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QUALITY OF LIFE AMONG CAREGIVERS OF CHILDREN WITH AUTISM IN QATIF CITY, EASTERN PROVINCE, SAUDI ARABIA

Medicine

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ABSTRACT

Caring for a child with autism has significant effects on caregiver quality of life (QOL). We evaluated QOL among 76 caregivers of children with autism who were enrolled from 2 autism centres in Qatif city, Eastern province, Saudi Arabia. The Arabic version of the Standard Recall Short Form 36 was used to collect demographic and caregiver QOL information. QOL was classified into 8 subscale domains; of these, the general health domain had the highest scores (66.8 ± 18.8) and the vitality domain had the lowest scores (49.7 ± 19.6). There was a significant positive correlation between caregiver family income and physical functioning domain score ($p = 0.023$), and between relation to the child and role limitation due to physical problems domain score ($p = 0.004$) and general health domain score ($p = 0.043$). This study highlights a critical need for service centre availability to caretakers of children with autism.

KEYWORDS

autism, caregiver, parent, quality of life

Introduction

Caring for a child with autism spectrum disorder (ASD) is challenging and has significant effects on family life. Autism a highly complicated neurodevelopmental disorder, as it is characterized by deficits in social communication and social interaction as well as restricted repetitive patterns of behaviour, interests, and activities ("American Psychiatric Association," 2013). Children with ASDs often exhibit more than 1 of these main ASD symptoms and many also suffer from associated symptoms, such as severe tantrums and sleep problems (Aman, 2004; Couturier et al., 2005). Additionally, the general health of these children is lower than that of typically developing children (Gurney, McPheeters, & Davis, 2006; Kuhlthau et al., 2010b; Kuhlthau et al., 2013).

There is an increasing interest in autism and autism research as a result of awareness of the effects of this condition on the lives of not only individuals with autism but also their families and caregivers. It is no wonder that there is a worldwide initiative to bring autism and other neurodevelopmental disorders to the forefront and develop strategies to decrease their burden on those directly affected and on society at large (Kheir et al., 2012).

At present, there is no accurate data regarding the prevalence of autism in Saudi Arabia; however, there is a relatively high prevalence of autism in Saudi families with a history of consanguinity (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). In a society where large extended families are the norm, the care of individuals with disabilities is largely the responsibility of the family (Fakhr El-Islam, 2008), such that family caregivers play a principal role in the care of children with autism in Saudi families.

ASD requires a multidisciplinary approach that makes use of the child's strengths to address his or her weaknesses with the goal of maximizing functioning, engendering independence, and improving QOL. To this end, children with ASD require on-going follow-up with specialized clinics (e.g., developmental and behavioural paediatricians, neurologists, psychologists, and psychiatrists) or a team of providers to monitor progress, make recommendations for behavioural programming, and screen for medical concerns (Carbone, Farley, & Davis, 2010).

Several studies have demonstrated that the provision of daily hands-on care to children with disabilities compromises the wellbeing of caregivers in the long term (Penning, 2004). Full-time caregivers experience increased symptoms of depression, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in marital relationships, and diminished physical health (Abbeduto et al., 2004; Davis & Carter, 2008; Magana & Smith, 2006; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Moreover, many parents of children with autism face financial problems due to high out-of-pocket health care expenses and underemployment or employment loss (Bromley, Hare, Davison, & Emerson, 2004; Kuhlthau, Hill, Yucel, & Perrin, 2005; Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010a).

Maternal caregiving burden and poor QOL have been strongly associated with factors such as lack of functional independence, severe maladaptive behaviours, and autism severity in affected children (Lin, 2011; Marciano & Scheuer, 2005). QOL is a multidimensional concept that includes physical, psychological, and social domains of health (McSweeny & Creer, 1995). According to the World Health Organization, QOL is defined as an 'individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns ("WHOQOL," 1995). When a chronic health problem or disability cannot be resolved and there is no realistic goal for therapy, the ultimate aim is to improve both patient and caregiver QOL (McSweeny & Creer, 1995). Research has demonstrated that the presence of a social support network perceived to be adequate by the caregiver can serve as a buffer for caregiver stress (Blanchard, Albrecht, Ruckdeschel, Grant, & Hemmel, 1995).

