

"Sudden cardiac arrest is a leading cause of death in the United States. Particularly alarming is that it disproportionately affects African-Americans and women – the majority of whom die before ever receiving emergency care – and that adequate data are not available for Hispanics."

Dr. Nelson L. Adams III President National Medical Association Sudden Cardiac Arrest: Advancing Awareness and Bridging Gaps to Improve Survival

White Paper

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Advisory Committee



ABC





Women Hear







Introduction

Every day, about 1,000 people die from coronary heart disease (CHD) and the majority of these deaths are a result of sudden cardiac arrest (SCA).¹ SCA is now one of the leading causes of death in the United States, accounting for the vast majority of the 310,000 deaths per year attributed to CHD[#] – more deaths than from lung cancer, breast cancer and HIV/AIDS combined.^{III} SCA is a problem with the electrical signals of the heart that causes the chambers of the heart to beat erratically – very fast and ineffectively – or not at all, preventing the heart from effectively pumping blood to the body and brain. It happens abruptly and without warning, and two-thirds of SCA deaths occur without any prior indication of heart disease.^{IV} Ninety-five percent of people who experience SCA die, within minutes.^V Although anyone can have SCA, including children, athletes and people in their early adulthood who have no sign of heart disease, it is most common in people with a prior heart attack (myocardial infarction) and/or a history of heart failure.

Cause of Death	Annual Deaths in the U.S.
Coronary heart disease	310,000
Lung cancer	162,500
Breast cancer	41,000
HIV/AIDS	14,000

SCA disproportionately impacts minorities – particularly African-Americans. A study on racial differences in the incidence of cardiac arrest and subsequent survival found that African-Americans were significantly more likely to experience cardiac arrest in every age group compared to whites.^{vi} Further, the survival rate after an out-of-hospital cardiac arrest among African-Americans was about one-third that of whites.^{vi} Even among patients admitted to the hospital, the survival rate for African-Americans was slightly more than half that for whites.^{vii} Further research on SCA among Hispanics is needed; little is known about the incidence of the disease in this population.

It is more difficult to determine the causative factors of SCA in women compared to men; 63 percent of sudden cardiac deaths in women occur in the absence of known coronary artery disease (CAD), compared to 48 percent in men.^{viii} Use of primary prevention methods such as cardiac catheterization and beta-blockers, for a sudden cardiac event, is less common in women than men, possibly contributing to the risk of SCA in women.^{ix}

Managing the underlying causes and various risk factors is a primary route to SCA prevention. One underlying cause, CAD, can be managed through treatment with medications or interventional procedures such as cardiac catheterization, balloon angioplasty or stenting.^x However, if a heart attack should occur resulting in left ventricular dysfunction, a patient's risk for SCA is significantly higher despite medication use. Some other underlying but far less frequent causes of SCA, such as hypertropic cardiomyopathy and Long Q-T syndrome, can be treated with beta blockers and anti-arrhythmic drugs upon diagnosis. Ironically, anti-arrhythmic medications can lead to arrhythmias and SCA.^{xi}

Treatment guidelines recommend implantable cardioverter defibrillators (ICDs) as the standard of care for patients at risk for SCA, given that these devices terminate 98 percent of life-threatening ventricular arrhythmias.^{xii} Despite this, studies have shown that the use of these devices and other innovative cardiovascular technologies is less common for African-Americans and women.^{xiii} As a result, a large percentage of patients at highest risk are not receiving a treatment that is proven to save lives – a problem exacerbated by an overall low risk assessment for SCA.^{xiv}



To address issues around disparities in care and to start a national dialogue about SCA, its symptoms and risk factors, the National Medical Association (NMA) convened a meeting in Washington, D.C. attended by more than 50 of the nation's leading cardiac care professionals, government officials and patient advocates. The event, the SCA Leadership Conference, highlighted the urgency to address this under-recognized clinical and public health problem. The Conference discussed the need to elevate SCA to a national health priority for all populations to effect better patient health outcomes.

Conference participants discussed what they deemed the six critical issues surrounding SCA:

- Health disparities associated with the disease
- Risk factors
- The need for more research
- Prevention measures
- Diagnosis and treatment options
- Public, patient and medical education

This White Paper is based on the data presented and the initiatives suggested by the participants and attendees at the *SCA Leadership Conference*. The goal of this communication is to create a better understanding of the high incidence of SCA, raise awareness of the risk of SCA in certain segments of the population, and galvanize healthcare professionals, researchers, patient advocates, policy makers and payers into action to reduce disparities in both primary and secondary prevention of the disease.

Describing Sudden Cardiac Arrest

SCA, also known as sudden cardiac death, occurs when the heart suddenly and unexpectedly stops beating. This happens when the heart's lower chambers (ventricles) suddenly develop a rapid, irregular rhythm (ventricular fibrillation) and the quivering ventricles cannot pump blood to the body and brain. Within seconds, the person will not have a pulse and will fall unconscious. Without immediate treatment, the person almost always dies.



