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Lived Experiences of Mothers, Children and Adolescents with Autism Spectrum Disorder based on Depression

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ABSTRACT

Objective: Depression is very common in children and adolescents with autism. However, little is known about the nature of these children's subjective experience of depression and the impact of depression on their lives. The purpose of the present study was to investigate the lived experience of mothers, children, and adolescents with autism disorder, focusing on depression.

Methods and Materials: The research method used a qualitative, phenomenological approach. The statistical population of the research was mothers, children, and teenagers with autism spectrum disorder in Bushehr city, who were selected by purposeful sampling. All children and adolescents had previously experienced at least one episode of depression. Their lived experiences were collected through semi-structured interviews. The recorded interviews were transcribed and analyzed using the Colaizzi method. In this research, 12 interviews were conducted with parents and children. The research sample included six mothers and six children and adolescents with autism.

Findings: The findings of the study are presented in 6 main topics, including problems in relationships with peers, experiences related to autism, feelings of pessimism and anhedonia, Impactful difficulties with focus and concentration, tendency to irritability, anger, and aggressive behaviors, and co-occurring relationships between anxiety and depression.

Conclusion: The present study highlights the key challenges of families and children and adolescents with autism disorder from depression and focuses on increasing awareness about the effects of depression symptoms on autism spectrum disorder.

Keywords: lived experiences, autism spectrum disorder, depression, mothers, children, adolescents.

Introduction

Autism Spectrum Disorder is a neurodevelopmental condition that affects various aspects of a child's development, particularly their interaction and communication with others and their experience of the surrounding world (Paul, 2007). According to the latest revised edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), pervasive developmental disorders are no longer categorized separately; instead, they are all recognized under the umbrella of Autism Spectrum Disorder, with the focus now placed on the severity and degree of impairment. Another significant change in the definition of ASD is the consolidation of diagnostic criteria into two core domains: impairments in social communication and interaction, and restricted, repetitive patterns of behavior, interests, or activities. The primary symptoms required for diagnosing ASD are summarized in three areas: impairments in verbal and nonverbal social interaction, communication and language deficits, and stereotyped and repetitive behaviors. These symptoms must manifest before the age of 9 for a diagnosis of autism to be made. Moreover, three levels of severity have been defined for ASD: Level 1 – requiring support, Level 2 – requiring substantial support, and Level 3 – requiring very substantial support (Association, 2023).

ASD affects approximately 1% of the global population, equating to more than 75 million individuals worldwide (Menezes et al., 2020). Reports indicate that the prevalence of autism increased significantly in the United States from 1996 to 2007. According to the most recent report from the Centers for Disease Control and Prevention (CDC) in 2023, the prevalence rate of autism in the U.S. was reported as 1 in every 36 children born. Given the recency of this report, it is likely that the prevalence in 2024 remains consistent (Maenner, 2023). In Iran, the prevalence of ASD in children is reported as 10 per 10,000 (Mohammadi et al., 2019).

Physicians and educators with direct experience working with individuals on the autism spectrum emphasize the high rate of psychiatric comorbidities in children and adolescents with ASD, which represent a significant concern for health, well-being, and even mortality (Matson & Nebel-Schwalm, 2007). Simonoff et al., (2008) reported that 70% of children aged 10–14 with ASD met the diagnostic criteria for at least one comorbid psychiatric condition, and 41% met the criteria for two or more, a much higher rate compared to typically developing peers (Simonoff et al., 2008). About 20–25% of these children experience psychiatric disorders within any given year (Patel et al., 2007). Depression is among the most commonly experienced psychiatric conditions in individuals with ASD (Greenlee et al., 2016), with recent reviews estimating the prevalence of depression among autistic children and adolescents as high as 83.33% (Stewart et al., 2022). In the general population, pre-adolescent depression occurs in about 1–2% of children, but its prevalence rises to 4–5% during mid-to-late adolescence (Jane Costello et al., 2006). Adolescent depression is a known risk factor for a range of adverse outcomes, including substance abuse, academic failure, interpersonal violence, unplanned pregnancies, and suicidal behaviors (McLeod et al., 2016)

For decades, research on ASD has primarily focused on understanding the core disorder itself, leaving little room for examining co-occurring emotional disorders. Moreover, depression in individuals with ASD is often overshadowed by diagnostic challenges or clinician bias—where depressive symptoms are misattributed as features of autism—thereby concealing clinical awareness of depression in autistic youth. Over the past decade, the growing number of adolescents with comorbid ASD and depression has exceeded clinical capacity for intervention globally (Pezzimenti et al., 2019). A recent meta-analysis revealed that individuals with ASD are nearly four times more likely to experience depression compared to the general population. Lifetime rates of depression in ASD are significantly associated with increasing age, average to above-average IQ, the use of structured interviews, and self-reporting measures (Hudson et al., 2019).

