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Knowledge, attitude and practice of parents' of children with congenital heart disease in a developing country

Abstract

Background: Congenital heart disease (CHD) is the most common type of birth defects and remain the leading cause of death from congenital malformations. The knowledge of the parents of children with CHD; is important for the long term wellbeing of their children. In 2017 we have conducted study looking at the knowledge of the parents of children with CHD; about the disease, after that study we have implemented some measures to improve the knowledge of the parents and we wanted to see if there was any improvement in the parents knowledge.

Objectives: To assess the parent's knowledge regarding diagnosis and management of their children with CHD.

Methods: This is a prospective questionnaire based study, conducted at the Paediatric Cardiology Outpatient clinic Ahmed Gasim cardiac Centre, over a six months period from June to November 2019.

Results: The total study population was 120 parents of children with CHD. Of these children, females were 65 (54.2%) and males were 55 (45.8%). The most common age group was 1-5 years old, with 51 (42.5 %) children. 71 (59.2%) of the study population resided in urban areas. 103 (85.8%) of the responders were mothers. 32 (31.0%) mother and 11 (64.7%) fathers were > 40 years old. 9 (52.9%) fathers and 37 (35.9%) mother were primary school graduate. 87 (84.5%) of the mothers were housewives, and10 (58.9%) fathers were unskilled workers. 66 (55%) and 54 (45%) of the parents were of moderate and low social class respectively. 14 (11.7%) children were known to have Down's syndrome. 60 (50%) had previous cardiac surgery, 26 (21.7%) had previous cardiac catheterizations and 3 (2.5%) had documented episodes of infective endocarditis. The commonest Cardiac diagnoses were Ventricular Septal Defect 49 (40.8%), Atrial Septal defect 23 (19.2%) and Tetralogy of Fallot 18 (15%). 118 (98.3%) were attending the appointment visits regularly. 119 (99.2%) confirmed that the diagnosis of their children heart problem was explained to them. 84(70%) reiterated their children heart problem correctly. 100 (83.3%) and 113 (94.2%) stated correctly the symptoms and risk factors of Infective Endocarditis (IE) respectively. 44 (36.7%) received information regarding the importance of oral hygiene, 102 (85%) were aware about need for antibiotics before dental procedures and 120 (100%) were aware about measures to maintain a good oral hygiene. The knowledge of parents was considered fair in 49 (40.8%), good in 46 (38.3%) and poor in 25 (20.8%).

Conclusion: The knowledge of the parents of children with congenital heart disease was generally good, but there is a room for improvement. Simple measures like providing more information especially written is beneficial. The knowledge of the parents should be assessed and measures should be implemented to improve the knowledge of the parents, empowerment of the parents will improve the wellbeing of children with CHD.

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Introduction

Congenital heart disease (CHD) is the most common major congenital anomaly, representing a major global health problem. The incidence is 8 -19 per 1000 birth. Congenital heart defects account for one third of babies with significant congenital anomalies diagnosed prenatally or in infancy.[1] It has been shown that having an accurate understanding of any chronic condition contributes to improved satisfaction with medical care, less distress, less confusion, better compliance with treatment and an improved emotional state.[2]

Specifically for children with CHD, parents having a sound knowledge of their child's condition, treatment and prevention of complications has been shown to promote better health related behaviour in their child by bettering their understanding of the cardiac problem, improving compliance with treatment and avoiding risky behaviour.[3] It is fundamental for patient engagement that they be health literate. This is more than just being able to read and understand health information it is about empowering them to exercise their autonomy. Patients with low health literacy have been shown to have poorer health status, are less likely to adhere to the treatment regimen and self-care plans, higher rates of hospital admission, experience more treatment and drug errors, and make less use of preventive services and measures.[4] Achieving greater health literacy in the population is integral to improving the health of disadvantaged populations and to tackling health inequalities.[4]

Infective endocarditis (IE), is one of the most significant complications of CHD, as it causes substantial morbidity and mortality despite modern antimicrobial chemotherapy and advances in the ability to diagnose and treat complications. It usually develops following a bacteraemia in individuals with underlying structural cardiac defects, bacteraemia may occur spontaneously, or follow everyday dental routine e.g. tooth brushing or complicate certain interventions, such as dental extraction.[5] Patients with congenital and acquired heart valve disease are at higher risk.[6] Studies had shown that the knowledge of the parents around oral hygiene and health is not as good compared to other domains e.g. lesions and drug treatment.[3,7] The incidence of IE could be reduced by improving the knowledge about oral health and hygiene.[8]

