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Research Article

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Socio-Economic Impact of Haemophilia in India: An Analysis of Indirect Costs and Work Day Loss

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ABSTRACT

Background: Haemophilia poses a substantial economic burden globally, yet studies on its impact in low- socioeconomic regions are limited. This cross-sectional study in a tertiary health care centre aims to evaluate the work day loss and indirect costs among haemophilia patients and their caretakers in a low-socioeconomic setting.

Objective: To analyse the impact of bleeding episodes on daily activities, calculate indirect costs, and determine work day loss among haemophilia patients and caretakers.

Method: Study design: Observational cross-sectional study with 50 haemophiliacs and their caretakers. Study duration: 3 months.

Methodology: Data collection involved a structured questionnaire encompassing patient demographics, bleeding episodes, hospital visits, work day/school day loss, and socioeconomic status. The severity of haemophilia was categorized as mild, moderate, or severe based on established criteria.

Result: Among 50 participants (Haemophilia A), the age group 15-39 years had the highest number of bleeding episodes. Mild category had 2.5 episodes while Severe haemophilia showed the 6.5 maximum average bleeding episodes. Average work day/school day loss increased with severity, with 17.4 days in mild category to 27.8 days for severe cases. Indirect costs for 3 months totalled 4,60,382 rupees, with lower socioeconomic classes experiencing higher percentage income loss.

Discussion: The results indicate a substantial societal and economic burden associated with haemophilia, particularly in low-income settings. The discussion emphasizes the need for tailored interventions, government initiatives, and improved treatment accessibility to mitigate the economic impact on affected families.

Conclusion: Haemophilia imposes a significant socioeconomic burden, with severe cases and lower socioeconomic status contributing more substantially.

Keywords: Haemophilia, Work Day Loss, Indirect Costs, Bleeding Episodes

Introduction

Haemophilia, the group of congenital X linked disorders primarily affecting males, is caused by deficiency of factor VIII and factor IX hindering the normal process of haemostasis and predisposing the haemophiliacs to spontaneous or post traumatic bleeding [1,2]. Genetic deficiency of factor VIII is known as haemophilia A and factor IX is known as Haemophilia B. [1]. Haemophilia is the most common hereditary disorder associated with life threatening bleeding [1]. The main clinical manifestation is intra articular bleeding [hemarthrosis] mainly affecting knee, elbow and ankle in decreasing order of frequency which begins even in childhood [3]. The diagnosis of haemophilia is based on prolonged partial thromboplastin time (PTT) and normal

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prothrombin time (PT) that point to abnormalities in intrinsic coagulation pathway. Factor specific assays of factor VIII or IX are the gold standard for diagnosis [1]. The treatment of haemophilia is based on the intravenous replacement of deficient clotting factors which in this case is factor VIII and factor IX. Infusions can be administered as prophylaxis, preventing bleeding episodes and reducing the incidence of arthropathies [4-7] or on demand after each bleeding episode. Since for episodic treatment patient has to be hospitalized for the variable time period according to the severity of disease, even if not hospitalized then for taking factors they have to attend hospital. Multiple number of hospitalizations of patient costs the patients and his caretaker's directly and indirectly. Indirect costs refer to work productivity losses [8]. Work productivity losses are estimated through lost earnings using wages as a proxy for work time output. Indirect costs include lost wages due to days of work absenteeism among those employed and unpaid haemophilia related caregiver time [8]. This may affect the employment of patient and his caretaker's if he is an adult or may affect his education if he is a school going. This can lead to the reduced employment opportunities of all of them. Reduced employment opportunities in turn increase the financial burden on patient as well on caretaker. Till today, many studies have been carried in U.S. and EUROPE to study the effect of severity of haemophilia on number of bleeding episodes and the burden of indirect costs on the society of people living in the U.S. and Europe who normally have high socioeconomic status but the study which accounts for burden of indirect costs on people living in country with low socioeconomic status are very few. In this context the present study aims to the societal burden of illness due to indirect costs on patients and caretakers of haemophilia as well as impact of bleeding episodes on patients and caretaker's daily activities, absenteeism and productivity.