Given the multidimensional needs of children with ASDs, an understanding of how caregiving affects caregiver QOL is essential. At present, assessments of ASD treatments are often limited to the measurement of effects in children; however, interventions for children with ASDs often require parental involvement and also aim to increase parental caregiving skills, self-efficacy, and knowledge of the disorder, and aim to reduce family stress (McConachie & Diggle, 2007). Thus, there is need for more rigorous evaluations of caregiver QOL in response to these interventions.

Rationale

1. Caring for a child with autism is challenging and can have a variety of effects on family life.
2. To the best of our knowledge, no study to date has assessed the QOL of parents/caregivers of children with autism in Saudi Arabia or in the context of Saudi culture.

The study results will provide evidence for the effects of caring for a child with autism on the life of the caregiver and direct health policy-makers in Saudi Arabia to provide improved and more focused support to caregivers with the aim of facilitating the development of healthy coping skills and improve family functioning.

Aim of the Study

The aim of this study was to assess and explore QOL among caregivers

of children with autism in Eastern province, Saudi Arabia.

Objective

- To evaluate QOL among caregivers of children with autism in Qatif city, Eastern province, Saudi Arabia.
- To identify factors that influence the QOL among caregivers of children with autism.

Literature Review

Autism is universal problem, yet publications from the Middle East in this field have been particularly rare. Previous research on children with ASD and the effects of raising a child with ASD have been largely limited to studies in Western families. Thus, there is limited information on ASD in non-Western developing countries where services for children with any form of special needs are less developed. This shortage of information has led to the unwarranted assumption that autism is rare in non-Western cultures (Samadi & McConky, 2011).

Recent research performed in the United States examined the effects of caregiving on parents of children with ASDs with a 5-dimension survey of health, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression ("EuroQol Group," 1990). Another tool, the short form 6-dimensional survey (SF-6D), evaluates caregiver effects using 6 health dimensions: physical functioning, role limitation, social functioning, pain, energy, and mental health (Brazier & Roberts, 2004). These tools have been validated for QOL evaluations in the context of autism care and have been extensively utilized for research in Western and other countries.

Parents of children with disabilities experience significant issues combining daily activities with care, have financial problems, and often experience depressive symptoms (Hoefman et al., 2014). A study performed in São Paulo, Brazil in 2013 assessed QOL in siblings of children with ASD using the self-response World Health Organization Quality of Life (WHOQOL)-BREF questionnaire and identified significant effects on the Environmental as well as Physical and Psychological domains. It was concluded that family individuality, coping strategies, social support, and received assistance directly influenced the perception of QOL in these subjects (Vieira & Fernandes, 2013). Another study performed in the United States compared the health-related QOL (HRQOL) scores of caregivers of children with autism to those of the general population and found that caregivers not only had lower HRQOL scores, but that care recipient factors such as level of functional impairment, social support, use of maladaptive coping, and burden all influenced caregiver mental HRQOL. Care recipient factors such as the extent of behavioural problems and social support influenced caregiver physical HRQOL (Khanna et al., 2011). These results emphasized the necessity of multi-dimensional intervention approaches designed to enhance family functioning, increase support services, and help caregivers to develop healthy coping skills.

A study performed in southern Taiwan in 2005 explored the impact of support groups on mental health and QOL in mothers of autistic children. A quasi-experimental pre-post control group design was utilized to examine the effects of a 10-week support group programme intervention. The results of this study demonstrated that there was no significant improvement in mental health in the intervention group compared to the control group at the end of the first month; however, subjective wellbeing and employment status had effects on mental health, indicating that subjective wellbeing had principal effects on QOL (Shu & Lung, 2005). Similarly, Allik, Larsson, and Smedge (2006) reported that the mothers of children with Asperger's disorder and high-functioning autism had lower physical HRQOL compared to mothers of typically developing children in a manner related to the extent of the child's behavioural problems. Mugno, Ruta, D'Arrigo, and Mazzone (2007) reported that QOL was lower among parents of children with autism than among parents of children with cerebral palsy, mental retardation, or typical development. In particular, the authors noted differences in the domains of physical activity, social relationships, overall perception of QOL, and health. Research conducted in Qatar in 2012 assessed QOL among caregivers of children with autism and typically developing children. Unlike the above-mentioned studies, there was no significant difference in QOL between caregiver groups, but caregivers of children with autism rated their health as poor and likely to get worse ($p < 0.05$) (Kheir et al., 2012). Taken together, these studies emphasize the importance of subjective wellbeing in caregivers.

