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ORIGINAL ARTICLE

Oral health experiences and perceptions of children with disabilities in the Kingdom of Saudi Arabia

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Abstract

Background: The clinical focus on oral health means there is a scarcity of evidence from the perspectives of children with disabilities because of the continuing exclusion of their views from oral health research. This study takes a rights-based approach, aiming to give disabled children a voice by exploring their oral health perspectives and experiences. In order to do this, innovative and inclusive methods are needed.

Aim: The aim was to include the voices of children with disabilities by representing their perspectives and experiences of oral health.

Design: An ethnographic study employed a purposive sample of 10 children between the ages of 9 and 15 years with a range of intellectual disabilities and physical impairments attending special centres in Riyadh, Saudi Arabia. All children in the sample were female. Pluralistic methods enabled the inclusion of children in the research. Thematic analysis was used to analyse the data.

Results: The study describes different inclusive methods to enable children's voices on oral health. Main themes were children's knowledge, and their oral health practices and experiences of visiting dental clinics. Children also described the physical barriers they experienced and their positive and negative feelings about oral health.

Conclusions: The study highlights that including children with disabilities in oral health research is possible, but that researchers need to be creative and be able to work in tandem with children. One goal for dental research is to include all children as active participants, working with them as collaborators. This would help transform services and reduce children's oral health inequalities.

KEYWORDS

dental care, disabled children, inclusion, oral health, special care dentistry, treatment experiences

1 | INTRODUCTION

Despite guidance from the United Nations Convention on the Rights of the Child advocating the inclusion of children with disabilities in health care, their voices and perceptions are absent in oral health research. Historically, the research into childhood disability either quantitatively measured degrees of impairment or concentrated on verbally articulate children.[1] Increased levels of social research now focus on utilising qualitative methodologies and methods to include the views of children with disabilities and explore what is important to them. Some children with disabilities were excluded from the research if they were pre-verbal or lacked verbal articulacy. This makes researchers responsible for considering diversity in research designs and developing inclusive research strategy skills to enable the active participation of children in research.[2-6]

Within oral health research, a recent systematic review reveals the exclusion of the voices and perceptions of children with disabilities.[7] This contrasts with oral health research with children without disabilities, which suggests a move towards more participatory research.[8,9] All children have the same rights, and therefore, equal consultation regarding support and services is important, particularly because children with disabilities are frequently marginalised and more subject to medical treatment and assessment.[10]

Some research suggests that people with disabilities experience poorer oral health than people without disabilities, with problems ranging from tooth decay and gingivitis to severe periodontal disease.[11,12] Some people with multiple impairments appear to have more complex oral health needs than people without impairments.[13] Yet, this fails to consider diversity within this group, and another study suggests that the self-reported oral health of people with intellectual disabilities is comparable to people without.[14] Clinical oral health studies conducted on children with disabilities report significant dental needs compared with children without disabilities.[15-17] Nevertheless, research on the perspectives of children with disabilities about oral health is scarce. Justifying research with a rights-based approach means using inclusive methods to obtain their perspectives, simultaneously representing their voices. The lack of inclusion about their views and perspective impacts service provision and policy because without this, identifying areas for improvement in oral health promotion initiatives and dental care services is difficult.[18] Therefore, this study aimed at exploring children's perspectives and experiences of oral health and dental services, representing their voices and including them in oral health and research.

Why this paper is important to paediatric dentists

- It provides examples of pluralistic inclusive research methods with children with disabilities.
- It produces evidence that children with disabilities can participate in oral health research.
- It highlights the need for professionals to give children the opportunity to make treatment decisions in a supportive environment.

2 | MATERIALS AND METHODS

2.1 | Study context

The geographic context for this ethnographic study is Riyadh, the Kingdom of Saudi Arabia (KSA). This paper is part of a wider research project exploring the views of 30 participants: 10 children, 10 parents, 5 healthcare providers and 5 educational professionals. It aimed at identifying ways of including disabled children in oral health and research and representing their voices. The data in this paper report only on the children's views and experiences.

