Coping with autism spectrum disorder (ASD) in Pakistan: A phenomenology of mothers who have children with ASD

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Coping with autism spectrum disorder (ASD) in Pakistan: A phenomenology of mothers who have children with ASD

Juveriah Furrukh¹ and Gulnaz Anjum¹*

Abstract: In this study, the authors have explored lived experiences of the mothers who have children with autism spectrum disorder (ASD). The study explored the lived experiences of the mothers of children with ASD, including but not limited to the mothers’ stress, behavioral difficulties, coping strategies, religious, and social support related experiences. This study incorporated the factors that played a part in mothers’ experiences about ASD and whether they receive enough social and educational support. Most mothers are part of the middle and upper-middle class as they can afford extensive therapies for their children. An interpretive phenomenological approach was adopted using 15 interviews conducted in the sociocultural context of Karachi. The interviews gave an in-depth analysis, showing the mothers to be loving and caring towards their child from the start of the journey. This article highlights the lack of institutional as well as emotional support for special populations in Pakistan; thus, the findings are crucial for the United Nations Sustainable Development Goals, to ensure inclusive and equitable quality education that has the potential to promote lifelong learning opportunities for all. This study is a preliminary research that explores experiences of primary caregivers dealing with ASD; hence, it has the ability to set the premise for dialog around inclusivity as well

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PUBLIC INTEREST STATEMENT

Autism Spectrum Disorder (ASD) is a lifelong developmental condition that affects individuals across the globe. While some people may be able to live relatively normal lives, others may encounter learning challenges and require continued specialist support. According to the Pakistan Autism Society (PAS), in Pakistan, there are more than 350,000 children with ASD. This article, therefore, is crucial in highlighting the lack of institutional and social support for primary caretakers of children with autism in Pakistan. The findings of this article endorse and advocate the 2016–2030 United Nations Sustainable Development Goals (SDGs), SDG 3: ensure healthy lives and wellbeing of all at all ages, and SDG 4: to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.
as future research including an onset for a comparative analysis between mothers from lower classes as compared to those from middle and upper classes.

Subjects: Psychological Science; Mental Health; Psychological Disorders - Adult

Keywords: autism spectrum disorder (ASD); stigma of mental health issues; coping with mental health issues; mothers of children with ASD; children with ASD; interpretive phenomenological analysis

1. Introduction

According to American Psychiatric Association (APA, 2013), autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent difficulties in communication and social interaction and by the presence of stereotyped patterns of interests, behavior, and activities. ASD being a lifetime condition involves persistent impairments in language, activities, and social skills of the persons leading to stressors for the primary caretakers, especially mothers.

Difficulties associated with primary caretaking of children with ASD pose stress, anxiety, and strong pressure on parents (Bitsika & Sharpley, 2017). Stress experienced by parents in the caretaking of children with ASD exceeds in comparison to parents of children with no disabilities (Giovagnoli et al., 2015; Rao & Beidel, 2009), as the former emotional and coping resources outweigh the demands of their parental role. Previous research has shown that the stress of parents of children with ASD becomes very high, so much so that 77% of the times it can be clinically significant (Kiami & Goodgold, 2017).

Coping with the difficulties of children with ASD is one of the main mechanisms by which primary caretakers adapt to the stress and anxiety of managing a child with ASD (Benson, 2014). Coping can be defined as the mechanism by which individuals respond to stress. In the initial research on prevalence of stress and the use of coping strategies by parents of children with ASD, Hastings et al. (2005) identified multiple coping strategies, e.g. active-avoidance of the stress; problem-focused coping by planning and seeking appropriate social support; engaging in positive coping; using religion or spirituality; and denial. Hastings et al. also found that problematic behaviors among children with ASD were associated with the use of maladaptive coping strategies by the mothers, which then results in even higher maternal stress.

Research to date has emphasized on utilization of coping strategies used by mothers of children with ASD. These strategies have been identified as an important mechanism of managing physical fatigue and stress for parents and in promoting their wellbeing (Seymour, Wood, Giallo, & Jellett, 2013). Seymour et al. also found that active-avoidance, using religion, and denial based coping strategies were reported to be maladaptive for mothers of children with ASD. These strategies were found to be negatively impacting the wellbeing of mothers and lead to higher levels of stress, anxiety, and depression.