Finally, one study performed in Riyadh and Jeddah, Saudi Arabia, utilized parental perception to evaluate oral HRQOL in children with autism and compared them to unaffected siblings. The study examined the effect of autism on family QOL by comparing the perceptions of parents of children with autism to those of parents of unaffected children. The results of this study suggested that childhood autism decreased oral HRQOL of both the affected child and family (Pani, Mubaraki, Ahmed, Alturki., & Almahfouz, 2013), but additional work is required to provide more detailed findings in the context of Saudi culture.

The above studies highlight the importance of measuring QOL among caregivers of children with autism, especially considering that there may be direct effects on the quality of care provided to affected children. Studies in general caregiving literature have indicated that care recipients are more likely to experience verbal abuse (e.g., screaming, yelling, or insulting) when caregivers have impaired mental and physical health (Beach et al., 2005). In the current study, we assessed QOL among caregivers of children with autism in Saudi Arabia in order to identify factors that influence QOL in a non-Western country.

Methodology

Study setting

Caregivers of children with autism recruited from 2 autism centres (Tawasul Center for Autism and Zohoor Almostaqbel Center) in Qatif city, Eastern province, Saudi Arabia.

Study design

A cross-sectional study conducted via self-administered questionnaire.

Study area

Qatif city is a governorate and urban area located in Eastern Province, Saudi Arabia. It extends from Ras Tanura and Jubail in the north to Dammam in the south, and from the Persian Gulf in the east to King Fahd International Airport in the west. This region has its own municipality and includes Qatif downtown and many other smaller cities and towns, with an estimated combined population of 98,259 as of 2017.

Study population

We included caregivers of children with a diagnosis of autism who were between the age of 3 and 14 years at the time of the study. For study purposes, the primary caregiver was defined as the individual in the family with primary responsibility for providing care to the child with autism.

Exclusion criteria

The exclusion criteria for caregivers of children with autism were: the presence of chronic a medical condition, recent (< 2 months) initiation of behavioural therapy, and/or recent (< 2 months) changes in the nuclear family's life (e.g., marriage, divorce, or death of a family member).

Study Variables

Dependent variables: The main dependent variable was QOL of caregivers of children with autism. QOL categories included physical functioning, social functioning, role limitation due to physical problems, role limitation due to emotional problems, mental health, vitality, bodily pain, and general health.

Independent variables: Independent variables were sociodemographic variables including age, gender, marital status, occupation, education level, monthly income, and number of children in the family.

Other factors: Other factors included emotional and family support groups, special education classes, financial issues, and transportation issues.

Sampling

Sample size calculation

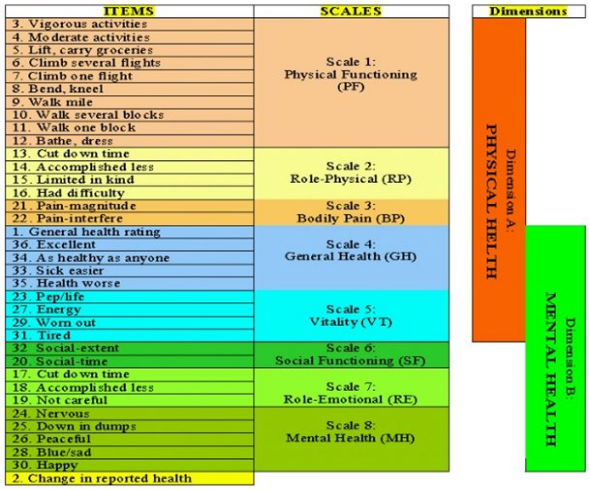
The sample included complete coverage of all caregivers from the 2 autism centres accounting for a total of 82 autistic children.

