Research Article

FREQUENCY OF AUTISM IN NUCLEAR AND JOINT FAMILY SYSTEM

Hamza Fayyaz[1], Azam Khan[2], Hina Samee ullah[3], Farah Khursheed[4], Saba Aziz[5], Mamona Riaz[3]

[1]Department of speech therapy, University of Lahore, Pakistan, [2]Department of speech and language pathology, Rashid Latif Khan University Lahore, Pakistan, [3]Department of speech and language Pathology, Riphah International University, Lahore Campus, Pakistan, [4]Department of speech and language pathology, Rising Sun Institute of Special Education, Lahore, Pakistan, [5]Department of speech and language pathology, Superior University, Lahore, Pakistan

Correspondence:
Hina Samee ullah
Department of Speech and Language Pathology, Riphah International University, Lahore Campus, Pakistan

Email:
hina.omer@riphah.edu.pk

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ABSTRACT

Autism, also known as autism spectrum disorder (ASD), is a neurodevelopmental disorder that affects social interaction, communication, and behavior. Autism is a lifelong developmental condition that affects individual's communication and interaction with others, as well as their understanding of the world. There is limited literature available from Pakistan, therefore this study was designed to find the frequency of autism in nuclear and joint family systems. This was a Cross-sectional observational study conducted in various healthcare settings, including the University of Lahore Teaching Hospital, Mayo Hospital, Orion Center, and Sehat Medical Complex, Pakistan from February 2023 to July 2023. Purposive sampling was the method of sampling used in this investigation (n=133). Parents or caregivers who have a minimum of one ASD-diagnosed child were included in this study. Parents or caregivers who do not have a child diagnosed with autism spectrum disorder (ASD) were excluded from this study. The investigation into the frequency of autism within joint and nuclear families' reveals that a majority of families with autistic children lean towards nuclear family structures. While joint families exist, they are less prevalent. The study also underlines that parental engagement is high across both family types, with over 90% actively participating in caregiving and decision-making.

Keywords: Autism spectrum disorder, Nuclear family, Joint family

INTRODUCTION

Autism, also known as autism spectrum disorder (ASD), is a neurodevelopmental disorder that affects social interaction, communication, and behavior. It is characterized by a wide range of symptoms and varying degrees of impairment, which is why it is referred to as a spectrum disorder. Individuals with autism often have challenges in understanding and engaging in social interaction (1). They may struggle with nonverbal communication cues like gestures, facial expressions, and body language. They may have difficulty forming and maintaining relationships and may prefer to be alone. People with autism may also have difficulties with verbal and nonverbal communication. They may have delayed or limited speech and struggle with understanding and using language effectively. Some individuals with autism may not speak at all and may rely on alternative communication methods. Another characteristic of autism is the presence of repetitive behaviors or restricted interests (2). This can manifest as repetitive movements (e.g., hand flapping, rocking), insistence on sameness or routines, intense focus on specific topics or objects, and a need for predictability. Many individuals with autism have heightened sensitivities to sensory input. They may be overly sensitive

or under reactive to sensory stimuli such as sounds, lights, textures, tastes, or smells (3). This can lead to sensory overload or avoidance of certain sensory experiences. Autism is a spectrum disorder, and individuals with autism can have a wide range of intellectual abilities. Some individuals may have average or above-average intelligence, while others may have intellectual disabilities (4). It is different from other disorders such as Attention Deficit Hyperactivity Disorder (ADHD), while there can be overlapping symptoms, such as difficulties with attention and impulse control, ADHD primarily involves challenges with attention regulation and hyperactivity (5). Intellectual disability refers to significant limitations in intellectual functioning and adaptive behaviors. Autism, on the other hand, is primarily characterized by difficulties in social communication and interaction, and the presence of restrictive and repetitive behaviors. However, it is possible for individuals with autism to have co-occurring intellectual disabilities (6).

