Palliation of Functionally Single Ventricle Patients in Sub-Saharan Africa—Is It Justifiable?

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Abstract

Resource constraints in many sub-Saharan African countries undermine efforts to provide the full spectrum of pediatric cardiology and cardiac surgery. Palliation of the child born with functionally single ventricle is the lowest priority for policymakers when viewed from the perspective of cost-effectiveness. This commentary focuses on the relative importance of different criteria that policymakers and the general public consider important in setting health-care priorities as it relates to palliation of the patient with functionally single ventricle in sub-Saharan Africa. It argues the position that cost-effectiveness analysis tends to exclude those with high cost-to-treat illness, and decisions made on that basis alone are not acceptable to the general population on whose behalf those decisions are made.

Keywords

CHD, univentricular heart, congenital heart disease (CHD), functionally univentricular heart, health policy (includes government regulation), cost analysis

Background—Angola

Angola is a middle-income sub-Saharan African country of roughly 24 million people. Malaria, diarrhea, acute respiratory infection, and malnutrition are the leading causes of child mortality. Sixty-six percent of children under-five suffer from anemia; only 49% of children with pneumonia and 53% of those with diarrhea are able to access and receive treatment.¹ One of the items in the trolley basket of health-care goods the government must pay for is surgical palliation of children born with functionally single ventricle (FSV). Now, we have the opportunity to read in this issue of the journal, the results of single ventricle palliation in Angola reported by Manuel and coworkers.² But it is difficult to shake off the question—why would you add palliating single ventricles to this country’s problems?

Functionally Single Ventricle Palliation in Angola—Improving Outcomes

Treatment of FSV is decidedly palliative, unlike the simpler and commoner “curable” lesions like ventricular and atrial septal defects. In spite of current improved survival rates, the treatment is also very expensive—the mean cost of treatment from birth to Fontan completion, through to adulthood was estimated to be US$390,601.³

In the report of Manuel and coworkers,² operative mortality was particularly high for stage 1 palliation: 45.2% for the modified Blalock-Taussig shunt and 11.7% for pulmonary artery banding. Although smaller numbers were involved, the Glenn and Fontan procedures also had high operative mortality (16.7% and 20%, respectively). The mortality in all stages exceeded those reported in somewhat similar settings.⁴ Also significant is the substantial rate of loss to follow-up (33.7%) in this study compared to 13% reported in similar settings.⁴

To be fair to the authors, these outcomes should be interpreted in the context of their results of the overall cardiac program in Angola which began in 2011—1,766 procedures (65% on-pump) performed on 1,682 children (44.9% neonates and infants) with 30-day mortality of 4.2%. Most procedures (76%) were performed in the Risk Adjustment for Congenital Heart Surgery (RACHS)—1, 2, and 3 categories.⁵ Considered in this context, the results of FSV palliation appears to be the bad apple among the lot. Taking out the bad apple would yield...
even better results for the remainder of the program, a commendable achievement in a sub-Saharan African setting. But we are still left wondering—where is the gap responsible for poor outcomes of FSV palliation in Angola?

The authors describe a state-of-the-art facility with an experienced foreign team on-site, but has what is now known to be standard care for FSV palliation been applied? The authors themselves pointed out deficiencies of perioperative care that may partly explain the high operative mortality. Operative mortality was attributed to sepsis-induced multi-organ dysfunction, shunt occlusion, low cardiac output syndrome, and aspiration pneumonitis, among others. These causes of operative mortality among FSV patients are well recognized; guidelines covering these aspects of care have been previously published and need no repetition here. The reported outcomes should therefore provide a strong institutional impetus for a search leading to corrective measures. The consequence of not doing so could be serious—public confidence may be eroded and patients may lose faith in the service. More importantly, political priority for the program’s continuation, so difficult to attain in sub-Saharan Africa, may be lost if policymakers begin to question the societal benefits of the program against the investment made.

