Health-Related Quality of Life Among Adult Hemophilic Patients in Nanakali Hospital, Erbil City

Ronak Azad Mustafa; Salih Ahmed Abdulla

Community Health Nursing, College of Nursing, Hawler Medical University. Iraq

E-mail: runak.azad3003@gmail.com

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Abstract

Background and objectives: Hemophilia is a rare, congenital bleeding disorder characterized by a lack of clotting factor FVIII (hemophilia A) or FIX (hemophilia B). The present study aims to evaluate health-related quality of life of adult hemophilic patients in Nanakali hospital in Erbil city

Methods: A descriptive cross-sectional study design has been carried out to evaluate health-related quality of life of hemophilic patients at Nanakali hospital in Erbil city. A non-probability, purposive sample size of (90) adult male patients with Hemophilia have been selected from Hemophilia department at Nanakali Hospital in Erbil city for data collection.

Results: indicating that the majority (41.1%) were aged between 18-23 years, with a mean age of 30.16 years (SD = 12.281). Regarding education levels, most participants have completed secondary school (23.3%) and hold a college degree and above (22.2%). The majority (87.8%) have hemophilia A, while Hemophilia B is 10%, and a small percentage (2.2%) has been acquired hemophilia. The severity of the disease is distributed between mild (37.8%), moderate (32.2%) and severe (30.0%) cases. The average health quality of life (HRQOL) was 3.16, which went from 1.33 to 5.11, SD (1.04), the total alpha coefficient was 0.684. Between dimensions, Family Planning (mean = 3.86) and work and school (mean = 3.82) showed the highest score suggestions in these areas. On the other hand, the dimensions had "partnership and sexuality" the lowest score (2.49). The total alpha coefficient was 0.684.

Conclusion: The research indicates that adult hemophilia patients experience moderate to poor health-related quality of life across several domains. The research findings emphasize the multifaceted impact of hemophilia on the health-related quality of life (HRQoL) of adult patients.

Keywords: *Health-Related Quality of Life Adult patient Hemophilia*

Introduction

Hemophilia is an X-chromosome-linked bleeding condition brought on by a faulty or insufficient clotting factor. Acute bleeding, pain, target joints or arthropathy, limited movement or even incapacity, and even potentially fatal cerebral hemorrhages follow from it. Ensuring lifetime therapy and consistent clotting factor injection will help to minimize the harmful effects of hemophilia on patients physical health and quality of life (Zhang et al., 2024). Their impact on joints and muscles leads to disability and loss of health-related quality of life (HRQoL) (Abdulrahman andEissa, 2022). Usually, severe acute and chronic diseases follow from repeated bleeding. Common are joint disorders with reduced range of motion. Patients, particularly those undergoing extended intense therapy with older factor concentrates, have been contaminated with several viruses, including hepatitis and human immunodeficiency virus (HIV), and may suffer from the infectious consequences of such exposure. Education, motivation, and success at work give a person information regarding the extent to which career advancement and contributions to society have been hindered as a result of hemophilia. Being less than half present at work or in school radically disrupts functioning as effectively as otherwise endowed (Furie et al., 1994). Health is seen as a significant measure of quality of life. In a limited context, health refers to bodily well-being. A person is deemed healthy if he is in a condition of non-illness. Nonetheless, it is evident that an individual's physical health alone does not fully represent their overall health status (Wang et al., 2024). The incidence of hemophilia in the United States is higher among males. Approximately 12 cases of hemophilia A per 100,000 males and 3.7 cases of hemophilia B per 100,000 males. (Soucie et al., 2020). The World Health Organization (WHO) characterizes quality of life (QoL) as “the individual's perception of their status in life within the framework of the culture and value system they inhabit, in relation to their goals, expectations, standards, and concerns.” Therefore, the significance of assessing the quality of life in individuals with hemophilia is evident. Quality of life indicators can assist in clinical decision-making by evaluating the severity of symptoms, potential treatment consequences, and the correlation between these symptoms and the patient's daily life (Trindade et al., 2019). Assessing the quality of life is essential. Health-related Quality of Life (HRQoL) assesses the total well-being of individuals with hemophilia, encompassing physical, emotional, and social dimensions. The aim of the study evaluated health-related quality of life of adult hemophilic patients in Nanakali hospital in Erbil city.

