



Status and Challenges of Care in Africa for Adults With Congenital Heart Defects

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Abstract

The 54 countries in Africa have an estimated total annual congenital heart defect (CHD) birth prevalence of 300,486 cases. More than half (51.4%) of the continental birth prevalence occurs in only seven countries. Congenital heart disease remains primarily a pediatric health issue in Africa because of the deficient health-care systems: the adults with CHD made up just 10% of patients with CHD in Ghana, and 13.7% of patients with CHD presenting for surgery in Mozambique. With Africa's population projected to double in the next 35 years, the already deficient health systems for CHD care will suffer unbearable strain unless determined and courageous action is undertaken by the African leaders.

Keywords

congenital heart surgery, adult congenital heart disease, health policy, health economics

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Introduction

In the current era, more than 90% of children born with congenital heart defects (CHDs) survive into adulthood¹ in regions of the world with adequate facilities for intervention. This improvement in survival occurred over the last seven decades prior to which less than 20% of children with CHD survived into adulthood.^{2,3} Consequently, a substantial population of adults live with CHD (in North America, adults constituted 54% of the total CHD population in 2000 and 66% in 2010).⁴

In many low- and middle-income countries, this survival advantage has not occurred principally because of inadequate facilities for surgical or interventional therapy. Adults living with CHD (ACHD) are either natural survivors or those who underwent surgical or interventional therapy in childhood. Many sub-Saharan African countries have no facilities for definitive CHD treatment, and so ACHD in Africa largely consists of natural survivors. Because of Africa's high fertility rate (in most countries, it is four or more births per woman), it is likely that a substantial number of patients with ACHD exist on the continent. Nonetheless, ACHD in Africa is poorly studied, and data to aid health-care planning and policy are desperately lacking. In a recent study that tracked ACHD research output

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Table 1. Birth Prevalence of Congenital Heart Defects, in Africa.

UQ Countries	Number	UMQ Countries	Number	LMQ Countries	Number	LQ Countries	Number
Nigeria	52,814	Ghana	6,168	South Sudan	3,099	Namibia	472
Ethiopia	23,866	Madagascar	6,116	Rwanda	3,008	Lesotho	425
DRC	22,853	Morocco	5,923	Benin	2,805	Gabon	405
Egypt	15,891	CI	5,882	Togo	1,907	Botswana	395
Tanzania	15,136	Mali	5,770	Tunisia	1,702	Swaziland	284
Uganda	12,100	BF	5,228	Sierra Leone	1,639	EQ	209
Kenya	11,737	Zambia	4,980	Eritrea	1,415	UC	200
Sudan	9,807	Malawi	4,907	Congo	1,274	Djibouti	179
South Africa	8,554	Chad	4,399	CAR	1,164	Mauritius	108
Mozambique	7,733	Senegal	4,109	Liberia	1,150	CV	80
Angola	7,437	Zimbabwe	3,544	Libya	1,024	ST&P	48
Algeria	7,263	Burundi	3,527	Mauritania	985	Seychelles	13
Niger	6,859	Guinea	3,300	Gambia	607	WS	No data
Cameroon	6,223	Somalia	3,272	G-B	493		

Abbreviations: BF, Burkina Faso; CI, Cote d'Ivoire; CV, Cape Verde; EQ, Equatorial Guinea; G-B, Guinea-Bissau; LMQ, lower middle quartile; LQ, lower quartile; ST&P, Sao Tome & Principe; UC, Union of Comoros; UMQ, upper middle quartile; UQ, upper quartile; WS, Western Sahara.

between 1995 and 2011, only 9 centers in Africa were reported as having scientific output compared with 190 in Europe; the number of ACHD centers per 10-million population was 0.1 in Africa (compared with 36 times of the figure in Europe).⁵ The status and challenges of ACHD care in Africa are thus poorly defined. In this communication, we review relevant data and recently published works from the five Africa subregions to describe the profile of ACHD in Africa and outline some of the key challenges of care.

