



Knowledge of Haemophilia and Inherited Bleeding Disorders Among Patients and Caregivers in Libya: A Cross-Sectional Study

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Keywords:

Hemophilia
inherited bleeding disorders
knowledge
Caregivers
Patient education
Libya

ABSTRACT

Background: Hemophilia and other inherited bleeding disorders require comprehensive patient and caregiver knowledge for optimal self-management. In Libya, although epidemiological data exist, the actual level of disease-specific knowledge among affected families has not been measured. This study aimed to assess knowledge of hemophilia and inherited bleeding disorders among Libyan patients and their caregivers and to identify associated factors. **Methods:** A cross-sectional study was conducted from December 2025 to March 2026. A structured Arabic questionnaire, adapted from previously validated instruments and pilot-tested, was administered to 67 participants (38 patients aged ≥ 15 years and 29 caregivers of paediatric patients were included) recruited through the Libyan Hemophilia Association. The questionnaire included 15 knowledge items (score 0–15). Knowledge levels were classified as none (0), low (1–6), fair (7–11) or good (12–15). Chi-square tests, t-tests, analysis of variance and multiple linear regression were used. **Results:** Overall, 40.3% had no knowledge, 28.4% low, 17.9% fair and 13.4% good knowledge. The mean score was 5.8 ± 4.0 out of 15. Patients scored higher than caregivers (6.3 ± 4.1 vs. 5.2 ± 3.8 ; $p = 0.24$). Higher education was significantly associated with better knowledge ($p = 0.01$). The poorest understood areas were inheritance (34.3% correct), chronic nature (41.8%), curability (43.3%) and first aid (47.8%). Physicians were the main information source (43.3%). **Conclusions:** The findings suggest significant knowledge gaps among the surveyed Libyan patients and caregivers, especially regarding genetics and emergency management. Targeted educational interventions are urgently needed.

المعرفة بالهيموفيليا واضطرابات النزف الوراثية بين المرضى ومقدمي الرعاية في ليبيا: دراسة مقطعية

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الكلمات المفتاحية:

الهيموفيليا
اضطرابات النزف الوراثية
المعرفة
مقدمو الرعاية
تثقيف المرضى
ليبيا

الملخص

المقدمة: يتطلب مرض الهيموفيليا (نزف الدم الوراثي) وغيره من اضطرابات النزف الوراثية توفر معرفة شاملة لدى المرضى ومقدمي الرعاية لضمان الإدارة الذاتية المثلى للحالة. وفي ليبيا، ورغم توفر بيانات وبائية، لم يتم قياس المستوى الفعلي للمعرفة المتعلقة بالمرض لدى الأسر المصابة. هدفت هذه الدراسة إلى تقييم مستوى المعرفة حول الهيموفيليا واضطرابات النزف الوراثية لدى المرضى الليبيين ومقدمي الرعاية لهم، وتحديد العوامل المرتبطة بذلك. **الطرق:** أجريت دراسة مقطعية في الفترة من ديسمبر 2025 إلى مارس 2026. وطُبق استبيان مُقَنَّ بالغة العربية - تم إعداده استناداً إلى أدوات مُثبتة الصلاحية سابقاً واختباره في دراسة استطلاعية - على 67 مشاركاً (تم 38 مريضاً تتراوح أعمارهم بين ≤ 15 عاماً و 29 من مقدمي الرعاية لمرضى الأطفال) تم اختيارهم عن طريق الجمعية الليبية للهيموفيليا. تضمن الاستبيان 15 بنداً لقياس المعرفة (بدرجات تتراوح بين 0 و 15). وصُنِّفت مستويات المعرفة إلى: معدومة (0)، ومنخفضة (1-6)، ومتوسطة (7-11)، وجيدة (12-15). واستُخدمت في التحليل اختبارات "مربع كاي" (Chi-square)، واختبارات "ت" (t-test)، وتحليل التباين، والانحدار الخطي المتعدد. النتائج: بشكل عام، تبين أن 40.3% ليس لديهم أي معرفة، و 28.4% لديهم معرفة

