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A Study of Stress Levels Among Hemophilia Patients' Relatives

Dr. Sandeep Nemlekar[1]*, Dr. Mrinali Tikare[2], Prof. Shalini Kakkar[3], Dr. Rinku Sharma[4]

[1]*Professor & CSR Chair, Chetana's Institute of Management & Research,
[2]Associate Professor - Human Resources, Chetana's Institute of Management & Research,
[3]Assistant Professor, Chetana's Institute of Management & Research,
[4]Assistant Professor, Chetana's Institute of Management & Research,

***Corresponding Author: -** Dr. Sandeep Nemlekar
*Professor & CSR Chair, Chetana's Institute of Management & Research,

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Abstract

In 'Inherited Genetic Blood Clotting Disorder' - 'Haemophilia', the child victim is saddled with uncontrolled bleeding even for minor cuts and bruises throughout life, hence the close family members and relatives are constantly under a lot of stress to avoid injury episodes in their child who is hitherto basking in a playful childhood age. Mind you this disease invariable affects almost entirely the male child only in particular. The main reasons of stress for relatives include the chronic joint pains of the child, the mentally draining never ending procedures of repeated blood transfusions, the lack of easy availability of these treatment facilities, the drain on funding resources, and the progression of this disease with little or no relief for an unknown period of time. In cases of hemophilic children, their parents seemingly carry the feel and burden of guilt always due to the 'Inherited Genetic' nature of this disease. The levels of stress faced by these unfortunate family members have not been addressed with adequate supportive measures and attention specifically in the Indian context. The present study focuses on various dimensions and extent of stress experienced by relatives/family members of Hemophilia patients.

The study used financial stress, relationship stress, commute stress, and fear of progression stress to be independent variables, and psychological stress to be dependent variables. The study's focus was on the 300 active members who are affiliated with the 'Hemophilia Federation of (India)'. The questionnaire was circulated to 100 samples using a stratified random sampling method and adhering to inclusion and exclusion criteria. However, only 64 responses were used for further analysis. Psychometrically tested measuring instrument developed by Zimmermann et al (2022) used for psychological stress, relationship stress and fear of progression stress. For financial stress and commute stress the scale developed by Heo, Cho & Lee (2020) and Kluger (1998) used respectively. All the scales were modified in accordance with DeVellis's (1991) guidelines. The Cronbach's alpha values of all measures were greater than 0.80.

The monthly income of all of these respondents was below Rs. 50000 and belonging to the maturity onset group. The initial descriptive analysis showed that all stress variables were at a moderate level. There is a strong, significant and positive correlation among 'Psychological Stress' (DV) and 'Fear of Progression', 'Financial Stress', & 'Commute Stress'. However, there is a moderate, significant and positive correlation between 'Psychological Stress' and 'Relationship Stress'. By using Multiple Regression, the study attempted to find out the best predictor of Psychological Stress experienced by the relatives of hemophilia patients.

The reasons behind the findings were discussed using the literature that was available. Identifying the best predictor and other contributing predictors can draw attention from all stakeholders in the healthcare industry, as well as regulatory authorities.

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1.0 Introduction

Stress can be defined as a state of worry or mental tension caused by a difficult situation. There are multiple causes of family stress, but the physical illness of close family members is more predominant. The relatives of the patient encountered various complicated circumstances. These include the patients' suffering, the appropriate treatment, the availability of treatment in the vicinity, financial arrangements, and the progression of the disease. The age of the patient also affects the tension of relatives or family members. When a patient is a child or at a younger age, parents and siblings experience a great deal of stress.

Inherited bleeding disorder is considered a serious disease worldwide, and nearly four lakh people are estimated to have the disorder (Inserro, 2022). Hemophilia is usually an inherited bleeding disorder in which the blood does not clot properly. Hemophilia is a common complication for young women who have recently given birth or are in the later stages of pregnancy. A recent study calculated the prevalence of hemophilia among infants at birth. According to Iorio et al. (2019) in upper-middle income countries, those born with hemophilia will have a 64% lower chance of living a life of normal duration and quality, 77% in middle income, and up to 93% in low-income countries. In Indian context, more than 1,36,000 people have been diagnosed by Prevalence. The number is 1 in every 10,000 male births (Financial Express, 17th April 2021).

