

ORIGINAL ARTICLE

REFERRAL PATTERN OF CHILDREN WITH CARDIAC DISEASES: A CROSS-SECTIONAL REVIEW OF REFERRAL DOCUMENTS IN THREE TEACHING HOSPITALS IN ADDIS ABABA

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Abstract

Background: Patients with hemodynamically significant structural heart lesions often become inoperable if early referral and intervention is not done. Contrarily, referring patients with hemodynamically-insignificant lesions congest the already busy tertiary centers. The study aim was to determine the proportion of hemodynamically significant cases with delayed presentation and their determinant factors.

Methods: A cross-sectional study design was used to collect data from 369 referral slips sampled using a single population proportion formula (95% CI, 5% margin of error, and 50% cases coming with a referral paper). Data was analyzed using SPSS software package version 25. Binary logistic regression analysis was done to determine factors associated with referral either to the Tikur Anbessa hospital versus Saint Paul and Yekatit 12 hospitals. Odds ratio with their corresponding confidence interval was used to assess the significance of association and statistically significant associations were declared at p -value < 0.05 .

Result: The overall magnitude of delayed presentation beyond 1 year of age among patients with hemodynamically-significant lesions was 54%. Saint Paul and Yekatit-12 hospitals combined had higher referral from primary institutions (AOR=2.68 95% CI-1.64-4.38, $p<0.001$). Tikur Anbessa hospital had higher referral of congenital heart disease and retention of feedback referral slips compared to the two hospitals (AOR=1.86, 95% CI-1.02-3.41, $p=0.004$) and (AOR=2.78, 95% CI -1.65-4.69, $p<0.001$). If the referring health worker was a specialist, and initial symptom was chronic and poly, the likely-hood of being referred to Tikur Anbessa Specialized hospital was higher (AOR=10.34, 95% CI-2.20-48.69, $p=0.003$) and 1.97, 95% CI-1.21-3.22, $p=0.007$) respectively. The time lapse between referral and reaching at the referral destination was longer in cases referred to TASH (AOR=2.91, 95% CI-1.74-4.88), $p<0.001$). Feedback slips were sent back to the referring health facilities in only 3% of cases.

Conclusion: Delayed presentation of patients with hemodynamically significant cardiac lesions was tremendous. and un sent or retained feedback referral slips were significant. Future research should focus on active searching for causes of delayed presentation using a well-designed and validated tool.

Keywords: Patients, Patients referral, Teaching hospitals, Rheumatic heart disease, Feedback referral

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Background

An early diagnosis and referral of patients is often a problem in low-income countries like Ethiopia and children with structural heart lesions (SHL) like all the other pediatric referrals are victims of an inefficient referral system (1). Delayed care-seeking, missed-diagnosis or late referral in structural heart lesions often results in pulmonary vascular disease (PVD), heart failure (HF), and infective endocarditis (IE)(2). In a study outcome reported from Kenya, the proportion of patients with hemodynamically-significant CHD who were diagnosed beyond one year of age was 60% (3). In the contrary, an innocent cardiac murmur remains a common indication for referring cases to a tertiary level with an unnecessary crowding of settings (4). According to one report, the problem of referring simple cardiac lesions in developing countries is paramount (5). Referral system is designed to optimize the use of the different levels of health services and avoid unnecessary congestion and waste of human and material resources in the specialized levels (6). A standard referral system is effective only if sufficient coordination between different health care levels is available. As a result, referral to the higher level will only be through the lower-level health care systems. Absent or poor feedback is a common problem in the referral system. In a well-organized health system, health workers in the higher levels should report the final diagnosis and treatment of all referred patients to the lower level in a stand-

ard form including their follow-up recommendations (7). The aim of the current study was to describe the pattern of referral of children with cardiac disease presented to three teaching hospitals of Addis Ababa.

