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Knowledge and barriers to accessing comprehensive care for hemophilia patients in Rwanda: A cross-sectional study

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Abstract

Hemophilia is a rare but severe bleeding disorder requiring lifelong management and consistent access to comprehensive care. In Rwanda, where only one hospital provides specialized hemophilia services, gaps in access remain poorly understood. This study aimed to examine the relationship between knowledge of hemophilia care, perceived barriers to healthcare, and access to comprehensive hemophilia services. Using a cross- sectional design, 102 hemophilia patients were surveyed with structured questionnaires. The study assessed participants' knowledge of hemophilia care and identified intrapersonal, interpersonal, and structural barriers to healthcare service utilization. Descriptive statistics, Spearman's correlation, and multiple regression analyses were used to analyze the data. findings revealed a mean knowledge score of 40.9%, indicating generally low level of knowledge. High mean scores were observed for intrapersonal (m = 3.17), interpersonal (m = 3.03), and structural barriers (m = 3.03), suggesting that intrapersonal, interpersonal, and structural barriers hinder access to care. The mean score for access to comprehensive care was low (m = 1.98). No significant correlation was found between knowledge and access (ρ = .058, p = .561), while strong negative correlations were found between access and intrapersonal (ρ = .711), interpersonal (ρ = –.745), and structural barriers (ρ = –.834), all statistically significant (p < .001). Regression analysis showed that structural barriers (β = –.55, p < .001, δr^2 = .715) were the strongest predictor of limited access, followed by intrapersonal barriers (β = –.15, p = .044). Knowledge, age, sex, and interpersonal barriers, place of residence, and educational attainment were not significant predictors. These findings highlight the critical need to address structural and psychological barriers to improve access to comprehensive hemophilia care in Rwanda. While educational interventions may increase knowledge, they must be coupled with systemic reforms to meaningfully enhance care delivery.

Keywords: Hemophilia, Comprehensive care, Healthcare access, Barriers to care, Patient knowledge, Rwanda, Health services accessibility

Introduction

Hemophilia is a rare hereditary bleeding disorder that is characterized by a deficiency or absence of blood coagulation factors with either factor VIII (hemophilia A) or factor IX (hemophilia B) [1]. This hereditary condition affects approximately 1 in 10,000 live births worldwide, with an estimated 819,000 individuals diagnosed with hemophilia globally [2]. This condition is characterized by protracted episodes of hemorrhaging, thereby leading to a serious complication in the form of joint destruction, intracranial hemorrhage, and potentially mortality if not treated or not managed effectively [3].

In developed nations, the care of hemophilia patients has enhanced so dramatically in the last few decades that it has greatly improved outcomes for patients and overall quality of life. Most importantly, the life expectancy of hemophilia patients comes close to the existing life expectancy of their non-hemophilia peers, because of guidelines for prophylactic treatment, improved recombinant clotting products, and better care access at multiple levels [4]. In Low- or Middle-Income Countries (LMICs), the situation reflects a massive gap because thousands of patients face severe challenges in accessing even basic care and treatment [5].

Rwanda shares many of the regional issues. Comprehensive hemophilia care remains relatively undeveloped, and services are concentrated in Kigali, at the Centre Hospitalier Universitaire de Kigali (CHUK), which is the country's main referral hospital. Factor replacement therapy was initiated in 2012 relying primarily on international donations, and factor replacement therapy is predominantly available in Kigali [6]. Geographic and financial barriers preclude rural patients from accessing specialized services. In addition, there is no national hemophilia registry, and historically only a handful of providers nationwide including one pediatric haemato oncologist have managed hemophilia cases [6]. These resource constraints combine to limit the

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country's ability to adequately diagnose, follow up, or provide equitable services.

The Rwanda Fraternity Against Hemophilia has emerged, providing advocacy and patient support and prescriptions for factor replacement therapy have increased in recent years. There are still significant barriers. The centralization of specialized services in the capital continues to deny rural patients emergency or preventative care in a timely manner. Without reliable epidemiological data planning services or allocating resources presents additional barriers to developing a national work plan and integrating hemophilia into the health system in Rwanda.