In the recent studies with the parents of children with ASD, mostly mothers, it is found that social support has emerged as one of the most beneficial coping strategies (Miranda, Mira, Berenguer, Rosello, & Baixauli, 2019). Social support is defined as the physical and instrumental assistance, attitudinal support, and resource and emotional burden-sharing. Bishop, Richler, Cain, and Lord (2007) have shown that the lack of or lower levels of social support for mothers of children with ASD can become a significant predictor of stress among the mothers. This lack of social support for mothers of children with ASD was shown to have a negative impact on the personal wellbeing of mothers. For example, Boyd (2002) has shown through multiple studies that more than 50% of mothers of children with ASD reported a decreased ability to cherish and enjoy life when they are raising their children with ASD. Furthermore, lower availability of social support has been shown to have a direct relationship with stress, anxiety, and depression among the mothers of children with ASD (Boyd, 2002).
Moreover, the presence of social support plays an important role in buffering the stress and anxiety among the parents of children with ASD (Pozo & Sarriá, 2014). According to Al-Kandari et al. (2017), this buffering effect has a significant relevance especially when the social support is being received by mothers from immediate family and close social groups; this in turn positively impacts the wellbeing of the mothers by increasing their ability to enjoy life. Furthermore, the higher are the levels of social support for the mothers raising a child with ASD, the lower are the levels of the negative impact generally produced by rearing a child with ASD (Lindsey & Barry, 2018). These buffering impacts include reduction in psychological stress, negative mood, anxiety, and depression (Benson, 2014; Lindsey & Barry, 2018).

Researchers have indicated that mothers of children with special needs feel responsible for the behavior of their child due to being more involved in their upbringing. If the child was unable to respond or was regressing, the mother blamed herself for failing (Ansari, 2002). A study showed that members of the local community blamed the mothers for not atoning for their sins, and hence they were given a child with disabilities (Minhas et al., 2015). Research reviews have indicated that individuals who are parents to children with ASD struggle with the life-long impairment of their children. Therefore, parents with limited support and resources must put even more effort and face additional parenting challenges which result in higher levels of stress (Papageorgiou & Kalyva, 2010; Yu, Zuk, & Gaab, 2018). This review was also indicative of the need for research required to understand the experiences of mothers in order to identify and understand the support needed by parents in managing and assisting their child with ASD.

Children with ASD and their parents are frequently stigmatized which causes stress among the caretakers and also hampers the coping abilities of the parents, particularly mothers. Oren Shtayermman defined stigmatized people as those “who possess a quality that others perceive as negative, unfavorable, or in some way unacceptable” (Shtayermman, 2009, p. 299). Stigmas associated with other mental and neurological conditions are common in all cultures (Campbell, 2006). For example, Campbell (2006) identified three types of stigma of mental illness that are: fear and exclusion, authoritarianism, and benevolence. However, there is limited research to show if these stigmas are associated with children with ASD and how the mothers of these children cope with these stressors.

Culture plays a significant role in the acceptance and understanding of neurological disabilities. If the disorder is perceived to be some sort of acceptance of “Allah’s will”, the parents might not be as willing to waste their resources on interventionist methods, and rather just feed and clothe the child (Ravindran & Myers, 2011). In Pakistan, the word disability holds different connotations (New, Rathore, & Ifitkhar, 2011). Usually, the disability is taken as a sign of punishment, and hence the families tend to hide the individuals with disabilities, fearing the negative stigma that is associated with the disorder. Nor is it easy for the individuals with disabilities to survive independently and tend to die of neglect (New et al., 2011). According to PBS (2018), demographic indicators for ASD in Pakistan are very high. Additionally, the association of neurological bases (see Bozzi et al., 2018; Draaisma, 2009; Li et al., 2017), mental regression (Davidovitch et al., 2000), refrigerator mothers (see Douglas, 2014) and perceptions of social stigma associated with ASD (Gray, 1993) have made the need for awareness about ASD crucial (see Gillespie-Lynch et al., 2015).