Severe hemophilia often results in a significant economic and psychological burden on patients, family members or relatives, caregivers, and the entire healthcare system. Hemophilia is a condition that affects the entire family of the patient throughout his lifetime. The growth and development of a person with hemophilia increase the complexity of family circumstances over time. Such family challenges can negatively impact the ability of the patient and his family to support in hemophilia care or adhere to a plan of treatment.

A diagnosis of hemophilia means that parents must deal with the loss of their hopes for the “perfect” baby. The initial reaction of parents is typically shocked, disbelief, or denial. After receiving the report of diagnosis, many parents, particularly mothers, feel guilty for having "given" this disorder to their baby. Parents may react confused and frightened about their child’s disease, which can lead to feelings of helplessness. Their worries often revolve around the child's future. In a nutshell, there are multiple psychological reactions exhibited by family members or relatives that result in varying stress levels. The present study focuses on various dimensions and extent of stress experienced by relatives/family members of Hemophilia patients.

2.0 Review of Literature

The extant literature of psychology and medical sciences defined stress in a different way. Although, the widely used definition of stress is any type of change that causes physical, emotional, or psychological strain. (Tikare et al. 2021). Nemlekar et al. (2018) stated that stress is a person's reaction to a stressor like a quality of surrounding or an impetus. It is a body's way of responding to a challenge. Recently Mental Health Foundation (2021) has declared that stress is the sensation of being overpowered or not able to handle the pressure related to mind or emotion. All individuals handle their stress diversely. Stress leads to the emotional state of worry, scare, annoyance, hostility, unhappiness, irritation, disappointment, and low spirit which ultimately resulted in physical illness.

In the last two decades, various studies have been conducted on stress among family members and relatives of patients. Some of the studies assessed the level of stress, depression, and anxiety of the patients' relatives or family members and indicated in higher level of mean. The level of of emotional distress was influenced by age, income, nature of the family types, residential area, and the level of education of patients’ relatives (Olabisi, 2020).

Zarei et al. (2015) has conducted study in Quchan's hospital by using an anxiety and stress scale (DASS) and found that families of patients who have been hospitalized in the ICU experience more anxiety and stress. Halain et al. (2021) reviewed six articles and explained the severity of the stress faced by family members. They mentioned the factors that affect family members and cause stress and anxiety when their relatives were in the ICU.

In 2008, Pang et al conducted a study on the causes of stress. According to the report, the family members of the admitted patients in the ICU were afraid of death, which was the highest stressor factor. The study of Lim & Zebrack (2004) categorized primary and secondary stressors of patients’ relatives. The primary stressors were patient impairment, the duration & intensity of care, ADL (activities of daily living) dependency, recurrence of illness and behavioral issues of the patient. Secondary stressors were caregiving demands, role change, responsibility, caregiver experience, and lifestyle interference. There were several contributing factors for the relatives of the patients such as stressful environment factor, socio-demographic & relationship of the family, restricted visiting hours, previous ICU experience and severity of the patient (Halain et al.,

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2021). The serious condition of the patient, unable to speak with the patient, seeing patients in ICU was the factors increase the family stress identified by Barth et al. (2016). Zarei et al. (2015) indicated factors such as informational ambiguities, unclear prognosis, fear of death of a patient, financial needs, disruption of the daily programs, unfamiliarity with the hospital environment and the regulations of care unit. Shoushi (2020) reported that the main causes of stress and anxiety in the patients' family members were the lack of support from healthcare staff and information required to recover at home.

Ugale & Dighe (2022) have used mixed research method with stress scale (Cohen, Kamarck and Mermelstein) on 100 family members of the critically ill patients in Maharashtra. The content analysis emerged eight themes which cause stress among family members namely, (1) Painful experience; (2) Feeling worried, nervous and tense; (3) Uncertainty and fear about recovery; (4) Difficult and challenging situation; (5) Financial problems; (6) Belief in God; (7) Social support; and (8) Satisfaction with health care team. The study indicated a significant association of stress with education, monthly family income, health status condition of the patient and relationship with the patient. The outcome of stress leads to frustration, anger, hopelessness, and severe depression.

