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Parent Stress, Coping Mechanisms, and Support Systems in Families of Children with Autism in Pakistan

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ABSTRACT

This paper addresses the many-faceted nature of stress, ways the parents coped with it, and the existing support network among the Pakistani parents whose children have Autism Spectrum Disorder (ASD). Raising a child with ASD is a global issue; however, it is specified in the Pakistani socio-cultural, economic, and healthcare environment. This study explores the reality of these families, pointing out the huge psychological and emotional cost paid by parents especially the mothers. Significant results show the role of parental stress to be compounded by delayed diagnosis impasse, inordinate shortage of accessible affordable professional services and rampant social stigmatization in parental health. In response, parents utilise a mixture of coping mechanisms with a heavy reliance on religious and faith based approaches combined with a more problem focused approach to attain educational and therapeutic treatments of their child. The paper also throws light upon the two-faced nature of the conventional joint family system that can be a life-saving support as well as a conflict and misunderstanding source. The results indicate an importance of elaborating the culturally sensitive lines of support services, creating awareness programs, incorporating awareness and stigma-reduction, and integrated policy frameworks to enhance the well-being of both children with ASD and their families in Pakistan. Finally, this study demands a system-wide transformation of the clinics-oriented perspective on autism to a family-oriented system of services.

Keywords: *Autism Spectrum Disorder, Parental Stress, Coping Mechanisms, Social Support, Pakistan, Family Dynamics*.

Introduction

Autism Spectrum Disorder (ASD) is a severe, complicated neurodevelopmental disorder that is defined by the persistence of difficulties in the social communication and interaction, and indicated by the appearance of restricted or repetitive manners, interests, or activities (American Psychiatric Association, 2013).2 Although the main diagnostic criteria are identical, experiences acquired when raising a child with ASD differ dramatically depending on the cultural, social, and economic context in which it happens. The parents of children with ASD report that they experience much more stress, anxiety, and depression than the parents of typically developing children and those with other developmental challenges (Hayes, 2017).2 The reasons behind these stressful experiences include the behavioral issues of the child, unclear prognosis, the financial implications of the child being under their care, and the continuous process of negotiating the educational and healthcare system.

These difficulties are compounded by a set of special circumstances in Pakistan, one of many developing countries (population of over 240 million people) in the region. The health infrastructure is overworked with an ominous shortage of skilled personnel including developmental pediatricians, child psychologists, and behavior therapists with a specialty in ASD (Khan, 2020). This causes such delays in the diagnosis and intervention which are the critical periods when a child could have its developmental pattern altered in a positive way. Additionally, the Pakistani society is highly collectivistic with tight linkage to family and social community.3 On the one hand, this tool can be a potential source of support but on the other hand, this bears the enormous pressure of abidance by the social norms. A child that does not follow a normal developmental process will bring shame and stigma to the family because it will isolate the family and be frowned upon (Iqbal, 2019). The overall ignorance towards the issue of ASD usually leads to the confusion, and the problematic behaviors have been attributed to a lack of parenting or spirituality, adding even more stress to the presenting parent.

The economic consequences are also devastating.4 Most of the special care facilities regarding ASD are available in the realm of the private sector and only in large cities, which makes them inaccessible and, consequently, financially unavailable to a significant portion of the population (Rehman, 2021). In many cases, parents with children affected by hereditary disorders have to choose between destroying their life savings in order to afford treatments or not getting any treatment at all. This economic pressure forms a long-term and overall frequently experienced stressor that affects the total family. In this light, it is extremely important to comprehend how Pakistani parents can handle these huge pressures and what kind of support systems they can refer to. This research, thus, offers to deliver a penetrating and sophisticated take on the processes of stress, the variety of methods adopted in dealing with it, and the character of both formal and informal support systems in the families of Pakistani origin that is raising a child with ASD.

