

Barriers to Utilisation of Dental Services among Children with Disabilities in a Coordinated Healthcare Programme in Mangalore in India: A Mixed Methods Study

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ABSTRACT

Purpose: *Unmet oral health needs affect the quality of life of individuals, especially if they are already at a disadvantage like children with special health care needs. Strategies to mitigate these disparities in India's diverse healthcare settings have hitherto been largely ineffective. This study was aimed to assess the utilisation and barriers to the use of dental health services among children with special health care needs, against the background of a coordinated healthcare programme implemented in Nitte (Deemed to be University), Mangalore, India.*

Method: *The study was conducted over a 6-month period, from September 2018 to February 2019. A mixed-methods design was concurrently employed for data collection. Utilisation of dental services was assessed quantitatively, and the barriers to dental services utilisation were assessed qualitatively through caregiver interviews, with a sequential data integration strategy.*

Results: *The quantitative data revealed gross underutilisation of dental resources by children (only 16% availed some form of dental treatment), and the prevalence of avoidance behaviour (63% showed reluctance and did not turn up for appointments). Restorative needs formed the highest unmet dental component among the children (67% required secondary dental care). In-depth interviews with the children's caregivers revealed that the presence of cognitive barriers could have a direct effect on the time and quality of dental care delivered to their children.*

Conclusion: *Cognitive barriers among caregivers appear to have a profound impact on the underutilisation of dental services in their children with special*

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healthcare needs. These barriers may be addressed within the integrated healthcare programme and the dental curricula through provisions for continued individual and community dental education, and motivational efforts that simultaneously target the caregivers and their children with special healthcare needs.

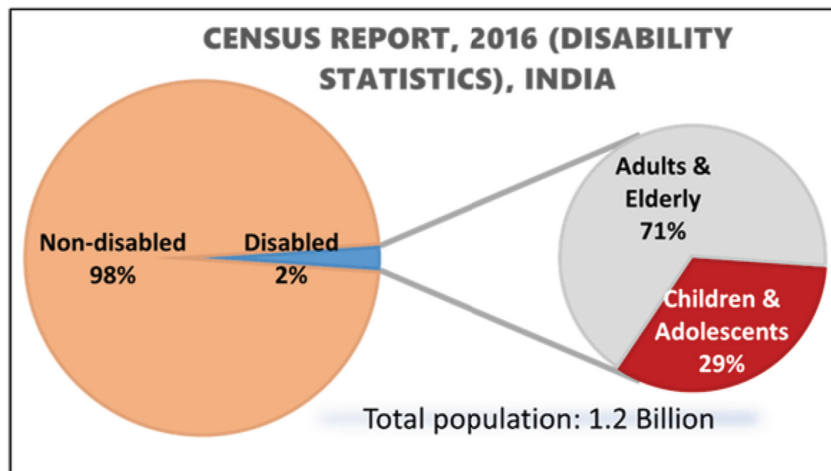
Key words: *caregiver perceptions, dental avoidance, mixed-methods study, dental education, dental health outcomes*

INTRODUCTION

The 2011 population estimates by the World Health Organisation's Disability report suggest that more than 15% of the world's population falls under the disabled category, and among them an approximate 93 million are children below 15 years of age (WHO & World Bank, 2011). Insights from the Global Burden of Diseases study 2019 further reports that these numbers are on the rise, with an acute need for health systems to catch up to the increasing trends in noncommunicable diseases and disabilities (Murray et al, 2020). In India, the Social Statistics Division of the Ministry of Statistics and Programme Implementation summarised the statistical profile for persons with disabilities in their 2016 release (Figure 1):

“As per Census 2011, in India, out of the 121 Cr population, about 2.68 Cr persons are ‘disabled’ which is 2.21% of the total population... The National Policy for Persons with Disabilities (2006) recognises that Persons with Disabilities are a valuable human resource for the country and seeks to create an environment that provides equal opportunities, protection of their rights, and full participation in society” (Ministry of Statistics & Programme Implementation, 2016).

Figure 1: Diagrammatic representation of the Nation's Disability Statistics, adapted from the 2016 Census report



From the report it also follows that nearly one-third of these individuals are children and adolescents.

Since India is often considered “a continent masquerading as a country,” there is an ever-present need for unique, informed policies that are specific to the population that needs to be benefited. To this end, the country’s state governments have been tasked with the responsibility to ensure that all children, irrespective of their disability status, can enjoy their fundamental rights without fear of discrimination. This goal remains unrealised as many of the state governments’ existing policies and healthcare services, including dental services, are underutilised (Mehta et al, 2015; Gambhir & Gupta, 2016; Kharbanda & Dhingra, 2017; Pathak, 2017; Krishnan et al, 2018).

Could this be because of a lack of understanding of the difficulties faced by the children and their families, or a failure to adequately incorporate their views in the policy making and refining process (Seymour, 2001; Singh, 2017)? With minimal coverage in the National Health Policies and budgetary allocations (Gambhir & Gupta, 2016), how does this reflect on the dental needs of these children with disabilities?

Good oral health has been associated with better physical, social, psychological, and behavioural outcomes, with a direct impact on an individual’s quality of life (WHO & World Bank, 2011; Krishnan et al, 2018). However, this aspect of health is usually given least weightage by the individual and by many health

professionals as well. This disparity becomes more evident while dealing with children with disabilities or special health care needs, and gets reflected as such in dental literature (Oredugba & Akindayomi, 2008; Mehta et al, 2015; Pathak, 2017; Mandic et al, 2018). It has also been shown that specific allocations for oral health-related activities receive minimal attention in the National budget, despite the need, and not many have enabled a systematic attempt to address these issues (Gambhir & Gupta, 2016; Petrova et al, 2014). A deeper understanding of the caregivers' perspectives on dental problems of their children with disabilities (also known as children with special health care needs) could go a long way in informing policy-makers and organisations about the reforms needed to enable better utilisation of the dental services offered to them.

