



Knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.

¹ Vaishali Ingole, Assistant Professor, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar,

² Ruchira Kadam, Assistant Professor, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar,

³ Trupti Kulkarni, Associate Professor and HOD, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar,

⁴ Pranjal Grover, Professor & Principal, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar.

⁵ Satish Pimpale, HOD & Professor, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar.

⁶ Apoorva Dighe, Associate Professor, TMV'S Lokmanya Tilak College of Physiotherapy, Kharghar.

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KEYWORDS:

Autism spectrum disorder (ASD), Knowledge, Government health schemes.

ABSTRACT:

Background: Children with Autism Spectrum Disorder (ASD) often require multidisciplinary interventions, including physiotherapy. The Indian government offers various health schemes to support such needs. However, the extent of caregiver's awareness and utilization of these schemes remains unclear.

Objective: To assess the level of awareness of Knowledge on Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.

Methods: A pre-post quasi experimental study was conducted among 60 caregivers of children diagnosed with ASD and receiving physiotherapy treatment. A workshop was organised at educational institute, lecture was delivered which included awareness on Niramaya scheme description, funding pattern, eligibility criteria, process, scheme renewal and claim process. A structured questionnaire in English/Hindi assessed their knowledge about disability certification, rights, benefits, and various government welfare schemes.

Result: The study revealed a significant lack of awareness among caregivers regarding disability and government welfare schemes. Many caregivers were unaware of the existence of disability certification processes and the rights and benefits available under various government schemes. This lack of knowledge contributes to the underutilization of rehabilitation services and other support mechanisms.

Conclusion: To improve the quality of life for children with ASD, it is imperative that their caregivers are well-informed about available rights and welfare schemes. Efforts should focus on educating caregivers and healthcare providers to bridge the knowledge gap and facilitate better access to support services.

INTRODUCTION

Autism spectrum disorder (ASD) is a childhood developmental disorder. It is characterized by multiple social, behavioural, and communication difficulties. ASD is accompanied by anatomical and functional changes in the brain of an ASD patient [1]. ASD could have varying degrees of severity, with some cases being moderate and others being severe. Severe cases necessitate a great deal of assistance and ongoing support. Patients with ASD have a tendency to repeat certain behaviours and might not want change in their daily routine [1].

This disorder affects one out of every 44 children, and it can affect people of all races and ethnic groups. As a

result, it is one of the most frequent developmental impairments among children [2]. There has been an increase in the incidence of ASD in the last two decades, and one possible reason for this increase is that, while this condition is a lifelong disorder, there is greater awareness of it today than in the previous two decades, and as a result, caregivers of ASD children are beginning to seek screening and diagnosis from a specialist [3].

ASD diagnosis is problematic because no direct tests, such as a blood test or particular biomarkers in the body, are available to confirm the diagnosis. A diagnosis for ASD is based on observing the child's behaviour [3]. In 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5 of the American Psychiatric



Association published their criteria for the diagnosis of ASD spectrum, adding pervasive developmental disorder and Asperger's disorder to the ASD spectrum. Before that, they were classified as different subgroupings of the ASD spectrum, but now they consider autistic syndrome, Asperger's disorder, and pervasive developmental disorder to be part of the ASD spectrum. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5, ASD is linked to a variety of mental disorders, including attention deficit hyperactivity disorder (ADHD), social anxiety disorder, depression, and intellectual disability [4-6].

Some of the risk factors for developing ASD include genetic and environmental variables [7]. Some medicines taken by the mother during pregnancy, such as valproic acid, have been linked to the development of ASD in children [8]. ASD is more likely to affect children born to older parents. Furthermore, the age of the pregnant lady, i.e., if the mother is over 40 years old, has an impact on the development of ASD [9]. Additionally, whether the mother was pregnant while suffering from hypertension or a viral or bacterial infection has a bearing on the development of the disorder [10]. A child's brother or sister is more likely than other siblings to have an ASD if he or she has an ASD. A genetic and chromosomal disorder, such as the Fragile X chromosome, can potentially cause ASD [11]. Besides, changes in the GABAergic, glutamatergic, serotonergic, and dopaminergic systems have been linked to ASD after exposure to neurotoxic chemicals [19].

There are many myths and misconceptions about ASD. For example, some people believe that vaccines are responsible for the development of ASD [11]. According to the World Health Organization website (WHO), there is no documented link between a vaccine and the development of ASD, and there is also no link between the MMR vaccine and the development of ASD disease [12-14].

There is no medical treatment for ASD that is able to cure the disorder. All the child's caregivers can do is to begin using special behavioural therapy, physiotherapy and occupational therapy as soon as the diagnosis is confirmed to help ASD patients develop new abilities such as talking, looking in their eyes, playing with peers, walking, and socializing [15]. The cost of ASD management is considered high because there are direct and indirect costs to the family, such as health costs and the cost of extra educational support that is required, particularly for children with intellectual disabilities,

which will place a financial strain on the family and, in many cases, result in mothers losing their jobs [16-18].

