

Guidelines for rehabilitation of children with cerebral palsy

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1. PREFACE

1.1. Why guidelines?

In the last few years on the international scene, and recently in Italy too, more and more attention has been paid to direct clinical practice to higher quality and more appropriate accessibility of health services. To achieve this, it has become necessary to stimulate the use of diagnostic and therapeutic procedures based on scientific evidence.

The 1998-2000 Italian National Health Programme and the subsequent Law 229-99 have suggested adopting guidelines to better match these needs.

Through them, it would become possible to reach the main aim which is to insure the highest appropriateness of intervention, reducing to a minimum the variability of medical choices in assistance strategies caused by subjective interpretation and lack of knowledge.

Another reason for today's interest in guidelines is linked to 2 other processes that are currently taking place in the Italian Health System: firstly institutional certification and secondly the continuous education of medical staff. The creation, use, knowledge and participation in the verifying procedures of guidelines are integral parts of both these 2 processes, which today every single medical operator must be involved in.

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1.2. Why guidelines in cerebral palsy rehabilitation?

The first criterion for appropriateness of a guideline is the relevance of the clinical topic that it considers. According to this point of view, there is no doubt that the rehabilitation of cerebral palsied children corresponds to the appropriateness criteria underlined by the Programma Nazionale Linee Guida (PNLG), the Italian National Programme for Guidelines, and the Annual Health Care and Research Policy.^{1, 2}

These criteria include demographic and social-economic factors (prevalence of the problem and social cost), clinical factors (severity of the condition), aspects linked to the variability of clinical practice in that specific health area, the potential capacity of guidelines to improve the level of assistance and its costs, and lastly the availability and quality of scientific evidence in literature or of widely accepted expert agreement. With the partial exception of the last item, in our country, cerebral palsy (CP) and the state of relative rehabilitation processes meet the previous criteria. Beside this, before the work done by Società Italiana di Medicina Fisica e Riabilitazione (SIMFER), the Italian Society of Physical and Rehabilitation Medicine, and Società Italiana di Neuropsichiatria dell'Infanzia e

dell'Adolescenza (SINPIA), the Italian Society of Child and Adolescence Neuropsychiatry,³ there had not been any attempts, either in Italy or in foreign countries, to create CP rehabilitation guidelines, with the sole exception of recommendations for a few limited aspects linked to surgical treatment or drug therapy.

This absence of guidelines should not be surprising, given that CP is one of the pathologies, in the history of rehabilitation medicine, where the greatest cultural, methodological and procedural conflicts have taken place. We can find many reasons for this.

The word "rehabilitation" itself, that refers to the loss of acquired functions rather than the difficulty in acquiring expected functions, in developmental age is met head-on with the word "abilitation"; analogously the nature of CP itself, expressed as a persistent disturbance, is in direct contrast with the concept of plasticity of the central nervous system (CNS), which, in any case, is the starting point of every possible recovery process. Even referring to the development of a normal child, some authors pursue the form, style and chronological sequence of each single performance that the child should be able to produce (rolling, creeping, crawling, etc.); on the other hand, other authors assert that first of all most attention must be paid to the problems the child must face and to the time period in which those problems must be solved (appointment of function). From a more drastic point of view, some authors think that normal development remains an incredibly inspirational model, but not applicable to the CP child, whose development must follow a different natural history, probably also with important differences among the various clinical CP forms (types).

Another controversy in CP is between those who use a top-down approach to CP treatment (the program mistakes performed by the CNS are the real problem, and the therapeutic interest should over all deal with these mistakes) and those who underline a bottom-up approach (we must first change the structural impairments of the locomotor apparatus through physiotherapy, drugs, orthosis and devices, orthopedic surgery, etc., so that the child can learn a different way of moving). Moreover, within the same top-down elements, CP treatment is influenced by the contrast between the motor aspects (posture and movement disturbances) and the perceptual ones (sensorial deficits, gnosis components, central representation alterations) and between the differences in learning problems and in adaptive behavior difficulties.

We should also keep in mind that CP treatment, nowadays, is influenced by the controversy between the interest for the motor repertoire (historically the aim of physiotherapy) and the attention to its use (theoretically the aim of occupational therapy) and between the "extremist" approaches (author outlined specific methods) and the "recreational" approaches, in which everything is considered suitable, because the most important thing is to do something (*i.e.* pet therapy).

For the above-mentioned reasons, the task of creating guidelines, today, according to most authors, is an extremely difficult challenge. On the other hand, however, the alternative of doing nothing has been defined by the scientific community as damaging and ethically incorrect.

In a period of profound change in the Italian Health System, the risk was that dubious if not actually dangerous rehabilitation procedures would all have the same credibility, such as methods without any scientific evidence, absolutely biased criteria to assess the work done, incorrect use of resources and insufficient investment in necessary rehabilitation elements, increase of profit orientated private health care, etc.

1.3. The work of intersociety commission and the obtained results

The experts commissioned for the drawing of these guidelines, initially created by SIMFER, to which SINPIA representatives were later added after the Consensus Conference in Bologna (2000), started to address the above-mentioned difficulties and to appreciate the importance of the assigned task.

It has not been a simple endeavour, as demonstrated by the fact that it has taken 4 years to write the final document.

One of the strengths of this document is the fact that, after much discussion and disagreement, in the end every member of the commission found his opinion ideally voiced in the final text and could recognize his personal contribution in the stated "Recommendations".

One other very important strength is the adoption of the general principles declared in the "Manifesto per la riabilitazione del bambino",⁴ which had already been previously approved by both Societies, from which many guideline recommendations have been inspired. According to the "Manifesto", rehabilitation in pediatric age must be considered as a complex procedure, composed of different, not separate or opposing, fields of intervention such as re-education,

(child and health system), education (family and school) and assistance (family and society).

Another strength to underline is that, in order to define the patient profile and his recovery possibilities, aspects not strictly clinical, such as family and social background, and not strictly linked to the child and his environment, such as structural and cultural resources of rehabilitation unit, must also be taken into account. One very much debated point was how to determine which fields of intervention and time spans are justified, avoiding on one hand that every therapeutic intervention can be deemed suitable in every situation and, on the other hand, accepting the fundamental principle of concluding the re-educational treatment (but not education and assistance), whatever the age of the child, when the justified conditions requested at the beginning no longer exist or have been substantially altered.

