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## **PSYCHOSOCIAL PROBLEMS OF MOTHERS OF CHILDREN WITH AUTISM IN TURKEY**

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## **Abstract**

Autism Spectrum Disorder (ASD) is neurodevelopment and neurobehavioral disorder characterized by inappropriate social interaction, difficulties in language development, repetitive behaviors and lack of communication skills. After the moment that parents learned their child diagnosed with autism, they start to experience many challenges socially, financially but moreover psychologically. The purpose of this study is determine what it is the social and psychological problems of mothers of Autism in Turkey and add to the literature some experience from Turkey.

After the literature on autism in Turkey is reviewed, the results of this study will be presented. Overall, findings of the current study suggested that unfortunately Turkish mothers of children with autism experience a considerable level of depression and anxiety. When it comes to the social support of mothers, results are not that negative. Even though mothers can not find enough time for socialization and having a good time, according to results Turkish mothers have enough support from friends and relatives.

In addition, the results of this research will be useful for professionals who will work with mothers of children with autism. This study also will be a helpful source for researchers and academics who will work in this in the area.

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## **Introduction**

Autism Spectrum Disorder (ASD) is neurodevelopment and neurobehavioral disorder characterized by inappropriate social interaction, difficulties in language development, repetitive behaviors and lack of communication skills.

After the moment that parents learned their child diagnosed with autism, they start to experience many challenges socially, financially but moreover psychologically. The purpose of this study improve knowledge of autism in Turkey and introduce what it is like to be the mother of a child with autism in Turkey. In addition, the results of this research will be useful for professionals who will work with mothers of children with autism.

## **Literature Review**

### **Historical Background**

Even before the "autism" named, there are some symptoms and treatments that may be an example of autism in history. For example, in *The Table Talk* (a collection of Martin Luther's sayings around the dinner table compiled by his followers later), Martin Luther described a story of a 12-year-old boy who may have been severely autistic (Wing, 1997).

Then, "Autismus" is a Latin word first used by the Swiss psychiatrist Eugen Bieuler in 1910 to define the symptom of schizophrenia. A Soviet psychiatrist Grunya Sukhareva is also used same description as to explain autism as "schizoid (eccentric) psychopathy" (Manouilenko & Bejerot 2015). For a long time, autism was often misunderstood or misdiagnosed as being schizophrenic or a different type of schizophrenia (Grinker, 2007). Of course, when we define the Autism, as a psychologist, we should apply to DSM first. In the beginning, DSM-I was also agreed that autism was a 'childhood schizophrenic' (APA, 1952). APA (American Psychiatric Association)'s categorization is also changed by time. To see these changes can be great to see how perspective to autism also changed by time in the field of psychology and in general;

DSM-I: Childhood schizophrenic.

DSM-II: Childhood schizophrenic and atypical, and withdrawn behavior.

DSM-III: In 3th DSM, they publish more traditional signs and symptoms to be diagnosed.

DSM-IV: They published 16 symptoms of autism and to be diagnosed, one should have at least 6 of them.

DSM-IV-TR: They published the same criteria but added include Autistic Disorder, Asperger's Disorder, Rett Syndrome, Childhood Disintegrative Disorder and PDD-NOS under the general umbrella of autism.

DSM-V: Will be revied deeply in diagnosis section of this paper, however, now APA separated autism into 3 parts; "Autistic disorder, Asperger's Syndrome, PDD-NOS.

In 1938, Hans Asperger from Vienna University used the word of autism in the modern sense in 1938 (Asperger H. 1938). The name of Asperger syndrome also comes from his name. Subsequently, in 1940, an Austrian psychiatrist Leo Kanner began to study autism scientifically with a small group of children with autism.(Thompson, 2014). Then, the name "Autism Spectrum" was used in 179 by Lorna Wing and Judith Gould. (Wing L, Gould J., 1979)

History of Autism in Turkey is a very limited subject. The earliest works about autism were only in major cities in İstanbul, Ankara, and İzmir, which were only academic centers. However, in 1989, the first medical center was established in Ankara University by Dr Mualla Öztürk.

Until the 2000's, there was not special education for children with autism provided by the state. Children with autism had the same education as children who do not have any intellectual disabilities. However, in 1999, the Ministry of Education

established "Autistic Children's Education(OCEP)" project. The implementation of this project was targeted at children with autism from 3 and 15 years old in local educational centers and units.

### **What is the Autism?**

Autism spectrum disorder (ASD) is neurodevelopment disorder characterized by a lack of social interaction, verbal and nonverbal communication. It also includes an avoidance of eye contact, lack of facial expression, does not express his or her feeling and also unaware of others feeling. ASD is generally diagnosed based on these symptoms in the first 3 years of children.

To better understanding, the definition of the fifth edition of the publication Diagnostic and Statistical Manual of Mental Disorders, DSM-V (American Psychiatric Association, 2013) should be considered. DSM-V divides autism into two symptomatic categories; The first one is Group A, which is characterized by social difficulties that combined with communication problems. The second category is the Group B is characterized by repetitive and restrictive behaviours. It will be reviewed deeply in diagnosis section above.

According to literature, children who diagnosed with autism also can be demonstrated other psychological and behavioral problems such as anxiety disorder (White SW, et al., 2009), sleep problems (Richdale AL, Schreck KA 2009), and other behavioral problems such inattention and hyperactivity (Simonoff S, et al, 2006).

### **Etiology**

Autism is a complex and multifactorial disorder that causes of genetic, environmental factors and brain abnormalities. As classically, in this paper also causes of autism will be separated into two subgroups; "genetic factors" and environmental factors.

## **I. Genetic Factors**

Many of autism diagnoses are actually part of genetic disorder, such as fragile X syndrome, tuberous sclerosis, phenylketonuria, or congenital infections secondary to rubella virus and cytomegalovirus. (Caglayan, A.O, 2010) (Noor B. A., 2019) Many studies suggest that genetic is the most important cause of autism, according to a research, siblings who born in a familiy with autism have a 50 times greater risk of autism. This rate reaches up to 82%~92% in monozygotic twins and 1%~10% in dizygotic twins. Single gene mutation may change developmental of neuronal and axonal structures synaptogenesis. (Szatmari P. Et al. 1998).

## **II. Environmental Factors**

However there are some very important environmental factors that can be cause of autism. The most of these enviromental factor are related with prenatal period such as toxins and infections that exposed by babies, abnormal melatonin combinations and maternal diabetes (Rossignol DA, Frye RE 2011). According to some other studies, the age of mother and father is also one of very important environmental factor. (Lyall, K. et al 2017) For example, (Holguín, 2003) claimed that the advanced age of the father or pregnant mother will increase the risk of autism because of some chemicals or lack of some chemicals that exposure to the baby during pregnancy.

There are also other environmental factors that should be taken into account when we interpret the etiology of autism. According to (Raymond 2004), mercury can be one of the dangerous chemicals for the brain development. He claims that if mercury goes to the body of the mother during pregnancy by sea fish or some kind of cosmetics, it blocks the development of the child's brain. Even though there is no scientific evidence of it, he also calls attention to mercury by vaccination of babies. (Jansen, V.A, 2003) He claimed that mercury is a component of vaccines and vaccines can cause autism.

## **Prevalence**

According to *Centers for Disease Control and Prevention*, 1 in 59 children has been identified with autism spectrum disorder (Zablotsky et al.). There were also some

racial and sex differences on the prevalence of autism. For example, males are four times more likely to be identified with ASD. Prevalence were higher for White children than Black children. And both groups were more likely to be identified with Autism when it compared with Hispanic children. (Zablotsky et al.)

The report also indicated that the prevalence of intellectual disability is 31% of children and affects all socioeconomic groups. According to the results of the report, minority groups were less likely to diagnosis later. It can be the reason why the prevalence of autism is higher among white children. Late diagnosis of autism is one of the greatest problems in the literature of autism. Because many studies have demonstrated that late diagnosis of autism causes late intervention and the late intervention causes irreparable problems for children with autism. Moreover, this paper claims that minority children are more likely to diagnosis later. In this paper, the role of culture, educational and socio-economic status of parents in autism and their effects on diagnosis and intervention will be investigated more deeply. (Zablotsky et al.)

### **Diagnosis**

Diagnosis of autism is very challenging subject since it has no specific diagnosis method such as blood test, other medical identification methods etc... Diagnosis methods of autism is usually very primitive and based on personal observations of doctors or families.

It may better to start from the very beginning of time (Kanner L, Eiisenberg L., 1957), from Leo Kanner diagnosis criteria of autism;

- 1- Individual with autism do not like to do not interact with others
- 2-Delays and disruptions in speech
- 3-Echolalia
- 4-Display repetitive and aimless behaviors
- 5-Normal intelligence and good memory.

## 7-Normal looking(appearance)

Of course, Kanner's criteria for diagnosis was one of the first. Even though it is the oldest one, very clear and undesirable for people who are outside of this field. By the time, new criteria have been established and added literature. For example Lotter's Rating Scale (Lotter V. 1966), DSM-III, DSM-III-R, ICD-10, DSM-IV, and DSM-IV-R. However, by 2019, we should focus on the latest version of criteria, which is recognized by all over the world and authorities, DSM-V Diagnostic Criteria Autism Spectrum Disorder;

- **Persistent deficits in social communication and social interaction across multiple contexts,**

1. Deficits in social-emotional reciprocity, abnormal social approach, failure in conversation, initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors, abnormalities in eye contact, inappropriate body language, deficits in the use of gestures, lack of facial expressions.

