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ORIGINAL REPORT

ACTIVITY AND PARTICIPATION OF CHILDREN AND ADOLESCENTS WITH UNILATERAL CONGENITAL BELOW ELBOW DEFICIENCY: AN ONLINE FOCUS GROUP STUDY

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Objective: **To assess whether children/adolescents with unilateral congenital below elbow deficiency experience activity or participation limitations and how they deal with those limitations.**

Methods: **A qualitative study using online focus group interviews was held with 42 children/adolescents (in 3 age groups: 8–12, 13–16, and 17–20 years), 17 parents and 19 health professionals. Questions were posted concerning activities, participation, prosthetic use, psychosocial functioning, and rehabilitation care. This study concerns the first two topics; activities and participation.**

Results: **Children/adolescents experienced only a few limitations, and there were no activities or participation situations that were impossible. The limitations experienced could be attributed mainly to environmental factors, e.g. people who lack knowledge of the child's capacities. Those factors were particularly decisive in transition phases. Children/adolescents and parents described numerous strategies applied to deal with the deficiency. Professionals described fewer strategies and emphasized the use of adaptive devices and prostheses more than other participants did.**

Conclusion: **Having unilateral congenital below elbow deficiency did not interfere with any activity, but not all children/adolescents had the ability to perform all activities. The strategies described by children/adolescents in managing their deficiency should be integrated into healthcare by providing realistic education about the various creative solutions and possibilities of adaptive devices and prostheses, and should be combined with specific training.**

Key words: unilateral congenital below elbow deficiency; online focus group interviews; functioning; activities; participation.

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INTRODUCTION

For two-handed people, daily functioning with one hand might appear difficult, but is this in fact the case? Some studies of the functioning of children and adolescents born with only one hand (unilateral congenital below elbow deficiency; UCBED) have shown otherwise. Obviously, being born with one hand is very different from a two-handed person using only one hand, but it appears that children and adolescents with UCBED are able to function quite well in daily life (1–3). But how do they actually function? And how do children and adolescents themselves think about their functioning? The current literature does not provide the answers. As such, it is necessary to investigate the functioning of children and adolescents with UCBED in a different way from with the standardised measurement instruments that are generally used. Therefore, this study presents qualitative research into the functioning of children and adolescents with UCBED. The qualitative data, combined with what has been found earlier with standardised measurement instruments can provide a complete picture of how children with UCBED function.

For the purposes of this study, we define functioning according to the Child and Youth Version of the International Classification of Functioning, Disability and Health (ICF-CY) (4), in which functioning encompasses, among other factors, activity and participation. Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may experience in involvement in life situations. According to the ICF-CY, both environmental and personal factors can affect activity and participation, and thus affect someone's functioning (4).

Although it is known that persons with UCBED may be able to perform an activity with or without a prosthesis, age seems to be an important factor in the functioning of children and adolescents using prostheses. Prosthesis wearers younger than 12 years perform more activities with the active grasping function of their prosthesis compared with older children (1).

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Furthermore, older children appear to use their prosthesis for different activities than younger children (1).

Differences in the perspectives between children with UCBED and their parents on functioning have been revealed previously (5). Parents of children with UCBED underestimated the functioning and overestimated the comfort of children with UCBED, compared with the children's own rates (5). A qualitative study into the experiences and needs of children with UCBED and their parents indicated that the inclusion of health professionals could provide extra information (6).

The first aim of this study 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.

METHODS

Study design

A qualitative study design using online focus group interviews was chosen. Online focus group interviews are an effective method for gathering people's opinions and experiences regarding disability and healthcare (7, 8). The online focus group interviews were held in the asynchronous form, meaning that participants themselves could decide when to log in and participate in the online discussions within a certain period of time (7). For these asynchronic focus groups, between 8 and 15 participants per discussion are recommended (9–13). Therefore, the aim of this study was to include approximately 12 participants in each group.