Methods

Study area and Period: The study was conducted at Tikur Anbessa specialized hospital (TASH), St Paul's Hospital Millennium Medical College (SPHMMC), and Yekatit 12 (YK12) hospitals between January 01 and February 30, 2019. TASH is a well-established referral hospital for chronic and severe health problems. It receives cases from regional hospitals from all parts of the country including Yekati-12 and SPHMMC hospitals. The pediatric cardiology unit at TASH is one of the four cardiology units in the hospital with three pediatric cardiologists and six pediatric cardiology fellows, three nurses, 3 echocardiographic and 2 electrocardiographic machines. The unit works in collaboration with the main cardiac center located in the premises of TASH. SPHMMC is a teaching hospital in Addis Ababa (AA) with a pediatric cardiology unit. Yekatit 12 hospital is one of the public hospitals affiliated with the two hospitals.

Study design: Cardiac referral slips dated back to December 2019 and before were collected retrospectively until the required sample size were obtained.

Study participants: Secondary data of children up to the age of 15 years with structural heart lesions who were referred to one of the three teaching hospitals with referral slip were the source of data. The data were collected in a semi-structured pre-tested questionnaire format.

Inclusion criteria: Children with cardiac symptoms, hemodynamically-significant or not, who for the first time brought with a referral slip were included.

Exclusion criteria: Cases referred for non-structural heart lesions, self-referred or verbally-referred cases and referral slips with grossly incomplete demographic data were excluded

Study variables

Age, sex, address, living area, referral distance, reason for referral, referring health worker, referring health institution, and echocardiographic diagnosis were collected as independent variables. Delayed presentation was the primary outcome variable. Secondary outcome variable includes details of the referral slip, time to arrive at the referral site after receiving the referral paper, specialists' recommendation, follow-up, and feedback referral.

Operational definition:

Referral: a process in which a health worker at one level having insufficient resources to manage a clinical condition seeks the assistance of a better facility at the same or higher level.

Referring facility: The health service organization that initiated the referral process.

Receiving facility: A health service facility that received patients or clients from referring facility.

Appropriate referral: defined when the referral is from the appropriate level, appropriate time, and with complete referral information as per the national ministry of health standard.

Patient referral feedback: The act of sending patient referral information back to the referring organization.

Teaching hospital: is a hospital or a medical center that provides medical education and training in addition to medical treatment to future and current health professionals.

Tertiary level specialist: refers to a certified pediatric cardiologist.

Feedback slips: second part of the referral paper. Feedback letters still attached with the incoming referral letter is equivalent with the "feedback letter that was not sent back to the referring health worker". Feedback letter detached from the incoming referral paper was equivalent with the "feedback letter sent to the referring health worker". Central referral hospital is referring to TASH for this particular study.

Primary institutions/level

1. Has three kinds of service points – health posts, health centers and primary hospitals. The Health Posts and Health Centers are organized into PHCUs, which is composed of a HC and five satellite HPs. Taken together, the PHCU provides services to a population of about 25,000 persons (8).
2. Hemodynamically-insignificant lesions (HISHL):-examples of HISHL are small ASDs, of patent foramen ovale, small VSDs, small PDAs, patient with innocent murmur, mild PA's. Hemodynamically significant structural heart lesions: -Those children with structural heart diseases in need of pharmacologic and/or surgical based treatment (9).

Ventricular septal defect (VSD), Atrial septal defect (ASD), pulmonary stenosis (PS), patent ductus arteriosus (PDA), aortic stenosis (AS), and coarctation of the aorta (COA) in older children have been defined as simple heart lesions as their post-operative prognosis is excellent. Similarly, all cyanotic-CHD and RVHD cases were defined as complex cardiac lesions since their post-operative prognosis is not as smooth as the simple lesions (10,11).

Delay in arrival to the referral destiny: was defined as the delay in arrival at the referral hospital beyond 72 hours after receiving the referral paper (12).

A “Poor” quality referral paper was defined when less than 50% information's were recorded on the referral slip, a “Fair” quality referral was defined when 51%-75% infor-

mation's were recorded, and “Good” quality referral was defined if > 75% required information's were recorded on the referral slip (13).

