Journal of Dentistry Indonesia

Volume 31 Number 1 *April*

Article 1

4-30-2024

Perceptions of Oral Health-Related Care for Children with Autism Spectrum Disorder: A Scoping Review

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Recommended Citation

AlBhaisi, I. N., Mohd-Said, S., Lim, Y., Mohd-Dom, T., Zakaria, A. I., & McGrath, C. P. Perceptions of Oral Health-Related Care for Children with Autism Spectrum Disorder: A Scoping Review. J Dent Indones. 2024;31(1): 1-10

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Cover Page Footnote

The authors thank the Deans of the Faculty of Dentistry, Universiti Kebangsaan Malaysia, Hong Kong University and Gaza Al-Azhar University for their continuous support of our collaborative research and publication efforts.

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doi: 10.14693/jdi.v31i1.1609

LITERATURE REVIEW

Perceptions of Oral Health-Related Care for Children with Autism Spectrum Disorder: A Scoping Review

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ABSTRACT

Objective: This review aimed to seek insights into the challenges faced by caregivers and children with autism spectrum disorder (ASD) when performing and accessing oral care and their recommendations to overcome the matter. Methods: Six electronic databases were used to search for published English full articles using a standardised strategy and grouped using thematic analysis as findings to the study's goal. Results: The initial screening found 46 relevant articles, but 21 were deemed eligible. Studies were mostly observational (18 cross-sectional surveys and 3 case-controls), retrieving data from online or face-to-face surveys and insurance health info. The perceptions and potential solutions made by parents, teachers, doctors, and individuals with ASD were diverse but mostly consistent in most studies with a focus on issues of oral health as low priority, incompetency in oral health care performance at home, children's cooperation and involuntary behaviours in dental settings, and constraints in related resources. Conclusion: Carers' lack of awareness and prioritisation of treatment for children with ASD, challenges in performing oral care at home, concerns over oral health care provided by caregivers in educational institutions and dental clinics, and challenges in accessing more supportive oral health care services were highlighted as barriers to oral care.

Key words: accessibility, adolescent, behaviour management, caregivers, developmental disabilities

How to cite this article: AlBhaisi IN, Mohd-Said S, Lim YJ, Mohd-Dom TN, Zakaria ASI, McGrath CP. Perceptions of oral health-related care for children with autism spectrum disorder: A scoping review. J Dent Indones. 2024;31(1): 1-10

INTRODUCTION

It is well-acknowledged that children with autism spectrum disorder (ASD), an early childhood onset and persistent neurodevelopmental condition, have multiple challenges with their motor, sensory and intellectual abilities that are affecting their daily oral health performances. The disorder impairs social interactions and communications. It is characterised as restricted, repetitive patterns of behaviour, interests in activities, and unusual sensory or sensitivities that can pose challenges for caregivers while managing the individuals daily.²

Oral care activities worsen with involuntary movements such as tongue thrust, bruxism, and lip biting. Furthermore, children with ASD often experience more caries and gingivitis and have higher unmet dental needs compared with other typically neurodevelopmental children of similar age. Poor oral health can contribute to significant discomfort in eating and speaking and may even cause sleep disturbances. This condition could inevitably bring about a lower quality of life and well-being.

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Understandably, carers of children with ASD, including parents, guardians, and schoolteachers, encounter challenges and stresses while handling the children in their daily chores: agitation with a crying child, dealing with stereotyping and self-injury, difficulties in feeding, seizures and sleep disturbances, lack of emotional reciprocity and unusual behaviours are amongst common daily challenges faced. ⁶⁻⁸ Parents frequently report that they are distressed by these issues and more distressed with the support (or lack of) given by others around them. ⁹ Hence, understanding the challenges faced and the problem-solving approaches can inform how best to implement supportive strategies for care, care at home, at school, and in the health care setting. ⁹

This scoping review aimed to systematically report on oral care-related issues for children with ASD at home, at educational institutions, and in the dental settings, as perceived by parents and guardians, teachers, healthcare professionals as well as individuals with ASD themselves, and provide critical information from the literature on strategies that may effectively solve these issues.

METHODS

This review reports the initial work from our project with the International Prospective Register of Systematic Reviews (PROSPERO reference: CRD42021239730), and ethics approval for the project was approved by the Research and Ethics Committee (reference: JEP-2020-757).

Search strategy and definitions

The study used the PICO strategy where the population (P) was children with ASD receiving oral care: their carers' views on (I) Interventions, including dental trauma, oral hygiene care, and any other interventions related to their oral health at home, in school and dental settings. Findings from the relevant studies were compared (C) to other children who received similar interventions, typically healthy children or children with other disabilities/disorders. Subsequently, the primary outcomes (O) investigated were oral health issues of children with ASD perceived by carers and caregivers.

