

Physiotherapeutic intervention in the outpatient care of persons with Down syndrome at the Institute of Physical Medicine and Rehabilitation at HC FMUSP

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ABSTRACT

Down Syndrome (SD) is the most common chromosomopathy in humans. It is known that, if properly stimulated, these people have the potential for full social inclusion. The objective of this study is to show the work done with this population by the Physiotherapy service provided by the multi-professional team at the Clinic for the Care of Persons with DS at the Institute of Physical Medicine and Rehabilitation at HC FMUSP. This clinic develops therapeutic activities for persons up to 18 years of age. The work is carried out in models, which are subdivided into: a DS General Stimulation Model which serves patients up to three years of age whose objectives are focused on the acquisition of motor marks, essential for neuropsychomotor development; a DS Child Development Model which helps children from four to eleven years of age that focuses on the development of more advanced motor skills, strength, posture, improvement of mobility, balance, and proprioception to optimize cerebellar activity and the consequent enhancement of static and dynamic balance; a DS Adolescent Model for those aged twelve to eighteen; and a DS Adult Model starting at age nineteen aimed at orthopedic and postural restoration in addition to providing health guidance. Physiotherapeutic monitoring is fundamental within the clinic for the care of a person with DS, for it stimulates the motor development of these children, along with the multiprofessional team and the family, respecting their time and favoring their potentials, in addition to acting to educate the family on health so as to prevent problems and promote the health of the person with DS and their nuclear family.

Keywords: Down Syndrome, Child Development, Motor Skills, Physiotherapy Modalities, Rehabilitation Centers

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Received on March 20, 2013.

Accepted on June 19, 2013.

DOI: 10.5935/0104-7795.20130010

INTRODUCTION

Down Syndrome (DS) is a human condition genetically determined by the presence of an extra chromosome 21, responsible for the physical and physiological characteristics that result in a delayed neuropsychomotor development. Despite that, when these people receive good medical care and stimulation, they have the potential to be fully included socially.

Described for the first time by John Langdon Down in 1866, people with low stature, straight hair, epicanthic folds, flattened nasal base, and slight to moderate intellectual deficit were called mongoloids. Considering that this was its first complete description, this group of signs and symptoms came to be known as Down syndrome, in recognition of its first researcher. The term "mongolism" was excluded from publications of the magazine *Lancet* (1964), World Health Organization (1965), and *Index Medicus* (1975) for its derogatory connotation, and to this day is considered archaic and prejudiced and must be avoided.¹

Since the description made by Langdon Down, the literature has listed many structural and systemic alterations associated with DS. Among the musculoskeletal alterations, irregularity of bone density, cartilage hypoplasia, generalized hypotonia, low stature, and ligament slackness are foremost.² The presence of these musculoskeletal alterations has an impact on the development of motor abilities such as delay in the acquisition of basic motor marks, which are acquired later than by healthy individuals.³ However, the appropriate stimulation made by qualified professionals helps these people in their development process. Therefore, the activity of the physiotherapist is studied in the care of people with DS at different age brackets at the Institute for Physical Medicine and Rehabilitation - HCFMUSP. This institution, recognized as a reference in physical rehabilitation, also offers care to people with DS, among other pathologies, since August 2010.

Development, functionality, and physical therapy objectives

The functionality development pattern in infancy begins with the acquisition of a wide spectrum of motor abilities that will enable controlling the body in different postures, static or dynamic.⁴ The three first years of life are marked by neurosensory maturation represented by motor and

language acquisitions. From three to seven years of age, the motor acquisitions become less intense and perceptible giving place to the development of cognitive expressions, socio-emotional aspects, and graphic communication.⁵ From seven years of age there is further development of the acquired motor and cognitive abilities, such as improvement of balance, psychomotricity, interaction, widening of world perception and understanding.

Despite the intellectual deficit and the delay in the neuropsychomotor development, the child with DS can show considerable progress with good stimulation from the environment, facilitated by qualified professionals and, above all, by its family.

In view of the premises mentioned above, the presence of a physiotherapist in the care program of a person with DS is fundamental in the composition of a multiprofessional team, made up of a physician, an occupational therapist, a nurse, a psychologist, and physical educator, a speech therapist, a nutritionist, and a social worker. The action of physiotherapy includes: evaluation, preparation of a physiotherapeutic diagnosis, construction of a situational diagnosis, of an individual care plan, and of the therapeutic goals sought by the multiprofessional team, followed by intervention and re-evaluation.

