

# Assessment of Knowledge and Awareness Towards Hemophilia in Normal Population of Karachi City, Pakistan

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## ABSTRACT

**Keywords:** Awareness, blood disorder, hemophilia, knowledge, Pakistan.

### Author's Contribution

All the authors contributed significantly to the research that resulted in the submitted manuscripts.

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**Background:** Hemophilia is an inherited blood disorder in which blood is not clot normally because of deficient of certain clotting factor.

**Objectives:** The purpose of this study was to assess the awareness for hemophilia in normal population and the sources of information from which they access knowledge of this disease.

**Design:** A closed ended questionnaire was given to normal population of Karachi city.

**Methodology:** A prospective cross sectional study was conducted in which 100 participants are involved. A convenient sampling was used and asked participant about awareness of this disease. For analyzing of data SPSS tools are used and descriptive statistics and chi square value was also calculated.

**Results:** According to our result it is shown that only 53% of population is known about this disease while 40% said they don't know about this disease. Female had more knowledge than male participants. Majority of participants who are graduate level are well-known about this disease. The chi square value was found to be 0.001.

**Conclusions:** This study was clearly focused that health care provider conducts such measures to increase the awareness of this disease of normal population and clear their concept about this high mobility disease.

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## INTRODUCTION

Hemophilia is an inherited disorder linked to X chromosomes that impairs in the blood clotting functioning. Hemophilic is classified as hemophilic A in which factor VIII is deficient and hemophilic B in which deficiency in factor IX is responsible. Hemophilia A is more common and has prevalence, taking place about 1:5,000 male births, whereas hemophilia B arise in about 1:25,000. The deficiency of either Factor VIII or

Factor IX results in a flaw in the intrinsic clotting cascade [1]. Another mild and uncommon hemophilic type is hemophilic C in which factor XI is deficient [2]. *Parahaemophilia* is a rare hemophilia which may be acquired/inherited and occurs because of deficiency of factor V. it's a mild and rare bleeding disorder [3]. Worldwide patients with severe hemophilia are around 400,000 [4].

History of this rare disease was very old and it seen in the tenth century where Abulcasis first described this disease [5]. Later Dr. John Conrad

Otto, in 1803, who was a physician, wrote about this disease as "a hemorrhagic disposition existing in certain families" in which he used to call the affected males as "bleeders" [6].

The life expectancy of hemophilic patient depends on how proper treatment they avail. If not sufficient treatment offered to these patients they may die before they reach adulthood. Although if hemophilic patients get appropriate treatment, the average life of these patients still 10 years less to those who do not have hemophilia [7].

One third of patients do not require treatment for stop bleeding because of superficial bruising variation to fatal bleeding in which ratios are 8% to 22% like intracranial, retroperitoneal, and gastrointestinal bleeding [8-9].

Hemophilia is clinically characterized from mild ailment to life threatening disease because of their huge variation in bleeding pattern. Acquired hemophilic A (AHA) patients have co-morbidities and using co-medications like anti-platelet drugs which also effects on their clinical picture and also need an entirely specific therapy [10-11].

Recently a number of reviews have published which explained the mechanism of this genetic disorder how these factors are inhibited or activated to typical hemostasis and blood coagulation [12]. In comparison of congenital hemophilia still no valid treatment available for Acquired hemophilia A patients [13,14]. But in certain clinical trials it is observed to treat this AHA WITH porcine factor VIII or recombinant factor VIIa [15-17].

In Pakistan there are roughly 18,000 peoples are victim of this disease according to statistical record. But the worst reality is that only 10% patients getting treatment while 90% patients are not received any treatment or they may be not even diagnosed.

The aim of this study was to evaluate the awareness of normal population regarding hemophilia so we conduct cross sectional survey to gather the data.

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## METHODOLOGY

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### Study area

The study was conducted in Karachi, Pakistan and for this survey normal population was used.

### Study period

This study was carried in time period from June 2017 to October 2017.

### Participants

We conducted a cross-sectional survey for investigating the knowledge of normal individual regarding the disease hemophilia. In this survey we take all age group individual from illiterate to master level. For this survey we take 100 participants and self administered forms are used to gather data.

### Questionnaire

A questionnaire was divided into two main portions. In first part we asked about the demographic characteristics of participants like age, gender, educational status and occupation. While in second portion we asked about the disease, its symptoms, precautions and treatment.

### Statistical Analysis

For analyzing the data statistical package of social science i.e. SPSS tools version 20 are used. Chi square and descriptive statistics are used. For categorical data frequency and percentage technique are applied.