The ACHD Population in Africa

High birth prevalence in the setting of restricted access to definitive therapy of CHD is the distinguishing feature of CHD care in Africa. We reported earlier the estimated birth prevalence of CHD in sub-Saharan Africa.⁶ We now report the continental birth prevalence including estimates from Northern Africa. As shown in Table 1, the 54 African countries have an estimated total annual birth prevalence of 300,486 cases (mean: $5,463 \pm 8,401$; median: 3,272), with profound variance among countries. More than half (51.4%) of the entire continental birth prevalence occur in only seven countries (Nigeria, Ethiopia, Democratic Republic of Congo [DRC], Egypt, Tanzania, Uganda, and Kenya). Africa's CHD birth prevalence was 23% (1,310,000) of the world prevalence in 2013,⁷ although its population was only 15% of the world's.

The size of the ACHD population is a function of both natural survival and (unnatural) survival of those who undergo surgical or interventional therapy. Access to surgical therapy of CHD within two years of birth in much of sub-Saharan Africa is less than 1%⁶; in Africa, the contribution from unnatural survival of CHD is thus likely to be very low. On the other hand, the high fertility rate in Africa resulting in a disproportionate burden of CHD makes the contribution from natural survival significant. A reasonable estimate from the presurgical era is a 10% to 20% survival rate into adulthood,^{2,3} the

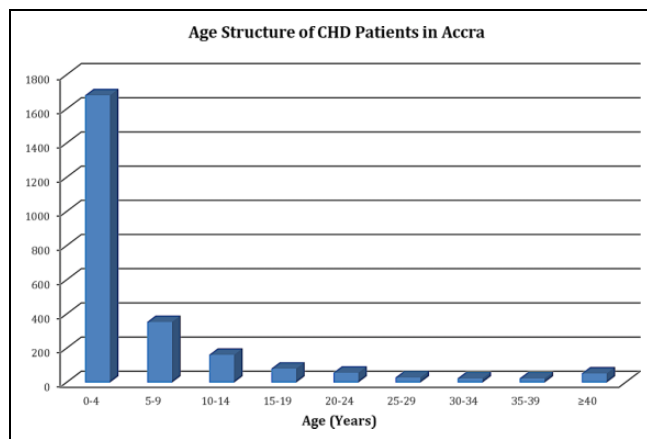


Figure 1. Age structure of patients with congenital heart defect (CHD) in Accra, Ghana (2011-2016).

equivalent of roughly 30,000 to 60,000 (10%-20% of 300,486) natural survivors joining the ACHD pool in Africa every year.

Survival Pattern of Children With CHD in Africa

The survival pattern of children born with CHD, in Africa, was evaluated using the experience in Ghana. The demographics of all patients diagnosed with CHD and seeking care at Ghana's National Cardiothoracic Center between January 2011 and May 2016 were assessed.

In that period, 2,464 patients with CHD (52.4% female) of mean age 5.9 ± 9.9 years (median 2 years) were seen. As shown in Figure 1, the population is largely composed of young children in the first five years of life, with a much smaller number surviving beyond this age to contribute to the older age-groups. This suggests an exaggerated mortality in the first five years of life, indicating that the greatest impact in

Table 2. Clinical Profile of Adults With Congenital Heart Defects, in Africa Regions.