Language Disorders as Autism can co-occur with specific language impairments or language disorders. However, individuals with specific language disorders typically have difficulties with language acquisition and usage, whereas individuals with autism have broader challenges in social interaction, communication, and repetitive behaviors. A study about Family types and cognitive deficits in autism was conducted in 2014 in India which explains that Autism is a lifelong developmental condition that affects how individuals communicate and interact with others, as well as their understanding of the world. It is a complex disability that typically emerges in early childhood and hinders a person's ability to engage socially, communicate effectively, and display repetitive or restricted behaviors. Autism is believed to originate before birth, making it a congenital birth defect. It is often referred to as an impaired disorder due to its impact on social skills, language and communication abilities, and repetitive behaviors. The condition is more prevalent in males, with a sex ratio of approximately 3.5 to 1, similar to other developmental disabilities. The estimated prevalence of autism is around 1 case per 1000 population. Some studies have pointed out specific risk factors associated with autism, such as premature birth or low birth weight, which may elevate the risk, particularly among girls born under these conditions (7).

A study was conducted about Quality of life in families of children with autism spectrum disorder in India, despite the importance of understanding autism and its contributing factors, one area that has received little attention is the relationship between family types and the development of autism. To address this gap, a recent study was conducted with the aim of evaluating various cognitive deficits in autistic children and exploring the influence of family structure, comparing joint families and nuclear families. The study involved 60 autistic children between the ages of 3 and 5, coming from diverse socioeconomic backgrounds. The participants were randomly selected and diagnosed using the Autism Checklist (AC) and Childhood Autism Rating Scale (CARS). Their cognitive abilities were assessed using Hema Pandey's Cognitive Development Test for Pre- schoolers (PCDTP), which includes six sub-tests covering Concept Formation, Information, Comprehension, Visual Perception, Memory, and Object Vocabulary. The results revealed that family type had a notable impact on cognitive deficits in autistic children. Specifically, in terms of Concept Formation, children from nuclear families exhibited significantly more deficits compared to those from joint families. In summary, the study's findings strongly support the notion that family structure plays a significant role in the cognitive functioning of autistic children. Children from joint families generally exhibited higher cognitive scores compared to those from nuclear families(8).

A study conducted in 2019 about Autism spectrum disorder and sibling relationships explains that currently, there is a limited amount of research in the field of speech-language pathology concerning the involvement

of siblings in the treatment of children with Autism Spectrum Disorder (ASD). Family Systems Theory (FST) offers valuable insights into the interconnections and dynamics of the family unit, making it a relevant and beneficial framework for future research and practice regarding sibling involvement in interventions. The core principles of FST are explored, followed by an overview of existing research on sibling relationships in ASD and the roles of typically developing siblings and those with ASD in intervention programs. The adoption of an FST framework has significant implications, and several considerations need to be taken into account at the child with ASD, sibling(s), and family levels. These considerations include factors such as developmental level, communication abilities, and individual strengths and challenges, which are crucial in promoting positive sibling involvement and overall family functioning. Developing family-centered intervention programs that include siblings for individuals with ASD is an area that requires further investigation. By utilizing the FST framework, researchers and clinicians can work towards creating innovative interventions tailored to each family's unique characteristics, aiming to optimize outcomes for each individual, enhance sibling relationships, and improve family dynamics (9).

A study was conducted about child and family factors associated with the use of services for preschoolers with autism spectrum disorder. This study looked at the factors that may influence how much and what kind of common private and in-school services—such as speech-language therapy (SLT), occupational therapy (OT), and applied behavior analysis (ABA)— children with autism spectrum disorders (ASD) receive. 137 families with preschool-aged ASD children from four states—Colorado, Florida, Minnesota, and North Carolina—were participants. The findings of the study showed that the kind and quantity of services used were influenced by child and family variables. Hispanic students received less SLT and OT in the classroom than White students. Greater cognitively impaired children received more SLT, while those with more severe autistic symptoms received more OT. Higher socioeconomic status parents were more likely to sign up their kids for OT and ABA (10).

