

Different diagnosis – different challenges in work participation?

Diagnostic issues in work participation in persons with Marfan syndrome (MFS) and congenital unilateral upper limb deficiencies (UULD).

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Background: In the clinical work we experience that different diagnosis may cause different challenges in work participation. Therefore, two studies with similar design and questionnaires were conducted at TRS of two diagnoses at the same time. UULD is a congenital, visible condition with deficient development of fingers / hand / arm. MRF is severe hereditary connective tissue disease that may cause aorta, visual and/or skeletal problems, and the physical limitations are barely visible and the symptoms are fluctuating. The purpose of this paper is to compare and discuss the differences and similarities of the challenges of work participation of having UULD and Marfan syndrome.

Methodological approach: The studies were initiated and conducted in co-operation with the User- Associations. A study-specific questionnaires, including questions about demographic characteristics, clinical features, chronic pain, fatigue (FSS) and issues related to education and work participation, were sent to all adults (20-67 y) registered with UULD and MFS at TRS.

Main findings: The demographical data were almost similar for UULD and MFS: mean age 40,5 y, more than half had higher educational level, about 30/40 % received partly of full disability pension, few had received vocational guidance and adaptations in work before retiring. Many reported chronic pain and severe fatigue. Factors significantly associated with reduced work participation were for UULD- increased age and reduced physical function, for MFS- increased age, lower education level and high fatigue

Conclusions and implications: The studies indicate that the perceived symptoms of the UULD and MFS give different challenges in work participation. Visible physical limitations may easily be remedied with physical adaptation and assistive devices, but adaptations in relation to invisible and fluctuating issues as fatigue and pain, are difficult. The particular challenges of different diagnoses are important to take into account when work-rehabilitation programs are developed.