Title:Trends and Referral Patterns of Ethiopian Pediatric Patients Seeking Treatment Abroad at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: A Retrospective Cross-Sectional Study.

A RESEARCH THESIS TO BE SUBMITTED TO ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, PEDIATRICS, AND CHILD HEALTH DEPARTMENT IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE SPECIALITY CERTIFICATE PROGRAM IN PEDIATRICS AND CHILD HEALTH.

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ADDIS ABABA UNIVERSITY COLLEGE OF HEALTH SCIENCES SCHOOL OF MEDICINE DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

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Acronyms/Abbreviations

AAU …….... Addis Ababa university

CC…….. Childhood cancers

CHD.....…..Congenital heart diseases

ETB…….Ethiopian birr

LMIC……Low- and middle-income country

HSO…… Health service organization

HSCT……. Hematopoietic Stem cell transplant

MD ……..Medical doctor

MT ……..Medical Tourism

NCD……..Non-communicable disease

OS……..Overall survival

PI…….Principal investigator

QI…….. Quality improvement

SPSS……Statistical Package for Social sciences

TASH…… Tikur anbessa specialized hospital

WHO…….World Health Organization

Abstract

Background: Referral is the process by which a health worker transfers care responsibility to another professional due to limitations in providing necessary treatment. In developing countries like Ethiopia, pediatric referral patterns for treatment abroad have received insufficient attention. Understanding these patterns can help address treatment-related health issues and improve patient quality of life. This study aims to provide valuable data that informs policy and practice regarding demographic characteristics, primary diagnoses, referral trends, and patient outcomes.

Objective: To assess the trends and referral patterns of Ethiopian pediatric patients seeking treatment abroad at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Methods: A facility-based, retrospective, cross-sectional study was conducted from 2022 to 2024 G.C, at Tikur Anbessa Specialized Hospital. Data were collected on demographics, diagnoses, medical and surgical interventions provided abroad, and patient outcomes using medical board-approved referral papers and phone interviews with attendants. The study included all children with referral papers during the study period. Data were analyzed using SPSS version 26, employing descriptive analysis, with results presented in tables & figures.

Result: The study surveyed 298 children with referrals for treatment abroad. Most participants were aged 1-5 years, with 52.5% male (male-to-female ratio of 1.1:1). Notably, 94% underwent imaging, primarily chest X-rays (73.1%**)** and echocardiograms (68.5%**).** Most referrals (63.8%) came from the Cardiac Unit, followed by the Hemato-Oncology Unit (21.8%)**.** Congenital Heart Disease (CHD) was the most common diagnosis, with Acute Lymphoblastic Leukemia (ALL) prevalent among oncologic conditions. The main reason for referral was surgical management **(**63.4%**),** followed by Hematopoietic Stem Cell Transplantation (HSCT) **(**12.1%**)**. Referral rates significantly increased over the study period, with 161 participants seeking treatment abroad, primarily in India (70.2%) and Israel (13%). While 95% of treated patients returned alive, the study revealed a concerning 15.1% mortality rate during treatment and **a** 20.8% rate of unknown outcomes, indicating critical gaps in follow-up care.

Conclusion- The steady increase in pediatric referrals abroad, particularly for CHD and childhood cancers, underscores an urgent need for enhanced local healthcare infrastructure to provide specialized interventions often unavailable in Ethiopia. Ideally, as hospital care improves, the need for referrals should decrease; however, the data suggests otherwise. Policymakers must prioritize pediatric health in national agendas, ensuring funding for local healthcare infrastructure to enhance access to essential treatments and reduce reliance on international referrals. The 20.8% of cases with unknown outcomes represents a significant data gap that limits our understanding of referral effectiveness. Improved follow-up care and robust patient tracking systems are essential for addressing these gaps, for monitoring the long-term impacts of these interventions on health outcomes. Furthermore, ongoing research for overall healthcare accessibility and enhancing pediatric patient management

Keywords: Pediatric referrals, congenital heart disease, childhood cancer, healthcare infrastructure, treatment abroad, Ethiopia, patient outcomes, referral patterns.

1. Introduction

1.1. Back ground

Referring patients to facilities where better management can be provided has long been a fundamental aspect of medical practice. Patients have historically been referred from one facility to another in search of improved care by well-trained practitioners in specific fields. This process comes with both advantages and disadvantages. (1)

Referrals abroad incur considerable expenses, including travel costs, stress, and interactions with embassies. They also require hard currency and the ability to find reputable hospitals and lodging, presenting significant challenges for patients, their families, and the country as a whole. (2)

The practice of referring patients abroad for surgical treatment has been in place for many years, and it has become more practical due to advances in medical tourism. While the flow of patients has traditionally been from developing to developed countries, there is now a growing trend of patients from Europe and the U.S. seeking surgical care in Asia or Africa. Additionally, referrals occur both between developed countries and among developing nations. (3)

The availability of essential and life-saving surgical care for children is limited and unequally distributed worldwide, with nearly two billion children and adolescents lacking access to safe, timely, and affordable surgical care (4). Congenital heart defects (CHD) are the most common congenital anomaly, occurring in one in every hundred live births and causing over 300,000 deaths globally each year. In low- and middle-income countries (LMICs), over 90% of CHD patients do not receive the necessary care, and disparities persist even in high-income countries. Consequently, nearly 200,000 children die unnecessarily from CHD every year. (5)

The global burden of cancer is also significant and on the rise. Each year, an estimated 400,000 children aged 0–19 years are diagnosed with cancer worldwide (6), with approximately 90% of these cases occurring in LMICs, where nearly 95% of children in this age group reside. Due to weaker health systems, cancers in these regions often go undiagnosed and untreated (7,8).In 2019, an estimated 100,000 children died from cancer (9).

1.2. Statement of the problem

The current population of Ethiopia is approximately 123,417,921, according to the latest United Nations data, making it the 12th largest population in the world. The median age in Ethiopia is 19.5 years, (10) with a significant proportion of the population comprised of younger individuals. Notably, 40% of the total population is under 15 years old (11). This demographic places many children in the at-risk age group for referral patterns of Ethiopian pediatric patients seeking treatment abroad, underscoring the significance of this issue.

The Ethiopian Cardiac Center performs between 100 and 200 surgeries per year, with a significant decrease during the COVID-19 pandemic, dropping to 40 to 50 surgeries annually. In 2024, however, the center achieved its highest output, performing 238 surgeries. Despite this improvement, patients face an average wait time of 32 months (2 years and 7 months) for surgery, with over 7,500 individuals on the waiting list. This situation persists despite two memoranda signed between the Ministry of Health, the Ethiopian Cardiac Center, Ethiopian Airlines, and Rotary Ethiopian Charity to provide free surgeries for 100 children, covering all related costs.

The burden associated with the referral patterns of Ethiopian pediatric patients for treatment abroad is understudied. To date, there is no published data in Ethiopia regarding this topic, at least to our knowledge. The Study also proposes actionable solutions to improve pediatric care in Ethiopia.

1.3. Significance of this study

Given the scarcity of research on the referral patterns of pediatric patients seeking treatment abroad, especially in the developed world, it is anticipated that there is minimal literature available. The few existing studies primarily focus on the adult population. However, due to the profound differences in biology and clinical presentation between adults and children, data obtained from adult populations cannot be directly applied to pediatric patients. Consequently, physicians often rely on data collected from populations with different demographic patterns than those of developing nations.

This study aims to provide valuable insights into the prevalence of referral patterns of Ethiopian pediatric patients seeking treatment abroad. It seeks to fill the significant gap in knowledge regarding this issue, not only for Ethiopia but potentially for other developing countries in sub-Saharan Africa. By doing so, it will enhance understanding of the main reasons for referrals abroad and identify the leading disease entities that prompt these referrals. Furthermore, this study will serve as a baseline for future research in this critical area.

