



THE CHALLENGES THAT MOTHER FACE WHEN TRYING TO RAISE AUTISTIC CHILDREN IN GAMPAHA DISTRICT

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ABSTRACT

Parenting a child with autism presents unique challenges that significantly impact mothers' emotional well-being, social interactions, and daily lives. This qualitative phenomenological study explores the lived experiences of nine mothers caring for children with autism in Sri Lanka. Through in-depth interviews, the research focuses on the emotional, social, and practical dimensions of caregiving. The phenomenological approach highlights deep engagement between the interviewer and informants, allowing for a rich exploration of the mothers' experiences within their daily context. The researchers aim to reveal the complex reality of raising children with autism by fully engaging in the mothers' experiences. The findings reveal that mothers grapple with a myriad of challenges, including emotional distress, social isolation, financial strain, and limited access to resources and support services. The diagnosis of autism not only impacts the child but also has profound effects on the entire family unit, leading to changes in relationships, disruptions in daily routines, and heightened stress and anxiety. This study contributes to a deeper understanding of the challenges faced by mothers raising children with autism in Sri Lanka, informing culturally sensitive intervention strategies and advocacy efforts.

KEYWORDS: Autism, Caregiving, Emotional Impact, Social Isolation, Financial Strain

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental illness identified by difficulties in social communication and the presence of limited, repetitive behavioral patterns (American Psychiatric Association [APA], 2022). According to the latest data from the Centers for Disease Control and Prevention (CDC), there is a prevalence rate of 1 in 54 children in the United States (Centers for Disease Control and Prevention, 2020). The global estimates of this phenomenon differ, with various research indicating rates that range from 0.09% in India to 1.07% in Sri Lanka (Singh et al., 2019; Weiss et al., 2009).

The diagnosis of ASD can greatly affect families, especially the emotional welfare of parents (Weiner et al., 2009). Parents frequently encounter difficulties about their child's deficiencies in communication and social skills, along with the accompanying behaviors (Fisman et al., 2018). These variables can lead to parental stress, feelings of guilt, and a pessimistic perspective (Weiner et al., 2009).

Studies conducted in several countries have identified the distinct difficulties encountered by women who are raising children with Autism Spectrum Disorder (ASD). Research conducted in Australia (Henderson et al., 2006), the United Kingdom (Green et al., 2009), and Canada (Baird et al., 2003) reveals that mothers commonly face emotional discomfort, social isolation, and financial difficulty. Jeon and Sim (2014) highlight the challenges that moms have in embracing their child's limits.

Raising a child with Autism Spectrum Disorder (ASD) poses distinct obstacles as compared to generally developing children (Weiner et al., 2009). Mothers frequently shoulder the primary burden of managing their child's impairment, resulting in emotions of grief, alterations in relationships, and a sense of being socially isolated (Fisman et al., 2018). According to Green et al. (2009), denial, sadness, and guilt are frequently observed as initial reactions to the diagnosis. Mothers may encounter restrictions on their personal social engagements and professional ambitions (Henderson et al., 2006). In addition, certain parents may be required to resign from their employment in order to attend to their child's needs and oversee therapeutic interventions (Weiner et al., 2009).

Although there is a significant occurrence of Autism Spectrum Disorder (ASD) in Sri Lanka, the amount of study conducted on this topic is currently restricted (Weiss et al., 2009). A study conducted in Sri Lanka revealed a notable deficiency in knowledge and understanding of autism among parents and healthcare practitioners (Weiss et al., 2009). The healthcare and educational institutions in Sri Lanka are hindered by resource limitations, which disproportionately affect families with children on the autism spectrum (Weiss et al., 2009).

Meeting the needs of mothers who are raising children with Autism Spectrum Disorder (ASD) necessitates a thorough and all-encompassing strategy. This entails enhancing the availability of healthcare, education, and social support systems. Gaining a comprehensive understanding of the unique obstacles encountered by moms through more study is crucial for the creation of efficient treatments and support systems.

MATERIALS AND METHODS

RESEARCH PLAN

The qualitative phenomenological research methodology was utilised to conduct interviews with the mothers of autistic children. The phenomenological approach promotes an engaged conversation and an inner awareness between the interviewer and the informants, while the phenomenological research design provides a welcoming position toward the life-world of the informant. This is done in order that a greater understanding may be gained of the situations in which mothers encounter issues like autism. This design is appropriate for the exploratory nature of this study because it will permit a more in-depth investigation of the experiences that mothers have had because qualitative research acknowledges that there are multiple truths and that a person's interpretation of an event is dependent on the social context in which they find themselves. In addition, this design will make it possible to examine the experiences of mothers in greater depth.

The Research Context and Population

The homes of the people who took part in the study, which were in the Gampaha district of Sri Lanka, were where most of the research took place. Because the researcher thought that conducting the research in the participants' homes would allow them to unwind and be free to express their genuine emotions without being overheard or interrupted, those homes were selected as the study venues. The participants in the study were mothers who had at least one child under the age of 14 who had been diagnosed with autism and who were receiving services for their condition from a speech-language therapist or at the Ayati Center, the National Center for Children with Disabilities. The Ayati center in Ragama is a national center that is run by the public and private partnership of the Medical Faculty of the University of Kelaniya, the Ministry of Health, and the collaborations of the Ministries of Education and Social Services, as well as benefactors in the form of generous business giants and giving personalities like Hemas Holdings, MAS Holdings, and Sri Lankan Cricket legends Kumar Sangakkara and Roshan Mahanama, who joined forces together to raise money. In addition, the Sri Lankan armed forces contributed a significant amount of manpower to the construction of the hub. It is a nonprofit group whose goal is to help children from poor families reach their full potential. The Ayati Center is committed to giving these people the tools they need to live their best lives

and reach their fullest potential by making big changes to their freedom and quality of life. This goal will be accomplished by empowering these individuals to live their best lives and achieve their fullest potential. Children who attend the center get medical care as well as therapies such as speech therapy, music therapy, vocational training, and activities of daily living, all of which help them develop into healthy, productive individuals.

