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A cross-sectional questionnaire-based study on quality of life in patients of hemophilia from Jamshedpur, Jharkhand

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ABSTRACT: Background: Haemophilia is a lifelong inherited bleeding disorder that can result in recurrent bleeding, pain, joint damage, restricted mobility, treatment dependence, and psychosocial distress. These consequences may substantially affect quality of life (QoL), particularly in settings where access to comprehensive haemophilia care is variable. This study assessed QoL and selected day-to-day concerns among people with haemophilia registered with the Haemophilia Society of India, Jamshedpur Chapter.

Methods: A registry-based, descriptive cross-sectional study was conducted among patients with documented haemophilia A or haemophilia B registered with the Haemophilia Society of India, Jamshedpur Chapter, Jharkhand, India. Data were collected from December 2024 to December 2025. Convenience sampling was used; 53 registered patients were approached, of whom 35 provided informed consent and were included in the quality-of-life analysis. Data were collected through interviewer-administered questionnaires in English or Hindi, according to participant preference and comprehension. Quality of life was assessed using the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. Domain scores for physical health, psychological health, social relationships, and environment were calculated according to the WHOQOL-BREF scoring protocol and transformed to a 0–100 scale, with higher scores indicating better perceived QoL. Descriptive statistics were used to summarise questionnaire responses and domain scores.

Results: Thirty-five participants had available WHOQOL-BREF scoring data. Only 6 participants (17.1%) rated their overall QoL as good or very good, and 10 (28.6%) reported being satisfied with their health; none reported being very satisfied with their health. Pain-related limitations were prominent, with 30 participants (85.7%) reporting that physical pain limited necessary activities to a moderate, very high, or extreme extent. In addition, 29 participants (82.9%) reported requiring medical treatment to function in daily life to a moderate, very high, or extreme extent. Dissatisfaction with sleep was reported by 11 participants (31.4%), while 22 participants (62.9%) reported experiencing negative feelings, including despair, anxiety, or depression, quite often, very often, or always. The physical-health domain had the lowest mean score (49.05 ± 13.94; n = 35), followed by psychological health (52.15 ± 8.66; n = 31) and environment (52.36 ± 13.43; n = 34). The social-relationships domain had the highest observed mean score

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(57.67 ± 14.22; n = 25), although this domain had the lowest number of valid responses.

Conclusion: Participants reported substantial pain-related functional limitation, dependence on medical treatment for daily functioning, and frequent negative emotional experiences. The findings support routine QoL assessment, pain evaluation, joint-health assessment, and psychosocial support as components of comprehensive haemophilia care. As this was a small, single-centre, cross-sectional study with incomplete clinical and demographic data, the findings should be interpreted descriptively and require confirmation in larger multicentre studies.

INTRODUCTION

Haemophilia is a lifelong bleeding disorder that results from deficiency of coagulation factors involved in normal haemostasis. It predominantly affects males because the common inherited forms are X-linked. Haemophilia A results from factor VIII deficiency, whereas haemophilia B results from factor IX deficiency. Haemophilia A is more common than haemophilia B and accounts for the majority of inherited haemophilia cases. [1] The clinical severity of haemophilia is determined by the residual plasma activity of the deficient clotting factor. Individuals with factor activity below 1 IU/dL are classified as having severe disease, those with activity between 1 and 5 IU/dL as having moderate disease, and those with activity between 5 and 40 IU/dL as having mild disease. [3]

The disorder is characterised by recurrent or prolonged bleeding episodes, which may occur spontaneously or after trauma and medical procedures. Repeated bleeding into joints and muscles may lead to chronic pain, restricted mobility, haemophilic arthropathy, physical disability, and reduced ability to participate in education, employment, and social activities. Bleeding may also occur at potentially life-threatening sites, including the central nervous system and gastrointestinal tract. Consequently, haemophilia affects not only physical health but also emotional well-being, social relationships, independence, and overall life satisfaction. [1]

The management of haemophilia has improved substantially with the availability of clotting-factor replacement therapy and advances in comprehensive haemophilia care. However, treatment remains a lifelong requirement for many patients and can impose considerable physical, emotional, and financial burden. Access to regular treatment may be particularly challenging in resource-constrained settings because of the high cost and limited availability of clotting factors, specialised laboratory support, rehabilitation services, and trained multidisciplinary teams. The World Federation of Haemophilia has estimated that a substantial proportion of people with haemophilia worldwide remain undiagnosed or inadequately treated. [4]

Quality of life is therefore an important patient-centred outcome in haemophilia care. It reflects the individual's perception of physical health, psychological well-being, personal relationships, and environmental circumstances. Previous research has shown that adults with haemophilic arthropathy experience impaired quality of life, particularly where pain, joint limitations, and reduced physical functioning are present. [5] Measuring quality of life can provide information that may not be captured by clinical measures alone, including the daily impact of bleeding symptoms, treatment requirements, social limitations, emotional distress, and unmet support needs.

