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Walking With The Spectrum: A Phenomenological Study On The Experiences Of Mothers Raising An Autistic Child

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ABSTRACT

This study explores the mothers' experiences raising an autistic child, the struggles they faced, the misconceptions they had, and the factors that altered their mental framework in effectively managing their child and their condition. Seven detailed semi-structured interviews of mothers raising a child with autism were conducted to understand their situation and the factors that affected them. A phenomenological methodology was used to uncover the lived experiences of these mothers. Results revealed the existence of seven distinct themes that provided insight into the experience of a mother raising a child with autism. Themes focused on the mothers' mental frameworks, including denial of red flags, mother-researcher, emotional paradox, and cognitive processing, indicating the mother's thought patterns and emotional processes in dealing with her child. Moreover, themes such as Family dynamics, Societal micro-aggression, medical resistance, the unspoken bond and redefining inclusion were noted for a comprehensive understanding of the experience of raising a child with autism. The results revealed that mothers lack the awareness to detect signs of autism and manage them effectively; health professionals and families need to collaborate to uplift the mother and child from chronic periods of stress.

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INTRODUCTION

Autism was first identified in a paper published by Kanner (1943); he termed it "early infantile autism." He described this disability as a severe impairment in communication and interaction. Kanner saw these children being resistant to change (Wing & Potter, 2002). The American Psychological Association describes autism as a pervasive developmental disorder characterized by impairments in social engagement and interaction, a deficit in social and emotional recognition and persistent, repetitive behaviours. Initially seen as different disorders with different levels of severity, Autism and Asperger's syndrome have been put into one category, the Autism Spectrum Disorder (ASD).

The birth of a child with a disability or the discovery of your existing child turning into what society considers "abnormal" often put families in a crisis. (Rapp & Ginsburg, 2001). Providing medical and therapeutic support becomes essential to these families lives. They are faced with the challenge of tailoring their lifestyle to suit their new family member's needs. This unexpected difference must be incorporated into the comprehensible narrative of kinship (Landsman, 2003). A child with autism may be a stressor, such as a lack of proper diagnosis to explain problem behaviour, defying social norms, and the disorder's duration and severity. (Bristol et al., 1988). Parents of children with autism have high-stress levels compared to other parents raising typical children.

This paper aims to explore the mothers' experiences, their conceptions about autism and how they interact with the child in relation to the world around them. Examining mothers' experiences raising an Autistic child in Pakistan has been challenging; as parents are often surrounded by the social stigma surrounding mental disorders (Khalid et al., 2020). This results in under reporting such cases, which makes new parents of an Autistic child feel further alienated. Therefore, this paper serves as a bridge to end the alienation the parents feel as they notice signs in their child and seek professional help without a sense of helplessness.

Most of the online literature deals with the crisis parents experience upon learning of their child's Autism diagnosis (Lappé et al., 2018; Latzer et al., 2021; Weiss et al., 2013). Limited Pakistani studies reveal the different factors that come into play before and after the diagnosis. This paper aims to provide a rich insight into the lives of the mothers raising a child with autism and her journey from noticing the signs to necessary interventions. The paper will serve as a starter guide for many mothers new to the diagnosis and unsure about their child's unusual silence and repetitive behaviours.

LITERATURE REVIEW

The medical models assert that autism is a neuro developmental disorder that has its origins in genes and neurological deficits. Early interventions are becoming a high priority in treating and managing autistic symptoms globally. On the other hand, social theorists such as Nadesan (2005), autistic adults (YouTube, 2007) and clinicians argue that autism can also be attributed to society, that it is created and constructed by the social forces existing within our society. According to them, society deems autistic behaviours abnormal and requires a shift in norms and values surrounding us. The social model advocates a distinction between the physical deficit or 'impairment' and the 'disability' caused by attitudes and infrastructures of society. Critics of the social model have argued that over-emphasizing the role of society denigrates the painful experiences of autistic children with debilitating impairments and the experiences of their caregivers, especially their mothers (Russell & Norwich, 2012). However, these models have been prevalent and studied in the western world, where logic takes over cultural norms and traditional mindsets. Here in our society, society acts as a reinforcement of disability and conforms to the act of continuously labeling a child disabled or abnormal.

