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Barriers to hemophilia care: A survey of healthcare professionals

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Abstract

Introduction. Hemophilia is a rare inherited bleeding disorder requiring multidisciplinary care, timely diagnosis, and continuous access to specialized treatment. Despite advances in replacement therapy, the quality of care depends largely on the organizational readiness of healthcare systems.
Objective. To identify barriers to hemophilia care based on a cross-sectional survey of healthcare professionals.
Methods. A cross-sectional survey was conducted among 101 healthcare professionals involved in hemophilia care, including general practitioners, pediatricians, hematologists, and nursing staff from primary healthcare facilities, regional hospitals, referral centers, and private organizations. A validated 33-item questionnaire assessed clinical competence, referral pathways, treatment accessibility, organizational barriers, and priorities for healthcare improvement. Descriptive statistics and Pearson's chi-square or Fisher's exact tests were applied ($p<0.05$).
Results. Hematologists comprised 52.5% of respondents, and 52.5% had completed hemophilia-specific training within the previous three years. Most participants reported adequate knowledge of hemophilia manifestations (89.1%), clinical guidelines (63.4%), and prophylactic treatment (75.3%), with hematologists demonstrating significantly higher competence than primary healthcare physicians (all $p<0.001$). Knowledge of referral pathways was reported by 72.3% of respondents,

whereas only 49.5% confirmed the availability of approved institutional referral pathways and 43.6% reported referral to a hematologist within 24 hours. Significant differences between professional groups were observed regarding referral pathway awareness, inter-level collaboration, and institutional referral systems (all $p<0.05$). Only 45.5% reported routine use of standardized clinical algorithms, 58.4% regular prophylactic follow-up, and 32.7% uninterrupted access to replacement therapy. Major barriers included procurement delays (26.7%), insufficient funding (19.8%), and poor coordination between healthcare providers (14.0%).

Conclusion. Although healthcare professionals demonstrated generally satisfactory clinical competence, important organizational gaps remain. Strengthening standardized referral pathways, expanding primary care education, improving coordination between healthcare levels, ensuring uninterrupted access to replacement therapy, and establishing a national hemophilia registry are essential to improve comprehensive hemophilia care in Kazakhstan.

Keywords: hemophilia, health services accessibility, delivery of health care, referral and consultation, health workers, survey.

1. Introduction

Hemophilia is a rare inherited bleeding disorder requiring coordinated multidisciplinary care, timely diagnosis and continuous access to specialized treatment [1]. Although its prevalence is considerably lower than that of most chronic diseases, delayed diagnosis or inadequate treatment may result in life-threatening bleeding, irreversible joint damage, disability, and reduced quality of life [2-4]. Recent advances in replacement and non-factor therapies have substantially improved clinical outcomes; however, their effectiveness depends not only on the availability of innovative treatments but also on the healthcare system's capacity to ensure early diagnosis, coordinated referral pathways, continuity of care, and equitable access to specialized services [5,6].

The increasing complexity of hemophilia management has expanded the role of healthcare professionals across all levels of healthcare. Adequate knowledge of the clinical manifestations of hemophilia, adherence to evidence-based treatment recommendations, timely referral to specialized centers, and effective collaboration between primary care providers and hematologists are essential for improving patient outcomes [7]. At the same time, organizational barriers, fragmented referral pathways, insufficient professional training, and inequalities in access to treatment remain important challenges affecting the quality of hemophilia care.

While considerable research has focused on advances in hemophilia treatment, substantially less attention has been paid to the organizational readiness of healthcare systems to deliver comprehensive hemophilia care. Organizational readiness encompasses healthcare professionals' clinical competence, implementation of standardized care pathways, multidisciplinary coordination, and access to specialized therapies [8,9]. Assessing these components enables identification of gaps in healthcare delivery and supports the development of evidence-based strategies for improving care for patients with hemophilia. In Kazakhstan, comprehensive data evaluating these aspects remain insufficient.

The aim of this study was to identify barriers to hemophilia care based on a cross-sectional survey of healthcare professionals.

