Dissertation Training

at

International Institute of Health Management Research

Between Support and Stigma: Experiences of parents of Children with Autism Spectrum Disorder: A qualitative study

By

Ms. Supriya

PG/24/107

Under the guidance of

Dr. Anuj Kumar Pandey

PGDM (Hospital & Health Management)

2024-2026

International Institute of Health Management Research

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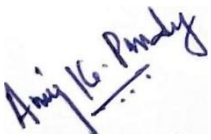
"Between Support and Stigma: Experiences of parents of Children with Autism Spectrum Disorder": A qualitative study

11th June 2026

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She comes across as a committed, sincere and diligent person who has a strong drive and zeal for learning.

We wish her all the best for future endeavours.



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I wish her all success in her future endeavours.

Best wishes Supriya!

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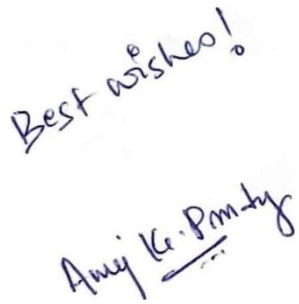
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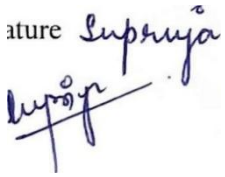
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- Academic courses at master's and doctoral level in health and hospital management to meet the growing need of skilled healthcare professionals.
- Research that has high relevance to health policies and programs at national and global level.
- Continued education through management development programs and executive programs for working professionals to help them upgrade their knowledge and skills in response to the emerging needs of the industry.
- Technical consultation to the national and state-level flagship programs to address the gaps in planning as well as implementation.

Over the years IIHMR Delhi has emerged as an institute of repute both nationally and globally for producing socially conscious, skilled and vibrant top-class health care management professionals. Our graduates are well-matched for the ever-changing health care sector and evolving social milieu. The institute has progressed as a leader in research, teaching, training, community extension programmes and policy advocacy in the field of health care. IIHMR has carved out a niche for itself through its cutting-edge academic curriculum, infrastructure, accomplished multi-disciplinary faculty and research. The Institute as an autonomous body of international stature has been developing leaders for several years to shape tomorrow's healthcare by equipping the students in the fields of health, hospital, and health information technology.

The Institute's dynamic health care research programmes provide rigorous training in management, health systems, hospital administration, health care financing, economics, and information technology.

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It is an esteemed pleasure to submit this research report and express my heartfelt gratitude to everyone who supported and guided me throughout this journey.

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Introduction

Between Support and Stigma: Experiences of parents of Children with Autism Spectrum Disorder": A qualitative study

Autism spectrum disorders (ASD) is a broad category of illnesses. They are distinguished by a certain level of communication and social interaction difficulties. Atypical activity and behaviour patterns, such as trouble switching between activities, attention to detail, and strange reactions to sensations, are additional traits.(1)

In 2021 about 1 in 127 persons had autism globally.(2) The prevalence of ASD in India is estimated to be between 1 in 68 to 1 in 100 children and this estimate varies across different regions and studies, partly due to diverse methodologies a nd populations.(3) The abilities and needs of autistic people vary and can evolve over time. While some people with autism can live independently, others have severe disabilities and require life-long care and support. Autism often has an impact on education and employment opportunities. In addition, the demands on families providing care and support can be significant. Societal attitudes and the level of support provided by local and national authorities are important factors determining the quality of life of people with autism.(3)

The *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5),* which medical professionals use to diagnose mental illnesses and developmental disorders, states that individuals with ASD frequently struggle with social communication and interpersonal interaction, have limited interests, and exhibit repetitive behaviours symptoms that impair their capacity to function in work, school, and other spheres of life.(4)

Characteristics of autism may be detected in early childhood, but autism is often not diagnosed until much later. People with autism often have co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder. The level of intellectual functioning among autistic people varies widely, extending from profound impairment to superior levels.(4) Hence, the child needs occupational therapy, it is a therapeutic method focusing on improving activity participation skills by addressing personal characteristics, activity, and environment that affect an individual's role performance.(5)

The understanding and treatment of autism spectrum condition have changed in recent years due to increased awareness, early diagnosis, and improvements in intervention techniques. There is a movement towards acceptance and support, as seen in the rise in therapeutic services, inclusive school policy, and more lobbying. Yet despite these positive gains, many parents and family carers still experience stigma, social rejection, and misunderstanding in their communities. (6). Social attitudes and structural impediments often prevent parents from providing optimal care for children with autism. Stigma, low awareness and misconceptions about autism that remain can lead to judgements in the workplace and the community that diminish flexibility and social support for parents. (7) Parents may struggle to attend therapy sessions or handle behavioural issues as employers may not comprehend the responsibilities of parenting in many contexts. Moreover, the absence of inclusive childcare services and supportive legislation significantly constrains the choices of working parents, who are thus required to juggle job and caring in the face of substantial stress. Carer burden and workforce involvement among parents of children with autism have been found to be associated with stigma and lack of institutional support (1)

For Ritu, mother of a five-year-old with autism, life is “a constant balancing act of care and judgment.” Her days are spent in therapy appointments, behavioural meltdowns and fighting for her child’s needs. But behind this, there is also an invisible weight or societal shame. Ritu routinely encounters unwanted advice and implied judgement about her child’s health in her community. There have been fewer family functions to social events and extended family relationships have become strained. It has been tough, but she does have a small support network of other parents in similar situations that she sometimes finds solace in. This interplay of support and stigma has ramifications for not only Ritu’s experience of caregiving, but also her emotional and social well-being. These experiences emphasise the need to understand how carers perceive and navigate social settings when raising children with autism.

