

Exploring the Barriers to Oral Health Care Perceived by Parents/Caregivers of Children with Disabilities in Qatar

Najat Abdrabbo Alyafei^{1*}, Bushra Naaz Fathima Jaleel², Tintu Mathew³

¹Head of Public Oral Health, Primary Health Care Corporation, Qatar

²Oral Public Health Coordinator, Primary Health Care Corporation, Qatar

³Biostatistician, Primary Health Care Corporation, Qatar

ABSTRACT

Background: The impact of dental diseases is more profound and prolonged among children with disabilities as they are reliant on their parents/caregivers for their oral health care as well as dental treatment needs as the parents/caregivers of these challenged children assume the primary decision-making role. The potential barriers perceived by the parents/caregivers have a significant bearing on the oral health of disabled children. We aim to elicit these barriers so as to provide valuable insights towards the planning and implementation of the oral health programs.

Objectives: 1. To explore the barriers to oral health care perceived by parents/caregivers of children with disabilities in Qatar. 2. To compare the perceived barriers between parents/caregivers of physically and intellectually disabled children.

Methodology: A cross-sectional, descriptive, questionnaire study was carried out among parents/caregivers of children with disabilities who attended eight Special Needs Public Schools in Qatar. A Chi-square test was employed to evaluate the association of perceived barriers with the type of disability.

Results: 84 parents/caregivers (89%) were not aware of the oral treatment facilities available for their challenged children. 79% reported a lack of awareness and knowledge regarding the prevention and treatment of dental diseases. 41% also perceived that the dentist would be reluctant to treat their disabled children.

Conclusion: The results of this study depict the potential barriers perceived by the parents/caregivers towards oral health care of their disabled children.

Keywords: Barriers; Parents; Caregivers; Disabilities; Children; Qatar

INTRODUCTION

Oral health is an integral component of overall general health, wellbeing, and quality of life of a person. World Health Organization (WHO) defines oral health as “a state of being free from chronic mouth and facial pain, oral and throat cancer, oral infection and sores, periodontal (gum) disease, tooth decay, tooth loss, and other diseases and disorders that limit an individual’s capacity in biting, chewing, smiling, speaking, and psychosocial wellbeing” [1]. In recent years, the importance of integrating oral health into National Public Health programs and Non-Communicable Disease (NCD) prevention and control strategies has been realized [2,3].

Access to health care is crucial for the wellbeing of all individuals.

Facilitating access is concerned with helping people to demand appropriate health care resources in order to preserve or improve their health [4]. Donabedian observed that ‘the proof of access to health care is the use of the service, not simply the presence of a facility’ [5]. Pechansky and Thomas further elaborated that the concept of access goes beyond service availability and includes the personal, financial, and organizational barriers to service utilization [6].

Barriers to care either limit or prevent people from receiving adequate health care. In the case of dental care, the most common barriers are financial hardship, geographic location of oral care facility, other pressing health needs, lack of awareness, and poor oral health literacy. Language, education, cultural and ethnic barriers

Correspondence to: Najat Abdrabbo Alyafei, MSDH, Head of Public Oral Health, Primary Health Care Corporation, Qatar, E-mail: n_alsalahi@hotmail.com

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may additionally compound the problem. In many circumstances, multiple issues are often involved.

The vision of ideal oral health care for any country can only be achieved when everyone has access to quality oral health care. Although there is extensive literature on access and barriers to oral health care services [7-11], there has been insufficient research focusing on oral health care issues faced by children with disabilities. Studies have shown that children and adolescents with disabilities appear to have poorer oral health than their non-disabled counterparts [12,13]. The impact of dental diseases is more profound and prolonged among children with disabilities as they are reliant on their parents/caregivers for their oral health care as well as dental treatment needs, and the parents/caregivers of these disabled children assume the primary decision-making role. The perspective of parents/caregivers has a significant bearing on the oral health of disabled children.

