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A Study On Psycho Social Problems Faced By The Bystanders Of Autistic Children

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Abstract

The present study titled “A Study on Psycho-Social Problems Faced by the Bystanders of Autistic Children” aims to examine the psychological and social challenges experienced by individuals who care for autistic children. Autism is a developmental disorder that affects communication, behaviour and social interaction. It not only impacts the child but also places a significant burden on caregivers and family members. This study focuses on understanding the everyday experiences and difficulties faced by these bystanders. A descriptive research design was adopted to study the existing conditions without any manipulation. The universe of the study includes bystanders associated with autism care centers, special school and therapy centers in Kozhikode, Kerala. A total of 50 respondents were selected using purposive sampling. Primary data was collected through a structured questionnaire using Google Forms, while secondary data was collected from books, journals and online sources.

The study covers different aspects such as psychological stress, anxiety, emotional burden, social isolation, financial difficulties and coping strategies used by the respondents. A pre-test and pilot study were conducted to improve the clarity of the questionnaire. The collected data were organized and analyzed using basic statistical methods. The findings indicate that bystanders of autistic children experience high levels of stress, anxiety and social challenges. Many respondents also reported limited support systems. However, they adopt various coping strategies to manage their difficulties. Based on the findings, the study suggests the need for increased awareness, better support services and effective interventions to reduce psycho-social problems. Overall, the study highlights the importance of providing adequate support to caregivers and improving their well-being.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects social interaction, communication, behavior, and sensory processing from early childhood. It is a lifelong condition with varying levels of severity, ranging from mild to requiring full-time care. Common characteristics in autism include difficulty in communication, delayed language and movement skills, problems in social relationships, and repetitive behaviors like hand flapping or strict routines. As stated by Pahil and Kumar (1991), parents of children with developmental disabilities experience significant stress and adopt various coping strategies. Similarly, Quine (1991) highlighted the impact of caring for a child with severe learning difficulties on the overall functioning of the family. Early identification (before age 3) is important and can be done through screening tools, parental observation and professional assessment. Although there is no cure, therapies, behavioral interventions and supportive environments help improve skills and quality of life. Autism may also be associated with conditions like anxiety, ADHD, epilepsy and in some cases, special abilities (savant skills). Causes are mainly genetic, with some influence from prenatal and birth-related factors.

Autism not only affects the child but also creates psycho-social, educational and financial challenges for caregivers (bystanders) such as parents, siblings and teachers. Families face stress, anxiety, depression, social stigma, isolation and financial burden due to therapy costs, special education and reduced income. Educational challenges include lack of inclusive schools, trained teachers, and frequent complaints about behavior. Work-related issues like absenteeism, job loss and reduced career growth also increase stress. Cultural beliefs and lack of awareness may delay proper treatment. However, coping strategies such as counselling, support groups, family support, awareness programs, self-care and professional guidance can help reduce stress and improve family functioning and child development.

Methodology

The present study adopts a descriptive research design to study the psycho social problems of bystanders of autistic children. The study is based on both primary and secondary data sources. Primary data was collected from 50 respondents from special school and therapy centers in Kozhikode, Kerala, using a structured questionnaire through purposive sampling method. While secondary data were obtained from journals books and articles. The collected data were systematically classified, tabulated and analyzed using simple statistical tools such as percentage analysis and frequency distribution. The Objective of the study is to study the socio demographic characteristics of the respondents, to identify the psychological problems experienced by the respondents, to examine the social challenges faced by the respondents and to suggest suitable measures to improve the coping mechanisms of the respondents.

Major Findings

The findings of the study indicate that the majority of respondents are adults in the 25–40 years age group, reflecting that caregivers of autistic children are primarily in their active parenting stage. Most respondents are female, highlighting that caregiving responsibilities are largely undertaken by women. The data also show that autism affects families across different religious backgrounds, with the majority belonging to the dominant religion in the sample. In terms of education, most caregivers have at least secondary-level qualifications. A significant proportion of respondents are unemployed or homemakers, suggesting that caregiving duties often limit employment opportunities. The majority belong to the middle-income group and reside in urban or semi-urban areas. Most families have two children, and the autistic children are predominantly aged between 5–10 years with a higher proportion of male children. Many caregivers have been providing care for more than five years, and most families report no history of autism in other members, indicating that the condition commonly affects a single child within the family.

The study further reveals considerable psychosocial challenges faced by caregivers. A majority of respondents report experiencing stress, anxiety about their child's future and difficulty managing their child's behaviour. Feelings of frustration, guilt and social judgment are also commonly reported, along with challenges in maintaining relationships and sharing emotions. Despite these difficulties, most caregivers report a strong emotional bond with their child. Many face issues related to physical health, lack of sleep, social isolation and limited time for personal activities. While moderate family support is reported by many, stigma, social exclusion and occasional negative experiences with healthcare professionals persist. Caregivers actively advocate for their child's needs, especially in education, though many struggle to access services.

Financial and occupational challenges are also significant, with concerns about future expenses, debt and difficulty balancing work and caregiving responsibilities. Overall, caregiving responsibilities heavily influence daily routines, mental well-being and quality of life.

Suggestions

Regular counselling and psychotherapy services should be made accessible to parents and family members of autistic children with trained psychologists appointed in government hospitals and special schools, along with crisis intervention for highly stressed caregivers. Community-based parent support groups with monthly meetings can promote sharing and coping, while regular mental health screening for caregivers and psychosocial assessment of siblings ensure overall family well-being. At the same time, autism awareness campaigns, public education to reduce stigma and training for teachers and community workers are essential. Government support through subsidies for therapies, financial counselling, strong implementation of disability rights laws and community-based rehabilitation programs is also crucial for inclusive and sustained support.

Social Work Intervention

Social work intervention is essential in addressing the psycho-social problems faced by caregivers of autistic children at multiple levels. At the individual level, social workers provide counselling, emotional support and coping strategies to manage stress and improve well-being. At the family level, they strengthen relationships, offer guidance on parenting and ensure the emotional needs of siblings can be addressed. At the group level, they facilitate parent support groups and conduct awareness programs to reduce isolation and enhance shared learning. At the community level, social workers promote autism awareness, reduce stigma and collaborate with schools and healthcare systems to encourage inclusive practices and early intervention. At the policy level, they advocate for effective implementation of disability rights, access to mental health services and government support such as financial assistance and subsidies for therapies, ensuring comprehensive care and support for families.

Conclusion

The study focuses on the psycho-social problems faced by bystanders of children with autism, emphasizing that autism affects not only the child but the entire support system. Bystanders experience high levels of stress, anxiety, emotional exhaustion and uncertainty due to continuous caregiving demands, behavioral challenges and concerns about the child's future, often worsened by lack of professional support. Social isolation is common as stigma, misunderstanding and negative societal attitudes lead to withdrawal and reduced social interaction. Financial strain further adds to their burden, as long-term therapies and caregiving responsibilities impact income stability. Overall, the study concludes that supporting the emotional, social and financial well-being of bystanders is essential for effective autism care, and that inclusive interventions addressing their challenges can improve caregiving environments and outcomes for autistic children.

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