Data Collection

Data collection tools

Demographic and other related information such as family support group attendance, special education classes, financial issues, and transportation issues were collected from participants. QOL was assessed using the Arabic version of the Standard Recall Short Form 36 (SF-36 v2) obtained by license agreement from QualityMetric (QualityMetric Inc. 2015). Research was conducted in the Jazan region of Saudi Arabia in 2013 to assess the reliability and validity of the SF-36 questionnaire. Cronbach's alpha and intraclass correlation coefficient analyses demonstrated high internal consistency (α = 0.72–0.90) across the 8 subscales, indicating that the SF-36 questionnaire is useful and valid for measuring QOL (Sheikh, Yagoub, Elsatouhy, Sanosi, & Mohamud, 2015). The SF-36 v2 consists of 36 self-administered questions, 35 of which are compressed into 8 multi-item scales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. Scales were assessed quantitatively on the basis of answers to 2–10 multiple-choice questions, which were used to calculate a score between 0 and 100 on the basis of well-defined guidelines (Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001). Higher scores indicated better health status. The scales of the SF36 are summarized in 2 dimensions; the first 5 scales comprise the Physical Health dimension and the last 5 comprise the Mental Health dimension. The scales Vitality and General Health are parts of both dimensions (Figure 1). The SF36 also includes a self-evaluation of change in health during the past year (reported health) that does not belong to any score or dimension. The scores of the 2 dimensions and the total SF36 score are based on mathematical averaging of the scale components.

Figure 1. The SF36 quality of life (QOL) scoring system and its scales and dimensions. Note that the *Vitality and General Health* scales are overlapping components of both the *Physical Health and Mental Health* dimensions.



Data collection techniques

Data were collected from all caregivers of children with autism 2 from both participating institutions. Each eligible participant received a copy of an invitation letter that contained brief information about the aim of the study, its importance, the value of his or her participation, and instructions on how to complete the questionnaire while insuring their confidentiality.

Data management

Data were entered into a personal computer and analysed using the Statistical Package for Social Sciences (SPSS) software version 23. All variables were coded before entry and verified before analysis.

Data analysis and statistical considerations

Patients' characteristics

Descriptive statistics were used to describe quantitative variables, including the mean ± standard deviation for continuous variables and the frequency and percentages for categorical variables (Table 1).

Bivariate analyses

The effects of patient characteristics on health status components (8 components of the SF-36) were evaluated by independent sample t-tests (Tables 6–8). Specifically, we compared physical functioning, role limitation due to physical health, role limitation due to emotional problems, vitality, emotional wellbeing, social functioning, bodily pain, and general health perceptions across socio-demographic characteristics. The level of significance was $P < 0.05$.

Regression analyses

Multiple linear regression models were used to identify important predictors of each health status component (Tables 4 and 5). In multiple linear regression analyses, $P < 0.05$ was the threshold for significance.

Ethical considerations

Permission from the family medicine program and the ethical committee of the Ministry of Health were ensured before data collection. All data were kept confidential and used only for the purposes of the study.

Results

Table 1 . Demographic characteristics of participants (n = 76).

Quantitative data description		Mean	Standard deviation
Age of autistic child		6.18	1.467
Age of child at diagnosis		3.09	0.803
Number of siblings of the child with autism		2.63	1.672
Qualitative data description		Frequency	%
Sex of the autistic child			
	Male	64	84.2
	Female	12	15.8
	Total	76	100
Nationality			
	Saudi	76	100
	Non-Saudi	0	0
	Total	76	100
Change in family environment			
	Yes	0	0
	No	76	100
	Total	76	100
Relation of caregiver to child			
	Mother	66	86.8
	Father	9	11.8
	Other	1	1.3
	Total	76	100.0
Caregiver level of education			
	Primary	4	5.3
	Intermediate	8	10.5
	Secondary	21	27.6
	Diploma	9	11.8
	Bachelor	33	43.4
	Postgraduate	1	1.3
	Total	76	100.0
Other siblings with autism or another disability			
	No	65	85.5
	Yes	11	14.5
	Total	76	100.0
Family income			
	Less than 5000 SR	18	23.7
	From 5000 to 9999 SR	32	42.1
	From 10000 to 14999 SR	10	13.2
	From 15000 to 19999 SR	11	14.5
	From 20000 to 24999 SR	2	2.6
	From 25000 to 29999 SR	1	1.3
	From 30000 to 34999 SR	2	2.6
	Total	76	100.0
Consanguinity			
	No relationship	37	48.7
	Double first cousin	16	21.1
	First cousin	10	13.2
	Second degree cousin	7	9.2
	Same qabila	6	7.9
	Total	76	100.0