The last aspect that must be underlined is the willingness to establish completely agreed upon aims with the family, which represents not only the ideal applicant and the final buyer of the improved but never normalized child, but also an important resource in the re-educational process itself (delivery of instruments and guidance to retrain what the therapist has been able to progressively teach the CP child).

1.4. The next steps: dissemination and validation of the guidelines

Rereading the final version of guidelines, approved by the 2 Societies, as we have done in these days, emphasizes, even after such a short time, that some parts could be modified, amended, clarified in their meaning and description or rewritten according to the PNLG manual¹ that was published after the work of the commission. It was, however, programmed that the approved text of guidelines would be updated within a 3 year period from their publication.

The following commitment of the commission members who wrote the guidelines is to develop indicators that allow for monitoring the effects of these recommendations on users, families, services and National Health System, etc. On this topic, a data base is being created, already available to all members of both Societies, containing a report based on the criteria contained in the guidelines and supplied with indicators to verify the work.

The effort spent on uniting experts with varying opinions and different backgrounds allowed us to experiment on a vast range of agreed choices.

We should not forget that the report of the Italian National Health Programme 2002-4, now available on the Health Ministry website, states that the topics and the essential objectives of the Italian Health System are:

- 1st project - the agreement on the appropriate and essential levels of assistance;
- 2nd project - creating an integrated web of social health services for assistance of chronic patients, elderly and disabled people;
- 3rd project - to grant and monitor the quality of health assistance and biomedical technologies.

The presence of common guidelines allows the insertion of CP child rehabilitation in the project of the Italian National Health Programme. It is a common opinion of the authors that the effort by experts coming from different scientific Societies, interested in CP rehabilitation, to agree on the main points, even with difficulties and compromises, is an important step in answering the user's needs.

Guide for reading

This document is composed of 3 parts: the introduction deals with the definition of the pathology that is the subject of these guidelines, their importance for clinical and organizational purposes, the mandate received from the 2 scientific Societies, the composition of the committee, the adopted work methodology, the addressers of the guidelines, the application fields, the monitoring and updating modalities. Then, there are the recommendations, organized in 3 sections: the definition of the functional profile of the patient, according to motor and non motor axes describing disabilities, the re-education intervention fields (goals), differentiated according to the age of the patient, and finally the operative methodology, which should be employed in the re-educational intervention. The appendix outlines suggestions about the re-education program, differentiated in relation to the age of the patient.

2. INTRODUCTION

2.1. Definition

The expression "cerebral palsy" in children defines a persistent, but not immutable, disturbance of the posture and of the movement due to alterations of the

cerebral function for pre-, peri- or postnatal causes, before growth and development are completed.^{5, 6}

The term “disturbance” indicates a condition, that is a permanent state, not only a disease, which can have a positive or negative outcome; a disturbance remains, whereas a disease can change. Other authors use for the same purpose the term encephalopathy.

The adjective “permanent” reinforces the concept of disturbance as a firm and definitive condition, that is not evolving, and it is only partially attenuated by the adjective “not immutable” which indicates how better or worst, spontaneous or induced changes are, however, possible. The lesion in itself does not evolve, but the demands of the environment on the nervous system become more and more complex, with consequential aggravation of the disability as a function of both the primitive damage and the deficits progressively accumulated over time because of the lack of acquisition of experiences and new capacities.

The expression “alteration of cerebral function” underlines that the palsy determines an inability of the nervous system rather than a deficit of one or more of the single apparatuses that form it (encephalon, cerebellum, brainstem, etc.). In this sense the term “cerebral” has to be interpreted as synonymous with the CNS and not with the brain.

The expression “growth and development of the nervous system”, that with a linguistic liberty refers to the adjective cerebral rather than to the noun function, conveys the meaning that the CP differentiates from the palsy in the adult as a lack of acquisition of functions, rather than a loss of functions already acquired. However, the expression remains ambiguous because it does not define which function is being referred to, even if it is generally attributed to posture and locomotion.

Notwithstanding these numerous specifications, the international definition of CP remains completely inadequate to draw the boundaries of the complex reality of this pathology, because it ignores some determinant components, such as sensitive and sensorial deficits, alterations of perception, distortions of mental representation, praxis and gnosis problems, difficulties in learning and acquiring, cognitive and relational disorders, just to mention some of the most important. In any case, damaged motor control always constitutes an explicit and investigable component present in CP from the beginning. Even if, in many cases, it does not represent the most important element, it is, however, considered the core of the problem.⁷

2.2. Premise

These guidelines are necessary because:

— Epidemiology: in our country,^{8, 9} as in all the other more industrialized countries,^{10, 11} the incidence of CP in infants has stabilized at approximately 2‰ (a new case every 500 births) for some time now. Notwithstanding the continuous improvement in assistance to pregnancy and delivery, this value has not diminished and it is inversely proportional to the decrease in neonatal mortality. It is logical to think that even in the future this pathology will continue to represent the prevalent factor of motor disability in developmental age.

— Clinical, social, parental and individual costs: CP as an impairment of the development of individual adaptive functions requires a long, complex rehabilitation process which involves health services, educational structures and social agencies. As the required interventions are not just limited to developmental age but continue over the whole lifetime of the individual, the costs for the community are enormous.

— Therapeutic, educational and medical care behavior: due to the extreme variability of the clinical aspects of CP, the complexity of the functions involved (not only motor), the natural evolution of patient competence in developmental age (given the natural history of the pathology of which the individual is affected) the therapeutic, educational and medical care proposals available for therapeutic purposes by the different agencies involved prove extremely inhomogeneous, if not clearly contradictory.

— Certification of child rehabilitation health structures: this procedure requires the statement of the processes and of the procedures carried out for the treatment of this pathology and the explicit declaration of the rationale which underlies the choices made in relation to the expected results and to the costs needed to achieve them.

Guidelines for the re-education of CP have not yet been adopted by other countries with a Health Service similar to ours.

2.3. METHODOLOGY

2.3.1. Mandate

SIMFER, in relation to its own statutory purposes and based on the directives of the Programming Department of the Ministry of Health, drafted a com-

mission, from its own members, of experts in the field of the rehabilitation of subjects affected by CP, to elaborate “Guidelines for the rehabilitation of children with cerebral palsy”.

