

Adaptation of the Quality of Life in Autism Scale (Parent Version) for use in Bangladesh

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ABSTRACT: Parents of children with developmental disabilities, particularly Autism Spectrum disorder, are known to be at risk for high levels of psychological distress. The present study aimed to adapt the Quality of Life in Autism Questionnaire (QoLA, parent-version) in the context of Bangladeshi culture. The sample included 50 participants. Participants were selected from the Institute of Paediatric Neurology and Autism (IPNA, BSMMU) and some special schools of Dhaka city. World Health Organization's (WHO, 2009) guidelines were followed in translating the QoLA and adaptation for use in Bangladesh. For the parent-report version of the QoLA, Cronbach's coefficients were 0.880 and 0.725 for part A and part B subscale items, respectively. The Pearson correlation coefficients for the test-retest reliability were $r=0.964$ for part A of the scale and $r=0.954$ for part B. These psychometric properties are comparable to those obtained in the initial QoLA validation study (Eapen et al. 2014). Results of this study demonstrate that the Bangla version of the QoLA (Parent version) provides a valid measure of quality of life and is suitable for use in Bangladesh.

KEYWORDS: Autism, Quality of life, Scale translation, Developing country.

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Introduction

There is a conceptual heterogeneity of autism. If we focus on the fact that autism is a psychiatric diagnosis based on certain behaviours, it is a neurological reality, possibly with a genetic basis. According to the Theory of Mind (ToM) hypothesis (Baron-Cohen, Leslie and Frith, 1985), autism is primarily a deficit in social functioning. Executive Functioning theory (Ozonoff, Pennington and Rogers, 1991) tells that it is a deficit in information processing. Thus, autism can be seen as one of the neurodiversity where children with ASDs are different from other neuro-typical children. The disorder places an enormous impact on daily lives of parents as they have to manage the child's various problems such as tantrum, aggression, self-harm, bizarre bodily movement, lack of normal language, inappropriate eating, toileting etc. (Hastings et al., 2005). Compared to other developmental disorders (Griffith et al., 2009) and parents of typically developing children (Ingersoll and Hambrick, 2011) parents of children with ASD, experience higher levels of stress. It is also evident that parental stress might be increased by factors like symptom severity, limited availability of services, and parents' skill in managing their children with ASD (Eapen et al., 2014)

Parents' quality of life is affected by raising a child with autism (Allik, Larsson and Smedje, 2006). Quality of life (QoL) is very subjective term as it is not scientifically measurable and the definition is not easily determined (Liu,

1975). One researcher (Abrams, 1973) defined quality of life as "the degree of satisfaction or dissatisfaction felt by the people with various aspects of their lives". Many authors offer different domains as the priority but priority will be subjective to the individual person's views. Quality of life is sometimes measured within one domain such as general health while other measures cover several domains. Domains such as health, income, and environment have an impact on a person's life satisfaction in general but the personality of the person will also impact on the measure of life satisfaction (Stuart-Hamilton, 2000). Quality of life (QoL) is a broad concept incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship with the surrounding (WHOqol Group, 1998). The generic health-related quality of life such as World Health Organization's Health Related Quality of Life-Short Form (SF36) measures global concepts. There are disease-specific QoL scales such as Stroke Specific Quality of Life Scale (Williams et al., 1999), Dermatology Life Quality Index (Finlay and Khan, 1994) and chronic illness related quality of life scales. Autism specific quality of life scale is needed as autism brings special demands on parent's life as children with autism are less able to express their needs, these children may also have secondary diagnosis such as epilepsy or intellectual impairment (Fombonne, 2003). Therefore, measuring mental health related factors such as stress and

psychological wellbeing, a broader and encompassing construct that is important to assess in parents of children with ASD is Quality of Life (QoL).

