



Enhancing Autism-Friendly Hospital Care: Strategies to Optimize the Healthcare Journey: A Literature Review

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Abstract

Individuals with autism spectrum disorder (ASD) often face unique challenges in maintaining optimal oral health and navigating the healthcare system. Dental professionals frequently encounter difficulties in providing effective treatment for patients with ASD. Furthermore, the compromised oral hygiene and high prevalence of dental caries observed in this population can lead to adverse consequences, and the need for more extensive dental interventions, including general anesthesia. This literature review aims to examine the current understanding of oral health in ASD, the challenges encountered in the provision of dental and medical care, and the strategies that can be employed to enhance the overall healthcare journey for individuals with autism spectrum disorder.

Keywords: Autism; Oral Health; General Anesthesia; Hospital Care; Strategies

Abbreviations

ASD: Autism Spectrum Disorder; QoL: Quality of Life; OHRQoL: Oral Health-related Quality of Life.

Introduction

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders characterized by impairments in social interaction, communication, and restricted or repetitive behaviors. The underlying causes of ASD, though not fully understood, are believed to involve a combination

of environmental and genetic factors [1]. ASD usually manifests in infancy or childhood and persists throughout an individual's lifetime [2]. Individuals with autism spectrum disorder (ASD) frequently experience a range of co-occurring conditions, including epilepsy, depression, anxiety, and attention-deficit/hyperactivity disorder. Additionally, they may exhibit challenging behaviors such as difficulty sleeping and self-injurious actions [3]. These various symptoms and behaviors are believed to be closely linked to the neurological changes observed in ASD, particularly in the cerebellum and limbic system [4]. The complex interplay between the neurological underpinnings and the wide-ranging clinical



manifestations of ASD can significantly impact the overall well-being and quality of life of those affected [5].

The psychological and emotional well-being of parents and caregivers of children with ASD is profoundly shaped by the behavioral challenges exhibited by their offspring. The demanding nature of addressing these complex behaviors can lead to elevated levels of stress, psychological distress, depression, and an overall diminishment in the quality of life experienced by the caregivers. The significant strain placed on the mental health and well-being of parents and guardians of children with ASD underscores the need for comprehensive support systems and resources to assist this vulnerable population [1]. The abilities and support needs of children with ASD can vary greatly, with some being able to live independently, while others have severe disabilities and require lifelong care and assistance. Raising a child with ASD can be highly stressful, as it involves adapting to the child's routine, navigating educational and healthcare systems, coordinating multiple caregivers, and dealing with limited availability of resources [1].

The global prevalence of ASD is estimated to be around 1 in 100 children, although the reported figures vary significantly across studies [3,6]. Recent data from the Centers for Disease Control and Prevention suggests that the prevalence may be as high as 1 in 36 children in the United States [7]. However, the prevalence of ASD in many low- and middle-income countries, remains largely unknown [3,6]. Despite the growing recognition of ASD as a significant social and economic issue in Saudi Arabia, particularly from the dental perspective that we can see when they are doing day case procedure under general anesthesia, there is a lack of research in this area compared to other countries [5]. The provision of oral healthcare for individuals with ASD can be complicated, as they may have difficulty communicating dental problems and exhibit various behaviors and reactions to even small changes. The goal of this review is to explore the various challenges and considerations and the unique needs for providing effective dental care for children with ASD and their hospital experiences. Additionally, to develop more tailored and patient-centered approaches to improve this population's oral health and overall healthcare outcomes [8].

Oral Health and Autism

Given the high prevalence of ASD, it is likely that an increasing number of dental practitioners will encounter children with ASD in their practice or be asked to provide treatment for this patient population. Recent studies have identified several factors that contribute to poor oral health in children with ASD, including difficulty tolerating oral care at home and in professional settings, sensory processing

differences, uncooperative behaviors, communication impairments, and challenges in accessing professional dental services [8]. The limited number of studies that have conducted normative oral health assessments in children with ASD have yielded conflicting results. However, some research has reported a higher prevalence of dental caries in autistic populations compared to non-autistic controls [9]. Additionally, the literature suggests that young autistic patients often exhibit poor oral hygiene standards, which may reach statistical significance [9-12]. Furthermore, the compromised dental status of children with autism, coupled with harmful habits such as bruxism, tongue thrusting, and lip biting, can lead to the development of certain malocclusions [9].

