

Exploring barriers to oral health care experienced by individuals living with autism spectrum disorder

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a developmental disorder that affects behaviour and communication skills. ASD is estimated to affect approximately 1 in 66 Canadians, with symptoms typically arising within the first 3 years of life. Individuals with ASD present with an increased burden of disease and face heightened barriers to oral care. **Objective:** This narrative literature review aims to raise awareness of the additional needs that individuals with ASD have when seeking oral care and to identify how barriers to such care may be reduced. **Methods:** Twenty-one articles were included in this review, with a wide range of study designs and methodologies. Search terms in PubMed, Education Source, and CINAHL databases included autism spectrum disorder, barriers, dental, dental hygiene, developmental disability, oral health, and unmet needs. **Results and discussion:** Key themes that emerged as barriers to care were behavioural challenges, inhibited social and communication skills, parental dependence, clinic environment, and abilities of oral health professionals to treat clients with special care needs. **Conclusion:** Current literature reveals that individuals with ASD face numerous barriers when accessing oral care and attempting to achieve adequate oral health, thus contributing to an increased burden of disease. Oral health professionals should aim to improve their understanding of special care populations such as the ASD community and raise awareness among health care professionals to work towards diminishing the barriers to care these populations experience.

RÉSUMÉ

Contexte : Les troubles du spectre autistique (TSA) sont des troubles du développement qui affectent le comportement et les capacités de communication. On estime que les TSA touchent environ 1 Canadien sur 66, et les symptômes se manifestent typiquement au cours des 3 premières années de la vie. Les personnes atteintes de TSA sont confrontées à un fardeau accru de maladies et à des obstacles plus importants en matière de soins buccodentaires. **Objectif :** La présente revue narrative de la littérature vise à susciter une prise de conscience des besoins supplémentaires qu'ont les personnes atteintes de TSA lorsqu'elles cherchent des soins buccodentaires et à cibler les façons qui permettent de réduire les obstacles à obtenir ces soins. **Méthodes :** Vingt-et-un articles comprenant un vaste éventail de modèles et de méthodologies d'études ont été inclus dans cet examen. La recherche dans les bases de données PubMed, Education Source et CINAHL comprenait les termes : troubles du spectre de l'autisme, obstacles, dentaire, hygiène dentaire, déficience développementale, santé buccodentaire et besoins non satisfaits. **Résultats et discussion :** Les thèmes clés qui ont émergé comme étant des obstacles aux soins buccodentaires étaient : les défis comportementaux, l'inhibition des aptitudes sociales et de communication, la dépendance parentale, l'environnement clinique et la capacité des professionnels de la santé buccodentaires à traiter les clients ayant des besoins spéciaux en matière de soins. **Conclusion :** La littérature actuelle révèle que les personnes atteintes de TSA font face à de nombreux obstacles lorsqu'elles accèdent aux soins buccodentaires et essaient d'atteindre une santé buccodentaire adéquate, ce qui contribue à un fardeau accru de maladies. Les professionnels de la santé buccodentaires devraient viser à améliorer leur compréhension des populations ayant des besoins de soins spéciaux, comme les personnes atteintes de TSA et à conscientiser les professionnels de la santé afin de réduire les obstacles aux soins auxquels sont confrontés ces populations.

Keywords: autism spectrum disorder; barriers; dental; dental hygiene; developmental disability; oral health care; unmet needs
CDHA Research Agenda category: access to care and unmet needs

INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disorder affecting communication skills and behaviour, with signs and symptoms typically arising within the first 3 years of life.¹ Caregivers of children with ASD tend to

notice atypical behaviours, such as a lack of response to the caregivers' presence, voice or touch, or disinterest in social interaction with peers, and delayed development in speech and communication.^{1,2} Repetitive movements,

PRACTICAL IMPLICATIONS OF THIS RESEARCH

- Dental hygienists should be aware of barriers faced by individuals with ASD and methods to overcome them to improve access to oral health care.
- Integrating special care education into dental and dental hygiene curricula can help educators provide future dental professionals with additional educational experiences and increased confidence in working with special care populations.

