
Master of Science Thesis

**COMPARISON OF QUALITY OF LIFE OF PARENTS OF
TYPICALLY CHILDREN WITH AUTISM SPECTRUM
DISORDER**

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**COMPARISON OF QUALITY OF LIFE OF PARENTS OF TYPICALLY
CHILDREN WITH AUTISM SPECTRUM DISORDER**

BY

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ETHICS STATEMENT

The thesis entitled " Comparison of Quality of Life of Parents of Typically Children with Autism Spectrum Disorder" was prepared and presented as a thesis. It was written by myself and per the scientific, academic rules, and ethical conduct. The idea/hypothesis of my thesis solely belongs to my supervisor and me. The research about the thesis was conducted by myself; therefore, all of the used sentences and interpretations within the work belong to me.

I declare the issues mentioned earlier to be correct.

20 July 2022

Abbas AL OMAIRI

ABSTRACT

COMPARISON OF QUALITY OF LIFE OF PARENTS OF TYPICALLY CHILDREN WITH AUTISM SPECTRUM DISORDER

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Master of Science in Nursing

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Autism spectrum disorder (ASD) is a neurological and developmental disorder characterized by social interaction and communication problems. The primary purpose of this research is to examine the quality of life levels of parents of children with Autism and compare them with the quality of life of parents of children with typical development. A comparative study was carried out in Paediatric Teaching Hospital (Autism center) and schools in Baghdad, Iraq, from 8 February 2022 to 1 June 2022. According to the research findings, except for general health perception ($p < 0.05$), the quality of life of parents of children with ASD was found to be lower in all domains of the whole-brief scale than those of parents of children with typical development ($p < 0.05$). When the quality of life of mothers and fathers of children with ASD was compared, no statistically significant difference was found between them ($p > 0.05$). Similarly, there was no statistically significant difference between the quality of life of mothers and fathers with typical development children ($p > 0.05$). This study shows a difference between parents of children with ASD and typically developing children's quality of life of parents of children with ASD is lower. These results also show how important it is to help families so that they can live better lives.

2022, 74 pages

Keywords: Autism spectrum disorder, Children, Parents, Quality of life.

ÖZET

OTİZM SPEKTRUM BOZUKLUĞU OLAN VE TİPİK GELİŞEN ÇOCUKLARIN EBEVEYNLERİNİN YAŞAM KALİTELERİNİN KARŞILAŞTIRILMASI

Abbas AL OMAIRI

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Otizm spektrum bozukluğu (OSB), sosyal etkileşim ve iletişim problemleriyle karakterize nörolojik ve gelişimsel bir bozukluk olarak tanımlanmaktadır. Her bireyin etkilenim düzeyinin, semptomlarının büyük farklılıklar içermesi nedeniyle "spektrum" bozukluğu olarak bilinmekte, genellikle yaşamın ilk iki yılında ortaya çıkması nedeniyle "gelişimsel bozukluk" olarak tanımlanmaktadır. Bu araştırmanın temel amacı, otizmlili çocuğa sahip anne babaların yaşam kalitesi düzeylerini incelemek, tipik gelişim gösteren çocukların anne babaların yaşam kaliteleri ile karşılaştırmaktır. Araştırma 8 Şubat 2022 - 1 Haziran 2022 döneminde Irak, Bağdat'taki Pediatri Eğitim Hastanesine (Otizm merkezi) devam eden 5-11 yaş arasındaki otizmlili çocukların ebeveynleri ve aynı şehirdeki devlet okullarına devam eden 5-11 yaş arasındaki çocukların ebeveynlerinin katılımıyla yapılmıştır. Bu çalışmaya toplam 200 ebeveyn dahil edilmiştir. Ebeveynlerin sosyodemografik özelliklerine ait bilgiler ebeveynlere sorularak kaydedildi ve ebeveynlerin yaşam kaliteleri WHOQOL-BREF ile değerlendirildi. Verilerin normal dağılımının tespit edilmesiyle her iki grubun değerlendirme sonuçlarının karşılaştırılmasında student t testi kullanıldı. Araştırma bulgularına göre; genel sağlık algısı ($p<0,05$) dışında whoqol-bref ölçeğinin tüm alanlarında OSB'li çocukların ebeveynlerinin yaşam kaliteleri tipik gelişim gösteren çocukların ebeveynlerinin yaşam kalitelerinden daha düşük bulundu ($p<0,05$). OSB'li çocukların anne ve babalarının yaşam kalitelerini karşılaştırıldığında ise anne ve baba arasında istatistiksel olarak anlamlı bir farklılık görülmedi ($p>0,05$). Benzer şekilde tipik gelişim gösteren anneler

ve babaların yaşam kaliteleri arasında da istatistiksel olarak anlamlı bir fark yoktu ($p>0,05$).

OSB’li çocukların ebeveynlerinin sosyodemografik özellikleri ile yaşam kaliteleri arasındaki ilişki incelendiğinde; ebeveynlerin daha çok kentsel alanda yaşadıkları ve bu durumun sosyal ilişkileriyle ($p=0,013$), eğitim seviyesinin ve aylık gelirinin çevresi ile (sırasıyla $p=0,033$; $0,016$) pozitif korelasyon gösterdiği bulundu. Diğer taraftan daha çok çekirdek aile (%52) yapısına sahip oldukları ve aile tipinin fiziksel sağlıkla negatif korelasyon gösterdiği bulundu ($p=0.005$). Total yaşam kalitesi puanları ise ailenin aylık geliri ile ilişkili bulundu ($p=0,037$).

Tipik gelişim gösteren çocukların ebeveynlerinin sosyodemografik özellikleri ile yaşam kaliteleri arasındaki ilişki incelendiğinde; ebeveynlerin daha çok kentsel alanda yaşadıkları ve bu durumun psikolojik sağlıklarıyla negatif yönde ($p=0,033$) korelasyon gösterdiği, çevresel koşullarının ve total yaşam kalitesi puanlarının ise ailenin aylık geliri ile pozitif yönde ilişkili olduğu bulundu ($p=0,022$; $0,010$).

OSB’li olan ve olmayan çocukların ebeveynlerinin diğer sosyodemografik özellikleri ile yaşam kalitesi değerlendirmeleri arasında ilişki bulunmadı ($p>0,05$).

Bu çalışma, OSB’li ve tipik gelişim gösteren çocukların ebeveynlerinin yaşam kaliteleri arasında fark olduğunu ve OSB’li çocukların ebeveynlerinin yaşam kalitelerinin daha düşük olduğunu göstermektedir. Bu sonuçlar aynı zamanda ailelerin yaşam kalitelerinin geliştirilmesi için desteklenme ihtiyacını ortaya koymaktadır.

2022, 74 sayfa

Anahtar Kelimeler: Çocuklar, Ebeveynler, Otizm spektrum bozukluğu, Yaşam kalitesi.

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INDEX OF ABBREVIATIONS AND SYMBOLS

ASD	Autism Spectrum Disorder
QoL	Quality of Life
APA	American Psychiatric Association
HICs	Hospital Incident Command Systems
AS	Asperger's syndrome
CDC	Center Disease Control
WES	Whole Exome Sequencing
CDD	Childhood Disintegrative Disorder
DSM-F	Diagnostic and Statistical Manual of Mental Disorders
MMR	Measles, Mumps, and Rubella
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
FDA	Food and Drug Administration

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1 INTRODUCTION

The autism spectrum disorder, sometimes described as (ASD), is a generic term that can refer to various conditions affecting one's mental health. The word "autism" comes from the ancient Greek word "cars," which means "oneself." This is where the English word "autism" comes from. It represents a person's "secluded self" in various settings. On the verbal, nonverbal, and search engine levels, Autism is usually described as presenting obstacles to social collaboration and interaction. It is not uncommon to be accompanied by difficulty in the classroom and health issues like insomnia and stomachaches (Murray and Healy 2015).

Autism is described as a spectrum condition, which means that various people are affected differently by it, that the intensity of symptoms can vary quite a bit from person to person, and that symptoms change over time in terms of type and appearance. The essential characteristics of Autism could be one of two main groups: enduring difficulties in social communication and engagement and confined, repetitive behavioral patterns, interest, or activity patterns (American Psychiatric Association APA 2013). Individuals with Autism frequently face discrimination or stigma, including unequal treatment, health excommunication, participation opportunities, education and training, and community engagement (WHO 2013).

ASD is an umbrella label for a set of neurodevelopmental conditions, including but not limited to autism disorder, Asperger's syndrome, and Persistent developmental disorder (Lo-Castro *et al.* 2010). ASD is the concept that applies to approximately one in one out of every (68 children) that are of age to attend school and have been recognized with the disorder. Autism Spectrum Disorder affects boys around 4.5 times more commonly than it does girls (Learmonth *et al.*, 2019). Twenty-eight percent of teenagers with ASD participate in self-destructive behaviors like pounding their heads against the table or scratching their skin with their nails (Murray and Healy 2015).