Subjects and Methods

Study Design and Setting

This descriptive cross-sectional study was conducted to evaluate the health-related quality of life (HRQoL) among adult male patients with hemophilia. The research took place at Nanakali Hospital for Hematology & Oncology, a government facility located in Erbil City, within the Kurdistan region of Iraq. Established on May 16, 2004, the hospital specializes in treating blood disorders and cancer, including leukemia and hemophilia. A dedicated hemophilia department was opened in 2023 to manage bleeding disorders such as hemophilia types A, B, and C, von Willebrand disease, and other related conditions.

Study Sample

A non-probability purposive sampling technique was employed to select 90 adult male patients diagnosed with hemophilia. All participants were recruited from the hemophilia department at Nanakali Hospital based on the following criteria:

- Inclusion Criteria:
    - Male patients aged 18 years and older
    - Diagnosed with any type of hemophilia
    - Willingness to participate and provide verbal consent
- Exclusion Criteria:
    - Female patients
    - Patients with other coagulation disorders
    - Participants involved in the pilot study

Ethical Considerations

The study received ethical approval from the Ethics Committee of the College of Nursing at Hawler Medical University. Additionally, official permission was obtained from the relevant health authorities at Nanakali Hospital. Participants were informed about the study objectives, and verbal consent was secured before data collection. Confidentiality and anonymity were strictly maintained throughout the research process.

Data Collection

Data were collected through a face-to-face interview technique using a structured questionnaire in the Kurdish language. The collection period extended from November 1 to February 20. The questionnaire was validated through a pilot study involving 10 randomly selected individuals to ensure its clarity and reliability.

Study Instrument

The questionnaire consisted of three main parts:

- Part I: Sociodemographic Information

Included details such as age, educational level, marital status, employment status, and socioeconomic status.

- Part II: Medical History

This non-standardized section, developed by the authors, covered clinical variables including:

- Type of hemophilia (A, B, C, or acquired)
- Disease severity (mild, moderate, severe)
- Duration under hematologist care
- Patient education on disease
- Number of hospital visits in the past year

- Satisfaction with healthcare organization
- Treatment regimen (prophylactic vs. on-demand)
- Presence of chronic illnesses

- Part III: Health-Related Quality of Life (HRQoL)

Assessed using the Haem-A-QoL questionnaire (version AU3.0, UK English), a validated disease-specific instrument designed for adults aged 18 and older. It includes 46 items across 10 domains: physical health, feelings, self-perception, sports and leisure, work and school, coping, treatment, future, family planning, and relationships/partners.

Data Analysis

Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to summarize the sociodemographic data, clinical characteristics, and HRQoL domains. Cronbach's alpha coefficients were calculated to evaluate the internal consistency and reliability of each HRQoL domain. To explore the relationships between sociodemographic factors (such as age, marital status, education level, occupational status, and socioeconomic status) and HRQoL, chi-square tests of independence were applied. A p-value of $\leq$ 0.05 was considered statistically significant.

RESULTS

Table1 illustrates the sociodemographic characteristics of the study participants, indicating that the majority (41.1%) were aged between 18-23 years, with a mean age of 30.16 years (SD = 12.281). Regarding education levels, most participants have completed secondary school (23.3%) or hold a college degree and above (22.2%), while smaller sizes have lower educational attainment. In addition, marital status data indicates that a high percentage of participants was 54.4% single, 43.3% were married and 2.2% were separated. When it comes to Regarding education levels, most participants have completed secondary school (23.3%) or hold a college degree and above (22.2%), 2.2% retired. In addition, the socio-economic status distribution indicates that 61.1% considers their position as good, while 26.7% consider it poor, and 12.2% consider it high. The study includes a total of 90 participants.

Table 2 indicate that the majority (87.8%) has hemophilia A, while Hemophilia B is 10%, and a small percentage (2.2%) has been acquired hemophilia. The severity of the disease is distributed between mild (37.8%), moderate (32.2%) and severe (30.0%) cases. When it comes to health conditions for self -assessment, more than half of patients (53.3%) considered health good, while 27.8% considered it fair, and 16.7% described it poor. A significant majority (86.7%) has been under hematological care for more than ten years, and almost all patients (97.8%) reported that their hematologists informed them about their condition. When it comes to the use of health services, 57.8% of patients were treated more than six times at Nanakali Hospital at the previous year, and 62.2% followed an OnDemand treatment regimen, while 37.8% received prophylaxis. The patient's satisfaction with the organization of medical care was high, with 53.3% it was excellent and 40% good. Chronic diseases were informed by 8.9% of patients.

