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Early Identification of Autism Spectrum Disorder in Rural Pakistan: Barriers and Strategies for Timely Diagnosis

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ABSTRACT

Early detection of Autism Spectrum Disorder (ASD) plays a critical role in better developmental outcomes, but rural Pakistan poses huge obstacles in the early detection of Autism Spectrum Disorder (ASD). This is an extensive literature study examining these impediments and recommends evidence-based, culturally competent steps in this region. The results incorporate three related areas of barriers. In the first place, the sociocultural determinants contribute to the delay of seeking medical help: these include insufficient level of enlightenment of the population, stigmatization and dependence on traditional healers. Second, a lack of trained experts, insufficient primary care training on developmental screening, and a broken path system of referral flow disseminates the health system barriers. Third, it is the lack of social and geographic accessibility due to poverty and the inaccessibility of an urban diagnostic centre which makes the services inaccessible to the majority of rural families. In order to prevail over such challenges, multi pronged attack is necessary. The strategies proposed are aimed at empowering Community Health Workers (CHWs) in terms of basic developmental surveillance and the introduction of community awareness campaigns. Such initiatives should be accompanied by the enhancement of the primary healthcare system including the introduction of screening into regular visits, task-shifting model and engagement of telehealth technologies. Lastly, a system of care with education reforms and supportive policy is the key to developing a sustainable tiered care. Policymakers, healthcare officials, and other community stakeholders must work together to develop a viable channel of early embracement to ensure timely diagnosis and management of ASD cases, thus enhancing the outcome of many more children in the country who have the disorder.

Keywords: Autism Spectrum Disorder, Early Diagnosis, Rural Pakistan, Healthcare Barriers, Community Health Workers, Task-Shifting, Telehealth.

Introduction

Autism Spectrum Disorder (ASD) is a sophisticated neurodevelopmental disorder characterized by lifelong impairment in social communication and interaction as well as impairments in restricted, repetitive patterns of behaviour, interest or activities (American Psychiatric Association, 2013). The prevalence of ASD is estimated to have increased in a stable manner in the past few decades all over the world. According to recent data, 1 out of every 36 children has

ASD (Maenner et al., 2023). The seeming rise is commonly estimated to be due to a better acceptance and awareness of the problem amongst the populace and professionals along with the changing of the criteria of diagnosis and through better detection practices rather than the apparent epidemic of the condition itself. An important pillar in long-term positive outcomes in ASD is early diagnosis and the best age is three. This fact is substantiated by the study by Zwaigenbaum et al. (2015), since early diagnosis will make it easier to implement intensive behavioural treatment that has been found to improve cognitive capacities, language, and adaptive functioning with a significant effect, and might also minimize the necessity of long-term care (Dawson et al., 2010). Such interventions typically comprise applied behaviour analysis (ABA), structured teaching, speech therapy and occupational therapy, and they should be provided persistently and in a reliable manner.

In affluent nations, they have come some way to instituting early ASD-screening and prevention systems. Regular developmental surveillance in the primary health care system, the incorporation of screening programs in schools, the increasing presence of multidisciplinary teams, and insurance or government coverage of ASD interventions have contributed to early identification, early initiation of intervention. The systems are however poor or poorly developed in low and middle income countries (LMICs) such as Pakistan. One of the most evident problems with the mental and developmental health of the population is evident in Pakistan, where over 240 million people live and more than 60 percent of them are rural residents (World Bank, 2023). A national survey on the treatment of mental disorders carried out by Mirza and Jenkins (2004) showed a huge mental treatment gap in the country a gap that is more immense when it comes to neurodevelopmental disorders like ASD that need multidisciplinary teams, unique diagnostic expertise, and high intensity care.

