

## Experienced Burden by Caregivers of Autistic Children

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### Abstract

**Background:** Autism is one of the developmental disorders, characterized by qualitative impairments in communication and social interaction and by restricted, repetitive, and stereotyped patterns of behaviors and interests.

**Aim of Study:** To assess burden experienced by family members of autistic children in Aseer Region, Saudi Arabia.

**Subjects and Methods:** Following a cross sectional research design a total of 157 caregivers of autistic children registered at three rehabilitative centers in Aseer Region were included. The Arabic version, of the validated Zarit Burden Questionnaire was used for data collection.

**Results:** Age of participants ranged from 23 to 61 years with a mean  $\pm$  SD of  $36.5 \pm 6.7$  years, and 58% were females. Most care-givers (86.6%) experienced burden, while 49% had mild grade of burden, 35% had moderate grade while 2.5% had severe grade. Experienced burden did not differ significantly according to participants' gender or educational levels. However, those who experienced burden were significantly older than those who did not ( $p=0.03$ ). The social component of burden was the most common among participants (89.2%), followed by physical (61.8%), financial (60.5%) and lastly the psychological (56.1%). Experienced financial burden did not differ significantly according to participants' gender or educational levels. However, those who experienced financial or psychological burden were significantly older than those who did not ( $p=0.02$  and  $p=0.04$ , respectively). Experienced physical burden did not differ significantly according to participants' gender or age. However, those who experienced physical burden had lower levels of education than those who did not ( $p=0.05$ ). Experienced social burdens did not differ significantly according to participants' personal characteristics.

**Conclusions:** Most caregivers, especially older ones, experience burden due to their autistic relative. The burden is mainly social, followed by physical, financial and psychological burdens. Financial burden is more among older caregivers, while the physical burden is more among less educated caregivers.

**Recommendations:** Support for caregivers of autistic children is highly needed to minimize their experienced burden. Provided support for caregivers should include social, physical, financial and psychological dimensions.

**Key Words:** Autism – Caregiver – Burden – Risk factors.

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### Introduction

**AUTISM** is one of the developmental disorders, characterized by qualitative impairments in communication and social interaction and by restricted, repetitive, and stereotyped patterns of behaviors and interests. Abnormal development is present before three years of age. The clinical features required for a diagnosis of autism to be made are set out in the International Classification of Diseases, 10th edition (ICD-10), and Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) [1].

Persons with autism have a history of language delay, and one fourth lose previously acquired skills, most commonly in the second year of life. One third of persons with autism develop epilepsy, and three fourths have mental retardation. Males are affected more commonly than females (3.5-4:1 male-to-female ratio) [1].

Autism Spectrum Disorder (ASD) has become more prevalent in recent decades. The Centers for Disease Control and prevention reported that approximately 1% of the world's population has ASD. This estimate is based on children at 8 years old because most children with ASD are identified by this age. There has been a reported increase in ASD in the US from 1 in 86 in 2007 [2] to 1 in 68 by 2014 [3]. Baron-Cohen et al., [4] indicated higher rates of 157 in 10,000 in the United Kingdom. Studies from outside North America and Europe, however, find lower rates of ASD [5,6].

In Bahrain Al-Ansari and Ahmed [7] and the United Arab Emirates [8] the rate is 4.3 and 2.9 out of 10,000 children, respectively. Reports from Oman indicate the rate of ASD is 1.4 per 10,000 (95% CI: 1.2 - 1.7) [5]. In Saudi Arabia, the rate is 4-6 in every 1,000 children [9]. An estimate from Saudi Arabia found a relatively lower rate of 1.8 per 1,000 children [10]. These low prevalence rates

are partly due to under-diagnosis and under-reporting. In 2002, 42,500 confirmed cases of ASD were diagnosed in Saudi Arabia [10].

For parents, sisters and brothers, the burden of living with an apparently uninterested child may produce a state of permanent hurt, shock and grief. Outside the home, the families of these normal-looking but severely handicapped and strangely behaved children are often exposed to public and humiliating embarrassments. Their lives may become severely limited, with consequent stress on the parents' marriage and effects on the mental health of everyone [3].

An extensive survey of literature revealed a dearth of information on the current number of confirmed cases of children with ASD in Saudi Arabia [11]. However, anecdotal information suggests an increase in the prevalence of ASD in Saudi Arabia [12].

The present study aimed to assess burden experienced by caregivers of autistic children in Aseer Region, Saudi Arabia.

