Developing the first Arabic quality of life for parents of children with autism (QoLA) scale: translation, cultural adaptation and psychometric validation

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Abstract

Purpose In this research, the first Arabic quality of life (A-QoLA) measure for the mothers and fathers of children with autism is translated and validated. While there have been several translations of the QoLA scale, to the best of our knowledge, there are no Arabic version of this scale.

Method To translate and validate the QoLA, 407 family members (mostly parents) participated in this research. Item total correlation and confirmatory factor analysis (CFA) were used for the scale validation process.

Results The results show that like QoLA, all the items in Part A of the A-QoLA were positively correlated with the total score except items 2, 4, 17, and 22 (which were deleted). In addition, the Part B outcome of the item total correlation showed that all the items had a positive correlation with the overall score. The CFA results show high internal validity and consistency confirmed the two-domain structure for QoLA after it was translated into Arabic.

Conclusion Our results have very important implications as autism is quite common in the Arab world, and the scale can be used across several Arabic-speaking countries to understand the impact of autism on families.

Keywords Autism, Quality of life (QoL), Validation, Psychometric properties

Introduction

Autism is a neurodevelopmental disorder characterized by impaired social functioning, language delays, and repetitive behaviors [8]. There has been an increase in the prevalence of diagnosis of autism around the world [25, 68]. Solmi et al. [56] found that this increase is partially due to an increase in diagnosing females with autism.

Therefore, it is important to investigate the impact of autism on the family and society. An increase in caring responsibilities for children with disabilities, including autism, was found to increase distress and impact quality of life of parents and caregivers [33, 44]. This is because caring for autistic children requires significant time (e.g., doctors' visits) as well as physical and emotional investment (possibly due to excessive vigilance of the children), which can increase stress levels in the parents and caregivers. In addition, given that children with autism prefer isolation, this can also carries over to the parents, which can in turn impact their social life [29]. Other studies also found that caring for children with autism can impact marital relationship [32]. Below, we discuss quality of life (QoL) for caregivers with an autistic child and how prevalent autism is in the Arab World.

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Quality of life for carers of autistic children

There have been a multitude of studies on the effect of autism on mental health, distress, and the QoL of parents or caregivers of individuals with autism [47, 61, 64]. [47, 61, 64]. For example, Davis and Carter [21] found that caregivers of an autistic child were more stressed, anxious, and depressed than caregivers of a typically developing child. Similarly, Bitsika and Sharpley [13] found that parents of children with autism reported more stress, anxiety, and depression than parents of typically developing children. Gray [31] found that the carers of an autistic child described experiencing more social stigma as well as decreased social support in comparison to carers of a non-autistic child. Along these lines, Dabrowska and Pisula [19] found that autistic children's mothers had lower QoL compared to those whose children were developing normally. Moreover, one study reported how low-income carers of autistic children score lower on QoL scales than in high-income parents [47], due to an increase in burden of care in parents with low income.

While most existing studies investigate QoL in either fathers or mothers of autistic children, one recent study [63] investigated the effect on both parents of having an autistic child, as well as family QoL. Wang, Hu, and Han [63] found that stress in both fathers and mothers impacted involvement with the children with autism. Further, mothers reported more parental stress compared to others, possibly due to more caring duties done by mothers [28, 54].

Autism in the Arab World and other Eastern Nations

The prevalence of autism varies by country and ethnicity (e.g., Hispanics vs. Caucasians, as in [67]). There are a dearth of studies on autism in the Arab World, compared to Western countries [4, 66]. However, the incidence of autism may be higher in some Arab nations than in Western countries. For example, in the UAE, one in approximately 150 newly born individuals is diagnosed with autism [62]. One study found that the prevalence and severity of autistic symptoms are more common among Arab Bedouin than in Jewish individuals with autism residing in the south of Israel [41]. Another study found that the severity of autistic symptoms may lead to a lower QoL in parents [59].

Marriage among family members, especially cousins, is quite common in the Arab World. It has been argued that consanguinity can increase the risk of developing autism [51]. Similar findings were also reported in India [42]. Furthermore, it was found that autism in children was more common among Somali citizens of Sweden, compared to non-Somali citizen. It was argued that this is due to marriage among family members [11]. However, another study argued that some other factors may lead to an increase in the prevalence of autism in the Arab world including exposure to air pollution and pesticides as well as vitamin D deficiency [62].