2.2 | Ethics

The directors of two city sites consented to this research. The University of Sheffield Ethics Committee (reference: 018466) approved this study. Following ethical guidance meant assigning pseudonyms to participants and altering identifiable characteristics to protect identity. Parents consented to meetings with their children. Children assented to participate with teachers present but could withdraw at any time. The study conformed to the Declaration of Helsinki guidelines.

2.3 | Participants

The study employed a purposive sample of child participants recruited from two different centres for disabled children in KSA. Initially, the lead researcher observed the centres for a month allowing children to become used to her presence before any other form of interaction occurred. Carers and teachers who best knew the children provided knowledge about who would be least distressed interacting with a researcher, and this guided recruitment. With assistance from carers and teachers in explaining the study, 10 children between 9 and 15 years of age with a range of mild to moderate impairments participated. Four

children had mild intellectual disabilities. Two of them had more than one impairment: one had a hearing impairment and epilepsy, and the other had a physical impairment and intellectual disability. Four children had moderate intellectual disabilities. Two had physical impairments resulting from cerebral palsy.

All participants were female because KSA segregates education to conform to social rules and norms. While the Ministry of Health in KSA permits access for male and female researchers to enter health centres for the purposes of care and treatment, the Ministry of Education has different rules. For a Saudi female researcher, it is socially unacceptable to enter all-male educational centres, and this unintentionally excluded the voices of male students in the current study.

2.4 | Data collection and analysis

Data collection included participant observation and interviews. Participant observation began with fieldwork, which was also continued during data collection. To gain more familiarity with layout, structure, routines, and institutional events, the main researcher visited research sites and observed for 3 hours, daily, and 5 days a week, for 3 months. This also enabled children to become familiar with her. A classroom observation schedule enabled observation of communication methods and the social interactions of the children with one another and other school members.

The study explored children's experiences, using pluralistic methods. This began by developing questions, with teacher input to guide the interview format, which occurred at school. Social conventions prevented the interviewer from visiting children's homes. Before the interviews, the lead researcher explained to the children what they might do together, and children were given time to talk about anything they liked. This aimed not only to maximise the children's confidence in expressing themselves but also to increase the researcher's confidence in understanding their communication method. Existing research guided the researcher on developing skills working with children, understanding children's communication methods and working on the child–researcher relationship. Disability activists view this as an essential part of the research process before conducting research activities.[19]

The main researcher received training in qualitative research methods prior to the study and conducted interviews with the children, either individually or in pairs at their request. Conducting the interviews for each child or pair occurred over five or six sessions. Each session took from 40 minutes to an hour on different days. This considered level of fatigue and the differing abilities of each child. Field notes supplemented the interviews and assisted the researcher with context and clarifying meaning when transcription and analysis occurred. It took 4 months to complete the interviews. All interviews were audio-recorded and transcribed verbatim.

Before the interviews, the researcher developed creative methods to elicit children's perceptions such as picture cards, games and guided tours. The choice and presentation of methods varied depending on each child's self-presentation, preferences, demonstrated abilities and comfort. Children appeared to find it easier to participate when engaged in activities.

Using pictures reflecting oral health and dental care stimulated conversation. Questions asked about each image included 'what is in the picture?' and 'what is known about it?' Semi-structured interviews in many cases resembled conversations more than interviews. Parental permission and children's assent occurred before the recording and interview transcription. Digital recording of all interviews took place alongside photographs of the arrangements and worksheets.

Four games designed to help children have fun while expressing their views included sorting, matching and an adapted matching game for those who were unable to hold a pen.

The children sorted A4 laminated pictures of healthy and unhealthy food according to their favourite food and then into 'good/bad for your teeth' categories. The children arranged the pictures thinking aloud about the comparisons between images and the logic of their decisions. After indicating satisfaction with the results, the children explained the order of selection. The researcher asked follow-up questions such as 'Why did you put this picture here?' and 'What is good about it?' The researcher took pictures of the final arrangements and recorded the interview.