Table No.: 01 Patient's Relative Stress: Causes

Antecedents of Stress	Patient Related Stress	Family Members – Own Life	Hospital Related
Age, Income, Nature of Family Types, Residential Area, Level of Education	Death	Responsibility	Hospital Environment
	Impairment	Role Change	Visiting Hours
	Duration of Care	Lifestyle Interference	Information Ambiguity
	Dependency	Financial Needs	Unclear Prognosis
	Recurrence of Illness	Routine Disruption	Hospital Regulation
	Behavioral Issues	Social Support	
	Unable to speak		

Source: Prepared

2.1 Gap in Literature

Till date, the literature has discussed the level of stress experienced by the family members of the patient. Furthermore, all the studies demonstrated the presence of one or more stressors, causes, or reasons that increase stress. Most of the studies were conducted on patients who either had cancer or were admitted to the ICU.

The present study is based on the stress of relatives of hemophilia patients. In the process of prolonged caring, hemophilia patients seek essential support from their families. It is also observed that hereditary factors are responsible for hemophilia, therefore the parents of children get stressed due to guilt.

The stress faced by family members of hemophilia patients has not received much attention specifically in the Indian context. The identification of stressors in the relatives of hemophilia patients could guide policymakers in designing strategies to cope with stress.

3.0 Methodology

In this study, the positivism paradigm was adopted based on an epistemological approach. To obtain insight into the magnitude and direction of various dimensions of stress variables, the study used correlational research design.

3.1 Objectives of the Study

1. To study the various dimensions of stress associated with relatives of Hemophilia patients.
2. To measure the degree of psychological stress, financial stress, relationship stress, commute stress and fear of progression stress experienced by relatives of Hemophilia patients.
3. To identify the impact of various dimensions of stress on psychological stress.

3.2 Details of Study Subjects

Family members are described as a person who belongs to a (particular) family; a (close) relative (Oxford, 2017) 'Hemophilia Federation (India)' having around 300 active members. After obtaining approval from competent authority the team of researchers circulated questionnaire among patients' relatives. Using a stratified random sampling method, subgroups of samples were identified. The inclusion and exclusion criteria for the study were as follows -

3.2.1 Inclusion Criteria

1. First-degree relatives of the hemophilia patients
2. First and second level of hemophilia patients' relatives
3. Middle-class income bracket
4. Knowledge of Hindi and/or English.

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3.2.2 Exclusion Criteria

1. Age group < 20 and above 60.
2. Illiterate Relatives
3. Inactive members
4. Non-consent

The hard-copy of the questionnaire was circulated to the 100 relatives. However, 20 relatives refused to be part of the study and 80 relatives filled out the questionnaire forms. For analysis purposes, only 64 forms were used after the removal of incomplete forms.

3.3 Details of Tool

In 2022, Zimmermann et al developed psychometrically tested measuring instrument for the assessment of cancer-specific distress in partners of cancer patients and called as QSC-P. By using EFA and CFA they validated the resulting scales and described as "Fear of Progression (10 Items)," "General Psychological Stressors (9-Items)," and "Relationship Stressors (4 Items)." They also mentioned that all scales showed very good internal consistency. The present study adopted following three scales by minor modifications and considered as variables.

3.3.1 Psychological Stress: Psychological stress is a popular term denoting processes believed to contribute to the onset and maintenance of a variety of mental and physical conditions (Scott et al. 2015). As discussed above from 'General Psychological Stressors' four following items adapted out of the nine items in the context of Hemophilia patients and their relatives-

PS1 I often feel tired and weak due to illness of my relative/child.
PS2 I feel exhausted due to illness of my relative/child.
PS3 It is difficult for me to get involved in other activities
PS4 I am often depressed due to illness of my relative/child.

The psychological stress was treated as a dependent variable in the study.

3.3.2 Fear of Progression: Fear of progression (or recurrence) is defined as the fear of the illness progressing or recurring in the same place or in another part of the body (Dinkel, Herschbach, 2018). By referring Zimmermann et al (2022), out of 10 items following four items adapted for the present study.