Another study showed that when there was a physical disability, parents easily accepted the disability, as opposed to the children with cognitive disabilities (Ansari, 2002). Also, a conservative society is more resistant to accepting children with cognitive disabilities as opposed to the modern society. In another study, mothers of children with ASD reported that the doctors did not have knowledge about the disorders and prescribed medicines which were not suitable for the long run. The mothers had to research on their own rather than depend on health professionals (Minhas et al., 2015). The mothers gave a mixed report on societal support as some communities were accepting, others were not.
A study indicated that disorders are misdiagnosed and not managed properly by the institutions in rural Pakistan which causes high levels of stress in the parents (Hamdani et al., 2014). Since there is a lack of institutional support, the extended members of the family had to provide support. The parents from rural areas had to travel for hours every day for treatment. On the other hand, there were some communities that were willing to have trainers locally who could help the children and provide a support system to the parents. The members of the community where the study was conducted were willing to create a group at the local health center from which everyone could benefit from.

Our research review suggests that researchers have started to document the effects of stigmatization among children with autism and their parents as well as the perception of autism in developed countries. However, during the last two decades, the focus has been on parenting stress and the capacity of the family system to adapt to the challenge of raising children with ASD which has led to relatively less research on the stress and coping strategies of mothers of children with ASD. Most of the research that has been conducted with mothers of children with ASD has focused on measuring stress and anxiety but to our knowledge the search on the lived experiences or phenomenology of mothers of children with ASD is still in infancy.

Furthermore, this research will aim to get a deeper insight into ASD related personal and social issues that can help in the assessment for parental and social support systems for the mothers of children with ASD community’s caregivers in general. Thus, this study may help in providing and promoting awareness-related recommendations for support system for parents and other caregivers associated with the community of parents of children with ASD.

2. Method

2.1. Research objectives
The first objective of this research was to explore the lived experiences of the mothers of children with ASD, including but not limited to the mothers’ stress, behavioral difficulties, coping strategies, religious, and social support related experiences. The second objective was to investigate how the process of diagnosis began, and how coping with ASD had changed over time.

2.2. Research participants
The participants were mothers of children with ASD from Karachi, mostly from middle and upper middle class families, who could afford all kinds of relevant therapies for their child. Even though there is no standard definition or measurement criteria for Socioeconomic Status (SES), social class, or income, due to the sensitive nature of the study, we used an IRB approved self-report categorization method to record the SES of the participants. We asked our participants and the institutions where we met these participants to place themselves on one of the four categories: High SES, Upper Middle SES, Middle SES, and Lower SES. Most participants were educated, and they belonged to Upper Middle and Middle SES and they understood it as a socio-economic indicator of their social status. We think it was critical that we would ask about this dimension as it is also pertinent to the issue of accessibility of various services for children with ASD.

There were a total of 15 interviews conducted. The age of the mothers ranged from 29 to 52 years. They all were born in Karachi and raised their children there only; however, one mother moved her family to Malaysia a few years ago and one mother moved to Islamabad a few years ago. All of the mothers were well versed in English as well as Urdu. All at least had a bachelor’s degree, all were married, and most were housewives. The interviews ranged from 40 min to an hour and 30 min. The questions aimed to answer the research objectives, and appropriate shaping of the questions took place according to the answers of the participants. The demographics of participants can be seen in Table 1.
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2.3. Procedure

Seven of the participants were recruited from the Inclusive Care Center (ICC Karachi). The authors were provided a list of names of mothers who would be willing to take part in the study. The remaining three were recruited from a Facebook group, Special Needs Pakistan. The participants signed a consent form, without any compensation, all participants assured that throughout the transcriptions and data analysis, confidentiality would be maintained. The authors conducted face-to-face interviews; all interviews were audi-taped in a private room at the center, after filling in a brief demographic questionnaire.

The interviews were conducted in Urdu (local/national language) and were translated after transcription to English. Most participants switched between languages during interviews as they had a good understanding of both languages. The authors themselves transcribed the interviews, and any details, which could reveal the identity of the participants, were deleted so that anonymity could be protected. The interviews were semi-structured; the conversation evolved according to the answers the mothers gave to the initial questions. Since this is an exploratory study of experiences of mothers of children with ASD, we used a bottom-up emic approach with triangulation of phenomenology (Anjum, Kamal, & Bilwani, 2019). Research questions were open-ended in order to incorporate the diversity of lived experiences of mothers. This also allowed for divergent themes. Questions were also added according to the flow of the conversation.

