Forum for Linguistic Studies 2025, 7(2)

ISSN:2705-0610 E-ISSN:2705-0602

A CRITICAL CARE ANALYSIS ON PATIENT WITH HAEMOPHILIA- CASE STUDY METHOD.

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ABSTRACT

Haemophilia is a hereditary bleeding disorder caused by deficiencies in coagulation factors, leading to abnormal bleeding. Haemophilia B, caused by Factor IX deficiency, often manifests through early signs such as gum bleeding, easy bruising, and fever. **Aims and objectives:** This study aims to conduct a critical care analysis of a haemophilia patient, focusing on clinical manifestations, early warning signs, treatment interventions, family coping strategies, and discharge planning. **Methodology:** A qualitative case study approach was used, with a non-probability purposive sampling method, focusing on a haemophilia patient from a selected hospital in Pune. The sample size comprised a single paediatric patient. **Results:** Key findings include the identification of early warning signs like gum bleeding and bruising. Immediate treatment with Factor IX replacement therapy was administered. Family strategies, including protective measures, were observed, but challenges related to emotional well-being and social isolation were noted. Gaps in discharge planning and follow-up were identified, pointing to systemic issues in patient care continuity. **Conclusion:** Effective haemophilia management requires early intervention, structured treatment protocols, and comprehensive family education.

Keywords: Haemophilia, Critical Care, Family Coping, Treatment Protocol, Discharge Planning

INTRODUCTION

Haemophilia, derived from the Greek words "philia" (love) and "hemo" (blood), is a common hereditary bleeding disorder. Deficiencies or defects in factor VIII and factor IX proteins cause hemophilia A and B, respectively, which may lead to excessive bleeding from minor wounds or, in some cases, spontaneous bleeding. Haemophilia C, a condition that is less prevalent, is caused by a deficiency in coagulation factor XI.[1]

Hemophilia affects around 30,000-33,000 people in the U.S., with 1 in 5,000 males being born with it. The disorder causes internal bleeding and is linked to several comorbidities, posing a significant healthcare burden.[2]

Haemophilia is mostly inherited, caused by gene changes affecting clotting factor production. The specific genes determine the type. In rare cases, acquired haemophilia occurs due to immune system damage to clotting factors, often linked to pregnancy, autoimmune disorders, or aging, with some cases having no known cause.[3]

The symptoms of haemophilia can vary based on the amount of clotting factor present in the blood. When clotting factor levels are slightly reduced, bleeding typically occurs after surgery or injury. In more severe cases, spontaneous bleeding can occur with little to no apparent reason. Common signs of spontaneous bleeding include excessive bleeding from cuts, injuries, surgeries, or dental procedures, frequent large or deep bruises, abnormal bleeding following vaccinations, pain, swelling, or stiffness in the joints, and blood in urine or stool. Nosebleeds without an obvious cause are also frequent, and in infants, unexplained fussiness could indicate internal bleeding.[4]

Haemophilia treatment aims to replace missing clotting proteins and prevent complications. This is done through clotting factor replacements, either from human blood or synthetically produced recombinant factors. Recombinant factors are preferred due to a lower risk of infection transmission. There are two main types of therapy: prophylactic therapy, which involves regular clotting factor administration to prevent bleeding, and demand therapy, used to treat bleeding episodes as they occur, typically for mild haemophilia.[5]

NEED OF STUDY

Haemophilia affects over 200,000 people globally, with an estimated 1.1 million cases due to underdiagnosis. In the U.S., approximately 33,000 males live with haemophilia. The condition is more common in males, with females accounting for 18% of mild cases and less than 1% of severe ones. Prevalence varies by region, with Thi-Qar, Iraq showing a rate of 9.5/100,000, higher than Iraq's national rate. This highlights the need for better diagnosis and treatment strategies.[6]

Haemophilia carriers, especially females, often face overlooked bleeding tendencies. A study showed inconsistent data on the prevalence of bleeding symptoms in carriers, especially females. While some findings suggest higher bleeding risks, the evidence remains insufficient to confirm this, emphasizing the need for more focused research.[7]

India lacks a national policy for genetic disorders, and while haemophilia has been well-studied, data on patient numbers, social costs, and genetic counseling availability are scarce. The country has the second-highest number of haemophilia A patients globally, with an estimated 50,000 affected individuals. This calls for enhanced public health strategies and more data collection.[8,9]

A case study approach to haemophilia in critical care is vital due to the disorder's complexity. Despite treatment advancements, managing acute bleeding and complications remains challenging.

AIM OF THE STUDY

This study aims to conduct a critical care analysis of a haemophilia patient, focusing on clinical manifestations, early warning signs, treatment interventions, family coping strategies, and discharge planning.

MATERIALS AND METHODS

This study adopts a qualitative approach using a case study design to critically analyze the care provided to a haemophilia patient at a selected hospital in Pune. This study uses a qualitative approach with a case study design to explore the critical care of a haemophilia patient. The research aims to analyze the management and treatment of a patient diagnosed with Haemophilia A or B, focusing on clinical assessments, disease history, and patient outcomes. A non-probability purposive sampling technique is employed, selecting one patient aged 1-12

years from a selected hospital in Pune city. Data is collected through interviews with the patient and family members, along with a review of medical records. Thematic analysis is used to identify patterns and themes from the qualitative data.

The research design is based on the case study method, offering an in-depth examination of the patient's experience. This approach allows the study to gather rich insights into the medical history, treatment process, and psychosocial factors influencing the patient's care. The study also incorporates a detailed assessment tool, divided into sections on demographic data, medical history, disease management, complications, and patient outcomes. This tool ensures comprehensive data collection and enhances the reliability of the results.

