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Nursing care for children with autism spectrum disorder within the scope of pediatric health and nursing

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ABSTRACT

Autism spectrum disorder (ASD) is one of the common neurodevelopmental disorders of childhood characterized by repetitive abnormal behavior, limited interests, and impairments in social communication and interactions. Although the prevalence of ASD is increasing day by day, the treatment and rehabilitation of the disease is important. In the process from the diagnosis of the child with ASD to his/her education and inclusion in the community, it is important to educate and guide the family with the awareness of health professionals and to interact with public and private institutions. In this process, the importance of effective nursing care increases. This review includes the clinical presentation, etiology, epidemiology, treatment methods and nursing care of ASD.

Keywords: Autism spectrum disorder, child, nursing care

INTRODUCTION

Autism spectrum disorder (ASD) was first described by Leo Kanner in 1943. Autism, derived from the Greek word "autos", means "self/self, own". The word autism was first used in 1908 by Bleuner to describe withdrawal in schizophrenia patients. Kanner (1943) used autism to describe social isolation and language impairments in children without schizophrenia or known psychiatric disorders. These children had repetitive behaviors that accompanied social isolation and linguistic disorders (Kanner, 1943). The American Psychiatric Association's DSM-5 (The Diagnostic and Statistical Manual of Mental Disorders), which is used in the definition of many psychiatric disorders, divides childhood pervasive developmental disorders into five groups and ASD is included in this group as childhood autism (APA, 2024).

ASD is defined as a neurodevelopmental disorder whose symptoms appear in childhood, characterized by repetitive behaviors, accompanied by social interaction disorder and linguistic disorders, and whose effects last a lifetime (CDC, 2023; Tohum Autism Foundation, 2017). Although autism symptoms are recognized during childhood, the earliest symptoms appear at the age of 2-3 years. The etiology of autism was initially thought to be influenced by genetic factors and the refrigerator mother's attitude (inadequate bonding, acting distant and indifferent to the child, not providing stimuli), but recent studies have argued that environmental and epigenetic influences may also be involved (Frewer, Gilchrist & Collins, 2021). According to the centers for disease control and prevention data for 2020, one in every 36 children has ASD (CDC, 2023). Although there is no definitive cure for ASD, treatments and therapies have an effect on reducing the severity of the symptoms of autism (Campisi, Imran & Nazeer, 2018).

A multidisciplinary treatment approach is essential in ASD and another factor in increasing the effectiveness of treatment is early diagnosis. Nurses have important roles in early diagnosis, follow-up and treatment. This review aims to present nursing care in addition to general information about ASD.

CHARACTER OF AUTISM SPEKTRUM DISORDER

Autism is considered as a childhood neurodevelopmental disorder and its symptoms vary according to the developmental period and chronological age. In order to be diagnosed, it is important to recognize the symptoms between 12-18 months after birth. Before 24 months, it is very difficult for parents to recognize the symptoms, but these symptoms can be observed by health professionals such as nurses and doctors during routine examinations (Aydın & Özgen, 2018). The average age of early diagnosis of ASD is reported to be after the 46th month (Tohum Autism Foundation, 2017).

Children diagnosed with autism are defined as "well-behaved babies" in the newborn period. The baby behaves as if it