3. Deficits in developing and maintaining, social relationships,

- **B. Restricted, repetitive patterns of behavior, interests, or activities,**

1. Stereotyped or repetitive motor movements, such as the use of objects, or speech

2. inflexible to routines, or ritualized patterns of verbal or nonverbal behavior, extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals.

3. Highly restricted, fixated interests that are abnormal in intensity or focus

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment

- **C. Symptoms must be present in the early developmental period**

- **D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**

There are some traditional methods of diagnosis of autism. One of them is screening (Pauline a. et al, 1999). In screening, a doctor has an interview with parents and play or talk with the child in order to see how he or she learns, speaks and behaves. There are also some other instruments and tools for screening method other than doctor control. They are more structured and professional, however, it is difficult to apply for younger children. For example, the Social Communication Questionnaire (SCQ) is a pretty useful tool for screening and observing children, however, it can be only applied for children who are around 4 years old. As a result, it is not purposeful for early diagnosis (Berument SK. Et al, 1999).

As mentioned above, screening toll can be a bit late for "early" diagnosis even though it is more professional. Among the diagnosis methods, the earliest one will be parent-based strategies without a doubt. Autism Diagnostic Observation Schedule (Lord C, Risi S, Lambrecht L, et al. 2000) is one of the tools that target children with very early age and tasks are given to parents. In this tool, parents should observe their babies by eye contact, calling their child's name and social plays.

Finally, to get more absolute diagnosis results, more evidence-based and medical assessment should be implied. According to literature the best medical diagnosis method should include a neurological examination. Other diagnostic assessments such as genetic tests, metabolic test is also recommended.

### **Early Diagnosis**

Early diagnosis of autism is very important because this allows young children with autism get their full potential through special education when their brain plasticity is more pronounced. Many studies have demonstrated that late diagnosis of autism causes late intervention and the late intervention causes irreparable problems for children with autism. Identifying autism symptoms earlier will prove early intervention, which will improve quality of life of individual with autism.

It should be clearly explained that what does early diagnosis mean? Traditionally, autism used to diagnoses at around 2-3 years, however, with the rising opportunities, easier access to medical centers and with the increased awareness and knowledge of the families, it failed to 1-2 years (Eaves and Ho, 2004). Moreover, many studies age of early diagnosis of autism is falling and will be younger. For example, according to Stone et al (2008) ‘Screening Tool for Autism in Two-year-olds’ can diagnosis even for children from 12 to 14 months ages. Without doubt, it is because more developed early intervention programs. New and more comprehensive early intervention programs made early diagnosis more possible.

According to (Bakare & Munir, 2011), there is a strong correlation between late diagnosis and non-verbal cases for children with autism. Another study also indicated that children with autism who diagnosed later less likely to integrate to society because early diagnoses improved social skills and behaviors and also diminished abnormal behaviors.. (Fountain et al., 2011) Early diagnosis of autism also improves prognosis and parent–child with autism relationships.

### **Levels of Autism**

When people talk about autism spectrum disorder, even unprofession people realized that there are diffirent levels of autism. To make it more professionally, most of the people talking about severity levels of autism. Even thought it is a complicated topic, thanks to DSM-V criteria, make it understanable to all people clearly;

- Level 1: “Requiring support”

Social communication: Individuals with autism in this category need some support in social situations. Because they may demonstrate difficulty to initiate social interactions.

Restricted, repetitive behaviors: Inflexibility, difficulty switching between activities. Problems of organization and planning movements.

- Level 2 “Requiring substantial support”

Social communication: In this case, an individual with autism need more support than Level 1. There will be deficits in verbal and nonverbal social communication skills. However, even with support, social interactions will be limited.

Restricted, repetitive behaviors: Inflexibility of behaviors, restricted-repetitive behaviors, difficulty changing focus or action.

- Level 3 “Requiring very substantial support”

Social communication: It is the most difficult part of Autism, severe is at its highest normally. Serious difficulties in verbal and nonverbal communication. Limited social interactions,

Restricted, repetitive behaviors: Extreme level of difficulty coping with change. Great distress/ difficulty changing focus or action. High level of Inflexibility of behavior as usual.

### **Treatment**

Unfortunately, all the expert agree that there is no cure, meditation, treatment or therapy to beat the autism completely. However, that does not mean there is no anything to help that person. There are lots of ways to decrease symptoms and increase the life of the individual with autism.

There are numerous treatment methods for autism. Including drug therapies, psychological therapies, cognitive, behavioral therapies, and art-music therapy, etc... Even though these therapies are not the final solution for autism. It has lots of benefits to children, individuals, and families of autism.

After reviewing the literature and looking over numerous treatment technics and therapies, many experts agree that "Applied Behavior Analysis" is one of the best options in autism intervention technics. Many studies demonstrated that ABA techniques are very well to build basic life skills such as looking, listening to others as well as complex skills like reading, understanding, learning new things, reasoning, adapting to different situations. (Baruah A., 2014)

These treatment methods such as "therapeutic and behavioral" are well known and classical techniques. There is also some interesting and alternative treatment method has been used to fight against autism. The first one is " Music Therapy". According to some resources, music therapy can be a good option for children with autism. (Reschke-Hernández, A. E., 2011). Other one of other interesting therapy is "Animal Therapy". In animal therapies, "Dolphin Therapy" is the most famous one. (Yusof S. M., Chia, K. N., 2012)

## **Parents**

Parents of children with autism the ones who carry the most of the responsibilities and difficulties as all parents whos children diagnosis with some mental or physical disabilities. For this paper, I would like separate these difficulties as two part; one of them is "material difficulties" the second one is "mental difficulties".

In this process, parents should be supportive each other. Because as (Hartley et al., 2010) reported that there is a high level of divorce among couples who have children with autism. Because as it will be seen in Turkey part, after their child diagnosed with autism, they started to fight more. (Alpaytaç, 2007). As it is indicated that the wife and husband blame each other because of their child's development problems. Even sometimes grandparents also interfere and manipulate the couple over their fight.

### **➤ Material Difficulties of Parents**

After a parent learnt that their child diagnosis with autism, it means they have to change all of their life and it will never be the same as before. They need to change their everyday activities, even working and sleeping hours. They need to sacrifice themselves from some of their hobbies, pleasures and activities. In summary, they have to modify themselves to their children (Banach et al., 2010).

Other difficulties is the financial burden of autism (Deanna L. S., Dana L. B., 2007) Since the child will need some special education, therapies, and programs which are quite expensive in many countries. It is why aids and supports to parents which are

provided by states are very essential in autism disorder. Even though this helps can not be permanent, at least it should be must be provided in the cases of if parents need to give up his her job, unexpected financial crises etc...

### ➤ **Mental Difficulties of Parents**

According to numerous studies, parents whose children diagnosed with autism experience some of the psychological problems such as "depression, anxiety, and stress". Moreover, some experts and researchers showed that, in many cases, parents of autistic child experience all of these psychological problems.

For example, (Nayab I., Ayesha K. B., 2013) indicated that levels of stress anxiety and depression of parents of the autistic child had increased after their child diagnosed. This study also indicated that the reasons why parents experience such diseases are family pressure and social acceptance, financial and professional difficulties.

As can be seen from the title, the main subject of the paper is mothers. According to (KüblerRoss & Kessler, 2005), mothers whose child diagnosed with autism mostly experience similar linear stages as bereavement. These stages are denial, anger, bargaining, depression, and acceptance (KüblerRoss & Kessler, 2005). Yirmiya and Salomon (2007) called this bereavement psychogoly as “metaphorical loss of a child”.

Another study also indicated that mothers of children with autism are more likely to experience insomnia and anxiety. However, according to this study, there were no other significant differences in other problems such as depression or psychosomatic symptoms between mothers who have children with autism versus control group(mother without an autistic chil). (Forough R., Sakineh Izadi. M., 2012)

Interestingly, according to the research, mothers whose child diagnosed with autism experience more stress than other parents with a child with any other disability (Mouridsen, Rich, Isager, & Nedergaard, 2007). Since we consider that it was a

longitudinal study(33 years) It may because of mothers of an autistic child have more stressful duties than other mothers.

Most of the literature about the impacts of having children with autism is limited to diagnosis period. Most of the research focuses on the psychological difficulties which are experienced after first shocked. However, the nurturing process is also stressful as diagnosis times. As it is known that even primary caregiver burden is very difficult for mothers who have children without any disorders, it is of course extremely more difficult for mothers who have children with intellectual disability. For example, (Smith, Oliver, & Innocenti, 2001) mentioned that raising children with autism lead mothers to fear of deficiency (Smith, Oliver, & Innocenti, 2001).

