

# EMPOWERING FAMILIES OF HEMOPHILIACS TO FACE CHALLENGES

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Disclosures: This study was conducted under the caregiver award category by Bayer Hemophilia Award Program [2007], the study will continue on the concept of building leaders in local communities .The second part of the study in context to training the trainer program for professionals is still in the follow up phase and will be published shortly.  
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**INTRODUCTION AND OBJECTIVES:** Key words: Care giver, empowerment, families, hemophilia  
Genetic bleeding disorders have a predilection to bleeds in the joints and muscles leading to early joint disintegration and disability.  
Disabilities are more prevalent in the developing countries due to compromised care. In the spectrum of difficulties encountered with hemophilia care, we mainly recognized problems like-unaffordable CFC costs, irregular and inconsistent availability of CFCs. Other identifiable problems were- few centers offering specialized hemophilia care, scarcity of professionals to deliver specialized skills to the PWH in proportion to the number of hemophiliacs registered  
In huge metropolitan areas long distances, costs of travel , and facing crowds on public transportation make it difficult for the PWH to reach the care center, thus delay the process of accessing the treatment. Provision of home rehab care and home based factor provision is unaffordable. Home care through care giver empowerment thus was thought be one of the better options to strengthen health status of the PWH.  
Most of the recommended home care programs are limited to factor infusion in the homes, this seems to be a model of priority in countries where factor is easily available and cost of the factor is not borne by the PWH or his family. Compatibility and compliance in following the home based factor infusion is most important. There seem to be no studies measuring the outcomes in relation to care giver empowerment in context to hemophilia care to date, care giver empowerment could be an option in countries where home based factor infusion is not possible .  
We recognize home care as not only limited to immediate delivery of CFC but, training the immediate care givers to execute competency in basic skills of conservative management, understanding the gravity of a presenting bleed and need for further referral to a center, monitoring the progress of the PWH, and handling the psychosocial needs of the family and the PWH. The overall education to the care givers, is assumed to allow them to effectively participate in the treatment and prevention of disability.

**OBJECTIVES:**

- Improving the knowledge and skill levels of caregivers.
- Assessing the psychosocial needs of families and PWH , enabling them to handle issues efficiently.
- Assisting care givers to identify and perceive changes, for appropriate decisions.

**METHODOLOGY:** Participants were recruited from four chapters of Maharashtra by telephonic calls and e-mail invites.30 participants recruited based on the inclusion criteria.

**Inclusion criteria :** A close care giver of the PWH [age of PWH 6-15 years ],Ability for procedural learning, educational level(ability to read and write), physical ability to execute the learnt procedures , initiative to participate through the training period and feasibility to travel during training and follow up sessions.

A detailed questionnaire was designed following repeated interviews with the care givers on different occasions. The questionnaire was validated by researchers working in the field of hemophilia. The participants were assessed on four components of the scale.

**Components of the scale were:** I. The knowledge level of care givers regarding hemophilia [26 points, score 1 poor level of knowledge, score 5 high level of knowledge]

II. Cognito- motor abilities of the caregivers [20 points , score 1 poor level of ability, score 5 high level of ability]

III. Perception of the PWH status by caregivers [12 points, score 1 no change, score 5 perceivable change]

IV. Impact of psychosocial factors on the caregivers [11 points ,score 1 least and score 5 high psychosocial ability]

V. Assessment on the Perceived Social Stress scale.

On the **First session** five experts guided five care giver[CG] groups, six in each group. They assisted in responding to the questionnaire to the participants. In the later half participants introduced them selves and discussed individual problems .Areas of deficits were identified through the discussions, questionnaire responses and used as anchors to focus on the components of training to the group.

**Second session: Education** to the care givers in the area of deficits of the knowledge, exercises, splinting, positioning, recognizing the gravity of bleeds, information about complications in hemophilia, antenatal diagnosis, career detection, etc.. This session was conducted through audio-visuals, power point presentations, demonstration of various bleeds, and their associated complications. Each session ended with an interaction , discussion amongst the group members, participants cleared doubts and shared their experiences of learning in the session.

**Third session:** Was demonstration on handling an acute bleed, clearing myths about the treatment , immediate need for factor infusion. Rest positions, applications of splints, icing, compression techniques, and exercises to be started at home after a bleed was explained to caregivers. The demonstration session was followed by hands-on practice to the partners in the group, under supervision of experts.

