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Public Health Science Agenda for Congenital Heart Defects: Report From a Centers for Disease Control and Prevention Experts Meeting

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Congenital heart defects (CHDs) are the most common type of birth defect, affecting ≈1% of births per year.[1] Although survival has been improving over time, there remain numerous gaps in the understanding of the public health impact of CHDs across the lifespan. Recognizing that there was "a lack of rigorous epidemiological and longitudinal data on individuals of all ages with congenital heart disease," the US Congress provided funding through the Appropriations Act of 2012 to the US Centers for Disease Control and Prevention (CDC) to investigate the gaps in understanding of the public health impact of CHDs.[2] Given the broad array of possible topics to address with limited resources, the CDC invited experts to a meeting on September 10–11, 2012, to seek individual input on the major gaps in the understanding of CHDs and to suggest public health strategies to address those gaps.

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Fifty experts attended the meeting representing diverse specialties and perspectives including medical content (CHDs), methods (public health strategies), and personal experience. The group included persons and stakeholders from varied disciplines (physicians, surgeons, epidemiologists, public health officials, advocates, and patients) with a broad representation of public health, professional, and CHD advocacy organizations (the full list of experts is included in the Acknowledgments section).

Prior to the meeting, participants received background information to lay the foundation for the meeting. Participants were asked to attend 1 of 2 live webinars hosted by the CDC to outline the public health framework for congenital heart defects. Participants also received articles covering key topics in public health and congenital heart defects for review on their own prior to the meeting.[3–6] Finally, at the initiation of the meeting, background presentations were delivered on the current state of knowledge for each of the 4 key areas: epidemiology, health services, long-term morbidity/mortality, and long-term psychosocial and neurodevelopmental outcomes.

For the major activity of the conference, invitees participated in 1 of 4 focus groups centered on 1 of those key areas. Each group was charged with 3 tasks: (1) identifying the key gaps in public health for CHDs, (2) brainstorming potential strategies to address those gaps, and (3) suggesting a prioritization of the identified gaps and strategies based on their potential impact and feasibility. The results of each group, with notable overlaps, were discussed by the full panel of participants to help guide an overall list of suggested major focus areas. After a large group discussion of the 32 gaps identified, the gaps identified as prioritized, in no particular order, included prevalence of CHDs across the lifespan, risk factors for development of CHDs, long-term outcomes for persons with CHDs, health services delivery for persons with CHDs, and public awareness of the burden and impact of CHDs. As outlined in Table 1, we have synthesized the prioritized gaps and their accompanying strategies into a public health science agenda for CHDs.

Table 1. Major Gaps and Strategies for a Public Health Science Agenda for Congenital Heart Defects

Key Gaps	Strategies to Address Gaps		
	High Impact, High Feasibility	High Impact, Moderate Feasibility	Moderate Impact, High Feasibility
Prevalence of congenital heart defects across the lifespan		Existing databases and electronic records Population based cohorts	Ongoing public health surveillance efforts Voluntary registries Mathematical modeling
Risk factors for development of congenital heart defects	Social determinants of health	Modifiable risk factors	Genetic associations Primary prevention strategies
Long-term outcomes for persons with congenital heart defects		Linkage of databases Longitudinal surveillance and research	Meaningful outcomes measures
Health services delivery for persons with congenital heart defects		Access to appropriate care Continuation of care from adolescence to adulthood	Costs of care Quality of care
Public awareness of the burden and impact of congenital heart defects	Public awareness campaign		Educational materials

What is Public Health Research/Surveillance?

In developing a public health science agenda for CHDs, it is important to first define the scope of "public health" and its associated scientific activities. Public health focuses on the health of the population rather than the health of an individual; thus public health efforts are typically prevention activities targeting a population to reduce morbidity and mortality on a population level.[7] A public health science agenda is a cycle of surveillance, research, and prevention activities (Figure).

The cycle's cornerstone is public health surveillance, which is a systematic process to monitor health through ongoing collection, analysis, interpretation, and dissemination of data to improve health.[8] Population-based surveillance data can be used to address key research questions about: the magnitude of the health problem, the natural history of the condition, the distribution of the condition across geographic regions or by specific characteristics (eg, maternal race or ethnicity), any changes in prevalence over time that might be due to changing exposures or changing technology for diagnosis, and/or the impact of prevention activities. Public health surveillance also serves as the source of population-based cases for additional public health research studies and is useful in planning for future resource needs.

