

Research Paper



A theoretical synthesis paper on: impact on parents having a child with autism spectrum disorder

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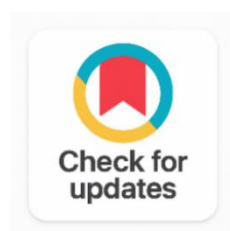
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ABSTRACT

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that has sparked extensive research and theoretical exploration over the decades. This paper synthesizes history and prominent theories underlying the etiology and characteristics of ASD, including the Theory of Mind (ToM), the Executive Dysfunction Theory, the Weak Central Coherence Theory, and the Enhanced Perceptual Functioning Model. By integrating insights from psychological, biological, and social perspectives, the paper aims to provide a comprehensive understanding of ASD's multifaceted nature. Additionally, implications for intervention and future research are discussed. Qualitative, quantitative and mixed methods are used to identify the result of studies. Additionally, the research studies are based on models of theories and concept and history related to ASD. There are number of research done in impacts on parents having child with Autism Spectrum Disorder based on different models. Some are theory based and some are concept based. Though there are multiple researches are obtained on impacts on parents having child with ASD, the studies are lack to identify the impacts on parents having child with ASD in Nepal. Despite significant advances in the study of ASD, its etiology and mechanisms remain only partially understood. Over the years, various theories have emerged to explain different aspects of the disorder. This synthesis paper examines these theories to present a holistic understanding ASD and highlight areas for further exploration.

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1. INTRODUCTION

The earliest descriptions of behaviors now associated with autism can be traced back to historical texts. However, autism as a distinct clinical condition was first identified in the 20th century. The term “autism” was introduced in 1911 by Swiss psychiatrist Eugen Bleuler, who used it to describe a symptom of schizophrenia involving extreme social withdrawal [1]. Although his interpretation differs from modern understanding, it marked the inception of the term’s use in psychiatry. Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent deficits in social communication and interaction, as well as restricted, repetitive patterns of behavior, interests, or activities [2]. The term “spectrum” denotes the wide range of symptoms and severity levels, which vary significantly among individuals—from those requiring substantial support to those who are highly functional and independent. Globally, the prevalence of ASD has increased significantly over the past few decades. Recent estimates indicate that approximately 1 in 36 children are identified with ASD [3]. Although the precise causes remain elusive, current research points to a multifactorial origin involving genetic, neurobiological, and environmental influences [4]. Improvements in diagnostic criteria and growing awareness have contributed to earlier detection and intervention, which are essential for optimizing long-term developmental outcomes. ASD affects individuals of all racial, ethnic, and socioeconomic backgrounds. Nonetheless, disparities in diagnosis and access to services remain a critical concern. Movements such as neurodiversity and global autism advocacy have increasingly emphasized the recognition of autism as a natural variation of human development, advocating for greater inclusion, acceptance, and support for individuals on the spectrum and their families [5]. In the context of Nepal, the 2021 National Census reported 4,886 individuals with autism among a surveyed population of 647,744, representing approximately 0.8% of the sample [6]. However, this figure likely underrepresents the actual prevalence due to diagnostic limitations and low public awareness. According to Autism Care Nepal, there may be as many as 300,000 children living with autism in the country [7].

Objective of the Study

The primary objective of this paper is to critically review and synthesize existing concepts, theories, models, and research methodologies related to childhood autism spectrum disorder and its impacts on parents. A key aim is to identify existing research gaps and guide future investigations in this field.

