Dissertation and Internship in

SIR GANGA RAM HOSPITAL

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A Report By

Lt Col Gopendra, PG/17/019

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On

TO STUDY WHETHER CHILD'S GENDER SUFFERING FROM CHD PLAYS A ROLE IN PARENTS DECISION TO UNDERTAKE SURGERY

International Institute of Health Management Research, New Delhi

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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

1.1.3.2 To manage staff and their roster

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

1.1.3.7 Streamlining day-to-day administrative hassles hampering functioning of the unit

1.1.4 Conclusive Learning

1.1.4.1 The department gave me an opportunity to acquaint myself with all aspects of management viz. operations, Human Resources and quality

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

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 2017 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 needs 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 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 India has acquired notoriety in terms of gender discrimination/ skewed sex ratio(male to female) standing at 943 females to 1000 males as per Census 2011. While some southern states, owing to higher literacy rates fared well, Northern states and Hindi heart land states fare very badly. With next census due in 2021, this ratio would likely to further increase. High birth rates in India (CBR of 20.4/1000 population as per SRS September 2017 Bulletin) would further increase this skewed sex ratio despite PNT Act being vigorously followed yet every other day we hear ever increasing female fratricide going on in all parts of the country barring southern and eastern regions.

2.1.5 There have been no studies to assess the OPD and IPD profile vis a vis gender is concerned and whether a child's gender plays a role in Parents decision to undertake surgical interventions at the Department of Paediatric Sciences at Sir Ganga Ram Hospital. Since CHD surgeries involve large sums of money (between two to nine lakhs depending on complications involved and No. of procedures involved), whether parents discriminate based on gender of the child to undertake life saving surgery, this study aims to assess the same.

2.1.6 The study subjects are 3083 cases who visited the OPD and 235 patients who underwent surgical intervention in the Department of Paediatric Cardiac Sciences between 01 May 2018 to 30 April 2019.

2.2 GENERAL OBJECTIVE

To assess the OPD and IPD profile of CHDs diagnosed gender wise 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 assess the effect of gender on decision by parents whether to get surgery done?

2.3.3 To compare the discrimination, if it exists, with any global study published in this regard.

2.4 REVIEW OF LITERATURE

2.4.1 In a study conducted in Department of Paediatrics, Patna Medical College and Hospital retrospectively analysed records of all live births in the hospital and all records of paediatric 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 [8-9].

2.4.3 In a prospective study conducted at All India Institute of Medical Sciences(AIIMS) New Delhi in department of Cardiology, parents or guardians of 405 consecutive children aged up to 12 years (271 boys,134 girls) who had been advised to undergo elective paediatric cardiac surgery were interviewed using a validated questionnaire. The status of the patients was reviewed after a year and the factors associated with non-compliance with treatment were analysed. Of the 405 patients studied, 44% (59/134) of girls had undergone surgery at 1 year compared with 70% (189/271) of boys In the in-depth interviews, apprehensions about future matrimonial prospects of girls, economic factors and lack of social support emerged as the major factors responsible for delays in undergoing surgery.

2.4.4 In a study conducted by the cardiologists at the Dayanand Medical College and Hospital in Ludhiana has brought out that even the promise of free treatment has not eroded the underlying gender bias among some parents that has earlier been documented in nutrition, immunisation and cardiac surgery

services. Their analysis has found 324 boys (62 per cent) in a sample of 519 children who underwent cardiac procedures, a finding that the cardiologists consider unusual because the incidence of congenital heart disorders is nearly the same in girls as in boys. The cardiologists observed that even after factoring in differences in the number of boys and girls with congenital heart disorders actually brought to the hospital for treatment, there was an absolute difference of nearly 9 per cent between boys and girls undergoing surgical interventions.

2.4.5 Another study conducted at AIIMS, New Delhi, department of Cardiology, reported Gender-based discrimination is reported across the

spectrum of pediatric healthcare including emergency, inpatient, outpatient and preventive care. It brought out that over the last five decades, the under-5 sex ratios are worsening in India with declining number of girls. Deliberate parental neglect of girls' essential and lifesaving medical care is also an important contributing factor apart from sex-selective abortions to the declining gender ratios.

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 May 2018 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.

2.5.6 **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 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.

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.