### Subjects and Methods

Following a cross sectional research design, this study was conducted during May and June 2017, a total of 157 care givers of autistic patients registered at three rehabilitative centers in Aseer Region, Saudi Arabia participated in the present study.

The Arabic version, which was translated and validated from the Zarit Burden Questionnaire. "The Zarit Burden interview" questionnaire is a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire. The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale [13].

Collected data were coded before computerized data entry. The Statistical Package for Social Sciences (SPSS Version 23) was used for data entry and analysis. Descriptive statistics (e.g. number, percentage, mean, range, standard deviation) were calculated and test of significance, (i.e.,  $\chi^2$  and unpaired *t*-test) were applied. *p*-values  $\leq 0.05$  were considered as statistically significant.

### Results

Table (1) shows that age of participants ranged from 23 to 61 years with a mean  $\pm$  SD of  $36.5 \pm 6.7$  years. More than half of participants (58%) were

females. Most participants were either secondary school educated (31.2%) or university educated (39.5%).

Table (1): Personal characteristics of participants (n=157).

Personal characteristics	Values
<i>Age (in years):</i>	
Mean $\pm$ SD	36.5 $\pm$ 6.7
Range (minimum-maximum)	38 (23-61)
<i>Gender:</i>	
Male	66 (42.0%)
Female	91 (58.0%)
<i>Educational level:</i>	
Illiterate	20 (12.7%)
Primary	17 (10.8%)
Intermediate	9 (5.7%)
Secondary	49 (31.2%)
University	62 (39.5%)

Table (2) shows that most participant caregivers (86.6%) experienced burden. About half of them (49%) had mild grade of burden, 35% had moderate grade while 2.5% had severe grade. Social component of burden was the most common among participants (89.2%), followed by physical burden (61.8%), then financial burden (60.5%) and lastly the psychological burden (56.1%).

Table (2): Experienced burden among participants.

Experienced burden	Values
<i>Experienced burden:</i>	
Absent	21 (13.4%)
Present	136 (86.6%)
<i>Total burden score:</i>	
Mean $\pm$ SD	35.7 $\pm$ 14.17
Range (minimum-maximum)	69 (1-70)
<i>Grades of burden:</i>	
Absent	21 (13.4%)
Mild	77 (49.0%)
Moderate	55 (35.0%)
Severe	4 (2.5%)
<i>Components of burden:</i>	
Financial	95 (60.5%)
Social	140 (89.2%)
Psychological	88 (56.1%)
Physical	97 (61.8%)

Table (3) shows that burden experienced by participant care-givers did not differ significantly according to their gender or educational levels. However, those who experienced burden were significantly older than those who did not ( $36.9 \pm 6.7$  years and  $33.6 \pm 5.6$  years, respectively,  $p=0.03$ ).

Table (3): Presence of total burden among participants' according to their personal characteristics.

Personal characteristics	Present (n=136)		Absent (n=21)		P-value
	No.	%	No.	%	
Age (in years)	36.9±6.7		33.6±5.6		0.03
<i>Gender:</i>					
Male	61	92.4	5	7.6	0.07
Female	75	82.4	16	17.6	
<i>Educational level:</i>					
Illiterate	19	95.0	1	5.0	0.26
Primary	14	82.4	3	17.6	
Intermediate	6	66.7	3	33.3	
Secondary	44	89.8	5	10.2	
University	53	85.5	9	14.5	

Table (4) shows that experienced financial burden did not differ significantly according to participants' gender or educational levels. However, those who experienced financial burden were significantly older than those who did not ( $37.4 \pm 7.1$  years and  $34.9 \pm 5.8$  years, respectively,  $p=0.02$ ).

Table (4): Presence of financial burden among participants' according to their personal characteristics.

Personal characteristics	Present (n=95)		Absent (n=62)		P-value
	No.	%	No.	%	
Age (in years)	37.4±7.1		34.9±5.8		0.02
<i>Gender:</i>					
Male	43	65.2	23	34.8	0.31
Female	52	57.1	39	42.9	
<i>Educational level:</i>					
Illiterate	13	65.0	7	35.0	0.07
Primary	14	82.4	3	17.6	
Intermediate	7	77.8	2	22.2	
Secondary	31	63.3	18	36.7	
University	30	48.4	32	51.6	

Table (5) shows that experienced social burden did not differ significantly according to participants' personal characteristics (Tables 5,6), respectively.

