Remittances Review
August 2024,
Volume: 9, No: 4, pp.924-950
ISSN: 2059-6588(Print) | ISSN 2059-6596(Online)

Received : 05 July 2024, Accepted: 20 August 2024

DOI: https://doi.org/10.33282/rr.vx9i2.53

Exploring Maternal Perspectives on Autism Spectrum Disorder in Pakistan: Communication, Stigma, and Intervention

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ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by challenges in social communication, accompanied by the existence of limited interests and repetitive actions. The global occurrence of ASD in children is estimated to be around 1–2%, with projected rates of 1% in wealthier nations and 1.4% in South Asia. The objective of this study was to explore how mothers perceive pragmatic communication and their intervention experience for their children with ASD in the context of Pakistan? Data was collected using in-depth interviews and analyses were performed using applied thematic analysis. Results revealed the lack of understanding of pragmatic communication in parents and severe social stigma towards the parents and their child with ASD in society. Results also revealed several treatment issues that parents of children with ASD face while seeking treatment for ASD. These include failure of specialized center-based approach, accessibility, lack of understanding among treatment professionals and financial constraints. Parents have multiple strengths that help them in their journey, and they have certain future goals for their children as well. The diversity of parents’ goals suggested the need for a more individualized approach to ASD intervention. Financial constraints along with other treatment issues justified the use of more cost-effective parent-mediated Interventions for training parents of children with ASD and involving community.

Keywords: Autism Spectrum Disorder (ASD), Parent-Mediated Interventions, Social Stigma, Pragmatic communication

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by challenges in social communication, accompanied by the existence of limited interests and repetitive actions. The global occurrence of ASD in children is estimated to be around 1–2% (Baxter et al., 2015), with projected rates of 1% in wealthier nations and 1.4% in Southern Asia (Elsabbagh et al., 2012). Autism spectrum disorder transcends social, cultural, and geographical boundaries. It deeply influences the social growth of children throughout their journey to adulthood (Howlin, 2013), and it is recognized as a significant economic load (Knapp et al., 2009). Approximately 45% of Pakistan's populace consists of individuals under the age of 18, amounting to a total of 96 million children (Khan, 2023). Support for children with ASD in Pakistan is extremely restricted, primarily concentrated in urban regions. The absence of an established system for directing children to developmental pediatric services exacerbates the situation (Rahman et al., 2016). Hence, the region experiences an almost 100% 'treatment gap' for community-based ASD interventions.

Over the past decade, there has been notable progress in addressing this challenge through the creation of empirical mental health programs. These packages are designed to be administered by less specialized healthcare professionals following concise training, all while being supervised by specialists. Referred to as 'task shifting', this approach has proven successful with various psychological disorders (Patel & Thornicroft, 2009). This stands as a pivotal effective approach in bridging the gap for psychological issues. The WHO's Program, mhGAP, has crafted a guide for evidence-based interventions intended for first-line care personnel, like the public health workers (Dua et al., 2011). This comprehensive manual encompasses recommendations for managing neurodevelopmental issues such as autism spectrum disorder (World Health Organization, 2016). Nonetheless, it suggests that prior to implementation, cultural adaptations should be made (Collins et al., 2011; Kieling et al., 2011).

Before bringing adaptation plans into action, it holds significance to grasp the current healthcare methods prevalent in the concerned population. Referred to as 'formative' research, these investigations have played a crucial role in shaping and executing interventions in various aspects of child health (Group, 2008; Lingam et al., 2014). Gaining insights into the familial outlook on care is vital, as healthcare approaches are heavily shaped by the context, faith and culture of the locals (Rahman et al., 2000). Parent’s viewpoint holds a main role in the designing and formulation of services for ASD, as most evidence-based interventions are designed to involve parents. By delving deeper into the beliefs and practices surrounding caregiving through formative research, it becomes possible to ensure that interventions are culturally attuned, make use of in-practice positive programs, and utilize suitable methods and procedures (Tomlinson et al., 2014). Programs that consider viewpoint of parents have a better chance of acceptance by the population.

This study aimed to investigate parents' understanding of pragmatic communication and their firsthand experiences raising children with ASD in Pakistan. The findings from this study will serve to assess the viability and reception of modifying and executing a parent led social communication intervention tailored for children on the autism spectrum.

The Pakistan Context

The sociodemographic characteristics of Pakistan resemble those of other South Asian nations, and the country has grappled with healthcare challenges since its establishment (Hafeez et al., 2023). With a population of approximately 240 million, more than 40% of which is under 18 years old, and 60% residing in rural regions, the literacy rates range between 50% and 60%, with women having lower rates. Predominantly, Islam is the major religion, accounting for around 97% of the population from various sects, while other religious minorities such as Christians, Hindus, Ahmadis, Sikhs, and Parsis are recognized constitutionally. Faith holds significant importance for people particularly in villages. Religious practices are considered most effective and authentic in these areas (Khan, 2023; Sarkar, 2014). Geographically, many regions of the country have challenging terrain, leading to limited access and costly travel. Almost, 60 million individuals live on less than two dollars a day which shows the purchasing power parity. Four out of ten children below the age of five suffer from malnourishment (Monaghan et al., 2015). The rates of infant and maternal mortality remain alarmingly high. Over the last two decades, economic growth has driven a migration trend from rural to urban areas.

