



**ABC Roundtable:
Addressing Disparities in Contemporary Care
of the Minority Patient with Valvular Heart Disease
Summary Recommendations**

*Developed in collaboration with participants of the Addressing Disparities in Contemporary Care
of the Minority Patient with Valvular Heart Disease Roundtable*

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Executive Summary

Valvular heart disease (VHD) is a degenerative condition characterized by improper heart valve functioning, either due to stenosis (narrowing of the heart valve) or regurgitation (leaky heart valve). For several years, the standard of care for the treatment of VHD has been open heart surgery, but more recently minimally invasive transcatheter procedures, such as transcatheter aortic valve replacement (TAVR) or transcatheter mitral valve repair, are now commonly used for appropriate patients. Despite the fact that new and emerging technologies are now widely available in most major hospitals, there still exists a major gap regarding access by minority patients to these life-saving procedures. Minority and underserved patients receive far fewer treatments for VHD, despite comparable surgical and transcatheter outcomes [1, 2]. Valvular heart conditions, poor socioeconomic status, bias within the healthcare system, lack of awareness about the benefits of treatment and quick recovery time, and mistrust of medical providers are all barriers that can contribute to treatment disparities among minorities and underserved patients [3, 4]. Although these barriers often link to disparities across multiple chronic disease states, the Association of Black Cardiologists convened an interdisciplinary roundtable specifically focused on VHD due to the disease's grave prognosis when these lifesaving procedures are not given. [4, 5]. This group came together to address the urgency of developing solutions for eradicating preventable differences in VHD outcomes. While many barriers were identified, roundtable participants elected to prioritize barriers with immediately actionable solutions.

Introduction

According to The Centers for Disease Control and Prevention (CDC), 20th century advances in medical treatment and public health strategies contributed to an unprecedented 30-year increase in average life expectancy in the United States. Recent successes in protecting health and promoting longevity have provided many opportunities for overcoming the challenges of an aging American society [6]. Nevertheless, amid America's transforming population landscape of aging and diverse individuals, a widening gap exists between lower income minorities and other underserved patients in terms of disproportionate access to care and treatment for chronic diseases [7]. For example, forty-two percent of African American men, and over 45% of African American women aged 20 and older, have high blood pressure [8, 9]. Chronic high blood pressure increases the likelihood of heart failure, a primary risk factor for valvular heart disease (VHD). Advanced age and other chronic diseases, such as diabetes, chronic kidney disease, obesity, and physical inactivity,



increase risk for VHD and complicate treatment [10, 11]. The average age at diagnosis for minorities with VHD is far younger than whites [2]. Additionally, having low income increases the widening disparities gap around receiving appropriate care and treatment [6, 12, 13]. Older white patients access VHD medical services at greater rates through major market insurance programs like Medicare that are unavailable to younger minorities. Avoidance of care and treatment, which is often seen in minority and underserved valvular heart disease patients, substantially contributes to chronic disease disparities, decreased quality of life and potentially early death within these population groups [12]. Early detection based on national screening and treatment guidelines can identify risk factors (i.e. chronic hypertension, obesity) at younger ages to prevent VHD's inherent effects.

Roundtable Proceedings

As an organization committed to the identification and mitigation of detrimental effects of cardiovascular disease, the Association of Black Cardiologists (ABC) convened a roundtable of 21 diverse clinical and industry professionals from government, providers, advocacy organizations, academia, and communications, in conjunction with the Cardiovascular Research Technologies (CRT) 2017 meeting. Participants worked to develop solutions that mitigate health disparities among minorities and underserved patients living with VHD through strategic priorities. Topics included the review of the disease landscape and health disparity findings (i.e. disease burden statistics by population), understanding clinical and government perspectives on research gaps, understanding patient and advocacy perspectives, awareness-building and communication perspectives for strategies appropriate to educate patients and providers, and consensus-building and prioritizing solutions of greatest impact. The diverse group of stakeholders enriched the capacity to comprehensively address access to care and treatment differences amongst minority and underserved populations.

