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# IMPACT OF DIETARY AND LIFESTYLE MODIFICATION ON NUTRITIONAL STATUS IN CHILDREN WITH HEMOPHILIA- A LONGITUDINAL STUDY

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**ABSTRACT**

**Background:** Hemophilia is a hereditary bleeding disorder characterized by recurrent bleeding episodes, particularly into joints and muscles, leading to chronic arthropathy and functional limitation. With improved survival due to factor replacement therapy and prophylaxis, long-term issues such as nutritional status, physical activity, and quality of life have gained increasing importance. Children with hemophilia are vulnerable to both undernutrition and overweight/obesity due to reduced mobility, recurrent pain, fear of physical activity, and socioeconomic factors. Addressing dietary habits and lifestyle practices may play a crucial role in improving overall health outcomes in this population. **Aim:** To evaluate the impact of dietary and lifestyle modification on nutritional status among children with hemophilia in a tertiary care center.

**Materials and Methods:** This longitudinal study included 60 children aged 0–18 years with hemophilia A or B registered at the Integrated Centre for Hemophilia and Hemoglobinopathy, Coimbatore Medical College Hospital. The study was conducted over 6 months (October 2024 to March 2025). Baseline anthropometric measurements were recorded, and nutritional status was assessed using WHO and IAP growth charts as appropriate for age. Individualized dietary counseling and lifestyle modifications, including physiotherapy-based strengthening and range-of-motion exercises, were provided. Follow-up assessments were conducted at the end of 6 months to evaluate changes in nutritional status. Clinical profile, treatment pattern, joint health score (HJHS), and social impact were also analyzed.

**Results:** At baseline, 13.3% of children were overweight, 13.3% were underweight, and 11.7% were obese. After intervention, overweight reduced by 62.5% (p=0.001) and underweight reduced by 75% (p=0.036), while obesity remained unchanged (p=0.699). Nutritional abnormalities were more common in older children. The majority had severe hemophilia (75%) and were on prophylaxis (63.3%). Joint health improved in 60.5% of children receiving prophylaxis. Functional limitations and school absenteeism were common.

**Conclusion:** Dietary and lifestyle modification significantly improved undernutrition and overweight among children with hemophilia, though obesity persisted. Integrating structured nutritional and physiotherapy interventions into comprehensive hemophilia care may enhance functional outcomes and overall well-being.

**Keywords:** Hemophilia, Nutritional status, Dietary modification, Lifestyle intervention, Children.

## INTRODUCTION

Hemophilia is a hereditary bleeding disorder caused by deficiency of clotting factor VIII (hemophilia A) or factor IX (hemophilia B), leading to recurrent bleeding episodes that predominantly involve joints and muscles. Repeated hemarthroses and soft-tissue bleeds can result in chronic synovitis, progressive hemophilic arthropathy, pain, reduced mobility, and limitations in participation in day-to-day activities. Over the last few decades, advances in factor replacement therapy, home infusion, prophylaxis, physiotherapy, and comprehensive care models have substantially improved survival and reduced catastrophic bleeding, shifting the clinical focus toward long-term outcomes such as functional independence, musculoskeletal health, and overall well-being across childhood and adolescence.[1] The global burden of hemophilia is substantial, but it is unevenly recognized and managed because diagnosis and access to factor concentrates vary widely between regions. Population estimates derived from national reports and global surveys show marked differences in reported prevalence between high-income settings and the rest of the world, reflecting both true epidemiologic variation and underdiagnosis in resource-limited settings.[2] In low- and middle-income regions, many children experience delayed diagnosis, episodic or inadequate factor availability, and reduced access to structured rehabilitation. Nutritional status has emerged as an important yet often under-addressed component of comprehensive hemophilia care. Children with hemophilia may face a "double burden" of malnutrition: some are undernourished due to chronic illness effects, reduced appetite during painful episodes, school absenteeism and psychosocial stress, or socioeconomic constraints; others develop overweight and obesity due to physical inactivity, fear-avoidance of movement, limitations from arthropathy, and sedentary lifestyles. Evidence from Indian pediatric settings highlights that nutritional concerns are clinically relevant: in a cross-sectional study of 50 children with hemophilia, overweight and obesity together accounted for a sizeable proportion, with the combined burden more prominent in adolescents than in younger children.[3] Excess adiposity has particular significance in hemophilia because it can amplify musculoskeletal problems and complicate treatment. Higher body weight increases mechanical loading on weight-bearing joints that are already vulnerable to bleeding-related damage, potentially accelerating pain, stiffness, and loss of range of motion. In addition, obesity may complicate prophylactic dosing strategies and increase overall treatment costs, while also raising the risk of metabolic comorbidities that can affect long-term health. A synthesis of evidence on obesity in hemophilia has emphasized that overweight/obesity is common globally and is associated with reduced joint mobility, chronic pain, and added disease burden, underscoring the need for structured weight management as part of routine care.[4] At the same time, managing nutrition in hemophilia must be integrated with safe and feasible lifestyle practices. Regular physical activity is now widely encouraged for children with hemophilia, provided that activity selection and intensity are tailored to bleeding risk, joint health, and prophylaxis status. Activity improves muscle strength, proprioception, balance, endurance, and psychosocial well-being, while reducing the functional decline that can follow repeated hemarthrosis. Guidance for children with chronic conditions, including hemophilia, supports individualized counseling and structured participation in safe exercise and sport, balancing benefits with injury risk and emphasizing appropriate supervision and medical input.[5] Physiotherapy plays a central role in translating "be active" advice into structured programs that families can follow. Practical resources developed for hemophilia care describe progressive exercise approaches focused on range of motion, muscle strengthening, and proprioception for commonly affected joints (knees, ankles, elbows), and emphasize that exercise selection must consider recent bleeds, target joints, pain, and established deformity.[6]