Public health research is designed to create generalizable knowledge that will apply to populations beyond the immediate study population being evaluated. Focused public health

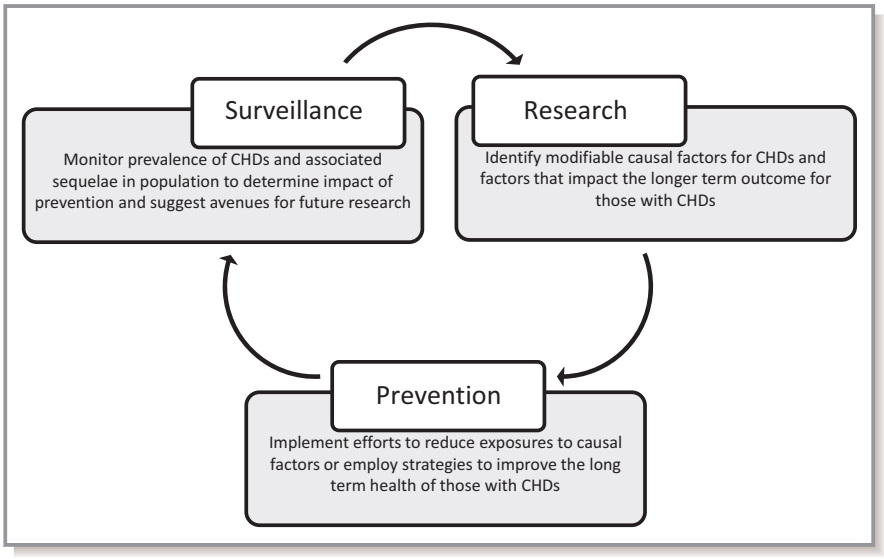

Figure. Public health cycle for congenital heart defects (CHDs).

research on CHDs includes specific studies to identify risk factors as well as studies of the prognosis and longer-term outcomes for those affected. A typical risk factor study of CHDs might assess maternal exposures during pregnancy to identify modifiable factors that can increase the risk of CHDs such as maternal smoking, maternal diabetes, or maternal medication use in early pregnancy (eg, opioid analgesics). Public health research outcomes studies also seek to identify factors such as optimal timing of medical care that can potentially improve the outcomes of those with CHDs. This includes health economic studies that assess the healthcare and nonhealthcare resources used by those with CHDs.

Modifiable factors identified through public health research can guide prevention activities. Primary prevention strategies attempt to modify risk factors to decrease the occurrence of CHDs, while secondary prevention strategies aim to improve the lives of people with CHDs. The public health cycle then loops back into surveillance to gauge the effectiveness of prevention strategies.

The convened conference identified 5 key areas for a CHD public health science agenda: prevalence of CHDs across the lifespan, risk factors for development of CHDs, long-term outcomes for persons with CHDs, health services delivery for persons with CHDs, and public awareness of the burden and impact of CHDs.

Prevalence of Congenital Heart Defects Across the Lifespan

While there are relatively robust estimates of CHD prevalence detectable at birth, there are no population-based data on the prevalence beyond early childhood in the United States.[1,9] The prevalence of CHDs across the lifespan is impacted by the mortality of each birth cohort and by relatively late diagnoses of CHDs not apparent during infancy. Robust estimates of CHD prevalence across the lifespan (newborns, children, adolescents, adults) would allow better characterization of the disease burden including morbidity, mortality, healthcare use and costs, nonhealthcare costs associated with CHDs, disability, and the potential longer-term impact of CHDs on education and employment. In the following section we review some of the established methods for estimation of disease states across the lifespan. Some combination of these methods applied to CHDs would provide a more accurate characterization of the burden of the disease across the lifespan.