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does not need its mother and is indifferent to strangers in the presence and absence of the mother (Ocakçı & Karakoç 2013). The process of diagnosing autism in children is usually completed 2-3 years after the symptoms appear (CDC, 2023). In the diagnostic process of autism, laboratory results are not sufficient to make a definitive diagnosis and behavioral criteria observed in the child are important (Korkmaz, 2010). Symptoms observed in the early period in children diagnosed with ASD are as follows: inability to smile warmly at others from the 6th month onwards, inability to smile, respond to sounds and other facial expressions from the 9th month onwards, inability to turn to names until the 12th month, inability to point to objects with fingers after the 12th month, no crying or gestures, inability to show interest in objects until the 14th month. month, inability to say a single word from the 16th month, inability to play symbolic games (such as feeding a doll) until the 18th month, inability to form simple two-word sentences after the 24th month (Törget, Özdemir & Selimoğlu, 2010). In later ages, these symptoms can be listed as avoiding eye contact, giving big reactions to small changes, exhibiting repetitive movements, delay in language and speech skills, not answering questions, being overactive or immobile, having obsessive interest, laughing and crying for no reason (Törget, Özdemir & Selimoğlı, 2010). The affect of children with ASD is often incompatible with the social context. Even if they know the rules of courtesy and etiquette, they may have difficulty following these behaviors. Social smiling may be absent. Difficulties with mood regulation may be frequent (Kadak & Meral, 2019) (Table 1).

Table 1. General symptoms of autism spectrum disorder	
Behavioral symptoms	
Repetitive movements	Uncontrollable tantrums
Routines or rituals	Obsessed with certain objects
Persistent behaviors	Self-harm
Uncontrollable tantrums	Pica
Obsession with certain objects	Exaggerated emotions
Impulsive behavior	
Communicative symptoms	
Delayed speech or inability to speak	Echolalia
Damage to language or vocabulary	Difficulties understanding instructions and problems
Abnormalities in tone of voice	Difficulties starting and maintaining a conversation
Avoiding eye contact when making requests	
Social symptoms	
Not reacting to your name	Prefer to play games alone
Poor eye contact	Reluctance to make friends
Resistance to touch and contact	Lack of empathy

Table 1. (APA, 2024)

Studies in the literature show that children with autism tend to gain weight (Anagnostou, 2018), have sleep problems, and experience delayed sexual development (Erbaş & Onur, 2022). Studies have shown regression in social speech and communication skills of children with autism after the period of normal development. Regression is seen in 25-30% of children with autism and frequently in the 13-18th months (Reyes, Norbert & Wiggins, 2024).

Children with ASD also have comorbid psychiatric diagnoses. These include attention deficit hyperactivity disorder, depression, bipolar disorder and anxiety disorders (Bougeard, Picarel-Blanchot & Schmid, 2021). In addition to psychiatric diagnoses accompanying ASD, there are also differential diagnoses such as schizophrenia and specific language disorders. In order to differentiate ASD from other psychiatric diagnoses, DSM-5 diagnostic criteria are important in determining the character of the psychiatric diagnosis.

The diagnostic criteria in DSM-5 for ASD are as follows (Töret, Özdemir & Selimoğlu, 2014).

A. Different social communication and interaction deficits:

- Inability to establish reciprocal social and emotional relationships
- Inadequacy in non-verbal communication behaviors in social interaction
- Inability to establish, maintain and understand relationships

B. Limited, repetitive behavior:

- Stereotypic/repetitive motor movements, object use or speech
- Excessive attachment to routine situations, verbal or non-verbal ritualistic behavior
- Abnormally limited interests in terms of intensity/focus
- Overreactivity or unresponsiveness to sensory stimuli or abnormal interest in sensory aspects of the environment

C. Symptoms must have started at an earlier developmental stage.

D. Symptoms cause clinical impairment in social, occupational or other important areas.

E. These disorders, intellectual disabilities and autism often co-occur.

Etiology

Although the causes of autism are not known exactly, there are ideas suggesting that prenatal complications, genetics, environment and family have an effect (Aydın & Özgen, 2018). The first genetic studies on autism were twin sibling studies. The incidence of autism in identical twins is higher than in fraternal twins (Özören, 2013). A meta-analysis concluded that autism is highly hereditary (74-93%), but non-genetic factors are also important risk factors (Tick, Balton & Happê, 2016). Another study on ASD-specific genetic risk factors shows a significant association between mutations and ASD (Lord, Elsabbagh & Baird, 2018). Bleeding during pregnancy, high blood pressure, premature labor, use of vacuum and forceps at birth, and infections that the mother has during pregnancy are thought to increase the risk of ASD in children (Ocakçı & Karakoç, 2013). In addition, heavy metal poisoning, gluten, casein proteins, vitamins or nutrients containing folic acid, decreased Omega-3 consumption, and increased antibiotic use are among the risk factors for ASD. When the family influence of ASD was examined, it was observed that risk factors such as advanced maternal and paternal age, socioeconomic or educational levels of parents, substance abuse habits in parents, and history of psychiatric illness were effective (Yıldız, 2020). In the first studies on ASD and the effect of the environment, it was observed that

