Barriers in Dental Care Delivery for Children with Special Needs in Chennai, India: A Mixed Method Research

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ABSTRACT

Purpose: *The study aimed to assess the barriers faced by children with disability, both qualitatively and quantitatively, from the perspectives of caregivers and dental practitioners.*

Methods: *A concurrent mixed method design was used. A sample of 195 dentists and 100 caregivers was selected through convenience sampling. A pre-validated questionnaire was used to assess the barriers faced by the children with disability in their care. Focus group discussions and in-depth interviews were conducted with caregivers. Descriptive statistics were computed using SPSS version 20 and thematic analysis of qualitative data was done using NVivo software.*

Results: *195 dentists and 100 caregivers responded to the survey. Majority of practising dentists (83.7%) reported inadequate training in handling children with special needs, while caregivers (38%) reported fear of dentist among the children as major barriers experienced in utilising dental services.*

Conclusion and Implications: *This study helps to identify the barriers faced by children with special healthcare needs. The findings highlight the need for hands-on training to be incorporated into the dental curriculum. It also suggests that improvements be made in dental clinics to accommodate these children in comfort. Due to limitations of the study, it is suggested that there is a need for further longitudinal studies that involve other family members of children with disability.*

Key words: *Developmental disabilities, dental utilisation, barriers, children.*

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INTRODUCTION

Based on the 2011 population estimates, over 1.86 billion people (or 15% of the world's population) are under 15 years of age and have a disability (WHO & World Bank report, 2011). The Convention on the Rights of the Child (1989) and the Convention on the Rights of Persons with Disabilities (2016) directed the governments of each state to be responsible and ensure that all children, irrespective of any disability, enjoy their rights without discrimination. Despite such efforts, it is well-documented that children with disabilities are often socially excluded and frequently lack access to primary as well as rehabilitative healthcare along with education (WHO, 2010).

Several studies have found that people with disabilities are more likely to experience inequalities in accessing healthcare. A number of qualitative (and mixed design) studies have explored the experiences of individuals with disability and their caregivers, in accessing health services. They have highlighted the barriers to accessing healthcare, which include communication difficulties, lack of motivation among caregivers and inadequate knowledge among doctors on the health needs of people with disability (Ali et al, 2013).

Although the physical health of an individual has numerous dimensions, oral health is one component that has a direct correlation with general physical health (Bharathi & Abhinav, 2012). Oral health is important for all children, especially for children with special health needs. Oral health of a person not only influences general physical health, but also has a strong impact on the psychological and social behaviour of a person (Bhambhal et al, 2011). Poor oral health is a known precipitating factor for various health conditions. Individuals with disabilities receive less oral care than the normal population, even though dental diseases are highly prevalent among them. It has been reported that dental treatment is the greatest unattended health need of people with disability (Jennifer, 2014). The primary aim is to provide optimal oral healthcare services to people with disability, and this would require proper planning and execution.

Various factors have been attributed as barriers to dental care access among children with special needs. Three main categories of barriers include structural, financial and personal/cultural barriers (Ishaque et al, 2016). Although barriers that limit access to healthcare services for children with disabilities have been identified through qualitative interviews, little is known about the difficulties children with disabilities encounter while receiving dental care treatment. This

exposes a gap in knowledge concerning the unmet dental healthcare needs and resulting oral health disparities that children with disabilities experience. The present study aims to assess, qualitatively and quantitatively, the barriers faced by children with disability. These include: inadequate disability parking, lack of ramps, presence of narrow doorways, problems in communication, lack of elevators, cramped waiting rooms, examination rooms that are too small to manoeuvre a wheelchair, absence of a dental chair that can accommodate a wheelchair, inaccessible restrooms, dentists' behaviour patterns towards children with disability, cost of dental treatment, and inability to express dental pain. Data obtained from this study could help in shaping disability-related policies locally.

Objectives

The objectives of the study include:

(1) Ascertaining the barriers faced by dental practitioners while treating children with special needs at private dental clinics in Chennai city in India;

(2) Understanding the barriers faced by caregivers in accessing private dental care services for children with disability.

METHOD

Study Design

A convergent mixed method research design was employed as it allowed both qualitative and quantitative data to be collected simultaneously from a single population.

