ORIGINAL ARTICLE

Arabic Translation and Adaptation of the CVID_QoL Questionnaire to Measure Health-Related Quality of Life of Adults with Common Variable Immune Deficiency

Traduction et adaptation en arabe du questionnaire CVID_QoL pour mesurer la qualité de vie liée à la santé chez les adultes atteints de déficit immunitaire commun variable

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Abstract

Introduction: Common Variable Immune Deficiency (CVID) is the most frequent symptomatic inborn error of immunity, associated with recurrent infections, autoimmunity, and malignancy. These complications substantially impair health-related quality of life (HRQoL). To date, no disease-specific HRQoL instrument has been validated in Arabic. This study aimed to translate, culturally adapt, and validate the CVID_QoL questionnaire for Arabic-speaking patients.

Methods: The CVID_QoL was translated and adapted into Arabic according to international cross-cultural guidelines. A pilot test was performed, followed by administration of the pre-final version to 20 adults with CVID at Abderrahim El Harouchi Hospital, Casablanca. Internal consistency was assessed using Cronbach's alpha, and test–retest reliability with intraclass correlation coefficients (ICC). Construct validity was evaluated through Pearson's correlations with the General Health Questionnaire-12 (GH-12) and the Short Form-36 (SF-36). Discriminant validity was tested using the Mann–Whitney U test across clinical subgroups.

Results: The Arabic CVID_QoL showed high internal consistency (Cronbach's $\alpha = 0.91$) and excellent test–retest reliability (ICC = 0.88). Convergent validity was confirmed by significant correlations between CVID_QoL domains and GH-12 and SF-36 scores (e.g., emotional functioning with SF-36 mental health, $r = 0.65$, $p < 0.001$). Discriminant validity was established by significantly lower scores among patients with recurrent infections, pulmonary complications, or autoimmunity ($p < 0.05$).

Conclusion: The Arabic CVID_QoL is a reliable and valid tool for measuring HRQoL in Arabic-speaking adults with CVID. It provides a valuable contribution for both clinical care and research. Larger, multicenter studies are recommended to further confirm its utility.

Keywords : Common Variable Immunodeficiency, Primary Immunodeficiency, Health-Related Quality of Life (HRQoL), Adults HRQoL, CVID_QoL

Résumé

Introduction : Le déficit immunitaire commun variable (DICV) est l'immunodéficience primitive symptomatique la plus fréquente, caractérisée par des infections récurrentes, des maladies auto-immunes et un risque accru de malignité. Ces complications altèrent considérablement la qualité de vie liée à la santé (QVLS). À ce jour, aucun instrument spécifique de mesure de la QVLS n'a été validé en langue arabe. L'objectif de cette étude était de traduire, d'adapter culturellement et de valider le questionnaire CVID_QoL en arabe.

Méthodes : Le questionnaire CVID_QoL a été traduit et adapté selon les recommandations internationales d'adaptation transculturelle. Un pré-test a été réalisé, suivi de l'administration de la version pré-finale auprès de 20 adultes atteints de DICV au CHU Abderrahim El Harouchi de Casablanca. La cohérence interne a été évaluée par l'alpha de Cronbach et la fidélité test-retest par le coefficient de corrélation intraclasse (ICC). La validité de construit a été étudiée par les corrélations de Pearson entre le CVID_QoL et les scores du GH-12 et du SF-36. La validité discriminante a été testée par le test de Mann–Whitney U entre différents sous-groupes cliniques.

Résultats : La version arabe du CVID_QoL a montré une excellente cohérence interne (α de Cronbach = 0,91) et une très bonne fidélité test-retest (ICC = 0,88). La validité convergente a été confirmée par des corrélations significatives entre les dimensions du CVID_QoL et celles du GH-12 et du SF-36 (par exemple : fonctionnement émotionnel avec santé mentale du SF-36, $r = 0,65$; $p < 0,001$). La validité discriminante a été démontrée par des scores significativement plus bas chez les patients présentant des infections récurrentes, des complications pulmonaires ou une auto-immunité ($p < 0,05$).

