Possible relevant studies found in databases n=87

Exclusion after screening for inclusion and exclusion criteria (n=70)

Studies relevant for review n=17

Excluded after screening full text (inappropriate patient group) (n=2)

Studies included n=15

Michielsen A., Wijk Van I., Ketelaarc M.
Rudolf Magnus Institute of Neuroscience and Centre of Excellence for Rehabilitation Medicine, University Medical Centre Utrecht and Rehabilitation Centre De Hoogstraat, Utrecht, The Netherlands

Participation and quality of life in children and adolescents with congenital limb deficiencies: A narrative review


Quality of Life
Participation
Psychosocial

13% Quality of life was similar between children with unilateral upper limb deficiency and the general population.
13% The prosthesis wearers had higher quality of life with respect to school functioning than non-wearers.
87% Children with limb deficiency demonstrated greater behavioural and emotional problems and lower social competence than the normative sample, but these results were not observed with myoelectric prosthesis.

Thirteen studies (87%) focused on psychosocial adaptation in children and adolescents with limb deficiencies. Participation had only been studied in two studies on different aspects like sports and going to school, but not as a concept of overall functioning. Quality of life was addressed in only one study.

Subjects: 21 - 489 children with congenital limb deficiency
Previous prostheses: n.a.
Amputation aetiology: congenital malformation
Age (range): from 8.4 to 14.8 years
Time since amputation (range): from 8.4 to 14.8 years

A narrative review:
Included publications: Cross-sectional studies (15)

Quality assessment: The 15 included studies were all classified as cross-sectional descriptive studies with low methodological quality. The included literature spanned the years from 1988 to 2006.

### Results

<table>
<thead>
<tr>
<th>Body Function</th>
<th>Activity</th>
<th>Participation</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mechanics</td>
<td>Pain</td>
<td>Grip patterns / force</td>
<td>Manual dexterity</td>
</tr>
</tbody>
</table>

#### Satisfaction and Quality of Life (QoL)

- Quality of life was found to be similar between children with unilateral upper limb deficiency and the general population.
  - Supporting publications: 1, Level of confidence: n.a.

- Quality of life was found to be similar when comparing children with unilateral upper limb deficiency wearing a prosthesis with children not wearing a prosthesis, with the exception of school functioning (significant higher quality of life was reported for prosthesis wearers compared with non-wearers).
  - Supporting publications: 1, Level of confidence: n.a.

- Eleven to twenty-year-old children with unilateral upper limb deficiency felt significantly happier than children in the general population, regardless of prosthesis use.
  - Supporting publications: 1, Level of confidence: n.a.

- Children with limb deficiency were not significantly different in how they perceive their physical appearance, social support, and their self-esteem compared with the general population.
  - Supporting publications: 13, Level of confidence: n.a.

- Children with limb deficiency were not more depressed and they do not experience a greater number of hassles than physically healthy peers.
  - Supporting publications: 13, Level of confidence: n.a.

- Children with limb deficiency demonstrated greater behavioural and emotional problems and lower social competence than the normative sample. In the subgroup of children fitted with myoelectric upper limb prosthesis no such symptoms were reported.
  - Supporting publications: 1, Level of confidence: n.a.

#### Activities of daily living (ADL)

- No significant differences were found in children with unilateral congenital upper limb deficiency in the domains "sports/physical function", "happiness" and "global function" when compared to the general population.
  - Supporting publications: 1, Level of confidence: n.a.

- No significant differences were found in the domains "sports/physical function", "happiness" and "global function" between unilateral upper limb prosthesis wearers and non-wearers.
  - Supporting publications: 1, Level of confidence: n.a.

* no difference (0), positive trend (+), negative trend (−), significant (++/−−), not applicable (n.a.)
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Author's Conclusion

“This review reveals a lack of knowledge on how children with congenital limb deficiencies participate and how their QoL is perceived. Their psychosocial functioning, although described as at risk, appears to be comparable to healthy peers. Participation and QoL are relatively new concepts in rehabilitation medicine and can be considered as key outcomes. Nowadays different measurement tools are available to measure both concepts. Children and adolescents with congenital LD are a considerable diagnosis group in rehabilitation medicine and therefore further studies are required to describe how they participate and how they perceive their QoL. This is important to guide the development of interventions to promote optimal participation and QoL in this population. Furthermore, identification of factors that influence participation and the relationship with QoL in children and youth with limb deficiencies needs to be explored. (Michielsen et al. 2006).”