SAMPLING

Qualitative research methods try to understand a phenomenon or its importance by looking into the "how" and "why" of a particular problem, process, scenario, subculture, scene, or series of social interactions. This is different from collecting a large number of samples at random. This is done in order to gain a better understanding of the phenomenon or its significance. Interpretive researchers usually draw conclusions based on incredibly small samples, typically consisting of 10 people or fewer. Nine mothers from the Gampaha district of Sri Lanka were selected for the study. Each of these mothers had at least one child receiving treatment for autism at the Ayati Center or from a private speech and language therapist. The sample was chosen with the assistance of a sampling approach that was designed with the help of the purposive sampling technique. Researchers were smart enough to use a method called "purposeful sampling" to pick cases with a lot of data from which they could get the specific details they needed to understand the challenges mothers face when taking care of their autistic children. This was done in order to ensure that the findings of the study would be accurate.

CRITERIA FOR SELECTION

Inclusion was predicated on successfully satisfying the following requirements. mothers who are currently raising a child who has been given a diagnosis of autism. Mothers who are interested in taking part in the study. Mother with a child younger than 14 years old, as the definition of "child" in the Employment of Women, Young Persons, and Children's Act sets the age limit for "child" at 14, and the definition of "child" in the National Child Protection Act No. 50 of 1998 sets the age limit for "child" at 18.

Criteria for Exclusion

As a result, the following conditions qualified as grounds for exclusion: Women who are mothers yet are not willing to participate voluntarily in the study. Mothers who suffer from mental illness and have difficulty expressing their feelings.

Equipment for the Collection of Data

On the basis of a review of the relevant literature and discussions with experts in the field, the researcher devised methods for conducting in-depth interviews for the purpose of analyzing lived experiences. A total of eleven open-ended questions were

posed during the in-depth interviews that were conducted with nine mothers of children diagnosed with autism. The objective of these interviews was to get insight into the opinions and experiences of the mothers. Take into consideration the question, "In what ways do you recognize autism?" Whenever more information was needed during an interview, deeper questions were asked to find out more. A digital recorder was used to capture the audio, and a notebook was used to record any significant details that came up while the interview was being conducted. Together, these two approaches were used to record the interview. This research instrument is divided into two parts.

Section I: Questions about demographic and social characteristics.

Section II: Open-ended questions about personal experiences as a parent of a child diagnosed with autism

Credibility.

Standard Sinhala, English, and Tamil were used for the interviews, and jargon was avoided as much as possible to improve the quality of the data. During the course of the interview, the researcher took notes on both the verbal and nonverbal cues provided by the participants. After ensuring that the functions of the mobile phone based digital recorder were working properly, an interview was then digitally recorded with the device. The researchers placed their own preconceived notions to the side during the phases of the study in which they were responsible for collecting and analysing the data. Researchers conducted in-depth interviews, transcribed the data that was collected as a result of the interviews, and took field notes in order to verify the accuracy of the material that they gathered. In addition to going over digital recordings and field notes, the researchers read the transcriptions several times in order to have a better sense of the whole. The accuracy of the information was maintained by collecting it up until it was no longer available. The replies of the mothers, both verbal and nonverbal, were captured on record. Each individual was questioned twice or three times to ensure that the results were accurate and reliable. Researchers contacted the person who was originally interviewed to verify the accuracy of the transcript and the interpretation of the interview. This was done to guarantee that both the transcript and the interpretation were correct. The transcription process was managed to ensure consistency by double-checking the meaning of key terms, and the results were discussed with a confirmed expert before they were interpreted. With the help of purposeful sampling, the researcher was able to get as much information as possible from a small number of participants. The study was more useful because it included detailed descriptions and direct quotes from the mothers' lives.

METHODS OF COLLECTING DATA

After submitting a proposal to the Ayati Center and obtaining permission from the center and the cooperation of mothers and therapists working under the direction of privately-practicing speech-language pathologists, the researcher separately requested permission to gather data from them. After getting the right permissions, the researchers contacted each of the mothers who could take part in the study individually to get their informed consent and talk about the goals of the study. On the day of the interview, mothers were given a courtesy phone call to remind them of the time and location that had been arranged according to their availability.

A written informed permission form, extra authorization for digital recording, and field notes were collected from each mother before the interview. The interviews were carried out in Sinhala, Tamil, and English, using the in-depth interview guidelines and the face-to-face interview method, respectively, at the homes of the participants and at the Ayati center. At first, open-ended questions were posed to the mothers in order to get them started on opening up about their ideas and feelings regarding the care that they provide for their autistic children. In between, more in-depth questions were asked to ensure that clarity and thoroughness were achieved. Each interview lasted approximately thirty to forty-five minutes. During interviews, the verbal and nonverbal responses of the mothers were both recorded and analyzed. For each in-depth interview, a digital audio recorder app on a cell phone was used to record the mother's words exactly as they were said. Field notes were also taken to keep track of any other information that was gathered and were kept for the whole study. After two or three sessions with every mother to collect data, the process was stopped after all of the information had been gathered.

