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List of Abbreviations

1.	SRGH :	Sir Ganga Ram Hospital
2.	CHD :	Congenital Heart Defect/Disease
3.	OPD :	Out Patient Department
4.	IPD :	In Patient Department
5.	Dept :	Department
6.	ASD :	Atrial Septal Defect
7.	VSD :	Ventricular Septal Defect
8.	TOF :	Tetralogy of Fallot
9.	PDA :	Patent Ductus Arteriosus
10.	DORV:	Double Outlet Right Ventricle
11.	TAPV :	Total Anomalous Pulmonary Venous Connection
12.	ICU :	Intensive Care Unit
13.	CI :	Confidence Interval
14.	BHU :	Banaras Hindu University
15.	TGA :	Transposition of the Great Arteries
16.	wef :	with effect from

Section 1

Organisational Profile



Sir Ganga Ram Hospital

1.1 ORGANIZATION PROFILE

1.1.1 About Sir Ganga Ram Hospital

Sir Ganga Ram Hospital is a 675-Bedded multi-speciality Hospital in New Delhi providing comprehensive healthcare services. It has acquired the status of a premier medical institution. The hospital was founded initially in 1921 at Lahore by Sir Ganga Ram (1851-1927), a civil engineer by profession and leading philanthropist of his times. After the partition in 1947, the present hospital was established in Karol Bagh, New Delhi on a plot of land of approximately 11 acres. The foundation was laid in April 1951 by the then Prime Minister of India Shri Jawahar Lal Nehru and inaugurated by him on 13 April 1954.

Sir Ganga Ram Hospital in India continues to maintain its charitable character in accordance with the wishes of its founder. Funds generated from the hospital services are partially utilised for providing free health care to the poor and needy caretakers. All development activities of the hospital are financed from internal resources, with no financial assistance provided by the government or other external agencies. The Sir Ganga Ram Hospital is committed to make available 20% beds of total strength for admission of indigenous and financially weaker section of the society. On these beds all facilities (boarding, lodging, investigations, medicines and operative procedures) are free.

1.1.2 About Department of Paediatric Cardiac Sciences

This department provides a full spectrum of evaluation, diagnosis and management of congenital heart defects/diseases (CHDs) including interventional therapy from foetus to adulthood. Services are provided by a team of one Paediatric Cardiac surgeon and four Paediatric Cardiologists, ably supported by trained Paediatric Cardiac Anaesthesiologist. The department has a dedicated high end echocardiography system capable of performing 3D/4D

echocardiography. The paediatric cardiology faculty perform both diagnostic and therapeutic interventional procedures in children and infants. Surgical interventions range from highly complex neonatal cardiac surgery to paediatric cardiac surgeries and surgical management of adults with CHDs. The department has a dedicated 8 bedded paediatric cardiac ICU.

1.1.3 Key Roles and Responsibilities

As a health management intern at the Department of Paediatric Cardiac Sciences, the following roles and responsibilities were entrusted to me:

1.1.3.1	To manage	stock and	inventory	planning
1111011	10		·	provine B

1.1.3.3 To keep track of cases scheduled to undergo surgery

1.1.3.4 To furnish inputs for expansion of the department

1.1.3.5 Streamlining maintenance of registers and other

documentation

1.1.3.5 Maintenance and updation of department's Hospital Information Management System module

1.1.3.6 Coordinate outreach services in conjunction with the hospital's Outreach Department

1.1.3.7Streamlining day-to-day administrative hassles hamperingfunctioning of the unit

1.1.4 Conclusive Learning

1.1.4.1The department gave me an opportunity to acquaintmyself with all aspects of management viz. operations, HumanResources and quality

1.1.4.2 The internship also facilitated deep understanding of internal working of a trust managed for-profit hospital of repute

