CLINICAL PRACTICE

The impact of home therapy interventions on treatment adherence and patient independence in haemophilia management in Assam, India

Anupam Dutta, Ajun Ngongpa, Papari Gogoi

Background: Haemophilia is an inherited bleeding disorder requiring regular factor replacement therapy, often necessitating frequent hospital visits. Home therapy (HT) has emerged as a viable alternative, improving patient independence and adherence. This study evaluates the impact of a structured home therapy intervention at Assam Medical College and Hospital on treatment adherence, self-infusion rates, and quality of life among haemophilia patients. **Methods:** This was a prospective interventional study conducted over from January 2023 to January 2024, involving 29 people with haemophilia (PWH). Participants underwent structured self-infusion training, nurse-led home visits, and education on prophylactic therapy. Data was collected at three time points (pre-HT, mid-HT, and post-HT) using standardised surveys assessing adherence, self-infusion rates, quality of life, and patient satisfaction. Statistical analyses included paired t-tests and McNemar's test for pre-post comparisons. **Results:** The study observed a 75% adoption of self-infusion, up from 38% at baseline. Prophylactic therapy uptake increased by 56%, while adherence to twice-weekly dosing improved from 76% to 83%. Patients reported 93% improvement in mobility and 82% reduction in joint pain and bleeding episodes. Dependence on healthcare providers decreased by 55%, as more patients transitioned to self-administration. The overall satisfaction score was 99%, reflecting high acceptance of the intervention. **Conclusion:** Structured home therapy significantly improved treatment adherence, self-infusion practices, and patient independence, reducing the burden on healthcare providers. The findings support home-based models as a scalable approach for managing haemophilia in resource-limited settings. Future studies should explore multicentre validation and integration of telehealth solutions to sustain these benefits.

Keywords: *Haemophilia; Home therapy; Self-infusion; Treatment adherence; Quality of life; Prophylaxis; Patient satisfaction*

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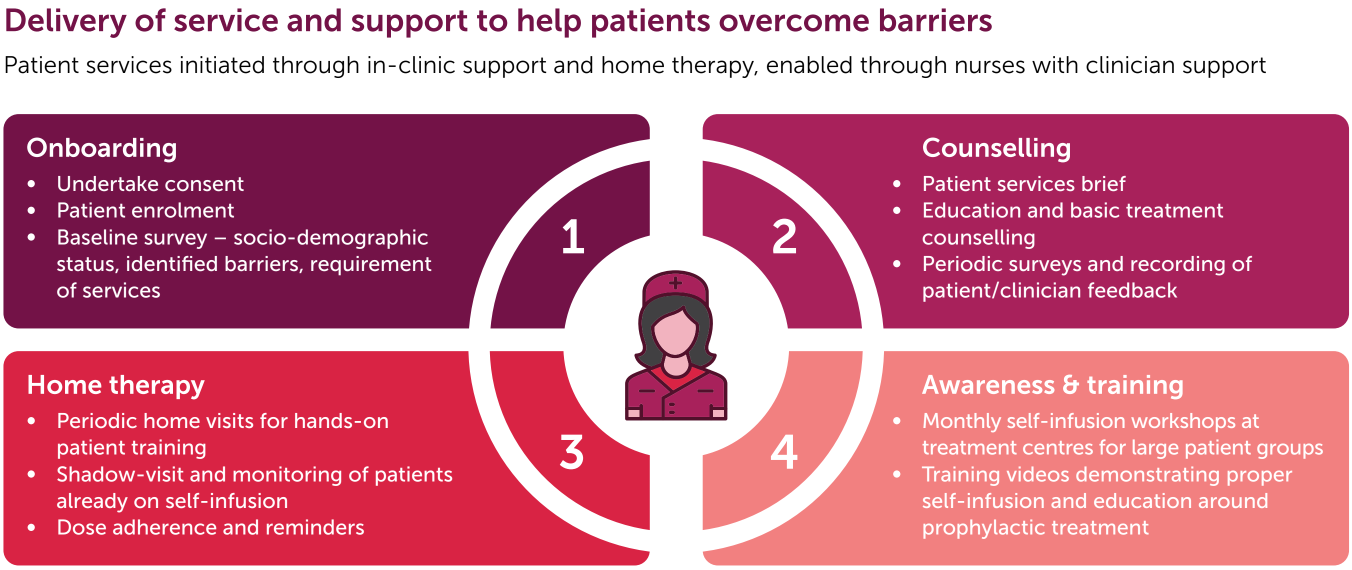
Haemophilia, a hereditary X-linked recessive bleeding disorder caused by a deficiency of clotting factor VIII (haemophilia A) or factor IX (haemophilia B), continues to pose significant health challenges globally, particularly in low- and middle-income countries (LMICs), including India [1,2,3] . The chronic nature of the disease, coupled

Figure 1. Structured delivery of services and support for patients with haemophilia
Outline of the four key components of the structured program designed to help patients overcome treatment barriers: onboarding, counselling, home therapy, and awareness training. These services were provided through coordinated in-clinic support and home visits by nurses with doctor oversight, ensuring patient education, self-infusion training, regular monitoring, and improved adherence to prophylactic treatment.