After the Consensus Conference, held in Bologna on December 11th-12th, 2000, also SINPIA, having previously received a similar mandate from the Programming Department of the Ministry of Health, enlisted some of its own members, experts in the field of the rehabilitation of subjects affected by CP, to participate in the work of the SIMFER commission, which became in this way the SIMFER-SINPIA Intersociety Commission, for the drafting of the guidelines.

According to the mandate received, these guidelines do not apply to the treatment of other neuro-psychiatric disorders if present in the child affected by CP (for example mental retardation, pervasive developmental disorders, etc.), when they represent the prevalent or principal disability for rehabilitation treatment in respect to the disorder of motor control. The rehabilitation of these disabilities is the subject of other specific guidelines.

2.3.2. Course Followed

These guidelines are based on efficacy data found in the literature and on expert opinion. Research into published studies was done through consultation of the following data banks: Med-line, Embase, Cochrane Library. In addition, with appropriate methodology, the existing guidelines have been researched on the internet and non-indexed literature, selected on the basis of direct knowledge by the members participating in the Intersociety Commission.

Efficacy evidence, obtained through a review of the literature, was analyzed by a panel of experts which formulated the recommendations through a non-structured group discussion over a 3 year period. The panel experts were chosen by SIMFER and SINPIA according to the following criteria: availability for the appointment, experience enhanced in the field for at least 10 years, prevalent professional commitment in this field or in one of its relative specific aspects, scientific publications in the field, competence acknowledged by the national and/or international scientific community, employment in various institutions (university, scientific institute, hospital, territorial organization, ONLUS structure connected

TABLE I.—*Evidence levels and strength of recommendations.*

Level	Studies
1	Several randomized controlled studies or systematic reviews
2	At least one randomized controlled study
3	No randomized studies, but different controlled studies with consistent results
4	High experts' consensus (unanimity)
5	Prevalent experts' opinion (majority)

to the National Health Service) coming from the greatest possible number of Italian regions.

The statements of the guidelines are supported more by a large quantity of descriptive work and operative praxis, based more on expert consensus, than on scientific evidence. Therefore, it was necessary to divide expert opinion into 2 different levels of scientific evidence: “strong consensus” when the opinion was unanimous, and “experts' prevalent opinion” when this opinion was held by the majority but not unanimously.

The efficacy proof (“evidence levels”) and the strength of the consequent recommendations, which support the formulated recommendations, have been graded as indicated in Table I.

The draft of the first version of guidelines was sent to Scientific Societies potentially interested in them, to the associations of health and social professionals involved in rehabilitation and to various patients and/or family associations of this field. The draft of the text was presented and discussed at a specific Consensus Conference held in Bologna on December 11th-12th, 2000, promoted and organized by SIMFER and conducted by SIMFER and SINPIA together.

The guidelines were then reviewed considering the observations expressed during the conference or later sent by regular mail, which on the whole supplied a strong positive opinion about the clinical contents and the applied methodological aspects.

2.3.3. Receiver of the guidelines

These guidelines for the rehabilitation of children affected by CP are addressed to specialized medical doctors responsible for individual rehabilitative projects and to other specialists who intervene in various ways in the evaluation and in the treatment of CP.

They are also addressed to all the technical components of the inter-professional rehabilitation team and to the families of the subjects affected by CP.

2.3.4. Application fields

These guidelines apply only to the field of re-education, a process which, together with education and assistance, contributes to making up the complex activity of rehabilitation of the child affected by CP.

With this premise, we think it is absolutely necessary to state that, in strict integration with these, similar guidelines for the care and the education of the child affected by CP must be drafted. For this purpose, in addition to re-education experts, other professional figures (pediatricians and general practitioners, psychologists, sociologists, social assistants, educators, play counsellors, etc.) will necessarily have to be involved, besides obviously the parent association representatives and the users themselves.^{12, 13}

Differently from what these guidelines proposed for re-education, reliable instruments are not known for assistance and education suitable to objectively measure child and family well being and the success of their social integration. Therefore, instead of proceeding according to cost-benefit logic, we think it is more useful to consider patient profile for this purpose and obtain from it the percentage of health and social resources to be assigned to educational and assistive tasks. Actually it is easy to demonstrate that the lower the chance of modifying the clinical circumstances therapeutically, either because of the gravity of the lesion or the complexity of the family and social situation, the more important the educational and assistive type of interventions which the patient and family require become.^{14, 15}

Recommendation of degree 3

Regarding the distinction within the complex rehabilitation process of the 3 re-educational, assistive and educational components, these guidelines have welcomed and mutually shared what was expressed in the "Manifesto per la riabilitazione del bambino".⁴

Rehabilitation is a complex process aimed at promoting a better quality of life for the child and for the family.¹⁶ Through direct and indirect actions, it deals with the individual in all physical, mental, sentimental, communicative and relational aspects (holis-

tic character), involving the family, social and environmental context (ecologic character). It is achieved through the formulation of the rehabilitative project and the different therapeutic programs active in the 3 fields of re-education, assistance and education.

Re-education is a responsibility of health workers and its goal is to develop and improve adaptive functions. It represents a discontinuous and limited-in-time process which necessarily terminates when, in relation to the most updated knowledge about biologic processes of the re-organization, for a realistic period no significant change occurs in the development and in the utilization of adaptive functions.

Education is a responsibility of the family, health workers and sector professionals and its goal is both to prepare the child to exercise a social role (training the disabled person) and to prepare the community, beginning with school, to welcome and integrate him/her (training people for the disabled person), in order to increase the resources and re-educational treatment efficacy.

The goal of assistance is the well being of the child and the family and it is a responsibility of health workers and social operators. It has to accompany the child and the family without interruption starting from the announcement of the diagnosis of disability. The resources to be destined to the family have to be calibrated considering its expressed needs and not the condition of modifiability of child's palsy.