**Fourth session** - hands on to the care giver by the expert first for all demonstrations as above, followed by CG to PWH with hand holding by the supervisor, on UB/LB joints.

**Fifth session** included demonstration of exercises on upper and lower body joints , to improve ROM ,strength and prevent muscle atrophy. The demonstration was followed by hands-on practice to the partners under supervision of trained experts.

**Sixth session** included a session on psychosocial problems of the PWH families, each person by this time had developed a feeling of belonging to the group and expressed themselves in the light of individual problems faced by them in society and at home.

**Seventh session** had a focus on motor skills training for infusion of factor by the care givers and self-infusion training for children above 10 years using demonstration and guided hands on.

**Eighth session** included reassessment of CG on the four components of the scale ,discussions on any queries and doubts ,CGs' living in close localities were identified to establish leaders in community . The care givers were monitored for their ability in continued care development for about 6- 12 months following the training as they attended the outpatient department of therapy .

Descriptive Statistics				
	N	Percentiles		
		25th	50th (Median)	75th
Knowledge pre	32	31.5000	44.5000	68.5000
Self ability pre	32	22.2500	32.5000	43.0000
Knowledge post	32	73.7500	87.0000	94.7500
Self ability post	32	58.0000	68.5000	78.0000

Seen in the above table there was a significant improvement in the percentile range pre and post knowledge level and self ability .

Ranks				
	N	Mean Rank	Sum of Ranks	
Knowledge post - knowledge pre	Negative Ranks	0 <sup>a</sup>	.00	.00
	Positive Ranks	32 <sup>b</sup>	16.50	528.00
	Ties	0 <sup>c</sup>		
	Total	32		
Self ability post - self ability pre	Negative Ranks	0 <sup>a</sup>	.00	.00
	Positive Ranks	32 <sup>b</sup>	16.50	528.00
	Ties	0 <sup>c</sup>		
	Total	32		

a. Knowledge post - knowledge pre- there were no negative score in the post training phase vis the pre training phase  
b. Knowledge post - knowledge pre- scores of the post training were more than the scores of the pre training phase  
c. Knowledge post - knowledge pre- there were no scores equal in the pre and post training phase  
d. selfabilitypost - selfabilitypre- scores during the post training were higher than pre training phase  
e. selfabilitypost - selfabilitypre- scores of post training were higher than scores of pre training phase  
f. Self ability post+ self ability pre- none of the scores were equal.

psychosocial component evaluated at the outset indicates that most of the families had limited social abilities and there was a great psychologic pressure on the families ,hence their overall psycho social participation suffered.

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid poor	13	40.6	40.6	40.6
Fair	11	34.4	34.4	75.0
good	8	25.0	25.0	100.0
Total	32	100.0	100.0	

Perception of the child at the end of training for any change observed by parents in the child on the subcomponents

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid poor	7	21.9	21.9	21.9
Fair	13	40.6	40.6	62.5
good	11	34.4	34.4	96.9
very good	1	3.1	3.1	100.0
Total	32	100.0	100.0	

PSS component: assessed on the psycho-social stressor scale which is a standardized scale there was a high impact of stress on the care giver, they were affected by the health status of the PWH.

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid High	14	43.8	43.8	43.8
very high	18	56.2	56.2	100.0
Total	32	100.0	100.0	

Test Statistics <sup>b</sup>		
	Knowledge post - knowledge pre	Self ability post - self ability pre
F	-4.937 <sup>a</sup>	-4.937 <sup>a</sup>
Asymp. Sig. (2-tailed)	.000	.000

a. Based on negative ranks.  
b. Wilcoxon Signed Ranks Test, indication is highly significant  
p value p<0.05.in both the the components.

**CONCLUSION:** Care giver empowerment is an essential component in hemophilia care ,especially in developing countries where there are limitations due to numerous factors that affect PWH care. Care giver training as a part of home care incorporated with home based factor infusion may be able to resolve many a problems at the outset of musculoskeletal bleeds and systemic bleeds, facilitate functioning of PWH by avoiding complications. Trained care givers may be able to assume leadership roles in community and be guides and role models for the newly diagnosed PWH families. Long term studies with bigger sample size need to be studied to emphasize on the above conclusion.

Audio visual training to group:



Demonstration of various clinical problems



Demonstration of exercises by experts to small groups



Application of Controlled pressure on joints , soft tissues



Peer practice in small groups



GROUP TRAINING

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