Recently there have been a massive improvement in therapy for congenital heart disease, both surgically and catheter based, despite this improvement several recent studies have shown that understanding of illness by children, adolescents, and adults with congenital heart disease remains far from ideal.[2] In 2017 we have conducted study looking at the knowledge of the parents of children with CHD; about the disease,[7] after that study we have implemented some measures to improve the knowledge of the parents and we wanted to see if there was any improvement in the parents knowledge.

Objectives

To assess the knowledge of the parents of children with CHD; about the disease, treatment and infective endocarditis (IE).

Methods

Study design:

The study was conducted in the Paediatric Cardiologyoutpatient clinic at Ahmed Gasim Cardiac Center, Khartoum North, Sudan. Ahmad Gasim cardiac centre is a tertiary cardiac centre that serves adults and children with heart diseases from all over the Sudan.

The data was collected using a pre-tested questionnaire, over a six months period from June –November 2019.

Inclusion criteria : All parents of children with CHD who are attending for follow up in the Paediatric Cardiology outpatient clinic during the data collection period were invited to participate in the study. Parents of children who are coming for the first time, and parents who are not willing to participate were excluded from the study.

Sample size and technique:

Since the population were known, the sample size was calculated using the following formula: $n = N/ (1+ N (e)^2)(35)$

Where n is the sample size, N is the population size (number of parents of affected children who fulfilled the study criteria) and e is the margin of error. Estimated population size (N) = 150 patients over six months .the calculated sample size (n) = 150/ (1+ (150 x o.o5x o.o5)) = 109.090

The sample was selected by convenience non-probability sampling technique.

All the parents who were accompanying their children to the outpatient clinic during the study period were invited to participate; if they fulfil the inclusion criteria.

The data was collected by questionnaire. The questionnaire was administered by one of the researcher (TFF); during an individual face to face interview with parents. All of the questions were presented in standardized manner, with further clarification if necessary.

The questionnaire included personal data of the patients such as age, gender and ; it also included the demographic data of the parents including age, residence, educational level, occupation, and socioeconomic status. A revised history; general and cardiovascular examination of the children was done to confirm the diagnosis and the information provided by the parents. From the medical records, some data was collected such as cardiac diagnosis, previous cardiac operations or cardiac catheterizations.

The parental knowledge was assessed under three domains: The child's cardiac diagnosis, current medications and IE. The cardiac diagnosis and current medications were verified by reviewing medical records and echocardiography reports. Data such as previous cardiac operations or cardiac catheterizations were collected from medical records.

Most of the questionnaire items were adopted from questionnaire used to assess parents' understanding of their child's heart disease; which was previously tested for validity and reliability.[3,7] Few items were adopted from questionnaires used to assess parents' knowledge of oral hygiene and infective endocarditis in children with congenital heart disease.[9,10]

Study variables

Dependent variables:

Level of parental knowledge on cardiaclesion, treatment and IE(symptoms, risk factors, dental hygiene care, antibiotics prophylaxis's before procedures).

Independent variables:

Patients' demographic data (age and residence), parents' demographic data (age, level of education, occupation and socioeconomic status).

Data analysis

Data were analysed using Statistical Package for Social Sciences (SPSS) (IBM Armonk, NY, USA) version 24. Frequency tables and charts were used. Chi square test was conducted for associations. A p value of equal or less than 0.05 was considered significant.

Scoring system:

In order to have a better assessment of overall knowledge, each positive answer in the knowledge domain carried one mark while a negative answer carried zero mark, this gave a total score range of0-9. Knowledge was categorised as Poor (0-3 marks), Fair (4-6 marks) and Good (7-9 marks). This scoring system was validated by previous studies.[3,7]

Ethical consideration

The study was granted ethical clearance from the Research and Ethical committee of the Sudan Medical Specialization Board, and from Ahmed Gasim Cardiac Centre ethical committee.