PROCESS OF ANALYSING DATA

There was no slowdown in activity between the collection of data and the subsequent analysis. On the same day that pertinent information was gathered, the interviewee's identity was replaced by a code number, and the interview took place. The data that the researcher needed were meticulously stored away in a file. The researcher created two copies of the recording to have a backup in case one of the copies was lost or damaged. The researcher played back each interview several times to ensure that she fully comprehended what was being said. The researcher then transcribed each interview word for word by the end of the same day. After finishing the transcription, the researcher went back and re-listened to each recording at least once more to double-check that everything was accurate. Some interviews were conducted in local languages, and the transcripts and translations of those interviews were afterward done in English. After then, the translation went through certain corrections to ensure correctness. The researchers delved headfirst into the data by reading the transcripts multiple times and took copious notes on the topics they deemed to be the most important issues brought up by the mothers.

RESULTS

According to Table 1.1, the ages of the mothers ranged anywhere from 23 to 36 years old. These nine mothers are all locals, having been raised in either the city or the suburbs. Within the group there are a total of nine people: seven Sinhalese, three Tamils, and two Muslims. Each of the mothers have completed some sort of education. More over 75 percent of the total population consisted of house wives. The majority of the ladies, six out of nine, came from nuclear families. Six mothers received formal autism training at the Ayati Center, while the remaining three women engaged in autism training of a non-formal kind, such as online awareness seminars.

Table 01

Facts pertaining to the mothers' socioeconomic status and demographics

(To protect anonymity, fictitious names have been used for the participants.)

No	Name of the participant	Age	Settlement	Religion	Ethnicity	Education Background	Social and Economic Status	Occupation
1	Akarsha	34	Urban	Buddhism	Sinhala	Bachelors	Positive	House Wife
2	Saleema	23	Semi-urban	Islam	Muslim	Grade 10	Negative	Working
3	Sulochana	32	Urban	Christian	Tamil	A/L	Negative	House Wife
4	Nushfa	34	Semi-urban	Islam	Muslim	O/L	Positive	House Wife
5	Akalanka	36	Urban	Buddhism	Sinhala	A/L	Positive	Working
6	Menisha	32	Urban	Christian	Sinhala	Masters	Positive	Working
7	Kamathi	32	Semi-urban	Hinduism	Tamil	Grade 10	Positive	Working

8	Wimathi	28	Urban	Buddhism	Sinhala	Diploma	Negative	House Wife
9	Araywathi	32	Semi-urban	Hinduism	Tamil	O/L	Negative	House Wife

(Source – Field Data 2023)

Table 02 :

The following tables provides an overview of the characteristics of children diagnosed with autism. The age difference between the youngest child, who was just six months old, and the oldest child, who was 10, was quite significant. Six of the nine children were male, and the diagnosis was made for seven of them when they were between the ages of three and four. After-school activities are available for all nine of the children to participate in. Six of the children were also capable of performing at least some of the most fundamental functions of life.

Autism-related characteristics of children

Age Group (Years)

Variables	Frequency ^a
<i>6 - 10</i>	<i>7</i>
<i>11 - 15</i>	<i>2</i>

(Table 2.1 - Source – Field Data 2023)

Sex

Variables	Frequency
<i>Male</i>	<i>6</i>
<i>Female</i>	<i>3</i>

(Table 2.2 - Source – Field Data 2023)

Child's age at the time of diagnosis

Variables	Frequency
<i>3 Years</i>	<i>3</i>
<i>4 Years</i>	<i>4</i>
<i>5 Years</i>	<i>1</i>
<i>12 Years</i>	<i>1</i>

(Table 2.3 - Source – Field Data 2023)

Participation of child

Variables	Frequency
<i>Care Center</i>	<i>4</i>
<i>Through Speech and Language Therapist</i>	<i>5</i>

(Table 2.4 - Source – Field Data 2023)

Capable of Self Care

Variables	Frequency
<i>Does Self-care</i>	<i>5</i>
<i>Lacking Self care</i>	<i>4</i>

(Table 2.5 - Source – Field Data 2023)

Identified themes

This is a narrative description of a mother's experience working with autistic children, written in the mother's own words. There were five primary themes and thirty-one minor themes throughout the piece. They included how individuals saw autism, how people responded to the disease, how people modified their parenting technique, how autism affected their day-to-day lives, and how people learned to manage it. The themes and subthemes that evolved from the experiences of the mothers of autistic children are showing quotations taken from interviews with those

mothers. Participants are given pseudonyms instead of being asked to give their real names so that the data can remain private..

The themes which have arisen from discussions with mothers of autistic children

01. Perception regarding autism

- Slow mental development
- Issues in behavior
- Constant illness throughout one's life
- Disorder of neurodevelopment

02. Acknowledgment of the problem

- Variations in Daily Life Capable of performing developmental responsibilities
- Learning through reinforcement
- The many different applications for the various materials that are accessible
- Precautions to ensure everyone's safety
- Assessing a child's ability to get along with others#

03. Relevance to daily lives

A. Considerations of a Physical Nature

- Physical effort

B. Emotional characteristics

- Denial
- Worry
- Sad
- Anger
- Anxious
- Relief

C. Societal considerations

- Isolation
- Ignorance

- Social blame

D. Aspects of the Economy

- Challenges faced by the economical hardship (With or without the current state of the economy)
- An unrealized potential for gainful employment

E. Adjustment procedures

- Respite care
- strategies with a primary emphasis on problems
- Spiritual coping
- Positive coping

Analysis of Autism-Related Perceptions

There was a significant variation in the responses of mothers to autism. Their perspective on autism was pessimistic, and they referred to it using pejorative phrases such as "mental retardation," "lifelong problem," "neurodevelopmental difficulties," and "behavioral trouble." One participant in an unstructured program at a daycare center, a 28-year-old lady, was asked to express her concept of mental retardation. She said that she thought it was "quite confusing.

