

PSYCHOSOCIAL ISSUES IN MOTHERS OF CHILDREN WITH HEMOPHILIA IN INDIA

INTRODUCTION & OBJECTIVE: Parents especially mothers are anxious about their children with hemophilia. If proper education & counseling is not available, they overprotect their children or neglect them. Mother in the family is highly victimized, especially in India. Illiteracy & poor socioeconomic conditions aggravate the situation. Harassment from husband & in-laws is common & she becomes psychologically depressed. Education & psychosocial support for mothers through camps is the main objective.



MATERIALS & METHODS: Services available includes diagnosis, treatment, counseling, prevention, education and rehabilitation camps. Camps are the main platform to discuss various problems & share their experiences. Rehabilitation camp for 25 mothers of children with hemophilia was organized. Psychosocial issues were discussed including prevention of hemophilia by carrier detection, prenatal diagnosis & economic rehabilitation. Mothers were advised to encourage their children for regular physiotherapy to build up joints/ muscles stronger, as stable joint will not bleed frequently. Games & exhibition of talents like singing, playing musical instruments, Quiz competitions were organized. Prizes were distributed to the winners. Physiotherapy kits were distributed & exercises were demonstrated to the mothers. First aid, PRICE therapy & proper application of ice during acute bleeds were educated. Pre & post camp analysis pro-forma were given to the mothers to analyze their psychosocial status. Rating scales were developed to assess the mother's psychological response to the presence of hemophilia in their sons, and their perception of their child's social and emotional adjustment.

Result: Among 25 mothers, 23 developed self confidences in bringing up their children including stigma reduction, 11 self employed in candle making & 8 honey bee breeding centre. Most of the mothers expressed their feelings about the confidence & courage derived during the camp to bring up their children successfully & evolve them into independent adolescent boys. Mothers had an opportunity to exchange their feelings & this camp developed bondages among them & determined to involve in the chapter activities & help other families.



CONCLUSION: Counseling and guidance, either individually or groups, will help parents to face any challenges in the life.



SMT. MEERA S HANAGAVADI
PRESIDENT,
WOMEN'S GROUP,
KARNATAKA HEMOPHILIA SOCIETY,
DAVANGERE.



Our Vision: Hemophilia without Disability, Children Free of Pain

