

Effectiveness of a preparatory aid in facilitating oral assessment in a group of Saudi children with autism spectrum disorders in Central Saudi Arabia

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ABSTRACT

الأهداف: تقييم فعالية كتاب في طب الأسنان صمم خصيصاً كإحدى (مساعدات تحضيرية) على سلوك مجموعة من الأطفال ذوي اضطراب طيف التوحد في السعودية خلال أول زيارة لهم لعيادة الأسنان في كلية طب الأسنان، جامعة الملك سعود، الرياض، المملكة العربية السعودية

الطريقة: الدراسة تتألف من قسمين استبياناً يستهدف الآباء والأمهات قبل وبعد الزيارة (2) والتقييم والفحص السريري للأطفال ASD خلال الفتره مامن يناير حتى يونيو 2016م.

النتائج: شملت الدراسة مجموعه 40 طفل من ذوي التوحد (75% ذكور و 25% إناث) بمتوسط عمر قدره 6.1 سنوات. هناك عدد كبير من الأطفال (47.5%) أظهروا سلوكاً إيجابياً أثناء إجراء فحص الأسنان. الكتاب المستخدم كان له تأثيراً إيجابياً على سلوك 37.5% من الأطفال وفقاً لتقييم آبائهم وفعالاً للغاية في تعزيز 67.5% معرفة الوالدين بأساليب العناية بالأسنان.

الخاتمة: أعرب الآباء عن آراء إيجابية بشأن استخدام الوسائل التحضيرية في عيادة طب الأسنان، ما يقرب من نصف الأطفال ASD أظهروا استفادة من المساعدات التحضيرية المستخدمه وفقاً لرأي الوالدين كما أظهرت الدراسة تحسناً في معرفة الوالدين بممارسات النظافة الصحية الفموية وأساليب العناية بالأسنان

Objectives: To evaluate the effectiveness of a specially-designed dental book (preparatory aid) on the behavior of a group of Autism Spectrum Disorder (ASD) Saudi children during their first dental visit to the College of Dentistry, King Saud University, Riyadh, Saudi Arabia.

Methods: A cross-sectional double-blinded pre-and post clinical study consisting of 2 parts; a survey targeting the parents, and a clinical oral examination of their ASD children was conducted between January and June of 2016.

Results: A total of 40 children (75% males and 25% females) with an average age of 6.1 years were included. Approximately 47.5% children acted positively during the dental procedure. The dental book had a positive effect on the behavior of 37.5% children according to their parents' evaluation and highly effective in enhancing the parents' dental knowledge (67.5%).

Conclusion: Parents expressed positive opinions regarding the use of preparatory aids in the dental environment. Approximately half of the ASD children benefit from the preparatory aid used according to the parents' opinion, and the follow up survey showed improvement in the parent's dental knowledge and oral hygiene practices.

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For years, studies have documented the insufficiency of dental care for children with special needs, both in general¹⁻⁵ and in particular for children with Autism Spectrum Disorders (ASD).⁶⁻⁸ The reasons for this deficiency of services were reported by researchers on a case-by-case basis, depending on both the type of disability or special needs of the patient, and the site of the facility where they were being treated.⁸⁻¹⁴ In

cases of children diagnosed with ASD, patients usually show different degrees of pervasive impairment in cognitive and/or perceptual functioning, verbal and nonverbal communication skills and social interaction, repetitive patterns of behaviors/interests/activities, and unpredictable reactions.^{6,15-17} Consequently, and due to the complicated and complex behaviors of this group of ASD children, overall management and dental care become a great challenge for both parents and dentists.^{2,6,7,13,14,18}

