Effectiveness of a one year oral health educational and preventive program in improving oral health knowledge and oral hygiene practices of a group of Autistic Egyptian children and their caregivers

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a neuro developmental disorder characterized by severe damage in social interaction, language, behavior and cognitive function.

Aim: The current study aimed to assess the effectiveness of a specially designated educational and preventive program for 1 year in reducing caries activity and preventing caries and periodontal diseases among group of autistic Egyptian children, also to assess the behavior of each child in every visit and to assess the effectiveness of a specially designated educational program in improving oral health knowledge, attitudes and oral practices of parents and caregivers of these children.

Basic research design: Longitudinal field trial with before and after comparison.

Participants: 30 Autistic Egyptian children (4-13 years old) and their parents/caregivers.

Clinical setting: Three academies for autism spectrum disorder, situated in Cairo, Egypt.

Interventions: Phase I: Information of the Cariogram parameters (caries experience, diet content, diet frequency, plaque amount, mutans streptococci, fluoride program, saliva secretion and saliva buffer capacity) were collected, which were used to generate the individual caries profile, based on which the children were divided into 3 risk groups. Phase II: Risk based preventive program was implemented. Phase III: At the end of 12 months, caries profile was generated again.

Main outcome measures: The effectiveness of the preventive program was assessed by comparing the baseline and follow-up caries profile for statistical analysis.

Results: A statistically significant difference was found in Frankl's behavior scale between the three periods of testing, regarding caries activity and periodontal diseases, a statistically significant difference was found between before and after the preventive program, on assessing dental knowledge of caregivers before and after the program, results showed that a statistically significance difference was found between the percentage of caregivers in answering the questions with right answers before and after the program where a higher percentage answered the right answer after the program than before.

Conclusions: Educational and preventive program was effective in improving the various caries risk factors and increasing the chance to avoid caries to autistic children and in increasing children and caregivers' dental knowledge.

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1. Introduction

Oral health has a significant impact on overall health and well-being of individuals across their life span [1]. Oral diseases such as caries and poor oral hygiene can have negative impacts on the life of healthy children as well as children with special health care needs (CSHCN) [2].
One such disability affecting the world population now at a
dramatic level is Autism spectrum disorder (ASD) [3], which is a
neuro developmental disorder characterized by severe damage in
social interaction, language, behavior and cognitive function. The
distinct patterns of the illness are unified in a classification system
referred to as ASD [4], traditionally subdivided into 3 large groups.
Classic autism (or “autism disorder”) is the most severe profile and
presents severe alterations on the cognitive, social, and behavioral
levels. ‘Pervasive development disorder not otherwise specified’, is
a diagnosis reached by including patients with similar problems to
autism, but which do not reach the diagnostic criteria in number,
severity, or age of presentation, and tend to present more activity,
social interaction, and empathy than classical autistics. Asperger
syndrome is characterized by a relatively normal language and
intellect quotient, but with a deficit in social abilities, a reduction in
the ability to show empathy, and often an unusual interest in
something [5]. These behaviors commence before the age of 3 [6].

Dental care for such patients is neglected as they often face
significant difficulties in accessing dental care; due to the difficulty
to locate a dentist specialized to treat such individuals and due to
difficulty to manage these children behavior [7]. As a result these
children are at an increased risk of developing dental and oral
diseases due to poor dietary habits, damaging oral habits such as
bruxism and oral self-injures [8].

Parents and caregivers are the primary decision makers in
matters of health care for children with special health care needs;
thus, they play an important role in achieving the best oral health
outcomes for their children. Parents should be educated and
participate in programs about importance of oral health care that in
turn also influences general health of their children. At the same
time there is a lack of studies and programs which have elicited
parental knowledge, attitudes, and practice (KAP) behaviors toward
oral health of children with autism spectrum disorder (ASD) [9].

1.1. Children and methods

The study proposal was submitted for approval and clearance
was obtained from the Ethical Committee of Faculty of Dentistry
Ain Shams University prior to implementation of the study. An
informed consent was obtained from the caregivers before starting
the study. They were informed that they could quit at any time
without penalty or loss of any benefits. An explanation of all steps
of the educational and preventive program was given to the autistic
participant children in a simple visual way also the aim of the study
and subjects and methods were detailed simply to the caregivers.

