

the commonest causes of fever with thrombocytopenia in our institute. In a majority of cases, thrombocytopenia was transient and asymptomatic, with only one case requiring platelet transfusion.

Epidemiology, Quality of Life and Late Effects

Ep_QoL_LE-1_V1.1

TO STUDY THE FACTORS AFFECTING QUALITY OF LIFE IN CHILDREN SUFFERING FROM HEMOPHILIA

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Background: Hemophilia is the most common severe bleeding disorder in the world caused due to a single gene mutation. India has the second largest number of Hemophilia patients in the world. Being a chronic disease, hemophilia has significant impact on the quality of life which needs to be assessed. This study was designed to assess the qol in children with hemophilia and identify the factors that predict their qol, in order to better plan and distribute the health care resources.

Material and Methods: This was a cross-sectional case control study which included 30 children suffering from Hemophilia as cases and 30 normal healthy siblings' as controls aged between 5-12 years. The quality of life assessment was performed using the Pediatric Quality of Life Inventory (PedsQoL) 4.0 Generic Core Scale. Two separate questionnaires were administered for children between age group of 5 to 7 years and 8 to 12 years. For the purpose of analysis Joint, Muscle and Intracranial bleeds were together classified as Major bleeds, whereas skin and mucosal bleeds as Minor bleeds. Data was analyzed using Stata Version 13. The means between two groups were compared using the unpaired and paired t-test (for different groups, and pre-and post-means respectively and Analysis of Variance (ANOVA) for comparison of means across more than two groups. The proportions were compared using the chi square test or the Fisher's exact test (for low expected cell counts).

Results: The mean age of the study group was 8.08 years, while that of the control group was 8.88 years. Eighty percent had Hemophilia A and 20% had Hemophilia B. Severe hemophilia was seen in 87% and 13% had moderate Hemophilia. The mean scores of the child self-report and parent proxy report (results of the questionnaire answered by the parent) of the study group was 79.81 and 72.75 respectively, which was significantly lower as compared to the control group, suggestive of impaired quality of life. The mean scores of the parent proxy report were significantly lower than the child report scores for both the study and control groups, indicating parents reporting of impaired quality of life of the affected children. Joint bleeds were present in 36.66%, 73.3% had muscle bleeds and 16.66% had intracranial bleeds. Target joints were present in 13.33%. The median number of hospitalizations was 3 from date of diagnosis till the inclusion of the patients in the study group. The quality of life was significantly affected in children with more number of bleeding episodes and with the presence of target joints. The qol was not significantly affected by the age of diagnosis, duration of illness and the socioeconomic status.

Conclusion: The Quality of Life of children with Hemophilia is significantly impaired as compared to the general population. Number of Hospitalizations, presence of target joints, number of bleeding episodes, age at diagnosis and duration of disease were associated with the quality of life of children with hemophilia and hence rehabilitation measures should be encouraged along with primary factor prophylaxis and encouraging the patients to learn home treatment to improve scores and quality of life.

Ep_QoL_LE-1_V1.2

QUALITY OF LIFE OF PARENTS OF CHILDREN SUFFERING FROM CHRONIC BENIGN HEMATOLOGICAL DISORDERS AND PEDIATRIC MALIGNANCIES

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Background: Haematological and oncological disorders are accorded a low public health priority in India, although they form a large group

collectively and have significant mortality and morbidity, accounting for immense suffering of patients and their family members. Prior research has emphasized on identifying these parental psychosocial risk factors in order to improve care and to reduce treatment abandonment, thus deliver the benefit of vastly improved therapeutic strategies in this field. This study aimed to evaluate the impact of chronic benign haematological disorders and paediatric malignancies on overall quality of life (QOL) and psychological status of parents in a low income setting and to correlate it with well-matched controls and socioeconomic status.

Methodology: We conducted a comparative cross sectional study. 94 parents of children diagnosed with benign haematological disorders and malignancies were enrolled in study group and 50 well matched parents of healthy children as control group. World Health Organization (WHO) QOL-Bref questionnaire was used for the assessment of the QOL in four domains, physical health (D1), psychological health (D2), social relationships (D3), and environment (D4) with 24 questions. This questionnaire has been translated and validated in over 40 countries. Depression Anxiety Stress Scale is a self-report instrument that quantitatively measures distress along the axes of three subscales: depression, anxiety and stress. The socioeconomic status was classified by Kuppuswamy scale which is a composite score of education, occupation and monthly income.

Results: Of 94 patients in study group, 58.5% (55) were males and 41.4% (39) were females aged 0-17 years. Of 50 patients in control group, 58% (29) were males and 42% (21) were females. The study group had 29.7% (28) cases of benign hematological disorders, 47.8% (45) hematological malignancies, and 22.3% (21) solid tumors. Mean score of QOL for study group in domains D1, D2, D3 and D4 was 50.28, 44.39, 51.09 and 42.74 whereas that of control group was 79.38, 76.32, 80.58 and 72.86 respectively. The difference was statistically significant ($p < 0.001$) in all domains. Mean depression, anxiety and stress score of the study group was 22.79, 19.77 and 22.96, whereas that of the control group was 7.1, 8.06 and 8.54 respectively and this too was statistically significant. 81.9% (77) belonged to the lower whereas 18.08% (17) belonged to the upper socioeconomic class in the study group. There was no statistical significance between the socioeconomic status of the study and the control group. The correlation between socioeconomic status and QOL was statistically insignificant in all domains except in D2 and hence QOL mostly reflects impact of the disease rather than the socioeconomic status.

Conclusion: Study group had diminished scores in all domains of QOL and were significantly more depressed, anxious and stressed. Poorer quality of life of study group was mostly due to impact of the disease rather than socioeconomic status. This study emphasizes the need to design effective interventions to aid these families and ultimately help in improving the outcome of these children.

Ep_QoL_LE-1_V1.3

METABOLIC SYNDROME IN CHILDHOOD CANCER – SINGLE CENTRE EXPERIENCE

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Introduction: Reavan in 1988 noted that several risk factors for cardiovascular diseases commonly cluster together, and he recognised them as a disease, named syndrome X, currently known as metabolic syndrome. Metabolic syndrome is a group of disorders related to insulin resistance, characterized clinically by central obesity, hyperglycemia, dyslipidemia and hypertension. There is a growing body of evidence indicating that pediatric cancer survivors are at a greater risk of developing metabolic syndrome. We studied the prevalence of metabolic syndrome in children with cancer who completed their treatment and on follow up.

Methodology: All relevant past medical data (of the disease, treatment and all events) were collected from the medical records. Tanner staging was performed, Height was measured using a Harpenden stadiometer. Weight/WAIST circumference were measured. The body mass index (BMI) was calculated as weight (kg)/(height (m)²). BMI \geq 90th centile as per CDC chart was taken as abnormal. Blood pressure was measured on the right arm of the patient. Presence of family history of diabetes, cardiovascular diseases and hypercholesterolemia were taken. Fasting Blood