2.4. Data analysis

Once the interviews had taken place, the data was transcribed and an interpretive phenomenological analysis (IPA) of the data was completed. IPA is a qualitative data collection and analysis method used to gather detailed examinations of lived experience of a distinct group of individuals. It capitalizes on very personal accounts of lived experience in idiographic descriptions rather than pre-existing preconceptions. IPA accentuates the humanistic aspects of data collection and interpretation which is a deal for this research endeavor. This method ensures that each participant can share details experience related to an issue which is complex and may have emotional implications for the participants (Smith & Osborn, 2015).

In order to ensure the anonymity of the participants during transcription and thematic analyses, any information that was unique to the participants was removed from the initial transcription. Only anonymous information was used and each interview was stored such that we gave a random numeric nomination from 1 to 15. Each number indicated one mother anonymously. The transcripts were reviewed once after each interview and the second time when all interviews were completed. This was done to follow the protocol for generating deeper insight and clearer meaning (Moustakas, 1994).

Furthermore, in order to use IPA, only lived and expected experiences of participants were used for thematic analyses as advised by previous IPA research (Khalid & Anjum, 2019). All significant and invariant experiences were noted down by identifying relevant and non-overlapping discrete answers about how the participants elaborated on their experiences. These statements were clustered into thematic structures. Structural descriptions illustrated how the experience happened, which included participants’ reflections on the setting and context for given experiences (Creswell, 2007). Initial analyses were done independently, in the second round the authors reviewed initial results and came to a consensus about the themes and example statements. Finally, a composite description was written to uncover the essence and meaning of the experiences. Quotes were chosen and presented as the voice of the mothers (Anjum & Godil, 2019; Ponteotto, 2006).

3. Results

A total of 282 non-repetitive and non-overlapping statements were identified from interviews. Arranging these statements into clusters resulted in the major themes that emerged from the interviews and statements of the interviewees were about experiences of mothers of children with ASD. The themes included whether the mothers were prepared for delay in milestones for their child, if they had an
awareness about the disorder upon the diagnosis, the stigma and blame they felt, how they coped with the support or the lack of it, and their anxiety about the future of their child. Some of the themes were not directly incorporated in the questions asked by the authors but emerged from the answers. For example, none of the questions asked directly about if the mothers expected a delay in milestones, but somehow most of the mothers discussed this as a major concern, and hence a new theme emerged. A few mothers mentioned the availability of support systems and resources they had experienced in other countries, and hence another additional theme emerged.

### 3.1. Delay in milestones

Six out of 15 mothers said that they were warned about the delay in milestones their child would have to face due to the problematic pregnancy they went through including problems like diabetes or regular bleeding, or because their babies were born prematurely. The delay in milestones did not imply the diagnosis of any disorder, but it implied delays in speech or motor skills. Two of the mothers went through a complicated labor and one of the two had a C-section and the baby was in the NICU (neonatal intensive care unit) for 22 days as she had contracted an infection. Even if the parents didn’t expect the diagnosis, they knew the child would have some problematic delays.

Initially I did not notice delays in mental development and milestones of my child. See, in the beginning (when the child was very young), I was only told the symptoms, the key terms such as fixation and no eye contact. Over time, the delay was more obvious and what I did was self-learning. I looked up the symptoms and the scheduling and the therapies. Once I got the grip, I took my child, I understood what she is apart from what autism is and then I blended both the things together.

I was told that the child will be slow, and I will have to be patient, for progress he will demand efforts of all kinds.

### 3.2. Lack of awareness

Out of 15, five mothers had not heard of the term “autism” before the diagnosis of their own child. They criticized that there is no awareness of the disorder. Moreover, the mothers admitted about the lack of therapies in Pakistan, and one even mentioned that most of the doctors in Karachi weren’t aware of the disorder. Two of the mothers used Google to look for available therapists, and two of the mothers admitted that the therapies are expensive especially as they are long term as opposed to short term. Upon the diagnosis, 7 out of 15 mothers had researched about the disorder themselves while the doctors explained symptoms and effects to two of the mothers. However, three parents claimed that they understood the disorder through their child, after a first-hand learning experience, rather than closely looking for the symptoms the doctor said they would find.

In Pakistan there are very few who know what autism is, what can you expect from common people. Level of awareness is poor.

While researching one afternoon, I found on Google search I found a therapist and had a meeting with her, and met her and told her everything.