Delivery of service and support to help patients overcome barriers

Patient services initiated through in-clinic support and home therapy, enabled through nurses with clinician support

Onboarding

- Undertake consent
- Patient enrolment
- Baseline survey – socio-demographic status, identified barriers, requirement of services

Counselling

- Patient services brief
- Education and basic treatment counselling
- Periodic surveys and recording of patient/clinician feedback

Home therapy

- Periodic home visits for hands-on patient training
- Shadow-visit and monitoring of patients already on self-infusion
- Dose adherence and reminders

Awareness & training

- Monthly self-infusion workshops at treatment centres for large patient groups
- Training videos demonstrating proper self-infusion and education around prophylactic treatment

with the high cost of factor replacement therapy and limited access to specialised care, severely hampers effective management and quality of life (QoL) for affected individuals.

The World Federation of Hemophilia (WFH) emphasises the importance of prophylactic treatment as the gold standard to prevent bleeding episodes, preserve joint health, and improve long-term outcomes [4]. However, despite these evidence-based recommendations, implementation remains suboptimal in India due to economic, infrastructural, and educational barriers.

One of the most critical issues is the financial burden associated with treatment. In many regions of India, people with haemophilia (PWH) depend on self-funded clotting factors, leading to high out-of-pocket (OOP) expenditures. A cost-benefit analysis of a government intervention in Maharashtra demonstrated that state-supported access to clotting factors led to a 21% reduction in annual OOP expenses and showed a benefit-cost ratio of 1.89, indicating substantial economic merit in public health investment [5].

Geographical challenges exacerbate access issues. Patients living in remote or rural areas often face long travel times to reach tertiary centres, leading to treatment delays and complications. This is particularly concerning during acute bleeding episodes, where timely intervention is critical. The resulting logistical constraints underscore the need for decentralised care models such as home-based therapy, which could provide timely and accessible treatment, reducing dependency on hospital-based infusions [5,6].

Additionally, educational gaps among healthcare providers further limit optimal haemophilia care delivery. A survey across Asia-Pacific haemophilia treatment centres found that lack of training, funding constraints, and limited access to continuing medical education hindered provider competence and guideline implementation [7].

In recent years, home-based therapy has emerged as a viable and patient-centric alternative that promotes independence, improves adherence, and enhances quality of life. International studies highlight the role of telehealth and remote interventions, including mobile reminders and digital infusion logs, in supporting self-management practices and improving patient outcomes [6,8]. Moreover, nurse-led educational interventions have been shown to significantly improve prophylactic treatment uptake and reduce healthcare provider dependence [8,9].

Given the complex landscape of haemophilia care in India, this study evaluates the feasibility, effectiveness, and patient satisfaction associated with structured home-based therapy in a resource-constrained setting. By focusing on real-world implementation at Assam Medical College and Hospital, this research aims to provide practical insights into scalable models of care that align with global standards while being responsive to local challenges.

METHODOLOGY

This study was designed as a prospective interventional study to evaluate the feasibility, effectiveness, and patient satisfaction associated with home-based therapy for haemophilia at Assam Medical College, Dibrugarh. Conducted from January 2023 to January 2024, the study aimed to identify barriers to home therapy, assess its impact on adherence and quality of life, and evaluate the role of nursing and educational interventions (Figure 1). A total of 29 PWH were enrolled in the program, with each participating for six months.

Study sample

The study included patients diagnosed with haemophilia A or B (mild, moderate, or severe), aged ≥2 years, previously dependent on hospital-based infusion therapy, and willing to provide informed consent. Patients were excluded if they had active inhibitors against clotting factors, cognitive or physical disabilities preventing self-infusion, or severe comorbid conditions limiting home-based care. The sample size was determined based on prior pilot data, assuming a 50% improvement in adherence, with a 95% confidence interval and 80% power.

Study design

The study employed a clearly defined model of structured home therapy, involving a planned, multi-component intervention designed to enable PWH and their caregivers to independently administer clotting factor concentrates at home with competence and confidence. This model encompassed four core elements: patient education, practical infusion training, supervised transition to home-based care, and continuous follow-up and support. Implementation began following the baseline survey conducted in February 2023, which assessed patient demographics, disease severity, treatment history, and barriers to home therapy. Eligible patients were enrolled between February and May 2023, each participating in the program for six months.

The training program (Table 1) was delivered by trained haemophilia nurses under the supervision of the treating physician, and guided by internal standard operating procedures (SOPs) developed at Assam Medical College. Training included:

- Monthly self-infusion workshops held at the treatment centre, where patients practiced venipuncture using arm mannequins and vein-locator devices;
- Video demonstrations on the reconstitution and administration of clotting factor concentrates, storage guidelines, and safe disposal of sharps;
- Individualised education sessions covering prophylactic schedules, recognition of bleeds, emergency contact plans, and maintaining treatment logs.

Each session typically lasted 45-60 minutes, and materials were provided in both English and local language (Assamese).

To support the transition to home therapy, nurse-led home visits were conducted at least once every month, during which patients demonstrated the infusion process under observation. Nurses offered real-time correction of technique, reinforced dosing reminders, and addressed any infusion-related concerns. During implementation, the team encountered logistical challenges, particularly in scheduling visits to remote outstation locations, and occasional interruptions in factor supply, which required coordination with government procurement agencies. Some patients initially expressed apprehension regarding venous access or needle phobia; these were mitigated through repeated counselling and caregiver involvement. This structured approach ensured that home therapy was not only introduced safely but was also sustained through regular reinforcement, supervision, and capacity-building at the household level.

