

Inclusive Feeding in People with Cerebral Palsy

Pérez Doménech Marta^{1,2*}¹Food and Health Lab, Institute of Materials Science, University of Valencia, Valencia, Spain²Joint Research Unit of Endocrinology, Nutrition and Clinical Dietetics, University of Valencia-Health Research Institute La Fe, Valencia, Spain

***Corresponding Author:** Pérez Doménech Marta, Food and Health Lab, Institute of Materials Science, University of Valencia and Joint Research Unit of Endocrinology, Nutrition and Clinical Dietetics, University of Valencia-Health Research Institute La Fe, Valencia, Spain.

Received: March 29, 2021**Published:** April 27, 2021© All rights are reserved by **Pérez Doménech Marta**.**Abstract**

Cerebral palsy is a motor impairment of the nervous system. Its incidence in developed countries is 2-2.5 per 1.000 newborns and it occurs before the first 5 years of life. This disorder affects an appropriate development of movement and posture, causing sensory, intellectual, emotional, attentional and urinary alterations as well as eating and swallowing disorders, among others. The latter entail that unappetizing and annoying ingestions comprising possible malnutrition. To avoid or ameliorate these alterations we will use introduce an inclusive diet, which intends to normalize dietary guidelines. To achieve this, different devices and strategies are made available to people with cerebral palsy in order to allow them to eat autonomously.

In the present article, 14 families from the Valencian community who have a member with cerebral palsy were polled. Physiological and motor difficulties involved in nutrition will be studied as well as percentages of patients using each aid. In addition, the degree of disability of those suffering from cerebral palsy will be related to the level of family stress.

Keywords: Cerebral Palsy; Including Feeding; Technical Aids; Family Stress

Abbreviations

ADD: Eating and Swallowing Disorders; CP: Cerebral Palsy; GMFCS: Gross Motor Function Classification System; WHO: World Health Organization

Introduction

Cerebral palsy (CP) is an affection of the nervous system. It is not a specific disease or syndrome, it groups together a heterogeneous set of patients with disorders of different cause and prognosis with a common denominator that defines them. They are a group of disorders in the development of movement and posture, capable of causing limitation of activity, attributable to alterations that affect the brain and maturation of the child [1,2].

It is the most common cause of motor disability in pediatric age, and it also persists into adulthood. Its prevalence has been stable for decades, with a value of 2-2.5 cases per 1000 live newborns in developed countries. At 8 years it reaches 3.3 cases per 1000 children [3].

This is a heterogeneous group of patients, making it difficult to classify them. According to the topographic location or extent of the affection, four types of CP are divided: monoplegia, hemiplegia, paraplegia and tetraplegia. On the other hand, classifying patients according to muscle tone or predominant motor disorder presents more value in the educational field, being able to distinguish: spastic, athetoid or dyskinetic, ataxic and mixed [4].

The causes vary from case to case, so no single factor can be attributed to it, although they all develop from brain injuries or abnormalities. The major but not exclusive cause is hypoxia. CP can occur both in the prenatal, perinatal or postnatal period, having the limit of manifestation in the first 5 years of life. It is due to bleeding in the brain, brain infections (encephalitis, meningitis, herpes simplex infections), head trauma, infections in the mother during pregnancy (rubella), or severe jaundice. Importantly, in many cases the cause of PC is never determined.

According to Puyuelo and Arriba (2000), CP is a motor impairment that is associated with various disorders such as: sensory disorders: vision, hearing and perception problems, intellectual, emotional and epileptic disorders [5]: in a review of 100 cases of childhood CP, it was found that 46% of patients had seizures [6]. In addition, attentional and cognitive, orthopedic, urinary, speech and language disorders and eating and swallowing disorders (ADD), which present high morbidity and mortality. Alterations in eating imply difficulty in sucking, biting, chewing, handling food in the mouth, controlling saliva and swallowing, as well as being an experience of communication and interaction. The disturbance in swallowing is known as dysphagia. These problems can lead to others such as lack of appetite, discomfort when eating or even not tasting food well, among others, which can lead, in turn, to malnutrition.

