

**Navigating the Dilemma of Early Autism
Diagnosis: Challenges Faced by Parents in
Kuwait and Implications for Timely Intervention**

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Navigating the Dilemma of Early Autism Diagnosis: Challenges Faced by Parents in Kuwait and Implications for Timely Intervention

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Abstract

This study explores the barriers to early diagnosis of Autism Spectrum Disorder (ASD) faced by parents in Kuwait. Utilizing a multi-case study methodology, three families with children aged four to six years were examined to gain a deep understanding of the emotional, financial, and systemic challenges encountered during the diagnostic process. Semi-structured interviews and documentary analysis were employed to collect detailed data, which were analyzed using thematic analysis. Key themes emerged, including diagnostic delays, inconsistent evaluations, emotional distress, and financial burdens. Parents reported a fragmented diagnostic system, where multiple departments and long waiting lists delayed formal diagnosis, complicating access to necessary early interventions. The emotional strain of navigating this uncertain period, coupled with cultural stigma and a lack of support, significantly impacted families. Financially, parents often resorted to expensive private therapies, further adding to the pressure. The discussion highlights the need for a centralized diagnostic system, improved public awareness, and expanded financial support for therapies like Applied Behavior Analysis (ABA). The study suggests that integrating emerging technologies, such as machine-learning algorithms for behavioral assessment, could streamline diagnosis and reduce delays, but cultural and systemic barriers must be addressed. Ultimately, the research emphasizes that systemic reforms are critical to improving the ASD diagnostic experience for Kuwaiti families, ensuring timely access to interventions and reducing the emotional and financial burden.

Keywords: Autism Spectrum Disorder (ASD) - early diagnosis – Kuwait - parental experiences.

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Introduction:

The Dilemma of Early Autism Diagnosis in Kuwait

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by significant impairments in social interaction, communication, and the presence of restrictive, repetitive behaviors (Yu et al., 2024). The early identification of ASD is critical, as research underscores the importance of timely interventions in enhancing long-term developmental outcomes (Dan & Stanescu, 2024). However, despite global advancements in diagnostic methodologies, many parents in Kuwait face substantial barriers when attempting to secure an early diagnosis for their children. These barriers create a paradox: while early intervention is known to be essential, achieving an official diagnosis often comes later, leaving families in a difficult position.

Typically, ASD symptoms often become evident to parents in the first two years of a child's life, with concerns commonly arising around social communication delays and repetitive behaviors (Waddington et al., 2023). However, formal diagnosis can reliably occur between the ages of 18 months and 3 years, depending on the severity of symptoms and access to diagnostic services (WHO, 2013). In some cases, due to delays in accessing services or variations in symptom presentation, diagnosis may not occur until much later, often around 4–5 years of age (Crane et al., 2016). However, in Kuwait, the diagnostic process is often delayed due to various systemic and cultural challenges. Parents frequently notice atypical developmental patterns, such as delayed speech or social withdrawal, and seek early intervention services even before an official diagnosis is confirmed (Dan & Stanescu, 2024). This pre-diagnostic phase is fraught with uncertainty. Many parents choose to pursue expensive behavioral and language therapies as a precautionary measure, fearing that any delay in treatment could have long-term repercussions on their child's developmental trajectory (Hrdlicka et al., 2024). Yet, without an official diagnosis, access to specialized services remains limited, further complicating the situation.

The situation in Kuwait is exacerbated by the scarcity of trained professionals and the long waiting lists for comprehensive evaluations. The burden of securing an early diagnosis is often placed on parents, who are left navigating a fragmented system of private services. For many families, the financial costs of these therapies, compounded by the emotional strain of uncertainty, present significant challenges (Alallawi, 2020). Furthermore, the cultural stigma surrounding developmental disabilities in the region can prevent some parents from seeking help early, delaying diagnosis and intervention (Alallawi, 2020).

This conundrum creates a complex dilemma for families. While early intervention is critical for optimizing the child's developmental outcomes, the delay in official diagnosis often leaves parents in a state of limbo. They are compelled to make difficult financial and emotional decisions regarding their child's care, uncertain whether the interventions they pursue pre-diagnosis will yield the best possible outcomes. This paper explores these challenges in depth, examining the barriers to early diagnosis of ASD in Kuwait and their impact on families. By addressing these challenges, this research seeks to propose solutions that can facilitate more timely diagnoses and equitable access to early intervention services.

Literature Review: Challenges in Early Autism Diagnosis in Kuwait

The diagnostic process for Autism Spectrum Disorder (ASD) is complex, with substantial barriers that often delay early diagnosis. Early intervention is crucial for improving long-term outcomes, but these delays can impede access to timely care, placing a significant burden on families (Malhi et al., 2023). This section will explore key themes drawn from the literature, highlighting the challenges related to diagnostic timelines, parental concerns, and the emotional and financial toll on families in Kuwait.

