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Review Article

Quality of Life of Persons Living with Bleeding Disorders in Africa: A Scoping Review

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Abstract

Background: Bleeding disorders such as haemophilia, von Willebrand disease, and other rare coagulation disorders are lifelong conditions that significantly affect physical, psychological, and social wellbeing. In Africa, limited access to diagnosis, treatment, and comprehensive care may further compromise quality of life (QoL). However, evidence on QoL among persons living with bleeding disorders across the continent remains fragmented.
Objective: This scoping review aims to map existing evidence on the quality of life of persons living with bleeding disorders in Africa, identify key determinants and gaps, and highlight implications for policy and future research.
Methods: The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Eligibility criteria were guided by the Population–Concept–Context (PCC) framework. We included studies involving persons with bleeding disorders in African settings reporting QoL outcomes. Searches were performed in PubMed/MEDLINE, Scopus, Web of Science, African Journals Online (AJOL), and grey literature. Data were charted and synthesized descriptively.
Results: A total of 21 studies were included, representing Nigeria, South Africa, Kenya, Cameroon, and Egypt. QoL domains assessed included physical functioning, pain, mental health, and social relationships. Common instruments used were WHOQOL-BREF, SF-36, EQ-5D-5L, and Haem-A-QoL. QoL was generally moderate to low, influenced by pain, joint damage, treatment burden, and limited access to comprehensive care. Few studies addressed paediatric populations or women, and certain domains such as sleep, energy, and leisure activities were under-assessed.
Conclusion: Persons with bleeding disorders in Africa experience moderate to low QoL, constrained by limited access to care and treatment burden. Region-specific interventions, culturally adapted QoL measurement tools, and patient-centred care models are critical to improving outcomes and informing health policy.

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1. Introduction

Bleeding disorders are inherited or acquired conditions characterized by impaired haemostasis, leading to prolonged or spontaneous bleeding. Common disorders include haemophilia A and B, von Willebrand disease, and rare factor deficiencies. These conditions require lifelong management and are associated with complications such as chronic pain, joint disease, disability, and psychosocial distress.

Quality of life (QoL) has become an increasingly important outcome in bleeding disorder management, reflecting physical, psychological, social, educational, occupational, and economic wellbeing [1–3]. In high-income countries, access to clotting factor concentrates and comprehensive care has improved QoL. In contrast, many African countries face limited diagnostic, therapeutic, and multidisciplinary care capacity, potentially compromising QoL [4].

Existing studies in Africa are small, heterogeneous, and geographically limited. There is no comprehensive synthesis of evidence describing QoL among persons with bleeding disorders across the continent. A scoping review is therefore warranted to map available evidence, identify gaps, and inform policy and research agendas.

Objective: To systematically map the literature on quality of life among persons living with bleeding disorders in Africa.

2. Methods

2.1. Study Design

This review employed a scoping review methodology in line with Joanna Briggs Institute (JBI) guidance, reported according to the PRISMA-ScR checklist [5].

2.2. Eligibility Criteria (PCC Framework)

- **Population:** Persons of any age living with bleeding disorders, including haemophilia A/B, von Willebrand disease, and rare factor deficiencies.
- **Concept:** Quality of life and related domains: physical, psychological, social, educational, occupational, and economic wellbeing.
- **Context:** African countries, across healthcare and community settings.
- **Inclusion Criteria:** Quantitative, qualitative, or mixed-methods studies. Studies reporting QoL outcomes or determinants. Peer-reviewed articles and relevant grey literature. Conducted in African settings.
- **Exclusion Criteria:** Studies outside Africa, animal studies and articles without QoL outcomes.

2.3. Information Sources and Search Strategy

Databases searched included PubMed/MEDLINE, Scopus, Web of Science, African Journals Online (AJOL), Cochrane Library, Embase, CINAHL, and Google Scholar. Grey literature included reports from haemophilia foundations and international organizations. Search terms combined keywords and MeSH terms related to “bleeding disorders,” “quality of life,” and “Africa.” Reference lists of included studies were screened for additional relevant publications.

