OVERVIEW

Expert opinions and first-person accounts brought a sense of urgency to the second annual Cardiovascular Health Policy Summit’s core message: Heart patients need timely, affordable access to appropriate care and medicine.

Held in Washington, DC, the event was convened by the Institute for Patient Access and hosted by the Alliance for Patient Access and the Partnership to Advance Cardiovascular Health. Patients, advocates, clinicians, Capitol Hill staff and government representatives used the day to explore how policies impact cardiovascular care across the country.

Former U.S. Surgeon General Kenneth Moritsugu, M.D., opened the day-long event by emphasizing the importance of good policy. “If we don’t have public policies that support and encourage access, we as health care professionals and advocates have failed our patients, and we will have failed our communities,” Dr. Moritsugu noted. He implored the audience to “keep the patient at the center” of advocacy and health care.

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Patients who need innovative medicines like cholesterol-lowering PCSK9 inhibitors are fighting to get them – and not always with success. In a panel discussion titled, “Access Anguish: When is Enough Enough?,” Keith Ferdinand, M.D., of the Association of Black Cardiologists reflected on insurance denials for at-risk patients with very high LDL cholesterol who have not responded adequately to statins. It’s a “huge problem,” Dr. Ferdinand remarked, noting that for certain patients, “Just eating salmon and jogging ain’t gonna do it.”

Delays in access can be dangerous, especially for patients who are born with a genetic predisposition to high cholesterol – a condition known as familial hypercholesterolemia, or FH. The condition defies stereotypes about high cholesterol, afflicting people who are otherwise healthy and active. Few understand the irony as well as Jeff Kwitowski, an FH patient who saw his father die at the age of 60 from a heart attack. “When I was 12 or 13, my cholesterol was already 400,” recalled Kwitowski, an avid runner. His daughter Cora has inherited the disease and also requires medication to lower her cholesterol.

Despite their risk, FH patients frequently face barriers to prescribed medicine. So explained Cat Davis Ahmed of the FH Foundation. Ahmed noted that 90% of FH patients go undiagnosed. Those who are diagnosed and then prescribed a PCSK9 inhibitor are “at the finish line almost” Ahmed described, “Then they’re denied.”
Harry Gewanter, M.D., of the Alliance for Transparent & Affordable Prescriptions explained that the “extremely opaque, extremely complex” drug supply chain is part of the problem. Pharmacy benefit managers, the middlemen who manage prescription drug benefits for major health plans, exacerbate the issue. PBMs may make coverage decisions based on what’s financially advantageous to them through the drug rebate system – even if those decisions put patients at risk by complicating access to medicine that prevents heart attack, stroke and death.

The issue has a years-long history. As Ryan Gough of the Partnership to Advance Cardiovascular Health explained in “A History of ‘No,’” rejection has been a matter of course for patients prescribed PCSK9 inhibitors since the drug came to clinic. While national rejection rates have declined over the three years since the Institute for Patient Access began issuing access report cards, the decline has been nowhere fast enough for patients.

And while insurers have argued that rejections occur because physicians prescribe the drugs to the wrong patients, data shows otherwise. IfPA’s most recent report card reveals that even patients who have diagnosed FH, are already on a statin, or have experienced a cardiovascular event are being denied at a rate of one in three.

The issue came to a head recently when manufacturers of PCSK9 inhibitors slashed their prices by 60%—but patients saw no cost benefit. Dr. Gewanter speculated that the lure of a higher rebate led PBMs to stick with the higher price tag rather than adjust to the new list price and reduce patients’ out-of-pocket burden.
EMOTION, STRESS & THE HUMAN HEART

Coverage denials and access challenges aren’t just stressful; they may also be unhealthy. In his keynote address to the summit audience, New York Times bestselling author and cardiologist Sandeep Jauhar, MD, described the interconnection between the physiological heart and the metaphorical one. Despite popular conceptions of love and the heart, Dr. Jauhar explained, “The heart does not originate feelings but is highly responsive to them.” Stressful events such as the loss of a spouse or sibling can actually trigger a physical change in the shape of the heart organ, Dr. Jauhar noted.

