Section: Medicine

Original Research Article

BARRIERS TO HOME BASED PROPHYLAXIS THERAPY IN PERSONS WITH HEMOPHILIA (PWH)

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Abstract

Background: Home-based prophylaxis is recommended for optimal management of hemophilia. However, barriers limit its implementation in developing countries like India. This study aimed to identify barriers to home therapy in India.

Materials and Methods: A qualitative study was conducted through interviews of 20 participants including persons with hemophilia, caregivers, healthcare workers and volunteers. Participants were randomly selected and interviewed using a semi-structured guide. Data was analysed thematically to identify barriers.

Results: Four major categories of barriers emerged - technical expertise in self-infusion, logistical challenges of home care, lack of motivation among patients and caregivers, and inadequate advocacy efforts. Difficulties finding veins, fear of improper injection, issues maintaining cold chain, and reluctance to start therapy due to complexity were reported.

Discussion: Barriers identified align with previous studies from other developing nations. Addressing skills-training, logistics, motivation and advocacy through targeted interventions like enhanced education, counselling and community engagement can help optimize home therapy uptake.

Conclusion: The study provides guidance on key barriers preventing optimal home prophylaxis in India to inform development of context-specific solutions.

Keywords: Hemophilia, home therapy, prophylaxis, barriers, qualitative research.

INTRODUCTION

Hemophilia is a congenital bleeding disorder caused by deficiency of clotting factors VIII or IX. It requires lifelong management through replacement therapy to prevent bleeding and joint damage. The World Hemophilia Federation recommends home-based prophylactic treatment as the standard of care for persons with hemophilia to allow near normal lifestyle. However, in developing countries barriers often limit optimal implementation of home therapy. India has a large hemophilia population but only a fraction receives regular prophylaxis at home. Previous studies from India have reported poor adherence to therapy and lack of access to care outside major cities. Home-based management can help overcome these challenges but little is known about the specific barriers faced. This qualitative study was conducted to investigate barriers to home prophylaxis from the perspective of patients, caregivers and healthcare providers in India. Identifying key barriers is essential to develop targeted interventions to improve uptake of home therapy. This can help persons with hemophilia in India achieve recommended treatment standards and have improved outcomes through prevention of bleeds and joint damage.

MATERIAL AND METHODS

This was a qualitative, descriptive study conducted at a hemophilia treatment centre in India. Data was

collected through semi-structured interviews with four groups - persons with hemophilia, their parents/guardians, healthcare workers, and volunteers involved in hemophilia care. A total of 20 participants were interviewed - 5 persons with hemophilia aged 18-40 years, 5 parents/guardians of children with hemophilia aged 5-18 years, 5 healthcare workers including doctors, nurses and counsellors, and 5 volunteers. An interview guide consisting of open-ended questions was used to collect data on perceived barriers to home-based prophylaxis therapy. (FIG.1)

Participants from each group were randomly selected to reduce selection bias. For persons with hemophilia and parents/guardians, a list of all eligible individuals meeting the inclusion criteria was generated. Using a random number generator, 5 individuals were randomly selected from each group. For healthcare workers and volunteers, all eligible individuals working in the hemophilia centre during the study period were listed. Again, 5 participants from each group were randomly selected using a random number generator. This random selection process ensured that the participants were representative of each group and the findings could be generalized to the larger population. Purposeful variation was also ensured by including participants from different age groups, education levels, and socioeconomic backgrounds wherever possible.

The interviews lasted 30-45 minutes and were audio-recorded with written informed consent from participants. Ethical approval for the study was obtained from the Institutional Ethics Committee prior to commencement of data collection. The recorded interviews were transcribed verbatim and anonymized to ensure confidentiality. The transcripts were analysed using thematic analysis to identify common themes and categories of barriers. Two researchers independently analysed the transcripts and then discussed any discrepancies to arrive at a consensus.

The data was triangulated between the four participant groups to validate the findings. Direct quotes from participants were used to illustrate the key barriers. Field notes were maintained during and after each interview to record non-verbal cues and contextual details. The study aims to understand barriers comprehensively to inform the development of targeted interventions to improve uptake of home-based prophylaxis in this setting.

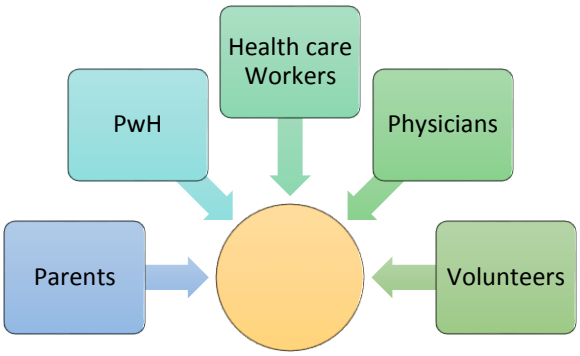

FIG.1- Pattern of Semi structured interviews

RESULTS

A total of 20 interviews were conducted with the four participant groups. On analysis of the interview transcripts, four major categories of barriers to home-based prophylaxis therapy emerged (FIG.2):

Technical expertise - All 5 PwH and 3 parents reported difficulties with locating veins at home and fear of self-injection due to lack of training. 2 healthcare workers acknowledged gaps in training patients for self-infusion.

