Original article

Development and Psychometric Validation of a Questionnaire for Assessing Organizational Mechanisms of Medical Care Delivery for Patients with Hemophilia

Elmira Kultanova [1], Zaure Dushimova [2], Yelena Ibrayeva [3], Oleg Khan [4], Raigul Ramazanova [5], Marat Pashimov [6], Lyazzat Syzdykova [7]

[1] PhD doctoral student, Karaganda Medical University, Karaganda; Analyst, Research Management Department, Research Institute of Cardiology and Internal Medicine, Almaty, Kazakhstan

[2] Associate Research Professor, Department of Fundamental Medicine, Al-Farabi Kazakh National University, Almaty, Kazakhstan

[3] Head of the Department of Clinical Trials of Medicinal Products, Research Institute of Cardiology and Internal Medicine, Almaty, Kazakhstan

[4] Hematologist, Highest Medical Category, Research Institute of Cardiology and Internal Medicine; Assistant Professor, Department of Internal Medicine, Kazakh National Medical University named after S.D. Asfendiyarov, Almaty, Kazakhstan

[5] Professor, Department of Internal Medicine, Kazakh National Medical University named after S.D. Asfendiyarov, Almaty, Kazakhstan

[6] Professor, Department of Anesthesiology and Resuscitation, Research Institute of Cardiology and Internal Medicine, Almaty, Kazakhstan

[7] Gastroenterologist, Medical Center "GASTROMED", Shymkent, Kazakhstan

* Corresponding author: dsrm.ricid@gmail.com

Abstract

Introduction. Hemophilia is a rare X-linked hereditary bleeding disorder requiring lifelong, resource-intensive, and multidisciplinary management. Despite substantial therapeutic advances, clinical outcomes are largely determined by the effectiveness of the organizational model of healthcare delivery. Standardized and psychometrically validated instruments for the quantitative assessment of organizational mechanisms in hemophilia care remain limited.

Objective. To develop and psychometrically validate a structured questionnaire for assessing organizational mechanisms of medical care delivery for patients with hemophilia and to identify systemic, economic, and interlevel barriers affecting the functioning of the care model.

Methods. A methodological study was conducted following established instrument development procedures, including conceptual framework development, item generation, expert assessment of content validity, pilot testing, and statistical evaluation of psychometric properties. The questionnaire was structured into four conceptual domains: clinical competence of healthcare professionals; referral pathways and interlevel coordination; organizational governance model; and accessibility of pharmaceutical provision and replacement therapy. The pilot study included 55 physicians involved in hemophilia care. Internal consistency was assessed using Cronbach's alpha coefficient. Construct validity was examined

through exploratory factor analysis with Varimax rotation. Sampling adequacy was evaluated using the Kaiser–Meyer–Olkin (KMO) measure and Bartlett's test of sphericity.

Results. The overall internal consistency of the questionnaire was high (Cronbach's α = 0,870), indicating strong reliability. Domain-specific α coefficients ranged from 0,672 to 0,843. The KMO measure was 0,761, and Bartlett's test was statistically significant (p < 0.001), confirming the suitability of the data for factor analysis. Exploratory factor analysis identified four factors with eigenvalues greater than 1, explaining 78,11% of the total variance. Factor loadings for the majority of items exceeded 0,70, supporting the multidimensional structure of the instrument.

Conclusion. The developed questionnaire demonstrated satisfactory psychometric properties, including high overall internal consistency and an empirically supported multidimensional factor structure. The instrument may serve as a standardized tool for the quantitative evaluation of organizational mechanisms in hemophilia care and may contribute to strategic planning, resource optimization, and system-level improvement in the management of rare diseases.

Keywords: hemophilia, questionnaire, organizational mechanisms, psychometric validation, healthcare organization.