"Children who have autism often display abnormal behaviors that are indicative of mental retardation." These behaviors include moving at a slower pace than average, engaging in frequent, pointless arguments, refusing to follow instructions, failing to pay attention to others, and acting independently. (P8).

Another person with autism who was 32 years old and had received training characterized her perspective as follows:

"Autism is a neurodevelopmental disorder that is present from birth on, and its symptoms include a child's inability to complete typical tasks, his or her inability to make eye contact or respond when being called, and his or her refusal to engage in social interaction." "Autism is a condition that manifests itself from birth onward." (P3).

Problem Identified and Recognized

All of the participants said that their child's poor development and unusual behaviors, such as not being honest, acting the same way all the time, not liking friends, staring all the time, doing the same things over and over, and avoiding eye contact, were early signs that their child was different from other kids. The most common way for mothers to recognize behavior in their children is when they observe challenges with

their children's speech, communication, and capacity to form relationships. Some mothers were able to recognize the warning signs right away, while others required a little bit more time to do so. The following is an excerpt from a participant's account of the impact of constrained and repeated activity, which was provided by the participant herself, who is 32 years old:

“Around the age of two and a half, he started exhibiting some peculiar behaviors, such as ignoring his environment and playing for extended periods of time with the same object. This continued until he was about three years old. He makes frequent use of the word “Mommy,” which gives the impression that it is one of his most often used words overall. Nobody in his family has a particularly close relationship with him. If someone tries to chat with him, he flatly refuses to engage in conversation with them. He gets a queasy feeling from the music's tempo. As a result of these symptoms, I started getting concerned that there might be something wrong with my child.” (P3)

Another participant talked about her own experience with a child who couldn't communicate well on his own. She said,

“Around the age of 2, I noticed a big drop in my child's language development. He doesn't say anything to himself while he's by himself, doesn't react when we approach, and appears to find solace in his aloneness. He takes tremendous delight in the challenge of keeping himself occupied for protracted stretches of time with just one item at a time. He seems to feel more comfortable when he's with his family, but he doesn't like any of our guests who have ever come to our house. He immediately begins sobbing anytime there is a new person in the house. As soon as the person who offended him has left the room, he immediately returns to his usual level of silence. Due to these factors, I was aware that there was something wrong with my child.” (P6)

In an effort to make sense of the symptoms they had noticed, the majority of the mothers (six out of nine) said they consulted external resources such as the internet and newspapers, and they also sought advice from friends and neighbors who also had children with autism. This was done in an effort to make sense of the symptoms they had noticed. All of the mothers had the same instinct that something was off with their children's behavior, so they took them to the pediatrician for assistance. A mother of a young child (age 23) who sought the guidance of her friends and neighbors in order to make sense of her child's experiences shared her experiences. Her friends and neighbors help her interpret her child's actions.

“Around the age of two and a half, several characteristics of the daughter started to become visible for the first time, such as her inability to finish words, her lack of tolerance, and her tendency to toss toys. I inquired for the guidance of a nearby resident whose child was going through the same challenges as mine. He strongly suggested going to the doctor at least once. Then, after doing some study on the

internet, both my husband and I came to the conclusion that his symptoms were indicative of autism. (P2)”

At the same time, all of the mothers said that they prayed to their gods and went to temples, churches, masjids, and kovils in the hopes that a miracle would happen. A god-fearing mother of 36 prayed constantly that her son would repent and turn his life around. Several of the ways in which she articulated her own personal experiences include the following:

“When I noticed that my child was having problems, I took my kid to several different temples and prayed for a solution. After I had finished spending time in prayer and meditation with God, I became aware that my young child was slowly developing the ability to communicate verbally. It's possible that he was able to communicate because he was older than average for his developmental stage, but I'd prefer to believe that his words were prompted by the worship that I led.” (P5)

Some mothers reported enrolling their child in private speech therapy with a Speech and Language therapist in response to medical recommendations, while others reported bringing their child to the Ayati Center for Speech and Language Therapy. Finally, a mother shared that she had signed her child up for a vocational training program that was financed by the Department of Social Development. Parents who enrolled their children in speech therapy reported being satisfied with the outcomes since their children were able to speak more effectively as a result of the therapy. One of her mothers gave a description of her daughter using her own words.

“On the advice of my child's doctor, I signed my child up for fifteen days of speech therapy at the Ayati Center. During that time, I was able to see that my child's condition was getting much better. As a direct result of this, I have been consistent with my sessions.”

Improvements in Parenting Approach

The mother made some adjustments to the way she parented in response to the advice given to her by medical professionals (physicians, pediatricians, or neuro-medicine doctors). Six of the people who responded claimed that they had enrolled their children in autism classes so that they might learn tactics for behavior modification, physical exercises, play therapy, or other strategies that are similar (matching, sorting, recognizing body parts, weather, colors, animals, fruits, etc.). In addition, parents reported witnessing favorable benefits as a result of the instruction. Someone in the group made a statement like, *“In the past, he had a bad habit of tossing things around, getting anxious whenever he heard the sound of a metronome, and being particularly averse to having his hair cut. After obtaining training, however, these kinds of behaviors progressively stopped occurring. (P3).*

Another mother expressed her feelings in a manner that was analogous to what I had experienced.

“In the past, he had displayed a belligerent attitude. He would assault everybody he came into contact with, tear at their clothing, and urinate and defecate in whatever location he happened to be in at the time. But after receiving instruction in skills such as hand washing, brushing, toileting, socializing, recognizing objects and body parts, matching, and color recognition, he is now able to sit independently, ask for help with visual aids, and begin to obey directions, so I believe there is progress being made.” (P4)

Six out of every nine parents have received training of some kind, whether it be in child care and handling, speaking, or the way of working with kids, and this has helped them change the way that they approach parenting their children (like eating, sitting, washing faces, toileting, wearing dresses, etc.). In addition, they acknowledged that it assisted them in knowing more about the capabilities that are developing in their child as well as any deficiencies that may exist. They kept watch; they were patient; they taught their children through repetition; and they kept their children occupied with toys, mobiles, and television. Mothers used visual aids as signals, encouragement, and rewards; they kept watch; they were patient; they taught their children; and they kept their children occupied. There was a mother who often shared stories about her childhood.

