ORIGINAL RESEARCH ARTICLE

Socioeconomic and Demographic Predictors of Parental Awareness in a Clinical Cohort of Congenital Heart Disease in India

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Abstract

Background Congenital heart disease is the most prevalent congenital disorder all over the world and leads to the death of infants in India. Socioeconomic and demographic factors contribute to the inequality of congenital heart disease outcomes despite the improvements in the accuracy of the diagnostic procedures and surgical interventions. The objective of the research was to determine the influence of parental education level, household income, residence, and awareness on early diagnosis, surgical treatment, and the postoperative process of pediatric patients with congenital heart disease.

Methods A retrospective study design was used to study the data of 996 children with structural congenital heart disease who were treated at a tertiary care center. The delay in diagnosis and low knowledge of congenital heart disease were identified as predictors with the help of multivariate logistic regression.

Results Low maternal education (OR: 3.67, $p < 0.001$), low household income (OR: 2.53, $p = 0.014$), and rural residence (OR: 1.69, $p = 0.006$) were significant predictors of lack of awareness regarding antenatal detection of congenital heart disease at 18-20 weeks. Even though 61.6% of patients received single-stage surgery, 81.7% had the option to follow up after surgery. The level of awareness of prenatal detectability of congenital heart disease amounted to 11.05% of the parents.

Conclusion Socioeconomic and geographic disparities are some of the factors in the delay of congenital heart disease diagnosis and surgical treatment. The incorporation of congenital heart disease screening awareness into antepartum programs, increased coverage under insurance plans, and multilingual communication methods are key to improving pediatric cardiac outcomes in India.

Keywords Cardiac surgical procedures, Congenital heart disease, India, Prenatal care, Socioeconomic factors

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1 Introduction

The most commonly occurring birth defect is congenital heart disease (CHD) in the world; CHD also accounts for one of the significant causes of newborn and infant morbidity and mortality. CHD is a disorder that is presently estimated to occur in nearly 9 in every 1000 live births globally. However, rates of this disorder vary across regions due to differences in diagnostic practices, access to medical care, and other sociodemographic factors.[1,2] In India, where the population size is about 16 percent of the world population, the prevalence of CHD was estimated to be between 8 and 10 per thousand live births. As such, it poses a big public health challenge.[3] An increase in CHD has been reported as an important source of residual infant death in low- and middle-income countries (LMICs), as neonatal mortality rates have stabilized in response to efforts to treat infectious causes and perinatal mortality.[4,5]

The burden of CHD is on the rise concerning awareness, but a significant challenge to timely diagnosis and management still exists in resource-limited conditions.[6] The significance of early identification through antenatal ultrasonography, typically performed at 18-20 weeks of gestation, lies in its ability to facilitate planned intervention or even termination of pregnancy in cases of severe deformities.[7] Nonetheless, CHD awareness in India is very low, which poses a worrying situation with a severe regional and socioeconomic gap.[8] Findings of both Indian and international studies point to the fact that maternal education, household economic status, CHD awareness among parents, home location, and adequate insurance strike a decisive note in where CHD is easily detected and treated at an early age.[9-11]

It has also been identified by research studies in the northern and central parts of India that children born in low-income or rural families are much less likely to have any kind of antenatal scan or any surgical intervention in time.[12,13] Further, it was found that maternal literacy is positively correlated with greater health-seeking behavior, more follow-ups, and better neonatal outcomes.[14] In eastern China, a cross-sectional study revealed that neighborhood-level poverty and maternal education act independently in determining the prevalence of CHD at birth;[15] the same has been validated across sub-Saharan Africa and Latin America, with postnatal outcomes proving to be even worse when children with CHD belong to a socioeconomically disadvantaged setting.[16]

This abundance of information is accompanied by a scarcity of Indian studies that directly investigate the correlation between sociodemographic determinants of CHD presentation at the time of diagnosis. Most of the available literature is either on clinical outcomes after the intervention or on overall prevalence rates in the country, with no disaggregation by education level, income group, access to insurance, or rural-urban residence.[17] This leaves major gaps in knowledge, especially regarding the parental decision-making process after an antenatal diagnosis and the structural inequities in access to diagnostic care.

To fill these gaps, the current study investigates the effects of socioeconomic and demographic variables, i.e., parental education level, income level, place of residence, and CHD awareness, on the diagnosis of congenital heart disease in India. Based on an observational study conducted in a tertiary care facility, the study attempts to gain a subtle insight into the role of social determinants of disparity in the detection and early management of CHD.