There is a stigma related to having a child with disabilities, including autism, in the Arab World [45]. For instance, stigma related to autism is more common in Lebanon than in the USA [45]. Similar findings were also reported in China. The stigma related to autism can impact treatment provision for children with autism [9]. Furthermore, as a related issue to stigma, support is much more limited for autistic children or their carers in the Arab world, compared to, for example, the USA [3]. Al-Salehi, Al-Hifthy, and Ghaziuddin [2] reported that in Saudi Arabia, cultural beliefs and misconceptions about autism hindered timely detection and accessing suitable services. Similar observations were reported in other Arab nations.

Only a limited amount of research has been conducted on the QoL of parents or carers of autistic children in the Arab world. Most are observational or qualitative. For example, in Saudi Arabia, one study reported that almost two-thirds of parents had below average QoL due to caring duties for children with autism [6]. Alenazi, Hammad, and Mohamed [6] also found that QoL in mothers was less compared to fathers. Interestingly, these findings mirror similar numbers reported in the USA, such that almost wo-thirds of mothers with children with autism also had high level of distress [58]. Similarly, compared to South Asian parents, Australian parents show higher QoL scores on the QoLA scale [55].

Rationale of study and aim

Many studies have been conducted worldwide to measure the QoL of parental carers of those with autism spectrum disorder [14],Eapen et al., [40, 49, 60]. Although many commonly used autism scales have been translated into Arabic, including the Revised Childhood Autism Checklist and its variants (M-Chat, [1, 16, 66]) and the Social Interaction Questionnaire (SCQ, [5]), there is currently no Arabic version of the QoLA. Therefore, the purpose of this research is the translation, cultural adaptation, and validation of the QoLA so that it may be used in Arabic-speaking nations, which we refer to here as A-QoLA. Based on the prevalence of autism in the Arab world, it is important to develop a scale that measures how autism affects the QoL of parents. As such, the research is an initial endeavor at translating and validating a common QoLA scale into Arabic.

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Methods

Questionnaires

The QoLA questionnaire was created by Eapen et al. [23]. Written authorization was gained from the lead author of Eapen et al. [23] to translate and validate the Arabic form of their research paper. The first part of the questionnaire demographic data and the QoLA itself consists of two subscales: Part A consists of 28 items and Part B consists of 20 difficulties commonly encountered by children with ASD. The authors of QoLA have shown that the scale has acceptable reliability and validity for both subscales [23]. Parents rate their overall view of their quality of life with Part A on a 5-point Likert scale ranging from 1 (not very) to 5 (very much). Four items are reverse scored (items 2, 4, 17, 22) and corrected before the total score is calculated. Total scores for Part A range from 28 to 140, with higher scores indicating better quality of life [23]. At the same time, in Part B, parents rated the perceived impact of their children's difficulties on them on a 5-point Likert scale ranging from 5 (not a big problem for me) to 1 (a big problem for me). Scores for Part B range from 20 to 100, with a higher score indicating that parents are less affected by children's difficulties. Scores for each subscale should be considered separately, as both scales reflect two different contexts related to parents of children with ASD [23].

Translation process

We translated the survey based on international guidance for translation research [57, 65]. The QoLA survey was translated from English into Arabic by two qualified translators who worked independently of one another, with each being fluent in both languages. Their two respective translations in Arabic and the English QoLA questionnaire were then examined to detect variations at the word and sentence level, as well as regarding their sense. During this procedure, a draft Arabic translation of the QoLA questionnaire was created by the principal investigator and team leader (PI-TL). The PI-TL version was then translated from Arabic into English by two different, qualified translators, who again worked independently. Their Arabic-to-English back-translations and our Arabic PI-TL version were then assessed for discrepancies of wording, sentence structure, meaning, and significance against the rubric, items, and form of response. We held meetings with the translators to resolve these discrepancies before the end version of the A-QoLA was agreed upon. The Institutional Review Board (IRB) of Al Ain University gave its assent to the research.

