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Review of caregiving practices in BRICS countries in context of Autism Spectrum Disorder

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Abstract

Brazil, Russia, India, China and South Africa (BRICS) are all developing nations whose landscapes are changing and economies are witnessing growth and progress. However, these nations abound with certain challenges, with creating impactful changes in the area of disability being one. Literature has emphasised the difficulties that individuals with disability are confronted with. These can be expected to become exacerbated when systems of support are not equipped enough to handle the multitude of challenges that may arise when the complexity of disability is not understood in all its shades. Moreover, it becomes evident through the lens of the family systems theory that the impact of disability is not restricted to the individual. Rather, the effects permeate the lives of family members and caregivers. Researchers in the field of psychology have attempted to understand these challenges that caregivers of children and adolescents with developmental disabilities such as Autism Spectrum Disorder are faced with. While these adversities remain, they are likely to become exacerbated by very real factors including the disproportionate distribution of resources, gap in creating robust support systems, limited focus on well-being of caregivers, paucity of healthcare facilities and widespread effects of the global coronavirus pandemic. The current review aims to examine the ambit of these risks, which appears to be wide for a community of individuals who are marginalized in several ways. Alongside, an attempt has been made to capture the lived experiences of caregivers bringing up a child diagnosed with Autism Spectrum Disorder, as they navigate through the process of caregiving. This review brings forth significant findings from existing literature and explores ways in which these challenges can be combated to create safer spaces.

Keywords: autism spectrum disorder, developmental disability, developing nations, caregivers

Introduction:

BRICS nations are identified as developing countries that hold significant potential for the future as major economies. However, akin to any other developing country, these nations too are faced with their own unique challenges. While some of these challenges continue to persist, some have at least partially been ameliorated. For instance, in an article entitled ‘Children in India’, reduction in the prevalence of poverty as well as the infant mortality rate has been described (UNICEF). However, it has also been highlighted that certain conditions remain as vulnerabilities for the children of the nation, ranging from concerns around lack of proper nutrition and prevalence of diseases, education related gaps to continued involvement of children in labour work (UNICEF). The article additionally notes that these vulnerabilities percolate into adolescence, and are especially true for adolescent females (UNICEF).

The developing years of children have major implications for their life ahead. These years are marked with important experiences across different areas of their lives ranging from socialisation experiences, systems of support, school adjustment and experiences within the peer group etc. Having high social support, healthy peer relations and positive school experiences can be expected to foster healthier development. Although there may be experiences which hamper healthy development which cannot be undermined, these seem to be exacerbated for a child living with developmental disabilities. Moreover, for an individual in the adolescence stage, these challenges can prove to be very demanding. Given that the challenges accompanying the phase of adolescence are standalone immense, it would be rational to assume that these may further get strengthened for those living with developmental challenges. The demands of their condition coupled with the expected stage related demands are likely to only increase the experienced strain; even more so for those with high support needs. When their needs are not met, it puts them at a disadvantage in comparison to their peers, especially when the right support systems and mechanisms are not in place. For instance, one may consider that the importance of one's peer group in this stage of development is nearly a well-established fact. Researchers have indicated as to how adolescents living with disability may be at a disadvantage in this critical area. For example, in a narrative review entitled 'Adolescents with Disabilities', it has been highlighted that adolescents may face challenges in friendship formation. Challenges associated with their disability may also put them at greater risk for becoming victims of bullying. The same could be attributed to factors associated with their disability, such as owing to deficits in the social domain of functioning. The same also poses the threat of lowered self- esteem. However, researchers also shared that when the right support systems are in place, such as the family and the school support mechanisms, better outcomes can be expected (Maxey et al, 2017).

