

Case Report

Being autistic during the COVID-19 process: from a public health nurse's perspective

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ABSTRACT

Parents have an important role in supporting, controlling and managing autistic children's daily life at home. During the COVID-19 pandemic, routine life has changed and a decision for social isolation has been made. The purpose of this case study is to provide an overview of how the child with autism performs daily activities during the pandemic process, the state of self-care skills, and what are the daily developer activities at home. Data collection methods used in this study are interviews and observations. The results of this study show that children with autism can be supported, supervised and guided effectively by their parents at home. It is thought that the case report will provide an idea for diagnosis, and create a training and consultancy program for public health nurses working with autistic children in the field.

Keywords: Autism spectrum disorder, Nurse, Pandemic

INTRODUCTION

Autism Spectrum Disorder (ASD) starts in childhood. It is a neurodevelopmental disorder characterized by restricted, repetitive patterns of behavior or interest, as well as disorders in social communication and social interactions.¹⁻³ It is stated that the prevalence of ASD is increasing today, and it is seen in one out of every 54 children.⁴

Due to the lack of healthy statistics in Turkey, it is "assumed" that there are approximately 550,000 ASD children in our country. When the parents, siblings, close relatives and circles of individuals with autism are also taken into account, we can talk about more than 2 million citizens affected by autism with limited treatment and special education centers in Turkey.⁵

Typically developing children, as a requirement of their development, can learn many skills through their natural interactions with their families in their daily lives. For a child with autism, this process becomes difficult and a systematic program of skill teaching is needed.⁶ The level of learning difficulty of children with autism in learning skills varies depending on the level of autism, their age and parental factors.⁷ Mothers and fathers can share the role of parenting a child with autism, but mothers have a greater role and responsibility in performing the daily living activities of a child with autism. The mother usually acts as the primary caregiver, and it has been determined that mothers perform 91.2% of the daily living activities at home of a child with autism.^{8,9} The mother's participation in daily skills training with their children with autism contributes to better recognizing their children's inadequacies and competences, increasing their self-confidence, reducing their stress level, and improving social relations with their children.^{10,11}

For children with autism who need routines in their family lives, daily lives have to be rearranged due to the effect of the pandemic. A curfew was imposed, social relations were limited, activities were canceled and the social support provided by family members was limited.^{11,12,13} In this situation, it was inevitable that tantrums, resistance to change, and behavioral problems would develop.^{14,15} It is important to determine the education needs of children with multiple disabilities and their families with long-term strategic planning in health and social areas that affect the whole life of individuals, such as the epidemic.^{16,17}

It is very important to identify the families who have children with multiple disabilities who stay at home during the COVID-19 process and who have difficulties in accessing social, education and health support as well as in many other issues. Public health nurses should be able to provide support in all aspects to the autistic child and his family, within the framework of their roles as caregivers, advocates, collaborators, trainers and counselors.¹⁸ This study provides an overview of how a mother teaches and educates her child with autism in daily life activities at home during the pandemic period. In this case report, public health nursing support was provided to the family regarding skills, and information was given about the skills they could perform. The study aimed to evaluate the effectiveness of the training and counseling services given to a child with ASD and his family from the perspective of a public health nurse.

CASE REPORT

The data in this case report were collected through interviews with a mother, observation of the child in a special education institution in İzmir, and online observation of the child at home. Due to the pandemic, home visits could not be made. Verbal permission was obtained from the private education institution before starting the study. The mother was informed about the study, and verbal and written consent was obtained regarding participation and use of the child's photographs for this study. No name is given to protect the privacy of the child, and "M" is used as the code name. The confidentiality principle has been observed. The researcher told the mother that the information obtained from her would not be shared with other individuals and institutions, and that the information would only be used for scientific purposes. The male case, who was born by cesarean section in June 2013 after a healthy pregnancy, was the first and only child of high school graduate parents. He started to sit at the age of nine months and walked at the age of one year. He first started pointing at objects at the age of 1.5 and said "bye-bye" and "mother". When he was 24 months old, he ceased eye contact, he did not respond when called, and he lost contact with people. For diagnosis, first of all, an examination was performed of the child's physical condition, and his development and behavior were evaluated by child psychiatry specialists. Doctors determined disorder

according to DSM-5 in all three domains (social-emotional opposition, nonverbal communication, developed-sustainable relationships) in the category of social communication disorder, and in areas in the category of repetitive-restrictive behavior (restricted, stereotyped interests, excessive adherence to routines, disproportionate reactions to emotional stimuli, stereotyped-repetitive speech, and object use). The child was diagnosed with ASD at the age of three and is still being followed up in Behçet Uz Children's Hospital.



