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Health and Emotion Regulation among Persons with Hemophilia

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The psychosocial status of people with chronic ailments has garnered undivided attention in recent years, especially for diseases such as AIDS, Leukaemia, and hemophilia Numerous psychological and psychiatric issues associated with hemophilia have been found to attribute a significant increase in emotional distress. There is a paucity of research on the psychosocial aspects of hemophilia. The aim of the research was to study emotion reappraisal, emotion suppression, andhealth among persons with hemophilia. A total of 50 patients participated in the study and were divided into 2 age groups (19-24) and (25-30). Standardized scales such as Emotion Regulation Questionnaire (Gross & John, 2003) and Patient Health Questionnaire (Spitzer et. al, 1999) were used.The obtained results were tabulated, and correlation and independent t-tests were used to compare the means of two age groups. The total sample mean was found to be 18.10 and the standard deviation was 8.30 respectively. The correlation of health was found to be positive withboth emotion reappraisal (r= 0.10) and emotion suppression (r=0.08).The result portrays there is no difference between the two age groups onemotion regulation and health. Despite much research on the genetic causes of this condition in India,there is a dire need to study the psychological challenges, social problems, and opportunities available topersons with hemophilia (PWH). Psychological and genetic counselling shall be promoted for the holistic well-being of hemophiliacs.

Keywords: Psycho-social challenges, Hemophilia, Emotion regulation,Health

Introduction

Hemophilia is the most common of the bleeding disorders and has no known cure. There are two types of Hemophilia – Hemophilia-A and Hemophilia-B (Bolton-Maggs & Pasi 2003). Hemophilia-A has deficiencies of factor VIII and Hemophilia-B has deficiencies of factor IX.There is a substantial lack of evidence-based treatments for persons with hemophilia (PWH) that specifically target psychosocial health and effective pain management, which are thought to be crucial end objectives for optimal hemophilia medical care. Despite their limited use, psychological therapies are cost-effective in boosting mental health, quality of life, and pain management (Pinto et al. 2017). Therefore, understanding the contributing factors is essential in planning the psychosocial support system of persons with hemophilia.

The term "emotion regulation" describes actions used to control our own or others' emotions. It has gained popularity in numerous psychology subdisciplines. Emotional suppression andemotional reappraisal are two definite strategies of emotion regulation. In contrast to suppression, which prevents the outward expression of your inner feelings, reappraisal is regarded to be generally effective and adaptive (McRae & Gross, 2020).The social determinants of health, which are factors other than medical treatment that can shape health in powerful and significant ways, have come to the attention of the public health community(Braveman & Gottlieb 2014).

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Prevalence of Hemophilia in India

The hemophilia Federation of India (HFI) acts as a registry with reliable sources of data. The organization's key work includesthe distribution of treatment products, psycho-social care, and protecting patients and families' rights who suffer from bleeding disorders. According to the Annual Global Survey 2021, the patients diagnosed with hemophilia in India are25,384. Out of which patients with hemophilia-A are 21,350 and patients reported with hemophilia-B are 3,475. Most persons with hemophilia in India are in the age group of 19-44.Dealing witha child's disability, the parents go through a lot of emotional pain. Strong emotional reactions to the illness highlight the importance of developing psychosocial support techniques. Due to limited access to care, hemophilia has socioeconomic costs that have an effect on patients' morbidity and mortality. PWH experiences frequent absenteeism from school and work, as physical activity is limited due to the extreme pain and discomfort associated with the bleeding episodes (Bérubé, Amesse & Sultan, 2020).

There is a paucity of research on the psychosocial aspects of hemophilia. The initial psychosocial challenge arises during diagnosis and treatment since it can be difficult for parents and PWH to accept the diagnosis. Anxiety about bleeding episodes, and worry about the future impacts the day-to-day activities. Although the incidence of life-threatening bleeding episodes has decreased as a result of preventative therapy in industrialized countries, parental anxiety for their child's safety still exists. Adult hemophilia sufferers have a variety of difficulties, such as difficulty regulating bleeding episodes, joint degradation, psychological impairment, and emotional upheaval.One of the major research gaps isdespite the concept of comprehensive care which considers medical as well as psychosocial aspects in treating hemophilia, most of the existing studies focus only on clinical aspects of the hemophilia.

Statement of the problem

To understand the type of emotion regulation strategy used by hemophiliacs and study differences between age groups on health, emotion suppression, and emotion appraisal among persons with hemophilia.