Findings from literatures indicate that the use of effective preoperative preparation, tailored operative care, and appropriate postoperative strategies can improve the dental care experience for individuals with autism, going for day case dental procedures [13]. Recommendations for moderating intensity and duration of twilight-state monitoring, increasing privacy and minimizing noise for recovery, controlling the environment to prevent anxiety-provoking situations, giving extra time for discharge and postoperative questioning, and clarifying that the individual must eat and drink before discharge are imperative. Improvements to follow-up procedures that may enhance the quality of care include avoiding telephone conversations and using picture schedules or written instructions, with a designated point of contact for all follow-up communications with the family [14].

Dental Care Challenges for Children with Autism

Children with ASD often present unique behavioral challenges that can complicate the provision of effective oral healthcare, particularly for dental professionals. These children may struggle with limited communication skills, heightened anxiety in unfamiliar environments, and aggressive behaviors that can hinder productive interactions within the clinical setting [8]. Additionally, poor manual dexterity and avoidance of eye contact can further exacerbate the difficulties encountered by healthcare providers [8]. A study conducted in Italy highlighted various factors contributing to the complexities of delivering dental care to this population, such as caregiver demographics, challenges during the examination process, and a lack of dentists experienced in managing the needs of patients with ASD [15]. Conversely, a Canadian pilot study found that implementing an optimized protocol, which included environmental modifications, specialized order sets, and support from child life specialists, resulted in 83% of anesthetic inductions being rated as excellent for children with ASD [16]. These

findings underscore the importance of tailored, patient-centered approaches in addressing the unique needs and barriers faced by individuals with autism spectrum disorder in the dental setting. Parents and caregivers also face difficulties in providing regular oral hygiene measures due to the uncooperative behavior of children with ASD [3]. These challenges can negatively impact the quality of life (QoL) of both the affected children with ASD and their caregivers [5,7].

Dental treatment under general anesthesia may be the only feasible option for some individuals with ASD, especially when extensive treatment is required [17,18]. Compared to typically developing children, those with ASD are more likely to receive nonstandard premedication before dental procedures and have poorer compliance during the induction of anesthesia [19]. However, this approach has its risks, with one study reporting a 1.1% overall complication rate, including issues like post-extubation croup and intraoperative bronchospasm [18]. A study of pediatric day-case anesthesia found that around 2.5% of over 10,000 cases resulted in unplanned hospital admissions, often due to surgical, anesthetic, or medical factors [20]. Another study on the oral health-related quality of life (OHRQoL) of Lithuanian children requiring general anesthesia for dental treatment concluded that their OHRQoL was significantly impaired, but improved after the dental procedures were completed under anesthesia [21].

Improving Hospital Experience in the Future

Experts emphasize that by implementing certain strategies, hospitals can create a more autism-friendly ecosystem, and create a more accommodating and supportive environment for children with autism and their families, enhancing the overall hospital experience. Communication and preparation are key elements. Providing detailed information about upcoming procedures, encouraging the use of familiar objects, and establishing clear communication plans can help reduce anxiety and ease the transition [22].

Modifying the environment to be calmer and less stimulating, offering private spaces for the child to retreat to, and providing opportunities for breaks and calming activities can also contribute to a more positive experience. Addressing the child's sensory needs, allowing them to wear comfortable clothing, and incorporating sensory-friendly therapies can further enhance their comfort and well-being during the hospital stay [12].

Collaborating with the family to understand the child's behavioral patterns and develop personalized coping strategies, along with involving trained professionals and using positive reinforcement, can lead to more effective behavioral support. Ensuring hospital staff receive training on autism and communication techniques, and encouraging them to be patient, flexible, and respectful of the child's needs, can foster a more understanding and accommodating environment [3]. Finally, a comprehensive discharge plan and guidance for the family on continuing the child's care can help facilitate a smooth transition back home and maintain a positive hospital experience in the future [2,23,24] Table 1.

Literatures addressing the role of day case surgery in providing dental care for individuals with autism is limited and in its infancy. The majority of available information focuses on general anesthesia rather than on surgical facilities which could provide care under conscious sedation alone [25]. Therefore, the role of day case surgical facilities (both hospital-based and community-based) in providing dental care for individuals with autism necessitates future research. Such a facility would be responsible for primarily providing dental services for children and adults with autism who had been referred after consultation in the community. This type of model has already been adopted successfully by the UK's Caring for Smiles Committee (which dates back to 1995), providing dental services for those with special needs as a satellite outreach service from main dental and surgical bases. Construction of models estimating necessary staffing levels, revenue flows, and break-even financial projections would be necessary prior to pursuing a further research proposal with external funding [26].