Figure 1: M is near the sea.



Figure 2: M is playing with mud aimlessly in the garden.

He completed his toilet training at the age of 6. M has been receiving special education for three hours a week for approximately 4.5 years. A total of six interviews and observations were conducted with the mother and M. The first four of the interviews were held face to face in the special education center and the last two were held online due to the pandemic conditions. The study was completed in a total of three months (August, September, October). Each interview lasted approximately 40 minutes, and during the interviews, M continued special education. The face to face interviews were made in a quiet and suitable room to make the mother feel more comfortable. The researcher who conducted the interview has experience in interviewing autism patients and their parents. The

researcher who collected the data was also attending undergraduate education in child development.

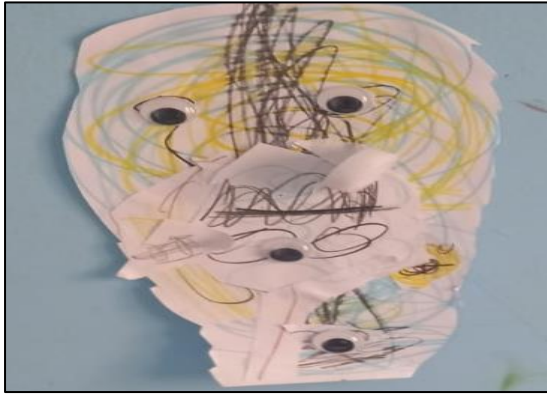


Figure 3: Painting activity.



Figure 4: M is playing with the cat.



Figure 5: M is learning how to make an omelet.

First interview

The researcher conducted the first interview at a private education center. First, M was observed in the garden of the center during the break hour of 20 minutes, and an attempt was made to communicate with him. In the

observation, it was observed that he did not show interest in his peers, he had limited interaction with people, he had difficulties in paying attention and responding to instructions, eye contact time was very short, he did not follow instructions, and he exhibited stereotypical behaviors. He made short sentences such as "We will buy ice cream", "We will go home", and his mother said that he could speak about 15 words nowadays. After the observation, M entered a 40-minute special education lesson. The researcher interviewed the mother while M was in class.

The mother is 30 years old, a housewife and a high school graduate. She has an only one child, and has been married for ten years. She described her socioeconomic status as medium. The health history of M since the first diagnosis was obtained. It contained the sentence "It has been learned that M spends a lot of time in the kitchen at home, loves to play with water and food, watches music channels on TV, swims in the sea, loves animals, and is very interested in animal pictures and figures." (Figure 1). Originally, Risperdal treatment was recommended because of the patient's irritability, aggression, and self-harming and repetitive behaviors, but It was stated that M had a sleep problem after Risperdal (1 x 0.75mg) treatment, which was regulated. The mother stated that because of the medication M had a large appetite, and in addition he liked to eat junk food and could not exercise, and so he gained weight. Currently, M is 45 kilos and 135 centimeters tall. Taking percentile calculations and references as a base, he was found to be in the ≥ 95 percentile range. The mother was given this information.

Because of the risk of COVID-19 infection and the children's refusal to accept hygiene regulations (refusing to wear a mask and not wanting to disinfect their hands), they were kept at home and did not socialize. The mother was asked to take photographs of all the daily activities which she performed with M for a week. The interview was ended because there was no more time, and a date was set for an interview the following week.

Nursing diagnoses on problems recognized after the first interview

First nursing diagnosis

Risk of infection relating to lack of awareness of dirty and clean

Aim

The aim was to protect the child from infections (COVID-19).