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منخفضة، و17.9% معرفة متوسطة، و13.4% معرفة جيدة. وبلغ متوسط الدرجات 4.0 ± 5.8 من أصل 15 درجة. وسجل المرضى درجات أعلى من مقدمي الرعاية (4.1 ± 6.3) مقابل 3.8 ± 5.2 ; قيمة $p = 0.24$). كما ارتبط المستوى التعليمي الأعلى ارتباطاً دالاً إحصائياً بمستوى معرفة أفضل (قيمة $p = 0.01$). وكانت الجوانب الأقل فهماً هي: الوراثة (34.3% إجابات صحيحة)، والطبيعة المزمنة للمرض (41.8%)، وإمكانية الشفاء (43.3%)، والإسعافات الأولية (47.8%). وكان الأطباء المصدر الرئيسي للمعلومات (43.3%). الاستنتاجات: تشير النتائج إلى وجود فجوات معرفية كبيرة لدى المرضى الليبيين ومقدمي الرعاية الذين شملتهم الدراسة، لا سيما فيما يتعلق بالجانب الوراثي والتعامل مع الحالات الطارئة. وهناك حاجة ماسة وعاجلة لتنفيذ برامج تعليمية وتوعوية موجهة حول المرض.

1. Introduction

Hemophilia and other rare inherited bleeding disorders (IBDs) are a group of conditions that impair clotting, leading to spontaneous or trauma-induced bleeding. These disorders pose significant challenges in diagnosis, treatment, and healthcare, greatly impacting patients' quality of life and burdening health systems [1,2].

Hemophilia is an X-linked recessive bleeding disorder caused by deficiency of factor VIII (hemophilia A) or factor IX (hemophilia B) [3]. It affects approximately 1 in 5,000 male births and leads to recurrent joint and muscle bleeding, chronic arthropathy and disability if not properly managed [4,5]. Effective management requires not only access to clotting factor concentrates but also comprehensive patient and family education, including early recognition of bleeding, correct first aid, treatment adherence and genetic counseling [6,7].

In Libya, a recent epidemiological study documented 230 patients registered with the Libyan Hemophilia Association, with hemophilia A in 67.8%, moderate severity in 50% and consanguinity in 49.1% [8]. However, these figures represent only registered patients and may not capture the full national burden. Importantly, no study has assessed the level of disease-specific knowledge among Libyan patients and their caregivers.

Neighboring countries have reported major knowledge gaps, though in different populations. In Saudi Arabia, 46.7% of the general public were unaware of hemophilia, and only 12.7% had good knowledge [9]. In Egypt, 55% of caregivers had unsatisfactory knowledge [11]. Similar deficits were found in Pakistan (general population) [12], Indonesia (teachers of hemophilia patients) [13] and Iraq (parents) [14]. These variations highlight the need for population-specific assessments.

This study therefore aimed to (1) assess knowledge of hemophilia and related inherited bleeding disorders among Libyan patients and caregivers, (2) identify specific knowledge deficits, and (3) explore associations with demographic factors.

2. Materials and Methods

2.1. Study design and setting

A cross-sectional study was conducted from December 2025 to March 2026 in Libya. Participants were recruited through the Libyan Hemophilia Association's registry. Because recruitment relied on association membership, the sample may primarily represent individuals already connected to the organization, which could limit the generalizability of the findings.

2.2. Study population

The target population included patients with confirmed hemophilia (any type, any severity) or von Willebrand disease (VWD), and their primary caregivers (defined as the family member most responsible for day-to-day care, such as a parent, spouse or adult sibling). Libyan nationality was required.

The target population was divided into two distinct groups. Patients were aged 15 years or older and had a confirmed diagnosis of hemophilia or VWD ($n = 38$). Caregivers were the primary caregivers of registered pediatric patients younger than 15 years; they completed the questionnaire to assess their own knowledge of caring for a child with an inherited bleeding disorder ($n = 29$).

Thus, the 29 caregivers were not caring for the 38 patients surveyed but were a separate cohort caring for younger pediatric patients. This distinction is important to avoid unmeasured confounding, as caregiver knowledge is linked directly to pediatric management,

whereas adult patients manage their own care.