Patient-reported outcomes are increasingly recognised as important in haemophilia research and care. Patients may value outcomes that extend beyond survival and bleeding control, such as functional ability, emotional well-being, treatment convenience, independence, and participation in normal life roles. [6] Understanding these experiences is particularly important when planning services for people with haemophilia, as clinical management should address both the medical consequences of bleeding and the broader psychosocial impact of living with a chronic disorder.

There remains a need to document the quality of life and day-to-day concerns of people with haemophilia in local settings. Such evidence can help identify areas requiring greater clinical, rehabilitative, psychosocial, and community support. Therefore, this study aimed to assess the quality of life of diagnosed patients with haemophilia A and haemophilia B registered with the Haemophilia Society of India, Jamshedpur Chapter, and to describe the difficulties experienced by participants in their daily lives.

MATERIALS AND METHODS

Study design and reporting

This registry-based, descriptive cross-sectional study assessed health-related quality of life among patients with haemophilia registered with the Haemophilia Society of India, Jamshedpur Chapter. The study is reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations for cross-sectional studies.

Study setting and period

The study was conducted among registered patients of the Haemophilia Society of India, Jamshedpur Chapter, Jamshedpur, East Singhbhum district, Jharkhand, India. Data collection was undertaken over one year, from **December, 2024** to **December,2025**.

Participants

Patients registered with the Haemophilia Society of India, Jamshedpur Chapter, were screened for eligibility.

Participants were eligible if they:

1. Had a documented diagnosis of haemophilia A or haemophilia B;
2. Were registered with the Haemophilia Society of India, Jamshedpur Chapter; and
3. Provided informed consent to participate.

For participants younger than 18 years, informed consent was obtained from a parent or legal guardian, and assent was obtained from the participant, where applicable.

Participants were excluded if they declined consent or assent, withdrew their participation, had an unconfirmed diagnosis of haemophilia, or had incomplete WHOQOL-BREF responses that did not permit valid calculation of the relevant domain score.

Sampling strategy and study size

Convenience sampling was used because haemophilia is a rare disorder and the study population was identified through the available registry of the Haemophilia Society of India, Jamshedpur Chapter. All eligible registered patients who could be contacted during the study period were invited to participate.

A formal sample-size calculation was **not performed, as this study is about a rare condition and participants were approached through registry.**. A total of **53** patients were approached, **35** provided consent, and **35** were included in the final analysis.

Data collection procedure

Data were collected by the principal investigator or co-investigator through interviewer-administered questionnaires. Before enrolment, participants and, where relevant, their parents or legal guardians were informed about the purpose of the study, study procedures, voluntary nature of participation, and confidentiality of the collected information.

The questionnaire was administered in English or Hindi according to the participant's language preference and comprehension. The Hindi version of the WHOQOL-BREF questionnaire was used for participants who were unable to respond in English. The source of the Hindi version is from Department of Community Medicine, All India Institute of Medical Sciences and is available in public domain.

For participants who were unable to read, each questionnaire item was read aloud by the investigator in the preferred language, and the participant's response was recorded without interpretation or suggestion. Completed questionnaires were checked for completeness at the time of data collection

Outcome measures

The primary outcome was health-related quality of life, assessed using the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. The WHOQOL-BREF consists of 26 items and evaluates four domains: physical health,

psychological health, social relationships, and environment. It also includes two individual items assessing overall quality of life and overall satisfaction with health.

Questionnaire items were scored according to the WHOQOL-BREF scoring protocol. Negatively phrased items were reverse scored before calculation of domain scores. Domain scores were calculated from the relevant items and transformed to a 0-100 scale, with higher scores representing better perceived quality of life. The handling of missing questionnaire responses was performed according to **WHOQOL-BREF scoring.**

Data management and statistical analysis

Data were entered into **Microsoft Excel** and checked for accuracy, completeness, and consistency before analysis. Participant characteristics were summarised using descriptive statistics.

Categorical variables were reported as frequency and percentage. Continuous variables were summarised as mean with standard deviation or median with interquartile range, as appropriate. WHOQOL-BREF domain scores were presented as the number of participants with valid domain scores. For item-level questionnaire responses, percentages were calculated using the number of participants with available responses to that item as the denominator.

As the study was descriptive in nature, no hypothesis-testing or comparative analyses were performed.

