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Original Research Paper

Homeopathy

AN OBSERVATIONAL STUDY TO ASSESS THE AWARENESS IN PATIENTS REGARDING THE TREATMENT OF HEMOPHILIA AT SOLA CIVIL HOSPITAL, AHMEDABAD.

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ABSTRACT **Aim** of this study is to access the awareness in patient regarding diagnosis and treatment of haemophilia. **Material & Methods:** Information comprise of essential information gathered in the wake of getting endorsement from the concerned moral panel and legitimate assent from the patients/relatives of hemophilia patients, The hospital based observational review; where this is a cross-sectional investigation of Adult and Paediatric patients who are experiencing hemophilia and who are come to the hemophilia day care Centre of sola Civil Hospital, Ahmedabad. **Result:** Among all the patients, 11.53% had awareness of their condition from birth, 63.84% gained awareness within the first 5 years, and 24.61% became aware after 5 years. Among adult patients, 83% were receiving on-demand treatment, while 13% were on prophylactic treatment for hemophilia. Among the pediatric patients, 82% were on on-demand treatment, while 18% were receiving prophylactic treatment for hemophilia. **Conclusion:** Awareness about hemophilia treatment is crucial to ensure early diagnosis, timely intervention, and improved quality of life for affected individuals. Increased awareness can help prevent complications, reduce the impact of bleeding episodes, and promote better access to specialized care. So, there are need to increase the awareness in patient regarding early diagnosis and treatment of hemophilia.

KEYWORDS : Hemophilia, Awareness, Bleeding disorder.

INTRODUCTION:

Hemophilia is characterized by a deficiency or dysfunction of clotting factors in the blood, which can result in prolonged bleeding after injury or spontaneous bleeding into joints and muscles. The two most common types are hemophilia A (caused by a deficiency of factor VIII) and hemophilia B (caused by a deficiency of factor IX). (1) Timely diagnosis and proper management are essential to prevent complications and ensure a better quality of life for individuals with hemophilia. (2) One of the primary challenges in managing hemophilia is achieving an early diagnosis. Awareness campaigns aim to educate healthcare professionals about recognizing the signs and symptoms of hemophilia in patients, particularly in newborns and young children. (3) Early diagnosis allows for prompt intervention and access to appropriate treatment. Hemophilia management has evolved significantly over the years. Factor replacement therapy, which involves infusing missing clotting factors, is a standard treatment. Hemophilia treatment centers (HTCs) play a crucial role in providing specialized care and educating patients about treatment options. Raising awareness about hemophilia is not limited to healthcare providers alone. (4) Patients and their families must also be well-informed about the condition. Awareness campaigns emphasize the importance of adherence to treatment regimens, regular check-ups, and recognizing potential bleeding episodes. (5) The journey of individuals with hemophilia is significantly influenced by awareness campaigns, which aim to reduce the burden of the disease, improve access to treatment, and enhance overall quality of life. (6) So, aim of this study to evaluate the awareness in patient regarding treatment of hemophilia.

MATERIAL & METHODS:

This is hospital-based observational study, which was conducted with proper consent from the patients or guardians of hemophiliacs and approval from the relevant ethical committee. where this is a cross-sectional study of all adult and pediatric hemophilia patients who visit the hemophilia day care center of the Sola Civil Hospital in Ahmedabad. An intensive clinical history of hemophilia patients was taken. For the purpose of studying the disease, the patients were then given a thorough clinical examination, relevant blood tests, and radiological imaging. At the hemophilia day care center at the Sola Civil Hospital, 130 patients, 80 of whom are adult males and 50 of whom are children, participate in the study. Consistently information was gathered from the Hemophilia Branch of Sola Common Emergency clinic and information were dissected in proper measurable programming. (N=130) The following is a clinical history: symptoms at the time of the patient's admission to the hospital, prior admission and treatment history, age at diagnosis, age at inhibitor development, family history of bleeding disorders, and previous bleeds or injuries. The following are aspects of the study of hemophiliac patients: Profile of coagulation: Bethesda Assay (for inhibitors), Prothrombin Time (PT), and Activated Partial Thromboplastin Time (APTT). Viral markers: HBsAg, HCV antibodies, and HIV I and II antibodies. FISH was used to evaluate disability and functional independence. Imaging by Radioactivity: for the purpose of radiologically classifying arthropathy, an X-ray, CT scan, and MRI of the patient's target joints, which are the joints that are most frequently affected. Every grown-up quiet ≥ 18-year-old, every pediatric patient ≥ 2-year-old and All patients of hemophilia An and Hemophilia B are included for this study. Pregnant women,There was no consent, Patients with constant liver infection, hypertension, and diabetes are excluded for the study. Patients taking anticoagulants gave their informed consent before participating in the study.

RESULTS:

The data was analyzed using the Arithmetic mean, and **ANOVA** test for the null hypothesis. The standard deviation, standard error, and correlation coefficient of 130 cases of hemophilia were studied.

