

ORIGINAL RESEARCH

Oral health needs and barriers to care in children with congenital heart disease

Hafizah Mohammad¹, Lily Azura Shoaib^{1,*}, Nabihah Dziaruddin¹, Norazah Zahari²¹Department of Pediatric Dentistry and Orthodontics, Faculty of Dentistry, Universiti Malaya, 50603 Kuala Lumpur, Malaysia²Department of Pediatrics, Faculty of Medicine, Universiti Malaya, 50603 Kuala Lumpur, Malaysia***Correspondence**lilyazura@um.edu.my
(Lily Azura Shoaib)**Abstract**

Background: The rising number of children with congenital heart disease (CHD) in Malaysia presents significant challenges for pediatric oral health. Global research shows that children with CHD have more dental problems and poorer oral health than healthy children. This study aimed to evaluate the oral health needs, barriers to dental care, and oral health status of Malaysian children with CHD compared to a healthy control group. **Methods:** A cross-sectional study was conducted at the Faculty of Dentistry Universiti Malaya (FoDUM) and Universiti Malaya Medical Centre (UMMC), involving 134 children aged 3 to 12 years, divided equally into the CHD group (67 children) and the control group (67 children). Data were collected through a parent-completed questionnaire assessing oral health needs and barriers to care for their children. Clinical oral examinations were carried out on the CHD children using the Lobene Modified Gingival Index Score, and their dental status was evaluated using the decayed, missing, and filled teeth (dmft/DMFT) index. Statistical analyses included Chi-square and Fisher's Exact tests to identify significant associations using SPSS version 29.0. **Results:** There was a significant association between children with CHD and never visiting a dentist ($p = 0.002$). The perceived need for dental check-ups was also significantly higher in children with CHD ($p = 0.049$). Children with CHD had significantly higher gingivitis scores ($p < 0.001$). A significant number of children with CHD were more afraid of the dentist ($p < 0.001$), anxious ($p = 0.005$), uncooperative during dental treatment ($p < 0.001$); additionally, their parents lacked knowledge about where to seek dental treatment ($p = 0.005$) and faced time constraints in bringing their child to the dental clinic ($p = 0.014$). **Conclusions:** Children with CHD have significant oral health needs and face considerable barriers to accessing dental care, highlighting the necessity for targeted interventions to improve their outcomes.

Keywords

Congenital heart disease (CHD); Oral health needs; Oral health status; Oral health; Barriers

1. Introduction

Children with congenital heart disease (CHD) are at a heightened risk of developing oral health problems, including dental caries and gingivitis, due to a combination of factors such as dietary habits, medication use, and compromised immune responses, especially during their early years [1]. Unfortunately, the oral health of children with CHD is often neglected. Previous studies consistently show that children with CHD have a higher prevalence of dental caries and poor oral hygiene compared to their healthy peers, with up to one-third requiring urgent dental interventions. These oral health issues can worsen their medical condition [2–5] and increase the risk of severe complications such as Infective Endocarditis (IE) [6].

Multiple factors contribute to the increased risk of caries and poor oral health in children with CHD, including frequent use of medications [7], hypoxia [4, 8], and higher counts of

microorganisms, such as *Lactobacilli*, *Fusobacterium*, *Prevotella*, *Capnocytophaga* and *Oribacterium* in their saliva [9–11]. Elevated inflammatory mediators also make them more susceptible to gingivitis [12]. Furthermore, low socioeconomic status [13], limited parental awareness [3, 4], and the presence of chronic medical conditions further complicate their oral health care.

While barriers to dental care are well-documented for other groups with special healthcare needs, such as those with autism or learning disabilities, research specifically focusing on children with CHD remains limited. A recent systematic review and meta-analysis updated the understanding of oral health outcomes in children with congenital heart defects (CHD). It compared caries prevalence between CHD children and healthy controls, finding that children with CHD are at a higher risk of dental caries. CHD patients had higher levels of dental

caries, gingivitis, plaque accumulation and enamel defects [14]. These oral health issues impact their daily lives, causing pain, difficulty eating, emotional distress and social challenges [15]. However, the differences were not statistically significant across all studies [14]. Currently, there is a lack of studies in Malaysia addressing the oral health-related issues and status among children with CHD, as well as the barriers they face in accessing dental care. Given the rising number of children born with CHD globally [16] and in Malaysia [17], it is essential to address not only their medical and surgical needs but also their oral health requirements.

This study aims to assess the oral health needs, oral health status, and barriers to dental care among children with congenital heart disease (CHD) receiving treatment at UMMC, in comparison to a healthy control group. The findings are intended to support the development of targeted interventions and strategies to improve oral health outcomes and facilitate better access to dental care for children with CHD. Fig. 1 presents an overview of the study framework.

2. Materials and methods

2.1 Study design

This cross-sectional study was conducted from February to June 2024 at Universiti Malaya involving FoDUM and UMMC. Prior to the conduct of the study, ethical approval was obtained from the Ethics Committee FoDUM (DF CD 2404/0008) and the Ethics Committee UMMC (MREC ID. NO: 20231211-13112). The institution serves as a tertiary referral center, receiving patients from both public and private clinics across multiple states. The study followed the principles outlined in the Malaysian Good Clinical Practice (GCP) Guidelines and the Declaration of Helsinki. Informed consent was obtained from parents or guardians before data collection, and participation was voluntary, with all data kept anonymous. All participants received an information sheet detailing the study and provided written consent prior to inclusion. Parents completed a questionnaire evaluating the child's oral health needs and barriers to accessing dental care, followed by an oral health assessment of the children.