Methodology

In order to attain these objectives, phenomenological approach was selected qualitatively. This approach was selected because it is appropriate in documenting the deep and lived, subjective experiences of the participants. The involved study was conducted in the form of demanding roundabout structured interviews among 20 parents (5 fathers and 15 mothers) who have children aged between one to twenty years diagnosed with ASD and living in the metropolitan city of Lahore. Purposive sampling was conducted with the recruitment of participants using clinical centers and support groups. The interviews were based on their diagnostic experience, ongoing issues, spiritual and psychological health, coping skills, and their sense of having the support of their family, community, and formal institutions. Thematic analysis methodology was used to identify patterns, analyse, and report the identified pattern with a view of completely understanding the key themes that characterized their experience.

Literature Review

Parental Stress as Autism

The evidence in the literature on stress levels and duration of stress among parents with children with ASD is overwhelming that they are consistently and highly stressed.6 This stress is not a one-time occurrence to the diagnosis but accumulation of day to day realities of care in addition to other children in the family. The main causes of this stress are apparently associated with the inner features of ASD. The most important predictors of parental stress are always the challenging behaviours of a child, which include aggression, self-injury, and severe tantrums (Davis, 2018). Moreover, communication difficulties can be a mighty torture to parents, and thus it forms a hurdle in comprehending the demands of the child and comforting them.

In addition to the symptoms experienced by the child, the diagnostic procedure can be a rather traumatic experience marred with fear and doubt. It can take parents years to find answers, and they meet a professional that does not possess in-depth knowledge of ASD and either misdiagnoses it or simply disregards their complaints (Crane, 2016). Such a diagnostic journey is emotionally and financially devastating to parents well before they are able to even consider receiving proper interventions. The pressure is also caused by a future-oriented nature as parents demonstrate very strong anxiety concerning the future well-being and independence of their child, their quality of life, and who would care about them when they pass away (Benson, 2016).

These cross-cultural stressors become larger on the background of South Asian cultures, and they include the culture of Pakistan. The problem of stigma has not lost its strength, and disability of a child is commonly perceived as the deficiency of the whole family, especially that of a mother (Hussain, 2018). These may result in blame, social exclusion and unwillingness to establish help out of the fear of judgment. The existence of the so-called perfect family that is forced to be demonstrated to the community makes many try to conceal the state of their child, thus making them feel extremely lonely.

Mechanisms of Cope: Survival Strategies

When one is subjected to such intense pressure, there is a need to devise coping strategies as a mechanism of dealing with both the emotional and practical pressures facing the mothers and fathers. There are two main types of coping and they are problem-focused and emotion-focused coping (6). Problem-focused coping constitutes a direct action coping style that tries to deal with the stressor by seeking information about ASD, emotion-focused coping involves learning therapeutic techniques, advocating educational services and managing finances (Lazarus, 1984). This forward thinking has been related to more successful psychological performance and more of a feeling of self determination. In the case of parents of children with ASD, this may include becoming a specialist in the disorders of their child and a champion of his/her rights. Emotion-focused coping on the other hand exist with the purpose to manage the emotional distress response towards the situation.7 This may entail attempts of seeking emotional support by others, employing humor, engaging in distractive measures or in changing the way the situation is characterized in a positive manner (Folkman, 2002). Some emotion-focused responses are adaptive, but responses which use avoidance, denial, or wishful thinking may be maladaptive over long periods of time.8

Religious or spiritual coping is a very clear method of coping in most of the collectivist and religious communities such as Pakistan. It entails seeking meaning, relief and strength through faith. Parents can pray more, be comforted by religious texts and view the situation with their child as a test or divine intervention (Pargament, 2001). Such a framework has the potential to help give a strong feeling of hope and acceptance, which can be a decisive psychological defence against desperation. A consequence of this excessive focus on the spiritual causes is the fact that they may put the implementation of evidence-based scientific interventions on hold (Ali, 2022).

Support Systems Role

Social support is a very important mediator of parental stress and well-being.9 Social support may be classified more generally as either informal or formal networks. The spouse, extended family, friends and neighbours are considered as informal support. A major pillar of this network is the marital relationship. The stress can be largely reduced through a healthy, supportive, cohesive relationship where one shares the caregiving responsibilities with the other (Hartley, 2015). The joint family system in which numerous generations co-reside offers a challenging image in Pakistan.10 On the one hand, such an environment can be of use as it can provide practical support in the form of childcare and financial support. Conversely, it can be an element of great stress because of the lack of privacy, an incompatibility of views regarding child-rearing, and the lack of information about ASD in older relatives (Javed, 2023).