SCA is not the same as a heart attack (myocardial infarction, or MI). A heart attack occurs when one or more of the vessels/arteries delivering blood to the heart are blocked. As a result, oxygen in the blood cannot reach a part of the heart muscle, causing damage to that part of the heart. While SCA may happen as a result of heart damage from a heart attack, it occurs especially when the *electrical system* to the heart's pumping mechanism suddenly becomes irregular. Problems with the electrical system may cause abnormal heart rhythms, called arrhythmias. During an arrhythmia, the heart can beat too fast or too slow, or it can stop beating entirely. SCA occurs when the heart develops an arrhythmia that causes it to stop beating.



Outlining the Scope of the Problem

The annual incidence of CHD deaths in the United States is estimated at 310,000^{xv}, the majority of which are attributed to SCA. Approximately 95 percent of SCA cases result in death.^{xvi} SCA occurs most often in adults in their mid-thirties to mid-forties and affects men twice as often as women^{xvii}, however women have less chance of recovering from an SCA event. SCA rarely occurs in children unless they have inherited a heart condition that predisposes them to SCA.^{xviii} Studies have shown that 30 to 50 percent of SCA survivors will experience another cardiac arrest



within one year. SCA is deadliest among certain segments of the population – particularly women and African-Americans:

- From 1989 to 1998, the rate of SCA increased by 21 percent among women ages 35 to 44, compared with a 2.8 percent decline among men in the same age group.^{xx}
- African-Americans are more likely to have SCA than whites and have less than a 1 percent chance of surviving a cardiac arrest.^{xxii}

At the SCA Leadership Conference, Clyde Yancy, MD, FACC, FAHA, FACP, medical director, Baylor Heart and Vascular Institute, and chief, Cardiothoracic Transplantation, Baylor University Medical Center, cited findings from the recently published Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT) – the largest trial evaluating the use of ICDs. The results of this study showed that mortality risk from SCA was significantly higher in African-Americans than whites.^{xxiii} In addition, compared to whites, African-Americans with SCA were younger and had more significant risk factors for SCA, including heart failure, lower ejection fraction[±], worse New York Heart Association functional class^{**} and higher prevalence of a history of ventricular tachycardia.^{*xxiv}

Many deaths from SCA can be prevented with immediate treatment with a defibrillator, which delivers an electrical shock to restore normal rhythm to the heart. Survival rates after cardiac arrest almost double when access to a defibrillator is provided.^{xxv} Survival can be as high as 95 percent if defibrillation is initiated within the first four to six minutes after SCA.^{xxvi} For each minute that defibrillation is delayed, the survival rate decreases by approximately 10 percent.^{xxvi} If treatment is delayed by more than 12 minutes after collapse, the survival rate significantly decreases to between two to five percent.^{xxviii}

 $[\]pm$ The percentage of blood pumped from the heart's ventricles with each heart beat

^{*} An abnormally rapid heartbeat

^{**} Classification of the extent of heart failure in a patient



After summarizing the scope of the problem, Dr. Yancy offered a solutions-oriented approach that helped shape the framework for the ensuing discussion on risk factors, disparity in care and diagnosis and treatment of SCA. He stated that for the Conference to be a success, the following issues must be addressed and acted upon:

- Reducing SCA disparities
- Promoting the use of medications and devices indicated in the broad population of SCA sufferers, irrespective of race and gender
- Elevating awareness of the risk of SCA in certain segments of the population
- Using guideline-driven, evidence-based medicine to appropriately identify and treat patients at risk for SCA

End Stage Renal Disease: A Precedent?

Dr. Yancy compared SCA with another serious, life-threatening condition, End Stage Renal Disease (ESRD). For decades, ESRD was associated with high morbidity and mortality, maldistributed access to care, and expensive, life-saving intervention. In October 1972, the federal government created the National ESRD Program, which extended Medicare benefits to cover the high cost of medical care (dialysis or transplantation) for most individuals suffering from ESRD. Dr. Yancy stated that such legislation may serve as a precedent for a similar "SCA Act."

