

One-year outcomes and intervention waiting time of patients admitted with congenital heart disease at Kenyatta National Hospital, Kenya

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Abstract

Introduction:

Congenital Heart diseases (CHD) are clinically significant structural heart disease present at birth. CHD is found in 8–15 babies per 1,000 live births. Delayed diagnosis and long waiting time to intervention may lead to poor outcome. The objective was to establish the one-year post diagnosis outcome, the waiting time from diagnosis to intervention and factors associated with one-year post diagnosis mortality.

Methods

This was a retrospective review of patient records for patient with CHD admitted to Kenyatta National Hospital (KNH) from 1st January 2016 to December 2021. We collected data and entered it into REDCap and then analyzed using R.

Results

We reviewed 1,703 patient records for the study. At diagnosis, a majority of the patients were children aged less than one year (53.6%) with 56.6% males. At one-year post-diagnosis, the mortality rate was 36.1%. Only 69 (37%) received recommended surgical intervention within one-year with a median time 59 (10–208) days. While 44 (67%) had undergone recommended catheterization within one year with median of 95 (13.5-188.8) days. Those whose intervention was outside the country took 349 (10.8-703.8) days to get intervention. Older children and those with Tetralogy of Fallot (TOF) were more likely to die.

Conclusion

Few children with CHD receive the recommended interventions. There is a long waiting time from diagnosis to intervention. Mortality for patients with CHD remains high. There are many gaps in the documentation for patients with CHD at KNH. There is need to shorten time taken from diagnosis to intervention for patients with CHD and to improve documentation for patients with CHD at KNH.

Introduction

Congenital heart disease (CHD) is the commonest birth defect worldwide, affecting millions of newborns every year[1–8]. CHD is a clinically significant structural heart disease present at birth with inclusion of few other lesions that manifest later in life but with the risk factors being present at birth. Noteworthy, although evidence indicates that Africa has the lowest regional prevalence of CHD[3], the prevalence of CHD is estimated at about 8–15 per 1,000 live births[1, 8]. Congenital heart diseases are broad and the

widely used terms are as per the International Paediatric and Congenital Cardiac Code (IPCCC) and the International Classification of Diseases (ICD-11)[9].

Some studies in Africa have established that among children admitted in paediatric wards with heart disease, congenital heart diseases are the most common with Ventricular Septal Defect (VSD) being the commonest CHD followed by Patent Ductus Arteriosus (PDA) and Tetralogy of Fallot (TOF) [1, 3, 10, 11]. Such studies in Kenya did not collect data from all units where cardiac patients are admitted and therefore may not be a true reflection of the hospital status. The common CHDs in children are much the same ones that present in adulthood such as atrial septal defect (ASD), Tetralogy of Fallot (TOF), ventricular septal defect (VSD) and Patent Ductus Arteriosus (PDA). However, in adulthood, they may present with complications such as pulmonary hypertension, Eisenmenger, heart failure, arrhythmias, infective endocarditis and stroke, and have been shown to worsen with age[12–15].

Congenital heart diseases are common anomalies that increase morbidity and mortality among children and adolescents[1, 8, 16–18], and whose outcomes can vary significantly depending on the region in which the patients live. In more developed countries, better outcomes are typically seen, whereas in countries like Africa and those with less development, the outcomes are often poor or not well documented[19–23]. Delay in intervention may portend worse outcomes. In addition, the number of cases diagnosed with CHD in Kenya that need surgical interventions is probably more than the number of operations carried out[21]. Delayed diagnosis and long waiting time to intervention may lead to deaths before intervention is undertaken or poor outcome when the intervention is finally undertaken[13, 23–26].

Globally, access to healthcare and diagnostic technologies are known to substantially impact the reported birth prevalence of CHD as early diagnosis and prompt referral to an intervention center before complications arise may improve outcomes[19, 22]. In Africa, obtaining medical care is challenging, and this is especially true for infants born with CHD, as many of them probably go undiagnosed. In the Sub-Saharan Africa, Kenya included, inadequate healthcare workforce and medical facilities are prevalent, leading to delayed diagnosis and limited treatment options [19, 26]. Thus, some patients end up being diagnosed late or are referred out of the country. Some may not afford the cost of care for such interventions. Additionally, critical forms of CHD rarely receive the medical interventions that can significantly improve or even save their lives[21, 27, 28]. Prenatal screening and newborn screening programs would improve outcomes by providing an opportunity for early referral to the appropriate place for intervention, although in Africa these are also often not well developed, with limited access to echocardiography and limited treatment options[16, 26–28]. These factors may lead to poor outcomes. Whereas in areas where resources, health workforce and appropriate facilities are available, there is early diagnosis, prompt intervention and possibly good outcomes.

