

Health-related quality of life and socioeconomic situation among diastrophic dysplasia patients in Finland

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Objective: The purpose of the present study was to gain a comprehensive view of the quality of life and socio-economic conditions in a more representative sample of patients with diastrophic dysplasia than previously presented.

Methods: The study sample comprised 115 patients with diastrophic dysplasia, aged over 18 years. The patients were contacted, and 68 patients (59%) agreed to participate in the study. They answered a structured questionnaire, which included the items of RAND-36 and Finn-Health Assessment Questionnaire (Finn-HAQ) questionnaires. The Finn-HAQ items were linked to the categories of the International Classification of Functioning, Disability and Health (ICF). Population controls for matching the participating patients for age and sex were identified in the Finnish population registry. Demographic and social factors (educational status, employment status and household income) were collected in separated questions.

Results: RAND-36 showed significantly lower physical functioning in the group of diastrophic dysplasia patients than in the control group. Also, the differences in scores for energy and social functioning were significant. In the mental component scales, no significant difference was found between the groups. When compared with the controls, we found significantly lower levels in all 3 ICF components of functioning in the group of patients when Finn-MDHAQ items linked to ICF were used. Almost 75% of patients with diastrophic dysplasia belonged to the group of people with minor/low income. Some or clear worsening of economic situation due to diastrophic dysplasia was reported by 25 (58%) female and 17 (68%) male patients.

Conclusion: In their daily living, patients with diastrophic dysplasia have marked physical difficulties, which affect their quality of life, participation in society and their financial situation. It seems that the mental situation is not greatly affected, but a more detailed study is needed to evaluate and illuminate the psychological consequences of this severe skeletal dysplasia. Overall, the pieces of information in the present study are of high importance when designing and reorganizing rehabilitation and in supportive therapy and treatment of patients with diastrophic dysplasia.

Biography

Liisamari Krüger has completed his Ph.D. at the age of 36 years from Nuernber-Erlangen University in Germany and postdoctoral studies from Helsinki University School of Medicine. She is the co-director of Rehabilitation-Center Orton in Helsinki, Finland. She has published scientific articles.

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