Such formal support systems are professionals and institutes, such as doctors, therapists, special education teachers, state officials, and parent support groups (Oprea, 2020). The availability of good quality, low-cost, formal support has always been associated with fewer instances of parental stress and better child consequences. Such services do not only involve direct intervention to the child but also arm the parents to deal with difficult behaviours and development of their children. Parent support groups are especially useful since they provide a specific level of emotional validation, pragmatic tips and a feeling of belonging in the same group of other individuals who have gone through a similar experience (Shore, 2021). Nevertheless, as it has been mentioned before, the supply of such formal support in Pakistan is extremely restricted and inexperienced, which leaves several families to experience the tribulations of autism essentially by themselves.

Results and Analysis

Complex tapestry in depth interviews with Pakistani parents described a unique design of struggle, resistance and hope. Their stories resulted in a number of evident themes that help to get an insight into the truth of child rearing with ASD in this particular setting.

The Situation: A Labyrinth of Confusion, The Diagnostic and Service Odyssey

The most common and yet very painful to all the parents was the long winding road to diagnosis and services. A bigger majority of the parents depicted a long and exasperating experience, with many parents missing the days moving back and forth among paediatricians, faith healer as well as ordinary physicians, and none of them identified the symptoms of ASD at an early stage. One of these mothers shared her experiences of how, after two long years, people had been telling her that it was only an anxiety of mother. The family physician informed him that he is only a late talker, he will be okay. I had a feeling everything was not right and no one believed me." This disregard of parental observations not only prevented an early turnaround of initiatives meant to help the affected children but also gave a sense of shame and insecurity to them.

After a long wait during which many tried to give the diagnosis, finally being done in a big city by a specialist, parents faced another barrier: the lack of therapeutic services, not to mention high cost. A very sharp gap between the services available and the needs of the population was highlighted in the interviews. As a father put it, number of good centers in a city of more than ten million people in Lahore is perhaps four or five. Waiting lists are months long and the price... it even exceeds my salary. We sold my wife jewellery to cover first six months of treatment." This so called financial tsunami puts families in a corner with no options to take and forms a system of two stories with quality care as a privilege of rich people. Absence of governmental funding of the schemes or insurance cover on ASD-related therapies was a key anger and helplessness issue.

The Perpetual Burden of Social Stigma: Weighing it, under a Microscope:" Under a Microscope

Stigma also remained as one of the most painful and socially disabling elements of the experience of the parents. It was not a theoretical notion but a reality that every day had to live and forced them to be extremely isolated. Parents cited instances of being judged, looked down upon, and blamed as the reason behind the condition of the child. The behavioural phenomena of ASD, including stimming, meltdowns or a lack of social reciprocity were misconstrued by family and society at large as disciplinary or spoilt children.

One mother told a heart wrenching anecdote: "We were not able to attend family weddings or get-together. When excited, my son flaps his hands and makes some sounds. He was shameful to the family according to my own sister. Just ever since then we were staying at home. Better than those looks and the talk." Although such an isolation is a form of protection, it also reduces the social sphere of the family, denying it the support of the community. The stigma especially affected the mothers as mothers are traditionally regarded being the main constructors of a child upbringing in Pakistan culture. Most mothers gave accounts of how their in-laws told them that the condition of their child was due to some defects or weaknesses on their part. This genderized blame compounds the already huge cost of being a caregiver with an added injection of anguish.

The centrality of Religious Coping - Faith is My Only Anchor

With the experience of system breakdowns and social rejections, an immense majority of parents referred to their Islamic faith as the most important coping mechanism. Religion gave them some way of assimilating their predicament, giving some meaning to their fight. It was often stated that their child was a kind of a test placed upon them by Allah (God). This view allowed them to change their already senseless tragedy to a way in which they could endure a spiritual test that would get divine rewards provided they were patient (sabr).