TABLE 2.6.1 : OPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

VARIABLE	RATE/FREQUENCY	PERCENT (%)
Gender (n=3083)		
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
Patients advised surgery(n= 526)		
Male	315	59.9
Female	211	40.1

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%. Out of 3083 unique cases, a total of 526 were advised admissions. Among them were 315 males and 211 females in a ratio of 59.9% and 40.1 % respectively

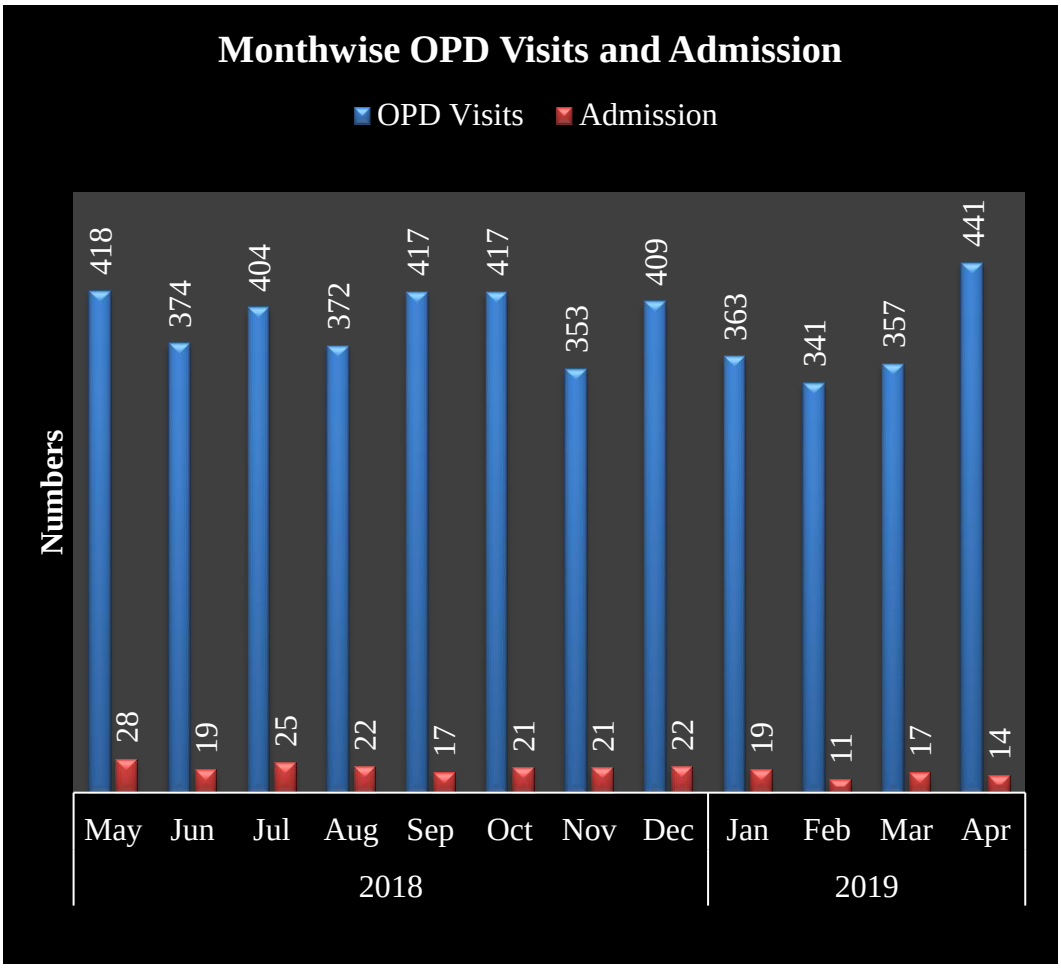

Figure 2.6.1 : Graph showing month wise OPD visits and admissions wef 01 May 2018 to 30 April 2019

Figure 2.6.2 : Graph showing month wise OPD visits distribution of males and females wef 01 May 2018 to 30 April 2019

While males had highest 291 OPD visits in month of October 2018, female's highest OPD visits took place in April 2019 at 175.