Table 1: Search Strategy

S/No	Database	Search Strategy
1	PubMed	”blood coagulation disorders”[MeSH Terms] AND (”quality of life”[MeSH Terms] OR ”quality of life”[Text Word]) AND (”Africa”[MeSH Terms] OR ”Africa”[Text Word])
2	AJOL	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
3	Google Scholar	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
4	Cochrane Library	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
5	Embase	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
6	CINAHL	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
7	Web of Science	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
8	ResearchGate	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa
9	Scopus	blood coagulation disorders AND quality of life OR quality of life AND Africa OR Africa

2.4. Study Selection

All records were imported into Rayyan software. Duplicates were removed. Three reviewers independently screened titles and abstracts, followed by full-text review. Discrepancies were resolved by discussion.

Table 2: PICO Table

Element	Description
Population (P)	Persons living with bleeding disorders in Africa
Intervention / Exposure (I)	Living with a bleeding disorder and receiving available care
Comparison (C)	None or between subgroups (e.g. treated vs untreated vs adults, countries)
Outcome (O)	Quality of life outcomes

2.5. Primary Objective

To map existing evidence on the quality of life of persons living with bleeding disorders in Africa.

2.6. Secondary Objectives

- To identify determinants and domains of quality of life assessed
- To examine measurement tools used to assess QoL
- To identify evidence gaps in research and care
- To inform policy development, health system strengthening, and future research priorities

2.7. Main Research Question

What is known about the quality of life of persons living with bleeding disorders in Africa?

Sub-questions

1. What QoL domains have been assessed?
2. What tools or instruments are used to measure QoL?
3. How do health system factors influence QoL?
4. What gaps exist in evidence across regions, age groups, and disorders?

Data Charting: A standardized extraction form captured: Author, year, country, Study design, sample size, Type of bleeding disorder, QoL measurement tool, Key QoL domains assessed, Main findings, Equity or health system issues

Data Synthesis: Data were synthesized descriptively in tables and narrative form. Emphasis was placed on equity dimensions: access to care, treatment availability, health system capacity, and socioeconomic constraints. No formal risk of bias assessment was performed.

2.8. PRISMA-ScR Flow Diagram

The study selection process is illustrated in Figure 1.