2.2 Inclusion and exclusion criteria

The study included Malaysian children aged 3 to 12 years, both with and without CHD, attending the Dental Clinics at the Faculty of Dentistry or the Pediatric Cardiology Clinic at UMMC. Children diagnosed with CHD by pediatric cardiologists were included in the CHD group including patients with both cyanotic (*e.g.*, Tetralogy of Fallot, Transposition of the Great Arteries) and acyanotic conditions (*e.g.*, Ventricular Septal Defect, Atrial Septal Defect). The prescription of infective endocarditis (IE) prophylaxis in clinical practice follows the Malaysian Clinical Practice Guidelines (CPG) [18]. Participants were required to have a Frankl Behavior Rating Scale score of 2 to 4, indicating a positive or neutral attitude toward dental treatment. Prior to each participant's involvement, researchers obtained parental consent. The inclusion criteria required that one parent or caretaker complete the questionnaire and be able to read and understand English or

Malay. Children with other underlying medical conditions besides CHD and those with a Frankl score of 1, indicating definitely negative behavior during oral health assessment, indicate extreme uncooperativeness, characterized by crying, screaming, physical resistance, or refusal to comply, often due to severe dental anxiety were excluded from the study.

2.3 Questionnaire

This study utilized a structured questionnaire adapted from Shoaib *et al.* [19] and Lai *et al.* [20]. The questionnaire underwent the process of translation into Malay language and content validated by a pediatric dentistry specialist with more than 20 years of clinical and teaching experience and a special care dentistry specialist with more than 10 years of expertise in both clinical practice and education, followed by face validation by this group of populations. It comprised four sections: children's socio-demographic background, parents' socio-demographic background, parents perceived oral health needs for their children, and barriers to dental care. This study then further categorized these barriers into four groups: child-related factors, parental factors, environmental factors and service provider factors.

2.4 Calibration

Prior to the data collection, inter- and intra-examiner calibration was done between the main researcher (HM), a post-graduate in Pediatric Dentistry at FoDUM, and a gold standard examiner—a dental specialist from the Pediatric Dentistry Unit, FoDUM, with over 10 years of clinical experience. Cohen's Kappa coefficient demonstrated near-perfect agreement, with an intra-examiner reliability of $\kappa = 0.88$ and a benchmark of $\kappa = 0.82$.

2.5 Oral health assessment (dmft/DMFT and Lobene modified gingival index score)

Two calibrated examiners conducted oral health assessments to determine the children's caries experience and Lobene Modified Gingival Index Score for the gingival health assessment. Dental caries status was measured using the decayed, missing and filled teeth (dmft/DMFT) index. Lower-case letters (d/m/f/t) were used for primary teeth, while uppercase letters (D/M/F/T) were used for permanent teeth. Gingival health was assessed using the Lobene Modified Gingival Index Score. The dentition was divided into six sextants (three upper and three lower). One index tooth per sextant was scored. In cases where the index tooth was not fully erupted, the adjacent deciduous tooth with the highest score was used. The index score for each tooth will be calculated by summing the scores of all recorded surfaces—labial/buccal, mesial, distal and lingual/palatal—based on the criteria in Table 1 and the score per individual will be determined by averaging the total scores across all examined teeth.

2.6 Data analysis

Statistical analyses were performed using IBM Statistical Package for Social Sciences version 29.0. (SPSS ver. 29.0. IBM Corporation, Armonk, NY, USA). The level of