2. Literature review

2.1. Overview of Trends and Referral Patterns of Pediatric Patients For Abroad Treatment

The World Health Organization has defined universal health coverage as the opportunity for individuals to access needed health services (including disease prevention, health promotion, treatment, rehabilitation, and palliative care) of sufficient quality to be effective, while also ensuring that the use of these services does not lead to financial hardship. (12)

Referral is a process whereby a health worker transfers the responsibility of care temporarily or permanently to another health professional, social worker, or community, in response to the inability or limitations in providing the necessary care. A facility can serve as both a referring and receiving unit depending on the circumstances. Referring patients to a place where better management can be provided is a longstanding element of medical practice. Patients have been referred from one facility to another in search of improved handling of cases by well-trained practitioners in that specific field. This practice has both advantages and disadvantages. (1)

Referrals abroad incur considerable expenses, stress, flight costs, and interactions with embassies. It also requires hard currency, locating appropriate hospitals, securing lodging, and other significant challenges for both patients and their families, and for the country as a whole (2). This situation is particularly evident in developing countries that send patients to developed nations. The same applies to Ethiopia, which struggles to provide such facilities. Developing countries often spend substantial amounts on investigations and surgical procedures abroad. Patients may also face alienation, language barriers, and the risk of deteriorating before reaching their destinations (2).

In Ethiopia, Addis Ababa University Medical Faculty (AAU MF), as the highest medical training, research, and service center in the country, frequently handles challenging cases. It often refers patients due to a lack of adequate subspecialty fields, experts, equipment, and investigative modalities.

The thought of undergoing surgery and recovering in a pleasant country with warm weather and relaxing surroundings can be appealing. However, there are several reasons why having surgery overseas may prove to be disadvantageous. The following issues should be considered during referrals abroad: very high surgical costs (typically associated with surgeries performed in developed countries), concerns about the standards of surgical practice, the number of visitors allowed, language barriers, travel complications, treatment costs, surgical waiting lists, and the potential consequences if something goes wrong. (1)

The availability of essential and life-saving surgical care for children is limited and unequally distributed worldwide, with nearly two billion children and adolescents lacking access to safe, timely, and affordable surgical care (4). Despite the significant burden of surgically treatable pediatric and congenital heart conditions in LMICs, the magnitude and distribution of the treating workforce are insufficient (13). As a result, patients often require management by visiting teams, treatment abroad, or must pay large sums to remain on domestic waiting lists, if such centers are available; otherwise, they risk death or life-altering morbidity (13).

In Africa, the population is expected to double by 2050 due to high fertility rates, with approximately 40% of all births and 40% of all children worldwide occurring in Africa (14). The steady incidence of congenital heart disease (CHD), regardless of race, geographical region, or social class, will inevitably lead to more children being born with CHD, especially in LMICs. The 54 countries in Africa have an estimated total annual CHD birth prevalence of over 300,000 cases, which is anticipated to rise rapidly alongside population growth. Without necessary healthcare investments, LMICs are significantly affected and suffer an unbearable strain (15).

Congenital heart defects (CHD) are the most common congenital anomaly, occurring in one in every hundred live births and causing over 300,000 deaths worldwide each year. In low- and middle-income countries (LMICs), over 90% of CHD patients do not receive the care they need, and disparities persist even in high-income countries (5). Without interventional or surgical care, approximately a quarter of these patients will die in their first year, and the majority will not live to see their fifth birthday, often passing away without a proper diagnosis (16). Consequently, nearly 200,000 children die unnecessarily from CHD each year (5).

The lack of cardiac centers, surgeons, non-surgical workforce, and supplies forces various countries to send patients abroad for cardiac surgery. In some countries, including smaller high-income nations, the total share of sending patients abroad for cardiac surgical care can be as high as 10–12% of the entire health budget (17). Nigerians spend approximately US$1 billion each year on international medical tourism, with cardiac surgery among the top specialties sought (18). India, a common destination for such referrals, issued 18,000 medical visas to Nigerian patients in 2012 alone, resulting in US$260 million in revenue, not including patients from other countries (19). In Kuwait, following the Iraqi invasion, cardiac surgery (for both pediatric and adult patients) accounted for 50% of cases sent abroad for treatment (20,21). This figure has significantly decreased in recent years, as two pediatric surgeons have been requested to visit Kuwait more than six times a year, and a senior adult cardiac surgeon from the USA has begun working at the Chest Hospital. This has helped reduce unnecessary and expensive chest evaluations and referrals (22,23).

The global burden of cancer is significant and increasing. In 2020, it is estimated that there were 19 million new cases and 10 million deaths across all age groups (24). Childhood cancers contribute substantially to the global disease burden, affecting children and their families worldwide. Each year, approximately 400,000 children aged 0-19 years develop cancer globally (6). About 90% of these cases occur in low- and middle-income countries (LMICs), where nearly 95% of children in this age group reside. In these countries, health systems are often weaker, leading to undiagnosed and untreated cancers (7,8).

In Ethiopia, averages of 6,000-10,000 childhood cancers are diagnosed annually. Approximately one-third of children with cancer in LMICs survive, compared to over 80% in high-income countries (12). Treatment services for childhood cancer must be multidisciplinary and include multimodal therapies throughout the cancer journey (25). The high survival rates in well-resourced settings are based on research-driven childhood cancer protocols (26). In 2019, an estimated 100,000 children died from cancer (9).

An article on referrals of Ethiopian orthopedic patients for treatment abroad reviewed all orthopedic referral papers from the country's largest tertiary teaching hospital for the entire year of 2008. A total of 115 orthopedic patients were referred for treatment abroad, most of whom were young males from Addis Ababa, the capital. A sharp and steady increase in the number of referrals abroad has been observed over the last five years (27).

Another study, titled "Referral of Surgical Patients Abroad: A 5-Year Review from a Tertiary Teaching Hospital in Addis Ababa, Ethiopia," collected and reviewed referral slips of patients sent abroad from September 2005 to August 2009 by the Surgical Department. A total of 331 patients were reviewed during this five-year period, with an average of 66 patients referred per year. There was an overall male preponderance, with 183 (55.3%) being male. Most referrals (232 or 70%) were residents from the capital. Neoplastic diseases, both benign and malignant, accounted for 155 cases, with primary brain tumors (either malignant or benign) comprising 74 cases. Ninety-seven of the cases had at least one surgical intervention performed prior to referral. The overall trend showed a slight decrease in referrals, with the main reason for referral being the need for better surgical intervention (249 cases) (28).

The three main departments at Addis Ababa University referring patients abroad are Internal Medicine, Orthopedics, and General Surgery. The average number of surgical patients referred per year (66) is relatively lower than the number of cases referred by the Orthopedics department in 2008 (115). It was observed that many of these referrals could have been avoided if the hospital had a wider range of subspecialty consultants (27). In similar African countries, consultants returning from advanced training in developed countries have helped reduce unnecessary referrals abroad and saved significant amounts of hard currency (29). In the face of understaffed units, patients are forced to seek care abroad, leading to higher mortality rates and poor prognosis (30). Neoplastic diseases, particularly malignant ones, continue to pose significant challenges, requiring better diagnostic evaluations and combined modality management approaches (surgery, chemoradiotherapy, and hormonal therapy), as evidenced by ongoing studies of surgical admissions in the department (31).