Ethical approval for the study was obtained from the institutional ethics committee. Written informed consent was gathered from the patient's guardian, ensuring confidentiality and the ethical use of the collected data. The analysis plan includes thematic analysis to identify emerging themes from the interviews, which was validated through member checking and peer debriefing. The study aims to contribute valuable insights to the understanding of haemophilia care, emphasizing early diagnosis, treatment, and the importance of family education in managing the condition effectively.

RESULT

Section 1: To critical care analysis of patient with haemophilia.

Table no 1: finding related to critical care analysis of patient with haemophilia

Codes	**Sub themes**	**Themes**	**Verbatim**
Gum bleeding, fever, bruising	Physical symptoms, clinical signs	Clinical Manifestations and Early Warning Signs	"Gum bleeding had occurred… also has fever… bruising easily."
Hospital visit, sample collection, factor replacement	Emergency care, medical response	Critical Care Management	"Assessment was done and samples collected… factor IX replacement therapy is given."
Factor IX therapy, monitoring	Treatment administered, standard protocol	Treatment and Intervention	"First they give general treatment after that factor replacement therapy was given."
Protective parenting, school absence	Social restrictions, emotional impact	Family Coping and Protection Strategies	"We don't allow the child to go to school… we protect him by staying at home."
Health education, counseling	Awareness efforts, support	Health Education and Emotional Support	"Yes, health education is given… yes, counseling was provided."
No follow-up	Gaps in resources, continuity of care	Limitations in Discharge Planning and Follow-Up	"No follow-up visit scheduled… no written or visual educational material provided."

A clinical manifestations of Haemophilia B in the pediatric patient, including gum bleeding, fever, and easy bruising, were key early warning signs that prompted timely medical attention. These symptoms, though subtle, are critical in preventing severe complications when addressed early. Upon presentation, the child received prompt assessment, investigations, and Factor IX replacement therapy, aligning with emergency haemophilia management protocols. This immediate intervention was essential in stabilizing the patient and preventing further deterioration. The management included general supportive care followed by Factor IX therapy, reinforcing the importance of early treatment in haemophilia care for better patient outcomes.

The family exhibited a highly protective approach by restricting the child's school attendance to minimize injury risks. While this strategy reduces physical harm, it may hinder the child's social development and emotional well-being. Overprotectiveness, although well-intentioned, could potentially lead to social isolation and impede the child's ability to adapt and cope with the condition. Therefore, balanced protection strategies and education are necessary for fostering emotional resilience.

Although verbal health education and counselling were provided, the absence of written or visual aids may limit the family's retention and broader engagement in the ongoing management of haemophilia. Continuous health education, supplemented with accessible materials, is essential for reinforcing learning, particularly for chronic conditions. Lastly, the lack of a follow-up appointment and educational materials at discharge highlights a gap in care continuity, increasing the risk of mismanagement or delayed responses to future bleeds. Effective discharge planning should include a clear follow-up schedule, resource support, and educational materials to ensure long-term health and reduce rehospitalization.

DISCUSSION

The findings of this study emphasize the critical aspects of managing a haemophilia patient, particularly the importance of early detection and prompt medical intervention. The child’s symptoms, such as gum bleeding, fever, and easy bruising, are typical indicators of Haemophilia B, prompting immediate medical attention. The use of Factor IX replacement therapy, as part of the established care protocol, was crucial in stabilizing the patient during the bleeding episode. However, the family’s protective approach, including restricting school attendance, could potentially hinder the child’s social development. This suggests that while safety is paramount, there should be a balanced approach to avoid social isolation. Additionally, the lack of written educational materials and follow-up care at discharge highlights significant gaps in continuity of care, underlining the need for clear discharge planning and accessible health education for families.

These findings align with the study by Bidyut, Kajal (2022), which also emphasized early diagnosis of haemophilia, especially between 12 to 24 months of age. Their study highlighted the importance of counselling sessions to educate both patients and families, which helps improve disease awareness, adherence to treatment, and overall quality of life for children.[10]

Further supporting these results, the study by Zalmai, et al. (2024) explored the patient experience of living with Haemophilia A, highlighting the ongoing physical, emotional, and social challenges despite advances in treatment. They found that individuals with haemophilia,

particularly across different age groups, face difficulties in managing their condition effectively in daily life[11]. The study emphasized the need for more convenient and effective therapies, ideally oral medications, to enhance daily functioning and improve the quality of life for patients. This underscores the need for ongoing advancements in treatment options to address these challenges. This study reinforces the importance of early intervention, continuous health education, and balanced protective strategies for haemophilia patients. It also highlights the need for more patient-friendly treatments that will enhance daily living and address the persistent challenges faced by individuals living with haemophilia. [11]

CONCLUSION

This case highlights the importance of early detection and prompt treatment in paediatric Haemophilia B, with Factor IX therapy playing a crucial role in clinical stabilization. However, gaps in family education, psychosocial support, and discharge planning remain. Overprotective caregiving and lack of follow-up care can negatively affect the child's long-term development and increase the risk of complications. To improve outcomes, it is essential to enhance health education, provide psychosocial support, and ensure a structured discharge plan that promotes continuity of care, ultimately supporting the child's overall well-being and development.

Conflict of Interest

The authors certify that they have no involvement in any organization or entity with any financial or non-financial interest in the subject matter or materials discussed in this paper.

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