Depression is a heterogeneous disorder characterized by a range of symptoms, including either or both anhedonia (loss of pleasure) and low mood, as well as various cognitive, physiological, emotional, and behavioral features (Association, 2023). Cognitive symptoms include attention difficulties, memory problems, impaired decision-making, negative biases,

and academic challenges. Physiological symptoms involve changes in sleep and appetite. Emotional symptoms include sadness, emptiness, low self-esteem, guilt, self-blame, anger, and irritability. Behavioral signs include crying, restlessness, and social withdrawal. In individuals with ASD, comorbid depression can have profound emotional, social, and behavioral consequences, such as worsening core autism symptoms like reduced social motivation and adaptive functioning (Ghaziuddin et al., 2002; Merikangas et al., 2010), decreased quality of life, increased caregiver burden, medication use, and service dependency (Magnuson & Constantino, 2011), as well as physical comorbidities such as gastrointestinal problems, seizures, emotional challenges like anxiety, and behavioral issues like aggression, inattention, and a high incidence of suicidal ideation and attempts (Joshi et al., 2013).

Children with ASD may exhibit classic depressive symptoms—such as sadness, anhedonia, cognitive and somatic complaints, and suicidality—as well as atypical presentations, including reduced interest in restricted interests or increased repetitive behaviors, along with decreased adaptive functioning and self-care. Cognitively able autistic youth with social motivation may experience sadness, irritability, anhedonia, sleep disturbances, appetite loss, self-deprecating thoughts, and intensified autism-related behaviors (e.g., more pronounced restricted interests), while those with intellectual disabilities may display increased crying, self-injury, aggression, perseveration, weight changes, and toileting issues (Chandrasekhar & Sikich, 2015; Charlot et al., 2008).

Preliminary evidence suggests that anhedonia is the strongest predictor of depression in autistic adolescents, while low mood—a classic symptom—is only the fourth most predictive (Bitsika & Sharpley, 2015). This indicates that depression in autistic youth may follow a different symptom pattern compared to neurotypical populations, with anhedonia being more prominent (Rice et al., 2019). These differences may lead to underdiagnosis and heightened clinical risks in autistic individuals. Depression is also a strong predictor of self-injury and suicide (Hetrick et al., 2011). One meta-analysis found that individuals with autism are three times more likely than the general population to engage in self-harm or suicide (Blanchard et al., 2021). This highlights the urgent need to understand the nature and impact of depression in children with ASD.

ASD and depression share overlapping features, such as affective flattening and social withdrawal, which can obscure diagnostic clarity and hinder recognition, description, and accurate identification of depression in autistic samples (Pezzimenti et al., 2019). Little is known about the longitudinal course of depression in autistic children and adolescents, although preliminary data suggest it may persist over time (Gotham et al., 2015). Children with greater experiences of bullying or social communication challenges may show sustained depressive symptoms (Rai et al., 2018).

Researchers have proposed several potential vulnerability factors for depression in individuals with ASD. Evidence suggests that the risk of depression increases during adolescence in ASD, similar to patterns in the general population. In adults with ASD, depression prevalence ranges from 50% to 77% (Lugnegård et al., 2011), indicating the need for early recognition and treatment. Studies show that children, adolescents, and young adults with ASD during transitional periods demonstrate high levels of negative self-perception (e.g., guilt, shame, worthlessness), maladaptive coping strategies (e.g., rumination), perceived stress, and difficulty with emotional regulation—all associated with depression in the general population (White et al., 2020). Those who utilize adaptive coping strategies (e.g., problem-solving, seeking social support) appear to be at lower risk for depression compared to those engaging in rumination or other maladaptive strategies (Rieffe et al., 2014). Impaired social communication and negative social feedback may increase vulnerability to depression. In autistic adults, higher social motivation is associated with greater loneliness (Mazurek, 2014), which in turn is strongly linked to higher rates of depression and suicide (Hedley et al., 2018).

Given the high prevalence, early onset, and persistent nature of ASD—and the substantial burden of psychiatric comorbidities—it is a significant public health concern. Among these, depression is the most common comorbid psychiatric disorder in individuals with higher-functioning ASD (Chandrasekhar & Sikich, 2015). Due to the lack of sufficient data regarding the presentation, risk factors, and course of depression in autistic children and adolescents, investigating the effects of comorbid depression in ASD is crucial.

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Moreover, most existing research on ASD has been quantitative, while qualitative studies exploring the lived experiences of depression in autistic youth are scarce. Yet children with ASD often have unique, varied experiences that cannot be fully captured by quantitative research alone. Therefore, qualitative approaches are vital to gaining a deep, nuanced understanding of their real experiences. The high prevalence of autism, especially when combined with depression, intensifies the caregiving burden and clinical challenges.