The qualitative literature on the lived experiences of parents of children with autism is scarce with few studies examining the combined influence of social support and stigma in the Indian context. Previous research has often examined clinical outcomes or studied these aspects in isolation. Therefore, this study is necessary to provide a more in-depth, contextual understanding of parents including working parent experiences that can guide more effective support systems and stigma-reduction strategies.”

Literature review

Parental Experience and Caregiving Burden in ASD

The long-term and unpredictable nature of ASD means that parents of children with the illness often have enormous caring responsibilities. ASD is associated with behavioural problems, developmental delays and co-occurring diseases such as anxiety, ADHD and epilepsy, all of which increase the requirement for care provision (6) Research suggests that caring for a child with ASD can take a toll on a parent's mental health, leading to stress, worry, depression and social isolation.

The need for ongoing therapy, such as occupational therapy and behavioural interventions targeted at enhancing functional and adaptive skills, also affects the caregiving burden (7) These solutions frequently call for ongoing parental participation, which might interfere with social life, work, and everyday routines.

Social Support and Its Role in Coping

Social support is important to assist parents deal with the challenges of parenting a child with ASD. Emotional, informational and practical support from friends, family, medical specialists and community organisations enhances parental coping and psychological well-being. Parents who have excellent support systems are better equipped to respond to the demands of parenting, But access to competent help is often hit or miss. Many parents complain about the lack of flexibility in their jobs, the lack of understanding in health care systems, and the lack of official support programs, which makes it more challenging for them to deal with caregiving chores efficiently. These problems are worsened by structural obstacles such as a lack of inclusive childcare and inadequate legislative support.

Stigma and Social Exclusion

Stigma is still a serious problem for families of children with ASD. Due to lack of awareness about autism and its behavioural signs, society often criticises, blames and misunderstands parents. Stigma is not restricted to the child but also impacts on carers, particularly mothers, who are often held responsible for the child’s behaviour or health. (8) Stigma occurs in many cultural situations such as India as social isolation, less involvement in community activities and strained family ties (9) found that caretakers often experienced perceived stigma (fear of censure) and enacted stigma (actual discrimination), which negatively affected their emotional health and willingness to seek treatment.

Interaction Between Support and Stigma

Recent research has pointed out the close association between stigma and social support in the context of parental experiences. Social support is a protective factor, yet stigma can be a huge barrier to accessing support systems since it deters parents from seeking help or joining in community networks. This cycle means that the caretaker burden increases as help decreases which further limits social engagement.

Research Gap

Although the field of research on ASD caregiving is developing internationally, most studies either focus on the clinical characteristics of autism or look at stigma and support separately. There is a lack of qualitative research in the Indian context that explores lived experiences of parents when cultural expectations, family structures and levels of awareness are vastly different from western settings.

Working parents of children with ASD, who face the additional challenge of balancing work and caregiving responsibilities, have also been under-researched. Understanding how parents simultaneously manage stigma and social support is important to develop culturally relevant interventions and policies.

Methodology

Research Question:

How are social support and stigma experienced by parents of children with autism?

Objectives:

Primary objective: To explore the lived experiences and social support and stigma among parents of children with autism.

Secondary objective:

- To explore barriers faced by parents in accessing adequate social support and services for their children.
- To examine coping strategies used by parents in response to stigma and caregiving challenges.

Study design: Phenomenology qualitative approach.

Study site: Future wings Paediatric occupational therapy clinic, Dwarka Delhi

Sampling approach: Purposive Sampling, it is best suited for exploratory research or when dealing with a very specific, niche, or hard-to-reach population.

Participant recruitment and eligibility criteria: Parents with a diagnosed ASD child in the various age range will recruit from the Paediatric Therapy and Neurodevelopmental Clinic from a Dwarka, Delhi.

Inclusion:

- Parents with a diagnosed ASD child,
- Parents who gave consent or willing to participate,
- At least one parent should be working.
- Mentally stable parents.

Exclusion:

- Parents who denied for consent,
- Parents who have language barrier.

Data collection methods and tools:

Data were collected from face-to-face in-depth Interviews with parents. Each participant was interviewed for about one hour (30-60 minutes) in a small, private, comfortable interview room. An interview guide will be employed, eliciting information about experiences regarding obtaining a social support during diagnosis, treatment and stigma experienced by parents. The tool has been adopted from various research and modified as per the context.

Interviews will be conducted using audio recording with consent. Observational notes will be taken during the interviews. Tools will be administered by the researchers in English and Hindi language. Respondents will be encouraged to express their views and feelings fully, with careful attention paid to their tone, facial expressions, demeanour, and body language, all of which will be recorded in detail. In case of any emotional distress, appropriate psychological support will be provided. Interviews will continue until relative saturation is reached, Generally, a single interview will be conducted but contact information will be retained in case clarification is needed later.

To ensure the qualitative rigor and trustworthiness, COREQ will be used as it covers three key domains: research team/reflexivity, study design, and analysis/findings and ensure quality and transparency, primarily in qualitative research, debriefing with participants at the conclusion of interview.

Data analysis:

The transcribed interviews were analysed using Braun, V. and Clarke, V. (2006) (10) Interpretative Phenomenological Analysis (IPA) is a qualitative methodology that focuses on how individuals make sense of their personal and lived experiences. The *first step* was to familiarization by reading the transcripts repeatedly, thereby deepening understanding and insight into the information contained therein. This produces descriptive, linguistic, and conceptual notes rather than summarizing categories and made free listed items. The *second step* generating emergent themes, this produces descriptive, linguistic, and conceptual notes rather than summarizing categories. The *third step* is emergent themes are arranged on a large sheet of paper or through qualitative software to find connections. Researchers map how themes fit together relationally, turning them into subordinate and superordinate themes. The *fourth step* is themes are checked against the original data to ensure the participant's voice remains centred while acknowledging the researcher's active interpretative role.