It is also imperative to note how the nature of the disability may have a unique impact on the individual and thus it would not be justified to categorize all individuals into one homogenous group. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5-Text Revision, 2022), for instance, has placed a group of conditions under a broad umbrella term of 'neurodevelopmental disorders'. These disorders are characterized as a group of conditions with their onset rooted in the early developmental period. The term 'neuro' relates to the differences in the brain processes associated with the condition, while the term 'developmental' signifies the period of onset as being the early developmental years for the child. The manual also highlights the specific challenges associated with these conditions. For instance, a child with Intellectual Disability is likely to face difficulties across different areas of functioning such as the conceptual, practical and the social domain; whereas a child with Autism Spectrum Disorder is likely to face difficulties in the areas of social interaction and social communication and may also have certain sensory challenges (DSM-5-TR, 2022). Given these differences in functioning across areas, it would be reasonable to expect a variation in the nature of the experienced challenges that puts them at a disadvantage when compared to their typically developing peers.

From a legal and awareness standpoint, developing nations indeed seem to have progressed. For instance, in India, the Rights of Persons with Disability Act (2016) is one such testament in this regard. The act has brought to light the responsibility entrusted with the government to uphold the rights of persons with disabilities. It has also recognized twenty-one disabilities which include certain neurodevelopmental disabilities such as intellectual and learning disabilities as well as the autism spectrum disorder (The Rights of Persons with Disability Act, 2016). The rights of persons with disabilities have also been specified through the act and include, but are not limited to, the right to reside in the community, protection from abuse and violence, access to justice etc. The act also seems to serve as a bridge towards creating a more inclusive society through recognition of the role of educational institutions, need for skill training and schemes for vocational provisions and space for employment. India seems to be adopting the principles of the social model of disability, whereby the role of individuals in creating a just society is acknowledged. However, some of these barriers continue to persist. The Central Board of Secondary Education (India) describes in the Accessibility Code for Educational Institutions (2021) that inclusion does not solely refer to infrastructural changes, it also includes the attitudes of acceptance and inclusion. Therefore, there is still a long way to go, especially where the disabilities are more 'hidden' in nature, such as in the case of learning disabilities. Another example of movement is witnessed through the example of Russia. Russia, in the year 2012 ratified the United Nations Convention on the Rights of Persons with Disabilities. The same is a step towards assuming greater responsibility towards the cause. Given that BRICS nations are developing countries, it is important to direct efforts toward designing interventions to support children and adolescents, for early identification and early intervention. Furthermore, interventions at the tertiary level alone are not sufficient, there is a need for preventive and promotive programs as well as scaling interventions at the secondary level. However, prior to the same, it is important to understand the areas where intervention may be required. This review is an attempt to map few such areas.

Literature Review:

Past literature from across different countries has extensively covered the impact that disability has on children. Research has shown that children with disabilities receive less social support and that their participation in activities, such as in the community is also thereby limited (Bedell et al., 2013). The researchers also brought to light that environmental factors were seen as barriers by parents, such as gaps in resources like adequate provision of services. An attempt to understand the impact of socio-economic factors on individuals with Autism Spectrum Disorder in Delhi and Jaipur highlighted gaps in resource access. These gaps ranged from those in education, vocation and diagnostic services. Lack of awareness around the condition was also noted which has implications for seeking the right kind of interventions. The social stigma associated with the condition is still prevalent and the authors shared that there may be a need for greater involvement at the macro level (Harman, 2014). Another important issue highlighted was that the needs of children with different disabilities may be varied. The needs of a child with cerebral palsy, for example, cannot be equated with the needs of those on the spectrum; and special educators may not be trained enough to deal with the nuances of the autism spectrum (Harman, 2014). Furthermore, the challenge of inclusion in the mainstream has also been noted owing to issues centred around negative attitudes around disability-of teachers, peers as well as parents; and gaps in adequate human and material resources. The danger of poverty may push individuals to the limit of dropping out of school. Furthermore, researchers have highlighted that parents and teachers may not be able to make an accurate estimation of the ability of the student with differing needs, which further compounds the concern (Singh, 2016).