2. Materials and Methods

A cross-sectional survey was conducted among healthcare professionals involved in the provision of medical care for patients with hemophilia in the Republic of Kazakhstan. The study included physicians from primary healthcare (general practitioners/therapists), pediatricians, hematologists, and nursing staff working at different levels of the healthcare system, including primary healthcare facilities, district hospitals, regional

hospitals, republican centers, and private medical organizations.

Eligible participants were healthcare professionals directly involved in the diagnosis, referral, treatment, or follow-up of patients with hemophilia. Individuals who did not provide informed consent or submitted incomplete questionnaires were excluded from the analysis.

Data were collected using a structured author-developed questionnaire designed to evaluate organizational aspects of hemophilia care [10]. The questionnaire comprised 33 items grouped into six domains: professional characteristics of respondents, clinical competence regarding hemophilia, organization of healthcare delivery and referral pathways, availability of treatment and pharmaceutical support, organizational barriers affecting healthcare delivery, priority directions for improving the organization of hemophilia care.

Clinical competence was assessed using Likert-scale questions evaluating knowledge of clinical manifestations, national clinical practice guidelines, preventive therapy, patient referral pathways, and organizational aspects of hemophilia management. Additional questions evaluated the availability of standardized care pathways, referral time to hematologists, access to replacement therapy, implementation of prophylactic treatment, organizational barriers, and proposed strategies for improving healthcare delivery.

The anonymous questionnaire was distributed electronically among healthcare professionals working at different levels of the healthcare system. Participation was voluntary. Completion of the questionnaire was considered to constitute informed consent.

Descriptive statistics were used to summarize participant characteristics and questionnaire responses. Categorical variables are presented as frequencies and percentages. Associations between professional groups and questionnaire responses were assessed using Pearson's chi-square test or Fisher's exact test, as appropriate.

A two-sided p-value <0.05 was considered statistically significant. Statistical analyses were performed using IBM SPSS Statistics version 31.0.2.0.

The study was conducted in accordance with the principles of the Declaration of Helsinki. Ethical approval was obtained from the Local Research Ethics Committee of the Research Institute of Cardiology and Internal Diseases (Protocol No.1, dated February 3, 2026). Participation was voluntary, all respondents were informed about the study objectives, anonymity and confidentiality were guaranteed, and informed consent was obtained electronically prior to participation.

3. Results

A total of 101 healthcare professionals involved in the management of patients with hemophilia participated in the study. Hematologists constituted the largest professional group (52,5%, n=53), followed by general practitioners (36,6%, n=37). Most respondents were employed in primary healthcare facilities (33,7%) or regional hospitals (27,7%). General practitioners were predominantly early-career physicians, with fewer than five years of clinical experience (59,5%), whereas hematologists more frequently had over 20 years of clinical practice (41,5%). Overall, 52,5% of respondents had received hemophilia-specific training within the previous three years (Table 1).

Table 1 - Social and professional characteristics of respondents

Characteristic	General practitioners, n (%)	Pediatrician, n (%)	Hematologist, n (%)	Nursing Staff, n (%)	Total n (%)
Speciality	37 (36,6%)	3 (3,0%)	53 (52,5%)	8 (7,9%)	101 (100,0%)
Years of clinical experience					
<5 years	22 (59,5%)	0	16 (30,2%)	1 (12,5%)	39 (38,6%)
5–10 years	9 (24,3%)	1 (33,3%)	6 (11,3%)	3 (37,5%)	19 (18,8%)
11–20 years	5 (13,5%)	0	9 (17,0%)	0	14 (13,9%)
>20 years	1	2	22	4	29

