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Quality of Life and Clinical Characteristics in a cohort of pediatric patients with hereditary angioedema due to C1-inhibitor deficiency

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Introduction

Hereditary angioedema (HAE) is a rare genetic disease characterized by recurrent attacks of angioedema. Evidence to what extent it affects patient functioning is limited in the pediatric population.

Aim

We aimed to determine the clinical characteristics and management of Polish children with HAE and to measure the health-related quality of life (HRQoL) of these patients.

Material and methods

This cross-sectional study was conducted among 21 pediatric patients and their caregivers, and respective 21 controls randomly selected from the general population. During routine follow-up visits, standardized pediatric quality of life questionnaires (PedsQLTM 4.0) were administered to all caregivers and adolescents (≥13 years). Caregivers also completed a structured medical interview regarding clinical characteristics and treatment of children with HAE during the previous six months.

Results

During this period, 57% of patients had low (group I), 24% moderate (group II) and 19% high (group III) HAE activity, corresponding to ≥10 attacks per 6 months. None of the patients

received long-term prophylaxis. Children in group III had lower HRQoL than other groups and controls on all dimensions of the PedsQLTM 4.0. The lowest scores in all groups were observed in the emotional functioning domain.

Conclusions

Our data demonstrate that the burden of HAE on the quality of life of children and their families encompasses a wide range of daily functioning.

Konflikt interesów: Autorzy nie zgłaszają konfliktu interesów.

Praca nie była do tej pory prezentowana na Międzynarodowym Kongresie PTA