University of Modena and Reggio Emilia

Faculty of Medicine

Department of Biomedical and Metabolic Science and Neuroscience

Paediatric palliative care

Disability

Adriano Ferrari

Rehabilitation Medicine, University of Modena and Reggio Emilia

Specialised Children Rehabilitation Unit, IRCCS Azienda Arcispedale Santa Maria Nuova, Reggio Emilia - Italy

Child rehabilitation

Rehabilitation medicine in paediatric field mostly deals with pathologies without any feasible possibility of an effective cure

- Cerebral palsy
- Neuromuscular diseases (dystrophies, myopathies, atrophies, myotonias, etc.)
- Spinal cord injuries (spina bifida, neuroblastomas, traumatic lesions, etc.)
- Genetic syndromes
- Congenital malformations (arthrogryposis, phocomelias, etc.)

So paediatric rehabilitation is necessarily a type of palliative care.

Cerebral palsy definition

- Cerebral Palsy is the leading cause of disability in first childhood
- Cerebral palsy is a persistent but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, as the result of interference during its development (The Little Club, 1958; Bax, 1964)
- Updated version: CP is a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain, arising in the early stages of its development (Much et al. 1992)
- In developed countries, the rate of CP is higher than 2/1000 (a new case every 500 births !)

Paediatric rehabilitation: from cure to care

- Since it is impossible to realise a definitive cure of these pathologies and it is impossible to speak about restoring normality, the goal of rehabilitation is to take care of children with their pathologies and not to cure the pathology of the children (A Milani Comparetti)
- So paediatric rehabilitation ideally is an accompanying action of the child and their family. In this sense, rehabilitation can be appropriately considered a type of palliative care
- The final destination of any rehabilitation journey should ideally be child independence, but can also be a "good" death (in case of progressive illness)

Independence

- *Independence* is impossible for anyone. In fact, we live in a society based on mutual dependency
- *Autonomy* is the ability to provide for oneself
- *Self-sufficiency* is the capacity to detect what needs to be done, that is to know what, who, why and how, also the possibility to ask for help
- *Self-determination* is the capacity to decide for oneself

In the paediatric field, self-determination is usually inhibited by adults, especially in conditions of illness/impairment, and even more in presence of disabilities (the parents decide for the good of the child = family-centred and not child-centred therapy)

So without self-determination, the child can never really become autonomous. In fact, the fundamental autonomy is the mental autonomy

Child rehabilitation

- It is a form of education that deals with the consequences of an illness and sometimes also with the consequences of received cures
- Most of the time, it is unable to correct the primary lesion, but all the same produces adequate compensations and suitable alternative solutions
- It does not restore normality, but is able to reciprocally adapt individuals, community and environment (physical and cultural) to each other
- It makes interaction, integration and independence (!) in some way possible

Child rehabilitation

- While in paediatric field, for **diagnosis**, the stated goal is to identify what is missing or has been lost or damaged, in order to repair or substitute it, in child rehabilitation, for **prognosis**, the challenge is undoubtedly to identify what is left and find out what can be done with it, in spite of the persistent pathology

- In other words:

  paediatric vision → the lesion (the compromised parts, what is missing)

  rehabilitation vision → the conserved parts (what is still left)

For this reason the key word for rehabilitation is therefore "nevertheless"

From diagnosis of lesion (paediatrician) to prognosis of function (physiatrist)

Child rehabilitation instruments

The rehabilitation instruments are:

- modifiability of the compromised function (compared to natural history of impairment and not to typical child development)
- learning ability (in cases of CNS lesions also this fundamental function is unavoidably involved)
- motivation of the child, i.e. willingness, initiative, determination, resilience, etc.

In fact, the principal actor of rehabilitation process, first of all is the child, their needs, their desires, their resources, including family, social and cultural facilities.

The most difficult patient is the child who refuses to participate

The parents realise this aspect and often speak of laziness.

Perverse alliance

When the child is termed lazy (demotivated), in the end, he/she is blamed for wanting to remain disabled against all collective efforts (thus going from being the victim to becoming the offender). In fact everyone tries to do more:

- Parents to feel adequate search for the best doctor
- Doctors to feel adequate prescribe the most advanced therapies
- Therapists to feel adequate perform an array of intensive and extensive therapeutic treatments.

But no one takes into consideration what the child wants or would like to do (perverse alliance against the child of Winnicott).

- What does the disabled child expect for their own future ?
- Their future is designed by others, so the child is unable to identify with this life project

First period: parent faults and regrets

This feeling is expressed through depression, insecurity, incomprehension, incapacity, impotence, lowering of self esteem, desire to give-up and escape, need to delegate to others, desire to expiate.
This can lead to:
→ Passivity in decision-making
→ Psychological dependence

Palliative care = training (delivery of programs / solutions / recommendations / exercises)

Second period: parent guilt and remorse

Need to satisfy self-availability in order to avoid feeling remorse due to do not being able to do enough, desire to redeem oneself, necessity to dedicate one's positive energy in something able to favour the child, hopeful expectation of success

- Aggressive pay-back (guilt transition: mother → professionals → society)
- Maniacal association

Palliative care → habilitation (delivery of knowledge)

Child rehabilitation principals

- Behaviour models, practical experience and positive emotions are the main components of the recovery process in child rehabilitation.
- Treatment in rehabilitation is a two-way street where the therapists must adapt themselves to the child so that the child can draw advantage from their therapy.
- Child rehabilitation and especially physiotherapy and occupational therapy are, in fact, therapeutic actions carried out by interaction.

