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Original Research Article

The effects of autism spectrum disorder in the family and the role of counselling in its empowerment

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ABSTRACT

Background: This study is to analyse the effects of autism spectrum disorder (ASD) on all family members and to focus on the benefits of counseling in the family. Qualitative research was carried out.
Methods: Twenty parents of children with ASD participated in the study and the tool used to conduct the research was the semi-structured interview.
Results: Results obtained were analyzed using the method of thematic analysis.
Conclusions: Analysis of the results highlighted the negative impact of ASD on the family due to the care required to raise a child with ASD. These impacts are economic, individual, family and social. Also, data obtained highlighted the important role of counseling that had helped the majority of families to found their balance and managed to cope with their anxieties and insecurities.

Keywords: Autism spectrum disorder, Counseling, Qualitative research, Semi-structured interview, Thematic analysis

INTRODUCTION

Autism spectrum disorder (ASD) represents a serious and multifaceted neurodevelopmental disorder that emerges in early childhood, with its characteristics typically manifesting before the age of three. Early signs are usually observed between the ages of seven and twenty-four months. In some cases, a lack of social responsiveness may be evident even before the child reaches six months of age.[1] Autism affects multiple areas of development, including cognitive, emotional, and social domains.[2] Symptoms vary depending on developmental stage, age, environment, severity, comorbidities, and the child's temperament. Delayed speech or regression in previously acquired speech skills are common reasons prompting parents to seek professional help. Autism is characterized as a spectrum because it is not homogeneous. It ranges from mild forms, involving minimal ASD traits and normal intelligence, to severe forms with multiple traits and significant intellectual disability. Most individuals on the autism spectrum exhibit significant deficits in information processing and communication. The vast variability of characteristics and heterogeneity make autism diagnosis and the design of effective therapeutic interventions challenging. In many cases, references to ASD include comorbidities, indicating that ASD may co-occur with other developmental disorders. Differences between children with ASD and those with intellectual disability manifest in emotional and social functioning. Other developmental disorders that may accompany ASD include epilepsy (often emerging in adolescence or later), blindness, deafness, depression, attention deficit hyperactivity disorder (ADHD), and others.[3] The impact of autism extends beyond the individual, affecting the entire family system. Numerous studies highlight the emotional, financial, and social strain experienced by families of children with ASD. Parents often report elevated levels of stress, anxiety, and depression compared to parents of typically developing children or those with other developmental conditions.[4,5] Marital relationships may be strained due to the constant demands of caregiving, financial burdens, and social isolation. Siblings may also experience emotional neglect or feelings of jealousy due to the disproportionate attention required by the child with ASD.[6] Parenting stress in these families is influenced by various demographic characteristics. Studies show that maternal stress levels tend to be higher than paternal ones, especially when mothers are the primary caregivers.[7] Other influential factors include low educational attainment, limited financial resources, single-parent status, and a lack of access to support services.[8] Furthermore, cultural expectations and societal stigma may further burden parents, impacting their psychological resilience and access to care.[9] In recent years, counseling has been identified as a crucial support mechanism for families dealing with the challenges of ASD. Counseling interventions can empower parents by improving their coping skills, strengthening family relationships, and increasing understanding of the child's condition. One such study, Stathopoulou et al parental stress levels in families with children on the autism spectrum and the effects of counseling programs.[10] The study also explored how demographic characteristics such as parental gender, education level, income, and marital status influenced parenting stress levels. It involved 101 parents and used a combination of demographic questionnaires, counseling intervention feedback, and the parenting stress index short-form scale. The findings revealed high stress levels, especially among mothers, single parents, and those with lower education and income. Parents who participated in group counseling programs reported improved relationships with their children and better emotional management.

