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Knowledge, Attitudes and Self-Reported Practices Regarding Hemophilia Care among Healthcare Workers: A Hospital-Based Cross-Sectional Survey

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Abstract **Objectives:** Hemophilia A and B are X-linked bleeding disorders caused by deficiency of Factor VIII or IX. India has an estimated 140,000 people with hemophilia, but only a fraction is formally diagnosed. This diagnostic gap directs early detection and management towards frontline Healthcare Workers (HCWs). Existing studies on HCW Knowledge, Attitude and Practice (KAP) around hemophilia are inconsistent, particularly for carrier status and emergency care. **Objectives:** To assess baseline knowledge of HCWs with respect to haemophilia presentation, inheritance and management and their attitudes and practices around multidisciplinary care and prophylaxis. **Methods:** A hospital-based cross-sectional survey included 260 doctors, nurses and laboratory technologists and used a questionnaire covering hemophilia knowledge, attitudes and self-reported practices. The survey period was three months. **Results:** Most respondents correctly identified the hereditary basis of hemophilia (86.2%), but carrier symptomatology and curability were correctly identified by only 71.5 and 63.8% respectively. Favourable attitudes toward Continuing Medical Education (CME) and multidisciplinary care were noted (>70%), yet confidence in stabilizing acute bleeds was low (57.3%) and practice scores were further low (63.1 and 62.3%). Pilot assessment showed good-to-excellent reliability. **Conclusion:** The responses indicate specific gaps in knowledge of carrier manifestations and curability and lower agreement with some confidence- and practice-related statements. Item-level endorsement cannot be interpreted as objectively observed clinical practice or a validated ranking of overall knowledge, attitudes and practice domains.

Key Words Hemophilia, Healthcare Workers, Knowledge, Attitude and Practice, Cross-Sectional Study, India, Bleeding Disorder

INTRODUCTION

Hemophilia is a chronic hereditary bleeding disorder due to the deficiency or dysfunction of coagulation factors [1]. Two main types of hemophilia recognized are Hemophilia A and Hemophilia B both caused by Factor VIII deficiency and Factor IX deficiency respectively. Both types predominantly affect male as it follows an X linked recessive pattern [1-3]. The estimated global prevalence of Hemophilia A 17.1 per 100,000 males while that of Hemophilia B is 3.8 per 100,000 males [2]. There is a pronounced diagnostic gap in India as there is stark discrepancy between the estimated count of Persons with hemophilia and those diagnosed by the World Federation of Hemophilia Annual Global Survey (WFH-AGS) 2024 being 140,000 and 26,352 respectively [4].

Hemophilia can clinically manifest as hemarthrosis, deep muscle bleeds and soft-tissue hematomas, with chronic arthropathy as a common long-term complication. While severe internal bleeds can be fatal such as intracranial haemorrhage [1,5]. The standard of care remains to be Factor replacement therapy and prophylaxis while persistence of access and safety challenges are observed in developing regions [2]. Use of modern recombinant products have reduced the historic risk of transfusion-transmitted infections (HIV, HBV, HCV) associated with older blood-derived products, substantially improving the safety [1,2]. Bleeding symptoms in female carriers are frequently under-recognised in clinical practice [6]. Achieving optimal outcomes for people with hemophilia depends on specialized multidisciplinary care and, critically, on strong awareness among frontline clinicians [1].

Despite comprehensive international guidelines advocating structured hemophilia care networks, significant gaps persist

in baseline assessment and recognition of atypical bleeding phenotypes among frontline healthcare workers in regional South Indian tertiary centers [2]. Global and regional studies report that clinical staff-particularly nurses and paramedical personnel-show wide variability and deficits in recognizing hemophilia-specific bleeding patterns, handling and interpreting factor assays and implementing immediate transfusion and emergency protocols [1,6]. A pronounced knowledge gap also exists regarding bleeding symptoms in female carriers, contributing to delayed diagnosis and inadequate counselling [5]. Identifying these targeted informational gaps is essential to designing effective institutional training and capacity-building programs [6].

Objectives:

- To evaluate the baseline knowledge of HCWs with respect to the clinical presentation, inheritance pattern, diagnostics and management of haemophilia
- To assess the attitudes and practice patterns of HCWs towards multidisciplinary care, specialized diagnostics and prophylaxis

METHODS

A cross-sectional, descriptive, hospital-based survey conducted over a three-month period at a tertiary care teaching hospital and its associated blood bank infrastructure in South India.