Pakistan's healthcare systems are grappling with significant challenges when it comes to delivering adequate care to its population. The country is facing a dual burden posed by the increasing prevalence of both infectious and non-communicable diseases, thereby putting immense strain on its healthcare infrastructure. Simultaneously, there is a concerning lack of substantial investment in public healthcare spending. In 2009, healthcare expenditure barely exceeded 1% of the gross domestic product (GDP). By combining resources from public, private, and external sources, the overall healthcare expenditure approximates 4% of GDP. The majority of these funds are directed towards physical health services, with a strikingly small proportion being allocated to mental healthcare provisions. This deficiency in the public healthcare system has led individuals to rely heavily on private healthcare providers and traditional healing practices. At present, these non-conventional healthcare providers cater to over 60% of the population's healthcare needs (Sarkar, 2014). Consequently, it is not uncommon to encounter traditional and religious healers within local communities. These practitioners are often the initial point of contact for individuals dealing with psychological disorders. This category of traditional healers encompasses figures such as peers and gaddinasheens, imams, herbal experts, as well as individuals practicing magic (Karim et al., 2004). It is evident that the demographic, social, cultural, economic, and healthcare framework in Pakistan diverges significantly from western developed countries. In these high-income countries, interventions are typically developed after empirical research.

METHODS

Literature review revealed a very few studies on parental perspective and experience related to ASD. No studies were found that explored the parents' understanding of social communication along with their treatment experience for their child with ASD. Thus, it was decided that a qualitative study should be conducted in Islamabad to collect primary data using in-depth interviews (IDIs). Islamabad is the capital city of Pakistan located in the northern part of the country. Adjacent to this city is Rawalpindi which is known as its twin city. The combined population of these 2 cities is approximately just a little over 5 million. The mixed urban–rural population of the twin cities represents the social and health infrastructure of Pakistan explained above.

Recruitment

For this Study, convenience and snowball sampling techniques were employed as outlined by Palinkas et al. (2015). The recruitment of parents took place informally through word of mouth within a network of parents who had children with ASD. The parents whose children were previously diagnosed with autism spectrum disorder by a specialist using the DSM-5 diagnostic criteria were approached. Announcement of the study was done through word-of-mouth referrals in private clinics and the OPD of the Government hospitals. Parents were encouraged to get in touch with the researcher for more details and potential participation. The criteria for participant selection encompassed the following: (a) parents with a child diagnosed with ASD; and (b) parents residing in Pakistan and possessing fluency in Urdu. The sample was intentionally inclusive, encompassing parents with recently diagnosed ASD children as well as those whose children had received ASD diagnoses in the past, thus ensuring a comprehensive range of perspectives. Diversity was prioritized within the sample to encompass various stages of child development, aiming to comprehensively address the significant aspects of their journey through interventions.

Participants

A total of eight individual mothers, each with at least one child diagnosed with ASD, took part in the study. It is noteworthy that all participants were mothers, as in the context of Pakistan, mothers predominantly serve as the primary caregivers for most children. The mothers' ages spanned from 29 to 41 years, and their children with ASD were aged between 3 to 6 years. All the participating mothers were married during the time of the interviews, and the average age of the mothers was approximately 34 years. Notably, the study did not take the parents' ethnic backgrounds into account. The study also considered the participants' sibling genogram, which involved having one or more siblings with ASD or having an ASD-diagnosed child as the sole sibling.

All the ASD-diagnosed children of the participating mothers were male. Given the relatively low prevalence of ASD in females and the limited sample size of this study, identifying a mother with a female ASD-diagnosed child proved challenging. The study did not delve into variations in the severity of ASD or the children's functional status. Lastly, the educational status of the children—whether they were home-schooled, attending mainstream schools, or receiving education in special education schools—was taken into account as well.

Table 1
Demographics of the Sample

Participant	Child's Age (Months)	Child's Schooling Status	Child's Gender	Mother's Age (Years)	Marital Status	Area	Family Structure	Mother's Education
P1	52	MSS	Male	34	Married	Rural	Joint	Bachelors
P2	41	MSS	Male	33	Married	Urban	Nuclear	Masters
P3	61	SES	Male	41	Married	Urban	Nuclear	Masters
P4	47	MSS	Male	36	Married	Urban	Nuclear	Masters
P5	45	HS	Male	31	Married	Rural	Joint	Intermediate
P6	40	MSS	Male	29	Married	Urban	Nuclear	Masters
P7	53	SES	Male	34	Married	Rural	Nuclear	Bachelors
P8	48	MSS	Male	35	Married	Urban	Joint	Masters

Note. MSS: Main Stream School; SES: Special Education School; HS: Home Schooled

Data Collection

The data collection phase spanned two months, commencing from November 28, 2021, to January 25, 2022. To ensure compliance and understanding, each participant formally agreed by signing a consent form and also furnished basic demographic information before the interviews commenced. The interviews were characterized by a semi-structured, comprehensive approach and were audio-recorded, reflecting in-depth exploration. These interviews, conducted by the researcher via phone, were necessitated by the global pandemic circumstances. This method was adopted as it was suitable and agreeable for all participants. The interview durations varied between 30 minutes and 1 hour, with an average duration of approximately 48 minutes.

