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Adaptation and Evaluation of a Quality of Life Questionnaire for Patients with Hemophilia in the Republic of Kazakhstan

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Abstract

Introduction. Hemophilia is a chronic inherited disorder that substantially affects patients' physical, emotional, and social functioning. In the context of modern therapeutic approaches, health-related quality of life is regarded as an important patient-centered outcome. Objective assessment of these parameters requires validated disease-specific instruments adapted to the linguistic and cultural characteristics of the target population.

Objective. To perform the linguistic adaptation and psychometric validation of the Russian-language version of the A36Hemofilia-QoL questionnaire for use in adult patients with hemophilia in the Republic of Kazakhstan.

Methods. A methodological study was conducted using a standardized forward–backward translation procedure, expert review, and pilot testing. The study included 30 adult patients with mild, moderate, or severe hemophilia A or B. Internal consistency was assessed using Cronbach's alpha for the total scale and individual domains. Construct validity was evaluated by exploratory factor analysis with oblique rotation. Statistical analysis was performed using IBM SPSS Statistics version 28.0.

Results. The Russian-language version of the questionnaire demonstrated conceptual equivalence to the original instrument and good acceptability among patients. High or acceptable levels of internal consistency were observed for several subscales, while lower Cronbach's alpha values were identified in certain domains, which may be attributable to the clinical heterogeneity of the sample and the pilot nature of the study. Exploratory factor analysis generally confirmed a satisfactory factor structure reflecting the physical, functional, emotional, and social dimensions of quality of life in patients with hemophilia.

Conclusion. The Russian-language version of the A36Hemophilia Quality of Life questionnaire appears to be a promising disease-specific instrument for assessing quality of life in adult patients with hemophilia in the Republic of Kazakhstan. Further studies with larger sample sizes are required to fully confirm its psychometric properties.

Keywords: hemophilia, quality of life, questionnaire, validation, A36Hemophilia-QoL.

1. Introduction

Hemophilia is a hereditary disorder of the hemostatic system characterized by a deficiency of coagulation factors VIII or IX and accompanied by a tendency to spontaneous or post-traumatic bleeding [1]. Despite significant progress in treatment due to the introduction of prophylactic replacement therapy, recombinant factors and non-factor drugs, hemophilia remains a chronic disease requiring lifelong medical supervision and having a significant impact on the physical, emotional and social well-being of the patient [2,3]. In older patients, especially those with a long history of the disease, chronic arthropathies, pain syndrome, limited mobility and difficulties in social adaptation often develop, which makes the assessment of quality of life a key component of comprehensive management [4].

One of the key clinical outcome measures in the management of hemophilia today is the assessment of quality of life, which allows an objective evaluation of the impact of the disease and the effectiveness of ongoing therapy [5]. Among standardized disease-specific instruments for patients with hemophilia, the A36Hemofilia-QoL questionnaire is widely used and was developed to assess the physical, psychological, and social aspects of life in individuals with hemophilia [6].

In international practice, both general (SF-36, EQ-5D) and specialized questionnaires, in particular Haem-A-QoL, are used to assess the quality of life of patients with hemophilia [7-9]. Universal instruments allow for internosological comparisons, but have limited sensitivity to the clinical features of hemophilia. The specialized questionnaire A36Hemofilia-QoL has a more comprehensive structure, as in addition to emotional and social aspects it provides a detailed assessment of physical functioning, joint involvement, pain, as well as treatment satisfaction and treatment-related difficulties. This ensures a more accurate reflection of the impact of the disease and therapy on the daily lives of patients with hemophilia and enhances the clinical relevance of the instrument. However, for the appropriate use of any questionnaire in a specific country, a process of cultural adaptation and psychometric validation is required, taking into account the linguistic, cultural, and clinical characteristics of the target population.

At present, there are no validated instruments in Kazakhstan that allow for a comprehensive assessment of the quality of life of adult patients with hemophilia in the Russian language while taking into account the specific characteristics of disease course in this population. This limits opportunities for conducting clinical and epidemiological studies, analyzing the effectiveness of different therapeutic strategies, and developing recommendations to improve the organization of medical care. The adaptation and validation of the

A36Hemofilia-QoL questionnaire will make it possible to standardize the assessment of quality of life, improve the quality of patient management, and expand the scientific research potential in the field of hemophilia.

The aim of the present study was to perform the linguistic adaptation and psychometric validation of the Russian-language version of the A36Hemofilia-QoL questionnaire for use in adult patients with hemophilia in the Republic of Kazakhstan.

