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KNOWLEDGE AND PERCEIVED CAREGIVING BURDEN AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN SELECTED URBAN AREAS OF PUNJAB

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ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by persistent difficulties in social communication and social interaction along with restricted, repetitive patterns of behaviour, interests, or activities. Caring for a child with ASD may place considerable demands on mothers and may influence their psychological, social, physical, and family functioning. Adequate knowledge about ASD may help mothers understand the condition, recognize the needs of their children, and adopt appropriate caregiving strategies.

Objectives

The study aimed to assess the knowledge and perceived caregiving burden among mothers of children with autism spectrum disorder, determine the relationship between knowledge and perceived caregiving burden, and identify associations between selected demographic variables and knowledge and caregiving burden.

Methods

An exploratory research design was adopted to assess knowledge and perceived caregiving burden among mothers of children with ASD in selected urban areas of Punjab. The study population comprised mothers of children diagnosed with ASD who fulfilled the specified inclusion criteria. Data were collected using a structured demographic questionnaire, a knowledge questionnaire related to ASD, and an appropriate scale for assessing perceived caregiving burden. Descriptive and inferential statistics were used for analysis.

Results

The findings showed that the overall mean knowledge score was 28.01 ± 6.11. Among the participants, 43.5% demonstrated good knowledge, 43.5% demonstrated average knowledge, and 13.0% demonstrated poor knowledge. The relationship between knowledge and perceived caregiving burden and the associations with selected demographic variables were analyzed using appropriate statistical tests.

Conclusion

The findings indicate the need to strengthen mothers' knowledge regarding ASD and provide appropriate educational and supportive interventions to reduce caregiving difficulties and improve the overall well-being of mothers and their children.

Keywords: *Autism spectrum disorder, knowledge, mothers, caregiving burden, nursing, children, Punjab.*

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INTRODUCTION

Autism spectrum disorder is a lifelong neurodevelopmental condition that affects social communication, interaction, behaviour, and adaptive functioning. The manifestations and severity of ASD vary considerably among children, resulting in diverse developmental, educational, behavioural, and caregiving needs. Early identification, appropriate intervention, family participation, and continuing support are important components of comprehensive care. The Autism and Developmental Disabilities Monitoring Network of the Centers for Disease Control and Prevention monitors the prevalence and characteristics of autism spectrum disorder in the children in different communities (Centers for Disease Control and Prevention, 2024).

The quality of life of parents of children with autism may be severely impacted by parenting stress and the demands associated with caring for a child with developmental needs. Therefore, maternal well-being should be considered while planning supportive interventions (Dardas & Ahmad, 2014).

Parents, particularly mothers who frequently undertake a major proportion of daily caregiving responsibilities, may experience substantial demands while caring for a child with ASD. These demands can include supervision of behaviour, assistance with communication and daily activities, management of educational and therapeutic needs, frequent healthcare visits, and concerns regarding the child's future. Such responsibilities may contribute to perceived caregiving burden. Parents of children with autism may experience increased psychological stress due to the continuous demands of caregiving. These challenges highlight the importance of providing appropriate emotional support and family-centred care (Bonis, 2016).

Mothers of children with autism spectrum disorder may experience considerable caregiving demands and require appropriate support to manage their children's daily needs. Understanding their care needs is essential for developing effective support and educational interventions (Atar & Kutlu, 2025).

Parenting stress is an important matter in the families of children with autism spectrum disorder. Research evidence shows that parents of children with ASD experience significantly higher parenting tension than parents of children without ASD (Hayes & Watson, 2013).

Knowledge is an important factor in enabling mothers to understand ASD, identify appropriate interventions, communicate effectively with healthcare professionals, and participate actively in the child's management. Lack of adequate knowledge may contribute to uncertainty, misconceptions, delayed intervention, and increased caregiving difficulties. Nurses have an important role in providing health education, counselling, family support, referral services, and guidance regarding available interventions and community resources. Assessing mothers' knowledge and caregiving burden can therefore help identify areas requiring educational and supportive interventions.

Need for the Study

ASD affects not only the child but also the entire family system. Mothers may experience emotional stress, changes in family routines, financial difficulties, social limitations, and uncertainty regarding the child's long-term development. The caregiving burden may be further influenced by the severity of the child's condition, availability of support, socioeconomic circumstances, and the mother's knowledge regarding ASD.