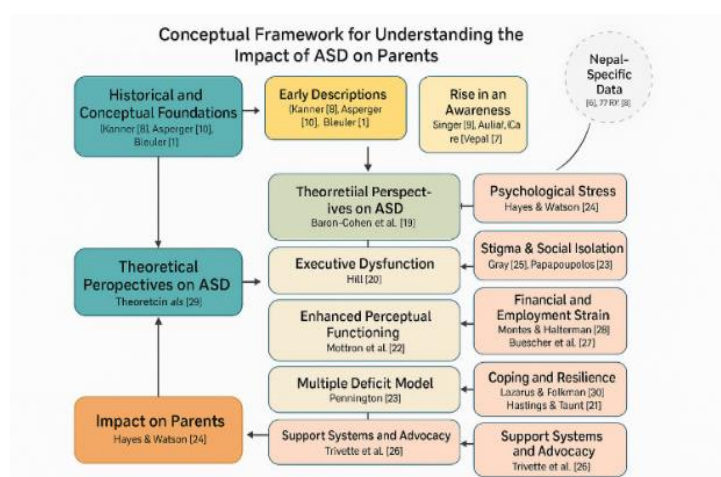


Figure 1. Conceptual Framework for Understanding the Impact of ASD on Parents

Figure 1 depicts the Conceptual Framework for Understanding the Impact of ASD on Parents. The conceptual flowchart of this synthesis paper illustrates the structured process undertaken in this study. It begins with the identification of relevant literature from various sources, including academic databases, books, and institutional reports. This input phase is followed by a systematic screening process based on predefined inclusion and exclusion criteria. The selected literature is then subjected to thematic analysis, through which key themes related to the historical evolution of Autism Spectrum Disorder (ASD), theoretical frameworks, and the impact of ASD on parents are extracted and synthesized. Finally, the output of this process is a comprehensive narrative that integrates historical context, theoretical perspectives, and parental experiences, providing a holistic understanding of the topic.

2. RELATED WORK

The earliest descriptions of behaviors now recognized as autism date back to historical texts, but autism as a distinct clinical condition was first identified in the 20th century, with Swiss psychiatrist Eugen Bleuler introducing the term “autism” in 1911 to describe a symptom of schizophrenia involving social withdrawal [1]. Autism Spectrum Disorder (ASD) is currently understood as a complex neurodevelopmental disorder characterized by persistent deficits in social communication and interaction, alongside restricted and repetitive behaviors, with wide variability in severity and functional abilities [2]. Globally, the prevalence of ASD has increased notably, with recent estimates indicating that approximately 1 in 36 children are diagnosed with the disorder [3].

Although the exact causes remain unclear, research supports a multifactorial origin involving genetic, neurobiological, and environmental factors [4]. Improvements in diagnostic criteria and increased awareness have contributed to earlier identification and intervention, which are critical for better outcomes. Despite affecting individuals across all backgrounds, disparities in diagnosis and service access persist, while neurodiversity movements advocate for autism as a natural human variation requiring acceptance and support [5]. In Nepal, official census data report a prevalence of about 0.8% among the surveyed population, but this likely underestimates the true prevalence due to diagnostic challenges and low awareness. Estimates from Autism Care Nepal suggest there may be as many as 300,000 children with autism in the country, highlighting significant gaps in recognition and resources [6], [7].

Although these studies contribute valuable knowledge, few offer an integrative synthesis combining historical, theoretical, and parental impact perspectives. This narrative review bridges that gap by thematically consolidating literature across time, theory, and family experience.

3. METHODOLOGY

Research Design

This study employs a narrative review approach to synthesize existing literature on the history, theories of Autism Spectrum Disorder (ASD), and its impact on parents. A narrative review was chosen to provide a comprehensive and integrative understanding of the evolution of ASD conceptualization, theoretical frameworks, and parental experiences.

Data Sources and Search Strategy

A systematic search of peer-reviewed articles, books, and authoritative reports was conducted using academic databases, including:

1. PubMed
2. PsycINFO
3. Google Scholar
4. Scopus
5. Web of Science

Keywords and Boolean Operators Used

1. "Autism Spectrum Disorder" OR "ASD"
2. "History of Autism" OR "Evolution of Autism Diagnosis"

3. "Theories of Autism" OR "Conceptual Frameworks of ASD"
4. "Parental impact of ASD" OR "Caregiver burden of Autism"
5. "Psychosocial effects of ASD on parents" OR "Parental stress and coping in Autism"

Additional sources, such as policy documents, institutional reports, and reference lists of key articles, were reviewed to ensure a comprehensive collection of relevant literature.