Ongoing Public Health Surveillance Efforts

When the 50 states, the District of Columbia, and Puerto Rico were surveyed in November 2011, 43 of the 52 respondents reported having a birth defects surveillance program that obtained data on CHDs.[10] Of these 43 programs, 41 reported data to the National Birth Defects Prevention Network for the December 2012 annual report.[11] Most programs ascertain infants diagnosed with a CHD before 1 year of age, and some included diagnoses in the first few years of life. Such ascertainment is useful for estimating the prevalence of CHDs at birth. Some longstanding surveillance programs estimate prevalence and survival of those infants with certain conditions (eg, Down syndrome, spina bifida) in childhood and adolescence by linking birth defects surveillance data to state death records and the national death index.[12,13] Strengths of these birth defect surveillance programs include being population-based and not being biased by issues of access or referral patterns. Limitations include the lack of information beyond infancy and variations in case definition, data sources, and ascertainment methodology (eg, active versus passive ascertainment).[9,14]

Population-Based Cohorts

Population-based longitudinal cohorts of persons with CHDs at any age could be established in a defined source population and then followed on a periodic basis such as with annual data abstraction of medical records. Although financially and logistically challenging, such a method would offer robust, population-based estimates of the changing prevalence of CHDs and their associated morbidities. This approach has been used to establish cohorts for Duchenne/Becker muscular dystrophy and hemoglobinopathies.[15,16]

Existing Databases and Electronic Records

Leveraging existing databases might provide an opportunity to estimate the prevalence of CHDs across the lifespan without undertaking resource-intensive data collection. To create a population-based estimate, the source population would need to be clearly defined, and multiple data sources would maximize completeness of case ascertainment. Some critical data sources for such an endeavor might include vital records (birth and death records), CHD specialty clinic records, hospital discharge records, and insurance databases (public and private). The expanded use of electronic health records may provide opportunities to search existing data and make accurate linkages between data sources.[17] Linkage and deduplication of these various sources would improve case-finding and allow a reasonable population-based estimate of persons with CHDs across the lifespan who are currently seeking care for their CHD or who die as a result of their CHD. Unfortunately, this strategy might be limited by the need for a CHD diagnosis to be specifically noted in a medical record. Variations of this approach are being piloted in 3 sites recently funded by CDC to conduct CHD surveillance among adolescents and/or adults.

Voluntary Registries

Persons with CHDs and/or their health care providers can log important diagnosis and descriptive information through voluntary registries. Registries (with or without personally identifying information) serve as a repository of people who potentially can be approached for outcomes research and longitudinal follow-up. However, self-identifying voluntary registries may not be representative of all persons with CHDs in the source population; enrollees may differ in terms of educational level, income, race/ethnicity, disease severity, access to healthcare, and insurance status. Studies from patient registries for other conditions (eg, cystic fibrosis) have potential selection bias with the registry overenrolling at 1 extreme of the disease spectrum.[18] However, despite their significant limitations of representativeness, this type of registry can provide a relatively low-resource approach to capturing some longitudinal data on a hopefully diverse sample of persons with CHDs.

Mathematical Modeling

Given the current lack of data to directly estimate the prevalence of CHDs across the lifespan in the United States, mathematical modeling has been used to apply estimates from available sources (ie, population-based data from Quebec) to the US population in order to estimate the number of persons living with CHDs in each age cohort.[19,20] Based on this modeling, the number of people in the United States with a CHD at any age was estimated to be at least 2 million, with at least half of these individuals being adults (≥18 years). As more current data become available, these estimates can be updated and informed by other data sources to improve their accuracy.

Risk Factors for Development of Congenital Heart Defects

While the causes of most CHDs are unknown, they are likely multifactorial in origin.[4,21] Although the available evidence on risk factors to guide effective primary prevention strategies is limited or inconsistent,[4] there are some established risk factors for CHDs and prevention strategies are in place. Much like an iceberg, however, it is likely that there are more unseen than seen causes of CHDs. Future research to delve deeper into causes is needed.

Modifiable Risk Factors

Maternal conditions such as diabetes, obesity, phenylketonuria, and rubella infection are established risk factors for CHDs.[4,22–24] Associations also have been identified between CHDs and maternal periconceptional medication use such as retinoic acid, valproate, phenytoin, and opioid analgesics.[4,25] Other medications or conditions also may be associated with CHDs, but it is difficult to differentiate the effect of the condition from the medication used to treat the condition.[4] There is also some evidence for association between CHDs and environmental factors such as maternal smoking and exposure to organic solvents.[4,26]

Despite clear documentation of these known risk factors, there is still a gap in identifying factors which, when modified, will have a large, demonstrable, public health impact on the prevalence of CHDs. Population-based case-control studies, such as the National Birth Defects Prevention Study (NBDPS), are 1 approach to assess the association of exposures with CHDs, and efforts should continue to analyze existing case-control data. However, differences in study methodology and resultant risk make comparisons across studies difficult. The impact of future work could be magnified by increased focus on standardizing case definitions and nomenclature, improving the quality of exposure data (eg, complement self-report with medical records data or biological samples), and exploring other innovative methods to gather data (eg, through patient support groups, biological modeling).