Data collection and procedure: - A half-day training about the purpose of the study and the questionnaires was given to nurses at each study hospital prior to the data collection. The principal investigator monitored the data collection processes daily. The quality of the referral paper was assessed against the 22 items adopted from the referral standard. A score of "1" was given for information properly recorded on each specific item and “0” score was given otherwise. Using the compute function, the average value was calculated and re-categorized in to a different scaled variable as “poor”, “Fair” and “Good” (8).

The management and follow up plan were decided by the principal investigator (a certified pediatric cardiologist). Thus, recommendations as Surgery, additional investigations, inpatient management, follow up at the tertiary center, or follow-up at the primary level were the recommendations recorded variables.

Sampling technique

The sample size was calculated using a single population proportion formula assuming a 95% confidence interval, a 5% margin of error, and 50% of cases coming to tertiary hospital with a referral paper. Thus, $N = (Z\alpha/2)^2 * P(1-P) / D^2 = (1.96)^2 * 0.5 * 0.5 / (0.05)^2 = 384$. Since the total pediatric cardiac referral in the three hospitals is estimated to be less than

10,000 population annually, a finite population formula, $SS/[1+\{(SS-1)/pop\}]$ was used. Thus, the final sample size was 369. The sample size was proportionately allocated to the 3 hospitals based on the case load ratio (199 for TASH, 89 for Saint Paul, and 81 for YK-12) hospitals. Annual estimated case load of structural heart lesions at TASH, SPHMMC and YK-12 hospitals at time of the study were 3,575, 1,947 and 1,608 respectively (from hospital HMIS data). Data were entered in to SPSS software package version 25, IBM USA. Manual proof reading was made to secure the data quality. Categorical data were analyzed and presented in numbers, frequencies, and proportions. Continuous data were presented in the form of mean, median, and standard deviation. Binary logistic regression analysis was made to determine factors affecting referral either to the central referral hospital or to the other teaching hospitals. Statistically significant associations were made at a p-value < 0.05.

Result

Out of the 369 analyzed cases, 207(56.1%) were females. The median referral age was 24 (IQR=100) months. Socio-demographic characteristics of the cases are displayed in Tables 1. The majority of cases were urban dwellers mainly, from surrounding Oromia towns. The overall proportion of delayed presentation beyond 1 year of age among patients with hemodynamically-significant lesions was 54%.

Table 1: Demographic characteristics of children with cardiac referral at three teaching hospitals of Addis Ababa.

| Characteristics | Number | Percent |
|------------------------------------|---------------|----------------|
| Age (months/years) | | |
| 0-3 | 43 | 11.7% |
| 4-12 | 106 | 28.7% |
| 13-60 | 95 | 25.7% |
| 5 -15 | 125 | 33.9% |
| Sex | | |
| Male | 162 | 43.9% |
| Female | 207 | 56.1% |
| Referring regions | | |
| Addis Ababa | 130 | 35% |
| Oromia | 144 | 39% |
| SNNPR | 30 | 8% |
| Amhara | 38 | 10% |
| Tigray | 1 | 0.3% |
| others | 21 | 6% |
| MI [§] | 5 | 1% |
| Referral Hospital | | |
| Tikur Anbessa specialized hospital | 199 | 53.9% |
| Saint Paul millennium hospital | 89 | 24.1% |
| Yekatit 12 hospital | 81 | 22.0% |
| Referral distance | | |
| ≤ 25 km | 156 | 42.3% |
| >25km | 213 | 57.7% |
| Patient dwelling area | | |
| Urban | 211 | 57.2% |
| Rural | 158 | 42.8% |