### **Fathers**

As it can be seen that the mean purpose of the study is mothers, I did not want to continue without mentioning fathers. Even though it is very well known that fathers are less likely to experience anxiety, stress, and depression related to children with autism (Dabrowska & Pisula, 2010), however, some studies do not agree with that statement. According (Dyer et al., 2009), fathers demonstrated less level of parental stress in the research because of they spent less time with time in childcare, but it does not mean that they become less sad.

As it mentioned several times in this paper, it is a very well known phenomenon that mothers have more stress level, more depression, and social problems. However, it does not mean that we can ignore the fathers of children with autism. A study indicates that fathers of children with autism experience a significantly higher level of stress in comparison to fathers who have children without autism or any other developmental disorders (Herring et al., 2006). One more study indicated that fathers of children with autism also experience a higher level of depression than fathers without a child with autism (Almansour MA, 2013)

One more study which investigated the quality of life (QoL) of fathers who raising children with autism spectrum disorder (ASD) found that fathers mostly demonstrate a high level of stress with the contribution factors such as difficult child

characteristics, fathers' level of education, low level of family income. (Ahmad M., Dardas A. L., 2015)

Another study conducted in Wales with parents who have children ages from nine to twelve who were diagnosed with autism demonstrated that mothers feel a high level of guilt and always questioning themselves like what they had done wrong. (Midence & O'Neill, 1999). Same study also conducted that mothers also experience a high level of neuroticism.

According to Mourisden et al. (2007), fathers of children with autism more likely to experience alcohol abuse than the general population. However, mothers of an autistic child did not show such a tendency (alcoholism) as fathers. The same study also measured and compared the depression level among mothers and fathers of children with autism. Results indicated that mothers experience a high level of depression compared to fathers. This result is not very unusual since many similar studies show the same results, however, in this study, interesting facts is father's depression rates were very high. However, the limitation of this study was to not investigating if there is a connection between alcoholism and low-level depression. In this case, over-drinking alcohol may be a sign of "hidden depression".

### **Social Isolation**

When literature about the mental health of parents of an autistic child has been reviewed it is visibly seen that one of the biggest issues of these parents is "socialization and isolation". Even other mental problems such as depression, low mood, etc... are connected with social isolation as mentioned above ((Nayab I., Ayesha K. B., 2013) in the study. A human being is a social animal, socialization is a basic human need as water, air, and sleep. According to the (Bekhet, Johnson & Zauszniewski, 2012), parents with children with autism feel a high level of social isolation.

It should be asked and clearly identified why parents of children with autism experience a high level of social isolation. Even though there are many studies which indicated different results in the level of depression, anxiety, and other diseases, almost all of studies agree about social isolation is experienced by parents of an autistic child in

high level. After clearly searching, the reason of social isolation can be described in the titles of "lack of understanding from friends and families", "lack of support from society". Moreover, parents may choose to self-isolation because of their's children's aggressive behaviors such as outbursts of anger and tantrum (Bekhet, Johnson and Zauszniewski, 2012). Same study (Bekhet, Johnson and Zauszniewski, 2012) also indicated that social stigma of society is a another reason why parents of children with autism "have to" chosee self-isolation.

In the literature review, the family part was one of the longest, because without taking the family into account, autism can not be evaluated. Because even though the child is the one who deals with this disorder, however, most of the psychological, financial, sociological and even sometimes biological difficulties experienced by parents. Parents are the most important subject in every stage of this disorder, from the beginning.

However, without parents, even treatments will not be as effective as with them. All most all the literature agrees that family support is the most important factor of treatment (Freedman & Boyer, 2000). Another study (Oono 2013) showed that the best treatment method is family-based one for children with autism. There are numerous other studies that indicated the same claim that autism treatment should be with parents. However, it is not limited to that. According to (Arango P., 1999) parents should choose a treatment strategy of their child and they must also have a right to control the treatment process. Even though at the begging it seems "too much" when it considered that "every single child with autism is special and they need special education by one by" it sounds logical. Because parents are the ones who know the child very well.

## **Culture**

Culture is one of the most important subjects in every topic as well as health issues. Because culture affects peoples' way of thinking, feeling, behaving, understanding and communicating. Of course autism is not a cultural phenomena, however culture plays very important role when it comes to diagnosis and treatment. Because these process decided and directed by parents of children with autism. When

the effect of family is taking into account, we can not make any interpretation without considering their cultural.

According to (Mandell & Novak, 2005), Anglo-American families ignore the social problems of their children with autism but they first notice language problems of children to apply for a professional diagnosis. On the other hand, Indian parents firstly notice the social problem before language. It may be the consequence of western individualistic and eastern collectivistic cultural characteristic.

A study is compared differences in English and Chinese parents in relation to interventions with autism has found that in England, autism symptoms are first noticed by teachers but In China, first concerns about childs' development problems came from parents. According to author, it is because mother model in Chinese culture. Mother is the one who responsible for raise children in the tradition of China, however the most of English women work as their husband so they spend time with their children less than Chinese mothers (Y. Liao, K. Dillenburger, I. Buchanan, 2017).

One study examines the effect of cultural differences factor on parenting perceptions diagnostic experience among the Latino community and White parents. Results indicated that Latino families' children with autism were diagnosed at later ages than white children and experienced greater delays between the first time that parents concerned about their child and the time of diagnosis professionally. (B. Ratto et al. 2015) However, study also did not investigate what cultural factors cause Latino parents' delay for diagnosis. Another study from U.S also found similar finding, According to (Fountain, 2011) Hispanic families tended to receive a later diagnosis of their children with autism.

According to another research, African-American children are diagnosed with autism almost more than one year later than other children in Usa (Mandell & Novak, 2005). Other studies from USA which investigate the diagnosis period of autism among African American children and White children found similar results. For example (Perryman, 2009) clamied that with his research, African American children diagnosis 6 months later than the White children. African-American families who have

children with autism are also less likely to have regular visits for interventions. (Mandell & Novak, 2005).

A study conducted in France and USA demonstrated that mean age of diagnosis of autism was not significantly different, however, according to study the differences was apply for genetic test in diagnosis period. Study showed that Only 27.8% of participats from USA had undergone diagnostic genetic test, whereas for the French participants the number was 61.7%. (Amiet et al. 2014)

A research indicated that Somalian mothers have some social problems when they have children with autism. According (Samatar, 2016), many parents from Somali hide their childrens' autism diagnosis because of negative social reaction. Some of participants reported that; *“ I afraid that my child will be labeled as “crazy “or “not normal”*. So this social problem also has negavite effects on childrens' intervention.

Other study investigated parental differences between minority and non-minority families of children with autism. Results found that ethnic minority parents pay less attention to communication and delay to search for intervention services. The good side of this study was the socio-economic background of parents clearly stated and most of the participant families chosen from middle-upper class families. (S. Tek, R. J. Landa, 2013)

According to some other sources, the linguistic barrier can be one of the biggest challenges to families from non-English speaking culture. According (Morrier, Hess, & Heflin 2008), many children with autism face difficulties during diagnosis and intervention process because of verbal parts of diagnosis. For example, in some cultures, there is no even word for autism and other components. In Chinese, autism means "fei" can be translated as "useless". This I s a very big problem for a Chinese child with autism during diagnosis when it comes to accepting such disorder.

## **Religion**

Certainly, religion is also an important part of a culture. Even though there are no satisfactory resources about how religious attitudes affect the diagnosis and intervention of autism, there are a couple of studies that may give us some information.

A study from Kenya suggests that regardless of the socioeconomic status, some families do not attempt to any modern intervention methods because of religion. Some families do not even apply to professionals for diagnosis but people believe that their children have a problem caused by evil spirits. Thus, instead of modern hospitals, these families go to some spiritual healers and prayers.

Some cultures may apply both medical, modern help and religious institutes at the same time. According to (Shaked & Bilu, 2006), Ultra-Orthodox Jewish families who has children with autism first go to hospital and d then seek help from a rabbi.

However, According to (Pitten k, 2008) there some positive effects of religious perspective. Latino mothers' Virgin Marry model gives them extra strength and patience also make them less depressed in the intervention period. Consequently, families' this positive attitude benefit to the treatment period.

As in diagnosis, the culture of families is also important for autism intervention period. (Zhang and Bennett, 2003) indicated that it is essential to establish extra effort during intervention especially multicultural families. It is important to make an extra effort for commucation, sharing information about treatment, recommendation clearly with families who have children with autism, particularly in the case family does not speak English. Same study also demonstrated that, if specialist tries to understand and give special attention to families' culture, treatment is more likely to be effective. (Zhang and Bennett, 2003)

### **Education and Socio-Economic Background**

Some studies indicated that the relationship between the early diagnosis of autism and economic status found no relationship between high income or neighborhood and autism diagnosis, however, there was a strong association with the education level of parents and diagnosis of autism recorded in earlier. Children with autism whom mothers have higher education status were twice likely to have a early diagnosis compared to children of mother with lower education level. ( Kelly B. Et al, 2017).

According to a study from Greece also has similar findings of the relationship between the educational level of parents and autism diagnosis. Even though Greek culture has a negative attitude toward intellectually disabled children and the most of the mothers find themselves in social isolation, however Greek parents with higher education level have more self-esteem and supportive to their children with intellectual disabilities.( Argyrakouli, E. & Zafiropoulou, M. (2003).). This is also another evidence that education level is a key factor in autism intervention.