Understanding SCA Risk Factors

Some cases of SCA occur in people who appear healthy and have no known heart disease^v; however, a number of risk factors have been identified that can help determine who is at risk. These include:

- Previous SCA: The number one risk factor for SCA is a previous cardiac arrest; 30 to 50 percent of people who survive an SCA will experience another event within one year.^{xxix}
- **Family history of SCA:** First-degree relatives of SCA patients have a 50 percent higher risk of heart attack or primary cardiac arrest.^{xxx}
- Heart failure: A low ejection fraction, e.g., less than 35 percent or less, may indicate heart failure, a chronic condition in which at least one heart chamber is not pumping well enough to meet the body's needs. Low left ventricular ejection fraction, or LVEF, is the strongest predictor of all-cause mortality in patients with cardiomyopathy.^{xxxt}
- Coronary artery disease: A study on gender differences among SCA survivors found that 80 percent of men exhibited signs of CAD, compared to around 40 percent of women who had signs of the disease.xxxii

In people diagnosed with congestive heart failure (CHF), SCA occurs at six to nine times the rate of the general population.*

 About one-half of all deaths in heart failure patients are characterized as sudden due to arrhythmias.[±]

* American Heart Association. Heart and Stroke Statistics – 2003 Update. Dallas, Tex.: American Heart Association: 2002

±Stevenson WG. Sudden death prevention in patients with advanced ventricular dysfunction. *Circulation*. 1993;88:2953-2961.

Research has shown that up to 75 percent of SCA patients have had a previous heart attack.*

* Myerburg RJ. Heart Disease, A textbook of Cardiovascular Medicine. 5th ed, Vol 1. Philadelphia: WB Saunders Co;1997:ch24 De Vreede-Swagemakers JJ. Out-of-Hospital Cardiac Arrest in the 1990s: A Population-Based Study in the Maastricht Area on Incidence, Characteristics and Survival. J Am Coll Cardiol. 1997;30:1500-1505.

Shen WK, Hammill SC. Survivors of acute myocardial infarction: who is at risk for sudden cardiac death? *Mayo Clin Proc.* 1991;66:950–962



- **Previous heart attack:** A previous heart attack raises the one-year risk of SCA by five percent.^{xxxiii} Studies have shown that people who have suffered a previous heart attack have a sudden cardiac death rate that is four to six times that of the general population.^{xxxiv}
- Other forms of heart disease: The study on gender differences and SCA found that 55 percent of women who survived a sudden cardiac event had underlying non-ischemic heart disease, including cardiomyopathy* (19 percent) and valvular heart disease[±] (13 percent).^{xxxv} This characteristic was uncommon in male SCA survivors.^{xxxvii}

Despite knowledge about SCA risk factors and the patient populations most affected (women and African-Americans), many physicians are still not identifying at-risk patients at the point of care. William Daniel, MD, Medical Director of Quality, Mid America Heart Institute, Saint Luke's Hospital, Kansas City, MO., cited a retrospective review that found only a 25 percent recognition rate of patients indicated for SCA assessment^{**} among physicians in 2005, coupled with only an 11 percent ICD implantation rate.^{xxxvii}

In addition, there is not a single screening test for diagnosing high SCA risk, and not all patients benefit from the available treatment options. John P. DiMarco, MD, PhD, of the Heart Rhythm Society (HRS), proposed a way of heightening awareness and increasing the knowledge of SCA in at-risk individuals. The HRS' SCA 360 Initiative is a new program aimed at changing treatment and referral behaviors among primary care and specialty clinicians, as well as influencing regulatory personnel and legislators toward supporting awareness, research and access to therapy.

Disparities in Care – Racial/Ethnic

The landmark 2002 Institutes of Medicine (IOM) report, "Unequal Treatment: Confronting Disparities in Health Care," concluded that racial and ethnic minorities experience a lower quality of healthcare services and are less likely to receive routine medical procedures compared to their white counterparts.xxxviii Some of the most convincing evidence of healthcare disparities comes from studies of racial and ethnic differences in cardiovascular care. according to Dr. Yancy. For instance, compared to whites, African-Americans – and in some



Populations with Equal Access to Health Care

IOM Report: Differences, Disparities and Discrimination³³ Definition of Disparities in Healthcare: "Racial or ethnic differences in healthcare that are not due to access-related factors, clinical needs, patient preferences and appropriateness of intervention."

cases, Hispanics – are less likely to receive appropriate cardiac medication, diagnostic procedures and surgery.^{xxxix}

Assessing potential sources of disparities in care

According to the IOM report, studies of racial and ethnic differences in cardiovascular care demonstrate that differences in treatment are not due to clinical factors, such as racial differences in the severity of coronary disease or overuse of services by whites. Rather, they are associated with a range of patient-level, provider-level and system-level factors, beyond access-related factors:^{xi}

* Inflammation of the heart muscle

- ** via AHA/ACC/ESC Guidelines
- \pm A condition in which one of the heart's four valves fails to open or close properly



Factors Associated with Disparity in Care

Patient-Level

- Disease burden, education/awareness, cultural and religious beliefs, patient preferences and language barriers
- Patient and physician relationship

Physician-Level

- Bias, stereotyping, prejudice
- Cultural competency/cultural proficiency
- Qualifications
- Underrepresentation of minorities in health professions

System-Level

- Differential in quality of care
- Access to subspecialty care
- Insurance status