[§]MI-missed information

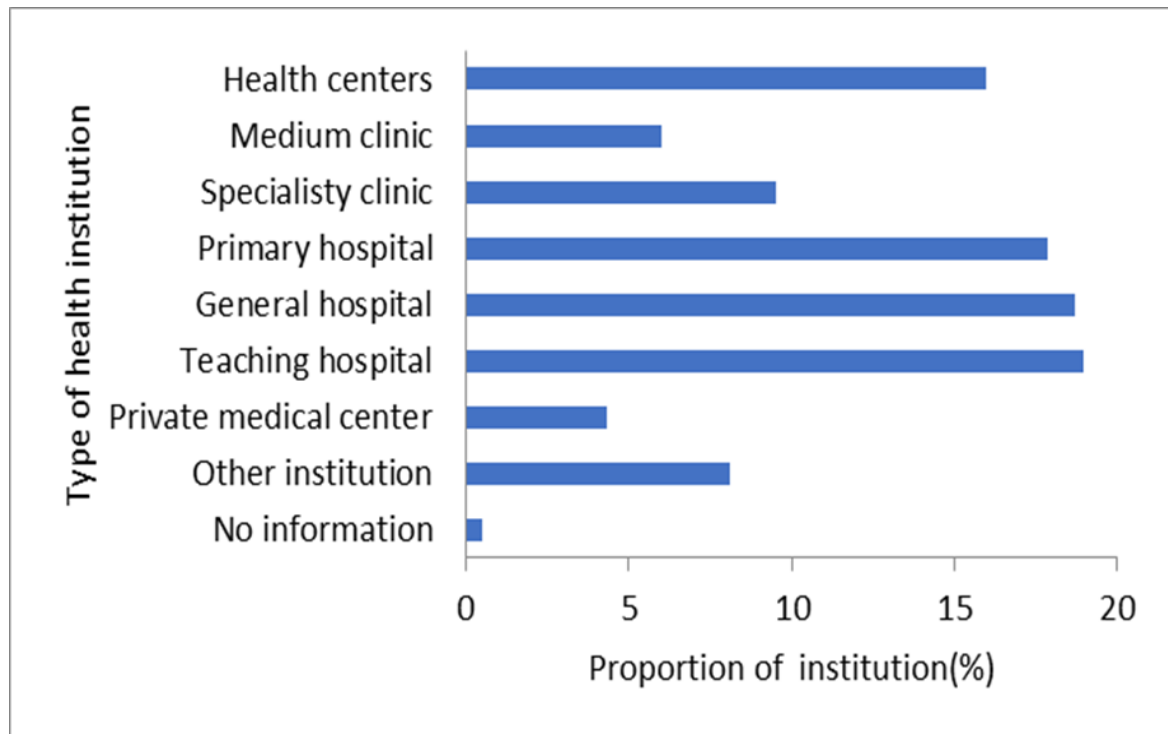


Figure 1- Referring health institutions to the three teaching hospitals of Addis Ababa

Table 2 shows factors determining referral to TASH or the other two teaching hospitals (SPHMMC and Yekatit 12 hospital). It was shown that if the referral were from the primary level institutions, it would less likely be to TASH. On the other hand, if the referring health worker was a specialist, the referral would be more likely to TASH than the other two hospitals. Similarly, if the initial presenting symptoms were chronic and poly symp-

toms, more likely the patient referral would be to TASH. Hemodynamically-insignificant lesions were equally referred to TASH and the other teaching hospitals. Arrival time to the referral destinations was longer in TASH than the other two hospitals. Similarly, a smaller number of feedback letters were detached from the main referral slips at TASH compared to SPHMMC-YEK-12 hospitals.

Table 2: - Factors affecting cardiac referral in children at three teaching hospitals of Addis Ababa.

| Variables | TASH | SP/Y12 hospitals | Crude OR (95% CI) | AOR | p-value |
|--|------|------------------|--------------------|----------------------|---------|
| Referral from ≥ 25 km distance | 126 | 87 | 1.68 (1.11-2.55) | 1.59 (0.97-2.62) | 0.069 |
| Referral from primary institution | 73 | 109 | 3.08 (2.02-4.72) | 2.68 (1.64-4.38) | <0.001* |
| Referral by specialist | 22 | 2 | 10.44 (2.42-45.09) | 10.34 (2.195-48.689) | 0.003* |
| Chronic-poly symptom on initial presentation | 137 | 81 | 2.43 (1.59-3.71) | 1.97 (1.21-3.22) | 0.007* |
| Echocardiographic Dx of CHD [©] | 155 | 87 | 0.30 (0.19-0.47) | 2.78 (1.65-4.69) | <0.001* |
| Hemodynamic severity | 70 | 64 | 1.11 (0.73-1.70) | 1.062 (0.64-1.76) | 0.818 |
| Delayed arrival after being referred | 99 | 36 | 3.69 (2.32-5.84) | 2.91 (1.74-4.88) | <0.001* |
| Feedback slip attached On the parent referral slip | 57 | 26 | 2.22 (1.32-3.73) | 1.864 (1.02-3.41) | 0.044* |

*-statistically significant. The reference variable is the outcome variable (the central referral hospital) TASH (code=1), the other outcome variable is SPHMMC-YEK-12 (code=0). Missed information cases were not included in the analysis.

