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The Persian version of Neurofibromatosis type 1 Adult Health-Related Quality of Life (NF1-AdQOL) questionnaire in Iranians: A validity and reliability study

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Abstract

Background: Because of the numerous problems created by neurofibromatosis type 1, particular quality-of-life evaluation measures are quite significant. In Iran, general instruments are used to assess the quality of life of the target group. This study aimed to translate and examine the psychometrics of the Persian version of the Neurofibromatosis Type 1 Adult Health-related Quality of Life (NF1-AdQOL) questionnaire.

Methods: This was a methodological and cross-sectional study. A total of 414 adult patients with neurofibromatosis type 1 in the Iranian Association of Neurofibromatosis were selected via convenience sampling. With the permission of the questionnaire's developer, the English version was translated into Persian using the standard back-translation procedure. Validity was assessed using face validity, content validity, exploratory, and confirmatory factor analysis. The reliability and internal consistency of the questionnaire were assessed by Cronbach's alpha and Spearman's correlation, respectively.

Results: The participants' mean age was 34.48±8.3 years. The 31-item questionnaire was translated into Persian, and based on content validity analysis, 2 items were removed. The adequacy of the sample size was acceptable (KMO = 0.940). Exploratory factor analysis revealed 4 factors. The scale had good reliability (Cronbach's alpha: 0.95), and the intraclass coefficient was 0.91. The total mean quality of life score was 93±25.18.

Conclusion: The finding showed that the Persian version of the questionnaire has good structural characteristics and is a reliable and valid instrument for measuring the quality of life of patients with neurofibromatosis 1.

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Highlights

What is current knowledge?

The quality of life of the neurofibromatosis community is evaluated with non-specialized tools in Iran. Generic QOL and skin HRQOL questionnaires do not measure the impact of disease-specific symptoms and/or concerns.

What is new here?

This study introduced a valid and reliable tool adapted to cultural differences to measure the QOL of NF1 patients in Persian.

Introduction

Neurofibromatosis type 1 (NF1), also known as Von Recklinghausen's disease, is the most common autosomal dominant genetic disorder (typically 1 in 3 500 births) affecting the peripheral and central nervous system (1). This condition is preliminarily described by the presence of 6 or more café-au-lait macules, intertriginous freckles, and 2 or more neurofibromas as the most considerable disease manifestation (2, 3). Signs and symptoms range from hearing loss, facial weakness, and poor gait, and cause chronic pain, pigmentary abnormalities, low-grade gliosis, skeletal dysplasia, and the involvement of numerous other organs, thereby significantly decreasing the quality of life (QOL) (4).

Dermatologists or pediatricians often make the clinical diagnosis of NF1 since it affects the skin at a young age and the neurological system later in life. The most common complaint among NF1 patients is aesthetic defects, as well as chronic discomfort and difficulty learning, which can lead to social issues, poor self-esteem, despair, and mental illnesses. Previous research has found that people with NF1 had a higher rate of depression and other mental problems than healthy persons (5, 6). All of the above challenges affect the quality of life of these patients. A meta-analysis in 2019 revealed that NF patients had lower QoL in all aspects than the control group (7). The term quality of life refers to an index representing the quality of all aspects of an individual's life. The need to evaluate NF patients' QOL is widely agreed upon, and different assessment tools have been designed to meet this need. Quality of life is usually measured by different tools such as the 36-Item Short Form Survey (SF-36), which is applied to survey the health status in clinical practice, research, health policy evaluations, and the general population. The Skindex-29 questionnaire analyzes the QoL among patients with dermal diseases (8, 9).

Crawford et al. developed a questionnaire to measure the specific effect of NF1 on adults' HRQOL (NF1-AdQOL) and determined the validity of the NF1-AdQOL using two widely utilized HRQOL measures, the Skindex-29 and SF-36v2 (10). This study aimed to evaluate the QOL of Iranian patients with neurofibromatosis and the validity and reliability of the Persian version of NF1-AdQOL.