Physiotherapeutic care

The care of people with DS at the IMREA-HCFMUSP clinic is organized by models according to the age bracket:

- General Stimulation Model: from zero to three years of age;
- Child Development Model: from four to eleven years of age;
- Adolescent Model: from twelve to eighteen years of age;
- Adult Model: from nineteen years of age and beyond.

GENERAL STIMULATION MODEL

Physiotherapeutic objective

The objectives of physiotherapeutic action in general stimulation lead to the acquisition of motor marks, essential for neuropsychomotor development. We call it general stimulation, and not precocious stimulation, guided by the theoretical presupposition of integrality admitted by the team. In that sense, we seek to broaden our view of the patient's needs as a whole, supported by the different knowledge of

the members of the team. We also chose not to use the term "precocious" out of an understanding that the therapy offered is a demand related to that time in the person's life, in which case it is not precocious, but well suited. Finally, the stimulation is not precocious because it does not seek to accelerate the stages of the evolution process, but to stimulate the neuropsychomotor development of these people.

The main objectives of the general stimulation program in the physiotherapy service are:

- Motor stimulation to acquire postural control;
- Motor stimulation to change and maintain postures with ease and stability;
- Postural facilitation to enable manual activities, with the use of accessories that may be made and/or provided by the parents or persons responsible for domestic use;
- To aid in developing protection and balance reactions;
- To use strategies to accelerate the achievement of main motor marks (sitting with and without support, crawling and/or dragging oneself, orthostatism with and without support, and acquisition of gait);
- Orientation for parents to be co-responsible for the physiotherapeutic objectives at home.

Physiotherapeutic evaluation

The first contact of the physiotherapist with the child occurs in the evaluation, in which the situational diagnosis determined for the child's motor development, which allows the process of general stimulation to be prescribed.

The first of four parts of the evaluation consists of collecting personal data, such as the child's age, whether it has followed and/or follows any stimulation program at another institution, any history of hospitalizations, complaints of pain and/or possible orthopedic injuries.

The second part of the process of evaluation is the physical exam to verify the amplitude of movements that can be preserved, reduced, or that are hypermobile. To evaluate the muscle tone we use the postural observation and the Xale and Leffèvre signs.⁶

The third part consists of applying the Alberta Infant Motor Scale (AIMS), a standardized scale, developed by Piper &

Darrah, that proposes to evaluate and monitor the overall development of breastfeeding children through the observation of spontaneous motor activity from birth until 18 months of age or until the acquisition of an independent gait.⁷ It was created to evaluate breastfeeding children in danger of developing neuromotor dysfunctions due to premature birth. It is an observational scale, easy to apply, with low cost, not requiring excessive handling of the child, and validated for use in Brazil.⁸ It must be applied by a child health care professional who knows about children's motor development.⁷ The AIMS quantifies the overall motor activity through a raw score, considering three criteria related to the quality of the movement: weight distribution, posture, and anti-gravitational movements. In Brazil, this scale has been widely used in research protocols for its practicality in evaluating the development of breastfeeding children and children inserted into follow-up programs in the Brazilian public health network. Although it is not a scale specific for DS children, it is applicable to this group.⁹ Finally, the last part of the evaluation consists of anthropometric measurements.

Physiotherapeutic intervention

The stimulation sessions take place at least once (1) a week and last 30 minutes each. During the sessions the physiotherapist is responsible for the child's stimulation process in addition to guiding parents and/or responsible parties on how to promote stimulation at home, since they are the ones who spend more time with the child.

In our experience, the 30 minute sessions showed better improvement of the child when compared to 60 minute sessions, since they expose the child to higher levels of fatigue, in addition to the lack of attention that can occur during a more prolonged stimulation session.

Until three years of age the intensive stimulation focused on the child with DS is a determinant for the development of nerves and nerve groupings. This would not only accelerate development and learning, but also have a long-term effect, reducing limitations in the nervous system of these children.¹⁰

To promote general stimulation, the treatment room is equipped with Bobath balls, proprioceptive board, stimulating toys with lights, colors, and sounds, a swing, DynaDisk, mirror, benches of different heights,

foams of various densities, and foam rolls for positioning, in addition to a great variety of other objects that may be therapeutic depending on their use (Figure 1). The stimulating environment is also prepared so that there are elements that awaken the curiosity of the child, but at the same time, do not disperse its attention. The use of decorations, figures, and toys spread around the room may, most times, make it difficult to focus the child's attention during a specific stimulation and/or activity.

One of the most relevant factors to consider, in the general stimulation process of a child with DS, is that they do not show movement disturbances, but rather a delay in their normal motor development. Thus, they must not be given techniques to treat limitations or restrictions of "abnormal" movements, for they do not present them, except those children with different diagnostics such as hemiplegia or neuromuscular diseases.