There are few centers that have Cardiology services for CHD in Kenya. As of 2022, there were three public facilities with diagnostic and interventional Cardiology services for CHDs in Kenya – Moi Teaching and Referral Hospital (MTRH) in Eldoret, Kenyatta National Hospital in Nairobi and Coast General

Teaching and Referral Hospital in Mombasa to which most patients from other public hospitals with suspected or confirmed CHD are referred for intervention and follow up.

Despite the significant attempts towards building an evidence base for CHD in Africa[2, 4, 5, 11, 16, 18, 26, 29–32], there still remains a limitation of accurate data on CHD burden, waiting time before intervention, and post-diagnostic outcomes in the Kenya and at large the Sub-Saharan Africa region. In addition, the number of patients with congenital cardiac disease on follow up at KNH and their outcome is unknown. This study therefore sought to generate the information that may also be used for other research around CHD in KNH as well as for advocacy and planning purposes in the region where interventions are thought to be low or with poor outcomes [13, 17, 21, 23–26].

Methods

Aim

The aims were to establish one-year post diagnosis outcome, the waiting time from diagnosis to intervention and factors associated with one-year post diagnosis mortality.

Study design

This was a cross-sectional study where records of all patients who had been admitted at KNH for the period 2016 to 2021 with a diagnosis of CHD and those with at least one year follow up in clinic were retrospectively reviewed. The one year follow up data formed the time point for the cross-sectional study to calculate point prevalence. The patient records were reviewed for one-year post-diagnosis outcome and the waiting time from diagnosis to intervention.

Study area and population

Kenyatta National Hospital (KNH) is one of the two national referral public hospitals in Kenya for patients with congenital heart disease. It is based in Nairobi, the capital city of Kenya. It has personnel and facilities for diagnosis, medical management, catheterization and surgery for some CHD. The KNH medical records department has clinical diagnosis for patients who have ever been admitted.

Study population

The study population included all patients diagnosed with a congenital heart disease from January 2016 to December 2021 and who had ever been admitted at KNH and with at least one year follow up in clinic. Records of patients listed as having heart disease but without supporting evidence from the investigation reports in their medical records file, those with patients with iatrogenic heart diseases, heart defects caused by trauma and preterm neonates diagnosed to have a patent foramen ovale and/or

patent ductus arteriosus were excluded from the study as these may not be considered as being truly CHDs.

Variables: The data collected included: age, gender, residence/home county, diagnosis and classification of the diagnosis (as per International Classification of Diseases (ICD-10)), intervention done, place where intervention was done, team that did the intervention, time from diagnosis to intervention and one-year post diagnosis status (outcome). Outcome was defined as being alive or dead. Waiting time was calculated retrospectively as the duration from when diagnosis and recommendation was made to the time the intervention took place. This data was retrieved from the medical records and entered into the study data collection form.

Data collection procedures

Data was collected in 2022 after ethical approval. The medical records of all patients diagnosed with CHD were retrieved from the KNH health information office and their medical records reviewed for relevance and the data required abstracted. Follow-up telephone calls for patients whose medical records did not have the required information were called to fill up gaps missing data [33]. The missing data was obtained from the patient/parent/guardian after explanation of the reasons for the call and seeking verbal informed consent from them on phone. The data required from each patient was entered into a data abstraction tool on the Research Electronic Data Capture (REDCap). Any incomplete fields or false data entry were flagged up by REDCap and actioned upon as appropriate. Most of the cardiac clinical diagnosis were recorded as what the Paediatric cardiologists diagnosed based on transthoracic echocardiogram findings. For those who had undergone extra investigations and surgeries, the final diagnosis after all the investigations and surgery is what was documented as the diagnosis.

