

ORIGINAL ARTICLE

Quality of life of caregivers of children with autism in Eastern Saudi Arabia

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ABSTRACT

Background: Despite of the established relevance of quality of life (QOL), research and the significant impact of having a child with autism, the QOL of caregivers of children with autism has been relatively understudied compared to other childhood problems. Thus, this study aimed to study the QOL and its predictors of principal caregivers of autistic children.

Methods: This study comprised parents of 105 autistic children attending 4 autism institutes in the eastern region of Saudi Arabia. The study was conducted from August 15, 2021, to October 31, 2021. QOL of the participants was assessed by short-form 36.

Results: Out of 105 parents of autistic children, 62 were females with a mean age 45.08 years. Majority (86.7%) of participants were married. Most of the participants (49.5%) had high level of education. The results showed a significant relationship between various socio-demographic variables and QOL. The findings of the study revealed that gender, age, monthly income and marital status were found to be the significant predictors of QOL of caregivers of autism children.

Conclusion: This study provided some evidence for the impact of caring for a child with autism on the life of the caregiver. It also gives an insight into areas relating to support provided to children with autism and their caregivers. The present study would help health policy-makers in Saudi Arabia to provide better and more focused support to children with autism and their caregivers.

Keywords: Quality of life, caregiver, children, autism, Saudi Arabia.

Introduction

Autism is a neurodevelopmental disorder characterized by impairments in communication and social functioning and the presence of restricted and repetitive behaviors [1]. According to the Centers for Disease Control and Prevention, the current prevalence rate of autism in the United States is 1 in 59 children [2]. This rate represents a 10-fold increase within the past 40 years, signifying a growing public health crisis, as service delivery systems struggle to meet the needs of individuals with autism. In the Gulf region, a systematic review of the epidemiology of autism revealed a prevalence ranging from 1.4 to 29/10,000 persons [3]. A study conducted in Taif, Saudi Arabia, estimated the prevalence of autism in primary school children aged 7-12 years was 0.035% [4]. Available literature has revealed no recent prevalence statistics for children with autism in Saudi Arabia [5]. The Ministry of Health in Saudi Arabia has indicated that one in every 160 children has autism [6]. With such a

high prevalence rate of autism, questions are being raised about its causes and its impact on the quality of life (QOL), not only of the sufferers but also of their family caregivers [7].

Despite the established relevance of QOL, research and the significant impact of having a child with autism, the QOL of caregivers of children with Autism has been relatively understudied compared to other childhood

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problems. As research suggested that children with autism drawing out different caregiving demands across their lifespan, it is important to inquire how QOL might be uniquely impacted for caregivers of children with autism [8]. Furthermore, there is limited research about QOL in caregivers of children for whom there are autism concerns, but no formal diagnosis. The lack of research about children with autism concerns are growing, given that this period is often a time of great distress for families as they navigate the service delivery system and tolerate uncertainty about their child's symptoms [9].

Up until now, only few studies have been conducted to determine the QOL of caregivers of autistic children in Saudi Arabia [10], but there is a dearth of research providing the socio-demographic predictors of QOL of principal caregivers of autistic children. The objectives of this study were to study the QOL and its predictors of principal caregivers of autistic children.

Subjects and Methods

This study comprised parents of 105 autistic children attending developmental abnormalities clinic at King Fahad Hospital in Hofuf city, Saudi Arabia. This hospital is affiliated to the Ministry of Health, the main service provider for children with intellectual disabilities. It provides medical, speech therapy, and behavioral intervention for autistic children. The study was conducted from August 15, 2021, to October 31, 2021. Parents of any child diagnosed with autism <1 year or with comorbidity, the presence of other siblings with disabilities, and those with chronic diseases were excluded from the study, as these conditions had a high impact on the QOL.

In order to achieve the goals of the present study, the different measures were used. QOL of the participants was assessed by short-form 36 (SF-36). Demographic questionnaire prepared by the researcher was also included in the study.

The information about demographic profile of the participants was collected with the help of questions related to their age, sex, and educational level, in addition to the information about their family i.e., area of residence, family type, income, housing status etc. Furthermore, the QOL was assessed by the Arabic validated version of the SF-36. The SF-36 health survey questionnaire (SF-36) is a 36-item Likert-type scale measuring eight domains on general health, physical functioning, physical role limitation, role limitation resulting from emotional issues, vitality, bodily pain, mental health, and social function [11,12]. The SF-36 questionnaires were scored for each domain; possible scores range from 0 to 100, with higher scores indicating better QOL. A mean score of QOL <50 for each domain was considered as poor.