SP-Saint Paul hospital, TASH-Tikur Anbessa specialized hospital, YK-12-Yekatit 12 hospital, CHD-congenital heart, RHD-rheumatic heart disease, CHF-congestive heart failure, HW-health worker, Dx-diagnosis, ©-cases with missed data were not included in the bivariate and multivariate analysis

The frequency of referral information on the referral slips is depicted in table 3. The proportion of good, fair and poor quality of the referral slips was 39.3%, 42.8% and 17.9% respectively. Hence, referring table 3 of this study, the referral quality for facility name, client's name, age, sex, client history, and reason for referral were graded as "Fair to Good" quality information. Accordingly, the overall proportion of delayed presentation beyond 1

year of age among hemodynamically-significant lesions was 54%. The feedback referral slip (second part of the referral paper) was not detached in 97% of the cases. Details of the referring institutions is displayed in figure 1. The indications for referral were shown in Figure 2 and specialists' recommendation was shown in Figure 3.

Table 3: Referral information contained on the referral slips of referred cases

| Referral information | Number | Percent |
|--|---------------|----------------|
| Referring health worker name | 307 | 68% |
| Referring health worker position | 88 | 19.6% |
| Initiating facility name | 355 | 78.9% |
| Initiating facility address | 261 | 58% |
| Date of referral | 246 | 54.7% |
| Telephone arrangement made before referral | 14 | 3.1% |
| Referring facility telephone number | 26 | 5.8% |
| Receiving facility name | 334 | 74.2% |
| Receiving facility address | 110 | 24.4% |
| Client's name | 353 | 78.4% |
| Client ID number | 198 | 44% |
| Client's age | 316 | 70.2% |
| Client's gender | 314 | 69.8% |
| Client's address | 69 | 15.3% |
| Clinical history | 345 | 76.7% |
| Clinical findings | 216 | 48% |
| Treatment given | 175 | 38.9% |
| Reason for referral | 343 | 76.2% |
| Accompanying document attached | 93 | 20.7% |
| Name of the referring health worker printed | 302 | 67.1% |
| Signature of the referring health worker printed | 354 | 78.7% |
| Date of signature printed | 105 | 23.3% |