The hypotheses are that maternal education, household income, rural living, and poor CHD awareness are substantially linked to late diagnosis and low access to prompt surgical intervention. The research will be used to guide specific policy measures and to facilitate fair access to pediatric cardiac care nationwide. To accomplish this goal, a retrospective hospital-based study of children with structural CHD was conducted, in which significant demographic factors were discussed according to CHD awareness, diagnostic process, and surgical outcomes.

2 Methods

This study aimed to explore how socioeconomic and demographic factors influence the clinical distribution and early detection of CHD among pediatric patients at a tertiary care hospital in India. It used a retrospective, observational study design and adhered to ethical guidelines approved by the institutional review board.

Study Design

It was a retrospective observational study conducted at a tertiary-level pediatric cardiac center in India. The study period was from January 2022 to January 2023. As the study was based on retrospective survey data, the Institutional Ethics Committee granted a waiver of approval, and all procedures were conducted in accordance with the Declaration of Helsinki (1975, revised 2013). Data collection started with written informed consent from all the participating parents or legal guardians. This was done for illiterate parents or guardians, in line with ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2017; Section 5). The process involved verbal explanation of the participant information sheet and consent form in simple local language, documentation via thumb impression, and mandatory presence of a literate impartial witness throughout to confirm understanding and voluntariness.

Study Population and Eligibility Criteria

The study involved 996 children who were diagnosed with CHD based on the results of two-dimensional echocardiography during the period of the study. The demographics and socioeconomic backgrounds of these patients were diverse, allowing for comprehensive analysis.[18]

Children were eligible for inclusion if they:

- Had a confirmed structural congenital heart defect.
- Were under 18 years of age at the time of diagnosis.
- Had complete demographic, clinical, and socioeconomic information available.

Exclusion criteria included:

- Children with acquired heart conditions (e.g., myocarditis, rheumatic heart disease).
- Missing or incomplete core demographic and socioeconomic data (e.g., at minimum: residence urban/rural, parental education level, or income category).
- Children referred late beyond 5 years of age (or beyond early childhood, e.g., > 2–3 years) without any antenatal/early information.

Data Collection

Face validity of the structured questionnaire was assessed by an expert committee comprising a pediatric cardiologist and an epidemiologist. After that, the data were collected using a structured questionnaire administered to parents during outpatient and inpatient visits. Clinical reports were also consulted to obtain the data regarding diagnosis, gestational age, and intervention status. All interviews were conducted by trained research personnel in participants' preferred language to ensure accuracy and cultural sensitivity.[19]

The key variables recorded included:

- Parental education: stratified as illiterate, primary, secondary, graduate, and postgraduate.

Household income: categorized as low (< ₹50,000/year), middle (₹50,000–100,000/year), and high (> ₹100,000/year).

- Residential location: classified as village, town, or city.
- Insurance coverage: grouped into public, private, or out-of-pocket/self-funded.
- CHD awareness was operationally defined as parental knowledge of the possibility of detecting congenital heart defects during the routine 18–20-week anomaly scan, as this represents a critical and under-utilized opportunity for early identification in the Indian setting. While broader aspects of health literacy (e.g., recognition of postnatal cardiac symptoms) are important, they were beyond the primary scope of this study, which focused on antenatal care disparities. It also included questions on decision-making regarding continuation or termination of pregnancy if CHD was diagnosed.
- Clinical parameters: gestational age, type of surgical intervention (single vs. complex), and pre/post-operative status.

All information was coded before input and kept under lock and key.

The flowchart below describes the study's methodological framework, including the study design, inclusion/exclusion criteria, data sources, and the major steps of the analysis. It describes how the 996 cases of CHD in children were chosen and how statistical analysis was conducted to evaluate the influence of the sociodemographic factors on CHD awareness and access to treatment. Figure 1 shows the retrospective design and the method of data collection, structured using questionnaires and clinical records. It also describes the analysis of the variables using descriptive statistics and regression models to determine the important associations.

