

# Cerebral Palsy (CP) and the panorama of therapy possibilities

## Introduction

Parents and experts are confronted with the syndrome of CP with a prevalence of 1 to 2 (3) per 1000 births. Considering the fact, that Down-Syndrome for example has a prevalence of 1 per 500 – 800 births (in industrial nations nearby 650), this seems for CP not to be a high rate. Nevertheless there are rarely two other syndromes, on which there are as many opinions about therapy- concepts and support for children, adolescents and young adults affected with CP and for their families in a global sense.

In case of CP there is now clear rule in which cases and how early the diagnosis should be made. In the debate on these questions there is the know-it-all attitude of some people obvious. They underestimate the fact, that the parents of these children affected by one of the syndromes mentioned above got mature and better informed. They have recognized the hybris of many experts and for that reason and out of desperation they are looking and searching for new concepts of treatment for therapy and support. They do not matter how out of place these methods seem to be at first sight.

But it were mainly parents, who made experts in the established medicine to wonder about unknown aspects of therapy possibilities. The well known and mainly in West – Europe used physiotherapeutic methods of Vojta and Bobath are examples of such initiatives by parents. These experts seem to have forgotten that these specialists for CP – therapy – Vojta and Bobath have their origin in the former Czechoslovakia.

Recently again parents discovered f. e. the so called methods of Conductive Education by Petö and the Neurointensive Rehabilitation by Kozijavkin in the east of Europe. They fight more and more for the acceptance of these methods by "Gesetzliche Krankenkassen" (Legal insurances in Germany) and the "Bundesausschuss Ärzte-Krankenkassen" (permanent round of experts, consulting these insurances) in Germany. These parents demand from the insurances - "Gesetzliche Krankenkassen" - to finance these new methods, which are in the special case of a patient as effective or ineffective as the established therapy methods of Bobath and Vojta that are accepted and financed without any limitations. According to a judgment by the "Bundessozialgericht" (Highest Court in Germany for Social affairs) in Germany the parents are right doing so. These judges argue that improvements f. e. in all day abilities as a result of a therapy concept can be a tool of a therapy - method. This point of vision is new because it includes an extension of what therapy should induce, too.

We now see, that experts with varying sense of distance decide which methods should be accepted and which not. They have recognized themselves by now, that they are on a thin ice with their opinions. But they do not admit that they decided mostly with at least one blind eye. It is known that parents do not give up until they have reached the best possible therapy - solution for their children. Looking at the attitude of experts, especially therapies in the field of CP there is more

ideology running than vision. Experts for CP could not come to a generally accepted agreement which criteria could be the basis for decisions whether a therapy method is effective or not. It is known these days, that vision can only grow realistically in society. Without of society it turns into utopia fast<sup>1</sup>. In our time both visions and utopias still exist concerning CP. It is frightening, that different institutions for therapy are offering ineffective therapies at the patients' expense.

There exist various opinions by doctors and therapists what could be effective for patients with CP and what not. Patients which grow up are not asked whether they would like to receive a therapy at all. In many cases emotional decisions are used. Patients are more or less passive. But there are more and more clear recommendations how carefully the individual needs of the patients have to be observed and so should be treated. It's obvious that the panorama of therapy possibilities has changed. To recognize this must be the absolute obligation to the people with CP concerned and their families.

## Panorama of therapy possibilities:

The predominant opinion on CP still is<sup>2</sup>:

- The symptoms are caused by a non- progressive illness of the brain.
- The classic symptoms are spasticity, hypotony, dystony, athetoses, ataxy and mixtures of these.
- The symptoms are manifestated during the first few years of life.

Obviously these statements have to be questioned: Which studies had been performed in the past on the question whether a single injury of the brain can cause consequences such as problems in the metabolism of the brain and the formation of scars next to the areas destroyed first. The single injury can be caused by immaturity of the brain of premature infants, hypoxia, infections of the brain, acidosis or by more than one risk - event. They take place pre, peri or directly postnatally. Today we know: CP is a syndrome with multiple signs of damage that surely do not only affect the development of motor abilities. It seems that mostly the sum of damages is of high importance for the severity of CP. The question which symptoms the therapy should be focused on, is nearly unanswered. The strict system of dividing the patients into the types of tetraplegia, diplegia .... does often not fit the patients at all.

