

ORIGINAL RESEARCH

Access to dental care for children with special health care needs: a cross-sectional community survey within Jeddah, Saudi Arabia

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Abstract

The aim of this study was to investigate the level of dental care access among children with special health care needs (CSHCN) in Jeddah, Saudi Arabia and the barriers hindering this access. Data of this cross-sectional study were obtained from self-administered surveys distributed through seven CSHCN centers. Children with autistic spectrum disorder (ASD), Down syndrome, cerebral palsy, and developmental delay were included. Univariate and bivariate analyses were conducted to describe the data. A total of 602 study participants were included in the analyses. Only 24.9% of the participated caregivers routinely visited the dentist for their CSHCN. Half of CSHCN caregivers found difficulties obtaining dental treatment. This trend was significantly greater in 12–18 years old children ($p = 0.013$) and in families commuting for more than one hour to dental clinics ($p = 0.045$). The most common reported barrier was fear of the dentist (61.6%) followed by child uncooperativeness (37.8%) and treatment costs (27.8%). CSHCN lack sufficient dental care for a variety of reasons, primarily fear of dentists, child uncooperativeness, and treatment costs. Dentists require more training and education to facilitate better access to dental care for CSHCN.

Keywords

Dental health services; Developmental disabilities; Cerebral palsy; Down syndrome; Autism spectrum disorder; Oral health

1. Introduction

According to the American Academy of Pediatric Dentistry, children with special health care needs (CSHCN) are defined as “those who have any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs” [1]. According to the World Health Organization (WHO), around 720 million people globally live with functional disability [2], and estimates that 93 million and 13 million children with CSHCN among 14-year-old and younger individuals live with “moderate or severe disability” and “severe disability”, respectively [2]. The term “special health care needs” includes, but is not limited to, autistic spectrum disorder (ASD), Down syndrome, cerebral palsy, and developmental delay [3]. Some of these conditions appear within a considerable sector of the general population. Globally, one in 160 children has an ASD [4], and at least one in six children experience a developmental difficulty [5]. In Saudi Arabia, one out of 554 live births is diagnosed with Down syndrome [6], and the prevalence rate of cerebral palsy, one of the most common neurologic disorders among Saudi children, is 23.4/10,000 [7].

As a population, CSHCN require special oral health care and are considered a high-risk group for dental diseases [8]. Typically, CSHCN experience severe difficulties with oral hygiene practices, often because of their motor, sensory, and mental disorders [9]. This results in an elevated risk for oral diseases throughout their lifetime, consequently negatively impacting their quality of life [10]. Children with ASD usually develop poor oral hygiene and gingivitis, increasing their risk for caries and periodontal diseases [11]. Due to their behavioral traits (difficulty with relationships and delayed speech development), they require the use of various basic behavior management techniques including the use of visual and verbal communications such as the use of picture book, short and repetitive phrases, patient-specific rewards at the end of the visit, and progressive desensitization. Advanced behavior management techniques may be used when appropriate when non-pharmacological techniques fail [12].

Although Down syndrome patients present with lower caries experience, their periodontal treatment needs are higher than other patients, as they usually suffer from severe periodontitis related to immunological deficiencies [13]. Down syndrome patients present with delayed eruption of primary and permanent teeth which reduces the time for the teeth being exposed

to cariogenic factors and this might play a role in the lower incidence of caries reported [14]. Additionally, Down syndrome patients have elevated salivary *Streptococcus mutans* specific immunoglobulin A concentrations which provide them with protection against dental caries [15]. Meanwhile, children with cerebral palsy experience a very high incidence of caries, alongside patterns of poor oral hygiene, based on a study conducted in Saudi Arabia [16]. Multiple risk factors in patients with cerebral palsy that lead to high incidence of caries. These factors include but not limited to the soft diet consumed by these patients, the difficulty to perform proper oral hygiene due to impaired movement and limbs spasticity, mastication and swallowing difficulties, the presence of some dental anomalies such as enamel hypoplasia [17, 18]. In addition to these conditions, patients with developmental delays may also suffer from orofacial diseases or conditions such as oral cancer, cleft lip/palate, amelogenesis imperfecta, and dentinogenesis imperfect [10].

Many general dentists are hesitant to treat patients with CSHCN due to the complexity of their medical conditions, patient behavior, and insufficient training and experience [19]. Therefore, few cases of CSHCN are usually seen by general dentists with advanced training [19], with the greatest amount of treatment falling to pediatric dentists, dental schools, and hospitals [20]. According to the World Dental Federation (FDI), people with disabilities are under-served in dental care [21]. For CSHCNs, dental care is the most deficient and unmet health care service [21].

