


Exploring quality of life, discrimination, and knowledge of parents of ADHD children in Saudi Arabia

A cross-sectional study

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Abstract

Attention-deficit hyperactivity disorder (ADHD) is the most common neurodevelopmental disorder in childhood. This study investigates the quality of life (QoL) of parents of children with ADHD, the discrimination they encounter, and their sources of information about the disorder. This cross-sectional study was conducted using an online questionnaire through Google Forms from March to April 2023. Study participants were recruited using a convenient sampling technique from patient records in 4 regions of Saudi Arabia. The questionnaire was sent through commonly used social media. QoL was assessed through the validated Arabic version of the World Health Organization Quality of Life Instrument, Short Form questionnaire. A total of 100 participants were recruited for this study. Most of the participants were from the southern region (80%, n = 80), 66.0% (n = 66) were mothers, 66.0% (n = 66) were married and 64% (n = 64) had a college degree. The mean scores of the physical, psychological, mental, environmental, total scales, and general QoL were (57.18 ± 13.67, 62.58 ± 17.49, 63.33 ± 23.12, 23.07 ± 12.87, 51.54 ± 14.34, 3.69 ± 1.06, respectively). Half of the population studied experienced discrimination with no significant differences between mothers and fathers (64% vs 68%, $P = .833$). The main source of information on ADHD was the Internet (49%) followed by schools (11%), and relatives (10%). Fifty-four percent of the participants have participated in workshops or seminars on neurodevelopmental disorders and 39.0% believed that schools and institutions are sufficiently equipped to support children with ADHD. ADHD had a profound impact on the QoL of parents, with a substantial portion facing discrimination due to their child condition. Additionally, parents showed a strong desire to acquire more information about ADHD, highlighting the need for a comprehensive understanding and support surrounding this condition.

Abbreviations: ADHD = attention-deficit hyperactivity disorder, QoL = quality of life.

Keywords: ADHD, discrimination, quality of life, source of information, stigma

1. Introduction

Attention deficit hyperactivity disorder (ADHD) presents as a condition marked by excessively elevated levels of hyperactivity, impulsivity, and inattention, with the onset typically occurring

before the age of 12 years.^[1,2] ADHD is the most common neurodevelopmental disorder in childhood, with an approximate worldwide prevalence of 5%.^[3,4] In 2019, the Global Burden of Disease study provided estimates of the worldwide age-standardized incidence and prevalence rates of Attention

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Informed consent was obtained from all the participants in this study.

The authors have no conflicts of interest to disclose.

The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

This study was conducted in accordance with the Declaration of Helsinki and approved by the research ethics committee of King Khalid University (ECM#2023-2125).

Tables and figures can be downloaded at: www.mdpi.com/xxx/s1.

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Deficit/ Hyperactivity Disorder (ADHD) throughout the lifetime. The figures were determined to be 0.061% (with a 95% Uncertainty Interval (UI) of 0.040–0.087) for incidence and 1.13% (with a 95% UI of 0.831–1.494) for prevalence. ADHD constituted 0.8% of disability-adjusted life years attributed to global mental disorders, and it should be noted that Global Burden of Disease assigned a mortality rate of zero to ADHD in this assessment.^[5] In a systematic review, the prevalence and risk factors of ADHD in Saudi Arabia were thoroughly examined. The pooled prevalence, as determined through observational studies, was found to be 12.4%. The prevalence of the ADHD subtypes was as follows; ADHD-inattentive was 2.9% (95% CI: 0.3%–23.3%), ADHD-hyperactive was 2.5% (95% CI: 0.2%–20.5%), and ADHD-combined was 2.5% (95% CI: 0.2%–20.5%). The study also revealed specific risk factors associated with an increased likelihood of ADHD. Children born to mothers with psychological disorders during pregnancy, inadequate vitamin B, allergic reactions, and those experiencing disabling muscle pain symptoms during pregnancy were linked to a heightened risk of ADHD.^[6] Despite the estimated high prevalence of ADHD among Saudi Children, there is a sparsity of literature looking into its effect on the children and their parent quality of life (QoL). Faden et al, investigated the QoL of parents of children with neurodevelopmental disorders. Their study showed that the effect on the QoL was exacerbated by the presence of severe symptoms and the diagnosis of autism. Additionally, there were no differences between mothers and fathers in their perception of the effect on their QoL.^[7] More than 60% of caregivers of children diagnosed with ADHD in Medina region reported experiencing a high burden on their lives, particularly evident among female caregivers.^[8]