Conclusion : La version arabe du CVID_QoL constitue un outil fiable et valide pour l'évaluation de la QVLS chez les adultes arabophones atteints de DICV. Elle représente une contribution précieuse à la fois pour la pratique clinique et la recherche. Des études multicentriques de plus grande envergure sont recommandées pour confirmer son utilité.

Mots-clés : Déficit immunitaire commun variable, Immunodéficience primitive, Qualité de vie liée à la santé (QVLS), QVLS Adulte, CVID_QoL

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What is known about this topic

• Common Variable Immune Deficiency (CVID) significantly impairs health-related quality of life (HRQoL) due to recurrent infections, autoimmunity, and long-term complications.

• Generic HRQoL instruments such as SF-36 are widely used but do not fully capture the disease-specific burden of CVID.

• The CVID_QoL questionnaire has been validated in Italian, Norwegian, and Turkish populations.

What this article adds

• This is the first Arabic translation and cultural adaptation of the CVID_QoL questionnaire.

• The Arabic version demonstrated strong psychometric properties, with high internal consistency, excellent test–retest reliability, and robust construct validity.

• It provides clinicians and researchers with a culturally adapted, disease-specific tool to assess HRQoL in Arabic-speaking adults with CVID.

Introduction

Health-related quality of life (HRQoL) is a multidimensional construct encompassing physical, emotional, and social well-being, increasingly recognized as a critical outcome in healthcare [4,5]. Its importance is particularly pronounced in chronic diseases, where therapeutic goals often shift from cure toward long-term management, prioritizing a patient's overall functioning and daily quality of life [6–8].

Inborn Errors of Immunity (IEI), also known as primary immunodeficiency disorders, are a heterogeneous group of rare genetic conditions characterized by immune system dysfunction [9]. Clinically, they manifest with recurrent infections, autoimmunity, malignancy, and inflammatory complications, all of which can profoundly impair HRQoL [10]. Recent updates in the IUIS phenotypic classification have expanded the understanding of IEIs, now including 559 distinct IEIs, among them 67 novel monogenic defects and 2 new phenocopies, underscoring the growing complexity and prevalence of these disorders [20].

Common Variable Immune Deficiency (CVID) is the most frequent symptomatic form of IEI, characterized by hypogammaglobulinemia and recurrent infections frequently accompanied by autoimmunity, pulmonary complications, and malignancy [12–14]. These complications impose a substantial disease burden, markedly diminishing the HRQoL of affected individuals [11,14].

Despite these consequences, there remains a lack of validated, disease-specific HRQoL instruments tailored for CVID patients in the Arabic-speaking world. Generic measures like the SF-36 and EORTC QLQ-C30, while valuable, may not capture the full scope of CVID-related challenges [15,16]. To address this gap, Quinti et al. developed and validated the CVID_QoL questionnaire in Italian patients [1]; subsequent validations in Norway [2] and Turkey [3] confirmed its psychometric strength across different populations.

However, no Arabic version of the CVID_QoL has been available. The absence of such a culturally and linguistically adapted tool has limited both clinical application and research involving Arabic-speaking patients with CVID. Given the disease burden and the imperative for patient-centered measures in culturally diverse contexts [17–19], this study aimed to translate and culturally adapt the CVID_QoL into Arabic and evaluate its psychometric properties in a Moroccan cohort of Arabic-speaking adults.

Methods

This study followed an established cross-cultural adaptation methodology to ensure the linguistic accuracy and cultural appropriateness of the CVID_QoL questionnaire for Arabic-speaking adults with Common Variable Immune Deficiency (CVID).