Barriers that are most often cited in literature as reasons for the underutilisation of dental health services among children with special health care needs include: financial burdens, high cost of dental treatments, inadequate access to care, non-availability of trained dentists willing to undertake their treatments, inflexibility of dentists, and fear and behaviour of the child in the dental office (Nicolopoulos et al, 2007; Brickhouse et al, 2009; Lai et al, 2012; Melbye et al, 2013; Weiner et al, 2016; Aljabri et al, 2018; Krishnan et al, 2018; Rajput et al, 2019).

The NITTE Special Child Care (NSPECC) programme is a unique integrated healthcare services platform that was instituted with the aim of facilitating easy access to affordable and subsidised health services under the organisation's health coverage network. Since 2015, the programme has run in tandem with the "Sarva Shiksha Abhiyana" (education for all) initiative of the state government of Karnataka, India. The platform serves to organise comprehensive and coordinated healthcare for children with special health care needs who are enrolled into the system through the Board of Education offices in the locality (Mangalore in Karnataka state), and for such children seeking care in the university hospital.

The integrated effort allows for an initial diagnostic screening and check-up for medical and dental complaints while providing the option for emergency, preventive, and minor corrective dental treatments to be done on-site. The dental coverage is done free of cost, by postgraduate residents of the Department of Paediatric and Preventive Dentistry, under supervision, and with appointments scheduled around the needs of the children and their caregivers. A key feature of this programme is the free transportation facility to and from their location that is made available to the children and their caregivers, every fortnight, as part of the package from the hospital administration. This has led to a rise in the

number of children with special health care needs being screened for their dental needs at NSPECC. Even so, the total number of children with special healthcare needs who avail these dental services has remained low, with only 5.2% of them reporting for their follow-up dental appointments (Statistics from 2016-2018). Thus, even after elimination of a majority of the barriers recorded in literature, the organisation's attempts to reach this population have been unfruitful in terms of their oral health recorded.

Objective

The present study was conducted to observe the dental needs and utilisation of dental services by children with special health care needs reporting to the NSPECC centre, from September 2018 to February 2019 (a 6-month period), and to explore the problems reported by their caregivers in availing the dental services on offer to the children.

METHOD

Bearing in mind the ongoing nature of the NSPECC programme, the current study was conducted simultaneously and without causing any overt disruption to the quality of services and healthcare guidance offered to the parents and their children with special health care needs.

Study Design

A dental record maintenance system was instituted at the beginning of the study period (September 2018) and it was made mandatory to record all dental information onto the system at NSPECC. Regular training sessions were given to the postgraduates in the Department of Paediatric and Preventive Dentistry to ensure uniform oral health screening and recording of data. These records were maintained prospectively by the postgraduate residents in attendance at the centre and by the Special Educators at NSPECC to form the dental records repository. The dental repository was regularly monitored by the Head of the Department of Paediatric and Preventive Dentistry, in close coordination with the NSPECC volunteers and organisers. The data for all the children who enrolled during the study period (population sampling for Quantitative data) was then collected by the principal investigator at the end of the study period (February 2019), with due permissions from the Department Head and the Dental Care Coordinator at NSPECC. All information relating to patient identifiers (such as child's name, caregiver name, home address, transport locations, etc.) were redacted by the

NSPECC coordinator before handing over to the principal investigator, in order to avoid bias and ensure child and caregiver confidentiality and privacy. The compiled dental statistics were then used to assess and analyse the dental needs of the children and the utilisation of dental services during the study period.

Study Participants

During the 6-month study period, all the children and their attending caregivers were observed and approached for recruitment into the study. To ensure maximum heterogeneity and variability of the opinions reported, the caregivers were shortlisted for interviews according to the nature of their children's disability and their willingness to participate in the informal interview conducted by the principal investigator (purposive sampling for Qualitative data). Neither the prior dental experiences of the child and caregiver, nor the caregivers' educational status or occupation were considered before inclusion into the study, in order to limit the extent of selection bias and ensure some level of representativeness. After getting their written informed consent to participate, a one-to-one interview was set up on-site with the caregivers in the presence of the NSPECC care coordinator.

Data Collection

Following dental screening of the children with special health care needs who reported to NSPECC between September 2018 and February 2019, their oral health status was communicated to the accompanying adults (usually their respective caregivers) and treatments were advised as part of the programme protocol. They were also informed about the dental services available to the children at free or reduced prices, including support services like transportation and assistance. The adults were then asked whether they would like to start their children's dental treatment at the centre, on the same day. Those who expressed reluctance were asked to elaborate on their reasons, before setting up an appointment for the treatment of the children. The caregivers were also encouraged to exchange telephone numbers with the dental team, to allow for flexibility in scheduling appointments to suit their convenience. The investigators in the study did not interfere in these interactions other than to ensure that adequate records were maintained in the NSPECC registry.

This informal approach enabled the researchers to work within the current system, and the open, qualitative nature of the study ensured that the caregivers did not feel judged. It was believed that the approach of handling the qualitative and

quantitative data collection separately, was useful in encouraging the caregivers to be open about their difficulties in meeting the dental needs of their children, without fear of upsetting and/or disturbing the postgraduates who were treating them.

Quantitative Data Analysis

The dental records obtained from the NSPECC registry were compiled and analysed for patient demographics, nature of the dental visit and reasons for non-utilisation of treatment. A summary of their dental profile (primary, secondary and tertiary treatments needed versus treatments availed of) was compiled. The data was then entered into MS Excel® before exporting to EZR software - version 1.37 (Kanda, 2013) for analysis. Descriptive summaries were computed, and Chi-square test was used to find any statistical significance in the trend of dental treatment utilisation.

Qualitative Data Analysis

The qualitative interview responses were audio-recorded with the consent of the caregivers, and transcribed and translated into English in MS Word®. Each transcript was then screened by the NSPECC coordinators for any personal information, before being assigned an alphanumeric reference code derived from the dental registry, unknown to the investigators in the project.