Aims and Objectives

- To analyse the impact of bleeding episode on patient and caretakers' daily activities during the last 3 months.
- To calculate indirect cost due to bleeding episode of every patient and then analyse the average burden of illness due to indirect costs during the last 3 months according to the socioeconomic status of the patient's family.
- To calculate the work day/school day loss of patient and their caretakers during the last 3 months according to the age of patient and severity of disease

Materials and Methods

Study Design

Observational cross sectional non interventional study Study-site tertiary health care centre Duration of study 3 months (July 2019-Oct 2019) Sample size 50 patients Inclusion criteria 1. Haemophilic patients of all age groups who have not suffered any comorbidities in past 3 months. 2. Caretakers of Haemophilic patients 3. People who are ready to give consent. exclusion criteria 1. Haemophilic patients who have suffered comorbidities like hepatitis, tuberculosis for which they have to get hospitalized. 2.hemophilic patients who have associated other bleeding disorder like von Willebrand disease (as both have same clinical features making it difficult to differentiate the symptoms of haemophilia with von Willebrand disease). 3. People who are not ready to give consent. All the subjects of haemophilia who visited tertiary health care centre were chosen as subjects if they fitted in inclusion criteria of the study. Informed consent was taken from patients and their caregivers.

During Above Mentioned Period, The Haemophilic Patients were visited and informed consent was taken from them, after that they were made to sit comfortably with the investigator in the room and case study form was filled by investigator carefully after asking the information from patient and their caretaker. The case study form All the information taken from the patients of haemophilia and their caretakers was filled in MS. EXCEL VERSION 2017 and master sheet was created. Statistical analysis of the data obtained was done using IBM-SPSS SOFTWAREVERSION 26.

For the purpose of analysis, the severity of Haemophilia was decided based on the amount of factor 8 and 9 in plasma according to the definition as provided by the World Haemophilia Federation. The socioeconomic status of patients was derived from modified B G PRASAD SOCIOECONOMIC SCALE, update 2019.

The study was started after taking clearance from institutional ethical committee.

Results

There was a total of 50 participants in the study. All of them belonged to Haemophilia A. All of them were classified into various groups according to age, severity, socioeconomic status.

Age According to age, the population were divided into 4 groups. The age of participants ranged from 0.6years to 0 years. The mean +/-standard deviation age of included participants is 20.692+/- 14.64years (median-16.5 years). In the result Table 1, we can see that the maximum participants in the study belonged to the group of 15-39 years.

Table 1: Showing Various Age Groups and The Number of Participants Of That Group p value=<0.001. where null hypothesis was all the categories of age group occur with equal probability. One sample chi square test was used for Analysis

Age Group	Frequency	%
0-4years	1	2%
5-14 years	19	38%
15-39years	24	48%
more than 40years	6	12%
TOTAL	50	100%

Severity: From Table 2 the maximum number of participants belonged to the mild severity.

Table 2: Showing The Severity of Hemophilia with Number of Participants Belonging to That Group Here p value=0.003 where null hypothesis was all the severity occur with equal probability. The statistical analysis was performed using chi square test

Severity	Frequency
Mild	25
Moderate	6
Severe	19
TOTAL	50

Number of Bleeding Episodes

The 50 participants suffered total of 198 bleeding episodes in last 3 months with a mean of 3.96+/- 4.076(median=3) bleeding episodes per participant. The number of bleeding episodes range from 1 to 18 bleeding episodes.

Relation of Number of Bleeding Episodes with Age

From Table 3 and 4 We can see that the maximum number of bleeding episodes occur in age group 15-39years.

Table 3: Showing the Descriptive Statistics of no of BLEED in last 3 months in different Age groups. P Value =0.008 which is Significant At 0.001. Pearson`s Correlation Value R=0.371. the table has been Obtained after Analysis done In SPSS Version 26

Descriptive Statistics			
Dependent Variable: NUMBER OF BLEED in last 3 months			
AGE in years	**Mean**	**Std. Deviation**	**N**
less than 4 yrs	1.00		1
5-14 yrs	3.16	1.537	19
15-39 yrs	4.58	4.745	24
more than 40 yrs	4.50	6.656	6
Total	3.96	4.076	50

From Table 4 we can also see that maximum frequency of members who suffered from 0-5,6-10, more than 10 bleeding episodes belonged to age group 5-14,15-39,15-39 years respectively.