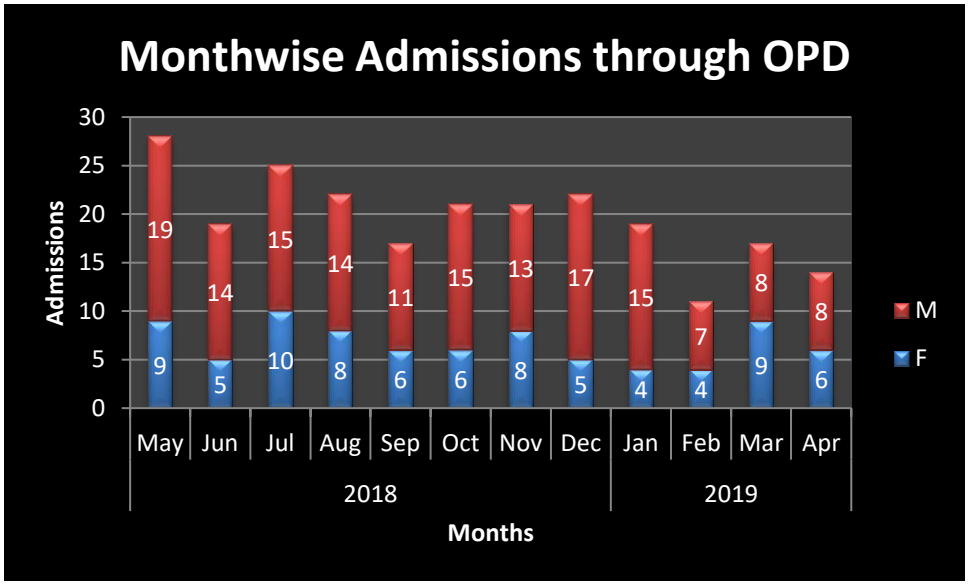

Figure 2.6.3 : Graph showing month wise admissions distribution of males and females wef 01 May 2018 to 30 April 2019

While males had highest 19 admissions in month of May 2018, females' highest admissions took place in April 2019 at 10.