	Western		Central Cameroon ¹¹	Eastern Uganda ¹²	Southern South Africa	Northern Egypt
	Ghana	Nigeria ⁹				
Period and patients	2011-2016; 244 patients; Age: 28.6 ± 14.2 years; ACHD 10% of all CHD	2001-2010; 143 patients; Age: 29.9 ± 14.7 years	2002-2008; 279 patients; Age: only 10% were older than five years	2007-2012; 124 patients; Age: only 13.5% older than 18 years	2003-2015; 109 surgical patients; Age: 22% were 10-18 years old; 78% older than 18 years	2016 Registry update; 151 patients; Age: 29 ± 12 years
Commonest defects	VSD, 34%; ASD, 26%; PDA, 12%; TOF, 12%; others, 16%	VSD, 39%; ASD, 36%; TOF, 10%; others, 15%	VSD, 39%; TOF, 26%; PDA, 12%; AVSD, 7%; ASD, 3%; others, 10%	ASD, 69%; VSD, 13%; others, 28%	ASD, 49%; AVSD, 15%; TOF, 11%; VSD, 9%; others, 16%	ASD, 25%; VSD, 13%; PS, 13%; TOF, 11%; Coarctation, 8%; others, 30%
Prior intervention	34%	2.1%	None	None	13%	17%
Complications/mortality	PHT, 6.1%; surgical mortality, 1.7%	PHT, 35%; heart failure, 15.4%	25 patients died on waiting list	Not specified	Surgical mortality 4%	Eisenmenger syndrome, 6%

Abbreviations: ASD, atrial septal defect; AVSD, atrioventricular septal defect; PDA, patent ductus arteriosus; PHT, pulmonary hypertension; PS, pulmonic stenosis; TOF, tetralogy of Fallot; VSD, ventricular septal defect.

improving survival into adulthood is achieved by interventions in the very early years of life. Unfortunately, in Africa, early intervention does not occur in the majority of patients with CHD. For example, the mean age at intervention for tetralogy of Fallot in Ghana was 5.0 ± 4.1 years for a palliative shunt and 8.4 ± 6.1 years for complete repair,⁶ and 8 ± 10 years in Mozambique⁸ for a cohort of patients with CHD. With the current prevailing circumstances in Africa, delaying intervention beyond five years seems inevitable in many countries, but it implies a greater number of lives lost even in countries where facilities exist for earlier CHD intervention. Failure to carry out early intervention for CHD in Africa is the primary reason for the predominance of natural survivors in the ACHD population of Africa.

Clinical Profile of ACHD in Africa Regions

An overview of the clinical profile of ACHD in selected countries from the five Africa regions (Western, Central, Eastern, Southern, and Northern) is shown in Table 2.

Western Africa: Ghana and Nigeria. The age profile of the ACHD (≥ 16 years old) cohort seen in Accra, Ghana, is shown in Figure 2. The spectrum of lesions is shown in Figure 3. The group made up only 10% (244) of all patients with CHD seen during the study period, a much smaller proportion than would be found in North America or Europe.⁴

Eighty-four (34.4%) patients had undergone surgical intervention (Table 3): 21 prior to the study period (follow-ups), 58 during the study period (primary operations), and 5 reoperations during the study period. One early death occurred (1.7%) among the 58 primary surgery cases. The patient was a 19-year-

old male with tetralogy of Fallot who underwent a right-modified Blalock-Taussig shunt and died suddenly on the fifth postoperative day from a suspected arrhythmia. Autopsy was performed but could not further clarify the cause of death.

From published data,⁹ the ACHD age profile seen in Nigeria was similar to the Ghanaian experience (Table 2). The very low number of previously operated patients is an indication of poor access to cardiac interventions in this country,¹⁰ which incidentally is the country with the highest CHD birth prevalence in Africa.

Central Africa: Cameroon. The St Elizabeth Catholic General Hospital's cardiac center in Shisong became operational in 2002 with humanitarian assistance. As shown in Table 2, between November 2002 and November 2008, a total of 279 patients with CHD were evaluated.¹¹ Twelve patients were operated on locally during humanitarian cardiac surgery missions, and 158 patients were left on the surgical waiting list; 25 patients died while on the waiting list. Currently the center performs 35 to 50 congenital heart operations annually in children, with five or less operations performed in the ACHD group.