Diagnosing major depressive disorder in the context of ASD is especially challenging due to the atypical presentation of depressive symptoms, overlapping symptom profiles, and the lack of standardized assessment tools for depression in individuals with ASD. Comorbid depression has serious implications for treatment, prognosis, and service delivery. Understanding the prevalence, assessment, and treatment of depression across the lifespan in individuals with autism—and identifying existing knowledge gaps—is therefore essential.

Accordingly, this study, using a qualitative approach, aimed to explore the lived experiences of depression among children and adolescents with ASD and their parents. The research sought to answer the following questions: What are the perspectives of autistic children on their experiences of depression? How does depression impact the daily life experiences of children with autism? Do children and parents agree on the children's thoughts about their own depression?

Methods and Materials

The present research employed a qualitative methodology using a phenomenological approach. Qualitative studies primarily aim to provide a rich understanding of certain aspects of human experiences through examining specific cases Polit & Beck, (2010). The data collection tool was in-depth semi-structured interviews. During the data collection process, interviews were recorded, transcribed, and coded. For those interviews that were not recorded, detailed notes were taken during the interview and subsequently transcribed in full. The criterion for ending the interviews was when no new information emerged from participants, i.e., data saturation was achieved, which occurred after the twelfth interview. The benchmark for saturation is the repetition of previously obtained data. In other words, when the researcher repeatedly hears similar statements and perspectives during interviews, data saturation is assumed to be achieved (Grady, 1998). In this study, 12 interviews were conducted with mothers and children/adolescents, with interviews lasting between 25 to 30 minutes for mothers and 15 to 20 minutes for children. Saturation was achieved after six mother-child interviews.

The sampling method was purposeful, aiming to gather the richest information relevant to the phenomenon under investigation and to achieve the study's goal of exploring the lived experiences of children and adolescents. To ensure ethical considerations, at the start of each interview, participants were informed about the research objectives, interview procedures, and data recording methods, and interviews were recorded with full consent. Participants were selected from among the parents and children who had visited the Iranian Rehabilitation Clinic in Bushehr. All participants had been diagnosed with Autism Spectrum Disorder (Hetrick et al.) by child psychiatrists and specialists, with ages ranging between 8 to 16 years. Additionally, the Gilliam Autism Rating Scale (GARS) was used as a diagnostic screening tool for ASD. According to DSM-5, ASD is classified into three levels: Level 1 (requiring support and supervision), Level 2 (requiring substantial support and supervision), and Level 3 (requiring very substantial support and supervision).

Inclusion criteria for mothers included: having a child with Level 1 ASD, willingness to participate in the interview, and the ability to recall and describe their child's emotional and behavioral conditions. Inclusion criteria for child and adolescent participants were: being 8–16 years old, confirmed diagnosis of Level 1 ASD, and comorbid depression diagnosed by specialists. Exclusion criteria included: any serious psychiatric or physical disorders in parents, or intellectual disability and physical health issues in children and adolescents with ASD.

In total, 12 participants were involved in the study: six children and adolescents with ASD whose mothers reported current or past depression in their child (5 boys and 1 girl). The mean age of mothers was 47.66 years, and the mean age of children was 12.16 years. All six children were diagnosed with Level 1 ASD (Table 1).

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Mothers completed a questionnaire including the following: demographic history (parent and child's age and gender), details of the ASD diagnosis (diagnosis name, who provided it—e.g., child psychiatrist—and child's age at diagnosis), information about any other neurodevelopmental diagnoses (type, age of diagnosis, and whether ASD was the primary diagnosis), and whether the child had been diagnosed with depression. All mothers confirmed their child's ASD diagnosis.

The children and their parents completed a set of questionnaires to describe the child's characteristics as thoroughly as possible. To assess ASD traits, parents completed the Autism Spectrum Quotient (AQ) Baron-Cohen et al., (2001), a 50-item screening questionnaire measuring behaviors associated with autism. Autistic adolescents aged 15 and 16 also completed the self-report version. Additionally, both parents and children completed the Children's Depression Inventory – Second Edition (CDI-2) to assess depressive symptoms (D'Angelo et al., 2018). A certificate confirming no intellectual disability was obtained from a child psychiatrist and clinical psychologist for each participating child. All families came from middle socioeconomic backgrounds.

Both children and parents independently participated in the semi-structured interviews, during which they also completed the depression questionnaire (child and parent versions). The 27-item questionnaire served as the basis for the interviews. Interviews focused on participants' personal experiences with each of the 27 items. Participants were asked how they or their child thought, felt, or behaved in relation to each item, and whether they had experienced anything else during depressive episodes.