Generally, several barriers increase the risks of oral diseases in children with disabilities including the complexity of the child's medical condition, financial constraint [22], transportation barriers, lack of knowledge where to obtain the needed services, inconvenient service time [23], barrier of finding a dentist to treat the child considering the child's behavior, previous unpleasant dental experience [24], reluctant dentist [25], and the long waiting time to receive dental treatment [26].

To date, little data have been gathered on oral health and access to dental care for CSHCN in Saudi Arabia. Therefore, this study sought to: (1) investigate the level of dental care access and utilization among CSHCN in Jeddah, Saudi Arabia, and (2) explore the challenges and barriers experienced by CSHCN to accessing oral health services. CSHCN included in this study were restricted to children with Autistic spectrum disorder (ASD), Down syndrome, cerebral palsy, and developmental delay.

2. Materials and methods

This cross-sectional study was conducted in Jeddah, the second-most populous city in Saudi Arabia, with a population over four million. The study was carried out between January 2021 and April 2021 [27]. All data were kept in a password-encrypted computer and the findings were only made available to the study team, used solely for the purposes of this research.

The online survey for this study composed of 21 close-ended questions in an Arabic language (**Supplementary material**). This survey was a modified version of a previously tested pilot survey [22]. The modified survey had also been previously tested on a selected sample of 15 CSHCN family members

that were not part of the study participants. The pilot study was conducted to evaluate the participants understanding of the survey questions and address any unclarity. The survey included questions that addressed socio-demographic data to be completed by the CSHCN caregivers, such as the child's age, sex, family size, child order, education, and household income. These were followed by questions about the condition of the CSHCN, parental perception of oral health, the types of dental treatment received, the locations of their treatment clinic, and their treatment provider. The final section of the survey included a set of questions about the caregivers' difficulties in securing treatment for their CSHCN, including difficulties in finding a dentist and reaching the dental clinics, alongside questions about the specific barriers limiting the acquisition of dental care.

The research team reached out to all governmental and private special care centers (17 centers) within Jeddah to accurately reflect the majority of CSHCN and caregivers. While only seven centers granted access to caregivers, these centers include both nonprofit organizations and private sectors covering a wide geographical area within the city and provided greater background variations within the sample. The survey was distributed to CSHCN caregivers through these seven centers through a secure online platform by the centers' administrations. The centers that participated were Help Center, Dar Noura, The First Autism, Maan, Badghish, Special Moms, and Omnyate Center. Eligible participants were recruited according to the inclusion and exclusion criteria. The inclusion criteria for this study were defined as such: Arabic speaking parents with special need child between the age of 3–18 years old with one of the following conditions: ASD, Down syndrome, cerebral palsy, or developmental delay. Exclusion criteria were children beyond the age limit and with medical conditions other than ASD, Down syndrome, cerebral palsy, and developmental delay.

All data were exported from Google Sheets into electronic datasheets (Microsoft Excel 16.38, Microsoft Corporation, Redmond, WA, USA) and all analyses were carried out using IBM Statistical Package for Social Sciences software (SPSS version 23, IBM, Chicago, IL, USA). The significance level was set at 5% ($\alpha = 0.05$). Data were reported as percentages and frequencies and analyzed using descriptive statistics. A Chi-square test was performed to determine whether there was a statistically significant difference between the frequencies of difficulty seeking dental treatment and other variables such as age group, income, education level, family size, travel time required to visit the dentist, and CSHCN conditions. In cases where questions allowed for multiple answers, such as in the last question of the survey addressing specific dental care barriers, percentages were calculated based on the caregivers' responses. The reported barriers were further categorized into patient-related, dentist-related, priority-related, and accessibility issues (Table 2). Patient-related factors included fear of the dentist, child uncooperativeness, and treatment costs. Dentist-related factors included a lack of facilities in the clinics, inadequate training or other reasons hindering dentists from treating CSHCN. Accessibility-related factors included difficulty in securing transportation to the clinic, either due to distance or access. Finally, priority-related factors included a