Sensory stimulation

Used to create an initial bond with the child, this is approached with eye contact,

somesthetic stimulation with different textures, kinesthetic stimulation with swings made of bed sheets, and proprioceptive stimulation with articular coaptations.

Development of motor marks

At the beginning of their motor development, children with DS take static and symmetrical postures due to their poor postural control. This hinders the acquisition of dynamic motor abilities such as postural transferences and locomotion. In that way, the motor abilities in each one of these postures are acquired when the static abilities are well improved.¹¹

Stimulating the motor marks seeks to indicate to the child's Central Nervous System the first experience of the movement not yet performed actively. In our service, we use the standard motor development pattern of a typical child (TC) only to guide the stimulation process, not to classify it.

The main motor marks worked in the general stimulation program in our service are:



Figure 1. Stimulation of cerebellar connections and brain stem with a ball

- Eye-contact and active movement of the head (TC: 2-3 months).
- Stimulation of hand medialization (TC: 2 - 4 months).
- Postural control (TC: 2 - 5 months).

It is important to emphasize caution while executing cervical stimulation in babies and children with DS, taking into account the incidence of atlanto-axial instability (AAI). It is known that this instability occurs in 15% of this population, and most times it is asymptomatic, with an estimate of spinal cord compression symptoms in only 1% to 2% of the cases.^{12,13} AAI in DS may be secondary to a bone abnormality of the odontoid process and/or may be linked to a flaw of the intrinsic collagen that provokes a transverse ligament slackness, leading to a chronic inflammatory process that weakens the entire ligament structure of the area. A radiological diagnosis is only possible when the child reaches three years of age and is asymptomatic.¹⁴ The AAI symptoms are directly related to those of myelopathy, which are: cervical or radicular pain, weakness, spasticity, muscle tone alterations, and hyperreflexia.¹⁴ The radiological exam is made with the head in flexion, and measuring the distance on the image between the odontoid process and the C1 posterior upper base. This measurement must not exceed 4.5mm, but if it does, it is diagnosed as AAI.¹³

Thus, it is important to point out the instructions for brusque movements of cervical flexion and extension. These movements may be present in playful activities such as "Serra-Serra Serrador" (similar to See Saw Margery Daw), somersaults, abruptly rolling with the child, and also when the child is older, in certain sports activities. In these cases, the activity must be well guided by the physiotherapist who, in tandem with the physician and radiological exam, will evaluate whether the activity is safe for the child (Figure 2).

- Trunk extension (TC: 2 - 4 months)
- Rotations (TC: 3 - 7 months).
- Trunk control (TC: 5 - 7 months).
- Sitting down (TC: 6 - 7 months).

One of the proposals for sitting down is in using the "tire" strategy. In our service, we use a car tire, duly sanitized. We line it with cloth and position the child inside it. Over the tire we place toys that call the attention of the child. In this way, the child has good dorsal and lateral support, while seeking better trunk stabilization. We also use the positioning pants: a pair of adult jeans, with the



Figure 2. Trunk extension stimulation with a ball

legs and hips sewn shut and filled with foam. To position the child seated in these pants, we support the "hips" of the pants on a wall, we seat the child supporting its back on this "hip" while crossing the legs of the pants in front of the child, as a belt, favoring its stability in this position (Figure 3).

- Positioning to crawl/drag oneself (TC: 8 - 10 months).

In our service, one of the most frequent questions parents make about the motor development of their children is whether the child needs to crawl. The child does not necessarily need to crawl, but being on all fours is essential for the biomechanical formation of the hips. Hips in DS are rotated outwards and are kept in extension, like in a biomechanical blockage (Figure 4). Among children with DS, 5% develop hip luxation or dysplasia and this may be explained by ligament slackness and/or muscular hypotonia.^{11,15} The acetabular formation is properly established according to the first movements and weight loads on the hips. That way, the more frequent this stimulation, the less will be the chances of developing acetabular dysplasia or other affections that compromise this articulation and, consequently, the less will be the risk of luxation.

Gait (TC: 14 - 18 months): To initiate the stimulation of gait, first we offer a support mechanism. We can use a toy that will help in this support, such as a little high cart that can be pushed, or even a towel or swimming pool spaghetti positioned under the arm pits and around the child's thorax. When the child is able to perform walk with more stability, we can adopt the strategy of wall support, which is to position the child in orthostatism against a wall. The therapist stays a few inches ahead of the child and shows a toy that calls the child's attention, so that he or she will follow it. The child will leave the wall and search for some stability and will walk towards the toy.

