

Feeding a child with cerebral palsy: parents' difficulties

A Alimentação da criança com paralisia cerebral: dificuldades dos pais

La alimentación de los niños con parálisis cerebral: la percepción de los padres

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Abstract

Background: The nutritional status of children with cerebral palsy (CP) is an issue where nurses have a major responsibility towards children and their parents.

Objectives: To assess the weight, height and body mass index of children with CP; To identify the caregivers' perception of the nutritional status of their child with CP; To identify the caregivers' difficulties in feeding their child; To identify the association between family functionality and the child's weight.

Methodology: Mixed study with a sample of 104 children and their father/mother (104). The Anthropometric Assessment Questionnaire was applied to parents.

Results: About 45% of children were below the 5th percentile. Most caregivers were aware of their child's weight-for-height deficit. These caregivers' difficulties were related to food spilling out of the mouth, choking, and frequent vomiting.

Conclusion: A high percentage of children with CP have weight-for-height deficit. Caregivers are aware of this issue, indicating difficulties in feeding their children. The families of children with weight-for-height deficit are the most dysfunctional families.

Keywords: child; cerebral palsy; parents; feeding

Resumo

Enquadramento: O estado nutricional das crianças com paralisia cerebral (PC) é uma problemática onde o enfermeiro tem uma enorme responsabilidade com as crianças e pais.

Objetivos: Conhecer o peso, altura e índice de massa corporal das crianças com PC; Conhecer a perceção dos pais relativamente ao estado nutricional do seu filho com PC; Identificar as dificuldades dos pais na alimentação da criança; Conhecer a relação entre a funcionalidade da família e o peso da criança.

Metodologia: Estudo misto. Amostra de 104 crianças e seu pai ou mãe (104). Aplicação do Questionário de Avaliação Antropométrica e Questionário aos pais.

Resultados: Cerca de 45% das crianças encontrava-se no percentil <5. A maioria dos pais tinha a perceção do défice estatura-ponderal do seu filho. As dificuldades centram-se na perda de alimento pela boca, engasgamento e vômitos frequentes.

Conclusão: Há uma elevada percentagem de crianças com PC com défice estatura-ponderal. Os pais têm a perceção desta problemática, enumerando dificuldades na alimentação dos seus filhos. As famílias de crianças com défice estatura-ponderal são as famílias mais disfuncionais.

Palavras-chave: criança; paralisia cerebral; pais; alimentação

Resumen

Marco contextual: El estado nutricional de los niños con parálisis cerebral (PC) es un problema en el que el enfermero tiene una gran responsabilidad, tanto con los propios niños como con los padres.

Objetivos: Conocer el índice de peso, longitud y masa corporal de los niños con PC; Conocer la percepción de los padres con respecto al estado nutricional de su hijo con PC; Identificar las dificultades de los padres en la alimentación del niño; Conocer la relación entre la funcionalidad de la familia y el peso del niño.

Metodología: Estudio mixto con una muestra de 104 niños y su padre o madre (104). Se aplicó el Cuestionario de Aplicación Antropométrica y el Cuestionario de Evaluación a los padres.

Resultados: Alrededor del 45 % de los niños estaba en el percentil <5. La mayoría de los padres era consciente del déficit estatura-peso de su hijo. Las dificultades de estos padres se centran en la pérdida de alimentos a través de la boca, la asfixia y los vómitos frecuentes.

Conclusión: Existe un alto porcentaje de niños con PC con déficit de estatura-peso. Los padres son conscientes de este problema y enumeran las dificultades en la alimentación de sus hijos. Las familias de los niños con déficit de estatura-peso son las más disfuncionales.

Palabras clave: niño; parálisis cerebral; padres; comida

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Introduction

Cerebral palsy (CP) is the most common motor disability in childhood. Children with CP often experience complex and heterogeneous clinical situations that are difficult to characterize and require constant monitoring (Andrada et al., 2012).

CP is a chronic condition – the prototype of disability in childhood - that leads to long-term functional limitations (Patel, Piazza, Layer, Coleman, & Swartzwelder, 2005).

Despite the improvement in perinatal care in developed countries, the incidence of CP has remained constant, with a rate of around 2.08/1000 live births in Europe (Andrada et al., 2012; Chagas et al., 2008; Magnus et al., 2012). In Portugal, there are approximately 200 new cases per year, and 90% will reach adulthood (Campos, 2013).