Table (6) shows that experienced physical burden did not differ significantly according to participants' gender or educational levels. However, those who experienced physical burden were significantly older than those who did not ( $37.3 \pm 6.9$  years and  $35.1 \pm 6.2$  years, respectively,  $p=0.04$ ).

Table (7) shows that experienced physical burden did not differ significantly according to participants' gender or age. However, percentages of caregivers who experienced physical burden were higher among those who were less educated (i.e., less than secondary education) than those with

higher education (i.e., secondary or university levels,  $p=0.05$ ).

Table (5): Presence of social burden among participants' according to their personal characteristics.

Personal characteristics	Present (n=140)		Absent (n=17)		P-value
	No.	%	No.	%	
Age (in years)	36.6±6.7		34.6±5.9		0.24
<i>Gender:</i>					
Male	56	84.8	10	15.2	0.31
Female	84	92.3	7	7.7	
<i>Educational level:</i>					
Illiterate	20	100.0	0	0.0	0.069
Primary	15	88.2	2	11.8	
Intermediate	9	100.0	0	0.0	
Secondary	39	79.6	10	20.4	
University	57	91.9	5	8.1	

Table (6): Presence of psychological burden among participants' according to their personal characteristics.

Personal characteristics	Present (n=88)		Absent (n=69)		P-value
	No.	%	No.	%	
Age (in years)	37.3±6.9		35.1±6.2		0.04
<i>Gender:</i>					
Male	38	57.6	28	42.4	0.74
Female	50	54.9	41	45.1	
<i>Educational level:</i>					
Illiterate	12	60.0	8	40.0	0.94
Primary	9	52.9	8	47.1	
Intermediate	6	66.7	3	33.3	
Secondary	26	53.1	23	46.9	
University	35	56.5	27	43.5	

Table (7): Presence of physical burden among participants' according to their personal characteristics.

Personal characteristics	Present (n=97)		Absent (n=60)		P-value
	No.	%	No.	%	
Age (in years)	37.0±7.1		35.9±6.5		0.33
<i>Gender:</i>					
Male	44	66.7	22	33.3	0.28
Female	53	58.2	38	41.8	
<i>Educational level:</i>					
Illiterate	13	65.0	7	35.0	0.05
Primary	15	88.2	2	11.8	
Intermediate	7	77.8	2	22.2	
Secondary	24	49.0	25	51.0	
University	38	61.3	24	38.7	

## Discussion

Results of this study showed that age of caregivers ranged from 23 to 61 years, more than half of them being females and most of them being well educated (either secondary school or university levels of education).

Similarly, Karst and Van Hecke [14] noted that caregivers who participated in support groups for autistic children were found to be mostly well-educated, females and more likely to be more than 35 years old. Anh [15] noted that caregivers of autistic children were mostly their mothers who are also well educated.

These findings reflect the characteristics of caregivers, who mostly volunteer to take care of the autistic child, being of a wide age range (from 23 to 61 years), mostly females who are more naturally equipped to provide care to children and educated enough to better understand how to handle a child with special needs.

Results of the current study indicated that most caregivers of autistic children experienced burden, with mild grade of burden among about half of participants and about one third having moderate grade while 2.5% had severe burden grade. Experienced burden did not differ significantly according to participants' gender or educational levels. However, those who experienced burden were significantly older than those who did not.

These findings are in agreement with those of Sharpley et al. [16], who reported that about 30% of parents experienced moderate to severe levels of anxiety while about 20% were experiencing clinically significant levels of depression. Further, 80% of these parents reported sometimes feeling "stretched beyond their limits". Parents of autistic children reported that dealing with child behavior problems was the greatest contributor to feelings of anxiety and depression, while both family support and parenting self-efficacy contributed to more positive parent mental health.

Anh [15] reported that older caregivers experienced more severe burden, worse physical health, and fewer adaptive skills. Nevertheless, Al-Dujaili and Al-Mossawy [17] reported no statistically significant association between the overall psychosocial burden score of caregivers with caregivers' socio-demographic characteristics.

It is understandable to discover that older caregivers for children with special needs may have

less coping abilities than younger ones. This finding indicates the higher need to provide more support to caregivers of autistic children, especially older ones.