Participants

Participants in this study were from United Arab Emirates, Jordan, Egypt, Oman, Bahrain, Saudi Arabia, Kuwait, Iraq, Qatar, Morocco, Algeria, Oman, Syria, and Palestine, and they were care givers (the vast majority were parents) of 407 autistic children who consented to be contacted ($n=407$). A recruiting letter, consent papers, and the A-QoLA were sent to caregivers. In the accompanying information, we asked the main carer to fill in the survey. Until they sent the surveys back, the families received mail correspondence or follow-up phone calls up to three times. Of the total care givers who responded by completing the questionnaire, 15.7% were men and 84.3% were women. The mean age of participants was 43.1 ± 96.6. The mean age of children with autism was 9.3 ± 4.7. The majority of the study sample was from the UAE ($n=180$, 44%) (Table 1).

Table 1 Demographic data of the sample ($n=407$)

Demographics	Groups	Frequency	Percentage
Parent gender	Male	64	15.7%
	Female	343	84.3%
Person completing the questionnaire	Sister	12	2.9%
	Mother	333	81.8%
	Father	60	14.7%
	Brother	1	0.2%
	Aunt	1	0.2%
Gender of child with autism	Male	319	78.4%
	Female	88	21.6%
Country	Iraq	1	0.2%
	UAE	180	44.2%
	Tunisia	3	0.7%
	Syria	8	2%
	Saudi Arabia	60	14.7%
	Qatar	5	1.2%
	Palestine	1	0.2%
	Oman	12	2.9%
	Morocco	7	1.7%
	Libya	7	1.7%
	Kuwait	16	3.9%
	Jordan	48	11.8%
	Iraq	2	0.5%
	Egypt	33	8.1%
	Bahrain	20	4.9%
	Algeria	4	1%
Parent age (mean ± SD)	43.1 ± 96.6	–––	–––
Age of child with autism (mean ± SD)	9.3 ± 4.7	–––	–––

Data analysis

The sample size for this validation study ($n = 407$) corresponds to the proportion accepted in the Krejci and Morgan table, suggesting that a sample of 384 is adequate for a populace of at least one million (KMT, [39]). The QoLA autism survey has not previously been studied in an Arab population, and the factor structure of the QoLA has not been confirmed. The researchers used confirmatory factor analysis (CFA) to ensure that the items comprising Parts A and B of the scale were compatible with the Arab cultural context.

Results

Item total correlation

Before conducting the factor analysis, the item total correlation between each item and the overall total for Parts A and B were calculated. The result revealed that all the items in Part A of the A-QoLA were positively correlated with the total score except that four items have a positive correlation ($r \leq 0.30$) which applies to items 2, 4, 17, and 22. Furthermore, the Part B score of the item total correlation shows that all the items had a positive correlation with the overall score ($r \geq 0.30$). Items 2, 4, 17, and 22 were deleted from Part A due to the poor items total correlation. Table 2 shows the result for item total correlation of both Parts A and B of A-QoLA. Results have indicated that A-QoLA items positively showed moderate to high correlation with the total scale score which means the items conceptually fit together (DeVon et al., [22]).

As shown in Fig. 1 and from Graphs 1 and 2, the correlation heatmap between Part A items is correlated positively with a value more than 0.50. Similarly, Part B items are positively and significantly correlated with each other.

Confirmatory factor analysis (CFA)

The measurement model of A-QoLA drew on a two-domain structure. Part A relates to the general perspective on QoL by the parents, while Part B relates to how severely the parents consider the autism symptoms of their child "particularly" affect their QoL. These are the same as in the original QoLA by Eapen et al. [23]. In the current study, CFA was carried out to confirm the same two-domain organization for the QoLA after being translated into Arabic. The initial model assumed that the A-QoLA for the QoLA had multiple dimensions and a two-domain organization. The model fit indicators were $\chi^2 = 3757$, DF $= 819$, and $p \leq 0.001$; also, the incremental fit indices were also calculated and the result shows that (CFI $= 0.763$, TLI $= 0.716$) were all ≤ 0.90. Additionally, the RMSEA value was 0.093. This fitness result shows most of the fitness indices are not adequate which require