Today it is clear, that CP may cause various risks for the development: problems with movements and posture, contractions and instability of the joints, difficulties concerning the motor-development of the hands, mental and sensoric (eyes and ears) problems, reduced communication, perception, participation, autonomic control and status of nutrition, education, partnership, training on the job, employment and whole life, In some cases: severe problems as fractures, epilepsy and osteoporosis.

It is more and more accepted that only multidimensional therapy - concepts can support these patients with CP coming to abilities for daily life. New therapy concepts are added to the once

mentioned before. So therapists and doctors have first of all to deal with the pros and contras of each method in detail which should be offered the individual patient. Patients and their relatives have the right to be informed precisely on all perspectives and advantages of all therapy-methods.

To conclude which attitude doctors and therapists should point out for different therapy - methods and possibilities of support for these individuals with CP should have (such as physiotherapists, ergotherapist specialised on Sensomotoric Integration by Jean Ayres, therapists doing Orofacial therapy by Castillo Morales, special educators, Montessori-therapists, music therapists and motopedians) this is unclear now. Now it's more than obvious that Integral Neurorehabilitation<sup>3</sup> gets through in the praxis. Such a method is the Neurointensive – Rehabilitation by Kozijavkin.

It is not necessary to mention, that CP can not be healed by such a multimodal concept as well. This is also impossible with an integral concept of treatment. The so-called recoveries of CP concern mostly with huge probability patients who never suffered from CP. The oposite is true; the so-called succes in therapy concerning CP depends on how severe the whole status of CP is.

There are some more criteria for coming to a concept of therapy for patients with CP:

- age of the child when it is primarily examined and at which time the diagnosis of CP has been suspected,
- severity of the CP,
- real age versus developmental age,
- the patients mental state (clinical psychologists are the experts to examine the cognitive development),
- the attachment figures (especially parents), social state,
- parents education,
- number of brothers and sisters,
- housing<sup>4</sup> and surrounding, employment of the father e.g.

The fact that each child's therapy- and support/rehabilitation - plan has to be put up individually gets more and more known. Each therapy interfering with the child without of stopping and thinking about purpose of the used method of therapy from time to time is senseless. Such treatments are huge cost - factors and they even harm patients. Because of this it is useful to check patients on their running development every three months:

- How far has the child developed?
- Have the aims of therapy calculated for the planned therapy-phase for mostly three months been reached? It should be recommended that a step by step therapy – concept should be offered worldwide.
- What are the aims for further therapy – phase?

So it's most important to have a concept of therapy dealing with patients suffering from CP. There is no question, that all therapy concepts focussing on functions together induce the possible success to the patients with CP. They especially meet the patients' needs in case they bare in mind that children and growing up individuals with CP should not only take part in the therapy passively but also and first of all actively.

It's the merit of A. Petö - we know in our days- that children with CP need education and therapy. So the definition of sickness and disability has been enlarged and widened by Petö especially for patients with CP as a model for sickness with the consequence of disability. Also such results had not been expected on Con-

ductive Education by Petö when it could be shown that children using this therapy concept profit especially for their hand motor functions in some aspects.<sup>5</sup> The research – project on Conductive Education of Petö was financed by the insurances Vdak and AEV in Germany(4). Until this project took place the development of hand motor functions concerning children suffering from CP was not enough considered by experts of CP. But this ability is very important for the training of techniques like eating or writing when children attend school at the age of 6 or 7 at the latest. Because of this fact children with CP must be allowed to take part in Conductive Education of Petö aged 3 to 4.

