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Family guidance for home-based physical rehabilitation of patients with cerebral palsy

[*Orientación familiar para la rehabilitación física domiciliar de pacientes con parálisis cerebral*]

[*Orientação familiar para reabilitação física domiciliar de pacientes com paralisia cerebral*]

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ABSTRACT

Cerebral palsy is the leading cause of childhood disability in the world. Addressing this issue is currently a necessity. In this order, systematizing the subject of family guidance in patients with Cerebral Palsy, as well as family involvement in the home physical rehabilitation process, is the objective of this research. During its development, the following methods were used: theoretical, historical-logical; analysis - synthesis, and inductive deductive, which allowed us to reach the answers that provide solutions to the existing shortcomings in the problem under investigation. In the empirical ones we find:



scientific participant observation, structured interview and document analysis, which allowed us to know the state of family guidance. The results show that this has been a subject studied in depth from different angles, with family guidance and its implication in the rehabilitation process being one of the less systematized subjects. We can corroborate with the bibliographic search the need to delve into this subject.

Keywords: cerebral palsy, rehabilitation, physical exercise, family guidance.

RESUMEN

La parálisis cerebral es la primera causa de discapacidad infantil en el mundo, en la actualidad abordar este tema es una necesidad, en este orden sistematizar la temática sobre la orientación familiar en pacientes con Parálisis Cerebral, así como la implicación familiar en el proceso de rehabilitación física domiciliaria, es el objetivo de este trabajo. Durante el desarrollo de la misma se utilizaron métodos: de nivel teórico, histórico-lógico; el análisis - síntesis, y el inductivo deductivo, que permitieron llegar a las respuestas que dan solución a las insuficiencias existentes en la problemática investigada. En los empíricos se encuentra: Observación científica participante, la entrevista estructurada y análisis de documentos, que permitió conocer el estado en que se encuentra la orientación familiar. Los resultados arrojados demuestran que este ha sido un tema estudiado con profundidad desde diferentes ángulos, siendo la orientación familiar y su implicación en el proceso de rehabilitación uno de los temas menos sistematizados. Podemos corroborar con la búsqueda bibliográfica la necesidad de profundizar en esta temática.

Palabras clave: parálisis cerebral, rehabilitación, ejercicio físico, orientación familiar.



RESUMO

A paralisia cerebral é a principal causa de incapacidade infantil no mundo. Atualmente, abordar esse tema é uma necessidade. Neste sentido, sistematizar a questão da orientação familiar em pacientes com Paralisia Cerebral, bem como o envolvimento da família no processo de reabilitação física, é o objetivo deste trabalho. Durante o seu desenvolvimento foram utilizados métodos: nível teórico, histórico-lógico; a análise síntese, e a indutiva-dedutiva, que nos permitiu chegar às respostas que fornecem soluções para as insuficiências existentes no problema investigado. As empíricas incluem: observação científica participante, entrevistas estruturadas e análise documental, que permitiram conhecer o estado da orientação familiar. Os resultados obtidos mostram que este tem sido um tema estudado aprofundadamente sob diferentes ângulos, sendo a orientação familiar e o seu envolvimento no processo de reabilitação um dos temas menos sistematizados. Podemos corroborar com a pesquisa bibliográfica a necessidade de nos aprofundarmos neste tema.

Palavras-chave: paralisia cerebral, reabilitação, exercício físico, aconselhamento familiar.

INTRODUCTION

Cerebral palsy (CP) is a residual neurological injury produced by non-progressive encephalon injuries, secondary to pre-, peri- and postnatal causes that are essentially manifested by an isolated motor disorder, or in most cases, associated with other speech, sensory, psychological, convulsive and learning disorders.

Researchers such as Blair (2018) define CP as a permanent movement and posture disorder due to brain dysfunction before growth and development are complete.

Gibson *et al.* (2021) states that CP describes a group of permanent and non-progressive disorders of the brain and posture that manifest early in life and are the result of a defect or injury to the immature brain, usually before the age of two.



CP encompasses a set of symptoms that differ qualitatively and in their severity from person to person, depending on the extent and location of the injury. However, in all of them, there is a weakness or problem in the use of the muscles, whose main symptoms are: alterations in movement control, muscle tone and posture.