Children with ASD frequently demonstrate impaired motor control, body awareness, and sensory integration and tend to participate in aggressive conduct against relatives or other children (Wagner *et al.*, 2019). ASD is a neurological disorder that can be identified more by the following symptoms: social reciprocity and communication skills that are severely damaged, as well as repetitive and minimal activities or desires (American Psychiatric Association, 2010). One in 88 people is thought to have ASD (Centers for Prevention of Disease Control 2018). The idiom "quality of life" (QoL) deals with subjective measures of the individual's physical, psychological, and social well-being (WHO 2011).

As outlined in this paradigm, QoL is defined as a desirable condition of human well-being that is global and culturally bound, has subjective and objective aspects, and is impacted by both environmental and personal (Schalock *et al.* 2011). The description of QoL varies according to the variables analyzed. As was said by (the Centers for Disease and Control Prevention CDC), QoL encompasses all aspects of one's life, from personal to contextual variables, and includes both "positive and negative aspects."

Autism is a neurodevelopmental condition that most commonly appears in children's early years (Dawson *et al.*, 2012). Disruption of social and communication skills, repeated behavior, and absurd aspirations are the hallmarks of this spectrum condition in children and adolescents (Canals *et al.*, 2018). As a result, Autism is prevalent in children, and all sectors of society, particularly educators, should be concerned. Children with Autism have poor mental, physical, and QoL due to the influence of Autism.

At all stages of functioning, kids have ASD struggle in social interactions. Both low-functioning persons who may not be able to sustain body language or connect to others as individuals and high-functioning people who are insecure or uncomfortable in peer social situations are affected by this (Hsiao *et al.* 2013). By educating parents about being their children's long-term therapists, a Chinese study is attempting to regulate Autism. By neglecting pragmatic difficulties related to socioeconomic differences and focusing solely on parental love for their children (Lin 2018).

People-centered planning uses the connotation of QoL as a conceptual and evaluation structure, a professional practice principle, and a public policy guide (Reinders and Schalock 2014, Mansell and Beadle-Brown 2012, Gomez *et al.* 2013). Disabilities that affect the development of the brain are referred to as ASD. All races, ethnicities, and socioeconomic classes are affected (Baio, 2012). In addition, researchers have implemented interventions and got some encouraging outcomes to improve the children's social abilities who have Autism (Gates *et al.* 2017).

Autism advocates frequently struggle to comprehend parents' difficulties with limited socioeconomic capital. This study argues that local disability advocates and researchers must give greater attention to what makes each place unique, like parenting cultural backgrounds in order to understand and tackle the urgent, existential, and long-term challenges encountered by parents managing Autism who do not have appropriate social capital, as well as the numerous links between disabilities and social and economic inequality (Hutchison *et al.* 2016).

1.1 The study's importance

ASD has still been considered a mystery ailment, despite the fact that its frequency has sadly witnessed a large increase over the past several decades (Zaky 2017). Globally, the occurrence of ASDs is reported to be one in 160 people, resulting in about 7.6 million years of life lost due to disability, or around 0.3% of the world's total disease burden. Because of the extensive range of research studies reporting on this topic, it is impossible to pinpoint an exact prevalence rate (Posar and Visconti 2018). According to well-controlled research, however, rates are much greater than previously thought. In many low and middle-income nations, the prevalence of autism spectrum disorders ASDs is unknown (WHO 2013).

One in 160 children in Europe has ASD, as claimed by "World Health Organization" (WHO) research; the world's average number of cases of Autism (is 61.9/10000), and half a million individuals in Australia are impacted by Autism (Bentez-Burraco *et al.*, 2016). ASD affects roughly 14.7 children out of every 1,000 US, or one for 68 children.

These numbers fluctuate greatly depending on the region of the country, gender, and race/ethnicity of the affected children (Khalifeh *et al.* 2016). Prevalence of Autism and Asperger's Syndrome in the United Kingdom ranged from 3.89 per 1,000 children to 11.61 per 1,000 children before the age of nine or ten; however, the prevalence of Asperger's Syndrome ASD was 40 percent higher in Cambridge in 2009. A more realistic number ranges from 11.3, with the most conservative estimates at 11.3, to 15.7, per 1,000 people (Al Abbady *et al.* 2017). The frequency of Autism is (26.6 out of 1000) children (Zhou *et al.*, 2019).

Exactly how many people in Africa are impacted by Autism is unknown. However, the Arab area has resulted in research on the frequency of Autism in Egypt. Approximately 23.8 percent of children in primary health care centers in Egypt were reported as having ASD and required extra clinical evaluation in 2016, according to an Egyptian community-based survey, with a three to one ratio of male to female (Chaya *et al.* 2016). Even though ASD's widespread prevalence in the Arab world is equivalent to that in Western countries, field research is still in its infancy. It did not exist until the late 1990s when the Arab world started paying attention to the issue (Alshaban *et al.*, 2017).

Centre for Disease and Control Prevention estimates that at least 150 children per 10,000 (one in every 42 boys and one in every 189 girls) have ASD because of the increasing prevalence of ASD around the world. Research activities to fully understand the increase in incidence, possible causes, and optimal approaches have increased (Vaan *et al.*, 2015). The burden of ASD is real, with a frequency of 153 of 10,000 infants aged 16-48 months in preschool childcare centers or nurseries (Shurafa 2017). More than 5,000 Iraqi children have been diagnosed with Autism as a result of the war, according to Guilford University's 2012 study, which found that at least 6,000 Iraqi children had been diagnosed with ASDs as a result of the conflict (Alnuaamy 2016).

In 2011, Cambridge University published a study revealing that 75 of every 10,000 Iraqi children were autistic (Alshemary 2019). They have reduced problematic behaviors of

children with ASD after completing a mindfulness-based constructive behavior support program for their caregivers (Singh *et al.* 2014).

Children who have Autism can benefit tremendously from early diagnosis and intervention, which can dramatically enhance their results. Beyond infancy, there are medical and nonmedical treatments and treatment options for people with Autism. Treatment options include behavioral therapy, pharmacological medicine, nutritional interventions, and complementary and alternative medicine (Kurzius-Spencer *et al.*, 2018). Additionally, mindfulness practice provides parents with an opportunity for self-nutrition, which energizes their parenting, which is frequently exhausted by the demands of parenting (Bögels and Restifo 2013).

1.2 Statement of the Problem

Complicated disorders, like Autism, are distinguished by challenges in communications and social interaction, as well as repetitive and stereotypical behaviors. Parents of autistic children are severely touched by many of the characteristics of ASD, such as limits in social skills, behavioral problems, and sleep problems. This study aims to determine how ASD affects parents' QoL and what circumstances cause a deterioration.

1.3 Hypotheses

1. H0: There is no difference between the sociodemographic characteristics of parents of children with ASD and parents of typical children.
2. H0: There is no difference in the QoL of parents of children with ASD and parents of typical children.
3. H0: There is no difference between the QoL of mothers and fathers.

1.4 Study Objectives

1. Determine the QoL levels experienced by the parents of children with ASD.
2. Compare the QoL for autistic children and parents of typical children.
3. Compare fathers and mothers in terms of QoL.

1.5 Limitations

It is impossible to draw generalizations about the entire population based on the results of this study because the data were gleaned from a sample selected from a particular city.

2 GENERAL INFORMATION

This chapter provides a summary of the relevant literature and research related to autism spectrum disorder, which includes the following:

2.1 A Look Back at the History of Autism (ASD)

Autism, instead of more generally known as Autistic Spectrum Disorder, is composed of impairments that affect development that falls under the category of developmental disorders. In 1911, Eugen Bleuler (1857–1939), a physician who studied people with schizophrenia who exhibited several symptoms now associated with Autism, coined the Autism term. To define people as having schizophrenia's aggressive regression into their dream world in response to overwhelming external perceptions or abilities (Jackson *et al.* 2018). Autism is a broad expression that refers to a "triad of impairments," a term coined by psychiatrist Dr. Lorna Wing of the United Kingdom (U.K.) to describe and categorize the behaviors of those with Autism as a "spectrum" or "continuum" (Liu 2009).

The physician, Leo Kanner at Johns Hopkins University, coined Autism in 1943 to talk about how a few of the children he watched behaved. Caner's description of Autism continues to use the term autism spectrum disorder to this day (Henninger and Taylor 2012). A report on a group of autistic children by the British National Assembly says that boys have Autism four times as often as girls, but the difference is four times bigger. However, as a result of diagnostic syndrome requirements, women exhibit more extreme behaviors that rely on behavioral characteristics as they appear in males. In contrast, females may respond to their peers and outperform males in verbal skills (Howlin *et al.*, 2013).

There are biological causes for Autism and its manifestations and severity, where differences in the capacities of both sexes play a significant role in environmental and social influences. Girls inherit chromosome X from their parents. Only the mother takes

the boys. According to the hypothesis, the child inherits an immune gene that protects against Autism from the father, making the child less likely to develop Autism (Lai *et al.*, 2015).

2.2 Prevalence of Autism Spectrum Disorder

In 1911, the German psychiatrist Eugen developed the concept of Autism as one of the signs of the worst forms of schizophrenia. As described by Bleuler, autistic thinking might be summarized as a child's attempt to escape reality's misery through the use of fantasies and hallucinations. As early as the 1920s and as recently as the 1950s, the term autism was used by psychologists, psychoanalytical practitioners, and psychiatrists in Britain to describe individuals with autism spectrum disorders (Posar and Visconti 2017).