The data from the interview transcripts was coded manually by the principal investigator using an inductive strategy. Identifiers used for coding included "teeth", "treat", "treatment", "dental" and "dentist". The codes were analysed using an interpretative phenomenological approach (Groenewald, 2004; Pringle et al, 2011) to analyse and identify relevant themes emerging from the dataset. These themes were then analysed against the Health Care Access Barriers (HCAB) model proposed by Carrillo et al (2011) (Fig. 2).

To ensure rigour, the validity of these themes was questioned and discussed with the co-investigators in the project. All conflicts were resolved by retracing the matched interview transcripts of the caregivers for discussion.

Ethical Considerations

The required ethical permissions were obtained from the institution and the information was relayed to the caregivers of the children at their visit to NSPECC

to adhere to the ethical guidelines of the university central ethics committee [NU/CEC/2019/0219]. Informed consent was obtained from caregivers and from children with the cognitive ability to make an informed decision (in the local language). Utmost care was taken to preserve the confidentiality and privacy of the participants in the study.

RESULTS

The total number of children who attended the NSPECC dental programme during the study period was 114. Of these, 96 were new enrolments and 18 were revisits to avail dental treatments. There were 69 males and 45 females. The mean age of the children was 12.5 ± 3.21 years (range 5-21 years). A summary of the children's special health care needs and their caregivers who were interviewed are indicated in Table 1.

Table 1: Distribution of Children enrolled at NSPECC during the Study Period (September 2018 – February 2019) and the Caregivers Interviewed, based on the Children's Special Health Care Needs

Special Healthcare Need (Disability Diagnosis)*	Number of Children enrolled	Number of Caregivers interviewed
Autism Spectrum Disorders	11	2
Behavioural Disorders	4	1
Down Syndrome	5	1
Intellectual Disabilities	17	3
Learning Disorders	27	2
Locomotor & Neuromuscular Disorders	17	4
Physical Impairments	4	1
Medical Disorders	8	1
Orofacial Cleft Deformities	2	1
Speech, Hearing & Language Impairments	11	2
Visual Impairments	12	2
Complex (Multiple) Disorders & Developmental Delays	5	1

*Categories are not mutually exclusive

Quantitative Aspect – Dental Treatment Needs

It was noted that 42 children required preventive and prophylactic dental care (oral prophylaxis, pit and fissure sealants, topical fluoride applications, etc.); 76 children required secondary dental care (cariious and non-cariious lesion restorations, restorations for teeth with deep cariious lesions, prophylactic crown placements, minor surgical procedures, etc.); and 25 children were in need of tertiary dental care (including orthodontic corrections, periodontal lesion repairs, space managements, etc.). In each of these treatment bands, despite the dental needs being conveyed to their caregivers and attenders, the proportion of children who availed the advised primary, secondary, and tertiary dental treatments remained as low as 7%, 6% and 20%, respectively (Table 2). No statistically significant associations were seen between the treatment needs and the treatments availed ($p=0.159$). Similar observations were also derived from the statistics for the secondary needs of the children ($p=0.338$).

Table 2: Summary of the Dental Profiles of the Children reporting to the Centre (treatment needs vs. treatment availed) between September 2018 and February 2019

Type of Dental Treatment*	Treatment Needed (% of total clients)	Treatment Availed (% of treatment needed)	Chi-square test ⁺
Preventive/Prophylactic Care	42 (36.8%)	3 (7%)	X ² =5.25 p=0.262
Secondary Care	76 (66.7%)	5 (6%)	
Tertiary Care	25 (21.9%)	5 (25%)	
Comprehensive Care	3 (2%)	1 (33.3%)	
Recall Examinations	108 (94.7%)	18 (16.7%)	
Type of Secondary Dental Care*	Treatment Needed	Treatment Availed	Fisher's Exact test ⁺
Restorative Care	177	3	p=0.338
Endodontic Care	62	0	
Minor Surgical Care	83	3	

*Categories are not mutually exclusive. +p- values >0.05–not significant; <0.05–significant

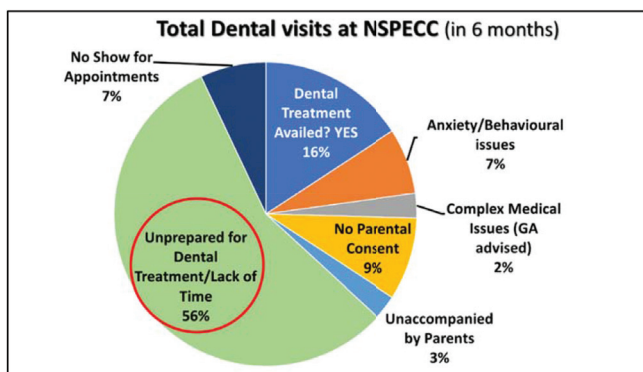
Dental education and oral hygiene instructions were imparted to all the children, regardless of their dental needs, in the presence of their caregivers and/or

attenders. Those who did not require any dental intervention (5 children had good oral health) were also included. Since this was part of the programme protocol at NSPECC, the statistics on this mandatory intervention were not included in the study data.

Semi-Quantitative Aspect – Treatment Delays (Utilisation)

A total of 6 children with special health care needs opted for dental treatment at NSPECC on the day of their dental screening, while appointments at a later date were scheduled for the rest. The reasons for delaying treatment were recorded and summarised (Figure 3). Of the children who were given appointments, only 12 reported for their respective dental treatments (including 1 child admitted for comprehensive oral rehabilitation under general anaesthesia).

Figure 2: Nature of Dental Visits at the Centre from September 2018 to February 2019 (6 months)



Thus, the reasons for requesting an appointment (and delaying the dental treatment) given by the caregivers and attenders of the children with special health care needs, where a majority of them did not show up, were listed and analysed. The following observations were made:

All the primary caregivers who accompanied the children were females, mostly mothers; the exceptions were an aunt, a grandmother, and a stepmother who accompanied one child each.