Data analysis

The data was analyzed using the R statistical package, version 4.3.1. To establish the one-year post diagnosis mortality of patients who had been admitted in KNH from January 2016 to December 2021 for Congenital Heart Disease, the total number of patients who had died by one-year post diagnosis was the numerator while the total number of patients diagnosed with CHD over the study period was the denominator. The missing data was reported as missing or unknown as a fraction of the category under consideration.

Results

Table 1
Study patient characteristics

Variable	(N = 1703, %)
Age group in years at first diagnosis	
≤ 1 month	20(1.2)
> 1month to < 1year	893(52.4)
1–5 years	258(15.2)
> 5–12 years	56(3.3)
> 12–17 years	20(1.2)
18–30 years	14(0.8)
> 30–40 years	21(1.2)
> 40 years	9(0.5)
Not documented	412(24.2)
Gender	
Female	739(43.4)
Male	694(40.8)
Not documented	270(15.8)
Ever been pregnant (n = 739, female adults)	6(0.8)
Facility of first referral (source)	
KNH wards/units	374(22.0)
Referred from a private hospital/doctor	198(11.6)
Referred from another public hospital	570(33.5)
Self-referral	25(1.4)
Not documented	536(31.5)

Socio-demographics, diagnosis and recommended treatment for CHD patients

As shown in Table 1, a total of 1703 patients were enrolled in the study. The majority (53.6%) of these patients were under one year old at diagnosis. There were more females (43.4%) than males (40.8%), and out of these females, only 6 had ever been pregnant. Among these patients at first diagnosis, 33.5% were referred from other public hospitals, 22.0% were from within KNH, while 11.6% were from private

hospitals as indicated in Table 1. More than eighty percent of these cases of congenital heart disease (CHD) were diagnosed at Kenyatta National Hospital (KNH).

As shown in Table 2, upon CHD diagnosis, medical management was initially recommended for 43.2% of these patients, while surgery was recommended for 14.1%, with the majority (77.5%) of surgeries being recommended in Kenya. Catheterization and conservative management were recommended for 3.8% and 3.3% of the patients, respectively.

The majority (62.9%) of patients recommended for surgery did not undergo the surgery, or this information was unavailable. The majority (97.1%) of surgeries were performed at KNH, with an average waiting time from diagnosis to surgery being 59 days (IQR: 10–208 days). Of the patients recommended for catheterization, 67.7% underwent the procedure, primarily at KNH, with an average waiting time to catheterization of 95 days (IQR: 13.5-188.8 days). Among patients referred for surgery outside the county, only 13% underwent the surgery. Among the 7 patients who sought treatment out of the country, the waiting time to treatment was 349 days (IQR: 10.8-703.8 days), as shown in Table 2

Table 2
Diagnosis and recommended treatment among CHD patients

Variable	(N = 1703, %)
Facility of CHD diagnosis	
Kenyatta National Hospital	1511(88.7)
Other/Unknown	192(11.3)
Recommended intervention at diagnosis	
Medical management	735(43.2)
Inoperable/Conservative management	57(3.3)
Surgery in Kenya	186(10.9)
Catheterization in Kenya	65(3.8)
Referral out of the country for surgery	54(3.2)
Not documented	606(35.6)
Recommended Surgical Intervention in Kenya taken place (n = 186)	
Yes	69(37.1)
No/Unknown	117(62.9)
Place of surgical intervention for those advised on local surgery (n = 69)	
Kenyatta National Hospital	67(97.1)
Mater Hospital - Kenya	1(1.4)
India-Manipal	1(1.4)
Referred out of the country for surgery (n = 54)	
Yes	7(13.0)
No	10(18.5)
Unknown	37(68.5)
Time to intervention (median, (IQR)) (days)	59 (10–208)
Recommended Catheterization in Kenya(n = 65)	
Yes	44(67.7)
No	10(15.4)
Unknown	11(16.9)
Place of Catheterization in Kenya(n = 44)	

Variable	(N = 1703, %)
Facility of CHD diagnosis	
Kenyatta National Hospital	43(97.7)
Mater Hospital	1(2.3)
Time to Catheterization (median, (IQR)) (days)	95 (13.5-188.8)
Country of intervention (For those who referred out of the country) (n = 7)	
India	5(71.4)
Israel	1(14.3)
Spain	1(14.3)
Time to intervention for those referred abroad (median, (IQR)) (days)	349 (10.8-703.8)

Outcome at one year and waiting time

Figure 1 shows the mortality at 1 year whereby of the 1703 patients admitted with CHD, 56.4% (n = 961) were alive, 36.1% (n = 615) died, and 7.5% (n = 127) with unknown status.