The data were first exported to Microsoft Excel and then to Statistical Package for Social Sciences (version, 22) computer software used for quantitative statistical analyses. Prior to analysis, all variables were screened

for possible code. Qualitative data were expressed as number and percentage, whereas quantitative data were presented as the mean and standard error. Multiple regression analysis was used to assess the association between demographic characteristics and QOL. $p \leq 0.05$ was considered as statistically significant.

Results

Out of 105 parents of autism children, males were 43 and females were 62. The mean age of these parents was 45.08 years. Majority (86.7%) of participant were married. Most of the participants (49.5%) were having high level of education. The percentages of participants belonging to urban and rural areas were 84.8% and 15.2%, respectively (Table 1).

With regard to different domains of QOL, it was shown that male participants scored higher in social functioning and bodily pain domain of QOL than female participants, whereas female participants scored better than male participants in vitality domain of QOL. High score in bodily pain indicates good QOL. In terms of age, participants with less age scored higher in general health and bodily pain domain of QOL, as compared with participants with more age. For marital status, married participants scored higher in physical functioning and bodily pain domain of QOL in comparison to participants who were divorced and widows. In terms of educational qualification, participants having more qualification perceived higher score in vitality domain of QOL.

Separate multiple linear regression analyses were performed to identify predictors variables for the general health, physical functioning, physical role limitation, bodily pain, mental health, role limitation emotion, vitality and social functioning QOL, as measured by the SF-36. Result of multiple regression analysis revealed that marital status ($\beta = -16.30$) was the strongest predictor in the physical functioning domain of QOL. The obtained results clearly revealed that marital status was negatively and significantly related to physical functioning domain. This means that married participants showed good physical functioning than female participants (Table 2).

For the physical role limitation domain, gender ($\beta = -15.15$) was found strongest predictor. Results clearly revealed that gender was found negatively and significantly related to physical role limitation aspect of QOL. This means that male participants showed good role limitation physical QOL than female participants. In regard to the social functioning QOL of participants results of multiple regression revealed that gender ($\beta = -11.75$) and monthly income ($\beta = 5.72$) were found significant predictors of social functioning QOL. The obtained results clearly revealed that gender was negatively and significantly related to social functioning domain of QOL. This means that male participants showed good social functioning QOL than female participants. However, monthly income was positively and significantly related to social functioning QOL. This showed that participants having

high monthly income experience better social functioning QOL than participants having low monthly income.

Result of regression analysis predicting bodily pain domain from different demographic factors revealed age ($\beta = -10.41$), gender ($\beta = -9.04$), and marital status ($\beta = -10.39$) as significant predictors of bodily pain QOL. High score in bodily pain indicates good QOL. These results clearly indicated that age was negatively and

significantly related to bodily pain domain. This means that participants with young age perceived good bodily pain QOL as compared to participants with more age. Also, result revealed that gender was found negatively and significantly related to bodily pain component of QOL. This means that male participants showed good bodily pain QOL than female participants. Similarly, marital status was found negatively and significantly related

Table 1. QOL scores (mean and standard deviation) according to demographic characteristics (n = 105).

