

Psychosocial issues in haemophilia- 100 case studies

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OBJECTIVES

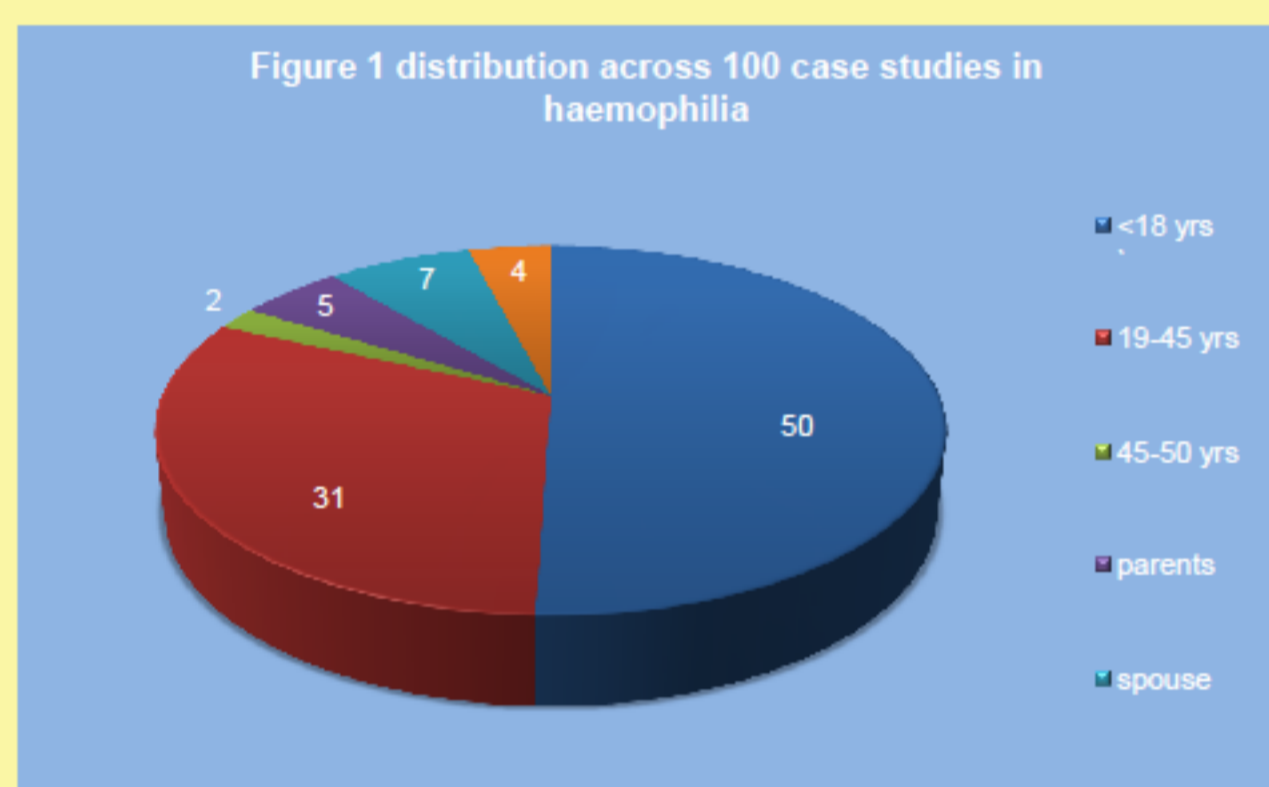
Haemophilia is a bleeding disorder which may develop chronic physical disabilities and psychosocial issues in absence of adequate treatment facilities. Treatment facilities have been far from adequate until recently in the northern State of Delhi in India. This study undertakes an assessment of the psychosocial issues faced by the haemophilia community.

METHODS

Out of current 1,156 patients registered in our haemophilia centre in New Delhi, the records of the psychosocial counseling in our Haemophilia Centre were analyzed from 100 consecutive case studies for the spectrum of psychosocial problems in Northern India. A 36-point proforma is used in our Haemophilia Centre for recording the psychosocial issues in a structured manner on the patients and families attending the Centre. Individual case study on the 84 persons/patients with haemophilia (PWH), 7 spouses, 5 parents, and 4 sisters constitute the material for this study.