2

Section 2

Dissertation Report

2.1 INTRODUCTION

2.1.1 A congenital heart defect/disease (con - together; genitus - born) is a problem with the structure of the heart which is present at birth. They are the most common type of birth defect involving the walls, valves and blood vessels of the heart. They have a spectrum varying simple conditions that don't cause symptoms to complex problems that cause severe, life-threatening symptoms. They are the most frequently occurring congenital disorder having just about more than one-quarters of all congenital birth defects. The birth prevalence of CHD is reported to be 8-12/1000 live births. High birth rates in India (CBR of 20.4/1000 population as per SRS September 2019 Bulletin) hint that approximately 150,000-200,000 children born with CHD in India every year, if a prevalence rate of 9/1000 live births is considered. Of these, approximately a third to a quarter need early intervention to survive the first year of life. Regional hospital-based data indicate these estimates. But, considering the high rates of maternal infections during pregnancy and significant unsupervised home deliveries, the actual numbers may be on the higher side. This scenario will definitely impact early detection of critical CHDs. A large pool of older infants and children who may have survived, despite no intervention, further compounds the magnitude of the problem. The mortality and morbidity due to CHD is expected to be very high in India since the majority of children are not intervened, ^[1].

2.1.2 Rapid advances in diagnosis and treatment of CHDs have ensured that in high-income countries, vast majority of children born with CHD in reach adulthood. However, in low- and middle-income countries (LMIC), this is not the case for children born with CHDs. It is because advanced care is not available to such children ^[1]. A very high chance of survival with good long-

term outcome can be ensured through access to early screening, diagnosis and treatment for babies born with CHD ^[2]. A majority of babies born with CHD in developing countries (including India) face the unavailability of such advanced paediatric cardiac care ^[3]. As compared to one cardiac center catering to a population of approximately 120,000 in North America; in Asia, one cardiac centre caters to a population of about 16 million people ^[4]. The ratio of one cardiac surgeon per 3.5 million in North America and Europe contrasts well in comparison with Asia where one cardiac surgeon caters to about 25 million population ^[5]. Considering these figures, number of children born with CHD in Asia have no or minimal access to advanced paediatric cardiac healthcare, resulting in a much higher child mortality rate compared with the rest of the world.

2.1.3 In India, most of the centres caring for CHD patients are in the private sector and may therefore not be affordable for the majority of the Indian population. The geographical distribution of these centres is also skewed depicting a clear paradox wherein many centres are located in regions with lower burden i.e. the Southern and Western states vis-a-vis states such as Uttar Pradesh, Bihar, Jharkhand and Madhya Pradesh, which presumably have much higher CHD burden due to higher birth rates. This aspect gains importance when considering critical CHDs (requiring intervention in first year of life). Government of India launched a flagship scheme in 2013 named Rashtriya Bal Swasthya Karyakram (RBSK) with a mandate to screen all children (aged 0–18 years) for early detection and management of birth defects and provision of comprehensive healthcare for all diagnosed cases ^[6]. It is likely that it might take some time this scheme makes a significant impact on overall CHD patient care, considering the huge volume of cases.

2.1.4 There are numerous hospital based prevalence and mortality studies pertaining to India. However, no specific studies exist with reference to trust managed, for-profit hospitals in North India assessing their OPD and IPD profile, in hospital mortality rate post surgical interventions and association between mortality and demographic characteristics. This study conducted at the Department of Paediatric Sciences, Sir Ganga Ram Hospital aims to assess the same. The study subjects are 3083 cases who visited the OPD and 235 patients who underwent surgical intervention in the Department of Paediatric Sciences between 01 May 2018 to 30 April 2019.

2.2 GENERAL OBJECTIVE

To assess the OPD and IPD profile of CHDs diagnosed in the Department of Paediatric Cardiac Sciences, Sir Ganga Ram Hospital, New Delhi.

2.3 SPECIFIC OBJECTIVES

2.3.1 To study the CHDs diagnosed in Department of Paediatric Cardiac Sciences of Sir Ganga Ram Hospital

2.3.2 To study the mortality rate for surgical interventions in diagnosed CHDs

2.3.3 To compare the mortality rates for surgical interventions to that of other eminent tertiary care hospitals

2.4 **REVIEW OF LITERATURE**

2.4.1 In a study conducted in Department of Pediatrics, Patna Medical College and Hospital retrospectively analysed records of all live births in the hospital and all records of pediatric first visit OPD and IPD patients aged between 0 to 15 years, for the time period from March 2015 to June 2016. CHD incidence rate of 10.5 per 1000 live births and prevalence of 26.4 per 1000 patients was observed ^[7].