Informed written consent was obtained from the parents after clear explanation. The confidentiality of the participants was considered throughout the study, the questionnaires were coded to protect the patients privacy. Any identified parents' knowledge gaps; were addressed at the end of the interview by the research doctor, we also provided the parents' with written information in simple Arabic language.

Results

120 children were included in the study, all the parents whom we approached agreed to participate in the study. 65 (54.2%) of the study participants were females, and 55 (45.8%) were males.51 (42.5%) of the study participants were in the 1-5 years old group, followed by 31 (25.8%) in the more than 10 years old, 26 (21.7 %) in the 6-10 years old group and 12 (10%) in the less than one year old (Figure1).

71 (59.2%) of the study participants were from urban areas, and 49 (40.8%) from rural area. 103 (85.8%) of the responders were the mothers of the patients, and 17 (14.2%) were the fathers.

32 (31.0%) mothers were more than 40 years old, followed by 26 (25.3%) in the 25-30 years group, 20 (19.4%) in the 31-35 years group , 17 (16.5%) mothers in the 36-40 years group and Eight (7.8%) in the less than 25 years old (Figure 2).

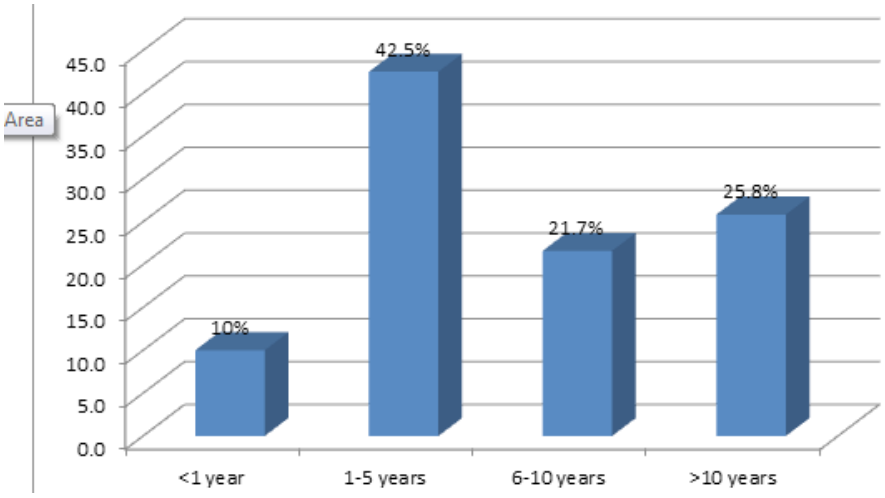

Figure 1 Children's Ages (n=120).

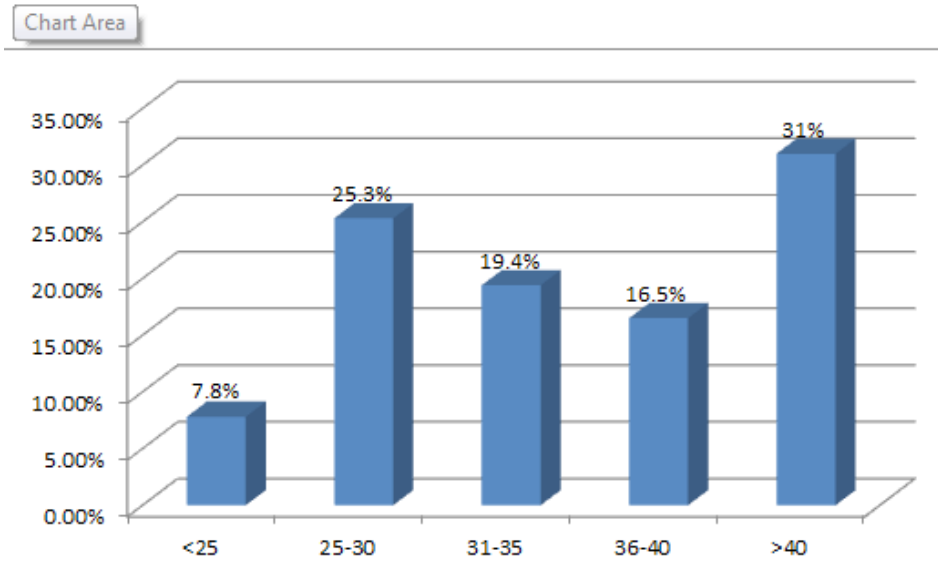

Figure 2 Mothers Age (n=103).