Disability amongst children is a matter of serious concern as it has wider implications. Parents are the most important persons in a child's life and render maximum assistance to children with disability. There are many special services which are required for children with ASD but their parents are not able to avail of those due to a lack of awareness regarding different programmes and schemes which are specially made for their child's benefit. For improving the quality of life of children with ASD, it is important that their parents are made aware of these rights.

To improve the quality of life of children with ASD, it is important that their caregiver, parents, special school educators, well-wishers are well aware of these rights. Very few studies have been conducted in India to assess the level of awareness of knowledge of Government Health Schemes among caregivers of children with ASD regarding the rights of their children with disability. Hence, a study was planned to determine the magnitude of awareness of health schemes amongst parents of children with autism spectrum disorder (ASD) regarding disability, disability certification, rights and benefits and welfare schemes.

AIM

- To study the knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.

OBJECTIVES

- To understand existing knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.
- To understand the effect of session delivered on knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.

HYPOTHESIS

- **Alternate hypothesis (H1):**

There is significant effect of session delivered on knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.



- **Null hypothesis (H₀):**

There is no effect of session delivered on knowledge of Government Health Schemes Among Caregivers of Children with Autism Spectrum Disorder.

METHODOLOGY

- Study design: Quasi Experimental Pretest and post- test study
- Sampling: Convenient sampling
- Sample size: 60
- Study setting: Educational Institute of special school.

Inclusion criteria:

- Parents of children diagnosed with autism spectrum disorder.
- Special school educators

Exclusion:

- Any other medical or surgical conditions.

Materials:

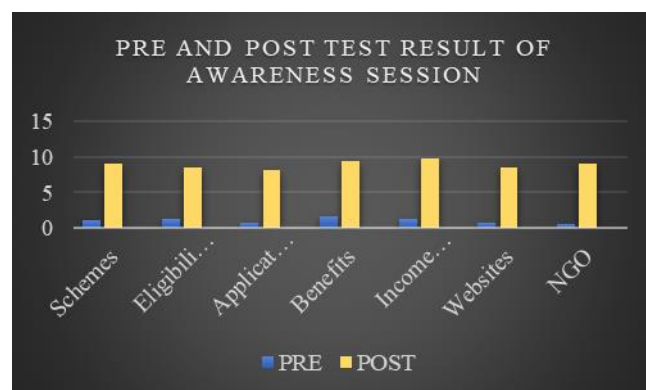
- Pen and paper
- Self-administered questionnaire
- Consent form
- Power point presentation
- Feedback form

PROCEDURE:

A study was conducted at Educational Institute at Kharghar area. Ethical clearance was obtained from the institute. Participants consent was taken. Lecture was delivered which included awareness on Niramaya scheme description, funding pattern, eligibility criteria, process, scheme renewal and claim process. A structured questionnaire in multiple regional language assessed their knowledge about disability certification, eligibility criteria, application process, benefits, and NGO's. In pre-test, questionnaire was administered in which subjects were asked to answer the questions based on their awareness regarding Government Health schemes. In post-test, the questionnaire was readministered to check the awareness of knowledge.

DATA ANALYSIS AND RESULTS:

Statistical analysis was done using paired t-test.



Graph 1

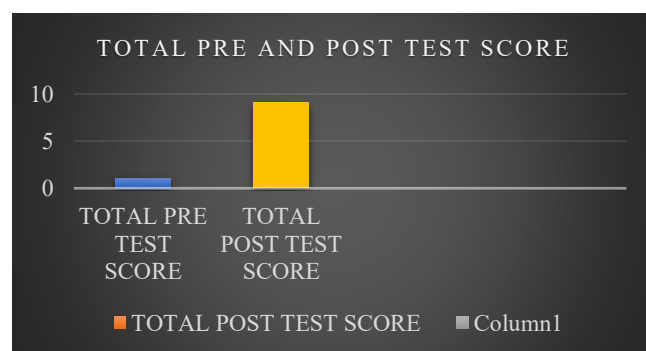
Comparison of pre and post scores of awareness session

	Sch eme s	Eligi bili ty Cri te ria	Appli cation proce ss	Ben efits	Inc ome gro up	Web sites	N G O
Pr e sc or e	1.06	1.36	0.69	1.56	1.23	0.73	0.57
Po st sc or e	9.10	8.55	8.11	9.45	9.66	8.43	9.06

Result: There is significant change ($p < 0.001$) in test score post awareness session.

Graph 2

Comparison of total pre and post scores of awareness session.





There is significant change ($p < 0.001$) in the total scores post awareness lecture.