Table 1

Demographic Characteristics of Participants

Autism Level	Age at Diagnosis	Child's Age	Mother's Age	Participating Parent
Level 1	5	12	53	Arya's Mother
Level 1	4	10	46	Reza's Mother
Level 1	3.5	13	45	Mohammad's Mother
Level 1	4	16	47	AmirAli's Mother
Level 1	3	8	44	Javad's Mother

Choosing a qualitative methodology places the lived experiences of children with autism and their parents at the center of exploring and interpreting meanings. A phenomenological approach was used to analyze experiences of depression. Each interview was listened to multiple times and transcribed word-for-word. After transcription, data analysis was conducted using Colaizzi's 7-step method and MAXQDA software. This method is highly reliable and well-suited for discovering, studying, and analyzing the intricacies of people's lives (Braun & Clarke, 2006).

The seven steps included:

1. Thorough reading of all participant descriptions and important findings;
2. Extracting significant statements and phrases related to the phenomenon;
3. Giving meaning to significant extracted statements, organizing participant descriptions, and categorizing common concepts;
4. [Step not numbered in original]
5. Converting all inferred ideas into comprehensive and complete descriptions;
6. Condensing these descriptions into a clear, concise, and factual summary;
7. Final validation.

Initially identified codes—especially those interpreted as meaningful—were revisited. For final validation, criteria of credibility and reliability were used. To ensure credibility, the analyzed data from each interview was presented to participants for feedback and necessary corrections. For reliability, the findings, including the main and sub-themes, were reviewed, discussed, and revised with psychology faculty experts.

While children and their parents sometimes held differing experiential perspectives, their accounts largely converged. Therefore, a multi-informant approach, commonly adopted in existing literature, was applied (Halsall et al., 2021). In the end, findings derived from both parents' and children's experiences were organized into main and sub-themes.

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Findings and Results

Following the analysis of the interview data, six main themes emerged from the interviews: (1) Difficulties in peer relationships; (2) Autism-related experiences; (3) Feelings of pessimism and anhedonia; (4) Concentration and attention difficulties; (5) Tendencies toward irritability, anger, and aggressive behaviors and (6) Comorbidity of anxiety and depression. Each theme is explained in detail below. These themes represent the various facets of challenges experienced by children and adolescents with autism spectrum disorder.

Table 2

Thematic Structure

Themes	Sub-themes	Codes
Difficulties in peer relationships	Difficulty maintaining peer relationships Restricted interactions	- Feeling the need to hide depressive symptoms from peers - Hiding aspects of self and personality from peers - Changes in friendships - Avoiding potential negative consequences of interacting with low-mood individuals - Withdrawing from friends and upsetting them - Lacking patience to respond, leading to temporary disconnection - Difficulty reconnecting with friends after mood improvement - Struggling to maintain relationships - Challenges in finding and meeting new friends - Growing distance from peers - Friends limited to online gaming - Overthinking social events and interactions - Conflicting feelings: is depression causing social withdrawal or vice versa? - Reduced contact during depressive episodes - Decreased social media interaction during depression - Installing software to block friends during bad moods - Preferring tablets and phones over outdoor play
Autism-related experiences	Autism traits Daily life difficulties	- Limited variety in diet - Restricting food types - Repeated meals - Increased restriction in food choice during sadness - Overall life becoming more restricted - Increased repetitive behaviors like pacing and hand movements due to co-occurring anxiety and depression - Sensory overload linked to depression - Absence of observable depressive behaviors like crying - Hiding depressive symptoms and suppressing tears - Masking emotions - Pessimistic outlook - Feeling low mood is normal in autism - Creating a hostile inner world for guidance - Feeling isolated and abandoned
Feelings of pessimism and anhedonia	Negative outcomes of pessimism and lack of joy	- Uncertainty about the future - Focus on negative rather than positive aspects - Pessimistic feelings - Difficulty completing tasks and developing skills - Feeling useless or pointless - Negative future outlook - Inability to enjoy activities - Inconsistent responses and contradictory enjoyment patterns to escape depression (e.g., differences in reading habits: distraction vs. disinterest) - Inability to enjoy typical outings like parks, zoos, or cinema - Overthinking and worry - Anxiety and depression interfering with pleasurable activities
Concentration and attention difficulties	Mental preoccupation and inability to control thoughts	- Lack of engagement in daily tasks and trouble finding enjoyable activities - Difficulty concentrating during depressive episodes - Focusing on stressors instead of priorities - Low energy for schoolwork and hobbies - Too many simultaneous thoughts and inability to focus - Reduced motivation and increased fatigue - Inability to guide thoughts - Excessive effort for routine tasks - Falling behind on school assignments - Stressing over social situations - Easily distracted - Focused inward rather than outward - Lack of enjoyment due to mental preoccupation
Tendency toward irritability, anger, and aggressive behaviors	Outward and inward-directed aggression	- Outward aggression like kicking and punching; in some cases, self-harm - Frustration with one's own actions - Annoyance toward peers and most people at school - Anger at home - General dissatisfaction and anger at the world - Mood swings and violent behavior during depressive episodes - Taking out aggression on siblings or school events - Getting upset over trivial matters - Irritability - Stopping activities like biking - Misinterpreting events, leading to more anger and sensitivity
Comorbidity of anxiety and depression	Symptom overlap between anxiety and depression	- Feeling anxious and depressed simultaneously - Anxiety as a primary cause of depression - Mental preoccupation with unrelated worries instead of focusing on realistic sources of anxiety