	(2,7%)	(66,7%)	(41,5%)	(50,0%)	(28,7%)
Frequency of contact with patients with hemophilia					
Regularly	8 (21,6%)	0	27 (50,9%)	4 (50,0%)	39 (36,6%)
Occasionally	29 (78,4%)	3 (100%)	26 (49,1%)	4 (50,0%)	62 (61,4%)
Number of patients managed					
1–2 patients	30 (81,1%)	3 (100,0%)	20 (37,7%)	4 (50,5%)	57 (56,4%)
3–5 patients	4 (10,8%)	0	11 (20,8%)	2 (25,0%)	17 (16,8%)
>5 patients	3 (8,1%)	0	22 (41,5%)	2 (25,0%)	27 (26,7%)
Hemophilia-specific training					
No	7 (18,9%)	0	13 (24,5%)	1 (12,5%)	21 (20,8%)
Yes, within the past 3 years	23 (62,2%)	1 (33,3%)	26 (49,1%)	3 (37,5%)	53 (52,5%)
Yes, more than 3 years ago	7 (18,9%)	2 (66,7%)	14 (26,4%)	4 (50,0%)	27 (26,7%)

Most healthcare professionals reported adequate knowledge of the principles of prophylactic therapy for hemophilia, with 75,3% selecting either "strongly agree" or "agree" (Table 2). Hematologists demonstrated the highest level of confidence, with 66,0% strongly agreeing that they were familiar with the principles of prophylactic therapy. In contrast, general practitioners most frequently selected "agree" (56,8%), while nearly one-third (29,7%) reported uncertainty regarding their knowledge. These findings suggest that, although overall self-reported knowledge was satisfactory, educational gaps remain among primary care physicians. Significant differences in self-assessed competence were observed across professional groups ($p < 0.001$).

Table 2 - Self-assessed clinical competence of healthcare professionals in hemophilia care

Response category	General practitioner (n=37)	Pediatrician (n=3)	Hematologist (n=53)	Nursing Staff, n (%)	p-value
Knowledge of the clinical manifestations of hemophilia					
Strongly agree	12 (32,4%)	2 (66,7%)	43 (81,1%)	3 (37,5%)	<0,001
Agree	20 (54,1%)	1 (33,3%)	5 (9,4%)	4 (50,0%)	
Neither agree nor disagree	1 (2,7%)	0 (0,0%)	0 (0,0%)	0 (0,0%)	
Disagree	4 (10,8%)	0 (0,0%)	1 (1,9%)	1 (12,5%)	
Strongly disagree	0 (0,0%)	0 (0,0%)	4 (7,5%)	0 (0,0%)	
Knowledge of clinical practice guidelines for hemophilia					
Strongly agree	5 (13,5%)	2 (66,7%)	34 (64,2%)	3 (37,5%)	<0,001
Agree	10 (27,0%)	0 (0,0%)	9 (17,0%)	1 (12,5%)	
Neither agree nor disagree	10 (27,0%)	0 (0,0%)	1 (1,9%)	1 (12,5%)	
Disagree	10 (27,0%)	0 (0,0%)	5 (9,4%)	3 (37,5%)	
Strongly disagree	2 (5,4%)	10 (33,3%)	4 (7,5%)	0 (0,0%)	

Knowledge of the principles of prophylactic therapy					
Strongly agree	3 (8,1%)	2 (66,7%)	35 (66,0%)	3 (37,5%)	<0,001
Agree	21 (56,8%)	0 (0,0%)	11 (20,8%)	1 (12,5%)	
Neither agree nor disagree	11 (29,7%)	0 (0,0%)	2 (3,8%)	3 (37,5%)	
Disagree	2 (5,4%)	1 (33,3%)	3 (5,7%)	1 (12,5%)	
Strongly disagree	0 (0,0%)	0 (0,0%)	2 (3,8%)	0 (0,0%)	

Most respondents reported awareness of the national referral pathway for patients with hemophilia (73/101; 72,3%). Effective collaboration between primary healthcare providers and hematologists was reported by 66 (65,3%) participants, whereas only 50 (49,5%) confirmed the availability of an approved referral pathway within their healthcare organization. Referral of patients to a hematologist within 24 hours was reported by 44 (43,6%) respondents, while 51 (50,5%) indicated that patient management was supported by a standardized referral pathway (Table 3).