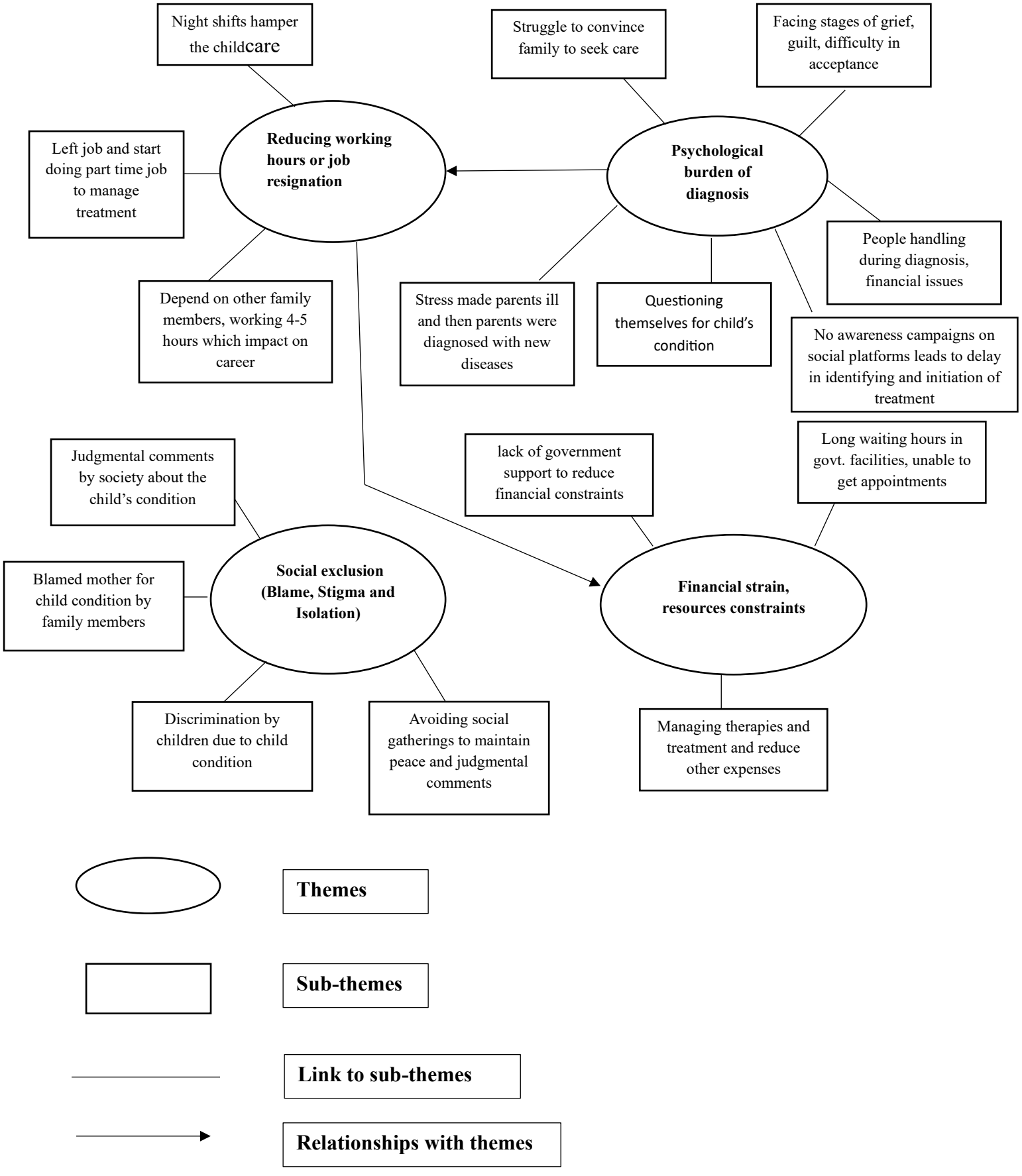
Results:

A total of six participants in all—four moms, one father, and one grandmother of children with ASD diagnoses were interviewed for this study. The participants came from a variety of professional backgrounds, including teachers, corporate workers, housewives, and personnel in the private sector.

Three of the kids with ASD were girls (50%) and three were boys (50%). Three of the kids were five years old, and three were six. The kids' ages ranged from five to six. Rehabilitation services ranged in length from 1.5 to 4 years. One participant reported two years of rehabilitation, one reported 1.5 years, and four reported four years of rehabilitation for their kids.