Figure 1: One-year outcomes of patients admitted with congenital heart disease at Kenyatta National Hospital, Kenya

Older children and those with Tetralogy of Fallot (TOF) were more likely to die than those without with adjusted odds for age of 1.99 (95%CI 1.21–3.34).

Discussion

From this study, a majority of the patients (53.6%) were children aged less than one year. As manifestations of CHD are often detected during the perinatal period and early infancy through routine screenings, clinical evaluations, and diagnostic imaging techniques, a number of studies have recorded younger patients presenting with CHDs [34–36]. There may be fewer older patients possibly due to early deaths for children with CHD and thus fewer survive into older age groups hence fewer older patients presenting for admission into hospital[23, 37]. Most of the patients were referred by other health workers for cardiac evaluation (67%) as would be expected for a referral facility. The patients came from across the country although the counties near Nairobi had a higher concentration. Distance to a health facility has been a known factor in seeking care services[36, 38].

Only 37% had received the recommended surgical intervention within an year, with median waiting time to surgery of 59 (10–208) days. This is comparable to a study by Azeez where 44% had received intervention for cyanotic CHD in children under 18 years[35]. In this study 67% had undergone the

recommended catheterization within one year with time to catheterization being median of 95 (13.5–188.8) days. In this study, the number of cases diagnosed with CHD and advised on interventions was more than the number of interventions carried out as has been documented previously[21, 36]. At diagnosis 54 (2.2%) of the patients were referred abroad for further intervention, with a median time of 349 (10.8–703.8) days from diagnosis to intervention for this group. The significant delay from diagnosis to intervention may mostly be attributed to financial constraints. These findings support evidence from existing studies which found that patients may not be in a position to cater for the costs of the recommended care and thus take long to get the intervention or do not get the intervention at all[17, 21, 26, 37–40]. At diagnosis 57 (3.4%) were deemed inoperable and were counselled on palliative care. This may be an indication of delayed diagnosis when complications have already set in. This is true as there is not a countrywide spread of diagnostic capability and adequate facilities for CHDs, leading to delayed diagnosis and appropriate intervention options as seen in other studies as well [19].

Mortality was considerably high (36%) and children diagnosed with TOF were more likely to die than those without with adjusted odds for age of 1.99 (95%CI 1.21–3.34). Some studies have reported mortality as high as 50% in some centers more so in low-income countries [23–25]. Older children were more likely to die than those aged less than one year. This may be due to more complications as they grow older[23, 37]. Some of the patients may have been diagnosed late or referred out of the country, yet they did not go as shown in this study. Some may not afford the cost of care for such interventions. Mortality rates from CHD tend to be higher in developing countries than in developed countries due to a combination of socioeconomic, healthcare, and infrastructural challenges. The lack of prompt and ready access to prenatal care and diagnostic resources frequently leads to undetected or late diagnosis of CHD, which in turn may result in delayed interventions and higher mortality rates. The problem is probably worsened by the inadequate healthcare infrastructure, including shortages of skilled healthcare professionals, specialized pediatric cardiac facilities, and surgical expertise, which restrict access to life-saving treatments and surgeries. Additionally, socioeconomic factors like poverty, malnutrition, and the absence of clean water and sanitation exacerbate the susceptibility to CHD complications and infections, which, in turn, elevates mortality rates. Due to the scarcity of resources and healthcare infrastructure, individuals born with CHD in low-resource countries are probably at a significantly higher risk of mortality than those in high-income countries where advanced medical care and resources are more accessible. To address this disparity, a multidisciplinary approach is required, including investments in healthcare infrastructure, training of healthcare professionals, and implementation of public health initiatives to improve prenatal care, early detection, and access to life-saving interventions. Admittedly, in this study, the high mortality may have been due to a selection bias of only admitted patients. The CHD patients who are likely to be admitted are the ones with complications or with comorbidities. These are the same ones more likely to die than the stable CHD patients being treated as outpatients. The high mortality is may be an indication of need for early diagnosis and intervention.