To our comprehension, there is no evidence of published research that summarizes the broad range of barriers perceived by parents/caregivers of disabled children in Qatar and this remains a significant gap in knowledge that is pertinent to be succinctly addressed. Hence, this study was accomplished to assess the barriers to oral health care perceived by parents/caregivers of children with disabilities and to compare the perceived barriers between parents/caregivers of physically and intellectually challenged children. The null hypothesis was 'there is no difference in perceived barriers between parents/caregivers of physically and intellectually challenged children'.

MATERIALS AND METHODS

This cross-sectional descriptive study was carried out among parents/caregivers of children with disabilities who attended eight Special Needs Public Schools in Qatar. This study was conducted in accordance with the Declaration of Helsinki. Necessary permissions were acquired from the principals of the respective schools. Written informed consent was obtained and the participation of parents/caregivers in the survey was voluntary and anonymous.

There are presently eight special needs public schools in Qatar affiliated to the Ministry of Education, with 220 children of varying degrees of physical and/or intellectual disabilities. All the parents/caregivers of children with disabilities studying in these Special Needs Schools were invited to participate in the study and the questionnaire was disseminated to all 220 parents/caregivers. The responses collected were analyzed.

A confidential, structured questionnaire was the basis to investigate the barriers to oral health care perceived by parents/caregivers of children with disabilities in Qatar. A cover letter stating the purpose of the study, contents of the questionnaire, an invitation to participate in the research, and informed consent forms together with the pretested structured questionnaires were delivered to the parents/caregivers through the school nurses of the respective Special Needs Schools. The school nurse distributed the documents to every child to take home and convey it to their parents/caregivers and the response was collected within 10 days of dissemination of the questionnaire. A message to remind the parents/caregivers to submit the response was issued, after 5 days.

The questionnaire was anonymized to obtain honest feedback. The study was voluntary and full confidentiality of the collected data was assured to the participants. They were also informed that they had the right not to participate or to withdraw from the study at any point of time without any ramifications. Respondents who signed the informed consent form constituted the study population. Parents/caregivers who did not return the consent form or gave incomplete responses to the questionnaire were excluded from the study.

The questionnaire was divided into 2 sections. The first section collected the demographic information about the parent/caregiver (age, gender, education level) and the child's age, gender, and type of disability. The second section consisted of 7 close-ended questions relating to the perceived barriers of parents/caregivers towards the oral health care of children with disabilities. The questionnaire was construed in English and translated into the Arabic language. The Arabic questionnaire was evaluated and modified by a panel of bilingual experts who was well versed in both Arabic and English, again later it was back-translated. The questionnaire was pretested on 10 parents/caregivers from another non-participating private special needs school and the questionnaire was finalized (Appendix 1).

The data was analyzed using Statistical Package for Social Sciences version 25. Descriptive analysis of data included frequency distributions in numbers and percentages. A Chi-square test was employed to evaluate the association of perceived barriers with the type of disability. The confidence interval was set to 95% and the assumed level of statistical significance was p value <0.05 .

RESULTS

100 parents/caregivers responded to the survey and returned the signed informed consent form and questionnaires during the 10-day response period. The overall response rate was 45%. Out of these only 94 were included in the final analysis after excluding the incomplete responses. These comprised of 25 (26.5%) males and 69 (73.5%) females, with a mean age of 40 years, ranging from 21 to 60 years. The majority of the parents/caregivers i.e. 43.6% were between the ages of 31 and 40 years, 38.4% were between 41 and 50 years, 9.5% were between 21 and 30 years, and 8.5% between 51 and 60 years. Among them, nearly one-third reported having University education, and above, 48% had attained school level and 18% reported having no formal education. The primary oral care providers for the majority of the children with disabilities were their mothers (83%), while only 4% were dependent on their nannies for oral care. 13% were combined to the category of "others" and these included the disabled students competent of oral self-care, oral care by siblings and other individuals.

The age of the students with disabilities in these special needs schools ranged from 6 to 46 years. Most of them (57%) were aged between 6 and 10 years, while 21% were between 11 and 15 years, 12% between 10 and 20 years. The disabled students more than 20 years of age (10%) additionally represent those undergoing training or those employed within the rehabilitation and vocational departments in the special needs schools. Among these students,

Table 1: Demographic characteristics of the study population.