Throughout the interviewing process, there were no instances of interruptions or disruptions originating from external sources, except for instances when participants needed to attend to their own children.

Interview questions. An interview schedule was constructed based on the research question for the semi-structured interviews shown in Table 2 below. These questions aim to facilitate the elicitation of stories, thoughts, and feelings about the target phenomenon (i.e., intervention journey of a child with ASD).

Table 2
Interview Questions in the Study

1. How was your child diagnosed with autism? How did it affect you at first??
2. What treatment and help have you received so far for your child? Was this treatment and help useful or not useful?
3. How has autism affected your child's verbal language development and use of non-verbal strategies?
4. Does your child lack social communication skills like using gestures, eye contact, facial expressions, words, and sentences? How has this affected your communication with him/her?
5. What difficulties does your child face while communicating with others due to these deficiencies?

6. How has this entire situation been like for you and your family?
7. What are your hopes and future expectations for your child and your family?

Interview procedure. Prior to conducting the interviews, a comprehensive overview of the research aims and the interview's nature was presented to the parents. The participants were provided with an advanced understanding of the interview inquiries that would be posed and the potential areas the researcher would explore to gather comprehensive insights. As the interviews concluded, participants were encouraged to share any additional points they deemed relevant. This approach aimed to ensure comprehensive coverage of the research topic until reaching material saturation, a concept elucidated by (Charmaz, 2006) denoting the point at which new data cease to introduce novel insights.

After each interview, meticulous field notes were documented, summarizing various aspects. This included an account of the interview itself, encompassing the context details like the interview's timing and location. Additionally, the researcher's reactions, encompassing emotional and cognitive responses, were noted, along with any perceived connections to emerging conceptual ideas. These field notes followed the framework outlined by Saldana (2009) and the approach established by Warren and Karner (2005).

Data Analysis

The data underwent analysis through applied thematic analysis using the framework analysis approach (Guest et al., 2011), which encompassed a sequence of five analytical stages: becoming acquainted with the data, establishing a thematic framework, categorizing, creating charts, and culminating in interpretation. Transcription is viewed as a powerful process of representation (Lapadat & Lindsay, 1999; Oliver et al., 2005). It is also a process of interpretation and generation of meanings (Halcomb & Davidson, 2006). Thus, the transcription style was carefully considered to reflect the theoretical underpinning of the research design.

Using the stance of naturalism, verbal and non-verbal elements of speech including emotions or pauses were also transcribed. Only the slight utterances like ‘mm’ or ‘hmm’ were not included. For instance, hilarity was recorded as (laugh) and pauses were recorded as (…). To ensure integrity of data, transcriptions were translated into English language with the help of a linguistic expert before beginning the steps of coding process.

In the initial two phases, two researchers independently executed the process. The transcribed and translated content of each interview was thoroughly reviewed to establish a connection with the original data. While acquainting themselves with the data, emerging codes were highlighted. A comparative assessment of these emerging codes was conducted to recognize prevalent themes. A thematic table was devised to systematically categorize the evolving codes into overarching themes along with their corresponding subthemes. The themes were scrutinized alongside corroborative data to create a coherent narrative. To gain a better perspective of the phenomenon, the researcher went through the process of epoché which means “The process through which we strive to set aside our assumptions and any preconceived notions we may hold about the subjects we are exploring.” (Langdridge, 2007).

Data Quality Assurance and Validation

To ensure rigor, several methods commonly employed in qualitative research were employed, encompassing an audit trail and team collaboration, triangulation, and member checks, as well as saturation checks.

Maintaining an audit trail throughout the study was paramount to ensuring transparency and bolstering the study's credibility, following the practices outlined by (Merriam & Tisdell, 2015). To foster self-reflection and enhance credibility, the researcher engaged in self-examination, documented within a reflective journal. Additionally, a team-based approach was integrated into the data analysis process to mitigate potential researcher bias. To facilitate potential replication, the study extensively reported the specifics of data collection and analysis.

The concept of triangulation, aimed at capturing diverse perspectives on a phenomenon, was effectively employed, such as gathering insights from both therapists and counselees to understand counseling experiences. In this study, engaging parents through interviews was deemed suitable for acquiring information, perceptions, and emotions related to the phenomenon. Multiple investigators, including the researcher, research assistant, researcher's supervisor, and an auditor, participated to minimize researcher bias through analyst triangulation, aligning with Patton's approach (2002). To further triangulate, the researcher's observation field notes during interviews served as supplementary data sources.