Participants

Children and adolescents in the age range 8–20 years were included in the study. From the age of 8 years children were considered to be able to share their opinion with others using a computer. The upper age limit of 20 years was chosen, because at this age adolescents were considered to have passed puberty and to have chosen their secondary or higher education. Children and adolescents were eligible for the study if they had a UCBED at the transradial level that was not caused by a syndrome. Both prosthesis wearers and non-wearers were included. In addition to the children and adolescents with UCBED, parents of these children and health professionals who work with this population also participated in the study. The children and adolescents were divided into 3 age groups: 8–12, 13–16, and 17–20 years. In the Netherlands, these age groups correspond to children at primary school, secondary school and secondary or higher education, respectively. Children, adolescents, and their parents were recruited from 4 rehabilitation centres in the Netherlands and from patient organisations. Assuming a 50% response rate, 24 possible participants per participating group were approached. One-third of the children and adolescents also received an invitation for their parent to participate. The aim was to include an equal distribution of age, gender, prosthesis wearers/non-wearers, and referring centre among the (parents of) children and adolescents. Parents could join the study independently from their children. Professionals were recruited from several rehabilitation institutions and orthopaedic workshops in the Netherlands. Rehabilitation physicians of cooperating rehabilitation centres were asked to distribute information packages over to their rehabilitation team (equal distribution of specialties). The study was approved by the medical ethics committee of the University Medical Center Groningen, the Netherlands (file number M09.079327). Written informed consent was received from all participants who participated in the online focus group interviews. In the case of minors, the parents/guardians gave informed consent.

Procedure

The online focus group interviews were held on a secured website containing 5 separate forums, 1 for each group of participants. The forums were open for discussion for 7 consecutive days. Participants who did not log in on the first research day were sent a reminder by e-mail on the second day. During the first 5 days of the week, at the beginning of each day, a question was posted on the forums (Table I). During the 2 weekend days, following the study-week, the participants had the opportunity to introduce their own discussion topics. Participants were asked not to use their own names or to mention the names of their rehabilitation centres or health professionals, in order to keep the discussions anonymous. During the entire week, two moderators (IdJ and HR-M) were participating in all forums continuously from 08.00 h to 23.00 h. The role of a moderator was to observe the discussions, to check that participants kept to the rules, and, especially, to post additional questions to provoke discussion and to obtain a greater in-depth insight into the answers of the participants. Both moderators were researchers in the field of child and hand rehabilitation. Furthermore, during the interviews, the moderators had extensive contact with a rehabilitation physician with great experience in working with this particular group of patients.

The topics offered during the study-week were: (*i*) activities, (*ii*) participation, (*iii*) prosthetic use or non-use, (*iv*) psychosocial functioning, and (*v*) rehabilitation care. This paper concerns the first two topics; activities and participation.

The questions corresponding to the topics were similar for all groups of participants; only the formulation of the questions was adjusted per group (14, 15) (Table I). Parents and professionals were asked to formulate their remarks from the child's perspective, in order to be able to compare the perspectives of children, parents and health professionals.

Data analysis

For analysing the qualitative data, a framework approach was used (16). This approach takes the formulated research questions into account, as well as new issues raised during the online focus groups. Thus, the framework approach can be characterised as both inductive and deductive in nature (16). A thematic framework was designed consisting of subjects mentioned frequently, clustered into themes related to the research questions. Ten percent of the data was analysed by two of the authors (IdJ and HR-M). They discussed the results, and as soon as consensus was reached and final adjustments and additions had been made to the thematic framework, one author (IdJ) further indexed the remaining 90% of the data. The labelled pieces of text were placed into a matrix, in order to gain an overview of participants' reactions on several topics.

RESULTS

A total of 77 participants participated in the online focus groups. In every group of participants, the pursued response

Table I. *Questions posted on the forum during online focus group interviews (formulated for children 8–12 years)*

Topic	Question
1. Activities	Tell us how you do the things others use 2 hands for?
2. Participation	Tell us if you can always take part in the things you want? Or do you sometimes choose differently because of your short arm? Can you give an example?
3. Prosthesis use	Tell us why you do or do not wear a prosthesis?
4. Personal functioning	Tell us how you feel about being different from other children because of your arm?
5. Rehabilitation care	Tell us how you appreciated the rehabilitation team and technicians? Do you have points of improvement for them?