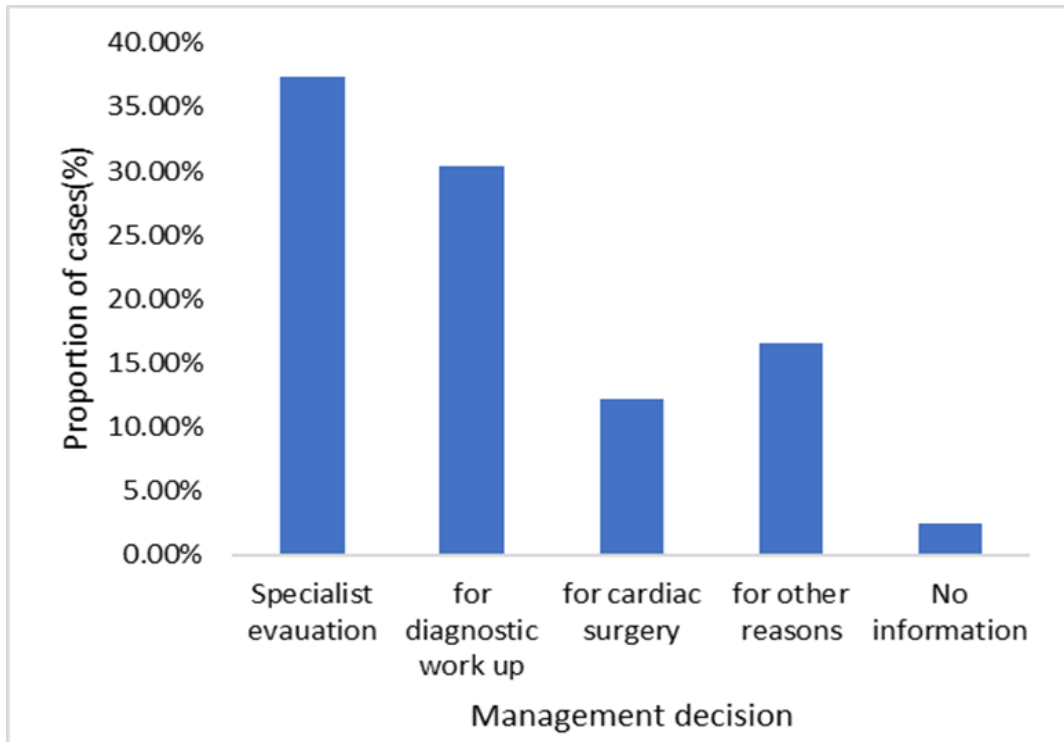


Figure 2: Reasons for referral of children with cardiac problem at three teaching hospitals of Addis Ababa.

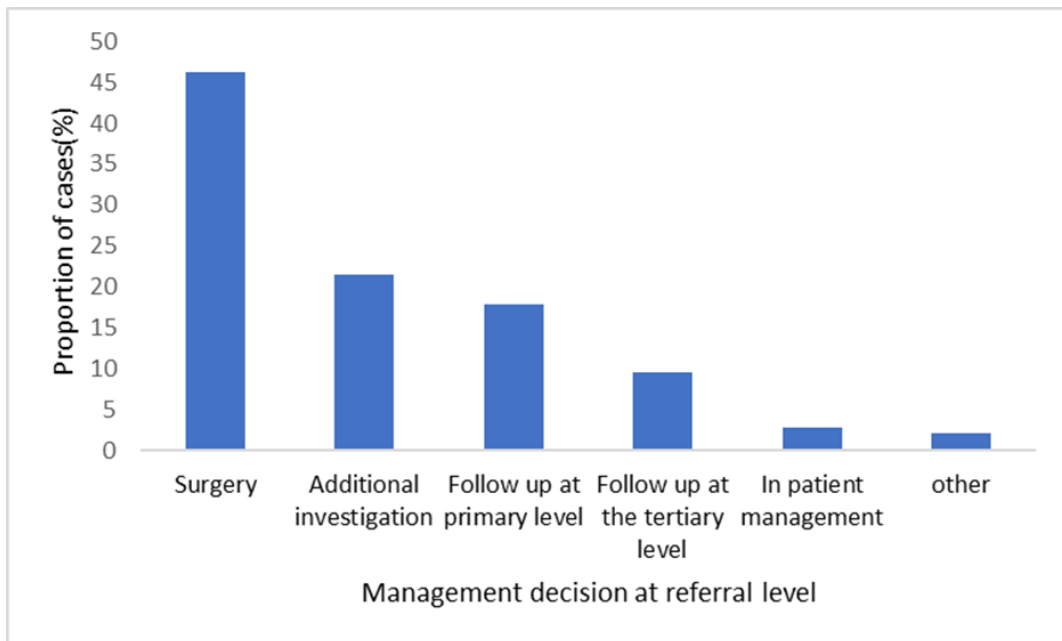


Figure 3: Tertiary level management recommendations to children with cardiac problem at the three teaching hospitals in Addis Ababa.

Discussion

More than half of the hemodynamically significant cases in this study had a delayed presentation. Furthermore, primary and secondary level institutions referred cases to the tertiary hospitals against the standard (8). Arrival time to the referral hospital was significantly delayed in the central referral hospital. Referral information particularly “referring health worker identity”, “pre-referral telephone arrangement”, “referring facility telephone number”, “receiving facility address” and “client identification number” were poorly recorded in the referral slips. The delayed presentation in the current study was assumed to be higher compared to other reports (14). It was reported that heart failure and pulmonary hypertension were associated with a delayed referral in CHD and with inoperability of cases (2).