Ensuring stability in the data's domains and categories, as well as substantiating data's linkage with research questions and the theoretical framework, necessitated a saturation check, in accordance with the guidelines by Hill (2012). The relatively sufficient sample size (n = 8) lent consistency to the study's findings. A concerted effort was made to interconnect individual outcomes with overarching categories within the cross-analysis, thereby bolstering the stability and comprehensiveness of the study.

Ethical Considerations

This research adhered to standard ethical considerations, encompassing aspects such as obtaining informed consent, respecting participants' entitlement to privacy and confidentiality, and safeguarding them against potential physical and emotional distress (Fontana & Frey, 2000). The research received official endorsement from the Advanced Studies and Research Board of the National Institute of Psychology at Quaid-i-Azam University in Pakistan. Every participant received an informative document detailing the study's purpose. Furthermore, the researcher verbally expounded on the study's objectives to each participant. A clear outline of the study's procedures was provided, and participants were given the autonomy to discontinue their involvement at any point without facing any unfavorable consequences. Written consent, indicating full understanding and agreement, was procured from all participants.

To maintain participants' anonymity, their personal identities were diligently safeguarded. Notably, during transcription, neither the participants' nor their children's names were documented. Once the research concluded, any audio recordings were securely disposed of. In the presentation of outcomes, pseudonyms (for instance, participant P1, P2, P3) were employed. The research foresaw minimal risk or harm for interviewees; nevertheless, the potential emotional sensitivity of some parents was acknowledged. Contingency plans were devised to offer counseling support to such individuals if deemed necessary and suitable.

RESULTS

Table 1 provides an overview of the study's participants' characteristics. The children's ages ranged from 3 to 6 years old. In line with the national numbers, individuals with lower levels of education predominantly hailed from rural areas, while urban areas were predominantly inhabited by nuclear families. This qualitative study primarily delved into parents' perspectives regarding various components of Bronfenbrenner's (1986) social ecological theory, including the microsystem, macrosystem, mesosystem, and exosystem. Participants perceived interactions within these systems as directly influencing their journey as parents. However, the study did not systematically explore parents' viewpoints on how the chronosystem impacts their child's intervention. In other words, the study did not cover parents' opinions on how environmental events and transitions throughout their child's life affect them or their intervention journey.

Through data triangulation, four distinct themes emerged: (1) Pragmatic Communication Problems & Social Stigma, (2) Treatment Issues, (3) Strengths, and (4) Future Goals. While problem definitions hold significance within the context of a problem-solving model, a decision was made to also investigate and extract parents' future aspirations and strengths, which represent the opposite side of the issue. The data analysis approach aligns with the problem-solving model and is in harmony with the principles of positive health orientation and a strength-based approach, as outlined by Haley in 1987 and Yeo in 1993. The themes and subthemes are presented in Table 3. The text below describes the subthemes extracted from the data within each of these themes. Quotes taken from the original interviews are given to better explain the subthemes within these themes.

Table 3

Themes and Subthemes of the Study

Themes	**Subthemes**
Pragmatic Communication Problems & Social Stigma	- Inability to Connect with Others - Behavioral Issues - Social Stigma in School - Social Stigma in Relatives
Treatment Issues	- Lack of Knowledge Among Treatment Professionals - Financial Strain - Spiritual Healers

Themes	**Subthemes**
Pragmatic Communication Problems & Social Stigma	- Inability to Connect with Others - Behavioral Issues - Social Stigma in School - Social Stigma in Relatives
Strengths	- Partner’s Support - Religious Coping - Support from Social Network
Future Goals	- Improving Communication - Getting Education

Pragmatic Communication Problems & Social Stigma. This theme was marked by the presence of pragmatic communication challenges and the social stigma encountered by parents of children with ASD. Parents encountered obstacles in their personal interactions with their children due to the pragmatic communication difficulties exhibited by their child, and they additionally experienced societal stigmatization.

Inability to connect with others. Five participants were bothered emotionally about their child’s inability to connect with others. These participants reported that their child is somewhat in a comfortable zone when the parents or a parent is around but as soon as an unknown person appears, they become very shy and reserved. Mothers believed that this weakness causes the incapability of their children to build new relationships and friends. Codes that emerged within this theme included *difficulty creating new relationships* and *avoiding people or appearing preoccupied when around others*:

(P1) "He doesn't talk when meeting someone new and becomes quiet."

(P6) "When a guest arrives, he doesn't come towards the drawing room."

