**Alina S. Kuzyakina, Maria V. Avxentyeva**

Sechenov First Moscow State Medical University, Moscow, Russian Federation

**Practice and Challenges of Rehabilitation Treatment for Children in Need of Upper Limb Prosthetics: Parents Survey**

**Corresponding author:**

*Kuzyakina Alina S.*, postgraduate of High School of Health Administration of Leadership Institute and Health Administration in Sechenov First Moscow State Medical University

**Address:** 109004, Moscow, Alexander Solzhenitsin str., 28, building 1, **e-mail:** Alina.bolshova@inbox.ru

**Received:** Oct 19, 2019, **accepted for publication**: Dec 27, 2019.

***Background.*** *Upper limb prosthetics can be required in many conditions, and congenital as well. The situation in Russian healthcare system with rehabilitation of children with upper limb prosthetics has not been studied before. The aim of the study is to**study current situation and challenges in rehabilitation of children in need of upper limb prosthetics due to congenital diseases.* ***Methods.*** *The simultaneous qualitative research was performed ― in depth semi-structured interview of parents whose children had got active prosthetics of upper limbs due to congenital diseases in the period from October 2017 to April 2018. There were 8 open-ended questions and 13 closed-ended question in the interview about availability and timeliness of rehabilitation, complexity and personality of the approach, observance of the phasing and continuity principles, and also involvement into rehabilitation process. The interview was performed after obtaining of the active prosthetic.* ***Results.*** *20 parents of children aged from 2 to 17 years from 8 regions of Russian Federation have undergone the survey. Only 75% of children undergone rehabilitation treatment over the years (before prosthetic positioning), and 93% of them only during the first phase (in health resort institution). Active prosthetic was delayed in 90% of cases. The complex and individual approach to rehabilitation was disrupted in 75% of cases. The child and his family were not actively involved in rehabilitation process in all cases. All respondents have mentioned low availability of rehabilitation. Most of the parents (80%) mentioned as well that they have to pay their own money to cover all the* *expenses.* ***Conclusion.*** *The interview of parents whose children are in need of active prosthetic revealed that one in four child did not get rehabilitation treatment. In cases when rehabilitation had been carried out many imperfection in its organization were identified. Low awareness about rehabilitation itself among parents and low interest in changing of the existing rehabilitation system were revealed.*

***Key words:*** *children, parents, prosthetics, active prosthetic, upper limbs, congenital diseases, rehabilitation treatment, in depth interview.*

(***For citation***: Kuzyakina Alina S., Avxentyeva Maria V. Practice and Challenges of Rehabilitation Treatment for Children in Need of Upper Limb Prosthetics: Parents Survey. *Voprosy sovremennoi pediatrii — Current Pediatrics*. 2019 ; 18 (6): doi: <https://doi.org/10.15690/vsp.v18i5.2062>)

**RESULTS**

**Fig.** Population sampling for the study

**Table 1.** Questions used for interviewing parents whose children are in need of active upper limb prosthetics

*Note*.

1 The rehabilitation met the criteria of phases if it have been performed on two phases of administration (procedure regulates 3 phases but there is no need for Phase 1 because such patients have no acute period of the disease). Continuity was considered as the transfer of information between two phases of administration (in particular general rehabilitation goals and objectives).

2 The rehabilitation was timely if a) first prosthetic care performed at the age of 6 months, b) rehabilitation treatment initiated since birth.

3 Complex approach in rehabilitation was: a) training how to use prosthetics during rehabilitation, b) participation of interdisciplinary team: at least exercise physiologist (or rehabilitation therapist), ergotherapist, clinical psychologist, c) involvement of modern technologies like virtual reality.

4 Individual approach in rehabilitation: a) availability of individual rehabilitation and abilitation programs, b) individual goals and aims setting with a child, c) working in natural environment ― school/kindergarten/home, г) individual exercises.

5 Continuous flow of rehabilitation was considered as regular exercises of parents with children at home.

6 Rehabilitation was considered available in the sphere of prosthetics if a) the installation of the prosthetics was completely covered by the government and compensation had already been received, b) paperwork period less than 2 months, c) paperwork was easy enough, d) information about prosthetics was provided by medical staff.

7 Final document needed for publicly-funded prosthetics are individual rehabilitation and abilitation programs. Important documents: certification for expertise (medical note 088/y-06); medical record from outpatient department; all medical testing; records on any conditions and chronic disease, if any; medical technical statement; printed X-ray.

8 Patient was considered as actively involved in rehabilitation process if parents а) knew legal environment about their rights on prosthetics and rehabilitation, б) indicated themselves as persons influencing the child's perception of the rehabilitation process, в) understood the importance of working with the child at home, г) believed that rehabilitation treatment to their children was necessary.

9 Regular exercises of parents with the child: physical exercises, gymnastics.

**Table 2.** The results of interviewing of parents whose children are in need of upper limb prosthetics

**Table 3.** Major challenges in rehabilitation of children in need of upper limb prosthetics due to congenital diseases (according to the data of parents interview)

**Table 4.** Quotations from the interview which demonstrate the problems of rehabilitation treatment

**STUDY LIMITATIONS**

*Small sampling size.* Interviewing of 20 parents will not allow to assay the prevalence and diversity of problems in rehabilitation treatment in targeted population of children in need of upper limb prosthetics due to congenital diseases. Unfortunately, till now there is no national database containing information on all children in need of prosthetics and on organizations providing such services. The difficulty in creating of bigger sample was also noted in foreign studies on prosthetics and post-prosthetics rehabilitation: most studies included less than 30 participants [19].

*State estimation of rehabilitation treatment based on parents opinion.* Parents do not have professional knowledge about the organization of medical care. Their estimations are subjective and can not be the only source of information on the quality and effectiveness of rehabilitation. However the family and the child are the final recipients of prosthetic and rehabilitation treatment. Their involvement in this process is crucial for the successful recovery. Thereafter, their vision of this question is important for development of further actions for rehabilitation improvement, it is impossible to implement them without family involvement. The lack of special knowledge among parents was one of the factors for choosing interviewing rather than questionnaire as a method of information collection. The content of some questions may or may not have been understood by respondents. For example: “what modern rehabilitation technologies have been used?” The answer should be interpreted with caution. Moreover some questions required clarification from the interviewer(for example, many parents did not understand what was included in the concept of "rehabilitation" and asked for an explanation of the used term).

*Extrapolated result of the research.* It is clear that the study includes parents who were able to find out the possibility of installing prosthetics in Moscow and come for this procedure. It can be assumed that children from less active families, from outlying regions, low-income families as well as children without parental care and children of wealthy parents who had appropriate financial opportunities (personal or from non-profit organizations) for prosthetics and rehabilitation in private and/or foreign clinics were not included in this study sample. It means that their rehabilitation experience was not taken into account

**FINANCING SOURCE**

Not specified.

**CONFLICT OF INTERESTS**

Not declared.