Aim

The purpose of the study was two-fold. To clarify the impacts of autism: The goal was to deeply understand the various consequences that autism has on the child's development, as well as on family life. This includes difficulties in emotional and social functioning, communication, and cognitive development. The psychological and emotional burdens on parents and other family members were also examined, especially the stress and anxiety associated with caregiving responsibilities and to analyze the benefits of counseling for all family members: The study focused on the positive outcomes of counseling interventions aimed at supporting and empowering family members. Through qualitative data collected from semi-structured interviews, it explored how counseling processes help reduce parental stress, improve parent-child relationships, and foster more effective communication and understanding of ASD. These interventions strengthen emotional resilience and facilitate adaptation to the child's developmental trajectory.

The study sought to answer the following research questions: 1. How do families experience and interpret the impact of an ASD diagnosis on their daily lives and interpersonal relationships? 2. In what ways do mothers and fathers experience and cope with stress related to raising a child with ASD? 3. How does the diagnosis of ASD influence the family's interactions with extended family members and their social environment? 4. What are the experiences of parents regarding the attention and support given to typically developing siblings in families with a child with ASD? 5. How do parents perceive the role and benefits of participating in counseling programs in relation to their parenting experience and family dynamics?

METHODS

The effects of ASD in the family and the role of counselling in this empowerment was assessed by eliciting the views of their parents, and related factors were explored.

Data collection process

The data collection process took place between November 2023 and May 2024 and was conducted in three main phases. In the first phase, an interview guide was developed in alignment with the research aims and questions. The semi-structured interview format was selected as the most appropriate qualitative method for exploring the lived experiences of parents of children with ASD, allowing for both consistency and flexibility in data collection. The second phase (December 2023-March 2024) involved an in-depth literature review. This step was essential in shaping the interview questions, identifying research gaps, and contextualizing the study within existing empirical findings. In March 2024, participant recruitment began using purposive sampling. Twenty parents (including both mothers and fathers) of children with formally diagnosed ASD were selected based on the following inclusion criteria: Being a parent or legal guardian of a child with a formal ASD diagnosis, having at least one year of lived experience with the diagnosis, and providing informed consent and willingness to voluntarily participate in the study.

Participants were recruited through multiple channels, including, counseling centers, and parent support networks. To reduce potential selection bias, care was taken to ensure participants were not exclusively recruited from the center with which the researcher is affiliated. Half of the participants were referred by independent professionals or online ASD support communities. Following initial contact, parents were given detailed information about the study's aims, the voluntary nature of participation, and the measures taken to ensure confidentiality. Interviews were conducted remotely via phone between April and May 2024, each lasting approximately 20-025 minutes. Interviews followed an open-ended question format, focusing on two primary themes: The impact of ASD on family and social relationships, and the perceived usefulness of parent counseling. Five core guiding questions were used to prompt discussion, while follow-up questions were adapted based on the flow of the conversation. Interviews were audio-recorded with explicit consent and transcribed verbatim.

Data collection tool

This study adopts a qualitative approach, with the semi-structured interview serving as the primary tool for data collection. Semi-structured interviews are widely recognized in qualitative research for their flexibility and capacity to yield rich, in-depth data.[11] Although they include a set of predefined questions, the format allows for variation in the order, phrasing, and depth of the questions depending on the flow of the conversation and the interviewee's responses.[12] This adaptability enables the development of rapport between the researcher and participant and promotes a more natural and meaningful dialogue.[13] Open-ended questions were employed to encourage participants to share their experiences freely, allowing their voices to emerge without restriction. This approach aligns with the interpretivist paradigm, which emphasizes understanding human experiences from the participant's point of view.[14] The semi-structured interview thus serves not only as a method of data collection but also as a means of co-constructing meaning through interaction.[15] The choice of this method is particularly appropriate given the aims of the study, which seeks to explore how families are affected by raising a child with ASD, and to capture their perceptions of the role of counseling in addressing the challenges they face. As Patton notes, qualitative interviews are especially useful for exploring complex emotional and social phenomena, as they allow participants to reflect on their lived realities in a nuanced and personal manner.[16] Moreover, this method facilitates the emergence of unexpected themes and insights, which are often overlooked in more structured forms of inquiry.[17] Through the use of semi-structured interviews, the present research seeks to capture the subjective experiences of parents, revealing both shared and unique patterns across their narratives. This emphasis on depth and context is a core strength of qualitative research making it a suitable methodology for addressing the research questions of this study.[18]