Methods

Participants

A total of 420 individuals with neurofibromatosis completed the online questionnaire (The response rate of NF1 patients was 52%), but 6 responses were deemed invalid and removed. In sum, 414 valid responses were used for the study. The participants were required to meet the following criteria: a) be above the age of 18 years; b) neurofibromatosis disease being defined by the Iranian Neurofibromatosis Association (physicians consider the following to diagnose the NF1: family history, genetic testing, café-au-lait macule size review, etc. (11)); and c) have no history of psychiatric disorder. Data were collected from March 2, 2022, to June 25, 2022.

Measures

Crawford et al. developed the Neurofibromatosis Type 1 Adult Health-related Quality of Life (NF1-AdQOL) in 2021 (10). It consists of 31 items and is graded on a 5-point scale from 1 (never) to 5 (all the time). The questionnaire included 3 subscales: emotions (cosmetic appearance) (12 items), functioning (social and learning) (11 items), and physical symptoms (8 items). The total score is computed by adding the scores of all items, and the total score range is 31 to 155. Higher scores imply a lower quality of life. The scale has excellent psychometric features, including a high internal consistency (α = 0.96) (10).

An online questionnaire was used to obtain demographic information such as age, sex, level of education, marital status, and job status.

Translation process

The translation and adaptation of the quality of life of adult neurofibromatosis 1 (NF1-AdQOL) for Persian was performed in 7 steps (12). Initially, the questionnaire was translated from English to Persian independently by 2 multilingual translators. The two versions were then compared and integrated by a third multilingual translator into a single version. Another bilingual translator then translated the current questionnaire back into the original language and compared it with the original version of the questionnaire. Finally, the prepared text was reviewed by 5 NF1 patients. We altered the word "neurofibromatosis" to "disease" based on the patients' comments, as many reported feeling awful when they read the disease's name.

Psychometric analysis

The questionnaire's face validity was assessed by 10 individuals with neurofibromatosis type 1. Due to the researchers' lack of access to the patients, the sessions were held on Google Meet. Questionnaire items were assessed based on whether they clearly related to what they measured, were acceptable for the participants, and achieved the aim adequately. The content validity ratio (CVR) and content validity index (CVI) were used to evaluate content validity. Fifteen experts evaluated the questionnaire items and classified them as essential, useful but not necessary, or unnecessary (13). The admission rate was 0.49, according to the Lawshe table (14). In this section, 2 phrases have been removed. Then, 15 more professionals assessed the questionnaire to evaluate CVI after applying expert comments and enhancing the terms (15). Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were used to examine construct validity, and 207 individuals participated in each analysis. The sample-to-item ratio, which is generally suggested for EFA, was used to determine sample size depending on the number of items. The ratio should be at least 5 to 1.

Statistical analysis

SPSS V. 18 (IBM Corp., Armonk, NY, USA) and Lisrel V. 18.80 were used to evaluate the psychometric features of the QOL. Since the number of original questionnaire items changed during the content validity examination process, EFA was performed to identify the number of factors. This analysis used principal component analysis with direct oblimin rotation to examine the basic construct of the items. The correlation matrix between the items was evaluated using Bartlett's test of sphericity ($p<0.05$). The Kaiser-Meyer-Olkin (KMO) test was used to evaluate sample quality (16), and the Kaiser index was used to calculate the number of factors. Table 1 displays the results of the data analysis and sampling adequacy examination.

Table 1. KMO and Bartlett's test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.940
Bartlett's Test of Sphericity	Approx. Chi-Square	4560.124
	df	406
	Sig.	< 0.001

Confirmatory factor analysis is a statistical technique used to confirm the factor structure of the amount of data that is observed. It was used to assess the model's fit. As widely used fit indices for CFA, the goodness-of-fit index (GFI), non-normed fit index (NNFI), normed fit index (NFI), root mean square error (RMSEA), comparative fit index (CFI), and degrees of freedom (CMIN/DF) were utilized in this study (17). Cronbach's alpha was determined to evaluate internal consistency (18). To determine replicability, a test-retest analysis was performed, in which 30 individuals completed the questionnaire twice, with at least 2 weeks in between, and the results were analyzed by Spearman's correlation (19).