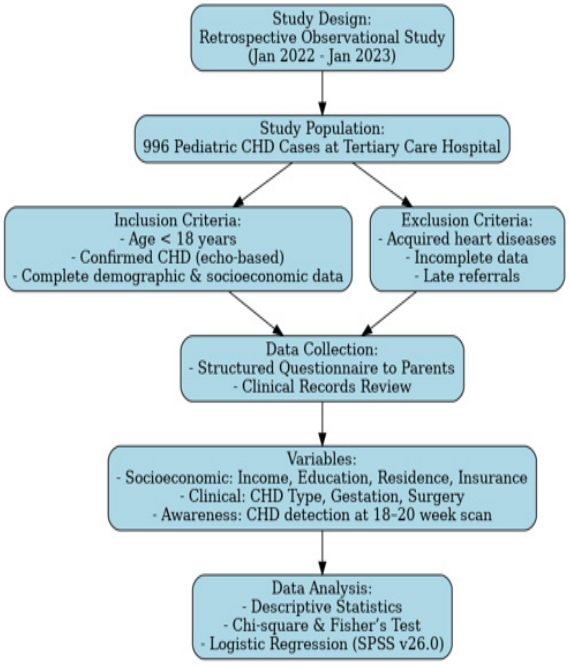

Figure 1 Flowchart of methodology that shows the participant selection, data collection, and analysis stages

Statistical Analysis

The data analysis was performed using IBM SPSS Statistics version 26.0. All the demographic, clinical, and socioeconomic variables were obtained as descriptive statistics. The categorical variables were reported as frequencies and percentages, whereas the continuous variables were reported as mean ± standard deviation. The Fisher's Exact Test and the chi-square test were used to conduct bivariate analyses to examine relationships among variables such as income level, education, and

CHD awareness. Due to the very small sample size in the high-income group (n = 6), this category was merged with the middle-income group for regression analysis to maintain statistical validity and avoid sparse data bias. To assess individual predictors of awareness of CHD during pregnancy and choice of termination, binary logistic regression was used. Adjusted odds ratio (OR) and confidence interval (CI) of 95% were reported. Although CHD subtype (cyanotic vs. acyanotic) is an important clinical confounder, it was not included in the regression model due to incomplete and inconsistent documentation in retrospective records, which could have reduced statistical power and introduced bias. A p-value < 0.05 was considered significant.

3 Results

This study analyzed 996 children with CHD to assess the effect of socioeconomic and demographic factors on early diagnosis and treatment. Tables and figures are incorporated into the thematic areas to make them easier to read and scientifically obvious.

Demographic and Socioeconomic Distribution

The demographic and socioeconomic context of the families with CHD is a crucial factor to obtain the context of understanding the disparities in healthcare access and awareness. The subsection describes the income levels and residential distribution of the families included in the study. The following baseline characteristics are essential for the analysis of associations with awareness of CHD in the antenatal period, treatment-seeking behavior, and outcomes.

Most of the children with CHD (60.15%) were in low - income families, whereas only 0.61% of them were in high - income families, showing a high socioeconomic bias. Regarding residence, a similar number of children lived in urban (38.66%) and rural (37.05%) environments, with fewer living in towns (24.30%). This allocation shows that CHD is common across all environments, although socioeconomic vulnerability is higher among low-income families (Table 1).

Parental Education and Surgical Trends

Parental education is one of the determining factors for health awareness, early diagnosis, and decision-making in pediatric diseases such as CHD. In this subsection, we show the educational level of both mothers and fathers in order to have an idea of the literacy status of the population being studied. This information helps contextualize subsequent conclusions about antenatal awareness of CHD, reactions to diagnosis, and the availability of treatment options, such as surgical treatment.

The educational level among mothers was dominated by those with only primary (40.27%) or secondary (35.25%) education; the percentages of graduates (11.05%) and postgraduates (0.81%) were very low. Fathers, on the other hand, were slightly better educated: 25.71% were graduates and 2.01% were postgraduates. The lack of educational differences between mothers and fathers can also affect family-specific health choices, especially regarding early CHD screening and understanding of medical advice (Table 1).

Table 1 Distribution of patients by income, residence, and education, and high-income group category merged with the middle-income group for regression analysis

Variable	Category	n (%)
Income group	Low	599 (60.15)
	Middle	391 (39.26)
	High	6 (0.61)
Residence	Village	369 (37.05)
	Town	242 (24.30)
	City	385 (38.66)
Education (mother)	Illiterate	126(12.66)
	Primary	401(40.27)
	Secondary	351(35.25)
	Graduate	110(11.05)
	Postgraduate	8(0.80)
Education (father)	Illiterate	49(4.92)
	Primary	272(27.31)
	Secondary	399(0.07)
	Graduate	256(25.71)
	Postgraduate	20(2.01)

CHD Awareness and Termination Preferences

CHD awareness was defined as parental knowledge of the potential to identify congenital heart defects during the 18–20-week anomaly scan. This sensitization is crucial in early prevention and decision-making in pregnancy. This sub-section provides information on the number of parents who were notified about the possibility of detecting CHD through the regular second-trimester scan and the way they felt about continuing or stopping the pregnancy in case CHD was detected before the birth. Such indicators play a decisive role in assessing the effects of CHD awareness on reproductive and health care decisions.