Table 3 illustrates that the average health quality of life (HRQOL) was 3.16, which went from 1.33 to 5.11. Between dimensions, Hemophilia and Family Planning (mean = 3.86) and work and school (mean = 3.82) showed the highest score suggests in these areas. On the other hand, the dimensions had "partnership and sexuality" the lowest score (2.49).

The total alpha coefficient was 0.684. While sports and Leisure (0.17) and self -concept and hemophilia (0.32) dimensions, the values were low, in other dimensions, they were from 0.53 to 0.99. This analysis highlights the effect of hemophilia on various aspects of life, family planning and work/school is the most affected.

Figure 1 highlights that family planning, work/school, and self-perception are major challenges for hemophilia patients, particularly those with severe conditions. On the other hand, partnership/sexuality and physical health are relatively less affected. These insights can help healthcare providers and support programs focus on the most impacted areas to improve patients' well-being.

Figure 2 presents the mean scores for health-related quality of life dimensions in hemophilic patients based on their treatment regimen (prophylaxis vs. on-demand). Patients on prophylaxis generally show higher scores across most dimensions compared to those on an on-demand regimen. The largest differences appear in physical health, coping with hemophilia, family planning, and partnership/sexuality, where prophylaxis patients report higher scores. In contrast, the differences are smaller in dimensions such as work and school, treatment, and thinking about the future.

Tabel 1: Sociodemographic Characteristics of the Study Participants

Variables		**Frequency**	**Percent**
Age	18-23	37	41.1
	24-29	14	15.6
	30-35	11	12.2
	36-41	11	12.2
	42 and above	17	18.9
Mean (Std. Deviation): 30.16 (12.281)			
Educational level	Illiterate	8	8.9
	Able to read and write	7	7.8
	Primary school	8	8.9
	Intermediate school	14	15.6
	Secondary school	21	23.3
	Institute	12	13.3
	College and above	20	22.2
Marital status	Single	49	54.4
	Married	39	43.3
	Separated	2	2.2
Occupational status	Governmental employe	15	16.7
	Nongovernmental employe	30	33.3
	Student	24	26.7
	Unemployed (health reason)	19	21.1
	Retired	2	2.2
Socioeconomic status	poor	24	26.7
	good	55	61.1
	high	11	12.2
Total		90	100.0

Table 2: Descriptive Statistics of Clinical Data

Variables		Frequency	Percent
Hemophilia type	Hemophilia A	79	87.8
	Hemophilia B	9	10.0
	Acquired Hemophilia	2	2.2
Disease Severity	Mild	34	37.8
	Moderate	29	32.2
	Severe	27	30.0
Self-assessed health	Very good	2	2.2
	Good	48	53.3
	Fair	25	27.8
	Poor	14	15.6
	Very poor	1	1.1
How long have you been seen by a hematologist?	Up to 1 year	1	1.1
	2-4years	1	1.1
	5–7 years	3	3.3
	8–10 years	7	7.8
	More than ten years	78	86.7
Does the hematologist inform you about the features of your disease?	Yes	88	97.8
	No	2	2.2
How many times have you been treated in Nanakali hospital during the last year?	One time	15	16.7
	Two-three times	12	13.3
	Four-six times	11	12.2
	More than 6 times	52	57.8
Treatment Regimen	Prophylaxis	34	37.8
	OnDemand	56	62.2
How do you satisfy the organization of medical care?	Somewhat Satisfactory	6	6.7
	Good Satisfactory	36	40.0
	Excellent	48	53.3
Do you have any chronic disease?	Yes	8	8.9
	No	82	91.1
If yes, mention it	Hypertension	3	37.5
	Hepatitis B virus	2	25.0
	Asthma	1	12.5
	Hepatitis C virus	1	12.5
	Epilepsy	1	12.5

Table 3: Mean Scores and Internal Consistency of The Dimensions That Comprise the Health-Related Quality of Life of Hemophilic Patients at Nanakali Hospital