The current study was based on the risk strategy for risk
assessment and risk management according to Petersson 2003 [10].
It was conducted in 3 consecutive phases. Phase 1 was completed in
one month which included identification of various caries risk
factors and then analyzing these factors to generate a caries risk
profile for each child. Phase 2 was completed in 12 months which
included a risk-based educational and preventive program and
phase 3 in one month which included analysis of the effectiveness
of the program.

1.2. Study population and data collection

A total of 30 Autistic Egyptian children with age range from 4 to
13 years with mild and moderate degrees of autism from three
different specialized academies for autism in Cairo, Egypt as well as
their parents and caregivers were selected to participate in present
study.

2. Methods

In phase one data were collected using the following methods:

2.1. Questionnaire

The questionnaire collected information about socio-
demographic data (parental education and occupation), medical
history of children, dental history (previous dental visits and oral
hygiene practices), dietary habits (snacking habit, daily snacking
frequency, preferred snacks type).

2.2. Clinical examination

Clinical examination was performed by the researcher in
a surrounding familiar to the child and in natural daylight with the
child seated on a chair using mouth mirror with good reflecting
surface and diagnostic probe. During the study procedure, ‘Tell-
Show—Feel and Do’ technique and different visual guide techniques
were used with all children. The examination included the following:

(1) Child behavior assessment using Frankl Behavioral Rating
scale [11].
(2) Intraoral examination under flash light and regular room
light to assess:
(a) Oral hygiene condition; using Silness and Löe plaque
index (PLI) [12]
(b) Caries prevalence and experience; following the World
Health Organization (WHO) criteria, using the dmft index
for primary dentition, DMFT index for permanent dentition,
and dft and DMFT indices for mixed dentition [13].

2.3. Saliva sampling

After clinical examination, salivary sampling was done for each
child to evaluate the salivary buffering capacity, estimate resting
Salivary Flow Rate and estimate Mutans streptococci & Lactobacilli
in Saliva using CRT bacteria kit.

2.4. Caries risk assessment (CRA)

CRA included identification of various caries risk factors and
then analyzing these factors to generate a caries risk profile for each
child. CRA was evaluated using Cariogram at base line before
beginning of program and after one year. When all the information
described in the previous steps were available (including the re-
sults of the saliva tests); the relevant information were entered into
the Cariogram computer program to calculate the caries risk for
each child. The various parameters were given a score on scale
ranging from 0 to 3 (0–2 for some factors) for each factor.

Phase Two was completed in 12 months which included a risk-
based educational and preventive program. The investigator’s
educational and preventive program was based on the data
collected from phase 1 and also on the caries risk profile for each
child which included protocols for preventive strategies and non-
operative intervention and was carried by the investigator of the
study with the help of caregivers and parents of children.

Regarding educational aspect of program; Behavioral Strategies
applied by the investigator of the Study during implantation of this
educational and preventive program for the autistic children were:
Successive Approaches, Tell-Show-Feel-and-Do Technique, Treat-
ment and Education of Autistic and related Communication —
Handicapped Children (TEACCH Technique), Modeling, Positive
Reinforcement concept and Training sessions.
A training educational workshop was organized by the main investigator of the study for children for oral health education using combination of flash cards, coloring sheets, games, songs, direct verbal communications and large models. Training was in the value of teeth and general health, self-care and effective use of fluorides, diet and nutrition, oral anatomy, causes and prevention of dental caries and periodontal disease. Additional to fluoridated toothpaste; all children received fluoride program in the form of fluoride varnish according to caries risk profile for each child.

Regarding preventive aspect of program; all children received oral hygiene orientations on tooth brushing technique. The technique taught is simple: first, circular movements on all buccal surfaces are carried out while teeth are occluded, followed by antero-posterior movements on occlusal and lingual surfaces of posterior teeth. Finally, lingual surfaces of anterior teeth are brushed in back-and-forth movements keeping the toothbrush in a vertical position [14].

If the children present erupting first permanent molars, child was oriented to use transversal technique on these teeth. For that, the toothbrush is placed bucco-lingually with the bristles toward the occlusal surface and the movement is made back-and-forth in a buccal-lingual direction. The use of fluoridated toothpaste was advocated for all ages with an amount equivalent to an uncooked grain of rice (for children up to 4 years old) or a pea-size drop (for children older than 4 years of age) [15].