According to another study that examined the relationship between early diagnosis of autism and economic status found no relationship between high income or neighborhood and autism diagnosis, however, there was a strong association with the education level of parents and diagnosis of autism recorded in earlier. Children with autism whom mothers have higher education status were twice likely to have a early diagnosis compared to children of mother with lower education level. ( Kelly B. Et al, 2017).

However there is a study from Sweden found some interesting results about relationship between socioeconomic background of parents and early diagnosis of autism. Even though, healthcare is free in Sweden, but there is still large differences between socioeconomic classes for early diagnosis autism. Families children with autism from higher socioeconomic background faced earlier diagnosis and intervention. (Rai et al. 2012)

### **Adulthood Autism**

There is a significant lack of literature for adulthood autism since almost all of the literature about autism is targeted to childhood. However, there are still some resources to do some interpretations and analyzes on that topic. When it comes to adulthood autism, there are some difficulties and also positive sides.

To start from the positive one, Wing (1972) suggest that when an individual with autism becomes an adult, they demonstrate more social and friendly behaviors to others. So it can be claimed that rehabilitation and socialization will be easier when an individual with autism became an adult.

Another positive argument about childhood autism was in language skills. Wing (1972) also claimed that adults with autism have less level of language deficits and also their skill of communication is more distinguishable.

Unfortunately, positive sides of adulthood autism can not go too far. Firstly, when children with autism became adult they realized that they are different than their peers. But according to (Cesaroni & Garber M. 1991), this self-recognition is not something positive since they also realized that they have some limitations than their peers.

The negative experience of being different may turn "negative self-image" and this negative consideration of self leads to low level of self-esteem among adult individual with autism. (Miedzianik and Coskins, 1997)

Normally, when the topic is adulthood autism, the most important subjects come to employment. As it will be reviewed more detailed in Turkey(Law) part of this paper, there is a special examination for people who have a disability as well as people with autism. (Osym, 2019). Even though there is some improvement of it, unfortunately, job prospects for an individual with autism are very limited. (Howlin P. Magiati I., 2017)

### **Autism and Other Disabilities**

From the beginning of this paper, we have presented that being parents of children with autism is a very challenging and difficult situation psychologically, physically, financially and socially. However, a question comes to mind; what about other disabilities? Maybe it is a limitation of the current paper that every parent with a disabled child experiences similar difficulties and these difficult conditions are not unique to autism. To investigate the answers to this question, we applied to literature.

According to (Baker JK, Seltzer MM, Greenberg JS, 2012), parents with autism experience more parental stress and less level of psychological well-being than parents of children with other disabilities. Another study (Hayes SA & Watson SL., 2013) tries to analyze differences between parental stress among 3 group;

1-Families of children with autism

2- Children who diagnosed with other disabilities(Down syndrome (DS), cerebral palsy, intellectual disability

3- Typically developing (TD) children

It is normal that parents with disabled children demonstrated a higher level of stress parents of typically developing children, however, as (Baker JK, Seltzer MM, Greenberg JS, 2012) reported, this study (Hayes SA & Watson SL., 2013) also showed that having children with autism causes more parental stress than other disabilities

As a limitation, I could not find any rational reason for this fact. There should be a clear answer of the question "why do parents of children with autism experience more level of parental stress and they have more psychological problems?". Even though I review the literature a little bit, I could not find any satisfactory. Some resources claimed that because of "social problems" however, it does not seem realistic since parents with other disabilities, especially "mental-intellectual disabilities" also difficult and they also experience social problems. So as a limitation, it should be answered and investigated deeply.

### **Stigma**

According to literature, the social stigma of individuals with autism is a very well known phenomenon.A systematic review conducted by (Ali et al 2012) with 20 studies that investigate the stigma of parents of children with autism from 1990 to 2012. Results indicated that social stigma is both destructive for individuals with autism and their families.

A very interesting study (Monique B., David M. F. 2018) indicated that individuals with autism experience a typical minority stigma. It is an interesting and logical perspective and to find a similarity between being an individual with autism and being a minority. Because of people with autism also a minority group.

There was another study (Gray E. D.,1993) that measures the social stigma level of parents of children with autism. For this study, 32 parents have children with autism and they found that parents are stigmatizing extremely. Moreover, again here there was the same detail, the same study showed that " There was a strong tendency for mothers to feel more stigmatized than fathers.

All of the studies above also indicated that individuals with autism and their parents who experienced stigma experience psychological and mental problems at the same time. And their mental problems are associated with the social stigma they faced. However, there is an intervention called SOLACE to reduce their mental problems associated with social stigma and improve their psychological well-being and increased resistance to stigma. A research conducted to measure the effectiveness of SOLACE found that this 8 weeks intervention program is highly effective. (Annemarie L. Chris P. Gurch R., 2019)

### **Comorbid Disorders**

There are numerous studies indicated that individuals with autism also experience other psychological and emotional disorders. According to (Lever & Geurts, 2016), almost 80% of individuals with autism experience one of the psychological disorders.

### **Anxiety**

Anxiety disorder is one of the most common comorbid disorder in autism spectrum disorder (Brittany M R., Adam B L. Eric A S., 2013) Some studies indicated that prevalent is no less than %30 (Sukhodolsky DG, Scahill L, Gadow KD 2008), some of them, for example (Russell et al., 2013) suggest that it is at least 50% of adults with autism experience anxiety disorder.

### **Depression**

Not as much as anxiety but depression is also one of the prevalent disorders among individuals with autism (Stewart ME. Et al., 2006) (Maya M., Nicole T., 2016),. In some studies, it is reported that prevalence is from 1% to 10% (Leyfer OT, Folstein

SE, Bacalman S 2006). So when depression among individuals with autism reviewed, it can easily found too many resources, so a low level of prevalence can be the reason for that.

### **Aggression**

According to research, individuals with autism more likely to demonstrate "aggression" behaviors than other people without any mental disability. Moreover, among individuals with other intellectual disabilities, aggression level is significantly higher among individuals with autism (Tsakanikos E. Et al., 2007).

### **Obsessive-Compulsive Disorder**

Studies found that OCD and Autism often can accompany each other and it may comorbid (Abramson RK Et al, 2005), however, according to some experts, these are classical repetitive behaviors of children with autism and it is normal for them to have some rituals.

### **Hyperactivity**

Hyperactivity, like other disorders, is not diagnosed together or come with autism disorder directly. So it means it does not mean every individual with autism also have hyperactivity but as a symptom, most of the time, they have reported in children with autism spectrum disorder together and co-occurrence. (B. A Corbett, L. J Constantine 2006)

## **In Turkey**

### **History**

Autism in Turkey does not have very long history. The earliest works about autism were only in major cities which were only academic centers. However, in 1989, the first medical center was established in Ankara. Until the 2000's, there was no special education for children with autism provided by the state. Children with autism had the same education as children who do not have any intellectual disabilities.

Currently, Turkey has the same diagnosis and intervention policies as other countries. DSM criteria is the standard evaluation method for diagnosis and for intervention, there are more than 30 departments in hospitals. However, there is still some problem with families from rural areas.

### **Prevalence**

According to ODFED( Federation of Autism Associations), there are approximately 550.000 individuals with autism. Since the main topic of the current paper is kids, the same resources indicated that there are 150.000 children(aged 0-14) with autism. But ODFED underlines insistently that their numbers are "conjectural". Another resource is Mersin Mersin Provincial Health Director Dr. Mustafa Kemal Başaralı indicated that there are 650.000 people with autism in Turkey. The numbers are almost the same and close to each other. It can be said that there is around 600.000 individual with Autism spectrum disorder and when their parents, siblings and close relatives taking into account, more than 3 million people are affected by autism in Turkey. When it is considered that the current population of Turkey is 80 million by 2019, this number is quite significant.(Otsimo, 2018)

### **Education**

Education is one of the most challenging subjects when it comes to children with autism. According to literature, there is almost no general education to apply all children with autism, however, it is always recommended that there should be

individualized education method that prepared by an educator that familiar with the autistic child.

When it comes to the education of children with autism in Turkey, instead of talking about facilities, opportunities, and system of education, we need to focus on more to problems and deficiencies. There are still many aspects of autistic children's education to improve and regularize. These main problematic aspects can be stated as; lack of facilities, lack of specialist such as a behavioral therapist, speech therapist" and lack of early intervention opportunities.

As it mentioned above, Özgül Gürel from Tohum Autism Foundation also points to lack of facilities. He reported that educational services which are provided by the state is very insufficient. The number of children with autism who have a chance to get public education is very low.

To be more clear, there are three main options for children with autism in Turkey to receive an education. The first one is "general education classroom in a regular state school", the second one is "special schools for children with intellectual disabilities" and the last one and also the best option is "educational centers for special only children with autism". Unfortunately, these special education centers for autistic children are limited. Özgül Gürel indicated that there are 51 educational centers (10 in Istanbul) for children with autism in all over Turkey. Since we consider that Turkey is a big country 79.81 million (2017), the number of centers seems very low.