Diagnostic Delays and Parental Experiences

Delays in receiving an autism diagnosis are well-documented across the literature, with research indicating that the diagnostic process can extend over several years. Waddington et al. (2023) noted that although parents often identify developmental concerns in their children by 18 months to 2 years, formal diagnoses are not typically made until children

are 4–5 years old. This delay is mirrored in other studies, where parents commonly report that their concerns about communication delays, lack of social engagement, and repetitive behaviors are either dismissed or misinterpreted by healthcare professionals (Crane et al., 2016). The consequences of such delays are profound, as early intervention—known to improve cognitive, social, and linguistic outcomes—becomes harder to access in the absence of a formal diagnosis.

In Kuwait, similar delays are likely exacerbated by systemic barriers such as a shortage of specialized professionals, long waiting times for appointments, and a lack of public awareness around ASD (Moharam & Toran, 2023). These issues are compounded by the emotional toll that accompanies the prolonged uncertainty parents experience. Many parents in various studies have reported feeling frustrated and disillusioned with healthcare systems that are unable to provide them with timely answers (Battanta et al., 2024). The emotional strain of navigating a prolonged and unclear diagnostic process is particularly challenging for parents who are left questioning their ability to secure the care their children need (Moharam & Toran, 2023).

Emotional and Financial Burdens of Diagnostic Delays

The emotional stress parents face during the diagnostic journey cannot be understated. Research consistently shows that parents of children with ASD experience significantly higher levels of stress compared to parents of neurotypical children or those with other developmental delays (Battanta et al., 2024). The lack of clear and timely communication from healthcare providers, coupled with the constant worry of missing the optimal window for early intervention, places an immense emotional burden on families. Crane et al. (2016) found that many parents report high levels of anxiety and frustration, particularly when their concerns are either dismissed or not addressed adequately by healthcare professionals. These findings align with those of Malhi et al. (2023), who demonstrated that emotional distress is further exacerbated by the social and cultural pressures parents face, particularly in regions where developmental disabilities are stigmatized.

In addition to emotional challenges, the financial strain of pursuing diagnostic evaluations and early interventions can be overwhelming. In many cases, parents pursue costly private therapies even in the absence of a formal diagnosis, fearing that any delay in treatment could irreversibly harm their child's development (Battanta et al., 2024). These expenses, which include behavioral therapy, speech therapy, and specialized education, are often necessary but financially unsustainable for many families. Studies from both high-income countries and developing regions underscore the economic burden that parents face, especially when public healthcare systems fail to provide adequate coverage for ASD-related services (Malhi et al., 2023). In Kuwait, where public services for ASD diagnosis and treatment may be limited, parents often turn to private providers, further compounding the financial challenges.

Parental Satisfaction and the Healthcare System

The literature indicates that parental satisfaction with the diagnostic process is closely tied to the efficiency and transparency of healthcare systems. Crane et al. (2016) found that the longer the delay in obtaining a diagnosis, the greater the dissatisfaction parents expressed with the overall process. Factors such as the quality of communication from healthcare professionals, the clarity of the diagnostic label provided, and the level of post-diagnostic support all play a significant role in shaping parental experiences. In regions like Kuwait, where the healthcare system may not be fully equipped to handle the complexities of ASD diagnosis, these factors become even more critical.

Research by Moharam and Toran (2023) highlights the importance of a well-structured and responsive diagnostic pathway, particularly for parents who are already dealing with the emotional challenges of raising a child with ASD. In contexts where healthcare systems are fragmented or under-resourced, parents are often left to navigate the diagnostic process on their own, further heightening feelings of isolation and stress. Studies emphasize the need for healthcare systems to be more responsive to parental concerns and to provide clearer pathways for diagnosis and intervention (Crane et al., 2016; Malhi et al., 2023).

The literature on early autism diagnosis reveals a clear pattern of diagnostic delays, emotional stress, and financial burden. These challenges not only hinder early intervention but also place immense strain on families, both emotionally and financially. Addressing these barriers requires systemic changes, including increased access to diagnostic services, better communication from healthcare professionals, and more robust support for families throughout the diagnostic process. As Kuwait continues to develop its healthcare services, it will be essential to address these gaps to ensure timely and effective care for children with ASD and their families.

Research questions

The present study aims to explore the experiences of parents in Kuwait as they navigate the process of obtaining an Autism Spectrum Disorder (ASD) diagnosis for their children. Given the critical importance of early diagnosis and intervention for children with ASD, understanding the various factors that affect the diagnostic journey in Kuwait is essential. This research seeks to examine the emotional, financial, and systemic challenges that parents face during this process. To achieve this, the following research questions are posed:

- 1- How do parents in Kuwait perceive the process of obtaining an early diagnosis for their children with Autism Spectrum Disorder?
- 2- What emotional challenges do parents in Kuwait face during the diagnostic process for Autism Spectrum Disorder?
- 3- What financial challenges do parents in Kuwait experience when seeking early diagnosis and interventions for Autism Spectrum Disorder?
- 4- What coping strategies do parents in Kuwait employ to manage the challenges they face during the early diagnostic process for their children with Autism Spectrum Disorder?

