

Peer Review File

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Reviewer A

The authors provide a sobering review of the current state of congenital cardiac care in Sub-Saharan Africa. This is a very well-written manuscript and highlights a significant humanitarian crisis.

- It would significantly add to the manuscript and also give the readers a perspective if the authors can add the approximate number of children and adults there are with congenital cardiac disease in Sub-Saharan Africa

A: Thank you for your observation. This information might better elucidate this public health problem. We have added this information in this version of the manuscript "The prevalence of CHD for sub-Saharan Africa children varies from 2.2 to 14.4 per 1000 live births. CHD contributes to approximately 1% of deaths per 1.000 live children. There are little data available regarding the prevalence of CHD in an adult population in Sub-Saharan countries. A study including more than 4.000 echocardiogram studies in adult patients observed a prevalence of 2.5% of CHD in this population. In addition, the total annual new caseload of CHD in sub-Saharan Africa using 2013 country data for extrapolation yields 258,875 CHDs cases (mean of 5,393+8,625; median 3,185; range 13-52,814). Six countries (Nigeria, Democratic Republic of the Congo, Ethiopia, Tanzania, Uganda, and Kenya) together accounted for 138,506, or 53.5%, of the total annual CHD burden in sub-Saharan Africa."

- Can the authors also state the current number of congenital cardiac surgeries that are approximately being performed every year in Sub-Saharan Africa?

A: We have added this information in this version of the manuscript "The number of congenital cardiac surgeries performed in this region of Africa is extremely lower than necessary; it is estimated that only 3% of necessitated children can undergo surgery (Zimmerman). A survey conducted in 2012 showed that in that year 1277 open heart operations were conducted in sub-Saharan Africa excluding the Republic of South Africa, translating into 1.6 open heart operations per million population."

Reviewer B

In general: the paper is well written and explores all significant points of the topic.

The authors present many challenges Sub-Saharan Africa faces in improving access, financial affordability, and high-quality outcomes for patients with congenital heart disease (CHD). They provide a balanced view of most of the various aspects. I invite their comments on the utility and value of "surgical safari" (by visiting teams). I also encourage Authors to add numeric data to

support their observations whenever possible.

A: Thank you for the observations. We appreciated your comments. We have added numeric data whenever available and possible.

Specific recommendations (I refer to line numbers of the manuscript):

52: To better expose the scope of the problem, I would prefer a specific statement on the mortality rate (x/1 million population) of CHD in the Sub-Saharan region about the mortality rate (x/1 million population) of communicable diseases

A: It has been improved. Thank you.

"Although communicable diseases are still responsible for 56% of deaths in sub-Saharan Africa, a decrement in this group of diseases has been observed. On the other hand, an increase in non-communicable diseases corresponding to 25% is currently also registered. Among the non-communicable ones, cardiovascular causes occupy almost half of this group and among which we find the CHD."

62-65: Please, provide numeric data

A: Numeric data were provided

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"The number of congenital cardiac surgeries performed in this region of Africa is extremely lower than necessary; it is estimated that only 3% of necessitated children can undergo surgery.."

116: What percentage of GNI is spent on treating CHD v communicable diseases concerning their respective mortality (please, see my remark to line 52.)

A: There are no specific data on GNI and how it is disbursed in African countries. What we know in Africa is that surgical conditions receive little or no priority in the national health plans of African countries. In a systematic review of the national health plans of 43 independent sub-Saharan African countries, all countries represented had documented plans and measurable targets for the reduction of HIV and tuberculosis.

Of the 4,064 health targets identified in these plans, only 2% were related to surgical conditions or surgical care (none to CHD); 33% of the policies had no surgical targets whatsoever. Surgical conditions that receive attention are the ones relating to ophthalmic care – trachoma surgery and cataract (31). So in Africa, communicable disease receive all the attention, CHD is hardly known by policy makers.

Chireshe, J., & Ocran, M. K. (2020). Health care expenditure and health outcomes in sub-Saharan African countries. *African Development Review*, 32, 349–361.

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117: This point was only mentioned, not described

A: Thank you for your observation. The issue of late diagnosis in Africa is well debated in the literature. In this narrative review, we did not want to spend too much time talking about the subject, although we recognize its importance. Therefore, we added a paragraph describing more about this topic in this new version of the manuscript.

"As opposed to developed countries where 90% of the cases receives a diagnosis before the first year of life (Richmond), most Sub-Saharan children are diagnosed after the first year of life. For example, the average age at diagnosis in Mozambique was four years old (12). In Angola, 283 children with VSD were diagnosed in a mean age of 29 months (2). In Nigeria, only 33% of the diagnoses are performed before the first year of age (Sani). These exemplifies the Sub-Saharan picture in terms of diagnostic timing."