The role of bias, stereotyping and uncertainty

Physicians must balance new information gained from the patient with their prior expectations (the "priors," e.g., the likelihood of patients' conditions based on age, gender, socioeconomic status, and race or ethnicity) to determine the diagnosis and course of treatment. If the physician has difficulty accurately understanding the symptoms or is less sure of the indications relied upon to make diagnostic decisions, he or she is "Cultural and linguistic competence increases the quality and effectiveness of care, health outcomes and well-being, patient-provider communication and satisfaction, and provider knowledge skills. Further, it decreases healthcare disparities, reduces the disproportionate burden of disease and mortality, addresses social and resource inequities, lowers system costs, and minimizes bias and discrimination – offering benefits not just to patients, but also their families, communities, healthcare providers and healthcare delivery systems."

- Dr. Clyde Yancy

likely to place greater weight on the "priors" and, consequently, make treatment decisions that are not as effective for the patient's needs.

Research suggests that patients' race or ethnicity influences healthcare providers' diagnostic and treatment decisions, as well as providers' feelings about patients. Dr. Charles Noble II, FACC, incoming Vice President of the Association of Black Cardiologists, cited a *New*

"Research has shown that low ICD referral rates are exacerbated among women and ethnic minorities due to bias that cannot be explained by earlier treatment disparities."

- Dr. Jack Lewin

England Journal of Medicine study on cardiac care, in which 720 physicians were shown a recorded interview and given other data about a hypothetical patient portrayed by an actor. Eight patients were videotaped – male and female, African-American and whites, ages 55 (deemed "younger") and 70 (deemed "older"). The physicians were asked to make recommendations for the patient's care. The results showed that cardiac care varied according to race and sex, even when insurance status, income, age and severity of conditions were controlled.^{xii} The study concluded that men and whites were more likely to be referred for cardiac catheterization than women and African-Americans, respectively, and African-American women were significantly less likely to be recommended for cardiac catheterization compared to white men.^{xii}



To combat issues in care delivery related to bias, stereotyping and uncertainty, Dr. Yancy suggested that cultural competence education be provided to health professionals. Cross-cultural education is a discipline that has been studied in mental health care and could

improve provider-patient communication by helping to eliminate the pervasive racial/ethnic disparities in medical care seen today.^{xiii} Progress has been made in this area, as accreditation bodies for medical training (e.g., Liaison Council on Medical Education and Accreditation Council on Graduate Medical Education) now have standards that require cross-cultural curricula as part of undergraduate and graduate medical education. However, more must be done.

African-Americans and SCA

Dr. Noble shared the results of a 2007 Journal of the American Medical Association (JAMA) study of more than 13,000 patients with documented heart failure and low LVEF who were discharged from one of the more than 200 hospitals affiliated with the American Heart Association (AHA) "Get with the Guidelines" Heart Failure Quality Improvement program. Not only was ICD implantation low overall - less than 40 percent of potentially eligible patients received the devicexliv - but also African-American patients were significantly less likely than white patients to receive ICD therapy, independent of other characteristics:*/v

- 33.4 percent of African-American men received ICDs, compared to 43.6 percent of white men.
- African-American females had the lowest rates of ICD use of 28.2 percent.

The Five Elements of Cultural Competence At the Individual Level

- 1) Acknowledging cultural differences
- 2) Understanding your own culture
- 3) Engaging in self-assessments
- 4) Acquiring cultural knowledge and skills
- 5) Viewing behavior within a cultural context

African-Americans and Disparities In Cardiac Care

 Research has shown that regardless of insurance coverage, African-Americans are less likely than non-minorities to receive many life-saving therapies.

Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare

 In 2002 in the United States, 74 percent of heart transplant patients were white and 77 percent were male.

American Heart Association (AHA). Heart Disease and Stroke Statistics-2004 Update. Dallas, Texas: AHA 2004.

 After sifting through 64,936 cases of patients treated under Medicare, researchers found that African-American Medicare patients received ICD devices at one-third the rate of whites.

Battle, Judy (news.mc.duke.edu)

Therefore, despite knowledge of an effective primary prevention method, ICD implantation use is low and significantly impacting survival rates.

Hispanic-Americans and SCA

Healthcare disparities also affect Hispanic-Americans. Edgar Gil, project director for Hispanic Outreach Initiative on Cardiovascular Health, National Alliance for Hispanic Health, cited findings from the Agency for Healthcare Research and Quality's 2007 National Healthcare Disparities Report. The report found that Hispanics have less access to care than non-Hispanic whites and disparities in the quality of care reported in previous years have not been reduced.^{xivi} Since 2005, Hispanic subgroups had a higher proportion of people uninsured all year than non-Hispanic whites.^{xivi} Mr. Gil added that little is known about SCA in Hispanics; further research is needed to determine the incidence rates and survival rates in this population.