Behavioral Issues. The majority of parents possessed only a minimal understanding of the condition. Parents that were highly educated possessed good understanding of ASD, with many parents from villages ascribing their child's illness as a test from a higher power and considering it a divine will. While some parents could recognize issues related to communication and social interaction as fundamental challenges, they struggled to link these difficulties to behavioral problems. The majority of parents lacked effective strategies for engaging, interacting with, or addressing problem behaviors in their children. Some perceived it as similar to intellectual disability, focusing mainly on concerns about delayed speech. On occasion, extreme measures like confining the child to a room were employed to manage behavioral issues. Codes extracted within this theme included *ignoring requests*, *self-harm* and *behave in socially inappropriate way*:

(P1) "No matter what I say to him, he just doesn't listen to me."

(P3) "If things don't go his way, he starts throwing tantrums."

(P4) "In front of people, he ends up doing exactly what he was told not to do."

Social stigma in schools. Parents of children with milder forms of ASD made efforts to enroll their children in mainstream education. However, they expressed concerns about the limited understanding of the condition among teachers, who often struggled to comprehend the specific needs of these children. A few parents, who were interviewed, expressed apprehension about sending their child to any educational institution out of fear that it might not be conducive to their well-being. Others recounted difficulties that their children encountered in school, including complaints from the school itself. Codes within this theme included *stigma by teachers* and *stigma by school management*:

(P5) "Every parent-teacher meeting, his teacher says that he's a difficult child compared to the rest of the class, and I spend more than half my time with him."

(P6) "There are complaints from his school that he hits other children almost every month."

Social stigma in relatives. Parents conveyed a diverse range of opinions regarding how their child was perceived by the community and relatives. Some individuals displayed a lack of empathy and intolerance, resorting to derogatory terms like "pagal" (mad) or "jhalla" (idiot) when referring to such children. Conversely, others showed greater compassion and recognized that these children had unique requirements, deserving of kindness, and understanding. Nevertheless, the prevailing stigma associated with the condition remained a significant source of apprehension for most parents. They expressed concerns about the possibility of mistreatment by the community and relatives, which consequently resulted in severely limited social interactions and opportunities for the child. Codes that emerged in this theme included *stigmatizing parents* and *stigmatizing family affection*:

(P2) "My sister-in-law always says that it's your influence that has spoiled his habits. Her own children are well-behaved."

(P8) "He is the eldest among his maternal and paternal cousins, and everyone believes that he has become so spoiled due to being excessively pampered."

Treatment issues. The theme itself was self-explanatory. It constituted several issues that parents faced while seeking treatment for their child with ASD. These issues, namely, *lack of knowledge among treatment professionals*, *financial strain,* and *spiritual healers*, represented both constraints within the families and/or within the larger ecosystem that provides ASD intervention.

Lack of knowledge among treatment professionals. Most of the highly educated parents who were well aware about the features of ASD reported that even the well-established medical practitioners had a restricted understanding of the disorder. Codes that were extracted within this theme included ‘l*ack of referral culture among clinicians* and *lack of debriefing the family about the nature of problem*:

(P2) "For two years, we kept taking him to a child doctor. We also gave him a brain tonic syrup, and he was improving with it, but no one even mentioned autism to us."

(P4) "Someone would just refer him to someone else, and from there, they would send him to someone else. This kept going on."

Financial strain. Parents who were residing in villages reported struggle in accessibility to services for their child. It was also reported that services were very expensive and mostly located in bigger cities, resulting in increased cost and requiring extra time to access them. Codes that emerged within this theme included *expensive treatment, financial burden* and *non-affordability*:

(P2) "You can calculate all the money that accumulates over the course of a month for his treatment."

(P4) "We are getting the treatment, but the fees are very high."

(P5) "These are such expensive treatments."

Spiritual healers. Parents, both in rural and urban areas, often turned to traditional spiritual healers, with many seeking them as the initial option for support. In numerous instances, these healers provided parents with guidance and a sense of relief. The names that emerged from this study for these traditional healers are “peer saab” and “baba jee”. Codes within this theme included *divine intervention* and *faith healing*:

(P5) "There's a 'baba jee' in our village. We sought his help as well. Mashallah,
there has been significant improvement with his treatment too."

(P6) "We also made him wear a ‘taveez’ to control him. Someone recommended
it. They don't charge money for it."

Strengths. The theme identified three strengths which occurred in the microsystem, macrosystem, mesosystem and exosystem. They are *partner’s support*, *religious coping*, and *support from social network*. There was one common characteristic among these strengths. Parent’s strengths or resources here were not financial or material, but mental, moral, and emotional support, within themselves or from their spouses, family members or their friends/ social network.

Partner’s support. Three parents found that their husbands acted as a strong support. Whenever they felt weak and were affected by the child’s conditions deeply, their husbands would be there to support them. Their husband’s traits were described as being calmer, logical, patient and supportive. These qualities helped mothers cope with their child’s conditions. Codes within this theme included *logistic support* and *emotional support*:

(P2) "They never refused, whether it required taking him to Lahore or visiting them on their working day. They would drop everything and just focus on him."

(P7) "Since we found out about autism, my husband has become more attentive to him and me. When he gets too agitated, he often takes him for a drive outside in the car. And from my expression, he can tell that I'm feeling overwhelmed now."