Children with disabilities are, above all, children (Pruitt & Tsai, 2009). The approach to children with special needs has improved significantly in recent decades (Folha, 2010).

Feeding problems and growth disorders are common in children with CP (Sullivan, 2009), which may have a significant impact on their health, namely at the psychological and functional levels, as well as on their socialization and survival.

Within health care teams, nurses should focus on helping the family to find the necessary resources and the most appropriate way to use them. They should also help parents to increase their own social activities, which they often neglect due to their child's condition. Work is organized in order to integrate children with disabilities and make their life as normal as possible, so as to provide learning experiences and, consequently, promote the development of their social skills, breaking down the barriers of social isolation. The early intervention through family support programs will strengthen family functionality, as well as promote the growth and development of the family members and the family as a whole (Ordem dos Enfermeiros, Comissão de Especialidade de Enfermagem de Saúde Infantil e Pediátrica, 2012).

Despite their disability, these children are still children and deserve all the care and attention. Many studies have been conducted in the area of Pediatrics, but unfortunately the same visibility is not given to children with cerebral palsy and the associated

complications that interfere with their growth and development.

The researcher considered it important to assess the weight, height and body mass index (BMI) of children with CP living in the area of Greater Lisbon, Portugal; to identify parents' perceptions of the nutritional status of their child with CP; to identify parents' difficulties in feeding their child with CP; and to identify the association between family functionality and the child's weight.

Background

A balanced and varied diet is an essential need of children, being underlined in the Declaration of the Rights of the Child. The World Health Organization (WHO) estimates that more than half of the deaths in developing countries are related to malnutrition, but most surviving children with nutritional deficiencies show impaired psychomotor development and significant emotional disorders (Ordem dos Enfermeiros, Comissão de Especialidade de Enfermagem de Saúde Infantil e Pediátrica, 2012). In recent years, there has been an increased awareness that children with CP are at high risk for malnutrition. The early identification of the risk factors for malnutrition is important to prevent complications associated with these children's behavior, health and growth as soon as possible (Sullivan, 2009).

Several authors have reported that there is an association between nutritional status and inadequate diet and poor food intake, underlining the importance of conducting research on these children's nutritional status (Magnus et al., 2012). According to Sullivan (2009), dysphagia contributes to malnutrition in children with CP. In a study conducted in North America, Sullivan identified a nutritional deficit and low growth in 90% of children, with 27% of them showing moderate to severe dietary changes.

According to Issã (2014), nutritional assessment aims to characterize and identify people's nutritional status, provide support for an appropriate intervention, and monitor its progress. Health professionals who work with children with CP should be alert to possible growth barriers, particularly those related to feeding, medication, comorbidities, congenital diseases, and environmental and hereditary factors (Direção-Geral de Saúde, 2015).

The presence of a chronic disease does not only alter the life of affected individuals, but it can also influence many aspects of the parents' lives. Having a child with CP becomes a great challenge for parents, since they must try to manage the child's health problems, as well as trying to keep their activities of daily living. Managing a family with a child with CP is more challenging on several levels, since this family needs to participate more actively in child care. Therefore, the existence of a child with CP changes the family structure, as this condition requires more time to provide care at home and more financial resources due to treatment expenses (Camargos, Lacerda, Viana, Pinto, & Fonseca, 2009; Macedo, Festas, & Vieira, 2012).

Childhood chronic diseases affect most of the families' tasks and responsibilities, and bring about additional concerns. At the same time, children's physical and emotional health, and cognitive and social functioning are strongly influenced by the quality of family functionality. In fact, families are usually faced with new demands, changes in their routines, constant changes and multiple re-adaptations, causing the disease to interfere at several levels: financial, professional, and personal, and in the interaction within and outside of the family (Augusto, 2012).

Sometimes, parents focus only on the disease-related deficits, without recognizing their child's potential. When families are supported in acquiring a proactive attitude toward the condition of disability, they are being helped to overthrow their own internal barriers that often emerge in case of limitations. Therefore, children with disabilities should constantly receive positive reinforcement for their skills and qualities (Ordem dos Enfermeiros, Comissão de Especialidade de Enfermagem de Saúde Infantil e Pediátrica, 2012) and significant responsibility of nurses.

Research questions

The following research questions were set out to address the issue under analysis: What is the weight, height and BMI with CP living in the Greater Lisbon area? What is the parents' perception of the nutritional status of their child with CP? What are the parents' difficulties in feeding their child with CP? What is the association between family functionality and the child's weight?