In mental health field, need for cross-cultural translation, adaptation and validation of psychological scales is enormous. Most of the instruments are developed in western countries which are also useful for non-western countries. There is no gold standard for the translation, adaptation, and validation of a measure cross-culturally, the literature agree that merely translating a scale in itself is inadequate (van Widenfelt et al., 2005). The purpose of translation is to achieve a conceptually equivalent version of the original instrument. Two guidelines are notable, these are 1: process of translation and adaptation of instrument by the World Health Organization (WHO, 2009) and 2: the guideline of the International Test Commission (International Test Commission, 2001).

The present study aimed to adapt a measure of quality of life for parents of children with autism. In Bangladesh context, the Quality of Life in Autism scale (QoLA- parent version) for parents of children with ASD is necessary in clinical settings. In a study (Rebeiro, Azad and Mahmud, 2019) conducted in Bangladesh, revealed that feelings of sadness, anger and helplessness were reported by parents of children with ASD. Thus, quality of life domains such as social activity, family burden, family activities, schooling, independence and parental concerns about their children's quality of life should also be explored when determining the impact of autism rather than examining symptoms alone. Mental health care professionals need to assess quality of life of parents of children with autism when providing service. This scale (QoLA) reflects two considerations, to measure a subjective wellbeing of parent, and measure the range of their child's disability that affect their life, and also measure the psychological distress they have.

Materials and Methods

Description of the Quality of Life in Autism Scale (QoLA): the quality of life in autism scale QoLA (Eapen et al., 2014) was developed in Australia. The scale was developed for parents of children aged 2-18 years. The QoLA had 48 items in two subscales (Part A and Part B). Part A including QoL items about their parents and in Part B parent determine how severe the autism symptoms of their child are "specifically" affecting the parents' quality of life. Part A includes 28 items designed to measure parents' overall perception of their quality of life (reverse 2, 4, 17, 22). Each item was measured on a five-point Likert scale ranging from one (not very much) to five (very much). Thus, scores on Part A ranged from 28 to 140, with higher scores indicated greater perceived QoL. Part B includes 20 items. The scores on part B ranged from 20 to 100, with higher scores indicated fewer problems for parents. The potential range for the QoLA total score was therefore 48–240. 39 families were involved in this study. There were two participant groups: clinical group included 23 parents of children with ASD and control group included 16 parents of children without ASD. The result showed excellent internal consistency ($\alpha = 0.94$ for part A and $\alpha = 0.92$ for part B) and good known group validity. The QoLA also showed positive correlation with four subscales of

World Health Organization's Quality of Life instrument-Short form, the WHOQOL-BREF ($r = 0.74$ to 0.91) that indicated good convergent validity. So the QoLA may be a valuable assessment tool.

Translation Procedure

World Health Organization (WHO, 2009) guidelines were followed for adaptation of the proposed questionnaire. Adaptation of the proposed scale was gradually advanced through the following steps.

Step-1: Translation of the original instrument in the target language (TL) was done by two independent translators whose mother language was Bangla. In addition, the two translators had distinct backgrounds. The first translator, who is a clinical psychologist, had knowledge about the content area of the construct of the instrument in the desired TL. The second translator, who is an English teacher of the Institute of Modern Language, University of Dhaka, who had no knowledge about the construct of the instrument.

Step-2: In step two, the two forward-translated versions of the instrument (TL1 and TL2) were compared with the original version of the instrument in the source language (SL) by a third bilingual independent translator regarding ambiguities and discrepancies of word sentences and meanings. Any ambiguities and discrepancies were discussed and resolve using an expert committee meeting approach. The expert committee was comprised of seven members including one paediatric neurologist, one psychiatrist, one professor of psychology, one professor of English and three authors. Preliminary initial translated version of the instrument in the TL (PI-TL) was generated in expert committee achieving consensus.

Step-3: Blind back translation of the preliminary initial translated version of the instrument was done by one independent translator who is a bilingual professional having knowledge of English culture. The translator had no knowledge about the content area of the construct of the instrument.