In 8 cases, despite the willingness of the parents, dental treatments could not be carried out because of anxiety and behavioural issues associated with the child. For 3 children with complex medical problems related to the severity of their

special care needs, comprehensive oral rehabilitation was advised under general anaesthesia, but they did not report for treatment. Ten parents were unwilling to comply with dental treatments for their children and were reluctant to give a reason for the same. Three children were accompanied by their school teachers and their parents did not give their consent for dental treatment (Figure 2).

The caregivers of 72 children reported that they expected only the medical evaluation to be conducted and that there would be no time afterwards for the dental procedures. Among them, 8 had readily agreed for a revisit but did not show up on the scheduled appointment date. The parents of the remaining 64 children showed varying degrees of reluctance and avoidance behaviour before agreeing to make an appointment (for which they did not report) (Figure 2).

Qualitative Aspect – Problems and Opinions

It was possible to conduct informal, in-depth interviews with the parents of 19 of the 64 children who were reluctant to avail of dental treatment and appointments. Their opinions are outlined below.

Opinion 1:

It was a common opinion among most of the interviewed parents that the primary teeth would *“eventually fall off”* and *“new, healthy teeth would come”*.

Opinions 2 and 3:

Nine of the parents informed the researchers that the last time they had taken their child for dental treatment, the child was *“very uncooperative,” “the dentist had a lot of difficulties”* and that *“it took a lot of time”*. In two of these cases, the dentists themselves had informed the parents that they could *“delay the dental treatment till the primary teeth fall off”*.

Opinion 4:

Seven of the interviewed parents reported that they had been to a doctor (physician) when their child had an infection in the gums and that they were *“prescribed medicines”* and *“there are no complaints now”*.

Opinion 5:

In 4 of the interviews, the parents noted that they were referred to a dentist by

their child's treating physician, but that they were unhappy with the referral and commented that the *"dentist was not good"*. When asked why they had felt so, the parents replied that it was because the doctor (in this case, the dentist) *"did not make the pain go away"*. The parents were able to *"go to another doctor"* (meaning, another physician) and *"get pain medicines"*.

Opinion 6:

One parent had already become frustrated with the healthcare system, remarking that *"You doctors take so much time, making us walk left and right, never telling us anything. You do not understand that we risk losing what little money we earn just by wasting time for all these useless treatments. My child doesn't need his teeth treated; they will fall off"*.

Opinion 7:

When discussing the dental needs of 5 of the children, the parents remarked, *"What is the need? My child does not have any problem (symptoms) now"*.

The emergent codes and themes identified from the caregivers' opinions were assessed and then compared against the HCAB model adapted for the study (Figure 2), in order to shed some light on how the dental perceptions of the caregivers had contributed to the high prevalence of oral health care needs among these children, screened at NSPECC (Table 3).

Figure 3: The Health Care Access Barriers (HCAB) model, adapted for the present study, to analyse the Themes emerging from the opinions of the Primary Caregivers

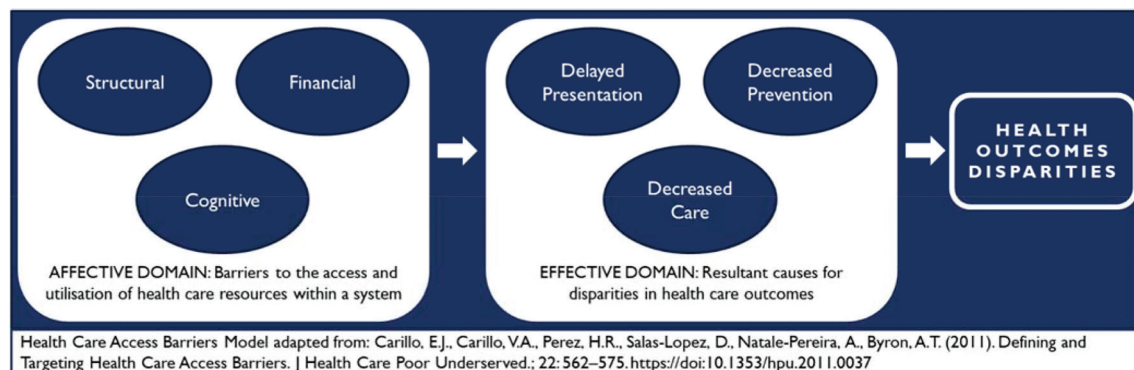


Table 3: Understanding the Barriers to Utilisation of Dental Services, based on the Opinions of the Caregivers

Reason for Unwillingness*	Theme Identified	Cognitive Barrier	Undesirable Outcomes	Oral Health Disparities
<i>"Teeth will eventually fall-off"</i>	Temporary nature of deciduous teeth	Health literacy	Decreased care & Decreased prevention	
<i>"New teeth will come"</i>				
<i>"Treatment is wasted"</i>		Understanding of treatment		
<i>"Child is uncooperative & difficult to treat"</i>	Past dental experiences & Awareness of health resources		Decreased care & Late presentation	
<i>"Treatment takes time"</i>	Prioritisation of dental needs	Health literacy	Late presentation	
<i>"Cannot come again and again (for treatment)"</i>				
<i>"Medicines can be given to get rid of dental problems"</i>	Understanding of diagnosis & treatment			
<i>"No problems in teeth (pain, swelling, bleeding) now"</i>				
Inappropriate/incomplete dental advice	Health literacy & Awareness of health resources			
Improper dental referrals				

*Categories are not mutually exclusive

DISCUSSION

A vast majority of the studies pertaining to dentistry fall under the category of quantitative research. The most obvious drawback of such study designs is that in trying to ensure robustness and generalisability, intricacies such as the individual experiences of the research participants are lost. Adding a qualitative component to the research design limits these disadvantages and enables a well-rounded representation of participant experiences. However, each of these research methods requires specific skill-sets that do not easily inter-mix. Thus, mixed-method studies are, in general, complicated and more difficult to undertake. While such studies are increasingly rare in the field of dentistry, they

add a wealth of information and have the capacity to inform, monitor and direct the flow of public health efforts, such as those outlined in this study.