According to the world health organization (WHO), disability is: "any restriction or absence due to a deficiency, of the ability to carry out an activity in the manner or within the range considered normal." Permanent disabilities, stemming from a pathological process and permanent, are classified into 5 degrees [7]:

- **Grade I:** Permanent deficiencies, they do not cause disability (0% disability).
- **Grade II:** Permanent deficiencies that cause mild disability (1 - 24% disability).
- **Grade III:** Permanent deficiencies that cause moderate disability (25 - 49% disability).
- **Grade IV:** Permanent deficiencies that cause severe disability (50 - 70% disability).
- **Grade V:** Permanent deficiencies that cause very serious disability. The subject cannot carry out the activities of daily life by himself, he needs the help of another person (> 75% disability).

On the other hand, the degree of functionality allows a quantitative and objective description of the patient's functional motor impairment. For this, the Gross Motor function classification system (GMFCS) scale is used, based on functional abilities and motor limitations in patients with neuromotor disorders, which is directly related to the performance of activities of daily living [8]. This questionnaire consists of 88 items grouped into 5 dimensions: 1. Supine and rolling 2. Sitting 3. Dragging, kneeling and crawling 4. Standing 5. Walking, running and jumping Each of the dimensions are evaluated on a 4-point scale. The item scores are added and calculated, classifying the patient into 5 levels:

- **Level I:** Roams without restrictions. Has limitations in more complex motor skills.
- **Level II:** Roams without technical assistance. Has outdoor and community limitations.
- **Level III:** Roams with technical aids. Has outdoor and community limitations.
- **Level IV:** Autonomous movement with limitations. Use a self-propelled wheelchair.
- **Level V:** Very limited self-scrolling, even with self-propelled technology.

To try to prevent ADD and therefore the previously mentioned malnutrition, we will approach therapy from the field of inclusive nutrition, highlighting the importance of family support. Inclusive nutrition tries to achieve the normalization of eating and sleep patterns in daily life, integrating the patient into the environment that surrounds him, with the greatest normality and autonomy possible, both at school and at home.

To facilitate feeding, avoid related problems and promote autonomy, we can use different technical aids, grouping them according to whether they are cutlery, plates, glasses, cups or other adaptations [9]. As for cutlery, we have standard cutlery, angular, standard modular, angled modular, soft modular, light modular, special, with universal support or with mitten. As for plates, we have: contoured plate with sloping bottom, with internal rim, with non-slip, thermal or rotating bottom. As for glasses, we have: transparent glass, cut-out and feeding cup with adjustable spout. In addition to all this, we also find tilting devices for jugs, lockable tetrabriks opener and manual pump for ingesting liquids.

Materials and Methods

The objective of this work is to study in the Valencian population with CP, the physiological and motor problems related to eating that they present, the tools to facilitate the diet they use and the degree of stress and coping in families related to the degree of disability that have.

A questionnaire has been sent to relatives of people with CP who attend a specialized day center. For the initial assessment, a structured questionnaire was used with 5 items that assess the sex, age, degree of functionality and degree of disability of the participants. For the assessment of the physiological and motor problems related to eating present in this population, the questionnaire of guidelines and eating habits (Annex 1) was used, which consists of 16 items [10]. To assess the technical aids used by people with CP, the questionnaire on tools to facilitate eating was used (Annex 2) [9]. This questionnaire is structured with 21 items included: cutlery, plates, glasses, cups and others adaptations. Participants should answer if they use it always, almost always, almost never, never (but they know it) or if they do not know it. In addition, it is accompanied by images of each technical aid. Finally, for the evaluation of the perception of stress and family coping, the questionnaire in annex 3 was used [11]. This questionnaire is structured with 43 items, which are scored from 1 to 5, with 1 being very little or not at all and 5 being a lot.