Methodological Approaches:

This study employs a multi-case study approach to explore the challenges faced by parents in Kuwait in obtaining early diagnoses for Autism Spectrum Disorder (ASD). A multiple case study design allows for an in-depth examination of individual experiences across different

contexts, while also providing insights into common challenges and patterns (Yin, 2018). By focusing on three families, each with a child between the ages of four and six, this research captures a detailed and nuanced understanding of the parental experience during the critical early diagnostic phase. The multi-case study approach is particularly well-suited for this study, as it provides a framework for exploring the complexity of the diagnostic process in relation to systemic and cultural factors (Stake, 2013).

This research uses also documentary analysis as a methodological approach to enhance understanding of the systemic and contextual factors affecting early autism diagnosis in Kuwait. Documentary analysis involves the systematic review of documents like policies and guidelines, offering additional insights beyond interviews (Bowen, 2009). It helps provide context, uncovering broader institutional influences that may not emerge through direct interaction with participants (Zina, 2021).

By integrating documents with case study findings, this method allows the researcher to identify gaps between official policies and real-world practices (Prior, 2016). This enhances the overall reliability of the research by triangulating personal narratives with institutional data, providing a well-rounded perspective on the challenges parents face.

Participants

The participants in this study consisted of three parents, each with a child diagnosed with Autism Spectrum Disorder (ASD) between the ages of four and six years. This specific age range was selected to explore the challenges and difficulties parents encounter during the critical early years of a child's development, a period marked by significant milestones in communication, social interaction, and behavior. The inclusion criterion ensured that each parent's child was formally diagnosed with ASD, as this timeframe allows for an in-depth analysis of the immediate concerns surrounding early diagnosis and intervention.

The sample was selected using an opportunity sampling method, which refers to the non-random selection of participants based on their accessibility and willingness to participate in the study (APA, 2020). In this case, the participating parents were personally known to the researchers, and all expressed a strong willingness to contribute to the

research. Their cooperation extended to sharing formal diagnostic documents concerning their children's ASD—a notable achievement, given the cultural context of Kuwait, where parents are often reluctant to disclose such sensitive information due to concerns about social stigma. This unique access to diagnostic documentation provided a rare and valuable insight into the barriers and challenges that exist within the diagnostic process in Kuwait.

Method

The primary research method utilized in this study is the semi-structured interview, a well-established qualitative approach for obtaining in-depth insights from participants. As Bryman (2012) suggests, interviews act as a critical investigative tool, enabling researchers to delve into the underlying causes of a particular phenomenon by directly engaging with individuals who have firsthand experience in the relevant field. This approach allows for a nuanced understanding of complex issues, ensuring that information is derived from its most authentic source. Therefore, in this study, semi-structured interviews were deemed appropriate for exploring the intricate challenges faced by parents during the early diagnosis of Autism Spectrum Disorder (ASD) in Kuwait.

The semi-structured interview format was selected for its balance between flexibility and focus. While providing the freedom to explore emerging themes, the interviews were structured around predetermined areas of inquiry, ensuring consistency across participants. Four key thematic areas, derived from an extensive literature review, guided the interview process. These thematic areas were chosen to address the most significant challenges parents face when seeking early ASD diagnosis for their children.

The interviews were divided into four sections:

Perceptions of the Diagnostic Process: This section explored how parents perceive the process of obtaining an early diagnosis for their child with ASD, including their experiences with healthcare professionals and the timeline of the diagnosis.

Emotional Challenges: The second section focused on the emotional toll the diagnostic process takes on parents, probing the anxiety, stress, and uncertainty that accompany the pursuit of an early diagnosis.

Financial Challenges: The third section examined the financial burden parents face, particularly in relation to the costs of private diagnostic services and early intervention programs in the absence of readily accessible public services.

Coping Strategies: Finally, the fourth section explored the coping mechanisms parents employ to manage the myriad challenges they encounter during the early diagnostic phase.

This methodological design, combining structured thematic inquiry with the adaptability of semi-structured interviews, facilitated a thorough investigation into the multifaceted challenges faced by parents of children with ASD in Kuwait. The use of semi-structured interviews allowed the researcher to capture both commonalities and unique experiences, yielding rich, detailed data that directly address the study's research questions.

Data Analysis

The data analysis in this study followed a systematic approach, guided by a framework suitable for qualitative research, as proposed by Taylor-Powell and Renner (2003). Given the semi-structured nature of the interviews, where predefined thematic areas were already established, the analysis focused on organizing the data around these existing themes, while remaining open to emergent sub-themes. This method allowed for a structured yet flexible interpretation of participants' responses, ensuring that the analysis was both comprehensive and aligned with the study's objectives.

The analysis began with an extensive reading of the interview transcripts and field notes. Initial impressions were documented to gain a holistic understanding of the data. The predefined themes—drawn from the literature on the challenges faced by parents of children with Autism Spectrum Disorder (ASD)—served as a guide for coding the data. These themes included perceptions of the diagnostic process, emotional challenges, financial challenges, and coping strategies. This thematic framework facilitated a focused exploration of participants' experiences

while allowing for the identification of additional sub-themes that emerged during the interviews.