Although there is a sizable body of literature in the general area of global hemophilia care access inequalities, most of this work focuses on high income countries or has made much generalized overviews of the challenges faced in LMICs [16,21]. Few studies have examined the specific barriers manifested in individual countries in sub Saharan Africa, while Rwanda in particular has been the focus of very little literature. The existing literature has largely been descriptive in nature, meaning that empirical evidence regarding the social, cultural, and structural determinants of accessing care for hemophilia has been limited [2]. Further, while previous literature based in LMICs has focused more on the clinical or epidemiological aspects around hemophilia, there has been a lack of evidence incorporating the perspectives of patients and caregivers, namely the populations most affected [7,8].

These perspectives are vital to understand, as access to hemophilia care mechanisms are influenced not only by medical aspects but are bound up in the dimensions of awareness, knowledge, economic situation, and cultural beliefs. Without the evidence on these multi-level barriers, health policy and program development could quite rapidly overlook the realities of patients and their families.

To fill this gap, the present study examines the relationship between knowledge of hemophilia care, barriers to accessing comprehensive care among patients and caregivers in Rwanda. It outlines knowledge, intrapersonal, interpersonal and structural barriers of care, and demographic aspects of access. This research provides local evidence to enact to inform policy, improve service provision and health outcomes for people with hemophilia in Rwanda.

Methods

Study design and setting

We conducted a cross-sectional survey in Rwanda between March and May 2025 to quantify knowledge of hemophilia care, identify intrapersonal, interpersonal, and structural barriers, and describe access to comprehensive hemophilia services. A cross-sectional design was chosen because it allowed estimation of current knowledge and perceptions and the examination of associations between explanatory variables (knowledge, barriers, demographic) and the outcome (access to Comprehensive care) at a single point in time.

Study population and eligibility

The study population comprised persons with a confirmed diagnosis of hemophilia registered with the Rwanda Fraternity Against Hemophilia and receiving care at the Centre Hospitalier Universitaire de Kigali or other hemophilia care facilities, together with their primary caregivers. Eligible respondent were if they were 18 years or older. For patients younger than 18 years, their primary caregiver of at least 18 years served as the respondent. All participants had to reside in one of Rwanda's five administrative provinces, provide written informed consent, and be able to read and understand the survey language. Caregivers were considered eligible if they were directly connected to the patient and actively involved in daily management and medical appointments. Patients with major comorbid conditions, severe cognitive limitations, or caregivers without sufficient knowledge of the patient's condition were excluded.

Sampling and sample size

We used stratified random sampling to ensure a good representation across Rwanda's five provinces. The minimum required sample was 102, calculated with OpenEpi (prevalence = 50%, 95% confidence level, 5% margin of error). Participants were selected proportionally from each province.

Data collection instrument

A structured questionnaire was developed following a review of relevant literature and consultation with subject matter experts. No existing validated instrument comprehensively addressed the study objectives; therefore, all items were self-developed based on prior studies and adapted to the Rwandan context for cultural appropriateness.

The questionnaire comprised three sections. The first section assessed knowledge of hemophilia care through 14 items on disease condition, treatment and management of hemophilia. Responses were scored and categorized into five levels: very high (81–100%), high (61–80%), average (41–60%), low (21–40%), or very low (0–20%). Cutoffs were adapted from prior studies and adjusted for this study in Rwanda. The second section examined barriers to access using 29 items covering intrapersonal (10 items), interpersonal (9 items), and structural (10 items) domains. Each item was rated on a four point Likert scale (1 = strongly disagree to 4 = strongly agree), with negatively worded items reverse-coded. Composite mean scores were interpreted as very high (3.26–4.00), high (2.51–3.25), low (1.76–2.50), or very low (1.00–1.75). The third section measured access to comprehensive care with 15 items assessing availability of specialized treatment, service accessibility, and satisfaction with care, using the same scale and interpretation bands.