Nurses played a pivotal role as educators and care coordinators in the structured home therapy program. They began with conducting hands-on training sessions, where study participants and caregivers were taught proper self-infusion techniques using arm mannequins and vein-locator devices. The nurses also facilitated video-based education on factor preparation, administration, and storage; following training, they undertook monthly home visits to monitor adherence to treatment, assess technique accuracy, and provide real-time feedback. During these visits, they reinforced dose timing, addressed complications, and documented progress. They also provided a point of liaison between the patients and the treatment centre, promptly reporting clinical concerns to the haematologist, coordinating factor availability, and ensuring continuity of care. Their ongoing support was central to building patient confidence and sustaining safe home therapy practices.

Throughout the study, participants completed two follow-up surveys: a mid-home therapy (HT) survey in October 2023 to assess initial improvements in adherence and satisfaction, and a post-HT survey in

Table 1: Structured Training Plan

	COMPONENT	DETAILS
1	Objective	To equip patients and caregivers with the skills and confidence to safely perform self-infusion and manage haemophilia at home
2	Target audience	People with haemophilia A or B (age ≥2 years) and their caregivers (if applicable)
3	Trainers	Trained haemophilia nurses and educators under supervision of the treating physician
4	Training timeline	Initial onboarding (Week 1), followed by **monthly reinforcement sessions** for 6 months
5	Training duration	Each session lasts **45-60 minutes** (can be extended as per individual participant's pace and understanding).
6	Mode of delivery	• In-person group workshops (monthly at the treatment centre) • One-on-one bedside or home-based training during nurse visits • Digital resources (videos, pamphlets, visual aids in English and Assamese)
7	Standard training content	1. **Understanding haemophilia:** What is haemophilia, types, inheritance, complications 2. **Importance of prophylaxis:** Preventive approach vs. on-demand treatment 3. **Reconstitution of factor:** Step-by-step mixing of clotting factor vials 4. **Infusion technique:** Hand hygiene, venipuncture, using vein-locators, sharps disposal 5. **Storage and transport:** Factor storage temperature, cold chain maintenance during travel 6. **Infusion log maintenance:** Recording date, dose, time, site, and any adverse reactions 7. **Emergency preparedness:** What to do during bleeding, who to call, and when to seek hospital care
8	Training tools	• **Mannequins and vein-locator devices** for practical demonstration • **Videos** in local language on infusion and dosing • Printed **handbooks** on self-care routines • **Infusion** kits provided for home use
9	Assessment methods	• Practical demonstration by patient/caregiver- • Q&A checklist on dosing, preparation, and complication recognition • Periodic nurse evaluation during follow-up home visits
10	Standardisation protocol	• All trainers (Nurses) follow a common SOP • Patient handouts and videos used uniformly across all sessions
11	Documentation	Training logs, session attendance, and competency checklists maintained by nurses and submitted monthly.
12	Challenges addressed	• Fear of venipuncture: Overcome with repeated mannequin practice • Literacy issues: Resolve via pictorial instructions and caregiver involvement • Remote access: Home visits to ensure no patient is left unsupported

December 2023, evaluating treatment compliance, self-infusion proficiency, and quality of life changes. The intervention specifically addressed key barriers such as long travel distances (enabled home therapy), unavailability of clotting factors (ensured supply), and lack of awareness (provided counselling and education). The intervention strategies included clinical support from nurses, educational materials such as training videos and patient manuals, and technology-driven adherence tools like SMS reminders for dosing and factor administration.

Data collection and analysis

All PWH were assessed for annual bleed rate, joint health, functional state and QoL, before and after implementation of home therapy, using standard validated methods including Haemophilia Joint Health Score (HJHS), Functional Independence Score in Haemophilia (FISH) and EQ-5D-5L. Adherence to therapy and patient satisfaction were assessed using structured questionnaires developed by the patient support program (PSP) team, based on WHO adherence frameworks and patient-reported outcome measures.

Table 2. Questionnaire to assess adherence to therapy and patient satisfaction

SECTION A: ADHERENCE TO THERAPY (To be completed by patient/caregiver)

1. How many doses of factor therapy were you prescribed per week?

☐ 1 ☐ 2 ☐ 3 ☐ Other: ____________________

2. In the past month, how many times did you miss a scheduled dose?

☐ 0 ☐ 1–2 ☐ 3–5 ☐ >5

3. If you missed doses, what were the reasons? (Tick all that apply)

☐ Forgot
☐ Factor not available
☐ Travel issues
☐ Felt well
☐ Fear or difficulty with infusion
☐ Other: ____________________

4. Who usually administers the infusion at home?

☐ Self ☐ Parent/Caregiver ☐ Nurse ☐ Go to hospital

5. Do you follow the prescribed dosing schedule regularly?

☐ Always ☐ Often ☐ Sometimes ☐ Rarely ☐ Never

SECTION B: PATIENT SATISFACTION (5-point Likert scale: 1 = Very dissatisfied, 5 = Very satisfied)

6. How satisfied are you with the self-infusion training you received?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

7. How helpful were the nurse visits to your home?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

8. How confident do you feel in managing your condition at home?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

9. Do you feel you have adequate knowledge about your treatment?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

10. Overall, how satisfied are you with the home therapy support provided?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Though not externally validated, these tools were piloted for clarity and cultural relevance. Data were collected at three time points — pre-therapy (February 2023), mid-therapy (October 2023), and post-therapy (December 2023) — via face-to-face interviews during clinic visits and nurse-led home visits (Table 2).