Table II. *Characteristics of participants of online focus groups*

Group	Response rate *n* (%)	Gender Male/female	Age, years Mean (SD)	Wearers *n* (%)	Never wore prosthesis *n* (%)
8–12 years	17 (68)	9/8	9.9 (.3)	2 (12)	6 (40)[b]
13–16 years	13 (52)	3/10	14.9 (1.4)	6 (46)	0 (0) [b]
17–20 years	12 (48)	4/8	18.3 (1.1)	5 (42)	0 (0) [b]
Parents	16 (64)	10/6[a]	12.7 (3.8)[a]	1 (6)[a]	5 (33)[a,b]
Professionals	19 (76)	8/11	–	–	–

[a] Characteristics of the children of participating parents.

[b] Non-wearers who never tried wearing a prosthesis.

SD: standard deviation.

rate was achieved (Table II). The 19 health professionals included 5 rehabilitation physicians, 6 prosthetists, 6 occupational and physical therapists, and 2 psychologists. Seventeen professionals were distributed equally over the 4 cooperating rehabilitation centres (5; 5; 4; 3). The remaining 2 professionals were employed at 2 other institutions. All included health professionals had at least 5 years of experience with rehabilitation of children with UCBED.

During the study week, there were high numbers of postings for each group on each topic (Table III).

Children and adolescents

Most children and adolescents did not experience limitations. They function as well as their peers, and are able to do all the things they like. For example, these two quotes underline this:

> *"I can't think of anything my friends do in which I cannot participate."* (18 year-old girl, wearer)
>
> *"I don't want to have 2 arms anymore; because I'm so used to it. And if I did have 2 arms, it would be very hard for me to learn everything you can do with 2 arms. I can simply do everything with my 1 arm and my short arm."*
> (13 year-old girl, non-wearer)

Most children and adolescents did not encounter limitations in self-care, school and leisure-time activities, sports, and playing musical instruments (Table IV). Children and adolescents said that they were perfectly able to participate in most situations. They described that they were able to participate in several sports clubs, make friends, go to the school of their choice, and have a side job (Table IV). It is notable that Table IV shows how children experience their functioning, and that it is not an assessment of actual performance. It should also be noted that it is possible that children with UCBED choose the activities they are capable of. Some children reported that this was the case for them and that they would have chosen other activities if they had had two hands. There were also children who did not take their short arm into consideration; they just chose the activities they liked to do and did not experience limitations in doing so.

However, not all participants succeeded in performing all activities or participating in all social situations. Activities that caused limitations for some participants were physical exercises, such as performing a handstand or a cartwheel, rope climbing, and exercises in rings. Ewampels of activities in which some participants were limited were tying shoelaces, judo, and playing guitar.

The limitations experienced were induced mainly by people in the child's environment, since they made judgements on the capabilities of the child or adolescent without any knowledge of these capabilities. This can be illustrated by two examples:

> *"Sometimes, I feel disappointed when doing physical exercises in school. My previous teacher thought of something else for me to do, for example when the rest had to do gymnastics. Now, I just sit on the side and do nothing."* (14 year-old girl, wearer)
>
> *"Recently, I had a bad experience with an interview for a job on the side. I got rejected for the job, purely based on prejudices with regard to my short arm. I felt so powerless."* (20 year-old girl, non-wearer)

Another reason for limitations was that the correct adaptive device or prosthesis could not always be made, which led to participation restrictions in, for instance, sports:

> *"I've tried to play hockey with my arm prosthesis, but it turned out to be very difficult, since I'm left handed and the adaptive device could not be fitted to a left-handed hockey stick."* (8 year-old girl, wearer)

Table III. *Number of postings during online focus group interviews*

	Children and adolescents, age groups					
Topics	8–12 years	13–16 years	17–20 years	Parents	Professionals	Total
Activities	34	29	24	31	34	152
Participation	38	43	48	32	24	185
Prosthetic use	50	44	44	34	28	200
Personal functioning	43	35	30	34	25	167
Rehabilitation care	29	26	16	22	27	120
Own topics	11	14	3	19	7	54
Total	205	191	165	172	145	878

