FUNCTIONING OF CHILDREN WITH UNILATERAL CONGENITAL BELOW ELBOW DEFICIENCY: AN ONLINE FOCUS GROUP STUDY

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Introduction

Children and adolescents with unilateral congenital below elbow deficiency (UCBED) seem to function quite well in daily life¹⁻³. However, current literature does not give insight into actual functioning of these children. Furthermore, it is unknown how the children and adolescents themselves think about their functioning. Functioning encompasses activity and participation according to the Child and Youth Version of the International Classification of Functioning (ICF-CY)⁴. Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may experience in the involvement in life situations. According to the ICF-CY, both environmental and personal factors can affect activity and participation, and thus someone’s functioning.

Aim of the study:

The first aim was to evaluate whether children and adolescents with UCBED experience activity limitations and participation restrictions and if they do, how they deal with those limitations and restrictions. Secondary aims were to examine differences in activities and participation for different age groups and to compare the perspectives of children, their parents and health professionals.

Patients

Children with UCBED aged 8-12, 13-16, and 17-20 years, parents and professionals participated in the study. Participants were recruited from several rehabilitation centers in the Netherlands. Furthermore, participants were invited to take part in the study through websites of patient organizations.

Methods

A qualitative study design was applied by using Online Focus Group interviews⁵. The interviews were held in the asynchronous form, meaning that participants could decide themselves when to log in and take part in the online discussions within a time frame of seven days. The online focus group interviews were held on a secured website containing five separate forums, one forum for each group of participants. During the first five days of the week, at the beginning of each day, a question was posted on the forums. Discussion topics were activities, participation, prosthesis use, emotional functioning and rehabilitation care. During the last two days, the participants had the opportunity to bring in their own discussion topics. The framework approach was used for data analysis.

Results

878 postings were received from 17 children of 8-12 years of age, 13 teenagers of 13-16 years of age, 12 adolescents of 17-20 years of age, 17 parents and 19 professionals. Having a short arm did not prohibit execution of any activity, but not all children were able to perform all activities. The children en parents mentioned numerous creative strategies to deal with a short arm. Although people in the direct (internal) environment of the child, such as parents and friends, can be supportive, it was remarkable how often people in the indirect (external) environment of the child were mentioned as a reason for a limited functioning of a child with UCBED. People in the external environment judge a child’s capacity without having sufficient knowledge about their abilities. Environmental factors were especially decisive in transitional phases, like going to a new school or applying for a new job. Personal factors also influenced the children’s and adolescent’s functioning. Not all children had the same cognitive or motor abilities, react in the same way emotionally or behave in the same way in social situations. Parents were positive about the functioning of their children. Overall, parents did not think their child experienced many limitations. Health professionals described fewer strategies to deal with limitations and emphasized benefits of prostheses more than other participants.

Conclusions

Children with UCBED don’t feel disabled, but environment can make them feel that way, especially in transitional phases. They have numerous strategies to deal with their deficiency. Prostheses are a minor solution to overcome limitations.

References