Results

The current study included 414 patients. Table 2 presents the demographic information of the participants. The majority of those who took part were female (70%) and single (65.7%). The participants' mean age was 34.48±8.3 (18-60) years.

Two items were deleted from the study during the evaluation of content validity (Item 30: I have headaches because of my NF1 condition, and Item 31: I have back pain because of my NF1 condition), and modifications were made to the form and richness of the words to improve comprehension. The CVR for the items was 0.6-0.9, and that of the overall scale was 0.75. The EFA results (KMO = 0.940) demonstrate the samples' sufficiency. The BTS results were statistically significant ($P<0.001$), resulting in the creation of a 4-factor solution as a domain. The CFA approved the 4 factors listed here: factor 1, emotions (cosmetic appearance) (9 items); factor 2, functioning (social and learning) (9 items); factor 3, unknown future (fear of the future) (7 items); and factor 4, physical symptoms (4 items). Figure 1 depicts the pebble chart for the image of the eigenvalue in each of the extracted items.

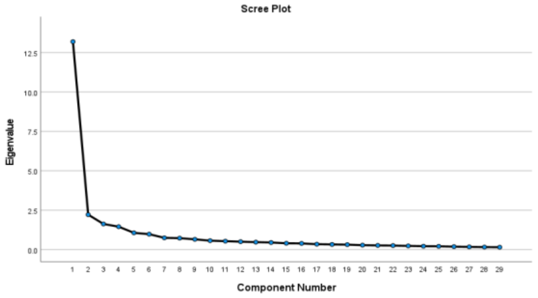

Figure 1. Pebble chart for the image of the eigenvalue in each of the extracted items.

Table 2. Adult patients with neurofibromatosis type 1 demographics and quality of life

	Exploratory factor analysis sample (n=207)	Confirmatory factor analysis sample (n=207)	Total (n=414)	Quality of Life	P-value
Variable	n (%)	n (%)	n (%)	Mean (±SD)	
Age group					
18-25 y	20 (9.7)	39 (18.8)	59 (14.3)	95.08 (±25.98)	0.93
26-35 y	90 (43.5)	84 (40.6)	173 (41.8)	92.72 (±27.38)	
36-45 y	79 (38.2)	63 (30.4)	143 (34.5)	92.69 (±25.32)	
>46 y	18 (8.7)	21 (10.1)	39 (9.4)	92.20 (±23.24)	
Sex					
Female	150 (72.5)	140 (67.6)	290 (70)	93.31 (±23.90)	0.85
Male	57 (27.5)	67 (32.4)	124 (30)	92.27 (±28.02)	
Marital status					
Single	138 (66.7)	134 (64.7)	272 (65.7)	93.20 (±26.34)	0.84
Married	69 (33.3)	73 (35.3)	142 (34.3)	92.60 (±25.54)	
Education					
High school diploma or below	113 (54.6)	105 (50.7)	218 (52.6)	96.26 (±25.74)	0.001
Bachelor's degree	67 (32.4)	73 (35.3)	140 (33.8)	92.27 (±24.16)	
Master's degree	25 (12.1)	29 (14.0)	54 (13.0)	82.20 (±22.86)	
Doctoral degree	2 (1.0)	0 (0)	2 (0.5)	79.00 (±7.07)	
Job					
Unemployed	55 (26.6)	60 (29.0)	115 (27.8)	99.86 (±23.62)	0.001
Self-employment	56 (27.1)	56 (27.1)	112 (27.1)	84.52 (±26.44)	
Homemaker	52 (25.1)	47 (22.7)	99 (23.9)	95.76 (±24.34)	
Employee	44 (21.3)	44 (21.3)	88 (21.3)	91.69 (±23.53)	

Values are presented as n (%), mean and standard deviation (±SD)
Significant at $P < 0.05$.

