Reference	Johansen H, Østlie K, Andersen L, Rand-Hendriksen S.						
	TRS National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospi- tal, Nesodden, Norway, Health-related quality of life in adults with congenital unilateral upper limb deficiency in						
	Norway. A cross-sectional study						
	Disabil Rehabil. 2016 Nov;38(23):2305-14.						
Study Population	Adults with upper limb congenital deficiency vs. able-bodied controls						
Major Findings	 The adults with upper limb congenital deficiency showed: 11% reduced physical health compared to able-bodied controls. 13% increased bodily pain compared to able-bodied controls. Strain and overuse problems due to strenuous compensatory techniques may first appear in adulthood. SF-36 mean score for adults with unilateral congenital upper limb deficiency and able-bodied norms 100 </td						
	Provision Social Section Activity Nerval Component						

Norwegian general population

Congenital unilateral upper limb amputees

All four physical subscales (physical functioning, role physical, bodily pain, and general health) as well as physical component summary, and two of four mental subscales (vitality and social functioning) were statistically lower in adults with upper limb congenital deficiency compared to able-bodied controls (p<0.05). The highest impact was observed in bodily pain category.

Population

Subjects: Previous prosthesis: Amputation causes: Mean age: Mean time since first fitting:

77 adults with congenital unilateral limb deficiency not reported 77 congenital malformations 42.7 years not reported

Study Design

Observational, cross-sectional study

The objective of this questionnaire-based study was to compare health related quality of life of adults with congenital unilateral upper limb deficiency with age and gender matched control group from Norwegian population.

Results

Body Function		Activity	Activity			Others	
	Pain	Grip patterns / force	Manual dexterity	Activities of daily living (ADL)	Satisfaction and Quality of life (QoL)	Training	Technical aspect

Category	Outcomes	Results for adults with upper limb congeni- Sig.* tal deficiency vs. able-bodied controls			
Satisfaction and Quality of life (QoL)	SF-36	All four physical scales (physical function- ing, role physical, bodily pain, and general health), as well as physical component summary, were statistically lower in adults with compared to normative data.			
	Two of four mental scales (vitality and s cial functioning) were lower in adults w upper limb congenital deficiency compa to able-bodied controls.				
		Lower health related quality of life was associ- ated with parenthood, living with a partner, comorbidity and chronic pain.	-		
		Higher health related quality of life was found in those who reported being students or work-ing.	+		

* no difference (0), positive trend (+), negative trend (-), significant (++/--), not applicable (n.a.)

Author's Conclusion "In this study of Norwegian adults with unilateral upper limb deficiency most of them had left sided, transverse, below elbow deficiency. A significant fraction of the total study population showed reduced health related quality of life in most subscales, mostly in the physical health domain, when compared to the general population. The effect of the unilateral upper limb deficiency to the health related quality of life seemed to be mediated mainly by changes on occupational status, occurrence of comorbidity and pain. Professionals who meet adults with unilateral upper limb deficiency must be aware of reduced the health related quality of life, especially in physical health domain. Individual adaptive measures that may prevent pain and loss of function (grip-improving devices, adapted environment, adapted physical exercise, pain management programs) should be implemented early and might prevent reduced health related quality of life." (*Johansen et al. 2016*).

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