A Comparative Study on Social Support among Persons with Hemophilia and Healthy Controls

Deepika Lohan[1*]
Research Scholar,
Panjab University, Chandigarh, India.

Dr. Rajesh Kumar[2*]
Associate Professor, Department of Psychology,
PG. Govt. College, Sector 46, Chandigarh, India.

Corresponding Author:- Deepika Lohan[1*], Dr. Rajesh Kumar[2*]

Abstract:- Hemophilia does not only affect patients physically but also socially and psychologically. In addition to family and friends, their larger support system frequently consists of medical experts and other specialists. The important concern of the present time is to confront the psychological burden associated with hemophilia. The primary aim was to compare persons with hemophilia and healthy controls on Social Support. PGI Social Support Questionnaire (P.G.I-S.S.Q) was used as a tool. The sample of the investigation comprised 180 males, out of which 90 were persons with hemophilia and 90 were healthy controls. The data was collected from the northern states i.e., Haryana, Uttar Pradesh and Punjab. t-test revealed that there is a significant difference on Social Support. Persons with Hemophilia scored higher than Healthy Controls on Social Support. One-way ANOVA was performed to compare the effect of three different age groups among PWH and came out to be significant. Hemophilia Treatment centers ought to have social workers and psychologists on staff to provide both individual and group therapy to gratify the unmet needs of PWH and their caregivers.

Keywords:- *Social Support, Persons with Hemophilia, Healthy Controls.*

I. INTRODUCTION

Hemophilia affects relationships in a variety of ways, with superior effects on education, socioeconomic status, and mental health. A social grid embraces all of an individual's social connections. It comes from a variety of people and places. Social support is defined by Barbara (1983) as comfort, aid, and information received through formal or informal encounters with persons or groups. The X-linked bleeding disorder hemophilia, which primarily affects boys, is brought on by a genetic lack of either factor VIII (hemophilia A) or factor IX (hemophilia B). The lack of anti-hemophilia factors is distinctively connected with physical health and mental health. It is also observed there are incidences of spontaneous bleeding which brings fear of uncertainty tagged with the disease. With an incidence of one in 5,000 male live births compared to one in 30,000, hemophilia A is more prevalent than hemophilia B (Berntorp and Shapiro, 2012). Consequently, being diagnosed with hemophilia, directly and indirectly, impacts the life and daily functioning of people associated with the disease.

Research on Hemophilia in India is one of the examples of need-based research (Ghosh, Shetty, and Sahu, 2010). Support groups for hemophilia have also contributed immensely to creating awareness amongst patients and maintaining treatment facilities. Persons with hemophilia frequently miss days at work and school because they are unable to engage in strenuous physical activity due to the severe pain and discomfort brought on by the hemorrhagic episodes.

Hemophilia organizations serve as powerful educators for affected families. There was a favorable association between disease knowledge and frequency of attendance at the society's monthly sessions (Pandey et al., 2003). Helgeson (2003) claims that social support refers to a wide range of factors that define the social environment or people who include others in their system.

- *Role of Social Support*

Adult males with hemophilia carefully consider when and where to disclose their disease to friends, coworkers, and love partners to prevent unfavorable reactions (e.g., being rejected, misunderstood, or abused). Close personal relationships can be difficult for adult persons with hemophilia. Similar to men without hemophilia, they focus their social energy on sustaining friendships, spending time with spouses or love partners, and, for men who have children, parenting and raising a family. The presence of a strong support system, including family and friends, can significantly impact the emotional well-being and overall quality of life of individuals. Sociodemographic factors may influence the availability and quality of this support.

- *Prevalence of Hemophilia in India*

The Hemophilia Federation of India (HFI) acts as a disease registry by modeling as a reliable source of data. The organization's key work includes providing psycho-social support, distributing factors, and fighting for the rights of people with bleeding disorders and their families. According to the Annual Global Survey 2021, the patients diagnosed with hemophilia in India are 25,384.