Table 3 shows the factor loadings of the 4-factor solution. The resultant domains explained 64.877% of the observed variance in the 29-item QOL.

Table 3. Factor loadings of the QOL on the rotated factor pattern matrix

No.	Factor1	Factor2	Factor3	Factor4	No.	Factor1	Factor2	Factor3	Factor4
q1			0.891		q16		0.392		
q2			0.804		q17				0.539
q3	0.341				q18		0.698		
q4		0.460			q19	0.403			
q5	0.830				q20		0.808		
q6	0.610				q21			0.556	
q7	0.902				q22	0.601			
q8				0.605	q23	0.832			
q9			0.667		q24		0.830		
q10				0.665	q25				0.455
q11		0.745			q26	0.513			
q12				0.640	q27	0.596			
q13		0.718			q28				0.563
q14		0.512			q29				0.719
q15		0.704							

The correlation of factor 1 with the other 3 factors was 0.424, 0.272, and 0.443, respectively. The correlation of factor 2 with factors 3 and 4 was equal to 0.390 and 0.404, respectively, and the correlation of factor 3 with factor 4 was equal to 0.287. The fit indices for the QOL are shown in Table 4.
The total scale's Cronbach's alpha was 0.953, and the coefficients for 4 factors were 0.93, 0.91, 0.82, and 0.76, respectively. The intraclass correlation of the total scale was 0.91 by Spearman's correlation.

Table 4. Model Fit Index summary

Model Fit Index	Admissibility	Result
χ^2 P-value (Chi-squared P-value)	> 0.05	> 0.001
RMSEA (Root mean square error of approximation)	< 0.08 perfect fit; .08-.10 good fit; >.10 weak fit	0.096
NFI (Normed fit index)	> 0.9	0.92
NNFI (Non-normed fit index)	> 0.9	0.94
GFI (Goodness of fit index)	> 0.9	0.90
CFI (Comparative fit index)	> 0.9	0.95
CMIN/DF (Minimum discrepancy function divided by degree of freedom)	< 3 good; < 5 sometimes permissible	2.75

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Table 5 shows the results of the NF1-AdQOL questionnaire for the participants. The overall mean QOL score was 93±25.18, with a range of 30 to 138. The mean scores for the 4 factors [emotions (cosmetic appearance), functioning (social and learning), unknown future (fear of the future), and physical symptoms] were

33.86 ±9.81, 26.89 ±10.08, 25.89± 6.45, and 10.18 ±9.95, respectively. The relationship between the demographic variables and NF1-AdQOL scores are shown in Table 2.

Table 5. Participants' NF1-AdQOL factors (N=414)