Recommendation of degree 5

The proposed distinction is important for distinguishing in the activity of sector operators which part can be measured through visible changes induced on the activities/abilities of the child (re-education), from what, on the contrary, cannot be recognized through objective changes in the patient, as for example in the prevention of deformities (intervention of the assistance field), the psychological or operative capacity of the family, the success of integration in school, the quality of the social integration of the patient, the degree of satisfaction for help received, etc.^{17, 18}

The formulation of the rehabilitation project and of the different therapeutic programs must obviously include integrated interventions necessarily made in the 3 fields of re-education, education and assistance. We want to emphasize, however, that the continuity element of the whole rehabilitation process is not

represented by re-education (physiotherapy, speech therapy, etc.) but by assistance. Particularly with the seriously disabled child, where very often an early re-education is powerless, this distinction is fundamental for justifying the difficulty in evaluating the actions of health and social technicians.

2.3.5. Updating the guidelines

The members of the Intersociety Commission pledge to examine the most recent literature¹⁹⁻³⁶ also in the future, in order to aptly identify current articles which can question the validity of these recommendations and to consequently modify them, if necessary.

These guidelines will be reviewed and updated in any case by the end of 2005.

2.3.6. Application and monitoring of guidelines

Monitoring of guideline application through the definition, by the 2 scientific societies SIMFER and SINPIA, of a series of indicators which the panel will develop in the near future, is contemplated.

3. RECOMMENDATIONS

The guidelines for the rehabilitation of children affected by CP are conceptually developed following 3 assumptions:

- 1) which type of subject (patient profile);
- 2) which ability/activity to achieve relative to the child's age (functional area meant as the justified intervention field);
- 3) how to proceed (adopted operative methodology).

3.1. Profile of the patient

It is necessary to describe a precise diagnostic functional profile of the patient using, in order to facilitate data collection and treatment, a multiaxial or multi-dimensional system consisting of 8 axes. Each axis includes various parameters. Besides the fundamental motor axis, other axes (lesional history, rehabilitation history, complexity, complications, family, rehabilitation services, child community) describe the non motor conditions and the contextual characteristics which, however, can significantly influence the subject's possibilities of motor recovery.

Patient profile is significant only for the considered age range. When passing from one age range to the next, it can be modified, updated, enhanced, completed or even totally redesigned, if the conquest of new knowledge makes it necessary. For this reason we do not say "diagnosis", which obviously would not substantially change very much passing from one age range to the next and which would just summarily outline the complex problem of palsy, but we say "functional profile of the patient", a less binding term in a formal sense, but closely linking it in the procedural sense.

The functional diagnostic patient profile has to be sufficiently precise to allow for a correlation between the nature of the disease and its natural history (palsy), re-educational project, adopted tools, interventions performed (therapeutic program) and final achieved modification (measurable result).

Recommendation of degree 4

3.1.1. Axes description

3.1.1.1. 1st axis. Motricity

It describes the disability components:

— localization according to Hagberg: tetraplegia, diplegia, triplegia, paraplegia, monoplegia, with the addition of double hemiplegia;¹⁰

— disease nature: floppiness intended as a reduction in the positive reaction of erectness; spasticity intended both as accentuation of the positive reaction of support (excess of contractile activity) and as an abnormal velocity dependent reaction to stretching (lack of muscle passivity); spasm in flexion, in extension, in torsion; dyskinesia and hyperkinesia of ballistic type, choreic type, athetoid type, dystonic type; ataxia as movement decomposition, coordination disease, deficit of equilibrium, perturbation of postural control; associated reactions as synergies, synkinesias, parasite movements, mannerisms, mirror movements, etc.

It is possible to note the simultaneous presence of different elements (mixed forms):

— presence of muscular retractions, of limitations, of articular (only if structured) or skeletal (only if important) deformities. Indication of the site and description of the entity (subluxation, open luxation, inveterate luxation, etc);

— attained level in postural organization: supine, prone, sitting (with or without support, with or with-

out help), standing (with or without support, with or without help). Attained level in the passage of position (from supine to prone, from prone to sitting, from sitting to on all 4s, from on all 4s to standing, etc.);

— attained level in the organization of locomotion: on the ground with or without devices, walking with or without devices, with manual or electronic wheelchair;

— attained level in prehension – manipulation (not differentiated grasping, differentiated grasping, operative capacities);

— attained level in oro-facial motility: facial expressions, suction, biting, mastication, deglutition, salivation control;

— characteristics of errors made at gesture and posture level: variability/stability (mastery of motor behavior and its predictability, stability of the strategy and its reproducibility, etc.).

Recommendation of degree 4

3.1.1.2. 2nd axis. Lesion history

It describes the most significant data of patient clinical history.

The precise collection of anamnestic data and of exams made to identify the lesion responsible for CP is also essential for problems of differential diagnosis with the genetic disorders (metabolic-degenerative). For this purpose, please refer to the specific guidelines for the diagnosis of CP approved by SINPIA during the Congress in Rimini in 2000.^{37, 38}

Among the most significant parameters we emphasize:

— hypothetic time of the lesion: prenatal, perinatal, postnatal;

— site of the lesion;

— extension of the lesion;

— nature of the lesion: anoxic, ischemic, haemorrhagic, infective, toxic, malformative;

— time of delivery (weeks of gestation);

— birth weight: <1 500 g; 1 500-2 500 g; >2 500 g;

— intrauterine growth (dystrophic, small for date, macrosomatic, etc.);

— indicators of perinatal encephalopathy (Apgar index, umbilical pH);

— pathology of pregnancy: threat of abortion, placenta previa, intrauterine infections, etc.;

— diagnostic investigations (neuroradiological, electrophysiological and laboratory) to confirm lesion.

Recommendation of degree 4

3.1.1.3. 3rd axis. Rehabilitation history

Rehabilitation history³⁸⁻⁴⁰ refers to:

— communication of the diagnosis;

— family psychological reaction to the diagnosis (adaptation process);

— start of the re-education treatment;

— pursued re-education approach;

— frequency and continuity of re-education treatment;

— child reaction to re-education treatment;

— adopted orthosis and aids;

— pharmacological interventions;

— surgical interventions;

— reasons for the possible change in the rehabilitation service and importance given by the family and the child to previous rehabilitation program.