A total of 76 participants consented to study participation. All participants were Saudi nationals. The mean child age was 6.18 ±

1.467 years (range, 3–10 years) and a majority (84.2%) were male. The mean child age at diagnosis was 3.09 ± 0.803 years. A majority of children (85.5%) had no other siblings (range, 0–7) or other disabilities. All participating caregivers did not report any recent changes in family environment such as divorce, marriage, or recent death. Most caregivers were mothers (86.8%) whereas only 11.8% were fathers, and 48.7% reported no consanguinity between parents. With regard to education level, 43.4% had a Bachelor's degree and 42.1% had an income level of 999–5000 SR.

Table 2. Availability of support services for autistic children and their families.

Services information						
	Available		Not available and we need it		Not available but we do not need it	
	Frequency	%	Frequency	%	Frequency	%
Special education classes for autistic children	24	31.6	52	68.4	0	0
Special education classes for parents	19	25.0	54	71.1	3	3.9
Special education classes for others caregivers	11	14.5	57	75.0	8	10.5
Transportation services	35	46.1	40	52.6	1	1.3
Support groups for parents	14	18.4	51	67.1	11	14.5
Activities after-school for children	6	7.9	68	89.5	2	2.6
Weekend activities for children	16	21.1	56	73.7	4	5.3

With respect to health services provision and use, 68.4% of caregivers indicated that special education classes were not available for their children despite the fact that they were necessary. A majority of caregivers did not have access to parental special education classes (71.1%) or family support groups (67.1%) to help them to cope, but indicated that they would attend if they were available. A small minority (3%) indicated that there was no need for such classes or groups. With regard to transportation services, 52.6% of respondents did not have transportation but noted that it was essential. The majority of children did not have after-school or weekend activities available (89.5% and 73.7%, respectively), but indicated that they would attend if available. Most caregivers (65.8%) indicated the desire for activities like special recreational clubs for autistic children and speech therapy classes.

Table 3. Quality of life domain scores for caregivers of children with autism.

Domains	Min	Max	Mean	Standard deviation
Physical functioning	5.	100.	65.72	26.84
Role limitation due to physical problems	25.	100.	60.27	22.30
Bodily pain	22.	100.	64.38	22.57
General health	25.	100.	66.86	18.88
Vitality	.00	100.	49.74	19.62
Social functioning	25.	100.	63.81	23.32
Role limitation due to emotional problems	8.	100.	63.28	24.65
Mental health	5.	100.	56.65	20.71

Caregiver scoring differed across domains (range, 49.7–66.8). When caregivers were directly asked about their general heath, 26.3% (20) said that they were in excellent health; 39.5% (30) said very good; 21.1% (16) said good; and 13.2% (10) said fair. The mean general health score was 66.86 ± 18.88. The general health domain had the highest scores whereas the vitality domain had the lowest scores (49.7 ± 19.6).

Table 4. Relationship between family demographics and physical and mental component summary scores.

Family demographics	Physical component summary		Mental component summary	
	B	P-value	B	P-value
Age of autistic child	0.382	0.529	0.675	0.478
Sex of autistic child	1.677	0.471	1.504	0.679
Age of child at diagnosis	0.793	0.471	0.854	0.620
Level of education	0.257	0.739	0.948	0.434
Number of siblings	0.734	0.156	0.286	0.723
Other siblings with autism or other disabilities	2.301	0.350	3.502	0.364
Family income	2.122	0.003	0.216	0.842
F-value	2.318		0.399	
P-value	0.035		0.900	
R-squared	0.193		0.039	
R	0.439[a]		0.199[a]	

Table 4 shows the results of multiple linear regression models. Controlling for 7 predictors, caregivers who had better family income tended to report higher scores on the physical component summary than caregivers with low family income (mean increase in SF-36 score = 2.122).