In studies carried out by several authors, among which are, Kleisnsterbar *et al.* (2014), they mention that a worldwide incidence of CP of 2 to 2.5 per 1000 live births has been estimated, with little variation between developed countries and slightly greater frequency in developing countries. In Cuba, there are between 11,000 and 13,000 cases.

Approximately one third of children with CP have a mild intellectual disability, the same number have moderate or severe disability, and the rest are intellectually normal. Mental disability is more common in children with spastic quadriplegia. One in three children with this condition has seizures, a normal and orderly mode of electrical activity in the brain that is interrupted by uncontrollable bursts of electricity.

According to the WHO, there are three aspects that are considered essential in the clinical picture of CP: delay in the development of new skills that can be expressed according to the child's chronological age, persistence of infantile behavior in all functions, including infantile reflex reactions and anomalies of various functions not seen in newborns and abnormal children, caused by the presence of pathological symptoms of upper motor neuron lesions: hypertonia, involuntary movements, and pathological responses.

Statements of studies carried out and stated in the sophiale vitt. PCI protocol, CP has standards for its treatment, among which are: the child is considered to have multiple deficiencies and not only physical, the treatment should focus on the neurological mechanisms of posture, balance, movement and will be complemented with procedures for muscles and joints when necessary.

Emphasis will be placed on exercising the various postural mechanisms that are absent or abnormal in all types of cerebral palsy or are absent in any motor development delay, the rehabilitation therapist should only deal with abnormal reflexes when they directly



interrupt activity, treatment should be applied early and treatment plans will be reviewed periodically to monitor the changes that occur in the prospective clinical evolution.

However, progress due to medical research indicates that many patients can enjoy near-normal lives if their neurological problems are adequately controlled. There is no standard therapy that works well for all patients, so the doctor must first work with a team of professionals to identify the child's unique needs and difficulties, and then create an individual treatment plan that addresses them.

Therapeutic exercise can range from highly selective activities, limited to specific muscles in certain parts of the body, to vigorous and general activities used to restore a convalescent patient to maximum physical condition. (Stadskleiv, Jahnsen and Andersen, 2017)

There is consensus regarding the treatment of CP patients, as it should be multidisciplinary and cover the different areas of need. With respect to the role of physical therapy, this is oriented towards the prevention of contractures and abnormal motor patterns, management of muscle tone, development of muscle strength and the promotion of physiological postures and movements.

The study of the family context is a complex process and has been investigated from different disciplines. Pedagogy has delved into the conformation of a family education, although it is a studied subject, it requires systematicity in achieving a more responsible performance of the family, which in cases such as CP is very necessary. These antecedents show the need to delve into the study of the orientation and involvement of the family in the process of home physical rehabilitation of CP patients due to the etiology and clinical picture that characterizes it.

The analysis of the theoretical-methodological basis consulted on family guidance for the treatment of CP patients shows the need to delve into its study, in order to offer this process with the quality and efficiency required by society.



The above and the review of the specialized literature on the subject justify the need for studies on family guidance and its direct implication in the physical rehabilitation process in CP patients. According to the procedure in Figure 1.

The fundamental information search skill for this research was based on the following criteria