Figure 1. Conceptual frame work

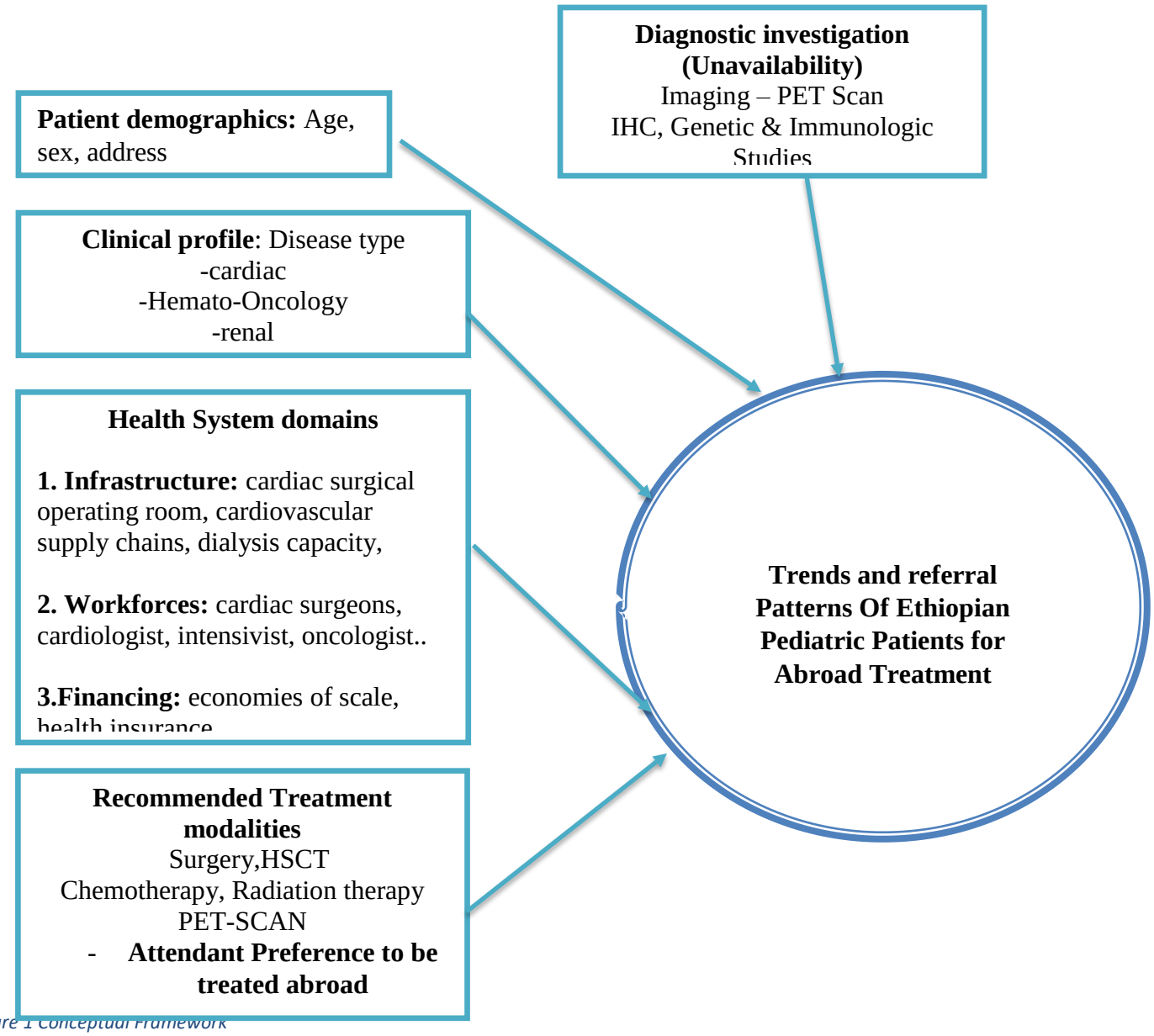

Figure 1 Conceptual Framework

Figure 1 Conceptual framework

3. Objectives

3.1. General objective

- To assess the trends and referral patterns of Ethiopian pediatric patients seeking treatment abroad over three years (from 2022 to 2024) at Tikur Anbessa Specialized Hospital, Ethiopia.

3.2. Specific Objectives

- To describe the demographic profile of pediatric patients referred for treatment abroad over three years.
- To assess the referral trends in recent years (to determine whether they are increasing or decreasing).
- To evaluate the types of diseases among pediatric patients referred for treatment over three years.
- To assess the factors or reasons leading to referrals for treatment abroad.
- To evaluate the magnitude of patients who received treatment following the medical board's summary.

4. Methods and materials

4.1. Study setting

The study was conducted at Tikur Anbessa Specialized Tertiary Hospital, established in 1974 and administered by Addis Ababa University. It is the largest and oldest teaching hospital in Ethiopia, providing education for approximately 300 medical students and 350 residents each year. The hospital has over 800 beds across surgical, gynecology and obstetrics, internal medicine, pediatrics, and emergency department wards. Additionally, it features an outpatient department (OPD) and specialized referral clinics, along with 7 X-ray machines, 3 laboratory rooms, and one CT scan diagnostic room. The hospital includes cardiac ICU rooms and specific surgical, medical, and pediatric ICU units, offering diagnostic and treatment facilities for approximately 370,000 to 400,000 patients annually.

The pediatric department, one of the major departments with various sub-units, contains 7 wards, a Pediatric Intensive Care Unit (PICU), a Cardiac Intensive Care Unit (CICU), a regular OPD, and 11 specialized referral clinics. These include a Cardiac clinic with 4 senior consultants and 6 fellows, a Chest clinic with 1 senior consultant and 3 fellows, an Emergency clinic with 1 senior consultant, an Endocrine clinic with 1 senior consultant, a Gastrointestinal clinic with 1 senior consultant and 1 fellow, a High-risk Infant clinic with 2 senior consultants and 2 fellows, an Infectious Disease clinic with 3 senior consultants and 1 fellow, a Neurology clinic with 2 senior consultants and 1 fellow, a Developmental clinic with 1 senior consultant, a Renal clinic with 3 senior consultants, a Rheumatology clinic with 1 senior consultant, and a Hematology-Oncology unit with 3 senior consultants and 8 fellows. This department holds multidisciplinary team discussions and decisions for approximately 50 pediatric cases per month, involving various departments.

The pediatric department serves approximately 54,000 patients each year across all units. Within the wards and ICUs, there are an average of 360 pediatric patients per month. Additionally, it handles around 4,000 outpatient cases each month from its regular OPD and specialized referral clinics. The majority of these cases come from the following clinics: Hemat-Oncology (900 cases), Cardiac (600 cases), Neurology (585 cases), Endocrine (300 cases), Emergency OPD

(290 cases), Infectious Disease (285 cases), High-risk Infant (270 cases), Renal (200 cases), Gastrointestinal (150 cases), and others.

4.2. Study period

From 1st January 2022 to 31st December 2024 G.C..

We will include children with referral papers approved by the board for abroad treatment, at the pediatric department registry, Tikur Anbessa Specialized Hospital over three years period.

4.3. Study design

The study was conducted by using an institutional-based retrospective cross-sectional descriptive-analytical study design.

4.4. Sampling technique

All of the patients that fulfill the inclusion criteria was studied in the mentioned time period

4.5. Sample size determination-

The total sample size for this study was determined based on the unique context of pediatric referral patterns for treatment abroad, as there is no published data on this prevalence. An estimated prevalence of 50% was used for calculations, reflecting the highest variability and providing a conservative estimate.

Using the single population proportion formula:

n= 422

$$n = \frac{Z^2 pq}{d^2}$$

N = total sample size **Z** = 1.96 **P** = 50% (0.5)

q = 1-p **d** = Margie of error 5% (0.05)

Based on these parameters, the calculation yielded a necessary sample size of n = 422. To account for potential missing or incomplete data, an additional 10% was added to this calculated value.

However, over the study period, only N = 298 cases were presented for review by the medical board for treatment abroad. Because this number is less than the initially calculated sample size, the finite population correction formula was applied to adjust the sample size estimation accordingly.

This methodology ensures that while the necessary sample size for robust conclusions was initially calculated to be larger, the actual sample size of 298 provides a relevant and realistic basis for drawing insights into pediatric referral patterns. Despite being smaller than the calculated value, this total represents the most accurate data set available for analysis during the study period and is adequate for understanding current referral trends and patterns.

4.6. Inclusion and exclusion criteria

4.6.1. Inclusion Criteria

- Children with an approved referral paper by the Board Committee for treatment abroad, including pediatric surgical referrals, from January 1, 2022, to December 31, 2024.
- Children whose parents or legal guardians are willing to sign a data release consent form

4.6.2. Exclusion criteria

- Children with incomplete medical records.
- Children with repeated referral papers for the same individual.

4.7. Operational definition

- **Referral**: A process by which a health worker transfers the responsibility of care, either temporarily or permanently, to another health professional or social worker due to an inability or limitation to provide the necessary care.

- **Referring Unit**: A health service organization that initiates the referral process.

- **Receiving Unit**: A health service organization that accepts patients or clients from referring units, ensuring that the required care is provided and returning the patient with feedback.

- **Medical Tourism (MT)**: The process of traveling outside the country of residence for the purpose of receiving medical care; specifically, the practice of traveling abroad to obtain medical treatment.

- **Overall Survival (OS)**: The time from the date of first diagnosis to the date of last follow-up or death from any cause.

4.8. Data collection and measurements

A structured questionnaire was used to collect data from medical board abroad referral papers, as well as from patients' attendants, families, and caregivers, through phone calls lasting at least 10 to 15 minutes. The interviews focused mainly on the referral details outlined in the questionnaires, including patient status after the medical board summary, the referral process, reasons for not going abroad for treatment, and the medical/surgical interventions provided along with their outcomes and the current conditions of the patients.