The patient records contained a substantial amount of missing data. As the records were not created for research purposes, they had a greater amount of missing information [41]. Originally, we had planned to contact the patients to obtain the missing data, but many could not be reached using the contact

information they provided. It is possible that the number of patients who received the intervention is higher than what was reported, as some may have received the intervention at other private facilities and their follow-up was transferred to those facilities, making them untraceable in the KNH health information system. Missing data is a significant challenge in many studies, particularly in retrospective studies where up to 55% of the data may be missing [42, 43].

Study limitations and minimization

The present study utilized a retrospective design, which is subject to certain methodological constraints. A prospective study would offer a more comprehensive and precise assessment of the outcome measures examined herein. Additionally, the study relied on patient medical records, which are susceptible to missing information. To address this, whenever information was lacking, patients were contacted by telephone to clarify the necessary details. While this approach minimized the number of incomplete records, it was not possible to reach all patients. The incomplete records were documented and were incorporated into the report delivered to the hospital, which may serve as a foundation for enhancing the quality of documentation and care provided within the hospital.

Finally, the health information department at KNH maintains and associates the medical record file number with the patient's clinical diagnosis exclusively for those ever admitted to KNH. It does not connect the diagnosis and the medical record file number for individuals who have received treatment as outpatients or in specialist clinics if they have never been admitted to KNH. This approach may introduce a selection bias of patients with poor outcomes, as those who have been admitted may be sicker and have a higher likelihood of experiencing a poor outcome.

Conclusion

Based on this study, it is evident that the majority of individuals diagnosed with CHD do not receive the recommended interventions, particularly in areas with limited resources. The lengthy time period between diagnosis and intervention is mainly due to issues related to access and affordability of these interventions. Mortality rates for CHD patients remain high in low-income environments. There are numerous gaps in the documentation for CHD patients at KNH, and it is crucial to reduce the time taken from diagnosis to intervention for these patients. Enhancing the medical records for CHD patients is essential to ensure that all relevant details, including recommended interventions, time to intervention, and patient outcomes, are captured.

Abbreviations

ASD

Atrial Septal Defect

CHD

Congenital Heart diseases

ICD
International Classification of Diseases
IPCCC
International Paediatric and Congenital Cardiac Code
IQR
Inter- Quartile Range
KNH
Kenyatta National Hospital
KNH-UoN ERC
Kenyatta National Hospital – University of Nairobi Ethics and Research Committee (KNH-UoN ERC
MTRH
Moi Teaching and Referral Hospital
PDA
Patent Ductus Arteriosus
REDCap
Research Electronic Data Capture
ToF
Tetralogy of Fallot
VSD
Ventricular Septal Defect

Declarations

Ethical approval, consent and publication

The study was carried out after approval (P250/04/2021) from the Kenyatta National Hospital – University of Nairobi Ethics and Research Committee (KNH-UoN ERC). This being largely a retrospective study using patient records, we obtained waiver of individual patient consent from the KNH-UON ERC. We obtained approval for verbal consent witnessed by a third party for those patients whose medical records did not have full information, and phone interviews were conducted. Those patients or guardians deemed in need of further attention were referred to the appropriate places for emotional and psychosocial support such as the patient support center within KNH. The ERC approval included presentation in scientific conferences and publication of findings.

Consent for publication

Not applicable as there is not contain data from any individual person. However, there was consent for publication was obtained from the KNH-UoN ERC and from all authors.

Availability of data and materials

Data and other materials used for this research are under the custody of the Kenyatta National Hospital (KNH) research and programs department (<https://knh.or.ke/index.php/medical-research-programs/>). They can be obtained on permission from the KNH administration and the ERC.

Competing interests

The authors declare that they have no competing interests.