Religious coping. Five participants demonstrated religious consolation as a tool for coping and cultivating optimism. Their belief system acted as a source for reducing stress and instilling hope for the future. Codes that were extracted within this theme included *positive religious coping* and *religious consolation*:

(P2) "Whatever Allah does, there is some good in it."

(P4) "The world is based on hope, and despair is a sin."

(P5) "He must have something in mind for everyone."

Support from social network. Four participants reported that they get productive support from within their social network. Most of this help came from extended family members. This support helped in reducing caregiver burden for the mothers. Codes that emerged within this theme included *family support* and *social support*:

(P1) "My sister is always available, and she doesn't get annoyed by him. She is quite attached to him."

(P8) "Sometimes, I leave him at my mom's house. He stays very happy there."

Future goals. This theme was characterized by parents' future goals and aspirations for their family outcomes. Parents had short term goals and far-reaching dreams for their child with ASD and for themselves. The details within this theme specified the kind of goals that parents wished to work toward.

Improving communication. Parents held a variety of short-term objectives for their children with ASD, stemming from their endeavors to address perceived challenges and issues related to their child's condition. For three parents, particularly those with younger children or children with more significant impairments, a crucial goal was enhancing communication. Given that deficits in both verbal and nonverbal communication are fundamental challenges for all children with ASD, these parents expressed a strong desire to witness their child comprehending and utilizing language as a means of communication and establishing connections with others. Codes within this theme included *treatment goals*, *improving pragmatic communication* and *improving verbal communication*:

(P2) "He is studying in school and receiving treatment alongside."

(P6) "My wish is that he has starts interacting with people like other children."

(P7) "The main issue is his speech. We need to get that fixed for him."

Getting education. Parents had a deep desire for their children to get formal education and prosper in society like all other kids. They wished to get education and treatment for their child simultaneously. Some had high academic goals for their children while others just wished for normal schooling. Codes that emerged within this theme included *academic goals* and *pragmatic goals*:

(P2) "I want him to study in school and receive treatment simultaneously."

(P4) "Just like every parent wishes for their child to receive the best education and excel in life."

(P5) "Just study like normal children; I don't expect him to be first in the class. Just maintain decent grades."

DISCUSSION

This study explored parents' understanding of pragmatic communication and their perspectives on the treatment journey for their children with autism spectrum disorder (ASD) in Pakistan. The findings, as summarized in Table 3, contribute to the emerging body of qualitative research, albeit limited, that can offer valuable insights for planning implementation research and service delivery not only in Pakistan but also potentially in other low-income countries. The themes presented in Table 3 shed light on the strengths and challenges in treatment, offering valuable information that intervention programs could consider. This information goes beyond the specific intervention itself and can address parental concerns and existing practices.

However, it's worth noting that the number of studies conducted in this field remains limited, primarily focusing on a few centers within this vast country. To comprehensively meet the varied and extensive needs in this domain, additional studies are highly desirable. Nevertheless, even within this restricted sample, the study's findings reveal more commonalities than differences, underscoring the relevance of this information for the purpose of service planning.

The study was carried out in two major cities of the country. Even in these urban areas, resources and trained professionals for ASD are scarce. When they were accessible, the cost was very high and difficult to afford for most parents. Majority of Pakistan's population resides in villages, far from the nearest urban centers. The research findings underscore the current calls for research that focuses on establishing community-based interventions and altering tasks to programs which can be administered by local providers, as suggested by Collins et al., (2011). The WHO's mhGAP program offers framework and methods for the aforementioned interventions, but additional empirical exploration is necessary to create or adapt practical treatment programs and identify suitable providers for their delivery.

For instance, a study conducted in Pakistan revealed that when specialized providers were not present, parents would appreciate a service ran by volunteers. In this scenario, family members of children with intellectual disabilities, who have received training and supervision from experts, would help other family members, as highlighted in Hamdani et al. (2014). Additional investigation on parent-mediated programs is warranted. Additionally, exploring the utilization of latest technology in executing training and administration of these community providers remotely is another avenue worth investigating, as suggested by Hamdani et al. (2014).

This study highlights that when parents, mainly mothers, lack access to respite or remedial care, they experience distress. Previous research in South Asia involving parents of young children facing similar challenges has utilized questionnaires and has consistently shown high levels of distress, particularly among mothers (Mirza et al., 2009; Rahman et al., 2008). Initial programs for autism spectrum disorder often involve parents directly, demanding substantial parental commitment for successful implementation (Kendall et al., 2013). Mothers enduring caregiver burden and psychological distress may require additional support. Therefore, it is crucial to consider maternal stress when designing and implementing such treatments.

The growing awareness of maternal distress along with depression, and their effects on child care and development, is now recognized as a significant health issue. (Rahman et al., 2008;

Wachs et al., 2009). New Approaches have been established to include interventions into childcare programs (Zafar et al., 2014). Including the entire family, even grandparents, is an important element of these approaches. It serves two purposes: first, it garners support for the mother, and second, it secures the family's commitment to the intervention. Community-based support groups led by volunteers have shown great success in enhancing various child health outcomes across South Asia (Tripathy et al., 2010) and could also be valuable in the dissemination of interventions for autism spectrum disorder.

