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A Comparative Study on Neuroticism among Persons with Hemophilia and Healthy Controls

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Abstract: The objective of the study was to compare Persons with Hemophilia and Healthy Controls on Neuroticism and compare cohorts of 15-18 years, 19-24 years and 25-30 years among Persons with Hemophilia. NEO-FFI-3 (Costa & McCrae, 1992), a standardized scale was used to measure neuroticism. 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. The comparison revealed t-ratio to be significant (t=1.07*). Analysis of variance was conducted on Persons with Hemophilia with age as an independent variable. Tukey's HSD test was used to study multiple comparisons. Results revealed that there was a statistically significant difference in the mean score of Neuroticism between at least two age groups (F(2, 87) = [78.90], p = .0001]). There is a need to impart awareness of the psychosocial burden that surfaces from living a life with hemophilia. Educational workshops on stress management for PWH can boost their well-being.

Keywords: *Neuroticism, Persons with Hemophilia, Healthy controls*

INTRODUCTION

A bleeding ailment called hemophilia causes blood to not clot properly and has no known cure. Hemophilia is exemplified by repeated bleeding in joints and muscles, causing severe pain and directing disability to death. Persons with hemophilia are not the only ones affected by the condition rather the disease has a severe psychosocial impact on all members of the family. The following five traits have been regarded as essential components of personality: 1. Extroversion 2. Agreeableness 3. Conscientiousness 4. Neuroticism 5. Openness to experience (Costa and McCrae, 1992). The present study has focussed on exploring the status of neuroticism among Persons with Hemophilia and Healthy Controls.

The significant characteristics of neuroticism are the propensity to feel negative emotions like fear, sadness, embarrassment, anger, guilt, and disgust. Men and women with high levels of neuroticism may also be more prone to irrational thoughts, be less able to control their impulses, and handle stress worse than others due to the disruptive emotions that interfere with adaptation. Individuals with low neuroticism are emotionally stable. They are often even-tempered, relaxed, and able to handle stressful events without getting irritated. A high score in neuroticism suggests more unpleasant characteristics.

According to the Annual Global Survey 2021, the patients diagnosed with hemophilia in India are 25,384. Out of which patients with Hemophilia-A are 21,350 and patients reported with Hemophilia-B are 3,475. Most PWH (44%) in India are in the age group of 19-44, 14% lie in the 5-13 age group, 11% in the 14-18 years of age group and 11% in the old age group (45 and above years). The lack of psycho-social support provided by treatment centers is one superficial emotional cost of this devastating disorder. 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.

Patient registries can aid in the advancement of understanding hemophilia treatment variations, describe care patterns, and disparities in the delivery and quality of care, identify factors that influence prognosis, and provide evidence on resource utilization (Stoffman et al., 2019). More than ever, we can aspire to give a rising number of hemophilia patients and their families more independence and relaxation. It is ultimately about the ability to free the brain, mind, and awareness from the restraints, worries, and restrictions of a serious condition and its treatment through moving towards a hemophilia mind-free state (Krumb & Hermans, 2021).

Genetic counseling should consider the individual's experiences and perceptions, as well as the social, cultural, and religious elements and circumstances that may influence genetic status decisions and alternatives. Genetic counselors can assist potential hemophilia carriers in understanding their bleeding and hereditary risks, as well as adapting to the medical, psychological, familial, and reproductive ramifications.

ROLE OF PSYCHOSOCIAL FACTORS IN HEMOPHILIA

Stress

According to Landreville et al. (2009), many individuals with chronic pain have impaired physical functioning. It is reasonable to feel frustrated by one's incapacity to carry out significant tasks that one cherishes

and once enjoyed. Anxiety, hopelessness, a decline in one's sense of identity, and lack of confidence are all psychological consequences of hemophilia. There is a burden of genetically transmitting a disease with serious consequences among PWH.

Personal Dispositions

An individual's strengths and deficiencies may significantly influence treatment outcomes. Assessment of factors, such as the locus of control, self-esteem, and psychological characteristics, such as resilience, anger, depression, and optimism, can be used to guide and inform individual care or research (Triemstra et al.,1998).

Pain tolerance

The lives of PWH are dominated by pain since it affects practically every area of daily life in a variety of ways. Joint impairment, fatigue, comorbidity, and perceptions of one's physical fitness are restricted by an individual's capacity to bear pain.