The definition of ASD used was based on the American Psychiatric Association classification for mental disorders within categories of DSM-IV or DSM-V, where ASD includes autistic disorders, Asperger's disorder, and pervasive developmental disorders not otherwise specified.² In this review, we defined the *Carer* and *Caregiver* as a person, either a member of the family or somebody who is paid, who takes care of a sick or old person at home.^{10,11}

Selection criteria and screening process

Electronic database searches were made through Scopus, PubMed, Cochrane Library, EBSCOHost, Google Scholar, and Web of Science from 1st January 1994 up to 1st January 2022 using sets of main keywords consisting of 'oral health', 'ASD', 'challenges', 'barriers', and 'children'. Selection of words and phrases was made using the Medical Subject Headings, MeSH (https://meshb.nlm.nih.gov/search), definition and similar words from the dictionary, and relevant keywords from related published references (Table 1). 12-14 The inclusion criteria chosen were original full-text articles for studies involving children aged less than 18 years old with ASD including case studies, observational studies, and clinical trials, and written in the English language.

The screening process involved firstly the selection of relevant studies based on their description and titles from each database. Then, results from all sources were pooled, and replicate studies were removed from the list. Known or recommended literature from citations in review papers was also looked for to broaden the search. Abstracts were scrutinised to select relevant studies. Full-text articles for the finalised list were subsequently obtained and read thoroughly to ensure their relevance before confirming their eligibility for the review.

Data selection, extraction, and analysis

Information on the included studies was retrieved by the members (S.M-S. and I.N.B.) and cross-checked independently. Relevant data were systematically collected from each eligible study: publication details (authors, and year), study design, aim of the study, population characteristics (number, gender, and age of the participants), attributes of population, methods of the study (style, scope, time/duration, language), findings related to outcomes namely the perceptions and/or concerns on oral health-related challenges at home or educational institutions, dental clinics and while getting access to dental care, and recommendations for solution or improvement of concern issues. Findings from the eligible articles were transcribed into a table and confirmed by other members. Finally, an analysis of the findings was thematically done to describe the review outcomes accordingly.

RESULTS

Study selection

The initial search yielded 68 papers from six databases and other resources with 22 replicates. Thirteen papers were excluded based on the irrelevance of their titles and/or abstracts, and twelve were excluded based on full-text ratings. Inter-rater reliability (κ statistic of agreement between the reviewers) was 80.7% during screening and 86% during the final data extraction. A

Table 1. Search strategy for systematic literature review.

Database	Search string	Limits / Inclusion
Scopus	((TITLE-ABS-KEY ("oral health") OR TITLE-ABS-KEY (caries) OR TITLE-ABS-KEY (periodontitis) OR TITLE-ABS-KEY (gingivitis))) AND ((TITLE-ABS-KEY (child) OR TITLE-ABS-KEY (toddler) OR TITLE-ABS-KEY (teenager) OR TITLE-ABS-KEY (adolescent) OR TITLE-ABS-KEY (juvenile) OR TITLE-ABS-KEY (newborn))) AND ((TITLE-ABS-KEY ("Autism Spectrum Disorder") OR TITLE-ABS-KEY (asd) OR TITLE-ABS-KEY (autism) OR TITLE-ABS-KEY ("Autistic Disorder"))) AND ((TITLE-ABS-KEY ("healthcare accessibility") OR TITLE-ABS-KEY ("Health Services Accessibility") OR TITLE-ABS-KEY (barrier*)))	Language: English Document: Articles or Review Subject Areas: Medicine and Dentistry Publication Stage: Final
Web of Science (WOS)	TS=(("Health Services Accessibility" OR "healthcare accessibility" OR barrier*) AND ("Autism Spectrum Disorder" OR ASD OR "Autistic Disorder" OR autism) AND (child* OR adolescent OR newborn OR juvenile OR toddler OR teenager) AND ("oral health" OR periodontitis OR gingivitis OR caries))	Language: English Categories: Dentistry Oral Surgery Medicine Timespan: All years Indexes: SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI- SSH, BKCI-S, BKCI-SSH, ESCI.
PubMed	("Health Services Accessibility" OR "healthcare accessibility" OR barrier*) AND ("Autism Spectrum Disorder" OR ASD OR "Autistic Disorder" OR autism) AND (child* OR adolescent OR newborn OR juvenile OR toddler OR teenager) AND ("oral health" OR periodontitis OR gingivitis OR caries)	Language: English Type: Full Text
EBSCOhost	AB ("Health Services Accessibility" OR "healthcare accessibility" OR barrier*) AND AB ("Autism Spectrum Disorder" OR ASD OR "Autistic Disorder" OR autism) AND AB (child* OR adolescent OR newborn OR juvenile OR toddler OR teenager) AND AB ("oral health" OR periodontitis OR gingivitis OR caries)	Source Field: Abstract or Author-

summary of the step-by-step search and selection using the PRISMA template for systematic literature review (http://prisma-statement.org/PRISMAStatement/ Checklist) is shown in Figure 1.