The next stage involved systematically coding the data according to these predefined themes. Using a thematic analysis approach, the researcher identified key patterns and recurring concepts within each theme. Special attention was given to areas where participants' experiences overlapped or diverged from the established literature, allowing for a nuanced understanding of both common and unique challenges. For example, recurring mentions of emotional stress and financial strain were highlighted and categorized under their respective themes, while unexpected coping mechanisms emerged as sub-themes.

In addition to interview data, documentary analysis was employed to further enhance the depth of the study. The formal diagnostic reports and school documents provided by the parents were analyzed using Bowen's (2009) framework for documentary analysis, which is a systematic procedure for evaluating documents to gain insights that may not be directly accessible through interviews. This method enabled the researcher to corroborate and cross-reference the interview findings with the formal records of diagnosis and educational interventions. Key aspects of the children's formal diagnoses were extracted, and attention was given to how these reports reflected or contradicted the parents' narratives regarding the challenges they faced. The analysis of these documents was particularly valuable in understanding the institutional and bureaucratic factors that influenced the diagnostic process.

Reliability and Validity

The reliability of this study was ensured through the application of Klein and Myers' (1999) framework, which emphasizes critical reflection on the socio-historical context, the dynamics between the researcher and participants, and the potential for multiple interpretations in qualitative research. This approach helped mitigate bias and reinforced the trustworthiness of the findings.

To strengthen the reliability of the data collection process, the interview schedule was rigorously reviewed by three experts in the field of special needs education. Their feedback ensured the clarity, relevance,

and alignment of the interview questions with the study's objectives, thus enhancing the quality of the data collected.

Inter-rater reliability was evaluated using Fleiss' Kappa (κ) statistic, which measures the level of agreement among multiple raters. The computed Kappa value of 0.71 reflects substantial agreement (Landis & Koch, 1977), indicating a high level of consistency in the coding process. This consistency adds credibility to the findings, affirming that the coding scheme was applied in a reliable and systematic manner.

As for the generalizability of the data, this study does not aim to generalize its findings to a broader population. Instead, the focus is on achieving a deep and nuanced understanding of the specific phenomenon under investigation—the challenges faced by parents of children with Autism Spectrum Disorder (ASD) in Kuwait. The insights gained are intended to provide a rich, context-specific exploration rather than broad generalizations, aligning with the goals of qualitative research to uncover detailed and meaningful perspectives.

Findings

Presenting Anonymous Children Diagnosed with Developmental Delays and ASD

Presenting Case Study 1:

Jassim is a male child, born in June 2018, who showed signs of speech delay by age two. Initially, a speech-language pathologist attributed the delay to the pandemic's impact on nurseries, and autism was not suspected. After six months of therapy, although speech improved, unusual behaviors persisted.

At age three, Jassem was diagnosed every six months by the Department of Evolutionary Medicine in one public hospital in Kuwait. However, the results were inconsistent. One report clarified that Jassem had a moderate cognitive disability, while another report, issued six months later, stated that Jassem had Autism Spectrum Disorder (ASD) with no mention of moderate cognitive disability. These conflicting diagnoses led the parents to lose trust in the public sector and turn to private healthcare providers.

Further assessments raised concerns about Autism Spectrum Disorder (ASD), but the child was initially diagnosed with language

delay. His parents sought early intervention and took him to Scotland, where he received Play2Talk® therapy to support his communication skills. Cognitive and motor skill assessments continued every six months, revealing developmental delays, particularly in social communication and motor coordination.

After being formally diagnosed with ASD by the Public Authority for Disabilities Affairs, Jassem was enrolled in Sanad Village in Dubai, a specialized center for autism, where he continues to receive targeted support tailored to his developmental needs. The diagnosis, combined with the interventions from Sanad Village, has helped the family focus on strategies to support his ongoing development.

Findings from Case Study 1: Jassim

Perception of the Early Diagnosis Process: Jassim's parents expressed deep frustration with the inconsistent diagnoses received from public healthcare in Kuwait. Initially, Jassim was diagnosed with a moderate cognitive disability, but later reports mentioned Autism Spectrum Disorder (ASD) without acknowledging the cognitive delay. This inconsistency led to a breakdown in trust. As his mother shared, *"We couldn't rely on the public sector anymore. One report said Jassim had a cognitive disability, the next said it was ASD. We had to seek help elsewhere because we couldn't afford to wait while our son's development stalled."* Consequently, the parents turned to private services abroad, seeking intervention in Scotland and Dubai.

Emotional Challenges During the Diagnostic Process: Emotionally, Jassim's parents endured significant strain, particularly due to the uncertainty surrounding their son's condition. *"The diagnosis kept changing, and we were left feeling helpless and anxious,"* Jassim's father shared. His mother added, *"I couldn't sleep at night, constantly worrying if we were missing a critical window for his development. It was a constant state of anxiety and disquiet, wondering if we were doing the right thing for him."* This emotional toll was exacerbated by the pressure to make decisions without clear guidance, leading to feelings of apprehension and deep distress.