	- Worrying about unlikely future events instead of common issues like academic failure - Anxiety disrupting daily routines and sleep - Anxiety interfering with enjoyment and leisure - Anxiety in social interactions - Anxiety in public settings (e.g., taxis, school, playground) - Link between anxiety and perceived aggression, reciprocity, and disproportionate behaviors - Connection between anxiety and pessimism - Low self-esteem and inability to improve one's condition - Difficulty participating in social activities

Sub-theme 1: Daily Life Challenges

One of the emerging findings from the data involved autism-related experiences. Children consistently reported that when they were in a low mood, they restricted their diets in terms of variety. For example, one child said, *"I used to eat different things like pasta, soup, and ash. But ever since I've felt sad, I'm not like that anymore—I just don't feel like eating them."* Others noted that their reasons for restricting food were due to a general lack of appetite: *"For me, my diet became less varied. I really didn't feel like eating, so I preferred simpler foods—things that were more ready-made and easier to eat."*

Some children mentioned that during periods of depression, they preferred eating the same meals every day, although they often were unaware of this behavior themselves, referring to their mothers' observations instead.

Parents also reported reduced food variety in their children's diets as a sign of depression. One parent said, *"They had less desire to eat and maybe just didn't want to try different foods."* Another said, *"If they were feeling more down, their food preferences became even more limited."* A third parent described how depression restricted their child's life overall, including their eating habits: *"Depression definitely limited his entire life—and his diet became more restricted too."*

Children also spoke about challenges using public transport and visiting public recreation areas, because others did not understand their differences and often responded negatively to unusual reactions to noises or movements—especially during low moods. This, in turn, triggered more severe reactions from others when depressive symptoms were more visible.

Sub-theme 2: Autism-Related Traits

One child referred to "increased agitation", which they described as heightened repetitive behaviors like pacing or hand-flapping during depressive episodes. They attributed this to comorbid anxiety experienced alongside depression.

Several parents mentioned sensory overload and its connection to depression. One parent linked their child's withdrawal to being "overly sensitive to sensory input", explaining that the child would often miss school holidays due to this.

More broadly, some children recognized that autism itself is linked with depression. One child stated that autism causes lifelong issues that may never be resolved. Some also reported not exhibiting observable depressive behaviors, which they connected to autism. One said: *"I'm just not someone who cries. I think that might be more common in people with autism."*

Parents also noted that their children often hid their depressive symptoms**:** *"My son doesn't like to cry, so if he does cry, it's a big deal. I can see how he fights back tears and tries to control himself. It's rare—he cried this afternoon, and that almost never happens. I can count on one hand how many times he's cried in a year. Then he puts the mask back on again."*

Another parent echoed the connection between autism and a constant low mood: *"I guess feeling low is just normal for him. If you have autism, it can feel like the world is a hostile place to navigate."* Another parent said their son had developed a pessimistic mindset tied to being autistic: *"He thinks, 'My autism isn't going to change, so how can anything else?'"*

One mother associated her child's isolation with depression, which she viewed as linked to autism**:** *"Autistic children become withdrawn and isolated—sometimes to protect themselves. I know there's a strong connection between autism and depression, and I think this is part of it."*

Main Theme 3: Impact of Pessimism and Anhedonia

Sub-theme 1: Negative Effects of Pessimism

Pessimism and a lack of joy were commonly described by children and parents as influential experiences. For example, children said things like: *"I've definitely felt this before—like, what's going to happen in the future?"* Or: *"Personally, I just feel like the negative things are more important than the positives."* One child directly

attributed their depression to pessimism: *"Yes, definitely. Pessimism was the main cause."*

Parents shared similar views: *"I think they just have a less positive outlook on things."* They explained that their children find it hard to settle into life or see a hopeful future. Another said: *"When he's in a bad place, he thinks everything is pointless—like what's the point of anything? So when life starts to feel meaningless, he doesn't see anything good in the future."*

Another mother explained her evolving personal pessimism, despite earlier hope: *"I used to think there must be a cure and with enough effort, we could succeed. I thought I could help him reach a good place socially. But the more I researched, the more I realized that this is something we'll have to live with forever. That realization made both of us more pessimistic."*