Mr. Gil cited the The Commonwealth Fund, Health Care Quality Survey 2001 and 2006 when emphasizing the importance of supporting community-based organizations delivering culturally proficient health care services to Hispanics and presented evidence of how language barriers hinder quality of care.

Finally, to improve quality of care and prevention of SCA among Hispanic-Americans and other communities, Mr. Gil recommended an increase in workforce diversity in health and science education professions as well as the importance of including cultural proficiency education for healthcare providers.

Toward Cultural Proficiency

"Culturally proficient providers and systems seek to do more than provide unbiased care as they value the positive role culture can play in a person's health and well-being. Cultural proficiency is characterized by holding culture in high esteem."

Delivering Health Care to Hispanics – A Manual for Providers / 4th Edition/ American Hospital Association & The National Alliance for Hispanic Health – Washington, D.C. 2007

Disparities in Care – Gender

Susan K. Bennett, MD, medical advisor to WomenHeart: The National Coalition for Women with Heart Disease, shared compelling statistics about the burden of cardiovascular disease in women. Cardiovascular disease is the leading cause of death of

"Early prevention is crucial. We must identify women who are at risk by educating physicians at the front line of care – OB/GYNs and primary care physicians – about SCA."

Dr. Anne B. Curtis

American women, killing 32 percent.^{xiviii} Approximately 500,000 women die of cardiovascular disease each year, exceeding the number of men who die from it.^{xiix} Yet, a 2005 study published in *Circulation* found that only eight percent of primary care physicians, 13 percent of OB/GYNS and 17 percent of cardiologists knew this fact.¹ The same study cited evidence that women receive suboptimal cardiovascular disease preventive care, which may contribute to worse outcomes compared with men.¹¹ This gap in care is in large part driven by the finding that recommendations for cardiovascular disease prevention were driven by risk-level assignment and that women were more likely than men to be assigned a lower-risk category, despite a similar calculated risk.¹¹

Women and SCA

SCA risk stratification among women remains a significant challenge. According to Dr. Bennett, sudden cardiac death is often the first symptom of heart disease in women. She cited a study that shows 69 percent of women who suffered cardiac death had no prior diagnosis of CAD.^{IIII} Dr. Anne B. Curtis, FACC,

"Although more American women have died from heart disease than men, they still undergo far fewer [cardiac] procedures. Compared to men, women at risk for SCA receive 20 percent fewer ICD placements than men at-risk for SCA."

- Dr. Susan K. Bennett

chief, Division of Cardiology, University of South Florida, reported that the Nurses Health Study – the single largest cohort study of women – found that of women who died from SCA, 69 percent had no reported history of cardiac disease, and only 43 percent reported symptoms before their death.^{IV}

A 2007 *JAMA* study of a nationally representative sample of more than 236,000 Medicare beneficiaries found significant gender differences in ICD implantation rates. Among patients with a prior heart attack and either cardiomyopathy or heart failure, women were 3.2 times



less likely than men to receive ICD therapy.[№] Similarly, women with a prior cardiac arrest or ventricular tachycardia were 2.4 times less likely than men with the same conditions to receive an ICD.[№]

Drs. Bennett and Curtis both stated that interventions are needed to raise awareness and facilitate adoption of prevention guidelines for treating women with cardiovascular disease. Educational efforts should be aimed at assisting physicians in identifying patients at risk for SCA and assessment, which may help reduce sex-based disparities in preventive care. Further research on effective strategies to improve physician and patient adherence to cardiovascular disease prevention guidelines is merited.

Providing Solutions to Eliminate Disparities

Jack Lewin, MD, CEO, American College of Cardiology (ACC), suggested that the fastest way to eliminate disparities for women, African-Americans and Hispanic-Americans is quality improvement at the point of care, facilitated by information technology that provides healthcare professionals and patients with the best scientific evidence. Dr. Lewin proposed a three-part process to accomplish this: 1) translating science into guidelines, core performance measures and appropriateness criteria; 2) providing this

The ACC's CardioSmart[™] is an example of information technology that helps empower patients to participate in their own health and well-being. CardioSmart is an interactive resource that offers a range of educational tools and resources to help patients learn more about their condition. In addition, the program reminds patients to schedule doctor visits and to fill their prescriptions.

information to clinicians to help guide them at the point of care; clinicians, in turn, can make necessary treatment decisions and educate patients about risk factors and treatment options (known as "clinical decision support"); and 3) measuring performance to determine whether decision support translates to better outcomes.