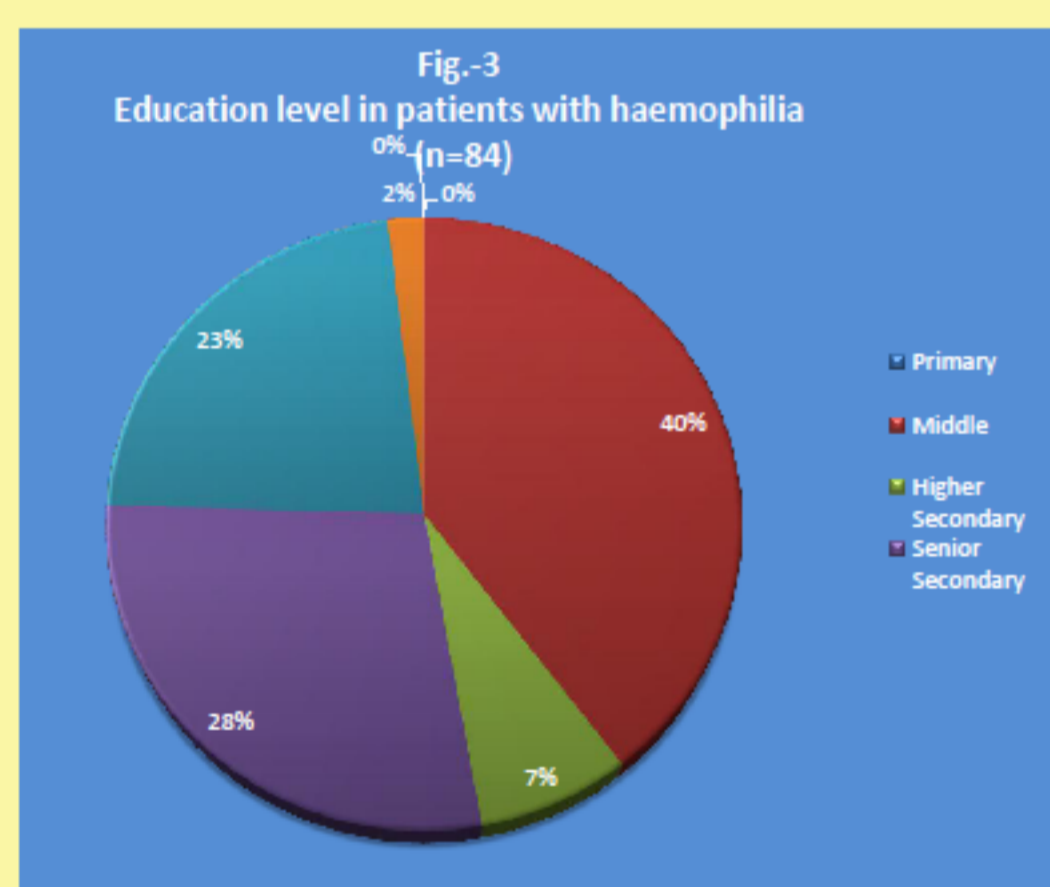
OBSERVATIONS AND RESULTS

Amongst the 100 case studies, PWH constituted 84 distributed across the age groups of <18 years, 19-45 years, and >45 years as 50/31/3 cases respectively. Haemophilia-A comprised 88% with severe cases making up 30% of all. Moderate severity haemophilia was present in 68% spread in a ratio of 5.6:1.



	Haemophilia A	Haemophilia B	TOTAL
Severe	25	Nil	25
Moderate	48	9	57
Mild	01	01	02
	77	10	84

Their education was adversely affected, with 90% dropping out at school level only.



In the 50 children under 18 years, only 9 were doing well. Twenty one (42%) had issues related to schooling- ranging from 'unable to be attentive to studies (13 cases)' to denied school admission (2 cases). Haemophilia bleeds affected schooling in only 3 cases and was demotivating in another 4 cases. Undue anxiety caused problems in 7 children. Parental overprotectiveness was seen in 10 instances though it resulted in timidity in only one child with haemophilia. Amongst the adults 19-45 years, 9 of the 31 were doing well. Half suffered from mental stress and anxiety from employment issues (6 cases), frequent bleeds (5 cases), and family related issues (4 cases). Three had not disclosed haemophilia status to their spouse. Another one resorted to drug abuse (pain-killer) whereas one committed suicide.

The family size even distributed (Fig.4) with most having more than 3 members, a quarter had more than 5 members in family.