Doing therapy and being a therapist are very different things:

- a psychoanalyst is a therapist without therapies (pure interaction)
- physical therapy (i.e. electric stimulation) is a therapy without any human interaction

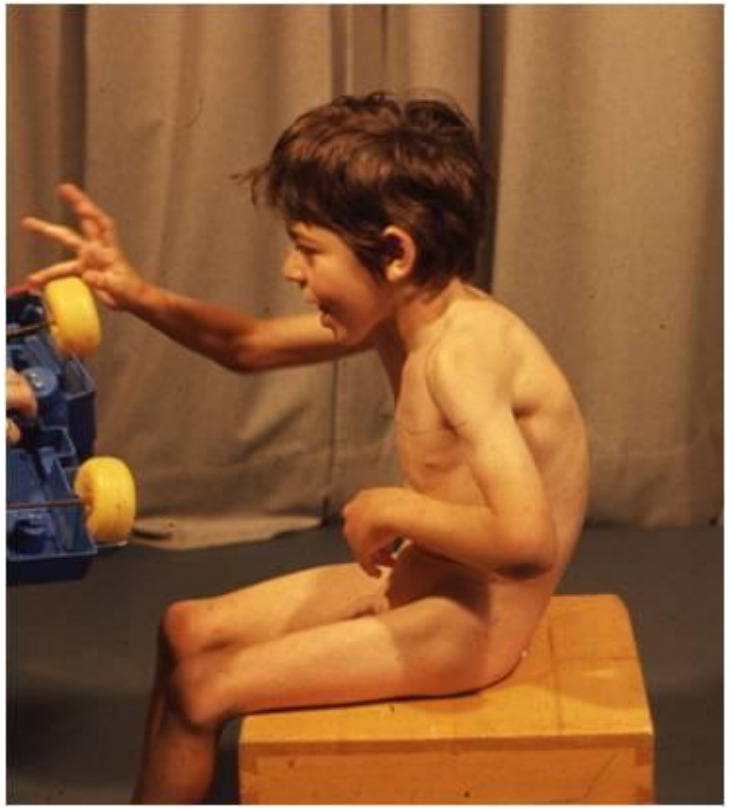
For this reason, A Milani Comparetti insisted on prescribing therapists and not therapies

Rehabilitation goals

- In order to facilitate the transferability of acquired competences and abilities, therapeutic proposals have to be "flavoured" with intrinsic pleasure. In fact, only positive experiences have the possibility to be conserved and repeated. Unpleasant experiences will be removed and forgotten.
- This represents the most difficult aspect in child rehabilitation. In fact, spasticity or loss of muscle strength, limited range of motion or bone deformity and restrained or compromised movements are often insuperable negative constraints.

Rehabilitation goals

- Therapeutic activities, on the other hand, are often tiring, exercises difficult to perform, some interventions aggressive, such as the adoption of orthoses and devices, and some painful such as surgical correction of congenital or acquired deformities.
- It is particularly difficult to generate pleasure (and fun) if the movement only produces tiredness, effort, discomfort, fear, failure and frustration.



Rehabilitation goals

- The environment of Rehabilitation itself could be psychologically isolating and stigmatising. In fact, the comparison with other patients can be encouraging (positive model in therapeutic group) but can also be detrimental (the more severely compromised patient in progressive pathologies or the image of the so-called become-adult).
- The possibility of identifying through an effective role-model a possible future for oneself is one of the greatest difficulties in the development of a disable child.
- The palsy compromises also the possibility of dreaming.

Rehabilitation constraints

- Immigration requires a continuous change in social integration on both parts (natives and immigrants) and in this process, culture and religious beliefs are important constraints. For sick children these constraints are even more binding than the original disability.
- The stigma of disability can contaminate also parents and relatives (vertical transmission).
- A disabled child can not be inherited by anyone (especially by siblings).
- So the disabled child has only a past and no feasible future and parents ask "what will happen after we are gone ?"

Rehabilitation goals

- The therapeutic effort directed at disabled children would be in any case insufficient in guaranteeing their full participation in society, if rehabilitation limits itself only to the education of the disabled individual.
- Indeed, it is necessary to educate general population to the presence of the disabled person, beginning with same aged children, in order for a true and complete integration in society to take place.
- The aim of rehabilitation is to shift from education of the disabled person to education about disabled persons

Conclusions

- Rehabilitation is a complex intervention on the population
- For this reason, the most important progress in child rehabilitation has been, in my opinion, the Italian law established 40 years ago, that allows all children, Italian and foreign, also all disabled children, all types of disabled children, to attend regular school (there is only one school and it is open for everyone, and that's all) .
- It is still, today, the only example of its kind in the world.

Conclusions

The logo of my master of paediatric rehabilitation. It is a sculpture of Graziano Pompili entitled re-archaeology. In my opinion it is the synthesis of paediatric rehabilitation. You can see the head of a child, the signs of the lesion and the procedures carried out for its repair. Both signs are recognisable. In the same way you can think about the outcome of the primary lesion and the proposed rehabilitation strategies.

Thank you