Table 2 Item total correlation between items and total score

Part A			Part B		
Item	R	Alpha	Item	R	Alpha
1	0.76	0.95	1	0.64	0.94
2	0.21	0.96	2	0.62	0.94
3	0.74	0.95	3	0.66	0.94
4	0.16	0.96	4	0.64	0.94
5	0.74	0.95	5	0.63	0.94
6	0.68	0.95	6	0.62	0.94
7	0.64	0.95	7	0.46	0.94
8	0.80	0.95	8	0.66	0.94
9	0.80	0.95	9	0.66	0.94
10	0.70	0.95	10	0.66	0.94
11	0.73	0.95	11	0.63	0.94
12	0.68	0.95	12	0.73	0.94
13	0.77	0.95	13	0.73	0.94
14	0.74	0.95	14	0.74	0.94
15	0.67	0.95	15	0.69	0.94
16	0.72	0.95	16	0.67	0.94
17	0.10	0.96	17	0.66	0.94
18	0.73	0.95	18	0.65	0.94
19	0.79	0.95	19	0.58	0.94
20	0.81	0.95	20	0.64	0.94
21	0.73	0.95			
22	0.10	0.96			
23	0.67	0.95			
24	0.64	0.95			
25	0.68	0.95			
26	0.76	0.95			
27	0.77	0.95			
28	0.62	0.95			

to add covariance between the scale item error. Subsequently, the adapted indicators were employed to see if covariance should be permitted between item errors.

Byrne [15] proposed the use of an adapted index with residuals in between two items (± 2.58). Covariances were added and the model retested and then the value of $\chi^2 = 1920$, DF $= 783$ and $p \leq 0.001$. A more exact CMIN/DF indicator found that the model fit was sufficient (CMIN/DF $= 2.45$, which is less than 3). To further increase the error covariance, stepwise fit indices were also calculated, with a score nearest to one indicating the optimal model fit. The resultant incremental index scores (CFI $= 0.91$ and TLI $= 0.90$) were all ≥ 0.90, suggesting that the model is very appropriate. The RMSEA score was 0.06, just under the cut-off of near 0.06. Item loading scores were 0.62–0.834 for factor 1 and 0.55–0.80 for factor 2, which are inside the allowable span of high loading values (all > 0.50) and all the standardized coefficients are significant ($\alpha < 0.001$). From Table 3, it can be seen that

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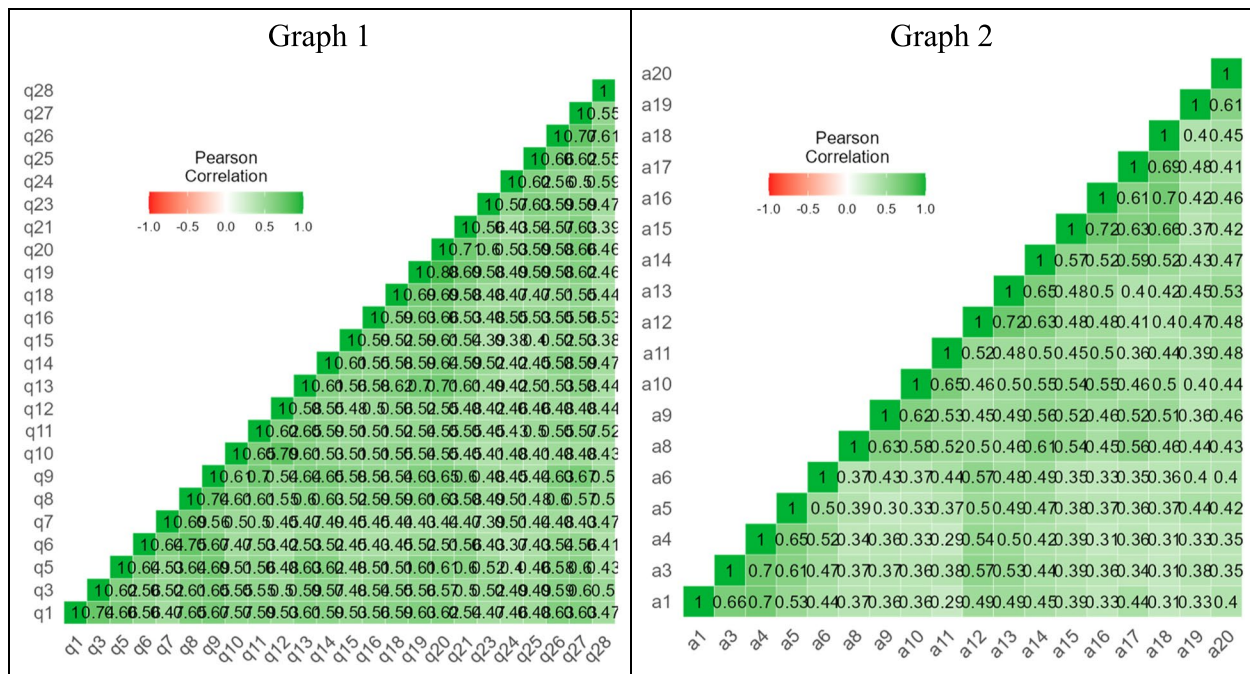
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Fig. 1 Graph 1 and 2 Correlation Heatmaps between Part A and B items