Sub-theme 2: Negative Effects of Anhedonia

Lack of enjoyment during depressive episodes was prominently highlighted by many children. For example, one said: *"Sometimes I really feel like I just can't enjoy things anymore."*

Responses varied. One child described an opposing pattern: *"The things I enjoy are a way to escape from it [depression]."* There was variation in how children experienced activities like reading. Some viewed reading as a distraction during depression: *"The only thing I did was read—it's something I used to do anyway. But it was more about escaping than actually enjoying it."*

Others mentioned not reading at all, or losing interest in hobbies. *"Sometimes you enjoy something a little—but it becomes so rare that you forget what enjoying something even feels like."*

Parents shared similar views. One said: *"He told me, 'Mom, I know I should enjoy it—I used to enjoy it. If we went to the zoo or the cinema, I should have felt happy—but I just didn't.'"* Parents often interpreted this as a result of overthinking and excessive worry. Another parent said that depression and anxiety directly interfered with their child's ability to enjoy things: *"The depression and anxiety really get in the way of anything he wants to enjoy."*

Main Theme 4: Attention and Concentration

Among children with autism spectrum disorder, a common interpretation of poor attention and concentration was that it hindered engagement in daily activities and enjoyment of pleasurable experiences. Children frequently described difficulty concentrating during episodes of depression. For example, one child stated: *"I just feel like I can't concentrate,"* explaining that their attention often shifted toward stress-inducing thoughts, reducing their ability to focus on necessary tasks. Another child echoed this sentiment: *"There are just too many thoughts going through your head at once—it makes it impossible to focus on just one thing."*

Children linked these concentration difficulties to low motivation and fatigue, explaining that excessive thinking and stress related to social situations left them with minimal energy for schoolwork or hobbies. One participant noted: *"You try too hard just to do normal tasks,"* and another described it as: *"Inability to concentrate means you can't guide your thoughts at all."* Another child commented: *"I really fell behind on my schoolwork,"* when discussing concentration issues during depressive episodes.

Parents also emphasized the connection between stress and concentration. One parent remarked: *"If my child is stressed or upset about the social aspects of school, that becomes the only thing he thinks about, and he just can't concentrate on anything else."* Another noted: *"He gets distracted because there are thoughts going on in his head."* Parents described how their children were often preoccupied with internal thoughts, making it difficult to engage with the external world: *"He's so caught up in his thoughts that he almost can't engage with what's going on around him." "It seems like all his concentration is inward—so he can't focus on reading or his art projects or crafts. He just can't apply his attention to anything."* One parent linked this mental preoccupation to the child's inability to enjoy things that previously brought pleasure.

Main Theme 5: Irritability and Aggression

Irritability, anger, and aggression were commonly mentioned by children as part of their depressive episodes. One child said: *"Sometimes I just feel like I don't know—I just want to kick something, and sometimes I punch the walls."* But anger was also internalized: *"I even thought of doing something like spraying pepper spray in my own eyes."* Another described self-directed frustration: *"There's a lot of resentment toward myself and my actions."* Some reported irritability toward peers: *"I was annoyed with everyone at school—there were only a few people I wasn't upset with."*

Parents reported signs of anger and aggression at home. One stated: *"He's dissatisfied with what's going on*

in his life. When he's sad, he shows it in different ways—you know, like being angry at people and the world." Another said: *"When he was depressed, he had more mood swings and showed more aggressive behavior."*

Aggression also extended to siblings. One parent noted: *"He was very aggressive toward his younger sister. He'd come home and blame everything that went wrong at school on her—he'd be aggressive and harsh and then get very upset afterward."* Another explained: *"He gets upset over the smallest things. We have to remove him from play because he feels like the world is against him."* One parent added: *"He used to go horse-riding, but we had to stop that—he would kick the horse and become angry with everything."*

The relationship between irritability, depression, and autism was described as complex. One parent said: *"Sometimes he gets angry just because of his autism—he doesn't understand things, or feels misunderstood. But when he's also depressed, that adds a heavy layer of sadness on top of the anger."*

Another parent pointed out that difficulties with communication and imagination, particularly in autistic adolescents, made group work very challenging. This could result in aggressive or inappropriate behavior—not because the child wanted to be rude, but because they preferred to avoid such situations. This social aversion likely impairs development of social skills, increasing the chance of friendship deficits. Given the importance of friendships during adolescence, this could lead peers to perceive them as withdrawn, strange, or indifferent, which may cause others to avoid or reluctantly interact with them. Consequently, these children become socially isolated, making future relationships with society difficult and contributing to depression.