AGE	No. PATIENTS	PERCENTAGE (%)
≥18 years	80	62
≤ 18 years	50	38

Table 1. Age Distribution of patients (N=130)

From the above table, total 130 patient is observed. Out of 130 maximum number of cases is more than 18 years of age constituting 62% and the minimum numbers of cases are in age below 18 years being 38%.(Table 1)

TYPES	PATIENTS	PERCENTAGE (%)
Hemophilia A	125	96
Hemophilia B	5	4

Table 2. According to types of hemophilia patients

Table 2 show that out of 130 patient, 125 patients suffering from hemophilia A and only 4 patients suffering from hemophilia B. (Table 2)

TYPES OF INJURY	BY BIRTH	UP TO 5 YEAR	ABOVE 5 YEAR	PERCENTAGE
FALL DOWN	0	5	8	10

INJURY	3	30	5	29.23
PATCHES/BRUISES	5	28	0	22.5
SMALL TUMOUR	1	2	0	17.69
SWELLING	3	15	18	27.69
DENTAL PROBLEM	3	3	1	5.38

Table 3. Data of adult and paediatric patient's onset of injury.

Table 3 indicates that among the total observed patients, 29.23% became aware of their condition when they experienced an injury, 27.69% during swelling, 22.5% when they noticed patches, 17.69% with the presence of a small tumor, 10% following a fall, and 5.38% when encountering dental issues.

TREATMENT	ADULT PATIENTS	ADULT PERCENT (%)	PAEDIATRIC PATIENTS	PAEDIATRIC PERCENT (%)
ITI	2	4	0	0
ON-DEMAND	67	83	41	82
PROPHYLAXIS	11	13	9	18

Table 4. Data according to on-treatment

On demand treatment means replacement of deficient factor concentrate is infused when a bleed occurs. Prophylaxis means the administration of clotting factors concentrates in anticipation of or to prevent bleeding. Table 4 illustrates that 67 adults and 41 pediatric patients opt for on-demand treatment, initiating treatment when bleeding begins. Conversely, only 11 adults and 9 pediatric patients are following preventive treatment measures.

DISCUSSION:

Hemophilia is rare genetic bleeding disorder caused by mutations in the genes responsible for producing clotting factors. These genetic mutations are typically inherited from one's parents, and they result in a lack of or insufficient clotting factor activity in the blood. (7).Hemophilia is an X-linked recessive disorder, which means that it predominantly affects males while females can be carriers. Patient awareness about the signs and symptoms of hemophilia is critical. (8) Encouraging patients to recognize the early warning signs of bleeding, such as pain, swelling, or difficulty moving a joint, can lead to prompt diagnosis and intervention. Timely treatment is essential to prevent complications and minimize the impact of the disorder on daily life.(9) In this observation study, within the entire group of observed patients, 29.23% recognized their condition upon sustaining an injury, 27.69% when faced with swelling, 22.5% upon noticing patches, 17.69% with the appearance of a small tumor, 10% subsequent to a fall, and 5.38% in the context of dental issues. (Table 3). Among all the patients, 11.53% had awareness of their condition from birth, 63.84% gained awareness within the first 5 years, and 24.61% became aware after 5 years. (Table 3). Hemophilia is managed through clotting factor replacement therapy. This involves infusing the missing clotting factor into the bloodstream to temporarily correct the deficiency. Treatment can be administered on-demand (in response to bleeding) or as prophylaxis (preventive therapy).(10) the adult patients, 83% were receiving on-demand treatment, while 13% were on prophylactic treatment for hemophilia. Among the pediatric patients, 82% were on on-demand treatment, while 18% were receiving prophylactic treatment for hemophilia. (Table 4) Locally, mindfulness regarding prophylaxis and on-demand treatment is less common. In order to mitigate the negative effects of these factors, the practice of prenatal pre-diagnosis during pregnancy ought to be increased.(11) Advances in treatment have significantly improved the quality of life for individuals with hemophilia. Gene transfer is being used to try to get rid of hemophilia, it hasn't been done on a large scale yet(12). It is likely that replacement therapy will see further advancements in the near future due to the availability of new therapeutic tools like factors VIII and IX with longer half-lives, more potent bypass factors and factors derived from the milk of transgenic animals.(13)Hemophilia can have a significant psychosocial impact on patients and their families. Patient awareness should extend to available psychosocial support services, such as counseling or support groups, which can help individuals cope with the emotional challenges associated with the condition.Encouraging patients to become advocates for the hemophilia community can foster a sense of belonging and purpose. Patients who are aware of the broader challenges faced by the hemophilia community may become active participants in advocacy efforts and initiatives to improve access to care and treatment.

CONCLUSION:

Hemophilia is a complex and challenging disorder that affects individuals and their families. Despite the difficulties, advancements in diagnosis and treatment have improved the outlook for those with hemophilia. Raising awareness, advocating for better access to care, and supporting ongoing research are essential components of managing this rare bleeding disorder and improving the lives of those affected. Patient awareness in hemophilia treatment is a multifaceted concept that encompasses knowledge, empowerment, and proactive engagement in one's healthcare journey. Healthcare providers, patient advocacy organizations, and families all play crucial roles in ensuring that individuals with hemophilia are well-informed and supported in their pursuit of optimal health and a fulfilling life despite the challenges posed by this condition.

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