Ethical considerations

Ethical approval was obtained from the **Institutional Ethics Committee of Manipal Tata Medical College** before commencement of the study (**Approval No.:MTMC/IEC/2024/92; Approval date: 13.12.2024**). Informed consent was obtained from all adult participants before data collection. For participants younger than 18 years, parental or guardian consent and participant assent were obtained.

Participation was voluntary. Participants could decline to answer any question or withdraw from the study at any time without any effect on their routine clinical care or services received through the Haemophilia Society of India.

Participant confidentiality was maintained throughout the study. Data were anonymised using unique study identification numbers, and identifying information was stored separately from the research dataset. The anonymised data were accessible only to the principal investigator, co-investigator, and authorised research personnel.

RESULT

A total of 35 participants with available WHOQOL-BREF scoring data were included in the quality-of-life analysis. The number of valid responses varied across domains because some questionnaires had missing item responses. All 35 participants had a valid physical-health domain score, whereas valid scores were available for 31 participants in the psychological-health domain, 25 participants in the social-relationships domain, and 34 participants in the environment domain.

Overall quality of life and perceived health

Overall quality of life and perceived health were assessed using the two general WHOQOL-BREF items. Of the 35 participants, 6 (17.1%) rated their overall quality of life as good or very good. Similarly, 10 participants (28.6%) reported being satisfied with their health; no participant reported being very satisfied with their health.

Selected item-level quality-of-life findings

Pain and treatment dependence were common concerns. Thirty participants (85.7%) reported that physical pain prevented them from performing necessary activities to a moderate, very high, or extreme extent. In addition, 29 participants (82.9%) reported needing medical treatment to a moderate, very high, or extreme extent to function in their daily lives.

Eleven participants (31.4%) reported being dissatisfied or very dissatisfied with their sleep. Negative feelings, including despair, anxiety, or depression, were experienced quite often, very often, or always by 22 participants (62.9%).

Table 1. Overall quality of life, perceived health, and selected WHOQOL-BREF item-level findings among participants (N = 35)

Outcome	Participants, n/N	Percentage
Good or very good overall quality of life	6/35	17.1
Satisfied or very satisfied with health	10/35	28.6
Very satisfied with health	0/35	0.0
Pain limited necessary activities to a moderate, very high, or extreme extent	30/35	85.7
Needed medical treatment to function in daily life to a moderate, very high, or extreme extent	29/35	82.9
Dissatisfied or very dissatisfied with sleep	11/35	31.4
Negative feelings experienced quite often, very often, or always	22/35	62.9

WHOQOL-BREF domain scores

WHOQOL-BREF domain scores were transformed to a 0-100 scale, with higher scores indicating better perceived quality of life. The highest mean score was observed in the social-relationships domain (57.67 ± 14.22), followed by the environment domain (52.36 ± 13.43) and the psychological-health domain (52.15 ± 8.66). The physical-health domain had the lowest mean score (49.05 ± 13.94).

Table 2. WHOQOL-BREF domain scores

WHOQOL-BREF domain	Valid responses, n	Mean ± SD	95% CI
Physical health	35	49.05 ± 13.94	44.26-53.84
Psychological health	31	52.15 ± 8.66	48.97-55.33
Social relationships	25	57.67 ± 14.22	51.80-63.53
Environment	34	52.36 ± 13.43	47.68-57.05

SD: standard deviation; CI: confidence interval. Domain-specific valid sample sizes differ because WHOQOL-BREF domain scores were not calculated when the number of missing responses exceeded the permitted limit for that domain.

DISCUSSION

This cross-sectional study assessed quality of life among 35 participants with available WHOQOL-BREF scoring data from the Haemophilia Society of India, Jamshedpur Chapter. Overall, quality of life was adversely affected across all four WHOQOL-BREF domains. The physical health domain had the lowest mean score (49.05 ± 13.94), followed by psychological health (52.15 ± 8.66) and environmental health (52.36 ± 13.43). Although the social relationships domain had the highest observed mean score (57.67 ± 14.22), this domain had the lowest number of valid responses and should therefore be interpreted cautiously. Only 17.1% of participants rated their overall quality of life as good or very good, and 28.6% reported satisfaction or high satisfaction with their health. These findings indicate that, despite advances in haemophilia care, many affected individuals continue to experience substantial limitations in their perceived health and daily well-being.