### 3.3. Feelings of the mothers upon the diagnosis

Three mothers reported having feelings of denial, two felt at peace and relieved as they could finally explain the behavior their child was exhibiting and knew how to proceed with the therapies. One of the mothers reported feeling heartbroken and disturbed upon the diagnosis. Since this was the first time she had heard about autism, she was overwhelmed to know that her son had autism. She was not able to help her son until she did not understand the diagnosis herself. Two of the mothers were worried about the future upon the diagnosis, as to how their child will grow up to be independent. None of the mothers felt that the diagnosis was a tragedy; they showered their child with extra love and attention and started with the therapies as soon as possible. One mother said
that it took a long time for her to accept the diagnosis, but as soon as she did, she immediately researched therapists and took hold of her child’s life. Upon debriefing one of the mothers, she was shocked that parents would view the diagnosis as a tragedy, rather than just accepting the child.

Heart broken. The initial reaction was that Allah please let it not be. It’s not like when you find out about a terminal disease or results about heart or lungs and we were like its temporary, it’d go away with therapy. Therapy would be done and it’s just for 1 to 2 years but now I know it’s lifelong.

Initial reaction doesn’t sink in; the denial phase was there. I think, I guess it didn’t sink in, let’s give it time, so if you want me to put a word to it, then it is denial. It wasn’t shock or anything; I think I allowed it to give it time. Upsetting as well when you realize.

3.4. Blame placed upon the mothers
Over the years, the awareness and acceptance of ASD have evolved and improved. The mothers, when asked this question “Did you ever feel blamed by anyone?”, reported as to not feeling this way in a specific context. However, one mother reported that one person had indirectly blamed her by asking her to leave her sins. One interesting finding was that one mother blamed herself, although she didn’t know why she felt that way. Another mother jokingly mentioned that she blamed the father’s side of the family, as there were a few children on that side who had learning disabilities. Later she said that it was the gynecologist who created problems during the labor, which resulted in autism in her child. Family members blamed one mother as she had a lot of sugar problems throughout her pregnancy, and her in-laws blamed her for having those problems. All in all, only one mother felt explicitly blamed by her family members, the others dealt with the negativity, which is another section altogether.

Once someone said ‘wazifa se gunnah chordein … [leave your sins] so I was like are you telling me that you know I should leave my sins? Thank you, good for you! That was just one person, so I wasn’t bothered. It depends on how you take it, depends on your personality.

By my family members of course. My in-laws, that you have diabetes and because of that your kids are like this. The other one is also at a risk; his older brother is autistic.

You do a huge mistake in your life, or you disobey your parents that Allah has cursed you this way. Secondly, you had sex while on your period that’s why Allah punished you like this.

These days my husband blames me that it’s your fault, but I know it is because he’s feeling guilty as there are a few children on his side of the family with problems.

3.5. Societal acceptance and social support
Most mothers felt that the key to being accepted by society is to first accept yourself and your child, and the rest follows suit. Most of them reported outright acceptance accepted by their family and friends, as opposed to any issues or problems with familial or social acceptance. However, the degree of acceptance did change with the effectiveness of therapy. One mother noted that she felt that as her child developed skills to outwardly present “normal behavior”, as a result of many therapies, society became more accepting than before.

Breaking it down, family and others. Friends haven’t been an issue with me. Family is accepting; I haven’t had any issue. Initially there were a lot of questions that why he does not speak, but me being the kind of person it didn’t really bother me. I took things on my own pace. As soon as you accept your child the way they are, people stop questioning. No issues from family.

I remember when H was not even diagnosed, I met a doctor from a hospital in Lahore and he asked me ‘Have you ever thought to kill yourself because of your child?’ I was like are you crazy? but years later I got to know that there is a percentage of mothers who in the fear of raising these kids and unable to manage them, attempt suicide as well.
3.6. Experiences abroad
The level of tolerance in our society is low as compared to the Western culture. The public in developed countries has awareness about the disorder, as a couple of mothers had noted when they went abroad for vacations. One wanted to relocate her son to a developed country because of the availability of resources there, and the inclusive attitude the public has. Another mother also wanted to leave her job here and move her son there so he can avail the animation classes there. One mother realized the awareness people have in the developed world, as well as the acceptance and tolerance as compared to here.

In our society, I myself have not been able to tell everybody what’s going around. But now, I’m taking some decisions that will change as I’m planning to shift him abroad to go to high school in Europe or America.

Here it is a huge problem; when we go abroad and tell someone that he has a problem delay, they’re very accepting to these things.