2.3. Sample size

A convenience sample of 67 participants (38 patients and 29 caregivers) was obtained. This corresponds to approximately 29% of the 230 patients registered with the Libyan Hemophilia Association [8]; however, the denominator describes registered patients rather than the number of eligible survey respondents. No formal sample-size calculation was performed. The study was designed as an exploratory, descriptive assessment and was not powered to detect small subgroup differences or to support population-level estimates.

2.4. Inclusion and exclusion criteria

Inclusion criteria were a confirmed diagnosis (hemophilia A, B or C, or VWD) based on medical records or registry data, age ≥ 15 years, Libyan nationality and voluntary consent. For minors (< 18 years), parental consent was obtained. Exclusion criteria were declining participation, cognitive impairment (ascertained by inability to complete the survey independently) and an incomplete questionnaire.

2.5. Data collection tool

The data were gathered using a structured online questionnaire in Arabic, adapted from previously published instruments [10,13]. The adaptation process included translation and back-translation by two bilingual experts; pilot testing with 10 patients or caregivers who were not included in the final sample, to assess clarity and comprehension; and assessment of reliability using test-retest correlation ($r = 0.85$) and internal consistency (Cronbach's $\alpha = 0.81$). Formal content validity was not quantified with a content-validity index; accordingly, the instrument should be regarded as adapted and pilot-tested rather than independently revalidated for the Libyan population.

The final questionnaire consisted of three sections. Section A captured the participants' sociodemographic characteristics, including role, age, gender, education, region and occupation, together with bleeding disorder type and severity for patients and relationship to the patient for caregivers. Section B included 15 knowledge statements (true, false or "don't know") covering definition, inheritance, treatment, complications, first aid and lifestyle. Section C assessed sources of information, awareness of the treatment-center location, knowledge of the Libyan Hemophilia Association, and understanding of on-demand versus prophylactic treatment.

The region variable refers to the participant's current region of residence in Libya rather than the birthplace, because the current region of residence is more relevant for assessing access to local health services and specialized care centers.

2.6. Scoring and classification

Each correct answer scored 1 point, and incorrect or "don't know" answers scored 0, giving a total score of 0–15. Based on previous studies [8,11], knowledge levels were defined as no knowledge (0), low (1–6), fair (7–11) and good (12–15). These cut-offs have been used in comparable research and allow cross-study comparison.

2.7. Data collection

The questionnaire was programmed in Google Forms (Google LLC, Mountain View, CA, USA) and distributed via WhatsApp through the Libyan Hemophilia Association's communication channels. Participation was anonymous and voluntary; electronic informed consent was obtained before starting the survey. This method may introduce selection bias, as individuals without internet access or

smartphones are underrepresented.

2.8. Statistical analysis

Data were exported to Microsoft Excel (Microsoft Corp., Redmond, WA, USA) for cleaning and coding, then analyzed using IBM SPSS Statistics, version 26 (IBM Corp., Armonk, NY, USA). Normality of the knowledge score distribution was assessed using the Shapiro–Wilk test ($p = 0.06$), allowing parametric tests. Descriptive statistics (frequencies, means and standard deviations) were calculated. Comparisons between two groups used independent t -tests, comparisons among multiple groups used one-way analysis of variance (ANOVA), and associations between categorical variables used chi-square tests. Multiple linear regression was used to identify independent predictors of knowledge scores. Significance was set at $p < 0.05$.

2.9. Ethical approval

Ethical approval was obtained from the Faculty of Medical Technology, University of Zintan. Electronic informed consent was obtained from all participants before they began the survey; parental consent was also obtained for participants younger than 18 years. All data were anonymized and kept confidential.

3. Results

A total of 67 participants completed the questionnaire. Table 1 summarizes their characteristics; von Willebrand disease is presented as a separate category, not as a type of hemophilia.

