic space, there's been a complimentary supportive care accessibility innovation that had to happen, that made it possible so that the innovation was not just something in a journal article, but it was something that could actually improve people's lives.

Karan Cushman:

Wow. Well, so yeah, I mean, we're talking about so many different elements of this. And I love how you say that it's gotten smaller or simpler in some ways. It's true, but yet we're unpacking all of what we mean by accessibility and the complications of that. And we haven't even talked about affordability, but I want to hit on a couple of things, real impact areas for the ACS. And as we think about precision medicine, we always say right treatment, right patient, that's the goal. And

that's assuming that someone has access to the testing. So, I wanted to back us into the work of the ACS Cancer Action Network, and one of those critical components of this is expanding insurance coverage for biomarker testing. That's where it all begins, right?

Dr. Arif Kamal:

Yes.

Karan Cushman:

Such a critical step. But even when testing happens and the cost of targeted therapies and care can still be out of reach for many patients. So, I'm wondering how is ACS helping close the gap both in access and affordability for people in those underserved or maybe more rural communities?

Dr. Arif Kamal:

Yeah. So, ACS CAN. The Cancer Action Network is our (c)(4) organization that is role is quite simple. It is a nonpartisan organization that as its north star, is increasing access to high quality cancer prevention, early detection and care for all Americans.

And so, if that's your north star, what you do is we want to preserve access, and that may be things like Medicaid has been one of the most impactful policy changes over the last 15 years that have really improved access to screening, which we know then leads to earlier detection and higher cure rates. I mean, that's pretty clear.

I mean, look, the cancer mortality rate has gone down by 34% since 1991. And that's a combination really, of less smoking, which has been a large part of the American Cancer Society Cancer Action Network's agenda as various things to make smoking disincentivized and to make sure there's the right coverage for smoking related illnesses, and also to promote early detection for non-tobacco-related cancers. And that's going to be everything. There’re five different cancers that have early detection or screening interventions.

ACS CAN is also very interested in making sure that when we have blood-based early detection tests, that there's a clear pathway to FDA review approval if that's where the evidence is. And then coverage determination decisions by Medicare such that when we get... Not if, but when we get to a place where we have blood-based early detection of multiple cancers, that will be a game changer for Americans because it will really get to the pancreas cancers and potentially the brain tumors and the ovarian cancers, these cancers that we really worry about and yet at the same time don't have screening tests for.

And so, as a North Carolinian where I live in North Carolina, I'm really proud of ACS CAN because most people wouldn't know this, but for Medicaid expansion for example, some of the loudest voices in the state capitals, regardless of the disease, agnostic to the disease, has been ACS CAN. So, when we expanded Medicaid in North Carolina, I even then was surprised to learn that my colleagues in ACS CAN were the loudest voice around Medicaid expansion because the idea is if we improve access to healthcare, then we will by nature nested in that we will improve access to cancer care. That the two things really can go hand in hand. And so, we're going to hopefully improve access to cardiac care and diabetes care and cancer care at the same time.

Dr. Arif Kamal:

And listen, as cancer becomes increasingly more of a chronic illness for many people, not for all, now that we have people living for years, for example, with cancer, it really requires then that the

policies to manage access to care that goes over the transom that really goes for years instead of months, that the investments in survivorship and other things really are going to have to change as well.

And I'm very proud of my colleagues at ACS CAN, last year I think touched 70 million lives through things like biomarker legislation, Medicaid work, follow-on testing, out-of-pocket costs. For example, if someone has a screening colonoscopy and it shows something that they need to go back in to do another colonoscopy, people had out-of-pocket costs related to that. So even the movement forward with things like the Affordable Care Act still left some gaps that made access harder. And ACS CAN has been at the forefront of all of those issues. So, I encourage everyone to say, listen, if you see something happening positive in a preserving access to healthcare, I can almost bet that ACS CAN is in that conversation.

Karan Cushman:

Well, and that's a fact. And that is certainly so true. Just I want to remind our listeners too, if you want to learn more about ACS CAN's biomarker testing legislation initiative, check out episode 62. We talked with Hilary Goeckner there and Kristine Ashcraft who are helping lead that effort. And there's some calls to action about how you can get involved and learn what's going on in your estate there.

On that same note, another area of ACS CAN is the roundtables. And I know that you're involved in helping lead several of those, one of those being the National Prostate Cancer Roundtable, which was, I think just launched last year. We spoke with Dr. William O earlier this year, two episodes, focused on prostate cancer. So much going on in that space in precision medicine and in so many ways. Can you talk a little bit more about the roundtables and why those collaborations among caregivers, providers, all the different stakeholders are so critical right now?