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## RESULTS

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### Demographic Characteristics

According to the result it is shown that 52% are the age between 18-27 years, 28% are lie between the age 38-47 years, and 10, 10% are the respondents having age 58-57 years, or more than 57 years respectively. If we consider gender it is observed that 70% are females while 30% are male respondents. And we consider our result according to education status so 8% are

done primary, 10% matriculation, 26% intermediate, 46% are Bachelors while 10% are completed their Masters. (Results are shown in Table 1).

#### Knowledge of disease:

According to our result it is shown that 54% participants are known about this disease, 40%

don't know and 5% are not hearing about this disease. When we asked do you know that hemophilia is a blood disorder only 53% give correct answer 19% gave wrong answer while 26% don't know about this disease. (Results are shown in Table 2).

**Table 1. Demographic information of participants.**

Characteristics	Frequency	Percent (%)
<b>Age</b>		
18-27yrs	52	52.0
28-37yrs	28	28.0
38-47yrs	10	10.0
48-57yrs or more	10	10.0
<b>Gender</b>		
Male	30	30
Female	70	70
<b>Education</b>		
Illiterate	0	0.0
Primary	8	8.0
Matriculation	10	10.0
Intermediate	26	26.0
Bachelor	46	46.0
Master	10	10.0

**Table 2. Knowledge of disease.**

Knowledge of Disease	Yes N (%)	No N (%)	Don't know N (%)
Do you know about hemophilia?	55 (54.4)	40 (39.6)	5 (4.9)
Is hemophilia is blood disorder?	54 (53.5)	19 (18.8)	27 (26.7)
Is hemophilia is inherited disorder?	50 (49.5)	20 (19.8)	30 (29.7)
Hemophilia can be acquired (not born with this disease but may be develop during lifetime)?	7 (6.9)	16 (15.8)	77 (76.2)
Hemophilia is more common among males than females	7 (6.9)	29 (28.7)	64 (63.4)
Heavy bleeding from minor cut and bruises are symptom of hemophilia?	49 (48.5)	17 (16.8)	34 (33.7)
Bleeding in urine and stool are sign of internal hemorrhage?	41 (39.6)	16 (17.8)	44 (43.6)
Internal bleeding is more harmful than external bleeding?	33 (32.7)	17 (16.8)	50 (49.5)
Is hemophilia treatment available?	14 (13.9)	26 (25.7)	60 (59.4)
Are hemophilic patient take aspirin or other NSAIDs?	7 (6.9)	29 (28.7)	64 (63.4)
Is hemophilia is lifelong disease?	25 (24.8)	17 (16.8)	58 (57.4)

**Sources of information**

The main source of this disease is academic books. 44% participants are obtained information from books, 10% from internet while 39% don't have any information regarding this disease. (Results are shown in Table 3).

**Table 3. Sources of information.**

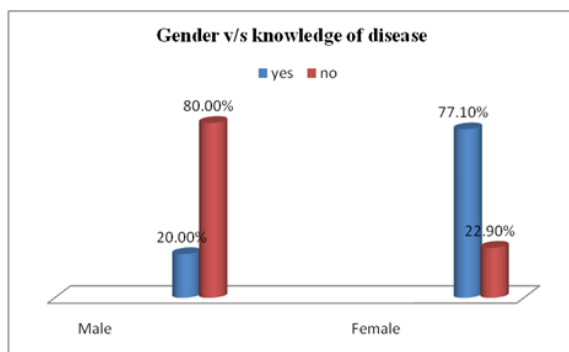
Sources	Frequency	Percent (%)
Academic books	44	44.0
Internet/TV	10	10.0
Newspaper/Magazines	6	6.0
Hemophilia Leaflets	1	1.0
no information	39	39.0

**Relation between gender & knowledge of disease**

When we compare gender v/s knowledge of this disease it is clearly observed that female had more knowledge of this disease as compare to male as shown in table: 4. The chi square value was 0.001 which is less than 0.05 means our result is significant. Results are also observed in Figure 1.