1. Introduction

Hemophilia is a rare X-linked hereditary disorder of hemostasis caused by deficiency of coagulation factor VIII (hemophilia A) or factor IX (hemophilia B), resulting in an increased tendency toward spontaneous and post-traumatic bleeding, predominantly affecting joints and soft tissues. The disease is characterized by a chronic progressive course leading to hemophilic arthropathy, reduced functional status, and impaired quality of life, thereby imposing a substantial social and economic burden on healthcare systems and patients' families [1].

According to the World Federation of Hemophilia, hundreds of thousands of patients with hemophilia are recorded annually in the global registry; however, the true prevalence of the disorder is likely considerably higher due to underdiagnosis, limited access to laboratory diagnostics, and the absence of comprehensive national registries in several countries [2,3]. The disease burden is particularly pronounced in resource-constrained settings, where patients frequently encounter delayed diagnosis, irregular access to clotting factor concentrates, and a lack of specialized treatment centers.

Contemporary therapeutic strategies have markedly improved the prognosis of hemophilia. The standard of care for severe forms consists of prophylactic administration of clotting factor concentrates with individualized dosing based on pharmacokinetic parameters [4,5]. The development of extended half-life factor products and the introduction of bispecific monoclonal antibodies, such as emicizumab, have significantly reduced bleeding rates, decreased the risk of disability, and improved treatment adherence [6–8]. Furthermore, advances in gene therapy offer promising prospects for long-term correction of the underlying coagulopathy.

Despite substantial therapeutic progress, clinical outcomes in patients with hemophilia are determined not only by pharmacological innovations but also by the effectiveness of the organizational model of healthcare delivery [9,10]. For rare diseases requiring lifelong management, the structural and process-related components of the healthcare system are of critical importance. These include clearly defined referral pathways, availability of specialized centers, continuity of drug supply, standardized laboratory monitoring, functional patient registries, integrated digital systems, and effective coordination across primary, secondary, and tertiary levels of care [11,12]. In resource-limited environments, the organizational architecture of the healthcare system ultimately determines equitable access to treatment, sustainability of drug supply, and the timeliness of prophylactic therapy.

In international practice, clinical guidelines for the diagnosis and management of hemophilia have been extensively developed; however, standardized instruments for the systematic assessment of organizational mechanisms of care delivery remain limited [13]. The majority of studies have focused on clinical efficacy of therapeutic interventions,

pharmacoeconomic analyses, and quality-of-life outcomes, whereas structural and managerial dimensions such as allocation of financial resources, centralized procurement models, interlevel coordination of care, and pharmaceutical supply logistics, have rarely been subjected to quantitative and psychometrically grounded evaluation.

The absence of a unified and psychometrically validated instrument hampers objective comparison of healthcare organizational models, limits the assessment of resource allocation efficiency, and constrains the analysis of associations between managerial decisions and clinical outcomes.

The development of a reliable and validated tool for evaluating organizational mechanisms would facilitate the transition from descriptive analyses to a quantitatively substantiated framework for assessing the effectiveness of hemophilia care systems. Such an instrument could provide an evidence-based foundation for strategic planning, informed managerial decision-making, optimization of resource distribution, and enhancement of transparency in healthcare delivery processes.

The aim of the present study was to develop and psychometrically validate a questionnaire designed to assess organizational mechanisms of medical care delivery for patients with hemophilia, and to identify systemic, economic, and interlevel barriers affecting the functioning of the care model.

2. Materials and Methods

This study was designed as a methodological investigation aimed at developing and psychometrically validating a questionnaire to assess organizational mechanisms of medical care delivery for patients with hemophilia. The study design adhered to contemporary recommendations for the development of measurement instruments in healthcare and comprised the following stages: conceptual framework development, item generation, expert review, pilot testing, and statistical evaluation of the instrument's psychometric properties.

The questionnaire was developed within a structural process framework for health system analysis, which encompasses the assessment of organizational structure, care delivery processes, and managerial mechanisms. The content of the instrument was informed by current clinical protocols for the diagnosis and management of hemophilia, standards of hematological care, regulatory documents governing pharmaceutical provision, and a comprehensive review of national and international scientific literature addressing organizational aspects of hemophilia care. In addition, expert consultations were conducted with hematologists and healthcare management specialists to ensure the relevance and contextual appropriateness of the instrument.