A study conducted in 2012 regarding the Parent and family impact of autism spectrum disorders, a review and proposed model for intervention evaluation explained that for parents and families, raising a kid with an ASD can be a challenging experience. When compared to parents of typically developing children and parents of children with other developmental disorders, parents of children with ASD experience more mental and physical health issues. These difficulties include decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health issues. High rates of divorce and lower overall family well-being underline the hardship that having a kid with an ASD may have on families, in addition to severe time and financial constraints. These adverse parent and family effects on the diagnosed child have a reciprocal unfavorable influence on them and may even lessen the beneficial effects of intervention (11). Although parent and family characteristics may have an impact on both the short- and long-term impacts of therapy, most ASD interventions are only evaluated in terms of child outcomes. It cannot be anticipated that even large gains in the diagnosed child will lessen the existing parent and family pain, especially given that the intervention's time and cost may cause even more disruption in the family. In order to properly reflect the transactional character of these relationships and incorporate these aspects, a new model of intervention assessment is presented(12). There is a rise in the children being diagnosed with ASD in Pakistan, but the data is still scarce therefore this study was conducted to explore frequency of children diagnosed with ASD in nuclear and joint family systems in Pakistan.

MATERIALS AND METHODS

This was an observational cross-sectional study conducted in various healthcare settings, including the University of Lahore Teaching Hospital, Mayo Hospital, Orion Center, and Sehat Medical Complex Pakistan, for six months from February 2023- July 2023. The sample size calculated for this study was n=133 where the prevalence (p) of autism was taken as 3.2%. The level of confidence (z) was taken as 1.96 and the value of precision (D) was taken as 0.0025. Purposive sampling was the method of sampling used in this investigation. Parents or caregivers who have a minimum of one ASD-diagnosed child were included in this study. The questionnaire was used in this study, aimed to gather demographic information and specific details related to potential risk factors. The questionnaire consisted of two sections: one focusing on the respondent's demographics, and the other focusing on information about the ASD child. The questions cover a range of topics such as family background, parental age, prenatal factors, birth-related complications, medical history, and environmental factors. By collecting this information, the questionnaire aimed to provide insights into the potential risk factors associated with ASD development and their impact on the affected child and their family. The questionnaire was used to collect data from the participants. Researcher provided detailed information regarding the study to the participants and also obtained their informed consent. The participants were informed about the objective of the study and its aspects and told about their right to withdraw any time. The questionnaire was designed to gather relevant information from patients, such as demographic data, medical history, symptoms, and diagnosis. The questionnaire was pre-tested before use to ensure that it is easy to understand and collect reliable data. The questionnaire had to be finished by the participants, and it took them about 10-15 minutes. The data was analyzed using the statistical software, Statistical Package for Social Sciences (SPSS version 2021). The results of the data are represented in the tables, charts, and graphs. Data was analyzed for their main values.

RESULTS

A total of 133 participants were included in this study, majority of participants had 3-5 children with autism (52%), 32% had 1-2, while 16% had more than 6 children in their family. The age of children ranged between 4-6 years in majority of cases (44%) ,35% were less than 3 years, and 21% had more than 7 years. Sibling data showed that 51% had 4-5 siblings, 33% had 1-3, 16% had more than 6 siblings. A total of 70% had nuclear family set up, 17% were living in joint family , 13% was single-parent family. Out of these 59% have extended family living with them. Among caregivers 43% had Bachelor's level education, 26% had Matric/Intermediate, 5% had Master's. 93% actively care for autistic child, 7% less involved. Out of these participants 59% were employed while 41% unemployed. A summary of the data is presented in Figures 1- 9.