Phoenix in Munich has been emerged from the foundation "Stiftung Pfennigparade e.V". Phoenix as a part of this foundation explained this Conductive Education as a concept for CP - treatment and built up the first professional training facility in Germany financed by the "Bayerisches Sozial- und Bildungsministerium". It did not stop its work therefore but also established a Centre in Munich, where children can be treated and supported according to this holistic concept. This holistic concept considers the motor interests of both children with and without CP. They want to learn and to look for a way of motor development practicable and suitable for their needs and be allowed to find it. Playing, repetition and competition (the idea of "who can yet do it better than me" is important) are the suitable and effective methods. The idea of supporting movements with singing had yet been discovered as positive by the rehabilitation of adults especially those having motor problems (condition after brain trauma and the brain with palsies e.g.). A. Petö took over these experiences and he was convinced to establish such a system of global rehabilitation and therapy. Activities being similar to those at Phoenix in Munich or Fortschritt e.V. as an institution spread over Germany for example are taking place in Ukraine but with other goals of therapy.

There the Neurointensive Rehabilitation after the method of Kozijavkin has been established some years ago especially in Lviv and Truskavets for thousands of patients with CP. The western world did observe this idea and organization with jealousy and critics not knowing the tools of this method and not having really personal impressions on this method. In Truskavets in the Carpathians and in the city of Lviv manual therapy, physiotherapy, physical therapy, massages and other therapies are offered as a global concept of treatment. There holistic medicine is the guiding principle as well. More than 10,000 patients have yet been treated in this centre. So far not much attention was paid to the contractions and shortening of tendons and even less to the fact that the continuous existence of such problems causes that the contract body gives abnormal information to the CNS. Obviously no therapy concept can be based on such information permanently.

The experts for Botulin - toxin treatment confirmed using their therapy - method that a child with CP needs proprioceptive stimulation, not only as a step for a short period of time. The developing more normal position of a joint can be such a stimulus for the brain. But the so called experts didn't have an interest in the past to find out which proprioceptive stimulations patients with CP need very early in their risky development.

The concept by Kozijavkin uses the knowledge that proprioception and its improvement are tools number one in case of CP. There in Ukraine has been realized that children with CP often suffer f. e. from vegetative problems like circulatory problems, problems in temperature regulation of the legs e. g.. Doctors for children know and especially the parents of the patients that these patients suffer f. e. from cold hands, legs. And the patients feel mostly uncomfortable from this misfeeling. Oddly

enough these symptoms are not recognized to require a treatment in the therapy concepts.

All experts know that it's important for children with CP to be able for a period of time to place the foot even on the ground or to open the hand. This requires different methods of treatment. The CNS seems to get used to more "normality" fast. So it must be a very important and extraordinary tool that patients come to a situation where more normal posture is messaged to the brain. This concept is the concept of the Kozijavkin-method. The CNS of the child with CP has reserves and resources in plasticity, too. Because of this fact the integral concept of therapy has to be used in any chance of learning. In this context it is getting clearer than ever before that orthopedic surgery can be also a part of an integral therapy concept, but only if the surgery neither mutes, nor even causes invalidity. There are many examples, mainly out of the past, in which orthopedic specialists worldwide operated disastrously. These operations were financed in whole and without of any questions in Germany by insurances. If an operation seems necessary or desirable, the experts have to coordinate the operation. That means, the orthopedist needs the physiotherapists advice and a neurofunctional knowledge. Coordination of the experts' experiences is important. Single-handed efforts of indications of surgery must be a part of the past now and even to be objected. Surgery as a part of such a therapy – concept must be made subtle. The improvement of functions must be realized individually.

In order to try and bring order into the confusing panorama of therapy - methods these are listed as follows:<sup>6</sup>

- Therapy methods based on somatosensory with mainly systemic results (e.g.: Voita, Bobath, Neurointensive Rehabilitation by Kozijavkin, Jean Ayres' therapy, Castillo Morales' therapy)
- Therapy methods based on the learning theory with mainly local results (e.g.: EMG- Biofeedback-Myofeedback, Trainig on a treadmill, Locomat, Feedback - therapy)
- Therapies to improve the adaptive functions (e.g.: Montessori – therapy, Music – therapy, Occupational therapy, Conductive Education and Therapy of Pető,
- Physical methods (e.g. Nasarov's Vibrations, the adaptation of orthopaedic auxiliary means)
- Psycho-social methods (e.g. behavior therapy, consulting of the parents, integration into self-help groups,
- Orthopaedic surgery

The social pediatricians and pediatricians as well as neuropediatricians, planning the coordination for such patients with CP, as well as orthopedic pediatricians, therapists and supporters have to be get linked as they were not in the past. All this experts together have to find the best possible treatment for the patient and his family. A network for CP – patients and families is necessary more than any before. Socialpediatric Centres and Sensomotoric Centres must be built up in Germany as around the world.