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avoidance behaviours, and the presence of comorbidities such as seizure disorders, sleep disturbances, diabetes, cardiovascular diseases, and gastrointestinal disorders are commonly noted as well.¹⁻⁴

In 2020 an estimated 1 in 54 children were diagnosed with ASD in the United States, while the most recent Canadian statistics from 2018 reported a diagnosis in 1 in 66 children, with males 4 times more at risk than females.^{5,6} The increase in ASD diagnoses over the last few decades may be a result of greater awareness of indicators of ASD among parents and health professionals and improvements in diagnostic tools and assessments rather than a true increase in prevalence.⁷ Although the etiology of ASD is unknown, risk factors may include a genetic component, being born to older parents or low birth weight.⁵ ASD is considered a spectrum disorder because it presents differently across individuals.⁸ Because of this variability, signs and symptoms range from mild to extreme, but typically include difficulty interacting in social situations, difficulty adjusting to changes in routine, repetitive behaviours, and elevated sensitivity to sensory input such as light and noise.⁸ Historically, diagnoses of autism were further categorized into subdiagnoses of autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified, and disintegrative disorder.⁹ However, the diagnostic criteria in the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* now combines these subcategories into one diagnosis of autism spectrum disorder to allow for a diagnosis better supported by research and clinical experiences.⁹

Literature indicates that individuals of all ages with ASD present with a high burden of oral disease, with caries and periodontal disease being the most prevalent disorders.¹⁰⁻¹³ Oral issues may be associated with ASD-related behaviours that inhibit adequate maintenance of oral health.¹⁴ Communication limitations, personal neglect, dietary habits, medication side effects, resistance to receiving oral care, and avoidance of social contact can affect the oral health of individuals with ASD.¹⁴ Research shows that food selectivity and refusal are more common among children with ASD than their typically developing counterparts, which can contribute to nutritional deficiency and increased caries risk.¹⁵ Additionally, children with ASD often do not receive necessary oral care due to elevated levels of distress and anxiety that may be associated with the many sensory stimuli in a typical dental office.^{4,12} People living with ASD often have a lower tolerance for dental visits, and their care is not necessarily easily accommodated in typical dental practice settings.¹⁶ Individuals with ASD also have an increased likelihood of being nonverbal and presenting with intellectual disabilities that impact their daily functions.¹³ Consequently, children with ASD face significant barriers when accessing oral care and present with many unmet needs, decreasing their overall quality of life.¹⁷ Furthermore, dependence on caregivers and lack

of autonomy in personal self-care habits act as barriers to oral health.¹⁸

Trends indicate that the prevalence of ASD has increased in recent years, and as self-regulated health care professionals, it is incumbent on dental hygienists to understand how to better serve the needs of this population and reduce their barriers to care.^{5,6} This narrative literature review thus aims to increase awareness of the additional needs that individuals with ASD have when accessing care and to identify how barriers to oral and systemic health care may be reduced.

METHODS

An electronic literature search of the PubMed, Education Source, and CINAHL online databases was conducted using a combination of the following search terms: autism spectrum disorder, barriers, dental, dental hygiene, developmental disability, oral health, and unmet needs. Relevant and credible literature was identified using the following inclusion criteria: full-text, peer-reviewed original articles published within the last 10 years and published in the English language. Twenty-one studies were reviewed, including longitudinal cohort studies, randomized controlled trials, and cross-sectional studies which employed quantitative, qualitative, and mixed-methods designs. Literature that did not include data on individuals with ASD, was not peer reviewed or was published prior to 2009 was excluded from this review. However, studies published earlier than the last decade were considered to evaluate evolving trends in the literature on ASD.

RESULTS

The examination of the literature on barriers to care faced by individuals with ASD identified a collation of key themes: behavioural challenges, inhibited social and communication skills, parental dependence, clinical environment, and attitudes and behaviours of dental professionals (Table 1).

Behavioural challenges

Children with ASD have a heightened sensitivity to physical, social, and emotional stimuli.¹⁹ As a result, daily oral health care routines have the potential to be a significantly challenging task for both children and their caregivers as compared to their typically developing counterparts. Research reveals that children with ASD display a wide range of behavioural challenges, which extends to their tolerance of oral care, both in office and at home.^{1,2,12,16,19-23} Parents of children with ASD report that there is inconsistency and variability in their behaviours and tolerance for daily activities, which often results in inadequate oral hygiene care and, thus, increased caries risk.^{2,16,24} Although oral aversion is commonly reported in children with developmental disabilities, some children tolerate electric toothbrushes better than manual toothbrushes due to their vibratory motions.¹⁶ An