ADHD is a prevalent and debilitating disease, frequently linked to other mental health disorders and causing a considerable burden on affected individuals, their families and the extended community.^[9] ADHD results in impairments in functioning across multiple settings such as school, home, and work environments, as well as a noticeable impact on various aspects of life, including academic achievements, social interactions, leisure activities, and home life.^[2]

Parents play a crucial role in caring for their children with ADHD, taking on responsibilities that differ from those faced by parents of unaffected children. These responsibilities encompass tasks such as initiating and facilitating professional assistance-seeking,^[10] managing the obscurities of ADHD treatment, and dealing with the substantial influence of ADHD on their children educational experiences.^[11] Family support has a strong correlation with improved health and more favorable psychosocial outcomes for children with chronic illnesses, and the dynamics within a family unit can change in conjunction with different developmental phases and varying degrees of autonomy.^[12] However, recent investigations in clinical settings have also revealed that ADHD in children exerts an adverse impact on the QoL of parents, in addition to their psychological well-being.^[4,13,14] QoL serves as a pivotal metric in steering healthcare decisions,^[15] and is of significant importance as a measure to assess the efficacy of healthcare.^[16,17] The definition of QoL has taken on various forms, often emphasizing an ideal state marked by general well-being where an individual functioning in various domains is shaped by the potential negative effects of diseases or disorders.^[16,18]

Parental knowledge of ADHD plays an essential role in shaping how they support their affected children, influencing aspects such as diagnosis, treatment, and treatment compliance.^[19] A review highlighted the importance of well-informed parental comprehension of ADHD for parents to make informed decisions about managing their children condition. However, many parents of children with ADHD tend to hold misconceptions about the disorder, underscoring the significance of accurate

information dissemination to facilitate effective caregiving and optimal outcomes for these children.^[20]

Discrimination stands as a significant obstacle to improving the quality of care and accessibility of mental health services. It was identified as a notable hurdle preventing the integration of individuals living with mental disorders into community activities, healthcare services, workplaces, and educational establishments.^[21] A study involving a community sample in South Africa demonstrated that a substantial majority of parents seeking treatment for their children ADHD encountered stigmatization associated with their children condition. Additionally, many parents acknowledged the prevalence of common misunderstandings regarding ADHD.^[22]

There is a scarcity of research investigating the burden, mental health consequences, exposure to stigmatization, and QoL experienced by caregivers of children diagnosed with ADHD in Saudi Arabia. This study proposes that parents of children with ADHD experience reduced QoL in addition to facing discrimination and stigmatization. This study aims to evaluate the QoL among the parents of children diagnosed with ADHD. Additionally, the study seeks to elucidate the discrimination they face and identify their sources of information on the condition.

2. Materials and methods

This cross-sectional study was conducted using an online questionnaire through Google Forms from March to April 2023. The study participants were recruited using a convenient and snow-balling sampling technique through the records of a non-governmental organization that works with children with ADHD and other learning difficulties. The questionnaire was sent through commonly used social media platforms (Instagram, Telegram, and Facebook). We included parents of children who were diagnosed with ADHD as indicated on their hospital medical records. The diagnosis was based on a clinical assessment by consultant physicians in the specialties of pediatrics, psychiatry, child and adolescent psychiatry, or developmental pediatrics based on the diagnostic criteria of The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.^[1]

2.1. Sample size calculation

Using G*Power software, the minimal sample size was 91 based on the following assumptions, the power of the study is 95%, alpha error is 0.05. Size effect of 0.384. The effect size was calculated based on the following assumption, the mean score of physical QoL was 50.7 ± 11.6 ,^[23] while the mean score of alternative hypotheses was 46.25.^[24] Our study included parents aged 18 years or older who willingly consented to participate. The exclusion criteria comprised parents with communication difficulties and parents lacking access to both a smartphone and the Internet.