Step-4: The back-translations was then compared by a multidisciplinary committee with the instructions, items, response format, wording, and grammatical structure of the sentences, similarity in meaning and relevance. The multidisciplinary committee panel was comprised of a methodologist (researcher or a member of the research team), a health care professional, and all four bilingual translators. Any ambiguities and discrepancies regarding cultural meaning and idioms in words and sentences of the instructions, the items and the response format between the back-translations and between each of the back translations and the original instrument in the SL was discussed and resolved through consensus among the committee members to derive a pre-final version of the instrument in Bangla (P-FTL).

Step-5: It was recommended by WHO guideline to pre-test pre-final version of the instrument among at least 10 respondents on target population. Pre-test of the pre-final version was done with five mothers of children with autism spectrum disorder due to unavailability of desired number of respondents. Pre-test respondents were administered the instrument and were systematically debriefed. In this debriefing session, respondents were asked whether they could repeat the question in their own words, what came to their

mind when they heard a particular phrase or term. The answers to these questions were then compared to the respondent's actual responses to the instrument for consistency.

Step-6: After pilot testing reliability and validity testing was done in a large sample of 50 parents of target population with the questionnaire. In this step the data was collected by one of the researchers. Rapport was built before collecting data from

the respondents. They were explained clearly about the purpose of the study. The participants were instructed to respond to Bangla translated quality of life in autism (QoLA) scale. Verbal and written consent for participating in the study was taken from them. The final questionnaire is given in the supplementary files.

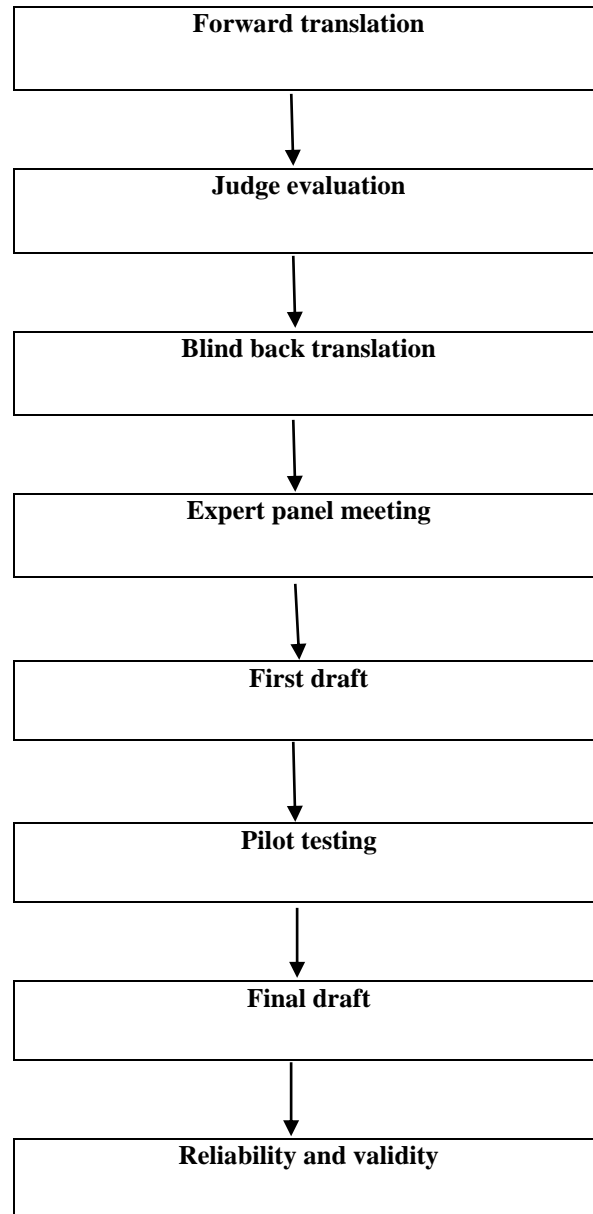


Figure-1. The process of scale adaptation

Sample

The sample included 50 parents (40 mothers, 10 fathers). Participants were selected from the Institute of Paediatric Neurology and Autism of Bangabandhu Sheikh Mujib Medical University (IPNA, BSMMU) and some special schools of Dhaka city.