The parents' challenge begins with providing proper home dental care for their children and ends with locating a designated clinic designed to accommodate special needs children with a qualified dentist willing to manage and treat them.^{2,8,12,19} To overcome such challenges, researchers working in the special needs field published various suggestions and recommendations to help both parents and dentists. For instance, major dental academics highly recommend the introduction of early home dental care, which includes daily tooth-brushing and diet control in addition to early dental visits to detect any dental problems and to apply preventive agents.²⁰ If the principle of "prevention is better than cure" is important to follow for all children, it is particularly crucial for children with special needs. Furthermore, many special needs organizations have utilized their websites to publish and spread beneficial information, such as different techniques and routines that can be used to manage children with special needs during daily tooth-brushing.^{21,22} Regarding dental facilities, several recommendations have been published to help general and pediatric dentists in planning the construction of their dental clinics to suit children with special needs.²³⁻²⁵ Additionally, a number of communication-aided approaches, such as applied behavioral analyses, visual pedagogies, pictorial or iconic images and social stories, have been proposed to aid behavioral changes among people with ASD.²⁶⁻²⁸ However, evidence of the value and effectiveness of such communication aids to improve oral health behaviors is still limited.

In Saudi Arabia, a search of available literature shows no previous studies were conducted to test the

effectiveness of such aids. In summation, the purpose of this study was to assess the effectiveness of a specially-designed dental book on the behavior of a group of ASD children during their first dental visit to the College of Dentistry, King Saud University, Riyadh, Saudi Arabia.

Methods. An extensive search of the existing body of published research in this area was conducted by MEDLINE and through secondary references to identify the current published literature. This was a cross-sectional double-blinded pre and post clinical study conducted between January and June 2016. The proposal was submitted, registered and approved by the ethical committee of the College of Dentistry Research Center at the College of Dentistry, King Saud University, Riyadh, Saudi Arabia. This study was conducted in accordance with the principles of the Helsinki Declaration. The study consists of 2 parts; a survey targeting the parents, and a clinical behavioral evaluation of their children. The survey consisted of properly defined interview questions to the parents of ASD children before and after their children's first dental visit using a modified version of a reliable questionnaire used previously.⁸

Forty children diagnosed with ASD were randomly selected from a special needs registration list, obtained from the College of Dentistry's special needs clinic at the Department of Pediatric Dentistry, King Saud University. The inclusion criteria included children, who, apart from their diagnosis of autism, were otherwise medically fit, with no previous dental experiences, between the ages of 5-9 years of both genders, who had received a copy of the dental book. Parents were contacted via telephone calls in which the purpose of the study was explained to them, with an emphasis on the voluntary participation. Parents were interviewed and the questionnaires completed prior to their first dental visit via telephone calls by a trained research assistant. Children with previous dental experiences were excluded from the study, but were still given appointment in the clinic for regular treatment. The questionnaire was designed to collect sociodemographic information such as: gender, current age of the child, parents' level of education, and family's average income. Also it included questions on the age of their children when diagnosed with ASD, the place of their diagnosis; any disabilities presented by the child; and any medical conditions. In addition, the questionnaire included

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questions regarding oral hygiene practice routines (frequencies of tooth brushing and type of tooth paste) and the presence of any dental caries, and other dental problems.

Preparatory aid. As part of another project, the author produced a children's book to assist both children and their parents in preparing for their first dental visit. The main features of the book were its simple Arabic language, carefully selected color scheme, and the friendly, inviting cartoons used to portray the characters in the narrative. The book focused on describing the waiting area, dental assistant, dentist, clinic, instruments, and materials to be used to perform a dental examination (namely, prophylaxis and topical fluoride) and other small details to help familiarize parents with the details and layout of the average dental clinic. At the end of the book, there was also a special page dedicated to give parents even more detailed information as well as dental tips and suggestions. The design of the book and language were reviewed and modified by experts in children's Arabic and special education before it was approved and registered at the Ministry of Culture and Information (Registration number ISBN:978-603-02-0122-8). The book is commercially available for purchase at a number of local bookstores under the title "My First Visit to the Dentist" in both Arabic and English (Figure 1).²⁹ The participating families (n=40) received the book free of charge from the author one week prior to their children's first dental visit. Parents were asked to visit the Pediatric Dentistry Clinic, College of Dentistry without their children to pick up the book and be familiarized with the location of the clinic and how to access the facility. In addition, parents were instructed to read the book with their children every day at the same time of their scheduled appointment at the College of Dentistry to prepare the child for a particular routine. On the scheduled day of the appointment, all the children received oral examinations, prophylaxes, and topical fluoride applications by senior postgraduate pediatric dental students as part of their regular special needs clinic.

