Challenges in work participation when lacking one arm, as congenital unilateral upper limb deficiencies (UULD).

Heidi Johansen OT, MSc[1], Liv Øinæs Andersen FT[1], Trine Bathen OT MSc[1], Svend Rand-Hendriksen MD, PhD[1,3], Kristin Østlie MD, PhD[2]
[1] TRS, National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Nesodden, Norway.
[2] Innlandet Hospital Trust, Department of Physical Medicine and Rehabilitation, Ottestad, Norway.
[3]Institute of clinical medicine, Faculty of Medicine, University of Oslo.

Contact person: Heidi.johansen@sunnaas.no

Background: The Norwegian Limb deficiency Association (NLDA) and professionals working with persons with congenital limb deficiency (CLD) have raised the suspicion that persons with UULD have a high prevalence of musculoskeletal pain and high prevalence of early disability pension compared with the Norwegian general population.
The purpose was to investigate challenges in work participation in adults with UULD and to examine how demographic and clinical features may influence work participation.
Methodological approach: A study-specific questionnaire including questions about demographic characteristics, clinical features, chronic pain, health related quality of life (SF-36) and fatigue (FSS) was developed in cooperation with the NLDA and sent to adults with UULD registered in TRS National Resource Center for rare disorders in Norway.
Major findings: Response rate was 52% (n=73), mean age was 41.0 (range 20-67) years and 69% were women. Near half had formal education ≥ 12 years, 26% had practical education/certificate. Less than half (45%) were employed full time and 15% received disability pension. Chronic pain was reported by 63%, severe fatigue by 32%. One quarter had sedentary work, while 15% had work that was physically demanding. Relatively few had received vocational guidance. Mean age for leaving work was 43 years. Reduced physical functioning and old age were the factors with highest significant association to lower work participation, not chronic pain (p=0.273) or fatigue (p=0.550).
C**onclusions and implications:** Adults with UULD may experience challenges related to work participation. A considerable portion had chosen practical education and practical professions, few had received vocational guidance and several quit work before retirement age. Reduced physical function was the most important factor related to low work participation. In future, rehabilitation programs for adolescents and adults with UULD should emphasize educational and work aspects, factors that may prevent reduced physical function, and include individualized vocational guidance.