Insufficient awareness, limited understanding, prevalent supernatural beliefs, and the stigma surrounding this disorder were widespread, particularly among rural and less-educated parents as opposed to their urban and more educated counterparts. Limited understanding of pragmatic communication deficit and inability of parents to connect this as a major symptom and result of ASD is a new finding in this study. Promoting community awareness in a culturally sensitive manner becomes a crucial component of developing services. This becomes especially significant for detecting early and then diagnosing such disorders, because early treamtents tend to yield better results. A study conducted in Pakistan demonstrated the efficacy of a school intervention in increasing awareness of mental health, not only among school children but also among their peers, parents and neighbors who were not attending school. (Rahman et al., 1998). Programs of this nature, alongside broader mass-media campaigns, should run concurrently with intervention execution to enhance understanding and diminish the labeling associated with these disorders. Eventually, this will foster increased acceptance towards children with these conditions within the public.

The research additionally indicated that a lot of parents, particularly in backward regions, still turn to traditional medical healers and religious clerics for instructions and support, and sometimes find their assistance beneficial. Completely dismissing these sources of support could pose challenges, as they often hold significant importance within the beliefs of parents. Saeed and co-authors have proposed a collective approach to working in conjunction with traditional medical healers and religious clerics (Saeed et al., 2000). According to this model, these healers and clerics can receive training in identifying most occurring mental disorders like anxiety, depression, and psychosis, as well as psycho-educating families about these disorders. They can refer cases to local healthcare services, emphasizing the necessity for formal care, while also continuing to give their traditional intervention. Such collaborative care models should be explored for ASD, as they may prove effective.

CONCLUSION

Numerous obstacles exist in delivering services to parents and children with ASD within Pakistan. Specialized center-based approaches are impractical and incapable for ensuring equitable care in the Pakistani context. In addition to this, parents' limited understanding of the nature of this disorder is also a hurdle in providing the ideal help to children with ASD. The adaptation of parent-mediated models and similar strategies, which are currently effective for addressing various child-related and mental health issues, holds promise for the management of ASD. These service models should take into account the influence of parental and family dynamics as part of their planning. There is a compelling need for additional research to explore and refine these strategies further.

REFERENCES

Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, *45*(3), 601–613.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, *22*(6), 723.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. sage.

Collins, P. Y., Patel, V., Joestl, S. S., March, D., Insel, T. R., Daar, A. S., Bordin, I. A., Costello, E. J., Durkin, M., & Fairburn, C. (2011). Grand challenges in global mental health. *Nature*, *475*(7354), 27–30.

Dua, T., Barbui, C., Clark, N., Fleischmann, A., Poznyak, V., van Ommeren, M., Yasamy, M. T., Ayuso-Mateos, J. L., Birbeck, G. L., & Drummond, C. (2011). Evidence-based guidelines for mental, neurological, and substance use disorders in low-and middle-income countries: summary of WHO recommendations. *PLoS Medicine*, *8*(11), e1001122.

Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., & Wang, C. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, *5*(3), 160–179.

Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. *Handbook of Qualitative Research*, *2*(6), 645–672.

Group, N. M. F. R. W. (2008). Developing community-based intervention strategies to save newborn lives: lessons learned from formative research in five countries. *Journal of Perinatology: Official Journal of the California Perinatal Association*, *28*, S2–S8.

Guest, G., MacQueen, K. M., & Namey, E. E. (2011). *Applied thematic analysis*. sage publications.

Hafeez, A., Dangel, W. J., Ostroff, S. M., Kiani, A. G., Glenn, S. D., Abbas, J., Afzal, M. S., Afzal, S., Ahmad, S., & Ahmed, A. (2023). The state of health in Pakistan and its provinces and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Global Health*, *11*(2), e229–e243.

Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, *19*(1), 38–42.

Haley, J. (1987). *Problem-Solving Therapy. San Francisco, CA (Jossey-Bass) 1987.*

Hamdani, S. U., Atif, N., Tariq, M., Minhas, F. A., Iqbal, Z., & Rahman, A. (2014). Family networks to improve outcomes in children with intellectual and developmental disorders: a qualitative study. *International Journal of Mental Health Systems*, *8*, 1–8.

Hill, C. E. (2012). *Consensual qualitative research: A practical resource for investigating social science phenomena.* American Psychological Association.

Howlin, P. (2013). Social disadvantage and exclusion: adults with autism lag far behind in employment -- prospects. *Journal of the American Academy of Child & Adolescent Psychiatry*, *52*(9), 897–899.

Karim, S., Saeed, K., Rana, M. H., Mubbashar, M. H., & Jenkins, R. (2004). Pakistan mental health country profile. *International Review of Psychiatry*, *16*(1–2), 83–92.