Table 1. Themes associated with barriers to care faced by individuals with ASD

Themes	Impact on oral care
Behavioural challenges	<ul style="list-style-type: none"> Limited ability to adhere to and comply with a recommended oral hygiene routine^{1,2,4,12,16,19-24} Oral aversion; limited tolerance of toothbrush & toothpaste¹⁶ Higher tolerance for an electric toothbrush than a manual brush due to vibratory motions¹⁶ Inconsistency in behaviour; steps to seeking care cause clients to feel overwhelmed²³ Food selectivity, often resulting in a highly cariogenic diet¹⁵ Altered response to behavioural conditioning when compared to typically developing counterparts¹⁶ Worse behavioural ratings on Frankl scale are common at dental appointments²⁵
Inhibited social & communication skills	<ul style="list-style-type: none"> Often unable to communicate pain, dental concerns or needs to caregivers or oral health professionals^{23,26} Non-verbal communication is essential when working with individuals with ASD^{12,13} Diminished ability to understand their own oral health needs¹⁶ Lack of cooperation with home care routine and oral examinations²⁰
Parental dependence	<ul style="list-style-type: none"> Individuals with ASD may not be able to perform oral self-care independently²⁴ Oral care is often not prioritized by guardians who may be overwhelmed with other aspects of caring for an individual with ASD such as feeding¹⁶ Guardians may not feel comfortable advocating for their child's oral care due to the intimidating nature of dental professionals¹⁹ Guardians struggle to ask for special accommodation at dental offices as they feel their children already create an additional burden for oral health personnel^{16,19}
Clinical environment	<ul style="list-style-type: none"> The physical dental clinic environment is often not conducive to treating individuals with ASD due to many visual, auditory, and tactile stimuli that create stress¹⁹ The waiting area is often busy and filled with strangers; waiting times tend to increase agitation and anxiety in individuals with ASD and their family members^{16,19}
Oral health professionals	<ul style="list-style-type: none"> Many professionals lack the educational preparedness to treat special care populations such as those with ASD¹⁹ Many families have been refused care for their child with ASD²⁰ Oral health professionals must provide highly individualized care to promote successful home oral care¹⁶ It is essential for oral health professionals to involve individuals with ASD and their caregivers when treatment planning for successful outcomes⁴

additional challenge in children with ASD is their altered response to behavioural conditioning.¹⁶ Individuals with ASD do not generally demonstrate an effective response to negative consequences for bad behaviour or rewards for good behaviour as their typically developing counterparts do.¹⁶ Furthermore, food selectivity is a common behavioural challenge in children with developmental disabilities, resulting in a predominantly cariogenic diet and, thus, increased caries risk when coupled with other risk factors such as inadequate biofilm control.^{15,19,21}

Literature shows that behavioural challenges are a predominant barrier to access to in-office oral care.²⁰ The Frankl behaviour scale is a ranking system commonly used in dentistry to assess a child's behavioural compliance during a dental appointment.²⁵ This scale typically ranges from 1 to 4, with a rating of 1 being the most behaviourally challenging (Table 2).²⁵ Children with ASD are more likely to be placed in the "negative" or "definitely negative" categories, exemplifying the behavioural challenges that this population experiences as a barrier to care.^{20,25}

Individuals with ASD feel most comfortable when they develop a consistent routine; unfamiliar stimuli and environments tend to cause distress and agitated behaviours in this population.^{12,18,19} These behavioural challenges are often associated with personal self-care

habits, both at home and in dental offices, which deter individuals with ASD and their caregivers from engaging in oral health actions.¹⁹

Inhibited social and communication skills

A commonly noted manifestation of ASD is a diminished ability to communicate and interact with other individuals in social situations.^{2,18-21} This symptom in individuals with ASD acts as a barrier to optimal oral and overall health as it often impedes their ability to advocate for themselves and their health.^{18,19} As a result, individuals with ASD are often unable to communicate their oral health needs to their caregivers or to their oral care providers. Guardians of children with ASD reported difficulty in recognizing dental pain in their children due to inhibited verbal communication skills.²⁶ This limitation emphasizes the importance of non-verbal communication methods for both caregivers and oral health professionals when working with this population.

Depending on the type and severity of ASD, social interactions have the potential to provoke anxiety among this population who are at an increased risk of anxiety disorders specifically related to oral care.^{16-19,21,27} An additional barrier arises from the inability of some individuals with ASD to understand their oral health needs,