Self-efficacy

According to Cataldo et al. (2013) increasing a person's ability to engage in physical activity has a positive effect on self-efficacy. Though PWH may have lower self-esteem than the general population and may be more susceptible to long-term sadness and anxiety, males with hemophilia are generally psychologically robust (Canclini et al., 2003).

REVIEW OF LITERATURE

Uytun et al. (2020) sought to assess psychiatric symptoms as well as the quality of life in children and adolescents with hemophilia. Twenty persons with hemophilia and twenty healthy controls, aged 6 to 16 years participated in the study. A sociodemographic questionnaire, Child Depression Inventory (CDI), the Spielberger State-Trait Anxiety Inventory (STAI),and the KINDLR Questionnaire were utilized as tools. The study found that children and adolescents with hemophilia had higher anxiety levels and were more likely to be diagnosed with a mental health disorder. On the State-Trait Anxiety Inventory-Trait and State-Trait Anxiety Inventory-Total, it was discovered that the patient group scored greater than the controls ($p< 0.05$). Psychopathology was found in 30% of the patients, with attention deficit and hyperactivity disorder (ADHD) being the most common diagnosis

(20%). In the regression analyses, it was discovered that the severity of hemophilia predicted Beck anxiety scores.

A person with hemophilia who experiences physical pain may experience depression. A study by Jiménez-Cebrián (2022) evaluated the effects of depression in adult hemophiliacs and compared them to healthy controls. 100 subjects made up the sample, with a median age of 42.50± 30. They recruited 50 hemophiliac patients from Spanish Hemophiliac Associations and another 50 healthy participants from a clinic Podiatry Practices (University of Malaga, Spain). Results from the Beck Depression Inventory (BDI) in Spanish were compiled. The fluctuation in BDI scores between the two groups showed a clear statistically significant difference ($p < 0.001$). When compared to healthy persons, patients with hemophilia performed worse, with a score on BDI of 7.50 to 11.25 points, as opposed to 2.50 to 5 points for healthy subjects. Only patients with hemophilia displayed the classifications for moderate and severe depression. Patients with hemophilia showed higher depression scores and range status when compared to non-patients. Patients with hemophilia were more likely to experience depression.

METHODS

A . Objectives and Hypotheses

A(1) Objectives

1. Comparison of Healthy Controls and Persons with Hemophilia on Neuroticism.
2. Comparing cohorts of 15-18 years, 19-24 years and 25-30 years among Persons with Hemophilia on Neuroticism.

A(2) Hypotheses

1. Group comparisons: Comparing Persons with Hemophilia and Healthy Controls

H0: There is no significant difference expected on Neuroticism among persons with hemophilia and healthy controls.

H1: There is a significant difference expected on Neuroticism among persons with hemophilia and healthy controls.

2. 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 Neuroticism.

H2: There is a significant difference in all three age groups on Neuroticism.

B. Sample

The sample of the investigation comprised 180 males, out of which 90 were persons with hemophilia and 90 were healthy controls. This sample was further divided into 3 age groups.

1. 15-18 years
2. 19-24 years
3. 25-30 years

The inclusion criteria for the sample consisted of males in the age range of 15-30 years only. The minimum educational qualification for the selection of participants was matriculation. The subjects were randomly selected from hemophilia treatment centers. Participants with a history of mental illness and physical illness except for Hemophilia or any participant having a history of substance/ alcohol dependence were excluded from the sample.

C. 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.
- Informed Consent was taken from the participants.

Tools used:

Neuroticism which is one distinctive component of personality was measured by using the NEO-FFI-3 developed by Costa & McCrae (1992). It is a 60-item self-report instrument. It is applicable for the age range of 12-99 years and hence, was used for persons with hemophilia and healthy controls. The measure uses a five-point Likert scale of responses ranging from ―strongly disagree to strongly agree.

RESULTS

The raw scores were analyzed using appropriate statistical analyses viz. Descriptive Statistics, t-test, One-way ANOVA, and Tukey HSD Post hoc test. Means and Standard Deviations, skewness, and kurtosis were tabulated for the various groups of the study.

t-ratios were calculated to find out significant differences between the means of persons with hemophilia and healthy controls. The comparison revealed t-ratios to be significant on Neuroticism (t=1.07).

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. Tukey's HSD test was used to study multiple comparisons.

One-way ANOVA was performed to compare the effect of three different age groups on Neuroticism. It revealed that there was a statistically significant difference in the mean score of Neuroticism between at least two age groups (F(2, 87) = [78.90], p = .00]). 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 Neuroticism.