Financial Challenges Experienced: Jassim's parents also faced considerable financial burdens in seeking an early diagnosis and appropriate interventions. His father explained, *"We spent about 40% of our monthly income on Jassim's therapies and evaluations, and that's not sustainable."* They elaborated that this amount covered *"travel to Scotland for Play2Talk® therapy, private cognitive and motor skill assessments, and eventually, enrollment in Sanad Village in Dubai."* Specifically, *"10% of our income went to travel expenses, 15% to private therapy sessions, and another 15% to ongoing specialized schooling."* These expenses created significant financial strain, further complicating the family's ability to cope with Jassim's condition.

Coping Strategies for Anxiety and Financial Pressure: In response to the emotional and financial pressures, Jassim's parents adopted several coping strategies. His mother stated, *"We leaned on each other emotionally, sharing our fears and trying to stay positive for Jassim's sake. We had to believe that things would improve."* Additionally, they found support through community networks of other parents dealing with similar challenges. *"Speaking to other families going through the same journey helped us realize we weren't alone. We exchanged tips and advice on managing stress."* Financially, the family had to adjust their lifestyle, as his father explained: *"We cut back on luxuries and started saving wherever we could. We also sought financial advice on how to manage long-term care costs."* This combination of emotional and financial adaptations helped them navigate the ongoing challenges.

Presenting Case Study 2:

Ahmad is a five years old male child who showed signs of developmental delays by age four, including minimal eye contact, repetitive movements, and speech limited to echolalia. Concerned by his rigid behaviors and lack of social interaction, his parents sought help from a pediatrician. Initial evaluations suggested possible Autism Spectrum Disorder (ASD), but due to long waiting times in the public sector, the family turned to a private clinic for further assessment. The child underwent the Autism Diagnostic Observation Schedule (ADOS) at a private center, which confirmed ASD, particularly

highlighting challenges in social communication and repetitive behaviors. The family then had to rely on private-sector therapies, including speech and occupational therapy, as government services had long delays.

At age five, the parents applied to the Public Authority for Disabilities Affairs for official recognition of the diagnosis, but the process was slow and took several months. Ultimately, the child was classified with moderate ASD, and while the official diagnosis took time, the private therapy helped him make gradual progress in communication and sensory regulation.

Findings from Case Study 2: Ahmad

Perception of the Early Diagnosis Process: Ahmad's parents expressed deep frustration with the lack of a clear pathway in the public sector. *"There was no single path to follow,"* his father said. *"We were constantly being referred from one department to another, each with its own long waiting list."* His mother added, *"It was overwhelming. The audio test alone took over a month to schedule, and then the IQ test was done at his school, while the psychological services department did another one. It was exhausting."* The most perplexing part for the parents was the autism assessment. *"We were referred to the Evolutionary Medicine department for the autism test, and it took only 20 minutes,"* his mother explained in disbelief. *"How can professionals assess a child's condition in just 20 minutes? It felt like they were rushing us out the door."* This fragmented approach left the parents feeling lost and unsupported. *"There were just too many separate departments involved. We didn't know who to turn to next,"* his father concluded.

Financial Challenges Experienced: Ahmad's parents described the significant financial strain they faced in ensuring their son received the necessary support. *"We spend around 3,000 Kuwaiti dinars each month just to cover Ahmad's needs,"* his father explained. One of the biggest costs was the additional Applied Behavior Analysis (ABA) sessions. *"The Public Authority only provided a few hours of ABA each week, which wasn't nearly enough for Ahmad,"* his mother shared. *"We had to*

go to the private sector for more sessions, and they're incredibly expensive."

Beyond therapy, they also had to hire professional care services for Ahmad while they were at work. *"Both of us work full-time, so we couldn't leave him unattended at home,"* his father said. *"Finding someone qualified to look after Ahmad who understands his condition and can support him properly adds to our monthly expenses."* These mounting costs left them feeling financially stretched, but they felt there was no alternative. *"It's not like we can cut back on these services—he needs them, and we're doing everything we can to support him,"* his mother added.

Coping Strategies for Anxiety and Financial Pressure: To cope with the emotional and financial pressures, Ahmad's parents developed a variety of strategies. *"We decided early on that we had to keep ourselves grounded,"* his father said, explaining how they prioritized their own mental health to manage the stress. His mother added, *"I started journaling my thoughts and feelings—it helped me process the overwhelming emotions."* In terms of financial coping strategies, the family had to make significant lifestyle adjustments. *"We cut back on vacations, dining out, and unnecessary expenses,"* his father explained. They also sought advice from a financial counselor to better manage the costs of ongoing therapy. *"We had to plan for the long haul, and getting professional advice helped us feel more in control,"* his mother shared. Additionally, they found emotional relief by connecting with other parents through support groups. *"Talking to other parents going through the same thing gave us comfort. We weren't alone in this battle,"* Ahmad's father concluded.