Total pre value score	1.04
Total post value score	9.08
p- value	0.001

Result: There is significant change ($p < 0.001$) in the total scores post awareness lecture.

DISCUSSION

In the past two decades, India has made significant progress in the disability and health schemes, leading to major legislative changes, such as the RPWD Act, 2016, and the National Trust Act, 1999. These laws, along with initiatives such as the Right to Education (RTE) Act, Government schemes for autism disorders such as the Niramaya scheme, Disha scheme, Vikaas scheme, Samarth scheme, GHARUNDA scheme and BADHTE KADAM scheme, have aimed to provide affordable Health insurance to persons with autism, cerebral palsy, mental retardation and multiple disabilities. However, the findings of this study reveal significant gaps in awareness and utilisation of these schemes amongst caregivers of children with ASD.

Our study shows that while a majority of caregivers are (9.08) are aware of government health schemes for autism children, there is a stark lack of knowledge about available government schemes, funding pattern, eligibility criteria, disability certificate, enrolment process, scheme renewal, claim process and legal rights. This is consistent with previous research, which also highlights a general lack of awareness amongst caregivers regarding benefits and schemes designed to support their children's needs. The limited awareness of initiatives such as the Universal Disability Identity card and the provisions under key legislations further hinder caregivers' ability to access necessary services. In this study, caregivers showed poor awareness on benefits regarding, Limit of Hospitalization (corrective surgeries, non-surgical, hospitalization), limit for Out Patient Department (medicines, pathology, diagnostic tests, regular medical check- up, dentistry) transportation costs which offer immediate practical value. However, knowledge of Government health schemes, including the Niramaya scheme, Disha scheme, Vikaas scheme, Samarth scheme, GHARUNDA scheme and BADHTE KADAM scheme remains notably poor. Similar findings were reported in other studies, which also pointed to

limited knowledge of health schemes amongst parents of children with autism spectrum disorders.

Few studies have been conducted on the awareness of primary caregivers of the human rights of their children with intellectual disabilities^[19-20] Bailey conducted research on awareness, use and satisfaction with services for Latino parents of young children with disabilities and results revealed that only a minority of the sample had limited awareness and use of medical, early intervention, special education and social services^[21] A survey conducted by Venkatesan on knowledge and opinion on rights, immunities and privileges for persons with mental retardation revealed that most of the respondents were able to correctly answer only half of the items in the questionnaire^[22]

Research done by Sharma on the assessment of awareness levels of parents showed that all parents knew that children have rights and entitlements but could list only few. Parents voiced that only a few have access to these services. They added that the rights for disabled children were neither acknowledged nor accorded by society. They expressed their disappointment with society for creating discriminatory experiences for their children^[23]

A reality check is quite startling as the majority of caregivers of children with disabilities are not aware regarding the health schemes and the ones who are aware are not able to avail of them. To improve the quality of life of children with disability, it is important that their caregivers are well aware of these schemes. Very few studies have been conducted in India to assess the level of awareness amongst caregivers regarding the schemes of autism spectrum disorders.

Importantly, the results underscore the significant influence on pre- test core of eligibility criteria, application process, websites, NGO, income group, benefits, of awareness levels. Caregivers with higher education and professional occupations demonstrated better knowledge of disability rights and welfare schemes. Hence, a study was planned to determine the magnitude of awareness of health schemes amongst parents of children with autism spectrum disorder (ASD) regarding disability, disability certification, rights and benefits and welfare schemes.



CONCLUSION

This study highlights three critical findings:

1. Low awareness of Government health schemes: There is a significantly low level of awareness regarding various associated welfare schemes amongst caregivers.
2. Underutilisation of services: A considerable gap exists between the availability of schemes-related benefits and caregivers' awareness of how to access these services, leading to substantial underutilisation.
3. Influence of socioeconomic factors: Caregivers' education and occupation significantly influence their awareness levels. Those with higher education or professional occupations demonstrate greater knowledge of disability rights and welfare schemes, highlighting the need for targeted educational programmes to bridge this gap.

In conclusion, this study emphasises the urgent need for improved awareness and accessibility of resources. Ensuring that all caregivers – regardless of their socioeconomic background – are informed about the available support and services is crucial for enhancing the quality of life and inclusion of children with disabilities in society. Targeted interventions, particularly in underserved communities, will be vital in reducing disparities and promoting equal opportunities.

RECOMMENDATIONS

To address the identified gaps, we recommend the following:

1. Awareness campaigns: Nationwide awareness campaigns should be launched, particularly in rural and suburban areas, to educate caregivers on available welfare schemes.
2. Training programmes for medical professionals: Training programmes should be initiated for healthcare providers to ensure they can effectively guide families through the disability certification and welfare process.
3. Improved accessibility: The implementation of district-level certification and camp-based services should be enhanced to reach underserved areas, making services more accessible.

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