Table 2. Frankl behaviour ranking scale²⁵

Frankl score	Behaviour presentation
1	<ul style="list-style-type: none"> Definitely negative Refusal of treatment, forceful crying, fearfulness, evidence of extreme negativism
2	<ul style="list-style-type: none"> Negative Reluctance to accept treatment, uncooperative, some evidence of negative attitude, but not pronounced
3	<ul style="list-style-type: none"> Positive Acceptance of treatment, cautious behaviour at times, willingness to comply with dentist, some reservation, follows directions cooperatively
4	<ul style="list-style-type: none"> Definitely positive Good rapport with the dentist, interest in dental procedure, laughter, enjoyment

contributing to a lack of cooperation with oral home care and clinical examinations in office settings.²¹ Although most of the literature on ASD and access to oral and overall health care focuses on children, adults with ASD often face additional challenges as they do not always have access to caregivers to aid them in their daily lives.²³ More specifically, adults who are labelled as “high functioning” individuals with ASD have difficulty maintaining social relationships and living independently as they are often not eligible for the same services as individuals with more severe manifestations of the condition.²³ This is a significant barrier that prevents access to oral care services and optimal oral and overall health.

Parental dependence

Children with ASD are typically dependent on their guardians, to varying degrees, to perform tasks in their daily lives. This dependence extends to oral hygiene home care which is often a challenging aspect of daily routines and not prioritized by guardians of children with ASD.^{16,19,21} Parents often report that their child’s immense dependence on them quickly leads to parental exhaustion and burnout, and oral care is typically a low priority; other essential tasks such as feeding their children and meeting their needs create a sense of overwhelm.¹⁶ Since individuals with ASD are often unable to perform their own oral care and may not tolerate the act of brushing their teeth, parents may have to resort to restraining their children, which can be both physically and emotionally challenging on a daily interval.^{16,19,28} An additional barrier faced by individuals with ASD with strong guardian dependence is the ability of their caregivers to advocate for their oral care. Studies suggest that parents often find oral health professionals to be intimidating and struggle to ask for special accommodations at dental offices as they feel their children are already placing an additional burden on oral health personnel.^{16,19}

Clinical environment

The physical environment of typical dental offices is generally not conducive to treating individuals with ASD. With several visual, auditory, and tactile stimuli, the dental

environment itself is a barrier to care for individuals with ASD.^{12,16,19} Sensory processing disorders are a common manifestation of ASD; they interfere with receiving adequate oral care, both preventive and restorative.^{2,19} With the dental office being an unfamiliar and uncomfortable setting for most individuals, the clinical ambiance of most dental offices tends to increase anxiety levels in populations living with ASD.

The waiting room adds another layer of difficulty in accessing oral care. The toys that generally appeal to neurotypical children may not appeal to children with autism, and waiting times can increase anxiety and agitation, potentially resulting in outbursts and tantrums.^{16,19} Being surrounded by strangers in busy areas with clients and office personnel also increases the stress levels of both children with ASD and their caregivers, who report that they feel embarrassed when people stare at their children in moments of outbursts or other negative behaviours.^{16,19}

The literature has reported success in implementing “desensitization” programs in which behavioural therapy is used to overcome fears and anxiety disorders through relaxation and stress management techniques, with gradual exposure to distressing situations.²⁹ A study exploring the effects of a mobile desensitization application coupled with in-office visits found it to be beneficial for children with ASD in reducing anxieties provoked by the unfamiliarity of clinical environments while increasing their understanding of positive oral health behaviours.²² However, it is important to note that caregiver support, together with positive attitudes and behaviours of oral health professionals, are critical for successful outcomes in desensitizing individuals with ASD to oral care.^{22,29}

Knowledge, attitudes, and behaviours of oral health professionals

Another barrier to care for individuals with ASD remains the oral health professionals themselves. The knowledge, attitudes, and behaviours of oral health personnel have a significant impact on the comfort, compliance, and satisfaction of individuals with ASD as well as their caregivers. Although there is limited literature on the

education of dental hygienists on ASD, there are evident gaps in the knowledge of dentists when treating this special care population. Literature indicates that there is a reluctance among dentists to treat children with autism as they do not feel confident in their educational preparation.^{19,20,30} Research reveals that a significant proportion of dentists do not feel their dental education adequately prepared them to work with special care populations and, thus, are less likely to provide care to developmentally disabled individuals post-graduation.³¹⁻³³ In contrast, those who received didactic and clinical training with special care populations reported increased positive attitudes and more confidence in providing treatment.³¹⁻³³ Dental hygiene students who had opportunities to work with children living with ASD in their entry-to-practice programs were better able to identify the characteristics associated with ASD and to develop and use visual supports to assist children with ASD in order to control their anxiety during dental prophylaxis procedures.³⁴ These findings emphasize the importance of incorporating experiences with special care populations within dental and dental hygiene curricula to promote competent oral health professionals who are comfortable working with clients with complex needs.