Another problem was as it mentioned lack of specialists who are really equipped about autism such as psychologists, behavioral therapist, language and speech therapies. Of course in every "human resources" problem, universities are the main base to solve the problem. However, as Özgül Güler reported that there is a lack of departments of special education in Turkish universities. The positive news is, according to The Higher Education Council of Turkey, there is a official workshop and action plan to improve it.

A study also demonstrated the human resource problem of autism in Turkey. The research conducted to measure the level of general knowledge of autism among Turkish public school teachers. There were 500 participants for this study and four

senior pre-service teachers. Results were not very satisfactory. The most of the teacher had very limited knowledge about autism, its main characteristics and about what to do in a such situations. As can be seen from this example, human source problem is not limited to lack of people, there is also a qualification problem of present already employed specialist (Salih R. et al., 2016)

Since main subjects of this paper Turkish mothers who have children with autism, we have to apply their thoughts, experiences and suggestions;

" "Many children show improvement with the support of their families but special education by the state is insufficient. There should be more schools and classes. The cost is too high for special schools for those children and is a serious economic burden for families. I believe this will significantly contribute to their rapid development,"

Said Gülşah Savsa who is the mother of ten-year-old boy with autism. Another mother, Hülya Saygı who has 18 years old daughter with autism and a member of Autism Foundation added;

"The education period for those children in state-funded special education centers are too short. Children have individual and group classes three hours in total for three days a week but it is not enough. You have to pay for extra classes in private special education centers and it is a challenge for families who cannot afford it," (Dailysabah, 2019)

Rather than these interviews, there are more studies that investigate the education issue of children with autism also applies to mothers. (Bilgin H. Kucuk L., 2010) indicated that "mothers of children with autism need more support from healthcare organizations, training and education programs".

However, literature is not always pessimistic in Turkey when it comes to Autism education. There is some positive side of it and some studies also demonstrate a develop. 175 students nursing and medical students participated in research to assess the level of general knowledge and awareness about childhood autism. Results indicated

that 138(78.9%) were aware of autism, 14(8%) of them being highly aware and 124(70.9%) moderately aware, whereas 37(21.1%) were not aware. Research also points out that females students were significantly more aware and knowledgeable than male students. (Lüleci et Al., 2016)

Another study asked a satisfaction level of Turkish mothers from Special Education Center of Turkey. They reported that education should be more personalized more since every child with autism is unique and may need different attention. Mothers also indicated that schools should arrange more meetings with mothers and include them to the education process. (Koydemir S., Tosun U., 2009) Literature also agrees with mothersç A study conducted to measure the effectiveness of parent involvement for early intervention programs and therapies found that if parents attend therapy, children's understanding and social observation skills to everyday situations improve visibly. (Wetherby & Woods, 2006)

Even though there were some suggestions and complaints, according to ((Koydemir S., Tosun U., 2009)), the general level of satisfaction was high. Mothers were mostly grateful to teachers. When their opinions asked about teacher, they summarized them as "involved, helpful and sympathetic."

A study conducted in Turkey indicated that education of children with should involve games and training centers should be included playgrounds (Deniz, 2019). There was one experimental group that exposed to education with game therapy and playing, other control groups did not have any special playing game therapies. Then, they had observed 12 weeks, 3 sessions a week, and a total of 36 sessions. After Autism Social Skills Profile Scale filled by the children's parents and teachers, the results of that scale showed that the experimental group exhibited a significantly higher social skill score than the control group (Deniz, 2019).

Until here, education of children with autism has been examined. However, we should not ignore the education of families too. As it mentioned above families involvement to the education process is extremely important. However, parents also need education if they have a child with autism. A study is examined the effectiveness of the parent training and education program for Turkish parents. The result showed that

mothers who get the education and special training of autism increase their interpersonal relationship skills, their problem-solving skills and their perceptions about their children with autism. Moreover, what makes this study so important is, rather than increasing information about his or her child's disorder, having the education and attending parent training program significantly decreased the parent's stress level which related to their child's autism symptoms. (Vardarci G., 2011)

## **Law**

The first law was established for children with special need in 1982-1983 in Turkey as "Law on Children in Need of Special Education". As it can be understood from laws' name state were generally helping children and families on education level. On 1997, a more serious law is passed. It was contained to established local schools and institutions which are responsible for education and needs of children with special disability.

However, still, Turkey needs to increase their services, laws, educational strategies and institutes for children with special needs. Finally, in 2005 the "The Disability Law" was passed which contained regulations in international standard. According to this new law, the state was not responsible for only the education of children but also have to provide health services, financial aids, accommodations, and psychological needs and job opportunities.

After this law, It became the obligation of the state to provide job opportunities for individual with disabilities as well as autistic individuals. One of the tasks of the early diagnosis and prevention clinics and education centers is training disable and autistic children for these future jobs. It works like this, there is a state examination for public employment in Turkey for polices, government offices workers, healths-social services, fire department, defenses, education, etc... And every state institutions should have a quota for disabled people and individual with autism. That diagnosis and prevention centers set their job training and educations which is compatible with these jobs.

To sum it up, laws for people with disability are pretty appropriate and compatible with international standards as most of the law in Turkey had to adapt to European Union standards in Turkey's integration process. Even though there were some special regulations for children with autism and their families, most of the time, autism used to consider as one of the mental disabilities and there was not a law which targets especially autism. However, in 2016, State Planning Institution declared 6 steps action plan for autism (Resmigazete, 2016);

- 1-Awareness and inter-institutional cooperation
- 2-Establishment of Early Diagnosis, Treatment and Intervention Chain
- 3-Development of Services for Families
- 4-Development of Educational Evaluation, Special Education, Supportive Education and Rehabilitation Services
- 5-Employment
- 6-Social Work, Social Assistance and Community Participation

### **Foundations and Organizations**

There are many foundations and associations for children with disabilities in Turkey like Istanbul Foundation for People with Mental Disabilities (IZEV), Turkey Training and Protection of Mentally Handicapped Children Foundation(Ziçev). These foundations are also interested in Autism. However, some foundations directly help children and families with autism.

One of them is Turkey Foundation for Support and Education of Autistic People (TODEV) which is found in 1997. Their mission is to find solutions to the problem of parents of children with autism. TODEV is focused on mostly "solidarity".

Another one is Autistics Association (AURA), It is the purpose to create "environment" to live humanely life for individuals with autism especially when they

reach adulthood. So it can be summarized that AURA is mostly focused on socialization and relationship of autistic individuals. Its mission is more educative than others.

According to my observations and literature review, TOHUM Autism Foundation is one of the most comprehensive autism centers in Turkey. It targets many aspects of autism such as information, support, education, socialization, vocational training, supporting the independent life of autistic adults.

### **Autism and Turkish Families**

According to (Alpaytaç, 2007) when Turkish parents first notice a problem with their child, mothers become more panic however at the same time Turkish fathers are less worried. The same study indicated that there two common processes for Turkish parents before their child with autism faces to diagnosis. The first one is "denial". In this period, families do not accept their child has some developmental problems. They do not apply for medical help for diagnosis and try to attempt other solution like religion and healing. They apply for Imams of local mosques or force their child to drink some "magical" teas. As in many culture, Turkish old people also more religious so they insist to apply for religion at the same time with hospitals to their children in the case they have ground children with autism and other developmental disorders.

All these traditional and religious cases about Turkish parents with an autistic child, unfortunately, cause to late diagnosis of children with autism. However, even though Turkish "traditional" culture has a negative influence on early diagnosis of autism, according to (Alpaytaç, 2007) it turns a positive effect on the intervention process. Turkish culture is more cooperative than the West, as a result, solidarity seems like a social task or outcome of good faith.

In the second process parents completely accept the situation and they experience emotions such as anger, guilt, shame, and depression. In this period, couple problems also start. Wife and husband blame each other because their child's development problems.

There was a study aimed to measure differences between the United States of America and Turkey in the level of parenting stress, ways of coping strategies against difficulties and family functioning of parents with a preschool-aged child with autism (Celimli S., 2009). Results demonstrated that Turkish mother with children of autism use more problem-focused coping strategies, while their American counterparts interpret problems more general. It is also indicated that Turkish mothers demonstrated more flexibility. Even though this was a very interesting study, Unfortunately, interpretation of results was not clean. However, as it can be understood that American mothers are more disciplined and straight about parenting style and coping ways while Turkish mothers focused on a problem instead of having a general strategy.

According to a study conducted in Turkey in order to measure the relationship between having a child with autism and mental difficulties found that parents of children with autism have a higher level of Emotional Exhaustion and burn-out after they are subjected to Beck Hopelessness Scale. Maslach Burnout Inventory. (Adıgözelova S., 2019)

As the main purpose of this paper is to investigate what it is like to be the mother of a child with autism in Turkey, it is going to be very helpful to review some previous experiences of mothers of children with autism in Turkey. It will be also useful to interpret and compare the current situation (as it is going be present in the methodology part) and previous experience of Turkish mothers (Dailysabah, 2019).

