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Assessment of knowledge about hemophilia, a genetic bleeding disorder amongst paramedical and nursing students

***[1] Shrivastava Manisha, [2] Shah Nehal, [3] Navaid Seema, [4] K Radha**

*[1] MD Professor and HOD, Department of Transfusion Medicine Bhopal Memorial Hospital & Research Centre Raisen Bye Pass Road, Near Karond Chowk Bhopal, [M. P.] India.

[2] PHD Research Scholar at Symbiosis International University, Pune. Department of Physiotherapy Bhopal Memorial Hospital & Research Centre Raisen Bye Pass Road, Near Karond Chowk Bhopal, [M. P.] India.

[3] MBBS Medical Officer, Department of Transfusion Medicine Bhopal Memorial Hospital & Research Centre Raisen Bye Pass Road, Near Karond Chowk Bhopal, [M. P.] India.

[4] PHD Vice Principal, Bhopal Nursing College, Bhopal Memorial Hospital & Research Centre Raisen Bye Pass Road, Near Karond Chowk Bhopal, [M. P.] India.

Abstract
Hemophilia is the most common hereditary coagulation factor deficiency occurring primarily amongst males characterized by bleeding in muscles and joints and can further lead to chronic pain and joint disease. Treatment of hemophilia involves replacement of the essential clotting factors at the time of bleeding episode and the management requires a multidisciplinary approach including paramedical and nursing health care workers. Less is known about knowledge and awareness amongst paramedical and nursing students concerning this disorder. This study aims at assessing knowledge of nursing and paramedical students about hemophilia and its management. The students, were subjected to a structured questionnaire (self-filled Pre Test) containing 20 multiple choice questions related to topics being covered in the lecture followed by an interactive lecture of one hour which covered the basic information about hemophilia, inheritance, incidence, clinical characteristics and its comprehensive management. The students were again subjected to post test (Self Filled) questionnaire containing same set of questions. A total of 167, 24% paramedical and 66% nursing students mean age 24.71, 114 females mean age 24.58 and 53 males mean age 24.56, participated in the study. The mean score of pre-assessment (n=146) and post assessment (n=167) were 5.75 (SD 3.31) and 11.64 (SD 3.35) respectively. There was a significant change in mean score of pre and post assessment, when compared (p<0.001). There was improvement in mean score of 5.89 (102.43%) over the Pre Test score. The total highest and lowest scores in pretest and posttest were 17&1; 20&5 respectively. There was a significant improvement in the score of each question. This study intending to increase awareness about hemophilia amongst healthcare workers showed that enhancement of knowledge of paramedical and nursing staff through awareness lecture is a good means towards changing the levels of attitude and developing effective national hemophilia programme for diagnosis, genetic counseling, patient education, psychosocial counseling and registry of patients.

Keywords: Hemophilia, genetic disorder, knowledge, nursing, paramedical students

Introduction

Hemophilia is a hereditary coagulation factor disorder occurring commonly in males. This bleeding disorder is characterized by bleeding in muscles and joints that can result in severe and chronic joint pain and joint disease [1]. Hemophilia A and B are single gene disorders, occurring due to a mutation either in coagulation factor VIII gene or Coagulation Factor IX gene deficiency respectively thereby resulting in deficient synthesis of coagulation factor VIII and IX [2]. There are three categories of hemophilia depending on the percentage of blood clotting factors: severe (<1% factor VIII/IX), moderate (1-5 factor VIII/IX) and mild (>5-40% factor VIII/IX). Severe hemophilia is characterized by spontaneous bleeding, moderated by bleeding with slight injuries and mild by bleeding during surgical procedures or from severe injuries [3]. The majority of joint bleeds (almost 80%) occur in knee, elbows, ankle and hip [4]. Almost 10-80% of people with hemophilia (PWH) are present in developing countries like India [5]. However the disease is under diagnosed and many cases are not yet registered. According to the recent survey of hemophilia federation of India [HFI] approximately 17000 cases are registered in India [6]. The management of hemophilia A and B includes the replacement of coagulation proteins throughout the life along with the comprehensive care of the patients including all medical and psychosocial aspects of the PWH. This requires better blood transfusion services such as plasma and cryoprecipitate from the screened blood donors. Replacement therapy required for hemophilia is very expensive although various support groups are working for providing the management of hemophilia and government in

various states have also started financial supports in order to provide the coagulation factors free of cost at some centres [5, 7]. If the bleeding episodes are treated early and adequately, severe joint disease can be prevented [8]. Almost 90 % of patients experience joint arthropathy as chronic degenerative changes [9]. Joint arthropathy results in chronic pain and long term issues with quality of life of the patients [10]. In hemophilic patients intramuscular injections should be avoided so as to reduce the risk of hematomas at the site of injections [9, 10].