Parents'/caregiver's characteristics		Number	Percentage
Age	21-30	9	9.5
	31-40	41	43.6
	41-50	36	38.4
	51-60	8	8.5
Gender	Male	25	26.5
	Female	69	73.5
Primary oral care provider	Mother	78	83
	Nanny	4	4
	Others	12	13
Highest level of education attained	University and above	32	34
	No formal education	45	48
No formal education		17	18
	Students' characteristics		Number
Age	10-Jun	54	57
	15-Nov	20	21
	16-20	11	12
	21-46	9	10
Gender	Male	47	50
	Female	47	50
Type of disability	Physical	39	41
	Mental	55	59

41% suffered from physical disabilities and 59% were mentally/intellectually challenged (Table 1).

The information revealed by the parents/caregivers about the barriers to oral health care of children with disabilities provides mounting evidence that quantifies some of the challenges they encounter. These have been summarized in Table 2. One of the pronounced barriers noted in our study was that the 84 parents/caregivers (89%) did not know where to take the child for treatment of his/her oral ailments. 79% reported a lack of awareness and knowledge about the prevention and treatment of dental diseases. 41% also perceived that the dentist would be reluctant to treat disabled children, while another 46% did not feel so. Interestingly, 60% of the parents/caregivers felt that the pedodontist (child specialist dentist) would provide dental care. Nearly one-third of the parents/caregivers reportedly perceived that it would take more than a month to obtain a dental appointment for their child with a disability. More positive responses were seen for questions on the accessibility of dental clinic, for which 49% responded in the affirmative, indicating that accessibility was not a barrier. Around 41% of parents/caregivers reported that time was a barrier to take care of the child's dental needs or treatment. No significant differences were noted when the perceived barriers were evaluated by the type of disability.

Table 2: Parents/caregivers responses to questions concerning perceived barriers to oral health care of children with disabilities.

Question	Parents/caregivers responses Total=94		Type of disability		P value
	Number (%)		Physical	Intellectual	
Don't know where to take the child for treatment of his/her oral problem	-		-	-	-
Yes	84 (89)		34	50	p=0.401
No	10 (11)		5	5	(N.S)
Could not get a dental appointment within a month	-		-	-	-
Yes	64 (68)		30	34	p=0.092
No	30 (32)		9	21	(N.S)
Dentist will not undertake the treatment of the disabled child	-		-	-	-
Yes	38 (41)		17	21	p=0.348
No	43 (46)		19	24	(N.S)
Don't know	13 (13)		3	10	-
Dental clinic is not accessible when needed	-		-	-	-
Yes	32 (34)		12	20	p=0.185
No	46 (49)		23	23	(N.S)
Don't know	16 (17)		4	12	-
Availability of pedodontist (child specialist dentist) to treat the child	-		-	-	-
Yes	56 (60)		23	33	p=0.141
No	19 (20)		5	14	(N.S)
Don't know	19 (20)		11	8	-
No time to take care of the child's dental need or treatment	-		-	-	-
Yes	39 (41)		17	22	p=0.445
No	55 (59)		22	33	(N.S)
Lack of awareness and knowledge about prevention & treatment of dental diseases	-		-	-	-
Yes	74 (79)		31	43	p=0.544
No	20 (21)		8	12	(N.S)

DISCUSSION

Disabilities are an umbrella term, covering impairments, activity limitations, and participation restrictions. According to the World Health Organization, impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. The WHO global disability action plan 2014-2021 is a significant step towards achieving health and well-being and human rights for people with disabilities. The action plan calls for WHO member states to enhance research on disability, collection of relevant and internationally comparable data and removal of barriers, and improving access to health services and programs for people with disabilities amongst other recommendations [14].