Neill et al (2020) in their review brought together works of researchers like Cortiella et al (2014) who have highlighted that for children with learning disabilities, the difficulties in learning and executive functioning affect not just their academic performance but also have implications for behavior and socio-emotional well-being. The researchers additionally highlighted that owing to associated behavioral difficulties, individuals may be subjected to exclusionary disciplinary action and thus may not get the required access to intervention. Neill et al (2020) also highlight that post-school transition may be challenging for adolescents with learning disabilities owing to academic difficulties as well as difficulties in social relationships. However, the researchers also posit that these challenges need not necessarily limit the adolescents if the right kind of intervention is in place. Singh and Balamurugan (2014) highlighted through their study with adolescents and young adults that a need for greater attention and facilities to cope with their difficulties was desired. The survey study suggested that certain external factors may be attributed to the condition such as lack of nutritional intake, which may impact growth and processing of brain functions. The researchers suggested that the family may have a role to play in the prevention of the condition as well its management. The need for the right kind of support was also indicated.

Another line of research has focused on the impact of neurodevelopmental disabilities on parents. Research has indicated that this impact may be seen in the form of increased stress and anxiety, frustration, feeling of loneliness as well as feeling the loss of the ‘dream child’ (Patel et al, 2010). Lee et al (2008) have also demonstrated a lowered quality of life for parents raising a child diagnosed with a neurodevelopmental disorder. The impact on parents’ levels of resilience and optimism has also been documented by Katrak et al (2021), with parents raising children with neurodevelopmental disorders displaying lower levels of optimism and resilience. While parenting has been termed as a fulfilling experience by many, this line of research highlights the impact of perceiving the ‘loss’ of the ‘dream child’. Qualitative research studies have highlighted experiences of both resiliency and vulnerability. For instance, Kermanshahi et al (2009) have described the experience as being akin to a pendulum swinging between two polarities of positive and negative feelings. Budak (2018) highlighted that mothers were concerned about the future of their child and also experienced changes in their family and social relationships.

In the Indian context, Gupta and Kaur (2010) indicated higher levels of stress associated with parenting a child with special needs. Gupta et al (2012), highlighted that the stress was also a by-product of the lack of support received from extended family members in raising the child. The same can also be interpreted in light of the stigma associated with conditions around which information and awareness is largely limited in our context. Jaiswal et al (2018) also indicated that parents may occasionally resort to unhealthy coping mechanisms such as escape-avoidance which was also linked to manifestation of psychopathology. Kaur et al (2019) indicated greater levels of anxiety in parents due to concern about the child's future and lack of support from the community members. The study on the impact on parents in the context of parenting a child diagnosed with a neurodevelopmental disorders is rather extensive.

1. Rationale of the Study:

The way disability is understood is changing over time. Literature and practice in the area of disability are witnessing movement towards inclusion. This can be seen in several forms such as through recognition of 'neurodivergence' and 'neurodiversity', in order to understand the unique wiring of individuals. However, change usually is a slow process and full inclusion, in certain respects, currently seems distant. Given this context, more research is needed to understand the complexities associated with neurodevelopmental disorders. This review is an attempt at integration of the work carried out in the area of understanding Autism Spectrum Disorder, in particular, to map the experiences of caregivers who are faced with several challenges. The paper is written in an attempt to bring out personal experiences of caregivers and any other associated structural inequities or challenges. Through the same, an attempt is made to highlight the areas where change is desired and can prove to be supportive for caregivers. In context of the family systems theory, it seems safe to assume that a positive change of such nature in one part of the system would have a positive reciprocal influence on individuals living with the condition. The review also attempts to make gentle explorations around changes that can be brought about in this area. Only once the condition and challenges are understood, can focused supportive work be carried out.

2. Research Questions:

The following review paper has been conceptualised based on the following research questions:

a. Where do BRICS nations stand currently with respect to the area of disability and creating a more inclusive society?
b. Are there any challenges that BRICS nations face with respect to progress in the area of disability, inclusion and rehabilitation?
c. What are the unique challenges facing the caregivers of children and adolescents with Autism Spectrum Disorder in BRICS nations?
d. What are some of the interventions that could serve as a source of strength and support for families bringing up a child with Autism Spectrum Disorder, in BRICS nations?
e. Can technological advancement play a role in the design and delivery of interventions?