Genetic Associations

Approximately 15% to 20% of CHDs have been linked to known genetic disorders such as Down syndrome, Turner syndrome, and 22q11.2 deletion.[27] Nevertheless, estimates vary widely as the field of cardiovascular genetics rapidly evolves with new technology and potential associations. Knowledge of a genetic abnormality may indicate other organ involvement, prognostic factors, and reproductive risks.[21] Population-based research could help identify genotype associations and assess the effects of gene-environment interactions on CHD development and determinants of health for those with CHDs.

Social Determinants of Health

Little is known about the distribution of CHDs stratified by factors such as race-ethnicity, residence, sex, or insurance/payor status and how these factors impact CHDs across the lifespan. Improved understanding of demographic, geographic, behavioral, and social determinants could guide targeted prevention strategies. For example, to improve prevention of neural tube defects in specific populations, researchers have evaluated the potential impact that corn masa flour fortification could have on folic acid intake.[28] One strategy to explore social determinants of CHDs would be to analyze current databases or link existing databases with census data or geocoding. Analyzing health disparities across

these various factors could inform primary and secondary prevention efforts.

Primary Prevention Strategies

Evidence on modifiable risk factors and determinants of health should be translated to expand public health prevention interventions. Work is needed to identify additional simple, reasonable, and effective public health prevention efforts for CHDs, and to assess their impact. For instance, all women of childbearing age should consume sufficient folic acid by taking a multivitamin containing folic acid, be screened for and control chronic conditions such as diabetes, and keep immunizations current. Furthermore, during pregnancy, women should discuss medication use with their doctor for potential teratogens, stop or avoid smoking and alcohol use, and avoid exposures to heavy metals, pesticides, and organic solvents.[4] Further research is needed to assess to what extent are these guidelines being followed and the impact of these prevention strategies.

Long-Term Outcomes for Persons With CHDs

With advances in medical and surgical care of CHDs over recent decades, it is expected that the large majority of patients with CHDs will live well into adulthood.[19,29] While survival has been extended for many conditions, the morbidity that accompanies this survival has not been well described on a population level. Prior large population efforts have investigated epidemiology among infants with CHD,[30,31] and "natural history" studies on less complex lesions focused mostly on surgical and cardiac outcomes.[32–35] What has been missing from previous studies is an evaluation of not only the superimposed conditions of adulthood such as hypertension, diabetes, and sleep apnea, but also the potential for the effects of CHDs (and its associated interventions) on the health of other organ systems, including liver, renal, and lung disease.[36–38] Addressing the lack of knowledge regarding the long-term physical, neurodevelopmental, psychosocial, and reproductive outcomes of the aging CHD population is an important area with the potential of having a high impact on improving the public health for persons with CHDs.

Linkage of Databases

One approach is to leverage and link currently existing databases and registries. A clear strength of this strategy is the wealth of data already being collected by a number of different databases and registries encompassing many aspects of overall cardiac care, including, but not limited to, the various clinical,[39] surgical,[40] critical care,[41] anesthesia,[42] and administrative databases[43] (Table 2). Rather than creating new databases, this strategy aims to foster collaborative opportunities for learning. Furthermore, while there are no population-based databases that are individually tracking long-term outcomes, merging information across databases over time may be able to provide valuable long-term outcomes data. A notable obstacle to this strategy is the absence of a global unique identifier.[44,45] Without such an identifier, this strategy will be limited by the ability to merge databases through probabilistic matching or other methods. The use of a global unique identifier has been instrumental in linking databases in other chronic conditions such as autism.[45] Therefore, the working group collectively recommends the establishment of a global unique identifier to facilitate effective global database linkage to allow tracking of long-term outcomes for CHD patients.