This study was the first of its kind to thoroughly assess the barriers to oral health care perceived by parents/caregivers of children with disabilities in Qatar. Depending on the type and level of disability, these children are directly reliant on their parents/caregivers for most of their daily activities, including maintenance of oral hygiene. Consequently, the parents/caregivers play a pivotal role in preventing oral diseases and promoting the oral health of this vulnerable group. The parents/caregivers are often the decision-makers in matters related to the oral health of the children. Their perspective has an important bearing on the oral health of children with disabilities.

The understanding of barriers perceived by parents/caregivers towards the disabled child unveils valuable disclosures about their awareness of the child's oral health condition, the priority given to oral health, and their keenness to seek dental treatment and preventive dental services. Studies conducted in Saudi Arabia and India reveal that parents/caregivers of children with disabilities visit the dentist only in case of emergency and absolute necessity [15-17]. Accessing oral health services for children with disabilities is a complex challenge. Access to health services implies the timely use of health services to achieve the best health outcomes. Many factors contribute as barriers to the multi-dimensional matrix of seeking oral care. The barriers may either be "Internal" e.g. oral health-related attitudes, beliefs, behaviors, perceptions about oral care, etc. or "External" e.g. cost of treatment, availability of dental professionals, transportation, etc.

In our study, we assessed the parents/caregivers perceived barriers for seeking care for their children with disabilities as the timely identification of such barriers is the first step in addressing these issues. Our study reveals that lack of knowledge about where to take the child for treatment of his/her oral problems was a substantial barrier among the 89% of the parents/caregivers. This figure is exceedingly higher than 18.2% reported in Poland [18]. This may be attributed to their general unawareness, oral health-related knowledge and attitudes, ethnicity, religious beliefs, and cross-cultural differences. Other factors suggested could be that the parents of children with disabilities tend to be isolated and cease to participate in social life [16,17]. Hence, they lack the awareness of the availability of dental clinics and specialist dentist in their geographical location to care for the oral health of their children with disabilities.

The second most frequently perceived barrier by the parents/caregivers was a lack of awareness and knowledge about the prevention and treatment of dental diseases. This finding is consistent with the reports from London [19] and Saudi Arabia [15]. It is important to lay emphasis that this finding reflects the low priority given to oral health among the study population and their lack of motivation. The natural history of most of the common dental diseases is such that they progress gradually, often without obvious signs and symptoms, until manifesting as pain in the oral cavity, in the advanced stages. Many of the parents/caregivers may face challenges in having the child keep his/her mouth open for a sufficient time to carry out oral hygiene procedures and eventually give up on tooth cleaning, owing to frustration due to lack of compliance from the disabled child.

The dental professionals should recognize and address these inevitable challenges faced by the parents/caregivers of children with disabilities at the earliest. At the forefront, Oral Health Education programs must be conducted to increase the parents'/caregivers' awareness about the prevention and treatment of dental diseases. The dental professionals should educate and empower the parents/caregivers to inculcate examination of the child's oral cavity regularly to identify any pathological changes in the earliest stages and pursue timely care so as to avert the child from suffering dental pain and discomfort. They should be trained to perform daily tooth brushing techniques if needed employing alternative oral hygiene aids or techniques acceptable to the disabled child. They should establish good communication with parents/caregivers and help them to cope with or work around these problems.

The attitude of the dental professionals may also hinder the parents/caregivers from seeking care. In our study, it was found that 41% perceived that the dentist would be reluctant to treat the disabled children, while another 46% did not feel so. This might have resulted from the misconceptions about the dentist's unwillingness to treat the disabled child. However, the parents/caregivers need to be apprised that every dental graduate is trained to provide basic preventive and treatment services to children with disabilities in their curriculum. They are specially trained in various behavior management techniques to deliver the required care. Only a select few cases presenting with coexisting medical conditions and complicated dental procedures require specialist care under general anesthesia. Even though dental professionals do not hesitate to provide dental care for children with disabilities, some studies have reported the inadequate experience as a barrier, which influences their decision to treat such children [20,21]. Further research in this regard is needed to establish whether the professional behavior towards children with disabilities is only perceived by the parents/caregivers or is authentic. It was interesting to note that 56% of parents/caregivers in our study knew about the availability of pedodontist (child specialist dentist) which is comparable to the results of another Indian study [16].