Characteristics of the studies

Of the 21 articles selected, 18 were cross-sectional studies12-29 and three were case-control studies (Table 2).30-32 The total carers involved were 3525 parents, 12,13,15,17-20,22-25,27,30,31 16,323 caregivers, 29 178 teachers,²⁸ and 75 doctors.¹⁴ The approximate age range for the carers was 21-85 years (mean 50 years old), and an almost female superiority over gender distribution was seen across the studies. Meanwhile, there were approximately 214,833 children with ASD, ages ranging from 2 years to 19 years old, and no mention of age for the other 737 individuals with ASD.^{30,32} Overall, 214,733 children with ASD aged between 2 to 17 years old from a total population of 497,068 children were involved. Nine studies compared carers of children with or without ASD. 12,19,20,22,23,25,27,30,31 In most studies, a printed questionnaire survey was the most frequent tool used^{12,13,15,20,22,25,28,30-32} besides face-to-face interviews or focus groups, 17-19,24,26 online surveys, 14,27,32 telephone calls and/or mail surveys, 23,27,29 and data source from the Medicaid insurance programmes. 16,21

Perceptions and areas of concern regarding oral health care-related issues

The studies reported seven critical themes for the perceptions of oral health care-related issues for children with ASD, namely: (1) Oral health needs are not a priority, (2) Limited self-oral health awareness and literacy among carers, (3) Challenges in performing oral health care at home, (4) Children's fear and anxiety towards dental care and dental professionals resulting in their uncooperativeness while being treated, (5) Unreceptive attitude and insufficient training of dental team, (6) Limited availability and unsupportive oral health care resources, and (7) Financial constraints and limited related supportive resources for oral health care for children with ASD (Table 3). In general, these perceptions can be grouped into four core issues:

- 1. carers' awareness and prioritisation of oral health care for children with ASD,
- 2. challenges of performing oral health care at home for children with ASD,
- 3. concerns over oral health care provided by caregivers in educational institutions and dental clinics, and
- 4. concerns/challenges in accessing a more supportive oral health care service.

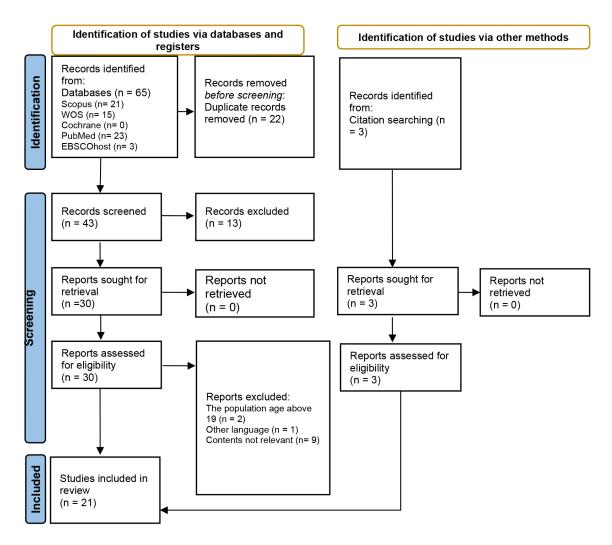


Figure 1. PRISMA flow diagram for literature searches.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ. 2021; 372:n71. For more information, visit: http://www.prisma-statement.org/

Recommended strategies and action plans

The reviewed studies recommended relevant strategies and action plans to address the carers' and caregivers' concerns. Generally, the strategy focused on six aspects: 1) improvement in population oral health awareness and literacy, 2) specialised training modules for caregivers, 3) better communication, ASD awareness, and cultural sensitivity for the dental team and carers, 4) creation of ASD-sensitive environment for better dental care experience, 5) improvement to dental care service provision at dental clinics, and 6) financial support/insurance for special needs dental care (Table 4).

DISCUSSION

Paper identification, agreement, and quality of reporting

This scoping review found amendable evidence on

repeated concerns of the carers and children with ASD on oral healthcare-related issues. From the search process, 21 eligible articles with good quality reporting were identified and analysed qualitatively using thematic narrations to answer the main research questions about perceptions and suggested strategies.³³

The body of the evidence discussed not only carers' experience in accessing and implementing oral health care affected by the consequence of the child's stage of ASD but also parental dental anxieties or the parent's fears and cultural implications because of their life experiences. These factors relate to individual-level or non-environment barriers, including communication barriers, social and behavioural issues, parents' anxiety, fear of dentists, and competing demands. They may lead to unmet dental needs for their children. Overall, the studies included in this review reported issues on the burdens for the population where 10.8% is time-related, 40% on financial issues,

 Table 2. Characteristics of studies reviewed.