Methodology

Type of study

Mixed descriptive and exploratory study.

Population and sample

The universe of this study consisted of children with CP and their parents (mother or father of each child) living in the Greater Lisbon area. The sample was composed of children with CP, born in Portugal between 2001 and 2006, inclusively, and being followed-up in the Medical Rehabilitation Center of Alcoitão (MRCA) and in the Centro de Reabilitação de Paralisia Cerebral Calouste Gulbenkian (CRPCCG) and their parents. A nonprobability random sample was used.

The following inclusion criteria were applied: children living in the district of Lisbon; born between 2001 and 2006; children being followed-up in the CPCCG and MRCA; children whose relative/caregiver accepted and signed the informed consent for participation in the study. The initial sample was composed of 150 children. Of this initial group, 21 died. Of the 150 children, 25 had no correct telephone contact or the caregiver did not answer the phone (after five attempts on different days). Thus, a total of 104 children participated in the study: 64 boys and 40 girls.

The children's percentiles were determined in accordance with the technical guidelines of the Directorate-General for Health.

Procedure for data collection

Initially the researcher went to both institutions with the purpose of gathering the sample. Children data are stored in computers at the institutions, and in these two moments the researcher selected the children/parents who met the inclusion criteria.

A total of 104 families were contacted for study presentation and interview scheduling. After the phone contact, during which the study was explained and the date for data collection was scheduled, the researcher met with the child's tutor to confirm that he/she had understood the study objectives and to sign the informed consent before starting.

Children who had a medical appointment were scheduled for the same day of their appointment. The Anthropometric Assessment Questionnaire (for the assessment of weight, height and BMI) and the

Parents' Questionnaire were applied. The Parents' Questionnaire was used to collect data on the parents' perceptions of their child's nutritional status and difficulties in feeding their child, and to apply the Family APGAR score (on family functionality). The study was initially explained and the informed consent was signed. The Parents' Questionnaire was built by the researcher after research on the state-of-the-art in this area and experts' consultation.

The children who had no medical appointment were scheduled according to their parents' availability.

The Parents' Questionnaire was answered by the mother or father, depending on their availability (104).

After data collection, we assessed the percentiles of children with CP and associated that information with the Family APGAR score, with a view to identifying the functionality of families with children with weight-for-height deficit. In order to explore this issue, we analyzed parents' perceptions of the nutritional status of their children and feeding difficulties. This latter aspect was further explored through an open-ended question, so that the problem under analysis could be exposed without restrictions and the actual difficulties of parents could be revealed. During the interviews, we had the opportunity to listen to parents, register their difficulties, feelings and concerns. Although promoting the parents' skills was not the initial objective of this study, given the difficulties mentioned and the researcher's knowledge in this area, there was an opportunity for a health education intervention. After the parents answered the open-ended question, the researcher indicated strategies/measures/solutions to help solve the problem. A pre-test was successfully performed.

Data analysis

For the statistical analysis, we used measures and procedures of descriptive and inferential statistics. Statistical Package for the Social Sciences (SPSS), version 20.0, was used.

For the open-ended question, we used Bardin's content analysis technique (2009), and the categories were defined a posteriori.

Ethical considerations

All ethical considerations inherent to a research study were ensured. The study design was submitted to and approved by the Ethics Committee of the Universidade Católica Portuguesa, the Ethics Committee of the MRCA and the Clinical Direction of the CRPCCG. All relatives (children's parents and guardians) gave their informed consent to participate in the study. Data were collected and analyzed by maintaining the confidentiality of the sampled subjects.

Results

After analysis of the percentiles of weight, height and BMI, we found that a high percentage of children were below the 5th percentile. With regard to weight, of the 104 children, 44.2% ($n = 46$) were below the 5th percentile, 53.8% ($n = 56$) were between the 5th and the 90th percentile, and 1.9% ($n = 2$) were above the 90th percentile. Similar results were also found in the percentile of height and BMI.

We found that the main caregiver had a correct perception of the child's nutritional status, with a statistically significant association between the relative's perception of the child's nutritional status and the weight percentile, $\chi^2(4) = 34.760, p = .000$. There was a significantly higher percentage of children below the 5th percentile whose family considered to be malnourished or poorly nourished (23.9% and 50.0%) and of children between the 5th and 90th percentile whose family considered to be adequately nourished (82.1%).