This is how one father put it: This life is temporary. This special child was given to us by Allah as He did not doubt the strength of our capabilities. Life is not easy and yet things look up because of our faith. We pray, we believe that He will open a way out of it." It was not quiet resignation. To most of the people it was an active, dynamic process of prayer, supplication (dua), and comfort in scripture, which gave them the emotional strength to carry on day to day advocacy and care giving. Although this might be incredibly reassuring, some parents admitted that some of the members of the community had religious issues with encouraging them to pursue scientific treatments, and they should always use prayers and spiritual solutions only, indicating that it might be a possible conflict between the evidence-based method and faith-based.

The Extended Family as a Double-Edged Sword": The Role of the Extended Family

The existing traditional joint family system that is characteristic of Pakistani society, turned out to be both a supportive and stressful factor that was complex and contradictory. Depending upon extended family in order to survive meant an invaluable network to some.11 Grandparents and aunties offered material assistance to take care of children, do chores, and sometimes, gave money. This form of pragmatic support was a major protection against burnout especially among mothers. The thankful words of one mother were, "I could not do it without my mother-in-law. She visits my other children when I have to be taking my son his therapy sessions. She can not always coincide with his condition, but still loves him and her help is a blessing."

But to many it was an endless family that caused great psychological problems. Being in close touch implied never-stopping unasked-one-to-give-advice, evaluation of their way of raising children, and unfavourable comparison with other children. Uneducated family members tended to spoil the strategies in the therapy. One mother said, "The therapist says we should have a hard schedule but his grandmother feeds him candy whenever he is upset so it all goes down the drain." People advise me that I am too hard on him and I should not mind him. They are unaware of the fact that the routine assists him to secured. This sustained tension at home brought about a stressing environment as parents were expected to not only be concerned with the needs of their child but also to have to deal with relatives and family members and their family relations that were often complicated and straining. Their support was not always unconditional, and the price of this was more often than not the parents' autonomy and peace of mind.

Discussion

The results of this research represent a microscopic picture of the enormous problems that Pakistani families of children having ASD face, and at the same time bring out their spectacular resilience. These stories make sense of and stretch the international research on parental stress, but they are permanently stamped with the cultural and structural realities of Pakistan. The parental stress which was recorded was not just a by-product of the disability of the child but is an institutionally magnified problem on parental stress through institutional deficiencies and social attitudes. The system of diagnosis and service provision outlined by parents is essentially the direct result of the failed attempt by a healthcare system to prioritize neurodevelopmental disabilities (Durkin, 2002). The absence of trained primary care providers to screen and detect early ASD indicators causes the decisive waste of time when early intervention is needed, as research has proven that it is the most crucial factor improving long-term outcomes (Zwaigenbaum, 2015). The following economic obstacles to the receipt of private treatment leads to a social equity crisis in that the ability of a child can be determined by the socioeconomic background of the family. This observation can be linked to similar findings concerning research on disability in other low- and middle-income countries where the state support is significantly lacking, and most care is privatized (Zaidi, 2017).

Looking more into the institutional failure, the consequences of a later diagnosis trickle down in all aspects of family life. The waiting game during the initial period of uncertainty is not idle; it is an active anxiety-ridden process in which there are no sure answers and it drains parents emotionally and financially well before the actual journey with autism begins. Parents fall into a gap of self-accusation and misunderstanding and start doubting their inner sense when being rejected by ill-trained practitioners. Such dynamic tends to bring about tension in the marriage union since parents can differ on the extent of the problem or the way forward to address the problem. The equity crisis is more than what can be considered as affordable as the geographical divide is very clear. Even specialized services, which are in any case limited, are almost confined to the big metropolitan cities such as Lahore, Karachi and Islamabad with large swathes of undeveloped rural territory with negligible facilities enjoying little to no support at all. To a family in a smaller town or village, gaining access to that care means not only an enormous financial sacrifice but it also means leaving home or constant hard travel that make it impossible to maintain their social support base or earning potential. Moreover, this vacuum of service leaves the parents with no choice but to screen this service vacuum and take up the roles of therapists, special educators and behavioural analysts in which they are not trained. This puts an excessive burden on them and makes the home an incessant clinical setting and a main cause of burn out in care givers.