FP1 I feel strong anxiety and panic when I think of the disease of the relative/child.
FP2 I am afraid of the extension/progression of my relative/child's disease.
FP3 The side effects and consequences of the treatment are/have been frightening.
FP4 In terms of the disease, I'm afraid of what the future will bring

3.3.3 Relationship Stress: Zimmermann et al (2022) defined 'Relationship Stressors' as dysfunctional partnership patterns in dealing with the illness and asks for physical closeness, communication behavior and stability of the partnership. In the context of Hemophilia patients and their relatives following items adapted.

RS1 Due to/since my relative/ child's illness my relationship has become more problematic with spouse
RS2 Due to/since my relative/child's illness we exchange less physical affection with spouse
RS3 Due to/since my child's illness my partner closes himself off from me.
RS4 Due to/since my child's illness our relationship is less resilient.

In the Indian scenario, the major part of the stress aroused due to lack of sufficient finances during treatment phase which led to the high-level stress. The operational definition and items were adapted from the research work of Heo, Cho & Lee (2020). They attempted to capture the comprehensive nature of financial stress, and proposed three dimensions affective (A), relational (R), and physiological (Ph).

3.3.4 Financial Stress: Financial stress has been conceptualized as the subjective perception of one's personal finances (Kim, Garman, & Sorhaindo, 2003) or inability to meet one's economic responsibilities (Northern et al., 2010). Financial stress is a psychophysiological response to the perception of imbalance, uncertainty, and risk in the realm of financial resource management and decision making (Heo, Cho & Lee, 2020).

FS1 I feel depressed because of my financial condition (A)
FS2 I frequently avoid attending family events because of my financial situation. (R)
FS3 My financial situation frequently interferes with my family relationship (R)
FS4 I have fatigue frequently because of my financial situation (Ph)

3.3.5 Commute Stress: The present study added one more variable as Commute Stress. The relatives of the Hemophilia patient have to take treatment from 'Special Hemophilia Treatment Centers (HTC)'. Travelling with the patient is a nightmarish situation.

In the context of employees' commute strain Kluger (1998) defined that the degree of strain by the length and hassles of their (employees) commute to and from work. This definition reflects the cognitive evaluation of the

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commute and affective reactions to the commute. For the purpose of the study the above definition adapted in the context of commute of the patients and stress experienced by the relatives of the patient. The scale developed by Kluger (1998) captured two variables, namely, 'Cognitive Commute Strain' and 'Affective Commute Strain'. The scale has 17 items and it was positively related with tardiness and somatic symptoms. Kluger (1998) found 0.92 coefficients alpha. However, for this study, researcher selected only three items as follows-

CS1 I fear about safety during commuting
CS2 Commute causes stress to me
CS3 I am worried about the length of my commute

3.6 Reliability of Tool

The five scales of stress showed very good internal consistencies as follows-

Table No. 02

Scales (Variables)	Cronbach Alpha	Number of Items	Used as
Psychological Stress	0.83	4	Dependent Variable
Fear of Progression	0.81	4	Independent Variable
Relationship Stress	0.85	4	Independent Variable
Financial Stress	0.86	4	Independent Variable
Commute Stress	0.80	3	Independent Variable

Source: Prepared

The above mentioned 19 items questionnaire used Likert Scale on 1-5 level starts from Strongly Agree to Strongly Disagree. Moreover, demographic variables like age, education, monthly income, marital status and level of disease were included.

4.0 Data Analysis

4.1 Demographic Profile – Patients Relatives

Table No. 03: Sample Distribution of All Respondents

Demographic Profile Total N = 64	Groups	Frequencies	
		N	Percentage
Marital Status	Married	39	61
	Unmarried	15	23
	Single Parent	10	16
Education	SSC or Less	16	25
	HSC or UG	15	23
	Graduate Degree	16	25
	Master or PG	17	27
Relationship with Patient	Brother	2	3
	Daughter	3	5
	Father	2	3
	Husband	2	3
	Mother	35	54
	Sister	7	11
	Son	6	10
	Wife	7	11
Monthly Salary	Less than Rs. 20000	31	48
	Rs. 20001 to 50000	29	45
	Rs. 50001 to 100000	1	2
	More than Rs. 100000	3	5
Age	20 to 30 Years	22	34
	31 to 40 Years	18	28
	41 to 50 Years	23	36
	51 to 60 Years	1	2

Source: Prepared

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The following observations were made from respondents' profile-

The 54% of respondents are mothers of patients (35). The educational qualification of the respondents was the graduate degree and post-graduate degree i.e. 52%. The majority of relatives surveyed were between the ages of 20 to 50 years. The monthly household income of the respondents is below Rs. 50000.