Here, the simplicity and robustness of the quantitative design was informative about the dental needs of the children with special health care needs and the utilisation of dental services offered; while the qualitative strategy permitted exploration of the mindset of the children's caregivers, and analysis of their rationale for not utilising the dental services. Quantitative Aspect

The findings in this aspect point to the gross underutilisation of dental services made available to the children with special health care needs who enrolled in the comprehensive and integrated health care programme at the institute – NSPECC (Table 2, Figure 3). In addition, they also indicate the presence of barriers to providing dental treatments to these children at outpatient centres and camp sites. It appears that the primary concern for the caregivers is meeting the demands and mitigating the constraints of the special health circumstances of their children; amidst this, dental needs receive low priority.

The low statistics appear counter-intuitive in light of the well-documented need for such an integrated dental and comprehensive healthcare programme (DeMattei et al, 2012; Dagli et al, 2017; Kharbanda & Dhingra, 2017; Pathak, 2017; Mandic et al, 2018). While the numbers show a definite improvement from previous years in the form of revisits (from 5.2% across 2016-18 to 16% during the short 6-month study period), they are still disappointing. The observed rise in the percentage could be due to the timing of the study which coincided with two long-vacation periods in the Indian school curricula as well as numerous festival holidays. This trend is often observed in various healthcare organisations that cater to the needs of children. Among children with special health care needs, this period could also be one of reduced stress and greater convenience for their caregivers, thus resulting in higher compliance in the form of dental treatment visits (Chi et al, 2014; Eigbobo & Etim, 2016). There is also a possibility that the researchers' insistence on collecting data regarding the reason for delay/avoidance of dental care could have prompted the caregivers to take part in the study and, therefore, increase the number of dental revisits.

The findings suggest that the most significant unmet oral health need among the study population was the secondary treatment, more specifically the restorative dental needs (Table 2). Considering the proportion of children who availed the advised secondary dental care, our results are in agreement with those of Mehta

et al (2015) and Mandic et al (2018). While maintaining that the preventive and restorative treatment needs of children with special health care needs should be a priority for public health efforts, this study highlights the need to explore a different aspect. We observe that there is a need to direct our focus toward a pre-existing problem that has received inadequate attention – that administrative solutions to public dental health problems must be met with awareness efforts at the primary level and within the population as well. This is highlighted by the lack of association between the treatment needs and the treatments availed across the dental dimensions documented here (Table 2). It was understood that despite preliminary dental education efforts at the centre, sufficient awareness had not been generated to effect a change in the behaviour or attitude of the caregivers.

Semi-Quantitative Aspect

Regarding the increase in revisits at NSPECC, it remains unclear why the caregivers' response was better than that observed in the previous years. If this was a result of being asked for their reasons by the attending postgraduates, it seems reasonable to assume that an inquisitive approach might simulate the appearance of concern towards the circumstances of the caregivers and their children. This further strengthens the view that in dealing with disadvantaged groups, even within the scope of dentistry, greater levels of empathy and reflective thinking become a prerequisite for creating a positive change in the pattern of utilisation of healthcare services. It also brings into question the empathy and emotional quotient levels of dental practitioners, particularly among postgraduate residents in the field of Paediatric and Preventive Dentistry. Aggarwal et al (2016) commented on the likelihood of a decline in empathy for patients among dental students who are ranked higher in the hierarchy of learning. They suggested that dental educators must consider strategies to improve communication and understanding, thereby improving patient management and interpersonal relationship skills among students at an early stage.

The current study laid the foundation to address the problems raised by this lacuna, by qualitatively exploring the reasons behind the avoidance behaviours of caregivers of the children with special health care needs enrolled in the programme (Table 3, Figure 3).

Qualitative Aspect

Chi et al (2014), in their research, remarked on the negative association between caregiver burden and preventive dental care utilisation. In the current study, by

relying on the caregivers' opinions, an understanding had emerged of the various barriers to the effective utilisation of dental services made available to children with special health care needs.

An overall lack of understanding and knowledge regarding dental disease, more specifically related to dental caries and its management, is evident among the caregivers (opinions 1, 2 and 3, 6, and 7). These appear to be, in part and to some extent, perpetrated also by the dentists and physicians who treat them (opinions 2 and 3, 4, and 6).

An underlying theme (from opinions 2 and 3) is the hidden reference to the temporary nature of treatments performed on primary teeth as these teeth are destined to fall off. According to the caregivers, dental needs were a low priority among the children's healthcare concerns, unless they encountered any overt distress in the form of symptoms like pain or swelling. Highlighted repeatedly, in many of the other opinions, is a lack of understanding about the importance of the primary teeth in the child's oral cavity (opinions 1- 5, and 7).

It also becomes evident (from opinions 4 and 5) that there has been minimal effort on the part of their physicians and treating dentists to educate the caregivers. Whether in providing treatment or prescribing medicines, it is the healthcare provider's duty to make sure that their patients understand the gravity of the disease and the treatment options presented. Without this, the practice of medicine and dentistry will soon become a poor imitation of the entire institution upon which the organisation of the healthcare industry was built. It is often said that "a little knowledge is a dangerous thing." Presenting the children and their caregivers with any amount of incomplete or inaccurate knowledge (opinions 2 and 3, 4, 5, and 6) is a precarious patient management strategy. Adding on from literature, this suggests that specialists, as well as general dentists, must be trained to handle information with care when dealing with disadvantaged and minority groups such as children with special health care needs and their caregivers (Brickhouse et al, 2009; Delli et al, 2013; Duker et al, 2017; Krishnan et al, 2018; Farlina & Maharani, 2018).