As part of the preventive strategy of the study, the children received at baseline and at every follow-up visit a new toothbrush and fluoride toothpaste with 1450 ppm NaMFP containing calcium-based abrasive.

2.5. For parents/caregivers; knowledge and practices assessment questionnaire was performed

Parents/caregivers attended with their children during clinical examination and during educational program. To assess their knowledge and attitudes towards dental health, a specifically designed questionnaire was used at the beginning and by the end of the study. The questionnaire aimed at measuring the information and knowledge that caregivers have about their teeth, their kids' teeth, oral hygiene, dietary practices, dentist and dental care.

The questionnaire was in the form of closed ended questions and completion of the questionnaire was carried out by the investigator of the study. (Interview leaded questionnaire).

An English form of the questionnaire was translated in Arabic for every parent or caregivers.

A training workshop was organized for the parents/caregivers for oral health education using macro models, slideshows, videos and printed instructions. These training workshops was repeated every 2 months. All parents/caregivers of these children received their educational counseling, assisted along with pictorial representation of the caries risk assessment of the individual risk factors and their effect on caries risk profile. Health education was based on Health Belief Model. Component of health education based on Health Belief Model [16]. The basic education revolved around the Cariogram interpretation of risk factors and includes counseling about the value of teeth and general health, self-care and effective use of fluorides, diet and nutrition, oral anatomy, causes and prevention of dental caries and periodontal disease.

Phase three was done at the end of 12 months of the preventive program all data for the Cariogram parameters was collected again in a similar manner to phase 1. Then all data were analyzed and the effectiveness of the preventive program was evaluated.

3. Results

A total of 30 Autistic Egyptian children participated in this study. (3 of them dropped out of study and 27 completed the whole program).

Frankl's Behavior Rating Scale: A statistically significant difference was found in Frankl’s behavior scale between the three periods of testing where (p ≤ 0.001) which indicates a spectacular improvement in children behavior after the program. According to Frankl’s behavior scale as shown in Fig. 1 and Table 1.

Preventing caries and periodontal diseases: No statistical significant difference was found in def mean values between the three time factors (Base line, mid and final) where (p = 0.098). Also, no statistical significant difference was found in def mean values between normal and autistic children where (p = 1). There was a statistical significance difference in plaque mean values between the three time factors (Base line, mid and final) where (p ≤ 0.001). A statistical significance difference was found between (Base line) and (Mid) where (p ≤ 0.001), also a statistical significance difference was found between (Base line) and (Final) plaque where (p ≤ 0.001). In addition; A statistical significant difference was found between (Mid) and (Final) where (p = 0.001). Fig. 2 A & B.

Reducing caries activity: Regarding caries activity, a statistically significant difference was found between before and after the preventive program where (p = 0.037). Results showed that (55.6%) of children had high caries risk and (44.4%) showed moderate caries risk before educational and preventive program. While after the preventive program, the majority of children showed low caries risk with (81.5%) and only (18.5%) showed moderate caries risk. Fig. 3 and Table 2.

Percentage of cariogram colors results: Results showed obvious decrease in “Bacteria” percentage (Red sector) as it was represented by (14%) before the program and (6%) after; with a statistically significant difference where (p = 0.007). Fig. 3 and Table 3.

For “Diet” (Dark blue sector) and “Susceptibility” (Light blue sector) also a statistically significance difference was found between before and after the program; results were (p = 0.013) and (p ≤ 0.001) respectively, which indicates a high effectiveness of the program as the percentage of both diet and susceptibility before the program were (14.5%) and (43.5%) respectively; and highly decreased to (6.8%) and (9.8%) respectively.

In addition, “Circumstances” (past caries experience plus general diseases) (Yellow sector) showed decrease in percentage from before (4.5%) to after (4.1%) but with no statistically significance difference (p = 0.756).

“Chance of avoiding caries” which is (Green sector) showed a very high improvement in results between before and after program with statistically significance difference (p ≤ 0.001) as its
Percentage before the program was (23.5%) and highly increased to (73.3%) after the program.

The effectiveness in improving knowledge: On assessing dental knowledge of caregivers before and after the program, results showed that a statistically significant difference was found between the percentage of caregivers in answering the questions with right answers before and after the program where a higher percentage answered the right answer after the program than before. However, at some questions, there was no statistically significance difference (p > 0.05) between caregivers’ answers before or after the program; for example, when they were asked about the effect of oral health on general health, effect of sweets on teeth and the importance of brushing teeth. While their knowledge was highly improved after the program concerning the importance of dental visits, fluoride role and number of both primary and permanent teeth.