Significant differences between professional groups were observed regarding awareness of referral pathways (p=0.005), assessment of inter-level collaboration (p=0.032), and the availability of institutional referral pathways (p<0.001). Hematologists more frequently reported awareness of referral pathways (44/53; 83,0%) compared with primary healthcare physicians (23/37; 62,2%). In contrast, no statistically significant differences were identified in the reported referral time to a hematologist (p=0.184) (Table 3).

Table 3 - Organizational readiness and referral pathways according to professional group

Professional group	Knowledge of the referral pathway	Effective collaboration between primary care and hematology services	Availability of an approved referral pathway	Referral within ≤24 hours
Overall, n (%)	73 (72,3)	66 (65,3)	50 (49,5)	44 (43,6)
General practitioner, n (%)	23 (62,2)	23 (62,1)	14 (37,8)	14 (37,8)
Pediatrician, n (%)	2 (66,7)	3 (100,0)	0 (0,0)	0 (0,0)
Hematologist, n (%)	44 (83,0)	38 (71,7)	29 (54,7)	28 (52,8)
Nursing staff, n (%)	4 (50,0)	2 (25,0)	7 (87,5)	2 (25,0)
p-value	0,005	0,032	<0,001	0,184

Most respondents supported key organizational strategies aimed at improving the quality of hemophilia care. Overall, 77,2% agreed that organizational and economic factors substantially influence the quality of healthcare delivery. Similarly, 72,3% recognized the importance of continuity of care across different levels of the healthcare system, while 74,3% supported the establishment of a national hemophilia registry, and 74,2% considered telemedicine essential for interregional collaboration (Table 4).

Table 4 - Assessment of organizational and management factors influencing hemophilia care (N = 101)

Statement	Strongly disagree, n (%)	Disagree, n (%)	Neither agree nor disagree, n (%)	Agree, n (%)	Strongly agree, n (%)
Organizational and economic factors influence the quality of hemophilia care	10 (9,9)	6 (5,9)	7 (6,9)	26 (25,7)	52 (51,5)
Continuity of care across healthcare levels	9 (8,9)	6 (5,9)	13 (12,9)	15 (14,9)	58 (57,4)
Establishment of a national hemophilia registry	12 (11,9)	6 (5,9)	8 (7,9)	21 (20,8)	54 (53,5)
Telemedicine for interregional collaboration	9 (8,9)	7 (6,9)	10 (9,9)	16 (15,8)	59 (58,4)

Overall, routine implementation of standardized clinical algorithms for hemophilia management was reported by 45.5% of respondents. Significant differences were observed between professional groups (χ^2=27.596, df=12, p=0.006; Monte Carlo p=0.010). Reported implementation was more common among hematologists (60.4%) and other healthcare professionals (57.1%) than among primary care physicians (24.3%) (Table 5). No significant differences were observed between professional groups regarding the routine provision of prophylactic follow-up (p>0.05).

Table 5 - Organizational readiness indicators according to professional group

Organizational measure	Primary care physicians, %	Hematologists, %	Other healthcare professionals, %	p-value
Routine implementation of clinical algorithms	24,3	60,4	57,1	0,006
Routine provision of prophylactic follow-up	48,6	64,2	63,6	>0,05

Overall, 58,4% of respondents reported that patients with hemophilia received regular prophylactic follow-up, whereas 25,7% indicated that follow-up was provided only occasionally and 15,8% reported that it was not performed on a regular basis. No statistically significant differences in the provision of prophylactic follow-up were observed between professional groups (Table 6).

Regarding treatment availability, 44,6% of respondents reported the routine use of clotting factor concentrates for home-based treatment. In addition, 46,5% indicated good knowledge of the national system for the provision of hemophilia treatment products. Regarding the availability of replacement therapy, 32,7% of respondents reported continuous availability, 35,6% reported periodic shortages, and 19,8% indicated that replacement therapy was not available in the required range of medications. Regular prophylactic therapy was reported by 54,5% of respondents (Table 6).