Treatments for SCA Still Underutilized

Treating SCA risk factors can help prevent SCA and prolong lives. A study of SCA survivors found that 80 percent of men and 40 percent of women exhibited signs of CAD, a leading risk factor for SCA.^{wi} Medications such as nitroglycerin and beta blockers can be prescribed to help lessen stress on the heart, and interventional procedures such as cardiac catheterization or balloon angioplasty also can help manage the disease.^[viii] Studies show that people who have suffered a previous heart attack have a sudden cardiac death rate that is four to six times that of the general population.^{ix} Treatment for heart attack survivors often includes aggressive medication along with cardiac rehabilitation - a medically-supervised program that includes nutrition counseling, an exercise program and education on controlling risk factors.[™] A study on gender differences and SCA found that 55 percent of women who survived a sudden cardiac event had underlying non-ischemic heart disease, including cardiomyopathy (19 percent) and valvular heart disease (13 percent).^{ki} Treatment for cardiomyopathy can include anticoagulant drug therapy to prevent clotting, antiarrhythmic drugs and beta or calcium channel blockers.™ The ACC/AHA guidelines for management of patients with valvular heart disease include monitoring patient symptoms, treating endocarditis, and even valve surgery.^{Ixiii}

Treatment guidelines recommend ICDs as the primary standard of care for patients who are at high risk for SCA, given that the likelihood of SCA survival with these devices is 98 percent.^{kiv} Evidence from three large clinical trials – Multicenter Automatic Defibrillator Implantation Trial (MADIT),^{kv} MADIT-II^{kvi}, and the SCD-HeFT^{kvii} – demonstrates that ICDs improve survival in



patients with significantly reduced LVEF. A fourth trial, the Antiarrhythmics Versus Implantable Defibrillators (AVID) trial, established the first-line use of ICDs for secondary prevention of SCA in patients who survive a life-threatening ventricular arrhythmia.^{kviii} The results of these trials have

"Documented LVEF is not leading to ICD use, especially for women and African-American patients."

- Dr. Charles Noble

helped shape current ACC/AHA guidelines, which recommend prophylactic ICD therapy for primary and secondary prevention of SCA in indicated heart failure patients.^{kix} However, even with existing guidelines and treatment algorithms that advocate prophylactic ICD therapy, many eligible patients still do not receive ICDs.

Dr. Daniel of the Mid America Heart Institute stated that a strategy aimed at helping physicians recognize important aspects of a patient's history and prompting them with guidelines for care would result in early adoption of evidence-based standards, with decreased variability of care and improved patient outcomes. According to Dr. Daniel,

"Implementing true quality processes allows us to deliver evidence-based, guideline-driven care. We owe that much to our patients, ourselves and our profession."

– Will Daniel, M.D.

Cardiovascular Consultants has incorporated this strategy in an "SCA Prevention Process," a clinical approach designed to achieve a higher recognition rate for patients at risk for SCA and greater compliance with current guidelines for appropriate implantation of ICDs. Dr. Daniel and his team presented a study evaluating this process at the AHA Scientific Sessions in November 2007. The results showed that a single clinic that adopted an SCA protocol identified significantly more patients at risk for SCA compared to several clinics without a similar protocol (93 percent versus 70 percent).^{Ixx} Further, with increased medical management through the use of SCA protocols, considerably more patients at the single site received an ICD at six months (41 percent versus 11 percent in sites without an SCA protocol).^{Ixxi}

Summary



"We should challenge ourselves to improve in the following areas related to SCA: consumer and physician education; research on its impact on the general population, women, African-Americans and Hispanics; impediments faced by healthcare professionals related to diagnosing and treating SCA; and the gap in translating existing guidelines into clinical practice."

Dr. Jack Lewin, CEO, American College of Cardiology

The NMA convened more than 50 of the nation's leading medical professionals and patient advocates at the SCA Leadership Conference to discuss evidence-based prevention and treatment strategies, along with actionable strategies and tactics to better identify disparities in care.

Given the high incidence of SCA and its disproportionate effect on certain segments of the population, addressing the risk factors, disparities in care, diagnosis and treatments, and policy initiatives to help reduce the burden of SCA should be a national public health priority. Public health and professional medical education should target increased awareness of the symptoms and signs of cardiac arrest and the promotion of evidence-based use of medical devices, especially in at-risk populations.

The need for advancing awareness of SCA goes beyond a greater acknowledgement of the incidence of the disease – it must incorporate a better understanding of the preventability of the condition to decrease unnecessary deaths. Effective SCA prevention must incorporate new ways of more accurately identifying and lowering the risk of SCA as well as encouraging risk factor reduction in apparently healthy populations. Healthcare providers, researchers, patient advocates, policy makers and industry must act now – individually and collectively – to create a heightened level of awareness about SCA and the racial/ethnic and gender disparities in care. Aggressive steps are needed to bridge the gap between clinical trial data and everyday clinical practice.

Understanding gaps in both the recognition of SCA and the use of therapy across gender and race should motivate professionals and consumers to learn more about these conditions. Moreover, the recognition and acceptance of treatment guidelines should encourage all physicians and other healthcare providers to implant ICDs in eligible, at-risk patients. In doing so, primary prevention will become an accepted practice and policy.