Knowledge and awareness about hemophilia amongst doctors, healthcare workers, PWH and their families is still inadequate. The awareness regarding the disease shall help the clinicians and supporting staff for better diagnosis, assessment and management of the disease there by helping in more registrations of the PWH, better collection of the data for better planning and structuring of the management of disease and its complications. The study was done with the objective to assess the knowledge and awareness of paramedical students regarding basic information about hemophilia, inheritance, incidence, clinical characteristics and comprehensive management of the disease.

Material and methods

A total of 167 students agreed to participate in the study. The students were informed in advance to attend the awareness lecture. A self-administered questionnaire was used to collect the information. It was an anonymous structured questionnaire containing 20 multiple choice questions designed to assess the basic knowledge of the students about hemophilia with maximum obtained marks '20' and minimum obtained marks 'zero'. The students were instructed to choose one right answer for one question for which every correct answer was given 1 mark and incorrect was given 0. There was no negative marking. The students were asked to fill the questionnaire just before the starting of the awareness lecture. The awareness lecture covered the basic information about hemophilia, inheritance, incidence, clinical characteristics and comprehensive management of the disease. The students were encouraged to answer all the questions so as to ensure that no question remained unanswered. The students were given opportunity to ask questions to make interactive sessions. There after the students were again subjected to a posttest questionnaire containing the same set of questions. The ethical approval and administrative approval for the study was obtained from the institutional ethical committee.

Statistics: Statistical analysis was done to calculate means, percentage and ranges and comparison of means were performed by using paired t –test at 95% CI and p value of <0.05 was considered significant.

Results

A total of 167 students, mean age 24.71, 114 females, mean age 24.58 and 53 males, mean age 24.96, participated in the study. 24% students were of paramedical institute and 66% students belonged to the nursing college and rest attendees were from other similar courses. The mean score of pre-assessment (n=146) and post assessment (n=167) was 5.75 (SD 3.31) and 11.64 (SD 3.35) respectively. There was a significant change in mean score of pre and post assessment, when compared (p<0.001). There was improvement in mean score of 5.89 (102.43%) over the pretest score. In pretest questionnaire 85 out of 146(58%) students scored between 0 to 5 and in posttest every student scored above 5 (n= 167). In pretest only 2 out of 146 students scored in the higher marks slot between16 to 20, whereas in posttest 19 out of 167 students scored between 16 to 20 marks slot (table 1). The lowest and highest pretest and post test scores were 1 and 17 and 5 and 20 respectively. Q4 and Q15 were about gender (male or female) affected in hemophilia and final cure of hemophilia respectively and were answered incorrectly by 95% and 93% participants in pretest respectively while the knowledge about the same improved significantly in the post test scores (table 2).

As evident from pretest scores of Q2, Q7 and Q8 the students were well aware about the fact that hemophilia is a bleeding disorder, about life expectancy of hemophilia and etiology, 46.57% (Q2), 51.36%(Q7) and 46.57% (Q8) participants answered correctly in pretest.

Table 1: Posttest questionnaire number range

Number Range	Pre test	Percentage	Post test	Percentage
0-5	85	58.21	0	0
06-10	50	34.24	54	32.33
11-15	9	6.16	94	56.28
16-20	2	1.36	19	11.3

Table 2: Question wise Assessment of the participants

Pre Assessment (number of participant=146)						Post assessment (number of participant =167)			
		Correct*	%	Incorrect**	%	Correct*	%	Incorrect**	%
1	Q1	56	38.35	90	61.65	95	56.88	72	43.12
2	Q2	68	46.57	78	53.43	142	85.02	25	14.98
3	Q3	45	30.82	101	69.17	22	13.17	145	86.82
4	Q4	6	4.10	140	95.89	68	40.71	99	59.29
5	Q5	41	28.08	105	71.91	101	60.47	66	39.53
6	Q6	37	25.34	109	74.65	62	37.12	105	62.88
7	Q7	75	51.36	71	48.64	114	68.26	53	31.74
8	Q8	68	46.57	78	53.43	157	94.01	10	5.99
9	Q9	18	12.32	128	87.68	61	36.52	106	63.48
10	Q10	41	28.08	105	71.91	61	36.52	106	63.48
11	Q11	26	17.80	120	82.20	52	31.13	115	68.87
12	Q12	24	16.43	122	83.57	108	64.67	59	35.33
13	Q13	56	38.35	90	61.65	148	88.62	19	11.38
14	Q14	48	32.87	98	67.13	110	65.86	57	34.14
15	Q15	10	6.84	136	93.16	124	74.25	43	25.75

