

AN EVALUATION OF THE AUTISM AWARENESS OF THE INDIVIDUALS CONSULTING TO FAMILY HEALTH CENTER

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Abstract: Autism Spectrum Disorder is a heterogeneous neuropsychiatric disorder and in the course of this disease the different levels of impairment in the social area, problems in the communication and behaviors and delay in the cognitive development are seen. Despite becoming decreasingly, the lifelong continuance of the severity and symptoms of the disease affects the communication skills, behaviors and the social life of an individual diagnosed with autism negatively. People's point of views about the autism and their level of information about the disease affect their behaviors oriented to the individuals with autism; and such behaviors directly affect the individuals diagnosed with autism and their developments. At this point, the perspective of people in society about autism is considered important. Based on this idea, the aim of the study was to determine the opinions of adults about autism and to make suggestions. Interview technique, one of the qualitative research methods, was used in the research. The study group of the research was determined by using criterion sampling, one of the purposive sampling methods. In this context, adults who came to a family health center in Ankara between 02.09.2020-11.09.2020, who did not have a family member with special needs and who agreed to participate in the study were included in the study. The data were collected with the "Personal Information Form" and "Semi-Structured Interview Form" prepared by the researchers. Adults' thoughts about autism were evaluated with descriptive analysis, and direct quotations were included in the results. According to the results obtained, adults have different views on the diagnosis, symptoms and causes of autism, and the welfare of individuals with autism; however, it can be said that there are deficiencies and errors in the information they have.

Keywords: disabled individual, autism, adult, interview

Introduction

Autism, a type of pervasive developmental disorder (PDD), has been increasing rapidly since it was defined by Leo Kanner in 1943 (Ratajczak, 2011). For this reason, experts from different disciplines are working on pervasive developmental disorders, and it is becoming an area that attracts more attention with the new information learned day by day (Kurt and Subaşı Yurtçu, 2017). Autism Spectrum Disorder, which is one of the pervasive developmental disorders, is a heterogeneous neuropsychiatric disorder with varying degrees of social impairment, problems in communication and behavior, and delayed cognitive development (Godwyn-Emmons & McKendry-Anderson, 2006; Siegel, 2002).

The severity and symptoms of autism persist throughout life, albeit generally at a reduced rate; It negatively affects the communication skills, behaviors and social life of the individual diagnosed with autism, and repetitive behaviors can be observed by rocking back and forth, clapping their hands or hitting their heads for long periods (Crowley, 2017, Siegel, 2002). As their hitting the shower there

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are problems such as spatial awareness, body awareness, self-care and cleanliness, self-destructive behaviors, intolerance to changes, crying for no reason, displaying anger behaviors, inability to make eye contact, excessive concern with the sensory properties of objects, pretending not to hear, not reacting to conversations, echolalic speech, having problems with emphasis and intonation, mixing personal pronouns (Bodur & Soysal, 2004; Gürsoy, Aydođdu & Aysu, 2019; İnce, 2017; La Valle, Plesa-Skwerer & Tager-Flusberg, 2020; Low & Lee, 2011; Özeren, 2013).

Many studies have been carried out on the definition of autism, its symptoms, causes and applications for individuals with autism, and important developments have been made on the subject. However, it seems difficult to ensure the welfare of individuals with autism without providing support for integrating them into social life or by isolating them from society. For this reason, studies on increasing the awareness of individuals in the society are also needed. Perspectives of people with autism in their social life and their knowledge levels about the characteristics of autism; affect their behavior towards individuals with autism. These behaviors directly affect individuals diagnosed with autism, their development and their families. Studies conducted on the views of families and teachers whose children have been diagnosed with autism about autism (Cassimos et al., 2015; Goin-Kochel and Myers, 2005; Goin-Kochel et al., 2020; Hebert and Koulouglioti, 2010, İnce, 2017, Taresh et al. ., 2020; Töret et al., 2014; Tunç & Alabay, 2018), it has been determined that there is no research to determine the awareness of adults about autism in the society. At this point, it is considered important to determine the perspective of people in the society about autism, to determine different perspectives, to lead the studies to be done in this direction and to raise awareness about autism. Based on this idea, it was aimed to determine the awareness of adults about autism in this study.

Materials and Methods

In this section, topics such as research model, study group, data collection tools, data collection and data analysis are included.