The initial pool of items was generated through a systematic review of the literature and structured expert discussions. The questionnaire comprised a socio-professional section and thematic domains addressing clinical, organizational, and managerial components of the healthcare system for patients with hemophilia. A five-point Likert scale (ranging from 1 "strongly disagree" to 5 "strongly agree") was applied to selected statements, enabling quantitative assessment of organizational and professional characteristics. The instrument also included dichotomous questions, multiple-choice items, and one open-ended question designed to elicit qualitative suggestions for improving the care delivery model.

Content validity was evaluated by an expert panel consisting of specialists in hematology and healthcare management with a minimum of 10 years of professional experience. Experts assessed the relevance, clarity, and domain alignment of each item. Based on their feedback, selected items were refined and the overall structure of the questionnaire was optimized.

The final instrument was structured into four conceptual domains reflecting: (1) clinical competence of healthcare professionals; (2) referral pathways and interlevel coordination; (3) organizational and governance aspects of the care system; and (4) accessibility of pharmaceutical provision and replacement therapy for patients with hemophilia. Scale-based items were used to assess internal consistency and to perform exploratory factor analysis in order to empirically examine the proposed domain structure.

Pilot testing was conducted among healthcare professionals involved in the care of patients with hemophilia. The primary objective of this phase was to evaluate the clarity of item wording, the logical coherence of questionnaire sections, and the overall time required for completion. Based on the feedback obtained, editorial revisions were implemented to enhance clarity, comprehensibility, and usability of the instrument.

Eligibility criteria included direct professional involvement in the management of patients with hemophilia and voluntary consent to participate in the study. The survey was administered anonymously; no

personally identifiable information was collected or processed.

The reliability of the scale-based sections of the questionnaire was assessed using Cronbach's alpha coefficient to evaluate internal consistency. Values of $\alpha \geq 0.70$ were interpreted as indicative of an acceptable level of internal consistency. Construct validity was examined through exploratory factor analysis with Varimax rotation to identify latent factors and to assess the correspondence between the empirical factor structure and the underlying theoretical model. The suitability of the data for factor analysis was determined using the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy, while the statistical justification for factor extraction was confirmed by Bartlett's test of sphericity. Statistical analyses were performed using SPSS software (version 30.0).

The study was approved by the Local Bioethics Committee of the Research Institute of Cardiology and Internal Medicine (Protocol No. 1, dated February 3, 2026). Completion of the questionnaire was considered as confirmation of voluntary informed consent to participate in the study.

3. Results

To ensure content validity, the questionnaire was submitted to an expert panel comprising specialists in hematology and healthcare management. Experts were asked to evaluate the relevance of the items to the proposed conceptual framework, the clarity of wording, and the absence of logical overlap between domains. Following expert review and consensus, editorial revisions were introduced, selected items were refined, and redundant statements were removed.

A total of 55 physicians involved in the management of patients with hemophilia at different levels of healthcare delivery participated in the study. The sample included professionals from both outpatient and inpatient settings, thereby enhancing the representativeness of perspectives across varying organizational contexts of care provision.

Participants occupied diverse functional roles within the system of care for patients with coagulopathies, including primary consultation, specialized follow-up, inpatient management, and complication monitoring. Consequently, the collected data reflect a comprehensive perspective of practicing clinicians on organizational mechanisms of care delivery, taking into account differences in resource availability, referral pathways, and interlevel coordination.

The psychometric analysis included 21 scale-based items of the questionnaire, grouped into four conceptual domains. Socio-professional characteristics of respondents and multiple-choice items aimed at identifying systemic barriers were analyzed descriptively and were not included in the calculation of internal consistency, as they did not represent a single latent construct.

Table 1 presents the results of the internal consistency assessment of the questionnaire domains using Cronbach's alpha coefficient. The analysis was conducted both for individual thematic domains and for the overall scale.

