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THE AQUATIC ENVIRONMENT – WAYS OF IMPROVING THE QUALITY OF LIFE FOR CHILDREN SUFFERING OF DIAGNOSED IMPERFECT OSTEOGENESIS (OI)

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Abstract

Purpose. Osteogenesis imperfecta, through its characteristics, drastically limits the possibilities of suffering children to move and develop programmes with physical character in order to improve the quality of life. Because of extreme bone fragility, there are very few work methods.

Objectives. The present paper serves the purpose of creating a theoretical and methodical approach regarding the ways through which children suffering from OI can improve their quality of life through the use of aquatic environment.

Methods. The study presents both a classification and a description of the methods and instruments used in aquatic environment for raising the quality of life for children suffering of OI. The effects and their role on the human organism are also explained.

Results. There was a major improvement of quality of life of the children with OI that followed our theoretical and methodical recommendations in aquatic environment.

Conclusions. The most efficient environment for improving the quality of life for children suffering from OI is the aquatic environment. With a carefully structured programme, acknowledged and applied by the suffering child in the aquatic environment, some of the following objectives can be accomplished: improving the quality of life for children suffering from OI, their psychological development, the development from an early age of a positive thinking, mandatory characteristic of children with OI in putting together a recovery programme for them.

Key words: osteogenesis imperfecta, quality of life, game, aquatic environment.

Introduction

Imperfect Osteogenesis (OI), as few know about, is a rare malady encountered in 1/15000 – 1/20000 people, occurring in all populations and both sexes. This estimate does not include the moderate forms of the malady which can occur. There are about 500 000 people affected in the world, which is about 0,008% of the total population. For example, in the United States the exact number of people with imperfect osteogenesis is unknown, but it is between 20 000 and 50 000 people (<http://www.oif.org/> - fast facts about osteogenesis imperfect). In France, the estimated number is about 3 900 people.

As a conjunctive tissue malady, hereditary by nature, characterized by the fragility of the bone system, OI was first named „the glass bones disease”. It is an anomaly regarding the production of collagen, the main fibrous protein of the bone structure, compound also present in skin, tendons, eye sclerotic and dentine, the main compound of the teeth. (Puiu, 2007).

The major consequence of OI is the occurrence of multiple fractures, but these are not followed by major trauma. In pregnancy, the heredity of this malady presents a risk of 50%. If a parent is diagnosed with OI, the chance of

transmitting the malady to the child is 50%. There are cases of OI transmitted as a recessive trait. There are healthy parents who carry the disease who can give birth to children having a chance of 50% of being carriers themselves, and of 25% of being affected by the malady. There are countless cases of parents with OI that gave birth to perfectly healthy children. (http://www.oif.org/site/pagename=AOI_Facts).

From the heredity perspective, OI does not have consequences on fertility. Some of the women with OI can suffer complications because of the bone system problems, but it is very important that all people suffering from this illness to be informed and receive information regarding their condition and the effects and consequences of birth.

It needs to be pointed out that the OI diagnosis is often associated with other maladies like : deformations of the skeleton (at arm, calves or spine level), little height, high laxity at joints level with possible sprains, contusions, etc., flatfoot, eyesight deficiencies, reduction or even loss of hearing, dental malformations (imperfect dentinogenesis), heart valves insufficiency, fatigue, excessive sweating.

One big problem with children suffering

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from OI is the development of movement capacity. Fear of accidents cummulates with all the shortcomings due to the above mentioned affections because different fractures happen very often.

From the motric education perspective, learning intervention is very difficult and restraint. But from our point of view, as well as the cummulated experience from practical programmes applied to children with OI, but also from studying specialty literature and sites, we can affirm that the aquatic enviroment represents the most efficient and safe way to better the quality of life of children with OI.

Purpose

This paper presents the advantages of using hidrokinetotherapy exercises for the development of movement capacity of children suffering from OI. The objectives of the activity monitor both phisical development aspects, motric, pshichic and social integration.

They particularize in muscle development, effort and movement capacity, correction of postural deficiencies, re-learning to walk, ballance development, coordination. Added to these are the enhancing of the psichological factor considered determinating from our point of view and with implications in the evolution of the recovery and socio-cultural integration processes.