Recommendation of degree 4

3.1.1.4. 4th axis. Complexity

Complexity⁴¹⁻⁴⁴ describes the associated pathological conditions able to influence significantly the process of motor recovery:

a) sensorial disorders: deficiencies of:

— visual system (visual acuity, ocular motility, visual field, eye/head movement dissociation);

— auditive system (auditive acuity, attention and orientation to auditive stimuli);

— olfaction (recognition of familiar odors);

— taste (recognition of familiar flavors);

— touch – temperature – pain;

— proprioception (sense of position, sense of movement, sense of pressure).

b) neuropsychological and relational disorders:

— attention disorders;

— perceptive disorders: codification, discrimination, attention, tolerance, perceptive coherence, illusions, hallucinations;

— memory disorders;

— gnostic disorders (somatoagnosia, spatial disorders);

- praxis disorders;
- dyslexia;
- cognitive and motor learning disorders (ideation, understanding of events, logic, initiative, curiosity, participation, willingness, etc.);
- communication disorders: reception, expression, understanding of the code, production, etc.;
- psychic and affective-relational disorders.

c) acquisition and generalization of motor learning disorders (passing from imitative, requested and voluntary execution of the task to spontaneous utilization of the learned ability in different contexts of daily life).

Recommendation of degree 4

3.1.1.5. 5th axis. Complications

They include:

- high morbidity for any reason;
- severe epilepsy;
- obesity;
- continuative assumption of drugs (*i.e.* antiepileptic, psychopharmacological, immunosuppressant, cortisone related drugs, etc.);
- conditions of severe family or social hardships (impossibility of continuative frequency of the rehabilitation service, lack of domestic space suitable for the proposed therapeutic activities, etc.);
- conditions of high emotional deprivation (parental depression, very frequent resorting to social services, temporary institution recovery, necessity to grant custody to another family, etc.);
- important traumatic events;
- poor agreement about the rehabilitation project between health service and family.

Recommendation of degree 4

3.1.1.6. 6th axis. Family

Concerning this aspect, it is important to consider appropriately:

- parental reliability (in respect to the delivery of instruments for the therapeutic exercise);
- difficulty of parental adaptation (negation and refusal, destiny fatalism, obsessive aggressiveness, vengeance behavior, accusations against the others, overspending and hyper protection, impotence for fear of committing mistakes, etc.);

- presence in the family of other problematic situations;
- inadequate physical living environment (including the lack of economic resources);
- presence of insurmountable home architectural barriers;
- impossibility to utilize at home the aids proposed in rehabilitation.

Recommendation of degree 4

3.1.1.7. 7th axis. The rehabilitation services

This aspect explores what the rehabilitation services offer:^{45, 46}

- ratio medical doctors/therapists;
- ratio therapists/patients (frequency and duration of the therapeutic sessions);
- availability of suitable places and of sufficient tools (aids, devices, tools, toys, etc.);
- accessibility and availability of transport systems supporting the rehabilitation service;
- adopted re-educational methodology and workloads;
- possibility of continuous education and of targeted professional specialization;
- possibility of access to specialist opinions (visual, orthopedic, neuropsychological, psychological, psychiatric aspects, etc.);
- possibility of collaboration with an orthosis workshop qualified in the child sector;
- presence of training or specialization people (physiotherapists, speech therapists, resident medical doctors, psychologists, educators, etc.).

Recommendation of degree 4

3.1.1.8. 8th axis. The child community

Finally, in the multiaxial approach other aspects have to be considered:

- possibility to attend a child community;
- availability of game and sport facilities;
- daily utilization of a special aids teacher;
- daily utilization of a special caregiver;
- presence of architectural barriers at school;
- behavior of peer group (welcome, acceptance, refusal, etc.);
- teacher behavior (involvement, delegation to others, renouncement, etc.).

Recommendation of degree 4

3.2. DESCRIPTION OF JUSTIFIED, AGE RELATED, FIELDS OF INTERVENTION

3.2.1. Age ranges

We identify the following age ranges: 0-2 years, 3-5 years, 6-8 years, 9-12 years, 13-18 years, over 18 years in order to allow a rational interpretation of the evolution of the principal functions, according to what is described in each justified field of intervention. Distinguishing age ranges, in fact, attributes a more precise value to the patient's functional diagnostic profile, allowing for a continuous revision in order to keep it always up to date.

Recommendation of degree 5

3.2.2. Justified field of therapy (intervention)

Starting from the patient's profile data, the following justified field of therapy describes:

- the architecture of the principal functions (activity/ ability) which is operated on in order to reach a therapeutic aim (object of the re-educational project);

Recommendation of degree 4

- the different types of principal functions, that can be assigned to the following areas: autonomic control, personal autonomy, locomotion, manipulation and praxis, sensation-perception and gnosis, cognition, communication, interrelationship;

Recommendation of degree 5

- the compatibility of the pursued therapeutic aims with the activities/abilities suitable for the age-range under consideration;

Recommendation of degree 5

- the priority of functional activities/abilities that a cerebral palsied child has to acquire in that specific age-range, namely the appointment (deadline) for the development. In this sense, the functional activities/abilities do not follow a predetermined hierarchic order (milestones), but change relatively to the subject's age-range. For example walking is an important goal for a subject between 0-2 years and 3-5 years; and can still be between 6-8 years in particular situations, but not after, except if there are extraordinary justifications (cut off time – “gate closure”). In place of walking, the conquest of sufficient autonomy in sitting posture,

with a manual or electronic wheelchair, becomes very important. This device can be suggested on the other hand even in a younger patient, between 3-5 years, if the prognosis for walking is negative;

Recommendation of degree 5

- we must agree at the same time that a continuation of re-educational treatment is not justified if, after a reasonable period of time, no significant change has appeared (“gate closure”);

Recommendation of degree 5

- the inability of the patient to learn and acquire the modifications produced on the function under consideration (which leads to a continuous demand for so called maintenance therapy) makes the continuation of the re-educational treatment unjustified.

Recommendation of degree 4

Patient assessment must take into account not only the single functional area involved, but also its relation to other areas, so that we can define the final level of acquired development and the influence that the considered area exerts on it. Inside each single functional area, the considered elements are specific for the different functions that form the examined area; each function can be observed (assessed), if necessary, with different cultural and operative tools. The tools employed usually vary inside each area in relation to patient age, emphasizing in this way the modification of the function. In the assessment of different performances it is important to analyze the details, without losing sight of the complexity of the existing interactions among the different functions and the individual as a whole, and between the individual and his environment (holistic and ecological approach to therapeutic intervention).⁴⁷⁻⁵³

In order to characterize the constitutive elements of the different functional areas, it is important to use not only descriptive behavior of the phenomenon (present, not present, partially present, emerging), but also underline if and how the child uses some strategies to adapt, to compensate, to substitute the performance, especially for their importance in guiding the therapeutic proposal.