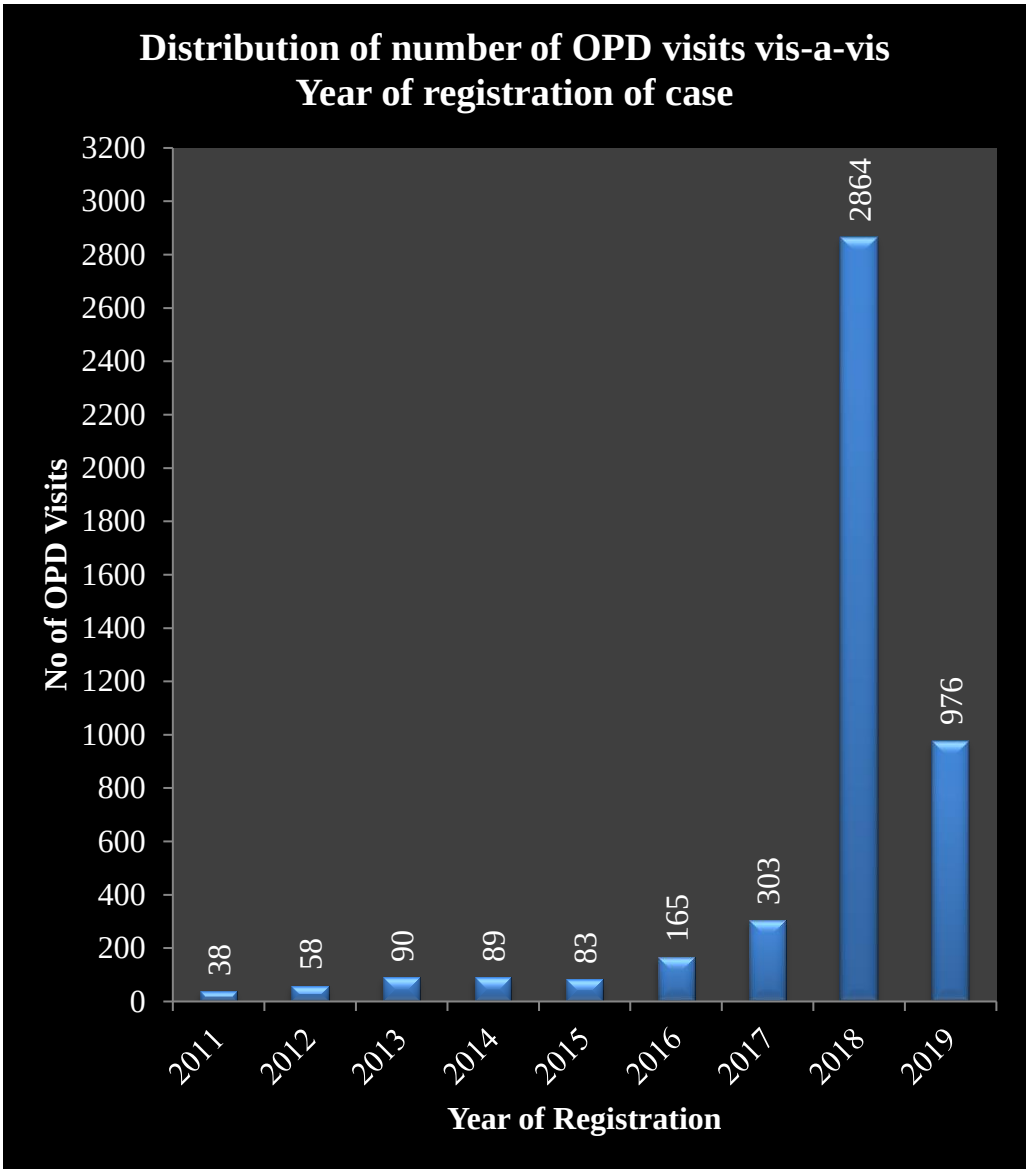

Figure 2.6.4 : Graph showing distribution of number of OPD visits vis-a-vis year of registration of case

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.

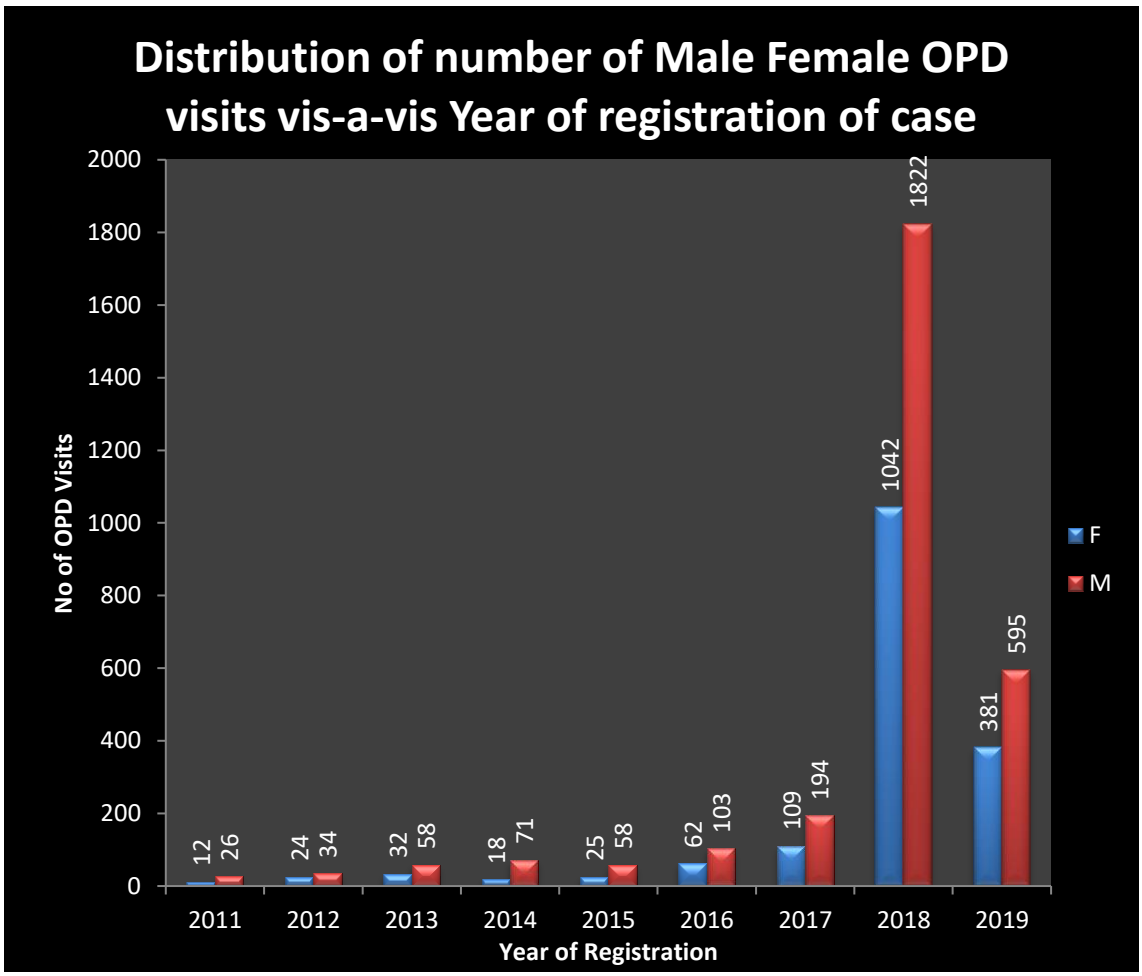

Figure 2.6.5 : Graph showing distribution of males/ females number of OPD visits vis-a-vis year of registration of case

The above graph shows that year 2018(as year of registration) had highest number of OPD visits at 1822 for males and 1042 for females.