For the matching game, children matched healthy/unhealthy foods with the appropriate tooth and explained their answers alongside follow-up questions such as 'What are the consequences of eating healthy/unhealthy food?' This worked well with children with intellectual disabilities but not those with physical disabilities due to the difficulties using a pen or a pencil. Design changes made the activity more inclusive for those with physical impairments by making four laminated sheets (see Figure 1). Although similar in content, the way of completing the activity was different. Children chose correct answers by placing stickers, using fingerprints, drawing circles using glossy paste or dragging the direction to correct answers.

The researcher also used guided tours of the children's learning environment. Each participant took the researcher to a school to show the places they loved or disliked. On stopping, the researcher asked questions such as

FIGURE 1 Matching game for children with physical disabilities

'What do you usually do here?', 'Why do you like or dislike this place?' and 'What can be done to improve things?' The children confirmed the content of the conversations, recorded and transcribed.

The researcher decided whether the interviews generated any new 'information' as a guide of when to stop. The depth of the study when working with the children added to the richness of the data. Yet, this type of data saturation did not form part of the analysis itself. Instead, the researcher followed the guidance of Legard et al who perceived the process of saturation as located principally at the level of data collection, separating it from the fuller process of data analysis and theory.[20]

2.5 | Analysis

Data analysis used inductive thematic analysis, which was concerned with the content of transcripts, allowing the data, rather than theory, to drive the analysis. Using the social model of disability as a lens, through which the data were viewed, enabled the researcher to tease out disabling barriers. Thematic analysis (TA) minimally organises and describes the data set in rich detail.[21] TA consists of six stages: (1) *familiarisation with data*: the lead researcher is a native Arabic speaker, and she transcribed and translated the interviews into English. Another native Arabic speaker, who is an interpreter, separately read and translated the transcripts. Comparison of the transcripts occurred, and discussion around any differences ensued. This process ensured accuracy with translation from Arabic to English. (2) *generation of initial codes*: where important features of the data related to the research question were collected; (3) *searching for themes:* this stage includes refocusing analysis on the broadest level of themes, rather than codes, sorting diverse codes into possible themes and collecting all relevant codes data extracts within the identified themes. This occurred through discussion with supervisors, who read the translated transcripts, offering insights into their interpretations. One of the supervisors is a qualitative research expert, and both have experience in analysis. (4) Discussion, refinement and elaboration of codes and themes occurred with all three authors with agreement on removal of minor themes and combination of other themes. (5) Decisions on 'the essence' of each theme occurred as to which elements of the data each theme captured to give the reader a sense of the theme. (6) The final write-up presented a concise, logical, coherent, non-recurring account of the data within and across themes.

3 | RESULTS

The results of this research illustrated that children with disabilities can participate in oral health research. Successful participation of children was facilitated through the use of creative methods during the data collection process. It emerged that using a range of creative approaches in this study while interviewing children stimulated their responses, becoming an effective way to deal with power differentials as the methods enabled the children's agency. Moreover, the children themselves appeared to view the activities as non-threatening and enjoyable. They offered similar comments, such as '*I love your class; this is really fun*' (Danah, 10).

Using games and pictures as prompts enabled child participation. Using many pictures for each research aspect increased the children's ability to express their views in more depth. The guided tour activity was productive because it facilitated the development of relationships with the children. It also increased their ability to chat informally and appeared to reduce the power imbalance compared with formal, structured interviews.

Findings from the activities with children revealed insights into children's knowledge, practices and experiences of oral health and dental services. The key themes from the children's interviews were as follows:

- Children's knowledge and practices of oral health and dental care
- Children's experiences of oral health and dental care.

3.1 | Children's knowledge and practices of oral health and dental care

Children in this study were able to describe the basic knowledge of oral health and the ways they implemented practices and dietary choices derived from different sources of oral health information.