“In the past, I lacked the experience necessary to know how to care for and handle a child in an appropriate manner. When I caught him engaging in annoying behaviors such as playing with the same color building blocks, ripping the pillow case and bed linens, assaulting his older sister, or eating random objects he discovered around the house, I would become enraged, yell at him, and beat him. I would do this whenever I saw him engaging in these behaviors. I would go into my room, close the door, and isolate myself so that I could cry. But after putting in some work, I realized that instead of trying to beat him physically, I should work on improving my mental strength so I can stay calm and take control of the situation. It dawned on me that, as a mother, it was my responsibility to teach these children the difference between right and wrong without getting upset at them for their mistakes.” (P4)

In addition, there were participants who were pleased with the training that they obtained from the casual sessions that were given at childcare centers. An individual the age of 32 who participated in the casual class reported as follows:

“Although I was given the opportunity to take part in an unstructured program for people with autism, I was never provided with any kind of formal training on the topic. Because of this, I was able to learn the best ways to deal with and teach autistic children, including how to handle and care for them.” (P7).

Life's Everyday Struggles and Triumphs

Physical Problems

Taking care of a child who has autism is difficult because it forces parents to navigate a different path to motherhood than the one they had envisioned for themselves. The participants in the study were put through a lot of physical strain because they had to keep a constant watch over their children. A woman who participated in the event and was 32 years old gave the following description of her thoughts and feelings over the experience:

“My child has difficulty with even the simplest of activities, which makes taking care of her a very difficult task for me. My entire existence revolves around taking care of her in any spare moment I have. As a result, I set my alarm for earlier than she does in order to complete my duties before she begins her day. If you don't get enough restorative sleep at night, it will be harder for you to deal with the challenges of the day.” (P9).

Problems Relating to Emotions

When asked about the overall impact of raising a child with autism, all of the mothers mentioned the emotional strain that comes along with it. Several of the mothers who participated in the study shed tears while discussing their experiences during the interviews that were part of the research. They stated that they had experienced tremendous emotional suffering as a direct result of their inability to accept the diagnosis that had been given to their child at initially. In addition, mothers shared their experiences of how difficult it was for them to manage the odd behaviours of their children prior to receiving a diagnosis. They were concerned about the future of the child as well as the difficulties that come with providing care for the youngster on a day-to-day basis. In addition, it was challenging for every mother to come to terms with the fact that her child had been diagnosed with autism. This is how one mother expressed how she felt.

“ When I was first informed that my child suffered from autism, I refused to accept the diagnosis. My first inclination as a parent was to look for someone or something else to pin the aberrant behaviour of my child on. Therefore, rather than simply accepting that as the explanation for my child's behaviour, I started looking for other possibilities. I insisted that the doctor investigate my child in every conceivable way in order to find out what was wrong with him. After that, however, all of the reports were considered to be normal.” (P2)

After receiving the news that their kid has a medical condition, some mothers have a sense of relief, while other mothers experience a terrible sense of meaning loss upon discovering that their child would not have the same prospects in life as other children. A mother who was overcome with grief described her ordeal as *“After discovering that my son had autism, I sank into a dark melancholy that lasted for a long time. Attending social occasions often ended in queries about my sick child,*

which only served to compound my despair. This was particularly difficult for me because I felt like I had no control over the situation.” (P1).

When their children misbehaved or when they received little support from relatives, mothers frequently responded with rage, which was another rapid response they displayed. Several mothers have expressed their annoyance to the media about how their children frequently interrupt them when they are attempting to do responsibilities around the house. According to the words of one participant who was 36 years old, *“Yes, I also have the pleasure of raising a second little child of my own. Consequently, it is only natural that I used to feel a great deal of anger each time these two youngsters fought. I’ve gone so far as to carry out their punishment on my own initiative. In addition, because he frequently comes along with me and gets in the way of my day-to-day activities, it is very difficult for me to concentrate on my homework and get it done.” (P8)*

Caring for any child may be a tough experience; however, doing so while also addressing the unique requirements of a child can be an exceptionally challenging endeavour. It’s normal to have low days every now and again. Without exception, mothers of children of all ages expressed concern on the transition of their children into their teen years. The fact that the youngster’s schooling, future employment, housing environment, or capacity to transition to maturity could not be predicted added an additional layer of anxiety to the scenario. According to what her mother said, the thing that kept her up at night was her concern for the future.

“The youngster I am raising has speech difficulties. As she is a girl, I am more concerned about her prospects. Each day, her bodily changes become more pronounced. It pains me to think about what she’ll do and how she’ll express herself while she’s having her period. How will she manage without me? When I’m old and dead, I won’t be able to help her with anything, and I worry about how she’ll continue to live and work without me.” (P9)

Social Problems

The mental and physical struggles that parents of autistic children frequently face are similar to those that their children face. Their families frequently encounter social problems such as social ignorance (2/2), social blame (5/5), and social isolation (7/9) as a result of the child’s out-of-the-ordinary actions. At the age of 32, she was a mother of two children, and she highlighted the social stigma she suffered. *“Many people pointed the finger of blame at me, stating that the child’s condition was my doing since I was too conceited, pampered, and educated. They proposed publicly shaming the child and physically abusing him in order to correct the child’s behavior. Other people in the past have also hypothesized that inadequate nourishment during pregnancy was to blame for the problem.” (P6).*