Main Theme 6: Co-occurring Anxiety and Depression

Sub-theme 1: Anxiety Interfering with Sleep and Activities

Another key finding involved anxiety experienced alongside depression. Anxiety was consistently cited by both children and their parents as a significant challenge. Children described overlapping feelings of anxiety and depression. For instance: *"I felt like the main reason for my depression was a kind of anxiety."* Another said: *"I think a lot of my depression is caused by being anxious. I'm always overthinking irrelevant things instead of focusing on real things I should actually be anxious about. So instead of worrying about failing schoolwork—which is a more realistic concern—I stress about something that might happen in the future."*

Parents similarly discussed how their child's anxiety affected daily life during depression. For some, sleep was significantly impacted**:** *"I'd say he struggles to sleep at night because of anxiety—he just can't fall asleep."*

Anxiety also disrupted the child's ability to experience joy and participate in daily activities. One parent said: *"Depression and anxiety really interfere with the things he wants to enjoy."* Another added: *"He had to stop several hobbies... partly because of the depression and anxiety he was experiencing."*

Sub-theme 2: Social Interaction Anxiety

Anxiety related to social interactions was also highlighted. For example, children experienced anxiety before leaving the house**,** during the taxi ride to school**,** and upon arriving at the playground. One parent noted that their child feared others might perceive their behavior as aggressive or inappropriate, even if it wasn't outwardly visible: *"He thinks he comes off as aggressive or disproportionate, but he doesn't really show that to others—it's all internal. Still, he's always deeply worried that he might be coming across that way."*

More generally, anxiety about the future was linked to the root of depression: *"Depression and anxiety really interfere with the things he wants to enjoy."*Another parent connected anxiety to pessimism and low self-worth:*"Anxiety begins when he feels powerless to improve his situation."*

They added: *"I think he has very low self-esteem and struggles to imagine how he could ever be part of society."*

Discussion and Conclusion

The present study aimed to explore the lived experiences of depression among children with autism spectrum disorder and their parents. This qualitative investigation into the perspectives of children and parents regarding depressive episodes in children and adolescents with ASD provided new insights into their emotional experiences. Six key themes emerged, including: difficulties in peer relationships, autism-related experiences, pessimism and lack of enjoyment, impairments in attention and concentration, increased

irritability, anger, and aggressive behaviors, and the comorbidity of anxiety and depression.

Some of the themes were closely tied to specific characteristics of ASD, such as restricted dietary variety and sensory overload. Other themes, such as anxiety symptoms, lack of focus, pessimism, anhedonia, and irritability, were consistent with experiences of depression observed in the general child population. The study elaborated on how depression impacts the everyday life of children and adolescents with ASD, both at home and in educational environments. Both children and their parents provided convergent insights into the child's experiences with depression, using illustrative examples.

In this context, further research on the experiences of depression among children and adolescents, particularly those with autism, is vital due to the significance of the symptoms identified in this sample.

A central finding of this research was the emphasis on difficulties in peer relationships as a core component of the depressive experiences of children and adolescents with ASD. This aligns with recent reviews reporting that peer rejection and victimization are common among adolescents with autism (Cresswell et al., 2019). Moreover, the findings are consistent with prior research that highlights the relationship between depressive symptoms and autism in children and adolescents (Rhodes et al., 2023), as well as studies of autistic traits and depression among university students (Zarekar et al., 2014). Individuals with autistic traits, such as poor communication skills, impaired social abilities, and difficulty shifting attention, tend to report higher levels of depression. Among these traits, difficulty in social communication, deficits in social skills, and cognitive inflexibility were positively correlated with depressive symptoms. These findings are in agreement with previous research that emphasizes the significant overlap between autistic traits and depressive disorders (Hudson et al., 2019; Joshi et al., 2013; Rhodes et al., 2023).

In the current study, parents reported that peer relationship challenges were often the cause of depression in their children. Some parents linked social withdrawal and isolation with vulnerability to depression, while others interpreted bullying in peer interactions as a more prominent contributor than mood disorders. As previous research suggests, social disconnection can have significant physical and psychological consequences (Pfeiffer et al., 2011).

A recurring theme was the self-awareness of autistic children regarding their different behaviors and their desire to hide these behaviors from peers, driven by fear or concern that these differences might lead to harm or exclusion. Both children and their mothers reported deliberately masking depressive symptoms. Findings indicated that nearly half of children in the general population feel shame and fear of being treated differently upon receiving a mental health diagnosis (Rhodes et al., 2023). Hiding autistic traits is common among individuals with ASD and poses challenges to mental health recognition and diagnosis.

This study found that children often attempted to conceal their depressive symptoms from parents and peers, which may contribute to the negative impact of masking on psychological well-being. Children described this effort as exhausting and draining, which could exacerbate or sustain depressive symptoms. While research on masking has typically focused on core autistic traits, these findings highlight the need to study masking of depressive symptoms in this population. These findings align with other studies that explore how children with ASD attempt to manage their difficult emotions through avoidance, isolation, and emotional suppression, which in turn weakens their ability to form meaningful social connections and contributes to low mood and feelings of exclusion (Santomauro et al., 2017).