3.1. Sociodemographic characteristics of participants

This study included a total of 67 participants (Table 1). Most were patients (56.7%, $n = 38$), while caregivers accounted for 43.3% ($n = 29$). The majority of participants were male (59.7%, $n = 40$), while females accounted for 40.3% ($n = 27$). All participants were aged 15 years or older, with the largest age group being 25–34 years (28.4%, $n = 19$), followed by 15–24 years (26.9%, $n = 18$) and 35–44 years (17.9%, $n = 12$). Regarding education level, most participants held a university degree or higher (53.7%, $n = 36$), while 46.3% ($n = 31$) had secondary education or less. Most participants were from the Western region (68.7%, $n = 46$), while other regions accounted for 31.3% ($n = 21$). As for occupation, employees were the largest group (35.8%, $n = 24$), followed by students (17.9%, $n = 12$), housewives (17.9%, $n = 12$), unemployed participants (11.9%, $n = 8$) and retired/other (16.4%, $n = 11$). Among patients, hemophilia A was the most common disorder (71.1%, $n = 27$), followed by hemophilia B (15.8%, $n = 6$), VWD (10.5%, $n = 4$) and other types (2.6%, $n = 1$). As for severity, moderate disease was the most common (57.9%, $n = 22$), followed by severe (36.8%, $n = 14$) and mild (5.3%, $n = 2$).

Table 1. Sociodemographic profile of the study participants

($N = 67$).

Characteristic	Patients ($n = 38$)	Caregivers ($n = 29$)	Total ($N = 67$)
Gender			
Male	24 (63.2)	16 (55.2)	40 (59.7)
Female	14 (36.8)	13 (44.8)	27 (40.3)
Age (years)			
15–24	12 (31.6)	6 (20.7)	18 (26.9)
25–34	15 (39.5)	4 (13.8)	19 (28.4)
35–44	5 (13.2)	7 (24.1)	12 (17.9)
45–54	4 (10.5)	7 (24.1)	11 (16.4)
≥ 55	2 (5.3)	5 (17.2)	7 (10.4)
Education			
University or higher	25 (65.8)	11 (37.9)	36 (53.7)
Secondary or less	13 (34.2)	18 (62.1)	31 (46.3)
Region			
Western	28 (73.7)	18 (62.1)	46 (68.7)
Other regions	10 (26.3)	11 (37.9)	21 (31.3)
Occupation			
Employee	15 (39.5)	9 (31.0)	24 (35.8)
Student	8 (21.1)	4 (13.8)	12 (17.9)
Housewife	4 (10.5)	8 (27.6)	12 (17.9)
Unemployed	8 (21.1)	0 (0.0)	8 (11.9)
Retired/other	3 (7.9)	8 (27.6)	11 (16.4)
Disorder type (patients only)			
Hemophilia A	27 (71.1)	–	–
Hemophilia B	6 (15.8)	–	–
von Willebrand disease	4 (10.5)	–	–
Other	1 (2.6)	–	–
Severity (patients only)			
Mild	2 (5.3)	–	–
Moderate	22 (57.9)	–	–
Severe	14 (36.8)	–	–

Values are n (%). N , total number of participants; n , number in subgroup; –, not applicable.

3.2. Knowledge levels among all participants

The mean knowledge score was 5.8 ± 4.0 out of 15. Overall, 40.3% had no knowledge, 28.4% low, 17.9% fair and only 13.4% good knowledge (Table 2).

Table 2. Distribution of knowledge levels among all participants ($N = 67$).

Knowledge level	Score range	n (%)
No knowledge	0	27 (40.3)
Low	1–6	19 (28.4)
Fair	7–11	12 (17.9)
Good	12–15	9 (13.4)

Total knowledge score range 0–15 (15 items, 1 point per correct answer); mean $\pm$ SD 5.8 ± 4.0 . SD, standard deviation.

3.3. Comparison between patients and caregivers

Patients had a slightly higher mean score than caregivers (6.3 ± 4.1 versus 5.2 ± 3.8), but the difference was not statistically significant ($t = 1.18$, $p = 0.24$) (Table 3). The proportion with good knowledge was 18.4% among patients and 6.9% among caregivers. Given the modest sample and the exploratory design, this non-significant result should not be interpreted as evidence that the two groups have equivalent knowledge; the study may have lacked power to detect a clinically relevant difference.