Table 6 - Availability of therapy and treatment provision for patients with hemophilia (N = 101)

Measure	Response category	n	%
Prophylactic follow-up	Yes, regularly	59	58,4
	Occasionally	26	25,7
	No	16	15,8
Home administration of clotting factor concentrates	Yes, regularly	45	44,6
	Limited	29	28,7
	No	27	26,7
Awareness of the national treatment provision system	Yes, well informed	47	46,5
	Partially informed	37	36,6
	No	17	16,8
Availability of replacement therapy	Always available	33	32,7
	Occasional shortages	36	35,6
	Frequent shortages	7	6,9
	Not available in the required range of medications	20	19,8
	Other / not specified	5	5,0
Provision of prophylactic therapy	Yes, regularly	55	54,5
	Limited	20	19,8
	No	1	1,0
	Do not know	25	24,8
Factors limiting access to treatment*	Procurement delays	23	26,7
	Insufficient funding	17	19,8
	Lack of coordination	12	14,0
	Delayed submission of procurement requests	6	7,0
	Inadequate forecasting of treatment needs	6	7,0
	Other	21	24,4

** Multiple responses were permitted; therefore, percentages may exceed 100%.*

The most frequently reported barriers to treatment access were procurement delays (26,7%), insufficient funding (19,8%), lack of coordination among healthcare professionals (14,0%), inadequate forecasting of treatment needs (7,0%), and delayed submission of procurement requests (7,0%) (Table 7). Stratified analysis according to the level of healthcare institution demonstrated significant differences in the availability of replacement therapy (p=0,035). In contrast, no statistically significant differences were observed in the routine use of home administration of clotting factor concentrates (p=0,167) or the provision of regular prophylactic therapy (p=0,066) across healthcare settings (Table 7).

Table 7 - Stratified analysis of therapy availability according to the level of healthcare institution

Measure	Primary healthcare (n = 34)	District hospital (n = 6)	Regional hospital (n = 28)	National referral center (n = 16)	Private clinic (n = 17)	p-value
Home administration of clotting factor concentrates						
Yes, regularly	11 (32,4%)	5 (83,3%)	17 (60,7%)	6 (37,5%)	6 (35,3%)	0,167
Limited	11 (32,4%)	0 (0,0%)	8 (28,6%)	5 (31,3%)	5 (29,4%)	
No	12 (35,3%)	1 (16,7%)	3 (10,7%)	5 (31,3%)	6 (35,3%)	
Regular prophylactic therapy						
Yes, regularly	21 (61,8%)	4 (66,7%)	17 (60,7%)	10 (62,5%)	3 (17,6%)	0,066
Limited	5 (14,7%)	1 (16,7%)	8 (28,6%)	2 (12,5%)	4 (23,5%)	
Do not know	8 (23,5%)	1 (16,7%)	3 (10,7%)	4 (25,0%)	9 (52,9%)	
No	0 (0,0%)	0 (0,0%)	0 (0,0%)	0 (0,0%)	1 (5,9%)	
Availability of replacement therapy						
Always available	17 (50,0%)	2 (33,3%)	9 (32,1%)	4 (25,0%)	1 (5,9%)	0,035
Occasional shortages	12 (35,3%)	3 (50,0%)	8 (28,6%)	7 (43,8%)	6 (35,3%)	
Frequent shortages	2 (5,9%)	1 (16,7%)	4 (14,3%)	0 (0,0%)	0 (0,0%)	
Not available in the required range of medications	3 (8,8%)	0 (0,0%)	4 (14,3%)	5 (31,3%)	8 (47,1%)	

4. Discussion

The present study provides a comprehensive assessment of the organizational readiness of the healthcare system to deliver care for patients with hemophilia based on a survey of healthcare professionals.The findings indicate that, despite a relatively high level of self-reported professional knowledge among healthcare professionals, substantial organizational challenges remain, particularly regarding patient referral pathways, implementation of standardized clinical algorithms, and access to replacement therapy.