Reference	Design	Details of participants studied	Details of the ASD children involved
Floríndez et al., 2019	- Cross-section, - interview face to face	 - 18 parents, caregivers, family members with children with ASD (10 families) / without ASD (8 families) - no. of children per family: 1 - 4 / 1 - 3 (mean 2.3 / 1.9 children) 	18 children: 10 (56%) ASD - Female 8, Male 2 - Age 6 to 12 years old
Mansoor et al., 2018	- Cross-section, - questionnaire	137 parents / guardians of children with ASD / no ASD in special needs centre	137 children: 84 (61%) ASD - Female 17, Male 67 - Mean age 8.83 / 10.87 years old
Duker et al., 2017	- Cross-section, - 2 focus group discussions at 3h per session	9 parents of child with ASD	9 children ASDMale 9Age: 5 to 18 years old
Nelson et al., 2011	- cross_section, - telephone, Mail, or conferences survey	1,128 parents of children with special health care needs	1,045 children: 32% ASD - Female 36%, Male 64% - Mean age 10.1 ± 4.4 years old
Fahlvik- Planefeldt & Herrstrom, 2001	- Cross-section, - questionnaire_and clinical examination of child	40 parents with/without ASD treated at the same dental clinic	40 children: 20 (50%) ASD - Female 40%, Male 60% - Age 3 to 19 years old
Du et al., 2019	- case control - questionnaire	515 parents of preschool children with/without ASD	515 children: 257 (50%) ASD - Female 40, Male 217 - Age: 32 to 77 months old
Stein et al., 2011	- Cross-section, - Online and mail survey	207 parents with children with/without ASD	111 children: 15.5% ASD / 38.4% ASD plu other disabilities, - Mean age 8.0 ± 3.02 y / 7.73 ± 3.09 years of
Barry et al., 2014	- Cross-section, - questionnaire	112 parents with children with ASD (56) / without ASD (56)	112 children: 56 (50%) ASD - Female 26, Male 86 - Mean age 9.82 ±3.27 years old
Lai et al., 2012	- Cross-section, - by mail	555 parents with children with ASD	555 children ASD - Female 91, Male 464 - Mean age 9.9 ±3.9 years old
Wiener et al., 2016	- Cross-section, - telephone survey	16,323 caregivers who attended the 2009–2010 National Survey on children with special health needs	2612 children - Female 34.8%, Male 65.2% - Age 2 to 17 years old.
Tong et al., 2017	- Cross-section, - questionnaire (pre- training and post- training)	 178 teachers in special education schools with children with ASD Female 49, Male 29 age 21 - 67 years old 	NA
Weil et al., 2011	- cross section, - web-based survey	 75 Doctors in special care unit who treated ASD patients. Female 38, Male 37 age 28 – 85 years old, mean 49 years old 	NA
Koneru & Sigal, 2009	- Case-control - self-administered and internet questionnaire	Persons with developmental disabilities	634 individuals: 71 (18.3%) ASD - Age NA - Gender NA
Schultz et al., 2001	- Cross-section, - interview survey	Children with developmental disabilities	12,539 children: 1,254 (0.1%) ASD - Age 2 to 17 years old
Chi et al., 2016	- Cross-section, - Medicaid program data	Children with/without ASD	30,059 children: 408 (1.4%) ASD - Female 15.2%, Male 84.8% - Age 3 to 17 years old, mean 9.5±3.8 year
Kranz et al., 2020	Cross-section,Medicaid program data	Children with/without ASD	447,918 children: 208 729 (46.6%) ASD - Female 34.1%, Male 65.9% - Age: below 6 years old

Reference	Design	Details of participants studied	Details of the ASD children involved
Floríndez et al., 2021	- Cross-section, - paper and electronic questionnaire	Children with/without ASD	60 children: 31 (51.7%) ASD - Gender NA - Age 8.5±3.2 years
Alshatrat et al., 2020	- case-control - printed questionnaire	Children with/without ASD	296 children: 147 (49.7%) ASD - Gender NA - Age ≤18 (n=103)
Alshihri et al., 2021	Cross-section,Electronic questionnaire	Children with ASD	142 Children with ASD - Female 29, Male 113 - Age 2.5-14 years (7.8 ±2.8 years)
Parry et al., 2021	- Cross-section, - Focus groups	Children with ASD	10 Children with ASD - Female 4, Male 6 - Age 8-18 years
Puthiyapurayil et al., 2021	- Cross-section, - self-report questionnaire	Children aged 4-12 years with intellectual needs (mental retardation, cerebral palsy, epilepsy, autism)	