11 (64.7%) of the fathers were older than40 years old, followed by Three(17.6%) in the 36-40 years old group, Two (11.8%) in the25-30 years old group, One (5.9 %) in the31-35 years old group (Figure 3).

37 (35.9%) mothers had primary school education level, followed by 34 (33.0%) who had secondary educational level, 17 (16.5%) had university education, 14 (13.6%) were illiterate and One (1%) had postgraduate education (Figure 4).

Nine (52.9%) of the fathers had primary school education level, followed by Four

(23.5%) illiterate, Three (17.7%) university graduate, One (5.9%) secondary school education level (Figure 5).

87 (84.5%) of the mothers were unemployed, followed by 10 (9.7%) who were professional, Six (5.8%) were unskilled workers (Figure 6).

10 (58.9%) of the fathers were unskilled workers, followed by Four (23.5%) who were skilled workers, Two (11.7%) professional, One (5.9%) administrative job (Figure 7).

66 (55%) of the study participants had moderate socioeconomic status, and 54(45%) had low socioeconomics status and none of high socioeconomic status.

50 (32.7%) of the study participants diagnosis was with VSD, followed by 23(15%) with ASD, 18 (11.7%) with TOF, some children had more than one lesion, in multiple lesions we only included the lesion if it was significant (Table 1).

67 (55.8%) of the study participants were on medications and 53(44.2%) were not on any medications. Regarding name of the medications, 64 out of the 67 (95.5%) who were on regular medications; answered the name of the medications correctly, Three parents (4.5%) gave an incorrect answer.

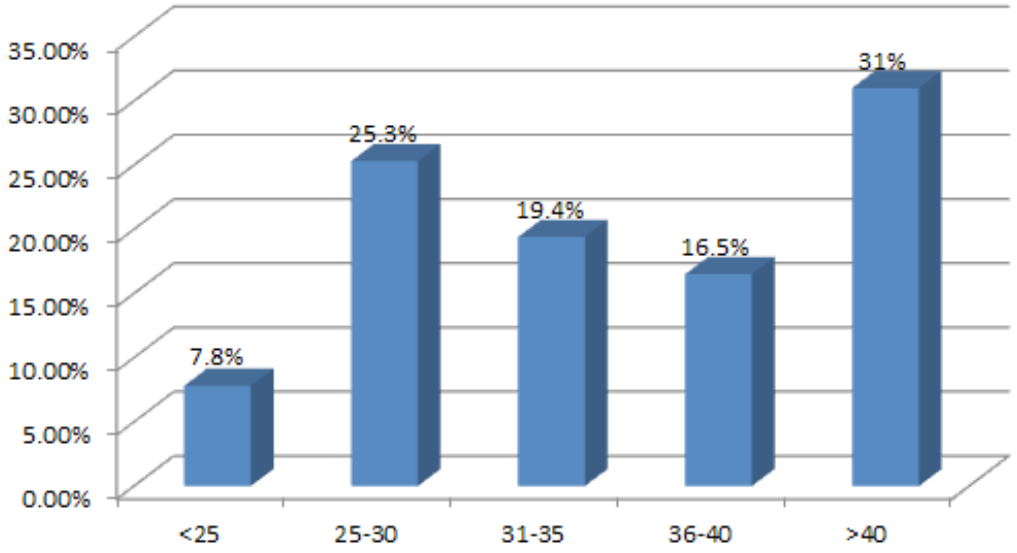

Figure 3 Fathers Age (n= 17).