2.4.2 Numerous studies have brought out the aspect of male preponderance in CHDs. In cases diagnosed with CHD, male-to-female ratios varying from 1:0.6 to 2.08:1 have been reported. These studies have also brought out that most CHDs are diagnosed between 1 month and 6 years of age and the most common acyanotic CHD is VSD and cyanotic CHD is Tetralogy of Fallot ^[8-9].

2.4.3 A study was conducted in United Kingdom on surgeries carried out in 5 paediatric cardiac surgery centres between 01 April 1997 and 31 March 1998. This study brought out that the overall mortality rate was 4.0% ^[10].

2.4.4 A study conducted in the Department of Cardiothoracic and Vascular Surgery, Institute of Medical Sciences and SS Hospital, BHU, Varanasi over a period of four and a half years to assess morbidity and mortality in cases which underwent surgical intervention brought out a mortality rate of 0.9%. The point of note is that only open heart surgeries were carried out here ^[11].

2.4.5 A study at Amrita Institute of Medical Sciences and Research Center, Kochi, Kerala evaluating patients upto 18 years undergoing congenital heart surgery from January 2010-December 2012, brought out an overall in-hospital mortality rate of 3.1% (which saw a decline from 4.3% to 2.2% in the study time period) ^[12].

2.4.6 A 12 years study from 2003 to 2014 conducted in a tertiary Public Health

Center in Brazil to analyze the in-hospital mortality in children and adolescents after surgery for congenital heart defects brought out that children who had undergone surgery with younger age and weight and had higher mortality ^[13].

2.5 METHODOLOGY

2.5.1 **Study Design :** Cross sectional, observational study

2.5.2 **Study Area :** Department of Paediatric Cardiac Sciences, Sir Ganga Ram Hospital

2.5.3 **Study Time Period :** 1 Year (01 May 2018 to 30 April 2019)

- 2.5.4 Study Population : OPD and IPD cases presenting in the study area
- 2.5.5 Inclusion Criteria : Following were the inclusion criteria

2.5.5.1 All cases which presented themselves in OPD wef 01 may2018 to 30 April 2019.

2.5.5.2 All cases which were admitted for diagnostics and/or surgical intervention after OPD visit in the above mentioned period.

2.5.5.3 All cases who underwent surgical intervention in the above mentioned period.

2.5.5.4 For mortality analysis, only those cases have been considered who expired in hospital after undergoing surgical intervention, during the same hospital admission as the operation and irrespective of the length of time since surgery.

2.5.6 **Ethical Considerations :** The study has been reviewed and approved by Student Research Board of IIHMR, New Delhi. Informed consent is of no relevance in this study as it is based on secondary data devoid of personal identifiers like name, address, geographical location etc.

2.5.7 **Sampling Technique :** This study did not entail sampling as the complete OPD and IPD cases pertaining to the above mentioned study period were considered

2.5.8 Sample Size : Not applicable

2.5.9 Mode of Data Collection : Secondary data collection from OPD

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registers, patient case sheets and Hospital Information Management System.

2.5.10 **Questionnaire :** Not applicable

2.5.11 **Analysis :** Data was compiled using MS Excel. Continuous data are summarized as mean and standard deviation or median with inter quartile range as appropriate. The data were analyzed using SPSS Statistics, version 26.0 (IBM). Mortality across the categories (age, and weight at time of surgery and gender) was compared using binomial logistic regression as age and weight are continuous independent variables and gender is a dichotomous categorical independent variable whereas mortality is a binary/dichotomous variable (categorical) dependant variable. P < 0.05 was considered as statistically significant.

2.6 **RESULTS**

During the period of 12 months, a total of 4666 OPD visits were logged by 3083 cases. The relevant profile of these OPD cases is shown in Table 2.6.1.

VARIABLE	<u>RATE/FREQUENCY</u>	PERCENT (%)
<u>Gender (n=3083)</u>		
Male	1954	63.4
Female	1129	36.6
Cases' Visit (n=3083)		
1 visit	2398	77.8
2 visit	315	10.2
3 visit	158	5.1
More than 3 visit	212	6.9
Admissions (n=3083)		
Admitted	231	7.5
1 admission	226	
2 admission	05	
Not Admitted	2852	92.5

TABLE 2.6.1 : OPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

3083 cases resulted in 4666 OPD visits because a few had more than one OPD visit. The maximum OPD visits by one case were 15. The 4666 OPD visits resulted in 236 admissions (wherein 226 cases had single admission episode and 05 cases had two admission episodes). Males accounted for 63.4% of cases who visited OPD and females accounted for 36.6%.

