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“There is always pressure”: Using discourse analysis to understand parents’ experiences of autism services in Saudi Arabia

By

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Abstract

Parents of children with autism spectrum disorder (ASD) face strong and complex feelings in accessing autism services, due to their inaccessibility, poor quality, and financial cost. In order to enhance these services, and improve the life satisfaction and quality of families who have children with ASD, more research is needed to understand parents' emotions, satisfaction, and dissatisfaction with autism services. As such, this qualitative study uses deductive and inductive discourse analysis to examine data collected from parents of ASD children in Saudi Arabia. The findings show that parents have more negative feelings towards autism services than positive. It is thus suggested that policy makers take effective action to improve diagnostic services and the quality of autism services, to reduce stressors on caregivers, and improve their life satisfaction and quality.

Keywords**:** Autism, Saudi Arabia, parents, Autism services, discourse analysis.

المستخلص

يواجه أولياء أمور الأطفال ذوي اضطراب طيف التوحد مشاعر قوية ومعقدة في الوصول إلى خدمات التوحد، وذلك بسبب صعوبة الوصول إليها، وضعف جودتها، وتكلفتها المالية. ولتحسين هذه الخدمات، وتحسين جودة حياة ورضا أسر الأطفال ذوي اضطراب طيف التوحد، هناك حاجة إلى مزيد من البحث لفهم مشاعر أولياء الأمور ورضاهم وعدم رضاهم عن خدمات التوحد. ولذلك، تستخدم هذه الدراسة النوعية تحليل الخطاب الاستنتاجي والاستقرائي لفحص البيانات التي جُمعت من أولياء أمور الأطفال ذوي اضطراب طيف التوحد في المملكة العربية السعودية. وتُظهر النتائج أن أولياء الأمور لديهم مشاعر سلبية تجاه خدمات التوحد أكثر من المشاعر الإيجابية. ولذلك، يُقترح أن يتخذ صانعو السياسات إجراءات فعالة لتحسين خدمات التشخيص وجودة خدمات التوحد، لتقليل الضغوط على مقدمي الرعاية، وتحسين رضاهم عن حياتهم وتحسين جودة الحياة.

الكلمات المفتاحية: *التوحد، المملكة العربية السعودية، أولياء الأمور، خدمات التوحد، تحليل الخطاب.*

Introduction

Autism spectrum disorder (ASD) is “a developmental disability” and complex disorder characterized by difficulties in social communication, repetitive behavior, and restricted interests (CDC, 2024). It is classified as a lifelong disorder, requiring special support and services (American Psychiatric Association, 2024). As such, meeting the needs of individuals with ASD often requires parental or caregiver interaction with various services, such as health care and educational services across the diagnosed individuals’ lifespans (Al Awaji et al., 2024). However, autism services are not always easily accessible, with multiple barriers reported by parents of individuals with ASD. For instance, professionals who lack training and understanding of ASD are likely to slow the diagnosis process, which delays access to autism services (Desmarais et al., 2018).

This study aims to fill the gap in research on parents’ experiences and satisfaction with autism services. In particular, it aims to develop a deeper understanding of parents’ experiences when they interact with autism services in Saudi Arabia. The ultimate aim is to improve outcomes for families and individuals with ASD, and to improve their satisfaction with autism services and support in the country.

Literature review

According to Solomon & Chung (2012), parents of children with ASD face strong and complex feelings. Beginning with the diagnosis process, parents experience intense emotions such as shock, denial, anger, helplessness, guilt, feeling lost, and sadness (Bravo-Benítez et al., 2019). Some parents reported feeling annoyed by physicians too busy to explain the disorder to them, while others were frustrated due to the long wait for a diagnosis (Hosseinpour et al., 2022).

After receiving the official ASD diagnosis, parents report feeling lost, with no directions to available services for their children (Corcoran et al.,2015) Many parents stated that taking care of their children is stressful and challenging, causing frustration and exhaustion (Hosseinpour et al., 2022). Some parents reported feeling isolated due to their children's behavior, while some felt ashamed (Solomon & Chung, 2012). In considering their children's future with ASD, many parents reported concerns and stress (Bravo-Benítez et al., 2019).

On the other hand, certain parents had a positive attitude, enjoyed parenting their children, appreciated their differences, and were thankful of having a child with ASD (Corcoran et al., 2015). According to Bravo-Benítez et al., (2019), raising a child with ASD significantly impacts caregivers' mental and physical health. As such, they recommend the diagnosis be conducted without delay to allow parents to adjust to and accept the new situation. They also emphasized the importance of having trained professionals who can monitor and ensure adequate emotional support, including providing the necessary coping strategies for managing the disorder.