Clinical trial number

Not applicable

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Author contributions

Conceptualization, design, and development of the data collection software, as well as data collection, analysis, interpretation, and drafting of the manuscript were overseen by BOO. DK contributed to the design and development of the data collection software, data collection, analysis, and interpretation, and also provided assistance in revising the manuscript. EK contributed to the design and data collection, and also aided in interpretation and revision of the manuscript. EC, NG, and CYJ all contributed to the design and data collection, and also participated in the revision of the manuscript. MJA and FNW aided in interpretation and revision of the manuscript

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Figures

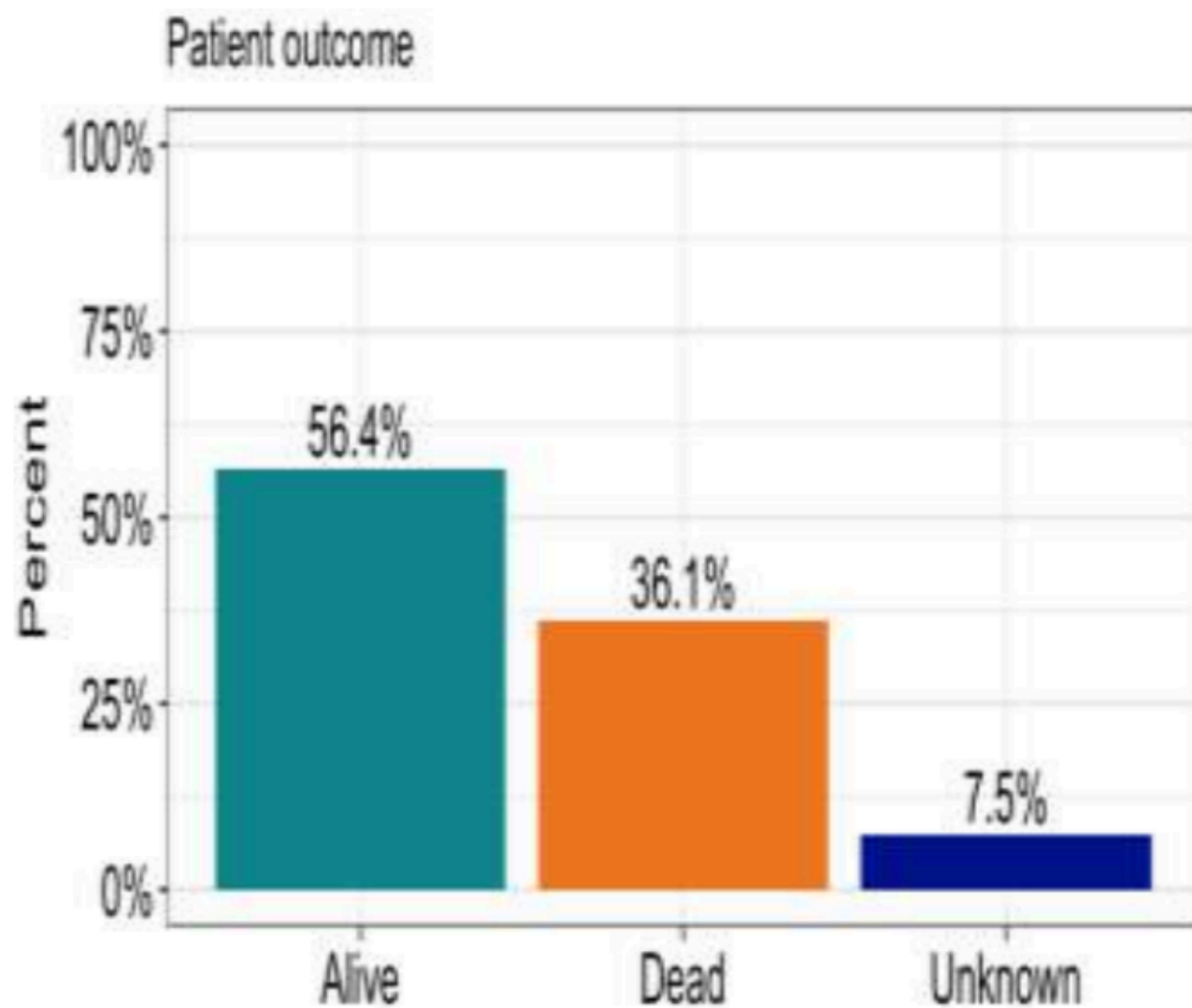


Figure 1

One-year outcomes of patients admitted with congenital heart disease at KNH, Kenya