One of the principal findings was the identification of statistically significant differences in clinical competence across professional groups. Hematologists reported significantly greater confidence in their knowledge of the clinical manifestations of hemophilia, clinical practice guidelines, and principles of prophylactic treatment than primary healthcare physicians. These findings are consistent with previous international studies demonstrating that contemporary hemophilia care requires healthcare professionals with specialized expertise, whereas insufficient awareness among primary care physicians remains an important contributor to delayed diagnosis and referral to specialized hemophilia treatment centers [11–13].

These findings underscore the need for targeted educational strategies for primary healthcare professionals. Improving awareness of the early signs of

hemophilia, referral pathways, and current treatment principles may facilitate timely diagnosis and referral to specialized hemophilia treatment centers. Continuing medical education and standardized referral algorithms could help reduce diagnostic delays and improve continuity of care.

The study also revealed inadequate organizational preparedness with respect to patient referral pathways. Although most respondents were familiar with referral procedures, one-third of respondents reported the availability of formally approved local referral pathways or the possibility of referring patients to a hematologist within the first 24 hours. According to the World Federation of Hemophilia Guidelines, effective hemophilia care requires clearly defined referral pathways, coordinated care across different levels of the healthcare system, and continuous multidisciplinary collaboration [14].

Another important finding concerns the implementation of standardized clinical algorithms. Only 45.5% of respondents reported their routine use, with primary healthcare physicians using such algorithms significantly less frequently than hematologists. Similar observations have been reported internationally, where implementation of evidence-based clinical protocols is recognized as a key strategy for ensuring standardized care, improving healthcare quality, and reducing variability in clinical practice.

Treatment delays caused by supply chain disruptions remain another important organizational challenge. Although prophylactic treatment is widely implemented, only one-third of respondents reported uninterrupted availability of clotting factor concentrates, while more than one-third indicated periodic supply interruptions. Procurement delays, limited resources, and inadequate intersectoral coordination were identified as the principal barriers. These findings are consistent with international evidence identifying equitable access to innovative therapies as one of the major organizational challenges, even in countries with well-established specialized hemophilia care. Previous studies emphasize that the effectiveness of modern therapeutic approaches depends not only on the availability of innovative treatments but also on the capacity of healthcare systems to ensure timely and equitable access for all eligible patients [6,15,16].

The strong support expressed by respondents for establishing a national hemophilia registry, expanding telemedicine services, and improving continuity of care highlights the perceived priorities for future development of hemophilia services. International experience indicates that integrated models of care based on specialized treatment centers, national patient registries, and multidisciplinary collaboration are associated with improved clinical outcomes, better treatment adherence, and more efficient utilization of healthcare resources [8,17,18].

The strengths of this study include the participation of healthcare professionals from different levels of the healthcare system, the comprehensive evaluation of organizational aspects of hemophilia care, and the opportunity to compare perceptions across professional groups. However, several limitations should be acknowledged. The cross-sectional design precludes causal inference, the findings are based on self-reported responses, and the relatively small number of pediatricians and nursing staff limited the statistical power of subgroup analyses. Furthermore, organizational indicators were assessed exclusively from the perspective of healthcare professionals and were not correlated with patient-level clinical outcomes.

Overall, the findings indicate the need for further improvement in the organization of hemophilia care in the Republic of Kazakhstan. Priority areas include strengthening the competencies of primary healthcare professionals, broader implementation of standardized clinical algorithms and referral pathways, improving coordination between primary and specialized care, establishing a national hemophilia registry, and ensuring sustainable access to replacement therapy. Implementation of these measures may facilitate alignment of the national healthcare system with contemporary international standards for comprehensive hemophilia care.

5. Conclusion

The present study identified key organizational challenges in the delivery of healthcare for patients with hemophilia, including limited access to therapy, diagnostic delays, the need to strengthen healthcare professionals' competencies, and improve continuity of care across different levels of the healthcare system. The establishment of a national hemophilia registry, implementation of telemedicine technologies, and optimization of patient referral pathways received strong support from healthcare professionals. These findings

highlight the need for further refinement of the organizational model of hemophilia care.

Conflict of Interest: The authors declare that they have no conflict of interest.