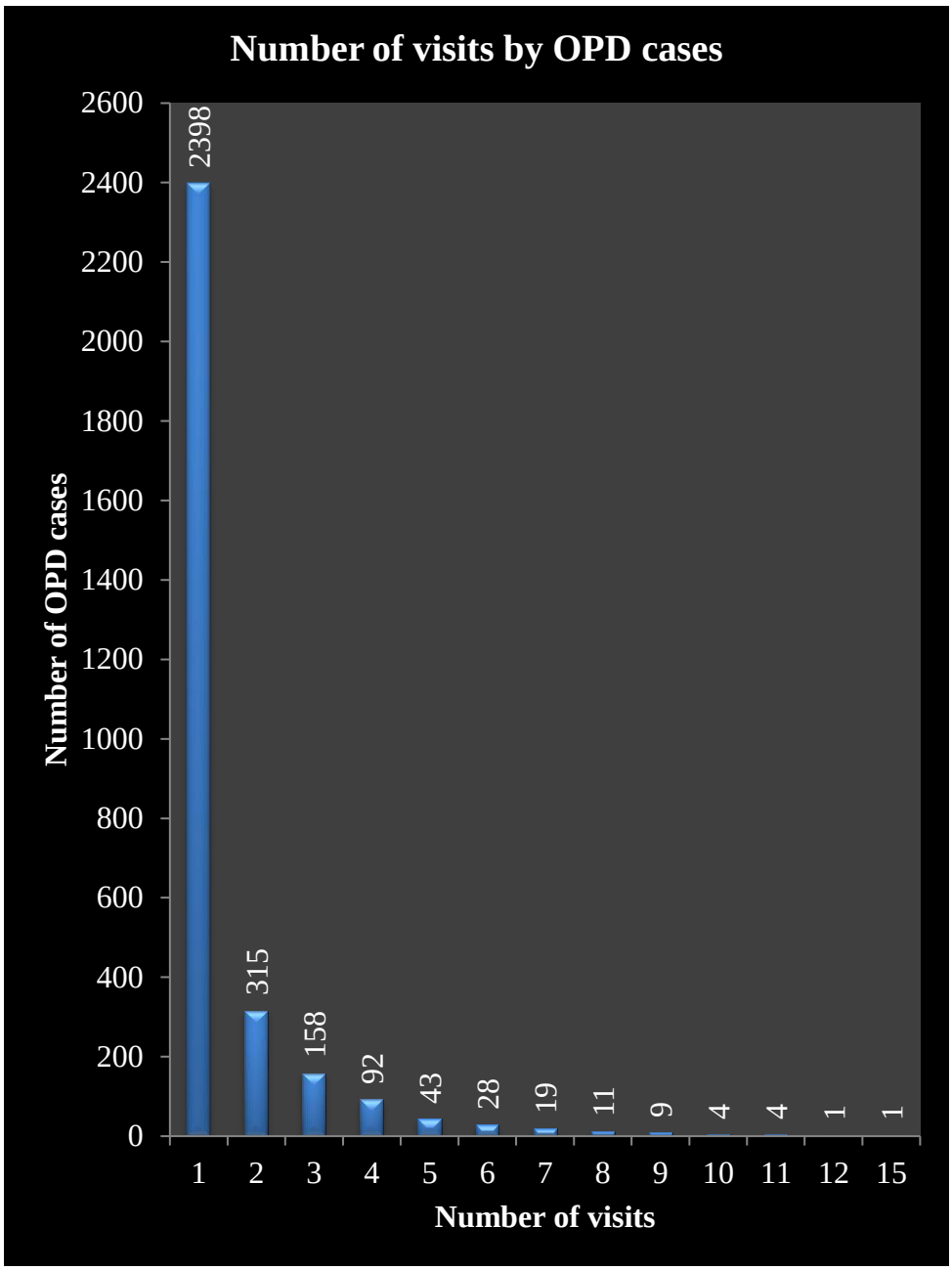

Figure 2.6.6 : Graph showing number of visits by OPD cases

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).