20.3% on employment-related burdens, and 16.3% of the population included in their studies does not meet the perpetual preventive dental care. In addition, some studies focused on 'environmental' barriers such as cost of care, getting appointments, accessibility, etc., and 'non-environmental' barriers, including child's behaviour, fear of dentists, competing demands, etc.^{23,29,31}

Key findings on perceptions of oral health-related issues

In this review, we found that in most studies, oral health needs were not prioritised due to a lack of dental-related complaints,²² urgencies in other health care needs,³¹ and essential life needs. 19 In contrast to a recent study showing that parents of preschool children with ASD had better dental knowledge and attitude,31 studies found self-reported lack of oral health knowledge in oral health literacy and children's intense sensitivity towards new environments and non-routine activities as a concern. 12-14,22,23,25,27,31,32 These reasons may well be contributing more to the distress while assisting in oral hygiene practices at home and schools/care centres, 18,22,27,28,31 and visiting dentists is stressful for both the carers and children. 14,18,32 In a related study, a parent perceived that his/her child had fractured a tooth and required dental treatment because of eating too much, eating too many sweets and crunchy food.3 In addition, location and logistic constraints, including travelling far from home to the dental clinic, getting on public transport to the clinics, and getting a parking space near the clinic entrances can make dental appointments tiresome. 12,13,19,26,29-32

Self-knowledge of oral health care among the carers and caregivers was identified as one of the primary concerns in implementing oral health education, whether at home or in schools. Only a few special schoolteachers knew the recommended frequency for an annual dental visit

and the use of fluoride. At the same time, very few are aware of the brushing techniques available and even give sugary rewards to children while in school.²⁸ A local study also reported a similar concern, where the existing special education teachers' programme does not cater for current knowledge and skills for future teachers to manage children with ASD, including the ability to recognise features of autism, build suitable teaching strategies and collaborate with parents and other professionals.25,34 While the contribution of culture and parent's life experiences were perceived as issues related to challenging tasks when performing oral hygiene care at home and lack/poor access to oral health care, 19,20 a recent study showed that parents of children with ASD do not feel stigmatised by the children's behaviour while in the public or specific environment, and supported by their religious beliefs to adopt positive views on themselves and their children, hence used this to cope with stress and support their actions in ensuring good quality of life for their children.35

Other perceived concerns were the unreceptive, unsatisfactory attitude and unavailability of sufficiently trained dental personnel, 13-15,17,18,22-24,27,28,31 unsuitable conventional and often insensitive treatment techniques used to restrain the child while undergoing dental treatment¹⁷ directly related to difficultly in sustaining the same dentists. Previous training from dental professionals was reported as among the important predictors for implementing oral health education (OHE) modules in the daily tasks of caregivers.²⁸ Trained caregivers were seen to be more confident and competent when giving OHE to children compared to those without earlier exposure to appropriate modules, and there was a willingness to be involved in OHE implementation at home/school among caregivers²⁸ and parents/family.19

Table 3. Perceptions and areas of concern regarding oral health-related issues.

Areas of concern Issues related to perceptions. 1. Carers' awareness and prioritisation of oral health care for children with ASD

Oral health needs were not a priority

- usually there is no dental complaint²²

- oral health is not a priority as compared to other essential life needs¹⁹

- there are other more urgent health care needs³¹

Limited self-oral health awareness and literacy among carers

- self-reported deficiency in oral health knowledge and unaware of the importance of maintaining good oral hygiene, discussing needs of visiting dentists can be challenging 25,28

2. Challenges of performing oral health care at home for children with ASD

Challenges in performing oral health care at home

- children need assistance during tooth brushing or always resist cleaning.
- they dislike toothpaste taste in their mouth²²
- toothbrushing can be a complex activity to do^{18,27}
- unable to keep still and time-consuming³¹
- assistance and/or special devices required^{18,31}
- 3. Concerns over oral health care provided by caregivers in the educational institutions and dental clinics

Children's fear and anxiety towards dental care and dental professionals resulting in their uncooperativeness while being treated

- uncooperative when seeing dentists due to fear^{13,14,15,20,22,23,25,27,31,32}
- uneasiness in a different environment e.g., bright lights and closed places¹² hence either displaying repetitive behaviour or restricted in their behaviour^{14,15}
 unable to tolerate the treatment^{18,32}
- existing medical conditions complicating dental treatment^{23,31}
- sensory sensitivities e.g., sudden change of taste, odour, head touch, 12,24,27 smell, sounds and taste sensory heightened, 14 dislikes toothpaste taste 31
- dislike feeling of toothbrush in mouth^{27,31} or anything done in the mouth²³
- parents feeling of embarrassment from child's behaviour³⁰
- 4. Concerns /challenges in getting access to a more supportive oral health care service