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Гемофилиямен ауыратын науқастарға күтім жасаудағы кедергілер: Денсаулық сақтау мамандарының сауалнамасының нәтижелері

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Түйіндеме

Кіріспе. Гемофилия үйлестірілген мультидисциплинарлық тәсілді, уақтылы диагностиканы және мамандандырылған емдеуге үздіксіз қол жеткізуді талап ететін гемостаз жүйесінің сирек кездесетін тұқым қуалайтын ауруы болып табылады. Орынбасушы терапияның айтарлықтай дамуына қарамастан, медициналық көмектің сапасы көбінесе денсаулық сақтау жүйесінің ұйымдастырушылық дайындығына тәуелді.

Зерттеудің мақсаты. Медицина қызметкерлерінің сауалнамасы негізінде гемофилиямен ауыратын науқастарға медициналық көмек көрсетудегі кедергілерді анықтау.

Әдістері. Гемофилияны емдеумен айналысатын 101 денсаулық сақтау маманы, оның ішінде жалпы тәжірибе дәрігерлері, педиатрлар, гематологтар және бастапқы медициналық-санитарлық көмек мекемелерінің, аймақтық ауруханалардың, мамандандырылған орталықтардың және жеке ұйымдардың медбикелері арасында көлденең зерттеу жүргізілді. Клиникалық құзыреттілікті, пациенттерді жолдама беру жолдарын, емдеуге қолжетімділікті, ұйымдастырушылық кедергілерді және денсаулық сақтауды жақсартудың басымдықтарын бағалау үшін тексерілген 33 тармақтан тұратын сауалнама пайдаланылды. Статистикалық талдау үшін сипаттамалық статистика әдістері, Пирсон χ^2 өлшемі және Фишердің нақты өлшемі пайдаланылды. $p < 0,05$ кезіндегі айырмашылықтар статистикалық маңызды деп саналды.

Нәтижесі. Гематологтар іріктеудің 52,5%-ын құрады, респонденттердің 52,5%-ы соңғы үш жылда гемофилия бойынша мамандандырылған оқудан өтті. Қатысушылардың көпшілігі гемофилияның клиникалық көріністері (89,1%), клиникалық нұсқаулар (63,4%) және профилактикалық терапия принциптері (75,3%) туралы

жеткілікті білім деңгейін көрсетті. Сонымен қатар, гематологтар клиникалық құзыреттілік тұрғысынан бастапқы медициналық-санитарлық көмек дәрігерлерінен айтарлықтай асып түсті (барлық жағдайларда, p<0,001). Пациенттерді бағыттау туралы хабардарлықты респонденттердің 72,3%-ы хабарлады, бірақ тек 49,5%-ы бекітілген жергілікті жолдама бағыттарының бар екенін растады, ал 43,6%-ы 24 сағат ішінде гематологқа жолдама алу мүмкіндігі туралы хабарлады. Кәсіби топтар арасында жолдама туралы хабардарлық деңгейінде, күтім деңгейлері арасындағы өзара әрекеттесуде және жергілікті бағыттардың қолжетімділігінде статистикалық тұрғыдан маңызды айырмашылықтар анықталды (барлық жағдайларда, p<0,05). Респонденттердің тек 45,5%-ы стандартталған клиникалық алгоритмдерді үнемі қолданатынын, 58,4%-ы пациенттерді жүйелі профилактикалық бақылауды және 32,7%-ы алмастыру терапиясына үздіксіз қол жеткізуді хабарлады. Негізгі ұйымдастырушылық кедергілер дәрі-дәрмектерді сатып алудағы кідірістер (26,7%), қаржыландырудың жеткіліксіздігі (19,8%) және денсаулық сақтау ұйымдары арасындағы үйлестірудің жеткіліксіздігі (14,0%) болды.