To eliminate subjective bias, a double-blind experiment format was followed, where both the students and the investigator: who was clinically supervising, were not aware which children had received the preparatory book. The Frankl³⁰ behavior scale was used to evaluate the behavior of the children during the first dental visit



Figure 1 - The cover of the book entitled "My First Visit to the Dentist". Registration number ISBN:978-603-02-0122-8.

procedure by the parents and the postgraduate students. The College of Dentistry's standard clinical form of the Department of Pediatric Dentistry Clinic was used to record the clinical findings and the children's behavioral levels according to the postgraduate students' evaluation. The parents' opinion on the effectiveness of the dental book on their children's behavior and on their own dental knowledge was recorded by interviewing the parents via another telephone call after the completion of the dental appointment. Parents were asked to rate the effectiveness of the book on the behavior of their children and on their own knowledge starting from 0 as absolutely not effective to 5 as highly effective.

Those patients who returned for a recall appointment 4 months later were asked to complete a follow-up survey of a few questions. The follow up survey evaluated preparatory aid use and the caregiver's opinion of its effectiveness after the dental treatment visit.

Data analysis. Data were entered into the computer and analyzed using the Statistical Program for Social Sciences (SPSS) version 21.0 (IBM Inc, Chicago, USA). Descriptive statistics (mean, standard deviation, frequencies, and percentages) were calculated for quantitative and categorical variables. Pearson's Chi-square test was used to observe the association between 2 categorical variables. Non-parametric statistical tests (Kruskal Wallis test and Mann-Whitney test) were used to compare the mean ranks of the response scores towards book aid by parents in relation to the study variables with more than 2 categories. Wilcoxon sign rank test was used to compare the response scores towards book aid by parents at 2 time

points (first visit and after 4 months. A p -value of ≤ 0.05 was used to report the statistical significance of results.³¹

Results. Forty families were included in the study and received the preparatory dental book before their first dental visit. The average age of the children was 6.1 years (75% males and 25% females). Most children (67.5%) were diagnosed with ASD in government hospitals. Twenty percent had mental disabilities. The parents' educational levels ranged between elementary and college graduates with a higher percentage of high school graduates among the mothers and college graduates among the fathers. In regards to the average family income, 50% of the participants had a monthly average family income of 5,000 to 10,000 Saudi Riyals (Table 1).

More than half (57.5%) of children practiced tooth-brushing irregularly, and 82.5% of them used toothbrushes, whereas 57.5% used fluoridated toothpaste. Most (62.5%) children received help during toothbrushing from their mothers and 50% had

dental problems. Approximately 47.5% children acted positively during their dental procedures (Table 2).

The data shows that the book was effective on the behavior of 37.5% of children according to their parents' opinion, whereas 97.5% of parents thought the book was effective or highly effective in increasing their own dental knowledge (Table 3).

The parents' opinion regarding the effectiveness of the dental book on their children's behavior and on their own dental knowledge when compared with relation to the pattern of brushing teeth, helping in brushing, dental problems, behavior during treatment and reason

Table 1 - Sociodemographic characteristics of 40 autistic children who received the preparatory dental book before the first dental visit (N=40).

| Sociodemographic variables | n (%) |
|--|-----------|
| Age (years) (mean±SD) | 6.1 ± 1.2 |
| Age at diagnosis (years) (mean±SD) | 2.6 ± 0.9 |
| Gender | |
| Male | 30 (75.0) |
| Female | 10 (25.0) |
| Place of diagnosis with Autism Spectrum Disorders | |
| Governmental Hospital | 27 (67.5) |
| Private Clinic | 8 (20.5) |
| University Hospital | 5 (12.5) |
| Children's disability | |
| Mental disabilities and seizures | 8 (20.0) |
| No disability | 32 (80.0) |
| Mothers' educational level | |
| Elementary | 7 (17.5) |
| Secondary | 2 (5.0) |
| High school | 15 (37.5) |
| Diploma | 2 (5.0) |
| College | 14 (35.0) |
| Fathers' educational level | |
| Elementary | 3 (7.5) |
| Secondary | 1 (2.5) |
| High school | 11 (27.5) |
| Diploma | 3 (7.5) |
| College | 22 (55.0) |
| Family income (Saudi Riyals) | |
| <5000 | 2 (5.0) |
| >5000-10000 | 20 (50.0) |
| >1000-20000 | 15 (37.5) |
| >20000 | 3 (7.5) |