II. REVIEW OF LITERATURE

Chiu et al. (2021) evaluated the connection between hemophilia patients' social involvement and influence on the family, self-perception, and social support. The Participation Scale for Children, the Self-Perception Profile for Children and Adolescents, and the Social Support Questionnaire were administered to 50 boys with hemophilia who were randomly selected. Pearson product-moment correlations revealed a significant relationship between the social participation of all participants and the self-perception subscales of global self-worth ($r= 0.6$, $P= 0.001$) and social acceptance ($r = 0.5$, $P= 0.001$). In addition to modest links with support from close friends ($r= 0.4$, $P= 0.01$), there were significant relationships between social activity and support from parents, teachers, and classmates ($r = 0.6$, $P= 0.001$).

HERO (Hemophilia Experiences, Results, and Opportunities) study was commenced in 2014 to gain a deeper knowledge of the psychological challenges that PWH faces. Parents were more inclined to share their son's diagnosis than PWH were, and the majority of them were happy with the support received from their son's classmates (74%), teachers (83%), and other adults in supervisory roles (85%). PWH were reluctant to communicate their diagnosis outside of family and friends. Overall, PWH and parents were happy with the help they received from their partners, families, friends, and social contacts (Cassis et al., 2014).

A qualitative study by Ratajová et al. (2020) was done to explore the coping mechanisms among persons with hemophilia. It was conducted on five adults with hemophilia utilizing a semi-structured face-to-face interview method. Using interpretive phenomenological analysis (IPA), transcripts were examined. Major emergent themes were social support, an external factor, and resilience as an internal factor in coping with the disease. Patients typically require assistance due to medical issues, which increases the demand for social support and creates a network that serves as a crucial psychological protective force. In the case of experts, psychologists play an important role in providing knowledge, support, and empathy during therapy, particularly in connection with procedures necessitated by hemophilic complications. Teachers can help children and young people with hemophilia assimilate into their peer group, as well as sports and social activities from which PWH are sometimes excluded owing to health concerns. Physicians and nurses offer assistance by openly addressing the disease. Unexpectedly, it was discovered that persons with hemophilia are eager to support others as well as receive support. The present study solely focuses on one variable i.e. Social Support which has significant importance in day-to-day life.

III. METHODS

A. Objectives and Hypotheses

➢ *Objectives*

- Comparison of Persons with Hemophilia and Healthy Controls on Social Support
- Comparing cohorts of 15-18 years, 19-24 years and 25-30 years among Persons with Hemophilia on Social Support

➢ *Hypotheses*

- Group comparisons: Comparing Persons with Hemophilia and Healthy Controls

✓ H0: There is no significant difference expected on Social Support among persons with hemophilia and healthy controls.
✓ H1: There is a significant difference expected on Social Support among persons with hemophilia and healthy controls.

- Age group comparisons: Comparing cohorts of 15-18 years, 19-24 years and 25-30 years among Persons with Hemophilia

✓ H0: There is no significant difference in all three age groups on Social Support.
✓ H2: There is a significant difference in all three age groups on Social Support.