Autistic children have very significant behaviours that attract attention. Our society sees it as a different human being altogether, which only exaggerates the stress level for the mother raising the child. Therefore, this study will tackle society's stigma attached and reinforced by the mothers' experiences raising the child. Baron-Cohen et al. (2009) acknowledged the stigmatizing potential of the ASD label and called for the term 'disorders' to be replaced with 'conditions'. Thus, ASD becomes ASC, 'autism spectrum conditions' in the literature of this school. A study conducted in Australia by Farrugia (2009) asserts that diagnosis helps harness a medical understanding of the child's behaviour and might help lessen the stigma attached to the parents as being neglectful parents raising a "spoiled child" instead, a child with different mental capabilities. However, many women in our country cannot reach the correct diagnosis stage, which further shapes their experiences of living on the spectrum with their children.

Diagnosis and health professionals

A study by Russell et al. (2010) conducted in the UK revealed that many a significant number of children who have not been diagnosed displayed the same symptoms as those who have received an official diagnosis. Studies show why some children never even reach a diagnosis or get access to the mental health services they require. Access barriers are controlled not just by the parents denying their child's unique needs but also by mental health professionals. A study by Howlin and Moore (1997) clearly illustrates the resistance of health professionals. They assert that parents are persistent in getting a diagnosis in many cases, but the clinicians enforce barriers.

On the contrary, some quantitative studies surrounding child psychiatry suggest that in some cases, access barriers are mediated by the parents. Diagnosis sets the precedence for how a child is handled in the coming years and helps give parents a guideline on managing their child effectively. Link and Phelan (2006) surmised that diagnostic labeling does exert an independent effect on the rejecting responses of the public, which exerts further pressure on the caretaker of the autistic child and, most importantly, the mother. Hence, it is essential to understand and decode the diagnosis process and assist the mothers in reaching the point of acceptance, getting access to diagnosis and specified guidelines for treatment.

According to Mansell and Morris (2004), many parents reported that getting a diagnosis was slow, chaotic, and poorly handled. Autism, a complex disorder, is hard to diagnose and recognize; most parents don't even realize that their child is autistic and are questioned by society and health professionals, which adds stress to the primary caregivers, the mother. Ambiguity leads to the mother visiting several doctors and clinicians to get a diagnosis. Often, they will convince themselves of the "best possible diagnosis", the one that fits them better than it fits the child's condition, further reinforcing the denial in this crucial stage of treatment.

Moreover, a study by Bernier et al. (2010) reported that in many parts of India, very few professionals are experienced in diagnosing and treating children with ASD. Because of this, many desperate families turn to spiritual healers. Most mothers are the primary caretakers in Southeast Asian societies. Unqualified clinicians often mislead these mothers into believing vitamins and prescription medicines will help heal the child's symptoms and do not work towards accepting the diagnosis, further adding stress and misleading the mother into believing autism has a cure. Bernier et al. (2010) also talk about how medical professionals and clinicians work in a close partnership in the United States to monitor a child's milestones and consequent developmental delays. Still, in a society like ours, language delays are not seen as symptoms of ASD but as cultural concepts such as boys speak later than girls.

Family Challenges

One of life's biggest challenges is to cope with something you do not have control over. In terms of marriage in the traditional Pakistani society, you cannot select the kind of household you are married into; high levels of stress come with adapting and adjusting to a new family. Theorists assert that low control situations often require an individual to develop new strategies whereby one changes the self to fit into the surrounding. Similar to when a woman is married into a new house, an additional adaptation from a mother is essential as she raises a child with autism (Weisz et al., 1994). Extended families in our culture are majorly unaware of this condition and continue to contribute towards raising the child based on traditional remedies for the cure and spiritual healers to manage symptoms. The mother, in this case, is often confused about what to follow and practice, as she wants the best for her child but is also constrained by joint family pressures. Mothers often withdraw from family gatherings and socialization as each family member has something new to add to the condition; recent speculations about the child's behaviour are often discussed at family social gatherings (Knapp et al., 2009).

Families also report feeling ostracized by those who do not understand ASD or the symptoms (Altiere & Kluge, 2008). The lack of education and support certainly adds to the already stressful and overwhelming task of raising a child with ASD. While each family situation is unique, parents who initially had a typically developing child and then saw a regression may experience elevated levels of self-blame, thinking they did something wrong that caused these problems with their child. Moreover, this blame and guilt feelings may remain unexpressed due to family norms. When left unacknowledged, these feelings can negatively impact the relationships that family members develop with each other and the professionals working with their children.