16	Q16	42	28.76	104	71.24	157	94.01	10	5.99
17	Q17	24	16.43	122	83.57	86	51.49	81	48.52
18	Q18	58	39.72	88	60.28	69	41.31	98	58.69
19	Q19	41	28.08	105	71.92	102	61.07	65	38.93
20	Q20	45	30.82	101	69.18	41	24.55	126	75.55

*Number of participant answered correctly

** Number of participants gave incorrect answers

Discussion

Spreading awareness about hemophilia is a key for early diagnosis and better management of the disease. There are limited or no studies related to spreading awareness of hemophilia amongst the paramedical and nursing students however similar studies of assessment of knowledge have been done for other medical disorders. As evident from our study most of the students were below 25 years of age and an intervention in form of an awareness lecture was just appropriate to bring in attitude towards recognizing and managing the disease like hemophilia during their career as health care professionals. A study on assessment of a classroom based infection control awareness programme evaluating the level of knowledge of medical and paramedical students showed improvement in the mean scores before and after the programme. The results of this study were similar to our study where use of intervention in the form of lecture was effective in improving the knowledge of students [11]. A similar study reported an enhancement in knowledge regarding universal precautions of bio safety among medical students with a response rate of 78% [12]. Another study in form of a cross-sectional survey has reported that awareness and education amongst nursing students improves their compliance towards hand hygiene after becoming health care professionals [13].

In contrast to our study where the awareness improved after the lecture, a cross-sectional study amongst health care workers and medical students concluded that students were already aware in high percentage [14]. A study from India, evaluated the effect of training among medical students about the awareness of speech and hearing disorder. The study showed significant improvement in the knowledge and awareness about speech and hearing disorders from 64% to 92% which was similar to our study, also suggesting the need of training/lectures in students in their education curriculum [15]. Ghaemi *et al.* in their study assessed the knowledge and attitude of the students and evaluated the impact of education and suitable method of presentation. They reported that both lecture and pamphlet education methods were effective in increasing the knowledge of the students. Lecture method was found more effective similar to our study where we report a significant improvement in the knowledge of the students [16]. A national survey from the United States, done by the National hemophilia foundation and the centres for disease control and prevention showed that there is lack of understanding of the disease management, diagnosis and treatment, prevention and management of the complications even in patients. They identified and recommended the awareness campaign programme as a key to prevent the complications and effective management of the disease [1]. Another study from Iran has shown that there is a lack of awareness amongst patients about hepatitis B and C transmission through treatment modalities like blood products and the study highlighted the need to improve the level of knowledge and attitude of these patients as well prevention of complications through education skill sessions and group discussions [17]. If health care workers like the paramedical and the nursing staff are made aware they can assist in not only the effective management and prevention of this disease but also in educating the patients. As the students were available in person for pre and posttest questionnaire the results of our study are reliable within the limitations. Our study highlights the need for increasing awareness about hemophilia amongst healthcare workers with special reference to the developing world. The World Federation of Hemophilia (WFH) has estimated that worldwide approximately 70% of hemophilia patients are under diagnosed and untreated. In developing countries like India the main focus of healthcare system is basic health care priorities, such as nutrition, immunization, sanitation, family planning and treatment of various infectious diseases such as tuberculosis, HIV, or malaria and hemophilia is considered as rare disorder [7]. The disease focus is being addressed by WHF by establishing hemophilia care programs and by educating and training healthcare professionals. The paramedical staff is the part of the effective rehabilitation of the patients with hemophilia and educating and increasing the level of awareness is of utmost importance. A review article discussing the epidemiology and social cost of hemophilia in India reported that India harbours the second highest number of global patients with hemophilia A. The reported number of patients with hemophilia A is 11,586 while the estimated prevalence could be around 50,000 patients. One of the key components of a programme for prevention and control of this genetic disorder has been suggested as training and competency development [18].

Conclusion

In order to provide better understanding of hemophilia management and prevention, awareness programs are important components. Enhancement of knowledge of paramedical and nursing staff through awareness lectures is a step towards changing the levels of attitude and developing effective national hemophilia programme for diagnosis, genetic counseling, patient education, psychosocial counseling and registry of patients. More studies with better design and measurement of outcomes regarding hemophilia awareness could be planned.

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