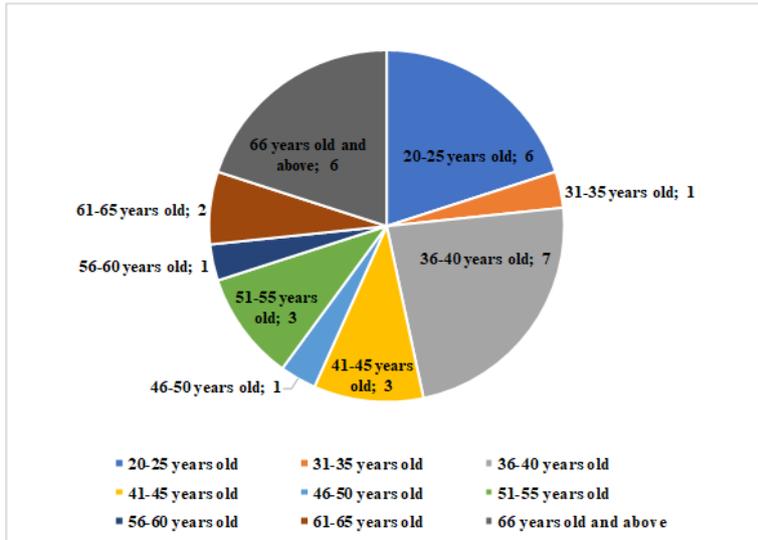
Research Model

This study, which was conducted to determine the awareness of adults about autism who applied to the family health center, was carried out in a qualitative research design. Qualitative research; It is the production of rich and descriptive data that can help understand people's lives through comprehensive questions about human experiences and realities (Arastaman, Fidan, & Fidan, 2018).

Working group

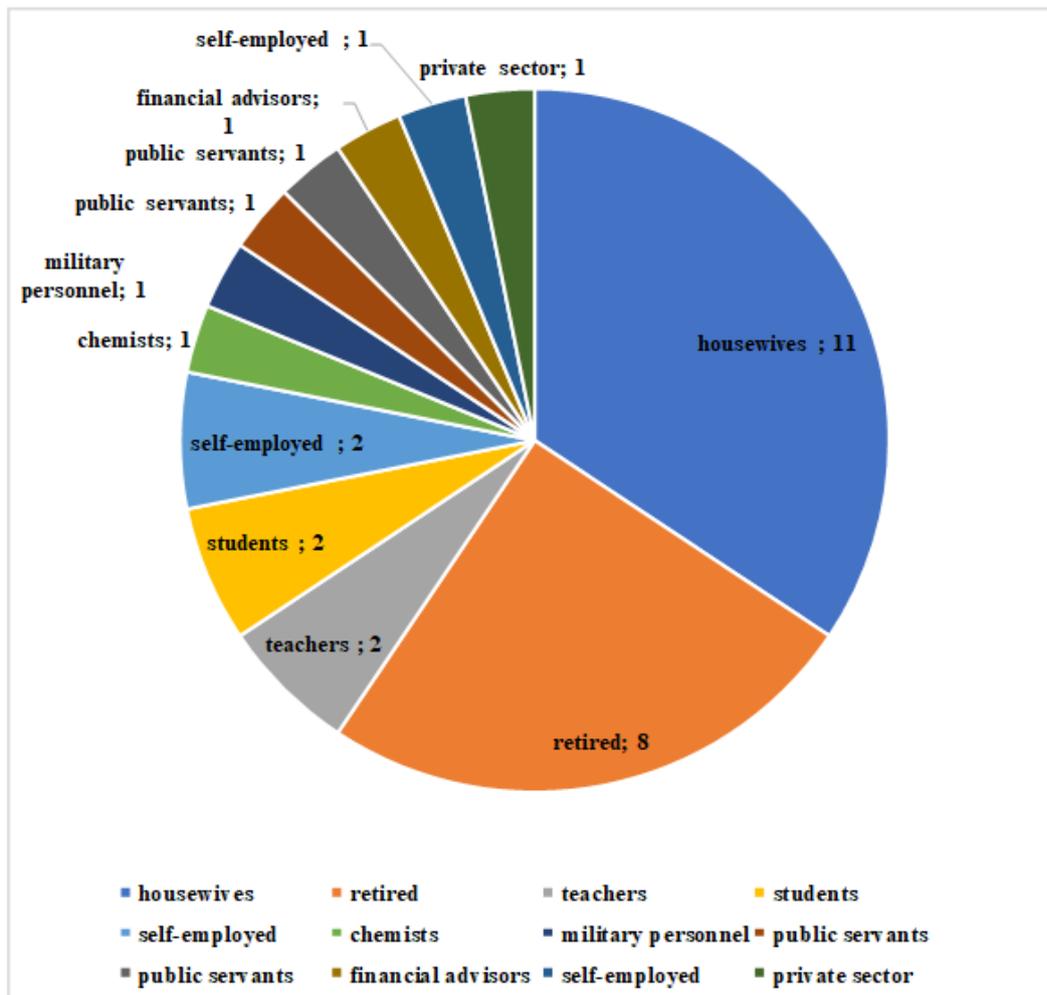
The most frequently used sampling methods in qualitative research are purposive, random, voluntary and universe sampling. In this study, it was determined by using criterion sampling, one of the purposive sampling methods. In this direction, "not having a person with special needs in the family" was accepted as a criterion in the research. 30 adults who applied to a family health center in Ankara city center and participated in the study voluntarily were included in the study.