Culture

One of the core problems of ASD is reciprocal social interaction. As a result, differences in cultural beliefs about appropriate social behaviour can affect the accurate diagnosis of ASD. For example, direct eye contact in Asian cultures shows disrespect. However, reduced eye contact is a clear symptom of and criteria for diagnosis of ASD; extending upon this idea, Bernier et al. (2010) assert that children in the Asian community may be avoiding eye contact due to respect and not ASD. Daley stated that since the Indians and Asians paid a lot of emphasis on social interaction, they should be able to identify a lack of social relatedness before those living in the west. However, the reality is far from this fact; Indian parents often delay the intervention and seek help for as long as two years after noticing their child's social delays and red flags.

In countries like China, the stigma regarding mental health is so severe that families feel ashamed about revealing that they have a child with a disability; autism, in particular, is seen as a devil disorder. It is considered that the parents and being punished for sins committed; hence they were given a child with a mental disorder (Wang et al., 2018). Culture molds and shapes our everyday lives and how we look at each other. Culturally mental disorders are seen as taboos, putting families in a difficult position. Primarily the primary caregivers of the autistic child. There has been limited research on the interaction of social and cultural forces with the mother's experiences in raising an autistic child.

Not only does culture tailor the way autism is seen, but it also affects the perceptions of treatment. When it comes to mental health, treatment options and course depend on the family's belief about the cause of the diagnosis, but an understanding of the cause varies across cultures. African Americans, Latinos and south Asians often view such conditions as a possible result of dietary or supplemental deficiencies. They are also less likely to go for proper medical treatments and interact with relevant clinicians to review the child's disorder and discuss prognosis. How the condition is perceived and what kind of treatment options make sense all depends on what culture the family belongs to; often, mothers in Pakistani culture are forced to follow the cultural norm and practices. Traditional values take over rational judgment and reasoning. This research will connect the role of culture to the experience of the mothers while they raise their unique children (Bernier et al., 2010).

METHODOLOGY

Research design

This study uses a qualitative approach to examine and test the hypotheses. As this study looks into the experiences and idea conceptions of the mothers with autistic children, transcendental phenomenology seems like the perfect tool to explore this matter in depth. We will learn what they know and don't and teach them what they know incorrectly about their children and their diagnosis.

Participants

In this research, the sample comprised seven mothers with autistic children; most of these mothers have children below the age of 6. Mothers are from different walks of life; some are working while some are homemakers; all are married and are raising the child with their husbands. All mothers also have an official diagnosis of autism for their child.

Data collection tool

Phenomenology uses in-depth interviews to gauge the experience of the individuals under study. It is a casual conversational approach to gathering information regarding their experiences and how they give meaning to these experiences in their lives (Gill & Liamputtong, 2009). The purpose of in-depth interviewing, as Taylor (2005) suggests, is to explore "the insider perspective" it helps capture the essence of the experience by the words used by the individuals themselves, which means how rich and reliable that data becomes.

Interviews were conducted with each mother individually, recorded with permission and will then be transcribed for data analysis. Moreover, Esterberg (2002) suggests that women have historically been silent. This method of interviewing and giving these women the space to share their stories gives them a platform to speak and narrate. Two-way permission-seeking intervention and interviews benefit both the researcher and the mothers.

Procedure

The interviews were conducted in a space and time comfortable and convenient for each respondent. Time and date were communicated and discussed beforehand to avoid delays. The interviews were audio recorded with the mothers' consent; they were ensured that the recordings will only be used to facilitate the analysis of the data collection phase. Interview questions were prepared and discussed with the subject matter experts beforehand to make sure each question was relevant and culturally sensitive to avoid any feelings of discomfort during the interview. Each research objective will be weaved into interview questions to gauge appropriate answers and avoid steering around in other irrelevant discussion topics.

DATA ANALYSIS

After data collection, each interview was transcribed word to word for analysis. This research used the phenomenological research method to counter the argument about the researcher's bias influencing the respondents' experiences or modifying the responses to suit the biases (Giorgi & Giorgi, 2003).