Pain and its consequences emerged as the principal concerns in this study. More than four-fifths of participants reported that physical pain limited the performance of necessary activities to a moderate-to-extreme extent, and a similar proportion reported requiring medical treatment to function in daily life. These observations are consistent with contemporary evidence showing that recurrent bleeding, chronic pain, joint impairment, and restricted mobility remain important determinants of health-related quality of life among people with haemophilia. In the European CHESS II and CHESS PAEDs analyses, target joints, pain, restrictions in social participation, and reduced opportunities for physical activity remained evident among people with haemophilia A despite contemporary treatment availability [12]. Similarly, the Nordic MoHem study reported that arthropathy adversely affected both physical activity and health-related quality of life among individuals with moderate haemophilia A and B

[13].

The low physical-health score in the present study should be interpreted in the context of these findings. Recent multivariable analysis of CHESS II data demonstrated that haemophilia severity and chronic pain were independently associated with poorer health-related quality of life [14]. A further CHESS II analysis found that factor VIII activity levels, bleeding outcomes, and quality of life are interrelated, supporting the importance of sustained bleeding prevention and pain management [15]. However, the present study did not collect sufficiently complete data on haemophilia type, severity, inhibitor status, joint disease, bleeding frequency, or treatment regimen. Therefore, it cannot be concluded that the observed physical-health impairment was caused by any specific clinical characteristic or limitation in treatment access. This is a major limitation and should be addressed in future studies.

Psychological well-being was also an important area of concern. Nearly two-thirds of participants reported experiencing negative feelings, including despair, anxiety, or depression, quite often, very often, or always. This finding supports the need to view haemophilia as a condition with psychosocial as well as physical consequences. The recent HemoLIFE study reported persistent impairments in quality of life, functional adaptation, leisure participation, and psychological well-being among individuals with haemophilia A without inhibitors [11]. These findings indicate that the absence of inhibitors alone does not eliminate the broader emotional and social burden associated with haemophilia. The relatively higher social-relationships score in the present study should not be interpreted as evidence of an absence of social burden, particularly because the social domain was available for fewer participants than the other domains.

Recent treatment studies provide important context for the potentially modifiable nature of quality-of-life impairment. Extended-half-life factor replacement has been associated with improvements in bodily pain, physical-role functioning, emotional-role functioning, and mental health in the LongHest Project [16]. Long-term prophylaxis with efmoroctocog alfa has also been associated with reduced pain and improvement in physical-health and emotional quality-of-life measures among individuals with haemophilia A [17]. Furthermore, the HemiNorth 2 study evaluated quality of life, physical activity, and joint health among people with severe haemophilia A receiving emicizumab, reflecting the increasing emphasis on patient-reported outcomes alongside bleeding control [18]. These findings do not establish treatment effects in the present study, since treatment exposure was not assessed; nevertheless, they highlight that pain, functional limitation, treatment burden, and quality of life are clinically relevant outcomes that should be routinely monitored.

The findings also have relevance in the Indian context. In a recent Indian cross-sectional study among children with haemophilia, disease severity, target joints, and inhibitor status were associated with poorer health-related quality of life [19]. In addition, a real-world study from Assam reported improvement in joint-health, functional-independence, and quality-of-life measures following 12 months of emicizumab therapy in individuals with haemophilia A [20]. While these studies cannot be directly compared with the present results because of differences in age groups, treatments, study design, and quality-of-life instruments, they reinforce the need for comprehensive care that addresses physical, emotional, functional, and treatment-related concerns.

This study has some limitations to discuss. Its cross-sectional design does not permit causal inference or assessment of changes in quality of life over time. The use of convenience sampling from a single regional haemophilia-society registry limits generalisability. The small sample size, domain-specific missing responses, and absence of a comparison group may have influenced the precision and interpretation of the findings. In addition, the lack of complete demographic and clinical data prevented subgroup analysis according to age, sex, haemophilia type, disease severity, inhibitor status, joint involvement, treatment modality, or bleeding history. The study also assessed perceived quality of life using a generic instrument; it did not include a haemophilia-specific quality-of-life instrument or a separately analysed structured assessment of felt needs.

Despite these limitations, the study provides preliminary patient-reported evidence of considerable physical and emotional burden among people with haemophilia registered in Jamshedpur. The findings support the integration of routine quality-of-life assessment, pain evaluation, psychosocial screening, and clinical assessment of joint health into haemophilia care. Larger multicentre studies using complete demographic and clinical data, a haemophilia-specific quality-of-life instrument, and longitudinal follow-up are needed to identify modifiable determinants of poor quality of life and to evaluate the effect of treatment strategies in this population.

CONCLUSION

Participants in this study reported impaired quality of life, with the greatest burden observed in the physical-health domain.

Pain-related limitation, dependence on medical treatment for daily functioning, and frequent negative emotional experiences were prominent. Comprehensive haemophilia care should therefore extend beyond bleeding control to include pain management, joint-health preservation, psychosocial support, and routine assessment of patient-reported outcomes.

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