2. Materials and methods

This methodological study was aimed at the translation, cultural adaptation, and validation of the disease-specific A36Hemofilia-QoL questionnaire designed to assess the quality of life of adult patients with hemophilia.

The A36Hemofilia-QoL questionnaire is a disease-specific instrument for assessing the quality of life of adult patients with hemophilia and consists of 36 items grouped into nine thematic domains (subscales) that reflect the key clinical, functional, and psychosocial aspects of the disease.

The structure of the questionnaire includes the following subscales: physical health (8 items), daily activities (4 items), joint damage (3 items), pain (2 items), treatment satisfaction (2 items), treatment-related difficulties (4 items), emotional functioning (5 items), mental health (3 items), and interpersonal relationships and social activity (5 items).

Translation and adaptation were conducted to enable the use of this instrument within the healthcare system of the Republic of Kazakhstan. The translation process followed established methodological criteria and included forward translation, reconciliation, back-translation, expert committee review, and pilot testing [10].

At the first stage, the original English version of the questionnaire was independently translated into Russian by two professional bilingual translators. Both translators were native Russian speakers, fluent in English, and had experience in translating medical and scientific texts.

Before commencing the work, the translators were provided with background materials, including the consent form, a description of the study objectives, characteristics of the target population, the intended mode of questionnaire administration, as well as clarifications of key terms and concepts used in the questionnaire items.

At the second stage, a meeting involving the translators and members of the research team was held, during which the forward translation versions were compared and reconciled. The primary focus was on achieving conceptual equivalence of the wording rather than literal correspondence. As a result of the discussion, a reconciled forward translation version was produced.

The reconciled Russian version was then back-translated into English by two independent translators who had not participated in the previous stages and had no access to the original questionnaire. The purpose of the back-translation was to identify potential semantic and conceptual discrepancies.

The research team conducted a comparative analysis of the original English version and the results of the back-translation. Any discrepancies identified were discussed jointly with the translators, after which the necessary revisions were made to the text. As a result, a preliminary Russian-language version of the A36Hemofilia-QoL questionnaire was developed.

The preliminary version of the questionnaire was pilot-tested in medical institutions providing care to patients with hemophilia. A sample of 30 adult patients was formed for the pilot testing. Inclusion criteria were age 18 years or older, a confirmed diagnosis of hemophilia A or B of mild, moderate, or severe severity, and written informed consent to participate in the study. No restrictions on treatment regimens were applied. Exclusion criteria included the presence of severe concomitant somatic or psychiatric disorders significantly affecting quality of life; acute bleeding episodes or hospitalization at the time of assessment; and cognitive impairments preventing accurate completion of the questionnaires.

Each participant was assigned a unique code known only to the researcher, ensuring data confidentiality. The questionnaire was accompanied by a cover letter explaining the objectives of the study, the voluntary nature of participation, and guarantees of anonymity. Completed questionnaires were collected over a three-week period.

Statistical data analysis was performed using IBM SPSS Statistics software, version 28.0 (IBM Corp., USA). Quantitative variables are presented as mean values and standard deviations.

The reliability of the Russian-language version of the A36Hemofilia-QoL questionnaire was assessed by analyzing internal consistency using Cronbach's α coefficient for the total scale and individual subscales [11]. Values of $\alpha \geq 0.70$ were considered indicative of acceptable internal consistency, with the interpretation of results taking into account the number of items in each subscale and the pilot nature of the study.

Construct validity of the questionnaire was assessed using factor analysis. Prior to factor analysis, data suitability was evaluated using the Kaiser–Meyer–Olkin (KMO) measure and Bartlett's test of sphericity. The principal component method was used for factor extraction, and factor rotation was performed using oblique Oblimin rotation with Kaiser normalization, given the expected correlations among quality-of-life domains.

To assess relationships between questionnaire domains, correlation analysis was performed using Spearman's correlation coefficient, due to the ordinal nature of the response scale and the potential deviation of the variables from a normal distribution. The level of statistical significance was set at $p < 0.05$.

3. Results and discussion

Across all stages of the linguistic adaptation process, no significant semantic discrepancies were identified between the original and the Russian-language versions of the questionnaire. The expert committee noted good conceptual equivalence of the wording and its consistency with the clinical realities of patients with hemophilia.

According to the results of the pilot testing, the majority of respondents reported that the questionnaire items were clear and easy to understand. No significant difficulties were identified during completion of the questionnaire. The mean completion time was 12.5 minutes, indicating that the instrument is feasible and acceptable for both clinical and research use.