With a target population comprising of healthcare professionals who are actively engaged in clinical or diagnostic work, including doctors (consultants and postgraduates), registered nurses and Medical Laboratory Technologists (MLTs).

The sample size was estimated using appropriate statistical methods and a final sample size of n = 260 was calculated.

Stratified random sampling was used to ensure a proportionate and balanced representation across the three professional categories.

Inclusion Criteria

Fully registered clinical professionals (doctors, nurses and laboratory technologists) actively working in clinical or diagnostic departments.

Exclusion Criteria

Administrative or non-clinical healthcare staff and staff on long-term medical leave.

Data were collected using a structured self-administered questionnaire (full validation documentation was not supplied), distributed both electronically and in person. The questionnaire contained domains covering socio-demographic characteristics and Knowledge (15 items, True/False format), Attitude (4 items) and Practice (5 items) domains, adapted from previously validated tools.

Prior to publishing the questionnaire was pilot tested on 25 healthcare workers (doctors, nursing officers and medical laboratory technologists) at the study site and these 25 HCWs were not involved in the final study to avoid inconsistencies in the result. Cronbach's alpha was computed separately for each domain from complete-case pilot responses to assess internal consistency and was found to be internally consistent.

Statistical Method

Reporting Clarification: Percentages for confidence, prophylaxis and referral items represent individual questionnaire endorsements unless an explicit and validated composite-score algorithm is supplied. The questionnaire, coding of negatively worded items, reliability statistics and nonresponse by occupational stratum are needed for reproducible between-group comparisons.

Survey data were tabulated, coded and analyzed using the Statistical Package for the Social Sciences (SPSS). In keeping with the study objectives of describing baseline knowledge, attitude and practice levels, data were summarized using descriptive statistics: categorical variables (Individual Knowledge, Attitude and Practice items) as frequencies and percentages, consistent with the response format of the instrument.

A participant information sheet and informed consent form were prepared and distributed along with the questionnaire. The study involved no direct patient intervention and participant identities were kept anonymous. The survey-based design incurred no financial charges, liabilities, or diagnostic costs to any participant; all operational expenses were borne by the primary investigators.

RESULTS

A total of 260 healthcare workers responded completely to the questionnaire. Cronbach's alpha was calculated on a pilot sample of 25 which indicated a good-to-excellent internal consistency across all three domains of the questionnaire (Table 1). A single knowledge component displayed a ceiling effect, as majority of responders were able to identify haemophilia as a hereditary disorder. This is since it's a fact and basic didactic knowledge rather than advanced disease pathology related questionnaire such as female carrier symptomatology.

About 61.5% of the respondents were female of which majority (63.1%) were aged 20-29 years with the largest professional group being doctors (50.4%), who were followed by nursing officers (36.2%) and medical laboratory technicians (13.5%). Over a third of respondents (36.2%) had less than one year of clinical experience and 41.9% reported prior exposure to a haemophilia patient (Table 2).

Correct-response rates across the Knowledge items ranged from 63.8-86.2% (Table 3). Recognition of hemophilia as a hereditary disorder was highest (86.2%), while the lowest responses were noted with the non-curable status of the disease (63.8%) and recognition of carrier symptomatology (71.5%).

A positive attitude was observed with respect to Continuous Medical Education (CME) on hemophilia and multidisciplinary care, the agreement exceeded 70% for both items. While many reported an under confidence in identification and stabilization of an acute bleed with only 57.3% agreement (Table 4).

Table 1: Internal Consistency (Cronbach's alpha) of the KAP Questionnaire Domains (Pilot Sample, n = 25)

Domain	Items	Cronbach's α	Interpretation
Knowledge	15	0.826	Good
Attitude	4	0.708	Acceptable
Practice	5	0.905	Excellent

Table 2: Demographic and Professional Characteristics of Respondents (n = 260)

Variable	Category	n (%)
Gender	Female	160 (61.5)
	Male	99 (38.1)
	Prefer not to say	1 (0.4)
Age group	20–29 yrs	164 (63.1)
	30–39 yrs	58 (22.3)
	40–49 yrs	26 (10.0)
	>50 yrs	12 (4.6)
Professional designation	Doctor (Consultant/SR/PG)	131 (50.4)
	Nursing officer	94 (36.2)
	Medical Lab Technician	35 (13.5)
Clinical experience	<1 year	94 (36.2)
	1–5 years	99 (38.1)
	6–10 years	29 (11.2)
	>10 years	38 (14.6)
Prior exposure to a hemophilia patient	Yes	109 (41.9)
	No	128 (49.2)
	Maybe	23 (8.8)