Number	**Relation to child**	**Occupation**	**Age of child with autism**	**gender of child with autism**	**Length of rehabilitation time (years)**
Sample 1	Father	Corporate employee	5 years	Female	2 years
Sample 2	Mother	Housewife	6 years	Female	4 years
Sample 3	Grand mother	Housewife	6 years	Male	4 years
Sample 4	Mother	Private job	6 years	Male	4 years
Sample 5	Mother	Teacher	5 years	Female	1.5 years
Sample 6	Mother	Corporate employee	6 years	Male	4 years

Four interconnected and relatively independent principal themes emerged from the data analysis: 1) Reducing working hours and job resignation, 2) Psychological burden of diagnosis, 3) Social stigma, Judgement, Public scrutiny, Avoiding public gatherings, 4) Financial strain and Resources constraints. Fifteen subthemes were identified in relation to these four master themes. The main results are shown in figure below


Night shifts hamper the childcare
Struggle to convince family to seek care
Facing stages of grief, guilt, difficulty in acceptance
Left job and start doing part time job to manage treatment
Reducing working hours or job resignation
Psychological burden of diagnosis
People handling during diagnosis, financial issues
Depend on other family members, working 4-5 hours which impact on career
Stress made parents ill and then parents were diagnosed with new diseases
Questioning themselves for child's condition
No awareness campaigns on social platforms leads to delay in identifying and initiation of treatment
Judgmental comments by society about the child's condition
lack of government support to reduce financial constraints
Long waiting hours in govt. facilities, unable to get appointments
Blamed mother for child condition by family members
Social exclusion (Blame, Stigma and Isolation)
Financial strain, resources constraints
Discrimination by children due to child condition
Avoiding social gatherings to maintain peace and judgmental comments
Managing therapies and treatment and reduce other expenses
Themes
Sub-themes
Link to sub-themes
Relationships with themes

Reducing working hours or job resignation

To meet the critical care requirements of their kid with autism spectrum condition, many carers reported making major changes to their jobs. These changes included cutting back on working hours, turning down chances for career growth, taking longer leaves of absence, moving to a more flexible position, or quitting entirely. Participants explained that these choices were required to meet their child's developmental requirements, handle behavioural issues, attend therapy sessions, and maintain constant supervision. Greater participation in caregiving was made possible by these changes, but they also brought about financial hardship, a loss of professional identity, career disruptions, and a greater reliance on other family members for financial support.

"phle main job krti thi, phle main matrimonial site par job krti thi, phir iski problem ke bad se maine waha chod diya tha" "Nahi abhi toh, wese kuch kam nahi krti bas tution classes waghreh krti hu."(S5)

Few expressed that raising a child with autism is a full-time responsibility. Even housewives, who are often assumed to be available for caregiving, described the experience as exhausting and difficult to manage without practical and emotional support from family, community, or healthcare services.

"Baccha mera pura focus isi par rehta hai, main itni alert rhti hu isko lekar kyuki yeh ek second ke ander, mera bacha matlab kuch bhi kam khrab kr skta hai…..Khi bhi jati hu tab bhi … or wese ghar me rhti hu tab bhi,…. Mera mtlab or baki kam bad me… phle main apne bacche ko dekhti hu."(S2)

"Main toh us time office ka mera esa ho gya than aa, usshe phle 8 hrs ka tha phir maine 5 hrs ka shuru krdiya tha"(S4)

Psychological burden of diagnosis

After learning about their child's health, several participants reported feeling a wide range of intense emotions, including shock, confusion, denial, despair, guilt, fear, and uncertainty. Sometimes the diagnosis was at odds with their hopes for their child's future, and raised concerns regarding long-term care, education, independence, social inclusion and developmental progress. Some carers reported feeling emotionally overwhelmed in the initial stages, particularly when they had minimal knowledge of autism and were confused about their

therapy alternatives. The psychological pressure was worsened by family reactions, cultural perspectives and the need to make crucial decisions about care and rehabilitation. In time many carers adjusted to the diagnosis but the emotional impact on the caregiving process remained strong.

"toh jo mere husband the naaa woh is bat se agree nhi krre the ki mere bacche me kuch kami ho skti hai, ... matlab unhe accept krne me problem aa rhi thi" (S2)

Few participants reported reluctance to acknowledge that their child might have a developmental disorder. This denial served as an emotional coping mechanism, allowing parents time to process the possibility of a diagnosis.

"har time mere dimaag me yahi chlta rhta tha, meri condition itni jada kharab hogyi thi, ki matlab muje chakkar aane lagye the, tension le le kar muje thyroid hogya tha, phir jada condition khrab hogyi tab waha se khud ko smbhalana shuru kiya"(S5)

"*ki hmare sath kyu hua? Phla question hi mann me yehi tha ki kyu? Matlab humne esa kya galat kiya humare bacche ke sath, ya toh humne chize kuch cheeze neglect kri, yaa khaane peene me kuch ese kra"(S6)*

Few individuals reported thinking back on their own behaviours and situations on a regular basis, wondering if their child's autism was caused by something they had done. Alongside these self-blaming emotions were feelings of remorse, powerlessness, and ongoing curiosity about what was causing the illness. Such ideas represented the caregiver's difficulty understanding the diagnosis and increased the emotional strain of providing care.

Social exclusion (Blame, Stigma and Isolation)

Every participant reported feeling misunderstood, condemned, or blamed by neighbours, family, and the larger community. Caretakers received criticism and unwanted advice because the child's behaviours were frequently seen as the consequence of bad parenting rather than a neurodevelopmental disorder. Emotional anguish and feelings of stigma were exacerbated by such responses.

Several individuals also mentioned avoiding social events, public areas, and family get-togethers out of concern for unfavourable remarks, humiliation, or rejection. Social isolation decreased social engagement, and a weakened sense of belonging were the long-term effects of these experiences. Carers often said that these experiences were exacerbated by society's ignorance about autism, which left them feeling alone and ignored.