3. Operational definitions:

The following section describes the key terms and words surfacing through the research paper:

a. Developmental Disability: Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behaviour areas (Centers for Disease Control and Prevention).

b. Autism Spectrum Disorder: Autism Spectrum Disorder is a neurodevelopmental disorder securing place in diagnostic classifications such as the Diagnostic and Statistical Manual of Mental Disorders (fifth edition). The condition is marked with difficulties in social communication and interaction, repetitive behaviours and interests (Centers for Disease Control and Prevention) and sensory concerns (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition).

c. **BRICS:** BRICS stands for Brazil, Russia, India, China & South Africa; referring to the major emerging economies from the world.

d. **Caregiver:** An individual who assumes the responsibility of providing assistance or taking care of the needs of another individual who may not be able to do so independently. This may include, for example, an individual living with an illness. In the context of health care, the same could signify an individual involved in the process of identification, prevention or treatment of an illness or disability.

4. Research Methodology:

6.1 Research Objectives:

The following research objectives were formulated and derived from the broader research questions:

i. To describe the experiences of caregivers of children and adolescents with Autism Spectrum Disorder residing in BRICS nations.
ii. To identify the major challenges confronting caregivers of children and adolescents with Autism Spectrum Disorder residing in BRICS nations.
iii. To suggest focused interventional strategies for better management of challenges faced by caregivers of children and adolescents with Autism Spectrum Disorder residing in BRICS nations.

6.2 Search Strategy:

Literature search was carried out using Google Scholar and PubMed database. An electronic based research strategy was used to attain research papers available in the public domain. Research carried out in BRICS nations was looked at exclusively. Certain website articles and data were also reviewed. All the identified resources were in the English language. Research paper titeles/abstracts were screened on the basis of their exploration of experiences of caregivers raising a child or adolescent with Autism Spectrum Disorder. Given the vast extant of literature, all studies in the area could not be included. Inclusion and exclusion criteria were pre-decided to ascertain the consideration of research articles for the current review. The studies under consideration followed different methodologies including both quantitative and qualitative approaches. Based on review of the abstracts, articles not relevant to understanding the experiences of caregivers were excluded as were those not pertaining to those raising a child or adolescent with Autism Spectrum Disorder. Studies not carried out in BRICS nations were also excluded.