		Never %	Rarely %	Sometimes %	Often %	Constantly %
Emotions (Cosmetic appearance)	1. Having NF1 bothers me.	7 (1.7)	48 (11.6)	79 (19.1)	70 (16.9)	210 (50.7)
	2. My NF1 condition affects the clothes that I wear.	49 (11.8)	42 (10.1)	66 (15.9)	70 (16.9)	187 (45.2)
	3. I am embarrassed by the way NF1 affects my physical appearance.	7 (1.7)	49 (11.8)	55 (13.3)	81 (19.6)	222 (53.6)
	4. I dress to cover my NF1 condition.	38 (9.2)	36 (8.7)	38 (9.2)	93 (22.5)	209 (50.5)
	5. I am hurt by the comments other people make about my NF1 condition.	48 (11.6)	70 (16.9)	75 (18.1)	83 (20)	138 (33.3)
	6. I am annoyed by other people staring at me because I have NF1.	48 (11.6)	66 (15.9)	68 (16.4)	79 (19.1)	153 (37)
	7. I avoid wearing swimwear because of the appearance of my NF1 condition.	61 (14.7)	31 (7.5)	34 (8.2)	50 (12.1)	238 (57.5)
	8. I feel self-conscious about how my NF1 condition affects my appearance.	39 (9.4)	80 (19.3)	69 (16.7)	71 (17.1)	155 (37.4)
	9. I am upset by NF1 lumps that cannot be hidden.	52 (12.6)	68 (16.4)	56 (13.5)	65 (15.7)	173 (41.8)
Functioning (Social and learning)	10. Meeting new people is difficult because I have NF1.	89 (21.5)	62 (15)	68 (16.4)	74 (17.9)	121(29.2)
	11. Having NF1 holds me back in life.	75 (18.1)	81 (19.6)	83 (20)	67 (16.2)	108 (26.1)
	12. My NF1 condition makes it hard to do my job and/or studies.	83 (20)	79 (19.1)	79 (19.1)	65 (15.7)	108 (26.1)
	13. I lack confidence because I have NF1.	56 (13.5)	59 (14.3)	91 (22)	74 (17.9)	134 (32.4)
	14. My NF1 condition affects my ability to make new friends.	118 (28.5)	81 (19.6)	64 (15.5)	69 (16.7)	82 (19.8)
	15. I feel angry because I have NF1.	35 (8.5)	70 (16.9)	89 (21.5)	86 (20.8)	134 (32.4)
	16. My NF1 condition makes it harder to keep friends.	172 (41.5)	91 (22)	61 (14.7)	29 (7)	61 (14.7)
	17. I find learning difficult because of my NF1 condition.	103 (24.9)	104 (25.1)	83 (20)	59 (14.3)	65 (15.7)
	18. My NF1 condition makes it harder to learn new things.	108 (26.1)	95 (22.9)	76 (18.4)	62 (15)	73 (17.6)
Unknown Future (Fear of the future)	19. I worry that the NF1 lumps will grow bigger.	14 (3.4)	26 (6.3)	59 (14.3)	68 (16.4)	247 (59.7)
	20. I worry about how NF1 will affect me in the future.	10 (2.4)	40 (9.7)	53 (12.8)	75 (18.1)	236 (57)
	21. I worry about getting more NF1 lumps as I get older.	13 (3.1)	36 (8.7)	46 (11.1)	78 (18.8)	241 (58.2)
	22. I worry that the NF1 lumps will turn cancerous.	102 (24.6)	79 (19.1)	79 (19.1)	57 (13.8)	97 (23.4)
	23. My NF1 condition interferes with physical relationships with a partner.	215 (51.9)	30 (7.2)	50 (12.1)	45 (10.9)	74 (17.9)
	24. I spend time thinking about my NF1 condition.	16 (3.9)	61 (14.7)	74 (17.9)	82 (19.8)	181 (43.7)
	25. I worry about passing NF1 on to my children.	54 (13)	12 (2.9)	23 (5.6)	47 (11.4)	278 (67.1)
Physical symptoms	26. I have NF1 lumps that hurt.	117 (28.3)	107 (25.8)	101 (24.4)	61 (14.7)	28 (6.8)
	27. The physical pain of NF1 affects my sleep.	210 (50.7)	90 (21.7)	67 (16.2)	27 (6.5)	20 (4.8)
	28. My NF1 lumps are physically irritating.	81 (19.6)	89 (21.5)	93 (22.5)	79 (19.1)	72 (17.4)
	29. My physical symptoms of NF1 are painful.	103 (24.9)	104 (25.1)	83 (20)	59 (14.3)	65 (15.7)