“kuch bhi bol deta hai… jesa ki mere bacche ki harkate dekh kar,…. “Ki yeh esa hai kya, isko kya problem hai? isko doctor ke dikhao ese…” (S2)

“starting me hmare liye sab kuch naya tha, hum phle hi bhot preshan the, phir hum bacche ko khi lekar jaare hai, log ke or 4 salah, who cheez bhot jada tough hoti hai jab koi apke bacche ke barre me kuch bhi galat bol rha hai” (S5)

unko lagta hai sab bacche toh ese hai yeh kyu ese behave krra hai ese, unko lagta hai “batameez” hai bacha, park me isko bolte the “tu jaa yeh toh autistic bacha hai”(S6)

Financial strain and Resource constraints

According to parents, raising a child with ASD put a significant financial strain on the family. Significant financial strain was brought on by the expenses of diagnosis, therapy sessions, special education, transportation, and continuing rehabilitation. To cover treatment-related costs, several participants reported having to reorganise household budgets, cut back on discretionary spending, or rely solely on one source of income.

Besides financial hurdles, parents also talked about the barriers to getting the essential resources and services. Often government support programs, travel distances, affordable services and lack of specialised therapy facilities impeded access to care in a timely manner. For several families, the burden of providing care was heightened by weighing treatment costs against everyday requirements at home.

“paisa manage krna bhot muskil hai,… kyuki hum itne jada matlab nahi kra skte, par phir bhi kra rhe hai……. crying….”(S2)

“thoda sa jaise mere husband ya meri koi job hoti toh jese hmari financial condition thodi or acchi hoti toh main isko thoda or accha time de pati ya or classes waghreh dilwa pati….”(S5)

A number of participants were worried that the government was not doing enough to help and support children with autism. This made it seem like they weren't paying as much attention to developmental disabilities as they were to other public health problems. Because of a lack of institutional support and financial problems, these situations show that how hard it is for kids with ASD to get all the care and interventions they need.

Discussion

The findings of this research highlight the complicated challenges faced by parents and other carers of children with ASD, particularly psychological distress, social exclusion and financial burden. Carers described the process of receiving an autism diagnosis as a life-changing event, often involving feelings of shock, denial, confusion and uncertainty. Some had difficulty accepting that their child had development problems, others questioned whether they were partly to blame. These results are consistent with other studies that reported despair, denial, guilt and emotional suffering among parents after an autism diagnosis. (8) The emotional burden was not limited to the point of diagnosis but extended through the caregiving journey and was reflective of the ongoing worries about the child's future, developmental growth and long-term independence. Similar findings were reported by (9) where carers adapt to the lifelong challenges of raising a kid with ASD, although often experience continuous psychological stress.

Another major conclusion of the study was the experience of social exclusion in the form of blame, stigma and alone. Instead of recognising autism as a neurological illness many carers reported being reprimanded by family members, neighbours and community members who often blamed the child's behaviour on faulty parenting. Some parents pulled out of social activities and cut down their interactions with others because of these experiences to avoid criticism and embarrassment. These results are consistent with the idea of courtesy stigma by (8), which states that stigma toward individuals with autism also extends to their families. In the Indian context, where kid behaviour is often viewed as a reflection of parental ability, carers may be more exposed to social criticism and blame. This social isolation can therefore add to the stress of carers and reduce access to emotional support. There is a need for greater public acceptance and awareness of autism. Another important problem highlighted by participants was finances.

Conclusion

This study looked at the real-life experiences of parents and caregiver, who care for children with ASD and showed the many problems they faced while doing their jobs. What the results show is how much serious psychological pain they go through, especially during the diagnosis. This sadness shows up as denial, self-blame, uncertainty, and worry about the future of their child. In addition to the questioning themselves, emotional effects, parents often face social

exclusion through shame, criticism, and loneliness, which makes it harder for them to connect with others and participate in social activities.
The carers were very adaptable and strong. Over time, they found ways and used some coping mechanism to deal with things and asked for help from their friends, family, and medical professionals. The results show how important it is for more people to know about autism, for orientation programs to reduce stigma, for rehabilitative treatments to be easy to get to and not too expensive, and for families to have a lot of support. Getting better help for child with ASD and their parents by making changes at the neighbourhood, policy, and psychological levels will improve their quality of life. In the end, it is very important to understand what parents go through to come up with family-centred solutions that promote inclusion, support, and well-being in health care and social settings in general.

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Annexures

Tools/Questionnaires:

Current age of child?

Profession of Father and Mother?

When did (at what age) you realized that your child has autism?

Was it told to you just after delivery?

If no, then who asked you to seek care?

What symptoms you perceived before seeking care?

Anyone within the family/society/relatives seeking care?

What was your response or reaction when you realized about the diseases? Describe a typical day caring for your child?

- *Probes:*
  Can you walk me through your day from morning to night?
  What activities require the most time and attention?
  How do you manage your personal time or rest?
  How does your child's condition affect your daily routine?
  Are there any particularly difficult moments in the day?

During your child's diagnosis, what personal challenges and difficulties did you face? How did you cope with these challenges?

- *Probes:*
  What was your first emotional reaction to the diagnosis?
  What was most difficult for you at that time (emotionally, socially, financially)?
  Who supported you during that period?
  What coping strategies did you use (emotional, religious, practical, social)?
  Did your coping change over time?

What are the biggest challenges you face?

- *Probes:*
  Are these challenges related to behaviour, communication, finances, or society?
  Which challenge affects you the most emotionally? Why?

Have these challenges changed as your child has grown?

How do you usually handle these difficulties?

How do friends and family react to your child?

- *Probes:*

  Can you describe specific reactions you have experienced?

  Do you feel supported or judged by them?

  Have relationships changed since your child's diagnosis?

  Are there people who avoid or distance themselves?

  Who supports you the most?

What changes have occurred in your family during the treatment period?

- *Probes:*

  How has family routine or roles changed?