The overall internal consistency of the questionnaire was high (Cronbach's $\alpha = 0.870$), indicating strong reliability and satisfactory homogeneity of the included items. This result confirms the psychometric robustness of the developed instrument and supports its use as a valid tool for the comprehensive assessment of organizational mechanisms in the delivery of medical care for patients with hemophilia.

Table 1 - Internal Consistency Indicators Across Questionnaire Domains

Domain	No. of items	Cronbach's α		Mean inter-item correlation	Corrected item–total correlation (range)	α if item deleted (range)
Clinical competence	5	0.775		0.45	–0.05 to 0.79	0.646–0.908
Referral and interlevel coordination	6	0.842		0.52	0.07 to 0.82	0.774–0.916
Organizational model and governance	5	0.843	0,870	0.55	0.26 to 0.82	0.762–0.901
Therapy accessibility and pharmaceutical provision	5	0.672		0.38	0.29 to 0.64	0.525–0.688

The analysis of internal consistency across domains demonstrated Cronbach's alpha coefficients ranging from 0.672 to 0.843. The highest reliability indices were observed in the domains Organizational Model and System Governance (α = 0.843) and Referral Pathways and Interlevel Coordination (α = 0.842), indicating substantial homogeneity of items within these scales. The Clinical Competence domain demonstrated a satisfactory level of internal consistency (α = 0.775).

In the domain Pharmaceutical Provision and Accessibility of Therapy, Cronbach's alpha was 0.672, which is considered acceptable for research instruments addressing complex organizational and managerial constructs and may reflect the multidimensional nature of the underlying concept.

Mean inter-item correlations ranged from 0.38 to 0.55, corresponding to optimal values for scales measuring constructs of moderate breadth. Corrected item–total correlations predominantly exceeded 0.40. The removal of individual items did not result in a meaningful increase in Cronbach's alpha in most domains, indicating structural stability and coherence of the scales.

The suitability of the data for factor analysis was confirmed by the Kaiser–Meyer–Olkin measure of sampling adequacy (KMO = 0.761) and a statistically significant Bartlett's test of sphericity (χ^2 = 830.990; df = 210; p < 0.001).

Exploratory factor analysis was performed using principal component analysis with orthogonal Varimax rotation and Kaiser normalization. In accordance with the eigenvalue > 1 criterion, four factors were extracted. The cumulative proportion of explained variance was 78.11%, indicating strong explanatory capacity of the derived factor structure for an organizational and managerial assessment instrument.

Factor loadings for the majority of items exceeded 0.70, demonstrating a strong association between the statements and their corresponding latent factors (Table 2). The high loading values may partially reflect conceptual proximity of item wording within domains. Communality estimates confirmed adequate representation of variables within the factor model, supporting retention of the full set of questionnaire items.

The resulting factor configuration was logically interpretable and reflected the core conceptual domains of the instrument: clinical competence of healthcare professionals, interlevel referral and coordination mechanisms, organizational and governance structures of the care system, and aspects related to pharmaceutical provision and accessibility of replacement therapy.

Table 2 - Factor Structure of the Questionnaire According to Exploratory Factor Analysis

Questionnaire Items	Clinical competence	Referral and interlevel coordination	Organizational model and governance	Therapy accessibility and pharmaceutical provision
I am knowledgeable about the clinical manifestations of hemophilia	0,955			
I am familiar with the national clinical protocol of the Ministry of Health of the Republic of Kazakhstan for hemophilia management	0,832			
I am knowledgeable about the principles of prophylactic therapy in hemophilia	0,871			
I am aware of the current standard of care for hemophilia	0,873			
In cases of life-threatening bleeding, clotting factor replacement therapy should be administered within an appropriate and timely interval	0,874			
I am familiar with the patient referral pathway within the healthcare system of the Republic of Kazakhstan		0,825		