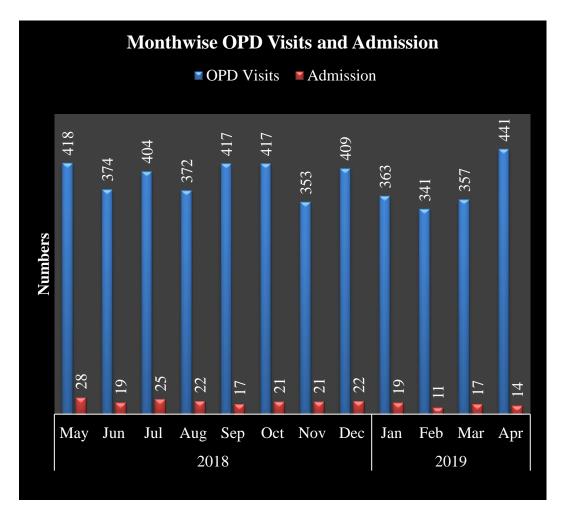


Figure 2.6.1 : Graph showing month wise OPD visits and admissions wef 01 May 2018

to 30 April 2019

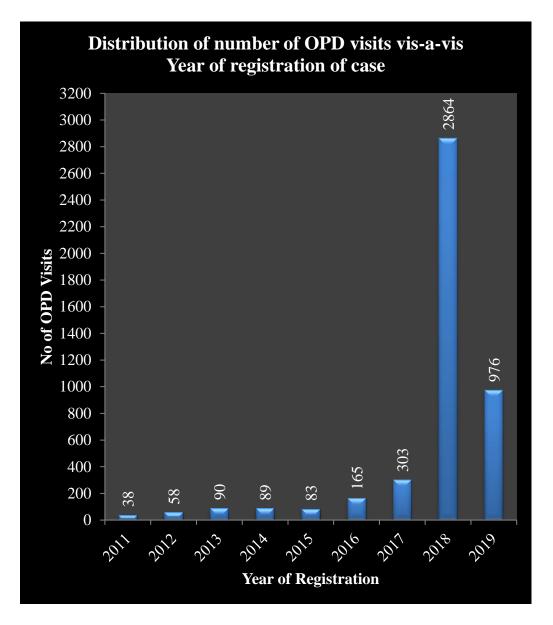


Figure 2.6.2 : Graph showing distribution of number of OPD visits vis-a-vis year of registration of case

Every case presenting in the OPD is allotted a unique identity number based on the year of first visit. The above graph depicts the distribution of total 4666 OPD visits based on the cases' year of registration.

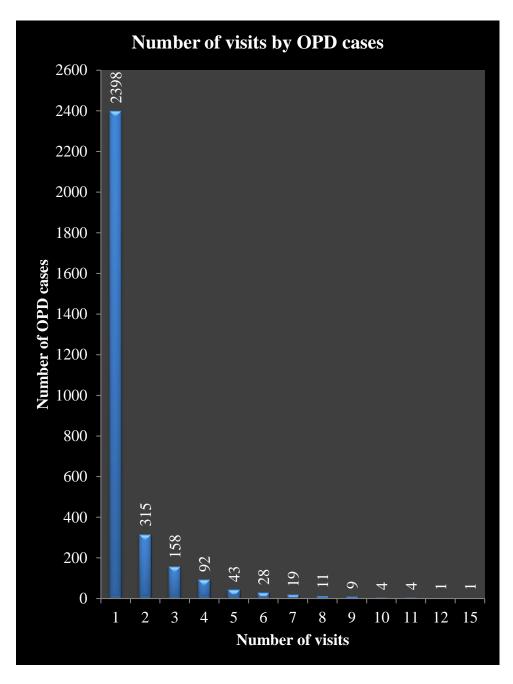


Figure 2.6.3 : Graph showing number of visits by OPD cases

The above graph depicts visitation pattern of OPD cases. Maximum OPD cases had single visit only (2398 cases). One OPD case had the maximum number of visits (15 visits).