This is worsened by the rural urban disparity in the health infrastructure and the quality/availability of services. Pervasive poverty, low literacy rates, deficient access to primary health care, and the cultural beliefs that inform how families perceive health, development and disability in rural communities typify communities in Pakistan. In these environments, caregivers or parents might not detect abnormal behaviours as manifestations of a medical or neurodevelopmental disorder when their child shows early signs of abnormalities in development. Rather, they will do this by blaming them on spiritual factors, family stigma, laziness, or they will simply state that it is only shyness thereby, postponing official assessment (Imran et al., 2011). In addition, even in those cases, when parents have their suspicions and address it to local sources of primary health care (typically local community health workers or primary care physicians), most do not receive training in developmental screening or have a knowledge of the red flags specific to ASD. Extensive instruments like the Modified Checklist of Autism in Toddlers (M-CHAT) will not be available, and providers will not have assurance on interpreting the screening outcomes. This frequently results in delays of referral, faulty diagnosis (e.g., attributing the symptoms of ASD to Intellectually disability, or behavioural difficulties), or a watch-and-wait policy. In most instances, the most available professional having the required medical degree in pediatric neurology, developmental pediatrician, or child psychiatrist could be found in a big city, putting families on the road to cover uncounted kilometres. In the case of poor rural households, the traveling to or from these places incurs prohibitive costs that may not only be direct monetary outlays on transport and the consultation but opportunity costs, including lost wages, childcare arrangements, and logistical burdens (Samad et al., 2022).

This has contributed to a high percentage of ASD children who are undiagnosed or are diagnosed too late after their early crucial years in rural Pakistan. The effects of late diagnosis are far-reaching: children experience a lost neuroplastic opportunity and an increased level of learning; families experience uncertainty, stress and emotional burden over an extended period; the child experiences even greater deficiency in his adaptive and functional skills compared to his peers. By the time they are finally diagnosed, most of the children have already exacerbated with serious cases of poor behaviour which become more challenging to control. Failure to intervene early aggravates the burdens of care giving long term in terms of emotions, social, and economically on families that are already vulnerable. It is necessary to address early diagnosis of ASD in rural Pakistan, therefore, on a multi-level scale since sociocultural, healthcare system, and social-economic factors must be taken into consideration and, correspondingly, a variety of solutions that revolve around community, system, and policy are to be considered. The present article provides a detailed set of analysis using systematic literature review. The review integrated the available background knowledge in this domain questioning academic databases, i.e., Google Scholar, PubMed, reports of global and regional organizations, e.g., the World Health Organization. Search terms consisted of a combination of the phrases “autism diagnosis rural Pakistan,” or “neurodevelopmental disorders Pakistan,” or “developmental screening low and middle-income countries,” or “early intervention autism Pakistan.” Out of the search results of the initial query, 30 of the most significant sources, peer-reviewed articles, books, and official reports, were chosen to be analysed in the context of in-depth thematic diversification.

The obtained literature was coded with the help of themes in order to classify barriers into three fundamental categories:

1. Social cultural barriers, including: lack of awareness, stigma, traditionalism, influence of gender norms (e.g., maternal blame), and family decision making behaviour.
2. Barriers within the healthcare system like narrow knowledge of the provider, insufficient number of specialists, ineffective referral links, absence of screening devices, and effective integration of the developmental observation into primary care.
3. Social factors such as poverty, unequal access to education, transport, and costs relating to care seeking.

In line with this, interventions and plans were grounded to three concurrent levels of responses, namely Community based interventions, that is, awareness campaigns through the local schools or mosques, training of community health workers on screening tools, caregiver education programs involving the use of culturally adapted materials.

Interventions in healthcare system such as capacity building (training primary care providers), development of the tele-consultation programs to bridge rural centers and urban specialists, incorporation of the developmental screening into routine maternal-child health visits and task-sharing models with non-specialist workers.

Advocacy to include ASD screening in national child health policies, finances to deploy mobile diagnostic teams, early intervention into prevalent health insurance schemes, and intersectoral cooperation between health, education, and social welfare may be imposed in the policy level.

Through an organization of the article following this barrier-strategy framework, the idea is to present a context-sensitive, multidimensional blueprint of enhancing early ASD diagnosis in rural Pakistan. This type of framework identifies both the quick-fix, locally implementable measures (e.g., training community health workers) and intermediate- to long-term investments (e.g.,

telehealth infrastructure, national policy changes) that in combination can build early detection and intervention systems on a sustainable basis.