Data analysis

For the analysis of the data derived from the semi-structured interviews, the method of thematic analysis was chosen, following the principles described by Braun and Clarke and adapted to the Greek context based on the guidelines of Isari and Pourkos.[18,19] Thematic analysis is a flexible method of interpretative processing of qualitative data, suitable for exploring experiences, perceptions, and the meanings that participants assign to specific phenomena.

The analysis process followed the following steps:

Stage 1-Familiarization with the data

Initially, all interviews were transcribed verbatim to ensure the validity and completeness of the material. This was followed by repeated reading of the transcripts, aiming for an in-depth understanding of the content and the formation of an initial overall picture of the participants' experiences.

Stage 2-Initial coding

At this stage, the transcribed material was analyzed line by line and meaningful segments were identified and coded. Each code represented a concept, emotion, or experience directly related to the aims of the study (e.g., *"lack of understanding from spouse," "feeling of guilt towards other children," "improvement after counseling"*). Coding was done manually, allowing the researcher to stay in close contact with the research material and enable the emergent understanding of the phenomenon.

Stage 3-Searching for and grouping codes into categories

Once the coding was completed, the codes were examined for similarities and differences and were organized into broader categories. Categorization was based on the conceptual relationship between codes and their recurrence among participants.

Stage 4-Theme development

The categories formed the basis for the development of themes, which act as meaningful axes that organize the findings of the study. Each theme is directly linked to the research questions and reflects a significant aspect of the parents' experience.

Examples of emerging themes include: Emotional impact of the ASD diagnosis on parents, influence on marital relationship and family cohesion, perceptions of counseling and personal empowerment and challenges in raising other children.

Stage 5-Reviewing and finalizing themes

The themes were re-examined to ensure that they clearly, consistently, and coherently reflected the content of the interviews. At this stage, repetitive elements were eliminated and themes with a common interpretative basis were unified.

Stage 6-Interpretation and connection with literature

Finally, each thematic unit was interpreted in depth, taking into account the personal context of the participants, as well as in relation to existing theoretical and empirical references in the literature. Through this interpretative process, the study's findings emerged, which are presented in the next section.

RESULTS

The sample population

In the present study, the sample consisted of parents of children on the autism spectrum. Specifically, an initial contact was made with potential participants with the aim of informing them about the content and purpose of the research. Subsequently, a telephone meeting was scheduled for those who expressed a desire to participate in the study. In particular, twenty parents of children on the autism spectrum participated in the study, 13 of whom were women aged between 33-55 years, and the remaining 7 were men aged between 40-53 years. Additionally, the ages of their children on the spectrum ranged from 4 to 20 years. Out of the 20 parents, 10 were members of the association for people with disabilities, where the researcher works, while the other 10 were recruited through referrals (Table 1 and 2). It is worth noting that the interviewees came from all over Greece to provide a more comprehensive view on the topic of the research. The main criterion that participants had to meet was being parents of children on the autism spectrum with children aged between 4 and 20 years. Therefore, the method chosen for sample collection was the Snowball Sampling method. This sampling method is one of the most popular in qualitative research due to its characteristics and the convenience it offers. During the research process, the researcher selects individuals who meet the criteria for participation, and these individuals, in turn, refer others they know who belong to the target group. Consequently, this method relies on networking.[20] From analysis and categorization of data, 2 major categories of themes emerged. First is family, economic, and social consequences that the family experiences due to ASD, and the second is family's need for psychological and counseling support from specialists in order to cope with the difficulties arising in their daily lives.

Table 1: Demographic information of parents.