Presenting Case Study 3:

Bader is a six years old boy exhibited behavioral challenges by the age of six, including rigid routines, difficulty with social interactions, and sensitivity to sensory stimuli. His parents sought private-sector assessments after becoming frustrated with long wait times in the public system. The private-sector evaluation suggested that, at first glance, he might appear to have Autism Spectrum Disorder (ASD), but closer

examination of his skills (such as language comprehension and problem-solving) indicated he might not meet the full criteria for ASD.

Despite this, the parents were confused as his school reported ongoing difficulties in social communication and repetitive behaviors. They enrolled him in a private special school where he began Applied Behavior Analysis (ABA) therapy. Unaware that the Public Authority for Disabilities Affairs covered ABA therapy and private school costs, the family paid out of pocket, assuming their child would only be eligible for government special schools, which they found lacking in services.

Eventually, the parents sought an official diagnosis from the Public Authority for Disabilities Affairs, which confirmed the child had ASD, based on DSM-IV criteria. His symptoms included persistent challenges in social communication, lack of eye contact, rigid routines, and repetitive behaviors. This conflicting information from the private and public sectors left the parents in a difficult position, navigating different interpretations of their child's condition while continuing to fund his private education and therapies.

Findings from Case Study 3: Bader

Perception of the Early Diagnosis Process: Bader's parents were left in a state of confusion and frustration due to the conflicting reports they received throughout the diagnostic process. *"We didn't know what to believe,"* his mother explained. *"The private sector told us he might not meet the full criteria for ASD, but then his school kept reporting issues with his social interactions and rigid routines. It just didn't make sense."* Bader's father added, *"It felt like every professional had a different opinion. First, they said it might be ASD, then they weren't sure. We felt completely lost."* Despite their confusion, the parents turned to a private special school for Applied Behavior Analysis (ABA) therapy to support their son, unsure of what else to do. *"We didn't even know the Public Authority covered ABA. We thought we had to pay out of pocket because the public schools weren't providing what he needed,"* his father said, expressing their frustration with the lack of clear information.

Emotional Challenges During the Diagnostic Process: Bader's parents experienced an emotional rollercoaster throughout the diagnostic

process, filled with confusion, self-doubt, and overwhelming anxiety. His father described the journey as *“a constant tug-of-war between hope and despair.”* He explained, *“One day we’d feel hopeful—thinking maybe he doesn’t have ASD, maybe it’s something else—but the next day we’d be crushed again when another issue came up, and the uncertainty would take over.”*

His mother shared a particularly difficult period: *“I remember breaking down after one of the evaluations. It just felt like no one had the answers. The private doctors were saying one thing, the school was saying something completely different, and we were caught in the middle, not knowing what to do or who to trust.”* She added that this emotional limbo took a toll on her mental health. *“There were days when I couldn’t even get out of bed because I felt so drained. I was constantly worried about Bader’s future—would he ever be able to live a normal life? Would we ever get the right help?”*

The inconsistency of the diagnoses also led to tension between the parents. *“We started questioning each other’s decisions,”* Bader’s father admitted. *“I’d say we should trust the private sector, while my wife would insist we follow up with the public doctors. It felt like we were second-guessing every decision we made for him.”* This tension added another layer of emotional strain to their already difficult situation.

The stress was further compounded by their interactions with friends and family. *“Everyone had an opinion,”* his mother explained. *“Some people told us we were overreacting, others thought we weren’t doing enough. It was exhausting trying to explain our situation to people who didn’t understand what we were going through.”* She went on to say, *“You feel like you’re constantly defending your choices, even though you’re just trying to do what’s best for your child.”*

The emotional weight also spilled over into their daily life. *“We couldn’t even enjoy simple things anymore,”* his father said. *“Going to the park or attending family gatherings became a source of anxiety. We were always on edge, worried about how Bader would react, how other people would see him.”* His mother added, *“It’s heartbreaking when you see your child struggling with things that seem so simple for other kids,*

like making friends or joining in games. I'd watch him, and I'd just feel this deep sadness, like we were losing time."

To help manage the emotional toll, the family eventually sought out psychological counseling. *"It wasn't just for Bader. We needed help for ourselves too,"* his mother explained. *"The stress was eating us alive, and we needed someone to guide us through this—someone to help us manage our own feelings of guilt and fear."* The counseling sessions provided them with a space to process their emotions and reflect on how to better support each other. *"It helped us regain some balance. We learned how to communicate better, how to manage our stress together instead of turning on each other,"* his father said. Despite the ongoing challenges, these sessions allowed them to regain some emotional stability and find strength as a family.

Financial Challenges Experienced: Bader's family found themselves in a financial spiral as they navigated the costs associated with his care. *"We never imagined we'd be spending this much. It started with just a few therapy sessions here and there, and before we knew it, our entire monthly budget was being swallowed up,"* his father admitted. Bader's mother elaborated, *"We were paying for everything out of pocket—private evaluations, additional ABA therapy, and even specialized educational tools. It felt like every time we turned around, there was another bill."*

The family was initially unaware that some of the therapies they were paying for could have been subsidized by the Public Authority. *"We didn't realize there were options for support,"* Bader's mother said. *"By the time we found out, we had already taken a loan just to cover everything. It felt like we had been blindsided."* They had taken a 40,000 Kuwaiti dinar loan, believing it was the only way to afford the necessary services. *"We had no idea the government could help with the ABA therapy. We just assumed private care was the only option because the public system didn't have enough resources,"* his father explained.