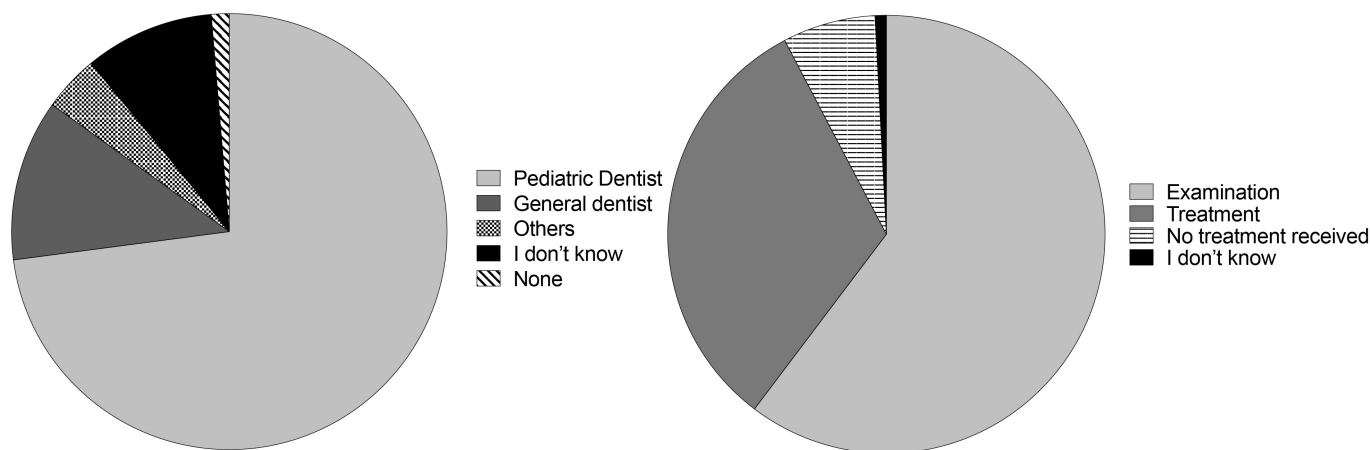


FIGURE 1. Distribution of treatment delivered to CSHCN and the treatment providers (n = 602). Examination and preventive measures include oral hygiene instructions, fluoride application and radiographs. While treatment includes extractions, fillings, and crowns.

lack of time or a denial of the importance of dental treatment.

3. Results

The total number of study participants were 669 who completed and returned surveys. CSHCN with medical conditions other than ASD, Down syndrome, cerebral palsy, and developmental delay were excluded, as well as those outside the age range established for this study. Sixty-seven study participants were excluded resulting in a total of 602 participants to be included for analyses.

Table 1 represents the demographic characteristics of the study participants and the main findings of the surveys. Questionnaires were mostly filled out by mothers (60.5%). Around 44.2% of the caregivers had a college degree or higher education. Almost half of participants (46%) had a monthly family income ranging between 7000 and 12,000 Saudi Riyal (SR), equivalent to 1866 to 3200 US dollars, respectively. Male and female CSHCN were almost equally distributed (53.7% and 46.3% respectively). The age of children in this study ranged from 3 to 18 years old with a mean age of 7.9 years. (Table 1). Children with Down syndrome and ASD were most common (49.2% and 38.7% respectively), followed by those with developmental delays (9.6%), and cerebral palsy (2.5%).

Only 150 (24.9%) of the surveyed caregivers reported routinely visiting the dentist for their CSHCN. Of those who visited the dentist, 84.6% had received dental examinations and preventive measures, while dental treatments were provided at a lesser extent. Most of the treatments were provided by paediatric dentists (Table 1 and Fig. 1).

When describing the challenges in obtaining dental care, almost half (52.2%) of the caregivers found it difficult. This trend appeared significantly more often in children between 12–18 years old ($\chi^2 = 8.54$, $p = 0.013$), and among families commuting for more than one hour to the dental clinic ($\chi^2 = 4.1$, $p = 0.045$). Moreover, families of CSHCN with cerebral palsy and developmental delays reported a significantly more difficulties in obtaining dental treatment when compared to families of CSHCN with ASD and Down syndrome ($\chi^2 =$

11.2, $p = 0.010$). Up to 80% of the families of children with cerebral palsy and developmental delays face difficulties obtaining dental treatment for their children, while only half of the families of children with ASD and Down's syndrome (49.4–50%) reported such difficulties (Table 2).

Family size and education level impacted the struggles in finding a treating dentist (Table 2). About 93% of families with lower education found it difficult to find a treating dentist as compared to 88% of families with higher education ($\chi^2 = 4.8$, $p = 0.020$). Similarly, larger families (more than 2 children) found it more difficult to find a treating dentist as compared to small families ($\chi^2 = 5.9$, $p = 0.013$).