Statistical analysis was conducted using descriptive statistics (mean, standard deviation, proportions, and percentages) to summarise participant characteristics. Comparative analyses included paired t-tests to evaluate pre- and post-intervention changes in self-infusion rates and adherence. The effect size (Cohen's d) was calculated to assess the magnitude of change following the intervention, and multivariate regression was used to identify predictors of improved adherence.

Study ethics

The study adhered to strict ethical guidelines. Ethical approval was obtained from the Institutional Ethics Committee (H), Assam Medical College, Dibrugarh (Reg no. ECR/636/Inst/AS/2014) No. AMC/EC/5876 dated 3rd June 2021. Informed consent was collected from all adult participants and guardians of minors. Patient confidentiality was maintained by anonymising data and securing records. The study was independently conducted without pharmaceutical sponsorship, ensuring no conflict of interest.

RESULTS AND OBSERVATIONS

The baseline profile of the 29 haemophilia patients enrolled in the study reveals important demographic

Figure 2. Baseline challenges and difficulties reported by study participants

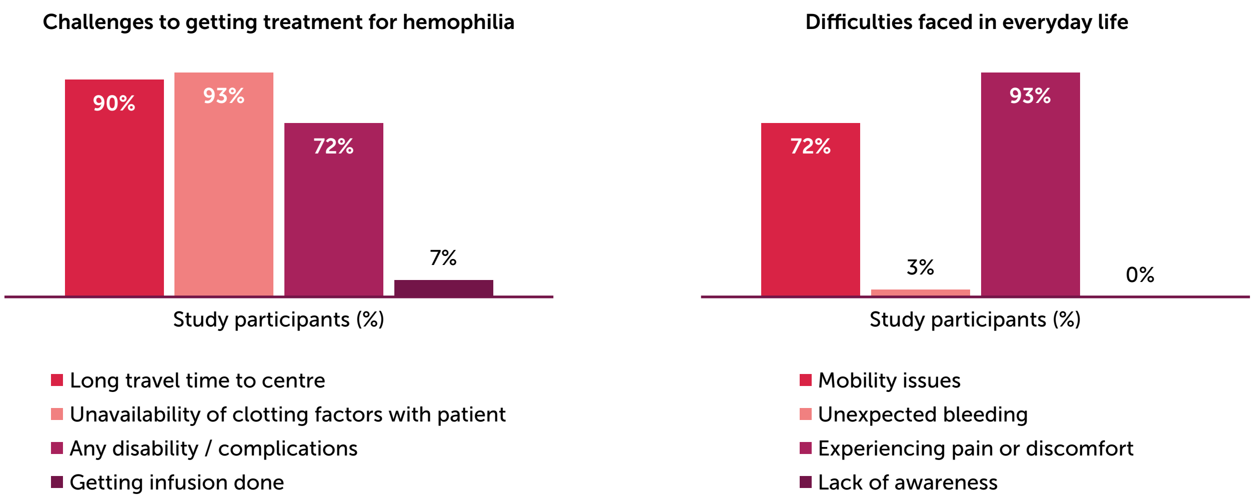


Table 3. Baseline demographics of study participants (n=29)

	NUMBER (N)	PERCENTAGE (%)
Age group		
2–6 years	3	11%
7–11 years	3	10%
12–16 years	5	17%
16–20 years	4	14%
21 years & above	14	48%
Education level		
Pre-School	11	38%
Primary	8	28%
Secondary	2	7%
Higher Secondary	7	24%
Graduate	1	3%
Haemophilia severity		
Mild	5	17%
Moderate	7	24%
Severe	17	59%
Treatment regimen		
On-demand	13	44%
Prophylaxis	16	56%

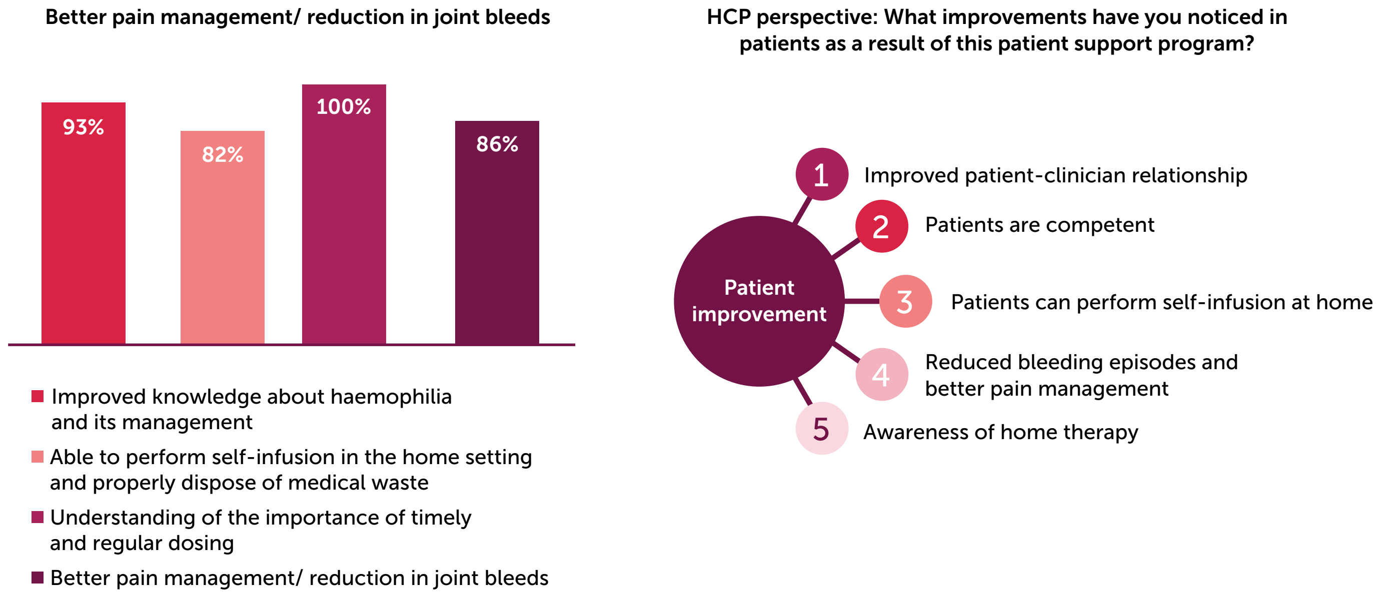
and clinical characteristics (Table 3). Nearly half of the patients (48%) were aged 21 years and above, while smaller proportions belonged to younger age groups, including 12–16 years (17%), 16–20 years (14%), 2–6 years (11%), and 7–11 years (10%). Educational background varied, with the majority having only primary (28%) or pre-school education (38%), and fewer patients reporting higher secondary (24%), secondary (7%), or graduate-level education (3%). In terms of disease severity, 59% of patients were classified as having severe haemophilia, 24% moderate, and 17% mild, indicating a significant need for continuous and accessible treatment. Regarding treatment regimens at baseline, 56% of patients were on prophylactic therapy, while 44% were still dependent on on-demand treatment, underscoring the need for improved awareness and adherence to preventive strategies. These insights formed the foundation for targeted interventions delivered throughout the home therapy program.