The statistics indicate that 11.05% of parents showed awareness of CHD, which implies a significant lack of prenatal health education. Of those who were aware, 50.51% said they would consider terminating the pregnancy in case of CHD, while 43.68% were willing to carry to term; the remaining 5.83% showed a high termination rate in parents who are aware, which could be due to fears of long-term prognosis, treatment costs, or availability of specialized cardiac care (Table 2).

Table 2 Antenatal CHD Awareness and termination response

Question	Yes (%)	No (%)	Don't Know (%)
Aware of CHD during anomaly scan (18–20 weeks)	11.05	88.96	–
Willing to terminate pregnancy upon CHD detection	50.51	43.68	5.83

Health System Coverage and Access

The issue of health insurance coverage is very important in defining the ability of families to receive timely diagnosis and treatment of CHD. This subsection presents the numbers of insurance types among CHD-affected families, highlighting inequalities in financial security and access to care.

Figure 2a shows the proportion of families with children affected by CHD according to the type of health insurance they have, namely public, private, and self-funded coverage. It provides details on the financial dynamics involved in accessing pediatric cardiac care. It also shows that the most prevalent type of insurance among families affected by CHD was public insurance, with 52.5% of families covered by it. Nevertheless, 29.2% were self-financed, meaning almost a third of families had to shoulder the financial burden themselves. Only 18.3% were privately insured, which highlights the lack of access to high-quality healthcare. The observations indicate that although public health care coverage helps a substantial number of families, a considerable proportion of the population has to incur substantial out-of-pocket expenses for CHD-related services.

Cultural and Household Factors Impacting Awareness

Sociocultural factors like family size and the language spoken at home may influence health literacy and CHD awareness. The next graphs evaluate the relationship between the language spoken at home and the number of family members, on the one hand, and CHD awareness in pregnancy on the other.

The following is a comparative overview of awareness rates of CHD in the antenatal period among families with Gujarati, Hindi, and English spoken at home. It will seek to establish the role of linguistic background in access to health information and the level of awareness.

English-speaking families had the highest awareness (23.6%), Hindi-speaking families had the second highest awareness (14.8%), and Gujarati-speaking families had the lowest awareness (10.2%). This implies that there is a close relation between language and access to health information, which is perhaps because of the readily available health communication literature and consultations in English. The comparatively lower awareness of regional language speakers indicates the necessity of multilingual outreach in public health.

The comparative graph of the CHD awareness level according to household size is given in Figure 2b. To analyze how family size affects awareness about the detection of CHD during pregnancy, it divides families into three categories: small (≤ 3 members), medium (4-6 members), and large (≥ 7 members).

Families with ≤ 3 members had the greatest CHD awareness level of 26.1%, whereas awareness in 4-6 member families and 7 or more member households decreased to 17.4% and 9.8%, respectively. This trend indicates a negative correlation between household size and health awareness. Larger families are at risk of being subject to a lesser degree of attention to individual health requirements or having a higher financial and educational burden, which reduces access to prenatal care services (Figure 2b).

Surgical Management and Postoperative Care

The nature of the surgical procedure and the access to postoperative care are the essential predictors of the accessibility and clinical outcome of CHD treatment. The distribution of single-stage and complex/multi-stage surgery and the proportion of patients who received structured postoperative follow-up over the period of the study are described in this subsection.