Mothers have said that the increasing responsibilities they have for their children's care and the fact that their kids might act up in public have cut down on the number and quality of their social contacts and interactions. A narrative on the challenges that a mother faces while she is alone,

“The condition of my children has a significant bearing on how I feel about myself. Taking care of him around the clock leaves me with no time for myself. Due to the fact that I couldn't stand to leave him home by himself, my social life was severely limited. If I were to bring him there, I'm scared he may behave in an unacceptable manner, such as by hurling food, beating people, or tearing people's clothes off of them. It is required of me to follow him everywhere he goes and keep watch over him at all times.” (P3)

The majority of mothers who have children with autism said that the presence of an autistic child in the home has an impact on the day-to-day activities and emotional state of the autistic child's sibling. Mothers also reported feeling guilty for the lack of care, attention, and love they provided to their children, who were unaffected by the condition. When questioned about her emotions, one mother responded as follows:

“My younger son does not have autism, but my elder son does. The younger sibling is not old enough to fully comprehend the seriousness of the issue at this point in time. My autistic son is completely unaware that he should appreciate and look out for his younger brother, despite the fact that he is the eldest sibling in the family. They constantly argue with one another over insignificant matters such as toys and cell phones. I guess I'll have to behave toward him as though he were a royal for a significant portion of the time. The fact that I couldn't spend as much time as I'd like with the younger one made me feel like the worst parent in the world. Because I have to look after my older son at a care program, I have no choice but to leave my younger son at home alone for the duration of the day.”

Economic Problem

The majority of mothers struggled with their finances due to the fact that their families only had one source of income, and they were required to spend a sizeable portion of that income on the medical treatment and therapy of their children. The illness of their kid also had a detrimental impact on the mothers' professional lives, which they had to deal with as a consequence. The vast majority of working mothers who were surveyed stated that it was impossible to balance their professional lives with those of their children. Some of the mothers came to the conclusion that they simply did not have the financial means to offer their child the specialized care that they were aware their child required. Concerned about her situation, a mother shared the following statement:

“I acquired my certification to instruct because I thought it would help me find a job, but unfortunately, her condition has hindered me from starting a career. I got my

certification to teach because I thought it would help me get a job. Because of this, we are currently having trouble making ends meet on a single salary due to the high cost of day-to-day living expenses and the child's medical expenses also it becoming worst because of this ongoing economic crisis in Sri Lanka. As a result, I will not be able to offer her any extra therapy at this time. The challenges we face in meeting our financial obligations have often been a source of contention between myself and my spouse.” (P1).

Adaptive Strategies

Every mother who was interviewed stated that she had attempted to deal with her situation in her own unique way, whether it was through positive coping (continuing to have hope for the future, establishing a goal, using treatment services), problem-focused coping (getting a job, getting autism training, attending a programme related to autism, beginning a care centre, getting social support), or religious coping.

Interim Care

Respite care, in which a child is temporarily placed in a care facility or school so that the parent can enjoy a period of stress-free independence, is one of the most common coping mechanisms, although every mother has her own unique set of coping mechanisms. However, respite care is one of the most common coping mechanisms. They also thought their kid would benefit more from the center's offerings and pick up some new skills. According to one mother, her coping mechanisms throughout her child's time in respite care included:

“Now that I have enrolled my child in a daycare centre, I have the entire day to myself and am able to focus on housework.”

Healing with Faith

Spiritual coping methods were mentioned by the majority of mothers, and the most common ones included having a strong faith in God and hoping for the best for their child. A mother of 34 years old who had accepted the reality of her child's condition shared her thoughts.

“In my opinion, God bestowed upon our family the gift of autistic children. How skillfully we ornamented them will determine how well this gift is received and whether or not it is accepted at all. If we take the time to adorn them beautifully, we will have a positive consequence; on the other hand, if we don't, we will have a negative one.”

Positive coping strategies

To deal with challenges, mothers have been observed surrounding themselves with optimistic ideas. Positive mothers reframe their thinking by holding on to the belief

that they will continue to do good deeds as long as they are alive. This is how one mother described her emotions:

“My viewpoint is that we should never stop going forward, that we should never dwell on the past, and that we should never let ourselves get mired in a rut by concentrating too intently on the past. Consider the past to be a nightmare, and do everything you can to put it in the past. My one and only reason for living is to make sure that my child has a life that is full of joy and good health, and because of this, I do everything in my power to think positively about my own capabilities. The more time we spend thinking about the problem, the less likely it is that we will be able to find a solution. Ignoring the obstacle and acting as if it has never been there is the most effective response. Ignoring the obstacle and acting as if it has never been there is the most effective. (P2)

Problem-Focused Methods

Problem-focused solutions for parents of autistic children include giving them social support and taking steps that directly address the problem. When they were in need of assistance, all of the mothers I spoke to said that they turned to their friends, their neighbors, and sometimes even their own parents. Another mother disclosed that she had recently been working on establishing what she calls an "autism care center" in order to support her own family as well as others who were in a similar situation. A mother who is 32 years old recounted her story as follows:

“I collaborated with a few other mothers who also have children with autism, and these days I am thinking of establishing a facility that provides assistance for autistic children and their families. To facilitate my son's development in this area, I take him to daycare every morning and remain there with him throughout the day. When I have some spare time, I'll go to one of the autism-related events that are put on by the Ayati center or somewhere or any of the many other government agencies that are located in my neighborhood from time to time.” (P6).

