Allied Health Professionals in Rheumatology (AHP) Abstracts

27. Paediatric rheumatology

WHAT DOES IT MEAN TO GROW UP WITH JUVENILE IDIOPATHIC ARTHRITIS?

D. Hilderson [1, 2,*], L. Eyckmans [1], R. Westhovens [3], C. Wouters [4], P. Moons [2]
[1]Department of Paediatrics, [3]Rheumatology, Department of Musculoskeletal Sciences, [4]Department of Paediatric Rheumatology, University Hospitals Leuven, [2]Centre for Health Services and Nursing Research, Katholieke Universiteit Leuven, Leuven, Belgium

Are you applying for a Travel Bursary?: Yes

Background: Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in childhood which typically starts before the age of 16. More than one-third of youngsters with JIA still experience active disease with significant morbidities in adulthood (1). Several studies using a quantitative design have shown a potential large impact of JIA on health related quality of life (2,3).

Objectives: The aim of the present study was to investigate what it means to afflicted adolescents/young adults to grow up with JIA using a qualitative approach.

Methods: A qualitative study was conducted using semi-structured, in-depth interviews of 11 patients with JIA. Patients were eligible for inclusion if they were between 18 and 30 years of age, if they were treated and followed up for JIA at the University Hospitals Leuven (Belgium). Selection of the patients was based on a purposive sampling technique. Interviews were tape-recorded and transcribed verbatim. Data were analysed using procedures inherent to the grounded theory approach.

Results: Five main themes emerged: physical impact, medication, relationships and family, friends, and perceptions of their future. The physical impact of JIA involved functional limitations, pain, and fatigue. Participants reported that their functional limitations had an impact on school participation and physical education; on activities of daily living, hobbies, and engagement in sports as well on job participation. These patients mentioned that their pain threshold had changed over the course of the disease: they also learned to moderate. Concerning fatigue, they learned to cope with fatigue by avoiding activities, setting boundaries, and using aids. Taking medication properly was difficult; side effects were seen as a problem. With regard to relationships and family, JIA affected the youngsters in their roles as family members and affected intimate relationships, their thinking about pregnancy and raising children. Indeed, the majority of the patients were afraid to become pregnant or to have kids. Most patients found friends who understood their situation and who were considered a big support. Some patients were afraid of what the future would bring.

Conclusion: A better understanding of the psychosocial needs of adolescents with JIA and getting insight into what it means to grow up with this condition will assist healthcare professionals to target interventions that are timely and effective in transitional care to adulthood. Different quantitative studies have highlighted the effect of JIA on various domains of health-related quality of life. This qualitative approach allowed us to reveal how the adolescents manage to cope with JIA throughout the disease course.

References: 1. Huygen ACJ, Kuis W, Sinnema G. Psychological, behavioural, and social adjustment in children and adolescents with juvenile chronic arthritis. Ann Rheum Dis 2000; 59: 276 – 282.

2. Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID: Outcome in adults with juvenile idiopathic arthritis: a quality of life study. Arthritis Rheum 2003; 48(3):767-75.

3. Duarte-Salazar C, Guzman-Vazquez S, Soto-Molina H et al.: Disability impact on quality of life in Mexican adults with juvenile idiopathic arthritis and juvenile ankylosing spondylitis. Clin Exp Rheumatol 2007; 25(6):922-7.

Has this abstract been identically presented or published before?: No

Would you be interested to discuss your poster with the Topic Chair during one of EULAR's Poster Tours: Yes

Disclosure of Interest: None Declared