Қорытынды. Медицина қызметкерлерінің клиникалық құзыреттілігінің жалпы қанағаттанарлық деңгейіне қарамастан, гемофилиямен ауыратын науқастарға күтім жасау жүйесінде елеулі ұйымдастырушылық қиындықтар сақталуда. Стандартталған пациенттерді жолдама беру жолдарын нығайту, бастапқы медициналық-санитарлық көмек бойынша оқытуды кеңейту, денсаулық сақтау деңгейлері арасындағы үйлестіруді жақсарту, алмастыру терапиясына үздіксіз қол жеткізуді қамтамасыз ету және гемофилияның ұлттық тізілімін құру Қазақстанда гемофилиямен ауыратын науқастарға кешенді көмек көрсетуді жақсарту үшін өте маңызды.

Түйін сөздер: гемофилия, медициналық көмектің қолжетімділігі, медициналық көмек көрсетуді ұйымдастыру, пациенттерді маршруттау, медицина қызметкерлері, сауалнама.

Барьеры в оказании помощи пациентам с гемофилией: Результаты опроса специалистов здравоохранения

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Резюме

Введение. Гемофилия представляет собой редкое наследственное нарушение свертывания крови, требующее своевременной диагностики, мультидисциплинарного ведения пациентов и непрерывного доступа к специализированной медицинской помощи. Несмотря на значительный прогресс в развитии заместительной терапии, качество оказания медицинской помощи во многом определяется организационной готовностью системы здравоохранения.

Цель исследования. Выявить барьеры в оказании медицинской помощи пациентам с гемофилией на основе анкетирования медицинских работников.

Методы. Было проведено поперечное исследование среди 101 медицинского работника, занимающегося лечением гемофилии, включая врачей общей практики, педиатров, гематологов и медсестер из учреждений первичной медико-санитарной помощи, региональных больниц, специализированных центров и

частных организаций.Для оценки клинической компетентности, путей направления пациентов, доступности лечения, организационных барьеров и приоритетов в улучшении здравоохранения использовался валидированный опросник из 33 пунктов. Статистическая обработка включала методы описательной статистики, критерий χ^2 Пирсона и точный критерий Фишера. Статистически значимыми считались различия при $p<0,05$.

Результаты. Гематологи составили 52,5% выборки, при этом 52,5% респондентов прошли специализированное обучение по вопросам гемофилии в течение последних трех лет. Большинство участников продемонстрировали достаточный уровень знаний клинических проявлений гемофилии (89,1%), клинических рекомендаций (63,4%) и принципов профилактической терапии (75,3%). При этом гематологи достоверно превосходили врачей первичного звена по уровню клинической компетентности (во всех случаях $p<0,001$). Осведомленность о маршрутизации пациентов отметили 72,3% респондентов, однако лишь 49,5% подтвердили наличие утвержденных локальных маршрутов направления пациентов, а 43,6% сообщили о возможности направления к гематологу в течение 24 часов. Между профессиональными группами выявлены статистически значимые различия по уровню осведомленности о маршрутизации, взаимодействию между уровнями оказания медицинской помощи и наличию локальных маршрутов (во всех случаях $p<0,05$). Лишь 45,5% респондентов сообщили о регулярном применении стандартизированных клинических алгоритмов, 58,4% о систематическом профилактическом наблюдении пациентов, а 32,7% о бесперебойной доступности заместительной терапии. Основными организационными барьерами являлись задержки закупок лекарственных препаратов (26,7%), недостаточное финансирование (19,8%) и недостаточная координация между медицинскими организациями (14,0%).

Выводы. Несмотря на в целом удовлетворительный уровень клинической компетентности медицинских работников, в системе оказания помощи пациентам с гемофилией сохраняются существенные организационные проблемы. Укрепление стандартизированных путей направления пациентов, расширение обучения в сфере первичной медицинской помощи, улучшение координации между уровнями здравоохранения, обеспечение бесперебойного доступа к заместительной терапии и создание национального регистра гемофилии имеют важное значение для улучшения комплексной помощи пациентам с гемофилией в Казахстане.

Ключевые слова: гемофилия, доступность медицинской помощи, организация оказания медицинской помощи, маршрутизация пациентов, медицинские работники, анкетирование.