4.2 Descriptive Analysis

The total sum score, mean and the standard deviation has been worked out for all variables and presented below-

Table No. 04: Sum, Mean and Standard Deviation of Variables

Sr. No.	Variable	Scale	No of Items	Sum	Mean	SD	Interpretation
1	Psychological Stress	1 to 5	4	714	11.16	4.001	Moderate Level Stress
2	Fear of Progression	1 to 5	4	845	13.20	3.884	Moderate Level Stress
3	Financial Stress	1 to 5	4	688	10.75	3.686	Moderate Level Stress
4	Commute Stress	1 to 5	3	547	8.55	3.013	Moderate Level Stress
5	Relationship Stress	1 to 5	4	630	9.84	3.691	Moderate Level Stress
6	Total Stress	1 to 5	19	3424	53.50	14.42	Moderate Level Stress

Source- prepared

The Mean scores of all variables under this study have indicated moderate levels of stress.

4.3 Inferential Statistics: Hypotheses Testing – Pearson Correlation

For testing the hypotheses, the correlation coefficient was computed by using Pearson Correlation technique. It describes the correlation between 'Fear of Progression' and Psychological Stress, Financial Stress, Commute Stress, and Relationship Stress.

Table No. 05: Correlation Coefficient

Pearson Correlation N = 64	Independent Variables	r	p value	Significant / No Significant
Psychological Stress	Fear of Progression	0.715	0.000	Significant Correlation
	Financial Stress	0.615	0.000	Significant Correlation
	Commute Stress	0.626	0.000	Significant Correlation
	Relationship Stress	0.327	0.008	Significant Correlation

**. Correlation is significant at the 0.01 level (2-tailed).

Source: Primary Work

4.3.1 Analysis:

There is a strong, positive correlation among 'Psychological Stress' (DV) and 'Fear of Progression', 'Financial Stress', & 'Commute Stress'. However, there is a moderate and positive correlation between 'Psychological Stress' and 'Relationship Stress'. These relationships were significant as p values were less than 0.05. Hence, the null hypothesis – *There is no significant correlation among 'Psychological Stress' and 'Fear of Progression', 'Financial Stress', 'Commute Stress', & 'Relationship Stress' was rejected.*

4.4 Predictive Statistics: Multiple Regression

The Multiple Regression technique has been used to explore the relationship between one continuous dependent variable and a number of independent variables or predictors. The following questions will be answered with the multiple regression technique-

1. How well do the four measures of stress predict Psychological Stress? How much variance in Psychological Stress scores can be explained by scores on these four scales of stress?
2. Which is the best predictor of Psychological Stress: Fear of Progression, or Financial Stress, or Commute Stress, or Relationship Stress?

4.4.1. Analysis

To counter the above questions, the multiple regression technique was used with the help of SPSS (21) package. **The preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity.** The following table presents the R and R Square value.

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Table No. 06: Model Summary

Model Summary				
Model	**R**	**R Square**	**Adjusted R Square**	**Std. Error of the Estimate**
1	.771a	.595	.568	2.631
a. Predictors: (Constant): Fear of Progression, Relationship Stress, Commute Stress, Financial Stress b. Dependent Variable: Psychological Stress				

Source: Prepared
(R Square = 0.595*100)

The model of 'Fear of Progression', 'Financial Stress', 'Commute Stress', & 'Relationship Stress' explains 0.59% of the variance in 'Psychological Stress' (DV).

The following ANOVA table shows the F value and statistical significance-

Table No. 07: ANOVA

ANOVA[a]						
Model		**Sum of Squares**	**df**	**Mean Square**	**F**	**Sig.**
1	Regression	600.167	4	150.042	21.683	.000[b]
	Residual	408.270	59	6.920		
	Total	1008.438	63			
a. Dependent Variable: Psychological Stress						
b. Predictors: (Constant), Relationship Stress, Fear of Progression Stress, Commute Stress, Financial Stress						

Source: Prepared

The ANOVA table indicated the significance value is less than 0.05 therefore; the above model reaches to statistical significance.