Results of the current study revealed that the social component of burden was the most common among caregivers of autistic children, followed by physical, financial and lastly the psychological components. Moreover, some personal characteristics were associated with significantly more burden among caregivers. Financial was significantly more among older caregivers and physical burden was more experienced among less educated caregivers. However, social and psychological burdens did not differ according to caregivers' personal characteristics.

These findings are in accordance with that of Brannan et al. [18], who reported that caregivers burden includes psychological, physical and financial components, of which the social burden occupies the highest. They added that more burden was associated with older and more educated caregivers.

Moreover, Lovell et al. [19] reported that caregivers of autism experience high level of burden which resulted in multidimensional psychological and physical health problems. These problems can be more associated with some personal characteristics of caregivers, e.g., older age or male gender.

Based on findings of the present study, it can be concluded that most caregivers, especially older ones, experience burden due to their autistic relative. The burden is mainly social, followed by physical, financial and psychological burdens. Financial burden is more among older caregivers, while the physical burden is more among less educated caregivers.

Therefore, management of autistic children should include the provision of support to caregivers socially, physically, psychologically and also financially, with special concern regarding those with risk of experiencing certain types of burden, i.e., financially for older caregivers or physically for more educated caregivers. Consequently, it seems essential to provide health education for caregivers of autistic children to raise their awareness and knowledge regarding autism management. This is also expected to improve their attitude toward management of autistic children.

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## مدى العبء الذى يتعرض له مقدمو الرعاية لأطفال التوحد

هدف الدراسة: تقييم العبء الذى يعانى منه أفراد أسر الأطفال المصابين بالتوحد فى منطقة عسير بالمملكة العربية السعودية.

منهجية البحث: إتبعنا هذه الدراسة نمط البحث المقطعى، حيث شارك فى هذا البحث ١٥٧ من مقدمى الرعاية للأطفال المصابين بالتوحد المسجلين فى ثلاثة مراكز تأهيلية بمنطقة عسير. وقد أستخدمت لجمع البيانات النسخة العربية من إستبيان "زاريت" لقياس العبء.

النتائج: تراوحت أعمار المشاركين بين ٢٣ و ٦١ سنة بمتوسط وانحراف معيارى بلغ  $36.5 \pm 6.7$  سنة، وكان ٥٨٪ من المشاركين فى البحث إناثا. وقد شعر معظم مقدمى الرعاية (٨٦.٦٪) عبئا، فى حين عانى ٤٩٪ معتدلا، وكان ٣٥٪ لديهم درجة معتدلة بينما كان ٢٠.٥٪ لديهم درجة حادة من العبء. ولم تختلف درجة العبء حسب النوع أو المستوى التعليمى للمشاركين. ومع ذلك، فإن أولئك الذين عانوا من عبء كانوا أكبر سنا من أولئك الذين لم يشعروا بعبء (ح=٠.٠٣). وكان المكون الإجتماعى للعبء الأكثر شيوعا بين المشاركين (٨٩.٢٪)، يليه المكون البدنى (٦١.٨٪)، ثم المكون المالى (٦٠.٥٪) أخيرا المكون النفسى (٥٦.١٪). كما لم يختلف العبء المالى بشكل كبير طبقا لنوع أو المستوى التعليمى للمشاركين. ومع ذلك، فإن أولئك الذين عانوا من أعباء مالية أو نفسية كانوا أكبر سنا من أولئك الذين لم يعانون من العبء (ح=٠.٠٤)، على التوالى). ولم يختلف العبء البدنى باختلاف نوع المشاركين أو أعمارهم. ومع ذلك، فإن أولئك الذين عانوا من العبء البدنى كانت مستويات تعليمهم أدنى من أولئك الذين لم يعانون ذلك العبء (ح=٠.٠٥). ولم تختلف الأعباء الإجتماعية وفقا للخصائص الشخصية للمشاركين.

الإستنتاجات: يواجه معظم مقدمى الرعاية، وخاصة كبار السن، عبئا. ويشكل العبء الإجتماعى المكون الأساسى، يليه المكون البدنى ثم المالى والنفسى. العبء المالى أكبر بين مقدمى الرعاية من كبار السن، فى حين أن العبء المادى هو أكثر بين مقدمى الرعاية الأقل تعليما.

التوصيات: هناك حاجة ماسة لتقديم الدعم لمقدمى الرعاية لأطفال التوحد وذلك من أجل تقليل العبء الذى قد يعانون منه. ويجب أن يتضمن ذلك الدعم أبعادا إجتماعية وبدنية ومالية ونفسية.