  Has caregiving affected marital or sibling relationships?

  Have there been financial or emotional changes in the household?

  How do family members share caregiving responsibilities?

  Has the diagnosis brought the family closer or created distance?

What kind of support is most helpful to you, and what is missing?

- *Probes:*

  What type of support helps you the most (emotional, financial, informational, practical)?

  From whom do you receive this support?

  What support do you wish you had but do not currently receive?

  Are there barriers in accessing support services?

  How do you feel when support is not available?

Have you felt blamed or judged for your child's behaviour?

- *Probes:*

  Can you describe any specific incidents?

  Who made you feel this way (family, society, teachers, healthcare workers)?

  How did those experiences affect you emotionally?

  How do you respond in such situations?

Has this changed over time?

Have you received any help from society, institutions, communities, or groups while caring for your child? If so, what specific assistance did you receive?

- *Probes:*

  Can you describe the type of help you received?

  How accessible were these services or groups?

  Which support has been most useful and why?

  Were there any difficulties in accessing support?

  Do you feel these services are sufficient?

What are your expectations for your child's treatment, recovery, and future? What social support do you hope to receive?

- *Probes:*

  What are your hopes for your child's future development?

  What kind of improvements would you like to see in treatment or services?

  What support do you wish society or government could provide?

  What worries you most about the future?

  What gives you hope?

At different stages of caring for your child, what psychological support do you most desire?

- *Probes:*

  When do you feel most emotionally stressed or overwhelmed?

  What kind of emotional support helps you most in those moments?

  Have you ever received counselling or psychological support?

  What kind of support would make a difference for you now?

  Who do you turn to when you feel emotionally low?

Participant information sheet

Title of the Study

Between Support and Stigma: Experiences of parents of Children with Autism Spectrum Disorder" A qualitative study.

Introduction

You are being invited to take part in a research study. Before you decide whether to participate, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully.

Purpose of the Study

The purpose of this study is to explore and understand how parents of children with autism experience the social support and stigma in their daily lives.

Why Have You Been Invited?

You have been invited because you are a parent of a child with autism and your experiences are valuable for this research.

What Will Participation Involve?

If you agree to take part:

- You will be asked to participate in an in-depth interview.
- The interview will focus on your experiences of caregiving, social support, and stigma.
- The interview may take approximately 30-60 minutes.
- With your permission, the interview will be audio-recorded to ensure accuracy.

Voluntary Participation

- Your participation is completely voluntary. You are free to refuse to take part or withdraw at any time without giving any reason. This will not affect you in any way.

Possible Risks or Discomforts

- Some questions may touch on personal or emotional experiences. If you feel uncomfortable at any point, you may choose not to answer any question or stop the interview.

Benefits of the Study

There may be no direct benefit to you personally. However, your participation may help improve understanding and support services for families of children with autism in the future.

Confidentiality

- All information you provide will be kept strictly confidential.
- Your identity will not be revealed in any reports or publications.
- Data will be stored securely and only the research team will have access to it.
- Any published findings will not include your name or any identifying details.

Right to Withdraw

- You may withdraw from the study at any time before or during the interview. You may also request that your data be removed (if applicable within the study timeline).

Contact Information

If you have any questions about the study, you may contact:

Researcher Name: _____
Institution: _____
Contact Number/Email: _____
Participant Name: _____
Signature: _____
Date: _____

Consent form

I have read and understood the information provided above. I have had the opportunity to ask questions and received satisfactory answers. I voluntarily agree to participate in this study.

Participant Name: _____

Signature/Thumb Impression: _____

Date: _____

Researcher's Signature: _____

उपकरण / प्रश्नावली

अपने बच्चे की देखभाल करते हुए आपका एक सामान्य दिन कैसा होता है?

प्रश्न (Probes):

- क्या आप सुबह से रात तक अपने पूरे दिन के बारे में बता सकते हैं?
- किन गतिविधियों में सबसे अधिक समय और ध्यान लगता है?
- आप अपने व्यक्तिगत समय या आराम को कैसे संभालते हैं?
- आपके बच्चे की स्थिति आपके दैनिक जीवन को किस प्रकार प्रभावित करती है?
- क्या दिन में कोई ऐसा समय होता है जो विशेष रूप से कठिन लगता हो?

आपके बच्चे के निदान (Diagnosis) के दौरान आपको किन व्यक्तिगत चुनौतियों और कठिनाइयों का सामना करना पड़ा? आपने उनसे कैसे सामना किया?

प्रश्न (Probes):

- निदान के बारे में जानने पर आपकी पहली भावनात्मक प्रतिक्रिया क्या थी?
- उस समय आपके लिए सबसे कठिन क्या था (भावनात्मक, सामाजिक, आर्थिक)?
- उस समय आपको किसका सहयोग मिला?
- आपने कौन-कौन सी सामना करने की रणनीतियाँ अपनाईं (भावनात्मक, धार्मिक, व्यावहारिक, सामाजिक)?
- क्या समय के साथ आपकी सामना करने की प्रक्रिया में बदलाव आया?

आपके सामने सबसे बड़ी चुनौतियाँ क्या हैं?

प्रश्न (Probes):

- क्या ये चुनौतियाँ व्यवहार, संचार, आर्थिक स्थिति या समाज से संबंधित हैं?
- कौन-सी चुनौती आपको भावनात्मक रूप से सबसे अधिक प्रभावित करती है? क्यों?
- क्या आपके बच्चे के बड़े होने के साथ ये चुनौतियाँ बदली हैं?
- आप सामान्यतः इन कठिनाइयों का सामना कैसे करते हैं?