Interventions

Learning situations where hygiene behavior by the child is necessitated will be supported through the mother. Signs and symptoms of infection will be taught to the

mother. Visitors will not be accepted to the house. Nutrition will be ensured to support the immune system.¹⁹

Second nursing diagnosis

The risk of excessive food intake in relation to an increase in appetite caused by the medication used.

Aim

The aim was to keep the child at a normal weight.

Interventions

The child's nutrition habits and way of eating will be determined. Weekly weight monitoring will be conducted. The child's physical development will be monitored at regular intervals. Information will be given on nutrition of the child and family and on suitable eating habits. It will be ensured that the child takes more exercise. Cooperation on diet will be ensured between doctor and dietician.¹⁹

Second interview

The second interview took place a week after the first. M was again observed 20 minutes before the interview with the mother. The nursing conclusions from the previous week's interview were discussed with the mother, and a short instruction was given on interventions planned regarding nutrition and the risk of infection. Questions were answered.

In the interview, it was learned how they had spent the week, and information was gathered on daily activities performed for M in house conditions in the pandemic. M's routine activities of daily life at home were as follows: M wakes up around 07:00, and his mother takes him to the toilet and helps him with toilet hygiene. His mother has tried to teach him to make his bed every morning, but M shows no interest. He can undress himself but he needs help in getting dressed. He has breakfast at 08:00, and when he has finished, at 09:00, he starts watching his tablet. After about an hour he starts to get bored, and he wants to go out. The house is a detached house with a garden and it is very close to the sea, and so M can easily go out in the pandemic and get fresh air. In the garden, he most likes to play with mud. He plays aimlessly with the mud (Figure 2). There is also a cat and some dogs in the house, and the family say they got the pets because M very much likes animals. From time to time, M wanders aimlessly around the house. In the afternoon he helps his mother cook, and expects to be praised for his skills. The mother says that she spends most of her energy during the day on M so that she gets very tired, and can only rest at night. It was stated that he spends time with his father after he gets home in the evening, and that he goes to bed at 22:00. The mother was asked to take a video of one of her daily activities with M over the week. Also, the researcher promised to provide

the mother with motivation by telephone on keeping to the nutrition plan.

Nursing diagnoses on problems determined after the second interview

First nursing diagnosis

Deficiency in self-care with respect to difficulty dressing and toilet hygiene

Aim

The aim was for the child to be able to meet his own self-care needs.

Interventions

High-level participation of the child in self-care activities, with the support of the mother. The child's participation in self-care activities will be assessed. Participation in self-care skills will be rewarded. The child will be encouraged and given opportunities.¹⁹

Second nursing diagnosis

Aimless restless wandering in the house.

Aim

Recognizing the factors affecting aimless wandering behavior.

Interventions

Factors reducing or increasing aimless wandering behavior will be assessed. The child will be directed to physical activity. Changes occurring during aimless wandering behavior will be observed and recorded by the mother. A secure environment will be ensured for the child (the topic of an autism-friendly house will be discussed).¹⁹

Third nursing diagnosis

Deficiency in use of spare time, activity and fun activities.

Aim

For the child to use his spare time meaningfully.

Interventions

Spare-time activities that he used to do and like will be investigated. Every day, activities will be planned which make the child look to the future (drawing, developing passive language skills, games establishing eye contact).¹⁹

Third interview

The third interview was held a week after the second interview, also in the private education center. The aimless wandering and deficiency in amusement activities determined the previous week were discussed with the mother as nursing problems, brief instruction was given on planned interventions, and questions were answered. Internet sources which could be a guide were shared.

Discussion continued about the activity video about M which the mother had taken for the third interview. A video taken of the mother and M in the kitchen making food was watched with the mother. The mother's support of M in daily activities was given appreciation. The mother said that she was working so that when M was an adolescent he would be more independent and be able to fend for himself. She said that it was sometimes an advantage that M was in the house during the pandemic, particularly that she kept on making him practice his daily activities and self-care skills at home. Because there was no particular restriction on children going out, he was able to spend time outside, but she said he did not interact or socialize with other children.

Nursing diagnoses on problems determined after the third interview

First nursing diagnosis

Impairment of Social Interaction in relation to the pandemic and the child's deficiency in social skills.