In our study, an attempt was made to explore some of the barriers perceived by parents/caregivers of children with disabilities. Though these are not very exhaustive, they provide us important insights into some of the perceived barriers. Further research is suggested to include other barriers like fear of pain anticipated by the disabled child [21], architectural provisions in the dental clinic to provide treatment to a disabled child on their wheelchairs [22] and the influence of the parents'/caregiver's oral health knowledge, attitude and behaviors towards their disabled child's oral health.

The State of Qatar has established high standards of health care and prohibits discrimination against people with disabilities. It can be stated that with one of the highest Gross Domestic Product (GDPs) in the world, the people of Qatar do not face financial obstacles for seeking health care or any transportation difficulties. Being a relatively small country, there is a good mix of government as well as private dental settings for the residents to access oral care. Specialized clinics within the Primary Health Care Corporation designed to reduce the anxiety of patients with Autism Spectrum Disorders have already been established to deliver comprehensive oral health care.

The barriers elicited in this study were perceived rather than factual. Dental professionals should hence assume a crucial role in breaking the barriers arising due to fallacious perceptions. Increasing the awareness of parents/caregivers about the availability of various treatment facilities, their location, and different modalities for prevention and treatment of oral diseases would go a long way in dispelling the potential perceived barriers. Additionally, it is reported that the parents/caregiver's oral health knowledge, attitude, and behaviors can either facilitate or hinder their child's oral health care or oral health-promoting behaviors. These barriers can be exterminated only through dynamic and empathetic communication between the dental professionals and parents/caregivers and by organizing well planned Oral Health Education and Promotion Programs tailored to the needs of children with disabilities which are culturally appropriate, acceptable and matched to the learning aptitudes of the parents/caregivers. These programs should facilitate overcoming the fallacious perceived barriers, empowering the parents/caregivers with the skills to maintain the oral hygiene of the disabled children.

Regular school-based dental screening programs alongside the delivery of preventive treatments like pit and fissure sealant and fluoride varnish, utilizing mobile dental units can contribute significantly to the improvement of the oral health of the children in this vulnerable group. McIver suggested that the use of audio-visual aids employing storytelling methodology and describing the dental procedure with pictures or simple texts help to familiarize and prepare the child for the treatment, thus achieving favorable and cooperative behavior from the disabled child [23].

It is well acknowledged that the nature and extent of disabilities vary widely and these children cannot be viewed as a homogenous cluster. Each category of disability poses myriad challenges to parents/caregivers with regards to oral care, in its own unique way. It is therefore important that dental professionals devise individualized oral health education and training programs that target specific challenges faced by the parents/caregivers [24].

It is worth mentioning that interprofessional coordination and collaboration with other health care workers, teachers at Special needs schools, and social workers can encourage parents/caregivers to adopt good oral hygiene practices, regular dental visits thereby reducing the need for dental treatment. Additionally, providing a dental directory or a link of the dental clinics in the vicinity of the Special needs school to parents/caregivers at the time of admission to the school might obviate delays in seeking oral care.

Though our study throws light on barriers perceived by parents/caregivers towards the oral health of children with disabilities, there were a few limitations. Data was collected using a

questionnaire which might have resulted in response bias. Since this was a preliminary study and the first of its kind in Qatar, we included all parents/caregivers of disabled children from public special schools in Qatar. Hence results cannot be extrapolated and generalized. Further studies on children with disabilities in Qatar are recommended.

CONCLUSION

Our study highlights certain barriers pertaining to Oral Health care access that exist amongst the parents/caregivers of children with disabilities in Qatar. These barriers hamper the optimal utilization of the Oral Health services available for children with disabilities. Identification and mitigation of such barriers is one of the stepping stones for planning and implementing Oral health Promotion Programs for children with disabilities.

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CONFLICT OF INTEREST

We do not have any conflict of interest to declare.

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