आपके मित्र और परिवार आपके बच्चे के प्रति कैसी प्रतिक्रिया देते हैं?

प्रश्न (Probes):

- क्या आप कुछ विशेष प्रतिक्रियाओं के बारे में बता सकते हैं जिनका आपने अनुभव किया?
- क्या आपको उनसे सहयोग मिलता है या आप स्वयं को आंका हुआ महसूस करते हैं?
- क्या आपके बच्चे के निदान के बाद रिश्तों में कोई बदलाव आया?
- क्या कुछ लोग आपसे दूरी बनाने लगे हैं?
- आपको सबसे अधिक सहयोग कौन देता है?

उपचार की अवधि के दौरान आपके परिवार में क्या परिवर्तन आए?

प्रश्न (Probes):

- परिवार की दिनचर्या या भूमिकाओं में क्या बदलाव आया?
- क्या देखभाल की जिम्मेदारियों ने वैवाहिक या भाई-बहन के संबंधों को प्रभावित किया?
- क्या परिवार में आर्थिक या भावनात्मक परिवर्तन आए?
- परिवार के सदस्य देखभाल की जिम्मेदारियों को कैसे साझा करते हैं?
- क्या निदान ने परिवार को और करीब लाया या दूरियाँ बढ़ाई?

आपके लिए किस प्रकार का सहयोग सबसे अधिक सहायक है, और क्या कमी महसूस होती है?

प्रश्न (Probes):

- किस प्रकार का सहयोग आपको सबसे अधिक मदद करता है (भावनात्मक, आर्थिक, जानकारी संबंधी, व्यावहारिक)?
- यह सहयोग आपको किससे प्राप्त होता है?
- ऐसा कौन-सा सहयोग है जिसकी आपको आवश्यकता है लेकिन वर्तमान में नहीं मिल रहा?
- सहायता सेवाओं तक पहुँचने में क्या कोई बाधाएँ हैं?
- जब सहयोग उपलब्ध नहीं होता, तब आप कैसा महसूस करते हैं?

क्या आपने कभी अपने बच्चे के व्यवहार के लिए स्वयं को दोषी ठहराया गया या आंका गया महसूस किया है?

प्रश्न (Probes):

- क्या आप किसी विशेष घटना का वर्णन कर सकते हैं?
- किसने आपको ऐसा महसूस कराया (परिवार, समाज, शिक्षक, स्वास्थ्यकर्मी)?
- उन अनुभवों का आप पर भावनात्मक रूप से क्या प्रभाव पड़ा?
- ऐसी परिस्थितियों में आप कैसे प्रतिक्रिया देते हैं?
- क्या समय के साथ इसमें कोई बदलाव आया?

क्या आपको अपने बच्चे की देखभाल के दौरान समाज, संस्थाओं, समुदायों या समूहों से कोई सहायता मिली है? यदि हाँ, तो आपको किस प्रकार की सहायता प्राप्त हुई?

प्रश्न (Probes):

- कृपया बताइए कि आपको किस प्रकार की सहायता मिली?
- ये सेवाएँ या समूह कितने सुलभ थे?
- कौन-सा सहयोग सबसे अधिक उपयोगी रहा और क्यों?
- सहायता प्राप्त करने में क्या कोई कठिनाइयाँ आईं?
- क्या आपको लगता है कि ये सेवाएँ पर्याप्त हैं?

अपने बच्चे के उपचार, सुधार और भविष्य को लेकर आपकी क्या अपेक्षाएँ हैं? आप किस प्रकार के सामाजिक सहयोग की आशा रखते हैं?

प्रश्न (Probes):

- आप अपने बच्चे के भविष्य के विकास के लिए क्या उम्मीद रखते हैं?
- उपचार या सेवाओं में आप किस प्रकार के सुधार देखना चाहते हैं?
- आप चाहते हैं कि समाज या सरकार किस प्रकार का सहयोग प्रदान करे?
- भविष्य को लेकर आपकी सबसे बड़ी चिंता क्या है?
- आपको आशा किस बात से मिलती है?

अपने बच्चे की देखभाल के विभिन्न चरणों में आपको किस प्रकार के मनोवैज्ञानिक सहयोग की सबसे अधिक आवश्यकता महसूस होती है?

प्रश्न (Probes):

- आप कब सबसे अधिक भावनात्मक तनाव या दबाव महसूस करते हैं?
- उन क्षणों में किस प्रकार का भावनात्मक सहयोग सबसे अधिक मददगार होता है?
- क्या आपने कभी परामर्श (Counselling) या मनोवैज्ञानिक सहायता प्राप्त की है?
- वर्तमान समय में कौन-सा सहयोग आपके लिए सबसे अधिक अंतर ला सकता है?
- जब आप भावनात्मक रूप से कमजोर महसूस करते हैं, तब आप किससे सहारा लेते हैं?

प्रतिभागी सूचना पत्र (Participant Information Sheet)

अध्ययन का शीर्षक

‘‘सहयोग और कलंक के बीच: ऑटिज़्म स्पेक्ट्रम डिसऑर्डर वाले बच्चों के माता-पिता के अनुभव’’ — एक गुणात्मक अध्ययन

परिचय

आपको एक शोध अध्ययन में भाग लेने के लिए आमंत्रित किया जा रहा है। भाग लेने का निर्णय लेने से पहले यह समझना महत्वपूर्ण है कि यह शोध क्यों किया जा रहा है और इसमें क्या शामिल होगा। कृपया निम्नलिखित जानकारी को ध्यानपूर्वक पढ़ें।

अध्ययन का उद्देश्य

इस अध्ययन का उद्देश्य यह समझना और जानना है कि ऑटिज़्म से प्रभावित बच्चों के माता-पिता अपने दैनिक जीवन में सामाजिक सहयोग (Social Support) और कलंक (Stigma) का अनुभव कैसे करते हैं।

आपको क्यों आमंत्रित किया गया है?