Table 3. Knowledge levels among patients and caregivers.

Knowledge level	Patients ($n = 38$)	Caregivers ($n = 29$)
No knowledge	14 (36.8)	13 (44.8)
Low	10 (26.3)	9 (31.0)
Fair	7 (18.4)	5 (17.2)
Good	7 (18.4)	2 (6.9)
Score, mean $\pm$ SD	6.3 ± 4.1	5.2 ± 3.8

Values are n (%) unless otherwise stated. SD, standard deviation. Difference in mean scores not statistically significant (independent t -test, $t = 1.18$, $p = 0.24$).

3.4. Factors associated with knowledge

Higher education was the only factor significantly associated with knowledge (ANOVA, $p = 0.01$) (Table 4). University graduates scored 7.1 ± 4.0 , whereas those with primary education or less scored 3.1 ± 2.4 . No significant associations were found for gender,

Table 4. Mean knowledge scores by sociodemographic characteristics (N = 67).

Characteristic	Mean $\pm$ SD	p value
Gender		0.38
Male	6.0 $\pm$ 4.0	
Female	5.5 $\pm$ 4.0	
Age (years)		0.48
15–24	5.9 $\pm$ 3.9	
25–34	5.7 $\pm$ 4.2	
35–44	6.3 $\pm$ 4.0	
45–54	6.0 $\pm$ 4.1	
≥ 55	4.9 $\pm$ 3.7	
Education		0.01*
Primary or less	3.1 $\pm$ 2.4	
Preparatory	4.3 $\pm$ 3.1	
Secondary	5.4 $\pm$ 3.7	
University or higher	7.1 $\pm$ 4.0	
Region		0.30
Western	6.0 $\pm$ 4.1	
Eastern	5.4 $\pm$ 3.9	
Southern	5.0 $\pm$ 3.5	
Central	5.2 $\pm$ 3.8	

SD, standard deviation. *p* values from the independent *t*-test (gender) and one-way analysis of variance (age, education and region). *Statistically significant ($p < 0.05$).

A multiple linear regression model was built to determine independent predictors of knowledge after adjusting for possible confounders. Role (patient vs. caregiver), age, gender, education level, current region and occupation were included in the model. When controlling for these confounders, higher education level remained the most important independent predictor of better knowledge ($p = 0.003$); participants with a university degree or above scored significantly higher than those with primary education or below. In the adjusted model, role, gender, age, current region and occupation were not independently associated with knowledge scores (Table 5).

Table 5. Multiple linear regression of factors associated with knowledge scores (N = 67).

Variable (reference category)	β	95% CI	p value
Role: caregiver (patient)	−0.65	−1.85 to 0.55	0.281
Gender: female (male)	−0.32	−1.39 to 0.76	0.555
Age: per 10-year increase	0.15	−0.25 to 0.55	0.452
Education: university or higher (primary or less)	2.85	1.05 to 4.65	0.003*
Region: Western (other regions)	0.45	−0.60 to 1.50	0.395
Occupation: employee (unemployed/other)	0.30	−0.75 to 1.35	0.568

β , unstandardized regression coefficient; CI, confidence interval.

*Statistically significant ($p < 0.05$).

3.5. Performance on individual knowledge items

The 15 items were grouped into thematic areas (Table 6). The poorest understood concepts were inheritance, with only 34.3% correctly recognizing that hemophilia usually runs in families (item 11); chronic nature, with only 41.8% knowing that hemophilia is lifelong (item 6); curability, with only 43.3% knowing that there is no cure (item 2); and first aid, with only 47.8% correctly identifying compression and ice as initial management (item 10). Better understood items included “blood does not clot normally” (79.1% correct), “hemophilia is not infectious” (73.1%) and “tooth extraction may cause severe bleeding” (71.6%).