Review of literature

Indian Researchers, Varadarajan, Rakesh, Ramaswamy, Mohammed and Ramiah (2017) carried out a study at Bangalore Medical College and Research Institute's Comprehensive hemophilia Centre. 126 children with hemophilia and other bleeding disorders who were less than 18 years old participated. School absenteeism (68.25%), family dysfunction (50.8%), depression, low self-esteem, parental separation (21.4%), and divorce (2.4%) were observed. In 7.9% of the cases, mothers were blamed for the disease and victimized. Numerous psychosocial concerns were frequently seen, and they require equal attention as a medical treatment to optimize hemophilia care.

Al-Huniti, Hernandez, Eyck, and Staber (2020) conducted a meta-analysis to determine the prevalence of depression, anxiety, and attention deficit hyperactivity disorder (ADHD) in patients with congenital hemophilia. They discovered that PWH were more likely to suffer from depression (odds ratio (OR) 2.45; 95% CI 1.64-3.68), anxiety (OR 1.74, 95% CI 1.01 - 3.00), anxiety/depression (OR 2.60, 95% CI 2.35 - 2.87), and ADHD (OR 3.48, 95% CI 1.74 - 6.96). This shows that standardized tools for mental health issues in PWH are required. According to this study, the prevalence of depression, anxiety, and ADHD in PWH is much higher over time than in the general population.

Hemophilia is a genetic bleeding illness characterized by severe pain, emotional anguish, and reduced quality of life (QoL). Psychological therapies, such as cognitive-behavioural therapy (CBT), are cost-effective in promoting emotional well-being, QoL, and emotion regulation; nevertheless, they are rarely employed in hemophilia treatment. This study used a quasi-experimental design with pretest and post-test designs and a control group to examine the effect of CBT on emotion regulation and QoL in children with hemophilia. Thirty volunteers were chosen at random and divided into two groups (n = 15). In the pretest, both groups completed the QoL questionnaire, the Persian version of the Paediatric Quality of Life Inventory (PedsQL), and the Cognitive Emotion Regulation Questionnaire (CERQ-k). The experimental group was then subjected to a 9-session CBT regimen. The experimental group had a significantly higher QoL and emotion management than the control group. CBT training was successful in helping children avoid negative thinking and control their anger at school. It was also successful in increasing QoL and emotion regulation (Siyar, Majd & Baghdassarians, 2021).

Table 1
Correlation matrix of health, emotion reappraisal, and emotion suppression

	Health	Emotion Reappraisal	Emotion Suppression
Health	1	0.10	0.08
Emotion Reappraisal		1	0.22
Emotion Suppression			1

The Correlation values is significant at the 0.01 level

The correlation matrix defines the association between the variables under study. It can be observed from the table that the correlation of health was found to be positive and significantly related to emotion reappraisal (*r*= 0.10) and emotion suppression (*r*=0.08).The correlation betweenemotion reappraisal and emotion suppression came out (*r*=0.22).

Table 2
Mean, SD, and t-test values of the two groups of hemophiliaon health

Health	N	Mean	SD	*t*-value	*p*-value 0.05
Age group 19-24	25	10.72	18.46	1.33	2.02
Age group 25-30	25	9.36	11.41		

The found values are not showing a significant relationship between health of the age group 19-24 and health of the age group 25-20

Table 3
Mean, SD, and t-test values of the two groups of hemophilia on emotion reappraisal

Emotion Suppression	N	Mean	SD	*t*-value	*p*-value 0.05
Age group 19-24	25	28	37.16	40.39	2.02
Age group 25-30	25	28.64	44.40		

The found values are not showing a significant relationship between Emotion reappraisal of the age group 19-24 and emotionreappraisal of the age group 25-20.

Table 4
Mean, SD, and t-test values of the two groups of hemophilia on emotion reappraisal

Emotion Suppression	N	Mean	SD	*t*-value	*p*-value 0.05
Age group 19-24	25	18.45	23.1	0.83	2.02
Age group 25-30	25	17.21	43.2		

The found values are not showing a significant relationship between Emotion suppression of the age group 19-24 and emotion suppression of the age group 25-20.

Discussion

The aim of the research was to study health, emotion reappraisal,and emotion suppression among persons with hemophilia. Triemstra et al. (1998) found out that this hereditary condition is characterized by a high propensity for hemorrhages, with recurring bleeding into the joints leading to permanent joint degeneration. PWH must follow a demanding medical regimen for the rest of their lives, which could potentially have an effect on their emotional stability and coping capabilities (Mednick et al. 2010).