आपको इसलिए आमंत्रित किया गया है क्योंकि आप ऑटिज़्म से प्रभावित एक बच्चे के माता-पिता हैं और आपके अनुभव इस शोध के लिए महत्वपूर्ण हैं।

भागीदारी में क्या शामिल होगा?

यदि आप भाग लेने के लिए सहमत होते हैं:

- आपसे एक विस्तृत साक्षात्कार (In-depth Interview) में भाग लेने का अनुरोध किया जाएगा।
- साक्षात्कार में आपके देखभाल संबंधी अनुभवों, सामाजिक सहयोग और कलंक से जुड़े अनुभवों पर चर्चा की जाएगी।
- साक्षात्कार में लगभग 30–60 मिनट का समय लग सकता है।
- आपकी अनुमति से, साक्षात्कार की सटीकता सुनिश्चित करने हेतु इसे ऑडियो रिकॉर्ड किया जाएगा।

स्वैच्छिक भागीदारी

- आपकी भागीदारी पूर्णतः स्वैच्छिक है।
- आप किसी भी समय बिना कोई कारण बताए भाग लेने से मना कर सकते हैं या अध्ययन से हट सकते हैं।
- इससे आपको किसी भी प्रकार की हानि या प्रभाव नहीं पड़ेगा।

संभावित जोखिम या असुविधाएँ

- कुछ प्रश्न व्यक्तिगत या भावनात्मक अनुभवों से संबंधित हो सकते हैं।
- यदि किसी भी समय आप असहज महसूस करते हैं, तो आप किसी प्रश्न का उत्तर देने से मना कर सकते हैं या साक्षात्कार रोक सकते हैं।

अध्ययन के लाभ

हो सकता है कि इस अध्ययन से आपको व्यक्तिगत रूप से कोई प्रत्यक्ष लाभ न मिले। लेकिन आपकी भागीदारी भविष्य में ऑटिज़्म से प्रभावित बच्चों के परिवारों के लिए बेहतर समझ और सहयोग सेवाओं के विकास में सहायक हो सकती है।

गोपनीयता

- आपके द्वारा दी गई सभी जानकारी पूर्णतः गोपनीय रखी जाएगी।
- किसी भी रिपोर्ट या प्रकाशन में आपकी पहचान उजागर नहीं की जाएगी।
- डेटा सुरक्षित रूप से संग्रहीत किया जाएगा और केवल शोध दल को ही इसकी पहुँच होगी।
- प्रकाशित निष्कर्षों में आपका नाम या कोई पहचान संबंधी जानकारी शामिल नहीं होगी।

अध्ययन से हटने का अधिकार

- आप साक्षात्कार से पहले या उसके दौरान किसी भी समय अध्ययन से हट सकते हैं।
- यदि अध्ययन की समय-सीमा के भीतर संभव हो, तो आप अपने डेटा को हटाने का अनुरोध भी कर सकते हैं।

संपर्क जानकारी

यदि आपको अध्ययन के बारे में कोई प्रश्न हो, तो आप निम्नलिखित से संपर्क कर सकते हैं:

शोधकर्ता का नाम: _____

संस्थान: _____

संपर्क नंबर/ईमेल: _____

प्रतिभागी का नाम: _____

हस्ताक्षर: _____

दिनांक: _____

सहमति पत्र (Consent Form)

मैंने ऊपर दी गई जानकारी को पढ़ और समझ लिया है। मुझे प्रश्न पूछने का अवसर मिला तथा मुझे संतोषजनक उत्तर प्राप्त हुए। मैं स्वेच्छा से इस अध्ययन में भाग लेने के लिए सहमत हूँ।

प्रतिभागी का नाम: _____

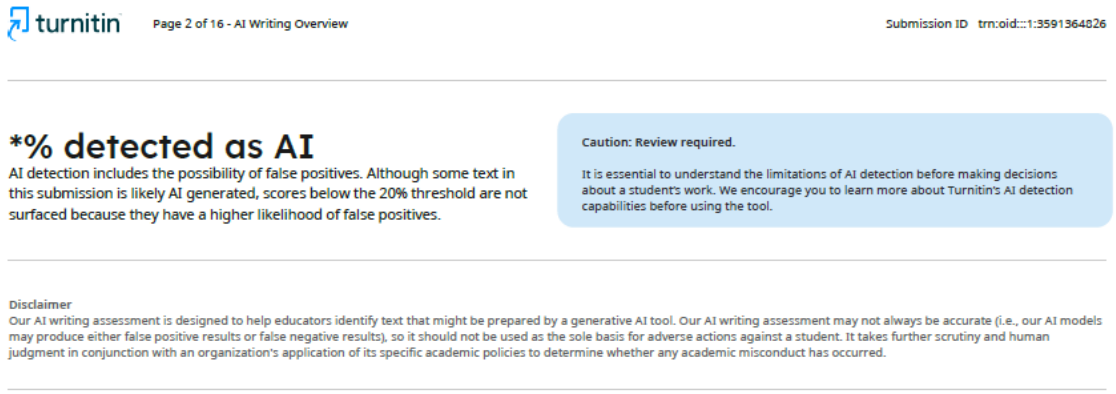
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Ms. Supriya D report

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