It can also be observed (from opinions 4 and 5) that there is a general trend among parents and caregivers to explicitly trust their consulting physicians since the children with special health care needs often require repeated medical attention. However, the dentist is only consulted if and when the physician requests a referral. This entails that the doctors and other healthcare workers,

in the caregivers' eyes, shoulder the responsibility for the oral as well as general health of the child, necessitating the need for increased cooperation among the various factions of the healthcare system.

On the other hand, even in the presence of a knowledgeable physician instituting a timely referral, the caregivers' satisfaction is more closely related to the symptomatic relief of oral infection than the management of the disease itself. This points firmly to the fact that many parents are unaware of the implications of adopting appropriate oral care strategies for their children with special health care needs, and resort to late presenting symptoms such as pain (and in some cases swellings or white discharge and bleeding gums) before seeking dental treatment. This destructive behaviour results from a lack of awareness and understanding, which can be met through more intense or incremental dental education efforts.

Educational efforts will be more effective if timed right; for instance, the parent who brings the child with a dental concern is already aware that a problem exists. The parent will be more alert and, on receiving dental education, the full implications of maintaining good oral health will quickly become apparent.

Krishnan et al (2018) commented on the disparity among dentists (who reported to have provided dental education to their patients), and parents (who reported to have received no dental education from their respective dentists). This calls for a reform in strategy among dental care providers, to consciously focus on imparting dental education in their patients, especially when dealing with children with special health care needs and their caregivers. Moving a step further, such dental education must also be imparted to other healthcare professionals, to enable them to make easy and ready dental referrals, with particular emphasis on deferring medical prescriptions for dental problems until the appropriate dental consultations are made (Waldman et al, 2001; Waldman & Perlman, 2002; Dagli et al, 2017).

Another hidden theme that emerges, after careful consideration of opinions 2 and 3, is that of guilt and shame associated with the specific behavioural concerns of their wards in a public setting such as the dentist's office. Past dental experiences of this nature often lead to a sense of hopelessness and increase the likelihood of improper prioritisation of the child's dental needs. These issues tend to have a cumulative effect on the caregivers' mindset, contributing over time to their strain and burden, which further escalates the possibility of late presentation of

dental needs among their children with special health care needs (Chi et al, 2014; Weiner et al, 2016).

Opinion 6 belies a matter of grave concern among the interviewed responses. It is clear from the parents in this situation that they have been scorned by the healthcare system, which remains unsympathetic to the plight of caregivers of children with special health care needs. This highlights the need for an integrated and charitable healthcare system, such as the one offered by NSPECC. However, without proper dissemination of knowledge and information along with the sincere cooperation of professionals within the healthcare community, any mistrust present in the minds of these caregivers would tend to persist.

The nature of the NSPECC programme limits the barriers to dental health care within the structural and financial domains; but even so, there is no accounting for the lost income among parents who are daily wage earners and who suffer most from the additional financial burden that comes with the long-term care of their children (Weiner et al, 2016). Unique solutions are required to cover these concerns among this disadvantaged population

Recommendations

On presenting these study results before an expert panel of paediatric dentists within the institution, the following suggestions were made to effect a change in the behaviour and raise dental awareness among caregivers of children with special health care needs (Figure 4):

- Make a conscious effort to build rapport with the child and the caregivers.
- Discuss the unmet dental needs of the child and where possible, include the child and the caregiver in the dental examination, demonstrating and describing the lesions in the oral cavity of the child.
- Dental education is best given following the clinical examination and discussion of the treatment needs of the child.
- Dental education efforts are more impactful if done in the presence of the child, engaging the caregiver and the child simultaneously.
- Oral hygiene instructions may be given to the child, but in the presence of the caregiver, including them in the discussion of directions in such a way that it modifies and adds onto their current oral care practices.

- Dental education and counselling must take into consideration the past dental experiences of the caregiver and the child, taking care to address as many of their issues as possible. Be patient and accommodating.
- It is recommended to keep the dental educational session, at the first visit of the child, taking care to explain every aspect of the unmet dental needs of the child. Following visits must be compounded with short motivational reinforcements as well.
- Always take into consideration the nature and extent of the child's special health care needs. It is crucial to find a way to work around the child's health circumstances.
- Instituting a timely reminder, reinforcement and recall period is as important as any educational effort.
- Be cognizant of the amount of dental information imparted and reinforced at each dental visit. Avoid overloading the child and the caregivers.
- It may be beneficial to institute a re-evaluation system against the educational efforts of the dental team.
- Always maintain adequate and accurate records of all dental procedures, including any special instructions given to the caregiver or child.
- Use colourful pedagogy charts for children and informative pointers in the form of pamphlets for caregivers to make for useful, at-home reminders.

Figure 4: Recommendations for Dental Practitioners working with Children with Special Health Care Needs and their Caregivers

Recommendations:
<ul style="list-style-type: none"> ▪ Build rapport & actively listen to their concerns.
<ul style="list-style-type: none"> ▪ Discuss unmet dental needs of the child. (Demonstrate during dental examination.)
<ul style="list-style-type: none"> ▪ Dental education – <i>Reiterative & Reflexive</i>. (Best done following clinical examination, along with the discussion of treatment needs and treatment schedule.)
<ul style="list-style-type: none"> ▪ Consider past dental experiences & address as many issues as possible.
<ul style="list-style-type: none"> ▪ Remember: Caregivers know their children best! <i>Work with them!</i> (Be patient and accommodating.)
<ul style="list-style-type: none"> ▪ Short counselling and motivational reinforcements at follow-up visits.
<ul style="list-style-type: none"> ▪ Always consider nature & extent of the child's special health care needs. (Find ways to <i>work around the child's health circumstances.</i>)
<p>**3R's: <u>Reminder-Reinforcement-Recall</u>.**</p>
<ul style="list-style-type: none"> ▪ Adequate & accurate records of dental procedures & instructions.
<ul style="list-style-type: none"> ▪ Periodically re-evaluate & re-assess educational efforts of the dental team.
<ul style="list-style-type: none"> ▪ Wherever possible: Use additional education aids – colourful pedagogy charts (children), A/V models# & informative pointers/pamphlets (caregivers).