Discussion

Quality of life is an important criterion for reviewing the existing conditions, and it is important to evaluate it with the right tools. In 2018, Soghi examined the quality of life of Iranian patients with neurofibromatosis using the tool Skindx-16 and reported that the participants' quality of life was moderate (20). In the present study, a questionnaire that was specially developed to record the quality of life of patients with neurofibromatosis was administered. Our results showed that the quality of life of the participants was moderate; however, according to the limitations of the study, it seems that the quality of life of the neurofibromatosis community is lower than the calculated level, and more attention should be paid to these patients. Different studies worldwide have also reported similar results. In Brazil, Bicudo et al. reported low physical and environmental quality of life for patients with neurofibromatosis type 1 (21). Moreover, in Canada, people with NF have a poor quality of life, and this is associated with pain, anxiety, and depression, which are common in NF (22). Results of a systematic review and meta-analysis after reviewing 12 studies from the United States, Italy, Greece, the Netherlands, France, and the UK reported that not only NF patients but also their families experience low quality of life (7).

In the present study, 47% of the participants had a university education. This value was 27% in Denmark and 38% in Canada (22, 23). One of the most important reasons for the high rate of university education in this study could be the selection bias; according to the inclusion criteria, only educated people were invited to the study. The patients' education level had a significant association with their quality of life; as the level of education increased, they perceived a better quality of life.

The current cohort had high unemployment rates, 52% in NF1. These are higher than Iran's unemployment rate, i.e., the proportion of the jobless population aged 15 and above, which was 9.2% in 2021 (24). This is indirect evidence of the social impact of NF1, as only half of the people were in paid employment. The patients' occupations had a significant association with their quality of life, so people with jobs experienced a better quality of life. In contrast, Hamoy-Jimenez et al. (2020) reported in their study that people's employment status does not affect their perceived quality of life (22). It should be considered that they used the SF-36 questionnaire to evaluate the quality of life, which may impact the results.

The results of this study introduced a valid and reliable questionnaire for the Iranian research community. In this study, 414 people participated in checking the validity and reliability of the QOL questionnaire, and based on the KMO test results, the sample size was adequate and acceptable (16). One of the limitations mentioned by Crawford et al. was the small sample size, which was well-covered in this study (10). The reliability of the QOL was 0.95, and the 4 determining factors also had acceptable values. The original version stated that the overall instrument reliability was 0.96 (10). If the reliability (Cronbach's alpha) of an instrument's subscale is 0.95, it suggests that the items are highly correlated and, therefore, redundant (25). The subscales in this study had Cronbach's alpha values less than 0.93. Furthermore, due to the relevance of the items, the research team did not limit the amount of additional items.

A strength of this study is its large sample size. We included participants from all over the country. The translated questionnaire is the first questionnaire in Persian to measure the quality of life of neurofibromatosis patients. This study also had limitations. The selection bias and the use of convenience sampling rather than random sampling are the major limitations that make it impossible to generalize the quality-of-life results to the entire population. It is suggested that future studies look at factors affecting the quality of life of neurofibromatosis patients.

Conclusion

The finding showed that the Persian version of the NF1-AdQOL questionnaire has good structural characteristics and is a reliable and valid instrument for measuring the quality of life of patients with neurofibromatosis 1. These findings can be used to improve the health of this group and their overall quality of life. Government agencies may create promotional campaigns related to NF1. Greater public awareness about NF1 should help minimize discrimination and improve the quality of life of patients. According to the findings, patients with neurofibromatosis have moderate quality of life.

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Ethical statement

All the patients gave informed consent for the use of data for research purposes. This study was conducted following receipt of the ethics approval (IR.GOUMS.REC.1400.364) from the Golestan University of Medical Sciences.

Conflicts of interest

There is no conflict of interest to disclose.

Author contributions

RJ was responsible for analyzing the data, drafting the manuscript, reviewing the manuscript, and approving the final version. FM was responsible for collecting data, analyzing the data, drafting the manuscript, and approving the final version. TA was responsible for collecting data and approving the final version. NA and

MH were responsible for collecting data. SG was responsible for reviewing the manuscript and approving the final version. AS was responsible for designing the study, reviewing the manuscript, and approving the final version. LJ was responsible for designing the study, reviewing the manuscript, and approving the final version. All the authors read and approved the final manuscript.

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