By raising awareness, field experts refer to this increase in prevalence as identifying and detecting diseases and improving their detection and detection capabilities. In Northern and Sub-Saharan Africa, few research studies examine the prevalence of Autism in children with intellectual disabilities. However, there is no research on ASD in children without intellectual disabilities. However, a significant increase in ASD was observed among children of Ugandan mothers and Somali women living in Sweden (Rey 2015).

In the 1950s, Autism was used to refer to infants with extreme hallucinations and imagination; in the 1960s, 'autism' was used to refer to a complete loss of symbolic unconscious existence. Until the 1960s, many scholars believed that Autism and schizophrenia were synonymous. Only then did medical professionals develop a distinct definition of developmental Autism (Wolfson 2017). Behavioral and language therapy is now considered the cornerstones of autism treatment. Additional treatments are added as necessary (Hoogsteen and Woodgate 2013).

The Autism Spectrum Disorder ASD has been recorded in 86.5% of all cases to hospital incident command systems (HICs). Given that hospitals house only 20% of the world's

population, this percentage represents a significant increase over the preceding decades. It is true that more than tenfold significantly raise in how many people have ASD in the U.S. alone since 1988 when it was estimated that about one out of every 2,008 eight-year-olds was affected (Lavelle *et al.* 2014). Early-onset with an 80% developmental delay begins in childhood. In contrast, the remaining 20% of autistic children usually develop up to two or three years when developmental deterioration or loss of ability begins (Rey 2015).

2.3 Overview of ASD

People with Autism are often diagnosed during their first three years of life, and their symptoms include an absence of social engagement and a tendency to engage in repetitive/restrictive behaviors. Although cognitive or early behavioral intervention can assist children in developing self-care, there is no known communication or social skills treatment. Only a small percentage of autistic children live independently as adults, but some do (American Psychiatric Association DSM-5 2013).

Regrettably, it was a perplexing diagnosis. Practitioners often misdiagnose the same patient since they cannot easily distinguish them. In order to provide a more precise diagnosis, medical professionals (along with teachers and therapists) often employ terminology like "extreme autism," "mild autism," and "high-functioning autism." Genuine diagnosis. While they were supposed to assist parents and teachers in determining a child's status on the autism spectrum, each professional had their definition of what constituted "mild" or "extreme" (Meguid *et al.*, 2021).

2.4 Causes and Risk Factors of ASD

According to reports, a neurological abnormality is the cause of Autism, the cause of which is unknown. Anomalies in the amygdala area in the brain, which is responsible for a child's social and emotional behavior, have been discovered. Numerous individuals with Autism have also reported having elevated serotonin levels (BROWN 2008).

However, science has yet to discover the valid reasons for infant ASD. Significant risk factors and various environmental and genetic factors include prenatal drug exposure and birth complications (Shelton *et al.*, 2014). Low birth weight, premature labor, birth asphyxia, and postnatal risk factors such as mercury exposure and autoimmune disease are all perinatal risk factors (Kaczynski and Henderson 2008).

2.4.1 Genetic Causes

What several researchers previously believed, that Autism is primarily a genetic disorder, was reaffirmed after a close examination of the evidence from previous studies. Autism is a hereditary condition described as social interaction, language acquisition deficits, and other cognitive difficulties (Fakhoury 2015). Whole-exome sequencing (WES), cytogenetics, and genetic interaction studies have revealed the disorder's genetic architecture to be complicated (Murdoch and State 2013).

According to research on twins and families, autism spectrum disorder ASD has a heritability of more than 80%. The WES, chromosomal microarray, and selective candidate gene analysis are the most commonly utilized techniques for ASD to find susceptibility genes. For example, WES has uncovered unique or rare genetic abnormalities in many populations, including ASD (Fakhoury 2015). On the other hand, Chromosomal microarray analysis is a cytogenetic procedure used to identify anomalies in the chromosomes in people with ASD (Zilina *et al.*, 2014). Various researches have shown that ASD is more likely to be caused by mutations in serotonergic and neuroligin genes, both of which affect depression and synaptogenesis (Sanders *et al.* 2012).

2.4.2 Environmental Factors

Although credible studies have not established evidence for additional environmental causes, they are mentioned. These environmental factors, which involve particular foods, heavy metals, contagious diseases, pesticides, alcohol, smoking, illicit drugs,

vaccines, and prenatal stress used in plastic products, are considered to be causes of Autism or may be significant in future research (Heuer *et al.* 2011).

The brain's growth and neurophysiology, like cell differentiation, synaptogenesis, and axon myelination, can be affected by environmental contaminants (Lyall *et al.*, 2012). Additionally, as demonstrated in children with ASD, prenatal exposure to cigarette smoke and recreational drugs may result in structural brain abnormalities (Tran *et al.*, 2013). Elements of a family's existence, including their finances, relationships, children's education, and mental health, may affect autistic children and their parents (Karimi *et al.*, 2017).

The presence and prevalence of ASD worldwide demonstrate not only prognosis but also uncertainty about the precise nature and etiology of the condition. Some scientists say ASD is a neurological and developmental disorder; others attribute it to genetic and environmental factors. Although scientists do not understand Autism, they have suggested genetic and environmental causes, implying that it plays a more significant role. Scientists studying genetic factors have identified genes as autism causes. The environmental component of Autism is concerned with something that can affect one's well-being outside the body (Sealey *et al.*, 2016).

2.4.3 Viruses and Vaccinations

The authors analyzed intestinal biopsy samples from children with and without Autism for the presence of the measles virus. 75 of the 91 children with Autism who had intestinal biopsy tissue tested positive for measles virus, compared to just five of the 70 children who did not have Autism. This was a worrying thing to find on the floor. Nevertheless, the second Wakefield paper had the same significant problems (Wakefield 2016).

Late-onset ASD is connected to measles, mumps, and rubella immunizations (MMR). It has been shown that there is no link between autism spectrum disorders like Aspergers

or Aspergers with immunizations and that the MMR vaccine is safe and effective for children of all ages. There was no proof of a link between vaccination and Autism in a meta-analysis of data from over one million people. Some parents and public personalities refuse to embrace these conclusions. Thus, litigation and class action suits persist (Videbeck 2010).

2.4.4 Pregnancy and childbirth problems

Before and during birth, both the mother and the father must consume specific vitamins and minerals. These components contribute to the strength of the fertilization method and the protection of pregnancy. Tobacco use, alcohol consumption, and substance abuse all have a significant impact on the pregnant mother's birth of a child with ASD, as do an unhealthy diet and the use of herbs without understanding the actual impact, which might lead to the pregnancy of an autistic child (Sullivan *et al.* 2015).

Before nine months of pregnancy and early cesarean section, the child is not able to receive breast milk, which is essential for the child's development of immunity, the mother's mental state during pregnancy and extreme fear of pregnancy, and frequent examination in the doctor's clinic for follow-up and fetus awareness. The frequency with which sonar is consumed contributes to the birth of an autistic child (Raphael-Leff 2010). Significant risk factors include low birth weight, jaundice, and postnatal infection. The fetal growth rate, the length of the pregnancy, and the genetic growth potential all combine to determine the weight at delivery of a newborn (Karimi *et al.*, 2017).

2.5 The Pathophysiology of ASD

In terms of pathophysiology, there are not any clear responses. However, new data has been discovered due to many previous studies. It is apparent that Autism is a result of a genetic predisposition; this is supported by the twin study, which found that the odds of the other twin acquiring Autism were 88% or higher if the first twin had it, but only

about a 30% chance of developing Autism in fraternal twins (Fain and Houde 2004). The severity of behavioral issues associated with autism spectrum disorder is also associated with gastrointestinal (G.I.) abnormalities, which suggests a gut-brain connection in which G.I. abnormalities contribute to the development or severity of ASD (Samsam *et al.* 2014).

2.6 Autism classification

2.6.1 Autistic Disorder

Individuals with Autism have difficulty interacting with others, communicating, and exhibiting unusual behaviors and interests. They have cognitive delays and language disorders, commonly referred to as "classic" Autism, in which certain behaviors are repeated indefinitely. Additionally, they have an obsessive interest in particular objects or pieces of information (Lord et al., 2018).

2.6.2 Asperger's Disorder

Asperger's syndrome (AS) has been diagnosed as a developmental problem that causes people to have a hard time communicating and interacting with others. People with AS also have limited interests and behave in the same way over and over again. Although the cause of Asperger's syndrome is unknown, an inherited (genetic) component is suspected.

In rare instances, infections during pregnancy, exposure to teratogenic agents, or toxic exposure may occur. Symptoms include decreased social activity, fewer friends, disinterest in making new friends, inability to express feelings, lack of eye contact, fewer facial expressions, inability to use gestures, poor communication, relationship loss, external stimulus sensitivity, and reliable and repeated behavior such as an arm wave (Saraswati 2018).