## MATERIALS AND METHODS

The study population comprised children diagnosed with hemophilia A or hemophilia B, aged 0–18 years, who were registered under the Integrated Centre for Hemophilia and Hemoglobinopathy at Coimbatore Medical College Hospital. The study was conducted over a period of 6 months, from October 2024 to March 2025, using a longitudinal study design with a sample size of 60 participants.

Children with hemophilia A or B aged 0–18 years registered in the Integrated Centre for Hemophilia and Hemoglobinopathy at Coimbatore Medical College Hospital were included in the study. Children were excluded if their parents did not provide consent for participation. Children with Gross Motor Function Classification System (GMFCS) levels III, IV, and V were also excluded.

A total of 60 children with hemophilia (type A and B), aged 0–18 years, were enrolled after obtaining informed consent from their parents. At baseline, anthropometric measurements were recorded for all participants. Length or height was measured using an infantometer or stadiometer respectively, and weight was measured using an electronic weighing scale. Height, weight-for-height, and body mass index (BMI) were calculated to assess nutritional status, and participants were classified as underweight, overweight, or obese based on these measurements.

For children under 5 years of age, nutritional status was assessed using WHO MGRS 2006 growth charts. Weight-for-height below the 3rd percentile was considered underweight, weight-for-height above the 97th percentile was considered overweight, and weight-for-height above the 99th percentile was considered obese. For children older than 5 years, IAP 2015 growth charts were used, where BMI below the 3rd percentile was classified as underweight, BMI above the 23rd adult equivalent was considered overweight, and BMI above the 27th adult equivalent was considered obese.

Each participant received individualized dietary modifications that were planned according to cultural, religious, and local practices. Lifestyle modifications were also advised, mainly through physiotherapy, including strengthening, stretching, balance training, coordination exercises, and range-of-motion exercises. These recommendations were formulated based on assessment using the Hemophilia Joint Health Score in collaboration with a physiotherapist.

Follow-up was ensured periodically through in-person meetings or telephonic contact to reinforce dietary and lifestyle recommendations. Participants continued to receive factor therapy as required, and care was adjusted accordingly during the follow-up period. At the end of 6 months, anthropometric measurements were repeated to assess the impact of dietary and lifestyle modifications on nutritional status.

## RESULTS

Table 1 shows the overall effect of dietary and lifestyle modification on nutritional status among the 60 children with hemophilia. At baseline, 7 children were obese, 8 were overweight, and 8 were underweight. After 6 months of intervention, obesity remained unchanged with 7 children still classified as obese, indicating no measurable improvement in this category (0% change) and the difference was not statistically significant ($p = 0.699$). In contrast, a clear improvement was observed in the overweight and underweight categories. The number of overweight children decreased from 8 to 3, showing a 62.5% reduction, and this improvement was statistically significant ($p = 0.001$). Similarly, underweight status improved markedly, reducing from 8 to 2 children, representing a 75% reduction, with statistical significance ($p = 0.036$).