The social stigma, which is almost everywhere in this study, is an influential cultural impediment. Unlike most individualistic cultures in the Western world, whereby a disability is considered a medical problem of the concerned individual, it appears in collectivistic cultures, such as Pakistan, to be a family affair that also comes less admirably with a topic of shame (Guler, 2021). The identifying of mothers as the ones receiving the most blame is a rude reminder of the patriarchal structures that remain rampant in the society (Ghuman, 2019). This makes it clear that government should focus on awareness programs that are not only informational but also culturally acceptable relying on respected community and religious figures as a means of dismantling stigmas and encouraging sensuality. The mechanics of this stigma are malicious and work both on a very open kind of exclusion and the more covert methods of social control. Explicitly, families are excluded in the main community activities that mark social life in Pakistan which includes weddings, religious gatherings and local events. The threat of having the child have a public meltdown or not act or behave in a conforming manner spawns a social withdrawal on the part of the parents as an act of prevention against the social eyes of pity or condemnation. The less obvious tortures come in the form of the endless flow of unsolicited advice and folk cures from the relatives and neighbours which, perhaps well-meant, acts to erode the confidence of the parents and the evidence based approaches they are attempting to take. This blame as a gender issue is a problematic case to mothers. Under the cultural context, a mother is regarded as the first guardian of the honour (izzat) in a family, and the child with a disability may be taken as a socially imposed representation of a personal or even a family defect. It may cause sour relationships with in-laws, marital conflict, and deep loss of self-esteem of the mother. Thus, more effective awareness programs have to go beyond clinical definitions of autism. They need to appeal to the strength of story, or by it, the empathy as a television drama, or social media personal testimonial, to demonstrate humanity, and the hard fought struggles of these families. Preaching to religious leaders to incorporate disability into a discourse of divine diversity and compassion would be a very powerful means of transforming this perception as an issue of judgment to one of support. The major conclusion with respect to the experience of these parents is the heavy use of religious coping. Although spiritual coping is a universal experience, the centrality of it in the lives of Pakistani parents implies that this particular resource is one of a few readily available and culture endorsed resources stipulated in the setting where formal help is absent. This conforms into the reason expressed by Pargament (2001) that people resort to religion in order to find meaning in situations that are uncontrollable and highly stressful. It is an effective psychological resource. Nevertheless, religious beliefs potentially conflicting with or slowing down the evidence-based care is also an important aspect which service providers should address strategically and with a sense of cultural consistencies that might include incorporating the notions of patience and hope, rooted into the religious beliefs, with scientific data on ASD.

This religious belief system forms a critical resistance to the shame that society imposes. Through the eyes of divine trust (amanah) and trial of faith, parents are also able to find the purpose and sense of dignity that isolates them against outside opinion. Sabr (patient forbearance) does not imply passive resignation however, but it is an active spiritual exercise that works on building resilience and emotional control in the face of everyday hardship. This inner source of control based on faith enables the parents to survive when external systems fall short of them. Nonetheless, the possible clash with evidence-based practice cannot be overestimated. This more so when family members or community people pressure someone to turn to faith healing or charms in other than the therapies that have been scientifically proven. This can put parents in an awkward situation as parents find themselves between the need to receive modern treatment and fear to be seen as non believing parents. Consequently, the right approach of professionals in this culturally competent way is not to attack these beliefs but to collaborate with them. A therapist may explain a behavioural intervention plan as not being contradictory to prayer, but as the practical order by which God will attend to the answer to the prayers, the tying of the camel which is required in Islamic tradition, along with trust in God. With the attitude of dignity and incorporation of these essential values of the culture, practitioners will develop the trust required to facilitate effective and evidenced care. Last but not least, the research clarifies the conflicting nature of the long family structure. It offers the physical and emotional work that the state cannot and it can become the most available form of informal support. However, it should not be overlooked because it can lead to discord and a loss of authority of parents (Javed, (2023). This implies that they should not either focus on the child in isolation or the parents in isolation but take the family-systems approach to interventions. Psychoeducational interventions to help the members of the extended family in understanding ASD might prove very helpful and might turn what was once a stressful source of assistance into a more coherent and knowledgeable system of support.