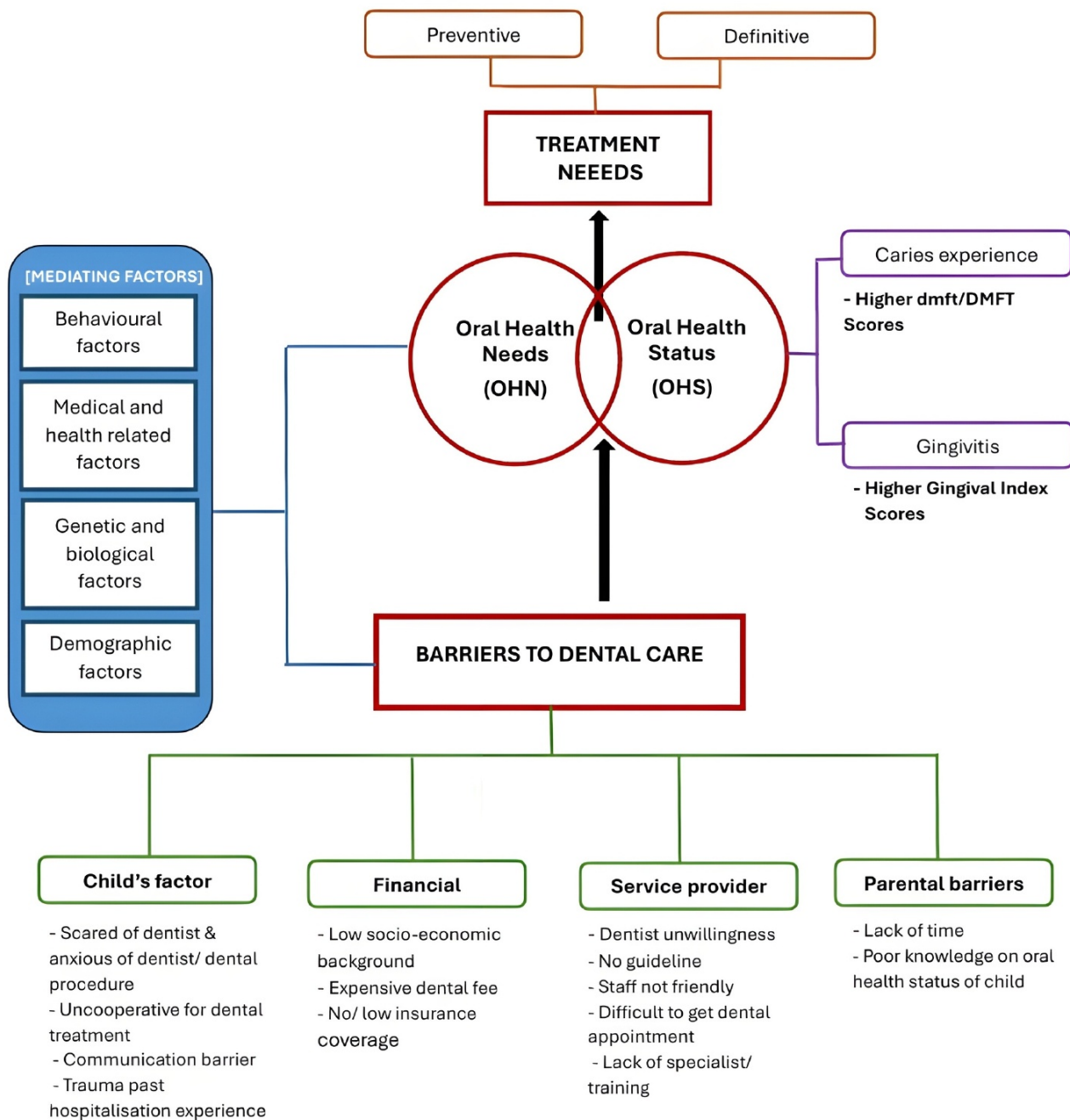


FIGURE 1. The research framework.

TABLE 1. Lobene modified gingival index score.

Scores	Criteria
0	Absence of inflammation
1	Mild inflammation or with slight changes in color and texture but not in all portions of gingival marginal or papillary
2	Mild inflammation, such as the preceding criteria, in all portions of gingival marginal or papillary
3	Moderate, bright surface inflammation, erythema, edema and/or hypertrophy of gingival marginal or papillary
4	Severe inflammation: erythema, edema and/or marginal gingival hypertrophy of the unit or spontaneous bleeding, papillary, congestion or ulceration

significance was set at $p = 0.05$. Descriptive analysis using numbers and percentages was used to exhibit demographic data. Chi-square and Fisher's Exact tests were used to determine the association between variables and to compare the CHD and the control groups.

3. Results

3.1 Children's demographic data

The study included 134 children aged 3 to 12, divided equally into the CHD group (67 children) and the control group (67 children). Table 2 summarizes the demographic characteristics based on the information obtained from the parents or guardians. In the CHD group, 52.2% were in the primary dentition stage (3–6 years), 29.9% were in the early mixed dentition stage (7–9 years), and 17.9% were in the late mixed dentition stage (10–12 years). The control group had similar age and gender distribution compared to CHD children, with 49.3% in the primary dentition stage, 37.3% in the early mixed dentition stage, and 13.4% in the late mixed dentition stage. The majority of children in both groups were Malay (CHD: 58.2%, Control: 82.1%), followed by Chinese (CHD: 26.9%, Control: 10.4%) and Indian (CHD: 10.4%, Control: 4.5%). The CHD group had a higher proportion of children on medication (35.8%), with none of the children on medication in the control group.

3.2 Parents/guardians demographic data

Table 3 summarizes the parent's/guardian's socio-demographic data. Most of the parents/guardians that

became the respondents in both groups were the mother (CHD = 83.6%, control = 62.7%) followed by the father (CHD = 14.9%, control = 31.3%), and subsequently others. In terms of the age group of the parents for both CHD and control groups, most of them were below 40 years old—50.7% in CHD and 64.2% in the control group. In terms of marital status, more than 90% of the caretakers in both groups were married: 94.0% in the CHD group and 97.0% in the control group, 6.0% were divorced in the CHD group, one (1.5%) was divorced in the control group and one (1.5%) was widowed in the control group. The education level of the parents/legal guardians in the CHD group is mostly diploma (46.3%), followed by degree (35.8%), then secondary school (14.9%) and master and PhD 1.5% each. In contrast to the control group, 46.3% of the parents/legal guardians had a degree, 25.4% had a diploma, 17.9% studied until secondary school, 10.4% had a master's and none for a PhD. The average monthly household income was based on the Household Income and Basic Amenities Survey Report 2019, Department of Statistics Malaysia. For the CHD group, listed below are the demographic characteristics of 62.7% of the parents/legal guardians with a household income of RM 4850–RM 10,960, followed by 14.9% less than RM 4800 and 22.4% of respondents with a household income of >RM 10,960. For both groups, most of the respondents worked in the government sector—32.8% for the CHD group and 34.3% for the control group, followed by the private sector at rank number 2 for both—35.8% in the CHD group and 26.9% in the control group.

TABLE 2. Demographic data of children.

Demographic characteristics	Children with CHD (Case), n = 67		Children without CHD (Control), n = 67		Total	
	n	%	n	%	N	%
Age (yr)						
3–6*	35	52.2	33	49.3	68	50.7
7–9**	20	29.9	25	37.3	45	33.6
10–12***	12	17.9	9	13.4	21	15.7
Gender						
Male	33	49.3	28	41.8	61	45.5
Female	34	50.7	39	58.2	73	54.5
Ethnicity						
Malay	39	58.2	55	82.1	94	70.1
Chinese	18	26.9	7	10.4	25	18.7
Indian	7	10.4	3	4.5	10	7.5
Others	3	4.5	2	3.0	5	3.7
Medication						
Yes	24	35.8	0.0	0.0	24	17.9
No	43	64.2	67	100.0	110	82.1

*Primary dentition age. **Early mixed dentition age. ***Late mixed dentition stage.

CHD: congenital heart disease.

TABLE 3. Demographic data of the parents/guardians.