RESULTS

After continuous reading and deep analysis of seven interviews, over 150 non-overlapping statements were identified and extracted from the interview transcripts. After which codes were assigned to new ideas and concepts, which led to the emergence of seven distinct themes that provided insight into the experience of a mother raising a child with autism. The mother's mental framework included four sub themes (denial of red flags, mother researcher, emotional paradox, CognitivMothere processing), Family dynamics, Societal Micro-aggression, medical resistance, The unspoken bond, Redefining inclusion, and Supportive care. Table A. 2

Mothers' mental frameworks

Denial of Red flags

A typical trait noted in the mothers was during the initial stages of noticing the "difference in their child" most of the participants narrated similar experiences leading to their child's diagnosis. Mothers claimed that they didn't feel anything was wrong at first and were reasoning with themselves about the individual differences of their children. While some felt that gender played a significant role in her child being a "hyper" child.

The following are essential supportive quotes:

"I was shopping for a different diagnosis." (Participant 4- T)

"I just felt that okay he's just different and didn't want to socialize, even I'm not very social and don't have a very friendly nature." (Participant 7- Z)

"I wasn't trying to deny that something is wrong with my child, I was genuinely not aware." (Participant 6-H)

Mother Researcher

Initially unaware of their child's condition and feeling bombarded with information from doctors in some cases. In most cases, the lack of relevant information from medical professionals created this new role for these mothers. They were not only raising a child but also studying their child. The initial emotion they felt when they came face to face with the word autism was a sense of hopelessness and feelings of being lost. During the interviews, almost all mothers explained how they felt they had just been given the biggest shock of their life and knew that life would need modifications. The modifications required them to study literature and simultaneously search for the right therapist to develop a partnership so that she could work effectively with her child.

"you know you get a lot of time while you're waiting for your child, while he's in therapy, so I read." (Participant 1-S)

"It was like I was thrown into a swimming pool with no one to hold onto except the internet." (Participant 4- T)

"I attend all her therapy sessions and learned the techniques, so I could practice with her." (Participant 3-A)

"There are so many OT positions I'm not yet aware of, there are so many diet programs that people are doing that I'm not aware of, there's so much to learn, it's a very vast subject." (Participant 3-A)

Emotional Paradox

The mothers in the study identified their feelings pre- and post-diagnosis; however, there appeared to be discrepancies between both periods. They initially quoted being devastated and experiencing a shift from everyday life to an atypical life. At the same time, they later accepted the diagnosis with grace and spoke about the contentment of their child's best capacity to perform in this world. They were conflicted with their emotions; how they couldn't truly express themselves made it clear that a paradox existed. Mothers did accept that schooling was not important but, in other instances, wanted to create situations for socialization and interaction for their children. They also tried to cope with the diagnosis positively, assigning qualities that suggested the child could make way through to the "normal" life.

"And I would want A to be really independent like any other child would be, I would want her to live a really normal life." (Participant 5- P)

"I would love for her to have a normal conversation with me but she's also very affectionate, her eye contact is also better. We do hugs and we sing songs together. We make silly jokes together, it's not like a conversation, conversation but we make silly songs and jokes and hugs and kisses and stuff, so we are better than, you know it's like the glass is half full actually instead of half empty." (Participant 3-A)

"So yeah, he's my hulk. I Fight with him sometimes too when I have something's on my mind and you know, I think he's my therapist. He is my therapist." (Participant 1-S)

Cognitive processing: Experiencing your child and, in most cases, your firstborn going through something you cannot simply understand is bound to overwhelm a mother. Most of the mothers went through this phase, where they deduced the diagnosis to simply speech delay to console their trembling conscious. Some of the mothers stated that they were constantly hoping and praying it was something they could "cure". On finally discovering autism, the most common feeling they associated with was a sense of devastation and that life would end. The possibilities of life had been reduced to nothingness and hopelessness—

some explained life in terms of two parts, life before diagnosis and life after diagnosis.

Following are supportive quotes:

"In the beginning yes, because you don't know what to do at that point. You know you become kind of unreceptive to everything that is being offered to you." (Participant 6-H)

"I was obviously very anxious to know what was going wrong, because there was definitely something wrong. I could see it. So, I wanted to know if it was just speech delay, which I was really just hoping and praying for." (Participant 1-S)

Family dynamics: Mothers explained how families reacted to the news of the diagnosis; some families, although literate and experienced in mental health issues, still raised questions. The mothers, in most cases, had to explain the condition and how there was no cure for autism, but in a state of complete denial, families were often actively seeking a cure for the disorder. Although in most cases, families proved supportive, some blamed the mother and her upbringing. Some families denied the possibility of a mental condition altogether, which is why one mother felt it was just appropriate to leave the family out of it.