The situation in Cameroon is typical of much of sub-Saharan Africa: Definitive treatment for CHD is heavily dependent on humanitarian assistance which is often insufficient to meet local needs. The ACHD population suffers as the few resources available are dedicated almost exclusively to children.

Eastern Africa: Uganda. The Uganda Heart Institute based at the Mulago Hospital Complex is the national referral center for treatment of cardiovascular diseases in the country. Cardiac operations without the use of cardiopulmonary bypass have

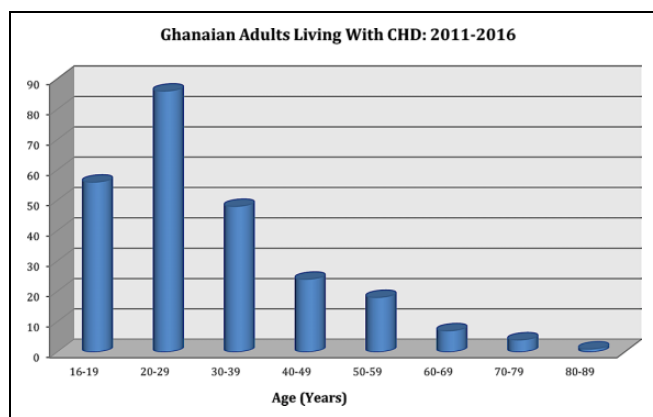


Figure 2. Age profile of adults living with CHD (ACHD) in Accra, Ghana.

Table 3. Surgery for Adults With Congenital Heart Defects in Accra, 2011-2016.

Follow-Ups	Primary Operations		Reoperations		n
	n		n		
Repaired VSD	11	ASD	19	AVSD-LAVV replacement	2
Repaired TOF	4	VSD	14	Total repair of TOF with previous MBTS	3
Repaired ASD	3	PDA	11		
Ligated PDA	2	TOF	5		
Repaired PS + ASD	1	AVSD	4		
		Others	5		
Total	21		58		5

Abbreviations: ASD, atrial septal defect; AVSD, atrioventricular septal defect; PDA, patent ductus arteriosus; PS, pulmonic stenosis; TOF, tetralogy of Fallot; VSD, ventricular septal defect.

been performed here since 1997. Cardiopulmonary bypass procedures began in 2007 with support from visiting teams. In a review involving 118 congenital heart repairs,¹² only 16 (13.5%) patients were adults (Table 2).

Southern Africa: Republic of South Africa and Mozambique. The Republic of South Africa has 35 cardiac centers performing an estimated 8,280 open heart procedures a year.¹³ Patients who underwent surgery for CHD in adulthood at the Groote Schuur Hospital in Cape Town from March 2003 to June 2015 were reviewed for this report (Table 2).

Recently, a South African ACHD study¹⁴ reported on 219 patients with mostly septal defects and right heart lesions, who underwent surgical intervention. Preoperative risk factors (severe pulmonary artery hypertension, endocarditis, left ventricular ejection fraction <30%, renal dysfunction, severe cyanosis, and polycythemia) were identified in 46 (19.8%) patients, most of which ostensibly resulted from long-standing CHD.

Unlike the rest of sub-Saharan Africa, the Republic of South Africa has had a comprehensive surgical program for several decades, and the need for dedicated ACHD centers is increasing, with patients presenting with complications and the need for reinterventions in later life.

In Mozambique, the ACHD group (older than 18 years) made up just 13.7% of 534 congenital heart cases reported.⁸

Northern Africa: Egypt. Egypt has 48 cardiac centers performing an estimated 16,000 cardiac operations per year.¹⁵ Unlike much of sub-Saharan Africa, Egyptian children born with CHD are covered by national health insurance. Adults with CHD receive support from charitable organizations, private insurance, or pay for services out-of-pocket. Recently, a clinical registry and an ACHD unit were established by the Cairo University Hospitals.¹⁶ The authors reviewed the current registry data on 151 patients for this report (Table 2). Notably, ACHD care in Egypt is among the best available on the continent.