Gülşah, mother of ten year old boy with autism says;

"a difficult process that needs one to have pattiene." "I didn't know the meaning of patience before Toygar. His condition taught me patience but I am happy that efforts I exerted for him eventually pay off. You have to have your children educated to overcome the challenges. We went through difficult times and needed support. For me, it was my family that gave me the biggest support. We gave Toygar our love and saw his condition improving,"

It is also one of the mean questions of our paper as it can be seen from the title of the study. Miss Savsa said, "We needed the support" so in anyway, "social support"

is the most important thing for mothers whose son is diagnosed with autism. It is why also the word "psychosocial" was chosen. In this example, Miss Savsa said: "I had enough support from my family". Hypothetically, Turkish culture is socially supportive to people who are in difficult condition as it will be mentioned below (in the Turkish Society part) in the name of good faith and solidarity.

However, there are some negative sides of the social structure of Turkey, especially to someone different. It will be also mentioned below from the literature, however, thanks to Miss Gülşah, she gives the perfect example from real life in her interview;

She says "playing games with children with autism definitely helps them in education and attending classes with children without the condition contributes to their improvement. Unfortunately, this is not the case in this country. Toygar attends a public school [in a class where children without autism also attend]. He likes to play with his friends but parents of some students do not want their children to mingle with him. I call people to not stay away from children with autism. This will make them happy and better integrated," (Dailysabah, 2019)

Turkish mothers who have child with autism experience high level of stress and emotional breakdown. They feel worry, hopeless and pessimist about their and child's future, because of their high level of responsibility. According to the study, lack of family support, insufficiency of the organizations create this negativity for Turkish mothers. (Sirin N., Tekin I. E., 2016)

A study from Turkey examined the relationship between psychological resilience of the mother of children with autism and emotional states (stress, anxiety, depression levels), after they measured Quantitative and Qualitative Investigation of Parental Resilience, the results demonstrated that mothers experienced less level of psychological and emotional problems such as depression, anxiety, and stress when their psychological resilience level increased. (Cicek M. N., 2019)

Another research was conducted with 43 mothers regarding their experiences with their autistic children (Bilgin H. Kucuk L., 2010), the finding suggests that stress

of Turkish mothers with autistic children is not limited with their children's responsibilities and difficulties that associated with autism, when it comes to future expectations, Turkish mothers with autistic children are again more stress than fathers.

One more study from Turkey aims to determine the depression levels of the parents of individuals with autism. (Gönen A. 2014,) According to results, parents experience depression but in mild level. The study also indicated that fathers demonstrated a lower level of depression than mothers. The results are not shocked, since almost many studies which target to investigate Autism in Turkey agree that Turkish mothers suffer more than father. It can be because of the role of women in Turkish culture. They should be more self-sacrifice herself to her family, they should devote herself to their children etc... However, it does not mean that Turkish fathers are careless about their child's development disorders and problems. It seems that this phenomenon is also culture. The reason that in every single study Turkish father seems less worry because of the role that given by society to Turkish males. In traditional Turkish culture, men should be more cold-blooded, calm and reticent. Consequently, even though they are worried about their child's future, health and sad, they can not demonstrate it easy. As a limitation, future studies should consider this very important cultural fact.

They were a study conducted in Ankara, Turkey with 18 middle-class fathers to experience with their children's autism disorder. After face to face interviews, the results were pretty significant; firstly, the fathers whose educational level is higher more likely to be cooperative with mothers. The education level of Turkish fathers also affects their relationship with their children with autism. The study indicated that Turkish fathers with a higher level of education have closer fatherhood with their children. The study also showed interesting results even though it is a bit out of general topic. It reported that traditionally masculine fathers become more "role-model" for their children. (Akoglu G. 2019)

Another research from Turkey conducted with 106 mothers of children with autism indicated very interesting findings. After mothers filled Autism Behavior Checklist and Beck Depression Scale, Beck Hopelessness Scale and Maslach Burnout

Scale, results were very significantly important. According to results, they were a correlation between Autism level and depression and hopelessness. As the autism severity of the child increases, mothers' hopelessness also increases. (Kandaş G., 2019,)

Another study conducted to introduce "what problems do Turkish mothers of children with autism have" demonstrated that the first reaction of Turkish mothers was "shock" of all participants(10/10). Mothers also reported that the first reaction follows;

Rejection(9 of 10)

Depression(6/10)

Self-Blame(4 of 10)

Denial(3/10)

However, the same study claimed that mothers' reactions as the second period follow more positive. Mothers reported that their current mood toward their children's disability is "Acceptance". It is a good process since Acceptance will cure automatically 3 of 4 negative reactions in the first process("Rejection, Self-Blame, Denial"). However, there is no evidence in the study that an Acceptance attitude can solve one of the biggest problems of mothers in the first period, which is Depression. Moreover, the study also showed that all of the participants experience a high level of stress. Mothers reported that their stress because of;

1-Exhaustion

2- Being the only person taking care of the child

3-Financial constraints

4-Negative attitudes of people towards the child

These results too important to investigate the current paper's research. The stressors that mothers reported demonstrated and proved the rightness of choice of the name of the title of the current paper. Because as it can be clearly seen that mothers here

have "social problem". They have not enough social support and as it can be seen in 4th one (Negative attitudes of people towards the child), public attitude is also very important for mothers' psychological welfare. (Koydemir S., Tosun U., 2009)

The same study (Koydemir S., Tosun U., 2009) demonstrated other effects of having the child with autism on mothers' personal life. According to results one of the biggest problems is career related ones, then, relationship problems follow it. Again, as it can be seen, problems of mothers somehow social problems. Because as this paper hypothetically focuses on "psychosocial" problems, that means it already thought "mothers may have social problems". To spread it more, when the researcher asked them what kind of problem, the highest response was "lack of social life".

But, at the end, mothers are hopeful about the future. The majority of them think their children will be able to take care of him/herself, and they hope that their child would have an occupation.

### **Autism and Turkish Society**

It is not a very well known phenomenon that perception of Autism of Turkish society. When it researched and scanned the literature, unfortunately, we can not get too much information. However, there is only one resource thanks to TOHUM foundation. There are two studies conducted by TOHUM in 2015 and 2017. According to results, in 2015 %29 of people had general knowledge about autism in Turkey, however this increased %58 by 2017. In the same report, this dramatic and rapid increased is explained as "great efforts given by TOHUM foundation to increase awareness by using all the communication methods". (Tohumotizm, 2017)

As the TOHUM's repost demonstrated that it is very well to see the increase of knowledge of autism in Turkey since Turkish culture's reaction to "unknown" is not very positive many times like many cultures. Unfortunately that reaction to "unknown" is one of the main roots of prejudices, racism, discrimination, xenophobia, sexism and many other problems in both Turkish and other societies.

In traditional Turkish cultural anything, "atypical" is something "ilginç", ilginç is a Turkish word that can be translated as "strange" but with a negative form. Of course, people don't do anything wrong consciously, however, negative "what is that?" "wow look at this" attitudes come as an automatic reaction when most of the Turkish people see something, someone, some cases with atypical to average social norms. Unfortunately, this is like that in autism to as well as other disabilities.

Of course, that is the first reaction, which is not completely but barely negative. However, as I mentioned above, immediately after that first reaction, "the solidarity" is coming as a natural reaction of Turkish culture. Solidarity is a positive cultural trait without doubt, but this positive characteristic also comes automatically as a negative first reaction. Because solidarity is not a "favor" that people do, it is a communal obligation.

### **Media**

Media is the most important component of Turkey and Turkish society. For political propaganda or advertisement, spreading a view or raise awareness to an event, media is the most useful and efficacious way in Turkey. It can be thought that "it is all same in all of the worlds" but in Turkey, it is more and things are a bit different. To give an example, Turkey is the 6th country that used Instagram platform more. However, the other five countries like United States of America, India or Russia, etc... more or less two times more population than Turkey. So it means almost every Turks have their own instagram account. I give that example because Instagram passed Facebook and by 2019 it is the most used social media platform in Turkey and also in the world.

As it is known that media is not as important as social media channels as the old days. So collecting information about printed media and television about autism in Turkey is a bit challenging. However, websites of newspapers are helpful data to have some information and overlook to a general tendency to the perspective of Turkish media on autism.

According to (Alpaytaç, 2007) from the 2000s to 2007, news about disabilities increases by years. Of course, even though it is an old study, but it gives us a general

tendency of Turks to disabilities in positive acceleration. From that date(2003-2007) to today(2019) it seems this identified is valid and medias' attention to disabilities still at an appropriate level. As mentioned, the data (Alpaytaç, 2007) was for "disabilities" in general. However, what is actually wondered here is the media's attitudes to "autism" in Turkey.

When all the newspaper archives and websites are scanned, awareness of Turkey to autism seems positive and dynamic. As mentioned above in the Foundations and Organizations part, this positive awareness is thanks to TOHUM, AURA, TODEV, and other associations.

Normally this awareness increases on April 2 World Autism Awareness Day, however in the last two couple of years it rises more than normal because of the First Lady of Turkey joined the celebrations and gives a speech about Autism.

Overall, Turkish media's attention and interest in Autism case are still not as wanted as people wish, yet, improvements promising for the future.