	N (%)	GH	PF	PRL	RLE	SF	BP	MH	VT
Gender									
Male	43 (41.0)	63.83 ± 13.08	68.37 ± 23.89	65.11 ± 41.95	55.75 ± 43.43	69.18 ± 25.05**	85.42 ± 19.48*	48.37 ± 8.54	43.37 ± 11.63
Female	62 (59.0)	60.48 ± 15.32	68.70 ± 26.59	50.40 ± 40.61	47.26 ± 42.01	56.85 ± 28.69	75.89 ± 22.32	47.48 ± 6.92	48.14 ± 10.56*
Age									
Below 30 years	26 (24.8)	63.62 ± 12.72*	72.10 ± 24.34	57.60 ± 40.91	42.32 ± 40.50	58.11 ± 31.22	87.21 ± 17.32**	48.32 ± 8.90	48.63 ± 11.90
30-50 years	69 (65.7)	62.90 ± 14.51	67.32 ± 27.06	57.23 ± 40.90	54.53 ± 43.19	65.02 ± 25.25	79.52 ± 21.01	47.40 ± 7.20	44.71 ± 10.83
50 and above	10 (9.5)	52.02 ± 15.60	67.54 ± 15.56	47.54 ± 47.73	46.65 ± 44.98	50.22 ± 33.80	61.80 ± 27.10	46.90 ± 6.85	50.00 ± 12.90
Marital status									
Married	91 (86.7)	62.63 ± 13.42	70.93 ± 25.09**	59.06 ± 41.08	51.59 ± 42.77	63.32 ± 26.53	81.73 ± 20.56**	47.69 ± 7.91	45.93 ± 11.49
Divorced	14 (13.3)	58.78 ± 19.96	53.21 ± 22.58	39.28 ± 42.41	45.19 ± 42.53	52.63 ± 34.73	67.22 ± 24.89	48.85 ± 5.25	47.85 ± 9.34
Monthly income									
<5,000 SAR	26 (24.8)	58.07 ± 15.17	63.46 ± 25.84	54.80 ± 38.74	46.10 ± 42.21	65.38 ± 29.85	83.58 ± 17.93	45.23 ± 6.67	43.84 ± 11.25
5,000-10,000	33 (31.4)	63.78 ± 11.99	71.21 ± 25.15	65.15 ± 39.98	57.51 ± 45.06	66.66 ± 25.12	79.49 ± 19.74	47.75 ± 6.55	44.84 ± 10.28
10,001-15,000	24 (22.9)	62.91 ± 16.27	65.62 ± 28.29	44.79 ± 42.97	47.17 ± 40.38	61.93 ± 31.38	78.42 ± 21.89	48.16 ± 8.70	46.66 ± 10.59
15,001 and above	12 (21.0)	62.27 ± 15.71	73.86 ± 21.87	57.95 ± 42.24	49.24 ± 43.29	50.56 ± 23.29	77.28 ± 28.08	50.72 ± 8.22	51.13 ± 12.24
Area of residence									
Rural	89 (84.8)	62.46 ± 14.73	70.28 ± 25.54	58.42 ± 41.95	52.00 ± 42.87	61.09 ± 26.81	79.99 ± 21.83	47.91 ± 7.81	47.02 ± 10.78
Urban	16 (15.2)	58.43 ± 12.87	59.06 ± 23.10	45.31 ± 38.96	43.70 ± 41.65	66.40 ± 33.45	78.70 ± 21.09	47.50 ± 6.51	41.50 ± 12.74
Academic qualification									
Primary	14 (12.33)	61.42 ± 14.99	56.78 ± 24.69	51.78 ± 37.29	66.60 ± 41.30	76.78 ± 23.94	84.19 ± 18.99	45.72 ± 8.10	38.92 ± 1.77
Intermediate	13 (29.5)	58.22 ± 13.45	66.12 ± 21.31	58.06 ± 42.02	45.11 ± 43.45	59.67 ± 28.63	81.32 ± 24.10	47.48 ± 6.98	45.64 ± 11.30
Secondary	15 (49.2)	63.84 ± 15.26	73.94 ± 26.84	58.17 ± 43.36	49.36 ± 42.98	60.53 ± 29.11	78.77 ± 21.84	49.15 ± 8.01	48.07 ± 10.71*
Bachelors	8 (7.6)	63.75 ± 11.57	63.75 ± 26.84	46.87 ± 41.05	54.11 ± 39.55	52.12 ± 12.93	73.32 ± 14.64	44.50 ± 4.98	49.75 ± 11.25

M = Mean; GH = General health; PF = Physical functioning; PRL = Physical role limitation; RLE = Role limitation emotional; SF = Social functioning; BP = Bodily pain; MH = Mental health; VT = Vitality.

All values are written in M ± SD.

*p = 0.01 (t-test), **p = 0.05 (one-way analysis of variance).

Table 2. Association between QOL and predictor variables.

Variables	GH		PF		PRL		RLE		SF		BP		MH		VT	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
Age	-3.3	0.1	-1.2	0.7	-2.3	0.7	5.3	0.4	0.1	0.9	-10.4	0.0	-0.2	0.8	-0.0	0.6
Gender	-3.8	0.2	1.1	0.83	-15.1	0.05	-6.6	0.4	-11.7	0.04	-9.0	0.0	-0.7	0.6	4.4	0.0
Academic qualification	2.0	0.3	4.0	0.2	1.8	0.7	-4.0	0.5	-1.9	0.6	-1.4	0.5	0.0	0.9	1.4	0.3
Marital status	-3.1	0.4	-16.3	0.03	-14.3	0.2	-3.8	0.7	-11.0	0.1	-10.3	0.0	2.4	0.0	3.0	.3
Monthly income	0.1	0.9	0.0	0.9	-4.9	0.2	-0.8	0.8	5.7	0.03	-2.8	0.1	1.8	0.0	2.2	0.0
Area of residence	-1.5	.7	-4.2	0.5	-13.1	0.2	-11.9	36	0.8	0.9	-2.7	0.6	0.6	0.7	-2.8	0.3
<i>R</i> ²	6%		9%		7%		2%		12%		18%		7%		14%	

GH = General health; PF = Physical functioning; PRL = Physical role limitation; RLE = Role limitation emotional; SF = Social functioning; BP = Bodily pain; MH = Mental health; VT = Vitality.

to bodily pain. This indicated that married participants showed good bodily pain than female participants.

