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Research Article

Analysis of Economic Burden on Person with Hemophilia – Observational Study

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Abstract

Background: In India, there is lack of national policy for the prevention and control of genetic illness. As Hemophilia is a rare genetic disorder that poses significant health challenges, it also imposes a substantial economic burden on healthcare payers, Person with Hemophilia (PwH), caregivers and society. By delving into the economic impact of hemophilia, this study uncovers the hidden costs that go beyond the immediate medical expenses. Thus, the present study aims to evaluate the economic burden on PwH and their caregivers.

Methods: A total 25 PwH were included in the study. The economic burden on both PwH and caregivers were evaluated using a standard performa consisted of different parameters that includes direct healthcare costs; indirect healthcare costs and impact of hemophilia on academic attendance of school going children. The time frame of the study was from December 2022 to February 2023.

Results: The mean total (direct and indirect healthcare) cost of (n=25) PwH was ₹ 103,894.36/- (median = ₹ 29,640/-) (IQR = ₹ 19,574.5/- to 74,190/-).

Conclusion: The study concluded that hemophilia is a costly disorder; driven not only by its high direct medical expenses but also by its significant indirect healthcare costs.

Keywords: Economic burden, Direct healthcare cost, Hemophilia, Indirect healthcare cost.

Abbreviations: PwH: Person with hemophilia

Introduction

Genetic disorders are rare conditions with a low public health priority in India, despite the fact that they cause huge suffering for patients and their families [1]. Beyond the clinical challenges experienced by person with hemophilia (PwH), this condition also imposes a significant financial burden on healthcare providers, PwH/caregivers, and society at large [2]. Treatment for hemophilia is centred on the episodic (on demand) or prophylactic (regular basis) infusion of FVIII or FIX concentrates to stop bleeding. Inhibitor development makes management of PwH more challenging and increases the risk of morbidity, severe bleeding, and disability. This significantly affects the quality of life of PwH and healthcare costs in comparison to non-inhibitors [3].

The management pattern in hemophilia has changed the once-mortal disorder into chronic but potentially well managed condition through the use of clotting factor and prophylaxis therapy [2]. It is important to understand the costs involved with hemophilia treatment from both payer and society perspectives given the high costs of clotting factors, the rising usage of prophylaxis, and novel extended half-life factor concentrate [4]. A small number of recent studies have examined the direct non-medical cost and indirect healthcare costs, which make up a smaller fraction of total direct costs but place a significant burden on PwH, their caregivers and society [4-6]. Based on this complex and changing scenario, this study aimed to analyse the current socioeconomic burden of PwH and caregivers.

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Material and Methods

A total of 25 subjects were recruited in the present study, out of which, 12 were children with age between 2-17 years and 13 were adults with age >18 years.

Subjects included males aged between 2 to 45 years who had been diagnosed with hemophilia A or hemophilia B with or without inhibitor, currently receiving on demand factor replacement therapy for hemophilia. Whereas other bleeding disorders like Von Willebrand disease, females diagnosed with haemophilia, subjects on prophylaxis and subjects with no bleed, in this period, were excluded from the study.

The economic burden on both PwH and caregivers was evaluated using a standard performa which consisted of different parameters such as direct healthcare costs (of clotting factor, drugs, specialist visits and hospitalization); indirect healthcare costs (included transportation, loss of wages) and impact of haemophilia on academic absenteeism of school going hemophilic children. The data collected over a three-month period was consolidated and the statistical measures of mean (median, Interquartile Range - IQR) were computed for various parameters.

Results

Cost Analysis: The mean total (direct plus indirect) cost of (n=25) PwH was ₹ 103,894.36/- (median = ₹ 29,640) (IQR = ₹ 19,574.5 to 74,190)

The total mean cost per employed subject (n=7) was ₹50,057.14/- (median = ₹ 32,700) (IQR = ₹ 20,990 to 94,990), for children (n=12) was ₹ 161,252.41/- (median = ₹ 19,624.5) (IQR = ₹ 18,630 to 82,400) and for unemployed subject (n=6) was ₹ 51,988.33/- (median = ₹ 38,600) (IQR = ₹ 23,062.5 to 71,080).

School/work Absenteeism

The average loss of working days of employed PwH (n=7) was 17.57 days, average loss of working days of caregivers of unemployed PwH (n=6) was 18 days and caregivers of children (n=12) was 16.25 days in 3 months.

The average school absenteeism of school going hemophilic children (n=8) was 23.25 days. Also, two children left school because of financial issues.

Specialist Visits and Hospitalization

The PwH with specialist visits included (n=25) visits to Pediatrician/General practitioner, (n=10) visits to physiotherapist, (n=2) visits to orthopedician, and (n=1) visit to dentist.

Overall, 24% (n=6) of PwH were hospitalized, out of which 20% (n=5) were children and 4% (n=1) were employed PwH. The mean length of hospital stays for those who were hospitalized (n=6) was 4.8 days.

Table 1: Describes the parameters covered under the direct healthcare and indirect healthcare costs.

Direct health care cost	
Parameters	**Explanation**
Clotting factors	It included the cost incurred by the government for PwH for their on-demand factor replacement therapy.
Drugs	It included the cost of medications used by PwH.
Hospitalization	It included the cost of hospitalization for PwH.
Specialist visits: 1. Pediatrician/General practitioner 2. Physiotherapy 3. Orthopedician 4. Dental	It included the cost of consultation or treatment incurred by the PwH/or caregiver during these visits.
Indirect health care cost	
Parameters	**Explanation**
Transportation	It included the cost of transportation incurred by the PwH and/or caregiver during their on-demand factor replacement therapy, hospital and specialist visits.
Loss of wages of PwH	It included the loss of wages of employed PwH due to their work absenteeism because of their illness.
Loss of wages of caregivers	It included the loss of wages of caregivers, which encompassed unemployed subjects and children.