After conducting the surveys, each of them is statistically studied. Percentage calculations were performed in questionnaires 1 and 2. While with questionnaire 3, to test the hypothesis that people with CP level 3 present a higher level of stress than those with level 5, a one-factor anova was performed where stress was measured on a 5-point freedom scale, where 1 meant low stress level and 5 signified high stress level. In turn, each question was answered on a scale from 1 to 5, where 1 = not at all, 2 = little, 3 = regular, 4 = a lot and 5 = a lot. The factor was the level of PC involvement. We performed all statistical analyzes using the IBM SPSS Statistics 20.0 software program.

Results and Discussion

14 families in the Valencian Community have been surveyed electronically, of which a family member suffers from CP. 9 women (64.3%) and 5 men (35.7%) were surveyed. According to age, it is

observed that 21.4% are 3 years old, with 57.1% of participants under 15 years of age and 42.9% over 15 years of age. Finally, according to the degree of disability and functionality: According to the degree of disability, it is observed that the majority of the participants (64.3%) are at level V (permanent deficiencies that cause very serious disability. only activities of daily living, you need the help of another person). While for level I and II there are no answers (Figure 1).

Figure 1: % of patients studied according to the degree of disability.

According to the degree of functionality, it is observed that the majority of the participants (57.1%) also belong to level 5 (very limited self-movement, even with self-propelled technology) (Figure 2).

Figure 2: % of patients studied according to the degree of functionality.

The results obtained in this study reflect that the majority of people always or sometimes have control of the head and trunk sitting (78.5%), sucking reflex (64.3%), biting reflex (85.7%), lip and jaw closure (100%), spontaneous swallowing (78.5%),

breath-swallow coordination (85.7%), deliberate chewing (85.7%) and ability to swallow liquid food (77.8%) and semisolid (78.5%), but not solid (35.4%), in addition, they present hypotonic tongue (78.6%) but not hypertonic (7.1%). In turn, the vast majority have nausea (92.8%), expel food through the mouth (93.4%) and have disordered tongue movements (64.3%), as well as poor mobility of the tongue, jaw and of the mandible (57.2%). The latter contribute to making the act of eating unpleasant and unappetizing.

Between 2001 and 2002, a study was carried out with 10 children who presented very severe neurological disability and without a level of food autonomy and, therefore, totally dependent on the adult. They studied functional disabilities in a theoretical way to apply them to the school cafeteria, both at an educational and psycho-motor level, with measures such as [10]:

- **Correction of the body position during feeding:** The position of the body and the head is necessary for a safe feeding, in addition, the comfortable positioning prevents the risks of falling. The head should be in the axis of the body, the trunk supported and straight and the neck in flexion so that the passage of the food bolus is slower and thus avoid bronchoaspiration.
- **Affection of the lingual functionality:** By means of stimuli such as a gentle intraoral massage. Foods of varied temperature and intense flavor are preferable.
- **Correction of the nausea reflex:** To reduce orofacial hypersensitivity, press the tongue or gently tap the lips in the direction of closure. Relaxation times are interspersed between the exercises to facilitate swallowing of saliva.
- **Correction of the sucking reflex:** Abandon the bottle and progress towards the spoon. They are looking for suitable spoons that are not rejected (silicone, hard plastic, adequate size,...). A less liquid feeding is started.
- **Correction of the bite reflex:** To desensitize the lips, tongue, gums and cheeks, they are rubbed between meals. Before a bite of the spoon remove it gently.
- **Correction of tongue protrusion:** Perform pressure and sliding massage therapy in the antero-posterior direction under the jaw, making it easier for the tongue to move backwards. Also perform pressure on the lower jaw area and at the end of each feeding, a basic cleaning of the entire oral cavity.