Although personalized oral care is essential for all clients, studies show that care must be highly individualized for clients with ASD.^{16,19} The oral health team must work as a coherent unit and be confident in their ability to adapt the environment to clients with intellectual and developmental disabilities. This adaptation extends to front desk staff as well, as they typically speak with the guardians over the phone and are often the first person clients see upon entering a dental clinic.¹⁹

Dental specialists may be better equipped to provide care for individuals with ASD due to a clearer understanding of behavioural management techniques. However, cost is often a restraining factor for families as many do not have dental insurance to cover the extensive care or sedation often required for treatment.^{16,17,19,20,35} Specialists such as pediatric dentists often have greater experience treating children with behavioural challenges, which may result in children with ASD receiving better care in an environment better suited to their needs. However, clearer directions for oral health professionals on where to refer clients with ASD are essential to improving access to care.³⁰

Literature indicates that individuals with special care needs, such as those with ASD, have a significantly higher probability of being refused services by oral health practitioners, usually due to inadequate experience with this marginalized population.²⁰ Studies reveal that most oral health professionals who refuse to treat individuals with autism do so because they lack confidence in treating special care clients and fear causing harm to their clients because of their behaviours and difficulty remaining still for longer periods of time.³⁰

DISCUSSION

Despite ASD's variability in presentation across individuals, common trends in barriers to oral care services were noted throughout the literature. These trends illustrate a pertinent need for a solution to the barriers experienced by this population.

Overcoming barriers

A clear theme in the literature indicates that the involvement of guardians in the oral care process for their child with ASD has the potential to create a positive experience and be beneficial in reducing some barriers to care. The input of guardians allows for transfer of valuable information about what works best for their child so that the process of providing oral care can be facilitated in a manner that feels more comfortable to the child.^{12,16,19-21} When interviewed, parents indicated that the use of a "pre-visit" questionnaire could be extremely beneficial, allowing both the family and oral health professional to adequately prepare for the visit.¹⁶ Questions to incorporate include those encompassing:

1. Child's developmental status, behavioural issues, and other diagnoses
2. Previous dental experiences and challenges
3. Current home care and challenges
4. Parental concerns and goals for dental visit
5. Useful preparation strategies for a dental visit
6. Factors that trigger both good and poor behaviour
7. Specific child or parent preferences¹⁶

The implementation of such a process could significantly reduce some anxiety and uncertainty surrounding dental appointments, which are often experienced by individuals with ASD as well as their family members. In addition, a reduction in anxiety could potentially reduce the need for sedation or general anesthesia, which is commonly requested or required to complete oral care with this population, further reducing barriers to care.

A clear referral pathway has also been identified in the literature as a way to improve access to care for individuals living with ASD.¹⁹ Parents report that their child's history of poor compliance during dental appointments may result in their not receiving necessary care by general dentists and that accessing care at a specialty office, such as a pediatric clinic, could result in better delivery of care if dentists are better equipped to treat special care populations.¹⁶ As there are higher costs associated with specialty clinics and sedation, greater access to funding through the government could improve access to care for this population.

Research gaps and future recommendations

A review of the literature revealed limited representation of adult populations living with ASD as most studies

evaluated access to care for children and youth up to 18 years of age. Additionally, it would be beneficial to understand the perspective of individuals living with ASD regarding their own self-described barriers to oral care, as the literature focused on the context of guardians' perceptions and experiences.

Directions for future research include a greater representation of all oral health professionals, such as dental hygienists, dental therapists, and certified dental assistants, in the experiences of individuals with ASD and their families. Although current research tends to focus on dentists, it would be beneficial to explore how those with ASD perceive other members of the oral health care team to understand how to better serve this population. Additionally, more research on the perspective of oral health care providers is required to understand their outlook and attitudes towards treating special care populations and how they could be better supported to increase their confidence in providing adequate care to all individuals, regardless of their background or special needs. Further methods of implementing entry-level education, whether in dental and dental hygiene curricula or through continuing education courses, should be explored to ensure better educational preparedness for all oral health professionals.

CONCLUSION

Current literature has shown that individuals with ASD face numerous barriers in accessing oral care and achieving adequate oral health, thus contributing to an increased burden of disease. Discussions stemming from this research articulate the importance of providing accessible and adequate care to special care populations. Augmenting curricula on special care populations in entry-to-practice dental and dental hygiene programs is paramount. Oral health professionals should aim to improve their understanding of special care populations such as the ASD community and raise awareness among health care professionals to work towards reducing the barriers to care that these populations currently experience.

CONFLICTS OF INTEREST

The authors have declared no conflicts of interest.

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