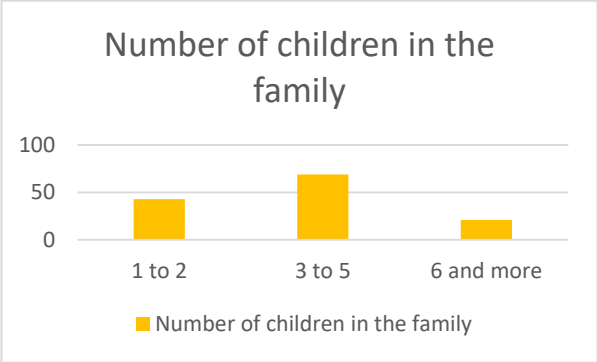

Figure 1. How many children do you have in your family, including the autistic child?

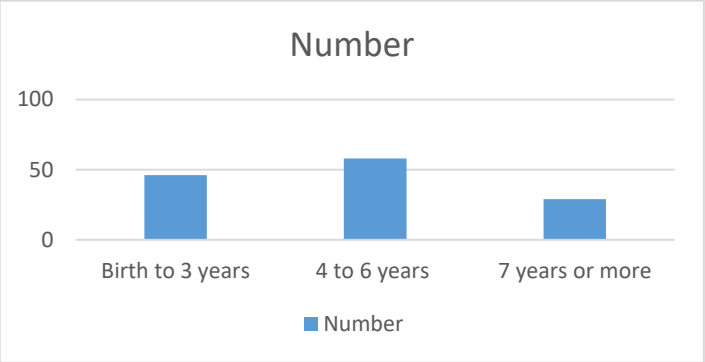

Figure 2. What is the age of your autistic child?

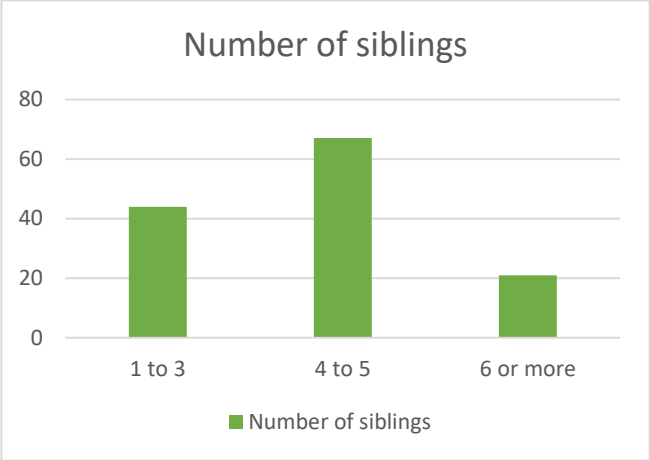

Figure 3. How many siblings does your autistic child have?

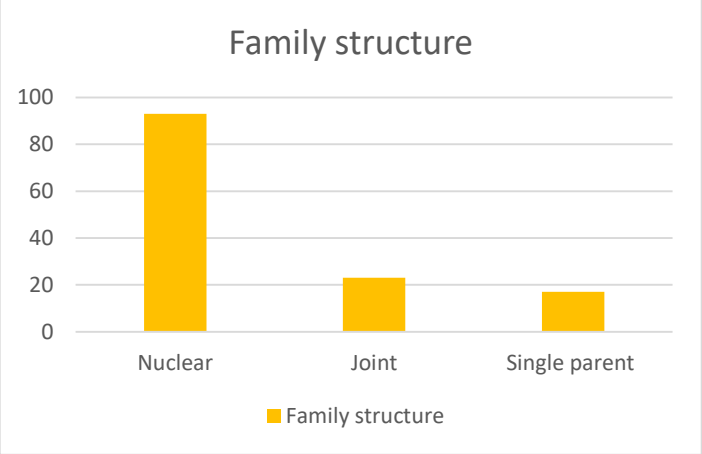

Figure 4. How would you describe your family structure (nuclear, joint, single-parent, blended, etc.)?