Theory

This research adopted life satisfaction theory, which defines life satisfaction as how an individual feels about his or her life most of the time, how much life has brought to him, or what is expected (Kainulainen et al., 2018). Another definition sees life satisfaction as an evaluation of the person's quality of life from his unique perception and criteria (Navroodi et al., 2018).

Although the relationship between life satisfaction and the quality of autism services is documented in the literature (Correale et al., 2022; Franke et al., 2019; Khusaifan & El Keshky, 2021), further research is needed on the lived experiences of parents with autism services, as having a child with ASD is often associated with less life satisfaction, and high levels of stress (Navroodi et al., 2018). Thus, the current research aims to fill this knowledge gap by comprehensively exploring parents' emotions towards and satisfaction with autism services.

Method

This qualitative study explored parents' satisfaction and dissatisfaction with autism services to develop a deeper understanding of their experiences in accessing such services. Pre-collected data from semi-structured interviews was used to answer a new set of unexplored research questions. The use of pre-collected data allows us to overcome various limitations, including funding, as noted by Coe et al. (2021).

Ethical considerations

The data was examined for further analysis using the original ethical protocol, in which parents gave written consent to the following statement: "data may also be presented in the future at conferences and published in academic journals and texts". Pseudonyms were used instead of the participants' real names to maintain anonymity and confidentiality. Many researchers encourage the reuse of data, for example Lamb et al., (2024), who argue that since participants share their time, thoughts, experiences, and emotions, the outcomes of such data should be maximized. However, reusing data remains an under-used technique in educational studies.

Research questions

- How do parents of individuals with ASD express their satisfaction with autism services?
- How do parents of individuals with ASD express their dissatisfaction with autism services?

Sample characteristics

Nine parents were selected using a purposive sampling technique. The criteria of selecting these parents were: the parents have a child or adult with ASD, they live and access autism services in Saudi Arabia.

The selected sample were seven mothers and two fathers, and all of them were Saudis apart from two mothers, one of whom was a resident, and the other was unknown. The age of the children ranged from 3 to 18 years. Table 1 shows the participants' demographics in terms of parental gender, child gender, number of children for each parent, and child age.

Table 1.

Participants' demographics (n=9)

Parents' code	Parent Gender	Child Gender	Number of children	Child Age
P1	Male	Male	1	11
P2	Female	Female – Male	2	13–18
P3	Female	Male	1	9
P4	Female	Male	1	8
P5	Male	Male	1	8
P6	Female	Female	1	3
P7	Female	Female – Male	2	18–24
P8	Female	Male	1	3
P9	Female	Female	1	11

Data analysis

The data analysis in the original research examined how parents described their experiences in accessing diagnostic services, early intervention services, educational services, and health services, focusing on the quality of services, rather than parental description of their experiences. Therefore, this research adopted discourse analysis to develop a deeper understanding of parents' experiences, satisfaction, and dissatisfaction, by examining their words. One of the strongest analysis methods in qualitative research, discourse analysis evaluates language and messages to provide a rich and deep understanding of different types of communications (written and spoken languages) (Coe et al., 2021). The aim of this research was to apply discourse analysis to the pre-collected qualitative data from nine interview transcripts. The transcripts consist of answers to the pre-research question: What are parents' perspectives on the quality of autism services for individuals with ASD in Saudi Arabia?

In order to disclose the meaning that underpins the text, the researcher followed these steps: First, the researcher asked what tones parents were using to express their satisfaction and dissatisfaction about autism services? At this stage, the researcher examined the phrases and words used, and coded them using Plutchik's Wheel of Emotions, which categorizes emotions into eight main categories. Half of these emotions are negative, and the other half are positive (Mohsin & Beltiukov, 2019). Second, the researcher used inductive discourse analysis to understand other emotions and feelings expressed by parents that were not covered by Plutchik's Wheel of Emotions, such as feeling upset and thankful. The data analysis was carried out manually because the amount of data is reasonable. The researcher coded the transcripts directly in Microsoft word, and then organized the codes in a Microsoft Excel spreadsheet. To better understand parents' feelings, the researcher listened to the audio recording and read the transcripts at the same time, which helped in understanding the intended meaning and the messages communicated through parents' tone of voice.