Children with approved referral papers during the study period were enrolled in the study. A pilot test of the questionnaire was conducted with a sample of 10 patients. These subjects were not included in the study results. Findings from the pilot study were utilized to modify questions in the standard questionnaire. The questionnaire consists of socio-demographic information, diagnostic investigations, referral details, including outcomes after treatment, and the current condition of the patient.

4.9 Data handling

The collected data was cleaned, stored, and checked for completeness and internal consistency. Soft copies of the data were stored on the hard drive, and a backup copy was saved on separate drives. Hard copies of the data were also securely stored.

4.10 Study variables

4.10.1 Dependent Variables

- Patient Referral Status
- Outcomes in the Referred Country
- Current Patient Condition

4.10.2 Independent Variables

- Demographic data: patient Age, Sex,..
- Presenting conditions
- Diagnostic Investigations
- Primary Diagnosis
- Referral Details & recommendation.

4.11. Data Quality Assurance

During the data collection, regular and periodic checks were made in order to promote and confirm quality by the primary investigator. its completeness was checked and coded.

4.12. Data analysis and Interpretation

After data cleaning and entry, analysis was done using the Statistical Package for Social Sciences version 26 (SPSS). Descriptive and analytical statistics was used to summarize data. Tables and figures were used to present the results.

4.13. Ethical considerations

Ethical approval was obtained from the Pediatrics and Child Health Department's Research and Publications Committee of the School of Medicine, College of Health Sciences, and Addis Ababa University. Respondents were clearly informed about the purpose of the study and the information required from them. There was no risk or harm to the participants associated with the study. Participant confidentiality was assured.

4.14. Dissemination of Findings

The result of the study was presented on the research defense day and a formal report was submitted to the Department PCH. The research output will also be published on local or international peer reviewed scientific journals and will be shared with the hospital, governmental agencies to allow for improvements and to provide the essential supportive care for pediatric children who underwent abroad treatment.

5. Result

During the study period, a total of 359 children presented to the Medical Board, of which 61 cases (17%) involved internal medical board evaluations, while 298 cases (83%) were for treatment referrals abroad.. as shown in the figure below

Medical board related characteristics of the study participants

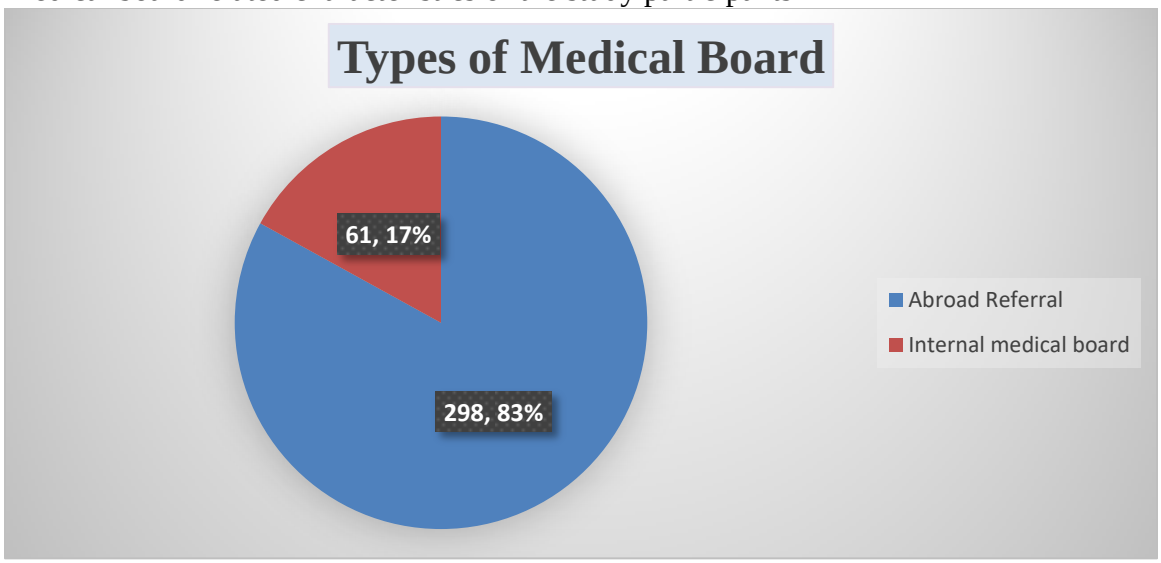

Figure 2 Types of Medical board characteristics of the study participants

Figure 2. Types of Medical board characteristics of the study participants

The current study focuses on abroad referral treatment (n=298).

Socio-demographic characteristics of the study participants:

The majority of the study participants were in the age group of 1-5 years, and 52.7% were male, resulting in a male-to-female ratio of 1.1:1. Notably, 94% of the participants had undergone imaging diagnosis, with chest X-rays accounting for 73.1% followed closely by echocardiograms (68.5%) of these imaging studies.

Table 1. sociodemographic characteristics of the Ethiopian Pediatric Patients Seeking Treatment Abroad

Table 1 sociodemographic characteristics of the Ethiopian Pediatric Patients Seeking Treatment Abroad

Variable	Frequency	Percent

Age		
<1	86	28.9
1-5	**103**	**34.6**
6-10	77	25.8
>10	32	10.7
Sex in years		
Female	141	47.3
Male	**157**	**52.7**
Present of imaging		
Yes	280	94
No	18	6
Types of imaging (n=280)		
Ultrasound	45	16.1
Chest x-ray	204	73.1
Echo-cardiogram	**191**	**68.5**
ECG	123	43.9
CT-scan	28	10
MRI	33	11.8
Others	12	4.3

Major of central tendency of the age of the study participants.

Statistics	
Age in months	
Mean	52.74
Std. Error of Mean	2.842
Median	39.00
Mode	72
Std. Deviation	49.068

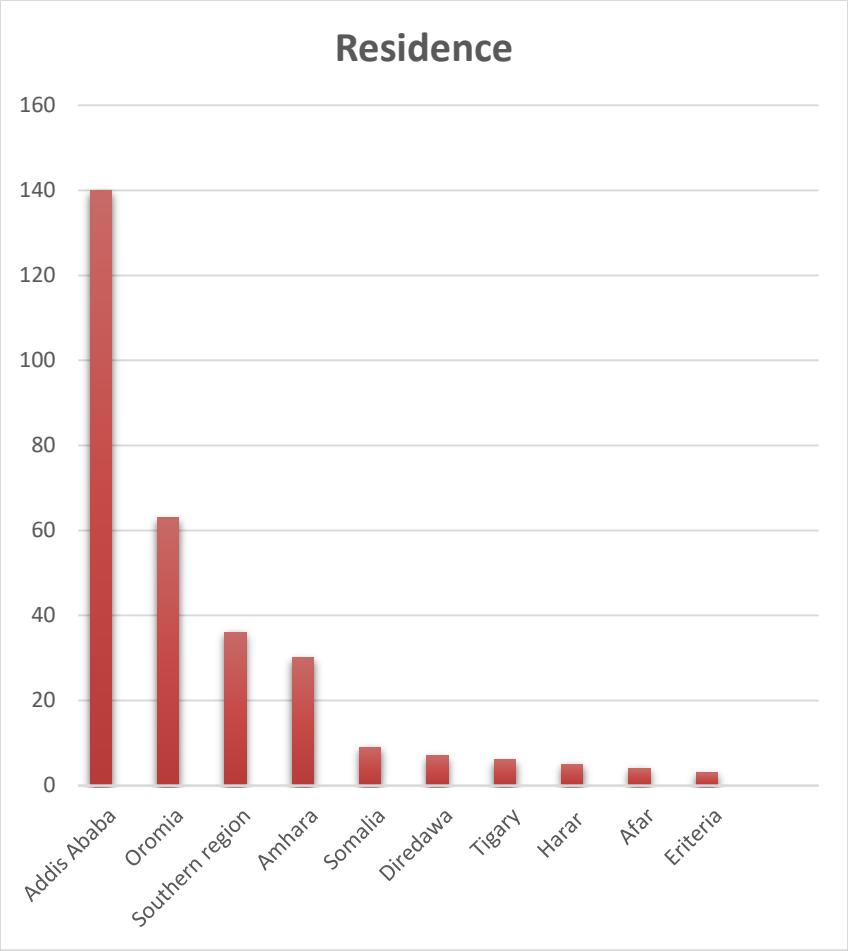

Figure 3 The study participants Residences

Figure 3.The study participants Residences

Primary diagnosis of study participants

The majority of the primary diagnoses among the study participants referred for treatment abroad were Congenital Heart Disease (CHD), followed by Relapses of Acute Lymphoblastic Leukemia (ALL). The detailed breakdown of these diagnoses is shown in the table below.