During the study period of 12 months wef 01May 2018 to 30 April 2019, a total of 257 surgeries were conducted on 235 patients. The relevant profile of these patients who underwent surgical intervention is shown in Table 2.6.2.

VARIABLE	<u>RATE/FREQUENCY</u>	PERCENT (%)
Gender (n=235)	11	
Male	161	68.5
Female	74	31.5
Age Profile (n=235)		
Neonate (Upto 28 Days)	19	8.1
Infant (Upto 365 Days)	98	41.7
Upto 5 Years	67	28.5
Upto 10 Years	28	11.9
Upto18 Years	13	5.5
Above 18 Years	10	4.3
Weight Profile (n=235)		
Upto 3 Kgs	19	8
Upto 6 Kgs	73	31.1
Upto 9 kgs	52	22.1
Upto15 Kgs	43	18.3
Above 15 Kgs	48	20.5

TABLE 2.6.2 : IPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

TABLE 2.6.2 : IPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

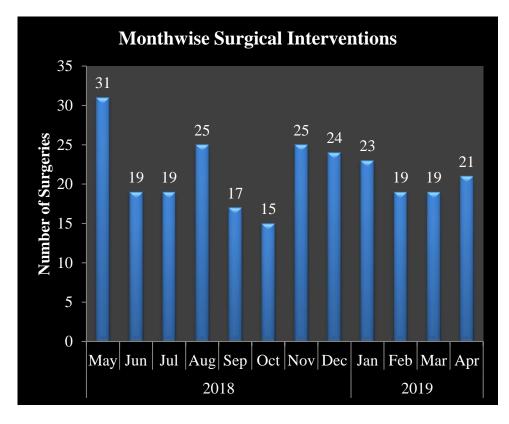
VARIABLE	RATE/FREQUENCY	PERCENT (%)	
Disease/Defect Profile (n=235)			
Acyanotic			
VSD	63	26.8	
ASD	26	11.1	
<u>Cyanotic</u>			
Tetralogy of Fallot	46	19.6	
TAPVC	13	5.5	
TGA	14	5.9	
Left/Right Heart Obstructive			
Pulmonary Artesia	19	8.1	
Coarctation of Aorta	7	3	
<u>Miscellaneous</u>	47	20	
Number of Surgeries (n=235)			
1 surgery	217	92.3	
2 surgery	14	6.0	
3 surgery	4	1.7	
Type of Surgeries (n=257)			
Open	214	83.3	
Closed	43	16.7	

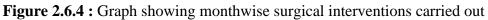
(continued)

TABLE 2.6.2 : IPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

VARIABLE	RATE/FREQUENCY	PERCENT
		<u>(%)</u>
Mortality Versus Type of Surgery		
<u>(n=235)</u>		
Open (O)	19	8.1
Closed (C)	17	0.1
	3	1.3
Gender Versus Mortality (n=235)		
Males	14 (12O+2C)	6
Females	8 (7O+1C)	3.4

(continued)





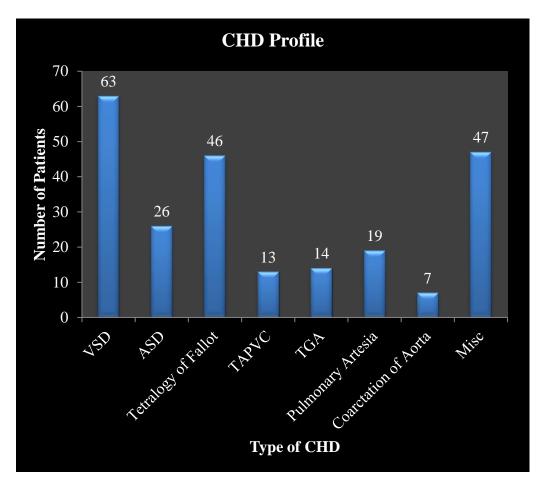


Figure 2.6.5 : Graph showing CHD profile of patients who underwent surgical

intervention

TABLE 2.6.3 : BINOMIAL LOGISTIC REGRESSION BETWEEN

MORTALITY AND DEMOGRAPHIC CHARACTERISTICS

Omnibus Tests of Model Coefficients								
	Chi-							
square df Sig.								
Step 1	Step 1 Step		3	0.628				
Block		1.739	3	0.628				
Model 1.739 3 0.4								

