



OPENING MINDS:
RESEARCH FOR SUSTAINABLE
DEVELOPMENT

Socio-demographic Characteristics of Families, with a Child Less Than 5 Years of Age having a Congenital Heart Disease and the Out of Pocket Expenditure of Those Families

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1 INTRODUCTION

Congenital Heart Diseases (CHD) are the commonest congenital abnormality found in the world and in Sri Lanka (Christianson *et al.*, 2006). There are several types of Congenital Heart Diseases and they are distributed in many countries in different geographical areas among different social groups. This distribution may associate with many factors, which are worth studying mainly to evaluate the disease burden to a country. The direct cause for CHD is unknown although there are related factors such as genetic disorders, consanguinity, maternal infections (Lissauer, 2017). But, risk factors or causes are not identified for a considerable amount of patients. So, the associated factors such as sociodemographic, economic, environmental and cultural exposures should be investigated in detail and should be shared in several settings. This can be used to understand multiple associations in order to develop a hypothesis to establish the causative

factors. Sri Lanka, as a country which provides free health care facilities for the whole population, bears the health care expenses of children with congenital heart defects as well. But as the services are not at the door step level, people have to reach certain specialized institutions to get services. Visiting these institutions from faraway places in a regular frequent manner to get the essential and required treatment, obviously causes a great burden to the whole family.

In Sri Lanka, estimated number of live births with a congenital heart defect for a single year is 3024 (Framework, 2013). Although they are scattered all over the country, there are very limited number of paediatric cardiology clinics functioning at present. Patients face unlimited number of difficulties while attending these clinics and the clinic at Sirimavo Bandaranaike Specialized Children's Hospital Peradeniya gives services to patients from several provinces of the country. Although all the treatment expenses of a congenital



heart disease patient are spent by the government via hospital clinic, there can be many opportunities for additional expenses during clinic visits and many other associated events. These expenses are called out of pocket expenses and studying and analyzing these expenses with sociodemographic characteristics of families, were the aims of this study.

2 METHODOLOGY

A descriptive cross sectional hospital based study was conducted at Sirimavo Bandaranaike Specialized Children's Hospital Peradeniya. Study was conducted for a period of six months from November 2014 to April 2015, after obtaining ethical clearance from the Ethical Review Committee Faculty of Medicine, Colombo. Children under 5 years attending the Pediatric Cardiology Clinic at the SBSCH Peradeniya during the study period, were considered as the study population. Children diagnosed with a congenital heart disease, presented with a diagnosis card and children less than five years of age were included to the study. Children with co-existing other congenital abnormalities, children attending the cardiology clinic due to any other reason other than the routine clinic visit, children who have undergone cardiac surgeries and children presenting with any other illness on the visiting day such as Respiratory tract infections and Urinary Tract Infections were excluded. Sample size was calculated by using the Lwanga and Lemeshow equation (Lwanga and Lemeshow, 1991) and it was 335. Systematic sampling required sample size. An interviewer administered structured questionnaire was used for data collection. The technique was applied to obtain the Questionnaire was prepared in English

and was translated to Sinhala and Tamil. Questions consisted of both open and close ended questions. The questionnaire consisted of three parts; socio demographic characteristics of the child, information regarding the congenital heart disease and information required to calculate the out of pocket expenditure for a clinic visit. Questionnaire was developed after extensive literature review and with the contribution of many expert ideas of several specialties in the subject stream. Data sheet was not validated, but was pretested one month prior to proper data collection. Collected data were entered into an Excel 2010 data sheet. After data had been cleaned, they were analyzed by using SPSS version 23 statistical software. Initially a univariate analysis was conducted and on selected variables a bivariate analysis was conducted. The total cost of a clinic visit was estimated by using the following variables; travelling, lodging and incidentals.

3 RESULTS

This study employed a Sample size was 335 and response rate was 100%. The sample consisted of children from seven districts of Sri Lanka, both gender/sex, and main ethnic and religious groups. Out of the 335 children who participated in the study, 47.2% were male (N=158) and 52.8% were female (N=177). There was no statistically significant difference between two genders of participated children ($P>0.05$). Ages of the children varied between 13 months to 60 months with a mean age of 37.1 months and SD was 14.5. Majority were in 37 months to 48 months age group (N=93:27.8%). Majority of the children were Sinhalese (N=270: 80.6%). There were five types of congenital heart diseases found in the study sample. They were; Atrial Septal



Defect (ASD), Ventricular Septal Defects (VSD), Tetralogy of Fallots (TOF), Patent Ductus Arteriosus (PDA), Mitral Valve Prolapse (MVP). Among them the most common (40.3%) congenital heart disease was MVP (N=135).

Total income of the families varied from Rs.12, 000/= to Rs.80, 000/= (Mean=Rs.23759.7: SD=Rs.9026.6). Majority (29.9%) of the families was included to the total income range between Rs.20, 000/= to Rs.24, 999/= (N=100). 23% of participants had taken support from outside people to attend the clinic but no one had to pay for them. 80.9% of employed parents could not attend to work on the clinic day, due to the

clinic visit. 23% of participants lost their daily income due to the clinic visit. None of the patients were given prescriptions to buy drugs from private pharmacies and none of them had to do investigations from private laboratories. All the health care services were provided by the cardiology clinic of Sirimavo Bandaranaike Specialized Children's Hospital. None of the participants had an insurance cover to reimburse the expenses of the clinic visit. 23% of children had withdrawn their savings to cover the expenses and 11 families had borrowed money from friends and relations.