To sum it up, ASD is a cognitive disorder that has been gaining prominence in the world and has substantial evidence that supports its early intervention. However, the environmental factors surrounding this scenario in LMICs complicate the burden of diagnosis like in rural Pakistan the set of sociocultural, systemic, and socioeconomic factors contribute to delayed diagnosis. The thematic review that takes place on the basis of systematically collected literature provides a way forward one that cross-links community awareness, capability of the health sector, and policies and improves outcomes of the affected children with ASD and their families.

Inhibitors to Early ASD Diagnosis in Rural Pakistan

There is a formidable list of interdependent obstacles that frustrate the pathway toward an early diagnosis of ASD in a child in rural Pakistan. Those can be divided into sociocultural, healthcare system, and socioeconomic factors.

Social Barriers

Among the most entrenched obstacles, one could find sociocultural issues which condition individual families to perceive, interpret, and react to the case of an atypically developing child. In most of the rural populations, the idea of ASD being a neurodevelopmental challenge is almost not heard. According to a study done in Pakistan, there was a huge percentage of inadequate knowledge of the causes and symptoms of autism (Imran et al., 2011). Irregular behaviours that they include the absence of eye contact, late talking or repetition of action is commonly misunderstood as a child that is being wilful, bad parenting style, or is just a momentary stage that will pass away. Lack of biomedical framework implies that parents will not be able to identify these behaviours with red flags, i.e., they have to be medically addressed. On top of this is the high level of stigma that exists towards people with disabilities in most regions of the Pakistani society. A behavioural disability will cause the child shame on the family causing impacts on social status and marital formation of siblings (Avan, 2015). The fear of negative societal reaction that can result in the social isolation of a child and overall family can drive parents to conceal the child issues and evade diagnosis (Ghuman et al., 2021).

When there is no biomedical knowledge, the supernatural or the religious tend to dominate. The symptoms of a child can be related to the so-called evil eye (nazar) or spiritual reasons. Therefore, a traditional healer (pir or hakeem) is not a doctor rather it is the first stop of many families. These healers offer culturally compelling interpretations and treatments and are vital in delaying any medical diagnosis which can take years (Rabbani et al., 2018; Shaikh & Hatcher, 2005).

Barriers of the Healthcare System

Rural Pakistan has a poorly developed system of healthcare that will not be able to sustain the heavy burden of recognizing ASD at an early stage. Specialized professionals like developmental pediatricians and child psychologists are much in short supply in the whole country. Roughly speaking, almost all of them are located in large cities, which leaves an urban population with a shortage of specialists in the rural population (Ghanizadeh et al., 2015).

Moreover, primary health care practitioners (Women and Nurses) as well as health care providers (General Practitioners (Gp) and Lady Health Workers (LHW) have insufficient training regarding child development and developmental disabilities. The LHWs are a pillar of maternal and child health, and their curriculums traditionally had little materials on developmental

screening (Haq & Iqbal, 2018). Therefore, when any of the parents raises any concern, the response is usually to wait and see and this slows the early intervention window. The other large systemic problem is the shortage of culturally validated screening tools. Standard methods: Majority of the tools that are most commonly used including the M-CHAT (Robins et al., 2001) were developed in the Western countries. Concerning play and social interaction parents in Pakistan may have diverse literacy levels, their questions would not bring much understanding to the condition, and systematic screening would occupy an impossible level (de Leeuw et al., 2020). The last, even when a provider feels that there is a delay, there is usually no clear and functional referral system. This system is disjointed, involving a weak link between the primary, secondary, and tertiary care systems, where families are lost in a maze of poor communication and incur huge expenses in a system that ends up being disappointing and frustrated (Khowaja et al., 2015; Nishtar, 2006).

Socio-economic and Geographic Obstacles

The socioeconomic realities and the geographical factors provide gigantic practical barriers to the rural families in Pakistan. Poverty is systemic and a considerable share of the people subsists as a small income (Pakistan Bureau of Statistics, 2021). The fees involved in diagnosis of ASD are prohibitive. They are not only the studying expenses on specialist consultations by a paid specialist but also the considerable indirect expenses connected with the transportation and accommodation of a child and loss of income by his parents (Janjua, 2014). To a family with limited finances that makes ends meet with difficulty, these costs are overwhelming. Another big problem is the sheer geography of Pakistan. Most of the rural communities are found in distant places with a poor road structure and lack of transportation. Geographic isolation implies that even with a desire to obtain diagnosis, the logistical task to be undertaken is enormous. Such a tyranny of distance guarantees that specialized healthcare becomes a privilege of urban residents who depend on the range of a car rather than the ability to benefit from the same healthcare provided to the urban population in a timely manner.

