JOURNAL of RAWALPINDI MEDICAL COLLEGE

Original Article

Analysis of Quality of Life of Teenagers with Hemophilia in Pakistan

Maryam Javed[1], Qurrat Ulain Hamdan[2], Usama Azam [3], Nawal Ali[4], Lubna Zafar[5], Tahira Zafar[6]

Abstract

Objective: To investigate the quality of life (QoL) of adolescents living with haemophilia and analyse the impact of sociodemographic factors, such as socioeconomic status, parents' qualifications, and clinical factors, including disease severity and type, on their physical and psychosocial health.

Methods: This was a descriptive observational study using association analysis. Fifty adolescents with haemophilia A or B were recruited from the Hemophilia Treatment Center (HTC) managed by the Hemophilia Patients Welfare Society. The Pediatric Quality of Life Inventory (PedsQL) was used to quantify QoL. Statistical analyses, including one-way analysis of variance and correlations, were performed to identify associations between QoL scores and baseline factors.

Results: The Majority of adolescents had compromised physical and psychosocial health. The mean physical health functioning scores and psychosocial health functioning scores were (44.03 ± 25.80) and (57.24 ± 18.03), respectively, indicating that both physical and psychosocial quality of life were compromised; however, physical health was more affected than psychosocial health. Analysis of the association between sociodemographic variables and physical and psychosocial health yielded statistically significant results for parents' qualification to physical and social functioning; however, the impact of clinical factors, such as disease severity and type, did not yield statistically significant results.

Conclusion: The QoL of most adolescents with haemophilia is compromised, regardless of disease severity or type. Parents' qualifications play a positive role in adolescents' physical and social functioning. We suggest incorporating regular psychological evaluations and parent psychoeducation into management plans to improve the quality of care and QoL.

Keywords: Hemophilia; Adolescents; Quality of Life.

Introduction

Haemophilia is a congenital blood disorder characterised by a deficiency or absence of blood clotting factors VIII or IX, resulting in haemophilia A or B, respectively.[1] This impairs the body's ability to clot in the event of an injury, resulting in prolonged bleeding. Based on the severity of the disorder, spontaneous bleeding may also occur internally in and around soft tissues, muscles, and joints.[2] The global population of haemophilia patients is expected to be 1,125,0000, according to a study published in 2019, with a prevalence rate of 1 in 3,333 births.[3] In Pakistan, the Hemophilia Foundation of Pakistan (HFP) projects that the actual population of haemophilia patients is 18,000, but only 10% of cases are registered in centres and facilities.[4] Issues, such as lack of education and awareness, limited care facilities, and the expense of treatment, cause haemophilia to remain neglected.[1]

Haemophilia is a physically and emotionally exhausting disorder. As there is no cure, its lifelong persistence and management with clotting factor concentrates and blood components not only causes financial strain on patients and their families but also becomes a source of prolonged psychological distress, in addition to physical discomfort.[5]

Among haemophiliac patients, paediatric populations are more susceptible to both physical and psychological stress caused by the crippling nature of the disease and the extensive management associated with it. It significantly hampers the physical and emotional quality of their life, with detrimental effects on their academics, extracurricular activities such as sports, and personal relationships.[6] The situation is more challenging for adolescents who are also learning to cope with physical and emotional developments associated with puberty. Therefore, understanding the impact of chronic illness on young patients' mental health is as important as the physical outcomes of the disease.[7] Recently, quality of life (QoL), specifically health-related QoL (HRQoL), has become a significant aspect of disease progression and clinical outcomes, especially for paediatric patients. It is a multidimensional concept that encompasses the physical and psychological functioning and well-being of individuals with a specific health condition.[8]

Many studies have shown that people with haemophilia have a compromised quality of life compared to healthy people.[2] Some studies on the quality of life of children and adolescents with haemophilia have been reported in recent literature,[6] including from South Asian countries like Afghanistan,[7] and India,[9,] but a lack of reported literature specifically from Pakistan is observed.

Contributions:
MJ QUH LZ TZ - Conception, Design
MJ QUH UA NA - Acquisition, Analysis, Interpretation
MJ QUH - Drafting
MJ QUH UA NA LZ TZ - Critical Review

All authors approved the final version to be published & agreed to be accountable for all aspects of the work.

Conflicts of Interest: None
Financial Support: None to report
Potential Competing Interests: None to report

Institutional Review Board Approval
DH/TZ/IRB-HTC-01
04-04-2024
Hemophilia Patients Welfare Society, Rawalpindi.