Instrument validation and reliability

Content validity was determined by a group of seven experts composed of a statistician, a methodologist, four public health and clinical experts, and a community health nurse. They reviewed the questionnaire for clarity, cultural appropriateness, and relevance prior to deployment.

We also completed a pilot study with 15 subjects to assess feasibility and clarity, the subjects from the pilot study were excluded from the final study survey sample. The pilot study elicited feedback for further refinement of item wording and format for better understanding. The reliability analyses show good internal consistency Cronbach's alpha of .83 for knowledge scale, .88 for barriers scale, and .81 for access to care scale.

Data collection procedures

Data were collected using printed questionnaires administered in person at Rwanda Fraternity against Hemophilia facilities or electronically via Google Forms distributed through secure patient networks. Trained research assistants administered the survey after obtaining informed consent. Each survey took approximately 20–25 minutes to complete. Only fully completed questionnaires were retained for analysis, and missing values in partial responses were excluded list wise.

Variables and measures

The main outcome was access to comprehensive care. This was measured using the composite mean score from the access section. The key explanatory variables included knowledge scores (percentage correct) and barrier scores (composite mean scores for intrapersonal barriers, interpersonal barriers, and structural barriers). The covariates included age (years), sex, education (years of education), and province of residence.

Data management and analysis

Data were recorded on Microsoft Excel 2016 and analyzed in SPSS Version 25. Descriptive statistics including means, standard deviations, frequencies and percentages were used to summarize participant characteristics, knowledge levels and barrier scores, and access comprehensive care outcomes for. The bivariate relationships were assessed through Spearman's rho correlation. A multiple linear regression analysis was performed to identify the independent predictors of access to outcomes, with knowledge and barriers and demographic variables as covariates. Regression assumptions were also assessed by checking linearity, multicollinearity, normality of residuals, and homoscedasticity.

Multicollinearity was assessed using variance inflation factors; there were none of which were >2.0, indicating that there was no substantial collinearity. Statistical significance was set at $p < 0.05$.

Result

Sociodemographic characteristics of participants (N = 102)

A total of 102 participants were included in the analysis. The mean age of patients was 13.0 years (SD = 8.66; median = 11.5; interquartile range [IQR] = 7.0–17.8; range = 1–37 years). Most participants were male (n = 99; 97.1%), while only three were female (n = 3; 2.9%). Participants were recruited across all five provinces with the largest proportion from Kigali City (n = 34; 33.3%), followed by Eastern Province (n = 31; 30.4%), Western Province (n = 17; 16.7%), Northern Province (n = 10; 9.8%), and Southern Province (n = 10; 9.8%).

Regarding educational attainment, nearly half had completed primary education (n = 49; 48.0%), 21 (20.6%) had secondary education, 29 (28.4%) reported no formal education, and 3 (2.9%) had university/tertiary education (Table 1).

Table 1. Sociodemographic characteristics of participants (N = 102)

Characteristic	n	%
Sex		
Male	99	97.1
Female	3	2.9
Province of residence		
Kigali City	34	33.3
Eastern Province	31	30.4
Western Province	17	16.7
Northern Province	10	9.8
Southern Province	10	9.8
Highest level of education		
No formal education	29	28.4
Primary	49	48.0
Secondary	21	20.6
University/Tertiary	3	2.9

Knowledge of hemophilia

Respondents' knowledge was assessed across three domains: knowledge of the condition, knowledge of available treatment options, and knowledge of management. The overall mean knowledge score was 40.9%. The lowest correct response rate was observed for treatment options (mean score: 29.8%), while knowledge regarding the management had the highest score (mean: 57.6%). Knowledge of the condition yielded a mean score of 38.6%. These findings indicate significant gaps in overall knowledge of hemophilia and its management (Table2).