Plans to Conduct a Timely Diagnosis

To solve the underlying obstacles to early detection of ASD, it will be necessary to employ a multi-pronged and implement multi-pronged holistic methodology that has been adjusted to the realities on the ground in Pakistan to address the rural population. The strategies should be realistic, scalable and culturally aware.

Community-Based Interventions

Reform should start at the grass roots level. It is necessary to achieve cultural awareness campaigns to make people learn about ASD as a medical condition. Messages should be framed in terms of development milestones that are easy to observe rather than heavy jargon and communicated through local languages via regional radio, television coverage, and community assembly. The use of influential people like the village elders and religious leaders can be a great facilitation towards discouraging stigma and adopting help-seeking (Patel et al., 2011). The strategy, which is the most critical in this area, is the empowerment of Community Health Workers (CHWs). The 100,000-plus network of Lady Health Workers (LHWs) within Pakistan is an untapped asset to developmental surveillance that cannot be overestimated (Haq & Iqbal, 2018). An essential component of developmental screening can be incorporated in their ordinary visits to households by extension of their role in a model of task shifting (WHO, 2008). It incorporates using simple modules based on pictures to train LHWs in the red flags in development and

providing them with a culturally modified observational checklist. This would deem LHWs as the pivotal entry-point of the referral chain, to detect children at risk and orient the families to the primary health facility (Rahman et al., 2016).

Developing the Primary Healthcare System

The primary care has to be developed to be a part of the developmental screening. It can be done by incorporating developmental screening into primary care by doing this at Basic Health Units (BHUs) and Rural Health Centers (RHCs) such as during routine vaccination visits. Such mainstreaming of developmental surveillance would normalize this process and eliminate stigma. It would imply that it would need to train GPs and other primary care personnel to administer a culture-adapted and validated screening tool. Moreover, telehealth and mHealth technologies may help to overcome the huge geographical distance between them. LHWs will have access to simple smartphones on which they can record and convey the screening information (Agarwal et al., 2016). A GP in a BHU in the rural setting would then be able to schedule a video consultation with a specialist team in a big hospital. Thanks to this hub-and-spoke system, specialists can teach staff and directives in local venues and talk in front of families, eliminating the necessity of expensive and challenging traveling (Sutherland et al., 2018). It has already been shown that this practice is viable in the South Asian setting through projects that are currently being developed to create mobile-based screening tools in neighbouring India (Divan et al., 2015).

Policy and Educational Reforms

The government should support the change in a top-down manner. The medical and nursing curriculum needs to be redesigned in order to introduce detailed modules on child development and developmental disabilities, and make sure that future health professionals have the required background knowledge (Durkin et al., 2015). The government must formalize and finance a hierarchical care system on ASD by the Ministry of National Health Services. Surveillance of LHWs followed by screening at primary care centres and further referral to special child development clinics at district level, would fulfil the mandate of full diagnostic assessment within this system. The large urban hospitals would be the third-level centers of excellence offering support and training to the lower levels (Ministry of Health, 2010). Importantly, the government should make services provided by means of this publicly based system free or significantly subsidized to ensure that there are no financial obstacles.

Conclusively, Pakistan needs an urgent National Autism Strategy. That policy would need to have funds to conduct population-based studies in order to know the actual prevalence of ASD as well as to help develop culturally suitable screening instruments within Pakistani populations. A national strategy would give a clear vision, restructure the resources and enact an action platform of enhancing the lives of individuals with ASD and their families within the country (Bolt, 2014).