Table IV. *Activities and participation situations mentioned during the online focus group interviews*

	Activity mentioned during interviews?				
	Children and adolescents, age groups				
Categories of activities (with examples)	8–12 years	13–16 years	17–20 years	Parents	Professionals
Self-care					
To butter bread, cut food, use cutlery, open a bottle, peel an apple, cook	o/×	o/×	–	o/×	–
To wash hair, make a ponytail	o/×	–	–	×	o/×
To put on a jacket, get dressed, close and open zip and buttons, tie shoelaces	o/×	o/×	o	o	×
School					
School activities; to cut, write, type	o	o	o	o/×	×
Physical exercises					
Rope climbing, swinging in rings	o/×	o/×	o/×	o/×	×
Gymnastics; handstand, cartwheel, bar	o/×	o/×	–	–	–
Ball games	×	o	×	×	–
Music					
Instruments					
Keyboard instruments; piano	o	o	o	o	–
Percussion instruments; drums, djembé	o	–	o	o	–
Wind instruments; trumpet, horn, panpipes	–	o	o	×	–
Stringed instruments; cello, guitar	–	–	o/×	–	–
To perform (on stage, give shows)	–	–	–	o	–
Sports					
Ball sports					
Field ball sports; soccer, handball, volleyball, korfball	o	o	o/×	o	o
Bat-and-ball; tennis, hockey, badminton	o	o/×	o	o	o/×
Target ball sports; golf, billiards	o	–	o	–	–
Dance; street-dance, jazz-dance, hip-hop	o	o/×	o	–	–
Martial arts; karate, taekwondo, judo	o/×	–	–	o/×	×
Snow sports; skiing	o	–	–	o	–
Skating sports; inline skating, speed skating	–	o	–	o	–
Water sports; swimming, snorkelling	o	–	–	o	–
Gymnastics; artistic gymnastics, majorette	–	o	–	–	o
Horse riding	o	o	o	o/×	–
Climbing	–	–	×	o	–
Leisure-time activities					
Inside activities; gaming, using the computer, tinkering, playing with Lego	o/×	o	o	o/×	×
Outside activities; skateboarding, rope jumping, playing with marbles	o	–	–	o	–
Social activities: going out, participate with friends, making contact with new people, flirting, relationships	o	o	o/×	o	×
Transport: cycling, driving a scooter, driving a car	o/×	o	o	o/×	o/×
Education: academy of arts, photography, computer science, education with children, university	–	–	o/×	–	×
Side job: in a store, cashier, postman, baby-sitter, restaurant	–	o	o/×	o	×

–: not mentioned at all; o: mentioned as causing no limitations; ×: mentioned as causing limitations; o/×: mentioned as causing no limitations, but also as causing limitation.

The third cause of limitations was more of a physical nature. For instance: pain in the short arm, arm pit or shoulder when performing an activity, losing balance, or having too little force to perform an activity.

Children and adolescents had several strategies to deal with the short arm (Table V). A distinction can be made between strategies that the child or adolescent came up with him- or herself and strategies for which help from someone or something in the environment was needed. Furthermore, there appeared to be some age-related differences regarding the chosen strategies. Some strategies were chosen less frequently by older children and adolescents, such as the use of adaptive devices and asking people in the direct environment for help. Adolescents described fewer creative or alternative strategies than did children. Health professionals also described an age-related difference regarding prosthesis use; they described the tendency for young children to wear a prosthesis for all kinds of activities during the entire day, while adolescents more often wore a prosthesis only during specific activities or situations.