Table 5. Relationship between service availability and the physical and mental component summary scores.

Services	Physical component summary		Mental component summary	
	B	P-value	B	P-value
Special education classes for autistic children	0.532	0.810	1.721	0.781
Special education classes for parents	3.304	0.149	1.473	0.817
Special education classes for others caregivers	1.242	0.516	2.535	0.636
Transportation services	1.980	0.242	0.756	0.873
Support groups for parents	1.052	0.524	4.333	0.350
After-school activities for children	2.63	0.385	10.699	0.209
Weekend activities for children	0.588	0.769	11.199	0.049
F-value	1.230		0.777	
P-value	0.299b		0.608b	
R-squared	0.112		0.074	
R	0.335a		0.272a	

Based on the results of multiple linear regressions (Table 5), caregivers who had weekend activities for their children tended to report higher mental component summary scores than caregivers who did not (mean increase in mental component score = 11.19).

Table 6. Differences in health-related quality of life domains by socio-demographic characteristics.

		Physical functioning			Role limitation due to physical problems			Bodily pain		
		Mean	SD	P	Mean	SD	P	Mean	SD	P
Gender	Male	64.9	27.1	0.591	59.8	22.7	0.710	66.1	22.5	0.121
	Female	69.5	25.9		62.5	20.4		55.0	21.1	
Siblings with other disabilities	No	64.3	27.6		60.0	21.5		63.6	22.6	
	Yes	74.0	20.8	0.266	61.9	27.7	0.793	68.8	22.7	0.485
Relation to child	Mother	65.2	25.7	0.700	57.1	20.7	0.004	62.2	22.5	0.098
	Father	71.1	36.1		79.8	22.2		78.0	18.5	

	Other	50.0			93.7			84.0		
Level of education	Primary	51.2	21.3	0.616	70.3	14.7	0.774	67.2	19.5	0.763
	Intermediate	64.3	25.5		63.2	24.4		56.8	27.3	
	Secondary	62.6	26.2		57.7	24.7		60.9	20.3	
	Diploma	64.4	29.6		63.8	27.5		62.5	25.7	
	Bachelor	69.0	27.7		58.3	20.0		68.2	22.9	
	Postgraduate qualification	100.		0.023	81.2		0.162	74.0		0.054
Family income	Less than 5000 SR	53.8	23.6		61.1	17.8		57.0	19.6	
	From 5000 to 9999 SR	62.1	27.4		60.7	25.7		64.4	24.4	
	From 10000 to 14999 SR	65.4	29.5		49.3	17.7		67.2	16.6	
	From 15000 to 19999 SR	86.8	17.9		60.7	19.3		68.1	21.2	
	From 20000 to 24999 SR	82.4	3.5		53.1	13.2		41.0	0.00	
	From 25000 to 29999 SR	70.0			68.7			100.0		
	From 30000 to 34999 SR	95.0	.00		100	.00		100.0	0.00	

Table 7. Differences in health-related quality of life domains by socio-demographic characteristics