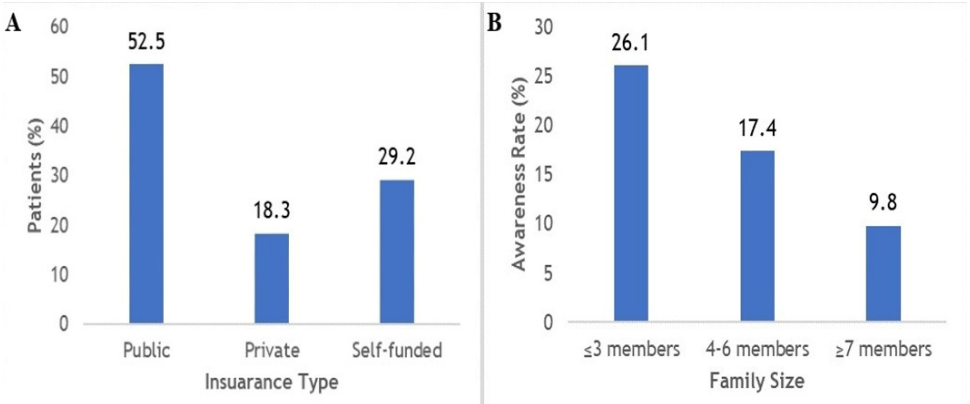

Figure 2 a) Distribution of insurance coverage among CHD-affected families; **Figure 2 b)** CHD awareness by household size

The statistics indicate that 61.55% of the children underwent single-stage corrective surgeries, whereas 38.46% of the children needed complex or multiple surgeries. It is noteworthy that 81.73% of the total number of patients received postoperative care, which indicates that the follow-up mechanism in the tertiary care setting is fairly strong. This level of post-op support implies institutional capability to provide follow-up care; however, 18.27% of the patients were not under any formal follow-up mechanisms.

Predictive Analysis of Risk Factors

This subsection presents the findings of a multivariate logistic regression model, which was run to assess which socioeconomic and demographic factors significantly predicted lower CHD awareness and delayed access to medical treatment. The model was based on maternal education, household income, location, and surgical outcomes.

Regression analysis showed that the lowest level of maternal education was the most significant risk factor for maternal awareness of CHD during the antenatal scan at 18-20 weeks (OR = 3.67; p = < 0.001). Low income was found to be an important risk factor (OR = 3.01, p = 0.002), as was village residence (OR = 1.69, p = 0.006). Access to postoperative surgery was also found to have a protective effect (OR = 0.15, p = 0.007), indicating that people who received surgical care had better outcomes and possibly more awareness or support systems. These results highlight the interaction of education, financial capacity, and geography in determining access to CHD healthcare in India (Table 3).

Table 3 Regression summary for congenital heart defect can be detected on antenatal scan at 18:20 weeks

Variable	OR	95% CI	p-value
Maternal education	3.67	2.41 – 5.59	<0.001
Low income	3.01	1.51 – 6.01	0.002
Village residence	1.69	1.17 – 2.45	0.006
Post-op surgery	0.15	0.04 – 0.59	0.007

4 Discussion

This article points to the significant contribution of sociodemographic factors, including maternal education, household income, place of residence, and CHD awareness, to early diagnosis and access to surgical care for CHD in India. The results support the noted relationship between a low level of maternal literacy and the lack of awareness of CHD, which inevitably contributes to late presentation. The findings are consistent with previous researchers, such as those of Jain et al.[18] and Dhar et al.[13] who revealed the same trends between maternal education and early detection and healthcare-seeking behavior in pediatric CHD populations in Central and Northern India, respectively.

The lack of antenatal CHD detection observed in the current study reflects the results of a previous study carried out by Nair and Radhakrishnan,[9] who stated that the use of prenatal screening was not high in North India because of a lack of awareness and infrastructural limitations. Additionally, Nair et al.[20] highlighted that even in a more resource-endowed area, such as Kerala, there are still systemic obstacles to early detection of CHD, underscoring the urgent need for comprehensive antenatal health education and access to services.

Socioeconomic status turned out to be a key factor in the present study. It was also revealed that children belonging to lower-income families were at higher risk of delayed diagnosis and treatment because of low access to specialized care due to financial limitations. Our observations align with the results of Xiang et al.[4] where the authors showed that the outcomes of CHD were much worse in socioeconomically challenged families, with the main reason being decreased access to immediate treatment. The article by Pan et al.[6] also confirmed the idea that geographic and economic disparities have a direct influence on the detection rates and birth prevalence of CHD.

The geographic location, especially rural residence, was found to be closely related to low CHD awareness and late referral. Similar problems in the rural pediatric population that were referred to tertiary cardiac centers were reported by Harikesh et al.[16] where logistical and resource constraints caused delays in diagnosis and treatment. These rural-urban disparities point to the dire need for decentralized pediatric cardiology services and improved infrastructure in outreach.