Following are some supportive quotes:

"Well, they were accepting, they knew that. But first of all, they would ask me if he would get cured. And I'm like this is like diabetes, this is going to stay with him for the rest of his life but yeah, we can manage it, and when they got that, they kind of were on board." (Participant 1-S)

"There were some people who would come to us and say "she doesn't say salaam", "she doesn't even know me."

"How are you raising her, she doesn't even respond to her own dada and daadi." "She doesn't even meet the kids.". So, I heard these few things often and on, sometimes she's going to act like she's deaf and dumb, when she wouldn't even respond to her name, it did make me very uncomfortable and upset." (Participant 3-A)

Societal micro-aggression. Remarks and judgments were quickly passed, and several mothers explained feeling confused and pressurized even more due to this aggressive verbal attitude. Some mothers quoted supermarket and flight encounters with their newly diagnosed or, in most cases, misdiagnosed child. They also quoted instances of meltdowns and how people adversely reacted to them. Belonging to a traditional society, Pakistanis are also culturally bound to interfere and often force co-parenting when raising children. Some mythical beliefs in curing autism were also discussed.

"umm so yeah it was really annoying, so the whole flight from here to the Uk, all I heard throughout the flight was that "apna bacha sambhaale, apna bacha sambhaale" (please handle your child) when the food was served, he was running around the aeroplane but I couldn't contain him. Towards the end I just got immune to it, no matter how much I try to explain, he has autism, he has special needs. They weren't really getting it. And it gives me anxiety. So much anxiety." (Participant 2-B)

"You take your child to a supermarket and he might just see something or hear something that he might react to and can start screaming you start to get really nasty looks, I still do. In the beginning, I would get really furious and I even picked a few fights with random strangers, who just leave me alone, he's a kid, and kids scream. But now I'm like I'm fine with it." (Participant 1-S)

Medical resistance and reluctance: Mothers explained how much time was wasted just getting an appointment for diagnosis. Upon getting an appointment, several of them were disappointed with how the professionals disclosed the diagnosis and tested their child. Mothers also felt they had to be their saviour in this field as no additional information or guidance was given to them. Furthermore, mothers felt that their children would have progressed a lot more had they gotten the right help at the right time.

Following are some supportive quotes:

"Initially it was not very helpful, because even we didn't know it was autism, we hadn't even thought of it. So, his pediatrician over here did a kind of a recommendation of a speech pathologist, that's it. They didn't even perform any cognitive tests or anything of that sort." (Participant 1-S)

"I think the psychologist will, the resident takes a very long history but Dr T takes a lot of time in explaining everything and Dr She doesn't give that much time, but in my case, I got very lucky." (Participant 2-B)

"It took me around 1 $\frac{1}{2}$ year just to get a diagnosis, just leave the treatment aside but just 1 $\frac{1}{2}$ year to know what was wrong with my daughter. I think if I could get a diagnosis at an earlier stage I could have done a lot because A had all the red flags and yes I struggled a lot, I consulted around 5-6 doctors and I got the final diagnosis at the age of 3.5 years" (Participant 5-P)

"Also, I live in Faisalabad where they didn't have a single clinical psychologist or a child psychologist, I had to travel all the way to Lahore or Karachi to get her a diagnosis. So, it really was a struggle going to another place and then consulting all the professionals." (Participant 5-P)

The unspoken bond: Despite everything changing in their life, given that they had to raise a differently able child, the mothers explained the nature of this unique bond that required no language. One would assume that since the disorder comes with limited socialization and limited reciprocal emotions, how did the mothers develop a deep emotional bond. In most cases, they missed that exchange of emotion and affection, but they deeply valued the bond and connection they had with their child. Most found resilience in how their child was the only one there for them, how that bond and connection uplifted them from the times of darkness they were thrown into with the diagnosis. Some felt it was hard to connect and had to develop a new way of approaching a child to communicate with him.