Table 2. The Primary diagnosis of study participants

Table 2 The Primary diagnosis of study participants

Primary diagnosis	Frequency	Percent
Cardiovascular diseases	**191**	**63.8**
CHD	**114**	**38.3**
Complex CHD	30	10.2

Down syndrome + CHD	23	7.8
Tetralogy of Fallot	7	2.3
MAM+CHD	5	1.7
AV block.	4	1.4
SEVERELY STUNTED+CHD	2	.6
Severe Valvular Aortic Stenosis	1	.3
A V-dissociation.	1	.3
Hypertrophic obstructive cardiomyopathy	1	.3
MAM+ Arrhythmia	1	.3
SCOA + HTN	1	.3
GDD +VHD	1	.3
Hematological-Oncologic diseases	**67**	**21.8**
ALL Relapses	**13**	**4.8**
Pancytopenia	12	4.5
Brain Tumor	3	1
AML relapse	3	1
Diamond Black fan Anemia	3	1
Left Eye Intraoccular Retinoblastoma	3	1
Neuroblastoma	2	.6
Non-Hodgkin's Lymphoma	2	.6
Ewing's sarcoma	2	.6
Aplastic anemia	3	1
Severe Allergy 2 ?	2	.6
RMS (Rhabdomyosarcoma	2	.6
Hodgkin Lymphoma	1	.3
Nasopharyngeal Carcinoma	1	.3
Hemophilia	1	.3
Wilms Tumor	1	.3
Right Humerus Ewing sarcoma.	1	.3
Juvenile myelomonocytic leukemia.	1	.3
Left orbital rhabdomyosarcoma	1	.3
Hemangioma	1	.3
Hepatoblastoma	1	.3
Non Rhabdoid sarcoma	1	.3
Osteogenic sarcoma	1	.3
Relapsed LCH	1	.3
Neurofibromatosis+ JMML	1	.3
Solitary lung metastasis	1	.3

Type A Thymoma	1	.3
hepato splenomegaly 2 to ?	1	.3
Massive Plural effusion 2 to ?	1	.3
GI diseases	**16**	**5.4**
CLD	5	2
IBD	3	1
Severe allergy	1	.3
Severe esophageal stricture	1	.3
Fulminant hepatitis A	1	.3
GAVE+ MWS	1	.3
Cholestatic jaundice	1	.3
Complicated Ulcerative colitis	1	.3
Intractable Diarrhea syndrome	1	.3
ALF	1	.3
Other diseases	**24**	**9**
Cerebral Palsy	6	2.2
Refractory seizure	3	1.2
Multiple Sclerosis	2	.7
CKD	1	.3
AKI	1	.3
Congenital pulmonary airway malformation	1	.3
Infantile Nephrotic syndrome	1	.3
Juvenile Myasthenia gravis	1	.3
Marfan syndrome and severe aortic root dilation	1	.3
Nephrotic Syndrome	1	.3
pectus excavatum + multiple joint heteroflexibility	1	.3
Progressive pulmonary fibrosis	1	.3
Renal Fanconi Syndrome	1	.3
SAM + Intellectual Disability + Quadriparesis Diffuse Cerebral	1	.3
Short stature secondary to ?	1	.3
Turner syndrome	1	.3
Total	298	100.0

Presenting condition characteristics

Most of the study participants presented with cardiac diseases, particularly Congenital Heart Disease (CHD), followed by Hematological-oncologic Diseases. This distribution of conditions is illustrated in the figure below.

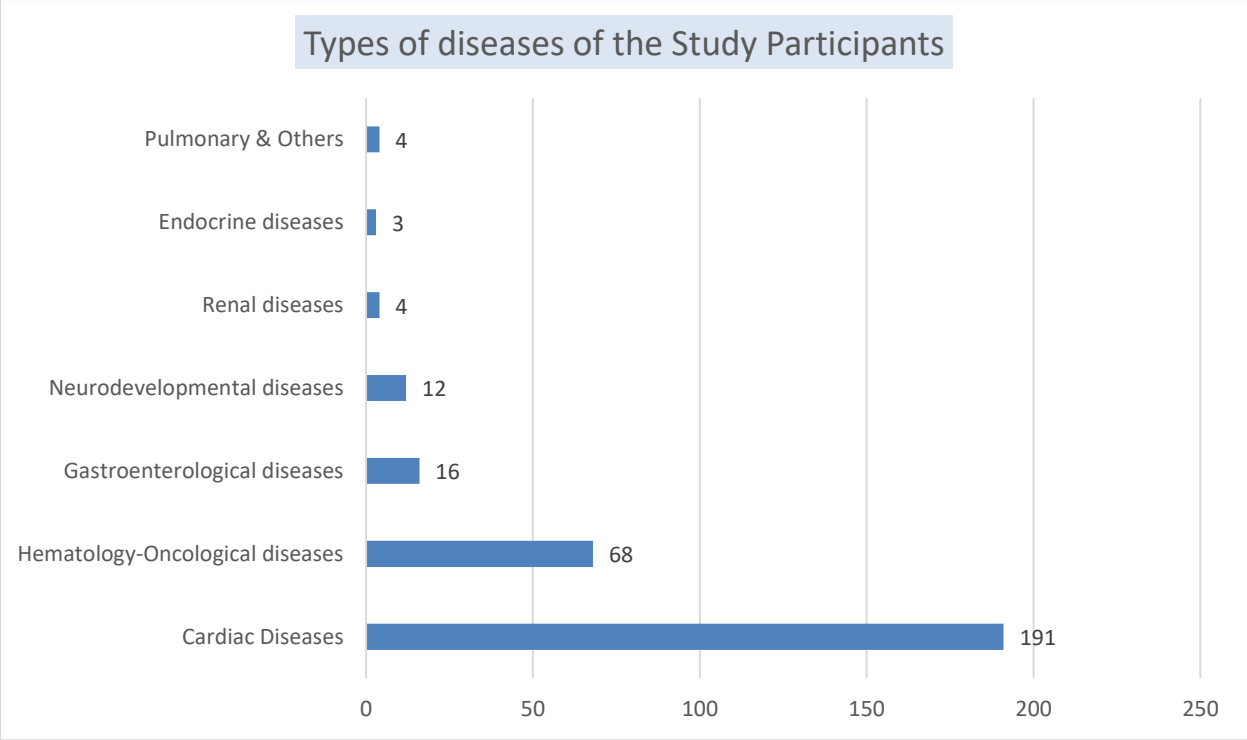

Figure 4 Types of diseases of the study participants

Figure 4. Types of diseases of the study participants

Trends of referral in the last three years

The study observed a notable increase in the number of referrals over the three-year period, with 79 referrals in the first year, rising to 101 in the second year, and reaching 118 in the third year. This upward trend demonstrates a growing recognition of the need for specialized treatment abroad. The trends are illustrated in the figure below.