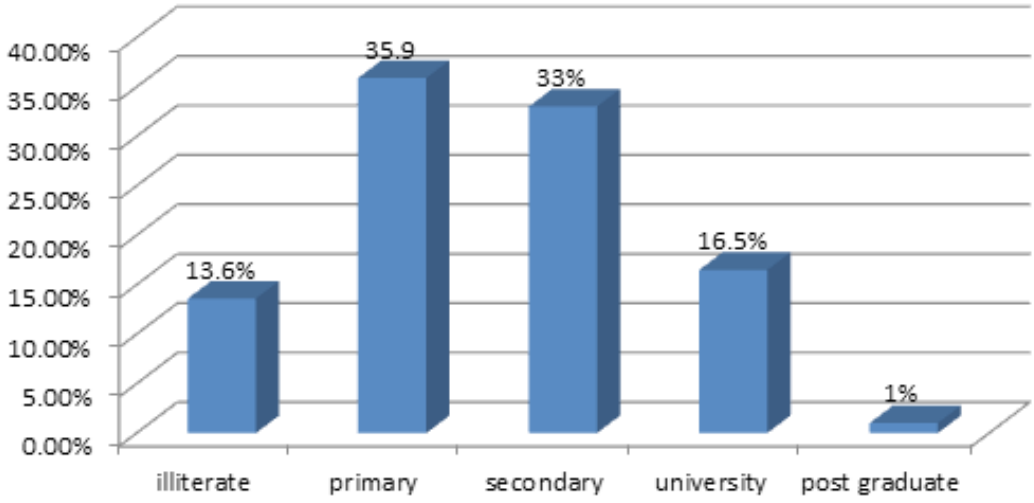

Figure 4 Mothers Educational Level (n=103).

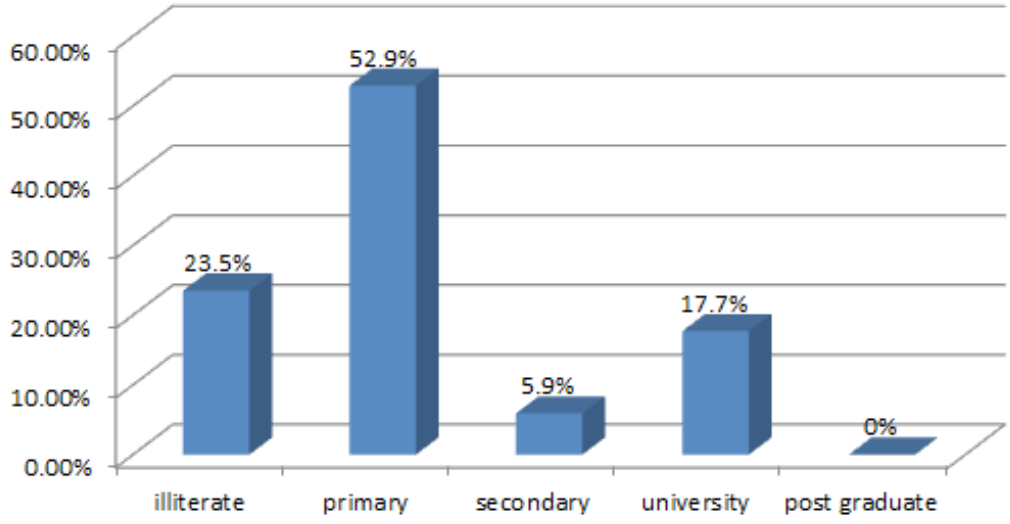

Figure 5 Fathers Educational Level (n=17).

Citation: Elshazali OH, Farah TF, Zaki M. Knowledge, attitude and practice of parents' of children with congenital heart disease in a developing country. *J Pediatr Neonatal Care.* 2020;10(5):125–132. DOI: 10.15406/jpnc.2020.10.00424

