Correspondence

Challenges of haemophilia care in India: Lest we forget

Sir,

In the editorial “Together we care: New challenges for global haemophilia treatment centers”, Franchini & Lippi1 have summarized the challenges which haemophiliacs are facing and the role of World Federation of Haemophilia (WFH) to meet more challenges2. In all the developed countries of the world the government and the medical insurance companies have been involved in the delivery of comprehensive haemophilia care. But not so in most developing countries including India. In our country people with haemophilia (PWH) are fighting their challenges without much help from Central and State governments through their national member organization i.e., Haemophilia Federation of India (HFI). Being a low volume high cost disease, in most developing countries haemophilia is utterly neglected. Though the WFH helped HFI in various ways they have been careful in keeping this vast country out of GAP (Global Alliance for Progress). The regulation to improve blood products and help given by National AIDS Control Programme of the Government of India has helped reducing the prevalence of HIV-1 infection among haemophiliacs from 13-14 to 6 per cent at present3. Infact a few haemophiliacs who born after 1988, are now HIV positive. However, the same cannot be said about other two transfusion transmitted hepatitis viruses. About 10-14 per cent of PWH in India have hepatitis B infection and 24-30 per cent of them are positive for hepatitis C3. This is unlikely to reduce without universal use of factor concentrates for haemophilia care. It is here that the Indian government needs to step in as financially it is not possible for any haemophilia patient to bear the burden of the cost of factor concentrates required for his treatment.

The management of haemophilia in developed countries has proceeded through hospital treatment, home therapy, secondary prophylaxis to most costly but very effective primary prophylaxis. In Indian hemophiliacs the factor concentrates have been used in negligible amounts, often to stop unstoppable blood loss and in extremely painful muscle and joint haematomas or in life threatening cerebral and GI bleeds.

In this context, the National Institute of Immunohaematology (NIIH) at Mumbai has been playing a central role for haemophilia care and research in India. In addition to being an International Haemophilia Training Centre (IHTC), the Institute developed certain investigative and haemophilia care facilities in this country and plays an active role in disseminating these research activities to rest of the country4-8.

The Institute has active collaboration with the Mumbai chapter of HFI and HFI itself. HFI is fighting an unequal battle to keep the PWH well and the time has come when both Central and State government must join hands so that we can realize the vision of WFH ‘Together we care’ and of HFI “Haemophilia without disability and children without pain”.

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References