Furthermore, practitioners were often sued for medical negligence when a patient referral is delayed beyond the expected time (15). Some centers recommend that referral to a pediatric cardiologist should be made in no longer than a week for hemodynamically significant lesions (16). Government facilities were the main referring institutions in this study. This observation may show the referral tier system in Ethiopia is well organized only in the government health facilities compared to the private institutions. Evidences also showed that health care referrals from private health facilities to tertiary public facilities face many challenges at different levels (17). However, a dif-

ferent observation was reported in Nigeria (18).

Though, further study is necessary, it seems likely that the community members use the government institutions more frequently than private institutions for economic reasons. Some private institutions preferred referring economically well-off patients abroad for medical treatment (19). The current observation helps to emphasize the need for appropriate schemes for the private institutions in the referral pathway.

Indications for referral were recorded in two-thirds of the referral slips, a comparable rate of record was reported from Saudi Arabia (20). In the majority of cases, the reasons for referral were “seeking a specialist evaluation” and/or “more laboratory investigations” a finding that commensurate with other report (21). Delayed arrival to TASH compared to the other two hospitals may be due to unseen barrier in the former, a finding that require further clarification.

Our finding showing that patients with chronic and poly-symptoms were referred to TASH was natural since TASH is a central-referral hospital receiving cases from all regions including SPHMMC and Yekatit 12 hospitals. Reports showed that single cardiac symptom was the common presenting symptom to primary care levels (22). The fact that there was no statistically significant difference in the two levels of referring institutions among those with in 25km distance and those from

≥ 25km indicated that even cases from the nearby health institutions were using the tertiary centers as that of far distance comers. This contradicts the referral standard and require verification. Similar observation was reported by others (23).

According to the decision of the pediatric cardiologist, 1 in 5 (20%) of the referred cases required follow-up only at the primary level. Reports showed that more than 50% of the population catered at the tertiary level in developing countries could be treated at the lower facility level (24). Patients seek care directly from hospitals because they perceived the hospitals are providing better quality services, less costly and are better stocked with drugs (25).

Referral information particularly “referring health worker identity”, “pre-referral telephone arrangement”, “referring facility telephone number”, “receiving facility address” and “client identification number” were poorly recorded in the referral slips. A similar information gap was reported by others (13). Telephone arrangement before referring was made only in 3% of the cases in the current study despite it’s importance in order to know the exact information needed by the receiving hospital staff. Likewise, very few feedback referral letters were sent to the referring health facility. Writing feedback referral helps to notify the result of the tertiary level management, and confirm the patient’s arrival at the referral hospital (22).

Conclusion: The proportion of delayed presentation among children with hemodynamically-significant cardiac lesions was measurably large probably due to delay in care seeking by the parent, or misdiagnosis by the health worker or reluctance to refer timely. Primary institutions using the tertiary hospitals is unnecessary burden to tertiary hospitals and require a solution. The referral information contained in the referral slips were markedly incomplete and feedback referral slips were rarely sent to the referring health facilities. The current finding will serve as a background information for future well designed and validated study on the subject. The importance of telemedicine bridging primary level health workers with the pediatric cardiologists at the tertiary level may help.

Limitation of the Study: This report was based on retrospective data analysis with likely incompleteness. Our operational definitions were not based on standard definitions. In addition, the principal investigator (a pediatric cardiologist) decided whether the proposed management and follow up plan was appropriate which may introduce ascertainment bias.

Declarations

Ethical consideration: -Author had the ethical clearance from the IRB of the three hospitals and the participants’ consent was waived.

Consent to publish: -NA

Data availability statement: All the necessary information is included in the manuscript.

Authors contribution: TM had the concept of the research question; He wrote the proposal and mentored the data collection. He was involved also in the data analysis and did the writeup.

Conflict of interest: The author declared no conflict of interest.

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