Aim

Achieving an increase in the child's socialization.

Interventions

Eye contact will be established with the child before giving instruction, and if necessary this will be repeated. The child will be supported in learning children's games and communication skills. Before the child is taken into a new environment, communication will first be established with one person, and after that the number of people will slowly be increased. After correct behavior, appropriate feedback will be given. Because of Covid-19 precautions, it will be recommended that he goes out in a protected way. It will be ensured that the family learns all of this, and that harsh criticism is avoided.¹⁹

Fourth interview

The fourth interview was held in the private education center a week after the third interview. The nursing problems determined in the previous weeks were discussed with the mother, and information was obtained on M's conformity. In particular, his eating of junk food was discussed, whether he was taking exercise such as

walking, and how his drawing activities were going (Figure 3).

Later in the interview, the adequacy of M's education during the pandemic and the alternatives were discussed. With the opening of schools, M started the lower autism class. There were three other children in the class with the same diagnosis, and their accommodation process was continuing. The mother stated that she was very worried about how the new process would go, and that she felt uncertainty. She also said that the opportunity for private classes for families with an autistic child were very difficult financially, and that a 40-minute private lesson cost 150 TL. She added that the 12 hours of class given by the government was useful, but was not sufficient. She said that she had had classes on ABA (Applied Behavior Analysis) for autistic children. The mother does not have an internet connection or a computer at home, and so she cannot follow the distance learning programs supplied by the government. The interview was ended with the mother being given an appointment for one month later, and it was agreed that another interview would be held one month later. She was reminded that during this time communication would be continued by telephone and messages.

Nursing diagnoses on problems determined after the fourth interview

First nursing diagnosis

Deficiency of knowledge connected with not knowing different education models in autism.

Aim

To provide the mother with knowledge of different education models.

Interventions

The mother's knowledge level of education models will be assessed. The mother will be encouraged to ask questions and these questions will be answered openly. Safe and effective communication will be established. Information will be given on suitable education methods and accessible sources (Education Information Net, Special Enjoyable Activities Calendar for Children etc.) The mother will be directed to people who are experts on the topic.¹⁹

Fifth interview

A month after the fourth interview, there was an increase in COVID-19 cases, and so the whole country was put into a partial lockdown, and interviews were conducted online and by telephone. In this way there was a chance to observe M at home. The question of whether or not the interventions planned for M had been carried out and the obstacles met in this regard were discussed. During the

interview, M wanted to eat, and in this way his nutrition plans were recalled, and it was asked whether he had gained weight. It was learned that he had gained 1kg in the past month. While he was eating, it was observed that M was eating more independently than previously, but his skill in using a fork and spoon still showed deficiencies. This was discussed with the mother, and she was asked for her support. Her questions were answered.

It was asked how his school education had progressed, and it was understood that uncertainties have reduced. M is attending school for four hours a day five days a week, and he goes for private education two days a week. He has started ABA education at home, and his self-care skills have been worked on. These positive developments have motivated the mother, and she was seen to be more dynamic.

Sixth interview

The sixth interview was held two weeks after the fifth interview. Again, there was a chance to observe M by telephone camera in his home environment. It was observed that M was very happy spending time with his cat. In this interview, what was done in the previous interview was repeated. Together with the mother, a general evaluation was conducted of the state of M. The mother said that every day in the past month they had done drawing and other activities, and they had played in the garden. He had improved his self-care skills along with his education. They had done a very good thing in getting pets because M wanted to take part in their care. His time spent with his mother in the kitchen had increased, and he could even break eggs by himself; and they had gone out for walks (Figure 4, 5). The mother was told that giving responsibility for some housework duties would develop M. For example, he could be given responsibilities like tidying up his toys and putting them in the right place, putting his books in order, folding his clothes, watering the plants, and clearing the table after a meal. The mother's support was appreciated, and she was urged to continue. Her questions were answered. The interviews ended here, but it was stated that she could continue to contact us any time she wanted either by telephone or by message.

DISCUSSION

The COVID-19 pandemic has been very difficult for all communities. In particular for children with ASD, the pandemic-related restrictions may have disrupted their current state of health and life routines. During the pandemic, in our single-case presentation based on interviews with a child with ASD and his mother, deficiencies in information were determined concerning the risk of COVID-19 infection, overeating, deficiency in self-care, aimless wandering, deficiency in fun activities, breakdown of social communication, and education models.