Table 1.1

Means and Standard Deviations, skewness, and kurtosis

Groups	Mean	SD	Skewness	Kurtosis
Total sample (n= 180)	17.93	8.09	-0.09	-0.99
Persons with Hemophilia (n= 90)	17.28	6.45	-0.32	-0.84
Healthy Controls (n= 90)	18.58	9.45	-0.12	-1.33
Persons with Hemophilia in the age group 15-18 (n= 30)	10.00	3.62	-0.06	-0.87
Persons with Hemophilia in the age group 19-24 (n= 30)	20.83	3.44	0.14	-0.35
Persons with Hemophilia in the age group 25-30 (n= 90)	21.00	4.50	-0.30	-1.26

Table 1.2

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

Sr. No	Variables	Healthy Controls (n=90)		Persons with Hemophilia (n=90)		t ratio
		M	SD	M	SD	
1	Neuroticism	18.58	9.45	17.28	6.45	1.07*

Table 1.3

Analysis of Variance of Neuroticism

Sources of variance	Sum of Squares	df	Mean Sum of Square	F- value	Level of significance
Between Groups	2383.889	2	1191.944	78.909	.0001
Within Groups	1314.167	87	15.105		
Total	3698.056	89			

Table 1.4

Homogeneous grouping of Neuroticism

Age Groups	N	Subset for alpha = 0.05	
		1	2
15-18 Years	30	10.0000	
19-24 Years	30		20.8333
25-30 Years	30		21.0000
Sig.		1.000	.985

Table 1.5

Tukey`s HSD test for Multiple Comparisons

Dependent variable: Neuroticism

Combination		Mean Difference (I-J)	Std. Error	p -value	95% Confidence Interval	
15-18 Years	19-24 Years	-10.83333*	1.00351	.0001	-13.2262	-8.4405
	25-30 Years	-11.00000*	1.00351	.0001	-13.3928	-8.6072

DISCUSSION

The primary aim of the present investigation was to compare Persons with Hemophilia and Healthy Controls on a psychosocial variable i.e. Neuroticism. Another aim of the study was to compare age group differences among Persons with Hemophilia. The disease's impact is not only limited to the patient but the progressive disability arising in the patient due to its chronic nature has a psychological and social influence on parents and caregivers as well.

A. Comparison of Persons with Hemophilia and Healthy Controls on Neuroticism.

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 Neuroticism. Hence, H1 hypothesis was accepted. Persons with Hemophilia scored lower than Healthy Controls on Neuroticism.

B. 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 Neuroticism. 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 neuroticism was significantly different between 15-18 years and 19-24 years (p = .0001). The mean value of neuroticism was significantly different between 15-18 years and 25-30 years (p = .0001). The mean value of neuroticism was not significantly different between 19-24 years and 25-30 years (p = .98).

The studies done earlier in this area have revealed mixed findings for the role of Neuroticism. Persons with hemophilia (PWH) may feel pain, depression, or anxiety, which can have a significant influence on their health-related quality of life. Using cross-sectional survey data from the MIND study, the researchers sought the perspectives of PWH and caregivers from Sweden, Finland, and Denmark on the management of hemophilia-related pain, sadness, and anxiety. The participants of the study include 343 PWH (103 mild, 53 moderate, 180 severe, and seven without severity information) and 71 caregivers. Pain was reported by 50% of PWH and 46% of caregivers in the previous 6 months. 28% of PWH experienced anxiety/depression. The presence of pain and anxiety/depression was linked to illness severity. With growing age, pain and depression/anxiety become more common (Carlsson et al., 2022).

Canclini et al. (2003) carried out a case-control study in which some psychological dimensions (social expectations, depression, state of anxiety, and self-esteem) were evaluated in a group of 60 hemophiliacs and an age, socioeconomic status, and educational background matched control group of 78 healthy individuals. The Beck Inventory, the Marlowe-Crowne Scale, and the S.T.A.I.-form were used as tools. The findings indicated that hemophiliacs have a fair psychological adaption to their disease. The present study has found the level of neuroticism is slightly higher in healthy controls than in persons with hemophilia.

CONCLUSION

Stopping the bleeding is not enough; musculoskeletal management is equally important, as is the mental health of PWH. They also experience higher levels of stress and a lower quality of life than nonaffected individuals (Beeton et al., 2005). Furthermore, other confounding variables such as parenting methods, marital

relationship, and child's temperament were not considered. In the treatment and follow-up of children and adolescents with hemophilia, as well as their parents, psychiatric aspects should not be overlooked.

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