Table 4: Showing AGE in years * Number of BLEED Crosstabulation created in SPSS VERSION 26. p value=0.374. chi square test was used for analysis. Pearson R=0.239, spearman R=0.234

			Number_BLEED			Total
			1-5	6-10	.>10	
AGE in years	0-4yr	Count	1	0	0	1
		% within Number_BLEED	2.4%	0.0%	0.0%	2.0%
	4-14yr	Count	18	1	0	19
		% within Number_BLEED	43.9%	16.7%	0.0%	38.0%
	15-39yr	Count	17	5	2	24
		% within Number_BLEED	41.5%	83.3%	66.7%	48.0%
	More than 40 yr	Count	5	0	1	6
		% within Number_BLEED	12.2%	0.0%	33.3%	12.0%
Total		Count	41	6	3	50
		% within Number_BLEED	100.0%	100.0%	100.0%	100.0%

Relation of Severity and Number of Bleeds

From Table 5, we conclude that the severe grade of haemophilia has the maximum average number of bleeding episodes

Table 5: showing variations of average number of bleeding episodes suffered in last 3 months according to the severity of disease. P VALUE = 0.001 which is significant at 0.01 level. Pearson's correlation value r = 0.447. Bivariate correlation has been used to perform statistical analysis. The table has been obtained after analysis done in SPSS VERSION 26

Descriptive Statistics			
Dependent Variable: NUMBER OF BLEED in last 3 months			
GRADE	**Mean**	**Std. Deviation**	**N**
MILD	2.52	1.327	25
MODERATE	3.33	1.211	6
SEVERE	6.05	5.902	19
Total	3.96	4.076	50
Total	3.96	4.076	50

Time of Presentation

The average time of presentation of 50 participants was found to be 8.07 +/-9.41years. The time of presentation ranged from minimum 0.3 years to a maximum of 47 years with a median of 6 years. In the Table 6 and Figure 1, 2, the participants belonging to the severe category present earliest at average age of 2.4 years.

Table 6: showing variations of average number of bleeding episodes suffered in last 3 months according to the type of treatment received by patients. P VALUE = 0.000 which is significant at 0.01 level. Pearson's correlation value r = 0.482. Bivariate correlation was used to perform statistical analysis. The table was obtained after analysis performed in SPSS VERSION 26

Severity	Average work day/school day loss of patient in 3 months In days
MILD	17.4
MODERATE	19.0
SEVERE	27.8

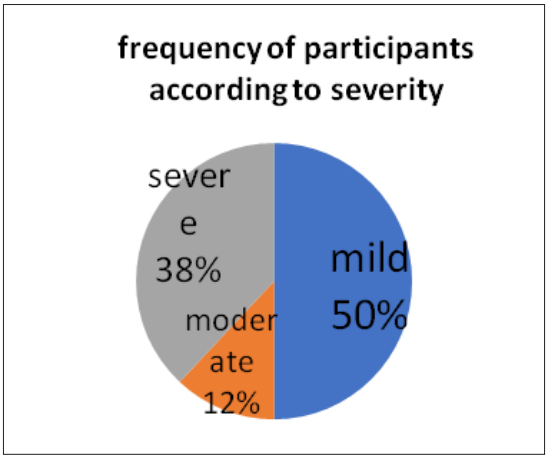

Figure 1: Depicting the Pie Chart Showing the Frequency of Participants In Percentage According to Severity of Disease

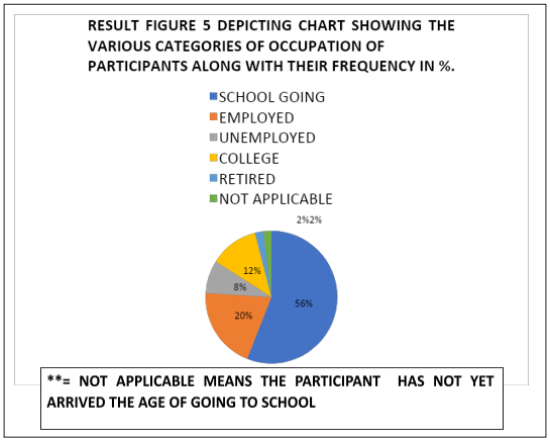

Figure 2: Depicting chart showing the various categories of occupation of participants with their frequency in %

Work Day/Schooldays Loss

The total number of work/school days lost by 50 participants are 1022days with mean of 20.44 +/-15.92 days and median of 16.5 days. The work day/school day loss of patient ranged from a minimum of 0 days to a maximum of 73 days.