The association between the weight percentile and the Family APGAR score was also statistically significant, $\chi^2(4) = 41.661, p = .000$, i.e. there are more children below the 5th percentile with a Family APGAR score of *family dysfunction* (56.5%) and children between the 5th and 90th percentile with a Family APGAR score of *highly functional family* (64.3%).

Qualitative study

In the parents' questionnaire, parents were asked to answer the open-ended question: "What are your major difficulties in feeding your child?". The following results were obtained after content analysis of the answers:

Table 1

Difficulties experienced by parents in feeding their child

Category	Semantic unit - examples
Unbalanced diet	"He doesn't eat soup, vegetables or fruit." (I2; December, 2012) "He doesn't eat everything. He just wants to eat pasta and rice. He doesn't eat meat or fish." (I41; May, 2013)
Food monotony	"He always eats the same thing; I don't know how to diversify." (I8; December, 2012) "I've been giving him the same food for several years now. I think he's fed up with it, but I don't know what else to do." (I13; March, 2013)
Shame	"I'm embarrassed in public, because everyone stares when I'm feeding him." (I8; December, 2012) "People stare at him with disgust, they don't get close." (I8; December, 2012)
Difficult access to adapted food outside the home	"When we go out, I always have to worry about taking food with us." (I8; December, 2012) "We have to choose carefully where we're having dinner, because his food always has to be grinded." (I30; April, 2013)
Inadequacy of technical aids	"The street wheel-chair has no inclination and makes it very difficult to feed him outside of the house." (I8; December, 2012)
Food spilling, choking and vomiting	"When I feed him, a lot of food comes out." (I13; March, 2013) "He chokes a lot because he wants to eat too fast and I don't know what to do." (I48; May, 2013) "He often vomits, even with the Domperidone®." (I96; July, 2013) "He chokes with liquids." (I99; September, 2013) "He usually spills a lot of food out of his mouth. He chokes a lot." (I103; September, 2013)
Time	"He takes a long time to eat and I still have to help his brothers." (I14; March, 2013) "As she takes a long time to eat and there are a lot of children at the school, she barely eats all day, because the professionals do not have much time to be with her." (I41; May, 2013)
Cooking food separately	"I always have to cook his food separately, because it is different from the rest of the family." (I17; April, 2013) "He never eats with the family. First, I prepare his food and give it to him and then the rest of the family eats." (I30; April, 2013)
Costs	"His supplements are very expensive." (I96; July, 2013) "We spend around 600€/month in food, plus 1800€/month in nursing support, because our son is mechanically ventilated and has a tracheostomy. The only governmental support is the ventilator. We have two children and the situation is becoming unbearable." (I50; June, 2013)

Note. I = Interview.

The most common difficulties mentioned by the parents were *food spilling*, *choking* and *vomiting*. Some of these children are known to have chewing and swallowing problems, which interferes with their feeding/hydration. These issues cause major anxiety to parents, not only because it leads to an inadequate diet, but also because of their children's risk of choking and aspiration of vomit.

We have revealed the results of this study, and will now compare our data with those obtained in other studies conducted within the same scope, in order to support the findings of the research study.

Discussion

The parents who participated in this study are fully aware of the magnitude of nutrition issues of children with CP. We found that most parents of children below the 5th weight percentile are aware of their

child's nutritional status, stating that they consider their child to be malnourished or poorly nourished. In a study conducted in the United States with parents of children with CP, Sullivan (2009) found that 39% of parents believed their child to be malnourished and 43% reported that feeding their child was a stressful and unpleasant moment. On the other hand, in a study carried out in Porto (Portugal) with parents of school-aged children (without disabilities), Macedo et al. (2012) found that these parents were less aware of the situation, since 49.9% of parents had a distorted perception of their child's nutritional status.

Family functionality was also associated with weight. After applying the APGAR Family score, we found that children in dysfunctional families had a lower weight percentile than children in highly functional families, who had normal weight percentiles.

Camargos et al. (2009) found that the lower the family's socio-economic status, the higher was the parent's burden and the lower was their quality of life,

and that parents with a higher socio-economic status were more in control of their well-being. In addition, caring for a child with a disability increases the need for resources, including time and money, which can increase the parents' burden whenever they are economically active members of the family.