The baseline survey identified barriers encountered by participants in accessing haemophilia treatment, and the key difficulties faced in their daily lives at the time of enrolment in the home therapy training program (Figure 2).

Long travel time to the treatment centre was reported by 90% of participants, highlighting the burden of distance and inadequate local healthcare availability. Unavailability of clotting factor concentrates was a barrier for 93%, indicating frequent stockouts and supply chain issues. Presence of disability or complications affected 72% of patients, reflecting the long-term musculoskeletal impacts of poorly controlled bleeding. Difficulty in getting infusions administered was noted by 7%, suggesting that while most patients had some access, a minority still faced procedural barriers.

Mobility issues were experienced by 72% of participants, consistent with haemophilic arthropathy and joint damage. Unexpected bleeding was still a concern for 3%, implying improved bleed anticipation or control for the majority. Pain and discomfort were reported by 93%, underscoring chronic pain as a significant contributor to decreased quality of life. Lack

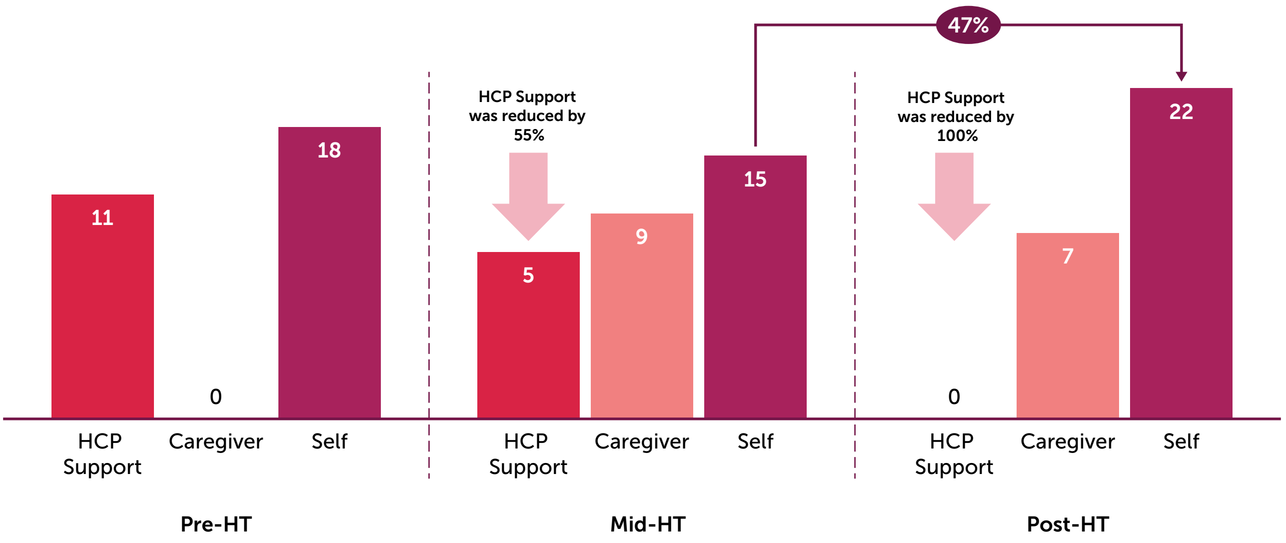
Figure 3: Patient outcomes following regular nursing support services



Better pain management/ reduction in joint bleeds

HCP perspective: What improvements have you noticed in patients as a result of this patient support program?