Inclusion and Exclusion Criteria

Inclusion Criteria

1. Peer-reviewed articles, books, and credible reports published in English.
2. Studies focusing on the historical development of ASD.
3. Literature discussing theoretical perspectives on ASD.
4. Research examining the impact of ASD on parents, including psychological, emotional, social, and financial aspects.
5. Publications from the 20th century onward to reflect the evolution of ASD conceptualization.

Exclusion Criteria

1. Articles not available in full-text.
2. Non-peer-reviewed sources with limited scientific credibility.
3. Studies focusing solely on interventions without discussing broader historical or theoretical perspectives.
4. Research focusing exclusively on children with ASD without parental impact analysis.

Data Extraction and Analysis

Relevant data were extracted, synthesized, and thematically analyzed to identify key themes related to:

1. The historical progression of ASD conceptualization.
2. Major theoretical frameworks used in ASD research.
3. The impact of ASD on parents across psychological, emotional, and social dimensions.

The findings were organized to present a chronological and thematic synthesis, highlighting shifts in scientific understanding and societal perspectives on ASD and parental experiences.

Limitations

As a narrative review, this study does not employ systematic meta-analysis or statistical synthesis. Findings are based on available literature, which may introduce publication bias or result in gaps in underrepresented areas of ASD research.

Method

This study utilized a secondary data analysis method. It aimed to summarize and synthesize existing literature on theories and models related to Autism Spectrum Disorder (ASD) and its impacts on parents raising children with ASD. The research reviewed peer-reviewed journal articles, books, and reports to extract major themes and key findings. The paper focused on a qualitative review approach, incorporating interpretive insights into the construction and concepts from existing studies, with particular attention to identifying research gaps and methodological strengths.

4. RESULTS AND DISCUSSION

A. Conceptual and Historical Review on ASD

1. Leo Kanner's Pioneering Work

In 1943, Leo Kanner first identified autism as a distinct clinical condition, describing 11 children with "autistic disturbances of affective contact" [8]. He observed hallmark features such as impaired social interaction, insistence on sameness, and language delays. Initially, Kanner speculated that emotionally

distant parenting might contribute to the disorder a notion that evolved into the now-debunked "refrigerator mother" theory [9].

2. Hans Asperger and Asperger Syndrome

Around the same time, Hans Asperger described children exhibiting autistic traits alongside intact language and cognitive functioning [10]. His work, published in 1944, remained largely unknown outside German-speaking countries until the 1980s when Lorna Wing introduced the term "Asperger Syndrome," later incorporated into DSM-IV [11].

3. Evolution of Diagnostic Criteria

The understanding and classification of autism have progressed significantly through successive editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM):

1. **DSM-III (1980):** Introduced the term "Infantile Autism" [12].
2. **DSM-IV (1994):** Recognized subtypes such as Asperger Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).
3. **DSM-5 (2013):** Consolidated all subtypes under the umbrella diagnosis of "Autism Spectrum Disorder" [13].

ASD is currently recognized as a spectrum of neurodevelopmental conditions marked by challenges in social communication, restricted interests, and repetitive behaviors. The Centers for Disease Control and Prevention (CDC) reports that approximately 1 in 44 children in the U.S. are diagnosed with ASD, reflecting growing awareness and improved diagnostic practices [14].

B. History of ASD in Nepal

In Nepal, awareness and recognition of autism lagged behind global trends until the 2000s. A significant milestone occurred in 2008 with the establishment of the Autism Care Nepal Society (ACNS) by a group of concerned parents [15]. That year, only 11 children were officially diagnosed with ASD, but by 2022, this number had increased to over 300—largely due to better awareness and diagnostic tools rather than an actual rise in prevalence [16].