Advancing awareness of SCA requires physicians and other healthcare providers, as well as patients, to seek more information about this serious condition. Reviewing risk factors and underlying racial and gender disparities in care, such as those outlined in this paper, will assist in elevating SCA awareness in an effort to save lives. In addition, greater knowledge is needed about evidence-based, guideline-driven treatments, including ICD therapy, which has been proven to prevent SCA-related deaths.



Call to Action

Prior to the conclusion of the Conference, participants joined in a call-to-action "brainstorming" session to identify steps that will help make SCA a national health priority – potentially leading to better diagnoses and, ultimately, improved patient outcomes through appropriate treatment. Participants agreed that a successful change in SCA health outcomes requires continual involvement from community and health leaders, and that the vital next step is implementation of programs and policies that will positively impact health outcomes. Participants discussed specific roles that individuals and organizations could play in being ambassadors of SCA prevention, across six critical categories.

I/we would like to be involved in the effort to make SCA a national health priority and will help in the following area(s):

Develop clinical performance measures for SCA prevention

- Develop core performance measures and appropriateness measures for SCA.
- Ask accreditation and "standardization" institutions to ensure that healthcare providers and institutions implement clinical practice guidelines for SCA prevention.
- Enhance guidelines with standards of care for underserved patient populations.
- Incorporate into electronic medical records methods to identify patients who are at known risk for SCA.

Raise awareness of SCA among consumers and healthcare professionals

- Enlist the support of patient advocacy and medical professional organizations to make SCA awareness a part of their respective agendas.
- Develop a public awareness campaign to educate consumers about the risk factors and prevention measures for SCA.
- Develop culturally appropriate and health literate communications tools (printed materials, public service announcements, Web sites) to serve as patient educational materials about risk factors for and prevention of SCA.
- Encourage patients to be screened for SCA where indicated (e.g., heart failure and post-heart attack).

Increase professional education on SCA

- Encourage healthcare professionals to identify patients who are at risk for SCA and apply appropriate prevention measures.
- Educate cardiologists, general practitioners, gynecologists, and nurses on SCA prevention to ensure that existing treatment guidelines are put into practice.
- Encourage physicians to earn continuing medical education credits for SCA.

Encourage policymakers to establish SCA as a public health priority

- Encourage policymakers to support reimbursement of SCA prevention and treatment.
- Increase federal funding for research, education and medical resources for SCA.
- Develop a transition document on SCA for the new presidential administration.

Create cultural proficiency in prevention and treatment of SCA to combat health disparities

- Create culturally proficient and health literate patient education materials.
- Develop cardiac registries in communities with large African-American and Hispanic populations.
- Increase research, particularly among the Hispanic population where research is limited, to identify biological differences in SCA prevention methods and treatment effectiveness.
- Educate healthcare professionals about the need for culturally sensitive physician education and communication, particularly on unacknowledged biases.

Enlist insurers to increase support of SCA prevention and treatment in all populations

- Educate health insurance providers about SCA and the impact of prevention and treatment programs.
- Encourage insurers to support reimbursement for SCA screening, prevention and treatment.



"Because racial and ethnic minority groups are expected to comprise an increasingly larger proportion of the U.S. population in coming years, the future health of America will be greatly influenced by our success in improving the health of these groups. Eliminating health disparities will require a national effort encompassing the public and private sectors, individuals and communities. A better understanding of the relationship between health status and different racial and ethnic minority backgrounds will enable communities to identify effective and culturally appropriate implementation strategies."

- Centers for Disease Control

Medtronic provided financial support for the SCA Leadership Conference.

¹ Centers for Disease Control and Prevention Office of Communication Fact Sheet: Racial and Ethnic Disparities in Health Status available at: http://www.cdc.gov/od/oc/media/pressrel/fs020514b.htm.



Resources

National Medical Association

The National Medical Association (NMA) is the largest and oldest national organization representing African American physicians and their patients in the United States. The NMA is a 501(c) (3) national professional and scientific organization representing the interests of more than 25,000 African American physicians and the patients they serve. NMA is committed to improving the quality of health among minorities and disadvantaged people through its membership, professional development, community health education, advocacy, research and partnerships with federal and private agencies. Throughout its history the NMA has focused primarily on health issues related to African Americans and medically underserved populations; however, its principles, goals, initiatives and philosophy encompass all ethnic groups.

1012 Tenth Street, NW Washington, DC 20001

Phone: 202-347-1895 Fax: 202-898-2510 www.nmanet.org

American College of Cardiology

Helping cardiovascular professionals Learn. Advance. Heal. The mission of the American College of Cardiology is to advocate for quality cardiovascular care—through education, research promotion, development and application of standards and guidelines—and to influence health care policy.

