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PARENT INVOLVEMENT AS CO-THERAPIST IN THE FOLLOW-UP PROGRAMME OF HOME PHYSIOTHERAPY

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Abstract: *Substantiation: Pediatric rehabilitation is a field where child's compliance is closely related to the parent's one, and, for a successful therapy, it is necessary to convey the information and include the parent in the process. Therefore, it is important to know the degree of parent involvement. Objective: Assessment of the degree of parents' compliance with the method of therapy induction during the period of child hospitalization for rehabilitation treatment. Materials and methods: One used an anonymous questionnaire with 23 questions and preformulated answers. One used statistical analysis with Excel software. Results: In most of the cases, mothers are those who accompany children to therapy, show interest in their involvement in the therapeutic programme after discharge, deem that the induction method and communication with the therapist and the medical team are very important. Children age and pathology were assigned to 5 categories. A significant segment of the participants in the study acknowledged the need to continue the programme at home but approached a healthcare professional for this. A small number did not continue the programme at home. Conclusions: mothers are open to continuing the therapy programme at home, the hospitalization period should be increased and access to outpatient pediatric services should by improved.*

INTRODUCTION

The life of families with children requiring long-term rehabilitation therapy is deeply affected, both financially and regarding the relationship among their members.(1)

The studies available in specialized literature regard both the involvement of parents in therapy and social adaptation of families to child disability.(1) The progress achieved in time promote both motivation and interest of the parents in continuing the therapy. The therapist becomes a partner along with the parent/child-school set.

In case of children with cerebral palsy, for example, the achieved progress is not clearly assignable to a specific therapy, as in case of autistic children, or to a sustained rehabilitation programme, on one hand and, on the other hand, the rhythm of such progress is individualized and, more often than not, very slow.

Within the Pediatric Neurorehabilitation Department of the Psychiatry Hospital Sibiu, we have been striving since almost 25 years ago to make a difference in involving parents in the therapy programme, in order to ensure continuity for one hand and, on the other hand, to achieve a change of perspective over child's disability.

AIM

Assessment of the degree of parents' compliance with the method of therapy induction during the period of child hospitalization for rehabilitation treatment.

MATERIALS AND METHODS

This study is a prospective one, aiming to analyse the degree of parents' involvement in continuing the physiotherapy programme after the end of the rehabilitation programme, with applicability in pediatric rehabilitation and in the social area.

The lot includes 94 participants, from among care givers of children hospitalized and/or treated in the integrated outpatient department during the period 2018-2019 in the Pediatric Neurorehabilitation Department of the Psychiatry Hospital Sibiu

One used an anonymous questionnaire with 23 questions and preformulated answers. One used statistical analysis with Excel software.

Work hypotheses:

1. Within the family, the mother is assigned the co-therapist role.
2. The doctor provides counselling on continuing the gymnastics and the physiotherapist initiates the parent in the physiotherapy programme.
3. There is a correlation between the induction method used by the physiotherapist and the continuation of therapy by the caregiver parent, at home.
4. The duration of the physiotherapy session and the duration of hospitalization are correlated to the degree of parent's involvement.
5. Parents resort to professional support for continuing the gymnastics programme at home, from fear of making some mistakes.
6. Addressability is an indicator of the satisfaction degree, addressability being reflected in the number of re-admissions and by the domicile area of the patients.

Interpretation of the results

The majority of the participants in the study (57.45%) are aged 30-39 years, and the gender distribution shows a major

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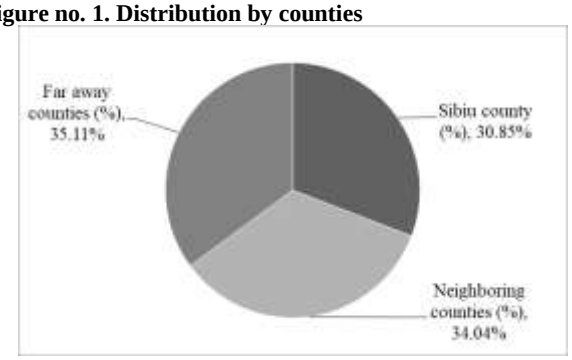
prevalence of the female one (87%).

Regarding origin environment, the majority of participants (57.45%) are from the urban environment. Regarding the domicile area, 34.04% are from neighbouring counties (Argeș, Alba, Vâlcea, Brașov and Mureș) while 35.11% from rather far away counties (Arad, Bacău, Bistrița – Năsăud, Botoșani, Brăila, Cluj, Constanța, Dâmbovița, Dolj, Maramureș, Mehedinți, Prahova, Suceava, București etc.)