Dr. Arif Kamal:

Yeah, I mean, super critical because collaboration takes intentionality. I think that when well-meaning people just when left our devices, we tend to put our heads down and work on the thing that we are working on, right? It's a disciplined approach, and there's passion there and so on and so forth. We've been doing roundtables as a proper noun at the American Cancer Society for over 30 years. In fact, we launched the first one, the National Colorectal Cancer Roundtable in the White House in 1997. And then most recently launched the Prostate Cancer Roundtable.

The idea is to create an organization of organizations so that ACS as a neutral convener can bring together all the voices in a particular field or space to be able to talk and put the patient at the center so that the conversation isn't about things that we might have to worry about on an every other day, which might be fundraising. There's a limited pot who's going to win in the fundraising battle in a marketing thing and stuff like that, is really intentional time to put any agenda other than what is best for patients, caregivers, and healthcare professionals at the center, and to come into a room and talk.

And so as a roundtable, these are year round convenings that oftentimes involve an annual meeting in person, but also include regular virtual meetings, steering committees, task forces that work on various different projects and things with the whole idea that the audience for the roundtable is America, and that to push things forward, you need to have a collective voice. And the roundtables oftentimes represent that voice.

Dr. Arif Kamal:

So, if you take the example of prostate cancer where there still remains some, well, I would say more than some, moderate to high confusion among primary care clinicians about PSA testing, MRI, digital rectal exams, things like that, that the only way to address that is to take a collective voice. But there's also so much happening in, even in the treatment space about management of local regional disease, local regional recurrence, et cetera, that it requires then sort of an organization of thought. And then importantly, how do we help our, again, taking the empathy for our colleagues in the clinical world, how do we not send out seven messages to busy clinicians out there? How do we talk with one voice about what needs to be done, what needs to be thought about, et cetera? And that's really the role of roundtables.

I think it's a major priority for the American Cancer Society because it's where we see our highest and best use as a convener, and where our only stake in that game is the improvement of the health of Americans. And if we keep that at the top of what we do, then it allows all the other things that on a day-to-day operations perspective we have to worry about, we can put that aside and come talk about what's best for everyone.

Karan Cushman:

I mean, personal experience. I think that is one of the areas where there is so much confusion and so much sensitivity, prostate cancer. I've been going through a diagnosis with my brother-in-law now. Maybe six months he needs in the middle of radiation, but it is such a windy road. You just spoke about how confusing it can be for primary care clinicians. Imagine the patients navigating all of this, and then how that might affect their lifestyle in a variety of ways. So that's just one area of cancer and a diagnosis that I wanted to lead us into.

This episode we started talking about the fact that the word cancer way back a century ago wasn't even talked about, that people kind of were diagnosed and put that in their back pocket, even amongst their family members and didn't talk about it. And we just spoke about prostate cancer, and that still kind of happens in prostate cancer. Breast cancer was maybe ahead and people have been talking about it. We wear pink ribbons. But there are still stigmas that exist.

And so, the idea of delivering personalized medicine and precision medicine really centers around not just the right test or the right drug, but it's about treating the whole person, something you're very passionate about, not just the disease. It has an element to the campaign, the Change the Odd campaign. I had the good fortune of meeting Patrick Dempsey last year. We talked a little sidebar about, I'm a cancer patient. I was treated in rural Maine. I've seen what that's like. I've seen the need to go and get multiple opinions, bring that all together, but ultimately be treated here at home. And the need for this concept of mobile units to reach more patients in rural communities. And mobile units not just to collect blood and maybe the medicine of things, but to be there for that empathetic and emotional support that the patients need sometimes more than they need their therapy.

Trevor Maxwell, a good friend of mine, went through the Dempsey Center. He is a stage 4 colorectal cancer survivor. He is a walking miracle and would not be alive if it wasn't for this surround sound support that we're talking about.

So, Dr. Kamal, before we wrap up, how do you feel about the work that the American Cancer Society is doing in their approach to whole person care? And is that as essential to you as the science when it comes to, in a sense, changing the odds for patients?

Dr. Arif Kamal:

Yeah, absolutely. I think that the default in cancer care, if ask the average person, describe to me what cancer looks like to you, I think the prevailing thought would be that people imagine it to be scary, anxiety-provoking, but also cold and impersonal and separating you from your good days, right? Listen, every clinician has their own approach to this.