Summary of ACHD Profile in Africa

Unlike what pertains in developed countries, CHD remains a pediatric disease in Africa; the ACHD population made up just 10% of 2,464 persons living with CHD in Ghana and up to 13.7% of 534 patients with CHD presenting for surgery in Mozambique. The population consists largely of natural survivors of CHD in the second and third decades of life; between 2.1% and 34.4% of patients with ACHD had undergone prior surgical intervention in the Africa regions assessed. The clinical profile of ACHD in Africa differs significantly from that seen in North America and Europe principally because of the lack of appropriate manpower and infrastructure and a disproportionate burden of pediatric CHD. Without the appropriate interventions, majority of infants born with CHD in Africa do not survive the first five years of life, leaving natural survivors suffering complications of long-standing disease in the ACHD pool. Patients with ACHD fare much better in Egypt and the Republic of South Africa where CHD services are superior.

Current Challenges of ACHD Care

Policy issues

Infrastructure, manpower, and health-care financing. In policy terms, grossly inadequate health-care infrastructure, a critical shortage of appropriate manpower, regressive health-care financing, and insufficient prioritization of CHD care constitute the greatest challenges in ACHD service provision in Africa.

The United States and Canada are home to 14% of the world's population, have 37% of the global health workforce, and spend about 50% of the world's financial resources for health. Conversely, sub-Saharan Africa, with about 11% of the world's population, is home to only 3% of the global health workforce, and spends less than 1% of the world's financial resources on health.¹⁷ In 2014, average per capita health-care expenditure worldwide was \$1,060 (\$8,990 in North America

and \$3,612 in the European Union) but only \$98 in sub-Saharan Africa. Twenty-four of the 30 countries with the lowest health-care expenditure per capita (<US\$60) in 2014 were in sub-Saharan Africa.¹⁸

In 2011, physician numbers in sub-Saharan Africa averaged 0.2 per thousand of the population compared to 3.5 in the European Union, and 2.4 in North America (the global average was 1.5).¹⁹ The situation is much worse in highly specialized care. In 2013, only 2.7% (933) of the 34,251 surgeons registered on the Cardiothoracic Surgery Network were based in Africa. In the same year, 12 open heart procedures were performed per million of the population in Africa compared with 158 per million in China and 1,038 per million in Germany.¹³ Institutional cost of open heart surgery in Africa ranges between \$6,000 and \$10,000 per case.^{7,20} Only a privileged few can afford this level of expenditure in Africa. Humanitarian surgical missions and philanthropic support have therefore become the major means by which the CHD care is provided in Africa. Such contributions are useful but constitute no lasting solution to a perennial problem. Nongovernmental organizations crucial in providing the funding for surgery in resource-limited countries focus their resources mainly on pediatric cardiovascular care²¹; few are dedicated to patients with ACHD. As a result, only a small proportion of patients with ACHD in Africa obtain the funding to undergo intervention. The foundation for a lasting resolution of these challenges lies in the development of strong economies across the continent, prioritization of CHD care, and progressive health-care financing.

Awareness. Whereas the need to provide specialized care for ACHD was recognized in Europe and North America as far back as 1973,²² no such awareness is apparent in much of Africa. There are no reports of dedicated ACHD centers on the continent apart from the one recently established in Cairo, Egypt. The number of adult cardiologists with adequate experience in ACHD care in Africa is unknown but expected to be very low. No dedicated ACHD training programs in Africa have been reported. Data on ACHD necessary for planning and effective policy are lacking. Awareness of the challenges of the ACHD population in Africa is an urgent advocacy need that remains largely unmet.