the loading scores for items remain in scale in both parts. Figure 2 shows the confirmatory factor analysis of the two-domain structure of A-QoLA.

The heterotrait-monotrait ratio of correlations (HTMT) was used to check the discriminate validity of scale domains. To assess discriminant validity, the value of HTMT should be less than 0.85 between any two constructs in scale (Henseler, Ringle, and Sarstedt, [34]). The result show that all the HTMT is less than 0.85 which means that the construct of the scales domains for the two factors discriminate validity.

Cronbach's alpha and composition reliability approaches were employed to check scale reliability in both parts. For factor 1, the alpha is 0.966 and the CR0.96 indicated high internal consistency. The result for the factors 2 alpha value 0.939 and CR 0.93 indicated high internal consistency (Table 4).

Discussion
As mentioned above, like QoLA, the A-QoLA has two parts, with Part A focusing on parents' general perspective on QoL and Part B on how severely parents consider the autism symptoms of their child impact their QoL. Results show that all the items in Part A of the A-QoLA were positively correlated with the total score except items 2, 4, 17, and 22. Accordingly, we have deleted these items from Part A. Moreover, the Part B outcome of the item total correlation shows all the items had a positive

correlation with the overall total. CFA was carried out to confirm the two-factor structure for QoLA after translation into Arabic. Results show high internal validity and consistency. As mentioned above, a forward English to Arabic translation of the QoLA survey was conducted, with the qualified translators having no information about the scale. Our results show adequate reliabilities of the two-part structure of A-QoLA.

Our study adds to other existing studies that have also translated and validated the QoLA into other languages including Malay [43, 53], Bengali [10], Persian [35], Turkish [46], Romanian [24], Spanish [24], and Hungarian [24]. Like all of these translations, our A-QoLA scale also showed high reliability and consistency. Like other studies and translations on QoLA, our study also confirmed the two-factor structure of the QoLA. This means that measuring QoL in parents (Part A of the A-QoLA) is a different construct from the effect of the child's autism spectrum disorder on the parents (Part B of the A-QoLA). In fact, some studies found that, unlike Part A, Part B of the QoLA varies greatly among different cultures. Future work should administer the A-QoLA to people in different Arabic countries to compare how Parts A and B different among different populations.

Furthermore, in the current work it should be noted that we have used formal not colloquial Arabic language as the latter varies massively across different Arabic-speaking countries [18]. This is consistent with