We consider that developing these aspects, the quality of life of these children can be enhanced, and they gain confidence in themselves.

Content

Phisical exercise represents the ideal means for enhancement of health if it is applied accordingly and adapted to specific situations. It will intervene, in equal measure, at an emotional and cognitive level, influencing the motric and social behaviour of persons who desire an improvement of life quality. (Grigore et. al., 2007).

When the option of applying physical exercise takes into consideration the advantages of the environment where it takes place, the teaching intervention can be enhanced.

In this context, we will answer the question :Why the aquatic environment, and implicitly hidrokinetotherapy (HKT) ?

We rally to the opinion that HKT is for people who cannot exercise in normal conditions in dependence to the force of gravity, people who have problems in supporting their own mobile body segments weight. (Vasile, 2010).

When the body is submerged under water to neck level, bodyweight is perceived as 10% of the bodyweight perceived when it is on the ground. The teaching intervention implies using

an array of passive and active techniques in which the subjects are in immersion. (Vasile, 2013)

Because, in the water, the body weight is sustained, the pressure on the bones, tendons and joints is minimal and the performance of activities in the aquatic environment can be considered ideal for children with OI. Thus, the aquatic environment has numerous favorable influences and determines specific effort.

As specified in *Interdisciplinary treatment approach for children with OI*, studies regarding the effect of hidrotherapy on children with OI have not been made (Chiasson, Munns, Zeitlin, 2004).

After realising a programme in which 2 subjects suffering from OI on a 2 year duration, an obvious development has been proved, from a psichological and morpho-functional point of view.

Subjects have achieved , from neuro-psychic point of view, a development of motric learning capacity of movement expresivity and cursivity, as well as developing the capacity of phisical relaxation (muscular, functional and psychic).

Regarding morphology, a favorisation of growth and phisical development processes has been noticed ; some of the atitudes and defficiencies present were corrected in a significant percentage.

Under functional aspect, an enhancement of the general effort capacity has been realised through swimming, and also an increase in the functional capacity of the cardio-vascular and respiratory apparatus.

From a social-educational point of view, subjects suffering from OI have integrated in a social group formed by subjects without defficiencies, forming the habit of sistematically practicing phisical exercise, in purposes both profilactic and therapeutic.

Although the advantages of training in water enviroment are obvious, we point out the fact that in specialty literature we have not found concludent data reffering to the programmes recommended for OI. In that manor and for this reason, we consider this paper as of actuality.

Relying on the 2 years practical experience throughout witch work has been done with 2 subjects diagnosed with OI, we have systematised a series of methodic directions for organising the systematic training in table 1, furthermore detailed.

Table 1. Recovery programme in aquatic environment :

AQUATIC RECOVERY PROGRAMME					
Recovery Programme	Objective	Effort type	Intensity	Duration	Frequency
Stage I Antrenament de inițiere(2-4 săptămâni)	Acommodation with water	Aerobic	60% of heart frequency	30-50 minutes	3-5 lessons/ week
Stage II Endurance Training (6-20 weeks) (reduced endurance)	Learning „crawl” and „backstroke” procedures, with accent on cardio-respiratory endurance.	Aerobic	70% of heart frequency	40-90 minutes	3-5 lessons/ week
Stage III Strength training (moderate endurance)	Muscle mass enhancement, with accent on balance and gaining a correct body posture	Aerobic	75% of heart frequency	60-90 minutes	3-5 lessons/ week

Utilitarian applications

The principle of individualisation represents the basics for organising any motric training programme. This principle, nominated by most theoreticians from sports and physical education domain (Dragnea, Mate – Teodorescu, 2002) becomes essential for adapted physical activities. Thus, the orientation of activity to the subject and his requirements will multiply their option of motric evolution and social integration (Teodorescu, Bota, Stănescu, 2007).

In the case of some subjects with OI, adapting the programme to the morpho-functional and motric characteristics, in paralel with the adequation of socialising situations and psychological intervention are essential.

As any programme applied in water, the aquatic recovery programme of subjects with OI began with basic training done on land. Subjects who participated were adequately equipped (bathing suit, special seeing goggles, swimming helmet, slippers, towel, bathrobe) and have presented medical proof with all tests and evaluations up to date that they can perform physical activities.