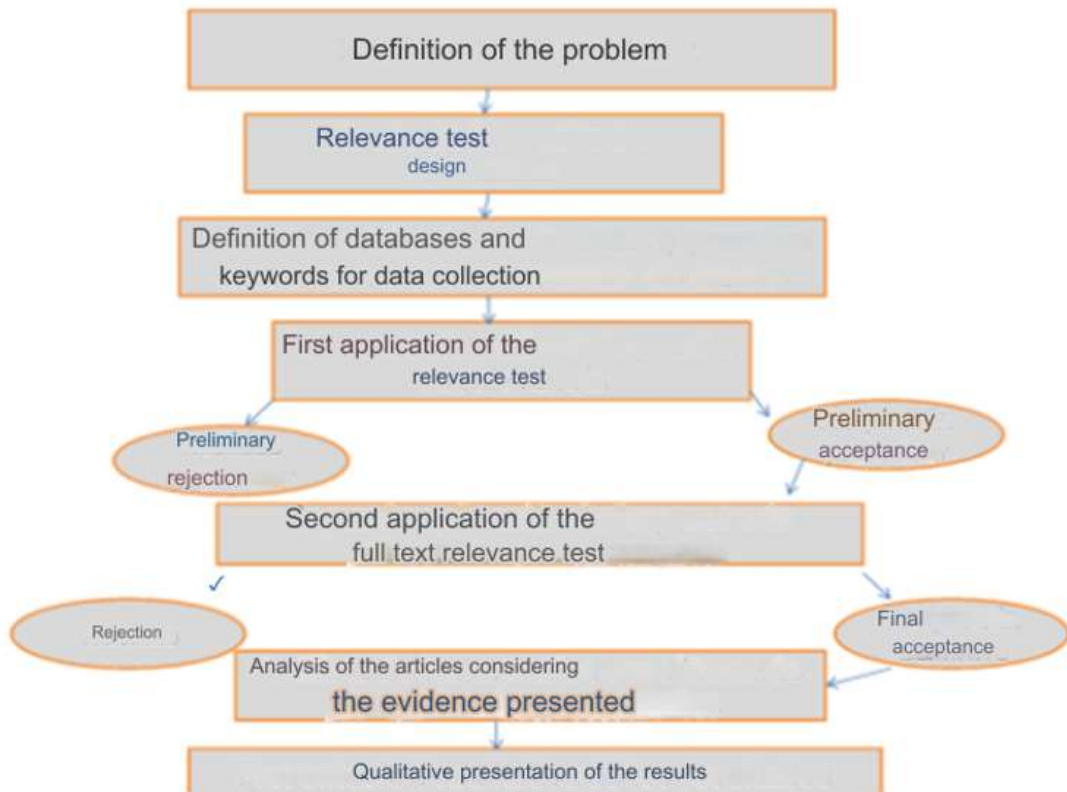


Fig. 1. - Flow chart for the systematic review of the literature

Source: Adapted from Costa et al. (2008)



DEVELOPMENT

Methodology for the research of information

The development of the present article required the use of theoretical and empirical methods. Specifically, the first group included historical-logic; analysis-synthesis, and inductive-deductive analysis. All of them, from a systemic point of view under the dialectical materialist approach, provided the implementation of a critical analysis of the theoretical-methodological foundations consulted on family guidance, which have a significant significance in the physical rehabilitation of people with PC (Cerebral Palsy). The empirical ones are participant scientific observation, structured interview, survey and analysis of documents, which allowed to learn more about the state of the family.

The theoretical frameworks of the findings reached, and the inclusion of the same in the process, have had little systematicity in terms of studies and research, which is currently a latent concern. The authors considered for this study were Castro (1996), Salazar (2004), Ares (1999), Mena (2015), and Turro (2019). In this way, the achievement of a suitable historical and trendy approach is guaranteed. The evidenced limitations are transformed into guidelines and methodological dynamism of the process.

Role of the family

The family is the fundamental base for the formation of the human being and is directly responsible for its evolution. It is the first environment for communication, relationships and the most important one for the development of people. Based on what was stated by Benitez (2017), Weller-Miller (1977) and Martinez (2021), it is assumed that the family constitutes an institution formed by a group of people united by blood and/or emotional ties, who live together in a common space for a significant amount of time, where material and spiritual needs are met, and stable emotional relationships are established (Ponce *et al.*, 2022).



Regarding the role of the family in health and the prevention of various diseases, authors have confirmed that:

Other research highlights the importance of psychological guidance, with educational and preventive purposes, which makes the work that the school can do with the family on the subject of sexuality novel.

On the other hand, Bermudez and Delgado (2019) highlight the role of social support and the leading role of the family, who have a child with special educational needs.

Castellano and Ramirez (2018) have dedicated themselves to the study of family coping in different pathologies, highlighting the need to prepare families so that they can successfully fulfill their role as part of society, research that has been directed to meet basic social skills.

In relation to how to achieve results in this regard, Coll (2017) poses the need for home rehabilitation, insofar as the role of the family is understood and the conditions in the home are created, so will the results in the patient's recovery be.

The functions of families as a social institution have changed over time and from one culture to another. As a group, its primary purpose is the socialization among its members, in addition to covering the basic needs of all kinds (affective and material). It can be determined that it fulfills basic functions, both towards the individuals that compose it (intrinsic functions) and towards society (extrinsic functions).