#A/V: Audio-Visual aids

Implications

In addition to the above, it is suggested that dental educators, administrators, and policy-makers in the field of preventive dentistry and dental public health must focus their undergraduate and postgraduate curriculum towards redefining and restructuring the art of imparting dental education to the public, particularly to those with special health care needs (Kenney et al, 2008; DeMattei et al, 2012; Petrova et al, 2014). The current study, like many others previously published in dental literature, clearly elicits the need to revamp our educational strategy for the next generation of dental practitioners and specialists; to redirect their attention towards a more inclusive system that lets healthcare professionals draw on the combined knowledge and resources in an attempt to improve disadvantaged communities like those with special needs, their caregivers and

families (Waldman et al, 2001; DeMattei et al, 2012; Petrova et al, 2014; Dagli et al, 2017).

There is an increasing gap between the oral health needs and the utilisation of dental services among children with special health care needs, as is supported by various studies in the dental literature. The reasons and causes for these disparities should be the central theme and focus of dental researchers, administrators, and practitioners. Qualitative and mixed-methods studies can aid in gathering suitable data for the institution of systematic efforts to address them.

The decision to employ a concurrent data collection strategy for this mixed-methods study helped avoid wastage of resources and also helped streamline the dental registry system at the programme. Research studies undertaken with a clear view to enhance clinical practice should ideally stem from and be rooted in current methods employed within the healthcare industry. This helps identify their lacunae and distinguishes new areas of focus for improvement. Such studies, when evaluated properly, can then lead to solutions to backtrack and bring about course corrections in the functioning of the organisation as a whole.

Limitations

It must be kept in mind that since the NSPECC programme primarily caters to the children enrolled with the Block Education Office in Mangalore *taluk* (administrative district), the results may be more specific to the population of this region; however, it does not limit the study's significance, mainly because such mixed-method studies are scarce in the dental literature.

CONCLUSION

In the current study setting, meeting the structural and financial barriers to dental services utilisation among the children with special health care needs did not cause the desired impact by increasing dental revisits or availing of treatments. Oral health needs among the children with special health care needs enrolled in the NSPECC programme remained high across the primary, secondary and tertiary treatment dimensions. Thus, it was observed that cognitive barriers may have a profound impact on the underutilisation of dental services among children with special healthcare needs and their caregivers, and consequently may require more intensive public health efforts on the part of dental practitioners, administrators and educators.

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REFERENCES

- Aggarwal VP, Garg P, Goyal N, Kaur P, Singhal S, Singla N, Gijwani D, Sharma A (2016). Exploring the missing link - Empathy among dental students: An institutional cross-sectional survey. *Dent Res J.*; 13(5): 419-423. <https://doi.org/10.4103/1735-3327.192279> PMID:27857767 PMCid:PMC5091000
- Aljabri MK, Gadibalban IZ, Kalboush AM, Sadek HS, Abed HH (2018). Barriers to special care patients with mental illness receiving oral healthcare. *Saudi Med J.*; 39(4): 419-423. <https://doi.org/10.15537/smj.2018.4.21560> PMID:29619496 PMCid:PMC5938658
- Brickhouse TH, Farrington FH, Best AM, Ellsworth CW (2009). Barriers to dental care for children in Virginia with autism spectrum disorders. *J Dent Child (Chic.)*; 76(3): 188-193.
- Carillo EJ, Carillo VA, Perez HR, Salas-Lopez D, Natale-Pereira A, Byron AT (2011). Defining and targeting health care access barriers. *J. Health Care Poor Underserved*; 22: 562-575. <https://doi.org/10.1353/hpu.2011.0037> PMID:21551934
- Chi DL, McMannus BM, Carle AC (2014). Caregiver burden and preventive dental care use for U.S. children with special health care needs: A stratified analysis based on functional limitations. *Matern Child Health J.*; 18: 882-890. <https://doi.org/10.1007/s10995-013-1314-x> PMID:23793537 PMCid:PMC3815970
- Dagli P, Singh J, Sheth J, Kakkad K (2017). Incorporation of dental screening in paediatric office practice. *Journal of Nepal Paediatric Society*; 37(2): 138-146. <https://doi.org/10.3126/jnps.v37i2.17028>
- Delli K, Reichart PA, Bornstein MM, Livas C (2013). Management of children with autism spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations. *Med Oral Patol Oral Cir Bucal.*; 18(6): e862-e868. <https://doi.org/10.4317/medoral.19084> PMID:23986012 PMCid:PMC3854078