Because of existing problems, children with OI present a greater sensibility from a psychic point of view, so we consider that before beginning the recovery programme, it is mandatory that a discussion between the child and the kinetotherapist takes place. The discussion must be warm, simple, in order for the kinetotherapist gain part of the child's trust. The rest will represent one of the essential objectives of the aquatic programme.

Children being involved, they must be acquainted from the beginning with the idea of not being dependent

on the parents, and to be able to stay and cooperate with specialised personell.

When the children are prepared from the psychological point of view to begin the recovery programme, they can advance to realising the first stages of the recovery programme.

Accommodation with water represents the first stage of the whole recovery process : a full showering occurs, while being held by the kinetotherapist and protected from external risk factors, and then carefully seated on the edge of the pool.

On entering the water, the attention of the kinetotherapist must be focused on the OI suffering child, in the idea to avoid possible accidents and to create a sense of confort and trust of the participant in the programme.

Entering the water is made gradually, without forcing the child with OI from any point of view, beginning with the lower limbs. The goal is a gradual accommodation of the organism to the water temperature. Because the aquatic environment represents the main environment of application of the recovery programmes, accommodation of the children with the water represents the first objective and we consider that it is the most important of the recovery programme.

Because the people suffering of OI, and mostly the children are overprotected by the parents or the people around them, accommodation to the water represents a very delicate and hard to solve problem.

Following the cumulated experience we consider that the foundation of solving this objective lie in the patience of the kinetotherapist and his communication with the participants. He must offer them his trust without forcing the participants in any way,



because the transit from dry environment to aquatic environment is only realised gradually and in the time imposed by them. Once accommodation with the aquatic environment has occurred, the work of the kinesiologist becomes considerably easier.

Accommodation and even adaptation to the water occurs at the same time the subjects get used to: impeded breathing because of water pressure, performing slow movement because of water resistance, losing balance because of the ascending force according to depth, lowering of body temperature because of water temperature, difficult orientation because of swimming on the back or without goggles, total body immersion and performing exercises with the head in the water.

The recovery programme is based upon the principle of progressivity regarding both duration and exercise complexity, simple-complex, easy-hard.

The duration of the programme applied to the children with OI is basically long term, becoming a necessary routine for suffering children.

We consider this to be the only actual alternative so that people suffering from OI can become independent. The programme must be entirely recorded in the personal chart of the subjects, for them to consult it at any time with the skilled person that tends to the programme. Another very important aspect is tied to the type of recovery programme: this can be individual or group.

From our point of view, the programme must contain an individual part, as well as a group part. We consider it necessary for the programme to start with an individual part, because the child requires enhanced attention, especially because he comes into contact with a new environment, the aquatic environment.

We recommend the individual part to be immediately followed by a collective programme, because the subjects can become examples for each other. The advanced subjects represent a successful model for the beginner subject, and the beginner subject will represent an example for the advanced subject. This will help to realise the progress in the recovery programme and will be considerably motivated.

In the case of people with OI, HKT perfectly adapts to their particularities. Its effects are those of fighting inflammations, decontraction and relaxation, and are benefic in fighting vicious attitudes present in children with OI, inherent muscular contractions and ligament and capsular retractions.

Recovery can be made and even high performance can be reached by children with OI, a goal set to be realised by one of the two subjects.

Evaluation of the participants will be made before applying the programme, periodically and continuously during the application of the programme, and also at the end of the programme, representing a summative or final evaluation (Ciolcă, 2012). The procedures used in the recovery programme will be the „Crawl” procedure and the „Backstroke” procedure. We consider that these procedures are the only ones that can be used and applied in the case of children with OI without negative consequences

Conclusions

- Because of the specificity of the disease and more precisely the high risks of fractures, the physical activity of children suffering from OI is very restrained. Because of the specific characteristics, the most efficient environment for the recovery programme for improving the quality of life of children suffering from imperfect osteogenesis is the aquatic environment. We consider this the best actual option for people with OI to become independent.
- The training programmes must combine in harmony the motoric and physiological aspects with those of improving the psychological factor.
- It is recommended that the duration of the recovery programme is the person's lifetime, becoming a routine necessary to the suffering subjects. The recovery programme will be based on the progressivity principle, both as duration and exercise complexity.

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