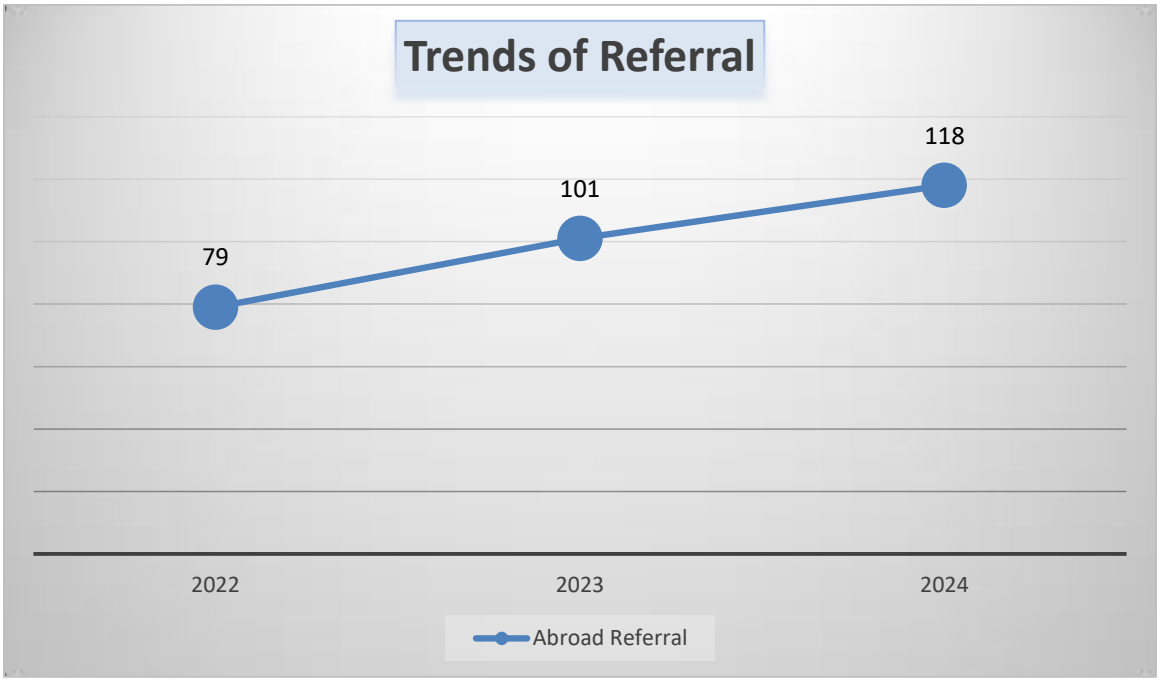

Figure 5 Referral related characteristics of the study participants

Figure 5. Referral related characteristics of the study participants

In this study, 298 participants were referred abroad for treatment, with 63.4% of these referrals for surgical interventions. Notably, 92.9% of the referrals were initiated by both caregivers and treating physicians, emphasizing the collaborative decision-making process. Additionally, 63.8% of the referred cases originated from the cardiac unit, indicating a significant need for specialized cardiac care.

Table 3. Referral related characteristics of the study participants

Table 3 Referral related characteristics of the study participants

Variable	frequency	Percent
Abroad Referral	298	100
Reason for aboard referral (n=298		
Surgical Management	190	63.4
Hematopoietic stem cell transplant	36	12.1
Neurosurgery	3	.9
Organ transplant	12	4
Pre-cardiac catheterization with possible surgery	20	6.7
Balloon valvuloplasty	4	1.3
Others	33	11.4
Request treatment to abroad made by (n=298)		
caregiver and treating physician	277	92.9
Caregiver	6	2
Treating physician	15	5.1
Presenting Unit of Pediatric Department for Abroad Referral (n=298)		
Cardiology	190	63.8
Gastroenterology	16	6
Hemato-oncology	67	21.8
Nephrology	5	1.7
Neurology and Developmental Clinic	13	4.4
Pediatric endocrinology	3	1
Others (Chest clinic..	4	1.3

Recommendations of the referral

The majority of the medical board's recommendations for abroad referrals focus on surgical management, followed by pre-cardiac catheterization and hematopoietic stem cell transplantation (HSCT). This is illustrated in the table below, which highlights the frequency and percentage of different treatment recommendations.

Table 4. Referral recommendation of the Treating physician

Table 4 Referral recommendation of the Treating physician

Recommendation for Abroad referral Treatment	Frequency	Percent
Surgical Management	**190**	**63.4**
Cardiac Surgical management	126	42.3
Pre-cardiac Catheterization and possible surgical	51	17.1
Balloon valvuloplasty	7	2.3
Balloon pulmonary valvuloplasty	2	.6
AVSD closure	1	.3
Corrective cardiac surgery	1	.3
Down syndrome + large perimembraneous closure	1	.3
hyperthrophic obstructive cardiomyopathy	1	.3
Other Cardiac Intervention	**6**	**2**
Pace maker insertion	4	1.3
EPS study and radiofrequency ablation intervention	2	.67
Transplantation	**46**	**15.4**
Hematopoietic stem cell transplantation	36	12.1
Liver transplant	7	2.4
Renal transplantation	2	.6
Lung transplantation.	1	.3
Other Surgical Intervention	**18**	**6.4**
PET-Scan and subsequent management	6	2
Palliative Surgical procedures	3	1
Neurosurgical Intervention	2	.6
Reconstructive surgery	2	.6
Maximal resection of the tumor	1	.3
Limb salvage surgery	1	.3
Medical evaluation and possible Surgical repair	1	.3

Kidney biopsy	1	.3
Radiation and possible excision.	1	.3
Medical Management and Therapies	**14**	**4.7**
Multidisciplinary management	4	1.3
Gastroenterologist unit (Inx and auto antibodies management	2	.6
Growth hormone treatment	2	.6
Lifelong hormonal replacement therapy	1	.3
Multiple superficial ulcers extending upto the transverse colon with Adenomatous polyps	1	.3
Chronic dialysis	1	.3
Beneficial medical therapies	1	.3
Better gross motor functioning and better inclusive education programs	1	.3
Specialized medical treatment.	1	.3
Investigations and Evaluations	**20**	**6.8**
Investigation	7	2.4
Investigation and treatments	3	1
Confirmation of diagnosis and treatment.	1	.3
Diagnostic work up	1	.3
Investigation and surgical correction	1	.3
Genetical assay	1	.3
Inhibitors diagnosis	1	.3
Intestinal transient time	1	.3
Hemodynamic evaluation	1	.3
Hypoglycemia provocation test and nuclear scan	1	.3
Molecular testing	1	.3
Skeletal survey.	1	.3
Other Recommendations	**4**	**1.3**
physical therapy interventions	2	.6
red cells transfusion	1	.3
treatment completion	1	.3
Total= Abroad referral treatment recommendations	298	100.0

Figure 6. Professional status of involving in medical aboard

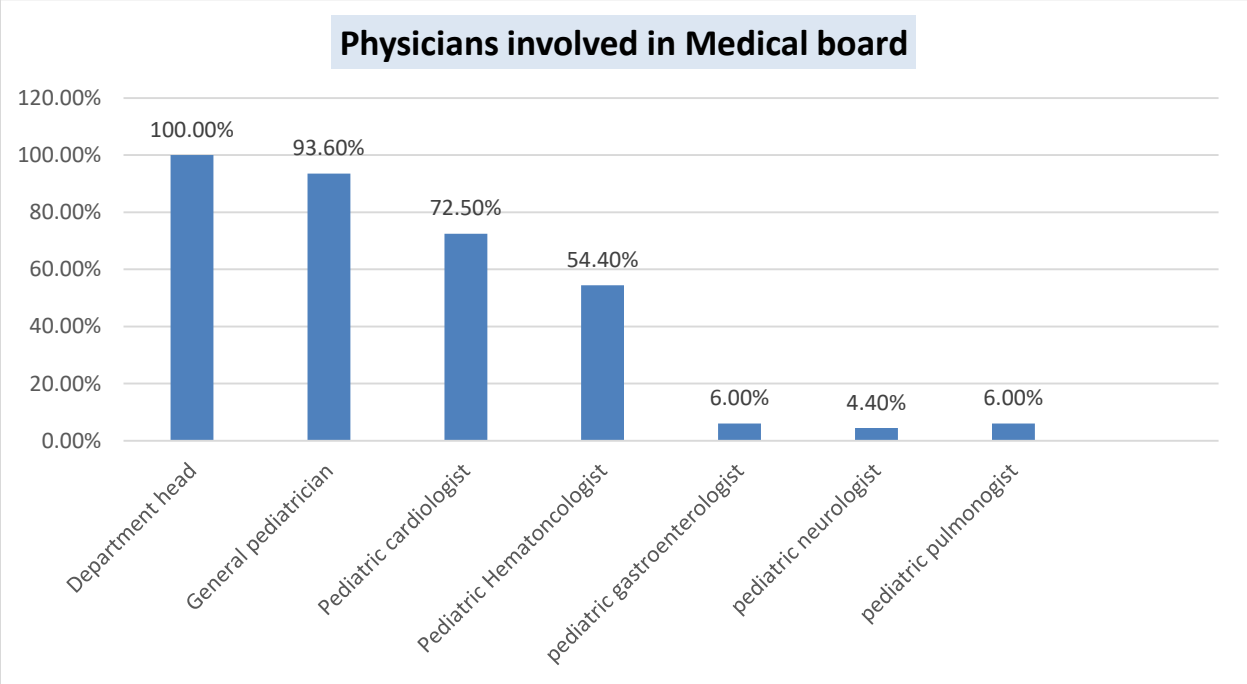

Figure 6 Professional status of involving in medical aboard

Patient status & medical abroad related characteristics of the patients

This analysis provides critical insights into the status of Ethiopian pediatric patients following medical board evaluations:

- 54% of patients sought treatment abroad, with 70.2% of these in India. 95% of those treated abroad returned alive, though 5% died during treatment outside the country. Current Status of Patients: Overall, 64.1% of patients are currently alive, while 15.1% have died during the process. 20.8% of patients have unknown outcomes,

Table 5. Patient status and medical related characteristics of the study participants.