Dimension	n	Mean	Minimum	Maximum	Standard deviation	Cronbach's alpha coefficient
Physical Health	90	2.80	1.00	4.80	0.91	0.89
Feeling Because of Hemophilia	90	2.84	1.00	4.75	0.87	0.79
Self-Perception	90	3.16	1.00	4.40	0.56	0.32
Sports and Leisure	90	3.65	1.60	5.80	0.54	0.17
Work and School	90	3.81	2.25	6.00	1.16	0.83
Dealing with Hemophilia	90	2.81	1.00	4.67	0.74	0.76
Treatment	90	3.21	2.25	4.50	0.47	0.58
Thinking About the Future	90	3.04	1.20	4.20	0.68	0.53
Family Planning	90	3.85	1.00	6.00	2.35	0.98
Partnership and Sexuality	90	2.49	1.00	6.00	2.15	0.99
Total	90	3.16	1.33	5.112	1.04	0.684

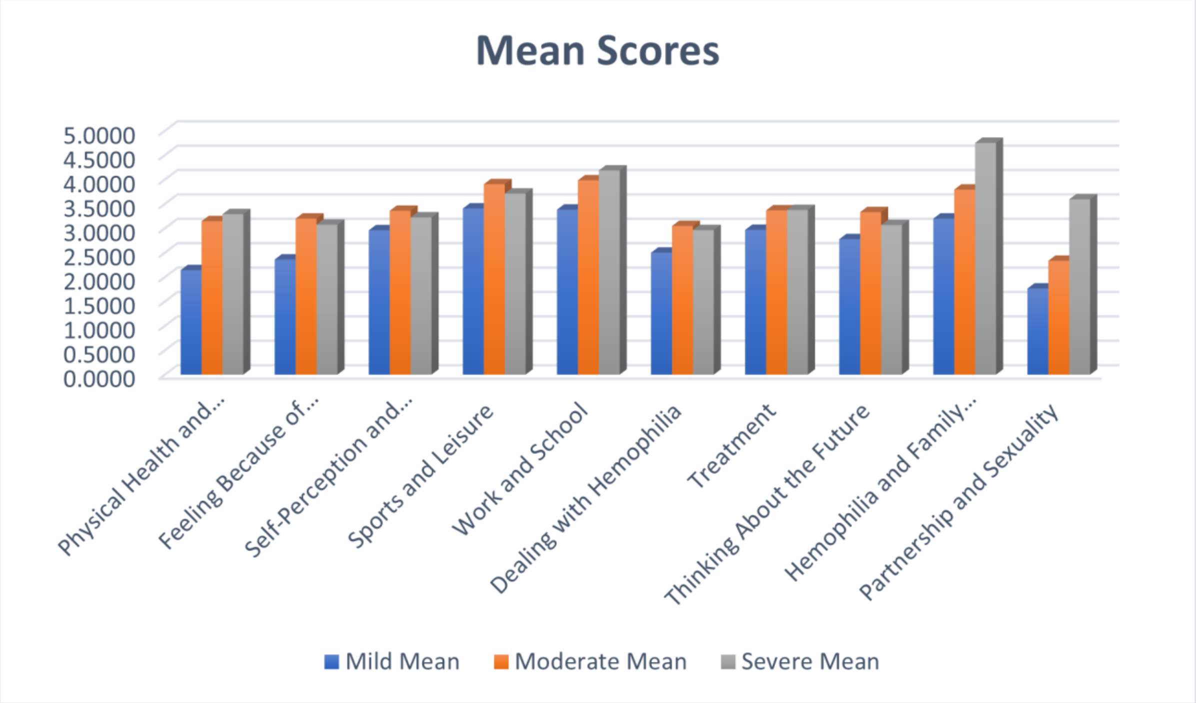

Figure 1 Mean Scores for Health-Related Quality of Life Dimensions by Disease Severity