Another age-related difference was that the environment was mentioned more often as a limiting factor by the two older age groups compared with the youngest age group. Those environmental factors in particular were an influence when the child or adolescent encountered new situations, as illustrated in the following examples:

> *"Adolescents with a short arm are sometimes not allowed to follow the secondary education they like. It isn't possible to get into police school, the army, and some sports educations."* (Health professional)

Table V. *Strategies of children and adolescents with unilateral congenital below elbow deficiency to deal with activity limitations and participation restrictions*

Level of strategy	Description	Example or quote
Internal – child him/herself[a]		
Solution with own body		
Short arm	The short arm is used actively, in order to grasp and lift things, or to lean on it	*"I use my stump all the time. I can grasp and hold things with it."* (17 year-old girl, non-wearer) *"When tying shoelaces, I use the elbow of my stump to hold the lace and with the end of my arm I can keep it tight."* (17 year-old boy, non-wearer)
Other body parts	Body parts, other than the short arm are used (knee, mouth, foot, arm pit)	*"When I cut the meat, I keep the end of the fork in my mouth, and I cut the meat with my long arm."* (8 year-old boy, non-wearer) *"Playing with Lego, he fixes the pieces using his foot. He does this especially with his big toe."* (parent of a 8 year-old son, non-wearer)
Creative alternatives	Inventing new, creative alternatives to deal with limitations and restrictions	Taping a drumstick on the short arm to play drums Wearing a sweatband around the elbow of the short arm for rope climbing or playing computer games with console accessories Tying the skipping rope around the short arm to be able to jump
Alternative choices		
Easier choices	An easier activity is chosen to guarantee good performance or participation.	*"I'm not so good at tying my shoelaces. I don't do that, because I've Velcro shoes"* (8 year-old boy, non-wearer)
Adjusted choices	There is an adjustment made to guarantee good performance or participation	Driving an automatic car, instead of manual shifting *"I go to another horse-riding centre, especially for disabled children."* (13 year-old girl, non-wearer)
Give up/avoid		*"I never eat with a knife and a fork"* (13 year-old girl, non-wearer) *"He is able to tie his shoelaces, but he usually tries to avoid it."*(parent of an 8 year-old boy, non-wearer)
External – environment[a]		
Direct environment		
Offering creative alternatives	People in the direct environment of the child think of creative alternatives to deal with limitations	*"My father made me a special post cart for my paper round, because it was tough to cycle with a heavy bag on my bike."* (13 year-old boy, wearer) *"When I was playing a computer game with friends, and I didn't succeed in holding the controller, we thought that a sweatband could be the solution."* (11 year-old boy, non-wearer)
Giving help/taking over	Child/adolescent gets help from people in the direct environment	*"[Peeling an apple] When I eat an apple, I most often ask my parents to peel it for me."*(14 year-old girl, wearer) *"It is hard to zip my jacket sometimes, but then I ask the teacher or a friend."* (8 year-old boy, non-wearer)
Indirect environment		
Rehabilitation centre	Professional help is applied to deal with limitations and restrictions	*"I received tips for tying shoelaces in the rehabilitation centre."* (17 year-old girl, non-wearer) *"It is our task to let children experience what they are capable of and to make contact with people who provide problems."* (health professional)
Adaptive device	An aid which is prescribed by a rehabilitation centre that helps a child/adolescent with certain activities	Adaptive device on bicycle: adjusted handbrake; pin on the steer Adaptive device on cutlery Adaptive device to play computer games Adaptive device to open zip of jacket Adaptive sports device (e.g. horse riding) Adaptive device of musical instruments (e.g. cello)
Prosthesis		Whole day use Use for cosmetic reasons or for special activities (sports, to play a musical instrument, cycling, at work)

[a] Internal strategies are solutions the child him/herself came up with. The external strategies contain strategies that were thought of by someone in the environment of the child or strategies using an aid (such as an adaptive device or prosthesis).

> *"He was anxious about going to secondary school. A new school, a new class. How would they react on his arm? We see the same thing when we go on holiday."* (Parent of a 13-year-old son, wearer)

Parents

Parents were positive about their children's functioning. Overall, parents did not think their child experienced many limitations, as shown in this example:

> *"When I read him [my son] the first question [of this forum]: 'when especially do you need help?', his spontaneous reaction was: "doing difficult sums". When I told him that this did not have anything to do with his arm, his answer was that especially when doing sums he needed help."* (Parent of an 8 year-old boy, non-wearer)

Parents gave a lot of examples of strategies their children used to deal with limitations. Many parents mentioned that the short arm is not taken into account in making decisions about sports, playing musical instruments, or school. In order to let their child find their own strategies to deal with limitations, parents stressed that they did not help their child very often.