That ambivalence is usually based on a generational divide of knowledge. Elder family members, e.g., old relatives working in a different cultural and historical context do not have the terminology and conceptual language set to describe a neurodevelopmental diagnostic condition such as autism. Although the efforts of help are of love origin, they may lead to actions that interfere with the necessary routine of the child breaking the dietary rules, acting against disciplinary methods, or over priming the child. This forms an unending low-pitched stress to any parent who has to strike a balance in coping with a child as well and in a subtle but firm manner, dealing with their own parents, whose culture is one where seniors and those with authority are deemed holy. The provided family-systems approach proposal should hence be a holistic one. This cannot be done simply by distributing pamphlets. It demands family-based interactive workshops that incorporate the grandparents and siblings. Such sessions may offer tangible material regarding ASD, educate on consistent behavioural approaches, and most importantly, offer a mediation between members of a family to express their personal fears and frustrations. Such discussions will be the fast track to eliminating the generational gap and creating the extended family by engaging in heightened levels of empathy and making the extended family a unified well-informed and really supportive team. The immense pressure that is placed on the nuclear family unit can be quite effectively relieved with the reinforcement of this fundamental informal support system.

Conclusion

The aim of the present study was to shed some light on the experiences of Pakistani parents with children with Autism Spectrum Disorder in relation to stress, coping and support. The results create a graphic image of a day-to-day combat against societal obstacles and colourism, which is answered with great strength and buoyed by faith and family relationships. Parents are confronted with a broken and costly healthcare system, the acquisition of a social stigma, the difficulties of complicated familial relations as well as in-depth and full-time care of their children. The intense stress that is associated with it is not a natural result of the condition their child faces but is rather an element that is generated through a socio-institutional system which is very much inadequate in its ability to support. This is the ongoing war that ultimately results in a perpetual state of tiredness, with parents many times neglecting own well being at the tomb of their children. Their worlds become small, aspirations are put on hold and their energy is stolen by an unceasing round of therapy sessions, behaviour therapy and advocacy.

The major coping strategy is a strong present religious belief, which gives a very strong source of meaning and psychological tenacity. Such spiritual foothold provides a counter message to the shame propagated in the rest of society, redirecting the focus on their child as a burden and instead viewing their child as a special trust. This inner strength testifies to the strength of human spirit to make purpose out of misfortune. The extended family provides important, but loaded informal support. To sum up, the welfare of such families depends on a multifaceted strategy. The governments should invest in the health infrastructure to guarantee accessible evidence based interventions and early diagnosis of the health issue. It involves not only construction of the clinics but a steadfast promise of enrolling the primary healthcare personnel of the country to be aware of the early manifestation of ASD, a national system of discounted therapeutic facilities and placing the resources of these facilities in the hands of individuals outside the major cities.

Moreover, there is a need to conduct culturally-sensitive public education activities that will eliminate stigma and achieve a more accepting society. Such campaigns cannot have a generic public service announcement just like it must be embedded within the cultural domain where people will rely on trusted figures in society such as community elders and religious leaders to promote a culture of empathy and acceptance. The objective should be to change the appraisal perspective of the society toward that of collective responsibility where neurodiversity of a child will not be viewed as something to fear. Lastly, support services should become family-centred and provide parents with both knowledge and skills but also involve family members or extended circle of relatives in order to create a greater and more understanding support system. It entails referring to the whole family as the unit of care. It will entail direct mental health support and respite care of parents to avoid burnout and purposefully designed workshops that will educate the grandparents, and aunts and uncles. The ultimate change of the extended family scenario in the given cultural context where it is used as the constant source of conflicts into the well organized and informed network of support may be regarded as one of the most effective interventions possible to implement. Unless such systemic changes are made, these exceptional parents will never cease to get lost in the maze on their own in search of the regular support in a sea of extraordinary parents and their children will never get the chance to become everything that they could be. The price of doing nothing is not only counted in the lives of individuals but an overall cycle of exclusion which lowers the public potential of all humans.

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