Review began 23/05/2025
Review ended 15/10/2025
Published 31/03/2026

How to cite this article: Javed M, Hamdan QU, Azam U, Ali N, Zafar L, Zafar T. Analysis of Quality of Life of Teenagers with Hemophilia in Pakistan. JRMC. 2026 Mar. 31;30(1).

https://doi.org/10.37939/jrmc.v30i1.2921

This study aimed to address this deficiency by evaluating the QoL of hemophilic adolescents from this neglected demographic. The potential impact of demographic and clinical risk factors on QoL was also evaluated.

Materials And Methods

This was a descriptive observational study with association analysis. It was conducted to analyse the QoL of adolescents living with haemophilia in Rawalpindi, Pakistan. This study was conducted in accordance with ethical standards and principles. The study received ethical approval from the Institutional Review Board (IRB) of HTC Rawalpindi on 4th April 2024. Ref No: DH/TZ/IRB-HTC-01. The total duration of study was 3 months from 1st October 2024 to 31st December 2024.

A non-probability consecutive sampling technique was employed. Data were collected over the course of one month, from October 1, 2024, to October 30, 2024. Fifty adolescents aged 13 to 18 years registered with the Hemophilia Patients Welfare Society (HPWS) in Rawalpindi were recruited from the Hemophilia Treatment Center in Rawalpindi. We included adolescents with any type of haemophilia A or B and mild, moderate, or severe disease severity. Adolescents with major comorbid physical or psychiatric disorders or intellectual difficulties were excluded from the study, as the objective of the research was to focus on the sole impact of haemophilia on QoL. Informed written consent was obtained from the parents and participants before data collection. The data collection process and merits of confidentiality were thoroughly explained to participants and their parents.

Baseline demographics and disease parameters were collected from all participants using a predesigned proforma. This included information on age, gender, educational qualifications, parents' education and occupation, monthly income, family structure, and number of siblings. Clinical parameters, such as disease severity and type of haemophilia, were determined based on blood clotting factor activity and the specific impaired clotting factor, respectively. This data was extracted from clinical records.

QoL was quantified using the Paediatric Quality of Life Inventory (PedsQL). It is a standardised instrument for measuring the QoL of children and adolescents aged 2–18 years. It may be administered to healthy individuals or patients with acute and/or chronic illnesses, such as cancer and blood disorders.10 The PedsQL consists of four Generic Core Scales for Physical, Emotional, Social, and School Functioning. The Physical Functioning Scale provides a Physical Health Summary Score, which quantifies the influence of physical aspects of disease on QoL. Scores of the remaining three scales—Emotional, Social, and School Functioning—are combined to calculate the Psychosocial Health Summary Score by summing the scores of all items on these three scales and dividing by the number of items answered. This summary score quantifies the psychological and social impact on QoL. Summary scores range between 0 and 100, where higher scores indicate better QoL.11

A translated and validated version of the PedsQL was used.12 Permission to use the translated version was sought from the authors of the version. Data were entered in SPSS (version 22). Demographics and clinical characteristics are expressed as frequencies and percentages, whereas age, generic scale scores, and summary scores from the PedsQL are expressed as means and standard deviations. The relationship between variables was analyzed by One-way ANOVA. A correlation matrix was computed to determine the relationship between continuous variables, using Spearman's rho to estimate correlations between ordinal variables and functioning scores. The value of r was stratified as follows to define the strength of association: < 0.3 denotes a weak association, 0.3 to 0.5 denotes a moderate correlation, 0.5 to 0.7 denotes a strong correlation, and >0.7 denotes a very strong correlation. Statistical significance was set at $p<0.05$ for all analyses. The confidence interval was set at 95%.

Results

The mean physical health summary score was 44.03 (±25.80), which shows compromised physical health, and the mean for psychosocial health was 57.24 (±18.03), which is better than physical health but far from adequate. The frequency distribution of physical and psychosocial health summary scores of all adolescents is presented in Figures 1a and 2, respectively, where higher scores indicate better QOL.