The family in society has important tasks, directly related to the preservation of human life as its development and well-being. The functions of the family are, biological function, the sexual appetite of men and women is satisfied, in addition to human reproduction, educational function, children are socialized early in terms of habits, feelings, values, behaviors, economic function, basic needs are met, such as food, shelter, health, clothing, supportive function, affections are developed that allow to value mutual aid and help to others and protective function, security and care are given to children, the disabled, the elderly and to all members (Cedeños-Mendez, 2005).



According to what was cited by Navas *et al.* (2013), Serrano-Céspedes-Louro (2016), Barreto and Marín (2018) and the results of the research carried out in Cuba by Ares (1999), Castro and Castillo (1999) have shown that despite the achievements that the family has reached in its objective and subjective living conditions, traditional forms of functioning are still observed, expressed in the uneven development that occurs between family roles and social roles and require professional support.

In Cuba, the Constitution of the Republic in chapter III published in 2019, establishes that the state recognizes the family as the fundamental cell of society and attributes responsibilities and functions to it, to protect, assist and facilitate the conditions to satisfy the needs and raise the quality of life of people with disabilities.

The well-being of the parents and the realization of activities outside the treatments will also be beneficial for the child with PC and his/her siblings, since it contributes to creating an atmosphere of naturalness and warmth throughout the family.

Family Guidance

An article referring to family preparation, Contreras *et al.* (2018), proposes preparation on environmental education for sustainable community development of families with children aged five to six, emphasizing the role it plays as an enhancer of integral development.

According to Lucas (2017), this addresses the need for family guidance to address emotional deficiencies in the development of Ecuadorian schoolchildren, emphasizing the function of the school-family relationship in the proper education of minors.

In the Cuban case, Cañedo (2005) argues that in the Cuban family, all the conditions converge to strengthen, in a more participatory daily manner, family education with an important component of addressing diversity. This aspect needs to be considered during family guidance regarding the physical rehabilitation process of people with cerebral palsy.



Scientific evidence links a proper lifestyle with exercise because it helps improve physiological, emotional, and psychological capacities. The World Health Organization highlights the important role of physical activity in achieving healthy aging and quality of life (Ortiz and Gómez, 2017).

All of the above demonstrates the importance of physical exercise in the treatment of people with neurological impairments, as well as the need to involve the family and the social environment to contribute to improving the quality of life of people with disabilities.

On the other hand, Duarte (2017) presents an educational plan and a guide for the proper management of children with cerebral palsy, led by the family, contributing to the rehabilitation of these patients. In addition, Morales (2014) addresses physical rehabilitation with family support for people with Spinocerebellar Ataxia Type II.

Another recent experience related to family preparation is that of Turro Arzuaga (2019), which presents a strategy for family guidance in the rehabilitation of chronic heart failure.

These backgrounds demonstrate the need to delve into the study of family guidance and involvement in the rehabilitation process of patients with cerebral palsy due to the etiology and clinical picture that characterizes it. This is due to insufficient research on this topic and the experiences developed regarding inappropriate situations in families with a child with cerebral palsy, including authoritarianism, overprotection, and at times rejection, which affect the proper development of these individuals. One of the actions should be directed towards promoting intellectual development, which facilitates understanding the disease, in order to help develop the potential of people with cerebral palsy.

Furthermore, the family requires greater attention if there is a person with a disability within it. An oriented and motivated family constitutes the first agent of change for the stimulation, education, and rehabilitation of these individuals.



Physical medicine and rehabilitation specialists view the family as the fundamental unit due to their participation in the education and training of patients with cerebral palsy. At home, they are the first to interact with the children, and they have a series of advantages over service professionals due to their motivations and experiences. Therefore, they cannot be left out of the rehabilitation process.

Family guidance is directed as a process of human educational influences on its members, based on internationally planned socio-psycho-pedagogical actions aimed at raising the level of family preparation to assume the functions that society has entrusted to them in order to raise their descendants.

When conducting a study on family guidance, the criterion of Ríos (1993) is assumed, distinguishing three levels:

1. Educational level of guidance: at this level, it is about providing the family with the appropriate means to carry out its educational function on all fronts and objectives that correspond to it as a primary group in which the processes that require contract and total communication with significant figures for the children must take place, whether they are children, adolescents, or young people.
2. Guidance development level: it aims to offer the family functioning criteria for both normal situations of family dynamics and for those that involve a child with cerebral palsy, which alter normal processes or phenomena, hinder the achievement of the educational and training objectives of the family as a nucleus of enriching coexistence and personal development.