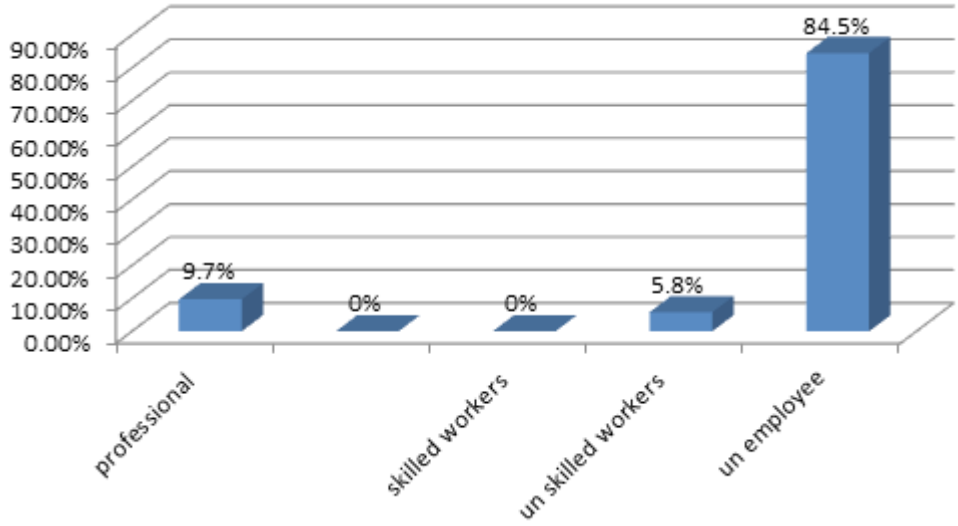

Figure 6 Mothers Occupation (n=103).

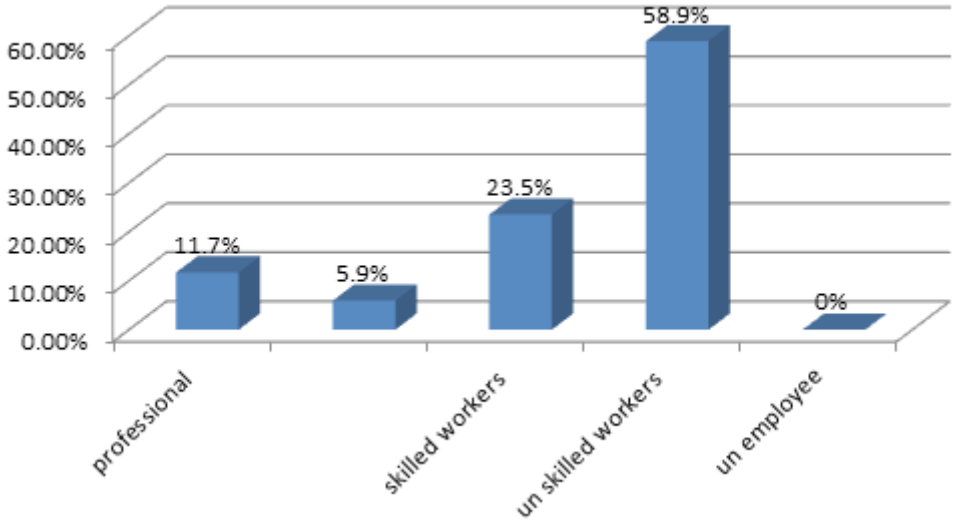

Figure 7 Fathers Occupation (n=17).

Table 1 CHD diagnosis (n=120, 153 lesions)

Diagnosis	Frequency	percentage
Ventricular Septal Defect	50	32.7
Atrial Septal Defect	23	15
Tetrology Of Fallot	18	11.7
Pulmonary Stenosis	13	8.5
Patent DuctusArteriosus	12	7.8
AtrioventricularSeptal defect	8	5.2
Pulmonary Hypertension	6	4
Transposition Great Arteries	3	1.9
Mitral Regurgitation	3	1.9
Complex CHD	10	6.5
Aortic stenosis and Coarctation	2	1.3

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Table Continued...

Diagnosis	Frequency	percentage
Subaortic Membrane	1	0.7
Hypoplastic Left Heart	1	0.7
Aortic Stenosis	1	0.7
TruncusArteriosus	1	0.7
Aortic Regurgitation	1	0.7

60 (50%) of the study participant have had surgical operation and 26 (21.7%) underwent cardiac catheterization.

118(98.3%) of the study participants were attending the appointment visits regularly, 119 (99.2%) confirmed that they have received information regarding their child condition.

84(70%) named the cardiac condition correctly, while 36 (30%) gave incomplete answer.

Three children (2.5%) developed IE, 113 (94.2%) of the study participants mentioned that their children didn't developed IE ever, Four (3.3%) parents said they do not know.

100 (83.3%) of the study participants knew symptoms of IE correctly, 20 (16.7%) did not knew the symptoms or their answer was incorrect.