Translation and Cultural Adaptation

The process was conducted in five steps:

1. Forward translation: Two independent bilingual translators translated the original English version into Arabic.
2. Reconciliation: A consensus version was produced by a committee that reviewed discrepancies and ensured conceptual equivalence.
3. Backward translation: Two additional bilingual translators, blinded to the original version, translated the Arabic version back into English.
4. Expert committee review: A multidisciplinary panel of immunologists, methodologists, and linguists compared the back-translated version with the original, evaluating semantic, idiomatic, experiential, and conceptual equivalence. Items were revised through an item-by-item review to ensure relevance, clarity, and cultural sensitivity.
5. Pilot testing: The pre-final Arabic version was tested with five CVID patients to assess comprehension and cultural relevance. Feedback informed further modifications.

Psychometric Validation

The final Arabic version of the CVID_QoL was administered to 20 adult patients with CVID who were followed at the national reference center for primary immunodeficiencies at Abderrahim El Harouchi Hospital, Casablanca. Eligible participants were Arabic-speaking adults aged 18 years or older with a confirmed diagnosis of CVID and able to provide informed consent. Patients with cognitive impairment or comorbid conditions likely to interfere with HRQoL assessment were excluded.

The validation process was conducted according to established psychometric procedures [17,18]. Internal consistency was evaluated using Cronbach's alpha, with values ≥0.70 considered acceptable [4,5]. Test–retest reliability was assessed in the same patients at a four-

week interval using the intraclass correlation coefficient (ICC), with values ≥0.80 considered excellent [1–3]. Construct validity was examined by calculating Pearson's correlation coefficients between the CVID_QoL domains and two widely used instruments validated in Arabic: the General Health Questionnaire-12 (GH-12) [16] and the Short Form-36 (SF-36) [15]. Finally, discriminant validity was explored by comparing CVID_QoL scores across relevant clinical subgroups, including patients with or without recurrent infections, pulmonary complications, and autoimmunity.

Instrument Description

The CVID_QoL is a disease-specific questionnaire originally developed in Italy by Quinti et al. (2016) to assess HRQoL in adults with CVID [1]. It consists of 32 items grouped into three domains: emotional functioning, relational functioning, and gastrointestinal/skin symptoms. Items cover aspects such as fear of worsening health, sadness, anxiety about the future, social isolation, ability to care for loved ones, diarrhea, joint pain, skin manifestations, and treatment burden. Responses are rated on a five-point Likert scale ranging from 1 (never) to 5 (always), with higher scores indicating poorer HRQoL. The instrument is designed for self-administration and requires approximately 10–15 minutes to complete. Robust psychometric properties have been demonstrated in several languages, including Italian, English, and Turkish [1–3], but no Arabic version was previously available.

For convergent validity, two generic HRQoL measures were employed. The GH-12 is a brief, self-administered screening tool designed to detect psychological distress and overall mental health problems in the general population [16]. It includes 12 items assessing anxiety, depression, social dysfunction, and loss of confidence, each scored on a four-point scale, with total scores ranging from 0 to 36. Higher scores reflect poorer psychological well-being. The GH-12 has been widely used in chronic disease populations and validated in Arabic [16].

The SF-36 is a generic HRQoL questionnaire consisting of 36 items grouped into eight domains: physical functioning, role limitations due to physical health, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health [15]. Two composite summary scores are also derived: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Each domain is transformed into a score ranging from 0 to 100, with higher scores reflecting better HRQoL. The SF-36 has been extensively validated in Arabic-speaking populations [15] and is widely used as a reference standard in HRQoL research. In this study, the GH-12 and SF-36 were used to assess the convergent validity of the Arabic CVID_QoL, with the hypothesis of moderate to strong correlations between emotional functioning and GH-12 mental health, as well as between CVID_QoL domains and corresponding SF-36 dimensions (e.g., relational functioning with social functioning, gastrointestinal/skin symptoms with general health and vitality).

