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## PEDIATRIC REHABILITATION IN CHILDREN WITH RARE DISEASES – PRELIMINARY REPORT

### REHABILITACJA U DZIECI Z CHOROBYMI RZADKIMI – DONIESIENIE WSTĘPNE

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#### **Abstract**

*As consultants in rehabilitation medicine and pediatrics sometimes we realize that most of our patients and their families are left unsupported and alone in terms of rehabilitation therapy during the treatment of their primary disease. Probably we forget that rehabilitation should be an integral part of every treatment process.*

*In the case of rare diseases, their basic treatment should be carried out in speciality facilities (speciality hospitals) where personel and equipment are able to run the most effective treatment. Rehabilitation medicine offers full range of cheap, non-invasive diagnostic tools. Well-chosen equipment can help with physical therapy and allow the independence of the child and full social integration. In an era of rapid change in civilization and progress of science, professionals use new technologies more often. This also refers to the field of rehabilitation medicine. Exoskeletons and lokomats created nowadays allow the use of new technologies in rehabilitation treatment processes. For specific disorders effective treatment may include even virtual reality (VR).*

*Early initiation of the rehabilitation process can improve the therapeutic effects and the overall outcome of the treatment, identifying the needs and realizing the available goals of rehabilitation that could build the sense of safety in the family and enhance their trust in the therapeutic team.*

**Key words:** pediatrics, rehabilitation, rare diseases

#### **Streszczenie**

*Jako lekarze specjaliści w rehabilitacji medycznej i pediatrii czasami zdajemy sobie sprawę, że większość naszych pacjentów i ich rodzin pozostaje osamotnionymi i zaniechanymi w zakresie rehabilitacji podczas leczenia podstawowego choroby. Prawdopodobnie zapominamy, że rehabilitacja powinna być integralną częścią każdego procesu leczenia.*

*W przypadku chorób rzadkich, ich podstawowe leczenie powinno być prowadzone w ośrodkach specjalistycznych (szpitalach specjalistycznych), gdzie zarówno personel, jak i urządzenia są w stanie zapewnić najbardziej skuteczną terapię. Rehabilitacja medyczna oferuje pełną gamę tanich, nieinwazyjnych narzędzi diagnostycznych. Dobrze dobrany sprzęt może pomóc w terapii fizycznej i pozwolić na niezależność dziecka oraz jego pełną integrację społeczną. W dobie szybkich zmian cywilizacyjnych i postępu nauki, specjaliści coraz częściej korzystają z nowych technologii. Odnosi się to również do rehabilitacji medycznej. Tworzone obecnie egzoskielety i lokomaty pozwalają na wykorzystanie nowych technologii w procesach leczenia rehabilitacyjnego. W niektórych przypadkach skuteczna rehabilitacja obejmować może nawet wykorzystanie wirtualnej rzeczywistości (VR).*

*Wczesne rozpoczęcie procesu rehabilitacyjnego może poprawić efekty terapeutyczne i ogólny wynik leczenia, identyfikując potrzeby i realizując możliwe do osiągnięcia cele, które budują poczucie bezpieczeństwa w rodzinie i zwiększają jej zaufanie do zespołu terapeutycznego.*

**Słowa kluczowe:** pediatria, rehabilitacja, rzadkie choroby

During our professional work as a consultant in rehabilitation medicine at the Early Intervention Centre and a pediatrician in University Clinical Centre we have realized most of our patients and their families are left unsupported and alone in terms of rehabilitation therapy during the treatment of their primary disease, could it be neurological, oncological, nephrological or pediatric. It seems we forget that rehabilitation should be an integral part of every treatment process [1]. This problem is also evident in children with rare diseases.

Not so long ago, we were consulting a 10 months old boy born with the hypoplasia (agenesis) of the urinary bladder and the urinary tract and with diastasis of the pubic symphysis. He was referred for rehabilitation only after a multi-step surgical correction of the urinary tract defects when the pubic diastasis had been completed. The position on the stomach was not allowed for him and we found him significantly delayed in his psychomotor skills, as it is lying on the stomach that the baby completes, towards the end of the first year of life, the mile stones of development crowned finally with reaching the supine position and independent gait. This case has drawn our attention to the question when the rehabilitation measures should be initiated in the treatment process. It concerns also the children with rare diseases.

Eight year old Matthew comprehended me this problem again. Matthew had been diagnosed with medulloblastoma at the age of four years and had spent the next half of his life in the oncology centre undergoing subsequent treatment regimens. Neurosurgical treatment with the adjunctive radiotherapy left him with spastic tetraplegy. The proper rehabilitation treatment was initiated only after the completion of the oncological treatment. During the hospitalization in the oncology ward a few physiotherapy consultations took place, but that was exclusively to improve patient's general status.

Both these patients needed systematic and adequate rehabilitation treatment. We have the irresistible impression that these children and their guardians were left to fend for themselves immediately after the end of the primary therapy, as if the treatment was over. The matter of rehabilitation was either neglected or left as a totally independent process. As we mentioned at the beginning, it is all so rare for the routine pediatric practice to involve rehabilitation consultants at the stage of primary treatment, which would enable to initiate the rehabilitation as soon as possible and plan it accordingly along the course of the disease. In this way patients or/and their care givers could realize the achievable goals and the normal development process could be restored as much as possible.