Table 2. Level of Knowledge of Hemophilia Patients and Caregivers Regarding their Knowledge of the Condition, Available Treatment Options, and Patient Management in Rwanda

Knowledge	Percentage of Correct Answers (%)	Qualitative Descriptor
Awareness of the Condition	38.6%	Low
Knowledge on Treatment Options	29.8%	Low
Knowledge on Management	57.6%	Average
Overall Mean Score for Level of Knowledge of the Respondents	40.9%	Low

Perceived barriers to accessing comprehensive care

Respondents reported varying levels of perceived barriers to care with intrapersonal barriers having a

mean score of 3.16 (SD = 0.82), interpersonal barriers a mean of 3.03 (SD = 0.86), and structural barriers a mean of 3.03 (SD = 0.88). The overall grand mean score for perceived barriers was 3.07 (SD = 0.56), suggesting that hemophilia patients in Rwanda experience high levels of barriers across all three domains (Table 3).

Perceived access to comprehensive care

Access to comprehensive care was evaluated in terms of availability of specialized treatment, accessibility of healthcare services, and satisfaction with care. Respondents reported low levels across all dimensions. Availability of specialized treatment had a mean of 1.80 (SD = 0.73), accessibility of services had a mean of 2.05 (SD = 0.89), and satisfaction with care recorded a mean of 2.05 (SD = 0.89).

The overall grand mean for access to comprehensive care was 1.98 (SD = 0.84), indicating low perceived access to comprehensive hemophilia care (Table 3).

Table 3. Perceptions of respondents regarding barriers to accessing comprehensive care for hemophilia patients in Rwanda

Barriers	**Mean**	**SD**	**Qualitative Descriptor**
Intrapersonal Barriers	3.16	0.817	High
Interpersonal Barriers	3.03	0.856	High
Structural Barriers	3.08	0.880	High
Grand Mean Score for Barriers	**3.07**	0.851	**High**
Access to Comprehensive Care			
Availability of Specialized Treatment	1.80	0.731	Low
Accessibility to Healthcare Services	2.05	0.888	Low
Satisfaction with Care	2.05	0.894	Low
Overall Access to Comprehensive Care	1.98	0.841	Low

Correlation between knowledge, barriers, and access to comprehensive care

Spearman's rank correlation revealed that knowledge of hemophilia care had no significant association with access to comprehensive care (ρ = 0.058, p = 0.561) with intrapersonal barriers (ρ = −0.711, p < 0.001), interpersonal barriers (ρ = −0.745, p < 0.001), and structural barriers (ρ = −0.834, p < 0.001) were all strongly and negatively associated with access to comprehensive care (Table 4).

Table 4. Relationship between knowledge, barriers and access to comprehensive care for hemophilia patients

Variable	**Spearman's rho**	**p-value**	**Interpretation**
Knowledge→ access to comprehensive care	0.058	.561	*Not Significant*
Intrapersonal Barriers→ access to comprehensive care	−0.711	<.001	*Significant, Strong Negative*
Interpersonal Barriers→ access to comprehensive care	−0.745	<.001	*Significant, Strong Negative*
Structural Barriers→ access to comprehensive care	−0.834	<.001	*Significant, Strong Negative*

Legend: 0.00-0.10 = Negligible; 0.10 -0.39 = weak Correlation; 0.40-0.69= moderate Correlation; 0.70-0.89 = strong correlation; 0.90-1.00= Very strong correlation

Predictors of access to comprehensive care

Multiple regression analysis was used to determine the predictors of access to comprehensive care. The structural barriers were the most significant predictor (β = −0.55; SE = 0.09; t = −6.52; p < 0.001) explaining 71.58% of the variance and intrapersonal barriers were also significant (β = −0.15; SE = 0.07; t = −2.04; p = 0.044) accounting for an additional 4.07% variance. Other predictors: interpersonal barriers, knowledge of hemophilia care, age, sex, level of education, and place of residence were not significant and explained negligible variance - making these insignificant to predicting access to comprehensive care. Overall, results suggest the structural and intrapersonal barriers primarily accounted for predicting access to comprehensive care among hemophilia patients in Rwanda (Table 5).