128-130: Does this phenomenon impact case-mix (e.g., HLHS-patients die neonatally without Prostin so that they will be missing from the case-mix presenting at a later age)?

A: Absolutely that this phenomenon has an impact on the case-mix. We have added a sentence clarifying this.

"This phenomenon obviously impacts the case-mix. "Univentricular neonatal hearts that require emergent diagnosis and surgical care with high mortality rates are rarely found in a later age in Sub-Saharan programs."

157-160: I do not clearly understand the Authors' point here. In most countries, pediatric cardiology is super-specialization that requires some training in cardiology or paediatrics. So, the point is not that these specialists would be candidates for pediatric cardiology but the incentives added so they choose for it.

A: We understand your point of view. At this point, we want to refer to pediatricians who are not cardiologists and cardiologists who are not pediatricians to be encouraged to work with patients with CHD, having not very extensive training just to attend to this emergency situation while training Pediatric Cardiologists.

We have changed the sentence to be clearer in this version of the manuscript:

"As it is easier to find pediatricians who are not cardiologists and cardiologists who are not pediatricians, a possible alternative would be to add specific training to this professionals and improve CHD care capacity in an emergent basis."

116-17: It would be useful to present a comparison to other areas in the world.

A: A: Thank you for your observation. The issue of late diagnosis in Africa is well debated in the literature. In this new version of the manuscript we added a paragraph describing more about this topic.

“As opposed to developed countries where 90% of the cases receives a diagnosis before the first year of life (Richmond), most Sub-Saharan children are diagnosed after the first year of life. For example, the average age at diagnosis in Mozambique was four years old (12). In Angola, 283 children with VSD were diagnosed in a mean age of 29 months (2). In Nigeria, only 33% of the diagnoses are performed before the first year of age (Sani). These exemplifies the Sub-Saharan picture in terms of diagnostic timing.”

184-201: I invite here an expansion on the various training aspects: individual/team training, onsite/remote coaching with the training center and most importantly: retention of talent

A: Its was added this to this section.

"The result of pediatric cardiac surgery is dependent on the intervention of various actors from different areas of expertise; and most of all they have to work properly as a team. There is an evident need to train specialists from the entire chain of care. Training for congenital heart surgery in Africa is challenging. Most countries just manage with a general CTS training program. This training can be onsite or remote coaching with the training centers and most importantly is the retention of talent and team training"

203-227: Infrastructure. I kindly recommend editing of this section. I invite the Authors' discussion on the various aspects: optimal institutional setting they propose, whether, it is a pediatric hospital, cardiac institute or else? I also miss their inclusion of a continuity-of-care plan, supply chain (consumables), equipment and even the basic necessities as uninterrupted electricity and tap-water supply. Then, the scope could be expanded to formation of local professional networks, cooperation with authorities, etc.

A: It is an interesting point and there is no such thing as one single right answer to these topics. Three different models have been proposed based on already succeed centers in Africa: The three models were used for developing cardiac programs in sub Saharan Africa. In Model 1 (Ghanaian–German, Namibian), a senior local consultant cardiac surgeon with governmental and private foundation funding developed national capacity building programs. Model 2 has been used in 21 centers. Visiting teams are funded by NGOs and charged with local staff training. Model 3 is used in Kenya. It is a modification of Model 1 where in the absence of an indigenous senior local

209-215: This section presents basic data and I feel they belong to the Introduction rather than into Discussion.

A: We have moved this sentence from the Discussion section to the Introduction. Thank you.

265-288: Authors provide an interesting case of outbound medical tourism from Africa. I, however, disagree with their conclusion that "Africa may not be that poor after all". I believe the word here is inequality. Governments have a strong mandate to provide equal opportunities for all their citizens and I believe a statement on that would naturally fit here and would lead the reader to the section.

A: Thank you for the observation; we have deleted this affirmation “Africa may not be that poor

after all” The authors agree with your opinion. The main issue in underdeveloped countries seems to be inequality. It happens the same in Brazil. At the same time, you can find the government paying for a child to travel from Angola to Europe and perform a complex CHD surgery, while another child may present a cyanotic spell and die due to a non-diagnosed Tetralogy in the same city. The Healthcare budget must be bigger and better distributed. There is the issue of corruption that jeopardizes this equality, but I think we should not focus on that.

I agree. The issue is healthcare inequity, making sure that everyone has a fair chance of getting treatment regardless of the cost. There is the general feeling among the lay public that certain categories of patients (like those with acute/severe illness, children, and the poor) have stronger moral claims on scarce health-care resources than others. When such patients are left untreated, the perception of unfair distribution of health benefits remains. That happens often with outbound medical travel from Africa where a few benefit to the detriment of many others.