Figure no. 1. Distribution by counties

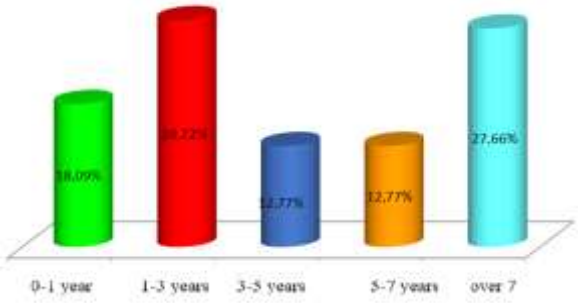


Regarding education level, college graduates prevail, representing 47.87% of the total, followed by high-school graduates, 29.79%.

The prevalent occupation is that of workers, out of whom 28.72% skilled workers and 7% unskilled workers; 14.89% declare themselves as office clerks, 11.70% private entrepreneurs and 35% selected the option ”other situations”.

Most of the admitted children are aged 1-3 years (28.72%) and over 7 years (27.66%), with the age segments 3-5 years and 5-7 years having an equal weight, namely 12,77% and the age segment 0-1 year is 18.09%

Figure no. 2. Age distribution of admitted children



The most frequent clinical diagnostics were grouped into 5 categories:

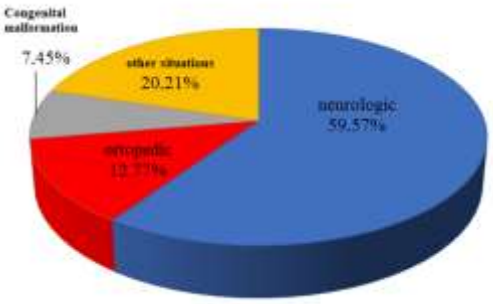
- Neurologic conditions (59.57%): development disorder, cerebral palsy, paresis of peripheral nerves, etc.
- Orthopedic conditions: scoliosis, kyphosis, congenital crooked legs
- Congenital malformations: spina bifida, Down syndrome, other syndromes
- Other situations

Among the studied lot, 38.30% were admitted for the first time, 2/3 of the lot were admitted for the second time (30.85%), and the remaining ones had been admitted for over 5 times in our department.

97.87% of the interviewed ones declared that they had been informed about the necessity to continue therapy after discharge.

Regarding the health professional who made the recommendation for continuing the physiotherapy programme at home, the handling doctor was mentioned by 27.17% of the respondents, the physiotherapist, by 16.30% of the respondents and most of them, namely 56.52% of them, selected the option according to which both professional categories made the recommendation.

Figure no. 3. Diagnostics



During the hospitalization, the child has 2 physiotherapy sessions a day, in most cases, the physiotherapy programme being provided by 2 therapists (61.70%). There are also cases when a single therapist provides both therapy sessions for the same child, but they are less frequent, 25.53%.

Most of the parents, namely 89.36%, decide upon readmission to resume the programme with the known physiotherapist.

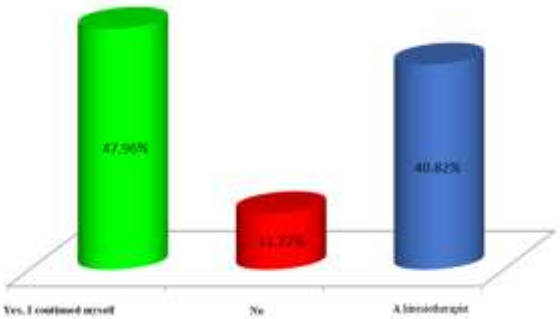
Most of the questioned subjects (90.43%) admitted that they had been initiated in the therapy programme of the child.

In most of the cases (52.94%), parents had been initiated by working under the physiotherapist’s supervision, and few of them had received only some explanations (12.94%) or explanations and demonstrations during the therapy programme, from the physiotherapist (34.12%).

A vast majority, namely 76.60% of the questioned subjects deemed that the number of therapy sessions was sufficient in order to be able to continue the programme after the discharge.

For the 23.40% of them who deemed that the time allotted for learning the programme was not sufficient, the most frequent reason quoted (54.55%) was the insufficient hospitalization time, followed by too short therapy sessions (45.45%).47.96% claimed that they had continued on their own the programme also after discharge, 40.82% resorted to a physiotherapist and only 11.22% said that they had not continued the programme.

Figure no 4. Situation regarding continuation of the therapy at home



From among the participants who did not continue the program at home, 45.45% claimed that they had not learned the programme, 36.36% invoked the fear of doing mistakes, 9.09% blamed the lack of time and the same percentile deemed that it

was not necessary to continue the therapy at home.