> I know the toothbrush and the toothpaste, we should brush our teeth daily, once in the morning, once at night, twice a day. We should have healthy food. Our family, mum, my brothers, and the teacher as well taught me how to brush my teeth and what is the healthy and unhealthy food.
>
> (Renad, 10)

The majority of children explained their answers while sorting the pictures (see Figure 2), which showed their understanding. Furthermore, some discussed the consequences of eating unhealthy food and gave a rationale for eating healthy food. Using creative methods enabled them to discuss their knowledge and practices in depth. In contrast, one-to-one interviewing only gleaned a surface level of knowledge.

> I arranged them like that because the healthy food strengthens the teeth, while the other breaks them, unhealthy food like chocolate and soft drinks, we should stay away from it to keep our teeth free from tooth decay.
>
> (Yara, 15)

Some children discussed their need for mothers to help them while brushing their teeth, acknowledging their mother's role and expressing awareness of the importance of this to oral health. Children with cerebral palsy considered supervision of brushing essential.

FIGURE 2 Practical example of using sorting game

> ...mum helps me to brush my teeth. I know how to brush, but I need help It's hard for me to brush my teeth because I'm young; mum needs to help me.
>
> (Renad, 10)

They did not mention the impact of their impairment on being able to care for their oral health. Instead, they presented themselves as 'too young' and knowing how but still needing help. By contrast, there were several children who cleaned their own teeth, refusing or without the need for support.

> I do it myself; no need to be assisted by anyone.
>
> (Yara, 15)

It is evident that some children considered oral health to be their responsibility and wanted to carry out oral health care unaided. Children with cerebral palsy reported that their mothers played a vital role in enabling them to maintain positive oral health. Although not explicitly discussed, this appears to indicate that some children accepted that they had different abilities and required more support for some areas of self-care.

Children were also able to articulate their insights about the dental clinic and dental treatment. The children were able to recognise the dental environment including dental equipment and were familiar with a range of dental procedures.

> ...the dentist checked my teeth, then she did the x-ray. She put something inside my

FIGURE 3 Illustrative pictures reflecting dental clinic

> mouth, then left the room. She gave me anaesthetic and then fixed my teeth. She filled half of my teeth, then she pulled out the other half.
>
> (Deema, 13)

Children expressed their knowledge of the need for dental treatment, by explaining the importance of going to the dentist, that is when and why they should go. They identified different reasons, such as going to a dentist for dental examination or treatment (mainly extraction) or if they felt pain.

> It is necessary to go to the clinic frequently. If we are in so much pain, for example and there is tooth decay, we need to go to the clinic. we go to pull out our affected tooth.
>
> (Gala, 12)

All participants had the experience of tooth extraction, with either local anaesthesia, general anaesthesia or relative analgesia. Extraction was the main treatment provided by dentists, and all children described the role of the dentist in terms of extraction. Other children indicated that they no longer went to the dentist, suggesting that there was no need to go to the dental clinic if they felt their mouth was healthy.

> No need for the clinic, my teeth are good. We only go if we have a problem with our teeth.
>
> (Haneen,11)

This group of children felt that going to the dentist was because either they were in pain or something was wrong. This underlines the issue that preventive advice may not be at the forefront of dentistry for this sample of participants.

3.2 | Children's experiences of oral health and dental care

Within this theme, children described their experiences when visiting the dental clinic, their positive and negative feelings about oral health care and the physical barriers experienced.

Most children asserted that they did not like visiting their dentist, explaining that they felt 'sad' when they had to go for a dental appointment, which might suggest some negative feelings concerning dental attendance. As an example, one participant commented when she saw the pictures (see Figure 3).