Independent Variables	в	S.E.	Wald	df	Sig.	Exp(B)	95% (Exp(B)	C.I. for
							Lower	Upper
Age_in_Days	0.000	0.000	0.743	1	0.389	1.000	1.000	1.001
Gender	0.304	0.473	0.415	1	0.519	1.356	0.537	3.424
Weight	-0.005	0.024	0.045	1	0.832	0.995	0.949	1.043
Constant	1.924	0.416	21.365	1	0.000	6.848		

An analysis for association was carried out between mortality post surgical intervention (dichotomous categorical dependent variable) and demographic characteristics like age, weight (continuous independent variables) and gender (dichotomous categorical independent variable). The association was gauged through binomial logistic regression as the dependent variable was dichotomous categorical and two of the independent variables were continuous. The output of binomial logistic regression is as depicted above.

OPD PROFILE

This study carried out in the Department of Paediatric Sciences, Sir Ganga Ram Hospital pertains to the time period wef 01 May 2018 to 30 April 2019. The relevant OPD visits' details were extracted from manually maintained monthly registers and patient case sheets.

A total of 3083 cases presented themselves in the OPD in the above mentioned time frame. Some of them had multiple visits thereby leading to a total OPD visit figure of 4666. 2398 cases i.e. 77.8% of the 3083 cases visited OPD just once in the study period. The male-to-female ratio of OPD cases works out to 1.73 : 1. Out of the 3083 cases who visited the OPD, 231 cases (7.5%) were admitted for either diagnostic or surgical intervention. Out of these 231 admission cases, 226 cases were admitted once and 5 cases were admitted twice in the said duration. A low percentage of admissions can be attributed to primary endeavours by the paediatric cardiologists to medically manage the cases till such time surgical intervention becomes imperative. There is no distinct pattern in the monthly OPD visits. The peak visits were in the month of April 2019 (441) and the least were in February 2019 (341). The admissions peaked in May 2018 (28) and were least in February 2019 (11). Whenever any case visits the OPD for the first time, a unique identity number (UID) is generated for him/her based on the year of first visit. An analysis of the OPD visits based on the UID brings forth that maximum visits during the study period were by cases registered in the year 2018 (2864, 61.4%).

IPD PROFILE

In the said study period, a total of 235 patients underwent 257 surgical interventions; meaning to say that a few underwent multiple surgical interventions. The surgeries peaked in the month of May 2018 (31) and were least in October 2018 (15). 217 cases underwent one surgical intervention (92.3%). The surgical interventions have been

classified as open (214, 83.3%) and closed (43, 16.7%). Of these 235 cases who underwent surgical intervention, a total of 141 cases had visited the OPD during the study period and were admitted. Considering 3083 OPD cases, this translates into a hospital prevalence of about 46 per 1000 OPD cases. 94 cases did not come in through the classic OPD route. They could have come in through inter departmental transfers or referrals, in all likelihood. The male-to-female ratio worked out to 2.2 : 1. This ratio is in consonance with the male preponderance seen in other studies ^[8-9]. Neonates upto 28 days from birth constituted 8.1% of the total cases. Infants aged between 29 days to 365 days from birth constituted the majority of the cases at 41.7%. This is in consonance with other studies which have brought out that most CHDs are diagnosed between 1 month and 6 years of age ^[8-9]. This could be attributed to referral from peripheral health centres and increasing use of echocardiography. Maximum cases were in the weight category between 3 kgs to 6 kgs (31.1%).

The type of CHD which had the maximum cases was VSD (63, 26.8%) followed by Tetralogy of Fallot (46, 19.6%). These findings are in consonance with other studies which have brought out that most common acyanotic CHD if VSD and cyanotic CHD is Tetralogy of Fallot ^[8-9]. 19 cases expired after undergoing open heart surgery and 3 cases expired after undergoing closed heart surgery indicating an overall mortality rate of 9.4%. Gender wise, 14 males and 8 females expired after undergoing surgical intervention. Age category wise cases aged upto 1 year had the maximum deaths (12 out of 22, 55%). Other studies have brought out mortality rates varying from 0.9% for only open heart surgeries to 4% for both open and closed heart surgeries ^[10-12]. The higher overall mortality rate can also be attributed to external factors like late referral and/or late presentation by cases and operational constraints of the hospital.