No additional strategies were mentioned by the parents to those that were already mentioned by children and adolescents (Table V). Parents, however, made some comments about the use of adaptive devices and prostheses:

> *"What makes it difficult is that an adaptive device or prosthesis has to be fitted first. Unfortunately, trying out several musical instruments without engagements isn't possible."* (Parent of an 8 year-old boy, non-wearer)

Parents argued that wearing a prosthetic device or prosthesis can make playing sports or instruments easier, but since devices have to be fitted first, it is impossible for a child with UCBED to try out different sports or musical instruments without further (financial) obligations. This point of view of parents was supported by the health professionals, who furthermore mentioned that special sports prostheses are not reimbursed by health insurance and although it is possible to fit a special sports device onto a prosthesis, it is (too) expensive to manufacture a socket especially for the adaptive device when a child does not wear a prosthesis. Thus, in that sense, some parents think that their children and adolescents are sometimes restricted in their opportunities. It should be noted that most of the parents in this group are parents of non-wearers.

Health professionals

Health professionals gave fewer examples of situations in which children and adolescents were able to function without any limitations than did children, adolescents and parents. According to professionals, the child's functioning can be limited by several factors. First, limitations experienced by the child can be caused by the child's cognitive and physical ability, motivation, dexterity, and creativity. Secondly, limitations may be caused by the family of the child, their financial situation, or may be due to norms and values in education. Thirdly, the environment or the social context of the child may cause limitations, most often caused by a lack of knowledge of the people in the environment of the child:

> *"The environment often causes more problems and difficulties than the child him or herself. Participation problems often exist, because people don't know what a child is capable of and they aren't familiar with the phenomenon."* (Health professional)

Health professionals described fewer strategies that children and adolescents with UCBED used to deal with their short arm, than did the other participants. The professionals also mentioned adaptive devices and prostheses more often as a strategy to deal with activity and participation limitations. Health professionals did not describe as many other strategies to deal with limitations, but mainly emphasized the use of aids and their potential benefits.

DISCUSSION

Having a short arm does not interfere with any activity, but not all children and adolescents have the ability to perform every activity. There are numerous creative strategies possible to deal with a short arm. According to the ICF-CY (4) functioning is influenced by environmental and personal factors, and this was confirmed by our results. 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 it, which limited children and adolescents with UCBED in their functioning. There were also more personally defined factors influencing the child'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. Of course, this also applies to children without UCBED. Having a short arm may set greater demands on the child's capacity to find strategies to deal with the short arm. This may be explained by differences in personal factors. However, personal factors have not been examined as such and further research is necessary to investigate this.

The results regarding environmental and more personally defined factors are supported by other studies that describe that factors such as personal characteristics of the child, environment, and family can be of influence on the participation of children with disabilities (17, 18).

More proximal amputations lead to a decreased function (19). Therefore, it is possible that the results in our study, for patients with a transradial deficiency, would have been different if children with a deficiency at a higher anatomical level had been included.

Age-related differences

Older children and adolescents (>12 years) gave more examples of limitations due to the environment than did the younger children. This may be due to the fact that older children and adolescents are entering new phases in their lives in which they become dependent on the judgements of others, for instance when they have to choose secondary or higher education, or apply for a job. These results are confirmed by Donkervoort et al. (20), who stressed that the transition into adulthood can be more difficult for children with disabilities than for their peers. The transition into adulthood encompasses several stages. At first, the adolescent is mainly dependent on adults (such as parents and teachers), and later on, the adolescent progresses towards an independent way of living (20). Our study showed that the stage in which adolescents are dependent on adults caused the most functional limitations for children and adolescents with UCBED. This information is valuable for health professionals of rehabilitation teams. It makes clear in which periods of the lives of children and adolescents extra help or advice might be needed from professionals. Besides empowering the child in coping with possible difficulties during transition phases, health professionals can also advise how to deal with people in the environment.