- **Improved lip and jaw closure:** Apply pressure under the jaw and massage the lips in the closing direction.
- **Improvement of tongue movements and initiation of chewing:** When chewing begins, food is given once in each area of the molars, since the tongue is directed towards the areas where the food is placed. The step to chewing is done progressively.
- **Improvement of respiratory function:** Problems such as dyspnea or respiratory failure are treated with exercise, drainage postures, the use of voluntary cough (when the patient collaborates) or provoked cough (does not collaborate), vibrations, increased expiratory flow rate, ...
- **Incoordination between breathing and swallowing:** Teach the Heimlich maneuver to all the people who feed in order to know how to react to the intrusion of a foreign body in the respiratory tract.

At the end of the study, progress such as: normalization of posture, decreased drooling, use of the upper lip, initiation of almost solid feeding, drinking by glass and normalization of basic oral hygiene, despite difficulties such as unadapted furniture were observed, limited staff time availability or insufficient staff among others [10].

In the second test used, we find that the majority of technical aids are unknown or not used, in addition, the low rate of the population that uses them is striking. All this may be due to their high cost, low advertising or the difficulty of obtaining them, since they can be found in few stores. Finally, the technical aids that are most used are standard cutlery and glasses with two handles, since these can be found in common stores and are similar to those used by people without disabilities [9].

Finally, the evaluation of health, which is the state of complete physical, mental, spiritual, emotional and social well-being, and not only the absence of conditions or diseases. Therefore, health is the state in which all functions are carried out normally [12,13]. In these patients, what really matters is the quality of life, which is the perception that individuals have about their position in life [14].

There are changes in the trend to the expected values from the first moment, this may be due to the fact that people with disability level 5 have more help either from a family member or a caregiver

and therefore more support, for what you ask such as “can express basic needs such as drinking, eating, sleeping, going to the toilet” “is able to express his feelings” “the motor problem he presents allows him access to leisure activities” “considers that he needs attention all the time” or “the family experiences high tension due to the demands of care and attention” among others, the families of patients with level 5 score less than with level 3 disability. In addition, it can be observed that all of them, regardless of the degree of disability, say they have little autonomy to carry out activities of daily living, use diapers and consider the demands of care as low. Finally, people with level 5 disability have more financial help from public administrations, so that families in group 3 have more financial limitations and allocate more normal expenses to care for them, in turn, they estimate that they do not receive the necessary institutional resources, so their future prospects are worse. All this means that the families of people with disability level 3 enjoy a worse state of well-being, enjoy less desired free time and do less things than they want, presenting a higher level of stress. This coincides with the study by Seguí, *et al.* which evaluated and diagnosed the degree of health of caregivers and concluded that emotional overload affects the physical health of caregivers and that the greater the overload, the greater the physical problems the family members will suffer [15]. The age of the child and the moderate disability category show a higher level of depression. Moreno, *et al.* describe the concept of physical health in caregivers as “the physical well-being of the family caregiver, while caring for a family member or significant other for an extended period of time” [16].

To normalize the diet in the family environment, in addition to the patient, the family is important, for this the perception of the stress level of 149 families was evaluated, passing them a questionnaire called EEAF-PC, in which 3 levels of stress were established depending on of the score obtained: mild, moderate or severe stress [11].

On the other hand, a meta-analysis was carried out, studying the depression of the mothers of children with and without developmental disabilities, concluding that there is a high level of depression in the mothers of children with disabilities [17].

Conclusion

- CP is associated with other sensory, intellectual, emotional, epileptic, attentional and cognitive, orthopedic, urinary, speech and language disorders and ADD, among others, causing disability and motor dysfunction. the nutritional risk is concerned.

- ADD disorders make eating difficult, being unpleasant and unappetizing and therefore causing malnutrition. To correct it, the implementation of measures such as correction of body position during feeding, improving the affectation of lingual functionality, correction of the nausea reflex, sucking and biting, correction of tongue protrusion, improvement of lip and jaw closure should be considered improvement of tongue movements, respiratory function and incoordination between breathing and swallowing.
- The inclusive diet tries to integrate the patient, with the greatest autonomy and normality possible in his daily life. Try to promote the act of eating and thus prevent possible malnutrition. For this, the use of different technical aids (cutlery, glasses, plates and others) is proposed. Although it has been seen that most of them are unaware or do not use these aids, they would be a good tool to improve intake.
- In this study, family members of people with level 3 disability have a higher level of stress than family members of people with level 5 disability, this may be due to the fact that they have less help from both caregivers and financial support from the public administrations and therefore more support.