Demographic characteristics	Children with CHD (Case), n = 67		Children without CHD (Control), n = 67		Total	
	n	%	n	%	N	%
Age						
<40 years old	34	50.7	43	64.2	77	57.5
≥40 years old	33	49.3	24	35.8	57	42.5
Relationship with child						
Mother	56	83.6	45	67.2	101	75.4
Father	10	14.9	21	31.3	31	23.1
Grandparents	0	0	1	1.5	1	0.7
Others	1	1.5	0.0	0.0	1	0.7
Marital status						
Married	63	94.0	65	97.0	128	95.5
Divorced	4	6.0	1	1.5	5	3.7
Widowed	0	0.0	1	1.5	1	0.7
Education Level						
Secondary School	10	14.9	12	17.9	22	16.4
Diploma	31	46.3	17	25.4	48	35.8
Degree	24	35.8	31	46.3	55	41.0
Master	1	1.5	7	10.4	8	6.0
PhD	1	1.5	0	0.0	1	0.7
Household Income per month						
<RM 4850	10	14.9	14	20.9	24	17.9
RM 4850–10,959	42	62.7	41	61.2	83	61.9
≥RM 10,960	15	22.4	12	17.9	27	20.1
Occupation						
Self-employed	6	9.0	14	20.9	20	14.9
Public sector employee	22	32.8	23	34.3	45	33.6
Private sector employee	24	35.8	18	26.9	42	31.3
Housewife	15	22.4	12	17.9	27	20.1
	Mean (SD)		Mean (SD)		Mean (SD)	
Working hours (per day)	6.3 (3.6)		6.4 (3.4)		6.4 (3.5)	
Working hours (per week)	32.2 (18.9)		36.3 (19.7)		36.3 (19.4)	

CHD: congenital heart disease; SD: standard deviation.

3.3 Oral health needs perceived by parents

Table 4 provides a summary of the oral health needs perceived by parents. A significantly higher proportion of parents in the CHD group perceived their children to need dental check-ups compared to the control group (82.2% vs. 63.2%, $p = 0.049$). More children in the CHD group had never visited a dentist than the control group (34.3% vs. 9.0%, $p = 0.002$). Parents in the control group were more likely to report regular dental visits every six months (38.8%) than the CHD group (20.9%). The perceived need for dental treatment, such as toothache relief and cleaning, was reported more frequently in the control group (28.9% vs. 11.1%, $p = 0.040$ for toothache). However,

the need for dental check-ups was significantly higher in the CHD group (82.2% vs. 63.2%, $p = 0.049$). Among parents in the CHD group who reported no perceived dental treatment needs, 62.5% attributed this to no problems with their child's teeth/mouth, while 37.5% cited the dental problem as less significant than the child's medical condition ($p = 0.001$).

3.4 Oral health status of the children

Table 5 summarizes the oral health status of the children's findings. Children with CHD had a higher prevalence of dental caries experience (dmft/DMFT $\neq 0$) compared to the control group (65.7% vs. 52.2%). However, this difference was not

TABLE 4. The oral health needs perceived by parents.

Questions	CHD Group		Control Group		p-value
	n	%	n	%	
The child has needed any dental treatment in the past 12 months					
Yes	45	67.2	38	56.7	0.126
No	17	25.4	27	40.3	
Don't know/Not sure	5	7.5	2	3.0	
If yes, type of treatment needed					
Treat toothache	5	11.1	11	28.9	0.040*
Cleaning of teeth	24	53.3	15	39.5	0.208
Remove teeth	10	22.2	13	35.1	0.195
Gum treatment	3	6.7	3	7.9	1.000 ^a
Dental check-ups	37	82.2	24	63.2	0.049*
Filling/Restoration	13	28.9	14	36.8	0.441
The arrangement of teeth is not nice	8	17.8	4	10.5	0.349
Dental treatment in the operating theater	4	8.9	0	0.0	0.121 ^a
If no, reason why					
No problem with their teeth/mouth	10	62.5	27	100.0	0.001 ^{a,*}
Dental problems are not a big problem compared to the medical problem	6	37.5	0	0.0	
The child has not received dental treatment in the past 12 months					
Yes	24	35.8	15	22.4	0.187
No	37	55.2	47	70.1	
Don't know/Don't remember	6	9.0	5	7.5	
How long since the parents visited the dentist					
Never been to the dentist	2	3.0	1	1.5	0.248
Less than 6 months ago	27	40.3	37	55.2	
6 months-1 year ago	5	7.5	7	10.4	
1–3 years ago	15	22.4	8	11.9	
More than 3 years ago	12	17.9	6	9.0	
Don't remember	6	9.0	8	11.9	
How often did the child visit the dentist					
Never	23	34.3	6	9.0	0.002*
Every 6 months	14	20.9	26	38.8	
Once a year	17	25.4	15	22.4	
Once in 2 years	2	3.0	7	10.4	
Only when pain	11	16.4	13	19.4	

^aFisher's Exact Test. *p-value is significant at $p < 0.05$. CHD: congenital heart disease.

TABLE 5. Oral health status of children.

Age groups	Variable	CHD (n = 67)		Control (n = 67)		p-value
		n	%	n	%	
3–12 years old (All dentition stages)						
	DMFT/dmft = 0	23	34.3	32	47.8	0.114
	DMFT/dmft ≠ 0	44	65.7	35	52.2	
	No Gingivitis	17	25.4	37	55.2	<0.001*
	Has Gingivitis	50	74.6	30	44.8	
3–6 years old (Primary Dentition Stage)						
	DMFT/dmft = 0	16	45.7	17	51.5	0.632
	DMFT/dmft ≠ 0	19	54.3	16	48.5	
	No Gingivitis	9	25.7	16	48.5	0.052
	Has Gingivitis	26	74.3	17	51.5	
7–9 years old (Early Mixed Dentition Stage)						
	DMFT/dmft = 0	4	20.0	10	40.0	0.150
	DMFT/dmft ≠ 0	16	80.0	15	60.0	
	No Gingivitis	6	30.0	12	48.0	0.221
	Has Gingivitis	14	70.0	13	52.0	
10–12 years old (Late Mixed Dentition Stage)						
	DMFT/dmft = 0	3	25.0	5	55.6	0.203 ^a
	DMFT/dmft ≠ 0	9	75.0	4	44.4	
	No Gingivitis	2	16.7	9	100.0	<0.001 ^{a,*}
	Has Gingivitis	10	83.3	0	0.0	

^aFisher's Exact Test; *p-value is significant at $p < 0.05$.