4. Discussion

Over the past decade, there has been an increase in reporting and increasing awareness of ASD. Knowledge and awareness of the condition has grown exponentially at all levels among the general public, parents, caregivers, health professionals and the whole research community [17,18].

Dentists are likely to have one or more children with this disorder in their daily practice and families. In adequate training of dentists, dental specialists and staff are barriers to accessing dental care and may explain the difficulty that parents of these children had in finding a dentist willing to treat their children. Mendoza stated that the Egyptian health care system played a limited role in providing care for children with ASD [19].

Thus the present study was conducted to find the solution for the prevention of dental caries and to implement oral health promotion strategies to improve oral health status of these autistic Egyptian children [20].

The present study was carried out on a group of autistic Egyptian children with age ranging between 4 and 13 years. The selection of this age group was based on the fact that ASD can be diagnosed starting at the age of 2.5 years and continues throughout life. The relatively chosen wide age range allows the study of disease manifestations to be at different developmental stages [21,22]. Male to female ratio was 4:1 in the current study; this might reflect the higher prevalence of autism in males more than females which concurs with the previously reported literature [23–25].

In the present study the behavior and compliance of each child was assessed by means of the Frankl behavior rating scale which is a simple uncomplicated and easy method to perform. Children with ASD showed at the beginning of current study uncooperative behavior; these findings agree with other studies which observed that most children with ASD had negative behavior to dental examination [23,24], while at mid and end of program of the present study children showed an improved
positive behavior; this is in accordance with a recent study by Marshall et al. which showed that 35% of patients with ASD were cooperative during dental appointment [26]. That’s why dental team may need to be creative in their approaches in examining patients with autism [27]; that was the reason why the investigator of the current study attended learning sessions to know how to deal with these autistic children.

Because children with autistic spectrum disorder (ASD) have difficulties in verbal communication and in complying with behavior modification in the traditional way. Therefore these

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**Fig. 4.** (A&B): Percentage of cariogram colors results.

**Fig. 5.** Knowledge of parents before and after the program.
children should be behaviorally guided with different behavior approaches [28,29]; that’s why the investigator of the present study used combination of approaches as the ‘Tell-Show-Feel-Do’ and the structured visual guide system, consisting of different drawings, picture prints, games and flash cards which worked as an effective tool in helping them to understand the procedure and behave well during the whole procedures of the program.

Collection of data regarding medical, dental, and dietary histories and habits was carried out by a self-administered questionnaire. Although questionnaires allow a standardized, relatively quick way of collecting data, respondents may respond superficially and they might not wish to reveal information they think they will not benefit from; but it was the easiest and simplest mean to gather information [30,31].

Cariogram model was used in this study to illustrate the caries risk profile of each child, to predict caries risk and as a health education aid in educating parents/caregiver of these autistic children. The advantage of the Cariogram model is that it detects and defines caries-risk of individuals under precise and constant criteria. It is a useful and easy understandable pedagogic tool, to parents and caregivers; highlighting the necessary steps to improve the green sector or to reduce the caries risk in near future and this is in accordance with other previous studies which used cariogram model to assess caries risk in children [32–34].

In the present study, the parent/caregiver was interviewed and child examined in the same single visit. Information regarding the nine factors was collected and transferred to ‘scores’ and these scores then entered into the Cariogram program operating on PC computer by investigator of current study.

The results of current study showed no significant difference in caries prevalence between children with ASD and previously reported normal known mean def in healthy children [35,36]. Other studies reported lower caries prevalence in patients with ASD than those in healthy patients [37,38]. In contrast, Marshall et al. investigated the association of ASD and Caries-risk Assessment Tool (CAT) and concluded that according to CAT, ASD is an indicator of high caries risk [39].

Salivary Lactobacilli counts were used to estimate the diet content score in the Cariogram, based on the fact that high carbohydrate intake is correlated with high LB count in saliva. This step was done by using a simple commercial kit, CRT bactetia Ivoclar Vivadent strips which was proven to be reliable and specific and was very easily used with these autistic children [40,41].