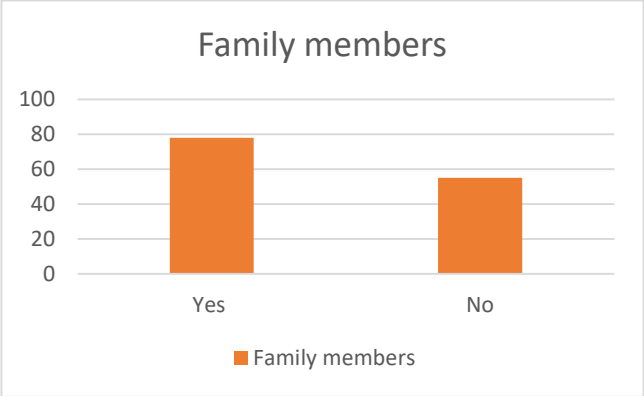

Figure 5. Are there any other family members living with you, such as grandparents or extended family?

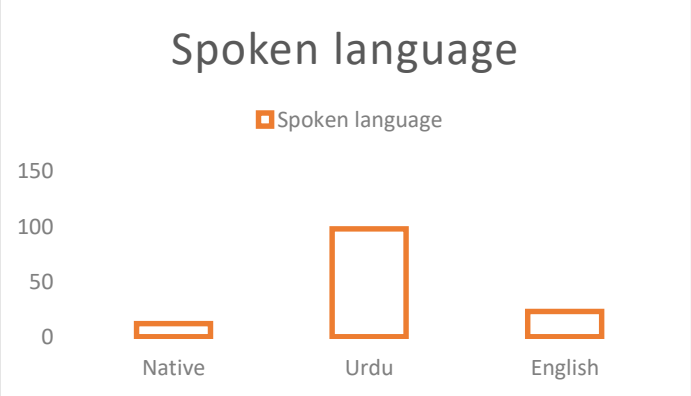

Figure 6. What is the primary language spoken at home?

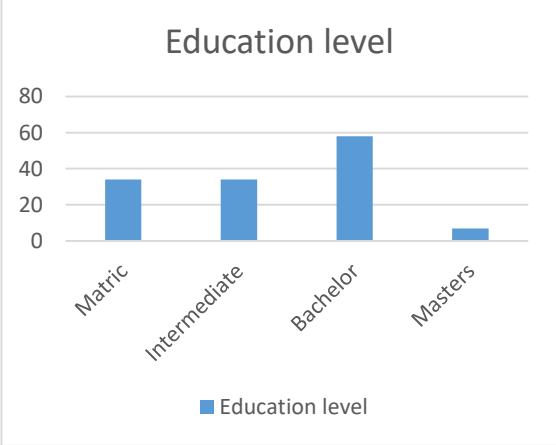

Figure 7. What is the highest level of education attained by the primary caregiver (parent or guardian)?

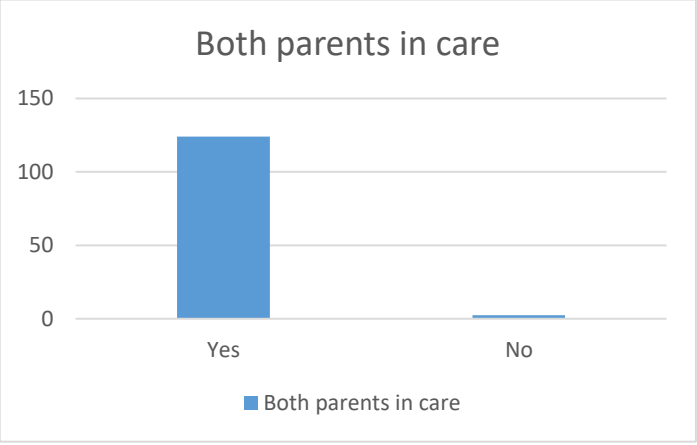

Figure 8. Are both parents actively involved in care-giving and decision-making for the autistic child?