Figure 1: Age of participants



Of the adults included in the study, 6 are 20-25 years old, one is 31-35 years old, 7 is 36-40 years old, 3 is 41-45 years old, one is 46-50 years old, 3 is 51-55 years old, one is 56 -60 years old, 2 of them 61-65 years old, 6 of them 66 years old and above.

Figure 2: The profession of the participants



Of the adults, 11 are housewives and 8 are retired. Among the adults included in the research, the ratio of teachers (2), students (2) and self-employed (2) is equal, and there are chemists, military personnel, public servants, financial advisors, self-employed adults and one adult working in the private sector. Of the adults, 13 are university graduates, 3 associate degrees, 6 high school, 4 secondary school, 3 primary school graduates and did not attend an adult school. While 6 of the adults have a single child, 11 of them have 2, 5 of them have 3 or more children, 8 adults have no children. 8 of the adults are single, 22 are married, 13 are working and 17 are not working.

This research is limited to the participants who applied to a family health center in Ankara within the specified date range.

Data Collection Tools

"Personal Information Form" and "Semi-Structured Interview Form" prepared by the researchers were used in the research. The Personal Information Form includes questions to obtain demographic information such as age, occupation, education level, marital status and number of children. In the Semi-Structured Interview Form, in order to determine the awareness of adults about autism take part questions such as; "What comes to mind first when you hear the word autism?", "Where did you hear about autism?", "What can be the symptoms of autism?", "What can be the causes of autism?", and "Autism What can be done to make individuals with a diagnosis feel comfortable in the society?" After the interview form was prepared within the scope of the research, it was sent to field experts (who work in the field of child development and special education) and the form was finalized as a result of the feedback received.

Data Collection

At the stage of data collection, firstly, the permission of the ethics committee was obtained (Protocol no: 07/11, Date: 01.09.2020). After obtaining the permission of the ethics committee, the aim of the study was explained by interviewing the managers of the family health centers to be included in the study, and a family health center that found the study appropriate was determined. In this center, the environment where the application can be made has been made ready. Adults who applied to Family Health Centers were interviewed, and data were collected between 02.09.2020 and 11.09.2020 by making face-to-face interviews with those who volunteered to participate in the research.

Analysis of Data

The analysis of the data obtained from the research was carried out with the descriptive analysis method. The data obtained in the descriptive analysis are summarized and interpreted according to the previously determined themes (Yıldırım & Şimşek, 2008). While performing descriptive analysis, it is aimed to put the raw data into a format that the reader can understand and use (Duban, 2010). The data obtained within the scope of the research were evaluated and interpreted with descriptive analysis, and direct quotations were included while presenting the striking results. While the citations were included, adults were coded as A1.....A30 in terms of compliance with research ethics, and the themes of the definition of autism, its symptoms and causes, and its acceptance in the society were formed by taking the opinions of field experts. Before the results obtained from the research were reported, the opinion of an expert who had general knowledge about the research topic was taken. Examining the research with various dimensions by reviewing errors such as dealing with inadequate results, themes based on closed answers, and misinterpreting data by experts increases the reliability of the research (Başkale, 2016).

Results and Discussion

Within the scope of the research, various questions were asked to adults to determine their autism awareness, and the results were presented and interpreted with the support of quotations.

It was observed that adults gave very different answers to the question asked to get their thoughts on autism. While 7 of the adults stated that they were "disabled individuals", 2 of them were "hyperactive", 2 of them were "disabled", 2 of them were "impairment" and 6 adults stated that they did not know. Also about autism; weight, genetic disease, someone in need, Miracle Doctor series (the first TV series about an autistic doctor in Turkey), mental and mental health disorder, mobility restriction, illness, obesity, giftedness, focusing problem and an adult "difficulty in communicating" While one adult gave the answer "social and communicative disorder". In this regard, They expressed their views as A7; "When I think of autism, I think of a disease", A8; "Individuals who have difficulty communicating with people" and A13; "I think about the disability and disability of children". Expressing that adults heard the concept of autism from television (8 adults) and their close circles (6 adults); some of the adults stated that they heard from school (6 adults) and from the workplace (4 adults). On the other hand, 6 adults have not heard from anywhere; they said they heard it for the first time.

