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Study of Quality of life in Hæmophilia Patiens

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Introduction

Hemophilia is a chronic genetic disorder characterized by deficiencies in clotting factors, leading to prolonged bleeding episodes. Hemophilia A (Factor VIII deficiency) and Hemophilia B (Factor IX deficiency) are the two most common forms. In regions with limited access to healthcare, such as Kashmir, hemophilia management is challenging, often affecting patients' quality of life (QoL).

Background

Patients with hemophilia experience recurrent bleeding episodes, joint damage (hemarthrosis), and chronic pain, significantly impairing their physical, emotional, and social well-being. Comprehensive management of hemophilia requires not only medical treatment but also psychological and rehabilitative support. Globally, various studies have highlighted the poor QoL in hemophilia patients due to limited mobility, frequent hospitalizations, and the psychosocial impact of living with a chronic disease. In Kashmir, the specific challenges faced by patients due to geographic isolation and healthcare access disparities have not been fully explored. Assessing the QoL in these patients can provide valuable insights into their needs and guide improvements in care delivery.

Aims and Objectives

1. To assess the overall quality of life (QoL) of patients with hemophilia
2. To identify the physical, emotional, and social challenges faced by these patients.

Methodology

This was a retrospective observational study conducted over a period of three months The study aimed to assess the quality of life (QoL) in haemophilia patients using the Haemophilia Quality of Life Questionnaire (Haemo-QoL), focusing on physical, emotional, and social domains. The study included 45 patients diagnosed with haemophilia who had been attending the day care center for treatment during the 3-month period. (1 August 2023 to 31st October 2023).

Results

The study included 45 patients, with 32 patients (71%) having Haemophilia A and 13 patients (29%) having Haemophilia B. The mean age of patients was 27 years, with a range of 5 to 50 years. A detailed analysis of the QoL was conducted using the Hemophilia QoL Questionnaire.

Physical Health

Pain and Mobility: 60% of patients reported chronic joint pain, particularly in knees and elbows, affecting their mobility. Hemarthrosis was a frequent complication, leading to functional limitations. Around 35% reported using assistive devices like crutches.

Bleeding Episodes: The median number of bleeding episodes in the past year was 10 (IQR: 6-15). Patients receiving prophylactic factor replacement therapy had fewer episodes compared to those on demand therapy ($p<0.05$).

Emotional Well-being

40% of patients reported anxiety and depression related to their condition. Younger patients (below 18 years) exhibited higher levels of distress due to restrictions on physical activities, while older patients expressed concerns about job prospects and family life.

22% of patients were undergoing psychological counseling at the day care center, showing improvement in coping mechanisms.

Social Functioning

50% of patients reported difficulties in maintaining social relationships, largely due to physical limitations and frequent hospital visits. Participation in school or work was restricted for 30% of patients, affecting their social integration.

Impact of Day Care Services

Patients attending the day care center regularly for factor replacement therapy and physiotherapy reported a better QoL, particularly in terms of pain management and mobility. The availability of physiotherapy services was cited as beneficial by 65% of the cohort.

Discussion

The findings of this study align with existing literature that highlights the negative impact of hemophilia on physical and psychological well-being. Similar studies by Manco-Johnson et al. (2007) and Plug et al. (2008) demonstrated that joint damage and chronic pain are major contributors to reduced QoL in hemophilia patients. In our study, hemarthrosis was the predominant cause of physical disability, underscoring the need for early intervention and regular physiotherapy. The emotional toll of hemophilia, particularly anxiety and depression, was comparable to findings by Poon et al. (2012), who reported high levels of psychosocial distress among patients. Interestingly, our study found that access to comprehensive care, including psychological counseling, was associated with better emotional outcomes, indicating the importance of holistic care.

One of the notable findings was the significant difference in QoL between patients on prophylactic therapy and those on demand therapy. This observation is consistent with the work of Gringeri et al. (2011), who reported that prophylactic treatment significantly reduces the frequency of bleeding episodes and improves long-term joint health, leading to a better QoL.

Summary and Conclusion

This study highlights the multifaceted challenges faced by hemophilia patients in Kashmir, particularly in terms of physical disability, emotional distress, and social isolation. However, there is a need to expand access to prophylactic treatment and psychological services to further enhance the QoL of these patients. Future studies should focus on long-term outcomes and the cost-effectiveness of different treatment modalities in resource-limited settings like Kashmir.

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