2.2. Data management

The questionnaire collected sociodemographic data such as the participants' geographic region (eastern, middle, northern, or southern), their relationship to the child (father or mother), their marital status (married or single), their educational level (primary, secondary, high school, or college), their self-reported economic status (low, medium, or high), their occupation (business, engineering, housewife, other, teacher, or unemployed), and their number of children (one child, 2 children, 3 children, or 4 or more children). To assess the QoL in our study, we chose the validated Arabic short version of the World Health Organization Quality of Life instrument.^[25] This tool features 4 subdomains designed to evaluate the QoL across 4 fundamental areas: physical, psychological, social, and environmental and has been extensively used in similar

context.^[17,18,26] The questionnaire is composed of 26 items; 2 explore the general health and the remaining items are distributed as follows: 7 items for the physical domain, 6 items for the psychological domain, 3 items for the social relationships' domain, and 8 items for the environmental domain. The responses to the items are scored on a 5-point Likert scale from 1 to 5. A higher score is given for more positive responses. Following data collection, the domain scores were computed by summing the respective item scores within each domain. These domain scores were then transformed onto a positive 0–100 scale, where higher scores signified a better QoL.^[27]

Comprehensive information about the purpose and objectives of the study was provided to all participants, giving them the autonomy to decide whether to offer their informed consent and participate in the study or not. Throughout the research process, the research team placed a significant emphasis on safeguarding the confidentiality and anonymity of the participants' personal data. Ethical approval was obtained from the University of King Khalid Research Ethics Committee (ECM#2023-2125), following the principles of the Declaration of Helsinki.

A statistical analysis was carried out using the R software, version 4.1.1. Categorical variables were expressed as frequencies and percentages. To compare 2 independent categorical variables, Pearson chi-squared test was used. This test was utilized for categorical variables with more than 2 levels, generating values ranging from 0 to 1. A value of 0 indicated that there was no association, while a value of 1 signified a perfect association. T-test and ANOVA were used to test the difference in QoL scores across the different studied groups. A *P* value below .05 was considered statistically significant for this analysis.

3. Results

A total of 100 participants were recruited to this study. As illustrated in Table 1, most of the participants were from the southern region (80.0%), followed by the middle region (11.0%), eastern region (5.0%), and northern region (4.0%). Two-thirds of the participants were mothers, and the remaining respondents were fathers. Additionally, 66% indicated being married at the time of the study. The majority of the respondents had a college degree (64.0%), followed by high school (29.0%), primary school (4.0%), and intermediate school (3.0%) degrees. The economic status was predominantly medium (77.0%), with 12.0% in the high category and 11.0% in the low category. Most of the participants were teachers (32.0%), followed by housewives (12.0%), businesspeople (8.0%), engineers (3.0%), and unemployed (5.0%). A total of 43.0% had 4 or more children, 25.0% had 1 child, 18.0% had 2 children, and 14.0% had 3 children.

Figure 1 shows that almost half of the surveyed fathers and almost half of the surveyed mothers were exposed to discrimination. The difference was not statistically significant (*P* = .833).

A significant proportion (54.0%) acknowledged noticing developmental differences in their children compared to their peers, as shown in Table 2. Approximately 43.0% sought therapy or interventions for their child neurodevelopmental disorder, 38.0% engaged with their child healthcare provider to inquire about developmental concerns, and 54.0% participated in workshops or seminars on neurodevelopmental disorders (Table 2). 11.0% reported as a difficulty understanding feeling, 37.0% complained of social isolation/peer sharing (37.0%), 49.0% of parents reported that they did not receive enough information about neurodevelopmental disorders, including ADHD, 39.0% believed that schools and institutions are sufficiently equipped to support such children, 39.0% interacted with other parents for shared experiences and support, and 66.0% perceived that society is becoming more aware and accepting of neurodevelopmental disorders.

Table 3 shows that there were statistically significant differences in total QoL score across different sociodemographic factors like marital status, number of children and occupation *P* value < 0.05.