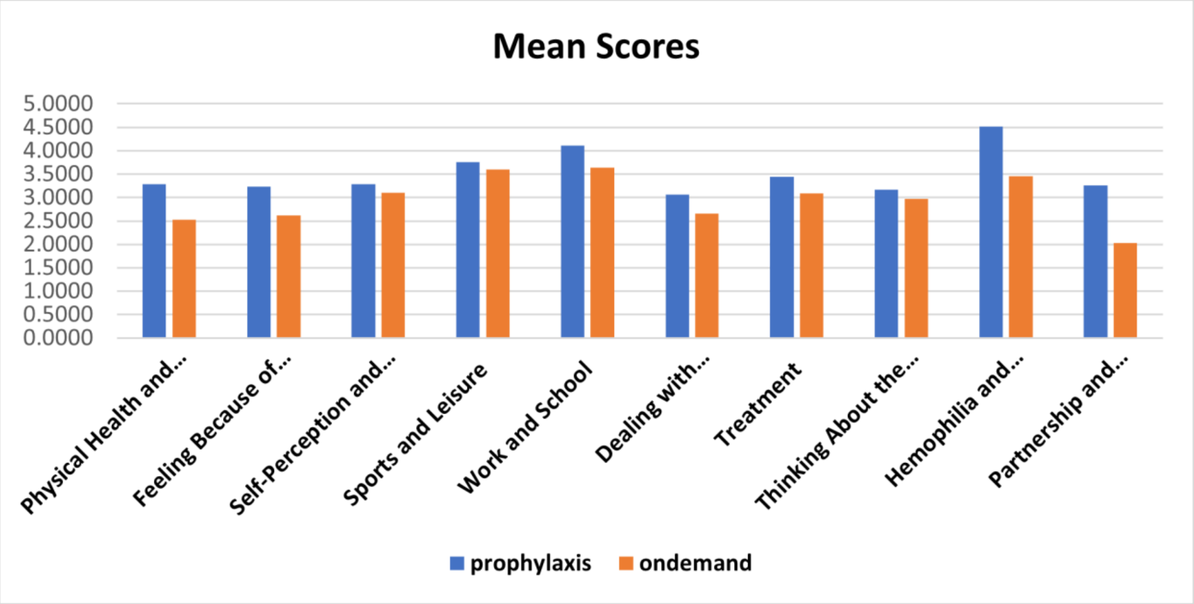

Figure 2 Mean Scores for Health-Related Quality of Life Dimensions by Treatment Regimen

Discussion

This study assessed health-related quality of life (HRQoL) of adult hemophilic patients in the Nanakali hospital for Blood Disease and Cancer in Erbil City. We analyzed 90 patients who were interviewed. The sociodemographic profile of the participants in the analysis presented in the previous chapter provides essential context for interpreting their health-related quality of life (HRQoL). Regarding age, the majority of participants were young adults aged 18–23 years (41.1%), with a mean age of 30.16 years (SD = 12.281) and a broader age range of 18–72 years. This younger age distribution may account for the relatively better health-related quality of life (HRQoL) observed in certain domains, such as mobility and independence. This is because older age has been linked to a higher incidence of joint complications and chronic pain in patients with hemophilia. Compared to the study done at the Ethiopian Hemophilia Treatment Centre, the backgrounds of participants in our study are quite different, which could affect HRQoL results (Iyar et al., 2024). Additionally, this demographic profile is consistent with the study conducted in 2023 by Abdulrahman and Eissa in Duhok, Iraq, which found that the mean age of participants was 27.85 years, close to the mean age of 30.16 years in the current sample, indicating a young adult population across both cohorts (Abdulrahman and Eissa, 2023).The educational attainment in the current study was relatively high, with nearly half of the participants having completed secondary education or higher. This level of education may enhance health literacy and self-management behaviors, potentially influencing their engagement with healthcare services. Specifically, about 55.5% of participants had finished secondary school or obtained a higher degree, which could lead to greater awareness of health issues, an increased likelihood of seeking medical attention, and higher satisfaction with the services received. However, it is important to note that the Ethiopian cohort had a larger proportion of participants with limited formal education. These differences in education were strongly linked to lower health-related quality of life (HRQoL) scores, especially in areas like physical health and access to treatment (Iyar et al., 2024). Concerning the occupational state, a significant proportion were either employed in non-governmental roles (33.3%) or were students (26.7%), while 21.1% were unemployed due to health reasons. This variation in employment status reflects the socioeconomic burden that hemophilia can impose, particularly in cases with more severe symptoms or complications.