A total of 30 respondents participated in the pilot testing. The mean age of the participants was 37.57 ± 9.08 years, ranging from 22 to 57 years. All respondents were male. Half of the participants (n = 15) had completed higher education (bachelor's degree). Secondary vocational education (college or technical school) was reported by 10 patients (33.3%), incomplete higher education by 3 participants (10.0%), and general secondary education (11 years of schooling) by 2 patients (6.7%).

The assessment of internal consistency of the Russian-language version of the A36Hemofilia-QoL questionnaire revealed heterogeneous reliability indices across individual subscales (Table 1). High Cronbach's α coefficients were obtained for the domains "Daily Activities" ($\alpha = 0.90$), "Interpersonal Relationships and Social Activity" ($\alpha = 0.93$), and "Emotional Functioning" ($\alpha = 0.85$), indicating high internal consistency of the items within these subscales.

The "Treatment Satisfaction" subscale demonstrated an acceptable level of internal consistency ($\alpha = 0.74$). Moderate Cronbach's α values were observed for the "Mental Health" domain ($\alpha = 0.64$), which may be attributable to the small number of items and the variability of psychological characteristics among patients with a chronic disease.

Low Cronbach's α coefficients were identified for the "Physical Health" ($\alpha = 0.48$) and "Treatment-Related

Difficulties" (α=0.42) subscales, which may reflect clinical heterogeneity of disease manifestations and differences in individual treatment experiences within the study sample. For the "Joint Damage" subscale, a negative Cronbach's α value was obtained, indicating extremely low variability of responses and homogeneity of clinical characteristics in the examined sample rather than deficiencies in the translation or the structure of the questionnaire.

Table 1 - Factor loadings of items of the Russian-language version of the A36Hemofilia-QoL questionnaire

Questionnaire item	**F1**	**F2**	**F3**	**F4**	**F5**	**F6**	**F7**	**F8**	**Number of items**	**Cronbach's α**
Physical Health (PH)									8	0,48
PH_Q1					–0,78					
PH_Q2	0,47				0,42					
PH _Q3			0,83							
PH_Q4					–0,32					
PH_Q5										
PH_Q6								0,84		
PH _Q7	0,56									
PH_B8								0,91		
Daily Activities (DA)									4	0,90
DA_Q1					–0,46					
DA_Q2	0,40				–0,61					
DA_Q3	0,63				–0,44					
DA_Q4	0,74									
Joint Damage (JD)									3	-1,22
JD_Q1					–0,88					
JD_Q2						0,88				
JD_Q3							0,46			
Pain (P)									2	-
P_Q1					–0,80					
P_Q2				0,57	–0,35					
Treatment Satisfaction (TS)									2	0,74
TS_Q1						–0,71				
TS_Q2								0,42		
Treatment-Related Difficulties (TRD)									4	0,42
TRD_Q1		0,78								
TRD_Q2		0,82								
TRD_Q3							0,94			
TRD_Q4		0,61								
Emotional Functioning (EF)									5	0,85
EF_Q1				0,94						
EF_Q2				0,53						

EF_Q3				0,45						
EF_Q4				0,45						
EF_Q5				0,70						
Mental Health (MH)									3	0,64
MH_Q1				0,92						
MH_Q2				0,92						
MH_Q3		0,80								
Interpersonal Relationships and Social Activity (IRSA)									5	0,93
IRSA_Q1	0,92									
IRSA_Q2	0,62									
IRSA_Q3	0,72									
IRSA_Q4	0,83									
IRSA_Q5	0,84									

Prior to conducting exploratory factor analysis, data suitability was confirmed by measures of sampling adequacy. The Kaiser–Meyer–Olkin (KMO) value indicated acceptable factorability of the data matrix, and Bartlett's test of sphericity was statistically significant ($p < 0.05$), supporting the appropriateness of applying factor analysis.

Exploratory factor analysis performed using the principal component method with oblique Oblimin rotation and Kaiser normalization identified eight factors with eigenvalues greater than 1. The cumulative proportion of explained variance was 81.45%, which represents a high value for quality-of-life questionnaires. Analysis of the scree plot further supported the appropriateness of an eight-factor structure.

The extracted communalities ranged from 0.63 to 0.95, indicating adequate representation of all items within the factor model and no need for item exclusion. Most items demonstrated factor loadings ≥ 0.40 on their respective factors and formed logically interpretable components reflecting the physical, functional, emotional, and social aspects of quality of life in patients with hemophilia.