Recommendation of degree 4

In the Appendix to these guidelines you will find some suggestions relative to the contents that must be stated, in the planning of the therapeutic program,

regarding the justified fields of intervention linked to each single age range. It is possible that the contents of a field have to be transferred into the successive one because, in the treatment of cerebral palsied children, it is necessary to follow the cognitive maturation of the subject and not only the chronological age. This becomes particularly important when delayed development in some specific areas is not due to the child's clinical conditions caused by CP or by a different pathway followed in the organization of knowledge, but as a consequence of a state of deprivation (see axis of complications).

3.3. OPERATIVE METHODOLOGY

In order to make re-educational treatment as effective as possible, it must be:

- timely, that is it must start as soon as possible (compatibly with the child's tolerance, his learning ability, his capacity to build a positive interaction with the therapist);

- intensive (1 h therapeutic session, ideally 4 or more times a week);

- continuous, at least in early life (naturally if the clinical conditions of the child allow for this). Any interruptions in re-educational treatment must be strictly in accordance with the therapeutic program.

Recommendation of degree 4

Any home physiotherapeutic treatment must be an exception and admitted only in accordance with a particular and temporary clinical condition of the child, because it could be antithetical to the teamwork model and therapeutic setting. Moreover, it is disadvantageous due to the absence of suitable environment, aids, instruments and devices.

Recommendation of degree 4

In order to plan a re-educational project related to each single justified field of intervention, we must adopt a procedure (rehabilitation methodology) that has to consider the following steps:

- 1) Functional evaluation (diagnosis of function).
- 2) Functional prognosis, that is the forecast of possible modifications.
- 3) Definition of treatment project and therapeutic program.

- 4) Therapeutic agreement (therapeutic contract) with the family.

- 5) Multidisciplinary approach and teamwork.

Recommendation of degree 4

- 1) Assessment and functional diagnosis of the patient through direct observation and an evaluation guided through the use of protocols built around the specific characteristics of the development of a cerebral palsied child. A clear definition and statement of the protocols used in patient assessment and in building the re-educational project is one of the criteria used to certify the rehabilitation structure.³⁸

Recommendation of degree 4

- 2) Declaration of the prognosis of function, that is of the predictive elements, both positive and negative, related to the functional area considered, on which the judgement of the possibility of reaching the expected final change, the aim of the re-educational project, is based. These elements must take into account the multiplicity of the functional areas involved and their reciprocal interactions (the therapeutic project is global, while the re-educational intervention, made by each single technical figure, is specific).

Recommendation of degree 4

- 3) The field of the re-educational project must consist of concrete activities/abilities aimed at realistic objectives. The re-educational project must not be planned in a standard manner (*i.e.* the application of a method as a universally prefabricated recipe), but must be adapted to the needs, the problems and the resources of that specific cerebral palsied child and his family, and must be constantly verified in this sense.

Recommendation of degree 4

- 4) The therapeutic program must be based on the evaluation of intermediate changes, or short and mid term objectives, for which the period of time must be declared in which the expected result can be reached. The methodology used to verify the child's progress in relation to the performed therapeutic intervention, is one of the criteria used to certify the rehabilitation structure.⁴⁵

Recommendation of degree 4

5) The organization based on therapeutic objectives may even justify the employment of a cyclic therapeutic treatment.

Recommendation of degree 4

6) It is important to state what therapeutic instruments we are going to use to obtain short term objectives (therapeutic exercises, setting, therapeutic interaction, drugs, devices, orthosis, tools, aids, parental and caregiver instructions, counseling to teachers, adaptive changes of environment, etc.) and the indicators that will be used to assess the obtained result. These instruments must be strictly connected with the justified field of the therapeutic intervention under consideration and must have undergone an international validation or must have been used at the same time by many different public or private centers or published in authoritative journals that deal with this field. The statement of instruments and procedures used to measure the effectiveness of the rehabilitation treatment is one of the criteria used to certify the rehabilitation structure.

Recommendation of degree 4

7) Since the instruments used in this procedure consist of the verification of patient acquisition of performances, that represent the achievement of the expected result (that is the intermediate or final change), it is necessary that the objective which we are trying to achieve (*i.e.* the different levels of change within the considered function) be described in terms of simplicity, possibility to be observed, communicability and measurability. In other words, we must be able to clearly compare how the child was before and after re-educational treatment.

Recommendation of degree 4

8) To guarantee the highest possible objectivity, it is necessary to use a standardized video recording procedure in addition to functional evaluation scales as an instrument able to measure change.

Recommendation of degree 4

9) To stipulate a therapeutic contract with family and child (if compatible with age and cognitive level) regarding the re-educational project, or the goals we intend to reach through the physiotherapeutic treatment.⁴⁶ Generally, the therapeutic contract should be renewed once a year.

Recommendation of degree 4

10) To outline the therapeutic project, a multidisciplinary approach is necessary. This means that professionals from different areas all have to simultaneously contribute to its realization (physician, child neuropsychiatrist, physiotherapist, orthotist, etc.).

Recommendation of degree 4

11) In order to define the therapeutic program, a positive and continuous interactive relationship between rehabilitation specialist and physiotherapists, respecting each specific area of expertise and responsibility, is necessary.

Recommendation of degree 4

12) The multidisciplinary rehabilitation team must be formed by an adequate number of people in relation to the number of patients followed, must have sufficient time also to project and check therapeutic intervention, must be included in a network of regional and national rehabilitation services for childhood and must adhere to the Continuous Educational Programme for Medicine.