Another limitation to database linkage is the inpatient bias of most existing databases, thus not allowing the capture of data in the outpatient or even nonclinical settings. This obstacle could be navigated by encouraging and fostering the creation and implementation of databases that track the outpatient experiences of persons with CHDs. Finally, efforts to link and compare databases may also be limited by variations in coding, nomenclature, and classification of CHDs. Administrative codes do not clearly distinguish some CHD phenotypes, which can have important etiologic differences.[46] Efforts to standardize CHD definitions and coding should be supported.

Although this strategy has challenging obstacles, they are not necessarily insurmountable and the potential positive impact is great. In addition to learning about patient-level outcomes for persons with CHDs, successful linkage of these databases may help identify benchmarks for care and inform screening and prevention efforts.

Longitudinal Surveillance and Research

An alternative to the linkage of existing databases is longitudinal surveillance of persons with CHD utilizing periodic surveys or medical abstraction. Longitudinal surveillance could provide information on a variety of outcomes—medical (eg, heart and other organs), neurodevelopmental (eg, special education needs and cognitive capacity), reproductive (eg, sexual/contraceptive practices, pregnancy, family planning, and heritability for offspring), and psychosocial (eg, employability and perceived quality of life). Once the incidence, prevalence, risk factors, and disparities of various outcomes are known, public health intervention efforts to change these outcomes can be developed. While such a study would be impactful on many levels, the feasibility is challenging given the estimated resources required. Multicenter and/or multiagency collaboration may help overcome this obstacle.

Table 2. Select Databases and Registries for Studying Outcomes for Persons With Congenital Heart Defects in the United States

Birth Defects Surveillance Programs (multiple)
Centers for Medicare and Medicaid Services (CMMS)
Congenital Cardiac Catheterization Project on Outcomes (C3PO)
Congenital Cardiovascular Interventional Study Consortium (CCISC)
Congenital Database of the Society of Thoracic Surgeons (STS)
Congenital Evaluation, Reporting, and Tracking Endeavor (CONGENERATE) (Canada and US)
Congenital Heart Surgeons' Society (CHSS) Research Databases
Early Intervention Databases (multiple)
Health Care Utilization Project (HCUP)—Kids' Inpatient Database (KID)
Health Care Utilization Project (HCUP)—Nationwide Inpatient Sample (NIS)
Health Care Utilization Project (HCUP)—State Inpatient Databases (SID)
HMO Research Network (HMORN)
Improving Pediatric and Adult Congenital Treatment (IMPACT) of the National Cardiovascular Data Registry of the American College of Cardiology Foundation (ACCF) and the Society for Cardiovascular Angiography and Interventions (SCAI)
Joint Congenital Cardiac Anesthesia Society—Society of Thoracic Surgeons Database
Joint Council on Congenital Heart Disease (JCCHD) National Quality Improvement Initiative
MarketScan® Research Databases
Mid-Atlantic Group of Interventional Cardiology (MAGIC) Catheterization Outcomes Project
National Association of Children's Hospitals and Related Institutions (NACHRI) Case Mix Comparative Data Program (CMCDP)
National Birth Defects Prevention Network (NBDPN)
National Birth Defects Prevention Study (NBDPS)
National Hospital Care Survey (NHCS)
National Hospital Discharge Survey (NHDS)
National Survey on Children with Special Healthcare Needs (NS-CSHCN)
Pediatric Cardiac Care Consortium (PCCC)
Pediatric Cardiac Genomics Consortium (PCGC)
Pediatric Heart Network (PHN)
Pediatric Hospital Information System (PHIS)
Pediatric Hospital Information System—Society of Thoracic Surgeons (PHIS-_STS) Linked Dataset
Slone Epidemiology Center's Pregnancy Health Interview Study/Birth Defects Study, Boston University
Special Education and other educational Databases (multiple)
State All-Payor Claims Databases (multiple)
State Hospital Discharge Databases (multiple)
Virtual Pediatric Intensive Care Unit Performance System (VPS)
Vital Records

Meaningful Outcomes Measures

Finally, no matter what strategy is employed to assess long-term outcomes, it is important to determine what measures are most meaningful and relevant for the CHD population. While mortality is one outcome of interest, outcomes such as disability-adjusted life expectancy or quality-of-life–adjusted life expectancy could allow comparison of CHDs to other chronic illnesses. Furthermore, improved metrics aimed at evaluating other medical or psychosocial outcomes would aid in building a comprehensive understanding of the long-term effects of CHDs. Although challenging, development of such key metrics will generate substantial impact by describing lifetime impact in easily understandable and measureable terms. The input of CHD patients and their families will be invaluable in the development of meaningful metrics of long-term outcomes.