Variables	Marital status	Age (in years)	Education	Occupation	Financial status	City
E1	Married	45	University degree	Homemaker	Moderate	Athens
E2	Married	50	University degree	Freelance professional	Comfortable	Athens
E3	Married	43	PhD	Civil servant	Comfortable	Larissa
E4	Married	55	University degree	Homemaker	Comfortable	Athens
E5	Married	40	Vocational diploma	Private employee	Moderate	Crete
E6	Married	38	Vocational diploma	Private employee	Moderate	Crete
E7	Married	33	Tertiary education	Homemaker	Moderate	Athens
E8	Married	33	Tertiary education	Homemaker	Moderate	Kavala
E9	Married	39	Vocational diploma	Homemaker	Moderate to difficult	Kavala
E10	Married	35	Tertiary education	Civil servant	Moderate	Larissa
E11	Married	36	Tertiary education	Private employee	Moderate	Larissa
E12	Divorced	50	Vocational diploma	Homemaker	Moderate	Kavala
E13	Married	47	Master's degree	Civil servant	Comfortable	Xanthi
E14	Married	47	Tertiary education	Homemaker	Moderate	Kavala
E15	Married	45	High school diploma	Private employee	Moderate to difficult	Kavala
E16	Divorced	40	Junior high school diploma	Worker	Difficult	Kavala
E17	Married	53	Master's degree	Civil servant	Comfortable	Xanthi
E18	Married	52	University degree	Freelance professional	Moderate	Athens
E19	Married	53	University Degree	Freelance professional	Comfortable	Athens
E20	Married	50	Municipal employee	University degree	Moderate	Drama

Table 2: Demographic and epidemiological characteristics of children.

Variables	Gender	Age (in years)	Educational level	Speech
E1	B	12	Special elementary school	Monosyllabic speech
E2	B	15	Special secondary school	Developed speech
E3	B	5	Special kindergarten	Monosyllabic speech
E4	B	20	High school graduate	Developed speech
E5	B	5.5	Mainstream kindergarten with support	Developed speech

Continued.

Variables	Gender	Age (in years)	Educational level	Speech
E6	B	5.5	Mainstream kindergarten with support	Developed speech
E7	G	5	Special kindergarten	No speech
E8	B	5	Special kindergarten	Monosyllabic speech
E9	B	5	Special kindergarten	No speech
E10	B	4	Special kindergarten	No speech
E11	B	4	Mainstream kindergarten with support	Developed speech
E12	B	18	Vocational high school with support	Developed speech
E13	B	18	Special vocational education and training workshop	No speech
E14	B	7	Special elementary school	Monosyllabic speech
E15	B	5	Special kindergarten	No speech
E16	G	4	Special kindergarten	No speech
E17	B	18	Special vocational education and training workshop	No speech
E18	B	20	High school graduate	Developed speech
E19	B	15	Special secondary school	Developed speech
E20	B	4	Special kindergarten	No speech

Consequences

Family

Most participants described the considerable impact of ASD on family dynamics, particularly on the marital relationship. As noted in previous literature, the demands of caring for a child on the spectrum often lead to emotional distance or tension between partners. Several participants reported relationship breakdowns, with some attributing their divorces directly to stress and challenges of raising a child with ASD. One parent reflected, *“We had reached a point where we didn't talk for a year because each of us was experiencing our own grief.”* Alongside marital strain, many parents expressed concern over the unintended neglect of their typically developing children. The heightened attention required by the child with ASD often left siblings feeling overlooked. Some families refrained from having more children altogether, citing emotional burnout and practical limitations.

Economic

The financial burden associated with ASD-related therapies emerged as a significant stressor. Many parents reported either leaving their jobs or being forced into employment to cope with the added costs. One parent shared that they had to quit their job, resulting in the family surviving on a single income and a modest state allowance. Another described how securing a diagnosis prompted them to immediately return to work, despite having recently given birth to another child. These narratives underscore the economic vulnerability experienced by families, often exacerbated by insufficient state support and a lack of accessible services.