2.6.3 Disintegrative Disorder

CDD stands for childhood disintegrative disorder, a clinical syndrome with autistic-like characteristics that typically affects children aged 2 to 10 who formerly obtained age-appropriate vocabulary and social. Adaptive abilities deteriorate dramatically, even though physical and neurological examinations reveal no apparent delay in the development of basic activities like language and social competence, communication, non-recognized face recognition, and odd object play (Bidaki *et al.* 2016).

2.6.4 Rett Disorder

Rett syndrome is a type of disorder of Autism. It is described by the lack of verbal abilities, frequent hand movements, empty eye contact, a lack of emotional exchange, sensory side impairment, walking on one's fingertips, an enlarging head, and digestive system disorders such as constipation. These characteristics are unique to females (Cass *et al.*, 2003).

2.6.5 Not Otherwise Specified Pervasive Developmental Disorder

Some people call this "atypical autism," while others call it (PDD-NOS). Autistic disorder or Asperger syndrome can be diagnosed in people who have some but not all of the symptoms of atypical Autism. Individuals not meeting the criteria to be diagnosed with Autism often display fewer and milder symptoms. Social and communication issues can only result from modest symptoms (Wolfson 2017).

Repetitive behavior and a focus on a few hobbies are symptoms of social and communicative loss in autistic children (APA 1994). Unfortunately, because there are no clear diagnostic criteria for PDD-NOS, it is frequently used as a blanket diagnosis for children who do not meet the norms of one of the other common developmental issues (Köse *et al.*, 2017).

2.7 Signs and Symptoms

While early signs and symptoms of ASD (Christensen et al., 2019) indicate that by the age of one year, the child stops responding to his or her name, shows little interest in pointing to things, avoids pretend games, constantly repeats the exact words in order to avoid making eye contact or conversing with others. Repeated phrases or phrases, disturbed by minor disruptions in routine, unusual responses to sounds, smells, or other sensory inputs.

The American Academy of Pediatrics advises developmental screening for all children up to the age of 24 months in order to detect autism signs as soon as they are 18 months old. A child's difficulties in making friends may be a concern for parents and teachers notice challenges with peer interactions, which may lead to a delay in detecting Autism in those with modest or limited speech deficits (Reinhardt *et al.* 2015).

It is possible to categorize the symptoms of ASD into two broad groups: primary and secondary symptoms (American Psychiatric Association 2013). The key indicators are a lessened ability to use language and engage in social interaction in addition to the recurrence of stereotypical behaviors (Weitlauf *et al.* 2013).

Most people with ASD can also develop secondary symptoms such as a lack of imitation or creative play, indifference to others' feelings, hypersensitivity to light and sound, frequent temper tantrums, a lack of motivation to meet new people and form friendships, a lack of initiative in conversation, social withdrawal or awkwardness, severe tantrums display an attachment to strange items such as car parts. Severe tantrums display a (Soto 2016).

Autism spectrum disorder is characterized by repetitive motor mannerisms, object use, and expressiveness. Distress at slight changes, rigid thought and behavior patterns, repetitive daily activities, great attention to specific interests and sensory sensitivities,

like hyperactivity or hypo-reactivity to pain and sensory input, sensitivity to loudness, and visual fixation by things or motion (Hagos 2017).

2.8 Diagnosis of ASD

Due to the absence of a medical test for ASD, diagnosing the disorder can be complicated. The child's behavior and developmental stage are used to make the diagnosis. Autism spectrum disorders ASD could be identified in children by the 18 months old in a few cases. Generally, a diagnosis provided by an experienced specialist at age two is exceptionally reliable. There are two steps in making an ASD diagnosis: diagnostic assessment and developmental screening (CDC 2014).

To diagnose psychiatric disorders, due to the complete absence of underlying processes and the inadequacy of the autism definition, the diagnosis is based primarily on behavioral symptoms as defined by the diagnostic criteria of published classifications (Hofmann *et al.* 2014). Autism spectrum disorder diagnosis is challenging in Arab countries because fewer clinicians are trained to do so. This increases the misdiagnosis or neglect of children with ASD in the early stages, making it more challenging to make a correct diagnosis (Eid *et al.*, 2017).

Several indicators to look for when conducting a spectrum disorder screen. According to the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-F) and an expert study, Autism is described by poor communication, limited social interaction, and behaviourally stereotyped patterns. Those broad definitions could be subdivided into particular symptoms of ASD in children (Adams *et al.*, 2016).

2.9 Management of ASD

2.9.1 Nonpharmacological Interventions

Behavioral Therapy: The most prevalent treatment for autistic children is behavioral therapy. Applied behavioral approaches have been shown to improve learning, communication, adaptive behavior, and appropriate social behavior in children with Autism for more than 30 years. Applied behavioral analysis (ABA) is used to improve behavioral and instructional skills to deal with particular situations. It is based on the reinforcement principle, rewarding desired behavior and eradicating undesirable reinforcement behavior (Spreckly and Boyd 2009).

Physical Therapy: Is prescribed to children with ASDs to improve their physical abilities by addressing dysfunction that impairs growth. Included are negative, resistance, active, and aerobic exercises. Exercises are frequently used with equipment such as balls, weights, balance boards, and exercise to increase muscle strength and endurance and improve body awareness and coordination. With water exercises, calendars, and swirls, the processor works one-on-one with the user. It lasted 45 minutes while the child was present. Physical therapy can occur at school and at home (Exkorn 2005).

Art Therapy: Art therapy can assist children with relationship development, sensory integration difficulties, communication skills, and self-development by eliciting an understanding of the child's emotional state, identifying conflicts, and resolving problems, all of which can be used to assist children with ASDs in expressing their feelings and thoughts (Exkorn,2005).

Play Therapy: Positive mutual relationships are complicated for children with ASDs to establish. Play therapy teaches these children the necessary skills for interactive play. The therapist incorporates games and activities into the session, such as allowing children to express their emotions through play. This convenient method of play also

helps children understand and express their emotions and cope with them (Roughan et al.,2019).

Music Therapy: Improved social connection, verbal communication, initiating acts, and socio-emotional reciprocity have all been found to benefit children and their families through music therapy (Geretsegger *et al.*, 2014). Music helps us feel better when we are in a bad psychological state, but it is not just for entertainment; psychologists and physical therapists utilize it to treat patients with cognitive disarray, psychological stress, and general physical and emotional fatigue (Ansdell and DeNora 2016).

Cognitive-Behavioral Therapy: Since the mid-nineteenth century, behavioral therapies have been widely used in the general population and are widely regarded as evidence-based (Hofmann *et al.* 2014). It has been found that teaching autistic children about their social and communication skills enhances their ability to engage with others while diminishing their autistic tendencies. These services include image-dependent communication, verbal communication, social storytelling, intentional action, visual action, and motor movements, among the most important. These methods and techniques aim to get autistic children into therapy (Thabtah 2018).

Occupational Therapy: Occupational therapy encompasses education, play, social interaction, and self-care. Children who exhibit the sensory integration difficulties associated with Autism. For children with Autism, occupational therapy is utilized to treat their self-stimulating habits, such as swaying back and forth or participating in other repetitive actions. Sensory integration deficiencies and difficulty in adapting to change and everyday routines are also addressed (Paul and Nodbury 2012).

Sensory Integration Therapy: Occupational therapists usually run programs like sensory integration therapy. For instance, an occupational therapist might make a program of sensory experiences for a child with Autism and help the child follow it. Sensory integration therapy helps kids learn to use all of their senses simultaneously, including touch, smell, taste, sight, and hearing. People say that this therapy can help with

complex or repetitive behavior. These behaviors can be caused by trouble processing sensory information (Lang *et al.*, 2012).

Early Intervention with Parental Involvement: Education for parents and counseling for needy families are both essential. However, they are not a replacement for each child's therapeutic intervention, which is more likely to succeed when integrated into a multidisciplinary intervention program (Dalwai *et al.* 2017).

Intervention in Social-Communication: Repetition and expansion of what the child says, sitting near, making eye contact, and mimicking the child's motions are some of the most common ways to help a youngster with communication difficulties. Parent-training systems like therapist-led coaching and video feedback can increase parental attention and responsiveness to child communication (Howes *et al.*, 2018).

2.9.2 Pharmacological Interventions

Aripiprazole and Risperidone are the only two drugs deemed fit for public consumption by the Food and Drug Administration (FDA) to alleviate troublesome irritability in children with Autism, which includes violence, self-injury, and severe tantrums (Klein and Kemper 2016). Risperidone, when administered in a fewer dosage (up to 2 mg/day in children between 20-45 kg and up to 3.5 mg/day in those weighing above 45 kg), has the potential to be helpful in some aspects of autism spectrum disorder (McCracken *et al.* 2002). Short-term use of Risperidone helped significantly, although there was an increased risk of weight gain, irritation, social disengagement/lethargy, hyperactivity, stereotyping, and incorrect expression (Jesner *et al.* 2007). Compared to a placebo, up to 15 mg per day of aripiprazole may be beneficial in treating irritability and hyperactivity, and stereotypy and excessive speaking in children. On the other hand, adverse symptoms such as weight gain, dizziness, slurred speech, and tremor may be more common (Hirsch and Pringsheim 2016).