Figure 4. Progressive shift towards self-infusion following nursing support and patient support program (n=29)



HCP support reduced by 100%

- 38% of study participants were on HCP support before the patient support program. These patients were trained in self-infusion or caregiver support infusions based on their profile.
- As a result, 7 study participants moved to caregiver infusion and 22 to self-infusion
- Of the 7 participants who moved to caregiver infusion, 6 were in the 2-9 years age group

Nursing support and the patient support program has helped study participants who were already on self-infusion treatment by correcting their technique. The program also improved patient compliance with treatment and dosage frequency.

of awareness was reported as negligible (0%), indicating good basic understanding of the disease among this cohort.

Significant improvements were observed in participants following structured training, support and nursing interventions (Figure 3). Self-infusion adoption increased from 38% to 75%, indicating enhanced patient confidence and autonomy in managing their condition. Prophylactic treatment uptake improved by 56%, reducing the reliance on on-demand therapy. Adherence to twice-weekly dosing increased from 76% to 83%, while the proportion of patients taking doses only once in two weeks decreased from 10% to 7%. This reflects better compliance with prescribed regimens.

Table 4. Results of joint health, functional status and quality of life of participants following home therapy intervention (n=29)

OUTCOME MEASURE	BASELINE MEAN ± SD	FOLLOW-UP MEAN ± SD	MEAN DIFFERENCE	P-VALUE
Annual Bleed Rate (ABR)	11.31 ± 5.90	6.86 ± 6.71	4.45	< 0.00001
Haemophilia Joint Health Score (HJHS)	12.83 ± 6.60	10.48 ± 8.36	2.34	0.0016
FISH (Functional Independence Score in Haemophilia)	14.97 ± 4.49	13.76 ± 5.35	1.21	0.0021
EQ-5D-5L (Quality of life)	9.24 ± 2.28	8.17 ± 3.24	1.07	0.0039

From the patient perspective, 93% reported better knowledge about their disease and its management, 82% were able to perform self-infusion safely at home and manage medical waste, 100% understood the importance of timely and regular dosing, and 86% reported improved pain management and fewer joint bleeds. Patient outcomes demonstrated marked improvements in quality of life, with 93% reporting better mobility and 82% experiencing reduced joint pain and bleeding episodes.

The healthcare providers (HCPs) involved reported enhanced patient-doctor relationships, increased patient competence, successful home-based self-infusion, reduced bleeding episodes with better pain control, and greater awareness and acceptance of home therapy among participants. These outcomes demonstrate the impact of consistent nursing guidance and patient education on self-management and treatment adherence.

HCP dependence was significantly reduced, with all participants transitioning to self-infusion or caregiver-assisted therapy (Figure 4). Initially, 38% of patients required HCP assistance. With structured nursing support and PSP intervention, HCP dependence dropped by 55% by the midpoint and was eliminated entirely by the end of the study period. Consequently, the proportion of patients self-infusing rose by 47% by the end of the program. Seven patients shifted to caregiver-supported infusions (mostly young children aged 2–9 years), and 22 transitioned successfully to self-infusion. This shift highlights the effectiveness of nursing guidance and educational interventions in empowering patients and families, improving treatment adherence, and reducing reliance on clinical support.

The overall patient satisfaction score was 99%, with training, counselling, and home nursing support receiving near-perfect ratings. Patient testimonials highlighted increased confidence in self-management and improved disease awareness.

All 29 patients who received structured home therapy training showed significant improvements across all key outcome measures. The mean Annual Bleed Rate (ABR) decreased from 11.31 ± 5.90 at baseline to 6.86 ± 6.71 at follow-up ($p < 0.00001$). Similarly, the Haemophilia Joint Health Score (HJHS) improved from 12.83 ± 6.60 to 10.48 ± 8.36 ($p = 0.0016$), while the Functional Independence Score in Haemophilia (FISH) increased from 14.97 ± 4.49 to 13.76 ± 5.35 ($p = 0.0021$). QoL, as measured by the EQ-5D-5L score, improved significantly from 9.24 ± 2.28 to 8.17 ± 3.24 ($p = 0.0039$). These findings indicate that the structured home therapy intervention effectively reduced bleeding frequency, improved joint health, enhanced functional independence, and positively impacted overall QOL (Table 4).

These findings suggest that structured home therapy interventions can enhance treatment adherence, improve patient independence, and reduce healthcare burden, demonstrating a sustainable model for haemophilia care in resource-limited settings.

DISCUSSION

The structured implementation of a nurse-led home therapy (HT) programme for PWH treated at Assam Medical College and Hospital demonstrated notable improvements in patient autonomy, uptake of prophylactic treatment, adherence to dosing schedules, joint health, and overall QoL. These outcomes are consistent with global evidence supporting patient-centred, decentralised models of care as the standard for chronic bleeding disorders [10,11].

Improvement in self-infusion capability and patient empowerment

In our cohort, the proportion of patients capable of performing self-infusion rose significantly from 38% at baseline to 75% post-intervention. This improvement is clinically meaningful, as self-management – the ability of PWH to actively manage their daily health and healthcare – supports better bleed management, which is vital in haemophilia care [4]. This progress was achieved through the dedicated efforts of haemophilia nurses, who empowered patients by providing sustained training and conducting regular home visits.

The importance of the nurse role in empowering PWH to self-manage their condition has been recognised and continues to be developed elsewhere, with nurses providing education and support in all aspects of self-management, including bleed recognition, prevention and management, and home treatment [12,13]. In the UK, the Haemophilia Nurses Association's core competency framework for haemophilia nurses includes a range of competencies linked to communicating with and supporting patients and their families. This includes teaching and reviewing self-management skills, enabling PWH to manage bleeding symptoms independently, and delivering patient education [14].