Social

In terms of social life, many families described a process of withdrawal-either self-initiated or as a response to stigmatization. Social events, such as gatherings and celebrations, were often avoided due to the sensory sensitivities or behavioral challenges associated with ASD. One parent shared, *“For the last 10 years, I have stopped going to weddings, christenings, birthdays… because I know that my son will not have a good time.”* Others noted that friends and relatives distanced themselves, highlighting a broader sense of social isolation.

Need and benefits of counseling support

Need for family support

Participants highlighted the emotional toll that ASD takes on the entire family. The experience of grief, chronic stress, and anxiety-particularly among mothers—was commonly reported. Many parents spoke of their initial shock and adjustment period following the diagnosis, often marked by confusion and psychological fatigue. One mother noted, *“Especially in the beginning, I didn't know where I stood; gradually I have found my rhythms, as I couldn't do otherwise.”* Such responses align with existing research suggesting that families of children with ASD often report lower quality of life and elevated psychological distress compared to families of typically developing children.

Benefits of counseling support for the family

Counseling was described as a crucial form of support for many families, providing both emotional relief and practical strategies. Some participants emphasized improvements in communication within the family, while others mentioned personal growth and increased resilience. One parent remarked, *“Counseling has helped me a lot to see things from George's perspective and to adapt to him rather than have him adapt to me.”* Overall, participants agreed that counseling contributed to a better understanding of their child, improved intra-family relationships, and helped manage the psychological challenges associated with raising a child on spectrum.

DISCUSSION

The present study explored the multifaceted impact of raising a child with ASD on family life, drawing from the narratives of participating parents. Consistent with existing literature, the findings indicate that caring for a child with ASD places a substantial emotional, physical, and psychological burden on parents, particularly mothers. Previous studies have documented heightened levels of stress, anxiety, and fatigue among these parents, who often face intensive caregiving demands, such as managing therapy schedules, behavioral challenges, and the child's ongoing developmental needs.[4,21] In agreement with earlier findings by Dardas and Ahmad, many participants in the current study reported that mothers tend to experience a lower quality of life than fathers.[22] This may be attributed to their more direct caregiving role and reduced participation in the labor market, which further exacerbates feelings of isolation and emotional strain.[23] Siblings of typically developing children were also reported to experience a sense of neglect, a phenomenon noted in the literature as a result of parents' disproportionate attention to the child with ASD.[6] Importantly, the findings suggest that the diagnosis of ASD often serves as a catalyst for family crisis. Most participants described experiencing overwhelming emotions upon receiving the diagnosis, including grief, anxiety, and sadness. This emotional impact appeared more pronounced among mothers, reflecting gendered differences in emotional labor and caregiving roles. These emotional responses are well-documented in previous research that highlights the stages of parental adjustment to a child’s diagnosis.[24] One significant theme that emerged was the strain ASD places on the marital relationship. Many parents discussed emotional distance, lack of communication, or even separation as a result of the intense demands placed on the couple. These findings resonate with earlier studies emphasizing the marital stress experienced by parents of children with ASD.[25] Additionally, a recurring issue was the social withdrawal of the family from their extended network. Some parents felt they were excluded by others, while others consciously distanced themselves due to their child’s sensory or behavioral sensitivities. This phenomenon has been identified in past research as "social invisibility" or "social retreat".[26] The financial burden of raising a child with ASD was also a key concern. Most participants described a sharp increase in therapy-related expenses and insufficient state support, echoing research that highlights the economic pressures faced by such families.[27] Furthermore, a traditional division of labor was evident in many cases, with mothers assuming full-time caregiving roles and fathers working extended hours to compensate financially-a dynamic that has been widely reported in studies of ASD-affected households.[28] In regard to family support structures, the study identified parental counseling as a particularly beneficial resource. While the data cannot statistically confirm hypotheses, it is clear from participants’ experiences that those involved in individual or group counseling reported enhanced coping skills, reduced anxiety, and improved communication within the family. These outcomes align with prior research underscoring the role of counseling in fostering parental resilience and family cohesion.[29,30] Thus, the current findings contribute to a growing body of qualitative research emphasizing the complex interplay between caregiving, emotional well-being, family relationships, and support systems in the context of ASD. They highlight the urgent need for integrated support services that address not only the child’s needs but also the psychosocial well-being of the entire family.