Logistical challenges - 4 parents and 2 PwH mentioned problems with collecting and safely storing factor concentrates at home due to lack of refrigeration or space. 3 parents said it was difficult to administer injections discreetly to avoid embarrassment in front of siblings.

Motivation - 3 healthcare workers felt that parents were hesitant to start home therapy due to perceived complexity. 2 volunteers said parents needed repeated counseling to feel confident. 4 parents expressed initial reluctance due to perceptions of therapy as difficult and time-consuming.

Inadequate advocacy - All 5 volunteers highlighted the need for more frequent workshops and awareness programs involving local communities and schools. 3 healthcare workers said advocacy efforts needed greater involvement of patient organizations.

Other minor barriers reported were financial constraints for some families, long travel distances to the hospital, and occasional product stock-outs. The findings were consistent across participant groups, indicating technical skills, logistics of care at home, lack of motivation and advocacy as major inter-related barriers. Addressing these barriers through targeted interventions like enhanced training, counselling, and community engagement was identified as a priority by participants.

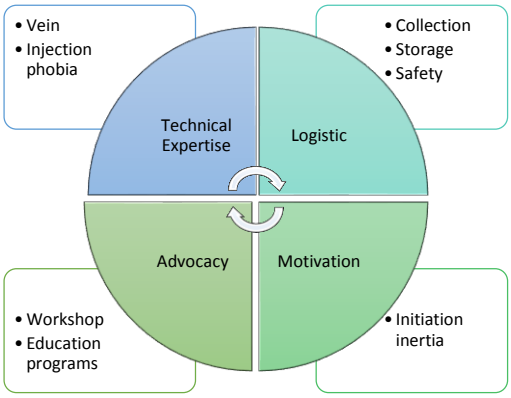

FIG.2 Four major categories of barrier

DISCUSSION

The findings of this study provide valuable insights into the key barriers preventing optimal implementation of home-based prophylaxis therapy among persons with hemophilia in India. The four major categories of barriers identified - relating to technical expertise, logistics, motivation and advocacy - are consistent with previous research from other developing countries.

A qualitative study from Egypt exploring barriers to prophylaxis therapy identified lack of knowledge and skills for self-infusion as a major challenge.[1] Participants in our study similarly reported difficulties with venous access and fear of improper injection at home due to inadequate training. Enhancing training programs for patients and caregivers, as suggested in other studies,[2,3] could help address technical barriers uncovered. The use of mobile health technologies and tele-mentoring may further aid skill development for home therapy in resource-constrained settings.[4]

Logistical issues of collecting, storing and discreetly administering factor concentrates at home emerged as a significant barrier. A mixed-methods study from Nigeria highlighted practical difficulties of maintaining an uninterrupted cold chain for products as a key impediment.[5] Targeted interventions like mobile refrigeration units and training on discreet administration techniques may help overcome logistical challenges found in our study.

Lack of motivation and reluctance among caregivers to start home therapy identified echoes the findings of qualitative work from Pakistan, where initial hesitation stemmed from perceived complexity of care.[6] Our study also concurs with previous evidence that repeated counselling and empowerment strategies are needed to boost self-care confidence over time.[7,8]

In terms of advocacy, a systematic review examining barriers globally found that limited community awareness and engagement negatively impacted care standards.[9] Expanding patient education and involving local leaders, as done successfully in Brazil,[10] could strengthen advocacy efforts as suggested by our participants.

Some limitations of our study must be acknowledged. As a single-centre qualitative inquiry, generalizability may be limited. Larger mixed-methods research incorporating quantitative assessment is warranted. Recall and reporting biases are possible due to the interview-based design.

In conclusion, by identifying key barriers comprehensively through stakeholder perspectives, this study provides valuable guidance to develop targeted interventions for improving home-based prophylaxis uptake in India. Addressing issues of skills-training, logistics, motivation and advocacy through multidisciplinary collaboration holds promise for optimizing care standards and outcomes for persons with hemophilia.

CONCLUSION

This qualitative study provides valuable insights into the key barriers preventing optimal uptake of home-based prophylaxis therapy among persons with hemophilia in India. The barriers identified - issues relating to technical expertise in self-infusion, logistical challenges in home care, lack of motivation among patients and caregivers, and inadequate advocacy efforts - are interlinked social and behavioural factors. Addressing these barriers comprehensively will be important to improve adherence to prophylaxis therapy and enable persons with hemophilia to lead active lives. Focused interventions such as enhanced training of patients and caregivers, counseling to boost self-care confidence, community engagement programs, and strengthened advocacy through patient organizations can help overcome these barriers. The findings also highlight the need for greater involvement of multidisciplinary healthcare teams and community partners in advocacy efforts. With a concerted effort towards solving the barrier issues uncovered in this study, home-based prophylaxis therapy can be optimized for persons with hemophilia in India.

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