Kendall, T., Megnin-Viggars, O., Gould, N., Taylor, C., Burt, L. R., & Baird, G. (2013). Management of autism in children and young people: summary of NICE and SCIE guidance. *Bmj*, *347*.

Khan, S. (2023, August 5). 2023 Census Results ‘Unanimously’ Approved at CCI Meeting. *DAWN*.

Kieling, C., Baker-Henningham, H., Belfer, M., Conti, G., Ertem, I., Omigbodun, O., Rohde, L. A., Srinath, S., Ulkuer, N., & Rahman, A. (2011). Child and adolescent mental health worldwide: evidence for action. *The Lancet*, *378*(9801), 1515–1525.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, *13*(3), 317–336.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Pearson education.

Lapadat, J. C., & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positionings. *Qualitative Inquiry*, *5*(1), 64–86.

Lingam, R., Gupta, P., Zafar, S., Hill, Z., Yousafzai, A., Iyengar, S., Sikander, S., Haq, Z. ul, Mehta, S., & Skordis-Worrel, J. (2014). Understanding care and feeding practices: building blocks for a sustainable intervention in India and Pakistan. *Annals of the New York Academy of Sciences*, *1308*(1), 204–217.

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research*, *53*(6), 559–570.

Monaghan, T., Boyer, A., Moyo, G., & Landwehr, J. (2015). *National Model United Nations*.

Oliver, D. G., Serovich, J. M., & Mason, T. L. (2005). Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces*, *84*(2), 1273–1289.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*, 533–544.

Patel, V., & Thornicroft, G. (2009). Packages of care for mental, neurological, and substance use disorders in low-and middle-income countries: PLoS Medicine Series. *PLoS Medicine*, *6*(10), e1000160.

Patton, M. Q. (2002). Qualitative research and evaluation methods. Thousand Oaks. *Cal.: Sage Publications*, *4*.

Rahman, A., Divan, G., Hamdani, S. U., Vajaratkar, V., Taylor, C., Leadbitter, K., Aldred, C., Minhas, A., Cardozo, P., & Emsley, R. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. *The Lancet Psychiatry*, *3*(2), 128–136.

Rahman, A., Mubbashar, M. H., Gater, R., & Goldberg, D. (1998). Randomised trial of impact of school mental-health programme in rural Rawalpindi, Pakistan. *The Lancet*, *352*(9133), 1022–1025.

Rahman, A., Mubbashar, M., Harrington, R., & Gater, R. (2000). Annotation: Developing child mental health services in developing countries. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, *41*(5), 539–546.

Rahman, A., Patel, V., Maselko, J., & Kirkwood, B. (2008). The neglected ‘m’in MCH programmes–why mental health of mothers is important for child nutrition. *Tropical Medicine & International Health*, *13*(4), 579–583.

Saeed, K., Gater, R., Hussain, A., & Mubbashar, M. (2000). The prevalence, classification and treatment of mental disorders among attenders of native faith healers in rural Pakistan. *Social Psychiatry and Psychiatric Epidemiology*, *35*, 480–485.

Saldaña, J. (2009). An introduction to codes and coding. The coding manual for qualitative researchers. *J. Seaman. Los Angeles, London. Singapore, New Delhi, Washington DC, SAGE*, 1–31.

Sarkar, S. (2014). Ethical issues relating to faith healing practices in South Asia: A medical perspective. *Journal of Clinical Research & Bioethics*, *5*(4), 1.

Tomlinson, M., Rahman, A., Sanders, D., Maselko, J., & Rotheram-Borus, M. J. (2014). Leveraging paraprofessionals and family strengths to improve coverage and penetration of nutrition and early child development services. *Annals of the New York Academy of Sciences*, *1308*(1), 162–171.

Tripathy, P., Nair, N., Barnett, S., Mahapatra, R., Borghi, J., Rath, S., Rath, S., Gope, R., Mahto, D., & Sinha, R. (2010). Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: a cluster-randomised controlled trial. *The Lancet*, *375*(9721), 1182–1192.

Wachs, T. D., Black, M. M., & Engle, P. L. (2009). Maternal depression: a global threat to children's health, development, and behavior and to human rights. *Child Development Perspectives*, *3*(1), 51–59.

Warren, C. A. B., & Karner, T. X. (2005). Discovering qualitative methods: Field research, interviews, and analysis. *(No Title)*.

World Health Organization. (2016). *mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: mental health Gap Action Programme (mhGAP)*. World Health Organization.

Yeo, A. (1993). *Counselling: A problem-solving approach*. Armour Publishing Pte Ltd.

Zafar, S., Sikander, S., Haq, Z., Hill, Z., Lingam, R., Skordis-Worrall, J., Hafeez, A., Kirkwood, B., & Rahman, A. (2014). Integrating maternal psychosocial well-being into a child-development intervention: the five-pillars approach. *Annals of the New York Academy of Sciences*, *1308*(1), 107–117.