Conflict of Interest

There is no financial interest or any conflict of interest.

Annexes

Annex 1: Guidelines and habits in eating.

Annex 2: Tools used to facilitate feeding.

Annex 3: Assessment of stress and coping in the families of patients with CP.

Bibliography

- Fontiveros M. "Niños con discapacidad motora dentro del terreno educativo. Cuáles son sus características dentro del terreno del área del lenguaje, sus necesidades educativas especiales y la identificación de las mismas". *Innovación y Experiencias Educativas* 27 (2010): 3-9.
- Lorente I. "La parálisis cerebral. Actualización del concepto, diagnóstico y tratamiento". *Pediatría Integral* 6 (2007): 687-698.
- Oskoui M., et al. "An update on the prevalence of cerebral palsy: a systematic review and meta-analysis". *Developmental Medicine and Child Neurology* 55 (2013): 509-519.
- Robaina G., et al. "Definición y clasificación de la parálisis cerebral: ¿un problema ya resuelto?". *Revista de Neurología* 45 (2007): 110-117.
- Puyuelo M and Arriba J. "Parálisis cerebral infantil". Aspectos comunicativos y psicopedagógicos orientados al profesorado y a la familia (1ª edición). ARCHIDONA: Aljibe S.L. (2020).
- Malagon J. "Parálisis cerebral: Clínica para la Atención del Neurodesarrollo". *Revista de Neurología* 67 (2007): 586-592.
- Buedo J. "Los centros base y la expedición del certificado de minusvalía". *Boletín Informativo de Trabajo Social* 8 (2005): 1:24.
- Rosenbaum P., et al. "Prognosis for Gross Motor function in Cerebral Palsy: creation of motor development curves". *American Medical Association* 11 (2002): 1357-1363.
- Gorges J. "Ayudas técnicas para facilitar la alimentación de las personas discapacitadas. Fichas de ortopedia". *Farmacia Práctica* 28 (2009): 108-112.
- Barroso L and García E. "Experiencia en educación terapéutica sobre disfunciones en la alimentación con alumnos de un colegio de educación especial". *Fisioterapia* (2003): 2:103-109.
- Badia M and Aguado A. "Escala de Estrés y Afrontamiento para familias con hijos afectados de parálisis cerebral". 1-1 (2000): 16.
- Real Academia Española. "Salud". Diccionario de la lengua española (23.ª edición). Madrid: Espasa (2014).
- OMS (organización Mundial de la Salud). "Cómo define la OMS la salud. Official Records of the World Health Organization". 2 (1946): 1-100.
- OMS (organización Mundial de la Salud). "International classification of impairments, disabilities and handicaps: A manual of classification relating to the consequences of disease". World Health Organization, Genova 1 (1980): 1-31.
- Seguí J., et al. "Factores asociados al estrés del cuidador primario de niños con autismo: Sobrecarga, psicopatología y estado de salud". *Annals of Psychology* 24 (2008): 100-105.
- Moreno M., et al. "Relación entre las características de los cuidadores familiares de pacientes con discapacidad y la percepción de su estado de salud". *Avances en Enfermería* 12 (2004): 27-28.
- Singer G. "Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities". *American Journal on Mental Retardation* 111 (2006): 155-169.

Assets from publication with us

- Prompt Acknowledgement after receiving the article
- Thorough Double blinded peer review
- Rapid Publication
- Issue of Publication Certificate
- High visibility of your Published work

Website: www.actascientific.com/

Submit Article: www.actascientific.com/submission.php

Email us: editor@actascientific.com

Contact us: +91 9182824667