Table 3: Knowledge Domain-Correct Response Rate by Item (n = 260)

Knowledge item	Correct, n (%)
Hemophilia is hereditary	224 (86.2)
X-linked recessive inheritance (A&B)	195 (75.0)
Male predominance	192 (73.8)
Carrier's risk of affected male child = 25%	205 (78.8)
Carrier females can have abnormal bleeding	186 (71.5)
Hemophilia is not fully curable	166 (63.8)
Prolonged oozing after minor trauma	197 (75.8)
Hemarthrosis as typical presentation	190 (73.1)
Post-circumcision bleeding as a sign	182 (70.0)
Bleeding after dental extraction	212 (81.5)
Weight-bearing joints most prone	205 (78.8)
Factor concentrates historically transmitted HIV/HBV/HCV	192 (73.8)
Factor assay is gold-standard diagnosis	198 (76.2)
Immediate factor replacement in acute bleed	210 (80.8)
Primary prophylaxis improves joint outcome	215 (82.7)

Table 4: Attitude Domain (n = 260)

Attitude item	Agree, n (%)	Neutral, n (%)	Disagree, n (%)
CME on hemophilia essential for staff	195 (75.0)	22 (8.5)	43 (16.5)
Multidisciplinary care necessary	190 (73.1)	28 (10.8)	42 (16.1)
Confident identifying/stabilizing a bleed	149 (57.3)	56 (21.5)	55 (21.2)
Prenatal screening/genetic counselling crucial	185 (71.2)	26 (10.0)	49 (18.8)

Table 5: Practice Domain (n = 260)

Practice item	Agree, n (%)	Neutral, n (%)	Disagree, n (%)
Family bleeding history documentation	193 (74.2)	12 (4.6)	55 (21.2)
Immediate factor replacement in trauma	183 (70.4)	25 (9.6)	52 (20.0)
Avoid IM injections during hemarthrosis	164 (63.1)	28 (10.8)	68 (26.1)
Consider maternal/sibling bleeding risk pre-procedure	162 (62.3)	42 (16.2)	56 (21.5)
Blood bank coordination for elective surgery	181 (69.6)	32 (12.3)	47 (18.1)

Practice scores were consistently lower than the corresponding attitude scores across matched domains. Agreement was highest for family bleeding-history documentation (74.2%) and lowest for pre-procedural assessment of maternal or sibling bleeding risk (62.3%) and avoidance of intramuscular injections during hemarthrosis (63.1%) (Table 5).

DISCUSSION

This cross-sectional survey of 260 frontline healthcare workers at a South Indian tertiary care center found generally good foundational knowledge of hemophilia's basic hereditary and clinical features, consistent with prior assessments of health-worker knowledge in resource-limited settings [1,6]. We observed that the knowledge was rather

poor for two clinically relevant key distinctions: Recognition that carrier females can experience clinically significant bleeding (haemophiliac female) and awareness that hemophilia does not have routine medications that can aid in its cure. The former finding reflects the under recognition of heamophilac females in the existing literature due to delayed diagnosis and inadequate genetic counselling for at-risk women [5]. The latter finding suggests a persistent misconception that may affect patient counselling and expectation-setting around long-term, prophylaxis-based management as recommended by international guidelines [2].

The positive attitude that is observed towards structured, multidisciplinary hemophilia care and continuing education mirrors the coordinated and comprehensive care models emphasised by international guidelines [2]. The lowest-scoring attitude item was the lack of confidence in identifying and stabilizing an acute bleed. This denotes a gap between favorable attitude and self-efficacy that has practical implications for emergency response. This pattern was also observed and even amplified, in the Practice domain, where we saw lowest observed scores in avoiding intramuscular injections during hemarthrosis and pre-procedural bleeding-risk assessment. Together, these findings point towards an attitude-to-practice gap than pure knowledge deficit. Many healthcare providers appear to value structured hemophilia care in principle but reported less consistent translation when it comes to the implementation of the same in day-to-day practice. This distinction helps in designing appropriate competency based, simulation supported training in hemophilia care as knowledge transferred didactically is unlikely to close a gap that appears concentrated in confidence and applied practice. This is consistent with other available literatures which call for competency based and simulation supported training modules and constant evaluation for routine hemophilia care and emergency management [1,3,4].