Data Analysis

Descriptive statistics were used to summarize sociodemographic and clinical characteristics of the study population. The reliability of the Arabic CVID_QoL was assessed by calculating Cronbach's alpha for internal consistency (values ≥0.70 considered acceptable) and the intraclass correlation coefficient (ICC, two-way mixed model, absolute agreement) for test–retest reliability (values ≥0.80 considered excellent).

Construct validity was examined using Pearson's correlation coefficients between CVID_QoL scores and the corresponding domains of the SF-36 and GH-12 instruments. Discriminant validity was evaluated by comparing CVID_QoL scores across relevant clinical subgroups using the Mann–Whitney U test.

All statistical analyses were performed using SPSS (version XX, IBM Corp., Armonk, NY, USA), with a significance threshold set at $p < 0.05$.

Results

This study was conducted at the National Center for Primary Immunodeficiency, Abderrahim El Harouchi University Hospital, Casablanca, Morocco. A total of 20 adult patients with CVID were included. The mean age was 35 years (SD = 12.3), and 55% were female.

Reliability

Internal consistency reliability was assessed using Cronbach's alpha, and test–retest reliability was evaluated with the intraclass correlation coefficient (ICC, two-way mixed model, absolute agreement) over a four-week interval. Results demonstrated excellent reliability for the Arabic CVID_QoL (Table 1).

Table 1. Internal Consistency and Test–Retest Reliability of the Arabic CVID_QoL Questionnaire

Domain	Cronbach's α	ICC (test–retest)
Total score	0.91	0.88
Emotional functioning	0.82	0.90
Relational functioning	0.79	0.85
Gastrointestinal/skin symptoms	0.70	0.80

These findings confirm that the Arabic CVID_QoL is both internally consistent and stable over time.

Validity

Convergent validity

Convergent validity was assessed using Pearson's correlation coefficients (r) between CVID_QoL scores and the GH-12 and SF-36 domains. Results showed strong and significant correlations (Table 2).

Table 2. Convergent Validity of the Arabic CVID_QoL Questionnaire

CVID_QoL Domain	Comparator	Correlation (r)	p-value
Total score	GH-12 (General Health Questionnaire-12)	0.67	<0.001
Emotional functioning	SF-36 Mental Health	0.65	<0.001
Relational functioning	SF-36 Social Functioning	0.58	<0.01
Symptom dimension	SF-36 General Health / Vitality	–0.45	<0.05

These correlations support the convergent validity of the Arabic CVID_QoL, indicating that it measures constructs consistent with generic HRQoL instruments while capturing disease-specific aspects of CVID.

Discriminant validity

Discriminant validity was examined using the Mann–Whitney U test to compare CVID_QoL scores across clinical subgroups [6,7]. As expected, the instrument was able to distinguish between patients with different clinical presentations. Patients with recurrent infections had significantly lower emotional functioning scores compared to those without infections ($p < 0.01$).
Patients with pulmonary complications showed lower scores in the gastrointestinal/skin symptom dimension ($p < 0.05$). Likewise, patients with severe autoimmunity had lower relational functioning scores compared to those without autoimmune manifestations ($p < 0.05$). These findings confirm that the Arabic CVID_QoL is sensitive to variations in clinical status and capable of discriminating between subgroups with different disease burdens.

Discussion

This study presents the first Arabic translation, cultural adaptation, and psychometric validation of the CVID_QoL questionnaire for adults with Common Variable Immune Deficiency (CVID). The results confirm that the Arabic version is a reliable and valid tool, culturally adapted for Arabic-speaking populations, and suitable for both clinical care and research. This contribution is significant, given the lack of disease-specific HRQoL instruments available in Arabic, despite the high burden of CVID and other inborn errors of immunity in the region.