➢ *Sample*

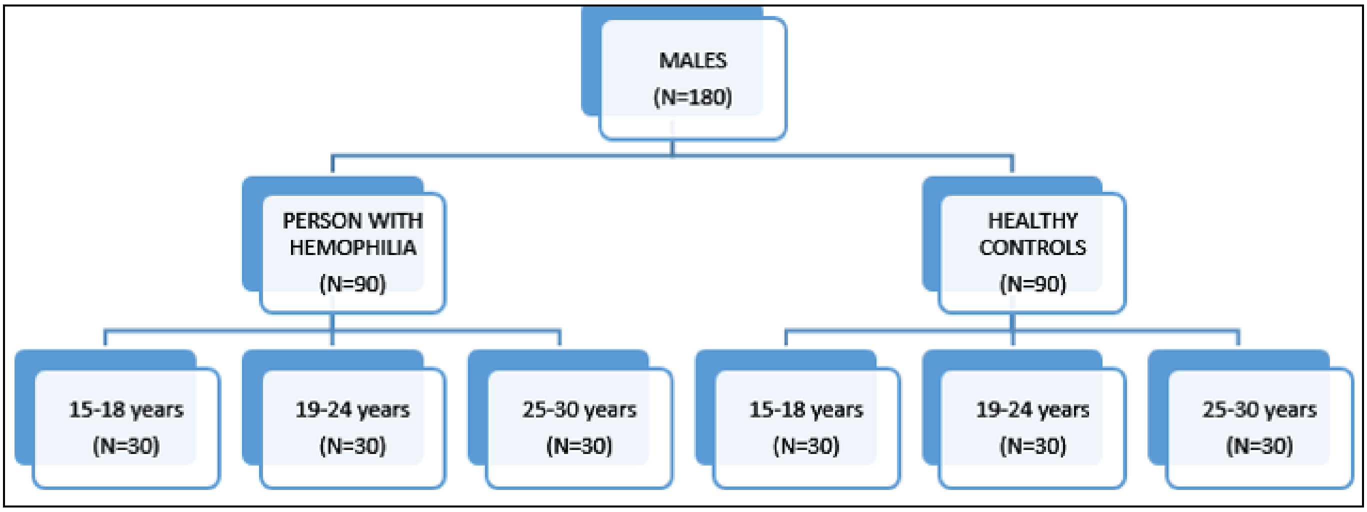

Fig 1 Schematic Representation of the Sample

B. *Procedure*

Data was collected from the northern part of India i.e., Haryana, Uttar Pradesh and Punjab. Males were selected for the present study with a confirmed diagnosis of hemophilia-A and hemophilia-B. The study considered persons with hemophilia for all the severity types (mild, moderate, and severe). Persons with hemophilia were contacted from hemophilia treatment centers and data was collected during educational and factor distribution camps being organized by various hemophilia societies. A sample for healthy controls was conducted through schools and colleges. The final sample was randomly selected and a systematic sampling technique was used.

➢ *Ethical Considerations*

- The participants were ensured that confidentiality would be maintained.
- Consent from the participants was collected when they had been fully informed Tools used
- PGI Social Support Questionnaire (P.G.I-S.S.Q) (Nehra et al., 1998)

PGI Social Support Questionnaire (P.G.I-S.S.Q) was constructed and standardized by Nehra, R., Kulhara, P., and Verma, S., Department of Psychiatry, PGIMER, Chandigarh. It is an 18-item and a valid measure. It is easy to interpret and reliable both in terms of consistency and stability of scores. It has been considered as an index of a wide variety of health, illness, recovery, coping situations, and treatment outcomes (Nehra et al. 1996).

IV. RESULTS

The raw scores were analyzed using appropriate statistical analyses viz. Descriptive Statistics, t-test, One-way ANOVA, and Tukey's HSD Post hoc test. Means and Standard Deviations, skewness, and kurtosis were tabulated for the various groups of the study.

Analysis of variance was conducted on Persons with Hemophilia with age as an independent variable. One-way ANOVA was employed with three levels of age viz. 15-18 years, 19-24 years and 25-30 years.

One-way ANOVA was performed to compare the effect of three different age groups on Social Support. It revealed that there was a statistically significant difference in the mean score of Social Support between at least two age groups (F(2, 87) = [11.40], p = .0001]). Tukey's HSD multiple comparison procedure was further performed. It revealed that there is a significant difference among three age groups (15-18 years, 19-24 years, and 25-30 years) on Social Support.

Table 1 Means and Standard Deviations, Skewness, and Kurtosis

Groups	Mean	SD	Skewness	Kurtosis
Total sample (n= 180)	48.52	6.80	0.20	-0.22
Persons with Hemophilia (n= 90)	50.84	7.08	-0.05	-0.39
Healthy Controls (n= 90)	46.40	4.99	-0.31	-0.45
Persons with Hemophilia in the age group 15-18 (n= 30)	46.40	4.99	-0.31	-0.45
Persons with Hemophilia in the age group 19-24 (n= 30)	53.87	7.04	-0.57	0.12
Persons with Hemophilia in the age group 25-30 (n= 90)	52.27	6.69	-0.13	0.06

Table 2 Means, Standard Deviations and t-ratio comparing Persons with Hemophilia and Healthy Controls (n=180)

Sr. No	Variable	Healthy Controls (n=90)		Persons with Hemophilia (n=90)		t ratio
		M	SD	M	SD	
1	Social Support	46.20	5.64	50.84	7.08	4.86*

Table 3 Analysis of Variance of Social Support

Sources of variance	Sum of Squares	df	Mean Sum of Square	F- value	Level of significance
Between Groups	927.289	2	463.644	11.406	.000
Within Groups	3536.533	87	40.650		
Total	4463.822	89			