While comparing the findings of this study with more resource-constrained settings elsewhere it was found that in the later settings while majority of the healthcare providers surveyed recognized hemophilia as a disease entity, fewer than 1% demonstrated a substantively good level of knowledge and most exhibited practices classified as harmful [7]. The current cohort demonstrated higher item-wise knowledge scores and predominantly favorable attitudes which could be due to the advantage of working within a specialized immunohaematology and blood-transfusion department, with an established hemophilia clinic with exposure to patients and structured protocols. This suggests that institutional context and specialist proximity and not professional cadre alone, meaningfully shape baseline KAP.

Questionnaire-based cross-sectional studies have similarly demonstrated that misconceptions and perceptions among healthcare recipients can influence engagement with appropriate treatment and follow-up care [8].

A cohort which constituted only nursing officers from the middle east scored high on the structured knowledge domain spanning definitions, symptoms and its recognition, diagnosis and treatment but simultaneously the majority of the cohort demonstrated a negative attitude towards hemophilia care which the authors contributed to the limited hands-on experience and the lack of prior hemophilia centric training in over half the sample [9]. The current cohort also showed a similar trend where while attitude remained positive, the confidence and practice lagged. The comparison of the two studies suggests a breakdown can occur at any point in the knowledge attitude practice flow. This break down depends on the context in the middle eastern cohort we observe that a knowledge-attitude disconnect exists due to the limited clinical exposure to hemophilia patients whereas the present cohort shows an attitude-practice disconnect due to the lack of competency-based emergency training despite exposure to hemophilia patients. Both cohorts point us to the direction of the same answer the need for supervised hands-on training rather than knowledge transfer by unidirectional didactic lectures.

This highlights the importance of genetic assessment and counselling in inherited disorders, particularly for individuals and families at risk of hereditary conditions [10]. Consistent with the favourable attitude toward genetic counselling observed in our cohort (71.2%), this attitude did not appear matched by adequate knowledge of carrier symptomatology or by provider capacity to deliver such counselling. We also noted the lack of awareness regarding the symptomatology among female carriers among the healthcare providers. A study that was conducted among the patient and their family cohort in China acts as a counterpart for this gap identified. This study observed that the 11 female relatives of persons with hemophilia remained uncertain about their own carrier status and had little to no knowledge about genetic testing, despite willing to undergo the same. They also mentioned the fear of a positive result, cost and privacy as a barrier [11]. While many identified their source of information as the primary treating physician it was stated that physicians who weren't haematologist could not advise them on carrier risk during pregnancy. This observation points out the lack of knowledge about carrier symptomatology or hemophiliac females among healthcare providers isn't an isolated observation. This points towards a missed opportunity for genetic counselling and risk informed reproductive/family planning decisions to be made among these carriers.

The pilot reliability analysis supports the psychometric soundness of the questionnaire, with good-to-excellent Cronbach's alpha values across all three domains. The single Knowledge item with zero variance reflects a ceiling effect from near-universal recognition of a very basic fact rather than a defect in the item, while the four items with weak or negative item-total correlations-largely relating to inheritance-pattern nuances and less common clinical signs-are reasonable, targeted candidates for rewording ahead of full-scale data collection and analysis.

CONCLUSION

This hospital-based survey identifies selected hemophilia-related knowledge gaps and variation in healthcare workers' self-reported confidence and practices. Item-level agreement should not be presented as objective clinical performance or as evidence of a ranked KAP composite without documented scoring validation. Focused education may be considered and its effects should be tested prospectively.

Limitations

- Single-centre study limiting the generalizability to other regions or care settings
- Cross-sectional design captures a single time point and fails to establish causal or temporal relationships between training exposure and KAP scores
- As practice was assessed by self-reporting a social acceptability bias may be present
- The reliability analysis was based on a small pilot sample reverification of the same with the complete sample was not conducted
- As current analysis is more descriptive demographic analysis as a direction for future with adequately powered subgroup sizes will provide a wider observation

Informed Consent Statement

Written informed consent was obtained from all individual participants included in the study.

Data Availability Statement

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author Contributions

V.R.V. and S.D. Conceived and designed the study; V.R.V., D.A. and Z.C. Collected the data; V.R.V. and U.M. Analyzed and interpreted the data; V.R.V. Drafted the manuscript; S.D., U.M., D.A. and Z.C. Critically revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

Ethical Statement

This study was conducted in accordance with the Declaration of Helsinki. No direct patient intervention was involved; the study was reviewed by the Institutional Ethics Committee, [SDUAHER Institutional Ethics Committee name], approval number [to be inserted]. A patient information sheet and informed consent form were used; participant identities remained anonymous.

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