Table 5 Patient status and medical abroad related characteristics of the study participants.

Variable	frequency	Percent
Patient Status After Medical Board Summary (n=298)		
Did not go	45	15.1
Died while processing	30	10.1
Unknown	62	20.8
Went Abroad	161	54
Place of abroad country(n=161)		
India	113	70.2
Israel	21	13
Italy	1	0.6
Romania	1	0.6
Saud Arabia	1	0.6
Spain	4	2.5
Sweden	3	1.9
Turkey	5	3.1
Uganda	1	0.6
USA	11	6.8
Reasons for not going abroad after the medical board summary (n=45)		
Financial constraint	32	71.1
VISA issue	13	28.9
Outcome in the referred country (n=161		
Came back alive	153	95
Died there	8	5
Current patient status (n=298		
Alive	191	64.1
Died	45	15.1
Unknown	62	20.8

Figure 7 Place of Abroad country

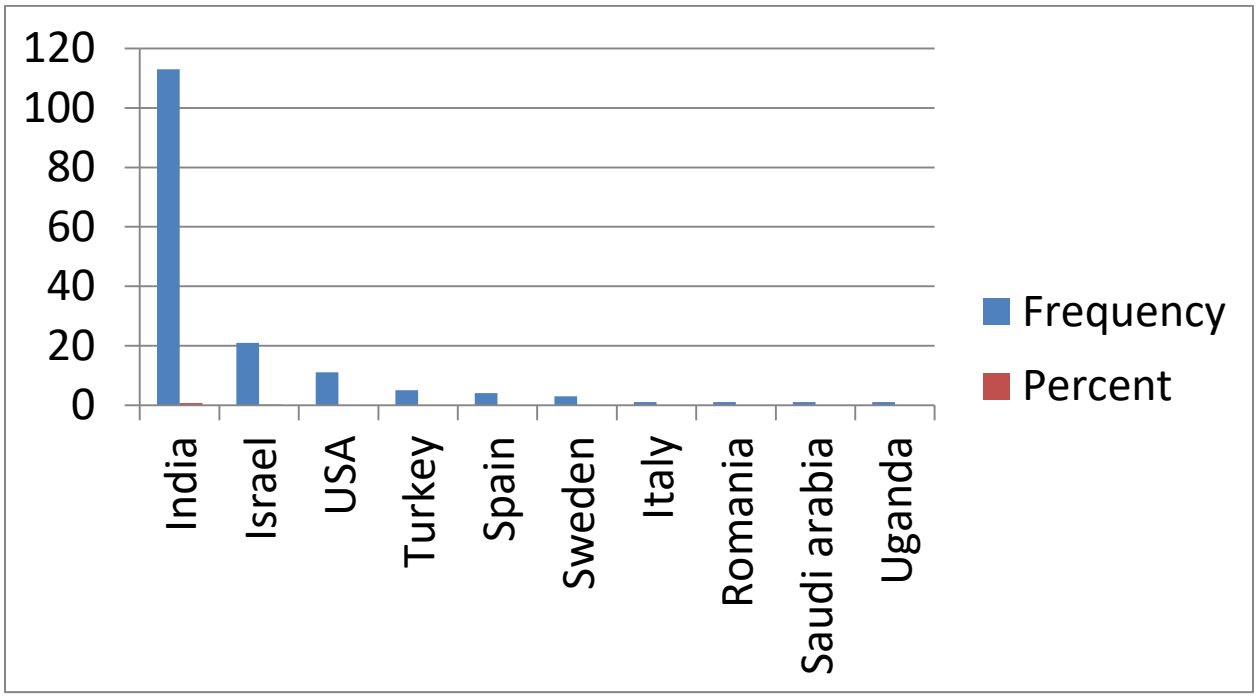

Figure 7 Place of Abroad Country

Table 6. The average activity of medical board in weeks, months and years

Table 6 The average activity of medical board in days months and years

Average activity of Medical board	Average numbers
Average number of patients presented per medical board	2
Average number of medical boards conducted per month	6
Total Number of Medical Boards Conducted Over the Last three Years	203
Per year number of attending in medical board	69

6. Discussion

This cross-sectional study assessed the trends and referral patterns of Ethiopian pediatric patients seeking treatment abroad over three years at Tikur Anbessa Specialized Hospital (TASH). The findings reveal critical insights into the significant reliance on international healthcare services, particularly for conditions such as congenital heart disease (CHD) and childhood cancers. This reliance aligns with existing literature indicating that developing countries like Ethiopia face substantial challenges in providing adequate healthcare services domestically. (1,2,4,7,24)

The retrospective cross-sectional methodology employed in this study, covering the period from 2022 to 2024, allowed for a comprehensive assessment of demographic characteristics, diagnoses, and outcomes associated with pediatric referrals. The sample size of 298 cases provides robust statistical power, enabling a reliable analysis of referral trends. The data indicate that the majority of participants were aged 1-5 years, with a slightly higher prevalence in males (52.7%). CHD emerged as the most common diagnosis among referred patients, corroborating existing literature that emphasizes the high burden of congenital conditions in low- and middle-income countries (LMICs) (13). Relapses of Acute Lymphoblastic Leukemia (ALL), the second most common diagnosis, reflects an urgent need for specialized oncological care, consistent with findings suggesting a rising incidence of childhood cancers in resource-limited settings (6). Notably, 63.8% of referrals originated from the Cardiac Unit, underscoring the broader global issue of disproportionately high burdens of surgically treatable pediatric conditions in LMICs (4,5).

Over the study period, referrals for treatment abroad increased significantly, growing from 79 cases in 2022 to 118 cases in 2024. Evaluating the types of diseases by specialty further emphasizes the demand for investment in pediatric healthcare services, as many referrals are driven by a lack of specific medical expertise and facilities within the country. The increasing referral rates observed in the study further highlight the urgent need for enhanced local capacity to manage these conditions effectively. Which is supported by other studies, A significant portion of childhood mortality from treatable conditions occurs due to inadequate access to necessary surgical and medical interventions (6,7).

Despite the strong findings, it is noteworthy that 20.8% of cases had unknown outcomes, highlighting a critical gap in follow-up care that can hinder a comprehensive evaluation of treatment effectiveness (28). This gap aligns with findings in other studies, emphasizing the importance of tracking patient outcomes to evaluate the efficacy of referrals and the quality of care provided (12,13). The lack of follow-up complicates understanding treatment efficacy and underscores the necessity for robust tracking systems to monitor patient care pathways. Effective follow-up protocols are essential for ensuring all patients receive the necessary support throughout their healthcare journey (9).

The implications of this study extend beyond TASH; policymakers and the Ministry of Health must recognize the urgent need for financial investment in healthcare infrastructure. As the population in Ethiopia continues to grow, the demand for pediatric healthcare services will correspondingly increase (14). Without proactive measures to strengthen local healthcare capabilities, the country risks perpetuating a cycle of referrals that strain financial resources and compromise patient safety and outcomes (15,16). The study's findings guide policy reforms aimed at establishing specialized facilities within Ethiopia for managing conditions like CHD and childhood cancers. Improving local healthcare capabilities can significantly reduce reliance on international referrals and enhance health outcomes (2).

Moreover, the study identified healthcare availability as a critical determinant influencing decisions to seek treatment abroad, with families compelled to look for treatment outside their home countries due to inadequate local resources. This aligns with previous research indicating that cost and access to specialized care significantly impact health-seeking behavior. Addressing these challenges through enhanced local services, by empowering local healthcare providers with the necessary skills, resources, economic support is crucial for effectively managing complex conditions and reducing the need for international referrals, which is supported by other studies in LMICs. (4,5,12,15,16,17,18,27,28,29)

7. Conclusion & Recommendation

This study provides vital insights into the trends and referral patterns of pediatric patients in Ethiopia, highlighting the urgent need for enhanced local healthcare services. The observed demographic trends, increasing referral rates, and specific factors influencing these referrals emphasize systemic gaps in pediatric care within the country.