Trustworthiness and Validity

To increase trustworthiness and validity, the research was conducted in accordance with the quality indicators suggested by Brantlinger et al. (2005). For the meaningful and relevant document indicator, this study used interview transcripts relevant to the research objectives. The second indicator of storing documents carefully was also followed, with each transcript named to facilitate easy access. The third indicator requires documents to be cited and sufficiently described; the researcher used sufficient quotations from the data, and cited them properly. Lastly, it is important to ensure the confidentiality of private documents, which was done by replacing participants' real names with codes, storing the data appropriately, and not sharing it with anyone outside the research project.

Findings

Overall, this study revealed that parents have more negative than positive feelings when they talk about autism services. The following is a detailed presentation of the research results, divided into two categories:

- Feelings communicated to express satisfaction
- Feelings communicated to express dissatisfaction

Feelings communicated to express satisfaction

Table 2 includes all the feelings communicated to express satisfaction. These feelings were in relation to the good quality of autism diagnosis services, their children's abilities and giftedness, and comprehensive autism services, good future, community inclusion and family support. These three main messages are further detailed below.

Message 1: Good quality of autism services and good diagnosis services

P6 expressed happiness regarding the good quality of autism services, and talked about the intervention and sessions provided to her son: "We apply at home and come back. There was work, there was work". In terms of expressing satisfaction about the diagnosis service, P4 said, "After we examined him again after a few years with a different doctor... thank God the report was fair...". In terms of expressing acceptance, parents expressed it in relation to accepting their child's diagnosis, and how it was delivered to them. As P2 said, "Once the correct diagnosis was made, I started to know how to deal with him in the right way."

Table 2: Feelings communicated to express satisfaction

Feelings	The message
Happy	Good quality of autism services and good diagnosis services
Satisfied	
Acceptance	
Proud	Of their children's abilities and giftedness
Hope	Comprehensive autism services Good future Community inclusion Family support

Message 2: Children's abilities and giftedness

Parents expressed pride in their children's abilities and giftedness. As P9 said, "In handcraft skills, she is ahead of her age and ahead of her time. She is creative in this area."

Message 3: Comprehensive autism services, good future, community inclusion, family support

Parents expressed hope in obtaining comprehensive autism services, a good future, community inclusion, and family support for their children. For instance, P1 said that his child needs "a professional rehabilitation center that includes all the services that any child with autism needs…". P2 hoped for a better future for her son, specifically stating that "I have hope that the situation at the university will be better," while P9 said she needs more family support.

Feelings communicated to express dissatisfaction

Table 3 lists the feelings parents communicated to express dissatisfaction. In particular, dissatisfaction was vented about poor diagnosis support and services, poor guidance after diagnosis, their children's health condition, their child's ASD, and taking care of their children. They also expressed dissatisfaction regarding the poor quality of autism services, difficulty in accessing services, the financial burden, fear about the future, and being isolated. Some parents further communicated their feelings in relation to poor family support, and community treatment.

Message 1: Poor diagnosis support and services, and poor guidance after diagnosis

Parents communicated varied feelings in regard to the diagnosis process; some parents were shocked and upset, such as P2, who stated that the psychiatric did not know what Asperger syndrome was, which "was a shock to me". Meanwhile, a lack of support after her child's diagnosis left P6 in denial, and feeling guilt and shame about the diagnosis. According to her, "But my son does not have an eating disorder. I suspect it is not autism." The lack of guidance by services providers left P3 feeling sad, stating that, "No one guides us or teaches us or tells us what is right or what we should do…"

Table 3: Feelings communicated to express dissatisfaction

Feelings	The message
Denial	Poor diagnosis support and services Poor guidance after diagnosis
Guilt	
Shame	
Sadness	
Anger	
Lost	
Sarcasm	
Surprise	
Upset	
Sadness	Child's health condition Child's ASD Taking care of their children
Confusion	
Exhaustion	
Anger	Poor quality of autism services, Difficulty in accessing services Financial burden
Frustration	
Overwhelmed	
Feeling judged	
Disappointment	
Surprise	
Shock	
Upset	
Sadness	
Fear	The future Isolation
Pressure	Poor family support Community treatment
Rejection	
Misunderstood	

Message 2: Children’s health condition, ASD, and caregiving

Parents expressed feeling sad about their children’s health; for example, P6 said, “Every month I have to give him antibiotics...” In terms of their children’s condition, P5 expressed feeling confused about what his child has. He stated that as a family, they “started reading and it became like, ‘This could be autism, it could be not, it could be this...’.” In addition, some families said that taking care of their children is difficult and tiring. According to P9, “As a mother, I am literally exhausted.”