CHD: congenital heart disease; DMFT/dmft: Decayed, Missing and Filled Teeth/decayed, missing and filled teeth.

statistically significant ($p = 0.114$). The mean dmft/DMFT score in the CHD group was higher than in the control group across all age categories, although the differences were insignificant. As compared to gingivitis, a significantly higher proportion of children with CHD had gingivitis compared to the control group (74.6% vs. 44.8%, $p < 0.001$). The severity of gingivitis was particularly pronounced in the late mixed dentition stage (10–12 years), with 83.3% of children in the CHD group exhibiting gingivitis. In contrast, none of the children in the control group were affected ($p < 0.001$).

3.5 Barriers to dental care

The findings on the barriers to dental care are illustrated in Table 6. Firstly, for the child factor, children with CHD were more likely to be afraid of the dentist (74.6% vs. 37.9%, $p < 0.001$), anxious during dental treatment (77.8% vs. 54.5%, $p = 0.005$), and uncooperative (71.0% vs. 41.5%, $p < 0.001$) compared to the control group. Additionally, children with CHD were more frequently reported as unable to communicate their dental problems to the dentist (57.1% vs. 34.8%, $p = 0.011$). The next factor is the parental factors; parents of children with CHD cited a lack of time to bring their child to the dental clinic (50.7% vs. 29.9%, $p = 0.014$) and not knowing where to seek dental treatment (23.9% vs. 6.2%, $p = 0.005$) as significant barriers. No significant differences were

observed regarding financial constraints as a barrier between the two groups. Similarly, no significant differences were found between the groups for the environmental factors such as transportation problems, distance to dental clinics, or waiting times, indicating that environmental factors did not pose a major barrier for either group. In contrast with the service provider factor, parents of children with CHD reported that dentists were unwilling to treat their children more frequently than the control group (20.3% vs. 3.0%, $p = 0.002$). Additionally, unpleasant behavior by dental staff was reported as a barrier by more parents in the CHD group (13.6% vs. 3.0%, $p = 0.045$).

4. Discussion

This study aims to evaluate the oral health needs, barriers to dental care, and oral health status of Malaysian children with CHD compared to a healthy control group.

The socio-demographic characteristics of children with CHD in this study are consistent with findings from a study conducted in the southern Malaysia state of Johor, which reported a slightly higher prevalence of CHD among females (51%) compared to males (49%) [17]. However, a systematic review of CHD by Liu *et al.* [21] indicated comparable incidence rates between both sexes. Additionally, the ethnic distribution in this study reflects the pattern reported in Johor

TABLE 6. Barriers to dental care among children.

Variables	CHD Group (n = 67)		Control Group (n = 67)		<i>p</i> -value
	n	%	n	%	
Barriers the child faced regarding receiving dental treatment					
Afraid of the dentist	47	74.6	25	37.9	<0.001*
Anxious during dental treatment	49	77.8	36	54.5	0.005*
Unable to communicate with the dentist about a dental problem	36	57.1	23	34.8	0.011*
Uncooperative/Difficult behavior	44	71.0	27	41.5	<0.001*
Barriers you faced as parents when seeking dental treatment for your child					
Unable to afford treatment	22	32.8	24	35.8	0.716
No time to send the child to the clinic	34	50.7	20	29.9	0.014*
No one else is able to send the child	36	53.7	25	37.3	0.056
Do not know where to seek dental treatment	16	23.9	4	6.2	0.005*
Barriers in the environment get dental treatment for your child					
Transportation problem	13	19.4	8	11.9	0.235
Distance too far	21	31.3	19	28.4	0.706
Too long waiting time	32	47.8	29	44.6	0.717
Barriers from service providers in getting dental treatment for your child					
The dentist was unwilling to treat my child	12	20.3	2	3.0	0.002*
Inadequate facilities	7	11.9	3	4.5	0.189 ^a
The dentist/staff were unpleasant	8	13.6	2	3.0	0.045 ^{a,*}

^aFisher's Exact Test; *p-value is significant at $p < 0.05$. CHD: congenital heart disease.

[22], with Malay children being the predominant group, followed by Chinese and Indian children.

In this study, most participants for both CHD and control groups were mothers. While research indicates a significant relationship between parental gender and oral health knowledge, with mothers being more aware than fathers [23], this study did not assess this relationship, as it focused on children's oral health needs, status and barriers to care. 35.8% of parents in the CHD group work in the private sector. Parental occupation has also been linked to caries prevalence, with children of skilled workers exhibiting lower DMFT scores than those of unskilled workers [24]. Additionally, studies in Malaysia, China and the United States of America have shown that lower socioeconomic status is associated with a higher risk of dental caries in children [24–27], emphasizing the socioeconomic gradient in oral health. In this study, most of the participants for both groups were from the M40 with an average monthly salary of RM 4850 to RM 10,959. In Malaysia, the M40 group represents the middle 40% of households based on income, positioned between the lower-income (B40) and higher-income (T20) groups.