Some items exhibited cross-loadings across factors, which is expected for clinical questionnaires assessing interrelated aspects of a chronic disease. Given their clinical relevance and satisfactory communality values, all items were retained in the questionnaire structure.

Correlation analysis of the factors revealed moderate associations between several components ($|r| \le 0.41$), supporting the appropriateness of using oblique rotation and reflecting the multidimensional nature of quality of life in patients with hemophilia.

Discussion. In the present study, linguistic adaptation and preliminary psychometric validation of the Russian-language version of the A36Hemofilia-QoL questionnaire were performed to assess the quality of life of adult patients with hemophilia in the Republic of Kazakhstan. The obtained results indicate conceptual equivalence between the translated and original versions and support the acceptability of the instrument for use in both clinical and research settings.

The translation and cultural adaptation procedure was conducted in accordance with internationally recognized guidelines, including forward and back translation, expert review, and pilot testing. The absence of significant semantic discrepancies and the positive evaluation of item clarity by patients indicate the adequacy of the Russian-language version and its consistency with the clinical realities of the target population.

The analysis of internal consistency revealed heterogeneous reliability indices across individual questionnaire subscales. High Cronbach's α values obtained for the "Daily Activities," "Emotional Functioning," and "Interpersonal Relationships and

Social Activity" domains are comparable to those reported for the original version of the questionnaire and its international adaptations, and they confirm the stability of measurement of functional and psychosocial aspects of quality of life in patients with hemophilia. The acceptable reliability level of the "Treatment Satisfaction" subscale indicates its suitability for assessing patients' subjective perceptions of therapy.

At the same time, the lower Cronbach's α values observed for the "Physical Health" and "Treatment-Related Difficulties" domains may reflect clinical heterogeneity of disease manifestations, differences in hemophilia severity, treatment regimens, and individual patient experiences. Similar findings have been reported in previous psychometric studies of disease-specific questionnaires in chronic conditions and do not necessarily indicate shortcomings of the instrument, particularly in the context of a limited sample size.

Exploratory factor analysis overall confirmed satisfactory construct validity of the Russian-language version of the questionnaire. The extracted eight-factor structure accounted for a substantial proportion of the total variance and was clinically interpretable, reflecting the key physical, functional, emotional, and social aspects of quality of life in patients with hemophilia. The presence of cross-loadings for some items is expected in clinical questionnaires assessing interrelated components of a chronic disease and did not warrant item exclusion at this stage of the study.

The limitations of the study include the absence of an assessment of test–retest reliability of the questionnaire. This analysis was not performed due to the cross-sectional nature of the assessment and the limited number of participants.

Overall, the study results indicate the promise of the Russian-language version of the A36Hemofilia-QoL questionnaire as a disease-specific instrument for assessing the quality of life of adult patients with hemophilia in the Republic of Kazakhstan and provide a foundation for further research and the implementation of standardized patient-reported outcome assessment in clinical practice.

4. Conclusion

This study performed the linguistic adaptation and preliminary psychometric validation of the Russian-language version of the A36Hemofilia-QoL questionnaire for adult patients with hemophilia in the Republic of Kazakhstan. The Russian version demonstrated conceptual equivalence to the original instrument and good acceptability among patients. Reliability analysis and exploratory factor analysis generally confirmed satisfactory psychometric properties of the questionnaire, while indicating that certain subscales require further verification. The findings support the need for future studies with larger samples to provide definitive confirmation of the questionnaire's validity.

Conflict of interest: No conflict of interest declared.

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Гемофилиямен ауыратын пациенттердің өмір сапасын бағалау сауалнамасын Қазақстан Республикасында бейімдеу және бағалау

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Түйіндеме

Кіріспе. Гемофилия-пациенттердің физикалық, эмоционалдық және әлеуметтік жұмысына айтарлықтай әсер ететін созылмалы тұқым қуалайтын ауру болып табылады. Қазіргі терапия жағдайында өмір сапасын бағалау маңызды пациентке бағытталған нәтиже ретінде қарастырылады. Осы көрсеткіштерді объективті бағалау үшін мақсатты популяцияның тілдік және мәдени ерекшеліктеріне бейімделген валидацияланған нозологиялық-спецификалық құралдар қажет.

Зерттеудің мақсаты. Қазақстан Республикасында гемофилиямен ауыратын ересек пациенттерде қолдануға арналған A36 Hemofilia Quality of Life сауалнамасының орыс тіліндегі нұсқасын лингвистикалық бейімдеу және психометриялық валидациялау жүргізу.