Based on the IPD data, an analysis was carried out using binomial logistic regression to assess the effect of, age and weight at time of surgery (continuous independent variable)

and gender (dichotomous categorical independent variable) on mortality (dichotomous categorical dependent variable). The logistic regression model was not statistically significant, $\chi^2(3) = 1.739$, p > .05. The Wald test ("Wald" column in Table 2.6.3) is used to determine statistical significance for each of the independent variables. The statistical significance of the test is found in the "Sig." column. From these results it can be seen that age (p = .389), gender (p = .519) and weight (p = .832) did not add significantly to the logistic regression model. This is not in consonance with the study conducted in a tertiary Public Health Center in, Brazil wherein children who had undergone surgery with younger age and weight had higher mortality ^[13].

2.8 CONCLUSION

From the results and discussion of the study outlined above, it can be said that:

2.8.1 The ratio of IPD to OPD cases (at 0.08:1 during the study period) is attributable to primary endeavours by cardiologists to manage cases medically till such time surgery becomes imperative.

2.8.2 The aspect of male preponderance in cases diagnosed with CHD has again been established.

2.8.3 Maximum cases diagnosed with CHD were children upto 5 years of age at the time of surgery.

2.8.4 The overall in hospital mortality rate was 9.4%, which is on the higher side. Maximum mortality was in cases aged upto1 year (12 out of 22 deaths).

2.8.5 The most common acyanotic CHD if VSD and cyanotic CHD is Tetralogy of Fallot.

2.8.6 There is no statistically significant association between age and weight at the time of surgery and gender vis-a-vis mortality. This analysis based on binomial logistic regression turned out to be contrary to other studies and paediatric cardiologists' experiential viewpoint that as age and weight reduces, chances of mortality increases. Empirically also maximum mortality was in cases aged upto1 year (12 out of 22 deaths).

2.9 LIMITATIONS

2.9.1 The study period was of 1 year wef 01 may 2018 to 30 April 2019 due to time constraints. This could have resulted in study population (OPD and IPD) not being typically representative of the hospital.

2.9.2 The study results cannot be generalised for tertiary care hospitals in other regions in India because of aspects like birth rates, prevalence in community, screening and referral system etc.

2.9.3 The effect of caregivers' economic status on decision to undergo surgical intervention has not been studied. It may be an important health seeking factor for cases visiting trust managed for-profit tertiary care hospitals.

2.9.4 Only in-hospital mortality was considered in our study. The effect on long-term mortality after corrective surgery was not studied.

2.9.5 The operational constraints of the Department of Paediatric Sciences viz. availability of cardiac OT on alternate day basis, single cardiac surgeon performing all surgical interventions etc. could not have provided a level playing field vis-a-vis other tertiary care hospitals.

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2.11 APPENDIX

Year & Month	OPD Visits	Admissions
2018		
May	418	28
Jun	374	19
Jul	404	25
Aug	372	22
Sep	417	17
Oct	417	21
Nov	353	21
Dec	409	22
2019		
Jan	363	19
Feb	341	11
Mar	357	17
Apr	441	14
Grand Total	4666	236

Year of Registration	OPD Visits
2011	38
2012	58
2013	90
2014	89
2015	83
2016	165
2017	303
2018	2864
2019	976
Grand Total	4666

Year and Month	Number of Surgeries	
2018		
May	31	
Jun	19	
Jul	19	
Aug	25	
Sep	17	
Oct	15	
Nov	25	
Dec	24	
2019		
Jan	23	
Feb	19	
Mar	19	
Apr	21	
Grand Total	257	

Gender, Type of Surgery & Survival	Number of Patients
Did Not Survive	22
Closed Surgery	3
Female	1
Male	2
Open Surgery	19
Female	7
Male	12
Survived	213
Closed Surgery	38
Female	6
Male	32
Open Surgery	175
Female	60
Male	115
Grand Total	235