Table 2 - Distribution of study variables (toothbrushing, behavior, and dental problems) among 40 autistic children.

| Study variables | n (%) |
|------------------------------------|-----------|
| Frequency of tooth brushing | |
| Irregular | 23 (57.5) |
| Once a day | 7 (17.5) |
| More than once | 10 (25.0) |
| Tools used | |
| Brush and tooth paste | 33 (82.5) |
| No answer | 7 (17.5) |
| Type of tooth paste | |
| With fluoride | 23 (57.5) |
| No answer | 8 (20.0) |
| Don't know | 9 (22.5) |
| Helper during brushing | |
| Mother | 25 (62.5) |
| Nanny | 5 (12.5) |
| Child himself/herself | 4 (10.0) |
| No answer | 6 (15.0) |
| Dental problems | |
| Yes | 20 (50.0) |
| No | 20 (50.0) |
| Behavior during treatment | |
| Definitely positive | 1 (2.5) |
| Positive | 18 (45.0) |
| Negative | 13 (32.5) |
| Definitely negative | 8 (20.0) |

Table 3 - Distribution of parents responses in regards to the dental book effectiveness on their Autism Spectrum Disorder child's behavior, and their own dental knowledge (N=40).

| Responses | n (%) |
|---|-----------|
| Effect of using aid on the child | |
| Absolutely not effective | 11 (27.5) |
| Not effective | 8 (20.0) |
| Neutral | 6 (15.0) |
| Less effective | 7 (17.5) |
| Effective | 7 (17.5) |
| Highly effective | 1 (2.5) |
| Effect of using aid on the parents | |
| Not effective | 1 (2.5) |
| Effective | 12 (30.0) |
| Highly effective | 27 (67.5) |

for not treating was analyzed. The analysis of the scores of the effect of the dental book on children shows a statistically significant difference in the mean rank of scores in relation to their pattern of brushing teeth, dental problems, behavior during treatment, and reason for not seeking treatment. The scores are statistically significantly higher in children who brushed ≥ 1 time, when compared with children who were irregular in their brushing ($p=0.001$). The scores were statistically significantly higher in children with dental problems, when compared with children without dental problems ($p<0.001$). The scores were statistically significantly higher in children with positive behavior during treatment compared with negative behavior ($p<0.001$). Scores were statistically significantly higher in children who mentioned 'no pain' as the reason for not seeking dental treatment, when compared with children who selected other reasons such as no special clinic, negative behavior, and no appointments ($p<0.001$) (Table 4).

The analysis of scores of the effect of the dental book on parents shows statistically significant differences in the mean rank of scores, in relation to their dental problems, behavior during treatment, and reasons for

not seeking dental treatment. The scores are statistically significantly higher in children who did not have dental problems, when compared with children who had dental problems ($p=0.013$). The scores were statistically significantly higher in children with positive behavior treatment when compared with children with negative behavior ($p=0.002$). The scores were statistically significantly higher in children who had mentioned 'no pain' as the reason for not seeking dental treatment, when compared with children who gave other reasons no special clinic, negative behavior and no appointments ($p=0.015$) (Table 4). The effectiveness of the dental book was assessed by comparing the distribution of responses towards the variables: pattern of brushing teeth, helping in brushing, tools used for brushing, type of tooth paste, dental problem, and behavior during treatment at the time of receiving the dental book and after 4 months of follow up. There was a statistically significant difference in the response of pattern of tooth brushing, where 57.5% of children who used irregular tooth brushing at the time of receiving the dental book were reduced to 35% after using the dental book and brushing teeth for one time has increased from 17.5% to 42.5%, which is

Table 4 - Comparison of mean ranks of autistic children's parents responses towards association between dental care aid in relation to other study variables of autistic children (N=40).