> The child is happy because the dentist doesn't hurt her. She is only teaching her how to brush, but the other child is sad like me. I cry when I go to the dentist; she hurts my teeth.
>
> (Danah, 10)

Five children emphasised the lack of interpersonal skills exhibited by some dentists. Frequently, dentists failed to communicate directly with children or involve them in decision-making. They also failed to adjust and adapt their communication to the patient's needs. Children in this study believed that dentists should provide more pieces of information about dental procedures. They often felt ignored in the consultations or 'talked over' if the caregiver was present, implying that they were not being included in the oral health encounter. One child reported:

> The dentist does not talk to me, and she never explains anything. She focuses only on fixing my teeth, and I would like her to tell me what she is doing without hiding anything. I think dentists like to talk to parents about what happened to the child, but I need to know everything.
>
> (Lina, 9)

Furthermore, children in this study indicated that they appreciated clear, honest and straightforward answers. They emphasised that the dentist must be accurate and honest in their advice.

> I don't like the dentist. All that she says is wrong. She pulled out my teeth. Now I don't have teeth at the back. I was wearing my headphone (she has a hearing impairment and headphone means hearing aid). I heard her very well. Why did she lie to me? I told

> her that I'm in pain, I just wanted her to clean them and take care of them, she agreed but she pulled them out instead. She is a liar. She also said, you should eat healthy, food, then your teeth will be white. I ate them, I have listened to her. But, still, my teeth are yellow.
>
> (Yara, 15)

Children also explained the possible barriers related to access to dental care such as the waiting times at the clinic, arrangement of appointments, cost of treatment and fear of dental clinic visits. One child commented:

> I wait for 5 hours; it's usually crowded, and I feel exhausted. Whenever I talk to the dentist to go in, he says there are other people waiting.
>
> (Joud, 14)

Children in this study reported various suggestions for improving dental care. They highlighted the necessity to provide a little incentive from the dentist in the form of small gifts and make the environment more child-friendly to make dental visits acceptable and thus may be one way of enabling children's perceptions to change from negative to positive.

> I would love the clinic if the dentist gave me a gift (toothbrush and toothpaste) and gave me colouring pens and paper.
>
> (Basmah, 11)

> ... The clinic has no toys or any colours on the wall; it's boring. It is a good idea if they ask us how we would like our dental clinic.
>
> (Joud, 14)

These results provide evidence of the exclusion of children's opinions from oral health care. It also sends a clear message that professionals either do not care to listen to children about the things that matter to them or more cynically that their voices do not count.

4 | DISCUSSION

The objective was met by demonstrating a range of research methods used with children in this study to support their inclusion in oral health research. The results demonstrated that enabling the voices of children entailed shifting the research relationship towards researching with children, using creative approaches and respecting their contributions as competent social actors. Children with disabilities were able to voice their experiences and demonstrate their practices of oral health clearly and effectively. They described oral health practices, discussing different sources of oral health information, which developed their knowledge. Some participants considered their own responsibilities in maintaining oral health, although it was clear that parents played a major role. Children also expressed their insights into the dental clinic and dental treatment, explaining their experiences and possible barriers to accessing dental care. This study contributes new understandings about Saudi children with disabilities' perspectives and experiences of oral health care, which were previously undocumented and unrecognised.

One of the interesting insights gained from the study was that children want to be respected, listened to, valued and given truthful information, and that many want to participate in decisions about their care. Children in this study revealed that they often felt ignored in the consultations or 'talked over' if the caregiver was present, implying that they were not being included in the oral health encounter. This appeared to suggest that oral professional attitudes revolved around a medical model of care, which views people as objects, not people as defined in the UN Convention on the Rights of the Child.[22] The medical model of care devalues and excludes children from discussions about oral health. The Convention emphasises treating a child with dignity, as an individual with the same fundamental rights of all human beings, including freedom, equality and privacy.[23] It further suggests that children must have access to the best healthcare standards. This implies that all children are rights-holders, even if they cannot express their rights and that anyone involved with children has the responsibility to promote and facilitate their voices being heard.[24]

Supporting the inclusion of children in oral health means applying a professional understanding of disability discourse in line with the social model of disability.[25] The social model is more inclusive in approach and proactively discusses how people with disabilities can participate on an equal basis with non-disabled people in activities. Making changes, even when it relates to time or resources, aims to include individuals with disabilities, and the onus is on the organisers of the event or activity to ensure accessibility.[26] Within this study, using the social model of disability suggested that the responsibility rests with the researcher to adjust activities to include children with disabilities. This contrasts with expecting children with disabilities to adapt their communication abilities to meet the researcher's expectations.