		Vitality			Social functioning			Role limitation due to emotional problems		
		Mean	SD	P	Mean	SD	P	Mean	SD	P
Gender	Male	49.9	18.1	0.804	62.5	21.9	0.259	62.3	24.6	0.468
	Female	48.4	27.1		70.8	29.8		68.0	25.0	
Siblings with other disability	No	50.5	19.4	0.378	64.4	22.7	0.585	62.9	24.5	.788
	Yes	44.8	21.0		60.2	27.2		65.1	26.5	
Relation to child	Mother	48.7	20.1	0.218	61.9	22.7	0.095	61.1	23.2	.092
	Father	53.4	12.9		79.1	24.2		75.0	30.6	
	Other	81.2			50.0			100.0		
Level of education	Primary	60.9	7.8	0.692	65.6	27.71	0.868	56.2	21.9	0.482
	Intermediate	51.5	27.0		71.8	27.3		68.7	26.6	
	Secondary	47.9	23.4		60.1	24.5		66.7	23.2	
	Diploma	53.0	24.7		66.6	25.7		54.8	24.6	
	Bachelor	47.6	14.1		62.8	21.5		61.8	25.4	
	Postgraduate qualification	68.7			75.0			100.0		
Family income	Less than 5000 SR	52.0	19.5	0.848	68.7	22.3	0.087	64.3	20.9	0.432
	From 5000 to 9999 SR	47.9	22.0		56.6	22.8		60.4	26.8	
	From 10000 to 14999 SR	49.3	14.2		62.5	26.3		60.8	25.1	
	From 15000 to 19999 SR	54.7	20.6		70.4	17.9		66.6	24.9	
	From 20000 to 24999 SR	34.3	4.4		56.2	26.5		50.0	11.7	
	From 25000 to 29999 SR	56.2			87.5			75.0		
	From 30000 to 34999 SR	43.7	8.8		100.	.00		100.	.00	

Table 8. Differences in health-related quality of life domains by socio-demographic

		General health			Mental health		
		Mean	SD	P	Mean	SD	P
Gender	Male	67.9	19.2	0.250	56.3	20.2	0.762
	Female	61.0	16.3		58.3	24.1	
Siblings with other disabilities	No	65.9	18.8	0.325	57.3	20.8	0.500
	Yes	72.0	19.1		52.7	20.4	
Relation to child	Mother	64.8	18.7	0.043	55.2	20.9	0.103
	Father	78.2	14.3		62.7	14.8	
	Other	95.0			95.0		
Level of education	Primary	83.0	14.4	0.027	65.0	7.0	0.457
	Intermediate	50.8	11.4		50.6	25.5	
	Secondary	71.1	18.1		61.0	23.1	
	Diploma	66.3	26.2		53.3	25.3	

	Bachelor	65.3	16.5		54.3	17.2	
	Postgraduate qualification	95.0			85.0		
Family income	Less than 5000 SR	63.8	22.6	0.587	67.1	22.9	0.750
	From 5000 to 9999 SR	55.5	22.6		67.3	18.4	
	From 10000 to 14999 SR	56.0	15.2		66.4	18.5	
	From 15000 to 19999 SR	50.9	19.9		69.1	15.7	
	From 20000 to 24999 SR	47.5	3.5		39.5	3.5	
	From 25000 to 29999 SR	55.0			65.0		
	From 30000 to 34999 SR	55.0	0.00		75.0	0.00	

characteristics.

The effects of caregiver characteristics on the 8 QOL domains are summarized in Tables 6–8. There was a significant positive correlation between caregiver family income and the physical functioning domain; caregiver families with an income of 15,000 SR or greater had significantly higher physical function (86.8 ± 17.9) compared to those with income less than 5000 SR (53.8 ± 23.6, p = 0.023). There was also significant positive correlation between relation to the child and the role limitation due to physical problems domain and general health domain. Fathers reported higher scores for role limitation due to physical problems (79.8 ± 22.2) and general health (78.2 ± 14.3) compared to mothers (p = 0.004 and 0.043, respectively).

Finally, there was a positive correlation between level of education and the general health domain. Caregivers with a higher level of education such as bachelor's and postgraduate qualifications reported higher scores for general heath compared to those with lower levels of education (p = 0.027).

Discussion

There is a dearth of research on HRQOL among caregivers of children with autism in Saudi Arabia. Only 1 previous study assessed HRQOL in a sample of Saudi caregivers of children with autism in Riyadh (Asi, 2016). While the present study is among the first to systematically investigate HRQOL in Saudi caregivers, there are no data regarding QOL in the general Saudi population to make comparisons. One study conducted at King Khalid University evaluated QOL among university students (Megahed, 2014); these students had significantly better physical functioning (79.37 vs. 65.7) and general health (70.47 vs. 66.8) compared to caregivers in our sample. Surprisingly, bodily pain among university students was worse compared to caregivers in our sample (38.47 vs. 64.3), and similar trends were observed for role limitation due to physical and emotional problems. Yet, it is critical to underscore that a university sample is unlikely to be representative of the general population.