Among families with CSHCN, 71% had difficulty reaching the dental clinic. This factor was greater in families of children cerebral palsy and developmental delays as compared to other conditions ($\chi^2 = 12.6$, $p = 0.048$). Likewise, families with less education struggled more in reaching dental clinics than families with more education ($\chi^2 = 6.1$, $p = 0.047$) as shown in Table 2. No statistically significant differences were found between families travelling for more or less than an hour to reach a dental clinic.

The last question of the survey questioned the exact reasons for barriers to dental treatment. One hundred and thirteen respondents did not identify any barriers, bringing the total number of participant respondents to this question to 489. The findings for this question are shown in Table 3. The most commonly reported barrier was patient-related (79.1%) in all four groups of CSHCN. Specifically, fear of the dentist was the most common factor (61.6%), followed by child uncooperativeness (37.8%) and treatment costs (27.8%). The second barrier was accessibility of dental clinics (41.5%). Around 65.6% of families travelling to the dental clinic for more than an hour reported accessibility to be a barrier to seeking dental care, compared to only 39% of those who travel for less than an hour.

Dental treatment barriers such as treatment costs, transportation limitations, and dental clinic locations were the most common barriers reported among families with lower income; only 29% of families with income greater than 12,000 SR reported

TABLE 1. Summary of the demographics and responses to the survey administrated to caregivers of CSHCN, Jeddah city, Saudi Arabia.

Variables	n (%)
Number of participants	602
Mean age of CSHCN (\pm SD)	7.95 (\pm 3.4)
Child Sex	
Male	323 (53.7)
Female	279 (46.3)
Education level of caregiver	
Less than college degree	336 (55.8)
College degree and higher education	266 (44.2)
Family income (Saudi Riyals)	
Less than 7000	191 (31.7)
7000–12,000	277 (46.0)
More than 12,000	134 (22.3)
Condition of CSHCN	
ASD	233 (38.7)
Down's syndrome	296 (49.2)
Cerebral palsy	15 (2.5)
Developmental delay	58 (9.6)
Family size	
Small family (1–2 children)	167 (27.7)
Large family (3 or more)	435 (72.3)
Child's order	
First born	151 (25.1)
Non first born	450 (74.8)
Main Results	
Importance of dental care (agree)	588 (97.6)
Routine visit (Yes)	150 (24.9)
Time to reach care	
Less than 1 hour	557 (92.5)
One hour and more	45 (7.5)
Difficult to obtain treatment (yes)	314 (52.2)
Difficulty reaching the dental clinic (yes)	431 (71.6)
Difficulty finding the dentist (difficult)	547 (90.9)
Treatment carried out	
Examination and preventive measures	509 (84.6)
Dental examination	478 (79.4)
Oral hygiene instructions	112 (18.6)
Fluoride application	202 (33.6)
Prophy	191 (31.7)
Radiographs	317 (52.7)
Treatment	270 (44.9)
Dental fillings	160 (26.6)
Crowns	54 (9.0)
Extraction	142 (23.6)
No treatment received	58 (9.6)
I don't know	7 (1.2)
Treatment provider	
Pediatric Dentist	439 (72.9)
General dentist	72 (12)
Others	25 (4.1)
I don't know	58 (9.6)
None	8 (1.3)

SD: Standard deviation, ASD: Autistic spectrum disorder, CSHCN: Children with special health care needs.

TABLE 2. List of significant factors associated with different types of difficulties: obtaining dental treatment, finding a treating dentist, and reaching the dental care.

	Frequencies (%)	chi square results	significant values
Difficulty in obtaining dental care			
Age			
3–6	47.9	$\chi^2 = 8.54$	$p = 0.013$
6–12	52.4		
12–18	68.9		
Time			
More than	66.7	$\chi^2 = 4.1$	$p = 0.045$
Less than	51.0		
Condition			
cerebral palsy	80.0	$\chi^2 = 11.2$	$p = 0.010$
developmental delays	67.0		
ASD	49.4		
Down syndrome	50.0		
Difficulty in finding a treating dentist			
Family size			
Small family (1–2 children)	86.2	$\chi^2 = 5.9$	$p = 0.013$
Large family (3 or more)	92.6		
Education level			
Less than college degree	93.2	$\chi^2 = 4.8$	$p = 0.020$
College degree and higher education	88.0		
Difficulty in reaching the dentist			
Condition			
cerebral palsy	81.0	$\chi^2 = 12.6$	$p = 0.010$
developmental delays	100.0		
ASD	72.1		
Down syndrome	67.9		
Education level			
Less than college degree	75.3	$\chi^2 = 6.1$	$p = 0.047$
College degree and higher education	66.9		

ASD: Autistic spectrum disorder.

