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Original Research Paper

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HEALTH PRACTICES OF PATIENTS WITH HAEMOPHILIA

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ABSTRACT

Objectives: The aim of this study was to assess the health practices of patients with haemophilia

Materials and methods: A quantitative research approach was used. The research design was non experimental descriptive design. A total of 80 patients, attending haemophilia clinic in Medical College Hospital, Kottayam were selected for the study by using non probability purposive sampling technique. The data collection instruments for the study included socio personal and clinical data sheet for collecting basic information and rating scale for assessing health practices The data was analyzed by using descriptive and inferential statistics.

Results: Majority of patients (67.50%) had poor health practices. Majority of patients (58.80%) had poor personal hygiene practices and more than half of the patients (53.80%) were good in practising activities and exercises. More than half of the patients (51.20%) were having poor practice regarding compliance to therapeutic regimen and prevention of complications.

KEYWORDS : Haemophilia; Health practices

INTRODUCTION

Haemophilia is a chronic disease and there is no cure for haemophilia A or B. Haemophilia is a rare genetic disorder where blood does not clot normally. It is heterogeneous disorder varying in severity and clinical behaviour.[1]

Estimated incidence of haemophilia A is 1 per 5000 male births and haemophilia B is 1 per 30000 male births. No ethnic or geographic association has been reported. Number of haemophilia patients in India, second highest global burden of patients after USA. India has at least 1.5 lakhs haemophilia and other bleeding disorder patients.[2] In India 80% of haemophilia cases are seen among the lower income groups. In Kerala there are 1487 cases of factor VIII deficiency, 387 cases of factor IX deficiency and 374 cases of other bleeding disorders registered with haemophilia chapters as on December 31, 2012. There are also persons suffering from deficiency of more than one factor.[3] People with bleeding disorder can live healthy and effective lives. If left untreated bleeding disorders can lead to disabling pain, acute joint injury and lethal internal bleeding. Bleeding contributes to the progressive deterioration of joints and muscles and this affects patient's well-being and their everyday activities. Early treatment of severe haemorrhage episodes is necessary to reduce long-term complications.[4]

METHODOLOGY

A quantitative research approach was used for the study. The research design selected for the study was non experimental descriptive design. A total of 80 patients, attending haemophilia clinic in Medical College Hospital, Kottayam were selected by using non probability purposive sampling technique.

The data collection instruments for the study included socio personal and clinical data sheet for collecting basic information and rating scale to assess the health practices. Socio personal data sheet consisted of 3 items which includes age, education and occupation of patients with haemophilia. It was filled by the investigator and clinical data sheet consisted of 8 items which includes type of haemophilia, severity, comorbidities, frequency of hospitalization, family history, presence of siblings affected with haemophilia, history of death of relatives due to haemophilia and parental consanguinity. It was filled by the investigator. Rating scale to assess the health practices was a three point scale which consists of 30 items regarding the health practices of patients with haemophilia with regard to personal hygiene, activity and exercises, compliance to therapeutic regimen and prevention of complications. There are 6 items related to personal hygiene, 8 items for activities and exercises, 5 items for compliance to therapeutic regimen and 11 items related to prevention of complications. The responses are regularly, occasionally and never and items were scored as two, one and zero respectively. Reliability of the rating scale to assess health practices of patients with haemophilia was established by test retest method using Karl Pearson correlation coefficient and it was found to be 0.77. Thus the tool was found to be reliable.

RESULTS

Findings of the study were discussed under the following headings:

Socio personal data of patients with haemophilia

Most of the patients (43.75%) belonged to the age group of 13-22 years. Majority of patients (58.80%) were studied up to high school. While considering occupation, most of the patients (38.75%) were students, 12.50% were government employee, 30% were private employee or self employed and 18.75% of patients were unemployed.

Clinical data of patients with haemophilia

Majority of patients (71.20%) had haemophilia A and had severe haemophilia (65%). Most of the patients (78.75%) were free from comorbidities. Majority of patients (46.25%) were not hospitalized, 20% admitted once, 15% twice and 18.75% were more than three times admitted during the previous year. More than half of the patients (52.50%) had family history of haemophilia. Majority (68.80%) had no hemophilia affected siblings and 31.20% had siblings with haemophilia. Most of the patients (72.50%) had no relatives who died due to haemophilia. Majority of patients (95%) had no parental consanguinity.

Health practices of patients with haemophilia

TABLE 1 Frequency distribution and percentage of patients with haemophilia with respect to health practices

(n=80)

Health practices	f	%
Good (45-60)	26	32.50
Poor (0-44)	54	67.50

Table1 shows that majority of patients (67.50%) had poor health practices.

TABLE 2 Frequency distribution and percentage of patients with haemophilia based on domains of health practices

(n=80)

Domains of health practices	Good		Poor	
	f	%	f	%
Personal hygiene	33	41.20	47	58.80
Activities and exercises	43	53.80	37	46.20
Compliance to therapeutic regimen	39	48.80	41	51.20
Prevention of complications	39	48.80	41	51.20

Table 2 reveals that majority of patients (58.80%) had poor personal hygiene practices. More than half of the patients (53.80%) were good in practising activities and exercises. More than half of the patients (51.20%) were having poor practice regarding compliance to therapeutic regimen and prevention of complications.