Table 4 Homogeneous grouping of Social Support

Age Age Groups	N NN	Subset for alpha = 0.05	
		1	2
15-18 Years	30	46.4000	
25-30 Years	30		52.2667
19-24 Years	30		53.8667
Sig.		1.000	.596
15-18 Years	30	46.4000	

Table 5 Tukey's HSD test for Multiple Comparisons Dependent variable: Social Support

Combination	**Mean Difference (I-J)**	**Std .Error**	**p-value**	**95% Confidence Interval**	
				Lower Bound	**Upper Bound**
15-18 Years	-7.46667 *	1.64620	0.001		
	-5.86667*	1.64620	0.002	-11.3920	-3.5413
				9.7920	-1.9413

V. DISCUSSION

The primary aim of the present investigation was to compare persons with hemophilia and healthy controls on a psychosocial variable i.e. Social Support. Another aim of the study was to compare age group differences among persons with hemophilia.

The majority of a man's contacts with people in his social surroundings, including friends, parents, guardians, professionals, nurses, and doctors, are accounted for by these quantitative markers of social support. PWH are enrolled as members of hemophilia societies. Belonging to an NGO gives them a strong support network. Hemophilia Federation India is a countrywide network of nonprofit organizations that support and provide care to males with hemophilia. It has a network of 87 chapters distributed over India (74 affiliated and 13 non-affiliated).

- *Comparison of Persons with Hemophilia and Healthy Controls on Social Support.*

To compare the two groups, t-test was applied to the overall sample as well as for each of the three age groups separately. A glance at t-ratio table (Table 1.2) comparing Persons with Hemophilia and Healthy Controls revealed that there is a significant difference on Social Support. Hence, H1 was accepted. Persons with Hemophilia scored higher than Healthy Controls on Social Support.

- *Comparing cohorts of 15-18 years, 19-24 years and 25-30 years among Persons with Hemophilia on Social Support.*

Analysis of variance table (Table 1.3) revealed that the F-ratio was significant for Social Support. Thus, H2 hypothesis was accepted. Tukey's HSD Test for multiple comparisons found that there is a significant difference among three different age groups of Persons with Hemophilia. The mean value of Social Support was significantly different between 15-18 years and 19-24 years (p = .0001). The mean value of Social Support was significantly different between 15-18 years and 25-30 years (p = .002). The mean value of Social Support was not significantly different between 19-24 years and 25-30 years (p = .59).

Researchers have been quite interested in the phenomenon of social support during the past thirty years, especially when it comes to health. Even after statistically correcting for baseline health state, previous research has shown that people with high quality or quantity of social networks have a lower risk of mortality compared to people with low amount or quality of social relationships (Berkman et al., 2000).

Ratajová et al. (2020) found two core themes from the qualitative analysis: social support as an external factor and resilience as an internal factor in coping with the disease. Hemophiliacs typically require assistance with health-related issues, which influences the amount of social support they need. In addition to offering helpful advice, their social support system serves as a crucial psychological shield. Unexpectedly, it was discovered that persons with hemophilia are eager to provide support to others in addition to wanting to receive it.

For children with chronic diseases, social participation restrictions may have a significant impact on their well-being as the inability to participate could lead to a stigma that could further restrict their social participation (Van Brakel et al., 2006). Boys with hemophilia who have unlimited access to safe, effective clotting factor concentrates and optimal comprehensive care report a high level of social support, with few barriers to their social participation. There were no appreciable variations found in the means of social support for children and adolescents among PWH (Chiu et al., 2021).

The Results of the present study are corroborated with the ICF model that states "a person's functioning and disability is the result of the dynamic interaction between the person's health conditions and the contextual factors in their life". In keeping with the ICF model, the data illustrate that the interaction between personal factors as well as the health condition of hemophilia is associated with the level of perceived social support. The significance of having a social support system has far-reaching effects. A PWH may have improved compliance, feel less depressed, and have a higher quality of life relating to their health if they believe they have strong social support (Iannone et al. 2012; Gringeri et al. 2007; Petrini & Seuser 2009).