TABLE 3. Barriers reported by caregivers to obtaining dental care for their CSHCN, Jeddah city, Saudi Arabia.

Reason of difficulty	Frequency (%)
Dentist related	142 (29.0)
Dentist unwilling to treat-lack of facilities	57 (11.7)
Dentist unwilling to treat-inadequate training	94 (19.2)
Dentist unwilling to treat-other reasons	40 (8.2)
Patient related	387 (79.1)
Fear of the dentist	301 (61.6)
Unable to sit in a dental chair or cooperate with the dentist	185 (37.8)
Accessibility	203 (41.5)
The dental clinic is too far away	20 (4.1)
Dental clinic difficult to reach	17 (4.5)
Transport difficulties	61 (12.7)
Financial cost	136 (27.8)
Priority	101 (20.7)
There's no time	40 (8.2)
There's no dental problem or treatment is irrelevant or unnecessary	62 (12.7)
Other reasons	31 (6.3)

these barriers as compared to 49% of families with lower income. Similarly, families with lower income and education chose “priority” as a reason more than families with higher income and education (25–27% and 9–11% respectively).

4. Discussion

This study revealed a lack of accessibility and utilization of dental care among CSHCN residing in the city of Jeddah, Saudi Arabia. Larger families and families with low income and education levels reported greater difficulty in accessing dental care for their CSHCN. Fear of the dentist, child uncooperativeness and accessibility of dental clinics were the main barriers reported. Previous reports agree with this study, demonstrating that the inadequacy of dental care for CSHCN is a major unmet healthcare need [21, 22, 24, 28, 29].

Generally, dental care for CSHCN necessitates specialized knowledge, increased awareness and care, adaptation to specific medical conditions, and reconciling procedures outside of the usual routine [1]. The ultimate goal is the strict adherence to preventive measures, because dental treatment is accompanied with the challenge of behavior management [30]. For example, children with developmental delay require slow and simple communication and sometimes it is helpful to allow caregiver facilitate interpretation. However, patients with profound developmental delay may benefit of advance behavior management techniques such as various sedation modalities, and anesthesia [12]. Another example is patients with cerebral palsy, they require special dental care and considerations including the risk of aspiration and sufficient head support during dental treatment, and the need for pharmacological behavior management techniques such as general anesthesia when extensive dental work is warranted [12].

The present study targeted CSHCN with ASD, Down syndrome, cerebral palsy, and developmental delay. Although a wide range of disabilities fall under the umbrella of special health care needs. These conditions were among the most prevalent disabilities both in Saudi Arabia and worldwide [6, 7, 31]. The reason for such a selection was to target the most common conditions experienced by CSHCN in the country and further to improve dental care accessibility and utilization for these populations. Moreover, other conditions were excluded to allow statistically acceptable numbers in each group in the analysis. Among the four targeted CSHCN in this study, Down syndrome and ASD were the most common, agreeing with previous reports nationally and worldwide of the predominance of these conditions among CSHCN [4, 6].

In the present study, only a fourth of the participated caregivers reported routinely visiting the dentist for their CSHCN. Dental treatments such as dental fillings, crowns, and extraction were provided with a lower rate. These results align with the findings of other studies, in which a lack of dental care is evident among CSHCN [21, 22, 24, 28, 29]. Regarding treatment providers, agreeing with previous reports, pediatric dentists are the primary providers of dental care for CSHCN and very few general dentists provide such a treatment [19, 20]. This could be attributed to the fact that a decent part of pediatric dentistry training is dedicated to delivering care to CSHCN [32]. The findings of this study suggest the demand

of dentists qualified to treat CSHCN. This highlights a need for introducing courses related to dental management for special health care needs patients in undergraduate programs, encourage and incorporate training of special health care dentistry in postgraduate programs, and provide continuing educations for private and public sectors to provide required skills in treating special health care needs children [20, 33, 34].