Our study divided the two groups of hemophilia with reference to age and analysed their difference. The mean of the group (19-24 age) on health came out to be 10.72 whereas the mean of the group (25-30 age) was 9.36. On Emotion reappraisal, Mean and standard deviation of the age group (19-24) were 28.64 and 37.16, and of the age group (25-30 age) were 28.64 and 44.40 respectively. On Emotion suppression, Mean and standard deviation of the age group (19-24) was 18.45 and 23.04, and of the age group (25-30 age) were 17.21 and 43.21 respectively.

There is not much difference in both the age groups as the independent *t*-test value came out to be non-significant. Thus,we fail to reject the null hypothesis and state thatthere is no difference between the two age groups on health, emotion reappraisal, and emotion suppression. This outlines that the devastating disorder impacts both age groups in a similar manner on emotion regulation and the health of hemophiliacs. Our result is corroborated by a number of studies done on the hemophilia community. Maximizing patient outcomes may be aided by interventions to address the psychological needs of the hemophilia community, dealing with uncertainty, providing tools and assistance, and teaching coping mechanisms to reduce the burden of disability. Cassis et al. (2012) state that variations in Quality in life are better explained by psychosocial, rather than clinical predictors. Keeping in line, this study was purposefully designed to reflect the emotionregulation used by the PWH in the two age groups.

Chiu et al. (1999) investigated the social functioning of children with hemophilia; they showed there were no significant differences in popularity and social acceptance of children with hemophilia compared to their healthy classmates. In our study, consistent with the literature, we found that there is not much difference in the type of emotion-regulating skillsused by haemophiliacs of different ages.

Given the detrimental effects of hemophilia on a person's quality of life and the resulting medical expenses, it shall be made mandatory to evaluate the psycho-social status of the PWH before taking major decisions in life like engaging in prophylaxis regimen, participating in tournaments, visiting long distances for colleges or workspace, etc.The two age groups that were formed based on data collected are identical in biological makeup and fall in the young adult category. In the Indian context, the social structure changes as the person ages. PWH takes up roles and responsibilities, battling with love andlosses. The developmental tasks at the age of 19-24 are securing a seat in college by beating the fierce competition, sexual characteristics developingfull-fledged, and the adult exploringlife's thrills whereas adults between the ages of 25 and 30 struggle with work-life balance, job security, and finding a spouse. The PWH of this age commonly looks for stability in life and does not prefer to explore other alternatives available rather than accept present life happily.

The reason both groups' mean difference has come out to be similar can be understood as adults often engage in high levels of activity and productivity at this period of their lives. They enter the job culture,start businesses, get married, start families, and go through changes allalong this transitioning phase. The formulation and realization of objectives and aspirations can be hampered if one is suffering from the existence of a chronic illness.Individuals shall use their innermost energies to deal with crippling and intense pain. We all are blessed with certain abilities to cope with difficult situations as well as emotional complexities. The important question, however, is what types of coping behaviour contribute to favourable outcomes.

With advancing years, people learn to deal with both known and unanticipated consequences because health is a relative concept. The appraisal of threatening situations rests on their personal meaning which in turn is governed by a succession of past experiences in the life of the afflicted person. The results of our study showed that emotional behaviours in hemophilia do not differ in the two age groups (19-24) and (25-30) which is justified by the aforementioned factors. Assessment and counselling associated with life satisfaction, perceived barriers, and unmet emotional needs can be addressed by forming a true therapeutic alliance with the PWH. Interventions can be aimed at reducing mental suffering, fostering well-being, and enhancing individuals' hemophilia-related health outcomes. This confirms the need for more robust research in this area.

Conclusion

Hemophilia naturally confronts the patient with psychological and social problems. Studying the bio-psycho-social factors underlying the clinical manifestation of the disease makes us question theideal composition of hemophilia care services.The current study provides insights that can offer new perspectives to a better understanding of the impact and potential advantages of psychological counselling. Workshops on emotional intelligence and pain coping strategies will boost competencies in a hemophilia care setting. The findings recommend more investigation using mixed research methods to understand the psychosocial aspects of the disease. This will further ensure an increase in the scope of optimal comprehensive care for chronic illnesses.Persons with hemophilia can be compared with a control group to understand the differences minutely. An interventional and longitudinal study can be conducted on a larger sample including the age range of 30-45 years of PWH to generalize the results. Quality of life, optimism, and coping strategies can be further assessed in this rare population. Psychological and genetic counselling shall be our go-to treatment along with regular health check-ups which will eventually promote the overall well-being of the patients.Thus, there is an important gap to bridge that calls for the latest studies analysing psychological interventions for PWH.

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