Guidance should not be reduced to a superficial and occasional contract, caused by motivations focused exclusively on the difficulties presented by the patient with cerebral palsy in the pedagogical area. It is necessary to promote that in this family guidance process, other series of measures are addressed that seek to raise, in all their dimensions, authentic advice that cannot be limited to what happens with parents and children on a single level.



3. Therapeutic treatment level of guidance: the purpose of this level is to provide the family with the appropriate techniques to elaborate and/or structure those aspects in which an alteration of the dynamics of the family system poses a serious threat to the functioning of the objectives, means, and procedures inherent to the family's own purposes as a context of knowledge and human improvement of its members.

Because of their importance, these levels are taken into account in the structure of the different family guidance sections, because in families with difficulties caused by the presence of a child with developmental abnormalities, which is the first negative impact within this nucleus, and which projects itself strongly in relationships with the children, it evidently causes family coexistence to be affected; in other cases, the family states that the children have educational demands that do not correspond to their real possibilities, which means that they do not form those value systems and behaviors necessary for life in society.

The family system of patients with cerebral palsy must be dynamic and develop throughout the life cycle, with stages of great changes and others of relative equilibrium according to the characteristics of the patient suffering from this pathology. In addition, it is not isolated in itself during the process of internal development, but rather constitutes a system that systematically receives the influence of other social factors.

The future of the child depends to a great extent on the way in which the closest family perceives and faces the disability. The first moments, after the confirmation of the diagnosis, are experienced with great confusion of feelings, sometimes contradictory, that range from the hope that there is a mistake to despair. Parents indicate that the communication of the diagnosis represents a major blow that disrupts their lives; the alternative is to equip themselves with knowledge about the disease, know the steps to take, and face life with enthusiasm and hope.



From the Medical Sciences, several authors have investigated the impact of brain damage on the family of having a child with cerebral palsy, including Alvarado *et al.* (2011), who have addressed the impact of brain injury on the family environment, stages of emotional reaction, factors for adaptation, the possibility of having external professional help as a crucial factor in family adjustment and needs, intervention in the environment, advice, and therapies. All reveal the importance of this nucleus to face any circumstance that arises with a member in the home.

In reviewing the bibliographies for this research, it is evident that the study of cerebral palsy has been investigated by different authors with theoretical conceptions that have contributed important elements in its evolution; as well as the different treatments for the improvement of these patients and their insertion into society, such as the rehabilitation process through physical exercise.

Other studies have addressed the elements to consider in the medical-rehabilitation process, among which are taking care of communication with the family, accompanying them in the process, giving them time to assimilate losses, valuing them as an essential part in the rehabilitation and readaptation of the affected person, promoting family cohesion and resources, and respecting their values. As well as providing them with guidance and support.

As a result, the scientific method used requires continuing to delve into future research, family guidance, and its implication in the rehabilitation process of cerebral palsy.

However, the analysis of the theoretical-methodological base consulted on family guidance for the treatment of patients with cerebral palsy shows the need to delve deeper into its study, in order to offer this process with the quality and efficiency required by society.

Hereinafter is a qualitative assessment of the results of the literature consulted for this research. Morales (2014), Duarte (2017), Lucas (2017), Contreras, Pérez, and Hernández (2017), and Arzuaga (2020) refer to preparing and guiding the family in different



contexts and patient pathologies. The difference with respect to the one carried out in this search is that it is not shown that they are directed to family guidance for the physical rehabilitation of patients with cerebral palsy.

A special look at the article requires delving into neurological diseases, as cerebral palsy is classified and grouped within this type of disorder. As evidenced in the publications, they are directed at ataxia, which shows the lack of theoretical experiences that reveal the need to delve into this type of study.

CONCLUSIONS

In the review of the investigations related to the topic, it is evident that the study of CP has been researched by dissimilar authors with theoretical conceptions that have contributed important elements in its evolution; as well as different treatments for the improvement of these patients and their insertion into society, such as the rehabilitation process through physical exercise. The analysis of the theoretical-methodological base consulted on family orientation has an essential weight in the physical rehabilitation of people with CP, however, its insertion in this process has had little systematicity in terms of studies and research, becoming in the present a latent concern, in order to offer this process with the quality and efficiency required by society.

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Conflict of interest statement:

The authors declare having competing interests.

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The authors have participated in the redaction of the manuscript and the documentary review.



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