3.7. The change in experiences overtime
Most mothers admitted that it was acceptance on their part, and the setting of a routine that got them through the years. Initially, all of them were confused as to how to proceed and the future was a big question mark; however, they went through the diagnosis, every stage at a time, and every therapy at a time, and managed to be where they are now today.

Back then you wouldn’t have imagined that in 10 years’ time, your child would be reading and going on the Internet and Googling; things do improve with time.

Right now, I’m more evolved and know what to do and I’m still learning but that time I was private, felt like I was in an unknown territory, didn’t know what was going to happen but now I have an idea where we’re headed or what tools to have to make him feel independent. I guess that’s the difference, educating myself has brought the change, therapies, you didn’t know this was a whole area, I didn’t know what OT, speech, play therapy were. I feel empowered and educated and now I have the tools to move forward.

I feel extremely exhausted sometimes but I am proud of son and myself. I constantly fear our future and where we want to head in future. My son is struggling but he is constantly moving forward in a renowned institute. I can image that life will be even harder once he will graduate and look for jobs, but I cannot afford to be hopeless. Hope is only friend we have.

3.8. Dealing with the negativity
Escape strategies and ignoring the reactions and judgments seemed to be the most welcomed coping mechanism among the mothers. However, a mother can only ignore her child being publicly berated to a certain limit. Some mothers indicated that they had become indifferent to what people said while others had to go for therapy.

And in the family, nobody says anything, but we avoid the gatherings of extended family. Since my husband and father-in-law belong in the forces, we try to keep busy with our own lives. I usually confine myself to my own house and avoid such meet-ups and gatherings.

Now, what people say doesn’t bother me that much. I’m now pretty much confident but sometimes I also lose my temper and start crying at weddings or family gatherings.

We had a lot of escape strategies; we didn’t used to go. And I started off with very limited closed options like for a little time went to the club, or mall or a shop.

There was a time when I had energy to deal with negative remarks of people, with time as my son has gotten worse, I am also feeling tired. I have started going to a therapist myself.
3.9. Support by husbands
Most mothers admitted that the husbands provided financial support and never put any limitations on their spending on therapies and relevant resource material; however, this was not the case when it came to the emotional needs of the child. Nine mothers reported that their husbands were not able to deal with their child’s emotional needs, they were focused only on financial support and were not emotionally unavailable. This can be attributed to the fact that most mothers were housewives and hence spend more time with their child, taking them to therapies and dealing with schoolwork.

I was an exhausted mother and I didn't have support from my husband as he was the eldest and there weren't any kids in his family. He didn't know how to handle kids.

It takes a while, and that has been tough for me. I've had to not only accept and work with my son, but my husband has not been willing to accept a lot of things and I'm stuck because of that.

He said that once he goes to classes, he’d grow out of it but that made me realize that he doesn't understand it. He didn't know how bad it was.

3.10. Support by siblings/effect on siblings
It is natural to assume that siblings who don’t have special needs might feel ignored by their parents as so much attention and resources are used on them. Eight mothers felt that their other children had been ignored, but they admitted that their children were strong and supportive to their sibling with special needs and engaged with them with utmost patience. One mother had issues between her two children, as the daughter felt neglected and demeaned in front of her brother.

What I've seen is, they love him unconditionally; he can do no wrong basically. Being on the spectrum, he talks very loudly, and sometimes enters his own world, and they walk around him and engage with him as long as he wants to be engaged. Most of the time they take him wherever they go.

He is really close to his brother, they skype every weekend and talk on WhatsApp. His brother is very caring and Masha Allah they're on very good terms.

3.11. Discrimination in workplace
Some of the mothers voiced their concern over the limited options of the future of their child. They admitted that workplaces don't look for children with special needs and this will be held against them during the process of job applications. They worried about the future that they can get their child through the school years, but what about after that.

Yesterday I was talking to someone, as long as they are kids, people are like he’ll be fine but when these kids grow up, acceptance level shrinks, when they have to go out and work and apply skills, like job opportunities, that is where the acceptance level drops, we don't want to hire someone with an intellectual disability because we are scared that what will he do, do mistakes, fight with others, not understand.

It's a very difficult question. But the thought of my son's future when me and his father will be no more is so frightening, it makes me crazy sometimes.

My son is very hardworking. I am sure one day he will finish his college too. Despite knowing that he will do well in his education, he will face discrimination in hiring process. Even If he gets hired, he will face discrimination by people at the work place.