Ethical Considerations

The research was approved by the Institutional Review Board - Ethics Committee of Ragas Dental College and Hospital. Informed consent was obtained from the participants and confidentiality of the information obtained was maintained throughout the study. All the study procedures involving the participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Setting and Study Sample

In Chennai, dental care needs are generally handled by private practitioners. The study sample consisted of 195 private dental practitioners in the city of Chennai, who were registered members of Tamil Nadu State Dental Council, and who had treated at least one child with disability in his/ her clinic in the recent past (3 months earlier).

The other participants were the caregivers of children with various disabilities who were being treated at a tertiary care centre -- National Institute for Empowerment of Persons with Multiple Disabilities – NIEPMD (Divyangjan) in the city. Only those parents or caregivers who spent more than 15 hours a day with children with disability were selected for the study. The sample consisted of 100 female caregivers of children with disability, whose children were between 3 and 15 years of age.

Study Instrument

Based on the Institution of Medicine model of healthcare utilisation, two questionnaires were developed to assess the barriers faced by dental practitioners and by caregivers of children with special needs. Both these questionnaires were content-validated using the C H Lawshe (1975) proforma. Six experts, two from each field - Pedodontics, Public health dentistry and Psychiatry - were asked to evaluate the questions on a three-point scale. The questionnaire was then face-validated among 20 practising dentists and caregivers. The questionnaire administered to caregivers was translated into Tamil, the local dialect, using the standard forward and back translation procedures.

Quantitative Data Collection

A 17-item structured questionnaire was given to dental practitioners and a 15-item structured questionnaire was administered to the caregivers. The questionnaire given to dentists sought demographic details and barriers faced by them during delivery of dental care services to the children with disability. The caregivers were given a questionnaire that assessed demographic factors and barriers they faced in accessing dental services for their children.

Between 15th November 2017 and 10th January 2018, 200 practising dentists and caregivers were contacted in person, by visiting private dental clinics and NIEPMD, a tertiary care centre in Chennai. Six trained dental students collected

data from the two sample groups. There was a response rate of 98% among practising dentists but only 50% among the caregivers.

A purposeful sample of 8 caregivers was selected for in-depth interviews. Selection criteria included caregivers of children with disability in different age groups and with a gender mix. The final sample consisted of 3 girls and 5 boys. Each participant represented one of the broad categories of disability, namely visual impairment, hearing impairment, physical disability, learning disabilities, autism, intellectual disability, multiple disabilities (cerebral palsy with intellectual disability). On completion of the in-depth interviews, a focus group discussion was also conducted between caregivers and each representative of the professionals involved in treating these children, namely one physiotherapist, one speech therapist and two occupational therapists.

Qualitative Data Collection

The caregivers were interviewed for a period of 20 minutes each to understand the oral health barriers they encountered while accessing dental care services. Interviews were in the local language. A topic guide was used to allow participants to share their experiences, and the conversations were recorded. These recordings were translated into English.

Following the in-depth interviews, a 30-minute focus group discussion with the caregivers and the professional therapist was conducted to validate previous information from literature and make additions as when deemed necessary. Detailed notes were taken down where possible during the focus group discussions and elaborated thereafter. The in-depth interviews and focus group discussions with the caregivers of the children with disability were conducted by the principal investigator.

Data obtained from focus group discussions was similar to that obtained from in-depth interviews; hence the qualitative data collection was terminated with these samples.

Quantitative Data Analysis

Data obtained was entered into Microsoft Excel 2007 and was analysed using SPSS version 20 for descriptive statistics.

Qualitative Data Analysis

The data from the interviews and focus group discussions were thematically analysed by the researchers using NVivo 10, a qualitative software package for data analysis.

RESULTS

Table 1 shows demographic details and responses made by the practitioners and caregivers to the questions.