Comparison with previous studies

The psychometric properties of the Arabic CVID_QoL are consistent with those reported in earlier validations. The original Italian study by Quinti et al. validated the CVID_QoL in 118 patients and reported Cronbach's α values between 0.74 and 0.84, and test–retest ICCs between 0.79 and 0.90 [1]. Similarly, Andersen et al. validated the instrument in a Norwegian cohort of primary antibody deficiency patients, finding α values of 0.91 for emotional functioning and 0.77 for relational functioning, though the gastrointestinal/skin symptoms domain had lower internal consistency (α = 0.66) [2]. More recently, Eyice et al. reported the Turkish adaptation of the CVID_QoL in 50 patients, confirming strong psychometric performance, with α = 0.92 for the total score and ICCs ranging from 0.78 to 0.89 across domains [3]. In our study, Cronbach's α ranged from 0.70 to 0.91 and ICCs from 0.80 to 0.90, placing the Arabic version within the range of previous validations and supporting its reliability.

Construct validity

Our results also support the construct validity of the Arabic CVID_QoL. Strong correlations were observed between CVID_QoL domains and established instruments such as the SF-36 and GH-12. Emotional functioning correlated with SF-36 mental health ($r \approx 0.65$), relational functioning with SF-36 social functioning ($r \approx 0.58$), and the symptom domain with SF-36 general health and vitality ($r \approx -0.45$). The total CVID_QoL score also correlated strongly with GH-12 ($r = 0.67$). These findings echo those of the Turkish validation, which demonstrated similar convergence with SF-36 [3], and further confirm that the CVID_QoL captures relevant aspects of patient experience that are not fully addressed by generic HRQoL instruments.

Discriminant validity and clinical relevance

A notable strength of the Arabic version is its demonstrated discriminant validity. CVID_QoL scores were significantly different across clinical subgroups: patients with recurrent infections reported worse emotional functioning, those with pulmonary complications scored lower on the symptom domain, and those with severe autoimmunity showed reduced relational functioning. This capacity to reflect clinical heterogeneity enhances its clinical utility and distinguishes it from generic instruments such as SF-36 or GH-12. While previous validations primarily focused on internal consistency and convergent validity [1–3], our findings underline the added value of the Arabic CVID_QoL in differentiating between clinically meaningful patient subgroups.

Implications for clinical practice and research

The availability of a culturally adapted Arabic version of the CVID_QoL has important implications. For clinicians, it provides a standardized, disease-specific tool to assess patient-reported outcomes, enabling better monitoring of treatment burden, psychosocial challenges, and disease progression. For researchers, it offers a validated instrument that facilitates cross-cultural comparisons and the inclusion of Arabic-speaking populations in multicenter studies, where disease-specific quality-of-life measures are increasingly required. Beyond CVID, this study highlights the need for culturally adapted HRQoL instruments across other immunodeficiency and chronic disease populations in the Arab world.

Limitations and future directions

Several limitations should be acknowledged. First, the relatively small sample size (n = 20) and single-center

setting limit the generalizability of our findings. This limitation, however, is shared with other early validation studies, such as the Norwegian cohort [2]. Second, the cross-sectional design did not allow assessment of responsiveness to clinical change, an important psychometric property for longitudinal follow-up. Third, while we ensured rigorous translation and adaptation, further confirmatory factor analysis in larger samples is required to verify the underlying structure of the Arabic version. Future research should therefore focus on multicenter studies with larger and more diverse cohorts, longitudinal validation to assess sensitivity to change, and exploration of clinical thresholds for meaningful score differences.

Conclusion

In conclusion, the Arabic CVID_QoL is a valid, reliable, and culturally relevant instrument for assessing HRQoL in adults with CVID. Its psychometric performance is comparable to that of the Italian [1], Norwegian [2], and Turkish [3] versions, and it provides valuable insights beyond generic HRQoL instruments. By capturing disease-specific aspects of CVID, the Arabic CVID_QoL can improve clinical care, support patient-centered research, and strengthen evidence-based decision-making in the Arab world. Larger, multicenter validation studies are recommended to consolidate these findings and extend their applicability across different clinical and cultural contexts.

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