Follow-up has always been problematic in sub-Saharan Africa because of poor communication and transportation, a situation compounded by low health literacy. Parents who fail to understand the palliative nature of the procedures and the lifelong follow-up commitment are likely to default on follow-up when socioeconomic and transportation problems take center stage during home care. Home monitoring strategies and specialized interstage outpatient clinics have enabled FSV programs in Western societies to substantially improve the chances of interstage survival to the Fontan procedure. These are difficult standards to meet in sub-Saharan African countries with fundamental and widespread lapses in health-care infrastructure and manpower distribution. It is not surprising that the authors report a loss to follow-up of 37%, seeing that theirs is the only cardiothoracic center in the country located in the northwestern corner.

Functionally Single Ventricle Palliation in Sub-Saharan Africa—Is It Justifiable?

Why would anyone add palliating single ventricles to the problems of a country where malaria, diarrhea, acute respiratory infection, and malnutrition are the leading causes of child mortality? The authors report that the government committed to increasing the number of Angolan patients with congenital heart defects receiving treatment by developing local capacity, hoping to reduce overall cost of treatment abroad; apparently palliating single ventricles happened to be included in that basket of “public goods.” Is that economically justifiable? Would it not be more efficient to dedicate the country’s limited resources to the correction of simpler and “curable” defects?

In terms of maximizing outcomes, resources devoted to running an FSV program will yield substantially more lives saved and at higher quality if committed instead to lower cost interventions for simpler, more prevalent, and “curable” defects. This represents the “best outcomes” approach to resource allocation. The counterargument is that every child has the right to a fair chance of getting treatment regardless of their diagnosis—the “fair chances” approach. The “best outcomes/fair chances” conflict is especially relevant in resource-poor settings.

In spite of the obvious economic efficiency implied by the “best outcomes” approach, 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. The “fair chances” approach, which is based on equitable distribution of health benefits, resonates with society’s feelings about the strength of claims of different patient groups. A resource allocation that violates such feelings tends to be perceived as unfair. This view of the public is at odds with the concern with allocative efficiency usually envisaged by economists, politicians, and health-care professionals. In a two-stage survey assessing the importance of costs in setting health-care priorities, the public viewed it as unfair to discriminate against patients with a high cost-to-treat illness, indicating that costs should not be a major factor in the prioritization. The general population places importance on several other criteria, but health policy decision-makers tend to consider that the lay public may not have thought through the trade-offs thoroughly. Some of the most important value choices were evaluated in a multicriteria approach for priority setting in Ghana using subjects chosen from policymakers having expertise and experience in the matter. The main factors evaluated were cost-effectiveness, equity of distribution, age of target group, disease severity, degree of health impact, and impact on the total national budget. Interventions that were cost-effective (cost per disability-adjusted life year less than the gross national income per capita), equitable and reduced poverty, targeted severe disease (health-adjusted life expectancy below 5 years), or the young (below 15 years old) had a higher probability of being chosen.

Thus, the choice between single ventricle palliation and surgery for “curable” defects does not appear to be a mutually exclusive one, even in resource-limited settings. The implication is that policy-makers have to find a way to do a bit of both. While that approach may seem grossly inefficient to some, it has to be appreciated that cost-effective analysis tends to exclude those with high cost-to-treat illness from a having a fair chance at treatment, and decisions made on that basis alone are not acceptable to the general population on whose behalf those decisions are made.

Conclusion

Manuel and coworkers report indicates that embarking upon an FSV palliation program in sub-Saharan Africa requires more than operating room skills, state-of-the-art infrastructure, political priority, and financial support of patients. Adherence to
tried-and-proven perioperative care protocols, continuity of care beyond hospital discharge with processes in place for parental education, and regular follow-up care are essential to obtain current acceptable outcomes. Any center in sub-Saharan Africa undertaking to treat such patients ought to view its commitment to these patients as all-encompassing and lifelong. Without such commitment, excellent outcomes obtained in a sustainable fashion are unlikely.

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