Although a number of caregivers in our sample utilized specialized services such as family support groups, others indicated that these services were unavailable to them. Studies elsewhere have suggested that utilization of support services provides some degree of perceived benefit, especially in the context of competing time and resource demands related to caring for a child with autism (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Saudi Arabia has made tremendous efforts towards improving and upgrading the available services in recent years. The 2 centres from which participants were recruited in the present study provide many free services, including speech therapy, parent support groups, and sibling days. Yet, the expressed need among a subset of participants in this study does reflect some of the challenges currently facing service providers in Saudi Arabia. Informal communications and interactions with service providers during the course of this project demonstrated that these challenges include long waiting lists, inconsistent and patchy services, inadequate staff numbers and expertise, and complicated referral processes.

A study from Japan (Yamada et al., 2012) reported that the average bodily pain, vitality, and mental health domain scores among mothers with children with autism were 68.7, 49.4, and 58.5, respectively, consistent with our study (64.3, 49.7, and 56.6, respectively). Additionally, a study in Qatar (Kheir et al., 2012) reported caregiver mental domain scores that were similar to those in our study (56). We found that Saudi caregivers with high family income reported better QOL physical component summary scores compared to those with low family income, similar to what was reported by Lee et al. (2009). This finding was likely attributable to the fact that the presence of a disabled child in the family serves as a source of financial and psychological pressure that exceeds pressures associated with typically developing children, such that parents of children with autism have greater difficulty meeting the necessary psychological, economic, and social needs of their children.

A previous study found that there were significant differences in QOL between fathers and mothers as caregivers (Kheir et al., 2012; Asi, 2016), with male caregivers usually having better QOL. In the present study, we similarly found that fathers reported better QOL than mothers, especially in the role limitation due to physical problems domain (79.8 ± 22.2) and general health domain (78.2 ± 14.3). These results are consistent with the findings of Hartley, Braker, Baker, Seltzer, and Greenberg (2012) but disagreed with the findings of Dardas and Ahmad (2014), which showed no differences in the level of QOL between mothers and fathers of children with ASD. Differences in the QOL of fathers versus mothers of children with autism may be related to differences in their relationships with their children. Future work is required to elucidate these differences in the context of Saudi culture.

The current study highlights critical factors that are necessary for promoting QOL in caregivers of children with autism. Specifically, the present research emphasizes the importance of after-school and weekend activities for autistic children in order to mitigate family and caregiver burden. Additionally, proper education about ASD plays a major role in helping families to understand what their child is going through. It is important for primary physicians to evaluate caregiver QOL as part of patient management.

Study limitations

This study was in part limited by a cross-sectional study design, which limited the evaluation of the temporality and causality of observed relationships. Second, the study may have been subject to selection bias, as individuals may have falsely described themselves as the primary caregiver. Housemaids from underdeveloped nations are commonly employed in Saudi Arabia through employment agencies, and regularly care for their clients' children for extended lengths of time. Notably, these housemaids are not equipped to work with autistic children. In such cases, parents may have been reluctant to admit the involvement of a housemaid.

Conclusion

The present study provides evidence for the effects of caring for a child with autism on caregiver QOL, and additionally informs strategies for supporting families of children with autism. These findings should be used to assist policy-makers in Saudi Arabia to provide better and more focused support for children with autism and their caregivers. An interventional study is needed to evaluate the effectiveness of support and entertainment programs for improving the QOL of children with

autism and their caregivers.

Recommendation:

In light of the conclusions of this research, the author makes the following recommendations:

1. To form focus groups among caregivers of children with autism to recognize their needs.
2. To stimulate care and service centres for children with autism to provide training programs and activities for parents and especially mothers of autistic children with the aim of improving QOL.
3. To direct charity, cooperative societies, and philanthropists to provide financial and economic support for families of children with autism and ensure that they are provided all the needs of their children.
4. To increase the awareness of autism, its associated socioeconomic burden, and its effects on family QOL.
5. Future studies are needed to explore other factors affecting the QOL of caregivers of children with autism spectrum disorders.

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