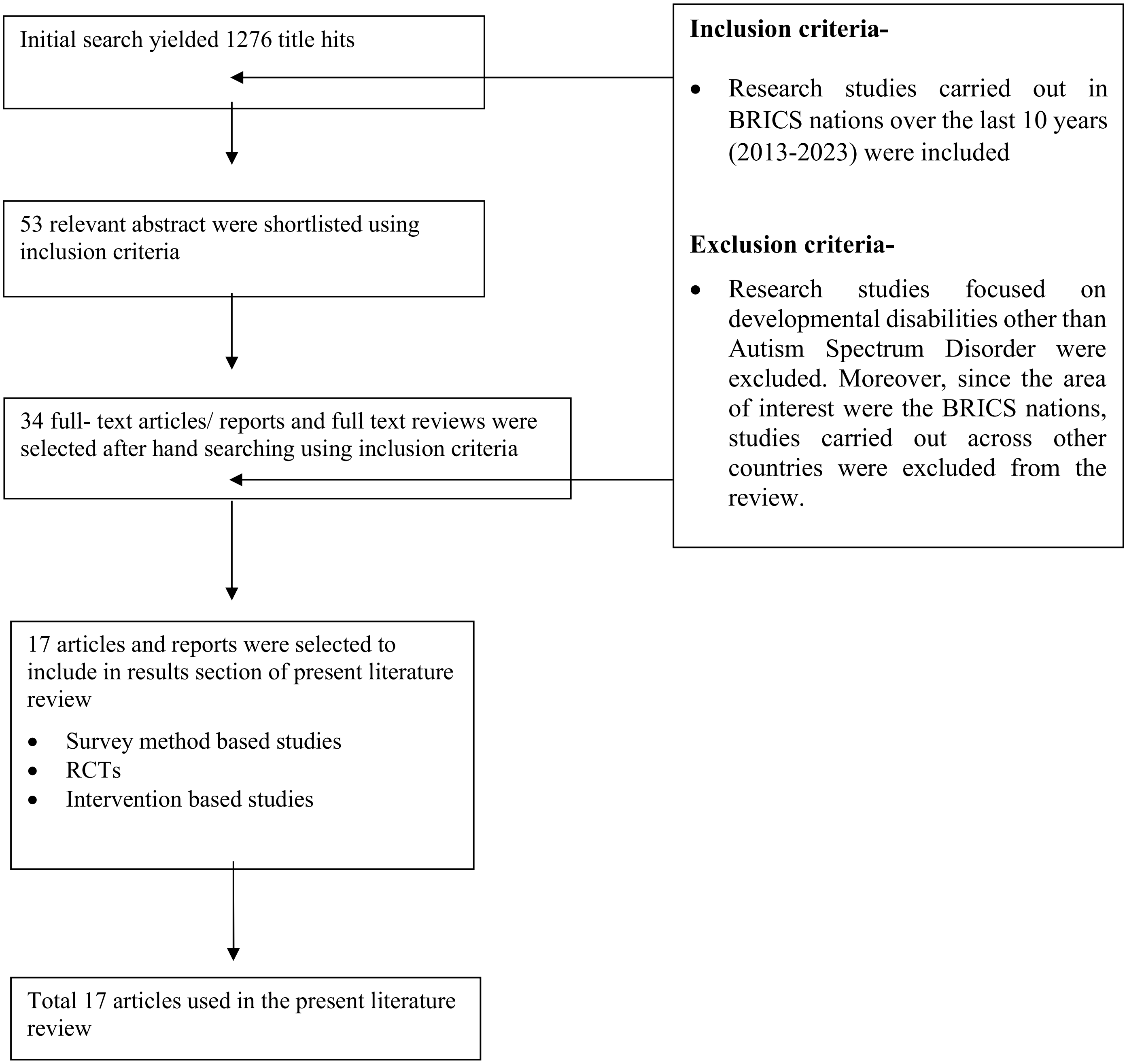
6.3 Inclusion & Exclusion Criteria:

Research studies carried out in BRICS nations over the last 10 years (2013-2023) were included while those carried out prior to 2013 were excluded from the current review. The primary area of focus was the experiences of caregivers raising a child or adolescent with Autism Spectrum Disorder. Keeping in view the objectives of the current study, research studies focused on developmental disabilities other than Autism Spectrum Disorder were excluded. Moreover, since the area of interest were the BRICS nations, studies carried out across other countries were excluded from the review.

6.4 Schematic Diagram of the Studies Reviewed:

The following figure represents a schematic diagram highlighting the process adopted for selection of the research papers:

Figure. Flow chart of search strategy



Initial search yielded 1276 title hits

53 relevant abstract were shortlisted using inclusion criteria

34 full- text articles/ reports and full text reviews were selected after hand searching using inclusion criteria

17 articles and reports were selected to include in results section of present literature review

- Survey method based studies
- RCTs
- Intervention based studies

Total 17 articles used in the present literature review

Inclusion criteria-

- Research studies carried out in BRICS nations over the last 10 years (2013-2023) were included

Exclusion criteria-

- Research studies focused on developmental disabilities other than Autism Spectrum Disorder were excluded. Moreover, since the area of interest were the BRICS nations, studies carried out across other countries were excluded from the review.