Author Name and Year	Age and Sample Size	Intervention and Control Tx	Out Come
Green, Woodman, et al. 2020 [15]	≤16 years; n =25986	640 children had unplanned admission for sudden surgical complications, pain, nausea, and vomiting	1. Pediatric day case surgeries has a 2.5% rate of unplanned admissions. 2. Cardiology, ENT, orthopedics and trauma has the highest rate of unplanned admission. 3. Airway problems, uncontrolled pain, and surgical complexities are the most factors encountered during recovery
Jankauskiene, Virtanen, et al. 2014 [21]	< 6 years; n =144	OHRQoL survey was conducted before dental Tx and one month after GA dental treatment	1. Pediatric patients requiring GA had an impaired OHRQoL and obvious improvement after GA dental Tx was noticed
Awad, Moore, et al. 2004 [20]	< 16 years; n =10772	Survey to determine the causes of unplanned hospital admissions in a university affiliated children's hospital	1. Reasons of unplanned admission were 54% surgical, 44% anaesthetic, 14% social, 11% medical, 4% unclassified. 2. Causes of admission were the same for both children and adults after a day surgery.
Logrieco, Ciuffreda, et al. 2021 [27]	3-15 years; n =275	2 questioners were used (one for parents to understand the difficulties encountered during dental tx) and (another for dentists to assess the barriers occurring during tx)	1. Questioner to understand the needs of autistic patients, new and proper procedures to treat autism patients.
Whipsey Bernstein, et al. 2019 [16]	3-17 years; n =18	Utilizing parental and provider feedback, a protocol including environment modification, anxiolysis plans, specialized order sets, and child life specialist (CLS) support was developed over a nine-month period. Autism severity scores (ASS), communication styles, triggers, and previous experiences were used to create individualized care plans in the preoperative clinic. Emotion and sedation scores in the same day surgery unit, at anesthesia induction, and in the post anesthesia care unit were recorded.	1. The primary outcome was the feasibility of a perioperative protocol for children with ASD. 2. Secondary outcomes included emotion and sedation scores pre- and post-anxiolysis medication and the quality of anesthetic induction. 3. Parental satisfaction was used both to gauge the efficacy of the intervention and to make modifications to the protocol
Shah Shah, et al. 2009 [28]	16 years, n =1	mixed the oral medications with 15 ml of Dr Pepper to mask the appearance and change the flavor of the drug for the pt	1. Combination increase the palatability and acceptability of medications in children and patients with developmental delay

Arnold Elliott, et al. [29]	3-11 years; n =121 ASD patients and n =881 non-ASD patients	medical records were evaluated for patients with and without ASD undergoing general anesthesia for dental rehabilitation from 2006–2011	1.Children with ASD seemed to have similar proper- active experiences as non-ASD subjects
Matton and Romeo [30]	18 years, n =2	The authors describe postoperative behavioral changes in 2 patients with autism spectrum disorder and attention deficit hyperactivity disorder that the patients' caretakers described as regression.	1. In both cases, behaviors representative of ASD and attention deficit hyperactivity disorder worsened after uncomplicated oral surgery after receipt of a general anesthetic in the operating room.
Rada [17]	5 to 57 years, n =50	Patient charts were reviewed retrospectively from the author's dental practice and hospital record in which the individual had a primary diagnosis by a physician of autism and required general anesthesia for comprehensive treatment.	1.General anesthesia is not without complications, and unique occurrences are a necessary consideration for special-needs populations.2. In addition, behavior challenges may occur which can be disruptive to hospital staff.
Campbell Shetty, et al. [18]	Up to 13 years; n =351	A retrospective review of 1 year's pediatric GA cases from January 1 to December 31, 2016	1. All the dental treatment for the 351 patients was completed uneventfully in 1 visit and no child needed to return for another anesthetic exposure. 2. In addition, behavior challenges may occur which can be disruptive to hospital staff.
Tran Chen, et al. [31]	3-17 years; n =37	They are undergoing GA for dental surgery participated in this study. Their anesthesia records were reviewed, and their parents answered telephone surveys to assess activity level, sleep disturbances, gastrointestinal disturbances, central nervous system effects, and respiratory depression. Three follow-up surveys were taken 8 h, 24 h, and 3 months post-surgery.	1.Most behavioral effects occur within 8 h post-surgery. 2. There are potential long term adverse behavioral effects in ASD children from GA
Nagendra, et al. [32]		Guide to pediatric dentists towards the dental management for patients with Autism spectrum disorders	1. The increased prevalence of ASD will increase the exposure for them by pediatric dentists. 2.Dentist must show compassion and provide the best care for those patients. 3.Oral health program that emphasizes prevention is considered important for ASD patients.