Moreover, the research is in line with the work of Animasahun et al.[1] on a Nigerian population; researchers found that socioeconomic and education levels were strongly associated with the time of diagnosis and clinical outcomes in cases of CHD, emphasizing the applicability of the same factors across regions in LMICs.

Although the patterns were strong, this study has limitations because of its retrospective character and single-center focus. Consequently, although the results are congruent with the regional literature, there is a need to be cautious when generalizing the findings to the national level. However, the overall similarity of these relationships implies that public health policy should be based on improving awareness of CHD during the antenatal period, expanding the outreach of diagnostics in rural areas, and removing financial barriers with the help of expanded insurance and support systems. The reinforcement of these areas might be a critical step toward decreasing diagnostic delays and improving surgical outcomes for CHD in India.

This research has several limitations. It was conducted at a single tertiary care center, which may introduce sampling bias and limit the generalizability of the results to other parts of India. The retrospective design is also dependent on the precision and completeness of the medical records and parental recall, which can influence the accuracy of the data. In addition, some confounding factors, including genetic predisposition or comorbidity, were not studied in detail. Although CHD type (cyanotic vs. acyanotic) was not included in the regression model, a more detailed classification of defect severity was not available, which may have limited a comprehensive assessment of the impact of clinical severity on antenatal awareness. In accordance with the findings, the following areas are worthy of further investigation:

- Multicenter Validation: Generalizing the research to other healthcare settings to confirm the effect of sociodemographic factors on CHD outcomes.
- Digital and Community Interventions: Exploring the effectiveness of mobile health tools and community-based awareness campaigns in improving CHD detection and decision-making.
- Policy-Oriented Research: Creating strong evidence to advocate for the inclusion of CHD awareness and access to care in national health policy platforms.

To offer a more comprehensive perspective, future research could include validated instruments evaluating both prenatal and postnatal awareness domains, such as comprehensive health literacy, including postnatal symptom recognition. Lower SES families in India face substantial obstacles to early detection and referral. The full spectrum would be better captured by prospective or community-based studies in the future, with active case-finding and minimal data loss. These directions can enhance both preventive and curative strategies for CHD, ensuring more equitable pediatric cardiac care. To offer a more comprehensive perspective, future research could include validated instruments evaluating both prenatal and postnatal awareness domains, such as comprehensive health literacy, including postnatal symptom recognition.

5 Conclusion

This research highlights the high influence of socioeconomic and demographic factors, especially low maternal education, rural living, low income, and poor awareness of CHD, on the clinical distribution and early detection of CHD in India. Regardless of increasing access to surgical procedures and insurance coverage, the results point to existing inequalities in early identification and care-seeking, particularly among disadvantaged groups.

The connections that are evident in multivariate analysis demand the reinforcement of public health measures, such as targeted antenatal education, the extension of fair healthcare insurance, and culturally sensitive communication methods. Multilingual awareness activities incorporated into antenatal visits and enhanced health insurance penetration are examples of actionable strategies that can be used to fill these gaps. Such measures can strengthen early CHD diagnosis and improve pediatric health equity in India in general.

Declarations

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Artificial Intelligence Disclosure
The authors confirm that no artificial intelligence (AI) tools were used in the preparation of this manuscript.

Authors' Contributions
Herin Patel conducted the study, collected the data, performed the literature review, and drafted the manuscript. Ashish Katewa designed the study, contributed to the literature review, supervised the study, and provided critical inputs. Bhavik Champaneri designed the study, supervised the study, conducted the literature review, and provided critical inputs. Pratik Shah performed data analysis and interpretation, conducted the literature review, and drafted and revised the manuscript. Dhara Patel performed data analysis and interpretation, conducted the literature review, and drafted and revised the manuscript. Kartik Patel conducted the literature review and drafted and revised the manuscript. Archit Patel conducted the literature review and drafted and revised the manuscript. Shobhit Mathur conducted the literature review and provided critical inputs. Ridhhi Dhanak conducted the literature review and provided critical inputs.

Availability of Data and Materials
The supporting data of this study are obtainable on request from the corresponding author.

Conflict of Interest
The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Consent for Publication
Not applicable.

Ethical Considerations
The current study was conducted in compliance with the Declaration of Helsinki's ethical guidelines. The U.N. Mehta Institute of Cardiology and Research Center's Institutional Ethics Committee in Ahmedabad granted ethical clearance under the Code of Ethics EC/Approval/04/CVTS/06/06/26.

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