Table 2 describes the age-wise distribution of nutritional status before and after intervention, showing that nutritional abnormalities were mainly present in older children. No child below 1 year had underweight, overweight, or obesity either at baseline or post intervention. Among children aged 1–5 years, underweight reduced from 2 to 1 after intervention, while there were no overweight or obese children in this age group. The most notable improvements were seen in the 6–12 years group, where underweight reduced from 4 children to none, indicating complete correction of undernutrition in that age band, and overweight reduced from 4 to 1. However, obesity in this group remained unchanged at 5 children both before and after intervention. In adolescents aged 12–18 years, underweight reduced from 2 to 1 and overweight decreased from 4 to 2, showing partial improvement. Similar to the 6–12 years group, obesity remained unchanged in adolescents (2 children both pre and post).

Table 3 outlines the distribution of hemophilia type and severity grading in the study population. Hemophilia A was the predominant diagnosis, accounting for 56 out of 60 children, while hemophilia B was present in only 4 children. Regarding severity, the majority of the participants had severe hemophilia, with 45 children classified as severe. Moderate hemophilia was observed in 9 children, and only 6 children had mild hemophilia.

Table 4 presents treatment patterns and major clinical complications. Most children were receiving prophylactic factor therapy (38 children), while 21 children were on on-demand therapy, and only 1 child had no follow-up. Adverse reactions to factor administration were rare, with only one child reporting a reaction, while 59 children had no adverse effects. Inhibitor status was reported among hemophilia A patients, where 7 children had inhibitors and 53 did not, showing that a small but clinically relevant proportion had inhibitor development. Life-threatening hemorrhages were reported in 4 children, while 56 had no such history, suggesting that although uncommon, severe bleeding events were present in a subset. Blood transfusion history was noted in 12 children, while 48 had never received transfusions, indicating that a portion of children required transfusion support, likely related to bleeding severity, delayed access to factor therapy, or previous major hemorrhagic events.

Table 5 explains genetic and family-related patterns. A family history of hemophilia was present in 20 children, while 40 children had no known family history. Among those with a positive family history (n=20), the most commonly affected relatives were grandfathers (6 cases) and cousins (5 cases), followed by maternal uncles (4 cases), great grandfathers (2 cases), and siblings (1 case). This distribution supports the inherited pattern of hemophilia, often transmitted through maternal lineage. Carrier testing status showed that only 13 mothers were confirmed carriers, while 47 parents were not tested, indicating a large gap in genetic evaluation and carrier identification.

Table 6 summarizes the social impact, activity patterns, joint health outcomes, and vaccination status. School absenteeism was common, with 37 children reporting absenteeism, while only 17 reported no absenteeism. Five were not applicable (likely younger children), and one child was home-schooled. Participation in sports activities was limited; only 5 children were involved in contact sports, 22 participated in non-contact sports, 28 were not involved in any sports, and 5 were not applicable. Daily activity impairment was highly prevalent, with 48 children reporting impact on daily activities and only 12 reporting no impact, suggesting significant functional limitation in the majority. Among children on prophylaxis (n=38), joint health assessment using HJHS at the end of the study showed improvement in 23 children, static status in 5, and worsening in 10. This indicates that while most children on prophylaxis had measurable improvement in joint health, a subgroup continued to deteriorate, possibly due to severe baseline arthropathy, poor adherence, recurrent bleeds, or delayed initiation of prophylaxis. Vaccination status showed that 42 children were fully immunised while 18 were partially immunised, reflecting reasonably good immunisation coverage, though a significant proportion remained incomplete, which is important given the risk of transfusion exposure and infections in bleeding disorders.

**Table 1: Effect of dietary/lifestyle modification on nutritional status (n=60)**

| Nutritional status (BMI/weight status) | Baseline n | Post-modification n | Improvement/Change | P value |
|---|---|---|---|---|
| Obese | 7 | 7 | 0% | 0.699 |
| Overweight | 8 | 3 | 62.5% reduction | 0.001 |
| Underweight | 8 | 2 | 75% reduction | 0.036 |

**Table 2: Age-wise distribution of nutritional status at baseline and after intervention**

| Age group | Underweight (Pre) | Underweight (Post) | Overweight (Pre) | Overweight (Post) | Obese (Pre) | Obese (Post) |
|---|---|---|---|---|---|---|
| < 1 year | 0 | 0 | 0 | 0 | 0 | 0 |
| 1–5 years | 2 | 1 | 0 | 0 | 0 | 0 |
| 6–12 years | 4 | 0 | 4 | 1 | 5 | 5 |
| 12–18 years | 2 | 1 | 4 | 2 | 2 | 2 |

**Table 3: Hemophilia type and severity grading (n=60)**

| Variable | Category | Number of patients |
|---|---|---|
| Type of hemophilia | Hemophilia A | 56 |
| | Hemophilia B | 4 |
| Severity grading | Mild | 6 |
| | Moderate | 9 |
| | Severe | 45 |