Table 5. Predictors of access to comprehensive hemophilia care

1	**Estimate (*β*)**	**SE**	***t***	***p***	**R^2 Change**
Intercept	4.33	0.18	23.49	< .001	–
Knowledge	0.04	0.10	0.39	.697	0.001
Intrapersonal Barriers	-0.15	0.07	-2.04	.044	0.040
Interpersonal Barriers	-0.05	0.10	-0.52	.607	0.005
Structural Barriers	-0.55	0.09	-6.52	< .001	0.715
Age	0.00	0.00	-0.94	.351	0.010
Sex (Female – Male)	-0.06	0.16	-0.36	.719	0.002

Place of Residence					
- Northern – Kigali City	0.02	0.10	0.18	.856	0.000
- Western – Kigali City	-0.06	0.08	-0.78	.435	0.000
- Eastern – Kigali City	0.01	0.07	0.12	.902	0.000
- Southern – Kigali City	-0.02	0.10	-0.24	.807	0.000
Educational Attainment					
- Secondary – Primary	0.00	0.08	0.04	.966	0.000
- University – Primary	0.02	0.18	0.12	.902	0.000

Discussion

This cross-sectional study examined the relationship between knowledge, barriers, and access to comprehensive care among people living with hemophilia in Rwanda. The research findings underscore the predominance of structural and intrapersonal barriers on access to care, while knowledge and demographic variables (age, sex, education and place of residence) were not significant predictors in the context of larger systemic and psychological limitations. This indicates the complex and layered interplay of determinants, with systemic inadequacies exerting a preponderant influence on health-seeking behaviors.

The lack of a strong relationship between having knowledge about hemophilia care and access to comprehensive care contradicts much of the existing literature where knowledge is frequently identified as an essential enabler of care [9]. Moreover, in many contexts, increased knowledge has been associated with more rapid symptom identification and greater adherence to recommendations [9]. Overall, however, the data from Rwanda illustrates that while increased knowledge may provide patients with the incentive to seek care, they are still

unable to satisfactorily address their knowledge-informed level of care due to logistical, infrastructural, and systemic limitations. Similar findings illustrated in the management of chronic and rare diseases in sub-Saharan Africa where informed patients are unable to access specialist treatment due to the centralization of care, as well as shortages of specialized providers [10].

Structural barriers were uniquely and negatively correlated with access to care, and were also the main predictors in the multivariate regression analysis, with over 70% of the variation explained by structural barriers. These results support the view that in resource poor contexts, the ability to provide care at the health system level is often a greater barrier to access than individual level barriers. In the case of Rwanda, patients who live outside of Kigali, where hemophilia care is still largely co-located, experience geographic barriers to access, or monetary barriers to receiving clotting factor replacement, physiotherapy, or surgery. Patients in urban areas still experience challenges accessing the services they need, with continued stock-out issues, limited diagnostic capacity, and workforce shortages [11].

The importance of intrapersonal barriers underscores the importance of psychological, emotional and attitudinal factors. Stigma, fear of medical procedures, low self-efficacy, and fatalism have all been shown as barriers to utilization of care, particularly in diseases such as hemophilia that are rare or stigmatized [12]. Psychosocial stressors have been shown to have a substantial impact on treatment adherence and engaging with care services across chronic conditions including HIV, sickle cell disease, and epilepsy [13,22]. While interpersonal barriers, such as limited family support or poor provider–patient communication, demonstrated strong association with access in bivariate analysis, they were not statistically significant in the multivariate model. This suggests that the effects of interpersonal dynamics could have a more decisive effect once bare bones structural barriers are mitigated. Similar patterns have existed in HIV and cancer care in East Africa, where social support tends to be a decisive factor in adherence and continuity once access is secured [14]. It seems in the current situation, that when there was insufficient capacity in the system to provide care, interpersonal support had limited opportunity to affect change.