312-316: Authors present a rather persuasive argument. I offer for their consideration that high quality standards should be initiated and enforced from the healthcare professionals themselves, not from the authorities. Change starts from within. Giants of Indian cardiac surgery did the same and that is why they were successful. I believe that moral basis could be an example for others to follow.

A: We agree with you and thank you for your contribution. It has been added to the manuscript. "The final recommendation is that high-quality standards should be initiated and enforced by the healthcare professionals, not only by the authorities. We must be the example to be followed by the authorities in countries with weak regulations."

344 onwards: I miss here important discussion on:

- The financial model of care: government-based, insurance reimbursement-based or private (along the Indian-model) they propose.
- Organizational model: where should a centre-of-excellence for CHD be based (pediatric hospital or cardiac centre: both adult/babies)?
- What regulations is the centre-of-excellence to follow, e.g., international professional guidelines proposed by WSPCHS, ASPCHS?
- How will the professionals be retained? I believe this is a rather important point that already starts in the training phase.

A: Well appointed observations.

Financial model of care: The vast majority of people cannot afford and need some financial risk pooling device (insurance) to help obtain service provided at public institutions. The downside with public institutions is often that remuneration of workers is suboptimal, and equipment and consumables may not be available throughout the year. As a result, service downtime compromises delivery and quality. Private providers tend to be more business minded but operate at a relatively higher service delivery price. A small percentage of people may be able to afford and therefore private providers should be encouraged to make quality services available – at least those who will travel outside the country can obtain quality care within the country from private providers. Occasionally, philanthropists are happy to sponsor care from an in-country provider rather than send the patient abroad. South Africa has the two systems that work relatively well –

better quality and reliability at the private hospitals but those who cannot afford can get service at public hospitals (longer wait times). Retention of the professionals is more difficult as the government cannot afford to pay them well. But if governments encourage private providers, then professionals can work in both public and private hospitals and reach a compromise.

Organizational model: where should a center-of-excellence for CHD be based, pediatric hospital or cardiac center: both adult/babies? Most countries without cardiac programs will start with an adult program not a pediatric one – because the funding and personnel requirements are not as great. Pediatric programs should start off within these adults programs until they gain some financial sustainability to stand on their own.

What regulations is the centre-of-excellence to follow, e.g., international professional guidelines proposed by WSPCHS, ASPCHS? Regulation model: The regulation can be made by the WSPCHS or by the ASPCHS or by the government. In our case, children's heart hospitals operated by governments are best housed within adult cardiac centers, as funding is always a problem.

How will the professionals be retained? I believe this is a rather important point that already starts in the training phase: Well, there is always the risk of losing talents. The better way to retain talents is to design a center of excellence with an enjoyable environment and consistent outcomes for the patients. Everyone looks forward to be part of a winning team. Another alternative is to arrange specific contracts between the professionals and the government, where once the professional is trained using government funds, he becomes obligated to fulfill an amount of time working for their population. Something like what is still in place and happened with Dr. Valdano Manuel and many others doctors in Angola.

365-385: I suggest that the concept of infrastructure building should be mentioned in this section. Clearly, most African countries not only need to establish cardiac centres for CHD but also to build/improve their social infrastructure. That would entail with benefits of having all the take-holders (i.e., constituents of the business: networking physicians, established referral routes, established continuity-of-care, insurance companies, supply chain of consumables, patient logistics, etc.) ready for action. In a broader aspect, infrastructure creates lots of opportunities and all could benefit, patients and families the most.

A: A great contribution to this section of the manuscript. We have taken it into account.

"Most African countries not only need to establish cardiac centers for CHD but also to build or improve their social infrastructure. That would entail with benefits of having all the take-holders (i.e., constituents of the business: networking physicians, established referral routes, established continuity-of-care, insurance companies, supply chain of consumables, patient logistics, etc.) ready for action. In a broader aspect, infrastructure creates lots of opportunities and all could benefit, patients and families the most."

Thank you for allowing me to review this excellent manuscript.

Reviewer C

Very well written article just a very few grammatical errors.

Is it also worth proposing collaborations between governments in sub Saharan Africa and higher income countries based on historical models such as the Commonwealth or current trading relationships

Many higher income countries have large overseas aid budgets that potentially be tapped into to fund relatively expensive infrastructure which is the first obstacle in making such projects viable.

Other bodied such as the World Bank and UN specifically because of SDG number 3 pertaining to child health.

Finally a mechanism of raising the profile of this enormous child health problem in the lower income countries so policy makers have to sit up and take notice of this ongoing tragedy due to public pressure.

A: Thank you for your observations! The English language has been edited throughout the manuscript.