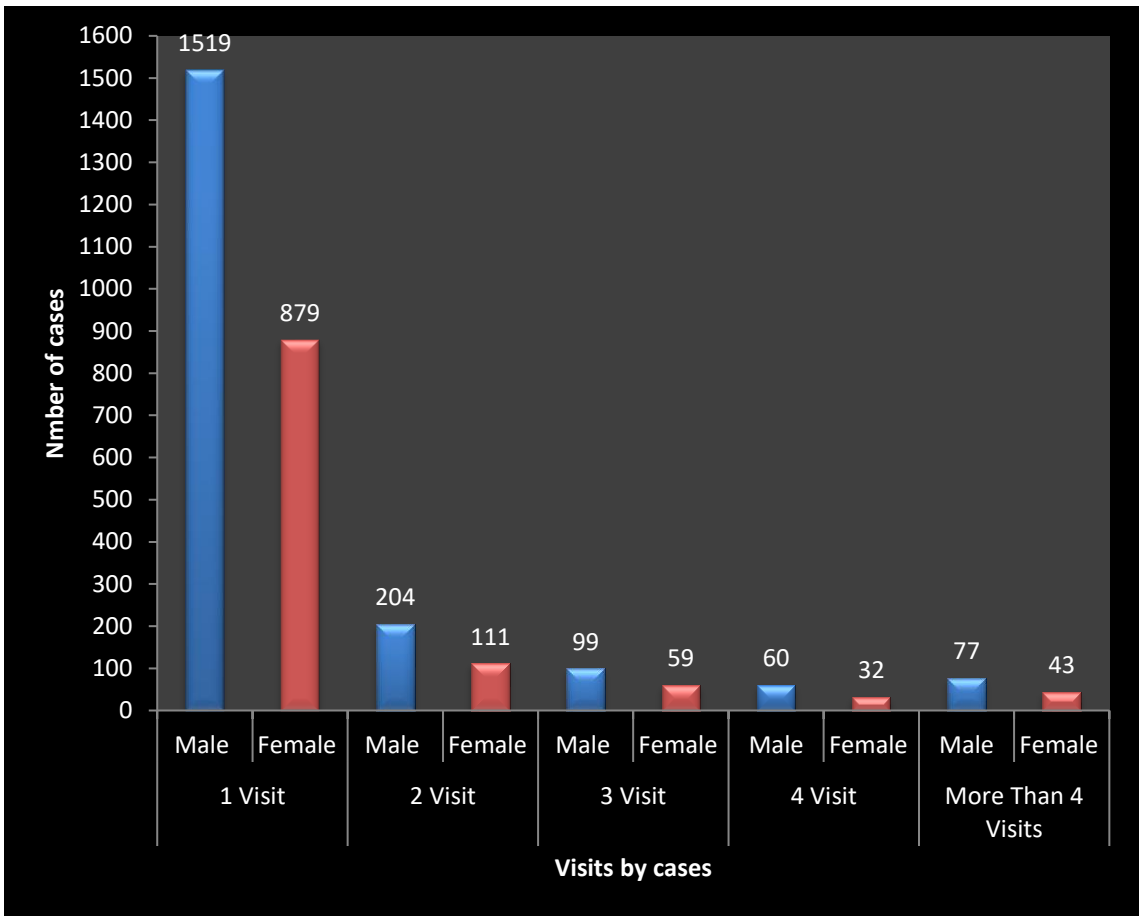

Figure 2.6.7 : Graph showing number of visits by OPD cases by males and females

The above graph depicts visitation pattern of OPD cases of males vis a vis females. Maximum OPD cases males had single visit only (1519 cases) while it stood at 879 for single visit by females. One male case had the maximum number of visits (15 visits) which has been shown above in clubbed visitation of more than 4 visits.

IPD Profile:

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.

TABLE 2.6.2 : IPD PROFILE OF DEPT OF PAEDIATRIC SCIENCES

VARIABLE	RATE/FREQUENCY	PERCENT (%)
Gender (n=235)		
Male	161	68.5
Female	74	31.5
Surgeries through OPD route(n=141)		
Male	100	70.9
Female	41	29.1
Surgeries through referrals/inter dept Transfers(n=94)		
Male	61	64.9
Female	33	35.1
Number of Surgeries (n=235)		
1 surgery	217	92.3
2 surgery	14	6.0
3 surgery	4	1.7