Ghafournia, Eshghi, et al. [33]	2-7 years; n =72	questionnaire for 2 days to fill complications occur with GA postoperatively	Most complications were attachments to parents, dental pain, inability to eat normal and excessive crying.
Vlassakova and Emmanouil [23]	Review	literature review that summarize the current experience and recommendations for the preoperative management of ASD group	1.The perioperative management can be challenging to ASD patients' parents, health care providers, and the patients themselves. 2. Developing preoperative protocol can improve their care. Further research is needed to identify best anesthetic management strategies, associated with lower rates of adverse reactions.
Friedlander Yagiela, et al. [2]	Review	MEDLINE search for the period 2000 through 2006 conducted using the term "Autism" to define the condition's clinical manifestation, dental and medical treatment and dental implications	1. Dentists must exhibit compassion when providing care to this group and their caregivers. 2. Dentists and staff members also must be aware that parents of patients with autism may have social or behavioral abnormalities or deficits in problem-solving skills.
Elliott, Holley, et al. [19]	2-19 years; 60 youth (32 with autism spectrum disorder, 28 typically developing)	Participants were presenting for outpatient surgery with general anesthesia, to be discharged the same day. Parents and research assistants rated children's anxiety at 3 time points (waiting room, preoperative holding, separation), and parents rated their own anxiety in the waiting room and at separation	1. There are differences in observer reports of anxiety in youth with ASD compared to typically developing youth that may impact perioperative management. 2. Altering the approach to management in for children with ASD could reduce anxiety.

Van der Walt and Moran [24]	Over 4 years; n =59	Unique management program for autistic children admitted for medical and surgical procedures requiring a general anesthetic. (telephone interview with parents by an anesthetist when the child is booked for a procedure and an Autistic Antiesthetic Questionnaire is completed). For autistic patients, the aim was for direct admission to the Day Unit and, in many cases, more severe cases bypass the Day Unit to a special quiet room adjacent to theatre. Autistic patients are admitted a short time (approximately 45 min) before the theatre list commences and scheduled to be first on the operating list.	1. The focus is on early communication with the patient's families, flexibility to individualize the admission process and anaesthetic plan with admission and early discharge on the day of surgery whenever possible
Limeres-Posse, Castaño-Novoa, et al. [22]		Literature review about the behavioral attitudes have been described that vary from total cooperation during even bloody procedures, to the absolute impossibility in conducting a simple oral examination.	1. There is no effective behavioral management technique for all ASD patients. Gathering all information pre-operatively is very important to individualize behavioral management strategies and develop a thorough treatment plan.
Rainey and van der Walt [34]	4-12; n =5	Five case reports which describe an integrated management program considering the special needs of autistic children and their families.	1. Oralketamine (6 to 7 mg/kg) has proven to be the most reliable preoperative sedative for these patients.

Table 1: Research Papers about Dental Procedures for Children with Autism.

Conclusion

Given the increasing number of patients with ASD seeking dental care, there is a growing demand for dentists who are specially trained and experienced in providing tailored, patient-centered services for this community. Adopting a personalized approach is crucial, as each individual with ASD presents with a distinct medical history, comorbidities, behavioral patterns, and medication regimens. The dental treatment plan should be developed in close collaboration with the patient's support network to ensure it aligns with their specific needs and preferences. By fostering this collaborative partnership, dental professionals can work to optimize the healthcare journey and improve oral health outcomes for individuals with autism spectrum disorder.

It would be future directions for more researches that can discuss providing dental services for those with special needs as a satellite outreach service from main dental and surgical bases. Construction of models estimating necessary

staffing levels, revenue flows, and break-even financial projections would be necessary prior to pursuing a further research proposal with external funding.

However, the successful establishment of such facilities would require a greater understanding of autism and would mark a major advancement in dental care provision for individuals with autism.

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