The lack of predictive power for demographic variables such as age, sex, education, and place of residence was also indicative of the concept of

universal scarcity. Contrary to our expectations based on urban–rural differences seen in other settings [15], in this study, place of residence was not a significant predictor of access. This may demonstrate that even urban residents of Rwanda still face severe access constraints given the national shortage of clotting factor products, lack of a decentralized care model, underinvestment in hemophilia-specific services [16.17]. The idea that geographic proximity to a facility does not guarantee access (and that access may be compromised due to inadequate staffing, infrastructure, or supplies at that local facility) is well established in health systems literature [15,18].

These findings offer support for a model where health access is driven most by systemic factors, second by psychological barriers of individuals, and least by knowledge or social support in the absence of systemic readiness [19], and systemic constraints eliminate the determinant roles knowledge or motivation have started to play in global health [20]. Rwanda has experienced health system strengthening for communicable diseases that has progressed considerably. Hemophilia and other rare and chronic conditions remain less prioritized, in terms of policy and public financing and investment.

The implications for policy and practice are huge. Interventions must draw on structural approaches first. These include reforms to include relocation of care from a national hospital to more local care that is easier to access; change can only occur with consistent supply of clotting factor concentrates; or, restructuring patient care in the district hospitals through the use of existing hospitals, or, at the very least patient contact, capacity building. Increasing knowledge and awareness of hemophilia management through educational media campaigns can only occur alongside genuine improvements in the availability and quality of care, because increased awareness with limited opportunity can measure only frustration and unmet expectations. While, psychosocial approaches to management of hemophilia such as peer support, counseling services and stigma reduction initiatives can enable patients to cope with the management of hemophilia, these approaches are only useful in a working system [13].

This study has several limitations that should be acknowledged, particularly its cross-sectional design which limits causal inference and prevents conclusions about the directionality or temporality of observed associations. The small and non-random sample constrained by the rarity of hemophilia may affect the generalizability of the findings. Although efforts were made to ensure geographic representation across Rwanda, the results may not fully capture the diversity of patient experiences nationwide. Future studies should look to employ a longitudinal or mixed-methods approach as well as recruiting a larger, representative sample, in order to build an evidence base for improving access to broad hemophilia care.

Conclusion

Access to comprehensive care of hemophilia in Rwanda remains limited primarily due to structural, intrapersonal, and interpersonal barriers. Knowledge of hemophilia among respondents was low and did not influence access to care. Instead, Structural barriers and intrapersonal barriers emerged as the most critical challenges. Demographic variables showed no significant associations with care access to comprehensive care. These findings of this study highlight the urgent need for targeted interventions that will address the structural limitations of the health system and the psychosocial needs of individuals living with hemophilia in Rwanda to ensure equitable and effective care delivery.

Implications for practice

Improving access to hemophilia care in Rwanda requires more than patient education.

Health professionals and program planners should prioritize reducing structural barriers such as transportation challenges and enhancing psychosocial support to address fear and stigma. Community-based outreach and decentralized services may improve equitable care access.

Implications for policy

Policymakers should consider integrating rare disease care, such as hemophilia services, into broader national health strategies. Investment in infrastructure, regional treatment centers, and financial support mechanisms can help bridge current gaps and ensure more inclusive healthcare

coverage.

Declarations

Ethical considerations

The protocol of this study was approved by both the Saint Louis University Research and Innovation Center Research Ethics Committee and the Rwanda National Research Ethics committee, the written informed consent was obtained from the participants before enrolment.

This study followed the ethical guidelines of the Declaration of Helsinki.

To maintain confidentiality, identifiable codes were used in the data collection, and a password locked database was used to ensure that personal identifiers were not collected.

Consent for publication

Not applicable. No identifiable participant information (such as names, images, or personal details) is included in this manuscript.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to confidentiality agreements with participants but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding information and author contributions

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Authors' contributions

Kwizera Jules Jordan conceptualized the study, designed the methodology, and led the data collection process. Allan Jay Espiritu, the academic advisor, provided guidance on study design and critically reviewed the manuscript for important intellectual content. All authors reviewed and approved the final manuscript and take full responsibility for its content.

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