Understanding the Barriers

Although a breadth of barriers was discussed, roundtable participants specifically acknowledged the lack of awareness about both the disease state and less invasive options, such as transcatheter aortic valve replacement (TAVR), significant research gaps, and limited minority participation in clinical trials, as the most adverse barriers that impact minority and underserved VHD patients. Understanding barriers better situates the roundtable for developing appropriate solutions.

- 1. African Americans are more likely to decline lifesaving treatment for Valvular Heart Disease.** Chiefly important to the roundtable was addressing why minority and underserved patients are more likely to decline life-saving treatment for VHD. It is not fully understood why these patients may be declining treatment or exploring treatment options. On the basis of their patient interactions, roundtable participants highlighted the burden of having, or treating, a chronic disease like VHD as a consideration for declined treatment. Minorities have earlier onset of VHD, therefore hindering their daily activities or ability to earn income. When patients are the primary income earners, they may not be able to afford the loss of earnings due



to extensive recovery, or forgo responsibilities as a caregiver to a child or other relative(s). Other factors may also play a role. Minorities and underserved patients typically involve family members in their care-seeking decisions [14]. Improving and broadening understanding among providers about these patient considerations could improve shared-decision making and better help patients and their families choose appropriate treatment options.

- 2. Unfamiliarity with the TAVR subject matter and uneven access to TAVR.** Approved by the FDA in 2011, transcatheter aortic valve replacement (TAVR) is a minimally-invasive treatment for severe aortic stenosis that offers the potential to reduce procedural morbidity, mortality, and cost of surgical valve replacement or repair, while accelerating patient recovery and quality of life. Nationally, the average TAVR patient is aged 83 years, male and largely white (96%) [1]. Young minorities represent a population that is not eligible for major market carriers, like Medicare, due to typical age of onset. Among all patients treated with TAVR, a similar (3-yr) survival rate, similar risks, and comparable outcomes were noted [3, 4, 15]. Surgical treatment affords most patients a healthier, longer life [3, 10, 16]. However, minorities and underserved patients are infrequently referred for cardiovascular surgical treatment as compared to whites [17], creating uneven access to TAVR.

While all the reasons for patients opting out of TAVR are not yet clearly understood, roundtable participants believe that anecdotal reports from patients, combined with the low percentage of treatment for minority and underserved patients, suggest meaningful patient and provider educational gaps. Frequently, facilities that are approved to conduct transcatheter procedures exclude facilities that minorities typically seek treatments. The Food and Drug Administration's SNAPSHOT program specifies which patient populations participate in clinical trials for FDA approved medications. However, devices like TAVR do not apply to SNAPSHOT, which creates ambiguity about minority and unserved patient access to TAVR and other devices. The National Institute of Health is bound by the 1993 Revitalization Act, a public law which requires a certain proportion of minority participation in clinical studies and trials in federally funded research. However, privately sponsored trials are not bound by these rules and may circumvent the parameters. The goal of diversifying the participants in clinical trials to increase access and awareness is commendable, but advancements are still necessary [19] to increase minority access to TAVR, similar emerging technologies, and knowledge about these devices. Roundtable participants believe that improving economic incentives for centers of excellence has the potential to encourage greater recruitment of historically underrepresented populations.

- 3. Patients' and providers' lack of understanding about valvular heart disease and its prevalence.** Roundtable participants identified another important barrier as patients' and providers' lack of understanding about valvular heart disease and its prevalence. Patients typically learn about VHD at the time of diagnosis with limited knowledge about the disease state. Today, over 500,000 patients have severe aortic stenosis and more than 800,000 people live with aortic stenosis. Severe cases typically seen in minorities (14% of cases) and underserved patients necessitate intervention, surgical or catheter-based treatment to eliminate



risk factors for VHD and preserve the strength and functionality of the heart muscle [11, 16]. Minorities are at increased risk for VHD's poor outcomes due to earlier onset (ages 65-70), more comorbidities that complicate treatment, and higher mortality risk. Additionally, and despite these higher risks for poor outcomes, minorities often have higher treatment refusal rates, as compared to whites. Yet, little is known about why patient's refuse life-saving procedures. [3, 4, 9]. If left untreated, valvular heart disease has a grave prognosis; fifty percent of people die within two years and only 20% live five years post diagnosis [16].