Occupational status differed significantly between the current study and the one conducted in 2024, which reported a high rate of unemployment, particularly due to health complications. In contrast, our study found that 76.6% of participants were either employed or currently studying (Iyar et al., 2024). Regarding marital status, data indicates that a significant percentage of participants were single (54.4%), while 43.3% were married and 2.2% were separated. Health challenges can influence personal relationships and family planning decisions. Another study found that a larger number of people with severe hemophilia were unmarried (74.03%) compared to those with mild or moderate hemophilia (54.79%), which may suggest that those with more severe disease face more social or physical challenges to getting married (Niu et al., 2022). In relation to the socio-economic status distribution, the current study indicates that 61.1% consider their position as good, while 26.7% consider it poor, and 12.2% consider it high. Economically, the Brazilian cohort showed significant financial constraints: over 51% reported a personal income of up to one minimum wage, and only 12.8% had a monthly income above three minimum wages (Ferreira et al., 2013). Concerning the types of hemophilia in the current study, the majority (87.8%) have hemophilia A, while 10% have hemophilia B, and a small percentage (2.2%) have acquired hemophilia. The severity of the disease is distributed among mild (37.8%), moderate (32.2%), and severe (30.0%) cases. There is a significant connection between the levels of severity and lower health-related quality of life (HRQoL), primarily due to more frequent bleeding events, joint damage, and physical limitations. These findings are consistent with the study conducted by Rambod et al. (2018) in Iran, which also reported that 88.2% of participants had hemophilia A. In terms of disease severity, a higher proportion of participants (52.5%) had severe hemophilia, with more severe cases linked to increased bleeding episodes, greater joint damage, higher reliance on treatment, and more physical and mental distress (Rambod et al., 2018). An additional study conducted in 2024 in Denmark examined a group of adult patients with bleeding disorders and found that hemophilia A was more common than hemophilia B. Among the 149 patients with bleeding disorders in that study, 50% had hemophilia A and 11% had hemophilia B. The remaining patients (39%) had von Willebrand disease. Furthermore, disease severity among hemophilia patients was reported as follows: for hemophilia A, 49% had mild severity, 10% moderate, and 37% severe. For hemophilia B patients in the sample, 56% had mild, 16%