In this study, children with CHD exhibited a greater need for dental care, as reflected in the higher proportion of them who needed dental check-ups and never visited a dentist compared to the control group. Studies suggest that regular dental visits are associated with better oral hygiene, fewer dental issues, and improved dietary control [28, 29]. Although the parents' recent dental visit rates were comparable between groups in this study, parents of control group children were more likely

to perceive the need for dental treatment for their children's toothaches than those in the CHD group. This is because the parents of children with CHD exhibit lower awareness of the implications of their child's condition on oral health [1]. This indicates a higher perceived need for treatment in the control group, as their parents, whose children visited the dentist, are more aware of their dental treatment needs. In contrast with a systematic review published recently, the study highlighted that while children with CHD may be at risk for dental issues, the perceived need for treatments like cleanings and fillings remains similar to that of other children [14]. In this study, the lack of perceived need for dental treatment among most parents of children with CHD was primarily attributed to their perceived absence of dental issues. Additionally, some parents prioritized their child's medical condition over oral health ($p = 0.001$), indicating that the study sample may have included children with less severe CHD. Furthermore, many parents may not recognize the need for early dental intervention, leading to delayed treatment until severe issues arise which may lead to the need for extensive oral rehabilitation under general anesthesia [30].

Despite the lack of a significant association between dmft/DMFT scores and CHD, children with CHD exhibited significantly higher gingival index (GI) scores, indicating a greater prevalence of gingivitis ($p = 0.001$). This association was most evident among children aged 10 to 12, where nearly all in the CHD group had gingivitis, while none in the control group did. Similar trends were reported in Sudan and Turkey, where children with CHD had higher GI scores than their

healthy counterparts [4, 9]. This could be due to younger children receiving more supervision during tooth brushing, which tends to decrease as they age. Our findings align with those of Ali *et al.* [9], who also reported higher rates of gingivitis in older children with CHD. Furthermore, this study has very similar findings to the study done recently in Turkey, which reported that children with CHD have more gingivitis than their healthy counterparts, even though the dental caries experience in the CHD group in the study is lower than the control [31]. This could be due to children with CHD having poorer oral health behavior and brushing less than twice per day [32]. Besides, parental lack of awareness of the importance of oral health and dental practice in children with CHD also contributes to poor oral hygiene [33]. The high prevalence of gingivitis in children with CHD highlights the need for preventive care and regular dental visits. Integrating dental services into pediatric cardiology could improve access and outcomes for this vulnerable group.

This study identified significant child-related barriers to dental care in children with CHD ($p = 0.05$), including greater dental fear, higher anxiety, communication difficulties and lower cooperation, compared to their healthy counterparts. These findings align with existing literature suggesting that children with CHD often experience increased dental anxiety, likely due to prior hospitalizations and medical interventions related to their cardiac condition [34, 35]. Behavior management challenges are common in children with chronic health conditions [35, 36], further complicating their access to necessary dental care, which is essential for oral and overall health. These findings highlight the need for tailored strategies to manage dental anxiety and improve behavior during treatment for children with CHD. In this study, parental barriers, such as time constraints and limited awareness of dental care access, were consistent with a study [37] highlighting the impact of unavailable services during free time. In contrast, research on children with learning disabilities found no association between lack of knowledge on where to seek care and barriers to dental access [19]. Interestingly, financial constraints were minimal, likely due to Malaysia's subsidized healthcare system, though other studies have identified cost as a significant barrier [37]. In the present study, transportation and waiting times were not significant barriers, highlighting the accessibility of healthcare in the urban city of Kuala Lumpur. Unlike a study in Iran, where long wait times were a major obstacle [37], parents in this study did not report issues with distance or wait times. However, some experienced difficulties with parking at dental clinics. In our current study, service-provider-related barriers were significant, as parents perceived reluctance among dental professionals to treat children with CHD, reflecting broader concerns about inadequate training and confidence in managing medically compromised patients [38–40]. Studies in Malaysia and internationally highlight gaps in specialty education, leading to limited provider experience and, in some cases, refusal to treat these children [38–40]. Additionally, Alfaraj in Saudi Arabia identified unfriendly and incompetent dental staff as key barriers [41]. Consistently, this study found that unpleasant behavior by dental staff was significantly associated with difficulties in accessing dental care for children with CHD.

One limitation of this study is the use of convenience sampling, which may introduce bias. The control group participants were recruited from FoDUM dental clinics, where many already had regular dental visits. To mitigate bias, only new patients and those seen in on-call cases were included. Additionally, the cross-sectional design precludes long-term follow-up. To address this, referral letters were issued to CHD parents, ensuring access to necessary dental care at Universiti Malaya. Moreover, as this study was conducted in an urban area, its findings may not be applicable to children with CHD in rural areas, where transportation and healthcare accessibility might be greater challenges. Future research should include non-urban populations to improve the applicability of these findings. Furthermore, this study did not account for the severity of CHD or the impact of common medications such as diuretics and ACE inhibitors, which could influence oral health outcomes. Future research should explore these factors to provide a more comprehensive understanding.

5. Conclusions

In conclusion, this study highlights the significant oral health needs and barriers to dental care faced by children with CHD. Comprehensive, multidisciplinary approaches are essential to improving their oral health outcomes and overall well-being. Children with CHD are at a higher risk of developing gingivitis and encounter considerable challenges in accessing regular dental care due to behavioral issues, parental constraints, and healthcare system limitations. Although there was no significant difference in dental caries experience, the elevated gingival index scores and high levels of dental anxiety and uncooperativeness indicate the need for specialized preventive and therapeutic strategies tailored to this group. Comprehensive interventions are needed, including targeted education programs for parents, integrated care involving pediatric cardiologists and dentists, and enhanced training for dental professionals to confidently manage children with special healthcare needs.

Future research should investigate the long-term impact of CHD on oral health and evaluate the effectiveness of specific interventions designed to improve oral health outcomes in this population. A multidisciplinary approach is crucial to improving oral health outcomes and overall well-being for children with CHD, ultimately reducing the risk of oral and systemic complications and enhancing their quality of life.