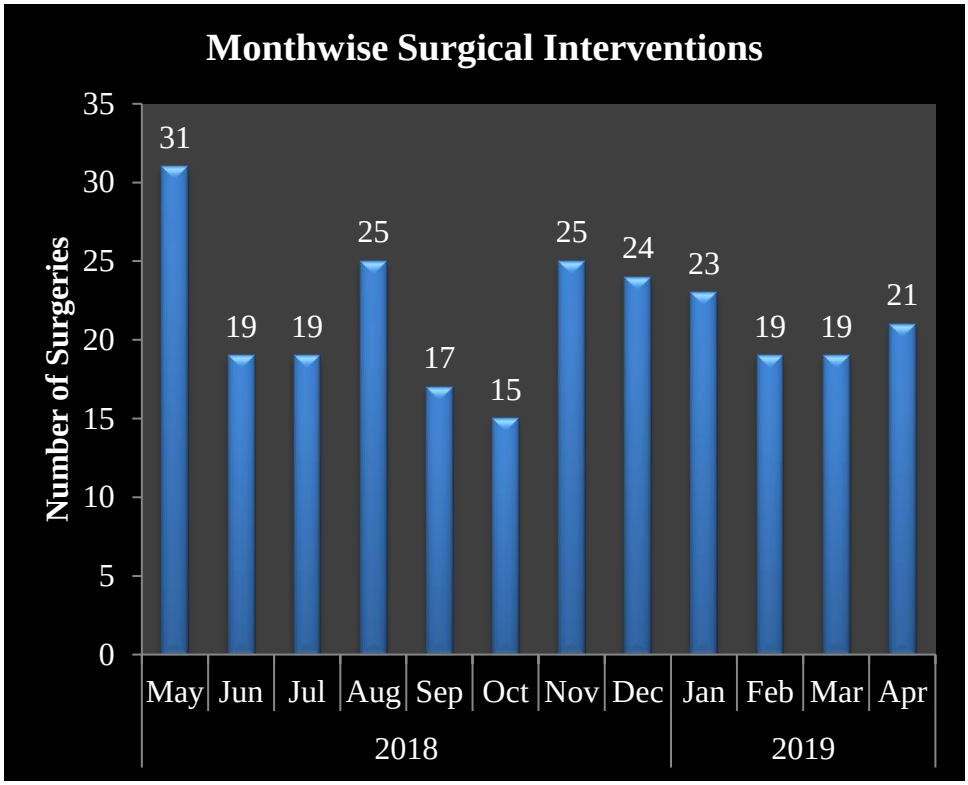

Figure 2.6.8 : Graph showing monthwise surgical interventions carried out

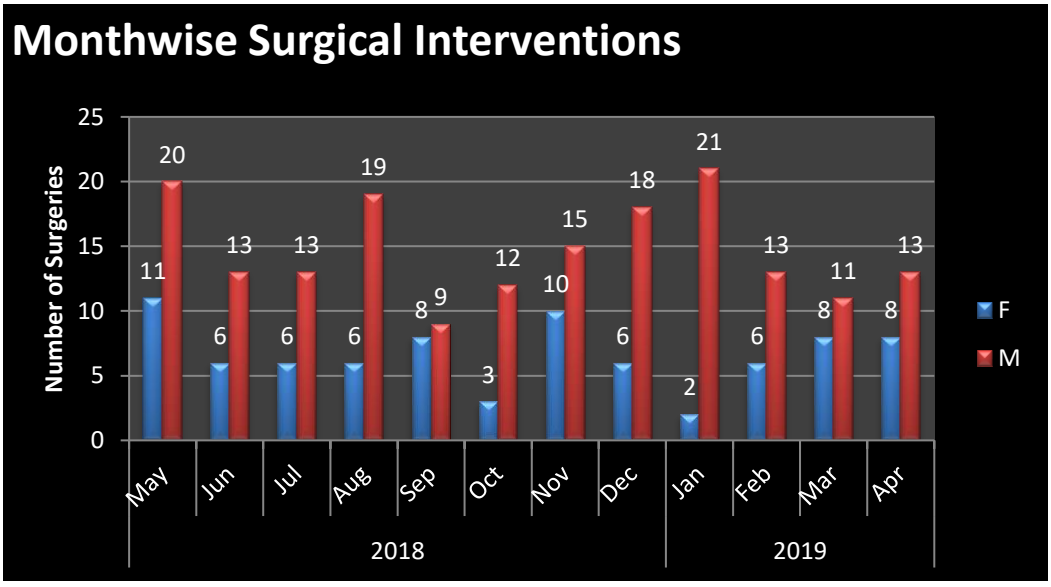

Figure 2.6.9 : Graph showing monthwise male vs female surgical interventions carried out during the study period wef 01 May 2018 to 30 April 2019

2.7 DISCUSSION

2.7.1 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%).

