QOL 11

Quality of life and health in patients with Haemophilia in Mexico

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Abstract

Introduction and Objectives: Hemophilia is a congenital bleeding disorder caused by a deficiency of coagulation factor VIII (FVIII) (in hemophilia A) or factor IX (FIX) (in hemophilia B). The deficiency is the result of mutations of the respective clotting factor genes (World Federation of Hemophilia, 2012). Trough its associated symptoms, functional limitations and treatment burden, directly impacts the health-related quality of life (HRQoL) of both patients and their families (Von Mackensen, 2007). In Mexico there is little research that contributes to the quality of life (QoL) in patients with Hemophilia. This study aimed to describe and analyze the health-related quality of life (HRQoL)of patients with Hemophilia according to the severity of the illness. Materials and methods: A sample of 56 patients with Hemophilia. Quality of life and health conditions were evaluated with the inventory INCAVISA created by Riveros, A., Sánchez, J., and Del Águila, M. (2009). The study design was quantitative, non-experimental, descriptive and transactional. Data were analysed using descriptive statistics using SPSS 21 for Windows. Levene test was used for equality of variances. Tukey test was conducted to found which specific group´s means (compared with each other) are different. Summary:27 patients with moderate Hemophilia, 21 patients with severe Hemophilia and 8 patients with mild Hemophilia. Deterioration in QoL appeared in the following areas: 50% in cognitive functions, 46.5% in attitudes to treatment, 37.5% in isolation and medically dependent individuals, 30.4% in physical performance, daily life and relationship with the health care, 28.5% in self-concept, 26.8% in relationship with family, 16.1% in free time and 10.7% in social and family networks. Significant differences according to the severity of the illness were found only in physical performance and medically dependent individuals. Using the analysis of variances, a significance was found between patients with severe and mild hemophilia (p=0.005 and p=0.037 in physical performance and medically dependent individuals respectively) and severe patients comparing with moderate patients (p=0-005 and p=0.057 respectively). Conclusions: Physical activity in patients with severe hemophilia is limited in relation to patients with mild and moderate hemophilia. Also, patients with severe hemophilia may maintain a passive attitude about their health care and feel uninterested in their illness. Psychological attention should focus on using informational and motivational techniques, social - emotional skill development, rehab, problem solving skills and cognitive restructuring.