Parents' difficulties in feeding their children

The parents' answers about the difficulties in feeding their children were varied and focused on different levels, namely: unbalanced diet, food monotony, shame, difficult access to adapted food outside the home, inadequacy of technical aids, food spilling, choking and vomiting, time, cooking food separately, and costs. In some accounts, we found clear references to the anguish of not being able to help their children more, feelings of powerlessness and frustration. We found that these parents have an enormous inner strength to fight and provide their children with a better quality of life.

Several parents mentioned their difficulties in feeding their children.

Their lack of balanced diet further emphasizes the fact that these children are poorly nourished and that parents are aware of this.

Pruitt and Tsai (2009) report that gastroesophageal reflux is common among children with CP, being present in more than 75% of them. Vomiting, esophagitis, and dysphagia may also be present. These problems can be minimized by elevating the back of the chair during the meal and offering the appropriate food to the child's situation. Patel et al (2005) added that the parents' use of inappropriate feeding techniques can interfere significantly with their children's nutrition and hydration. Food aspiration is one of those risks, which can lead to severe problems such as pneumonia, airway obstruction, and even death.

The elevation of the back of the chair during the meal is essential to feed the child properly. The consistency of the food should be adapted to the child's constraints and needs in order to reduce the risk of food aspiration. These children should be followed-up by health professionals, in order to minimize parents' frequent difficulties in feeding their children (Magnus et al., 2012).

A proper position, along with the use of technical aids, is essential to a successful feeding. Parents should

use a children's spoon, adapted in size and material, in order to facilitate chewing and swallowing. Many parents are unaware of these strategies (Patel et al., 2005).

The various difficulties experienced by parents in cooking and feeding often lead to food monotony. Meals have to be cooked separately, and there is often the need to prepare different food for the child with CP. Parents often choose food that is faster to cook, with the same consistency, and that they are certain that their child likes. In this way, there is no diversity in food/nutrients.

Parents reported that they sometimes feel embarrassed for their child outside their home. Besides the initial disappointment, the presence of a family member with a cognitive impairment implies a series of critical situations for the family, usually accompanied by painful and conflicting feelings and emotions. In this journey, both the family and the *special child* will need to overcome their own fears, frustrations and limitations on a daily basis - direct effects of the social stigma which the whole family faces (Felicissimo, 2009).

The time factor was also mentioned by several parents, since this process requires coordination and concentration both from the children and their parents. Some parents have other children and little time in their daily lives, and the extended amount of time spent feeding their child with CP affects parents' routines and quality of life. According to Wilson and Hustad (2009), children with CP take more time to complete their meals, and the amount of time available for meals at home or at school is often not enough for these children. This sometimes leads to reduced food intake, since parents tend to associate the time spent in feeding with the amount of food ingested.

In the study by Wilson and Hustad (2009), 41% of children with CP finished a meal in 10-20 minutes, 44% in 20-30 minutes, and 16% in 30-60 minutes. Clawson, Kuchinski, and Bach (2007) added that a child with CP took 15 times more time than a healthy child to finish a meal, and that the mother of a child with CP spends 3.5 hours per day feeding her child, whereas the mother of a healthy child spends 0.8 hours.

Parents reported that the meal of their child with CP had some specific characteristics (pasty, liquid, made with a certain type of food), and often had to be cooked separately from that of the rest of the family.

Parents considered this to be a difficulty, especially when they have more children, due to the time and costs associated with this specificity.

The cost was another issue raised by some parents as restricting factor for the children's better quality of life. The lack of support and the need to miss work sometimes to care for their child leads to major economic difficulties.

Intervention with the parents after the results

Several parents reported that their child choked and spilled food during meals. By further exploring this issue, we noted that parents often fed their child very liquid food in a very horizontal position, using a spoon too large for the child, and were unable to correctly put the food into the child's mouth. Parents were explained that the back of the chair should be in a more vertical position because a horizontal position hinders swallowing, causing choking. They were also explained that, after the meal, the back of the chair should remain in an upright position in order to promote digestion and minimize the risk of vomiting (Rogers, 2004).

Many parents refused to give their children water, since they choked a lot with water and more liquid food. None of the parents who mentioned this issue had heard of a thickener. We explained its objective, how to use it and where to purchase it. This solution allows parents to give water to their children and, by adding the thickener in mashed soup or fruit, to minimize the risk of choking or food aspiration (which is very common among these children).