An example for this is the Kinderzentrum Munich with the unique Institute for Social Pediatrics and Adolescent Medicine of the Ludwig – Maximilians University in Munich, which is enlarging its spectrum of therapy - methods in order to be able to offer a special treatment for each child CP and with its special needs. Therefore without a detailed diagnostic - procedure no therapy can start. This has to be established as a fixed rule in any independent therapist's office, too.

It is shocking, how often therapies are used, not knowing the child's individual profile of development, f. e. may it suffer from CP

or not. Therapy and the look at the development are linked and must be an obligation in each centre with such a profile. In many cases these rules are not respected in the system of health care. In principle the "child should choose the therapy (Voss. H. von, 2004). This must be a rule for the future in a very global sense. Therapists and specialists should be aware that the patients show signals which special therapy they need in their special and individual age. Because of infants can not express their needs clearly a fitting method has to be found by the effort of a direct or indirect diagnostic - procedure. And it should not be forgotten: Young adults have to agree with the special therapy. Therapy may not take place without an agreement by them. Further that should be a rule: Each therapy- method must be explained by the specialists so that parents and older patients can understand the background of a therapy - method also the risks (e.g. fractures and stomach bleeding in case of physiotherapy, manual therapy e. g.). Any question of the parents and patients if older must be answered before starting the therapy. Parents and especially young adults have to agree to a planned therapy – intervention in a written form.

### Summary and conclusion

Children and (young) adults with CP need an integral focused concept according to a so called Neurointensive-Rehabilitation. This concept can only be put up interdisciplinary and individually for the patient. All concepts of therapy and support have to be checked for their efficiency permanently as a part of quality assurance.

Also there exists a huge amount of various therapies; there must be offered impulses of development in each individual patient. In order to discover them the idea that all progress is based on therapy should be qualified. Some children reach steps of development without of any doctors or therapists. This is calming, notwithstanding that we know the whole panorama of therapy possibilities. But fatalism is not accepted for patients with CP. As early as it can be realized patients, if older, and parents must be informed on the panorama of therapy methods for CP. Criticism on therapy methods are only allowed if the specialist has an intensive knowledge on a mentioned therapy method. More than in the past it's now urgent that research focuses for children with diseases financed therapy-studies. Without such a research – concept pediatrics will come to an end.

<sup>1</sup> Neue Züricher Zeitung (NZZ), 31.7.2006

<sup>2</sup> Executive Committee for the definition of cerebral palsy (2005). Dev. Med. Child Neurol. 47, 571- 576

<sup>3</sup> Voss, H. von (2002) Die infantile Zerebralparese (ICP) als Herausforderung für Diagnostik, Therapie und Rehabilitation. KG Intern 3

<sup>4</sup> Voss H. von, Blank R. (2002) Modellprojekt Pető – Wirksamkeit und Wirtschaftlichkeit der Konduktiven Förderung nach Pető bei Kindern mit infantiler Zerebralparese im Kindergarten- und Vorschulalter in: Die Infantilen Zerebralparenen – Bilanz zu einem kontrovers diskutierten Syndrom im Kindes- und Jugendalter. Sozialpädiatrie aktuell (Hrsg. H. von Voss). Kirchheim Mainz, 285

<sup>5</sup> Blank R., Voss H. von (2002) Konduktive Förderung nach Pető. Shaker Aachen

<sup>6</sup> Blank R. (2006) Persönliche Mitteilung 24.7.2006, München

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