Figure 2 shows that the Internet is the most frequently encountered source of information (49%), followed by schools (11%) and relatives (10%).

As illustrated in Table 4, the means of the total, physical, psychological, mental, and environmental scores were 51.54 ± 14.34 , 57.18 ± 13.67 , 62.58 ± 17.49 , 63.33 ± 23.12 , and 23.07 ± 12.87 , respectively. Mothers showed slightly higher scores in physical and psychological domains and fathers had slightly higher scores in environmental domains. Total and mental domain scores were almost similar between parents. Despite these differences, the statistical analysis (*t*-test) indicated that these variations were not statistically significant (*P* > .05). In addition, the general QoL score did not show statistically significant difference between mothers and fathers.

Table 3 shows that there were statistically significant differences in total QoL scores across different sociodemographic factors like marital status, number of children and occupations (*P* < .05).

4. Discussion

In this research, our objective was to evaluate the QoL, and extent of discrimination faced by parents of children with ADHD in Saudi Arabia. Our findings revealed that approximately 50% of parents indicated experiencing discrimination from their community, with no notable differences between mothers and fathers. Additionally, we aimed to investigate the

Table 1
Demographic data of the participants.

Studied variable		N (%)
Region	Eastern	5 (5.0%)
	Middle	11 (11.0%)
	Northern	4 (4.0%)
	Southern	80 (80.0%)
Relationship to the child	Father	34 (34.0%)
	Mother	66 (66.0%)
Marital status	Married	66 (66.0%)
	Single	34 (34.0%)
Education level	Primary	4 (4.0%)
	Intermediate	3 (3.0%)
	High school	29 (29.0%)
	College	64 (64.0%)
Economic status	Low	11 (11.0%)
	Medium	77 (77.0%)
	High	12 (12.0%)
Occupation	Business	8 (8.0%)
	Engineering	3 (3.0%)
	Housewife	12 (12.0%)
	Other	40 (40.0%)
	Teacher	32 (32.0%)
	Unemployed	5 (5.0%)
	Number of children	Four or more children
One child		25 (25.0%)
Three children		14 (14.0%)
Two children		18 (18.0%)
Child gender	Boy	63 (63.0%)
	Girl	37 (37.0%)
Age at diagnosis of ADHD	1–5 yr	62 (62.0%)
	<6 yr	62 (62%)
	6–10 yr	8 (8.0%)
	11–15 yr	3 (3.0%)
	16–18 yr	27 (27.0%)

ADHD = attention-deficit hyperactivity disorder.