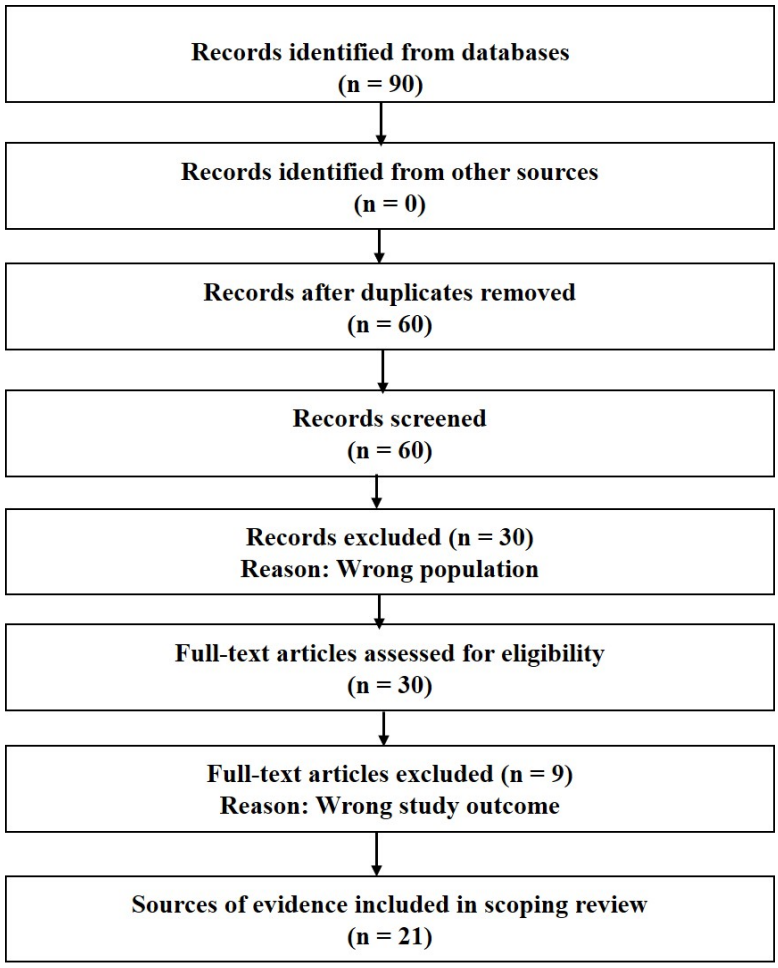

Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Scoping Review (PRISMA-ScR)

2.9. Study Characteristics and Quality of Life Focus

A total of 30 studies were included in this scoping review. Of these, 21 studies (70%) explicitly assessed Quality of Life (QoL) among persons living with bleeding disorders using validated health-related quality of life (HRQoL) instruments, structured questionnaires, or clearly defined psychosocial and functional outcome measures. The remaining 9 studies (30%) focused primarily on clinical management, adherence, laboratory outcomes, or guideline development, with QoL either indirectly inferred or not formally measured.

The QoL-focused studies included diverse populations: children, adolescents, adults, women of reproductive age, and caregivers, and covered a range of bleeding disorders including haemophilia A and B, von Willebrand disease (VWD), inherited bleeding disorders, afibrinogenemia, and heavy menstrual bleeding (HMB). Most studies employed cross-sectional or observational designs, with only a few prospective or interventional studies evaluating changes in QoL following prophylaxis or therapeutic interventions.

3. Results

3.1. Study Selection

Using the search strategy across PubMed, AJOL, Google Scholar, Cochrane Library, Embase, CINAHL, Web of Science, ResearchGate, and Scopus, a total of 90 articles were identified. After deduplication and title/abstract screening,60 studies were eligible for full-text review. Following full-text assessment, 21 studies met inclusion criteria (Figure 1, PRISMA flow diagram).

3.2. Prisma-Aligned Narrative Summary (Qol Focus)

Of the 30 studies included in this scoping review, 21 studies explicitly addressed Quality of Life (QoL) among persons living with bleeding disorders using validated health-related quality of life (HRQoL) instruments, structured questionnaires, or clearly defined psychosocial and functional outcomes. The remaining 9 studies focused primarily on clinical management, adherence, laboratory outcomes, or guideline development, with QoL either indirectly implied or not formally assessed.

QoL-focused studies spanned children, adolescents, adults, women of reproductive age, and caregivers, and included populations with haemophilia A/B, von Willebrand disease, inherited bleeding disorders, contact-related bleeding manifestations, and heavy menstrual bleeding (HMB). The majority were cross-sectional or observational, with limited longitudinal or interventional designs.

Table 3: Classification by Qol Tools Used

1. Validated Generic QoL Tools	SF-36	Ávila-Sánchez et al [6] Hassan & Schapkaitz [7] (multiple studies) Abdiyeva [8]
	EQ-5D	Kenet et al [9]
2. Bleeding-Disorder–Specific QoL Tools	Haemo-QoL (Arabic version)	Tantawy et al [10]
	WFH QoL Measures	Pierce et al [11]
3.HR QoL / Structured Questionnaires (Not Fully Specified)	Mahlangu et al [12], Koekemoer et al [13, 14] Casini et al [15], Shapiro et al [16], Nwagha et al [17].	
4.Literature-Derived / Narrative QoL Evidence	Du et al [18] (systematic review on VWD), Batran et al [19], Perolla & Kalaja [20] Huisman et al [21].	
Key Gap: There was no Africa-specific validated QoL instrument consistently applied across studies, and tool heterogeneity limits cross-study comparability.		