Recommendation of degree 4

13) The therapeutic agreement implies that the therapeutic project cannot be dictated to or imposed on the child and his family; instead active involvement of the family must be pursued, maintaining a clear distinction of reciprocal roles (care taking). Responsibility for the rehabilitation project and the therapeutic program cannot be given to the parents, but must be assumed by the rehabilitation specialist. At the same time it is indispensable to inform the parents on the therapeutic goals to achieve (and their temporal limits) and on the instruments used to obtain them. So that the parents can acquire both a greater knowledge about the possibilities and the limits of child recovery and have a better understanding of the outcome that the executed rehabilitation program will have on daily activities. It is not correct to give parents the role of therapist, delegating to them the therapeutic intervention (it obliges them to take on responsibilities that should not be theirs), and would be otherwise reciprocally incorrect to give all the responsibilities of the therapeutic activities exclusively to the therapist. Instead, it is necessary to identify, together with the parents, a series of situations in which the cerebral palsied child can perform useful experiences in everyday activities which are helpful and consistent

with the ongoing process of recovery. For the child to generalize abilities learned in specific therapeutic situations, enhancing his everyday performances, while the parents observing carefully the child's behavior can give the rehabilitation specialist pertinent information suitable for a more correct therapeutic intervention. A similar active and collaborative involvement must be also pursued with the educational and scholastic structures.⁵⁴⁻⁶¹

Recommendation of degree 4

14) Each pediatric rehabilitation unit must have in place a quality evaluation system in order to assess statements of received treatment by users (parents and patients).

Recommendation of degree 4

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4. APPENDIX

4.1. Age range 0-2 years

Autonomic area:

- adaptation to extra uterine environment;
- circadian rhythm: asleep/awake, hungry/full, calm/active etc.;
- respiration (frequency and pattern);
- alvus and diuresis;
- feeding: sucking, chewing/deglutition, meal duration, posture for feeding, development and differentiation of taste (from sweet to salty), etc.

Personal autonomy area:

- autonomy in eating with hands;
- basic ability to use a piece of cutlery (spoon or fork);
- ability to open a box in order to remove its contents;
- tolerance/collaboration of/in assistance procedures (*i.e.* to be dressed, undressed, cleaned etc.)

Locomotor area:

- ability to control and change posture in the different positions (supine, prone, sitting, etc.) with or without devices or orthoses;
- ability to change and control head, trunk, upper and lower limb movements, etc.;
- ability to move autonomously on the ground: prone/sitting, with or without simple aids (baby walk-

er, tricycle without pedals, Bobath triangle or similar aids-devices, etc.);

- ability to walk autonomously with or without aids, etc.;
- ability to climb or go down stairs, to overcome small obstacles, etc.;
- walking and simultaneously holding, pushing or pulling objects (walkers, toys, etc.) with or without aids.

Manipulation area:

- Grasping (body positioning and orienteering in order to reach, hold, release, throw, place an object, etc.);
- grip adaptation on the object (different types of grasping), to transfer an object from one hand to another, to explore it, to put it down according to its physical characteristics, etc.;
- eye-hand or eye-hand-mouth coordination, etc.;
- ability to anticipate type of grasp (preadaptation), in relation to the previous manipulation experiences;
- functional application and possibility to transfer the ability learned from one context to another, etc.

Perception area:

- Sight: perception of space near and far from the child (visual field), figure-background distinction, etc.;

- eye movements: eye contact, eye catching (capture, fixation, ability to follow a moving object);
- hearing: perception, orienteering, reaction and tolerance to noise, voice recognition;
- taste: ability to distinguish (perceptual attention) the different tastes: sweet, salty, bitter, tart, spicy, etc.;
- proprioception: tolerance to postural changes, to emptiness, to depth, etc.;
- touch: being touched, tactile exploration and discrimination, tolerance to temperature and different textures;
- perceptual integration and configuration among different sensation apparatuses.

Cognitive area (ability of mental representation):

- observation and recognition of different body parts related to self or others;
- activity with the object (reproduction of simple movement patterns, their differentiation and generalization, simple aim-directed pattern integration, analysis and discovery of different object effects, mental object image retention);
- ability to explore surrounding environment and recognize places, objects, and types of play organization;
- socially motivated actions and imitation behavior for words or gestures (to wave hello, to point, to pretend to eat, to drink, to feed a doll, etc.);
- adaptation to different social situations (eating, bathing, going for a walk, playing etc.);
- ability to foresee results and anticipate adaptation of an action (implying the ability of mental representation and coinciding with the search for problem solving strategies);
- writing gestures with simple tools (felt pen): modifying strategies from scribbling to drawing a closed circle;
- attention spans and differentiation of attention behaviors in different situations etc.

Communication area:

- orienting in relation to sounds, noises, voices;
- verbal comprehension;
- non verbal communication: grimacing, smiling, communication gestures, pointing, showing;
- verbal communication: types of crying, vocalization, lallation, words and short phrases (2 words);
- focused attention on communication, suitable communicative and intentional answers (verbal and non verbal);
- verbal and gesture imitation behavior etc.

Emotion-relationship area:

- ability to distinguish between family components and strangers;
- attention to adults, to the tick-tock of a clock, tolerance to separation from caregivers and initial experimentation of psychological autonomy from reference figures;
- ways of crying and receiving comfort, different behavior between family members and strangers;
- self control and ability to differentiate emotional statuses and to tolerate low level frustration.

4.2. Age range 3 - 5 years

Autonomic area:

- rhythm: asleep/awake;
- alvus and diuresis;
- feeding: chewing, meal duration, taste differentiation.

Personal autonomy area:

- sphincter control and asking to go to the toilet (alvus and diuresis), use of hygienic apparatuses;
- autonomy in food assumption using 2 pieces of cutlery (spoon and fork);
- ability to cooperate in assistance procedures (*i.e.* dressing, undressing, cleaning, performing personal hygiene and tidying things and storing them, etc.);
- danger/risk awareness.

Locomotor area:

- ability to change and control posture in different positions (supine, prone, sitting, etc.) and head, trunk, upper and lower limb movements, etc.;
- ability to move autonomously: supine/prone/sitting, with or without simple aids;
- ability to make postural changes from and to the upright posture;
- ability to walk autonomously and smoothly with or without aids;
- ability to climb or to go down stairs, to overcome obstacles inside or outside home, etc.;
- ability to use complex devices (tricycle with pedals, bicycle with small training wheels, manual or electronic wheelchair, walkers, etc.).

Manipulation area:

- specialized manipulation (to button clothes, to hold cutlery or a pen, to turn pages, to press buttons on a remote control device);

- training in the use of electronic instruments (mouse, keyboard, etc.);
- functional use of objects for different aims;
- ability to favorably adapt and modify environment.