My style has been largely shaped by a chaplain that I worked with at the Mayo Clinic 15 years ago, and the way she opened up conversations was to really learn about a person, because she said, "No one's going to trust you on your clinical skills until they trust you on your humanity." And I think that's absolutely true, is that people have choices. I mean, there are oncologists and their oncology nurses, and you can choose where you want to go. And so, when patients bring this to opinion by the concept of clicking with another person or whatever, I think really what they're saying is, "I want our humanities to align." And fundamentally it doesn't mean you have to come from the same background or have ever wanted to hang out with each other in any other context, but it does mean that there's a trust and a rapport there that you are looking for.

And so, when I start my consults with patients and caregivers, I ask them to share with me a photo on their phone that's meaningful to them. And I imagine they think it's probably small talk or maybe I'm still reading the chart and I don't know what's going on or something, and I'm just trying to kill some time, but there's a lot of intentionality to that, because as it turns out, most people have a phone and most people have pictures on their phone that are very meaningful to them.

The activity, the assignment of picking just one, I find it to be very telling because people, one, will probably struggle. Then when they show you one, they will invariably smile while showing it to you. And then they will tell you something about that photo that you would not have gleaned from their medical record or your sense of how they're dressed or where their addresses for their house is, et cetera. You'll find something about their humanity that makes them smile, brings them joy, and is something that is clearly important to them. And if you start there, it's very clear that you know what you're working towards.

So, when a grandmother shows me a picture of her holding her kid her grandkid on a beach in North Carolina, then I say, "Ah, so we want more of that." And she goes, "Yeah, I want more of this." And so that this might be more days on the beach, that this might be more energy to hold my grandkid on a beach, that this might be get my care closer to the beach, that this might be to have memories and pictures of her and her grandkids at the beach surrounding her as she passes away, right?

The idea is that we can encourage hope when we recognize that hope is a dynamic construct, that the thing that we hoped for when we were 15 and a half, when Arif was 15 and a half was to pass his driving test us. The thing Arif hoped for when he was a very smitten 24-year-old, is that the girl he is proposing to would say yes. And the thing that he has hoped for when he was 30 is to have a healthy baby girl.

The thing is that there's always a reason to have hope. The reality though, is it changes for a person newly diagnosed with cancer versus a person like my mom with metastatic cancer, is that there is something to hope for. It might be to feel more comfortable, spend more time on the beach. Maybe it's to hope for more days. Maybe it's to hope for cure. Depending on the situation, there's multiple hope for.

Dr. Arif Kamal:

I think that what we have to do in healthcare has helped people identify what that hope is and align with them to say that "I am on your team to help you find more of what that is." And that ultimately, if that is the noble calling in healthcare delivery, then wow, what an amazing reason to wake up in the morning, not only as a clinician, but as a patient and caregiver, because it means fundamentally, we're after the same thing.

And as I encourage my colleagues who might be listening to me or others who are thinking about their experiences in healthcare, is I think we need more of that. Maybe not what a reef does, but we need more of those moments where we connect on a human level. Because even if you think about, precision medicine sounds cold, artificial intelligence sounds impersonal. There's a lot of these potential emotional threats to the delivery of compassionate care that people might interpret, right? People might interpret precision medicine as, "I'm going to get treated as a number." They might interpret AI as, "I'll never see a person again." But when I think of these things as tools to help amplify our humanity, tools to help us make our compassion more precise, tools to help us show up better as clinicians, then they are exactly the tools that we need and will help us meet our overall goal.

And I think fundamentally, that's why I'm in healthcare, and I think that's why a lot of my colleagues are in healthcare too, is we signed up for this in that sense because there was this sense of a noble calling. But I think along the way, there's a lot of distractions in a lot of ways to get lost along the way. And to think that the most compelling thing a person does as an oncologist is to pick the right chemotherapy, fundamentally think that the world has gotten somewhat easier. We're picking the right chemotherapy. I can figure that out. But what's most rewarding to me is getting to see the picture of my patient holding their grandkid at the beach, seeing them smile and then thinking, "Okay, how do we get you there? Let's get started on this journey together."

Karan Cushman:

Yes. And so, for you, the concept of precision medicine is delivering that ultimate experience that patient chooses, whatever that might be.