Heart House 2400 N Street NW Washington DC, 20037

Phone: (202) 375-6000 Fax: (202) 375-7000 www.acc.org

Association of Black Cardiologists

Founded in 1974, the Association of Black Cardiologists, Inc., (ABC) is a nonprofit organization with an international membership of over 600 health care professionals. The ABC is dedicated to eliminating the disparities related to cardiovascular disease in all people of color.

5355 Hunter Road Atlanta, GA 30349

Phone: (800) 753-9222 Fax: (404) 201-6601 www.abcardio.org



National Alliance for Hispanic Health

The National Alliance for Hispanic Health is the premier organization focusing on Hispanic Health. Alliance members reach over 14 million Hispanic consumers throughout the U.S.

1501 16th Street N.W. Washington, DC 20036

Phone: (202) 387-5000 Fax: (202) 797-4353 www.hispanichealth.org/

WomenHeart: The National Coalition for Women with Heart Disease

WomenHeart is the only patient-led national non-profit organization that educates and advocates for the 8 million American women living with heart disease. With 16,000 members and 50 local support groups, WomenHeart gives women heart patients and physicians a platform to spread the common message of early detection, accurate diagnosis and proper treatment so all women can lead healthier lives.

818 18th Street, NW Suite 930 Washington, DC 20006

Phone: (202) 728-7199 Fax: (202) 728-7238 www.womenheart.org

Heart Rhythm Society

The Heart Rhythm Society is the international leader in science, education and advocacy for cardiac arrhythmia professionals and patients, and the primary information resource on heart rhythm disorders. Its mission is to improve the care of patients by promoting research, education and optimal health care policies and standards.

1400 K Street, NW Suite 500 Washington, DC 20005

Phone: (202) 464-3400 Fax: (202) 464-3401 www.hrsonline.org

Sudden Cardiac Arrest Association

The Sudden Cardiac Arrest Association (SCAA) is an organization singularly focused on sudden cardiac arrest. SCAA identifies and unites survivors, those at risk of sudden cardiac arrest, as well as others who are interested in being advocates on SCAA issues in their communities and beyond.

1133 Connecticut Avenue, NW 11th Floor Washington, DC 20036

Phone: (866) 972-SCA Fax: (202) 719-8983 www.suddencardiacarrest.org



Sudden Cardiac Arrest Leadership Conference

Advisory Committee Dr. Mohammad N. Akhter, M.P.H. Executive Director, National Medical Association

Ivonné Fuller Bertrand Associate Executive Director, National Medical Association

Dr. Jack Lewin CEO, American College of Cardiology

Dr. Charles Noble Vice President, Association of Black Cardiologists

Edgar Gil Project Director Hispanic Outreach Initiative on Cardiovascular Health, National Alliance for Hispanic Health

Lisa Tate CEO, WomenHeart: The National Coalition for Women with Heart Disease

Kathy Pontzer Vice President Health Policy, Heart Rhythm Society

Chris Chiames Executive Director, Sudden Cardiac Arrest Association

Speakers

Dr. Nelson L. Adams III President, National Medical Association

Dr. Mohammad N. Akhter, *M.P.H. Executive Director, National Medical Association*

Dr. Clyde W. Yancy, FACC, FAHA, FACP Medical Director Baylor Heart and Vascular Institute & Chief, Cardiothoracic Transplantation Baylor University Medical Center

Michaela Gagne Former Miss Massachusetts (2006-2007)

Valerie Ramsey Author, Public Speaker, Model, Public Relations Manager Pebble Beach Resort

Dr. William E. Matory Continuing Medical Education Director, National Medical Association

Dr. Jack Lewin CEO, American College of Cardiology

Dr. Charles Noble II, FACC Electrophysiologist, Capitol City Cardiology, Incoming Vice President, Association of Black Cardiologists

Edgar Gil Project Director for Hispanic Outreach Initiative on Cardiovascular Health, National Alliance for Hispanic Health



Dr. Susan K. Bennett, FACC Clinical Director, Women's Heart Center, The Cardiovascular Center at The George Washington University Hospital and WomenHeart Scientific Advisory Council

Dr. Anne B. Curtis, FHRS, F.A.C.C., FAHA Professor of Medicine and Chief of Cardiovascular Medicine, University of South Florida

Dr. William Daniel

Clinical Associate Professor of Medicine University of Missouri, Kansas City & Medical Director of Quality Mid America Heart Institute & Director of Quality, Director of EMR Solutions Cardiovascular Consultants, P.A.

Lisa Hines, *MS, BSN* Senior Program Director, National Quality Forum

Dr. John P. DiMarco, FHRS Chair SCA 360 Task Force, Heart Rhythm Society

Dr. Jack Lewin CEO, American College of Cardiology



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