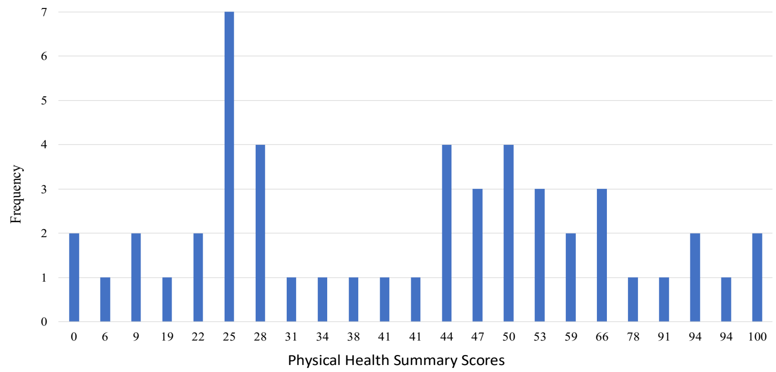

Figure 1: Frequency Distribution of Physical Health Summary Scores of All Adolescents

The mean age of the participants was 15.44 ± 1.79 years. Most participants were currently studying (92%) and lived in nuclear families (66%). Parents generally had limited education, with 70% of mothers and 46% of fathers having qualifications below matriculation. Nearly half of the families earned between 20,000 and 40,000 PKR per month, and 36% earned less than 20,000 PKR/month, indicating a predominantly low-income group.

Table 1: Detailed description of the recorded particulars of the adolescents.

Characteristic	Frequency	Percentage
Gender		
Male	48	96
Female	2	4
Educational Status		
Studying	46	92
Not Studying	4	8
Grade, if studying		
Primary	4	8.7
Middle	21	45.7
Matriculation	17	37
Intermediate	4	8.7
Family Structure		
Nuclear	33	66
Joint	17	34
Number of Siblings		
1-2	10	20
Up to 4	25	50
More than 4	15	30
Mother's Qualification		
No formal education	14	28
Up to Primary	11	22
Up to Middle	10	20
Up to Matric	5	10
Up to Bachelors	10	20
Father's Qualification		
No formal education	7	14
Up to Primary	1	2
Up to Middle	15	30
Up to Matric	16	32
Up to Bachelors	11	22
Monthly Income		
Less than 20,000 PKR	18	36
20,000 – 40,000 PKR	24	48
40,000 – 60,000 PKR	3	6
More than 60,000 PKR	5	10
Disease Severity		
Mild	6	12
Moderate	22	44
Severe	22	44
Joint Deformity		
Yes	10	20
No	40	80
Type of Hemophilia		
Type A	39	78
Type B	11	22

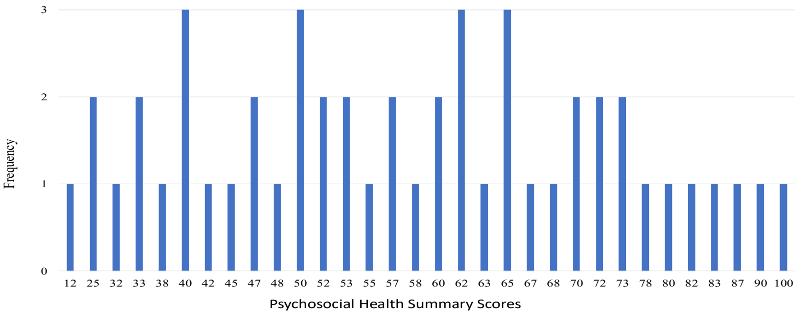

Figure 2: Frequency Distribution of Psychological Health Summary Scores of all Adolescents

Table 2 shows one-way ANOVA to estimate associations between nominal variables like educational status, family structure, joint deformity, and type of hemophilia and means of physical and psychosocial functioning scores. No significant correlation is seen between any of these variables.

Table 2: One-way ANOVA for Nominal Variables

Nominal Variable	Continuous Variable	Means		Sum of Squares (Between Groups)	df (Between Groups)	Mean Square (Between Groups)	F	p-value
Educational Status	Physical Health Score	Studying:	37.22 ± 19.68	1524.45	1	1524.45	4.021	0.051
		Not Studying	16.87 ±15.99					
	Psychosocial Health Score	Studying:	57.63±18.43	87.809	1	87.809	0.266	0.608
		Not Studying	52.75±13.45					
Family Structure	Physical Health Score	Nuclear	38.21±20.49	662.25	1	662.25	1.66	0.203
		Joint	30.52±18.74					
	Psychosocial Health Score	Nuclear	57.64±18.36	15.407	1	15.407	0.046	0.830
		Joint	56.47±17.87					
Joint Deformity	Physical Health Score	Yes	26.00±12.75	1152	1	1152	2.97	0.091
		No	38.00±20.94					
	Psychosocial Health Score	Yes	48.70±10.41	912.49	1	912.49	2.91	0.094
		No	59.38±18.96					
Type of Hemophilia	Physical Health Score	A	35.80±21.02	7.64	1	7.64	0.01	0.892
		B	34.86±17.09					
	Psychosocial Health Score	A	56.36±18.46	137.24	1	137.24	0.41	0.52
		B	60.36±16.80					