Results:

The following table depicts the papers considered for final review:

S.No.	Title of the Paper	Authors	Name of the Journal, Year of Publication & Volume	Methodology	Study Outcome
1.	Stress and coping styles in mothers of children with Autism Spectrum Disorder	Nivedhitha Selvakumar, Anuja S. Panicker	Indian Journal of Psychological Medicine, 2020	Quantitative, correlational research	Affected quality of life including symptoms of depression, stress and anxiety symptoms. Adoption of positive coping styles.
2.	Burden of care perceived by the principal caregivers of autistic children and adolescents visiting health facilities in Lucknow city	Jain et al	Indian Journal of Public Health, 2019	Cross-sectional study	The process of caregiving can be demanding, with effects on areas such as caregiver's own routine.
3.	Challenges of the caregivers in managing a child with Autism Spectrum Disorder— A qualitative analysis	Tathgur & Kang	Indian Journal of Psychological Medicine, 2021	Qualitative research; in-depth interviews	The process of caregiving is associated with several challenges such as impact on their own well-being
4.	The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder	Desai et al	Transcultural Psychiatry, 2012	Qualitative research; interviews	Parental experiences could be classified into separate phases with their own defining features
5.	Quality of life of caregivers of autistic children and adolescents	Jain et al	Indian Journal of Community	Cross-sectional study	Different factors determine the quality of life of

	visiting health facilities in Lucknow city, Uttar Pradesh, India: A cross-sectional study		Medicine, 2019		parents, including factors such as knowledge regarding the condition and the family structure.
6.	Family quality of life of South African families raising children with Autism Spectrum Disorder	Schlebusch et al	Journal of Autism and Developmental Disorders	Survey Research Design	Effects on emotional well-being were indicated. Quality of life was influenced by several factors such as income and family structure.
7.	Parents' Voices: experiences and coping as a parent of a child with autism spectrum disorder	Reddy, Fewster & Gurayah	South African Journal of Occupational Therapy, 2019	Qualitative research study, interviews.	Challenges of parents were reported such as gaps in resources, unsatisfactory professional guidance, lack of awareness, stigma etc. and adopted different ways which facilitated the process of coping.
8.	Experiences of father carers of children with Autism Spectrum Disorder: An exploratory study	Pottas & Pedro	Journal of Psychology in Africa, 2016	Qualitative, exploratory study employing interviews.	Themes highlighted challenges such as access to resources, difficulties in relationships, difficulty meeting career-related demands etc.
9.	Fathering a Child with Autism Spectrum Disorder: An Interpretative Phenomenological Analysis	Martins, Walker & Fouche	Indo-Pacific Journal of Phenomenology, 2013	Multiple, single case-study design	Revealed the experience of different emotions; with a higher frequency of difficult emotions. Challenges such as those on the social lives were highlighted. Moreover, fathers

					adopted different ways of coping.
10.	Caring for Children Diagnosed with Autism Spectrum Disorder: Caregivers' Experiences	Mazibuko, Shilubane & Manganye	Africa Journal of Nursing and Midwifery, 2020	Qualitative study, interviews	A number of challenges were reported which ranged from increased stress, financial strain, resource gaps etc.
11.	The resilience of parents who have children with autism spectrum disorder in China: a social culture perspective	Zhao & Fu	International Journal of Developmental Disabilities, 2022	Qualitative study, interviews	Resilience in parents developed through multiple factors such as acceptance of the condition, the process of caregiving and social support.
12.	A qualitative study on the experience of stigma for Chinese parents of children with autism spectrum disorder	Catalina Sau Man Ng & Sally Sui Ling Ng	Scientific Reports, 2022	In-depth interviews, qualitative study	The study highlighted that stigma permeates in several, different ways.
13.	Parenting stress in Chinese mothers of children with autism spectrum disorders	Wang et al	Social Psychiatry and Psychiatric Epidemiology, 2013	Cross-sectional study design	Higher stress was reported. Several factors were explored in the current study ranging from behavioural symptoms of the child as well as financial support being provided by the government.
14.	Social support and family functioning in Chinese families of children with Autism Spectrum Disorder	Lei & Kantor	International Journal of Environmental Research and Public Health, 2021	Cross-sectional survey design	The study highlighted the importance of social support for families with a child diagnosed with autism spectrum disorder