Relation of Work Day Loss/School Day of Patient in Last 3 Months with Severity of Disease

We can see from the Table 7 that as the severity of the disease is increasing, the average number of work days/school 1days lost is increasing. The maximum work day/school days loss of 27.8days from 73 average working days accounting for 38% of work days/school days loss in patients of severe haemophilia.

Table 7: Showing The Variation Average Work Day/School days Loss of Patient in Last 3 Months with the Age Groups in Years. P VALUE=0.109 and pearson's correlation= 0.229. The statistical analysis has been performed using bivariate correlation

Age In Years	Average Work Day/School Day Loss of Patient In 3 Months in Days
0-4 years	0
5-14 years	16.4
15-39 years	24.2
more than 40 years	21.8

Relation of Work Day Loss/School Day of Patient in Last 3 Months with Age Group of Patients

From the Table 8, we can see that the maximum work day/school day loss of patient in 3 months was found in the age group 15-39 years.

Table 8: Showing Variation of Average Work Day Loss of Patient In 3 Months with The Severity of Disease. P Value = 0.003 And Pearson Correlation Value Of 0.416. The Statistical Analysis Is Performed Using Bivariate Correlation

SEVERITY	Number OF WORK DAY LOSS OF caretaker IN 3 MONTHS
MILD	5.3
MODERATE	7.2

Relation of Work Day/School Day Loss of Caretaker In Last 3 Months with Age Group Of Patients

The total work day loss of caretaker of 50 participants is 394 days with mean of 7.88 +/-6.9 days and a median of 6 days.

The result Table 9 shows that the maximum work day loss of caretaker occurs when the patient belonged to the age group of 5-14 years.

Table 9: showing the variation of work day loss of working members of the caretaker in last 3 months with of patient in years.p value=0.959 and pearson's correlation value of -0.008.The statistical analysis has been perfo using bivariate correlation

Age Of Patient in Years	work day loss of caretaker in 3 months in days
0-4 YEARS	7
5-14 YEARS	8.1
15-39 YEARS	7.7
MORE THAN 40 YEARS	8

Relation of Work Day Loss of Caretaker in Last 3 Months with Severity Of Disease

As seen with patients, the work day loss of caretaker in last 3 months also shows proportional increase with severity as

the number of bleeding episodes increase with the increase in severity.

As seen from Table 10, the maximum work day loss of caretaker in last 3 months is seen in the haemophilia of severe grade, i.e.,11.5 days out of 73 working days accounting for 15.7% of working days.

Table 10: Showing Frequency of People Belonging to Particular Socioeconomic Status and Average Loss of Patient of Particular Status Due To Indirect Costs In %. P VALUE= 0.016 WHICH IS SIGNIFICANT AT 0.05 LEVEL. PEARSON CORRELATION VALUE= -0.340. THE Statistical Analysis Has Been Performed Using Bivariate Correlation

Socioeconomic Status	Frequency	Average loss of patient due to Indirect costs in percentage
upper class	8	8
upper middle class	17	12.58
middle class	7	17.45
lower middle class	11	24
lower class	7	20.34
	50	

Indirect Costs

The total indirect costs for 3 months of 50 participants was found to be 4,60,382 rupees which on extrapolating for 1 year comes out to be 18,41,528rupees. The indirect costs for 3 months varied from minimum of 160 rupees to maximum of 1,12,680 rupees. The mean indirect costs for 3 months were 9207+/-19305 rupees with median of 3336 rupees. If we try to calculate the mean indirect costs of entire year then it comes out to be 36828 rupees.

Relation of Average Loss of Patient Due to Indirect Costs on Percentage with Socio-Economic Status of the Patient

Out of 50 participants, maximum number of participants belonged to upper middle class socioeconomic status. Also, from the Table 10, we can see that the maximum percentage loss of family income occurs in the lower middle class socioeconomic status followed by lower class of socioeconomic status.