Regarding the evaluation of physiotherapist's attitude regarding the child and parent, in most cases, one or more of the following 3 options were selected:

a. the physiotherapist was punctual and observed the session duration 40.2%
b. the physiotherapist was careful and managed to relax the child 25.8%
c. the physiotherapist was kind to me and the child 33.5%

In most of the cases, all the above 3 options were selected together.

76.60% of the subjects deemed that 2 therapy courses per year were not sufficient.

Regarding the communication between the physician and care giver, 94.68% of the subjects deemed that they had received sufficient information regarding child's condition and treatment during hospitalization.

The degree of parent satisfaction regarding the physiotherapy service is very high: 69.16% declared that they were very satisfied and 25.53% declared themselves as satisfied.

DISCUSSIONS

The distribution by age category may be explained by the increased average age of first-time mothers in Romania (27.1 years) and also of the age for all births (28.6 years) according to The National Institute for Statistics (INS). Across Europe, the age of first birth is 29.3 years, even more in some states, e.g. Italy (30.1 years) and Spain (30 years) being at the top and Azerbaijan, with 23.9 years, the average age for the first birth.(2)

According to INS studies, in 2018, 33.9% of the persons acting as a caregiver for a child are females, versus 30.9% males. In Romania, the task of looking after child within the family is still a female one. Other studies showed data regarding preponderant mothers' involvement in looking after children with disabilities.(3,4)

The fact that 61.15% of the participants are from other county than Sibiu shows that this department represents a national centre.

The education level may be a predictability indicator regarding parents' compliance with learning the therapy programme, namely a high level of education means an increased chance of parent participation in the therapy act. Almost half of the respondents are college graduates, followed by high-school graduates. At national level, the high education level (tertiary) is 16.2% and it is the lowest across Europe. Ireland is at the top of the list, with 42.08% of the population graduated a form of higher education.(4) On the other hand, in Romania, people aged 20 to 34 who graduated a form of higher education have a rate of work integration 21.2% higher than those with a lower education level.

The occupation structure of the lot is not correlated to the degree of education, as it would have been expected, the vast majority being workers, and the high proportion of participants who selected the option "other situations" is acting as personal caregivers of the child with disability.

The age of the children whose parents took part in this study is another indicator helping in the assessment of parents' degree of involvement. For parents of babies and of children over 7 years, the task might be easier: the gymnastics programme for the baby can be learned easier by the parent and the child over 7 may have a better compliance. However, the proportion of babies is representative for the pediatric rehabilitation services, as over 18% of parents have children under 1 year.

According to our study, the highest addressability occurs in case of neurologic conditions, especially cerebral palsy and development disorder. Many studies focused on the assessment of the results of physiotherapy programmes carried out by parents at home, most of them involving chm with cerebral palsy and development delay.(5)

The pathology treated within our department is of chronic type. The highest occurrence is represented by neurologic conditions. Coming back for readmission to the same department ensures continuity of therapeutic intervention and presents several benefits: the child returns to a known environment, the therapy programme is continuously adapted, the parent has the opportunity to compare the programme continued at home to the programme recommended at the previous discharge.

The handling doctor and the physiotherapist are members of the same therapy team, the doctor outlines the rehabilitation programme and the therapy plan and the physiotherapist sets, based on those recommendations, the physiotherapy programme. Parents are present in the physiotherapy sessions. Their presence is aimed to reduce the degree of anxiety in the child and in the parent and, also, to facilitate communication with the physiotherapist and learning of the physiotherapy programme. It is very important that mothers notice the way of therapy intervention of the physiotherapist. In order to learn, it is necessary sometimes to have enough time to learn just one method at once.

There is interest in the study of the results regarding guided intervention of parents in programmes continuing the therapy provided by professionals, as it results from a meta-analysis on speech development in children with Down syndrome whose parents continued the programme at home under professional guidance.(5)

Upon readmission, most of them wanted to approach the same physiotherapist for continuing/resuming the therapy. This is beneficial both for the child, who accepts easier the therapy with a known person, and for the success of the therapy, as, upon readmission, the physiotherapist performs a re-evaluation of the child, re-adapting the therapy and being able to check if the parent carried out at home the programme for which the parent had been trained. In addition, the parents can check their own level of understanding and the manner of performing the programme. The benefit from the fact that both physiotherapy sessions are carried out by the same physiotherapist is that all the involved persons know each other, communication is easier, more efficient and the compliance is easier to achieve. The downside is that the programme can end in routine that may reduce motivation both in the child and in the therapist or the parent.