A 2018 retrospective study analyzing data from 2010 to 2015 found that the average age of diagnosis was 58 months, with 76% of cases being male. Most diagnosed children resided in urban areas, especially Kathmandu [17]. Despite progress, significant challenges persist. Advocacy groups estimate that up to 300,000 individuals in Nepal may be living with autism, underscoring widespread underdiagnosis, particularly in rural and underserved regions [18].

C. Theoretical Review on Models of ASD

1. Theory of Mind (Tom)

This theory posits that individuals with ASD struggle to understand that others have thoughts, feelings, and perspectives different from their own. This deficit in mentalizing abilities helps explain social and communicative impairments [19]. However, it does not account for non-social symptoms such as sensory sensitivities.

2. Executive Dysfunction Theory

This model attributes core ASD symptoms to impairments in executive functions like planning, cognitive flexibility, and inhibition. It is particularly useful in explaining repetitive behaviors and rigidity [20], but its explanatory power is limited by its lack of specificity to ASD and insufficient coverage of social challenges.

3. Weak Central Coherence Theory

Developed by Uta Frith, this theory suggests that individuals with ASD tend to process information in a detail-focused way, neglecting broader context. While this can explain both cognitive strengths (e.g., rote memory) and challenges (e.g., interpreting social situations), it does not fully explain sensory or behavioral issues [21].

4. Enhanced Perceptual Functioning (EPF) Model

This framework emphasizes the heightened sensory perception and attention to detail often observed in individuals with ASD [22]. It shifts the narrative from deficits to perceptual strengths, though it does not adequately explain social communication impairments.

5. Integrative and Multifactorial Models

Recognizing the limitations of single-theory models, Pennington proposed the Multiple Deficit Model, which posits that ASD arises from the interplay of several cognitive and neurobiological deficits [23]. This multifactorial approach allows for a more comprehensive understanding of the condition's heterogeneity.

D. Impacts on Parents Raising Children with ASD

1. Emotional and Psychological Impacts

Parents of children with ASD commonly experience high levels of anxiety, depression, and chronic stress [24]. These psychological burdens are often intensified by the unpredictability of the child's behavior and the stigma surrounding the condition [25]. According to Family Systems Theory, a child's diagnosis affects the entire family system, with mothers frequently bearing the brunt of caregiving responsibilities [26].

2. Social and Economic Impacts

The lifetime cost of caring for an individual with ASD—including therapies, special education, and health services—can surpass \$2.4 million in the U.S. [27]. Many families face financial strain due to reduced work hours or job loss among caregivers [28]. Additionally, social stigma and limited community support contribute to parental isolation and reduced quality of life [29].

3. Coping and Resilience

Despite these challenges, many parents develop resilience through adaptive coping strategies. Based on Stress and Coping Theory [30], methods such as mindfulness practices, participation in support groups, and positive reframing can significantly alleviate stress. Some parents also report experiencing personal growth, enhanced empathy, and a deeper appreciation of life [31].

E. Research Gaps Identified

1. **Lack of Longitudinal Studies:** Few studies track the long-term effects of raising children with ASD.
2. **Cultural and Socioeconomic Gaps:** Most research reflects Western, middle-class perspectives, neglecting variations across cultures and classes.
3. **Intersectionality:** Little is known about how gender, race, or socioeconomics shape parental experiences.
4. **Support Systems:** The differential impact of formal vs. informal support remains under-theorized.
5. **Role of Fathers:** Research has disproportionately focused on mothers.
6. **Resilience Frameworks:** Theoretical models explaining long-term positive adaptation remain underdeveloped.

F. Implications for Intervention and Research

Understanding ASD theories can enhance intervention design

1. ToM-based social skills programs
2. Executive function training via CBT
3. Educational strategies tailored to cognitive profiles
4. Parental support through behavioral training

Future research should pursue longitudinal designs and integrate findings from genetics and neuroscience to understand ASD more comprehensively.