Table 2: Demographic profiles of the pwh.

Demographic Profile	No. of subjects (Total=25)
Age	
Children (2-17 years)	12
Adults (> 18 years)	13
Hemophilia status	
Hemophilia A	21
Hemophilia B	2
Hemophilia A inhibitor +ve	2
Hemophilia B inhibitor +ve	-
Employment status	
Employed subjects	7
Unemployed subjects	6
PwH dependent on caregivers	18
(Including children and unemployed subjects)	
School going children	8

Table 3: Showed the mean of direct and indirect healthcare costs of PwH in 3 months duration.

Categories	Direct healthcare Cost in (₹)		Indirect healthcare cost in (in ₹)	
	Mean (median)	IQR	Mean (median)	IQR
Employed subjects (n=7)	40,844.29 /- (28,390)	14,390 to 76,890	9,212.85/- (7,600)	4,990 to 9,320
Children (n=12)	151,774.16/- (14,375)	10,635 to 61,800	9,478.25/- (7,840)	4,449.75 to 11,475
Unemployed subjects (n=6)	39,991.67/- (21,375)	14,382.5 to 57,892.5	11,996.66 /- (12,085)	6,707.5 to 16,420

Discussion

In this study, the primary focus was on understanding the economic challenges faced by Person with Hemophilia (PwH) and their caregivers. The assessment involved analyzing various parameters, including both direct and indirect healthcare costs,

as well as the impact of hemophilia on academic attendance of school going children. The financial burden was significantly influenced by high medical expenses associated with hemophilia, such as clotting factors, hospitalization, and specialist visits. Additionally, indirect costs like medical transportation and the loss of working days for both PwH and their caregivers further exacerbated the economic strain.

A study with a sample size (n=212) of PwH revealed a mean total cost (direct plus indirect) of $195,332, with a median of $139,571 [4]. However, in the present study with a sample size of 25 PwH, the mean total cost was notably lower, at $1,266.73 (cost converted into U.S $), with a median of $361.39 (cost converted into U.S $).

Moreover, the impact of hemophilia extended beyond the PwH, affecting their parents or caregivers. A different study found that parents missed an average of 3.2 days of work annually due to their child's hemophilia, while among adults, the average work absenteeism was 16 days [4]. In this study, we observed that the average loss of working days for caregivers of children (n=12) was 16.25 days, for unemployed PwH (n=6), it was 18 days and for employed PwH (n=7) experienced an average loss of 17.57 working days.

The employment status among adult PwH also posed a significant concern. In a separate study, out of 47 PwH in the 18+ age group, 24 (51%) were unemployed [7]. Correspondingly, in this study, out of 13 adults with hemophilia, 6 (46%) were unemployed.

The impact of hemophilia on education was also notable. In a different study, the average number of school days lost or absenteeism due to bleeding episodes was reported to be 19.2 days [1]. Present study found a similar trend, with an average school absenteeism of 23.25 days in three months (n=8).

In a previous study, four PwH discontinued their education because their caregivers believed that attending school would heighten the risk of injury [8]. In present study, we observed that two children left school, either due to concerns about the potential for injury or as a result of financial constraints. The burden of hemophilia was underscored by cases of PwH dropping out of school due to concerns regarding injury risks or financial limitations, reflecting the comprehensive impact on their lives and choices. Additionally, the financial burden extended to transportation costs for hospital visits and shortages of clotting factors in their local treatment areas. Indirect costs were mainly associated with the loss of wages for employed PwH and caregivers.

Many PwH were unemployed due to disease-related impairments, placing an additional burden on their caregivers. Caregivers also experienced frequent job shifts due to their own work absenteeism caused by caring for their hemophilic child. In addition to the high expenses directly associated with hemophilia, patients also encounter financial challenges related to transportation costs required for hospital visits. The cost of transportation can be a significant burden, particularly for those living in rural or remote areas where healthcare facilities may be far from their residences.

It's crucial to note that in our hospital, the clotting factors necessary for hemophilia treatment are provided free of cost to PwH, alleviating some financial strain on the individuals. However, the high cost of these clotting factors, covered by the government, contributes to the overall financial burden associated with the disease and strains public healthcare resources.

Furthermore, the study aims to convey that consistent comprehensive care for Person with Hemophilia (PwH) is benificial in reducing the occurrence of bleeds and deformities, ultimately alleviating the burden on PwH, their caregivers, and society.

Conclusion

The study concluded that hemophilia is a costly disorder, not only due to its high direct medical expenses but also because of its significant indirect healthcare costs. Although, it is beyond doubt that the cost of therapy associated with the purchase of clotting factor concentrates is extremely large and the whole burden is being faced by the government and indirectly borne by the taxpayers, but the indirect costs of treatment also need to be considered in deriving the ultimate Health Economics and Outcomes Research (HEOR). Ours being a developing country, with majority of population belonging to a lower middle socioeconomic status, the policies of government in the future, drafting of guidelines for therapeutic management of PwH community should include these indirect costs also. This study is just an attempt at looking into this, yet unexplained parameters in the management of hemophilia. More such studies and data are required to bring up the operational guidelines for management of this disorder in future.

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