ASD developed as a reaction to the "cold mother" approach. In studies conducted in the following years, it was observed that parents of children with ASD exhibited obsessive behavior and did not have enough emotional interaction with their children (Ocakçı & Karakoç, 2013). In the literature review on vaccines and autism effects, which is one of the common discussions in recent periods, it was found that measles, rubella and mumps vaccines do not increase the risk of ASD, do not trigger ASD in susceptible children and do not increase ASD cases in certain periods (Hviid, Hansen & Frisch, 2019).

Epidemiology

In the first epidemiologic study on the prevalence of ASD, it was thought to be 4/10.000. Although the same diagnostic criteria are used in the prevalence of ASD, there has been a significant increase in recent years (Fombonne, 2005). Without ignoring the effect of risk factors in the increase in ASD prevalence, it is emphasized that increased awareness, easier access to health services, and geographical differences also have an effect (Fombonne, 2005; Lai, Lombardo & Baron-Cohen, 2014). ASD can be seen in every society regardless of race, social group and social status (Aylward, Gal-Szabo & Taraman, 2021). In the United States, the prevalence rate of ASD is 1.7% in children aged 4 years and 1.8% in children aged 8 years. Although the age ratios in European countries vary (e.g. Germany 0.38% in the 0-24 age range, Spain 1.55% in the 3-5 age range), the prevalence rate is 0.38%-1.55%. According to recent world epidemiologic data, the incidence of ASD is higher than 1/100 (Bougeard, Picarel-Blanchot & Schmid, 2021). According to ASD gender distribution studies, the incidence rate in girls is 1/189, while this rate is 1/42 in boys (CDC, 2023).

AUTISM SPECTRUM DISORDER TREATMENT

The priority in the treatment of children with ASD is early diagnosis. In addition to recognizing the signs and symptoms of ASD, it is very important to use screening programs appropriate for the age and scope of the child. When diagnosing children with ASD, the appropriate treatment method is selected after a detailed developmental history and observation of behavioral phenomena (Okoye, Obialo-Ibeawuchi & Obajeun, 2023). The Table 2 below shows the screening programs used.

Table 2. Autism spectrum disorder screening programs
First level screening tools
Early Childhood Autism Screening Scale
Modified Early Childhood Autism Screening Scale
Early Screening Questionnaire for Autistic Traits
Communication and Symbolic Behavior Scales-Developmental Profile
Pervasive Developmental Disorders Screening Test-I
Early Developmental Stages Questionnaire
Second level screening tools
Communication and Symbolic Behavior Scales Behavior Sample
Pervasive Developmental Disorders Screening Test-II
Social Communication Questionnaire
Two-Year-Old Autism Screening Test

Table 2 (Çetinoğlu, 2019)

There is no definitive treatment method for ASD, which begins in early childhood and whose symptoms persist throughout life. The therapies and treatments aim to improve the child's long-term independent skills, reduce unwanted behaviors, and facilitate school adaptation and peer interactions (Campisi, Imran & Nazeer, 2018).