Table 4: Mapping Of Qol Domains Across Studies

Physical Health	Bleeding frequency Pain and joint disease Fatigue and functional limitation	Reported in: Hemophilia, VWD, afibrinogenemia, HMB studies
Psychological / Emotional Wellbeing	Anxiety, depression Fear of bleeding episodes	Strongly reported in: Women with HMB, caregivers, adolescents
Social Functioning	Treatment burden School/work absenteeism Social participation Stigma	Reported in: Haemophilia, inherited bleeding disorders, VWD
Economic & Treatment Burden	Cost of care Loss of income Dependence on humanitarian aid	Reported mainly in: LMIC-focused reviews and African studies
Women-Specific Domains	Menstrual health Reproductive health Impact of anticoagulation	Reported in: HMB and anticoagulation studies (South Africa, Colombia, Morocco)

3.3. African and Lmic Evidence Gap Analysis

Despite Africa bearing a high burden of underdiagnosed bleeding disorders, the evidence base shows: Under-representation of African populations in global QoL studies,

- Limited longitudinal QoL data and Sparse data on von Willebrand disease QoL in Africa
- Minimal inclusion of contact phase deficiencies
- Poor access to psychosocial support services

The scoping review by Huisman et al [21] explicitly highlighted Africa as the largest evidence gap region for bleeding-disorder QoL research.

Key Findings

- QoL was consistently lower among persons with bleeding disorders compared to healthy populations.
- Pain, disability, and treatment burden were the primary determinants of reduced QoL.
- Psychosocial support and access to comprehensive care were limited, especially in LMIC contexts.
- Evidence gaps exist in pediatric populations, women with bleeding disorders, and longitudinal assessment of QoL.

3.4. Implications for Global Health Equity

The review highlights stark disparities in access to care and QoL outcomes between African patients and those in high-income countries. Many studies emphasize the need for regionally validated, context-appropriate QoL instruments and for interventions that address both medical and social determinants of health.

- QoL was generally moderate to low.
- Pain, joint damage, and treatment burden were the primary determinants of reduced QoL.
- Access to comprehensive care and psychosocial support was limited.
- Few studies included paediatric populations or women.
- Evidence gaps exist in longitudinal assessment and intervention studies.

4. Discussion

This scoping review demonstrates that bleeding disorders substantially impair quality of life across physical, psychological, social, and economic domains. Although 70% of included studies assessed QoL, marked heterogeneity in assessment tools and populations limits comparability across regions. Importantly, global QoL evidence remains dominated by data from high-income countries, while African populations—where diagnostic delays and treatment gaps are common—remain under-represented.

Studies consistently showed that prophylactic therapy improves QoL, particularly by reducing bleeding frequency, joint damage, and psychosocial stress. However, limited access to prophylaxis, laboratory diagnostics, and psychosocial support in African settings continues to negatively influence QoL outcomes. Women with bleeding disorders or heavy menstrual bleeding were disproportionately affected, with significant impacts on physical functioning, emotional wellbeing, and social participation.

Evidence on von Willebrand disease and contact phase deficiencies in Africa was notably sparse, despite emerging data suggesting these conditions are underdiagnosed yet common. This gap highlights the urgent need for targeted QoL research beyond haemophilia, especially in low-resource settings.

4.1. Justification of Qol Tool Choice

Given the absence of Africa-specific QoL instruments, the use of SF-36 and EQ-5D remains pragmatic due to their validation across diverse populations and comparability with global literature. However, incorporation of bleeding-disorder-specific tools (e.g., Haemo-QoL) and contextual adaptation is essential to capture culturally relevant psychosocial burdens in African populations.

