

Perspathers and Mothers Perspectives of Autism Spectrum Disorder Children about Autism Services in Saudi Arabia

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Abstract:

This research explores the perspectives of fathers and mothers of children with Autism Spectrum Disorder (ASD) regarding autism services in Saudi Arabia. Despite commendable efforts by the government and organizations like the Saudi Autism Center, there is a need for a deeper understanding of the experiences and challenges faced by families accessing these services. Mothers, often primary caregivers, navigate unique challenges, while fathers may encounter distinct barriers. This study aims to bridge the existing gap in literature by comparing the perspectives of fathers and mothers, shedding light on their roles, self-efficacy, and priorities within the context of autism services. The participants included 265 mothers and 64 fathers aged between 30 and 39 years, reflecting an 80-20% distribution. The study explored demographic information, parental roles, self-efficacy, and perspectives on various services using a survey. Results indicated that mothers perceive a greater role in their child's life, influencing their self-efficacy. Fathers expressed a need for awareness and intervention services, emphasizing parental involvement, while mothers prioritized well-equipped autism centers, qualified specialists, and information linkage. This study provides valuable insights into the diverse needs of families affected by ASD and highlights the importance of tailoring support services to address both parental perspectives. Limitations include participant imbalance and a focus on Saudi Arabian services, suggesting the need for broader, more diverse research to enhance.

Keywords:

ASD children, Parents of ASD children, self-efficacy, Saudi Arabia.

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Introduction:

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by challenges in social interaction, communication, and repetitive behaviours (APA, 2013). In recent years, there has been a growing awareness of ASD in Saudi Arabia, leading to increased attention on the provision of autism services. As the prevalence of ASD continues to rise globally, understanding the unique perspectives of parents, particularly fathers and mothers, becomes crucial for providing effective and tailored support services.

Saudi Arabia has made noteworthy strides in the realm of autism services in recent years, reflecting a growing awareness and commitment to supporting individuals with ASD. The government has demonstrated a proactive stance by implementing measures to improve awareness, diagnosis, and intervention for individuals affected by ASD. Initiatives such as the Saudi Autism Center have played a pivotal role in advancing the quality of services available. For instance, the Saudi Autism Center has been instrumental in offering diagnostic assessments, therapeutic interventions, and support programs tailored to the unique needs of individuals with ASD and their families (Alshaban, 2018). Additionally, various support organizations have emerged, contributing to the multifaceted landscape of autism services in the country.

Despite these commendable efforts, the overall effectiveness of these services and the nuanced experiences of families navigating the system remain areas of ongoing exploration. The study sheds light on the impactful role of the Saudi Autism Society, emphasizing the need for continuous research to assess the outcomes and address any gaps in the existing services. Furthermore, the complex nature of ASD necessitates a comprehensive understanding of how these initiatives are perceived and experienced by the families they aim to assist. A more in-depth investigation into the day-to-day challenges faced by families and the effectiveness of interventions is crucial for refining and enhancing the support structures currently in place. By delving into the lived experiences of families with ASD children, researchers and policymakers can gain valuable insights into the areas that require attention and improvement, ultimately contributing to the ongoing evolution of autism services in Saudi Arabia.

Review of the Literature

Mothers often play a central role in the care and support of children with ASD. Research indicates that mothers tend to be more involved in seeking and utilizing autism services (Alquraini, 2019). Mothers may have unique insights into the challenges and successes of these services, as they are often the primary caregivers. Their perspectives are influenced by the daily interactions, emotional bonds, and advocacy roles they assume for their children (Al-Gamdi et al., 2020).

Mothers of children with ASD often find themselves at the forefront of seeking and utilizing autism services in Saudi Arabia. Research by Alquraini (2019) emphasizes the central role mothers play in the care and support of their children with ASD. These mothers, as primary caregivers, are deeply involved in daily interactions, therapeutic interventions, and advocacy for their children within the complex landscape of autism services. They navigate the challenges of accessing services, including dealing with limited awareness,

societal stigma, and financial constraints (Al-Gamdi et al., 2020). Mothers' perspectives are multifaceted, reflecting their emotional bonds, coping mechanisms, and experiences with various support systems. The qualitative case study delves into the experiences of Saudi parents raising children with ASD, shedding light on the emotional and practical aspects of caregiving. Understanding mothers' perspectives is crucial for tailoring autism services to address the unique needs and challenges faced by Saudi mothers, ultimately contributing to the holistic well-being of the entire family.