2.10 The Role of Nursing in Autism Spectrum Disorder

Autism is a disorder that occurs in early childhood and has no definitive cure. However, its detection at an early stage increases the chances of treatment success. Autism is first noticed mainly by family members, nurses, physicians, or other health professionals who monitor the child's development (Sayan and Durat 2007). Pediatric nurses can help with an early diagnosis with a physical examination that they will do in child care and growth-development monitoring. For early detection, the nurse needs to know the normal growth development process of the 0-6 age group and be able to recognize the differences from the typical. The nurse should take the initiative when she realizes something is wrong with the child's development. Accordingly, it would be appropriate for the nurse to diagnose nursing within the scope of the process, initiate relevant initiatives and guidance, and guide the family. The nurse should emphasize the importance of ensuring maternal-infant interaction from the newborn period onward for early diagnosis and that children should be taken to health checks regularly until the age of one. After the child is diagnosed with autism, the nurse should get information from the family about the child's routines, what he likes and doesn't like, and evaluate the child's abilities, nutrition, bathroom, and toilet skills related to self-care. Assessments should also include the child's communication skills, interactive adaptation, and response to other people (Sayan and Durat 2007).

The nurse should also have the family in the treatment, inform the family about the treatment to be applied, and question the family's support systems. In this direction, families of children with autism spectrum disorder need help from each other and therapists to cope with the problems they are experiencing. The nurse can also evaluate them within the group by families to come together. The cost of treatment concerning parents due to their lack of social support and economic issues, burnout, difficulties with their typically children, and children diagnosed with autism on topics such as the right to agree on educational matters must be directed to areas. In early diagnosis, public health nurses within the framework of primary health care should direct their work by considering the prevalence and incidence of autism. In addition, developmental disorders can be

detected early in line with risk diagnosis studies for autism and influencing factors (Ocakçı and Karakoç 2013).

The nurse working in the unit related to children diagnosed with autism should know to apply the principles and techniques of behavioral, auditory, and educational therapy used in care. For example, children diagnosed with autism do not like to be touched and hugged, but they are very interested in music and rhythmic swinging behavior. The nurse can make the mother and child get closer by making the mother touch the naked area of the child's body accompanied by music and shaking behavior, stroking it. It seems that when the children are provided with the necessary educational support, they are primarily freed from this problem and can continue the rest of their lives by fusing with their peers and society. The delay in language development is the first symptom that usually attracts the attention of families of children diagnosed with autism. The disorder, which was limited to language and speech in the early periods, has been expanded and treated as a disorder in the communication process today (Potts and Mandleco 2012). Children diagnosed with autism have severe deficiencies in using language for social communication purposes. Methods such as line teaching, replication are used to teach children diagnosed with autism the skills of interacting, starting, and maintaining a mutual conversation. Line teaching aims to teach children with Autism spectrum disorders more than to make them talk or answer questions by giving clues. The goal is for children to learn to speak (chat) mutually (Vuran 2007). For children without language development, the family should be told that it will be helpful to patiently repeat one or two songs every day, which should guide families.

3 MATERIALS AND METHOD

3.1 Design of the study

A comparative study was carried out in Paediatric Teaching Hospital (Autism center) and schools in Baghdad, Iraq, from 8 February 2022 to 1 June 2022.

3.2 Study Setting

This study was conducted in Paediatric Teaching Hospital (Autism center) and five elementary schools located in the same neighbourhood (AL-Either elementary mixed school, Al-Iraq Al Muntasir elementary school for boys, Al-Yusr elementary mixed school, Al-Kuwait elementary mixed school, and Makkah Al-Mukarramah elementary mixed school), in Iraq. Schools located in the same city and campus close to the hospital area, where children between the ages of 5-11 can attend, were selected.

The hospital provides diagnostic, curative, medical, surgical and dental services for all children up to the age of sixteen. The hospital contains various subspecialties in the areas of (bone-marrow transplantation, haemophilia, oncology, endocrine center in addition to the autism center). The autism center was founded in 2018 as a psychological consultant center which has an unlimited number of autistic children with their parents. There are nurses who work in the Autism centre, and there are paediatricians and psychiatrists. Approximately 20 children stay in the hospital and 400 children apply to the hospital for diagnosis, treatment and controls per month. Among these children, 100 parents who agreed to participate in the study and met the criteria were reached.

3.3 The Study Sample

The sample consisted of parents who agreed to participate in the study. Parents were interviewed face-to-face by the researcher and informed about the study; their written consent was obtained.

The research sample consisted of a total of 200 parents. As a consequence of the G power program's analysis, it was determined that it is necessary to compare 0.94 power with 200 data points (two groups of 100 data for parents of typical children and 100 data for parents of autistic children) at a significance level of 0.05. Therefore, it was decided to use a sample of 200 participants who agreed to participate in the research.

3.3.1 The Sample's Inclusion Criteria

The research sample was chosen depending on the inclusion criteria: parents of children with ASD aged 5-11 years who have been admitted to the autism center, and parents of typically developing children. Children between the ages of 5 and 11 were included in the study. We aimed to interview the parents of children in the youngest age group of 5, at the age when the diagnosis is finalized and education programs are started, and the oldest 11-year-old children who have not yet experienced the problems brought about by puberty and adolescence.

3.3.2 Criteria for the Study's Exclusions

Parents of children with a diagnosis other than autism spectrum disorder, parents with mental problems, and parents who refuse to participate were excluded from the study sample.

3.4 Study Tools and Collecting Data

Sociodemographic characteristics of the parents were evaluated with the form created by the researchers, and their quality of life was evaluated with Whoqol-Bref. Signed consent was obtained from all parents. The consent form is shown in Appendix 1.

3.4.1 Parents and children's information form

The sociodemographic information of the family was recorded by asking the parents.

3.4.2 Whoqol-Bref

Whoqol-Bref was used as the scale that measured the QoL developed by the World Health Organization in 1996 (WHO 1996) and adapted to the Arab community by conducting a validity and reliability study by Ohaeri and Awadalla in 2009 (Ohaeri and Awadalla 2009). An Arabic-language study found that the scale's Cronbach's alpha coefficient was 0.93 for the WHOQOL-BREF scale, the physical health domain was 0.80, the psychological health domain was 0.77, the realm of the social relation was 0.69, and the environmental part was 0.83. The scale accounts for 58.3 percent of all variance (Ohaeri and Awadalla 2009). Our study found that the scale's Cronbach's alpha coefficient was 0.79 for the WHOQOL-BREF scale, the physical health domain was 0.72, and the psychological health domain was 0.76, respectively, the social relationships domain was 0.73, and the environmental field was 0.74.

The WHOQOL-100, which consists of 100 questions, and the WHOQOL-BREF, which consists of 26 questions chosen from among the 100, were developed due to pilot studies carried out in 15 centers worldwide. It occurred by taking one question for each of the 24 sections of the WHOQOL-100 and adding two questions on general health and QoL (The WHOQOL Group 1994; The WHOQOL Group 1995). The answer choices range from 1 (not satisfied at all/very bad) to 5 (very satisfied/very good). The scale is comprised of the following four sub-dimensions: physical health domain (7 items),

psychological domain (6 items), social relationships domain (3 items), and environment domain (8 items). In addition, the perception of general health is questioned with two questions that do not count in the total WHOQOL-Bref scale. Each section and area scores a maximum of 20 points or 100 points. When the final score of the WHOQOL-BREF scale subgroups comes in high, this means that the QoL levels are high and vice versa. This scale was developed to be appropriate for use for ages 18–65 years (WHO 1996). The assessment form is shown in Appendix 2.

3.5 Statistical Analysis

When evaluating the data, IBM SPSS Statistics 21.0 Ver. (SPSS Inc, Chicago, IL, USA) package program was used. The descriptive values are number, percentage, arithmetic mean, and standard deviation. According to the typical distribution characteristics of the data related to the One-Sample Kolmogorov-Smirnov test for both groups, the values of the two groups were compared using the student t-test. Relationships between variables were evaluated with Pearson correlation analysis. The significance level is taken as ($p < 0.05$).

3.6 Approval by the Ethical Committee

In order to make the process of collecting information from participants easier, ethical approval has been taken from the Scientific Research Evaluation Ethical Committee at Çankırı Karatekin University (No. 24, Date: 07/02/2022). An administrative directive sent to Medical City/Baghdad (Paediatric Teaching Hospital) from the Iraqi Ministry of Health allowed the study. The study's aims and methods were explained to the participants, and after giving their written and verbal consent, the researcher began collecting data.

Ethical Approval Forms are shown in Appendix 3 and 4.

4 RESULTS

Sociodemographic information on parents and their children is shown in table 4.1. In table 4.1, the period of the child diagnosed with ASD for the study sample is between 1-3 years (64.0%); regarding the number of children in the family, the results indicate that (≥ 4) are (66%). At the same time, the Parents of typical children show that having two children represents (74%). The residence shows that (99%) lived in urban areas, and the group parents of typical children lived about (81%) in urban areas too. Additionally, the results indicate that the majority (55%) of the study sample are female in two study groups, regarding parent's education, university stage represents in two samples (33% and 37%) respectively. Relative to the parents' occupational, the results show that (26%) are male and employed and (41%) are female and unemployed. However, The parents of typical children indicated that (29%) are male and employed, while (29%) are female and unemployed. In addition, about half of the study (52%) have a small family in the type of family demonstration. However, in the group of parents of typical children, the result shows that (54%) are extended family. Concerning the family monthly income, the study displayed (85.0% and 55.0%) between 300-900 thousand IQD, respectively. Finally, the Housing Ownership, the finding of the study show that (58%) have owned a house, and (62%) have Owned a house for the parents of typical children group too.