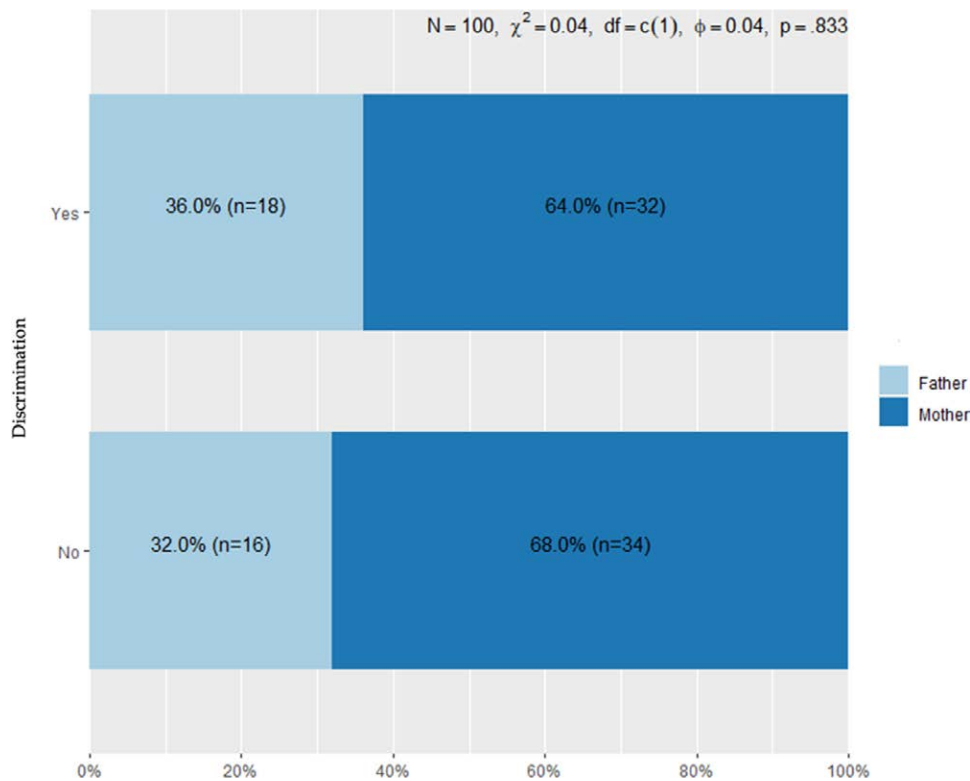


Figure 1. Experience of discrimination among parents references.

Table 2

Insights and perceptions: Experiences of parents of children with ADHD.

Parents' perspectives	N (%)
Have you ever noticed any developmental differences in your child compared to their peers? (yes)	54 (54.0%)
Have you ever sought out therapy or other interventions for your child neurodevelopmental disorder? (yes)	43 (43.0%)
Have you ever spoken to your child healthcare provider about any concerns you have regarding their development? (yes)	38 (38%)
Have you ever attended any workshops or seminars on neurodevelopmental disorders? (yes)	54 (54%)
Affected child social behavior:	
Aim to distinguish between friends and strangers.	4 (4.0%)
Avoiding/ignoring other children.	7 (7.0%)
Difficulty picking up on social cues.	15 (15.0%)
Difficulty understanding feelings.	11 (11.0%)
Problems playing with other children.	7 (7.0%)
Social and personal boundaries.	6 (6.0%)
Social isolation/peer sharing.	37 (37.0%)
Other.	13 (13.0%)
Do you feel that there is enough information available to parents about neurodevelopmental disorders? (yes)	49 (49.0%)
Do you think that schools and other institutions are adequately equipped to support children with neurodevelopmental disorders? (yes)	39 (39.0%)
Have you ever spoken to other parents who have children with neurodevelopmental disorders to share experiences and support? (yes)	39 (39.0%)
Do you think that society as a whole is becoming more aware and accepting of neurodevelopmental disorders? (yes)	66 (66.0%)

ADHD = attention-deficit hyperactivity disorder.

primary channels of information utilized by parents to learn about ADHD. The Internet emerged as the predominant source of information, with nearly 50% of the surveyed parents relying on it to gain insight into their children medical condition. Furthermore, a significant portion of these parents believed that they lacked adequate information, especially from schools, highlighting the need for more comprehensive knowledge. We also found that all domains of QoL were affected, especially the environmental domain with some variables having an association with lower QoL like being single, having 1 child with ADHD and being unemployed.

A large sector of the parents included in this study reported discrimination. Similarly, research conducted within mental healthcare settings has yielded significant insights into the prevalence of discrimination faced by individuals seeking mental healthcare, with the reported rates spanning from 16% to 44%.^[28] Stigmas and discrimination, as initially explored by Goffman in his groundbreaking 1963 work, have evolved into a widely recognized global phenomenon with far-reaching implications for both individuals and society.^[29] Operating at the macro- and micro-sociological levels, stigmas and discrimination present a significant threat to individual well-being and

societal functioning. By impeding access to essential healthcare services, obstructing vital social support networks, amplifying social anxieties, and impeding societal integration, stigmas and discrimination emerge as a multifaceted challenge.^[30] Their complexity is underscored by the intricate interplay of processes such as labeling, stereotyping, separation, and a loss of status, which collectively contribute to their enduring impact.^[31]