An “orphaned specialty.” In Africa, there are no clearly defined age limits for transfer from pediatric to adult care and patients with ACHD receive no particular specialty care. In some African countries like Ghana and parts of Nigeria, pediatricians are limited to caring for patients not older than 12 years. There are not enough pediatric cardiologists in Africa, and the few available are preoccupied with cardiac problems of children. The adult cardiologists in Africa focus largely on hypertension, rheumatic heart disease, and cardiomyopathies, with little exposure to CHD. In Africa, adolescents with congenitally malformed hearts and patients with ACHD are thus caught in a nebulous transitional zone of age and disease. They are considered too old by pediatric cardiologists and “too pediatric” by adult cardiologists. Although ACHD is now a valid subspecialty in developed countries, in much of

Africa it represents an orphaned specialty without specialists, specialized centers, or clearly defined needs.

Clinical issues. The African context imposes several twists to the well-known clinical problems of the ACHD population, the most pertinent being late presentation, and deficiencies in electrophysiological and obstetric services.

Complications of late presentation. The majority of patients with ACHD in Africa receive a first-time diagnosis in adulthood. The complications of long-standing unrepaired CHD are thus common in this patient population. The work of Long and coworkers¹⁴ provides the most comprehensive single-center data in Africa on such complications in a surgical cohort of 219 patients seen over a 20-year period. Most of the complications such as pulmonary hypertension, ventricular dysfunction, and renal dysfunction among others are the end organ repercussions of long-standing untreated disease. Their findings are supported by others who have noted a similar spectrum of complications.^{8,9}

Inadequate arrhythmia management. Cardiac rhythm status is often a paramount issue in the management of patients with ACHD. Arrhythmias account for up to 37% of emergency admissions of patients with ACHD.²³ Important arrhythmias reduce the quality of life and contribute to a risk of sudden death. Close electrophysiological follow-up is therefore essential in the care of patients with ACHD. In 2014, a Pan African Society of Cardiology survey on pacing and electrophysiology did not find any electrophysiology centers in all of sub-Saharan Africa (except South Africa and Senegal), leaving a population of roughly 912 million people without such a service.²⁴ The management of arrhythmias in the ACHD population in Africa is ostensibly grossly inadequate.

Poor obstetric care. Roughly half of patients with ACHD are female. In Africa, most are of childbearing age. Pregnancy in these patients is a high-risk event as the management often occurs in centers with little expertise in caring for patients with ACHD. Recently, Sliwa and coworkers²⁵ reported on 225 consecutive pregnant women (mean age: 28.8 ± 6.4 years) presenting to a single tertiary care center in South Africa. Congenital heart disease was the commonest problem diagnosed in 32% of the 152 women presenting in a higher risk group (modified World Health Organization classes II-IV). Maternal mortality rate within the six-month postpartum follow-up period was 5.9% (9 of 152), with all deaths occurring in symptomatic women (WHO class III or IV risk group). There was one perinatal death (a perinatal mortality rate of 7 of 1000 live births). Where facilities are available, a combined obstetric and cardiology clinic managing pregnancies complicated by maternal heart disease managed to have good outcomes in Africa.²⁶ Such coordinated care however occurs rarely in Africa, and it is likely that ACHD is a significant cause of maternal mortality and morbidity in Africa regions lacking such care.

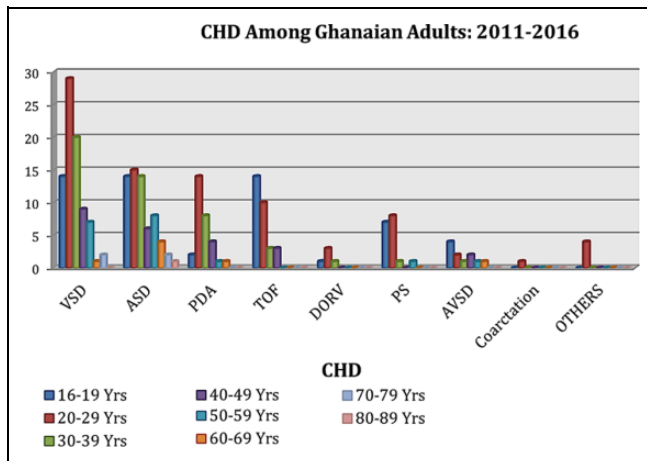


Figure 3. Congenital heart defects among Ghanaian adults. ASD indicates atrial septal defect; AVSD, atrioventricular septal defect; DORV, double-outlet right ventricle; PDA, patent ductus arteriosus; PS, pulmonary stenosis; TOF, tetralogy of Fallot; VSD, ventricular septal defect.