It is opportune to have the possibility of choosing the physiotherapist and the doctor, in order to achieve good communication and quality medical services for the satisfaction of the patient and care givers. The answers to this question prove that this opportunity is achieved within our department.

Not only that the rehabilitation programme followed by the child during hospitalization is carried out in the presence of the parent, but physiotherapy is the procedure with the highest therapy potential, with the most important result it is recommended to maintain continuity.

At national level, the alternative of referring the child upon discharge to an outpatient centre is extremely low, as, on the one hand, the child qualifies for only 2 courses of rehabilitation therapy per year in the rehabilitation outpatient units having contracts with The National Health Insurance Authority (CNAS) and, on the other hand, the number of private outpatient units is low, the costs are prohibitive and children with disabilities need daily physiotherapy.

CNAS does not provide funding for physiotherapy sessions for home treatment.(6)

For this reason, namely in order to ensure continuity after discharge, we use to initiate the parents in the therapy technique within our department.

It is important to know which is the initiation method in order to determine which of those is the most efficient method. There are however considerations related to the activity in the department that may determine the selection of the method regardless the physiotherapist's preferences.

Not only the physiotherapy programme, but also the initiation method has to be adapted to the age and condition of the child and also to parent's availability. There is the possibility that the parent deems his initiation in therapy as a waste of time from the time assigned to therapy, thinking that the immediate effect is more important than the long-term one. Another situation influencing the selection of the initiation method is the time availability of the physiotherapist, who can only carry out the initiation within the time assigned for the scheduled session and cannot extend the time for communication with the parent as another patient is waiting.

The physiotherapists and the handling doctor should find the proper mode of induction regarding the daily home programme and the rhythm of repeating the programme so that to achieve maximum compliance of the parent treatment.(7)

The therapy programmes are customized, therefore one cannot carry out a group programme as within support groups, as a solution for parent counselling provided by other professionals (counsellor, doctor).

The occupational therapy is another therapy means which parents may continue at dome, A study from 2018 involving 2 groups of children with development retard, one experimental and another one as a reference group, children being aged 0-6 years and having development ages 10-69 months. The children in the experimental group continued at home the occupational therapy programme, being assisted by parents who had been initiated by professionals, while children in the reference group did not continue the programme at home. After 2 months, the results showed significant differences in the results of the experimental group compared to the children in the reference group.(8)

In general, the duration of hospitalization in our department is similar to that in other hospital environments at national level, namely 12 days.

During hospitalization, the children have 2 physiotherapy sessions a day, plus other methods, such as massage, electro-therapy, occupational therapy, psychomotor stimulation by games and, for school-age children, participation in the educational programme. Regarding physiotherapy, during one stay in hospital, there are 20 sessions, as the period includes in general 10 business days.

On the other hand, patients in the specialized outpatient unit have only one physiotherapy session, meaning 10 sessions per rehabilitation course.(6)

The physiotherapist needs a certain time, sometimes up to one week, in order to determine the customized physiotherapy programme, this situation being seen mostly in case of babies. The remaining time is sometimes not sufficient for the parent to learn the programme.

The short duration of the physiotherapy session may be a challenge in learning the physiotherapy programme. In case of little children, it is recommended that the physiotherapy session be short, because of the low capacity of facing effort; in case of the Vojta therapy, which is extensively used within the department, the maximum duration of the session is of 20 minutes (for babies under 4 months, the duration is of 10 minutes).

The duration of the physiotherapy session in general varies between 20 minutes and 45 minutes, depending on the selected method, this being the actual therapy duration. A large proportion of the parents, as seen in the occupational distribution, are employed. The fact that they resort to a healthcare professional for continuing the programme at home may be assigned to their lack of time, lack of confidence in their ability to carry out the programme properly or to the way in which the physiotherapist conveyed the information. This situation may place a financial burden on the family. The large proportion of those who admitted that they had not continued physiotherapy at home reveals a situation that has to be approached within another study.

The fear of making mistakes, the stress felt by the parent is a difficult obstacle against parent involvement as co-therapist. It is possible that this reason is also one of the causes for which there are parents declaring that they did not learn the programme.

It is important to find out, subsequently, the reason for which they deem it is no longer necessary to continue at home, despite the fact that they acknowledged initially that they had been informed about the need to continue the therapy.

The parents communicate also with other parents, not only with the physiotherapist. Therefore, they evaluate in an informal manner the physiotherapist's approach.

