

Psychosocial Issues & Support for PwH & Their Families In India



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ISSUES



SUPPORT



INTRODUCTION :----

Challenges: Management of Hemophilia is a great challenge to the team. It is because of low level of awareness, not only among general public but also in Medical & Paramedical community. About 25% of world Hemophilia populations live in Asia. In our country it is estimated about 1 lakh, but 15000 PwH are identified & registered. Education & Counseling is very difficult as most of our families are illiterate & poverty adds to the misery of suffering as treatment is very expensive & beyond the reach of common man. Government & Insurance Company makes difficult to provide timely treatment & leads to various complications.

Problems in Parents: Parents especially mother worries much about "How to bring up the child?", overprotect their children which affects the psychological growth of the child.

Problems in Children: Repeated bleeds makes most of the children remain absent from the school or college, do not get proper education & cannot be placed in a good job. Psychological problems like fear, inferiority complex, guilt, depression & dependency are commonly seen. Most of the adolescents are in a dilemma whether to get marry or whether to tell about the disorder to the girl etc.

Problems in Ageing: There are certain burning problems as they age. Because of the disabling arthropathy, chronic pain becomes common companion affecting quality of life.

Problems in Girl/Women: Mother is highly victimized in the family, especially if there is a family history- Harassment from the husband & in-laws for bringing Hemophilia into their family. Guilty feeling at every instance of bleeding episodes & a painful cry of her child.

Consanguinity: Consanguineous marriages are common in our state, commonly seen in rural areas. Because of this practice, Hemophilia spreads in the family.

OBJECTIVES: 1) Create Awareness, 2) Accept, Learn and to live with Hemophilia, 3) Improve Quality of life.

METHODS:-

Education & Counseling: We reassure & give moral support. Give them some management tips like Dental care, Physiotherapy & the importance of RICE & AHF infusion. Suggest them to participate regularly in parents meet, camps & other welfare program & also motivate them to take some responsibilities & help other families.

Camps – Children: Camps are the best occasion for children to make them cheerful & slowly learn how to live with Hemophilia. This allows our children to come out with their talent or develop interest in the activities.

Camps – Youth: Youth camps are being organized regularly, we teach them Naturopathy & Yoga. To bring self-confidence, personality development sessions are included in the camp. Adolescent are trained self-infusion so as to treat the bleed at the earliest.

Women's Group: We have formed Women's Group in our society with the main aim of creating a platform for all women of Hemophilia family to come together, share their experiences & build self confidence among them. We also educate them about Carrier detection & prenatal diagnosis. We visit schools & colleges to create awareness among the students & also the staffs

Workshops: We have organized psychosocial workshops inviting professionals in Psychiatry & the interaction will be so open that our Hemophilia families feel the need of such workshops regularly.

RESULT :



Team Work: Women's Group is the backbone of the society in organizing various activities. We believe in team work & each one of us are satisfied in reaching poor Hemophilia families.

CONCLUSION: Our Children lack in the clotting protein but not zeal in their life.



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Vision: Hemophilia without Disability, Children Free Of Pain.