Listed below are some example quotes:

"Like he won't come running to me to hug me or share something with me like that. I have to get into his world, I have to sit with him and I have to see what he's doing, maybe tease him a bit, you know engage him. And I wasn't used to that, I have never done that with any child, I didn't have to do it with my daughter." (Participant 4-T)

"with Y, I had to also rewire my brain with Y also, his needs, his personality, because I was very used to my daughter coming to me and you know having that communication with her, with Y you have to get down to his level, you have to understand what he is trying to communicate with you, what he's doing, what his interests are, what he would like." (Participant 4-T)

Supportive Care

Some mothers did emphasize the need for such support groups to cater to the mental health and well-being of the mother. In contrast, some mothers felt that they did not want any further information on how to raise their children. They do not need to interact more with other mothers because it was starting to become more of a comparison on the spectrum and information overload rather than help or support. Furthermore, the mothers felt it was challenging to find the right kind of support in terms of therapies for their children. Once they did, the therapists became their emotional support along the way; however, it came with financial costs and a tiresome routine.

Following are supportive quotes from the transcripts:

"No, I'm okay. I think the more information you are bombarded with the more you start to, It's a very personal belief. That you start doubting yourself more." (Participant 1-S)

***"** But nobody has the time to sit down with a mom and counsel her or not where her kid needs to go or what she needs to do with him next. Not about how she is doing, nobody asked me."* (Participant 6-H)

" Mothers they overlook, it's very important to look after your own mental health first. I used to sit here with the Aba therapist and she used to tell me to do this with him, do that with him but you know when I used to go home, I used to feel so overwhelmed with my emotions that I used to feel paralyzed." (Participant 4-T)

Redefining Inclusion: Although mothers expected the bare minimum to a great extent, they wanted to see their children amalgamate into society well and become independent at least due to the uncertainty that surrounds their condition. Mothers, however, did emphasize how they wanted their child to behave morally and ethically correct, which indicated they worried about society's inclusion or, in a worst-case scenario, exclusion and isolation. Hopes and expectations surrounding their child were focused on societal roles and milestones. They expected their children to one day study and get an education but also understood their child's capacity and what was best for them.

"Masha Allah Masha Allah she's not very dysfunctional with her physique also, so we hope that she studies well. Right now my priority is her education."(Participant 3-A)

"Inclusion is not just placing a child in a particular system and being able to tell people that yeah our kid also goes to a mainstream school, no. For these children, you have to think what is most beneficial for them, yes I do send him to a playgroup and it has worked wonderfully for his social skills."(Participant 4-T)

"And I would want A to be really independent like any other child would be, I would want her to live a really normal life. So in the future, I hope that I am strong enough to take of my daughter, I hope she can become independent." (Participant 5-P)

"Now for me, we love Y to bits, he is our baby, we love him, but it's just that we aren't going to be around forever, that's something that bothers me the most."(Participant 4-T)

DISCUSSION

This study gives voice to the seven mothers raising their autistic children, strong and literate women who have been subjected to a shift in their lives. Yet, they persist and tackle challenges they face regarding their differently able child. The rates of autism have increased in Pakistan, but the acceptance and inclusion have been inversely proportional. Mothers of autistic children have become a marginalized group under the spectrum umbrella. Questions are raised, and pressure is exerted on these primary caregivers who strive to be supportive of their child.

The mother's emotional well-being has been subjected to many external factors. First being thrown into this new world of autism, the mothers struggled to find their way through. The majority of the mothers, although belonging to literate households, some even working mothers, explained how unaware they were in detecting the red flags of autism. However, substantial research indicates that the signs of autism can be seen as early as before age two (Kleinman et al., 2008). In most of the participant's cases, they started noticing and understanding the signs and symptoms after the second and some even after the third birthday. For example, Daley (2004) found that Indian parents started recognizing signs in their children 6 to 10 months later than parents of autistic children in the west. Reasons such as cultural views and stereotypes that "boys speak later" normalized many social and speech delays for the parents living in India, a society with a culture very similar to the Pakistani society.