Table 4.1 The distribution of the samples by their sociodemographic factors for parents of children with ASD and for parents of typical children

Variables	Groups		Parents of children with Autism (n=100)		Parents of typical children (n=100)	
			n	%	n	%
Age at which ASD was diagnosed (years)	<1		0	0	0	0
	1-3		64	64.0	0	0
	4-5		34	34.0	0	0
	>5		2	2.0	0	0
Number of children in the family	1		0	0	26	26.0
	2		6	6.0	74	74.0
	3		28	28.0	0	0
	≥4		66	66.0	0	0
Residence	Urban		99	99.0	81	81.0
	Rural		1	1.0	19	19.0
Parents Gender	Female		55	55.0	55	55.0
	Male		45	45.0	45	45.0
Parent's Educational Status	Illiterate		0	0	3	3.0
	Literate		9	9.0	16	16.0
	Primary Stage		34	34.0	13	13.0
	High School		24	24.0	31	31.0
	University Stage		33	33.0	37	37.0
Parents Occupational Status	Employed	Female	14	14.0	26	26.0
		Male	26	26.0	29	29.0
	Unemployed	Female	41	41.0	29	29.0
		Male	19	19.0	16	16.0
Type of Family	Small family		52	52.0	46	46.0
	Extended family		48	48.0	54	54.0
Family Monthly Income: (Iraqi Dinar IQD)	<300 thousand IQD		1	1.0	39	39.0
	300-900 thousand IQD		85	85.0	55	55.0
	<900 thousand IQD		14	14.0	6	6.0
Housing Ownership	Owned		58	58.0	62	62.0
	Rent		42	42.0	38	38.0

The general health perception scores of parents with autistic children were found to be (3.33 ± 0.38), while the scores of parents of typical children were (2.94 ± 0.27). Parents of autistic children were found to have higher general health perceptions ($t=8.275$; $p=0.000$).

Table 4.2 compares the QoL of parents with and without autistic children. It is seen that the quality of life in both groups is below 50%. However, the quality of life of parents of children with ASD was lower than the quality of life of parents of typical children in all subgroups and total ($p = 0.000, 0.000, 0.000, 0.000, 0.000$), respectively.

Table 4.2: Comparison of Whoqol-Bref among parents of autistic children and the parents of the typical children

WHOQOL-BREF	Parents of children with ASD	Parents of typically children	Statistically analysis	
	Mean $\pm$ SD	Mean $\pm$ SD	t	p
Physical Health	10.21 $\pm$ 0.62	11.88 $\pm$.80	16.491	0.000
Psychological Health	7.06 $\pm$ 0.70	8.69 $\pm$ 0.53	18.420	0.000
Social Relationships	3.27 $\pm$ 0.45	4.51 $\pm$ 0.52	17.885	0.000
Environment	8.96 $\pm$ 0.90	10.28 $\pm$ 1.06	9.428	0.000
Total WHOQOL-BREF	7.38 $\pm$ 2.03	8.84 $\pm$ 2.21	18.212	0.000

$p < 0.05$, SD = Standard deviation, t = Student t test

Table 4.3 shows no statistical differences among parents of autistic children between mothers and fathers in all the WHOQOL BREF domains ($p= 0.913, 0.167, 0.913, 0.505, 0.771$), respectively.

Table 4.3 Investigation of the differences between the quality of life for fathers and mothers of children with ASD

WHOQOL-BREF	Mothers (n=55)	Fathers (n=45)	Statistically Analysis	
	Mean±SD	Mean±SD	t	p
Physical Health	10.21±0.66	10.20±0.57	0.109	0.913
Psychological Health	7.15±0.67	6.96±0.73	1.391	0.167
Social Relationships	3.25±0.49	3.29±0.41	0.109	0.913
Environment	8.90±0.97	9.03±0.81	0.669	0.505
Total WHOQOL BREF	7.38±2.13	7.37±1.92	0.291	0.771

$p<0.05$, n= number, SD = Standard deviation, t = student t test

The study results show no statistically significant differences among parents of typical children between mothers and fathers in all WHOQOL-BREF domains, ($p = 0.811, 0.272, 0.535, 0.293, 0.898$) respectively (Table 4.4).

Table 4.4 Investigation of the differences between the quality of life of fathers and mothers of typical children

WHOQOL-BREF	Mothers (n=55)	Fathers (n=45)	Statistically Analysis	
	Mean±SD	Mean±SD	t	p
Physical Health	11.90±0.85	11.86±0.74	0.239	0.811
Psychological Health	8.74±0.57	8.63±0.47	1.104	0.272
Social Relationships	4.54±0.48	4.48±0.56	0.622	0.535
Environment	10.18±0.97	10.40±1.17	1.058	0.293
Total WHOQOL BREF	8.84±2.21	8.84 ±2.24	0.128	0.898

$p<0.05$, n= number, SD = Standard deviation, t = Student t test

Table 4.5 examines the relationship between the WHOQOL-BREF and the sociodemographic characteristics of parents of autistic children. While there was a correlation between residence and social relations, there was no correlation between other WHOQOL-BREF total and subgroups ($p=0.346, 0.852, 0.013^*, 0.856, 0.337$), respectively. Regarding parents' gender, there is no statistical correlation among parents of autistic children's parents' gender and total WHOQOL-BREF and subgroups ($p>0.05$). Concerning parents' educational status, the study shows no statistical correlation among parents of children with ASD between parents' educational status and total WHOQOL-BREF subgroups except environment ($p= 0.275, 0.264, 0.834, 0.173, 0.033^*$) respectively.

Regarding parents' occupational status, the study's findings indicated no statistical correlation among parents of autistic children's parents' occupational status and total WHOQOL-BREF and subgroups ($p>0.05$).

It was observed that there was a statistical correlation between family type and physical health ($p=0.005$). No statistical correlation exists between the type of family and Total WHOQOL-BREF and subgroups ($p=0.109, 0.422, 0.044, 0.159$, respectively). Regarding family monthly income, the study shows a statistical correlation between the family monthly income and total WHOQOL-BREF and environment ($p=0.037, 0.016$, respectively). No statistical correlation exists between family monthly income and other WHOQOL-BREF subgroups ($p= 0.285, 0.199, 0.385$, respectively). Finally, the housing ownership results show no statistical correlation among parents of autistic children between housing ownership and total WHOQOL-BREF and subgroups ($p>0.05$).

Table 4.5: Correlation between the Quality of Life of parents of children with ASD

Variables	Correlation	Physical Health	Psychological Health	Social Relationships	Environment	Total Whoqol Bref
Residence (n=100)	r	0.095	0.019	0.248**	-0.018	0.097
	p	0.346	0.852	0.013	0.856	0.337
Parents Gender (n=100)	r	-0.011	-0.139	0.051	0.067	-0.029
	p	0.913	0.167	0.614	0.505	0.771
Parent's Educational Status (n=100)	r	0.110	0.113	0.021	0.213*	0.137
	p	0.275	0.264	0.834	0.033	0.173
Parents Occupational Status (n=100)	r	-0.103	-0.130	-0.086	-0.078	-0.130
	p	0.310	0.197	0.397	0.440	0.197
Type of Family (n=100)	r	-0.276**	0.161	-0.081	-0.202	-0.142
	p	0.005	0.109	0.422	0.044	0.159
Family Monthly Income (n=100)	r	0.108	0.129	0.088	0.240*	0.208*
	p	0.285	0.199	0.385	0.016	0.037
Housing Ownership (n=100)	r	-0.022	0.002	0.216	0.115	-0.035
	p	0.825	0.983	0.031	0.253	0.728

P<0.05, r: Pearson correlation coefficient

Table 4.6 examines the relationship between the WHOQOL-BREF and the sociodemographic characteristics of parents of typical children. While there was a correlation between residence and psychological health, there was no correlation between other WHOQOL-BREF total and subgroups ($p=0.586, 0.033^*, 0.924, 0.116, 0.475$), respectively. Regarding parents' gender, the study's findings indicated no statistical correlation among parents of typically developing children between parents' gender and total WHOQOL-BREF and subgroups ($p>0.05$).

Concerning parents' educational status, the study's findings indicated no statistically correlation among parents of typical children between parents' educational status and total WHOQOL-BREF and subgroups ($p>0.05$).

Regarding parents' occupational status, the study's findings indicated no statistical correlation among parents of typical children between parents' occupational status and total WHOQOL-BREF and subgroups ($p>0.05$).