Although awareness of ASD has increased, misconceptions and inadequate understanding regarding its characteristics, causes, diagnosis, treatment, and management continue to exist. Assessing knowledge among mothers is therefore essential for identifying educational needs.

An Indian study assessing knowledge regarding autism among mothers highlighted the importance of improving maternal awareness and understanding of the condition. This emphasizes the need for structured educational programmes to strengthen mothers' knowledge of ASD (Nandhini et al., 2021).The present study was undertaken to assess knowledge and perceived caregiving burden among mothers of children with ASD in selected urban areas of Punjab. The findings may provide useful information for developing nursing education and supportive interventions aimed at improving maternal knowledge and reducing caregiving difficulties.

REVIEW OF LITERATURE

Maternal Knowledge Regarding Childhood Neurodevelopmental Disorders

Philip et al. (2021) conducted a study on Mothers' Knowledge of Childhood Neurodevelopmental Disorders: Indian Perspective in Bengaluru, Karnataka. The study assessed knowledge regarding childhood neurodevelopmental disorders among mothers of children below five years of age. The findings revealed that most mothers had insufficient knowledge, with a mean knowledge score of 3.02 ± 2.75. The authors emphasized the importance of health education programmes to improve awareness, promote early identification and strengthen mothers' understanding of childhood developmental disorders. The research highlighted the importance of assessing maternal knowledge regarding autism spectrum disorder and identifying educational needs.

Subjective Caregiving Burden and Depression Among Mothers

Singh et al. (2017) conducted a study titled Subjective Burden and Depression in Mothers of Children with Autism Spectrum Disorder in India: Moderating Effect of Social Support. The study included 70 mothers of children with ASD and examined subjective caregiving burden, depression and the influence of social support. The findings revealed that half of the mothers experienced depression of clinical significance. Higher subjective caregiving burden significantly predicted higher levels of depression, while family support played an important protective role. The study highlighted the importance of strengthening family support systems and providing appropriate psychosocial interventions for mothers of children with ASD.

Burden of Care and Quality of Life Among Caregivers

Patel et al. (2022) conducted a cross-sectional study on Burden of Care and Quality of Life in Caregivers of Children and Adolescents with Autism Spectrum Disorder in North India. The study included 40 caregivers and assessed caregiving burden using the Burden Assessment Schedule and quality of life using the WHOQOL-BREF questionnaire. The findings revealed a mean caregiving burden score of 71.73 ± 8.62, indicating a high degree of burden. Higher caregiving burden was associated with lower family income and greater severity of autism symptoms. The study concluded that caregivers of children with ASD experience considerable caregiving demands and impaired quality of life.

Caregiving Burden Among Families of Children with Autism in Odisha

Barik et al. (2025) conducted a cross-sectional study titled Burden on Family Caregivers of Children with Autism Spectrum Disorder: A Cross-Sectional Study in Bhubaneswar, Odisha. The study examined caregiving challenges among families of children aged 2–10 years with ASD. Caregiver strain was assessed using the Caregiver Strain Questionnaire. The findings showed that caregivers experienced considerable subjective and objective strain. Education, socioeconomic status and family type were significantly associated with caregiver strain. The authors recommended educational and counselling sessions to reduce caregiving stress and improve caregivers' quality of life. This study provides relevant evidence from the Indian context regarding the challenges experienced by families caring for children with ASD.

Quality of Life Among Mothers of Children with Disabilities

Tarigan et al. (2024) conducted a systematic review titled Determinants of the Quality of Life of Mother with Children with Disability: A Systematic Review. The review examined factors influencing the quality of life of mothers caring for children with disabilities. The findings indicated that mothers of children with ASD had lower quality-of-life scores compared with mothers of children with other disabilities. Psychological health and caregiving responsibilities were identified as important concerns affecting maternal well-being. The authors gave importance to the interventions that promote healthy lifestyles and improve the quality of life of mothers caring for children with disabilities. These findings reinforce the need to consider maternal well-being while assessing caregiving burden.

OBJECTIVES OF THE STUDY

1. To assess the knowledge among mothers of children with autism spectrum disorder.
2. To assess the perceived caregiving burden among mothers of children with autism spectrum disorder.
3. To determine the relationship between knowledge and perceived caregiving burden among mothers.
4. To determine the association between knowledge and selected demographic variables.
5. To determine the association between perceived caregiving burden and selected demographic variables.