**Table 4: Treatment pattern and key clinical complications (n=60)**

| Parameter | Category | Number of patients |
|---|---|---|
| Frequency of factor use | No follow up | 1 |
| | On demand | 21 |
| | Prophylactic | 38 |
| Adverse reaction following factor use | No | 59 |
| | Yes | 1 |
| Presence of inhibitors (Hemophilia A) | No | 53 |
| | Yes | 7 |
| History of life-threatening hemorrhages | No | 56 |
| | Yes | 4 |
| History of blood transfusion | No | 48 |
| | Yes | 12 |

**Table 5: Family history and carrier status (n=60)**

| Parameter | Category | Number of patients |
|---|---|---|
| Family history of hemophilia | Yes | 20 |
| | No | 40 |
| Relation among those with family history (n=20) | Cousin | 5 |
| | Grandfather | 6 |
| | Great grandfather | 2 |
| | Maternal uncle | 4 |
| | Sibling | 1 |
| Carrier status of parents | Carrier Mother | 13 |
| | Not tested | 47 |

**Table 6: Social/functional impact, vaccination status, and joint health outcome**

| Parameter | Category | Number of patients |
|---|---|---|
| History of school absenteeism (n=60) | No | 17 |
| | Yes | 37 |
| | Not applicable | 5 |
| | Home schooling | 1 |
| Involvement in sports activities (n=60) | Contact | 5 |
| | Non-contact | 22 |
| | Not applicable | 5 |
| | Not involved | 28 |
| Impact on daily activities (n=60) | No | 12 |
| | Yes | 48 |

| | | |
|---|---|---|
| HJHS status in patients on prophylaxis at end of study (n=38) | Static | 5 |
| | Improvement | 23 |
| | Worsening | 10 |
| Vaccination status (n=60) | Immunised | 42 |
| | Partially immunised | 18 |

## DISCUSSION

The nutritional shifts seen after the intervention (overweight reduced from 8/60 [13.3%] to 3/60 [5.0%], p=0.001; underweight reduced from 8/60 [13.3%] to 2/60 [3.3%], p=0.036; obesity unchanged at 7/60 [11.7%], p=0.699) support the concept that weight extremes other than established obesity may respond within a short follow-up when calorie quality, meal patterning, and safe activity are reinforced. Similar concerns have been raised in hemophilia populations where excess weight is increasingly common and contributes to functional limitation; Wong et al. (2011) emphasized that prevention and management of overweight/obesity should be integrated into routine hemophilia care and highlighted the joint and mobility consequences of higher BMI, which aligns with why our program focused on individualized diet and physiotherapy-based lifestyle change.[7]

The age pattern in our cohort—no nutritional abnormality below 1 year, modest underweight in 1–5 years, and clustering of overweight/obesity in school-age children and adolescents—mirrors the broader observation that excess weight rises sharply with age in people with hemophilia. In our data, overweight was concentrated in 6–12 years (4→1) and 12–18 years (4→2), while obesity persisted in 6–12 years (5→5) and 12–18 years (2→2) despite other improvements. Chang et al. (2019) reported that overweight/obesity prevalence increased from 7.1% in ≤10 years to 34.5% in 11–18 years, and also linked weight status with joint outcomes, which is consistent with our finding that obesity was harder to reverse over just 6 months—especially in older age bands where reduced activity and established arthropathy may perpetuate weight gain.[8]

Our disease distribution (Hemophilia A 56/60 [93.3%], Hemophilia B 4/60 [6.7%]) and severity profile (severe 45/60 [75%], moderate 9/60 [15%], mild 6/60 [10%]) reflect the expected predominance of Hemophilia A and the referral bias toward severe cases in tertiary centers. Pawan et al. (2021) similarly described Hemophilia A as the major subtype in an Indian tertiary-care setting and highlighted that severe disease forms a substantial share of clinically registered cohorts, supporting the representativeness of our sample for high-burden pediatric hemophilia care in resource-constrained pathways.[9]

Most children in this study were on prophylaxis (38/60 [63.3%]) rather than purely episodic treatment (21/60 [35.0%]), and joint health outcomes among those on prophylaxis were encouraging, with HJHS showing improvement in 23/38 [60.5%], static in 5/38 [13.2%], and worsening in 10/38 [26.3%] at study end. Mandal et al. (2019) demonstrated that even low-dose tertiary prophylaxis improved patient-centered outcomes (quality of life) in severe hemophilia A, supporting our observation that sustained prophylaxis—alongside lifestyle/physiotherapy—can translate into functional gains, although a notable subgroup may still worsen due to advanced baseline arthropathy, delayed prophylaxis initiation, or ongoing bleed burden.[10]