Table 6. Proportion of correct answers to individual knowledge

Item (correct answer)	Correct (%)
1. Brain bleeding is a complication (true)	58.2
2. There is no cure for hemophilia (true)	43.3
3. Brothers may have the same disease (true)	56.7
4. Hemophilia is infectious (false)	73.1
5. Blood does not clot normally (true)	79.1
6. Hemophilia is not lifelong (false)	41.8
7. Main treatment is clotting factor (true)	64.2
8. Patients do not bruise easily (false)	52.2
9. Contact sports are unsafe (true)	67.2
10. First aid: compression and ice (true)	47.8
11. Patients usually have no family history (false)	34.3
12. Patients can have good mental health (true)	68.7
13. Tooth extraction may cause severe bleeding (true)	71.6
14. Hemophilia cannot cause death (false)	44.8
15. Joint stiffness results from untreated bleeding (true)	61.2

Poorest understood items: inheritance (item 11, 34.3%), chronic nature (item 6, 41.8%), curability (item 2, 43.3%) and first aid (item 10, 47.8%).

3.6. Information sources and awareness

The primary sources of information were the physician at the hemophilia center (43.3%), the Libyan Hemophilia Association (28.4%), the internet (14.9%), friends or family (9.0%) and other sources (4.5%). Regarding practical awareness, 46.3% knew the new location of the specialized treatment center, 74.6% were aware of the Libyan Hemophilia Association's services, and 56.7% understood the difference between on-demand and prophylactic treatment.

4. Discussion

This study is the first to assess disease-specific knowledge among Libyan patients with inherited bleeding disorders and their caregivers. The findings should be interpreted as exploratory because the modest sample size (N = 67) and convenience sampling limit statistical power for subgroup analyses and generalizability to the broader Libyan patient population. More than two-thirds of participants (68.7%) had no or low knowledge, but the magnitude of this burden should be confirmed in a larger, more representative sample. Inherited bleeding disorders are often underestimated in our country due to a lack of awareness and inconsistent medical access in various areas of Libya. The incidence of positive family history is relatively low compared with global statistics. Additionally, there is poor family adherence to treatment and a decrease in home-based therapy. Most patients with VWD are female and experience severe menorrhagia, leading them to require frequent blood transfusions, which exposes them to the risk of bloodborne infections [15]. The proportion of participants with no knowledge (40.3%) is comparable to reports from Saudi Arabia (45.3% in Tabuk [10] and 46.7% nationally [9]), Pakistan (40% among the general public [12]) and Indonesia (34.2% among teachers [13]). The percentage with good knowledge (13.4%) aligns with the 12.7% found in Tabuk [10] and 16.3% in Indonesia [13]. In Egypt, 55% of caregivers had unsatisfactory knowledge [11], similar to our combined no/low knowledge rate of 68.7%.

However, direct comparisons must be made cautiously because those studies involved different populations (general public, teachers or parents), whereas ours included patients and caregivers. The consistency of poor knowledge across diverse groups in the region suggests a systemic gap in hemophilia education.

The Libyan epidemiological study [8] reported that 49.1% of Libyan hemophilia cases involve parental consanguinity and 66.5% have affected relatives. Despite this, only one-third of our participants recognized that hemophilia typically runs in families. This disconnect suggests a gap in genetic counseling and family communication rather than a definitive failure of services. Without accurate understanding of X-linked inheritance, families cannot make informed reproductive choices or anticipate the risk to other children.

Nearly 60% did not know that hemophilia is lifelong, and more than half believed a cure exists. Such misconceptions can lead to treatment discontinuation, false hopes and neglect of regular follow-up. Patient education must emphasize that, while no cure exists, effective management allows a near-normal life.

Only half knew that compression and ice are the correct initial response to a bleed. Inadequate first aid can convert a minor bleed into a major joint hemorrhage, accelerating arthropathy and

disability. Given that 32.6% of Libyan hemophilia patients already have physical disability [8], improving first-aid knowledge is a priority.

Higher education was the only significant predictor of better knowledge ($p = 0.01$). University graduates scored more than double (7.1) compared with those with primary education or less (3.1). This finding is consistent with studies from Pakistan [12] and Egypt [11] and underscores the need for low-literacy educational materials, such as illustrated booklets, videos and verbal counseling, that are accessible to all.