Diet frequency was measured in each subject by the intake frequency questionnaire (the interview method), where we recorded how many times items were taken per ordinary day that can promote acid formation (even a small snack, biscuits or sweets). Gathered information of the current study showed that these children had high intake of snacking habits and sweets; this is similar to other study done by Petersson G.H. et al. which showed that children with ASD had eating disturbances due to idiosyncrasies and sameness in diet [42]. While a study done by Loo et al. observed a lower frequency of snacking and more regular behavior at meals for children with ASD than unaffected children [23].

None of the subjects examined had been given any fluoride supplements or rinses and they all drink tap water. The only method to deliver fluoride to the mouth in most of subjects was tooth brushing using fluoridated toothpaste. Fluoridated tooth paste was less commonly used by children with ASD than healthy children.

The Silness–Loe Index, 1964 was used to estimate the oral hygiene conditions of the subjects examined. It was easier to use than any other oral hygiene index especially in these autistic children. Most of the children with ASD had brushing problems and needed supervised brushing which could be related to their behavioral disturbances, restricted interests and activities, limited manual dexterity and sensory issues. Several previous authors showed same results with the present study which documented the need for improving oral hygiene routines in individuals with ASD due to their poor gingival condition [43,44].

Salivary levels of MS are considered to reflect the number of tooth sites colonized by these bacteria [45]. In the present study, the scoring of salivary MS levels was done by using CRT bacteria Ivoclar Vivadent Strips Which had been proved to be a simple, reliable and valid commercial kit to measure MS counts [46,47]. In the present study, positive correlations were found between different levels of mutans streptococci infection and caries experience in the children (dmfs). This agrees with the results of earlier study by Kohler et al. [48], who all pointed to an increase in the caries incidence with increased level of MS in saliva.

Non-bleeding pH 0–14 M Colorplast strips were used for estimation of the salivary buffering capacity. These strips were found to be a simple, practical and reliable method and easily used with these autistic children [49]. As regard salivary flow of autistic children in the current study, no difference was observed in flow rate, pH, and buffer capacity between before and after program and between normal levels of normal children; this is parallel to Bassoukou I.H. et al. [50] who showed in their study that children with ASD had similar salivary flow rate and buffering capacity to healthy children. While other study by Rai K. et al. mentioned that children with ASD showed significant reduced salivary secretion than normal levels [51]; this may be attributed to the use of different techniques of estimating salivary flow secretion.

At the baseline of the present study almost half of the autistic children (46.7%) showed moderate caries risk profile and the almost the other half of children (53.3%) showed high caries risk profile. While after the extensive 12 months educational and preventive program (Fluoride program, diet counseling, health education and modification of oral hygiene habits) a significant reduction in caries risk profiles to be (8.5%) of children in the moderate risk group and (81.5%) in the low risk group; these results are in accordance to Renuka P. et al. whom stated in their study that there was a significant improvement in chance of caries avoidance in all disabled children included in their study after their educational and preventive program [52].

Also there were improvements in the scores for Mutans streptococci, plaque amount, diet frequency and content following the preventive program which reduced the mean percentages of the bacteria and diet sectors. The circumstances sector changed very little being based on general health and past caries experience.

Parents/guardians role is crucial. To be effective, care takers should be equipped with knowledge and attitude towards maintenance of oral hygiene and good diet practice of their child. Knowledge of risk factors gives the parents an opportunity to reflect over their child’s situation and an option to take a personal responsibility for their child’s future oral health, results of the current study showed a significant awareness of oral health care for parents and caregivers after educational program. Early contact with parents once a child is diagnosed with ASD is paramount to promote good oral health. Comprehensive oral health educational programs should be implemented to support the use of supervised or assisted brushing with fluoride toothpaste and so that parents understand the role of diet in caries. The importance of oral health on general health should also be emphasized [53].

5. Conclusions

1-Children with autism or communication disorders can be treated in an environment of decreased fear and anxiety by utilizing the structured visual guide intervention.
2. Children with ASD have normal caries prevalence but poor oral hygiene and gingival condition, they are more likely to have tooth brushing problems and need supervised tooth brushing.

3. Cariogram software could also be used as an effective health educational tool in changing children and parents’ caregivers’ attitudes and behaviors towards good oral hygiene and dietary habit maintenance.

4. Educational and preventive program was effective in improving the various caries risk factors and increasing the chance to avoid caries to autistic children and in increasing children and caregivers’ dental knowledge.

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