CHILD DEVELOPMENT MODEL

Physiotherapeutic objectives

In this group, the objectives are focused on the development of more advanced motor abilities, such as strength, posture, improvement of motor skills, balance and proprioception to optimize cerebellar activity, and consequent improvement of static and dynamic balance, in addition to



Figure 3. Adapted pair of adult jeans

guidance on the promotion of health and prevention of illnesses.

Physiotherapeutic evaluation

This evaluation is in the same data collection made in the general stimulation evaluation, however, instead of applying the AIMS, we used the Rosa Neto Motor

Development Scale (EDMRN - *Escala de Desenvolvimento Motor de Rosa Neto*).

This scale is an instrument composed of various batteries of tests to evaluate the motor development of children from two to eleven years of age.^{16,17} The EDMRN Manual is quite didactic, illustrated, and easily applicable.

- The complete scale is composed of the following tests:
- Fine motor skills (manual ocular)
- General motor skills (coordination)
- Balance (static posture)
- Body scheme (imitation of posture and speed)
- Spatial organization (perception of space)
- Temporal organization (language, temporal structures)
- Laterality (hand, eyes, and feet)

The batteries of tests consist of 10 motor tasks each, applied to children between two and eleven years of age, organized progressively in degree of complexity, attributing to each successful task a value corresponding to a motor age (MA), expressed in months. At the end of the application, depending on the performance of each battery, a specific MA is attributed to the child, in each one of the areas, and then the general motor age (GMA) and the negative age (NA) of the child is calculated. The general motor age is obtained by the sum of the MAs of all the batteries applied divided by the number of batteries. The negative age is obtained by the difference between the chronological age (in months) and the GMA.¹⁶ In our service, we consider an NA of up to 24 months to be within the standard for children with DS, considering all the biomechanical and physiological alterations already discussed.

Despite the broad approach offered by the test, for the physiotherapeutic evaluation we used only the General Motor Skills and Balance tests. They consist of a set of 10 motor tasks each, with progressive degrees of difficulty, divided by age bracket, as shown in Chart 1, below.

After applying the test, a footprint is collected by a pedigraphy instrument and posterior analysis of the instep to classify it as flat, normal, or arched foot, in addition to the anthropometric evaluation.

Physiotherapeutic intervention

The sessions in the child development model, as well as in the general stimulation, take place once (1) a week and last 30 minutes each. The physiotherapist participates in the entire therapeutic process with the child, in addition to orienting the parents and/or responsible parties on the continuation of this work at home.

In the child development model, the physiotherapeutic intervention seeks to reinforce some activities that may not be fully established, in addition to developing

gait and static and dynamic balance, with the following proposals:

Gait (TC: 14 - 18 months): it is proposed that the child walk on various surfaces and circumstances - on pillows, in straight lines, with many people around them or through obstacles.

Dynamic balance (TC: from 18 months to 4 -5 years of age): after the acquisition of gait, we add "circuits" to the interventions. These circuits must be initiated slowly and in a simple manner, on stable surfaces with few architectural barriers, slowly including new challenges with more elements. All the circuit proposals must be presented in a playful context, that is, presented as a challenge to the child, so that he or she feels motivated to conclude the entire circuit. For example, the surface of the spaghetti foam may become a bridge, the elastic bed may become a lake or swimming pool, among other possibilities, imagining them together with the child, stimulating his or her creativity and abstract thinking (Figure 5). Our experience shows that in that way we obtain more attention and adhesion to the activity.

It is vital, therefore, that the parents be made aware of the importance of their presence and participation in the attendance room and that they be active agents in the continuation of this phase of the maturing process development of the motor functions outside the therapeutic environment. We believe the therapeutic process cannot be limited to 30 minutes weekly, but must be continued at home for better results. Many times, parents interpret the moment the child is under the care of a physiotherapist as a moment when they do not need to pay attention to the child, unloading the responsibility for the child on the therapist alone. Considering that the therapeutic intervention in this treatment model is to point out activities in which the child needs more attention, it is fundamental that the parents participate and interact, so that they feel like part of the process, because this is the pre-supposed theory of shared care followed by the multiprofessional team at the IMREA-HCFMUSP.