moderate, and 28% severe cases (Clausen et al., 2024). More than half of the patients (53.3%) rated their health as good, while 27.8% considered it fair, and 16.7% described it as poor. This finding aligns with a study published in the Journal of Clinical Medicine, which noted that a significant proportion of patients rated their overall health status as average, despite experiencing functional limitations and symptoms that impacted their daily routines (Sremic et al., 2024). Additionally, this study corresponds with the majority of positive self-assessment findings, indicating that 77.2% of hemophilia A patients rated their current health as good or very good, while 19.3% rated it as satisfactory (Muhlbacher et al., 2020). Regarding the duration of care by a hematologist, the current study found that a significant majority (86.7%) of patients have been under hematological care for more than ten years. This indicates a long duration since diagnosis and highlights sustained access to specialized care. Living with this condition for an extended period emphasizes the need for effective long-term treatment. Similarly, a study conducted by Iyar et al. reported that 77.1% of patients had been diagnosed for over ten years. This finding underscores the importance of recognizing that a longer duration since diagnosis is associated with decreased health-related quality of life (HRQoL) (Iyar et al., 2024). When it comes to the use of health services, 57.8% of patients were treated more than six times at Nanakali Hospital at the previous year frequency might be affected by treatment regimen, disease severity, and proximity to healthcare facilities. This result is similar to the study showed that majority of participants (47.1%) reported visiting the hemocenter between 6 to 10 times in the past year (Trindade et al., 2019). In my study, 62.2% followed an on-demand treatment regimen, while 37.8% received prophylaxis a lesser number of patients in this research received prophylaxis treatment, and the majority of therapies used were on-demand, which may be associated with limited accessibility or cost limitations. Also, these findings in the present study can be contrasted with the results of Mühlbacher et al. (2020), where 73.7% of patients preferred regular drug administration (prophylactic treatment), while only 26.3% selected on-demand therapy (Muhlbacher et al., 2020). Chronic diseases were informed in the current research by 8.9% of patients, with hypertension most common (37.5%), followed by hepatitis B (25%), and asthma, hepatitis C, and epilepsy were affected by 12.5%. Lower HRQoL among hemophilic patients living with the disease for a longer time could be explained mainly due to the progression and worsening of the disease conditions and disability. The finding conducted by Trindade et al. in (2019) showed that more than half of the participants (58.8%) reported no comorbidities, while 41.2% had at least one co-existing health condition. Among those with comorbidities, the most common were arterial hypertension and depression, followed by asthma, heart disease, and osteomuscular disease (Trindade et al., 2019). In our study the findings emphasize the multifaceted impact of hemophilia on the health-related quality of life (HRQoL) of adult patients. The research indicates that adult hemophilia patients experience moderate to poor health-related quality of life across several domains. The highest impairments were found in the dimensions (physical health, self-perception, emotional impact, sports and leisure, work and school. On the other hand, the best scores in HRQoL were related to treatment satisfaction, dealing with hemophilia, the future, family planning, partnership, and sexuality. Physically, many report joint pain, movement difficulties, and daily activity limitations. Emotionally, patients frequently feel burdened, worried, frustrated, or excluded due to their condition. Participation in sports and leisure activities is significantly restricted, often requiring careful planning and limiting spontaneity. Based on the results of this research, it can be said that patients show moderate awareness of their condition, though few feel fully in control during bleeding episodes. Treatment dependence among patients is significant, as many rely on factor concentrates and medical support. Despite this reliance, overall satisfaction with the care they receive is generally positive. Overall, the condition imposes considerable physical and emotional burdens, but many patients adapt and manage aspects of daily life effectively. Several studies conducted throughout different countries have evaluated the quality of life in adult patients with hemophilia using various instruments. Notably, Custodio et al. indicated that the patients showed the worst performances in the domains of “sports and leisure and physical health, reflected by the high scores obtained, indicating greater impairment in HRQoL and across all age groups in both HA and HB, where a large proportion of patients indicated that hemophilia limited their physical mobility, participation in sports, and spontaneous social activities, ultimately impacting their overall well-being and independence (Custodio et al., 2022). Similar to a study conducted in Greece, it was one of the first to provide evidence on HRQoL in patients with hemophilia, comparing it with normative data from a corresponding male population. It indicated that people with hemophilia experience considerable diminished quality of life, as measured by the Haem-A-QoL disease-specific instrument, with a higher impact on physical health (PH) and sports/leisure (SL) domains (Varaklioti et al., 2018). Additionally, physical health was identified as the second most affected domain in both our study and the study by Ferreira et al. (2013). In addition, our result, similar to the score from a study conducted in Duhok, Iraq, showed that hemophilic patients experienced significant impairment of QoL, particularly after developing arthropathy and restricting physical activity (Abdulrahman and Eissa, 2022). On the other hand, the study by Allhaidan et al. reported that the average HAEMO-QoL-A total score was 99.89, ranging from 44 to 146. The "treatment concerns" dimension had the lowest average score, which indicates a worse QoL, while the "work/school, family, and social life" dimension was the least affected among the participants (Allhaidan et al., 2018). Another aspect that should not be overlooked is the treatment regimen. Our study indicates that the average scores for health-related quality of life factors among hemophilic patients vary according to their medical regimen (on-demand vs. prophylactic). When comparing patients on an on-demand regimen to those on prophylaxis, the latter generally report higher scores across most categories. Notably, physical health, coping with hemophilia, family planning, and partnership/sexuality exhibit the most significant differences, with prophylactic patients consistently scoring higher. Prophylaxis is primarily administered to severe cases. This observation is supported by a study conducted in Sweden, which found that prophylaxis is predominantly utilized for severe cases (96.4%), with some application in moderate cases. This evidence suggests that treatment strategies are tailored based on each individual's bleeding risk and frequency, while on-demand treatment is typically preferred for mild cases (Lindvall et al., 2012).

Conclusion

In conclusion, this study highlights health-related quality of life among patients with hemophilia. The findings emphasize the multidimensional nature of hemophilia management, demonstrating that the quality of clinical care significantly impacts the overall quality of the patient's life. Age was identified as a crucial factor influencing both quality of life ($p = 0.029$) and access to health services ($p = 0.001$), while marital status was found to affect quality of life ($p = 0.005$). Patients with hemophilia face considerable physical, emotional, and social challenges, including limitations in sports participation, dependence on treatment, and concerns about the future. These findings highlight the importance of a comprehensive approach to hemophilia care that considers not only the medical aspects but also the emotional and psychological challenges associated with living with the condition.

Recommendations

- To evaluate the HRQoL in hemophilia patients, long-term research including big samples can be conducted.
- Qualitative research can support additional investigations into HRQoL perception among hemophilia patients.
- Researchers can explore how healthcare professionals perceive hemophilia.
- Comparative research can help to evaluate HRQoL in hemophilia as well as in healthy adults.

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Conflicts of Interest

The authors declare that there are no conflicts of interest related to this work.

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