In the current study, greater difficulties in reaching dental clinics and obtaining dental treatment were reported more significantly by families with children suffering from cerebral palsy and developmental compared to their counterparts with ASD and Down’s syndrome. It seems possible that these findings are probably associated with the limitations in physical activities, motor disabilities, and the need for special transportation are mainly associated with cerebral palsy and developmental delays [35, 36]. Saudi Arabia has implemented a comprehensive access program for people with disabilities and developed regulations to ensure and regulate accessibility for people with disabilities in buildings. The implementation of these services need to be continuously reemphasized in all buildings including dental clinics, specifically in rural communities and other hard-to-reach areas [37]. Some of the arrangements that facilitate access to dental care to CSHCN are providing dental care with lower fees and ensuring that dental clinics are well-equipped to treat these patients [22].

Another important factor in these findings was family education level. Families with education levels lower than a college degree had a greater difficulty accessing dental care, specifically struggling with reaching or finding a dentist as compared to families with higher education. Our findings also revealed that families with lower income had greater difficulties, reporting more barriers due to treatment costs, clinic location and transportation more frequently as compared to wealthier families. These trends are well-documented in literature where caregivers’ demographics, such as education and socioeconomic levels, played a significant role in hindering dental treatment, both in Saudi Arabia and worldwide [26, 28].

The survey further investigated the barriers and limitations hindering parents and caregivers from seeking dental treatment through two aspects. First, the survey asked about the degree of difficulty in reaching and finding dentists, as well as receiving dental care. Second, the survey asked about the specific barriers behind these difficulties. To better understand the results, we sorted the responses into the following categories: patient-related, dentist-related, and accessibility-related, and priority-related.

When investigating the precise barriers hindering dental treatment, patient-related factors were the most reported, specifically fear of the dentist and child uncooperativeness. These were followed by factors related to accessibility, such as treatment costs and transportation. These results somewhat disagree with another survey conducted in Qatif, Saudi Arabia. In their survey, the major barriers to accessibility were a lack of time and the ineffective design of dental clinics in treating CSHCN [28]. A possible explanation for this variation might be attributed to the fact that their sample consisted mostly of patients with developmental disabilities (44%), while this study’s sample consisted largely of patients with Down’s syndrome and ASD. Patient-related factors, such as fear

and uncooperativeness, highlight the importance of having a positive experience with the treating dentist, especially for CSHCN. These barriers can be addressed by educating general dentists and providing them with more experience in treating CSHCN [19, 33].

This study was subject to some limitations, including a possible selection bias in providing online surveys. Families with technology barriers may have not been adequately represented in our study. Also, future studies should conduct a more comprehensive list of treatment provided by the dentist to CSHCN including pulp therapy and antibiotics prescription. Additionally, our findings may not be generalizable due to the use of a non-probabilistic sampling approach. Although this study includes results from multiple treatment centers, future research should represent multiple regions in Saudi Arabia. Finally, surveying dental professionals to understand the limitations preventing them from treating special health care needs would benefit further studies greatly, incorporating their perspective into potential solutions.

The findings of this study revealed that several barriers to dental care for CSHCN exist such as fear of the dentist, child uncooperativeness, the accessibility of dental clinics, treatment costs, and transportation difficulties. Based on the findings of the present study, the authors suggest reemphasizing the present accessibility regulations in private and public dental clinics. Moreover, special educational programs should be offered to families of CSHCN to familiarize them with the available facilities for their children to obtain the needed dental care. Dentists require more education and training in management of CSHCN cases to allow better access to dental care, particularly in underserved areas. Future studies should focus on a national survey to address different areas of the country, as well as dental health plans designed to overcome these barriers. Although the present study focused on the most common CSHCN in Saudi Arabia, however, future studies should broaden the data to include further special health care needs conditions and examining their oral health status.

5. Conclusions

The current study comprehensively explored the main barriers facing children with special health care needs in accessing oral health needs, primarily fear of dentists, child uncooperativeness, and treatment costs. The study provided information to dental educational institutes and clinics on the challenges experienced by children with special health care needs. Dentists require more training and education to facilitate better access to dental care for CSHCN.

AUTHOR CONTRIBUTIONS

SMA—designed the research study. SAA and AAA—conducted the surveys. SSZ and GYB—analyzed the data. SSZ and GYB—wrote the manuscript. All authors read and approved the final manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was obtained from the Research Ethical Committee at the Faculty of Dentistry, King Abdulaziz University (number 2060221). This study was reported in accordance with Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) standards. Participating parents/caregivers were informed that participation is voluntary, and the confidentiality of their personal information is protected. They were required to sign a consent form that briefly explained the study objectives.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

SUPPLEMENTARY MATERIAL

Supplementary material associated with this article can be found, in the online version, at <https://oss.jocpd.com/files/article/1600040999905574912/attachment/Supplementary%20material.pdf>.

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