In assessment for the risk of infection, it was seen that our case had difficulties with the routine measures against COVID-19 infection. He did not wear a mask, and used disinfectant with the help of his mother. It is reported in the literature that, similar to our case, new routines such as mask wearing, the use of hand disinfectants and staying at home in quarantine meet strong resistance by those with ASD.²⁰

It was found that our case was overeating, and the mother was given information on not giving him junk food. In a study by Stankovic et al., it was found that a child with ASD was very picky about kinds of food in the pandemic, or insisted on eating the same kinds of food.²¹

Skills of daily life such as personal hygiene, preparing food or managing money are important for an independent life. Researchers have shown that many individuals with ASD display impairment of daily life skills in relation to cognitive skills.²² In our presentation, the eight-year-old ASD case was seen to have inadequate daily life skills, and it was clear that he needed support. For this reason, it is necessary that the parents teach these skills to a child with ASD. The pandemic gave an opportunity to deal with a child individually. In this period, being able to independently carry out daily life activities, if only partially, reduces dependence on the parents.^{8,23}

It was found that our case wandered around the house aimlessly, and arrangements in the house were recommended. If children with ASD are supported for physical exercise in the pandemic, very positive results can be achieved and physical activity suited to the purpose can be performed. In a study by Esentürk, it was reported that in the pandemic, families experienced problems with including children with ASD in physical activities in the home environment. In the study, the families stated that they did not want to make their children do wrong actions, but that if they had enough information, they could encourage the children's physical activity.²⁴ In a study by Uzunçayır and İlhan, parents stated that they were not able to provide much of a suitable space for children to run off their energies in the quarantine period. Participating mothers stated that their children adapted more to physical activities, that they were open to learning, that their stress and anxiety levels fell, and that their problematic behaviors reduced.²⁵ Not adequately meeting the need for physical activity of children with ASD during this period could lead to physical and psychological problems.²⁶

During this time, a disruption of socialization skills was observed in our case. When it is considered that in the pandemic individuals are obliged to change their manner of socialization, it was observed in that our case, a child with ASD continued at school and private education with the support of his parents, and developed and improved his communication despite the pandemic.^{27,28} No experimental or mixed studies were found showing the

effect of the pandemic on the socialization skills and fun activities of children with ASD.

Most of the time, children with ASD spend their free time, watching television or using a tablet for example, alone or with their mothers. They spend little time participating in conversations or carrying out activities with their peers. The way they spend their time is related to their age, gender, mental inadequacy, the severity of their syndrome and dysfunctional behaviors, the number of siblings, the mother's education, their legal status and the family's income.^{8,23} Parents stated that they had difficulty in supplying the necessary games or products and in working out new arrangements in order to get children with ASD to spend time with their siblings and to open up new areas of interest.²⁹ In our case, the mother's supportive and participatory attitude, the presence of one sibling, his age, the fact that the house had a garden, and the family's adequate income all had a positive effect on the development of the child with ASD.

CONCLUSION

It was seen that as in our case of ASD, that it is of great importance for nurses to be involved in the development plans of children with multiple disabilities. During the pandemic, it has become very difficult to reach the families, primary care providers and children. In this way, public health nurses must make use of all opportunities, give nursing diagnoses, start suitable intervention and direction, and act as guides for the family. In this study, in which nursing care was conducted for an eight-year-old child, first of all the basic situational factors were evaluated. A determination was made of the child's inadequacies in such areas as conformity to hygiene rules, socialization, self-care skills, receipt of private education, and eating. Because the mother was providing primary care, the plan was advanced by talking to the mother. Support was obtained from family members to target the child's lack of independence. Advances were achieved in activities such as drawing and in some daily home skills, and the mother was supported in participating in education. It was found that during the pandemic staying at home developed relationships between family members, family members spent more time together, and the child with ASD was happier. It is thought that this case study report will provide ideas for public health nurses working in the field with children diagnosed with ASD in planning education and counselling programs.

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