Our findings reinforce the vital contribution of the haemophilia nurse and the need for a structured learning module to advance haemophilia care. Integrating telehealth-based mentoring, digital infusion logs, and remote counselling can further enhance skill retention and promote self-efficacy among PWH—an approach particularly valuable for those in rural and semi-urban settings.

Increased uptake of prophylactic regimens

Our data revealed a 56% increase in the uptake of prophylactic therapy following the structured nursing intervention. Prophylaxis remains the gold standard for preventing spontaneous bleeds and preserving long-term joint function [11,15]. However, suboptimal compliance remains a widespread challenge in many low- and middle-income countries [16]. Evatt underscores the need for sustainable decentralised models to overcome systemic barriers and improve patient outcomes worldwide [13]. Our findings reaffirm that accessible, context-sensitive nursing support is pivotal for expanding prophylaxis uptake in India.

Improved adherence to treatment and dosing frequency

Adherence to the recommended dosing frequency is vital for bleed prevention and long-term joint health. In our cohort, adherence to the prescribed twice-weekly dosing schedule improved from 76% to 83%, while infrequent dosing patterns decreased. Counselling has been shown to be an effective approach that nurses can use to supplement other methods, building a multifaceted strategy to enhance adherence; tackling non-adherence seems to demand continuous efforts and follow-up [17]. Khair highlights how proactive nursing engagement fosters trust and reinforces treatment routines [12].Furthermore, consistent prophylaxis initiated early in life can prevent joint disease, justifying continued investments in adherence support [15].

Positive impact on joint health and quality of life

Improved mobility and pain reduction were reported by 93% and 82% of patients, respectively, following the intervention. These self-reported gains align with existing literature showing that well-managed prophylaxis and timely infusions effectively preserve joint function and reduce disability [15,18]. García-Dasí et al. demonstrate a clear correlation between adherence to prophylaxis and better QoL scores in paediatric patients, highlighting the broader psychosocial benefits of optimal disease control [9]. Integrating adjunct interventions — such as remote physiotherapy and structured pain education — has further potential to maximise functional outcomes.

Reduced healthcare dependency and economic advantages

One of the most significant outcomes in our study was a 55% reduction in reliance on hospital-administered infusions, illustrating a successful transition to patient-managed or caregiver-administered treatment. This shift is consistent with global efforts to decentralise haemophilia care, thereby reducing the burden on tertiary care infrastructure and reallocating resources to patients with complex needs [11]. Home therapy has been shown to not only reduce hospitalisation costs but also to improve cost-effectiveness by preventing expensive complications associated with untreated bleeds [11,19].

Strengths and limitations

This study provides important regional evidence supporting structured nursing interventions and home therapy in an Indian context. By implementing a tailored educational programme complemented by telehealth tools, we have demonstrated that sustainable, patient-centred models are feasible even in resource-limited settings. Future programmes should consider broader digital integration for real-time dose tracking and remote monitoring, as suggested by recent trials [20]. Additionally, training caregivers — particularly in paediatric cases — can ensure equitable access to home-based therapy for younger patients who cannot self-infuse independently [21].

Despite these encouraging outcomes, the study has some limitations. The sample size was modest and derived from a single institution, meaning the results may not be generalisable. The sample size was determined based on feasibility and resource availability within the defined program duration, rather than formal power calculations based on effect size assumptions. However, a significant proportion of PWH at the treatment centre were already on home therapy at baseline, meaning the study could specifically targeted those patients who faced significant barriers to adopting or sustaining home-based care, as identified through the baseline survey. Therefore, while the small sample size may limit generalisability, the study provides valuable insights into real-world implementation challenges and practical solutions in a resource-constrained setting, forming a basis for larger multicentre or regional studies in the future.

CONCLUSION

The implementation of a structured home therapy intervention at Assam Medical College and Hospital has significantly improved treatment adherence, self-infusion practices, and quality of life for PWH attending its haemophilia centre. The findings of this study demonstrate that empowering patients through education, nursing support, and self-infusion training can reduce dependence on healthcare providers while enhancing treatment outcomes. The increase in self-infusion rates (from 38% to 75%), along with a 56% rise in prophylactic treatment uptake, highlights the effectiveness of the intervention in promoting self-management.

Study participants reported reduced joint pain, improved mobility, and better disease understanding, leading to greater independence in their care. The decrease in reliance on direct healthcare provider support reinforces the potential of home therapy in alleviating the burden on the healthcare system. Participants' overall satisfaction score (99%) suggests that structured counselling, periodic follow-ups, and patient education were well received and instrumental in achieving high compliance rates.

Further multicentre studies with larger sample sizes and long-term follow-ups are necessary to validate these findings, assess the sustainability of improvements, and develop a robust framework for nationwide implementation of home therapy in haemophilia care. Future interventions could benefit from the integration of telehealth solutions, such as remote monitoring and digital adherence tracking, to enhance patient engagement and long-term treatment success.

In conclusion, this study reaffirms the role of home-based interventions in transforming haemophilia care by making treatment more accessible, patient-centric, and sustainable. The success of this model highlights its potential applicability to other resource-limited settings, offering a scalable approach to improving chronic disease management beyond haemophilia.

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Consent

Informed consent has been obtained from the participants in the study reported in this paper.

Conflict of interest

The authors have advised no interests that might be perceived as posing a conflict or bias.