## **Methodology**

For this study, I used qualitative research, because I thought the interview is the best way to collect data of socio-psychological conditions of the mothers of children with autism. As my supervisor, Dr. Valtelini suggested that it is better to interact with participants in face to face setting. The interview also a preferable way to collect data because it is easy to manage the process and understanding what the participants feel about how they think, how they feel with observing their voice tone, facial expression and the way they answer.

To use qualitative research(interview) also important to be respectful to participants and ethical issue. Because while interview, I have never asked direct questions that may hurt participants. I also did not mention or used the word of "autism" during interviews.

### **Purpose**

Unfortunately, there are significantly limited resources about autism in Turkey in general. Even though it is possible to find some literature of it, looking closer into the lives of the families of autistic children, especially mothers are insufficient.

Therefore, this study aims to have some information about mothers of children with autism who are influenced by autism more than anyone else. More clearly, we want to analyze if there are some socio-psychological effect of having children with autism in Turkey and in Turkish society.

### **Ethical Concerns**

As my supervisor, Dr. Enrico Valtellina and my Professor Dr. Pietro Barbetta suggested me to follow ethical issues and carefully chose and ask questions during the interview. Firstly, with their suggestion, I have never used the word "autism" in my questions. Secondly, never tried to ask close ending, forcing or router question to take the answer I will need and try to keep interwiev and conversation in "chating" mood. Lastly, I carefully read Ethical Principles of Psychologists and Code of Conduct of the APA and try to talk with self-awareness.

I politely inform them about my thesis and project, asked them to have some notes during the conversation. I also told them that if they do not want to share their names and ages or other personal information, it is okay to protect privacy. None of the participants did not ask such requests.

### **Data Collection**

To investigate the social and psychological problems of mothers with autistic children, I created interview protocols and asked my questions to each of mothers one by one. They were 17 questions, mostly open-ended. I choose mostly open-ended questions because of ethical concerns that as I mentioned previously to not hurt the participants and to support them to express their feelings and opinions fully and freely. However, the responses given to these questions by me was to provide answers that I need for my research.

### **Data Analysis**

I used thematic analysis method to analysis data. Firstly, I carefully read all the notes that I took during the interviews. Then I coded them and underline the words that can be answers of my research question.

### **Coding and Themes**

There were 3 main themes as mentioned "depression and anxiety", "stress level" and "social life". After I read the transcripts of interviews and analyzes them carefully, some words took my attention and I thought that these "words" can be answers of my questions in general. It is how I coded the transcribes of interview and reach the answers. Here are codes for each theme;

- Depression, Anxiety and Stress
  - (Mood)
  - (Energy)
  - (Future)

- (Nervous)
- (Sleep)
- (Anger)
- (Pains)

➤ Social Life

- (Support)
- (Time)
- (Judgment)
- (Tired)

### **Participants(Mothers)**

- **Ayşe:**

She is 34 years old housewife, with a 7 years old boy with autism. Her husband works in a tourism company. She likes to enjoy going to a cafeteria with her son Buğra on the top of Kusadaşı, where you can see a beautiful view of the Aegean Sea and port of our city. Buğra likes to have ice-cream while her mom enjoys her coffee. They were financially good until 2 years ago before the currency crisis of Turkey happened. Moreover, the number of tourists arriving from Europe has decreased because of the last Political crisis between Turkey and the West. Now Miss Ayşe and her family and some financial concerns. She was the youngest and most talkative one, Thanks to her I got too many useful information and data.

- **Özlem:**

42 years old, coffee shop manager. divorced with her husband. Özlem's mother is mostly responsible for taking care of child in general while she works. Her son with autism is 9 years old. She is grateful to her mother because of taking care of her son. And she added that "his grandmother take care of him more than me and

my older brother. She looks happy, she did not have a happy marriage before but know she told that it is peaceful to live with my mom and being around with my friends. She told me that "she very satisfied with her job" so even though she did not mention directly her financial condition, she seems good and no financial problems.

- Sevil

50 years old housewife, her husband works as a real estate agent. Her son is 15 years old. Miss Sevil was a very quiet lady, but the interview also went well with her while she was very enthusiastic to help me since she often told me that "I admired you, you are doing well". Without asking she also mentioned her husbands' problems with job and added that "last financial crisis" also affected them.

- Meral:

36 years old, works as a secretary in hospital. Her son is 3 years old. Her husband is technician. Meral was an excited, fast-loud talker and a little bit aggressive lady (she also personally reported that) but as I will analyze deeply in results part, even she had a high level of aggression (both my observe and self-report) she was the participant that demonstrated less level depression symptoms. It can be the effects of her job. Working as a secretary in the "patient registration center" in the public hospital of our city is does not seem an easy job normally. She did not report any financial problem, she did not have any family problem.

- Suzan:

38 years old, she has her own clothes shop, divorced, she has 6 years old son. During the day a special caretaker taking care of her son who is graduated from special education faculty. She never mentioned her husband, she preferred to talk mostly about her business. She was also one of the participants that demonstrated less level of depression and a high level of "hope" from the future. I realized that her business makes her happy and actively involves her in real life. Because she has lots of future plans for her business. First, making bigger to her shop than opening a second branch of her clothing store in İzmir (3th largest city of Turkey). She did not have any financial problem, she was very in love with her son and accept the

condition. It was a difficult interview, I could not keep the subject where I want to get data but as it mentioned in the ethical concern part, I did not force Miss Suzan to take the information I need. but she answered all of my questions politely.

- Asya:

40 years old housewife, Asya is not originally from this city(Kuşadası). She is from too far Trabzon in the East-Black Sea region. Thanks to her younger sister, she found a job in a hotel where she also work in manager position. Asya works as an assistant cook, however she works only 3 months in my city, actually many Turks from different regions come to my city to work in the tourism season(June-July-August). Miss Asya is one of them. Her husband works in a marketing company in Trabzon, her son with her husband and mother-in-law in their home city. Rafter than this 3 months tourism season, she does not work but instead taking care of her son.

### **Setting**

There were no special places for the interview. All the interview took place in a same coffee shop in the centre of Kuşadası, expect for Ms. Suzan asked me to come her own shop because she can not leave it.

### **Questions:**

Questions of interviews were aimed at determining depression, anxiety, stress and social isolation level of mothers who have children with autism. As my supervisor suggused me, I have never asked a direct question about autism and their possible stress.

- General Question;

This questions are just to get some general information about participant and to make them feel more relax and comfortable.

1-What is your name?

2-What is your age?

3-How many children do you have?

4- What is your Marital status?

5- Do you work? If yes what do you do?

- Depression, Anxiety and Stress Level;

1-How often did you feel tired out for no good reason?

2-How often did you feel hopeless?

3-Interest or pleasure in doing things?

4-Being mother is very difficult work, how do you feel?

6-how often did you feel nervous?

7-Do you experience irritability, sadness, or anger?

8- Do you experience Headaches or other?

- Social Life;

These questions are to determine their social life in general, whether or not they experience social isolation because of their children's disability.

1-how do you spend your time?

2-what are you doing in your free times?

3- how is your relationship with friends?

4-How did your family and friends react after your child diagnosis?

As It can be seen, there is no almost direct question about autism. As mentioned above it is because to not make participant uncomfortable. However, prepared questions were only useful to start talking in general. They did not help me to learn more about my participants, getting answers to my questions and to reach the answer to the main question of this paper. Moreover, I could not ask direct questions as my supervisors suggest me to not do and general ethical concern. But, I could get answers of my questions, actually whatever I want easier than I thought. Mothers were more enthusiastic than me and they did anything to help me.

## **Results**

In this chapter, It will be analyzed participants' responses to the interview questions. For the get results, in other words, to find answers to my main question "what are the psychosocial problems of mothers of children with autism in Turkey", I used thematic analysis methods to get what I want. As it explained in the data analysis section, I underlined some word that can be useful for me such as "future" for example, it can be a good criterion for the level of hope and even depression. Because if the mother says something positive about "future" it can be considered a better mood, if it is negative, it means there is a problem to investigate.

### **Depression and anxiety:**

Even though depression and anxiety mostly examine together and trigger each other, I did not take this impression on most of the participants. It seems that depression symptoms, which is the highest and most significant theme on all of the categories, did not trigger symptoms of anxiety. I could not find signs of anxiety except for one participant.

As mentioned above symptoms of depression where highest, 4 of 6 participants demonstrate strong signs of depression according to my own personal coding works. However However, It can not be easy said that the other 2 mothers did not have any signs of depression. One of them illustrated a mild level of depression, and the last one has a very small level of melancholia. As I reviewed to literature, It is not as severe as to diagnosed with depression. As a result;

4 mothers: depression

1 mother: mild level of depression

1 mother: no depression

**Mood & Energy:** When coding, energy and mood words were used too many times by mothers in negative form. 5 of the 6 participants have negative mood changes during the day without any reasons. I named it "negative mood changes" because as they told me and I realized from their answers, change of the mood never goes from good to bad but always follows the circle of normal to low mood.

None of the 6 participants do exercise, any sport or they have no hobby at all. They told me that they have no "energy", time and "motivation" because of work and "care of children". Normally, we should consider that "low mood and energy" have different reasons like deficiency of vitamins, etc... However, the mothers directly reported that "having children!" even though not mentioning the disorder.