With regard to the mental health QOL of participants results of multiple regression revealed that monthly income ($\beta = 1.83$) was found significant predictors of mental health. These results clearly indicated that the mental health was positively and significantly related to mental health domain. This showed that participants having high monthly income experience better mental health than participants having low monthly income. For vitality domain of QOL, gender ($\beta = 4.40$) and monthly income ($\beta = 2.24$) were found strongest predictor. Results clearly revealed that gender was found positively and significantly related to vitality domain of QOL. This means that male participants showed more vitality than female participants. Similarly, monthly income was found positively and significantly related to vitality. This indicated that participants having high monthly income experience more vitality than participants having low monthly income.

Discussions

The present study was conducted to examine QOL of caregivers of children with autism in Eastern part of Saudi Arabia. It was hypothesized that demographic factors would significantly predict QOL of caregivers of children with autism. The results showed a significant relationship between various socio-demographic variables and QOL. The findings of the study revealed that gender, age, monthly income and marital status were found to be the significant predictors of QOL of caregivers of autism children.

Findings of the present study regarding gender differences in QOL showed significant differences between male and female participants on the measure of SF-36. In the domain of role limitation due to physical health, social functioning and bodily pain, male participant reported

better QOL in comparison to their counterpart female participants. These results regarding gender differences in QOL of the participants extended support to the previous studies showing differences between males and females in QOL [13-15]. Better QOL reported by the male participants in the present study might because of a tendency to perceive their personal health as excellent and that they always feel energetic, as compared with females. This is in line with the cultural norms of the Saudi Arabia where men are generally considered to be the stronger and dominant sex, thus men perceive themselves to be so. These factors might be more responsible for better QOL among male participants. However, these issues could not appropriately be explained by the current study and requires further investigation. In the present study, female participants scored higher than males in vitality domain of QOL, females had handful of experiences and maturity to manage their health and maintain their vitality in comparison to male participants.

Several researches have suggested the effect of marital status on the QOL of parents with autism [16]. In the present study, the married participants have better physical functioning and bodily pain domain of QOL as compared to the divorced and widows. The results are in line with previous studies which examined marital status and QOL [16]. Previous findings reported that married people have strong QOL than those who are single or divorced due to the social support received from their spouse [17]. Another research examined the relationship between marital status and mortality. The results indicated that people who were single or widow showed higher mortality in particular diseases compared with those who were married [18]. In the present study, good QOL among married participants might because of care and support provided by their spouses especially while dealing autism children.

Regarding the impact of monthly income on parents with autism children, the findings of the present study

indicated that participants with high monthly income showed better social functioning, mental health and vitality as compared to the participants with low monthly income. These results regarding relationship between monthly income and QOL of the participants received extended support from previous studies [15,19-21]. Previous findings suggested that low income badly affects self-esteem, blocked aspirations, increased frustration, reduced efficacy, fatalism and lower mastery and personal control [22].

The findings of the present study indicated that the pain domain of QOL is better among the caregivers whose were young as compared to old age participants. This result is consistent with the previous findings suggested that sociodemographic factors such as parental age, educational level and lower income have been associated with higher parental stress [23,24].

Several limitations of the present study must be noted. First, the data of the present study were collected from only one region of Saudi Arabia. Data gathered in this context might therefore be unique, and it is entirely possible that a replication of this study in different parts of the country might yield different results. Second, the convenience sampling method of caregivers of children with autism in eastern region was not likely to be representative of all caregivers in other regions of the Saudi Arabia. Therefore, further study needs representative samples in order to establish the generalizability of findings on caregivers of children with autism living in other parts of the country. Third, the cross-sectional design used in the present study does not allow drawing conclusions regarding causality. Longitudinal research would be needed to support such conclusions. Lastly, sample size of the present study was relatively small and homogeneous which also limits generalization.

Conclusion

The present study demonstrated the differences in scores of different domains for the QOL related to various demographic factors. Gender, age, marital status, and monthly income were found strongest predictors of QOL. This study provided some evidence for the impact of caring for a child with autism on the life of the caregiver. It also gives an insight into areas relating to support provided to children with autism and their caregivers. The present study would help health policy-makers in Saudi Arabia to provide better and more focused support to children with autism and their caregivers.

List of Abbreviations

BP	Bodily pain
GH	General health
MH	Mental health
PF	Physical functioning
PRL	Physical role limitation
QOL	Quality of Life
RLE	Role limitation emotional

SF	Social functioning
VT	Vitality

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Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

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Consent to participate

Written informed consent was obtained from all the participants.

Ethical approval

Ethical approval was granted by Institutional Review Board of King Fahad Hospital-Hofuf via letter number 23-EP-2021, dated 15-08-2021.

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