Trends over the past three years indicate a steady increase in pediatric referrals abroad, particularly for congenital heart disease (CHD) and childhood cancers. This underscores the necessity for local healthcare infrastructure to provide specialized medical interventions that are often unavailable domestically. Despite a high return rate of patients (95% returning alive), the significant 15.1% mortality rate during treatment raises critical concerns regarding the quality of care received abroad. Furthermore, the 20.8% of cases with unknown outcomes represents a substantial gap in data that limits our understanding of the overall effectiveness of these referrals. This lack of follow-up information not only hinders the assessment of treatment success but also signals potential deficiencies in post-referral care systems.

To address these issues, policymakers should invest significantly in local healthcare infrastructure to ensure that pediatric facilities can provide comprehensive and specialized care. This includes establishing centers of excellence for the management of CHD and other pediatric conditions to reduce the need for international referrals. Additionally, creating financial assistance programs can support families in accessing local treatment options, thereby reducing reliance on international referrals.

This study serves as a call to action for the Department of Health and the Addis Ababa Health Bureau to prioritize pediatric healthcare development in Ethiopia, ensuring that children receive timely and adequate care within their home country. Ongoing research and robust follow-up mechanisms are essential for monitoring the long-term impacts of these interventions on health outcomes and overall healthcare accessibility for pediatric populations. Collectively, these efforts can contribute to a more robust pediatric healthcare system in Ethiopia, ultimately enhancing the quality of life for children across the nation.

Recommendations for Policymakers and Ministry of Health

1. **Strengthening Local Health Infrastructure:**
   Investment in specialized pediatric care facilities within Ethiopia is crucial. Allocate funding to enhance the infrastructure of TASH and similar facilities, ensuring they are equipped to handle specialized pediatric cases effectively.

2. **Enhancing Follow-Up Care:**
   Development of robust patient tracking systems is essential to monitor outcomes post-referral. Implementing follow-up protocols can facilitate a better understanding of treatment effectiveness and patient prognosis, addressing the significant gap of unknown outcomes.

3. **Training and Capacity Building:**
   Training more pediatric specialists and healthcare providers in complex medical conditions can help reduce reliance on treatment abroad. This can be achieved through partnerships with international institutions and training programs.

4. **Health Policy Reforms:**
   Policymakers should prioritize pediatric health in the national health agenda, ensuring that funding is allocated to improve access to essential surgical and medical treatments domestically. Policy reforms should aim to establish specialized facilities for managing conditions like CHD and Childhood cancers within Ethiopia, promoting local healthcare improvements over dependence on medical tourism.

5. **Collaboration with NGOs and International Bodies:**
   Collaborating with non-governmental organizations and international health bodies can enhance resource availability, facilitate knowledge transfer, and support ongoing healthcare initiatives aimed at improving pediatric health outcomes.

6. **Community Awareness and Support Programs:**
   Developing community support programs can help families navigate the healthcare system and understand the importance of early diagnosis and intervention for conditions like CHD and childhood cancers. Launch campaigns to educate families about available local services and the importance of seeking care within the country, thereby reducing the stigma associated with local treatment options.

In conclusion, while this study sheds light on the complex landscape of pediatric referrals in Ethiopia, it also highlights the pressing need for systemic improvements to ensure that children receive necessary and timely care within the country. By focusing on local capacity building and effective follow-up care, Ethiopia can significantly enhance health outcomes for its pediatric population.

8. Strength & Limitation of Study

This study represents pioneering research in pediatric referrals within Ethiopia, addressing a critical knowledge gap in this area. By utilizing a substantial dataset from Tikur Anbessa Specialized Hospital, the research enhances the statistical power of its findings and provides valuable insights into referral patterns. Analyzing data from 298 pediatric patients, the study offers a solid statistical foundation for drawing conclusions about referral trends. The retrospective cross-sectional design presents a comprehensive snapshot of these patterns, informing potential improvements in healthcare services. Comprehensive data collection, achieved through medical board records, referrals, and interviews with attendants or families, facilitated an in-depth analysis of patient demographics, diagnoses, and referral details. The study highlighted key trends, particularly in referrals for congenital heart disease (CHD) and childhood cancers, contributing valuable knowledge to the understanding of healthcare access issues in Ethiopia. Furthermore, by focusing on unknown outcomes and specific demographics, it illuminated significant gaps in follow-up care, underscoring the urgent need for enhanced pediatric healthcare services.

However, this study is not without its limitations. The focus on data from a single institution may limit the representativeness of the findings for pediatric patients seeking care across the country. Additionally, the retrospective nature of the study may introduce inconsistencies stemming from varying record-keeping practices. Potential reporting bias exists, as the accuracy of the medical board's summaries and classifications could influence the assessment of disease types and referral reasons. Furthermore, the lack of follow-up information on long-term outcomes for patients post-treatment restricts the evaluation of referral effectiveness. External factors, such as changes in health policies and socioeconomic variables impacting healthcare access, may not be fully accounted for, limiting the contextual understanding of the findings.

Despite these limitations, this study serves as a foundational work that paves the way for future research and improvements in pediatric healthcare in Ethiopia, highlighting the urgent need for continued exploration and development in this critical area.

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Annex: Questionnaire
Date: _____
Number: _____

Patient Demographics

1. **Name: _____**
2. **Age: _____** (in years)
3. **Sex:**
    - Male
    - Female
4. **Medical Record Number (MRN): _____**
5. **Address/Phone Number: _____**
6. **Caregiver Name: _____**
7. **Presenting Condition:**
    - Cardiac Emergency
    - Oncologic Emergency
    - Other (please specify): _____
8. **Date of Medical Board (DD/MM/YY): _____**

Diagnostic Investigations

9. **Was any imaging performed?**
    - Yes
    - No
10. **If yes, what imaging modality was performed?** (Select all that apply)

- A. Ultrasound
- B. Chest X-ray (CXR)
- C. Echocardiogram (ECHO)
- D. CT Scan
- E. MRI
- F. Other (please specify): _____

11. **Primary Diagnosis: _____**
12. **Type of Medical Board:**

- A. Internal Medical Board
- B. Abroad Referral

Referral Details

13. **Reason for Referral:**

- A. Cardiac Surgery
- B. Hematopoietic Stem Cell Transplant (HSCT)
- C. Neurosurgery
- D. Organ Transplant
- E. Other (please specify): _____

14. **Request for Treatment Abroad Made By:**

- A. Attending Physician
- B. Treating Physician
- C. Caregiver

15. **Presenting Unit of Pediatric Department for Abroad Referral:**

- A. Cardiology
- B. Gastroenterology
- C. Hemato-Oncology
- D. Nephrology
- E. Neurology
- F. Pediatric Endocrine
- G. Pediatric Surgery
- H. Pulmonology & Critical Care

16. **Recommendations from Medical Board:** _____
17. **Complete Diagnosis:** _____
18. **Participants of Medical Board:** (Select all that apply)

- A. Department Head
- B. Pediatric Cardiologist
- C. General Pediatrician
- D. Pediatric Hemato-Oncologist
- E. Pediatric Nephrologist
- F. Pediatric Pulmonologist & Critical Care
- G. Other (please specify): _____

19. **Patient Status After Medical Board Summary:**

- A. Went Abroad
- B. Did Not Go
- C. Died While Processing
- D. Unknown

20. **If the answer to Q19 is A, which country did they go to for treatment?**

- A. India
- B. Israel
- C. Turkey
- D. USA
- E. Other (please specify): _____

21. **If the answer to Q19 is B, reasons for not going abroad after the medical board summary:**

- A. Financial Constraints
- B. Visa Issues
- C. Other (please specify): _____

22. **Outcomes in the Referred Country:**

- A. Came Back Alive
- B. Died There

23. **Current Patient Condition:**

- A. Alive
- B. Deceased
- C. Unknown

24. **Average Number of Patients Presented per Medical Board: _____**
25. **Total Number of Medical Boards Conducted per Month Each Year: _____**
26. **Total Number of Medical Boards Conducted Over the Last Five Years: _____**