Association is significant at p-value <0.05

Table 3: Correlation Matrix for continuous variables (Spearman's rho)

	Number of Siblings	Mother's Qualification	Father's Qualification	Monthly Income	Disease Severity	Total physical health	Total psychosocial health	Emotional_Functioning_Score	Social_Functioning_Score	School_Functioning_Score	Physical_Functioning_Score
Number of Siblings	1.000	-.210	.076	.171	.159	.061	.108	.030	.115	.173	.061
Mother's Qualification		1.000	.517**	.329*	-.120	.315*	.363**	.207	.421**	.208	.315*
Father's Qualification			1.000	.684**	-.051	.111	.324*	.250	.381**	.204	.111
Monthly Income				1.000	.122	.166	.195	.035	.280*	.276	.166
Disease Severity					1.000	.216	.147	.186	.172	.093	.216
Total physical health						1.000	.650**	.497**	.590**	.543**	1.00**
Total psychosocial health							1.000	.794**	.897**	.768**	.650**
Emotional_Functioning_Score								1.000	.578**	.387**	.497**
Social_Functioning_Score									1.000	.626**	.590**
School_Functioning_Score										1.000	.543**
Physical Functioning Score											1.000

**Correlation is significant at the 0.05 level (2-tailed).*
***Correlation is significant at the 0.01 level (2-tailed).*

Discussion

This is the first study to evaluate the quality of life and its domains in adolescents living with haemophilia in Pakistan. The sample reported has some notable characteristics; for instance, 96% were boys, which is in line with the incidence of haemophilia being an X-linked disease,[13] Most of the participants belonged to low socioeconomic backgrounds, with 84% living on less than Rs 40,000 (143 USD) per month, similar to the participant proportion of approximately 86% in the lower-middle and lower socioeconomic classes in India [9], and 95% from Afghanistan.[7]

The PedsQL results indicate that most members of the study population have poor QoL, with mean scores for the study population being midway between the best and worst values. Physical health is poorer than psychosocial health, which is predictable. Since haemophilia is a chronic health issue that leads to joint-related disabilities, physical health is directly compromised.[14]

Reported low QoL scores correspond to similar studies from India, Afghanistan, China, Iraq, and Egypt, which contrasts with higher overall scores on QoL instruments in adolescents from the US, Canada, Australia, and Europe.[6] This may be linked to the overall low socioeconomic status reported in the aforementioned Asian countries, except China; therefore, this variable may be more significant than disease status in terms of QoL of these young people, although access to healthcare may also play a pivotal role, as China is also reporting low QoL, with less well-distributed access to healthcare is less well-distributed. [15]

Education did not seem to be affected for most of the study participants, as 46 out of the 50 adolescents were attending school. This is in line with a large global cohort study in which most teenagers continued their education, especially those in the group that had received inhibitor therapy as prophylaxis.[16] This status was also not significantly associated with mean quality of life scores in our study, although lower mean scores were noted for physical health functioning in children who were not studying, which is in line with the findings of Limperg et al., wherein attending school was positively correlated with better quality of life.[17]

Living with joint deformities is bound to impact the quality of life of any individual.[18] Ten participants in this study reported having joint deformities. Similar figures were reported in a retrospective analysis of data from 70 patients at the Yale Hemophilia Center, and 20 patients had reported joint bleeds.[19] Joint bleeds lead to joint deformities, and one-third of patients experience joint disease in adolescence.[20] This has a significant impact on quality of life, and it is also evidenced by the findings of this study, as well as the lower mean scores noted for both physical and psychosocial functioning for participants with joint deformities (Table 2). However, this association was not found to be statistically significant. This may be due to the nearly homogenous quality of life results for all participants, leading to a small observable difference.