Әдістері. Тікелей және кері аударма, сараптамалық бағалау және пилоттық тестілеу рәсімдерін пайдалана отырып әдіснамалық зерттеу жүргізілді. Зерттеуге Гемофилиямен ауыратын 30 ересек пациент кіреді. Зерттеуге жеңіл, орташа немесе ауыр дәрежедегі A немесе B гемофилиясы бар 30 ересек пациент қатысты Ішкі келісу жалпы шкала мен жекелеген домендер үшін альфа Кронбах коэффициентін пайдалана отырып бағаланды. Құрылымдық жарамдылық көлбеу айналмалы эксплораторлық факторлық талдау әдісімен талданды. Деректерді статистикалық өңдеу IBM SPSS Statistics 28.0 нұсқасының бағдарламалық жасақтамасын қолдану арқылы жүзеге асырылды.

Нәтижесі. Сауалнаманың орыс тіліндегі нұсқасы түпнұсқаға тұжырымдамалық эквиваленттілікті және пациенттер үшін жақсы қабылдауды көрсетті. Бірқатар ішкі шкалалар үшін ішкі келісімділіктің жоғары немесе қолайлы көрсеткіштері алынды, ал жекелеген домендер бойынша іріктеменің клиникалық гетерогенділігіне және зерттеудің пилоттық сипатына байланысты болатын Кронбах альфа коэффициентінің төмен мәндері анықталды. Эксплораторлық факторлық талдау Гемофилиямен ауыратын науқастардың өмір сапасының физикалық, функционалдық, эмоционалдық және әлеуметтік аспектілерін көрсететін сауалнаманың жалпы қанағаттанарлық факторлық құрылымын растады.

Қорытынды. A36hemofilia Quality of Life сауалнамасының орыс тіліндегі нұсқасы Қазақстан Республикасында Гемофилиямен ауыратын ересек пациенттердің өмір сүру сапасын бағалаудың перспективалы мамандандырылған құралы болып табылады. Құралдың психометриялық қасиеттерін түпкілікті растау үшін кеңейтілген үлгідегі қосымша зерттеулер қажет.

Түйін сөздер: гемофилия, өмір сапасы, сауалнама, валидация, A36Hemofilia-QoL.

Оценка и адаптация опросника для оценки качества жизни пациентов с гемофилией в Республике Казахстан

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Резюме

Введение. Гемофилия является хроническим наследственным заболеванием, существенно влияющим на физическое, эмоциональное и социальное функционирование пациентов. В условиях современной терапии оценка качества жизни рассматривается как важный пациент-ориентированный исход. Для объективной оценки данных показателей необходимы валидированные нозологически-специфические инструменты, адаптированные к языковым и культурным особенностям целевой популяции.

Цель исследования. Проведение лингвистической адаптации и психометрической валидации русскоязычной версии опросника A36Hemofilia Quality of Life для использования у взрослых пациентов с гемофилией в Республике Казахстан

Методы. Проведено методологическое исследование с использованием процедуры прямого и обратного перевода, экспертной оценки и пилотного тестирования. В исследование включены 30 взрослых пациентов с гемофилией. В исследование были включены 30 взрослых пациентов с гемофилией A или B лёгкой, средней или тяжёлой степени. Внутренняя согласованность оценивалась с использованием коэффициента альфа Кронбаха для общей шкалы и отдельных доменов. Конструктивная валидность анализировалась методом эксплораторного факторного анализа с наклонным вращением. Статистическая обработка данных проводилась с использованием программного обеспечения IBM SPSS Statistics версии 28.0.

Результаты. Русскоязычная версия опросника продемонстрировала концептуальную эквивалентность оригиналу и хорошую приемлемость для пациентов. Для ряда подшкал были получены высокие или приемлемые показатели внутренней согласованности, тогда как по отдельным доменам выявлены низкие значения коэффициента альфа Кронбаха, что может быть связано с клинической гетерогенностью выборки и пилотным характером исследования. Эксплораторный факторный анализ подтвердил в целом удовлетворительную факторную структуру опросника, отражающую физические, функциональные, эмоциональные и социальные аспекты качества жизни пациентов с гемофилией.

Выводы. Русскоязычная версия опросника A36Hemofilia Quality of Life является перспективным специализированным инструментом для оценки качества жизни взрослых пациентов с гемофилией в Республике Казахстан. Для окончательного подтверждения психометрических свойств инструмента необходимы дальнейшие исследования с расширенной выборкой.

Ключевые слова: гемофилия, качество жизни, опросник, валидация, A36Hemofilia-QoL.