Every patient deserves educational opportunities to promote appropriate care-seeking behaviors. General and specialty providers require enhanced education on VHD risk factors and cultural competence to omit missed diagnoses in atypical patients (i.e. younger minorities). Effective and efficient action is necessary to enhance clinical awareness about the risks of VHD in minorities and underserved patients to eliminate health disparities.

Solutions

In addition to the immediate solutions identified below, roundtable participants also explored future solutions, such as insurance/coverage improvements, better aligned incentives and greater diversity in the provider workforce and selection of facilities approved to conduct transcatheter procedures. However, roundtable participants emphasized the importance of focusing on immediately actionable items, which are described in more detail below.

- 1. Conduct patient outreach pre-survey/TAVR or post-refusal of treatment.** Additional research regarding patient expectation of treatment options, patient social influences in deciding on treatment options, and barriers to accepting treatment could provide the gateway to bridging the TAVR and/or surgical denial gap for minority patients. Receiving information pre-TAVR or surgery allows providers to address patient concerns and properly navigate shared-decision making with patients and caregivers. Post-refusal patient outreach and research allows providers and other medical stakeholders to follow-up with patients about treatment after possible initial shock of diagnosis. This provides an active outlet for providers to continue to learn about the most adverse barriers and best options for a patient on an individual level. Another source of research and outreach support is public health surveillance data, electronic health records or insurance claims data. These sources for collecting VHD care and treatment patterns for minority patients can be helpful in shedding light on the unclear causes for minorities opting out of surgical treatment. Understanding the causes can enhance provider understanding and promote interpersonal relations and care practices. Studies show that minorities and underserved patients frequently partner with family members when they seek care [15, 18, 20]. Both patient and family member surveys may prove viable in dissecting reasons for treatment denial. Companion provider surveys can gauge clinical awareness for VHD symptoms in minorities and understand treatment referral patterns. The aforementioned information can also help develop appropriate, informed, and effective strategies to increase patient and provider awareness through health education materials and national initiatives.



- 2. Develop a taskforce to increase education and awareness.** Patient education is a pivotal step in optimizing treatment in minorities and underserved patient populations. The primary objective is to encourage partnerships for strengthening communication and awareness around valvular heart disease. Recommended strategies include convening a taskforce of varying clinical, industry and community organizations to address disparities, conducting focus groups for understanding care and treatment-seeking behavior (and use this as basis for communication), and enacting diverse communication modalities that reach underserved patients where they are (i.e. digital platforms), as well as understanding who they are (via providers). Powerful and impactful stakeholder messaging is essential to effectively reach minority and underserved patients, their caregivers and the providers that care for and treat them. Supporting partnerships and information sharing between clinical, industry and community members can have far-reaching implications for eradicating differential care and treatment access among minorities and the underserved who are living with valvular heart disease.

- 3. Develop national campaign to address disparities.** Roundtable participants expressed the need for a national awareness campaign as an initial strategy in an ongoing effort to raise the profile for valvular heart disease. Greater attention to VHD is vitally important due to high mortality rates among minorities and the significant impact on elderly patients across all racial groups [13, 20]. Unlike typical VHD patients, minority and underserved patients experience early onset, between ages 65-70, and are not necessarily elderly. Death of these VHD patients can leave families without a caregiver or breadwinner and communities without important figures. Minority and underserved families more often consist of one income-earner per household, and have higher risk factors for VHD [3-5, 9, 20]. A social marketing campaign is an effective public health practice for reaching large groups within a targeted audience to encourage behavior change, and gain greater insight into their care-seeking behaviors [21, 22]. Roundtable participants emphasized key communication techniques for education, awareness, and other general communication considerations. As a first step to building an effective campaign, roundtable participants believe that additional research to understand population characteristics is essential to promote health behavior change through messages and modalities that resonate—especially among minority and underserved populations.