**Table 4. Relation between gender & knowledge of disease.**

	known		Chi Square
	Yes N (%)	No N (%)	
Gender			0.001
Male	6 20.0%	24 80.0%	
Female	54 77.1%	16 22.9%	
Total	60 60.0%	40 40.0%	



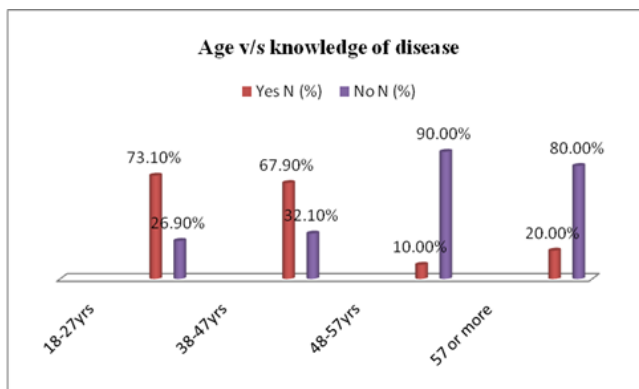
**Figure 1. Relation between gender & knowledge of disease.**

**Relation between age & knowledge of disease**

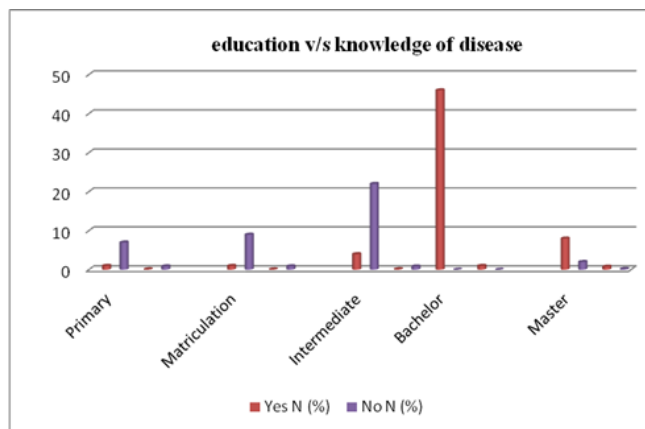
By comparing the knowledge of disease v/s age results show that from age 18-27 participants had more knowledge of this disease followed by 38-47 years of age, complete result are shown in table. The chi square value was also calculated and it shows 0.00 that means our result is highly significant. Results also seen in Figure 2.

**Table 5. Relation between age & knowledge of disease.**

Age	Known		Chi Square
	Yes N (%)	No N (%)	
18-27yrs	38 73.1%	14 26.9%	0.00
38-47yrs	19 67.9%	9 32.1%	
48-57yrs	1 10.0%	9 90.0%	
57yrs or more	2 20.0%	8 80.0%	
Total	60 60.0%	40 40.0%	



**Figure 2.** Relation between age & knowledge of disease.



**Figure 3.** Relation between education & knowledge of disease.

**Relation between education & knowledge of disease**

The relation between knowledge of disease in education clearly shows that participants having bachelor degree are more knowledge than primary or secondary educated participants as shown in Table 6. the chi square value observed is 0.002 mean the result is highly significance. Results also shown in Figure 3.

**Table 6. Relation between education & knowledge of disease.**

Education	Known		Chi Square
	Yes N (%)	No N (%)	
Primary	1	7	0.002
	12.5%	87.5%	
Matriculation	1	9	
	10.0%	90.0%	
Intermediate	4	22	
	15.4%	84.6%	
Bachelor	46	0	
	100.0%	0.0%	
Master	8	2	
	80.0%	20.0%	
Total	60	40	
	60.0%	40.0%	

**DISCUSSION**

Hemophilia is a blood disorder. It is a rare disorder, the population of this disease may be small but the victim of this disease suffers more physically, psychologically or economically than other disease. Because of the small population affected by this disease impressive work was not done for this disease as compare to other disease. In past when we talked about the consequence of this disease, it is observed that the patients who suffered from this disease had a very short mortality or morbidity. But due to advances in medical field from last two decades it is not untreated now and patient mortality rate also decreases. Males are more prone to this disease because of X linked recessive inheritance. From several literature surveys it is observed that there is no specific race or ethnicity of this disease.

By conducting survey it is also observed that in Pakistan only small majority of patients are registered in Pakistan hemophilic society so we cannot know exact quantity of these patients. It is reasonability of patient's family that they should registered their patient so they can receive standard treatment guidelines.

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## CONCLUSION

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Hemophilia is a rare genetic disorder so its diagnosis and treatment strategy still unknown to majority of population. The mobility of this disease is still very high and consequences result in joint damage and internal hemorrhage. The aim of our study was to assess the knowledge of this disease in normal population and it is clearly known that majority of people don't know about this disease, its symptom or treatment, so it's necessary to conduct such measures by the health care provider that should increase the normal population awareness about this disease.

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