Inhibitor presence among hemophilia A patients in our cohort was 7/56 (12.5%), which is clinically meaningful because inhibitors complicate factor replacement and increase bleeding morbidity and costs. The RODIN study by Gouw et al. (2013) showed that early intensive/high-dose FVIII treatment episodes increased inhibitor risk, whereas prophylactic treatment was associated with reduced inhibitor incidence after a threshold exposure period, emphasizing why careful treatment planning, avoidance of unnecessary intensive exposure where possible, and adherence-supportive prophylaxis models matter in pediatric practice.[11]

Life-threatening hemorrhage was reported in 4/60 (6.7%) in our cohort, indicating that severe bleeds persist despite availability of factor therapy for many children. Touré et al. (2022) described life-threatening bleeding as a major complication in a large cohort and analyzed its characteristics and outcomes over long follow-up, reinforcing that even with evolving care, identifying high-risk patients (severe disease, inhibitors, poor access/adherence) and strengthening rapid response pathways are essential—particularly because our study also included a small subgroup with inhibitors and a quarter of prophylaxis patients still showing HJHS worsening.[12]

A history of blood transfusion in 12/60 (20%) suggests that a substantial subset required supportive care for significant bleeding or anemia-related complications, which remains an important safety and infection-prevention consideration in hemophilia services. Tagariello et al. (2008), although focusing on acquired hemophilia A, highlighted transfusion support as a key component during serious hemorrhagic phases, underscoring the broader principle that transfusion often signals severe bleeding burden and should prompt systematic review of bleed prevention strategies, inhibitor screening, and optimization of prophylaxis and rehabilitation to reduce future high-risk episodes.[13]

Family history was present in 20/60 (33.3%), and only 13/60 (21.7%) had documented carrier-mother status while 47/60 (78.3%) were not tested, demonstrating a large gap in genetic evaluation. Mehta and Reddivari (StatPearls, updated regularly; accessed via NCBI) describe hemophilia as an X-linked recessive disorder with carrier females and variable family history due to de novo mutations; our findings align with this framework and point to missed opportunities for genetic counseling, cascade screening, and earlier diagnosis in at-risk male infants, which can reduce diagnostic delay and prevent preventable bleeding morbidity.[14]

Although our results tables did not enumerate "first symptom at presentation," the absence of nutritional abnormalities below 1 year in our cohort and the broader need for early identification are relevant to infant presentation patterns in hemophilia. Kulkarni et al. (2009) reported, in infants diagnosed before age 2 years, that early bleeding sites and timing provide practical signals for clinicians and families, emphasizing that targeted anticipatory guidance and early linkage to comprehensive hemophilia centers can prevent severe first events and support earlier initiation of prophylaxis and rehabilitation—factors that may ultimately also influence growth and nutrition trajectories through reduced morbidity.[15]

The social and functional burden in our cohort was substantial: school absenteeism affected 37/60 (61.7%), daily activities were impacted in 48/60 (80%), and nearly half were not involved in sports (28/60 [46.7%]) with only 22/60 (36.7%) participating in non-contact sports. Kar et al. (2007) documented significant disability in Indian patients with hemophilia and discussed system-level constraints that contribute to functional impairment; our high rates of daily activity limitation and reduced sports participation are consistent with the disability burden described in Indian contexts and support the need for integrated prophylaxis, physiotherapy, and safe-activity counseling to preserve participation and quality of life.[16]

Vaccination coverage in this study was moderate-to-good (42/60 [70%] immunised; 18/60 [30%] partially immunised), but the sizable partially immunised fraction is clinically important given the background risks tied to blood exposure, transfusions, and healthcare contact in bleeding disorders. Karim et al. (2013) described pediatric hemophilia clinical profiles in a tertiary setting and highlighted the broader care needs of children with hemophilia; our vaccination findings reinforce that comprehensive hemophilia care must also ensure routine preventive health measures (including completion of immunization schedules) alongside bleeding control, rehabilitation, and nutritional support.[17]

## CONCLUSION

This longitudinal study demonstrates that structured dietary counseling combined with individualized lifestyle and physiotherapy interventions significantly improved underweight and overweight status among children with hemophilia over a 6-month period. However, obesity remained unchanged, indicating the need for longer and more intensive interventions for sustained weight reduction. The high burden of severe disease, functional limitation, and school absenteeism underscores the importance of integrating nutritional monitoring into comprehensive hemophilia care. Early identification and continuous follow-up with multidisciplinary management can enhance joint health, functional outcomes, and overall quality of life in this population.

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