The costs weren't limited to therapy. *"We also had to hire someone to look after Bader while we were at work,"* his mother added. *"It wasn't just any caregiver. We needed someone who understood how to handle*

his specific needs, which meant the fees were even higher.” She described how finding a qualified caregiver who could manage Bader’s sensory sensitivities and social difficulties was a challenge, but one they had no choice but to face. “There were months when we couldn’t save anything. Every dinar was going to Bader’s care, and still, it felt like we weren’t doing enough.”

Even though the costs kept piling up, the family never felt they could compromise on Bader’s well-being. *“At the end of the day, it’s for his future. We couldn’t bear the thought of cutting back on his therapies, even if it meant pushing ourselves to the financial edge,”* his father said. The burden weighed heavily on them, but they remained determined. *“We had to sell one of our cars to keep up with the payments,”* his father revealed. *“We didn’t even think twice. Everything goes toward making sure Bader has what he needs, but it’s exhausting knowing you’re constantly walking on a financial tightrope.”*

Bader’s mother echoed the emotional toll of these financial decisions. *“We’ve had to make so many sacrifices,”* she said. *“We cut back on family outings, vacations, even small things like eating out. It’s hard, especially when you see other families doing these things, and you’re just scraping by. But you do it because you love your child and you know it’s worth it.”* The emotional and financial strain weighed on the family, yet they persevered, always hopeful that the sacrifices would pay off in the long run. *“We just keep telling ourselves this is temporary, that we’re doing everything we can to give Bader the best shot,”* his father concluded, though the uncertainty of how long they could maintain this level of spending remained a constant source of stress.

Coping Strategies for Anxiety and Financial Pressure: To cope with both the emotional and financial challenges, Bader’s parents developed several strategies. *“We started seeing a psychologist to help us manage our stress and anxiety,”* his mother explained. *“It helped to talk things out and get professional support for our own mental health.”* In terms of financial pressure, the family had to make tough decisions. *“We had to tighten our budget—no more holidays, no extra spending,”* his father said. *“Every dinar went toward Bader’s care, and it still didn’t feel like enough.”* The loan they took helped ease the immediate financial burden,

but they knew it was a temporary solution. *“We just focused on the long term,”* his mother shared, *“hoping that with time, things would improve for Bader, and we could slowly get back on our feet.”* Despite the overwhelming challenges, the parents found ways to persevere through the combination of professional help and personal resilience.

Discussion

This study has highlighted several critical barriers in the early diagnosis of Autism Spectrum Disorder (ASD) in Kuwait. These findings, while reflective of broader regional trends, underscore systemic inefficiencies specific to the Kuwaiti healthcare context. The discussion below focuses on the key challenges identified and provides recommendations grounded in both the study's findings and relevant literature.

Diagnostic Challenges and System Fragmentation

The fragmentation within Kuwait's diagnostic process emerged as a significant issue. Parents were required to seek assessments across multiple, often disconnected, departments, leading to long delays and inconsistent diagnoses. This disjointed approach not only adds to the confusion but also impacts the accuracy and timeliness of diagnoses. For instance, in one case, a speech-language pathologist initially dismissed concerns about ASD, attributing symptoms to environmental factors, a trend noted in other Gulf studies as well (Qoronfleh et al., 2019). Such delays in diagnosis have been documented across the region, with diagnostic fragmentation undermining the consistency and thoroughness of assessments (Al-Farsi et al., 2019).

Research from Saudi Arabia indicates that the use of standardized protocols for diagnostic procedures can reduce inconsistencies and delays (Al-Maliki & Al-Juhani, 2023). Implementing a centralized diagnostic system in Kuwait, modeled on best practices seen in Europe, such as the UK's National Health Service (NHS), would address these challenges by reducing the need for families to navigate multiple institutions and professionals (Male et al., 2023). A centralized system would ensure a more streamlined and coordinated approach, ultimately improving diagnostic accuracy and reducing delays.

Emotional Challenges for Families

The emotional toll on families navigating the ASD diagnostic process in Kuwait is profound. The uncertainty caused by conflicting reports and the lack of clear guidance leaves many parents feeling isolated and anxious. As one parent explained, the diagnostic process often felt like a "rollercoaster" of emotions, where hope and despair fluctuated with each new assessment. This is consistent with findings from other Gulf countries, where the lack of timely, clear communication from healthcare providers exacerbates emotional distress (Chinar & Geradi, 2022).

In particular, the confusion caused by inconsistent diagnostic outcomes adds to this strain. A study in Oman found similar issues, with parents reporting frustration at having to reconcile conflicting diagnoses from different professionals (Qoronfleh et al., 2019). In the Kuwaiti context, these challenges are compounded by the lack of psychological support services tailored to parents going through the diagnostic process. Establishing dedicated counseling services to help families manage the emotional strain would be a crucial step in alleviating this burden.