Discussion

Community engagement, the reinforcement of primary healthcare, and reform of policies are the essential elements of a triad of mutually reinforcing strategies required to enhance the early diagnosis of Autism Spectrum Disorder (ASD) in rural Pakistan. These strategies do not occur in isolation as single interventions but instead, successful execution of these strategies hinges on the ability to ensure a planned and coordinated implementation strategy. In the absence of this coordination, individual work will have very short achievements that cannot correct the existing

systemic, sociocultural, and structural issues preventing the possibility of timely diagnosis and intervention. One of the key elements of such an integrated approach is the empowerment and use of the Lady Health Workers (LHWs). As one of the state-sponsored programs, the LHW program can already reach most places in rural settings as it serves as an intermediary between the formal healthcare infrastructure and the rural population. This already established network provides a special platform through which developmental surveillance can be established at the grass root level. One of the possible solutions, which have been known to address the problem of healthcare workforce shortage especially in low- and middle-income countries is task-shifting in which some of the diagnostic and screening tasks that specialists perform are delegated to non-specialist health workers who have undergone some training (WHO, 2008). This model is also quite applicable in the case of ASD since there is a high degree of developmental pediatricians, child psychiatrists, and other experts in rural Pakistan. With the training of the LHWs to be able to recognize the early developmental red flags, the screening would be more accessible, way ahead of time, and community-based.

Placement of LHWs is a strategically placed decision that cannot be just a logistical one but, a culturally informed one. In most rural communities, credibility is strongly connected with familiarity, cultural synchronicity, among other aspects of long-term stability of healthcare providers. LHWs belong to the same communities in which they work and thereby have the trust of local families. Through this positioning, they can dispel the misconceptions and counteract stigma to support a biomedical perspective of developmental disorders like ASD (Rahman et al., 2016). With this, the LHW approach on screening will be able to overcome both barriers to access and social and cultural challenges in early diagnosis at the same time. Nevertheless, task-shifting has a great potential, although it is not a complete solution. The concept must be considered as an alarming element in a well-endowed system of primary healthcare. The screening of potential cases of ASD by LHWs should be complemented with effective, simple, and workable referral channels to the higher institutions to which the diseases can be confirmed and abuse opening interventions follow. The presence of such pathways is necessary so that the initial efforts of detection can be not an endpoint itself, instead, this is only the first tier of an intervention continuum. To reinforce the main healthcare system and help it cope with these pathways is thus an indispensable condition to succeed.

Technology is one such tool, which is transformative, and this is within this context. The use of telehealth services can provide the ability to provide virtual expansion of specialty care into the underserved and rural districts. With the use of digital mediums, experts in the urban locations can offer consultation, case conferences, and trainings to primary care providers in other places. With this measure, this dilemma of specialist maldistribution can be significantly minimized, which enables the organization to increase its diagnostic coverage without the necessity to physically override the expert staff who has been highly trained (Sutherland et al., 2018). Such process of leapfrogging conventional infrastructure may have a lower cost than trying to recreate city-level infrastructures across all districts in resource-constrained settings. However, there is a lot of system-level preparation that requires the introduction of telehealth in the ASD diagnosis and care processes. Access to reliable internet connectivity and sufficient hardware in the health facilities that are located in rural areas must be provided technologically. It is also paramount to formulate standard operating procedures to determine how the telehealth should be used in developmental assessment to promote consistency, quality, and culture sensitivity. Both on-site

providers and remote specialists should be trained in order to maximize the utilization of such platforms. In addition, telehealth must not be an alternative to face-to-face assessment, particularly in situations in which multi-faceted behavioural observations or comorbidities are present.

Although task-shifting and technological interventions can establish the working model to increase the ASD capacity of diagnosis, policy and political will is necessary to ensure its sustainability. Lack of special government investment will probably ensure continued fragmentation and short-termism of pilot projects, no matter how well planned. At the national stage, there is need to obtain funding to support training programs, modify existing diagnostic equipment to local languages and cultural settings and subsidize its services to make them financially accessible to low-income families (Nishtar, 2006). In this respect, a National Autism Strategy should be created as a decisive policy tool. This kind of approach would outline national goals, assign resources, draw up roles and responsibilities in relation to various ministries, and establish accountability channels (Bolt, 2014). An effective National Autism Strategy would also give the space required to incorporate ASD screening into services that already exist such as those centred on maternal and child health to normalize developmental screening within the context of overall health care providers. It would allow systematic cooperation among health, educational, and social welfare sectors since ASD care encompasses the health care sector, inclusive education, professional training, and provision of social support services. Moreover, national policy assistance may enable working out international collaborations to perform technical assistance, funding, and capacity building.