Table 1: Demographic Characteristics and Responses to the Questionnaire of both sets of Participants

Characteristic Variable	Practitioners (%)		Caregivers (%)
Gender			
Male	56.2		0
Female	43.8		100
Education			
High School	-		35.6
Bachelor's Degree	41.7		15.8
Master's Degree	58.3		4
Diploma	-		25.7
Not Educated	-		18.8
Questions Asked			
Questions to Dental Practitioners	**Dentist's response n (%)**	**Questions to Caregivers**	**Caregiver's response n (%)**
Dental Visit Between 1- 3 Children per Month	154(79.4)	• Priority • Frequency of Dental Visit	96(95) 45(44.6)
Type Of Disability - Intellectual	83(42.4)	• Communication difficulty of Child Yes	94(93.1)
Not Aware Of Disabilities Act 1995, Bill 2014	125(64.4)		

Need To Incorporate In Curriculum & Training	176(90.7)	Satisfactory Knowledge of the Practitioner	98(97.8)
Perceived Barrier: Inadequate Training	165 (83.7)	• Perceived Barrier: Fear of Dentist	39(38.6)
• Common Condition Seen: Dental Caries • Preferred Modality of Care- Oral Hygiene Instructions	82(42.3) 96(46.4)	• Ability to Manage in Clinic No • Preferred Modality of Care- Not Interested in General Anaesthesia Treatment	93(93.1) 92(91.9)
Source of Knowledge: Consulting Specialist	91(46.9)	Skill of Dental Practitioner Satisfactory Yes	76(75.4)
Infrastructure Present Comfortable Yes	104(53.4)	Availability of Dental Facilities Comfortable	24(23.4)
Financial Concessions Given	153(78.9)	Financial Concessions Given	75(74.3)

The questionnaire was given to 200 dentists and 200 caregivers who were identified as initial samples but only 195 dentists and 100 caregivers completed the questionnaire. Majority of the dentists were individual practitioners; 101 or 52.1% of them had less than 5 years of private dental practice experience and 94 or 47.9% had at least 10 years or more of private dental practice experience. Children with intellectual disability were the most frequently seen clients with disability in dental clinics, yet 125 or 64.4% of the dentists were unaware of the Right to Disability Act (2016) and around 176 or 90.6% of them felt the need to incorporate training on children with special needs in their curriculum. About 165 or 83.7% of the dentists reported inadequate training in handling children

with special needs as major barriers, whereas 39 or 38.6% of caregivers reported infrastructural limitations of dental clinics as a barrier to access by the special children. Most of the dentists - 96 or 46.4% - preferred to manage clients with special needs by giving oral hygiene instructions and carrying out preventive procedures. About 162 or 83% of the dentists reported that they educate the caregivers on maintaining the oral tissues and preventing diseases, whereas 70 or 69.7% of the caregivers reported that they had received no such advice from dentists. Around 152 or 78% of the dental practitioners reported that they showed consideration for the financial status of the children with disabilities and their families; similarly, 75 or 74.3% of the caregivers stated that the doctors gave them fee concessions. A majority of the practising dentists - 125 or 64.4% - reported discomfort while treating the children with disability in the regular dental chair; likewise, 70 or 69.8% of the caregivers reported that their child felt discomfort while sitting in the currently available dental chair.

Qualitative Analysis Results

All the participants were asked to describe the difficulties they face when they seek dental care for their special children. Four themes emerged from the in-depth interviews and focus group discussions. Two of them were about the barriers they face while receiving dental treatment: 1) Discomfort the special child has in adapting to the regular dental chair, and 2) Cost of treatment. The third theme was about the care the doctors give while providing treatment for their child and the fourth theme suggested some modifications to turn the dental clinics into a barrier-free environment.

1. Impact of the Regular Dental Chair on the Special Children

The regular dental chair posed some problems for the caregivers as they found it difficult to make their children with disability sit there for the required length of time.

> "Child is not interested in receiving treatment but is fine with just opening her mouth. She does not like the bright light focussed on her" (Mother of a 5-year-old child with hearing impairment).

> "It is difficult to transfer her to dental chair so it will be useful if we can do something to the chair so that she can accommodate herself on the chair" (Mother of a 15-year-old child with Cerebral palsy).

The dental chair was not the only problem. Other dental equipment in the clinics also caused inconvenience for the children.

> "He hates mouth drills. He flees from that place the moment he hears the awful sound of drill" (Mother of a 6-year-old autistic child).

However, in contrast to the above statement, dental drills were a source of happiness and excitement for a few children.

> "She is fine with the treatment but needs either myself or my brother by her side while treatment is going on and she is very happy to hear various sounds in dental clinics" (Mother of a 6-year- old child with visual impairment).