Moreover, it was also noted that the mothers felt their child was just a different child, and there was nothing unusual or atypical about their child's characteristics. In some cases, it's not denial; it's just a lack of acceptance and awareness of the possibility of autism. Gentles et al. (2019) framed this concept very well by calling such parents "Autism naïve parents". Their research claimed that parents sought the roots of what they perceived to be isolated problems unrelated to autism- such as approaching testing services for possible hearing problems, speech delay or the possibility of impaired language development. Most of the mothers also clearly stated this behaviour and explained that they were not ready to accept the red flags and consider autism the problem their child was facing. One mother even suggested that she was "shopping for another disorder", a disorder of less intensity, a condition with a possible cure. Most mothers also stated they hoped and prayed that it wasn't autism. Carlsson et al. (2016) further described how Parents of Swedish origins expressed a shared sense of urgency before they approached clinical help for their child, as they perceived that their child was different in a non-worrisome sense. Therefore, it can be said that it is a common trait of parents who start noticing signs of their child being different.

Most immediate families held stereotypical views and enquired about sanity; some claimed that the mother was being a "neglecting mother" or worrying for no reason. Some husbands took a stand, while most took a step back and assumed it was solely the mother's responsibility to nurture the child. The first-line interventions for ASD are generally parent-mediated, requiring considerable parental effort for effective delivery (Kendall et al., 2013). Some mothers reported that upon discovering their child's diagnosis and going to therapies with them, they experienced a state of paralysis. They could not use the techniques taught at treatment and would sit and watch their child, sometimes just crying all day. In this case, the mothers felt they needed that extra support and had no one; in some cases, these mothers found resilience in their children and picked themselves up. Maternal health and mental distress are seen as a public health challenge now. Rahman et al. (2008) outlined strategies that have been developed to integrate early childhood interventions in child care programs. Thus, fathers and the immediate family circle should be involved in this process because it will help the mother and give her the support she needs and help achieve buy-in for intervention for the whole family. Progress in the child only takes place when the environment he spends the most time in is conducive and supporting.

The ambiguity of their situation further exerted pressure on these parents, the stress levels elevated, and they just felt like they were "thrown into a swimming pool and didn't know how to swim to reach the surface. Various research papers belonging to the South Asian culture have shown a similar picture that suggests that parents are under immense emotional burden and stress when they discover the reality of their child's mental health (Desai et al., 2012).

Furthermore, it was also noted that upon finally noticing the signs of autism in their child, mothers wanted immediate help to cater to the different needs of their child. Mothers stated that the diagnostic procedure took too long and felt they wasted time. Research also indicates that even in the UK, an average delay of 3.5 years was noted in getting a diagnosis for ASD, and half of the parents were dissatisfied with the diagnostic procedure (Keenan et al., 2010). Once they found out what was wrong with their child, after a long wait, that was only approachable to some of the participants. A participant living in Faisalabad complained about the unavailability of a centre for diagnosis or even a professional child psychologist to assess her daughter; the participant reported immense stress and anxiety travelling to seek medical help and diagnostic assistance. Reed and Osborne (2018) also said a negative impact of diagnostic practices on the mothers related to high levels of anxiety and depression. They suggested that providing information and sources throughout the process of diagnosis and assessment might help in countering the levels of stress and anxiety the mother experiences. They would be further helpful in explaining it to the rest of the family, another factor that was constantly highlighted and was personally requested to be shared with the world of researchers and policymakers. The mothers felt a considerable gap needed to be filled; they demanded that other mothers and caregivers get some helpful brochures and literature to assist them along the process. Despite having access to one of Karachi's best hospitals, mothers still complained about the lack of awareness among the general pediatricians and nursing staff. Nobody gave clear guidelines but were instead making sweeping conclusions about the child without evidence and systematic testing. Therefore, it can be said that the medical facilities and the professionals were not accessible, and even if one was lucky to get access to these professionals, it was not helpful meeting with them as the information and guidelines are given out were limited. Hence, the mother had to learn independently and become the researcher for her child, trying to find the best possible therapy.

Consequently, wasting a lot of time and money. In a study conducted in Egypt, 8 out of 14 mothers complained about how financially draining therapies and doctors' consultations were (Gobrial, 2018). The mothers who took part in the study seemed exhausted and were constantly overwhelmed with routines and schedules. They struggled with managing multiple roles at a time and faced a complete life imbalance. They expressed themselves in the questions asked about how life is different now, and all they spoke about was their routines to and from therapy. They had very little time to just "be". Being requires that people have time to discover themselves, think, reflect, and simply just exist (Wilcock, 2002). Their social lives were limited to only a few close friends who knew about their child, as it was exhausting to explain their child's condition to new people constantly. Some mothers also stated that if people were more aware, they wouldn't mind sharing the information. Unaware people make sweeping conclusions, making the mothers feel much more uncomfortable. This further indicates why there needs to be a support system for mothers to function as mothers and as human beings.