In this study, we found that the Internet was the main source of information for nearly half of the participants. Nearly the same percentage of participants attended workshops or webinars to improve their knowledge of ADHD. Nonetheless, about half of

the participants reported that they did not receive enough information about the disorder. Moreover, schools and institutions did not provide sufficient information. A study that was conducted in Saudi Arabia by Alanazi et al^[32] explored the source of information acquisition among teachers. They found that reading books (32.8%) followed by online resources (28.7%), TV and media (14.6%), magazines, and social media (23.9%) were the main sources of information acquisition. A substantial proportion of teachers (76.7%) indicated having attended courses or training on ADHD, but only 40.4% felt adequately informed about the condition. It seems that online resources are becoming more easily available; with just a few clicks, a person can access different resources inclusive of scientific, sociological, psychological, and academic domains. In addition, many seminars are given through online services such as webinars, which adds to the availability of different resources online and explains why the majority of people use the Internet as a source of information. Nonetheless, it is crucial to emphasize the need to exercise caution when assessing the accuracy of information found online, a facet that was not specifically examined in this study.

In this study, all the domains of QoL were found to be impacted, with the environmental domain facing the greatest level of disruption. Some sociodemographic characteristics were found to significantly affect the QoL total score including marital status, occupation and number of children. This aligns with different studies that addressed the role of sociodemographic factors on QoL.^[33,34] It is worth noting that the adverse effects of the coronavirus disease 2019 have had a negative impact on the QoL of the Arab population.^[26] This situation may further exacerbate the decline in the QoL of parents with children diagnosed with ADHD. In a similar context, Befera and Barkley research underscored that mothers of hyperactive children experienced higher levels of depressive symptoms and strained marital relations when compared to mothers of typical children.^[35] Xiang et al^[36] assessed the QoL of parents of children with ADHD in Hong Kong; they reported that the parents of children with ADHD had significantly lower scores in the physical, psychological, social, and environmental QoL domains. Similar findings have been reported in other areas of the Arab world, such as Egypt and Tunisia, and other areas

Table 3
Association between sociodemographic factors and QoL score.

Variable		Score (mean ± SD)	P
Region	Eastern	49.95 ± 8.86	.084
	Middle	47.44 ± 18.59	
	Northern	35.67 ± 7.95	
	Southern	53.00 ± 13.79	
Marital status	Married	53.79 ± 11.62	.0282
	Single	47.18 ± 15.72	
Educational level	Primary	46.08 ± 20.32	.538
	Secondary	59.19 ± 13.36	
	High school	49.59 ± 13.53	
	University degree	52.41 ± 14.46	
Economic status	Low	41.88 ± 10.09	.056
	Middle	52.94 ± 14.00	
	High	51.44 ± 17.21	
Occupation	Housewife	47.65 ± 17.28	.039
	Teacher	53.21 ± 12.52	
	Other	55.21 ± 12.57	
	Unemployed	39.41 ± 11.6	
Number of children	One child	44.92 ± 14.85	.044
	Two children	51.12 ± 15.83	
	Three children	53.77 ± 11.79	
	Four children	54.84 ± 13.23	

QoL = quality of life.