Some parents mentioned that their children choked with solid foods such as meat and fruit. We addressed the possibility of grinding food, since this allows for the necessary nutrient intake and the child does not need to make a lot of effort to chew. In addition, the risk of choking and food aspiration is substantially minimized (Patel et al., 2005).

Parents often used a large spoon to feed the child, which is unsuitable for children with swallowing/chewing difficulties, because it occupies a large part of the oral cavity and takes a large amount of food. We suggested that parents should try using a smaller spoon and insert it by slightly pushing the tongue down to facilitate swallowing. While inserting and removing the spoon from the oral cavity, several children get hurt and bleed from their gums, because

they are often unable to close their mouths and have fragile gums (Patel et al., 2005). The use of silicone spoons was suggested to parents who reported this situation.

Parents also mentioned the issue of food monotony in the child's diet, resulting from the parents' comfort or from the child's reluctance to accept new foods. Children sometimes do not want new flavors, especially if they do not like them. However, a balanced diet, with a diversity of nutrients, is essential. We also explained that, whenever possible, the family's meal should be similar to the child's meal so that the child could feel that if everyone is eating, he/she can also eat.

These were some of the strategies discussed with parents. The feedback has been very positive, and several parents called the researchers to thank for *the big help*. Many parents reported that, after they started using the provided strategies, their child was not choking as often or even stopped choking, were no longer spilling food out of the mouth, and that they were already able to vary the food and offer water. In view of the above, we found that the adopted measures met the parents' needs. The difficulties in feeding were initially assessed and then interventions were suggested, which benefitted both the children and their family.

Throughout the research study, we encountered some limitations that were easily overcome. The major limitation was related to the small number of studies about this issue in Portugal, which made it difficult to establish comparisons with the Portuguese context. This limitation further motivated us to conduct this study, emphasizing the increased need for support experienced by these children and parents.

Conclusion

Children with CP may have oral motricity limitations and chewing and swallowing difficulties, which sometimes lead to feeding issues and the consequent delay in growth. Growth parameters revealed weight-for-height deficit in approximately 1/3 of the children, whose weight, height and BMI was below the 5th percentile. This delay in growth is associated with severe comorbidities, namely pressure ulcers, decreased muscle strength, immunodeficiency, and decreased bone density. Most parents had a correct

perception of their child's nutritional status, and were aware of this issue.

When parents were questioned about their difficulties in feeding their child, their answers varied, with most of them mentioning food spilling, choking and vomiting. Some parents also mentioned the type of food and cooking method, as well as the time spent, the difficulty in accessing adapted food outside of the home, shame, and the inadequacy of technical aids.

The numerous difficulties experienced by parents can have a direct impact on family functionality. Families with children with weight-for-height deficit showed a higher level of dysfunction, whereas most of the families of children who were between the 5th and 90th percentiles were highly functional.

The accurate and regular assessment and monitoring of anthropometric data must not be neglected in children with CP because of they are at high risk of weight-for-height deficit. Nurses should measure, record, assess, intervene, and, if necessary, refer these children. The nurse monitors children with CP since their birth and over the course of their lives (school health, primary care, early intervention team, rehabilitation centers), and is the health care professional of choice for assessing the children's growth and development and intervening in the activities of daily living, namely feeding.

The nurse also plays a key role in supporting these children's parents. Like all other parents, they have doubts, fears and feelings of anxiety, but, above all, they have a child with a disability, and often require emotional, theoretical and practical support. The nurse has a vast technical-scientific, emotional and relational knowledge, and is in a privileged position to support and accompany parents.

Children should be assessed taking into account all their limitations, thus they require careful and specific monitoring. The provision of support to the parents of children with CP with a view to helping them overcome their difficulties will promote their mental health and quality of life. Only then will it be possible to fully develop the children's skills, their participation, and social, family and academic inclusion. Parents should be supported and guided since their child's early ages, and also provided with the access to integrated empowerment and educational support programs developed by a multidisciplinary team, where nurses play an important role and have a major responsibility. We hope that further studies can be conducted in

this area, including studies comparing the growth of children with and without a gastrostomy, and the evolution of the weight-for-height deficit in children taking protein and calorie supplements, as well as action-research studies on nursing follow-up consultations with children with CP and their parents.