**Future:** When it comes to ask, learn and interpret mothers' emotions, hopes and plans about the future for both themselves and their children and families, it was difficult and I had to use my empathy, observation and interpretation skills more than others. Because they never said something negative, but my general impression was negative too. Because they prefer to say "we will see", "I hope it will be good-okay", or some facial impressions that tell you "I don't know" "I don't care", "We live and see".

**Nervous:** When I coded the interview, I realized that some of the participants used the word "nervous" too many times when we talk about their experiences about life and their children. For example "I feel nervous", "I felt nervous" "It was very nervous" etc... However, as I mentioned it does not seem long term anxiety but short term event-oriented tensions. Apart from the word of "nervous" I could not find any word which is related to anxiety.

**Sleep:** 4 of 6 participants have difficulty with sleeping. Even though I did not target to learn their sleep quality to interpret their level of anxiety (because sleep problems mostly considered one of the signs of anxiety) they automatically mentioned

their sleep problems and difficulties. This sleep problem was not limited with such as "I can't sleep in nights" or "I have trouble falling asleep". They told me many different forms of sleep problems.

**Anger:** Unfortunately, all of the participants experience and used the word of anger in a different form when they mentioned their daily life, relationships with others and business life. In this case, it is something worse than anger, it is a passive form of experience a negative feeling. Because their anger is mostly passive-aggressive and not goal-oriented, but case-oriented and manipulated by others.

**Pain:** Almost all participant, 5 of 6 mentioned some kind of causeless pain mostly in their head and stomach. As it has known that that kind of pains is usually considered basic signs of stress. I did not have any question to investigate any of their stress oriented pain, however, when they mentioned I asked a bit details and they told me that like mobile pains, starts from (for example) head then shoulder and finally stomach to evening.

As can be seen in the literature review part, mothers of children with Autism in Turkey were demonstrating a high level of stress, depression, and hopelessness. So, the results in this part are overlapped with previous literature from Turkey.

### **Social Isolation**

Turkey(literature from Turkish resource). In these two parts, one thing was common and never changed according to different perspectives and researchers which are "social isolation" and other social problems of mothers of children with autism. For example, even though the majority of studies argued that mothers of children with autism experience a high level of stress, however, another research may claim that "yes they experience but very mild level". In the isolation problem, there were no such exceptional studies.

It would not be an exaggeration to say 100% of the literature argues that mothers of children with autism experience a high level of social isolation in the world as well as in Turkey. Now in this part, it will be investigated if our participants also

experience social isolation or other social problem. If yes we will search for the answer of the question of "what factors contribute of it and what pushes them to this situation".

**Support:** When it comes to support, especially social support from families, friends, and relatives, results were highly positive when it compares to other themes. They give the examples of social support such as "phone calls, visiting them at home and telling them if you need anything you can call us". That kind social support seems very effective and positive to mothers with children with autism. Because when they explain this kind of attitudes from their environment, their face impression was visibly happy and their mood increase positively.

**Time:** All of the participant report that "time" is a problem for them to socialization. However, with the worker moms, housewives also claimed that they have no time because "care of their children".

**Judgment:** It was also clear that all the mothers did not want to be in society because of judgment. But of course, these judgmental attitudes did not come from friends or relatives, participants were mostly complainant about public attitudes and people's reactions from outside. Even though people did not say anything but judicial looks make mothers less out-going people. 5 of 6 participant directly report that they withdraw from social environments because they have felt that they were being judged by others. Moreover, they told me that the "questions" of people make them irritate and they describe these questions as "saçma" in Turkish which means unnecessary, weird and unwarranted. I did not ask "what kind of questions as the rule that we follow from the beginning of this study to not ask questions to hurt mothers during the interview. However, these were some hurtful questions about their child's disability.

**Tired:** Firstly, I asked them "How often did you feel tired out for no good reason?" to indicate some kind of emotional problems as it can be seen above. Because "level of tired" question was in "depression part". However, all mothers without any exceptional mentioned that they experience a high level of tiredness in their daily life. Moreover, that tiredness is not a connection with some psychological stress, that was a straight physical tired. It is why I had to add it to the "social life" part, but not "depression" part. Being a mother is already a difficult job, however, being the mother

of a child with a disability is needed extra dedication. Spending too many time for your children is already tiring, plus for working mothers, it is, of course, more difficult. It is why most of the time they chose to stay at home and relax.

Again here there is a strong overlapped between the results and literature. Almost the whole literature agreed that Turkish society is helpful, supportive and in solidarity with mothers and parents of children with autism. The results of the current paper also demonstrated same phenomena. Almost all the mothers were not maybe %100 happy and fully grateful to their families, friends, and relatives, however, they were pretty "satisfactory" the supported that they have. And also some participants' parent was responsible for taking care of their child. So, even this can be showed that they have enough support.

Of course, most of our participants were "young-middle aged" mothers. They may need other "psychological support" justifiably. When they say "okay maybe not %100 but, thank god, fortunately, I have enough support from my friends, my families, and my husband. That "not %100" emphasis may be an abroad travel, a dinner in a good restaurant or going out for a night. Noone cant knows that exactly but guessing it not that difficult. Because mothers were not mentioning any "fun" fact of their lives. It was clearly visible that mothers need a social life like everybody on the world need.

## **Discussion**

Overall, findings of the current study suggested that unfortunately mothers of children with autism experience a considerable level of depression and it is very clear without any doubt. In the literature review part, I realized that the depression of mothers of children with autism rises three main bodies; the first one is "frustration". Frustration is a normal human reaction to an unwanted or unexpected negative event. It seems normal and temporary. In my study, I did not feel that it is a reason for the depression of mothers with autism.

The second reason is "difficulties of care of children with a disorder". It is also normal. motherhood is a difficult job, in any case, however, being the mother of an autistic child is more for sure. So beyond the psychological difficulties, it also

physically exhausting. Over and above physical difficulties can trigger mental health too. So as the literature review, it is clear also in the current study that the "burden of responsibility" is one of the main reasons for depression of mothers of autism.

The third one was future anxiety. Almost all the mothers in the current study were worried about her families' future, especially her child with autism. It was not only anxiety of "what my child going be", they even think worse cases such as "what will my child does if something bad happens to me". In numerous studies, the same phenomena were observable in the literature review part.

When it comes to the social life of mothers, results are not a pessimist. Firstly, we must define clearly what does "social or social life means". It means first "support" psychologically and physically. And second "having a good time" or just "fun" like every human need and deserve to have.

According to results, it is clearly visible that Turkish mothers have enough support from friends and relatives. As mentioned in the literature review part, solidarity is a social task or outcome of good faith. So it can be said the support part of socialization is pretty positive.

When it comes to "having a good time" unfortunately it does not seem as positive as the support part. It is clear that they have no enough time for even having just a coffee. Every mother may have difficulty to have free time for having fun however when mothers of children with autism go somewhere with their children, people's staring behavior makes them feel uncomfortable normally.

There are lots of recommendations lists for mothers to help better their children with autism however as seen in literature mothers are the ones who get negatively affected in this process. So, Instead of recommendations to mothers for their children, in this section, it will be presented some practical tips to mothers for themselves in order to maintain their mental-health, make them feel better and happier and improve the quality of life. Following recommendations will be in the light of literature and current research.

There should be a support group for mothers of children with autism. They can even create such a group via social media, and it would be good for them to be in keep in touch, support each other and help. It is also beneficial for them psychologically. Since it is clear that one of their problems is socialization and social isolation, it would be good for them to be in solidarity.

Couple therapy should be also a beneficial option for mothers to apply to a psychologist for it with her husband or partner if they live together since it was clearly visible that couples who have children with autism more likely to have problematic relationships. So it will be better for them to get some professional support.

Rather than a couple of therapy, the mother also should seek some professional help individually. Because since it was the mean topic of our paper, mothers who have children with autism more likely to experience depression, stress and social isolation. So it is why they are the one who needs professional support more.

However, professional help can not be effective if the mother does not try the best for themselves. Mothers should take care of themselves. Sport and exercises should be a great option for them for both mental and physical help. As I reported in the results part, none of the participants do any exercises or sports, I think it must be higher in western countries. Moreover, more should get help more than the caregiver if she is financially eligible to have more free time for relaxing and having fun.

### **Limitation**

Limitations of this should is a small sample size and simple profile. Since there are around 500.000 individuals with autism in Turkey, 6 is a very small percent of them. The second limitation is a simple profile. 5 of 6 the participants were originally from the Kuşadası, and only one of them was not but she used to live in the Kuşadası almost half of the year because of work. So all participants were from the same sociopolitical group and middle class. For future studies, it would be great if participants were socio-culturally different such as a more conservative mother Anatolian region of Turkey or a Kurdish mother from the eastern part of Turkey.

## **Conclusion**

In this research, my main purpose was to determine what it is the general social and psychological problems of mothers of Autism in Turkey and add to the literature some experience from Turkey. It would be useful for us, psychologists to know the problems of mothers of an autistic child if we professionals really want to and aim these individuals.



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