The interaction between primary healthcare organizations and hematology specialists is well-established and ensures timely patient referral	0,831		
A formally approved patient referral pathway is implemented in my organization	0,871		
The average time to referral to a hematologist in my organization is clinically appropriate	0,842		
A standardized management algorithm for patients with hemophilia is implemented in my organization	0,871		
Primary healthcare plays a key role in the early detection of hemophilia	0,804		
The management of patients with hemophilia should be centralized		0,876	
The establishment of a unified national registry would improve the quality of hemophilia care		0,838	
Telemedicine is necessary to facilitate interregional coordination in hemophilia management		0,885	
A formalized management protocol for hemophilia patients is implemented in my organization		0,763	
A quality monitoring system for hemophilia care is in place in my organization		0,894	
Clotting factor replacement therapy is accessible in my organization			0,905
Prophylactic follow-up of patients with hemophilia is routinely conducted			0,802
Prophylactic therapy is administered on a regular basis to patients with hemophilia			0,855
I am informed about the pharmaceutical provision mechanism for patients with hemophilia in the Republic of Kazakhstan			0,833
Home-based administration of clotting factors is practiced among patients in my care			0,877

Overall, the results of the exploratory factor analysis support the multidimensional structure of the developed instrument and its consistency with the proposed theoretical framework. For definitive verification of the factor structure, conducting a confirmatory factor analysis (CFA) on a larger and independent sample would be methodologically appropriate.

Thus, the findings are aligned with contemporary approaches to evaluating organizational models of care in rare diseases, where structural and managerial components of the healthcare system play a pivotal role. The development of a standardized assessment instrument enables a transition from qualitative descriptions of systemic challenges to their quantitative stratification and longitudinal monitoring of organizational performance and change.

4. Conclusion

The present study represents a pilot psychometric evaluation of an instrument developed for the quantitative assessment of organizational mechanisms in hemophilia care delivery. The findings support the applicability of the questionnaire for assessing key structural and managerial components of the care system.

The results are consistent with Donabedian's structure–process framework, which emphasizes that clinical outcomes are shaped by characteristics of the organizational environment [14]. In rare diseases requiring long-term and resource-intensive management, effective referral pathways, coordinated care processes, functional patient registries, and sustainable pharmaceutical supply are critical determinants of therapeutic continuity.

The developed questionnaire demonstrated satisfactory psychometric properties, including high overall internal consistency and an empirically supported multidimensional factor structure aligned with the theoretical model of organizational mechanisms in hemophilia care.

These findings provide a foundation for further large-scale validation and for the application of the instrument in research and health system evaluation aimed at optimizing organizational models of care for rare diseases.

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Гемофилиямен ауыратын науқастарға медициналық көмек көрсетудің ұйымдастырушылық механизмдерін бағалауға арналған сауалнаманы әзірлеу және психометриялық валидациялау

Култанова Э.Б. [1], Душимова З.Д. [2], Ибраева Е.Т. [3], Хан О.Р. [4], Рамазанова Р.М. [5], Пашимов М.О. [6], Сыздыкова Л.И. [7]

[1] PhD докторант, Қарағанды медицина университеті, Қарағанды; Ғылыми зерттеулер менеджменті бөлімінің аналитигі, Кардиология және ішкі аурулар ғылыми-зерттеу институты, Алматы, Қазақстан
[2] Фундаменталды медицина кафедрасының доцент-зерттеушісі, Әл-Фараби атындағы Қазақ ұлттық университеті, Алматы, Қазақстан
[3] Дәрілік заттардың клиникалық сынақтары бөлімінің жетекшісі, Кардиология және ішкі аурулар ғылыми-зерттеу институты, Алматы, Қазақстан
[4] Гематолог-дәрігер, Кардиология және ішкі аурулар ғылыми-зерттеу институты; Ішкі аурулар кафедрасының ассистент-профессоры, С.Ж. Асфендияров атындағы Қазақ Ұлттық медицина университеті, Алматы, Қазақстан
[5] Ішкі аурулар кафедрасының профессоры, С.Ж. Асфендияров атындағы Қазақ Ұлттық медицина университеті, Алматы, Қазақстан
[6] Анестезиология және реанимация кафедрасының профессоры, Кардиология және ішкі аурулар ғылыми-зерттеу институты, Алматы, Қазақстан
[7] Гастроэнтеролог-дәрігер, «GASTROMED» медициналық орталығы, Шымкент, Қазақстан