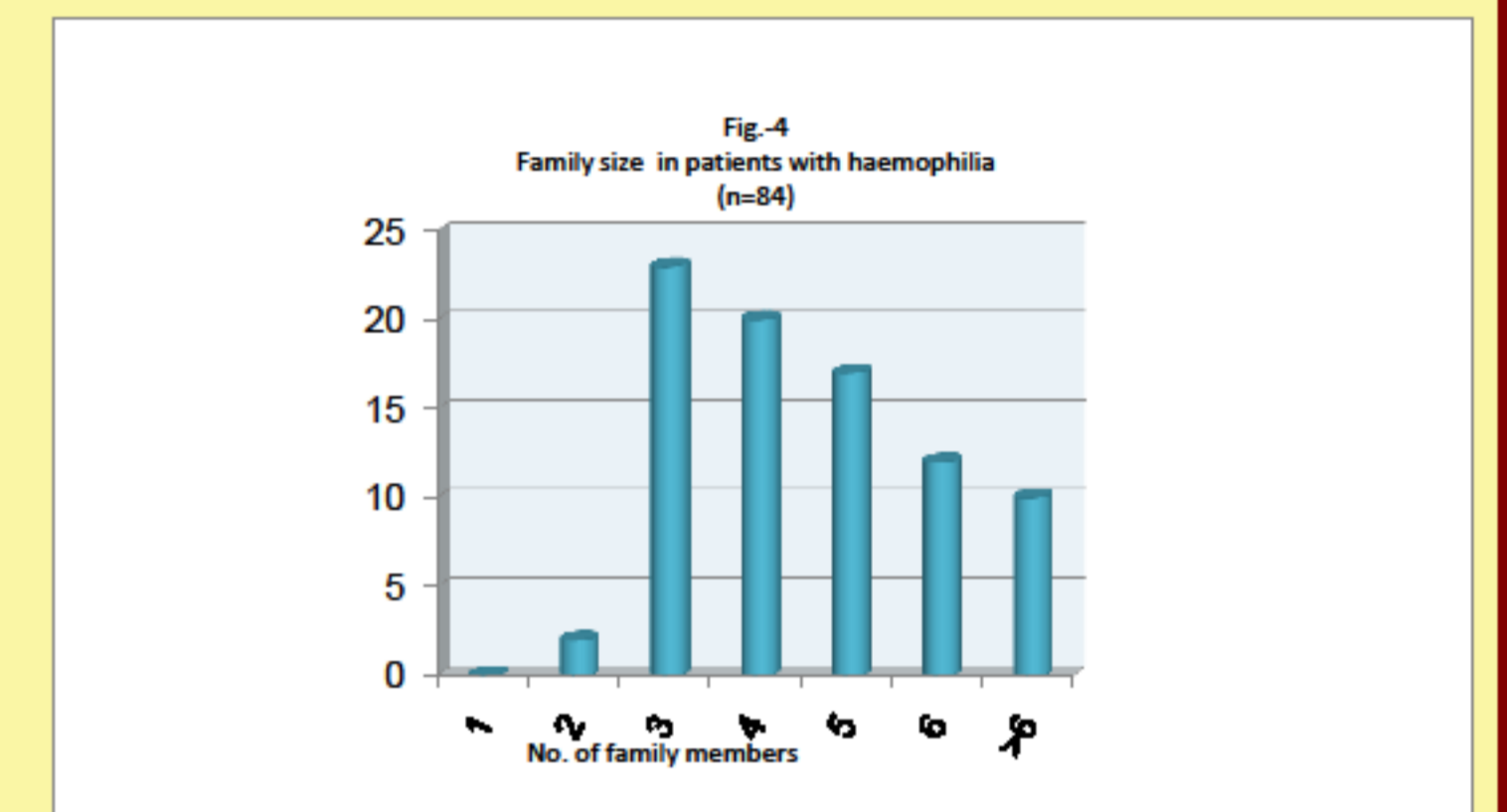
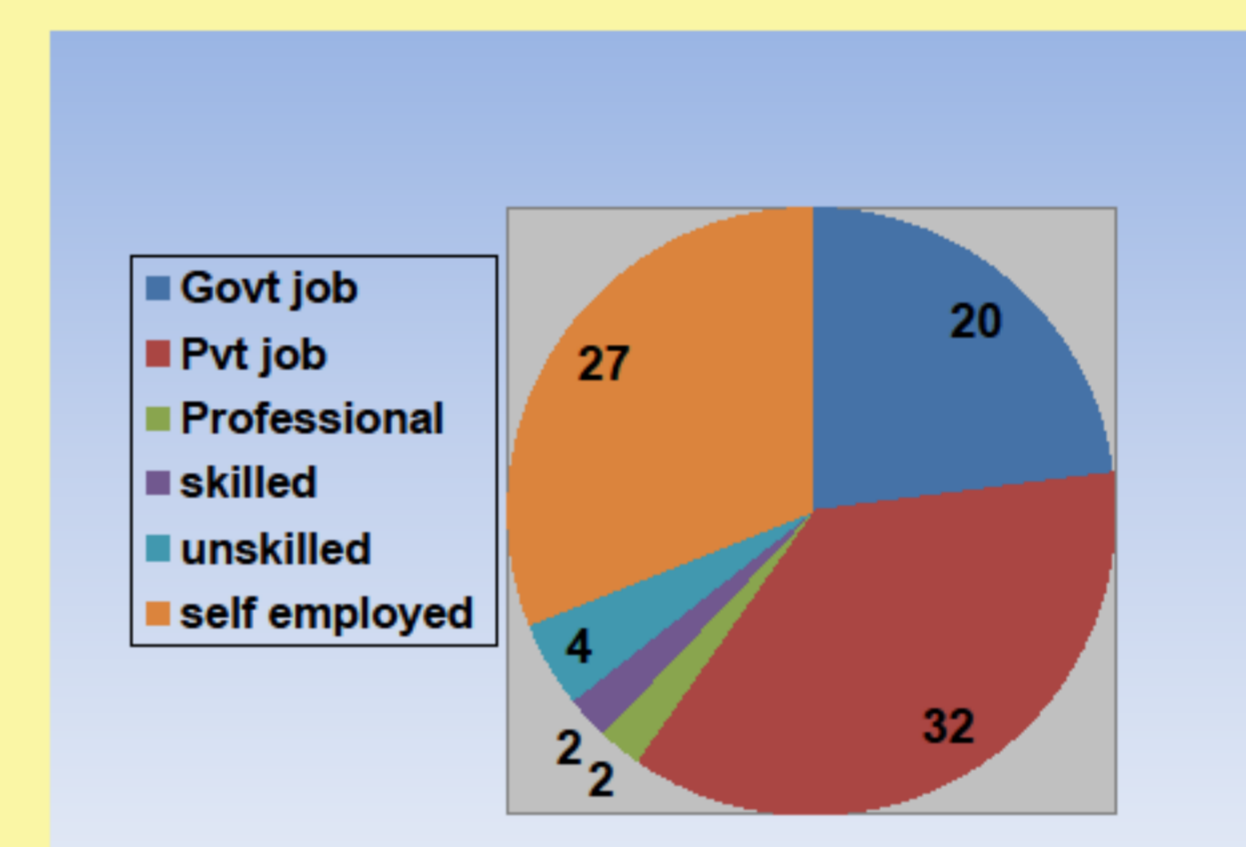