Fathers, while also integral to the well-being of children with ASD, may encounter distinct challenges and possess unique perspectives regarding autism services in Saudi Arabia. Almalki et al. (2021) highlight that fathers may face barriers in accessing support services due to work commitments and societal expectations. These challenges may result in fathers being less visibly involved in the day-to-day care of children with ASD, but their perspectives are equally valuable for understanding the broader family dynamics. Research suggests that fathers may experience feelings of isolation and lack of support, emphasizing the need to explore and address these issues to ensure their active participation in the caregiving process (Al-Gamdi et al., 2020). The study by Almalki et al. (2021) specifically investigates the barriers faced by fathers in accessing services for ASD in Saudi Arabia, providing insights into their unique challenges and opportunities for intervention. Recognizing and understanding fathers' perspectives is essential for developing inclusive and family-centered autism services that consider the diverse roles within Saudi Arabian families affected by ASD.

In conclusion, recognizing and understanding the perspectives of both fathers and mothers of children with ASD in Saudi Arabia is crucial for the holistic development and enhancement of autism services in the country. Mothers, often the primary caregivers, bring

a wealth of insights into the day-to-day challenges, coping mechanisms, and advocacy efforts within the intricate web of autism services (Al-Gamdi et al., 2020; Alquraini, 2019). Fathers, though sometimes less visibly involved due to societal expectations and work commitments, offer unique perspectives that contribute significantly to the broader family dynamics (Almalki et al., 2021). Recognizing and appreciating these distinct viewpoints is essential for tailoring support services to address the diverse needs of Saudi families affected by ASD.

Despite the importance of considering both parental perspectives, it is noteworthy that there remains a notable gap in the literature regarding comparative studies between mothers and fathers. The majority of research has predominantly focused on mothers, leaving a significant void in our understanding of the experiences, challenges, and contributions of fathers within the context of autism services in Saudi Arabia (Almalki et al., 2021). Bridging this gap by conducting more studies that explicitly compare and contrast the perspectives of mothers and fathers will not only enrich the existing knowledge but also inform policies and interventions that cater to the unique needs of each parent. Ultimately, a comprehensive understanding of both maternal and paternal viewpoints will contribute to the creation of more inclusive and effective autism services that address the diverse dynamics within Saudi Arabian families affected by ASD. This research aims to understand the differences between the perspectives of fathers and mothers of children with autism spectrum disorder regarding autism services in Saudi Arabia. The study seeks to shed light on the complexities of both viewpoints, examining the unique experiences and challenges faced by each parent in accessing and utilizing autism services in the country.

Methods:

Participants and procedure:

The study included a total of 329 parents, with 265 mothers and 64 fathers participating. This means that fathers comprised 20% of the total participants, while mothers accounted for 80%. In South Africa, it is common for mothers to be expected to be the primary caretakers of children, while fathers are typically seen as the providers (Mutua & Sunal, 2012).

The majority of parents in the study were between 30 and 39 years old and were married. Of the fathers, 91% were employed, while only 31% of mothers were employed, resulting in 60% of mothers being unemployed. In terms of education, most parents had a diploma or bachelor's degree. Only 10% of fathers had a higher level of education, while a mere 2% of mothers did (table 1).

When it came to the number of children with ASD, the majority of participating parents had only one child with ASD, accounting for 96% of the total. A small percentage, 3%, had two or three children with ASD. In terms of the age range of children with ASD, 35% fell between the ages of 3 and 4, while 61% were older than six years. The age of diagnosis varied, with 64% of children being diagnosed between 4 and 3 years old, and 23% being diagnosed before the age of two. Lastly, the study found that the majority of ASD children were boys, constituting 71% of the participants, while girls made up 29%.

table1. Participated fathers and mothers' demographic information

Demographic variables	Fathers 20%	Mothers 80%
Age:		
Less than 20	7%	9%
20 to 29	2%	15%
30 to 39	48%	51%
40 to 49	36%	25%

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More than 50	8%	1%
Maternal status		
Married	86%	84%
Divorced	2%	11%
Widow	1%	2%
participants' occupation		
employee	91%	31%
unemployed	5%	60%
student	5%	3%
other	0%	6%
Education level		
primary	0%	5%
Intermediate	5%	9%
Secondary	40%	31%
Diploma and Bachelor	45%	53%
Higher education	10%	2%

Instruments:

An E-copy survey link was distributed to the parents through autism center across the SA via emails and text messages. The link opens a E-copy survey through website (monkeysurvey). The study aims and procedure was explained to the directors of the autism centers through an official letter.

The author *used E-survey to reach as many participants as possible*. The survey contains small introduction and the study information sheet written by the author. Then parents and ASD children' demographic information. Lastly, a listed number of services to be rank in Likert scale. Using Likert scale which Willits et al. (2016) defined as a tool to assess personal respondents' attitudes. There were three levels to choose from: very important, somewhat important, and not important. 4) open ended question where participants can add any services that is not listed. The reason of choosing an e-survey in to recruit large number of participants as possible and to encloud participant from different region.