Dr. Jauhar, himself a heart patient with a family history of cardiovascular events, explained that emotional well-being can influence heart health. He described how his paternal grandfather was sitting down to lunch with family and friends when he crumpled to the floor. The heart attack killed him and left emotional scars on his son, Dr. Jauhar’s father.

Given the overlap between emotional and physiological hearts, it’s understandable that research suggests stress management may be even more strongly correlated with artery disease than exercise, Dr. Jauhar explained. Meanwhile, patients who are depressed after heart attack are more likely to die than those who are not.

“The emotional heart affects its biological counterpart in surprising and mysterious ways,” Dr. Jauhar summarized.
RURAL HEALTH CHALLENGES

Despite the importance of access, patients face a growing number of challenges — especially patients who live in rural areas of the United States.

In a panel discussion titled, “Disparities in Rural America: Nurses’ View from the Front Lines,” Martha Biddle, PhD, of the University of Kentucky College of Nursing explained that her patients typically face multiple co-morbidities — “four-five active disease processes for most patients,” Biddle described. Rates of obesity are also higher in rural Kentucky, and patients’ risk profile is likely elevated.

Rural isolation makes managing those conditions that much harder. Biddle described patients who drive one-two hours to see a cardiology specialist.

And then there’s access to medicine itself. Eileen Handberg, PhD, of the University of Florida Health noted that some patients have 10 or more medications. Even a modest co-pay, $5 or $10, can become unmanageable for these patients given the number of drugs they take.

After the physician leaves the exam room, Handberg explained, she sometimes asks patients, “Can you afford these medications?” Their answer is often “no.”

Prior authorizations required by patients’ insurers can make access still more complicated. Kim Newlin, who moderated the discussion, quipped, “I didn’t go to school and learn how to get prior authorization.”

Policymakers are working to address rural health challenges, explained Cara James, PhD, of the Centers for Medicare & Medicaid Services. James described the agency’s efforts, which aim to improve the quality of rural health and the sustainability of rural hospital systems while also giving communities the autonomy to design a program that works best for them.
Comorbidities introduce another layer of complexity to the situation. Sarah Cassagrande, PhD, of Social & Scientific Systems, Inc. explained that the prevalence of diabetes has steadily risen in recent years, with people with diabetes having an increased risk of cardiovascular disease and stroke. Despite their risk, however, more people are “missing important points of contact with physicians, which can result in more comorbidities.”

Perhaps that’s because the burden of navigating the health care system’s complexities rests almost solely with the patient. “You go to two different doctors, and you’re the person who has to coordinate,” explained Connie Newlon of WomenHeart, who at 47 years old has undergone quadruple bypass and continues to deal with a family history of heart disease as well as comorbid conditions. The frustration resonated with Jim Barton of Mended Hearts, who explained that his cardiologist felt pressed for time, further increasing the pressure on patient and provider alike.
As the day’s final panel conveyed, at least one way to improve care for comorbid patients may be to offer a more holistic, team-based approach for patients with both diabetes and cardiovascular disease. “This is a huge issue, a multifaceted issue,” explained Alyssa Pressley, of the American Heart Association. The organization recently launched a “Know Diabetes by Heart” campaign to raise awareness about the connection between the two conditions.

Nancy D’Hondt, RPh, CDE, of the American Association of Diabetes Educators emphasized the importance of empowering people with diabetes to better understand and manage their disease.

But for some regions this is a tall order. Robin Diggs Outlaw, MPH, of the District of Columbia Department of Health described the “staggering” rates of diabetes seen in DC, where African American residents are three-four times more likely than other residents to have diabetes.

The group emphasized the value of evidence-based self-management programs, diabetes education and lifestyle changes for patients. But they also noted the growing importance of medications that carry cardiovascular benefit in addition to treating diabetes. Not allowing patients to access these therapies is “not allowing physicians to practice to the top of their game” explained panel moderator John Anderson, MD, of The Frist Clinic.

The event closed with remarks from Nick Morse of the American College of Cardiology. Morse reiterated the day’s themes of access and advocacy, urging participants to continue conveying the voice of patients to policymakers and to put the day’s sentiments into action.
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