The following table of coefficient explained the variables included in the model contributed to the prediction of the dependent variable.

Table No. 08: Coefficients

Coefficients[a]													
Model		**Unstandardized Coefficients**		**Standardized Coefficients**	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	**Beta**			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	-.031	1.324		-.023	.982	-2.680	2.618					
	Fear of Progression	.460	.118	**.446**	3.910	**.000**	.224	.695	.715	.454	.324	.527	1.898
	Financial Stress	.205	.136	**.189**	1.502	**.138**	-.068	.478	.615	.192	.124	.434	2.303
	Commute Stress	.337	.144	**.254**	2.339	**.023**	.049	.625	.626	.291	.194	.583	1.715
	Relationship Stress	.004	.108	**.003**	.034	**.973**	-.212	.219	.327	.004	.003	.696	1.437
a. Dependent Variable: Psychological Stress													

Source: Prepared

The 'Fear of Progression' (IV) shown the largest beta coefficient 0.446 with less than 0.05 sig. value. The 'Fear of Progression' of patients' relatives make the strongest, significant unique contribution (20%) to explain 'Psychological Stress' (Dependent Variable) compare to the variance explained by other variables in the model is controlled for.

The beta value for 'Commute Stress' is 0.254 with less than 0.05 sig. value. It has a statistically significant contribution (7%) to the prediction of the 'Psychological Stress' (Dependent Variable).

However, 'Financial Stress' and 'Relationship Stress' did not make a statistically significant contribution to the prediction of the 'Psychological Stress' (Dependent Variable).

By using Unstandardized Coefficients, the following Regression Equation emerges–
(Y = b0 + b1x1+b2x2)

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Psychological Stress = -0.31 + (0.460) *x1 (FP) + (0.205) *x2 (FS) + (0.337) *x3 (CS) + (0.004) *x4 (RS)

4.4.2 Results of Multiple Regression

The model, which includes four independent variables like Fear of Progression', 'Financial Stress', 'Commute Stress', & 'Relationship Stress' explained 0.59% of the variance in 'Psychological Stress' (DV) (Answer to Question 1). 'Fear of Progression' (beta 0.446) is making a statistically significant unique contribution to the prediction of the 'Psychological Stress' (Dependent Variable) (Answer to Question No. 2).

5.0 Discussion and Conclusion

The present study investigated the level of various stress levels among relatives of haemophiliac patients. Haemophiliac patients seek essential support from their families as it requires prolonged care. According to the statistical model, fear of progression and commuting stress are the two stressors that have the biggest impact on psychological stress. However, financial stress and relationship stress among family members remained insignificant.

It has been proven that the patient's relatives experience increased stress levels and disruptions in their daily lives. The uncertain health conditions of their loved ones caused them to face both physical and emotional challenges. Due to the illness of a haemophilic patient, most of them experience fatigue, depression, and exhaustion. It's not easy for the relatives of the hemophilic patient to get involved in other activities. Thus, a patient's health condition had a profound emotional impact, causing intensified feelings of helplessness, guilt, sadness, and anxiety. Family members have to take on additional responsibilities aside from caregiving, such as managing medical appointments and understanding medical jargon. Uncertain medical outcomes and critical decisions could amplify stress levels.

The fear of prolonged critical health and potential complications is a major source of anxiety and worry. The fear of recurrence may still exist even after successful treatment if the disease is progressive. Hypervigilance about a patient's condition impacts the well-being of relatives. Personal and professional commitments are disrupted by disease progression due to the close monitoring of patients and the priority seeking of medical consultations.

The financial burden and exorbitant treatment costs often cause stress among relatives of patients in other medical cases. However, compared to other stressors, financial stress has taken a back seat for the relatives of haemophilic patients. It may be possible that family members have made some provisions by keeping contingent reserves or buying health insurance.

Relationship stress is concerned about attention to other family members, exchange of affection, social life, and time. The prolonged illness of haemophilic patients can cause emotional stress for relatives, as they become dysfunctional in their relationships and limited in physical activities. Misunderstandings occur because of a lack of communication, which is the reason for the overwhelming tense situation. The emotional turmoil disrupts balance and stability and offers relationship stress with uncertainty about the future. Moreover, caregiving duties may limit social interactions and social participation.