According to the survey, participants came from nine region out of thirteen, a total from thirty-three city.

Statistical Analysis:

To understand the participants' perspectives, the author investigated the role of parents in caring for their child with ASD. Parents were asked to indicate their responsibility for their child's day-to-day routine. The results showed that 77% were mothers, 17% were fathers, and 6% were others (sister, brother, nanny/caretaker).

To examine the participants' self-efficacy, participant fathers and mothers were asked throughout the survey to assess themselves by ranking their knowledge about autism. They were instructed to choose a value from 1 to 5, with 1 representing minimum knowledge and 5 representing the highest knowledge. The results indicated that the majority of fathers, at 33%, ranked themselves at one, suggesting that the majority believe they have low knowledge. Only 5% of participants ranked themselves with 5. (see figure 1).

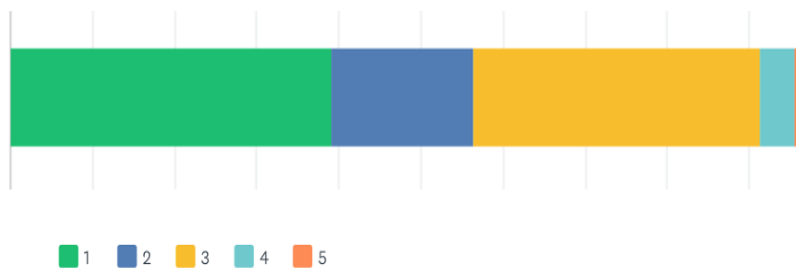


figure1. Fathers' self-efficacy

On the other hand, mothers' self-efficacy was somewhat different; most mothers (27%) ranked themselves between 3 and 5, and 20% ranked themselves as five. This indicates that mothers believe they have adequate knowledge about autism (see figure 2). This

illustrates that both believe that they know more than fathers about their ASD child's condition.

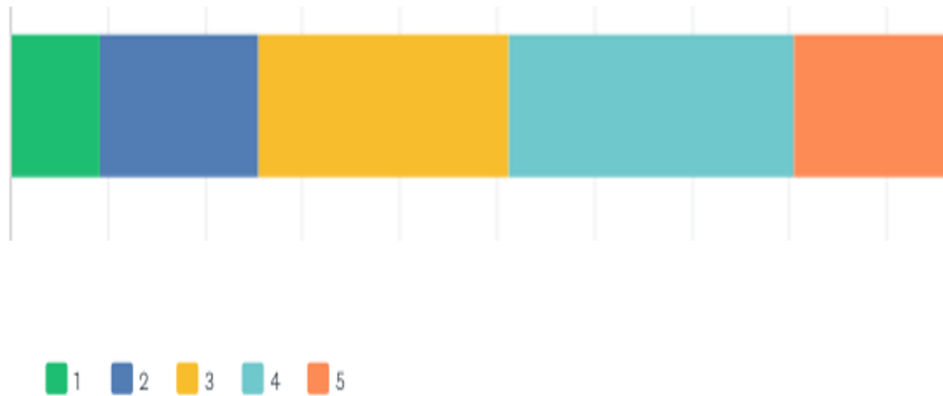


Figure 2. Mothers' self-efficacy

A survey was distributed to fathers and mothers of children with ASD, asking them to evaluate various services. A total of 93 fathers and 468 mothers completed the survey, resulting in a total of 561 responses. The responses of fathers and mothers were analyzed separately to understand each parent's perspective on autism-related services. The survey aims to examine the parents' perception regarding service for ASD children in SA; therefore the survey contains questions asking parents to rate number of services.

Overall, the majority of participants found that most services are necessary and important. However, this study focuses on highlighting the services that scored the highest and those that were ranked as least needed.

Fathers identified awareness services, intervention services, and parents' roles as the most needed services. Over 95% of participating fathers felt that these services were lacking and needed development. The study revealed that fathers emphasized the need for awareness services, such as educating students about autism and

raising awareness in society. They also stressed the importance of intervention services, including starting intense sessions at an early age and delivering sessions covering all skills (speech, education, mobility). Additionally, fathers highlighted the significance of involving parents in the ASD child's plans, fostering open communication with specialists/teachers, and administration.

On the other hand, over 95% of mothers believed that the most needed services included providing a sufficient autism center, qualified specialists, linking information between centers and hospitals/clinics, and similar intervention services as fathers. Mothers placed a high emphasis on having an affordable and accessible autism center. The study also indicated that mothers recognized the importance of developing and training specialists/teachers. Lastly, mothers believed that linking information about ASD children between clinics/hospitals and autism centers could be beneficial for the child.