Pharmacological Treatment

Although the drugs used in the treatment of ASD are not specifically aimed at treating ASD, they facilitate the child's adaptation to social life and education through pharmacotherapy, which has effects such as reducing hyperactivity and increasing attention (Volkmar, Siegel & Woodbury-Smith, 2014). In a randomized controlled study conducted to investigate the effect of risperidone and aripiprazole on children and adolescents, it was concluded that it had a positive effect on irritability and aggression (Fung, Mahajan & Nozzolillo, 2016). This treatment has an effect on the reduction of aggression, irritability, self-harm, and repetitive movements in ASD cases (Kadak & Meral, 2019). Methylphenylidate, which is used in the treatment of Attention Deficit and Hyperactivity Disorder (ADHD), can be used in the treatment of comorbid ADHD in ASD, but the response rate to treatment is lower due to the more frequent side effects in these individuals (Lord, Elsabbagh & Baird, 2018). Evidence-based studies on the specific and comorbid treatment effects of medications used in ASD cases are limited.

Special Education

There is the idea that children with ASD have problems in functions mediated by sensory organs such as learning and interpretation. Within the framework of this idea, multidisciplinary education programs aim to improve the mental and behavioral skills of children with ASD by increasing their sensory functions (Ocakçı & Karakoç, 2013). Activities for balance, position and movement sensations, mostly provided by occupational therapists, are one of the trainings. This training is carried out in a planned and controlled manner. These activities include brushing the body, swinging in a hammock, squeezing the knees and elbows. Trainings for children with ASD are prepared individually, taking into account the strengths and weaknesses of the child, and the family is included in the training to facilitate the integration of the training into social life. The participation of the family in the training is also important for the continuation of the treatment at home. The training content is generally focused on strengthening verbal and non-verbal communication, increasing academic success, and increasing social, motor and behavioral skills (Volkmar, Siegel & Woodbury-Smith, 2014).

NURSING CARE OF AUTISM SPEKTRUM DISORDER

ASD is one of the most common neurodevelopmental disorders in childhood, which is becoming more and more widespread in the world and for which there is no definitive treatment (Hirota & King, 2023). In the process from the diagnosis of the child with ASD to his/her education and inclusion in the community, it is important to educate and guide the family with the awareness of health professionals and to establish interaction with public and private

institutions. Within the scope of pediatric health and diseases, the main goal of the nurse is to ensure the healthy physical, social and intellectual development of children and adolescents in the community, and to identify family and environmental problems at risk that impair child health at an early stage. Early diagnosis of ASD, which is a pervasive developmental disorder, increases the success in treatment. In this context, the role of pediatric nurses in primary health care services gains importance. The nurse should know the growth curve of the 0-6 age group and should be able to detect unusual situations (Aydın & Özgen, 2018). They should guide the child and family with nursing interventions in line with their findings.

After the child is diagnosed with ASD, the nurse should get information from the family about the child's routines, likes and dislikes. The child's basic skills and care practices such as feeding status, toilet and bathing habits should be questioned. The nurse should explain the child's treatment process to the family, involve the family in the treatment and access data on the family's support systems (Magalhães, Lima & Silva, 2020). In order to improve the support systems of the family, the nurse should provide an environment to meet the families of children diagnosed with ASD. The nurse can conduct group assessments with the families who come together. As a result of the evaluations, cooperation should be developed for the economic support needs of the families and the correct orientation studies for the school and treatment problems of the children (Ocakçı & Karakoç, 2013). Nurses who provide nursing care to children with ASD should have sufficient knowledge about ASD. Children with ASD do not like contact and hugging, but they are interested in rhythm and music (Zülkar. Söyünmez & Gürhopur, 2020). With a holistic approach, the nurse provides an effective care to strengthen the bond between mother and child by making the child with ASD embrace with the mother accompanied by music (Ocakçı & Karakoç, 2013). In order to improve the child's language and speech skills, the family is recommended to sing one or two songs a day with their child. Although children are indifferent in the first process, it is seen that they start to speak echolalically in the following processes (Ocakçı & Karakoç, 2013). The nurse should determine the child's need for education and rehabilitation and refer them to the necessary institutions. In these referrals, they should also cooperate with other health professionals if necessary. Communicative and social problems caused by ASD and sudden tantrums may cause difficulties for caregivers (Ravi & Mendonc, 2023).