Ethical Consideration

Ethical clearance was obtained from the Department of Clinical Psychology, University of Dhaka. Written informed consent was taken from all participants in the study prior to data collection. All data was anonymous and confidentiality of the participants was maintained throughout the study.

Data Analysis

Items can be termed as the most important unit of any scales. All the characteristics and usability of a scale heavily depend

on the nature of the items. Three methods were followed for item analysis of the scale using SPSS version 20. The first method was “corrected item total correlation”, the second method was “Cronbach’s alpha if item deleted” and the third method was “inter item correlation” of items. Then the psychometric properties of the scale such as reliability, validity were calculated using SPSS version 20.

Results and Discussion

Before establishing reliability and validity of the scale, translation of the scale in Bangla language followed some necessary steps. Through this translation, content validity was established in our cultural context.

Reliability of the Questionnaire

Reliability of the scale was assessed by internal consistency and test-retest methods. Details of the results and procedure are presented here (Table 1 & Table 2).

Internal consistency was assessed by Cronbach’s Alpha which is widely used method. SPSS-20 was used for the analysis. Cronbach’s alpha for part A of the questionnaire was found to be 0.880 which is usually good level of internal consistency (“ $\alpha \geq .9$ – Excellent, $.9 > \alpha \geq .8$ – Good, $.8 > \alpha \geq .7$ – Acceptable, $.7 > \alpha \geq .6$ – Questionable, $.6 > \alpha \geq .5$ – Poor, and $.5 > \alpha$ – Unacceptable” (George and Mallery, 2001)

Table-1. Reliability statistics for Part A of the scale

Cronbach,s Alpha	Cronbach,s Alpha based on Standardized items	N Items
.880	.880	28

Table 1 shows that Cronbach’s alpha for part A was found to be 0.880 which is on good level.

Table-2. Reliability statistics for part B of the scale

Cronbach’s Alpha	Cronbach’s Alpha based on Standardized items	N Items
.725	.732	20

Table 2 shows that Cronbach’s alpha for part B was found to be 0.725 which is also acceptable.

Test-retest Reliability

To establish the stability of the scale test-retest reliability was assessed. A total of 44 participants were approached for this purpose. The questionnaire was administered in two occasions

with an interval of one week. The correlation coefficient between the score of two administrations was found at the 0.01 level significant (Table 3).

Table-3. Test-retest reliability of part A and part B of the questionnaire (n=44)

QoLA	First Testing		Second Testing		<i>r</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Part A	82.80	12.517	81.98	10.165	.964**
Part B	53.36	8.419	54.70	7.226	.954**

**Correlation is significant at the 0.01 level (2-tailed)

Validity of the Questionnaire

Validity is defined as the extent to which an assessment instrument measures what it is designed to measure (Aiken,

1997). There are three major types of validity namely content validity, criterion validity, and construct validity. Only content validity was worked out for the measure.

Content Validity

Content validity of a test is to be built during the construction which indicates that a scale's content validity can be ensured through systematic item construction, selection and analysis (Lynn, 1986). In the present study the systematic steps were followed to adapt the present questionnaire; as support for the content validity of the scale. In the adaptation of the present questionnaire all the items were evaluated by a large group of judges who were practicing in the field of health and mental "Corrected Item Total Correlation" the second was "Cronbach's Alpha If Item Deleted" and the third was "Inter Item Correlation" of the items.

health professions. After completing judge evaluation, we accumulated the possible Bangla options from the comments of the judges. Then we tested the questionnaire in field. After that we arranged a meeting to select the translation and made corrections and additions. This systematic evaluation indicates the content validity of the scale.

Item Analysis

Three methods were used for item analysis of the scale because it is an important property of a scale. The first was "Corrected Item Total Correlation" the second was "Cronbach's Alpha If Item Deleted" and the third was "Inter Item Correlation" of the items.