Table 11: Showing the frequency of occupation of the patient with respect to socioeconomic status. P value = 0.001and pearson correlation value of 0.749. The statistical analysis is performed using bivariate correlation

Socioeconomic status	School going	Employed	Unemployed	College	Retired	Not applicable**
Upper class	4	1	1	0	1	1
Upper middle class	9	1	1	6	0	0
Middle class	4	3	0	0	0	0
Lower middle class	6	4	1	0	0	0
Lower class	5	1	1	0	0	0
	28	10	4	6	1	1

Inhibitors

Out of 50 participants, 4 participants had inhibitors in plasma, 20 participants didn't have inhibitors in the plasma and rest 26 had no idea about inhibitor status of their plasma.

Site of Bleed

It can be observed from Table 12 that, the most common site of bleed is knee joint followed by tooth bleed

Table12: showing the site of bleed with its Frequency

TOOTH	11
GUMS	1
BRAIN	2
URINE	1
TOTAL	50

Relation of Number of Hospitalizations with Severity of Disease

From Table 13, we can see that patients with severe haemophilia were hospitalized maximum number of times.

Table 13: Showing Number of Hospitalizations in Each Grade of Severity of Disease

Grade	Total Number of Hospitalizations of Each Grade
Mild	5
Moderate	1
Severe	8

Discussion

With an overall population of more than 1.3 billion, India has 21,824 registered people of hemophilia of which 17,606 have Hemophilia A and 2715 people have Hemophilia B. Data from this study was used to analyze the societal burden of only hemophilia A on the society. Total indirect cost of 50 participants came out to be 18,41,528 rupees which is only of 0.2% patients of hemophilia registered in India. The mean annual indirect costs spent by hemophilic patient came out to be 36,828 rupees. We can see that even after providing free factor in Hospital, the costs spent by Hemophilic patient is 33 times higher than the income spent of India's GDP on public health care. (The annual per capita money spent on public health care is 1112 RUPEES as per data of 2018). The maximum average loss of income of the family income was 24 % in lower socioeconomic classes

which is three times high compared to 8% loss in people of high socioeconomic class.

The mean time of presentation was 8.06 years, the mean number of bleeding episodes in last 3 months came out to be 3.96 which accounted for mean 20.44work day/school day loss of patient and mean 7.88work days lost of caretaker.

However, A study conducted in Pune, Maharashtra published in 2014, to estimate the out of pocket (OOP) expenditure of a person with hemophilia concluded that expenditure on treatment ranged from 1.5% to 12% of the monthly income of the family.

Our study has many limitations.1. short time interval of 3 months making it very difficult to collect the data from every patient registered. 2. The study collects the retrospective data based on the recall of patient and the data registered in the diary of patient 3. Patient who are unemployed or partial work day employed only may have consented to participate in the study, so the actual work days lost by full time employed people cannot be estimated.

Despite few limitations our study provides much significant amount of information regarding the variation of number of bleeds with age of patient and severity of disease, average number of workdays/schooldays loss with respect to age of patient and severity of disease, annual mean indirect costs of hemophilic patients, comparison of average loss of patients due to indirect costs in patients of various socioeconomic groups. These data estimate the burden of Hemophilia on the patient, caretaker and the society. Many more studies are required to be done on calculation of burden of Hemophilia and carrying out comparison of burden of Hemophilia A with Hemophilia B so that the government and various organizations can carry out interpretations from such data and work to increase the quality of life of Hemophilic patients.

Conclusion

Despite being a rare genetic disorder, Hemophilia accounts for significant economic burden on the patients, caregivers and the health care systems in India. Each bleeding episode suffered by a patient apart from affecting a patient affects the whole family of the patient by significant amount.

Hemophilia is a costly disorder, not only because of its high medical expenses, but also because of high indirect costs incurred due to functional disability of adult patients and under-employment or unemployment of parents of affected children with hemophilia. Lost wages from working part time or being unemployed due to hemophilia and travel costs are the major factors of total indirect costs as evident from the results (although not statistically analyzed). The huge travel costs spent by Hemophilic patients can be reduced significantly if the factor is made available in every hospital of the country rather than making it available only in Hemophilia treatment center (HTC) of big cities. The Hemophilia Federation of India have taken a very big step by making the factor available free of cost at HTC of big cities after initial registration costs but the indirect costs due to wages lost for work day loss suffered by patients can be reduced significantly if government create the programme providing incentives for Hemophilic patients thereby working to increase the quality of life spent by Hemophilic patients.

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Author Contributions: All authors have contributed equally to the study conception, design, drafting, review, and finalization of the manuscript

Conflict of Interests: The authors declare that they have no conflict of interest.

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