Perception area:

- sight: visual orientation, recognition, figure-background distinction, etc.;
- hearing: tolerance and reaction to sudden or unknown noises;
- proprioception: tolerance to movement, to emptiness, to instability, etc.;
- touch: tactile discrimination and recognition.

Anticipatory abilities:

- ability to use symbolic representations (subsequent imitating, making believe play);
- individual or group play;
- simple and complex classification and ordering games;
- problem solving;
- prolonged attention spans and differentiation of attention behaviors in different situations, etc.;
- complex writing gestures (drawing).

Communication area:

- learning specific code for communication, ability to name objects;
- use of conventional signals to say yes, no, to approve, to refuse, to attract, to reinforce, etc.;
- comprehension of contextual and non contextual orders;
- listening and comprehension of simple stories;
- investigation to understand why;
- ability to use facilitating instruments in order to express themselves (alternative communication);
- vocabulary and grammar enhancement through the use of correct language structures.

Emotion-relationship area:

- adaptation to new environments;
- to have internal emotional references and possibility to tolerate longer separation periods from reference figures;
- interaction in a child community and ability to express different behaviors with peers;
- different behavior between family members and strangers;
- ability to negotiate and to minimize conflicts, to

control impulses, to work out emotional experiences, to tolerate frustration.

4.3. Age range 6-8 years

Personal autonomy area:

- activity daily living (*i.e.* dressing, undressing, bathing, tidying and storing things, etc.);
- sphincter control and use of hygienic apparatuses;
- use of cutlery and meal time behavior;
- ability to use specific devices and simple apparatuses for environment control, etc.

Locomotor area:

- walk with or without aids in the house or outside (if justified);
- postural changes from one device to another;
- postural changes and overcoming obstacles with aids/devices (autonomy in complex environment);
- use of devices to control posture;
- use of manual or electronic wheelchair.

Manipulation area:

- functional use of suitable tools for specific aims (*i.e.* with specialization);
- training in the use of keyboard and computer devices;
- training in the use of tools and devices;
- training in autonomy in daily living activity.

Perceptual area:

- multi sensorial exploration of complex objects;
- tolerance to acceleration and deceleration.

Cognitive area (anticipatory abilities):

- emergence of cognitive decentralization, thought reversal, invariance;
- relation to family and school environment;
- development of basic functions such as memory and selective attention;
- elaboration of experiences and memories and their generalization;
- school performance (reading, writing, calculating) and training to use tools to make basic operations simpler (*i.e.* visual scanning);
- emerging of metacognitive strategies (thinking about goals, alternative possible solution analysis etc.) and of basic functions such as memory and attention;

- problem solving.

Communication area:

- listening and verbal comprehension;
- training in the use of computer devices for communication (written and verbal);
- increased and alternative communication (for example Bliss Symbols).

Emotion-relationship area:

- awareness of personal needs and desires;
- respect of roles and rules, to accept duties and responsibilities;
- ability to express and share emotional statuses;
- ability to distinguish between fantasy and reality;
- ability to be autonomous in family and out of family experiences;
- interest in peer group and ability to play a role within this group.

4.4. Age range 9-12 years

Personal autonomy area:

- preparing and serving simple food (to pour, to peel, etc.);
- use of simple or adapted tools to control environment;
- ability to point out simple adaptive changes that improve environment.

Locomotor area:

- use of devices and aids for postural control;
- use of manual or electronic wheelchair in outdoor environments with or without adult supervision.

Manipulation area:

- specific training in the use of computer and other electronic devices;
- specific training in the use of work tools;
- specific training in the use of common home devices (telephone, stove, etc.)

Perceptual area:

- simultaneous control (integration between perceptual and motor functions);
- automatic execution.

Cognitive area:

- problem solving;
- school performances (reading, writing, calcu-

lating) and training in the use of tools to make basic operations simpler (for example visual scanning);

- reinforcement of metacognitive structures (thinking about goals, possible alternative solution analysis, etc.) and of basic functions such as memory and attention;

- reflection about experiences and memories and creation of rules;

- ability to reason and judge experiences.

Communication area:

- listening and verbal comprehension;
- training in the use of computer and other electronic devices for communication (written and verbal);
- increased and alternative communication (for example Bliss Symbols).

Emotion-relationship area:

- ability to reflect in order to begin to accept and elaborate the experience of the illness;
- social role assumption, ability to develop friendship;
- ability to distinguish and control emotional statuses;
- ability to be autonomous in family or out of family experiences;
- awareness of learning abilities.

4.5. Age range 13 – 18 years

Personal autonomy area:

- to be able to stay alone at home autonomously (how to survive);
- to do the shopping and prepare and serve food for him/herself or others;
- autonomy in community services.

Locomotor area:

- use of electronic wheelchair outside home without adult supervision;
- use of public transport.

Manipulation area:

- functional use of tools, instruments and devices aimed at personal and environmental autonomy with aids;
- to take care of the house: autonomy and independence;
- work training.

Perceptual area:

- simultaneous control of different activities.

Cognitive area (formal operations):

- to think about experiences and memories (putting them into episodic context and organizing them into time sequences) creating more general schemes;
- assuming responsibility for decisions and pursuit of autonomy;
- judgment of his/her and other people's behavior;
- ability to think about factual events or hypothetical problems;
- pursuit for problem solving guided under hypothesis and successive checking.

Communication area:

- listening and verbal comprehension;
- training in the use of computer and other electronic devices for communication (written and oral) and use of different codes (for example Bliss Symbols);
- ability to adapt messages to the context and to the addressee;
- ability to keep a secret, or perform a task.

Emotion-relationship area:

- ability to reflect in order to begin to accept and elaborate the experience of the illness;
- social role assumption, auto responsibility;
- ability to be autonomous in family or out of family experiences;
- sexual identification and maturation;
- imagining of personal interests aimed at an eventual work position and social role.

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- S. Pignatelli, USL, Taranto;
- A. Pirari, USL Nuoro Hospital, Nuoro;
- G. Rubini, Motory Rehabilitation Unit, ULSS 20, Verona;
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- G. Tarditi, Piedmont USL 8, Turin;
- A. Turconi, IRCCS Medea, Bosisio Parini (Como).