Unreceptive attitude and insufficient training of dental team

- vulnerability and mistrust of carers on authorities/dental team to handle their children; unsatisfied with the dental care they received and what they required^{15,18,24}
- dental staff become anxious or nervous when giving treatment^{23,30,31}
- lacks verbal communication skills, may have difficulties providing treatment and understanding what the child is experiencing^{14,30}
 some cases get rejection from general dentists; ^{15,17,25} difficult to get referral for dentists
- some cases get rejection from general dentists; 15,17,25 difficult to get referral for dentists or special needs dentists¹⁷
- dentists' refusal to use the general anaesthesia for dental procedures due to complications with common failure of sedation¹⁸
- training materials not enough for caregivers²⁸
- racial and ethnic discrimination during receiving oral health care (social determinants)²⁰

Limited availability and unsupportive oral health care provisions

- not easy to find dentists with special needs care knowledge and skill^{13,15,22,24,25,27,28,31}
- problems with suitability of dentist or dental clinic with their child,¹⁷ no suitable clinics within the neighbourhood³¹
- 'insensitive' clinic environment: too many activities and movements in the clinic that can distract the child, use of restraints during treatment, use of drugs to calm the child¹⁷
- difficult to get suitable and convenient appointments^{13,20,30}
- long waiting time at dental clinic^{12,13,30}

Financial constraints and limited related supportive resources for oral health care for children with ASD

- cannot afford the high cost of dental treatment, 10,13,15,17,20,25,26,29-32 expensive to even having their own toothbrush¹⁹
- unsupportive insurance coverage and limited financial resources^{13,19,20,30}
- too time-consuming to get proper transportation to clinic 12,19,25,26,32
- parking issues once arrived and getting into the clinic: parking area to far or inconvenient to drop-of or pick up the child in front of clinic entrance^{12,30}
- time constrain and may affect their wage trying to get off work to bring child to clinic^{26,29,31}
- unsupportive resources e.g., lack of childcare service for other children when the parent must bring the child for dental care²⁶

Table 4. Recommended strategies and action plans to improve perceptions of oral health-related issues for carers of children with ASD.

1. Improve Carers Awareness on Oral Health and Oral Health Care

health awareness and literacy:

- Improvement in populations' oral Provide better oral health knowledge and oral health literacy for the population¹⁹ and parents/ carers^{20,24,26} e.g., via webpages or platforms for referral and access to dental care^{17,30}
 - Frequent visits to dental clinics to decrease child's uncooperativeness during their actual dental appointment²²

2. Special Training for Caregivers

Specialised training modules for caregivers:

- develop and use ease educational strategies e.g., single training sessions of information $talks^{28}$
- integrate the oral health education and given materials in the schools^{25,28}
- special visual aids to overcome communication challenges¹⁴
- apply behavioural interventions e.g., tooth-brushing social stories and oral desensitisation30,31
- calming auditory stimulation to decrease mal-adaptive behaviours or anxiety^{25,27}
- different approaches e.g., massage of oral muscles before brushing³¹

Better communication, ASD For dental professionals: awareness and cultural sensitivity for dental team and carers:

- better awareness of sensory over responsively²⁷
- more trainings for special care, 12,15,24 didactic and clinical training 30
- better referral protocol^{22,32}
- consider cultural implications and sensitive to families and children's
- creating socio-culturally appropriate interventions, including those utilising community health workers and participatory methods²⁰

For parents/carers:

- Increase knowledge and awareness on associated clinical manifestation¹³
- provide awareness of possible effect of sensory sensitivities, treatment options, and effective methods to control their child^{17,24}

3. Create / Improve on Dental Care Service Support

better dental care experience:

- Create ASD-sensitive environment for prepare and make the best environmental adaptations for the children¹⁷
 - modification and flexibility e.g., positive reinforcement and tell-show-do 13,24,30 and supporting autonomy by engaging the child in decision-making²⁴
 - sharing photos and telling social stories of the dental clinic before their dental appointment e.g., photo of waiting room, dental surgery / unit12

Improvement to dental care service provision at dental clinics:

- wider and improved access to children with ASD^{25,26} such as web-based networks including specialised dental offices31
- behaviour management by trained and experienced dentists
- Utilising strategies to adapt the sensory environment in the dental office by minimising the effects of possible noxious stimuli^{15,27,39}
- special considerations for appropriately timed dental appointments for the day, 13,24 pre-specified appointment¹²
- additional resources, e.g., maintain dental homes for children with ASD,16 have regular collaboration with child psychiatric care¹⁸
- reserved and easy access parking spaces to the clinic entrance¹² reduce delays or no waiting time for access to dental surgery immediately upon

Financial support/insurance for special needs dental care:

- consider dental care insurance coverage for higher costs¹⁹
- reduced costs for the special needs29
- Medicaid policies for better access to specialised dental care^{15,21}

FUTURE DIRECTION

While the results of this scoping review showed a considerable amount of evidence and repeated concerns over oral healthcare-related issues and their recommended strategies, the impact of these perceived concerns and the effectiveness of the strategies on the oral health status of children with ASD remains to be quantified. This knowledge would be a valuable insight to fully understand the extent of the carers' and

caregivers' expressed concerns on their actionability in actual efforts to access and perform or provide oral health care. Further studies are required to investigate these specific areas and their impact more qualitatively to facilitate and improve oral health care access, improve oral health care outcomes and oral health status, and the general wellbeing of children with ASD.