DS ADOLESCENT AND ADULT MODELS

Physiotherapeutic objective

About 20% of the people with DS present musculoskeletal disorders, many times



Figure 4. Positioning to stimulate being on all fours and crawling

needing orthopedic surgical intervention to improve mobility and relieve pain.¹¹

Musculoskeletal disorders are provoked mainly by hypotonia and its consequent muscular weakness, which is more pronounced during adolescence and in the adult years, since in this period of their lives, these people become less active.¹⁸ The muscle strength of the upper limbs¹⁹ and of lower limbs²⁰ is 50% less in people with DS when compared to the general population. This muscle strength deficit, besides provoking musculoskeletal alterations, is also responsible for a negative impact on the ability to perform daily life activities. Prominent among these disorders are cervical instability, scoliosis, hip pathologies, and patellar and shoulder instabilities.¹¹ Approximately 20% of those with DS experience patellar instability and 8.3% of those are institutionalized; 4% of those not institutionalized present subluxation of the knee.²¹ Studies show that 52% of DS people have scoliosis -

this is more frequent in the thoracic column and generally is accompanied by some kind of cardiac surgical intervention.^{22,23} Almost everyone in this group shows an average angle of 7 degrees per segment; curiously this incidence has fallen to 4.2% in the population that received physiotherapeutic care early on.²⁴

In view of these considerations, the physiotherapeutic intervention in the population of adolescents and adults with DS seeks to aid in the orthopedic and postural re-establishment, in addition to providing orientation in the promotion of health and in the prevention of illnesses.

Physiotherapeutic evaluation

In the evaluation of adolescents and adults with DS we used the musculoskeletal standard evaluation adopted by the physiotherapy service at the IMREA-HCFMUSP. This includes data on identification, their main complaint, current disease history,

Chart 1. Tasks for general motor skills and balance by age bracket

AGE	GENERAL MOTOR SKILLS TASK	BALANCE TASK
2 years	climb on a bench	balance oneself on a bench
3 years	jump over a rope	balance oneself on one knee
4 years	jump in the same place	balance oneself with the trunk flexed
5 years	jump 20 cm high	balance oneself on the balls of the feet
6 years	walk in a straight line	make the static "limp foot"
7 years	make the "limp foot"	make a figure - 4
8 years	jump from 40 cm high	balance oneself squatting
9 years	jump into the air	balance oneself with the trunk flexed
10 years	make the "limp foot" with a matchbox	balance oneself on the balls of the feet with eyes closed
11 years	jump over a chair	static "limp foot" with eyes closed

**Figure 5.** Circuit proposal with various tasks, steps, and jumps

pain classification, verification of movement amplitudes and muscle strength referring to the compromised area, and observational postural evaluation. The Postural Evaluation involves the identification and localization of the body areas relative to the line of gravity; and it must determine whether one body area or articulation deviates from the ideal postural alignment. The therapeutic objectives and procedures are determined from the data collected. Re-evaluations are made monthly.

Physiotherapeutic intervention

For this group the physiotherapeutic intervention is determined according to individual needs. Therapeutic procedures

apply thermal physical means, such as ice or moist heat, or electrotherapeutic means, such as TENS in cases of pain, or even therapeutic ultrasound in cases of inflammation. However, the emphasis of the treatment is based especially on kinesiotherapy, so as to favor gain in muscle strength and postural balance. Kinesiotherapeutic activities consist of isotonic exercises in series that go from 10 to 12 repetitions with progressive loads. The muscle groups worked are related to the objectives pre-determined in the physiotherapeutic evaluation.

Orientation on posture is given during the sessions to persons with DS as much as to the caregiver. They focus mainly on the balance of physiological curvatures of the

vertebral column, on the internal rotation of the knees, and external rotation of the shoulders, which are the body areas most frequently affected in the adolescent and adult populations with DS.

The caregiver's participation in the sessions is vital, so that the orientation is asked and reminded constantly, not merely at the moment of the physiotherapeutic care.

CONCLUSIONS

As the result of a limited sensory experience, the child with DS has problems in physical, cognitive, and sensory integration, which diminishes his or her functional abilities and creates delays in its development.

Here, development is considered as the acquisition of motor, cognitive, and emotional marks, so it is correct to say that the child with DS does not have an exact age for acquisition of each stage of development, depending heavily on the stimulation received and on its own condition. The child has its own individual chronology and reaches its development in the sequence that is most appropriate, convenient, and possible. The role of the physiotherapist is to stimulate the multiprofessional team and the family, the motor development of these children, respecting its time and valuing its potentials, in addition to acting as a health educator to the family, so as to prevent illnesses and promote the health of the person with DS and its family.

Determining factors in the success of the therapy were:

- the shared care strategy,
- the integrality of the care,
- the duration of treatment and,
- the playfulness in the intervention.

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