In the specialty outpatient unit, access is allowed only based on the referral letters from the family doctor or from another specialist doctor and, according to the framework contract, there are only two founded therapy courses per year.(6)

In my opinion, access to treatment is limited within the specialty outpatient unit, the child being a patient with peculiarities. For babies, the development during the first year of life requires quarterly reassessments, sometimes even more frequent. When rehabilitation is necessary, two sessions daily for 10 days a year are not sufficient. Quarterly reassessment is also necessary for school-aged children, especially for those with static spinal disorder during the growth periods. Under such circumstances, admissions might not be justified from a medical point of view and the treatment can be carried out in an outpatient regime. The limitation imposed by the framework contract can however cause an undesired development of the health condition as some administrative regulation is limiting access to medical services. The majority of the parents deemed that 2 therapy courses per year were not sufficient.

Communication is a very important parameter for the quality of the medical service. In states with advanced economies, pediatric rehabilitation programmes are focused on the children and their families and the therapy is initiated after a home visit.

A study comparing the conservative approach, namely conventional therapy in pediatric rehabilitation (focused on the therapy team) versus the family-based therapy, (focused on the family and its needs) proves that the results of focusing on the family are clearly superior both regarding motricity performances and regarding compliance with treatment.(9)

In our department, the parent takes part together with the child in the examination, in the physiotherapy sessions, in the psychological assessment and in electrotherapy or massage sessions. The handling doctor is the first coming in contact to the child and the parent and is under the obligation to provide information regarding the health condition, the treatment programme, its effects and, sometimes, even the patient's circuit within the department. Similar to the trends in other countries, the parent becomes a partner for the therapist and the most important elements in this relationship are information, communication and the partnership spirit.(10) Based on the answers provided by care givers, the communication within our department is adequate.

The indicator of caregivers' satisfaction is a tool for the assessment of the quality of medical services within our department, useful both in order to know how the therapy is being perceived and as it makes us maintain high quality standards.

However, one should mention a reservation, namely that parents know a long-term rehabilitation is necessary for their children, that they intend to come back for other treatment courses and this situation may influence their opinion.

The COVID-19 pandemics led to reduced access of children with disabilities to rehabilitation therapy in specialized centres and the isolation measures imposed in such situation highlighted the need of involving the parents in the therapy.

A solution presented by a study carried out in Israel was tele-medicine. During a 5-month period, one carried out over 2300 therapy sessions for 147 children and one evaluated the process feedback from the perspective of healthcare professionals, parents and children. The result was compared from the perspective of conventional therapy and of tele-medicine and the conclusion was that the efficiency is increased in case of combining the two approaches.(11).

CONCLUSIONS

1. The task of care for the children and continue the rehabilitation programme is an obligation of the mothers, in most cases.
2. The communication between doctor/therapist and the careers is real within our department and its goal is to involve the parent and rehabilitation as co-therapist.
3. This goal cannot be achieved on the long-term as much as it would be possible in order to improve life quality for the children and their families. It would be necessary to change the approach by making a point of public health policy the issue of placing the child and family as focus of rehabilitation programmes.
4. Despite the fact that a vast majority of the participants acknowledged that they had been initiated in a comprehensive manner (explanation, demonstration followed by hands-on trial under therapist's supervision), only 1/3 of the parents said that they were doing the physiotherapy program at home on their own and 1/3 said they were using a professional provider in order to avoid making mistakes.
5. This situation might be caused by the low number of initial sessions and their short duration and, on the other hand, by the individual capability of the doctor or physiotherapist to convey information and reduce parent's anxiety in relation to child's condition. In order to change this situation, time is needed: longer duration of the therapy session necessary for the assessment of the child, for interaction with the parent and for understanding the therapy programme.
6. The addressability from a geographical perspective (2/3 of participants are from neighbouring and far-away counties) and, from a re-admission perspective (2/3 of the participants are at their 2nd admission or had more than 2 admissions) is a quality indicator for the quality of the medical activity within our department.
7. The direct appreciation regarding the quality of the medical activity (physiotherapy) is largely considered as satisfactory (25.53% satisfied and 69.16% very satisfied).
8. It is necessary to evaluate the result of parents' involvement in the therapy at home within a separate study on this topic.

Proposals

1. The amendment of the framework contract regulating the terms of granting medical care, medication and medical devices within the health insurance system, by increasing the number of rehabilitation courses for children.
2. The implementation of a nation-wide tele-medicine programme allowing the parent to communicate directly from home with the therapist and the handling doctor, periodically, according to a pre-established programme, in order to adapt the therapy programme to child's progress. A legal framework is necessary to provide the organizational and financial setup.
3. Modification of the personnel layout at department level: increased number of physiotherapists.

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