3.12. Advice to others
Based on their negative experiences, the mothers had advice for anyone that would be willing to listen. The advice mostly included tolerance and patience for their child, and to understand what
the mother is going through rather than giving bad parenting looks or passing judgmental comments. The most interesting thing to note was that the advice did not only include children with ASD, but children with any kind of special needs or disabilities, the mothers were empathetic to others after their experiences with their own children.

The community should get educated about autism and other related disorders so that they know how to behave and help towards a productive society where everyone is respected for their neurodiversity. Don’t turn your back; single out, judge or bully ASD kids and their parents. Reach out into the world of autism and interact with ASD kids on their terms in a way that they understand. Create environments (at schools, hotels, parks, malls) that are autism friendly.

Now the thing is, awareness should be built in at the very smallest level, there should be proper chapters or classes where about these children, not only autism but physical impairment or weakness or somebody who is obese, all these things, children should be given empathetic learning on a very small level.

4. Discussion

The purpose of this study was to explore how mothers experience and navigate their experiences with their child with autism spectrum disorder (ASD). The sample consisted of 15 mothers, from the middle/upper middle class, who could afford the extensive therapies that their child required. This paper gives voice to the mothers of children with ASD who shared their experiences, positive or negative, and the things they worried about the most or wanted for their child, that were unavailable to them. The mothers gave a detailed account, through the prompt of the questions, of their experiences from when the child was diagnosed until the stage the child is right now.

None of the mothers had specific notions about ASD before the diagnosis; in fact, that was the first time most, almost all of the mothers had heard of the term. This was not unusual as the educational institutes in Pakistan don’t incorporate the study of disabilities in their programs. There are a few ASD awareness workshops held in the country, but they are not enough. The Centre where most of the sample was selected from was invited to a conference in Dubai in 2016. The mothers experienced first-hand learning; a hands-on training of the disorder with their child. The ones who had heard of the term were not receptive of the diagnosis; however, due to the upbringing of such families, the mothers or the parents could not abandon the child, and quickly adapted to the routine of their child and started the required therapies immediately. It can be said that the mothers did not have time to adjust, but in fact they had to adjust to the diagnosis within no time, for the betterment of their child as most had adopted early intervention approaches. From the data collected, there was not any direct blame placed upon the mother, only indirect comments.

In a Pakistani society, it is very easy for onlookers to judge the children when they behave out of the norm in the public; however, the children aren’t as judged as much as the mothers. Mothers’ parenting style is labeled as “bad” as they are unable to control the behavior of their children. Despite the low level of empathy in society at large, mothers of upper middle classes love and support their child as how they are, whether with special needs or without. And as experience evolved over time, the children are not considered as autistic children, rather as children with ASD, with separate personalities to the disorder (Martin, 2013). The mothers, except for one, did not consider it to be a short-term problem, rather something that stays as part of the child’s personality throughout their lives, and it’s up to the parents to accept the disorder as part of their child, rather than focus on curing the disorder.

The mothers initially used coping strategies, which included escape strategies, a total avoidance of any and all social gatherings. However, with time the mothers accepted themselves more and their situation became more routinized, they started to take their child out, in front of family members, and to malls and restaurants for short periods of time, and then gradually increased the amount of time. The first strategy adopted by mothers was that of escaping the negativity around them by avoiding it, but then came to
terms with listening to it and ignoring it altogether. As discussed in the literature review, a study showed that mothers felt responsible for the behavior of their child as they were the ones who spent more time with them (Ansari, 2002). The results of this study showed that mothers blamed themselves only when they were pushed into the blame by significant others, for example, immediate family members because their opinion counted the most.

One important aspect that all the mothers discussed was the acceptance from their side, more than anything else. It was accepting them, not letting any negativity get to them that helped the mothers move on with their lives in terms of therapies and schooling. Some of the mothers initially internalized the negative comments, resulting in them hiding out at home and avoiding social gatherings; their escape strategies. The participants had expressed how painful it was for them to be subjected to such blatant questioning by their own family members. Many women thought if the parents accepted the diagnosis to be Allah’s will, they would feed and clothe the child, rather than spend time on therapeutic activities. One of the mothers who admitted that it was Allah’s will did not adopt that attitude but instead focused and worked hard with her child in developing her skills.