The lack of psychoeducation for parents following a diagnosis also plays a role in exacerbating stress levels. Research from the UK has shown that providing parents with information and support immediately after an ASD diagnosis can significantly reduce anxiety and improve outcomes for both the child and family (Beresford & Mukherjee, 2023). Kuwait could benefit from similar programs to offer families the emotional and practical support they need to navigate the complexities of ASD diagnosis and care.

Financial Strain and Inadequate Public Support

Financial challenges are another critical barrier for families seeking early diagnosis and interventions for ASD in Kuwait. With long wait times in the public sector, many families are forced to seek private care, which places a heavy financial burden on them. In this study, families reported spending substantial sums on private therapy and assessments, often taking out loans to cover these costs. This mirrors findings from other Gulf countries, where reliance on private healthcare services is

often the only viable option due to under-resourced public systems (Al-Farsi et al., 2019).

In Qatar and Oman, efforts have been made to address this by expanding public sector support for ASD-related therapies, but these initiatives are still in their early stages (Qoronfleh et al., 2019). In contrast, Kuwait has yet to implement a comprehensive financial assistance program for families with children diagnosed with ASD. Increasing government subsidies for therapies like Applied Behavior Analysis (ABA) and making them available through public healthcare services would significantly reduce the financial strain on families and ensure that all children have access to the support they need, regardless of their financial situation.

Moreover, the lack of awareness among families about available financial support exacerbates this burden. Public awareness campaigns could play a critical role in ensuring that families are informed about their rights and the financial assistance available to them. In the UK, similar initiatives have been instrumental in helping families navigate the financial aspects of ASD care (Underwood et al., 2021).

Advances in Diagnostic Technologies and Future Directions

Recent technological advancements offer promising solutions to some of the challenges associated with early autism diagnosis. Rani and Verma (2024) introduced a novel approach that leverages machine-learning algorithms to analyze video recordings of children's activities. This activity-based diagnostic method has the potential to reduce the time required for a formal diagnosis by identifying key behavioral markers in a controlled setting. By automating parts of the diagnostic process, such technologies could alleviate the strain on overburdened healthcare systems and provide parents with earlier access to interventions.

However, while these innovations represent a significant step forward, their implementation in regions like Kuwait may face hurdles. The integration of such technologies into existing healthcare systems requires significant investment, both in terms of technology and the training of professionals to use these new tools. Moreover, cultural and

systemic barriers—such as the stigma surrounding developmental disorders—must be addressed to ensure widespread adoption and accessibility of these diagnostic tools (Rani & Verma, 2024).

Recommendations for Systemic Reform

To address the challenges identified in this study, several reforms are recommended. First, Kuwait should prioritize the establishment of a **National Autism Diagnostic Center**, where all necessary assessments, therapies, and support services are consolidated under one roof. This would ensure a more streamlined diagnostic process, improve consistency in assessments, and reduce delays. Lessons can be drawn from Oman and Qatar, where efforts to centralize services have already begun to show promise (Qoronfleh et al., 2019).

Second, expanding **public awareness campaigns** is crucial. Many families are unaware of the financial support available to them, and clearer communication from government institutions could alleviate some of the financial strain that families currently face. Finally, **legislative changes** are needed to ensure that therapies like ABA are fully covered by the public healthcare system. As the findings show, many families are forced to pay out-of-pocket for these therapies, which places undue financial pressure on them. By expanding public coverage for essential therapies, Kuwait can ensure that all children with ASD have access to the care they need.

Conclusion

The early diagnosis and care pathways for children with Autism Spectrum Disorder (ASD) in Kuwait are hindered by significant systemic challenges. Fragmented diagnostic processes, long waiting periods, and inconsistent assessments delay timely interventions, leaving families confused and emotionally burdened. These issues, combined with the financial strain of seeking private care, illustrate the need for urgent reforms to improve access to services and support for families navigating the complexities of ASD.

However, there are clear opportunities for improvement. Establishing a centralized diagnostic center would streamline the process, providing more consistent evaluations and reducing delays in accessing care. Moreover, technological advancements, such as machine-learning tools

for analyzing behavioral data, hold promise for accelerating the diagnostic process and reducing the strain on healthcare systems. While their implementation may pose challenges, such innovations could play a vital role in improving early detection.

Expanding public awareness about available financial support and enhancing government subsidies for therapies like Applied Behavior Analysis (ABA) are also crucial. These steps would help to alleviate the financial burden on families and ensure that all children have access to the necessary interventions, regardless of their socioeconomic status.

Ultimately, addressing these systemic issues will significantly improve the quality of care for children with ASD in Kuwait. By streamlining the diagnostic process, embracing new technologies, and providing stronger financial support, Kuwait can ensure that children receive the timely interventions they need to thrive. These reforms are not only vital for improving health outcomes but also for supporting the emotional and financial well-being of families across the country.

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