Moreover, it was noted that although the mothers unconditionally loved and accepted their child, who was now differently abled, they experienced a paradox of emotions. Knowing the child's capacity and embracing the truth of his skills, the mothers later expressed how they wished their child could be "normal" and have a "normal life and family." Kanzer (1983) studied "Papers on psychoanalysis" by Loewald and made a beautiful comment about parenting and expecting normality from a child or accepting that you are good enough as a parent; he said that part of being a good caregiver of a child with autism is expecting what a child can become. Faith and expectations are part of this child-parent relationship, the reciprocity of these is part of this relationship, and it takes time to learn and, in this case, relearn these expectations. These normal hopes are part of that unrealistic fantasy that allows the parent to mourn the loss of normality and serves as an adaptive function that leads them to expect and believe they are the "good enough" parent (Gombosi, 1998).

CONCLUSION

The primary caregivers, the mothers, go through nine months of holding a child in her womb and goes through the tiresome process of labour to bring a child into this world. Overwhelmed by the new life already and excited to see this child grow, the mother has expectations from her child. Hopes and wishes are reduced to minimal upon discovering your child are different. This research aimed to explore the factors contributing to the stress a mother experiences while raising a child with autism in a country like Pakistan. Subjected to societal pressures and family-changing dynamics, the mother struggles to find her way through and make peace with her child and herself. The research community of Pakistan needs to address these issues and educate the masses so that no child is left undiagnosed or, in common cases, misdiagnosed. Every new mother is lost, but every new mother with an autistic child is in darkness; we as a society need to create this awareness so that the lives of the different do not become complicated. Counsellors and policymakers must work with parents and make their interactions at an earlier stage more aware and meaningful; thus, creating a partnership between a counsellor and the parent seems like a plausible solution to the problems of both the mother and the child. The findings indicate the need for sensitivity to mothers' varying states of awareness and knowledge of their child's autism and the need to tailor parent support interventions to address the specific challenge that may arise in the future.

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APPENDIX

Table A. 1.

Participants

Participant	Age of Child	Age of diagnosis	Gender of child	Siblings	Family type
Participant 1-"S"	6 years	2 years	Male	1 sister	Joint family
Participant 2 -"B"	4 years	2 $\frac{1}{2}$ years	Male	4 sisters	Nuclear Family
Participant 3- "A"	3 years	2 $\frac{1}{2}$ years	Female	1 brother	Joint Family
Participant 4- "T"	3 years	2 $\frac{1}{2}$ years	Male	1 sister	Joint family
Participant 5 –"P"	5 years	3 $\frac{1}{2}$ years	Female	Only child	Joint family
Participant 6-"H"	4 years	2 years	Male	1 brother	Nuclear family
Participant 7-"Z"	5 years	3 years	Male	Only child	Joint family

Table A. 2.

Mother’s Mental Frameworks

Themes	Meaningful Sentences
Mother mental frameworks: Denial of red flags	-seeing is not believing -Denial state of mind -Different not disabled. -Accounting for individual differences
Mother mental frameworks: Cognitive processing	-Depressive thinking -Reductionist approach -shopping for alternative diagnosis -Internalized guilt -Enveloped in newfound world. -seeking calmness and organization
Mother mental frameworks: Mother researcher	-Well read -Self taught -Preoccupation with reading -Therapy break utilization
Mother mental frameworks: Emotional paradox	-Finding resilience -Seeking normality -Positivity with grace -Inclusion with acceptance
Family dynamics	-Newness to disorder -Denial of truth -Guilt inducing -non cooperative co-parenting.
Medical resistance	-Lack of guidance -Inappropriate diagnosis -Waiting is never ending -Accessibility and availability only for elite and connected people
Societal micro-aggression	-Traditional beliefs -Cultural responsibility to dictate child rearing. -Questioning parenting -Judgmental notions -Different not disabled.
The unspoken bond	-body language connections -child savior -small achievements seen as life changing.
Redefining inclusion	-independence -uncertainty and fear -normality and integration