# **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 for professionals is still 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. We thank Bayer healthcare for their invaluable support.

**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.

Descriptive Statistics					
		Percentiles			
	Ν	25th	50th (Median)	75th	
Knowledge pre	32	31.5000	44.5000	69.5000	
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	

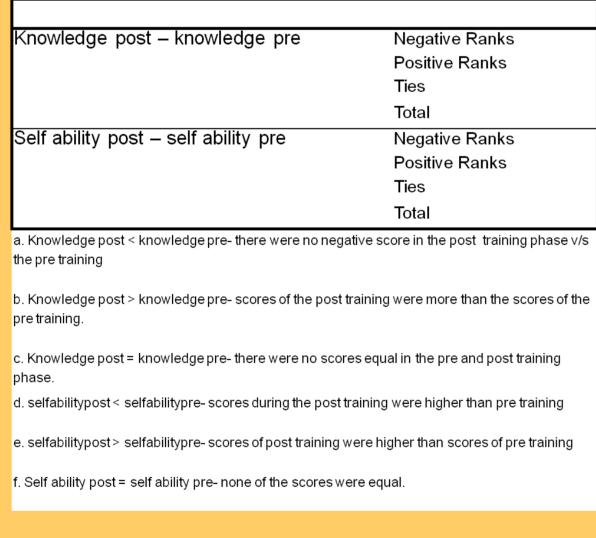
Seen in the above table there was a significant improvement in the percentile range pre and post knowledge level and self ability .

#### Test Statistics<sup>b</sup>

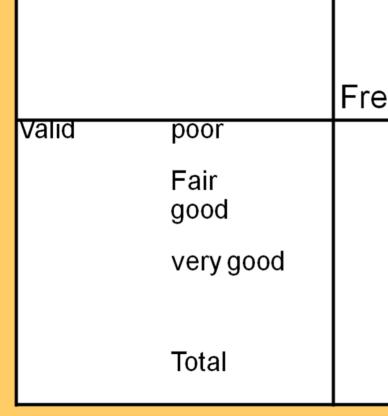
	Knowledge post – knowledge pre	Self ability post – self ability pre
Z	-4.937 <sup>a</sup>	<b>-4</b> .937ª
Asymp. Sig. (2-tailed)	.000	.000

a. Based on negative ranks.

b. Wilcoxon Signed Ranks Test, indication is highly significant p value p<0.05.in both the the components.



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



**<u>CONCLUSION</u>**: 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.

Ranks	5				
	N	Mean Rank	Sum of Ranks		
Negative Ranks	0ª	.00	.00		
Positive Ranks	32 <sup>b</sup>	16.50	528.00		
Ties	0 <sup>c</sup>				
Total	32				
Negative Ranks	Od	.00	.00		
Positive Ranks	32°	16.50	528.00		
Ties	Of				
Total	32				
re in the post_training phase v/s					

equency	Percent	Valid Percent	Cumulative Percent
7	21.9	21.9	21.9
13	40.6	40.6	62.5
11	34.4	34.4	96.9
1	3.1	3.1	100.0
32	100.0	100.0	

**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.

practice to the partners under supervision of trained experts. of individual problems faced by them in society and at home.

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

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			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	

## PSS component: assessed on the psycho-social stressor

	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	

## P43 Poster ID 631 Educational and Communication Model

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

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

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.

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.

#### Audio visual training to group:





Application of Controlled pressure on joints, soft tissues



**REFERENCES:** 1] CONCEPT PAPER, WHO Guidelines on Health-Related Rehabilitation (Rehabilitation Guidelines) December 2012

2] Measuring health-related quality-of-life in haemophilia patients A MINERS, C SABIN, K TOLLEY and C LEE Royal Free Hospital, London Introduction

3] Financial impact of life with haemophilia A RODRIGUEZ RAMIREZ,\* D DOURADO and C CASTEGNARO \*Madrid, Spain; Hemofilia Portugal, Portugal, Lisboa, Portugal; and Instituto Ricerca Economica, Italia, Milan, Italia 4] The impact of chronic disease on the family G. GOLDSTEIN and G. KENET The National Hemophilia Center, Sheba Medical Center, Te-Hashomer, Israel, Haemophilia (2002), 8, 461–465] 5] Delivery of haemophilia care in the developing world.A SRIVASTAVA, Department of Haematology, Christian Medical College Hospital, Vellore, India SRIVASTAVA Department of Haematology, Christian Medical College Hospital, Vellore, India, Haemophilia (1998), 4, (Suppl. 2), 33±40]

5]Emotional and behavioural problems and family functioning in children with haemophilia: a cross-sectional survey M. EVANS, D. COTTRELL\* and C. SHIACH The Roseberry Centre, St Luke's Hospital, Marton Rd, Middlesbrough, TS4 6] AF, UK, \*The Academic Unit of Child and Adolescent Mental Health, 12a, Clarendon Road, Leeds, LS2 9NN, UK, and Manchester Royal In®rmary, Oxford Road, Manchester, M13 9WL, UK, Haemophilia (2000), 6, 682±687]. 7]Meeting the needs of hemophilic children in developing A.Chaunsumrit, hemophilia (1998), 4, (suppl. 2) 19-23.

Demonstration of various

Demonstration of exercises by experts to small groups



GROUP

TRAINING

Peer practice in small groups