4.2. Strengths and Limitations

Strengths

- Broad geographic coverage across Africa and LMICs
- Inclusion of women, children, and caregivers
- Use of both generic and disease-specific QoL instruments
- Identification of major evidence gaps

Limitations

- Tool heterogeneity limits cross-study comparison
- Predominance of cross-sectional designs
- Under-representation of VWD and rare bleeding disorders
- Limited longitudinal QoL data from Africa

Table 5: Summary of Included Studies

S/no	Author (Year)	Country	Study Design	Population	Bleeding Disorder	QoL Tool	Key Domains	Key Findings	Equity Issues
1	Ávila-Sánchez et al [6]	Colombia	Cross-sectional	Women of reproductive age	Heavy menstrual bleeding	SF-36	Physical, emotional	HMB associated with poorer QoL	Limited access to gynecologic care
2	Obeagu & Obeagu [22]	Africa (review)	Narrative review	Youths	HIV-related anemia affecting coagulation	Not specified	Physical, hematologic	Anemia worsens overall health and coagulation	Resource-limited settings
3	Mahlangu & Gilham [23]	South Africa review	Guideline /	PWH	Hemophilia A/B	Not applicable	Clinical management	Severity classification and treatment guidelines	Limited prophylaxis access
4	Nwagha et al [24]	Nigeria	Multicenter observational	PWH	Hemophilia A	Self-reported adherence	Adherence, bleeding frequency	Better adherence reduces acute bleeds	Resource-limited adherence support
5	Mafisa et al [25]	South Africa	Retrospective	Adults	Hemophilia A	Clinical assessments	Physical function, anemia	Chronic bleeding impacts daily life	Limited laboratory resources
6	Pierce et al [11]	Global (WFH)	Program evaluation	PWH	Hemophilia A/B	WFH QoL measures	Access, treatment outcomes	Humanitarian aid improves QoL	Inequities in low-income countries
7	Mahlangu et al [12]	South Africa	Retrospective	Adults & adolescents	Hemophilia A with inhibitors	HRQoL tools	Bleeding events, treatment safety	Prophylaxis improves QoL	Limited access to inhibitor treatment
8	Mahlangu & & Van Zyl [26]	South Africa	Review / narrative	PWH	Hemophilia A/B	Not specified	Daily function, mobility	Prophylaxis allows more active lives	Blood product shortages
9	Koekemoer et al [14]	South Africa	Cross-sectional	Adults	Inherited bleeding disorders	HRQoL questionnaire	Mental health, physical	Chronic bleeding impacts QoL and mental health	Limited psychosocial support
10	Hassan & Schapkaitz [7]	South Africa	Cross-sectional	Adult women	Bleeding disorders on anticoagulation	HRQoL survey	Physical, social	HMB and anticoagulation impact QoL	Inadequate clinical support for HMB
11	Kenet et al [9]	East Asia & Africa	Prospective observational	PWH	Hemophilia A	HRQoL, EQ-5D	Bleeding frequency, physical, social	Prophylaxis reduces bleeding and improves QoL	Variability in access across sites
12	Casini et al [15]	Asia & Africa	Observational / clinical	Adults	Afibrinogenemia	HRQoL questionnaires	Physical, clinical outcomes	Younger age and prior bleeding affect QoL	Rare disorder, limited treatment access
13	Du et al [18]	Global (systematic review)	Systematic review	All ages	VWD	Various	Physical, social	VWD significantly impacts QoL	Diagnostic delays, limited awareness
14	Mahlangu et al [27]	South Africa	Prospective observational	Adults & adolescents	Hemophilia A with inhibitors	HRQoL tools	Bleeding events, safety	Prophylaxis improves QoL	Limited inhibitor treatment access
15	Mahlangu et al [28]	South Africa	Review	PWH	Hemophilia	Not specified	Daily function, mobility	Prophylaxis allows active lives	Blood product shortages
16	Hassan & Schapkaitz, [29]	South Africa	Observational	Women on anticoagulation	HMB	SF-36 / clinical	Physical, social	Heavy menstrual bleeding reduces QoL	Limited anticoagulation monitoring