ABBREVIATIONS

CHD, Congenital heart disease; DMFT/dmft, Decayed, Missing and Filled Teeth/decayed, missing and filled teeth; FoDUM, Faculty of Dentistry, University of Malaya; GI, Gingival Index; IE, Infective Endocarditis; UMMC, Universiti Malaya Medical Centre; GCP, Good Clinical Practice; CPG, Clinical Practice Guidelines.

AVAILABILITY OF DATA AND MATERIALS

The data presented in this study are available on reasonable request from the corresponding author.

AUTHOR CONTRIBUTIONS

LAS—designed the research study. LAS and HM—developed the research framework. HM—performed the research and analyzed the data. LAS, ND and NZ—assisted in research conduct. All authors contributed to the manuscript preparation and approved the final manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was obtained from the Ethics Committee, Faculty of Dentistry, Universiti Malaya (FoDUM) (DF CD 2404/0008) and Ethics Committee, Universiti Malaya Medical Centre (UMMC) (MREC ID. NO: 20231211-13112). Informed consent for minor patients was obtained from their parents or legal guardians. This study is conducted in compliance and adheres to ethical principles outlined in the Malaysian Good Clinical Practice (GCP) Guideline and follows the Declaration of Helsinki. Consent to participate was obtained from the participants prior to the data collection.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

REFERENCES

- [1] Schulz-Weidner N, Logeswaran T, Schlenz MA, Krämer N, Bulski JC. Parental awareness of oral health and nutritional behavior in children with congenital heart diseases compared to healthy children. *International Journal of Environmental Research and Public Health*. 2020; 17: 7057.
- [2] Hallett K, Radford D, Seow WK. Oral health of children with congenital cardiac diseases: a controlled study. *Pediatric Dentistry*. 1992; 14: 224–230.
- [3] Ali HM, Mustafa M, Nasir EF, Lie SA, Hasabalrasol S, Elshazali OH, *et al*. Oral-health-related background factors and dental service utilisation among Sudanese children with and without a congenital heart defects. *BMC Oral Health*. 2016; 16: 123.
- [4] Saraç F, Dereioğlu ŞŞ, Şengül F, Laloğlu F, Ceviz N. The evaluation of oral health condition and oral and dental care in children with congenital heart disease. *Journal of Clinical Medicine*. 2023; 12: 3674.
- [5] Hazarika SJ, Jnaneswar A, Jha K. A Comparative assessment of dental caries experience in relation to nutritional status among 6–12-year-old school-going children and those with congenital heart disease in Bhubaneswar city. *International Journal of Clinical Pediatric Dentistry*. 2024; 17: 1–6.
- [6] Bumm CV, Folwaczny M. Infective endocarditis and oral health—a narrative review. *Cardiovascular Diagnosis and Therapy*. 2021; 11: 1403–1415.
- [7] Karikoski E, Sarkola T, Blomqvist M. Dental caries prevalence in children with congenital heart disease—a systematic review. *Acta Odontologica Scandinavica*. 2021; 79: 232–240.
- [8] Pimentel EL, Azevedo VM, Castro Rde A, Reis LC, De Lorenzo A. Caries experience in young children with congenital heart disease in a developing country. *Brazilian Oral Research*. 2013; 27: 103–108.
- [9] Ali HM, Mustafa M, Hasabalrasol S, Elshazali OH, Nasir EF, Ali RW, *et al*. Presence of plaque, gingivitis and caries in Sudanese children with congenital heart defects. *Clinical Oral Investigations*. 2017; 21: 1299–1307.
- [10] Pourmoghaddas Z, Meskin M, Sabri M, Norousali Tehrani MH, Najafi T. Dental caries and gingival evaluation in children with congenital heart disease. *International Journal of Preventive Medicine*. 2018; 9: 52.
- [11] Schulz-Weidner N, Weigel M, Turujlija F, Komma K, Mengel JP, Schlenz MA, *et al*. Microbiome analysis of carious lesions in pre-school children with early childhood caries and congenital heart disease. *Microorganisms*. 2021; 9: 1904.
- [12] Mohamed Ali H, Mustafa M, Suliman S, Elshazali OH, Ali RW, Berggreen E. Inflammatory mediators in saliva and gingival fluid of children with congenital heart defect. *Oral Diseases*. 2020; 26: 1053–1061.
- [13] Oliver KJ, Cheung M, Hallett K, Manton DJ. Caries experience of children with cardiac conditions attending the Royal Children's Hospital of Melbourne. *Australian Dental Journal*. 2018; 63: 429–440.
- [14] Moussa C, Savard G, Estrade L, Bourgi R, Kharouf N, Denis F, *et al*. Dental health in children with congenital heart defects: a systematic review and meta-analysis. *Journal of Clinical Medicine*. 2024; 13: 7022.
- [15] Bsesa SS, Srour S, Dashash M. Oral health-related quality of life and oral manifestations of Syrian children with congenital heart disease: a case-control study. *BMC Oral Health*. 2023; 23: 316.
- [16] Liu Y, Chen S, Zuhlke L, Black GC, Choy MK, Li N, *et al*. Global birth prevalence of congenital heart defects 1970–2017: updated systematic review and meta-analysis of 260 studies. *International Journal of Epidemiology*. 2019; 48: 455–463.
- [17] Mat Bah MN, Kasim AS, Sopian MH, Alias EY. Survival outcomes for congenital heart disease from Southern Malaysia: results from a congenital heart disease registry. *Archives of Disease in Childhood*. 2024; 109: 363–369.
- [18] National Heart Association of Malaysia, Academy of Medicine Malaysia. Clinical practice guidelines for the prevention, diagnosis & management of infective endocarditis. 2017. Available at: <http://www.moh.gov.my> (Accessed: 28 February 2025).
- [19] Shoaib L, Mohamed Rohani M, John J, Omar RA, Zainuddin N, Lim S, *et al*. Oral health needs and barriers to care in children with learning difficulties. *Malaysian Journal of Medicine and Health Sciences*. 2023; 19: 278–287.
- [20] Lai B, Milano M, Roberts MW, Hooper SR. Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012; 42: 1294–1303.
- [21] Liu Y, Chen S, Zühlke L, Babu-Narayan SV, Black GC, Choy MK, *et al*. Global prevalence of congenital heart disease in school-age children: a meta-analysis and systematic review. *BMC Cardiovascular Disorders*. 2020; 20: 488.
- [22] Mat Bah MN, Sopian MH, Jamil MT, Abdullah N, Alias EY, Zahari N. The birth prevalence, severity, and temporal trends of congenital heart disease in the middle-income country: a population-based study. *Congenital Heart Disease*. 2018; 13: 1012–1027.
- [23] Alshammari FS, Alshammari RA, Alshammari MH, Alshammari MF, Alibrahim AK, Al Sineedi FA, *et al*. Parental awareness and knowledge toward their children's oral health in the city of Dammam, Saudi Arabia. *International Journal of Clinical Pediatric Dentistry*. 2021; 14: 100–103.
- [24] Anwar DS, Mohd Yusof MYP, Ahmad MS, Md Sabri BA. Family influences on the dental caries status of children with special health care needs: a systematic review. *Children*. 2022; 9: 1855.
- [25] Yusof N, Muhammad Ghazali LA, Zulkifle NS. Social & behavioral risk factors and early childhood caries—a cross-sectional study on preschool children in Shah Alam. *Compendium of Oral Science*. 2021; 8: 11–20.
- [26] Vasireddy D, Sathiyakumar T, Mondal S, Sur S. Socioeconomic factors associated with the risk and prevalence of dental caries and dental