- DeMattei RR, Allen J, Goss B (2012). A service-learning project to eliminate barriers to oral care for children with special health care needs. *J Sch Nurs.*; 28(3): 168-174. <https://doi.org/10.1177/1059840511432473> PMID:22215649
- Duker LIS, Henwood BF., Bluthenthal RN, Juhlin E, Polido JC, Cermak SA (2017). Parents' perceptions of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration. *Res Autism Spectr Disord.*; 39: 63-72. <https://doi.org/10.1016/j.rasd.2017.03.002> PMID:29098015 PMCID:PMC5662021
- Eigbobo JO, Etim SS (2016). Trends in dental treatment of children at the University of Port Harcourt Teaching Hospital, Port Harcourt, Nigeria. *Sahel Medical Journal.*; 19: 220-226. <https://doi.org/10.4103/1118-8561.196373>
- Farlina A, Maharani DA (2018). Barriers of utilisation of dental services among children and adolescents: A systematic review. *Padjadjaran Journal of Dentistry*; 30(3): 150-162. <https://doi.org/10.24198/pjd.vol30no3.15001>
- Gambhir RS, Gupta T (2016). Need for oral health policy in India. *Ann Med Health Sci Res.*; 6(1): 50-55. <https://doi.org/10.4103/2141-9248.180274> PMID:27144077 PMCID:PMC4849117
- Groenewald T (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*; 3(1): 42-55. <https://doi.org/10.1177/160940690400300104>
- Kanda Y (2013). Investigation of the freely available easy-to-use software 'EZR' for medical statistics. *Bone Marrow Transplantation*; 48: 452-458. <https://doi.org/10.1038/bmt.2012.244> PMID:23208313 PMCID:PMC3590441
- Kenney MK, Kogan MD, Crall JJ (2008). Parental perceptions of dental/oral health among children with and without special health care needs. *Ambul Pediatr.*; 8(5): 312-320. <https://doi.org/10.1016/j.ambp.2008.04.005> PMID:18922505
- Kharbanda OP, Dhingra K (2017). Oral health inequality in India: Perspectives and solutions. *Nature India Special Issue: Oral Health Inequalities and Health Systems in Asia-Pacific.*
- Krishnan L, Iyer K, Madan Kumar PD (2018). Barriers in dental care delivery for children with special needs in Chennai, India: A mixed method research. *Disability, CBR and Inclusive Development*; 29(4): 68-82. <https://doi.org/10.5463/dcid.v29i4.739>
- Lai B, Milano M, Roberts MW, Hooper SR (2012). Unmet dental needs and barriers to dental care among children with autism spectrum disorders. *J Autism Dev Disord.*; 42(7): 1294-1303. <https://doi.org/10.1007/s10803-011-1362-2> PMID:21909827
- Mandic J, Jovanovic S, Mandinic A, Ivanovic M, Kosanovic D, Milicic B, Zivojinovic-Toumba V (2018). Oral health in children with special needs. *Vojnosanit Pregl.*; 75(7): 675-681. <https://doi.org/10.2298/VSP160707372M>
- Mehta A, Gupta R, Mansoob S, Mansoori S (2015). Assessment of oral health status of children with special needs in Delhi, India. *RSBO Revista Sul-Brasileira de Odontologia*; 12(3): 244-251.
- Melbye M, Huebner CE, Chi DL, Hinderberger H, Milgrom P (2013). A first look: Determinants of dental care for children in foster care. *Spec Care Dentist.*; 33(1): 13-19. <https://doi.org/10.1111/j.1754-4505.2012.00312.x> PMID:23278144 PMCID:PMC4065575

Murray CJL, Lopez AD, Vos T, Lim SS, et al (2020). Five insights from the Global Burden of Disease Study 2019. *Lancet*; 396: 1135-1159.

Nicopoulos M, Brennan MT, Kent ML, Brickhouse TH, Rogers MK, Fox PC, Lockhart PB (2007). Oral health needs and barriers to dental care in hospitalized children. *Spec Care Dentist.*; 27(5): 206-211. <https://doi.org/10.1111/j.1754-4505.2007.tb00348.x> PMID:17990481

Oredugba FA, Akindayomi Y (2008). Oral health status and treatment needs of children and young adults attending a day centre for individuals with special health care needs. *BMC Oral Health*; 8(1): 30. <https://doi.org/10.1186/1472-6831-8-30> PMID:18945371 PMCID:PMC2579283

Pathak M (2017). Oral care delivery through primary health centers at Bangalore Urban District, India - A situation analysis. *Contemp Res J Multidisciplinary Sci.*; 1(1): 92-98.

Petrova EG, Hyman M, Estrella MRP, Inglehart MR (2014). Children with special health care needs: Exploring the relationships between patients' level of functioning, their oral health, and caregivers' oral health-related responses. *Pediatr Dent.*; 36: 233-239.

Pringle J, Drummond J, McLafferty E, Hendry C (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*; 18(3): 20-24. <https://doi.org/10.7748/nr2011.04.18.3.20.c8459> PMID:21560922

Rajput S, Kumar A, Puranik MP, Sowmya KR (2020). Oral health inequalities between differently abled and healthy school children in Bengaluru - A cross-sectional study. *Spec Care Dentist.*; 40(1): 55-61. <https://doi.org/10.1111/scd.12432> PMID:31710118

Seymour WS (2001). In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research*; 1(2): 147-168. <https://doi.org/10.1177/146879410100100203>

Singh A (2017). Commentary: Societal determinants of oral health inequalities in Asia-Pacific. *Nature India Special Issue: Oral Health Inequalities & Health systems in Asia-Pacific.*

Social Statistics Division (2016). Disabled persons in India. A statistical profile. Ministry of Statistics and Programme Implementation, Government of India. http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016.pdf [Accessed on 25 Sep 2018].

Waldman HB, Perlman SP, Swerdloff M (2001). Children with mental retardation/developmental disabilities: Do physicians ever consider needed dental care? *Ment Retard.*; 39(1): 53-56. [https://doi.org/10.1352/0047-6765\(2001\)039<0053:CWMRDD>2.0.CO;2](https://doi.org/10.1352/0047-6765(2001)039<0053:CWMRDD>2.0.CO;2)

Waldman HB, Perlman SP (2002). Providing dental services for people with disabilities: Why is it so difficult? *Ment Retard.*; 40(4): 330-333. [https://doi.org/10.1352/0047-6765\(2002\)040<0330:PD SFPW>2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040<0330:PD SFPW>2.0.CO;2)

Weiner RC, Vohra R, Sambamoorthi R, Madhavan SS (2016). Caregiver burdens and preventive dental care for children with autism spectrum disorder, developmental disability and/or mental health conditions: National survey of CSHCN, 2009-10. *Matern Child Health J.*; 20(12): 2573-2580. <https://doi.org/10.1007/s10995-016-2083-0> PMID:27465058 PMCID:PMC5124399

World Health Organisation (WHO), World Bank (2011). World report on disability. Geneva: WHO. Available at: http://www.who.int/disabilities/world_report/2011/en/index.html [Accessed on 9 Feb 2019].