Parents' educational achievement was significantly correlated with quality of life scores; mothers with less education had teenagers with low scores on physical and psychosocial functioning, while less educated fathers negatively impacted the social functioning scores of their children, but not overall quality of life. This is further evidence of the essential contribution of mothers to the lives of growing children and adolescents, especially the positive impact of higher education.[21]

Disease severity was not related to quality of life scores, which, on the face of it, seems counterintuitive and is also in contrast to the impact of disease severity seen in other similar studies. [22,] similar findings of no statistically significant impact of haemophilia severity on quality of life scores have been reported in China,[23,] and Indonesia.[24] These findings indicate that quality of life (QoL) is compromised in all adolescents, regardless of disease severity. This suggests that psychosocial factors, rather than clinical severity alone, play a key role in determining well-being. Adolescents with chronic illnesses often experience social isolation, academic disruptions, and mental health challenges, such as anxiety and depression, which significantly lower QoL.[7,8]

Conclusions

This study shows that most adolescents living with haemophilia in Rawalpindi report a compromised quality of life, both in terms of physical and psychosocial health. However, this is not correlated with disease severity or type of haemophilia but rather with parents' education levels and low socioeconomic status. These alarming statistics indicate the need to incorporate psychological assessments and interventions for both patients and their families into regular treatment regimens. Regular counselling sessions for patients can help healthcare providers gain deeper insights into the nuanced challenges young patients may be facing. Safe low-impact sports and physical activities should be designed by physical therapists to encourage exercise and fitness. Quality of life can also be improved by working at the national level to improve literacy rates and economic stability.

Author Information

1. Postgraduate, Resident, Rawalpindi Medical University 2. Assistant Professor, HOD Child and Adolescent Mental Health, Rawalpindi Medical University 3. Project Management Officer, Hemophilia Treatment Center 4. Psychologist Internee, Rawalpindi Medical University 5. Deputy Director Hemophilia Treatment Center/President Hemophilia Patients Welfare Society, Rawalpindi 6. Director, Hemophilia Treatment Center
Corresponding author: Dr. Maryam Javed Maryamjaved98@gmail.com

References

1. Perolla A, Kalaja B. Improving Hemophilia Care in Low-and Middle-Income Countries: Addressing Challenges and Enhancing Quality of Life. Cureus. 2024 Jun 21;16(6). https://doi.org/10.7759/cureus.62817
2. Ahmed Y, EL-Moazen A, Abu-Rehab RA. Evaluation of the Quality of Life in Children with Haemophilia. The Egyptian Journal of Hospital Medicine. 2023 Jan 1;90(1):328-34. https://doi.org/10.21608/ejhm.2023.279613
3. Iorio A, Stonebraker JS, Chambost H, Makris M, Coffin D, Herr C, et al. Establishing the prevalence and prevalence at birth of haemophilia in males: a meta-analytic approach using national registries. Ann Intern Med. 2019;171(8):540-546. https://doi.org/10.7326/m19-1208
4. Haemophilia Foundation - Pakistan (HFP). Country Factsheet: Haemophilia in Pakistan [Internet]. 2024 [cited 2024 Jul 4]. https://haemophilia.org.pk/
5. Palareti L, Melotti G, Cassis F, Nevitt SJ, Iorio A. Psychological interventions for people with haemophilia. Cochrane Database of Systematic Reviews. 2020;(3). https://doi.org/10.1002/14651858.CD010215.pub2
6. Azeredo-da-Silva AF, Zanotto BS, Kuwabara YS, Mata VE. Quality of life in children and adolescents with haemophilia A: A systematic review and meta-analysis. Res Pract Thromb Haemost. 2023;7(1):100008. https://doi.org/10.1016/j.rpth.2022.100008
7. Mousavi SH, Dayer MS, Pourhaji F, Delshad MH, Mesbah-Namin SA. Determinants of quality of life in children and adolescents with haemophilia in Kabul, Afghanistan. Arch Iran Med. 2019;22(7):384-389. https://journalaim.com/Article/aim-3577