Table 3 Loading values for the two factors

Factor	Indicator	Estimate	SE	Z	p	Stand. estimate
Factor 1	q1	0.94	0.05	18.50	<.001	0.78
	q3	0.90	0.05	17.30	<.001	0.75
	q5	0.96	0.05	17.90	<.001	0.76
	q6	0.91	0.06	15.50	<.001	0.69
	q7	0.78	0.06	13.80	<.001	0.63
	q8	1.06	0.06	19.10	<.001	0.80
	q9	1.10	0.06	19.90	<.001	0.82
	q10	0.94	0.06	16.10	<.001	0.71
	q11	1.03	0.06	17.30	<.001	0.75
	q12	0.84	0.05	15.40	<.001	0.68
	q13	1.03	0.05	19.10	<.001	0.80
	q14	1.00	0.05	18.30	<.001	0.78
	q15	0.83	0.05	15.80	<.001	0.70
	q16	0.90	0.05	17.10	<.001	0.74
	q18	1.01	0.06	17.40	<.001	0.75
	q19	1.07	0.05	19.70	<.001	0.81
	q20	1.07	0.05	20.40	<.001	0.83
	q21	1.00	0.06	17.80	<.001	0.76
	q23	0.86	0.06	14.70	<.001	0.66
	q24	0.77	0.06	13.60	<.001	0.62
	q25	0.85	0.06	14.90	<.001	0.67
	q26	0.99	0.06	17.60	<.001	0.75
	q27	1.00	0.05	18.30	<.001	0.78
	q28	0.89	0.07	13.60	<.001	0.62
Factor 2	a1	0.77	0.06	12.00	<.001	0.57
	a3	0.86	0.07	12.20	<.001	0.58
	a4	0.86	0.07	11.50	<.001	0.55
	a5	0.77	0.06	12.20	<.001	0.58
	a6	0.84	0.07	12.70	<.001	0.60
	a8	1.04	0.06	16.20	<.001	0.72
	a9	1.05	0.07	15.80	<.001	0.71
	a10	1.02	0.06	15.80	<.001	0.71
	a11	0.94	0.06	14.60	<.001	0.67
	a12	1.11	0.07	16.60	<.001	0.74
	a13	1.07	0.06	16.60	<.001	0.74
	a14	1.11	0.06	19.20	<.001	0.81
	a15	1.12	0.07	16.00	<.001	0.71
	a16	1.00	0.07	15.10	<.001	0.69
	a17	1.03	0.07	15.40	<.001	0.70
	a18	0.98	0.07	14.60	<.001	0.67
	a19	0.86	0.07	12.60	<.001	0.59
	a20	0.83	0.06	13.80	<.001	0.64

other studies that usually use classical Arabic translation in validation studies. Accordingly, our results point to a general and wide use of the A-QoLA across several Arabic-speaking nations and populations [12, 17, 20, 27].

Limitations

One limitation of the current study is that we did not investigate elements of QoL, which is a complex construct with several elements, such as emotional wellbeing, material wellbeing, personal development, social
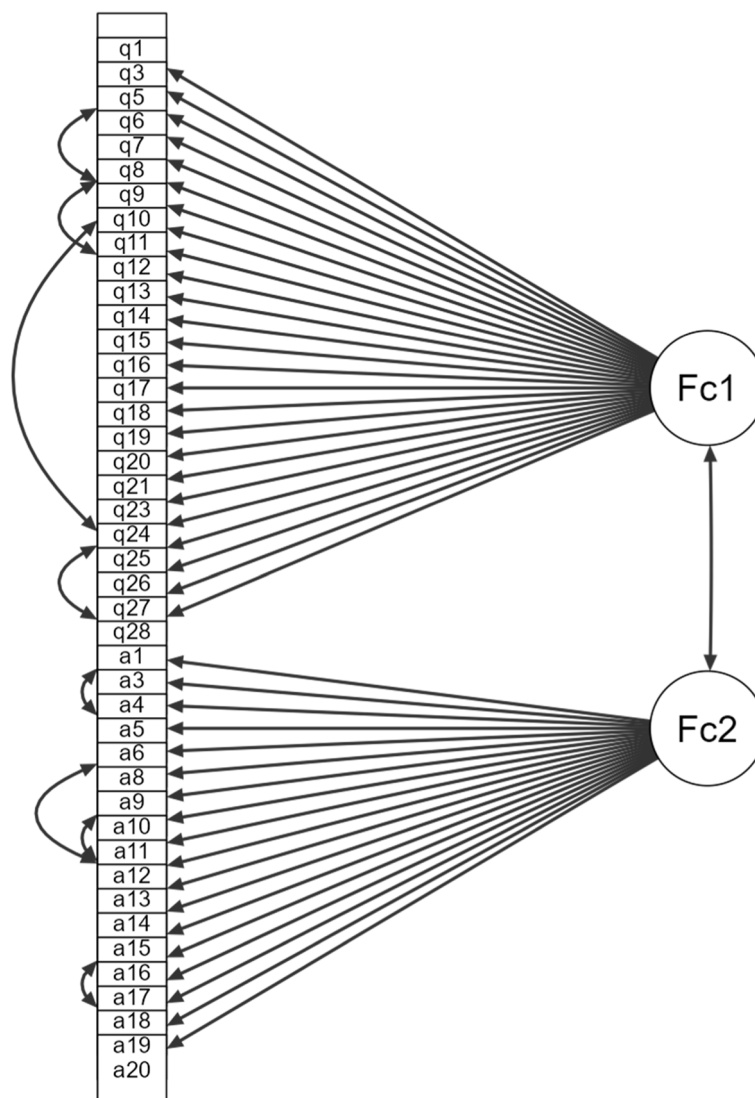
Fig. 2 CFA of the two-domain organization of A-QoLA