VI. CONCLUSION

Hemophilic centers ought to employ social workers and psychologists on staff to provide both individual and group therapy to gratify the unmet needs of PWH and their caregivers. The study merits further research on quantifying the relationships between clinical parameters and psychosocial outcomes in the hemophilia community.

REFERENCES

[1]. Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. Social science & medicine (1982), 51(6), 843–857. https://doi.org/10.1016/s0277-9536(00)00065-4

[2]. Berntorp, E., Boulyjenkov, V., Brettler, D., Chandy, M., Jones, P., Lee, C., Lusher, J., Mannucci, P., Peak, I., & Rickard, K. (1995). Modern treatment of hemophilia. Bulletin of the World Health Organization, 73(5), 691–701.

[3]. Cassis, F. R., Buzzi, A., Forsyth, A., Gregory, M., Nugent, D., Garrido, C., Pilgaard, T., Cooper, D. L., & Iorio, A. (2014). Hemophilia Experiences, Results and Opportunities (HERO) Study: influence of hemophilia on interpersonal relationships as reported by adults with hemophilia and parents of children with hemophilia. Hemophilia : the official journal of the World Federation of Hemophilia, 20(4), e287–e295. https://doi.org/10.1111/hae.12454

[4]. Chiu AS, Blanchette VS, Barrera M, et al. (2021) Social participation and hemophilia: Self-perception, social support, and their influence on boys in Canada. Res Pract Thromb Haemost. 5(12627). https://doi.org/10.1002/rth2.12627

[5]. Ghosh, K., Shetty, S., & Sahu, D. P. (2010). Hemophilia care in India: innovations and integrations by various chapters of Hemophilia Federation of India (HFI). Hemophilia, 16(1), 61–65. https://doi.org/10.1111/j.1365-2516.2009.02097.x

[6]. Gringeri, A., von Mackensen, S., Auerswald, G., Bullinger, M., Perez Garrido, R., Kellermann, E., Khair, K., Lenk, H., Vicariot, M., Villar, A., Wermes, C., & Hemo-QoL Study (2004). Health status and health-related quality of life of children with hemophilia from six West European countries. Hemophilia : the official journal of the World Federation of Hemophilia, 10 Suppl 1, 26–33. https://doi.org/10.1111/j.1355-0691.2004.00876.x

[7]. Helgeson V. S. (2003). Social support and quality of life. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 12 Suppl 1, 25–31. https://doi.org/10.1023/a:1023509117524

[8]. Hemophilia Federation India (2023). About HFI. https://hemophilia.in/index.php/about-us/about-hfi

[9]. Iannone, M., Pennick, L., Tom, A., Cui, H., Gilbert, M., Weihs, K., & Stopeck, A. T. (2012). Prevalence of depression in adults with hemophilia. Hemophilia : the official journal of the World Federation of Hemophilia, 18(6), 868–874. https://doi.org/10.1111/j.1365-2516.2012.02863.x

[10]. Nehra, R., Kulhara, P., and Verma, S.K. (1996). Adaptation of social support questionnaire in Hindi. Indian Journal of Clinical Psychology. 23, 33-39.

[11]. Pandey, G. S., Panigrahi, I., Phadke, S. R., & Mittal, B. (2003). Knowledge and attitudes towards hemophilia: the family side and role of hemophilia societies. Community genetics, 6(2), 120–122. https://doi.org/10.1159/00007300

[12]. Petrini, P., & Seuser, A. (2009). Hemophilia care in adolescents--compliance and lifestyle issues. Hemophilia : the official journal of the World Federation of Hemophilia, 15 Suppl 1, 15–19. https://doi.org/10.1111/j.1365-2516.2008.01948.x

[13]. Ratajová, K., Blatný, J., Poláčková Šolcová, I., Meier, Z., Horňáková, T., Brnka, R., & Tavel, P. (2020). Social support and resilience in persons with severe hemophilia: An interpretative phenomenological analysis. Hemophilia : the official journal of the World Federation of Hemophilia, 26(3), e74–e80. https://doi.org/10.1111/hae.13999.

[14]. Van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: measuring a key concept in public health. Disability and rehabilitation, 28(4), 193-203.

[15]. World Federation of Hemophilia. Report on the Annual Global Survey 2021. https://www1.wfh.org/publications/files/pdf-2324.pdf . Accessed December 12, 2022.