76 (63.3%) were not fully informed about the importance of oral hygiene in CHD, only 44 (36.7%) of the study participants were fully informed about importance of oral hygiene.

113 (94.1%) of the study participants answered IE risk factors question correctly, Seven (5.9%) did not know or gave incomplete answer.

102 (85%) knew that children with CHD will need antibiotic for dental procedure. All the parents knew about measures for maintain good oral hygiene.

105 (87.5%) of the study participants were non syndromic, 14 (11.7%) of them had Down's syndrome and One (0.8%) had Noonan's syndrome.

49 (40.8%) of the study participants had fair awareness level, followed by 46 (38.4%) had good awareness level and 25 (20.8%) had poor awareness level.

There was significant statistical association between educational level and awareness level (Table 2).

Table 2 Educational level and awareness score, n=120

Education Level	Awareness Score			Total
	Good	Fair	Poor	
Low (Primary or Less)	18	26	20	64
High(Secondary or above)	28	23	5	56
Total	46	49	25	120

p value = 0.01

(p value = 0.01), and receiving enough information and awareness level (Table 3) (p value =0.03).

There was no significant difference between mothers and fathers awareness (p value =0.08), or difference in the awareness between the parents according to age (p value= 0.38), and there was no significant difference in the awareness between the socioeconomic groups (p value = 0.44).

Table 3 Information received and awareness score n=120

Information received	Awareness Score			Total
	Good	Fair	Poor	
Yes	46	49	24	64
No	0	0	1	56
Total	46	49	25	120

P value = 0.03

Discussion

The study has been conducted in the outpatient clinic of Ahmad Gasim cardiac center during the period from June - November 2019. One hundred twenty children were included in this study. 54.2% were females and 45.8% were males. The commonest age group was 1-5 years old with 42.5% of the children (Figure 1), this pattern is similar to the pattern reported from previous studies from Sudan.[7,8]

More than half of the study population came from urban areas, this was consistent with a previous study from our centre;[7] according to the world bank , 65% of Sudan population lives in Rural areas;[11] which indicated that urban population have a better access to health service compared to rural population.

The majority of the responders were mothers, this is the same pattern seen in previous studies from Sudan,[7] mothers tend to attends the clinics with their children and tend to look after them e.g. giving medications, this pattern is also seen in studies from other parts of the worlds.[3]

31% of the mothers were more than 40 years old. This pattern of maternal age appear advanced comparable with other studies from Sudan.[7,12] Primary and secondary school education was predominant type of education among the studied. parents, this parental education profile is in keeping with previous studies from Sudan.[7] 84.5%of the mothers in this study were housewives and this is in line with other studies from Sudan.[7,12] World Bankdata,[13] showed the Percentage of female labour force in Sudan is 26.26% of total labour force; this high figure of unemployment among our group of mothers could be explained by the fact that mothers with children with chronic illness e.g. CHD tend to stay at home to look after them.

Regarding socio-economic status, more than half of the parents in this study were of moderate social class and the rest were of low socioeconomic status. This reflects the pattern of socio-economic status in our community; parents of high socioeconomic status tend not to come to public hospital; and this is in keeping with other studies from Sudan.[7,12]

50% of children in this study had undergone previous surgery, and 21.7% underwent cardiac catheterisation. These two figures are higher than what had reported previously in Sudan[7,12] but is lower than what was reported from other parts of the world;[3] this may reflect recent advances in surgical and catheterization intervention in Sudan.

More than half of children in this study were receiving cardiac medications, and 95.5% of their parents, were aware of the name, dose and schedule of the medication. This is a very good number and much higher than the figure of63.6% we reported from the same centre in 2017.[7] After that study we implemented changes like giving parents more time with the centre pharmacist to discuss the medication, doses, schedule and side effects, obviously this have improve things.

98.3% of patients were attending the appointment visits regularly , regular follow up is very essential for the wellbeing of those with CHD;[14] and in a recent study from our centre (unpublished data); not attending the clinic regularly was a risk factor for IE.