Table 1: Sociodemographic Characteristics of Participants

Gender	Number	Percentage (%)
Male	158	47.2
Female	177	52.8
Age		
13-24	94	38
25-36	61	18.2
37-48	93	27.8
49-60	86	26
Ethnicity		
Sinhala	270	80.6
Tamil	32	9.6
Muslim	31	9.3
Other	2	0.2
Type of CHD		
VSD ¹	102	30.4
ASD ²	76	22.7
PDA ³	11	3.3
TOF ⁴	11	3.3
MVP ⁵	135	40.3
Total	335	100

¹Ventricular Septal Defect; ² Atrial Septal Defect; ³Patent Ductus Arteriosus; ⁴Tetralogy of Fallots; ⁵Mitral Valve Prolapse.

Table 2. Total Family income and Out of pocket expenditure for clinic visits

Family income (Rs.)	Number	Percentage (%)
<15,000	23	6.9
15,000-19,999	93	27.8
20,000-24,999	100	29.9
25,000-29,999	42	12.5
30,000-34,999	28	8.4
>35,000	49	14.6
Out of pocket expenditure		
<500	13	3.9
501-1000	118	35.2
1001-1500	137	40.9
1501-2000	42	12.5
>2001/=	25	7.5
Total	335	100

5 DISCUSSION

The study sample consisted of children from seven districts. Majority was from the central province. Although there was a female predominance in the study sample, according to the statistics the Male: Female ratio of the population of Sri Lanka was 47.1: 52.9 in 2012/13 (Central Bank of Sri Lanka, 2016). Data mentioned in the study sample approximately overlap with this information. According to the population statistics there was a Sinhala Buddhist predominance identified in the districts which were included to the study. There were 80.6% of Sinhalese and 81.8% of Buddhists in the study sample (Statistics, 2012).

According to the study done by Marelli, *et al.* (2007), 52% of congenital heart disease children were females. Majority of the Congenital Heart Disease children had Ventricular septal Defects and the second commonest disease was Atrial Septal Defect. Mitral Valve prolapse was not considered in most of the studies but patients born with Mitral valve prolapse had abnormal heart sounds and therefore they were followed up at clinics for 2-3 years. At the end they were reassured and discharged from the clinic after

prescribing prophylactic antibiotics only for necessary situations. During this period of clinic visits, many opportunities for expenses were generated. Therefore significant attention was paid on mitral valve prolapse during this study, although clinically not serious.

According to the mean income of a family, four main social classes were identified by the Senses and Statistics Department of Sri Lanka. They are very poor, poor, middle and rich (Department of Censes and Statistics, 2009). Mean income of the poor social class was Rs.15, 760/= and the mean of the middle class income was Rs.32, 590/=. According to the present study mean of the monthly income was Rs. 27,759/=. So the mean income of this study falls between the mean income of poor and middle social classes. And in the present study, most of the mothers were educated up to GCE O/L. In the present study, there were no children representing the rich social class. This observation generates two hypotheses; either CHD is not present in this social class or they are not attending the government health care institutions for services.

According to the study done in 2015 in India, majority of the Congenital Heart



Disease patients are from the upper middle class (43%) and lower middle class (37.5%) families (Raj *et al.*, 2015). Majority of patients of the present study also represented middle and poor social classes. At the Indian context, family expenses due to hospitalization for surgeries to correct Congenital Heart Disease were studied and it was calculated as 0.93% of their annual family income. A median of 15 working days was missed annually due to hospitalization. In the present study 80.9 % of participants had missed working days due to clinic visits. Majority had managed their expenses within their monthly income. But in India, Majority (96.1%) had to depend on other external sources to cover up their expenses

There is an opportunity of calculating the non-medical out of pocket expenses of patients who had undergone corrective cardiac surgeries. Calculating the non-medical expenses during the period of preparing for surgeries and during the period of hospital stay can be done by using the 'Review diary method' practiced in USA (DiFazio and Vessey, 2013). Generally there are limitations for leading a normal life after undergoing a cardiac surgery. The impact of those conditions should be evaluated by using a validated technique.

4 CONCLUSIONS AND RECOMMENDATIONS

Majority were Sinhala Buddhists from the central province and they showed a slight female predominance. Among congenital heart diseases Mitral Valve Prolapse showed the highest prevalence. Average out of pocket expenditure for a single clinic visit was Rs.1246.80 (SD=Rs.650.80) Expenses for transport and food were highest among out of pocket expenses.

People should be directed to do necessary behavioral changes to minimize the out of

pocket expenses. Reducing the period of stay at the clinic by allocating a time and providing an efficient service during that time can be used to minimize the expenses for food, lodging and transport. This study can be expanded to calculate the non-medical out of pocket expenses when undergoing a corrective surgery. The psychological effects generated on a congenital heart disease child when living with the limitations of life should be studied in detail.

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