- treatment trends in children: a cross-sectional analysis of national survey of children's health (NSCH) data, 2016–2019. *Cureus*. 2021; 13: e19184.
- [27] Zhang T, Hong J, Yu X, Liu Q, Li A, Wu Z, *et al.* Association between socioeconomic status and dental caries among Chinese preschool children: a cross-sectional national study. *BMJ Open*. 2021; 11: e042908.
- [28] Alhareky M, Nazir MA. Dental visits and predictors of regular attendance among female schoolchildren in Dammam, Saudi Arabia. *Clinical, Cosmetic and Investigational Dentistry*. 2021; 13: 97–104.
- [29] Mallineni SK, Alassaf A, Almulhim B, Alghamdi S. Influence of tooth brushing and previous dental visits on dental caries status among Saudi Arabian children. *Children*. 2023; 10: 471.
- [30] Kolçakoğlu K, Korkut DI, Yücel G, Kızılcı E. Dental approaches in children with congenital heart disease treated under general anesthesia for oral rehabilitation. *Medicina Oral, Patologia Oral, Cirugia Bucal*. 2024; 29: e451–e457.
- [31] Aksakal SD, Guven Y, Topcuoglu N, Kulekci G, Aktoren O. Assessment of oral bacteria potentially associated with the mobile microbiome in children with congenital heart disease. *Journal of Clinical Pediatric Dentistry*. 2024; 48: 47–56.
- [32] Karikoski E, Sarkola T, Blomqvist M. Oral health behavior during early childhood in children with major congenital heart defects. *International Journal of Paediatric Dentistry*. 2023; 33: 278–288.
- [33] Rexhepi A, Latifi-Xhemajli B, Kutllorci T, Bajrami S, Ahmeti D. Caries experience and knowledge about oral health importance among children with congenital heart diseases in Kosovo. *Brazilian Research in Pediatric Dentistry and Integrated Clinic*. 2022; 22: e210056.
- [34] Hughes S, Balmer R, Moffat M, Willcoxson F. The dental management of children with congenital heart disease following the publication of Paediatric Congenital Heart Disease Standards and Specifications. *British Dental Journal*. 2019; 226: 447–452.
- [35] Karhumaa H, Lämsä E, Vähänikkilä H, Blomqvist M, Pätälä T, Anttonen V. Dental caries and attendance to dental care in Finnish children with operated congenital heart disease. A practice-based follow-up study. *European Archives of Paediatric Dentistry*. 2021; 22: 659–665.
- [36] Kankaala T, Määttä T, Tolvanen M, Lahti S, Anttonen V. Outcome of chair-side dental fear treatment: long-term follow-up in public health setting. *International Journal of Dentistry*. 2019; 2019: 5825067.
- [37] Vali L, Zare Z, Jahani Y, Kalavani K. Investigating the access barriers to oral and dental health services for children from the perspective of parents attending the health centers of Kerman. *Dental Research Journal*. 2023; 20: 49.
- [38] Alamri H. Oral care for children with special healthcare needs in dentistry: a literature review. *Journal of Clinical Medicine*. 2022; 11: 5557.
- [39] Mohamed Rohani M, Mohd Nor NA. Dental students' perception on disability equality training as part of the special care dentistry curriculum. *Journal of Dental Education*. 2021; 85: 690–698.
- [40] Star JM, Flores A, Leyva E, Foertsch C. Barriers to routine dental care for children with special health care needs. *Special Care in Dentistry*. 2024; 44: 592–599.
- [41] Alfaraj A, Halawany HS, Al-Hinai MT, Al-Badr AH, Alalshaikh M, Al-Khalifa KS. Barriers to dental care in individuals with special healthcare needs in Qatif, Saudi Arabia: a caregiver's perspective. *Patient Preference Adherence*. 2021; 15: 69–76.

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