15.	Experiences of family members of children diagnosed with autism spectrum disorder	Magalhãesa et al	Revista gaucha de enfermagem, 2021	Qualitative study, interviews	The study highlighted the experience of different emotions; adapting to changes such as those needed in the routine. Furthermore, the study highlighted the need for support for the family.
16.	Profile of service use and barriers to access to care among Brazilian children and adolescents with Autism Spectrum Disorders	Araripe et al	Brain Sciences, 2022	Cross-sectional study, adopted survey method	Highlighted challenges associated with access to quality care. The study looked at the same in context of socio-demographic factors.
17.	Burden of mothers of children diagnosed with autism spectrum disorder: mixed method study	Vilanova et al	Revista gaucha de enfermagem, 2022	Mixed-method study	Burden of care felt by mothers raising children on the spectrum.

Discussion:

The process of parenting is a rather complex process which warrants no single definition. Moreover, the experience of bringing up a child with a developmental disability further compounds this complexity. The nature of the challenges caregivers are confronted with can be expected to change shape and form as a child grows and transits from one stage to the next. Moreover, the movement through the grief cycle also captures the experience of caregivers. This movement too does not seem to be linear and is much more complex than what any terminology can capture. Research carried out in BRICS nations has highlighted the experience of caregivers bringing up children with Autism Spectrum Disorder which has been explored through the current review. Largely it has been highlighted that the experience of caregiving is sought with a number of emotions and challenges. These have ranged from experiencing stress and strain, difficulty in balancing demands of work, adjustment to newer roles and experiencing symptoms of anxiety and depression. Moreover, the felt burden of care has also been reported. To accommodate the needs and demands of a child or adolescent with the condition, in a certain way implies the need to bring a shift or change in one's own routine, which again seems to become an area for adjustment for the caregiver. The process of caregiving has been shown to have implications not just for the emotional well-being and quality of life of the individual caregiver, but also for the spousal marital relationship and other social relationships.

It is important and hopeful to witness through the research, the way in which caregivers cope and the several factors that influence the impact of these challenges. Researchers have shown, for instance, that knowledge of the condition, acceptance of the condition and social support are all factors that can influence the experience of caregivers. The same has implications for practitioners and those willing to design supportive interventions. Empowering parents through reliable dissemination of information and psychoeducation could be one such step. A second could be to help parents move through the grief cycle such that they can move towards acceptance. Increasing systems of social support can also be another empowering step. Research has also highlighted that parents use different ways of coping, including positive coping strategies. Enabling parents towards more mindful use of these strategies can perhaps prove to be helpful, as can support amongst parents. Some of these strategies can also be tested for their efficacy with individual families to enable focus on emotional well-being and respite of caregivers. Another significant area highlighted through the research has been that of structural challenges and limitations. Largely, this has taken the form of gap in provision of resources and access to good quality care and information. The inequities seem to be further perpetuated by the income and economic inequities existing in developing countries such as the BRICS nations. Stigma too seems to permeate through these societies which can be internalised by families as well. The same also calls for change at the macro level. To combat these challenges, while work at the governmental and macro level seems essential, it appears that work is also required at more informal levels and grassroot levels. Given the gaps in services and trained manpower, empowerment at the beginning, at the community level itself seems imperative. Moreover, it is also important to note that greater and steady work is towards providing family interventions may be the need of the hour. While it is essential to take care of the needs of the child and adolescent through interventions, it seems equally important to take care of the needs of the caregivers. If caregivers are burnt out through the process of caregiving, it can be assumed that the effects are going to permeate through the other subsystems in the family, be it the child or other relational systems. The same is especially true when seen through the lens of the family systems theory.

Lastly, as we are currently living in a technology-driven world, in the era where changes are rapidly taking place with the advent of chatbots such as ChatGPT

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