Call to Action

As stakeholders in the patient and cardiovascular spaces, we believe it is crucial to address healthcare access and treatment disparities in minorities and underserved patients with valvular heart disease, as these patients experience high mortality rates with low treatment rates. By crafting collaborative and diverse solutions, we aim to increase disease state and treatment awareness of VHD among minority patients, and encourage treatment. We encourage collaboration in progressing key solutions identified in the *ABC Roundtable: Addressing Disparities in Contemporary Care of the Minority Patient with Valvular Heart Disease*.



Supporting Participants: The Association of Black Cardiologists

- Seun Alli, MD (**Program Co-Chair**)
Director, Structural Heart Program, Novant Heart and Vascular Institute
- Aaron Horne, Jr., MD, MBA, MHS (**Program Co-Chair**)
Structural Interventionalist, Cardiac and Vascular Interventional Group (CVIG), Medical Director, Structural Heart Program, Methodist Dallas Medical Center
- Barbara Hutchinson, MD, PhD, FACC
President, Association of Black Cardiologists
- Cassandra McCullough, MBA
CEO, Association of Black Cardiologists
- Felix Sogade, MD, FACC, FHRS
Chairman of the Board, Association of Black Cardiologists
- Cheryl Pegus, MD, MPH
Chair Elect, Association of Black Cardiologists

Supporting Roundtable Participants

- Yele Aluko, MD, MBA, FACC, FSCAI
Executive Director, Americas Advisory - National Healthcare, Ernst & Young LLP
- Lindsay Clarke, JD
Vice President, Health Programs, Alliance for Aging Research
- Deborah Crabbe, MD, FACC, FAHA
Representative, American Heart Association
Professor of Medicine, Temple Heart and Vascular Institute, Lewis Katz School of Medicine
- Candace DeMatteis, JD, MPH
Acting CEO, Heart Valve Voice US
- Patrice Desvigne-Nickens, MD
Medical Officer, Division of Cardiovascular Science, National Institute of Health
- Jennifer Donelan
Director, Media Relations Division, Prince George County Police Department, Former Television Reporter, WJLA
- Michael Hargrett, MS
Senior Director Business Operations, American College of Cardiology
- David Holmes, MD
Professor, Mayo Clinic College of Medicine
- G. Mark Jenkins, MD, FACC
President and CEO, Cardiac and Vascular Interventional Group (CVIG), Methodist Hospitals of Dallas
Former Board Member, Association of Black Cardiologists
- Donald May, MPA
Executive Vice President, Payment and Healthcare Delivery, AdvaMed
- Susan Peschin, MHS
President and CEO, Alliance for Aging Research
- Lamman Rucker
Screen Actor, Association of Black Cardiologists
Celebrity Ambassador
- Bernard Vasseur, MD
U.S. Food and Drug Administration, Division of Cardiovascular Devices

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About the Association of Black Cardiologists (ABC)

Founded in 1974, the Association of Black Cardiologists, Inc., (ABC) is a nonprofit organization with an international membership of 1,700 health professionals, lay members of the community (Community Health Advocates), corporate members, and institutional members. ABC is dedicated to eliminating the disparities related to cardiovascular disease in all people of color and seeks to promote the prevention and treatment of cardiovascular disease, including stroke, in blacks and other minorities and to achieve health equity for all through the elimination of disparities. The association's aggressive goal is to reduce cardiovascular disease 20% by 2025.

Contact ABC

122 East 42nd Street, 18th Floor
New York, NY 10168-1898

Phone: 800-753-9222 Fax: 888-281-3574

Contact: Cassandra McCullough, MBA

Website: <http://abc cardio.org/>



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