CONCLUSION

Our review found diverse perceptions on oral health-related issues mostly focused on the carers' lack of awareness and prioritisation of oral health care for children with ASD, challenges of performing oral health care at home, concerns over oral health care provided by caregivers in the educational institutions and dental clinics, and concerns or challenges in getting access to a more supportive oral health care service. Improved carers' awareness towards oral health care, special training for caregivers, and creating and improving dental care service support were suggested as strategic plans to improve the carers' perceptions.

CONFLICT OF INTEREST

The authors reported no potential conflict of interest.

ACKNOWLEDGMENT

The authors thank the Deans of the Faculty of Dentistry, Universiti Kebangsaan Malaysia, Hong Kong University and Gaza Al-Azhar University for their continuous support of our collaborative research and publication efforts.

REFERENCES

- Al-Maweri SA, Halboub ES, Al-Soneidar WA, Al-Sufyani GA. Oral lesions and dental status of autistic children in Yemen: A case-control study. J Int Soc Prev Community Dent. 2014; 4(Suppl 3):S199-203.
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
- 3. Ismail NAS, Ramli NS, Hamzaid NH, Hassan NI. Exploring eating and nutritional challenges for children with autism spectrum disorder: Parents' and special educators' perceptions. Nutrients. 2020; 12(9):2530.
- 4. Lam PP, Du R, Peng S, McGrath CP, Yiu CK. Oral health status of children and adolescents with autism spectrum disorder: A systematic review of case-control studies and meta-analysis. Autism. 2020; 24(5):1047-66.
- 5. Eslami N, Movahed T, Asadi M. Parents' perceptions of the oral health-related quality of life of their autistic children in Iran. J Clin Pediatr Dent. 2018; 42(6):422-6.
- 6. Hastings RP. Child behaviour problems and partner mental health as correlates of stress in

- mothers and fathers of children with autism. J Intellect Disabil Res. 2003; 47(Pt 4-5):231-7.
- 7. Jx L, Si O, Vy L, Ar FN. Parenting stress among Malaysian parents of children with Autism Spectrum Disorder (ASD). Med Health. 2017; 12(1):42-55.
- 8. Nikmat AW, Ahmad M, Oon NL, Razali S. Stress and psychological wellbeing among parents of children with autism spectrum disorder. ASEAN J Psychiatr. 2008; 9(2):65-72.
- 9. Cappe E, Wolff M, Bobet R, Adrien JL. Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. Qual Life Res. 2011; 20(8):1279-94.
- 10. Oxford University Press dictionary [Internet]. Oxford (UK): Oxford Learner's Dictionaries; c2021. Carer. Available from: https://www.oxfordlearnersdictionaries.com/definition/english/carer?q=carer
- 11. Oxford University Press dictionary [Internet]. Oxford (UK): Oxford Learner's Dictionaries; c2021. Caregiver. Available from https://www.oxfordlearnersdictionaries.com/definition/english/caregiver?q=Caregiver
- 12. Barry S, O'Sullivan EA, Toumba KJ. Barriers to dental care for children with autism spectrum disorder. Eur Arch Paediatr Dent. 2014; 15(2):127-34.
- 13. Lai B, Milano M, Roberts MW, Hooper SR. Unmet dental needs and barriers to dental care among children with autism spectrum disorders. J Autism Dev Disord. 2012; 42(7):1294-303.
- 14. Weil TN, Bagramian RA, Inglehart MR. Treating patients with autism spectrum disorder--SCDA members' attitudes and behavior. Spec Care Dentist. 2011; 31(1):8-17.
- 15. Alshihri AA, Al-Askar MH, Aldossary MS. Barriers to professional dental care among children with autism spectrum disorder. J Autism Dev Disord. 2021; 51(8):2988-94.
- Chi DL, Momany ET, Mancl LA, Lindgren SD, Zinner SH, Steinman KJ. Dental homes for children with autism: A longitudinal analysis of Iowa Medicaid's I-Smile program. Am J Prev Med. 2016; 50(5):609-15.
- 17. Duker LIS, Henwood BF, Bluthenthal RN, Juhlin E, Polido JC, Cermak SA. Parents' perceptions of dental care challenges in male children with autism spectrum disorder: An initial qualitative exploration. Res Autism Spectr Disord. 2017; 39:63-72.
- 18. Fahlvik-Planefeldt C, Herrström P. Dental care of autistic children within the non-specialized Public Dental Service. Swed Dent J. 2001; 25(3):113-8.
- Floríndez LI, Floríndez DC, Floríndez FM, Como DH, Pyatak E, Baezconde-Garbanati L, Polido JC, Cermak SA. Oral care experiences of latino

