

LA CALIDAD DE VIDA DE LOS CUIDADORES DE NIÑOS CON ENFERMEDADES CRÓNICAS: ERROR INNATO DEL METABOLISMO Y DE LA EPILEPSIA DE DIFÍCIL CONTROL

L.R. UCHÔA-FIGUEIREDO^{1,2}, A.C. PONTES¹, E.B.L. PETEAN^{1,2}

¹HOSPITAL DE LA FACULTAD DE MEDICINA DE RIBEIRÃO PRETO -HCFMRP-USP, Ribeirão Preto - SP, Brazil, ²FACULTAD DE FILOSOFÍA CIENCIAS Y LETRAS DE RIBEIRÃO PRETO – FFCLRP-USP, Ribeirão Preto - SP, Brazil

THE QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH CHRONIC ILLNESS: Inborn Error of Metabolism and Epilepsy Difficult to Control.

UCHÔA-FIGUEIREDO, L. R., PONTES, A. C.; PETEAN, E. B. L.;
Hospital of the Medical School of Ribeirão Preto - HCFMRP-USP
Faculty of Philosophy and Letters of Sciences Ribeirão Preto - FFCLRP-USP

Several studies have described the impressive nature of chronic disease on quality of life of caregivers. Objective of this study is to evaluate the quality of life of caregivers of children with chronic diseases, epilepsy and difficult to control Inborn Error of Metabolism (IEM). Thus, 71 caregivers were assessed, and 50 with epilepsy and 21 with EIM at least two years of care, whose children are accompanied in the child neurology service HCFMRP-USP, of both sexes, aged up to 12 years. Whose onset of illness occurred before the three (3) years of age of the child and at least two (2) years. Data collection was conducted in a meeting and used the instrument of quality of life, developed by OMS, WHOQOL-bref, The analysis of the instrument was made using the SPSS statistical program and the data were correlated with the variables of characterization the sample: age, family income, education and length of care, through the technique of Squares. The satisfaction with their quality of life, for both caregivers of children with epilepsy as EIM, was low in all areas assessed, particularly in social relations. Relations with age and family income, for both diseases, was directly proportional, however, the time of care that relationship has been on a reverse for caregivers of EIM and proportional in the case of epilepsy. It is concluded that the child's illness interferes in the daily life and relationships of caretakers and directly in the quality of life of caregivers, indicating the importance of supportive information, techniques and exchange of experiences provided by a multi-professional team is also emphasized and in particular the intervention of the Occupational Therapy.