Health Services Delivery for Persons With Congenital Heart Defects

Understanding and implementing optimal health services in a systematic manner presents an opportunity for improving health outcomes for patients with CHDs. By ensuring access to appropriate care, transitioning care from adolescence to adulthood, quantifying the costs of care, and improving the quality of care delivered, the overall public health of persons with CHDs can be optimized. As discussed above, comprehensive tracking and assessment of persons living with CHDs is essential to the development of the most efficacious treatment plans, but these treatment plans can only be effective at the population level if delivery of health services is pervasive and efficient.

Access to Appropriate Care

Access to appropriate care is of paramount importance for those with CHDs. Barriers to receiving care include lack of education, lack of adequate insurance, unemployment, and lack of proximity to a specialized care center.[47] A key issue for the public health science agenda for persons living with CHDs is to understand and overcome the challenges in access to care for all ages. The Patient Protection and Affordable Care Act of 2010, Pub. L. 111-148 will improve access to health insurance and health care for millions of Americans, and therefore is likely to improve access for many people with CHDs. However, there might still be other challenges for this population related to healthcare access. For example, there may be a growing gap between the demand for providers trained in caring for adults with CHDs and the supply of those providers. The recent establishment of Adult Congenital Heart

Disease (ACHD) as a cardiovascular subspecialty by the American Board of Medical Specialties is a critical first step in addressing this gap, but it is not the sole solution. Notable barriers to increasing the number of subspecialty providers include a lack of appropriate training centers, excess length of time for additional training, and the existing debt burden of trainees. Another essential needed change is the enhancement of general adult cardiologist training in the care of adults with less complex CHDs. This approach will allow for more accessible care for most CHD patients while leaving more time for ACHD specialists to care for the most complicated cases.

Continuation of Care From Adolescence to Adulthood

It is well documented that many adolescents and young adults with CHD are either lost to follow-up or are not receiving recommended care.[48,49] Identifying CHD patients who fail to maintain care as they transition to adulthood and facilitating the transition process will improve the continuity of care and ultimately optimize quality of life and life expectancy.[50] The underlying cause of poor continuation of care is likely multifactorial, including lack of ACHD provider availability, lack of patient and parent awareness of the severity of their illness and resulting need for lifelong care, and lack of consistent processes for transition and transfer of care. In locations where appropriately trained adult providers are available, developing lifelong centers of care that foster close collaboration between pediatric and adult providers may help facilitate seamless transition and full physician knowledge of patient history in a setting familiar to the patient. Regionalization of specialty center care may support such an approach. With the diversity of care models across the United States no one strategy is likely to be optimal for all locations and/or patients. Therefore, extramural grants aimed at the development of lifespan-focused treatment centers for CHDs could support pilot demonstration projects that may be reproduced and expanded to other regions.

Costs of Care

In an environment of limited resources and rapidly rising costs, delivering value in health care has become a key focus throughout our healthcare system.[51] There is relatively little known about the costs of care for children with CHDs, and even less known for adults. Not knowing or realizing the value of healthcare interventions can impede innovation and hamper ultimate care and outcomes. However, by using various national administrative and clinical datasets, one can begin to estimate the cost of care for persons with CHDs. These cost estimates can draw attention to the health needs of CHD patients. Involving health economists might assist with identifing opportunities for improving CHD resource use.

Quality of Care

It is important to ensure that proven, effective, value-based strategies are implemented appropriately and consistently. For example, there is substantial variation in initial perioperative management of patients with single ventricle physiology.[52] Such variation may lead to differences in health outcomes and costs.[3] Minimizing practice variation may improve health outcomes and efficiency. A quality improvement initiative is one approach to reducing variation and optimizing medical practices. Quality improvement initiatives are continuous cycles of using data to identify, develop, and implement strategies to change and improve practices. Strategies for quality improvement have the potential for great impact because they help to limit unnecessary variability, reduce costs, and improve health outcomes on a grand scale. Unfortunately, there are also formidable barriers to improving the quality of care, most notably a lack of sufficient and reliable evidence upon which to base guidelines. In the absence of such evidence, expert opinion and experience must serve as the basis for quality improvement efforts. Strategies to collect better evidence, therefore, are imperative and will depend on the building blocks offered by better lifespan tracking of CHD patients, as discussed above. An example of such an effort is the National Pediatric Cardiology Quality Improvement Collaborative of the Joint Council on Congenital Heart Disease,[53] a multicenter collaborative to prospectively collect data and track outcomes on infants with single ventricle physiology. Simply identifying the key strategies to improve quality will not be enough; these efforts must be widely disseminated, adopted, and tracked. Appropriate incentives and penalties—financial or otherwise—may help with the implementation of quality initiatives and, hopefully, with the ultimate improvement in patient outcomes.