2.7.2 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%). Of these 235 cases who underwent surgical intervention, a total of 141 cases had visited the OPD during the study period and 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].

2.7.3 There were a total of 526 patients who were advised surgery when they presented themselves in OPD out of which 315 were males and 211 were females giving a ratio of 1:0.67.

2.7.4 During the study period, a total of 235 patients were operated upon out of which 161 were males and 74 were females giving a ratio of 1:0.46.

2.7.5 Out of the above 235 patients, 141 came through the OPD route with 100 being males and 41 were females giving a ratio of 1:0.41.

2.7.6 Remaining 94 patients(325-141) were either referrals from other hospitals or inter department transfers. Here there were 61 males and 33 females giving a ratio of 1:0.54.

2.7.7 Against a ratio of 1:0.67 advised surgical intervention, an average of 1:0.47 males to females are actually being operated in this paediatric cardiac centre.

2.8 **CONCLUSION**

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

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

2.8.2 The ratio of male to female advised surgery in OPD is 1:0.67.

2.8.3 The ratio of male to female actually operated upon is 1:0.46.

2.8.4 The surgeries through OPD route among male and female gives a ratio of 1:0.41.

2.8.5 Inter departmental transfer or referral from other hospitals gives a ratio of 1:0.54 among male and females.

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 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.

2.9.5 This study alone, due to its short duration and no contact with parents (caretakers), cannot conclusively say that the gender bias which is brought out is due to what reasons. A detailed questionnaire based interviews needs to be undertaken by another study to pin point why this gender bias exists.

2.10 REFERENCES

2.10.1 Saxena A. Congenital Heart Disease in India: A Status Report. Indian J Pediatr. 2018;55:1075-1082.

2.10.2 Warnes CA. The adult with congenital heart disease: born to be bad. J. Am. Coll. Cardiol. 46(1), 1–8 (2005).

2.10.3 Tchervenkov C, Jacobs J, Bernier P et al. The improvement of care for paediatric and congenital cardiac disease across the World: a challenge for the World Society for Pediatric and Congenital Heart Surgery. Cardiol. Young. 18(Suppl. 2), 63–69 (2008).

2.10.4 Pezzella T. Worldwide maldistribution of access to cardiac surgery. Letter to the editor. J. Thorac. Cardiovasc. Surg. 123(5), 1016 (2002).

2.10.5 Hoffman JI. The global burden of congenital heart disease. Cardiovasc. J. Afr. 24(4), 141–145 (2013).

2.10.6 Rashtriya Bal Swasthya Karyakram (RBSK). Child Health Screening and Early Intervention Services under NRHM, Ministry of Health & Family Welfare, New Delhi, Government of India. 2013. http://nrhm.gov.in/images/pdf/programmes/RBSK/Operational_Guidelines/Operational%20Guidelines_RBSK.pdf

2.10.7 Kashyap PK, Jaiswal AK. Study of prevalence of congenital heart diseases in children. National Journal of Advanced Research Volume 3; Issue 1; January –2017; Page No. 52-53. Online ISSN: 2455-216X

2.10.8 Vyas PM, Oswal NK, Patel IV. Burden of congenital heart diseases in a tertiary cardiac care institute in Western India: Need for a national registry. Heart India 2018;6:45-50.

2.10.9 Meshram RM, Gajimwar VS. Prevalence, profile, and pattern of congenital heart disease in Central India: A prospective, observational study. Nig J Cardiol 2018;15:45-9.

2.10.10 Stark J, Gallivan S, Lovegrove J, Hamilton JRL *et al*. Mortality rates safter surgery for congenital heart defects in children and surgeons' performance. The Lancet; Mar 18, 2000; 355, 9208

2.10.11 Siddharth L, Mathur SK, Das NN, Gupta RK *et al*. Surgical outcome of congenital heart disease cases: a single unit analysis in an upcoming centre in Eastern Uttar Pradesh, India. International Journal of Contemporary Medical Research 2016;3(6):1842-1844.

2.10.12 Khera R, Jain S,Lodha R, et al. Gender bias in child care and child health:global patterns doi:10.1136/archdischild-2013-303889

2.10.13 Chhabra ST,Masson S, Kaur T, et al. Gender bias in cardiovascular healthcare of a tertiary care centre of North India Heart Asia 2016;8:42–45.