Nearly all the caregivers found it difficult to make their children open their mouths and show their teeth to the doctors, though a few reported no problem.

> "There is no problem while getting treatment in dental clinics" (Mother of a 6-year-old child with ADHD).

2. Financial Constraints

Most of the respondents felt dental treatment was very expensive in private clinics as compared to dental hospitals.

> "Most dental treatments we got it done in hospitals so they are not costly" (Mother of a child with hearing impairment and intellectual disability).

Some who felt dental treatments were costly, managed to pay the amount in instalments.

> "Dental treatments are costly, we manage it by asking dentist to reduce the fee sometimes, else we will somehow pay it in instalments" (Mother of an autistic child).

3. Impact of Dentist's Behaviour towards their Child

Everyone felt that the dentists understood their child's problem and were empathetic and careful while treating them.

> "They understand my child's problem and treat with great concern and talk very well with my child" (Mother of an autistic child).

They also reported that the dentists were considerate and helped to transfer the child from the wheelchair to the dental chair.

"Dentist understands my child's problem and even helps us in transferring our child from her wheelchair to the dental chair" (Mother of a child with physical disability).

4. Modifications Suggested

The caregivers suggested certain modifications which they felt would make the dental clinics barrier-free for their special children. They felt that pleasant coloured rooms at the clinics, with soft music playing in the background, might help to reduce the children's anxiety and fear, which in turn would improve their rapport with the dentist. Reducing the noise produced by the dental equipment would also help in making the children remain seated in the dental chair for longer duration.

"He likes music and videos; if we play his favourite music he may show his teeth for some time" (Mother of a child with learning disability).

"If you can put some soft music in his ears he may show his teeth" (Mother of a child with learning disability).

Parents of children with physical disabilities mentioned the difficulty in using the present dental chair which, if modified to suit the wheelchair, would be of great help to them.

"It is difficult to transfer her to dental chair so it will be useful if we can do something to the chair so that she herself can sit into the chair" (Mother of a child with Cerebral palsy).

A few of them suggested that if only the members of the dental team would inspire confidence in their children, they would cooperate well with the dentists.

DISCUSSION

Oral health is an important aspect of general health, and is all the more important for children with special health needs. Oral care for individuals with disabilities or illnesses receives less attention than it does among the normal population, although the former often have more dental ailments. It has been reported that dental treatment is the greatest unattended health need of people with disabilities (Bhambhal et al, 2011). Their oral health may be neglected because of the disability, a demanding disease or limited access to oral healthcare. Moreover, because of their restricted level of functioning and their limited ability to undergo an oral

examination, people with disabilities present specific challenges when their oral health is attended to. Lack of oral health services to these segments of the population is worrisome and is a major drawback (De Jongh et al, 2009).

Majority of the practising dentists (83.7%) conveyed inadequate training as a barrier in managing these children at their private dental clinics. These findings were in congruence with a study reported by Adhyanthaya et al (2017) who stated that 84.6% of dentists felt a similar lack of training.

Fear of dentists was expressed as one of the major barriers by caregivers (38.6%) of children with disability, whereas a study by Sharifa (2013) reported a slightly higher percentage of caregivers (52.4%) mentioning a similar fear among children with disability. According to Bhambhal et al (2015), difficulties in accessing oral healthcare services for individuals with disability may be explained by their physical problems, which are often exacerbated by associated medical problems, the side effects of medication, and the disability itself. Another explanation may be the children's lack of cooperation during treatment. The report by Linda et al (2011) stated that 39% of caregivers mentioned uncooperative children as a barrier while utilising dental services, whereas in the present study about 7% of the caregivers reported that their children with disability cooperated or remained passive while receiving treatment at the dental clinic.