References

- Andrada, M., Batalha, I., Calado, E., Carvalhão, I., Duarte, J., Ferreira, C., & Folha, T. (2012). *Paralisia Cerebral aos 5 Anos de idade em Portugal. Crianças com paralisia cerebral nascidas entre 2001-2013*. Lisboa, Portugal: APPC.
- Augusto, C. (2012). A família da criança com paralisia cerebral: Perspetivar o papel do enfermeiro na construção da resiliência familiar. *Revista Sinais Vitais*, 101, 23-25.
- Bardin, L. (2009). *Análise de Conteúdo*. Lisboa, Portugal: Edições 70.
- Camargos, A., Lacerda, T., Viana, S., Pinto, L., & Fonseca, M. (2009). Avaliação da sobrecarga do cuidador de crianças com paralisia cerebral através da escala Burden Interview. *Revista Brasileira de Saúde Materno Infantil*, 9(1), 31-37.
- Campos, A. (2013, Março 19). Há mais casos de paralisia cerebral nas pequenas e nas grandes maternidades. *Jornal Público*. Retrieved from <https://www.publico.pt/sociedade/noticia/ha-mais-casos-de-paralisia-cerebral-nas-pequenas-e-nas-grandes-maternidades-1588372>
- Chagas, P. S., Deffilipo, E. C., Lemos, R., Mancini M., Frônio, J., & Carvalho, R. (2008). Classificação da função motora e do desempenho funcional de crianças com paralisia cerebral. *Revista Brasileira de Fisioterapia*, 12(5), 409-416.
- Clawson, E., Kuchinski K. S., & Bach, R. (2007). Use of behavioral interventions and parent education to address feeding difficulties in young children with spastic diplegic cerebral palsy. *NeuroRehabilitation*, 22, 397-406.
- Direção-Geral de Saúde. (2015). *Nutrição e deficiência(s). Programa nacional para a promoção da alimentação saudável*. Lisboa, Portugal: Autor.
- Felicíssimo, A. (2009). Conhecer a convivência da família com o doente psicótico: Intervenções psicoeducativas na linha comportamental de Fallon. *Revista Portuguesa de Enfermagem de Saúde Mental*, 1, 23-32.
- Folha, T. (2010). *Paralisia Cerebral na Região de Lisboa e Vale do Tejo: Factores de risco, caracterização multidimensional, inclusão escolar* (Masters Dissertation). Universidade Nova de Lisboa, Escola Nacional de Saúde Pública, Portugal.
- Issã, R. (2014). *Avaliação do estado nutricional e ingestão energética em indivíduos com paralisia cerebral* (Masters Dissertation). Universidade do Porto, Faculdade de Ciências da Nutrição e Alimentação, Portugal.

- Macedo, L., Festas, C., & Vieira, M. (2012). Perceções parentais sobre estado nutricional, imagem corporal e saúde em crianças com idade escolar. *Revista de Enfermagem Referência*, 3(6), 191-200
- Magnus, M. O., Andersen, G. L., Andrada, M. G., Arnaud, C., Balu, R., Dela Cruz, J.,... Vik, T. (2012). Gastrostomy tube feeding of children with cerebral palsy: Variation across six European countries. *Developmental Medicine & Child Neurology*, 54(10), 938-944.
- Ordem dos Enfermeiros, Comissão de Especialidade de Enfermagem de Saúde Infantil e Pediátrica. (2012). *Guias orientadores de boa prática em enfermagem de saúde infantil e pediátrica: Entrevista ao adolescente e promover o desenvolvimento infantil na criança*. Lisboa, Portugal: Autor.
- Pruitt, D. & Tsai, T. (2009). Common medical comorbidities associated with cerebral palsy. *Physical Medicine & Rehabilitation Clinics North America*, 20(3), 453-467.
- Rogers, B. (2004). Feeding method and health outcomes of children with cerebral palsy. *Pediatrics*, 115(Suppl. 2), S28-32.
- Patel, M. R., Piazza, C. C., Layer, S. A., Coleman, R., & Swartzwelder, D. M. (2005). A systematic evaluation of food textures to decrease packing and increase oral intake in children with pediatric feeding disorders. *Journal of Applied Behavior Analysis*, 38(1), 89-100.
- Sullivan, P. (2009). *Feeding and nutrition in children with neurodevelopmental disability*. London, England: Mac Keith Press.
- Wilson, E. M., & Hustad, K. C. (2009). Early feeding abilities in children with cerebral palsy: A parental report study. *Journal of Medical Speech-Language Pathology*, 17(1), 31-44. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2688002/pdf/nihms57357.pdf>