17	Shapiro et al [16]	Multinational	Phase 3 trial	Hemophilia A/B	Hemophilia	HRQoL questionnaires	Physical, social	Prophylaxis improves QoL and social participation	Access to new therapies limited
18	Abubakeer et al [30]	Libya	Cross -sectional	Hemophilia under patients	Hemophilia	Clinical assessments	Physical, treatment burden	Hemophilia diagnosed; treatment improves QoL	Regional disparities in care
19	Abdiyeva, [8]	Morocco & Africa	Cross-sectional	Perimenopausal women	Abnormal uterine bleeding	SF-36 / clinical	Physical, emotional	AUB reduces QoL	Limited gynaecological care
20	Koekemoer et al [13]	South Africa	Cross -sectional	Adults	Inherited bleeding disorders	HRQoL	Physical, psychosocial	Bleeding disorders impair daily life	Access and support gaps
21	Hassan & Schapkaitz [31]	South Africa	Observational	Women on oral anticoagulants	HMB	SF-36	Physical, social	Heavy menstrual bleeding affects QoL	Limited anticoagulation monitoring
22	Mokhtar et al [12]	Egypt	Prospective longitudinal	Paediatric patients	Inherited bleeding disorders	Not specified (clinical outcomes proxy)	Physical health, bleeding severity	High bleeding burden; registry essential for monitoring outcomes	Limited diagnostic infrastructure; single-centre data
23	Batran et al [19]	MENA region	Narrative review	Patients & caregivers	Haemophilia A	Literature-derived	Economic, physical, psychosocial	Significant economic and QoL burden, worsened by bleeding episodes	Inequitable access to novel therapies
24	Perolla & Kalaja [20]	LMIC-focused	Narrative review	Patients & caregivers	Haemophilia	Literature-based	Psychosocial, caregiver burden	Caregiver strain significantly affects QoL	Resource inequity; reliance on humanitarian aid
25	Babington-Ashaye et al [32]	Senegal	Mixed-methods	PWH & carriers	Haemophilia	Structured questionnaire	Knowledge, beliefs, psychosocial	Poor knowledge and stigma negatively affect QoL	Cultural beliefs; limited education
26	Tantawy et al [10]	Egypt	Cross -sectional	Children & adolescents	Haemophilia A	Haemo-QoL (Arabic)	Physical, emotional, school	Moderate–severe QoL impairment	Language adaptation needed
27	Nwagha et al [17]	Nigeria	Clinical audit	Children	Haemophilia	Clinical + QoL assessment	Joint health, daily activity	Prophylaxis improved QoL and joint outcomes	Limited national prophylaxis coverage
28	Gillham et al [33]	South Africa	Cross-sectional	Female relatives	Haemophilia	Psychosocial survey	Anxiety, reproductive health	Low uptake of genetic counselling	Gender inequity; access barriers
29	Diop et al [34]	Senegal	Descriptive	PWH	Haemophilia	Not specified	Social, economic	Improved care modestly improved QoL	Scarcity of specialists
30	Huisman et al [21]	Global	Scoping review	Children	Bleeding disorders	Multiple	Physical, psychosocial	Major evidence gap from Africa	Under-representation of LMICs

5. Conclusion

Bleeding disorders significantly impair quality of life across multiple domains, particularly in African and low-resource settings. Despite growing recognition of QoL as a critical outcome, substantial evidence gaps persist, especially for von Willebrand disease and rare coagulation disorders. Standardized, culturally adapted QoL assessment and improved access to diagnosis and treatment are essential to achieving equitable bleeding-disorder care globally.

Policy and Practice Implications

Strengthen health systems to improve access to clotting factor concentrates and multidisciplinary care. Develop culturally relevant, region-specific QoL instruments. Promote patient-centred care addressing mental health, pain management, and social support. Prioritize research in underrepresented populations, including children, women, and longitudinal studies.

Global Health Equity Lens

Disparities exist between African patients and high-income countries. Integrating QoL assessment into health policy can support equitable care, resource allocation, and improved outcomes for patients in LMICs.

Ethics and Dissemination

Ethical approval was not required as the review involved analysis of published literature. Findings will be disseminated through peer-reviewed publications and presentations at relevant scientific meetings.

Article Information

Disclaimer (Artificial Intelligence): The author(s) hereby declare that NO generative AI technologies such as Large Language Models (ChatGPT, COPILOT, etc.), and text-to-image generators have been used during writing or editing of manuscripts.

Competing Interests: Authors have declared that no competing interests exist.

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