Recommendations for parental support

Based on the findings of this study and the existing literature, the following recommendations are proposed to enhance parental support for families of children with ASD:

Accessible and inclusive counseling services

Counseling programs should be designed to address the specific emotional and practical challenges faced by parents of children with ASD. These programs can improve parental mental health and family dynamics by providing coping strategies, emotional support, and educational resources.[31]

Respite care services

Providing parents with temporary respite care allows them to rest and recharge, thereby reducing stress and preventing burnout. Studies have shown that respite care improves parental well-being and overall family functioning.[32]

Parent training programs

Training programs should focus on teaching parents effective behavior management techniques and communication strategies to better support their child’s development. These programs have been linked to improved outcomes for both parents and children.[33]

Peer support networks

Establishing peer support groups enables parents to share experiences, exchange advice, and gain emotional support from others facing similar challenges. Peer networks have been shown to reduce feelings of isolation and increase resilience among parents.[34]

Policy and financial support

Advocacy for increased governmental support, including subsidies for therapies and educational resources, is critical. Financial stress is a major concern for families, and providing sufficient financial assistance can alleviate this burden (Kogan et al).[35]

Community awareness and inclusion initiatives

Raising community awareness about ASD can foster a more inclusive society, reducing stigma and promoting understanding. This enables families to participate more actively in community activities and enhances their social integration.[35]

Research limitations

At this point, it is important to acknowledge the limitations of the present study. Firstly, a key limitation was the relatively small number of interview questions. This restriction stemmed primarily from the limited time availability of the participating parents. Most had between twenty and thirty minutes at their disposal and often opted to be interviewed during their child's therapy sessions the only window of free time in their schedules. Consequently, many interviews took place under time constraints. In response, the researcher prioritized the development of a concise yet focused set of questions that would elicit meaningful and relevant data within the limited timeframe. A second limitation concerns the researcher's limited experience, as this study represents her first formal research project. While every effort was made to ensure methodological rigor, it is acknowledged that certain oversights may have occurred errors that a more seasoned researcher might have anticipated or avoided. Nevertheless, these experiences provided valuable insights and contributed to the researcher's ongoing development and critical reflection on the research process.

Suggestions for further research

With the completion of the present study, two proposals for future research emerge: Future research could focus on the societal barriers faced by individuals with disabilities, including ASD, and investigate the specific needs of parents raising children with disabilities. Such a study would provide insights into the structural and attitudinal obstacles these families encounter and propose solutions to foster a more inclusive society. Another avenue for research could explore the challenges and opportunities surrounding the integration of individuals with ASD into higher education and their subsequent professional rehabilitation. Examining the support systems required for their academic and career success would contribute to developing targeted programs that promote independence and long-term societal inclusion.

CONCLUSION

This study showed that ASD imposes significant emotional, physical, and financial challenges on families, profoundly affecting their overall well-being. Parents, particularly mothers, face heightened levels of stress and reduced quality of life, while marital relationships and sibling dynamics are often negatively impacted. Social isolation and financial strain further exacerbate these challenges, with traditional labor divisions intensifying care giving responsibilities for mothers. The study also demonstrated the transformative role of parental counseling in empowering families. Participation in counseling programs, whether group or individual, significantly helped families manage stress, improve communication, and gain a deeper understanding of their child's needs. These improvements were directly linked to the child's development and the overall resilience and empowerment of the family. In conclusion, this research highlights the critical importance of systemic support for families of children with ASD. Policymakers and practitioners must prioritize the provision of accessible counseling services and adequate financial assistance to alleviate the multifaceted burdens these families face. Parental counseling stands out as a cornerstone intervention, enabling families to navigate the complexities of ASD and fostering a supportive environment for both the child and the family as a whole.

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