99.2% of parents acknowledged that they have received information about their children cardiac condition, this was reflected in the total awareness score ,which was high or fair in 79.1%and poor in 20.9% compared to a figures of 57.5%and 42.5% for high and poor respectively in our previous study.[7] Regarding knowledge of parents about child's heart disease, the majority of parents mentioned their children heart problem correctly, only 0.8% did not know the name of the cardiac condition , this figure is consistent with the figure we had in our previous study,[7] and it is higher than the figures reported from other studies from Sudan[12] and other parts of the world.[3] This may reflect the improvement in knowledge and may indicate that the time we invested in counselling the parents is giving dividends as reflected in the awareness score.

Regarding cardiac diagnosis, ventricular septal defect (VSD) was the most common diagnosis encountered, similar to the pattern from Sudan and other parts of the world.[15,16] 83.3% stated the symptoms and risk factors of IE correctly. This percentage is good compared to other studies from Sudan and globally.[3,12] Only 44 (36.7%) of the study participants were fully informed about importance of oral hygiene , the rest of did not receive information or the information was not complete .Studies from Brazil[9] and Ethiopia[17] showed 50 % of their participants were fully informed; all of these results are quite low. This is a worrying figure as studies has showed that low grade but repeated bacteraemia occurs more frequently during daily routine activities such as tooth brushing, flossing or chewing; especially in patients with poor dental health,[18] so a good oral hygiene and health is very crucial in the prevention of IE, and measures have to be implemented to improve this figures.

previous study by Ali et al.[19] showed that a group of Sudanese children with CHDs were more severely affected with gingivitis and caries than the control group without CHD, this association between CHD and severe oral disease, is a risk factor for IE.85% of the participants knew about the need to take antibiotics for dental procedures, this figure is quite good compared to studies from Brazil[9] and Ethiopia[17] in both of them about 50% knew about the need for antibiotic; but still we think this number should be higher as the risk of IE is quite high in the developing world.[20]

All the parents knew about measures for good oral hygiene e.g. tooth brushing, reducing sugar intake and using tooth paste that is supplemented with Fluoride. This is a very encouraging result.

In this study three children (2.5%) had documented episodes of IE, previous studies from Ethiopia[17] and Saudi[21] reported incidence of (1.6%) and (3%) respectively which is consistent with our figure of 2.5%.

In Cheuk et.al[3] study, parents who were aware of IE had older children, higher education attainment and more likely to be professionals, administrators, or skilled workers. In study done in Sudan (32) awareness of IE was related to the fathers' educational attainment and occupation while it was not related to mothers' occupation or educational level. The previous study we did in 2017[7]suggested that being young, well educated, living in urban area has a positive impact on knowledge score.

Our study suggest that well educated parents that had received enough information regarding their child's condition, will have a high awareness score. Although the results are good compared to other studies and to our previous study, but we still feel that the knowledge of the parents could and should be improved. Evidence from the literature review suggests that well designed and written information, such as leaflets, can be useful learning aid when used in combined with professional consultation and advice. It improves health knowledge and later recall, it is most effective if the information is personalized.[4]

Limitation

This is a single centre study, but the number of participants is adequate and the centre receive patients from the whole of the country.

Conclusion

The awareness level of the parents was good. The awareness score is higher in well educated parents. The knowledge of the parents had improved compared to the previous study done 2017, this proves that awareness could be improved by simple targeted educational activities e.g. printed information, allowing more time in the clinics and using all doctor and patients/parents contacts as educational opportunity, checking knowledge is very important as it will have impact on the wellbeing. We need to work on improving the knowledge about IE prevention e.g. dental hygiene, regular dental check.

Recommendation

medical professional, should be aware that ongoing and continuous education of parents and patients is the cornerstones of the management plan of children with congenital heart disease.

We should check the knowledge of the parents on each clinical contact, to identify any gaps in the knowledge; that needs to be rectified. In our population knowledge about oral hygiene is the area that needs to be addressed most.

Implementation of preventive oral health program for children with congenital heart disease focusing on oral hygiene education as well as regular preventive dental visits are vital in the management of children with CHD. Oral and dental care services should be a part of the CHD setup.

To make use of easy accessible resources to improve parental knowledge such as parents' information leaflets designed in simple language, social media, TV and internet.

Note

This work is part of a thesis submitted for partial fulfillment of MD degree in Clinical Paediatrics and Child Health, Sudan Medical Specialisation Board.

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