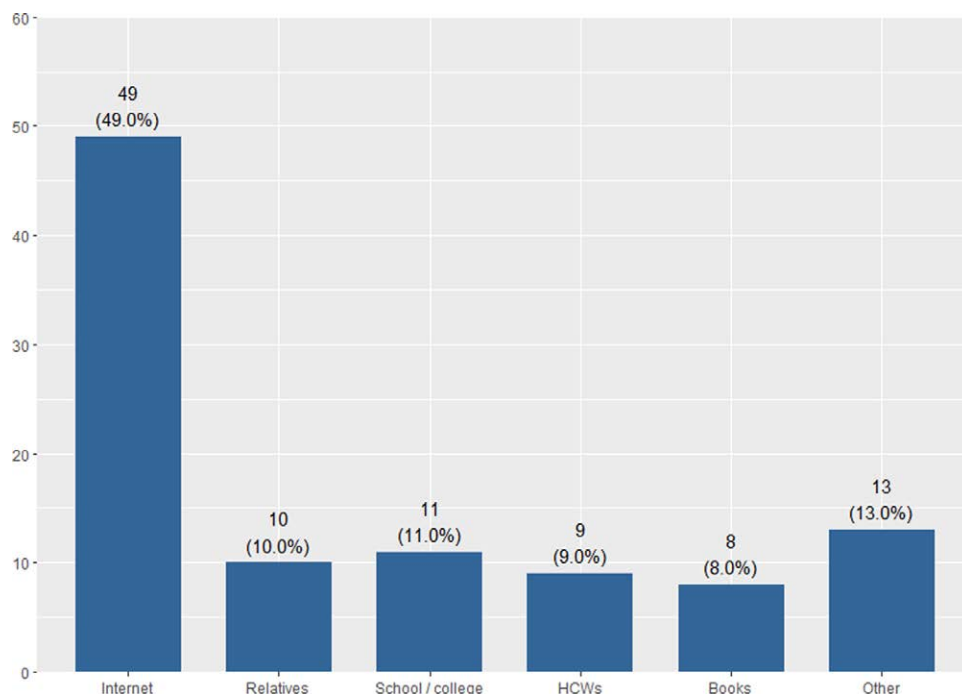


Figure 2. Sources of information about ADHD. ADHD = attention-deficit hyperactivity disorder.

Table 4**WHOQOL-BREF for parents of children with ADHD.**

Domain	Total	Fathers	Mothers	T	P
Physical	57.18 ± 13.67	55.78 ± 14.83	57.90 ± 13.09	-0.73	.464
Psychological	62.58 ± 17.49	61.27 ± 15.67	63.26 ± 18.85	-0.54	.593
Mental	63.33 ± 23.12	63.73 ± 20.19	63.13 ± 24.64	0.12	.904
Environmental	23.07 ± 12.87	23.99 ± 10.40	22.59 ± 14.02	0.52	.608
Total score	51.54 ± 14.34	51.19 ± 12.99	51.72 ± 15.08	-0.17	.862
General quality of life	3.69 ± 1.06	3.76 ± .987	3.65 ± 1.102	0.503	.616

ADHD = attention-deficit hyperactivity disorder, WHOQOL-BREF = The World Health Organization Quality of Life Instrument, Short Form.

around the world.^[13,37,38] Indeed, parents of ADHD children experience much higher levels of parenting stress than parents of typically developing children. It has also been stated that the parents' physical and psychological well-being is harmed as a result of dysfunctional, ineffective parenting and a lack of involvement in parent-child interactions, as well as child maltreatment.^[39] This may explain the relatively low QoL among parents of ADHD children. Furthermore, caregivers of ADHD children have worse physical health, psychological health, and social interactions than caregivers of non-ADHD children; this is due to their children health condition, which causes exhaustion, tiredness, stress from inattention, aggressive behavior, and a difficulty in building social interactions and peer relationships with others.^[40]

5. Conclusions

ADHD stands as a widely recognized and prevalent neurodevelopmental disorder that has extensive repercussions for individuals and their families. Our findings paint a compelling picture: around half of parents reported facing discrimination within their communities, and, notably, this trend did not show significant variation between mothers and fathers. The Internet has emerged as the dominant source of information, with nearly half of this study participants relying on online resources to gain insights into their children ADHD. Furthermore, a significant number of these parents expressed a sense of inadequate information, particularly when it came to input from educational institutions. This highlights the pressing need for more comprehensive information dissemination and the launching of medically supported Internet sources in Arabic for a better understanding by the general population. It is noteworthy that all domains of QoL were impacted, with the environmental domain being particularly affected. These findings collectively underscore the challenges faced by parents of children with ADHD and emphasize the importance of addressing discrimination and stigmatization, improving information accessibility, and improving support and the overall QoL for both parents and their children.

6. Strengths and limitations

This research is subject to several primary limitations. First, the small sample size restricts the generalizability of the results. Second, the inherent nature of the cross-sectional survey design introduces the potential for recall bias. A control group was not included in the study, limiting our ability to make comparative assessments. The absence of a longitudinal approach also inhibits our ability to establish causality. Despite these limitations, it is worth noting that our study employed validated questionnaires, enhancing the internal consistency of our findings and contributing to the overall reliability of the results. It is also one of few studies that have assessed the QoL of parents of ADHD children in Saudi Arabia.

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