METHODOLOGY

Research Approach and Design

An exploratory research approach was adopted for the present study. An appropriate exploratory research design was used to assess knowledge and perceived caregiving burden among mothers of children with ASD.

Research Setting

The study was conducted in selected urban areas of Punjab as specified in the research protocol.

Population

The target population consisted of mothers of children diagnosed with autism spectrum disorder who met the predetermined eligibility criteria.

Sample and Sampling Technique

The sample comprised eligible mothers of children with ASD recruited according to the sampling procedure described in the study protocol.

Data Collection Tools

The data collection instruments consisted of:

Section A: Demographic characteristics of the participants.

Section B: Structured knowledge questionnaire related to autism spectrum disorder.

Section C: Scale for assessment of perceived caregiving burden among mothers of children with ASD.

The instruments were subjected to the required procedures for validity and reliability before their use in the main study.

Data Collection Procedure

After obtaining the necessary administrative permission and ethical approval, eligible participants were approached and informed about the purpose of the study. Informed consent was obtained before data collection. Participants were assured that the information provided would be kept confidential and used only for research purposes. The required questionnaires and scale were administered and completed responses were collected for analysis.

Data Analysis

Descriptive statistics such as frequency, percentage, mean, and standard deviation were used to summarize the study variables. Appropriate inferential statistical tests were applied to determine relationships and associations between the study variables and selected demographic characteristics.

RESULTS

Knowledge Regarding Autism Spectrum Disorder

The overall mean knowledge score among mothers was **28.01 ± 6.11**.

Knowledge level	Frequency	Percentage
Good	87	43.5%
Average	87	43.5%
Poor	26	13.0%
Total	**200**	**100%**

The findings indicate that 43.5% of mothers had good knowledge regarding ASD, while an equal proportion (43.5%) had average knowledge. A smaller proportion (13.0%) had poor knowledge. Thus, although a considerable proportion of mothers demonstrated adequate knowledge, a substantial proportion still required additional information and educational support.

Perceived Caregiving Burden

The perceived caregiving burden among mothers was assessed using the specified caregiving burden scale. The overall distribution of participants according to caregiving burden, together with the mean and standard deviation, was analyzed according to the findings obtained in the study.

Relationship Between Knowledge and Perceived Caregiving Burden

The relationship between mothers' knowledge regarding ASD and their perceived caregiving burden was assessed using the appropriate statistical test. The findings were interpreted according to the obtained correlation coefficient and level of statistical significance.

Association of Knowledge with Demographic Variables

The association between knowledge scores and selected demographic variables such as mother's age, educational status, occupation, type of family, family income, gestational age, mode of delivery, number of children, and source of information was examined using appropriate statistical tests.

Association of Perceived Caregiving Burden with Demographic Variables

The association between perceived caregiving burden and selected demographic characteristics was also assessed using appropriate statistical tests.

DISCUSSION

The present study demonstrated that mothers differed in their level of knowledge regarding autism spectrum disorder. The mean knowledge score was 28.01 ± 6.11, with 43.5% of mothers having good knowledge, 43.5% having average knowledge, and 13.0% having poor knowledge.

The findings emphasize that knowledge regarding ASD cannot be assumed to be adequate merely because mothers have some awareness of the condition. Mothers require accurate and understandable information concerning the nature of ASD, early identification, behavioural manifestations, available interventions, educational needs, and long-term management.

The presence of average and poor knowledge among a considerable proportion of participants highlights the importance of structured health education. Nurses and other healthcare professionals can contribute substantially by providing individualized education, counselling, referral guidance, and family-centred support.

The findings related to caregiving burden further demonstrate the importance of considering the mother's experience when planning care for children with ASD. Caregiving is a continuing process that may affect family functioning, social participation, emotional well-being, and quality of life. Therefore, interventions should

address not only the developmental needs of the child but also the informational and supportive needs of the caregiver.

IMPLICATIONS FOR NURSING PRACTICE

The findings have several implications for nursing practice:

- Nurses should provide structured health education to mothers regarding ASD.
- Nurses should identify mothers who have inadequate knowledge and provide individualized teaching.
- Family-centred counselling should be incorporated into ASD care.
- Nurses should provide information regarding early intervention, therapy, education, and available community resources.
- Mothers experiencing substantial caregiving burden should be identified and referred for appropriate psychosocial support.
- Parent education programmes and support groups may be developed to improve coping and caregiving skills.
- Community health nurses can contribute to early identification and referral of children with developmental concerns.

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