The study's results related to type of family show no statistical correlation among parents of typical children between the type of family and total WHOQOL-BREF and subgroups ($p>0.05$). Regarding family monthly income, the study shows a statistical correlation between the family monthly income and the environment and total WHOQOL-BREF ($p=0.022, 0.010$), respectively. No statistical correlation exists between family monthly income and other WHOQOL-BREF subgroups ($p=0.285, 0.199, 0.385$, respectively). Finally, the results of the housing ownership display that there is no statistical correlation among parents of typical children between housing ownership and total WHOQOL-BREF and subgroups.

Table 4.6: Correlation Between The Quality of Life Parents of Typical Children

Variables	Correlation	Physical Health	Psychological	Social Relationships	Environment	Total Whoqol Bref
Residence (n=100)	r	0.055	-0.213*	0.010	0.158	0.072
	p	0.586	0.033	0.924	0.116	0.475
Parents Gender (n=100)	r	-0.024	-0.111	-0.063	0.106	0.013
	p	0.811	0.272	0.535	0.293	0.898
Parent's Educational Status (n=100)	r	-0.046	0.113	0.111	-0.096	-0.003
	p	0.650	0.163	0.272	0.343	0.973
Parents Occupational Status (n=100)	r	0.026	-0.172	-0.047	-0.166	-0.140
	p	0.796	0.088	0.641	0.099	0.164
Type of Family (n=100)	r	-0.119	0.061	-0.057	-0.033	-0.065
	p	0.236	0.545	0.576	0.746	0.523
Family Monthly Income (n=100)	r	0.187	0.148	0.139	0.228*	0.257*
	p	0.063	0.142	0.167	0.022	0.010
Housing Ownership (n=100)	r	0.149	0.006	0.097	0.056	0.112
	p	0.138	0.953	0.339	0.580	0.265

P<0.05, r: Pearson correlation coefficient

5 DISCUSSION

In our research results, it is seen that the quality of life of people is generally low. This situation reveals the difficulties faced by the Iraqi people as a country that has gone through a war. It is seen that the quality of life of parents with autistic children is lower than that of other parents in all areas, together with the difficulties of having an autistic child with life difficulties. Although this situation is expected, it is worth examining in terms of other variables.

It takes a considerable amount of time and effort to properly look after children who have autism spectrum disorders, as well as financial resources from the family. The findings of this study revealed that parents' lives were profoundly impacted by their children's ASDs (Brouwer *et al.* 2009). Deficiencies in parental QoL can be explained by the difficulties these parents confront. Stress, sleep deprivation, and exhaustion have all been linked to parents of autistic children, and these factors are likely to impair their physiological and physical well-being. Increased obligations and the high financial requirements of caring for children with ASD may also limit parental socialization and hinder their potential for making reasonable adjustments to their surroundings (McCann *et al.* 2012).

In our study, the sociodemographic information on parents and their children shows that the high period of the child diagnosed with ASD was between 1-3 years which represent (64.0%); this result is inconsistent with the findings of a study that was carried out by Fayyadh and Faraj (2020). In that study, the researchers mentioned that 35% of the children in their sample had autism for 3 to 5 years. This study also shows that having more than four children in the family was associated with the highest results in the families that have autistic children this results was associated with that conducted by Jeejo and Noori (2021) which mentioned that the percentage of households with three children or more is greater than 40%. While the families of typical children had two children, which represented the high result. This study also found that nearly all of the samples lived in cities, which is similar to the findings of Zhou and colleagues (2019), who discovered that more than 83 percent of the people in their sample lived in cities. For parents of children with autism spectrum disorder,

the highest degree of schooling was at the university level, while for parents of typically developing children, it was at the elementary school level. Similar findings were reported by Mohsin and Abed Neamah (2019), who estimated that over 60% of parents in the community were literate. An explanation for the parents' lack of education could lie in the challenges they had as children, which may have led them to drop out of school for a variety of reasons. The family monthly income in our study came in at a moderate level in both groups. This would reflect the difficult situation that the Iraqi families faced during their lives, especially those having an autistic child.

When comparing the quality of life of mothers and fathers of children with ASD, we found no statistically significant differences in any of the WHOQOL-BREF domains. Like when comparing the QoL of typically children between fathers and mothers, there was no statistically significant difference in all the WHOQOL-BREF domains. In contrast to the findings of three studies undertaken by (Allen et al. 2013, Allik et al. 2006, and Kheir et al. 2012), substantial disparities were discovered between mothers and fathers, with mothers expressing significantly lower levels of quality of life than fathers did. QoL explains the results of our study as a concept. The majority of researchers believe that the concept of QoL is made up of both subjective and objective measures (Summers *et al.* 2005). In other ways, the meaning of QoL can be interpreted in various ways by various individuals. As a result, the singularity of each person is an essential component in determining the quality of life. Therefore, even while there were no statistically significant differences between mothers and fathers in their views of their quality of life, this does not necessarily mean that they both interpreted the idea in the same way. "individuals' view of their place in life in terms of the culture and value systems in which they live and in connection to their objectives, aspirations, standards, and concerns" is the definition of QoL that is used in this study (WHO 1996). Because of this, it is generally accepted that the responses of parents of children with ASD to questions about their QoL reflect their subjective assessments of those experiences. It should also be noted that in the context of raising a kid with Autism, both mothers and fathers may experience the same quality of life.

Most previous studies evaluating the relationship between income and QoL found a positive correlation. A parent's ability to provide for their children's health and well-being may improve if they have a better standard of living. People from low-income families appear less likely to seek medical advice even in countries like the United Kingdom, where health care is provided at no cost (DeVoe *et al.* 2007). Parents of low-income families may also be hesitant to demand help for themselves or their children due to their previous experiences with service support. Low-income families may benefit from therapeutic programs tailored to their unique circumstances. Supporting these families might be made more accessible by utilizing community-based programs that encourage parental empowerment and rely on mutual support. Parental economic resources may also boost the quality of life for parents and their children (Knowles *et al.*, 2006).

The findings of this study reveal that the quality of life of parents of children with ASD is affected by their children's ASD. It is seen that economic income is the most effective factor on people's quality of life. Considering the special needs of children with ASD, it is seen that the economic situation is even more important for the families of children with ASD.

In general, the majority of Iraqi families struggle due to the inadequate medical care that is provided for them. Access to primary health care centres is difficult to obtain. Most families, especially those with children who have autism or other illnesses, do not get any help from the government (Al Hilfi *et al.* 2013). Iraq's health system is still struggling to recover from years of war, sanctions, loss of health workers, looting, and political interference. Health facilities and the health workforce are inequitably distributed to meet the country's health needs. Although the Ministry of Health is addressing this need, creation of equitable access to health care throughout Iraq is an arduous and complex undertaking. Ostensibly, the family health-care approach forms the basis of Iraq's health system, yet the major investments continue to flow into secondary and tertiary health facilities. Health strategy remains weak and uncoordinated, still heavily focused on clinical services, while major public health problems such as mental disorders, obesity, and non communicable diseases are not being fully addressed (Jadoo *et al.* 2021). Many contemporary therapeutic

approaches are not available to Iraqi patients, and it typically takes a significant amount of time before advancements in medical knowledge and treatment skills make their way to Iraqi patients. Practice patterns change from institution to institution and area to region, which results in variable health outcomes and expenditures associated with care (Al Hilfi *et al.* 2013).

It has been established that the assistance provided by the nurse to the individual diagnosed with autism is an essential component in the operation of the work process in nursing (De Sena *et al.* 2015). Reveals the need for a cautious look, free of biases, attentive to the needs of others and their pain; given that the majority of the time there is the problem of oral expression on the part of the autistic, it is the responsibility of the nurse to listen and provide holistic care (Simpson *et al.* 2016). The nurses act as a liaison between the autistic child's caretakers and the multidisciplinary team since they are the health team's eyes and ears and the parents' voice (De Sena *et al.* 2015). It is important to point out that for the nursing team to be of assistance to the parents in the process of listening to them, an approach to the concerns that surround them is required. This is done with the intention of paving the process to educate the families of children who have autism spectrum disorder (ASD) on how to deal with the difficulties and how to best drive the well-being of everyone involved (Simpson *et al.* 2016).

6 CONCLUSION

This study shows a difference between parents of children with ASD and typical children's quality of life of parents of children with ASD is lower. These results also reveal the need for families to be supported to improve their quality of life.

According to the research findings, except for general health perception ($p < 0.05$), the quality of life of parents of children with ASD was found to be lower in all domains of the WHOQOL-BREF scale than those of parents of children with typical development ($p < 0.05$). When the quality of life of mothers and fathers of children with ASD was compared, no statistically significant difference was found between them ($p > 0.05$). Similarly, there was no statistically significant difference between the quality of life of mothers and fathers with typical development children ($p > 0.05$).

When the relationship between sociodemographic characteristics and QoL of parents of children with ASD was examined; It was found that parents mostly lived in urban areas, and this situation showed a positive correlation with their social relations ($p = 0.013$), education level, and monthly income with the environment ($p = 0.033$; 0.016 , respectively). On the other hand, it was found that they mostly had a small family (52%), and family type negatively correlated with physical health ($p = 0.005$). Total QoL scores were found to be associated with the monthly income of the family ($p = 0.037$).