DISCUSSION

This goes over everything from the very beginning to the very end, including the results, the conclusions, and the recommendations. The findings are discussed in the context of previously known facts, and the findings of published studies are connected to the experiences of mothers who care for children who have been diagnosed with autism in the real world. The primary objective of the study was to enquire about the difficulties that mothers experience in their daily lives when caring for their autistic children. Analyses of in-depth interviews with nine mothers of autistic children shed light on the difficulties these mothers faced and the solutions they found to these difficulties.

Perceptions on autism spectrum disorders

This research brought to light a number of crucial topics, the first of which was the viewpoints of mothers on autism. The attitudes of mothers on autism were all over the map. Mental retardation, developmental delays, and problematic behaviours are all ways that moms can characterise their children who require continual assistance and care throughout their whole lives. These children are often referred to as "special needs" children. According to the findings of the study, the vast majority of mothers considered autism to be a form of developmental disability and believed that their child's condition was caused by a combination of factors. These factors included, but were not limited to, developmental delay, medical disorder, genetic disorder, and neurodevelopmental problems that began before birth or in infancy.

The Acknowledgement of the Problem

In this particular study, it was the mothers who were the ones who first noticed their children exhibiting symptoms of an abnormal condition. These symptoms included withdrawing from social interactions, preferring to be alone, playing for long periods of time with the same toy, failing to make eye contact with others, and acting in a repetitive manner. It is a confirmation of the findings of the New York study that the manifestations of autism vary greatly depending on the child's developmental and chronological age, and that these manifestations can include a wide range of behavioural symptoms such as hyperactivity, impulsivity, aggression, self-injurious behaviour, and temper tantrums. The New York study found that children with autism had a greater likelihood of engaging in self-injurious behavior than children without autism.

When asked what they did to receive help, the majority of mothers responded that they took their child to the pediatrician as soon as they noticed something was wrong, regardless of whether it was an abnormal pattern of behavior or a delay in the child's development. At the same time, other people started researching the symptoms of the child online, comparing them to those of their own children or those of their siblings and neighbors. A study that was conducted in both the United Kingdom and the United States came to the same conclusions; it indicated that mothers were confused by the behavioral difficulties and developmental delays exhibited by their children. Some mothers read books, went online, and had in-person conversations with other mothers of autistic children in order to do study on the subject and seek the opinions of those women. These mothers almost always sought help from their child's pediatrician as their first point of contact, and those doctors were more likely to be supportive and helpful throughout the diagnosis process.

Those mothers who took their children to a pediatrician and claimed their doctors listened to their concerns and assisted them in locating a nearby center where their children might receive treatment and education stated that their pediatricians were

understanding and helpful. Seven out of eight moms whose children received training reported significant changes in both the behavioral and developmental skills of their kids after receiving the training. According to the findings of a study that was conducted in both the United States and Canada, specialized therapies, such as speech and language therapy, occupational therapy, and vocational training, can improve an individual's ability to communicate, increase their level of independence in activities of daily living, and enhance their ability to adjust socially and behaviorally. In addition, treatments that focus on parent training contribute to the development of children by enhancing the interactions between parents and children. It went into great depth about how delighted and relieved parents were with the training they received for their young child with autism as a result of parent training interventions. Specifically, the training helped the parents better understand how to help their children.

Experiences of Everyday Life

Problems of a Physical and Emotional Nature

When it comes to raising and caring for children with special needs, their mothers face a lot of challenges. It is the person who is receiving care who suffers the most from the physical symptoms that might be brought on by the stress of continually being on call for their care. These symptoms include exhaustion, interrupted sleep, and weight loss. In addition to the physical obstacles of caring for a crippled child, mothers had to contend with the emotional challenges of coping with their own denial, fear, and resentment in relation to the child's condition. This was in addition to the physical challenges of caring for a defective child. The mothers were anxious since they did not know what the future held for their children. It's possible that this is because there is no dependable organization in place to help youngsters who are in need. A great number of mothers have expressed their hope that their offspring will grow up to have what they refer to as a "normal" life or will acquire the knowledge and abilities necessary to be self-sufficient. The vast majority of mothers have already started getting ready to teach their future children the life skills (skills needed for daily living) that will help them become independent. These life skills are referred to as "daily living skills." This is in line with the results of a study done in Turkey, which found that the first thing mothers do when they hear their child has a disease is to reject it. A study that was conducted in Africa that was very similar to the one conducted in the United States found that parents in Africa initially refused or questioned the diagnosis, indicating either a lack of knowledge of the illness or an unwillingness to accept the possibility that their child could develop it. In both the Greek and American studies, it was discovered that mothers were the major caregivers for their children. In both countries, mothers thought that their most important job was to take care of their children and make sure that care was coordinated with their other daily tasks, like keeping the house clean and taking care of the rest of the family.

Many mothers said that the stress of caring for a child with a chronic illness hurt their own mental health and made them feel helpless and powerless, which made them more pessimistic about their child's future.

Social Problems

Having autistic children in the house hurt the moms' social and financial standing. Because they spent so much time caring for their autistic children, these mothers frequently felt isolated. Because of their children's antisocial behavior. Because their kids didn't get along with other people, they couldn't go to religious ceremonies or other formal events. Educated ones had lectured them, telling them that the condition of their child was the result of their own irresponsibility, over intelligence, and excessive coddling of the child. All of these problems not only cause disruption in the lives of the parents, but they also have a negative impact on the lives of the children and the rest of the family as a whole. This, in turn, causes problems in the relationships that exist between the family members and the members of the community. This is in line with the findings of a study that was carried out in the United States. The study found that mothers experience social deprivation when they can't keep in touch with their friends from before they had kids. This could be because they don't have enough free time, are worried about how their kids will act, or want to avoid social stigma because of these things. This is consistent with the findings of the study. Residents also knew more about the signs of autism and blamed the mothers of autistic children, thinking that the mothers' personalities and activities had something to do with their children's autism.