Some of the participants' experiences were consistent with how depression is described by neurotypical children, including changes in appetite. When asked specifically about food habits during low moods, children with ASD reported that their already limited diet became even more restricted. This suggests that depressive states in these children may not only reduce food intake but further narrow the range of foods consumed, aligning with one of the clinical criteria for depression—change in appetite (Association, 2023). Such dietary limitations may reflect increased repetitive and restricted behaviors in response to depressed mood. Further research with larger and more diverse samples is needed to better understand this issue.

Sensory overload in social contexts was linked to social withdrawal. Mothers reported that increased social isolation could serve as a precursor to depression. Both children and parents emphasized the complex

relationship between autism and depression, particularly when navigating the complexities of a neurotypical world.

Anhedonia and pessimism about the future emerged as significant factors impacting these children. These experiences were similar to those reported in the general population. Participants also described a lack of motivation, fatigue, and a tendency to ruminate on negative interactions, all of which interfered with daily functioning in areas such as school and hobbies. Several children reported withdrawing from social interactions due to anxiety, which increased the risk of depression.

Children and adolescents in this study frequently described difficulties in shifting attention, being preoccupied with thoughts, and inability to focus on daily tasks—all characteristics related to both autism and depression. Rumination was highlighted as a common depressive experience in both autistic and non-autistic individuals (Watkins & Baracaia, 2002). Although participants reported high levels of inattention and distractibility, their concerns focused more on past experiences and intrusive thoughts.

Anxiety was also identified by children and mothers as a major contributor to depression. The comorbidity of anxiety and depression is well established in the general population. Findings suggested that autism-specific anxiety triggers—such as disruptions in routines or sensory sensitivities—alongside social difficulties and miscommunication, contributed to challenging behaviors, avoidance, and difficulty expressing anxiety verbally (Ozsivadjian et al., 2012).

Irritability, a diagnostic criterion of depression in children and adolescents (Association, 2023), was commonly reported. Participants described being annoyed or angry with peers, being easily provoked, or reacting strongly to others—symptoms that may reflect both normative development and childhood depression. In this group, the association between irritability and depression appeared particularly pronounced. A large cohort study found that irritability explained 51% of the relationship between social communication difficulties and depressive symptoms in individuals with autism (Eyre et al., 2019).

Overall, children and their parents presented converging narratives of the child's depressive experiences. Across themes such as depression-autism interaction, peer challenges, anxiety, and anhedonia, both perspectives aligned and added depth. Including parental accounts enhanced the richness of the data. These findings are consistent with prior research demonstrating alignment between autistic youths and their parents in areas such as masking behaviors (Halsall et al., 2021), emotion regulation difficulties Santomauro et al., (2017), and anxiety (Ozsivadjian et al., 2012).

The findings of this study shed light on several key aspects of the lived experience of depression in children and adolescents with autism spectrum disorder. These insights can inform needs assessment, mental health support services, and intervention planning by psychologists, social workers, and other relevant institutions. Ultimately, such efforts may contribute to the empowerment and improved functioning of this population.

Some limitations should be acknowledged. Despite the rich and novel data collected through this qualitative approach, the sample size was relatively small and age range limited. Participants also varied in their level of independence and depth of responses, depending on their developmental stage. Given the high prevalence of depression in children and adolescents with autism Stewart et al., (2022), future research should include larger samples sufficient to explore the development of depression more comprehensively. The complex interplay between autism, depression, and co-occurring anxiety also necessitates careful interpretation of findings.

Despite the known prevalence of depression in this population, few studies have explored the lived experiences of affected children. More attention in this area is warranted. This study not only highlights how depression impacts the lives of autistic youth but also emphasizes the importance of developing assessment tools tailored to this group. These tools should capture how depressive experiences may qualitatively differ from those of neurotypical peers and should focus on identifying changes in behaviors related to neurodevelopmental conditions.

The present study focused solely on mothers as primary caregivers. Including fathers in future research is strongly recommended. Due to cultural diversity in Iran, it is also suggested that similar studies be conducted in other cities and across varying levels of autism. Additionally, the limited body of qualitative empirical research in this field posed challenges in

comparing and evaluating findings. Future research is needed to address these gaps.

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Declaration of Interest

The authors of this article declared no conflict of interest.

Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants. Ethical considerations in this study were that participation was entirely optional.

Transparency of Data

In accordance with the principles of transparency and open research, we declare that all data and materials used in this study are available upon request.

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Authors' Contributions

All authors equally contribute to this study.

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