When the relationship between sociodemographic characteristics and QoL of parents of typical children is examined; It was found that parents mostly lived in urban areas, and this situation was negatively correlated with their psychological health ($p = 0.033$), while their environmental conditions and total quality of life scores were positively correlated with the monthly income of the family ($p = 0.022$; 0.010) respectively. No correlation was found between other sociodemographic characteristics of parents of children with and without ASD and quality of life assessments ($p > 0.05$). According to this study, there is a difference between the quality of life of parents of children with ASD and typical children. The quality of

life of parents of children with ASD is lower. These results also show how important it is to help families so that they can live better lives.

Our recommendations based on the results of this study:

It is seen that parents with autistic children need support in all areas in terms of physical health, social, psychological and environmental aspects. This situation should be handled in a multi-faceted manner and health policies should be created to address this need.

Supportive practices of nurses working in the field should be expanded for children with ASD and their families.

It is important to increase the number of health professionals in family counseling and to expand family support programs.

Families need to be supported psychosocially in order to support their parenting skills and improve their quality of life. It is one of the important approaches in terms of public health studies.

Families should be informed about their child's condition and future expectations.

Family counseling and rehabilitation services should be developed so that the family can communicate and guide their child. Guidance studies of nurses in this area should be expanded.

Parental support programs should be developed to improve parents' coping and problem-solving skills.

Social and economic opportunities should be provided to prevent social isolation and increase the participation of individuals in life.

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APPENDICES

APPENDIX 1. Consent Form

Informed Voluntary Consent Form

Dear Participant,

We ABBAS OUDAH WAHEED AL OMARI and Ass. Prof. Dr. MELTEM YAZICI GÜLAY invite you to participate in the research entitled "Investigation of quality of life for parents of children with autism spectrum disorder" which conducted by us. Before deciding whether or not to participate in this research, you need to know why and how the research will be conducted. Therefore, it is very important to read and understand this form. If there is something that you do not understand and is not clear to you, or if you want more information, ask us. Participation in this study is completely voluntary. You have the right not to participate in the study or to withdraw from the study at any time after participating. Your response to the study will be interpreted as your consent to participate in the study. Do not be under pressure or suggestion from anyone while answering the questions on the forms given to you.

Date:

APPENDIX 2. Questionnaire form

Socio-demographic Data:

1. Child's age: year
2. Child's gender: Male Female
3. How long ago was the child diagnosed with ASD? years
4. Number of children in the family?
5. Children's series between siblings:
6. Residence: Urban Rural
7. Parent's Gender: Male Female
8. Parent's educational status:
 - a. Illiterate
 - b. Literate
 - c. Primary stage
 - d. High school
 - e. University stage
9. Parent's occupational status: Employed Unemployed
10. Type of family:
 - a. Small family (consisting of parents and children)
 - b. Extended (Composed of parents, children, grandparents, uncles)
11. Family monthly income: (Iraqi Dinar IQ):
 - a. More than 300
 - b. between 300-900
 - c. More than 900
12. housing ownership:
 - a. Owned
 - b. Rent

World Health Organization Quality of Life Scale- Short version (WHOQOL- BREF)

This questionnaire is about your health and aspects of your life. Please answer all questions. If you are not, sure which answers you want to choose, try to choose the answer that suits you best and can be considered your first answer. You must take into account all your standards, hopes, tastes and interests. We ask you to think about your life (lifestyle) over the past two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1- How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2- How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
3- To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4- How much do you need any medical treatment to	1	2	3	4	5

function in your daily life?					
5- How much do you enjoy life?	1	2	3	4	5
6- To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	A little	A moderate amount	Very much	Extremely
7- How well are you able to concentrate?	1	2	3	4	5
8- How safe do you feel in your daily life?	1	2	3	4	5
9- How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
10- Do you have enough energy for everyday life?	1	2	3	4	5
11- Are you able to accept your bodily appearance?	1	2	3	4	5
12- Have you enough money to meet your needs?	1	2	3	4	5
	Not at all	A little	Moderately	Mostly	Completely
13- How available to you is the information that you need in your day-to-day life?	1	2	3	4	5

14- To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
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The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very poor	Poor	Neither poor nor good	Good	Very good
15- How well are you able to get around?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16- How satisfied are you with your sleep?	1	2	3	4	5
17- How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18- How satisfied are you with your capacity for work?	1	2	3	4	5
19- How satisfied are you with yourself?	1	2	3	4	5
20- How satisfied are you with your	1	2	3	4	5

personal relationships?					
21- How satisfied are you with your sex life?	1	2	3	4	5
22- How satisfied are you with the support you get from your friends?	1	2	3	4	5
23- How satisfied are you with the conditions of your living place?	1	2	3	4	5
24- How satisfied are you with your access to health services?	1	2	3	4	5
25- How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
26- How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

APPENDIX 3. Ethical Approval from Çankırı karatekin Üniversitesi



T.C. ÇANKIRI KARATEKİN ÜNİVERSİTESİ ETİK KURUL DEĞERLENDİRME FORMU



Toplantı No:	24
Araştırmamanın Yürütücüsü:	ABBAS AL OMAIRI
Araştırmamanın Başlığı:	Otizm Spektrum Bozukluğu Olan Çocukların Ebeveynlerinin Yaşam Kalitesinin İncelenmesi.
Karar Tarihi:	07-02-2022
Kurul Görüşü:	Kabul Edilmiştir. Araştırmamanın/Projenin uygulanabilirliği konusunda bilimsel araştırmalar etiği açısından bir sakınca yoktur.

SONUÇ: Kabul Edilmiştir. Araştırmamanın/Projenin uygulanabilirliği konusunda bilimsel araştırmalar etiği açısından bir sakınca yoktur.

Başkan
Prof. Dr. Hüseyin ODABAŞ
İMZA

Başkan Yardımcısı
Doç. Dr. Ela Özkan CANBOLAT
İMZA

Üye
Prof. Dr. Gülcihan YILDIRIM
İMZA

Üye
Doç. Dr. Hakan ÇOLAK
İMZA

Üye
Doç. Dr. Bilgehan TEKİN
İMZA

Üye
Doç. Dr. Emine ÇELİKSOY
İMZA

Üye

Üye

APPENDIX 4. Ethical Approval from Iraq

Irak Cumhuriyeti

Sağlık/Çevre Bakanlığı

Tıp ve Eğitim İl Müdürlüğü

Eğitim ve İnsan Gelişimi Merkezi

Sayı: 48203

Ordumuz ve biz vatana duvar oluyoruz

Tarih: 22/12/2021

çankırı Üniversitesi/Türkiye'y

M/görevi kolaylaştırmak

M. Eğitimli çocukları koruma bölümü olarak Yüksek lisans öğrencisi Sayın ABBAS OUDAH WAHEED ALOMAIRI'ın isteğine dayanarak, araştırmasının gereklerini yerine getirmek amacıyla görevini kolaylaştırmak için gereğinin yapılmasına itirazımız bulunmamaktadır.

Bilginize..... Saygıyla

Doktor

Hasan Muhammed Abbas El Tamimi

Genel Müdür

12.10.2021

İş bu belge, Ben yeminli tercüman DUA DABABO tarafından kopya'ya uygun olarak Arapça'dan Türkçe'ye çevrilmiştir. (Ankara 28\12\ 2021).

İş bu belgenin Arapça'dan Türkçe'ye dairemize kimliği saklı Yeminli tercümanımız DUA DABABO tarafından tercüme edildiğini onaylarım.

CURRICULUM VITAE

Personal Information

Name and Surname : Abbas AL OMAIRI

Education

MSc	Çankırı Karatekin University Graduate School of Health Sciences 2020-Present Department of Nursing
Undergraduate	Baghdad University Nursing College Department of Nursing
	2010-2014

Work Experience

Professional nurse at Baghdad Medical City / Private Nursing Home Hospital, Baghdad (May 2015 - October 2020)

[Professional nurse (Intensive Care Unit)], [Baghdad Medical City / Private Nursing Home Hospital] [4/5/2015 – 1/7/2018]

[Continuing Medical Education], [Kidney Diseases and Transplantation Center], [Baghdad, Bab Al-Moadham] [24.6. 2015 – 10.6.2016]

[Head of the Continuing Medical Education Unit], [Baghdad Medical City / Private Nursing Home Hospital], [Baghdad, Bab Al-Moadham] [22.08.2017 – 1.7.2018]

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[Emergency nurse], [Baghdad Teaching Hospital], [Baghdad, Bab al-Moadham] [5/6 / 2016- 5 / 7/2016]

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[Intensive Care Unit], [Private Nursing Home Hospital], [Baghdad, Bab Al-Moadham] [1/8/2019 - present]

[Deputy Head of the Rescue Team], [Private Nursing Home Hospital], [Baghdad, Bab Al-Moadham] [22.09.2017 - present]

[Central Operations], [Private Nursing Home Hospital], [Baghdad, Bab Al-Moadham] [21/5/2015 - 31/6/2015]

[Medical convoy], [Iraqi Ministry of Health], [Baghdad, Bab Al-Moadham] [5/1/2016 - 4/4/2017]

Courses

Critical Cases Course at the International Institute of Medicine (Sep. 2017 – Nov. 2017).