Table 1. Summary of Key Impacts, Theoretical Frameworks, Research Gaps, and Implications for Parents of Children with Autism Spectrum Disorder

| Domain | Key Points | Theoretical Frameworks | Research Gaps | Implications for Intervention/Reseach |
|---|---|---|---|---|
| Emotional and Psychological Impact | - High levels of stress, anxiety, depression- Emotional exhaustion, especially in mothers- Strained spousal and sibling relationships | Family Systems Theory (Bowen, 1978) | - Limited longitudinal perspectives- Underexplored intersectionality (gender, race, etc.) | - Need for emotional support programs- Tailored interventions recognizing caregiver roles |
| Social and Economic Impact | - High cost of therapy, healthcare, education- Reduced employment or job loss- Social isolation due to stigma | None explicitly stated; aligns with ecological models | - Cultural/socioeconomic diversity lacking in research | - Culturally sensitive support models- Financial aid and policy interventions |
| Coping Mechanisms and Resilience | - Use of problem- and emotion-focused strategies- Support groups, mindfulness, positive reframing- Reports of personal growth and increased empathy | Stress and Coping Theory (Lazarus & Folkman, 1984) | - Lack of theoretical models on resilience over time | - Promote peer-led support groups- Develop frameworks on adaptive resilience |
| Support Systems | - Role of both formal and informal networks- Online vs. in-person support effectiveness unclear | Not well-theorized | - Differential impacts of support types not studied | - Research into efficacy of varied support forms |
| Father's Role | - Fathers underrepresented in research- Emotional and social experiences understudied | None stated | - Gender-specific impacts poorly understood | - Inclusion of fathers in intervention programs and research |
| Future Directions | - Incorporate neuroimaging and genetic insights- Explore developmental changes in parental experience | Theory of Mind (ToM), Executive Function models | - Integration of biological and psychosocial data lacking | - Develop integrated, lifespan-based intervention models |

Table 1 provides a comprehensive overview of the major domains affecting parents of children with Autism Spectrum Disorder (ASD). The emotional and psychological tolls especially on mothers has been well-documented, yet longitudinal and intersectional perspectives remain scarce. Social and economic burdens, though often discussed, require more culturally nuanced exploration. While parents employ a range of coping strategies, there is a need for theoretical models that account for resilience over time. Notably, support systems and the role of fathers are under-researched, underscoring the need for inclusive and diversified studies. Finally, emerging directions point toward a more integrated understanding that includes biological, psychological, and social dimensions, which may guide more holistic intervention strategies.

5. CONCLUSION

Autism Spectrum Disorder is a complex condition that requires multifaceted explanations. Theories such as the Theory of Mind, Executive Dysfunction, Weak Central Coherence, and Enhanced Perceptual Functioning offer valuable insights into different aspects of the disorder. By integrating these perspectives, researchers and practitioners can better address the needs of individuals with ASD, paving the way for more effective interventions and support systems. The journey of parenting a child with Autism Spectrum Disorder is both challenging and transformative. While parents face significant stressors, they also demonstrate resilience and adaptability. By understanding the multifaceted impact on parents and implementing targeted interventions, society can better support these families, fostering an environment where both parents and children with ASD can thrive. While Nepal has made notable progress in recognizing and supporting individuals with Autism Spectrum Disorder, ongoing efforts are essential to enhance awareness, improve diagnostic services, and provide accessible interventions across the country.

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|---------------------------|---|---|----|----|----|---|---|---|---|---|----|----|---|----|
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C : Conceptualization

M : Methodology

So : Software

Va : Validation

Fo : Formal analysis

I : Investigation

R : Resources

D : Data Curation

O : Writing - Original Draft

E : Writing - Review & Editing

Vi : Visualization

Su : Supervision

P : Project administration

Fu : Funding acquisition

Conflict of Interest Statement

Authors state no conflict of interest.

Informed Consent

Not applicable since this is synthesis paper.

Ethical Approval

Not applicable since this is synthesis paper.

Data Availability

Data availability is not applicable to this paper as no new data were created or analyzed in this study. This is just a synthesis paper.

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