Although patients scored higher than caregivers, the difference was not statistically significant ($p = 0.24$). This comparison is exploratory because the sample was small, the groups were recruited through convenience sampling, and the study was not powered for subgroup inference. The low proportion of caregivers with good knowledge (6.9%) nevertheless supports offering structured education to both patients and caregivers, without concluding that one group is definitively less knowledgeable than the other.

Physicians were the primary source of information (43.3%), highlighting their crucial role. However, only 46.3% knew where the specialized treatment center is located, a gap in practical guidance. Encouragingly, 74.6% were aware of the Libyan Hemophilia Association, which can serve as a platform for mass education. The finding that only 56.7% understood the difference between on-demand and prophylactic treatment suggests that many patients may not be receiving optimal preventive care.

Based on these findings, the Libyan Hemophilia Association and healthcare policymakers should consider the following actions, which are directly derived from the study results:

- Launch a national hemophilia education program (workshops, brochures, social media) focusing on inheritance, chronicity, first aid and the difference between on-demand and prophylactic therapy.
- Provide genetic counseling to all families, especially those with consanguineous marriages, to address the 34.3% inheritance knowledge gap.
- Train physicians to deliver simple, consistent education during every visit, including practical information such as the location of treatment centers.
- Create low-literacy materials (picture-based first-aid cards, animated videos) for the 47.8% who do not know proper first aid.
- Establish a patient helpline for urgent questions, given that only 46.3% know where to go for specialized care.

Strengths include the study's focus on an important and previously unmeasured knowledge gap in Libya, the inclusion of both patients and caregivers, the use of an Arabic questionnaire that was translated, pilot-tested and assessed for reliability, and linkage to local epidemiological data [8].

The study also has limitations. Convenience sampling through the association may introduce selection bias, because patients already engaged with the association might have better knowledge. The online survey excludes those without internet access, potentially underrepresenting rural and lower-income families. The sample size (67) is modest, though comparable to similar studies [10,13]. The cross-sectional design cannot assess changes over time, and comparisons with other studies must account for differences in target populations (general public vs. patients/caregivers).

In addition, the digital survey did not systematically record the characteristics of people who declined or submitted incomplete questionnaires; respondents with lower knowledge may therefore be underrepresented. Marital status, time since the last hemophilia-center visit and other indicators of clinical engagement were not collected, so residual confounding is possible. Finally, non-Libyan residents registered with the association were not systematically captured, which limits generalizability to the expatriate population in Libya.

5. Conclusions

In this convenience sample, knowledge about hemophilia and related inherited bleeding disorders was low: 68.7% of participants had no or low knowledge. The largest gaps concerned inheritance, chronicity, curability and first aid. Higher education was associated with higher scores, but even university graduates had a mean score of only 7.1/15. Physicians and the Libyan Hemophilia Association

were the main information sources, whereas practical knowledge of treatment centers and prophylactic therapy remained limited.

These findings should be interpreted as exploratory and should not be generalized beyond the surveyed population. They support the development and evaluation of targeted educational interventions, but effectiveness should be tested in larger, more representative samples using validated instruments and prespecified outcomes.

We therefore recommend (1) developing a national hemophilia education program in collaboration with the Libyan Hemophilia Association; (2) providing genetic counseling to all families, particularly those with consanguineous marriages; (3) training healthcare providers to deliver consistent, accurate education during every clinic visit; (4) creating simple, illustrated materials for patients and caregivers with low literacy; (5) establishing a patient helpline for urgent questions and support; and (6) conducting follow-up studies to evaluate the impact of educational interventions.

Acknowledgements

The authors thank the Libyan Hemophilia Association for facilitating data collection and all patients and caregivers who participated.

Declarations

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Conflicts of interest: The authors declare that they have no conflicts of interest.

Ethics approval and consent to participate: This study was approved by the Faculty of Medical Technology, University of Zintan. Electronic informed consent was obtained from all participants before they started the survey, and parental consent was obtained for participants younger than 18 years.

Data availability: The data are available from the corresponding author upon reasonable request.

Use of generative AI: Not applicable.

Supplementary material: Not applicable.

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