TABLE 3 Frequency distribution and percentage of patients with haemophilia with respect to health practices related to personal hygiene

(n=80)

Personal hygiene	Regularly		Occasionally		Never	
	f	%	f	%	f	%
Brushes the tooth twice	50	62.50	30	37.50	0	0
Uses soft bristle tooth brush	66	82.50	8	10.00	6	7.50
Uses flossing	16	20.00	12	15.00	52	65.00
Dental check up	9	11.20	31	38.80	40	50.00
Wears well fitting foot wear	74	92.50	2	2.50	4	5.00
Takes daily bath	80	100	0	0	0	0

Table 3 shows that 62.50% patients brushed the tooth twice, 82.5% used tooth brush with soft bristle and 92.50% worn well fitting foot wear regularly. Most of them regularly follow health practices related to personal hygiene except dental checkup (11.20%) and flossing tooth (20%).

TABLE 4 Frequency distribution and percentage of patients with haemophilia with respect to health practices related to activity and exercises

(n=80)

Activity and exercises	Regularly		Occasionally		Never	
	f	%	f	%	f	%
Sleeps 7 to 9 hours	53	66.25	20	25.00	7	8.75
Rest for at least 1 hour during day	34	42.50	33	41.25	13	16.25
Performs exercises	31	38.80	29	36.20	20	25.00
Avoids contact sports	56	70.00	9	11.20	15	18.80
Avoids strenuous activity	46	57.50	23	28.75	11	13.75
Wears dress independently	43	53.75	26	32.50	11	13.75
Goes to toilet without support	41	51.25	27	33.75	12	15.00
Does activities of daily living	37	46.25	31	38.75	12	15.00

Table 4 shows that more than two by third of patients (66.25%) regularly slept 7 to 9 hours at night. Nearly half of the patients regularly avoided strenuous activity like weight lifting (57.50%), worn dress independently (53.75%), went to toilet without support (51.25%) and avoided contact sports (70%). Only few patients were regularly performed exercises (38.80%), took rest for at least one hour during day time (42.50%) and did the activities of daily living without support (46.25%).

TABLE 5 Frequency distribution and percentage of patients with haemophilia with respect to health practices related to compliance to therapeutic regimen

(n=80)

Compliance to therapeutic regimen	Regularly		Occasionally		Never	
	f	%	f	%	f	%
Consults the doctor	36	45.00	39	48.80	5	6.20
Takes pain killers for joint pain with doctors order	51	63.75	22	27.50	7	8.75
Adjusts the doses of medicines by consulting doctor	61	76.25	17	21.25	2	2.50
Takes clotting factors	38	47.50	35	43.75	7	8.75
Does not take over the counter medications	33	41.20	28	35.00	19	23.80

Table 5 shows that more than half of the patients took pain killers for joint pain with doctor's order (63.75%) and adjusted the doses of medicines by themselves with consulting doctor (76.25%) regularly. Only few patients regularly consulted doctor (45%), took clotting factors (47.50%) and did not take over the counter medications (41.20%).

TABLE 6 Frequency distribution and percentage of patients with haemophilia with respect to health practices related to prevention of complications.

(n=80)

Prevention of complications	Regularly		Occasionally		Never	
	f	%	f	%	f	%
Able to identify bleeds early	47	58.80	28	35.00	5	6.20
Observes entire body for any bruising	37	46.20	36	45.00	7	8.80
Takes precautions to avoid injuries	59	73.80	13	16.20	8	10.00
Avoids the drugs that cause bleeding	60	75.00	13	16.20	7	8.80
Request for avoiding intramuscular injection	62	77.50	9	11.25	8	10.00
Uses protected braces during activities	25	31.20	32	40.00	23	28.80
Applies pressure over minor cuts	45	56.20	16	20.00	19	23.80
Pinches the nose during nasal bleed	19	23.80	24	30.00	37	46.20
Applies bandage for joint pain.	61	76.20	16	20.00	3	3.80
Applies ice packs for joint bleed.	54	67.50	20	25.00	6	7.50
Wears an identification tag	56	70.00	11	13.80	13	16.20

Table 6 shows that. 80% were regularly able to identify bleeds early. 46.20% regularly observed entire body for any bruising/ any bleeding. Majority of patients (73.80%) regularly took precautions to avoid injuries while handling sharp instruments, 75% avoided the drugs that cause bleeding, 77.50% requested for avoiding intramuscular injection as far as possible, 76.20% applied compression bandage for the reduction of joint pain and 70% worn an identification tag regarding condition. More than half of the patients regularly applied ice packs for joint bleed (67.50%) and applied pressure over minor cuts or injuries (56.20%). Only few patients regularly used protected braces or splints during activities like playing (31.20%) and practised pinching the nose during nasal bleed (23.80%).

CONCLUSION

Majority of patients (67.50%) had poor health practices and 32.50% had good health practices. Majority of patients (58.80%) had poor personal hygiene practices. More than half of the patients (53.80%) were good in practising activities and exercises. More than half of the patients (51.20%) were having poor practice regarding compliance to therapeutic regimen and prevention of complications.

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