GENETICS AND GENODERMATOSES

QUALITY OF LIFE EVALUATION IN EPIDERMOLYSIS BULLOSA – QUESTIONNAIRES FOR PATIENTS AND FAMMILIES OF PATIENTS.

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Introduction: Epidermolysis Bullosa (EB) is a group of skin and mucous membranes blistering genetic diseases associated, with gene mutations for keratin, laminin and collagen. EB can be classified into four main types based on the layer of the skin affected: EB simplex (EBS), junctional EB (JEB), dystrophic EB (DEB), and the recently added Kindler syndrome (KS).

Objective: The aim of the study was to examine the quality of life among patients of EB and parents of patients with EB using worldwide questionnaires supplemented with author's questions.

Materials and Methods: The study was based on two questionaires: EB- specific quality of life (QOLEB) and Dermatitis Family Impact Questionnaire (DFIQ) in the Polish language version. The questionnaire was available online and placed on the DEBRA-national charity that supports individuals and families affected by EB.

Results: A total of 73 responses to questionnaires were obtained (20 EB patients and 53 family members). In our study 14 (70%) patients suffering from DEB and 3 (15%) suffering from JEB and 3(15%)EBS. Based on the results of questionnaires for EB patients- the majority of patients (55%) defined the disease as moderate, then severe (40%). Among patient with EB woman (60%) were more than men; the highest group of patients were suffering from DEB subtype (74%). Among the parents, there were also more woman (69%) than men and the most DEB's parents fullfiled questionnaire.

Conclusions: We can conclude, that overall women are more likely to respond to the questionnaire and to cooperate. Polish EB have greater negative impact in Polish population of EB patients versus Dutch and Brazilian population.
Moreover, in can give profit for the family of the patient, providing data of how the disease affects the family life.