Fig-5 Jobwork of the families with haemophilia (n-84)



All families had one or more working members- 24% in some government employment, 38% private job. Labour and menial jobs accounted for 30%. Higher end jobs were in 2/84 families, both as medical doctors.

Three out of the 7 spouses felt cheated for non-disclosure of the husband's haemophilia status before marriage and even afterwards, thus leaving no respect for the husbands. The other 4 were from a lower social strata and resigned themselves to their fate.

Amongst the five parents, 3 had undue anxiety. Two parents were superstitious with no faith in modern medicine with negative implications on the haemophilic children

Two out of 4 sisters interviewed were ignorant whereas the other 2 were anxious for their future career and marriage.

CONCLUSIONS

- Nearly 80% of haemophilia cases have psychosocial problems.
- The adverse impact on formal school education is present in nearly half the cases (45%) of severe to moderate haemophilia.
- Nearly 90% did not make it beyond the school level.
- The family jobwork indicates the lowliness of priority in managing their haemophilic children compounded by good family size.
- Whereas schooling related issues are the most important in children, it is the jobs and family related issues amongst the adults
- The spouse often feel cheated for not knowing the haemophila status of the husband before and even after marriage. Often they resign to their fate.
- Sisters of the haemophilics too face the anxiety and the dilemma of their future including marriage. .
- Since the psychosocial issues vary with age and the social milieu, it is more important than the standard medical treatment to individualize their identification and management.

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