Studies from the perspectives of parents and clinicians conducted in Saudi Arabia identified similar barriers to those found in this research, but the key difference is that they excluded children.[26] Over one-third of children with disabilities were referred for general anaesthetic

with little attempt made to treat them without and over one-half of children in one study had no experience of routine dental care.[27] Research in other countries has suggested that finding an appointment and long waiting lists are barriers to accessing dental services. These studies suggested that such barriers could be mitigated using private services, but several researchers cited cost as the highest barrier.[28,29] This study in Saudi Arabia reflected this work, with children citing cost as a particular obstacle to accessing private clinics, and this triangulated with their parents' experiences. In this study, children reported extraction as the main treatment provided by dentists, without any mention of prevention. This suggests that the priority for regular dental treatment or preventive dental care for children with disabilities was low and not at the forefront of dentistry for this particular sample of participants. These findings further support a systematic review in other European, North, and South American and Australian countries, with different health systems, which report similar barriers.[30] da Rosa et al failed to discuss the facilitators of access to oral health services for people with disabilities studies in their review, which may resolve barriers to accessing dental services.

This study achieved its aim but exhibited some limitations including the relatively small sample size of 10, although working closely with children with communication impairments and intellectual disabilities takes time and the study itself was time-limited. Female children's voices dominated the sample, although cultural considerations meant it was not possible to enter boy's schools. The exclusion of participants with more profound impairments was a limitation, and gaining access to children with more profound impairments for this type of research in Saudi Arabia is a challenge because of privacy issues within the family. Lastly, the sample was limited by the age range of 9–15 years.

4.1 | Reflexivity

The primary researcher is a female native Arabic speaker and is from the same culture and social background as the children. The researcher accepted that power differentials are never fully addressed but attempted to minimise them as much as possible by dressing similarly to the school staff, using non-technical language and reflecting on her educational background. Furthermore, to ensure reflexivity throughout the research process, two female researchers, belonging to a different cultural background, participated in discussions on the data analysis. Their insight became advantageous because they were able to identify problems and ask questions which the primary researcher took for granted because she was from the same culture, and this added depth to the analysis. Clarifying or revealing hidden meanings assisted with additional interpretation and reflection undoubtedly influenced the study results. The process increased the quality of the ethnography and reduced the possibility of researcher bias. The researcher also used source and methodological triangulation in the study. These approaches reduced claims of subjectivity, producing genuineness, credibility and enhancing the trustworthiness of the research.

Overall, children with disabilities experience forms of marginalisation and exclusion in oral health. The evidence suggests that oral health professionals fail to include disabled children. Moreover, access to oral health care is an area that appeared challenging for the children.

This study underscores the contribution that children with disabilities can make to oral health research, through employing inclusive methods. Future research in the field of oral health should not underestimate the ability of children with disabilities to participate in dental research. Researchers need to find the most effective ways of engaging children with disabilities that consider their knowledge, abilities, contexts and interests while aiming to elicit their views on the development and evaluation of services both now and in the future.

AUTHOR CONTRIBUTIONS

Maram Ali M Alwadi devised the methods, collected and analysed the data, and led the writing. Sarah R Baker commented on methods, supported data analysis, guided the writing and commented on the draft. Janine Owens conceived the idea for the whole study, commented on methods, trained MAW in qualitative research, assisted in data analysis, guided the writing and commented on the draft.

CONFLICT OF INTEREST

The authors declared that there are no possible conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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