It was seen that adults gave more than one answer with different opinions about the symptoms of autism. Seven of the adults stated that they did not know. In addition, looking at a certain point unconsciously (3 adults), hyperactivity (3 adults), rhythmic repetitive (stereotypical) movements (3 adults), social and communicative disorder (2 adults), inability to make eye contact (2 adults), giftedness (2 adults), appetite-obesity (2 adults), slow learning, unresponsiveness, aggressive, stuttering, watching moving machines (such as washing machine), attention deficit, mental disability, thought disorder, limited movements, behavioral disorder, twitching of hands. answers were also given. Two adults gave descriptions of Down Syndrome and told the symptoms of Down Syndrome for autism. An adult replied, "Some of them are not obvious at all". In this regard, A5; "Some of them are never obvious. It was never obvious that my friend's child had autism. He was very clever. While expressing his opinion as "He also graduated from the university", A30 expressed his opinion as "His hands are big, they laugh all the time, the shape of their heads is different". It has been observed that adults do not have enough information about the symptoms of autism as well as its causes. It seems that more than half of adults (16) do not know the causes of autism. When the other answers given are examined; 3 of the adults stated that genetics and 2 of them stated that consanguineous marriage causes autism; There are also adults who state that autism is caused by drug use during pregnancy, vaccines, chromosomal abnormalities, brain damage, ready-to-eat foods, diseases.

It has been determined that 10 of the adults do not have an idea about the acceptance of individuals with autism in society. While 5 of the adults stated that they should be treated like normal individuals; society being tolerant (3 adults), providing education to adults in the society (3 adults), changing the perspective (2 adults), improving living conditions (2 adults), education for individuals with autism (2 adults), providing education opportunities under equal conditions (2 adults)), it is seen that the number of those who stated that the programs about autism should be watched (1 adult) are close to each other.

Conclusion

Within the scope of the research, the first thing that comes to mind when adults are called autism was asked, and when the results were examined, it was seen that different answers were given. When these

answers are examined, it is noteworthy that although concepts related to autism (focusing problem, communication difficulties, social problems, etc.) are used, concepts unrelated to autism (such as limitation of movement, obesity) are also used. However, it is seen that there are adults who cannot express their opinions about autism. These results show that adults do not have enough information about autism. Using the right concepts and definitions about autism can only be possible by observing, researching and interacting with individuals with autism in the family or environment. As a matter of fact, Tunç and Alabay (2018) revealed in their research that included mothers, teachers, academicians and children with autism, that the answers given by teachers working in the field were different and unusual compared to other groups. In the study of Töret et al. (2014) in their study with parents of children with autism, parents defined autism as disorders in social-communicative behaviors, emotion and behavior disorders, and language-speech disorders. Yazıcı and Akman (2018), on the other hand, in their research with preschool teachers, used autism-related concepts such as stereotyped behaviors, social interaction, communication, developmental disorders, and brain dysfunctions intensively.

Adults stated that they heard the concept of autism mostly from social media tools, their close circles, the places they work and the schools where their children study. This result can be seen as a reason for the first finding of the study. In order to obtain accurate information about a subject, it will be correct to reach reliable sources. However, it can be said that those who somehow hear the concept of autism and those who have autism around them have a higher level of knowledge about autism. Er-Sabuncuođlu (2016)'s research with preschool teachers proves this. In the aforementioned study, those who have heard the term autism spectrum disorder have a higher level of knowledge than those who have not; In addition, it has been determined that most of the teachers who have autism in their families are in the category of knowledgeable about the concept of autism.

23.3% of adults stated that they did not know about the symptoms of autism. On the other hand, it was observed that a significant portion (70%) conveyed different and accurate information about the symptoms of autism. On the contrary, it is noteworthy that two adults made descriptions of Down syndrome for the symptoms of autism. Considering the other descriptions, it is seen that autism and Down syndrome are confused with each other, and this is thought to be due to the fact that individuals with autism often show symptoms characterized by Down syndrome (Lukito et al., 2017). Considering the symptoms of autism, the lack of visual (eye structure, etc.) features such as down syndrome once again reveals the necessity of information and awareness studies. Symptoms of autism are not limited to what adults express. In addition, individuals with autism exhibit spatial awareness and body awareness problems (İnce, 2017), personal care and cleaning problems (Low & Lee, 2011), self-harming behaviors (such as hair pulling, lip biting, hitting their head against a hard place) (Özeren, 2013), sensitivity to changes (Bodur & Soysal, 2004).