It is necessary for the relatives of hemophilia patients to get treatment from Special Hemophilia Treatment Centers (HTC). Traveling with the patient can be a nightmare situation. Patients' relatives find long commutes challenging, which makes it difficult for them to provide physical comfort to patient. The frustration of commuting stress is compounded by transportation delays and public transport challenges.

6.0 Suggestions and Recommendations

Caring for a loved one can be quite challenging and stressful. Various support and patience are required along with the patient's journey as it is full of stressful experiences. Regularly updated communication channels with family members and healthcare employees are required so that concerns and fears leading to stress may be reduced. Maintaining a healthy lifestyle and following self-care will provide relaxation to the patient care. Emotional support can be gained by joining online similar support groups so that the benefits of counselling on stress will serve as a coping strategy to mitigate stress levels.

Social support engagement is a must needed method to break away from stress. Understanding the complexities of medical treatment and following the required medical advice will help to reduce uncertainties and anxiety among relatives. All individuals react differently to stress levels, but it is important to tailor the suggestions so that stress burdens can be reduced, and a sense of control can be maintained. Delegating responsibilities will help to lighten the burden and will focus on providing more emotional support to loved ones. Engaging in stress management activities provides relaxation in balancing mental stress from the prevailing situation.

The major role is expected from other family members, friends and society to reduce the intensity of the stress by clear and non-judgemental communication. More resources could be explored seeking financial aid from government support, non-profit organizations, and foundations so that stress can be reduced. Mindfulness techniques and relaxation will shift the focus to the present moment rather than dwelling on future uncertainties. Planning needs to be done in case of

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exploring optimal transportation routes using technology applications so that delays can be avoided, and stress can be reduced.

7.0 Implications of Study

Although the study was conducted only in active members of the federation with small samples, the findings of the study are useful for every section of society. There are multiple articles available on haemophilic patients, but not a single research work has been published on the stress of relatives of patients. The study's findings and discussion touch upon what is expected by the government, healthcare organizations, online groups of relatives, other family members, friends, employers, insurance companies, and the overall society.

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Annexure I

Questionnaire (For Relatives)

Name of Patient's Relative: ……

Relationship with Patient: ……

Relatives Age:	20 to 30 Years	31 to 40 Years	41 to 50 Years	51 to 60 Years

Relative's Education	SSC	HSC/ Diploma	Graduate	Post Graduate

Relative's Family Monthly Income	Less than Rs. 20000	Rs. 20000 to 50000	Rs. 50000 to 1 Lac	More Than 1 Lac

Marital Status of Relative	Married	Unmarried	Single Parent

Level of Disease	First Level	Second Level	Third Level

Please read the following statements and indicate your feelings by putting a tick - mark in the appropriate column.

SR. No.	Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
PS1	I often feel tired and weak due to illness of my Haemophilic relative					
PS2	I feel exhausted due to the illness of my Haemophilic relative.					
PS3	It is difficult for me to get involved in other activities					
PS4	I am often depressed due to the illness of my Haemophilic c relative					
FP1	I feel strong anxiety and panicky when I think of the disease of the Haemophilic relative					
FP2	I am afraid of the extension/progression of my Haemophilic relative's disease.					
FP3	The side effects and consequences of the treatment are/have been frightening.					
FP4	In terms of the disease, I'm afraid of what the future will bring					
FS1	I feel depressed because of my financial condition					
FS2	I frequently avoid attending family events because of my financial situation.					
FS3	My financial situation frequently interferes with my family relationship					

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FS4	I have frequent fatigue because of my financial situation					
CS1	I fear about safety of Haemophilic relative during commuting					
CS2	Commute causes stress to me					
CS3	I am worried about the length of my commute					
RS1	Due to my special attention to Haemophilic relative other family members feel neglected.					
RS2	Due to Haemophilic relative's illness, I exchange less affection with other family members					
RS3	Due to Haemophilic relative's illness my other family members are closed off themselves of me.					
RS4	Due to Haemophilic relative's illness my relationship is less resilient with other family members.					