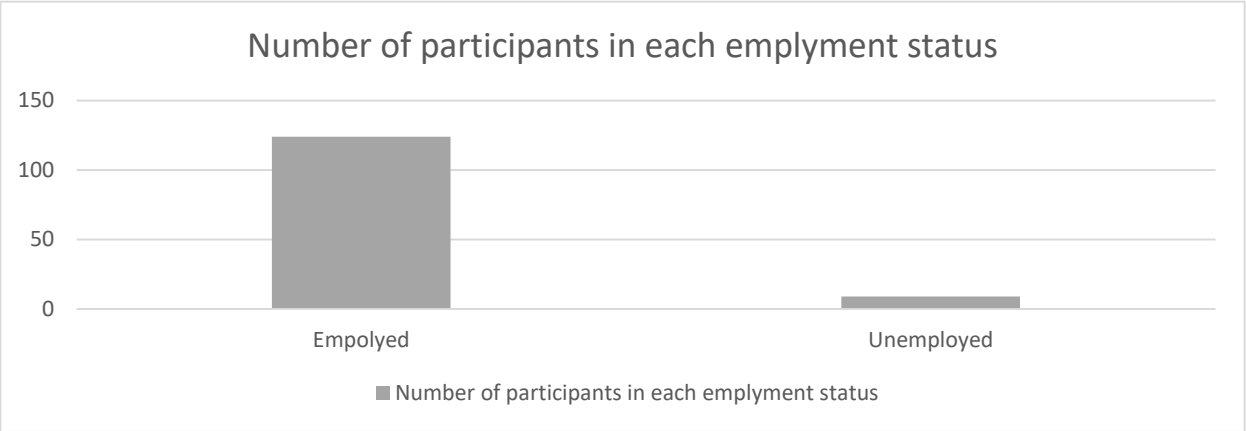

Figure 9. What is the employment status of the primary caregiver(s)?

DISCUSSION

In the present study, it is noteworthy that a substantial majority of families, comprising approximately 70% of the total sample, exhibit a nuclear family structure as their predominant familial arrangement. This observation is in stark contrast to the findings of a previous study, the distribution of family structures between joint and nuclear family setups was evenly balanced, with each accounting for a 50% share of the sampled families. However, the landscape of family structures in our current study also reveals that a significant number of families continue to follow a joint family setup. This shift in the family structure landscape between the two studies underscores the evolving nature of family dynamics and their role in contemporary society, thereby highlighting the need for further examination and analysis in order to better understand the underlying factors contributing to this notable transformation(8) The analysis of the primary caregivers' employment status reveals a well-distributed and balanced distribution, with 59% of them currently engaged in gainful employment, while the remaining 41%were unemployed at the time of data collection. This distribution bears resemblance to the findings of a previous study, where the employed segment constituted 55% of the total primary caregiver population, highlighting a consistent pattern in the employment dynamics of this demographic. A stable and robust local economy, along with consistent employment opportunities, could result in a similar distribution of employed(13)

The educational attainment of primary caregivers in the current study exhibits a notable degree of variability, with a substantial portion of them having achieved a Bachelor's degree, constituting approximately 43% of the participant. This observation underscores the diverse educational backgrounds of the primary caregivers involved in this study.

This pattern of high educational attainment among caregivers echoes findings from a previous study, it was noted that 53% of fathers had graduated from a higher educational institution, while 39% of mothers had similarly accomplished this educational milestone. The consistency in the prevalence of graduation levels among parents in both studies highlights the significance of education within the family context, with a substantial proportion of caregivers in both cases (8). The study's focus on family structure and autism prevalence might overlook other significant factors that contribute to the dynamics of raising an autistic child. The study's relatively small sample size might not adequately represent the diversity and complexity of family structures and their relation to autism prevalence

CONCLUSION

The investigation into the frequency of autism within joint and nuclear families reveals that a majority of families with autistic children lean towards nuclear family structures. While joint families exist, they are less prevalent. The study also underlines that parental engagement is high across both family types, with over 90% actively participating in care giving and decision-making.

Conflict of interest:

Authors declare no conflict of interest

Ethical Consideration

The study was approved by local research ethics committee, informed consent was taken from all the participants and their identity was anonymized.

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