Dr. Arif Kamal:

Absolutely. And I think that if compassion equals empathy plus action, we have to start with the empathy before we start with the action, right? One is informed by the other. And if empathy means looking at a picture on a phone, great. That's my approach. If empathy means, "Tell me about yourself. Tell me what does a good day look like to you? Tell me what you're worried about or hopeful for when you think about the future," I think that curiosity and humility are integral to empathy because the opposite to that is hubris. And hubris does not engender empathy because if I know it all, then I don't need to understand your journey. I will pretend to know it, predict to know it, or tell you about my journey. And the reality is that in that moment, that's actually not as helpful oftentimes as clinicians think.

Dr. Arif Kamal:

And in fact, if you look at the literature, there's good literature to show that physicians in particular are very likely to interrupt a patient within the first 20 seconds of them talking.

Dr. Arif Kamal:

And oftentimes, I think we come from a good place, which is we believe that if you tell me about your upcoming trip to Disney World, and I tell you about the time I went to Disney World, that we are relating to each other. And there's nuance to that for sure.

Dr. Arif Kamal:

But I think that the challenge that I would say to my colleagues is, what if you hear that story and then ask a question as opposed to making a statement about your own experience? Ask them, "Is Disney World a really favorite place you like to go?" Because I think that curiosity, humility, helps you understand the person as a whole person. Then you understand how to be empathic to them. Because listen, I've met people who every vacation they take, they like to go to Disney World. And I'm like, "Okay. All right." Well, and then my mind starts working. If I'm taking care of them in North Carolina and I know it's going to be a 10-hour drive for them to get there to Disney, then I'm starting to think, "Well, how do I put a treatment plan together in place where they can still manage to be able to drive maybe with their partner along the highway from North Carolina, Florida," right?

So again, to the unaided eye, it may seem like small talk, but I think that that's really where empathy comes from, is listening, asking questions, being curious, understanding this person as a whole person. And I think that's honestly the fun of being an oncologist. Again, picking chemotherapy, you can look in a book and find that. I think the really rewarding part about being in medicine is the privilege of getting to know another person because we have such license to be able to do that.

As a clinician, I can ask you almost anything, and we will get to know each other, and really dive deep into who you are as a person, not only biologically, but spiritually, emotionally, relationally, financially, logistically, all the different ways. What a privilege to be able to do that. And I say that is the calling of medicine, is this immense privilege to be able to get to know someone on a deeper level than otherwise you might get to. And then the biology and the management of the disease comes along right behind that because it's tailored to that.

But I don't think the privilege of being an oncologist is knowing that there are seven different ways to treat lung cancer, and I'm going to pick the right one. Fundamentally, I think as a scientist, as a clinician, that's kind of table stakes. The real work is then appreciating someone's humanity and bringing compassion in the right way.

Karan Cushman:

So true. Well, Dr. Arif Kamal, chief patient officer of the American Cancer Society, where can folks reach out to you? Where are you active on social media most and how can folks follow you if they want to learn more about your work and obviously things at ACS?

Arif Kamal:

ACS shows up really strong in social media. So, I would look for our main branded pages on LinkedIn and Instagram and TikTok. You might accidentally run into me doing a dance or something trendy as well, which is I think again about trying to get the word out about these important messages. Obviously, you can find me on LinkedIn and X and other places too.

Dr. Arif Kamal:

What I'd encourage is we have this really important opportunity to get the word out about the hopefulness around cancer. I mean, I think for too many decades the message has been bad luck, bad genetics. And while bad things still happen to good people all the time, and in this country about every 15 seconds someone's diagnosed with cancer, it's also important to recognize that about half of all cancers have a modifiable risk factor.

So, the reason that I'm active on social media and we as an organization are active, is to change the narrative around cancer from lack of agency, lack of control, which I get it. I don't want to talk about things I don't have agency and control around either. I mean, we avoid things that we cannot control. That is the human condition. But you know what? There's some really good news here that if half of cancers we can take control in some way, whether that is screening, whether that is putting on sunscreen, whether that is putting something different on our plate today than we might have yesterday, what an amazing message to say that we have control over a destiny.

And there's nothing more, I think, satisfying than to talk to people over a dinner conversation or to see them at an airport or wherever I'm at and say, "Hey..." They say, "Oh, you're wearing American Cancer Society. Swag." I like to wear a little swag, so they'll say, "You work for American Cancer Society" and they go, "When are we going to cure cancer?" And I say, "You know the bigger question is, when are we going to start eating better and when are we going to [inaudible 00:55:38] sunscreen and when are we going to start using less tobacco? And when are we going to have more conversations about healthy weights and healthy sleep and healthy social connections? Because the answer to your question starts with answering these questions first. And when we can do that, we will find that that bigger goal is absolutely within reach."