Table 4 Reliability coefficient for the VEDAS four-scale construct

Factor	Alpha	Composition reliability
Factor 1	0.966	0.96
Factor 2	0.939	0.93
Overall scales	0.79	

functioning, and physical and psychological health [30, 52]. Most prior studies did not investigate elements of the quality of life constructs, with some exceptions. Future work should investigate how subprocesses of QoL are impacted among the parents or carers of autistic children. It is expected that carers may show worse scores on social functioning components of QoL, possibly due to reduced social interactions with others.

Another limitation in the current study is not using the family quality of life scale. This scale is also important and commonly used as it measures family wellbeing in general, and not only parents [7]. Many works have indicated that living with an autistic child can impact the QoL of the entire family [36, 48]. Several studies have also reported a relationship between family quality of life and A-QoLA [7, 63]. However, it is important to note that future studies should investigate whether the family quality of life and A-QoLA scales are separate constructs or perhaps measure a very similar construct.

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Future research

Future research should also investigate potential interventions for ameliorating low QoL among the parents and carers of autistic children. Along these lines, Estes et al. [26] found parent-mediated intervention for children with autism not only improved child outcomes but also reduced parental stress and improved parent–child interactions. Tomanik, Harris and Hawkins [58] found that parents who reported higher levels of social support had lower levels of distress. Other studies found that perceived social support can moderate the effect between Distress and QoL in parents with children with autism as well as other special needs [37]. Accordingly, providing social support to the parents of children with autism is likely to improve their QoL, particularly parents of low socioeconomic status.

Future work should investigate whether the acuteness of a child's autism and any co-occurring clinical conditions may increase parental distress and impact QoL. It is well known that many of the children with autism also present with other co-morbid developmental disorders [38]. For example, studies found that schizophrenia share many genetic factors with autism [50]. In addition, studies should investigate other potential influences on QoL in autistic children's parents, such as age, income, and availability of social support, among others. Cultural differences in the QoL of these parents should also be investigated. It is predicted that in societies where one parent is taking a large caring role for the children, those parents may show very low quality of life.

Conclusions

This work is the unique in providing a valid, culturally sensitive Arabic translation of the scale of the QoL of caregivers and parents of autistic children. Our results show high internal validity, reliability, and consistency of the newly developed A-QoLA. This is quite significant and important as there are 22 Arabic-speaking countries in the Middle East as well as other Arabic-speaking populations in several countries who can benefit from the use of this scale.

Abbreviations

QoLA	Quality of life measure for parents of children with autism
A-QoLA	Arabic quality of life measure for parents of children with autism
QoL	Quality of life
IRB	Institutional Review Board
PI-TL	Principal investigator-team leader
CFA	Confirmatory factor analysis
SD	Standard deviation
M	Mean

Availability of data and materials
Upon justified request, the corresponding author will provide the materials used and analyzed in this work.

Declarations

Ethics approval and consent to participate
This study was conducted according to the recommendations of the Al Ain University administration.
All participants gave written and informed consent in accordance with the Declaration of Helsinki.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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