



**ORIGINAL RESEARCH PAPER**

**Nursing**

**LOWER DOSE PROPHYLAXIS AND HOME THERAPY – A 5-YEAR REAL WORLD EXPERIENCE FROM HEMOPHILIA TREATMENT CENTRE ALUVA IN A RESOURCE LIMITED SETTING**

**KEY WORDS:**

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**INTRODUCTION**

At present, prophylactic therapy is the treatment of choice to be considered for people with haemophilia (PWH) to prevent bleeding and minimize the disease complications. In a patient with severe hemophilia, regular prophylaxis with adequate factor concentrates administered at home, is effective to prevent bleeding episodes, excruciating pain and importantly, transportation to a healthcare facility. Giving prophylaxis therapy and maintaining the optimum dosage for a long duration as home therapy is so challenging in a low economic country like India. The major limitations are the increased expense of factor concentrates, Government policies on hemophilia treatments, lack of skill for self-infusion and limited vein access in young children.

**MATERIALS AND METHODS**

29 people with hemophilia A and B under the age of 18 years old who are under regular prophylaxis and homotherapy for the last 2 years at HTC Aluva from 2018 to 2020 are included in the analysis. The data before home therapy and after home therapy were retrospectively collected. In these patients receiving prophylaxis, an escalating dose of 250 IU of Factor VIII or 600 IU of factor IX twice weekly was used depending on the diagnosis. . Additional factor was also given if it required. Those patients whose caregivers had learnt self-infusion and began receiving prophylaxis of factors as home therapy were finally recruited. The demographic data and logistic data were collected pre- and post-home therapy. The cost incurred includes cost of travel, food, lodging and loss pay.

**RESULTS**

Out of 29 PWH, 28 got trained for self-infusion (home based therapy). The average age of PWH underwent home therapy was 10.8 years (SD = 4.02 years). 23 of them received factor VIII and remaining 5 received factor IX. The mean duration of receiving prophylactic therapy in PWH was 3.6 years (SD = 1.2 years). The mean duration since the beginning of home therapy was 2.8 years (SD = 1.3 years). There is a significant reduction in the number of hospital visits ( $0.25 \pm 0.7$  days/month vs  $6.5 \pm 3$  days/month,  $p < 0.001$ ), number of days of school/work absenteeism ( $0.6 \pm 1.1$  days/month vs  $5.2 \pm 4.9$  days/month,  $p < 0.001$ ) and cost incurred (Rs 226.8  $\pm$  115.8/month vs Rs 1426.7  $\pm$  583.8/month,  $p < 0.001$ )

**CONCLUSION**

This is the first study looking at the logistic improvements with home therapy of prophylaxis. With educational session on self-infusion and well-planned home therapy with low dose prophylaxis, the PWH and their caregivers are not required to visit the HTC to be infused twice a week. It also helps reducing transportation cost to the healthcare facility. Regularly planned infusion of factor concentrates at home is an effective treatment to prevent bleeding episodes and excruciating pain, especially for people with severe hemophilia