Public Awareness of the Burden and Impact of Congenital Heart Defects

While the medical community is beginning to realize the increasing public health burden and impact of the aging CHD population, many persons with CHDs remain unaware of the long-term impact of their disease and the need for lifelong care.[6] Adolescents often have unrealistic expectations of their life expectancy and the severity of their cardiac conditions.[54] Educating patients about their disease and the need for appropriate, lifelong care provided by a healthcare team knowledgeable in the nuances of these “new” diseases should

optimize outcomes for patients and lessen the potential negative public health impact of the diseases.

Public Awareness Campaign

A public awareness campaign emphasizing the need for lifelong care should address two main populations. First, the campaign should encourage people currently receiving care for a CHD to remain in lifelong care, even during periods of good health. Physicians who treat individuals with CHDs must become patient educators, emphasizing the need for lifelong care. Guidelines that highlight the need for continuous care across the lifespan would help both patients and clinicians. Second, the campaign should develop a recapture component designed to reach adolescents and adults with CHDs who have been lost to care, particularly those with a history of a moderate or complex lesion.[55] To reach and benefit the maximum number of individuals, a recapture campaign might require print media, television advertising, and social media.[56] Care should be taken not to stigmatize individuals with CHDs and to be sensitive to the complex psychosocial issues of having a lifelong congenital condition. This could be achieved through positive "branding" of a lifelong care public awareness campaign as was demonstrated in a recent CDC campaign to increase physical activity among children.[57]

There are several challenges associated with the development of a public health awareness campaign. First, CHDs are a heterogeneous group of congenital anomalies; thus, a general definition of CHDs of varying severity should be used to connect with the largest possible audience. Second, health literacy and access to care likely varies tremendously throughout the CHD population; a public awareness campaign should, therefore, target multiple audiences in a variety of ways. Third, a campaign of this specificity and scope will require considerable funding; multiorganizational collaboration will maximize the effectiveness of the campaign. It is hoped that knowledge gained through population-based surveillance and research will inform educational campaigns targeted to specific populations and issues.

Educational Materials

Public awareness of the impact and burden of CHDs is not enough. Patients need to become better educated regarding their diseases and thus empowered to ensure appropriate, lifelong care. Educational materials targeted toward the general public, public health professionals, physicians, schools, and individuals with CHDs could be made available and accessible through websites, healthcare provider locations, professional organizations, and patient groups. Ensuring a variety of educational materials will enable a broader understanding of CHDs and reach a wide audience.

Topics of interest may include treatment guidelines (eg, on neurodevelopmental and psychosocial outcomes) and educational materials for special populations such as children, adolescents, adults of various ages, and pregnant women. CDC and other websites could provide general information to increase public awareness of CHDs, provide materials for affected individuals, state the goals of public health research, identify risk factors and prevention strategies for CHDs and their comorbidities, and announce when milestones in CHD prevention and care have been reached.

Future Directions

CHDs are an important public health issue based on their prevalence, severity, and impact across the lifespan. The public health science agenda for CHDs can help guide future surveillance, research, prevention, and communication efforts to ensure that resources are being directed to address the most significant knowledge gaps affecting the growing population with CHDs. The overall public health objectives are to prevent CHDs when possible by better understanding the causes and implementing successful intervention efforts, and improve the longer-term outcomes including reducing mortality, morbidity, and other adverse consequences for all those with CHDs. Coordinated efforts among federal agencies, professional organizations, advocacy groups, individual care providers, researchers, and other key stakeholders to implement this public health science agenda for CHDs could result in significant progress in addressing these CHD public health objectives.

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