So, I think there's a really important public health message there. There's a word-of-mouth message there. But I would say overall, when we hear the word cancer, we need to start hearing this concept of hope, hope for less of it, hope for less chance of dying of it, hope for more things we can do about it to prevent it, hope for more survivors and success stories that that's where we need to go. And I think if I'm active on social media and the organization's active on social media, it's to help evangelize this really important message of hope.

Karan Cushman:

Well, thank you Dr. Kamal, I couldn't agree with you more. In fact, for me as a patient, I don't even remember when I first heard the word cancer when it was spoke about for me. But today the way I hear it is it has given me this amazing place to spend time with folks like you. And it's incredibly positive, the connection, the empathy. It is a unique community. And I think the term fear, of course, lives there, but it's so far beyond that.

And I wanted to just ask you one more question. So, when you're not thinking about the hope of things in the realm of cancer, what are you doing? Whether it's on the weekend, on vacation, are you at Disney? What are you doing for yourself?

Well, I have a 12-year-old and an 8-year-old, and my wife's an ICU doc. And so, you can imagine over the last handful of years it's been trying times for us as a family. I think we joke somewhat tongue-in-cheek with colleagues and friends and others that between an ICU doc and a cancer doc, you would ideally not meet us professionally. You probably want to meet us at Target instead.

Dr. Arif Kamal:

So, I think we are very intentional as a family of kind work-hard play. So, I think you're going to find us at the beach. You're going to find us playing tennis or golf. You're going to find us

gardening, walking around our yard. I think we show up better for others when we take time to fill our cup up on our own. And that's why I encourage my colleagues to do that too; is you need to find... I think oftentimes clinicians think about this as, "What's my what else?" And I think that oftentimes doctors think about, "I'm going to be a good clinician. And then what else am I? I'm also a good researcher. I'm a good administrator, I'm a good teacher, I'm a good this, I'm a good that. What else do I have?" And I think for really well-driven professionals, you need a "what else" do you wake up in the morning for. And for my case, it's my family and the things we do together.

Karan Cushman:

Wise words, Dr. Kamal. Thank you for sharing your advice, your work, and your journey with us. From treating oncologists to leading national patient-centered efforts at ACS, your story really reflects what this series is about, which is bringing precision medicine and care to everyone with both purpose and compassion.

Next up, we circle back with our collaborator and good friend Dr. Kashyap Patel, and dive into the world of liquid biopsy, an exciting and rapidly evolving space in oncology. Make sure you hit subscribe so you don't miss the next episode. And we'll see you next time.

About Our Guest

Arif Kamal, MD, MBA, MHS, FACP, FAAHPM, FASCO
Chief Patient Officer, American Cancer Society

Dr. Arif Kamal is the inaugural chief patient officer for the American Cancer Society. In this role, he drives coordinated efforts to accelerate progress against cancer through the organization's patient, caregiver, and healthcare professional mission initiatives.

Dr. Kamal oversees the organization's support network, patient navigation services, educational programs, patient and caregiver lodging and transportation, 24/7 contact center, digital patient support resources, and organizational efforts that impact the full cancer continuum across 20,000 global communities. He is also a practicing oncologist and palliative care physician in North Carolina and an associate professor of medicine and population health at the Duke University School of Medicine. In 2017, Dr. Kamal co-founded Prepped Health, a company that develops innovative technology solutions to educate and engage people facing serious illness and their caregivers.

Dr. Kamal is active with several national professional organizations, currently serving as the president for the American Academy of Hospice and Palliative Medicine board of directors. He has published more than 225 peer-reviewed scientific articles and is recognized as an international expert in supportive oncology and palliative care. He has been a guest on Good Morning America and interviewed by The New York Times, CNN, NPR, The Washington Post, and USA Today.

Dr. Kamal received his medical degree from the six-year combined B.A./M.D. program at the University of Missouri-Kansas City. He completed his internal medicine residency and a hospice and palliative medicine fellowship at the Mayo Clinic, and a hematology-oncology fellowship at

Duke University. He holds a Master of Health Science in clinical research from Duke University and a Master of Business Administration from the University of Massachusetts Amherst.

Dr. Kamal lives in Chapel Hill, North Carolina, with his wife and two children.