Comparing perspectives

Health professionals more often described the use of adaptive devices and prostheses as a strategy to deal with limitations in activities and participation than did children, adolescents, and parents. Furthermore, it was noteworthy (and in contrast to what might be expected) that professionals described fewer strategies to deal with activity or participation limitations than the other participants. This may be because many of the solutions described in Table V would not be recommended by a professional, as they may be considered degrading or damaging to other body parts. However, it may also indicate that health professionals are not yet informed about all the other strategies that children and adolescents with UCBED choose to deal with the short arm. Adaptive devices and prostheses appear not to be the only solution for children; it would be helpful for health professionals to take note of all the other strategies applied. Instead of fitting a child with an adaptive device or prosthesis, which can be time-consuming and expensive (at least in the Netherlands), it would be more appropriate to inform children with UCBED about the numerous creative and alternative strategies that are possible with a short arm. Another possibility is to bring together children and adolescents with UCBED, because it was evident on the forum in this study that these children are capable of helping each other, by giving each other advice about how to deal with activity and participation limitations.

Methodology

The present study is the first to gather qualitative information about functioning of children and adolescents with UCBED. The method used in this study was online focus group interviews. The online version of focus group interviews has several advantages over traditional focus group interviews (7). The online methodology is more accessible for participants compared with the traditional focus group method, in which a meeting has to be scheduled. Thus, it enables access to populations that are difficult to include, such as participants with diseases with low prevalence or extensive geographical spread. The anonymity during the interviews results in participants feeling more comfortable to share their opinions (7). The online focus group interviews brought a lot of new information, which could not have been gathered by means of quantitative research. Not only information about functioning, but also extensive descriptions were gathered of how certain activities were performed, situations are handled, and what strategies are applied to deal with the short arm. In particular, the information about the strategies the children have found for themselves to use the short arm in activities and participation can be of clinical value for health professionals who advise children with UCBED and their parents.

Strengths of the study

The response rates of participants who were willing to enter this study were very high; for some groups of participants almost 80%. Furthermore, more than 120 postings per discussion topic were collected, which enabled us to obtain a complete picture of how children and adolescents with UCBED deal with their deficiency in daily life.

During the online focus group interviews two moderators were continuously online to monitor the reactions given by participants. Thus, the moderators were able to interfere in the discussions where necessary in order to avoid irrelevant conversations.

Study limitations

An unequal proportion of prosthesis wearers and non-wearers was included in the youngest age group of the children and in the parents group, due to outdated information provided by the rehabilitation centres. This may have introduced some bias into our results, since the advantages of a prosthesis might have been underexposed. A second limitation of the study might have been initiated by the topics chosen for the study. Limitations in activities or participation did not evoke as many mutual discussions as we hoped for. Although there were many postings, most were informative rather than provoking discussion, despite the fact that the moderators stimulated discussions where possible. A possible explanation is that the participants did not experience their short arm as a functional disability, meaning that there was no reason for discussion.

Finally, it would be interesting to include (parents of) children younger than 8 years of age, since they might be more insecure about the future and encounter different difficulties. However, we did not consider it feasible for children younger than 8 years to participate in online focus group interviews.

Conclusion

This study showed that having UCBED did not interfere with any activity; however, not all children and adolescents had the ability to perform all activities. Personally defined factors appeared to influence the child's functioning, but further research into personal factors is required. A child's functioning was especially limited by environmental factors, mainly during transition phases. It is advisable to pay extra attention to transition phases during rehabilitation. Health professionals mentioned fewer and less diverse strategies to deal with the deficiency, and put more emphasis on adaptive devices and prosthetic use. The wide variety of strategies used by children with UCBED to deal with activity and participation limitations should be known by health professionals working with these children and should be integrated in healthcare. This integration can be realised by providing realistic education about the various creative solutions and the possibilities of adaptive devices and prostheses, and should be combined with specific training.

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