In addition to structural and systemic factors, one should consider the effectiveness of cultural change as the factor that allows diagnosing ASD earlier. In Pakistan rural areas, disability is understood through multi-dimensional dynamics of religion, conventional values, and societal expectations. Lack of understanding of the causes behind developmental differences can make individuals deny, experience stigma and social isolation of the affected families through misconceptions such as spiritual punishment, negligence on the part of parents, and supernatural reasons. Engagement campaigns can start changing these perceptions, especially the ones using the authority of the local community members and familiar stories (Avan, 2015). Nevertheless, change of culture is a gradual process and no one can quickly expect it to change. Thus, the work of promoting awareness needs to be carried out on the long-term road that would be supported with the presence of the consistent messages and the obvious changes of the availability of the services. Along with the above consideration, another important consideration that comes out in the analysis is the critical research gap; that is, scanty Pakistan-specific; rural data on ASD. The majority of available evidence is either found by extrapolating on the urban populations or by using international studies that lack relevance in terms of the cultural applicability. Such a disparity weakens the capability to develop strategies that are in fact evidence based and context sensitive. As an example, it is hardly possible to define the scope of required resources, establish realistic goals, and observe progress properly without stable prevalence rates in rural areas. It is necessary to implant and carry out epidemiological as well as implementation research in the locale. It is also possible that such a study may investigate the efficacy and acceptability of certain measures, including LHW-led screening, or telehealth-based consultations in Pakistani rural environments.

Besides, the creation of local evidence would lead to successful advocacy. When accurate data is provided to policymakers illustrating the extent of a problem, the reasonableness of a proposed solution and the possible payback in terms of improved developmental outcomes on one hand and lowered social costs in the longer-term on the other, there is a greater chance of resources being allocated to address the problem. Such evidence may be yielded by research collaborations among non-governmental organizations, universities and government agencies. Efficient enhancement of early diagnosis of ASD in rural Pakistan will rely on an integrated plan that combines community outreach and reinforcement of primary care and policy changes. The empowerment of LHWs is one of the easily implementable measures as it will allow task-shifting that will take advantage of the existing human resources and increase screening coverage. This should be backed up with a strengthened primary healthcare system that has credible referral pathways that are complemented by the introduction of telehealth in attempts to cover the geographical difference in the availability of specialists. Public accountability: At the policy-making level, to enshrine these changes, institutionalize the engine of long-term funds, and ensure that the system is accountable requires a National Autism Strategy. Although the cultural change is a gradual process, it can be boosted by a long-term campaign of raising awareness, and the success of all initiatives will eventually rely on the production of evidence that is strong and Pakistan-specific. Such an evidence-based and comprehensive strategy is the only way to dismiss the long-standing obstacles to the early diagnosis of ASD in rural Pakistan and open the door to the better health outcomes of the affected children and families.

Conclusion

The experience of a Pakistani child with Autism Spectrum Disorder could now be described with the greatest degree of disadvantage; one that is characterized by a quiet war against the wall of ignorance, stigma, broken systems. That early intervention critical window time, which is the gate to a more promising future is most often not obtained because of the lack of awareness, resources, and the available expertise.

This issue is, nevertheless, not insolvable, although it is too colossal. The way ahead is through a multiple level fabric that can turn the community health workers into active developmental screeners, focus the screening as part of primary healthcare system and the use of technology to reduce the distance between the rural communities and the specialized knowledge. Such efforts should be spearheaded by the strong national policies that reform medical education, implements clear and funded pathways of care, and is readily committed to making diagnosis and care a right, rather than a privilege.

It is the bigger and also much needed goal to be able to create a system which would be able to identify ASD at the earliest stage in all the parts of Pakistan. It is an investment in human potential of a country and an indicator of the society committed to social justice. The transition, in Pakistan and elsewhere, between a passive waiting model and an active, community-based model of identification will mean transforming the lives of thousands of children and families, and moving beyond a future of marginalization to a new one of possibility, awareness and support.

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