Economic Problem

Children and teens who have been diagnosed with autism need care 24 hours a day, 7 days a week, as well as regular evaluations and ongoing treatment. It is possible that one or both parents will need to give up their employment in order to care for their children, which can be challenging for the family's financial situation. The mothers who participated in the study exhibited indicators of economic strain as well. It was necessary for mothers to give up their careers in order to care for their disabled children. In addition to that, they had to shell out a substantial amount of money for expensive toys, therapies, and treatments for their child. Qualitative research has shown that 24 percent of families with autistic children have to cut back on their work hours or stop working altogether because their child needs constant care and monitoring. This lends credence to the assumption that moms are economically distressed. Furthermore, the costs of health care for families with children with ASD were found to be significantly higher than the costs of health care for families with children with other types of special health care needs. According to the findings of a study conducted in Greece, similar factors, such as insufficient insurance coverage for essential therapies and high out-of-pocket expenses for intensive interventions, result in mothers being forced to make significant adjustments to their lifestyles in order to

meet the financial and logistical demands of caring for their children (i.e., speech and occupational therapy, psychotherapy).

Coping Strategies

When viewed through an ecological lens, many different systems are ameliorating the hardships these women face. The mothers who spoke to the study said that the support they received from their religious communities, autism support groups, extended families, and friends helped them raise their children with autism. We may categorise the tactics moms employed to deal with the pressures of daily living into four broad categories.

Care for a short time away from a primary caregiver comes first. All mothers ultimately decided to enrol their children in respite care at the centre. The results of a study conducted in Sydney corroborate this, demonstrating that respite care helps families by giving them a break from caring and allowing them to do things they can't do when the child with ASD is at home, such as relaxing and focusing on other activities.

Second, mothers utilised solution-oriented approaches (such as seeking medical help and social support), and one mother even opened a care centre to aid children on the autism spectrum. These results are in keeping with those of the English study, which found that mothers of children with ASDs used problem-focused tactics (such as treatments/interventions for the child and social support).

Finally, all mothers turned to religion as a means of coping, praying for a healing miracle. They went on a religious pilgrimage, making stops at several temples. This is consistent with the results of a research conducted in India, which indicated that moms caring for children with autism spectrum disorders were less stressed when they had access to intervening variables like optimism, faith in gods, and religious support.

And last, women are perceived as using positive coping as a way to lessen the strain of raising children with autism. These findings are consistent with those of a study done in India, which found that parents' optimistic outlooks are crucial to their capacity to deal with the stresses brought on by their child's impairment. Consistently, it was demonstrated that optimistic expectations give families a better chance at success and a higher quality of life, both of which are important for helping a child reach his or her full potential

CONCLUSION

As a whole, the path of a mother who is also responsible for the care of her children is a challenging one, as the findings of this study have demonstrated. The journey that each mother takes through life with her challenged kid is unique. During the early diagnostic phase, they may experience physical exhaustion, difficulty sleeping, and loss of appetite, in addition to mental discomfort caused by anxieties about public judgement, anger at their child's annoying behaviour, and anxiety about the future. Because of the significant expense of the medical and treatment intervention, they are having serious problems with their finances. Many mothers find that the best way to deal with the pressures and challenges of day-to-day life is to cultivate a diverse set of coping methods.

Implications

The findings of the study could be helpful to social workers, nurses, and other health care providers who are interested in learning more about the similarities that exist among families with autistic children. Because of this, they would be able to better cater to the requirements of persons who have autism as well as the requirements of their families by adapting the care they provide to the particular circumstances of each individual. To fulfil the needs of women who are parenting children with autism, policymakers and health care planners may also find it valuable to plan and intervene in the programme. The findings of this analysis have the potential to serve as a reference point for future research that is conceptually comparable. The findings of this research on autistic mothers' coping techniques may help other parents better adjust to the challenges they face when raising children with autism.

The significance of social workers for parents of autistic children.

The support that social workers provide to families who are coping with the challenges of raising a child with autism spectrum disorder is one of a kind. The function of the social worker in the growth and development of an autistic child's life has evolved to include a variety of aspects, including socioeconomic, psychosocial, and welfare issues. The autistic child may benefit from the hands-on approach that the social worker takes, which may be good for the child's development and health. The researchers are advocating for the construction of specialised schools and institutions for children with autism, such as Ayati, based on the findings of their study. The actions taken by the government of Sri Lanka to increase awareness about autism and the significance of early intervention can have a positive impact not only on the life of the child but also on the lives of the parents.

LIMITATIONS

1. The mothers' responses ranged in subject matter and level of detail, depending on the quality of their relationship with the interviewers, the particulars of the circumstance, and the reasons they were participating in the study.
2. Due to the sensitive nature of the subject matter covered in the survey, it is possible that some respondents choose to withhold information or provide alternate answers.

Recommendation

Mothers who have children with autism have reported experiencing a wide variety of challenges, some of which have an impact on their health, relationships, economics, and social lives. According to this result, therefore, it is recommended that medical personnel give particular attention to mothers and guide them through the process of receiving therapy.

In order to fix the problems with this study, more research needs to be done on autistic children in a wider range of places and times.

It is strongly suggested that media-based efforts be made to help the general public learn more about autism spectrum disorder.

If you want the results of the study to be valid in other settings, it is essential to replicate the research using a mixed-method design that incorporates both qualitative and quantitative approaches. Only then will the results be robust.

In order to have a better understanding of the challenges that mothers of autistic children face in the larger community, a support system for the social work profession should be established. This will allow for the appropriate intervention to be carried out on autistic children as well as family-related issues.

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