In situations that require hospitalization or prolonged hospitalization, children with ASD may develop anxiety and anger. This process causes difficulties in nursing care (Gettis, Wittling & Palumbo-Dufur, 2018). Before providing care and treatment for a child with ASD, ways of establishing a secure bond with the child should be explored. The first people to be contacted are families who are the primary caregivers. After obtaining sufficient information from the family, it is important to provide care and treatment considering the clinical symptoms of ASD for the safety of the child and effective care and treatment. Assessment questions that will help in the admission of children with ASD to the clinic are questions aimed at getting to know the child and identifying his/her reactions, such as how your child expresses his/her wishes and needs, what are the situations that increase the child's anxiety, how the child expresses pain, how the child's best way of communication is (verbal, visual, drawing, etc.) (Kouo & Kouo, 2021). Children with ASD are at risk of injury, as a pediatric nurse, we need to ensure the safety of the patient. Aggression, anger and violence can be seen in children with ASD. It is generally characterized by the incompatibility seen in the change of environment due to the child's lack of development of social adaptation skills. In these cases, the child's behavior should be controlled, his mood should be evaluated, and environmental safety should be ensured. Precautions should be taken against possible risks in case of environmental changes. Hard objects, fragile objects and sharp edges in the environment should be removed from the child. Additionally, children with ASD are in the risk group for physical and sexual abuse. The nurse should inform the family about this. It should be explained that the child should be closely monitored for damage, wounds and scars on his body. Depending on the area of the wounds and marks on the body, places that indicate harassment and abuse should be introduced, brochures should be prepared and education should be given to families (Mughal, Faziy & Saadabadi, 2022). Children may develop a risk of nutritional imbalance due to picky eating behavior due to ASD. The pediatric nurse should closely follow the growth percentile curve of the child with ASD and prevent possible developmental delay or obesity (Tar, 2021). Families may have difficulty in the caregiver role because they do not have enough information about autism. The pediatric nurse should involve the family in care and treatment by obtaining information about the child's routines, skills, and routines (Magalhães, Lima & Silva, 2020). There are studies supporting the positive effects of nursing care on children with ASD and their families (Ahmed, Muhammed & İbrahim, 2019; Saied, Sayed & Mohamed 2024). The nursing care provided for children with ASD within the scope of pediatric health and diseases nursing plays a key role for the health of the child and family.

CONCLUSION

Autism spectrum disorder, one of the common neurodevelopmental disorders of childhood, is a difficult-to-diagnose disease with no definitive treatment. Early diagnosis plays an important role in the course of the disease and the quality of life of the child in the future. Early diagnosis of ASD, which is difficult to be recognized by families, increases the chance of early diagnosis as a result of routine examination or careful observation by nurses and physicians. The responsibility of pediatric nurses is very important. Pediatric nurses should be familiar with the character of ASD, closely follow the growth monitoring for each child aged 0-6 years and intervene in abnormal situations. The early identification process will also contribute to ASD incidence and prevalence studies and lead to the elimination of risk factors. Following the diagnostic process, pediatric nurses should prioritize the treatment and rehabilitation systems appropriate to the disease character of the child with ASD. Early treatment and purposeful rehabilitation of ASD, which has no definitive cure, has a high contribution to the child's adaptation to society and academic success. Pediatric nurses should also take initiatives to eliminate obstacles that negatively affect child health in the family. The responsibilities of the nurse in the treatment and follow-up of children with ASD in the clinic are to determine the priorities

by mastering the situations that will prevent the care and treatment of the child due to the character of the disease. As a result, it is important for the nurse, who is a member of a multidisciplinary team, to take part in every stage of the child with ASD and the family to bring the child and the family to the maximum level of well-being.

ETHICAL DECLARATIONS

Referee Evaluation Process

Externally peer-reviewed.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

All of the authors declare that they have all participated in the design, execution, and analysis of the paper, and that they have approved the final version.

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