| Study variables | Effect of using aid on child | | Effect of using aid on parents | |
|--------------------------------|------------------------------|---------|--------------------------------|---------|
| | Mean ranks | P-value | Mean ranks | P-value |
| Brushing teeth | | 0.001* | | 0.518 |
| Irregular | 15.83 | | 19.09 | |
| One time | 20.00 | | 21.43 | |
| More than one time | 31.60 | | 23.10 | |
| Helping in brushing | | 0.050 | | 0.637 |
| Mother | 23.30 | | 21.28 | |
| Nanny | 20.40 | | 23.10 | |
| Child himself/herself | 20.75 | | 17.25 | |
| Not applicable | 8.75 | | 17.25 | |
| Dental problem | | <0.001* | | 0.013* |
| Yes | 11.80 | | 15.95 | |
| No | 29.20 | | 25.05 | |
| Behavior during Tx | | <0.001* | | 0.002* |
| Positive | 29.92 | | 25.97 | |
| Negative | 14.92 | | 16.00 | |
| Definitely negative | 7.19 | | 14.81 | |
| Reason for not treating | | <0.001* | | 0.015* |
| No special clinic | 17.53 | | 16.60 | |
| No pain | 31.36 | | 27.00 | |
| Negative behavior | 11.31 | | 16.44 | |
| No appointments | 9.17 | | 20.50 | |

*Statistical significant, Tx - treatment

Table 5 - Comparison of study variables (tooth brushing, disability, and dental problems) of autistic children (N=40) who had received dental care aid and after 4-5 months (follow up).

| Study variables | After receiving dental care aid | After 4-5 months (follow up) | P-value |
|----------------------------------|---------------------------------|------------------------------|---------|
| Pattern of tooth brushing | | | 0.021* |
| Irregular | 23 (57.5) | 14 (35.0) | |
| One time | 7 (17.5) | 17 (42.5) | |
| More than one time | 10 (25.0) | 9 (22.5) | |
| Helper for brushing | | | 0.820 |
| Mother | 25 (62.5) | 35 (87.5) | |
| Nanny | 5 (12.5) | 4 (10.0) | |
| Child himself/herself | 4 (10.0) | 1 (2.5) | |
| Not applicable | 6 (15.0) | - | |
| Tools used | | | - |
| Brush and toothpaste | 33 (82.5) | 40 (100) | |
| Not applicable | 7 (17.5) | - | |
| Type of toothpaste | | | - |
| With fluoride | 23 (57.5) | 40 (100) | |
| Not applicable | 8 (20.0) | - | |
| Don't know | 9 (22.5) | - | |
| Dental problems | | | 0.005* |
| Yes | 20 (50.0) | 12 (30.0) | |
| No | 20 (50.0) | 28 (70.0) | |
| Behavior during Tx | | | <0.001* |
| Definitely positive | 0 (0.0) | 0 (0.0) | |
| Positive | 19 (47.5) | 32 (80.0) | |
| Negative | 13 (32.5) | 5 (12.5) | |
| Definitely negative | 8 (20.0) | 3 (7.5) | |

*Statistically significant, Tx - treatment

statistically significant ($p=0.021$). In addition, there was a statistically significant difference in the distribution of the response towards dental problems, in which 50% of children who had dental problems at the time of receiving the dental book were reduced to 30% after using the dental book ($p=0.005$). Also the proportion of children who had positive behavior during treatment at the time of receiving the dental book (47.5%) increased to 80% after using the dental book, which is highly statistically significant ($p<0.001$) (Table 5).

Discussion. Children with ASD may be incapable of cooperating in the dental setting as their developmental impairments may lead to great difficulty in interacting with the dental team and understanding and following instructions. Compliance could be enhanced by the use of the traditional tell-show-feel-do technique and by giving short, clear commands and positive verbal reinforcements.^{6,23,32} In the event of failure on that front, the use of pharmacological behavioral management aids such as nitrous oxide, conscious sedation and general anesthesia often become the alternative of choice, especially for those requiring extensive dental treatment. However, the parents of children with ASD tend to prefer more basic and less invasive techniques that are less costly and less likely to pose medical risks to their children.³³