Future challenges. The current problems notwithstanding the future of ACHD care in Africa are expected to be even more challenging. This is so because of the unprecedented population growth expected in Africa in the next several decades. According to the United Nations children's agency, projected trends in world population can be expected to create huge economic opportunities as well as new risks for political instability and extreme poverty in Africa.²⁷ Although every other continent is seeing a slower rise in births, or even a decline, United Nations Children's Fund projects that 41% of the world's births, roughly 1.8 billion babies, will occur in Africa over the next 35 years. The total African population is projected to nearly quadruple to about 4.2 billion by the end of the century, by which time about 40% of all humans (and nearly half of all children) will be African.²⁸ From the very high accuracy of previous UN projections of population growth rates,²⁹ it seems highly probable that the burden of pediatric CHD in Africa is set for a dramatic increase in the next few decades, with important spin offs into the ACHD pool. It is likely that some pediatric CHD will undergo intervention and roll over into the adult CHD population. This will be in addition to the natural survivors, a reasonable estimate being that of the presurgical era (10%-20% of the annual incidence). This could mean a CHD incidence of 18 million cases (1% of 1.8 billion) over the next 35 years. If 10% to 20% of these survive into adulthood as in the presurgical era, an extra 1.8 to 3.6 million persons shall be added to the ACHD population in the same period, most coming from the group of seven nations with the highest fertility rates on the continent (Niger, Nigeria, DRC, Ethiopia, Tanzania, Uganda, and Kenya). The consequent increase in health-care service demand must be countered by commensurate or superior economic performance (Figure 4), otherwise already deficient African health-care systems will suffer unbearable strain. The UN report calls for "courageous and determined action" to face the challenges of the African

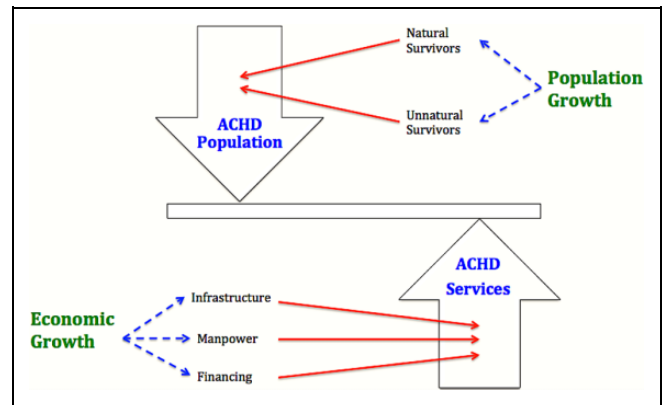


Figure 4. High fertility rates in Africa lead to population growth and increase the number of natural survivors of CHD; unnatural survivors may also increase if the surgical and interventional therapies increase. The resulting growth of the ACHD population creates an increased demand for ACHD services that can only be supported by commensurate or superior economic performance to fund outlays in infrastructure, manpower training, and health-care financing.

population boom. In terms of the ACHD challenge in the future, such courageous and determined action will involve substantial investments in cardiovascular manpower, infrastructure, health-care expenditure, and health systems organization.

Study Limitation

This study has used data from just seven countries to represent the status of ACHD care in the various Africa regions. The data used may not necessarily be generalizable to the other African countries as resources differ substantially across the rest of the continent.

Declaration of Conflicting Interests

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