The good example of early cooperation between pediatric, orthopedic and rehabilitation team, which lead to the success, was the case of a boy in his first 26 weeks of life with severe arthrogryposis [2] or three years old girl with the Blount disease diagnosis [3]. In both these situations early rehabilitation treatment prevented the patients from surgical intervention.

In Poland, NFZ (Narodowy Fundusz Zdrowia – National Healthcare Fund), as part of state health care, refunds the rehabilitation of children in outpatient, home, one-day

hospital or centre and inpatient departments. The rights to rehabilitation services reimbursed from public funds is entitled only to the patient using a healthcare provider who has a contract with NFZ [4]. Service providers can be bodies created by the authorities (e.g. Samodzielny Publiczny Zakład Opieki Zdrowotnej (SPZOZ) – Public Healthcare Centre) or other with different legal formulas (trusts, limited companies, etc.) [5]. One of the most popular service provider in children rehabilitation in Poland are Early Intervention Centres founded by Polish Association for the Mentally Handicapped.

According to the guidelines of the National Consultant in Rehabilitation Medicine from 2010, rehabilitation is an integral part of medical treatment. Early rehabilitation should be carried out in primary hospital wards where the basic treatment takes place and specialist physician in rehabilitation medicine serves in examination and implementation of procedures for the rehabilitation treatment. In such conditions rehabilitation treatment procedures are conducted by the physiotherapist. Speciality rehabilitation treatment should take place in rehabilitation wards, where the head of department is a physician specialist in rehabilitation medicine. In the rehabilitation ward full inpatient care is provided [6].

In the case of rare diseases, their basic treatment should be carried out in speciality facilities (speciality hospitals) where personnel and equipment are able to run the most effective treatment. Such therapy should include rehabilitation as the integral part of the treatment, in the early phase based on consultation and recommendations of rehabilitation specialist physician and in the later stages on the speciality rehabilitation.

Rehabilitation medicine offers full range of non-invasive diagnostic tools. Prechtl's method allows for early detection of neonates at risk of cerebral palsy [7]. Detailed physical examination, the observation of the gait pattern or classifications such as: GMFM – Gross Motor Function Measure [8], FMS – Functional Mobility Scale [9], PEDI – Pediatric Evaluation of Disability Inventory [10], can help with the assessment of the child's prognosis regarding the function and self-sufficiency in the future. Well chosen equipment can help with physical therapy, which may in some cases include prosthesis or choice of orthoses, to allow the independence of the child and full social integration.

We must also note that in an era of rapid change in civilization and progress of science, professionals use new technologies more often. This also refers to the field of rehabilitation medicine. Exoskeletons and lokomats created nowadays allow the use of new technologies in rehabilitation treatment processes. For specific disorders effective treatment may include even virtual reality (VR) [11]. Some rehabilitation centres create their own research points. For example Toronto Rehabilitation Institute is having – iDAPT Centre for Rehabilitation Research – one of the most technologically advanced rehabilitation research centre in the world [12].

Early initiation of the rehabilitation process could, for Matthew, the above-mentioned patient, improve the therapeutic effects and the overall outcome of the treatment. Identifying the needs and realizing the available goals

of rehabilitation could build the sense of safety in the family and enhance their trust in the therapeutic team, which are both beneficial for any treatment process.

Let me mention pioneers of rehabilitation, Howard A. Rusk, widely considered as “the father of rehabilitation medicine” [13], and also Wiktor Dega [14]. In the Dega’s rehabilitation model, rehabilitation should not follow the primary treatment but should be planned as its integral part. Rehabilitation is not just an addition to the basic treatment, but as surgery or any other type of treatment, should be included in the whole chain of therapeutic procedures. Not only the organ affected by the disease undergoes rehabilitation, but it involves the whole organism [1]. In some cases, especially in rare diseases, the process of rehabilitation can take place for whole life.

The different models of rehabilitation medicine were already described, however we have to look for novel perspectives using current level of knowledge, possibilities in exchanging our findings in enormous fast time and new technologies, but we also have to remember that the old ones used in full range can be full of benefit.

We strongly believe and our professional routine shows that early initiation of the physical rehabilitation and continuous form of this treatment helps to achieve goals faster, in many cases preventing patients from surgical intervention.

Please let me encourage my colleagues pediatricians and specialists in rehabilitation medicine to share experience in the treatment of patients with rare diseases at different stages of their therapy also in children with rare diseases.

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#### Author’s contributions/Wkład Autorów

According to the order of the Authorship/Według kolejności

#### Conflicts of interest/Konflikt interesu

The Authors declare no conflict of interest.

Autorzy pracy nie zgłaszają konfliktu interesów.

**Received/Nadesłano:** 21.11.2015 r.

**Accepted/Zaaceptowano:** 01.12.2015 r.

**Published online/Dostępne online**

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