- parents/caregivers with children with autism and with typically developing children. Int J Environ Res Public Health. 2019; 16(16):2905.
- Floríndez LI, Como DH, Floríndez DC, Vigen C, Floríndez FM, Cermak SA. Identifying gaps in oral care knowledge, attitudes, and practices of latinx parents/caregivers of children with and without autism spectrum disorders. Health Equity. 2021; 5(1):185-93.
- 21. Kranz AM, Ross R, Sorbero M, Kofner A, Stein BD, Dick AW. Impact of a Medicaid policy on preventive oral health services for children with intellectual disabilities, developmental disabilities, or both. J Am Dent Assoc. 2020; 151(4):255-64.e3.
- 22. Mansoor D, Al Halabi M, Khamis AH, Kowash M. Oral health challenges facing Dubai children with Autism Spectrum Disorder at home and in accessing oral health care. Eur J Paediatr Dent. 2018; 19(2):127-33.
- Nelson LP, Getzin A, Graham D, Zhou J, Wagle EM, McQuiston J, McLaughlin S, Govind A, Sadof M, Huntington NL. Unmet dental needs and barriers to care for children with significant special health care needs. Pediatr Dent. 2011; 33(1):29-36.
- 24. Parry JA, Newton T, Linehan C, Ryan C. Dental visits for autistic children: A qualitative focus group study of parental perceptions. JDR Clin Trans Res. 2021; 8(1):23800844211049404.
- 25. Puthiyapurayil J, Anupam Kumar TV, Syriac G, R M, Kt R, Najmunnisa. Parental perception of oral health related quality of life and barriers to access dental care among children with intellectual needs in Kottayam, central Kerala-A cross sectional study. Spec Care Dentist. 2022; 42(2):177-86.
- 26. Schultz ST, Shenkin JD, Horowitz AM. Parental perceptions of unmet dental need and cost barriers to care for developmentally disabled children. Pediatr Dent. 2001; 23(4):321-5.
- 27. Stein LI, Polido JC, Mailloux Z, Coleman GG, Cermak SA. Oral care and sensory sensitivities in children with autism spectrum disorders. Spec Care Dentist. 2011; 31(3):102-10.

- Tong HJ, Lee HY, Lee YT, Low Y, Lim CR, Nair R. Factors influencing the inclusion of oral health education in individualized education plans of children with autism spectrum disorders in Singapore. Int J Paediatr Dent. 2017; 27(4):255-63.
- Wiener RC, Vohra R, Sambamoorthi U, Madhavan SS. Caregiver burdens and preventive dental care for children with autism spectrum disorder, developmental disability and/or mental health conditions: National survey of CSHCN, 2009-2010. Matern Child Health J. 2016; 20(12):2573-80.
- Alshatrat SM, Al-Bakri IA, Al-Omari WM. Dental service utilization and barriers to dental care for individuals with Autism Spectrum Disorder in Jordan: A case-control study. Int J Dent. 2020; 2020;3035463.
- 31. Du RY, Yiu CKY, King NM. Oral health behaviours of preschool children with Autism Spectrum Disorders and their barriers to dental care. J Autism Dev Disord. 2019; 49(2):453-9.
- 32. Koneru A, Sigal MJ. Access to dental care for persons with developmental disabilities in Ontario. J Can Dent Assoc. 2009; 75(2):121.
- 33. Braun V, Clarke V. Thematic analysis. In: Cooper H, Camic PM, Long DL, Panter AT, Rindskopf D, Sher KJ, editors. APA handbook of research methods in psychology Vol. 2 Research designs: Quantitative, qualitative, neuropsychological, and biological. Washington DC: American Psychological Association; 2012. pp. 57-71.
- 34. Toran H, Westover JM, Sazlina K, Suziyani M, Mohd Hanafi MY. The preparation, knowledge and self-reported competency of special education teachers regarding students with autism. Pertanika J Soc Sci Humanit. 2016; 24(1):185-96.
- Chu SY, Park H, Lee J, Shaharuddin KKB, Gan CH. Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism. Child Care Health Dev. 2020; 46(4):485-94.

(Received October 23, 2023; Accepted March 6, 2024)