Since autism is a disorder that emerges from childhood and its effects continue for life (Aydın & Özgen, 2018), early diagnosis is considered important. Lack of knowledge about the symptoms of autism creates an obstacle to early diagnosis of children with autism. Early diagnosis and information are needed to "create" an autism-friendly environment around children with autism (Fernell, Eriksson, & Gillberg, 2013). Early diagnosis allows the intervention to start early, allowing the child's development to be supported at an earlier period. It can be said that early intervention is more cost- and time-efficient than the "wait and see" approach (Koegel et al., 2014).

When adults were asked about the causes of autism, it was seen that more than half did not know about this issue. When the other answers were examined, they emphasized that environmental and psychological reasons, especially genetic reasons, consanguineous marriage and errors during pregnancy, were effective. When the results were examined in detail, it was seen that although a

significant part of them did not have knowledge about the causes of autism, those who had knowledge pointed out many factors for the causes of autism.

The reason why the adults included in the study are not having autistic individuals in their families may be the reason for their lack of knowledge about the reasons. Families with a disabled child will ask, "Why is my child disabled?" They take their child to many health institutions by seeking an answer to the question. After taking the history of the child's illness, the doctors can inform the family about the possible causes or the family can obtain information through various sources. Thus, they can have more information about the causes of disability or disability. It is stated that autism is caused by genetic, environmental and immune-related factors (Berken et al., 2010, Dufault et al., 2009; Preislerowicz, 2015). In studies on parents of children with autism, parents have also suggested that autism-like conditions are the cause. Hebert-Baltus and Koulouglioti (2010), examining studies on parental beliefs about the causes of autism, revealed that parents have a wide variety of beliefs about the cause of their children's autism, including genetic factors, events surrounding the child's birth, and environmental influences in early childhood. Goin-Kochel and Myers (2005), in their research with the parents of 327 children with autism, found that the beliefs of the parents about the causes of autism were very diverse, but they argued that genetic and external mechanisms (for example, vaccines, environmental toxins) were more effective. Selkirk et al. (2009) documented that the most common genetic cause was stated in their study on 255 parents with autistic children.

While some (33.3%) of individuals with autism state that they do not have any information about feeling comfortable in the society, others state that they should behave like normal individuals, be tolerant towards them, give awareness training to people in the society, take precautions against negative perspectives or change their perspectives, change their life conditions. They emphasized the improvement of autism, providing education to individuals with autism, ensuring their access to education under equal conditions, and diversifying and disseminating programs promoting individuals with autism on different platforms. It is thought that the suggestions of adults to support individuals with autism are important in terms of their socialization, supporting and developing their competencies. Since the problem that individuals with autism have the most difficulty with is social communication and interaction, studies in this field will also contribute to their socialization. The deficiencies of individuals with autism in social communication and interaction make it difficult for them to learn how to deal with and manage complex social emotional problems (Ahles et al., 2017). It is emphasized that individuals with autism should be supported in the fields of education, work and health in order to increase their well-being (Billington, 2006; Della Fina & Cera, 2015; Murphy, 2020). It is stated that practices for children and individuals with autism contribute in many areas such as ensuring their comfortable and effective adaptation to society, establishing close relationships with other people, communication, creative thinking, sensory integration, language development, problem solving, self-regulation, uncertainty and adaptation to change (Kurt and Subaşı Yurtçu, 2017).

It has been observed that adults have insufficient knowledge and limited perspectives on individuals with autism. This result suggests that society's perceptions of individuals with autism may be negative. These perceptions may be due to the prejudices of the society and their inability to get to know the disabled people closely as a result of the limitations in their interaction with the disabled people. All disabled individuals, whether they have autism or another disability, are at risk of being excluded by society. Indeed, many studies on the exclusion of persons with disabilities confirm this. Disabled individuals have employment problems due to exclusion (Howlin, 2013), they isolate themselves from society because they have problems integrating with society (Özbulut & Özgür-Sayar, 2009), parents and their disabled children avoid socializing because they cannot receive social support (Yüksel & Tanrıverdi, 2019).

As a result of the research, it can be said that information studies about autism should be done intensively. It may be remarkable that these information studies are prepared through many channels in a way that will attract people's attention. Awareness studies can be carried out for all disability groups. It can be suggested that awareness activities related to autism should be carried out continuously, regularly and in a way that reaches all segments of the society, not in certain time periods. In addition, it may be recommended to conduct more research on autism.

Limitations

The research is limited to 30 adults who applied to family health centers in Ankara city center.

Declaration of Interest Statement

The authors declare that they have no conflict of interests.

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