Around 43.8% of dentists were comfortable in delivering preventive treatments to children with disability, which concurred with findings by Adhyanthaya et al (2017) who mentioned that 30.8% of dentists gave only oral health education and preventive treatment to these clients. The study also reported that dentists had difficulty in gaining access to their mouths. Therefore, dental practitioners with limited experience in treating children with disabilities are more likely to avoid treating these clients as they may feel inadequate, lack the required skills and be reluctant to treat individuals who display resistant and maladaptive behaviour. This concept was supported by the findings of the study done by Rao et al (2005) which reported a significant correlation between experience and treatment rendered by dentists to their clients with disabilities. Another interesting finding of the current study was regarding oral health education that 63% of the practising dentists claimed to have imparted to the caregivers; when caregivers were assessed regarding the same, 69.7% of them denied having received any such instructions from the dentists. These results were in accord with the study by De Jongh et al (2009), where 98% of dentists claimed that they provided oral

health instructions to the caregivers, but only 37% of these caregivers agreed that they had been instructed.

Lack of proper infrastructure at their respective clinics was reported by 64.4% of the dentists. This was in harmony with the report of Edward and Merry (2002) who had mentioned that 86% of the clinics lacked proper infrastructure to facilitate ease of access to children with disabilities. Among the caregivers, 86.4% cited lack of adequate facilities in dental clinics as one of the major barriers in accessing dental care services. However this was in contrast to the findings reported by Gerreth and Lewcika (2015) in their study, where only 3% of the caregivers felt the architectural limitations of dental clinics were barriers in accessing dental services. This difference can be explained by the disparity in socioeconomic status and policy differences in the countries where the respective studies were carried out.

Several studies have mentioned financial constraints as a major barrier while utilising dental care services (Linda et al, 2011; Sharifa, 2013; Bhaskar et al, 2016). This was in contrast to the results of the current study, as 74.3% of caregivers reported that the dentists showed consideration while fixing the fee for children with disabilities.

About 69.8% of the caregivers reported that their children with disabilities experienced discomfort when using the regular dental chair. This was in consensus with the findings of Sharifa (2013) and Ishaque et al (2016) which had mentioned that 28.2% and 31.2% of the caregivers had reported the same, respectively.

Analysis of the various aspects considered in this study leads to the conclusion that providing care for children with special needs is governed by multiple factors which include skill, appointments, dental equipment and infrastructure from the dentists' side, with financial, time, attitude, anxiety and compliance from the caregivers' side. Some of these variables overlap, making a complex interrelation between the dentists and the caregivers.

The current study highlights the value of mixed method analysis. In a concurrent design, both qualitative and quantitative data are collected at the same time, giving preference to one form of data over the other if needed. The purpose of using a concurrent mixed method study design is to use both qualitative and quantitative data to more accurately define relationships among variables of interest. The qualitative research corroborated the findings about the barriers faced by caregivers in accessing dental care services for their children with

disabilities, while also providing additional data on the underlying reasons for this and highlighting explanatory pathways in the difficulties they encountered. Understanding these issues in greater depth is essential for stringent policy framing and implementation at the community level, to promote the delivery of dental care to this population.

CONCLUSION

This is one of the very few studies to have explored, quantitatively and qualitatively, the perceptions of both caregivers of children with disabilities and private dental practitioners who, by and large, render dental services for these children. Through a survey of both private dental practitioners and caregivers of children with disabilities, important findings were reflected in this study. The caregivers reported that fear of the dentist was a major barrier that children with disabilities faced, whereas the majority of dentists felt that inadequate training among the dental fraternity was a major barrier they faced when treating children with special needs.

These findings highlight the need for incorporating dental and disability education into the dental curriculum, as well as conducting more hands-on sessions and training workshops to improve the efficiency of dentists in handling clients with special healthcare needs. Also, more awareness campaigns on oral health should be organised for caregivers of clients with disabilities, in order to motivate them to utilise dental healthcare services.

Limitations

A few limitations have been identified in this study. There is a possibility of bias, as self-reported information is subjective in nature. The participants may have under- or over-reported the information if they perceived it to be socially desirable (Aschengrau and Seage, 2003). Although an accurate response rate could not be calculated, a low percentage of caregivers participated in this study compared to the number invited to participate. Studies with low response rates are susceptible to self-selection bias. Although the sample size for mixed methods research tends to be lower than for purely quantitative research, there was a relatively low sample size for the quantitative analysis portion of the study

The current study only included caregivers and practising dentists. There is also a need to understand the barriers faced by persons with disabilities from the

perspectives of full-time attenders/ nurses who are employed to care for children with disabilities at dedicated institutions.

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