8. Zaky EA. Pediatric Chronic Diseases and Health Related Quality of Life. Psychology & Psychological Research International Journal. 2023;8(2):1-2. https://doi.org/10.23880/pprij-16000338
9. Dsouza A, Nayak D, Kurien A, Pai MS, Nayak BS. Description of health related quality of life of children and adolescents with haemophilia from India. Вопросы гематологии/онкологии и иммунопатологии в педиатрии. 2020;19(3):12-16. https://doi.org/10.24287/1726-1708-2020-19-3-12-16
10. Lambe T, Frew E, Ives NJ, Woolley RL, Cummins C, Brettell EA, et al. Mapping the Paediatric Quality of Life Inventory (PedsQL™) generic core scales onto the Child Health Utility Index–9 Dimension (CHU-9D) score for economic evaluation in children. Pharmacoeconomics. 2018;36:451-65. https://doi.org/10.1007/s40273-017-0600-7
11. Vanz AP, Van de Sande Lee J, Pinheiro B, Zambrano M, Brizola E, da Rocha NS, et al. Health-related quality of life of children and adolescents with osteogenesis imperfecta: a cross-sectional study using PedsQL™. BMC pediatrics. 2018;18:1-6. https://doi.org/10.1186/s12887-018-1077-z
12. Mustafa N, Maqsood A. Construct validation of Urdu version of Pediatric Quality of Life Inventory: evidence from Pakistan. The Journal of Mental Health Training, Education and Practice. 2024;19(4):227-38. https://doi.org/10.1108/jmhtep-06-2022-0046
13. Moretti L, Bizzoca D, Buono C, Ladogana T, Albano F, Moretti B. Sports and Children with Hemophilia: Current Trends. Children. 2021;8(11):1064. https://doi.org/10.3390/children8111064
14. Dutta H, Choudhry D, Atri SK, Sangeeta, Jhandai M. Association of psychological and physical health with quality of life in patients with haemophilia: a brief review. International Journal of Research in Medical Sciences 2024;12(9):3549–3553. https://doi.org/10.18203/2320-6012.ijrms20242645
15. Li B, Chen J. Barriers to community-based primary health care delivery in urban China: A systematic mapping review. International Journal of Environmental Research and Public Health. 2022 Oct 4;19(19):12701. https://doi.org/10.3390/ijerph191912701
16. Mahlangu J, Oldenburg J, Callaghan MU, Shima M, Mancuso ME, Trask P, et al. Health-related quality of life and health status in persons with haemophilia A with inhibitors: A prospective, multicentre, non-interventional study (NIS). Haemophilia. 2019;25(3):382-391. https://doi.org/10.1111/hae.13731
17. Limperg PF, Joosten MMH, Fijnvandraat K, Peters M, Grootenhuis MA, Haverman L. Male gender, school attendance and sports participation are positively associated with health-related quality of life in children and adolescents with congenital bleeding disorders. Haemophilia. 2018;24(3):395-404. https://doi.org/10.1111/hae.13420
18. Gualtierotti R, Solimeno LP, Peyvandi F. Hemophilic arthropathy: current knowledge and future perspectives. Journal of Thrombosis and Haemostasis. 2021 Sep 1;19(9):2112-21. https://doi.org/10.1111/jth.15444
19. Chiari JB, Prozora S, Feinn R, Louizos E, Gallagher PG, Bona R. Joint bleeds in mild hemophilia: Prevalence and clinical characteristics. Haemophilia. 2024 Mar;30(2):331-335. https://doi.org/10.1111/hae.14939
20. Mizoguchi Y, Tani C, Aizawa M, Tomioka K, Shimomura M, Nishimura S, et al. Age-specific incidence of joint disease in paediatric patients with haemophilia: A single-centre real-world outcome based on consecutive US examination. Haemophilia. 2023 Sep;29(5):1359-1365. https://doi.org/10.1111/hae.14848
21. Mahadevan R, Fan S. Differential effects of parents' education on adolescent well-being outcomes. Child Indicators Research. 2021 Dec;14(6):2495-2516. https://doi.org/10.1007/s12187-021-09856-7
22. Elsafy OR, Mohammed MA, Abdelfatah NR, Ishtaiwi IE. Impact of Hemophilia on Health-Related Quality of Life in Pediatric Population. Egyptian Journal of Hospital Medicine. 2021;85. https://doi.org/10.21608/ejhm.2021.199590
23. Qin X, Zhang A, Zhao X, Zhou T, Xia Z, Yu G. Investigation and Analysis of the Current Status of Health-Related Quality of Life in Adolescents with Hemophilia in Hubei Province. British Journal of Hospital Medicine. 2024 Aug 30;85(8):1-2. https://doi.org/10.12968/hmed.2024.0199
24. Wardhani AN, Ugrasena ID, Andarsini MR, Larasati MC, Cahyadi A, Suryawan A, et al. Analysis of the Clinical Factors Affecting the Quality of Life in Children with Hemophilia A. Education. 2022;12:57-1. https://doi.org/10.51542/ijscia.v3i1.12