Educational and behavioral preparation aids such as visual pedagogy, tablets and computer applications, social stories,^{21,34,35} books and pictures series can also be used to describe a situation and designed to prepare a child for a new experience.^{26,36,37} However, as in the case of other behavioral management techniques, they are not effective for every child. Despite that, they are relatively inexpensive, easy to administer, and have been shown to be useful in affecting non-dental behavioral changes for up to 60% of ASD children.^{27,38} This level of success may therefore be achievable with similar types of dental aids preparation. The use of such simple aids is not only potentially effective, but has also been shown to be an intervention that is well accepted by families that have used them.^{37,39}

A search of available literature reveals no studies were conducted in Saudi Arabia to test the effectiveness of the previously mentioned educational and behavioral aids on ASD children in the dental setting. Resistance to changes in daily routine has been recognized to limit ASD patients in developing a positive attitude at the

dental clinic.^{25,40} Accordingly, in this study, a costumed rate, time, and immediacy routine in introducing the dental book information to the participated children were followed with anticipation to achieve a positive attitude towards their dental visit. The effectiveness of such a routine was also supported by Floyd et al⁴¹ in a qualitative observations study.

Structural language anomalies, impairments, and learning disabilities in children with ASD have been theoretically and practically documented.⁴² The children selected for this study were between the ages of 5 and 9 years, diagnosed with ASD, and not misdiagnosed with other disabilities with similar symptoms to autism. Furthermore, most children with ASD have their introduction to reading and writing skills at roughly this age.^{42,43}

The effect of the book used in this study was not as prominent in children as that of their parents. Many parents considered the book effective on their children's behavior in various degrees during the first dental visit and the treatment visits. Conversely, other parents thought that their children did not dedicate much attention in following the sequence of the pictures or that the book simply did not interest them, which was not unexpected, knowing the nature of the ASD and that some of the children had mental disabilities. However, the book was greatly appreciated by almost all of the participating parents who considered the book highly useful to the extent of their dental knowledge. In addition, the parents expressed their gratitude for the opportunity to prepare themselves for the dental visit according to what they read in the book. Furthermore, the parents expressed their gratitude to the research assistant during phone calls regarding the effort made to invent new aids to help them and their children to achieve a smooth first dental visit. It was encouraging that none of the parents thought the book was definitely not effective or slightly not effective for their own dental knowledge. Even though the parents' opinion about the use of alternative aids was not part of the questionnaires, a number of parents suggested the use of actual pictures as an alternative to the cartoons used in the dental book to make the pictures more realistic to the perception of their children. Some other parents suggested an electronic copy of the book as an alternative, because their children preferred to interact with digital and computer applications over standard paper books. This may reflect the power of media on both children in general and ASD children specifically, though this assumption likely warrants further investigation. Marion and his group of researchers reported similar parents' propositions.³⁹

In general, it is difficult to gauge the effectiveness of such preparatory aids on ASD children or their preference of digital or regular aids. But according to the parents' feedback, it is highly recommended to dental clinics to use preparatory aids in multiple formats and make them available to families with special needs. Whilst we have no way of knowing truly how much the children themselves may benefit from these aids, their parents, at the very least, could find some assistance and maybe even comfort in knowing that they are not alone in their struggle and that resources exist to aid them in their endeavors. The level of the parent's education and the average family income made no significant differences to the results of the current study.

This was a preliminary investigation of the use of dental preparatory aids for children with ASD in Saudi Arabia. Further research should investigate the effectiveness of different aids in improving patient behavior in the dental environment and focus on the optimum timing and frequency of use.

Study limitations. Limitations of the study included a small sample size, limited follow up cases, and the use of only one type of preparatory aid.

In conclusion, parents expressed positive opinions regarding the use of preparatory aids in the dental environment. A large group of the ASD children studied benefited from the preparatory aid used according to parents' opinion and the follow up survey showed improvement in the parent's dental knowledge and oral hygiene practices.

Recognizing children with ASD as individuals and utilizing principles of learning by a dental team can provide high-quality dental care for patients with ASD. Further study by including a larger sample sizes of children with ASD in Saudi Arabia is highly recommended.

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