REFERENCES

1. Ghosh K Ghosh K. Overcoming the challenges of treating hemophilia in resource-limited nations: a focus on medication access and adherence. *Expert Rev Hematol* 2021; 8: 721-730. doi: 10.10.1080/17474086.2021.1957826.
2. Ndoumba-Mintya A, Diallo YL, Tayou TC, Mbanya D. Optimizing haemophilia care in resource-limited countries: current challenges and future prospects. *J Blood Med* 2023; 14: 141-146. doi: 10.2147/JBM.S291536.
3. Mahlangu J, Diop S, Lavin M. Diagnosis and treatment challenges in lower resource countries: State-of-the-art. *Haemophilia* 2024; 30(S3): 78-85. doi: 10.1111/hae.14956.
4. Srivastava A, Santagostino E, Dougall A, et al.; WFH Guidelines for the Management of Haemophilia panelists and co-authors. WFH Guidelines for the Management of Haemophilia, 3rd edition. *Haemophilia* 2020;26 Suppl 6:1-158. doi: 10.1111/hae.14046. Erratum in: *Haemophilia* 2021;27(4):699. doi: 10.1111/hae.14308.
5. Singh P, Mukherjee K. Cost-benefit analysis and assessment of quality of care in patients with haemophilia undergoing treatment at National Rural Health Mission in Maharashtra, India. *Value Health Reg Issues* 2017; 12:101-106. doi: 10.1016/j.vhri.2016.11.003.
6. Qian W, Lam TT, Lam HHW, Li CK, Cheung YT. Telehealth Interventions for Improving Self-Management in Patients With Haemophilia: Scoping Review of Clinical Studies. *J Med Internet Res* 2019; 21(7): e12340. doi: 10.2196/12340.
7. Lam JCM, John MJ, Street A; Asia Pacific Haemophilia Working Group (APHWG). A survey of characteristics and current educational needs of haemophilia treatment centers within Asia Pacific. *Res Pract Thromb Haemost* 2018; 2(3): 508-517. doi: 10.1002/rth2.12108.
8. Lock J, Raat H, Peters M, et al. Optimization of home treatment in haemophilia: effects of transmural support by a haemophilia nurse on adherence and quality of life. *Haemophilia* 2016; 22(6): 841-851. doi: 10.1111/hae.13043.

9. García-Dasí M, Aznar JA, Jiménez-Yuste V, et al. Adherence to prophylaxis and quality of life in children and adolescents with severe haemophilia A. *Haemophilia* 2015; 21(4): 458-64. doi: 10.1111/hae.12618.
10. Khair K. Haemophilia: diagnosis, management and nursing care of patients. Nursing Times [online] 2021; 117: 10, 34-38. *https://www.nursingtimes.net/haematology/haemophilia diagnosis-management-and-nursing-care-of-patients-13-09-2021/*.
11. Evatt BL. The natural evolution of haemophilia care: developing and sustaining comprehensive care globally. *Haemophilia* 2006;12 Suppl 3: 13-21. doi: 10.1111/j.1365-2516.2006.01256.x.
12. Khair K. The changing role of the specialist haemophilia nurse. Nursing Times [online]. 9 August 2021. *https://www.nursingtimes.net/haematology/the-changing-role-of-the-specialist-haemophilia-nurse-09-08-2021/*.
13. Mulders G, Uitslager N,Kavanagh M, et al. The role of the specialist nurse in comprehensive care for bleeding disorders in Europe: an integrative review. *Haemophilia* 2024; 30(3): 598-608. doi: 10/1111.hae.14974.
14. Pollard D, Harrison C, Dodgson S, et al. The UK haemophilia specialist nurse: Competencies fit for practice in the 21st century. *Haemophilia* 2020; 26(4): 622-630. doi: 10.1111/hae.14002.
15. Manco-Johnson MJ, Abshire TC, Shapiro AD, et al. Prophylaxis versus episodic treatment to prevent joint disease in boys with severe haemophilia. *N Engl J Med* 2007; 357(6): 535-544. doi: 10.1056/NEJMoa067659.
16. Stonebraker JS, Brooker M, Farrugia A, Srivastava A. A study of reported factor concentrate use around the world. *Haemophilia* 2010; 16(1): 33-46. doi: 10.1111/j.1365-2516.2009.02131.x.
17. Van Camp YP, Van Rompaey B, Elseviers MM. Nurse-led interventions to enhance adherence to chronic medication: systematic review and meta-analysis of randomised controlled trials. *Eur J Clin Pharmacol* 2013; 69(4): 761-70. doi: 10.1007/s00228-012-1419-y.
18. Makris M. Prophylaxis in haemophilia should be life-long. *Blood Transfus* 2012; 10(2): 165-168. doi: 10.2450/2012.0147-11.
19. Miners AH, Sabin CA, Tolley KH, Lee CA. Assessing health-related quality of life in individuals with haemophilia. *Haemophilia* 1999; 5(6): 378-385. doi: 10.1046/j.1365-2516.1999.00347.x.
20. Santaella ME, Bloomberg M, Anglade D. Home infusion teaching practices at federally funded hemophilia treatment centers in the United States of America. *Res Pract Thromb Haemost* 2017; 1(1): 81-89. doi: 10.1002/rth2.12020.
21. Hansson H, Castor C, Larsen H, Topperzer M, Olesen M. Development of an eHealth intervention in pediatric home infusion therapy: Interview study of needs and preferences of parents and health care professionals. *JMIR Pediatr Parent* 2025; 8:e63260. doi: 10.2196/63260.

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