In contrast, most fathers expressed that integration services should not be provided to their children with ASD. A small percentage of both fathers (5%) and mothers (4%) agreed that there was no need to provide a specific diet to their ASD children and that a nanny/home caretaker was not crucial. The study also revealed that some mothers (6%) did not consider awareness services necessary, as they ranked them as not needed.

Discussion:

This study has showed the different preceptive between father and mother of ASD children. To help us to understand that a foundation aspect was ought to be investigated; which of them have main role in the child life. This can help us to understand the role that each one play in the ASD child life which may impact their perspective on autism related services. The result shows that most mother have greater role in their child life; meaning that they may be aware of

their ASD child needs. According to Mutua & Suna; 2102, in the Arab culture, mothers take a great role of primary childcare, and the fathers are more likely to providing financial support. The mothers' great role may have impacted the result of parents' self-efficacy. As the results shows that most mothers as an expert in their ASD child condition. Similar, Hotez, Swanson & Sigman (2019) found out that parents' engagement has a reflection and self-evaluation. The authors have found that parents with high self-efficacy are more likely to have greater desire to increase their role and knowledge.

The comprehensive exploration of parental perspectives on ASD services, as revealed through this survey, sheds light on the intricate needs and priorities of families affected by having ASD children. Fathers' emphasis on awareness programs, intervention services, and active parental involvement underscores the urgency for targeted educational initiatives and practical support (Fondacaro, Fondacaro & Camilleiri, 2022, Moerschbacher, 2019). These findings align with previous research that has highlighted the importance of involving fathers in ASD interventions, as they play a crucial role in advocating for their child's needs and accessing appropriate services (Camila & Benson, 2020). Conversely, mothers highlighted the paramount importance of a well-equipped autism centre, qualified specialists, and efficient information linkage between healthcare facilities and autism centres (Moerschbacher, 2019). These findings are in line with previous studies that have emphasized the significance of accessible and comprehensive healthcare services for children with ASD and their families.

As the result shows, mothers believe that they have satisfactory knowledge about autism compared to fathers. However, it is important to note that fathers tend to have higher levels of education than mothers (see table1). This suggests that having a higher education does not necessarily reflect on the level of knowledge about autism (Geelhand, P., Bernard, P., Klein, O. *et al.* 2019).

Gender differences in knowledge about autism can be influenced by various factors, including societal expectations and roles. Research has shown that mothers often take on the primary caregiving role for children, including those with autism, which may contribute to their perception of having more knowledge about the condition (Kate, Smith & Russell (2018). On the other hand, fathers may have different priorities or responsibilities that limit their involvement in learning about autism (Giambattista, Ventura, Trerotoli, Margari & Margari, 2021, Kate et al., 2018). It is worth noting that these findings are based on general trends and may not apply to every individual or family. Each family's dynamics and circumstances can vary, leading to different levels of knowledge and involvement in understanding autism.

The shared concern for intervention services by both parents, with mothers emphasizing accessibility and affordability, underlines the diverse and evolving needs within the ASD community. This emphasizes the importance of addressing barriers to accessing intervention services, such as financial constraints and limited availability of specialized providers, in order to meet the needs of families more effectively. A study conducted in Jordan found that 71.5% of children with ASD received rehabilitation services, but there were still barriers to accessing these services (Babalola, T., Sanguedolce, G., Dipper, L. *et al.* 2024). Some common barriers reported in other studies include long waitlists, financial constraints, and a lack of knowledge about where to go or who to contact (Boulton, Hodge, Levu, Ong, Silove & Guastella, 2023). These barriers can significantly delay the start of intervention services, potentially impacting the child's development and progress. This indicates that those barriers are international and essential solutions should be addressed.

In conclusion, Understanding the different perspectives between fathers and mothers is crucial in the context of autism services as it

can greatly impact the evaluation and development of these services. By considering the unique viewpoints of both parents, service providers can gain a deeper understanding of the needs and preferences of families with children on the autism spectrum. This understanding can lead to more effective and tailored support for these families.

Limitation:

This study possesses certain limitations. Firstly, it exhibits an imbalance in participant demographics, with a greater representation of mothers compared to fathers. Secondly, the scope of this study is confined to parents who have children with autism and have undergone specific services in Saudi Arabia. These limitations should be considered when interpreting the findings, as they may impact the generalizability and broader applicability of the results. Given the identified limitations in this study, there is a clear need for further research to enhance the comprehensiveness and generalizability of findings. Future investigations should strive for a more balanced representation of both mothers and fathers as participants to ensure a comprehensive understanding of parental perspectives. Additionally, expanding the scope beyond parents who have experienced services in Saudi Arabia would contribute to a broader and more diverse understanding of the challenges and experiences faced by families with children with autism. This broader approach could provide valuable insights applicable across various cultural and geographical contexts, ultimately contributing to more robust and widely applicable knowledge in the field.

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