Message 3: Poor quality of autism services, difficulty in accessing services, and financial burden

Parents communicated many feelings related to the poor quality of autism services. For instance, P3 was angry that “There are very few places that accept children with ASD.” Another parent talked about feeling judged when she visits a hospital; “They judge only from the first time they hear that they are disabled.” In terms of financial burden, P9 reported her family “is financially exhausted” from accessing private services.

Message 4: The future and being isolated

Some families communicate feeling afraid of the future and of being isolated. P2, for instance, indicated that, “There are definitely concerns about his future relationships…” In terms of their fear of being isolated, P9 said, “I am afraid that…we will return to be isolated again.”

Message 5: Poor family support and community treatment

Parents felt pressurized and lacked support. According to P7, “There is always pressure, pressure on the family from the society and the child.” In terms of feeling rejected, parents expressed feeling that their children are unwanted by society.

Discussion

Emotions play a significant role on people’s happiness and satisfaction about their life; this research thus focuses on this aspect to improve parents’ quality of life. The researcher found that parents have positive feelings when the autism and diagnosis services are of good quality, in line with findings from other studies such as McCrimmon and Gray (2021), where parents highlighted that good diagnostic services and a diagnosis from a multidisciplinary team was satisfying, and met their needs. In addition, Smith-Young et al. (2020) stated that parents were relieved after the diagnosis result, and appreciated the good quality of autism services that improved their children’s abilities, which was seen in this study as well. Furthermore, the researcher found that parents were proud of their children’s abilities, similar to Myers et al. (2009), who found that a small number of parents were happy with their children’s uniqueness, and accepted their children the way they are, and Cororan et al. (2015), who found that some parents were happy with their children’s accomplishments.

On the other hand, the researcher found that parents to be dissatisfied when autism services are poor, and diagnosis services are inefficient. This was reported in various other studies, such as Gholipour et al. (2023), and Hemdi and Daley (2017). In particular, the findings show that negative attitudes by medical staff provoked parents’ negative feelings such as frustration and anger about the quality of autism services and the difficulty in accessing such services, corroborated by other research (Hosseinpour et al, 2022; Myers et al., 2009; Smith- Young et al., 2020). In addition, parents have negative feelings during the diagnosis process, as also seen in Bravo-Benítez et al. (2019), and lack support post-diagnosis, as noted by Hosseinpour et al. (2022). Similarly, the researcher saw parents report negative feelings about the lack of guidance and information after their children’s diagnosis, which was also evident in other studies (Hemdi & Daley, 2017 and Smith-Young et al., 2020). Lastly, parents reported feeling exhausted due to taking care of their children (Bravo-Benítez et al., 2019; Myers et al., 2009).

The above findings make it clear that a good diagnosis process and good quality of autism services have a major impact on parents' happiness and life satisfaction. As such, it is important for policy makers and service providers to take parents' perspectives into account in developing support and services for these children.

Research strengths and limitations

The findings of this study are unique in terms of highlighting aspects that satisfied or dissatisfied parents about autism services. It is a novel study that applied Plutchik's Wheel of Emotions and used deep discourse analysis to understand parents' feelings when they talk about autism services, adding to the literature in terms of understanding parents' perspective in regard to autism services. This study had a small sample, making it difficult to generalize the findings, it is recommended that future research is conducted on a larger sample, directly asking parents about their feelings and personal experiences when accessing autism services for their children with ASD. This research provided in-depth insights about parents' personal experiences, and the impact of autism services on their life satisfaction.

Conclusion

This study gives a deep insight into parents' psychological needs when it comes to their children with ASD. Parents need to learn various coping strategies through counselling services, social support, and psychological support, as they face numerous challenges after their child is diagnosed with this lifelong condition. Given that this study findings are consistent with the findings of other international research, it can be concluded that autism services are international issues that need to be addressed by governments worldwide to maximize the life satisfaction of people affected by autism and their caregivers. For example, improving the diagnosis process is needed on an international level, as is reducing families' financial burdens, providing quality autism services, and increasing support for affected families.

Further research should be conducted on the factors affecting such parents' life satisfaction and happiness, as well as on the wellbeing of parents who take care of children with ASD, as this condition usually increases stressors on the whole family, and parents in particular.

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