Furthermore, according to the Pakistan Autism Society (PAS), there is no reliable data for the cases or prevalence of ASD in Pakistan, but the population has become more and more visible. PAS reports that developmental bodies from South Asia estimate indicate that in Pakistan there are 350,000 children with ASD. These statistics make the findings of this study very significant in the context of Pakistan.

It is important to note that several participants expressed disgruntlement about the lack of educational support available in Karachi. Some of the mothers had bad experiences regarding the assessments and therapists, and they had to go through a lengthy system of looking for proper schools which would incorporate the needs of their child. Mothers of children with ASD see the schools in Karachi as non-inclusive because they do not have an academic framework that includes children with special needs. According to mothers, arrangements and implementation of inclusive academic framework are essential and should be considered mandatory by all schools, in order to create an inclusive environment.

It is up to the academic organizations as well to incorporate and accommodate children with special needs, which was the concern of some of the parents. Therefore, it is not only the responsibility of the schools, but the professional organizations also need to include a department for adults with special needs. Schools and organizations need to employ them in the areas they are interested in or skilled in. Such initiatives have the potential that people with special needs can become their own advocates in the future. The lack of societal acceptance is related to the lack of social support the parents receive, even from their own family members. Therefore, support mechanisms are needed for the mothers too so that they can gather social and emotional support for taking care of children with ASD.

The mothers did not believe their child to have negative characteristics, rather they focused on the child’s positive personality traits. It seemed that these mothers from Karachi were resilient and they have coped well. They had good advice for others and wanted more support at the community level. It is important to note that these mothers represented the middle and upper middle socio-economic class and do not represent the experiences of those from the lower socio-economic class. Further, the findings of this study do not represent the situation in the rural and remote regions. It is more likely that the mothers in the rural set-ups would have no awareness as they have lower access to diagnostic and clinical facilities. Hence, the implications would be even stronger for mothers residing in rural areas.

5. Limitations
This study has a few limitations that restrict the generalizability of our findings. First and foremost was the limited sample size of 15 mothers. In Pakistan, people are very resistant to accepting the prevalence of autism among their children, mainly due to the taboos associated with mental health and cognitive conditions. Therefore, we had to spend more than a year in the field in order
to interview these 15 women. Although this study only had only 15 participants, it still gave an idea about the mindset and the experiences the mothers have in Pakistani society.

In addition to the numeric representation, the participants’ pool could have been bigger and more diverse as the mothers were all from upper middle class; however, due to limited time and resources, this study could not incorporate a diverse sample. Since the study took place in Karachi, the biggest metropolitan city of Pakistan where many resources available the mothers did not seem worried about the therapies and options for coping with their children with ASD.

The study was also limited because it focused only on the experiences of mothers and not the fathers or other family members. Although, in Pakistan, generally men are not involved in the primary caregiving for children but maybe that indicates that there is a stronger reason for engaging fathers for such interviews and research. No research has so far talked to the fathers of children with ASD. It would be helpful to elaborate systematically on how fathers experience stigma of ASD.

Overall, although Karachi represents 25 million of the population, the findings cannot be generalized, as the sample was small and only from one socioeconomic background; that is where mothers could read/write, afford therapies for their child, and enroll them in schools. Even in the same country, we cannot generalize the findings to other classes as they don’t have the resources for therapeutic interventions. However, this study can give a head start to explore the conditions of children with ASD in this society and their reception and incorporation into everyday activities, and to promote awareness, as most parents suggested this. The sample was also experientially limited as it only included the mothers who had years of experience with their child’s ASD. We did not include a diverse sample such as mothers who recently or just discovered the diagnosis. Hence, it is possible that these mothers had time to adjust to the situation and as a result were in a better position than newly informed mothers to be.

6. Conclusion
Essentially, this study explored the experiences of mothers of children with ASD in the urban sociocultural context of Karachi, Pakistan. The mothers loved and supported their children even when their reactions were close to denial, they were courageous. They spent very less time in grieving. Instead, many of them were more focused on coping than grieving. Some took a hands-on approach, left their work, and became housewives just to give their child the best they could afford. The mothers stressed acceptance, emphasized the need for awareness in our society, which would lead to more availability of resources in Pakistan, the major point of issue that most of them experienced. This study can be used as a starting point for future research on the experiences of mother of children with ASD in our society, and work towards an inclusive environment.

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