Түйіндеме

Кіріспе. Гемофилия - сирек кездесетін, Х-байланысты, тұқым қуалайтын гемостаз ауруы, ол өмір бойы, ресурстарға тәуелді және көп салалы күтімді қажет етеді. Терапиялық жетістіктерге қарамастан, клиникалық нәтижелер көбінесе денсаулық сақтауды ұйымдастырушылық модельдің тиімділігімен анықталады. Гемофилиядағы ұйымдастырушылық механизмдерді сандық бағалауға арналған стандартталған және психометриялық тұрғыдан тексерілген құралдар қазіргі уақытта шектеулі.

Зерттеудің мақсаты. Гемофилиямен ауыратын науқастарға медициналық көмек көрсетудің ұйымдастырушылық механизмдерін бағалауға арналған сауалнаманы әзірлеу және психометриялық валидациялау, сондай-ақ пациенттерді басқару моделінің жұмыс істеуіне жүйелік, экономикалық және деңгейаралық кедергілерді анықтау.

Әдістері. Әдістемелік зерттеу жүргізілді, оның ішінде тұжырымдама кезеңдері, сұрақтар қорын қалыптастыру, мазмұнның жарамдылығын сараптамалық бағалау, пилоттық тестілеу және құралдың психометриялық қасиеттерін статистикалық тестілеу болды. Сауалнама төрт сала бойынша құрылымдалды: мамандардың клиникалық құзыреттілігі; бағыттау және деңгейаралық өзара әрекеттесу; ұйымдастырушылық және басқару моделі; және дәрі-дәрмектер мен алмастыру терапиясының қолжетімділігі. Пилоттық зерттеуге гемофилиямен ауыратын науқастарды емдеуге қатысқан елу бес дәрігер қатысты. Сенімділік Кронбахтың α коэффициентін қолдану арқылы бағаланды. Құрылымның жарамдылығы варимакс ротациясымен зерттеуші факторлық талдауды қолдану арқылы талданды. Деректердің сәйкестігі КМО индексі және сфералықтың Бартлетт сынағы арқылы расталды.

Нәтижесі. Сауалнаманың жалпы ішкі консистенция коэффициенті α = 0,870 болды, бұл сенімділіктің жоғары деңгейін көрсетеді. Домен бойынша α мәндері 0,672-ден 0,843-ке дейін болды. Іріктеу жеткіліктілігінің

Кайзер-Мейер-Олкин өлшемі 0,761 болды; Бартлетт сынағы статистикалық тұрғыдан маңызды болды (p < 0,001), бұл деректердің факторлық жарамдылығын растады. Факторлық талдау 78,11% кумулятивті түсіндірілген дисперсиясы бар төрт факторды берді. Көптеген элементтер үшін факторлық жүктеме 0,70-тен асты, бұл құралдың көп өлшемді құрылымын растайды.

Қорытынды. Әзірленген сауалнама қанағаттанарлық психометриялық қасиеттерді көрсетті, соның ішінде жоғары жалпы ішкі консистенция және эмпирикалық түрде қолдау тапқан көп өлшемді құрылым. Құралды гемофилиямен ауыратын науқастарға көмек көрсетудің ұйымдастырушылық механизмдерін сандық бағалау үшін пайдалануға болады және стратегиялық жоспарлау, ресурстарды бөлуді оңтайландыру және сирек кездесетін ауруларға арналған науқастарға көмек көрсету жүйесін жақсарту үшін негіз бола алады.

Түйін сөздер: гемофилия, сауалнама, ұйымдастырушылық механизмдер, психометриялық валидация, денсаулық сақтау ұйымы.