Table-4. Corrected item total correlation and Cronbach's alpha if item deleted for Part A

Items of Part A	Corrected item total correlation	Cronbach's Alpha if item deleted
Item1	.600	.872
Item2	.394	.877
Item3	.542	.873
Item4	.244	.880
Item5	.508	.874
Item6	.418	.876
Item7	.529	.873
Item8	.534	.874
Item9	.502	.874
Item10	.523	.873
Item11	.212	.880
Item12	.551	.873
Item13	.538	.873
Item14	.157	.882
Item15	.567	.873
Item16	.255	.880
Item17	-.136	.891
Item18	.681	.869
Item19	.443	.875
Item20	.507	.874
Item21	.679	.870
Item22	.226	.881
Item23	.381	.877
Item24	.395	.876
Item25	.552	.872
Item26	.437	.875
Item27	.587	.872
Item28	.328	.878

Among 28 item of part A (Table 4), 22 items have corrected item- total correlation above 0.3; which is encouraging as well as good internal consistency among items. But 6 items (item no. 4; 11; 14; 16; 17; 22) have item –total correlation below 0.3 which indicates fairly bad internal consistency among items and deletion of those items will increase Cronbach's alpha of the total scale. However, Cronbach's alpha of the total scale is not so high after deletion of those items (" $\alpha \geq .9$ – Excellent, $.9 > \alpha \geq .8$ – Good, $.8 > \alpha \geq .7$ – Acceptable, $.7 > \alpha \geq .6$ – Questionable, $.6 > \alpha \geq .5$ – Poor, and $.5 > \alpha$ – Unacceptable" ⁽¹¹⁾). The Cronbach's alpha of the total scale without deletion of any item was ($\alpha = 0.880$) good and after deletion of those items the Cronbach's alpha of the total scale is good ($.9 > \alpha \geq .8$ – Good).

A high positive inter item correlation indicates the coherence of the items of a scale in measuring a construct. A very high (above 0.80) correlation between two or more items indicates the possible redundancy of items. In such cases it is better to deduct those items into a single one. Data analysis part-A (Appendix-1.) showed that there is no inter item correlation which is above 0.80.

Among 20 item of part B (table 6); 10 items have corrected item- total correlation above 0.3; but 10 items (item no.2; 3; 4; 6; 7; 9; 10; 13; 14; 20) have item –total correlation below 0.3 which indicates fairly bad internal consistency among items. It indicates deletion of those items will increase Cronbach's alpha of the total scale.

Table-5. Corrected item total correlation and Cronbach's alpha if item deleted for Part B

Items of part B	Corrected item total Correlation	Cronbach's Alpha if item deleted
Item 1	.547	.696
Item 2	.284	.715
Item 3	.208	.722
Item 4	.264	.717
Item 5	.394	.715
Item 6	.044	.734
Item 7	.297	.719
Item 8	.379	.704
Item 9	.249	.715
Item 10	.119	.709
Item 11	.378	.718
Item 12	.320	.730
Item 13	.174	.708
Item 14	.281	.712
Item 15	.418	.724
Item 16	.384	.707
Item 17	.371	.708
Item 18	.343	.710
Item 19	.312	.713
Item 20	.227	.720

Table-5 shows that none of the items would increase the reliability if they were deleted except item no.6. Deletion of item 6 slightly increase (from .725 to .734) Cronbach's alpha of total scale and it is acceptable (" $\alpha \geq .9$ – Excellent, $.9 > \alpha \geq .8$ – Good, $.8 > \alpha \geq .7$ – Acceptable, $.7 > \alpha \geq .6$ – Questionable, $.6 > \alpha \geq .5$ – Poor, and $.5 > \alpha$ – Unacceptable"⁽¹¹⁾).

Inter-item correlation analysis of Part-B shows that there is no inter item correlation which is above 0.8 (Appendix-2).

Conclusion

The study is not without limitations. There were no translator whose mother language was English, though the original author was contacted for feedback on back translation. Psychometric analysis was done on a relatively small respondents (50 parents of autistic children) as autism is low prevalent in our country. Despite the limitations of the study, quality of life in parents of autistic children can be assessed objectively with this scale.

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