Разработка и психометрическая валидация анкеты для оценки организационных механизмов оказания медицинской помощи пациентам с гемофилией

Култанова Э.Б. [1], Душимова З.Д. [2], Ибраева Е.Т. [3], Хан О.Р. [4], Рамазанова Р.М. [5], Пашимов М.О. [6], Сыздыкова Л.И. [7]

[1] PhD-докторант, Карагандинский медицинский университет, Караганда; Аналитик отдела менеджмента научных исследований, Научно-исследовательский институт кардиологии и внутренних болезней, Алматы, Казахстан
[2] Доцент-исследователь кафедры фундаментальной медицины, Казахский национальный университет имени аль-Фараби, Алматы, Казахстан
[3] Руководитель отдела клинических испытаний лекарственных препаратов, Научно-исследовательский институт кардиологии и внутренних болезней, Алматы, Казахстан
[4] Врач-гематолог, Научно-исследовательский институт кардиологии и внутренних болезней; Ассистент кафедры внутренних болезней, Казахский Национальный медицинский университет имени С.Д. Асфендиярова, Алматы, Казахстан
[5] Профессор кафедры внутренних болезней, Казахский Национальный медицинский университет имени С.Д. Асфендиярова, Алматы, Казахстан
[6] Профессор кафедры анестезиологии и реаниматологии, Научно-исследовательский институт кардиологии и внутренних болезней, Алматы, Казахстан
[7] Врач-гастроэнтеролог, Медицинский центр «GASTROMED», Шымкент, Казахстан

Резюме

Введение. Гемофилия представляет собой редкое Х-сцепленное наследственное нарушение системы гемостаза, требующее пожизненного, ресурсозависимого и междисциплинарного сопровождения. Несмотря на существенный терапевтический прогресс, клинические исходы во многом определяются эффективностью организационной модели оказания медицинской помощи. Стандартизированные и психометрически обоснованные инструменты для количественной оценки организационных механизмов при гемофилии в настоящее время ограничены.

Цель исследования. Разработка и психометрическая валидация анкеты для оценки организационных механизмов оказания медицинской помощи пациентам с гемофилией, а также идентификация системных, экономических и межуровневых барьеров функционирования модели ведения пациентов.

Методы. Проведено методологическое исследование, включавшее этапы концептуализации, формирования пула вопросов, экспертной оценки содержательной валидности, пилотного тестирования и статистической проверки психометрических характеристик инструмента. Анкета была структурирована по четырём доменам: клиническая компетентность специалистов; маршрутизация и межуровневое взаимодействие; организационно-управленческая модель; доступность лекарственного обеспечения и заместительной терапии. В пилотном исследовании приняли участие 55 врачей, вовлечённых в ведение пациентов с гемофилией. Надёжность оценивалась с использованием коэффициента α Кронбаха. Конструктная валидность анализировалась методом разведочного факторного анализа с варимакс-ротацией. Пригодность данных подтверждалась показателями КМО и тестом сферичности Бартлетта.

Результаты. Общий коэффициент внутренней согласованности анкеты составил $\alpha = 0{,}870$, что свидетельствует о высоком уровне надёжности инструмента. Значения α по доменам варьировали от 0,672 до

0,843. Мера адекватности выборки Кайзера–Мейера–Олкина составила 0,761; тест Бартлетта был статистически значимым (p < 0,001), что подтвердило факторную пригодность данных. В результате факторного анализа выделено четыре фактора с кумулятивной долей объяснённой дисперсии 78,11%. Факторные нагрузки большинства пунктов превышали 0,70, что подтверждает многомерную структуру инструмента.

Выводы. Разработанная анкета продемонстрировала удовлетворительные психометрические характеристики, включая высокую общую внутреннюю согласованность и эмпирически подтверждённую многомерную структуру. Инструмент может использоваться для количественной оценки организационных механизмов оказания помощи пациентам с гемофилией и служить основой для стратегического планирования, оптимизации распределения ресурсов и совершенствования системы ведения пациентов при редких заболеваниях.

Ключевые слова: гемофилия, анкета, организационные механизмы, психометрическая валидация, организация здравоохранения.